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Notes on the formatting, design & use of this book

Before reading this book, please note:

1. As some visitors to the HFME website (www.hfme.org) or readers of this book may only ever read one HFME paper, each paper has been designed to be a stand-alone resource which focuses on one aspect of Myalgic Encephalomyelitis (M.E.) but which also includes a brief rundown of the basic facts of M.E. Thus there is significant repetition of the basic facts of M.E. (and related topics) from paper to paper in this book.

If you have read the basic facts once and have no need to be reminded of this information again, please just skim over the repetitive sections when you encounter them in future papers.

2. The papers in this book were originally created to be published online, and distributed for free, on the HFME website. There are many small differences in how information is presented online and in print form. In an ideal world each HFME paper would have been completely reformatted and reorganised, before being included in this book. Unfortunately, due to the serious illness and disability suffered by the author/s, total reformatting and reorganising of each paper was not possible.

Thus this book includes some minor formatting inconsistencies. Where further information is recommended, the links given are in an online format (i.e. HTML links appear here as underlined text). There are also almost certainly some minor grammatical errors.

However, we ask readers to ignore these superficial imperfections and to focus on the far more important fact that the information given in this book on M.E. (and related topics) is rock solid. It has been compiled using information from the world’s leading M.E. experts – and a large number of M.E. patient accounts spanning many decades – and is of the highest quality. This is information that is currently unknown by most of the public, the media, doctors and even patients themselves, and that desperately needs to become known – this is why those involved with HFME have produced this book, despite their serious illness and disability caused by M.E.

3. To be able to follow any of the ‘links’ to further information given in this book (represented by underlined text), just go to the HFME website, view the online version of the relevant paper, and click on the relevant link.

4. If you would like printouts of any of the papers in this book for yourself or to hand out to doctors or others, you can download free printable copies of each paper in this
book from the HFME website. See the ‘Document downloads’ page on the website for more information.

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Section 1. Treating and living with M.E. - Overview
Myalgic Encephalomyelitis (M.E.) can be so overwhelming in so many different ways that it can be very hard to know how to even begin dealing with it. It can so quickly negatively affect almost every aspect of your life and become completely overwhelming in every way. Some ideas for where to start include:

1...Make sure you have been correctly diagnosed

The fact that a person qualifies for a diagnosis of ‘CFS’ or ‘ME/CFS’ (a) does not mean that the person has Myalgic Encephalomyelitis (M.E.), and (b) does not mean that the person has any other distinct and specific illness named ‘CFS’ or ‘ME/CFS.’

A diagnosis of CFS – based on any of the CFS definitions – can only ever be a misdiagnosis. Fitting any of these criteria is meaningless and should never be accepted as an end point of the process of diagnosis. The list of illness and conditions which are often misdiagnosed as ‘CFS’ is long and includes: depression, PTSD (and various other organic and non-organic mental illnesses), adrenal deficiency, various post-viral fatigue syndromes and other fatigue syndromes, systemic yeast infections (Candida), vitamin deficiencies, burnout or emotional exhaustion, chronic Epstein-Barr, post-glandular fever (or mononucleosis) fatigue syndromes, Fibromyalgia, athletes over-training syndrome, multiple sclerosis, Lupus, Lyme disease or Borrelia burgdorferi, multiple chemical sensitivity syndrome, gulf war illness and cancer.

It is vitally important that each of these patients find out what their true diagnosis is so that they may finally receive appropriate treatment and support.

While most M.E. patients will be misdiagnosed with ‘CFS’ this does not mean that M.E. is the same as ‘CFS’ as the vast majority of those given a ‘CFS’ diagnosis do not have M.E.

2...Avoid overexertion

Even minor levels of physical and cognitive activity, sensory input and orthostatic stress beyond an M.E. patient’s individual post-illness limits causes a worsening of the severity of the illness (and of symptoms) which can persist for days, weeks or many months or longer. In addition to the risk of relapse, repeated or severe
overexertion can also cause permanent damage (eg. to the heart), disease progression and/or death in M.E.

3...Work towards learning to accept your illness
Starting to accept that you have a serious illness is a difficult but important process that can take anywhere from months to years. Accepting illness does not mean happily resigning yourself to your fate and to being severely ill for the rest of your life, but is about acknowledging the reality of your illness; acknowledging that it isn’t something that is going to just conveniently disappear if you ignore it for long enough or think positively enough and/or that there is no quick fix available and that it is something you will have to deal with and adjust to – at least for now.

As discussed in the previous section, continually denying or ignoring your illness and pushing through the symptoms and limitations (until you completely collapse) can only be counterproductive, or even dangerous. Acceptance of the limitations of the illness at as early a stage as possible is crucial to long-term outcome and will also save you many unnecessary and potentially very severe (or even semi-permanent or permanent) relapses and a lot of pain and suffering in the short and the long term.

4...Educate yourself (and those around you) about M.E. and seek appropriate support
Along with coping with the physical effects of the illness it is also important that you educate yourself about the illness as much as you are able in order to seek appropriate physical, financial and emotional support.

5...Try to find a knowledgeable doctor
This is absolutely vital, and very much easier said than done. The issue of correct diagnosis is incredibly difficult currently. M.E. is very easy to diagnose and to recognise and is quite distinct from various other diseases, and can reliably be tested for, but the problem is that most doctors do not have this information and have been fed an enormous amount of misinformation about M.E. and about ‘CFS.’

Finding doctors that can help with treatment is not so difficult however, which is very good news.

6...Modify your diet
Diet is so important in M.E. It has such a strong effect on the immune system, on hormones, on gut health and the level of neurological and cognitive problems and the body's ability to detoxify, and so on. The right diet can reduce cancer risk. Treating the gut problems of M.E. is also one of the first steps in treating M.E. itself and cannot be ignored.
The health of the gut affects neurological health to a significant degree. Diet can also increase or reduce inflammation and have positive or negative effects on many different hormones and neurotransmitters.

Food affects the body in the same powerful ways as do prescription drugs, and so must be considered with the same amount of respect. Food is not merely fuel, it is MEDICINE.

7...Modify and detoxify your environment
Chemical sensitivities are common in M.E. as are allergies or sensitivities to various airborne allergens. So modifying your environment and the products you use is essential.

8...Look into treatments for M.E. and improving your health
Intelligent nutritional and other interventions can make a significant difference to a patient’s life. Appropriate biomedical diagnostic testing should also be done as a matter of course (and repeated regularly) to ensure that the aspects of the illness which are able to be treated can be diagnosed, treated and then monitored as appropriate.

Testing is also important so that potentially dangerous abnormalities (which may place the patient at significant risk) are not overlooked.

9...Learn how to avoid inappropriate or harmful treatments and scams
Those proffering inappropriate, dangerous or fraudulent treatments or who make false or misleading claims about the efficiency of some treatments for M.E. usually do so due to ignorance about the vast difference between M.E. and ‘CFS.’ Some treatment regimes are also outright scams that are aimed at many different patient groups and not just M.E. patients. It is important to be aware of some of the most commonly promoted scams so that false hope, financial loss and loss of health can be avoided.

10...Learn to avoid and minimise stress
Stress unequivocally does not cause M.E. (and can not EVER cause M.E.) but as with most illnesses, stress can exacerbate the symptoms of the illness. Unfortunately, stressful situations also become harder to handle when you have M.E. and so it is important to avoid as many stressful situations, tasks and people as possible. The stress you can’t avoid you’ll need to learn to minimise as best you can.

If you are able to meditate (some sufferers lose this ability or simply cannot listen to anything) this also may help considerably with stress reduction. Talking about what is bothering you to friends, family or to other M.E. sufferers in your support group may also help. Some sufferers also pour out (or vent) their feelings into private journals; whatever works best for you.
The most intense source of ‘stress’ in an M.E. sufferers life is the M.E. itself (of course) and it is completely normal to feel sad, mad, angry, irritable and frustrated sometimes because of your illness. (Indeed it would be abnormal if you did not feel these things sometimes). It is also normal and necessary for you to spend time grieving for what you have lost through the illness sometimes too; to feel sorry for yourself somewhat, and to cry as much as you need to. At other times however, you will need to try to find ways to take your mind off thinking about yourself, to try to distract yourself from such thoughts.

11...Learn strategies to help with the cognitive symptoms of M.E.
The cognitive symptoms of M.E. can often be some the most severe and disabling of the entire illness, and so also some of the most concerning. These include problems with memory, problems with thinking and making decisions, difficulty learning new tasks and much more. Various treatments may improve these effects to some extent but modifying the way you do things can also really help.

12...Consider becoming involved in M.E. activism and advocacy
Unfortunately, while many M.E. advocacy groups started out doing excellent work to improve things for M.E. sufferers, today this is no longer true in many (or even most) cases and so the need is great for individual M.E. sufferers to participate in M.E. activism and advocacy. (Most groups are actively working AGAINST our interests and against science and ethical concerns.)

Aside from the gains to the M.E. community in the longer term however, this sort of activity can also greatly benefit the participant individually. It can provide a real sense of purpose, achievement and of pride. It is also a healthy and positive way to channel your anger and frustration at how poorly M.E. sufferers are treated (or how badly you have been treated).

Conclusion
Living with and coping with M.E. is no easy feat. Hopefully every M.E. sufferer (and every parent of a child with M.E.) reading the ‘Treating M.E.’ section will have found something here that perhaps you were not aware of before, and that is helpful in some way. The very best of luck – and health – to you all.

For more information on each of these 12 topics, and links to all the major HFME papers on these topics, please see part 2 of this paper.
...Make sure you have been correctly diagnosed: More information

Despite the fact that the new name and definition of CFS were created in a response to an outbreak of what was unmistakably M.E., this new name and definition did not describe the known signs, symptoms, history and pathology of M.E. It described a disease process which did not, and could not exist.

As M.E. expert of more than twenty years Dr Byron Hyde explains,

Do not for one minute believe that CFS is simply another name for Myalgic Encephalomyelitis. It is not. The CDC 1988 definition of CFS describes a non-existing chimera based upon inexperienced individuals who lack any historical knowledge of this disease process. The CDC definition is not a disease process. It is (a) a partial mix of infectious mononucleosis /glandular fever, (b) a mix of some of the least important aspects of M.E. and (c) what amounts to a possibly unintended psychiatric slant to an epidemic and endemic disease process of major importance. Any disease process that has major criteria, of excluding all other disease processes, is simply not a disease at all; it doesn't exist. The CFS definitions were written in such a manner that CFS becomes like a desert mirage: The closer you approach, the faster it disappears and the more problematic it becomes.

Today there are more than nine different CFS definitions. Just like the original Fukuda definition of CFS produced in 1988 however, none of these definitions defines any distinct illness. All they do ‘define’ is a heterogeneous population of sufferers from psychiatric and miscellaneous non psychiatric states which have little in common but the symptom of ‘fatigue’ (a symptom not associated with M.E. at all until the CDC become involved in 1988.)

Thus whether or not you fit the Fukuda definition of CFS is entirely irrelevant in determining whether or not a person has M.E. (or any other illness). Fitting any of these ‘CFS’ criteria is meaningless and should never be accepted as an end point of the process of diagnosis.

Many with M.E. will be MISdiagnosed with Fukuda CFS – merely by default; the severe and disabling metabolic, neurological and cardiovascular abnormalities central to M.E. unfortunately mistaken for simple ‘fatigue.’
The terminology is often used interchangeably, incorrectly and confusingly. However, the DEFINITIONS of M.E. and ‘CFS’ and ‘chronic fatigue’ are very different and distinct, and it is the definitions of each of these terms that is of primary importance:

a. People with **chronic fatigue** may be tired because of cancer, Multiple Sclerosis, vitamin deficiency, a sleep disorder, depression or a large number of other reasons. Fatigue or chronic fatigue is a symptom of many illnesses. Up to 20% of the population may currently suffer from some form of chronic fatigue.

b. **Chronic Fatigue Syndrome** is an artificial construct created in the US in 1988 for the benefit of various political and financial vested interest groups. It is a mere diagnosis of exclusion (or wastebasket diagnosis) based on the presence of gradual or acute onset fatigue lasting 6 months. If tests show serious abnormalities, a person no longer qualifies for the diagnosis, as ‘CFS’ is ‘medically unexplained.’ A diagnosis of ‘CFS’ does not mean that a person has any distinct disease (including M.E.). The patient population diagnosed with ‘CFS’ is made up of people with a vast array of unrelated illnesses, or with no detectable illness. According to the latest CDC estimates, 2.54% of the population qualify for a ‘CFS’ (mis)diagnosis. Every diagnosis of ‘CFS’ can only ever be a misdiagnosis.

c. **Myalgic Encephalomyelitis** is a systemic neurological disease initiated by a viral infection. M.E. is characterised by (scientifically measurable) damage to the brain, and particularly to the brain stem which results in dysfunctions and damage to almost all vital bodily systems and a loss of normal internal homeostasis. Substantial evidence indicates that M.E. is caused by an enterovirus. The onset of M.E. is always acute and M.E. can be diagnosed within just a few weeks. M.E. is an easily recognisable distinct organic neurological disease which can be verified by objective testing. If all tests are normal, then a diagnosis of M.E. cannot be correct.

M.E. can occur in both epidemic and sporadic forms and can be extremely disabling, or sometimes fatal. M.E. is a chronic/lifelong disease that has existed for centuries. It shares similarities with MS, Lupus and Polio. There are more than 60 different neurological, cognitive, cardiac, metabolic, immunological, and other M.E. symptoms. Fatigue is not a defining nor even essential symptom of M.E. People with M.E. would give anything to be only severely ‘fatigued’ instead of having M.E. Far fewer than 0.5% of the population has the distinct neurological disease known since 1956 as Myalgic Encephalomyelitis.

A correct M.E. diagnosis can only be determined by looking at legitimate descriptions and definitions of the illness such as the descriptions of the late Dr Melvin Ramsay; a doctor with over 30 years experience with M.E., plus the excellent descriptions created by the brilliant Dr Dowsett, Dr Richardson and most especially Dr Byron Hyde the world’s leading M.E. expert, including Dr Hyde’s new Nightingale Definition of M.E. A specific series of objective scientific tests can also help confirm the diagnosis, and should be fully utilized if at all possible.
Every patient deserves the best possible opportunity for appropriate treatment for their illness, and for recovery. This process must begin with a correct diagnosis if at all possible; a correct diagnosis is half the battle won.

- For more information on what a ‘CFS’ diagnosis means, and a list of many of the illnesses most commonly misdiagnosed as ‘CFS’ see: The misdiagnosis of CFS.
- For more information on the financial and political issues surrounding the creation of ‘CFS’ and the bogus psychological paradigm of CFS see: What is ME? And Who benefits from 'CFS' and 'ME/CFS'?
- For information on how authentic M.E. is characterised and diagnosed see: Testing for Myalgic Encephalomyelitis, and What is Myalgic Encephalomyelitis? See also: The Nightingale Definition of M.E by Dr Byron Hyde – this paper is essential reading for anyone with an interest in M.E. as are the other Dr Hyde papers: A New and Simple Definition of Myalgic Encephalomyelitis and a New Simple Definition of CFS and The Complexities of Diagnosis
- For more information on why the disease category of CFS must be abandoned, including the use of confusing and misleading terms such as ‘ME/CFS’, ‘CFS/ME’ and others, see: Why ‘CFS’ must be abandoned and What is M.E.?
- If you have been misdiagnosed with ‘CFS’ and you aren’t at all sure that you have M.E. or you know for sure you don’t have M.E., then don’t despair, see the new must-read paper: Where to after a 'CFS' (mis)diagnosis?
- Note that the information given in the ‘Treating M.E.’ paper is appropriate only for patients with genuine neurological Myalgic Encephalomyelitis.

2...Avoid overexertion: More information

M.E. is primarily neurological, but because the brain controls all vital bodily functions virtually every bodily system can be affected by M.E. Again, although M.E. is primarily neurological it is also known that the vascular and cardiac dysfunctions seen in M.E. are also the cause of many of the symptoms and much of the disability associated with M.E. – and that the well-documented mitochondrial abnormalities present in M.E. significantly contribute to both of these pathologies.

There is also multi-system involvement of cardiac and skeletal muscle, liver, lymphoid and endocrine organs in M.E. Thus Myalgic Encephalomyelitis symptoms are manifested by virtually all bodily systems including: cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, gastrointestinal and musculo-skeletal dysfunctions and damage.

M.E. is an infectious neurological disease and represents a major attack on the central nervous system (CNS) – and an associated injury of the immune system – by the chronic effects of a viral infection. There is also transient and/or permanent damage to many other organs and bodily systems (and so on) in M.E.

Upon becoming ill with M.E. patients can achieve only 50% (or less) of their pre-illness activity levels. It is vital that patients stay strictly within these limits, in order
to prevent further bodily damage. The single biggest factor determining recovery and remission from Myalgic Encephalomyelitis at this point (aside from dumb luck) is undoubtedly appropriate rest and the avoidance of overexertion in the early and/or severe stages of the illness. If you have M.E. you must give yourself the best possible chance for recovery and REST appropriately.

The importance of this cannot be overestimated. It is vital that M.E. patients avoid physical over-exertion and are never encouraged to exercise (or be active) beyond their individual limits particularly in the early and acute stages of the illness, but also at any stage of the illness. There is nothing to be gained by people with M.E. pushing themselves beyond their individual physical limits as this can only result in unnecessary relapses and increased (or extreme) pain and suffering and so be counterproductive. Permanent damage (eg. to the heart) and disease progression may also be caused and there have also been reports of sudden deaths in M.E. patients following exercise (or after a long period of sustained overexertion).

Exercise or exertion intolerance is one of the many characteristics that separates M.E. so distinctly from a variety of ‘post-viral fatigue states’ or other primarily ‘fatiguing’ illnesses. M.E. should never be diagnosed without this feature being present. In addition to physical activity, relapse and symptom exacerbation in M.E. are also caused by cognitive exertion, sensory input and orthostatic stress, beyond the patient’s individual post-M.E. limits.

Note that ‘fatigue’ and feeling ‘tired all the time’ are not at all the same thing as the very specific type of paralytic muscle weakness which is characteristic of M.E. (and is caused by mitochondrial dysfunction) and which affects every organ and cell in the body; including the brain and the heart. This causes – or significantly contributes to – such problems in M.E. as; cardiac insufficiency (a type of heart failure), orthostatic intolerance (inability to maintain an upright posture), blackouts, reduced circulating blood volume (and pooling of the blood in the extremities), seizures (and other neurological phenomena), memory loss, problems chewing/swallowing, episodes of partial or total paralysis, muscle spasms/twitching, extreme pain, problems with digestion, vision disturbances, breathing difficulties, and so on.

These problems are exacerbated by even trivial levels of physical and cognitive activity, sensory input and orthostatic stress beyond a patient’s individual limits. People with M.E. are made very ill and disabled by this problem with their cells; it affects virtually every bodily system and has also lead to death in some cases. Many patients are housebound and bedbound and often are so ill that they feel they are about to die. People with genuine Myalgic Encephalomyelitis would give anything to instead only be severely ‘fatigued’ or tired all the time.

Fatigue or post-exertional fatigue (or malaise) may occur in many different illnesses such as various post-viral fatigue states or syndromes, Fibromyalgia, Lyme disease, and many others – but what is happening with M.E. patients is an entirely different (and unique) problem of a much greater magnitude.
Several studies supposedly show that graded exercise therapy (GET) is a useful treatment for ‘CFS’ but the reality is that such studies have selected patients solely on the presence of ‘chronic fatigue.’ Thus these studies are only relevant to chronic fatigue patients and not to those with M.E. (Those conducting the studies have also been found to have vested financial interests in the outcomes, unsurprisingly.) Some of the patients with primary fatigue or with a variety of different illnesses misdiagnosed as CFS may improve with exercise (or CBT; cognitive behavioural therapy) but this is irrelevant in determining appropriate treatments for M.E. patients as these patient groups are entirely unrelated. If a patient improves with exercise, that patient simply does not have M.E.

Dr Paul Cheney explained about M.E. patients that:

If patients draw down their lifestyle to live within the means of the reduced cardiac output, then progression into congestive cardiac failure (CCF) is slowed down, but if things continue to progress, a point will be reached where there is no adequate cardiac output, and dyspnoea will develop, with ankle oedema and other signs of congestive cardiac failure. In order to stay relatively stable, it is essential for the [M.E.] patient not to create metabolic demand that the low cardiac output cannot match.

As M.E. expert Dr Melvin Ramsay summarises, ‘The degree of physical incapacity varies greatly, but the [level of severity] is directly related to the length of time the patient persists in physical effort after its onset; put in another way, those patients who are given a period of enforced rest from the onset have the best prognosis.’ Patients must determine for themselves a level of activity that is not needlessly restrictive, but which stops unnecessary relapses and disease progression – and which also leaves the body with enough resources to try to heal and to restore a higher level of health and ability.

• For more information on the importance of avoiding overexertion in M.E. see: Treating M.E. - Avoiding overexertion and Assisting the M.E. patient in managing relapses and adrenaline surges plus Hospital or carer notes for M.E., The ultra-comprehensive M.E. symptom list and Why patients with severe M.E. are housebound and bedbound.

• See also What it feels like to have Myalgic Encephalomyelitis: A personal M.E. symptom list and description of M.E. and What M.E. feels like to me, Group comments on the importance of avoiding overexertion in M.E., M.E. case studies plus The effects of CBT and GET on patients with M.E. and Patient accounts of GET.

• Note that even if the diagnosis of M.E. is not 100% certain, it cannot hurt to make sure the patient rests in the acute phase of the infection. Resting is beneficial in the early stages of all viral diseases and so benefits may also be seen to some extent even if the patient turns out not to have M.E.
3...Work towards learning to accept your illness: More information
Continually denying or ignoring your illness and pushing through the symptoms and limitations (until you completely collapse) can only be counterproductive, or even dangerous. Acceptance of the limitations of the illness at as early a stage as possible is crucial to long-term outcome and will also save you many unnecessary and potentially very severe (or even semi-permanent or permanent) relapses and a lot of pain and suffering in the short and the long term.

See Coping with M.E. emotionally for further information on this topic.

4...Educate yourself (and those around you) about M.E. and seek appropriate support: More information
I. Educate yourself as much as you can medically and politically about M.E. This will help you in many ways; it will help you avoid inappropriate and bogus treatments, make you more knowledgeable about legitimate treatments and make you better able to defend yourself if you are faced with ignorant claims about the illness – and so much more. Knowledge is power! This self education is invaluable for every M.E. sufferer.

II. Educate those around you so that they will know better than to believe the baseless propaganda surrounding the illness and be more likely to give you the physical and emotional support you need (and perhaps be willing to stand up for you and your rights, if the occasion ever demands it).

III. Find out what financial support is available and what the requirements are to qualify for it if you are severely affected enough to need to do so (as most if not all M.E. sufferers will be) and make your application. (None of us ever thought we would be forced to have to rely on welfare, but M.E. gives most of us no choice in this and so there is no shame in doing what you must do to live.) Delaying this unduly may lead to serious financial vulnerability as claims may not go through as quickly as we need them to, and so the sooner you apply the better.

IV. Find out about other services in your area that might be appropriate or that you might need; meals on wheels, house-cleaning services for the disabled, housebound library services, or which local shops will home deliver, and so on. If an advocate service is available near you (and you are severely affected enough to need one) this would also be well worth looking into (an advocate is someone who will advocate on your behalf to make sure that you receive adequate medical and other care).

V. It is also important that you do your best to support yourself emotionally. For your own emotional wellbeing, it is important to stop accepting the blame for getting ill in the first place (or for remaining ill) if ignorant friends, family or doctors have been filling your head with this sort of bunkum (or trying to). It is just nonsense. Nobody causes themselves to get M.E. through anything that they did such as; overwork, ‘stress,’ a perfectionist (or type ’A’) personality, not ‘eating right’ or childhood abuse or trauma or anything else. M.E. is not a
form of burnout and even with the most positive attitude in the world you CANNOT will yourself well from M.E. It just doesn’t work like that unfortunately. (If it did almost none of us would still be ill.) Try hard not to let stupid and ignorant comments get to you, you have more than enough to cope with just dealing with the REALITIES of M.E. let alone having to deal with things people have just made up about the illness or things they say to you purely out of ignorance.

VI. One of the best ways to maintain your emotional health is to join an M.E. support group either online or one which meets in person. It helps so much to know that there are so many people who are going through the same thing as you are and that you aren’t alone. You might have to hunt around a bit to find a group that you really like and that suits you but when you do it will likely be well worth it. (Finding groups which match your own severity level is particularly important.) Hopefully you will make yourself some new friends who will help you cope with every stage of your illness, and who you will support in turn (which can also be rewarding at times).

VII. If you have tried your hardest to educate particular friends or family members about the truth about the illness but they continue to make nasty or belittling comments or to blame you for your illness (or even to withhold physical or other types of support that you need), you may have to disassociate yourself from them for the time being (if this is possible). It is important to always remember that these sorts of nasty and thoughtless comments say much more about them than about you; happy and well-adjusted people do not repeatedly heap abuse or scorn on people who happen to become very physically ill through no fault of their own. There really are no excuses for this, nobody deserves such poor treatment but especially not someone already dealing with something as horrific as M.E. If you can possibly avoid such people, you should avoid such people – for as long as they continue to act this way.

• See What is M.E.? for further information on all aspects of M.E.
• The best papers to print out to give to friends and family members about the truth about the illness but they continue to make nasty or belittling comments or to blame you for your illness (or even to withhold physical or other types of support that you need) are ‘A Million Stories Untold’ and So you know someone with M.E.? plus M.E.: The shocking disease and M.E. vs MS: Similarities and differences
• The best information for carers and hospital staff or family members on how to appropriately care for someone with M.E. is in Hospital or carer notes for M.E. and The HFME M.E. ability and severity scale checklist
• If you have M.E. see Support Groups and Coping with M.E. Emotionally.

5…Try to find a knowledgeable doctor: More information
For more information on this topic see: Finding a good doctor when you have M.E. and Testing for M.E.,
See Testing for M.E.: Plan D for discussion of the ways in which patients seek a diagnosis in practice, and a ‘Plan D’ for patients who are forced to diagnose themselves.

6...Modify your diet: More information
For more information on this topic see: Food as medicine in M.E.

7...Modify your environment: More information
It is important to use safer personal care and cleaning products and to drink filtered water. For more information on this topic see: Toxin avoidance and M.E.

8...Look into treatments for M.E.: More information
The following HFME papers focus on different aspects of M.E. treatment:

- A quick start guide to treating and improving M.E. with aggressive rest therapy, diet, toxic chemical avoidance, medications, supplements and vitamins and Deep healing in M.E.: An order of attack. If you only read two papers on treatment, these two are recommended.
- Symptom-based management vs. deep healing in M.E.
- Recognising and managing healing reactions in M.E.
- What if vitamin/mineral/protocol 'x' didn't work for me?
- Why research and try treatments when some groups claim an M.E. cure is coming soon?
- Sources of further information on the scientific validity, effectiveness and safety of orthomolecular/holistic/environmental medicine and the overwhelming problem of vested financial interest group bias in modern medicine and media
- Treating M.E. in the early stages

The following HFME papers focus on different aspects of M.E. management:

- Practical tips: Practical tips for living with M.E.
- Cognitive tips: The HFME reminders and cognitive tips list
- Tips on coping: Tips for coping emotionally with M.E.
- Adrenaline surge and relapse tips: Assisting the M.E. patient in managing relapses and adrenaline surges
- Computer and technology tips: Assisting the M.E. patient in the use of computers and technology
Treating M.E.: The basics

- Personal care tips: Assisting the M.E. patient in managing bathing and haircare tasks and Assisting the M.E. patient in managing toileting tasks
- Blood test tips: Assisting the M.E. patient in having blood taken for testing
- Tips for carers: Hospital or carer notes for M.E. and Why patients with severe M.E. are housebound and bedbound

9...Learn how to avoid inappropriate or harmful treatments and scams: More information
For more information on this topic see:

- The effects of CBT and GET on patients with Myalgic Encephalomyelitis.
- Comments on the 'Lightning Process' scam and other related scams aimed at M.E. patients
- Important notes on using the HFME's treatment information
- XMRV, 'CFS' and M.E.

10...Learn to avoid and minimise stress: More information
The most intense source of ‘stress’ in an M.E. sufferer’s life is the M.E. itself (of course) and it is completely normal to feel sad, mad, angry, irritable and frustrated sometimes because of your illness. (Indeed it would be abnormal if you did not feel these things sometimes). It is also normal and necessary for you to spend time grieving for what you have lost through the illness sometimes too; to feel sorry for yourself somewhat, and to cry as much as you need to. At other times however, you will need to try to find ways to take your mind off thinking about yourself, to try to distract yourself from such thoughts.

As with comparable neurological illness such as multiple sclerosis or Parkinson’s, along with the primary symptoms of the illness some sufferers of M.E. will also experience a smaller number of organic emotional or psychological symptoms. Possible symptoms include; emotional lability (mood swings), irritability, anxiety or panic attacks, emotional flattening or a degree of lack of inhibition. The damage to the parts of the brain which control emotion are of an identical nature to those that affect physical function; these emotional symptoms are an organic part of the illness caused by the same anatomical and physiological damage to the brain as sleep disorders, seizures or any other neurological problems or symptoms are.

Exacerbations of emotional symptoms in M.E. also tend to be linked to exacerbations in physical symptoms, there are most often not environmental triggers. The degree of severity of these symptoms varies considerably from patient to patient; some will have significant problems, others will have mild or only occasional problems and some will be unaffected. Like any other part of the illness, it is up to you (and your doctor) to try to minimise the effects of these symptoms as best you can.
If any of these emotional symptoms becomes a real problem for you however, or appears to be worsening (particularly feelings of depression, grief or sadness) and you feel you might benefit from outside help; it is important to find someone who is knowledgeable about M.E. to advise and treat you for these problems for this to be helpful. Psychologists or counsellors who see your emotional symptoms as your primary illness (rather than as a reaction to – or symptoms of – an organic and systemic serious neurological illness) and as the chief cause of your physical disabilities will be of little help and indeed (as you can imagine) could make things even worse for you emotionally. It will also pay to shop around until you find someone who you think is a good match for you; don’t expect to necessarily like the first person you see and don’t let a few bad experiences put you off if this is something you truly need. Hopefully your perseverance will pay off in the longer term.

See Coping with M.E. Emotionally and Sadness, grief, depression, anxiety and M.E. (A nutritional approach) for more information. For a list of online support groups see: Support Groups.

- You might also like to buy (or borrow free from the library), different books on stress reduction and meditation; some are better than others so keep looking until you find one you like. The most severely affected will be too ill to meditate, but if you are up to it, it can really help; not the symptoms of the disease, but help you think more clearly and feel calmer and happier.

- See The Ultra-comprehensive Myalgic Encephalomyelitis Symptom List for more about the symptoms of M.E., and stress quotes for more about stress and M.E. (and why stress can never cause anyone to have M.E.)

- Remember too that eating lots of sugar or high GL/GI foods can have a significant effect on mood and can leave you with erratic emotional highs and lows and irritability as you go into or come down off a sugar high. (M.E. means very often we tolerate sugar very poorly compared to pre-illness). You may be surprised how much more calm and in control and happy (and not at all moody!) you feel on a healthier/more appropriate diet.

- If possible, having a pet cat (or fish or dog other animal) to keep you company can help with stress and the loneliness caused by the isolation that is so often an inescapable part of M.E.

11...Learn strategies to help with the cognitive symptoms of M.E.: More information
See Practical hints for living with M.E. and The HFME reminders and cognitive tips list.

12...Consider becoming involved in M.E. activism and advocacy: More information
Start small by just educating yourself and then those around you about the facts about M.E.; friends, family and fellow sufferers. That might be enough for you (and
everyone doing just that would really help), or you might then like to look at writing letters of complaint to politicians, or to the media or to your local M.E. group; tell them what needs to change, what the real facts are and how important this is. Where you go from there is limited only by your imagination …and your illness level (unfortunately!).

- See M.E. Activism and Advocacy for more information on this topic (and for information on why many or even most M.E. groups are now some of the worst sources of information on M.E. available and how and why many are unbelievably now working directly against the best interests of M.E. sufferers). See also: Who benefits from 'CFS' and 'ME/CFS'?; What is M.E.? Why the disease category of ‘CFS’ must be abandoned; Smoke and Mirrors and Research and Articles in Context.

- See also Problems with 'our' M.E. (or CFS, CFIDS or ME/CFS) advocacy groups which is available in text form and also as an animated video.

- See also: Problems with the so-called "Fair name" campaign: Why it is in the best interests of all patient groups involved to reject and strongly oppose this misleading and counter-productive proposal to rename ‘CFS’ as ‘ME/CFS’ and Problems with the use of 'ME/CFS'

To read a complete list of the articles and resources available on HFME suitable for different groups – severe M.E. patients, M.E. patients, patients misdiagnosed with ‘CFS,’ doctors, the media, friends and family of M.E. patients, carers and so on – see the Information Guides page.
Section 2: Important notes on using HFME’s treatment information
Important notes on using HFME’s treatment information - Summary
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Please read this information before starting any new treatment.

- For the best results, an individualised nutrition and supplementation plan should be created in partnership with a qualified holistic practitioner. Ideally, this practitioner would also be the patient’s doctor. The information on HFME should be used only as an additional source of information, as a starting point for the patient’s own research efforts and for discussions with their own practitioner.

- The best results are achieved by following a comprehensive nutrition and supplementation plan, rather than only taking a small number of supplements.

- As much reading as possible should be done before starting any new treatment. Read all of the information about the treatment available on HFME in full and, if possible, some of the items in the relevant extra recommended reading sections as well. Read as much and as widely as you can.

  The information on general M.E. treatment on the HFME website is best read together with one or more (or all) of the following books: The Vita-Nutrient Solution, Orthomolecular Medicine for Everyone: Megavitamin Therapeutics for Families and Physicians, Fire your Doctor: How to be Independently Healthy and The Optimum Nutrition Bible (and also perhaps one of the books on vitamin C). Borrowing or buying these books and combining the information in them with the information on the HFME site (or book) is highly recommended.

- Before starting any new treatment the patient should: (a) make sure they are aware of all the cautions relating to using it safely, such as whether it must be taken with food or not, with other related supplements or in divided doses, (b) check that it is compatible with all current medications (and supplements) being taken, (c) check that it is safe for any other conditions they may have (such as diabetes or kidney problems), and (d) discuss it with their doctor or qualified holistic practitioner (if at all possible).

- Any new supplement should be started at a low dose and the dose should only be raised gradually. If you are sensitive to supplements, start at minuscule dose: perhaps 1/10th of the normal dose or less, or a few crumbs of a crushed tablet taken once a week. Try only one new treatment at a time, if possible. (Simultaneously starting 3 or 4 or more of the treatments listed in ‘A quick start guide to treating and improving M.E.’ may cause problems.)

- It should not be assumed that ‘natural’ means safe. Vitamins, minerals, enzymes and herbs etc. taken at medicinal doses can have drug-like effects and
can potentially cause significant relapse or worsening of some symptoms. Reading as much as you can about each treatment and starting very slowly are important with EVERY treatment.

- Taking supplements is not a replacement for eating well, getting enough rest and avoiding overexertion, having good sleep habits, limiting emotional stress and avoiding toxic chemical exposures. There is little point in giving the body the substances it needs to try to heal itself while at the same time causing more damage in other ways.

- The treatments mentioned here are certainly not miracle cures for long-term M.E., and no promises can be made about outcomes.

  Promises of easy cures in many books and articles should be treated with the contempt that they deserve! Many of these contemptible false promises are made on the false assumption that ‘CFS’ means M.E., made in many general books and articles on health, nutrition and vitamins. Some diseases misdiagnosed as ‘CFS’ may well be easily treated and cured, but this has no relevance to M.E. patients any more than it does to MS patients.

  Particular treatments will not necessarily give particular outcomes. The aim here is to give your body its best possible chance to at least partly heal itself by giving it some of the basic tools and materials it needs to heal itself. No specific level of improvement can or should be guaranteed, with any treatment.

- HFME's collation of information on M.E. treatment is and will always be a work in progress, as with any guide to treatment. M.E. patients and M.E. experts are always invited and encouraged to submit any additional information or comments they may have. It is recommended that readers periodically check the HFME site for updates.

- Please read the full-length version of ‘Important notes on using HFME’s treatment information’ for more information

**Disclaimer:** HFME does not dispense medical advice or recommend treatment, and assumes no responsibility for treatments undertaken by visitors to the site. It is a resource providing information for education, research and advocacy only. In no way does reading this site replace the need for an evaluation of your entire health history from a physician. Please consult your own health-care provider regarding any medical issues relating to the diagnosis or treatment of any medical condition.

**Acknowledgments:** This paper has been edited by Lesley Ben.
Please read this information before starting any new treatment for your condition.

**Introduction**

- Please note that it is extremely important to obtain an accurate diagnosis before looking into useful treatments. Many diseases and conditions share common symptoms. If you treat yourself for the wrong illness (or a specific symptom of a complex disease without looking at the cause of these symptoms) you may delay legitimate treatment of a serious underlying problem and/or make some of your symptoms worse. The greatest danger in self-treatment is most likely to be self-(MIS)diagnosis.

- If possible, find a doctor that is also an expert in nutritional medicine, orthomolecular medicine or that says they practice holistic medicine. This way you get the best of both worlds test and treatment-wise, and you also raise the chances significantly that your doctor will be savvy to the amount of spin and financial bias in the medical culture. They may be more likely to be able to disregard the ridiculous misinformation about M.E. that is so common and be wise enough to treat you for the disease/physical problems you actually have (although some of course will still believe the ‘CFS’ nonsense is real, and applies to you and to M.E., so you do still have to keep trying different doctors until you find a sufficiently intelligent and educated one). Various websites provide lists of holistic or orthomolecular medicine experts in each country. Use Google to find them.

  If it is not possible to find a doctor that is also a specialist in orthomolecular medicine, it may be necessary to work with both a doctor and an orthomolecular medicine expert to get the best treatment advice. The best person to diagnose you correctly is not always the best person to offer you treatment advice, and vice versa.

  (Unfortunately there are a large number of very poorly trained naturopaths, acupuncturists and nutritionists etc. out there that will give very incomplete, substandard or even dangerous medical advice. Just as importantly, such individuals should not be trusted with the task of diagnosing you with ANY condition, as they are simply not qualified to do so and lack access to the appropriate testing. A lot of money can easily be wasted with this type of poor quality services, serious relapses can be caused by inappropriate treatments and there can also be a high emotional cost. The emotional cost of false promises and
false hope or actually being blamed for the naturopaths lack of skill and your own lack of improvement, as often happens, can be enormous.

To be clear, most mainstream doctors also provide a similarly low quality service to M.E. patients. They too can not be trusted to provide correct diagnosis or treatment, will often make the patient far more ill by recommending inappropriate treatments and/or give false hope of recovery based on statistics for Candida or PVFS, and so on. Trying to find a good quality health professional that will do more good than harm is very difficult for most M.E. patients.)

- For the best results, create an individualised nutrition and supplementation plan in partnership with a qualified holistic practitioner. (Ideally, this person would also be your doctor.) Use the information on HFME only as a starting point for discussions with your own practitioner and your own research efforts.

- The best results from supplementation come from following a comprehensive nutrition and supplementation plan, rather than taking a small number of supplements in isolation.

   It is probably better to take a larger number of things at a smaller dose, than just a few things at very large doses; that way you make sure no important bases are left completely uncovered. The general idea of orthomolecular medicine is that it is probably a better idea to improve your health generally, by giving your body the raw materials it needs to heal all of itself, rather than just chasing and trying to treat dozens of individual symptoms one by one or looking for medications which just mask symptoms while doing nothing to actually improve what is causing them, or indeed masking symptoms while making the actual problem even worse.

- Before starting any new treatment read as much about it as you can. Read all of the information about it available at the HFME in full and, if possible, some of the items in the relevant extra recommended reading sections as well. Read as much and as widely as you can. The information on general M.E. treatment on the HFME website is best read together with one or more (or all) of the following books: The Vita-Nutrient Solution, Orthomolecular Medicine for Everyone: Megavitamin Therapeutics for Families and Physicians, Fire your Doctor: How to be Independently Healthy and The Optimum Nutrition Bible (and also perhaps one of the books on vitamin C). Borrowing or buying these books and combining the information in them with the information on the HFME site (or book) is highly recommended. (See the book reviews page on the HFME website for information on each book.)

   This is about personal responsibility for your health. Unfortunately no-one else can do all of this for you! Almost certainly, nobody is as motivated as you are to get yourself well, not even your doctor. Please take in as much information on treatment as possible. The best results come form a partnership between doctor and patient. Being passive is much easier, but it not at all linked with the best outcomes.

- Before starting any new treatment (a) make sure you are aware of all the cautions attached to using it safely, such as whether or not it must be taken with food, with other related supplements or in divided doses etc. (b), check that it is compatible with all current medications (and supplements) being taken, (c) check that it
is safe to take when any secondary conditions you may have (such as diabetes or kidney problems) are taken into account and (d) discuss it with your doctor or qualified holistic practitioner (it at all possible).

The information on HFME is a general guide only, and cannot possibly take into account the medications and additional diagnoses YOU may have. You must also do your own research if you have these other issues.

- If you are taking more than the basic amount of anything, it is especially important to read up on it first if you can to avoid problems that could, with the right knowledge/precautions, have been easily avoided.

- Be aware that taking some supplements may mean changing or stopping some prescription medications. When taking blood sugar lowering drugs, adding chromium or high dose vitamin C will likely mean you need less of that drug or be able to stop taking it, and the same is true with heart drugs and hawthorn. Vitamins and herbs can be just as powerful as drugs, and if you change what supplements you take this will likely affect the amount of drugs you need. Always discuss slowly lowering the doses of drugs, where appropriate, with your doctor. (The same doctor which prescribed them for you.) Do not stop taking any medication suddenly.

  As Dr Atkins explains however, this process may be far easier said than done if the doctor that prescribed the medication for you has little or no knowledge of nutritional medicine. If this is the case Dr Atkins suggests trying to educate your doctor about nutritional medicine. If your doctor refuses to learn, find a new doctor that will or, even better, a new doctor that is already an experienced nutritional medicine expert.

Starting treatments gradually and managing intolerances to supplements

- Start any new treatment at a low dose and only raise it gradually. If you are sensitive to a wide variety of supplements, start at a minuscule dose: perhaps 1/10th of a normal dose or less, or a few crumbs of a crushed tablet taken once a week. Where you have a gel capsule or similar product which can’t be broken up into crumbs, you might instead take one full capsule (of a low strength) a fortnight to start with and work up from there slowly. It might be best to take 3 or 4 months to work up to taking a full dose of a supplement.

- Try only one new treatment at a time, if possible, so you know exactly what it is that is helping or causing problems. The items mentioned in the ‘A quick start guide to treating and improving M.E.’ treatment list should never all be tried at once. This could only guarantee problems of some kind. The body likes gradual change.

- Do not assume that 'natural' means safe. Vitamins, minerals, enzymes and herbs etc. taken at medicinal doses can have drug-like effects and can potentially cause significant relapse or worsening of some symptoms. Reading as much as you can about each treatment and starting very slowly are important with EVERY treatment.
Most of the supplements mentioned in ‘A quick start guide to treating and improving M.E.’ will probably be well tolerated. However, some M.E. patients in particular have problem tolerating all but very few supplements, and sometimes even those who generally tolerate vitamins well will have an unexpected problem with one or two particular products. Problems tolerating a supplements my be felt as a worsening of your general condition, headaches, stomach aches, feeling more unwell than usual or in very rare cases, anaphylaxis.

Some M.E. patients have a hard time tolerating many basic supplements. A last attempt at these supplements for these patients may be to only take each problematic supplement once every 4 - 7 days, and see if that avoids the problem. You might also try the patches and cream products available with some supplements.

Some nutritional experts suggest that sometimes a paradoxical negative reaction can occur to some supplements because the body is very low in that particular vitamin. Some supplements may also provoke new symptoms which are not merely annoying side-effects but instead healing reactions that mean the supplement is working and doing what it is supposed to. (For example, vitamin C and garlic can cause detoxification reactions). Feeling somewhat worse after starting a new supplement is not always a bad sign. To minimise such symptoms, start at a low dose and build up the dose very slowly.

Some reactions to medications are actually reactions to cheap fillers used in pills and capsules, or gels made using plastics/petrochemicals. Switching to a different brand, or a pure powder, may solve the problem. In some cases you may be able to get around this problem by buying supplements in a pure power form and either taking them in water, or making your own capsules by buying an inexpensive capsule machine and some empty capsules. (Do not try this if you are severely affected by M.E. as it is hard work!) This can save you money too.

If you are sensitive to fillers etc. it is also a good idea to look for very concentrated products such a products which contain a whole day’s dose of a substance in one drop, for example. If you often have problems such as this, make sure you only ever buy one small bottle of a product, until you know you will be able to tolerate it and look our for brands which are more careful than most about which types of fillers they use.

Buy powders where it is appropriate, to avoid cheap fillers used in pills and capsules.

Another way to avoid taking in unnecessary substances with supplements is to cut open soft gels and to swallow the contents with some water, and then throw away the empty capsule. This saves your stomach from having to work to digest and dissolve the tough gelatine/glycerine capsule. This is NOT recommended for terrible tasting supplements such as fish oil but may work well for others with a very mild and inoffensive taste such as ubiquinol and vitamin E. (The only way to find out which supplements this may be appropriate for is to conduct taste tests.)
Note that while HFME provides some information about drug and herb interactions and other treatment cautions it should not be assumed that this comprises a complete list of cautions. It does not. This is why further reading of general health books and other relevant information is recommended.

**Evaluating benefits from supplementation and determining maintenance doses**

- Supplements must be tried for a minimum of 3 - 4 months before a judgement can be made on effectiveness. While many effects are seen in weeks or months, it may actually take 4 - 6 months up to 2 years for the full benefits to be seen. In other words, benefits may keep increasing for up to 2 years! (Major portions of the body are rebuilt in 2 to 4 months. All of the soft tissues in the body recycle every two years. So very noticeable results should be achievable, realistically, in a 4 month to 2 year time period.)

- Before taking any supplement, educate yourself about what the usual starting and long-term dose of a substance is, and the highest dose that is routinely taken and that may be taken safely. Calculate a suitably low starting dose and then slowly raise the dose, monitoring any changes in your condition carefully. Let how you feel be your guide to your correct dose (along with the appropriate testing, if at all possible). At a predetermined point (which should be well before any issues with toxicity could arise) stop raising the dose and instead merely maintain it.

- Take supplements until you see a benefit (within safe dosage levels), then stop taking them to see if the benefit disappears, then start it again to see what happens. If you can, do this once or twice with each supplement to make sure they are a good use of your money.

- Keep a weekly list of what medications you change, and how you felt that week and so on. This can be very brief. Monitor yourself for the effects of each new treatment to help you and your doctor decide what is working and what is not.

- Orthomolecular doctors have commented that with treatment at first you may just look better. Then you may notice that you feel better and last to come may be the ability to function better. These experts also say that diseases which you have had for a very long time will be much slower to improve than newer onset diseases.

- While some treatments demand a stable higher dose for benefits to be maintained, the dose you need when starting a treatment may be higher than the maintenance dose in some cases. Taper your dose down slowly until you find the lowest amount of it you can take while still seeing the same benefits.

- If at all possible, take your pills at 2 or even 3 separate times daily, perhaps having a different pill box for each of your three main meals. The more you divide your doses, the more of the supplement you will absorb – this is especially true of water soluble vitamins such as the B vitamins.

- Information given on dosages by the HFME is only a very general guide. Again, the HFME papers are designed to be merely a starting point in your research on dosages and treatments, not by any means the last word. If it is at all possible for you, it is highly recommend that you do as much extra reading from high quality
Treating M.E.: The basics

resources as possible. At the very least, PLEASE READ the full ‘Treating M.E.’ paper (or book) which gives more information about these treatments and, just as important, what to AVOID with treatments. If possible, read all or at least one of the first four books listed previously.

• While various books and websites are recommended for extra reading, M.E. patients should be very cautious about solely relying on such non-M.E. specific information to determine how likely they would be to react badly to certain substances at certain dosages.

For example, many books on general health advise that taking 300 – 600 mg of lipoic acid can help many conditions and is well tolerated. However, this is a supplement that many or even most M.E. patients have to go very slowly with and take only at doses of 100 mg or less. So taking 300 – 600 mg of lipoic acid may be fine for many people, but for those with M.E. taking such a dose even for a few weeks could lead to a severe reduction in ability levels and symptoms (anywhere from 40% and upwards) that will last for several months, as lipoic acid is fat soluble and takes a long time to leave the system. Similar examples could be given for TMG, cysteine, garlic, inosine and various other supplements (and other substances).

Some supplements will not be tolerated by M.E. patients at any dose, others may be well tolerated by some patients but not by others. M.E. patients may have to work up to a full dose of some supplements very slowly to avoid problems while for others, the best way to take it to work up slowly to a much lower dose than would normally be recommended.

It is recommended that general books on health be read together with the ‘Treating M.E.’ paper which at least points out some of the most well-known problems M.E. patients have in tolerating certain supplements and medications. Generally speaking, notes on tolerance in general health books should be ignored by M.E. patients and no treatment should just be started suddenly at a full dose (as is often advised) and without acknowledging the possibility of tolerance issues.

• Do not rely on any one book or website for all your information (including this one).

Further notes on dosages

• Children’s dosages are usually worked out based on their body weight percentage compared to a full-grown adult, however there are some exceptions and a small percentage of supplements which are not appropriate for children so please read as many of the books listed in the reference sections as possible if you have a child with M.E..

• Dosages given in this guide are designed to be suitable for those with M.E., a serious neurological disease. Seriously ill patients require far higher amounts of certain vitamins than healthy people. The dosage information given in this paper should NOT be used to determine correct dosages for any supplement for healthy people.
Measures: 1 gram (g) is equal to 1000 milligrams (mg). 1 milligram (mg) is equal to 1000 micrograms (mcg).

Click here to download a free M.E. medication – and medication budget – chart in Word format, from HFME.

Notes on importing supplements

- Make sure you are allowed to import each supplement into your country if you are buying from overseas companies, to avoid fines and products being seized. The laws vary considerably in each country.

References and updates

- The information on M.E. treatments provided by the HFME is a summary and amalgamation of (a) the work of M.E. experts such as Dr Hyde and Dr Dowsett, (b) the pathology of M.E. as described by these experts and what it tells us about possible similarities to other diseases that are lucky enough to have had a lot of research funding, (c) nutritional medicine research, (d) information provided by the world’s leading nutritional and orthomolecular medicine experts (many of whom are also doctors and have treated many thousands of patients) and where possible, (e) the leading experts in the particular vitamin or nutrient being discussed.

The information on tolerance of medication and supplements by M.E. patients has been taken in part from the books listed in the references section and also from the author’s extensive reading on M.E. and the treatment of disease and use of nutritional supplements in general, the author’s own experiences as an M.E. patient (to a limited extent) and, more importantly, the author’s own experiences in talking to thousands of M.E. patients at length about all issues relating to M.E., for the last decade. (Both in public groups and privately.)

The HFME’s aim is to summarise (and simplify) as much of this information as possible, for the benefit of M.E. patients that are severely restricted in their ability to read, due to M.E. and that could not get all of this information any other way. While further reading is highly recommended if at all possible, for some patients, even reading this information will be an enormous struggle or impossible.

- Attempts have been made to use as many different sources of information on nutritional or orthomolecular medicine as possible and to find the highest quality information on each topic. Readers that feel that certain other books or articles would be useful additions to those already sourced are invited to submit them to the HFME. (Please provide the appropriate details and references.) Accuracy is very important to the HFME.

- For practical reasons, each comment on treatment has not been individually referenced. To read a list of the books, articles and websites used to inform each HFME treatment paper, see the references section at the end of each paper or the main references section.
Any overview of nutritional, orthomolecular or herbal medicine, or on the treatments most important for those with M.E., will always be a work in progress. The information provided on this site (or indeed, any site or book) should not be considered ‘the last word’ on any topic. This information will continue to be updated on the HFME website at least on an annual basis for some time to come as more information comes to light and as more research is produced.

The HFME’s collation of information on M.E. treatment will always be a work in progress, as with any guide to treatment. M.E. patients and M.E. experts are always invited and encouraged to submit any additional information or comments they may have, particularly on issues related to how well certain treatments are tolerated and problems they may cause. It is also recommended that readers periodically check the HFME site for updates.

**Final points**

- Taking supplements is not a replacement for eating well, getting enough rest and avoiding overexertion, having good sleep habits, limiting emotional stress and avoiding toxic chemical exposures. There is little point in giving the body the substances it needs to try to heal itself while at the same time causing more damage and problems.

- The treatments listed here are not any type of miracle cure for long-term M.E., and no promises can be made about outcomes. (Promises of easy cures in many books and articles should be treated with the contempt that they deserve! As should the assumption that ‘CFS’ means M.E. in any of these general books and articles on nutrition and vitamins etc. Some diseases misdiagnosed as 'CFS' may well be easily treated and cured, but this has no relevance to M.E. patients any more than it does to MS patients.) Treatment a, b and c together will not always give you outcome d. The aim here is to give your body its best possible chance to at least partly heal itself by giving it some of the basic tools and materials it needs to heal itself. No level of improvement can or should be guaranteed, with any treatment.

- The scientific validity and safety of nutritional, orthomolecular and holistic medicine is well established, although this is as yet not widely acknowledged in mainstream media or medicine (and so society in general) primarily for reasons involving politics and financial vested interests. Despite this, of course not all patients are willing to deviate from mainstream drug-based medicine. This is their individual choice and must be respected. The HFME fully respects such a decision and a patient’s right to make it. The information on treatment provided by the HFME, however, is for those patients that do have a genuine interest in this type of medicine or that are at least interested in finding out more about it.

- For information about the HFME and the aims of the HFME please see the About HFME page.

**Disclaimer:** The HFME does not dispense medical advice or recommend treatment, and assumes no responsibility for treatments undertaken by visitors to the site. It is a resource providing information for education, research and advocacy only. In no way...
does reading this site replace the need for an evaluation of your entire health history from a physician. Please consult your own health-care provider regarding any medical issues relating to the diagnosis or treatment of any medical condition.
Opinions vary widely about all aspects of treating serious diseases.

In the following discussion papers I’m combining a summary of some of the available research and a personal opinion based on my own experiences on a number of topics related to treatment that are not widely discussed, in the hopes it may help others in the same position that I was in a few years ago. I would never ask or expect anyone to blindly substitute my opinion for their own and do not claim to be presenting the ‘last word’ in Myalgic Encephalomyelitis (M.E.) treatment or to have all the answers. It’s designed to be food for thought.

These are my current conclusions but they may change over time somewhat with more reading and more input from others. Learning about health and healing is a never ending process.

Parts of these papers are specific to M.E. but much of the content would be equally appropriate for any other serious neurological or other disease.

Even if you have very different ideas from my own about treatments, I hope that you will find some of the information here useful or helpful to you in some way.

Individual papers in this section include:
- Symptom-based management vs. deep healing in M.E.
- Recognising and managing healing reactions in M.E.
- What if vitamin/mineral/protocol ‘x’ didn't work for me?
- Why research and try treatments when some groups claim an M.E. cure is coming soon?

Disclaimer: The HFME does not dispense medical advice or recommend treatment, and assumes no responsibility for treatments undertaken by visitors to the site. It is a resource providing information for education, research and advocacy only. In no way does reading this site replace the need for an evaluation of your entire health history from a physician. Please consult your own health-care provider regarding any medical issues relating to the diagnosis or treatment of any medical condition.
Myalgic Encephalomyelitis (M.E.) is a difficult disease to treat. The idea that you would try a lot of different treatments one by one, discarding those that make you feel more ill and continuing with those which decrease symptoms or disability, seems like a ‘no brainer.’

Unfortunately, due to something known as a ‘healing reaction’ the problem is not at all that simple.

Many different nutrients and therapies can cause problematic symptoms and side effects which are an indication that the treatment is not a good fit for you and should be discontinued. However, some supplements and therapies may also provoke symptoms which are not merely annoying side-effects but instead healing reactions that are a very good indication that the nutrient or therapy is working and doing what it is supposed to.

It may seem counter-intuitive but this means that feeling somewhat worse after starting a new treatment is not always a bad sign. Sometimes, it is a very good sign and even an essential sign that deep healing is occurring.

In his must-read article ‘Deep Healing Versus Symptom Removal’ Dr Lawrence Wilson writes,

Deep healing is quite different from symptom removal. Symptom removal is the type of doctoring offered by the medical profession and by most holistic doctors as well. Symptoms are the focus, by and large, and the goal is to make them go away. The problem is that symptoms often point to deeper imbalances that are not usually not addressed.

Deep healing is a much more profound process. It has to do with restoring the body to its former state of health. This means restoring its energy production system, its oxidation rate, its minerals ratios and much more. Symptom removal occurs as a “side effect” of these programs.

Healing therefore usually takes longer and involves lifestyle changes as well. It is more work for both the client and the practitioner. Lifestyle, in fact, is always central and this is a good way to tell if your doctor is focused on symptoms or on deeper healing. In the long run, however, it saves time and lots of money, and may save your life as well.
It is important that the symptoms from healing reactions remain at a level that the patient can handle however. Very intense healing reactions can be more than your body can cope with and can even be dangerous and potentially fatal in some cases. M.E. patients in particular must go very slowly when it comes to treatments causing healing reactions. Slow and steady progress is the goal.

What treatments can cause healing reactions and what symptoms can they cause? Healing reactions can be caused by treatments which boost antioxidant status, promote detoxification, the clearing of infections or which allow various enzyme reactions to take place which were not possible before or by anything that helps the body to heal and to function better.

The symptoms of healing reactions can include muscle cramps and spasms, aches and pains, rashes, strange odours and tastes, heart palpitations and blood pressure changes, tiredness, gastrointestinal or bowel changes, foggy thinking, headache and nausea, or a worsening of the illness generally.

(Additional practical information is given on managing healing reactions in the other sections.)

Why are symptomatic approaches so popular?
In his excellent article ‘Deep Healing Versus Symptom Removal’ Dr Lawrence Wilson explains that symptomatic approaches are so popular because:

1. They appear simple. This means they are largely superficial and easily understood by doctors and patients alike. Balancing methods are much more difficult to comprehend and to practice, as well.
2. Doctors, drug companies and hospitals love them. This is sadly the case because the patients never really get well. They always come back with the next symptom or problem, so it is good for business. Even the socialized medical systems of Europe, Canada and elsewhere continue this stupid and costly methods of drug medicine. Most holistic physicians are still recommending symptomatic treatments, in my estimation. Many are still interested in having the patient come back many times. Many feel they simply cannot stay in business if they truly healed people. Therefore, no matter what they profess, they are less interested in deeper balancing methods that actually heal the patient at deep levels. However, overall they are much better than conventional medical doctors I have met.
3. Symptomatic approaches ask very little of the patient in most cases. The person is allowed to keep eating junk food, skip adequate rest and sleep and ignore the problems in their lives.

Why are symptomatic approaches so problematic?
The problem with symptomatic approaches to treating serious diseases includes that,
They are superficial and don’t deal with the causes of illness.

They are very costly as the patient is never healed and so needs continual retreatment and side-effects cause additional symptoms which must then also be treated which means that a patients requires more care over time rather than less.

Adverse events and unintended consequences often occur. Diuretic drugs may dangerously lower potassium or magnesium levels, for example, or stain drugs may dangerously lower CoQ10 levels. Antibiotics drugs may also kill all the ‘good bugs’ in a person’s system, leading to yeast infections and other secondary problems. Adverse events may be mild while others kill people every day.

They tend to mask deeper problems by eliminating warning symptoms. As Dr Lawrence Wilson explains:

Simple fatigue can signal a small cancer in the body or a pending heart attack. However, most doctors, faced with this common complaint, do little or no testing to find out if something deeper is amiss. Instead, they may advise the patient with fatigue to exercise more, take a nap, take a vacation or worse, have a cup of coffee or tea. By following this advice, however, the patient often masks or obscures the original symptom of fatigue. This often leads to worse problems in the following months or years.

In her excellent book, Detoxify or Die, Dr Sherry Rogers writes,

You and your doctor have been screwed into believing every symptom is a deficiency of some drug or surgery. You've been led to believe you have no control, when in truth you're the one who must take control.

Unfortunately, the modus operandi in medicine is to find a drug to turn off the damaged part that is producing symptoms. A simple example is the prescription of calcium channel blockers, the number one drug used by cardiologists for angina, hypertension, congestive heart failure, or arrhythmia. But as with any drug, this does not fix anything that is broken. It merely poisons normal physiological pathways, thereby forcing the chemistry in a direction that attenuates symptoms.

Since nothing has been done in terms of getting rid of the underlying cause, the disease continues. In addition the missing fatty acids and minerals in the cell membranes that house and calcium channels are not identified and repaired. Nor are the sequestered membrane chemicals that caused the damage, like unavoidable PCBs and Mercury, gotten rid of. If this were not enough perpetuation and acceleration of damage, the side effects of drugs are not innocuous. For example, calcium channel blockers have been shown by MRI to cause definitive shrinkage of the brain and loss of brain function, a side effect rarely mentioned by clinicians or news media.

It should not come as a shock that this type of information is ignored, since studies in the Journal of the American Medical Association document how the practice guidelines for American medicine are made by physicians who receive compensation from the drug industry. (Choudhry, JAMA 2002; 287: 612-617). In addition so is the FDA, the very government regulatory body that approves drugs,
riddled with advisers with financial ties to (and is heavily lobbied by) the very
drug industry that is seeking its approval. And as the New England Journal of
Medicine and Journal of the American Medical Association warm, even the hired
clinical investigators for new drugs may have their price.

**Why is deep healing safer than much of the symptom-based and drug-based medicine available?**

Dr Sherry Rogers explains that with treating the causes of disease, ‘A life sentence to
medications that block physiologic pathways is avoided.’ She continues,

Bear in mind that since medications do not fix anything, they allow the underlying
problem to continue uncorrected and actually accelerate. Meanwhile, new
symptoms and new seemingly unrelated diseases are the inevitable consequence
of this biochemical faux pas.

Furthermore, drug side effects are the leading cause of death. The Journal of
the American Medical Association shows that far in excess of 106,000 people die
per year in hospitals from diagnosed drug side effects. But as former FDA head
Dr. David Kessler has shown in the same journal, less than 1 percent of adverse
medication reactions are reported to the FDA. As other researchers have shown,
over 16,000 people die each year just from gastrointestinal hemorrhaging from
NSAIDs, while another 100,000 get congestive heart failure from them. As well
NSAIDs cause osteoporosis and hip and knee degeneration, necessitating joint
replacement. And these are just some of the side effects of one category of drugs.
NSAIDs as an example of only one group of medications, are fatally toxic to
thousands of people each year by damaging joints, lungs, kidneys, eyes, hearts,
and intestines. And they are covered by insurance.

No wonder the Journal of the American Medical Association study shows the
death by prescribed drugs in the hospital's is the number four cause of death in
United States. But that study ignores the hundred thousand people who get
congestive heart failure each year just from the NSAIDs. This would more than
double the statistic making drug reactions in hospitalized patients the number
three cause of death. And this does not look at death outside of the hospital, nor
deaths unrecognized as being attributable to drug side effects. As Dr. David
Kessler, previous head of the FDA, has reported in the Journal of American
Medical Association a maximum of 1-5 percent of adverse medication effects get
reported to the FDA.

**Immediate benefits with treatment may not be benefits at all**

Some of the treatments which may have little or no effect or make you feel more ill at
first may in fact be the best ones for you. It is also possible that some of the
treatments which make you feel better very quickly are the ones that you should
strictly avoid!

Dr Paul Cheney recently commented that patients should in fact be very wary of any
treatment which causes an improvement in disability levels within hours or days. He
saying (note that some of this text has been helpfully paraphrased by other authors rather than being a word for word exact excerpt from Dr Cheney’s lecture):

Fundamental therapy does not instantaneously result in improvement. As a matter of fact, anything that would improve you within a matter of minutes, hours, or days is, in fact, not therapy at all. It is palliation—symptom suppression—which in fact may not be helping you at all.

Symptoms are usually manifestations of defence responses and reflect but do not cause the underlying problem.

Symptom-based treatment alone is therefore flawed at best and dangerous at worst: to treat symptoms without understanding the underlying disease process can cause death: the third leading cause of death is treatment by physicians, which kills 250,000 people per year (the first being heart disease and the second being cancer) -- most drugs are not aimed at the primary cause of disease but at symptoms and are therefore dangerous.

If you fix the defence mechanism, at some deep level you can worsen symptoms.

This is such an excellent and very important point, I’m tempted to print it here in 20 point bold, italicised and flashing type in lurid green with pink stripes!

For example, the drug Provigil makes some patients feel better right away perhaps because it stimulates nitric oxide production, but over time, this drug actually makes the underlying condition worse, and can leave the patients much more ill than they were before they began it. The same is true of the many stimulant drugs sometimes prescribed to treat ‘fatigue.’ Like caffeine, they may enable more to be done at first, but over time the patient ends up more ill. Forcing the body to rely on detrimental adrenaline bursts to get tasks done, or blocking the mechanisms of the disease which help prevent further damage from taking place are not good long-term strategies, although they may appear to help in the short term, unfortunately. Patients may often notice symptoms improving and perhaps abilities improving but that they do not feel more well, or they feel less well generally than previously.

Compare this to nutrients such as ALA (alpha lipoic acid), vitamin C, iodine, magnesium and programs involving juicing and sauna use. These treatments contribute to real healing, and so almost always make patients feel somewhat sicker before they feel better. They also take at least 6 months if not a year or two before the full results are seen. These types of healing treatments also work far better when they are used in combination, and as part of a comprehensive treatment regime, and not singly.

If a person were unaware of the fact that a positive initial effect were not always positive, and a negative initial effect were not always negative one may very easily come to the completely twisted conclusion that stimulants and drugs such as Provigil were the most effective treatments for M.E. and that ALA, vitamin C, iodine, magnesium and anything that boosted antioxidant status or promoted detoxification should be strictly avoided. There is also a real danger that ignorant physicians may
come to this conclusion, particularly where M.E. patients are mistreated as patients suffering primarily with mere ‘fatigue’ with no serious pathology.

**What is this type of medicine called?**

I’m told that what I am describing here is probably best referred to as a combination of orthomolecular medicine, environmental medicine and holistic medicine. Although really it is just good medicine.

**Orthomolecular medicine** (also sometimes known as nutritional medicine) is a system for the prevention and treatment of disease based on the knowledge that each person’s biochemical environment is genetically determined and individually specific. Therapy involves supplementation with substances naturally present in the body (for example vitamins, minerals, trace elements and amino acids) in the optimal amounts for that individual at that time to correct nutritional deficiencies and the resulting biochemical abnormalities. The term ‘orthomolecular’ was devised by Nobel Prize winner Dr Linus Pauling and loosely translated means ‘the right molecule in the right amount.’

**Environmental medicine** deals primarily with the effects of the environment on humans including water and air pollution, toxins and other problematic substances in food and in the products we use, vaccinations and travel.

**Holistic medicine** is a system of medicine which considers man as an integrated whole, or as a functioning unit. It is characterized by its focus on the whole person as a unique individual, on the energy of the body and its influence on health and disease, on the healing power of nature and the mobilization of the body's own resources to heal itself, and on the treatment of the underlying causes, not symptoms, of disease.

Other terms may also be used, such as nutritional balancing, nutritional medicine, biomedical treatment, integrative medicine, functional medicine, nutrigenomics and natural medicine etc., and others may prefer to avoid any type of new terminology whatsoever.

Standard and cutting-edge testing also plays an important role in some aspects of this type of medical care, as do some ‘mainstream’ medical practices. (The term mainstream is problematic as what is mainstream in one country may be referred to as ‘alternative’ in another.) All useful treatments and tests are used, without bias. The best is taken from each different type of medicine and all of the resources that are available. Many orthomolecular, holistic and environmental practitioners are also doctors.

The best of all worlds is to find a trained doctor that also specialises in holistic, environmental or orthomolecular medicine. Advice can be sought on individual issues by nutritionists, detoxification experts, dieticians and experts in any one of a number of relevant fields. But only doctors have range to the full array of tests,
treatment and knowledge. For more information see: Finding a good doctor when you have M.E.

Good doctors in this field have a lot to offer M.E. patients. Far more than very nearly all ‘CFS’ or ‘ME/CFS’ or ‘CFIDS’ specialists or centres, most of which deal with ways of coping with mere ‘fatigue’ which are inappropriate or harmful for those who actually have M.E.

What are some basic principles of this type of medicine?
There are 3 basic principles:

1. Get the good stuff in. Give your body the fuel and tools it needs to work at an optimum level. Good food, nutrients and all the proper vitamins, minerals and antioxidants. Make sure you aren't deficient in anything important as the different nutrients all work together.

2. Get the bad stuff out. Make sure your body can detoxify out all the toxic substances and toxic by-products of bodily processes properly. Stop as many toxins from getting in in the first place, and do a detoxification program to get rid of the ones you have. Stop doing or eating the things which cause inflammation and have a pro-oxidant effect, and so on.

3. Reduce your body’s total load. The total load concept is that lessening the body’s overall burden/work and stress level in one area, will improve health generally and improve the body’s ability to heal because the body’s total load (or burden) is lessened. Fixing one problem frees up bodily resources that can be then be used to help other parts of the body function getter or to heal.

A good orthomolecular or nutritional expert will also help you:
- Avoid toxins and anti-nutrients
- Avoid anything you react badly to or are allergic to in your diet
- Heal the gut and improve digestion
- Start a detoxification regime
- Eliminate secondary infections (infection in the teeth, or parasitic infections etc.) and treat the primary infection, if present/still active
- Educate you about how to eat well and to lower insulin and blood sugar levels (by eating the ratio of protein, fat and carbohydrate that suits your body best)
- Boost the immune system
- Boost mitochondrial function
- Boost antioxidant levels
- Reduce inflammation
- Make sure you have the optimum amounts of the most important nutrients
- Avoid causing further damage by excessive stress including oxidative stress (in M.E. this would include avoiding overexertion)
• Try to heal or restore the function of other areas in the body which need attention, specific to each individual disease. (In M.E. this may involve supporting good cardiac function, metabolic function, adrenal and thyroid function and repairing the myelin sheaths)

Addressing all of these things takes a huge burden off the body and allows it to more easily make the various homeostatic adjustments necessary for good health. When body doesn't have to waste all its resources and energy slowly processing toxic waste, for example, it can use that energy to power up the very energy hungry immune system. This means getting fewer new infections and an increased likelihood of clearing long held ones. When the gut is healed food will be will digested better and so you'll start taking in more nutrients from the food you eat. No disease can be healed without first healing the gut. With all your body systems having a far lighter burden to carry plus all the nutrients they NEED, overall health is improved as is your body's ability to heal from serious disease.

The body needs to have the optimum amount of every essential nutrient. Ill people have higher requirements for nutrients than do healthy people. Every molecule of something toxic detoxified, leaves you with fewer molecules of an important nutrient, for example. The key to supporting the body’s task of healing is not new and ever more exotic or specialised drugs or herbs, but a focus on all the nutrients we need to live and for our bodies to function optimally and to heal as much as is possible.

As Andrew Saul PhD explains,

Good nutrition and vitamins do not directly cure disease, the body does. You provide the raw materials and the inborn wisdom of your body makes the repairs. Someday healthcare without megavitamin therapy will be seen as we today see childbirth without sanitation or surgery without anaesthetic.

The need for a balance between symptom management and deep healing in M.E.
There are times when a symptom-based approach is appropriate in M.E.

This includes times when symptoms are self-limiting (such as due to a healing reaction) and with certain conditions in which a symptomatic response is very necessary including overwhelming infection, very high blood pressure, severe cardiac arrhythmia, any cancer or other similar situations; in this case emergency medicine is an excellent choice as one must deal with the life threatening symptom before trying to correct underlying problems that may be causative.

Symptomatic medicine is also appropriate in long-term or advanced diseases where not treating the symptom may cause deterioration or a lack of progress in the overall healing program, such as with symptoms such as severe pain and sleeplessness – particularly where the treatment has little or no effect on the overall program of healing. There is little point trying to give the body of someone with M.E. all the
materials it needs to heal if the person cannot sleep for more than a few hours a day and is extremely stressed, unwell and overexerting and putting enormous stress on the body.

Where possible, it is desirable to also treat the cause of symptoms at the same time and to go with the most minimal and safe effective symptomatic treatment available.

In the case of improving sleep, this might mean first trying to remove stimulants from the diet, to meditate and to improve sleep hygiene. The next step might be calcium and magnesium taken at night or by L-tryptophan or inositol supplements or a low nightly dose of melatonin. After that, a higher dose of melatonin may be trialled or low dose melatonin combined with the methylcobalamin form of B12 (to try and reset the sleep/wake cycle). As a last resort, and for a limited period of time, prescription sleep drugs may be trialled. The idea is that more serious measures are not taken unless the milder and simpler measures have proven unsuccessful.

**Which nutrients promote deep healing and also improve symptoms in the short term?**

Some of the treatments used in deep healing can also have a positive effect on symptoms, most notably vitamin C (at an opti-dose) and liposomal glutathione. As vitamin C experts Dr Levy explains, Vitamin C is the premier extracellular antioxidant and glutathione is the premier intracellular antioxidant. Vitamin C and glutathione are powerful and important antioxidants taken alone and have an even more powerful synergistic effect when they are taken together.

They both give the body the ‘rapid and profound influx of electrons’ needed to fight disease and to support heart, lung and brain health and immunity says Dr Levy, who also adds that ‘Virtually all diseases and toxins/poisons cause sickness and death through their electron stealing activity.’

In the book *GSH: Master Defender Against Disease, Toxins and Ageing*, Dr Levy continues,

> Since no one has ever seen an electron, for most people it remains a theoretical entity. It is this invisibility that makes it so difficult to accept them as real entities that reliably treat diseases more effectively than antibiotics or prescription drugs. Yet this is precisely the case.

> Even though it is not possible to give a teaspoon of electrons to a sick child, one can administer medications and/or nutrients that are extremely rich in their electron content. Once a sufficient quantity of electrons is delivered to the body, it brings what can only be described as fantastic clinical results when compared to traditional medical therapies. And, this has already been shown to be true for a wide variety of medical conditions.

Glutathione and vitamin C and other antioxidants are not cure-alls, particularly when it comes to the treatment of long-term diseases. It is also true that prevention is far easier with these treatments than cure. But Dr Levy does explain that even where the
disease is too far advanced to be reversed the administration of reduced glutathione and vitamin C can at least provide reliable symptomatic relief.

*Is this about mainstream medicine and cutting-edge science always being the wrong choice compared to what is often called ‘alternative’ medicine?*

No, there are a lot of quacks in BOTH fields of medicine! People that treat only symptoms, try to persuade you that square pegs can fit in round-holes and then blame YOU when their unscientific approach fails or that are a waste of time and money and just trying to make a quick profit from you come in both types.

What is being advocated is basic good quality medical care that looks at all the evidence and that tries to promote actual bodily healing using the most appropriate tools and testing available. Having the best quality medical care from all the different fields and areas of medicine which are effective.

It isn’t even about a battle between drugs and nutrients. The goal is to have access to the best and most appropriate cutting-edge science and treatments, without just being limited to mainly drug or surgery based-options. Many different vested interest groups control a lot of what can be done in medicine right now. But we are free to look at all the available science and we should do so. We need all the best of everything to beat something as hardcore as M.E.

*The important distinction is between medicine which works and medicine which doesn’t, not some artificial line between so-called ‘mainstream’ and ‘alternative’ medicine.*

It is a myth that orthomolecular, holistic and environmental medicine rejects science, is not backed up by evidence and research and is not scientific. Orthomolecular expert Abram Hoffer MD explains that it is in fact mainstream medicine, as it is most often practiced, that is not scientific. He writes,

Modern medicine is not scientific, it is full of prejudice, illogic and susceptible to advertising. Doctors are not taught to reason, they are programmed to believe in whatever their medical schools teach them and the leading doctors tell them. Over the past 20 years the drug companies, with their enormous wealth, have taken medicine over and now control its research, what is taught and the information released to the public.

In Detoxify or Die, Dr Sherry Rogers writes,

I have to laugh when people ask me if I do alternative, herbal, acupuncture or holistic medicine. ‘No,’ I reply. ‘We do state-of-the-art medicine. In other words, we find the biochemical, nutritional and environmental causes and cures rather than blindly drugging everything. Sure, herbs are gentler, safer and more physiologic than drugs and holistic medicine attempts to incorporate many diverse modalities, etc. But there is no substitute for finding the underlying biochemical
causes and cures. This is \textit{real} medicine. This is where medicine should and would have been decades ago, if it had not been abducted by the pharmaceutical industry.

Drugs are essential for turning off certain bodily systems in emergencies, pain medications are essential for some patients, but they don't actually fix anything. They don’t get to the cause. This type of medicine is well suited to emergency use to a large extent, but the same approach just isn’t appropriate for chronic health problems and disease prevention.

To use a car analogy, all drugs do is turn off the 'no petrol/gas' light (the symptom) they do nothing whatsoever to actually GET more petrol etc. (the cause of the problem). As Dr Sherry Rogers writes,

\begin{quote}
Drugs do not cure anything, they merely turn off poisoned and malfunctioning pathways. That is why their classifications are anti-inflammatory, ant-acid, beta-blockers, alpha-blockers, calcium channel blockers, angiotensin inhibitors or ACE inhibitors, HMG COA a reductase inhibitors (cholesterol-lowering drugs), selective serotonin reuptake inhibitors or SSRI, etc. And by not fixing the underlying problem, they allow it to worsen as the innocent patient accumulates side effects from the drug as well.
\end{quote}

The best news about this type of medicine is that much of the treatment is not disease specific, so you don’t necessarily need to have doctors expert in M.E. to help you make real progress with it. It is also affordable and parts of it can even be done without any medical assistance although we may need to go much slower on the programs than most other patients.

\textit{Is this about ‘natural medicine’ always being better than drugs?}

No! Natural does not always mean safe. It is about using the right sorts of treatments for the kind of disease we have.

The issue is that no matter what other treatments are tried, making sure your body has all the materials it needs to run properly is an essential part of any program aimed at reclaiming lost health. No drug can take the role of any of these nutrients and full health will never be achieved while these low nutrient levels remain untreated or while the load of toxic chemicals is high.

One may choose to focus only on an orthomolecular/nutritional treatment approach, or to combine orthomolecular medicine with some symptom-minimising drugs or nutrients or herbs, or an environmental medicine approach, or any other treatment or program. Orthomolecular medicine be combined with any of these other approaches and only increase its chance of success. It is not an either/or choice if you do not choose for it to be. Orthomolecular medicine is essential no matter what other treatments are tried. Even for those who prefer to wait in hope for a miracle cure in a pill, and find nutritional medicine very ‘unsexy’ and unexciting, it makes sense to fix
what deficiency related damage can easily be fixed now, so that any future treatment has a higher chance of success.

**How do I find a good orthomolecular, holistic or nutritional expert?**

The terrible lack of M.E. educated doctors does not actually leave us with no treatment options, thankfully. Doctors experienced in treating similar diseases such as MS and Lupus and so on, can offer a lot to the M.E. patient.

Possible problems getting treatment advice from doctors not educated about M.E. specifically include:

- May not understand all the bodily systems affected by M.E. and M.E. pathology.
- While the best doctors will be aware that ‘CFS’ is just a wastebasket diagnosis and be able to tell right away that someone with M.E. has obvious neurological and cardiovascular pathology, some good doctors may confuse M.E. with ‘CFS’ or not see past a ‘CFS’ misdiagnosis. ‘CFS’ will also mean very different things to each of these types of doctor, including thyroid or adrenal issues, post-viral fatigue syndromes, burnout, emotional issues and so on.
- Doesn’t understand the fragility of M.E. patients, how disabled they are physically and cognitively and how easily they can relapse with even minor exertion such as attending a medical appointment.
- Doesn’t understand or expect the degree of relapse which can occur with treatments and need to go VERY slow compared to other patients. M.E. patients may need to go far more slowly with new treatments, especially treatments that aid detoxification, than other very ill patients.

Despite these drawbacks, good doctors in this field still have a lot to offer M.E. patients, particularly those that are also qualified doctors. To read more about how to find an expert in orthomolecular, holistic or environmental medicine that may be able to help you, see: Finding a good doctor when you have M.E.

**I haven’t found a good doctor yet, can I do some parts of the program myself, now?**

Having solid medical advice and support every step of the way is ideal. It is also possible to do *some parts of* this type of program safely by yourself, while you try and find a trained professional to help you, if you are prepared to do so in a responsible and intelligent manner and to first spend a lot of time reading and researching before you do so. Andrew Saul PhD in his book ‘Fire your doctor: How to be independently healthy’ writes,

In newspapers, magazines and on television, the public has been warned off the very vitamins and other supplements that have been repeatedly proven to reduce illness in practically every instance. The effective use of food supplements and natural diet saves money, pain and lives... and you have been told not to do it. If
you want something done right you have to do it yourself. This especially includes your healthcare. One of the most common questions about vitamin therapy is, are huge doses safe? This book will help answer that question once and for all, and while we are at it, here’s the answer in advance. Yes. Megadoses of vitamins are very safe. Vitamins do not cause even one death per year. Pharmaceutical drugs, taken as directed, cause over 100,000 deaths annually. Still it is granted that we need access to all the tools that medicine and technology can provide, when used with caution. We must also fully use our natural resources of therapeutic nutrition and vitamins. To limit ourselves to pharmaceutical medicine is like going into the ring to fight the champ with one hand tied behind our backs.

There are absolutely times when we need professional help, but we can act to greatly reduce the frequency of those times and far beyond what we have been told. Time in front of a computer screen can teach us a lot more than time in front of a movie screen. But hasn’t health information on the internet been described as the mother lode of all quackery? Of course it has, but as you learned in kindergarten, calling names does not make it so. There is a practical alternative to blind trust, use your noodle and see for yourself. Be your own doctor; manage your own case, live healthier today.

Andrew Saul PhD also makes the following comments,

Most people’s fear of self-care centres on three common fallacies.
1. You are not educated enough to treat yourself, that is what doctors are for
2. Natural therapies are not powerful enough to cure real diseases
3. Megavitamin therapy is dangerous

These are not facts, these are beliefs, and they are all unfounded. Jazz musician Eubie Blake said it best “It is not what we don’t know that harms us, but what we do know that ain’t so”. If your doctor does not believe in using vitamins, not only is that doctor behind the times, that doctor is not being scientific. Therapeutic nutrition is not a matter of belief; it is a matter of confirmed clinical experience. Belief systems can be wrong.

Modern drug based medicine is as incomplete as a novel written with three vowels. As discordant as a symphony constructed using only some of the notes. High dose nutritional therapy is the much needed missing part of our vocabulary of healthcare. The fight against disease needs all the help it can get.

**Final comments**
The topic of deep healing is a complex one. This paper aims to provide only a very basic overview of this topic for patients new to this subject. It is an informal summary of some of the books and articles I have been reading lately (they have each added a little bit to the puzzle). I find these ideas and concepts compelling and they make an enormous amount of logical sense to me in comparison to endlessly chasing new symptoms.
It is recommended that patients do as much reading as possible from the reference list of this paper, and all the other HFME health papers, and that all nutritional and detoxification programs are individually designed and monitored throughout by a qualified medical expert.

**References and recommended reading:**
- Detoxify or Die by Dr Sherry Rogers
- Sauna Therapy for Detoxification and Healing by Dr Laurence Wilson (book)
- Deep Healing Versus Symptom Removal and The Emergency Health Paradigm Versus Nutritional Balancing by Dr Lawrence Wilson.
- INFRARED SAUNA THERAPY and DETOXIFICATION PROTOCOLS by Dr Laurence Wilson.
- An Overview of the Philosophy of The American Academy of Environmental Medicine (PDF)
- Principles That Identify Orthomolecular Medicine by R. Kunin, MD
- Orthomolecular Medicine - Revisited by Ray C. Wunderlich, Jr., M.D.
- The Practice Guidelines of The American Academy of Environmental Medicine
- Fire Your Doctor! How to Be Independently Healthy by Andrew W. Saul
- How to live longer and feel better by Linus Pauling
- Doctor yourself : natural healing that works by Andrew W. Saul
- Curing the Incurable: Vitamin C, Infectious Diseases, and Toxins by Dr Thomas E. Levy
- GSH: Master Defender Against Disease, Toxins and Ageing by Dr T. Levy
- Orthomolecular Medicine For Everyone: Megavitamin Therapeutics for Families and Physicians by Abram Hoffer

More recommended reading:
- Ascorbate: The Science of Vitamin C by Dr. Hickey and Dr. Roberts
- Clinical Guide to the Use of Vitamin C The Clinical Experiences of Frederick R. Klenner, M.D.
- Dr. Atkins' Vita-Nutrient Solution: Nature's Answer to Drugs by Robert C. Atkins
- Foods and Supplements to Balance Phase 1 and Phase 2 Liver Detoxification and Pathological Detoxifiers and Environmental Illness and Detoxification Profile Results - The Pathological Detoxifier and Chronic Illness from the EI Illness Resource Blog
- Good Health in the 21st Century by Carole Hungerford
- Juicing, Fasting and Detoxing for Life by Cherie Calbom
- Liver Detoxification Phase II Support: Overview
- No More Heartburn: The Safe, Effective Way to Prevent and Heal Chronic Gastrointestinal Disorders by Sherry A. Rogers
- Optimal Nutrition for Optimal Health by Thomas E. Levy
- Our Toxic World: A Wake Up Call by Doris J. Rapp
Treating M.E.: The basics

- Redefining CBT? by Margaret Williams, 10th November 2006 and The Heart of the Matter by Carol Sieverling and Dr Cheney, April 2005. (Thank you all for your hard work in typing out the words of Dr Cheney and making them available in a written format, it is much appreciated!)
- The Ascorbate Effect in Infectious and Autoimmune Diseases by Robert F. Cathcart, M.D.
- The Detoxification Enzyme Systems by Frank M. Painter, D.C.
- The Healing Factor: Vitamin C Against Disease by Irwin Stone
- The New Optimum Nutrition Bible by Patrick Holford
- VITAMIN C, TITRATING TO BOWEL TOLERANCE, ANASCORBEMIA, AND ACUTE INDUCED SCURVY Robert F. Cathcart, III, M.D.
- VITAMIN C: The Real Story by Steve Hickey, PhD and Andrew Saul

Relevant quotes

“People’s ability to detoxify certain substances is as unique as their fingerprints or their face. There is as much as a 500 fold different in people’s detoxification abilities with different chemicals.” Dr Sherry Rogers

“The CHF patient has more drugs on board than most other diseases. Meanwhile the real underlying causes, which can be totally correctable, go consistently ignored by medicine. And once a congestive heart failure victim starts accumulating drugs, it is extremely rare if any drugs are withdrawn. Instead his physicians steadily pile on more to keep pace with his worsening symptoms. The number of drugs should tell you that medicine doesn't have a clue as to what the true underlying cause is for CHF.” Dr Sherry Rogers

Sometimes a reason for insurance rejections is that the therapy is not "reasonable and customary". But I should not be penalized for physicians’ lack of knowledge. For example, according to the Journal of the American Medical Association (June 13, 1990), it is reasonable and customary for 90 percent of physicians to fail to look for something as rudimentary and lifesaving as a magnesium deficiency in over 1033 patients hospitalized for cardiovascular problems. A sad fact is that many of these patients died from myocardial infarction secondary to arrhythmias and their undiagnosed magnesium deficiencies. Instead they were loaded up with many symptom masking drugs.

It is "reasonable and customary" for over 16,000 patients to die in the hospital each year just from gastrointestinal hemorrhaging secondary to non-steroidal anti-inflammatory drugs. It is "reasonable and customary" for over 100,000 patients to get congestive heart failure each year secondary from non-steroidal anti-inflammatory drugs (Page, 2000). And it is "reasonable and customary" for patients to have $50,000 of bypass surgery, even though they start re-clotting their new vessels within six months.

And it is "reasonable and customary" for doctors to British prescribe Mevacor, Pravachol and other HMG COA reductase inhibitors to lower cholesterol, when many
proven and safe nutrients will do the same without side effects. Meanwhile the cholesterol-lowering drugs inhibit the gene for this enzyme, thereby turning off the body's production of coenzyme Q10 (Willis). This medication induced coenzyme Q10 deficiency in turn leads to depression, fatigue, a mitochondrial dysfunction, high blood pressure, cardiomyopathy, periodontitis, congestive heart failure and more (Tomasetti, Folker, Jusy, Nakamura, Mortensen). But the patient thinks he is getting a bargain at over $100 a month because his cholesterol level looks good on paper.

Drugs do not cure anything, they merely turn off poisoned and malfunctioning pathways. And we know why the practice guidelines for every medical disease make it look as though every symptom is a deficiency of some drug (Choudhry). Arthritis becomes a Celebrex deficiency, heartburn becomes a Prilosec deficiency, and depression becomes a Prozac deficiency. Fortunately there are many heavily reference books that document the unethical practices of the drug industry in perpetuating the pharmacologic feast for patients, rather than finding and getting rid of the underlying causes. Sherry Rogers

“If people let the government decide what foods they eat and what medicines they take, their bodies will soon be in as sorry a state as are the souls who live under tyranny.” Thomas Jefferson

“Unless we put medical freedom into the Constitution, the time will come when medicine will organize into an undercover dictatorship to restrict the art of healing to one class of men and deny equal privileges to others; the Constitution of the Republic should make a special privilege for medical freedoms as well as religious freedom.” Attributed to Dr. Benjamin Rush, M.D., a signer of the Declaration of Independence

“The doctor of the future will prescribe no drugs but will interest his patients in the care and nutrition of the human frame and in the cause and prevention of disease.” Thomas Edison.

“Orthomolecular treatment does not lend itself to rapid drug-like control of symptoms, but patients get well to a degree not seen by tranquilizer therapists who believe orthomolecular therapists are prone to exaggeration. Those who've seen the results are astonished.” Abram Hoffer, M.D., Ph.D.

“Do something to improve your health. I think we should leave no stone unturned in our search for better health. I also believe that you get out of your body what you put into it. Your body will respond to your efforts to improve your health. The time to start is right now. Another old saying: "If not now, when? If not here, where? If not you, then who?"” Andrew Saul PhD

“Modern medicine’s narrow approach, to treat every disease as if it were a drug deficiency, has resulted in a steep price for humanity. It is obvious millions have died prematurely since vitamin C was first discovered over 80 years ago. Brave and resolute men and women, Albert Szent-Györgyi, Irwin Stone, Linus Pauling, Ewan Cameron, Emil Ginter, Matthias Rath, Andrew Saul, Tom Levy, Steve Hickey, Raxit Jariwalla, John T. Ely, Hilary Roberts, and others promoted the idea of vitamin C
therapy but were readily dismissed, even belittled.” Bill Sardi, author of You Don’t Have to Be Afraid of Cancer Anymore

“There is a principle which is a bar against all information, which is proof against all argument, and which cannot fail to keep man in everlasting ignorance. That principle is condemnation without investigation.” William Paley (1743-1805)

Disclaimer: HFME does not dispense medical advice or recommend treatment, and assumes no responsibility for treatments undertaken by visitors to the site. It is a resource providing information for education, research and advocacy only. In no way does reading this site replace the need for an evaluation of your entire health history from a physician. Please consult your own health-care provider regarding any medical issues relating to the diagnosis or treatment of any medical condition.
Some nutrients and therapies may provoke symptoms in Myalgic Encephalomyelitis (M.E.) which are not merely annoying side-effects but instead healing reactions that indicate that the supplement is working and doing what it is supposed to.

Healing reactions can be caused by treatments which boost antioxidant status, promote detoxification, the clearing of infections or which allow various enzyme reactions to take place which were not possible before or by anything that helps the body to function better and so to heal.

This includes high-dose vitamin C, iodine, magnesium, FIR sauna use, garlic (and other strongly antiviral substances), the anti-Candida diet, lymphatic drainage massage, probiotics, a vegetable juice regime and the supplementation of any important or essential nutrient that was previously at a very low level.

**What symptoms can a healing reaction cause?**

The symptoms of healing reactions can include muscle cramps and spasms, aches and pains, rashes, strange odours and tastes, heart palpitations and blood pressure changes, tiredness, gastrointestinal or bowel changes, foggy thinking, headache and nausea, or a worsening of the illness generally.

Dr Lawrence Wilson MD comments that old infections may ‘flare up’ or be ‘retraced’ as they are healed due to repeated sauna use, and that detoxification methods such as the sauna can cause almost any symptom imaginable. Thus the symptoms of a healing reaction can be very varied.

Healing reactions can also impact on mood and how we feel emotionally in several ways. The release of some toxic materials into the bloodstream can cause anxiety, sleeplessness or agitation or low mood, for example.

Changes can also be positive. At the end of a healing reaction the body may have more energy than it has previously had which may allow you to deal with feelings that previously were suppressed due to illness. (Feeling feelings and working through emotional issues and having emotional breakthroughs takes health and energy!) When you start to feel better, you may find that you quite effortlessly have a very positive emotional breakthrough of some sort.
**Minimising healing reactions**

To minimise the symptoms of a healing reaction always start the program or nutrient at a low dose and build up the dose very slowly.

To slow down a healing reaction, cut right back on the treatment causing the problem or stop it entirely until you’re feeling better. Gentle long-term detoxification is much safer, less risky and more successful than extreme regimes which are completed in a matter of weeks or months.

Dedicated detoxification regimes, for example involving sauna use, can be made much safer if all vitamin and mineral deficiencies (including trace mineral deficiencies) are assessed and dealt with BEFORE treatment begins. It is also important to treat a ‘leaky gut’ before starting a detoxification regime.

To make detoxing safer still, tests such as the ‘Detoxification Profile’ can be run to check whether you have any problems with your detoxification pathways that could be fixed before treatment begins.

The work of detoxifying uses up and depletes nutrients. For example, for every molecule of a chemical detoxified you lose one molecule of glutathione and one molecule of ATP. So it is also important to make sure you take some phase I and phase II detoxification supports as well as general mitochondrial supports when you are detoxifying.

Phase I detoxification involves mobilisation of toxin and phase II involves the elimination of the mobilised toxins. If phase I is powering along and phase II is weak, you will feel very ill as your body will be flooded with mobilised toxins that your body cannot excrete. There six phase II detoxification pathways:

- Glutathione conjugation
- Amino acid conjugation
- Methylation
- Sulfation
- Acetylation
- Glucuronidation

Phase II detoxification supports include the B vitamins, vitamin C, selenium, zinc, magnesium, glycine, cruciferous vegetables, onions, garlic, curcumin, EGCG, Isothiocyanates, taurine, Quercetin, calcium d-glucarate, amino acids and ellagic acid. The most essential phase II support is glutathione (GSH), which if supplemented must be taken via injection, nasally or using a liposomal delivery system rather than orally. (See the Liposomal glutathione and M.E. paper for more information.) Extra protein may also be needed in the diet when detoxifying heavy metals.

Having at least 2 bowel movements daily is essential during any detoxification program. Extra support can also be given to the liver during detoxification by taking
Silymarin and by having daily or regular enemas. Daily enemas are said to stop a detoxification reaction cold and many patients find them absolutely essential for dealing with healing reactions and pain. For more information see the Enemas for detoxification in M.E. paper.

Also very important on any type of healing or detoxification regime, is to very carefully avoid doing more physical damage and taking in any more toxins. Toxin avoidance is key.

It is very important to rest even more than usual when you are doing something that will likely cause healing reactions. The body needs all the energy and resources it can get in order to heal well. It is also important not to start doing a lot more if your healing program is working and you are feeling more well, this extra energy should be saved as much as possible for more healing.

**Which healing reaction symptoms should not be treated?**

Mild-moderate fevers will often occur during healing reactions. It is important to ride out these fevers and not to stop them with drugs unnecessarily. Your body is causing a fever for a reason, because it is part of a healing process and so retarding this process is counter-productive. A healing reaction involving a mild-moderate fever is often seen as a very good sign. Only in the very unlikely event that the fever becomes high enough to become dangerous should it be treated with paracetamol.

Loose stools or diarrhoea will sometimes occur during healing reactions and particularly during detoxification regimes. It is important to drink lots of extra water and to take in extra electrolytes at this time and not to stop this problem with drugs unnecessarily. Your body will often use loose stools as a way of getting something toxic out of the body as quickly as possible. Taking drugs to stop the diarrhoea can leave you feeling very unwell as the body is forced to hold onto the toxic material much longer than is desirable.

If loose stools occur often and independent of treatment regimes then it is likely that something in the diet is causing the problem and an elimination diet may be necessary to weed out the culprit. Foods that cause loose stools should be avoided as this may represent a food allergy or intolerance and the food may be inflaming and irritating the gut in various ways.

**What is a ‘Herxheimer’ reaction?**

The Herxheimer reaction is an excretion of toxins from dying organisms (eg. Candida), sometimes called a ‘die off’ reaction. This reaction occurs when toxins and wastes are being released faster than the body can eliminate them.

In the case of an anti-Candida regimen, it is the waste products produced from the Candida Albican fungus dying off. Herx or die-off symptoms can include nausea, flu-like symptoms, sweating and headaches and generally just feeling very ‘off’ or
‘poisoned’ and unwell. Both body and brain can be affected. People with M.E. are particularly vulnerable to this as their livers may not be working efficiently and also because their bodies are already so dysfunctional (e.g. mitochondrial, central nervous system, brain and cardiac dysfunction).

Warm baths, a detoxification bath, extra rest, extra vitamin C supplements and drinking more water may help. If the symptoms are very severe you may wish to add back some foods from your old diet to slow down the reaction if it is diet-mediated or lower the amount of the particular nutrients you are taking that may be causing the reaction.

**Healing the whole body, not just M.E.**

When the body heals it does so in its own order and indiscriminately. It doesn’t heal any one thing, it just heals everything as much as it can. Although we may be undertaking a treatment program to deal with M.E., other problems may improve first. Scars and other skin conditions may improve, or diabetes might improve, well before the core M.E. symptoms improve.

**How can a person with M.E. tell the difference between a healing reaction and an M.E. symptom?**

It can be very difficult to tell at time if a new symptom or worsening of the illness is a healing reaction or is ‘just’ a new M.E. symptom or a worsening of M.E. generally.

The easiest way to tell if it is a new treatment causing a problem is to stop the treatment and see what happens. When this is done and the treatment is at fault, the symptoms will often resolve within a matter of days. The exception to this is fat-soluble supplements such as lipoic acid, fish oil and vitamins A, D and E. Fat soluble supplements take much longer to leave the system and so it is always a good idea to go even more slowly than usual when upping your dose of these substances.

Most M.E. patients, and probably all of those M.E. patients that have been ill for several years or more, know their usual reaction to activity and other potentially harmful activities or stimulus, very well. If something doesn’t add up, and you know you’ve much more ill than you should be in relation to how active you have been and how much you have been resting, strongly suspect a healing reaction (or perhaps the onset of a cold or flu).

In his book on sauna therapy, Dr Lawrence Wilson suggests asking yourself the following 5 questions in order to work out if you are experiencing a healing reaction or a worsening of your illness. These excellent questions were written in regard to sauna therapy only, but may also apply to some extent to other treatments as well.

1. **Have you been following the sauna, diet and rest program fully?** If so, a healing reaction is more likely, as the body will have everything it needs in order to detoxify.
2. Were you feeling better right before you felt worse? Healing reactions require energy. Energy often increases on a healing program until it is sufficient to initiate a reaction. Often a reaction occurs just when you are feeling stronger.

3. Did the symptom ever occur in the past? If so, a healing reaction is more likely as old symptoms often recur during sauna therapy.

4. Is the symptom odd or unusual? Sauna therapy can cause odd symptoms or odd combinations of symptoms quite different to what you would usually expect of your primary disease. Toxins are layered in the body at a cellular level. Some are more deeply buried than others. Rather than selecting one mineral to detoxify, saunas respect the body’s wisdom and natural order in removing toxins. This is a much safer if slower approach and means that what is being detoxified may vary from one day to the next.

5. How long has the symptom persisted? Healing reactions will usually only last a few days or at most, a week or two. A reaction lasting more than 2 weeks is less likely to be a healing reaction. The exception to this is when retracing a very chronic or deep-seated condition, which could take weeks or even months.

How can a person with M.E. tell the difference between a healing reaction and an inappropriate treatment?

Working out if a treatment is making you feel more ill because it is causing a healing reaction or because you are allergic or intolerant of it in some way can sometimes be difficult.

Whether or not it makes sense to persevere depends on a number of factors including how essential the nutrient is to life and to health and how likely it is that you could be allergic to it or react badly to it. Knowing as much as possible about each treatment is very helpful here.

For example, people can be allergic to garlic and it can hurt a delicate stomach even at low doses. Garlic is a useful substance but not an essential vitamin or mineral. So if you find you are feeling worse while taking even a low dose of garlic it may be best to discontinue this supplement and to perhaps try another one that has similar properties.

None of the herbs that can be taken medicinally are essential to life and so they should not be given as much attention as all the basic vitamins and minerals, for example.

On the other hand, feeling worse while taking vitamin C is almost certainly going to be due to a healing reaction. We need vitamin C to live, it’s absolutely essential. Vitamin C experts have commented that while some patients need to raise the dose very, very slowly, true vitamin C allergy or intolerance does not exist. (Very rarely a problem with corn-sourced vitamin C may occur in individuals very sensitive to corn which may require substitution with a non-corn-sourced vitamin C product.) Feeling
very ill after starting a small dose of vitamin C may even be an indication that there is an extreme need for this substance. So feeling worse at the beginning of taking vitamin C is going to be very common, and these symptoms are absolutely worth persevering with, although the dose should always be raised very slowly so that symptoms stay mild. It may also be worth experimenting with different brands, in case one of the fillers used in making the vitamin C tablets is the real cause of the problem.

Orthomolecular expert Andrew Saul PhD explains,

Vitamin C is the world’s best natural antibiotic, antiviral, antitoxin and antihistamine. This book’s recurring emphasis on vitamin C might suggest that I am offering a song with only one verse. Not so. As English literature concentrates on Shakespeare, so orthomolecular therapy concentrates on vitamin C. Let the greats be given their due. The importance of vitamin C cannot be overemphasised.

**Severe reactions**
If at all possible dedicated detoxification regimes should always be done with the help of an experienced medical professional. Detoxifying faster than your body can cope with can make you feel very ill and can also be dangerous, even fatal.

Dedicated detoxification programs should not be attempted by the very severely ill and should be delayed until some extra strength returns.

Some very unpleasant reactions may be able to be stopped with extra vitamin C (orally or via IV or a liposomal delivery system). If serious symptoms persist, medical attention should be sought.

The best way to tackle detoxification and the clearing of infections and other treatments which lead to healing reactions is slowly and surely – and this goes double when one is treating a disease such as M.E.

**More information:**
- Treating M.E.: The Basics - Overview and introduction
- Important notes on using the HFME's treatment information
- Antioxidants and M.E.
- High-dose vitamin C and M.E.
- Liposomal glutathione and M.E.
- FIR saunas and M.E.
- Candida and M.E.

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does reading this site replace the need for an evaluation of your entire health history from a physician. Please consult your own health-care provider regarding any medical issues relating to the diagnosis or treatment of any medical condition.
The question of whether a certain treatment can be said to have been tried or not is not as black and white as it first seems.

When one is talking about symptom-modifying substances/drugs particularly where there is a small difference between the lowest and highest dose usually taken, determining the effect of a trial is fairly simple. Trying treatments such as Hawthorn extract, Baclofen, Piracetam, Tramadol and other prescription pain-relieving drugs or Neurontin for 3 months at the recommended dose constitutes a very fair trial of the benefits of these treatments. What you see after 3 months or so is what you will get - although additional or new negative effects may appear over time and benefits may possibly also lessen over time.

When one is talking about substances that are not so much treatments as nutrients that are absolutely essential to life and healing without which no other treatment can possibly restore anything like full-health and wellbeing, determining whether or not a true trial has been completed is more complex. Completing a truly fair trial of these essential substances is also far more important for patients with Myalgic Encephalomyelitis (M.E.)

What factors might make a trial I’ve done unreliable or incomplete?
Some of the factors which may make sure a trial of an important or essential nutrient is not incomplete or invalid include the following:

- **Adequate duration of the trial.** Many nutrients take 3-6 months to show their main effects and in some cases several years or longer may be needed to see the full effects. Symptom suppression is fairly instant, but actual healing of disease takes time. Healing of long-term disease is an even slower process.

- **Adequate dosage for you as an individual, for this time in your life.** The dosage is everything with many essential nutrients. People vary in their needs for basic nutrients by many hundred percent. This makes RDI tables ridiculous, particularly as Dr Hoffer also explains that in ill people the range is even greater. In addition to biochemical individuality, people that are seriously ill and/or that have long-standing deficiencies will need far more of a nutrient than will healthy people. Age and gender and many other factors also influence how much of each nutrient you need at a particular time. While one person may be fine taking in only 5 mg of
one of the B vitamins daily, another person may need several grams of that vitamin for a period of time for their serious health problem to start improving. It is important to find the optimal dose for you of each nutrient, your own ‘optidose.’ Sometimes this is determined using various tests and measurable physical changes and sometimes by the reaction of the body to different levels of the substance, or a combination of all three.

- **Adequate frequency of dose.** Frequency of dose is particularly important with the water-soluble nutrients, in particular the B vitamins and vitamin C. Frequency of dose is everything with vitamin C. It can sometimes be the difference between life and death and can often be the difference between seeing a mild improvement and a large one.

- **Part of an entire program.** It is inappropriate to test each nutrient individually, as if it were a drug. These substances all work together and are synergistic with each other. It is never a good idea to just take large amounts of any one or two nutrients while neglecting all the others. The B vitamins must be taken together in similar amounts, it is not a good idea to just take one or two of them in large amounts, for example. All the different nutrients work best when taken as part of a comprehensive nutritional regime, or at the very least when taken with their most important co-factors and synergistic nutrients.

- **Part of a program which stops further damage being done to the body.** The positive effect of any treatment will be masked or completely hidden if overexertion, poor diet and serious chemical exposures are continuing. It is impossible to towel yourself dry if you are still standing under the shower, as it were.

- **Right type of the nutrient taken.** Taking the wrong form of a nutrient can stop it from having the desired effect. For example, even though they are both forms of vitamin B3 niacin has a very different effect to niacinamide. An injectable, liposomal, sublingual or coenzymated form of a supplement can also have very different effects than a pill or capsule taken orally.

- **Not looking at gut health first.** Very poor gut function may stop supplements being absorbed properly.

It is so important with essential nutrients not to dismiss them easily, based on insufficient data. Too quickly writing off substances that your body needs to live and to heal as ‘not worth taking’ or ‘ineffective’ is really unwise. These are not drugs which either work or don’t work, these are nutrients which every persons body needs to carry out all the hundreds of enzyme reactions and other bodily processes necessary for life. It’s non-negotiable, whether other treatments are tried at the same time or not.
No matter what else you do, if you don’t have adequate levels of vitamin D in the body, you will have an increased likelihood of contracting infections and poor bone health. If you don’t have adequate levels of magnesium in the body you will have stiff and possibly also painful muscles, poor bone health, poor sleep, may find it difficult to relax and will have problems with detoxification. If you don’t have adequate levels of vitamin C in the body almost all bodily processes will not be running as well as they should and your immune system will not be functioning at anything like its full capacity. The list goes on. No drug can make up for these deficiencies if they exist.

But what if taking nutrient ‘x’ made me sicker?

Having a bad reaction at one time to some of these substances does not necessarily mean that they should no longer be taken or that they do not suit you at this time. Other factors entirely may be at play.

Bad reactions to taking important and essential nutrients can be due to the following factors:

- **Fillers and binders.** Different products will use different fillers and binders in their products. A patient may react very badly to a supplement only to have no reaction at all to the same supplement from a different manufacturer. It may be necessary to try a few different brands if a bad reaction occurs, or where possible to buy a pure powder form of the supplement which does not contain any extra ingredients at all. Rarely, reactions can also occur to the plastic containers that powders are stored in when the plastic off-gasses into the supplement and reactions to plastics can also occur when plastic IV bags are used to deliver nutrients by IV.

- **Allergies to the source of the nutrient.** For example, ALA may be sourced from potatoes and vitamin C may be sourced from corn. Severe allergies to these foods may mean that one also cannot take supplements that use that food as a source. It may be necessary to search out nutrients with different sources.

- **A healing or detoxification reaction.** This can easily be mistaken for an intolerance to a particular substance when in fact it indicates that the body had a real need for the substance and is using it to begin healing. Sometimes more marked reactions can occur when a person is very low in a nutrient, as the supplementation allows bodily reactions and processes to occur which had not been possible previously. (For more information on this topic please read the HFME paper on recognising and managing healing reactions in M.E.)

- **Not starting gradually.** Starting to take some nutrients at a full-dose all at once can make a person very ill, while the exact same dose worked up to over weeks or
even months may cause no problems at all. Patients with M.E. will often have to raise doses of some nutrients very slowly.

- **Lacking supportive therapy.** Starting to take some nutrients singly and at a full-dose all at once can make a person very ill, while the exact same dose combined with the appropriate supportive nutrients may cause no problems at all.

- **Taking the wrong form of the nutrient.** This can cause problems with tolerance or a lack of positive results. Problems can arise with cheaper brands not using the most appropriate form of the nutrient and instead using a cheaper substitute with a similar sounding name. The products made by cheaper brands may also not contain the ingredients listed on the bottle at all. If possible, buy products from reputable brands that have been independently tested and certified.

- **Not taking the nutrient as recommended.** Nutrients taken on an empty stomach instead of with food, as recommended, can cause problems.

**What does constitute a fair trial of a nutrient?**

Each nutritionally educated doctor may define a fair trial of each substance differently. So it is up to us as patients to find the best doctor we can to advise us on these issues and also to do as much reading of high-quality material produced by the experts in this field as we can so we can cope up with our own answers.

Working out an appropriate dosing range for each nutrient involves:

- Talking to your nutritionally educated doctor about his or her experience and recommendations in this area.
- Researching what is the safe dosing range for each nutrient and what is the usual dosing range for this nutrient for someone in your condition.
- Having the appropriate tests (if applicable) as often as necessary.
- Monitoring the way your body reacts to the nutrient at different doses.

With vitamin D, for example, I don’t think one can be said to have really ‘tried it’ and explored what it has to offer if one hasn’t maintained a blood level of 55-70 ng/ml (either through sun exposure or taking vitamin D3 or both) for at least 6 months. Just taking an arbitrary 400 – 2000 IU daily just doesn’t cut it if you have a severe deficiency and haven’t had much sun exposure for years as is the case with many M.E. patients. At blood levels below this, probably not much benefit will be felt, if any. Getting the appropriate vitamin D testing and learning about what are considered optimum vitamin D levels is essential. It is so easy and inexpensive and vitamin D levels are often very low in M.E. This is my own opinion based on the reading I have done to date on this topic.

Working out the correct dose of vitamin D is fairly simple, as it is with some of the other nutrients. Selenium for example is almost always taken at a dose of between 200 – 400 mcg and zinc is almost always taken at a dose of between 20 – 60 mg.
Treating M.E.: The basics

My opinion on what would constitute a ‘bare minimum’ solid trial of vitamin C is for the chronically ill M.E. patient to slowly work up to a bowel tolerance oral dose very slowly, and to then maintain it for at least 6 months. This might be anywhere from 15 – 40 grams or more taken daily in perhaps 6 – 10 divided doses. Orthomolecular experts explain that there is no condition that vitamin C at the right dose can’t help, and if benefits are not seen this is an indication that a higher dose is needed. Benefits in M.E. may only begin to appear once a dose of 10 – 20 g daily is reached. A full trial of vitamin C for serious chronic disease would involve 2 – 6 sachets of liposomal vitamin C also being taken daily in addition to the bowel tolerance dose taken orally. The only way to get the full powerful anti-viral effects of this substance is to take it either via IV or with a liposomal delivery system as taking it orally will not get the blood levels high enough for this to occur. (See the main vitamin C paper for details.) Generally the more ill a person is the higher their requirement for vitamin C becomes. Thus what is a fair trial with vitamin C depends entirely on how ill someone is. What is a fair trial for seasonal allergies is not a fair trial for M.E. or any other very serious disease.

Dr Emanuel Cheraskin, Dr Ringsdorf and Dr Sisley explain in ‘The Vitamin C Connection’ that,

There are more than ten thousand published scientific papers that make it quite clear that there is not one body process (such as what goes on inside cells or tissues) and not one disease or syndrome (from the common cold to leprosy) that is not influenced -- directly or indirectly -- by vitamin C.

**What is I can only tolerate a small dose? Are smaller doses are better than none?**

Sometimes in M.E. even when you’ve tried many different brands and types and so on, only a very small amount of a particular major vitamin or mineral can be tolerated. The body is just too ill to cope with the boosted bodily processes and extra healing it helps to occur.

Even when this is the case, it is still very important to keep taking the small dose you can, even if it is only a half tablet a fortnight or a month. Every bit helps and you may find that you can raise the dose very very slowly upwards over the months without problems. This may well not be an easy process but it may be very worthwhile.

Patients that are very ill and sensitive to treatment should always use and trust their own judgement about whether or not they are strong enough to trial any new nutrient at a particular time. Even then, an extra warning about going extra slow probably couldn’t hurt. Nobody is more motivated to get well and to start getting well than someone very severely ill with M.E. and so it can sometimes be tempting to push forward with a program a little more than is wise but this should be resisted.

Stopping a trial because you need time to recover and rebuild your strength for a while makes sense. But none of the major nutrients should be written off, completely
abandoned or judged a ‘failed trial’ unless they really have been thoroughly investigated and had an in-depth fair trial which has shown that it really is not possible for any of the substance to be taken by you at this time.

Genuine intolerances do occur in M.E. of course, but it is just so important not to assume that this is what has happened when in fact it may be a filler or nutrient-type issue and you may be needlessly missing out on correcting a very easy to treat low nutrient level that may be causing or contributing to some of your worst symptoms and holding you back from improvement. M.E. is such a terrible disease the body needs all the tools to fight it that it can get!

**Are bigger doses always better? Do I need to take the biggest dose possible to get the biggest benefits?**

No. There is no point taking far more of a nutrient than your body needs and can use. It wastes money, wastes bodily energy and other resources with its processing and assimilation, and can also possibly have undesirable side-effects or cause an imbalance in the body or with other nutrients in some way.

The goal of nutritional or orthomolecular medicine is to work out what the optimal dose is of each nutrient needed for the individual’s body to function optimally. As well as it possibly can. This means that one must avoid taking too little AND too much of each nutrient.

Sometimes the term ‘mega-dose’ is used, but orthomolecular experts Dr Levy and Dr Hoffer explain that a more accurate term is ‘opti-dose.’ Large doses are sometimes used when the patient has a very high need for a particular nutrient, but the goal of such a therapy is to give the patient their optimal dose or opti-dose of a particular nutrient at that point in time. It is not to have all patients arbitrarily takes the largest doses of each substance possible. It is also uncommon for these large doses to need to be maintained over time.

**What are the major nutrients we need to be familiar with?**

Vitamins include vitamin A, the B vitamins and vitamins C, D, E and K. (Vitamin K supplementation is rarely necessary.) Vitamins A, D, E and K are fat soluble, while the B vitamins and vitamin C are water soluble. Some vitamins function as hormones, regulators of mineral metabolism, regulators of cell and tissue growth and differentiation, antioxidants, precursors for enzyme cofactors (that help enzymes in their work as catalysts in metabolism) or bound to enzyme catalysts as coenzymes (detachable molecules that function to carry chemical groups or electrons between molecules).

*All of the vitamins are important as each vitamin really does ‘everything’ as all of the vitamins are needed for the body to function optimally.*
The most important minerals include calcium, chromium, copper, iodine, iron, magnesium, manganese, molybdenum, potassium, selenium, sodium and zinc. Trace minerals such as vanadium, lithium, germanium and others are also important. (Supplementation of iron and copper is usually unnecessary and not recommended.)

Dr Hoffer explains that we need about 45 different nutrients in optimal quantities. He also explains that no nutrient works alone, and that an enzyme reaction that needs three different nutrients to take place, requires all three nutrients and so no one nutrient should be considered more important than the other.

Some nutrients can be obtained in reasonable amounts in food, while others will sometimes or always require the use of supplements to ensure optimal levels. It is not true as some claim that the optimum levels of all nutrients can be obtained through diet alone.

Supplements are necessary, for the following reasons:
- The soils used to grow our food are often very depleted.
- The levels and types of toxic pollution and toxic chemicals we are exposed to are vastly higher now than they were in the past (which requires far higher levels of nutrients than were necessary in the past, to deal with them).
- Many nutrients in food are fragile and only remain fully intact when food is picked and then eaten immediately. Storing foods for long times and heavily processing foods can dramatically lower nutrient levels in the food and may destroy some nutrients entirely; for example, oranges have been found to contain between 100 mg of vitamin C and 0 mg of vitamin C, each.
- The high levels of sugar in the diet of many people is also problematic as sugar is an anti-nutrient.
- Many people have very poor digestion and absorb nutrients from food very poorly, and so higher doses in supplement form are needed for adequate amounts ot be absorbed.

Supplements are necessary and eating well is also important. As Dr Sherry Rogers writes, ‘What you eat has more power over disease than any medication your doctor can prescribe. Food is awesomely powerful.’

Some personal observations on this issue
I’m writing this paper because I have made most of the mistakes detailed in this paper at one time or another and many of them more than once. I wish I understood years ago about nutrients what I understand now and I’d like to perhaps to try to give others following a similar trajectory the benefit of this information sooner than it’d take them to do all the reading necessary to work it all out themselves. Time really is of the essence when it comes to treating M.E. effectively so sharing knowledge is important.

Some of my biggest mistakes include the following:
• **Taking inadequate doses.** A good doctor said to me many years ago that ‘if something is working for you, it is often worth seeing if maybe taking more of it will give you even more of an improvement (where appropriate), your body may need even more of it than you are currently taking.’ I have been really taking this advice to heart lately and I feel it has been paying off. Many of the things I am taking now and that are helping me to noticeably improve each month I had taken for many years but at (unbeknownst to me) completely inadequate doses. This includes primarily vitamin C, vitamin D, the B vitamins, CoQ10 as ubiquinol, iodine and magnesium. The dose really is everything.

I am angry at all those poor quality books and websites that I put so much faith in that were all parroting the same unscientific and fanciful nonsense about how 1000 – 3000 mg of vitamin C, 400 – 800 IU of vitamin D, 15 - 50 mg daily of each of the main B vitamins, 90 – 180 mg of CoQ10 as ubiquinone, 200 mcg of iodine and 400 – 600 mg of magnesium daily is a perfectly adequate dose for everyone. It’s utter hogwash! A complete fantasy based on no good science at all! I remember I actually felt slightly smug back then, thinking that not only was I was taking the right amounts of these nutrients but even a little bit extra as an insurance policy. I thought I was guaranteed to be getting the maximum benefits possible from each of them. I’ll also admit that I felt slightly smug that I was being very financially responsible, and spending only what was really ‘necessary’ on nutritional supplements. But all along my body was getting nowhere near the levels of these nutrients it actually needed and nowhere near the levels it needed to do any real healing. I’d far rather have had better health all these years than have saved the few measly dollars I did, it goes without saying. It was such a false economy and I bitterly regret it now.

• **Trying each supplement individually.** I had no idea that supplements worked synergistically, and so I used to try each treatment one by one to determine of it was worth continuing. I didn’t understand that they worked very differently to drugs and did far more than just suppress symptoms and so should not be trialed like drugs. I’ll also admit that I again felt slightly smug that I was being very financially responsible, and spending only what was really ‘necessary’ on nutritional supplements by only continuing with those things that gave me a noticeable benefit within a few months. I thought this was the smart way to go about things, but now the word ‘smart’ isn’t the one that first comes to mind when I consider this past behaviour of mine. It was a misuse of logic based on incomplete data. I am getting a far more positive effect now from trying more optimal doses of many essential substances at the same time. Everything works together but only as well as your weakest link.

• **Not starting supplements gradually enough** (vitamin C, lipoic acid).

• **Mistaking healing reactions for an intolerance to a nutrient** (vitamin C, lipoic acid).

• **Not fully understanding the enormous importance of gut health and of diet.** As I have recently learned, good gut health is vital to recovering from any disease as the gut houses half the body’s detoxification system and half of the immune...
system. Food should be treated with the same respect as a prescription drug.

- **Disparaging treatments which were suited to a variety of different diseases and instead almost totally preferring to look at the pathology specific to M.E. to see how this might suggest appropriate treatments.** That one can get very good and relevant advice from orthomolecular experts that know nothing about M.E. really is great news. Dealing with people that are experts in both Orthomolecular medicine and M.E. would be ideal. But issues surrounding detoxification, good gut health, determining the opti-dose of the major nutrients and boosting the immune system are common to many neurological diseases and other diseases, including M.E. These issues really are very important in M.E. and addressing them can promote real healing in M.E. There is so much good information available, just waiting for us to take notice of it. Much of it is even free.

- **Disparaging treatments modalities such as detoxification, sauna therapy, juicing and enemas too easily and putting them in the ‘lightweight’ category and without properly researching them adequately.** Detoxification is key, as the theory is that toxin and heavy metal accumulation and other factors lead to a lack of nutrients, which then makes you far more susceptible to infections. This is then where the M.E. virus comes in. So detoxification really is getting to the root cause of the illness, although of course we do know that M.E. is caused by a virus. M.E. is caused by a virus but the fact we are ill may be due to this virus combined with a lack of nutrients and a high toxic load and so treating all 3 of these problems just makes sense.

- **Not understanding the ‘total load’ concept.** My worst symptoms were cardiac, cardiovascular and neurological and so I wanted only cardiac, cardiovascular and neurological treatments. I didn’t understand that improving my liver health and lessening my toxic load generally and so on, would be the best way to improve those symptoms. You don’t just detoxify to improve liver health, but because it helps improve everything, all your worst symptoms.

I used to look at nutrients as drugs and wondered what they would each do for me and if they would be worth trying to improve a particular symptom. I only wanted to take a small number of the most vital ones. Now I look at things very differently. My attitude now is of knowing from the start that all the major nutrients are worth evaluating and perhaps supplementing, and will improve my health generally in some way by facilitating healing. This is because my body actually needs them to function and to heal and this system of nutritional healing tools is only as strong as its weakest link. It might not be easily noticeable at first or it might even make me sicker and it might not happen overnight but I’m confident that no matter what my body will function better and heal more with reasonable amounts of the most important nutrients rather than without. It has to.

As Dr Sherry Rogers explains in her book ‘Detoxify or Die,’

No doctor can cure you. No medicine can cure you. But you can cure you. The evidence will astound you that medicine has had the answers for health all along.

www.hfme.org
The secret is in getting your body so chemically unloaded and nutrient primed, that it heals itself.

I’m not sure if long-term severe M.E. can be completely or even almost completely cured as such, but I think working to heal as much of it as it is possible to heal is a worthy and exciting goal.

Opinions vary widely about all aspects of treating serious diseases. Even if you have very different ideas from my own about treatments, I hope that you have found some of the information here useful or helpful to you in some way. All the best to everyone reading.

More information
For more information on all aspects of M.E. treatment, including detailed information about each of the main vitamins and minerals, please see Treating M.E. - The basics and A quick start guide to treating and improving M.E. with aggressive rest therapy, diet, toxic chemical avoidance, medications, supplements and vitamins on the HFME website.

Relevant quotes
‘Modern drug based medicine is as incomplete as a novel written with three vowels. As discordant as a symphony constructed using only some of the notes. High dose nutritional therapy is the much needed missing part of our vocabulary of healthcare. The fight against disease needs all the help it can get.’ Andrew Saul PhD in ‘Fire your doctor: How to be independently healthy’ 2005

Good nutrition and vitamins do not directly cure disease, the body does. You provide the raw materials and the inborn wisdom of your body makes the repairs. Someday healthcare without megavitamin therapy will be seen as we today see childbirth without sanitation or surgery without anaesthetic. Andrew Saul PhD in ‘Fire your doctor: How to be independently healthy’ 2005

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Orthomolecular, holistic and environmental medicine experts explain that drugs just can’t cure diseases like Myalgic Encephalomyelitis (M.E.) and that the only way to get anywhere is to get to the causes of why the body can’t heal itself and to work to resolve as many of them as is possible.

The constant claim that a cure for M.E. is ‘just a few years away, if only we can get a lot of support and funding and all stay positive’ is pure propaganda by various self-interested or sold-out ‘CFS’ or ‘CFIDS’ or ‘ME/CFS’ or other groups or individuals, unfortunately. At best it is an unethical ploy to gain higher levels of funding and support. At worst it is a way to keep patients politically passive, ignorant and not explosively angry with the total lack of real political change over the last 20 years.

It’s a distraction from the fact that NOTHING has changed with regards to M.E. patients’ basic rights being violated, the lack of access to basic welfare entitlements, the high rate of appalling medical abuse, the lack of education about the reality of M.E. in medical schools and to the public and the lack of proper and prompt diagnosis and medical care.

Why should anyone bother with messy, complicated and ‘nasty’ activism and time-consuming self-directed research when we’re told a cure is on the way and science is just about to save us? The problem is that the cure is always ‘just around the corner’ but it never eventuates.

Furthermore, because of the complete lack of political progress, the science that is being produced is very shaky as it invariably involves a wildly mixed patient group that may or may not even contain any M.E. patients. Not only is such sloppy science extremely unlikely to benefit patients with M.E., it is also extremely unlikely to benefit any other distinct patient group involved. When we go along with the claims that all we need to do to is ‘trust them’ and ‘have faith’ and ‘stay positive’ and that any type of critical thinking or analysis is ‘letting the side down’ or ‘just being pointlessly nasty and mean’ and that politics, history, logic and definitions don’t matter at all compared to whatever is this years claimed ‘great big hope’ we make sure that real progress NEVER happens.

We are fighting a political battle, not a scientific one. If the battle over M.E. were merely based on science, it would have been over before it was even begun. There is more than enough science to back up what experts such as Ramsay, Dowsett and
Hyde have said about M.E. right now, as there was before the ridiculous ‘CFS’ concept was even created. M.E. can be diagnosed now using a series of tests in just the same way that many other diseases are and much is known about the pathology of M.E. and the mechanisms behind many of the symptoms and disability of the disease. The reason M.E. patients are abused and denied basic care is entirely political. A lack of good science is just not the problem.

Even if hugely overstating the progress and importance of their research is something researchers feel they must do in order to keep getting funding for their latest work on ‘CFS’ or ‘ME/CFS’ it doesn’t follow that patients like us have to keep blindly believing them. We need to be able to tell the difference between a media release whose purpose is to hype up what is happening as much as possible, and reality, and look at the actual science being produced objectively and critically.

If a new groundbreaking treatment were to somehow be produced from the latest hyped ‘CFS’ or ‘ME/CFS’ research, it is extremely unlikely to be relevant to actual M.E. patients. None of the ‘CFS’ definitions nor the ‘ME/CFS’ definition in use are definitions of M.E. and none selects a 100% M.E. patient group. But even if this new research were relevant to M.E. patients to some extent by some miracle, it is also extremely unlikely to have an effect on long-term patients in the same way as newly ill patients. This is a fact that those hyping the ‘a cure is nearly here, our battle is almost over’ very rarely if ever even acknowledge – that treating the newly ill is an utterly different prospect to treating patients that have been ill for many years. To string along desperately ill and abused patients that have been ill for many years with false hope in this way is cruel.

For long-term M.E. patients, regaining health is not simply about fixing any one aspect of M.E. and nor is it purely about killing the virus that caused M.E. While it’s true that evidence of active enteroviral infection has been found in M.E. patients that have been ill for over 10 years, what must also be healed for health to be regained is all the damage and deficiencies that this virus has caused over many years. It is not at all as simple as merely killing the initial virus, or this virus and any other co-infections even, not by a long shot! This is only one part of the problem, and probably not the most challenging part either.

Healing years of toxin build-up and damage to detoxification systems, abnormal gut function and damage to the brain, the immune system, the mitochondria and the myelin sheaths is something that drugs really can’t do very well, if at all. Even with genetic cures, any and all nutrient deficiencies and problems with the way bodily systems work must also be fixed for anything like full health to be regained. No drug can take the place of a properly functioning body that has all the nutrients it needs to function optimally and so this work still needs to be done for health to be regained regardless of any other treatments.

In looking at the likelihood of a cure we can also learn a lot by looking at what has been happening with similar diseases that haven’t been politically persecuted in the same way that M.E. has. We can look at diseases such as lupus, Multiple Sclerosis,
motor neuron disease, Alzheimers’ and Parkinson’s disease and all the millions of dollars put into finding drug cures for these diseases. They still don’t have any. All they have, in some cases, are ways to minimise some symptoms and to slow (but not stop or reverse at all!) disease progression to some extent. M.E. research is decades behind and has none of their research budget, not even 1% of it. ‘CFS’ and ‘ME/CFS’ research is of very questionable value to M.E. patients and is poorly funded. Genuine M.E. research is almost nonexistent. Considering all of these factors one would have to logically conclude that the hopes for an M.E. drug cure coming soon or even in our lifetimes for long-term patients are fanciful and not at all realistic.

The preliminary stem cell research happening now does seem to be very promising for all sorts of serious diseases but the days when this treatment will be available to more than a privileged few are at least 5 – 10 years away. It also remains to be seen whether M.E. patients will be given access to this treatment and seen as as ‘worthy’ of such an expensive intervention as patients with similar but more medically accepted diseases.

There are many advantages for us individually and as a group in using the best that medicine has to offer now and trying to heal as much as possible now, as the HFME book ‘Treating M.E.’ explains. Focus on bodily healing also helps to reduce the chances of secondary infections gaining a foothold. It is bizarre that so much focus has been given recently to treating ONE possible secondary infection in M.E. – which may very well be of minor or no significance or importance in M.E. – and so little has been given to boosting the immune system and health generally in order to prevent UNTOLD NUMBERS of secondary bugs causing all sorts of damage. Prevention is always far easier than cure and so this is an important if very ‘unsexy’ issue that needs our attention, even if it is not as well publicised as others due to a lack of any possible financial benefits resulting from it for any one group.

**Can M.E. be cured in the acute stages, if correctly diagnosed, right NOW?**

It is very possible that it can. Treating M.E. in the earliest stages of the infection is very different to treating long-term M.E., particularly where significant damage has been caused by overexertion and other factors. This is yet another reason why focus on correct early diagnosis and treatment of M.E. is so important. For more information on this important topic see the ‘Treating M.E. in the acute stages’ paper.

**But what if the hope of an M.E. cure one day is all that gets you through your days?**

Many of us are very drawn to and attracted by the slick marketing of new science and the promise of easy solutions always ‘coming soon’ and most of all that the idea that a very serious disease like M.E. could of course only be treated with a serious new drug. I doubt that any of us are fully immune to these very attractive and intoxicating ideas, no matter how much knowledge we might have to the contrary. (I know I am not, not in the least.) The idea that our best hope for healing is a ‘new miracle drug’ is so incredibly deep seated in so many of us. We’ve been programmed to believe this myth from when we were small children and it has been continually reinforced all our
lives through our media; a media with a very strong drug-based-medicine bias. Going against popular public perception and the media in this way can be difficult and isn’t often something that occurs without effort.

We are all different in the ways we use to cope with the problems life throws at us. For some patients the need to have faith in a drug cure coming soon is unshakeable and is essential to keeping going. But even if one chooses to hold on to this belief, why not prepare for the miracle drug the best way possible by letting your body heal as much as it can beforehand and so increase the chances of it working? Hope is essential. But it’s also so important to deal with what is possible and happening right now as well, so you get the best of both worlds.

Hope can also be combined with logic and critical thinking and not just remain intact, but stronger than ever! Even wildly optimistic hope. (The kind that a group of my severely affected M.E. friends and I all found we have in common, find essential and have termed ‘blind over-optimism’ or BOO.) Hope and critical thinking are not mutually exclusive. One can keep the hope at the same level, but merely switch the focus of it on to something else.

Have hope but do not let it make you passive, or miss health and advocacy opportunities available now. Do not let it make you support projects which reinforce the myths surrounding M.E. that harm us so much, work against the best interests of patients or which cruelly and unfairly offer false hope to desperate patients before their claims are even remotely backed up by research. Don’t let a need for hope make us easily manipulated as tools by those with vested interests in opposition to our own.

Wildly optimistic hope is essential for living with something as awful as M.E. but so is critical and logical thinking and genuine advocacy if we’re ever to really improve the terrible situation we find ourselves in for ourselves and for all the future M.E. patients to come.

**More information**
For more information see:
- A warning on ‘CFS’ and ‘ME/CFS’ research and advocacy
- Who benefits from 'CFS' and 'ME/CFS'?
- Are we just ‘marking time’?
- Problems with 'our' M.E. (or 'CFS' 'CFIDS' or 'ME/CFS' etc.) advocacy groups
- Putting research and articles into context
- Problems with the use of 'ME/CFS' by M.E. advocates
- Treating Myalgic Encephalomyelitis - The Basics
- What is M.E.?

**Relevant quotes**
“Human progress is neither automatic nor inevitable... Every step toward the goal of justice requires sacrifice, suffering, and struggle; the tireless exertions and passionate concern of dedicated individuals.” Martin Luther King Jr.
In the meantime you may wish to read some of these excellent books and articles on the topic:

- **Why are doctors ignorant about nutrition?** by Dr Ray Strand (PDF).
- **Orthomolecular Medicine For Everyone: Megavitamin Therapeutics for Families and Physicians** by Abram Hoffer.
- **Detoxify or Die** by Dr Sherry Rogers
- **An Overview of the Philosophy of The American Academy of Environmental Medicine** (PDF)
- **Principles That Identify Orthomolecular Medicine** by R. Kunin, MD
- **Orthomolecular Medicine - Revisited** by Ray C. Wunderlich, Jr., M.D.
- **The Practice Guidelines of The American Academy of Environmental Medicine**
- **Dr Atkins Vita-Nutrient Solution: Nature's Answer to Drugs** by Dr Atkins
- **Fire your doctor! : how to be independently healthy** by Andrew W. Saul.
- **The NEW optimum nutrition bible** by Patrick Holford.
- **How to live longer and feel better** by Linus Pauling.
- **The Sinatra Solution** by Dr Sinatra
- **The Emergency Health Paradigm Versus Nutritional Balancing and Deep Healing Versus Symptom Removal** by Lawrence Wilson, MD
- **Death By Prescription: The Shocking Truth Behind an Overmedicated Nation** by Ray D. Strand M.D.
- **What Your Doctor Doesn't Know About Nutritional Medicine May Be Killing You** by Ray D. Strand M.D.
- **Politics in Healing: The Suppression and Manipulation of American Medicine** by Daniel Haley
- **Prescription For Disaster.**
- **Instinct Based Medicine: How to survive your illness and your doctor**
- **Medical Fascism in the USA, Australia and the UK**
- **The Medical Mafia**
- **The Truth About the Drug Companies : How They Deceive Us and What to Do About It**
- **Death by Medicine**
- **Mass Murder in Medicine**

**Relevant quotes**

There was no way my patients could receive health benefits from optimal levels of nutrients without supplementing their diet. It became very obvious to me that my patients needed to supplement their diet with high-quality, complete and balanced nutritional supplements for the best protection against chronic degenerative diseases. Dr Ray Strand.

Taking high-quality, complete and balanced nutritionals are the least expensive health insurance policy you will ever purchase. Dr Ray Strand.

"In the last century the practice of medicine has become no more than an adjunct to the pharmaceutical industry and the other aspects of the huge, powerful and immensely profitable health care industry. Medicine is no longer an independent profession. **Doctors have become nothing more than a link connecting the pharmaceutical industry to the consumer.**”----Dr Vernon Coleman

The medical establishment works closely with the drug multinationals whose main objective is profits, and whose worst nightmare would be an epidemic of good health. Lots of drugs MUST be sold. In order to achieve this, anything goes: lies, fraud, and kickbacks. Doctors are the principal salespeople of the drug companies. Guylaine Lanctot, M.D.
The question we are probably asked most often at HFME is 'where can I find a doctor in my area that will test me appropriately for M.E. and is experienced in treating M.E.?'

The short answer sadly is that there are almost none. If there were lots of them, we wouldn't have started the HFME. At the very least the M.E. doctors list would be featured VERY prominently on the site!

The lack of doctors educated about M.E. etc. is WHY we are trying to instigate and support real political change in this area, and why we need your help with this, if things are ever to change. It is pretty much the whole point! This lack of basic knowledge in the medical system and lack of knowledgeable doctors is why the HFME exists and why we work so hard to try and effect real change in this area through education.

Unfortunately progress is difficult and very slow. Far fewer patients are interested in participating in M.E. activism as are interested in finding a doctor. The lack of doctors and good medical care also contributes hugely to the severe disability level of many M.E. patients and makes contributing to activism efforts almost completely impossible for many patients. It’s a catch 22 situation. If we all had better medical care we’d be far more able to participate in real advocacy, but to get this better medical care we first need a lot of very solid advocacy.

That is the bad news. Now for the good news...

While finding a doctor knowledgeable about correctly diagnosing and testing for M.E. is extremely difficult, finding doctors which can help with treatments and improving the condition generally to some extent using basic principles which apply to many different diseases similar to M.E. is far less difficult.

There are also measures that patients can take all on their own to investigate the diagnosis of M.E. and to help to treat M.E. and stop it from worsening, right now.

Thus the situation for M.E. patients is dire but not completely without some glimmers of hope also, as this paper will explain in more detail.

Sections include:
The difficulties in obtaining an accurate M.E. diagnosis are not due to a lack of appropriate science or tests

Testing for M.E. Plans A, B, C and D

Links to some of the most well-known doctors knowledgeable about M.E.

Educating a willing and intelligent doctor about correct M.E. diagnosis

Different doctors for diagnosis and for treatment – an important distinction!

Finding a doctor that can devise an individualised orthomolecular / holistic / environmental medicine program for you to help your body heal

Websites which can help you find a doctor specialising in orthomolecular / holistic / environmental medicine near you

Quick diagnosis is key with M.E.

Avoiding overexertion in the early stages of M.E. is absolutely ESSENTIAL

Calling all good doctors! Add your name to the future HFME international good doctor’s list.

Part 2 includes the following sections:

- Other problems faced by M.E. patients looking for correct diagnosis and treatment
- What are some basic principles of orthomolecular / holistic / environmental medicine?
- Serious problems to be aware of with many or even most of the natural therapists currently in practice

The difficulties in obtaining an accurate M.E. diagnosis are not due to a lack of appropriate science or tests

A correct diagnosis is half the battle won. However, being medically assessed by a knowledgeable doctor who is able to diagnose M.E. correctly is unfortunately far easier said than done. Scientific diagnostic methods and ethical concerns have been skewed by politics and financial concerns. For more information on why this is the case, please see: Who benefits from 'CFS' and 'ME/CFS'? and What is Myalgic Encephalomyelitis?

On a purely scientific level we have more than enough information to diagnose patients with M.E. using objective tests, by taking detailed case notes and conducting a detailed physical exam etc. within just a few weeks of the onset of the disease. If the will and the funding were there, doctors could right now be given the information to diagnose all cases of suspected M.E. Scientifically, it would be no more difficult to do this with M.E. than with other diseases such as Multiple Sclerosis or Lupus.

A series of tests can confirm or eliminate a diagnosis of M.E. If all tests are normal then a person does NOT have M.E. M.E. is no more difficult to diagnose through
using a series of tests than MS. In fact, it has been suggested that diagnosis of M.E. is significantly less difficult and more reliable than that of MS.

The problem is not that tests for M.E. don’t exist. They do, but doctors – and many patients – are unaware of this. The information on testing is not generally known and accepted due to the nefarious influence of political and financial vested interest groups. There are overwhelming financial and political incentives for researchers to IGNORE the evidence on the diagnostic tests for M.E. in favour of the bogus and untestable ‘CFS’ (or ‘subgroups of ‘ME/CFS’) construct, and so on. Thus doctors who gain their understanding of M.E. from such flawed research – as almost all do – wrongly believe that the disease cannot be diagnosed by tests.(tested for).

Diagnostic tests for M.E. exist, as described in Testing for M.E. Despite the existence of these tests, the unfortunate reality is that many people who suspect they have M.E. do not have access to the appropriate tests or to doctors who are able to make a diagnosis.

**Testing for M.E. Plans A, B, C and D**

There are probably four main routes a patient’s quest for a confirmation of the diagnosis of M.E. can take. For the purposes of this paper I’ve labelled them Plans A, B, C and D:

**Plan A.** A very small number of lucky patients will be able to see an M.E. specialist such as Dr Byron Hyde, and have their suspicion of an M.E. diagnosis either confirmed or denied, with a very high degree of accuracy, by appropriate testing and taking a detailed case history. This is the best possible scenario.

**Plan B.** The second best option would be to have a doctor who is not an M.E. expert but is sympathetic and intelligent and willing to use Dr Hyde’s new testable Nightingale Definition of M.E. to make a diagnosis, again by appropriate testing and taking a detailed case history. This also has a high degree of accuracy.

**Plan C.** The patient may be unable to get a doctor to follow the Nightingale Definition of M.E. to make a correct diagnosis. The doctor may, however, agree to perform some tests which are relevant to M.E.; the doctor may not be willing to order expensive brain scans, but may perform cheaper and simpler tests. These tests may add significant weight to a suspected M.E. diagnosis. Unfortunately the doctor may or may not be able to interpret the results of these tests. Plan C can be subdivided into:

- Plan C(a) in which the doctor can be trusted to interpret the results of the tests, and
- Plan C(b) in which the doctor is ignorant, so the patient is forced to interpret the results for themselves. This method may have a high degree of accuracy, if a series of these tests are done and most or all are highly indicative of M.E.,
and if the patient’s case history and core symptoms and illness characteristics also fit M.E. See appendix 1 for a brief description of the case history, core symptoms and illness characteristics which fit M.E.

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Appendix 1:

Case history:
- Acute onset
- Virus infection evident 1-4 weeks before onset

Core symptoms:
- Significant neurological symptoms
- Significant cognitive problems which worsen with overexertion (problems with speech and talking, reading and writing, basic mathematics, memory and memory recall and learning new tasks)
- Problems coping with orthostatic stress
- Problems coping with sensory inputs such as noise, light and movement
- Lack of temperature regulation
- Muscle weakness, paralysis, pain (affecting all muscles including the heart and which may also affect breathing and vision)
- Blood pressure and pulse abnormalities due to overexertion
- Problems with balance, vertigo and proprioception
- Sensitivities to many different foods, drugs and chemicals
- Significant gastrointestinal and digestive disturbances
- Sleep disorders (reversed sleep/wake cycle, difficulty initiating sleep, lack of deep sleep etc.)
- Temporal lobe seizures and other types of seizures

Illness characteristics:
- Patient is immediately able to maintain 50% or less of their pre-illness activity level
- Severity of symptoms waxes and wanes markedly
- Many symptoms are caused by reduced circulating blood flow of up to 50%
- Muscle strength is normal at first, but muscles quickly become weak/paralysed with use
- Delayed exacerbation of symptoms after overexertion (typically 48 hours)
- Severe exacerbation of symptoms with only minor activities beyond the patient’s limits
- Overexertion can seriously harm or kill the patient
- Rest in the early stages of the disease brings the most positive long-term
outcome
- A long-term or lifelong disease affecting children and adults
- Occurs in outbreaks as well as sporadically

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If only a small number of these tests are done however, or the results are inconclusive or the case history/symptom profile doesn’t fully tally with M.E. then the patient may still be left uncertain as regards an M.E. diagnosis.

Tests which patients may find doctors more willing to do, compared to expensive brain scans etc., and which are indicative of M.E. (particularly when done in combination) include the following:

- Romberg test or tandem Romberg test (positive in more than 95% of M.E. patients) – this is a test which can be done in your doctor’s rooms.
- Neurological examination – this is a test which can be done in your doctor’s rooms.
- Poor man’s tilt table test – this is a test which can be done in your doctor’s rooms. This involves taking your blood pressure and pulse while sitting and then while standing in order to tests for POTS etc. See Testing for M.E. for details.
- Low natural killer cell numbers/percentage and function (cytotoxicity) – this is a blood test. This test is abnormal in most M.E. patients, often strikingly so. The level of NK cells and NK Cells function also seems to correlate with illness severity.
- Apoptosis is often raised (this is programmed cell death: known to be raised in infection) – this is a blood test
- Abnormal ANA (indicates autoimmune disease) – this is a blood test
- Glucose tolerance test – this is a blood test
- An unusually low sedimentation rate of <5mm/hr is common in M.E. and can occur in 40% or more of patients (although there may also be brief periods where there is an elevated rate >20mm/hr). ESR rates as low as 0 have been documented in M.E. patients, and levels of 1 and 2 are very common. This is a blood test and this test is included if you have a full blood count test done. Dr Byron Hyde reported in 1989 that, “To my knowledge, there are only five diseases that have a pathological low sedimentation level: Myalgic Encephalomyelitis, sickle-cell anemia, hereditary sperocytosis, hyper-gammaglobulinemia [and] hyper-fibrogenemia.’
- A 24 hour Holter monitor (a type of heart monitor) may show repetitively oscillating T-wave inversions. It is important that doctors know what they are looking for with this test or else patients may be given a falsely normal report. See Testing for M.E. for details. This test may be able to be conducted at a
patient’s home. If you are housebound, ask the people fitting/supplying the Holter monitor if this is possible.

- Physical exam. See Testing for M.E. for details.

Patients may also find that once abnormalities are shown on some of these tests, doctors may then be more willing to do more expensive or involved tests such as brains scans.

Note that of course none of these tests are unique to M.E. and the results are of course abnormal in other diseases. Many of the symptoms of M.E. are also seen in many other diseases; a person must have the core/unique symptoms and features of M.E. (and combinations of symptoms and features) to be given a correct M.E. diagnosis.

It is the combination of a series of these abnormal test results, combined with a case history and core symptom profile that fits M.E. that strongly indicates M.E., not merely abnormalities shown on a small number of these tests, or a patient merely having some of the same minor symptoms as an M.E. patient.

**Plan D:** Sadly, all most patients are left with is plan D. They have little or no appropriate medical care at all. Patients may only be given the most basic of general tests, and when these show no abnormalities (as is the case with up to 90% of M.E. patients) further testing is denied, and often the very concept that the patients is ill at all is denied. (This despite the facts that as with all illnesses, of course tests will come out ‘normal’ if completely the wrong tests are done!)

Alternately, sometimes minor abnormalities are found in basic testing, for example hypothyroidism, and these minor issues are incorrectly assumed to be the sole or primary medical problem. When the patient exhibits little improvement in their condition as these minor secondary issues are given standard treatments, patients are often bizarrely accused of exaggerating (or even outright faking) their symptoms and disability.

With no access to appropriate medical care or testing at all, all a patient that suspects that they have M.E. can do is read as much as possible about M.E., and carefully evaluate their own case study to see how well it fits, or doesn’t fit, detailed and accurate accounts of M.E. This can be very useful, up to a point, as accurate descriptions of M.E. which describe the unique features of M.E. will resonate very strongly with genuine M.E. patients. (Most notably, descriptions by Dr Byron Hyde, Dr Elizabeth Dowsett and Dr Ramsay.)

The biggest problem with this endeavour, however, is that much of what is written about M.E. is of questionable or very poor quality, and almost all of it is tainted by the concept of ‘fatigue’ and ‘CFS.’ Many patients will relate to poor quality or inaccurate information given about M.E. – or ‘CFS’ or ‘CFIDS’- that do not have M.E. but instead some other disease which is often misdiagnosed as ‘CFS.’ Just as
bad, some very poor quality ‘CFS’ information will sometimes be given using the term M.E.

The concept of ‘ME/CFS’ and vague mixed definitions such as the Canadian ‘ME/CFS’ or ICC criteria confuse the issue even further. Many patients qualify for a ‘ME/CFS’ diagnosis (or rather, misdiagnosis) and relate to information given about ‘ME/CFS’ that do not have M.E. (This would include patients with Fibromyalgia, Lyme disease, athlete’s over-training syndrome, various post-viral fatigue syndromes, Behcet’s disease, Multiple Sclerosis, B12 deficiency and so on.) The Canadian ‘ME/CFS’ criteria is not a definition of M.E., merely another meaningless and unhelpful ‘CFS’ definition which happens to add in a small amount about some of the least important aspects of M.E. As with the ‘CFS’ definitions, it selects a heterogeneous (mixed) patient population as does the new ICC criteria.

Patients unsure of their diagnosis are recommended to look carefully at descriptions of some of the illnesses most commonly misdiagnosed as ‘CFS’ (or M.E.). See: The misdiagnosis of CFS. If you aren’t sure what your diagnosis is, but you are sure it isn’t M.E., then you need to find a good doctor, preferably a skilled diagnostician. You do NOT need to see any type of ‘CFS’ expert, and in fact should avoid such individuals! A diagnosis of ‘CFS’ can only ever be a misdiagnosis.

For some patients however, this may still leave not quite 100% sure of whether or not M.E. is the correct diagnosis. The ‘D’ in plan D, may as well stand for ‘desperate.’ Plan D, means having no plan at all and having access to no appropriate medical testing at all. Being left in ‘no man’s land’ as regards your suspected M.E. diagnosis. Fairly sure but... not quite certain, due to a lack of appropriate supportive objective testing.

So what do you do if you are in this terrible situation? This is a question I am asked very often, in personal and HFME emails. It is very hard to know how to reply. After much thought, I have written a new paper on this topic. See the paper Testing for M.E.: Plan D for discussion of the ways in which patients seek a diagnosis in practice, and a ‘Plan D’ for patients who are forced to diagnose themselves.

Links to some of the most well-known doctors knowledgeable about M.E.
There are a very small number of doctors very experienced in diagnosing or treating M.E. While not every patient can see one of this select group of doctors, their names are listed here for those that may possibly be able to.

- Dr Byron Hyde in Canada is the best doctor there is for the diagnosis of M.E. Dr Hyde may or not be taking new patients, but you may be able to book a phone consult with Dr Hyde, or have MRI or other brains scans interpreted for you during a phone consult. The NRF may also be able to recommend a doctor in your area that is familiar with Dr Hyde’s Nightingale definition of M.E. Dr Hyde is a very respected preeminent M.E. expert.
• Dr Chia in the USA is an enteroviral expert with a lot of experience in treating patients with enteroviral infections, including M.E. patients. He offers treatment with interferon and matrine, among other treatments. Dr Chia’s offices can also be contacted in order to arrange enteroviral testing via post.

• Dr Paul Cheney in the USA has a lot of experience in treating patients with cardiac insufficiency and the other neurological and mitochondrial issues caused by M.E. While he does not make the proper distinctions between M.E. and ‘CFS’ at all times historically and with definitions, it seems that Dr Cheney is a very good choice when it comes to treating M.E. for those that can afford to see him.

Dr Hyde and Dr Cheney in particular are very expensive doctors to see. Please note that while Dr Chia and Dr Cheney do have a lot to offer in the area of treatment, they do not properly make the full distinction between M.E. and ‘CFS’ unfortunately.

Remember that while only a few patients with M.E. can actually see Dr Hyde, every M.E. patient can and should be familiar with his Nightingale definition of M.E. This is a testable M.E. definition and not merely yet another redefinition of the bogus disease category of ‘CFS.’

The same is true of Dr Chia and Dr Cheney. Much of their work on treatment theories is available online for free, or for a fee in the case of Cheney’s latest work.

**Educating a willing and intelligent doctor about correct M.E. diagnosis**

If your doctor is not as knowledgeable about M.E. as he or she could be, but is the best you can find, you may also like to bring in printed research or papers on M.E. that you think might be useful. As there is only one Dr Hyde, sometimes the best option many of us have right now is to find a doctor that does not know much about M.E. but is compassionate, intelligent and willing to learn and to read Dr Hyde’s Nightingale M.E. definition.

It will also be helpful to write a detailed medical history before your first visit.

It is also very important that you are able to have some of the tests which can be used to confirm an M.E. diagnosis, to remove all doubt that this truly is the only correct diagnosis for you. For more information see: Testing for M.E. and Testing for M.E.: Plan D

Note that some charities may offer doctor recommendations although the quality of the doctors recommended here is very variable, or even abysmal, as there really are almost no actual M.E. charities anymore even though some charities do wrongly still use terms such as ‘ME/CFS’ or even M.E.

**Different doctors for diagnosis and for treatment – an important distinction!**
It is important to be aware that the doctor that is best qualified to diagnose you with M.E. will not always be the best doctor to advise you on treatments.

In an ideal world one doctor would do both of these things, but in practice it is probably best to look at the questions of diagnosis and treatment, very separately.

Many doctors that may not necessarily be appropriately educated in making a diagnosis of M.E. have a lot to offer in terms of treatment. Some of these doctors may also be willing to learn about correct M.E. diagnosis and so printing out a copy of the Nightingale M.E. definition to give to them is recommended, where you think this may be appropriate and helpful.

**Finding a doctor that can devise an individualised orthomolecular / holistic / environmental medicine program for you to help your body heal**

Finding a doctor that is knowledgeable about M.E. specifically is extremely difficult. However, finding a doctor that is experienced in treating diseases similar to M.E. (such as MS or Lupus etc.) is far less difficult.

The differences between the different types of medicine are as follows:

**Orthomolecular medicine** is a system for the prevention and treatment of disease based on the knowledge that each person's biochemical environment is genetically determined and individually specific. Therapy involves supplementation with substances naturally present in the body (for example vitamins, minerals, trace elements and amino acids) in the optimal amounts for that individual at that time to correct nutritional deficiencies and the resulting biochemical abnormalities. The administration of vitamin C in therapeutic doses is one of the most important and commonly used means of treatment in Orthomolecular medicine.

**Environmental medicine** deals primarily with the effects of the environment on humans including water and air pollution, vaccinations and travel, etc.

**Holistic medicine** is a system of medicine which considers man as an integrated whole, or as a functioning unit. It is characterized by its focus on the whole person as a unique individual, on the energy of the body and its influence on health and disease, on the healing power of nature and the mobilization of the body's own resources to heal itself, and on the treatment of the underlying causes, not symptoms, of disease.

Other terms may also be used, such as nutritional balancing, nutritional medicine, biomedical treatment, integrative medicine, functional medicine, nutrigenomics and natural medicine etc., and others may prefer to avoid any type of new terminology whatsoever.

Good doctors in this field have a lot to offer M.E. patients. Far more than very nearly all 'CFS' or 'ME/CFS' or 'CFIDS' specialists or centres, most of which deal with ways of coping with mere 'fatigue' which are inappropriate or harmful for those who
Treating M.E.: The basics

Actually have M.E. Generally speaking, ‘CFS’ or ‘CFIDS’ or ‘ME/CFS’ experts or ‘treatment centres’ should be avoided by M.E. patients like the plague!

If possible, find an expert in one of these fields (or more than one of them) that is also a qualified doctor so that you can also have any tests you may need – both private and practitioner-only. Appropriate testing plays a very important role in this type of medicine, as do some prescription drugs at times. All useful treatments and tests are used, without bias. The best is taken from each different type of medicine and all of the resources that are available. Many orthomolecular, holistic and environmental practitioners are also doctors.

In her book ‘Detoxify or Die’ Dr Sherry Rogers explains,

I have to laugh when people ask me if I do alternative, herbal, acupuncture or holistic medicine. ‘No,’ I reply. ‘We do state-of-the-art medicine. In other words, we find the biochemical, nutritional and environmental causes and cures rather than blindly drugging everything. Sure, herbs are gentler, safer and more physiologic than drugs and holistic medicine attempts to incorporate many diverse modalities, etc. But there is no substitute for finding the underlying biochemical causes and cures. This is real medicine. This is where medicine should and would have been decades ago, if it had not been abducted by the pharmaceutical industry.

For more information on this topic the following papers are essential reading:

- Symptom-based management vs. deep healing in M.E.
- Recognising and managing healing reactions in M.E.
- Sources of further information on the scientific validity, effectiveness and safety of orthomolecular/holistic/environmental medicine and the overwhelming problem of vested financial interest group bias in modern medicine and media

Possible problems getting treatment advice from doctors not educated about M.E. specifically include:

- May not understand all the bodily systems affected by M.E. and M.E. pathology.
- While the best doctors will be aware that 'CFS' is just a wastebasket diagnosis and be able to tell right away that someone with M.E. has obvious neurological and cardiovascular pathology, some good doctors may confuse M.E. with 'CFS' or not see past a 'CFS' misdiagnosis. 'CFS' will also mean very different things to each of these types of doctor, including thyroid or adrenal issues, post-viral fatigue syndromes, burnout, emotional issues and so on.
- Doesn't understand the fragility of M.E. patients, how disabled they are physically and cognitively and how easily they can relapse with even minor exertion such as attending a medical appointment.
- Doesn't understand or expect the degree of relapse which can occur with treatments and need to go VERY slow compared to other patients. M.E. patients
may need to go far more slowly with new treatments, especially treatments that aid detoxification, than other very ill patients.

Despite these drawbacks, good doctors in this field still have a lot to offer M.E. patients. Some may also be quite willing to read and learn more about M.E.

*Websites which may help you find a doctor specialising in orthomolecular / holistic / environmental medicine near you*

Note that of course the quality of those practicing orthomolecular, holistic or environmental medicine varies widely, as does the principles and methods they employ in their practice. Many of them will not practice medicine as described in *Symptom-based management vs. deep healing in M.E.* and so it is recommended that you ring or email a doctor and ask some questions before committing to seeing them.

Please also be aware that while some may claim to specialise in ‘CFS’ very rarely if ever will they know even the basic facts of M.E., or understand that M.E. is not ‘CFS.’

Websites from organisations:
- List of worldwide practitioners on Orthomolecular.org
- American College for Advancement in Medicine (ACAM)
- The Center for Holistic Medicine
- ACOEM’s Occupational Medicine Doctor Finder Service
- Patrick Holford’s website
- Institute for Functional Medicine: Find a Functional Medicine Practitioner
- International College of Integrative Medicine
- American Holistic Medical Association
- Australian College of Nutritional & Environmental Medicine
- Canadian Society for Environmental Medicine
- Biocomp Laboratories provides a list of holistic dentists.

Websites from individual doctors:
- The excellent Dr Sherry Rogers offers fixed-price phone consults
- Dr Carolyn Dean
- Dr Lawrence Wilson offers consults (worldwide) with doctors trained by him to analyse hair test results and to apply nutritional healing.

If you are interested in having vitamin C or the B vitamins by IV or IM, use the phone book or the internet to ask various qualified orthomolecular medicine
practitioners near you if they offer this therapy and if they are experienced in providing it.

This is not a complete list. If you’d like to suggest a website that could be added to this list, please do so. The inclusion of a website in this list does not guarantee its quality. HFME takes no responsibility for any problems which may arise as a result of seeing any of the doctors listed here. Investigate any doctor before you see them and proceed with caution.

Make sure you arrive at your first appointment with a full written medical history and any a copy of any relevant test results you may have. It is also helpful to have read as much as you can about this type of treatment beforehand.

**Educate yourself about the cutting-edge treatment options available so that you can partner with your doctor to secure yourself your best possible health outcome**

It is important for you as a patient to read as much as you can about different types of treatments, nutrients, issues related to diet and gut health, and so on. Medicine works much better when there is a partnership between the doctor and patient with both having some input. The doctor cannot do everything for you, and a patient that relies on the doctor to do everything will not end up getting the best care.

For more information on treating M.E. please see the HFME e-book *Treating M.E.: The Basics*.

This a free 300 page + fully referenced resource created especially for M.E. patients using information from some of the world’s leading orthomolecular medical experts, and others. It is divided up into many short sections which can be read one at a time and contains several overviews of various topics to help make comprehension easier for those suffering with M.E.

**Quick diagnosis is key with M.E.**

Patients quickly diagnosed and treated for M.E. have a much greater chance than other patients at regaining some or even all of their lives back. Correct diagnosis and treatment is extremely important in M.E., albeit one of the most difficult things to obtain within the current ignorant and corrupted medical system.

M.E. is a testable and scientifically measurable disease with a number of unique features. It is not difficult to diagnose medically even within just a few weeks of onset, using a series of objective tests.

For information on how M.E. is best treated in the early stages of the disease see the new paper: *Treating M.E. in the early stages*

For more information see: *Testing for M.E.* and The Nightingale Definition of *Myalgic Encephalomyelitis* by Dr Byron Hyde – the world’s preeminent M.E. expert.
It is very important to be aware that merely qualifying for a diagnosis of ‘CFS’ or ME/CFS’ is not at all the same thing as a genuine diagnosis of M.E. Vast numbers of patients qualify for these diagnoses that do not have M.E. and in fact if ‘CFS’ definitions are strictly adhered to, M.E. patients will not qualify for this misdiagnosis due to always having significant abnormalities on objective testing and on physical exam. For more information please see: What is M.E.?

**Avoiding overexertion in the early stages of M.E. is absolutely ESSENTIAL**

M.E. patients who are able to rest appropriately and avoid severe or repeated overexertion in the early stages of M.E. have repeatedly been shown to have the most positive long-term prognosis.

The importance of avoiding overexertion at this stage of M.E. just cannot be overstated. Resting in the early stages of M.E. or pushing through to remain active despite symptoms can be the difference between a normal life and very severe disability lasting decades or even death.

- For more information on the importance of avoiding overexertion in M.E. see: Treating M.E. - Avoiding overexertion and Assisting the M.E. patient in managing relapses and adrenaline surges plus Hospital or carer notes for M.E. and Why patients with severe M.E. are housebound and bedbound.
- See also Treating M.E.: The basics, What it feels like to have Myalgic Encephalomyelitis: A personal M.E. symptom list and description of M.E. and What M.E. feels like to me, Group comments on the importance of avoiding overexertion in M.E., M.E. case studies plus The effects of CBT and GET on patients with Myalgic Encephalomyelitis and Patient accounts of GET.
- Note that even if the diagnosis of M.E. is not 100% certain, it cannot hurt to make sure the patient rests in the acute phase of the infection. Resting is beneficial in the early stages of all viral diseases and so benefits may also be seen to some extent even if the patient turns out not to have M.E.

**Calling all good doctors! Add your name to the future HFME international good doctor’s list**

This proposed new paper will list some of the good and the not-great-on-ME-facts but helpful-in-some-ways doctors out there.

Doctors can be specialists in vitamin IVs and very knowledgeable about how to nutritionally treat neurological and immune diseases generally, or even better, nutritional experts that are also doctors. Or they might just be good quality cardiologists, or neurologists, and so on. Doctors of all kinds that can see past the misinformation and are willing to treat patients based on their actual symptoms and pathology and to listen to the patient.
Do you have any names you think should be added to this international M.E. patients doctors list? If you are a doctor, would you like to add your own name to our list?

*If you are a doctor that is currently using the ‘Nightingale Definition of M.E.’ to correctly test and diagnose patients with M.E. then we would love to hear from you in particular.*

If desired, your details and name can be made public on the site or kept private and only released to patients on a one-on-one basis by private email.
Other problems faced by M.E. patients looking for correct diagnosis and treatment

Finding a good doctor is absolutely vital, and very much easier said than done for M.E. patients. The issue of correct diagnosis is incredibly difficult currently. M.E. is very easy to diagnose and to recognise and is quite distinct from various other diseases, and can reliably be tested for, but the problem is that most doctors do not have this information and have been fed an enormous amount of misinformation about M.E. and about 'CFS.'

Most often M.E. patients are told they have 'CFS' or 'CFIDS' or 'ME/CFS' - based on the various 'CFS' definitions - none of which is a useful or meaningful diagnosis. This is also often combined with inappropriate advice to exercise or to 'positive think' the way to health. Patients may be told that they will never recover and can't be treated or that they will recover fully within 5 years, neither of which is accurate as regards M.E.

Patients will also sometimes be misdiagnosed with depression when the inability to be active due to cardiac insufficiency etc. is confused with the very different problem of fatigue and apathy caused by a lack of motivation to be active. M.E. patients may also be misdiagnosed with an anxiety disorder if a doctor misinterprets the patient's problem of low blood pressure and other symptoms on standing or sitting (which may be managed by lots of fidgeting and changing of position) with mere anxiety symptoms. Doctors that make these misdiagnoses have clearly not listened even remotely to what their patients are telling them about their illness onset and their symptoms and are not conducting the appropriate tests as M.E. has very little in common with both of these conditions. (It is not a mistake that a conscientious and dedicated doctor could make.)

A big problem for many patients is being sent to different specialists who each claim that the illness resides entirely in their own speciality. (As the old saying goes, when one has a hammer, soon everything starts to look like a nail!) An M.E. patient may be sent to all allergist, and be told that once they take extreme steps to remove all allergens from their home environment, that full health will be restored.

When this doesn't happen, the allergist will usually either offer no explanation or apology at all, and stop seeing the patient or blame the patient for not following their advice carefully enough, or even 'choosing to be ill.' The same patient may then be sent to a rheumatologist, and be told that they have Fibromyalgia. Treatments
completely inappropriate for M.E. may then be recommended such as exercise and antidepressants, and the patient may be told 'all patients with Fibromyalgia are able to work, if they can struggle on and toughen up a bit and aren't lazy, why can't you?'. Of course it is hardly ethical or logical that patients with one disease have their severity and disability level compared to those with an entirely different disease, yet this is something M.E. patients face routinely unfortunately. It is very frustrating and in some cases amounts to serious medical abuse.

Patients with M.E. may also be sent to many different specialists, none of which knows anything at all about M.E., and be told that they have MS, POTS, NMH, Reynaud's, Fibromyalgia and so on. They may be given a dozen or more different diagnoses for what is actually just a classic case of M.E. This may not be so terrible in some cases, if at least the patient is treated well and given support appropriate for their level of disability. But it can cause huge problems where doctors try to treat each of these misdiagnosed diseases with the standard treatments, which will often be inappropriate for M.E. and cause the disease to worsen. (Just because M.E. and some of these other diseases share some symptoms, this does not mean that these symptoms have the same cause or response to treatment, or the same prognosis.)

**What are some basic principles of orthomolecular / holistic / environmental medicine?**

There are 3 basic principles:

1. **Get the good stuff in**. Give your body the fuel and tools it needs to work at an optimum level. Good food, nutrients and all the proper vitamins, minerals and antioxidants. Make sure you aren't deficient in anything important as the different nutrients all work together.

2. **Get the bad stuff out**. Make sure your body can detoxify out all the toxic substances and toxic by-products of bodily processes properly. Stop as many toxins from getting in in the first place, and do a detoxification program to get rid of the ones you have. Stop doing or eating the things which cause inflammation and have a pro-oxidant effect, and so on.

3. **Reduce your body's total load**. The total load concept is that lessening the body's overall burden/work and stress level in one area, will improve health generally and improve the body's ability to heal because the body's total load (or burden) is lessened. Fixing one problem frees up bodily resources that can be then be used to help other parts of the body function better or to heal.

A good orthomolecular or nutritional expert will also help you:

- Avoid toxins and anti-nutrients
- Avoid anything you react badly to or are allergic to in your diet
- Heal the gut (improve digestion, treat leaky gut and Candida if present)
- Start a detoxification regime
- Eliminate secondary infections and treat the primary infection, if present/still
active

- Educate you about how to eat well, with the ratio of protein, fat and carbohydrate that suits your body best
- Boost the immune system
- Boost antioxidant levels
- Make sure you have the optimum amounts of the most important nutrients
- Avoid causing further damage by excessive stress including oxidative stress (in M.E. this would include avoiding overexertion)
- Try to heal or restore the function of other areas in the body which need attention, specific to each individual disease (in M.E. this may involve supporting good cardiac function, metabolic function, adrenal and thyroid function and repairing the myelin sheaths.)

Addressing all of these things takes a huge burden off the body. When body doesn't have to waste all its resources and energy slowly processing toxic waste, for example, it can use that energy to power up the very energy hungry immune system. This means getting fewer new infections and an increased likelihood of clearing long held ones. When the gut is healed food will be will digested better and so you'll start taking in more nutrients from the food you eat. No disease can he healed without first healing the gut. With all your body systems having a far lighter burden to carry plus all the nutrients they NEED, overall health is improved as is your body's ability to heal from serious disease.

The body needs to have the optimum amount of every essential nutrient. Ill people have higher requirements for nutrients than do healthy people. Every molecule of something toxic detoxified, leaves you with fewer molecules of an important nutrient, for example. The key to supporting the body's task of healing is not new and ever more exotic or specialised drugs or herbs, but a focus on all the nutrients we need to live and for our bodies to function optimally and to heal as much as is possible.

As Andrew Saul PhD explains,

Good nutrition and vitamins do not directly cure disease, the body does. You provide the raw materials and the inborn wisdom of your body makes the repairs. Someday healthcare without megavitamin therapy will be seen as we today see childbirth without sanitation or surgery without anaesthetic.

For more information on this topic the following papers are essential reading:

- Symptom-based management vs. deep healing in M.E.
- Recognising and managing healing reactions in M.E.
- Sources of further information on the scientific validity, effectiveness and safety of orthomolecular/holistic/environmental medicine and the overwhelming problem of vested financial interest group bias in modern medicine and media
Serious problems to be aware of with many or even most of the natural therapists currently in practice

There are a lot of very poor quality therapists currently practicing in the field of natural medicine. For example, it seems these days that almost everyone who visits a naturopath will be told, no matter what their state of health, that they have a Candida problem! (And that they need to stop eating wheat and dairy products too.)

The amount of training and knowledge about diseases varies enormously from one naturopath to the next. While some do a lot of good, have thousands of positive case studies that would be the envy of a huge number of traditional doctors and have an enormous amount of scientific knowledge, others know very little and have almost no qualifications.

Unfortunately, not only do many naturopaths over-diagnose Candidiasis, it is also quite common for such individuals to tell a person with M.E. that they have a Candida problem causing all their symptoms and that once this infection is treated that they will be well and be able to resume their normal healthy life. All of the MANY symptoms and features of M.E. that don't fit Candidiasis (which is almost all of them) are ignored. Then, when this doesn't happen (because of course even if the patient does have Candidiasis, this is only a very, very small part of their serious health problems caused by M.E.) they blame the patient for not trying hard enough to get well or for not sticking to the program well enough.

These 'professionals' often fail to see that it is their own lack of skill and qualifications that has led them to misdiagnose and mistreat the patient and that they are actually behaving abusively, inappropriately and very unfairly and cruelly. If you are unlucky enough to encounter such a person, do not let their insults to your character affect you as they are all about THEIR ignorance and lack of professionalism and nothing to do with you at all. Do not continue to see them professionally and if you can, try to educate them politely about the reality of M.E. (in printed form) as you leave!

Natural medicine experts who perceive M.E. as a form of 'chronic fatigue' of a state of 'low energy' and treat you accordingly can cause significant harm (as the exercise or activity intolerance of M.E. is protective - and is of course NOT fatigue or tiredness - and artificially increasing activity levels with stimulants (or other means) can be extremely harmful and cause significant relapse in the short term, and may also have serious long-term consequences.).

As with a primary Candidiasis misdiagnosis, this ignorance of the facts of M.E. can also lead to vast overconfidence and overestimations by the practitioner in the effectiveness of treatments being recommended and the likelihood of recovery. Again, this can give the patient false hope which when (inevitably) lost, can be very hard to deal with emotionally and some practitioners may then compound this upset by then unfairly placing the entire blame for the lack of expected progress squarely on the patient.
Some of these concerns are also relevant to being treated by traditional medical doctors and specialists; any person treating you for this illness must know how to avoid causing you harm.

Generally speaking, naturopaths and similar professionals that are not also doctors are not equipped to diagnose patients correctly, but can sometimes be very useful for recommending treatments post-diagnosis.

Good and very good natural therapists do exist, but they are probably in the minority. Amongst the legitimate practitioners there are a lot of quacks out there who just want to take your money and will say anything they have to, to make you keep giving it to them. Many will be interested in treating symptoms, rather than finding and treating the actual causes of symptoms. One naturopath or nutritionist may be very different to another and it is up to you as a patient to check out a practitioners credentials and ask some questions before booking your first, and certainly your second, consult. If you don’t feel confident in your practitioners training or abilities, find someone else more worthy of your time and money as soon as possible.

The recommendation of some orthomolecular / holistic / environmental experts in this paper is also in no way a blanket recommendation for all the different types of natural or nutritional therapists available. It is not a recommendation for crystal healing, past-like regression therapy or homeopathy, for example. It is very important to judge each type of natural medicine on its own merits and not to reject all of them together just because one area may lack scientific evidence or positive results.

What matters is the distinction between medicine that works, and medicine that doesn’t not some artificial line between so-called mainstream or so-called alternative medicine.

For more information on this topic see Symptom-based management vs. deep healing in M.E.

**Disclaimer:** HFME does not dispense medical advice or recommend treatment, and assumes no responsibility for treatments undertaken by visitors to the site. It is a resource providing information for education, research and advocacy only. Please consult your own health-care provider regarding any medical issues relating to the diagnosis or treatment of any medical condition.
Section 4: Quick start guides
The most important thing with M.E. is to get the foundations in place first so you stop causing further bodily damage through overexertion and make sure you don’t give your body any extra work to do so the focus can be kept on healing the core damage you already have. If this stage is not done, and taken very seriously, you’ll just keep getting sicker, no matter how many treatments you try. Your body’s healing mechanisms just won’t be able to keep up.

Once you have these basic foundations in place (or almost!), then you might like to look more seriously at what you can do to safely make sure your body has all the raw materials it needs to try to heal itself and to prevent further damage to some extent. And to make you feel better, function better, minimise or treat symptoms and reduce secondary disease risk – now.

The best news about M.E. is that unlike MS, if we can avoid further permanent damage, rest appropriately and give our bodies a real chance to heal, M.E. most often has a tendency to improve over time. M.E. is not automatically progressive over time despite all types of treatment, as MS often is. How much recovery occurs varies, with those who are newly ill or that have avoided serious bodily damage caused by overexertion having a huge advantage over the rest of us, and far more reason to hope for large improvements. (As Dr Ramsay has explained, a virtually complete remission is a real possibility if M.E. is treated with aggressive rest therapy in the very earliest stages.)

There is almost always hope of at least some small or maybe even moderate improvements, even for those that do have significant bodily damage incurred through years or decades of overexertion and poor care. Stability can be achieved with proper care and rest for all but the most extremely severe patients, according to Dr Dowsett. This is bleak undoubtedly but is at least more hopeful than the utterly terrifying continual deterioration of function many patients are currently living with.

In practice, however, M.E. disability most often gets much worse over time as so very few M.E. patients are given the appropriate care and support. Many lose their chances for recovery with unethical and unscientific advice to exercise or forced exercise programs – if not their lives. It’s a scandal, an unbelievably immoral financial scam and an absolute tragedy, on a massive scale. This has to stop, and has
to BE stopped. There is a desperate need for real activism and advocacy, very little of which is happening currently as patients and others follow one slick “pseudo-advocacy” scam after another. Scams that seem to be in the interest of patients at first glance, but which actually just entrench the misinformation and the abuse even more, give further aid to our abusers and keep patients from participating in genuine and effective advocacy. We must stop so many with M.E. NEEDLESSLY losing almost everything to decades upon decades of very severe illness, disability and shocking abuse. 20 years is ENOUGH. Knowledge is power. For more information please see: What is M.E.?

In the meantime, with strict adherence to a program of avoiding overexertion and some solid nutritional support (etc.) there is absolutely real hope of getting at least part of your life back and some real quality of life back. Your situation is absolutely NOT completely hopeless.

For more information on genuine healing in M.E. see: Symptom-based management vs. deep healing in M.E.

The foundations of treating M.E.
1. Strictly avoid overexertion by following the 80% rule.
Work out how much you can do every day without becoming sicker, and then do only 80% of that. To have each day the same activity-wise is the goal. Avoid adrenaline crashes where you can operate outside your normal ability levels for a hour or a day but then spend a long time after much sicker; days or even weeks or months or longer.

(If you are absolutely forced to operate outside your limits sometimes, or quite often, due to not having the basic care and support you need... sincere commiserations. Just do the very best you possibly can and best of luck with your support level improving in the future.)

Think about all your priorities, and realise that if you have been overexerting something WILL have to give and you will have to save your abilities for just those few things highest on the list, at least for now. Doing otherwise means you will have to give up even more in the long term.

Try resting significantly more for a week and see which symptoms improve, if any. If you feel a lot better, you may still be doing too much in your usual routine and may need to cut back. Intensive rest therapy in M.E. is not fun, or easy. It’s anything but, as anyone with M.E. will tell you. But it is unfortunately absolutely necessary.

Remember that it is absolutely true (as Dowsett and others have said) that just doing the basic tasks of living IS ENOUGH by itself to stop significant deconditioning. (The scaremongering about deconditioning is about politics subverting science. A scientific sham involving ‘medically unexplained fatigue patients’ and not actual M.E. patients at all!)
Over time, when/if you are able to do a little more in a day with no payback, you will just know, and can then adjust your activity levels accordingly. Nobody with M.E. will ever do far less than they are physically capable of doing. Resting so much is incredibly difficult.

For more information see: What is M.E.?, The importance of avoiding overexertion in M.E. plus Assisting the M.E. patient in managing relapses and adrenaline surges – this paper includes a list of tips on resting for M.E. patients.

2. **Give your body proper rest. Be kind to yourself and let go of all guilt associated with giving your body the rest it needs.**

If you are well enough (and unfortunately many with M.E. are not), increasing your ability to rest even further through doing breathing exercises, or relaxation and mediation CDs can be very helpful. It may also help to make your living space very restful for the eye (and thus your poor brain, in its constant low-level seizure state). Real rest requires that you rest cognitively and emotionally just as much as physically.

*(If this all seem like far too much emphasis on rest and seem sin any way at all silly, bizarre, excessive and/or unnecessary, then it is very strongly recommended that a diagnosis other than M.E. is very thoroughly considered. If you are reading this and don’t think your disease is primarily neurological and involves cardiac insufficiency due to mitochondrial failure, and it wasn’t acute onset, or your disease was diagnosed based merely on the exclusion of other diseases, then it is also very strongly recommended that a diagnosis other than M.E. is very thoroughly considered. See: What is M.E.? or Misdiagnosis for more information Misdiagnosis is rampant in this area unfortunately due to medical ignorance of the basic facts, but a correct diagnosis is half the battle won.)*

3. **Clean up your diet.**

Eat good, nutritious whole food and avoid chemical additives and foods you react to. See Food as medicine in M.E. for more information.

4. **Clean up your environment and avoid toxic chemicals and products.**

See Toxin avoidance and M.E. for more information.

5. **Get yourself some emotional support.**

Get support from family and friends if you can, through educating them about M.E., so that those around you will help you in your mission to improve your health rather than hinder it.
If you can’t get support from friends and family, or even if you can, support and camaraderie from fellow patients is essential. Nowhere else will you get such useful tips, practical advice, understanding support and compassion and be able to also feel good about yourself (and useful) by giving these valuable and life-changing things to others. To know deep inside that you aren’t alone, and that so many of us are suffering with the exact same symptoms and problems you are... is indescribably helpful, validating and self-esteem restoring.

If you aren’t well enough to join an online group, perhaps email/write to/phone a small number of fellow patients you get on well with and have things in common with. Having the right support helps you emotionally, but also helps you stay within your limits physically as this is very hard to do if you don’t understand your disease and also accept it. See: Tips for coping with M.E. emotionally for more information.

The most important supplements, medications and vitamins for M.E.
Treating M.E. with supplements is mostly about giving your body the extra vitamins and enzymes etc. it needs when dealing with illness and giving your body the things it needs to try to heal itself and that also make you feel better, reduce or treat some symptoms and have a reduced risk of disease in the present.

Supplements/medications are listed below in general order of importance.

Note that the first 7 items, with the exception of ubiquinol, are all very inexpensive and can all be purchased for perhaps just a dollar a day, in total. More good news for the majority of M.E. patients which do not have the luxury of appropriate (or any) medical care is that only a small number of items on the list require a doctor’s script, most are easily obtainable online or in your local supermarket. The final piece of good news is that virtually all the items listed here are very, very safe. (The remaining one or two products are also very safe but do require that some minor precautions are taken in their use or that dosage limits are carefully observed.)

More information on each of these supplements/medications is given in section 2.

Overview:
1. A good quality high-potency multi-vitamin and multi-mineral supplement
2. High-dose vitamin C
3. Magnesium and calcium
4. High-dose B vitamins
5. Reduced CoQ10 - ubiquinol
6. Natural vitamin E
7. Potassium and unrefined sea salt
8. Omega 3 oils: EPA/DHA (fish oil)
9. L carnitine
10. Probiotics
11. Vitamin A and/or natural beta carotene
12. Vitamin D3  
13. Digestive enzymes  
14. Hawthorne extract  
15. Iodine  
16. Lipoic acid  
17. Anthocyandins, Silymarin, and an antioxidant complex  
18. Trace minerals  
19. Other very important supplements/prescription drugs which are needed by some, but not all, patients  
20. Other useful Krebs citric acid cycle (metabolic/mitochondrial) supports  
21. Other useful general supplements.

1. A good quality high-potency multi-vitamin and multi-mineral supplement  
Essential. Antioxidant, strengthens the immune system, improves mitochondrial function, facilitates energy release/utilisation from food, supports thyroid function, supports female hormonal health and healthy teeth, promotes better wound healing, treats peripheral neuropathy, promotes detoxification processes, promotes healthy skin, hair and nails, improves general wellbeing, improves ability to cope with stress, natural antidepressant and improves resistance to secondary diseases. Better taken in divided doses (2 - 4), if possible, as the B vitamins are water soluble and don’t stay in the body long.

Consider taking a double dose to get larger amounts of each vitamin etc. at a low price (after checking there are no ingredients for which a double dose would be too high). Toxicity is not a concern but make sure the supplement is stimulant, iron and copper free. Generally well tolerated in M.E. if the dose is raised slowly.

A sample ingredient list is as follows (based primarily on LEF’s excellent ‘Two-per day’ multivitamin and mineral tablets):

- Vitamin A 5000 IU or more (as retinol or from beta carotene, or both),  
- Thiamin (vitamin B1) 50 – 100 mg, Riboflavin (vitamin B2) 50 – 100 mg, Niacin (vitamin B3) 50 mg or more, Pantothenic acid (vitamin B5) 100 mg or more, Pyridoxine (vitamin B6) 75 – 150 mg, Biotin (vitamin B7) 300 mcg or more, Inositol (vitamin B8) 50 mg or more, Folate (vitamin B9) 800 mcg, Vitamin B12 300 mcg or more, PABA (sometimes called vitamin Bx) 30 mg or more, Choline (a B vitamin) 20 mg or more,
- Vitamin C 500 mg or more,  
- Vitamin D (preferably D3) 100 IU or more,  
- Vitamin E (natural) 50 IU or more,  
- Calcium (token amount usually included, due to bulk),  
- Magnesium 100 mg or more (token amount usually included, due to bulk),  
- Potassium (token amount usually included, due to bulk),  
- Iodine (from kelp) 150 mcg or more,  
- Zinc 30 – 60 mg,
- Selenium 200 - 400 mcg,
- Manganese 2 – 5 mg,
- Chromium 200 mcg or more,
- Molybdenum 100 mcg or more,
- Boron 3 – 6 mg,
- Some lutein, zeaxanthin and lycopene (all carotenoids), or a mixed carotenoids complex.

Products worth taking a look at include:
- Life Extension Foundation’s (LEF) ‘Two-per day’ multivitamin and mineral tablets.
- Thorne Research, Basic Nutrients III without Copper and Iron.
- Thorne Research, Basic Nutrients I without Copper and Iron.
- Allergy Research Group, Nutricology, Multi-Vi-Min without Copper and Iron. This product may be a good choice for those that are very sensitive to supplements as the dosages are lower and the product has been formulated with very intolerant or allergic individuals in mind.
- Garden of Life, Living Multi, Optimal Formula. This food-based product may also be a good choice for those that are very sensitive to supplements as the dosages are lower and the product has been formulated using food-based nutrients.
- Super 2 Daily Vitamins & Minerals, (with fish oil and iron-free), by Carlson Labs.

Inexpensive.

2. **High-dose vitamin C**

Essential. Antioxidant, antihistamine, antitoxic, antiviral, anticarcinogenic, anti-inflammatory, strengthens the immune system (vitamin C is the master immune boosting nutrient), improves blood flow to the brain, supports adrenals (which also supports the thyroid), improves mitochondrial function, improves general wellbeing, improves ability to cope with stress, reduces pain, improves asthma, prevents tooth loss, promotes wound healing, supports healthy joints and improves resistance to secondary diseases.

High dose C can markedly improve your tolerance of certain chemicals and also has many other additional benefits, and its importance in M.E. treatment cannot be overstated. (May possibly be able to cure M.E., as with polio and other viral diseases, if given by IV or as Lypo-C to bowel tolerance in the very earliest stages of the infection – in the first weeks or months of illness.)
Oral dosage varies considerably, starting at 4 to 10 g (as an absolute minimum) and going up to a bowel tolerance dose, which is ideal in M.E. (perhaps 15 -30 g on average). The most effective forms of vitamin C however are vitamin C given by IV and liposomal vitamin C (Lypo-C) which is a new delivery system of vitamin C utilising nanotechnology, which offers the same effect as IVC in a much smaller, cheaper and easier to administer form. See the paper on liposomal vitamin C for more information.

Toxicity is not a concern. Well tolerated by most M.E. patients so long as the dose is raised slowly. When the saturation dose is reached, mild transient gas or diarrhoea occurs which is an indication the dose should be lowered by 10%. The goal is to take as much as possible without experiencing mild gas. Please see the extensive information in the paper on High-dose vitamin C and M.E. for more information. Oral vitamin C is inexpensive

3. Magnesium and calcium
Essential. Improves mitochondrial function and cardiac/muscle function (magnesium is the hearts most important mineral), helps the body metabolise sugar, treats leg cramps, improves asthma and PMS mood swings. Magnesium is an essential mineral involved in over 300 enzyme actions in the body. Magnesium is essential for normal heart function, nerve impulse transmission, muscle relaxation and calcium management.

Magnesium can be taken orally in the form of tablets, capsules, powders or liquids, administered via injection or IV, or absorbed transdermally (through the skin). Magnesium is absorbed very poorly orally (although liquids are absorbed better than tablets or capsules), moderately well transdermally (more than twice as well with direct skin contact than with baths), and at a very high rate through injections and IVs.

Tests for magnesium levels are available, but magnesium experts suggest that the best test is to take magnesium for 1 - 3 months and see if you feel better on it. Most people are deficient in magnesium and will benefit from taking larger amounts of magnesium for 1 - 3 months (or 12 months or more if only oral supplements are taken) to fully replenish their magnesium levels and to reach 'cell saturation.' Magnesium levels should always be raised gradually. For information on reaching cell saturation with magnesium and the different types of magnesium available, see the ‘Magnesium and M.E.’ paper.

Once maximum benefits have been realised from higher doses of magnesium, the dose can be lowered to a maintenance dose. This may be 1200 - 1500 mg or a somewhat higher dose, depending on your individual need. At this time it is important to make sure you take calcium and magnesium in a 1:2 ratio, in favour of magnesium. (Or if you prefer, a 1:3 ratio in favour of magnesium, as suggested by Dr Carolyn Dean; you need to use your own judgement here.). Also note that according
to the book 'The Vitamin D Cure' it is important NOT to take more than 600 mg of calcium daily, if your vitamin D levels are optimal (above 40 ng/ml). Vitamin D increases the absorption rate of calcium, as does magnesium. So this could mean taking 600 mg of calcium daily and 1200 mg of magnesium, for example, if you followed the 1:2 ratio.

Magnesium is involved in the production of ATP and is also a muscle and brain relaxer. Some patients take their last dose of magnesium late at night as they find it helps them sleep, while others make sure to take their last dose by late afternoon lest it leave them feeling too energised to sleep. Good forms of calcium are calcium citrate, angstrom calcium and calcium AEP. Note that most calcium is only 4 – 10% absorbed, but angstrom calcium (and magnesium) is almost 100% absorbed due to its small size and so the doses used are much much lower than with other forms (eg, 20 mg or less). Well tolerated by M.E. patients. Inexpensive (though this depends on dosage and type).

4. High dose B vitamins
Essential, if budget allows. The B vitamins play an essential role in the Krebs energy cycle, support the adrenals and proper neurological, cognitive and cardiac function, help maintain and repair the myelin sheath, help lower homocysteine levels and help the body cope with stress.

B vitamins given by IV have the most powerful effect, generally speaking. In some cases, however, particularly where liver function or metabolic function is very poor, coenzymated B vitamin products will be the best choice, and all other forms of B vitamins will have little or no effect.

Taking 150 mg daily of a B vitamin complex product should bring noticeable effects and benefits within 2 - 4 weeks. It should improve wellbeing generally, improve concentration, improve mood and make you feel more able to cope with stress. You should really be able to feel a significant difference. If 150 mg of an oral B complex is taken for a month with little or no effect, a sublingual coenzymated B complex product should be trialled. Try 2 or 3 sublingual lozenges daily (depending on the brand).

Patients that have access to a doctor experienced in giving vitamins by injection or IV may also want to try this method of treatment for a period of time to see if it provides extra benefits (if budget allows). For more information see ‘The B vitamins and M.E.’ paper.

Because the B vitamins are so intertwined, it is important to take B vitamins as a complex rather than taking a large amount of one or two B vitamins and possibly creating new imbalances. Individual B vitamins should never be taken without also taking a B complex product of a roughly similar strength.
The B vitamins are water-soluble and any excess is readily excreted in the urine and so B vitamins are generally low in toxicity. Generally well tolerated in M.E. Inexpensive/moderately priced depending on dosage.

5. Reduced CoQ10 - ubiquinol
Essential, if budget allows. Antioxidant, improves neurological and cardiac function, improves mitochondrial function, and improves general wellbeing and sleep. Some doctors argue that CoQ10 should be considered a vitamin. CoQ10 is essential for energy in every cell of the body, allowing the cells to live longer. The heart is utterly dependent on CoQ10.

Dosage is usually 100 – 300 mg and up to 400 mg in severe illness. Should be taken with a meal containing fat, to increase absorption. Toxicity is not a concern at doses up to 400 mg.

Very well tolerated by most M.E. patients if the dose is raised very slowly and started at 25 -50 mg daily. Even if all you can afford is one 50 mg capsule every two days, or even once a week, this dose is still absolutely worthwhile. Moderately priced/quite expensive depending on dose.

6. Natural vitamin E
Essential, if budget allows. Antioxidant, strengthens and regulates the heartbeat, enables the heart to do more work with less oxygen, promotes wound healing, helps prevent blood clots and strengthens the immune system (and many other bodily processes).

It is important to take some of each of the eight different types of vitamin E, and not just alpha-tocopherol. Gamma-tocopherol is particularly important and current research suggests that it is beneficial to take twice as much gamma-tocopherol as alpha-tocopherol. So an ideal daily vitamin E intake would include 400 IU (270 mg) of alpha-tocopherol plus around 540 mg of gamma-tocopherol, 200 mg of delta-tocopherol and 14 mg of beta-tocopherol), plus a mixed tocotrienols product taken once daily.

If a lower level of vitamin E supplementation is desired, due to financial or other reasons, then the daily dosages given above can be halved. (This lower level of supplementation can also be halved again, if necessary. It is far better to take a lower level vitamin E than none at all.) For more information see the ‘Vitamin E and M.E.’ paper.

Expect to wait at least 3 months to see an effect from vitamin E supplementation, as vitamin E is fat soluble and takes a while to build up in the body (particularly in the brain). Vitamin E is well tolerated by M.E. patients generally, but it is highly recommended that the dose be raised gradually and that the final desired daily dose is
worked up to over at least 2 or 3 months. Toxicity is not a concern. Very inexpensive.

7. Potassium and unrefined sea salt
Essential. Increases blood volume thus improving cardiac function and general wellbeing, treats leg cramps and relaxes muscles, improves blood sugar control. Potassium is needed for growth, building muscles, transmission of nerve impulses, heart activity etc. Potassium and sodium work together allowing the nervous system to transmit messages as well as regulating the contraction of muscles. Your body needs at least 3500 mg of potassium daily, but some of this amount will come from your food.

Dosage in M.E. is usually 1000 - 1500 mg potassium and ¾ - 1 tsp of Celtic sea salt (or other unrefined sea salt) daily. To make a blood-volume-boosting electrolyte drink mix together ¼ teaspoon of Celtic sea salt and 500 mg of potassium in powder form (eg. potassium gluconate) in a glass of water. (A small amount of honey to improve the taste is an optional addition, if you feel you really need it. Liquid magnesium could also be added to the drink). The drink is best taken on waking and two or three times daily overall, spaced throughout the day. It should be limited to three drinks daily, maximum.

Another way to take in potassium and Celtic sea salt is to sprinkle a salt substitute made from potassium chloride liberally on your food each day, and to add a tablespoon of Celtic sea salt to your daily bath (or to your food). (Or up to half a cup of the salt in your bath – or a foot bath – if you only have baths once a week or less.)

For more information see the ‘Unrefined sea salt and M.E.’ paper.

Toxicity or side effects are not a concern; unless the dose is raised very high. Compound pharmacies may also sell potassium in a concentrated liquid form if your doctor is willing to prescribe it. Well tolerated by M.E. patients, although the dose should be raised slowly rather than a full dose taken all at once. Talk to your doctor before taking potassium if you have diabetes or kidney problems. Very inexpensive.

8. Omega 3 oils: EPA/DHA from fish oils
Essential, if budget allows. Anti-inflammatory, protects the myelin sheath, thins the blood, natural antidepressant, improves mitochondrial function, improves sleep, helps hormone balance, improves insulin resistance and improves CNS and cardiac function.

Cod liver oil is an excellent source of omega 3 oils and it also contains significant amounts of vitamin A, K2 and vitamin D. It is several supplements in one, and contains all the natural cofactors making it more potent. Dosage is usually ½ to 1 teaspoon daily of fermented cod liver oil, or 1 teaspoon to 1 tablespoon of high vitamin cod liver oil – making sure that the level of vitamin D is appropriate for you
and that your vitamin A intake from all sources doesn’t exceed 30 000 IU daily. The Westen A. Price Foundation considers cod liver oil far superior to fish oils, as fish oils are a very highly processed product and do not have the same high vitamin content.

For more information on where to source the highest quality cod liver oils, see the ‘Liver, liver extracts, cod liver oil and M.E.’ paper.

The amount of cod liver oil usually recommended as a maintenance dose is enough to give you 10 000 IU of vitamin A daily. Extra EPA/DHA, where necessary, can be taken in the form of fish oils. With fish oil, look for products which are mercury and toxin free, and have IFOS certification, if possible. Good brands include Carlson’s and LEF. Dosage is usually 2 - 3.6 g of EPA and DHA (combined).

Toxicity is not a concern. Must be taken with at least 270 mg of natural vitamin e. Very well tolerated by most M.E. patients if the starting dose is low and the dose is raised slowly. Somewhat expensive/quite expensive depending on dosage.

9. **L Carnitine**

Very helpful, if budget allows. Improves mitochondrial function, improves cardiac and neurological function and improves general wellbeing. Dosage is usually 1 – 2 g, taken in 3 or 4 divided doses daily, although some patients may find they need 3 or 4 g to get the full effects from L carnitine, or even 5 or 6 g in severe cases. The maintenance dose of L carnitine may be lower than the initial dose, although in some patients the initial dose must be maintained to prevent relapse.

Acetyl L carnitine may also be helpful in improving neurological and cognitive problems, but is not as essential as L carnitine which works to improve cardiac function. Too much ALC can also cause neurological overstimulation for those with neurological diseases involving seizure states such as M.E. and so a small dose of just 500 mg is recommended. ALC is not recommended where seizure problems are severe.

L Carnitine should not be taken in doses of more than 1 g at a time, as less carnitine is absorbed when higher doses are taken. L carnitine works synergistically with CoQ10. Toxicity is not a concern. Well tolerated by M.E. patients. Moderately priced.

10. **Probiotics**

Essential, if budget allows. Improves general wellbeing, adds to antioxidant defence, improves digestive health (and can stop diarrhoea and constipation), improves absorption of food and supplements and improves food intolerances and resistance to some secondary diseases.
Dosage is usually 25 billion organisms, but 100 to 200 billion organisms daily may be even more beneficial in M.E., if budget allows. Look for high strength human strain probiotics such as VSL#3.

Toxicity is not a concern. Well tolerated by most M.E. patients if the starting dose is low and the dose is raised very slowly. Best taken on an empty stomach. A small percentage of M.E. patients find they are unable to tolerate probiotics at any dose. Inexpensive/quite expensive depending on dosage.

11. **Vitamin A and/or natural beta carotene (from d. salina)**

Essential, if budget allows. Antioxidant, improves hormone stability in women, supports adrenals, improves function of thymus gland, promotes blood sugar balance/insulin resistance, improves skin health, strengthens the immune system (and many other bodily processes) and improves resistance to secondary diseases.

Dosage for beta carotene is usually 25 000 – 50 000 IU. Beta carotene converts to vitamin A in the body, although this process is very inefficient in those with hypothyroidism (or diabetes) – which includes most M.E. patients. For M.E. patients with hypothyroidism, vitamin A is a better choice than beta carotene this reason.

Some doctors recommend that an initial loading dose of 25 000 IU of vitamin A be taken for one month, and then the dose dropped down to a more typical dose of 5000 – 10 000 IU daily. For patients that do not have hypothyroidism, both beta carotene and vitamin A can be taken at these doses. One of the best sources of vitamin A is cod liver oil. This contains many important factors that are not seen in isolated supplements of vitamin A, and is considered to be a far safer type of vitamin A than the synthetic varities. Dosage of vitamin A from all sources should be limited to 30 000 IU daily and the usual maintence dose form cod liver oil is 10 000 IU daily. For more information on where to source the highest quality cod liver oils, see the ‘Liver, liver extracts, cod liver oil and M.E.’ paper.

Beta carotene toxicity is not a concern as any excess is simply secreted from the body (although in hypothyroidism taking large amounts of beta carotene may place unnecessary strain on the liver). Very high doses, 100 000 IU or more, may cause a harmless yellowing of the skin. Vitamin A is fat soluble and so toxicity can be a concern at very high doses over long periods of time; when taking over 25 000 IU daily for long periods of time in particular, further reading and periodic testing is essential. Vitamin A should be limited to 5000 IU in pregnancy, and by women that may possibly become pregnant. Note that vitamin D and A are linked and that a delicate balance must be maintained; without vitamin D, vitamin A can become ineffective or toxic, and without vitamin A, vitamin D can become ineffective. Well tolerated by M.E. patients. Very inexpensive.

12. **Vitamin D3**
Essential, if budget allows. Strengthens bones and the immune system, supports the pancreas, promotes well-being, improves digestion, responsible for the regulation of over 2,000 genes in your body and improves resistance to secondary diseases. It is a hormone as well as a vitamin. For information on vitamin D please see the ‘Vitamin D and M.E.’ paper.

Vitamin D is fat soluble so toxicity can be a concern at high doses. Periodic vitamin D testing is a good idea at any dose, to avoid too high and too LOW a dose being taken. The dose of fat soluble supplements should be raised very slowly as negative effects can take a long time to appear and to dissipate. Well tolerated by M.E. patients, at the right dose.

Note that vitamin D and A are linked and that a delicate balance must be maintained; without vitamin D, vitamin A can become ineffective or toxic, and without vitamin A, vitamin D can become ineffective. It is also essential to take adequate magnesium when taking vitamin D. Very inexpensive (and unnecessary if, unlike most M.E. patients, one is able to get the recommended sun exposure each week.)

13. Digestive enzymes
Important, if budget allows. Improves digestive health, improves food intolerances and supports the pancreas and the heart (by saving them the significant efforts needed to digest food) which improves general wellbeing and physical functioning.

Dosage is usually 1 – 2 capsules taken with the three main meals. Some doctors recommend plant based products, others prefer enzymes from animal products. Plant enzyme products will often contain mould. Different brands vary considerably, some sell basic products which may work perfectly well for some people, while others sell products suitable for those who need a very powerful product. It may be helpful to try several different brands. Dr Sherry Rogers recommends the Digestive Aid #34 product.

Where stomach acid is low, betaine HCl taken before meals can be essential. Low acid levels in the stomach can prevent you form taking in minerals and other nutrients even if you’re taking large amounts of them in supplemental form. Sufficient stomach acid is also needed to beat Candida overgrowth. Suspect low stomach acid where there is a feeling of fullness, flatulence or nausea after taking supplements. Betaine HCl can cause problems if it is taken when stomach acid is NOT low. Tests for low stomach acid include the Heidelburg test, the gastrogram or the magnesium hydrogen breath test.

Some doctors recommend that betaine HCl only be taken after one these tests has shown low acid levels, and under medical supervision. Others recommend a cautious at-home trial of betaine HCl where low stomach acid is suspected. To trial the product at home Dr Sherry Rogers recommends that one capsule be taken daily with one meal, and the dose slowly raised to 1 – 2 capsules with every meal. If the
stomach burns the dose should be lowered or the product should be discontinued. Good Betaine HCl products include Thorne’s Betaine HCl & Pepsin.

Another choice for improving digestion is unfiltered raw apple cider vinegar, ½ to 1 tablespoon taken before meals.

To work out which combination of digestive aids work best for you, you’ll need to go through some trial and error. Toxicity is not a concern. Well tolerated by most M.E. patients if the starting dose is low and the dose is raised very slowly. Inexpensive/moderately expensive depending on dosage and strength.

14. Hawthorne extract
Helpful for reducing symptoms, if budget allows. Improves cardiac function, improves shortness of breath, reduces inflammation and allergies. Dosage is usually 1000 mg of a standardised extract (made from the flowers and leaves of the plant – crataegus monogyna – not from the berries). Some patients may find they need 1500 mg, or after a period of time taking a higher dose, can drop the dose down to 500 mg with no loss of benefits.

Toxicity is not a concern. Some heart medications may have to be gradually adjusted downwards after Hawthorn supplementation, and this should be done with the assistance of the doctor that prescribed them. Well tolerated by most M.E. patients if the dose is raised slowly. Very inexpensive.

15. Iodine
Essential, if budget allows. Iodine is an essential element. Although its main function is in the production of thyroid hormones by the thyroid gland, other organs in the body have a need for iodine in order to function normally. Iodine is also an important part of any detoxification regime. When thyroid levels have been shown to be low, this may be an indication that an iodine loading test may be necessary.

The 24 hour iodine loading test (a urine test available from companies such as VRP) indicates whether or not additional iodine supplementation may be beneficial. For more information see the ‘Iodine and M.E. page. Inexpensive.

16. Lipoic acid or reduced lipoic acid
Helpful, if budget allows. Antioxidant, aids detoxification, helps the body convert food to energy more efficiently, improves insulin resistance, improves neuropathy, improves mitochondrial function. Dosage is usually 100 – 300 mg ALA, or 50 – 150 mg of reduced alpha lipoic acid (which is twice as powerful).

Lipoic acid depletes biotin and so extra biotin should be taken with lipoic acid. The lower doses of lipoic acid may be adequate for M.E. Can cause severe relapse in M.E. unless the starting dose is low and the dose is raised very, very slowly. Lipoic acid is
fat soluble so too high a dose may take a while to cause problems. Many patients can only tolerate the lower doses. Inexpensive.

17. **Anthocyanins, silymarin and/or an antioxidant complex product**

Very helpful, if budget allows. Antioxidant. Look for a product containing at least 50 mg of Pycnogenol, grape seed extract and green tea extract (or all three ideally), plus some ginkgo, curcumin, silymarin, rosemary extract, resveratrol and various standardised bioflavonoid and fruit extracts. (The most important antioxidants such as vitamins A, C and E etc. have already been discussed.)

Dr Atkins recommends that 100 – 200 mg of Pycnogenol or grape seed extract (or a combination of the two) be taken by those with neurological disorders. (Anthocyanins are a large subcategory of the bioflavonoid family and one of the major antioxidants. They are the pigments that give fruits their vivid colours. Anthocyanins are powerful antioxidants that replenish vitamins C and E when they become oxidized. Supplements such as Pycnogenol, Hawthorn (berries), bilberry extract and grape seed extract contain large amounts of Anthocyanins, as do foods such as grapes, all the berries, green tea, cherries, eggplant and red cabbage.)

Silymarin is the most potent of all herbal detoxifiers, and supports liver health. Taking Silymarin daily is essential during any detoxification regime, if budget allows. Dr Sherry Rogers recommends 1 – 3 capsules or more of the Super Milk Thistle X product daily. This supplement should be started at a low dose.

Calcium D glucarate is also a useful supplement for detoxification as it helps the body get phthalates from plastic products out of the body. This supplement is one patients should start taking at very low doses and go very slowly with.

Antioxidants work far better in combination than singly. Toxicity is not a concern. Well tolerated by most M.E. patients if the starting dose is low and the dose is raised very slowly. Moderately priced with high quality products.

18. **Trace minerals.**

The following trace mineral products may be useful:

- **IntraMIN** is a 100% organic liquid trace mineral supplement containing 70+ trace minerals that are super hypo-allergenic, drug free, and preservative free. It is said to be well tolerated by even the most chemically sensitive individuals. This product contains the same trace minerals found in unrefined sea salt but in a more concentrated and possibly better absorbed form. Dr Sherry Rogers recommends this product.

- A trace mineral product such as LEF’s **Trace Minerals** may be helpful if your multivitamin product doesn’t contain quite enough zinc, manganese, molybdenum and so on. Dr Sherry Rogers explains that the fact this product has copper as
copper glucinate in it means that it isn't the dangerous form of copper used in many cheap and nasty supplements, and so is very safe to take.

- **Biosil (silicon)** is recommended as an ‘electrical system’ booster by experts such as Dr Atkins and Dr Sherry Rogers. Biosil also greatly improves hair, nails and skin. Dr Atkins recommends 3 – 6 mg daily. Dr Sherry Rogers recommends Biosil drops.

- **Germanium** is an antioxidant found in garlic, comfrey, aloe vera and ginseng and is thought to promote health through its ability to regulate the uptake of oxygen in the cells (thus increasing cellular energy etc.). Note that the water-soluble trace mineral germanium, if taken, should only ever be in the organic Ge-132 form according to Dr Atkins. He also recommends that no more than 25 – 300 mg be taken daily. Around 1 mg daily may be obtained through eating germanium-rich foods. Before taking supplemental germanium it is recommended that patients first take a hair elements test.

- **Low doses of trace minerals such as Lithium and (organic) Germanium, as indicated by a hair elements test.**

19. **Other very important supplements which are essential in M.E. and which would also feature very high up on this list, except that they are not generally needed for every single M.E. patient, include the following;**

- **Melatonin (500 mcg to 3 mg usually sublingual tablets)** taken at night to promote sleep and reset the sleep/wake cycle. Effective and well tolerated for most but not all M.E. patients (for some it leaves them feeling very groggy in the mornings). May require a doctor’s script.

- **Ashwagandha extract (200 mg standardised extract)** for problems with adrenaline bursts etc. (or Rhodiola extract. Avoid if you have an overactive thyroid.) This herb may taken for a period of time and then stopped and restarted, to maintain the benefits.

- **The vast majority of M.E. patients will suffer with low adrenal and thyroid output. As with low thyroid output, the question of whether or not low adrenal output in M.E. should be boosted directly or treated more gently and indirectly via a more general deep healing program is a difficult one. The ways in which these problems are tested for, managed and treated are explained in Adrenal and thyroid issues and M.E.**

20. **Other useful Krebs citric acid cycle (metabolic/mitochondrial) supports** – along with the very important ubiquinol, carnitine, B vitamins, vitamin E, fish oil and magnesium already mentioned – which are not essential but which some patients find useful to varying degrees include:

- **Taurine (1 – 2 grams daily)** is an important nutrient for supporting detoxification and energy production.
Essential fatty acids are essential for good mitochondrial function. This includes EPA, DHA, phosphatidyl choline and cod liver oil.

D-ribose (3 g once or twice daily, will very often be very poorly tolerated and cause relapse in M.E., so proceed slowly and with caution, if at all. This supplement can provide big benefits, but there is also a big risk of relapse. Perhaps start with a dose as small as 100 – 1000 mg daily.)

Alpha ketoglutarate and/or malic acid (1 – 2 g, well tolerated),

Octacosanol (dosage is usually 6 mg at a minimum, although doses of 15 – 30 mg may be more appropriate. Buy the natural rather than the synthetic form.)

Sublingual APT (two to three lozenges daily, well tolerated).

Coenzyme A precursors (vitamin B5 as either pantethine or pantothenic acid, at least 200mg of either form although note that at least twice as much CoA will be formed with pantethine. Coenzyme A also works with CoQ10 in improving detoxification.)

Carnosine (50 to 500 mg, starting dose must be low and the dose must be raised very slowly as this supplement can cause problems and worsened illness).

21. Other useful general supplements, which are not essential but which some patients find useful to varying degrees include: Omega 6 and 9 supplements (from emu oil or flaxseed/borage oil etc.), calcium AEP, Octacosanol, ginkgo, inosine, medicinal marijuana (for adults only, where available legally), garlic, chlorella, extra molybdenum or chromium, silymarin, Biosil/silicon, quercetin, lecithin, liquorice (containing Glycyrrhizin), Brahmi, Matrine, curcumin, Sphingolin (a myelin sheath precursor), propolis and ginger.

Notes on this text
a. Prices quotes used to determine basic costs ratings are in US dollars or Australians dollars (which are almost the same as I write this) and are based on an average dose of a high quality branded supplement. Prices are correct as of late 2009. Very inexpensive = Under 20 cents daily, inexpensive = 20 to 40 c daily, moderately priced = 40 to 70 c daily, somewhat expensive = 70 to 90 c daily and quite expensive = over 90 c daily.

b. The dosage and toxicity information has been taken primarily from the following books and websites;

- Orthomolecular Medicine For Everyone: Megavitamin Therapeutics for Families and Physicians by Abram Hoffer,
- Dr Atkins Vita-Nutrient Solution: Nature’s Answer to Drugs, (Early in his career, Dr Atkins worked with vitamin C pioneer Dr F. Klenner, and considered him a nutritional medicine mentor.)
- Fire your doctor! : how to be independently healthy by Andrew W. Saul
- The NEW optimum nutrition bible by Patrick Holford,
- How to live longer and feel better by Linus Pauling,
• LEF’s Disease prevention and treatment
• VITAMIN C, TITRATING TO BOWEL TOLERANCE, ANASCORBEMIA, AND ACUTE INDUCED SCURVY by Robert F. Cathcart, M.D.
• Ascorbate: The Science of Vitamin C by Dr Hickey and Dr Roberts,
• VITAMIN C: The Real Story by Steve Hickey, PhD and Andrew Saul,
• The Journal of Orthomolecular Medicine
• DoctorYourself.com

The first 4 books listed here in particular are very highly recommended. Ideally M.E. patients would read at least one of these. They contain useful information on the history of vitamin therapies, information on why they are not yet mainstream, far more detailed information about what each supplement does, and so on. Check your library first, then maybe look at BetterWorld books for cheap second-hand paperback copies or audiobooks (some are under $4). Some are also available as e-books, from Lulu. Click here to read book reviews of some of these books.

c. Probably the best way to use the ‘Quickstart guide’ is to go through it twice. The first time, go slowly down the list and take each of the desired supplements at around half the recommended strength. Once you have worked all the way down the list (or as far as you’ve decided to go), go back to the start of the list and one by one, slowly bring each supplement up to full strength.

The benefit of going through the list twice is that you make sure you have thoroughly covered the basics before you start taking a high-dose of any one supplement.

d. For information on how to use the ‘Quickstart guide’ on a tight budget, please see the paper: ‘A quick start guide to treating M.E. – on a budget’

Please read ‘Important notes on using the HFME’s treatment information’ before starting any new treatment.
Additional information on some of the treatments listed in part 1:

1. **A good quality high-potency multi-vitamin and multi-mineral supplement** additional information:

**Zinc**

Zinc is an essential trace mineral. There are over 70 metalloenzymes known to require zinc for their functions. Zinc is involved in protein synthesis and carbohydrate metabolism, and is a constituent of insulin. Zinc is involved in the health of the immune system, assists vitamin A utilisation and is involved in the formation of bone and teeth. Zinc is critical to wound healing, and surgery or trauma can decrease the level of zinc in the body.

The article *Zinc and the Zinc Taste Test* (produced by a company called Dietary Research Limited in the UK) explains that,

Zinc is an essential trace element. It is one of the most important of the trace elements needed by the body. Of the many hundreds of protein enzymes present in the body, which allow its chemistry to work, zinc is required by over two hundred of them. It can thus be seen how a deficiency of zinc can affect so many different functions. Zinc deficiency can result in many symptoms, including: loss of appetite, growth retardation, diarrhoea, tremor, hair loss, dandruff, a dry skin rash, white lines on fingernails, increased allergic sensitivity, disturbance of menstrual periods, pre-menstrual syndrome, delay of wound healing, loss of taste or smell sensation, dyslexia, poor night vision, photophobia (sensitivity to light), depression, sleep disturbance, hyperactivity, reduced fertility, loss of sex drive, pre-eclampsia (toxaemia) of pregnancy and post-natal depression.

It has been observed that those suffering with any of the auto-immune diseases (such as multiple sclerosis, rheumatoid arthritis, psoriasis, etc); atopic problems (allergy, eczema, asthma or migraine); or many of the inflammatory diseases (such as osteo-arthritis, M.E. or irritable bowel syndrome), have a consistent, and often severe, zinc deficiency, which is greatly benefited by a programme of zinc replacement therapy.

Zinc is of vital importance in MS and other auto-immune diseases, partly because of its effect in promoting the production of PGs but, more importantly perhaps, because, by acting in its capacity as an antioxidant co-factor in the
enzyme, superoxide dismutase, it helps maintain the integrity of the essential fatty acids that contribute to the regeneration of the myelin.

Various zinc preparations may be used, including possibly chelated zinc, zinc citrate, zinc picolinate, or zinc gluconate. Zinc sulphate is the most common (and cheapest) presentation but should be avoided due to the frequent occurrence of gastric irritation and dyspepsia.

The best method of accurately determining zinc status is through measuring white blood cell levels. Serum zinc is routinely used as a screening tool however as it is a cheaper test. Hair tests can be an unreliable test of zinc status as elevated hair zinc may be indicative of low zinc in the cells or contamination from the use of zinc-containing shampoos, although low zinc levels shown on a hair test is likely to be indicative of poor zinc status. White spots on the nails are a sign of a zinc deficiency.

The zinc taste test appears to be of some value in determining general zinc status. Food and drink should be avoided one hour before the test. A room temperature solution of zinc sulphate in purified water should be prepared at a concentration of 1gm/litre. (The solution can be kept for 6 months if refrigerated, but should be left at room temperature for 2 hours before it is used for testing.) 5 – 10 ml of this solution should be held in the mouth for exactly 10 seconds.

The article Zinc and the Zinc Taste Test explains that,

This simple and non-toxic test was devised and developed by Professor Derek Bryce-Smith, Professor of Biochemistry at Reading University. Professor Bryce Smith is an established authority on zinc and numerous other biochemical topics.

For the zinc taste test, the defined standards are:

**Grade one response:** no specific taste sensation: tastes like plain water. This indicates a major deficiency of zinc.

**Grade two response:** no immediate taste is noticed but, within the ten seconds of the test, a 'dry' or 'metallic' taste is experienced. This indicates a moderate deficiency.

**Grade three response:** an immediate slight taste is noted, which increases with time over the ten second period. This indicates a deficiency of minor degree.

**Grade four response:** an immediate, strong and unpleasant taste is experienced. This indicates that no zinc deficiency exists. If this is the response to the first test done then obviously the diet already contains sufficient zinc and no supplement need be taken. If this is the response, however, after a period of zinc supplementation then the diet, prior to the supplement being given, must be assumed to have been deficient. Thus, if a relapse to this deficient state is to be further prevented a regular maintenance dose of zinc is required. One 15-20mg dose per day is usually sufficient for this purpose.

The therapeutic dosage of zinc is 30 – 60 mg. A zinc dosage of 50 mg or more should be worked up to over several weeks, rather than begun at this dosage level. Chronic ingestion of more than 100 mg of zinc daily may be immunosuppressive. Zinc should be limited to 100 mg daily, from all sources. Zinc lozenges, and to a lesser extent liquids, are better absorbed than zinc tablets. For more information on zinc.
supplementation please see the excellent Zinc and the Zinc Taste Test article or the books The Vita-Nutrient Solution and Fire your Doctor: How to be Independently Healthy.

**Selenium**

Selenium is an essential mineral which works closely with vitamin E. The antioxidant properties of selenium are related to this interaction as well as its active selenoprotein involvement in glutathione metabolism. These activities make selenium one of the most important antioxidant and immune system boosting nutrients. Selenium is also necessary for thyroid health as it is involved in converting T4 into T3.

The therapeutic dosage of selenium from diet and supplements is 200 - 400 mcg. This is a very safe but effective dose. (Total ingestion of selenium from diet and supplements should not exceed 750 mcg, and some sensitive individuals should not exceed 600 mcg. Doses over 750 mcg should be used under a doctor's supervision only. Selenium can cause serious problems if too much is taken. It has a far smaller therapeutic window than most nutrients. Pregnant women must be especially careful to monitor their intake of high selenium foods such as brazil nuts, as well as take lower strength selenium supplements than other women.)

Brazil nuts are very high in selenium. Brazil nuts may contain as much as 544 micrograms of selenium per 30 grams (1 ounce). Eating a few of these nuts each day can easily make up for a taking a multivitamin that is low in selenium and should always be taken into account when determining your daily selenium needs from supplementation. Click here for more information or see The Vita-Nutrient Solution and Fire your Doctor: How to be Independently Healthy.

**Manganese**

Manganese is an essential mineral found in trace amounts in tissues of the body. It is known as a cell-protector. Most of the 10 – 20 mg of manganese in the body is contained in bone, the liver and the kidneys. Manganese is essential to several critical enzymes necessary for energy production, bone and blood formation, nerve function and protein metabolism. It is involved in the metabolism of fats and glucose, the production of cholesterol and it allows the body to use vitamin B1 and vitamin E. It is also involved in the building and degrading of proteins and nucleic acid, biogenic amine metabolism, which involves the transmitting of nerve impulses. Manganese is very important in seizure disorders as it lessens seizure activity and lowers the threshold for seizures. Manganese promotes healthy DNA and RNA and reduces cell damage. Manganese is an important antioxidant as it is one of the minerals required to form SOD (superoxide dismutase) which protects against cell-damaging free radicals.

The usual therapeutic dosage of manganese is generally 2 – 11 mg. Some experts recommend doses as high as 15 – 50 mg (particularly when treating a deficiency). A daily intake of 50 mg daily is generally considered safe. Zinc and vitamin C aid
absorption of manganese. Hair elements tests can be used to check manganese levels. Dr Atkins recommends that the dosage of manganese not be looked at in a vacuum. He recommends that manganese should be taken with 2 – 5 times as much zinc. For example, a good ratio would be 10 mg of manganese taken with 50 mg of zinc, or 12 mg of manganese taken with 60 mg of zinc.

Accumulation in people with cirrhosis or liver failure may contribute to neurological problems and Parkinson's disease-like symptoms. Click here for more information or see The Vita-Nutrient Solution and Fire your Doctor: How to be Independently Healthy.

**Chromium**
Chromium is an essential trace element involved with proper metabolism of carbohydrates and lipids in the body. The therapeutic dosage of chromium is generally 200 - 600 mcg. More chromium is needed where there are problems with blood sugar control and glucose tolerance. Where these problems are milder, 200 – 300 mcg may suffice. Chromium should be taken under medical supervision in people with diabetes taking blood sugar lowering drugs or insulin injections as chromium supplementation may mean that the dosages of some of these drugs can be, and will need to be, lowered. Click here for more information or see The Vita-Nutrient Solution and Fire your Doctor: How to be Independently Healthy.

**Boron**
Boron is a trace mineral as fundamental to bone health as calcium and magnesium. The usual therapeutic dosage of boron is generally 3 mg. For more information see The Vita-Nutrient Solution and Fire your Doctor: How to be Independently Healthy.

**Molybdenum**
Molybdenum is an essential trace mineral and may be useful in the treatment of certain cardiovascular conditions, asthma, allergies and mercury toxicity. Molybdenum helps detoxification. Molybdenum is a vital part of three important enzyme systems - xanthine oxidase, aldehyde oxidase, and sulfite oxidase - and so has a vital role in uric acid formation, iron utilization, carbohydrate metabolism, and sulfite detoxification. Molybdenum strengthens teeth.

The therapeutic dosage of molybdenum is generally 100 - 1000 mcg or more, although sometimes much higher doses are used in detoxification programs. Dr Atkins recommends 200 – 500 mcg daily for healthy people and doses of up to 2000 mcg for those battling chemical sensitivities or yeast infections. Molybdenum should be avoided by those with gout. Click here for more information or see The Vita-Nutrient Solution and Fire your Doctor: How to be Independently Healthy.
Note that the above dosage information given above is not necessarily what should be expected to be in any multivitamin, it refers to the therapeutic dosage (and safe upper limits) of each vitamin overall. The amounts of each mineral in a good quality multivitamin and mineral product may suffice, or additional supplementation may also be required for some minerals, depending on the desired dosage. Individual mineral supplements should NOT be taken unless one is also taking a good quality (multivitamin and) multimineral product.

To read at length about the different roles and benefits of zinc, manganese, selenium, chromium and molybdenum (and the different forms of each mineral) and so on, please see the books on nutritional medicine in the references section, most notably: The Vita-Nutrient Solution and Fire your Doctor: How to be Independently Healthy.

Copper must be kept in balance as an excess can increase free radical activity, and cause tissue damage. There is a much smaller difference between a healthy level and a too-high level with copper than there is for many other minerals. The same is true for iron, and this is why copper- and iron-free multivitamins are most often recommended.

High copper and iron can put a person at grave risk for heart disease and blocked arteries and at an increased risk for cancer. High copper levels can cause migraines and eye damage. Iron can cause feed bacterial infections. Women are more susceptible to high copper levels than men and so it is even more important that women buy copper-free supplements unless testing indicates a copper deficiency. Some people, those with copper water pipes in particular, already have high copper levels. Copper is highest in foods such as soy, nuts and seeds and for most, dietary intake is probably adequate.

Copper from cheap and nasty multivitamin products such as Centrum is to be avoided at all costs. It is far better to take no vitamins at all, or to take good quality vitamins just a few times a week than to use a products such as this one which contain a toxic form of copper. Studies have shown that Centrum provides NO health benefits and it is known that this type of inorganic copper is linked to Alzheimers disease.

Iron should only be taken where low iron levels have been shown on testing. Testing for iron levels may be indicated where periods are very heavy and/or where the diet is entirely vegetarian. If testing via a serum ferritin test indicates that iron supplementation is necessary, the only form safe to take is heme iron (as a stand-alone supplement). Synthetic non-heme iron can accumulate in the body to harmful effect while heme iron does not have this problem. Synthetic non-heme iron is the type included in most iron-containing supplements and multivitamins as it is cheaper. This type of iron also destroys vitamin E. Another reason to buy iron-free supplements. Vitamins C and A help you absorb more iron from your food (eg. red meat). Calcium taken at the same time as iron containing foods blocks absorption of iron.
Watch out for multivitamin products which contain cysteine, TMG, lipoic acid, garlic, Echinacea and/or mushroom extracts. Cysteine and TMG may be very poorly tolerated in M.E., and lipoic acid and garlic may only be okay at lower doses and if this dose is worked up to slowly.

2. **High-dose vitamin C** additional information: For more information see the ‘High-dose vitamin C and M.E.’ paper.

3. **Magnesium and calcium** additional information: For more information see the ‘Magnesium and M.E.’ paper.

4. **High-dose B vitamins** additional information: For more information see ‘The B vitamins and M.E.’ paper.

5. **Reduced CoQ10 - ubiquinol** additional information: Make sure you buy a good quality brand – such as Jarrow or Life Extension, which have superior absorption. Start at a low dose and work up very slowly to avoid side effects; start at 50 mg every second day for 2 or 3 weeks, then (if you are handling that dose) go up to 50 mg daily for 2 or 3 weeks and so on, up to your optimum dose.

6. **Natural vitamin E** more information: For more information see the ‘Vitamin E and M.E.’ paper.

7. **Potassium and unrefined sea salt** additional information: Note that standard refined table salt should be avoided.

Increased natural/untreated salt intake is recommended by several M.E. experts, along with other electrolytes, to help increase blood volume. Low circulating blood volume is well-documented in M.E. This type of salt also helps support adrenal function, immune system function and brain function. 1 tsp of salt daily in total is probably sufficient. (Note, however, that Cheney recommends ¼ to ½ of a teaspoon of sea salt be dissolved in a glass of water and taken two or three times a day to help boost blood volume. So this may mean up to 1 ½ teaspoons of salt daily. He recommends patients start with the lower dose and work up.).

If you are drinking a lot of water and still feel thirsty, this may be a sign you need more electrolytes. Without enough electrolytes in your water, drinking large amounts of water can actually leave you feeling even more thirsty. Some M.E. patients like to make their own blood-volume-boosting electrolyte drink to take on waking, and anytime they need an urgent boost (as described previously). Ideally, potassium levels would be monitored periodically while this treatment is undertaken. Electrolyte
drink mixes are available to buy but are often far more expensive, less potent and full of aspartame and other fillers (and refined salt).

Potassium levels should be monitored carefully, and extra potassium given, if you are taking liquorice or the drug Florinef. (Note that Florinef is NOT recommended.)

For more information see the ‘Unrefined sea salt and M.E.’ paper.

8. Omega 3 oils: EPA/DHA from fish oils, more information: Essential fatty acids cannot cure M.E. (as some unethical and unscientific individuals have claimed, undoubtedly using ‘fatigue’ patient groups) but they are an essential part of an M.E. treatment regime.

Omega 3 (EPA and DHA) supplementation in the form of cod liver oil or fish oil is vital. Make sure you buy a good quality brand that filters out all the mercury and other contaminants from their fish oil; ONLY buy fish oils which have been certified by the IFOS (for example, Life Extension brand). If you buy contaminated fish oil of poor quality it can do you a lot more harm than good. Avoid Krill oil (due to impurities).

Never take more than 5000 mg of EPA and DHA without medical supervision and medical testing of your AA/EPA ratio via blood tests however, as this can cause serious adverse events. For more information see the book/website of The Anti-Inflammation Zone).

Although it is not as essential as Omega 3 supplementation as we get a lot of Omega 6 in our diet usually, if you can afford it, you may also like to take a smaller amount of Omega 6 in the form of Borage oil or emu oil. Standard dosage is 240 – 480 mg daily. You could also add 1000 mg of linoleic acid (Omega 6) and/or alpha linoleic acid (Omega 3) in the form of Perilla oil or Flaxseed oil. Flaxseed oil also contains Omega 9 as oleic acid. Note that EFAs must always be taken in combination with antioxidants, especially vitamin E (at least 270 mg).

For information on sourcing the best fermented cod liver oil and high-vitamin cod liver oil please read the paper ‘Liver, liver extracts, cod liver oil and M.E.’


10. Probiotics additional information: Probiotics must be taken every day to have a sustained benefit.

Recently Dr de Meirleir recommended VSL#3, a very strong probiotic (450 billion cells). Note that this doctor is not an M.E. expert and his research may or may not be partially relevant to M.E., but this strong probiotic may also help M.E. patients as it
mimics the bacteria normally present in the bowel. Note however that such high doses may be very helpful, but may also initially cause a worsening of symptoms due to die-off and so must be started very slowly. In some patients high doses may not be tolerated, so proceed with caution. Australian link, US/international link 1 and link 2. He also recommends a probiotic called MutafloR, but this product is made in and primarily available in Germany, although some German pharmacies will ship it to you. It is also available via prescription in countries such as Australia. This product may be available in the US and Canada in early and late 2010, respectively.

If you decide to try this high strength probiotic (at a dose of a full packet daily, or a half or a quarter), perhaps you might buy a 25 billion cells per capsule product first, to make sure you can tolerate even this moderate strength probiotic.

Note that chlorine kills beneficial bacteria, so drinking your probiotic powder with chlorinated water may be a huge waste of money so make sure you have a good quality water filter. (Fluoride in water must also be avoided.)

70% of our immune response comes from intestinal tissue and so probiotics really can play an important role in preventing various infections form taking hold. Prebiotics such as FOS may also possibly be helpful to some extent and you may want to take both. Women may benefit from taking a double dose of their usual probiotic in the week before their period. The balance of bacteria in the gut is fragile and can easily be disrupted by factors such as antibiotics, poor diet and also the menstrual cycle.

11. Vitamin A and/or natural beta carotene (from d. salina), more information: Natural beta carotene is best as it contains small amounts of the other carotenoids, which work better together, like the B vitamins do. It’s also helpful to eat lots of carrots and watermelon and other carotene containing foods to make sure you get a good mix of all the carotenoids. You may also choose to forgo a beta carotene supplement and instead have 1 cup of fresh carrot (or watermelon) juice daily, which gives you roughly 20 000 IU of vitamin A (from carotenes). Green vegetables also contain high levels of beta carotene. See www.nutritiondata.com for exact figures on BC content for other vegetables.

Vitamin A at 50 000 IU was shown in one study to reduce heavy menstrual bleeding, and when combined with folate and boron, vitamin A may also help to improve hot flushes and other menopausal symptoms.

As vitamin A is fat soluble, it’s possible to buy a higher strength supplement and perhaps take it only every second day, to save some money. (The same is true of vitamin D.) Absorption is improved by taking vitamin A (and D) with a fat containing meal. Cod liver oil is the best source of vitamin A. Symptoms of vitamin A deficiency include diarrhoea, poor night vision and mouth ulcers.

The Weston A. Price website states,
Concerns about vitamin A toxicity are exaggerated. While some forms of synthetic vitamin A found in supplements can be toxic at only moderately high doses, fat-soluble vitamin A naturally found in foods like cod liver oil, liver, and butterfat is safe at up to ten times the doses of water-soluble, solidified and emulsified vitamin A found in some supplements that produce toxicity. Additionally, the vitamin D found in cod liver oil and butterfat from pasture-raised animals protects against vitamin A toxicity, and allows one to consume a much higher amount of vitamin A before it becomes toxic.

The Westen A. Price Foundation recommends vitamin A from fermented cod liver oil, and a maximum of 30 000 IU of vitamin A daily from all sources.

Women that are pregnant or may become pregnant are generally recommended to take no more than 6000 IU of synthetic vitamin A daily. Very high vitamin A levels can cause problems for the foetus but so can very low vitamin A levels. Women in either of these positions should read more about safe vitamin A supplementation in pregnancy before taking any supplements, to make sure they are making the best and safest choices and if at all possible, have vitamin A testing done. The Western A. Price Foundation warns that solidified, water soluble and emulsified vitamin A is not the best choice.

12. **Vitamin D3 additional information:** For more information see the ‘Vitamin D and M.E.’ paper.

13. **Digestive enzymes additional information:** Enzymes may also improve health generally, as the body uses an enormous amount of cellular energy digesting food (hence why digestion is poor when M.E. is severe or there is serious overexertion) and letting your body avoid this task may leave you feeling significantly less ill, and/or possibly able to be slightly more active.

14. **Hawthorne extract additional information:** Hawthorn extract can improve serious cardiac and circulatory problems, as shown in this study. Note that this should be Hawthorn capsules made from the flowers and leaves of the plant (crataegus monogyna), not from the berries (crataegus laevigata). The extract should be 1.8 – 2% vitexin. Hawthorne is a potent bioflavonoid and antioxidant. Expect to wait 6 – 8 weeks to see effects. Hawthorne is best taken consistently to see benefits.

15. **Iodine additional information:** For more information see the ‘Iodine and M.E.’ paper.

16. **Lipoic acid or reduced lipoic acid more information:** Patients sensitive to potatoes and nightshades should look for ALA products which are not made from potatoes.
17. An antioxidant complex additional information: Quercetin is an antioxidant that increases resistance to allergic response. Quercetin serves as a potent inhibitor of histamine and cytokine release from mast cells and basophils. Bromelain and vitamin C may also be useful in helping to control allergies (combined Quercetin and Bromelain supplements are widely available). Dosage is usually at least 500 mg.

Rosemarinisc acid is a potent antioxidant that also assists with phase I and phase II detoxification.
A quick start guide to treating M.E. – on a budget

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It is probably a good idea to take a little bit of everything and at least cover the basic well, if you can’t afford to take every supplement you’d like to at the recommended dosages.

The following list provides a jumping off point for working out your own cut-down supplement regime for treating M.E. The idea is to start at the top of the list and work down as far as your budget allows. The first 4 supplements listed are the most important.

This list is a general guide to cutting costs and lowering dosages only. It does not contain all the necessary information about supplement benefits, cautions, types and so on. This paper is not designed to be used in isolation and must be read with the main ‘Quickstart guide’ paper.

A minimum and maximum cost per week has been calculated for each product based on the minimum and maximum dosages mentioned. Click on the name of each supplement to view the actual products the costings are based on. At the time of writing (May - July 2010), there is little more than 10% difference between the currencies in the US, Australia, Canada and New Zealand. The figures listed in this document could be considered accurate for all of these currencies, within 10 to 20% or so.

<table>
<thead>
<tr>
<th>Vitamin and nutrients</th>
<th>Dosage</th>
<th>Minimum cost per week</th>
<th>Maximum cost per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multivitamin and mineral supplement</td>
<td>Dosage is as stated on the bottle, or twice that amount if appropriate and particularly if this is the only supplement you can afford to buy. (See below for more information on choosing a good multi)</td>
<td>1.63</td>
<td>3.26</td>
</tr>
<tr>
<td>Vitamin C</td>
<td>4 – 10 grams daily in powder form, in 2 – 4 divided doses, mixed with half as much aluminium-free bicarb soda (or 1 sachet of Lypo-C daily, at a cost of $1, if budget allows).</td>
<td>0.91</td>
<td>2.36</td>
</tr>
<tr>
<td>B vitamin</td>
<td>Take a 100 mg B complex product 1 – 1 ½</td>
<td>0.70</td>
<td>1.61</td>
</tr>
<tr>
<td>Supplement</td>
<td>Description</td>
<td>IPAMRT</td>
<td>IPAMTT</td>
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<td>-------------------------</td>
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<tr>
<td>B complex</td>
<td>times daily. If you do not feel a noticeable positive effect within 2 – 4 weeks, buy a bottle of coenzymated <em>sublingual</em> B complex to try at a dose of 1 daily (or 2 daily to start with). This product may be essential if your body does not coenzyme B vitamins very well. (This can occur where illness is severe).</td>
<td></td>
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</tr>
<tr>
<td>Magnesium</td>
<td>You may choose to buy a better absorbed form of magnesium such as magnesium oil (5 cents a ml) or magnesium chelate and take less of it (600 mg at least), or to buy a cheap and fairly poorly absorbed form and take a higher dose (1000 - 1500 mg). If you don’t take a calcium supplement with your Mg, make sure to eat a high-calcium diet.</td>
<td>0.98</td>
<td>2.10</td>
</tr>
<tr>
<td>Calcium</td>
<td>Take 350 – 600 mg of calcium in powder form daily.</td>
<td>0.28</td>
<td>0.48</td>
</tr>
<tr>
<td>Vitamin E</td>
<td>To add to the 200 IU of alpha tocopherol in your multi, take a gamma-E product 4 – 6 times weekly, and a mixed tocotrienols product once a week or once a fortnight.</td>
<td>0.69</td>
<td>1.24</td>
</tr>
<tr>
<td>Unrefined sea salt</td>
<td>Try to use ¼ to ½ a teaspoon (1.5 – 3 g) of this salt in food or in water each day. (Coarsely ground products may be slightly less expensive than finely ground products.)</td>
<td>0.01</td>
<td>0.02</td>
</tr>
<tr>
<td>CoQ10 as ubiquinol</td>
<td>50 mg taken 1 – 4 times weekly.</td>
<td>0.23</td>
<td>0.93</td>
</tr>
<tr>
<td>Vitamin D</td>
<td>If you can, try and get 15 minutes of FREE sun 3 times a week in summer and 3 hours a week in winter – if you can do that you may not need vitamin D supplements at all. To save money you may choose to only take a D supplement in winter, or when you haven’t got your weekly recommended sun exposure. If you can’t get any sun at all due to illness, perhaps you could take 10 000 IU of vitamin D3 1 – 2 times weekly (to make sure your levels aren’t extremely low, at least, if not optimal). As vitamin D is fat soluble, money can be saved by taking larger doses less often. Cod liver oil is the best form of vitamin D but may be more</td>
<td>0.06</td>
<td>0.12</td>
</tr>
</tbody>
</table>
Treating M.E.: The basics

<table>
<thead>
<tr>
<th>Supplement</th>
<th>Dosage</th>
<th>Minimum cost per week</th>
<th>Maximum cost per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>L carnitine</td>
<td>250 – 500 mg daily of the best value form you can find. (Most likely a powder.) Carnitine is especially important if you are vegetarian.</td>
<td>0.51</td>
<td>1.02</td>
</tr>
<tr>
<td>Fish oil/cod liver oil/omega 3s</td>
<td>Take one 1000 mg softgel (containing 600 mg EPA/DHA) every second day, daily or twice daily – or 1 – 3 teaspoons cod liver oil daily. If your omega 3 intake is lower than ideal, make sure you strictly follow an anti-inflammatory diet. (The more anti-inflammatory your diet is the less fish oils you need.)</td>
<td>0.70</td>
<td>2.80</td>
</tr>
<tr>
<td>Probiotic</td>
<td>Buy a super-high strength probiotic powder such as VSL#3 which contains 450 billion cells per sachet, and (somehow) divide it into 18 daily serves of 25 billion cells, or perhaps even 36 daily serves of 12.5 billion cells. (Perhaps try making your own little foil wraps or tipping the powder into a small bottle and finding a VERY small spoon.) For the best effect from probiotics, follow a strict sugar-free diet.</td>
<td>0.65</td>
<td>1.30</td>
</tr>
<tr>
<td>Lipoic acid</td>
<td>A 300 mg capsule taken weekly or fortnightly.</td>
<td>0.05</td>
<td>0.10</td>
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WEEKLY TOTALS: 7.40 17.34

Special needs supplements

<table>
<thead>
<tr>
<th>Supplement</th>
<th>Dosage</th>
<th>Minimum cost per week</th>
<th>Maximum cost per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vitamin A</td>
<td>If your multi doesn’t contain enough vitamin A, or it contains vitamin A mostly or entirely as beta carotene and you have thyroid problems, a 20 000 IU vitamin A product can be taken 1 – 2 times weekly (as this vitamin is fat soluble). Cod liver oil is the best source, but can be more expensive.</td>
<td>0.03</td>
<td>0.06</td>
</tr>
<tr>
<td>Digestive enzymes</td>
<td>If you need help with digestion but can’t afford to take digestive enzymes every day, you could buy a bottle and take a capsule only when your digestive problems are at their worst, perhaps 2 – 4</td>
<td>0.28</td>
<td>0.56</td>
</tr>
</tbody>
</table>
Treating M.E.: The basics

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times weekly on average. You may also want to read the section on improving digestion in the main ‘Treating M.E.’ paper.

<table>
<thead>
<tr>
<th></th>
<th>For extra cardiac health support, take a 500 mg capsule 1 – 2 times weekly.</th>
<th>0.08</th>
<th>0.16</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Hawthorn extract</strong></td>
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<td></td>
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</tr>
<tr>
<td><strong>Methylcobalamin</strong></td>
<td>If needed to help reset the sleep/wake cycle, this form of B12 can be tried at a low dose. Split a 5 mg MB12 sublingual tablet into four. Take ¼ of a sublingual tablet 1 – 2 times weekly.</td>
<td>0.06</td>
<td>0.12</td>
</tr>
<tr>
<td><strong>B12</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td><strong>Melatonin</strong></td>
<td>If needed to help reset the sleep/wake cycle and to initiate and deepen sleep, split a 5 mg sublingual tablet into four to seven pieces (or thereabouts, depending on how much you need to get an effect). Take ¼ to 1/7th of a sublingual tablet daily before retiring. (If MB12 and melatonin don’t work, try inositol 1 – 2 g daily.)</td>
<td>0.15</td>
<td>0.28</td>
</tr>
</tbody>
</table>

**Additional notes and cost cutting tips**

- If you only have a few dollars spare a week to spend, probably your best bet would be to buy a good multivitamin and mineral supplement that contains decent amounts of vitamin A, the B vitamins, vitamin C, D and E, as well as zinc, selenium, molybdenum, mixed natural carotenoids and so on. The best I have found so far is Life Extension two-a-day multivitamin and mineral supplement. It costs 22c a day and so $1.63 a week, and contains far greater amounts of most vitamins and minerals than most other products, and is cheaper than many other brands while still being produced by a good quality company. (The only downside is that it contains the wrong form of vitamin D, but then so do 99% of multivitamins).

- Multivitamin and mineral supplements are such good value, if you have a very limited budget you might consider taking 4 a day instead of the recommended 2. (Once you have made sure that there isn’t too much of any one ingredient for this to be appropriate.)

- Other additions you might make to your supplement regime, if budget allows, are (a) to double your vitamin C intake and to add a daily zinc lozenge at the first sign of a cold or flu, (b) to double your ubiquinol and carnitine dosage for a week if you’re having severe cardiac symptoms or just a general severe relapse that week and/or (c) to add extra vitamin B1 to your regime to improve cardiac function, pain and heal neurological damage/improve neurological function.

- If you only have a small amount to spend, it is of course more important than ever to try to make sure you are getting the ‘most bang for your buck’ and that
you find the best supplements at the best prices. Look at lots of different brands in lots of different shops, and see if it might be far cheaper to import certain items rather than buy them in your own country. Buying online will often be far cheaper than buying supplements at chemists. Prices for supplements can vary hugely, by more than even 50%, so if you can, shop around. Price is important but so is quality, buying the cheap supermarket brands such as ‘Centrum’ may be worse for your health than taking nothing at all.

- Save money on supplements by buying high dosage capsules or tablets and then splitting them into halves or quarters (or grinding them up) or in the case of fat soluble supplements, taking high-dosage supplements less often.

- Save money by buying supplements in powder form and either making your own capsules or adding them to water and drinking them. Supplements widely available in powder form include: the B vitamins, vitamin C, Carnitine and Acetyl L Carnitine, Lecithin, various amino acids, prebiotics (FOS), Chlorella, Calcium and Magnesium. You can save sometimes up to 50–75% off the usual price by buying pure powders, you also avoid synthetic fillers. Try buying powders from Life Extension, VRP, iHerb (or from www.purebulk.com).

- Save money by buying in bulk. A one kilo bottle of vitamin C crystals will costs you far less than 4 or more smaller bottles (and far less than vitamin C tablets or capsules).

- Save money on buying saline nasal sprays by making your own saline mixture and using it with a netti pot. Unscented castile soap is a cheap and non-toxic liquid soap much cheaper than some SLS-free and non-perfumed products.

- If there are gaps in your supplement regime it is also more important than ever that you try to fill them with your diet. Make everything you eat work for you and avoid empty calories and spending ‘wasted money’ on foods that don’t give you much real nutrition. Instead of drinking normal black tea, drink green tea, or ginger tea, or ginkgo tea. Instead of eating sugar-filled (or chemical filled) flavoured yogurt, eat a piece of fresh fruit. Instead of adding sugar to your tea, add Manuka or Jarrah honey. Instead of a flavoured cream cheese dip with crackers, buy or make a bean dip, avocado dip or salmon dip and eat it with fresh vegetable crudités. Instead of corn flakes or sultana bran (or other heavily processed sugary cereal) eat organic steel cut oats as porridge or muesli. Instead of reconstituted low quality meat in the form of sausages, chicken nuggets, fish fingers, or pre-prepared chicken schnitzel, eat fresh or tinned salmon or fresh lightly cooked lean beef or chicken. Instead of mashed potato, have a bowl of spinach with pine nuts, or a vegetable stir fry. Instead of rice cakes or crackers, or corn cakes, eat some fresh unroasted nuts and seeds, and so on.

- If you can’t afford much by way of extra supplements, it is a very good idea to add some super-foods to your diet. Some of these items such as bones for stock and some organ meats, are also very inexpensive. Super-foods include:
o Bone broths (stock) or slow-cooked meat dishes made with meat with bones in.

o Organ meats; especially liver (preferably organic and grass-fed) and/or cod liver oil or FCLO.

o Vegetable juices (carrots/greens).

o Traditionally sprouted and fermented foods (e.g. sauerkraut, sprouted broccoli seeds).

o Coconut oil.

- Add ginger and garlic to your diet if you can.

- Buying the cheapest brands can be a false economy when the supplement industry isn’t well regulated. It is best to stick to quality brands as much as possible otherwise you might save a bit of money but end up having supplements which don’t contain anywhere near the amount of active ingredients as stated on the bottle. (Life extension foundation, Carlson’s, VRP, Jarrow, Source naturals and Metagenics are very good brands, although of course there are other good quality brands out there.) Look for brands which make a point of advertising the quality of their products and say that they are tested for potency, and that give you more than just the bare minimum amount of information about the supplement (and how it has been produced). Buying better quality brands doesn’t necessarily mean more expense, often you find that the good quality brands are very competitively priced or even much cheaper than some other brands.

- Be serious about toxin avoidance as the fewer toxins you take in, the fewer vitamins your body needs to cope with them.

- Look into replacing expensive cleaning products with bicarb soda and vinegar etc. See if your library has a book on how to do this, or search the internet for instructions.

- If your pension goes up by 10$ a week, or you quit smoking and save 20$ a week, or something else happens to save you a small amount of money each week, pretend that you don’t have that extra money (if you were managing on that previous amount) and have it automatically taken out of your usual account each week and put into a fee-free savings account, for use in case of emergency.

- Get as many health books as you can for free from the library. If you can only buy one book on treatment, I’d recommend a copy of Dr Atkins Vita-Nutrient Solution: Nature's Answer to Drugs. It is WONDERFUL and so detailed yet easy to read, and you can buy used copies for $4 or so from Betterworld books. Postage is free in the USA and around $4 worldwide.

- This guide is general in nature and cannot take into account your individual differences. For best results, work out an individual treatment program tailored to your individual needs (and test results) with your qualified holistic practitioner.
- This is a very cut-down supplement program, but it is still a program that can effect significant results. It is quite possible that effects may take longer to appear than with a full-strength program, although this really depends as always on how soon treatment begins after the onset of M.E.

  Many of us that are currently severely ill went the first 3 or 4 or even 5 or more years without having any treatment for the disease at all. Without taking a single vitamin pill or having any other type of nutritional support. So I hope you’ll agree that even starting such a basic treatment and diet plan, particularly at any time within such a time period really does give you a better shot at some recovery than many of us have had, and is a real cause for hope, ‘ideal’ dosages or not!

So many of us are living in real poverty, and it is hard to see how this will change while we have so few genuine advocacy groups and while so much so-called ‘activism’ is supportive of the very same propaganda causing and perpetuating the abuse and neglect, unfortunately.

So if you can do some activism for M.E. or help the HFME in its activism work, please do!
The paper A quick start guide to treating and improving M.E. with aggressive rest therapy, diet, toxic chemical avoidance, medications, supplements and vitamins looked at which treatments are the most important in M.E. This paper examines in what order all the different treatments and management techniques are best implemented.

Before starting any new treatment, please read: Important notes on using the HFME's treatment information. This paper discusses many vital ways to follow treatment programs safely and the importance of proper research and medical support. Please don’t assume that all non-prescription treatments and substances cannot do you any harm. This is just not true, especially as many of these treatments can cause something called a ‘healing reaction.’ Following this program without reading this paper first could make you very ill!

At a minimum this paper should be read together with the following papers. This reading can be spread out over many months:

- Important notes on using the HFME's treatment information
- Symptom-based management vs. deep healing in M.E.
- Recognising and managing healing reactions in M.E.
- A quick start guide to treating and improving M.E. with aggressive rest therapy, diet, toxic chemical avoidance, medications, supplements and vitamins
- Food as medicine and M.E.

Stage one

a. Make sure of your M.E. diagnosis as much as you reasonably can. This is very important not because the program below is likely to harmful to those with other diseases, but because a misdiagnosis may mean you miss out on a treatment that is disease specific and perhaps curative or even life-saving, and because having a correct diagnosis of a disease other than M.E. almost certainly means better social and financial support and medical care.

Be aware that merely qualifying for a (mis)diagnosis of ‘CFS’ or ‘ME/CFS’ in no way means that you have M.E. See: The misdiagnosis of CFS, Testing for Myalgic Encephalomyelitis and Testing for M.E.: Plan D.
b. *Treat the infection in the earliest stages if possible.* If you were hit with acute onset M.E. *very recently*, please see the paper *Treating M.E. in the early stages* and go through the information there, first.

c. *Strictly avoid overexertion.* M.E. patients who are able to rest appropriately and avoid severe or repeated overexertion have repeatedly been shown to have the most positive long-term prognosis. The importance of avoiding physical, cognitive, orthostatic and sensory overexertion in M.E. just cannot be overstated. See: *The importance of avoiding overexertion in M.E.* and *Assisting the M.E. patient in managing relapses and adrenaline surges*.

d. *Educate yourself about M.E. as much as you can.* Make sure you don’t negatively affect your health by being taken in by any of the myths or misinformation surrounding M.E. Reading as much as you can about your disease will also help you to get the support you need from those around you. See: *What is Myalgic Encephalomyelitis?*

e. *Find a knowledgeable doctor that can help advise you on treatment.* For more information see: *Finding a good doctor when you have M.E.*

f. *Take notes and document all your changes.* Buy a notebook, and briefly note down any big changes you make that day or week to your diet or to supplementation and any worsening or improvements in your condition. Then you’ll have some clues as to the cause of any problems that arise without having to rely on an unreliable memory. Notes can be very brief, and not written daily, and still be effective.

**Stage two**

a. *Improve your diet and the health of your gut.* No disease can be healed while the gut is functioning poorly. The gut houses half of the immune system and the detoxification systems and poor gut health means not absorbing the nutrients necessary for healing from food or supplements. Each change to the diet should be made over 1-2 weeks to avoid or at least minimise problems.

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<thead>
<tr>
<th>Step</th>
<th>Description</th>
<th>Date started</th>
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<tbody>
<tr>
<td>1.</td>
<td>Eliminate sugar and processed foods from the diet, and eat only (or nearly only) whole foods. Strictly avoid all foods containing trans fats. Switch to organic food if possible, or locally grown produce as a second best. (If budget allows.)</td>
<td>Date</td>
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<td>2.</td>
<td>Go on an elimination diet, so</td>
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that you can find out which foods you react badly to and avoid them. (An ELISA food allergy test may also be helpful in this process, as may doing regular pulse tests to determine a raised heart-rate in response to food allergies and intolerances.) A rotation diet may be necessary.

3. Eliminate other possibly problematic food from the diet such as caffeine, fermented foods, mouldy foods and replace table salt with unrefined sea salt.

4. If it makes sense to you to do so after reading ‘Food as medicine,’ start eating nightshade-free, gluten-free, grain-free, legume-free and/or dairy-free.

5. Work out the ideal ratio of fat, carbohydrate and protein in your diet for your body and learn to choose low GI and GL foods.

6. Add some real super-foods to your diet, if desired, such as: Bone broths (stock) or slow-cooked meat dishes made with meat with bones in. Organ meats; especially liver (preferably organic and grass-fed) and/or cod liver oil or FCLO. Vegetable juices (carrots/greens). Traditionally sprouted and fermented foods (e.g. sauerkraut, sprouted broccoli seeds). Coconut oil

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<td>4.</td>
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<td>5.</td>
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<td>6.</td>
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</table>
b. *Reduce your toxic load.* Change the types of personal care and cleaning products you use, don’t smoke or drink alcohol, and buy a water filter. For more information see: [Toxin avoidance and M.E.](#)

c. *Start getting some nutrients in.* Slowly work up to taking a full daily-dose of a good quality multivitamin and mineral product over weeks or months depending on your sensitivity level. For more information and product links see: [A quick start guide to treating and improving M.E. with aggressive rest therapy, diet, toxic chemical avoidance, medications, supplements and vitamins](#)

Once you’re taking a half or full daily-dose of the multi, start to slowly work up to taking some extra vitamin C every day. Aim to take at least 5 - 10 grams daily orally in divided doses or 1 sachet of liposomal vitamin C daily, or both. (If you feel confident about raising the dose further there is no problem with going up to a bowel-tolerance dose now, or the liposomal vitamin C equivalent, but this is optional.) For more information see: [Vitamin C and M.E.](#)

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<thead>
<tr>
<th>Multivitamin and mineral daily</th>
<th>Date started</th>
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<th>Notes</th>
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<tbody>
<tr>
<td>Vitamin C, 5-10 grams daily and/or liposomal vitamin C x 1</td>
<td>Date started</td>
<td>Date completed</td>
<td>Notes</td>
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d. *Make sure you’re having at least two bowel movements daily.* Constipation places a toxic burden on the body and can even be fatal in extreme cases. If dietary changes and making sure water intake (2 litres daily, or more) is adequate isn’t enough to ensure two bowel or more movements daily, a daily vitamin C or magnesium flush may be helpful. For instructions see the section on treating specific symptoms in: [Treating M.E. - The Basics](#). Coffee enemas can also be used for this purpose, if disability allows. See: [Enemas for detoxification in M.E.](#)

### Stage three

a. *Further improve your gut health, if necessary.* Treat issues such as Candida and a ‘leaky gut’ if they exist and start taking small amounts of probiotics if you haven’t already. Digestive enzymes may also be helpful. Tests can be used to determine the presence of Candida overgrowth and a ‘leaky gut.’ For more information see: [Candida and M.E. and Food as medicine](#).
b. *Increase your levels of the basic nutrients.* Increase the amounts of vitamins A, the B vitamins, vitamin E and the major minerals such as magnesium, potassium plus also calcium. Start working through the listing for each of these nutrients in the HFME *A quick start guide* but at the lower or mid-range end of the dosages indicated, unless you feel able to go a little higher without problems. Depending on your sensitivities a quarter dose of each of these nutrients may be enough at this time.

<table>
<thead>
<tr>
<th>Probiotic daily (if not already being taken)</th>
<th>Date started</th>
<th>Date completed</th>
<th>Notes</th>
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<tr>
<td>Digestive enzymes daily (if not already being taken)</td>
<td>Date started</td>
<td>Date completed</td>
<td>Notes</td>
</tr>
<tr>
<td>Candida diet/testing/treatment</td>
<td>Date started</td>
<td>Date completed</td>
<td>Notes</td>
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<tr>
<td>Leaky gut investigation/treatment</td>
<td>Date started</td>
<td>Date completed</td>
<td>Notes</td>
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c. Consider a daily or weekly coffee enema regime. Coffee enemas (or colonics) help lift the burden of the liver which is beneficial for healing and can immediately make you feel less ill and poisoned. Enemas are not for everyone. Some patients will be too ill to even attempt them and they should also be avoided if they cannot be done without causing a relapse of any kind. See: Enemas for detoxification in M.E.

d. Consider starting a daily niacin flush regime. Taking enough of the flushing form of niacin 3-4 times daily to flush each time is recommended by some doctors. This dilation of blood vessels helps get the nutrients you are taking to all the parts of the body and brain where they are needed. Dosage should begin at just 25 mg daily and be worked up very slowly. The final dose is likely to be between 25 mg and 300 mg. The flush should always be mild and last no longer than 10 minutes. See: The B vitamins and M.E.

e. Consider starting some meditation and relaxation exercises. Often M.E. patients are too ill for such tasks but if health allows, consider starting a meditation program or perhaps a relaxation program. It is very important to be relaxed during and after

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<tr>
<th>Extra vitamin A (if needed) from cod liver oil</th>
<th>Date started</th>
<th>Date completed</th>
<th>Notes</th>
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<tr>
<td>Extra B vitamins</td>
<td>Date started</td>
<td>Date completed</td>
<td>Notes</td>
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<tr>
<td>Extra vitamin E (if needed)</td>
<td>Date started</td>
<td>Date completed</td>
<td>Notes</td>
</tr>
<tr>
<td>Extra vitamin magnesium, calcium and potassium.</td>
<td>Date started</td>
<td>Date completed</td>
<td>Notes</td>
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<tr>
<th>Daily niacin flushing</th>
<th>Date started</th>
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<th>Notes</th>
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eating so that the body has more resources available to digest the food and so an after-meals relaxation program may be a good idea. See: Meditation, relaxation, breathing exercises and M.E.

☐ f. Consider getting some sun exposure. You might also try and to get a little bit of sun exposure on your arms and legs a few times a week to boost your vitamin D levels, but only if this is possible without any kind of relapse. The darker your natural skin colour, the more sun exposure you will need. Vitamin D levels can also be tested at this time, if desired. See: Vitamin D and M.E.

☐ g. Investigate your thyroid and adrenal function and consider supportive treatments. Low thyroid and adrenal output are a core part of M.E. and are seen in nearly all patients. As with low thyroid output, the question of whether or not low adrenal output in M.E. should be boosted directly or treated more gently and indirectly via a more general deep healing program is a difficult one. Low adrenal and thyroid output may well be a protective mechanism, protecting our bodies from further harm. For more information on these important issues including the appropriate testing please read Adrenal and thyroid issues and M.E.

Stage four

☐ a. Increase the vitamin C dose further. Start to slowly raise the amount of vitamin C taken every day. Aim to take at least 10 - 20 grams daily orally in divided doses or 2-3 sachets of liposomal vitamin C daily, or both. (If you feel confident about raising the dose further there is no problem with going up to a bowel-tolerance dose now, or the liposomal vitamin C equivalent, but this is optional.) See: Vitamin C and M.E.

Starting to take a sachet of liposomal glutathione (GSH) daily (or weekly) at this time is also recommended, if budget allows. For more information see: Liposomal glutathione and M.E.

<table>
<thead>
<tr>
<th>Vitamin C, 10-20 grams daily and/or liposomal vitamin C x 2</th>
<th>Date started</th>
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<tbody>
<tr>
<td>Liposomal GSH</td>
<td>Date started</td>
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<td>Notes</td>
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☐ b. Start taking a wider variety of nutrients. Start working through the listings for cod liver oil/fish oil, CoQ10, L carnitine, vitamin D (possibly as cod liver oil), B12 and lipoic acid in the HFME A quick start guide but at the lower end of the dosages
indicated, unless you feel able to go a little higher without problems. Depending on your sensitivities a quarter dose of each of these nutrients may be enough at this time. If finances are tight, see the budget section of A quick start guide for tips.

<table>
<thead>
<tr>
<th>Drug</th>
<th>Date started</th>
<th>Date completed</th>
<th>Notes</th>
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<tbody>
<tr>
<td>Cod liver oil/fish oil</td>
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<tr>
<td>CoQ10/ubiquinone</td>
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<tr>
<td>L carnitine</td>
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<tr>
<td>vitamin D (as cod liver oil or D3)</td>
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<td>B12</td>
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<td>Lipoic acid</td>
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- c. Consider daily vegetable juicing. Fresh vegetable juice is very easy for the stomach to digest, allows you to stock up on valuable enzymes and other nutrients and aids in detoxification. 250 – 750 ml of vegetable juice daily can be consumed with a meal or between meals. See: Vegetable juicing and M.E.

Stage five
- a. Consider the Klenner protocol for neurological disease. Dr Klenner’s B vitamin protocol for M.S. and other neurological diseases has been used for over 40 years. It aims at healing and reversing existing neurological and other damage and the damage to myelin sheaths. Advocates claim that it is potentially curative, depending on the severity of the condition prior to treatment. The protocol involves daily B1 injections and moderate to high amounts of B vitamins and other nutrients taken orally.
The length of the program depends on the length of time a person has been ill. For patients ill for many years it may take 5 years or more for the full results to be seen, and a lower-dose maintenance program is required for life. Read as much as you can on this protocol and then make up your own mind. See: The B vitamins and M.E. and Dr. Klenner's B vitamin (neurological disease) protocol and M.E.

**Stage six**

☐ a. *Get your vitamin D level tested.* This simple test will indicate whether or not you need to get extra sun exposure or take extra vitamin D3, for optimal health. You may also consider having a test of your iodine levels done and taking extra supplemental iodine if necessary. The iodine test needs to be ordered and interpreted by a doctor, but a reputable and reliable vitamin D test can be bought online without assistance from a doctor or can be done by your doctor. See: Vitamin D and M.E. and Iodine and M.E.

<table>
<thead>
<tr>
<th>Vitamin D test</th>
<th>Date taken</th>
<th>Result</th>
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<tbody>
<tr>
<td>Iodine test</td>
<td>Date taken</td>
<td>Result</td>
<td>Notes</td>
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☐ b. *Increase the vitamin C dose to maximum.* If budget allows, aim for a daily bowel-tolerance oral dose of vitamin C or the liposomal vitamin C equivalent, or a combination of the two. This will need to be taken in at least 6 divided doses. See: Vitamin C and M.E.

<table>
<thead>
<tr>
<th>Vitamin C, bowel tolerance dose orally daily and/or liposomal vitamin C x 2 - 6</th>
<th>Date started</th>
<th>Date completed</th>
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☐ c. *Increase the dosages of the nutrients you’re taking, if necessary.* Start working through the listings again, one by one, on the A quick start guide but at the mid-range to high end of the dosages indicated, or as high as you feel is appropriate and necessary. If finances are tight, see the budget section of A quick start guide for tips.
d. *Consider having a hair elements test done.* This test can indicate whether or not certain trace mineral levels are very low and need to be supplemented in small doses.

**Stage seven**

a. *Consider starting an FIR sauna program for detoxification.* Wooden FIR saunas cost over $1000 but cheaper units can be bought for around $200 and used as is, or converted to be used lying down. NIR saunas can also be built or bought for around $300 - $500, and can be adjusted for use by the bedbound. Sauna programs should not be attempted until you feel you have some extra strength to spare as sauna use causes healing reactions and requires that you have extra rest.

Very ill patients can start at just 10 minutes once a week or fortnight and work up only very slowly, to make sure that healing symptoms remain mild. FIR sauna programs will usually last 2 years or more for serious diseases like M.E. with the goal being to work up to an hour or so of use daily, if possible. It is important to correct nutritional deficiencies before starting a sauna program, to boost vitamin C, ALC, ALA and glutathione levels during sauna therapy to support phase II detoxification and also to replace the water and minerals that are lost during sauna use, as you go. For more information see: FIR saunas and M.E.

b. *Consider regular coffee enemas and an annual gallbladder flush.* Liver support is very important during an FIR sauna detoxification program. See: Enemas for detoxification in M.E.

c. *Consider a heavy metal detoxification regime.* If after 1 – 2 years of sauna use you feel that your progress has stalled and you are no longer improving noticeably every few months, this may be an indication that you have a higher heavy metal load than the sauna can deal with. The sauna is excellent for removing pesticides and plastics and other chemicals from the body. It also removes heavy metals from the body, but this occurs much more slowly. A heavy metal detox should not be attempted while sauna use is still causing significant healing reactions. For information on how to safely detoxify heavy metals, the book ‘The High Blood Pressure Hoax’ by Dr Sherry Rogers is recommended.

**Stage eight**

a. *Make constant adjustments to your program as needed.* Your dietary needs may change over time, tests such as the vitamin D and iodine tests need to be retaken periodically, larger doses of some nutrients needed at the start of therapy may no longer be needed several years later, you may be at the end of an intensive FIR sauna program and be able to switch to a lower maintenance level, and so on. You need to constantly make decisions on how to adjust all the things you are doing over time, based on medical advice, research and the response of your own body to the changes you make.
Suggestions on ways to use this paper

- If desired this paper can be used as a personal progress chart. You can mark a circle or tick beside each stage you have completed and fill out the tables included with some of the sections in order to more easily chart your own progress. (This may be for your own benefit or to help make it clearer to friends and family and carers why you’re doing what you are doing and how they can help you with it.) It is recommended that this paper be printed out and kept handy in a display book or on the wall or similar if used for this purpose.

- If you don’t want to use this as a form to fill out, you may like to delete all the tables included in the document before you print, to save on paper.

Notes on this text

- *Why is vitamin C emphasised so much and so early?* Vitamin C in pharmacologic doses improves immunity (meaning you’ll get fewer colds and flu), boosts the immune system, improves your sensitivity to chemicals, lessens allergic reactions or intolerances to foods, supports your adrenals, helps you cope with stress, and is a powerful antioxidant and anti-inflammatory substance. It also has a powerful anti-viral effect (if taken by IV or liposomal delivery system). It helps all the body’s organs and systems work better, is a very important part of deep healing but makes you feel brighter, less ‘poisoned’ and more well generally in the short term. Vitamin C is incredibly important and beneficial. The only problem is that taking too much too fast can make you feel awful. But if one raises the dose very slowly healing reactions caused by raising the dose of vitamin C can be very much minimised or even eliminated.

- *Why aren’t I feeling the vitamin C benefits much?* A lack of obvious benefits from vitamin C may be seen in severe disease even at a dose of 10 – 20 grams daily or more. The more severe the disease generally, the higher a dose is needed. A lack of improvements indicates that a higher dose is necessary. It may take 10 – 20 g daily for even the mildest benefits of vitamin C to be seen in M.E., this is quite likely. For more information see: [Vitamin C and M.E.](#).

- *How long does it take to see improvements?* It takes as long as it takes unfortunately. Progress varies depending on biochemical individuality, what doses you’re taking and which nutrients you’re taking, how long you were ill before treatment began, how much damage you did to your body before treatment began, how well rested or stressed you are, your individual toxic load and daily chemical exposures, how healthy your gut is, your age and sex, and so many other factors. It also depends on how long it has taken you to work through the different stages.

- *Do the different parts of each stage need to be done in order?* Not necessarily. Some items have been grouped together because they can be overlapped to some extent or even done concurrently while others are in the same section because they are linked in a particular order. Use your own judgement to work out when doing things in order is and isn’t appropriate.
• **How long should it take to work through all these stages?** Probably many months or even a year or more. How long it takes depends on easily you can take supplements and make dietary changes without relapse. Some patients can take a full-dose of a multivitamin within a few days with few problems while for others this may take a long time and many different brand products may have to be tried. Again, it takes as long as it takes. After a while you should have a good idea of how sensitive to supplements you are and how fast or slow you should introduce new things.

• **What are the general principles used to construct this list?**
  
  o Spending a lot of time and money investigating supplements and detoxification regimes will likely not get you anywhere fast if serious overexertion is continuing (physical, cognitive, orthostatic or sensory), toxin exposure is high, constipation is occurring and the diet is poor.

  o It is important to heal the gut as much as possible before embarking on a dedicated supplement/treatment program. Poor gut function will prevent healing and also prevent supplements and the nutrients from food from being absorbed properly.

  o It is better to take small amounts of all the necessary basic vitamins and minerals etc. rather than very large amounts of one or two things (or exotic herbs or other supplements that the body does not actually *need* to function).

  o Increasing the doses of supplements gradually is important and it reduces the likelihood of problems. The body likes gradual change.

  o It is important to make sure that you have treated any serious vitamin and mineral deficiencies before embarking on a dedicated detoxification program (or taking large amounts of nutrients involved in detoxification, such as magnesium). It is also important that the patient feel up to being made a bit worse for a period of time, before starting a detoxification regime.

  o It is important to understand that many essential treatments can make the patient feel worse at first and that this is not always a sign that the treatment should be discontinued. A ‘healing reaction’ can sometimes be a very good sign. For more information see: Symptom-based management vs. deep healing in M.E. and Recognising and managing healing reactions in M.E.

  o It is just as important to avoid the inappropriate and unhealthy treatments and foods as it is to try useful treatments and eat nutrient-rich food. Knowledge is power.

  o Various tests can be used to find out what is happening in the body and to determine the most appropriate treatments in M.E. This includes tests for Candida, the ‘leaky gut’ test, food allergy testing, gluten sensitivity testing, iodine testing, vitamin D testing, detoxification profile testing and so on. Your trained orthomolecular/holistic/environmental medicine expert will be able to advise you on which tests are necessary for you and when. For more
A program such as this one requires the patient to take responsibility for their own health and to be adequately research and document all new treatments.

- In addition to this program other treatments, tests and symptomatic treatments may be necessary depending on your individual health issues.

- Before starting any new treatment, please read: Important notes on using the HFME's treatment information. Other recommended HFME papers are:
  - A quick start guide to treating and improving M.E. with aggressive rest therapy, diet, toxic chemical avoidance, medications, supplements and vitamins
  - Symptom-based management vs. deep healing in M.E.
  - Recognising and managing healing reactions in M.E.
  - What if vitamin/mineral/protocol 'x' didn't work for me?
  - Why research and try treatments when some groups claim an M.E. cure is coming soon?
  - Sources of further information on the scientific validity, effectiveness and safety of orthomolecular/holistic/environmental medicine and the overwhelming problem of vested financial interest group bias in modern medicine and media
  - Finding a good doctor when you have M.E.
  - Food as medicine and M.E.
  - Useful health books for M.E. patients

Disclaimer: HFME does not dispense medical advice or recommend treatment, and assumes no responsibility for treatments undertaken by visitors to the site. It is a resource providing information for education, research and advocacy only. In no way does reading this site replace the need for an evaluation of your entire health history from a physician. Please consult your own health-care provider regarding any medical issues relating to the diagnosis or treatment of any medical condition.
Section 5: Additional papers on M.E. treatment:
Low thyroid and adrenal output are very common in M.E.

Testing for thyroid problems
Even if thyroid problems are not detected on the first test, M.E. undermines the thyroid gland and so thyroid problems can develop later and so it's a good idea to test thyroid function repeatedly (Free T4, T3 and TSH), at least at yearly intervals. Reverse T3 testing may also be useful.

The author of the book *The Brainpower Plan* (along with many other experts) explains that standard tests for thyroid function are up to 30% inaccurate and that a more accurate way to check thyroid status is the Barnes method. This is a self administered thyroid temperature test.

Upon waking, before getting out of bed, place a thermometer under your armpit and take your temperature. The result is your AM basal temperature. Normal is between 97.8 and 98.2 Fahrenheit (36.5 and 36.7 Celsius). If your temperature is below 97.8 F (or 36.5 C) for 4 days, then this indicates that your thyroid output is low. Note that women should not do this test during their period as this can alter the results.

The book *Prescription for Nutritional Healing* recommends that a morning temperature of 96 F (35.5 C) means a starting dose of 3-4 grains of armour thyroid, and 97 F (36 C) means 1-2 grains.

The temperature test is very accurate, but it should be noted that temperature can also be affected by low adrenal output. Suspect low adrenal output if your temperature is erratic from one day to the next, at the same time of day. Also note that low adrenal output and low thyroid output are linked, and low function in one may be compensated for by the other.

The thyroid peroxidase antibody test (TPO) and an antithyroid antibody test (ATA) may also be useful. See the articles *Thyroid Scale Matrix*, *Low Metabolic Energy Therapies* and *Thyroid Scale Overview* by Bruce Rind MD for more information on thyroid testing.

Testing for adrenal problems
Adrenal function can be tested via blood tests measuring cortisol levels (usually once or twice daily) and via a 24-hour urine collection test. These tests must be ordered by a doctor.

For patients that prefer private testing VRP offers several simple saliva tests measuring cortisol levels as well as the levels of various other hormones, if desired. The basic cortisol kit measures am/noon/evening/pm cortisol. 24 hour saliva tests give you far better information than the one time blood test that doctors will tend to recommend and also gives you far more specific information than the 24 hour urine test.

Dr Wilson’s book on interpreting hair mineral analysis testing also explains how to use this simple test to assess thyroid and adrenal function. Low blood pressure can also be an indicator of low cortisol levels. As the Westen A. Price Foundation explains,

The regulation of blood pressure is a mysterious process which involves at least three mechanisms working in complex relation to each other. Receptors—called baroreceptors—which reside in various organs and detect changes in arterial pressure. These receptors adjust the pressure by altering the force and speed of the heart’s contractions, as well as the resistance in the arteries. The renin-angiotensin system (RAS), involves hormones secreted by the kidneys. When blood pressure drops, the kidneys compensate by activating a vasoconstrictor called angiotensin II. When the kidneys do not produce enough of this hormone, blood pressure will also be low. Aldosterone is a steroid hormone produced by the adrenal cortex, which stimulates sodium retention and potassium excretion by the kidneys. When aldosterone is increased, the body retains fluid retention and blood pressure is raised. Alternately, low aldosterone production will result in low blood pressure.

**Causes of thyroid problems**

Dr Sherry Rogers explains that there are environmental, nutritional and metabolic causes of thyroid problems.

*Environmental:* Food allergies, chemical and mould toxicities, goitrogens from soy and other foods, and high levels of fluoride (especially in drugs such as Prozac), heavy metal and chemical contamination from things such as cadmium, mercury, PCBs, dioxins and phthalates (plasticisers). Cadmium can lower T3 but not raise TSH. It can lower thyroid function in a way that leaves the TSH test completely normal.

*Nutritional:* Low levels of the nutrients needed to make thyroid hormone such as selenium, zinc and iodine. Poor cell membrane function can cause thyroid problems as can high levels of trans fats.

*Metabolic:* Candida overgrowth and the use of NSAIDs (Celebrex and ibuprofen), can lead to a ‘leaky gut.’ This in turn triggers the body to make antibodies that attack
and destroy its own thyroid gland. This can be tested for using a thyroid antibodies test.

Other causes include virally caused damage to mitochondria, pituitary gland problems and chronic infections.

**Causes of adrenal problems**

There are also environmental, nutritional and metabolic causes of adrenal problems. Adrenal burnout tends to occur in M.E. over time very often, particularly where the patient is regularly ‘running on adrenaline’ and overexerting. For more information on this topic please see: Assisting the M.E. patient in managing relapses and adrenaline surges

When the adrenal glands are too weak to handle the stress of the body’s normal metabolic energy they may force a down-regulation of energy production. Hashimoto’s Thyroiditis and Grave’s Disease can also cause adrenal stress and low adrenal output. Severe caloric restriction can be another cause of adrenal and thyroid problems.

**Treating thyroid problems**

The question of whether or not low thyroid output in M.E. should be boosted with medications such as armour thyroid or treated indirectly via a more general deep healing program is a difficult one. It is possible that giving the thyroid gland the nutrients it needs will be enough, but this may depend on how long the thyroid has been dysfunctional and how severe the problem is, and what the actual cause of the problem was to begin with. Longer term and more severe cases will likely require more support than milder and newer cases. It is also important to keep in mind that low adrenal and thyroid output may well be a protective mechanism, protecting our bodies from further harm and that supplementing thyroid hormone may send a signal to the body to slow down thyroid hormone production even further. These are issues that should be discussed with your holistic medical expert.

Thyroid problems in children can cause problems with brain development and lowered intelligence.

Basic thyroid support includes B complex vitamins with an emphasis on vitamin B1, selenium, zinc, vitamin D and C, magnesium, manganese, iodine, DHA and EPA and adequate dietary protein. All of these are essential. Also important are strict toxin avoidance and a detoxification regime, avoiding goitrogenic foods and trans fats in foods and treating a ‘leaky gut.’ High-dose vitamin C can help protect against damage caused to the thyroid gland by heavy metal exposure.

Dr Rogers explains that for some patients raising zinc, iodine and selenium levels and starting a detoxification and toxin avoidance regime will be enough to treat thyroid problems and there will be no need for products such as armour thyroid. She also
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recommends that patients eat a diet high in brassica vegetables and take an indolplex supplement twice daily to help prevent thyroid cancer, as well as breast and prostate cancer.

A more intensive program will also include thyroid glandular substance (for up to 6 months) in milder cases and daily armour thyroid tablets for more severe cases.

**Vitamin D, Iodine and the Thyroid Gland**

The article, *Vitamin D – the Re-discovered Key to Illness Prevention*, by Tony Pearce RN explains that vitamin D, Oestradiol (E2) and thyroid hormone belong to a class of steroid hormones termed ‘C-ERB’ and as such they are structurally similar, closely related and possess the capacity to influence the other’s expression. This article explains that one recent study (*Lee, 2007*) found that ‘sufficient’ Vitamin D (more than 40 ng/ml) is required for optimal triiodothyronine (active thyroid hormone – T3) ‘receptor expression.’ Vitamin D is also thyroid and cortisol hormone ‘sparing’ when optimum 25(OH)D levels are maintained (60 - 80 ng/ml). Vitamin D testing is an essential part of any thyroid treatment program.

Iodine is an essential element. Although its main function is in the production of thyroid hormones by the thyroid gland, other organs in the body have a need for iodine in order to function normally. When thyroid levels have been shown to be low, this may be an indication that an iodine loading test may be necessary. This test (available from companies such as VRP, though requiring a doctor’s consent) indicates whether or not additional iodine supplementation may be beneficial.

**Armour Thyroid vs Thyroxine**

Note that ‘Armour thyroid’ is far more beneficial and better tolerated than Thyroxine, Synthroid, Levoxyl, levothyroxine, Eltroxin, Oroxine and Levothyroid etc. This product should always be the first choice over T4-only medications. Thyroxine etc. may place stress on the adrenals, and also does not properly treat low thyroid output as it contains only T4 and not also T3. The body also uses up precious enzymes trying to convert T4 to T3.

As the ‘Stop the thyroid madness’ website and book explains,

The theory was that T4 would convert to the T3 needed for the body. But in nearly ALL patients on T4 meds, the T4 does NOT convert into an adequate amount of T3, leaving you with symptoms that neither you OR your uninformed doctor realize are related to inadequate treatment. In other words, healthy thyroids are NOT meant to rely solely on T4-to-T3 conversion!

But there’s even more to the problem: it’s called the TSH lab. Around 1973, the TSH lab test was developed. Based on a sampling of several volunteers, a so-called “normal” range was established—.5 to 5.0 (recently lowered to 3.0). But volunteers with a history of family hypothyroid were NOT excluded, leaving us with a range that leans towards being hypothyroid! In fact, the TSH RARELY corresponds to how a patient feels. There is a large majority of patients who have
a “normal” TSH, even in the “one” area of the range, and have a myriad of hypothyroid symptoms.

So what’s the solution? Patients and their wise doctors are returning to a medication that was successfully used from the late 1800’s onward: natural desiccated thyroid hormones, more commonly known as Naturethroid, Erfa’s Canadian “thyroid”, Armour, etc. They are made from pig glands, meet the stringent guidelines of the US Pharmacopoeia, and gives patients EXACTLY what their own thyroids give them—T4, T3, T2, T1 and calcitonin.

Additionally, patients who are working with certain wise doctors are not dosing by the TSH. Instead, they raise their desiccated thyroid according to three criteria (and not in any particular order): 1) the elimination of symptoms 2) getting a mid-afternoon temp of 98.6 using a mercury thermometer, while maintaining a normal, healthy heart rate, and 3) getting their free T3 towards the top of the range (in the presence of healthy adrenal function).

On a T4-only medication, we have noted that the majority of patients have a less-than-optimal free T3, a mid-afternoon temp lower than 98.6, and/or the continuation of some hypothyroid symptoms for the rest of your life, no matter how high your doctor raises it.

Some groups warn that you need to chew up either Armour or Naturethroid to release the desiccated thyroid from the cellulose filler. Make sure to take armour thyroid as far away from calcium supplements as possible, as calcium can reduce how well this medication is absorbed. At the very least take them 2 hours apart, or 4 hours apart if you can. (The same is true for supplements containing iron, or estrogen and supplements or foods containing soy.) Armour thyroid should be taken in at least 2 or 3 daily doses. Some patients, especially those with adrenal issues, dose 4 to 5 times daily.

If upon starting desiccated thyroid you experience new-onset symptoms such as anxiety, insomnia and shakiness, this may be a sign that you may need adrenal support. As the ‘Stop the thyroid madness’ website and book explains,

    Cortisol is needed to distribute thyroid hormones to your cells, and if you are not making enough cortisol from sluggish adrenals, your blood will be high in thyroid hormones, producing the above symptoms. Adrenal support is used to give back to your body what your adrenals are not, which in turn allows the thyroid hormones to get to your cells.

Feeling ‘hyper’ after beginning to take Armour thyroid can also be an indicator that you need to take only T3 containing medication, or that you have simply raised the dose too quickly, as the Natural Thyroid 101 article explains. A starting dose is usually 1 grain (less for those with severe adrenal issues) and this is raised by half a grain every few weeks until the optimum dose is reached.

Treating adrenal problems
Generally it is recommended that adrenal issues be treated BEFORE thyroid issues, as treating thyroid issues first places more stress on the adrenals.

As with low thyroid output, the question of whether or not low adrenal output in M.E. should be boosted with cortisone tablets or treated more gently and indirectly via a more general deep healing program is a difficult one. It is possible that giving the adrenal gland the nutrients it needs will be enough, but this may depend on how long the adrenals have been dysfunctional and how severe the problem is. Longer term and more severe cases will likely require more support than milder and newer cases. It is also important to keep in mind that low adrenal and thyroid output may well be a protective mechanism, protecting our bodies from further harm and that supplementing adrenal hormone may send a signal to the body to slow down adrenal hormone production even further. These are issues that should be discussed with your holistic medical expert.

When cortisol levels are tested to be extremely low, doctors may feel the need to immediately prescribe daily cortisone tablets. Dosage is usually under 20 mg daily. Hydrocortisone and Isocort are usually recommended. Hydrocortisone gives you simply cortisol whereas Isocort etc. gives you the entire adrenal cortex, but many patients seem to prefer HC and find it to work better than Isocort. Minimum dosing is 3-4 times daily. Generally this type of adrenal support is designed to be short term, lasting a few years just to give the adrenals a rest so that they can heal and begin working normally again without assistance.

Basic adrenal support includes vitamin C, B complex vitamins with an emphasis on vitamin B5 (1- 2 grams is recommended daily by Dr Wilson) and B6, unrefined sea salt, vitamins A and E, iodine and manganese. Eating a diet containing adequate fat and protein and that is lower in sugar and carbohydrates is also important. Daily carbohydrate intake may be best reduced to a maximum of 75 – 100 grams. Some of the additional fat taken in should be as cod liver oil to supply vitamin A. The adrenal cortex cannot make adrenal hormones out of cholesterol without vitamin A. Stimulants should be strictly avoided. Also important are strict toxin avoidance and a detoxification regime.

Avoiding overexertion and getting adequate rest is absolutely essential in rebuilding adrenal function.

A more intensive program will also include adrenal glandular substance (for a limited time period), and then, finally, daily prescription cortisone tablets.

Low adrenal output is linked to low stomach acid, so this finding may be an indication that Betaine HCl or apple cider vinegar may be helpful.

Ashwagandha is an inexpensive adaptogenic herb that can be useful in treating the adrenal exhaustion which often occurs over time in M.E. Ashwagandha works by delaying release of cortisol by the adrenals. (This helps to prevent the adrenals from becoming exhausted and aids in the repair of the gland once it is already exhausted.)
Ashwagandha also supports thyroid function. It also has a sedative effect and can greatly improve sleep, improve your ability to handle emotional stress, and it can also calm the central nervous system. Ashwagandha can also have positive effects on the immune system (by increasing the number of T and B cells), be neuroprotective, be an antioxidant and an antidepressant and may possibly also be anti-cancer. (It may also be useful for degenerative neurological diseases such as Parkinson’s and Alzheimer’s.) It is usually well-tolerated. Note that you may need to take LESS thyroid meds when taking Ashwagandha so make sure you reassess your thyroid mediation level after taking this supplement. Significant effects are often seen after just 3 weeks though it may take 3-4 months for the full benefit to become evident. Make sure you buy ashwagandha that is standardized to contain a minimum of 8% withanolide glycosides, a minimum of 32% oligosachharides.

References and further reading:
- Assisting the M.E. patient in managing relapses and adrenaline surges, Vitamin D and M.E., Unrefined sea salt and M.E., Iodine and M.E., and The B vitamins and M.E. on the HFME website.
- Detoxify or Die by Dr Sherry Rogers. Dr Rogers recommends taking 25 mg of DHEA twice daily (for a limited time) to see if the adrenals are weak, and comments that taking cortisone and thyroid medications is problematic as it sets up feedback inhibition and tells the body not to produce these hormones.
- T4-Only Meds Do Not Work, Take your Temp!, Natural Thyroid 101 and Armour vs. Other Brands (this article contains an excellent overview of different natural and synthetic thyroid products) from the Stop the Thyroid Madness website.
- Dr David Brownstein’s book IODINE: Why you need it Why you can't live without it and Iodine – An Important Mineral Today by Lawrence Wilson MD, plus the HFME paper on iodine.
- Low Metabolic Energy Therapies written by Bruce Rind, MD. This excellent article includes a checklist of which symptoms are adrenal and which thyroid related and is on the Weston A. Price website.
- Thyroid Scale Matrix and Thyroid Scale Overview by Bruce Rind, MD. Information on how to interpret testing.
- Low Blood Pressure from the Western A. Price Foundation.
- The article Those durn adrenals: How they can wreck havoc in many thyroid patients gives some very useful information on adrenal testing (including a temperature test) and cortisone supplementation.
- Dr Wilson’s book on interpreting hair mineral analysis testing explains how to use this simple test to assess thyroid and adrenal function. See Nutritional Balancing and Hair Mineral Analysis by Dr. Lawrence D. Wilson. The book is a very interesting read. Some of this information is also available on his website.
- Clinical value of 24-hour urine hormone evaluations Townsend Letter for Doctors and Patients, Jan, 2004 by Alan Broughton.
- *Vitamin D – the Re-discovered Key to Illness Prevention* by Tony Pearce RN
- Information on the role of each vitamin in supporting adrenal and thyroid function is available in many of the books on vitamins and nutrients listed in the references section. This includes The Vita-Nutrient Solution, The Optimum Nutrition Bible, and others.
Each member of the B vitamin family has unique therapeutic properties. What the B vitamins have in common is that they occur together in nature, and they are responsible for producing energy from the carbohydrates, proteins and fats in our foods.

The B vitamins play an essential role in the Krebs energy cycle, support the adrenals and proper neurological, cognitive and cardiac function, help maintain and repair the myelin sheath, help lower homocysteine levels and help the body cope with stress.

The B vitamins are water-soluble and any excess is readily excreted in the urine and so B vitamins are generally low in toxicity. When nutrients are water soluble it means that they are not stored in the body for long and so supplements must be taken in 2 or 3 or more doses spread throughout the day rather than all at once.

Because the B vitamins are so intertwined, it is important to take B vitamins as a complex rather than taking a large amount of one or two B vitamins and possibly creating new imbalances. Individual B vitamins should never be taken without also taking a B complex product of a roughly similar strength.

B vitamins are supplied by foods such as eggs, meat, nuts, seeds and unprocessed whole grains and some fruits, vegetables and beans.

Different ways of taking B vitamins
Many M.E. patients do far better taking B vitamins intravenously (by IV) or intramuscular (IM) injections or in their coenzyme (or ‘active’) forms, than orally.

To get the most powerful effect from B vitamins they should be given by IV, generally speaking. The next best choices in order of preference are: B vitamins injected IM, B vitamins in coenzyme and sublingual forms, B vitamins in sublingual OR fat soluble forms and standard oral vitamin B supplements.

In some cases, however, particularly where liver function or metabolic function is very poor, coenzymated B vitamin products will be the best choice, and all other forms of B vitamins will have little or no effect. (This is explained further in the section on coenzymated B vitamins to come.)
What follows is a basic overview of each of the B vitamins. (If you're overwhelmed by too much information, then just skip this section and know that you can easily cover your basic needs just by taking an oral or coenzymated/sublingual B complex product 1 – 2 times daily. Getting the B vitamins you need need not be complicated!)

**A basic overview of each of the B vitamins**

**Vitamin B1**

Vitamin B1 is essential in treating cardiomyopathy and chronic heart failure as it improves cardiac function. Vitamin B1 also improves peripheral neuropathy, nerve function and chronic pain and is known as ‘the brain energiser.’ Vitamin B1 also improves the body's ability to withstand stressful conditions and strengthens the immune system. Vitamin B1 is one of the most important B vitamins for M.E. patients.

Vitamin B1 is also an important nutrient for patients with Alzheimer's, an overactive thyroid, serious mental health or addiction issues, learning difficulties and lead poisoning.

The therapeutic dosage of thiamin (vitamin B1) is generally 50 – 300 mg but may sometimes be significantly higher (when used to treat severe pain or neurological disease). Dr Atkins explains that a dose of 1 – 4 g daily, taken orally, may be used to treat pain. 150 – 300 mg daily is the dosage used to cardiomyopathy or chronic heart failure and 400 mg daily is the dose needed to treat depression (and to act as a mood elevator). Peripheral neuropathy treatment requires B1 injections (or benfotiamine supplements).

Dr Klenner’s neurological disease treatment protocol strongly emphasises vitamin B1 as it plays an important role in the metabolic cycle, facilitating muscle function and also aids in the remyelination of damaged nerves. (Klenner’s protocol recommends 1g of thiamine HCl taken orally thirty minutes before meals and at bedtime, plus 400 mg of thiamine given IM 5 – 7 days a week – plus large amounts of each of the other B vitamins. See the notes section of this paper for details.)

Dr Atkins recommends a dose of 1400 mg of B1 daily in Parkinson’s disease (and similar neurological diseases) and writes that in his opinion, higher daily doses than 1400 mg should be taken only under medical supervision. (This seems a very sensible guidelines to follow. Note that this 1400 mg figure may be made up of any combination of oral or sublingual thiamine HCl, benfotiamine or activated vitamin B1.)

**Thiamin diphosphate** (TDP), also called thiamin pyrophosphate (TPP) or cocarboxylase, is the active, coenzyme form of vitamin B1. This may be the best form of B1 for treating severe pain (including Fibromyalgia).

TPP is a critical link between the glycolytic cycle and its main energy-producing cycle, the Krebs’ cycle, and plays key roles in the Krebs’ cycle itself. TPP
participates in the conversion of amino acids into energy and is a key coenzyme in the pentose phosphate pathway, which provides red blood cells with their energy. TPP is also critical in fatty acid synthesis, synthesis of the key neurotransmitter acetylcholine, and for nerve cell membrane function (this is critically important since the nerves’ messages must pass along its cell membrane).

A synthetic fat soluble form of vitamin B1 called benfotiamine (belonging to the family of compounds knows as "allithiamines") is also more bioavailable and physiologically active than thiamin. Benfotiamine raises the blood level of TPP, the biologically active coenzyme of thiamine. Benfotiamine controls formation of advanced glycation end-products (AGEs) and helps maintain healthy cells in the presence of blood glucose. This form of vitamin B1 takes longer to have an effect, as it is fat soluble rather than water soluble. Dosage is 150 to 1000 mg daily.

**Vitamin B2**

Vitamin B2 is an antioxidant involved in energy production. It is one of the major nutrients involved in recycling glutathione. Riboflavin limits the cell damage caused by stroke or heart attack and minimises respiratory damage from various toxins. Low vitamin B2 levels increase the risk of depression. Signs of B2 deficiency include cracks at the corners of the mouth and difficulty adjusting to darkness or bright lights.

The therapeutic dosage of riboflavin (vitamin B2) is generally 50 – 200 mg. Riboflavin may cause urine to turn a bright yellow colour. (This is not cause for concern. It is a sign that you are taking enough B2 and that it is being properly absorbed, according to Dr Atkins.)

**Flavin mononucleotide** (FMN), also called riboflavin phosphate, is one of the two metabolically active coenzyme forms of vitamin B2. FMN is the precursor for the other B2 coenzyme, FAD. FMN is also involved in bioconverting B6 to its coenzyme form.

**Vitamin B3**

Vitamin B3 is critical for energy production as well as heart health and optimal circulation. It is involved in over 50 reactions that turn fat into energy. Vitamin B3 comes in two forms, niacin and niacinamide. While both will meet the body’s requirements for B3, their overall therapeutic qualities differ.

Niacinamide helps osteoarthritis (at a dose of 1.5 – 2 g daily) and may help prevent diabetes. Niacinamide will not cause skin flushing but neither will it improve blood circulation. Like niacin, niacinamide has a gentle sedating effect.

Niacin can improve heart health and circulation, promote relaxation and relieve anxiety. Niacin taken at night can promote sleep. Niacin is one also of the major orthomolecular treatments used at high doses to treat schizophrenia and other mental illnesses.
Doses of niacin larger than 50 mg should be taken as flush-free niacin/inositol hexanicotinate (IHN) where the ‘niacin flush’ is undesirable. The niacin flush is a harmless feeling of warmth that occurs when certain amounts of niacin are taken, and lessens over time. There is some uncertainty whether or not flush-free niacin could be used instead of the plain niacin recommended by Dr Klenner and others for those who wish to avoid the ‘niacin flush’ that these doctors want patients to aim for. Some doctors recommend flush-free niacin as an excellent replacement for niacin and comment that is has all the same benefits as standard niacin, just without the flushing.

Taking enough of the flushing form of niacin 3-4 times daily to flush each time is recommended by some doctors, including Dr Klenner who includes it as an essential part of his protocol. This dilation of blood vessels helps get the nutrients you are taking to all the parts of the body and brain where they are needed. Dosage should begin at just 25 mg daily and be worked up very slowly. The flush should always be mild and last no longer than 10 minutes.

Note that vasodilating drugs will need to be lowered with niacin or IHN supplementation and this should be done with the help of the doctor that prescribed these drugs for you.

The three forms of B3 are generally safe to supplement in moderate doses of 500 mg. More than 1000 mg of niacin should be taken under a doctor’s care. To improve heart health, a dose of 800 – 2400 mg IHN daily is usually necessary, according to Dr Atkins. For basic health maintenance, 100 mg of niacinamide daily will suffice. High doses of niacinamide may cause nausea or extreme drowsiness in some people.

Nicotinamide adenine dinucleotide (NAD), is one of two main metabolically active forms of vitamin B3. The other is NAD phosphate (NADP). Some doctors suggest that taking NAD has little effect however, and recommend instead a sublingual supplement containing NADH. (Enteric coated NADH is not recommended.) NADH is a coenzyme, antioxidant form of vitamin B3. Dosage for sublingual NADH is 10 mg tried for 4 weeks. If this initial dose is ineffective, the dose may then be raised to 20 mg daily.

Some find NADH very helpful, while others feel it is not worth the expense and than taking extra B2 and B3 (as niacin or IHN) gives a much more powerful effect.

**Vitamin B5**

Vitamin B5 supports the adrenals and can help patients with adrenal problems lower their cortisone dosage as it allows the adrenal glands to produce more cortisone. Vitamin B5 helps in the formation of acetylcholine, the metabolism of fatty acids, and the incorporation of fatty acids into cell membrane phospholipids. It is also involved in making steroid hormones, vitamin A, vitamin D, and cholesterol. Pantethine helps to control yeast infections, helps the body with detoxification issues
which arise as a result of a yeast infection and helps treat autoimmune diseases and allergies.

Vitamin B5 is available as pantothenic acid and pantethine. Both forms have their own unique therapeutic effects and often they are both prescribed for a patient. The therapeutic dosage of pantothenic acid and/or pantethine is generally at least 200 mg daily.

Pantethine is a combination of pantothenic acid (vitamin B5) and beta-mercaptoethylamine. Pantethine is the precursor to coenzyme A (CoA), the critical starting point in the Krebs energy production cycle. (CoA also works with CoQ10 in improving detoxification.) While both forms of B5 can be used to make CoA, at least twice as much CoA will be formed with pantethine as opposed to pantothenic acid.

To tame inflammation, allergies or an autoimmune condition the dosage is 600 – 900 mg of both pantethine and pantothenic acid daily, according to Dr Atkins. Pantethine is one of the few B vitamins also available in sublingual form.

**Vitamin B6**

Vitamin B6 is a natural antihistamine and detoxifier and helps lower homocysteine levels. It is also integrally involved in women’s health, diabetes and heart disease prevention, arthritis treatment and immune system strength and a useful treatment in neurological and mental disorders. One of the signs of vitamin B6 deficiency is the inability to recall dreams.

The therapeutic dosage of pyridoxine (vitamin B6) is 75 – 200 mg. More than 200 mg of B6 should not be necessary. Vitamin B6 should be taken with a magnesium and zinc supplement. (Without an additional magnesium, zinc and B complex supplement, doses of B6 above 500 mg can cause temporary sensory neuropathy: a numbness or tingling in the arms or legs.) Doses of 200 – 400 mg may sometimes be used for some of the conditions mentioned previously (if a higher doses prove necessary) under medical supervision.

**Pyridoxal-5′-Phosphate** (PLP or P-5′-P) is the main metabolically active coenzyme form of vitamin B6. It is primarily in the liver that P-5′-P is synthesized from pyridoxine, with the help of enzymes that require vitamin B-2, zinc and magnesium for their activity. P-5′-P is associated with numerous enzymes, many or which are involved in the conversion of amino acids into the neurotransmitters dopamine, norepinephrine and serotonin. P-5′-P is also required for the synthesis of the hemoglobin molecule. Only 20% as much P-5′-P is needed as compared to standard pyridoxine supplements.

Dr Atkins comments that many people cannot convert pyridoxine into its active form. He recommends that at least 20% of the B6 supplemented should come from P-5′-P.
Biotin, vitamin B7
Biotin is particularly important in childhood. Biotin promotes healthy skin, hair and nerves. Dosage for biotin starts at 50 – 180 mcg. The therapeutic dosage of biotin is 300 – 3000 mcg or more. Dosages of 2 -4 mg may be used to treat hypoglycaemia.

Inositol, vitamin B8
Inositol is the relaxing and sleep inducing B vitamin. Inositol is needed for cell growth and is required by the brain and spinal cord. Dosage begins at 25 – 150 mcg.

As Dr Atkins explains, the therapeutic dosage of inositol for improving sleep and relieving insomnia is 1 – 1.5 g taken at bedtime. At a dose of 6 - 18 g daily, inositol is a safe and effective treatment for obsessive compulsive disorder (and also depression and panic disorders) and can replace tranquilisers and sleeping pills. For moderate anxiety Dr Atkins recommends 1 – 2 g daily.

Folate B9
Folate helps to lower homocysteine levels, is needed in red blood cell formation, can prevent neural tube birth defects, may improve skin problems and peripheral neuropathy, is essential for brain and nerve function and is a useful treatment in various neurological and mental disorders. Folate can also treat chronic pain (at a dose of 6 mg and when combined with some B12).

Doses of 40 mg daily or more can improve transient or long-term diarrhoea and various intestinal disorders such as Crohn’s disease and colitis. Folate at a dose of 40 – 60 mg daily has oestrogen-like effects and can be used by women who cannot tolerate the side-effects of standard oestrogen replacement therapy. 50 mg of the methyl form of folate is sometimes used to treat depression.

Standard synthetic folate supplements (folic acid) may not be adequate. Some experts claim that they may not be well utilised and may even be converted into glutamate and so be brain excitatory (something that does not happen with natural/activated folate). 20% or more of the population are also not able to utilise standard folate supplements properly due the MTHFR genetic mutation. These individuals require the special natural form of folate called L-5-Methyl Tetrahydrofolate (or Metafolin) and absorption of this form of folate may be blocked by standard folic acid supplements. Less L-5-Methyl Tetrahydrofolate is needed than standard folate. This supplement should be started at very small doses in M.E., i.e. 1/10th of a tablet.

The therapeutic dosage of folate is 1 mg (1000 mcg) or more. Dr Atkins recommends a dose of 3 – 8 mg of folate daily for those with neurological or cardiovascular disorders, 10 – 20 mg for those with high homocysteine levels and 20 – 60 mg daily for those with cancer, menopausal symptoms and severe colitis. Dosage recommendations for folate vary widely. In rare cases, doses over 15 mg daily may cause gastrointestinal and sleep problems.
It is important to take extra folate when extra B12 is taken; at least 1 mg (1000 mcg). To enhance the body’s absorption of folate, take a probiotic supplement. Folic acid is one of the safest supplements.

**Vitamin B12**

Vitamin B12 guards against stroke, lowers homocysteine levels, improves general wellbeing and sleep, improves allergies and asthma, treats peripheral neuropathy, is required by the body to make myelin, is needed for healthy nerve function, improves CNS function and cognitive function, can help normalise low blood pressure (and low blood pressure or faintness on standing), improves digestion, plays an important role in forming red blood cells and supports detoxification processes. Doses over 1mg should also be taken with at least 1 mg of folate. There are several different forms of vitamin B12.

*Hydroxycobalamin:* This form of B12 is longer acting and raises blood levels of B12 higher. The therapeutic dosage of vitamin B12 as hydroxycobalamin is usually 1 – 5 mg, or sometimes 10 mg at the beginning of treatment. May reset the sleep/wake cycle too severely at higher doses, requiring that the dose be lowered.

*Dibencozide:* Extra B12 as dibencozide may also be useful and is also well tolerated in M.E. Dibencozide is a primary coenzyme form of vitamin B12. It is required for processing branch chain amino acids through the Kreb's cycle for sustained energy production and is involved in methionine and choline metabolism, red blood cell formation, and maintaining the integrity of myelin (a fatty insulation that covers some nerves), as well as promoting normal folic acid metabolism. Sublingual dosage is 1 mg or more daily.

*Methylecobalamin:* Methylecobalamin is an active coenzyme form of vitamin B12, is essential for cell growth and replication. It is more concentrated than other forms of B12 in the cerebral spinal fluid where it can be used by the central nervous system. It donates methyl groups to the myelin sheath that insulates certain nerve fibers. It also plays a role in maintaining a healthy sleep/wake cycle, as well as normal nerve function.

Large doses may work too well to reset the sleep/wake cycle. They may reduce total sleep time and promote early waking causing severe relapse in M.E. Thus, this form of B12 should only be tried at very low doses to start with (as B12 takes months to leave the system) and may only be able to be tolerated in very low doses longer term in some patients. As with activated folate, a good starting dose may be just 1/10\textsuperscript{th} of a (1 mg) tablet a day. Where MB12 is well tolerated, dosage is 1 – 5 mg daily. 200 – 500 mcg daily (plus some extra B12 in another form) may be a better dose if problems caused by MB12 with the sleep/wake cycle are severe.

Another way to get some of the benefits of methylecobalamin B12 is to take hydroxycobalamin. Despite the fact it is not an activated form of vitamin B12, this form of B12 is one of the most beneficial and highly recommended in M.E. as it is a
potent detoxifier. A small part of hydroxycobalamin supplements taken will be turned into methylcobalamin by the body, and so hydroxycobalamin also has a positive but more subtle effect on the sleep/wake cycle that is less likely to cause relapse. For more information on B12s effect on the sleep/wake cycle see the section on sleep in the main Treating M.E. paper.

_Cyanocobalamin_: This form is okay to take if it is included in small amounts in multivitamins or B complex products but should never be the form of B12 chosen when purchasing a stand-alone B12 supplement. At high doses hydroxycobalamin, methylcobalamin or dibencozide rather than cyanocobalamin must be used to avoid the toxicity of the cyanide in the later.

Vitamin B12 may be injected or given by IV, or taken equally effectively via sublingual tablets. There is no need for injections if you can find a good sublingual product, as these articles explain: Vitamin B12 Shot Problems and Vitamin B12 Shot Side Effects. At higher doses, both sublingual and injectable B12 are well absorbed so choose which you prefer and is more cost effective.

Whichever form you take, it is essential to start at a low dose and work up slowly as B12 (especially hydroxocobalamin) helps with detoxification. Going slow is also very important as if enough is taken to too-severely affect the sleep/wake cycle this can then take several months to wear off, as B12 is stored in the muscles and in organs. B12 is well tolerated by most M.E. patients although some patients seem unable to tolerate this supplement in anything but a tiny dose. B12 is extraordinarily safe even in high amounts.

The effects from B12 may seem to wear off after a long period of treatment, so some doctors recommend stopping B12 treatment for a month and then restarting it to get around this problem. Note that HB12 in sublingual form can be hard to find, click here, here, here, here or here for links. Vitamin B12 may also be well absorbed intranasally, according to the ‘Fire your doctor!’ book.

_Choline_
The therapeutic dosage of choline (a B vitamin) is 50 - 1150 mg or more. Choline is a component of lecithin. Choline may be supplemented equally well via lecithin granules (1 – 3 tsp daily) or phosphatidylcholine.

_PABA Bx_
While it is not actually a B vitamin, para-aminobenzoic acid (PABA) is sometimes included in B complex supplements in small amounts as it helps us synthesise folic acid in our gastrointestinal tract. PABA may be prescribed to treat autoimmune disorders at a dose of 500 – 1500 mg daily.
The therapeutic dosage of PABA (sometimes called vitamin Bx) is up to 250 - 500 mg.

**Oral B vitamin supplements**

Probably the easiest and cheapest way to take a B vitamin supplement is to take a 50 mg B complex capsule or tablet 2 – 3 times daily or a 100 mg product 1 – 1 ½ times daily (along with a good quality multivitamin).

(Note that B complex products labelled ’50 mg’ do not contain the same amount of each of the B vitamins, as this would be inappropriate. The ’50 mg’ refers to the dosage of the main vitamins such as vitamin B1 and B2 etc.)

Some M.E. patients may find that oral B supplements are adequate, but that somewhat higher doses are needed due to absorption problems caused by M.E. Where higher doses of some of the B vitamins are required, one or more additional single B vitamin products may also be taken with the B complex product in oral, sublingual or injectable form.

**Taking B vitamins in activated and/or sublingual forms**

In order for B vitamins to be utilized by the body, they must first be converted into their active coenzyme forms by the liver. This conversion takes time and requires metabolic energy, which may be in short supply in M.E. For most healthy, young individuals, this conversion of synthetic B vitamins into coenzymated vitamins does not present a problem. However, in older, ill or nutritionally-deficient people or certain individuals with a particular biochemical deficiency, the conversion may be problematic. When this occurs, supplementing with non-coenzymated B vitamins may have little effect.

Our livers are working harder than ever before with the hugely increased amount of toxins they have to process and neutralise in the 21st century. This is one reason why the liver’s ability to coenzymate vitamins into their active forms can be greatly impaired (which can affect our entire biochemistry). Some people also have particular problems converting vitamin B6 or folate to their active forms. For these people, only the coenzymated form of these vitamins will be able to be used by the body.

Where there are problems converting one or more of the B vitamins into their active coenzyme forms by the liver coenzymated sublingual B vitamins will be by far the best choice of B supplement. In studies with chronic alcoholics (a group at high risk of poor liver function) large doses of B vitamins were given by IV. Normally, the administration of these IVs would raise the body’s coenzyme levels, but in the case of liver-impaired alcoholics, it did not. This shows that a compromised liver may not be able to Coenzymate vitamins optimally. Thus when a person cannot convert B vitamins properly, even injections or IVs of non-coenzymated vitamins will have
little or no effect. So for some people, the optimum way to take in B vitamins is not by IV but through coenzymated products.

Coenzyme forms of vitamins are biologically identical to those used by the body, making them highly bioavailable, especially when they are also in a sublingual form. Sublingual tablets are absorbed rapidly into the highly capillarised tissues found in the cheeks and under the tongue and enter the bloodstream intact, without the risk of being degraded or diminished by the digestive system. Taking coenzymate and sublingual forms of B vitamins also conserves valuable metabolic energy and reduces the load on the (probably very overworked already) liver. Vitamins taken in this form will also be faster acting.

Smaller doses are needed when the coenzymate forms of vitamins are taken and when nutrients are taken sublingually. Coenzymated forms of vitamin B are up to five times more biologically active than other forms. One study using both sublingual and oral supplements (testosterone in this case) found that the absorption of the sublingual was twice that of the oral dose.

Taking 150 mg daily of a B vitamin complex product should bring noticeable effects and benefits within 2 - 4 weeks. It should improve wellbeing generally, improve concentration, improve mood and make you feel more able to cope with stress. You should really be able to feel a significant difference. If 150 mg of an oral B complex is taken for a month with little or no effect, a sublingual coenzymated B complex product should be trialled. Try 2 or 3 sublingual lozenges daily (depending on the brand). A short trial of this nature is a very good idea in M.E. and is very highly recommended.

A bottle of sublingual coenzymated B complex containing 60 lozenges (a month’s supply) costs around $14 (USD/AUD/NZD/CAD). Coenzymated sublingual B vitamins can be bought singly or as a complex. Note that not all of the B vitamins are available in a coenzymate form, only vitamins B1, B2, B3, B6, B12 and folate.

The downside of sublingual vitamins is the higher cost and taking in so much mannitol or sorbitol and other undesirable substances. Sourcing coenzymated sublingual vitamins can also be somewhat difficult. The leading brand in this area is US company Source Naturals. Source naturals makes a good quality coenzymated B complex, plus sells each of the coenzymated B vitamins individually as well. A product called Smart City Coenzymated B formula is available in Europe. The Holistic Heal website sells coenzymated B12 (plus hydroxycobalmain B12) and folate. Solgar sells activated folate as Metafolin. Methylcobalamin B12 is widely available in sublingual form as is activated B6 in non-sublingual tablet form.

Avoid products which contain a mixture of standard and coenzymated B vitamins and which do not disclose how much of each type is contained in the product. (You may be paying a premium price for a product that contains only 1% or less of the more expensive coenzymated form of the vitamin. If the percentages are not listed, assume the coenzymated vitamin percentage in the product is very low!)
### Selected coenzymated B vitamins price comparison chart

<table>
<thead>
<tr>
<th></th>
<th>B1</th>
<th>B2</th>
<th>B3</th>
<th>B6</th>
<th>B12</th>
<th>Folate</th>
<th>Price per unit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Source Naturals <em>sublingual</em> coenzymated B complex. Also contains 75 cmg biotin and 12 mg B5.</td>
<td>7 mg</td>
<td>5 mg</td>
<td>&lt;5 mg</td>
<td>5 mg</td>
<td>440 mcg (DB12)</td>
<td>(200 mcg folic acid only)</td>
<td>0.23</td>
</tr>
<tr>
<td>Source Naturals <em>sublingual</em> coenzymated B1</td>
<td>16 mg</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0.18</td>
</tr>
<tr>
<td>Source Naturals <em>sublingual</em> coenzymated B2</td>
<td>18 mg</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0.16</td>
</tr>
<tr>
<td>Source Naturals <em>sublingual</em> coenzymated B6</td>
<td>17 mg</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0.09</td>
</tr>
<tr>
<td>Source Naturals non-sublingual coenzymated B6</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>67 mg</td>
<td>-</td>
<td>0.16</td>
</tr>
<tr>
<td>Solgar non-sublingual coenzymated B6</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>50 mg</td>
<td>-</td>
<td>0.15</td>
</tr>
</tbody>
</table>

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**Taking B vitamins in injectable or IV form**

Intravenous administration of nutrients can achieve serum concentrations not obtainable with oral, or even intramuscular administration.

B vitamin injections or IVs must be administered by an experienced and qualified practitioner and thus may not be a practical or affordable option for all M.E. patients.

Individual B vitamins may be given via injection, and this may be combined with an oral or sublingual B complex product, or a B complex product may be given via injection or IV. IV vitamin expert Dr Klenner says of B vitamin complex given by IV, ‘Intravenous medication can be given daily; it should be administered at least twice weekly. Due to sensitivity possibilities, we always have the patient take the intramuscular injections for three weeks before starting intravenous therapy.’

Some doctors may offer a ‘Myers’ cocktail’ which is an IV containing B vitamins, magnesium and calcium in particular amounts. This IV may be taken once or twice weekly or more (along with daily B vitamins etc. given orally each day). This treatment must be administered by an experienced and qualified practitioner. For more information on this treatment and instructions for doctors on how to make the IV, see the excellent article: Intravenous nutrient therapy: the "Myers' cocktail" by IV vitamin expert Alan R. Gaby. He explains,

All ingredients are drawn into one syringe, and 8-20 mL of sterile water (occasionally more) is added to reduce the hypertonicity of the solution. After gently mixing by turning the syringe a few times, the solution is administered slowly, usually over a period of 5-15 minutes (depending on the doses of minerals...
used and on individual tolerance), through a 25G butterfly needle. Occasionally, smaller or larger doses than those listed in Table 1 have been used. Low doses are often given to elderly or frail patients, and to those with hypotension. Doses for children are lower than those listed, and are reduced roughly in proportion to body weight. The most commonly used regimen has been 4 mL magnesium, 2 mL calcium, 1 mL each of B12 (as hydroxycobalamin), B6, B5, and B complex, 6 mL vitamin C, and 8 mL sterile water.

As the Myers’ cocktail only contains a relatively small amount of vitamin C, full-strength vitamin C IVs may also be given (perhaps on alternate days). The preservatives used in vitamin C or B complex IVs (or injections) can cause problems in some patients and preservative free preparations may be a better (if more expensive) choice. Patients that are very sensitive to chemicals may do better when glass rather than plastic IV bags/flasks are used.

While the Myers’ cocktail is generally very well tolerated, the magnesium (and calcium) in the Myers’ IV may cause problems for those with low blood pressure – which includes M.E. patients. For this reason, it may be preferable to get a Myers’ cocktail without calcium and magnesium and to take these supplements separately. (Magnesium should be taken in transdermal or liquid form, if possible, rather than orally, in this instance.) As with standard B complex IVs, it is recommended that the vitamins be given IM first for several weeks before the IVs begin.

Some doctors may follow the Klenner protocol for treating neurological diseases which involves high dose vitamin C and B vitamins given by IV and injection as well as orally.

**Taking B vitamins in liposomal forms**

The B vitamins have recently become available in a liposomal delivery system. A liposomal B complex product is now available from Livon Labs and the product is called AGE blocker. The downside here is that the B vitamins are not available individually and so it may not be possible to get enough B1 or other more desired B vitamins without getting more than needed of the other B vitamins as well as the other nutrients included in the product.

Liposomal delivery systems make nutrients very bio-available and so smaller amounts are needed than with oral forms.

**Vitamin B cautions**

Occasionally, high-dose B vitamins may interfere with sleep. If you have trouble getting to sleep at night, try taking your B vitamins as early in the evening as possible and see if this helps.
Betaine trimethylglycine (betaine TMG or TMG) may be included in some B complex formulas. Such products may be best avoided as TMG is often very poorly tolerated in M.E. and can cause severe relapse while the supplement is taken and for a week or so afterwards. If well tolerated however, TMG is a beneficial supplement as it aids in the process of methylation. TMG is probably best taken alone to start with, at very small doses of just 100 - 200 mg.

B vitamins given by IV or IM should be given by medical practitioners that have considerable experience in this area. The collected works of Dr Klenner and the article Intravenous nutrient therapy: the 'Myers' cocktail by Alan R. Gaby are essential reading for patients and doctors involved with IM or IV B vitamin therapy. These papers include all sorts of useful cautions and extra information that comes with administering this treatment to many thousands of patients over many years.

Dr Atkins warns that women who need to shrink uterine fibroids, or prevent breast cancer recurrences, or deal with endometriosis or fibrocystic breasts should limit supplemental folate to 600 mcg daily.

An advantage of water-soluble nutrients is that any side-effects wear off very quickly. The exceptions to this are benfotiamine, which is a fat-soluble form of vitamin B1, and vitamin B12. Side effects from vitamin B12 (such as changes to the sleep/wake cycle) take several months to wear off, as B12 is stored in the muscles and in organs.

Additional notes on treating M.E. in the earliest stages and the Klenner protocol for neurological disease

While there is as yet very little information in the literature about treating M.E. in the acute stages of infection, certain inferences can be made by how similar diseases such as poliomyelitis, Myasthenia Gravis and Multiple Sclerosis (and Coxsackie enteroviral infections) have been treated.

There is evidence that a poliomyelitis infection can be overcome with the administration of large doses of vitamin C by IV, over several weeks, if this treatment begins as soon as possible after the infection has begun. High dose vitamin C by IV is also used to treat Multiple Sclerosis, Myasthenia Gravis and other neurological diseases, along with high doses of the B vitamins by IV (particularly vitamin B1). The effectiveness of this protocol – the Klenner protocol – depends in part on how early it is begun (how much damage the body has sustained already, in other words).

a. Dr Klenner’s protocol for poliomyelitis. For polio Dr Klenner recommends ascorbic acid given intravenously at 300 to 500 mg per kg of weight (or oral vitamin C to bowel tolerance if this is all that is available), muscle massage, plus thiamin 100 to 250 mg a day for three months afterwards to help rehabilitate the nerves.

b. Dr Klenner’s protocol for Multiple Sclerosis, Myasthenia Gravis and other neurological diseases. Dr Klenner notes that ‘Early M.S. cases will respond quickly’
and cites examples where the protocol has taken 2 weeks to work in some early cases, and 5 years or more of constant treatment to be effective in longer-term cases. One paper makes the statement that it may take a year of treatment for every two years spent ill with MS for the full benefits of treatment to be seen. (He also notes that a cut-down version of his treatment protocol may also work but that it may take much longer and not be effective in some cases.) He says: “Any victim of Multiple Sclerosis who will dramatically flush with the use of nicotinic acid and has not yet progressed to the stage of myelin degeneration, as witnessed by sustained ankle clonus, can be cured with the adequate employment of thiamin, B complex proteins, lipids and carbohydrates. We had patients in wheelchairs who returned to normal activities after five to eight years of treatment.”

For more information on this program see the paper: Dr. Klenner’s B vitamin (neurological disease) protocol and M.E.

References
To read at length about the different roles and benefits of each B vitamin, please see:

- The Vita-Nutrient Solution, Orthomolecular Medicine for Everyone: Megavitamin Therapeutics for Families and Physicians, Fire your Doctor: How to be Independently Healthy and The Optimum Nutrition Bible
- Clinical Guide to the Use of Vitamin C The Clinical Experiences of Frederick R. Klenner, M.D. and Response of Peripheral and Central Nerve Pathology to Mega-Doses of the Vitamin B-Complex and Other Metabolites and Observations On the Dose and Administration of Ascorbic Acid When Employed Beyond the Range Of A Vitamin In Human Pathology by Dr Klenner.
- Intravenous nutrient therapy: the 'Myers' cocktail in Alternative Medicine Review, Oct, 2002 by Alan R. Gaby (PubMed link) This article includes instructions for doctors on administering the Myers’ cocktail.
- Dr Atkins Vita-Nutrient Solution: Nature's Answer to Drugs by Dr Atkins
- Orthomolecular Medicine For Everyone: Megavitamin Therapeutics for Families and Physicians by Abram Hoffer.
- The NEW optimum nutrition bible by Patrick Holford
- Fire your doctor! : how to be independently healthy by Andrew W. Saul.
- How to live longer and feel better by Linus Pauling.
- Coenzymated™ Sublingual B-Vitamins: A Radical Step in the Evolution of Vitamin Supplements by Source Naturals (a company which makes these vitamins)
- Various papers by Dr Paul Cheney on the use of hydroxycobalamin injections
- The Overlooked Role of Chronic Infection in Neurodegeneration and Its Reversal Using Nutraceutical Agents (PDF), by Dr Marshall
- MTHFR information from the Genetics Home Reference website
- Nutrigenomic Testing and the Methylation Pathway by Dr Amy Yasko (MTHFR information)
- The Sinatra Solution by metabolic cardiologist Dr Stephen T. Sinatra
- Alternative Medicine Magazine's Definitive Guide to Sleep Disorders: 7 Smart
Ways to Help You Get a Good Night's Rest by Herbert Ross and Keri Brenner
- Circadian rhythm sleep disorders by Kathryn J. Reid, PhD, Anne-Marie Chang, PhD, Phyllis C. Zee, MD, PhD. Center for Sleep and Circadian Biology, Northwestern University, Evanston, IL 60208, USA
- Information on melatonin and vitamin B12 by Dr Michael T. Murray, N.D.
- Methylcobalamin B12 supplement benefit and side effects by Ray Sahelian, M.D.
- Circadian Rhythms by Andrew B. Hollander
- The United Mitochondrial Disease Foundation website.

Klenner protocol references are available in the paper: Dr. Klenner’s B vitamin (neurological disease) protocol and M.E.

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Relevant quotes
“Intravenous administration of nutrients can achieve serum concentrations not obtainable with oral, or even intramuscular (IM), administration. For example, as the oral dose of vitamin C is increased progressively, the serum concentration of ascorbate tends to approach an upper limit, as a result of both saturation of gastrointestinal absorption and a sharp increase in renal clearance of the vitamin. The highest serum vitamin C level reported after oral administration of pharmacological doses of the vitamin is 9.3 mg/dL. In contrast, IV administration of 50 g/day of vitamin C resulted in a mean peak plasma level of 80 mg/dL. Similarly, oral supplementation with magnesium results in little or no change in serum magnesium concentrations, whereas IV administration can double or triple the serum levels, at least for a short period of time. Various nutrients have been shown to exert pharmacological effects, which are in many cases dependent on the concentration of the nutrient. For example, an antiviral effect of vitamin C has been demonstrated at a concentration of 10-15 mg/dL, a level achievable with IV but not oral therapy.”

Intravenous nutrient therapy: the "Myers' cocktail" by Alan R. Gaby

“This treatment works so dramatically in Myasthenia Gravis, that should a given patient’s physician refuse to administer this schedule, I have this recommendation: One gram thiamin hydrochloride one hour before meals and at bed hour, and during the night if awake. Niacin taken at the same time, and in amounts sufficient to produce a good body flush. Two hundred mg. calcium pantothenate and 100mg pyridoxine before meals and at bed hour. Ten grams ascorbic acid, taken in divided doses. Naturally, the full schedule will afford more dramatic response.” Frederick Klenner M.D.
“Coenzyme A (COA, the active form of pantothenic acid) is in limited supply in M.G. It intercepts pyruvic acid at the end point of glucose metabolism. Another enzyme, cocarboxylase, splits the carboxyl group (COOH) away from pyruvic acid to form CO$_2$ and free hydrogen. The remaining two carbon fragment (acetate) join with coenzyme A to form acetyl coenzyme A. A high energy package named NADH$_2$ is formed from the carboxyl group from pyruvic acid and a sulfur group from coenzyme A.

Thiamin is important in all this energy production as two molecules of thiamin combined with two molecules of phosphoric acid become cocarboxylase. This enzyme must be present for the continuance of the metabolic cycle. When thiamin is deficient, pyruvates and lactate accumulate, and at the neuromuscular junction the nerve end plate becomes swollen and poorly operative. That same enzyme is necessary for the syntheses of acetylcholine, the neurotransmitter that initiates muscle contraction. “Thiamin deficiency inhibits lactic acid metabolism.” A thiamin deficiency means a cocarboxylase deficiency. Liver enzymes are mainly responsible for the phosphorylation of thiamin to cocarboxylase. Liver disease would obviously reduce this synthesis. “The activity of choline esterase (breaks down acetylcholine) is inhibited by this same double thiamin unit.”

In the conversion of fatty acids to energy some of the same enzymes are necessary: coenzyme A, hydrogen carriers (niacin-adenosine-dinucleotide) and Vitamin C. The latter acts as a hydrogen transport.

He puts Myasthenia Gravis and Multiple Sclerosis in the same therapeutic group as he found thiamin was the key to the therapy. M.G. is a genetically transmitted disease and M.S. is triggered by a virus and mimics poliomyelitis. Nerve damage in M.S. is due to microscopic hemorrhages in the nervous system. During healing, scar tissue contracts clamping off capillary flow and nutrition. This wasting results in loss of the myelin sheath protection.

He felt that remyelinating these damaged nerves was every bit as hopeful as the myelination that occurs normally in infancy with nothing more spectacular than breast milk. It requires two years of treatment to repair the damage caused by one year of the disease.

He cites works in the late 1930s by Stern at Columbia University who used thiamin intraspinally for the treatment of Multiple Sclerosis with astonishing results. After 30 mg of thiamin was injected into the spinal canal of paralyzed MS. victims, they had a temporary remission. They could walk for a while. And Stern felt it was a B$_1$avitaminosis. It was known at that time that polyneuritis can cause degeneration of myelin sheaths.” Frederick Klenner M.D. (comments abbreviated, summarized and annotated by Lendon H. Smith, M.D.)

“The Myers' often produces a sensation of heat, particularly with large doses or rapid administration. This effect appears to be due primarily to the magnesium, although rapid injections of calcium have been reported to produce a similar effect. Too rapid administration of magnesium can cause hypotension, which can lead to lightheadedness or even syncope. Patients receiving a Myers' should be advised to report the onset of excessive heat (which can be a harbinger of hypotension) or lightheadedness. If either of these symptoms occurs, the infusion should be stopped.
temporarily and not resumed until the symptoms have resolved (usually after 10-30 seconds). Patients with low blood pressure tend to tolerate less magnesium than do patients with normal blood pressure or hypertension.

For elderly or frail individuals, it may be advisable to start with lower doses than those listed. When administered with caution and respect, the Myers' has been generally well tolerated, and no serious adverse reactions have been encountered with approximately 15,000 treatments. In 1995, the author's last year in private practice, the cost of the materials for a Myers' was approximately $5.00. The use of preservative-free nutrients at least doubled the cost of materials. Nursing time and administrative factors represented the majority of the cost of IV nutrient therapy. In 1995, the author's fee for a Myers' was $38.00. Other doctors have charged as little as $15.00 or as much as $100.00 or more. Since 1995, the cost of most of the injectable preparations has increased by 50-100 percent.” Intravenous nutrient therapy: the "Myers' cocktail" by Alan R. Gaby

“The early papers by Dr Fred R. Klenner provide much information about the use of large doses of Vitamin C in preventing and treating many diseases. These papers are still important.” Linus Pauling, Ph.D.
Many M.E. patients do far better taking B vitamins intravenously (by IV) or intramuscular (IM) injections or in their coenzymate (or 'active') forms, than orally. For some patients, oral supplements are fine but somewhat higher doses are needed to overcome problems with absorption.

- B vitamins given by IV have the most powerful effect, generally speaking. In some cases, however, particularly where liver function or metabolic function is very poor, coenzymated B vitamin products will be the best choice, and all other forms of B vitamins will have little or no effect.

- Smaller doses are needed when the coenzymate forms of vitamins are taken and when nutrients are taken sublingually. Coenzymated forms of vitamin B are up to five times more biologically active than other forms and sublingual supplements may be twice as well absorbed as oral supplements.

- Taking 150 mg daily of a B vitamin complex product should bring noticeable effects and benefits within 2 - 4 weeks. It should improve wellbeing generally, improve concentration, improve mood and make you feel more able to cope with stress. You should really be able to feel a significant difference. If 150 mg of an oral B complex is taken for a month with little or no effect, a sublingual coenzymated B complex product should be trialled. Try 2 or 3 sublingual lozenges daily (depending on the brand).
  
  A short trial of this nature is a very good idea in M.E. and is very highly recommended as it's an easy way to see if perhaps your body is not converting the B vitamins to their useable forms very well. If this is the case a far more noticeable effect will be seen from the coenzymate product than from standard B vitamin products.

- Patients that have access to a doctor experienced in giving vitamins by injection or IV may also want to try this method of treatment for a period of time to see if it provides extra benefits (if budget allows). A B complex IV, a Myers’ cocktail IV or a vitamin IV made to the specifications of Dr Klenner may be useful in M.E. Intravenous administration of nutrients can achieve serum concentrations not obtainable with oral, or even intramuscular administration.

- The B vitamins are water-soluble and any excess is readily excreted in the urine and so B vitamins are generally low in toxicity. When nutrients are water soluble it means that they are not stored in the body for long and so must supplements must be taken in 2 or 3 or more daily doses spread throughout the day.
• Initial doses may be quite different to maintenance doses. Over time, the doses of some of the B vitamins given at therapeutic doses may be able to be lowered. They may also no longer need to be injected or given by IV. How you feel should be used to determine the correct dosage of each of the B vitamins over time.

• Individual B vitamins should never be taken without also taking a B complex product of a roughly similar strength. High-dose B vitamins may interfere with sleep. If you have trouble getting to sleep at night, try taking your B vitamins as early in the evening as possible and see if this helps.

• As an absolute minimum dosage it is important to take 50 – 100 mg of B1, B2 and B6, 100 – 200 mg of B5, 100 – 250 mg of B3, 800 mcg of folate and 500 mcg of B12. This is roughly the amount of each of the B vitamins contained in a good quality multivitamin or a 50 mg B complex supplement.

Combining different B vitamin products
Many M.E. patients choose to take more than one B vitamin product at a time, depending on their needs. As a very general example, the daily intake of B vitamins may be as follows:

• A daily multivitamin, a 50 mg B complex product x 2 -3, 500 mg of flush-free niacin, plus some sublingual B12 daily

• A daily multivitamin, a 100 mg B complex product x 1, 400 mcg of activated folate, plus some sublingual B1 and B12 daily

• A daily multivitamin, a 50 mg B complex product x 2, 500 mg of flush-free niacin, 250 mg of B1 as benfotiamine, plus a sublingual coenzyme B complex 2 times daily, plus some sublingual B12 daily

• A daily multivitamin, a 50 mg B complex product 3 times daily, 250 mg of niacin, plus weekly B1 injections

• A daily multivitamin, a sublingual coenzyme B complex 3 times daily, flush-free niacin 1000 mg, plus some extra sublingual B1, B12 and NADH daily

• A daily multivitamin, a sublingual coenzyme B complex 3 times daily, flush-free niacin 250 mg, plus some extra sublingual pantethine, B1 and B12 – plus a B complex (or Myers’ cocktail) IV twice a week, for the first 1 – 6 months.

Supplementing some of the B vitamins individually, along with a B complex product
Some of the B vitamins that are most important or beneficial for M.E. patients to supplement in higher doses (if budget allows) than are included in a B complex product include the following:

• Vitamin B1 as thiamine HCl or TDP/TTP (coenzymated B1) or benfotiamine, improves cardiac function, pain, cognitive and neurological function and aids in the remyelination of damaged nerves.

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• Vitamin B3 as niacin or IHN (flush free niacin) can improve heart health and circulation, promote relaxation and relieve anxiety. It is also critical for energy production.

• Vitamin B5 as pantethine, supports the adrenals, boosts coenzyme A production, helps the body with detoxification issues which arise as a result of a yeast infection and helps treat autoimmune diseases and allergies.

• Vitamin B12 as hydroxycobalamin (or dibencozide or methylcobalamin IF this form is well tolerated) supports detoxification, improves allergies and asthma, is required by the body to make myelin, is needed for healthy nerve function, improves CNS function and cognitive function and can help normalise low blood pressure (and low blood pressure or faintness on standing).

• Activated folate (L-5-Methyl Tetrahydrofolate) works with vitamin B12, helps to lower homocysteine levels and is essential for brain and nerve function.

Please see the full-length B vitamins paper for more information and for references.
Dr. Klenner and those who continued his work after his death have had a lot of success in treating diseases similar to M.E., such as Multiple Sclerosis and Myasthenia Gravis, with a high-dose B vitamin protocol combined with a general nutritional protocol.

Results are sometimes seen within just a few weeks where the patient was treated while the disease was in the early stages although patients that had been ill for many years sometimes took 5 years or more to respond.

Dr Klenner explains,

Any victim of Multiple Sclerosis who will dramatically flush with the use of nicotinic acid and has not yet progressed to the stage of myelin degeneration, as witnessed by sustained ankle clonus, can be cured with the adequate employment of thiamin, B complex proteins, lipids and carbohydrates. We had patients in wheelchairs who returned to normal activities after five to eight years of treatment.

Considering the safety of this treatment protocol and the similarity of the diseases discussed and studied, and M.E., a reasonably compelling case can be made for its being tried in M.E. also – in combination with high-dose or saturation level vitamin C.

The benefits of correcting any nutritional deficiencies and making sure that the body has all the nutrients it needs to function properly and to have the immune system fully powered up and to heal, are well documented. It is also well documented that a body suffering with a serious infection will have a much higher need for certain nutrients than a person that is healthy.

**Dr Klenner’s protocol for Multiple Sclerosis, Myasthenia Gravis and other neurological diseases.**

Dr Klenner worked on perfecting his MS and MG protocol for over 30 years. His treatment protocol for Multiple Sclerosis, Myasthenia Gravis and other neurological diseases in 1980 included the following:

- Thiamin HCl (Vitamin B<sub>1</sub>) one gram (1000 mg) taken thirty minutes before meals and at bedtime.
• Nicotinic Acid (Niacin; Vitamin B₃) 50 mg to 300 mg, depending on flushing of skin, thirty minutes before meals and bed time.
• Riboflavin (Vitamin B₂) 250 mg after meals and bed time.
• Pyridoxine (Vitamin B₆) 100 mg after meals and bed time.
• Calcium pantothenate (pantothenate acid/Vitamin B₅) one gram after meals and bed time.
• Lecithin. 1200 mg one capsule after meals and at bed time.
• Vitamin A (palmitate) one 50,000 unit capsule after breakfast and supper.
• Vitamin E (d-alpha tocopheryl acetate) 400 I. units. Four capsules at bedtime.
• Niacinamide (Vitamin B₃ amide) 500 mg, tablets. One after meals.
• Magnesium oxide 300 mg tablet. One tablet after meals and before bed time.
• Folic acid. Two milligrams after each meal.
• Zinc gluconate 10 mg, three times each day. Take several hours after vitamin B2.
• Protein supplement containing eighteen amino acids.
• Intramuscular injection, given five to seven days each week.: Thiamin HCl, (B₁), 400 mg daily, pyridoxine (B₆) 150 mg daily, cyanocobalamin (B₁₂) 1500 mcg daily, riboflavin (B₂) 75 mg daily, niacinamide (B₃) 150 mg daily.
• At least 10 – 20 grams of vitamin C daily orally or by IV.
• RNA and DNA tablets (100 mg of each, taken one to three times daily) are helpful to some patients.
• 500 – 1500 mg of inositol.
• A higher protein diet is recommended.

Dr Klenner says of B vitamin complex given by IV,

Intravenous medication can be given daily; it should be administered at least twice weekly. Due to sensitivity possibilities, we always have the patient take the intramuscular injections for three weeks before starting intravenous therapy.

Finding a qualified doctor is important. If you still cannot find a qualified doctor, do the best you can by reading as much as possible and buying your own sublingual and coenzyme B vitamin complex tablets and so on. Some aspects of the treatment can be started alone while you continue your search for a helpful doctor.

**The importance of vitamin B1**

Dr Klenner’s neurological disease treatment protocol strongly emphasises vitamin B1 as it plays an important role in the metabolic cycle, facilitating muscle function and also aids in the remyelination of damaged nerves. Dr Klenner writes,

The importance of thiamin in treating Myasthenia Gravis and Multiple Sclerosis cannot be over-emphasized. Two molecules of thiamin hydrochloride in combination with two molecules of phosphoric acid is cocarboxylase. For the
reaction to acetyl coenzyme A plus oxaloacetic acid to continue through to citric acid with the release of coenzyme A, cocarboxylase must be present. If this reaction does not take place, due to one of many factors, there will be no coenzyme A present to react with another molecule of pyruvic acid to set in motion the elements necessary for the continuance of the metabolic cycle. In thiamin deficiency, both pyruvates and lactate accumulate in the blood. Pyruvates also accumulate at the neuro-muscular junction causing cloudy swelling of the distal portion of the nerves. Cocarboxylase, also known as diphosphothiamine, is necessary in the synthesis of acetyl-choline and in the control of its hydrolysis. The activity of choline esterase of serum is also strongly inhibited by cocarboxylase. The chief chemical factor in both diseases is thiamin hydrochloride. Other fractions of the B-complex are also essential but in lesser amounts.

Myasthenia Gravis is due to genetic fault, most likely involving an intermediate lethal gene or group of genes. Multiple Sclerosis is more complex. The initial pathology is sickness caused by the Coxsackie virus. This virus mimics poliomyelitis, and for many years accounted for thousands of so-called polio cases. This virus, like the polioviruses, can cause paralysis but never permanently. The nerve damage is the result of microscopic hemorrhages in the central nervous system. With the contraction of the scar at the site of bleeding, the vessels carrying nutrients to the nerve cells are virtually clamped off. This leaves nerve tissue, in many instances, alive but not capable of work. As time goes on, this wasting of nerve tissue results in loss of its myelin protection. This is similar to electrical wires that have lost their insulation when exposed to the wear of daily use, or exposure to the elements.

Dr Klenner makes the following comments about the history of thiamine in treating neurological diseases,

In the late thirties, Stern from Columbia University, was employing thiamin hydrochloride intraspinally with astonishing results in Multiple Sclerosis. He reported taking patients to the operating room on a stretcher, and following 30 mg. thiamin given intraspinally, they would walk back to their room. The response was relatively transient, but it led Stern to believe that Multiple Sclerosis was nothing more than vitamin B1 avitaminosis, the modus operandi being damage to the filter bed of the choroid plexus. Stern also found that the effective dose of vitamin B1, when given in the lumbar subarachnoid space, was too close to the lethal dose as was demonstrated in dogs.

Stern’s hypothesis was backed by the knowledge that degeneration of the myelin sheaths of peripheral nerves as well as of the ganglion cells of the brain and spinal cord can be produced in experimental polynuereititis. Similar findings are observed in starvation, even when the supply of thiamin appears to be adequate. One school of thought regards the neurological syndrome of polynuereitis as a functional defect concerned with the neurons. From 30 years of observation, I am certain that in Myasthenia Gravis and Multiple Sclerosis, it is not a functional defect, nor is it due to impaired diffusion which would deny to the total
metabolism sufficient quantities of the vitamin to satisfy the requirements of the neuro-muscular systems.

The problem is supply and demand. In this light, Dr. Leon Rosenberg of Yale University Medical School, in working with B vitamins, distinguishes between vitamin-deficiency diseases and vitamin-dependent diseases. He states that the successful treatment of vitamin-dependent diseases requires dosages up to 1,000 times the calculated minimal daily requirement. 1.3 mg. has been established for thiamin hydrochloride which would indicate that in the pathological conditions being considered, the daily requirement would be at least 1300 mg.

Moore, in 1940, published a monograph on the use of high intravenous doses of nicotinic acid for the cure of Multiple Sclerosis. Moore employed a drug combination called Nicobee. This preparation contained 100 mg. nicotinic acid and 60 mg. of thiamin in each 10cc solution. Many of the components of the B-complex must also be administered in varying amounts, along with thiamine hydrochloride, since they too exert a dynamic influence in general metabolism. Many believe that the B vitamins are actually metabolic reagents. Hoagland has referred to them as protective catalysts.

Note that the focus in many of Klenner’s articles is M.S. and M.G., and that while we have no direct evidence that this protocol is successful for M.E. patients, the Klenner protocol has been used in many other neurological diseases with success. The mention of enteroviral infections and the success of this protocol in treating patients with neurological diseases caused by this type of infection also has particular relevance to M.E. as M.E. is also a neurological disease caused by an enterovirus.

Advocates of the Klenner program today consider daily 400 mg vitamin B1 injections as an essential and non-negotiable part of the therapy and that all oral forms are inadequate and will not provide the same level of healing. Purely oral forms of the other vitamins however, seem to be an acceptable substitute.

B1 as sublingual coenzymated thiamine (TDP or TPP), benfotiamine or liposomal thiamine is the best choice for patients that cannot yet access vitamin B1 injections. High enough doses of these types of B1 may in fact have the same effect as 400 mg of thiamine injected daily. But as yet the research on the success of this substitution and how it should best be done has not been completed and so sticking with the daily injections is seen as the safest way to go.

TPP is a critical link between the glycolytic cycle and its main energy-producing cycle, the Krebs’ cycle, and plays key roles in the Krebs’ cycle itself. TPP participates in the conversion of amino acids into energy and is a key coenzyme in the pentose phosphate pathway, which provides red blood cells with their energy. TPP is also critical in fatty acid synthesis, synthesis of the key neurotransmitter acetylcholine, and for nerve cell membrane function (this is critically important since the nerves’ messages must pass along its cell membrane).
Thiamin diphosphate (TDP), also called thiamin pyrophosphate (TPP) or cocarboxylase, is the active, coenzyme form of vitamin B1. It is available in sublingual form as part of a B complex, and singly.

Benfotiamine (belonging to the family of compounds knows as "allithiamines") is more bioavailable and physiologically active than thiamin. Benfotiamine raises the blood level of TPP, the biologically active coenzyme of thiamine. Benfotiamine controls formation of advanced glycation end-products (AGEs) and helps maintain healthy cells in the presence of blood glucose. This synthetic form of vitamin B1 is fat soluble rather than water soluble. Dosage is usually 150 to 1000 mg daily.

The B vitamins have recently become available in a liposomal delivery system. A liposomal B complex product is now available from Livon Labs which contains decent amounts of vitamin B1. The product is called AGE blocker. The downside here is that the B vitamins are not available individually and so it may not be possible to get enough B1 without getting more than needed of the other B vitamins as well as the other nutrients included in the product. Liposomal delivery systems make nutrients very bio-available and so smaller amounts are needed than with oral forms.

The importance of the niacin flush
Taking enough of the flushing form of niacin 3-4 times daily to flush each time is recommended by some doctors. This includes Dr Klenner who includes it as an essential part of his protocol. This dilation of blood vessels helps get the nutrients you are taking to all the parts of the body and brain where they are needed. Dosage should begin at just 25 mg daily and be worked up very slowly. The flush should always be mild and last no longer than 10 minutes.

Dr Klenner writes,

We recommend whichever dose will produce a strong body flush. Niacin dilates the blood vessels, even those that have been compressed by scar tissue, allowing a greater amount of nutrient material to reach the cell laboratory or factor comprising muscles and nerves. This constant, repeated dilatation of the blood vessels acts in the same manner as the dilating urethral catheter to correct constriction. One is chemical, the other is mechanical. Hot fluids taken at the same time as the niacin will enhance the flush. Pyridoxine has been a suggested stimulant. The lack of constant flushing in Multiple Sclerosis is disappointing but not hopeless. It will require a longer time to achieve results.

Some patients will flush sometimes and not at other times, even during a single day. If no flush develops within 45 minutes, the dose should be repeated. A delayed reaction of several hours can occur, and should this be superimposed upon a previous medication, the result could be severe. Do not scratch when itching from niacin. Just press the area with your fingers, or better still, with a cube of ice.
The importance of liver extract injections
Advocates of the Klenner program today consider twice-weekly liver injections as an essential and non-negotiable part of the therapy. Liver contains vitamin B12, iron and vitamins A and D. Dr Klenner explains that liver also, ‘Contains factors still unknown but essential in metabolism.’

Eating some fresh cooked organic grass-fed calf or beef liver each day, or taking a tablespoon or more of a wholefood liver power (placed on the tongue and swallowed quickly with water while holding your nose) or liver extract capsules is recommended for patients that cannot yet access these types of injections. The advantage of the freshly cooked whole liver and liver wholefood powers is that they are not defatted, as are many encapsulated liver products. This means that they still contain all the original fat soluble vitamins such as vitamin A and D.

Taking some CoQ10 daily is also considered a partial-substitute for large amounts of liver products, according to the Gerson protocol.

The importance of vitamin C
The vitamin C taken daily on this program is very important. Dr Klenner inspired Linus Pauling and Irwin Stone to expand the research on the great benefits of Vitamin C.

Taking B vitamins in activated and/or sublingual forms
In order for B vitamins to be utilized by the body, they must first be converted into their active coenzyme forms by the liver. This conversion takes time and requires metabolic energy, which may be in short supply in M.E.

Where there are problems converting one or more of the B vitamins into their active coenzyme forms by the liver coenzymated sublingual B vitamins will be by far the best choice of B supplement. In studies with chronic alcoholics (a group at high risk of poor liver function) large doses of B vitamins were given by IV. Normally, the administration of these IVs would raise the body’s coenzyme levels, but in the case of liver-impaired alcoholics, it did not. This shows that a compromised liver may not be able to Coenzymate vitamins optimally. Thus when a person cannot convert B vitamins properly, even injections or IVs of non-coenzymated vitamins will have little or no effect. So for some people, the optimum way to take in B vitamins is not by IV or IM but through coenzymated products.

Coenzyme forms of vitamins are biologically identical to those used by the body, making them highly bioavailable, especially when they are also in a sublingual form. Sublingual tablets are absorbed rapidly into the highly capillarised tissues found in the cheeks and under the tongue and enter the bloodstream intact, without the risk of being degraded or diminished by the digestive system. Taking coenzymate and sublingual forms of B vitamins also conserves valuable metabolic energy and reduces
the load on the (probably very overworked already) liver. Vitamins taken in this form will also be faster acting.

Smaller doses are needed when the coenzymate forms of vitamins are taken and when nutrients are taken sublingually, as compared to taking standard oral forms of a vitamin.

**How long should this program be continued**

Benefits may be lost if this treatment is stopped too soon and so it should be continued as long as is necessary. A more scaled down program may be necessary life-long once the intensive program is completed.

Dr Klenner notes that ‘Early M.S. cases will respond quickly’ and cites examples where the protocol has taken 2 weeks to work in some early cases, and 5 - 10 years of constant treatment to be effective in longer-term cases. One paper makes the statement that it may take a year of treatment for every two years spent ill with M.S. for the full benefits of treatment to be seen. (He also notes that a cut-down version of his treatment protocol may also work but that it may take much longer and not be effective in some cases.)

Patients often report seeing noticeable improvements in their condition within 1 – 6 months of starting the vitamin B1 injections.

For the duration of the full treatment, vitamin C should be kept at 10 – 20 grams daily or at saturation level.

**Are there other somewhat similar programs or regimes?**

Myers’ cocktail therapy is similar in some ways to the Klenner protocol. Both focus primarily on the B vitamins but the Myer’s cocktail regime does not include injections of liver extract nor high levels of vitamin A and E.

A ‘Myers’ cocktail’ is an IV containing B vitamins, magnesium and calcium in particular amounts. This IV may be taken once or twice weekly or more (along with daily B vitamins and other basic supplements given orally each day). This treatment must be administered by an experienced and qualified practitioner. For more information on this treatment and instructions for doctors on how to make the IV, see the excellent article: Intravenous nutrient therapy: the "Myers' cocktail" by IV vitamin expert Alan R. Gaby. He explains,

All ingredients are drawn into one syringe, and 8-20 mL of sterile water (occasionally more) is added to reduce the hypertonicity of the solution. After gently mixing by turning the syringe a few times, the solution is administered slowly, usually over a period of 5-15 minutes (depending on the doses of minerals used and on individual tolerance), through a 25G butterfly needle. Occasionally, smaller or larger doses than those listed in Table 1 have been used. Low doses are
often given to elderly or frail patients, and to those with hypotension. Doses for children are lower than those listed, and are reduced roughly in proportion to body weight. The most commonly used regimen has been 4 mL magnesium, 2 mL calcium, 1 mL each of B12 (as hydroxycobalamin), B6, B5, and B complex, 6 mL vitamin C, and 8 mL sterile water.

As the Myers’ cocktail only contains a relatively small amount of vitamin C, full-strength vitamin C IVs may also be given, perhaps on alternate days.

The Gerson juicing program for cancer and degenerative diseases is similar in some ways to the Klenner protocol, although there are far more differences than similarities. Both consider regular flushing with niacin and injections of liver extract given twice weekly or more as essential to the success of the therapy, and both therapies recommend regular injections of vitamin B12. The differences between the programs are many however. The Gerson program recommends a very low-protein diet, while the Klenner protocol involves a high-protein diet. The Gerson program recommends that very few supplements be taken and places a very large focus on diet (and hourly vegetable juicing), while the Klenner protocol involves large amounts of many different types of supplements and only gives basic dietary advice. The Gerson program recommends only small doses of vitamin C, while the Klenner protocol involves a high dose of vitamin C, and so on.

Both of these programs may also have something to offer the M.E. patient, whether followed in part or more faithfully. Reading up on both of them is highly recommended.

An important note on the Gerson Protocol: I have some serious reservations about the Gerson Protocol being used for M.E. and question whether:

(a) A very low fat, salt and protein diet is appropriate for M.E. patients for a period of months let alone for 2 years or more. (This goes against the evidence presented by a huge number of reputable health experts and also the evidence of a vast number of M.E. patients and patients with other neurological or mitochondrial diseases that find they feel very unwell if they don’t have a reasonably high protein intake.)
(b) An 80% raw foods diet is appropriate considering that most M.E. patients have poor digestion caused by poor blood flow to the stomach which can make eating even a small amount of raw food very painful. This would be counter-productive as well, as little would be absorbed.
(c) The direction to avoid so many other important supplements is the best thing for M.E. patients.
(d) Any moderately-severely M.E. affected patient would be well enough to do all the enemas and have the hourly juices required (even if they could afford the full program financially, which is also a big ask) without relapse.

While parts of the program (including upping vegetable and vegetable juice intake daily and supplementing with some of the B vitamins and with liver) make a lot of
sense and are mentioned here, this should not necessarily be taken as a recommendation of the full program for M.E. patients.

**Finding a doctor that can administer the Klenner protocol**
Finding a doctor that is knowledgeable about M.E. specifically is extremely difficult. However, finding a doctor that can safely administer nutrients by injection or IV and that is experienced in treating diseases similar to M.E. (such as MS or Lupus etc.) is far less difficult. Use the phone book or the internet to ask various qualified holistic, environmental, or orthomolecular medicine practitioners near you if they offer this therapy and if they are experienced in providing it.

If possible, find an expert in one of these fields (or more than one these fields) that is also a qualified doctor so that you can also have any tests you may need. For more information see: Finding a good doctor when you have M.E.

**Cautions and other notes on this treatment**
Occasionally, high-dose B vitamins may interfere with sleep. If you have trouble getting to sleep at night, try taking your B vitamins as early in the evening as possible and see if this helps.

Betaine trimethylglycine (betaine TMG or TMG) may be included in some B complex formulas. Such products may be best avoided as TMG is often very poorly tolerated in M.E. and can cause severe relapse while the supplement is taken and for a week or so afterwards. If well tolerated however, TMG is a beneficial supplement as it aids in the process of methylation. TMG is probably best taken alone to start with, at very small doses of just 100 - 200 mg.

Dr Atkins warns that women who need to shrink uterine fibroids, or prevent breast cancer recurrences, or deal with endometriosis or fibrocystic breasts should limit supplemental folate to 600 mcg daily.

The Klenner protocol is very low risk, and so the risk to benefit ratio is good. The doses may have to be raised far more slowly in M.E. due to severe supplement tolerance issues, however, and each supplement will be better off being introduced individually rather than all at once.

Vitamin B1 given by injection can very occasionally cause an anaphylactic reaction and so injections should always be started at a very low dose. Dr Klenner comments that while this reaction can occur, he has not seen it occur once in all the thousands of patients he treated.

B vitamins given by IV or IM should be given by medical practitioners that have considerable experience in this area. Note that the vitamin B3 injections once recommended by Klenner may cause problems in some patients and so are no longer
recommended. Preservative-free injectable vitamins should be used if at all possible as patients may sometimes react badly to these preservatives.

The information given in this paper is a very cut-down summary of Klenner’s recommendations ONLY. It does not include the various cautions and additional details that are so important to effective and safe treatment. Please read the papers listed below before starting this program.

This paper should be read together with the papers The B vitamins and M.E. and High-dose vitamin C and M.E.

Klenner protocol references and additional reading:

- Clinical Guide to the Use of Vitamin C The Clinical Experiences of Frederick R. Klenner, M.D. and Response of Peripheral and Central Nerve Pathology to Mega-Doses of the Vitamin B-Complex and Other Metabolites by Dr Klenner.
- The Klenner Protocol for MS article by Dr Klenner. In this two-part series Klenner defines an orthomolecular treatment of MS that has been effectively employed by Dale Humpherys and other patients. (For Humpherys' report, see his article in the December 2005 issue of the Townsend Letter.)
- My Multiple Sclerosis: A Real Story presented by Homer. For more information on following the Klenner protocol for MS, including case studies and detailed practical information on the nutrients involved and where to source them, plus links to some of the Klenner protocol doctors accepting patients around the world, this site is highly recommended. See also: Begin the Klenner protocol and Liver Extract Rocks!
- Multiple Sclerosis a cure in search of doctors, Dr. F.R. Klenner’s Protocol for MS, The true story of FDA terrorism, MS is not “hopeless” and Update on Dr. Klenner’s treatment for MS by Dale Humpherys in the Townsend Newsletter.
- The Benefits of Liver, Cod Liver Oil, and Dessicated Liver by Chris Masterjohn
- Calf’s liver information by WH Foods.
- Beef liver information by Nutrition Data.
- Fire your doctor! : how to be independently healthy by Andrew W. Saul.
- Dr Atkins Vita-Nutrient Solution: Nature's Answer to Drugs by Dr Atkins
- Dietary Healing & Detoxification: A simple reference guide for those with chronic degenerative disease or cancer choosing the Gerson Therapy by Kathryn Alexander.
- Healing the Gerson Way: Defeating Cancer and Other Chronic Diseases by C. Gerson and B. Bishop.
- The Gerson Therapy: The Amazing Juicing Programme for Cancer and Other Illnesses by Charlotte Gerson and Morton Walker
Additional B vitamin references are available in the paper: The B vitamins and M.E. This paper on the work of Dr Klenner is designed to be read together with the B vitamin paper.

Relevant quotes
“A native of Pennsylvania, Dr. Klenner attended St. Vincent and St. Francis Colleges, where he received his BS and MS degrees in Biology. He graduated magna cum laude and was awarded a teaching fellowship there. He was also awarded the college medal for scholastic philosophy. There followed another teaching fellowship in Chemistry at Catholic University, where he pursued studies for a doctorate in Physiology. Dr. Klenner then migrated to North Carolina and Duke University to continue his studies. Taken in tow by Dr. Pearse, chairman of the department, he was finally persuaded to enter the school of medicine. He completed his studies at Duke University and received his medical degree in 1936. Dr. Klenner served three years in post-graduate hospital training before embarking on a private practice. Although specializing in diseases of the chest, he continued to do General Practice because of the opportunities it afforded for observations in medicine. His patients were as enthusiastic as he in playing guinea pigs to study the action of ascorbic acid. The first massive doses of ascorbic acid he gave to himself. Each time something new appeared on the horizon, he took the same amount of ascorbic acid to study its effects so as to come up with the answers. Dr. Klenner’s list of honours and professional affiliations is tremendous. He is listed in various Who’s Who registers, and has published many scientific papers throughout his career. Dr. Klenner is a Fellow: The American College of Chest Physicians; Fellow & Diplomate: The International College of Applied Nutrition; Fellow: The American Association for the Advancement of Science; Fellow: The American College of Angiology; Fellow: The American Academy of Family Practice; Fellow: The Royal Society of Health (London); Fellow (Honorary): The International Academy of Preventive and Orthomolecular Medicine; Fellow: International College of Angiology; and Founder-Fellow: American Geriatrics Society.” Response of Peripheral and Central Nerve Pathology to Mega-Doses of the Vitamin B-Complex and Other Metabolites

This treatment works dramatically in M.G. An abbreviated schedule can be effective. One gram thiamin four times a day, niacin, enough to produce a flush four times a day, 200 mg calcium pantothenate four times a day, 100 mg pyridoxine four times a day, 10 grams of C in divided doses, glycine one tablet four times a day. This treatment is effective, but the full therapy will afford more dramatic response. Dr. Klenner felt that most cases (80%) of Multiple Sclerosis had their origin in an illness—probably a coxsackie virus—compatible with a summer “flu”. He mentioned other theories of the etiology of M.S., but was convinced that the scar tissue that forms around the nerves and produces the symptoms “is the end result of microscopic hemorrhages following virus invasion.” He believed that in M.G. the thymus gland was hyperplastic in many cases, and that muscle antibodies might account for others, but the importance of the excessive pyruvates at the neuromuscular junction has to be recognized as the basic cause of the hypotonia. Frederick Klenner M.D. comments abbreviated, summarized and annotated by Lendon H. Smith, M.D.
“Coenzyme A (COA, the active form of pantothenic acid) is in limited supply in M.G. It, COA, intercepts pyruvic acid at the end point of glucose metabolism. Another enzyme, cocarboxylase, splits the carboxyl group (COOH) away from pyruvic acid to form CO₂ and free hydrogen. The remaining two carbon fragment (acetate) join with coenzyme A to form acetyl coenzyme A. A high energy package named NADH₂ is formed from the carboxyl group from pyruvic acid and a sulfur group from coenzyme A.

Thiamin is important in all this energy production as two molecules of thiamin combined with two molecules of phosphoric acid become cocarboxylase. This enzyme must be present for the continuance of the metabolic cycle. When thiamin is deficient, pyruvates and lactate accumulate, and at the neuromuscular junction the nerve end plate becomes swollen and poorly operative. That same enzyme is necessary for the syntheses of acetylcholine, the neurotransmitter that initiates muscle contraction. “Thiamin deficiency inhibits lactic acid metabolism.” A thiamin deficiency means a cocarboxylase deficiency. Liver enzymes are mainly responsible for the phosphorylation of thiamin to cocarboxylase. Liver disease would obviously reduce this synthesis. “The activity of choline esterase (breaks down acetylcholine) is inhibited by this same double thiamin unit.”

In the conversion of fatty acids to energy some of the same enzymes are necessary: coenzyme A, hydrogen carriers (niacin-adenosine-dinucleotide) and Vitamin C. The latter acts as a hydrogen transport.

He puts Myasthenia Gravis and Multiple Sclerosis in the same therapeutic group as he found thiamin was the key to the therapy. M.G. is a genetically transmitted disease and M.S. is triggered by a virus and mimics poliomyelitis. Nerve damage in M.S. is due to microscopic hemorrhages in the nervous system. During healing, scar tissue contracts clamping off capillary flow and nutrition. This wasting results in loss of the myelin sheath protection.

He felt that remyelinating these damaged nerves was every bit as hopeful as the myelination that occurs normally in infancy with nothing more spectacular than breast milk. It requires two years of treatment to repair the damage caused by one year of the disease.

He cites works in the late 1930s by Stern at Columbia University who used thiamin intraspinally for the treatment of Multiple Sclerosis with astonishing results. After 30 mg of thiamin was injected into the spinal canal of paralyzed MS. victims, they had a temporary remission. They could walk for a while. And Stern felt it was a B₁ avitaminosis. It was known at that time that polyneuritis can cause degeneration of myelin sheaths.” Frederick Klenner M.D. (comments abbreviated, summarized and annotated by Lendon H. Smith, M.D.)

Disclaimer: HFME does not dispense medical advice or recommend treatment, and assumes no responsibility for treatments undertaken by visitors to the site. It is a resource providing information for education, research and advocacy only. In no way does reading this site replace the need for an evaluation of your entire health history from a physician. Please consult your own health-care provider regarding any medical issues relating to the diagnosis or treatment of any medical condition.
High dose vitamin C is one of the most useful and widely-used treatments for M.E.

Vitamin C in an appropriate dose:

1. is a powerful antioxidant (and also helps recycle other antioxidants),
2. is anti-carcinogenic (reduces the risk of developing various cancers),
3. supports the immune system by improving the host response to disease (making the body more able to fight off any secondary infections) and improving the function of white blood cells,
4. can stop recurrent boils (furunculosis) (people with this condition may have defects in white blood cell function that are correctable with vitamin C supplementation),
5. has antiviral and antibacterial effects (it controls and maintains phagocytosis),
6. supports the adrenal glands (and supporting the adrenals also supports the thyroid),
7. supports the cardiac/cardiovascular system and assists in the maintenance of peripheral circulation (including improving the blood flow to the brain) and maintaining capillaries,
8. is a natural chelator and helps to remove heavy metals and other toxins from the body (this improved detoxification may markedly improve your tolerance of pollution and toxic chemicals),
9. safeguards the body from the effects of high blood sugar (glycation) and helps to normalise blood sugar and improve hypoglycaemia. Vitamin C is important in the digestion of food, the biochemistry of the body's utilization of carbohydrates, proteins, and fats and it has a pronounced activating effect on insulin,
10. reduces the severity of colds, flu’s, and Candida infections,
11. has an antihistamine effect and can reduce or prevent symptoms of hayfever and food allergy,
12. can prevent asthma attacks (and possibly some SIDS deaths),
13. helps to reduce the toxic load of metabolised fat which occurs during weight loss, and helps support the liver during weight loss,
14. acts as an electron donor for eight different enzymes,
15. aids in the formation of liver bile,
16. may have an antidepressant effect and help the body handle emotional stress better,
17. counteracts some of the damaging effects of aspirin and heighten its pain killing effect, and also acts as an pain reliever in its own right (at bowel tolerance doses),
18. increases the therapeutic effect of different drugs and medicines by making them more effective (less of a drug is required if it is taken in combination with large amounts of ascorbic acid),
19. can help improve joint mobility (if serum levels of C are high, synovial fluid is thinner allowing for easier joint movement) and reduce inflammation and fever,
20. helps with connective tissue repair (especially collagen) and maintaining healthy teeth and bones (high dose vitamin C can help reduce tooth loss and cavities),
21. helps promote wound healing,
22. promotes eye health in many different ways (prevents cataracts, glaucoma etc.),
23. helps to produce the neurotransmitters serotonin and norepinephrine,
24. can cause sensations of overwhelming physical wellbeing,
25. is essential to the proper functioning of the central nervous system.

What effects can high dose vitamin C have?
Some doctors claim vitamin C taken at a very high dose can greatly affect the course of a disease or even be curative if taken in very early stages where the virus infection is still active and there is little long term bodily damage caused yet. For those who have not been ill with M.E. for very long, this treatment should be seriously considered and may be of great benefit or even curative, and the only risk (when the dose is raised slowly) is temporary mild gastric upset. It’s hard to find any reason why this treatment should not be strongly recommended, or even mandatory, for anyone in the acute early stages of M.E.

Some long-term M.E. patients report significant improvements with very high dose vitamin C treatment also. It can cause feelings of intense physical wellbeing and improvements in many different neurological, cardiac and other symptoms. In addition to improvements in the condition generally, high dose vitamin C is also worth considering in M.E. due to its ability to help fight off secondary infections and reduce cancer risk and chemical sensitivities. Again, it’s very hard to find any reason why this treatment should not be strongly recommended, or even mandatory, for
anyone with long-term M.E. There is much potential for benefit and the only risk (when the dose is raised slowly) is temporary mild gastric upset.

Another significant benefit of high dose vitamin C is it may be a useful treatment for many conditions misdiagnosed as M.E. or given a meaningless ‘CFS’ misdiagnosis. So it is still one to try where the diagnosis of M.E. is not 100% certain, or if all a person has as yet is a bogus ‘CFS’ diagnosis, while the search for a correct diagnosis continues. (Diseases which may benefit from high dose vitamin C include Lupus, MS, Lyme disease, post-viral fatigue syndromes, glandular fever/mononucleosis, Candida, sick building syndrome, MCSS, hepatitis and cancer. Dr Levy discusses 3 days of IVC being able to cause a complete resolution of symptoms in post-viral fatigue syndromes caused by glandular fever/mononucleosis.)

Vitamin C is involved in almost every bodily process and helps our bodies maintain homeostasis. Irwin Stone explains in his book on vitamin C that,

Throughout the evolution of the vertebrates, including the mammals, Nature has used ascorbic acid to maintain physiological homeostasis. In simple nontechnical terms, this means that when stressful situations arose which disturbed the biochemical equilibrium of the animal, ascorbic acid was produced in increased quantities to get things running normal again. The amount of ascorbic acid produced is related to the severity of the stresses and if enough was produced soon enough, then the animal was able to survive the bad biochemical effects of the stresses. If, however, the enzyme system for producing ascorbic acid was overwhelmed or poisoned by the stresses and too little ascorbic acid was produced, then the animal succumbed. Man, unable to produce his own ascorbic acid, could not take advantage of this natural protective process. Instead stresses only further depleted his low stores of this vital metabolite. Now he can easily duplicate this time-tested defensive mechanism by reaching for the bottle of ascorbic acid and swallowing additional quantities whenever he is subjected to biochemical stresses. In duplicating this normal process for combating stresses, man has one great advantage over the other mammals -- he can get an unlimited supply of ascorbic acid without being dependent upon an enzyme system which may not produce enough, quickly enough. All man needs to know is how much to take.

One of the outstanding attributes of ascorbic acid is its lack of toxicity even when given in large doses over long periods of time. This has been recognized since the 1930s, and ascorbic acid can be rated as one of the least toxic substances known of comparable physiological activity. It can be administered in huge doses, intravenously, without registering any serious side effects.

High dose vitamin C is not any type of miracle cure for chronic M.E., and no promises can be made about outcomes; that treatment a, b and c together will always give you outcome d. The aim here is to give your body its best possible chance to at least partly heal itself by giving it some of the basic tools and materials it needs to heal itself.
What is the best dosage?

Daily dosage recommendations given for vitamin C in M.E. and other serious diseases vary widely. Failure to benefit from Vitamin C use is usually due to inadequate amounts being used for too short a period of time, say vitamin C experts. These same experts state that there is no syndrome or disease which cannot benefit significantly from the right amount of high dose vitamin C. Quantity, frequency and duration are the key.

Conservative approach: For proponents of high dose vitamin C, a very conservative dose for serious illness would be 6 to 10 grams daily taken orally and broken up into two, three or four hourly doses. (A dose of 3 to 5 g daily is the conservative daily recommendation for healthy people to help maintain health, although some experts recommend 15 g daily for basic health maintenance.)

Note that it may take a dose of 10 – 15 g until noticeable benefits from vitamin C therapy are felt in M.E. such as improvements in chemical tolerance and overall wellbeing. Lack of benefit at doses much lower than this should not be taken as an indication that high dose vitamin C would be ineffective.

Moderate approach: Many proponents of high dose vitamin C recommend that vitamin C be taken orally to bowel tolerance in serious illness. This dose varies from person to personal and generally speaking those who are more severely ill often can tolerate a higher dose. Dosage in M.E. may vary from perhaps 15 to 50 g (or even 100 g) daily, taken in divided doses every hour or every two or three hours with extra taken just before bedtime. Vitamin C has an active life of only 3 – 4 hours once ingested. There are no large storage depots for ascorbic acid in the body and any excess is rapidly excreted. (Figures are never given for M.E. specifically of course, but these amounts are comparable to those recommended for AIDS, MS and active enteroviral infections such as Coxsackie.)

Vitamin C by IV is vastly more effective, but of course IVs are not always possible or practical and not all patients can afford liposomal vitamin C. Most vitamin C experts prefer to administer vitamin C by IV or liposomal vitamin C, but do add that oral vitamin C can also have significant benefits at high doses when taken regularly for a significant period of time.

Dedicated approach: Liposomal vitamin C is less expensive and easier to take than vitamin C by IV, and preliminary evidence shows that this form of vitamin C may be taken up intracellularly even more effectively than vitamin C given IV. This form of vitamin C avoids the gastic upset of standard vitamin C supplements. The usual dosage is 2 – 6 (1 g) sachets daily, taken in divided doses.

Very dedicated approach; Many proponents of high dose vitamin C recommend that vitamin C be taken intravenously (or sometimes intramuscularly) to bowel tolerance in serious illness. Often taking additional vitamin C orally to bowel tolerance, is also recommended. Taking 2 – 6 sachets of liposomal vitamin C 10
minutes before the IV may also greatly increase intracellular uptake of vitamin C from the IV.

Patients and doctors may wish to first try 4 – 6 sachets of liposomal vitamin C daily, before trying vitamin C IVs or a combined liposomal vitamin C and vitamin C IV regimen.

Vitamin C IV dosage is usually 25 – 50 g or up to 150 g daily, or perhaps higher in acute stages of the disease. IVs may be given 1-3 times weekly (and may also contain B complex vitamins to form a ‘Myers’ Cocktail’). Taking high dose vitamin C via IV will produce far more pronounced effects than taking it orally, and the amount able to be given without causing gastric problems will be much higher. This approach is necessary most of all where there patient is still in the acute early stage of the infection but it can also provide an extra benefit for long-term patients as well.

Whichever dose is taken, note that it is very important in M.E. that this dose is worked up to gradually.

What does ‘to bowel tolerance’ mean, and why is this recommended?
The amount of ascorbic acid which can be taken orally without causing temporary stomach rumbling, excessive gas, or diarrhoea when a person is ill sometimes is over ten times the amount they would tolerate if well. The increased tolerance is somewhat proportional to the toxicity of the disease being treated (although of course there are exceptions where healthy people can tolerate high amounts and very ill people who are unable to take even small amounts). The theory is that gastric problems only occur when a person is given more vitamin C than they need. It is only that excess amount of ascorbate not absorbed into the body which causes diarrhoea; what does not reach the rectum, does not cause diarrhoea. Thus diarrhoea is not just a troublesome side-effect to be managed, but a useful short-term symptom which helps you measure how much vitamin C your body needs at any one time.

Dr Robert F. Cathcart states that,

Over the past ten-year period I have treated over 9,000 patients with large doses of vitamin C. The effects of this substance when used in adequate amounts markedly alters the course of many diseases. Stressful conditions of any kind greatly increase utilization of vitamin C. Ascorbate excreted in the urine drops markedly with stresses of any magnitude unless vitamin C is provided in large amounts. However, a more convenient and clinically useful measure of ascorbate need and presumably utilization is the BOWEL TOLERANCE. The amount of ascorbic acid which can be taken orally without causing diarrhea when a person is ill sometimes is over ten times the amount he would tolerate if well. This increased bowel tolerance phenomenon serves not only to indicate the amount which should be taken but indicates the unsuspected and astonishing magnitude of the potential use that the body has for ascorbate under stressful conditions.
How does one titrate vitamin C to bowel tolerance?

To titrate oral vitamin C to bowel tolerance start by taking just 1 g of vitamin C daily every day for a week. If there are no problems, increase this to 2 g every day for the next week, and so on, until you either reach bowel tolerance (or the dose you have decided to stop at), or you get close to the 15 g mark. If you have reached 15 g daily, have no problems and want to keep going until you find your bowel tolerance dose, you may then like to start adding an extra gram of vitamin C every day instead of every week.

Remember to always space out the doses during each day as much as you can. If you experience any problems, cut back your dose slightly and stop raising the dose until they resolve.

When increasing your dose over time, at some point mild stomach rumbling, excessive gas, bowel pressure or diarrhoea will occur. Experts say the amount of vitamin C your body needs is somewhere between 80 and 90% of the amount that causes gastric upset. When the right amount of vitamin C has been found, there will be no gas etc. (if there is, too high a dose is being taken and the dose should be cut back by 10% or 20%).

The aim is to take the dose just below what would cause diarrhoea. Vitamin C experts state that to achieve the best results, it is absolutely necessary that high dose vitamin C IVs be given or oral vitamin C very close to bowel tolerance.

Again, it is important that vitamin C at high doses is taken in as many divided doses as possible. If you were taking 15 g of C daily for example, you would have to break this up into at the very least 5 equal doses, taking a 3 g dose every 3 hours or so. Larger doses taken all at once may cause gas that would be avoided if instead smaller doses were taken more often. See ‘The high-dose vitamin C checklist for M.E. patients’ below for more information.

Note that while generally speaking, the more ill you are the more vitamin C your body needs and can use, Linus Pauling explains that it is also true that biochemical individuality also affects how much vitamin C you need. Some people need far more vitamin C than average, while others can take much less and still get the same effect. Thus a dose of 2 g daily may be enough for one healthy person to avoid most colds and flu, while another (also healthy) person may need 10 g daily to get the same effect. This is why titrating to bowel tolerance is recommended, rather than just set amounts for each disease being given. You need as much vitamin C as it takes for your body to get the job done, no more and no less.

The importance of raising the dose gradually

Irwin Stone explains in his book on vitamin C that:
Even though ascorbic acid is rated as one of the least toxic materials, man has been exposed to such low levels of it for so long that suddenly taking comparatively large amounts, orally, may provoke side reactions in a small percentage of certain hypersensitive individuals. Ascorbic acid in the mammals is normally produced in the liver and then poured directly into the bloodstream. This completely avoids the digestive tract, which is normally the route for man.

Evidence for these side reactions may be the appearance of gastric distress, vomiting, diarrhea, headache, or skin rashes, all of which disappear on reducing or eliminating the ascorbic acid. Tests should be conducted on these hypersensitive individuals to determine whether their symptoms can be avoided or controlled by substituting the non-acidic sodium ascorbate, by taking the doses with meals, or by gradually building up to the required dosage instead of initially prescribing and starting with the full dosage. In many cases, an initial intolerance to ascorbic acid disappears.

Many vitamin C experts recommend patient start immediately with high dose IVs, but in M.E. this will often cause relapse – a relapse that could be avoided if instead the patient was allowed to gradually increase their vitamin C intake one extra gram weekly or daily or less, and only given vitamin C by IV when they had built up an appropriate tolerance for such a high dose. (Remember that oral vitamin C is less well absorbed than vitamin C by IV. Before taking 10 g of vitamin C by IV, see if you can get up to 20 g C daily orally first.)

Note that vitamin C dosage should be built up gradually, and the same is also true for lowering the dose of vitamin C, to avoid any minor problems.

Vitamin C can often be taken in very high doses by M.E. patients, if this dose is worked up to slowly, it seems many M.E. patients bodies need high levels of this vitamin and benefit significantly from it. Going very, very slowly should prevent herxheimer reactions, rashes, night-sweats and so on (symptoms which mean the C is doing what it should and your body is working to heal itself and is detoxing etc.) The Herxheimer reaction is an excretion of toxins from dying organisms (eg. Candida), sometimes called a ‘die off’ reaction. A detox bath may possibly help minimise these herxheimer symptoms (feeling unwell, headaches or nausea or flu-like symptoms), but most important is to cut the dose right back and go VERY slowly – but don’t give up.

Unfortunately, however, a very, very small percentage of M.E. patients can possibly only tolerate low doses, and cannot take more than 2g of C daily without small sores appearing in the mouth. (Dr Cathcart comments: ‘A few patients complaining of small sores in the mouth with taking of small doses of ascorbate had them clear with bowel tolerance doses.’) Experts comment that a true vitamin C allergy does not occur.

Even at high doses vitamin C is very safe, please read the extra information links provided for more information on problems which may occur, however, albeit rarely. Claims that high dose C causes kidney stones or problems absorbing B12 are a myth.
Serious illness creates an increased need for vitamin C. Even when supplements of vitamin C are taken well above the RDA, in some cases scurvy (an acute vitamin C deficiency disease) can still occur. Fatigue, easy bruising, and bleeding gums are early signs of vitamin C deficiency that occur long before actual scurvy develops. Vitamin C supplementation is also essential for those that smoke, drink alcohol or take steroids, antidepressants or the pill.

Elderly patients may have more problems tolerating high oral doses, but may be able to tolerate IV vitamin C well. Infants, children and teenagers will often tolerate far more vitamin C orally or by IV, proportional to their body weight, than adults. Vitamin C is said to be one of the safest substances you can ingest.

How does one work out the maintenance dose of vitamin C?
Vitamin C is one of those supplements where continued use is needed to maintain the effect. If there is a benefit from high dose oral vitamin C to bowel tolerance, after several months cut back the dose slowly day by day and observe the effect. The aim is to take the lowest dose possible that still gives you the desired effect. There is no point in taking far more than is needed. This maintenance dose may be much less than the initial ‘bowel tolerance’ dose. Those that wish to stay on a ‘bowel tolerance’ dose will find that the body’s tolerance to vitamin C increases over time.

Taking more vitamin C on those days the body is coping with more stress (cold weather, surgery, overexertion etc.) may be helpful, and it may also be helpful to immediately raise the dose as high as can be tolerated at the first signs of a cold or flu.

High dose vitamin C can interfere with local anaesthetic injections, so vitamin C should be avoided the morning of the dentist visit and resumed immediately after the appointment.

Note that while many effects of high dose vitamin C will be seen immediately, some benefits (such as the antihistamine effect) may take 2 to 3 weeks, or somewhat longer, to become fully apparent.

Which form of vitamin C should one take orally?
Generally speaking, the form of vitamin C recommended to take orally is plain ascorbic acid.

(Ester Cs and ascorbyl palmitate are not more effective than plain ascorbic acid, according to recent books on high dose vitamin C. Nor are ‘natural’ sources of C.)

The Vitamin C Foundation explains that not all forms of vitamin C are created equal. The form of vitamin C taken by the late Nobelist Linus Pauling was ascorbic acid. Pauling took his ascorbic acid in water and he added some bicarbonate (baking) soda
to make a buffered, more alkaline and effervescent pleasant tasting drink. (It is recommended that you wait for the drink to stop fizzing before you drink it.)

Robert Cathcart MD explains that mineral ascorbates may not be as effective,

I noticed that it was not entirely clear that the dramatic effects are always with ascorbic acid orally and sodium ascorbate intravenously. I have not been able to achieve the ascorbate effect with mineral ascorbates orally. Mineral ascorbates are fine forms of vitamin C but when you are really sick, the mitochondria are failing in their refueling of the free radical scavengers with electrons. The ascorbic acid carries 2 extra electrons per molecule where the mineral ascorbates seem to carry only one (plus per molecule the mineral ascorbates are heavier due to the mineral weighing more than the hydrogen the mineral replaces). So the mineral ascorbates are not potent enough to accomplish the ascorbate effect. There may be other reasons that we do not appreciate additionally.

Ascorbic acid (hydrogen ascorbate) is the form of vitamin C made in the livers (or kidneys) of most animals. This form is highly reactive and biologically active. While the vast majority of vitamin C experts recommend that only pure ascorbic acid be taken orally and warn that buffered forms are not as effective, a small number of experts do not make this same distinction and do recommend the buffered varieties. According to vitamin C expert Robert Cathcart MD, however, twice as much of any other form of the vitamin than ascorbic acid is required to achieve therapeutic results when taken by mouth.

Taking pure ascorbic acid can upset the stomach of M.E. patients, however. Ascorbic acid tablets or capsules may be a better choice where the taste of ascorbic acid in water is intolerable but there are no problems once it reaches the stomach. These forms also protect tooth enamel.

For those that cannot tolerate plain ascorbic acid, adding bicarb soda is probably the easiest way to buffer the solution. The Vitamin C Foundation explains that the total mass of sodium bicarbonate in the blood of an adult human is typically around 10 g. Any excess sodium bicarbonate is excreted by the kidneys. Dissolving ascorbic acid and sodium bicarbonate in water yields a solution of sodium ascorbate and carbonic acid, which releases carbon dioxide into the water. (So you have sodium ascorbate in seltzer water.) Sodium ascorbate has been administered intravenously in doses up to 50 g, without adverse affects. When bicarb soda is taken with ascorbic acid in the correct ratio, this mixture does not upset the pH of the blood. This is why it is important not to take more bicarb soda than is needed to neutralise the ascorbic acid. For every 1 teaspoon of ascorbic acid, roughly ½ a teaspoon of bicarb soda should be added. That is a 2:1 ratio, by mass. Sodium ascorbate is well tolerated because the sodium ion is plentiful in the bloodstream, more so than magnesium or calcium ions, for example.

Vitamin C expert Dr Thomas Levy explained in his article The Many Faces of Vitamin C, that:
Sodium ascorbate is probably the best and certainly the least expensive of the mineral ascorbates for regular supplementation at relatively high doses (six grams or more daily). Many doctors and patients fear the regular dosing of sodium, however, due to the long-standing medical admonition to minimize sodium intake, especially for hypertension and cardiac failure patients. Indeed, sodium chloride (table salt) has long been known to facilitate fluid retention (increased plasma volume), a state that directly aggravates hypertension and heart failure. However, it appears that only sodium really results in significant fluid retention when administered with the chloride anion. Sodium when given with the anions citrate, ascorbate, or bicarbonate does not appear to adversely affect hypertension or to increase blood volume.

Because of these findings, it has been directly suggested that the concept of "sodium-dependent" hypertension should be changed to "sodium chloride-dependent" hypertension (Kurtz and Morris, 1983; Kurtz et al., 1987). Anecdotally, I have never found multi-gram doses of sodium ascorbate to adversely affect blood pressure or blood volume status. However, since there always appear to be exceptions to every rule in biology, anyone who notices elevated blood pressures or ankle edema after high doses of sodium ascorbate would probably be well-advised to supplement with a different form of vitamin C.

Buffered powders of vitamin C may well not be as effective, but if it is all that can be tolerated then it is still very much worth taking. When taking mineral ascorbates (buffered vitamin C), remember to take into account the amount of this mineral in working out overall intake. Taking very large amounts of calcium in particular will be problematic and should be strictly avoided. Potassium, manganese, zinc, molybdenum, and chromium ascorbates can also easily be taken at too high a dose when multi-gram doses of vitamin C are taken and so are only appropriate when taken at low doses. The best form is sodium ascorbate, followed by magnesium ascorbate.

Look for vitamin C powders that make claims about purity (100% pure and pharmaceutical grade), about being fine powders that are more easily dissolved, and that are free of common allergens and toxic chemicals etc. If possible, it may be preferable to buy a GMO free C too. Some patients prefer supplements certified as corn free.

Buy only high quality aluminium free or pharmaceutical grade bicarb soda, if at all possible. (For example Bob's Red Mill Aluminum free baking soda.)

When taking ascorbic acid powder in water without bicarb soda, drink it with a straw to prevent the acid liquid from making contact with (and damaging) your teeth and rinse the mouth well with water after each dose.

It is generally recommended that vitamin C powders are mixed with water and swallowed as soon as possible to prevent oxidation, although Linus Pauling does say
that vitamin C in water can be kept in the fridge for several days without significant oxidation.

The form of vitamin C used for IVs is always sodium ascorbate. IVs of vitamin C should never contain preservatives, and patients may benefit from the use of smaller bore needles than may typically be used for adults. Sometimes IV liquids are cased in glass rather than plastic for those with severe chemical sensitivities. See this article for doctors on how to make intravenous C solutions. IM injections of vitamin C, as with IVs, should also be in the form of sodium ascorbate as plain ascorbic acid is too acid to be used for this purpose. Dr Cathcart writes:

I watch patients for hypoglycemia (I encourage patients to eat while taking the IV), and dehydration (I encourage water and [to] slow the IV down.) I also see headaches afterward but not so much since I have been emphasizing the continuing high doses of oral ascorbic acid as soon as the IV is over. Actually I give oral ascorbic acid while the IV is going to get a double effect. Bowel tolerance goes up while the IV is running but one has to be careful to stop giving oral C about an hour before the IV stops or else you may get diarrhea as soon as the IV stops. The oral ascorbic acid is then started again 1/2 to 1 hour after the IVC stops.

Vitamin C powder, made into a paste with a small amount of water and applied to the affected area with a cotton swab can be used to treat receding gums and also various types of fungal conditions, rashes and skin lesions. If the skin is broken, plain ascorbic acid will string, so a better choice would be buffered vitamin C power or ascorbic acid powder with some bicarb soda added. You might treat just one side at first, so you can see more clearly exactly how well the paste is working. Oral thrush can be treated with a vitamin c spray, while twice daily inserts of 250 mg buffered vitamin C tablets can be used to treat vaginal thrush.

**Additional notes on high dose vitamin C for M.E.**
When taking high doses of vitamin C in the longer term, it is highly recommended that some calcium and magnesium, at least 5000 IU of vitamin A and a multi-mineral tablet also be taken. Some doctors recommend that high dose vitamin C always be taken with 500 mg – 2 g of vitamin B5, depending on the vitamin C dose.

Some doctors also recommend that 1 g of bioflavonoids be taken whenever you take more than 1 g of vitamin C, although many experts (such as Linus Pauling) say that this is unnecessary and that all that is needed is basic ascorbic acid and lots of it. It should also be noted that eating reasonable amounts of fruit and vegetables every day also provides bioflavonoids in amounts that may easily equal what is contained in some bioflavonoid products. So you can easily skip buying extra bioflavonoids and choose to try to get them from your diet instead. You may also already be taking supplements such as Hawthorne, Ginkgo or Silymarin, which also contain bioflavonoids.
Foods which contain vitamin C (and so the co-factors that go with it) include: capsicums/peppers, cabbage, broccoli, cauliflower, strawberries, lemons, kiwi fruit, melons, oranges, grapefruits, limes and tomatoes.

Bioflavonoid types (sometimes referred to as ‘vitamin P’) include: Dihydroquercetin, Hesperidin and Rutin, Pycnogenol, Hawthorne, Quercetin, citrus bioflavonoids, soy bioflavonoids, Quercetin, Grape seed extract, Ginkgo, Bilberry, Silymarin and Green tea extract. Click here to learn more about bioflavonoids. When taking 6 to 10 g or more of vitamin C as tablets and you want to also take some bioflavonoids, it may be preferable to buy three or so different types for a wider variety of bioflavonoids. For example, the following three vitamin C products have different bioflavonoids included; link 1, 2 and 3.

When taking over 10 g daily, powders will most likely be preferable to tablets, see links 1, 2 and 3, 4, 5 and 6. Buying pure powders saves money and also means avoiding ingesting large amount of fillers used in various pills. When buying pure ascorbic acid powder, note that one teaspoon = 4.5 g of vitamin C. Always store your vitamin C in a cool, dark and dry area. Do not refrigerate vitamin C.

Like all vitamins and supplements, you need to check that before you try them that they do not react unfavourably with any prescription (or other) medications you are taking or that these medications won’t affect the effectiveness of your vitamin C treatment. If you are taking NSAIDS, aluminium-containing antacids, nitrate medications for the heart, tetracycline or Warfarin in particular, please do more reading before starting to take extra vitamin C. Please also read the ‘important points to remember with supplements/medications’ section in A quick start guide to treating and improving M.E. with aggressive rest therapy, diet, toxic chemical avoidance, medications, supplements and vitamins.

Vitamin C is one of the most essential treatments for M.E. Other important treatments perhaps equally worth investigating and considering include the following: CoQ10 (as ubiquinol), vitamin B12 (as hydroxocobalamin), omega 3 essential fatty acids, a good quality multivitamin and multimineral supplement (without iron, copper or stimulants), probiotics, an antioxidant complex (containing adequate vitamin A and E, Selenium and Zinc if there isn’t enough of each already in your multivitamin, as well as some Pycnogenol and grape seed extract), digestive enzymes, Magnesium-Calcium, Potassium-Salt, L Carnitine/Acetyl L Carnitine and Hawthorn extract. For more information on these treatments please see: Treating M.E.: The basics

More information
- VITAMIN C, TITRATING TO BOWEL TOLERANCE, ANASCORBEMIA, AND ACUTE INDUCED SCURVY and The Ascorbate Effect in Infectious and Autoimmune Diseases by Robert F. Cathcart, M.D.
- Ascorbate: The Science of Vitamin C by Dr Hickey and Dr Roberts,
- VITAMIN C: The Real Story by Steve Hickey, PhD and Andrew Saul,
• Orthomolecular Medicine For Everyone: Megavitamin Therapeutics for Families and Physicians by Abram Hoffer,
• Fire your doctor! : how to be independently healthy by Andrew W. Saul
• The healing factor: Vitamin C against disease by Irwin Stone
• How to live longer and feel better by Linus Pauling
• Clinical Guide to the Use of Vitamin C The Clinical Experiences of Frederick R. Klenner, M.D. and Observations On the Dose and Administration of Ascorbic Acid When Employed Beyond the Range Of A Vitamin In Human Pathology By Fred Klenner, MD.
• Vitamin C & Treatment of Cancer: Part I by Gary Null, PhD
• Vitamin C, RDA's and Politics by Steven Wm
• The excellent Vitamin C Foundation site.
• Recommended Pauling Therapy Dosage for Heart Patients and Prevention
• The Many Faces of Vitamin C by Dr Thomas Levy
• Multiple Sclerosis Treated with Injectable Vitamin B1 & Liver Extract by Dale Humpherys
• About "Objections" to Vitamin C Therapy by AW Saul
• Spencer A, Saul AW. Vitamin C and cardiovascular disease, Orthomolecular Medicine News Service, June 22, 2010
• Saul AW. How to destroy confidence in vitamins when you do not have the facts. Orthomolecular Medicine News Service, Jan 11, 2010.
• Saul AW. Putting the “C” in cure: Quantity and frequency are the keys to ascorbate therapy. Orthomolecular Medicine News Service, Dec 15, 2009.
• Intravenous nutrient therapy: the "Myers' cocktail" by Alan R. Gaby
• Pharmacokinetics of vitamin C: insights into the oral and intravenous administration of ascorbate
• Dr Levy’s presentation to the 35th Annual Cancer Convention pt3-4 (a video which talks about liposomal vitamin C)
• List of international suppliers of liposomal vitamin C sachets from Livon labs
• Click here to read an except form one of Dr Levy’s books on vitamin C.
• PC Liposomal Encapsulation Technology by Robert D. Milne, see also: http://www.vitaminc.co.nz/pdf/LIPOSOMAL-ENCAPSULATION-ROBERT-D.-MILNE-MD.pdf
• Click here and here to read about the possible role of high dose vitamin C in treating polio and other viral diseases.
• Click here to read about Linus Pauling’s high dose vitamin C/lysine cardiac protocol.

References
The information in this article was taken primarily from the papers and books listed above. Click here to read book reviews of some of these books.

Further articles are listed on the High-dose vitamin C and M.E. page. (Note that in all the articles listed here, where ‘CFS’ (or even M.E.) is referred to, what is being discussed is not M.E., nor any other neurological disease. Some doctors refer to general miscellaneous chronic fatigue sufferers while others refer to patients with post-viral fatigue syndromes caused by glandular fever/mononucleosis etc.) ‘CFS’ and M.E. are NOT the same. For more information on why some falsely claim ‘CFS’ and M.E. are synonymous terms please see: What is M.E.?

Relevant quotes
“A new idea is first condemned as ridiculous and then dismissed as trivial, until finally, it becomes what everybody knows.” William James (1842-1910), American Philosopher

"Vitamin C should be given to the patient while the doctors ponder the diagnosis.” Dr Frederick Klenner, M.D.

"The medical profession itself took a very narrow and very wrong view. Lack of ascorbic acid caused scurvy, so if there was no scurvy there was no lack of ascorbic acid. Nothing could be clearer than this. The only trouble was that scurvy is not a first symptom of a lack but a final collapse, a premortal syndrome and there is a very wide gap between scurvy and full health."- Albert Szent-Gyorgyi, Nobel-prize winner for his discovery of vitamin C

"There are more than ten thousand published scientific papers that make it quite clear that there is not one body process (such as what goes on inside cells or tissues) and not one disease or syndrome (from the common cold to leprosy) that is not influenced -- directly or indirectly -- by vitamin C." Dr Emanuel Cheraskin, Dr Ringsdorf and Dr Sisley in THE VITAMIN C CONNECTION. (Quotes taken from the C for yourself website).

“Modern medicine is not scientific, it is full of prejudice, illogic and susceptible to advertising. Doctors are not taught to reason, they are programmed to believe in whatever their medical schools teach them and the leading doctors tell them. Over the past 20 years the drug companies, with their enormous wealth, have taken medicine over and now control its research, what is taught and the information released to the public.” Abram Hoffer MD
“Modern drug based medicine is as incomplete as a novel written with three vowels. As discordant as a symphony constructed using only some of the notes. High dose nutritional therapy is the much needed missing part of our vocabulary of healthcare. The fight against disease needs all the help it can get.” Andrew Saul PhD in ‘Fire your doctor: How to be independently healthy’ 2005

‘Vitamin C is the world’s best natural antibiotic, antiviral, antitoxin and antihistamine. This book’s recurring emphasis on vitamin C might suggest that I am offering a song with only one verse. Not so. As English literature concentrates on Shakespeare, so orthomolecular (megavitamin) therapy concentrates on vitamin C. Let the greats be given their due. The importance of vitamin C cannot be overemphasised.’ Andrew Saul PhD in ‘Fire your doctor: How to be independently healthy 2005

“Intravenous administration of nutrients can achieve serum concentrations not obtainable with oral, or even intramuscular (IM), administration. For example, as the oral dose of vitamin C is increased progressively, the serum concentration of ascorbate tends to approach an upper limit, as a result of both saturation of gastrointestinal absorption and a sharp increase in renal clearance of the vitamin. The highest serum vitamin C level reported after oral administration of pharmacological doses of the vitamin is 9.3 mg/dL. In contrast, IV administration of 50 g/day of vitamin C resulted in a mean peak plasma level of 80 mg/dL. Similarly, oral supplementation with magnesium results in little or no change in serum magnesium concentrations, whereas IV administration can double or triple the serum levels, at least for a short period of time.

Various nutrients have been shown to exert pharmacological effects, which are in many cases dependent on the concentration of the nutrient. For example, an antiviral effect of vitamin C has been demonstrated at a concentration of 10-15 mg/dL, a level achievable with IV but not oral therapy.” Intravenous nutrient therapy: the "Myers' cocktail" by Alan R. Gaby

“The dynamic flow model refutes the current low-dose recommendations for dietary intakes and links Pauling's mega-dose suggestions with other reported effects of massive doses of ascorbate for the treatment of disease. Recent studies confirmed that plasma vitamin C concentrations vary substantially with the route of administration. Only by intravenous administration, the necessary ascorbate levels to kill cancer cells are reached in both plasma and urine.’ This article It contains graphs that show you that with oral dosage, the maximum Vitamin C concentration in blood is only 225 micromol, while the maximum Vitamin C concentration in blood is 15 millimol (15,000 micromol), which is about 67 times more.” Pharmacokinetics of vitamin C: insights into the oral and intravenous administration of ascorbate

Disclaimer: The HFME does not dispense medical advice or recommend treatment, and assumes no responsibility for treatments undertaken by visitors to the site. It is a resource providing information for education, research and advocacy only. Please
consult your own health-care provider regarding any medical issues relating to the
diagnosis or treatment of any medical condition.
To start, buy perhaps 3 or 4 bottles of 1000 mg (1 gram) vitamin C tablets or capsules choosing from buffered forms such as sodium ascorbate, magnesium ascorbate or calcium ascorbate – or perhaps some of each – or 3 or 4 bottles or so of a mixed buffered vitamin C product.

- Sodium ascorbate, calcium ascorbate, magnesium ascorbate or mixed buffered vitamin C powders are fine too, and cheaper, if you are very sensitive to fillers used in tablets and capsules and can handle the extra effort of mixing vitamin C drinks, but otherwise tablets or capsules are easiest to begin with.

- If you can find some, magnesium ascorbate tablets are probably the best choice, as often patients are low in magnesium as compared to calcium.

- Don’t worry about bioflavonoids, they are not necessary. It is okay if some tablets have some in, they shouldn’t cause problems, but there is really no need to pay a lot extra to have them. They are just a very small added bonus, and you’ll be getting some from your diet and perhaps other supplements (such as hawthorne and antioxidant complexes) anyway. What is really important is the high dose vitamin C.

- Note that taking vitamin C with food makes it gentler on your stomach.

- As you slowly raise your dose, note that the ideal amount of vitamin C to take is just below the level that causes mild gas and bloating. If you reach the level that you experience these symptoms, cut back your dose by 1 g daily until the symptoms stop and that is your ideal daily dose. For most with M.E., this will be above 8 g daily.

- If you start to experience some mild additional symptoms (flu-like symptoms, headaches or night-sweats etc.) at any point due to raising your vitamin C dose as described below, go back to how much you were taking the week before you started to experience problems. Stay at that dose for two or three weeks and then try slowly raising your dose again. (After that you might prefer to stay at each level for two or three weeks, instead of one, if you feel you are particularly sensitive to supplements.)

- Week 1: Starting Sunday the _____ of ______________ Take one gram of vitamin C with your lunch each day this week; one 1000 mg tablet (or 1 g of powdered vitamin C, in water).
o Week 2: Starting Sunday the _____ of ______________ Take one gram of vitamin C with your lunch and dinner each day this week. (Two 1 g tablets daily).

o Week 3: Starting Sunday the _____ of ______________ Take one gram of vitamin C with your breakfast, lunch and dinner each day this week. (Three 1000 mg tablets daily in total, taken at least 3 hours apart and with food).

o Week 4: Starting Sunday the _____ of ______________ Take one gram of vitamin C with your breakfast, lunch and dinner each day this week. (Three 1 g tablets daily in total, taken at least 3 hours apart and with food).

o Week 5: Starting Sunday the _____ of ______________ Take two grams of vitamin C with your breakfast, and one gram with lunch and dinner each day this week. (Four 1 g tablets daily in total, each 1 or 2 g dose taken at least 3 hours apart and with food).

o Week 6: Starting Sunday the _____ of ______________ Take two grams of vitamin C with your breakfast and lunch, and one gram with dinner each day this week. (Five 1 g tablets daily in total, each 1 or 2 g dose taken at least 3 hours apart and with food).

o Week 7: Starting Sunday the _____ of ______________ Take two grams of vitamin C with your breakfast, lunch and dinner each day this week. (Six 1 g tablets daily in total, each 2 g dose taken at least 3 hours apart and with food).

o Week 8: Starting Sunday the _____ of ______________ Take two grams of vitamin C with your breakfast, lunch and dinner each day this week as well as one extra time a day, with a snack. (Eight 1 g tablets daily in total, each 2 g dose taken at least 3 hours apart and with food).

You are now getting some of the benefits of taking high-dose vitamin C such as increased resistance to secondary infections and cancer! You may wish to leave it there, but if you are desperate and determined to get every last benefit from vitamin C that you can, and you haven’t felt the enormous sense of physical wellbeing that high dose vitamin C causes (and you want to!), and you’re are up to a bit of hassle in taking doses of powdered vitamin C more often, then please read on.

o Week 9: Starting Sunday the _____ of ______________ Take two grams of vitamin C with your breakfast, lunch and dinner each day this week as well as two extra times a day, with a snack. (Ten 1 g tablets daily in total, each 2 g dose taken at least 2 ½ hours apart and with food).

o Week 10: Starting Sunday the _____ of ______________ Now that you are taking 10 g of vitamin C daily, it is a good time to switch to powdered vitamin C. Powdered vitamin C is often much cheaper than tablets or capsules and contain NO fillers or additives. Make sure you choose a buffered form with no fillers (as listed above). A mixed form may be best, as you want to always check you aren’t getting too much magnesium and calcium.

For this first week, replace two of your five 2 g doses of vitamin C tablets with 2 g of vitamin C powder in water. (You may wish to draw yourself up a small chart so you can remember what to take each day and mark off all the doses you have taken so you don’t take them twice.) To find out how much power makes 1 g, read
the bottle. To measure your amounts correctly, you may wish to buy a measuring spoon set. You are still taking 10 g of vitamin C daily.

- Week 11: Starting Sunday the ______ of ______________ This week, replace all five of your 2 g doses of vitamin C tablets with 2 g of vitamin C power in water. (If you are very ill on waking, you may choose to keep your first vitamin C dose of the day in tablet form, if that is easier for you.) You are still taking 10 g of vitamin C daily.

- Week 12: Starting Sunday the _____ of _____________ This week, add an extra 2 g vitamin C dose each day, with food if possible. Try to have each of your six doses at least 2 hours apart. You are now taking 12 g of vitamin C daily.

- Week 13: Starting Sunday the ______ of ______________ This week, raise all six of your vitamin C doses to 2.5 g. Try to have each of your six doses at least 2 hours apart, and with food if possible. You are now taking 15 g of vitamin C daily.

- Week 14: Starting Sunday the _____ of ______________ This week, raise all six of your vitamin C doses to 3 g. Try to have each of your six doses at least 2 hours apart, and with food if possible. You are now taking 18 g of vitamin C daily.

- Week 15: Starting Sunday the ______ of ______________ This week, raise all six of your vitamin C doses to 3.5 g. Try to have each of your six doses at least 2 hours apart, and with food if possible. You are now taking 21 g of vitamin C daily.

If you would like to keep raising your dose, as you have still not reached saturation level, you have two choices now. You can start taking your 3.5 g dose more often, say every 2 hours or every 1 ½ hours or even every hour, or you can keep to only having six doses a day and increase the size of those doses.

The first option is by far the better option. You are far less likely to have gastric disturbances if you take lower amounts of vitamin C more often, as opposed to higher amounts less often. Your body will also absorb more of the vitamin C if you take smaller doses less often.

You’ll likely have to experiment a bit until you find the schedule and dose that is right for you.

You might have to do some experiments with how much vitamin C you can have at one time without having gastric problems and make sure you don’t go above that.

You may find that you are one of those patients that is able to have vitamin C away from meals with no problems at all and so find you are able to have doses more often each day without having to time them to go with meals.

You may wish to use an electronic timer, to remind you to take your vitamin C as often as you need to. (Timer programs are available for use while you are on the computer too.)

Again, the ideal amount of vitamin C to take is just below the level that causes mild gas and bloating. That is often anywhere from 15 to 50 g in M.E. If you reach the
level that you experience these symptoms, cut back your dose by 10% or so or until the symptoms stop, and that is your ideal daily dose.

Vitamin C buffered with minerals such as salt, calcium and especially magnesium has been recommended here as these forms are the gentlest on the stomach, and may perhaps be well tolerated where pure ascorbic acid is not. However, if your stomach can tolerate it, pure ascorbic acid powder or tablets or capsules is said by experts to be a much more effective form of vitamin C especially when patients are very ill and have mitochondrial problems (as explained in the main vitamin C paper). So once you have worked out how much vitamin C you are able to take daily, and how often, you might like to buy a small bottle of ascorbic acid powder to see if you will be able to switch to this preferred or ideal form of vitamin C. Ascorbic acid tablets or capsules may be a better choice where the taste of ascorbic acid in water is intolerable, and these forms also protects tooth enamel.

To buffer ascorbic acid with bicarb, it should be mixed with half as much bicarb soda. So for every ½ teaspoon of ascorbic acid, you would mix in ¼ teaspoon of bicarb soda. It makes a quite pleasant drink, that is not at all acidic and wont ruin tooth enamel etc. Some patients tolerate it well even on an empty stomach. You might want to start by mixing some pure ascorbic acid powder into your buffered vitamin C powder (making sure to have it with meals at first), starting with ¼ and then ½ and then ¾ and if you are still having no problems, try a complete switch. If all you can tolerate are the standard buffered forms then so be it, but it’s a good idea to at least try pure ascorbic acid to see how you go as this form may be TWICE as effective as vitamin C buffered with calcium or magnesium etc. Remember to buy only high quality aluminium free or pharmaceutical grade bicarb soda, if at all possible. (For example Bob’s Red Mill Aluminum free baking soda.)

Note that you MUST take the amount of calcium and magnesium in any buffered vitamin C you are taking into account when working out how much extra of both of these to take, especially if you have treated a vitamin D deficiency. If you have vitamin D levels above 20 ng/ml you should NOT be taking more than 600 mg of calcium from supplements daily (see the main vitamin D paper for more information). This is VERY important, especially now as you are starting to take quite large doses.

You will probably have to include some sodium ascorbate powder or pure ascorbic acid powder in your mix to make sure you aren’t getting too much magnesium and (more importantly) calcium as you start taking higher doses of vitamin C. For buffering large doses of ascorbic acid, only sodium (or bicarb soda) is physiologically benign.

Another option once you’ve reached a high or even bowel tolerance dose with oral vitamin C, and are still after further improvements, would be to try liposomal vitamin C or vitamin C IVs, or both.
Taking high dose C long-term is very safe. When taking high doses of vitamin C in the longer term however, it is highly recommended that some calcium and magnesium, at least 5000 IU of vitamin A and a multi-mineral tablet also be taken. All of this may seem a lot of effort, and it is to some extent, but the reason many of us stick with taking high-dose C long-term is the significant benefits. It can really be worth it. For more information see the main vitamin C paper.
Liposomal vitamin C and M.E.
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The term liposomal comes from two Greek words: 'lipos' meaning fat and 'soma' which means body. Liposomes were discovered in the UK in 1961. As well as vitamin C, liposomal nano-technology has been used as a delivery system for anti-cancer drugs such as Doxorubicin, Camptothecin and Daunorubicin and to deliver enzymes and nutritional supplements to foods.

Liposomal or lypospheric vitamin C (Lypo-C for short) is a new form of vitamin C delivery that is taken orally, just like vitamin C powders or tablets, but that has an absorption rate similar to that of vitamin C given intravenously (IV).

As The Vitamin C Foundation explain,

Almost 100% absorption is the key. Liposomal vitamin C is released from the liposomes in the liver almost perfectly imitating the animal release of vitamin C. The liposomal form of vitamin C may become important oral cancer adjunct by helping to maintain high blood levels of ascorbate - vitamin C, especially in people who have trouble tolerating ordinary pills due to gas and diarrhoea.

Our tests with liposomal vitamin C have been amazing. No gas or diarrhoea at double the dosages that usually create these effects in our subjects. The Foundation recommends utilizing Lypo-C after you reach bowel tolerance with ordinary ascorbic acid.

‘Liposome-encapsulated Ascorbate Liposomes were first proposed as a unique drug delivery system approximately 35 years ago (Bangham, 1995; Gregoriadis, 1995). One of the primary reasons for utilizing a liposome-encapsulation delivery system is to assure a near complete absorption of the encapsulated nutrient or drug into the bloodstream. The physical qualities of the liposome also eliminate the need for digestive activity before absorption.’

How much does liposomal vitamin C cost?
Lypo-C is significantly more expensive than standard vitamin C powders or tablets, although it is still significantly cheaper than vitamin C given by IV.

A 50 g vitamin C IV may cost roughly $110 to $150; 50 g of Lypo-C costs roughly $50 to $70, while 50 g of plain ascorbic acid costs roughly $2 to $5.
A standard dose for a vitamin C IV is 50 g and the cost is $110 to $150; a standard dose of Lypo-C is 2-6 packets, costing $2 to $6; a standard high dose of 25-50 g of plain ascorbic acid costs roughly $1 to $5.

The absorption, bio-availability and tolerance level of each type of vitamin C must be taken into account along with price, however.

**How well is each of the different types of vitamin C absorbed?**

The amount of vitamin C that enters the bloodstream with oral vitamin C is around 20%. For Lypo-C this figure is around 90%, and IVs deliver 100% of the vitamin C into the bloodstream directly.

Vitamin C given by IV is vastly superior to vitamin C taken orally. Vitamin C experts Dr Levy explains that after much experimentation and deliberation, he has concluded that liposomal vitamin C may in fact be superior to vitamin C given by IV, but that the most powerful clinical effect may be achieved with a combination of the two.

In a recent lecture, Dr Levy explained that Lypo-C may be far more readily absorbed intracellularly than IVC. This makes it far more clinically effective as intracellular absorption, where the vitamin C gets inside the cells that are most in need of it, is ‘your ultimate bio-target.’ He explains that he has observed the superiority of liposomal vitamin C as compared to IV vitamin C in practice many, many times, though he readily acknowledges that this theory has not yet been rigorously proven.

In the lecture Dr Levy states ‘5-6 g of liposomal vitamin C is more effective clinically than 50 g of vitamin C by IV.’

He goes on to talk about the benefits of liposomal vitamin C in developing countries such as Africa, where he has been working recently, where it is impossible to administer the 48 hour or more constant IV vitamin C favoured by vitamin C experts such as the late Dr Frederick Klenner. He describes one case where he was able to successfully treat a patient seriously ill with hemorrhagic dengue fever with 10 – 12 sachets of Lypo-C given over 2 days, where previously he would have had to administer hundreds of grams of vitamin C by IV to have had the same effect. Dr Levy also comments that he has observed these same affects in many other diseases.

To view the video of this lecture, see: [Dr Levy’s presentation to the 35th Annual Cancer Convention pt3-4](#)

Dr Levy writes:

I found that liposome encapsulated vitamin C, taken orally, was roughly 10 times more effective clinically in resolving infectious diseases than the IVC. Having given thousands of IVCs and taken hundreds myself, this was difficult to comprehend, even though the clinical observation was quite straightforward. I subsequently realized that the liposome gave the ultimate bioavailability:
intracellular delivery, including the mitochondria, endoplasmic reticulum, and even the nucleus. 2 to 6 packets daily covers most individuals for most situations.

**How well is liposomal vitamin C tolerated by the gut?**
Liposomal vitamin C utilises nano-technology and so is very small, and requires no digestive activity prior to assimilation. The liposomes are rapidly absorbed in the small intestine and then transported intact throughout the bloodstream to the cells that need it. This means that it may be the best choice for those patients that cannot tolerate the gut irritation caused by standard oral vitamin C supplements or that wish to reduce the load on the gut due to severe M.E. (which causes a lack of blood flow to the gut).

Lypo-C also has no binders, fillers, gelatines, capsule materials, dyes, sweeteners, or flavourings common with tablet and capsule supplements. It contains a mixture of ‘essential phospholipids’ – predominately phosphatidylcholine – and pharmaceutical-quality ascorbic acid.

**How does one take liposomal vitamin C?**
Lypo-C is sold in 1 g sachets. One pours the contents of the sachets into a glass of water and then drinks it. Lypo-C is best taken 15 minutes before meals. Some people say they like the taste of this supplement, and others say it tastes terrible.

Only one sachet should be taken at a time, and the doses should be spread out as much as possible over the course of a day. Dosage is usually 2 – 6 sachets daily.

**Is having vitamin C by IV still worthwhile?**
Dr Levy says that if you are very ill, then you should not replace vitamin C by IV with Lypo-C – you should have both. He believes that if you have some liposomal vitamin C and then you have a 50 g vitamin C IV, will absorb even more vitamin C from the IV intracellularly because of the liposomes circulating in the blood and waiting to facilitate that second stage of absorption and bioavailability. Again he comments that while he has observed this effect in many of his patients, it is yet to be proven.

Looking at Dr Levy’s comments, it seems as if 1 g of Lypo-C may be considered roughly comparable with 10 g of IVC. LivOn Labs, a manufacturer of Lypo-C, state that 1 g of Lypo-C is at least 8 times as powerful as 1 g of vitamin C taken orally.

**Conclusion**
There are many ways that liposomal vitamin C may be combined with other forms of vitamin C. How much Lipo-C is taken may depend on budget and tolerance. For example, one might:
- Take 8 – 30 g of ascorbic acid powder (with bicarb if needed) plus 1 – 4 sachets of Lypo-C daily
- Take 8 – 30 g of ascorbic acid powder daily, plus 2 – 4 sachets of Lypo-C once or twice a week or once a fortnight.
- Take 2 - 4 sachets of Lypo-C daily, plus 2 extra sachets of Lipo-C once or twice a week.
- Take 2 - 6 sachets of Lypo-C daily, plus a 50 g vitamin C IV once a week.
- Take 8 – 30 g of ascorbic acid powder plus 1 – 4 sachets of Lypo-C daily, plus a 50 g vitamin C IV administered (at the doctor’s surgery or at home with the assistance of a friend or family member that is a qualified nurse) once or twice a week or once a fortnight (and trial discontinuing the IVs after 6 months).
- Take 8 – 30 g of ascorbic acid powder plus 1 – 4 sachets of Lypo-C daily, plus a 50 g vitamin C IV administered once or twice a week or once a fortnight (and trial discontinuing the IVs after 6 months).

It is generally recommended that Lypo-C and/or vitamin C by IV be used only after bowel tolerance has been reached with ordinary oral vitamin C, or at least a reasonably high dose. Building up the dose slowly is ideal.

This new nano-technology vitamin C delivery system may be a good choice and a wonderful new discovery for those that can afford it. It provides an alternative to IVs and for those who do not have access to IVs.

This treatment should be trialled for at least 2-3 months. After 6 – 12 months of treatment it may not be necessary to take such a high dose as was needed at the beginning of treatment. The maintenance dose of vitamin C is often much lower than the initial effective dose. See the main vitamin C paper for more information.

More information on liposomal and IV vitamin C:
- Dr Levy’s presentation to the 35th Annual Cancer Convention pt3-4 (a video which talks about liposomal vitamin C)
- The Many Faces of Vitamin C by Dr. Thomas E. Levy (mentions Lipo-C, recommends avoiding calcium ascorbate and offers information to physicians which are interested in prescribing Lipo-C.)
- List of international suppliers of liposomal vitamin C sachets from Livon labs. Liposomal vitamin C from LivOn Labs is the form recommended and used by Dr Levy. Some brands of liposomal vitamin C may not be reputable and may not be selling the same quality product.
- LivOn Labs Lypo-Spheric Vitamin C Part 1 (video)
- Click here to read a free except from one of Dr Levy’s books on vitamin C.
- PC Liposomal Encapsulation Technology by Robert D. Milne, see also: http://www.vitaminc.co.nz/pdf/LIPOSOMAL-ENCAPSULATION-ROBERT-D.-MILNE-MD.pdf
- The Vitamin C Foundation website.
Vitamin C: The Facts, the Fiction, and the Law (presented by Dr Levy in New Zealand on 9/17/2010). The powerpoint lecture on vitamin C and the law can be found here and the video listing is: Thomas Levy Talks To Vitamin C Can Cure Coalition Part 1/9 (video)

- Vaccination---The Shot That Keeps on Shooting by Dr Thomas Levy MD
- Curing the Incurable with Vitamin C: (video) with Dr Levy
- Antioxidant Balance is Essential to Health (video) with Dr. Thomas E. Levy
- Pulsed Intravenous Vitamin C (PIVC) Therapy by Dr. Thomas E. Levy
- Vitamin C and Severe Influenza: a case report by Dr. Thomas E. Levy
- Vitamin C, Pulmonary Embolism, and Cali, Colombia by Dr. Thomas E. Levy
- Curing the Incurable: Vitamin C, Infectious Diseases and Toxins by Dr Thomas E.Levy
- Dr. Donsbach Pt7 Liposomal Anti-Cancer Formula - Health Freedom Expo 2009 (video)
- Protective Effect of Coenzyme Q10-loaded Liposomes on the Myocardium in Rabbits with an Acute Experimental Myocardial Infarction

Always talk to your vitamin C educated doctor for dosage information specific to your own case. If you don’t have such a doctor, it is highly recommended that you try and find one. For more information on vitamin C generally, including why the other antioxidants should be taken with vitamin C and how to determine a ‘bowel tolerance’ dose of vitamin C and adjust your dose over time, see the main HFME vitamin C paper.

Relevant quotes
"As they researched their book ASCORBATE, Hickey and Roberts began to wonder if Pauling's offense had been to discuss openly the properties of a substance that threatens the profitability of medicine. If the claims for vitamin C are correct, it might replace many lucrative and expensive medications. " ASCORBATE: The Science of Vitamin C

"Many viral infectious diseases have been cured and can continue to be cured by the proper administration of Vitamin C. Yes, the vaccinations for these treatable infectious diseases are completely unnecessary when one has the access to proper treatment with vitamin C. And, yes, all the side effects of vaccinations...are also completely unnecessary since the vaccinations do not have to be given in the first place with the availability of properly dosed vitamin C." Dr Thomas Levy M.D., J.D. in Vitamin C, Infectious Diseases and Toxins p30

"Amazingly, vitamin C has actually already been documented in the medical literature to have readily and consistently cured both acute polio and acute hepatitis, two viral diseases still considered by modern medicine to be incurable." Thomas E. Levy, MD, JD
‘All three children had different doctors. The little girl under Klenner's care was given 10,000 mg of vitamin C as a slow intravenous "push" with a 50 cc syringe every eight hours for the first 24 hours and then every 12 hours for two more doses. Following this she was given 1,000 mg of vitamin C every two hours by mouth. Klenner also notes that a 40,000-unit dose of antitoxin was injected into the little girl's abdomen. The other two children received the antitoxin as well, but they did not receive any vitamin C. They both died but Klenner's patient survived, later becoming a nurse.’ Vitamin C, Infectious Diseases, and Toxins: Curing the Incurable by Thomas E. Levy, M.D.

"Acute viral hepatitis...is easily and completely curable with treated promptly with adequate doses of vitamin C ...some evidence indicates that a high dose of vitamin C for a long enough period of time would probably resolve (chronic hepatitis) as well in many of the cases......A significant benefit of properly dosed vitamin C would be the elimination of any need or reason to vaccinate people against hepatitis." Dr Thomas Levy M.D. in Vitamin C, Infectious Diseases and Toxins p. 60

‘Effective treatment involved much more than eliminating the initial or primary cause.’ Dr Levy
Low vitamin D levels are very common in the general population. It is estimated that there are more people deficient in vitamin D than there are people with normal vitamin D levels.

M.E. causes many patients to spend significant time bedbound and/or in the home and so to get very little sun exposure. Symptoms such as photophobia and seizure-like problems following even minimal light exposure are also extremely common in M.E. Considering these factors it is probably the very rare M.E. patient that does NOT have a low vitamin D level. Low vitamin D levels can negatively affect the health of M.E. patients (as well as the general population) in many significant ways.

The good news is that vitamin D levels can be tested at home, easily, reliably and for a reasonable cost – and that restoring low vitamin D levels to the optimal level is also easy, safe and inexpensive.

What does vitamin D do in the body?
Vitamin D strengthens bones and the immune system, supports the pancreas, may support sugar tolerance, may reduce susceptibility to skin disorders and heart problems, promotes well-being, improves digestion, is responsible for the regulation of over 2,000 genes and improves resistance to secondary diseases (including cancer and colds and flu etc.).

The role of vitamin D in potentially regulating many functions in the cardiovascular system is just beginning to be understood. Vitamin D, calcium and magnesium all play a critical role in muscle function. Very low vitamin D causes muscle twitching and cramping and prevents the muscles from contracting or relaxing properly. Without sufficient vitamin D, bones can become thin, brittle, or misshapen. Vitamin D affects how all minerals are used by the body.

Vitamin D has anti-inflammatory effects and boosts the immune system. The Vita-Nutrient Solution book by Dr Atkins explains that, ‘The immune system’s vitality rises and falls directly with vitamin D’s concentration in the body. A vitamin D measurement is one of the factors that doctors use to predict the length of survival for someone with AIDS.’
Vitamin D is a unique hormone as well as a vitamin. Our skin is part of the vitamin D endocrine system, and vitamin D3 is really a preprohormone.

Low vitamin D levels can also cause or contribute to symptoms such as; muscle cramps, muscle twitching, muscle and bone pain, loss of muscle strength and coordination, tooth and jaw pain, tooth loss (those with tooth loss almost always have low vitamin D), headaches, poor concentration, restless sleep, joint pain or swelling, constipation or diarrhea or both, urinary urgency or frequency or both, weight gain (and/or the metabolic syndrome), tiredness and depression (seasonal depression/SAD). Low vitamin D levels can also increase the risk of kidney stones (as vitamin D is necessary for proper calcium absorption and when calcium levels are low the kidneys tend to hold onto calcium). Low vitamin D levels may also contribute to obesity.

M.E. patients that are able to improve their formerly low vitamin D levels will often see significant improvements in pain levels, and many of the other symptoms listed above. (This will occur to a more limited extent when these are the core symptoms of M.E. involving loss of muscle strength etc.)

Vitamin D is even more important in children than adults.

**What is the ideal range of vitamin D on testing?**

Vitamin D experts differ somewhat in what they consider to be the optimal level of vitamin D.

- The book *The vitamin D cure* by James Dowd M.D. puts the optimum level of vitamin D between 50 - 70 ng/ml, with the lowest possible acceptable (though still not optimal) level being 35 ng/ml. This author considers toxicity a concern only at doses above 100 to 120 ng/ml.

- The *Use of Vitamin D in Clinical Practice* recommends optimum levels of 40 - 70 ng/ml for healthy people, and optimum levels of 55 - 70 ng/ml for those with serious illnesses such as diabetes or MS (and so on). These authors consider toxicity a concern only at doses above 150 ng/ml.

- The authors of ‘Vitamin D, A Neglected ‘Analgesic’ for Chronic Musculoskeletal Pain’ recommend levels of vitamin D between 30 - 50 ng/ml, and consider toxicity a concern only at doses above 150 ng/ml.

- Dr Mercola considers the optimum level of vitamin D to be between 50 to 70 ng/ml (and between 70 and 100 ng/ml in cancer and heart disease) and considers toxicity a concern only at doses above 100 ng/ml.

- Vitamin D expert Bruce Hollis considers toxicity a concern only at doses above 250 ng/ml.

- Frank Lipman M.D., the founder and director of Eleven Eleven Wellness Center in New York City, considers the optimum level of vitamin D to be between 50 - 80 ng/ml.
• The vitamin D council and John Cannell MD consider the optimum level of vitamin D to be between 50 - 80 ng/ml.

• Zoltan Rona M.D. in the book Vitamin D: The Sunshine Vitamin, considers an optimum level of vitamin D to be between 40 - 100 ng/ml.

• Dr Brownstein makes the following statement about vitamin D levels, ‘Optimal vitamin 25-hydroxy D3 levels are in the range of 40-80ng/ml. However, some patients with autoimmune or neurological disorders such as MS feel better with higher vitamin D levels--sometimes in the range of 100-150ng/ml. Following serum calcium levels can prevent problems from excess vitamin D supplementation. My experience has shown that vitamin D is extremely safe, even at higher doses.’

• Dr Sherry Rogers recommends a vitamin D level of at least 60 ng/ml.

• The Westen A. Price Foundation considers an optimum level of vitamin D to be between 30 - 50 ng/ml. They believe that levels higher than this are not yet supported by the evidence and may be safe only if they are combined with adequate levels of vitamin A and vitamin K2. They explain that these vitamins may protect against vitamin D toxicity as even a moderate increase in the amount of vitamin D in the body increases the need for vitamins A and K2 enormously.

• C. Norman Shealy M.D. Ph.D. (in VITAMIN D BOOSTS IMMUNITY and VITAMIN D: THE CURE FOR MANY DISEASES? And VITAMIN D 3-MOST CRITICAL SUPPLEMENT) does not seem to mention a specific vitamin D test measurement, but recommends a dosage of 50 000 IU weekly for all patients (so long as there are not kidney problems, NO calcium is taken and vitamin D and calcium levels are measured every 3 months) and says that this is even more important where there is serious illness. Shealy comments,

For individuals over 140 pounds, 50,000 units daily is generally safe if you do not take any calcium supplements and have normal kidney function. BUT, if you do that you must check calcium levels frequently. The amount of calcium in a multivitamin/mineral is fine and calcium foods are fine. If you do choose to take 50,000 units daily, do not check your D 3 level for at least 8 months, as it will be very high for at least that long. HOWEVER, check your calcium level in about 6 weeks and at least every 6 months! If you are not going to check the calcium levels, do not take more than 50,000 units of D 3 once a week!! Blood calcium levels are the only test related to the D 3 that make sense. If your blood calcium level is within the normal range, then there is no known toxicity.

Mainstream medicine will usually claim that so long as the vitamin D level is above about 20 ng/ml that there is no deficiency of vitamin D and so there is no benefit to be gained by raising levels higher than this. But newer evidence does not support this claim. The article ‘Calcium and Vitamin D Diagnostics and Therapeutics’ explains that,

It is quite possible that there are two levels of vitamin D sufficiency. One level requires that the serum vitamin d 25 hydroxy levels be at least 20 ng/mL to satisfy
the body's requirement for... calcium absorption, bone calcium mobilization and bone mineralization. The second level may need higher circulating levels of vitamin d 25 hydroxy for maximum cellular health.

The Vitamin D Council’s John Cannell MD writes that:

Levels should be above 50 ng/ml (125 nmol/L) year-round, in both children and adults. Thanks to Bruce Hollis, Robert Heaney, Neil Binkley, and others, we now know the minimal acceptable level. It is 50 ng/ml (125 nmol/L). In a recent study, Heaney, et al expanded on Bruce Hollis's seminal work by analyzing five studies in which both the parent compound (cholecalciferol) and 25(OH)D levels were measured. They found that the body does not reliably begin storing cholecalciferol in fat and muscle tissue until 25(OH)D levels get above 50 ng/ml (125 nmol/L).

The average person starts to store cholecalciferol at 40 ng/ml (100 nmol/L), but at 50 ng/ml (125 nmol/L) virtually everyone begins to store it for future use. That is, at levels below 50 ng/ml (125 nmol/L), the body uses up vitamin D as fast as you can make it, or take it, indicating chronic substrate starvation—not a good thing. 25(OH)D levels should be between 50–80 ng/ml (125–200 nmol/L), year-round.

In 'Circulating 25-Hydroxyvitamin D Levels Indicative of Vitamin D Sufficiency: Implications for Establishing a New Effective Dietary Intake Recommendation for Vitamin D', the author makes the following comment,

Vitamin D deficiency should be defined as less than 32 ng/ml circulating 25(OH)D. I have arbitrarily set the toxic level at 100 ng/ml, which is a conservative estimate, because true vitamin D toxicity is well beyond this.

Looking at the evidence it seems reasonable for those with M.E. to aim for a minimum vitamin D level of around 50 ng/ml. The upper limit could be up to 70 - 80 ng/ml, but as an upper limit of 60 ng/ml is enough to get most or all of the benefits from vitamin D some patients may prefer this more conservative upper limit. These levels give M.E. patients all the potential benefits of vitamin D without coming close to the levels thought to be toxic.

As The vitamin D council state, ‘Levels of 50-80 ng/mL are “natural” levels, that is, levels normally achieved by people who work in the sun.’

**What is the best type of vitamin D test?**

To diagnose vitamin D deficiency by blood test, the only useful test is a 25-hydroxyvitamin D test. 25-hydroxy-vitamin D or 25(OH)D is the circulating form of vitamin D and is routinely used to diagnose vitamin D deficiency.

The vitamin D council offers a reliable vitamin D test kit that can be ordered online and sent to your home. The big advantage of this test for M.E. patients is that is that it can all be done over the internet and by post, and the price is cheaper than many other companies also. The vitamin D council charge $220 USD for four kits (either to be
used by 4 people or 1 or 2 people that would like to retest their vitamin D levels over time) or $65 USD for one kit. They explain:

This is a home test for 25(OH)D, requiring a finger or heel stick to get several drops of blood. You order the test kit, which ZRT will ship to you. After receiving your kit either you, or someone you know in the medical field, will do a finger or heel stick and put the blood on the blotter included in the kit. You will then send the blotter paper back to ZRT in the envelope provided. ZRT will perform the 25(OH)D test in their lab and send the results directly back to you. The Vitamin D Council has verified that results obtained by ZRT are accurate and correspond very well to the results given by both LabCorp and DiaSorin RIA. These tests are good for either adults or children and avoid the venipuncture many children dislike. A portion of the proceeds from the sale of each test will be donated to the Vitamin D Council by ZRT to help us in our mission to end the worldwide epidemic of vitamin D deficiency.

The serum 25(OH)D test is also available from several other companies including VRP and the LEF.

In the US, this type of vitamin D test may be covered by insurance. In countries such as Australia, Australian citizens may also be able to get the appropriate vitamin D test done for free or at a greatly reduced cost, so you may prefer to ask your doctor about vitamin D testing through these schemes before paying for your own test. (Make sure your doctor gives you the right kind of vitamin D test however, the 25(OH)D test, and not the useless 125(OH)D test.)

Note that brief sun exposure can spike your vitamin D levels temporarily, so make sure you take your test on a day when you have had little sun exposure (or at least no more than is usual).

Are any other tests necessary before or while taking vitamin D supplements?
The vitamin D cure book explains that to determine the most exact dosing, the 25(OH)D vitamin D test can be done in combination with the following 2 tests:

- Intact PTH (to detect primary hyperparathyroidism which can cause high calcium and vitamin D levels)
- Calcium (vitamin D increases the absorption of calcium significantly, and so checking that calcium levels are not high before beginning vitamin D supplementation is sometimes recommended).

This book also explains however that not only is the standard vitamin D test is enough for most patients, but that it is not necessary to always perform a vitamin D test before beginning vitamin D supplementation if the patient is in a high risk group for low vitamin D status. A checklist to determine if one falls into the high risk category (as almost all M.E. patients will) is available in The vitamin D cure book, or for free online on ‘The vitamin D cure’ website.
Frank Lipman M.D. also recommends that, ‘If you are taking high doses (10,000 IU a day) your doctor must also check your calcium, phosphorous, and parathyroid hormone levels every three months.’

**How much vitamin D should one take?**

The vitamin D council writes that a one size fits all approach is not appropriate with vitamin D, and that:

As a general rule, old people need more than young people, big people need more that little people, heavier people need more than skinny people, northern people need more than southern people, dark-skinned people need more than fair-skinned people, winter people need more than summer people, sunblock lovers need more than sunblock haters, sun-phobes need more than sun worshipers, and ill people may need more than well people.

The vitamin D council recommends as a general guideline that those in a high risk of vitamin D deficiency (due to poor UV exposure) should take the following amounts of vitamin D, and then have their vitamin D levels tested 3 months later. (They also note that these amounts are likely very conservative and that high amounts will often be needed to get vitamin D levels in the optimum range.)

Healthy children under the age of 1 years should take 1,000 IU vitamin D3 per day—over the age of 1, 1,000 IU vitamin D3 per every 25 pounds of body weight per day. Well adults and adolescents should take 5,000 IU vitamin D3 per day.

Frank Lipman M.D. says that taking the right amount of vitamin D3 is crucial, and that most doctors tend to underdose. He recommends that the 25(OH)D test result be used to determine the dosage given, where the vitamin D level is low (below 50 ng/ml),

If your blood level is 30-45 ng/ml, I recommend you correct it with 5,000 IU of vitamin D3 a day for three months under a doctor's supervision and then recheck your blood levels.

If your blood level is less than 30 nanograms per milliliter (ng/ml), I recommend you correct it with 10,000 IU of vitamin D3 a day under a doctor's supervision and then recheck your blood levels after three months. It takes a good six months usually to optimize your vitamin D levels if you're deficient. Once this occurs, you can lower the dose to the maintenance dose of 2,000-4,000 IU a day.

The vitamin D cure book however, explains that dosage determined based on weight is safer and more accurate than flat universal dosing, no matter the set amount. The author of The vitamin D cure. James Dowd M.D., states that it is appropriate patients in a high risk category for low vitamin D status, or that have been shown to have a low vitamin D level through testing, take 25 IU of vitamin D3 per pound or 60 IU per
kilo of bodyweight, daily. If one is in a high risk group, even without a vitamin D test before hand, this dosage will not result in a vitamin D level beyond what is safe.

(Note that where the weight is over 300 pounds/135 kilos, this equation may over- or underestimate the level of vitamin D supplementation required and so vitamin D tests are highly recommended for such patients after a few months of supplementation at this level.)

The book explains that for any **extended period of time** (even if one has no sun exposure at all), one shouldn’t need more than 40 IU of vitamin D per pound of body weight daily (or 85 IU per kilo) as this raises the blood level by 50 ng/ml. Thus even if the level was extremely low to begin with, for example 5 ng/ml, the level would be raised to 55 ng/ml at this dosage, which is in the optimal range for health.

The **vitamin D cure** includes a very useful chart which explains exactly how many units of D3 one needs to take per pound or kilo of body weight to take to reach a level of 40, 50, 60 or 70 ng/ml, depending on what ones current level of vitamin D has been shown to be via testing. This chart can not be reproduced here for reasons of copyright, but it is recommended that if possible a copy of this book be bought or borrowed from a library.

The Westen A. Price Foundation has some quite different ideas about vitamin D dosages and forms compared to many vitamin D experts. They recommend only vitamin D from cod liver oil, as they explain that this form contains the right ratios of vitamin A and K2 to vitamin D, and also contains all the important natural cofactors of these vitamins which are not included in commercial vitamin D products. They also write that because all of these synergistic vitamins and cofactors are included in cod liver oil, a lower dose of vitamin D is needed to raise vitamin D levels in the blood as compared to other products. (One example described the same blood level of vitamin D being achieved with 2800 IU of vitamin D3 from cod liver oil as compared to 7000 IU of synthetic vitamin D3.) The usual dosage is ½ to 1 teaspoon of fermented cod liver oil daily or 1 teaspoon to 1 tablespoon of standard cod liver oil daily, always making sure that the total intake of vitamin A from all sources is less than 30 000 IU.

For these reasons high quality cod liver oil is probably a superior way to raise vitamin D levels, as compared to taking the standard vitamin D3 products although what is most important is just making sure that vitamin D levels are in the optimum range, whichever of the two products is used.

No matter which type of vitamin D is taken, the correct level of vitamin D supplementation required can be determined very accurately through periodically retaking the vitamin D test and adjusting dosages upwards or downwards as is appropriate.
**Which form of vitamin D should one take?**

Only vitamin D3 (cholecalciferol) is real vitamin D, all other compounds (for example vitamin D2 or ergocalciferol) are either metabolic products or chemical modifications.

Any high strength vitamin D3 product in the form of softgels, drops or sprays will likely be adequate. Super-concentrated drops are probably the best form as they allow for more exact dosing and with 2000 IU in every drop in products such as LEF’s vitamin D drops, one can take in high amounts of vitamin D with the fewest fillers and unnecessary additives and at the least cost.

Vitamin D and A are linked and a delicate balance must be maintained; without vitamin D, vitamin A can become ineffective or toxic, and without vitamin A, vitamin D can become ineffective. The Westen A. Price Foundation explains that cod liver oil contains the right ratios of vitamin A and K2 to vitamin D, and also contains all the important natural cofactors of these vitamins which are not included in commercial vitamin D products. They recommend cod liver oil as the best way to supplement vitamins A, K2 and D, and the best form of cod liver oil as fermented cod liver oil. The second best form is high vitamin cod liver oil.

The amount of cod liver oil usually recommended as a maintenance dose is enough to give you 10 000 IU of vitamin A daily. Where extra vitamin D is required – due to very low sun exposure as in M.E. – and it cannot be gotten from cod liver oil without raising the vitamin A intake too high, extra cod-liver oil source vitamin D capsules can be taken such as the Solar D Gems product form Carlson’s Labs. (Extra EPA/DHA, where necessary, can be taken in the form of fish oils.)

The best choice for vitamin D supplementation is probably fermented cod liver oil, followed by high-vitamin cod liver oil and standard vitamin D3 products. For information on sourcing the best fermented cod liver oil and high-vitamin cod liver oil please read the paper ‘Liver, liver extracts, cod liver oil and M.E.’

**How often should vitamin D supplements be taken?**

As vitamin D is fat soluble, it is possible to take a larger dose less often (perhaps every 2, 3 or even up to 7 days instead of every day) which may be more convenient and possibly less expensive. So if your daily vitamin D dose was calculated to be 5000 IU daily, you could take 10 000 IU every second day, or 35 000 IU once a week.

(Buying lower doses of vitamin D softgels wastes money when it is possible to buy the higher doses, and just take them less often.) Vitamin D should be taken with a meal containing fat, and that is also low in fibre if possible, to increase absorption.

Buying high-strength vitamin D products can be a problem in some countries where only 1000 IU products are made, and products over 1000 IU cannot be imported (without prescription) and may be confiscated. This includes Australia and New
Zealand. In Australia, a fee of $47 may also be payable where high-strength vitamin D products are intercepted. For more information on this see the LEF website and the appropriate government websites. (Note that Australian import guidelines can be very difficult to get the facts on, unfortunately.) It is recommended that you check your country’s import rules and regulations before importing anything that may be restricted.

**Do any other supplements have to be adjusted when vitamin D levels are raised?**

YES! The appropriate level of calcium supplementation varies enormously depending on vitamin D status, as vitamin D is required for proper calcium absorption.

According to *The vitamin D cure* book when vitamin D levels are very low (under 20 ng/ml), a dosage of 1000 to 1200 mg of calcium daily is appropriate as the body will only be able to absorb a very small amount of this calcium (25%). While vitamin D levels are slowly being raised, a dosage of 500 - 600 mg is appropriate. (At a vitamin D level of 35 ng/ml, calcium absorption increases to 30 - 40%).) When vitamin D levels are optimal, calcium supplements may not be necessary at all but this depends to some extent on your diet.

As *The vitamin D cure* explains, if you eat at least 6 servings a day of fruits and vegetables and do not consume large amounts of acid producing foods such as cheese, grains and legumes – in other words, if you have a ph neutral diet – then it is not necessary to take any extra calcium. When the diet is acid causing however, more minerals such as calcium, magnesium and potassium are needed to buffer the acid. If not enough of these minerals is taken in from your diet or supplements, your body will obtain them from its ‘vaults’ – your bones, muscles and joints. So if your vitamin D level is optimal, but your diet is acid causing overall, then 300 mg (up to a maximum of 600 mg) of calcium daily in a supplement may be necessary. To find out if your diet is ph neutral, or how to lower the acidity in your diet, see one of the many useful websites or books on this topic.

It is very important that if one has optimal vitamin D levels (or anywhere over 40 ng/ml) that no more than 600 mg of calcium be taken daily. It is also important that enough magnesium be taken with vitamin D, as vitamin D cannot be used by the body properly if there is not adequate magnesium present. Aim for at least 600 mg daily, and up to 1000 mg daily. (Higher doses, where necessary, should be taken under medical supervision.)

Adequate vitamin A and K2 are important when vitamin D levels are raised.

Note that diuretic drugs deplete the body of minerals such as calcium, magnesium and potassium and so these drugs should be avoided (unless there is a real medical need).
As vitamin D is fat soluble, it takes longer to have an effect than water soluble substances such as vitamin C. Most of the effects from raising vitamin D levels will be seen in 3 months although it may take 6 months for the full effects to be seen, and 6 months to correct a severe deficiency.

**How often should vitamin D testing be repeated?**

Some people may feel more comfortable having their vitamin D levels checked before starting any type of dedicated vitamin D supplementation.

If possible, vitamin D levels should be checked (or rechecked) 3 months after beginning to take a certain amount of D3 in order to determine whether or not this dose needs to be adjusted. Some doctors also recommend 3 monthly tests of ionised calcium levels.

Some experts recommend that retesting be done at 3 monthly intervals until the desired vitamin D level is reached (as this gives valuable feedback on how the dosage of vitamin D should be adjusted over time), and that this continue until 2 tests have consecutively shown this same optimum level. Once this has occurred, annual vitamin D testing is recommended.

**What about getting some vitamin D from food or from the sun?**

There is only a very small amount of vitamin D that can be obtained via the diet (excluding cod liver oil ingestion), and so sun exposure and supplements are the main sources of vitamin D.

People who are obese or that have a severe deficiency are unlikely to normalise levels with sun alone. People with M.E. are also very unlikely be able to get very much sun at all, due to the symptoms of M.E. and it is not recommended that M.E. patients get sun exposure at the cost of relapse when supplements can do the job with no payback. Although sun exposure is the best way to get vitamin D, it is not worth an M.E. relapse of any kind (as this defeats the purpose).

Most M.E. patients will need to reply completely on vitamin D supplements, or almost completely, but if some regular sun exposure is possible then this is recommended, although there are a few points to be aware of first. As the *Use of Vitamin D in Clinical Practice* explains, ‘When fair-skinned people sunbathe in the summer they produce about 20,000 IU of vitamin D in 30 minutes.’ But how much vitamin D ones body makes from the sun depends on several factors such as the amount of melanin in your skin and where you live and what season it is. Exactly how much sun you need depending on these factor is explained on many different websites such as the Mercola site and also in books such as *The vitamin D cure*.

Dr Mercola explained recently about vitamin D that,

Vitamin D3 is an oil soluble steroid hormone. It’s formed when your skin is
exposed to ultraviolet B (UVB) radiation from the sun (or a safe tanning bed). When UVB strikes the surface of your skin, your skin converts a cholesterol derivative in your skin into vitamin D3. However, the vitamin D3 that is formed is on the surface of your skin does not immediately penetrate into your bloodstream. It actually needs to be absorbed from the surface of your skin into your bloodstream. New evidence shows it takes up to **48 hours** before you absorb the majority of the vitamin D that was generated by exposing your skin to the sun! Therefore, if you shower with soap, you will simply wash away much of the vitamin D3 your skin generated, and decrease the benefits of your sun exposure. So to optimize your vitamin D level, you need to delay washing your body with soap for about two full days after sun exposure. Now not many people are not going to bathe for two full days. However you really only need to use soap underneath your arms and your groin area, so this is not a major hygiene issue. You’ll just want to avoid soaping up the larger areas of your body that were exposed to the sun.

Note that one cannot overdose on vitamin D that comes through exposure to the sun. The body will only make as much vitamin D as is needed after sun exposure.

Most M.E. patients, like MS patients, get sicker in even mild heat. This may be minimised by getting sun only in the late afternoon in summer, and in cooler months putting your head in the shade while getting some sunshine on your uncovered arms and legs. Getting sun on your nails, especially your toenails, may also help prevent fungal nail infections. Little and often may be more doable than spending longer periods of time in the sun and also more effective as regards improving your vitamin D status.

Never get so much sun exposure that you are sunburned. The aim is to become only very slightly pink. Where skin is very pale, 20 - 30 minutes of sun exposure a day is ideal and more than this may not provide benefits.

**What is the problem with taking vitamin D2 instead of D3?**

Vitamin D2 was the first synthetic form of Vitamin D and is the form of vitamin D in all **Vegan Vitamin D**.

The article ‘The Value of Vitamin D3 over Vitamin D2 in Older Persons’ explains that ‘D2 (ergocalciferol) has lower bioactivity, poorer stability, and shorter duration of action, resulting in approximately 33% lower potency compared with vitamin D3.’ Kerri Knox RN of the Easy Immune Health website also explains that, If it were simply an issue of worse absorption, then you could simply take more to do the same job. But unfortunately, vitamin D2 just doesn't DO the job that vitamin D is supposed to do. One consequence of vitamin D deficiency is that the parathyroid gland becomes overactive, altering calcium metabolism. When vitamin D is replenished, then parathyroid hormone is lowered back to normal levels. But in a few studies, the parathyroid hormone was NOT decreased to...
normal with the administration of vitamin D2, but it DID decrease to normal with the Vitamin D3!

Note that prescription vitamin D is always vitamin D2 (and not D3), and so should be avoided. Small amounts of vitamin D2 may often be included in multivitamins. This is not harmful in small amounts, but this vitamin D2 should not be counted towards the amounts of vitamin D3 needed to optimise vitamin D levels.

**What about potential toxicity from vitamin D?**

There are very rarely problems from vitamin D taken at doses below 10 000 IU. Problems are rare but there is small risk of problems developing with taking too high a dose. There is a much higher risk however of vitamin D levels being low, which can also cause serious problems. Doing nothing is not always the safer option.

Symptoms can develop after taking vitamin D due to low magnesium levels as the body uses up magnesium when it converts vitamin D into its active form in the body. The very few side effects of taking vitamin D are almost always due to low magnesium levels. (Magnesium is the most important co-factor needed to utilise vitamin D but others include: vitamin K, zinc, boron, and vitamin A.)

High calcium levels can also be a problem when taking enough vitamin D. It is NOT appropriate to have high/optimal vitamin D levels and to keep taking 1000 g or more of calcium.

Note that vitamin D supplementation is not recommended for individuals with high blood calcium levels (hypercalcaemia). People with kidney disease, sarcoidosis, primary hyperparathyroidism and those who use cardiac glycosides (digoxin) or thiazide diuretics should consult a physician before taking supplemental vitamin D. As John Cannell MD from the The vitamin D council explains,

Vitamin D is safe when used in physiological doses (those used by nature). **Physiological doses** are doses of at least 5,000 IU per day, from all sources (sun, diet, and supplements). Should **hypercalcemia** occur with such doses, it is due to **vitamin D hypersensitivity syndrome**, not **vitamin D toxicity**. Vitamin D hypersensitivity syndromes include conditions such as primary hyperparathyroidism, occult cancers (especially lymphoma), or granulomatous disease (especially sarcoidosis). In such cases, treatment of vitamin D deficiency should be done under the care of a knowledgeable physician. A serum 25(OH)D, serum 1,25(OH)2D3, PTH, and SMA will lead the clinician in the right direction.

John Cannell MD continues,

Is vitamin D toxic? Not if we take the same amount nature intended when we go out in the sun. Vieth attempted to dispel unwarranted fears in medical community of physiological doses of vitamin D in 1999 with his exhaustive and well-written review. His conclusions: fear of vitamin D toxicity is unwarranted, and such
unwarranted fear, bordering on hysteria, is rampant in the medical profession. Even Ian Monroe, the chair of the relevant IOM committee, wrote to the Journal to compliment Vieth's work and to promise his findings will be considered at the time of a future Institute of Medicine review. That was more than two years ago.

In 1999, Vieth indirectly asked the medical community to produce any evidence 10,000 units of vitamin D a day was toxic, saying "Throughout my preparation of this review, I was amazed at the lack of evidence supporting statements about the toxicity of moderate doses of vitamin D." He added: "If there is published evidence of toxicity in adults from an intake of 250 ug (10,000 IU) per day, and that is verified by the $25(OH)D$ concentration, I have yet to find it."

Like most medication, cholecalciferol is certainly toxic in excess, and, like Coumadin, is used as a rodent poison for this purpose. Animal data indicates signs of toxicity can occur with ingestion of 0.5 mg/kg (20,000 IU/kg), while the oral LD50 (the dose it takes to kill half the animals) for cholecalciferol in dogs is about 88 mg/kg, or 3,520,000 IU/kg. This would be equivalent to a 110-pound adult taking 176,000,000 IU or 440,000 of the 400 unit cholecalciferol capsules. Vieth reports human toxicity probably begins to occur after chronic daily consumption of approximately 40,000 IU/day (100 of the 400 IU capsules). Heavy sun exposure when combined with excessive supplement use is a theoretical risk for vitamin D toxicity, but if such a case has been reported, I am not aware of it. Physician ignorance about vitamin D toxicity is widespread. A case report of four patients appeared in the 1997 Annals of Internal Medicine, accompanied by an editorial warning about vitamin D toxicity. However, careful examination of the patients reveals that both papers are a testimony to the fact that incompetence about vitamin D toxicity can reach the highest levels of academia. See worst science for a full critique.

It is true that a few people may have problems with high calcium due to undiagnosed vitamin D hypersensitivity syndromes such as primary hyperparathyroidism, granulomatous disease, or occult cancers, but a blood calcium level, PTH, $25(OH)D$, and calcitriol level should help clarify the cause of the hypersensitivity. Although D can be toxic in excess, the same can be said for water.

As a physician, I know that psychotic patients should drink about 8 glasses of water a day. However, many would hurt themselves by regularly drinking 40 glasses a day (called compulsive water intoxication). So you could say that water has a therapeutic index of 5 (40/8).

Heaney's recent research indicates that healthy humans utilize about 4,000 units of vitamin D a day (from all sources). However, 40,000 units a day, over several years, will hurt them. Therefore, vitamin D has a therapeutic index of 10 (40,000/4,000)—twice as safe as water. We are not saying vitamin D is as safe as water, we are saying vitamin D is safe when used in the doses nature uses.

Dr Norm Shealy explains that,

One of the myths rampant in the medical profession is vitamin D toxicity. There are numerous papers demonstrating the safety of at least 10,000 units of D3 daily and one published paper states that 50,000 unit daily is a safe level. One clinical
report of D toxicity occurred in a man who had taken 156,000 to 2,604,000 units of D for two years! He recovered uneventfully. In general the risk of large dosages of D is that of excess calcium, so that those taking more than 10,000 units daily should never take calcium supplements. Individuals with hyperparathyroidism or some granulomatous diseases, which leads to excess calcium in the blood, should not take large dosages of D-for them probably 2,000 units of D 3 daily is the maximum to be used. My vitamin D level (on 50,000 units daily) is quite high, but my calcium level is normal.

The Weston A. Price Foundation explains that levels higher than 50 ng/ml should always be combined with adequate levels of vitamin A and vitamin K2. They explain that these vitamins may protect against vitamin D toxicity as even a moderate increase in the amount of vitamin D in the body increases the need for vitamins A and K2 enormously. This is why they recommend vitamin D from cod liver oil and sun exposure only.

According to the Mayo Clinic, side-effects (or possibly, early overdose symptoms) from vitamin D (which emerge within days or weeks of starting vitamin D supplements) include bone pain, constipation (especially in children or adolescents), diarrhoea, drowsiness, dryness of mouth, headache (continuing), increased thirst, increase in frequency of urination, especially at night, or in amount of urine, irregular heartbeat, itching skin, loss of appetite, metallic taste, muscle pain, nausea or vomiting (especially in children or adolescents) and unusual tiredness or weakness.

Late symptoms of vitamin D overdose (which emerge within weeks or months of starting supplements) include bone pain, calcium deposits (hard lumps) in tissues outside of the bone, cloudy urine, drowsiness, increased sensitivity of eyes to light or irritation of eyes, itching of skin, loss of appetite, loss of sex drive, mood or mental changes, muscle pain, nausea or vomiting, protein in the urine, redness or discharge of the eye, eyelid, or lining of the eyelid, runny nose and weight loss. Late symptoms of severe vitamin D overdose (which emerge after months or years of starting supplements) include high blood pressure, high fever, irregular heartbeat and stomach pain (severe).

Supplements of vitamin D work well to raise vitamin D levels, although they do raise the risk of side effects, overdose and toxicity to some extent as compared to getting vitamin D from sun exposure. (There have been zero reported incidences of overdose on Vitamin D from too much sunshine.) Raising the dose of vitamin D supplements slowly helps to minimise any possible side effects as does taking extra magnesium and less than 600 mg of calcium. (Side effects are NOT the same thing as an overdose. Overdoses on vitamin D cause high vitamin D levels and high blood calcium levels – a medical emergency.) As vitamin D is fat soluble, side effects will take days or weeks to disappear.

If you think you may be experiencing a vitamin D overdose, stop taking vitamin D and calcium right away and have your doctor test your vitamin D and calcium levels.
Again, Vitamin D toxicity/overdose is thought to be extremely rare. As Kerri Knox RN explains, the majority of documented vitamin D overdoses are from:

- Children whose parents accidentally give them massive doses of vitamin D
- Elderly people incorrectly taking massive vitamin D dosages
- Adults who take more than 10,000 IU's per day for long periods of time.
- ‘Industrial Accidents' where massive quantities of vitamin D are put into fortified foods in error

For more information on side-effects, overdose and toxicity please see the excellent article: Vitamin D Overdose by Kerri Knox RN, The vitamin D cure by James Dowd M.D., or the Vitamin D Council website.

More information
The following books and websites are highly recommended sources of additional information.

- The book The vitamin D cure by James Dowd M.D. is highly recommended and contains a very solid overview of this topic, and a lot of simple practical advice for patients and doctors. This book is thoroughly researched and referenced.
- The Vitamin D Council website. This website contains links to many different studies on vitamin safety and effectiveness and also provides an easy to understand overview of this topic. The Executive Director of this group is John Cannell MD.
- Everything You Ever Wanted to Know About Vitamin D by Dr Frank Lipman. Frank Lipman MD, is the founder and director of the Eleven Eleven Wellness Center in NYC, a center whose emphasis is on preventive health care and patient education.
- Vitamin D Overdose and other articles on vitamin D compiled (using the latest research) by Kerri Knox RN, of the Easy Immune Health website including The ‘easy immune health’ Fact Sheet on Vitamin D (PDF)
- My Vitamin D Recommendations by Dr Brownstein
- To read about C. Norman Shealy M.D. Ph.D.’s high dose vitamin D protocol for serious disease, see VITAMIN D BOOSTS IMMUNITY and VITAMIN D: THE CURE FOR MANY DISEASES? and VITAMIN D 3- MOST CRITICAL SUPPLEMENT.

Note that in all the books and articles listed here, and below, where ‘CFS’(or even M.E.) is referred to, what is being discussed is not M.E., nor any other neurological disease. Some doctors refer to general miscellaneous chronic fatigue sufferers while others refer to patients with post-viral fatigue syndromes caused by glandular fever/mononucleosis etc.) ‘CFS’ and M.E. are NOT the same. For more information on why some falsely claim ‘CFS’ and M.E. are synonymous terms please see: What is M.E.?
Reference list:

- The book *The vitamin D cure* by James Dowd M.D.
- The vitamin D council website
- Vitamin D Overdose and other articles on vitamin D compiled by Kerri Knox RN, of the Easy Immune Health website including *The ‘easy immune health’ Fact Sheet on Vitamin D (PDF)*
- VITAMIN D BOOSTS IMMUNITY and VITAMIN D: THE CURE FOR MANY DISEASES? and VITAMIN D 3- MOST CRITICAL SUPPLEMENT by C. Norman Shealy M.D. Ph.D.
- The Vita-Nutrient Solution by Dr Atkins
- The Dr Mercola website
- Vitamin D: The Sunshine Vitamin by Zoltan Rona M.D.
- Vitamin D’s Crucial Role in Cardiovascular Protection by William Davis, MD (on LEF)
- Startling Findings About Vitamin D Levels in Life Extension® Members by William Faloon
- Vitamin D report: Cancer Prevention and Other New Uses by Russell Martin (on LEF) – plus many other LEF articles on vitamin D
- Vitamin D – A Neglected 'Analgesic' (*Summary*)-Practitioner Briefing - 7 pages
- Vitamin D – A Neglected 'Analgesic' for Chronic Musculoskeletal Pain An Evidence-Based Review & Clinical Practice Guidance (*Full Report*) - Clinical Recommendations with 170 research citations - 50 pages
- Vitamin D: A Champion of Pain Relief (*Patient Brochure*) - 6 pages
- Vitamin D and cardiovascular disease. Giovannucci E.
- Calcium and Vitamin D Diagnostics and Therapeutics
- Use of Vitamin D in Clinical Practice
- 'Circulating 25-Hydroxyvitamin D Levels Indicative of Vitamin D Sufficiency: Implications for Establishing a New Effective Dietary Intake Recommendation for Vitamin D'
- Michael F. Holick’s article 'The Vitamin D Epidemic and its Health Consequences'
- Prospects for Vitamin D Nutrition: Dr Reinhold Vieth, PhD
- Creighton Study Shows Vitamin D Reduces Cancer Risk
Treating M.E.: The basics

- Everything You Ever Wanted to Know About Vitamin D by Dr Frank Lipman
- Vitamin D – the Re-discovered Key to Illness Prevention, by Tony Pearce RN
- Vitamin D Prescription: The Healing Power of the Sun & How It Can Save Your Life by Eric Madrid MD

Relevant quotes:
‘Vitamin D stands uniquely apart from all other vitamins. Vitamin D is actually a hormone that plays a central role in metabolism and also in muscle, cardiac, immune, and neurological functions, as well as in the regulation of inflammation.’ Dr Andrew Weil in the foreward to ‘The Vitamin D Solution’

If you think of it evolutionarily, it's the oldest hormone on this Earth. I don't think that this is going to be a flash in the pan. Dr Michael F. Holick, Vitamin D expert.

Because vitamin D is so cheap and so clearly reduces all-cause mortality, I can say this with great certainty: Vitamin D represents the single most cost-effective medical intervention in the United States. Dr Greg Plotnikoff, Medical Director, Penny George Institute for Health and Healing, Abbott Northwestern Hospital in Minneapolis.

I believe [vitamin D] is the number one public health advance in medicine in the last twenty years. Dr John Whitcomb, Aurora Sinai Medical Center.

Light is the basic component from which all life originates, evolves, and is energized. Light and health are inseparable. ~ Ken Ceder, former co-director Hippocrates Health Institute, Boston, Massachusetts.

Sunlight is more powerful than any drug; it is safe, effective, and available free of charge. If it could be patented, it would be hyped as the greatest medical breakthrough in history. It's that good. Mike Adams, natural health researcher and author.

This is like the Holy Grail of cancer medicine; vitamin D produced a drop in cancer rates greater than that for quitting smoking, or indeed any other countermeasure in existence. Dennis Mangan, clinical laboratory scientist.

No other method to prevent cancer has been identified that has such a powerful impact. Dr Cedric Garland, Vitamin D expert.

Vitamin D is a hormone... powerful, potent, and paleo-to-the-core. Since pre-paleolithic times, Vitamin D has been produced in our skin from the UVB radiation of sunlight. The sun indeed powers nearly all life on earth. It is essential and signals...
reproduction, energy and longevity for not just humans but all land and marine plants, prokaryotes, and animals. Dr BG, pharmacologist.

I would challenge anyone to find an area or nutrient or any factor that has such consistent anti-cancer benefits as vitamin D. The data are really quite remarkable. Dr Edward Giovannucci, Vitamin D expert.

In all my many years of practice of medicine, I've never seen one vitamin, even vitamin C, have such profound effects on human health. Dr Soram Khalsa, board-certified internist and medical director for the East-West Medical Research Institute.

We estimate that vitamin D deficiency is the most common medical condition in the world. Dr Michael F. Holick, Vitamin D expert.

Vitamin D is cholecalciferol, a hormone. Deficiencies of hormones can have catastrophic consequences. Dr William Davis, cardiologist.

Vitamin D3 is regulated by P450 enzyme systems that are in turn decoupled due to low NADPH levels in CFS. This raises important questions regarding the reasons that may underlie low D3 levels typical for most CFS cases. The finding of increased intracellular calcium by UK investigators may also play into the reasons for finding low D3 in CFS. Given these deeper issues that may underlie D3 levels suggests that aggressive D3 therapy may not be the best course of action in CFS. D3 is a highly regulated pro-hormone and there could be good reasons for it to be down-regulated in CFS. Dr Paul Cheney. (Note that when Cheney talks about ‘CFS’ he is talking about a mixed patient group. Sometimes his comments relate to M.E., as when he discusses cardiac insufficiency, but more often they refer to an unscientific mix of M.E. facts and facts about various mixed patient groups which merely qualify for a ‘CFS’ misdiagnosis. ‘CFS’ is not the same thing as M.E. and these two terms are NOT interchangeable. ‘CFS’ is always a misdiagnosis. Cheney’s views on politics cannot be in any way supported by HFME. However, it is impossible to say a) if Cheney’s theory on vitamin D is correct or b) if this theory is correct, if it has any relevance for actual M.E. patients – many of whom have low vitamin D levels because they are bedbound and cannot and do not ever get any sun.)

Vitamin D deficiency is an unrecognized, emerging cardiovascular risk factor, which should be screened for and treated. Vitamin D is easy to assess, and supplementation is simple, safe, and inexpensive. James H. O'Keefe MD, cardiologist and Director of Preventive Cardiology, Mid America Heart Institute, Kansas City, Missouri.
The vitamin D checklist for M.E. patients
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There are a number of different ways to go about getting optimum vitamin D levels, depending on your level of medical care and your financial resources, and so on.

Option 1. The standard approach

A. To determine if you fall into the high risk category of low vitamin D levels, complete the checklist in The vitamin D cure book, which is also available free online.

B. If you are at high risk for low vitamin D levels (or you know you have low vitamin D levels as you have had no sun exposure for years or decades), then start taking either 5000 IU of vitamin D3 daily (as recommended by The Vitamin D Council), or 25 IU of vitamin D3 per pound or 60 IU per kilo of your current body weight, daily (as recommended by The vitamin D cure book). If possible, do this under a doctor’s supervision.

C. After 3 months of taking these supplements, take a 25(OH)D test to check your vitamin D levels (and also an ionised calcium levels test, if possible).

D. If your 25(OH)D test shows that you need to raise your vitamin D levels, take 10 000 IU of vitamin D3 daily if your level is below 30 ng.ml and take 5000 IU daily if your level is 30-45 ng/ml (as recommended by Frank Lipman M.D.). Or follow the precise recommendations given on dosages for different tested deficiency levels (per pound or kilo of body weight) given in The vitamin D cure book. (This book explains that for any extended period of time, even if one has no sun exposure at all, one shouldn’t need more than 40 IU of vitamin D per pound of body weight daily (or 85 IU per kilo) as this raises the blood level by 50 ng/ml. Thus even if the level was extremely low to begin with, for example 5 ng/ml, the level would be raised to 55 ng/ml at this dosage, which is in the optimal range for health and very safe.)

E. After 3 months of taking these supplements, take a 25(OH)D test to check your vitamin D levels. If you still need to raise your vitamin D levels, continue taking this same dose for another 3 months and then retest.

F. See below for information on how often to retest vitamin D levels once optimum levels have been reached, and how to adjust your vitamin D dosage accordingly. For your own safety and convenience, please make sure you read all of the information given below.
Option 2. The cautious approach (for those that are cautious and have reasonable access to medical care)

Before starting any supplementation, ask your doctor to give you a 25(OH)D test – or buy your own at-home test online. Then follow the guidelines given above in Option 1 from point D onwards (or the instructions of your doctor).

Option 3. The very cautious approach (for those that are very cautious and also have access to high-level medical care)

- Before starting any supplementation, ask your doctor to give you the following 3 tests to check you aren’t one of the very rare individuals for whom taking extra vitamin D (at this time) could be harmful: the 25(OH)D test, the intact PTH test and a test measuring your calcium levels.
- Then follow the guidelines given above in Option 1 from point D onwards (or the instructions of your doctor).
- Note that Frank Lipman M.D. also recommends that, ‘If you are taking high doses (10,000 IU a day) your doctor must also check your calcium, phosphorous, and parathyroid hormone levels every three months.’

Vitamin D testing: To diagnose vitamin D deficiency by blood test, the only useful test is a 25-hydroxyvitamin D (25(OH)D) test. The optimal level on testing is often said to be 50 – 80 ng/ml, but if you prefer a slightly more conservative approach you may like to aim for 50 – 60 ng/ml. Toxicity is not a concern under 100 ng/ml. The Vitamin D Council offers a reasonably priced and high quality do-at-home vitamin D test (or a set of four tests for a discounted price). Check first that you can’t get a test for free through your doctor, however.

Vitamin D and obesity: If you weigh over 300 pounds or 135 kilos, vitamin D tests are highly recommended after a few months of supplementation at the levels recommended per pound or kilo in the The vitamin D cure book, as at this weight this equation may significantly under- or over-estimate the level of vitamin D required.

Vitamin D and children: Vitamin D is even more important in children than adults. However, the dosages for vitamin D3 supplementation given in this paper are for adults and are not suitable for children. The Vitamin D Council recommends the same amount of vitamin D supplementation for adolescents as adults, and recommends that, ‘Healthy children under the age of 1 years should take 1,000 IU vitamin D3 per day—over the age of 1, 1,000 IU vitamin D3 per every 25 pounds of body weight per day.’ 25 pounds is equal to 11.4 kg. If at all possible, children should take vitamin D supplements under medical supervision and testing should be done every 3 months until an optimal level is reached and also until 2 tests have consecutively shown this same optimum level. Once this has occurred, annual vitamin D testing is recommended. A maintenance dose of vitamin D (lower than the
A dose needed to raise vitamin D levels (initially) may be necessary to keep levels in the optimum range.

**Vitamin D supplements**: Any high strength vitamin D3 product in the form of softgels, drops or sprays will suffice. The dose can be taken daily, or you can take all seven days worth of vitamin D once a week. Vitamin D should be taken with a meal containing fat (and low in fibre, if possible).

**Time taken to reach optimal levels**: If vitamin D levels are very low, as they will be for the majority of severely affected patients, it will take around six months for levels to become optimal. Levels will raise very gradually in other words, as vitamin D is fat soluble.

**Calcium supplementation**: You MUST adjust your calcium intake as you start raising your vitamin D levels. Taking 1000 – 1200 mg of calcium daily is necessary when vitamin D levels are very low but it is not appropriate as your vitamin D levels become optimal and could cause calcium levels to become too high. Do not take more than 600 mg of calcium daily once you have started raising your vitamin D levels and once your levels are optimal. If you take 10 000 IU of vitamin D daily, or more, you may need to stop taking calcium altogether and you should have your calcium levels checked regularly. If you have a pH neutral diet, then you may not need to take any calcium at all. If your diet is slightly acidic, you may need 300 – 600 mg of calcium daily.

**Magnesium supplementation**: Make sure you are also taking at least 600 mg of magnesium daily if you are taking any vitamin D supplement.

**Vitamin D from the sun**: People who are obese or that have a severe deficiency are unlikely to normalise levels with sun alone. People with M.E. are also very unlikely to get very much sun at all, due to the symptoms of M.E. But if some regular sun exposure is possible (without relapse of any kind) and you would like to get some sun as well as take some supplements then this is recommended, and you may like to find out how best to go about it on websites such as the Mercola site and in books such as *The vitamin D cure*.

**Repeating vitamin D tests**: If possible, vitamin D levels should be checked (or rechecked) 3 months after beginning to take a certain amount of D3 in order to determine whether or not this dose needs to be adjusted.

Many experts recommend that retesting be done at 3 monthly intervals until the desired vitamin D level is reached (as this gives valuable feedback on how the dosage of vitamin D should be adjusted over time), and that this continue until 2 tests have consecutively shown this same optimum level. Once this has occurred, annual vitamin D testing is recommended.

Once vitamin D is at an optimum level, the amount of vitamin D you are taking should be reduced to an amount that lets you maintain the optimum level you desire. Thus a
maintenance dose of vitamin D (lower than the dose needed to raise levels from low to optimal) may be necessary to keep levels in the optimum range. This may be from 2000 – 5000 IU daily, or perhaps slightly more in some individuals depending on weight and levels of sun exposure etc.

Note that vitamin D supplementation is not recommended for individuals with high blood calcium levels (hypercalcaemia). People with kidney disease, sarcoidosis, primary hyperparathyroidism and those who use cardiac glycosides (digoxin) or thiazide diuretics should consult a physician before taking vitamin D.

Please see the main vitamin D paper for more information on the benefits of vitamin D, the safety and toxicity or vitamin D, and for references. It is highly recommended that this paper be read in full (and, if possible, some of the additional recommended resources also). These papers has been created purely for the use of those very ill patients that are unable to read or fully take in the books and websites used to produce this summary, and is designed to be used as a starting point in patients’ research efforts.

Disclaimer: HFME does not dispense medical advice or recommend treatment, and assumes no responsibility for treatments undertaken by visitors to the site. It is a resource providing information for education, research and advocacy only. Please consult your own health-care provider regarding any medical issues relating to the diagnosis or treatment of any medical condition.
Vitamin E is a master antioxidant and the body's most potent fat-soluble antioxidant. Vitamin E is crucial for protecting against free radical damage.

Vitamin E also strengthens and regulates the heartbeat (and is very important in preventing and treating heart disease and cardiac conditions), enables the heart to do more work with less oxygen, promotes wound healing, helps prevent blood clots, improves fertility and some PMS and menopause symptoms, reduces the risk of heart disease, cancer, stroke and cataracts and strengthens the immune system (and effects many other bodily processes).

Vitamin E increases the body's production of CD4 cells, natural killer cells, and certain antibodies, boosting overall immunity without overstimulating the immune system or aggravating autoimmune disorders. Vitamin E can also slow down the mental decline associated with some neurological disorders. Dr Atkins explains that vitamin E supplementation is essential for diabetics and that, 'When vitamin E levels are low, the risk of acquiring type 2 Diabetes rises by a ratio of four to one.'

What is vitamin E?

Contrary to popular belief, vitamin E is not just alpha-tocopherol. As vitamin E expert, and author of book The Vitamin E Factor, Andreas M. Papas, Ph.D. explains,

Unlike some vitamins, which consist of a single compound, vitamin E consists of eight different compounds, four tocopherols and four tocotrienols (designated as alpha, beta, gamma and delta). Our food contains all eight compounds. Alpha-tocopherol became synonymous with vitamin E for two reasons: (1) It is the most abundant of the eight in our (and in other animals) bodies; (2) It is the most effective of the eight to support reproduction—which we thought was vitamin E’s main function. Are the differences between the eight vitamin E family members a big deal? Yes. These eight members have some similar but other different functions. Where they go in our body varies, especially for alpha-tocopherol versus the others.

Thus it is important when supplementing vitamin E that we take some natural alpha-tocopherol and also some of the other 7 vitamin E compounds. As gamma-tocopherol is far more effective than alpha-tocopherol at reducing nitrogen radicals and reducing inflammation, it is also advisable for those with serious diseases such as M.E. to take...
some extra gamma-tocopherol. (Gamma-tocopherol is the most prevalent form of vitamin E in nature. Gamma-tocopherol reduces nitrogen dioxide back to NO or reacts with it to form a harmless compound. Very preliminary data also suggests that gamma-tocotrienol may have a similar effect.) There is some vitamin E in foods (such as nuts and seeds, wheat germ, sweet potato, cauliflower and peas) but this is not enough to provide the benefits shown in vitamin E research, and so vitamin E supplements are necessary.

Natural vs synthetic and esterfied vs unesterfied vitamin E
Unlike most vitamins, with vitamin E there is a real difference between natural and synthetic. It is very important to buy only natural vitamin E. When buying alpha-tocopherol make sure to buy d-alpha tocopherol and NOT dl-alpha tocopherol. (Watch out for that lower case L after the D.) If the bottle does not say if it contains natural or synthetic vitamin E, assume it is a synthetic product.

Make sure to also buy an unesterfied form of alpha-tocopherol. This form of vitamin E is ‘muzzled’ and the body needs to work to ‘demuzzle’ it chemically before it can be used by the body, which may be a problem in serious diseases such as M.E. (particularly in larger doses). The alpha-tocopherol contained in powders and multivitamins will almost always be esterfied, as this makes the product more stable. Esterfied alpha-tocopherol in a multi is fine, but make sure that when buying a stand-alone alpha-tocopherol product that you avoid this form. When you see terms such as ‘succinate’ and ‘acetate’ written after d-alpha-tocopherol, this lets you know that it is an esterfied product.

Note that only alpha-tocopherol is sold in synthetic and esterfied forms. The other 7 vitamin E compounds are only available in natural and unesterfied forms.

IU vs milligrams
The system of measuring vitamin E in ‘International units’ came about when it was thought that alpha-tocopherol was the only important vitamin E compound. But this system only tells part of the story (see The Vitamin E Factor book for more information on the history of vitamin E and the IU system of measurement). Today, very often alpha-tocopherol is measured in IU and the other 7 vitamin E compounds are measured in milligrams. (If a conversion is necessary, however, note that one IU of natural alpha-tocopherol is equal to 0.67 milligrams of natural alpha-tocopherol. [Online converters are also available.]

Proper Absorption of Vitamin E
Vitamin E is better at preventing disease than treating it. Andreas M. Papas, Ph.D. states that conditions such as leaky gut syndrome (a condition very often seen in M.E.) can impede the absorption of vitamin E and that,
Vitamin E deficiency can go undetected for a long time. Once damage is found, it is largely irreversible. This is especially so for damage to nerve tissue. For proper absorption of vitamin E, low fat diets can be bad. A healthy person absorbs oils (which include vitamin E) through micelles (tiny spheres), which carry the oil/fat compounds through our intestine wall. The fat is put into these unique tiny spheres (micelles) with a water-loving (hydrophilic) outer layer. There is also a special, unique form of vitamin E labeled TPGS. It is water soluble and forms its own tiny spheres so it can be more easily absorbed by people with diseases like AIDS who need it.

A water-soluble source of vitamin E, such as Aqua-E, allows for improved absorption in patients with diseases of malabsorption that affect the liver, pancreas, or intestines. Aqua-E forms its own micelles—small spheres that have a water-loving exterior to allow the vitamin E to make contact with the lining of the gut—and contains all eight members of the vitamin E family.

(Note that vitamin E expert Andreas M. Papas PhD is a founding member of Yasoo, the producer of ‘Aqua-E.’) Several different companies manufacture water soluble vitamin E. Look for tocopheryl succinate polyethylene glycol 1000 (TPGS) or do a search for ‘water soluble vitamin E.’

Loose stools that appear to have lots of fat in them and extreme weight loss may be a sign of severe problems absorbing fat from the diet. Most often patients with absorption problems will have decreased absorption levels however, rather than a complete inability to take in any vitamin E at all (this is quite rare). Thus if one cannot afford expensive water soluble vitamin E products, taking a reasonable dose of standard vitamin E (all 8 types) will still allow some vitamin E to be absorbed. Andreas M. Papas’s book on vitamin E gives more information on the need for water soluble vitamin E, and how this product can be combined with other fat soluble vitamins to also improve their absorption.

A biochemical antioxidant profile test may be useful if problems absorbing vitamin E are suspected as this test measures the levels of beta carotene, vitamin A and vitamin E in the blood.

Toxicity and vitamin E
Andreas M. Papas, Ph.D. explains that, ‘Unlike other fat-soluble vitamins, toxicity of vitamin E is very low probably because it is not stored in the liver.’ While mild gastrointestinal upset may occur at very high doses, daily doses of 1600 IU or more have been given for significant periods of time with no toxicity.

Vitamin E precautions
Vitamin E thins the blood, as so should be discontinued before surgery. More vitamin E may be needed if large doses of vitamin A or fish oil are taken (while CoQ10 recycles vitamin E).
Topical use of vitamin E

Andreas M. Papas, Ph.D. explains that esterfied forms of alpha-tocopherol are not appropriate or effective for use in topical oils and creams (as the skin can’t break them down properly) and that the only useful form for topical application is unesterfied natural vitamin E. Vitamin E oils can improve healing and be useful in treating burns and various types of sores. A few drops from a vitamin E capsule or oil may treat problems with earwax even better than olive oil.

The correct dosage and types of vitamin E

Dosages typically given for alpha-tocopherol vary from 400 – 800 IU or sometimes up to 1200 IU, however, this ignores the evidence which suggests that taking this one form of vitamin E alone isn’t as effective or as safe as taking all 8 at once. Andreas M. Papas, Ph.D. recommends in his book on vitamin E that those with serious neurological diseases take 400 IU (or approximately 270 mg) of alpha-tocopherol daily, plus 400 mg of mixed tocopherols and tocotrienols. This gives a total of 670 mg of vitamin E daily. (He also recommends that over the age of forty that this dosage be doubled. Note however that the first dosage recommendation given is still quite high, and so doubling it gives a very high dose that may or may not be necessary for all patients.)

Recent studies have shown that taking alpha-tocopherol alone can lead to a depletion of gamma and delta-tocopherol which is problematic as more and more studies are showing the benefits of gamma-tocopherol in particular.

At this time, experts suggest that this problem is best solved by making sure that one takes at least twice as much gamma-tocopherol as alpha-tocopherol as well as some of each of the other 6 types of vitamin E in the proper proportions. While the issue of alpha- vs. gamma-tocopherol requires more research before it can be fully understood, Lyle MacWilliam from the LEF explains that,

Although less is known about gamma tocopherol than about alpha tocopherol, recent evidence suggests that the gamma form is an important weapon in defending against cardiovascular disease. Several investigations confirm that higher tissue concentrations of gamma tocopherol are associated with lower rates of illness and death due to cardiovascular events. Numerous studies suggest that gamma tocopherol may provide powerful protection for the heart. While both forms of vitamin E have disease-preventive actions that reflect their individual chemistries, it is their combination that likely accounts for the powerful preventive effects observed in epidemiological, retrospective, and laboratory studies. Consequently, to highlight one form and exclude the other is to sell both forms short.

So if one wanted to stay with Papas’s recommendation of taking 670 mg of vitamin E daily (made up of some of each of the 8 types of vitamin E) and also take into account the new research recommending that twice as much gamma-tocopherol as
alpha-tocopherol be taken, then one may decide on a daily vitamin E intake as follows:

- Approximately 170 mg (250 IU) of alpha-tocopherol
- Approximately 345 mg of gamma-tocopherol, 115 mg of delta-tocopherol and 8 mg of beta-tocopherol
- 50 mg of mixed tocotrienols

This gives a daily total of approximately 688 mg.

There are several ways to go about getting these specific amounts and types of vitamin E.

- One could take one 200 IU softgel of natural alpha-tocopherol daily, plus around 50 IU of extra natural alpha-tocopherol used as an antioxidant in various other supplements such as fish oil and ubiquinol, plus eight ‘gamma-E’ softgels EACH WEEK each containing 300 mg of gamma-tocopherol (and also roughly 100 mg of delta-tocopherol and 7 mg of beta-tocopherol), plus a 50 mg mixed tocotrienols product once daily.

- One could take a multivitamin that contains 200 IU of natural (though probably esterfied) alpha-tocopherol, plus around 50 IU of extra natural alpha-tocopherol used as an antioxidant in various other supplements such as fish oil and ubiquinol, plus eight ‘gamma-E’ softgels EACH WEEK each containing 300 mg of gamma-tocopherol (and also roughly 100 mg of delta-tocopherol and 7 mg of beta-tocopherol), plus a 50 mg mixed tocotrienols product once daily.

- One could take a multivitamin that contains 250 IU of natural (though probably esterfied) alpha-tocopherol, plus eight ‘gamma-E’ softgels EACH WEEK each containing 300 mg of gamma-tocopherol (and also roughly 100 mg of delta-tocopherol and 7 mg of beta-tocopherol), plus a 50 mg mixed tocotrienols product once daily.

- One could take a daily multivitamin that contains 50 IU of natural (though probably esterfied) alpha-tocopherol, plus a 400 IU alpha-tocopherol softgel every second day, plus eight ‘gamma-E’ softgels EACH WEEK each containing 300 mg of gamma-tocopherol (and also roughly 100 mg of delta-tocopherol and 7 mg of beta-tocopherol), plus a 100 mg mixed tocotrienols product every second day.

If a lower level of vitamin E supplementation is desired, due to financial or other reasons, then the daily dosages given above can be halved. (This lower level of supplementation can also be halved again, if necessary. It is far better to take a smaller amount of vitamin E than none at all.)

If the total amount of alpha-tocopherol in a daily multivitamin and other supplements is slightly higher than 250 IU, it may be necessary to up the gamma-E intake to 9 weekly instead of 8 to keep the ratios the same. If daily alpha-tocopherol intake were only 200 IU, then perhaps gamma-E intake could be taken down to 7 weekly instead of 8, to again keep the ratios the same.
At least 50 mg of mixed tocotrienols daily is ideal (or 50 mg every second or third day, if financial restraints are an issue). If financial restraints are less of an issue, it may also be worthwhile considering a high-dose tocotrienol complex of up to 200 mg daily, as this has been shown to be helpful for those with various types of heart disease.

Dr Sherry Rogers recommends a very high daily vitamin E intake (in serious illness) of 1–2 E Gems Elite, 1 Gamma E Gems, and 1–2 Tocotrienols, all from the Carlson Labs brand.

Prices vary considerably, so some research of different brands is necessary. Perhaps companies such as Carlson Labs, Jarrow and LEF which offer several good vitamin E products are a good place to start. Looks for brands, like these three, which list all the individual amounts of each compound and don’t just say ‘mixed’ tocopherols or tocotrienols, as such products very often give you more of the cheaper compounds (such as the alphas) and less of the more expensive and more beneficial ones. Look at the products from these brands to see what the proper percentages of each tocopherol and tocotrienol should be (percentages similar to those found in nature).

Expect to wait at least 3 months to see an effect from vitamin E supplementation, as vitamin E is fat soluble and takes a while to build up in the body (particularly in the brain). Vitamin E is well tolerated by M.E. patients generally, but it is highly recommended that the dose be raised gradually and that the final desired daily dose is worked up to over at least 2 months.

References and recommended reading list
- The Vitamin E Factor book by Andreas M. Papas, Ph.D.
- Vitamin E: A New Perspective by Andreas M. Papas, Ph.D.
- What Makes Gamma Tocopherol Superior to Alpha Tocopherol by Lyle MacWilliam MSc FP on LEF
- Vitamin E Malabsorption: Common, Extremely Serious and Preventable by Andreas M. Papas, Ph.D.
- The Vitamin E Factor—Summary and Review
- Get the Straight Facts on Vitamin E Tocopherol by Smart Publications
- The Vita-Nutrient Solution by Dr Atkins

Relevant quotes:
‘Free radicals are cellular renegades; they wreak havoc by damaging DNA, altering biochemical compounds, corroding cell membranes, and kill cells outright.’ Time, April 6, 1992

"Vitamin E is Nature’s master antioxidant" Scientific American, March/April, 1994
‘The nerves in the brain are the most susceptible to damage from free radicals. Vitamin E is the best antioxidant to fight free radicals, which attack the membranes of nerve cells.’ The Vitamin E Factor—Summary and Review

‘Although alpha tocopherol has been shown to be a better antioxidant than gamma tocopherol, gamma tocopherol is a better anti-inflammatory. It is very good at controlling chronic inflammation-related diseases including arthritis, cancer, cardiovascular disease, and neurodegenerative disorders such as Alzheimer's disease. Recent evidence indicates that gamma-tocopherol may be a more powerful chemopreventive than alpha-tocopherol, and that it is better at inhibiting cancer cell proliferation.’ Get the Straight Facts on Vitamin E Tocopherols

Disclaimer: The HFME does not dispense medical advice or recommend treatment, and assumes no responsibility for treatments undertaken by visitors to the site. It is a resource providing information for education, research and advocacy only. Please consult your own health-care provider regarding any medical issues relating to the diagnosis or treatment of any medical condition.
The amount of research on the topic of magnesium is 'staggering' according to magnesium expert Dr Carolyn Dean. Magnesium (Mg) is the fourth most abundant mineral found in the body. Magnesium makes up approximately 0.05% of the body weight, around 50 - 60 % of which is found stored in the bones and teeth. Most of the remaining 40 - 50% is found in muscles and soft tissues with the brain and the heart having a high concentration.

- Magnesium is an essential mineral involved in over 300 enzyme actions in the body
- Magnesium is essential for proper mitochondrial function, and can improve mitochondrial function. Mg is critical for cell metabolism, growth of cells, cell division, cellular homeostasis and the production of ATP. Mg produces and transports energy. Mg helps to transport other minerals across cell membranes and affects cell mechanisms controlling muscle and nerve cell activity. Mg is important for the metabolism of many essential nutrients and substances, including calcium, potassium, phosphorus, zinc, copper, sodium, hydrochloric acid and acetylcholine.
- Magnesium calms the brain and CNS as well as the muscles and the heart. Mg can be helpful in reducing neurological overstimulation and raising the threshold for seizures. Optimum Mg levels are associated with deeper sleep and more refreshing sleep. Mg is necessary for the production of melatonin.
- Magnesium improves cardiac function and is essential for normal heart function. It is the heart's most important mineral. Mg is effective at preventing or reducing spasms within blood vessels in the heart, and keeping the heart rhythm steady.
- Magnesium reduces homocysteine levels, and regulates the synthesis of cholesterol (by inhibiting the enzyme required for cholesterol synthesis).
- Magnesium improves muscle function, and treats and prevents muscle cramps and gastrointestinal and oesophageal spasms.
- Low magnesium levels often contribute to or cause chronic pain. Mg both works to block pain reception and also can act on the sources of pain. It can therefore treat the causes of pain, rather than purely offering symptomatic relief. Causes of pain treated with Mg may relate to inflammation, toxicity, cell wall rigidity, mineral deficiencies or imbalances, and so on. Mg is also highly effective for
relieving pain because it is a non-competitive antagonist of the N-Methyl-D-Aspartate (NMDA) receptor site.

- Magnesium is essential for detoxification and protects cells from aluminium, mercury and lead etc. It may protect the brain from the toxic effects of certain chemicals. Two of the principal conditions that allow glutamate to shift form a neurotransmitter to a dangerous neurotoxin are low ATP levels (with any cause) and low Mg levels. Mg can improve symptoms of chemical sensitivity.

- Magnesium acts as a cell tonic and reduces inflammation in blood vessels (as measured by reduced levels of C-reactive protein).

- Magnesium is essential for proper nerve impulse transmission.

- Magnesium is essential for calcium management and reducing calcium deposits in arteries (a risk factor for artery blockages and thromboses). Normal levels of magnesium prevent calcification of organs and tissues. Without adequate magnesium, calcium will not function as it should. If magnesium levels in the body are low, calcium is taken out of the bones and teeth and into the tissues.

- Magnesium helps the body metabolise sugar and is essential for the synthesis and absorption of protein foods. Without Mg insulin is not able to transfer glucose into cells, meaning that glucose and insulin build up in the blood causing various types of tissue damage. Mg keeps insulin under control, without Mg episodes of low blood sugar can occur.

- Magnesium improves asthma and allergies. Histamine production and bronchial spasms increase with Mg deficiency.

- Magnesium improves immune function (white blood cells require adequate magnesium to function).

- Magnesium can improve PMS symptoms and is essential during pregnancy.

- Magnesium activates vitamins B1, C and E.

- Magnesium helps to maintain the structural integrity of DNA.

- Magnesium taken in transdermally indirectly boosts DHEA levels (and avoids the side effects of synthetic DHEA supplementation). DHEA is the most prevalent and essential hormone in the human body.

- Magnesium deficiency contributes to stroke and heart attack, and magnesium can aid in recovery after a stroke. Mg has an important role to play in preventing blood clots and keeping the blood thin (much like aspirin but without the side effects).

- Magnesium deficiency often contributes to or causes headaches and migraines. (Mg can trigger dozens of health conditions if it is deficient.)
Magnesium improves skin and gum health, and strengthens hair and nails as well as bones and teeth. Mg deficiency causes an unhealthy balance of phosphorus and calcium in saliva, which damages teeth.

Magnesium is found in unprocessed whole grains, greens, nuts and seeds (and chocolate).

Metabolic cardiologist Stephen T. Sinatra MD considers L carnitine, CoQ10, D ribose and magnesium the 'awesome foursome of cardiovascular health' and writes, 'More than seventy-five years ago, medical scientists declared magnesium to be an essential nutrient, indispensable to life.'

Jay S. Cohen MD, author of The magnesium solution for high blood pressure, makes the statement that, 'Most doctors are wary of supplements that come with all sorts of promises and miracle stories. They should be and so should you. Fortunately, magnesium comes with scientific evidence that dwarfs the evidence presented for many top-selling prescription drugs.'

**What are the symptoms of magnesium deficiency?**

Symptoms of magnesium deficiency include muscle cramps, restless legs syndrome, heart palpitations, morning stiffness, cramps, chest tightness or inability to take a deep breath, chocolate cravings and headaches or migraines. Raising magnesium levels to optimum may also help stop oesophageal spasms and tremors or shakiness, reduce pain levels, treat vertigo, make sleep deeper and more restful/refreshing, as well as reduce sensitivity to sudden loud noises and bright lights and neurological overstimulation generally.

With more severe magnesium deficiency numbness, tingling, seizures, personality changes, frequent urination, extreme hunger and thirst, blurry vision that changes from day to day, abnormal heart rhythms, and coronary spasms can occur.

Magnesium deficiency can cause a number of symptoms which can mimic anxiety or behavioural disorders or depression. These include symptoms such as anxiety, panic attacks, anger, nervousness, disorientation, hyperactivity and restlessness with constant movement, loss of appetite, nausea, lethargy, depression, and insomnia. (Magnesium deficiency is one cause of these symptoms but is of course not the only possible cause.)

For more information on the symptoms of magnesium deficiency see the Magnesium for life website or the website of magnesium expert Dr Carolyn Dean.

**How common is magnesium deficiency?**

Magnesium deficiency is very common. In 2006, the World Health Organization reached consensus that a majority of the world's population is magnesium deficient. The US Daily Value for magnesium is approximately 320 mg per day for women and
more than 400 mg per day for men. These magnesium dosages are considered far too low by holistic medicine experts and experts in the field of magnesium, yet many people (72% of participants in one 1995 study) do not even reach these low targets.

Research shows that most people only take in only about half these listed amounts, or less. The reasons for such low magnesium intake are the mineral depletion of our soils, the popularity of processed foods (magnesium is lost when food is refined) and the increase of calcium intake, via dairy products or supplements, without a corresponding increase in magnesium (as high calcium intake impedes proper absorption of magnesium). It is also a problem that fluoride in our water supply binds to magnesium particles and renders them unavailable for use in our body, and that where there are digestive problems magnesium may not be well absorbed even when the diet is high in magnesium. The use of diuretic drugs also severely depletes magnesium.

Thus while eating a whole food diet containing the foods high in magnesium such as whole grains, greens, nuts and seeds is important, magnesium supplements are also necessary.

**What are the different ways that supplemental magnesium can be taken?**

Magnesium can be taken orally in the form of tablets, capsules, powders or liquids, administered via injection or IV, or absorbed transdermally (through the skin).

Oral magnesium supplements are poorly absorbed even by those with no digestive problems (10-50%), so absorption can be a real problem in a disease like M.E. where there are significant gut issues and problems. Because absorption is so low, oral doses of magnesium need to be high but this can lead to gastrointestinal problems. The laxative effect is a limiting factor with oral magnesium, that is not present or is very much reduced with transdermal, IV or injected magnesium. Thus magnesium may not be able to be raised to optimum levels with oral magnesium alone.

Magnesium injections or IVs are probably the best and fastest way to take in magnesium (as Cheney explained in his 2007 lecture). But this option is not always practical or accessible for all patients, particularly as magnesium may need to be injected several times per day, long-term.

Transdermal magnesium is better absorbed than magnesium taken orally, and can be almost as effective as magnesium injections. Its use is far less involved and perhaps safer than injections or IVs, when transdermal magnesium is used at high doses. Transdermal magnesium experts have observed that this method of taking on magnesium seems to have the advantage of letting the body absorb magnesium where it is needed and only as much as is needed. In contrast, the amount taken orally and via injection involves a lot more guesswork and potential for side effects from too high a dose. However, these experts have also made it clear that their observation and
opinion that only as much transdermal magnesium as is needed is absorbed has not yet been proven in studies, and that more research is needed in this area.

There are also other benefits to using magnesium oil over other forms of magnesium. Transdermal magnesium, magnesium taken in through the skin, can indirectly raise DHEA levels, making this form of magnesium a useful treatment for menopausal symptoms and PMS symptoms. Enhanced natural production of DHEA can also help promote adequate sleep (in accordance with circadian rhythms). DHEA is the master hormone from which many other hormones are made (eg. estrogen). Raising DHEA levels naturally avoids the problems caused by supplementing these other hormones directly. (Estrogen hormone replacement raises risk of blood clots, for example and while synthetic DHEA is a commonly-used nutritional supplement, evidence points to the greater safety and effectiveness of naturally-produced/endogenous DHEA, including lower risks from adverse effects, according to magnesium expert Mark Sircus Ac OMD.)

IV and transdermal magnesium bypasses the liver (reducing the load on the liver). Mark Sircus Ac OMD, says,

> Transdermal (skin) application of magnesium is actually superior to oral supplements in many ways and is the best practical way magnesium can be used as a medicine besides by direct injection. Transdermal magnesium delivers high levels of magnesium directly through the skin to the cellular level, bypassing common intestinal and kidney problems associated with oral use.

Magnesium deficiency can inhibit oral magnesium absorption, and so IV or transdermal magnesium may be necessary for a time if magnesium deficiency is severe, to help the person overcome this problem. IV and transdermal magnesium also do not have the same limits on the rate and amount of uptake and assimilation as oral magnesium.

According to magnesium expert Mark Sircus Ac OMD, magnesium deficiency can be corrected via oral magnesium supplements in 6 - 12 months, via transdermal magnesium in 4 weeks, and in 2 weeks via IVs or injections.

**What are the best oral forms of magnesium?**

Good oral forms of magnesium are amino acid chelates such as magnesium glycine or lysine or taurate.

Magnesium oil can also be taken orally, in small amounts (around 5 - 10 ml) diluted in water, and is also a very good choice for an oral magnesium supplement.

According to magnesium expert Dr Carolyn Dean magnesium oxide is not recommended (except as a laxative!) as only 4% of the magnesium in it is absorbed. Dr Carolyn Dean recommends the use of magnesium oil plus magnesium tautate and (good quality) citrate, and in some cases, angstrom magnesium. She comments on her website,
The dosage of angstrom magnesium is low, compared to the other forms of magnesium, because it's fully absorbed. The average dosage is 18 mg taken two to three times a day. (My current recommendation is Health Shop 101.) Angstrom Liquid Magnesium is the form I use personally to avoid the laxative effect. It’s absorbed 100% at the cellular level. Minerals enter cells through channels 5 angstroms wide (about 5 billionth of a meter). We normally rely on plants to break magnesium down to this size but some companies use a process that breaks magnesium down to 5 angstroms. In my experience 72 mg of angstrom magnesium has the same beneficial effect as 5-10 times the other forms of magnesium, which means 360-720mg with no laxative effect and with a stronger beneficial effect.

You know you have too much magnesium when you get a laxative effect from pills and powders yet your magnesium deficiency symptoms are still present. Your answer then is to back off by one dose and add angstrom magnesium. Magnesium is one of those super-safe minerals that you can take without fear of build up or side effects. There are people who shouldn't take magnesium - those with bowel blockage, heart block, on dialysis, or myasthenia gravis. Even so, I've counselled clients on dialysis and with myasthenia gravis who've taken angstrom magnesium with no ill effects.

There is also magnesium (or calcium) AEP, which confers significant additional health benefits along with the magnesium.

Jack Samuels, President of the Truth in Labeling Campaign, explains why we should avoid most oral magnesium products,

Most, but not all of the magnesium being sold "over the counter" is chelated with neurotoxic substances. Magnesium glutamate is clearly of concern because the magnesium is chelated to neurotoxic glutamic acid. Magnesium aspartate is clearly of concern because the magnesium is chelated to neurotoxic aspartic acid, an amino acid that has been found by neuroscientists, in animal studies, to load on the same receptors in the brain as does glutamic acid, to cause identical brain lesions and neuroendocrine disorders as glutamic acid, and to act in an additive fashion with glutamic acid. Magnesium citrate is of concern because the magnesium has been chelated with citric acid. Most of the citric acid used in this country is made from corn. Producers of corn based citric acid do not take the time nor undertake the expense to remove all protein from the product. During production, the remaining protein is broken down, resulting in some glutamic acid and some aspartic acid. Some magnesium product producers now try to hide the presence of neurotoxins by stating that their magnesium is chelated with protein or with an amino acid.

Magnesium can also be taken partly orally, and partly transdermally, if desired. This is recommended by transdermal magnesium expert Mark Sircus Ac OMD.
Oral magnesium should always be taken in at least 3 - 4 divided doses to increase absorption, reduce the chance of a laxative effect and because having all your magnesium at one time may leave you feeling over-stimulated (or have too strong an effect on the heart). Magnesium is best absorbed on an empty stomach. Where there is low stomach acid, Betaine HCl supplementation may be necessary to help oral magnesium (and other nutrients) be absorbed. (This is not necessary if magnesium oil is taken orally, due to its chloride content.) For more information on types of oral magnesium see Dr Carolyn Dean's website.

**Magnesium injections and IVs**

Talk to your doctor about the use of magnesium injections or IVs, and always have your first injection or IV under medical supervision. Too much (or too little) magnesium can seriously affect the heart and this is especially a concern where magnesium levels are raised very quickly as with injections or IVs. If possible, start the dose very low and have two or three or more smaller injections each day rather than larger doses less often.

Where there is a very severe or acute magnesium deficiency, magnesium injections are the most appropriate treatment.

**What is magnesium oil? How is it applied and used?**

Magnesium oil is called an oil but is in fact just refined seawater that has a slightly oily feel due to the high magnesium content. Magnesium oil is a high-density solution of concentrated magnesium chloride (roughly a third) and trace minerals suspended in pure water. (Forms which are not taken from the ocean are not ideal.)

Magnesium oil can be sprayed or rubbed on the skin, or can be added to baths or foot baths. More magnesium is absorbed through direct skin application than in a bath. More magnesium will be absorbed where 15 ml of magnesium oil is applied to the skin, than where 30 ml (1 oz) of magnesium oil is added to a bath. Thus the most cost-effective way to use transdermal magnesium is by applying it directly to the skin.

Magnesium oil can be sprayed on the legs to treat restless legs syndrome, or sprayed on any other part of the body where there is muscle pain, or just sprayed on the parts of the body that are most convenient to spray. A magnesium bath can be calming, and may be ideal where there is anxiety or an inability to wind down after the day and go to sleep or extreme pain or headache.

How much magnesium is absorbed transdermally varies from person to person and there are no exact figures available. More research is needed on the absorbability and bioavailability of transdermal magnesium.

As with all other forms of magnesium, it is important to break your magnesium doses up as much as possible rather than having one large daily dose. Thus if you have a
nightly magnesium bath or foot bath, make sure you take your oral magnesium supplements or use magnesium directly on the skin (if applicable) as far removed from your bath time as possible. (You may choose to rub a small amount of magnesium oil on your skin on waking, and have magnesium tablets just before breakfast, lunch and dinner, for example, before having your nightly magnesium bath before going to bed.)

**Magnesium tests**

A test for cellular magnesium called EXATEST is available at [www.exatest.com](http://www.exatest.com). There is also the serum ionised magnesium test, the sublingual magnesium assay and the magnesium loading test. Not all of these tests may be widely available. Note that standard blood tests for magnesium levels are useless according to magnesium experts, as only 1% of magnesium circulates in the bloodstream.

Eating a whole foods diet and taking 500 -1000 mg, or even 1500 mg, of oral magnesium daily does not necessarily mean that magnesium levels are optimal, and that taking extra magnesium may not provide significant improvements. (Absorption of oral supplements may be extremely poor in M.E. and the need for magnesium in serious diseases such as M.E. is much higher than in healthy people.)

Magnesium expert Dr Carolyn Dean recommends that patients try taking magnesium for at least 1 - 3 months to see if it provides any benefits, and that while some of the tests listed previously can be helpful, this is probably the best way to test for magnesium deficiency.

**How much magnesium is needed?**

Patients who have been low on magnesium for many months or years may need to take an elevated dosage for a period to restore intracellular magnesium levels. This is sometimes referred to as a 'cell saturation' regimen, and is usually conducted over a period of 1 - 3 months (or up to a year if only oral magnesium is used).

Thus magnesium dosage depends on whether you are on a 'cell saturation' regimen - or merely a maintenance dose. The maintenance dose of magnesium will be much lower than the dose needed at the beginning of treatment. Dr Atkins recommends a maintenance dose of 1000 mg of magnesium daily for healthy people, and more for those dealing with illness or injury. So 1200 - 1500 mg is probably the minimum needed by M.E. patients, as a long-term or maintenance dose.

The amount of magnesium needed to reach 'cell saturation' should be worked up to slowly. The amount of magnesium taken should be slowly raised, using how you feel as a guide. On the topic of magnesium dosage Dr Carolyn Dean writes,

*It's about how you feel, not about a standardized amount. Make a list of magnesium deficiency symptoms and rate how much they affect you on a scale of*
1 to 10. You can find symptom lists in my *Magnesium Miracle* book or an online article by the same name. (Or the eBook *How To Change Your Life With Magnesium.*) After writing down your baseline of symptoms, take enough magnesium to relieve them. That's all there is to it.

There is far more to M.E. than just magnesium deficiency, of course, so for us it is about working out how much magnesium is needed to reduce (or eliminate) some of the magnesium deficiency related symptoms as much as possible, (rather than about all symptoms disappearing). In other words, keep raising the dose until significant benefits are seen (or side effects such as a laxative effect occur). When the benefits have stopped increasing and have stabilised, stop raising the dose and continue to monitor your symptoms.

Once maximum benefits have been realised from higher doses of magnesium, the dose can be lowered to a maintenance dose. Let how you feel guide how much magnesium you take.

Some M.E. patients may prefer to take a simpler and more certain and conservative approach and to slowly work up to a dose of 1000 mg daily and then to maintain that dose long-term. (This approach may or may not allow the full benefits of magnesium to be seen, in each case.)

More magnesium is needed if the diet is high in sugar, during pregnancy and breastfeeding, where there is heavy menstrual bleeding and/or PMS, where vitamin D levels are optimal, during stressful periods or where there is adrenal exhaustion and where the thyroid is overactive.

**What about Epsom salt baths?**
According to Daniel Reid, author of 'The Tao of Detox,' magnesium sulphate/Epsom salts are rapidly excreted by the kidneys and therefore difficult to assimilate. Thus you need larger amounts of it and the effects don't last as long as with magnesium chloride. Epsom salts should be the preferred form only where there is a special requirement for the sulphur (as there may be in conditions such as Autism).

Sulfate has an influence over almost every cellular function. Sulfate attaches to phenols and makes them less harmful, and sets them up for being excreted from your kidneys. A lot of these potentially toxic molecules are in food. Sulfate is also used to regulate the performance of many other molecules. Many systems in the body will not function well in a low-sulfate environment. Sulfur is so critical to life that the body will apparently borrow protein from the muscles to keep from running too low.

While magnesium chloride is the preferred form of magnesium, having the occasional Epsom salts bath should not be a problem and may be beneficial. For purposes of cellular detoxification, again, the most effective form of magnesium is magnesium chloride, which has a strong excretory effect on toxins, drawing them out through the pores of the skin. Magnesium chloride also restores cellular magnesium
to optimum levels. For more information on this topic see the articles: Why Magnesium Chloride? and Magnesium Chloride Vs Magnesium Sulfate.

**What are the benefits of the chloride in magnesium chloride oil?**

As the Transdermal Magnesium Therapy book and website explains,

Chloride is a major mineral nutrient that occurs primarily in body fluids. As the principle negatively charged ion in the body, chloride serves as one of the main electrolytes of the body. Chloride, in addition to potassium and sodium, assists in the conduction of electrical impulses when dissolved in bodily water. The electrolytes are distributed throughout all body fluids including the blood, lymph, and the fluid inside and outside cells. The negative charge of chloride balances against the positive charges of sodium and potassium ions in order to maintain serum osmolarity. In addition to its functions as an electrolyte, chloride combines with hydrogen in the stomach to make hydrochloric acid, a powerful digestive enzyme that is responsible for the break down of proteins, absorption of other metallic minerals, and activation of intrinsic factor, which in turn absorbs vitamin B12. The mineral supplement chloride is very different from the gas chlorine. In summary, chloride is a highly important, vital mineral required for both human and animal life. Without chloride, the human body would be unable to maintain fluids in blood vessels, conduct nerve transmissions, move muscles, or maintain proper kidney function.

**Restrictions on magnesium use**

Magnesium supplements should be discussed carefully with your doctor if you are experiencing any significant kidney problems (including kidney infections), as kidney problems can lead to minerals such as magnesium not being excreted from the body normally so that they build up to unhealthy or unsafe levels. Symptoms of magnesium toxicity can start with nausea and weakness, then progressively worsen until there is confusion, extreme musculoskeletal weakness, slurred speech, low blood pressure and slow pulse.

Magnesium may be a problem for those with Myasthenia Gravis, or those with an excessively slow heart rate. (Mg may make the heart rate even slower as it relaxes the heart.) Those with heart conditions may find that taking magnesium can lessen the need for heart medication. These patients should be under a doctor's supervision to guide this process. Magnesium acts as a muscle relaxant, and so your anaesthetist should be advised that you are taking magnesium before any surgery as less muscle relaxant drugs may be needed.

- Unfortunately, none of the experts on magnesium has any real knowledge of the distinct neurological disease known as M.E. If they did it is very possible that M.E. patients may be added to the list of patients where a little extra caution regarding magnesium supplementation at higher doses is required. For those that have distressing cardiac ‘episodes’ with overexertion (where the heart feels as if it
Taking too high a dose of magnesium suddenly or not separating out the daily intake of magnesium into 3 or 4 smaller doses may provoke one of these episodes. These episodes may or may not be life threatening but they are certainly very distressing and worth avoiding on that basis alone. Sudden high magnesium doses may also provoke too strong a detoxifying effect, causing relapse. Avoiding magnesium is not the answer, as there is a large potential to benefit in M.E. (as with other neurological or cardiac disorders) and magnesium deficiency is very common and causes its own significant problems. What is needed is a bit of caution and patience. With some extra caution, this problem can be avoided:

- Always start taking magnesium at a low dose. (Ignore recommendations of higher doses printed on the product label. It’s easy to get carried away with magnesium and to want to raise the dose quickly once you see some real benefits at lower doses, but try to resist this urge.)

- Build up your dose slowly, only raising your dose slightly every week or two. Let how you feel be your guide.

- Make sure to always take your magnesium in 3 or 4 divided doses, do not take it all in one go.

- If you’re taking magnesium more than one way, remember to ALWAYS adjust down each of the dosages. (Do not take a full dose of oral AND transdermal magnesium AND a full strength magnesium bath, obviously.)

- Note that transdermal magnesium may possibly be somewhat safer than other forms with regards to avoiding overdose (though this is not yet proven) but this should not be taken to mean that the same amount of caution is not necessary. It is absolutely possible to take in enough magnesium this way to over-stimulate the heart in M.E. and so as with other forms, the dosage should only every be raised slowly.

- Be on the lookout for early signs that you may need to lower your dose of magnesium significantly including feelings of hyperactivity, pressure or other unusual feelings in the chest, muscle spasms, redness (where you have applied transdermal magnesium) or diarrhoea. By raising the dose slowly, these symptoms should be able to be stopped while they are at a mild stage by lowering your dose significantly.

Unless there are kidney problems, taking too much magnesium (as with vitamin C) will most likely result in loose stools.

**What is the correct ratio of calcium to magnesium?**
The ratio of calcium to magnesium is important. Magnesium balances calcium in the body. Too much calcium flushes magnesium out of the cells and lowers the effectiveness of both minerals. Chronic overconsumption of calcium causes magnesium deficiency and chronic magnesium deficiency accelerates deposition of unabsorbed calcium in the body.
Too much calcium in the brain can cause cells to fire off electrical impulses repeatedly until cell death occurs. High calcium levels may contribute to some degenerative diseases, decrease absorption of magnesium and be a health risk factor. If magnesium levels in the body are low, calcium is taken out of the bones and teeth and into the tissues. If there is excess calcium in the blood and tissues, this can lead to inflammation or calcification of the joints. To keep calcium in the bones rather than in the soft tissues, a steady supply of magnesium is needed. Magnesium and vitamin D are just as important as calcium in preventing and treating osteoporosis. As much as 60% of the body’s stores of magnesium are found in bones. March Sircus Ac OMD explains,

After an overabundance of calcium ions enters cells, magnesium ion concentration can precipitously decline. This describes the process of calcification of cells caused by overabundance of calcium relative to magnesium. The process may be characterized as a positive feedback loop whereby increasing levels of calcium lead to reduced cellular energy production, ineffective cell transport systems, and reduced levels of magnesium, which is then replaced by additional calcium. As the presence of calcium increases to levels beyond the capacities for cells to remove it, deposits form that can appear anywhere in the body. This process of calcification has negative impacts upon health, including significant adverse effects on detoxification systems, antioxidant systems, cellular energy production, glucose metabolism, nervous system excitation, and acceleration of the aging process.

Calcium and magnesium are usually recommended to be taken in a 2:1 ratio, but newer evidence shows that this is not ideal and that the ideal ratio may be somewhere between 1:1 and 1:1.25, in favour of magnesium. Magnesium expert Dr Carolyn Dean goes one step further. She recommends, and makes a very compelling case for, a ratio of calcium to magnesium of 1:2, in favour of magnesium. (Twice as much magnesium as calcium.) Dr Carolyn Dean recommends angstrom calcium, and writes,

Angstrom-sized calcium is at a particle size between a nanometer and picometer and fully absorbed at the cellular level. It’s taken in small dosages and there is nothing left over to calcify any part of the body.

Dr Carolyn Dean also comments on her website that for some patients the best ratio of calcium to magnesium is 1:3, in favour of magnesium, in her opinion. She also recommends that calcium from the diet be taken into account when looking at what dose of calcium supplement to take as it is common for many people to currently be taking in calcium and magnesium in a 1:5 or even up to a 1:15 ratio, in favour of calcium.

Dr Sherry Rogers comments that recommendations for people to take 1500 mg of calcium daily are foolish, inappropriate and unbalanced.
Calcium is plentiful in sardines, sesame seeds, pinto beans, salmon with bones, cooked spinach, almonds, brazil nuts, bok choy and dairy products. Most often our diets are low in magnesium and high in calcium.

Dr Atkins comments that for many people calcium supplements are not necessary and also recommends that no more than 1200 mg of calcium be taken lest it start to interfere with magnesium (and zinc and iron) absorption.

Also note that according to the book 'The Vitamin D Cure' it is important NOT to take more than 600 mg of calcium daily, if your vitamin D levels are optimal (above 40 ng/ml). Vitamin D increases the absorption rate of calcium, as does magnesium.

Calcium must stop being promoted as the ‘star’ mineral. All the minerals are important and the correct ratios are important and too much calcium can be harmful to health – despite popular opinion. See the Dr Carolyn Dean or Magnesium for life websites for more information on this topic.

**Sourcing magnesium chloride oil**

Magnesium oil is widely available. In Australia, try the Australian-made Echolife magnesium oil. In other countries, try the US Ancient Minerals brand. These are both high quality brands, along with retailers LL's Magnetic Clay and Global Light.

Magnesium oil should be roughly a third magnesium chloride. Whichever brand you choose, make sure the magnesium oil you buy has been tested for mercury and heavy metal content.

Some companies also sell premade magnesium creams. Magnesium flakes are also available for use in the bath. (Always store magnesium flakes in an airtight container as they will turn to liquid if exposed to the air for long enough.) Note that magnesium flakes are over 90% magnesium, and so you'll only need to use a third as much in each bath or foot bath, as compared to magnesium oil.

**Reference and recommended additional reading list**

- Transdermal magnesium therapy : A New Modality for the Maintenance of Health by Mark Sircus.
- The miracle of magnesium by Dr Carolyn Dean.
- Dr Carolyn Dean’s website
- The article on Nebulization and transdermal magnesium baths: prime therapeutic options for medication administration for children by Mark Sircus Ac OMD
- The article on High dose magnesium by Mark Sircus Ac OMD. This article discusses taking oral magnesium sulfate at a dose of up to 5 g of elemental magnesium, broken into many smaller doses, worked up to slowly by the patient and based on their individual tolerance.
- The Sinatra Solution by Stephen T. Sinatra MD
Note that in all the books and articles listed here, where 'CFS' is referred to, what is being discussed is not M.E., nor any other neurological disease. Some doctors refer to general miscellaneous chronic fatigue sufferers while others refer to patients with adrenal exhaustion, burnout, environmental illness/MCSS or post-viral fatigue syndromes caused by glandular fever/mononucleosis or EBV etc. when the term 'CFS' is used. The myth that 'CFS' is a distinct condition (and easily cured) is unfortunately supported by almost all of these doctors. While some patients which qualify for a misdiagnosis of 'CFS' may experience a near or complete resolution of symptoms with the administration of magnesium, M.E. patients should be aware that such claims have nothing to do with M.E. and that M.E. is not simply magnesium deficiency, but a distinct and complex neurological disease. (None of these books or articles contains any information on M.E., no matter which terms they may use.)

Additional references list

- Stand Back and Watch the Miracle Working Power of Magnesium by Dr Carolyn Dean
- The Vita-Nutrient Solution by Dr Atkins
- Holy Water, Sacred Oil - The Fountain of Youth by Dr Norman Shealy, MD., Ph.D. This book documents Dr Shealy's research into the use of magnesium chloride transdermally (absorbed via the skin).
- The Magnesium Factor by Dr Mildred Seelig MD. NPH, MACN. A renowned researcher of magnesium, Dr Seelig advocated the use of transdermal magnesium to boost magnesium levels.
- Magnesium chloride for health and rejuvenation by Walter Last
- The magnesium solution for high blood pressure by Jay S. Cohen MD
- The Tao of Detox by Daniel Reid
- Magnesium Oil by Frank A. Cooper

Relevant quotes

Therapy with magnesium is rapid acting, has a safe toxic-therapeutic ratio and is easy to administer and titrate. Magnesium is economical, widely available and has a long established safety and tolerability profile in myocardial infarction. Magnesium chloride has the advantage of being administered intravenously, intramuscularly, and orally as well as vaporized through a nebulizer, and as a lotion transdermally. In anesthesia and intensive care, the preferred administration route is IV. Mark Sircus Ac OMD.

Magnesium in general is essential for the survival of our cells but takes on further importance in the age of toxicity where our bodies are being bombarded on a daily basis with heavy metals. Glutathione requires magnesium for its synthesis. Glutathione synthetase requires y-glutamyl cysteine, glycine, ATP, and magnesium ions to form glutathione. In magnesium deficiency, the enzyme y-glutamyl transpeptidase is lowered. According to Dr Russell Blaylock, low magnesium is associated with dramatic increases in free radical generation as well as glutathione depletion and this is vital since glutathione is one of the few antioxidant molecules known to neutralize mercury. Without the cleaning and chelating work of glutathione
(magnesium) cells begin to decay as cellular filth and heavy metals accumulates; excellent environments to attract deadly infection and/or cancer. Mark Sircus Ac OMD.

Without sufficient magnesium, the body accumulates toxins and acid residues, degenerates rapidly, and ages prematurely. Mark Sircus Ac OMD.

I talk all day and every day about magnesium but many people are focused on calcium. Women especially are led to believe that calcium, and lots of it, is necessary to keep their bones from crumbling away. Medically we just imagine that bones are made of calcium and don't realize the interplay between the two. However, if you've read anything I've written about magnesium, you'll know that magnesium is the dynamo behind calcium. They are both necessary and equally important for strong bones and many other processes in the body. Here are the words of one of my clients. "It was news to me and might be a shock to your readers, too, when you say to take 1/3 as much calcium as magnesium. All the magnesium/calcium pills I could find had twice as much calcium and magnesium in them. And the other shock was that you hardly advise calcium pills anymore but recommend angstrom calcium."

Calcium (in the carbonate, citrate and gluconate forms) is only 4-10% absorbed. Unlike magnesium, calcium doesn't flush itself out with diarrhea if you take too much. Calcium, instead, causes constipation and builds up in the body. Some researchers are saying calcium supplements are responsible for an increase in calcification causing heart disease, kidney stones, gall stones, heel spurs and fibromyalgia. Part of that buildup has to do with the fact that few people take magnesium with their calcium. It also has to do with the type of calcium taken. Dr Carolyn Dean.

A few people have told me that when they first start taking magnesium they feel worse. They feel fatigued or more toxic or their blood pressure becomes too low. One person even said they felt more anxious. What's the reason for such an extreme reaction? I believe that some people may be so deficient in magnesium that when they start taking it they turn on the hundreds of enzymes that have slowed down to a crawl. Now with magnesium they are driving hundreds of metabolic functions and that excess activity might exhaust the body or rev it up making them feel more anxiety. Dr Carolyn Dean.

Magnesium chloride and Vitamin C have similar toxicity profiles with overdose from both resulting at worst usually in diarrhea unless the kidneys are seriously compromised. Mark Sircus Ac OMD

Magnesium deficiency is often misdiagnosed because it does not show up in blood tests - only 1% of the body's magnesium is stored in the blood. Mark Sircus Ac OMD

Modern medicine is supposed to help people not hurt them but with their almost total ignorance of magnesium doctors end up hurting more than they help for many of the medical interventions drive down magnesium levels when they should be driving them up. Many if not most pharmaceutical drugs drive magnesium levels into very
dangerous zones and surgery done without increasing magnesium levels is much more dangerous then surgery done with.

The foundation of medical arrogance is actually medical ignorance and the only reason ignorance and arrogance rule the playing field of medicine is a greed lust for power and money. Human nature seems to be at its worst in modern medicine when it should be at its best. It is sad that people have to suffer needlessly and extraordinarily tragic that allopathic medicine has turned its back on the Hippocratic Oath and all that it means. Mark Sircus Ac OMD

Prof. Delbet also performed experiments with the internal applications of magnesium chloride and found it to be a powerful immune-stimulant. In his experiments phagocytosis increased by up to 333%. This means after magnesium chloride intake the same number of white blood cells destroyed up to three times more microbes than beforehand. Walter Last

Transdermal (skin) application of magnesium is actually superior to oral supplements in many ways and is the best practical way magnesium can be used as a medicine besides by direct injection. Transdermal magnesium delivers high levels of magnesium directly through the skin to the cellular level, bypassing common intestinal and kidney problems associated with oral use. Mark Sircus Ac OMD

Dr Jay Cohen, MD, states that "When you take magnesium tablets or capsules, your body absorbs only 30 percent of the magnesium they contain. With many top-selling products, absorption is much less, as little as 10 percent."

Magnesium as well as chloride have some important functions in keeping the body in shape; young and healthy.
Chloride is required for production of gastric acid each day and is also needed to stimulate starch-digesting enzymes. Magnesium rejuvenates and prevents the calcification of our organs and tissues that is characteristic of the old-age related degeneration of our body.

Using other magnesium salts is less advantageous because these have to be converted into chlorides in the body anyway. We may use magnesium as oxide or carbonate but then we need to produce additional hydrochloric acid to absorb them. Many aging individuals, especially with chronic diseases who desperately need more magnesium cannot produce sufficient hydrochloric acid and then cannot absorb the oxide or carbonate. Table salt is sodium chloride, Epsom salt is magnesium sulphate - it is soluble but not well absorbed and acts mainly as a laxative. Chelated magnesium is well absorbed but much more expensive and lacks the beneficial contribution of the chloride ions. Chelated magnesium seem to lack the infection-fighting potential of the magnesium chloride, as W. Last wrote in his excellent article. Mark Sircus Ac OMD

In general, for a large adult, spraying one ounce of magnesium oil a day all over the body is recommended for six months to recover cellular levels with that adjusted downward for children depending on their age and size. This coupled with oral intake, especially for adults, is necessary to get the maximum kick out of magnesium.
When magnesium levels are at extremely low levels intravenous application is an option and is often necessary in emergency situations. Very strong therapeutic magnesium baths yield another level of effect which competes quite handily with intravenous applications but they are no a substitute for them in emergency situations obviously.

Sensitive care must be taken especially with children as to dose levels, water temperature and magnesium concentrations. Muscle spasms might occur on rare occasions if one forgets to get out of the tub so it is necessary to supervise children and the length of time they remain soaking in magnesium chloride. All strong reactions like redness in local areas to diarrhea or even muscle spasms are indications to reduce concentration. Mark Sircus Ac OMD (Note that this recommended dose of 30ml/1 oz is for a LARGE adult, and that in M.E. this dose should be worked up to very slowly and applied in 2 or 3 divided doses and that this dose may not suit everyone with M.E. Taking a lower dose for a longer time period may be a safer choice in M.E.)

Beyond the roles played by magnesium in helping to prevent osteoporosis and to increase bone density, Dr Mark Sircus notes that cultures in which the ratio of calcium to magnesium intake is low (e.g., Japan) enjoy superior cardiovascular health and a relatively low rates of cardiac death. Conversely, cultures consuming the highest ratios of calcium to magnesium (e.g., Australia, USA, and Scandinavian countries) exhibit among the highest rates of cardiovascular diseases in the world. It is clear to Dr Sircus and others that cultures (and individuals) maintaining high magnesium intakes generally do not suffer from heart-related diseases to anywhere near the same degree in comparison to cultures (and individuals) not maintaining high intakes (i.e., those consuming relatively lower intakes of magnesium). He notes that the Japanese, for example, derive most of their magnesium from consuming sea vegetables and single-cell algae (e.g., chlorella and spirulina), and a wide variety ocean-related food sources. The daily intake of magnesium in Japan may be as high as 560 milligrams. It is also worth noting that the Japanese have among the lowest intakes of calcium from dairy products and exhibit one of the lowest mortality rates in the world. Magnesium is required for healthy heart function. The Integrated Health website.

Without enough magnesium, cells simply don't work. Dr Lawrence Resnick, MD, of Cornell University

**Disclaimer:** The HFME does not dispense medical advice or recommend treatment, and assumes no responsibility for treatments undertaken by visitors to the site. It is a resource providing information for education, research and advocacy only. Please consult your own health-care provider regarding any medical issues relating to the diagnosis or treatment of any medical condition.
Magnesium can be taken orally (via tablets, capsules or liquids), via injections or IVs, or transdermally (through the skin). It is also important to eat foods rich in magnesium such as grains, greens, nuts and seeds.

Magnesium is absorbed very poorly orally (although liquids are absorbed better than tablets or capsules), moderately well transdermally (more than twice as well with direct skin contact than with baths), and at a very high rate through injections and IVs. Many transdermal magnesium experts support the idea that that transdermal magnesium is the safest and most effective method of administering magnesium as it allows the body to only absorb as much magnesium as is needed (which is not the case with IVs, injections and oral magnesium supplements). In emergencies, magnesium injections or IVs are essential however.

Eating a whole foods diet and taking 500 -1000 mg, or even 1500 mg, of oral magnesium daily does not necessarily mean that magnesium levels are optimal, and that taking extra magnesium may not provide significant improvements. (Absorption of oral supplements may be extremely poor in M.E. and the need for magnesium in serious diseases such as M.E. is much higher than in healthy people.)

Tests for magnesium levels are available, but magnesium experts suggest that the best test is to take magnesium for 1 -3 months and see if you feel better on it.

Most people are deficient in magnesium and will benefit from taking larger amounts of magnesium for 1 -3 months (or 12 months or more if only oral supplements are taken) to fully replenish their magnesium levels and to reach 'cell saturation.'

Magnesium can be taken both orally and transdermally at the same time and this may be the easiest and safest way to reach 'cell saturation.' The amount of magnesium needed to reach 'cell saturation' should be worked up to slowly. The amount of magnesium taken should be slowly raised, using how you feel as a guide. On the topic of magnesium dosage, Dr Carolyn Dean writes,

It's about how you feel, not about a standardized amount. Make a list of magnesium deficiency symptoms and rate how much they affect you on a scale of 1 to 10. You can find symptom lists in my Magnesium Miracle book or an online article by the same name. (Or How To Change Your Life With Magnesium.) After writing down your baseline of symptoms, take enough magnesium to relieve them. That's all there is to it.
There is far more to M.E. than just magnesium deficiency, of course, so for us it is about working out how much magnesium is needed to reduce (or eliminate) some of the magnesium deficiency related symptoms as much as possible, rather than about all symptoms disappearing. (Magnesium deficiency can cause some of the non-core symptoms seen in M.E. and worsen the severity of many other M.E. symptoms.) In other words, keep raising the dose slowly until significant benefits are seen. When the benefits have stopped increasing and have stabilised, stop raising the dose and continue to monitor your symptoms.

Some M.E. patients may prefer to take a simpler and more certain and conservative approach and to slowly work up to a dose of 1000 mg daily and then to maintain that dose long-term. (This approach may or may not allow the full benefits of magnesium to be seen, in each case. Less than 1000 mg may also be adequate in some patients, particularly if well-absorbed forms are used.)

- If possible, take smaller doses of magnesium at least 3 – 4 times daily, rather than having one large daily dose. (Thus if you have a nightly magnesium bath or foot bath, make sure you take your oral magnesium supplements and/or rub magnesium oil directly on the skin as far removed from your bath time, and each other, as possible.)

- Once maximum benefits have been realised from higher doses of magnesium, the dose can be lowered to a maintenance dose. This may be 1200 - 1500 mg (in 3 – 4 divided doses) or a somewhat higher dose, depending on your individual needs. Again, let how you feel guide how much magnesium you take long-term.

- At this time it is important to make sure you take calcium and magnesium in a 1:2 ratio, in favour of magnesium. (Or if you prefer, a 1:3 ratio in favour of magnesium, as suggested by Dr Carolyn Dean, or the 1:1 ratio recommended by some other experts; you need to use your own judgement here.). Also note that according to the book 'The Vitamin D Cure' it is important NOT to take more than 600 mg of calcium daily, if your vitamin D levels are optimal (above 40 ng/ml). Vitamin D increases the absorption rate of calcium, as does magnesium. So this could mean taking 600 mg of calcium daily and 1200 mg of magnesium, for example, if you followed the 1:2 ratio.

- Individuals vary in their requirements for supplemental magnesium due to biochemical individuality. Redness, diarrhoea and spasms are signs that too much magnesium has been taken and that the dose must be significantly lowered.

- Magnesium is involved in the production of ATP and is also a muscle and brain relaxer. Some patients take their last dose of magnesium late at night as they find it helps them sleep, while others make sure to take their last dose by late afternoon lest it leave them feeling too energised to sleep.

- Talk to your doctor before taking extra magnesium if you have kidney problems or an extremely slow heart rate. If you are very sensitive to supplements, or very ill or have very severe cardiac problems, you may wish to take a very cautious approach and start on a much lower dose of magnesium and raise the dose far more slowly, than is suggested here.
**Oral magnesium notes:** Good oral forms of magnesium are amino acid chelates such as magnesium glycine or lysine or taurate. There is also (good quality, corn-free) magnesium citrate in powder or capsule form. There is also angstrom magnesium and magnesium-AEP.

Magnesium oil can also be taken orally, in small amounts (around 5 - 10 ml) diluted in water, and is also a very good choice for an oral magnesium supplement. (If the taste is unpleasant it can be masked with some fruit or vegetable juice, or a magnesium oil and water 'shot' can be followed with a juice 'chaser.') Small amounts of magnesium oil can also be added to your drinking water. If you leave the home, 5 – 10 ml of magnesium oil can be added to 1.5 litres of water in a portable (reusable) BFA-free plastic bottle or stainless steel water bottle (or similar) and sipped throughout the day. If you are at home all day, either fill a 1.5 litre glass bottle with filtered water and 5 – 10 ml of magnesium oil or pour out four glasses of water at the start of each day and dose each with a small amount of magnesium (and any other liquid supplements that need to be taken throughout the day).

If you aren’t currently taking magnesium, start at 100 - 200mg daily. Then add just 100 - 200 mg of additional magnesium every week, to minimise any problems. (Magnesium helps the body to detox, which can lead to relapse if it occurs too quickly.) Magnesium is best absorbed on an empty stomach.

The laxative effect at high doses may be a limiting factor in trying to raise magnesium levels purely using oral supplements. Take supplements with meals and broken up into 3 or 4 smaller daily doses to help minimise this problem. Cut back the dose if you still experience a laxative effect. If you wish to keep raising the magnesium dose, add some transdermal magnesium to your regime.

**Notes on magnesium injections and IVs:** Follow the advice of your doctor on this topic. (The Cheney 2007 DVD may also be of assistance here. He recommends subcutaneous magnesium injections several times daily.) Make sure to have at least the first few injections or IVs in the doctor's office, in case the magnesium affects the heart too strongly. If possible several lower strength injections daily rather than larger doses less often. Where there is a very serious or acute magnesium deficiency, magnesium injections are the most appropriate treatment.

**Transdermal magnesium notes:** Look for magnesium chloride oil that has been tested for heavy metal content, and is derived from the ocean. It should also be a third magnesium chloride. (Perhaps try the high quality Echolife or Ancient Minerals products.) Magnesium chloride oil can be sprayed or rubbed directly on the skin, or added to a bath or footbath.
When determining the correct amount of magnesium oil to use, it is elemental magnesium that is important. Different brands of magnesium oil may contain slightly different amounts of elemental magnesium. (I teaspoon of magnesium oil will contain roughly 400 – 500 mg of elemental magnesium. To get an exact figure, check the label of the particular brand you have chosen.)

<table>
<thead>
<tr>
<th>Magnesium oil in teaspoons and tablespoons</th>
<th>Magnesium oil in ml</th>
<th>Magnesium oil in ounces</th>
<th>Magnesium chloride content</th>
<th>Elemental magnesium content</th>
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<tbody>
<tr>
<td>1 teaspoon</td>
<td>5 ml</td>
<td>1/6 oz</td>
<td>2 g</td>
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<tr>
<td>2 teaspoons</td>
<td>10 ml</td>
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<td>4 g</td>
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<td>1 tablespoon</td>
<td>15 ml</td>
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<td>2 tablespoons</td>
<td>30 ml</td>
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<td>12 g</td>
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<tr>
<td>4 tablespoons</td>
<td>60 ml</td>
<td>2 oz</td>
<td>24 g</td>
<td>6 g</td>
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The first time magnesium oil is applied to the skin use only a very small amount on an area of skin that isn't particularly sensitive. (For example, an arm or a leg or the top of your foot.) Some people experience only a very mild tingling, while others feel a more irritating burning sensation. For some these sensations last for a minute or less, while for others they may persist for 30 minutes or more. If the magnesium burns or tingles uncomfortably when applied to the skin, wash the skin immediately. Thereafter, dilute the magnesium oil 50/50 with distilled water or mineral water, or use a magnesium cream, or use magnesium oil in the bath. (With repeated use of the oil, the burning or tingling is said to lessen and so you may want to retest your skin's sensitivity after a month or so of use.)

Magnesium oil sprayed or rubbed on the skin. More magnesium is absorbed through direct skin application than in a bath. More magnesium will be absorbed where 15ml of magnesium oil is applied to the skin, than where 30 ml/1 oz of magnesium oil is added to a bath. Thus the most cost-effective way to use transdermal magnesium is by applying it directly to the skin.

Magnesium oil can be sprayed on the legs to treat restless legs syndrome, or sprayed on any other part of the body where there is muscle pain, or just sprayed on the parts of the body that are most convenient to spray. Apply transdermal magnesium to the skin two or more times daily. It can be washed off after 20 - 30 minutes if the burning or tingling is too intense, or left on all day. (Magnesium oil is absorbed over a 1 – 2 hour period, but Dr Carolyn Dean has commented that MOST of the magnesium is absorbed within 20 – 30 minutes.)
Magnesium oil can be added to any skin lotion, to reduce skin irritation. You can also make a body lotion by combining equal parts of magnesium oil, organic coconut oil and aloe vera gel. Spending time really rubbing the oil in may increase absorption.

As a starting dose, spray or rub at 1 teaspoon (5 ml) of magnesium chloride oil on the body every day for 2 weeks, in two divided applications. Then try 2 teaspoons (10 ml) for 2 weeks, and then perhaps 3 teaspoons (15 ml) for 2 weeks. 10 – 15 ml may well be enough for many people, particularly when combined with oral supplementation.

Where there is a long-term magnesium deficiency, the dose may gradually be raised higher. Amounts of up to 2 tablespoons (30 ml/1 oz) or more may be used for this purpose (depending on your weight), for a period of months but may not be suitable for everyone and must be worked up to slowly. The maintenance dose necessary will likely be much lower than this however.

**Magnesium baths.** Magnesium baths will not cause skin irritation. Baths or foot baths should use warm (but not hot) water and last at least 20 - 30 minutes. (The longer one stays in the bath, the more magnesium is absorbed.) If possible, soak your legs up to mid-calf level when using a foot bath.

As a starting dose, use 1 tablespoon (15 ml) of magnesium chloride oil in a bath or foot bath 4 - 7 times weekly, for 2 weeks. Then try 2 tablespoons (30 ml/1 oz) for 2 weeks, and then perhaps 3 tablespoons (45 ml) for the next 2 weeks. 30 – 45 ml may well be enough for many people, particularly when combined with oral supplementation.

Where there is a long-term magnesium deficiency, the dose may gradually be raised higher. Amounts of 4 - 8 tablespoons (60 - 120 ml) or more are commonly used for this purpose. Amounts of 8 - 16 tablespoons (120 - 240 ml/4 - 8 oz) are also often used for several months where deficiency is severe, but may not be suitable for everyone and must be worked up to slowly. The maintenance dose will likely be much lower than the last two figures mentioned however. Magnesium chloride baths may also be taken less often when all that is required is a maintenance dose, perhaps 3 - 4 times weekly.

(Note that magnesium expert Mark Sircus Ac OMD explains that baths intended for strong therapeutic effect and administered by professionals may contain as much as 2 - 4 pounds of magnesium oil. These baths contain roughly 1500 and 5000 mg/l magnesium, which is 1 to 4 times the sea concentration, but still a much lower concentration than the Dead Sea concentration of up to 40,000 mg/l magnesium. For more information on magnesium baths given by professionals for severe magnesium deficiency see the Magnesium for life website, but DO NOT make these professional strength baths at home! It is not known as yet if these very strong baths are at all appropriate for M.E. patients, or very ill M.E. patients, even if done under medical supervision. It may be best for those with M.E. to take more moderate doses for a longer time than very high doses for a short time.)
Other ways to use magnesium oil. Magnesium used as a mouth wash can be helpful with gingivitis. Very highly diluted magnesium added to an eye bath or eye spray may help improve eye spasms. Magnesium is an injection fighter and has been used for many years to cleanse wounds. A magnesium compress can be made to treat painful muscles; soak a thin cotton cloth in magnesium oil and lay it on the affected area, covered with an old towel or some cling-film or a hot water bottle, for 30 - 60 minutes.

For more information on magnesium, and for references, please see the main Magnesium and M.E. paper.
Calcium AEP (Calcium 2-amino ethyl phosphoric acid or Ca-AEP or Ca-2AEP) is considered by some doctors to be one of the top two most effective treatments for Multiple Sclerosis (along with octacosanol). It may possibly also help those with M.E., as the two diseases share significant similarities. (However, as yet no research has been done on M.E. patients and their response to Ca-AEP, predictably).

Ward Dean MD writes,

In 1941, a unique form of calcium, Calcium 2-amino ethyl phosphoric acid (Ca-AEP or Ca-2AEP) was discovered by the eminent biochemist Erwin Chargaff. Chargaff found that Ca-AEP was a vital component in the structure of cell membranes. The significance of Chargaff’s work was largely ignored for the next two decades.

An analysis of more than 2,000 [MS] patients who were treated with colamine salts in Germany over the course of 24 years revealed greater efficacy from Ca-AEP treatments than other known treatments. In 1986, Dr George Morrissette conducted a retrospective poll of patients in the USA who originally had begun Ca-AEP treatment in Germany for MS. 82% of the almost 300 patients that entered the study showed a positive benefit from Ca-AEP therapy. And when treatment began in the early stages of MS, positive results rose to 92%.

In European clinics, Ca-AEP is used in the treatment of gastritis, duodenitis colitis, ulcer pain and other disturbances of the GI tract. Ca-AEP therapies have also produced good results in relieving tissue inflammation due to gastritis and GI tract autoimmune disorders.

Ca-AEP is one of a number of colamine phosphates—vitamin-like metabolites and cell membrane integrity factors, that are required for cellular membrane functions. Among these functions, Ca-AEP is known to act as:

1) Cell Sealer and Protector.
2) Electrolyte and Nutrient Carrier.
3) Maintains Cell Electrical Charge.

The role of Ca-AEP has been studied for more than 30 years. This vitamin-like factor, like carnitine and coenzyme Q10, appears to be very important for optimum health.

Studies over the past 30 years have shown that Ca-AEP is essential for neurotransmission, nerve impulse generation, and muscular contractions. Ca-AEP protects cells against penetration by aggressive substances such as toxins, bacteria and viruses, but permits penetration and transport of nutritive substances.
Leading Ca-AEP expert Dr Hans Neiper explains that, ‘Calcium 2-AEP is especially effective for repairing cell membrane damage. In Germany, calcium, potassium and magnesium 2-AEP are officially declared as the only active substances for the treatment of MS.’

Ca-AEP gives real neurological improvements in MS and is also very beneficial in the early stages of type 1 and 2 diabetes, and is also recommended for autoimmune conditions and demyelinating conditions. (M.E. falls into both of these latter two categories.) Ca-AEP may also be used to treat osteoporosis, asthma and other lung diseases, gastrointestinal disorders, allergies, blood pressure and circulatory problems, cancer, ALS, sarcoidosis, inflammatory disorders (including rheumatoid arthritis) and kidney problems. It has also proved effective at reducing the damaging after effects of viral infections. Magnesium/calcium/potassium-AEP (Membrane integrity factor) calms the CNS and is said to be useful in neurological conditions involving overstimulation, including hyperactivity and anxiety disorders.

Ca-AEP is sometimes known as membrane integrity factor or vitamin M1 for short.

Oral supplements are available, although some doctors prefer to give IV Ca-AEP or both injectable and oral forms. Dr Atkins recommends a dosage of 1500 – 4000 mg Ca-AEP taken orally for those with autoimmune disorders and/or where blood tests have shown ANA levels to be raised (this finding is common in M.E.). For those with MS he recommends that one 400 mg/10 cc vial of Ca-AEP be injected intravenously every second day along with 3 – 6 capsules of magnesium/calcium/potassium-AEP daily. For those with ALS the recommendation is two vials every day.

M.E. patients may find it very difficult to source vials of Ca-AEP suitable for injecting IV or doctors willing to prescribe or administer these injections, and may have to make do with capsules and so follow the above recommendation for autoimmune disease rather than for MS. Ca-AEP should never be injected intramuscularly. Oral dosage should start at no more than 500 mg in M.E. and be raised only slowly.

The section on determining the correct ratio of calcium to magnesium in the Magnesium and M.E. paper MUST BE READ before beginning treatment with calcium AEP, or any other calcium product.

(Some M.E. patients may prefer to take mostly magnesium AEP, rather than calcium AEP or magnesium/calcium/potassium-AEP to avoid ingesting large amounts of calcium. Information on how Ca-AEP supplements relate to standard calcium supplements in terms of causing problems at high doses is very difficult to find however. The theory that Ca-AEP may possibly be an exception to this low-calcium-supplementation-is-best rule is supported by the fact that doctors such as Dr Atkins recommend that calcium always be limited to a maximum of 1.2 g daily but also recommend multi-gram doses of calcium AEP to those with MS and other autoimmune disorders. Please contact the HFME if you become aware of solid
information on how Ca-AEP supplements relate to standard calcium supplements in terms of causing problems at high doses.)

Dr Atkins notes that while the vast majority of MS patients benefit from Ca-AEP treatment, unfortunately a small percentage become sicker. 5000 case studies confirm the efficacy of calcium AEP in MS.

References and additional reading list
- The Vita-Nutrient Solution by Dr Atkins
- Membrane Integrity Factor Aids Treatment of Multiple Sclerosis, Asthma and Osteoporosis by Ward Dean, M.D. and Jim English
- Mineral Transporters Hans Nieper, M.D. (To read more about Ca-AEP and MS, including the ‘1999 Intravenous Calcium EAP Survey for Multiple Sclerosis’ see the articles available through Brewer Science Library website.)

Relevant quotes
Toxic treatments do more harm than good in the long run. The best physician is your own body. We must strengthen, not weaken, its defenses. Hans A. Nieper, M.D.

Preventive medicine is the most important guideline to follow, requiring less effort and less money for better results in the prevention of illness and the protection of our health. Hans A. Nieper, M.D.
Dr Stephen T. Sinatra considers coenzyme Q10 (CoQ10), L carnitine, D ribose and magnesium the ‘awesome foursome’ of cardiovascular health.

Dr Sinatra explains that while 1 + 1 will always equal 2 in mathematics, in metabolic cardiology and nutritional medicine, when you are talking about substances that are synergistic with each other such as the ‘awesome foursome’, 1 + 1 might equal 5 or even 10. In other words, the benefits of taking more than one of these substances at a time may far outweigh the benefits seen from taking any of them alone.

The heart and the brain are especially rich in mitochondria. This makes them especially vulnerable to mitochondrial damage and the resulting decrease in energy output. Both the brain and the heart (with its extraordinary non-stop work) need an enormous amount of energy.

Dr Sinatra explains that,

It’s all about ATP (adenosine triphosphate). Hearts, skeletal muscles and every other tissue in our bodies have an absolute need for ATP as their primary energy currency. Cells and tissues will cease to function if they are not provided with a constant and stable supply of energy. Both the total pool of energy substrates (ATP) in the cell and the cell’s ability to recycle these compounds are fundamental to healthy energy metabolism and cell function.

When hearts are stressed by disease, energy substrates, called purines, wash out of the cell and the total pool of cellular energy becomes severely depleted. Disease also disrupts the heart’s ability to recycle its remaining energy through the oxidative phosphorylation mechanisms. The combination of energy pool depletion and metabolic dysfunction contributes to the severity of the disease and impacts the physiological health of the heart. The same is true for skeletal muscles that are stressed through disease or high-intensity exercise.

CoQ10 and L carnitine are major players in the energy recycling metabolic pathways. D ribose is the only compound used by the body to replenish depleted energy stores and rebuild energy pools. Magnesium is a vital mineral used by the enzymes that make energy synthesis and recycling possible.

Or as Dr Sinatra explains; D ribose fills the tank, CoQ10 and L carnitine helps convert this fuel to energy (helps the engine run properly) and magnesium is the glue that holds it all together.
**Coenzyme Q10**

CoQ10 is an enzyme that occurs naturally in the mitochondria of every cell in your body. It plays a key part in metabolizing energy from food. CoQ10 was first isolated in 1957. Since then, scientists have studied its effects on a wide variety of illnesses and conditions.

- CoQ10 plays an important role in stabilising cell membranes.
- CoQ10 is essential in directly supporting ATP recycling in the mitochondria of the cells. This is especially important for tissues that use a lot of energy, such as the heart and the brain.
- Dr Sinatra explains that CoQ10 helps any type of cardiomyopathy, congestive or even hypertrophic. It impacts on both systolic and diastolic dysfunction, improving quality of life.
  
  (This is an important distinction for M.E. patients as Dr Cheney recently explained the type of cardiac insufficiency that lies at the heart of M.E. is best described as *diastolic* heart failure or (‘compensated’) *diastolic cardiomyopathy*.

  The right ventricle circulates blood to the lungs, while the left ventricle circulates blood to the rest of the body. The ventricles empty when the heart contracts to pump out blood (the systole), and fill when the heart relaxes (the diastole). Diastolic dysfunction means that the heart does not have enough energy to relax between contractions and so the ventricles fill with blood in a dysfunctional way and an inadequate amount of blood is pumped by the heart with each contraction. (Dr Sinatra explains that a great deal more energy is needed for the heart muscles to relax, than for them to contract. It requires immense cellular energy.) This diastolic dysfunction is best measured using an impedance cardiograph machine. See the Dr Paul Cheney page for more information.)
- Without CoQ10 the electron transport chain would completely break down. This loss would be catastrophic. There has to be an EXCESS of CoQ10 in the mitochondria to be maximally effective.
- CoQ10 is an antioxidant and reduces cancer risk.
- ATP supports such as CoQ10 support immunity, as the immune system has high ATP needs.
- CoQ10 has neuroprotective effects against mitochondrial toxins.
- CoQ10 plays an important role in reducing platelet size, distribution, stickiness and limiting platelet aggregation and activation. CoQ10 helps prevent blood clot formation.
- Diseased gums may be a sign of low CoQ10 levels.
- Spontaneous abortion is linked with low CoQ10 levels.
- Research indicates that if levels of CoQ10 decline by 25% our organs may become deficient and impaired. If levels decline by 75% serious tissue damage and even death may occur.
- CoQ10 decreases cardiac mortality.

Dr Sinatra found that while 85% of his cardiac patients responded to CoQ10 alone, 15% needed to take CoQ10 and L carnitine before significant benefits were seen (even where blood levels of CoQ10 were shown to be high).

Although CoQ10 comes in two forms, ubiquinone and ubiquinol, for many years ubiquinone was the only CoQ10 supplement available. Advances in CoQ10 manufacturing processes in Japan have recently led to ubiquinol supplements becoming widely available. According to Dr Sinatra, 15 mg of the (reduced) ubiquinol form of CoQ10, is equal to 50 mg of the ubiquinone form of CoQ10. So ubiquinol raises blood levels of CoQ10 just over three times as well as standard ubiquinone.

(To create cellular energy, the body has to convert ubiquinone into ubiquinol. Aging and other factors however slow down or stop this conversion from happening, leading to low CoQ10 levels. If you are one of these that has a problem converting ubiquinone, then ubiquinol will have an even stronger effect, in comparison with ubiquinone. The ability to convert ubiquinones into its usable form decreases with age. Some studies show ubiquinol as being up to 8 times as bioavailable as ubiquinone. The contradictions in some CoQ10 clinical research are mostly due to the reduced bioavailability of some types of CoQ10. Water miscible forms are best absorbed, while powder forms are least well absorbed. The other problem is that many studies use only very low doses of ubiquinone, such as 200 mg.)

Ubiquinol is the preferred form of CoQ10 and is better value than ubiquinone, per absorbed milligram. Ubiquinone may cause some side effects at high doses (eg. 1200 mg), however, as ubiquinol supplementation can give these same high blood levels at much lower doses, the potential for side effects is also much reduced. Ubiquinol has been shown to peak blood levels 6 hours after ingestion.

**L carnitine**

The name carnitine is derived form the latin ‘camus’ for flesh as carnitine was first isolated form meat sources. Nutritionist Robert Crayhon, author of *The Carnitine Miracle*, explains that strictly speaking, carnitine is not an amino acid and that carnitine does not in fact contain the amino group (NH2). He explains that carnitine is a coenzyme, a water-soluble vitamin-like compound. And that carnitine is similar to choline, one of the B vitamins-and, like various B vitamins, carnitine helps us turn food into energy. More specifically, it is essential for the burning of long-chain fatty acids.

The heart depends on adequate concentrations of carnitine for normal heart function.
The primary role of carnitine is to help transport fatty acids into the energy producing units in the cells - the mitochondria, where they can be converted to energy. This is a major source of energy for the muscles, including those of the heart. Carnitine increases the use of fat as an energy source.

Carnitine is useful in clearing the bloodstream of ammonia and aids in creating glycogen, used to store essential glucose. Carnitine transports waste products out of the mitochondria, thus ensuring that toxic metabolic waste products do not accumulate. Carnitine reduces the accumulation of lactic acid, which is responsible for the burn felt inside the muscles with exercise.

Carnitine can help to prevent muscle atrophy.

Carnitine protects the heart from damage when a heart attack or a spasm cuts off the oxygen supply. Recent research has shown that carnitine can aid in recovery after a heart attack. Michael Murray N.D., author of ‘The Pill Book: Guide to Natural Medicines’ writes, ‘Subjects taking carnitine showed significant improvements in heart rate, blood pressure, angina attacks, rhythm disturbances, and clinical signs of impaired heart function compared to the subjects taking placebo.’

Low thyroid function may indicate a need for carnitine to help overcome low energy levels and the tendency to gain weight.

Carnitine can improve insulin sensitivity in those with type 2 diabetes.

Kidney dialysis rinses away amino acids, causing weak, tired condition, which is threatened by high triglycerides. Carnitin supplements may be advisable in such situations.

At doses of 1 – 3 g carnitine reduces blood triglycerides. (As the LEF website explains, ‘Carnitine combines with enzymes found in the mitochondrial membrane to transport fatty acids into the interior of the mitochondria, where they are oxidized to provide fuel for the generation of energy. In the absence of carnitine, fatty acids are not oxidized, but, instead, are transformed into dangerous triglycerides.’)

Carnitine is an antioxidant and enhances the effectiveness of antioxidant vitamins C and E. Carnitine is synergistic with pantethine (vitamin B5).

Carnitine is manufactured by the body if sufficient amounts of iron, vitamin B1, vitamin C, niacin, vitamin B6, lysine, and methionine are available. Food sources of carnitine include meat, poultry, fish, and dairy products are the richest sources of L-carnitine. Grains, fruits, and vegetables contain little or no carnitine. Robert Crayhon points out that due to high consumption of red meat, the Stone Age hunter probably got at least 500 mg of carnitine a day, and possibly as much as 2 grams. Today the average carnitine intake is estimated at a mere 30 to 50 mg a day. Strict vegetarians consume practically no carnitine.
L carnitine is generally not well absorbed, and is best absorbed on an empty stomach. There are several different forms of carnitine;

- L carnitine fumarate is absorbed at a slightly higher rate than pure L carnitine and L carnitine tartrate. It is stable enough to be available in capsule form. L carnitine fumarate has a double effect as the fumarate is a free radical scavenger and also plays a part in the krebs energy cycle.

- Pure L carnitine draws moisture and so is not suitable for use in capsules and tablets. It is commonly used in liquid carnitine products and pure carnitine powders. It has a very mild taste when mixed with water and is a good choice of carnitine.

- For angina and other cardiovascular applications, a new form of carnitine known as L-propionylcarnitine appears to be the most effective form of carnitine, although it may also be the most expensive and difficult to source. (Look for products labelled Glycocarn.)

- L carnitine tartrate is an adequate form of L carnitine. When mixed with water it has an unpleasant tart taste.

L carnitine is thought to be one of the safest nutritional supplements on earth, according to Dr Sinatra.

_A special warning about buying low quality carnitine supplements:_ If you are using a Chinese made product, you could be putting your health in danger. Products containing the D isomer can cause cells to not function properly and possibly die. If you cannot find out the D isomer content of a product, then do not buy that brand of carnitine. D-carnitine supplements should be avoided. The D isomer, which is not biologically active, can compete with the L isomer. To ensure a safe product, buy only Sigma Tau or Lonza carnitine products.

**Information on acetyl L carnitine:** Nutritionist Robert Crayhon, author of _The Carnitine Miracle_, explains that for neurological disorders it appears that acetyl L carnitine (ALC) is the best form of carnitine. ALC improves cognitive function and increases mitochondrial energy output (especially when combined with lipoic acid). Besides enhancing fatty acid transport and utilization, ALC also increases the density of neurotransmitter receptors, the levels of neurotransmitters such as acetylcholine and dopamine. It also reduces the accumulation of lipofuscin (a metabolic waste product related to lipid peroxidation, seen at particularly high levels in dementia), counteracts glycation and promotes melatonin production. Acetyl-L-carnitine also restores cortisol receptors, acts as an antioxidant and boosts the levels of glutathione and CoQ10.

Supplementation with ALC has been shown to reduce degenerative processes in the nervous system, and improve memory and learning ability. According to Nutritionist Robert Crayhon, ‘acetyl-L-carnitine qualifies as the superstar of neuroprotection.’
One side effect of acetyl L carnitine is vivid dreams, possibly due to increases melatonin production. Too much ALC can also cause neurological overstimulation for those with neurological diseases involving seizure states such as M.E. and so a small dose of just 500 mg is recommended. ALC is not recommended where seizure problems are severe.

ALC is one of the most important supplements to be taken after a stroke, to help speed recovery. For stroke patients, the recommended dosage is usually 1500 mg.

**D ribose**

D ribose (or ribose) is a simple 5-carbon sugar found in all living cells. Dr Sinatra explains that,

> Until 1944, D-ribose was thought to be primarily a structural component of DNA and RNA with little physiological significance. But a series of studies, culminating in 1957, revealed that this sugar molecule played an intermediate role in an important metabolic reaction called the pentose phosphate pathway. This reaction is central to energy synthesis, the production of genetic material, and for providing substances used by certain tissues to make fatty acids and hormones.

Several notable papers were published in 2003. One study showed that D-ribose improved diastolic functional performance of the heart, increased exercise tolerance, and significantly improved the quality of life of patients.

Research continues here and abroad. Yet, despite the powerful scientific evidence, very few US physicians have even heard of D-ribose outside of their first-year medical school biochemistry class, and fewer still recommend it to patients. We lucky ones who are familiar with it have the wonderful gratification of seeing it help our patients on a regular basis.

Ribose is a very well studied product. More than 100 papers have been completed or published on its cardiovascular health benefits. In short:

- Ribose plays a role in the manufacture of glucose, which is used in the body in metabolic processes, including energy production and, cyclically, production of ribose. Ribose also converts to pyruvate, which can combine with oxygen in the metabolic pathways to produce adenosine triphosphate (ATP) - the energy source for all muscles. Ribose is the prime ingredient in the production of ATP.
- Ribose is found in heart and muscle cells, but the body cannot manufacture it quickly enough to meet the demands of metabolic stress experienced during strenuous exercise or diminished blood flow or where there is metabolic insufficiency.
- Ribose improves the relaxation of the heart that allows it to fill properly with blood. Thus ribose improves diastolic heart function. (As explained previously, this has special relevance and importance for M.E.)
• Ribose is vital in the formation of nucleotides, compounds needed by the heart and skeletal muscles, as well as other body cells. Nucleotides are required for the body to produce energy for muscle cells; manufacture protein, glycogen and nucleic acids (RNA and DNA); form the cyclic nucleotides responsible for controlling calcium and other electrolytes; and relax the heart and muscle cells.

Dr Sinatra goes on to write,

Supplemental D-ribose absorbs easily and quickly through the gut and into the bloodstream. About 97% gets through. Studies have shown that any amount of D-ribose you give to energy-starved cells gives them an energy boost. At the University of Missouri, researcher Ronald Terjung has shown that even very small doses (the equivalent of about 500 mg) of D-ribose increase energy salvage in muscles by more than 100%. Larger doses increase the production of energy compounds by 340-430%, depending on the type of muscle tested, and improve the salvage of energy compounds by up to 650%. Most amazing is that when muscles are supplemented with D-ribose, they continue to add to their energy stores even while they actively work! Until this study was reported, it was thought that muscle energy stores were only refilled in muscles at rest.

An adequate dose of D-ribose usually results in symptom improvement very quickly—sometimes within a few days. If the initial response is poor, the dose should be increased until the patient feels relief. Logically, the sickest patients stand to gain the most.

The half-life of ribose is only 30 minutes.

**Magnesium**

See the Magnesium and M.E. paper for information on all aspects of magnesium.

**Restrictions and cautions on the use of CoQ10, L carnitine and D ribose**

Certain drugs, such as those that are used to lower cholesterol or blood sugar levels, may reduce the effects of CoQ10. The LEF explains that,

A large number of drugs deplete Coenzyme Q10. These include such widely used tricyclic antidepressants as Elavil (amitriptyline) and Tofranil (imipramine), the anti-psychotic drug Haloperidol, cholesterol-lowering statin drugs such as Lovastatin and Pravastatin, beta-blockers, anti-diabetic sulfonylurea drugs such as Glucotrol (glipizide) and Micronase (glyburide), and the anti-hypertension drug Clonidine. These common drugs, as well as several others, interfere with the body's synthesis of CoQ10 and may cause a deficiency of this crucial compound, so important for energy production and protection against free radicals. This drug-induced depletion can be particularly serious in the elderly, who already suffer from aging-related CoQ10 deficiency.

It is particularly ironic that drugs prescribed to heart patients result in lower
levels of CoQ10, since the heart has an enormous need for CoQ10 for its energy production. In fact, a CoQ10 deficiency first manifests itself in cardiovascular symptoms. The authors warn, "The results of some studies suggest that congestive heart failure is primarily a coenzyme Q10 deficiency disease." The same may be true of cardiomyopathy, heart muscle impairment which may lead to heart failure. The authors also list other symptoms of CoQ10 deficiency, including angina, cardiac arrhythmias, mitral valve prolapse, high blood pressure (which may lead to stroke), gum disease, low energy and a weak immune system (which may result in greater susceptibility to cancer). Recently it has also been discovered that CoQ10 is very important for brain health, and may help prevent Parkinson's disease and Alzheimer's disease. The importance of CoQ10 can hardly be overemphasized.

To reiterate; statin drugs, tricyclic antidepressants and beta blockers deplete CoQ10 and if CoQ10 is not given at the same time as these drugs, cardiomyopathy or CHF may result. Overactive thyroid or a pulsating heart requires additional CoQ10. CoQ10 may alter the body’s response to warfarin and insulin.

CoQ10 shows very few significant side effects, though some patients report insomnia and restlessness when treated with high doses of CoQ10 supplements. If this occurs, the dose should be lowered until the symptoms resolve. No serious side effects have been reported from the use of coenzyme Q10. Some patients using CoQ10 have experienced Other possible side effects include rashes, nausea, upper abdominal pain, dizziness, visual sensitivity to light, irritability, headache, heartburn, and fatigue. Generally CoQ10 is well tolerated in M.E. However, some M.E. patients say they can only tolerate low doses of CoQ10, while others find they need very high doses to see the full benefits of CoQ10.

The effects of CoQ10 on pregnant and nursing women and very young children have not been studied and so this supplement is not recommended for these patient groups.

Patients being treated with AZT, Doxorubicin, Isotretinoin or Valproic acid should speak to a physician before taking any L-carnitine supplements. Anticonvulsant drugs may lower the effectiveness of carnitine supplements. Renal patients may need a lower dose of carnitine. Carnitine supplementation will often mean that the dosages of various heart drugs will need to be lowered; this process should always involve the doctor that prescribed the drugs and be very gradual – do not stop taking any medication suddenly.

Carnitine is a very well tolerated and safe supplement. It does not appear that L-carnitine causes significant side effects, although high doses taken on an empty stomach may cause diarrhea. Other possible but rare side effects include body odor, rash, and increased appetite. This supplement is generally very well tolerated in M.E.

Dr Sinatra explains that,

The toxicology and safety of D-ribose have been exhaustively studied. The supplement is 100% safe when taken as directed. There are no known adverse
drug or nutritional interactions associated with D-ribose use. Thousands of patients have taken D-ribose at dosages up to 60 grams per day with minimal side effects. However, even though there are no known contraindications of D-ribose therapy, we recommend that pregnant women, nursing mothers, and very young children refrain from taking D-ribose simply because there is not enough research on its use in these populations. D-ribose can actually lower blood glucose levels; therefore, insulin-dependent diabetics should check with their physicians before starting on the supplement.

The only problems usually mentioned with regard to D-ribose (in books are articles) are infrequent minor gastrointestinal side-effects or feelings of faintness where a large dose is taken on an empty stomach. However, of all the supplements listed here D ribose by far the one most likely to cause problems or to not be tolerated even at lower doses in M.E. (Unfortunately many D ribose experts seem to not have encountered many or any M.E. patients and are unaware of this problem.)

Many M.E. patients become very ill when trialling D ribose and so it is very important to start at doses much lower than the 5 g usually recommended as a starting dose. D ribose can cause far more than gastrointestinal upset in M.E., it can cause severe relapse and loss of quality of life. (A short improvement in function maybe also followed by a ‘crash.’ Dr Cheney has commented that in a small number of patients ribose seems to be metabolised as a sugar rather than a component of ATP production, or metabolised anaerobically which results in lactic acid build up in the body – rather than the ribose being used primarily to make more ATP, which is the idea behind ribose supplementation.

Thankfully, the negative affects from D ribose do pass quickly, usually within a few days. D ribose should be taken with meals (or at least mixed into juice, milk, or fruit) to offset the blood-glucose-lowering effect.

D ribose should be discontinued if no benefits are seen or only very small benefits are seen as there is a possibility that the sugar content could feed ‘bad’ bacteria and contribute to Candidasis or gas and bloating. Dr Cheney made a complete turnaround in 2009 on ribose, commenting that it is ‘toxic’ to patients and makes problems worse. While Dr Cheney should by no means be assumed to be absolutely correct in his every comment (he does NOT study a 100% M.E. patient group after all and is not what one might call politically aware), this is another reason to cease ribose supplementation unless it is very clearly helping significantly. Where D ribose is not helpful, patients may want to instead try sublingual NADH or ATP lozenges.

There are still enormous benefits to be had from the combination of CoQ10, L carnitine and magnesium, with or without additional D ribose supplementation.

CoQ10, L carnitine and D ribose tests
Testing the blood levels of CoQ10 may be very helpful, both in determining the correct dose of CoQ10 needed and to determine, where there is a lack of response to
CoQ10, if this may be caused due to a lack of absorption (or perhaps a product not containing the amount of CoQ10 stated on the label, and so on). This test is widely available.

Dr Sinatra explains that researchers agree that CoQ10 blood levels of 2.5 ng/ml and preferably 3.5 ng/ml are required to have an impact on severely diseased hearts. Dr Sinatra recommends Quest labs for CoQ10 tests. The LEF also offers a CoQ10 blood test, for US patients.

Testing of carnitine levels is not usually necessary before carnitine supplementation according to Dr Sinatra. (For information on the tests necessary to diagnose carnitine deficiency see the eMedicine/Web MD website)

Testing D ribose levels is useless as ribose has such a short half life in the body.

**Dosage recommendations**

CoQ10/ubiquinol: Dr Sinatra recommends the following daily CoQ10 dosages (note that the ubiquinol figures have been rounded to the nearest 25 mg):

<table>
<thead>
<tr>
<th>Ubiquinol dosage (rounded figures)</th>
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<th>Recommended:</th>
</tr>
</thead>
<tbody>
<tr>
<td>25 - 50 mg</td>
<td>90 – 150 mg</td>
<td>As a cardiac disease preventative.</td>
</tr>
<tr>
<td>75 - 100 mg</td>
<td>240 – 360 mg</td>
<td>For cardiac arrhythmia, angina and those taking statin drugs.</td>
</tr>
<tr>
<td>100 - 175 mg</td>
<td>360 – 600 mg</td>
<td>For dilated cardiomyopathy and congestive heart failure.</td>
</tr>
<tr>
<td>175 – 350 mg</td>
<td>600 – 1200 mg</td>
<td>To improve quality of life in Parkinson’s disease.</td>
</tr>
<tr>
<td>350 mg or more</td>
<td>1200 mg or more</td>
<td>Where there is greatly reduced immunity, such as in cancer.</td>
</tr>
</tbody>
</table>

Although there is no specific dosage given for M.E. (nor for many other diseases) by Dr Sinatra this is not necessarily a significant problem. Dosage will depend on disease severity which can vary considerably in M.E. and there are also significant differences in the dose needed from person to person and so dosage recommendation can only ever be general guidelines, as Dr Sinatra explains.

In addition, we do know that M.E. has some similarities to Parkinson’s and can be a similarly disabling neurological disease and that (anecdotally) those with moderate – severe M.E. will most often need doses the same as those listed for Parkinson’s
disease, in order to experience an improvement in quality of life. (1200 mg of ubiquinone daily is often quoted as a standard dosage for Parkinson’s patients.)

The dosage of CoQ10 in M.E. can be guided by blood levels of CoQ10 or by raising the dose until the patient experiences significant improvement, or both. The maintenance dose of CoQ10 should then be adjusted downwards as much as possible, without losing the benefits. For patients that are severely affected the maintenance dose may need to stay the same as the initial dose, in order to prevent relapse.

CoQ10 should be taken in 2 – 3 divided doses (with food). Do not take medium -large doses all at once.

Dr Sinatra recommends that patients be pre-treated with CoQ10 prior to any type of cardiac surgery. He also comments that very severely ill patients may need three times as much CoQ10 as others. Benefits from CoQ10 will often be seen in 1 – 4 weeks but it may take several months for the full effect to become apparent.

L carnitine: For those with serious cardiac issues, as in M.E., pure L carnitine should be trialled at 250 – 750 mg taken 4 times daily, according to Dr Sinatra. (For a total intake of 1 to 3 grams daily).

If improvement is not seen at 3 g, the dose may need to be raised to 4 g or in severe cases, 5 or 6 g. The maintenance dose may be able to be significantly lower than the initial or pharmacologic dose, although in severe cases the initial dose will need to be maintained long-term to prevent relapse. How you feel should be your guide to determining your best L carnitine dosage long-term.

Do not take doses larger than 1 – 1.5 g at a time as absorption is greatly reduced with large doses. L carnitine is best taken in 3 – 4 divided doses.

D ribose: The usual recommendation for D ribose where there are serious cardiac issues is to take 5 g (roughly two teaspoons), two or three times daily, according to Dr Sinatra, for a total intake of 10 to 15 grams daily.

In very severe cases doses of 15 – 30 g may be recommended. (Two teaspoons = 4.5 g D ribose. 1 teaspoon = 2.25 g, ½ teaspoon = 1.125g, ¼ teaspoon = 562 mg.)

A very cautious starting dose in M.E. may be 280 mg (1/8 th of a teaspoon) taken daily, in divided doses, for the first week and raised 280 mg a week or a fortnight until a dose of 5 g (or more) is safely reached or the treatment must be stopped due to its causing relapse. Note that having smaller doses less often may increase your tolerance of D ribose and that buying powders rather than tablets may make taking (and measuring) smaller doses easier to manage. (If you can work out how to measure 1/16 th of a teaspoon, you could make this your daily starting dose instead. Or
you could even have $1/8^{\text{th}}$ or $1/16^{\text{th}}$ of a teaspoon of D ribose every second day or a week, to start with.)

Make sure to take D ribose with food to minimise its effect on blood sugar levels. D ribose is best taken in 2 – 3 or more divided doses. Ribose gives improvements in a few days.

**Magnesium:** See the [Magnesium and M.E.](#) paper for information on all aspects of magnesium.

All four of these supplements are very safe to take long-term.

**Antioxidants and mitochondrial supports**

Nutritionist Robert Crayhon explains that mitochondrial supports ‘should be combined with antioxidants to compensate for the increased production of free radicals that is a by-product of greater energy output. Older people especially need to take extra antioxidants to compensate for this.’ Lipoic acid is one of the most important antioxidants, along with vitamin E and vitamin C. CoQ10 is also an antioxidant.

Dr Sinatra recommends that 50 -100 mg of lipoic acid (and also a daily multivitamin, extra vitamin C and fish oil) always be taken along with the ‘awesome foursome.’ He states that to help neutralise free radicals, nurture your mitochondria and delay aging, life-long supplementation with CoQ10, L carnitine, lipoic acid and vitamins C and E is essential.

**References and recommended additional reading list:**

- The Sinatra Solution by metabolic cardiologist Dr Stephen T. Sinatra
- L carnitine and the heart by metabolic cardiologist Dr Stephen T. Sinatra
- The CoQ10 Phenomenon and Coenzyme Q10 and the Heart by metabolic cardiologist Dr Stephen T. Sinatra
- The Carnitine Miracle by Robert Crayhon, M.S. (plus Review: The Carnitine Miracle by LEF)
- Enhancing Cardiac Energy with Ribose by Stephen T. Sinatra, MD, and James C. Roberts, MD
- Dr Atkins Vita-Nutrient Solution: Nature's Answer to Drugs

**Additional references**

- Carnitine and Thyroid Disease: Why Hyperthyroid Patients Need Carnitine by LEF
- Coenzyme Q10 Effective for Migraine Prevention from New Hope Natural Media
- D-Ribose: Energize Your Heart, Save Your Life by Julius G. Goepp, MD
Drugs That Deplete - Nutrients That Heal by LEF
How CoQ10 Protects Your Cardiovascular System by LEF
L-Carnitine Aids Circulation in Legs - Nutrition Science News
L-Carnitine May Prevent And Treat Hyperthyroidism - InteliHealth
Natural Approaches In the Treatment of Congestive Heart Failure by Dr Sergey A. Dzugan on LEF
Natural Prescriptions For Parkinson's Disease by LEF
Nutrients To Boost Mitochondrial Function by LEF
The First Therapy Shown To Slow Progression of Parkinson's Disease by LEF

Relevant quotes
“Both carnitine and CoQ10 promote energy to cardiac muscle cells. It is important to note that this action is physiological and is not similar to the pharmacological effects of drugs that affect the heart rate and contractibility of the heart.” Dr Sinatra in ‘The Sinatra Solution’
Coenzyme Q10 (CoQ10), L-carnitine, D-ribose and magnesium are the 'awesome foursome' of cardiovascular health. These substances are synergistic with each other and so the benefits of taking more than one of these substances at a time may far outweigh the benefits seen from taking any of them alone.

- CoQ10 and L-carnitine are major players in the energy recycling metabolic pathways. D-ribose is the only compound used by the body to replenish depleted energy stores and rebuild energy pools. Magnesium is a vital mineral used by the enzymes that make energy synthesis and recycling possible. Or as Dr Sinatra explains; D-ribose fills the tank, CoQ10 and L-carnitine help convert this fuel to energy (helps the engine run properly) and magnesium is the glue that holds it all together.

- While some M.E. patients may only be able to tolerate lower doses of CoQ10, carnitine and magnesium are generally well tolerated in M.E. Ribose is often not well tolerated and/or ineffectual in M.E. and so this supplement is often avoided in favour of the other three. There are still enormous benefits to be had from the combination of CoQ10, L-carnitine and magnesium, with or without additional D-ribose supplementation.

- Dr Sinatra explains that researchers agree that CoQ10 blood levels of 2.5 ng/ml and preferably 3.5 ng/ml are required to have an impact on severely diseased hearts.

- The initial doses and maintenance doses of these substances may be quite different. After the initial phase, the maintenance dose of each nutrient should then be adjusted downwards as much as possible, without losing the benefits. For patients that are severely affected the maintenance dose may need to stay the same as the initial dose, in order to prevent relapse.

- CoQ10 is best taken as ubiquinol rather than as ubiquinone. According to Dr Sinatra, 15 mg of the (reduced) ubiquinol form of CoQ10, is equal to 50 mg of the ubiquinone form of CoQ10. Carnitine can be taken as pure L-carnitine, or as L-carnitine fumarate, L-propionylcarnitine or L-carnitine tartrate.

- Supplementation with CoQ10, carnitine, ribose and magnesium should be combined with a multivitamin and antioxidant supplementation regime.

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The dosage of CoQ10 in M.E. can be guided by blood levels of CoQ10 or by raising the dose until the patient experiences significant improvement, or both. CoQ10 should be taken in 2 - 3 divided doses, with a fat containing meal. Do not take medium - large doses all at once.

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In very severe cases doses of 15 - 30 g may be recommended. (Two teaspoons = 4.5 g D ribose. I teaspoon = 2.25 g, ½ teaspoon = 1.125g, ¼ teaspoon = 562 mg.)
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Make sure to take D ribose with food to minimise its effect on blood sugar levels. D ribose is best taken in 2 - 3 or more divided doses. Ribose gives improvements in a few days.

**Magnesium:** See the [Magnesium and M.E.](http://www.hfme.org) paper for information on all aspects of magnesium.

For more information and for references please see the main coQ10, L carnitine and D ribose paper.
Iodine is an essential element. Although its main function is in the production of thyroid hormones by the thyroid gland, other organs in the body have a need for iodine in order to function normally.

Iodine also plays an important role in any detoxification or immune system strengthening program as well as in treating and preventing fibrocystic disease of the breast and ovarian cysts. Iodine will shrink fibrocystic breast lumps, fibroids, and ovarian cysts, reduce the risk of certain cancers and is particularly important for the health of the adrenal gland.

A mixture of iodine (Lugol’s) and DMSO applied topically every day for several months is an effective treatment for fungal toenail infections and may also improve keloid scars or boils.

In the article Iodine: The Miracle Mineral by Chris D. Meletis ND, he explains:

Iodine is an element in the halogen family, members of which also include fluorine, chlorine, bromine and astatine. These other halogens can compete with iodine for uptake from the intestines and can replace iodine in physiological reactions. Bromine and chlorine are both widespread environmental contaminants. In addition to its use as a flame retardant, bromine has also replaced iodine as a dough softener in bread making. Animal models indicate that with increased intake, bromide replaces iodine in the thyroid. Bromide treatment in iodine-deficient rats induces hypothyroid symptoms including decreased T4 and increased thyroid gland size. Similarly, animal models have shown that bromine can induce goiter, decrease iodine concentration in the thyroid and increase iodine excretion.12

Also, research indicates that supplementation with iodine and selenium decreased the amount of bromine taken up by the thyroid gland by 50 percent compared to non-supplemented rats. Iodine deficiency is at epidemic proportions and iodine deficiency or sub-clinical deficiency is more common than previously believed. Due to the variety of health conditions associated with this deficiency, taking an iodine sufficiency test to determine iodine status and optimizing iodine levels with Iodoral, ATP Cofactors and selenium should be considered as part of any health maintenance plan.
Symptoms and signs of low iodine levels include goiter, dry eyes, hair loss, brittle hair and nails, slow pulse, constipation, dry mouth, dry skin with a decreased ability to sweat, decreased stomach acid, ovarian or breast cysts and poor thyroid function. Iodine is essential for proper temperature control.

When thyroid levels have been shown to be low, this may be an indication that an iodine loading test may be necessary. The 24-hour iodine sufficiency test (a simple urine test available for around $100 from companies such as VRP, with a doctor’s consent) indicates whether or not additional iodine supplementation may be beneficial. Testing should then be repeated after 4-6 months to monitor proper iodine doses.

Low iodine levels most often cause low thyroid output, but in some cases can cause hyperthyroidism.

If the tests shows that iodine supplementation is necessary, the types of iodine usually recommended to take are Lugol’s and Iodoral (Iodoral is Lugol’s iodine is tablet form). The non-radioactive, inorganic iodine, as in Lugol’s / Iodoral, is very safe and does not build up in the body as any excess is excreted by the kidneys within 24 hrs. (This is why the iodine loading test is so accurate as an indicator of whole-body iodine levels.)

Some doctors recommend nascent iodine as the best quality iodine supplement and consider it far superior to Lugol’s, especially where the patients is very sensitive to supplements and medications. The therapeutic dose is also lower with nascent iodine. Mark Sircus writes,

Nascent iodine contains approximately 400 mcg per drop so 10 drops is 4 mg and 100 drops is only 40 so it’s safe to take much higher dosages than is suggested on the bottle. It is very important to remember though that one should not shoot straight up to these dosage levels. One should start at low dosages and monitor for detox reactions.

Dr. Abrahams recommends taking 50 mg of Iodine/Iodide as Lugol’s solution (8 drops) daily for 3 months as a loading dose. Lugol’s solution is available online at varying concentrations. Then his recommendation is that dose should be gradually reduced to the 12.5 mg (2 drops) maintenance dosage under the supervision of a knowledgeable health care professional. Dr Abrahams feels that 14 to 15 mg of iodine/iodide daily is the upper maximum of safety for long term use. This is close to Dr. James Howenstine’s (another prominent iodine advocate) recommended dose of 12.5 mg daily.

One producer of nascent iodine explains that nascent iodine is consumable iodine in its atomic form rather than its molecular form. It is an iodine atom that has an incomplete number of electrons. It is paramagnetic; the iodine atoms can hold an electromagnetic charge. This “charged” state is held by the atom until diluted in water and consumed, whereby it gradually loses energy over a 2-3 hour time span. During this time, nascent iodine is recognized by the body as the same iodine that is
produced by the thyroid and is absorbed effortlessly by the body. (The body has to expend energy to use the Lugol’s form of iodine, another reason that nascent iodine is a better choice in M.E.)

Small frequent doses should be taken on an empty stomach. Dosage is usually 3-5 drops taken 3-5 times daily. Patients that cannot afford to take the more expensive nascent form of iodine long-term may wish to at least begin iodine supplementation with this safer and gentler form, before switching to Lugol’s.

Dr Brownstein writes,

Food that is present in the digestive tract will oxidize iodine to iodide, which is not corrosive to the gastrointestinal tract. Oral iodine appears to be inactivated by combination with gastrointestinal contents. Absorption is poor due to rapid conversion of iodine to iodide and this might explain why one needs to take very high doses of Iodoral or Lugol's compared to Nascent Iodine, which seems to bypass the digestive tract altogether, meaning its absorption starts right in the mouth and continues through direct penetration of the stomach tissues.

Iodine supplements may enhance the response of the body to thyroid hormones and so the dose of thyroid replacement medications may have to be lowered once iodine supplementation has begun. Iodine supplementation over 1 mg should be prescribed only if indicated by the results of iodine testing.

Iodine plays a role in helping the body to sweat and so is recommended for patients using FIR saunas.

The optimal requirement of the whole human body for iodine has never been studied, and RDA amounts are based on the small amounts needed to prevent goiter etc. Therefore, the optimal amount of this element needed for physical and mental wellbeing is unknown. The mainland Japanese consumed roughly 3 to 10 mg daily and they are one of the healthiest people on planet earth (based on demographic studies).

Table salt is not necessary for good health and should be eliminated from the diet completely or as much as is possible. It is an unnatural and highly refined product. This includes iodised table salts. (Iodised table salts contain very small amounts of iodine which are not very available to the body. It is enough to prevent goiter, but nowhere near enough to provide the optimum levels of iodine the body needs.)

Iodine expert Dr David Brownstein promotes the use of magnesium as a supplement “synergistic” to treatment with iodine and also recommends that patients take extra selenium with iodine. He explains,

As with using any nutritional supplement, a comprehensive holistic treatment plan provides the best results. Magnesium is an important part of the iodine treatment plan. Magnesium deficiency is very common. Magnesium is nature’s relaxing
agent. Magnesium levels (via red blood cell magnesium levels) should be assessed and supplementation instituted. Magnesium supplementation will likely ensure optimal results with iodine.

Dr Brownstein notes that around 5% of patients may experience side effects from iodine supplementation, these include; acne, a metallic taste in mouth, sneezing, excess saliva and frontal sinus pressure. Iodine can also cause a detox reaction if it is started at too high a dose, and without a basic nutritional program being implemented first. Iodine supplementation should be started at a low dose and this dose raised only slowly to minimise the risk of side effects. Very sensitive patients should at least begin treatment with nascent type of iodine.

Iodine taken after the evening meal may interfere with sleep, and so iodine is best taken earlier in the day if possible.

More information and references:
- Dr David Brownstein’s book IODINE: Why you need it Why you can't live without it
- Clinical Experience with Inorganic Non-radioactive Iodine/Iodide (article) by Dr Brownstein
- Epidemic of Bromine Toxicity by Dr Brownstein.
- Iodine - Bring Back the Universal Medicine (e-book) Mark Sircus, Ac., OMD
- Iodine Phobia and Salt Truth Mark Sircus, Ac., OMD
- Iodine (I) - General Discussion from the DC Nutrition website.
- Iodine: The Miracle Mineral by Chris D. Meletis, ND
- The Iodine 4 health.com website.
- The Wonders of Iodine by Jonathan V. Wright, M.D. Nutrition & Healing, 11/1/2002 Newsletter
- Iodine sufficiency of the whole human body, Effect of daily ingestion of Iodoral and The safe and effective implementation of orthoiodosupplementation in medical practice by Dr Guy Abraham
- Goitre and upset iodine metabolism and Iodine and trace elements in the promotion and maintenance of metabolic excellence by Dr Myers.
- Iodine – An Important Mineral Today by Lawrence Wilson, MD

See also:
- Ovarian iodide uptake and triiodothyronine generation in follicular fluid. The enigma of the thyroid ovary interaction, A.B. ´Slebodzi´nski, Professor emeritus
- Breast Cancer and Iodine: How to Prevent and How to Survive Breast Cancer by David M. Derry MD
- The Story of Iodine Deficiency : An International Challenge in Nutrition by Basil S. Hetzel
- Werner & Ingbar's The Thyroid: A Fundamental and Clinical Text, 8th edition (The classic text on the thyroid used by endocrinologists. Excellent chapters on various topics by different authors, according to the Iodine 4 Health website.)
A review of the latest information on iodine and the thyroid and a preliminary report of my clinical trial, Iodine and Fibrocystic Disease and Thyroid, the most common hormone problem by Dr David Beaulieu

A Rebuttal of Dr. Gaby's Editorial on Iodine by Guy E. Abraham, MD and David Brownstein, MD

Orthoiodosupplementation in a primary care practice and Iodine Insufficiency FAQ Flechas JD

The Great Iodine Debate by Sally Fallon Morell

Additional notes:
Note that prices quoted are in US dollars or Australians dollars (which are almost the same as I write this) and can also be considered accurate to within 10 to 20% for the Canadian or New Zealand dollar.

Relevant quotes
Iodine can be concentrated in the ovaries, and Russian studies done some years ago showed a relationship between iodine deficiency and the presence of cysts in the ovaries. The greater the iodine deficiency, the more ovarian cysts a woman produces. In its extreme form, this condition is known as polycystic ovarian disease. Iodine and trace elements in the promotion and maintenance of metabolic excellence.

Iodine stabilizes the heart rhythm, lowers blood pressure, and is known to make the blood thinner as well, judging by longer clotting times seen by clinicians. Iodine is not only good for the cardiovascular system, it is vital. Dr. Michael Donaldson

When using the Nascent Iodine one can dose pulse every two hours orally taking each individual dose up to as many as 20 drops and even at this level we are no where near points of iodine toxicity and tolerance. Mark Sircus, Ac., OMD

A great feeling of security for a parent comes from administering a medicinal like iodine. It is what I give my children instead of dangerous antibiotics when they are sick. It is what I use when the first symptoms of flu approach and it does spare one the worst of that misery. Mark Sircus, Ac., OMD

Iodine is the trigger mechanism for apoptosis (that natural death of cells) and the main surveillance mechanism for abnormal cells in the body. Iodine triggers the death of cells which are abnormal or which have normal programmed death as part of their life cycle. David M. Derry MD

Of all the elements known so far to be essential for health, IODINE is the most misunderstood. Yet, it is by far the safest of all the trace elements known to be essential for human health. It is the only trace element that can be ingested safely in amounts up to 100,000 times the RDI. It is estimated by myself and other clinicians that probably 90% or more of the population of the United States is grossly deficient.
in Iodine. In fact, it must be noted that Iodine is the single most deficient nutrient in the world --- with approximately 70% of the world's population deficient. The collective experience of many medical clinicians over 3 generations has shown that Iodine therapy in the range of 12.5mg to 50mg daily doses to be safe and effective in treating signs and symptoms of Iodine deficiency. The current recommended daily intake (RDI) is only 150 micrograms (.15 mg). This is hardly enough Iodine for the Thyroid gland let alone the rest of the body. W. W. Greene, D.C.

Based on numerous studies, optimum supplementation of Iodine is also highly recommended for those patients who are receiving Thyroid Hormone therapy. It is also interesting to note that the mammary glands are the tissues most often found in the body to “compete” effectively with the Thyroid Gland for Iodine; hence 50% or more women in the U. S. have been diagnosed with Fibrocystic Breast Disease. Iodine supplementation will cure this problem in 6 to 8 weeks. And, it was shown in JAMA, 1976 (Journal of the American Medical Association) that if women who have Iodine deficiencies are prescribed T4 thyroid medication (Synthroid & Levoxyl), this T4 medication further increases their risk for Breast Cancer. This same association has also been shown when women have been prescribed Armour’s Thyroid. W. W. Greene, D.C.

Recent studies indicate that the essential element selenium is a component of the enzyme responsible for converting thyroxine to T3. It remains to be determined whether the systemic utilization of iodine is impaired in subjects deficient in selenium. Iodine (I) - General Discussion from the DC Nutrition website.

Medical Iodophobia is the unwarranted fear of using and recommending inorganic, non-radioactive iodine/iodide within the range known from collective experience of three generations of clinicians to be the safest and most effective amounts for treating symptoms and signs of iodine/iodide deficiency (12.5-50 mg./day). Dr. Guy Abraham, 2004

*The [RDA for iodine] levels were set up to prevent goiter only without concern for other body tissue requirements.* National Health & Nutrition Survey (NHANES) showed that iodine levels in the United States declined 50% while thyroid illness, breast, prostate, endometrial and ovarian cancers increased. The World Health Organization (WHO) claims that an iodine deficiency is the world’s greatest single cause of preventable mental retardation. 72% of the world’s population is affected by iodine deficiency. Why iodine?

In addition to fixing almost all cases of breast cysts, iodine also has a remarkable healing effect on ovarian cysts, and even on skin cysts. (For the latter, I recommend rubbing in iodine right over the cyst.) Iodine (I) - General Discussion from the DC Nutrition website.

Dr. Abraham believes the dose of iodine for maintaining sufficiency of the whole body is at least 13 mg per day (100 times the paltry RDA) – six mg for the thyroid, five mg for the breasts, and two mg for the rest of the body. Men would likely need
less, though not always. Iodine (I) - General Discussion from the DC Nutrition website.

“Iodine deficiency may cause the ovaries to develop cysts, nodules and scar tissue. At its worst this ovarian pathology is very similar to that of polycystic ovarian syndrome (PCOS). As of the writing of this article I have five PCOS patients. The patients have successfully been brought under control with the use of 50 mg of iodine per day. Control with these patients meaning cysts are gone, periods every 28 days and type 2 diabetes mellitus under control.” Orthiodosupplementation in a primary care practice Flechas, J.D.

As I started to use larger doses of iodine (12.5-50mg/day), I began to see positive results in my patients. Goiters and nodules of the thyroid shrank. Cysts on the ovaries became smaller and began to disappear. Patients reported increased energy. Metabolism was increased as evidenced by my patients having new success in losing weight. Libido improved in men and women. People suffering with brain fog reported a clearing of their foggy feelings. Patients reported having vivid dreams and better sleep. Most importantly, those with chronic illnesses that were having a difficult time improving began to notice many of their symptoms resolving.”

If there is severe deficiency, spot urine iodine levels at or near zero or low iodine loading tests results (<50% excretion), higher iodine levels are generally needed. To maximize absorption and retention of iodine, doses of 25-50mg may be needed in patients. Clinical Experience with Inorganic Non-radioactive Iodine/Iodide by Dr Brownstein, 2005

Iodine also helps remove all toxic substances from the body for similar reasons. By enhancing thyroid activity, metabolism is stimulated or enhanced in a very healthful way. This dramatically improves the body’s ability to remove toxic chemicals and other subtle toxins from the tissues. Lawrence Wilson MD

Disclaimer: HFME does not dispense medical advice or recommend treatment, and assumes no responsibility for treatments undertaken by visitors to the site. It is a resource providing information for education, research and advocacy only. Please consult your own health-care provider regarding any medical issues relating to the diagnosis or treatment of any medical condition.
Essential antioxidants:
- Vitamin A (as retinol or beta-carotene)
- Vitamin C
- Vitamin E
- Vitamin B12
- CoQ10
- GP (Glutathione peroxidase), which can be supplemented directly via injections or liposomal products, indirectly (e.g. NAC - see below), or by supplementing its precursor selenium
- NAC (N-acetylcysteine) is not an antioxidant, but it works to restore glutathione.
- SOD (Superoxide dismutase), which can be supplemented directly (e.g. GliSODin), or by supplementing its precursors zinc, copper, iron and manganese

Non-essential anti-oxidants (beneficial extras):
- Lipoic acid, which can be supplemented directly (e.g. ALA/Alpha Lipoic Acid), or obtained from food
- Phytonutrients [phyto = from plants]

To clarify, phytonutrients are referred to in two ways, either as 1) the nutrient itself, or as 2) the natural source of the nutrient. For example, bilberries are a natural source of bioflavonoids.

1) Phytonutrients: Anthocyanidin, probably the most important. Also bioflavonoids and lycopene
2) Natural sources of phytonutrients: Ginkgo biloba, pycnogenol (pine bark), grape seed extract, turmeric, bilberries, and others. There are many natural substances which have antioxidant action.

About Antioxidants
Antioxidants can be particularly helpful for people with M.E. because they work to clear the toxins which overwhelm our bodies. M.E. involves mitochondrial dysfunction, in which impeded cell metabolism results in harmful free radicals which the body cannot clear. (Free radicals are highly unstable molecules which interfere with necessary chemical processes in the body.) Thus people with M.E. produce more free radicals than healthy people. Free radicals damage cells, cause inflammation and vascular damage (which in turn can cause brain dysfunction), muscle and joint pain,
and generally poison the body. Free radicals also cause damage which is not specific to M.E., such as aging and cancer.

In addition to the fact that people with M.E. produce higher than normal levels of free radicals just by being alive, the world we live in produces free radicals in our bodies; pollution, electro-magnetic radiation and fried food produce free radicals, which is why people with M.E. are advised to avoid these threats as much as possible. Antioxidants clear free radicals from the body, and assist with detoxification and repair.

**How antioxidants work**
Antioxidants work together to disarm harmful free radicals. They all work together in a chain, each one dealing with the product of the action of the previous one. Vitamin E disarms the free radical, but in the process produces a vitamin E radical, which needs to be dealt with. Vitamin C recycles vitamin E, disarming the vitamin E free radical. Glutathione recycles vitamin C. CoQ10 also recycles vitamin E. Beta-carotene and anthocyanins also recycle vitamin C, as does lipoic acid. Anthocyanins also recycle glutathione.

**How B12 works (a special case)**
Vitamin B12 isn't one of the conventional antioxidants, but it is very important for people with M.E. The body has lots of systems for clearing free radicals (e.g. CoQ10 and manganese-dependent SOD within the mitochondria, while outside the mitochondria there are vitamins A, C, E, zinc- and copper-dependent SOD, glutathione peroxidase, acetyl L carnitine etc.) However, when these don't work sufficiently well, Vitamin B12 takes over their functions.

As described above, normal cell metabolism results in free radicals. Cell metabolism in people with M.E. produces more free radicals than in healthy people. Nitric oxide causes brain dysfunction. The hypothesis is that these free radicals may cause some of the symptoms of M.E.

Vitamin B12 is the most powerful scavenger of nitric oxide, therefore helping the symptoms of M.E.

**How to take antioxidants**
Antioxidants work together, and should be taken together. Often antioxidant supplements have many of these nutrients combined.

Antioxidants can be taken as supplements. However, these can be expensive and beyond the pockets of M.E. sufferers, so it is worth noting that some antioxidants can be obtained from food (though obviously in less concentrated doses than in supplement form).
Vitamins A and E - these are fat-soluble, so it is possible to overdose on supplements, particularly vitamin A (the body will excrete excess water-soluble vitamins in urine, but cannot clear fat-soluble vitamins so easily). If taking supplements, make sure the dose is appropriate.

Vitamin C - this is an important vitamin to supplement, as it has so many roles (immune system, etc.), and it is very difficult to obtain enough from food (food loses vitamin C rapidly during storage).

Vitamin B12 - there are issues about absorption, so B12 should be taken as a supplement sublingually (under the tongue). Some doctors recommend injections.

Glutathione - supplementing glutathione directly is not recommended unless it is in the injectable or liposomal form.

Selenium (precursor to glutathione peroxidise) - from brazil nuts or supplements.

Lipoic acid - from liver and yeast or supplements. Lipoic acid is a versatile antioxidant as it is both water- and fat-soluble, so it can protect against free radicals from many foods.

Phytonutrients - lycopene from tomatoes, bioflavonoids from berries. Fruit and vegetables generally are full of phytonutrients. Although some fruits and vegetables are high in particular phytonutrients, beware of so-called 'superfoods.' These are often no higher in phytonutrients than other fruits and vegetables, but are extremely expensive because of the 'superfood' label. Eating many different types of fruits and vegetables and many different coloured fruits and vegetables is far preferable to eating large amounts of a small number of so-called 'superfoods.'

Warning
The detoxifying effect of antioxidants releases toxins into the body. This can cause a Herxheimer reaction, in which the person feels extremely sick (both body and brain can be affected). People with M.E. are particularly vulnerable to this, as their livers, which should clear toxins, may not be working efficiently and also because their bodies are already so dysfunctional (e.g. central nervous system, brain and cardiac dysfunction). People with M.E. should be cautious in taking some antioxidants, and start with small doses. This seems particularly true of ALA and NAC. Many M.E. patients may find they have to avoid cysteine altogether.

References
Most of the above was taken from:
• Patrick Holford's 'New Optimum Nutrition Bible 2004' (Holford is the founder of the Institute of Optimum Nutrition in London, and he works with Higher Nature company on formulating supplements).
• Dr. Sarah Myhill, 'Diagnosing and Treating Chronic Fatigue Syndrome' a book which is available from her website www.drmyhill.co.uk (Unfortunately Dr. Myhill does not focus on M.E., - and makes little if any distinction between genuine neurological M.E. and 'CFS' or even various types of 'chronic fatigue' unbelievably, and again, unfortunately - which means that some of her advice is not right for our illness, but she provides useful information on treatment (but NOT diagnosis), to a certain extent).

Part 2: RNase L, cancer risk, antioxidants and M.E. by Lesley Ben
The immune system has two types of cells, T helper cells 1 and 2. Th1 works inside the cell against intra-cellular pathogens such as viruses, cancer, yeast and intra-cellular bacteria like mycoplasma and chlamydia pneumonia. Th2 works outside the cell against extra-cellular pathogens in blood and other fluid, such as allergens, toxins, parasites and bacteria (i.e. normal extra-cellular bacteria).

M.E. causes a switch in the immune system, away from Th1. Th1 cells are suppressed and Th2 cells are activated. M.E. patients have more Th2 cells than Th1 cells. They also typically have low natural killer (NK) cells which are the weapons of the Th1 system, and high white cells and antibodies, the weapons of the Th2 system.

Thus the anti-viral immune system is suppressed, while the antibody-mediated antibacteria, anti-allergen etc. system is activated. So M.E. patients over-respond to allergens and toxins etc. They are under-defended against viruses and yeasts etc, and may be unable to keep viruses from past exposure suppressed, so may get viral re-activation.

In a nutshell:
Th1 = inside cell, protection from viruses etc
Th2 = outside cell, protection from allergens, toxins, bacteria etc
M.E. causes a switch from Th1 to Th2
M.E. patients are Th1 suppressed and Th2 activated

This is why:
- M.E. patients are particularly vulnerable to viruses, yeasts etc. and viral re-activation
- M.E. patients over-respond to allergens, toxins etc, i.e. allergic reactions, MCS etc

The role of RNaseL in immune response
RNaseL is like a footsoldier with limited powers, trying to hold the line against the enemy while waiting for the cavalry to arrive. RNaseL prevents pathogens from reproducing, waiting for Th1 to come and kill them. The problem is that in Th1-
suppressed M.E. sufferers, Th1 never comes to the rescue. RNaseL gets worn out. It eventually shifts into exhausted mode, the more deadly and toxic Low Molecular Weight form (discovered by Suhadonlik). Eventually RNaseL disappears altogether.

Another factor in the decrease of RNaseL is that it is a protein and requires growth hormone. Human growth hormone (HGH) is suppressed in this illness. In a 2008 lecture, Byron Hyde discussed growth hormone manufacture in stage 4 sleep, of which M.E. sufferers get little or none. Lack of growth hormone wipes out RNaseL.

Thus RNaseL status changes over time, a process which may take many years. There may initially be high levels as RNaseL is activated in response to pathogens, then it diminishes, changes to LMW form, and disappears. Tests of RNaseL status can be used to chart the progression of disease.

Despite many claims to the contrary, abnormal RNaseL is not specific to M.E. Abnormal RNaseL levels are not specific to M.E. RNaseL activation giving raised levels is common to immune response to viruses and infection.

However, the Low Molecular Weight form of RNaseL, the exhausted 'after-burner' form, was discovered in ‘CFS' patients by Suhadolnik. The molecular weight of RNaseL is normally 80 kDa, but Suhadolnik discovered RNaseL in ‘CFS' patients of 37 kDa. The presence of this Low Molecular Weight form has been seen as specific to the illness, but this assumes that 'CFS' is a distinct disease or a distinct patient group which is clearly not at all the case.

My thoughts on LMW form:
1) Suhadolnik was looking at ‘CFS' patients, not M.E., and I don't know by what criteria his patients were selected.
2) The LMW form certainly indicates that something is very wrong with immune function. It hasn't been discovered in patient groups other than ‘CFS' ones, but as ‘CFS refers to a very large and mixed patient group it cannot be said to be unique to any patient group, and certainly not to M.E.

In M.E. the immune system is both down regulated AND upregulated at the same time
This puzzled me for a long time, and I couldn't make any sense of different studies which talked about up- and down-regulation.

Things fell into place for me when I understood that the immune system normally acts in two different ways, depending on the type of pathogen it encounters - but that in M.E., one response is suppressed and the other is activated.

As described, Th1 cells respond to intra-cellular pathogens: viruses, cancer, yeast, mycoplasma & CPN. Th2 cells respond to extra-cellular pathogens: allergens, toxins, bacteria & parasites. In M.E., Th1 is suppressed & Th2 activated - for me, this was
helpful to understand, because it explains why we are often vulnerable to viruses, but at the same time, develop allergies when we over-respond to allergens.

May I add a bit more to the story? This next bit amazed me, with the low-down cunning of biological organisms:
It's not quite that there are two different systems, the Th1 & Th2 system, but rather that at first, Th cells are neither one nor the other - they start as Th0 cells, what Cheney calls 'naive or unformed cells.' When an invading pathogen comes along, they convert to either Th1 or Th2, depending which type the pathogen is.
It's so clever, how 'naive' Th0 converts to the appropriate defence, depending on the type of threat - if it encounters virus, cancer etc, a cytokine called Interleukin-12 is produced, which causes the Th0 cell to turn into a Th1 cell, all ready to fight. If the Th0 cell encounters allergen, toxin etc, another cytokine called Interleukin-10 is produced, which turns the Th0 cell into the appropriate Th2 fighter. (I had read about cytokines and Interleukin, and never really understood it - now I picture the different kinds of Interleukin as chemical messengers, running from the invading army to the waiting defenders, telling them what kind of fighters to turn into, to best fight off the approaching threat.)

As the 'naive' Th0 cells grow up into the appropriate type of fighter, depending on the threat, they develop the appropriate type of weapons. (I picture a young child, responding to the messenger by suddenly growing up into a fighter, taking up the right kind of weapons.) The weapons developed if the cell becomes a Th1 cell are cytotoxic T cells and Natural Killer cells. In other words, these are the weapons that fight viruses, cancer etc. The Th2 cell has different weapons, including antibodies.

The following bit amazed me: even though the defenders are so clever, turning into the appropriate type of cell with the appropriate type of weapons to fight off whatever the threat is - the attackers can be even cleverer!
Some cunning viruses MIMIC the other sort of threat! (I laughed in amazement when I understood this.) Some viruses like CMV & HHV6 give off a chemical messenger similar to the one that indicates they are the other sort of threat, i.e not a virus but an allergen, toxin etc. (i.e. a peptide similar to Interleukin-10). They pretend! They disguise themselves!

(Although do note that we know for a fact that herpes viruses do NOT cause M.E., and that this has been scientifically proven for decades.)

The defenders are deceived, and the Th0 cells turn into the wrong sort of fighters, Th2 cells. The poor body is defenceless against the real threat, having no Th1 cells, and instead has useless Th2 cells running around, causing other problems like allergies etc.

From the virus's point of view, it wins its survival by deceiving the body into thinking it isn't a virus but something else, so that the body's defences are mobilised to fight off another kind of threat, and don't kill off the virus.
Not only that, but the virus also helps his friends - other viruses that might want to invade in future. The body gets stuck switched to Th2 mode, so that it's permanently Th1-suppressed and Th2-activated.

Cunning blighters!

**Cancer**
M.E. increases our susceptibility to cancer, particularly Non-Hodgkins Lymphoma. I don't mean to be alarmist, and there are things we can and should do to protect ourselves. I've only recently understood the mechanics of the cancer connection in simple terms, and even though I find it frightening, I was glad to feel at least I understood it a bit.

Our vulnerability to cancer is due to the decrease in RNaseL, as described previously. RNaseL provides cancer protection. Lack of RNaseL leaves the person susceptible to cancer.

This is why some M.E. patients develop cancer (particularly Non-Hodgkin's Lymphoma), typically some years after the onset of M.E. As described above, as the disease wears on, RNaseL diminishes, changes to the LMW form, and then is gone. This process, which leaves the patient vulnerable to cancer, may happen over many years. Some M.E. patients develop cancer 10, 15 years or more after they developed M.E.

I believe that the fact that an occurrence of cancer was caused by M.E. is often lost, and the cancer is seen as separate misfortune, because the above is not widely-enough understood. Such deaths are deaths attributable to M.E. - this is yet another way in which M.E. may be a fatal disease.

It is good to know about this possible susceptibility to cancer, I believe, so that we are motivated to protect ourselves. We should avoid known carcinogens such as pollution, electro-magnetic frequencies, deep-fried or burnt food, chemicals in food, etc. We should take anti-oxidants. We should investigate substances which may have anti-cancer properties.

**More information**
Unfortunately Dr. Paul Cheney in the U.S. talks about 'CFS' and 'CFIDS' and does not distinguish fully between M.E. and 'CFS' but I feel that his work can be illuminating, as explained in the comments in Question: Is Cheney talking about M.E. or 'CFS'? on HFME. For a more detailed explanation of the above see: Balance the Immune System (Th1/Th2) by Dr. Cheney and other articles and lectures by Dr. Cheney.

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Part 3: Liposomal glutathione and M.E. by Jodi Bassett

www.hfme.org
As Lesley Ben explains in her HFME paper on antioxidants, direct oral glutathione supplementation is not recommended. This is because the supplement breaks down into its different parts in the stomach; glutamate, l-cysteine and glycine.

Recently, however, a new delivery system for glutathione has become available and is thought to be far more effective than glutathione given by injection (which while effective to some extent, only has a half life of 2 minutes in the body) and it is certainly more practical. It utilises nanotechnology to deliver glutathione to the bloodstream and the cells of the body in a way that protects it from degradation by the stomach.

As LivOn labs explain, there are 3 main functions of glutathione (Glutathione Sulfhydryl or GSH):
GSH is the cell's master antioxidant. Not only does GSH function very well as an intracellular antioxidant, but it also recycles Vitamin C, Vitamin E, lipoic acid and peroxide, the cell's other vital antioxidants.
GSH is a powerful detoxifier. The liver, as the body's primary filter, contains more GSH than any other organ or tissue in the body. Not only does GSH neutralize many toxins, but it is also key in their elimination from individual cells and the body. This means GSH is a powerful chelator.
GSH is "super food" for T-killer cells, T-helper cells, basophils, phagocytes, microphages, and leucocytes, greatly empowering these first line defenders in the human immune system.

Glutathione gets to the mitochondria in the cell more effectively than vitamin C can. Overall immune status is inextricably linked with glutathione levels and brain injuries of all kinds are known to cause lowered glutathione levels.

The phosphatidylcholine (PPC) contained in liposomal products also has health benefits as it contains omega 3 and 6 fatty acids and choline, a B vitamin. Liposomal delivery of nutrients represents is 98% absorbed and is an energy sparing delivery system, it doesn’t require the body to use up electrons to use the supplements as other forms do. Considering that oxidative stress is an extensively documented cause of symptomatology and worsening of all diseases, this is a very important advantage.

As vitamin C experts Dr Levy explains, Vitamin C is the premier extracellular antioxidant and glutathione is the premier intracellular antioxidant. Vitamin C and glutathione are powerful and important antioxidants taken alone and have an even more powerful synergistic effect when they are taken together. They both give the body the ‘rapid and profound influx of electrons’ needed to fight disease and to support heart, lung and brain health and immunity says Dr Levy, who also adds that ‘Virtually all diseases and toxins/poisons cause sickness and death through their electron stealing activity.’

In the book GSH: Master Defender Against Disease, Toxins and Ageing’ Dr Levy continues,
Since no one has ever seen an electron, for most people it remains a theoretical entity. It is this invisibility that makes it so difficult to accept them as real entities that reliably treat diseases more effectively than antibiotics or prescription drugs. Yet this is precisely the case.

Even though it is not possible to give a teaspoon of electrons to a sick child, one can administer medications and/or nutrients that are extremely rich in their electron content. Once a sufficient quantity of electrons is delivered to the body, it brings what can only be described as fantastic clinical results when compared to traditional medical therapies. And, this has already been shown to be true for a wide variety of medical conditions.

Glutathione and vitamin C and other antioxidants are not cure-alls, particularly when it comes to the treatment of long-term diseases. It is also true that prevention is far easier with these treatments than cure. But Dr Levy does explain that even where the disease is too far advanced to be reversed the administration of reduced glutathione and vitamin C can at least provide reliable symptomatic relief.

Glutathione levels can also be boosted indirectly through taking ALA, methionine, sesame oil, garlic, whey, carnitine, vitamin C and selenium. Carnitine and ALA taken together are particularly effective at raising GSH levels, according to Dr Levy.

**More information and references**

- For more information on liposomal glutathione see Dr Levy’s excellent short book on glutathione ‘GSH: Master Defender Against Disease, Toxins and Ageing’ and the LivOn labs website.
- To buy liposomal glutathione or vitamin C see the List of international suppliers of liposomal vitamin C sachets from Livon labs. Liposomal vitamin C from LivOn Labs is the form recommended and used by Dr Levy. Some brands of liposomal vitamin C may not be reputable and may not be selling the same quality product.
- **PC Liposomal Encapsulation Technology** by Robert D. Milne, see also this PDF summary.
- Glutathione is also available from some compound pharmacies in a nasal spray form.
- Note that in high doses vitamin C functions as an antioxidant rather than a vitamin and so high-dose vitamin C is also a very important supplement for M.E. patients. For more information see the HFME papers [High-dose vitamin C and M.E.](http://www.hfme.org) and [Liposomal vitamin C and M.E.](http://www.hfme.org).

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Chemical sensitivities are common in Myalgic Encephalomyelitis and Multiple Sclerosis, and many other diseases.

This is due to reduced cellular energy and liver function and other factors. Symptoms provoked by chemical sensitivities can range from mild to very severe. Modifying your environment and changing the types of products you buy is essential if you have M.E., or any other disease causing chemical sensitivities or poor liver function.

**Airborne contaminants**

Chemical sensitivities may occur to indoor and outdoor chemical air contaminants. This can produce allergic reactions, although not all chemical sensitivities are IgE mediated. Airborne allergens and toxins can include: pollen, dust, animal dander, petrol/gasoline, paints and varnishes, mould, smoke, cigarette smoke, plastic and glue-out gassing, perfumes and other personal care products and cleaning products.

Avoid paraffin candles as these release toxic fumes as they burn. Alternatives are beeswax and soy candles and both are widely available (try eBay for candle making kits or packets of readymade candles). Avoid being around smokers, and if you smoke, quit.

Avoidance of the contaminants that make you ill is the first and most important step. Air filters may also be useful or necessary. Filter types include HEPA filters and charcoal filters. Filters are most often used in the home, but in-car portable models are also available.

**Water contaminants**

See the paper ‘Pure water and M.E.’ for more information.

**Household or furniture contaminants**

- New carpeting can be extremely toxic. Tiled floors are usually recommended for those with severe chemical sensitivities.
- Low VOC (volatile organic compound) paints should be used wherever possible.
- Furniture and built-in shelving and cabinets made of fibreboard can make
patients ill when they are new and will continue to off-gas for some time. If possible buy used furniture made of wood that has not been recently revarnished, or metal.

- Latex beds should be avoided.
- Bedding made from 100% cotton is usually recommended.
- New appliances such as computers can off-gas chemicals for many months.

**Personal care products**

Every personal care product; every shampoo, deodorant, hair dye, moisturiser, cleanser and toothpaste we use is absorbed through the skin and so are all the products we use to clean our dishes and cutlery and to clean our clothes and sheets. Even if there is no immediate effect on you, these products are best avoided by M.E. patients (and everyone else!) for a number of reasons, not least of which is that they are often carcinogenic.

It may feel very overwhelming at first having to change many different products that you commonly use, but you’ll probably soon find a few brands and products that you feel comfortable sticking to.

**Deodorant:** Products containing aluminium or perfumes or other toxic ingredients should be avoided. Deodorants are available which are made with plant-based ingredients and essential oils, or salts. These are a good choice, but some experts recommend that, if possible, a person undergoing any type of detoxification program should avoid deodorant entirely.

Anything applied to the skin has to be processed by the liver, and so reducing the work the liver has to do just makes sense when you are trying to heal. It also makes sense not to stop sweating, as this is a way that the body can get toxins out of the body.

**Soap:** Avoid products containing sodium laureth sulphate (SLS), or sodium lauryl ether sulfate (SLES), perfumes or parabens and other nasties. Many different products are available which are made with plant-based ingredients and come with or without essential oils. These are a better choice, but the best choice is probably unscented liquid castile soap.

Antibacterial hand washes often contain toxic ingredients and should be avoided.

Remember that there is no need to soap up your whole body each day. This strips the skin of its natural oils and can lead to skin problems including acne and rashes. Most days, using a small amount of soap and water on your face, underarms and groin is enough.
**Shampoo:** As above. Many different products are available which are made with plant-based ingredients and come with or without essential oils. The products which are unscented are the best choice here.

**Toothpaste:** Avoid all toothpastes containing fluoride, this is very important. It is important to avoid fluoride in water as well, but a day’s worth of toothpaste contains far more of this ingredient than a day’s worth of fluoridated water.

**Moisturiser:** Many different products are available which are made with plant-based ingredients and come with or without essential oils. The products which are unscented are the better choice here. The best choices are pure organic coconut or olive oil, or shea butter or similar.

It is probably more important to ‘get it right’ with products such as moisturisers and deodorants that are applied to the skin and not washed off right away, than with cleansers and other products which only touch the skin for a short period of time.

Most if not all hair dyes should be avoided. Avoid chemical hair-removal products, fake-nails, nailpolish, fake-tan products and all make-up which contains synthetic fragrances and other harmful ingredients. Avoid all products made using petroleum by-products, such as Vaseline.

If you have a few essential oil-based products that you really love, perhaps you might consider only using them very occasionally, or applying them to your clothing away from your nose so that others can smell them, but you cannot.

**Women’s personal care products**
Standard tampons are bleached and are usually recommended to be strictly avoided by those with chemical sensitivities. Tampons often contain dioxins, phthalates and pesticides. Non-toxic tampons are essential as the membranes of your reproductive tract are highly absorbent, much more so than your skin.

Pads that are strongly scented should also be avoided where possible. Reusable washable pads are also available and may be suitable for some patients.

Chemical free pads and 100% organic cotton non-bleached cotton tampons are a much safer choice. If you can afford only chemical free pads or tampons, choose tampons.

A newish product called a ‘mooncup’ is also a less toxic alternative, although it does require a bit of extra work and effort to manage which may not be possible for all patients.

**Cleaning products**
The standard types of toxic cleaning products should be avoided by M.E. patients, and everyone else. Instead buy some of the safer, plant-based non-toxic alternatives which are now widely available, reasonably priced and just as effective as more traditional toxic products. They are often far better quality products, much nicer to use, and smell better too.

Avoid anything that makes you feel ill when you smell it and remember that you’ll be eating small amounts of whatever product you choose to clean your dishes with! You’ll also absorb the products used to clean your shower and bath, through your skin.

For this reason you may choose to make some of your own cleaning products using vinegar and bi-carb soda and so on. There are many books and webpages which will tell you how. Textured cleaning gloves designed to be used just with water may also be a good choice.

**Clothing**

Clothing made from natural fibres such as cotton or silk is recommended. New clothes should be washed in vinegar or bi-carb soda (or washed normally) before being worn for the first time.

**Art, craft and hobby supplies**

Oil paints are made by combining crushed rocks or bone etc. with pure seed oils, and so are not toxic to smell. The problem arises when traditional varnishes or turpentine is used. Use plain mediums such as linseed oil and use odourless turps as a solvent, making sure to only use it at the end of a painting session to briefly clean your brushes.

Acrylic paints can give off toxic fumes. If a safer type of paint can’t be found, a different medium may be a good idea.

Avoid toxic glues and paints involved with all hobbies. Wear gloves and a mask when handling mulches and manure while gardening, and try to find safer alternatives to some of the more toxic garden supplies such as pesticides.

**Pesticides and herbicides etc.**

Pesticides should never be used in the home. Do not use fly spray. If there are problems with ants or other insects outside of the home, various safer alternatives are available. This information is available online.

Do not wear insect repellents containing chemicals such as DEET, or similar. Avoid going outside when insects are rampant, or use alternatives made with various essential oils.
Always sit on a rug or towel on the grass, to avoid contact with pesticides used on the grass. If you regularly spend time on the grass somewhere you may want to enquire about when pesticides were used so that you can avoid being near the grass around those times.

Avoid carbamates, organophosphates, organochloride and dioxins. Pyrethroids are not a safe form of pesticide.

**EMF radiation**

Some patients with M.E. say they are very sensitive to EMF radiation, while others don’t seem to notice any problems.

There is some evidence (although it is not yet conclusive) that high levels of this type of radiation can contribute to neurodegeneration in diseases like M.E. and also potentially increase cancer risk. You can read more about EMF in this article on stopping neurodegeneration.

If you feel EMF radiation may be a significant problem for you, you might want to purchase a machine that measures EMF (or ELF) radiation, so that you can be aware of and limit your exposure. You may also want to do some reading about ‘earthing; or ‘grounding’ yourself as a way to minimise the harm of EMF radiation.

As a general rule; keep at least an arms length away from major electrical appliances such as ovens and televisions and half an arms length away from smaller appliances such as alarm clocks and lights – for as much of the day as is possible. The good news is that it is fairly easy to greatly reduce your exposure with just a few changes to how you arrange and interact with your appliances.

**Drugs and medications**

It is important to take only those drugs which are strictly necessary. As Dr Ray Strand explains,

> All medications cause increased oxidative stress. They are a foreign substance the body has to work harder to metabolise and eliminate. This puts increased demand on many of the metabolic pathways in the liver and the body as a whole.

It is very important to discuss all changes to medications with the doctor that prescribed them for you. Do NOT just sudden stop taking any medication, as this may be dangerous for you.

Many drugs can be replaced with herbs or nutrients which have a similar action, but which do not place as much stress on the body. The artificial colourings, fillers and tablet coatings used on many prescriptions drugs can also cause problems for M.E. patients and others with chemical sensitivities.
Vaccines may contain contaminants such as mercury. Bromide and fluoride are often used in many drugs.

**Food and drink**
- Many harmful chemicals used as colourings, preservatives and flavourings are included in processed food. Avoid processed food and focus on whole foods. Where budget allows, foods should be classified organic. Buying fresh produce from a local farmer’s market is a second best to buying organic.
- It is important to identify and avoid any food that you are allergic to or intolerant of.
- Avoid eating any green parts on carrots or potatoes, as these are toxic.
- Don’t store or heat food in aluminium, plastic or Styrofoam.

For more information see: Food as medicine and M.E.

**Miscellaneous**
- Buy used books where possible, to avoid the smell of new ink and paper.
- Avoid dryer sheets.
- Avoid chlorine swimming pools, or at the very least, make sure to wash off the chlorine and change into dry clothes afterward as soon as possible.
- Consider having mercury fillings removed by a qualified dentist, and never have new mercury fillings inserted.
- Avoid soft smelly plastics in shower curtains, fake flowers and plastic containers.
- Avoid natural gas heaters.
- Some cat litter products contain a form of silica which is an antigenic adjuvant which can trigger more allergies and immune system dysfunction. When inhaled by those who are immune compromised it can cause serious respiratory complications. Use other types of cat litter or wear a mask when changing cat litter if you aren’t sure if the type you have is safe or not.
- Having IVs means you are taking in a lot of chemicals from the PVC bags and tubes and so detoxification nutrients are a good idea in combination with any IV. IVs should be avoided unless necessary.

**Tips on finding the chemicals which cause symptoms**
The usual questions asked are:
- Do you feel better inside or outside the house?
- Do you feel better at home or on holiday?
Answering these questions may give some clues about which chemicals you need to avoid, or may be useless for M.E. patients that are made sicker by going outside or travelling whether chemical exposures occur or not. The picture is also complicated in M.E. as opposed to Multiple Chemical Sensitivity Disorder, as patients with M.E. are made ill by many other things than chemicals and the severity of the disease changes from one hour, day or week to the next.

If possible, you may benefit from having your house analysed by experts in this field. Doris Rapp recommends living on the outskirts of a city, in a house at least 15 – 20 years old.

You may also have to find out when and where chemical sprays are used in your workplace or at your school or university.

**How hardcore do I have to be in avoiding contaminants?**

Some patients choose to make only a minor effort to clean up their environment, some patients are extremely dedicated about toxin avoidance, and many sit somewhere between these two extremes.

Stopping making changes just at the point that you no longer experience symptoms on exposure to the products you use is the first step. But going beyond this level is recommended too, because doing so:

- May improve some symptoms that you did not know were linked to chemical exposures.
- Reduces the load on your liver, which gives your body more resources to use for long-term deep healing.
- May improve your condition in the short term, by reducing the load on the liver and freeing up some metabolic energy.
- Makes it less likely that your condition will deteriorate due to cumulative chemical exposures.

The liver is the second-largest organ in the body and one of the most important. It has been likened to the body’s equivalent of the engine in a car. The liver plays a vital role in regulating fat and balancing hormones, digestion and circulation. The main job of the liver is to get rid of foreign substances. Dr Sherry Rogers explains that when it comes to avoiding toxic chemicals in order to reduce the load on the liver and promote deep healing, every little bit helps. Chemicals act synergistically with each other. This means that 1 plus 1 doesn’t equal 2 but sometimes 10 or more.

Nutrients such as vitamin C can greatly reduce symptoms provoked by chemical exposures (at a dose of 20 grams daily or more), but avoidance of these toxic chemicals is of primary importance. Prevention is always better than cure.
Remember that not every toxic item is listed in this paper, and that if you can smell a noxious chemical then it is in your bloodstream.

Remember too that it takes time to work through all the items on this list. Research has to be done, products have to be found and tested and so on. Nobody is expected to read this paper and be doing everything perfectly within a few weeks or months. (Although I’ve made huge changes to many of the products I use over the last 15 years, I’d give myself a ‘could do better’ rating for many of the categories listed here. Just writing this paper has made me aware of several things I need to change that I was not aware of before. If you think the author of this paper eats nothing but 100% organic food, never kills the odd scarily enormous spider with fly-spray and then quickly leaves the room, or never uses essential oil products just because they smell nice, you’d be wrong!)

Having the information on this topic is empowering and helps you make the best choices you can, and do the best you can with toxin avoidance.

**How do I avoid products which have just been ‘greenwashed’?**

There are a lot of products out there that are the same old harmful chemical containing products but which have merely added ‘natural’ or ‘herbal’ or ‘nature’ or ‘pure’ to their names, or added a small amount of synthetic or natural essential oils to the original product.

You need to learn how to tell these types of fake products from the real thing. You might start by looking at quality brands such as Weleda, Aubrey Organics, Now Foods, Avalon Organics and others. In Australia brands such as Sukin, Natural Instinct, Tinderbox, Biologika, Miessence, A’kin and Alchemy are recommended. In the Netherlands you might look for brands such as Simple, No Perfume, Flussig, Mineral Deo from MM Cosmetic and others.

**How do I rid my body of the toxic load I already have?**

If all this is seeming depressing or overwhelming, the great news is that you can greatly reduce your toxic load at home through the use of an FIR sauna, and by taking supportive supplements such as vitamin C and liposomal glutathione.

For more information on detoxification, please see:

- Symptom-based management vs. deep healing in M.E.
- Recognising and managing healing reactions in M.E.
- FIR saunas and M.E.
- High-dose vitamin C and M.E.
- Magnesium and M.E.
- Unrefined sea salt and M.E.
- Iodine and M.E.
References

- Detoxify or Die by Sherry Rogers MD. (Click here to read a PDF extract from the book focusing on FIR saunas, in PDF format).
- Pain Free in Six Weeks by Dr Sherry Rogers
- Detoxification Through the Skin by Mark Sircus Ac., OMD
- Sauna Therapy for Detoxification and Healing by Dr Laurence Wilson (book)
- INFRARED SAUNA THERAPY, DETOXIFICATION PROTOCOLS and DEEP HEALING VERSUS SYMPTOM REMOVAL by Dr Laurence Wilson
- Whole Body Detoxification: Far-Infrared Sauna Use by Mary Laredo
- Deep Healing Versus Symptom Removal and The Emergency Health Paradigm Versus Nutritional Balancing by Dr Lawrence Wilson.
- Our Toxic World: A Wake Up Call by Doris J. Rapp
- Good Health in the 21st Century by Carole Hungerford
- Juicing, Fasting and Detoxing for Life by Cherie Calbom
- Dietary Healing & Detoxification: A simple reference guide for those with chronic degenerative disease or cancer choosing the Gerson Therapy by Kathryn Alexander.
- The Pollution Within from National Geographic
- Is Your Family Toxic? by James Ferguson (Extracted from The Vitamin Murders: Who Killed Healthy Eating in Britain)
- Everyday Exposures website
- Bringing Devon Back... A Family's Crusade
- Fluoridation / Fluoride Toxic Chemicals In Your Water
- The Fluoride Deception by Christopher Bryson, a review
- Fluoride: The Deadly Legacy by Gary Null

Relevant quotes

“People’s ability to detoxify certain substances is as unique as their fingerprints or their face. There is as much as a 500 fold different in people’s detoxification abilities with different chemicals.” Dr Sherry Rogers

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Saunas have long been considered an excellent way to remove toxins from the body and to treat and improve diseases where detoxification is severely compromised, such as in Multiple Chemical Sensitivity Syndrome.

Mild to severe symptoms of chemical sensitivity are very common in M.E., and many other features of M.E. also contribute to, or suggest, serious problems with detoxification in the disease. Using saunas to safely remove as much of the toxic load from the M.E. patient as possible, without causing systemic problems and relapse, could have many beneficial effects on symptoms of toxic overload and also the course of the disease generally.

There is also a significant amount of research supporting the use of FIR saunas in different types of cardiac diseases, which also has relevance to patients with M.E.

**What is the difference between traditional saunas and Far Infrared (FIR) Saunas?**

The therapeutic advantages of the infrared sauna as compared to a traditional sauna are considerable.

FIR saunas are far better tolerated by patients who are sensitive to high temperatures than traditional saunas because they do not raise the body’s core temperature. Many patients can tolerate an FIR sauna who can not tolerate traditional saunas, warm baths or even warm weather conditions.

Patient advocate Mary Laredo explains, in her ‘Natural News’ article ‘Whole Body Detoxification: Far-Infrared Sauna Use’ that,

Infrared saunas warm the body instead of heating the surrounding air. Traditional steam saunas heat the air and require temperatures ranging from 150 – 200 [approximately 66 – 93C] degrees Fahrenheit to promote perspiration, whereas a heat range of 110 – 140 [approximately 40 – 60 C] degrees in an infrared sauna produces the same results. The cooler air temperature is more tolerable to heat-sensitive individuals and allows for sessions of up to forty-five minutes, nearly twice as long as in a typical steam sauna session.

The softer heat of an infrared sauna also penetrates deeper into the skin - as much as 1 ½ inches - and draws out more toxins than a steam sauna, according to Dr. Aundrea Adams of the International Institute of Holistic Healing, who
compared the detoxification findings of the two sauna types.

Dr. Adams summarizes a report which concludes that sweat from a traditional sauna was up to 97% water, while the sweat released in an infrared sauna was only 80 – 85% water. The remaining 15 – 20% was comprised of heavy metals, sulfuric acid, sodium, ammonia, uric acid and fat-soluble toxins.

Sherry Rogers MD is an international specialist in Environmental Medicine. In her book ‘Detoxify or Die’ she extols the benefits of the Far Infrared sauna for patients with many different types of diseases and explains that FIR saunas allow toxins to be mobilized and excreted without causing systemic poisoning. Dr Rogers writes, in ‘Detoxify or Die,’

What is the best way to get rid of toxic chemicals including pesticides, heavy metals and hydrocarbon residues when you cannot tolerate a sauna? When a sauna makes you feel weak, sick, have a fast heart rate, faint, dizzy, panicky, headachy or just plain miserable, what is the solution? The far infrared sauna. Thanks to improved technology, the far infrared sauna is far safer and infinitely more tolerable, because it uses a heat energy that penetrates tissues, triggering mobilization of chemicals from subcutaneous fat storage, directly into the sweat. This activating penetration allows for a much lower overall temperature to be used (as I'll show you later), one that is enjoyable and not torture.

But more importantly, you haven't forced the body to bear very high temperatures (160 degrees and higher), pulling chemicals back into the bloodstream where they can duplicate original symptoms. Instead they slip out the back door, so to speak, from just under the skin storage directly into the sweat. Over weeks and months there is an equilibrium, or chemicals that are stored in other organs slowly and safely disseminate throughout the body and eventually empty into subcutaneous fat. It is the chemical load that is stored beneath the skin that is the main area activated by the far infrared sauna.

The far infrared sauna (FIRS) has been proven by specialists at the famed Mayo Clinic to improve heart failure, even when nothing more could be done by medicine. And in Japan, clinicians and researchers have confirmed its life-saving properties when nothing else could be done.

Preferably start with an oil change to get rid of trans fatty acids, and restore missing fatty acids while correcting mineral deficiencies, like selenium, manganese, zinc and magnesium, to facilitate safer detoxification. The formula is really quite simple. The problem is it doesn't make any money for the drug industry that owns medicine. In fact the Journal of American Medical Association (JAMA 287: 6 12- 6 17, 2002) documented how over 87% of physicians who make up the panels of "experts" who determine the practice guidelines for medicine receive compensation from the drug industry. These are the guidelines that your doctors and insurance companies follow.

The bottom line is that sweat is the only proven method for getting the most damaging toxins out of the body. There are no drugs, no surgery, no chelation, nor other detoxification methods with before and after measurements proving that unwanted chemicals like PCBs and pesticides were eliminated.
What other benefits can FIR saunas have?

Far Infrared therapy has been shown in several medical studies to have numerous health benefits. The heat from an FIR sauna can decrease joint and muscle stiffness and pain directly, relax the muscles, improve flexibility and relieve muscle spasms.

FIR saunas can also:

- Reduce pain and increase endorphin production
- Improve skin tone by unclogging pores and improving circulation
- Reduce cellulite and fat stores (where fat stores are higher than necessary in order to store a high level of toxins)
- Improve the immune system (increasing the number of leukocytes in the blood) and increase resistance to infections
- Help fight chronic infections
- Reduce the load on the liver and kidneys (by doing some of their detoxification work for them)
- Speed up metabolic processes of vital organs and glands, including endocrine glands.
- Inhibit the development of pleomorphic microforms (fungis, yeasts, bacteria and molds).
- Cause a ‘fever reaction’ of rising temperature than can neutralise viruses and other infections. (Heating tissues for 15 minutes can cause weak cells to die including cells infected with viruses, mutated cells or tumour cells)
- Inhibit the ‘fight or flight’ response (during the sauna)
- Allow many temperature dependent enzyme reactions to take place that otherwise would not in patients that have a low body temperature due to low thyroid hormone levels
- Dramatically improve circulation and relieve internal congestion

The importance of working with an experienced medical professional

Any serious detoxification regime should always be done under the supervision of an experienced medical professional and approached cautiously and very gradually in M.E. where there is such a huge potential for relapse. Detoxifying the body of toxins faster than the body can get rid of them can be very dangerous or even fatal. Saunas can also cause death, if the fluid and minerals lost during their use are not replaced.

A medical professional with experience in detoxification programs will ensure that FIR saunas are appropriate for the patient and direct them in their safe usage.

Before each FIR sauna
Some experts recommend dry-brushing the skin for 5-10 minutes with a natural bristle brush before a sauna to remove dead skin cells, allow free perspiration and to stimulate circulation and the lymphatic system. This should be followed by a quick warm shower.

For many M.E. patients, the sauna itself is probably enough to do at one time, and so instead, the patient might try and lightly exfoliate themselves all over in the bath the day before using a bath mitt or brush.

Patients should avoid using skin lotions as much as possible as this clogs the pores and inhibits respiration and the skin’s waste removal processes.

Some experts recommend taking vasodilators before a sauna – including niacin, bromelain or digestive enzymes – to make it easier for the chemicals to get out.

Because the FIR sauna is effective at removing toxic chemicals and heavy metals from the body there is a possibility of side effects. Dr Rogers recommends that patients take various nutrients before the sauna, in order to minimise any symptoms caused by a ‘healing reaction,’ ‘healing crisis’ or a ‘detox reaction.’ These include: magnesium chloride (magnesium oil), zinc, calcium and tri-salts. She also recommends correcting mineral deficiencies such as selenium, manganese, zinc and magnesium before having saunas to facilitate safer detoxification.

Detox symptoms can include: muscle cramps and spasms, rashes, strange odours and tastes, heart palpitations and high blood pressure, gastrointestinal changes, headache and nausea. These symptoms are normal but if they become severe, medical attention should be sought.

Patients should wait an hour after eating to have a sauna and always drink adequate water before, during and after the sauna. M.E. patients may also want to have an extra electrolyte drink before and/or after each sauna (containing salt and potassium). The best time for a sauna may be on waking, right before bed or at the time of day the M.E. patient is at their best physically.

Dr Rogers recommends that patients measure their blood pressure, pulse, respiration rate and weight before and after the first few saunas, and mid-sauna as well, if the patient is very fragile. If the BP or pulse go up by 10 points or more or temperature reaches 100 F/37.7 C, the patient should leave the sauna and make the next sauna of a shorter duration and/or at a lower temperature and perhaps also increase the amount of water and minerals taken during the sauna. If the patient weighs less than before the sauna this indicates that not enough water was taken during the sauna.

During an FIR sauna
Not pre-heating the sauna lets your body slowly adjust to the heat and so is recommended.
Once in the sauna, perspiration usually begins after 15 – 20 minutes. If sweating is difficult, this may be because the body has a significant heavy metal and toxic chemical burden. Regular sauna use may lead to increased perspiration over time as the patient’s detoxifying abilities improve.

Patients or carers should make sure that time spent in the sauna is carefully monitored. Most saunas feature a timer for this purpose. Staying in the sauna for too long can cause serious problems.

It is very important to regularly wash the sweat off the body with a towel during a sauna, otherwise many of the toxins expelled may be reabsorbed through the skin! It is also very important to always lie on a fresh towel in the sauna, to avoid contamination.

If the sauna becomes too hot or stifling, patients should open the door, window or zip for a while. Patients who begin to feel very unwell for any reason, must get out of the sauna straight away.

If the patient’s skin becomes clammy, or they feel weak or nauseous, they must GET OUT immediately as these could be signs of heat exhaustion. If the patient stops sweating, they must GET OUT immediately as this may be the initial stage of heat stroke. If these symptoms do not resolve, medical attention should be sought.

**Increase the time spent in an FIR sauna gradually**

Patients should not have saunas for longer than 10 - 20 minutes once a day for the first few weeks or months as this may cause massive healing reactions that could even be dangerous. Very ill patients should start with having a sauna for 10 – 20 minutes only, once a week, at only 100 F/40 C. Patients can then slowly increase the number of saunas they have each week, depending on their tolerance (and the recommendations of their doctor).

If patients experience significant negative detox symptoms, the frequency, duration or temperature of saunas should again be reduced.

Healthy people may work up to having once or twice daily 30-60 minute saunas at a temperature of up to 130 F or 55 C. For M.E. patients, it may be best to always stay on the lower temperature settings of 100 - 120 F or 40 - 48 C and to work up to a once or twice daily sauna lasting 30 minutes. Dr Sherry Rogers recommends working up slowly over weeks or months to an hour of sauna time daily, over one or two sessions, at a temperature of 120 – 130 F or 48 – 55 C.

Saunas over 1 hour long are never recommended and most experts recommend a maximum daily sauna time of 2 hours.
After a period of a year or two, depending on the severity of the illness, a once or twice a day sauna regime may be able to be cut back to twice weekly with no loss of benefits, according to Dr Rogers.

**After an FIR sauna**

It is often recommended that an FIR sauna be followed by a cold shower however this would make many patients ill. M.E. patients may do better following a sauna with a very quick warm shower, or warm bed bath. For some, there may be no need for bathing afterward as all the towelling off of sweat may leave the skin feeling nice and clean.

One way to work out how much water needs to be drunk after a sauna, is to weigh the towels used to mop up the sweat, before and after each sauna.

Dr Rogers recommends that patients consume a detox cocktail after each sauna (1-2 times daily) containing vitamin C (5g) and Alpha Lipoic Acid (300 – 600 mg) and glutathione. This cocktail revs up both stages of detox, according to Dr Rogers. She also recommends that patients take a multi-vitamin and mineral tablet 2 hours or more after the sauna.

**Additional notes on sauna use and detoxification by Dr Sherry Rogers**

- All disease is caused by free radicals or ROS. Toxic chemicals in the body increase ROS.

- The work of detoxifying uses up and depletes nutrients. For example, for every molecule of a chemical detoxified you lose one molecule of glutathione and one molecule of ATP.

- Never have a sauna if you don’t have on hand: tri-salts (salt, potassium and calcium), liquid magnesium and a cool floor or shower handy (in case of overheating). Make sure to clear up any mineral deficiencies before starting sauna therapy as this therapy will make such deficiencies worse. It is also important to take in significant amounts of each of the minerals throughout the therapy to replace what is lost through sweating.

- In case you feel terrible after a sauna, have on hand: extra water, potassium citrate, calcium citrate, zinc, sea salt and coral calcium. First, lie down and drink water with tri-salts and take some calcium or magnesium if you think a lack of these may be the problem. If you crave salt, take ½ - 1 tsp in water. Try different minerals if these don’t do the trick in a few hours or at most a day. For a fast fix take all the supplements a half hour apart so you can see which one worked.

- When having sauna therapy 2 x multimineral tablets should be taken daily along with extra magnesium, salt, calcium and potassium. The following should also be taken 1 – 4 times weekly: selenium (400 – 1000 mcg), chromium (400 – 1000 mcg), vanadium (400 mcg – 7 mg), iodine (400 mcg), lithium (400 mcg), **Biosil**
drops and boron (3 – 6 mg).

- Some patients have such damaged autonomic nervous systems that they cannot sweat or feel very ill if they try to sweat. These patients may benefit from having ‘Detoxification Profile’ testing before having saunas to make sure that their bodies can cope with the detoxification process.
- If 15 minutes is all that can be tolerated in a sauna, consider having more than one short sauna each day.
- Liver supporting nutrients include: ALA, selenium and Silymarin.
- Glycine can be added to each detox cocktail to make it more potent; 500 – 1000 mg with each cocktail is the appropriate dose.
- Dr Rogers recommends glutathione as Reconcostat.
- Over half of the body’s detoxification systems and immune system is in the gut, so you can’t heal from serious disease without first achieving good gut health.
- Kyolic aged garlic extract and probiotics are recommended for good gut health, Seavive is recommended to help heal a leaky gut.
- Other supplements recommended include Indolplex, Biosil, OPC, choline, carnitine and calcium D glucarate. A high-strength multi-mineral regime is essential during detoxing, as well as nutrients which support phase I and phase II detoxification.
- Don’t ever detox to the point you feel terrible. If you feel awful, cut right back with what you are doing. Slow and steady is the way to go.
- NEVER have another sauna if you haven’t completely recovered from the last one.

**Additional notes on sauna use and detoxification by Dr Lawrence Wilson**

- The amount of salt lost in a sauna through sweating gets lower over time. While 15 – 30 grams may be lost daily at first, over time this may drop to only 3 – 4 grams.
- Body temperature may rise 1 – 4 degrees in an infrared sauna.
- Sauna therapy programs are far safer than fasting programs. Sauna use is safe for most but very low or unbalanced salt, potassium, calcium and magnesium levels could make it dangerous for some and these levels must be assessed and addressed before sauna therapy begins.
- If possible, it is best to expose the head during sauna use, but only once you are 4 or 5 months into sauna therapy. It can also be helpful to expose the palms of the hands to the sauna heaters.
- Shower off immediately after a sauna but don’t use soap, plain water is enough.
- Healing reactions may occur throughout the day after a sauna, and may sometimes persist for days or even weeks. Healing reactions are the reason many people give up on sauna therapy, but these reactions are an essential sign that the sauna is
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doing what it is supposed to do and so they should be expected. If healing reactions are at all severe, slow down your sauna use until they are at a more manageable level.

- Make sure you give your body lots of extra rest when you’re having sauna therapy and going through detox. If possible, have a medical professional on hand to help you manage the symptoms from your healing reactions.
- Toxins are layered in the body at a cellular level. Some are more deeply buried than others. Rather than selecting one mineral to detox, saunas respect the body’s wisdom and natural order in removing toxins. This is a much safer, if slower approach.
- Toxins can cause defective gene expression, so even where genetic abnormalities can be shown the cause can still be toxins and poor detoxification.
- Sauna use can improve EMF sensitivity.
- Saunas improve circulation without a huge expenditure of energy (as in exercise).
- If you are very ill, have a friend or attendant on hand during your sauna.
- Clean your sauna once a month with Oxiclean (or similar).
- Sauna therapy is recommended for 2 years, in severe illness.

Additional FIR sauna cautions

Pregnant women and those with open cuts or burns or any type of implant or internal infection (i.e. dental, joints) should avoid sauna use. Patients should always remove contact lenses before entering the sauna. Saunas should be avoided 48 hours after an acute joint injury. Saunas may increase blood flow during menstruation.

Patients using any prescription drugs, should check with their physician or pharmacist for any possible change in the drug's effect due to any interaction with infrared energy.

Saunas may cause problems in those with Lupus, MS, hyperthyroidism and haemophilia or other bleeding disorders. They should not be used in children under the age of 5.

M.E. patients should never spend time in a sauna SITTING UP! This can cause severe relapse and possibly disease progression. Even where non-severely affected patients are able to sit up with little discomfort, sitting up while using a sauna is a complete waste of valuable cardiac output and places additional and unnecessary stress on the body, which may very easily make this treatment counter-productive.

The book Multiple Chemical Sensitivity: A Survival Guide by Pamela Reed Gibson warns that intensive 1 week or 6 week sauna programs (which may involve 6 or more hours of daily saunas as well as high dose detox supplements) can have a devastating effect on MCS patients, possibly even causing strokes and seizures, and so should be strictly avoided. A far safer and less risky approach is to have an FIR sauna at a
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moderate heat for 20 minutes every second day, she recommends. (Research compiled by the author of the book using a MCS patient group shows that FIR saunas were of great benefit for 40% of responders, a moderate benefit for 19%, no benefit for 10% and the remainder had an adverse effect from the treatment. The results were very similar in this patient group for coffee enemas with 40% of respondents rating them as being of ‘great benefit.’) Symptoms of chemical sensitivity are very often part of M.E., although M.E. and MCS are very different diseases.

Again, self-treating with an FIR sauna can be dangerous. A medical professional with experience in detoxification programs will ensure that FIR saunas are appropriate for you and direct you in their safe usage.

**Buying an FIR sauna**

FIR saunas can be bought for anywhere between $200 and $1500 or more. Portable models are available, some of which also fold up for easy storage, as well as the traditional ones made of wood.

Canadian Hemlock wood saunas: The benefit of this type of FIR sauna is that they are solidly constructed and come with a warranty that lasts 2 – 5 years or even a lifetime warranty, depending on price. This is the best type of sauna to buy, if budget allows. A one person model costs around $1,000 but unfortunately, these will be unsuitable for most M.E. patients as they must be used sitting up. So M.E. patients who need to have saunas while lying down may choose either a two person sauna with a 1.2 metre bench length, or a three person sauna with a bench length of 1.5 – 1.6 metres. Four person saunas will probably be the best option for those with a very large budget and lots of spare room in the house. Which sauna is best depends on the budget, the patient’s height and also, possibly, how willing and able they are to scrunch up their legs in the sauna a little bit to save some money.

Some saunas will be installed by the seller, while others are sent in pieces for two people to assemble (tool free and glue free) in half an hour or so. Optional extras include coloured lights, built-in CD players and external as well as internal controls. Some sauna sellers may be willing to negotiate on price a bit so it doesn’t hurt to ask about possible discounts.

Portable FIR saunas: The benefit of this type of FIR sauna is that it is relatively cheap, allows the head to remain heat-free and with a bit of modification and can possibly be used lying down. (The unit can be used on its side, or the patient can curl up in it lying down with their head sticking out of the opening at the bottom with a bit of adjustment to the zip. For shorter patients only!) Large sized models may also be available for those over 105 kg or those wanting more space to lie down in. Portable FIR saunas cost around $200.

Dome-design portable FIR saunas: This type of sauna is designed to be used lying down but is also almost as expensive as wood saunas and may not represent as good value. Dome-design portable FIR saunas cost around $1000 to $5000.
FIR sauna blankets: The benefit of this type of FIR sauna is that it is relatively cheap, allows the head to remain heat-free and can easily be used lying down. They may or not be as effective as enclosed saunas. Cocoon-type saunas are also available. FIR sauna blankets cost around $300 to $400.

Make sure the product states that it is FAR infrared. The quality between different products varies and some models may not be as good as others. Note that in her book ‘Detoxify or Die’ Dr Rogers ONLY recommends wood saunas. (The links given to products here may or may not be good choices for purchase and may or may not be available for purchase in your country. Patients must research buying a sauna carefully and/or ask their doctor for product recommendations. Patients must always take into account the product’s warranty and safety features, the company’s return policy and whether or not they sell replacements parts.)

**Other important notes on detoxification**
Avoiding chemicals in personal care products, in the home and in food is of the utmost importance on any detoxification program. Eating an alkaline diet containing lots of fresh and unprocessed fruits and vegetables is equally important. Patients must also take care to avoid any vitamin and mineral deficiencies.

Another well-established way of lowering the body’s toxic load is the coffee enema. A daily enema is highly recommended during sauna therapy by experts such Dr Lawrence Wilson and Dr Sherry Rogers, in order to minimise healing reaction symptoms. For more information on this treatment see the ‘Enemas for detoxification in M.E.’ paper.

At the very least it is **absolutely essential** to have at least one bowel movement daily while undertaking ANY detoxification regime, including an FIR sauna program. Two or three bowel movements daily is ideal. The shorter the ‘transit time’ of fecal material in the bowel, the less time there is for fermentation and for toxins to be reabsorbed into the body.

**References and additional recommended reading list:**
- Detoxify or Die by Sherry Rogers MD. (Click here to read a PDF extract from the book focusing on FIR saunas, in PDF format). *This book is essential reading for patients and for doctors interested in sauna therapy.*
- Pain Free in Six Weeks by Dr Sherry Rogers
- Detoxification Through the Skin by Mark Sircus Ac., OMD
- Sauna Therapy for Detoxification and Healing by Dr Laurence Wilson (book)
- **INFRARED SAUNA THERAPY, DETOXIFICATION PROTOCOLS and DEEP HEALING VERSUS SYMPTOM REMOVAL** by Dr Laurence Wilson
Whole Body Detoxification: Far-Infrared Sauna Use by Mary Laredo

Additional references:
- Is Your Family Toxic? by James Ferguson (Extracted from The Vitamin Murders: Who Killed Healthy Eating in Britain)
- Bringing Devon Back... A Family's Crusade
- Sauna Detoxification Therapy: A Guide for the Chemically Sensitive by Marilyn McVicker
- Detoxify or Die by Sherry Rogers, MD review by Irene Alleger
- Sauna Therapy for Detoxification and Healing reviewed in Townsend Letter for Doctors and Patients, Oct, 2006 by Beatrice Trum Hunter
- FIRS Therapy by Justin Tobias, M.D.
- MCS: A Survival Guide by Pamela Reed Gibson. This book warns that intensive 1 week or 6 week sauna programs can have a devastating effect on MCS patients, possibly even causing strokes and seizures, and so should be strictly avoided. A far safer and less risky approach is to have an FIR sauna at a moderate heat for 20 minutes, every second day. Research compiled by the author the book using a MCS patient group shows that FIR saunas had a great benefit for 40% of responders, a moderate benefit for 19%, no benefit for 10% and the remainder had an adverse effect from the treatment.
- Juicing, Fasting and Detoxing for Life by Cherie Calbom
- The Pollution Within from National Geographic
- Repeated Sauna Treatment Improves Vascular Endothelial and Cardiac Function in Patients With Chronic Heart Failure Journal of the American College of Cardiology March 6, 2002 (Volume 39, Number 5)
- Effects of Repeated Sauna Treatment on Ventricular Arrhythmias in Patients With Chronic Heart Failure (study)
- Saunas Improve Results for Heart Patients by author Patricia Palmer
- Repeated thermal therapy improves impaired vascular endothelial function in patients with coronary risk factors (study)
- Our Toxic World: A Wake Up Call by by Doris J. Rapp
- Detoxing - Far Infrared Sauna (FIRS) by Dr Sarah Myhill. This paper includes product links for UK patients. (Note that Dr Myhill uses the term ‘CFS’ to refer to a strange and unscientific mix of information on various patients who merely qualify for a ‘CFS’ misdiagnosis, and patients with M.E. Experienced and educated patients can easily tell which information actually relates to M.E. and which does not, but beginners must be cautioned about relying on any non-general information from Dr Myhill, unfortunately.) Dr Myhill writes:
Most chemicals come out in the first few minutes of saunaing; so you do not have to "boil" yourself for hours to get a result! The best results are achieved from many short sessions (e.g. one daily just to the point of sweating; but you may want to start with two sessions a week and build up). Once you have a covering of sweat, this means chemicals will have been mobilized from the subcutaneous tissues onto the skin. At this point shower off at once. If you do not wash off the released chemicals, they will simply be reabsorbed. After 24 hours, chemicals redistribute from deeper tissues into the superficial layers, and the process can be repeated. This way, after some weeks of saunaing, chemicals will gradually be drawn out from even deeper layers. It is very likely that massage will help by physically mobilising chemicals stuck in fat.

The key point to remember is that sweat does not contain just the bad things; it also contains the good minerals. This is because sweat is in fact blood without the protein and cellular content. So it is important to rehydrate with a physiological mix of minerals.

Far Infrared Saunaing does not damage the skin. I have now seen several patients who have had fat-biopsies done before and after sauna detox regimes. So far, everyone has been able to reduce their chemical load substantially. It is clear, then, that the sweating techniques are effective. As a compelling example: one patient saw his chemical load reduce to 25% after a daily sauna for 3 weeks.

**Additional notes:**

- Note that prices quoted are in US dollars or Australians dollars (which are almost the same as I write this) and can also be considered accurate to within 10 to 20% for the Canadian or New Zealand dollar.

- *Far infrared saunas vs Near infrared saunas:* While FIR saunas are by far the most commonly used and recommended saunas for medical use, a smaller group of medical experts consider NIR saunas the superior option. NIR advocate Lawrence Wilson MD explains that NIR saunas are lower EMF emitters and have several other advantages over FIR saunas. For more information, and to make up your own mind on this issue, see: Dr Laurence Wilson’s book *Sauna Therapy* (which includes instructions on how to make your own NIR sauna at home), and the articles: *Far Infrared Versus Near Infrared Saunas*, *Infrared Sauna Therapy* and *What is A Near Infrared Sauna?* *(Please note that the HFME does not support the political views expressed on Dr Wilson’s website. Only the medical information portion of the site is recommended by HFME.)*

- For patients living in Western Australia I can personally recommend ‘Triple Health Saunas’

**Relevant quotes**
“As a holistic physician, I am ever searching for better ways to heal the body that are safe, inexpensive, and powerful enough to handle today’s health disasters. Over the past four years, I have incorporated infrared lamp saunas as a healing and detoxification modality. Rarely have I seen such an impressive aid for healing many diverse conditions.” Dr. Larry Wilson

“The sweating process gently and safely helps eliminate all heavy metals and toxic chemicals. Medical studies demonstrate that most toxins can be eliminated through the skin, relieving the burden on the kidneys and liver. Sweating increases dramatically in most people after several months of daily sauna use. Sweating during exercise is not nearly as effective for detoxification because exercise activates the sympathetic nervous system. Sympathetic nervous activity inhibits toxin elimination.” Lawrence Wilson MD

“Begin with only 20 minutes in the sauna. After a few weeks, only if you feel well enough to do so, you may increase to 30 or even 40 minutes. Never begin with sessions longer than 20-minutes once a day because this can cause massive healing reactions that are unpleasant and even dangerous. If debilitated or very heat sensitive, begin with 15 minutes or less in the sauna. Always leave a sauna at once if you feel very faint, if you stop sweating, or if your heart starts to race”. Lawrence Wilson MD

“By far the most important health benefit of an effective far infra red sauna is it's efficiency in removing toxins from the body. This is achieved by a process called "resonate absorption" whereby the frequency of the far infra red waves matches the frequency of the water in the cell, causing toxins to be released into the blood stream and excreted through sweat. Increased blood circulation caused by sweating stimulates the sweat glands, releasing built up toxins and waste”. Sue Pollock, ND. Ballina Naturopathics.

“Always rest for 15 minutes after a sauna session. Shower off and then relax after a sauna session to allow the body to readjust. Do not go right back to daily activities. It is best to use a sauna first thing in the morning or the last thing at night. These are the times one is most relaxed and it will be most effective. The more one relaxes, the more one will sweat. Use a sauna twice a week to twice a day. However, always begin with a maximum of one session daily for no more than one-half hour. If one is very debilitated, begin with once a week. Work up to daily use as you are able to do so.” Lawrence Wilson MD

“I do a sauna every day and have for a number of years. Usually I go to the YMCA and they have a regular dry sauna. Recently I got an infrared and I was intrigued that the sweat felt different, less watery, and slimier. It made me think there was some truth to the assertions being made about far infrared and its ability to draw more toxins then the standard regular sauna”. Dr. David Minkoff

“Healing reactions are temporary symptoms that occur as toxic substances are eliminated and chronic infections heal. Symptoms vary from mild odors, tastes or rashes are very common and usually pass quickly. Some people feel great fatigue
after sessions and this is normal. Some people have bowel changes, aches, pains or headaches. Old infections may flare up as they are healed due to repeated sauna use”. Lawrence Wilson MD

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Saunas have long been considered an excellent way to remove toxins from the body and to treat and improve diseases where detoxification is severely compromised, such as in MCS.

Mild to severe symptoms of chemical sensitivity are very common in M.E., and many other features of M.E. also contribute to, or suggest, serious problems with detoxification in the disease. Using saunas to safely remove as much of the toxic load from the M.E. patient as possible, could have many beneficial effects on symptoms of toxic overload and also the course of the disease generally.

FIR saunas are far better tolerated by patients that are sensitive to high temperatures than traditional saunas because they do not raise the body’s core temperature. Many patients can tolerate a FIRS sauna that cannot tolerate traditional saunas or warm baths/weather.

Far Infrared therapy has been shown in several medical studies to have numerous health benefits in addition to detoxification. It can decrease joint and muscle stiffness and pain directly, relax the muscles, improve flexibility and relieve muscle spasms. FIR saunas can also increase blood flow, reduce pain and increase endorphin production, improve skin tone by unclogging pores and improve the immune system.

FIR saunas can be bought for anywhere between $200 and $5000 or more. Portable models are available, some of which also fold up for easy storage, as are saunas made of wood. M.E. patients should never spend time in a sauna SITTING UP!

Any serious detoxification regime should always be done under the supervision of an experienced medical professional, and approached cautiously and very gradually in M.E. Detoxifying the body of toxins faster than the body can get rid of them can be very dangerous or even fatal. Saunas can also cause death, if the fluid and minerals lost during their use are not replaced.

Before the sauna: Exfoliating before the sauna can be helpful. It is essential to drink extra water before, during and after the sauna and also to replace lost minerals such as magnesium, calcium, salt and potassium. Because the FIR Sauna is effective at removing toxic chemicals and heavy metals from the body, there is a possibility of side effects. Dr Rogers recommends that patients take various nutrients before the sauna, in order to minimise any symptoms caused by a ‘detox reaction.’ These
include: magnesium chloride (magnesium oil), zinc, calcium and tri-salts. She also recommends correcting mineral deficiencies such as selenium, manganese, zinc and magnesium before starting a sauna regime, to facilitate safer detoxification.

**During the sauna:** The sauna can cause detox symptoms which can include: muscle cramps and spasms, rashes, strange odours and tastes, heart palpitations and high blood pressure, gastrointestinal changes, headache and nausea. These symptoms are normal but if they become severe, medical attention should be sought. Patients that begin to feel very unwell must get out of the sauna right away. It is very important to wash the sweat off the body with a towel during a sauna, otherwise many of the toxins expelled may be reabsorbed through the skin!

**After the sauna:** Dr Rogers recommends that patients consume a detox cocktail after each sauna containing vitamin C and Alpha Lipoic Acid, plus a multi-vitamin later in the day.

Saunas should last no longer than 10 minutes to begin with. Patients must begin with short saunas at the lowest temperature setting (or 100F/40 C) perhaps once a week, or once a fortnight or less, depending on tolerance. After a year or so, a once a day sauna regime may be able to be cut back to a once a week maintenance program.

Avoiding chemicals in personal care products, in the home and in food is of the utmost importance on any detoxification program. Eating an alkaline diet containing lots of fresh and unprocessed fruits and vegetables is equally important. Patients must also take care to avoid any vitamin and mineral deficiencies.

For more information on this topic including a full list of cautions on FIR sauna use, links to FIR sauna products and a reference list, please see the full-length version of this paper.
Nobody likes the idea of enemas on first hearing about them. Enema advocate Dr Sherry Rogers explains that even she found the idea of enemas quite repellent at first, and was initially determined never to try them herself nor recommend or talk about them to patients or anyone else.

But she was won over by their unique benefits over time and now says that if one is just too squeamish to be interested in learning more about them and trying them (if health allows), then one must not be in very much pain or very ill!

*(A personal note from the author: After reading a lot of very impressive information about the health benefits and safety of enemas, I think she has a point, and I must admit that it was this tough attitude of hers that made me bite the bullet and seriously consider this therapy, finally. With M.E. being the devastating disease it is, surely quickly reducing pain levels and some of the symptoms of M.E., improving overall health and long-term outcomes is worth a little bit of mere squeamishness, awkwardness and discomfort. Each day of M.E. is many, many, many times worse than an enema experience could ever be after all!)*

Dr Sherry Rogers writes that enemas are one of the best, safest, easiest, quickest and safest techniques to reduce pain, improve liver health and to reduce ‘healing reactions’ and symptoms from detoxification programs. She adds that to pass them up not because one is too ill to do them but because they are unconventional or slightly unpleasant is to put up with needless pain and suffering.

Benefits of enemas include the following: reduced pain levels (in 90% of patients no matter what the cause of the pain), improved circulation and detoxification, removal of parasites, weight loss (due to old waste matter being removed), reduced load on the liver, reduced allergies and a stronger immune system, improved skin, improved bowel movements and a reduction of many other symptoms of various conditions; especially if the condition is caused or exacerbated by an over-acidic or toxic condition in the body.

The coffee enema improves the detoxification capacities of the liver by increasing the activity of a family of enzymes called glutathione S-transferase by as much as 700% above normal, and also improves the detoxification abilities of the gallbladder and the kidneys.
The most common enema: The coffee enema

The most commonly recommended enema is the coffee enema. This has nothing to do with the caffeine content of the coffee making a person feel ‘wired’ and in fact it is important that the coffee in the enema is not absorbed systemically and that the patient remain relaxed.

Patient advocate Mary Laredo explains, in ‘Whole Body Detoxification: The Coffee Enema’ that,

*The Gerson Therapy* explains that caffeine and palmitates (chemicals in coffee) work synergistically to stimulate and cleanse the liver and blood. Without entering the digestive tract the caffeine is absorbed through the bowel wall, via blood vessels, and makes its way directly to the liver.

The caffeine exposure causes the liver's portal veins and the bile ducts to expand which increases the release of diluted toxic bile. The enema fluid triggers peristalsis (intestinal muscle contractions) and the efficient removal of wastes from the body. As a result of the enema the liver becomes less congested with debris, which makes room for the filtering process of yet more bodily toxins.

For nearly nine decades the coffee enema has proven itself to be effective at cleansing and restoring the liver, reducing and eliminating cancerous debris, and relieving severe pain from countless origins. It is yet another tool in the detoxification arsenal that should not be dismissed by anyone determined to prevent disease, reclaim their health or otherwise impede the ill effects of living in a toxic world.

Are enemas appropriate for M.E. patients?

This treatment is recommended by Dr Sherry Rogers and is also part of the Gerson cancer therapy. However, this treatment may not be appropriate for those with M.E. which is a disease involving tachycardia, cardiac insufficiency and often, diarrhoea. Contraindications for enema therapy include:

- Patients with renal, cardiac or respiratory failure (must get medical advice beforehand)
- Hypertension, tachycardia
- Patients with renal, cardiac or respiratory insufficiency
- Diarrhoea

For these reasons M.E. patients should always discuss enema therapy with their doctors beforehand. It is also important to start with only very small amounts of water and very small amounts of coffee, until one is sure that this treatment can be safely tolerated. Medical supervision is also essential if more than one enema is taken daily.

An enema program can have significant benefits, particularly if a person is on an FIR sauna or other detoxification program and so should be considered cautiously but also not dismissed out of hand for the reasons stated above.
M.E. patients (and other fragile patients) may become significantly more ill after coffee enemas as they significantly boost liver function. Patients doing daily enemas are advised to increase the amount of coffee in them very slowly in order to avoid a relapse of symptoms. Some patients may wish to focus on other types of enemas and only have coffee enemas once or twice a week.

Enemas can also cause relapse in M.E. purely because of the physical exertion and orthostatic stress involved in setting them up, having them and tidying up afterwards. Patients need to:

1. Hang the enema kit set up, warm up the water, assemble the necessary accessories (lubricant and a clock) and set up towels and cushions on the bathroom floor. This may take 2 – 4 minutes.
2. Expel the enema, while sitting upright on the toilet. This may take 2 – 5 minutes.
3. Clean and tidy away all the items. This may take 1 – 5 minutes.

Thus patients with no assistance need to be well enough to be upright for 5 – 10 minutes, to be able to have an enema without overexerting themselves. Patients who can have a carer do steps 1 and 3 will still need to be well enough to be upright for 2 – 5 minutes. The most overexertion avoiding option is to have a carer do steps 1 and 3, and to modify step 2 so that a bedpan is used instead of a standard toilet. If this still causes overexertion, then enemas are probably best avoided until some improvement in the condition has taken place.

Another problem for M.E. patients wanting to try enemas is the muscle weakness which affects all muscles including those involved in bowel control. Patients with very poor muscle control may not be able to hold in the enemas or able to tell in time when they can no longer hold them in, making enemas inadvisable.

**Coffee enema recommendations by experts**

- Dr Sherry Rogers recommends that a 1 litre coffee enema be prepared daily, and taken in two sessions about 10 minutes apart. She recommends that each enema be held for 10 minutes and contain 2 tablespoons of coffee (giving a total of 4 tablespoons of coffee daily).

- Lawrence Wilson recommends a 500 – 750 ml coffee enema once daily, and two or even three times daily when one is going through a healing reaction (to help reduce the symptoms). He recommends that each enema be held for 15 minutes and contain ½ to 4 tablespoons of coffee. Dr Wilson writes that more than 500 – 750 ml is not really necessary, although he does also comment that for very severe illness he recommends patients at least start with a 1 litre enema, if possible.

- Kathryn Alexander, Gerson therapy expert, recommends a 1 litre coffee enema taken up to 4 times daily, each containing 4 tablespoons of coffee and held for 15 minutes.
For best results, Dr Wilson recommends that an enema program be continued for at least a month, and ideally, for a year where illness is severe. He also comments that they should not be necessary for longer than 2 – 5 years.

**Types of enema kits**

Enema kits consist of a bag or can and silicone or PVC tubing. Clear bags or cans are often recommended as these allow you to see clearly how much water is left in them. Where chemical sensitivities are present a stainless steel can or silicone bag with silicone tubing is the best choice and latex should be avoided. Closed bags are said to be easier to use, while open bags or cans are much easier to clean. Silicon tubing is a better option than PVC, if possible.

The enema kit should hold at least 1 litre of water and one that holds 2 or more litres may be ideal. Enema kits are relatively inexpensive and usually cost between $30 and $70 (AUD / USD / CAD / NZD).

**How to prepare and take a coffee enema**

These instructions are for a 500 ml coffee enema but may be modified to suit a larger volume or different type of enema.

Note that the first few coffee enemas should contain only 1 teaspoon of coffee. This prevents jitters from poor caffeine tolerance and allows one to determine how much coffee can be comfortably tolerated. Some patients may be fine with 2- 4 tablespoons eventually, while others may only be able to tolerate ½ a tablespoon or less. For the very first enema, keep it really simple and just use pure warm water or pure warm water and a small amount of unrefined sea salt.

1. Buy an enema bag or can with silicon tubing and a can of organic ground coffee (not instant or decaffeinated)
2. Boil 500ml of water and ½ - 2 tablespoons of coffee for 2 minutes OR heat the water and coffee using a coffeemaker OR place the water and ground coffee in a container, stir thoroughly and soak overnight.
3. Cool the liquid until gently warm, or if the liquid is cool, heat it until it is gently warm.
4. Filter the liquid through a fine strainer.
5. Pour the liquid into the clean enema bag and hang it at about waist height.
6. Lie on the floor and insert the lubricated tube into your rectum.
7. Unclamp the hose and let the entire amount flow in (or half the liquid, if you’re doing a 1 litre enema in two sessions) then remove the tube.
8. Rest lying down for 10 – 15 minutes.
9. Expel the water and faeces into the toilet.
10. Repeat, if desired.

11. Wash the enema bag and tube thoroughly with soap and water, towel dry and then hang to dry fully.

**Additional enema notes**

- Set the enema kit up anywhere one can lie down comfortably and be very near to the toilet. This may be in a bedroom, in the bathtub, or on the bathroom floor on some towels. While one should not walk around while holding the enema, it may be possible to walk to a bed to lie down more comfortably after taking the enema lying on the bathroom floor.

- The enema bag can be hung on a door handle using a coathanger. Hanging it from somewhere quite high like the shower head may cause the water to be released too fast.

- Always have a bowel movement before having an enema so there is room for the water to be held. If necessary drink lots of water and consume some prunes or other natural laxative.

- Use filtered water for enemas. Make sure to boil chlorinated water for 10 minutes before use in an enema if it has not been removed by a filter.

- The enema tip can be lightly lubricated using saliva, soap or a small amount of oil such as olive oil. Avoid petroleum based lubricants.

- Before inserting the enema tip, make sure to clear any air in the tube by running water through it. Insert the enema tip gently and slowly. It may help to bend forward slightly. Some patients prefer to lie on their backs, with knees drawn towards the chest.

- Add the water slowly, and at no more than 250 mls of water every 90 seconds. Turn the water flow off if cramping occurs, and wait until cramping stops before resuming.

- Clamp the tubing of, and stop the flow of water into the bowel if there is any sensation of discomfort or fullness. You may need to do this several times. Massaging your lower abdomen during the enema may be helpful.

- Longer tubing in the enema kit may allow more room to move and so find a more comfortable resting position.

- It may help the water to move around the colon by lying on the right side, left side and back for 5 minutes each while holding the enema water.

- If you have trouble holding the enema you may need more practice, also make sure the water is not too hot or cold, or add less coffee to the enema. Never force yourself to retain the enema when you feel you can’t. If the enema can’t be held for long it may be an option to have 2 or 3 short enemas.

- It is okay if some water remains inside after going to the toilet after an enema. This may mean you are dehydrated.
• Periodically run boiling water, peroxide, or other comparable antimicrobial agent (eg. grape seed extract) through the empty bag to discourage mould growth when not in use. If you use a toxic chemical cleaner to clean the bag, your enema could make you very ill! Using a mouldy or infected bag could also leave you very ill.

• Coffee enemas taken at night may interfere with sleep, although some patients take an extra enema in the night to help get back to sleep when woken by a headache etc.

• Enema equipment should be used by only one person and not shared.

Other types of enemas
Enemas can be done using just warm water. Adding 1 – 3 drops of essential oils such as peppermint or lavender to the warm water can stimulate peristalsis and immune function. 1 teaspoon of unrefined sea salt can be added to each litre of enema solution to make an electrolyte enema. The Gerson protocol also recommends chamomile tea enemas and castor oil enemas, in addition to coffee enemas.

Side effects from enemas
Hypoglycaemia can occur after enemas so medical advice and supervision is essential in diabetic patients. For most, a small meal after an enema may solve this problem.

It is very important to make sure that mineral intake is adequate before starting an enema program. Replacing lost fluids and electrolytes is also critically important. M.E. patients must be sure to avoid ever becoming dehydrated or low in electrolytes.

Rashes, pimples, boils, acne and abscesses may be a sign that the other detoxification organs such as the liver are really struggling and unable to keep up, therefore shifting some of the burden to the skin. Improving detoxification through daily enemas or FIR sauna use may cause these skin problems to become worse before they get better.

Dr Lawrence Wilson writes,

When done properly, coffee enemas do not cause habituation, constipation or any rectal problems. They will cause some constipation in a few cases, but often this is because the fecal matter is removed daily, so there is less to remove. In 30 years of clinical nutrition practice, I have not seen any significant negative effects of coffee enemas at all. However, observe the following cautions.

Hemorrhoids, anal or rectal fissures and rectal prolapsed: These conditions, if severe, can make doing coffee enemas a little painful or even impossible. In my experience, mild cases of hemorrhoids are not a problem.

Ralph Moss reports that the US Office of Technology Assessment "cites the case of the two Seattle women who died following excessive enema use. Their deaths were attributed to fluid and electrolyte abnormalities. One took 10 to 12 coffee enemas in a single night and then continued at a rate of one per hour. The other
took four daily. As OTA points out, 'in both cases, the enemas were taken much more frequently than is recommended in the Gerson treatment.'"

As Moss says: "In general, coffee enemas are an important tool for physicians who try to detoxify the body. This is not to say they are a panacea. They certainly require much more research. But coffee enemas are serious business: their potential should be explored by good research - not mined for cheap shots at alternative medicine or derisively dismissed as yet another crackpot fad."

References and recommended sources of further information:

- Detoxification Protocols and Coffee Enemas by Lawrence Wilson MD
- Detoxify or Die by Dr Sherry Rogers
- Pain Free in Six Weeks by Dr Sherry Rogers
- Dietary Healing & Detoxification: A simple reference guide for those with chronic degenerative disease or cancer choosing the Gerson Therapy by Kathryn Alexander.
- Whole Body Detoxification: The Coffee Enema by Mary Laredo
- Healing the Gerson Way: Defeating Cancer and Other Chronic Diseases by C. Gerson and B. Bishop.
- The Gerson Therapy: The Amazing Juicing Programme for Cancer and Other Illnesses by Charlotte Gerson and Morton Walker
- Coffee Enemas and Liver Detoxification (radio interview) and Using Enemas Safely by Kristina Amelang.
- Juicing, Fasting and Detoxing for Life by Cherie Calbom

Relevant quotes

“Less than 10% of all the chemicals in our environment have even been partially tested for safety.” Juicing, Fasting and Detoxing for Life by Cherie Calbom

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Managing colds and flu and M.E.
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Treating M.E.: The basics

Preventing and managing colds and flu effectively is a very important part of managing M.E. well generally.

**Is there a changed immunity to colds and flu (and other infections) in M.E. over time?**

Yes. Right after the onset of M.E. the patient seems to get every single bug going around. A little bit later on, in the acute/severest stages of M.E. (which often persists for a number of years or perhaps decades) patients often find that their immune system is so hyper-responsive that they get no colds or flu’s at all during this time.

Finally starting to get these infections again in M.E. is acknowledged to be a sign that the immune system is not so overactive and that the illness is improving overall. It’s a very positive sign that shows that your condition IS improving overall.

However, the experience and effect of colds and flu themselves may quickly become anything but positive. Having one infection after another can make life miserable and can cause the symptoms of M.E.to worsen to the point of a serious relapse. The patient can become very weak and disabled. So whilst being able to catch colds and flu again is overall a good sign, it is also very important to do everything possible to prevent these annoying secondary infections and to minimise them as much as possible when they do occur.

**Preventing and treating colds and flu**

Starting to get colds and flu again is a very positive sign. However, if you are getting a lot of different viruses and they are lasting for a longer than usual time, you may wish to reduce your risk of getting viral infections by taking extra vitamin C, vitamin A, D and zinc with your usual multi, if you aren’t already. A whole-foods based diet and appropriate rest are also important parts of boosting your immunity.

You can reduce your risk of getting viral infections by taking extra vitamin C, vitamin A and D and zinc with your usual multi, if you aren’t already. A whole-foods based diet (with minimal sugar and also possibly, grains) and appropriate rest are also important parts of boosting your immunity. Also helpful is eating garlic regularly and washing your hands regularly. (Antibacterial soaps are very much not recommended.)

Low body temperature caused by low thyroid function is one cause of recurrent infections.
Resistance to infections is greatly reduced following the completion of an FIR sauna program, and by the regular use of colonic or enemas. Resistance to infection is very much lowered during any type of detoxification regime, however.

**Treating colds and flu with high-dose vitamin C**
Linus Pauling recommends that at the very first sign of a cold or flu etc., 1 to 2 g of vitamin C (or more) is taken and that this dose be repeated hourly. Enough vitamin C should be taken to suppress symptoms or until bowel tolerance is reached. (However, even if you can only take 6 – 10 g this will still minimise the symptoms to a more limited extent and is still worthwhile.)

It is very important to take the vitamin C as soon as possible after noticing symptoms as the more this is delayed, the less chance there is that you can fully suppress the infection. Linus Pauling recommends always carrying some vitamin C tablets with you when you go out for this reason. Because the vitamin C is suppressing the infection rather than eradicating it, it is important to keep taking the high dose of vitamin C for at least a week afterwards, or else the symptoms may come back. High dose vitamin C is very important as not only does it suppress the symptoms of colds and flu and reduce their severity and duration, but it also greatly reduces your risk of serious secondary infections that may follow these initial infections such as pneumonia and so on.

To make vitamin C nasal drops, mix 100 ml of water with 3 g of sodium ascorbate. 20 drops should be dropped into each nostril with an eye dropper. This raises the concentration of vitamin C in the nasal passages a thousand times higher than oral doses can reach, and may be a useful way to help more quickly improve your cold or flu.

**The importance of rest in treating colds and flu**
Linus Pauling explains that it is especially important with the flu that you put yourself on bedrest/near total rest for at least 24-48 hours after your temperature has gone back to normal, as well as when you are at the most severe stage. Giving your body the best chance to fully recover from any infection can only benefit you in the long term. It is also important to begin resting as much as possible at the first signs of the flu, as well as making sure to drink 2.5 – 3 litres of water daily at this time, as this can also help to prevent the flu becoming severe.

Continually catching colds and flu may be a sign that you are overexerting and/or that you need more assistance in tasks of daily living than you are currently receiving.

**Additional ways to fight colds and flu**
When the nose is so blocked that breathing or sleeping become difficult, using a netti pot can be helpful. Saline nasal sprays can also make you more comfortable, help you breathe easier and deter secondary bacterial infections in the sinuses. Some doctors
recommend that they be used at the first sign of a cold or flu and the advantage of sprays as opposed to a netti pots, is that the spray is easier to use many times daily and outside of the house.

Maintaining good bowel health and utilising treatments such as colonics and enemas helps the body deal better with infections (by reducing the body’s overall toxic burden) and recover from the symptoms of them much quicker.

It is also very important to avoid sugar when you have an infection as sugar suppresses the immune system and can interfere with vitamin C utilisation. This includes grains and fruit juices.

Dr Joseph Mercola explains that as long as your temperature remains below 102 degrees Fahrenheit (38.9 degrees Celsius) there is no need to lower it. Drugs such as aspirin and paracetamol should only be taken when absolutely necessary, such as if you have a temperature greater than 105 degrees F (40.5 degrees C), severe muscle aches or weakness. Dr Lawrence Wilson recommends lowering a fever gently with a sponge bath before resorting to drugs, where the fever is up to 103 degrees F. The body uses fever to fight infection and so allowing the body to maintain the fever helps you to feel better sooner. Make sure to check your temperature regularly during a fever.

Dr Mercola also writes,

I don’t advise over-the-counter medications, but one simple treatment you can try that is surprisingly effective against upper respiratory infections is hydrogen peroxide. Many patients have had remarkable results in curing colds and flu within 12 to 14 hours when administering a few drops of 3 percent hydrogen peroxide (H2O2) into each ear. You will hear some bubbling, which is completely normal, and possibly feel a slight stinging sensation. Wait until the bubbling and stinging subside (usually 5 to 10 minutes), then drain onto a tissue and repeat with the other ear. A bottle of hydrogen peroxide in 3 percent solution is available at any drug store for a couple of dollars or less. It is simply amazing how many people respond to this simple, inexpensive treatment.

Gargling with warm water and a tablespoon of apple cider vinegar at the first sign of symptoms may be helpful as can eating extra ginger. A few drops of oregano oil or olive leaf extract in water or extra fresh or capsulated garlic may also be helpful. It should be noted however, that some M.E. patients react badly to these immune-boosting substances so they are probably best avoided unless you already know that you can tolerate them well or have previously built up a tolerance to them.

Should you take cold and flu drugs which help you keep going through the illness? 
No, and especially not if you have M.E. Rest is very important during viral illnesses, and people have died from being very active while suffering with such viruses as
these viruses can affect the heart. Not resting at the first sign of illness will only make the symptoms last much longer and will increase the risk of complications.

**Should you get a flu vaccine?**

This is a personal choice, but in a word – no. It is one thing to possibly undertake some risk for one-off vaccines for serious diseases but to have a vaccine *annually* that is very likely to leave you feeling quite ill after it as your body works to develop immunity to the strain of the flu covered by the vaccine, contains toxic ingredients such as mercury and which is very far from being completely effective and may even make you more susceptible to the flu the next year, makes little sense.

As Dr Sherry Rogers explains, the flu vaccine is different every year and so each year’s flu vaccine is the most untested drug on the market – do you really want to make yourself the guinea pig for an untested product?

Is it really worth risking an M.E. relapse or serious side-effects and issues that may last a lifetime for just one year of a limited amount of protection from some strains of the flu? It is hard to see how the answer could be yes. Remember that HUGE sums of money are at stake with the promotion of the flu vaccine and it is not all that it seems or all that the media presents it as, just like with M.E. itself.

It is far better to boost immunity to ALL viruses by having a whole food based diet, having adequate vitamin D and C and A and zinc and so on. These therapies also have the ‘side effect’ of also being good treatments for M.E. generally.

Also remember to practice good hygiene when someone in the house has a flu you don’t want to catch. Have them cover their mouths when they cough, stay at least a few metres away from you and wash their hands before handling anything that you will touch, and so on.

If you do choose to have a flu shot or any other vaccine, it is also very important to make sure you are as healthy as possible before being injected with it, in order to reduce the likelihood of problems. This includes making sure you aren’t deficient in any of the major vitamins and minerals. It is also important to never have more than one vaccine at a time.

For more information see the book ‘Saying No to Vaccines.’

**What about other vaccines?**

Please read the links and websites listed below before having any of the other non-flu vaccines. Make sure you are fully aware of all the risks and dangers before making your choices.

**More information and references:**
• How to live longer and feel better by Linus Pauling.
• Dr Atkins Vita-Nutrient Solution: Nature's Answer to Drugs by Dr Atkins
• Orthomolecular Medicine For Everyone: Megavitamin Therapeutics for Families and Physicians by Abram Hoffer.
• The NEW optimum nutrition bible by Patrick Holford
• Fire your doctor! : how to be independently healthy by Andrew W. Saul.
• Optimal Nutrition for Optimal Health by Thomas E. Levy.
• Intravenous Vitamin C Saves NZ Man with Flu Damaged Lung
• Dr Levy’s presentation to the 35th Annual Cancer Convention pt3-4 (a video which talks about liposomal vitamin C)
• Clinical Guide to the Use of Vitamin C The Clinical Experiences of Frederick R. Klenner, M.D. and Observations On the Dose and Administration of Ascorbic Acid When Employed Beyond the Range Of A Vitamin In Human Pathology By Fred Klenner, MD.
• Swine flu pandemic outbreak sweeping through Britain even though 70 percent were vaccinated last year, Twenty reasons why vitamin D is better than a swine flu vaccine and Flu vaccines judged ineffective and Vitamin D proven far better than vaccines at preventing influenza infections from Natural News.
• Plus Flu Vaccines, pharma fraud, quack science, the CDC and WHO -- all exposed by Richard Gale and Gary Null, Flu shots are virtually worthless, says new British Medical Journal analysis, Flu vaccines revealed as the greatest quackery ever pushed in the history of medicine, Ten questions about flu vaccines that doctors and health authorities refuse to answer, Seasonal flu vaccines increase risk of pandemic H1N1 flu, stunned scientists discover, Profit Driven Swine Flu Propaganda - Pump Up the Volume - Part Four and New research: no good scientific evidence flu shots are effective or safe for elders and Virginia teen athlete in wheel chair after H1N1 vaccine from Natural News.
• Top Vaccine Health News from Dr. Joseph Mercola, This Year’s Flu Vaccine Is More Dangerous than You Think, Will This Year’s Flu Vaccination Plan Bring Protection or Deception? and Swine Flu Vaccine Causes Narcolepsy among Children.
• VITAMIN C, TITRATING TO BOWEL TOLERANCE, ANASCORBEMIA, AND ACUTE INDUCED SCURVY and The Ascorbate Effect in Infectious and Autoimmune Diseases by Robert F. Cathcart, M.D.
• Ascorbate: The Science of Vitamin C by Dr Hickey and Dr Roberts,
• VITAMIN C: The Real Story by Steve Hickey, PhD and Andrew Saul,
• Vitamin C: The Facts, the Fiction, and the Law (presented by Dr Levy in New Zealand on 9/17/2010). The powerpoint lecture on vitamin C and the law can be found here and the video listing is: Thomas Levy Talks To Vitamin C Can Cure Coalition Part 1/9 (video)
• Vaccination---The Shot That Keeps on Shooting by Dr Thomas Levy MD
• Sugar Increases Polio Risk -- Lessons For Other Viral Infections from Mercola
Ringsdorf, W., Cheraskin, E. and Ramsay R. Sucrose, Neutrophilic Phagocytosis and Resistance to Disease, Dental Survey. 1976;52(12):46-48

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Relevant quotes
“The news is out: Vitamin D is better than the swine flu vaccine at halting H1N1 infections. In fact, without vitamin D, chances are that a vaccine won’t generate much of an immune response in the first place.” Natural News

“Flu vaccines are a perfect storm of neurological stress (mercury, myelin chicken antigen, adjuvants, and attenuated virus – not to mention potential contamination). The risk of problems is magnified in individuals with immunologic and/or digestive problems, which is the target audience. How many infants and children must suffer brain damage before public health goons wake up?

Then there is the issue of whether or not flu vaccines even work. Seldom is a flu vaccine a perfect match for the flu strain that is coming around. It may give a partial boost, which in my opinion pales in comparison to a robust and healthy natural immune response. The flu can rapidly mutate within 24 hours to escape any given vaccine. The only real chance you actually have is the health of your own immune system.

You would think that with all the billions of dollars involved there would be hard core proof that flu vaccines provide a benefit. Each year public health officials try to promote some study that is typically flawed. In general, the only proven benefit is for individuals stuck in a nursing home (living in a Petri dish with no way out). For the general ambulatory population, proof of any benefit is woefully lacking. There is proof that the more immunizations a person has the worse their immune system works as they get older. All the false alarms create too many T-memory cells that don’t want to do anything. It’s like having a bunch of old generals sitting around the table telling war stories, and nobody wanting to go into action.

No doubt, the public health propaganda for flu shots will be in full swing this year. Fear is the mantra. The fear is misplaced; it should be of the flu shot itself. Remember, public health is never in the best interest of any one person. If public health officials convince enough gullible people to take a flu shot then why do you or your children “need” one? The focus should be on strengthening your own immune system and helping your children to do the same. There are no short cuts to a healthy immune system.” Natural News

“It was also reported that expired or unused flu vaccines contained the mercury preservative thimerosal. The substance is so hazardous that it cannot be disposed of regularly. If such a vaccine contains something so toxic, you cannot guarantee its safety.” Dr Mercola
Disclaimer: HFME does not dispense medical advice or recommend treatment, and assumes no responsibility for treatments undertaken by visitors to the site. It is a resource providing information for education, research and advocacy only. In no way does reading this site replace the need for an evaluation of your entire health history from a physician. Please consult your own health-care provider regarding any medical issues relating to the diagnosis or treatment of any medical condition.
Sadness, grief or reactive depression can occur in M.E. as a result of the severe restrictions on daily living and basic communication, the extreme loss of quality of life, uncertainty or despair over welfare benefits and the money needed to support basic living, as well as the lack of acceptance, ridicule and neglect from the media, society, doctors and even close friends and family members that so often accompany M.E.

Feelings of sadness and grief are NOT medical problems that need to be treated, they are normal and healthy reactions to traumatic events. Where feelings of sadness start to become severe and have a large impact on daily life, or there are thoughts of suicide, the problem may become what is known as reactive depression; depression caused by life events (and which is not natural or endogenous).

Anxiety may also become a problem for M.E. patients, this may occur as a reaction to M.E. and the stresses that come with it, or may in fact be a symptom of M.E. (as M.E. affects all aspects of the brain and CNS). When symptoms such as anxiety or emotional lability or feeling ‘hyper’ and talking very fast etc. are part of the damage to the CNS caused by M.E., they will improve as the disease improves.

(Emotional lability might manifest as feeling fine and happy and not at all upset, but then crying, perhaps even uncontrollably, at a ‘touching’ TV commercial or a commercial featuring a cute animal or baby, for example. This sort of symptom is very different to actual depression. Feeling ‘hyper’ and talking fast are caused by the damage to the CNS, and can also occur after overexertion when the body releases a flood of adrenaline to cope with being placed in physiological difficulty.)

Depression and anxiety have many causes and how well any treatment will work depends on the actual cause of symptoms. ANY ‘one-size-fits-all’ approach is doomed to failure, for the majority of people.

It is probably a good idea to start with the safest and least risky approach, which would be the nutritional approach. Relaxation, mediation and breathing exercises can also be helpful, particularly when combined with a nutritional approach. Maintaining relationships with friends and family and talking to those in a similar situation to you is also very important. (See the ‘Mediation and relaxation exercise and M.E.’ and ‘Tips for coping with M.E. emotionally’ pages for more information.)
Depression and anxiety can also occur in M.E., as well as the general population, due to a lack of certain nutrients. Severe illnesses deplete the body of certain vitamins and minerals and enzymes etc. and increase the daily requirement of these substances. The brain is far more sensitive to biochemical imbalances and nutritional deficiencies than any other organ of the body. Lack of nutrients and an excess of ‘anti-nutrients’ such as lead or chemical additives can cause many different mental health symptoms.

For some people, symptoms of anxiety and depression completely resolve once magnesium deficiency or vitamin C deficiency is treated. The same may be true of other substances such as the B vitamins as well.

It is also important to be aware that while there may be solid reasons for feelings of depression or anxiety etc. due to life circumstances, nutritional deficiencies and issues of toxicity could be making these symptoms far worse than they would otherwise be. Correcting these issues may make some symptoms much milder and/or make stressful events easier to cope with and so on.

The first step in trying to improve symptoms of depression and anxiety through nutrition is to clean up the diet. Following the dietary guidelines recommended on HFME can improve symptoms of depression and anxiety, in several different ways. In short:

- Remove sugar and processed foods from the diet (and anything else you know you react to). Most important of all, particularly if you have anxiety problems, is to strictly avoid sugar. There is a direct link between mood and blood sugar balance.
- Eat fat, protein and low GI and GL carbohydrates, lots of nutritious whole foods that do not contain additives and preservatives and so on. If possible, buy organic food.
- Eliminate (or at least reduce) caffeine. Caffeine raises insulin levels in a similar way to sugar.
- Eliminate (or at least reduce) alcohol. Alcohol is a depressant and also depletes your body of a number of nutrients.
- Eliminating wheat and dairy may or may not be necessary. The only way to be sure is to stop eating these foods for a month and see if you feel better.
- Eat every 3 – 4 hours to prevent blood sugar levels from becoming low. Make sure meals contain some fat, protein and carbohydrate as eating meals made up almost entirely of carbohydrates can lead to blood sugar highs and lows and mood swings and anxiety.

For some, this change of diet may be enough to resolve symptoms of depression or anxiety.

Some deficiencies may not be able to be resolved through diet alone, however, and may require supplementation.

Starting a general supplement program which covers all the basics is a very good idea before starting to take any supplement at higher doses.
Some of the most common supplements that can help to treat or improve depression and anxiety including the following:

- Magnesium 800 - 1000 mg or more (depending on individual need), in 4 divided doses. Transdermal magnesium may be a better choice for depression as it also boosts DHEA levels (and so all the hormones that are made from DHEA) which can also improve depression in some people. Over 80% of people in the western world are low in magnesium. Low magnesium levels are the sole cause of depression, restlessness, anxiety and panic attacks in a significant percentage of people. For more information see the ‘Magnesium and M.E.’ page.

- A good quality multivitamin and mineral supplement or B complex product containing adequate amounts of each of the B vitamins. Vitamin B1 50 – 100 mg, B2 50 – 100 mg, B3/Niacin 500mg (subclinical deficiencies of vitamin B3 can cause symptoms of agitation and anxiety), B5 100 mg + (this vitamin is needed for hormone formation and the uptake of amino acids and the brain chemical acetylcholine, which combine to prevent certain types of depression), B6 50 – 100 mg (vitamin B6 is needed in the manufacture of serotonin, melatonin and dopamine), B12 500mcg +, folate 800 mcg + (folate is necessary for the production of SAM (S-adenosyl methionine), choline, inositol 1 – 2 g (at this dose, inositol may improve depression and anxiety and sleep).

  If you do not feel a noticeable positive effect from basic B vitamin supplementation within 2 – 4 weeks, buy a bottle of coenzymated sublingual B complex to try at a dose of 1 daily (or 2 daily to start with). This product may be essential if your body does not coenzymate B vitamins very well. (This can occur where illness is severe).

  Make sure to take extra vitamin B6 if you are also taking the contraceptive pill or hormonal replacement therapy. These drugs (as do many or even all drugs) deplete vitamin B6.

- Vitamin C, minimum dose 1 – 2 grams daily, although 5 – 10 g or more may be needed by some people to improve symptoms of depression (and other symptoms known to be improved with vitamin C). One of the most common effects of inadequate vitamin C is depression.

  Vitamin C plays an important role in the production of serotonin, it catalyzes the manufacturing of serotonin. Serotonin is a brain chemical, a neurotransmitter, responsible for your mood. Vitamin C is therefore one of the valuable natural antidepressants for patients with depression associated with low level of serotonin. Andrew W. Saul PhD explains how to ‘make your own norepinephrine’ as follows,

- A depletion of the neurotransmitter called norepinephrine may result in poor memory, loss of alertness, and clinical depression. The chain of chemical events in the body resulting in this substance is: L-phenylalanine (from protein foods) -> L-tyrosine (made in the liver) -> dopa -> dopamine -> norepinephrine -> epinephrine.

  This process looks complex but actually is readily accomplished, particularly if the body has plenty of vitamin C. Since one's dietary supply of the first ingredient,
L-phenylalanine, is usually adequate, it is more likely to be a shortage of vitamin C that limits production of norepinephrine. Physicians giving large doses of vitamin C have had striking success in reversing depression. It is a remarkably safe and inexpensive approach to try.

- **Tryptophan 500 - 2,000 mg** daily from supplements, or from foods such as lentils, dried peas, navy, pinto, red kidney or soy beans, tahini, brazil nuts, cashews, hazelnuts, peanuts, pumpkin seeds, sesame seeds, eggs and poultry and other fresh meats, including organ meats. (Note that tryptophan is restricted for sale in some countries, including Australia.) Note that tryptophan supplements may not be well tolerated in M.E., along with 5-HTP. Andrew W. Saul PhD says, ‘Tryptophan is broken down into anxiety-reducing, snooze-inducing niacin. Even more important, tryptophan is also made into serotonin, one of your body’s most important neurotransmitters. Serotonin is responsible for feelings of well-being and mellowness.’

- **Lecithin 2.5 – 5 g.** Andrew W. Saul PhD explains how to ‘make your own acetylcholine’ as follows,
  
  Acetylcholine is the end neurotransmitter of your parasympathetic nerve system. This means that, among other things, it facilitates good digestion, deeper breathing, and slower heart rate. You may perceive its effect as "relaxation." Your body will make its own acetylcholine from choline. Choline is available in the diet as phosphatidyl choline, found in lecithin. Lecithin is found in egg yolks and most soy products. Three tablespoons daily of soya lecithin granules provide about five grams (5,000 milligrams) of phosphatidyl choline. Long-term use of this amount is favorably mentioned in The Lancet, February 9, 1980. Lecithin supplementation has no known harmful effects whatsoever. In fact, your brain by dry weight is almost one-third lecithin!

  Note that lecithin also contains choline and inositol and so the stated amounts of these supplements may not be necessary when taking lecithin.

- **Chromium 400 - 600 mcg.** Chromium may be helpful in treating ‘atypical’ depression.

- **L carnitine 1 – 2 g.** L carnitine may alleviate depression in some patients, at this dose. Acetyl L carnitine may also be helpful at a dose of 500 mg (although it may increase neurological overload in some patients).

- **Armour thyroid.** Correcting a thyroid deficiency can improve symptoms of depression in some cases.

- **DHA and EPA fatty acids from fish oil, 1 – 2 grams or more.** Researchers have found that omega 3 fatty acids (DHA and EPA) raised levels of the important neurotransmitter serotonin, in the brain. Omega 3 fatty acids have been shown to improve anxiety, sleeping problems, sadness, decreased sexual desire and suicidal tendencies. A month or more is needed to see the full effects.

- **Vitamin D, at the dose indicated by testing.** Low vitamin D levels can cause depression. **Vitamin D** has profound effects on the brain, including the neurotransmitters involved in depression and seasonal affective disorder.
• Zinc 30 – 60 mg. When zinc is low, copper in the body can increase to toxic levels, resulting in paranoia and fearfulness.

• Potassium depletion is frequently associated with depression and tearfulness.

• Manganese is needed for proper use of vitamins B and C. A deficiency may contribute to depression stemming from low levels of the neurotransmitters serotonin and norepinephrine. Manganese also helps prevent hypoglycaemic mood swings (as does chromium).

• A safer alternative to valium is niacin, according to Andrew W. Saul PhD. He writes that,

> Niacin/vitamin B-3 is so effective against actual psychoses that half of all mental ward inmates in the South were able to be released once a depression-era deficiency of this vitamin was corrected. Niacin in appropriate doses acts as a natural tranquilizer and induces relaxation or sleep. It is non-addictive, cheap, and safer than any pharmaceutical product. Dosage varies with condition. The best author on the subject is Abram Hoffer, M.D., whose experience dates back to the early 1950's. He routinely gave at least as much vitamin C as he did niacin.

Patients may wish to substitute flush-free niacin for regular niacin if they do not wish to experience the ‘niacin flush.’

• 5 Hydroxytryptophan (5-HTP) is an alternative to the traditional antidepressants used to treat unipolar depression. It comes with its own cautions and warnings, and is not suitable for long-term use but may still be a safer alternative to prescription antidepressant drugs. Patrick Holford explains that, ‘In play-off studies between 5-HTP and SSRI anti-depressants, 5-HTP comes out slightly better.’

> See the ‘Important extra treatment cautions and warnings relevant to M.E.’ section for more information about 5-HTP and before taking 5-HTP.

• SAMe, at the dosage recommended on the bottle. (SAMe may help some M.E. patients with depression but this supplement may not help others and may be poorly tolerated, at least in part as it can improve the process of methylation. SAMe can cause the same severe problems in M.E. as supplementation with cysteine. For this reason, many of the other supplements listed here and probably a better first choice for M.E. patients. This supplement should be started at a very low dose in M.E., perhaps 1/10th of a tablet.) SAMe should not be taken by those diagnosed with bipolar disorder.

The following herbs may also be useful in reducing symptoms of depression or anxiety:

• St John’s Wort, 300mg x 3. St John’s Wort works in a similar fashion as a SSRI in that it inhibits serotonin reuptake. Try to find 300mg capsule of standardized extract that contains 0.3% hypericin and 5% hyperforin. Expect to wait 6 weeks to see effects. Note that St John’s Wort should NOT be taken with antidepressant
drugs. St. John’s Wort may increase sedation when narcotics are administered during surgery.

- **Ashwagandha** is an herb that has many effects, including acting as an antidepressant.
- Herbs such as chamomile and catnip make a soothing tea.

Note that this information on nutritional and herbal treatments is in no way specific to M.E. and may just as easily be used as a reference by those with other diseases than M.E. or for whom depression or anxiety is their only health problem.

For information on the different forms, dosage, cautions and so on for each vitamin or mineral etc. mentioned here, please see the main ‘Treating M.E.’ paper or the ‘A quick start guide to treating and improving M.E. with aggressive rest therapy, diet, toxic chemical avoidance, medications, supplements and vitamins’ paper, or the specific HFME paper on that particular vitamin or mineral etc. Do not start any treatment at the full dose right away (or on it’s own) and do not start any new treatment without reading this information first.

**Testing for deficiencies and problems which may contribute to or cause symptoms of anxiety or depression**

Some of the nutritional deficiencies that can cause symptoms of depression or anxiety can in fact be tested for.

The problem is that there are many different tests and so having lots of these tests may not be practical economically. The website [www.mentalhealthproject.com](http://www.mentalhealthproject.com) may be useful here as it offers free questionnaires which may help pinpoint the causes of symptoms and let you know which symptoms are linked with which deficiency.

(Even so, it may still be far simpler and cheaper to try taking some fish oil for several months rather than to have levels of essential fatty acids tested, and so on. This is particularly relevant when you are talking about all those vitamins and minerals etc. which are relatively inexpensive and essential to good health anyway. It makes more sense just to take them and see how you feel than to have expensive testing.)

Mental health problems can be caused by or worsened by

- A deficiency of essential fatty acids. A deficiency of essential fatty acids is treated by supplementing the appropriate essential fatty acids (eg. fish oil)
- Blood sugar imbalance. Blood sugar imbalance or poor glucose tolerance is treated in various ways, but what is essential is a low sugar diet, and a balance between low GI and GL carbohydrates, fat and protein in the diet. Chromium supplementation may also be helpful in keeping blood sugar levels stable.
- Underactive or overactive thyroid. Underactive thyroid is treated with thyroid replacement therapy (eg, Armour thyroid.)
- Adrenal issues. Supplementation with cortisone may be necessary to treat adrenal insufficiency.
• Hormonal issues. Some hormonal issues, such as PCOS, are treatable with diet.
• Food and chemical (and drug) allergies and intolerances. Food and chemical allergies and intolerances are managed via avoidance of problematic foods and chemicals.
• Drug-side effects. For example, beta blockers affect the CNS and can cause malaise and depression. Some drugs may have to be discontinued (with medical assistance).
• Heavy metal toxicity. Heavy metal toxicity is improved by first avoiding further heavy metal exposure, and then a detoxification regime. (Dental fillings containing mercury can worsen depression.)
• High homocysteine levels. High homocysteine levels are brought down with adequate B vitamins and zinc.
• Low serotonin levels. May be treated with 5-HTP.

Relevant tests include:
• Essential fatty acid testing
• Glucose tolerance testing
• Thyroid function tests
• Adrenal function tests
• Various tests of hormone levels
• Food allergy and intolerance testing
• Hair elements test
• Homocysteine levels testing
• Neurotransmitter screening test
• Platelet serotonin test

For more information on testing for causes of mental health issues, see the ‘The NEW optimum nutrition for the mind’ book by Patrick Holford and his www.mentalhealthproject.com website.

Conclusion
A combination of dietary changes, vitamins, herbs and so on may be necessary to successfully treat symptoms of depression and anxiety. Relaxation and mediation exercises may also be helpful.

For the best results, an individualised nutrition and supplementation plan should be created in partnership with a qualified holistic practitioner. Ideally, this practitioner would also be the patient’s doctor. The information on HFME should be used only as an additional source of information, as a starting point for the patient’s own research efforts and for discussions with their own practitioner.

The best results are also achieved by following a comprehensive nutrition and supplementation plan, rather than only taking a small number of supplements, and by doing as much reading as possible before starting any new treatment.
For some patients, some form of talking therapy may also be useful or even vital. In general, patients themselves are most likely the best judge of whether or not there are serious psychological issues that need to be dealt with and if counselling or psychotherapy is necessary. These issues may have occurred many years prior to M.E. and be entirely unrelated to the disease, or may involve problems coping with poor treatment by friends and family etc. since becoming ill or coping with the severe limitations of the disease itself.

For more information on this topic, please see the reference list for this paper. If depression or anxiety is a serious issue for you, perhaps you may consider buying (or borrowing) one or more of the books listed.

All the very best to everyone reading this paper.

Additional notes on this topic
1. The best way to improve sadness and grief caused by loss of quality of life in M.E. is of course to lessen the severity of the disease overall. See the ‘A quick start guide to treating and improving M.E. with aggressive rest therapy, diet, toxic chemical avoidance, medications, supplements and vitamins’ paper, for more information on this important topic.

For information and tips on coping with M.E. emotionally, reducing stress (and issues around finding a good counsellor or therapist, where one is desired) see the Coping with M.E. Emotionally paper and the main ‘Treating M.E.’ paper.

2. Prescription antidepressant drugs are very often poorly tolerated by people with M.E. Where depression is severe and antidepressants drugs may be a necessary last resort, the initial dosage used should always be very small (1/10th of a normal dose or less) but even at this dosage many people with M.E. cannot tolerate these drugs at all. Some particular antidepressants may cause other serious problems: Doxepin is known to cause heart problems (which is particularly concerning considering the well known cardiac issues in M.E.) and Serzone (a drug which has been taken off the market in some countries but not others) is linked with liver failure. Prozac contains a lot of toxic fluoride and has been described as a product that act as a fertiliser for cancer. See the Real depression help website to read about serious cardiac and other side effects of certain antidepressants drugs.

M.E. patients whose doctors recommended antidepressants as a treatment for M.E. (rather than a treatment for depression, or prescribe them where there is no anxiety or depression) should NOT accept this advice. Antidepressant drugs are in no way a useful treatment for M.E. and can and often do cause severe relapse.

(On a personal, and anecdotal note, it is difficult to put into words how terrible it is to be so ill with M.E. and to have so many horrific physical symptoms suddenly, and then to be given a prescription antidepressant drug – when you are NOT depressed. It can very quickly make life utterly miserable, as the ability to look on the light side of
things, to laugh and to feel happiness and joy, and so on, is taken away. When you are so ill that all you have left is your mind, your humour and your personality...to have access to this taken away for weeks or months by an inappropriate drug is appalling. What makes this even worse is that the drug has no possible benefit; the risk of physical or emotional fallout is enormous, and the risk of benefits is zero! Not a good deal or a sensible risk by anyone’s standards. If you know you are not depressed, do not take antidepressant drugs even at the urging of your (M.E. ignorant) doctor. Stand up for yourself and what you know about your own condition.)

3. It should NOT be assumed that all or even most M.E. patients are suffering with depression. This is not the case.

The rate of clinical depression seen in M.E. is similar to, and not higher than, that seen in comparable illnesses such as rheumatoid arthritis. (Of course, depression is a common disease, and it does not make you immune from other diseases. So some patients with depression will also end up having other conditions as well, over time. This includes M.E., plus MS and Parkinson’s and all other diseases.)

Although a minority of M.E. patients will have a clinical depression, more often some patients are instead dealing with natural and expected levels of grief and sadness for what they have lost. If these feelings are present, they are not evidence of a psychiatric disease but simply a normal and healthy reaction to an extremely distressing life experience and extreme levels of physical suffering. The only ‘treatment’ needed is an improvement in the severity of the condition, and in many cases probably also greater levels of appropriate medical, financial and/or social support. As one long-time M.E. sufferer explained, ‘The desperation one gets periodically from being so ill is not at all the same thing as ‘clinical depression'. Give me an even somewhat better day physically – and my mood improves quickly and dramatically!’

4. Exercise is highly recommended for non-M.E. patients in the treatment or management of depression, and for good reason. In M.E., however, any level of activity over an individual’s limits can only worsen all symptoms. It will NOT have an antidepressant effect where even minor relapse or a worsening of symptoms is caused. There are no exceptions to this rule.

References and recommended reading list
- The Doctoryourself.com article on depression
- The Doctoryourself.com article on anxiety attacks
- The www.mentalhealthproject.com website
- The Real depression help.com website
- Dr Atkins Vita-Nutrient Solution: Nature’s Answer to Drugs by Dr Atkins
- Depression cured at last by Dr Sherry Rogers.
- The NEW optimum nutrition bible by Patrick Holford
- The NEW optimum nutrition for the mind by Patrick Holford
Relevant quotes
‘There is a curious contradiction at the heart of the drug-based approach to depression. The treatment is based on correcting a biochemical imbalance in the brain. So you might think a scientific approach would be to check whether depressed patients actually had an imbalance and if so, exactly which neurotransmitters were low so they could be given a boost. But that is not what happens. Instead, the diagnosis of depression is based solely on a checklist of psychological symptoms, which doesn’t tell you anything about what is going on with brain or indeed body chemistry.’ Patrick Holford

“But how does folic acid, a cheap vitamin with no side effects, compare to anti-depressants? Three trials published in 2003 and involving 247 people addressed this question. Two, with 151 participants, assessed the use of folic acid in addition to other treatment, and found that adding folic acid reduced HRS scores on average by a further 2.65 points. That’s not as good as the results with 5-HTP but as good, if not better, than anti-depressants. These studies also show that more patients treated with folic acid experienced a 50 per cent greater reduction in their HRS after ten weeks, compared to those on anti-depressants.” Patrick Holford

“The evidence suggests that the nutritional approach it not only more effective. It’s also practically free of serious negative side effects. So why not do it? Well, you could argue that there’s not enough research to conclusively prove all the benefits we’ve discussed here. You might be thinking that many of the trials are small, although well designed. That’s true to an extent, and it’s also unlikely to change: there’s little profit to be made from non-patentable nutrients such as omega-3, folic acid or 5-HTP. Psychiatrist Dr Erick Turne from the Mood Disorders Center in Portland, Oregon, who uses 5-HTP in his practice, says: ‘Unfortunately, because 5-HTP is a dietary supplement and not a prescription pharmaceutical, there is comparatively little financial incentive for extensive clinical research.’ Also, since no benefits for nutrients can be put on their packaging, and there's no army of reps or marketing budget, most people simply don’t know about these highly effective, and considerably safer nutritional options.

But then there’s the other, now-familiar problem: most doctors are also unfamiliar with food-based medicine. ‘A doctor receives virtually no training in nutritional...
approaches to depression. It’s an obvious oversight, given the wealth of evidence,’ says André Tylee, professor of primary care mental health at the Institute of Psychiatry. But that is no reason why you shouldn’t try it yourself with the help of a trained clinical nutritionist.” Patrick Holford
For those times when we are overwhelmed by the severity of a symptom, or feeling very unable to cope with our limitations or all of the frustrations that come with M.E., meditation and relaxation and breathing exercises can help, to some extent. They can help you cope right away with an awful moment or hour or day (if you are well enough to do them), and even improve your ability to think clearly and be calmer generally, if you practice then often.

Not everyone with M.E. is well enough to handle each suggestion listed below, but I hope you’ll find at least one you can manage.

**The 4-7-8 Breathing Exercise** by Andrew Weil MD (from the Mercola site. NOTE: Make sure the volume is turned DOWN if you click on this link!)

The key to this exercise is to remember the numbers 4, 7 and 8. It’s not important to focus on how much time you spend in each phase of the breathing activity, but rather that you get the ratio correct.

Here’s how it’s done:

- Sit up straight
- Place the tip of your tongue up against the back of your front teeth. Keep it there through the entire breathing process
- Breathe in silently through your nose to the count of four
- Hold your breath to the count of seven
- Exhale through your mouth to the count of eight, making an audible “woosh” sound
- That completes one full breath. Repeat the cycle another three times, for a total of four breaths

You can do this exercise as frequently as you want throughout the day, but it’s recommended you don’t do more than four full breaths during the first month or so of practice. Later you may work your way up to eight full breath cycles at a time.

The benefits of this simple practice are enormous and work as a natural tranquilizer for your nervous system.

Personally, I think one of its greatest values may be gained when you combine it with your meals. Most of us eat three meals a day, so it makes remembering to do it easier.
Also, I believe that combining it with the attitude of gratitude for the healthy meal you just ate, or are about to eat, can have a powerful, beneficial influence on your health.

**Full Chest and Abdominal Breathing** by Mercola

This method is simply a deepening of the breath. Take slow, deep, rhythmic breaths through the nose. When the diaphragm drops down, the abdomen is expanded allowing the air to rush into the vacuum created in the lungs. Then the chest cavity is expanded, allowing the lungs to fill completely. This is followed by a slow, even exhalation which empties the lungs completely. This simple breath practice done slowly and fully, with intention, concentration and relaxation activates all of the primary benefits of therapeutic breath practice. In Qigong and Pranayama the breath is retained for additional benefit. Application Suggestions:

- Health maintenance: 6 to 10 repetitions, 2 to 3 sessions per day.
- Health enhancement: 6 to 10 repetitions, 4 to 6 sessions per day.
- Disease intervention: Start slowly and build up to 15 to 20 repetitions, in 10 to 15 sessions per day. Getting started: 2 to 3 repetitions, once or twice per day.

Remember to keep it easy and fun.

**Alternate Nostril Breathing**

Using your thumb on your right nostril and your pinky and third finger (the finger right next to your pinky finger), hold your right nostril closed and inhale up your left nostril. Pause, and while your lungs are full of air, switch your fingers so that your left nostril is closed. Then exhale out your right nostril. Then inhale up your right nostril, pause, and again while your lungs are full of air, switch your fingers so that your right nostril is closed. Exhale. Repeat this process about 12 times. This breath is often done in preparation for deep relaxation or meditation.

You will notice that usually one or the other of the nostrils is more open. If you breath on a small hand mirror, the patch of mist from one nostril will be larger than from the other.

The ancient practitioners of Yoga in India were aware of the significance of this and employed this knowledge to enhance health and consciousness. Western science did not notice this phenomena until the 1800's. It has been found recently, through the application of current neuroscience, that the practice of alternate nostril breathing helps to balance the right and left hemispheres of the brain. Applications Suggestions:

- Health maintenance: 10 to 12 repetitions, 2 to 3 sessions per day.
- Health enhancement: 10 to 12 repetitions, 4 to 6 sessions per day.
- Disease intervention: Start slowly and build up to 15 to 20 repetitions, 8 to 10 sessions per day or up to even 100 repetitions in a single session.
- Getting started: 10 to 12 repetitions, once or twice per day. Notice that this method is very quieting.

The relaxation response
This is another extremely simple method that initiates the relaxation response. Begin by taking slow deep breaths. Repeat these messages to yourself.

- "My hands and arms are heavy and warm" (5 times).
- "My feet and legs are heavy and warm" (5 times).
- "My abdomen is warm and comfortable" (5 times).
- "My breathing is deep and even" (10 times).
- "My heartbeat is calm and regular" (10 times). "My forehead is cool" (5 times).
- "When I open my eyes, I will remain relaxed and refreshed" (3 times).

Application Suggestions:
- Health maintenance: 2 to 3 sessions per day.
- Health enhancement: 6 to 10 sessions per day.
- Disease intervention: Start slowly and build up to 10 to 15 sessions per day. Until you are well you have time to do this.
- Getting started: 2 to 3 sessions per day.

Meditation guide for peace of mind from Free Meditations

Meditation handbook

Happy for No Good Reason by Swami Shankarananda. A book on meditation which comes with a CD.

The Relaxation Response

‘The Relaxation Response’ is the name of a book published by Dr Herbert Benson of Harvard University in 1968. In a series of experiments into various popular meditation techniques, Dr Benson established that these techniques had a very real effect on reducing stress and controlling the fight-or-flight response. Direct effects included deep relaxation, slowed heartbeat and breathing, reduced oxygen consumption and increased skin resistance. This is something that you can do for yourself by following these steps:

- Sit quietly and comfortably.
- Close your eyes.
- Start by relaxing the muscles of your feet and work up your body relaxing muscles.
- Focus your attention on your breathing.
- Breathe in deeply and then let your breath out. Count your breaths, and say the number of the breath as you let it out (this gives you something to do with your mind, helping you to avoid distraction).
- Do this for ten or twenty minutes.

Download/listen to free relaxation and meditation audio files from healthylifestyle.com. Includes links to peaceful music, relaxation and meditation and guided imagery audio files. This page also has similar links.

Go to YouTube or Google to search for many more free relaxation and mediation techniques. Or you may want to see if you can borrow mediation CDs from friends or
family or from the library. Some of the relaxation promoting Hemisync CDs may be useful for M.E. patients, just make sure they aren’t the type aimed at ‘increasing energy’ etc. or else they will make you more ill.

If you’re not up to listening to a guided meditation, you can mediate by just trying to live in the moment. Let all thoughts come and go, without paying much attention to them. Look that the things around you, really look at them one at a time; describe in your mind exactly what you are seeing. Describe the colours, shapes and textures without making any sort of judgements about them. If you are able to, you may want to do this exercise outside, looking at the garden.

You can also listen to very peaceful music such as Mozart, or some of the more mellow World music, and concentrate on just listening to the music. Let all thoughts come and go, without paying much attention to them.

You may find, as many M.E. patients do, that spending all your time in a very messy and cluttered room full of bright colours and lots to look at makes it much harder to relax. Post-illness you may need to focus on making the room you spend most of your time in very peaceful by making things orderly, and removing clutter and non-restful colours etc. You may find that as your health improves, however, that you are able to cope with being in rooms which have more going on visually, without feeling more ill.
The information contained in most of ‘Treating M.E.’ is aimed at those that have been ill with M.E. for years or even decades. For those that have only been ill with M.E. for a very short period of time, a different and/or more aggressive approach may be called for.

Time is of the essence when you are treating M.E. in the early stages. Every day counts. There are also far fewer issues with detoxification and sensitivities when a person has not been ill with M.E. for very long, and so less likelihood that treatments will cause problems to some extent. For these reasons the advice given in the main ‘Treating M.E.’ paper about starting each treatment very gradually and only one at a time may POSSIBLY be best ignored when M.E. is treated in the earliest stages.

Quick diagnosis is key
Patients quickly diagnosed and treated for M.E. have a much greater chance than other patients at regaining some or even all of their lives back. Correct diagnosis and treatment is extremely important in M.E., albeit one of the most difficult things to obtain within the current ignorant and corrupted medical system.

M.E. is a testable and scientifically measurable disease with a number of unique features. It is not difficult to diagnose medically even within just a few weeks of onset, using a series of objective tests.

For more information see: Testing for M.E. and The Nightingale Definition of Myalgic Encephalomyelitis by Dr Byron Hyde — the world’s leading M.E. expert.

It is very important to be aware that merely qualifying for a diagnosis of ‘CFS’ or ME/CFS’ is not at all the same thing as a genuine diagnosis of M.E. Vast numbers of patients qualify for these diagnoses that do not have M.E. and in fact if ‘CFS’ definitions are strictly adhered to, M.E. patients will not qualify for this misdiagnosis due to always having significant abnormalities on objective testing and on physical exam. For more information please see: What is M.E.?

Avoiding overexertion in the early stages of M.E. is absolutely ESSENTIAL
M.E. patients who are able to rest appropriately and avoid severe or repeated overexertion in the early stages of M.E. have repeatedly been shown to have the most positive long-term prognosis.
The importance of avoiding overexertion at this stage of M.E. just cannot be overstated. Resting in the early stages of M.E. or pushing through to remain active despite symptoms can be the difference between a normal life and very severe disability lasting decades or even death.

- For more information on the importance of avoiding overexertion in M.E. see: Treating M.E.: Avoiding overexertion and Assisting the M.E. patient in managing relapses and adrenaline surges plus Hospital or carer notes for M.E. and Why patients with severe M.E. are housebound and bedbound.
- See also Treating M.E.: The basics, What it feels like to have Myalgic Encephalomyelitis: A personal M.E. symptom list and description of M.E. and What M.E. feels like to me, Group comments on the importance of avoiding overexertion in M.E., M.E. case studies plus The effects of CBT and GET on patients with Myalgic Encephalomyelitis and Patient accounts of GET.
- Note that even if the diagnosis of M.E. is not 100% certain, it cannot hurt to make sure the patient rests in the acute phase of the infection. Resting is beneficial in the early stages of all viral diseases and so benefits may also be seen to some extent even if the patient turns out not to have M.E.

**Different treatment approaches for treating M.E. in the acute stages**

Once M.E. has been diagnosed (or is strongly suspected), there are a number of different approaches that can be taken, including the following:

- **Approach 1:** Treat the patient with drugs such as Pleconaril or Interferon
- **Approach 2:** Treat the patient with saturation dose IV vitamin C: A powerful broad spectrum anti-viral substance.
- **Approach 3:** Treat the patient with saturation dose vitamin C and high-dose B vitamins by IV and a comprehensive nutritional protocol.

**Approach 1: Treat the patient with drugs such as Pleconaril or Interferon**

M.E. is an enteroviral disease. Following the administration of a rapid PCR (Polymerase Chain Reaction) test which shows evidence of an enteroviral infection, drugs such as Disoxaril, Enviroxime, Piradovir and Pleconaril can be used effectively to block the passage of the virus to the brain, if given early enough, explains M.E. expert Dr Elizabeth Dowsett. This ‘rapid’ test can be read within just 5 hours.

Dr Dowsett explains,

These “capsid blocking” drugs provide a perfect fit into the minute chamber through which the live virus must pass into the cell. The dimensions are the same for all enteroviruses yet examined. Thus, nature has, by some miracle, provided us with a ready made “natural” means of cure! *The “Capsid” is the virus coat which has to be discarded before the virus can reproduce. “Capsid Blocking Drugs” prevent this from taking place.*
If the American multicentre placebo controlled randomised trial of PLECONARIL in neonatal disease is successful, what a chance we have to treat, stop and prevent enteroviral illness now! Please talk to your MP as soon as possible about why similar studies are not being carried out within the UK despite large amounts of money being provided!!

At the same time, vaccines have been produced, but not yet used against coxsackie B viruses. These can prevent a whole variety of enterovirus diseases, and, (using rapid PCR) we can anticipate which virus strains will be coming next year to prevent further infections in baby nurseries and in school children, in the future.

The article, A Novel Antipicornaviral Agent: Pleconaril, explains,

Although pleconaril was not submitted to the FDA for approval of enteroviral meningitis or other life-threatening enteroviral infections, it should be considered as possible first-line therapy through the company's compassionate use program. Enteroviruses are the most common cause of meningitis in the United States and an important cause of encephalitis, poliomyelitis, myocarditis, hemorrhagic conjunctivitis, hand-foot-mouth syndrome, pleurodynia, and nonspecific febrile illnesses. Pleconaril administered within 48 hours of symptom onset at stated dosages decreased the duration and severity of enteroviral meningitis and offered other improvement in patients with other severe enteroviral infections. It is clear that additional studies are required to evaluate fully the risk-benefit potential of pleconaril before wide-scale clinical administration can be advocated.

Pleconaril may or may not be available currently. Similar drugs are being developed however and may be available in the near future.

As Dr Dowsett is no longer seeing patients, it may be a very good idea to have your doctor contact US enteroviral expert Dr Chia for information on how best to test for and appropriately treat enteroviral infections such as M.E. in the earliest stages.

Dr Chia may recommend drugs such as Ribavarin and interferon-y and interferon-delta for acute enteroviral infections. He claims a high success rate with such treatments (around 50% of patients are greatly improved) although it should also be noted that high rates of increased disability are also seen in the initial stages of treatment, this treatment can be very expensive and relapses may occur in some patients as the infection is being managed rather than cured. Dr Chia considers that there are no quick answers to the enteroviral problem and that effective enteroviral drugs are many years away.

The Enteroviral Foundation writes:

**Beta Interferon** is used to treat viral myocarditis patients with enteroviral infections. While indicated for the treatment of multiple sclerosis, this injectable drug is not approved by the US FDA for the treatment of any viral infection; although it seems to show success in Europe. It still can be used "off label" by physicians but the risk and benefit need to be clearly defined before starting this
treatment. Side effects can be difficult to tolerate in some patients. The treatment is a six-month protocol 8x10^6 IU Betaferon or Beneferon/injection, given every other day. The cost is close to $2500 to $3000/month.

**The combination of alpha and gamma interferons** has been used to treat a limited number of enterovirus patients with an efficacy of 45%. Patients with severe body pain seemed to respond the best, and the remission could last more than 2 years. The 3-month treatment is not US FDA-approved and costs approximately $5000/month. The side effects can be significant.

Regardless of which treatment options are used, Dr Chia’s enteroviral tests are very highly recommended. The test costs around $250.

- For more information on Pleconaril please read: Pleconaril - A New Drug For Enteroviral Infections *(Significantly good news for all who care about M.E.)* by Dr Elizabeth Dowsett. See also: A Novel Anticorona-viral Agent: Pleconaril and other resources online.
- For more information on the work of Dr Chia, please see the HFME Dr Chia page and other resources online including Dr. Chia’s Research Foundation: the Enviromed Foundation. (Note that unfortunately Dr Chia does not fully make the distinction between M.E. and ‘CFS.’)
- For more information about enteroviral infections and M.E. outbreaks please see: The outbreaks (and infectious nature) of M.E. and What is M.E.? Extra extended version

**Approach 2: Treat the patient with saturation dose vitamin C by IV: A powerful broad spectrum anti-viral substance.**

While there is as yet very little information in the literature about treating M.E. in the acute stages of infection, certain inferences can be made by how similar diseases such as poliomyelitis, Multiple Sclerosis and Coxsackie enteroviral infections have been treated. There is evidence that a poliomyelitis infection can be overcome with the administration of large doses of vitamin C by IV, over several days or weeks, if this treatment begins as soon as possible after the infection has begun. The same has been shown to be true of many other infections such as dengue fever, viral hepatitis, chickenpox and herpes, tetanus, malaria, measles, mumps, viral encephalitis and so on.

High or saturation dose vitamin C by IV is also used to treat Multiple Sclerosis, Myasthenia Gravis and other neurological diseases, along with high doses of the B vitamins by IV (particularly vitamin B1). The effectiveness of this protocol depends in part on how early it is begun; how much damage the body has sustained already, in other words. If a positive effect is not seen, this is an indication that the vitamin C dose is insufficient.

The evidence supporting the use of high-dose vitamin C in diseases similar to M.E. is substantial and convincing. Do not immediately reject this treatment because of the...
poor reputation of this treatment, or any vitamin or nutrient-based treatment, promoted by the heavily biased mainstream media. Be aware that many studies of vitamin C have in fact been set up to fail by using ridiculously small doses, and that the media is overwhelmingly biased towards drug based medicine. Saturation dose vitamin C produces improvements and changes to the immune system and cardiac system etc. that are not merely subjective but which can be measured using objective testing. These changes can also be reversed by withdrawing the vitamin C treatment. (For more information on this treatment see the links below.)

Vitamin C at a saturation dose assists in the treatment of viral infections by aiding the production of interferon. Vitamin C is far safer to take than interferon however.

Saturation-dose vitamin C may not only greatly lessen the severity of the infection but actually potentially cure it. The other added bonus of this treatment is that it is also very safe and may even be equally effective if M.E. turns out not to be the correct diagnosis as this treatment is also very effective against toxins and different types of poisoning as well as many other viruses and other issues.

How to begin this treatment:

1. The most important first step is finding a doctor that can advise you about your treatment options and that can safely administer vitamin C (and other vitamins and nutrients) by IV. Use the phone book or the internet to ask various qualified holistic, nutritional, environmental, or orthomolecular medicine practitioners if they offer this therapy and if they are experienced in providing it. If possible, find an expert in one of these fields (or more than one of them) that is also a qualified doctor.

2. Book an appointment with the best practitioner you can find. Advise them that you would like to start treatment as soon as possible, and would like to be given your first vitamin C IV right after your first consult. If possible, vitamin C should be given by IV daily at a dose of at least 25 grams. Doses of around 150 grams daily have been used successfully to treat other enteroviral infections.

If you have a week or so to wait until your appointment read as much as possible about how high-dose vitamin C works to kill viruses and start taking vitamin C orally in multi-gram doses, on your own, working up to bowel tolerance as quickly as possible. Unless you are having a daily vitamin C IV, extra oral vitamin C to bowel tolerance is probably essential even once IVs have begun.

If you cannot find a qualified doctor or cannot get to one, work up to a bowel tolerance dose of vitamin C on your own, if possible using liposomal vitamin C which vitamin C expert Dr Levy explains can be just as effective at the right dose as IVC. (See the ‘High dose vitamin C and M.E. paper for information on how to do this.)

Dr Levy explains that the best option for acute infections is a combination of liposomal vitamin C and vitamin C by IV and that given a choice of only one or the other, the better choice is liposomal vitamin C. The fourth best option is ascorbic acid
taken orally to bowel tolerance and the fifth best option is sodium ascorbate taken orally to bowel tolerance.

At your first consult, give your doctor a detailed medical history and if possible, some basic medical information about M.E. Explain that it is a neurological disease similar to MS and polio which also causes mitochondrial and cardiac dysfunction and insufficiency. (Make sure they don’t try and treat you as if you were merely ‘tired’ or apathetic or depressed or had a mere ‘PVFS’ or similar. This could be disastrous for your health.)

The body’s response to the vitamin C by IV will determine what dose should be given and for how long. An experienced practitioner will be able to advise you on how to adjust this treatment over time. Saturation dose vitamin C should always be continued at least 48 hours after symptoms of an acute infection subside, says vitamin C expert Dr Levy.

- For more detailed and practical information please see: High-dose vitamin C and M.E.
- Probably the best book on this topic is ‘Curing the Incurable” Vitamin C, Infectious Diseases and Toxins’ by Dr Thomas E. Levy MD. It is very detailed and yet easy to read for patients and for doctors, it contains excellent historical and up-to-date information, has over 1200 scientific references and is also the only vitamin C book I am aware of that talks in depth about the new liposomal vitamin C products as well as all the other forms. I recommend it highly.
- Some doctors may recommend that other anti-viral or immune boosting substances be taken at the same time as the vitamin C. This may include 200 – 400 mg of zinc, 500 mcg of selenium, 400 000 IU of vitamin A and 2400 – 3200 mg of garlic and 5000 IU of vitamin D taken daily, for a limited period of time.

**Approach 3: Treat the patient with saturation dose vitamin C and high-dose B vitamins by IV and a comprehensive nutritional protocol.**

It is possible that saturation level vitamin C alone can cure M.E. if given in the earliest stages. However, it is also possible that other nutrients may have an important role to play at this time, particularly when the administration of vitamin C by IV has been delayed or has not been given at the correct dose or for the appropriate duration.

Doctors such as Dr Klenner have had success with treating diseases similar to M.E., such as Multiple Sclerosis and Myasthenia Gravis, with a high-dose B vitamin protocol combined with a general nutritional protocol. Results were sometimes seen within just a few weeks where the patient was treated while the disease was in the early stages although patients that had been ill for many years sometimes took 5 years or more to respond. Considering the safety of this treatment protocol, a reasonably compelling case can be made for its being tried in the early stages of M.E. also – in combination with saturation level vitamin C.
The benefits of correcting any nutritional deficiencies and making sure that the body has all the nutrients it needs to function properly and to have the immune system fully powered up and to heal, are well documented. It is also well documented that a body suffering with a serious infection will have a much higher need for certain nutrients than a person that is healthy.

**How to begin this treatment:**
1. Follow step 1 and 2 as described in ‘Approach 2’ of this paper.

2. As soon as possible after starting the vitamin C IVs ask your doctor about also receiving a B vitamin complex by IV or injection and about starting to take a good quality multivitamin some vitamin E and A and an IV or IM or transdermal magnesium supplement plus some calcium. Some doctors may offer a ‘Myers’ cocktail’ which is an IV containing B vitamins, magnesium and calcium in particular amounts. This IV may be taken once or twice weekly or more (along with daily B vitamins etc. given orally each day).

The B vitamins have also recently become available in a liposomal delivery system. A liposomal B complex product is now available from Livon Labs and the product is called AGE blocker.

For more information on the Klenner protocol see: Dr. Klenner’s B vitamin (neurological disease) protocol and M.E.

Finding a qualified doctor is important. If you still cannot find a qualified doctor, buy your own (possibly sublingual and coenzyme) 50 mg B vitamin complex tablets (3 daily) or liposomal B complex product, plus a good quality multivitamin (containing adequate zinc and selenium), some vitamin E (in the dose described in the vitamin E paper) and A (5000 IU at least) and a magnesium supplement (600 mg or more, in transdermal or liquid form, ideally) and some calcium.

Liposomal glutathione may also be very beneficial at this time as it has a synergistic effect with vitamin C.

Also ask your doctor about also taking 500 mg of acetyl L carnitine or more (as it helps heal brain injuries) and at least 500 mg of carnitine, and 50 mg of CoQ10 as ubiquinol, some liposomal glutathione (the only form worth taking) and a good quality probiotic daily. A good quality probiotic may not just improve digestive health but may actually help to actively fight an enteroviral infection and so a case could be made for high-dose probiotics being taken in the early stages of M.E. in particular.

Additional vitamin B12 as hydroxycobalamin by injection or sublingual tablet can also be helpful. You may want to follow the entire HFME ‘Quick start guide’ – minus the Hawthorne and other symptomatic treatments. Your well-trained doctor may also have various other helpful suggestions for you, based on his or her own clinical experience and/or your individual test results. Make sure you research every
new treatment thoroughly before starting it, however, including checking the information available on HFME.

Benefits may be lost if this treatment is stopped too soon and so it should be continued as long as is necessary. Vitamin C should be kept at saturation level during this time. B vitamin IVs may only be necessary for the first 6 months (depending on the severity of the condition), whereupon the B complex vitamins can be taken orally several times daily instead. If your doctor has experience in giving vitamin C or B complex vitamins by IV they will most likely be able to guide you appropriately in these matters.

**Finding a doctor that can administer IV vitamin C**
Finding a doctor that is knowledgeable about M.E. specifically is extremely difficult. However, finding a doctor that can safely administer vitamin C (and other vitamins and nutrients) by IV or injection and that is experienced in treating diseases similar to M.E. (such as MS or Lupus etc.) is far less difficult. Use the phone book or the internet to ask various qualified holistic, nutritional, environmental, or orthomolecular medicine practitioners near you if they offer this therapy and if they are experienced in providing it.

If possible, find an expert in one of these fields (or more than one of them) that is also a qualified doctor so that you can also have any tests you may need.

For more information see: Finding a good doctor when you have M.E.

**Other general guidelines**
Eat as well as you can, avoiding sugar and processed foods. Avoid chemical additives in food as much as possible. Drink at least 2 litres of filtered water daily. Avoid toxic chemicals in personal care products and cleaning products as much as possible.

For some patients a detoxification regime involving FIR saunas may also be a necessary part of treatment. This is the case where the patient may have a lowered immunity to viruses due to high heavy metal levels. Various tests can be used to determine a patient’s heavy metal levels, and to identify other areas where the body isn’t functioning as well as it should or where nutrient deficiencies exist.

Again, the simple fact of avoiding overexertion alone would be enough to stop many newly ill people becoming as severely affected as patients such as myself. Give your body the rest it needs. Do not push yourself to do things that you are too ill to do without significant relapse. This step is absolutely VITAL. The sooner you rest properly and stop further bodily damage occurring the easier healing will be. Prevention is far easier than cure!

**Treatment cautions**
Before starting any of these treatments, please make sure to read the entirety of the HFME’s papers or sections on vitamin C and the B vitamins, etc. as well the ‘Important notes on using HFME’s treatment information’ paper. The books and articles listed in the reference section of the vitamin C paper are also highly recommended reading.

Which approach is best?
We know for sure that rest in the early stages of M.E. greatly improves the prognosis, and we know for sure that saturation-dose vitamin C can cure some viral diseases if they are treated aggressively in the early stages. But it is difficult to say which of these approaches or other approaches (or which combination of them) is best, as we simply do not have the research which would give us these answers for M.E.

My own opinion is that if it is at all possible the saturation-dose vitamin C regime should be tried as it carries no risk and has such a large chance of improving or even curing M.E. in the early stages.

Possibly the best way to treat M.E. is a combination of approaches one, two and three. That is what I would aim for if I were able to go back in time and treat my M.E. in the acute stages. I’d very strictly avoid overexertion, eat well, get Chia’s enteroviral testing done (and as much other relevant testing as possible), take saturation-dose vitamin C (which naturally and safely raises interferon levels) and some B vitamins by IV or IM and follow a full nutritional protocol.

While it's very easy to be clear about the basic facts and history of M.E. with just a bit of quality reading, the area of M.E. treatment is nowhere near as black and white. Even people that have read the same information may have very different ideas of how to implement it. Ideas on how M.E., and all diseases, should be treated varies hugely. Some support an orthomolecular approach as described in this paper, others prefer to stick with the mainstream drug-based and symptom-based approach, some patients favour a combination of these two approaches and others still see little point in any of the existing treatment options and consider any money spent on treating M.E. completely wasted. There are so many different and opposing opinions and even experts in each field disagree with each other. Patients must read as much as possible and make up their own minds.

What is really needed is new genuine M.E. research. Any new and genuine M.E. research not wasting time on vague ‘CFS’ or ‘ME/CFS’ patient groups would be welcome but anything that would help doctors effectively treat M.E. in the early stages and prevent a lifetime of severe disability would be especially welcome.

The problem is that even if we knew already how to treat M.E. in the early stages – and considering the effect of saturation dose vitamin C on various acute viral infections we may actually have a potential cure right now – M.E. patients would still suffer unnecessarily as so very few patients are correctly diagnosed with M.E. AT ALL currently, let alone diagnosed quickly.
M.E. can be quickly diagnosed right now, medically speaking. The reason this doesn’t happen is purely political. This means that no amount of extra M.E. research will change this terrible position, and certainly not any number of further ‘CFS’ and ‘ME/CFS’ studies doing little but muddying the waters even further and distracting patients desperate for anything that seems like good news from the real issues.

For more information on the political barriers facing M.E. patients, and all those misdiagnosed with ‘CFS’ that do not have M.E., please see: What is M.E.? and Who benefits from 'CFS' and 'ME/CFS'?

**Final comments**

It often takes M.E. patients many years to be diagnosed, if they can get a correct diagnosis at all. So very few patients receive any sort of appropriate early treatment.

We know that the earlier M.E. is treated, the better the outcome will be, but it is impossible to put exact dates on it or to give exact prediction of any kind about the degree of improvement. If M.E. could be treated with any or all of these protocols within a few weeks that would be wonderful and the chances of near or total recovery may be significant. A cure may even be possible.

This paper does not aim to provide the ‘last word’ in acute M.E. treatment, merely a place for people to begin their research. This is just the guide to treating M.E. in the acute stages that I wish I had had access to when I was first ill.

It is highly recommended that patients do as much extra reading as possible in order to come to their own conclusions and make their own choices.

The very best of luck, and the very best of health, to everyone reading.

**Notes on this text:**

- M.E. patients ill less than five years: Treating M.E. aggressively as described in this paper within 1 - 2 years of onset may also produce exciting results, depending on how much the patient has overexerted themselves in that time etc. It is impossible to say for certain as yet. Generally the 5 year mark is quoted as being when M.E. becomes far more difficult to improve, although this may be partly because patients misdiagnosed with M.E. will often improve and recover within 5 years (such as those with various PVFS).

  If you’ve been ill 2 years or less it seems there is probably real cause for hope. The same may even be true for those ill less than 5 years. Either way if you’re in either of those positions you are just not facing the same uphill battle that those who have been very ill for 10 years or more are, which is great news for you. You have a real chance at getting a good part of your life back so you need to grab at this chance with both hands as soon as possible!
• Long-term M.E. patients: There is real hope for improvement at all stages of M.E., or at least stabilisation, with the correct treatment. Treatment is far more difficult in long-term and very severe cases than with the newly ill, but can still make an absolutely enormous difference to quality of life and the severity of the disease as well as to cancer risk and so on.

  None of us with M.E. is completely powerless as regards significantly improving our condition, and that is a fact! While it is true that we don’t have anything like a cure for severely affected long-term patients, some real improvements can be made. A 10%, 20% or 30% improvement may not seem like much, but can make a big difference to the life of someone with severe M.E.

  Approach 3 as recommended for those in the early stages of M.E. can still be very helpful in long-term M.E., and is recommended, although the doses may have to be raised far more slowly due to more severe supplement tolerance issues and each supplement may be better off being introduced individually rather than all at once.

  When M.E. is long term treatments must not just fight the initial viral infection, but help the body heal the damage caused by the virus and the deficiencies and other issues caused by the virus – a far more difficult task.

• Children with M.E.: The treatments recommended in Approach 3 for adults with M.E. are the same as are recommended for children with M.E. EXCEPT the dosages must be lowered depending on the size and age of the child. Many doctors recommend giving seriously ill children vitamin C to bowel tolerance and this is recognised as safe. See the books listed in the various references sections for information on how to calculate dosages for children (for example, the ‘Fire your Doctor’ book).

  If you have a child that has M.E., fight as hard as you can for them to be quickly diagnosed, tested and treated and to prevent them from overexerting. Some adults have no choice but to overexert, but children have a much better chance of getting the rest they need and having a more positive outcome, if they have a parent willing to really fight for them and their rights. When a child has M.E. is NOT the time to take a doctor’s ignorance or recommendation of inappropriate psychological therapies or ‘no’ as the final answer. Keep searching for a good doctor for your child if you don’t yet have one.

• Dr Klenner’s protocol for poliomyelitis. For polio Dr Klenner recommends ascorbic acid given intravenously at 300 to 500 mg per kg of weight (or oral vitamin C to bowel tolerance if this is all that is available), muscle massage, plus thiamin 100 to 250 mg a day for three months afterwards to help rehabilitate the nerves.

• Dr Klenner’s protocol for Multiple Sclerosis, Myasthenia Gravis and other neurological diseases. Dr Klenner notes that ‘Early M.S. cases will respond quickly’ and cites examples where the protocol has taken 2 weeks to work in some early cases, and 5 years or more of constant treatment to be effective in longer-term cases. One paper makes the statement that it may take a year of treatment for every two years spent ill with MS for the full benefits of treatment to be seen. (He also notes that a cut-down version of his treatment protocol may also work but
that it may take much longer and not be effective in some cases.) He says: “Any victim of Multiple Sclerosis who will dramatically flush with the use of nicotinic acid and has not yet progressed to the stage of myelin degeneration, as witnessed by sustained ankle clonus, can be cured with the adequate employment of thiamin, B complex proteins, lipids and carbohydrates. We had patients in wheelchairs who returned to normal activities after five to eight years of treatment.”

For more information on this program see the paper: Dr. Klenner’s B vitamin (neurological disease) protocol and M.E.

References
For references see the main ‘Treating M.E.’ paper, the ‘Quick start’ paper plus the HFME’s papers on the B vitamins, vitamin C, vitamin E, magnesium (and calcium), ubiquinol and carnitine. The main references are as follows:

- Clinical Guide to the Use of Vitamin C The Clinical Experiences of Frederick R. Klenner, M.D. and Response of Peripheral and Central Nerve Pathology to Mega-Doses of the Vitamin B-Complex and Other Metabolites and Observations On the Dose and Administration of Ascorbic Acid When Employed Beyond the Range Of A Vitamin In Human Pathology by Dr Klenner.
- The Klenner Protocol for MS article by Dr Klenner. In this two-part series Klenner defines an orthomolecular treatment of MS that has been effectively employed by Dale Humpherys and other patients. (For Humpherys' report, see his article in the December 2005 issue of the Townsend Letter.)
- My Multiple Sclerosis: A Real Story presented by Homer. For more information on following the Klenner protocol for MS, including case studies and detailed practical information on the nutrients involved and where to source them, this site is highly recommended.
- Intravenous nutrient therapy: the ”Myers' cocktail in Alternative Medicine Review, Oct, 2002 by Alan R. Gaby (PubMed link) This article includes instructions for doctors on administering the Myers’ cocktail.
- VITAMIN C, TITRATING TO BOWEL TOLERANCE, ANASCORBEMIA, AND ACUTE INDUCED SCURVY and The Ascorbate Effect in Infectious and Autoimmune Diseases by Robert F. Cathcart, M.D.
- Ascorbate: The Science of Vitamin C by Dr. Hickey and Dr. Roberts.
- VITAMIN C: The Real Story by Steve Hickey, PhD and Andrew Saul.
- Orthomolecular Medicine For Everyone: Megavitamin Therapeutics for Families and Physicians by Abram Hoffer.
- Dr Atkins Vita-Nutrient Solution: Nature's Answer to Drugs
- Fire your doctor! : how to be independently healthy by Andrew W. Saul.
- The healing factor: Vitamin C against disease by Irwin Stone.
- How to live longer and feel better by Linus Pauling.

Klenner protocol references are available in the paper: Dr. Klenner’s B vitamin (neurological disease) protocol and M.E.

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**Relevant quotes**

“Intravenous administration of nutrients can achieve serum concentrations not obtainable with oral, or even intramuscular (IM), administration. For example, as the oral dose of vitamin C is increased progressively, the serum concentration of ascorbate tends to approach an upper limit, as a result of both saturation of gastrointestinal absorption and a sharp increase in renal clearance of the vitamin. The highest serum vitamin C level reported after oral administration of pharmacological doses of the vitamin is 9.3 mg/dL. In contrast, IV administration of 50 g/day of vitamin C resulted in a mean peak plasma level of 80 mg/dL. Similarly, oral supplementation with magnesium results in little or no change in serum magnesium concentrations, whereas IV administration can double or triple the serum levels, at least for a short period of time.

Various nutrients have been shown to exert pharmacological effects, which are in many cases dependent on the concentration of the nutrient. For example, an antiviral effect of vitamin C has been demonstrated at a concentration of 10-15 mg/dL, a level achievable with IV but not oral therapy.” Intravenous nutrient therapy: the "Myers' cocktail" in Alternative Medicine Review, Oct, 2002 by Alan R. Gaby

“All ingredients are drawn into one syringe, and 8-20 mL of sterile water (occasionally more) is added to reduce the hypertonicity of the solution. After gently mixing by turning the syringe a few times, the solution is administered slowly, usually over a period of 5-15 minutes (depending on the doses of minerals used and on individual tolerance), through a 25G butterfly needle. Occasionally, smaller or larger doses than those listed in Table 1 have been used. Low doses are often given to elderly or frail patients, and to those with hypotension. Doses for children are lower than those listed, and are reduced roughly in proportion to body weight. The most commonly used regimen has been 4 mL magnesium, 2 mL calcium, 1 mL each of B12 (as hydroxycobalamin), B6, B5, and B complex, 6 mL vitamin C, and 8 mL sterile water.” Intravenous nutrient therapy: the "Myers' cocktail" in Alternative Medicine Review, Oct, 2002 by Alan R. Gaby

“This treatment works so dramatically in Myasthenia Gravis, that should a given patient’s physician refuse to administer this schedule, I have this recommendation: One gram thiamin hydrochloride one hour before meals and at bed hour, and during the night if awake. Niacin taken at the same time, and in amounts sufficient to
produce a good body flush. Two hundred mg. calcium pantothenate and 100mg pyridoxine before meals and at bed hour. Ten grams ascorbic acid, taken in divided doses. Naturally, the full schedule will afford more dramatic response.” Frederick Klenner M.D.

“The Myers' often produces a sensation of heat, particularly with large doses or rapid administration. This effect appears to be due primarily to the magnesium, although rapid injections of calcium have been reported to produce a similar effect. Too rapid administration of magnesium can cause hypotension, which can lead to lightheadedness or even syncope. Patients receiving a Myers' should be advised to report the onset of excessive heat (which can be a harbinger of hypotension) or lightheadedness. If either of these symptoms occurs, the infusion should be stopped temporarily and not resumed until the symptoms have resolved (usually after 10-30 seconds). Patients with low blood pressure tend to tolerate less magnesium than do patients with normal blood pressure or hypertension. For elderly or frail individuals, it may be advisable to start with lower doses than those listed. When administered with caution and respect, the Myers' has been generally well tolerated, and no serious adverse reactions have been encountered with approximately 15,000 treatments. In 1995, the author's last year in private practice, the cost of the materials for a Myers' was approximately $5.00. The use of preservative-free nutrients at least doubled the cost of materials. Nursing time and administrative factors represented the majority of the cost of IV nutrient therapy. In 1995, the author's fee for a Myers' was $38.00. Other doctors have charged as little as $15.00 or as much as $100.00 or more. Since 1995, the cost of most of the injectable preparations has increased by 50-100 percent.” Intravenous nutrient therapy: the "Myers' cocktail" in Alternative Medicine Review, Oct, 2002 by Alan R. Gaby

“The early papers by Dr. Fred R. Klenner provide much information about the use of large doses of Vitamin C in preventing and treating many diseases. These papers are still important.” Linus Pauling, Ph.D.

Disclaimer: HFME does not dispense medical advice or recommend treatment, and assumes no responsibility for treatments undertaken by visitors to the site. It is a resource providing information for education, research and advocacy only. In no way does reading this site replace the need for an evaluation of your entire health history from a physician. Please consult your own health-care provider regarding any medical issues relating to the diagnosis or treatment of any medical condition.
A number of tests are available privately that can help you and your doctor learn more about how best to treat your illness and how it has affected your body, and just as importantly; which treatments to avoid.

These tests are not at all useful for the diagnosis of M.E. and abnormalities in these tests are seen in many different illnesses. They are to help with determining treatment only.

While some of these tests can be organised without the aid of a doctor, some do require a doctor’s permission. Also, you really do need the help of a qualified doctor to help interpret the results of many of these tests, if at all possible. Some tests can be done entirely by post, while others unfortunately require visits to blood drawing centres or your doctor’s offices.

The following list includes some of the tests that may be useful in some way, listed in alphabetical order.

- **AA/EPA ratio tests.** “The AA:EPA ratio is a measure of the pro-inflammatory potential of your cells. The higher the ratio, the greater the amount of silent inflammation you have.”

- **Amino acid testing.** “The Amino Acids Urine Test provide different views into body function and can be utilized by the medical practitioner for different purposes. Urine amino acids are discarded by the body as excess, or “wasted” because of kidney malfunction or nutritional imbalance. Amino acids play a role in many other body functions as well, including neurotransmitter functioning, cholesterol and carbohydrate metabolism, and detoxification processes.”

- **Biochemical antioxidant profile test.** “This test may be useful if problems absorbing vitamin E are suspected as this test measures the levels of beta carotene, vitamin A and vitamin E in the blood (and how well antioxidant enzyme systems are functioning). In all, nine measures of antioxidant status are measured, giving a comprehensive indication of your antioxidant status. There is also the new less expensive and ‘TRAP’ test (total reactive antioxidant potential). This will indicate if there’s an antioxidant problem but doesn’t define which nutrients are missing.”

- **Blood type test.**

- **C reactive protein test.**
• Candida Antibodies (IgG, IgA, IgM) and Candida Antigen testing.
• Celiac Profile testing.
• Cell-free DNA in blood plasma test. This test measures cell degeneration. Low levels are found in healthy people, and increases are associated with serious disease (eg. M.E., cancer, stroke, etc.). Cell degeneration is one measure of how ill you are, but most/all people with M.E. will have increased cell degeneration, so it's not clear whether this test is necessary. Similarly, C-Reactive Protein tests measure the total amount of inflammation within the body. This will likely be high in M.E., but also in many different diseases.
• Comprehensive Detoxification Profile: This test analyses saliva, blood, and urine after challenge doses of caffeine, aspirin, and acetaminophen, to assess phase I and phase II functional capacity of the liver to convert and clear toxic substances from the body. This profile includes markers for oxidative stress and important antioxidants.
• Comprehensive digestive stool analysis. “The Comprehensive Stool Analysis detects the presence of pathogenic microorganisms such as yeast, parasites, and bacteria which contribute to chronic illness and neurological dysfunction. It provides helpful information about prescription and natural products effective against specific microorganism strains detected in the sample. The test also evaluates beneficial bacteria levels, intestinal immune function, overall intestinal health (presence of occult blood, short chain fatty acids analysis, pH, and mucus) and inflammation markers.”
• Comprehensive Parasitology.
• Detoxification Profile Testing: This test analyses saliva and urine after challenge doses of caffeine, aspirin, and acetaminophen, to assess phase I and phase II functional capacity of the liver to convert and clear toxic substances from the body. It can be a very useful test to have before beginning a detoxification program.
• DetoxiGenomic Profile: This test evaluates SNPs associated with increased risk of impaired detoxification capacity especially when exposed to environmental toxins. It also identifies individuals potentially susceptible to adverse drug reactions.
• Fatty acid analysis. “The Comprehensive Fatty Acids Test report includes 30 markers and total levels of saturated, monounsaturated, polyunsaturated, omega 3, omega 6, and fatty acids. The primary reason for this test is to determine if levels of essential fatty acids and other beneficial fatty acids are adequate. Additionally, peroxisomal and mitochondrial disorders of fatty acid metabolism can be determined. *This test is available only in the US and Canada. (The Essential Fatty Acids Test includes 17 markers, including levels of nutritionally important omega 3, omega 6, omega 9 fatty acids and saturated fatty acids.)”
Genomic testing. This is relevant to methylation problems and how appropriate the Yasko protocol might be for you. Although as this test is so extremely expensive, some suggest trying the protocol and just seeing if it works for you. It includes a stone age diet, a good multi-vitamin and mineral supplement with no copper or iron in it, essential fatty acids, vitamins C and D, D-ribose, CoQ10, Acetyl L-Carnitine, NAD, Phosphatidyl serine complex, probiotics, and help for methylation with 2 - 5mg of B12 daily as hydroxocobalamin and 200 - 800mg folic acid as methyltetrahydrofolate although M.E. patients in particular need to start at much, much lower doses and may only ever be able to tolerate far lower doses than this as we have significantly more problems and more severe illness than many other patients that this protocol is specifically designed for. (Note that Dr Cheney has recently said that Methyl B12, Folapro and D-Ribose as recommended by Dr Yasko, are not appropriate for M.E. patients and will make them sicker. He has also said that while there is a methylation block in M.E. patients, this is protective in M.E. and so trying to treat it may be counterproductive.) Methylation problems are just one of many in M.E. This also means that we are unlikely to experience the same miraculous results as those on the protocol that do have primarily methylation related illnesses (which may be misdiagnosed as ‘CFS’). M.E. is far more complex than this unfortunately.

Glutathione test. “Glutathione combines with selenium to form glutathione peroxidase to form a powerful antioxidant in the cell. The production of glutathione is the way our cells counter-balance all of the oxidative stress which occurs during normal cellular metabolism. Glutathione is also perhaps the major regulator of the release of metals, especially zinc. Reduced glutathione (GSH) mediates the transfer of zinc. Conversely, oxidized glutathione (GSSG) releases zinc to be transferred to enzymes. Glutathione has also shown to detoxify heavy metals such as cadmium, mercury, arsenic, and many other toxic organic chemicals such as benzene.”

Hair elements tests or hair mineral analysis. An easy and useful hair test which tests for heavy metals such as mercury as well as the levels of various trace minerals. Remember that this test does NOT in any way indicate the body’s total load of mercury or other heavy metals in the body. It is a hair test and it shows how much of each mineral is contained in the hair. During detoxification regimes which mobilise heavy metals, more heavy metals may appear in the hair, for example. This is a good sign as it means that your heavy metal burden is being lowered. There are several other complexities when it comes to reading and interpreting hair tests also. They should not always be taken at face value and they require proper interpretation. For more information see Dr L. Wilson’s book on hair mineral analysis.

HEMEX blood clotting tests and Homocysteine blood tests (link 2)

Hepatic Detox Profile. “Assessment of status phase l and phase ll detoxification. Assessment of chemical exposure and impaired liver function.”

IgE Inhalant Allergy Advanced Test

IgG (ELISA) food allergy tests test for around 100 different IgG food
allergies. Tests must be quantitative; they must tell you not just that you have a certain allergy, but how severe it is also. (The IgG/IgE test offered by US company VRP is around half the price of the one offered by York Labs in the UK.) There is also the ALCAT - Food Allergy & Chemical Sensitivity/Intolerance Test.

- **Immune Deficiency Profile**
- **ION tests from MetaMetrix.** The Metametrix ION (Individual•Optimal•Nutrition) Profile is a combination of analyses that measures levels of organic acids, fatty acids, amino acids, vitamins, minerals, and antioxidants.
- **Leaky gut test (intestinal permeability).** “This test is a powerful and non-invasive assessment of small intestinal absorption and barrier function in the bowel. This test analyzes urine for the clearance of two non-metabolized sugars, lactulose and mannitol. The Intestinal Permeability Assessment directly measures the ability of two nonmetabolized sugar molecules mannitol and lactuloseto permeate the intestinal mucosa. Mannitol is easily absorbed and serves as a marker of transcellular uptake, while lactulose is only slightly absorbed and serves as a marker for mucosal integrity. To perform the test, the patient mixes premeasured amounts of lactulose and mannitol and drinks the challenge substance. The test measures the amount of lactulose and mannitol recovered in a urine sample over the next 6 hours. This test identifies Leaky Gut and malabsorption.”
- **Live Blood Microscopy and the Dried Layer Blood Test.**
- **Metabolic Panel, Comprehensive.** The Comprehensive Metabolic Panel (14) checks your body’s metabolism. It can identify metabolic deficiencies and imbalances and tell you if you need to add certain dietary supplements.”
- **Oxidative Stress Analysis, Blood & Urine:** This test identifies markers of hydroxyl radical activity, urine lipid peroxides, reduced glutathione, superoxide dismutase, and glutathione peroxidase, following a challenge dose of aspirin and acetaminophen.
- **Ph test strips.** Urine or saliva pH test strips are available from VRP and iHerb.
- **Purged parasites test.** This test induces loose stools to check the digestive tract for parasites. It is a stoll sample test.
- **Quantitative H. Pylori antibodies test.**
- **SMAC test.** “This test is a useful combination of electrolyte, kidney profile, and liver profile data. Additional tests found in the SMAC-25 (tests can differ from lab to lab) screen for levels of calcium, magnesium, phosphate, cholesterol, triglycerides, and others.”
- **SpectraCell.** This blood test can identify missing vitamins and minerals for targeted nutritional replacement.
- **Superoxide Dismutase (SOD) Assay.** “Superoxide dismutase (SOD) is one of the most important antioxidative enzymes. It catalyzes the dismutation of the superoxide anion into hydrogen peroxide and molecular oxygen. The sensitive
SOD assay kit utilizes WST-1 that produces a water-soluble formazan dye upon reduction with superoxide anion. The rate of the reduction with a superoxide anion is linearly related to the xanthine oxidase (XO) activity, and is inhibited by SOD (see below). Therefore, the inhibition activity of SOD can be determined by a colorimetric method.”

- **The Nutrition and Vitamins Panel.** “The Nutrition and Vitamins Panel is comprised of the following tests: Metabolic Panel Vitamin A, E, and Beta Carotene Profile Vitamin B1, Blood Vitamin B6, Plasma Vitamin B12 and Folates Vitamin C Vitamin D, 25-Hydroxy Vitamin E, Serum Nutrition & Vitamins Panel is a complex analysis of your vitamin and nutritional status, coupled with a check of your body’s metabolism.”

- **Thermography testing.** This test can help identify sites of inflammation, pain and cancers.

- **Urinary organic acids test.** “The Organic Acids Test (OAT) provides a metabolic “snapshot” based on the products the body discards through the urine. These small, discarded organic acid molecules are byproducts of human cellular activity, the digestion of foods, and the metabolism of gastrointestinal flora. At certain levels, organic acids in urine may be indicators of toxicity or “markers” of metabolic pathways. Metabolites of yeast or gastrointestinal bacteria appear against the background of normal human metabolites and provide an assessment of yeast and bacterial activity.”

- **Urine toxic metals test.** “Urine toxic and essential elements analysis is an invaluable tool for the assessment of retention of toxic metals in the body and the status of essential nutrient elements. Toxic metals do not have any useful physiological function, adversely affect almost every organ system and disrupt the homeostasis of nutrient elements.”

- **Vitamin D test/ 25(OH)D test.** This test is available through your doctor and also from the Vitamin D Council and other organisations without a doctor’s permission. The Vitamin D council test can be done by post.

- **Water quality testing.** This test analyses the contaminants in your drinking water.

- **Yeast Culture w/ Sensitivity Test.** “We have frequently found that some children or adults may not adequately respond to antifungal treatment. In some cases, this response failure may be due to the use of inappropriate antifungal treatment. This stool testing for common yeast includes sensitivity to both drugs and natural products.”

- **Zinc taste test.** This very simple test can be done in-office by most nutritionally trained doctors. A very inexpensive test kit is also now available from VRP.

**Places to source tests include:**
- Genova (formerly ‘Great Smokies Labs’) (US but has agents in many other countries. Their UK agent is Individual WellBeing Diagnostic Laboratories.)
• ImmunoSciences Labs, Inc.(US)
• The Great Plains Laboratory, Inc.
• BioLabs(UK)
• Metametrix Clinical Laboratory (US)
• Doctor’s Data is an online company in the US which sells test kits which can be done at home and then mailed in.
• Life Extension foundation sells tests to US patients only and only those who can get to blood drawing centres.
• VRP is an online company in the US which sells test kits which can be done at home and then mailed in.
• York Labs is an online company in the UK which sells test kits which can be done at home and then mailed in.
• Holistic Heal is an online company in the US which sells test kits which can be done at home and then mailed in.
• Australian Biologics and ARL Pathology provide tests for Australian patients.
• Dr Chia in the US offers a number of different enteroviral tests.

More information on which tests to have and when, and how to interpret the results
Tests require correct interpretation by a skilled practitioner if they are to be of any use. A qualified orthomolecular, environmental or holistic medicine practitioner that is also a doctor is the best person to advise you on which tests to have and what they mean.

Books that contain excellent information on this type of testing include:
• No More Heartburn: The Safe, Effective Way to Prevent and Heal Chronic Gastrointestinal Disorders by Dr Sherry A. Rogers. This book has excellent information on the tests involved with Candida and a leaky gut as well as some of the vitamin and mineral and fatty acid profiles. It explains which tests to get done and why they may or may not be necessary, and also explains how to interpret the results.
• Detoxify or Die by Dr Sherry A. Rogers. This book has excellent information on the tests involved with detoxification as well as some of the vitamin and mineral and fatty acid profiles. **Dr Rogers recommends the Cardio ION to everyone that is very ill, and can afford this very comprehensive series of tests.**
• Nutritional Balancing and Hair Mineral Analysis by Dr. Lawrence D. Wilson
• Hair Test Interpretation: Finding Hidden Toxicities by Andrew Hall Cutler. (Note that I have not personally evaluated this book).
• The Optimum Nutrition Bible by Patrick Holford.
• Laboratory Evaluations in Modern Medicine or Laboratory Evaluations for Integrative and Functional Medicine. An essential book for doctors. “Your
For more information on tests see also the following website (‘CFS’ information aside), the EI resource site and Dr Lawrence Wilson’s website, plus the Doctor’s Data Website.

**Further notes on health tests**

- Tests of immune function may be useful in letting you know how well an immune system supporting treatment is working, these include tests of NK cell levels and NK cell cytotoxicity, T lymphocytes and circulating cytokines. These are tests that are available only through your doctor.

- Mitochondrial tests are not included on this list as every M.E. patient has significant mitochondrial abnormalities and would benefit from taking some type of mitochondrial support supplements. (It is also true that patients with many different diseases misdiagnosed as ‘CFS’ will have some level of mitochondrial abnormalities – as Dr Myhill’s work shows – and so positive tests for mitochondrial abnormalities cannot be used to prove an M.E. diagnosis. Dr Myhill unfortunately (and bizarrely, considering her obvious exposure to legitimate research and genuine M.E. patients) makes little if any distinction between various unrelated ‘fatigue’ patients misdiagnosed as ‘CFS’ and genuine M.E. patients – to the detriment of both patient groups.)

- XMRV tests are in no way recommended. For information see: XMRV, 'CFS' and M.E.

- Applied Kinesiological Testing is a type of muscle testing involving biofeedback which is practiced by some health professionals to help determine the best treatment options for a patient. For more information see: Many Uses of Muscle Testing and What is Kinesiology & Muscle Testing?

- Blood pressure and pulse readings can be taken at home and can be useful in determining the level of overexertion experienced and when to stop a task and rest, and so on. For more information see: Testing for M.E.: Plan D

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evidence-based resource for the biochemical basis of chronic illness. A must-have desk reference for laboratory testing associated with nutritional and metabolic medicine.”
Section 6: Treatments for particular M.E. symptoms and problems
Treating M.E.: The basics

www.hfme.org

Treatments for particular M.E. symptoms and problems

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FROM WWW.HFME.ORG

1. Testing for and treating low thyroid and adrenal output
2. Changed immunity to cold and flu bugs (and other infections) in M.E. over time
3. The importance of daily bowel movements and treating constipation in M.E.
4. Treating the mitochondrial dysfunction of M.E.
5. Resetting circadian rhythms and the reversed sleep/wake cycle seen in M.E.
6. Improving sleep
7. Treating chronic pain
8. Treating the low level seizures and ‘sensory storms’ seen in M.E. (plus, the benefits of medicinal marijuana for seizures and pain in M.E.)
9. Dealing with noise sensitivity
10. Treatments for improving a ‘leaky’ gut
11. Lowering homocysteine levels
12. Improving blood sugar control and hypoglycaemia
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27. Can I or should I still donate blood if I have M.E.?
28. Am I at a greater risk of contracting cancer because I have M.E.?
29. I’m overwhelmed trying to work out which supplement brands to buy, can you help?
30. I’m having one of those days where I just don’t want to take any more supplements, what should I do?
31. Notes on applying for the appropriate/necessary benefits/welfare/disability support
To read about why focusing primarily on symptomatic treatments is not the best way to go, see the thought provoking article: DEEP HEALING VERSUS SYMPTOM REMOVAL by Lawrence Wilson MD or read the new HFME paper: Symptom-based management vs. deep healing in M.E.

1. Testing for and treating low thyroid and adrenal output in M.E.
For information on thyroid and adrenal issues, please see the Adrenal and thyroid issues and M.E. paper.

2. Changed immunity to cold and flu bugs (and other infections) in M.E. over time
Right after the onset of M.E. the patient seems to get every single bug going around. A little bit later on, in the acute/severest stages of M.E. (which often persists for a number of years or perhaps decades) patients often find that their immune system is so hyper-responsive that they do not get any cold or flu bugs at all during this time. Finally starting to get these infections again in M.E. is acknowledged to be a sign that the illness is improving overall. It’s a very, very positive sign.

For information on preventing and treating colds and flu and why flu drugs and vaccinations are not a good idea, please see the ‘Colds and flu and M.E.’ paper.

3. The importance of daily bowel movements and treating constipation in M.E.
It is extremely important for M.E. patients to have at least 2 bowel movements daily. The longer the transit time between food being eaten and the wastes being expelled, the more chance there is for the food to ferment and for the toxic load of the liver to be increased. This can make you feel very ill and cause a number of other serious problems.

For many patients, finding the diet that is right for you and which avoids your food intolerances and allergies, treating Candida and Leaky Gut Syndrome will help to normalise bowel movements. But when this isn’t effective, it may be necessary to do a daily vitamin C or magnesium flush to get your two daily bowel movements.

According to Dr Sherry Rogers, to do a vitamin C flush, take ½ to 1 teaspoon of vitamin C power in water every hour, until you have a bowel movement. Then, cut back your daily dose to the point where you have 2 normal bowel movements daily.

To do a magnesium flush, take ½ to 1 teaspoon of magnesium oil in water each day and very slowly increase your dosage until you have a bowel movement. Then, cut back your daily dose to the point where you have 2 normal bowel movements daily. Too much magnesium can cause heart problems and so the vitamin C flush should probably be the first choice here.

To speed up transit time and improve liver health even further, whether suffering from constipation or not, it may also be a good idea to look into coffee enemas for...
detoxification. For more information on this therapy see the ‘Enemas for detoxification in M.E.’ paper. Poor thyroid function can also be a cause of constipation.

4. Treating the mitochondrial dysfunction of M.E.
A large body of research spanning many decades has unequivocally implicated mitochondrial dysfunction as an essential/core feature of M.E. Mitochondrial problems, or the cardiac insufficiency it causes, are the cause of most M.E. symptoms. Mitochondrial (or krebs cycle) supports are a useful treatment for M.E. (including some of the cardiac and cognitive problems of M.E.).

Dosages given here are for adults, and are only a rough guide. (Note that while some patients may experience some benefit at lower doses, some of us need high doses of some of the mitochondrial supports to really get the full effect. This applies most of all to CoQ10 and Carnitine; some of us do best on 2 -3 g of Carnitine and find we need 300-400 mg of ubiquinol CoQ10.) To learn more about the mitochondrial defects in M.E. (including more information on dosages) see: United Mitochondrial Disease Foundation (see the treatments page) and the Dr Cheney page. To see some of the abundance of M.E. mitochondrial research available see Mitochondrial Muscle Research. (Note that some doctors prefer to prescribe injections of magnesium rather than oral supplements; see the section below for a warning about the administration of very high doses of oral or injectable magnesium.)

Coenzyme-A (CoA) is the most active metabolic enzyme in the body - that triggers so many metabolic processes. CoA is the vital catalyst needed to utilise Co-Q10, NADH and other energy producing metabolic enzymes. CoA is also a potent natural detoxifier, can aid in treating Candida infections, and allows the adrenals to produce more cortisol. CoA levels are raised by taking precursors such as pantethine.

5. Resetting circadian rhythms and the reversed sleep/wake cycle seen in M.E.
The reversed sleep/wake cycle common in M.E. may be treated with nightly melatonin. Dosages usually range from 300 mcg, to 3 mg. Start at a low dose and work up slowly only if you need to.

Evidence indicates methylcobalamin B12 has some metabolic and therapeutic applications not shared by the other forms of vitamin B12. MB12 has also been shown to help reset the sleep/wake cycle. M.E. patients are not recommended to ever take methyl B12 at high doses due to toxicity concerns, however low doses of up to 1mg daily (taken on waking) may be well tolerated and may be necessary to reset the sleep/wake cycle, along with melatonin. However, M.E. patients often have set highs and lows of symptoms and abilities throughout the day, and sometimes MB12 can work too well to reset circadian rhythms; leaving the patient waking at too early a time where they are too unwell to cope with wakefulness and suffer increased symptom severity and vulnerability to relapse from overexertion. Problems which
would be avoided if the patient could wake only a few hours later. MB12 may also work so ‘well’ that overall sleep duration is reduced, which would be undesirable. If either problem occurs, the MB12 should be discontinued until the effect wears off, and then restarted at a reduced dose. Through trial and error, it should be possible to work out the dosage needed to achieve the desired sleeping and waking time. This may be as low as 0.5 mg weekly or even fortnightly or monthly. Taking the MB12 intermittently (on and off) rather than at a set dose every day/week etc. may also be necessary.

(Note that if you are taking hydroxocobalamin B12, it is possible that you may not need to also take MB12, as HB12 may be readily converted into the coenzyme forms of B12 – methylcobalamin and dibencozide – by the body. Most studies looking at resetting circadian rhythms have used MB12 however and so it is unclear whether or not this form may be needed in addition to HB12 for this purpose. It is possible that HB12 is all that is needed, but some evidence suggests that the conversion is very inefficient and so not very much HB12 is converted to MB12, so you may still need both. If you are absolutely desperate to reset your sleep/wake cycle urgently, you may prefer to take the safer bet of a small dose of MB12 rather than relying on HB12.)

Light exposure in the morning can also be helpful although very few M.E. patients will be able to tolerate this, unfortunately, due to photophobia and seizure issues.

Additional notes: ‘Benzo’ drugs may reduce melatonin and NSAIDS suppress melatonin. B12 deficiencies have been shown to suppress melatonin production. Deficiencies of magnesium, B1 and B6 may also reduce melatonin levels since these nutrients are essential in activating the enzymes that facilitate production of serotonin and melatonin. A warm bath before bed raises melatonin slightly. This information is taken from the references listed in the main vitamin B paper. Dr Dowsett’s Special Feature on sleep problems may also be useful to read.

6. Improving sleep
Vitamin B12, magnesium and CoQ10 (ubiquinol) can have a remarkable and very positive effect on sleep initiation and quality. Ashwagandha, L-tryptophan and inositol (at a dose of 1 – 2 g) can also greatly improve sleep and let you go to sleep more easily. Niacin taken at night can also improve sleep.

7. Treating chronic pain
Pain can be minimised by making sure your vitamin D levels are optimal, avoiding overexertion, avoiding foods from the nightshade family (and all other foods you react to, or that are inflammatory) and by taking 20 grams or more of vitamin C per day plus adequate magnesium. Other substances that may be helpful include curcumin, medicinal marijuana, fish oil and Octacosanol. Stretching, heat packs and massage may also be helpful. It is also important to make sure you have a good quality bed that provides the proper support.
It is important to try these very safe options and to try to treat the possible cause of the pain with these vitamin ins and supplements before moving on to medications with serious side-effects. If serious pain still persists, however, opiate-based pain medication may be something you need to look into.

8. Treating the low level seizures and ‘sensory storms’ seen in M.E.
Seizures are a big problem in M.E. Many patients will suffer absence seizures (petit mal seizures), myoclonic seizures (or jerks) and other types of conscious seizures or ‘sensory storms’ due to noise and light exposure and mental overstimulation and so on. The first part of treating these seizures is avoiding overstimulation and overexertion as much as possible. Secondly, improving seizures involves improving/treating the M.E. itself, so things like mitochondrial supports, vitamin C and B12 and so on, all those supplements which can improve function generally, will also help reduce seizures.

The book by Verillo and Gellman says, in the section on seizures, that you can sometimes stop a seizure from happening if you can withdraw from stimulation and get the brain into a meditative state very quickly as soon as you start to feel it coming on, as seizures don't happen during alpha brain wave states which occur during meditation. Seizures occur during theta or beta brain wave states only. It is hard to know how practical this advice is for those with M.E. who may have great difficulty meditating but it may at least be worth a try. (This may only work where there is an obvious trigger such as excessive television or light exposure etc. They also say to avoid neurotoxins in food, in pesticides and cleaning products etc. and that the drug Wellbutrin should also be avoided by those suffering seizures. Nutritional supplements which may be helpful in reducing seizures include magnesium, taurine, vitamin B6, manganese and zinc and possibly also small doses of GABA. Drugs which may help according to this book include Klonopin and Diamox (although these drugs may cause other problems and are not recommended by some).

Diet is also very important, foods containing MSG for example excite the neurons and increase neurological overstimulation. So avoiding MSG and aspartame is very important, as well as the aforementioned pesticides etc. Sage should also be avoided, along with DMAE. Some M.E. patients recommend the drug Neurontin as being very helpful in reducing seizures and neurological overstimulation generally. Please see the warning on this drug below, however, before use. Another drug which may be useful in reducing seizures is Piracetam, see below for details. (Piracetam is a derivative of the amino acid GABA.)

Some patients with M.E. will experience grand mal seizures. If this occurs, please see a neurologist if at all possible. General treatments for grand mal seizures may be needed, but make sure to start at very doses to make sure the drug will be well tolerated.

The benefits of medicinal marijuana for seizures and pain in M.E.
A controversial treatment for reducing seizures and "excitatory neurotoxicity," and one not widely available (unless you are in California, Canada or Holland etc.) is medicinal marijuana. This drug has many side effects however (it may trigger mental illness in susceptible individuals and may interfere with memory in the short-term), so extensive research and weighing of the risks and benefits is recommended before use. This drug should only be used by adults, as it may cause long-term problems with memory and learning in the growing brain which do not occur in adult brains.

Medicinal marijuana may be useful for: pain relief, relief from nausea, increased appetite, sleep initiation, as a general relaxant and muscle relaxant, reduction or cessation of tremors and repetitive shaking, it may help remove neurological ‘blocks’ to starting or continuing activities, and may help balance the immune system (and reduce hyper-active immune responses). If possible, vaporizing the drug is healthier than smoking it. The drug may also be eaten in food, but as dosage cannot be precisely controlled and the effects last 12 hours or more this will likely be undesirable. Medicinal marijuana is often used effectively in cancer, HIV/AIDS and also other neurological and muscular diseases such as Multiple Sclerosis. For more information on risks, benefits and legal issues you may wish to view the excellent 2009 BBC documentary ‘Cannabis: The evil weed?’ on YouTube.

9. Dealing with noise sensitivity

This can be one of the very worst symptoms of M.E. The pain can be indescribable. To some extent this problem is part of the seizure disorder seen in M.E. (and neurological overstimulation), but it also involves mitochondrial dysfunction, and so the suggestions for treating seizures and mitochondrial dysfunction in M.E. are also appropriate here. It is also true to say that probably the best way to improve symptoms of noise sensitivity is to improve M.E. generally. (Magnesium is also very important as a symptom of low magnesium levels is sensitivity to noise.)

It would be so wonderful if everyone with M.E. could have access to a fully sound-proof (and very dark) room (and a decent doctor and proper medical care, but that is another issue!).

Other things which may help with this terrible symptom include:
1. Background noise from a heater or fan, or very softly playing classical or new-age music
2. Noise cancelling headphones (or earplugs)
3. A no- or low-sugar diet can help reduce symptoms of noise sensitivity
4. Double glazed windows, and extra thick solid wood doors with rubber seals along the edges (so that when the doors are closed the room is almost airtight) are very expensive but can help recuce the amount of noise that enters a room remarkably. (This may only be an option where a new house is being built. It may also be worth talking to acoustic experts to see if any other noise blocking materials can be used in building. Insulating the walls and roof may also be helpful in reducing noise.)
5. If a new house is being built, designing it so that the patient’s room has no walls which are external will help cut down noise from the outside world to a large extent.

6. If noise from neighbours or the road is too much, putting objects in the way can help. This includes trees, bushes, and rainwater tanks etc.

6. If noise from the outside world is very bad, having a bath may help as the exhaust fan may block some of the noise. The bathroom may also perhaps not have any walls which are external and so be a much quieter room, and the warmth of the bath itself may be soothing.

7. Ducted air-conditioning usually requires that a door be left open to allow proper air flow, but this can let in noise horribly. Vents can be fitted to the roof however, which allow air flow without an open door or window.

8. Where noise is extreme and will persist for days or longer, it may be advisable to try and secure accommodation with a friend or family member, or paid accommodation, for this time period. (Even where the person is housebound, the relapse from the travel may be less than the relapse from the noise. This is of course a difficult and horrible choice to have to make, as it is always lose-lose.)

10. Treatments for improving a ‘leaky’ gut
See the ‘Increased intestinal permeability (‘leaky gut’), lectins, saponins, gliadin, phytic acid and M.E.’ paper in ‘Food as medicine’ for information on this topic.

11. Lowering homocysteine levels
All chronic disease cause high homocysteine levels and this is documented in M.E. specifically also. High homocysteine levels can be lowered with (a combination of) products which improve the process of methylation such as: sublingual (or injectable) vitamin B12, Betaine (TMG), vitamin B6, and Folic Acid. You can have your homocysteine levels checked by York labs. TMG can cause severe relapse, or may not be tolerated at all so go very very slowly or skip this one and just take the B12, B6 and Folate.

12. Improving blood sugar control and hypoglycaemia
See the ‘Hypoglycaemia, insulin resistance and M.E.’ paper in ‘Food as medicine’ for information on this topic.

13. Improving breathing problems and breathlessness
Muscle problems, particularly those affecting the muscles around the lungs and restricting breathing may need treatment with a muscle relaxant drug such as Baclofen.

14. Improving dry eyes
Dry eyes may be improved by taking GLA capsules, vitamin C and vitamin B6, as these supplements can help increase tear production. Potassium, phosphatidylcholine, ALC and zinc may also be helpful along with **hyaluronic acid supplements**.

Dr Sherry Rogers writes that the most common cause of dry eyes is low omega 3 oils in comparison to omega 6 oils. She recommends testing to determine your fatty acid ratios if possible, or taking larger doses of cod liver oil for a few months to try and fix the problem. She recommends treating and fixing this problem rather than just treating the symptom with eye drops, as dry eyes are indicative of bigger problems happening internally.

Dry and itchy eyes can also be caused by airborne allergens.

Some patients like to make their own ‘artificial tears’ spray by adding water and salt (enough so that it tastes about as salty as normal tears) to a sterilised spray bottle and spraying a mist into the eyes as needed. This bottle should be emptied and redone at least once a week to avoid infections.

**15. Improving peripheral neuropathy**
Peripheral neuropathy can be treated with folate given IM, or large doses of vitamin B1 given orally or by IM or IV or vitamin B12 given sublingually or by IM or IV.

**16. Improving vertigo**
The most important supplements to improve vertigo are ginkgo, magnesium, ginger, piracetam and vinpocetine. Recommended nutrients also include vitamin B complex, vitamin B3 as niacin, vitamin B6, vitamin C, vitamin E, choline, and adrenal supports. A low sugar diet may also help improve symptoms of vertigo.

**17. Treating hair loss**
One of the main causes of hair loss is thyroid problems, and this is followed by other hormonal problems. Treating these issues may reduce, or even stop, hair loss in M.E.

Hair loss can also be caused by low levels of vitamin C. Other nutrients linked to hair loss are vitamin A, the B vitamins, vitamin D, E, and K, calcium, magnesium, iron, iodine, selenium and zinc.

A silicon supplement called ‘Biosil’ can greatly improve hair health and hair thickness and nail health (although this will probably not treat the cause of the hair loss). Biotin (vitamin B7) is also said to be able to improve hair and nail quality. Hair loss can be caused by many serious diseases, including M.E. Therefore, the best way to treat hair loss may be to treat and improve the underlying disease itself.

**18. Dental health and M.E.**
Fluoride-free toothpaste, and good dental hygiene is very important as there seems to be an increased risk of tooth loss in M.E. Floss daily if possible and try fluoride free toothpastes such as Periobrite (VERY minty) and Xyliwhite (mild tasting) or similar. Do not brush teeth within an hour of eating as this can damage tooth enamel. Important supplements for dental health are vitamin C and ubiquinol. Vitamin C and Biosil can help prevent tooth loss, and ubiquinol improves blood flow to all areas of the body including the mouth. Vitamin D levels should also not be allowed to become low as vitamin D promotes strong teeth and bones.

For more information on healthy dentistry, and why root canals and mercury-containing fillings should be strictly avoided, you may like to read the following books: Whole-Body Dentistry: Discover The Missing Piece To Better Health and Uninformed Consent : The Hidden Dangers in Dental Care.

19. Improving cognitive abilities in M.E.
Some M.E. patients tell of significant improvements in cognitive abilities from taking Piracetam. LEF explains that ‘Piracetam is a derivative of the amino acid GABA that increases the sensitivity of receptors in the brain involved in memory and learning. Piracetam is called a nootropic drug because of its ability to enhance the mind. Studies in both animals and humans have demonstrated that piracetam can improve memory, increase attention and cognition, improve spatial learning, and enhance motor mechanisms. Piracetam is used to increase intelligence, information processing ability, concentration, memory, and creativity. It has been shown to harmonize and synchronize the spheres of the brain by anchoring information within the brain. Suggested dose: Piracetam should be used in doses ranging from 1600 to 2400 mg a day taken first thing in the morning.’

Piracetam may also be a useful treatment for Myoclonic jerks and Raynaud’s phenomenon, may help improve the problem of seizure-like events following exposure to light and may also help improve vertigo caused by brain injury. Piracetam should be taken with choline if headaches occur during treatment. Some countries consider it a supplement rather than drug. This drug must be started at a very low dose and treatment must not be stopped suddenly. Expect to see effects within an hour to a few days.

A herbal alternative to Piracetam is Brahmi (also known as Bacopa monniera). Like Piracetam, Brahmi is a nootropic, a drug that enhances cognitive ability. The herb also has antioxidant and anti-anxiety effects.

Another important supplement for good cognitive and neurological health, as well as health generally, is phosphatidyl choline. Note that Lypo-C supplements contain 1 gram of each vitamin C and phosphatidyl choline in a nanotechnology delivery system.

20. Safely treating high blood pressure when you have M.E.
Treatments for high blood pressure (or which work to normalise blood pressure) include ubiquinol (CoQ10), garlic supplements, hawthorn extract, fish oil, and folate. Supplementing with calcium magnesium and potassium can also be helpful. Eating 4 stalks of celery daily can help lower high blood pressure due to its luteolin content (luteolin, or tetra-hydroxyflavone, has the potential of healing or repairing the peroxisomes).

Some of these treatments have been tested specifically in relation to improving high blood pressure with favourable results. Google these terms for more information on some of these studies.

Note that M.E. is very strongly associated with very LOW blood pressure and high blood pressure is uncommon in M.E. Drugs which treat high blood pressure may have serious unintended consequences in M.E. and may be counter-productive and detrimental to overall health.

21. Reducing the risk of blood clots in M.E.
Due to the fact that inactivity and circulation problems are major risk factors for blood clots, M.E. patients may be at an increased risk of this serious and life-threatening problem. Other risk factors include weight gain, diabetes, taking HRT or the pill, an elevated homocysteine level and cigarette smoking.

Magnesium and garlic have been shown to be as effective as aspirin at reducing the risk of blood clots. Also associated with reducing blood clot risk are CoQ10, vitamin E and fish oil. There is also ginkgo (60 – 120 mg), curcumin, ginger and bromelain.

Another natural alternative to daily mini-aspirin, which is problematic and not at all recommended, is Nattokinase (according to Dr Cheney) and Silymarin (according to Dr Sherry Rogers). Aspirin taken daily can double your risk of having a stroke and also lead to increased intestinal permeability.

Also note that pregnancy is an additional risk factor for forming blood clots in the legs and pelvis. Talk to your doctor about safely reducing the risk of blood clots while pregnant as some supplements should not be taken during pregnancy.

(Please note that garlic, ginkgo and high levels of vitamin E, taken together increase the risk of bleeding problems. Ginkgo should not be taken with aspirin. If you are taking prescription blood thinners check with your doctor before taking any of the supplements listed here.)

22. Improving liver function in M.E.
St Mary’s Thistle, or Silymarin, is an important antioxidant that helps support liver function in M.E. Dosage is usually 100 – 300 mg or more. Start at a low dose and work up slowly. Expect to wait 8 – 12 weeks to see results.
Dr Sinatra’s website explains, ‘Artichokes, dandelion, root vegetables (carrots, beets), sulfur-containing foods (eggs, garlic, and onions), water-soluble fibers (pears, oat bran, apples, and beans), and cabbage family vegetables (broccoli, Brussels sprouts, and cabbage) all optimize healthy liver and gut function. You can also juice many of the abovementioned fruits and veggies, which also aids in the detoxification process by providing live enzymes.’

Eating freshly cooked liver, having liver injections, or eating powdered organic beef liver also helps boost liver function.

Treatments which can greatly boost liver function are coffee enemas and FIR sauna therapy. Dry skin brushing can also be helpful. For more information see the papers ‘Enemas for detoxification in M.E.’ and ‘FIR saunas and M.E.’

23. Additional useful therapies and products for M.E.

Products:

- Very important for reducing the work-load of the heart are leg raising cushions – these can and should be used day and night in the severely affected especially. This is very important.
- To a lesser extent, medical quality (and carefully measured for correct fit) knee high or thigh high compression stockings may also be helpful, particularly for those who spend a significant amount of time out of bed, or are extremely severely ill. Waist high stocking may be even more help, if also more uncomfortable.
- Hot packs to treat neck and back pain.
- Ice packs to treat the unique head pain experienced by M.E. patients at the base of the skull, and other headaches
- Neti pots are a cheap and easy way to flush out and clean your nasal passages; just add salt and water. Very good for clearing out a blocked-up nose, caused by allergies. (Steroid nasal sprays may still be necessary in some cases however, along with extra vitamin C.)
- Moisturiser and exfoliating gloves (or creams) can help keep your skin from drying out, and prevent too much hard dry skin building up. (When people are very inactive, the natural exfoliation processes do not occur in the same way, so manual exfoliation may be necessary.) Look for products made with natural oils and free of parabens etc.
- A body brushing brush with natural bristles can be used to improve the circulation.
- Clay face masks and clay or salt baths for detoxification.
- Vitamin e oil may be useful to treat rashes and other skin conditions, along with vitamin C applied topically.
- Having good back support in the recliners or beds where the day is spent is very important. Old saggy beds can cause back and pain problems that may be mistaken as M.E. symptoms.

Other types of treatments/therapies/programs:
• Professional massage to relieve stiffness and pain. You can also massage your neck, hands and feet yourself.
• Lymphatic drainage massage.
• Chiropractic care form a trained professional (if needed).
• Acupuncture (not useful to treat M.E., and attempts at this will often cause relapse, but may in some cases be useful if used to treat pain. Watch out for being left still for a long time once the needles are in, as this can be very painful and muscles may become very stiff and painful).
• Applied Kinesiological Testing is a type of muscle testing involving biofeedback which is practiced by some health professionals to help determine the best treatment options for a patient. For more information see: Many Uses of Muscle Testing and What is Kinesiology & Muscle Testing?
• Good dental care every day is very important and so is the care of a good quality holistic dentist, at times.

24. Miscellaneous other potentially useful treatments

Octacosanol. Octacosanol (C28H58O) is a 28 carbon long-chain saturated primary alcohol, and is the active ingredient in wheat germ oil. It is found in wheat germ oil, sugar can and spinach. Octacosanol may improve function in M.E. as it can increase the body's ability to use oxygen during exercise. As a variety of studies confirm, octacosanol can boost muscular strength (including that of the heart). Many of the minor tonic actions and cardiovascular benefits attributed to octacosanol may have to do with its ability to affect fat metabolism, blood platelet stickiness, and cholesterol production. The long chain fatty alcohol is thought to repair and stabilize destroyed portions of myelin sheath and promote neuron regeneration, and is used in many different muscular and neurological diseases (MS, ALS, cerebral palsy etc.). In short, Octacosanol is very beneficial for improving heart function, reduces pain and is a valuable nutrient for the CNS.

Spinach or wheat derived Octacosanol supplements are available, and synthetic versions should be avoided. Dosages of octacosanol range from 1 - 40 milligrams daily, depending on the severity of the medical problem. A minimum effective dose may be 6 - 8 mg, although doses of 15 – 30 mg may be more appropriate in MS and so also M.E. There appears to be no toxic effects at these dosage levels. Octacosanol is very safe, however as it thins the blood it should not be taken with blood-thinning drugs (or the Parkinson’s drug levodopa).

Low-dose naltrexone strengthens the immune system and may improve cognitive function. Dosage is 3 - 4.5 mg taken before bed. Toxicity is not a concern with LDN. Well tolerated by most M.E. patients if the dose is raised very slowly, although some minor symptoms/side-effects such as headaches may occur in the first few weeks. Requires a doctor’s script. Note that this drug should never be taken in combination with any drugs which are opiates (eg. codeine, Tramal/Tramadol etc.)
**Inosine.** Inosine is an anti-viral that enhances NK function. Leading M.E. expert Dr Byron Hyde was involved in a trial for Inosine for M.E. in 2003 which showed positive results. Dr Cheney says about Inosine in the article Balance the Immune System (Th1/Th2) and Basic Protocol/Treatment Plan: ‘It appears to raise IL-12 and lower IL-10, which turns off Th2 and turns on Th1. It is also called Imunovir and is very nontoxic, very safe. Week one, take 6 tablets a day, Monday through Friday, and none on the weekend. Week two, take 2 tablets a day, Monday through Friday, and none on the weekend. Repeat this cycle. But do not treat every month. Do two months on and then one month off of this “pulsing” dose.

This medicine works best when you do not treat regularly. If you treat continuously at the same dose, it stops working.’ Inosine should only be used under direct supervision of your health care professional, do not just take this medication yourself. Before beginning with this product it is best to get a baseline on NK function, then test again after having been on the product for one to three months. (Each Immunovir tablet is 500 mg according to this information on the product and you take the same quantity of Inosine as Immunovir or Isoprinosine. Inosine is now freely available and relatively inexpensive.)

This supplement will often be poorly tolerated by M.E. patients.

**Matrine.** The Chinese medicine called Matrine may be useful, according to Dr Chia. He recommends the product Equilibriant. Equilibriant contains vitamins A and D, calcium and selenium, as well as extracts of olive leaf, shiitake mushroom, shrubby sophora root, astragalus root and licorice root. (However, bizarrely, a caution is given about this not being appropriate for those with autoimmune components to their disease, which absolutely includes M.E. One wonders therefore if what is being discussed is merely a subgroup of ‘CFS’ and not in fact, M.E.? It is impossible to say, sadly.)

Matrine and oxymatrine are the two major alkaloid components found in sophora roots. They are obtained primarily from Sophora japonica (kushen), but also from Sophora subprostrata (shandougen), and from the above ground portion of Sophora alopecuroides. Matrine may be a useful treatment for coxsackie infection. Click here, here or here for more information on Matrine.

**Cramp bark.** Cramp Bark can help relieve muscle spasms and menstrual cramps.

25. What is the prognosis for M.E.?

Myalgic Encephalomyelitis has many different and unpredictable outcomes. The illness can generally be; progressive or degenerative, chronic (and relatively stable), or relapsing and remitting. In some cases M.E. may also be fatal.

Unfortunately the myth that ‘everyone recovers eventually’ is just not true for M.E. patients, but many patients are lucky enough to experience some level of improvement over time, and so there is reason for hope. (Everyone will probably
recover eventually from various post-viral fatigue syndromes, but M.E. is an entirely
different and unrelated disease to PVF syndromes with different symptoms, onset,
pathology and prognosis.)

Full spontaneous recoveries, where the person is restored to normal functioning are
thought to occur in up to 6% of patients (although experts warn that these are
remissions rather than true recoveries and that relapse is unfortunately a future
possibility for these patients). A significant number of patients will experience partial
spontaneous remissions; where functioning improves markedly but there is still a
mild to moderate level of disability present. (‘Spontaneous’ means that these
improvements were natural, and not the result of treatment.) Around 25 - 30% or
more of cases are progressive, degenerative or extremely severe. (The best way to
look at this is that most cases are NOT progressive, degenerative or extremely
severe…and even if you are severely affected, improvement IS possible for you in
the future; particularly if you can strictly avoid overexertion. Dr Dowsett says that
stabilization is possible at any stage of the disease so long as there is appropriate rest
and treatment).

For what it is worth, every single person I’ve spoken to about it, that has been lucky
enough to have recovered 70% or more of their pre-illness function was diagnosed
early, treated appropriately and able to rest adequately in the early stages of the
illness. With the right care and rest, M.E. does not have to be progressive, and
significant recovery can happen and does happen. Even if you didn’t get the rest you
needed in the early stages, rest and proper care in later stages, consistently, can still
let you recover to some degree. It may not be 70%, but even 30% or 40% ability
levels are nothing to sneeze at when you have been so severely ill.

The most severely affected sufferers too are almost always those who were the most
active (either through ignorance or by force) in the earliest stages of their illness, and
thereafter (myself included). Avoiding overexertion is almost EVERYTHING when
you are looking at getting your best possible prognosis with M.E. This can’t be
stressed enough.

The fact that we are limited in how active we can be with M.E., is a protective
mechanism that stops us from causing further – and even more permanent and severe
– bodily damage. M.E. is NOT FATIGUE and should never be treated medically in
the same way as ‘fatigue.’

For more information please make sure you read the new ‘A quick start guide to
treating and improving M.E. with aggressive rest therapy, diet, toxic chemical
avoidance, medications, supplements and vitamins’ paper.

If you are able to, it is a good idea to monitor and keep records of your symptoms and
the severity of your illness over time. Remember that it is not safe to assume that all
new symptoms will be M.E. as unfortunately having M.E. does not make you
immune from developing other illnesses.
26. ‘Dual diagnoses’ and M.E.
Despite the fact that severe pain is a well known and very common symptom of M.E. many M.E. sufferers who have pain are told that they now also supposedly have ‘Fibromyalgia.' But if pain is a recognised symptom of M.E. then how does an additional Fibromyalgia diagnosis made purely on the presence of pain make sense? Patients who have Fibromyalgia and patients with primary M.E. can be easily distinguished from each other with various tests (and other means), so what do tests show in patients who supposedly have both?

Interestingly, when patients have both illnesses the test results given are the ones for M.E. only. So do these M.E. patients really also have Fibromyalgia, or do they just have severe pain as part of their M.E.? As you might expect, these test results strongly suggest the latter.

The same is true of multiple chemical sensitivity syndrome (MCSS); symptoms of chemical sensitivity are part of the core symptoms of M.E. and have long been associated with M.E.(as well as with several other autoimmune illnesses such as multiple sclerosis and Lupus) and so there is no need for an additional diagnosis of MCSS to be made. Just because you may fit a definition of Fibromyalgia, or MCSS, or irritable bowel syndrome (IBS) this does not mean that your symptoms are caused by the same aetiological or pathological process, or will respond to various treatments the same way, or will have the same prognosis as those people who have primary Fibromyalgia, MCSS or IBS, or anything else. See M.E. and other illnesses and The misdiagnosis of CFS for more information.

See Myalgic Encephalomyelitis: The Medical Facts for more on the prognosis of M.E. and the 3 Part Myalgic Encephalomyelitis Ability and Severity Scale: a tool for monitoring the course of your illness over time.

27. Can I or should I still donate blood if I have M.E.?
In some countries M.E. is not specifically listed as an exclusionary illness which prevents you from legally donating blood while in other countries M.E. sufferers are specifically banned. If you have M.E. (or even suspect you have M.E.) however you should not donate blood whatever the law states because of the possibility of infectious agents being passed on through your blood. This is a real possibility.

28. Am I at a greater risk of contracting cancer because I have M.E.?
Sadly, there is some evidence to suggest that this is the case. BUT it is good to know about this possible increased susceptibility to cancer, so that we know how important it is to do what we can to protect ourselves beforehand. That means avoiding known carcinogens such as air pollution, cigarettes and alcohol, high levels of EMF radiation, deep-fried or burnt food and chemicals in food (eg. nitrates) and personal care products (eg. SLS and some hair dyes), etc., investigating and taking substances which may have anti-cancer properties such as antioxidants (vitamins A, C and E,
selenium, zinc and mixed natural carotenoids) and avoiding overexertion (as this increases free radicals).

Problems with methylation, left untreated, may also increase cancer risk. The Good Health in the 21st Century book explains that decreased glucose tolerance alone increases risk factors for some cancers.

In essence, the things that reduce your cancer risk are also the same things that are involved in treating M.E. in the best way possible anyway.

- For more information see the short article: Th1 and Th2, cancer and M.E.
- If you already have cancer (and M.E.), see: Say No to Cancer and Alternative Medicine: The Definitive Guide to Cancer and The Natural Way to Heal: 65 Ways to Create Superior Health. Books such as The NEW optimum nutrition bible and to a lesser extent (the focus here is more on doing what you can to avoid cancer in the first place) Dr Atkins Vita-Nutrient Solution: Nature's Answer to Drugs each have useful chapters on how to potentially improve your outcome with diet and supplements and are at least well worth a read also (although you should ignore 100% of anything they have to say about treating ‘CFS’ as this will be irrelevant or inappropriate with regards to M.E.). If you cannot afford to buy these books, please email me for other suggestions.

29. I’m overwhelmed trying to work out which supplement brands to buy, can you help?
I’ve recently created two Amazon lists which feature some of my own favourite brands of supplements and vitamins, and also other items and tools of use to the M.E. patient. The main reasons for doing so were to make my own supplement purchasing tasks easier by having links to all the different products in one place, and also to save me time each week from finding the links to individual products each time someone asked me for one.

Patients that have very little time online may wish to use these lists as a quick way to get a starting point for their own purchasing decisions, and so I am including links to them here for those that are interested. (I’ve had a lot of positive feedback for including such information.)

List one: Excellent supplements list
List two: Excellent tools and devices list

Amazon uses the term ‘wish list’ to describe a list of products created in this way, but I’m using it instead as a ‘recommendations list’ or ‘favourite things list.’ I receive no monies at all from anyone choosing to buy any supplement or device or tool from either of these lists, and highly recommend that patients shop around and find the best deals and products for them, and which best suit their own individual needs, at whichever other retailers they may prefer.
30. I’m having one of those days where I just don’t want to take any more supplements, what should I do?

Dr Sherry Rogers explains that when you have one of those days when you just really don’t feel like taking any supplements, you should listen to your body and have a day off. Our bodies can only take in so much for so long before it has to take some time to assimilate it all and put it to work.

It may actually be a good idea to have one supplement-free day the same day each week.

On this day you might plan to either take no supplements at all, or only those things that would make you feel worse that day if you didn’t take them; this may include vitamin C, B vitamins, betaine HCl and digestive enzymes (and any prescription drug that should not be stopped suddenly). Vitamin C is probably best taken every day as going from a high dose one day to none at all the next day may negatively affect immunity for a short period of time. Vitamin C doses should be raised slowly and reduced slowly, so the body has time to adapt.

With the above caveats, you may even choose to take supplements only every second day.

31. Notes on applying for the appropriate/necessary benefits/welfare/disability support

The rules and procedures for applying for and qualifying for social security payments due to illness vary considerably in each country and so a comprehensive analysis of all of them is another (very difficult) whole essay in itself. There are a few things that might be useful in many cases however, and these include:

- Always keep photocopies of everything you send in for your own records (and in case they lose anything).
- Having test results which show abnormalities can only help your claim so get appropriate testing done if at all possible. (This will also help you to help confirm your diagnosis if any doubt remained). See Testing for M.E. for details.
- If the doctor who is helping you with your claim is a GP, it might be useful to ask this doctor to give you a referral to a specialist (one who is at least somewhat educated about M.E.) as this may carry far more weight. (Illogically, this will likely be true even if your GP is very knowledgeable about M.E. and has been treating you for years and if the specialist knows very little about M.E. and has only seen you for a few minutes!)
- Keeping a daily activity log for a week or so may also be useful in making it very clear to everyone involved your exact level of disability and exactly how your illness affects your daily life.
- When you fill in all the various forms which ask you to explain your level of disability and what you can and can’t do, remember that you should NEVER fill
them in as if they were asking you about what you can do on your ‘best possible
day.’ For example, if you are asked if you can leave the house and you say that
yes you can, it will very likely be assumed that this is something that you can do
easily, and even daily – without any real issues. This will cause very serious
problems for you if the facts are that yes you can leave the house; but only about
once a month or so, and only when you can have complete rest for a week
beforehand and if even then you’ll also spend another two weeks collapsed and
very ill from the outing afterwards. You get the idea. These types of forms
typically do not allow for or understand the variability of M.E. (or any other
illness) and so to avoid misunderstandings and dangerous (and utterly disastrous)
overestimations by the relevant agency about your physical and other abilities,
you must always fill in forms as if they were asking about what you can
RELIABLY do; What are you able to do every day? What can you still always do
even on your worst days? How much or what are you able to do each day without
this activity worsening the severity of your condition over time?

- US links: Dealing with a flawed Social Security Disability system: Guilty until
  proven innocent and How to process the social security disability application and
  get approved: Filing for Disability Benefits
- Australian links: ACOSS Ten Myths & Facts about the Disability Pension
- UK links: Benefits and Work website information on DLA and incapacity benefit
- Please send any further information or links on this topic to HFME.
Section 7: Treatment cautions and warnings relevant to M.E
Important extra treatment cautions and warnings relevant to M.E.  
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Note that **folic acid** supplementation without B12 supplementation can mask B12 deficiency and cause **neurological damage** in very rare cases. Folate should not be taken without additional B12.

**Cysteine** and N-Acetyl Cysteine supplementation should probably be strictly avoided by M.E. patients. (One doctor even speaks about two M.E. patients who both committed suicide due to the effects of taking just 1000 mg of NAC. This supplement can cause many of the physical problems seen in M.E. to WORSEN and for mercury to be released into the system.) Cysteine can also cause Candida to change into pleomorphic types that are more aggressive and difficult to eradicate. Note that those who have problems with NAC may also have problems with taking SAMe and whey protein. If you take Glutathione, take only the liposomal form.

**Naproxen** has been implicated in possible mitochondrial damage

**Excitotoxins** such as aspartate (NutraSweet/aspartame), glutamate (MSG), and homocysteine can cause cell death when their actions are prolonged. For more information about the need to avoid aspartame see links 1, 2, 3, 4, 5 and 6. M.E. patients also need to avoid: chlorine, fluoride, 5 HTP supplements, trans fats in food and tryptophan supplements. Unnecessary medicinal drugs should also be minimized. NSAIDS should be avoided in particular and can be replaced with Turmeric/Curcumin. Also very problematic are SSRIs which should be avoided if at all possible. For more information see this neurodegeneration PDF, which explains:

Although many factors can play a direct role in the initiation of neurodegeneration, the two forces which interact at the cellular level are free radicals formed by the reactive oxygen species and reactive nitrogen species, and secondly, excitotoxins, such as glutamate (monosodium glutamate or MSG), aspartate (i.e. NutraSweet) and homocysteine. Excitotoxins are neurotransmitters which can cause cell death when their actions are prolonged. Excitotoxins are neuro-toxins that are often added to foods, such as aspartame, and MSG (monosodium glutamate, also known by other names such as "natural flavors", texturized protein, "spices", etc.)
5 Hydroxytryptophan (5-HTP) is an alternative to the traditional antidepressants used to treat unipolar depression. 5-HTP is more likely to be well-tolerated than standard prescription antidepressants. 5-HTP is not a general M.E. treatment (and should be avoided by M.E. patients that are not suffering with significant depression) but may be used by some patients that have pre-existing depression or for whom depression has become an issue since becoming ill (particularly where this affects sleep). However, 5-HTP can cause problems in those with IBS-type symptoms and is generally not recommended for those with significant digestion or gut problems – or those with cardiovascular conditions or peripheral neuropathy. It can also cause decreased libido and extreme and vivid nightmares. One article explains about 5-HTP, ‘As you would expect, digestive disturbances and vivid dreams are both commonly reported side effects with all treatments that affect serotonin levels, such as the SSRI antidepressants, like Prozac or Paxil.’ 5-HTP can also cause hypomania, insomnia and euphoria which could cause serious relapse in M.E.

If depression is a significant problem, this is probably still a far better treatment option than standard antidepressants (along with St John’s Wort). However, it is advised that dosage start at a very low level and be raised slowly in case of side effects and that this medication be taken under medical supervision. 25 - 50 mg daily may be enough and higher doses may make side-effects more likely. If you notice mood swings, feeling ‘drunk,’ rashes or flushing, insomnia, worsening depression or gastrointestinal problems etc. it is important to stop taking 5-HTP completely (perhaps lessening your dose to zero over a few days to prevent withdrawal symptoms). Note too that 5-HTP and St John’s Wort should never be combined with each other or with MAOI or SSRI antidepressants drugs as this risks serotonin syndrome. Some experts also warn that 5-HTP is not suitable for long-term use and should be used for no more than 3 months (to prevent serotonin levels from becoming too high and because a tolerance may be built up to the medication).

Avoid Provigil as it stimulates nitric oxide, says Dr Paul Cheney. Dr Cheney also warns against the use of hyperbaric oxygen chambers in M.E. as well as Benicar. On Benicar he writes: “Angiotensin II has two receptors that we know of, and we only understand the first, AT1. When Angiotensin II binds to AT1, it increases the hormone Aldosterone, which in turn increases blood volume. Big issue! If you block AT1 with an ARB [like Benicar], down will go your Aldosterone, and down will go your blood volume, and you could be in a heap of trouble. ARBs that bind to AT1 will constrict blood volume.”

Having your tablets with low-fat meals or no fat meals will stop you fully absorbing some nutrients, as sometimes some fat is needed for absorption (eg. CoQ10 and vitamin D).
Antidepressants are very often poorly tolerated by people with M.E. Small doses of certain antidepressants may be prescribed to deal with symptoms of pain, sleep or depression (particularly pre-existing depression) but will not affect or improve the illness as a whole. The dosage used should always be very small (1/10th of a normal dose or less) but even at this dosage many people with M.E. cannot tolerate these drugs at all.

Some particular antidepressants may cause other serious problems: Doxepin is known to cause heart problems (which is particularly concerning considering the well known cardiac issues in M.E.) and Serzone (a drug which has been taken off the market in some countries but not others) is linked with liver failure.

Probably the most harmful ‘treatments’ for M.E. (along with the recommendation of antidepressant drugs) are cognitive behavioural therapy (CBT) and graded exercise therapy (GET). For more information on why these inappropriate interventions are so often forced on M.E. patients, and the extremely severe and long-term harm they can cause (including deaths) see: The CBT and GET database

The above comments apply equally to other psychologically based ‘treatments’ touted by some groups as being very beneficial or even curative for ‘chronic fatigue’ (a term used interchangeably with CFS and M.E. by these groups) such as ‘Reverse Therapy,’ ‘Mickel Therapy,’ ‘Emotional Freedom Techniques’ (EFT) and the ‘Lightning Process.’ These treatments may or may not be useful to those with fatigue caused by various emotional or behavioural problems, but they simply cannot improve authentic M.E. If a person has improved with these therapies they have not been correctly diagnosed with M.E. (or they have been lucky enough to have a natural remission of the illness at the same time these ‘treatments’ were undertaken).

Psychological therapies such as these can no more repair the serious organic damage to the brain, cells and organs in M.E. than it can do so for those with multiple sclerosis or Parkinson’s. Success with these treatments on fatigue sufferers has no relevance whatsoever to those with M.E. The only change likely to be seen with these ‘treatments’ in those with M.E. is a ‘lightening’ of their wallets! (as many have already commented.) As with similar therapies such as CBT however, the severely affected in particular (but also those with moderate M.E.) may also be made considerably more ill short- or long-term by these inappropriate and (physically and mentally) cruel interventions. They can often cause very severe relapse. If these treatments don’t work, the victim is blamed for ‘not trying hard enough.’ So there can also be a huge emotional cost from being subjected to what amounts to serious emotional abuse.

All these ‘treatments’ are, is well-publicised money-making scams designed to prey on society’s most vulnerable members. What they are doing is sicker than we are, truly. It’s lower than low. See: The CBT and GET database for more information and if family members are pressuring you to participate in scams such as the Lightning
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process, Reverse therapy, Mickel therapy, EFT and so on, see the new The Lightning Process (etc.) scam page.

**Beta blockers** (often prescribed for cardiac irregularities) can actually cause disease progression in M.E. and so are very much not recommended for M.E. sufferers. Forcing the body to operate at a higher level than it can cope with and suppressing or masking symptoms, only causes harm long-term. Beta blockers decrease heart rate and heart output and interfere with renin. Side effects of beta blockers include an increase in triglycerides, nervous system disturbances (confusion, nightmares, depression, excitement), slow heart rate and left ventricular dysfunction. *Congestive heart failure can occur due to the use of beta blockers! This is well known!*

Some M.E. patients tell of significant improvements in cognitive abilities from taking nimodipine. Nimodipine (brand name Nimotop) is a **calcium channel blocker** specific to the central nervous system. Dr Sherry Rogers warns that, ‘calcium channel blockers have been shown by MRI to cause definitive shrinkage of the brain and loss of brain function, a side effect rarely mentioned by clinicians or news media. Bear in mind that since medications do not fix anything, they allow the underlying problem to continue uncorrected and actually accelerate. Meanwhile, new symptoms and new seemingly unrelated diseases are the inevitable consequence of this biochemical faux pas.’ Magnesium provides all the positive benefits of calcium regulation with none of the dangers and downsides of calcium channel blocker drugs.

It is possible that the drug **midodrine** also has the same problem as beta blockers – forcing the body to raise blood pressure and thus relieve some symptoms, but at the cost of long term health. The blood pressure is lowered in M.E. as a protective mechanism against death, forcing the body to override this mechanism seems ill-advised. Drug induced overexertion. If the orthostatic problem is only neurological, a problem of the wrong signals being sent from the brain to the body, then a drug such as this can absolutely be a very useful treatment. But where there is serious cardiac insufficiency and mitochondrial problems too, this treatment could be very dangerous. I would not try this medication myself and nor do I feel at all comfortable recommending it in any way to other M.E. patients. It seems a far safer bet to instead try products which actually improve cardiac function with no risks (not just mask symptoms) such as ubiquinol, magnesium, hawthorne and so on. (Note that this is just my personal opinion based on what I have read about the problems with beta blockers in M.E. etc.)

**NSAIDS** can make inflammation worse in the long term and can be replaced with Curcumin or other nutritions. Aspirin and ibuprofen should also be strictly avoided. Aspirin taken daily can double your risk of having a stroke, increase damage to the eye and risk of deafness and all three of these drugs can lead to increased intestinal permeability. In ‘Detoxify or Die’ Dr Sherry Rogers writes,
Over 16,000 people die each year just from gastrointestinal hemorrhaging from NSAIDs, while another 100,000 get congestive heart failure from them. As well NSAIDs cause osteoporosis and hip and knee degeneration, necessitating joint replacement. NSAIDs as an example of only one group of medications, are fatally toxic to thousands of people each year by damaging joints, lungs, kidneys, eyes, hearts, and intestines.

Drugs do not cure anything, they merely turn off poisoned and malfunctioning pathways. That is why their classifications are anti-inflammatory, ant-acid, beta-blockers, alpha-blockers, calcium channel blockers, angiotensin inhibitors or ACE inhibitors, HMG COA a reductase inhibitors (cholesterol-lowering drugs), selective serotonin reuptake inhibitors or SSRI, etc. And by not fixing the underlying problem, they allow it to worsen as the innocent patient accumulates side effects from the drug as well.

**Cortisone injections** worsen the pain in the long-term.

**Steroidal nasal sprays** such as Rhinocort, used excessively, can cause Candida overgrowth in the throat.

**The Marshall protocol** is recommended for ‘CFS’ with an almost religious zeal by some patients and groups. There is no good evidence however, or any evidence that it is appropriate for M.E. or that it is safe for those with M.E. (or anyone with a different disease which may qualify for a ‘CFS’ misdiagnosis for that matter!) This treatment can be very dangerous because (among other problems it causes) it actually exacerbates the immune system deficiencies of M.E. As you would expect, serious side-effects and relapses have been widely reported by M.E. sufferers. Some sufferers have relapsed severely with this treatment, and are still very severely affected years later. Some say they have come very close to death from it, or close to suicide because of how severely ill it made them even many years on. For more information please see: [Paper 1](#), [2](#), [3](#) and [Paper 4](#).

This treatment is just inappropriate for genuine M.E. patients. Many M.E. patients have heard just horrific first person accounts of this ‘treatment.’ It has ruined a lot of lives. Please don’t take this extreme risk if you have M.E. It may possibly help some patients (or it may not!) but those are not M.E. patients.

Zoltan Rona M.D. recently released a book called: *Vitamin D: The Sunshine Vitamin*. The best part of this book, for me, was his two page section talking about the unscientific nature of the ‘Marshall Protocol.’ Zoltan Rona M.D. writes, ‘I have witnessed a lot of crazy treatments over the past 30 years, but none are as abusive as the Marshall Protocol. This protocol is not only illogical but also downright dangerous. At best, it can be labelled as a pretence of scientific thought.’ Rona goes on to talk about the fact that ‘Dr’ Marshall is in fact NOT a medical doctor, but is an electrical engineer! He explains that the protocol, which promotes attaining very,
very low vitamin D levels and taking antibiotic drugs long-term, is ‘damaging to one’s health and can lead to death.’ He advises anyone that is currently following this dangerous and illogical protocol to ‘get off it immediately.’

The Marshall Protocol scam has given so many very ill patients false hope and left them even sicker than when they began it, and also risked their lives. So three cheers to Rona for including some serious warnings about it in his book. I hope so much they will be heeded by those following the protocol and those aggressively promoting it to others. This pseudo-scientific ‘treatment’ has caused ENOUGH harm.

Taking the **contraceptive pill or hormone replacement therapy** increases the need for vitamin B6, vitamin B12, vitamin C, folate and zinc.

Many M.E. patients become severely ill, and relapse severely and/or long-term, with **antibiotics**. (The same is true of antifungals as well as different types of antivirals, although their use in M.E. is far more established. We know that M.E. is not a bacterial infection as is Lyme disease). If you do decide to try antibiotics for whatever reason, sure to always also take high-strength probiotics and extra B vitamins.

**The Fluoroquinolone antibiotic drugs** (Cipro, Levaquin, Floxin, Tequion and others) ‘are the most toxic and dangerous antibiotic in clinical practice today’ according to the Fluoroquinolone Toxicity Research Foundation. They go on to say, ‘We cannot even begin to count the number of lives these drugs have destroyed rather than saved in the past forty years.’ This antibiotic can destroy lives, according to many patients. The adverse drug reactions (ADRS) associated with the Fluoroquinolones include: tendon and muscle pain, insomnia, burning pain, digestion disorders, anxiety, heart problems (including heart failure), vision disorders, ringing in the ears, rashes, blood sugar problems, depersonalization, toxic psychosis, mental disorders, seizures, pain, liver failure, kidney failure, irreversible peripheral neuropathy and other adverse reactions. The Fluoroquinolone drugs are anything BUT a safe and effective antibiotic and are clearly not worth the risk. The problems caused by the drug do NOT always resolve once the drug is stopped; the drug can cause permanent and irreversible additional health problems (both physical and mental).

For more information please see the Fluoroquinolone Toxicity Research Foundation website or The Flox Report by Teo Boomer. The Fluoroquinolone Toxicity Research Foundation says ‘This article consists of the descriptions of the adverse toxic effects caused by the quinolone and fluoroquinolone class of antibiotics, suffered by previously healthy patients. Many of these injuries are irreversible and permanent in nature. In addition, this article contains data obtained from many individual "first person" reports, as well as information that comes from reputable mainstream medical sources which are readily available to the public.’ See also The White Paper by David T. Fuller. The Fluoroquinolone Toxicity Research Foundation says, ‘More
than fifty percent of the fluoroquinolones have been removed from clinical practice, or their use severely restricted, due to such inherent toxicity. This White Paper details the case against the manufacturers of the drugs found within this class who have put profit and greed ahead of patient safety. The serious nature of these adverse reactions are well known by the various manufacturers who have gone to great lengths to both minimize and trivialize these reactions.’

I am including this information after being contacted by a (lovely) M.E. patient named Kate who has tragically had her life utterly destroyed by this drug. Despite finding typing very difficult, Kate was determined to try and get the word out to fellow patients so that nobody else would have to suffer the same terrible fate. For more information on these drugs, and Kate’s story see HFMEs Fluoroquinolone page.

**Stimulants** of any kind are not a useful or safe treatment for M.E. They may give an immediate benefit of increased activity in the very short term, but longer term this is counter productive as the disability of M.E. is in part protective and transgressing your activity boundaries in this way can only lead to unnecessary extended relapses and disease progression. There have also been deaths in M.E. related to overexertion.

Even where **DHEA** deficiency can be documented, administration of DHEA can cause severe relapse in M.E. DHEA can cause panic attacks, insulin resistance and other serious problems and should not be taken without levels being monitored regularly with a conjugated DHEA test, says Dr Sherry Rogers.

**Echinacea** is often recommended to boost the immune system in healthy people but in M.E. parts of the immune system are already dysfunctional and upregulated and so this will only worsen this problem and so should be avoided by people with M.E. (some of the symptoms of M.E. are caused by this upregulation). Echinacea is not appropriate for long term use and may also reverse the effects of certain steroids.

**Cats claw or Samento** should be avoided by those with autoimmune diseases (including M.S.)

**Ginseng** can stimulate adrenal glands and increase production of interferon (which can increase symptoms in M.E. sufferers) and is also a stimulant. **DMAE** can also make seizure problems worse in M.E.

Be wary of ‘**homoeopathic**’ products (such as Bioglan brand homoeopathic melatonin sold in Australia) as they do not actually contain any active ingredients! Bioglan melatonin doesn’t contain ANY melatonin. So if you think you have tried
melatonin and Bioglan ‘melatonin’ didn’t work for you, then actually you haven’t tried it at all.

Some patients report huge benefit from Neurontin, while others have a very negative effect from the drug. (So this is one that should be taken with caution to begin with.)

Ablation surgery is not a good idea, explains Dr Sherry Rogers. She says that in one in ten patients it causes shortness of breath or heart failure by destroying the nerve that controls the diaphragm. It also doubles the rate of stroke and increases the risk of a heart attack. Stents are also not a good idea as they are blood clot magnets. For more information on why ablation and stents are so dangerous and unhelpful see her book ‘Is your cardiologist killing you?’ and her ‘Total Wellness’ newsletters.

Lyrica should be avoided as it causes seizures and promotes a high incidence of cancers as a side-effect, explains Dr Sherry Rogers.

Tyrosine is the precursor to adrenaline and taking it can make you feel manic. This supplement should only be taken under medical supervision and where a deficiency has been shown on testing.

Coumadin or warfarin is a very dangerous drug that should be avoided. Dr Sherry Rogers explained in her January 2011 newsletter that, ‘The evidence is screamingly clear that [Coumadin] rips calcium out of bone and dumps it in heart vessels and valves. Coumadin accelerates coronary artery disease, osteoporosis, cancer, arthritis, high blood pressure, aging and other maladies.’

For information on how to safely get off this drug with nutrients, see the book ‘Is your cardiologist killing you?’ or this article. The right nutrients don’t poison over 16 pathways in the body, can keep you clot-free even better and safer plus with exponential benefits and no side effects. If you do take Coumadin make sure to take some K2 daily, as Coumadin poisons this nutrient and it is needed to prevent cancer.

The first time you have an injection of magnesium – or vitamin B12 – this should always be done in your doctor’s surgery in case you have an adverse reaction (magnesium can adversely affect cardiac function and some people react badly to the preservatives in B12 injections). Also note that vitamin B12 supplementation (oral or injectable) should also always be combined with a B vitamin complex supplement so that you don’t have an imbalance of the B vitamins.
Some doctors are prescribing Mestinon, (a myasthenia gravis drug) for M.E. Mestinon is pyridostigmine bromide, a drug which can further disrupt or damage the acetylcholine system in the brain (a system known to be severely dysfunctional in M.E.). This drug is not appropriate or safe for M.E. sufferers (and is even thought to be one of the possible causes of Gulf War Illness; an illness with some similarities to M.E.)

Vitamin C does not cause kidney stones, this is a myth that is still unfortunately being unhelpfully passed around as fact. Evidence actually suggests that vitamin C at a high dose can reduce your chances of kidney stones and that what does cause kidney stones is; inadequate water intake, low vitamin D and B6 status, low potassium and magnesium intake and the use of antacids. Vitamin A may also help to inhibit kidney stone formation.

Treatment for panic attacks will never be useful if in fact the ‘panic attacks’ are misdiagnosed neurally mediated hypotension (NMH) and/or postural orthostatic tachycardia (POTS) – a fast heart-rate or problems with blood pressure on standing. Both of these are always a big part of M.E. but some doctors are not aware of this and so may misdiagnose these problems as being due to ‘panic attacks.’ Of course you may actually feel panic or even terror when you experience severe NMH or POTS, but this is as a reaction to the terrifying and excruciating symptoms and pathology, not as a cause of them.

Suspect you have NMH or POTS and not panic attacks when you: have never had an attack when lying down and when you have most of your attacks and all your most severe attacks when sitting or standing still. Also be suspicious if these attacks improve if you fidget or move about, learn significantly forward or backward constantly when sitting, or crouch down or lie down and when you feel perfectly calm, relaxed and happy and not at all anxious before they happen.

Disclaimer: The HFME does not dispense medical advice or recommend treatment, and assumes no responsibility for treatments undertaken by visitors to the site. It is a resource providing information for education, research and advocacy only. Please consult your own health-care provider regarding any medical issues relating to the diagnosis or treatment of any medical condition.

Relevant quotes
“Modern medicine is not scientific, it is full of prejudice, illogic and susceptible to advertising. Doctors are not taught to reason, they are programmed to believe in whatever their medical schools teach them and the leading doctors tell them. Over the past 20 years the drug companies, with their enormous wealth, have taken medicine over and now control its research, what is taught and the information released to the public.” Abram Hoffer MD
“Modern drug based medicine is as incomplete as a novel written with three vowels. As discordant as a symphony constructed using only some of the notes. High dose nutritional therapy is the much needed missing part of our vocabulary of healthcare. The fight against disease needs all the help it can get.” Andrew Saul PhD in ‘Fire your doctor: How to be independently healthy’ 2005
Myalgic Encephalomyelitis (M.E.) is a debilitating neurological disease which has been recognised by the World Health Organisation (WHO) since 1969 as a distinct organic neurological disorder. It can occur in both epidemic and sporadic forms, over 60 outbreaks of M.E. have been recorded worldwide since 1934.

What defines M.E. is not mere 'fatigue' but a specific type of acquired damage to the brain (the central nervous system) caused by a virus; an enterovirus. Myalgic Encephalomyelitis is an acutely acquired illness initiated by a virus infection with multi system involvement which is characterised by post encephalitic damage to the brain stem; a nerve centre through which many spinal nerve tracts connect with higher centres in the brain in order to control all vital bodily functions – this is always damaged in M.E. (Hence the name 'Myalgic Encephalomyelitis')

So although M.E. is primarily neurological, symptoms may be manifested by virtually all bodily systems including: cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, gastrointestinal and musculo-skeletal dysfunctions and damage. Symptoms are also caused by a loss of normal internal homeostasis - the body/brain no longer responds appropriately to certain levels of: physical activity, cognitive exertion, sensory input and orthostatic stress.

M.E. is an infectious neurological illness which affects all races and socio-economic groups and has been diagnosed all over the world with a similar strike rate to multiple sclerosis. Children as young as five can get M.E., as well as adults of all ages. M.E. can be extremely disabling. 25% of M.E. sufferers are severely affected and housebound and bedbound. In some cases Myalgic Encephalomyelitis is fatal. M.E. is similar in a number of significant ways to illnesses such as multiple sclerosis, Lupus and Polio.

This is not simply theory, but is based upon an enormous body of mutually supportive research and clinical information. Confirmation of this hypothesis is supported by electrical tests of muscle and of brain function (including the subsequent development of PET and SPECT scans) and by biochemical and hormonal assays. Newer scientific evidence is increasingly strengthening this hypothesis. M.E. is not 'medically unexplained.' If all tests are normal, then a person does not have M.E.
In addition to physical activity, cognitive activity and orthostatic stress patients with Myalgic Encephalomyelitis are also very likely to relapse with anaesthesia and need extra care during all stages of surgery. This is well-documented. The articles below give more information on many of the different issues to be aware of regarding anaesthesia/surgery and M.E. In summary:

- Surgery for the M.E. patient should be avoided if at all possible
- M.E. patients must advise their anaesthetist and doctor of the problems M.E. patients face with anaesthesia (and that their body will not react normally to it in a number of ways) so they can be prepared for this (and educated about it)
- M.E. patients may also want to make their doctors aware of the characteristics (and severity) of M.E. generally (see: What is Myalgic Encephalomyelitis?)
- Patients should also inform the doctors about their orthostatic problems so doctors can avoid placing them in positions which will negatively affect their blood pressure and heart-rate during and post surgery. Patients should also advise doctors of any other relevant problems eg. Known chemical or drug allergies or intolerances etc.
- The M.E. patient should be hydrated prior to surgery and additional saline administered as needed
- Less anaesthetic will often be required than normal for M.E. patients. Doctors/anaesthetists should start with a smaller dose than usual and then add more only if needed
- Caution is required with muscle relaxants and M.E. patients
- M.E. patients may need higher doses of pain medications
- Certain drugs may need to be avoided by those with M.E. (eg. histamine releasing drugs, adrenaline containing injections in dentistry)
- Certain common drugs may be replaced by other drugs that are more suitable. For example, adrenaline containing anaesthesia in dentistry can be replaced with adrenaline and preservative free Prilocaine HCL
- Respiratory functions of M.E. patients should be carefully monitored during surgery, along with cardiac function (these are the two areas most likely to be problematic in these patients)
- Magnesium and potassium supplementation may be required prior to surgery, and supplements such as high-dose vitamin C may be of use before and after surgery (though vitamin C should be avoided the day of surgery)
- Patients should tell their doctors about all herbal medicines they are taking, as well as prescription medication as some of these can adversely affect surgery/anaesthesia
- Longer recovery time should be planned for with M.E. patients as relapse caused by surgery and anaesthesia is common. In some patients this relapse will be very severe and prolonged (perhaps also permanent in some cases; the previous low level of health is never regained)
- M.E. patients may want to consider wearing a medic alert bracelet in case they require emergency surgery and nobody is available to inform the doctors of their M.E. and the extra care that must be taken with regards to surgery and anaesthesia
See the articles below for more information on anaesthesia and Myalgic Encephalomyelitis.

To read more about all aspects of M.E. (and to view the references for the introductory text) see: What is Myalgic Encephalomyelitis? This fully referenced paper can also be downloaded in Word and PDF formats.

Doctors or other hospital staff caring for M.E. patients are also encouraged to read the following papers on this topic:

- Hospital or carer notes for M.E.
- Why patients with severe M.E. are housebound and bedbound
- The importance of avoiding overexertion in Myalgic Encephalomyelitis

Before reading this text, please see the notes below for more information on the terminology of M.E. and ‘CFS’ and why these are anything but synonymous terms.

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**A brief introductory note on terminology and definitions:**

It is important to be aware that Myalgic Encephalomyelitis and 'CFS' are not synonymous terms and should not be used interchangeably, and that 'fatigue' is not a defining nor even essential feature of M.E. M.E. is defined by a variety of serious (testable) neurological, cardiac, cardiovascular, metabolic and other abnormalities - not by mere 'fatigue.'

Myalgic Encephalomyelitis is a distinct, scientifically verifiable and measurable, acute onset, organic neurological disease. ‘CFS’ in contrast, is not a distinct disease. ‘CFS’ doesn’t exist. Every diagnosis of CFS – based on any of the CFS definitions – can only ever be a misdiagnosis.

CFS was created in the 1980s in the US in response to an outbreak of what was unmistakably M.E., but this new name and definition did not describe the known signs, symptoms, history and pathology of M.E. *It described a disease process that did not, and could not, exist.* The fact that a person qualifies for a diagnosis of 'CFS' (a) does not mean that the patient has Myalgic Encephalomyelitis (M.E.), and (b) does not mean that the patient has any other distinct and specific illness named ‘CFS.’

The bogus disease category of ‘CFS’ has undoubtedly been used to impose a false psychiatric paradigm of M.E. by allying it with psychiatric fatigue states and various unrelated fatigue syndromes for the benefit of insurance companies and various other organisations and corporations which have a vested financial interest in how these patients are treated, including the government.
When the terms CFS, CFIDS, ME/CFS, CFS/ME, Myalgic Encephalopathy or ME-CFS are used what is being referred to may be patients with/facts relating to any combination of:

1. Miscellaneous psychological and non-psychological fatigue states (including somatisation disorder)
2. A self limiting post-viral fatigue state or syndrome (eg. following glandular fever/mononucleosis.)
3. A mixed bag of unrelated, misdiagnosed illnesses (each of which feature fatigue as well as a number of other common symptoms; poor sleep, headaches, muscle pain etc.) including Lyme disease, multiple sclerosis, Fibromyalgia, athletes over-training syndrome, depression, burnout, systemic fungal infections (candida) and even various cancers
4. Myalgic Encephalomyelitis patients (despite the fact none of the CFS definitions describes M.E., many M.E. sufferers are given a ‘CFS’ misdiagnosis by default).

The terminology is often used interchangeably, incorrectly and confusingly. However, the DEFINITIONS of M.E. and CFS are very different and distinct, and it is the definitions of each of these terms which is of primary importance. The distinction must be made between terminology and definitions.

**Chronic Fatigue Syndrome** is an artificial construct created in the US in 1988 for the benefit of various political and financial vested interest groups. It is a mere diagnosis of exclusion (or wastebasket diagnosis) based on the presence of gradual or acute onset fatigue lasting 6 months. If tests show serious abnormalities, a person no longer qualifies for the diagnosis, as ‘CFS’ is ‘medically unexplained.’ A diagnosis of ‘CFS’ does not mean that a person has any distinct disease (including M.E.). The patient population diagnosed with ‘CFS’ is made up of people with a vast array of unrelated illnesses, or with no detectable illness. According to the latest CDC estimates, 2.54% of the population qualify for a ‘CFS’ (mis)diagnosis. Every diagnosis of ‘CFS’ can only ever be a misdiagnosis.

**Myalgic Encephalomyelitis** is a systemic neurological disease initiated by a viral infection. M.E. is characterised by (scientifically measurable) damage to the brain, and particularly to the brain stem which results in dysfunctions and damage to almost all vital bodily systems and a loss of normal internal homeostasis. Substantial evidence indicates that M.E. is caused by an enterovirus. The onset of M.E. is always acute and M.E. can be diagnosed within just a few weeks. M.E. is an easily recognisable distinct organic neurological disease which can be verified by objective testing. If all tests are normal, then a diagnosis of M.E. cannot be correct.

M.E. can occur in both epidemic and sporadic forms and can be extremely disabling, or sometimes fatal. M.E. is a chronic/lifelong disease that has existed for centuries. It shares similarities with MS, Lupus and Polio. There are more than 60 different neurological, cognitive, cardiac, metabolic, immunological, and other M.E. symptoms. Fatigue is not a defining nor even essential symptom of M.E. People with M.E. would give anything to be only severely ‘fatigued’ instead of
having M.E.’ Far fewer than 0.5% of the population has the distinct neurological disease known since 1956 as Myalgic Encephalomyelitis.

The only thing that makes any sense is for patients with M.E. to be studied ONLY under the name Myalgic Encephalomyelitis – and for this term ONLY to be used to refer to a 100% M.E. patient group. The only correct name for this illness – M.E. as per Ramsay/Richardson/Dowsett and Hyde, and the more than sixty outbreaks of M.E. recorded worldwide, and so on – is Myalgic Encephalomyelitis.

M.E. is not synonymous with CFS, nor is it a subgroup of CFS. (There is no such thing as a subgroup of CFS; there is no such disease as "CFS.’) M.E. is not a primarily fatiguing condition, nor is it a wastebasket diagnosis or ‘medically unexplained’ as ‘CFS’ is. There is no such disease as ‘CFS’ – that is the entire issue. The vast majority of patients misdiagnosed with ‘CFS’ do not have M.E. The only way forward, for the benefit of society and all patient groups involved, is that:

1. The bogus disease category of ‘CFS’ must be abandoned completely.
2. The name Myalgic Encephalomyelitis must be fully restored (to the exclusion of all others) and the World Health Organization classification of M.E. (as a distinct neurological disease) must be accepted and adhered to in all official documentations and government policy.

For more information on why the bogus disease category of 'CFS' must be abandoned for the benefit of all the patient groups involved, (along with the use of other vague and misleading umbrella terms such as ‘ME/CFS’ ‘CFS/ME’ ‘CFIDS' and 'Myalgic Encephalopathy' and others) see: What is Myalgic Encephalomyelitis?

Before reading these quotes below and documents linked to below, please be aware of the following facts:

1. Myalgic Encephalomyelitis and ‘Chronic Fatigue Syndrome’ are not synonymous terms. The overwhelming majority of research (and articles) on ‘CFS’ or ‘CFIDS’ or ‘ME/CFS’ or ‘CFS/ME’ or ‘ICD-CFS’ does not involve M.E. patients and is not relevant in any way to M.E. patients. If the M.E. community were to reject all ‘CFS’ labelled research/articles as ‘only relating to ‘CFS’ patients’ (including those which describe those abnormalities/characteristics unique to M.E. patients), however, this would seem to support the myth that ‘CFS’ is just a ‘watered down’ definition of M.E. and that M.E. and ‘CFS’ are virtually the same thing and share many characteristics.

A very small number of ‘CFS’ studies/articles refer in part to people with M.E. but it may not always be clear which parts refer to M.E. The A warning on ‘CFS’ and ‘ME/CFS’ research and advocacy paper is recommended reading and includes a checklist to help readers assess the relevance of individual ‘CFS’ studies to M.E. (if any) and explains some of the problems with this heterogeneous and skewed research/advocacy.
Note that the inclusion of a link to an article on this site does not necessarily denote support for all parts of the article it was taken from, or support for the terminology used in this article, nor total support for all articles created by this author.

In future, it is essential that M.E. research again be conducted using only M.E. defined patients and using only the term M.E. and that M.E. activism also focuses entirely on M.E. The bogus, financially-motivated disease category of ‘CFS’ must be abandoned.

2. The research and articles referred to on this website varies considerably in quality. Some is of a high scientific standard and relates wholly to M.E. and uses the correct terminology. Other studies are included which may only have partial or minor possible relevance to M.E., use unscientific terms/concepts such as ‘CFS,’ ‘ME/CFS,’ ‘CFS/ME,’ ‘CFIDS’ or Myalgic ‘Encephalopathy’ and also include a significant amount of misinformation. For more information see A warning on ‘CFS’ and ‘ME/CFS’ research and advocacy and the more detailed paper Putting research and articles on M.E. into context.

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**So you are going to have surgery?** Advice on anaesthetics and pain control for those with M.E. by Dr Dowsett (Word format)

M.E. results in widespread neurological changes throughout the body, which may deteriorate in the older age groups (for example, some 20 to 30 years after onset of their illness). Patients and carers should always take responsibility for informing, reminding, or carrying printed material to G.P.’s other doctors surgeons and dentists involved in planning surgery or making referrals. The best person with whom to discuss this will be the anaesthetist on the team. In case of emergency surgery make sure that relatives or friends accompanying the patient are aware of these problems and can speak to the surgical team. This includes dentistry, orthodontic treatment, day stay or inpatient procedures.

1. Sedative analgesic drugs
These control pain but not inflammation, e.g. codeine and morphine. M.E. patients are nearly always very sensitive to these due to their effects upon the central nervous system, especially the Reticular Activating Spinal Network. This is responsible for maintaining wakefulness and alertness but is frequently damaged especially in young people at the onset of the illness. **Side effects:** may include drug dependency, which is not as common as thought when used in a controlled fashion to prevent severe pain, respiratory depression, postural hypotension, dizziness and fainting and possibly the need for increasing dosage as tolerance develops.

2. Non Sedative analgesic drugs
These include agents such as Paracetamol and several other drugs freely available over the counter (OCT). They control pain but not inflammation and can have serious
side effects if taken in excess, especially upon the liver, and interfere with other drug therapy.
Non Steroid Anti-inflammatory Drugs - e.g. aspirin and Neurofen are sold without prescription but also have serious side effects such as allergy, bleeding, e.g. gastric haemorrhage and interference with other prescribed drugs.

3. Muscle Relaxants
These may be required for general surgery and abdominal operations. They work by blocking nervous transmission to muscles. The effect in M.E., where muscles may be weak, wasted or otherwise damaged is much greater than in normal people.

4. Pain
This is always a serious problem in M.E. and additional or alternative methods of anaesthesia maybe required, e.g. spinal anaesthetic or local nerve block.

5. Dysfunction of the Autonomic and Enteric Nervous Systems
The former may be associated with a rapid or irregular pulse and problems with blood pressure control and the latter with gastrooesophageal reflux and vomiting.

6. Respiratory problems
These can be due to weakness of the diaphragmatic and chest muscles, or to asthma and chronic obstructive airways disease, especially in smokers. The anaesthetist may need to order tests of respiratory function well in advance of any operation.

7. Muscle, Joint and other Orthopaedic Problems
These, together with muscle weakness, may affect the correct support of the patient and the positioning of limbs on the operating table in order to avoid damage to superficial nerves.

Summary
The patient with M.E., compared with a normal person, requires less anaesthetic and caution with muscle relaxants, e.g. half the dose at onset with careful increments during operation, more painkillers, but caution with sedative analgesics and more time to recover. Day surgery may be inappropriate and the need for home support after discharge must be considered. Local anaesthetics, e.g. in dentistry, dermatology, and accident departments should be adrenaline free.

[This article is recommended as a good brief overview to print out for your doctor. Dr Dowsett has treated literally thousands of individual patients with the illness and has over 20 years experience in studying M.E. This is probably the only article here that we can be sure relates 100% to actual M.E. patients. See the notes at the top of this paper for more information.]

Dr Paul R. Cheney, MD, PhD, on anaesthesia in 1992

"I would recommend that potentially hepatotoxic anesthetic gases not be used including
Halothane. Patients with Chronic Fatigue Syndrome are known to have reactivated herpes group viruses which can produce mild and usually subclinical hepatitis. Hepatotoxic anesthetic gases may then provoke fulminate hepatitis. Finally, patients with this syndrome are known to have intracellular magnesium and potassium depletion by electron beam x-ray spectroscopy techniques. For this reason I would recommend the patient be given Micro-K using 10mEq tablets, 1 table BID and magnesium sulfate 50% solution, 2cc IM 24 hours to surgery. The intracellular magnesium and potassium depletion can result in untoward cardiac arrhythmias during anesthesia. For local anesthetics, I would recommend using Lidocaine sparingly and without epinephrine."

[Dr Cheney has treated literally thousands of individual patients with the illness and has over 20 years experience in studying M.E. Unfortunately there is some mixing of M.E. and ‘CFS’ and the terminology used is of ‘CFS.’]


"I have used the following anesthesia with success during surgery on CFIDS patients. First, I perform skin tests for all the agents I am considering with the patient. With CFIDS patients, I recommend Diprivan (propofol) as the induction agent; Versed (midazolam), fentanyl (a short-acting narcotic) and droperidol (an anti-nausea agent) during the anesthetic; and a combination of nitrous oxide, oxygen and isoflurane (commonly called Forane) as the maintenance agent.

In contrast to the above agents, there is a group or commonly-used anesthetic agents which are known to be histamine releasers and are probably best to be avoided by CFIDS patients. This group includes the thiobarbituates such as sodium pentothol, which is probably the most common induction agent, but is a known histamine releaser. In addition, there is a broad group of muscle relaxants in the Curare family, namely Tracrium and Mevacurium, which are also potent histamine releasers and should be avoided by CFIDS patients.

Since so many of these histamine releasing agents are commonly used during emregency surgery, it would be advisable for you to wear a medical alert bracelet in the event you are unconscious and would have to have an anesthetic. I would mention on the bracelet that you cannot receive any histamine releasing drugs."

[Note that no other part of this site is necessarily recommended. The term ‘CFIDS’ is not supported by this site, and note that this term should not be considered synonymous with M.E.]
Enhanced sensitivity of the peripheral cholinergic vascular response in patients with chronic fatigue syndrome

'The results of this study show enhanced cholinergic activity in the peripheral microcirculation of patients with ME/CFS. This enhancement was specific for acetylcholine. We could not determine why the patients have acetylcholine supersensitivity in the skin microcirculation. However, many of the symptoms of chronic fatigue syndrome, such as temperature sensitivity, gastrointestinal difficulties, problems with sleep, and orthostatic intolerance, are consistent with altered cholinergic activity, and the findings might have important implications for features of chronic fatigue syndrome that involve vascular integrity.'

CFS Patent Gow et al.

'Previous reports have hypothesised that CFS is a form of channelopathy - a disorder of membrane ion channels. There are several reports in the literature which we believe strengthen the hypothesis that the vacuolar H+ATPase plays a pathogenic role in CFS.

Local anaesthetics, which are known to act on ion channels, have an adverse effect on patients with CFS/ME. It has been demonstrated also, that in some patients with CFS/ME, there are morphological changes to the red blood cells. Remarkably, a study by Nishiguchi et al, has demonstrated that the local anaesthetic lidocaine can induce reversible morphological transformation of human red blood cells and that this change is mediated by the activation of vacuolar H+ATPase. In addition, Li et al have shown that the gene is involved in iron binding in red blood cells.

The ion channel gene is a member of the vacuolar H+ ATPase proton transporting gene family. This family of genes is directly involved with the phosphocreatine-dependent glutamate uptake by synaptic vesicles. The gene is responsible for vesicle docking/exocytosis during neurotransmitter release and is a major constituent of synaptic vesicles associated with intracellular membrane structures. We have demonstrated, using H MRS that there is a perturbation of the choline/creatine
balance in the CNS. This finding has been corroborated by Puri et al. As stated above, this type of gene is directly involved in the creatine pathways. We have previously demonstrated that patients with CFS have low body-potassium levels. Bailey et al have shown a relationship between potassium depletion and up-regulation of H+-ATPase.

As stated above, viruses have often been associated with CFS. Virus entry into cells may be mediated by H+ATPase. In addition to viral infection affecting neurotransmitter function, there is a large body of evidence to show that the vacuolar H+-ATPase is also invoked.

[This is the only part of this paper relevant to anaesthesia. Note that no other part of this article is necessarily recommended]


[This is cholinergic defect is relevant to problems with anaesthesia in M.E. patients. Note that no other part of this site is necessarily recommended. The term ‘CFS’ is not supported by this site, and note that this term should not be considered synonymous with M.E.]

Herb Cures add to Risk of Surgery from "Metro" Wednesday 11th July 2001 (on 25% M.E. Group)

Commonly used herbal remedies could cause serious complications for patients undergoing surgery, experts warned yesterday. Dangers included bleeding, heart problems, low blood sugar and dangerous reactions with conventional drugs.

Researchers said doctors should obtain a complete history of any herbal medicines their patients were taking before booking them in for operations. They studied the effects of eight popular preparations – echinacea, ephedra, garlic, ginko, ginseng, kava, St John’s wort and valerian.

Direct effects including bleeding from garlic, ginkgo and ginseng, heartbeat irregularities from ephedra and low blood sugar from ginseng. Reactions to drugs involving kava and valerian included increasing the sedative effect of anaesthetics. Among possible risks associated with St John’s wort was a rise in the potency of a range of drugs used during operations.

See more articles on this topic:
Virtual Anaesthesiology Textbook
The Virtual Anesthesiologist
Treating M.E.: The basics

Herbal Medicine & Anesthesia
Herbal Medications and Anesthesia: Another Study Warns About Problems
Herbal Agents and Anesthesia

ME and Surgery from the 25% M.E. Group

‘I have had severe ME since 1992. In 1998 I had a general anaesthetic which affected me very badly, leaving me extremely weak and totally bedbound. I learnt to stand and walk again with the help of a community physiotherapist who came twice a week. It was 11 months before I could walk to the bathroom and two years before I began to pick up again, but I am still not able to walk as far as I could prior to surgery.

The dilemma I now find myself in is that my Consultant has suggested a further operation. I’m wondering if anyone else has had any experience in which they fared better, perhaps their anaesthetist was aware of the potential effects of anaesthesia on severely affected ME patients. Alternatively, has anyone been adversely effected at their first operation and fared better the second time around?

If anyone would like to contact this person, please email the Web Team on webmaster@25megroup.org ‘

[This article is included to illustrate the potential severity of relapses caused by surgery. Relapses from anaesthesia (as well as physical activity) may be long term or even permanent; the previous level of health may never be regained in some cases.]

Recommendations for Persons with Chronic Fatigue Syndrome (or Fibromyalgia) Who Are Anticipating Surgery by Dr. Charles W. Lapp, MD January 8, 2008

Intracellular magnesium and potassium depletion has been reported in CFS. For this reason, serum magnesium and potassium levels should be checked pre-operatively and these minerals replenished if borderline or low. Intracellular magnesium or potassium depletion could potentially lead to cardiac arrhythmias under anesthesia.

Up to 97% of persons with CFS demonstrate vasovagal syncope (neurally mediated hypotension) on tilt table testing, and a majority of these can be shown to have low plasma volumes, low RBC mass, and venous pooling. Syncope may be precipitated by catecholamines (epinephrine), sympathomimetics (isoproterenol), and vasodilators (nitric oxide, nitroglycerin, a-blockers, and hypotensive agents). Care should be taken to hydrate patients prior to surgery and to avoid drugs that stimulate neurogenic syncope or lower blood pressure.

Allergic reactions are seen more commonly in persons with CFS than the general population. For this reason, histamine-releasing anesthetic agents (such as pentothal)
and muscle relaxants (curare, Tracrium, and Mevacurium) are best avoided if possible. Propofol, midazolam, and fentanyl are generally well-tolerated.

Most CFS patients are also extremely sensitive to sedative medications - including benzodiazepines, antihistamines, and psychotropics - which should be used sparingly and in small doses until the patient’s response can be assessed.

Herbs and complementary and alternative therapies are frequently used by persons with CFS and FM. Patients should inform the anesthesiologist of any and all such therapies, and they are advised to withhold such treatments for at least a week prior to surgery, if possible. Of most concern are:

1. *Garlic, ginkgo, and ginseng* (which increase bleeding by inhibiting platelet aggregation);
2. *Ephedra or ma huang* (may cause hemodynamic instability, hypertension, tachycardia, or arrhythmia),
3. *Kava and valerian* (increase sedation),
4. *St. John’s Wort* (multiple pharmacological interactions due to induction of Cytochrome P450 enzymes),
5. *Echinacea* (allergic reactions and possible immunosuppression with long term use).

The American Society of Anesthesiologists recommends that all herbal medications be discontinued 2 to 3 weeks before an elective procedure. Stopping kava may trigger withdrawal, so this herbal (also known as awa, kawa, and intoxicating pepper) should be tapered over 2 to 3 days.

HPGA Axis Suppression is almost universally present in persons with CFS, but rarely suppresses cortisol production enough to be problematic. Seriously ill patients might be screened, however, with a 24-hour urine free cortisol level (spot or random specimens are usually normal) or Cortrosyn stimulation test, and provided cortisol supplementation if warranted. Those patients who are being supplemented with cortisol should have their doses doubled or tripled before and after surgery.

Summary Recommendations
1. Ensure that serum magnesium and potassium levels are adequate.
2. Hydrate the patient prior to surgery.
3. Use catecholamines, sympathomimetics, vasodilators, and hypotensive agents with caution.
4. Avoid histamine-releasing anesthetic and muscle-relaxing agents if possible.
5. Use sedating drugs sparingly.
6. Ask about herbs and supplements, and advise patients to taper off such therapies at least one week before surgery.
7. Consider cortisol supplementation in patients who are chronically on steroid medications or who are seriously ill.
8. Relapses are not uncommon following major operative procedures, and healing is said to be slow.

Anaesthetics and ME

A Consultant Anaesthetist (Dr F.L.M of the McNeil Centre for Research in Anaesthesia Philadelphia)
“When there may be neural involvement by a disease, spinal or epidural anaesthesia is not recommended because of the risk of worsening symptoms” “Normally, a depolarizing muscle relaxant is used, (but) in persons with neuromuscular disease such as demyelination, which has been decribed for (ME), this drug has a known risk of causing potassium release from muscle, which can lead to cardiac arrest” “Because of chronic muscle weakness, breathing may be impaired (and) muscle weakness increases the risk of respiratory failure” “More care than usual is appropriate in the case of (ME)”.

Caesarean Sections

'Whether you are considering an elective cesarean or are just aware that an emergency section may be necessary there are several issues surrounding c-sections that are of particular interest to ME/CFS sufferers.'

[Note that this is not necessarily a recommendation of any other part of this site, and is not a recommendation of the term ‘ME/CFS’]

Anesthesia & Procedure Preparation Information

Factors to consider for anesthesia include speaking to the anesthesiologist ahead of a procedure about your blood pressure and heart rate variabilities, choosing the type and dosage of anesthesia to minimize symptoms during and after, and even what positions your body will be in and for how long while under anesthesia and how that will affect your [illness]. Preparations include adjusting medications and supplements to decrease bleeding time, increasing supplements that promote wound healing if you have good experience with them, and adding in guided mediation for a successful outcome.

Our short answer
Our one minute answer for this complex topic is: ask for non-histiming releasing
anesthetics and ask for a lower than normal dose if you are drug sensitive. Give overseers permission to add more in needed, better to add more later than start too high. Ask for your blood pressure and heart rate to be monitored extra carefully since you might have a very sensitive autonomic nervous system. If you have pre-medicated with antibiotics before for procedures, check the latest guidelines. If possible and appropriate in your case, ask for the IV fluid to have potassium in it. (Ringer's Lactate solution has both calcium and potassium in it and was very good for my home IV rehydration approach. Plain saline was too stimulating. -Elly.) For more in depth discussion, keep reading...

You have valuable experiences to consider
Consider your past experiences with surgical anesthetics, dental anesthetics, prescription pain medications, and over the counter pain relievers. Also, think about any herbs, supplements, drugs, and foods that are known to dilate or constrict blood vessels. Anything unusual in your history could be a good clue for determining how to best proceed. Maybe you can spot a pattern about classes of drugs. Perhaps you can remember if you had something before that worked well and track down its name.

IV difficulties: Spasming blood vessels, being too upright
In a great MVPS/Dysautonomia video, Al Davies, MD, of Mediscene, spoke of how many people have their blood vessels go into spasm, making it very difficult to properly insert a needle or catheter. Keeping up our treatments that help our other kinds of spasms, electrolytes (calcium, magnesium, time-release prescription potassium) and using calming techniques (guided imagery, focusing on being there for help, distracting yourself) can help. Just letting the nursing staff know you go into spasm and extra patience is required on everyone's part may help everyone relax and succeed.

Ask the staff if you can lie down when they insert the IV needle in preparation for any procedure last week. You may not have needed to in the past, but if you are doing worse, this may help you get through a long stressful procedure. You may have to ask days in advance of procedure, and then again the day before, and then the day of. You may have to ask your doctor to write a note about it with the referral for the procedure. Inform nurses about any vasovagal syncope (fainting) reactions you've had in similar situations. Report tendencies to feel faint often, especially when dehydrated or hungry/fasting.

Fasting
Many procedures require fasting. Many of us don't do so well if we get too hungry. If this is true for you, insist upon or ask for your doctor's help in getting the earliest possible appointment in the day that makes sense for you. Some people get more nauseated and weak from having not eaten and they can't make it through a procedure. Ask if food really affects the results, how much, and if the choice is to relapse and not make it through the test vs eating a little because you need to complete it if they will make an exception.

Blood Volume, Hydration

www.hfme.org
Often there is giving blood for tests beforehand, taking your fluids, electrolytes, plasma and all those other goodies in blood. Just drinking water or water and electrolytes is not going to replenish you enough, and probably not fast enough. Ask if can do any of the blood work longer in advance so they can take less closer to the procedure. Tell them if you usually feel worse after giving the blood for blood tests. Sometimes they take large amounts of blood -- and don't really expect it could have an effect on someone, even if they know you suffer from dehydration. Spell it out, calmly repeat it, write it down for them, put it on a medical alert document.

Staying hydrated, keeping the water and electrolytes intake is great, but it can be overdone. That water has to go somewhere and there may be no opportunity once procedure starts to use a restroom. Always use the last chance they offer to empty your bladder. If you need a wide open IV, you may need a urinary catheter so you won't be so uncomfortable. Consider a moderate, but steady amount of oral fluids or a slow but steady IV drip instead.

Go without
Several procedures can be done with less or no anesthesia! Perhaps you don't need any or the same kind most people get. Dentists can do small to medium fillings with no anesthetic. For some surgical procedures that most people get general anesthesia, it is possible to ask for a local and stay conscious.'

Medical ID, Wallet Cards

Sometimes, just having a medical ID shows you've gone to the trouble of putting this information in one place and feel it important enough to show and that can get you some respect. Until you can set one up, carry some index cards or a page of information in your wallet or purse to refer to or hand to someone if you can't talk. You may need one approach for general and one for emergencies.

Having a wallet ID card or an medical condition identification dog tag or such is one thing, knowing what to put on it is another! Sometimes it can be better to just say the simplest of things on the ID, and keep updating a file elsewhere. Some suggestions from our members have been drug sensitivities, complicated history, heat sensitivity, needs IV fluids, dehydrates easily, sensitive to anesthesia, orthostatic intorance, postural tachycardia, wheat and dairy sensitivity, administer Ringer's lactate, reclining recommended.

[Note that this is not necessarily a recommendation of any other part of this site]

David S. Bell, MD, FAAP, Published in Lyndonville News, September 2001

Patients with CFS struggle with anesthesia. If a CFS patient has surgery, there is the additional burden of recovering from the surgery on top of [the symptoms of the illness] to start with. While this is an over-simplification, I think the concept works.

Years ago, I had expected CFS patients to be dropping like flies during surgery,
surgeons not understanding the illness, anesthesiologists using the wrong anesthesia and an already fragile state to begin with. But it hasn't happened. So, general advice for a patient with CFS would be, Don’t have surgery if you don’t need it, but if you have to have it, have it and expect to feel even more [ill] for a while afterwards. Somehow this statement does not seem very elegant.

There has been concern that the type of anesthesia is critical. My personal feeling on this is that the type is not so important, but the amount of fluid support is going to determine how [ill] you feel afterward. I have heard some patients say that with an extra liter of saline they seemed to recover quite well. So I would advise the anesthesiologist not to be stingy with the saline unless there were clear indications to cut back on fluids. This area could be studied if there were interest among physicians, but so far it has not been.

[Note: Dr Bell does not seem to be aware of the serious/life threatening cardiac and respiratory problems which can occur during surgery in patients with M.E. Nonetheless, they do exist and are well documented. One can only assume that Dr Bell does not see very severely affected patients perhaps, or even that he no longer sees M.E. patients AT ALL but instead treats various fatigue patients misdiagnosed as CFS. Bell’s most recent work on ‘fatigue’ and ‘CFS’ makes this hypothesis seem very likely. He seems to have abandoned studying M.E. and is now focused solely on various fatigued patient groups, sadly.]

Tips on Anesthetics and Hospitalization for People with Multiple Chemical Sensitivities by Susan Beck

Hospitalization For The Chemically Sensitive Selene Anema, RN.

Summary of Anesthesia Issues for Post-Polio Patients

Read Dr. Calmes' article, "Anesthesia Concerns for the Polio Survivor," from the Spring 1997 issue of Polio Network News (now Post-Polio Health).

Two case studies of ‘CFS’ anaesthesia from India

[This article on anaesthesia mixes primarily ‘CFS’ information with a small amount of M.E. information. The patients involved may have ‘CFS’ or M.E., it is impossible to tell from the information given. This article reinforces many harmful myths about M.E. and its link to ‘CFS.’]
NCF Anesthesia protocol for ‘CFIDS/ME’

The protocol recommends that any anesthesia avoid using the sodium channel.

[Note that this site is not recommended. The site, including this article on anesthesia mixes primarily ‘CFS’ information with a small amount of M.E. information.]

Surgery Compiled by Melissa Kaplan

(This first section is paraphrased from the site, by M.E. patient Lesley)

ANAESTHESIA
- potentially hepatotoxic anaesthetic gases should not be used (Cheney) (also Lapp)
- anaesthetic with adrenaline (epinephrine) should not be used (Cheney)
- histamine releasers, including sodium pentothal, should not be used (Patrick Class)(also Lapp)

DRUGS
- muscle relaxants in the Curare family, such as Tracrium and Mevacurium, should not be used (Patrick Class)

WOUND HEALING
- wound healing in ME patients may be abnormally slow

POSSIBLE PROBLEMS DURING SURGERY
- ME patients may have intra-cellular magnesium & potassium depletion, causing cardiac arrhythmia under anaesthetic. Patient should be given magnesium & potassium before surgery (Micro-K using 10mEq tablets, 1 table BID and magnesium sulfate 50% solution, 2cc IM 24 hours to surgery) (Cheney) (also Lapp)
- catecholamines, sympathomimetics, vasodilators, and hypotensive agents should be used with caution on ME patients (Lapp)
- ME patients should be hydrated prior to surgery (Lapp)

Surgeons, anesthesiologists and support staff need to be aware of the following anomalies:
- neurally mediated hypotension (NMH) or orthostatic hypotension (OI)
- low red blood cell count
- low blood plasma volume
- hypercoagulation (thick blood - a low sed rate [0-5] is often seen)
- alkalotic (urine pH < 6, venus blood ph > 7.4)
- drug and food sensitivities
- chemical sensitivities, including plastics, vinyl, disinfectants
- poor absorption of nutrients in the gut
- leakage out of the gut ("leaky gut") of non-assimable particles
Treating M.E.: The basics

- abnormally low (up to 50% below normal) oxygen release from red blood cells
- 80+% chance of severe herxheimer effect from some antibiotics
- many supplements act as blood thinners and anticoagulants
- low NK levels, or abnormal numbers of immature NK cells, coupled with hyperactive Th2 immune activity

[Note that this is not necessarily a recommendation of any other part of this site]

Informal notes on the issue of funding biomedical research into ME/CFS
Margaret Williams, 17th July 2006

Some local ME groups have already generated and run small-scale projects in conjunction with local universities, but are in need of central financial support to replicate their findings (which are important in helping to manage the day-to-day problems that are seen in ME/CFS). Some of these studies have involved identifying key features of ME/CFS, for example, in conjunction with the University of Sunderland, the local ME group identified a hypersensitivity to adrenaline in local anaesthesia used in dental practice, which, because of the induced cardiovascular responses, has immediate value and ought to lead to a broader study. Taking care not to use adrenaline makes a big difference to patients' well-being and safety, not to mention to the stress levels of dental practitioners. Other local group findings relate to pain control, for instance, the study of the slow infusion of lignocaine carried out by a consultant rheumatologist, with promising results. Unfortunately, the rheumatologist in question is about to retire and his replacement is refusing to continue with the study. Surely the practical implications to the enhanced well-being of those with ME/CFS of such studies deserve the relatively modest financial support that is needed?

[Note that the term ‘ME/CFS’ is not supported by this site, and note that this term should not be considered synonymous with M.E.]

Hospitalization for the Chemically Sensitive Patient, in Loving Memory of Selene Anema, RN

Diagnosing Food and Chemical Susceptibility. WJ Rea. Continuing Education Sept 1979:47-59

Immunology and Anaesthesia. PJ Simpson. Anaesthesia Review 1985:67-84


What to do if you have ME. *MEAC 1987*

Anaesthetics; and ME / CFS. *ANZMES 30: 1988*


Ask the Doctor. CFIDS Chronicle, Summer 1994:82

Anaesthetics and ME / CFS. ME Singles Newsletter, Summer 1996

Some anaesthetics may pose a risk to sensitive people. Article. *Green Network Feb 1997.13*


CFIDS and anaesthesia: what are the risks? EA Crean. *CFIDS Chronicle, Winter (January) 2000:11-13*

**Disclaimer:** The HFME does not dispense medical advice or recommend treatment, and assumes no responsibility for treatments undertaken by visitors to the site. It is a resource providing information for education, research and advocacy only. Please consult your own health-care provider regarding any medical issues relating to the diagnosis or treatment of any medical condition.

**Relevant quotes**

It is increasingly clear that in [M.E.], a diminished threshold for oxygen toxicity exists, and that each patient will have a unique threshold. These findings have a significant negative effect on Emergency Room (A&E) and operating theatre uses of oxygen during surgery – a patient with [M.E.] could be given too much oxygen and be killed on the operating table. Hyperbaric oxygen could have a very negative impact on some [M.E.] patients. Dr Paul Cheney [video lecture]
Section A: Food as medicine in M.E
‘The road to health is paved with good intestines.’ Dr Sherry Rogers.

M.E. sufferers will need to modify their diet post-illness and work to improve their gut health.

There is no single diet that will be suitable for every person with M.E. unfortunately. The best diet is one that makes you feel as well as possible, is as practical, varied, nutritious and healthy as possible and that lets you maintain your most healthy weight.

**Summary of main points: What to avoid**

- Avoid processed foods as much as possible
- Work out what foods you are allergic to or intolerant of using either an elimination diet, the pulse test or IgG testing and avoid those foods and work on healing the gut so that food allergies caused by gut issues no longer occur
- Work out which foods don’t digest well and avoid those foods (eg. raw vegetables and fruit or whole nuts with skins on)
- Avoid stimulants (coffee), sugar and chemical sweeteners such as aspartame
- Avoid yeasty, mouldy or pasturised fermented foods (breads, cheeses and vinegars)
- Avoid wheat and soy (and possibly all grains and legumes)
- Consider avoiding foods from the nightshade family (potato/tomato/eggplant) and limit goitrogens
- Avoid eating a very high carbohydrate diet, with little protein or fat
- Avoid fasting or juice fasts

**Summary of main points: What to eat**

- Eat primarily a whole foods diet with lots of variety
- Eat as many different meats, seeds and different-coloured fruits and vegetables as possible
- Try to have some protein, fat and carbohydrate with each small meal or snack
- Eat healthy fats and proteins until satiety, and limit carbohydrate intake to what your body can handle; probably somewhere between 60 and 150 grams of (digestible) carbohydrate a day is ideal
Try to eat a small meal at least every 3-4 waking hours
Buy organic, locally grown and non-GMO foods as much as possible
Drink 2.4 litres of filtered water daily

This list may seem overwhelming at first, but remember that you may not need to make absolutely all changes, and that you can change perhaps only one thing a week or a month and that there is no need to make all changes all at once. Finding the right diet for you takes time and lots of trial and error.

Diet is so important in M.E. It has such a strong effect on the immune system, our hormones, our gut health and our level of neurological and cognitive problems and our ability to detoxify and so on. The right diet can increase or reduce cancer risk. Treating the gut problems of M.E. is also one of the first steps in treating M.E. itself and cannot be ignored.

The health of the gut affects our neurological health to a significant degree. Diet can also increase or reduce inflammation and have positive or negative effects on all sorts of different hormones and neurotransmitters. Food affects the body in the same powerful ways as do prescription drugs, and so must be considered with the same amount of respect.

Food is not merely fuel, it is MEDICINE.

Good gut health involves the entire digestive system including the liver, pancreas, bowels and gallbladder, not just the stomach.

Good gut health may involve:
- Drinking adequate filtered water
- Eating a varied whole foods diet
- Avoiding foods which you are allergic to or intolerant of and foods which irritate the gut
- Taking Betaine HCl or apple cider vinegar or similar if stomach acid is low
- Taking digestive enzymes to reduce the load on the pancreas
- Taking a good quality probiotic product daily and/or homemade 24 hour yogurt
- Taking dietary and other steps to heal a ‘leaky gut’ or increased intestinal permeability
- Coffee enemas, Silymarin, lipoic acid, FIR saunas and other liver health boosting treatments
- Doing a periodic gallbladder flush or castor oil pack
- Adjusting the diet (or doing a vitamin C or magnesium flush or an enema) so that there are 2-3 bowel movements daily and at the very least, one bowel movement daily
- Strict toxin avoidance
- Avoiding overexertion and ‘running on adrenaline’ generally and especially around mealtimes
For more information on eating a nutrient dense diet and improving gut health generally see the following excellent books:

- Eat Fat, Lose Fat by Sally Fallon
- Nourishing Traditions by Sally Fallon
- Deep Nutrition: Why Your Genes Need Traditional Food by Catherine Shanahan
- Good Calories, Bad Calories: Fats, Carbs, and the Controversial Science of Diet and Health or The Diet Delusion: Challenging the Conventional Wisdom on Diet, Weight Loss and Disease (or the shorter version, Why We Get Fat: And What to Do About It) by Gary Taubes
- Breaking the Vicious Cycle (The SCD diet book) by Elaine Gottschall
- The GAPS diet book by Natasha Campbell-McBride
- The Primal Blueprint by Mark Sisson or Primal Body, Primal Mind: Beyond the Paleo Diet for Total Health and a Longer Life by Nora T. Gedgaudas
- The Coconut Oil Miracle by Bruce Fife and Jon J. Kabara (or any other Fife book on coconut oil).
- No More Heartburn: The Safe, Effective Way to Prevent and Heal Chronic Gastrointestinal Disorders by Sherry A. Rogers
- The Untold Story of Milk By Ron Schmid
- Salt your way to health by Dr Brownstein

These books are the main references used in the ‘Food as Medicine’ paper. The authors of most of these books, with the exception of Dr Rogers and some others, also have websites where you can get much of the information for free.

For more information on all aspects of M.E. treatment please see: Treating Myalgic Encephalomyelitis. This is THE most important document for M.E. patients!

Important papers in the document include:

- Symptom-based management vs. deep healing in M.E.
- Recognising and managing healing reactions in M.E.
- Deep healing in M.E.: An order of attack
- Important notes on using the HFME’s treatment information

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This paper will be continue to be updated regularly (at least annually). Please check back at the website periodically to make sure that you have the most up-to-date version of this paper available.
1. Eat primarily a whole foods diet with lots of variety

Processed food contains far fewer nutrients than fresh unprocessed food and often contains many harmful chemicals. Eat as many different meats, seeds and different-coloured fruits and vegetables as possible. This makes sure you get lots of different nutrients and also can help prevent intolerances to certain foods developing.

Fresh food is best. Frozen food is to be avoided where possible, but is still a far better choice than canned food which should be avoided.

It is important that M.E. patients have as nutrient dense and antioxidant rich a diet as possible, and include as many different types of foods as possible. Try to include:

- Up to 60 - 120 grams of seeds and nuts, raw and UNROASTED (especially sesame seeds, almonds, cashews, walnuts, pistachios and macadamias) and preferably soaked in salted water for 6 – 12 hours and then dried.

- Five to ten or more serves of vegetables (especially broccoli, broccoli spouts, broccolini/tenderstem, cabbage, cauliflower, brussel spouts, garlic, spinach, lettuce, cucumber, zucchini, avocado, radishes, turnips, parsnips and carrots) moderately cooked or slow cooked to preserve more enzymes and vitamins and to make them more digestible than raw vegetables. ‘Baby’ varieties of vegetables are especially good too if you can get them.

- One to three serves of fruit, (especially bananas, berries, cherries, melons, peaches, pineapple, apples and plums). Try to eat a lot of different colours of fruit and vegetables. Cooked fruit may be digested more easily.

- Quality protein sources (cooked through, but not excessively browned or blackened if possible as this creates problems with oxidation) such as organic chicken, turkey or red meat and eggs, plus some fresh or frozen fish. Tuna etc. should be limited to once a week or less due to its mercury content. Raw fish (sushi) is also good so long as you can get fresh uncontaminated fish. Chicken or beef livers are also a good meat choice, although they must be organic and only eaten a few times a week otherwise too much vitamin A may be taken in.

- A small serve daily of medicinal honey such as Manuka or Tea tree may be beneficial.

- Herbal teas may be helpful; mint tea for digestion, ginger for nausea, green tea for antioxidants and so on.
• Extra coconut oil for cooking and olive oil for dressing vegetable dishes.

Almost all food in the supermarket is processed in some way, but when experts talk about avoiding processed food, what is being referred to is probably better described as heavily processed food. For example, packets of raw shelled nuts and seeds, packets of dried fruit and so on are of course processed foods, but they are only very minimally processed. They have been ‘messed with’ only in very minor ways, and are not much changed from their original state. These types of products contain only ‘real’ ingredients and no extra additives or cheap fillers (although it pays to check the labels for hidden dangers in some brands/products).

Heavily processed foods would include things like cakes and biscuits, chewing gum and chocolate bars, sauces and gravies, instant noodles, potato chips and ice cream. Many other products will be somewhere in-between these two extremes and you’ll have to use your own judgement about whether or not they are healthy choices for you. You may find that it depends a lot on the brand and type of product, and that you need to read all labels carefully. Avoid artificial preservatives, colourings and flavourings.

The amount of nutrients and vitamins in plants starts being reduced as soon as it is picked, and the longer the time between when plants and picked and eaten the worse the loss is. If you or someone you live with enjoys gardening, you might consider starting a vegetable patch so you can eat food as soon as it is picked.

Eat the fruits and vegetables that are in season.

2. Buy organic food as much as possible
All food should be organic wherever possible, or at least very well washed or peeled where appropriate. Organic unprocessed whole foods should make up most of your diet. A second best to organic produce is locally grown produce.

Avoid GM (genetically modified or transgenic) foods as much as possible. Many processed food products contain GM foods. Fresh fruit and vegetables are usually safe, but watch out for seedless grapes and seedless watermelon.

If budget allows, organic grass-fed beef and lamb and free range chicken is the best choice along with organic free-range eggs.

3. Investigate your individual food allergies and intolerances
Food allergies and intolerances are extremely common in M.E. Both food allergies and food intolerances may also occur and can fluctuate with the severity of the illness. A rotation diet may be necessary for some sufferers (where particular foods are eaten only once in a 4 day period).
Food allergies are IgE mediated (and so may be tested for using standard tests) and include most commonly: eggs, corn, milk, soy, sugar, wheat, and yeast.

IgG food allergies may now also be tested for. (York labs and VRP let you do this testing at home, although the tests are quite expensive; York labs far more so than VRP). Or you can try to identify them yourself using an elimination diet. i.e. Eating a very limited diet for 14 days or more and then slowly introducing suspect foods back in one at a time each 48 hours and monitoring yourself for any ill effects. Note that IgG allergies can often be delayed up to 3 days, while IgE allergies occur within an hour of ingesting the offending food.

A pulse test can also be useful in determining reactive foods. The pulse is taken before eating, and 30 minutes after eating for several hours. A consistent speed up of the pulse after eating a food signifies an allergy or intolerance to that food.

Wheat, rye and barley contain the allergens gluten and gliadin. Oats only contain gluten.* If you can’t tolerate wheat, rye or barley you might be able to get away with eating oats (if you are only sensitive to gliadin and not gluten). Otherwise, you might want to try brown rice, millet and/or buckwheat.

(*Note that gluten-free oats are now available. New research shows that actually oats don’t contain gluten naturally, but almost all oat products are contaminated with it during processing, in the form of wheat. What this means is that even if you are sensitive to gluten, you should be able to tolerate certified gluten free or wheat free steel cut oats. If you have a severe gluten problem however, you must check with your doctor first.)

4. Avoid sugar and sweeteners
Sweeteners include sugar, dextrose, glucose, fructose, high fructose corn syrup, splenda, aspartame and saccharin. Stevia is safe to use in moderation although it seems to cause severe headaches in some patients.

Avoid products which are modified to be very low fat or fat free as they will often be full of either enormous amounts of sugar or chemical additives or both and will often have the same calorie content anyway, or leave you feeling so unsatisfied due to the lack of fat that you need to eat twice as much!

Sugar is an anti-nutrient and has many serious negative effects and so must be avoided as much as possible. If you are eating a lot of sugar, reduce your levels slowly to minimise withdrawal symptoms (and be prepared to be in a terrible mood for a while!). Eliminate or at least significantly reduce high Glycaemic index/load and high sugar foods such as large amounts of rice, milk and milk drinks, fruit yogurt or flavoured commercial yogurt and ice cream, commercial breakfast cereals (all of them), corn and potatoes (and go easy on bananas and mangoes and dried fruit too), all commercial fruit juices, sugary sauces, pasta and soft drinks (soda) and anything
else containing high levels of sugar, preservatives and other problematic chemicals, trans fats, hydrogenated oils or that is heavily processed or that is ‘fast food.’

Some recommend a fructose malabsorption test, and following a low fructose diet. A diet low in carbohydrate/sugar can also help to reduce symptoms of noise sensitivity/hyperacusis (and Candida problems).

5. Avoid stimulants
Stimulants such as coffee, tea, caffeinated soft drinks, some herbal teas which contain ginseng, lomatium, mate and ma huang should be avoided by the M.E. patient.

6. Avoid MSG and Aspartame (NutraSweet)
Aspartame and MSG (and cysteine) must be very strictly avoided by all M.E. patients as they can cause the disease to seriously worsen. They are excitotoxins and contribute to neurodegeneration. According to neurosurgeon Russell Blaylock M.D., author of ‘Excitotoxins, the Taste That Kills’ excess glutamate literally excites neurons to death—they run out of energy, degenerate, and die. The easiest way to avoid MSG and Aspartame, and all other excitotoxins, is to avoid all processed foods as most/almost all processed foods contain excitotoxins.

If you do eat processed food, make sure to avoid those containing hydrolysed vegetable protein, yeast extract or autolysed yeast, calcium caseinate, sodium caseinate, gelatin, hydrolysed oat flour, potassium glutamate, plant protein extract, carrageenan or vegetable gum, chicken, beef or pork smoke flavourings, soy sauce, (most but not all) whey protein and soy protein and anything ultra pasteurised, protein fortified or fermented as these are hidden sources of MSG or glutamate. Avoid especially commercial soups, sauces, and gravies, stocks, broths, and bouillons. (Although glutamate is a normal neurotransmitter in low doses, some experts argue that free glutamates in high doses over time can have the same affect as MSG.)

Often these excitotoxins may simply be labelled as ‘natural’ flavourings. (This list is taken from the book The Brainpower Plan which also explains: ‘Researchers for food giants clamour on about glutamate not being able to reach an intact blood-brain barrier, but this is not true because glutamate has been shown to enter the brain where there is a chronic elevation of blood glutamine present.’)

Note that the glutamates in meat and eggs do not cause the same problems to intestinal villi inducing malabsorption of nutrients and then shower the body with their inflammatory lectins once absorbed by the body as do foods such as wheat, dairy and soy.

7. Avoid soy and wheat (and possibly all grains and legumes)
There is information which suggests that M.E. patients (as with MS patients) should avoid gluten even if we can’t detect an obvious reaction to it, which means avoiding wheat, rye and barley. The Good Health in the 21st Century book explains that all opiates from all sources, including those found in gluten and diary products, can deregulate the activity of NK cells.

All grains including corn, plus soy and all legumes may well be best avoided in M.E. Gluten and soy contain very high levels of dietary estrogens, which are inflammatory, immune suppressive, and neurologically stimulating. They are also rich in the non-essential, neurostimulating amino acids glutamate and aspartate. For more information on avoiding these foods, see Foods to Avoid, Foods to Enjoy, The Epilepsy Diet Made Simple and the gut absorption recovery diet (GARD). See also: Why the food pyramid with its recommended 10 or so serves of grains a day isn’t healthy, and why whole grain wheat products are not health food.

See also: Gluten ataxia in perspective and Effects of wheat germ agglutinin on human gastrointestinal epithelium: insights from an experimental model of immune/epithelial cell interaction.

This is a very complex subject and there are a lot of opposing views. My personal opinion, which has changed recently with some of the books I have been reading, is that there are good reasons for those with autoimmune diseases to completely avoid all grains (including corn), legumes (including sprouted grains and legumes which still contain saponins, which contribute to a ‘leaky gut’) and soy products, whether an obvious reaction to them has been observed or shown in testing, or not.

For more information see: The Paleo Diet Cookbook and Good Health in the 21st Century.

For more information on saponins and lectins see the ‘Increased intestinal permeability (‘leaky gut’), lectins, saponins, gliadin, phytic acid and M.E.’ paper. This paper also contains a summary of the Paleolithic diet.

An important note on Coeliac disease and a gluten-free diet: If there is any chance that a person may have celiac disease, they should only embark on a gluten-free diet once they've already been tested for Coeliac disease. Unfortunately, the various tests available don't work for those who have been on a gluten free diet, and if the person’s condition deteriorates and they suspect they have Coeliac disease, they will be too ill to do the gluten challenge that is necessary to get an accurate test result (which requires large amounts of gluten to be eaten for weeks at a time). Also note that occasionally tests for gluten sensitivity return false negatives. Unfortunately, all tests so far (except the gene test which only rules out genetic susceptibility to Coeliac disease) require the consumption of gluten. Those with very severe reactions to gluten that are very ill and unable to do the gluten challenge may be advised that testing isn’t worth it and that if you have a strong reaction from just a small amount of gluten, you just shouldn't consume it. Sadly, patients with non-diagnosed Coeliac
disease may not receive many of the benefits that those with a formal diagnosis have easy access to.

8. Avoid heavily processed dairy products
Commercial dairy products made with cows’ milk should also be avoided by M.E. patients. They are a highly processed food and the pasteurisation process damages the proteins in the milk making them more allergenic.

All pasturised milk products are not healthy food choices as the process of pasturising milk damages the proteins in it. Modern dairies freely use antibiotics on the cows and the milk may contain high levels of growth hormone. But many people including those that cannot drink commercial dairy foods have no problem at all drinking properly prepared raw milk from certified dairies. This includes dairies producing cow’s milk and also possibly milk from other animals such as goats. Dairy products from goats’ milk may be better tolerated than products made from cows’ milk.

You may want to go dairy-free for 3 months, then slowly add back raw goat or raw cow milk products and monitor yourself for symptoms. The trial should be discontinued if negative effects occur. If no negative effects are evident, even after going on and off raw dairy foods several times, then you can healthfully add raw dairy products to your diet. Raw milk contains enzymes and beneficial bacteria that aid in its own digestion.

Good quality full-fat raw milk is safe to consume, despite the wealth of misinformation surrounding it which would suggest otherwise. However, raw dairy products may cause problems for those with very weak immune systems such as AIDS patients, and so M.E. patients should try this food (in the form of 24 hour yogurt) very slowly at first and perhaps delay trying it unless they feel they have a little bit of strength to spare at the time of the trial.

Some patients will do better with no dairy, while some may do very well with some raw milk products that have been cultured and do not contain high levels of lactose. The best choices are homemade ghee and 24 hour homemade raw milk yogurt. Plain raw milk is not a good choice as it is high in lactose, a type of sugar.

The Western A. Price website says,

Pasteurization destroys enzymes, diminishes vitamin content, denatures fragile milk proteins, destroys vitamins C, B12 and B6, kills beneficial bacteria, promotes pathogens and is associated with allergies, increased tooth decay, colic in infants, growth problems in children, osteoporosis, arthritis, heart disease and cancer. Calves fed pasteurized milk do poorly and many die before maturity. Raw milk sours naturally but pasteurized milk turns putrid; processors must remove slime and pus from pasteurized milk by a process of centrifugal clarification. Inspection of dairy herds for disease is not required for pasteurized milk. Pasteurization was instituted in the 1920s to combat TB, infant diarrhea, undulant fever and other diseases caused by poor animal nutrition and dirty production.
methods. But times have changed and modern stainless steel tanks, milking machines, refrigerated trucks and inspection methods make pasteurization absolutely unnecessary for public protection. And pasteurization does not always kill the bacteria for Johne’s disease suspected of causing Crohn's disease in humans with which most confinement cows are infected. Much commercial milk is now ultra-pasteurized to get rid of heat-resistant bacteria and give it a longer shelf life. Ultra-pasteurization is a violent process that takes milk from a chilled temperature to above the boiling point in less than two seconds. Clean raw milk from certified healthy cows is available commercially in several states and may be bought directly from the farm in many more.

Please note that this website recommends Real Milk—that is, milk that is full-fat, unprocessed, and from pasture-fed animals. We do NOT recommend consumption of raw milk from conventional confinement dairies or dairies which produce milk intended for pasteurization. Nor do we recommend the consumption of lowfat or skim raw milk—there are important protective factors in the butterfat. Real Milk, that is, raw whole milk from grass-fed animals (fed pasture, hay and silage), produced under clean conditions and promptly refrigerated, contains many anti-microbial and immune-supporting components; but this protective system in raw milk can be overwhelmed, and the milk contaminated, in situations conducive to filth and disease. Know your farmer! For sources of raw milk, go to our WHERE pages or contact your nearest local chapter of the Weston A. Price Foundation.

9. Avoid nightshades
Foods from the nightshade family (potato, capsicum, eggplant and tomato and tobacco), often cause problems for those with arthritic-type pain and may need to be avoided by some patients. Others may be able to tolerate small to moderate amounts of these foods with no problems. Patients may wish to avoid these foods for 3 months or so and monitor their symptoms before deciding whether or not to include these foods in the diet.

Lipoic acid made from potatoes should be avoided by those with nightshade sensitivities.

These foods also contain compounds which can contribute to a ‘leaky gut’ and so these foods may be best avoided whether reactions are evident after eating them or not. For more information see: ‘Increased intestinal permeability (‘leaky gut’), lectins, saponins, gliadin, phytic acid and M.E.’

10. Strictly avoid fasting
Fasting should be strictly AVOIDED by all M.E. sufferers (including juice fasts) as this can lead to relapse and severe worsening of symptoms or even be dangerous.

11. Work out the protein, carbohydrate and fat ratio that is right for you
Many sufferers will do better on a moderate protein and moderate carbohydrate diet and by eating small meals every 2-4 hours. High carbohydrate diets and low salt, low fat or very low calorie diets are not appropriate for M.E. sufferers, generally speaking. Try to have some protein, fat and carbohydrate with each small meal or snack in order to make you feel full and to prevent high insulin levels (which causes many serious problems as well as promoting weight gain).

That old line that ‘a calorie is a calorie is a calorie’ is actually not true. A group of people on diets with the same lowered calorie content but with different amounts of protein, carbohydrate and fat will lose very different amounts of weight, or weight can even be gained when a diet is very high in carbohydrate.

As the book Mastering the Zone explains, ‘A calorie of fat has a different hormonal effect than a calorie of protein, which has a still different hormonal effect than a calorie of carbohydrate.’

The easiest way to start is to eat good fats and high-quality protein until you are satiated, eat unlimited non-starchy vegetables but limit carbohydrate intake to 60 – 100 grams spread throughout the day, or perhaps 60 – 80 grams if you desire to lose weight. There is no need to count calories even if you are trying to lose weight and 2000 – 2500 calories a day is probably ideal, according to Sally Fallons excellent book Eat Fat, Lose Fat.

If you prefer a more mathematical approach you could go to a website like www.nutritiondata.com or www.whfoods.com and try to put together a diet where your calories are made up of 20% protein, 50% good fats, and 30% (low glycaemic load) carbohydrates. See how you feel after a few weeks on such a diet and then make any changes that you think will suit you better. If you need to lose weight you might try restricting (digestible) carbohydrates to 60 – 80 grams a day.

For more information on losing weight slowly and safely, and without calorie restriction, see the excellent book Eat Fat, Lose Fat. This book also contains lots of information about how to eat to heal the body as well.

A summary of the Paleolithic diet is given in the ‘Increased intestinal permeability (‘leaky gut’), lectins, saponins, gliadin, phytic acid and M.E.’ paper. For more information on losing weight and managing hypoglycaemia in M.E. see the paper ‘Hypoglycaemia, insulin resistance and M.E.’

12. Avoid bad fat and eat good fats.
Avoid high levels of animal fats as they may not be digested easily, and can increase inflammation. Trim all your meat well and buy the leanest mince you can. Eggs do contain animal fat, but also contain many other beneficial nutrients. Avoid trans fats and hydrogenated oils, these mostly occur in processed foods. Vegetable oils should also be avoided.
The best oils to use are olive and coconut oils. Healthy fats are also contains in nuts and seeds and avocados. Don’t aim for a fat free diet if you have M.E.; eating good fats is enormously important in M.E. Getting 30% of your calories from fat is an absolute minimum and many of us need a lot more fat than that to be healthy.

The diet described in this paper is also an anti-inflammation diet. Note that the most inflammation promoting foods are animal fats from red meat and egg yolks, and vegetable oils such as corn oil and the oils used in margarines (which are high in Omega 6 fatty acids and polyunsaturated, and cause an inflammatory response in the brain). You may like to read Cancer and Inflammation. Books promoting the Paleolithic Diet (Hunter-Gatherer) are good resources for M.E. patients.

13. Consider daily vegetable juicing
For more information see: Fruit and vegetable juicing and M.E.

14. Make your diet pH balanced
A rough guideline is to eat 75-80% alkaline foods and a maximum of 20-25% acid forming foods. For a list of which foods are in each category, click here. (You can buy urine or saliva test strips to test your acid balance at home. These strips are also available from VRP and iHerb.)

For more information read the article Acid-base or pH Balancing by Lawrence Wilson MD.

15. Limit excessive goitrogen intake
Goitrogens are compounds contained in some foods that can interfere with the absorption of iodine into your body and can result in poor thyroid gland function or thyroid gland enlargement (goiter).

Foods that contain goitrogenic compounds are soy beans, Brussels sprouts, broccoli, spinach, strawberries, peaches, pears, bok choy, radishes and horseradish, cabbage, cauliflower, peanuts, millet, pine nuts, collard greens, Kale, canola and canola oils, mustard greens, flaxseed, hemp seeds, pumpkin seeds, turnips and rutabagas.

Some of these foods, such as the cruciferous vegetables (broccoli, cabbage etc.) are high in goitrogens, while others such as peaches, strawberries, bamboo shoots, millet, peanuts, pears, pine nuts, radishes, strawberries, sweet potatoes and spinach are considered by most sources to be only mildly goitrogenic.

The good news is that many health professionals believe that cooking may inactivate goitrogens. Boiling broccoli is said to reduce the goitrogen content by 1/3. It is recommended that you cook goitrogenic foods, both the vegetables and the fruits, and also limit their consumption somewhat. Moderate intake may be okay but high intake is probably best avoided.
How much cooking is necessary is unclear. Some sources recommend 10 minutes cooking to inactivate goitrogens, others 30 minutes, and others still talk about steaming vegetables as being enough to deactivate significant amounts of the goitrogen content from food.

There are also certain chemicals which can have a goitrogenic effect on your thyroid function. They include: Amiodarone, carbamazepine, iopanoic acid, Lithium, phenobarbitone, phenytoin, potassium perchlorate, propylthiouracil, rifampin, sulfadimethoxine and SSRI’s like Celexa and others. Gluten may also inhibit thyroid function.

Dr. Brownstein states that taking more iodine will counteract eating some goitrogenic foods and that fluoride, chlorine and bromides are goitrogens too.

For more information see the articles Eat goitrogens in moderation….and that includes soy and soya!, What are goitrogens and in which foods are they found? plus Dr David Brownstein’s book IODINE: Why you need it Why you can't live without it. See also: Adrenal and thyroid issues and M.E.

16. Other foods which can cause problems.

- Gas producing foods (onions, cabbage, brussels sprouts, broccoli),
- Spicy foods (chilli may contribute to a ‘leaky gut’)
- Raw foods (which may be very difficult to digest, and to chew)
- Wheatgrass juice does not contain gluten but it seems to still cause problems for many with celiac disease, and still contains some of the substances which cause problems with those with a wheat allergy. Wheatgrass juice also contains lectins which can leave you feeling ill, and so is probably best avoided. These symptoms can sometimes unfortunately be mistaken for a ‘detox reaction.’ Wheatgrass also contains WGA (wheat germ agglutinin) which is an antinutrient that may potentially have adverse health effects.
- Acid foods.
- Alcohol and cigarettes may also be poorly tolerated and should be avoided. (Cigarettes, like many paints, contain cadmium which is quite toxic). Alcohol intolerance in particular is very common in M.E.; alcohol should be avoided as this can worsen the illness significantly.
- Avoid nitrates as they are carcinogenic and often used in ham, bacon and salami etc.
- Avoid fermented and mouldy foods such as vinegar, mustard, mushrooms and cheese etc. Some self-serve bins at supermarkets and health food stores may have mould problems.
Avoid very well browned/blackened food as this increases free radical formation. Cook food through, but try not to excessively brown food or cook at very high temperatures.

Legume sprouts still appear to contain considerable concentrations of saponins; the secondary compounds responsible for increasing gut permeability. Alfalfa sprouts (which are actually in the pea family) have an especially high concentration.

Egg white is a complex mixture of 40 proteins, about a third of which have toxic or lethal effects in bacteria and microorganisms similar to lectins. Some experts suggest that eggs whites may play a role in autoimmune disease and that this food should be avoided by patients with M.S. and other autoimmune diseases such as M.E. Some such as Dr Mercola suggest that eating eggs raw may avoid most or all of the allergens. He writes, ‘Eggs generally are one of the most allergic foods that are eaten, but I believe this is because they are cooked. If one consumes the eggs in their raw state the incidence of egg allergy virtually disappears. Heating the egg protein actually changes its chemical shape, and the distortion can easily lead to allergies. So, if you have not been able to tolerate eggs before you will want to consider eating them uncooked.’ Read the entire raw egg article before trying this if you have an egg allergy, and be aware that many patients still report egg allergy problems with raw eggs.

Some experts recommend that patients with autoimmune diseases strictly avoid tomatoes due to their tomato lectin content which has the capacity to interact with the immune system in a way that may promote autoimmune disease. Tomatoes also contain alpha tomatine which can act as an adjuvant and boost the immune response to tomato lectin, and also increase gut permeability.

Flax has been questioned as a food due mainly to the presence of toxic cianoglicosides (limarin), vitamin B6 antagonist factors and other antinutritional factors, including cyanogenic glycosides, trypsin inhibitors, phytic acid, allergens, and goitrogens. Human consumption of flax is banned in France and limited in Germany, Switzerland, and Belgium. The USDA puts a limit on the amount of flaxseed that can be included in human diets. Like many other foods (cashews and some beans etc.), flax contains very small amounts of cyanide compounds, especially when consumed raw. 2 tablespoons daily is sometimes recommended as a maximum daily dose. For more information see the WAPF site.

All salicylates, whether natural or synthetic, may cause problems for those who are intolerant towards them. They can worsen the pain of inflammation. Overall, most fruits, especially berries and dried fruits, contain high levels of salicylates. As a general guide, fruits with a less sharp flavour such as pears, pawpaw and mango are often lower in salicylates compared to those with a sharp flavour such as oranges, berries and pineapples. Salicylate content is often contained in the peel of fruit and vegetables. Herbs and spices contain extremely high levels of salicylates, as do many brands of coffee. Patients with
inflammatory conditions such as Lupus are said to function best on a low salicylate, alkaline-forming diet. (It is also sometimes recommended that patients with Lupus avoid eating oranges.)

17. Maintain a healthy weight as much as possible
M.E. makes gaining weight extremely easy for many of us, unfortunately. Losing excess weight is important in M.E. due to the cardiovascular aspects of M.E. Excess bodily fat can also promote higher levels of inflammation. If you need and want to lose weight, this must be done very slowly, just 0.5 – 2 kg or 1 – 4 pounds a month roughly at most, and without causing any hunger or weakness or increases in symptoms (and of course, without increasing activity levels beyond your limits, or at all).

To lose weight safely, you may wish to look at books such as The Schwarzbein Principle (which advocates eating healthy fats and proteins until satiety and limiting carbohydrate to 60 grams daily, spread equally over 3 meals and 2 snacks a day) and Eat Fat, Lose Fat.

Fasting should be strictly AVOIDED by all M.E. sufferers (including juice fasts) as this can lead to severe symptom worsening/relapse or even be dangerous (as with similar diseases such as mitochondrial diseases). Tests which require fasting beforehand may not be possible for some M.E. patients.

Of course some M.E. sufferers instead have the at least equally difficult problem of needing to gain weight. Tips on gaining weight include cooking foods such as vegetables so that you can fit more of them in, extra protein shakes and nuts and oils, avoiding very-low carb diets and foods that you are allergic to or that disrupt bowel health or cause loose stools. Most important is a deep healing program that looks at all the problems the body is having as a whole, and attempts to correct them.

For more information on losing weight in M.E. see the paper ‘Hypoglycaemia, insulin resistance and M.E.’

18. Drink enough water
Drinking around 2.4 litres of water daily is also important. Dr Cheney says while it is common for M.E. to cause excessive thirst (in a bid by the body to increase blood volume and improve cardiac insufficiency) that water intake should not exceed two litres unless there is a lot of sweating. Some of us may need an extra glass of water daily on top of this amount, and feel very unwell without this extra intake, but be very careful adding much more than that (and make sure you read the section on adding electrolytes to your water).

You CAN drink too much water, and this can be dangerous or even fatal; it is up to you to carefully work out how much water you need to function optimally. As a
general rule, if your urine is clear you have had too much water, and if it is deep yellow, orange or brown you need more water. Urine should be straw coloured/pale yellow, some say even colourless. If your lips are dry/painful, it might mean you need more water.

Some doctors recommend that for optimum digestion of food, water (and cold water especially) should not be consumed for 10 minutes before, and 2 hours after meals. Following this recommendation would mean taking tablets that need to be taken with food 10 – 15 minutes before meals. (Taking tablets with food means taking them during a meal, or 15 minutes before or after a meal.) There is disagreement over whether or not avoiding water consumption during and after meals makes any difference to digestion. If digestion problems are significant, this idea may be worth a try.

For information on which type of water filter is best, and why plastic cups, jugs and water bottles should be avoided, see: Toxin avoidance and M.E. For information on the importance of staying hydrated see: The Dangers of Dehydration

19. Just do your best with your diet
Sticking to a strict diet 100% of the time is something that few if any of us will find easy. Having a strict diet to follow that is quite different from the average diet can be hard mentally, physically, financially and also socially. Choosing foods for health reasons when most people choose foods because they taste nice, are familiar, cheap and convenient is hard.

Reasons for non-compliance with dietary restrictions include:

- The fact that it is almost impossible to resist sugar and carbohydrate cravings during and after overexertion.
- Budgetary constraints.
- Problems preparing food due to illness.
- Problems buying food due to illness.
- Problems checking each condiment label carefully for harmful ingredients due to illness.
- Problems chewing some foods due to illness.
- Cravings for foods that one has an allergy to.
- Nausea.
- Feeling like you just have to have some sort of treat and food is one of the very few treats you are still able to have while being so ill.
- Being unsure of what the best things to eat are.
- Feeling the need to fit in with what other family members or friends are eating.
- Feeling the need to eat a certain food so you don’t appear rude to friends and family.
- Needing to eat so often, which can leave you with no ‘safe’ foods left at the end of the day.
The symptoms of most food problems are delayed rather than immediate which can make them easier to ignore, and some affect health negatively overall rather than causing identifiable symptoms.

- A desire to sometimes eat the foods you grew up eating and have many memories around.
- A desire to want to eat a certain way for ideological reasons, which can make you ignore signs that the diet is not appropriate for you (e.g. vegetarianism or veganism).
- A desire to be part of a celebration or a cultural or religious event linked to certain foods.

It is just not true that a diet isn’t worth sticking to if you can’t follow it perfectly. Benefits can still be had where there is a high degree of compliance that isn’t 100%. While having high standards and taking this subject seriously is important, few of us probably manage to eat perfectly for years at a time. (I sure don’t, unfortunately.) We need to find the balance between constantly beating ourselves up for not being ‘perfect’ and also not having very low standards which negatively impact our health and wellbeing in the short- and long-term.

Some patients advocate the ‘I’m ill and life is hard so I may as well treat myself with foods I like each day, even if I know they aren’t good for me’ idea. I’d argue that although dietary changes are hard and annoying and often not fun, ignoring something that has such a huge potential to improve our health long-term and can stop improvements from occurring if ignored, when the disease is as hideously severe as M.E., just doesn’t make sense.

It is important to read as much as you can on the topic of diet, have the appropriate tests, take the time to work out what the ideal diet is for you at this time and try to follow that diet as closely as possible – allowing for the various constraints you are dealing with.

Good gut health is essential to improving any disease. So just do your best with your diet, accepting that you are human and will make mistakes. Check out the ‘Healthy treats’ page for some restricted-diet-friendly recipes.

Additional notes:
- Note that none of these dietary changes will instantly cure M.E. (and anyone who claims they do is not talking about legitimate M.E. patients!) but they may significantly reduce some symptoms and aid healing and so very much affect quality of life and even the course of the disease to some extent. You may be surprised how much better you feel with the right dietary changes, even if your disability level changes little, at first.
- In addition to avoiding chemicals which cause reactions, cigarettes and alcohol should also be avoided (alcohol may even cause disease progression in mitochondrial diseases such as M.E.).
Note that in imperial measurement 1 litre = 0.22 gallons.

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This paper is an attempt to summarise and simplify the information contained in the best books on diet.


**Foods to eat**

**Seasonal vegetables.**
Special emphasis on green leafy vegetables, cruciferous vegetables and sea vegetables and other colourful vegetables. Preferably organic or locally grown. Best slow cooked until just soft and cooked through. 5 – 10 servings daily.

**Seasonal fruits.**
Not as nutrient dense or important as vegetables, and the high carbohydrate content of some fruits must be taken into account. Preferably organic or locally grown. 1-2 pieces daily is ideal, especially if weight gain is an issue.

**Fresh vegetable juice.**
An excellent addition to the diet daily or at least weekly. Must be freshly pressed. Best when made with a special emphasis on green leafy vegetables. Preferably use...
organic or locally grown or home grown produce. Small amounts of sour fruits such as berries, lemons and green apples can be added for flavour.

**Eggs.**
Four or more can be eaten daily, with or without the whites. Some of the whites should be discarded if lots of eggs are eaten or eggs are eaten raw (egg whites contain an anti-nutrient that is partially destroyed by cooking). Preferably organic and free-range.

**Meats.**
The best choices are organic and free-range or pastured/grass fed meats cooked with the bones in. Buying organic meats should be a higher priority than buying organic fruits, vegetables and other foods. Game meats are also an excellent choice. Try to eat lots of different types of meats if possible rather than sticking to one type. Meats should not be overcooked or excessively browned.

**Organ meats.**
Organ meats can be far more nutritious than muscle meats. The best choice is liver and this should be eaten at least once a week if possible. Sourcing high quality organic and free-range or pastured/grass fed livers is a must. Avoid livers from commercially farmed animals. Brains are also very nutritious.

**Bone broths.**
Stock made by cooking bones with water for 6 hours or more is very healing for the gut and nutritious; full of minerals, gelatine and glucosamine. It also tastes wonderful when used as the base for soups or sauces and a big batch can be frozen for later use. Sourcing bones from high quality organic and free-range or pastured/grass fed animals is ideal.

**Raw cultured vegetables.**
A small amount of unpasturised raw cultured vegetables eaten with each meal can aid digestion and provide probiotics. Small amounts of unpasturised apple cider vinegar or Swedish bitters taken in water with meals can also have the same effect. Sauerkraut, ginger carrot or kimche can be made easily and cheaply at home.

**Homemade yogurt and kefir.**
Homemade yogurts contain vastly more probiotics than in-store varieties especially if they are allowed to culture for 24 hours. Kefir is a yogurt-like drink that contains beneficial yeasts as well as probiotics and is also easy to make at home. Yogurt can be made with coconut milk, or good quality raw organic milk. Kefir can be made with coconut milk or water, raw milk or a combination of water and sugars such as molasses. Non-dairy yogurt and kefir may be the best choice for many patients especially while the gut is healing.
Nuts and seeds.
Choose organic nuts and seeds if possible. Always soak and dry or soak and sprout seeds and nuts before eating them, to make them easier to digest. Avoid pre-roasted or salted nuts and seeds. Avoid peanuts (a legume) due to mould content.

Healthy fats for use heated.
The best fats to cook with are the stable saturated fats such as organic virgin coconut oil, palm oil, butter or ghee and lard or tallow. Olive oil can also be used for cooking but only at moderate temperatures. Oils should not be heated above 160 degrees C/320 degrees F. Around 30 – 60% of the calories in the diet should come from fats. Adding 1 – 3 tablespoons of virgin coconut oil to the diet daily has many health benefits.

Healthy fats for use unheated.
Good quality flaxseed oil, pumpkin seed oil, olive oil and avocado oil can be used in small amounts to dress vegetable dishes.

Herbs and flavourings.
Lots of garlic and ginger and other herbs are okay to use, especially fresh herbs. Spicy condiments may be better avoided. Raw honey has many health benefits and can be used to add flavour to drinks and other dishes in small amounts (due to a high carbohydrate content). Unrefined sea salt should be used liberally to add flavour to all types of meat and vegetable dishes.

Foods to think about
Some foods are neither good for everyone or bad for everyone, but fit into a sort of grey area. Their merits and lack of merit are often debated passionately by health experts, with much disagreement. These include:

Grains and legumes.
Grains and legumes are problematic as they contain phytates, lectins, opiates (grains), gluten (grains), can be estrogenic and mimic hormones (soy) and are very high in carbohydrate. This makes eating them in large amounts little different to eating pure sugar. Grains and legumes can significantly contribute to weight gain, hypoglycaemia and lack of satiety after meals. They are also highly allergenic foods, may cause digestion problems due to high fibre content and may be very mouldy and toxic (sprayed with anti-mould agents and pesticides). Grain and legume crops are also disastrous from an environmental standpoint and there is some good evidence that our genes are just not designed to handle grains and legumes in our diets, and certainly not in the large amounts often eaten today.
Many people will do best if grains and legumes are avoided entirely. But it does seem as if some people can do okay eating them in limited quantities. Trial and error is the only way to work out which group you are in at this time, although some experts do recommend strictly avoiding all dairy foods and gluten while you are trying to heal a damaged gut.

If grains and legumes are eaten this is probably best done only in small amounts, and restricted to those grains and legumes that are organic (and so not genetically modified) and have been properly prepared by soaking and drying, sprouting or fermenting. Soy foods should be avoided by pregnant women, babies and small children and eaten only in small amounts and in traditional fermented forms by others.

Nightshade vegetables.
Foods from the nightshade family – potato, capsicum, eggplant, tomato and tobacco – often cause problems for those with arthritic-type pain or autoimmune disorders and may need to be avoided by some patients. Others may be able to tolerate small to moderate amounts of these foods with no problems. Patients may wish to avoid these foods for 3 months or so and monitor their symptoms before deciding whether or not to include these foods in the diet.

It should also be noted that even if no negative effect is seen when adding these foods to the diet that these foods also contain compounds such as saponins which can contribute to a ‘leaky gut’ and so these foods may be best avoided whether reactions are evident after eating them or not.

Dairy products.
Commercially available pasturised and homogenised dairy products are highly processed and anything but healthy natural whole foods. The Western A. Price website says,

Pasteurization destroys enzymes diminishes vitamin content, denatures fragile milk proteins, destroys vitamins C, B12 and B6, kills beneficial bacteria, promotes pathogens and is associated with allergies, increased tooth decay, colic in infants, growth problems in children, osteoporosis, arthritis, heart disease and cancer.

Processed milk can cause allergies and be very difficult to digest. Lactose intolerance is one issue surrounding milk but there are also many others. For example, modern dairies freely use antibiotics on the cows and the milk may contain high levels of growth hormone.

The best choices of dairy foods are organic ghee (clarified butter), 24 hour homemade organic raw milk yogurt and homemade organic raw milk kefir. When
raw milk is made into yogurt or kefir the sugars are eaten by the probiotic bacteria, leaving you with a very low lactose food that is digested very easily. Plain raw milk is not a good choice as it is high in lactose, a type of sugar.

Some people seem to do very well eating small amounts of raw, high fat and fermented dairy products, while others are best off avoiding all dairy products. Trial and error is the only way to work out which group you are in at this time, although some experts do recommend strictly avoiding all dairy foods and gluten while you are trying to heal a damaged gut. Aside from the various health concerns many people also believe that it is just not natural or a good idea to drink milk once we are no longer babies, or from other animals, and this is also a valid point.

**Raw vegetables and fruit.**
Many of us may be better off avoiding raw fruits and vegetables. Cooked (but not overcooked) vegetables are much easier to chew and to digest. Some patients also need to strictly avoid eating over-ripe fruits.

**Coffee.**
Coffee can contribute to a ‘leaky gut’ and can also worsen adrenal exhaustion issues. Some experts advise avoiding coffee entirely, while others feel that a cup a day is fine so long as it isn’t providing an ‘energy boost’ effect in any way. (If it is this means that it is stressing your adrenals and so detrimental to your long-term health.)

**High fibre foods.**
Gut healing diets such as the GAPS diet and the specific carbohydrate diet recommend avoiding high fibre foods while you are working on healing the gut. This would include grains and legumes as well as fibrous vegetables such as parsnip and the woody parts of broccoli and cauliflower.

**Disaccharide and starch containing foods.**
Gut healing diets such as the GAPS diet and the specific carbohydrate diet recommend avoiding disaccharide and starch containing foods while you are working on healing the gut.

Most sugars and all grains are disaccharides and must not be consumed while on GAPS as a compromised gut wall is unable to digest them. Starches in the form of potatoes, sweet potatoes, arrowroot flour, potato flour, cocoa powder and almost all beans and legumes must also be avoided as starch is also a complex molecule that is not well digested when gut function is poor. (Undigested food in any form provides the perfect environment for pathogenic viruses, bacteria, and fungi to thrive.)

Small amounts of high-fibre flours such as coconut flour may be okay for some patients but may cause issues for others.
Foods containing fructose.
Some patients have an issue with fructose absorption.

Protein powders.
Protein powders can be useful in providing an easy source of protein especially where eating is difficult due to illness. But protein powders are also a high processed food and some health experts recommend avoiding them entirely. They are probably best kept for emergencies and for use in patients that have a need for a liquid diet or that are not able to taken in other forms of protein. A protein shake is not the best way to get your protein but is far preferable to not taking in enough protein at all.

Foods to avoid

- Sugar
- Large amounts of high carbohydrate foods and too much of the daily calories coming form carbohydrates with not enough fat and protein.
- Highly processed foods including all boxed cold cereals, biscuits, crackers etc.
- Table salt
- Artificial sweeteners
- Stimulants (coffee)
- Overcooked foods
- Overheated and oxidised oils
- Pre-roasted nuts
- Tinned foods should be minimised or eliminated, with the possible exceptions of foods such as tinned sardines and coconut milk
- Unnatural oils such as all margarines, processed vegetable oils and unnatural trans fats
- Foods containing bromides such as bread
- Mouldy, yeasty or vinegar containing foods (with the exception of unpasturised apple cider vinegar and brewers yeast)
- High mercury fish such as tuna
- MSG containing foods (products containing hydrolysed vegetable protein, yeast extract or autolysed yeast, calcium caseinate, sodium caseinate, gelatin, hydrolysed oat flour, potassium glutamate, plant protein extract, carrageenan or vegetable gum, chicken, beef or pork smoke flavourings, soy sauce, (most but not all) whey protein and soy protein and anything ultra pasteurised, protein fortified or fermented as these are hidden sources of MSG or glutamate.)
- Excessive goitrogen intake
Notes

1. Vegetarian diet: A healthy vegetarian diet is very possible, if lots of eggs and raw milk and saturated fats in the form of coconut and palm oil are eaten, according to the Weston A. Price Foundation (WAPF).

They do warn that it is not possible to get all the nutrition we need from a vegan diet and that this can have serious consequences for health, usually in the individual in the short and long-term, but certainly and more worryingly in the next generation. An extremely low-fat or low-protein vegetarian diet is also not recommended. See the WAPF site for more information.

2. Weight loss. Slow weight loss is best and is best achieved (as the books listed below explain) by eating good quality proteins and fats to satiety and limiting carbohydrate intake to 50 to 100 grams daily. This should be made up of mostly non-starchy vegetables and a small amount of fruit. There is no need to restrict non-starchy vegetable intake and these vegetables should be eaten in large quantities. Fat should make up 30 – 60% of daily calories. There is no need to restrict calories or to exercise to lose weight. For maintenance carbohydrate intake is raised to 75 – 150 grams daily, depending on individual tolerance. For more information see:
   - Eat Fat, Lose Fat by Sally Fallon.
   - The Primal Blueprint by Mark Sisson.
   - The Schwarzbein Principle by Dr Schwarzbein.
   - Why We Get Fat and Good Calories, Bad Calories by Gary Taubes.

3. Hypoglycaemia. The best diet to control hypoglycaemia is the diet outlined above in the section on weight loss. Eating 6 or more small meals daily may also help, along with making sure to have some fat or protein with very carbohydrate food you eat. Eating ample protein and fat is important in controlling hypoglycaemia.

4. Very low carbohydrate diets. These diets may be fine for some individuals but some doctors comment that those patients with certain metabolic or adrenal problems and that have problems converting protein to carbohydrate easily do best when they take in a moderate amount of carbohydrate through their diet. M.E. patients may feel better long-term on diets which contain at least 50 grams of carbohydrate daily and are probably best advised to avoid very low carbohydrate diets at least in the long term. Eating 20 grams of carbohydrate or less daily may be problematic long term and cause stress on the body as well as unnecessarily restricting nutrient-dense vegetable intake.

5. Functional foods. Patients should add functional foods such as high-probiotic yogurt, kefir, garlic, vegetable juices, cultured vegetables and raw milk to the diet very slowly, to avoid relapses caused by healing reactions. This is explained in more
6. Macronutrient ratios. The easiest way to work out your own healthiest macronutrient ratios is to eat good quality fat and protein until satiety, eat non-starchy vegetables abundantly and then to add the amount of fruit and starchy vegetables that doesn’t upset your blood sugar levels, doesn’t take away your satiety after meals or cause weight gain. Probably somewhere between 50 and 150 grams of carbohydrate daily. Your body will let you know how much protein and fat it needs and most of us will not overeat these foods, in the absence of a too-high carbohydrate intake.

- Fat should generally make up 30 – 60% of calories daily. We need at least 30% of our calories from fat to be healthy. At least 2-3% of this 30% should be in the form of omega 6 fatty acids, and at least 1-1.5% should be in the form of omega 3s – from food or from a combination of food and supplements. In the case of a 2000 calorie diet this would mean 2.2-3.3 grams of omega 3 fatty acids daily, and 4.4 – 6.7 grams of omega 6 fatty acids. These percentages should be doubled during pregnancy, explains lipid expert Mary Enig Phd.

- Too much protein is harmful to the kidneys and high fat diets are far healthier than very high protein diets, which can stress the kidneys. Eating too little protein is also undesirable. Protein should generally make up 15 – 30% of daily calories.

- Carbohydrates should generally make up roughly 15 – 40% of daily calories, depending on individual carbohydrate tolerance and whether or not there is a need or desire to lose weight.

For more information on macronutrient ratios see:

- Eat Fat, Lose Fat by Sally Fallon.
- The Primal Blueprint by Mark Sisson.
- The Schwarzbein Principle by Dr Schwarzbein.
- Why We Get Fat and Good Calories, Bad Calories by Gary Taubes.

More information

For more information on any of the books recommended in this paper please see the Book Reviews page on the HFME website.

For more information on diet please see the entire Food as Medicine paper on the HFME website.
This paper looks at which nutrients it is better to get in food form rather than as a supplement in powder, capsule or pill forms.

The benefits of getting as many nutrients as possible from your diet include:

- Money saved on supplements
- Need to buy fewer supplements and so less shopping hassle
- Unhealthy foods and anti-nutrient foods are replaced with nutrient dense foods
- Food sourced nutrients may perform better than supplements
- Food sourced nutrients may contain co-factors that supplements lack
- Taking fewer pills can decrease the load on your digestive system and so improve digestion
- The consumption of fillers in pills is minimised

This paper is coming soon!
Section B: More information on dietary and health issues
Hypoglycaemia

Blood sugar control may be able to be improved with supplementation with: vitamin C and D and the B vitamins, chromium, vitamin B5 (as Pantethine if possible), biotin, magnesium, manganese, zinc and vanadium. (Do not take a higher dose of Vanadium than is suggested on the bottle.)

Hypoglycaemia in M.E. is also affected by low cellular energy levels, hence why people with M.E. have very severe hypoglycaemia during and after overexertion. M.E. patients often exhibit abnormal glucose tolerance curves on testing. However, this test (and finger-prick tests of blood glucose levels) may also be normal in M.E. (and other diseases involving problem with ATP production such as post-polio syndrome) despite very clear problems with foods high in carbohydrate and sugars.

Patients with M.E. may also have a delayed effect with the GGT, registering a normal test result during the three hour duration of the test but then feeling extremely unwell and collapsing for an entire day an hour or more later.

As Dr Wilson explains in his excellent article on Hypoglycemia,

Confusion occurs regarding the definition of hypoglycaemia. The standard medical definition is a serum glucose level of less than about 65 mg/ml.

However, many patients undergoing a glucose tolerance test or GTT experience symptoms of hypoglycaemia in spite of normal serum glucose levels.

I heard of one case in which a patient undergoing a 5-hour GTT ripped off her clothes and ran naked through the streets, although her serum glucose level was normal. In a less dramatic example, another patient fainted right in their chair during the test when the serum glucose was normal. Clearly the GTT is missing something.

What is missing is a better definition of hypoglycaemia. It is not just low glucose in the blood. It is really related to low energy production at the cellular level. What happens during a GTT is that just giving a dose of sugar by mouth, as is done for this test, upsets glucose metabolism sufficiently that the entire glucose regulatory mechanism is occasionally thrown out of kilter and this produces the bizarre symptoms. It also produces false positives, false negatives and other aberrations on the GTT. If the laboratory measured the insulin levels during the test, as Dr. Robert Atkins, MD and others have suggested, it would give a much clearer picture. But even with this, it is only measuring sugar in the blood.

What is required for energy production? Adequate cellular energy production requires that enough glucose reaches the cells, not only an adequate
supply of glucose, but also that it finds its way into the cells through the cell membranes. Once in the cells, it also requires that the mitochondria of the cells are able to burn or metabolize the glucose to form ATP. It also requires that the ATP is able to be utilized, meaning consumed or metabolized to ADP, and then recycled or reprocessed again into ATP. In short, any problem in these chemical pathways will cause hypoglycemic symptoms.

Dr Norman Shealy explains that any endocrine dysfunction in the pancreas and adrenal glands as well as the pituitary, thyroid or sex glands may result in organic hypoglycaemia. Poor liver function can also be a cause.

For these reasons, hypoglycaemia in M.E. may also be improved with various mitochondrial supports and also adrenal, thyroid and liver supports. Probably the best way to treat it is to improve the condition overall however and to instigate a deep healing program.

Dietary changes are also important in managing hypoglycaemia. Dr Lawrence Wilson explains that chronic low glucose levels often occur where adrenal and thyroid output is low. (Low adrenal and thyroid output is almost universal in M.E.) This can make patients constantly crave sweet foods, and sometimes starchy or salty foods as well. Eating protein or fat every few hours and eating 5 or 6 small meals a day helps manage this problem. When protein intake is low, cravings for sweet foods can become extreme in this instance. This is an attempt to compensate for low blood sugar levels. Raising protein and fat in the diet and cutting right back on sweet and starchy foods will reduce the stress on the adrenals and pancreas and allow them to rebuild.

As the GTT is such an incomplete test and many patients know very well before the test that fasting and drinking the sugar solution will make them feel terribly ill, M.E. patients are also most likely best off avoiding the relapse-inducing GTT and instead having a simple finger-prick blood glucose level test.

Repeated severe attacks of hypoglycaemia can cause permanent brain damage.

**Insulin resistance**

Weight loss and weight gain independent of dietary changes are both common in M.E. but if you seem to be suddenly gaining more weight (particularly around the stomach area), you may have developed a problem with insulin resistance (in women this may also be diagnosed as polycystic ovarian syndrome or PCOS).

25 – 40% of the population may suffer with insulin resistance and the percentage of those that have a milder problem with carbohydrates may be as high as 75%. Some people deal with carbohydrates in food very well, but many of us do not!

The symptoms of insulin resistance include: tiredness, intestinal bloating, hypoglycaemia, feeling sleepy or passing out after eating high carbohydrate foods.
such as pasta or desserts, feeling hungry or craving something sweet after you’ve just eaten, weight gain particularly around the stomach or buttocks, skin tags, feeling agitated and moody with almost immediate relief once food is eaten and/or dark patches of skin (especially around the neck).

Excessive intake of carbohydrates is usually what causes insulin resistance but insulin problems are also a part of M.E. (abnormal glucose tolerance tests are very common in M.E.) Whatever the cause, insulin resistance is a pre-diabetic condition which can and should be tested for and which if not treated can lead to type 2 Diabetes.

Treatment for insulin resistance and hypoglycaemia involves lowering your insulin levels with a controlled carbohydrate diet. Traditional low fat/high carbohydrate diets will exacerbate the problem.

**Diet tips for managing and improving hypoglycaemia and insulin resistance**

- Eat a whole foods diet, and avoid processed foods (especially processed grains).
- Eat 5 or 6 small meals daily.
- Eat within an hour of waking.
- If you’re trying to lose weight, be aware that the percentage of your diet’s calories that come from carbohydrate, fat and protein is far more important than merely how many calories you are eating. High carbohydrate diets can cause weight gain, even when calories are low in people that don’t deal with carbohydrates well and/or have insulin resistance. The idea is not to eat as few carbohydrates as possible, but to find the amount of daily carbohydrate intake that you feel best on and which allows you to maintain a healthy weight. It is a ‘controlled carb’ diet. Finding out the optimal level of carbs for you involves trial and error. Those with severe insulin resistance and/or that have a lot of weight to lose may do better on diets containing less carbohydrate, at least for a certain period of time.
- Be aware that the glycaemic load of a food – how much carbohydrate it contains – is far more important than its listed glycaemic index. The index only tells you how fast the carbohydrate is released.
  
  For example, carrots have a much higher glycaemic index rating than brown rice, so according to the GI brown rice is a healthier choice for those with insulin resistance. Carrots are rated as almost as bad as eating pure sugar according to the GI, it’s ridiculous! Yet when you look at the GL of carrots and brown rice, the story is very different. Half a cup of raw chopped carrots has 5.8 g of carbohydrate in it, plus 1.7 g of fibre. (When calculating ‘net carbs’ or ‘digestible carbs’ the amount of fibre is subtracted from the total carbohydrate score, as the fibre lessens the effect of the carbohydrate on insulin levels). Half a cup of cooked brown rice contains around 23 g of carbohydrate, 3 g of which is fibre.
- A high carb diet can cause weight gain, but it is also important to be aware that a very very low carb diet can also cause weight gain. High carb diets increase
insulin levels, leading to weight gain. Very low carb diets may trigger an increase in cortisol, which can also cause weight gain. Dr Dowsett also explains that M.E. patients should avoid very low carb diets, due to the severe metabolic problems in the disease which may be worsened by a lack of carbohydrate in the diet. As a basic rule it is not recommended to ever go below 40 grams of carbohydrate daily; 20 – 40 grams of carbohydrate daily is just not enough for most people. Cutting down to 60 – 80 grams daily for a period of time will almost certainly be low enough and even this level will be lower than is necessary for some people.

The easiest way to start is to eat good fats and high-quality protein until you are satiated, eat unlimited non-starchy vegetables but limit carbohydrate intake to 60 – 100 grams spread throughout the day, or perhaps 60 – 80 grams if you desire to lose weight. There is no need to count calories even if you are trying to lose weight and 2000 – 2500 calories a day is probably ideal, according to Sally Fallon’s excellent book Eat Fat, Lose Fat.

If you prefer a more mathematical approach you could go to a website like www.nutritiondata.com or www.whfoods.com and try to put together a diet where your calories are made up of 20% protein, 50% good fats, and 30% (low glycaemic load) carbohydrates. See how you feel after a few weeks on such a diet and then make any changes that you think will suit you better. If you need to lose weight you might try restricting (digestible) carbohydrates to 60 – 80 grams a day.

- Water loss can occur in the first few days of a lower carb diet which can make you feel ill. So when beginning a diet change to reduce the carbohydrate level of your diet, always make this change gradually and perhaps also consider taking extra electrolyte drinks daily.

- Following a controlled carbohydrate doesn’t mean having to avoid juicing. The effects of juices on blood sugar levels can be reduced in the following ways:
  - Juices should be taken at least twice daily instead of all at once.
  - Around 350 ml of carrot juice daily is ideal. Higher amounts may not be suitable for some M.E. patients.
  - Carrot or beetroot juice can be diluted with cucumber or zucchini or other low carb green juices.
  - Around 1 litre of juice daily may be a good maximum for those with insulin resistance.
  - Fruit juice should be kept to a minimum, and perhaps restricted to small amounts of juice from green apples, fresh berries, lemons and limes taken together with vegetable juices.
  - **Juices** may be best taken on an empty stomach and then followed by a meal containing significant protein or fat or both, 10 -15 minutes later. This allows the juice to digest easily on its own, and the fat and protein foods then reduce the effect of the juice on blood sugar levels.

- Carbohydrate content in the diet should be spread fairly evenly throughout the day.
Higher carbohydrate foods such as fruits should be eaten with a food containing some fat or protein, or both.

Eat a high-fibre diet by including lots of fresh cooked or raw vegetables in your diet.

Don’t worry too much about calories. If you’re eating the right foods then they will take care of themselves. Make sure to not dip below 1600 calories a day if you’re female and 1800 a day if you’re male. Higher calorie diets than these are healthier and can still result in significant weight loss, where the right foods and the right level of carbohydrate, fat and protein is eaten. It may be very possible to lose weight eating the same calories you do now, just with fewer calories form carbohydrate. It is also not necessary to exercise to lose weight, or to be hungry at all; both things will likely be beyond M.E. patients!

Slow weight loss of 0.5 – 1 kg a week or less is always best. Losing weight increases oxidative stress and so losing weight fast could put extra stress on the body. Losing weight fast can also leave you feeling very ill as all sorts of toxic chemicals that were stored in fat are released into the bloodstream. Taking extra detoxification nutrients such as vitamins C, ALA, ALC, Silymarin and GSH when losing weight is a very good idea.

Nutrient-rich foods, foods high in fat and protein and foods which aren’t refined carbohydrates will leave you feeling more satisfied after eating as will foods that have bulk such as larger servings of vegetables. Refined carbohydrate foods and sugary foods can very easily leave you much hungrier than before you ate them! They make even make you pass out if the amount of sugar in them is very high.

Avoiding eating very large meals as this will cause insulin levels to rise. Eat until you’re just full, but never until you are absolutely stuffed.

More information
- Eat Fat, Lose Fat by Sally Fallon
- Good Calories, Bad Calories by Gary Taubes
- The Paleo Diet Cookbook
- Deep Nutrition
- Living Low Carb: Controlled-Carbohydrate Eating for Long-Term Weight Loss by Jonny Bowden
- For more information on hypoglycaemia, and why glucose tolerance tests only tell part of the story and may be classed as normal even where hypoglycaemia is a very severe problem, see the article HYPOGLYCEMIA by Lawrence Wilson MD.
- For more information on insulin resistance see the Healing Daily site or any of the books on nutritional medicine listed in the references section.
- Nutritional Balancing and Hair Mineral Analysis by Dr. Lawrence D. Wilson
- Comments on the USDA Dietary Guidelines on WAPF

- The glycaemic index versus the insulin index and Glycaemic index versus glycaemic load by Get Zoned Australia

‘One factor that doesn't affect a food's index is the configuration of its sugars, that is, if they're joined together in long chains, like in pasta, or if they're separate, like in sweet foods. This comes as a great surprise to most people because we've always been told that complex carbohydrates are healthy and simple sugars aren't, but the fact is that our tummies can't tell the difference between the two. Before any carbohydrate is taken up into the blood it must be broken down into simple sugars, and the rate that this occurs, that is, the glycaemic index, doesn't depend on the initial configuration. Complex carbohydrates are not healthier than simple sugars.

The glycaemic load of a meal has a much greater effect on its insulin index than its glycaemic index, so the total amounts of carbohydrates that we're consuming should be the focus of our efforts if we're trying to control blood sugar levels. Even if we chose high indexed carbohydrates, if we don't eat too many of them our blood sugar won't be too out of control. Eating a small amount of "bad" carbohydrates is not unhealthy. But as we've just learnt, too many "good" carbohydrates are still bad for us.

Having said all of this, if we choose the really good carbohydrates, the vegetables that are high in fibre and therefore not very carbohydrate dense, we'll find it quite difficult to eat too many of them at once anyway. There are plenty of exceptions to watch out for though. Some breads and some pastas have low indices but are still very dense. Even some breakfast cereals are now claiming to be "healthy" because of their lowish index. Remember though that one bowl-full still delivers a high glycaemic load and therefore still has a dreadfully high insulin index.’ Get Zoned Australia
‘The road to health is paved with good intestines.’ Dr Sherry Rogers.

This paper explains some of the basics of healing the gut in a very brief and easy to read format.

**Supplements that help the gut to heal**
Vitamin A, omega 3s, zinc, glutamine, liposomal GSH, phosphatidylcholine and vitamin C. There is also Seavive, silymarin, GLA (Gamma-linolenic acid) and licorice.

**Foods that help the gut to heal**
Fermented cod liver oil (vitamin A with cofactors plus omega 3s), bone broths (glucosamine and gelatine), sardines (and other fish high in omega 3s), coconut oil (which contains very high levels of MCTs) and butter (which contains butyric acid).

**Supplements that can aid digestion**
Betaine HCl, probiotics, digestive enzymes, apple cider vinegar, Swedish bitters, ox bile tablets, unrefined sea salt and B vitamins.

**Foods that can aid digestion**
Raw cultured vegetables, bone broth or stock or foods such as soups and sauces made from them, kefir, yogurt with high levels of probiotics, apple cider vinegar, Swedish bitters, coconut oil, fermented cod liver oil and unrefined sea salt.

**Food that are easy to digest**
Vegetable soups made with stock, bone broths, slow cooked vegetable and meat dishes (cooked in stock), soaked and dried nuts and seeds, lightly cooked egg yolks, pureed cooked vegetable dishes, raw cultured vegetables, high probiotic (homemade using raw milk or coconut milk) coconut oil, yogurt, raw milk or coconut or water kefir, beet kvass and freshly made vegetable juices.
Potentially difficult to digest foods
Unsoaked nuts with their skins on, raw fruits and vegetables, grains and legumes (especially when they are unsoaked or unsprouted), overcooked meats or eggs, dairy products containing lactose and that have been homogenised, foods containing complex sugars and very high fibre foods. Foods you are allergic to should also be avoided.

Foods which may aggravate a leaky gut
Coffee, alcohol, sugar, spicy foods, foods containing lectins (grains, legumes, dairy and nightshades) foods containing saponins, gliadin or glycoalkaloids, food additives and processed foods.

Improving digestion through proper food combining
Fruit should be eaten alone on an empty stomach, meat and eggs (proteins) should be eaten with non-starchy vegetables. Starchy vegetables and grains should be eaten with non-starchy vegetables.

Drinking large amounts of water with meals should be avoided. Do not drink for at least 15 minutes before you eat or 1 hour after a meal.

Eat when relaxed and chew your food slowly. To digest well, your body needs to be in parasympathetic nervous system mode and not hyped up on adrenaline. Digestive enzymes should be taken when eating protein and fat containing foods and also betaine HCl if needed. Fermented drinks such as kefir or a serve of cultured vegetables should be take with each meal to aid digestion.

Other issues to look into for better gut health
Candida, parasitic infections, leaky gut, dysbiosis, food intolerances, too fast or too slow food transit time (diarrhoea or constipation) and detoxification enemas.

Other types of detoxification programs which may be useful in healing
FIR sauna use, high dose vitamin C, body brushing or salt scrubs, gallbladder and liver cleanses, castor oil packs, magnesium/salt/ACV or clay baths, neti pot use, colonics and lymphatic drainage massage.

Make sure to give yourself an oil change!
 Certain fats are essential for good health and for healing the gut. An oil change is an essential part of healing. Make sure you get some coconut oil, olive oil, fermented cod liver oil, vitamins E, D, K and A, butter, organic free-range eggs, organic pastured meats and soaked and dried nuts and seeds. Strictly avoid trans fats and processed vegetable oils.
Gut healing programs and books
The following books are highly recommended. You can learn more about each of them on the ‘Book reviews’ page.

- **Eat Fat, Lose Fat** by Sally Fallon, **Deep Nutrition: Why Our Genes Need Real Food** by Catherine Shanahan, **Know Your Fats** by Mary Enig PhD and **Nourishing Traditions: The Cookbook that Challenges Politically Correct Nutrition and the Diet Dictocrats** by Sally Fallon and Mary G. Enig PhD. These books explain the importance of eating good-quality animal foods, avoiding soy foods and processed foods, ample healthy fats including saturated fats and eating lots of traditional foods including organ meats, bone broths and raw cultured vegetables. The first book describes a high fat, moderate protein and limited carbohydrate diet. The books by Sally Fallon also talk about the importance of soaking and drying seeds and nuts and of similarly properly preparing all grains and legumes. Unfortunately these books talk little about food allergies, the importance of supplements or gut issues or the fact that many do better avoiding grains and dairy - at the very least until a lot of healing of the gut has taken place.

- **No More Heartburn: The Safe, Effective Way to Prevent and Heal Chronic Gastrointestinal Disorders and Wellness Against All Odds** (and other books) by Sherry A. Rogers. This book recommends a whole foods diet containing no nightshade foods, no yeast foods, and eating in a relaxed state to aid digestion. Dr Rogers also recommends that for some patients with very poor digestion, eating only cooked fruits and vegetables may be necessary as well as Betaine HCl and digestive enzyme supplements.

- **GAPS Diet** by Natasha Campbell-McBride (plus to a lesser extent **Breaking the Vicious Cycle: Intestinal Health Through Diet** by Elaine Gloria Gottschall.) This book explains the importance of eating good-quality animal foods, eating cooked foods exclusively while the gut heals, having vegetables juices, having ample healthy fats including saturated fats and eating lots of traditional foods including organ meats, bone broths and raw cultured vegetables. This book also explains that avoiding certain fibrous foods and sticking to certain types of carbohydrates can help heal the gut and prevent fermentation in the gut leading to digestive and Candida problems. This book describes a new way of looking at the issue of Candida that is far more logical and far-reaching than a mere anti-Candida diet which only treats this symptom of a poor gut rather than the cause.

- **The Primal Blueprint** by Mark Sisson. This book explains that a healthy way to maintain your weight and have good health is to eat whole foods, avoid grains and legumes and dairy foods, eat healthy fats and proteins until satiety but to limit carbohydrates to around 50 - 100 grams a day if you need to lose a bit of weight and 100 - 150 grams if you need only to maintain your weight. The book describes a high fat, moderate protein and limited carbohydrate diet. This book explains the importance of eating good-quality animal foods, ample healthy fats including saturated fats and eating lots of traditional foods including organ meats and lots
and lots of vegetables. Unfortunately this book places little emphasis on cultured foods, the need for cooked foods, food allergies or gut issues.

- **The Schwarzbein Principle** This book explains that a healthy way to maintain your weight and have good health is to eat whole foods, eat healthy fats and proteins until satiety but to limit carbohydrates to around 60 grams a day if you need to lose a bit of weight. These carbohydrate grams should be spread throughout the day, and not eaten all at once. Unfortunately this book places little emphasis on cultured foods, the need for cooked foods, food allergies or gut issues.

*More information*

Digestive enzymes may greatly aid digestion and also help to support the pancreas, and a supplement called [Betaine HCl](http://www.hfme.org) may also help digestion if stomach acid is low. Raw apple cider vinegar has some of the same benefits of Betaine HCl, but is milder. It can very much help you to digest meals that are high in fat.

Probiotics are also essential as is vitamin A and the gut-healing saturated fatty acids found in coconut oil and butter.

Some groups claim that the more foods we eat raw the healthier we will be, while other dispute this, and explain that humans have been heating for a very long time and that in fact cooking food makes many of the vitamins etc. more available to the body and so all vegetables we eat should be cooked. What we know for sure is that raw vegetables will often be very difficult for M.E. patients to digest and may need to be avoided completely or almost completely until and unless digestion improves. Even then, eating most of your daily vegetable intake in a cooked form makes more sense than following a strict raw food regimen. Sometimes just lightly steaming vegetables will be enough, while others may need more moderate cooking to be digested well. Fruit may also be better tolerated if it is lightly cooked or even stewed first.

Fruits and vegetables that are juiced are FAR easier to absorb the nutrients from than fruits and vegetables eaten whole.

To make meats more digestible, they can be marinated in lemon, lime or tomato juice or raw apple cider vinegar before being cooked. Soaking meats in these acid mediums pre-cooks them slightly and denatures them and makes them more digestible. (This is why marinated meats are more tender.) Cooking meat or eggs for too long or at a very high heat can also make them hard to digest. Meats should be cooked slowly until they are ‘medium.’

Other ways to improve digestion include waiting to eat until you are hungry.

Eating a largely raw food diet can be very painful and counter-productive for the M.E. patient as it requires so much more effort from the body to break down the food. Food can sit in the stomach undigested and cause pain and other symptoms.
During a severe relapse or period of very severe illness, it can be helpful to give your stomach a digestion ‘holiday’ by eating well-cooked pureed foods such as pureed meat and vegetable soups, cooked vegetable and fruit purees, vegetable and fruit juices and chicken and vegetable congee. Some of these foods can be prepared using a slow cooker (NOT a pressure cooker). This can make cooking easier too as the slow cooker makes meat fall apart when it is cooked and makes vegetables very soft, so foods don’t need so much chopping before being cooked. Foods slow cooked in this way are also much less work to chew and swallow.

Notes and references
- Dr Chia explains in his research that the symptoms that M.E. patients commonly attribute to ‘Irritable bowel syndrome’ (IBS) may in fact be caused by chronic enteroviral infection of the stomach.
- Raw Food Versus Cooked Food and The Vitamins by Lawrence Wilson MD
- Eat Fat, Lose Fat by Sally Fallon, Deep Nutrition: Why Our Genes Need Real Food by Catherine Shanahan, Know Your Fats by Mary Enig PhD and Nourishing Traditions: The Cookbook that Challenges Politically Correct Nutrition and the Diet Dictocrats by Sally Fallon and Mary G. Enig PhD.
- GAPS Diet by Natasha Campbell-McBride (plus to a lesser extent Breaking the Vicious Cycle: Intestinal Health Through Diet by Elaine Gloria Gottschall.)
- No More Heartburn: The Safe, Effective Way to Prevent and Heal Chronic Gastrointestinal Disorders and Wellness Against All Odds (and other books) by Sherry A. Rogers.
- The Primal Blueprint by Mark Sisson and The Schwarzbein Principle
- The Body Ecology Diet by Donna Gates

Relevant quotes
“What you eat has more power over disease and aging than any other medicine your doctor can prescribe. Food is awesomely powerful.” Dr Sherry Rogers.

“Many people advocate eating raw foods to obtain the “food enzymes” they contain. My experience is that this is not important. It is true that all foods contain certain enzymes that are damaged or destroyed by most cooking. Gentle steaming preserves a few of them.

However, food enzymes are not the same as the digestive enzymes that are required to digest your food. It is not true that foods contain the enzymes needed to digest the food. Your body, not the food, must supply the bulk of the enzymes needed to digest the food. This is the important point.

The only foods that I suggest people eat raw is certified or good quality raw dairy products and some other oils such as olive, flaxseed, and hempseed oils.” Dr Lawrence Wilson
Increased intestinal permeability ('leaky gut'), lectins, saponins, gliadin, phytic acid and M.E.

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Increased intestinal permeability

Increased intestinal permeability, sometimes referred to as a ‘leaky gut’ plays a role in causing, prolonging and worsening autoimmune diseases.

Author of The Paleo Diet Cookbook, Dr. Loren Cordain, writes,

Intestinal epithelia act as a physical barrier between the outside and the inside of the body, meaning that the intestinal lumen is technically outside the organism. When the intestinal barrier is disrupted, it allows increased passage of gut luminal antigens derived from food, bacteria and viruses into the organism. In case of bacteria derived antigens, lipopolysaccharide (LPS) is the most commonly studied and utilized antigen to induce acute immune stimulation, this is known as endotoxemia (the presence of endotoxins - a toxin that forms an integral part of the cell wall of certain bacteria - in the blood which may cause hemorrhages, necrosis of the kidneys, and shock). In addition, endotoxemia is associated with low-grade chronic inflammation, insulin resistance and T2D. In a recent human study it was demonstrated that LPS induced low-grade chronic inflammation in adipose tissue in T2D humans.

Lectins, saponins and gliadin increase intestinal permeability and allow increased passage of gut bacteria from intestinal lumen to peripheral circulation. LPS - an antigen found in gram-negative bacteria cell membranes - interacts with TLR-4, leading to inflammatory cytokine production and low-grade chronic inflammation, which is at the root of insulin resistance.

Dr Sherry Rogers explains that a leaky gut can cause food intolerances, chemical allergies, autoimmune disease and Candida and that victims of a leaky gut may also develop nutrient deficiencies, even where high-dose supplements are being taken.

Substances which contribute to a ‘leaky gut’ include:

- Lectin, saponin and gliadin containing foods
- Glycoalkaloid containing foods
- Antacids containing alum
- Alcohol
- All NSAID drugs including ibuprofen
- The contraceptive pill
Seavive is recommended to help heal a leaky gut by Dr Sherry Rogers, along with GLA (Gamma-linolenic acid) and phosphatidylcholine – both of which are essential for healing the gut in her opinion. Glutamine may also be helpful, she explains (glutamine may not be well tolerated in M.E.). Dr Rogers comments that all drugs which act on the gut cause the gut to malfunction.

A leaky gut may also be improved by supplementation with: Lecithin, Licorice, high strength probiotics, cabbage powder, digestive enzymes, zinc, vitamin A and butyric acid.

**Lectins**

If you have tried all sorts of food combinations and you still can’t find foods which you can tolerate, you may want to try to avoid foods high in problematic lectins.

Research in lectinology is in its infancy. If feel you have already worked out a diet that works for you, you may well wish to ignore this complex topic but this information is included for the benefit of those patients who many need it. The Lectin Report states that:

Think of a lectin as a protein containing a key that fits a certain type of lock. This lock is a specific type of carbohydrate. All life forms, plant and animal, insect and fungus have cell membranes that contain carbohydrates that sit within and project from the membrane. If a lectin with the right key comes in contact with one of these 'locks' on the gut wall or artery or gland or organ it 'opens the lock', that is disrupts the membrane and damages the cell and may initiate a cascade of immune and autoimmune events leading to cell death.

Lectins may bind to the gut wall and damage the gut lining, are not altered by digestive enzymes, and may alter gut permeability and pass through the gut into general circulation. Lectins can cause alterations in gut function that may be related to colitis, Crohn's Disease, Celiac-Sprue, IBS and gut permeability. Lectin damage to the gut wall may allow other non-lectin proteins to cross undigested into general circulation and cause allergic reactions, including anaphylaxis. Type or types of lectin and one's susceptibility (genetic susceptibility) cannot be determined by blood type. D'Adamo tested lectins with blood cells. Lectin intolerance reactions occur in the gut, general circulation (artery walls and the like), brain, gland or organ as well as red blood cells. Sensitivity of one type of cell does not necessarily determine whether another type cell will or will not react. You may react to lectin toxicity due to genetics, intensity of exposure, failure of immune factors to protect you, viral infection, bacterial infection or gut permeability induced by medication or infection. Lectin intolerance is not an 'allergy'. A person may be lectin intolerant and not have antibodies to the suspect food when given an allergy test whether blood or skin or saliva.

The most common potentially 'toxic' lectin containing food groups are
o grains, especially wheat and wheat germ but also quinoa, rice, buckwheat, oats, rye, barley, millet and corn,
o legumes (all dried beans, including soy and peanuts),
o dairy (perhaps more so when cows are feed grains instead of grass),
o Nightshades (includes potato, tomato, eggplant and pepper).
o eggs

These are the most common lectin families that cause problems. To see how you respond to lectins in these foods, eliminate the suspect group for 7-10 days. Don't eat any of the group. Check to make sure none of the lectins are contained in other foods you consume. After abstaining for 7-10 days eat a significant amount of the suspect group over one day. Eat other foods as well. Do not eat any more of the test group for two days after the test day. Look for symptoms of intolerance: bowel changes, sleep changes, mood changes, memory impairment or any other significant changes you can relate to the ingestion of the food group. It may take a day or so for the symptoms to appear. If you think you have found a lectin incompatibility avoid the food. You can test again in a few weeks. If every time you avoid the food your symptoms resolve and every time you eat it they return you have found a lectin you should not eat. (Millet, wild rice and plain white rice are usually safe substitutes while testing grains.)

Symptoms could be obvious, such as gas, bloating, diarrhea or constipation (or both, alternating). Less obvious symptoms may include headache, fatigue, 'indigestion', skin problems including hives, psoriasis, swollen joints or water retention. For severe symptoms or conditions eliminate all of the major suspect groups, all grains, all legumes, and all dairy. Add the nightshades, potato, tomato, eggplant and pepper, to your restricted list if your symptoms are associated with rheumatic or arthritic complaints. If you respond to this elimination diet by a resolution of symptoms keep out the food group/s for a minimum of six months to one year before reintroducing the group/s. If symptoms reappear consider lifelong avoidance.

The subject of avoiding lectins is fairly new, so writing a summary is very difficult. This is just a brief introduction to this topic. For more information you may like to read The Lectin Report, Introduction to "Lectin," and Foods to Avoid, Foods to Enjoy.

Books promoting the Paleolithic diet are good resources for low lectin menus.

Saponins
It is recommended that foods containing saponins are avoided by M.E. patients and all patients with autoimmune diseases.

Author of The Paleo Diet Cookbook, Dr. Loren Cordain, writes, Saponins are glycoalkaloids (a family of poisons commonly found in the plant species Solanum dulcamara - nightshades) produced by plants, technically known
as steroid glycosides or triterpenoids, are formed by a sugar compound (glucuronic acid, glucose or galactose, among others) and aglycone (non-sugar molecule) portion\textsuperscript{30-32}. The aglycone portion binds the cholesterol molecule on gut cell membranes. When certain amounts of saponins bind cell membrane cholesterol molecules of the intestinal epithelial cells at a 1:1 ratio, the sugar portion of the saponins bind together, resulting in a complex molecule consisting of cholesterol and saponins. This new molecule disrupts the gut barrier and increases intestinal permeability. This has been shown in humans who consume a diet rich in alpha-solanine and alpha-chaconine - two of the saponins found in potatoes\textsuperscript{31}. On the other hand, saponins have adjuvant-like activity, which means that they are able to affect the immune system leading to pro-inflammatory cytokine production\textsuperscript{33, 34}, ultimately inducing insulin resistance.

Foods that contain saponins include:
- legumes
- soy
- potatoes
- green tomatoes (and the other nightshade vegetables)
- amaranth
- alfalfa sprouts

For more information see Consumption of Nightshade Plants and The Paleo Diet Cookbook

\textbf{Gliadin}
Gliadin, found in wheat, increases gut permeability and contributes to low-grade chronic inflammation.

\textbf{Phytic acid}
Whole grains, legumes and nuts may best be prepared by soaking, sprouting or sour leavening to neutralize phytic acid, enzyme inhibitors and other anti-nutrients. Unless phytic acid is broken down, it blocks absorption of important minerals like calcium, iron, magnesium and zinc. Enzyme inhibitors in grains stress the pancreas and inhibit digestion. Many cultures have a long history or soaking and sprouting grains and legumes.

- Oats can be soaked in acidulated dechlorinated water (ie. water that has lemon, lime or tomato juice or raw apple cider vinegar added to it) for 12 hours before you eat them. Others recommend that this is done for 24 hours and that the soaking oats must be kept at about 100 degrees F (on a hotplate). Once the oats have been soaked, discard the soaking water and cook as usual. (For a further reduction of phylates, oats should be soaked, sprouted and then cooked.)
- Beans and legumes should be soaked overnight. Rinse them well before soaking, and then add 1 tablespoon of lemon juice per cup of dechlorinated
water. Leave to soak overnight, then rinse well again before cooking. (For a further reduction of phylates, beans and legumes should be soaked, sprouted and then well cooked.)

- Soak brown rice in dechlorinated water for 24 hours at room temperature, rinse well and then cook as usual. (This will break down about 50 percent of the phytic acid.)
- Soaking seeds and nuts for 12 – 24 hours and then possibly also roasting or cooking them (slowly) removes some of the phylates.

As an added advantage, soaked foods such as grains and legumes often take less time to cook.

Note that many experts recommend far more involved and lengthy processes to reduce phylate levels even further, so this is only a very basic beginner’s guide. How important reducing levels of phylates is also depends on how much grains, legumes, seeds and nuts you eat, it is more important the more of these foods you eat. If one is avoiding all grains and legumes and eating only nuts and seeds, then avoiding phylates is not so important and soaking the nuts and seeds may not be necessary.

Weston A. Price explains that,

Sprouting releases vitamins and makes grains and beans and seeds more digestible. However it is a pre-fermentation step, not a complete process for neutralizing phytic acid. Consuming grains regularly that are only sprouted will lead to excess intake of phytic acid. Sprouted grains should also be soaked and cooked.

It is not necessary to completely eliminate phytic acid from the diet, only to keep it to acceptable levels. In the context of a diet rich in calcium, vitamin D, vitamin A, vitamin C, good fats and lacto-fermented foods, most people will do fine on an estimated 400-800 mg per day. For those suffering from tooth decay, bone loss or mineral deficiencies, total estimated phytate content of 150-400 mg would be advised. For children under age six, pregnant women or those with serious illnesses, it is best to consume a diet as low in phytic acid as possible.

In practical terms, this means properly preparing phytate-rich foods to reduce at least a portion of the phytate content, and restricting their consumption to two or three servings per day. Daily consumption of one or two slices of genuine sourdough bread, a handful of nuts, and one serving of properly prepared oatmeal, pancakes, brown rice or beans should not pose any problems in the context of a nutrient-dense diet. Problems arise when whole grains and beans become the major dietary sources of calories— when every meal contains more than one whole grain product or when over-reliance is placed on nuts or legumes.

To learn how to soak, sprout and ferment all types of grains and legumes see the book Nourishing Traditions or the Living with Phytic Acid article from the Weston A. Price Foundation, or do some Google searches for these terms.
The Paleolithic diet

An easy way to avoid lectins, saponins, gliadin and phylates is to follow the Paleolithic diet. This diet also helps you avoid processed food and is good for managing insulin resistance and hypoglycaemia in M.E. and possibly also Candida and increased intestinal permeability.

Foods included on this diet:
- All unprocessed lean meats including organ meats and game meats
- Eggs (unless autoimmune disease is present, in which case they may be best avoided)
- All fresh fruits
- All vegetables except potatoes, peas, beans and snow peas and corn (and tomatoes and the other nightshade vegetables where autoimmune disease is present)
- All nuts and seeds (except peanuts, which aren’t a nut but a legume)
- All coconut products including coconut oil

Foods to avoid on this diet:
- Processed meats
- All grains, including corn and sprouted grains
- All legumes, including peanuts, soy and sprouted legumes
- Vegetables such as potatoes, peas, beans and snow peas and corn (and tomatoes and the other nightshade vegetables, possibly)
- Vegetable oils

All foods should be organic/free-range where possible.

Some Paleo diet advocates (such as myself) are okay with adding small amounts of honey, unrefined sea salt, coffee and tea, protein powders made from eggs or hemp, olive oil and cocoa products that are 85% or more pure to the diet, even though they aren’t strictly Paleo food items, while others recommend avoiding these products.

The usual recommendation for lunch and dinner is to eat a fist sized serve of meat and to fill the rest of the plate with vegetables and to then have some fruit and maybe some seeds/nuts later on for dessert. Protein foods from animals are recommended to make up around 40 - 50% of daily calories.

The Paleo diet is probably as close to the ideal diet for M.E. as we can get. Having said that, there is no one diet that is right for everyone and so we must each find the diet that works for us. The Paleo diet is absolutely one that is worth trying for at least a few months however and reading a bit more about.

For more information see The Paleo Diet Cookbook and the Paleo Diet blog and many more resources available online and in bookstores. For more information on improving gut health generally see No More Heartburn: The Safe, Effective Way to Prevent and Heal Chronic Gastrointestinal Disorders by Sherry A. Rogers
The idea that eating too much saturated animal fat and having high cholesterol levels is dangerous to your heart and blood vessels is nothing but a myth. These theories are very popular but also very wrong!

Common myths about fat and cholesterol include the following:

- High fat foods cause heart disease.
- High cholesterol levels cause heart disease.
- High-fat foods (especially those high in saturated fats) raise blood cholesterol.
- Cholesterol clogs your arteries and so do saturated fats.
- Animal studies prove the saturated fat and high cholesterol = heart disease theory.
- Lowering your cholesterol level will lengthen your life.
- Eating only or primarily polyunsaturated oils is good for you.
- The anti-saturated fat and low-cholesterol campaign is based on good science.
- All scientists support the saturated fat and high cholesterol = heart disease theory.

Most of the information given on fats and oils and cholesterol is not based on science. The 1950s research by Ancel Keys, a very early and very vocal proponent of the lipid hypothesis, tailored the facts to fit his own pet theories and the science in this area has not improved in quality since then.

The current obsession with cholesterol levels has been described by some as ‘the greatest scam in the history of medicine.’

The anti-cholesterol campaign creates immense prosperity for researchers, doctors, medical journals, and the food industry and most especially for drug companies which produce statin drugs. Statin drugs are some of the most profitable drugs ever created and have brought in billions and billions of dollars to those that sell them.

Uffe Ravnskov, MD, PhD, author of several books on the cholesterol myths, writes, Cholesterol is not a deadly poison, but a substance vital to the cells of all
mammals. There are no such things as good or bad cholesterol, but mental stress, physical activity and change of body weight may influence the level of blood cholesterol. High cholesterol is not dangerous by itself, but may reflect an unhealthy condition, or it may be totally innocent.

Lipid expert Mary Enig PhD comments in the Weston A. Price Foundation quarterly magazine, ‘There is no need to worry about your cholesterol levels. This is a phony issue.’

**What sort of HIGH cholesterol numbers should I be worried about?**

It is common for people with cholesterol levels well within a normal range to be told that they have high cholesterol levels that urgently need to be treated with measures such as statin drugs. As lipid expert Mary Enig PhD comments in the Weston A. Price Foundation quarterly magazine:

> Blood cholesterol levels between 200 and 240 mg/dl are normal. These levels have always been normal. In older women, serum cholesterol levels greatly above these numbers are also quite normal, and in fact they have been shown to be associated with longevity. Since 1984, however, in the United States and other parts of the western world, these normal numbers have been treated as if they were an indication of a disease in progress or a potential for disease in the future.

In the US, cholesterol levels are measured in mg/dl while almost all of the rest of the world uses mmol/L, which is more accurate. 200 – 240 mg/dl is equivalent to 5.2 – 6.2 mmol/L.

Note that the concepts of ‘good’ and ‘bad’ cholesterol also do not stack up. See some of the books listed in the references section for more information.

**What are some of the causes of high cholesterol levels?**

Low thyroid hormone levels can cause high cholesterol levels but one of the main causes is believed to be chronic inflammation.

(Note that what is being discussed here are genuinely very high cholesterol levels; those way above the average 240 mg/dl or 6.2 mmol/L measures.)

High cholesterol levels are a response to something going wrong in your body. Cholesterol is produced whenever your cells become damaged, as it’s a necessary component in making new healthy cells. As Dr Mercola explains,

> If you have a lot of damaged cells, you’re also going to have a lot of
cholesterol in your bloodstream. This is a good thing, in a sense, because it means your cells are being repaired. Now, while most conventional doctors would see all that cholesterol and put you on toxic cholesterol-lowering drugs, a more knowledgeable doctor would search for what’s causing the damage in the first place.

Whatever you do, don’t fall for the mistaken belief that the lower your cholesterol goes, the better. If you lower your cholesterol through artificial means (statin drugs) without addressing the underlying causes, your body will continue to degenerate.

Leave the decision of how much cholesterol your body needs up to your body, and make the right lifestyle choices to keep your cells in their top condition. This way you get the best of both worlds: the right amount of cholesterol and a body in tip-top shape.

Chronic inflammation can be caused by high grain, refined carbohydrate and sugar intake, eating foods cooked at high temperatures, eating oxidised oils, eating trans fats, excessive polyunsaturated fat intake, smoking and excessive emotional stress. In order to lower your inflammation levels these factors must be addressed.

**Do foods containing cholesterol need to be avoided?**

No. Eating foods containing cholesterol only increases your cholesterol levels a minuscule amount so small as to be difficult to even measure, if at all. Uffe Ravnskov MD PhD writes,

> Your body produces three to four times more cholesterol than you eat. The production of cholesterol increases when you eat little cholesterol and decreases when you eat much. This explains why the "prudent" diet cannot lower cholesterol more than on average a few per cent.

There is no need to eat tasteless and unsatisfying food in the hope that avoiding dietary fats and cholesterol will benefit your health. Nobody ever needs to, or needed to, eat those disgusting and wasteful egg-white-only omelettes or swap tasty fats, oils and spreads for margarine or fat-free salad dressings!

There is no need whatsoever to limit egg consumption to one egg daily or to follow a low-fat diet plan to try to protect heart health. (There is also no need to follow a low calorie or low salt diet; if you use unrefined sea salt.) Foods high in cholesterol are some of the most nutritious foods we have. Foods which should be avoided are not healthy foods such as eggs, coconut oil, butter and olive oil but processed foods, refined carbohydrates, sugar and trans fats. Foods such as eggs, butter and coconut oil etc. need only be avoided if one has an allergy or intolerance to them and lard and suet need only be avoided by those that are vegetarian.

Foods containing trans fats include margarine and almost all baked goods and processed foods containing fat including biscuits, crackers, pies, cakes, breakfast
cereals and so on.

**What sort of LOW cholesterol numbers should I be worried about?**
Cholesterol performs many vital functions in the body and low cholesterol levels can cause a number of serious problems including aggression, suicide attempts and depression, slower brain function, a weaker immune system, hormone deficiencies, greater cancer risk and a shorter life span. Low cholesterol levels are also linked to Parkinson’s disease. Low cholesterol levels are a real concern.

Different experts define low cholesterol levels differently. Some recommend not letting levels drop below 4.7 mmol/L or 180 mg/dl, while others prefer that it always stay above 5.2 mmol/L or 200 mg/dl for optimum health. Below 3.8 mmol/L or 150 mg/dl is a real danger zone. As Dr Mercola explains, ‘Every single one of your cells needs cholesterol to thrive - including those in your brain.’

So why are we told that we need excessively low cholesterol levels to be healthy? Yet again, the answer is that vested interest groups have been allowed to interfere with science. Many of those doctors that were given the task of defining what ‘low cholesterol’ is and what the lowest possible treatable level was were linked to statin-drug-producing drug companies.

**What tests are more useful for determining cardiovascular disease risk?**
Far more useful blood tests to assess your cardiovascular disease risk (and your general health) than tests of cholesterol levels include: blood sugar and insulin tests, CRP tests, Homocysteine level tests, thyroid function tests, and blood pressure and pulse tests.

**I still want to lower my cholesterol levels, how should I go about it?**
Statin drugs should be avoided by all persons but particularly those that are dealing with significant illness or disease. Some doctors say that patients with genetic challenges of familial hypercholesterolemia may possibly be an exception, although many others argue that even then these risky drugs are not needed.

Statin drugs may dangerously lower CoQ10 levels and are associated with a large number of side effects, some of them permanent. Other side effects included increases in blood glucose levels, tendon problems and an increase in liver enzymes, leading to permanent liver damage. Because of this latter risk, people taking the drugs must have their liver function tested periodically. Nausea, diarrhea, abdominal pain, constipation, headaches and skin rash are other known side effects. Side effects are also not rare. One study showed that 98% of patients taking one statin drug had muscle problems. The German drug-maker Bayer withdrew its statin drug Baycol (cerivastatin) from the U.S. market after it was found to be responsible for 31 deaths from a muscle-destroying side effect. Statin drugs can cause polyneuropathy (nerve damage that causes pain in the hands and feet and trouble walking). The list of statin...
drug side effects is long.

Statin drugs MUST be strictly avoided by any woman that is pregnant or may become pregnant. As Uffe Ravnskov, MD, PhD explains, ‘Pregnant women taking statins may give birth to children with malformations more severe than those seen after thalidomide.’ These deformities also do not seem to be rare in those taking statin drugs, as the book ‘The Great Cholesterol Con’ explains.

Mary Enig PhD writes:

In his book The Cholesterol Myths, Dr. Uffe Ravnskov tells us what happens to an older woman who has normal high serum cholesterol levels. When her blood is tested in a forced cholesterol checkup, the cholesterol myth is used to justify treatment of her nonexistent disease state and she loses her vibrant state of good health.

Dr Sherry Rogers says that there is no logical reason at all to ever take statin drugs, as they are so risky and unhelpful. If one does take statin drugs, or has a family member that takes them, it is important to know that some of the side effects and risks (including of sudden cardiac death) can be reduced by taking a daily coenzyme Q10 supplement, as statin drugs deplete the body of CoQ10. Taking daily CoQ10 is essential for anyone taking a stain drug. A daily high-quality multivitamin is also a good idea.

Safer alternatives for lowering high cholesterol levels, where this is desired, include red rice yeast and policosanol (in supplement form, not in margarine). Other supplements that can lower or normalise cholesterol but which are also beneficial or even vital to cardiovascular health more generally include:

- Niacin
- A high-quality omega 3 supplement (such as from cod liver oil, or fermented cod liver oil, or fish oil or through dietary sources such as sardines, or eating organ meats such as brains.)
- Magnesium is essential for good heart function and low magnesium levels are a significant cause of cardiac deaths. (See Detoxify or Die by Dr Sherry Rogers for more information.)
- Vitamin C may play an important role in preventing heart disease, for more information search for information on the Matthias Rath and Linus Pauling vitamin C theory of heart disease as described in Why Animals Don't Get Heart Attacks but People Do

But again, the best way to improve your health is to look at why your cholesterol level might be high (if it really is) and to treat the cause. Your body tends to make more cholesterol when it’s in a chronically inflamed state, so you need to work out what causes your underlying inflammation. If you do all the right things with your
diet, nutrition and lifestyle this is the best way to improve all aspects of your health.

Very high cholesterol actually is a 'risk factor' for heart disease in men, along with hundreds of other risk factors such as smoking, obesity, high blood pressure, lack of exercise, psychological stress, baldness, snoring and eating too much or too little of a steadily increasing number of various food items. It should be noted that a risk factor is not the same as a cause, that high cholesterol levels have only shown to be a risk factor in men (in women high cholesterol levels have been shown to be protective and linked with a longer lifespan) and that the level of high cholesterol being discussed here is very high at over 350 mg/dl or 8.9 mmol/L. High cholesterol also seems be beneficial for both men and women, as they become older.

In his June 2001 newsletter, The John R. Lee M.D. Medical Letter, Dr Lee writes,

High cholesterol levels can be one of many symptoms of heart disease, just as a runny nose can be one of many symptoms of the flu. Forcing cholesterol levels down with drugs without addressing the underlying conditions that caused the symptom in the first place, and then declaring that the drugs reduce heart disease, is like taking an antihistamine when you have the flu and then declaring that you've cured it because your nose stops running. I won't go into any detailed speculations about who's paying whom to tell Americans that 20 percent of them need to be taking a cholesterol-lowering drug, but suffice it to say that these recommendations have to do with money, and not with your optimal health.

**What fats and oils should I be eating?**
There is no need to fuss about fats too much. We just need to eat a variety of different fats and make sure to stick to natural fats that have not been highly processed or poorly handled.

There is no need to avoid saturated fats. All fats are a mix of saturated and unsaturated fats. Some saturated fats have anti-cancer benefits. Saturated fats have anti-bacterial and anti-viral properties and around 50% of the fat in mother’s milk is from saturated fats. Saturated fats have been an important part of hunter-gatherer diets for many thousands of years and were an important part of more modern diets until about 75 years ago. Your body makes saturated fats because it needs them! In her book ‘Know Your Fats’ Mary Enig PhD writes,

The body needs saturated fatty acids for at least half, and sometimes much more, of the fatty acid part of the phospholipids that form the membranes of the cells. For those who don't understand why the human body makes saturated fatty acids -- it is because the saturated fatty acids are required. For some people, the fats in the diet are either too polyunsaturated or too low.

Saturated 18-carbon stearic acid and 16-carbon palmitic acid are the preferred foods for the heart, which is why the fat around the heart muscle is
highly saturated. The heart draws on this reserve of fat in times of stress.

Saturated fatty acids constitute at least 50% of the cell membranes. They are what gives our cells necessary stiffness and integrity. They play a vital role in the health of our bones. For calcium to be effectively incorporated into the skeletal structure, at least 50% of the dietary fats should be saturated. They are needed for the proper utilization of essential fatty acids. Elongated omega-3 fatty acids are better retained in the tissues when the diet is rich in saturated fats.

The scientific evidence, honestly evaluated, does not support the assertion that "artery-clogging" saturated fats cause heart disease. Actually, evaluation of the fat in artery clogs reveals that only about 26% is saturated. The rest is unsaturated, of which more than half is polyunsaturated.

Saturated fat sounds scary and gluggy and is often described as 'artery clogging' and 'not heart healthy' but the truth is very different. Saturated fat also isn't saturated by some sort of horrific 'glop' but by hydrogen! The same element that is in water.

The only healthy oils to cook with are virgin or extra virgin olive oil, ghee, butter, palm oil and virgin coconut oil plus also tallow and lard. Oils such as flaxseed oil, pumpkin seed oil, sunflower seed oil and others are best used in small amounts, unheated and drizzled on vegetables once they have been cooked.

Foods containing fat with vitamin D (and A) in it are also very healthy additions to the diet and include foods such as organ meats, skin and fat from certain land animals (organic/free-range chickens, red meat from organic grass-fed cows and wild caught animals eating a natural diet), as well as shellfish and oily fish. (Animal foods only contain lots of vitamin D if they are allowed to have frequent sun exposure.) Supplementation with cod liver oil, or even better; fermented cod liver oil, is also highly beneficial to health.

If possible, choose only meat from organic/free-range chickens, red meat from organic grass-fed cows and wild caught animals eating a natural diet. These animals have the traditional types and ratios of fats in them and not the very high amounts of omega 6 fats seen in grain fed cattle, for example. Organic butter is also a better choice than non-organic.

Using oils at too high a temperature can damage them and cause them to oxidise. Olive oil is best used at a low heat only, while ghee, butter, lard, palm oil and virgin coconut oil can handle moderate temperatures. Deep frying of food, excessive browning of food or heating oils above 160 C or 320 F should be avoided.

Foods containing damaged cholesterol should also be avoided, this includes foods such as powdered eggs and powdered milk. Powdered milk is added to reduced-fat
milks to give them body and so reduced fat dairy products should be avoided in favour of full-fat dairy products. (The best quality dairy products are those which have not been damaged by pasteurisation or homogenisation, but this is another topic!)

Products containing hydrogenated vegetable oils such as canola and soy and man-made trans fats should be strictly avoided. Naturally occurring trans fats in foods such as butter do not cause the same problems and are safe to consume. Note that the label ‘trans-fat free’ on products does not mean it is trans-fat free.

Rancid oils should be thrown away; let your taste buds be your guide and if an oil tastes ‘off’ then don’t use it. Make sure to store oils away from light and heat. This applies particularly to the non-saturated oils which are far more likely to become rancid than more stable oils such as coconut oil and butter.

As the author of ‘Fat: It’s Not What You Think’ writes, ‘Stop fooling with fats and cook with butter and lard!’

**Exactly how much of each type of fat should I eat for optimum health?**

If you’re the technical type and would like some very detailed information about the properties about each of the different types of fats, the proper ratios of omega 3 and 6 fats and how much of total calories should come from each of these in the diet then you may like to read the book *Know Your Fats* by Mary Enig PhD which contains all of these facts and much more, or the summary paper on fats by the Weston A. Price Foundation.

How much fat should be included in a healthy diet?

Low-fat diets are not healthy and are not even a good way to lose weight as books such as ‘Good Calories, Bad Calories’ by Gary Taubes and ‘Eat Fat, Lose Fat’ by Sally Fallon and Mary Enig PhD explain. Mary Enig PhD and Sally Falklon write,

Saturated fats from animal and vegetable sources provide a concentrated source of energy in the diet; they also provide the building blocks for cell membranes and a variety of hormones and hormone like substances. Fats as part of a meal slow down absorption so that we can go longer without feeling hungry. In addition, they act as carriers for important fat-soluble vitamins A, D, E and K. Dietary fats are needed for the conversion of carotene to vitamin A, for mineral absorption and for a host of other processes.

Mary Enig PhD explains that we need to get at least 30% of our calories from healthy natural fats, and that for some of us 30% is not enough and we may need significantly more.
I became very interested in this topic a few months ago, and so I ordered every book my local library had on fats and cholesterol and I even bought a few of the very good ones that weren’t at my library. This paper is an attempt to summarise a mammoth amount of information. I have tried to stick to providing only the basic facts along with most of the focus on the all-important practical advice and tips for health contained in these books. To read detailed information about the history of the lipid hypothesis, how the science was skewed and what the science really shows, and so much more, reading on or more of the following books is highly recommended.

The first three books in particular destroy the lipid hypothesis with example upon example of logical flaws and twisted science that should be enough to impress any reader.

For more information on each book you can also read the Amazon reviews I’ve done of most of the books here by viewing my profile page on the site.

These books are for those people that are able to think for themselves. Read at least one of these books and make up your own mind!

- For information on the positive role that saturated fats and cholesterol play in the body, what the difference is between saturated and unsaturated fats, and so much more see Know Your Fats by Mary Enig PhD. Some of this information is also included in an abbreviated format in Eat Fat, Lose Fat by Sally Fallon and Mary Enig PhD and their very good article online.
- Good Calories, Bad Calories or The Diet Delusion (the same book with two titles) by Gary Taubes. A summarised version of this very long book is also available, it is called Why We Get Fat: And What To Do About It.
- The Cholesterol Myths: Exposing the Fallacy That Saturated Fat and Cholesterol Cause Heart Disease or Fat and Cholesterol Are Good For You by Uffe Ravnskov

See also the following books:
- Ignore the Awkward.: How the Cholesterol Myths Are Kept Alive by Uffe Ravnskov
- Deep Nutrition by Catherine Shanahan
- The Cholesterol Hoax and Detoxify or Die by Dr Sherry Rogers.
- The Primal Blueprint by Mark Sisson
- Fat: It’s Not What You Think by Connie Leas
- The Great Cholesterol Con by Malcolm Kendrick
Treating M.E.: The basics

- **Nourishing Traditions** by Sally Fallon
- **Cholesterol: The Real Truth** by Sandra Cabot.
- **Real Food** by Nina Planck.
- **Nutrition and Physical Degeneration** by Weston A. Price.

See also the following articles:

- **Cholesterol and Heart Disease: A Phony Issue** by Mary G. Enig, PhD
- **Why is 200mg/dl (5.2mmol/l) a 'Healthy' Cholesterol Level?** by Mary G. Enig, PhD
- **The truth about saturated fats** by Mary Enig, PhD, and Sally Fallon
- **Weston A Price.org Cholesterol and Heart Disease: A Phony Issue**
- **Mary Enig on cholesterol and coconuts**
- **Cholesterol Deceptions** by Dr George Georgiou
- **Making sense of your cholesterol numbers** by Dr Mercola.
- **Why low cholesterol is not good for you** by Dr Mercola.
- **Cholesterol is not the enemy** and **Caring for your cholesterol** by Dr Carolyn Dean
- **Why Sugar Is More Dangerous Than Cholesterol** by Dr Sinatra
- **The Soft Science of Dietary Fats** (and other articles) by Gary Taubes, in the March 30, 2001 issue of *Science*
- **Milk Homogenization & Heart Disease** and **The Great Con-ola** by Mary Enig PhD.

Relevant quotes

‘Numerous surveys of traditional populations have yielded information that is an embarrassment to the Diet Dictocrats. For example, a study comparing Jews when they lived in Yemen, whose diets contained fats solely of animal origin, to Yemenite Jews living in Israel, whose diets contained margarine and vegetable oils, revealed little heart disease or diabetes in the former group but high levels of both diseases in the latter. (The study also noted that the Yemenite Jews consumed no sugar but those in Israel consumed sugar in amounts equaling 25-30% of total carbohydrate intake.) A comparison of populations in northern and southern India revealed a similar pattern.’ Mary Enig PhD and Sally Fallon

‘The relative good health of the Japanese, who have the longest life span of any nation in the world, is generally attributed to a low fat diet. Although the Japanese eat few dairy fats, the notion that their diet is low in fat is a myth; rather, it contains moderate amounts of animal fats from eggs, pork, chicken, beef, seafood and organ meats. With their fondness for shellfish and fish broth, eaten on a daily basis, the
Japanese probably consume more cholesterol than most Americans. What they do not consume is a lot of vegetable oil, white flour or processed food (although they do eat white rice.) The life span of the Japanese has increased since World War II with an increase in animal fat and protein in the diet. Those who point to Japanese statistics to promote the low fat diet fail to mention that the Swiss live almost as long on one of the fattiest diets in the world. Tied for third in the longevity stakes are Austria and Greece—both with high-fat diets.’ Mary Enig PhD and Sally Fallon

‘High serum cholesterol levels often indicate that the body needs cholesterol to protect itself from high levels of altered, free-radical-containing fats. Just as a large police force is needed in a locality where crime occurs frequently, so cholesterol is needed in a poorly nourished body to protect the individual from a tendency to heart disease and cancer. Blaming coronary heart disease on cholesterol is like blaming the police for murder and theft in a high crime area.’ Mary Enig PhD and Sally Fallon

‘Homogenization: This is the process whereby the fat particles of cream are strained through tiny pores under great pressure. The resulting fat particles are so small that they stay in suspension rather than rise to the top of the milk. This makes the fat and cholesterol more susceptible to rancidity and oxidation, and some research indicates that homogenized fats may contribute to heart disease.’ Mary Enig PhD and Sally Fallon

‘The media’s constant attack on saturated fats is extremely suspect. Claims that butter causes chronic high cholesterol values have not been substantiated by research—although some studies show that butter consumption causes a small, temporary rise—while other studies have shown that stearic acid, the main component of beef fat, actually lowers cholesterol. Margarine, on the other hand, provokes chronic high levels of cholesterol and has been linked to both heart disease and cancer. The new soft margarines or tub spreads, while lower in hydrogenated fats, are still produced from rancid vegetable oils and contain many additives.’ Mary Enig PhD and Sally Fallon

‘One frequently voiced objection to the consumption of butter and other animal fats is that they tend to accumulate environmental poisons. Fat-soluble poisons such as DDT do accumulate in fats; but water-soluble poisons, such as antibiotics and growth hormones, accumulate in the water fraction of milk and meats. Vegetables and grains also accumulate poisons. The average plant crop receives ten applications of pesticides—from planting to storage—while cows generally graze on pasture that is unsprayed. Aflatoxin, a fungus that grows on grain, is one of the most powerful carcinogens known. It is correct to assume that all of our foods, whether of vegetable or animal origin, may be contaminated. The solution to environmental poisons is not to eliminate animal fats—so essential to growth, reproduction and overall health—but to seek out organic meats and butter from pasture-fed cows, as well as organic vegetables and grains. These are becoming increasingly available in health food

www.hfme.org
stores and supermarkets and through mail order and cooperatives.’ Mary Enig PhD and Sally Fallon

‘More than three (3) decades after the initial fraudulent report, the anti-animal fat hypothesis continues to lead the nutrition agenda. It was a false issue then, and it remains a false issue today.’ Mary Enig PhD in ‘Know Your Fats.’

‘The common scenario is that of a highly intelligent person . . . who finds a research task that will lead to funding from the food and/or pharmaceutical industry or from the industry-controlled government agencies. If that research shows an adverse effect of any of the new foods studied, this is frequently ignored. . . . Of course, the research that is done by the industry-supported scientists is good basic research, and it usually is of great interest so as long as it supports the food industry or avoids a clash with the industry it is promoting. What seems so ironic, is that the very foods (saturated fats and cholesterol) that people are avoiding are the very foods that are healthful. When it comes to fat, this really has become the age of the flat earth.’ Mary Enig PhD in ‘Know Your Fats.’

‘But what about heart disease?’ This is the response of many Americans when advised to consume the foods of their ancestors, foods like butter, whole milk, eggs and meat. Fear of saturated fat and cholesterol has put a solid brick wall between the consumer and satisfying nutritious food – and filled the coffers of the food processing industry.’ Sally Fallon

‘The fourth and last wrong measure of probability I shall take notice of, and which keeps in ignorance or error more people than all the other together, is... the giving up our assent to the common received opinions, either of our friends or party, neighbourhood or country. How many men have no other ground for their tenets, than the supposed honesty, or learning, or number of those of the same profession? As if honest or bookish men could not err; or truth were to be established by the vote of the multitude: yet this with most men serves the turn. If we could but see the secret motives that influenced the men of name and learning in the world, and the leaders of parties, we should not always find that it was the embracing of truth for its own sake, that made them espouse the doctrines they owned and maintained.’ John Locke

‘Frankly, the recommendation of the American Heart Association, government health agencies, and the media, — that people switch from saturated fats to polyunsaturated vegetable oils — has probably killed and crippled more Americans than both World Wars.” Former brain surgeon Russell Blaylock MD

The cholesterol campaign is “the greatest scientific deception of this century, perhaps of any century.” Physician and scientist George Mann

“The public is so brainwashed, that many people believe that the lower your cholesterol, the healthier you will be or the longer you will live. Nothing could be further from the truth.” Paul Rosch MD FACP
“If you have come to believe you can ward off death from heart disease by altering the amount of cholesterol in your blood, whether by diet or by drugs, you are following a regime that has no basis in fact.” Edward Pinckney MD former co-editor of the Journal of the American Medical Association

“The current campaign to convince every American to change his or her diet, and in many cases to initiate drug ‘therapy’ for life is based on fabrications, erroneous interpretations and/or gross exaggerations of findings and, very importantly, the ignoring of massive amounts of unsupportive data.” Russell Smith MD

“The idea that saturated fats cause heart disease is completely wrong, but the statement has been “published” so many times over the last three or more decades that it is very difficult to convince people otherwise unless they are willing to take the time to read and learn what all the economic and political factors were that produced the anti-saturated fat agenda.” Mary Enig PhD

“Fearing to lose their soft money funding, the academicians who should speak up and stop this wasteful anti science are strangely quiet. Their silence has delayed a solution for coronary heart disease by a generation. Those who manipulate data do not appreciate that understanding the nature of things cannot be permanently distorted - the true explanations cannot be permanently ignored. Inexorably, truth is revealed and deception is exposed. ...In due time truth will come out. This is the relieving grace in this sorry sequence.” Professor Mann

“Your fear of dying--if you happen to be one of the great many people who suffer from this morbid preoccupation- may well have made you a victim of the cholesterol controversy. For, if you have come to believe that you can ward off death from heart disease by altering the amount of cholesterol in your blood, whether by diet or by drugs, you are following a regime that still has no basis in fact. Rather, you as a consumer, have been taken in by certain commercial interests and health groups who are more interested in your money than your life.” Professor Mann's

“One must be bold indeed to attempt to persuade large segments of the populations of the world to change their accustomed diets and to threaten important branches of agriculture and agribusiness with the results of such uncontrolled, primitive, trial and error type explorations. Certainly modern science is capable of better research when so much is at stake.” Raymond Reiser

“The public is so brainwashed, that many people believe that the lower your cholesterol, the healthier you will be or the longer you will live. Nothing could be further from the truth.

The cholesterol cartel of drug companies, manufacturers of low fat foods, blood testing devices, and others with huge vested financial interests have waged a highly successful promotional campaign. Their power is so great that they have infiltrated medical and governmental regulatory agencies that would normally protect us from such unsubstantiated dogma.
The current campaign to convince every American to change his or her diet and, in many cases, to initiate drug "therapy" for life is based on fabrications, erroneous interpretations and/or gross exaggerations of findings and, very importantly, the ignoring of massive amounts of unsupportive data...It does not seem possible that objective scientists without vested interests could ever interpret the literature as supportive.” Professor Rosch
Candida Albicans overgrowth or Candidiasis is a problem that is hugely over-diagnosed and also under-diagnosed. It seems these days that almost everyone who visits a naturopath will be told, no matter what their state of health, that they have a Candida problem! (And that they need to stop eating wheat and dairy products too.) Mainstream medicine seems to have the opposite problem and many doctors are unwilling to even discuss the possibility of a Candida problem and how it may be treated.

Candida Albicans is a yeast (fungus) organism that occurs naturally in everyone. Healthy people often develop Candidiasis (also known as Intestinal Candidiasis) after having a course of antibiotics, but with the correct treatment the symptoms of the infection can be completely eliminated. For those with weak immune systems, however, such as patients with M.E., cancer and AIDS, Candidiasis is a problem that will often have to be managed long-term.

The symptoms of Candidiasis can include bloating, gas, constipation, diarrhoea and other digestive complaints, inflammatory bowel disease, vaginal yeast infections, fungal infections on the nails, cravings for sweet food, fuzzy thinking and tiredness, headaches with sinus involvement, histamine allergic reactions, food and chemical intolerances, sore joints, chest pain, and thrush white tongue.

The reason Candidiasis must be treated as a serious problem when it occurs in M.E. patients is not just to prevent the relatively minor symptoms it can cause, but because it can exacerbate more serious pre-existing problems and further stress the immune system. In other words, it is not just the symptoms that it causes that are problematic, but the damage that it causes – exacerbation of leaky gut syndrome and food allergies and intolerances and the immunological and toxicity problems that derive from those issues. Leaving Candidiasis untreated can impede or even prevent significant recovery from M.E. as a whole.

As the Easy Immune Health site explains, there is some controversy over whether or not what is commonly referred to as Candidiasis is in fact caused by Candida. Anti-Candida programs are best carried out with the help of an experienced nutritional consultant. In the absence of access to extensive testing and experts in this field however, many patients decide to try the anti-Candida diet and to see how they feel – particularly where there are overt signs of a Candida-like infection such as a white coated tongue (oral thrush) or vaginal thrush, or sudden new problems such as ‘allergies’ to yeast containing supplements taken orally, bloating and gas (and similar
symptoms) after eating mould containing foods (such as cheese and bread) and/or reactions to breathing air from rooms affected by mould.

**Treatment step one: Minimise risk factors for Candida**

Other risk factors for Candidiasis – aside from the immune weakness caused by M.E. – include eating a lot of sugary or very high-carbohydrate foods, having mercury amalgams (fillings), drinking chlorinated water, taking the contraceptive pill or cortisone and drinking alcohol and having uncontrolled diabetes. Wearing underwear made of synthetic fabrics that don’t ‘breathe’ and tight-fitting clothes can also contribute to vaginal thrush. M.E. patients are very unlikely to be drinking alcohol (although mouth wash that contains alcohol is also problematic), but if possible, see if you can arrange a good quality water filter to eliminate chlorine from your drinking water and also try to minimise or eliminate as many of these other factors as is possible.

It is important not to look at treating Candidiasis in isolation from improving general health and improving M.E. If you are following the basic guidelines recommended on HFME for M.E. treatment including avoiding overexertion, cleaning up your environment, eating a good diet, minimising stress and basic nutritional support then you will also be minimising your risk of infections such as Candidiasis. There is little point in trying to treat Candidiasis without following these basic health guidelines first.

**Treatment step two: The anti-Candida diet**

A very important step in treating this condition is changing the diet. Anti-Candida diets are low in sugar, carbohydrate and fermented and yeast-containing foods. It is also an alkaline and anti-inflammatory diet. As the anti-Candida diet is to a large extent fairly ideal for M.E. patients anyway, trying it should probably not be considered a terribly risky idea.

**What to eat:** meat, eggs and low-carbohydrate vegetables. There are some vegetables that will actually inhibit the growth of Candida, these include: raw garlic, onions, cabbage, broccoli, turnip, kale, cucumber, brussel sprouts, cauliflower, peppers, celery, radish, eggplant, asparagus, spinach, zucchini, okra, tomatoes, avocado.

**What to avoid:** Avoid starchy vegetables such as carrots, sweet potatoes, potatoes, yams, corn, all squash (except zucchini), beets, peas, parsnips and all beans (except green beans) plus aged cheese, additives and preservatives, chocolate, caffeine, fruit, gluten-containing foods, mushrooms, sugar and vinegar.

Opinions vary on whether or not a small amount of fruit and nuts are okay in the anti-Candida diet. Keeping both in the diet is probably a good idea to make sure you are getting enough good fats and enough carbohydrates (and cutting carbohydrate levels down too much and/or too quickly can leave you feeling very unwell, unnecessarily.) If you decide to add some nuts to your diet, stick to freshly cracked whole nuts if
possible and avoid peanuts or nuts that are obviously mouldly. If you decide to add a piece or two of fruit a day, avoid acidic types like oranges, limes, pineapples, grapefruit, lemons and tomatoes, plus all dried fruits and very high-carbohydrate fruits such as bananas and mangoes. You may also decide to just follow the standard diet advice provided in the ‘Food as medicine in M.E.’ section if your problem is not severe, as this may easily suffice.

This diet can absolutely make you sicker, especially at first. This may be a sign that the diet is working, and that a Herxheimer or die-off reaction is occurring. (This is sometimes referred to as a ‘herx’ reaction for short.) This reaction occurs when toxins and wastes are being released faster than the body can eliminate them. In this case, it is the waste products produced from the Candida Albican fungus dying off. Herx or die-off symptoms can include nausea, sweating and headaches and generally just feeling very ‘off’ and unwell. If this is the case, warm baths, extra vitamin C supplements and drinking adequate water may help. If the symptoms are very severe you may wish to add back some foods from your old diet to slow down the reaction, before starting to slowly get back to the anti-Candida diet fully.

However, it is also possible that feeling sicker on this diet means that you are eating something now that you weren’t before, or more of something you are before, that you are intolerant of or allergic to. Discovering which foods are causing you problems may mean doing an elimination diet or taking an ELISA test. (Unfortunately it can be very difficult to tell which of these reasons for your feeling worse on this diet is the right one.)

In addition to following an anti-Candida diet, Dr Lawrence Wilson, also explains that sauna therapy can be helpful. He writes,

Since candida albicans is a normal inhabitant of the human body, it is really just an opportunist organism. This means that if the body is out of balance in certain ways, it tends to overgrow. Correct the imbalances and the problem will go away. This is a much better solution than staying on special diets or taking toxic drugs for the problem.

Toxic chemicals found in the home, air, water and food also accumulate in the liver and elsewhere, and may impair the body’s ability to protect itself against candida overgrowth. Sauna therapy can significantly speed up the improvement in candida infection. It assists the elimination of toxic metals, toxic chemicals and other poisons that may accumulate within the body. It also inhibits the sympathetic nervous system, improves circulation and oxygenation and directly disables candida organisms to some degree. Sauna therapy is thus one of the finest methods of eliminating candida overgrowth.

For information on sauna therapy see the FIR saunas and M.E. page.

**Treatment step three: Boosting the immune system**

Make sure you are taking substances that naturally boost the immune system, such as vitamins A, C, D and E and selenium and zinc. These supplements are essential for
M.E. treatment for many reasons, whether or not one does actually have Candidiasis. As explained previously, these supplements should always be started very slowly. In the case of vitamin D, tests should also be conducted to determine your level of vitamin D before long-term or high-dose supplementation.

*Treatment step four: Probiotics*

After a month or so following the anti-Candida diet, it may be advisable to start taking probiotics, if you aren’t already. As explained previously, probiotics should always be started very slowly to reduce the risk of relapse caused by die-off reactions (and in case you are one of the small percentage of M.E. patients that cannot tolerate probiotics). The minimum dose is 25 billion organisms per day, but if possible, a dose of at least 100 billion organisms may provide far greater benefits.

If vaginal thrush is severe, inserting probiotic capsules may help (and there are also fast acting over-the-counter creams that may help in the short term too) and/or two 500mg buffered vitamin C tablets inserted daily.

Probably for many M.E. patients, adhering to these four steps long-term will be enough to control Candidiasis. These three steps are all also basic ways to treat M.E. generally, and so have many other benefits as well. They are a very good idea whether or not Candidiasis is actually an issue. After 1-3 months on the strict anti-Candida diet, you can add back all the different types of vegetables, fruit and nuts and even possibly small amounts of grains and legumes (as per the general advice given on diet previously in ‘Food as medicine in M.E.’). If any foods cause headaches or other symptoms due to mould content (for example mushrooms) then of course do continue to avoid them.

If problems indicative of Candidiasis such as white coated tongue (thrush) or vaginal thrush are still present after 3 or more months, however, you may wish to consider trying some of the anti-fungal treatments available.

*Treatment step four: anti-fungal treatments*

If any of the previous steps made symptoms much worse, be prepared for anti-fungal treatments to make the condition far worse still. Some patients may be too ill to attempt such treatments even at a low level, while other may find they can only take small amounts of these substances and need breaks of several weeks or more in between treatments.

While the other steps mentioned here are essential parts of treating M.E. and so whether or not a person actually has Candidiasis isn’t enormously important (to some extent), the same is not true of anti-fungal treatments. It is difficult to say whether or not most M.E. patients with Candidiasis would benefit from taking antifungal substances. Some patients report a benefit from them and others are made much sicker by them for months afterwards and cannot continue treatment. These treatments should be handled with extreme caution in M.E.
It is a good idea to start with those substances that are known to be effective but are also well tolerated and mild on the system. Caprylic acid (a medium chain fatty acid that is naturally found in coconut and palm oil) is now widely accepted as an effective treatment for Candidiasis and is most likely the best treatment to start with. Caprylic acid is available in capsules but can also be obtained by adding coconut oil to the diet (or using it as a moisturiser) as 20 g of good-quality coconut oil contains 1.6 g of caprylic acid. It is probably the most commonly recommended anti-fungal. Oatstraw tea is also a good product to start with, as it is very gentle and good for the gut.

There is also Pau d’Arco, Artemisia, cloves, garlic, Goldenseal (for short term use ONLY), oregano oil, black walnut, aloe vera, olive leaf extract and grapefruit seed extract. (Pantethine may also be helpful.) Some substances, such as Pau d’Arco, are fairly mild while other such as grapefruit seed extract must be taken as a last resort as they kill everything in the gut, good and bad, and so require that a person be very strong before attempting such a treatment. Garlic and Goldenseal may be as effective as Caprylic acid, but both are often very poorly tolerated by M.E. patients as they also have strong anti-viral properties. Garlic may need to be taken at a low dose to be well tolerated. Also note that aside from garlic, most of these anti-fungal substances are not appropriate for long-term use.

Again, investigate which substances are least likely to cause problems, start at very low doses, and make sure that if you start to feel very unwell that you take a break for several weeks (or until you feel up to it) before starting again. It is also okay to decide to stop treatment with the anti-fungal substance if it is just making you too ill and you fear serious relapse. Make sure too that you always take probiotics with anti-fungal treatments (as some anti-fungals kill off good and bad bacteria).

**Conclusion**

Some patients report significant benefit from following the anti-Candida diet and taking some of the anti-fungals mentioned here, while others experience little benefit or are made much sicker and so general recommendations are difficult. This guide was written to provide some general advice on this topic, and to make this treatment as safe for M.E. patients as possible.

Again, it is important not to look at treating Candidiasis in isolation from improving general health and improving M.E. If you are following the basic guidelines recommended on HFME for M.E. treatment including avoiding overexertion, cleaning up your environment, eating well, minimising stress and basic nutritional support then you will also be minimising your risk of infections such as Candidiasis. There is little point in trying to treat Candidiasis without following these basic health guidelines first.

**Additional notes on this text**
1. **Testing for Candidiasis.** The Candida Diet website explains that there are three ways that doctors can test for Candida:

- **Blood Test:** An Anti-Candida Antibodies test. There are 3 antibodies that should be tested to measure your immune system's response to Candida - IgG, IgA, and IgM. High levels of these antibodies indicate that an overgrowth of Candida is present.
- **Stool Analysis:** Your stool is directly analyzed for levels of yeast, pathogenic bacteria and friendly bacteria.
- **Urine Tartaric Acid Test:** This test detects tartaric acid - a waste product of Candida yeast overgrowth. An elevated test means an overgrowth of Candida.

2. **Other causes of symptoms.** Other causes of Candidiasis-like symptoms include (among many others); leaky gut syndrome, food allergies and intolerances and gluten sensitivity. Even where symptoms are caused by Candida overgrowth, problems with leaky gut syndrome or increased intestinal permeability will probably also be contributing to symptoms and so it may be a good idea to try to treat each of these problems at the same time.

3. **Candidiasis misdiagnosis and M.E.** The amount of training and knowledge about diseases varies enormously from one naturopath to the next. While some do a lot of good and have an enormous amount of scientific knowledge, others know very little and have almost no qualifications. Unfortunately, not only do many naturopaths over-diagnose Candidiasis, it is also quite common for such individuals to tell a person with M.E. that they have a Candida problem causing all their symptoms and that once this infection is treated that they will be well and be able to resume their normal healthy life. All of the MANY symptoms and features of M.E. that don’t fit Candidiasis (which is almost all of them) are ignored. Then, when this doesn’t happen (because of course even if the patient does have Candidiasis, this is only a very, very small part of their serious health problems caused by M.E.) they blame the patient for not trying hard enough to get well or for not sticking to the program well enough. These ‘professionals’ often fail to see that it is their own lack of skill and qualifications that has led them to misdiagnose and mistreat the patient and that they are actually behaving abusively, inappropriately and very unfairly and cruelly. If you are unlucky enough to encounter such a person, do not let their insults to your character affect you as they are all about THEIR ignorance and lack of professionalism and nothing to do with you at all. Do not continue to see them professionally and if you can, try to educate them politely about the reality of M.E. (in printed form) as you leave!

Generally speaking, naturopaths and similar professionals are not equipped to diagnose patients correctly, but can be useful for recommending treatments for various conditions that have already been properly diagnosed (using the appropriate testing, the taking of a detailed medical history and a detailed physical exam conducted by a qualified physician).

4. **Antibiotic drugs and Candida.** Antibiotics destroy both harmful bacteria and good bacteria. When antibiotics destroy friendly bacteria it gives the Candida a chance to
begin to multiply. If you take antibiotics for any reason, make sure you take lots of extra probiotics and B vitamins.

5. Vitamin B6 and Candida. According to Dr Atkins, two-thirds of women with Candidiasis don’t metabolise vitamin B6 properly. For this reason it is recommended that women with Candidiasis take part of their vitamin B6 in the activated form of pyridoxal 5’ phosphate. Extra B1 is also a good idea with Candidiasis.

**References**
- Candida Albicans Or Chronic Intestinal Yeast infections by Lawrence Wilson MD
- How to Successfully Overcome Candida by Bee Wilder
- The Easy Immune Health website (and the Candida pages) by Kerri Knox RN
- The Candida Diet website
- Candida Albicans yeast infection, diet, symptoms, treatment
- The information I have gotten through discussing Candida with many M.E. patients in groups and in private emails over many years has also informed this piece, to some extent. Further information and feedback from patients however, is always welcome.

**Acknowledgments:** Thank you to Aylwin and Ginny for contributing to this paper, and for Ginny for submitting the section on Coeliac disease featured in this paper.

‘*Progress in medical science is, as a rule, achieved only after overcoming the manifestations of a fixed mental status, ranging all the way from violent and vitriolic opposition down to apathy and deadly inertia.*’ Dr Edwin F. Bowers
Section C: Food preparation issues and recipes
Avoid or minimise microwave cooking

Recent research shows that microwave oven-cooked food suffers severe molecular damage. When eaten, it causes abnormal changes in human blood and immune systems.

The January 1996 edition of the Townsend Letter for Doctors and Patients explained, cooking in a microwave oven is not safe. Atoms, molecules and cells are hit by the hard electromagnetic irradiation of microwaving reverse polarity over one billion times a second. Even in the low energy range of milli-watts, no atom, molecule or cell of any organic system can withstand such destructive power.

Molecules are forcefully deformed, their quality impaired. The electrical potentials between the outer and inner side of the cell membranes – the very life of the cells – are neutralised. Natural repair mechanisms are suppressed; and cells, forced to adapt to a state of emergency, switch from normal aerobic to anaerobic (without oxygen) respiration. Instead of water and carbon dioxide, this fermentation produces hydrogen peroxide and carbon monoxide. The newly formed radiolytic compounds are unknown to man and nature; the impaired cells become easy prey for viruses, fungi, and other micro-organisms.

Microwaving destroys some nutrients and turns some amino acids into carcinogens. Established science and government claim all this doesn’t hurt people eating irradiated food; but neither scientists not governments ever tested their claims.

Dr Hans Hertel of Germany did the first and only, small but well controlled study of the effects of micro-waved nutrients on the blood and physiology of humans. The blood of those who consume micro-waved food for two months showed pathological changes compared to matched controls eating food cooked with heat. The changes included a decrease in all haemoglobin values and deterioration in cholesterol, especially the HDL and LDL (high and low density cholesterol) values and ratio. Lymphocytes (white blood cells) showed a more distinct short term decrease after the intake of micro-waved food than after normally cooked foods.

Moreover, warming breast milk in a microwave oven destroys 98% of its immunoglobulin – A antibodies and 96% of its liposome activity, reducing the milks resistance to infectious E.coli.

As of yet, it is true that no official government research has shown microwaved food to be harmful but as M.E. patients will already be aware, studies can VERY easily be constructed in such a way as to ensure that problems will not be found particularly...
where there is a vested financial interest in doing so and absence of evidence is not the same as evidence of absence. So what this comes down to is personal choice about whether or not to use a microwave (or to even own a microwave) after reading some of the evidence detailing the problems they can cause and how much risk to your health is acceptable. Do some reading and make up your own mind.

Alternatives to microwaving food include steaming meat and vegetables in a bamboo steamer, immersing vegetables in boiling water for a few minutes to cook them, letting frozen meat and other foods defrost naturally, and of course, eating leftovers cold.

If you do use the microwave, even occasionally, make sure you always only microwave using microwave safe glass or ceramic dishes and never heat food in plastic containers or while it is covered in plastic wrap.

If you feel you have no choice but to microwave food due to illness, some experts argue that just keeping it for quickly reheating already cooked meats and vegetables, rather than cooking them from raw for long period of time will avoid some of the worst problems with microwave cooking, at least.

- For more information see: Microwave Cooking is Killing You, The Proven Dangers of Microwave Ovens, Microwave Cooking, the Hidden Hazards and Microwaving & Irradiation.

**Choose the right cookware**

Choose your cookware with care, if you can. Use only glass, stone, stainless steel or cast iron cookware. Make sure to season cast iron cookware with coconut oil before using them. Cast iron cookware coated with heavy duty enamel is also a good choice (try Ikea).

Avoid pans with non-stick or Teflon coatings as these can cause you to ingest some of those chemicals through gases released during cooking. Avoid aluminium cookware as it can neutralise digestive juices and cause you to ingest too much aluminium which can be problematic. For the same reasons, cooking in aluminium foil should also be avoided.

Avoid storing food in plastic containers or aluminium foil, and replace these with glass containers and wax paper. (Or a layer of wax paper touching the food, and then a layer of foil on top of that.)

Avoid using plastic or aluminium cooking utensils such as spoons and spatulas.

- For information on some alternatives to stainless steel pots and pans, see the article Cookware, Non–Stainless Steel Alternatives.
Buying, cooking and preparing food is so hard (or impossible) and makes me so much more ill, how can I try to minimise this?

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It’s impossible to offer suggestions that will suit all different ability levels and living situations etc., but some ideas of where to start might include:

Shopping ideas:
- See if you can order your groceries online and have them delivered. (See too if you qualify for any type of help; for a paid carer for part of the day or ‘meals on wheels’ or similar.)
- If you can’t get to the shop as often as you’d like, you may have to make sure you have a good stock of long lasting foods on hand so that you can put off shopping if you are exceptionally unwell. Good choices would be frozen meat, frozen spinach, frozen fruit or frozen fruit juice or some dried fruit, lots of nuts and seeds and good quality dark chocolate (85% cocoa). Generally speaking, frozen vegetables are more nutritious (and often taste better) than tinned.
- See if shops have a motorised wheelchair you can use while you are shopping.
- Buy in bulk where appropriate to save money and effort. This can save a lot of money with meat especially. Buy big meat trays and freeze it in individual one or two meal sized servings.
- If anyone offers you help, take them upon it and ask them to shop for you or cook for you either on a regular basis or if they would be on call for when you are at your most ill.

Cooking/food preparation ideas:
- Make your lunch and dinner (and maybe breakfast too) about 20 or 30% larger than you need, and then eat the leftovers later. That way you get six meals out of three (which is really helpful when so often M.E. patients need so many small meals per day to combat blood sugar problems and other metabolic problems).
- Make large batches of soup or casseroles and freeze leftovers in meal sized containers to be reheated later (either to eat over the next few weeks or to have there in case of emergency). Perhaps you could have one day a week that you spend doing your weekly cooking, or similar.
- If you have oats for breakfast, make enough for 3 or 4 days at a time and store it ready to serve in bowls in the fridge. You could also do the same with brown rice so you can add a small amount to each of your dinners for a few days.
- Cut steak or chicken fillets in half so they are half as thick, this way they’ll take less than half as long to cook.

- Some quick meal ideas with chicken: 1.) Roll a split chicken fillet in spices (turmeric and cumin, or mild paprika etc.) and cook lightly in coconut oil. While the chicken is cooking, roughly cut up your veggies (eg. cauliflower and broccoli florets) and cook them for a minute or so in the same pan as the chicken once the chicken is cooked. 2.) Cook chicken and veggies as before, except without using spices, and instead serve the chicken with a dipping sauce (eg. cranberry sauce, or salsa).

- Some quick meal ideas with beef: 1.) Cook a split steak lightly in coconut oil. While the steak is cooking, roughly cut up your veggies (eg. cauliflower and broccoli florets) and cook them for a minute or so in the same pan as the steak once the steak is cooked. Serve the steak with or without some sauce on the side (eg. tomato). 2.) Cook steak and veggies as before, except marinate the steak the night before to make it more tender or add spices while cooking.

- If you often cook the same sized bits of meat in the same way, you could even put a timer on for when it is time to turn them. You could put the meat on, put the timer on and then spent a few minutes roughly cutting up your veggies while lying down. When the timer goes off, get up to turn the meat over and then rest and lie down for a few minutes before getting up when the timer goes off the second time to put the meat on a plate and lightly cook the veggies and then pour them over the meat to serve. (And then go lie down again to eat!) You could also cook three or so of these chicken and steak meals described above at a time and eat them over the next few days, perhaps reheating only the vegetables where appropriate (as sometimes microwaved meat tastes and smells awful!)

- You could cook a roast chicken or two on the weekend and eat it in different ways for the next 3 or 4 days. (eg, cold chicken salad, chicken with cranberry sauce, or chicken reheated in a spicy sauce.)

- If you cook the same things a lot, add variety with different spices. Spices are better than sauces generally, they are cheaper and last longer and are often additive free. Don’t forget to add salt where appropriate too, it enhances flavour and also has health benefits.

- You may find one dish dishes such as stews and casseroles are easiest, where everything cooks together.

- If you buy a slow-cooker, you can put the meat and vegetables (or lentils) in hours earlier than you want to eat, and there is no standing up and stirring to do etc. Cut up the veggies lying down and/or at your best time of day (and then put them in the fridge) or you could even leave everything almost whole and it’d still all work out. Just cut whole carrots into 3 or 4 pieces for example and cut chicken fillets into two. Meat comes out very tender in slow cooker is another advantage, making it easy to chew and digest. If you can, put veggies in later so they don’t get too mushy (unless you like that).

- Replace some vegetable dishes with vegetable juices.
• In an ideal world, nothing would be microwaved, but of course this is the easiest cooking method if you are very ill and so all we can do is minimise its use as much as possible. Perhaps vegetables can be immersed in boiling water for a few minutes instead of microwaved, or leftover meats can be served cold, and so on.

• Get free recipes online on various Paleo diet websites.

Drinks and water, and miscellaneous:
• Keep a water jug near your bed. You might also like to have extra water bottles/jugs, enough for a few days so you don’t have to cart it in as often. Pouring out four glasses of water twice a day can sometimes be easier than standing up to pour water on eight separate occasions.

• Use a straw to drink and save valuable being upright time.

• Boil the kettle once and then put a few cups of herbal tea in a thermos you can drink from for hours afterward. You could also reheat soup once and put the leftovers in a thermos ready to eat as a preheated snack later.

• Frozen drinks are a good idea when it is very hot. Freeze a water bottle overnight.

• Buy special arthritis friendly cutlery if you think it will help. Make sure you have good sharp knives, both to cut up your raw fruit and veg and meat with, and to eat your meal with. The amount of muscle powder needed is so much less when you have good knives so they are essential for M.E. sufferers.

• Write lists about what leftovers you have in the fridge and freezer and when you cooked them, make notes about what you need to buy next time you shop and about what you will eat for the next week or month. Whiteboards are ideal. You could even write up a weekly chart and eat the same things on certain days of the week so you don’t have to think about what to eat each day. Monday to Wednesday you could have oats for breakfast, beans for lunch and chicken for dinner. Thursday to Sunday you could stick to millet for breakfast, lentils or chick peas for lunch, and either red meat or fish for dinner. For some this would be too boring, but if you are very cognitively impaired, order and routine and lists can be essential.

• If someone else cooks for you, write lists clearly stating what you can and can’t eat.

• Use reusable ‘shower cap’ type elasticised plastic covers when you put foods in the fridge instead of standard cling film. They are easier to use and cheaper.

• Keep extra cutlery etc. in the room you eat in to save making repeat trips to the kitchen.

• Keep everything in the same places so you don’t waste time looking for things.

• If you can, put your food on a tray to carry it to your room or table so you only have to make one trip. If the tray is hard to carry, see if you can get a small wheeled table or trolley to put it on.
Emergency foods:

- Keep a stash of snack foods near your bed in case you need food quickly or are too ill to get up. Good choices would be nuts (and nut butters), seeds, dried fruit such as apricots, berries, coconut and apple (you could make your own tasty trail mix containing all of these ingredients), fruit (apples will keep for a while), a protein shake* ready to go that just needs water added and good quality 85% cocoa dark chocolate.

- If you are very ill, you might like to consider having a small fridge and/or kettle or hotplate in your bedroom (if you can stand the noise) although make sure it isn’t too close to where you lie.

- Try to make sure you have some frozen meals in the freezer ready to go in case of emergency (if you have good periods enough to be able to prepare for later in this way).

- If you are desperate and decide to order a fast food delivery, get a whole chicken that you can make several meals from, along with some fruit and vegetables (fresh if you can). Don’t waste money buying overpriced side dishes and drinks etc.

- More tips are available on the Practical Tips page and in the paper on making foods easier to eat which follows. If you’ve tried everything and are still having real problems, you may unfortunately require tube feeding.
Chewing and swallowing food is very hard for me, what can I eat and/or how can I modify food so I can handle it better?

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Obviously, before you go on to having liquid meals, you’d want to try modifying normal foods first; mashing veggies (pumpkin, turnips, carrots etc.) and eating meat either blended up or minced. Dishes with spiced minced meat in them and veggies cooked for long enough to be soft can be ideal as can eating nut butters instead of nuts (eg. almond and cashew nut butters). You could also:

- Try using a slow cooker to cook meat and veggies etc. until they are very soft. Make up large batches of stews etc. and freeze them in meal-sized batches either to eat over the next few weeks or to have there in case of emergency.
- Make tuna patties, or chicken patties and so on, with minced meat and spices etc. These can be easier to chew and to cut up than non-minced meats.
- If normal mashing and slow-cooking isn’t enough, try blending food even finer using a food processor.
- Eat some fruits and vegetables in juiced form. Combine with a teaspoon of coconut oil to make them more filling.
- Eat dips made in the food processor. You could serve them with mashed veggies.
- Look up lap banding sites for food ideas as often those with lap bands need mushy foods.
- If you cook the same things a lot, add variety with different spices. Don’t forget to add salt where appropriate too (to enhance flavour and also for its health benefits).
- Make sure food has fibre, protein and fat in it in the right ratios so that it is satisfying, and not too much carbohydrate.

If this isn’t enough and you need more liquid meals, there are a number of things you could try.

Products like Ensure (or Boost or Fortisips or similar) are commonly recommended to all sorts of ill people but most of them are really not good for you. They’re just very expensive sugar water with some low quality protein and vitamins added. (One article I read said you’d be just as well-off drinking a can of coke and having half a cheap multivitamin!) They are also full of all sorts of nasty chemicals, and not only not very filling but can actually make you even hungrier afterward. They also lack...
many important nutrients and fibre and the sugar in them can cause a number of problems, including rotting teeth.

A far better quality meal replacement, especially for those with extensive food allergies, is Alpha ENF. I have been told by one M.E. patient (that was severely allergic to MSG and to all foods except rice and chicken) that it was the only type of meal replacement or protein shake that she could tolerate. (The product is hypoallergenic, although not 100% allergy safe as this isn’t possible.) Note that the product is not very high in protein compared to carbohydrate and so this may also cause problems for some sufferers, but Alpha ENF sounds well worth a try if you have need of such a product – and there is also a pure protein/amino acids version available, plus a sugar free version. There seem to be no other comparable products of this type. If you have extreme allergies this product can be a sole food source.

Probably one of best ways to start is too look at what a normal whole food diet contains and try to emulate that as much as possible rather than looking for an all in one heavily processed product that probably costs a fortune and delivers far less than promised. Ideas include:

- Buy a good quality protein powder*, and mix it up with a banana or berries, and a teaspoon of olive oil plus some flaxseeds for fibre.
- You could try some of the organic tinned soups available if you are desperate and can’t cook (some organic frozen meals can also be okay but make sure you check the labels).
- In addition to vegetable powders, you might like to try super green food powder and similar. These contain extracts of many different fruits and vegetables etc. and are high in antioxidants and other nutrients. (Although if you have a real problem with allergies, you will be better off buying ingredients or supplements individually so you can see exactly what you can and can’t tolerate).
- Make a clear broth from beef or chicken stock, as an alternative to protein powder*.
- Uncooked oats can be added to protein shakes* for added fibre. Blend well.
- Don’t worry about buying protein powders* with added vitamins, take a multivitamin tablet instead. The ingredients will probably be cheaper and of better quality. If you do take anything with added vitamins in it, make sure this doesn’t mean you need to adjust your medications/supplements.
- Drinking freshly prepared fruit and vegetable juices of a far healthier way of getting the daily requirement of carbohydrates than drinking prepared meal replacement products which are high in sugar such as 'Ensure.' A person needing an entirely liquid or soft-food-only diet may drink several glasses of fruit and vegetable juice daily, along with several rice, pea, hemp or dairy-based protein shakes containing some flaxseed oil, olive oil or coconut oil - plus perhaps some well-blended soups or cooked vegetables or nut butters (and a fibre supplement).
• Again, make sure food has fibre, protein and fat in it in the right ratios so that it is satisfying, and not too much high GI carbohydrate. Include as much real organic whole food as possible. Try to eat at least 3 decent serves of protein a day, a small amount of good fats with every meal, and at least 7 - 10 serves of fruit and vegetables each day.

No matter how balanced and nutritionally dense your liquid meals are, sadly you will possible always stay feeling not quite satisfied, as our body senses when we chew and this sends signals indicating fullness to the brain and so if we don’t chew our food, we wont feel as full no matter what we eat (according to new research). But at least having enough fat, fibre and protein etc. in your meals is going to be far better for you and more filling than drinking sugary meal replacement drinks. Make sure you eat at least every 2- 3 hours too, don’t let yourself get too hungry (if possible).

There are no perfect answers of course, all we can do is the best that we can at the time with what resources we have. The very best of luck to you in working your diet out.

**What sort of protein powders or shakes are best?***

Protein powders can be made from cows’ milk (undenatured or heavily processed), goats’ milk, or from peas. There is also egg white protein powder, brown rice protein powder, soy protein powder and liquid protein supplements and hemp protein powder. There is a lot of conflicting information out there about which protein shakes are best and which need to be avoided. Many articles say that most protein shakes on the market contain free glutamates and so should be strictly avoided as they can cause serious neurodegeneration, but they are somewhat vague about which ones ARE safe.

What we definitely want to avoid are overly or highly processed powders, such as those that are hydrolysed and/or ultra pasteurised. The article The Overlooked Role of Chronic Infection in Neurodegeneration and Its Reversal Using Nutraceutical Agents recommends only pesticide-free whey protein produced solely by ion-exchange (yielding 25% glycomacropptides for unparalleled hormone, immune and neurological support). This includes products such as Life Extension’s undenatured whey protein. Undenatured whey protein has a number of benefits for the immune system but must be started very slowly, as it can cause relapse in some M.E. patients and so may not be tolerated at first, or at all. Conversely, some M.E. patients report an improvement in their overall condition with this type of protein powder. (Dr Cheney recommended this product for many years, but now says he does not recommend it and feels it may have a detrimental effect on patients.)

Others recommend hemp shakes such as the one made by Nutiva brand, as the powder is only very minimally processed, while others say that Alpha ENF is a standout product and far better tolerated than many other powders and is also hypoallergenic (you might prefer the protein based version). So one of these three
may be the ones you might like to try first, depending on your specific needs. A protein powder made from goats’ milk that is organic and minimally processed such as Jarrow Goat Milk Protein may be a better choice than a cow milk product.

It is very hard to be sure exactly which other shakes are safe from free glutamates and other problematic MSG-like ingredients and which are not, unfortunately. It is hard to find a clear definition of what is minimally processed and what exactly isn’t, and where the cut off point is. Another problem is that many brands give you insufficient information about what sort of processing their product has undergone. (If you have more detailed information on this topic please let me know.)

Perhaps the best protein supplement is organic powdered beef liver. Beef liver powder (that can be put on the tongue and swallowed with water while holding your nose) is lightly cooked and not defatted and so is far closer to being a whole food than all the protein powders described above. It is high in protein, vitamin A and other nutrients. It should be limited somewhat in the diet due to the possibility of getting too much vitamin A. This type of ‘protein powder’ is also not suitable for adding to fruit drinks etc. as other milder tasting powders are, unless you have a very strong stomach!

Paleo diet advocates usually recommend only egg white, flaxseed or hemp protein shakes. The beef liver powder would also fit in this category.

Other general protein shake rules are to get unflavoured powders if you can to avoid the extra added chemicals, avoid products with added sugar or Aspartame and always look for non GMO and organic products. Start with small containers of each powder until you find the one you tolerate best, then buy in bulk to save money if possible.
Recipes for healthy treats

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Sometimes you just want a treat but one which won’t make you feel awful and that still means you are avoiding foods that don’t agree with you. Special foods for birthdays and other celebrations are also important. Here are some of the recipes I have collected that are dairy-free, soy-free, egg-free, wheat-free, grain-free, legume-free, nightshade-free and gluten-free but hopefully not taste-free!

**Sweet potato chips:** Slice a sweet potato very thinly, using a slicer device if you have one. One large sweet potato makes lots of chips for about 3 people or 2 very hungry ones. Spread the slices out on two large baking trays, greased with coconut oil. Bake in a hot oven until crispy but not brown all over or burned, probably 10 – 20 minutes. (How long this takes depends on how thin you’ve sliced the sweet potato and where the trays are in your oven). Lightly salt the chips using unrefined sea salt and serve immediately. They can also be sprinkled with rosemary, if desired. These chips taste as nice as potato crisps yet are full of beta carotene and all the important nutrients in coconut oil!

**Coriander/cilantro pesto:** Combine in a blender 1/3 to 1 cup raw or toasted (unsalted) cashew nuts, 2 cups of fresh coriander, (and some fresh rocket if you’re lucky enough to have some in the garden), and a few cloves of garlic. When combined, slowly add in 1/2 a cup or so of olive oil until you have a smooth paste. Add salt and pepper to taste. You can also add some chilli flakes if you like, or lime juice or ginger. This is delicious spread on cold or warm chicken, warm fish or used as a dip for vegetable sticks. If you put it in a small bowl and cover the pesto with a light coating of olive oil to stop it oxidising it can last up to 2 weeks in the fridge. If you have a garden, or can manage a single potplant, consider growing coriander for pesto purposes. Pesto can also be made with basil.

**Chocolate covered nuts:** Melt 30 grams of 85% cocoa chocolate (Lindt is a good brand as it has no dairy products in it. The Dagoba or Nui brands, or others, may be even better. You may also want to look for ‘slave free’ brands). Lying down, dip half the brazils, cashews or hazelnuts in the melted chocolate and put on a foil covered plate or tray to set in the fridge.

**Chocolate covered berries:** If you can get good strawberries or cherries, chocolate covered berries are even better than the nuts! Chocolate covered frozen bananas are
also good, and coconut can be added on top while the chocolate is still melted or you can just add some coconut to melted chocolate to make your own coconut rough.

**Fruit sorbet:** Juice some fruit that is cheap and in season or that you have a lot of. For every 100 ml (3.5 floz) of juice, add ½ to 1 tablespoon of honey, or more or less honey to taste. Very sweet fruits such as red grapes and mangoes need very little honey, if any at all. Put sorbet in a sealed container in the freezer, and after 4 hours take it out and scrape it all up with a spoon. It is ready to eat at this time and also lasts well for 2 weeks in the freezer. Serving 3 or 4 flavours and colours of sorbet together in a bowl arranged in stripes makes it extra nice.

**Creamy coconutty fruit sorbet:** Follow the sorbet recipe above except add some coconut milk or cream to the juice before you put it in the freezer. This works best with tropical fruits such as pineapple and mango. You can also add back ½ (or all) of the fruit pulp to the mixture, if desired, to bulk it up a bit and last longer.

**Coconut hot chocolate:** Add 800 ml of water, 3 tablespoons of cocoa, a dash of salt and 1 – 2 tablespoons of honey to a saucepan and bring to the boil, while stirring. Boil for 2 minutes. Reduce the heat and add 400 ml coconut cream. When the mixture is warmed through, take it off the heat and add ½ - 1 tablespoon of vanilla extract. Pour hot chocolate into three mugs and enjoy! Tastes lovely fresh and hot, or cold and refrigerated the next day. (Amounts of each ingredient can be adjusted to suit your own preferences.)

For an alternate recipe using coconut oil rather than coconut cream, see the Free Coconut Recipes site.

**Coconut fruity milkshake:** Add to a blender 400 ml of coconut cream, 800 ml water, 1 – 2 tablespoons of honey, half a tablespoon of vanilla extract, 1 – 1 ½ cups of fruit (berries, mango, pineapple, chopped and/or frozen bananas etc.) and a dash of salt. Blend well and then serve chilled. Makes about 4 serves. Lasts for up to 4 days in the fridge in a sealed container. (Amounts of each ingredient can be adjusted to suit your own preferences.)

**Coconut and vanilla ice cream:** Add 800 ml of coconut cream, a dash of salt, 2 – 4 tablespoons of honey, and a 1 – 2 tablespoons of vanilla extract to a saucepan and warm on a low heat until all ingredients are dissolved. Refrigerate mixture for 2 hours or freeze for about 20 minutes. Add mixture to an ice cream maker and follow the manufacturer’s directions, then freeze in a sealed container. (If you don’t have an ice cream maker, freeze the mixture until it is about half set, then put it in a food processor, and then refreeze it. This improves the texture.)

Other flavourings you can add to the ice cream mix before putting it in the churn include: coffee, frozen berries and frozen chopped bananas. Coconut ice cream keeps for up to 2 weeks in the freezer. (Remember that this sort of ice cream isn’t full of chemical preservatives and so doesn’t last as long as commercial ice cream.)
Lime and ginger cooler: Add some iceblocks to a jug of filtered water, along with a cup of cooled ginger tea (of the pure ginger powder variety, made using 4 or 5 teabags) and either fresh lemon or lime juice or a few tablespoons of frozen lemon or lime sorbet. Mint leaves can be added in for decoration. This drink can also be kept in the fridge in a glass bottle and used as an anti-nausea treatment.

Frozen berries and fresh exotic fruits (coconuts, mangoes, persimmons etc.) are a treat all on their own.

Stewed fruit: This is a good way to eat fruit that is a little bit over-ripe or under-ripe or a bit flavourless and not very sweet as the cooking makes the fruit taste better. Cooked fruit can also be easier to digest and less acidic. Cut up fruit and place in a saucepan with a bit of water and a small amount of honey. Cook until fruit is just soft. Works well with green apples, rhubarb, apricots and other stone fruit. The cooked fruit keeps in the fridge in a sealed container for up to 3 days.

Fruit crumble: All the above comments about fruit ripeness and type apply here too. To make a fruit crumble add sliced fruit to an ovenproof dish, along with a bit of water. Then add a crumble on top of chopped or crushed nuts mixed with desiccated coconut, honey and some melted coconut oil. Cook in a moderate oven until lightly browned. Can be served with a dollop of coconut cream on top.

Mixed fruit platter: If there are two or more people present, a fruit platter can be a good dessert as you get to eat a smaller amount of three or more fruits rather than just one piece of fruit, plus you don’t have to peel or cut up the fruit as you eat. If you have a spare 30 seconds you might also arrange fruit ‘artfully’ into towers or spirals or abstract shapes or whatever else, to make the person you’re making it for (M.E. patient or not), smile. Slices of chocolate covered banana or a little bowl or scoop of sorbet can be added to the centre of the plate.

Carolyn Dean's Chocolate Banana Cream Pudding: Pulse 4 small frozen bananas, 120 ml (4 oz) coconut milk, and 2 tablespoons cacao powder in a food processor or high-speed blender until smooth and creamy. Serve with sliced strawberries and/or blueberries. Serves 2. (Ordinary cocoa powder can be substituted for the cacao powder, if this is easier.) From the highly recommended Carolyn Dean website/newsletter.

Key Lime Mousse: Blend 2 ripe peeled/pitted avocados, the juice of 2 limes, 1 teaspoon vanilla extract, and 2 tablespoons honey in a food processor until smooth and creamy. Serve in a dessert cup with a sprig of mint and very thinly sliced strawberries. Serves 2. (Lemon juice can be substituted for the lime juice, if this is easier. More lemon or lime juice can be added too for a stronger tasting dessert.) From the highly recommended Carolyn Dean website/newsletter.

Guacamole dip: Mash 4 avocados and then add the juice of one lemon, ¼ finely chopped (red) onion, ¼ cup finely chopped coriander/cilantro, a teaspoon of unrefined sea salt, 2 tablespoons of coconut cream and a tablespoon of olive oil,
mashing until mixture is smooth. Adding a small amount of chilli flakes is optional. Cover the bowl and place in the fridge for 1 hour before serving.

Other recipes that can be looked up:
- Liver pâté (using coconut cream in place of butter)
- Salmon pâté (using coconut cream in place of cream cheese or tofu)
- Coconut flour cake with coconut frosting
- Coconut flour persimmon muffins (contains eggs)
- Coconut choc chip biscuits or gingerbread or choc chip scones

**A coconutty reminder:** Remember before going nuts on delicious coconut recipes that coconuts really do have anti-viral properties and that adding huge amounts of coconut products to your diet all at once can really make you feel awful and cause a big healing reaction. Pace yourself though and there should be no problems. Freshly made coconut cream or juice can also be used in place of tinned coconut cream, where available, for an even healthier treat.

**A note on Lindt 85% chocolate:** This chocolate does unfortunately contain trace amounts of soy lecithin which may be unacceptable for some people.

Further recipe suggestions are welcomed, especially if you have made them up yourself!
The recipes on this page are mostly given as links and book recommendations. This was done in order to keep this paper brief, and also because printing recipes in full would be an unfair use of material from other authors.

As you can see from the information given below, an easy way to get almost all these recipes is to buy the excellent book ‘Nourishing Traditions’ by Sally Fallon. This book is highly recommended and also contains many other recipes than those listed.

For a quick read on why traditional foods are so important see this [WAPF article](#).

**Sauerkraut (raw cultured cabbage)**
Sauerkraut is delicious and can be eaten even by those who cannot tolerate cabbage eaten raw or cooked as it is high in digestive enzymes and probiotics and easy to digest. It is also easy to make. A tablespoon or up to half a cup can be eaten with meals.

Online recipes: Nourished Australia, The Nourishing Cook, GAPS Diet Australia, The Nourishing Cook (cabbage juice tonic)
Books which feature recipes: Nourishing Traditions (includes a cultured garlic recipe)

**Ginger carrots (raw cultured carrots)**
Ginger carrots are high in digestive enzymes and probiotics and easy to digest. They are also lower in carbohydrate than non-cultured carrots as the good bugs eat a lot of the sugar. This recipe is very easy to make and the ginger is optional. You can also try Kimchi. A tablespoon or up to half a cup can be eaten with meals.

Online recipes: Nourished Australia (kimchi), The Nourishing Cook
Books which feature recipes: Nourishing Traditions

**Fermented beet kvass**
A drink full of probiotics and digestive enzymes. Half to one cup is taken with meals as a digestive aid.

Online recipes: The Nourishing Cook
Cultured dairy products
Cultured dairy products include clabbered milk, yogurt, cultured butter and kefir. The best form of yogurt is 24 hour yogurt which is very high in probiotics. The best milk to use is high quality raw milk.

Online recipes: The SCD Diet Website (24 hour yogurt), The Nourishing Cook.

Books which feature recipes: Nourishing Traditions

Cultured coconut products
Cultured coconut products as yogurt can be made from home-made coconut milk or canned coconut milk or cream.

Online recipes: Angela’s Kitchen, Small Footprint Family.

Books which feature recipes: The Body Ecology Diet

Dairy kefir
To find raw milk in your area, visit the Weston A. Price Foundation website and click on the ‘Real Milk’ link.

Online recipes: Nourished Australia.

Books which feature recipes: Nourishing Traditions

Water or coconut kefir
A different type of kefir grain is needed to make coconut water or water kefir, you need to buy water kefir grains.

Online recipes: Yemoos


Ghee
Ghee is also known as clarified butter. Clarifying butter is easy to do and removes the dairy proteins from the fat and leaves you with a fat useful for cooking and which does not contain dairy proteins.

Online recipes: Nourished Australia

Books which feature recipes: Nourishing Traditions

Traditional animal fats such as lard
These fats can be safely used for cooking. If possible choose to make your cooking fats from organic pasture-raised meats.

Online recipes: Nourished Australia  
Books which feature recipes: Nourishing Traditions

**Bone broth and stock**  
If possible organic pasture-raised meats are the best choices.

Online recipes: The Nourishing Cook, The WAPF,  
Books which feature recipes: Nourishing Traditions

**Liver pate**  
Liver is one of the most important nutrient dense foods, but must be prepared well to be palatable.

Online recipes: Nourished Australia, The WAPF (gourmet organ meat recipes), The WAPF (liver recipes and facts).  
Books which feature recipes: Nourishing Traditions, Deep Nutrition

**Sprouted seeds and nuts**  
Sprouting nuts makes them far easier to digest.

Online recipes: Nourished Australia  
Books which feature recipes: Nourishing Traditions

**Soaked and dried crispy nuts/seeds**  
Soaking and drying nuts makes them taste better and makes them far easier to digest. Nuts and seeds can be dried in a very slow oven, using a dehydrator or in the sun.

Online recipes: Hazelnuts or Pecans or Almonds or Walnuts from The Nourishing Cook, Nourished Australia.  
Books which feature recipes: Nourishing Traditions

**Ginger tea**  
Grate a piece of ginger half as big as one of your finger into two cups cold water in a small pan. Bring to a boil, the turn off the heat and let it steep. The longer you steep it the stronger the drink will become. When you have it as strong as you want it, add honey and lemon to taste and enjoy.

You can also add an extra nutrient boost to ginger tea, or any other tea, by melting 1-3 tablespoons of coconut oil in it.


**Coconut milk**
Make your own coconut milk.

Online recipes: Coconut Connections
Books which feature recipes: Nourishing Traditions and Eat Fat, Lose Fat
Section D: Special category foods and drinks for M.E.
While juice fasts are not appropriate for M.E. patients, taking in some of the daily fruit and vegetable intake in juice form does have a number of advantages.

Eating the ideal amounts of fruits and vegetables each day in M.E. can be problematic due to difficulties in chewing and swallowing, difficulty chewing large amounts of food, difficulty preparing large amounts of food and nausea.

Juicing some of the fruits and vegetables eaten daily saves effort chewing, reduces the arm and hand strain involved in using cutlery, increases enzyme, vitamin and mineral intake, can make fruits and vegetables easier to digest, can make the diet healthier and more filling, can allow a larger amount and different types vegetables to be eaten, may promote weight loss by allowing the stomach to fill up with vegetables rather than other less healthy foods and makes it easier to have a high alkaline forming diet. Juiced fruits and vegetables may also be easier for a patient or carer to prepare than other vegetable dishes.

Different types of juicers

Probably the most popular type of juicer is the centrifugal juicer. Other types of juicer include single and twin gear cold press juicers and two step hydraulic press juicers. Each type of juicer has its won pros and cons.

**Centrifugal juicer pros:** inexpensive (many models are under $100), quick and easy to use and assemble and widely available.

**Centrifugal juicer cons:** very noisy, poor energy efficiency, produces only average quality juice which is quickly oxidised, destroys many of the enzymes in the juice due to its high speed, produces significantly less juice than other juicers, produces juice with a fair amount of fibre, shredded fruit and vegetable pieces and foam in it, can be a hassle to clean, can’t juice wheatgrass, the unit needs cleaning after a certain amount of juice has been made as the inside fills with pulp.

**Single gear cold press juicer pros:** low noise, produces ultra high quality ‘live’ juice with lots of intact enzymes, vitamins and minerals, makes better tasting and more brightly coloured and less oxidised juice than centrifugal juicers, some models have a self-cleaning function (eg. Coway JuicePresso), the pulp is ejected from the machine at the same time as the juice (from a different spout) which allows for continuous juicing, inexpensive replacement parts are available.

**Single gear cold press juicer cons:** quite expensive ($290 to $700).
Twin gear cold press juicer pros: same as the single gear, except the juice may be of a slightly higher quality and slightly more juice will be extracted, the higher-end units may last many years longer and may have all stainless steel parts, and some may also be dishwasher safe (eg. the stainless steel Angel Juicer).

Twin gear cold press juicer cons: very expensive ($700 to $1400), some twin auger models may be slightly fiddly to set up and may require the changing of a screen mid-juicing if going from vegetables to fruit, replacement parts can be very expensive on some high-end models.

Two step hydraulic press juicer pros: Makes the highest quality juice possible (with a very low fibre content), plus the best tasting juice and extracts the highest possible amount of juice.

Two step hydraulic press juicer cons: very extremely expensive ($3000 for the Norwalk juicer), quite noisy, and said to be difficult, fiddly and time consuming to use and to clean.

Buying a juicer
Centrifugal juicers are not ideal and a single gear cold press juicer is a much better choice, if budget allows. If the budget doesn’t stretch to a cold press juicer however, average quality juice is still far better than no juice at all!

Homemade juice from any type of juicer is far superior to any pre-packaged and pasturised (dead) juice product. These juice products are far lower in enzymes and vitamins and may contain preservatives and other chemicals and are not considered ‘live’ juice as fresh juices are.

When buying a juicer, take into account how easy it is to use, set-up and clean, the quality of the juice it produces, which foods it juices, its warranty and the company’s return policy and the availability and cost of spare parts. Patients may want to try borrowing a juicer from a friend or family member for a few weeks to see if they can tolerate drinking juices, before buying their own machine.

Some juicer selling websites feature videos of each juicer, so you can see how easy each model is to use and to clean. Reading reviews on each of the different juicers you are considering can also be helpful. How easy a juicer is to clean is very important as most juicers need to be cleaned immediately after each use.

Some juicers can also be used to make nut butters and other products.

General juicing notes
Juice fasts and all-juice diets are not appropriate for M.E. or patients with any other metabolic or mitochondrial disease. Fruit and vegetable juices must be combined with normal meals (preferably containing a protein source and some cooked vegetables) or else the juices will ‘go straight through’ and the body will not have
time to absorb the nutrition from them.

M.E. patients will generally be better off juicing vegetables with a low glycaemic load and low glycaemic index, rather than very high GL vegetables and fruits. Drinking a lot of carbohydrate or sugar all in one go can lead to problems with blood sugar, hypoglycaemia and increased hunger.

Juices from zucchinis, celery, broccoli, cauliflower, capsicums, cucumbers, lettuces, melons and cabbage may be better tolerated than juices from carrots, beetroot, oranges, apples and other fruits. Patients may have to go easy on these higher GI and GL juices, or omit them entirely if problems dealing with sugars are very severe. Small amounts of carrot or apple juice can be added to other less palatable juices to make them taste better, and this may be a better way to enjoy these juices rather than just drinking them on their own.

Patients with severe problems dealing with carbohydrate rich foods may find that juices have a far less noticeable effect on mood and hypoglycaemia if they are taken together with a handful of nuts or some other fat or protein containing food.

Juices should always be consumed within 30 minutes, no matter which type of juicer they have been produced with, for maximum enzyme and vitamin content.

Non-centrifugal juicers are a better choice for those with poor digestion, as these juicers do not destroy the natural enzymes in the produce which aid in their digestion by the body.

What to juice and how?
Most juicing advocates recommend that only organic produce be used for juicing, or at least as much organic or home-grown produce as possible. Fruits and vegetables juiced should also be as fresh as possible and in season. Fruits and vegetables should be washed well prior to juicing, and should not be pre-cut ready for juicing very much ahead of time.

Fruits and vegetables that can be juiced include: zucchinis, celery, broccoli, cauliflower, capsicums, beetroot, cucumbers, lettuces, melons, spinach, cabbage, endive, kale, watercress, bok choi, carrots, tomatoes, brussel sprouts, radishes, oranges, apples, pears, pineapples and other fruits.

Note however that some vegetables are said to be healthier if they are cooked, to remove problematic compounds. This includes cabbage, spinach and broccoli. Patients may wish to follow this advice or see how they feel after drinking juices from these vegetables. (Opinions vary considerably on the benefits of a raw food diet vs. cooked vegetables. It is probably best to go with what feels right with your own body.)

Watermelon can be juiced along with its seeds, while apples should always be cored.
before juicing. Orange peel should not be juiced. Wheatgrass juice should be limited to 30 ml/1 oz daily as larger amounts can be difficult to digest. Cucumber juice may also be difficult to digest. Ginger, garlic and parsley can be added to juices for added flavour and for their health benefits. Patients may want to search online or see if their library stocks any books on juicing, to get some ideas for healthy and tasty juice combination ideas.

Fruits that can just as easily be eaten, are eaten only in small amounts as a treat, or that are very enjoyable to eat such as mangoes or berries should probably NOT be juiced, and just enjoyed as is.

It generally takes double the amount of vegetable or fruit matter to produce the amount of juice required. So 250 grams of vegetables will produce 125 ml of juice.

Fruit and vegetable juices can aid in detoxification and so the amount of juice taken daily should be increased only gradually, to reduce the chance of any ‘detox’ or healing reactions.

How much juice should be taken daily?
How much produce is juiced daily will vary depending on several factors. These include how much other fruits and vegetables can be eaten, whether or not the patient eats a lot of grains and legumes and how well the patient tolerates the carbohydrates in the juice. It can be easy to go overboard with juicing and to consume too much carbohydrate. Drinking the juice of 4 or 5 or even 6 apples or oranges is very easy, while one would rarely if ever eat this many apples or oranges at one sitting!

Patients may want to restrict themselves to a total daily intake of 2 – 4 servings or pieces of fruit daily and 6 – 10 cups of vegetables – or whichever amounts work best for them. 25 - 50% or any other percentage of this daily intake may be turned into juice. Setting limits on how much juice is consumed at one sitting may also be helpful. For some patients 250 ml at one time may be adequate while others may be able to manage 500 ml.

For information on balancing the amount of fat, protein and carbohydrate in the diet, please see the HFME paper Treating M.E.: Food as medicine.

Using the juicer when the patient is on a liquid or soft-food-only diet
Drinking freshly prepared fruit and vegetable juices of a far healthier way of getting the daily requirement of carbohydrates than drinking prepared meal replacement products which are high in sugar such as ‘Ensure.’

A person needing an entirely liquid or soft-food-only diet may drink several glasses of fruit and vegetable juice daily, along with several rice, pea, hemp or dairy-based protein shakes containing some flaxseed oil, olive oil or coconut oil – plus perhaps some well-blended soups or cooked vegetables or nut butters (and a fibre
supplement).

For information on liquid diets and meal replacements drinks please see the HFME paper Treating M.E.: Food as medicine.

**Additional notes**

- **Adjusting mineral and water intake when juicing:** Drinking lots of mineral rich juices may mean that a patient is able to cut back on calcium supplements, and that they will need to drink less water each day.
- See [www.nutritiondata.com](http://www.nutritiondata.com) for exact figures on the beta-carotene, vitamin and mineral content of different vegetables and fruits.
- Patients with poor tolerance of carbohydrate-rich foods may need to take extra magnesium, B vitamins, vitamins C and D and chromium. See Treating M.E.: The basics for more information.

**References and sources of further information:**

- Dietary Healing & Detoxification: A simple reference guide for those with chronic degenerative disease or cancer choosing the Gerson Therapy by Kathryn Alexander.
- Juicing, Fasting and Detoxing for Life by Cherie Calbom.
- Raw Juices Can Save Your Life by Sandra Cabot.
- The Juicers Australia website.
- The Wonders of CARROT JUICE by John B. Lust
- The Energise for Life website.
- Healing the Gerson Way: Defeating Cancer and Other Chronic Diseases by C. Gerson and B. Bishop.
- The Gerson Therapy: The Amazing Juicing Programme for Cancer and Other Illnesses by Charlotte Gerson and Morton Walker.
- Fire your doctor! : how to be independently healthy by Andrew W. Saul.
- The NEW optimum nutrition bible by Patrick Holford.

**Additional notes:**

- Note that prices quoted are in US dollars or Australians dollars (which are almost the same as I write this) and can also be considered accurate to within 10 to 20% for the Canadian or New Zealand dollar.

**Relevant quotes**

“What you eat has more power over disease and aging than any other medicine your doctor can prescribe. Food is awesomely powerful.” Dr Sherry Rogers.
“Most patients suffering from chronic degenerative disease or cancer are nutritionally depleted and, as a consequence, usually suffer from poor digestive capacity. This poses a vicious cycle: the greater the chronic illness, the more the digestive capacity is impaired and the more nutritionally depleted the patient becomes. In order to heal, the patient needs maximum digestive capacity and absorption and a plentiful supply of nutrients. The nutrients the patient requires involves copious amounts of organic vegetable produce. By juicing we ensure that the bulk of the diet is not only raw with living nutrients, but easily assimilated by the most weakened digestion.” Kathryn Alexander.

“Providing you use the appropriate grinding and pressing mechanism in juice preparation (see equipment) you will extract only the nutrient and enzyme-rich juice, free of fibre which ordinarily taxes the digestive system and inhibits the direct absorption of nutrients/enzymes. So you will ensure that your uptake of nutrients is with the minimum digestive effort.” Kathryn Alexander.

“Carrots are very detoxifying; in juice form they are able to draw toxins out of the cells. In agriculture they are seen to have the same capacity; farmers will crop carrots to “clean” the soil (another reason to beware of juicing commercial carrots). In traditional Chinese literature carrots are regarded as a liver stimulant, or supporting Liver Qi.

The green juices are tonifying and build the blood. They are rich in iron and magnesium, along with other trace elements not found in carrots. The patient requires a broad spectrum of nutrients and therefore the green juice becomes essential. Many patients are extremely deficient and would not make good their deficiencies without the green juice.

The addition of apples to the juices is critical. Green apples are the best for their high levels of malic acid and pectin. When the pulps of both the apple and vegetable are mixed together before pressing, the malic acid solubilizes and extracts a greater nutrient value than the vegetable would produce on its own. Additionally the pectin in apples is an immune-stimulant.” Kathryn Alexander.

“Green juices contain lots of chlorophyll which is incredibly effective in detoxifying our bodies. Chlorophyll can help make our bodies strong, detoxify the liver, can purify and help to rebuild our blood cells (as the molecular structure is very similar to haemoglobin which moves oxygen through our blood), remove mold, parasites and myco/exotoxins from the body and (as many, many studies show) can help prevent and remove cancer cells.” The Energise for Life website.

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Eating liver is very good for your liver. Eating adrenal glands is good for your adrenals, eating thyroid glands is good for your thyroid, and eating tongue...is just disgusting! (Sorry, I couldn’t resist!)

Liver products contain high levels of the fat soluble vitamins A, K2 and D. They also contain many important cofactors for these vitamins. Liver products are abundant sources of arachidonic acid, EPA, DHA, carnitine, lipoic acid, and the B vitamins. Charts of the nutrients found in liver can be found here and here.

When it comes to getting the nutrients from liver there are four main options:

- Add some cooked liver into the diet
- Take a liver extract in pill form daily.
- Take cod liver oil daily.
- Have an injections of liver extract.

**Eating freshly cooked organic liver**

Around 100 – 120 g weekly of freshly cooked organic liver, from grass-fed animals, is the amount often recommended. Probably the best way to eat it is to combine it with lots of seasonings in a pâté. Liverwurst without additives is another option.

For good pâté recipes browse the internet or look at books such as *Eat Fat, Lose Fat: The Healthy Alternative to Trans Fats* and *Nourishing Traditions* by Sally Fallon, or websites such as the Weston A. Price Foundation website or the article *Five Tips For Cooking Liver That Had My Husband Going Back For Seconds*. Additive-free pre-prepared versions may also be a good choice.

Raw liver is not considered safe to consume. Dr Sherry Rogers recommends buying fresh liver, freezing it in 15 gram serves (for 2 weeks) and blending up 30 – 60 grams daily and then adding it to a glass of vegetable juice, to cover up the taste.

For information on why good quality liver is not full of toxins (as popular opinion would have us believe) see *Liver Q&A: Why Liver is NOT Full of Toxins and Where To Find Good Liver*.

**Liver extracts in pill form**
Eating freshly cooked organic liver is a better choice than a liver supplement, but where fresh liver is not available or not desirable to eat, supplements are a good second-best choice.

The best type of liver extract is freeze dried. This form is far superior to dessicated and defatted forms.

A whole food liver powder is also available. If it is not possible to eat fresh liver, this product could be a very healthy addition to your diet. The advantage of the freshly cooked whole liver and wholefood liver power (placed on the tongue and swallowed quickly with water while holding your nose) is that they are not defatted, as are many encapsulated liver products. This means that they still contain all the original fat soluble vitamins such as vitamin A and D.

The disadvantage of whole food liver powder is that it really does taste terrible. (No, I have never tasted it before but to me it tastes like.... GRAVE DIRT! Just unbelievably awful.)

**Cod liver oil**
The best form of cod liver oil is fermented cod liver oil (FCLO). Fermented cod liver oil has not been subjected to any high heat processing which destroys vitamin content. That is unique so far in the industry. Fermented cod liver oil is much higher in vitamins A, D and K2 without the additional of synthetic vitamins. Significantly lower doses of vitamins A and D from FCLO may be needed as compared to synthetic versions of these nutrients which do not contain the all-important cofactors which may enhance the body's uptake and usage.

Cod liver oil is also rich in the omega 3 fatty acids DHA and EPA.

The dosage is usually 1 teaspoon daily for adults, and 2 teaspoons daily for those fighting serious illness.

For a list of suppliers of fermented cod liver oil see the Westen A. Price Foundation website’s **Cod Liver Oil Basics and Recommendations** and FCLO page. This product is considered as a superfood rather than a supplement and is also considered by the Westen A. Price Foundation as a far superior source of Omega 3s compared to fish oil. (Which they explains is always heat treated and heavily processed, as well as not containing vitamins A, D and K2.) They also recommend that cod liver oil always be combined with a diet containing whole foods and good sources of healthy saturated fats such as butter or coconut oil.

FCLO is more expensive than other cod liver oils. If FCLO doesn’t fit into the budget, standard or high-vitamin cod liver oils from Carlson’s and Twin labs are the next best choices. Dosage is usually 1 teaspoon to 1 tablespoon daily.

Dr Sherry Rogers explains that cod liver oil is crucial for the control of over 1000
genes as well as repair of the mitochondria.

**Liver extract injections**
Advocates of the Klenner program today consider twice-weekly liver injections as an essential and non-negotiable part of the therapy, crucial to its success. Other forms of liver are considered not as potent. Dr Klenner explains that liver, ‘Contains factors still unknown but essential in metabolism.’

The Gerson juicing program for cancer and degenerative diseases is similar in some ways to the Klenner protocol. Both consider injections of liver extract given twice weekly or more as essential to the success of the therapy, although the Gerson program also recommends daily liver extract tablets. Taking some CoQ10 daily is also considered a partial-substitute for large amounts of liver products, according to the Gerson protocol.

**Combining different sources of liver products and vitamins A and D**
The amount of vitamin A and D in any liver products you are taking should always be taken into account when deciding the dosage of other products containing these vitamins. A limit of 30 000 IU of vitamin A from all sources is recommended as safe by Sally Fallon and Mary Enig.

Eating freshly cooked liver/taking liver extract tablets/having liver injections is often recommended to be combined with taking cod liver oil daily as well.

Vitamin D levels should be checked periodically to determine the correct dosage of all vitamin D containing foods and supplements.

Women that are pregnant or may become pregnant are generally recommended to take no more than 6000 IU of synthetic vitamin A daily. Very high vitamin A levels can cause problems for the foetus but so can very low vitamin A levels. Women in either of these positions should read more about safe vitamin A supplementation in pregnancy before taking any supplements, to make sure they are making the best and safest choices. The Western A. Price Foundation warns that solidified, water soluble and emulsified vitamin A is not the best choice. See the reference list for links.

High levels of vitamin A should be avoided by alcoholics.

**Other animal product superfoods**
Eating meat has many health benefits, but to get the most benefit from eating meat it is best to eat all 3 types of animal products, if possible. These are: organ meats, bone broths (stocks made with animal carcasses) and muscle meats.

If possible, all of these meats should be from organic grass-fed animals. Also where possible, meats should be from a wide variety of different animals including game.
Game meats include venison, deer, wild boar, emu, ostrich, buffalo, rabbit and kangaroo. Where possible choose sustainably caught meat. Most of us are limited in what meat we have access to and can afford financially (including me) but these ideal options are listed for those few that are lucky enough to have the option to include them.

Types of seafood known to be high in mercury should be eaten only very occasionally, if at all.

Free range eggs are a very healthy food to add to the diet providing that allergies to eggs aren’t a problem, nor the lectins which can be produced by eating eggs.

Raw milk contains enzymes and beneficial bacteria that aid in its own digestion and is a very good dietary choice if made into kefir or 24 hour yogurt – if it is well tolerated and form a reliable and high quality source.

Another healthy addition to the diet may be lacto-fermented drinks and foods.

References and further reading:
- Beef liver information by Nutrition Data.
- Calf’s liver information by WH Foods.
- Clinical Guide to the Use of Vitamin C The Clinical Experiences of Frederick R. Klenner, M.D. and Response of Peripheral and Central Nerve Pathology to Mega-Doses of the Vitamin B-Complex and Other Metabolites by Dr Klenner.
- Cod Liver Oil Basics and Recommendations
- Cod Liver Oil Manufacturing Written by David Wetzel
- Cod Liver Oil: The Number One Superfood Written by Krispin Sullivan, CN
- Dietary Healing & Detoxification: A simple reference guide for those with chronic degenerative disease or cancer choosing the Gerson Therapy by Kathryn Alexander.
- Eat Fat, Lose Fat: The Healthy Alternative to Trans Fats by Mary Enig and Sally Fallon. An excellent book on diet and how to improve health and lose weight with coconut oil and a whole-foods diet. Contains lots of good recipes.
- Healing the Gerson Way: Defeating Cancer and Other Chronic Diseases by C. Gerson and B. Bishop.
- My Multiple Sclerosis: A Real Story presented by Homer. For more information on following the Klenner protocol for MS, including case studies and detailed practical information on the nutrients involved and where to source them, plus links to some of the Klenner protocol doctors accepting patients around the world, this site is highly recommended. See also: Begin the Klenner protocol and Liver Extract Rocks!
- Nourishing Traditions by Sally Fallon.
- The Benefits of Liver, Cod Liver Oil, and Dessicated Liver by Chris Masterjohn
- The Gerson Therapy: The Amazing Juicing Programme for Cancer and Other
Illnesses by Charlotte Gerson and Morton Walker

- The High Blood Pressure Hoax by Dr Sherry Rogers
- The Klenner Protocol for MS article by Dr Klenner. In this two-part series Klenner defines an orthomolecular treatment of MS that has been effectively employed by Dale Humpherys and other patients. (For Humpherys' report, see his article in the December 2005 issue of the Townsend Letter.)
- What is real milk? Website

“We have pointed out that concerns about vitamin A toxicity are exaggerated. While some forms of synthetic vitamin A found in supplements can be toxic at only moderately high doses, fat-soluble vitamin A naturally found in foods like cod liver oil, liver, and butterfat is safe at up to ten times the doses of water-soluble, solidified and emulsified vitamin A found in some supplements that produce toxicity. Additionally, the vitamin D found in cod liver oil and butterfat from pasture-raised animals protects against vitamin A toxicity, and allows one to consume a much higher amount of vitamin A before it becomes toxic. Liver from land mammals is high in vitamin A but low in vitamin D, and should therefore be consumed with other vitamin D-rich foods such as lard or bacon from pasture-raised pigs, egg yolks, and oily fish, or during months in which UV-B light is sufficient to provide one with adequate vitamin D.” Sally Fallon and Mary Enig.

“Once a standard supplement in traditional European societies, cod liver oil provides fat-soluble vitamins A and D, which Dr. Price found present in the diet of primitives in amounts ten times higher than in modernized diets. Cod liver oil supplements are a must for women and their male partners, to be taken for several months before conception, and for women during pregnancy. Growing children will also benefit greatly from a small daily dose.” Sally Fallon and Mary Enig.

“In general, the test totals are substantially higher for vitamin D than one would find in any industrialized cod liver oil. Whereas the highvitamin cod liver oil contains almost 12,000 IU vitamin A and 1200 IU vitamin D per teaspoon (five milliliters), the fermented oil contains 4,000 - 9,000 IU vitamin A per teaspoon and 3,000 - 4,000 IU vitamin D. The vitamin levels likely test lower because we are only testing for retinol and palmitate, not for all the other vitamin A isomers.” David Wetzel

“Most of those who have consumed the fermented cod liver oil report that it is not as fishy tasting as the industrialized varieties. However, because it is a lacto-fermented product, it can leave a slight sting on the back of the throat, which some find bothersome. It is best to take the oil mixed with a small amount of warm water, swallowing quickly. Adding something acidic such as lemon juice, apple cider vinegar or kombucha may help with the tingling at the back of the throat. Others report good results adding a little honey or maple syrup or “chasing fat with fat” by following the cod liver oil with cream, egg yolk or butter. Another way to minimize the throat tingle effect is to take it during or after a fatty breakfast.” David Wetzel

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Eating meat has many health benefits, but to get the most benefit from eating meat it is best to eat all 3 types of animal products, if possible. These are: organ meats, bone broths (stocks made with animal carcasses) and muscle meats.

If possible, all of these meats should be from organic grass-fed animals. Also where possible, meats should be from a wide variety of different animals including game. Game meats include venison, deer, wild boar, emu, ostrich, buffalo, rabbit and kangaroo. Where possible choose sustainably caught meat. Most of us are limited in what meat we have access to and can afford financially (including me) but these ideal options are listed for those few that are lucky enough to have the option to include them.

Bone broths contain many different nutrients in easy to absorb forms. They are a good source of calcium, glucosamine, chondroitin and MSM. They are made by cooking animal carcasses over a low heat in water for hours at a time. The longer the stock is allowed to develop the more flavoursome it will be. Six hours is ideal, if this is possible.

The stock can then be used as a base to make all sorts of dishes including vegetable soups and vegetable and meat soups. Stock can be made from red meats and also chicken and fish.

For stock recipes see the books and articles by Sally Fallon listed below.

References

- Eat Fat, Lose Fat: The Healthy Alternative to Trans Fats by Mary Enig and Sally Fallon. An excellent book on diet and how to improve health and lose weight with coconut oil and a whole-foods diet. Contains lots of good recipes.
- Nourishing Traditions by Sally Fallon.
- Broth is Beautiful by Sally Fallon on the Weston A. Price Foundation

Relevant quotes

“In the old days, people made soups and stocks out of animal bones and cartilage, but no longer. The elimination of soups and stocks from our diets has contributed to digestive problems as well as joint problems. Stock and soups made from the bones of chicken, turkey, duck, beef, lamb and fish are anti-microbial, anti-inflammatory,
and contain nutrients which help build the integrity of the digestive tract. When a person is suffering from a digestive disorder, a soup based on bone stock can bring fast relief.” WAPF (Weston A. Price Foundation)

“All traditional cultures . . .
1. Consume some sort of animal protein, including organ meats and fat, every day.
2. Consume foods that contain very high levels of minerals and fat-soluble vitamins (vitamin A, vitamin D and vitamin K2 found in seafood, organ meats and animal fats).
3. Consume some foods with a high enzyme and probiotic content.
4. Consume seeds, grains, and nuts that are soaked, sprouted, fermented, or naturally leavened in order to neutralize a portion of the naturally occurring anti-nutrients in these foods.
5. Consume plenty of natural fats but no industrial liquid or hardened (partially hydrogenated) oils.
6. Consume natural, unrefined salt.
7. Consume animal bones, usually in the form of gelatin-rich bone broths.
8. Provide extra nutrition for parents-to-be, pregnant women, breastfeeding women and growing children, to ensure the health of the next generation.
9. Do not consume refined or processed foods, including white flour, refined sweeteners, pasteurized and lowfat milk products, protein powders, industrial fats and oils and chemical additives.” WAPF
Coconut oil is a healthy saturated fat which is very easily digested and absorbed compared to other oils. Coconut oil is absorbed directly from the intestines into the portal vein and sent straight to the liver, whereas other fats require pancreatic enzymes to break them into smaller units. It is highly nutritious and provides a quick source or energy just like sugar but without the negative effect on health and insulin levels. The fat in coconut oil is used rapidly and not stored.

Coconut oil also has many other medicinal benefits. Research has shown that coconut oil will:

- Improve digestion and nutrient absorption
- Increase immune defences and decrease inflammation
- Fight bacterial, fungal and viral infections and prevent degenerative disease
- Assist with weight loss
- Protect the liver and prostate
- Improve dry eyes and skin
- Treat diabetes

**Lauric acid**

Roughly 50% of the fatty acids in coconut oil are lauric acid – the same medium chain fatty acid found in human breast milk. Lauric acid has the additional benefit of being formed into monolaurin in the human body.

**Monolaurin**

Monolaurin is the compound in coconut oil responsible for fighting numerous types of infections. A large body of research has established the ability of lauric acid and monolaurin to fight bacterial, fungal and viral infections.

Dr Sherry Rogers explains that, ‘Monolaurin actually disintegrates the lipid envelope or membrane of viruses, destroying their main defence.’ It stops viruses form replicating and from attaching to cells. She adds that monolaurin has been shown in studies to dissolve the protective membrane from 14 types of human viruses including measles, flu, herpes simplex, chickenpox, EBV, cytomegalovirus and SARS-type viruses.
**Capric acid**
Coconut oil also contains capric acid, a substance that has antimicrobial properties. Capric acid is transformed into ‘monocaprin’ in the human body.

**Caprylic Acid**
Coconut oil also contains caprylic acid, a substance that is specifically effective for killing candida overgrowth on contact in the intestines.

**Dosage and uses**
Dosage of coconut oil used medicinally is usually at least 1 – 3 tablespoons daily. Some recommend doses of 5 – 6 tablespoons daily. 3 – 4 tablespoons of coconut oil is the equivalent of eating half a fresh coconut.

The article *Mary Enig Ph.D. on the Effects of Coconut Oil on Serum Cholesterol Levels and HDLs* explains, ‘Based on her calculations on the amount of lauric acid found in human Mother's milk, Dr. Enig suggests a rich lauric acid diet would contain about 24 grams of lauric acid daily for the average adult. This amount could be found in about 3.5 tablespoons of coconut oil or 7 ounces [210 grams] of raw coconut.’

Improvements in energy levels may be seen at a dose of 1 teaspoon taken 3 times daily, according to coconut oil author S. Gursche. At least 3 tablespoons daily is often recommended for weight loss – along with a reduced or moderate intake of carbohydrates in the diet, cutting out all processed carbohydrate foods and including other types of healthy fats in the diet.

Caprylic acid can cause nausea and several of the antiviral and antifungal compounds in coconut oil can cause herxheimer reactions. Thus coconut oil should only be started at a dose of one teaspoon daily and raised slowly. Taking ½ a teaspoon of raw apple cider vinegar with the coconut oil taken at each meal can aid in digestion of the oil, if a digestion aid is needed.

Expect to wait 4 – 6 weeks to see an effect.

Coconut oil is perfect for cooking as it isn’t damaged by high temperatures. Taken with meals it can aid digestion. Sally Fallon of the Western A. Price Foundation recommends that 1 tablespoon be taken before or with each main meal to improve health and also to facilitate weight loss.

Coconut oil can also be used as a moisturiser for skin, a lip balm or as a hair conditioner. Coconut oil is used in good quality baby milk formulas. It can also be used topically to treat rashes.

Supplements of monolaurin and caprylic acid are also available. Dr Sherry Rogers recommends two 300 mg monolauren capsules be taken 3 times daily at the first sign of an infection, and for several weeks after the infection has cleared. (Note that such a
Treating M.E.: The basics

high dosage may cause an extreme herxheimer reaction in M.E. patients and so is not necessarily recommended.) Dr Rogers comments that antiviral drugs may predispose patients to cancer years after their use.

Which type to buy

The best type to buy is organic extra virgin cold pressed coconut oil. The second best type is organic virgin coconut oil. Other types are refined and bleached and not recommended.

Coconut oil is stable at room temperature and does not need refrigeration. It has a very subtle coconutty taste and is usually solid at room temperature. In warm weather, the oil liquefies.

Fresh coconut flesh and milk is also a healthy addition to the diet. Canned coconut milk or cream can also be a healthy part of the diet, particularly if products can be found that do not contain emulsifiers or harmful preservatives. Canned food products are not ideal however.

Good fats and bad fats: A recap

The Westen A. Price Foundation explains that the following newfangled fats can cause cancer, heart disease, immune system dysfunction, sterility, learning disabilities, growth problems and osteoporosis:

- All hydrogenated and partially hydrogenated oils (this includes margarine and many baked goods and processed foods containing fat)
- Industrially processed liquid oils such as soy, corn, safflower, cottonseed and canola
- Fats and oils (especially vegetable oils) heated to very high temperatures in processing and frying; trans fats.

Healthy fats include extra virgin olive oil, coconut oil, fat from animal meat including cod liver oil, butter (if dairy does not cause problems), palm oil, expeller-expressed sesame and peanut oils (if allergies aren’t a problem) and expeller-expressed flax oil (in small amounts).

Further reading and references:

- *Eat Fat, Lose Fat: The Healthy Alternative to Trans Fats* by Mary Enig and Sally Fallon. An excellent book on diet and how to improve health and lose weight with coconut oil and a whole-foods diet. Contains lots of good recipes.
- *The Untold Truth About Virgin Coconut Oil* by Ian Blair Hamilton and Cassandra Bond (a free e-book). Highly recommended. Provides a short history lesson as well as a lesson on politics and how they affect health.
- *Coconut Oil: Discover the Key to Vibrant Health* by S. Gursche. A great short little book filled with interesting facts and research on coconut oil.
Treating M.E.: The basics

- Nourishing Traditions by Sally Fallon.
- The Coconut Diet by Cherie Calbom
- Know Your Fats, A New Look at Coconut Oil, More Good News on Coconut Oil, The Oiling of America and The Latest Studies on Coconut Oil on the Weston A. Price website.
- The High Blood Pressure Hoax by Dr Sherry Rogers

See also:
- Know Your Fats by Mary Enig
- Coconut: In Support of Good Health in the 21st Century by Mary Enig
- Primal Body-Primal Mind: Empower Your Total Health The Way Evolution Intended by Nora Teresa Gedgaudas
- Nutrition and Physical Degeneration by Weston A. Price
- Deep Nutrition: Why Your Genes Need Traditional Food by Catherine Shanahan
- A New Look at Coconut Oil by Mary Enig
- Effects of Coconut Oil on Serum Cholesterol Levels and HDLs
- Health Oils from the Tree of Life (Nutritional and Health Aspects of Coconut Oil)
- Coconut Oil in Health and Disease: ITS and Monolaurin's potential as cure for HIV/AIDS
- The Benefits of Coconut Oil
- Virgin Coconut Oil and Diabetes
- Virgin Coconut Oil and Viruses
- Virgin Coconut Oil and HIV/AIDS
- Unsaturated Vegetable Oils - Toxic
- Oils in Context
- Killer Fats
- Coconut Oil - Miracle Medicine and Diet Pill
- Coconut Cures (and other coconut book recommendations) at Shirley’s Wellness cafe
- Fats That Heal, Fats That Kill : The Complete Guide to Fats, Oils, Cholesterol and Human Health by Udo Erasmus

“From 1999 - 2000 a study was done at San Lazaro hospital in Manila by Conrado S. Dayrit, MD, and the affect of coconut oil and monolaurin on the viral load of HIV patients. It was found that lauric acid did bring down the viral load of HIV patients. Dr. Dayrit is now conducting similar studies on the SARS virus, since the coconut oil consuming Philippines population was relatively unaffected by the recent SARS outbreak in China and other countries.” Virgin Coconut Oil and Viruses

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consult your own health-care provider regarding any medical issues relating to the diagnosis or treatment of any medical condition.
A healthy addition to the diet may be lacto-fermented drinks and foods.

These foods are full of natural enzymes and probiotics. This includes kombucha, coconut kefir, kvass and sauerkraut and many others. Some products can be made at home or bought pre-prepared. These products may not be for everyone and products must be chosen carefully and assessed for quality before consuming.

Starting portion sizes should be very low. Some patients may react badly to the dairy products used to make these foods or to the fact that they are fermented.

More information on raw milk and lacto-fermented foods as well as recipes are contained in the following books:

- **Eat Fat, Lose Fat: The Healthy Alternative to Trans Fats** by Mary Enig and Sally Fallon.
- **Nourishing Traditions** by Sally Fallon.
Garlic is sometimes used by M.E. patients for its anti-viral, anti-inflammatory and anti-fungal properties.

Garlic can also reduce the risk of blood clots, improve cardiovascular function generally and regulate blood pressure, boost immunity by causing an increase in natural killer immune cell activity, treat Candidiasis and parasitic infections and help protect the liver from the effects of toxic chemicals. Garlic also acts as a catalyst for Hawthorn's effectiveness, can relieve chest pain (angina) and is an antispasmodic.

Garlic has many different benefits and many of them are relevant to M.E.

The article *Garlic: the bountiful bulb* by Carmia Borek Ph.D. explains that, The chemistry of garlic is complex, with over 100 different compounds that contribute to its effects. Garlic contains a wide range of substances, including antioxidants, which are enhanced by aging garlic extract and act together to help prevent atherosclerosis, heart disease, stroke, cancer and aging, as well as boost immunity and help increase memory and life span. Garlic and garlic supplements as well as garlic components, notably stable organosulfur compounds, have been shown to influence cancer by several mechanisms: prevent mutations, prevent the binding of carcinogens to DNA, increase the destruction of carcinogens by producing enzymes that do the job, prevent later stages in cancer, enhance immunity and stop the growth for some human cancer cells.

(In six weeks, patients with AIDS receiving aged garlic extract showed an enhancement of natural killer cells from a seriously low level to a normal level. In another human study, subjects were given garlic powder for three months. Blood samples tested for white cell activity, showed an increased capacity of the immune cells to engulf the E. coli bacteria. Garlic and garlic preparations increase the activity of immune cells, including macrophages, that kill infectious invaders.)

In certain parts of China people eat about 20 grams of garlic a day, approximately 8 medium size cloves. In Germany, most adults take a daily garlic supplement to promote health. In the United States the use of garlic preparations as supplements has been rapidly escalating in recent years. Garlic supplementation in our daily diet may be one of the best options to prevent aging and disease and therefore extend life. Various garlic products on the market offer an alternative but require careful viewing of the manufacturer's standardization of the product and of the bioavailability of the compounds in the supplement. Those who want to increase their daily dose of garlic but avoid garlic breath can turn to regular use of aged garlic extract, a deodorized standardized, highly bioavailable supplement, whose benefits are well researched.

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**The HUMMINGBIRDS’ FOUNDATION for M.E. (HFME)**

*Fighting for the recognition of Myalgic Encephalomyelitis based on the available scientific evidence, and for patients worldwide to be treated appropriately and accorded the same basic human rights as those with similar disabling and potentially fatal neurological diseases such as Multiple Sclerosis.*

**Garlic and M.E.**

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The botanical name of garlic is Allium sativum. Garlic has been used for over 60 centuries, especially in Asia, for medicinal purposes and as a culinary ingredient. Over 200 recently published papers confirm garlic's benefits.

What is the best form of garlic to take?
Dr Atkins recommends aged odourless garlic extract, as it is the most studied form of garlic (and the most convenient).

In a 3 week trial on AIDS patients, 6 capsules of aged garlic extract (Kyolic 100) was been shown to be more effective in improving NK cell function than 8 cloves of fresh raw garlic daily (160% vs 140%).

Many doctors and garlic experts recommend Kyolic Aged Garlic Extract in various books and articles as it is organic, odourless, standardised and well researched.

If the odour is not a problem and there are no gastrointestinal problem, fresh raw (or lightly cooked) garlic may also be a good choice of garlic supplement. The biggest downside is that there is no way of knowing how potent the garlic you are buying is, and this can very enormously.

Look for healthy looking garlic bulbs (with large cloves, for easier peeling) that have not sprouted. Garlic should be stored in a cool dark place.

Garlic capsules can also be combined with ingestion of raw or lightly cooked garlic.

Is allicin content important when choosing a garlic supplement?
According to experts in garlic, contrary to popular belief, there is in fact no evidence that the active compound in garlic is allicin. Allicin is transient and highly unstable. It does not seem to be a biologically active compound of garlic. No garlic supplement contains detectable amounts of allicin, and so, as Dr Atkins explains, we should be very wary of products which promote their allicin content.

What is the appropriate dosage for garlic?
The effects of garlic increase the higher the dosage. How much garlic should be taken depends on why it is being taken and a person’s individual tolerance for garlic. Different experts also recommend quite varied dosages for garlic.

- A preventative dose of garlic (to be taken by healthy people) is often stated as being around 1 clove daily, or 300 mg of standardised aged dried garlic extract.
- Pharmacologic garlic dosage for thinning the blood and improving cardiovascular and immune function is often stated as being around 2-6 cloves per day (or more) or 600-1200 mg of standardised aged dried garlic extract.
For treatment of candida infections, Dr Atkins recommends 75 – 1500 mg of standardised aged dried garlic extract daily.

For acute (short term/immediate) treatment of infectious disease, Dr Atkins recommends 2400 – 3200 mg of standardised aged dried garlic extract daily. Patrick Holford recommends that 3 – 6 cloves of garlic be taken for acute (short term/immediate) treatment of infectious disease. (For best results, garlic should be taken as soon as possible after the infection has begun.)

M.E. patients may wish to take lower medium- or long-term doses of just ½ - 1 garlic clove daily or 75 - 150 mg of standardised aged dried garlic extract, depending on how well garlic is tolerated and why it is being taken. It is also important to start at a very low dose and work up in M.E., to reduce the risk of significant relapse.

It should not be assumed that garlic cannot pack a big punch just because it is a 'natural' supplement and a commonly eaten food. While there is no need to fear occasional and low-level garlic use in cooking, garlic taken daily and at higher doses can potentially cause significant problems. Garlic is a potent antibiotic and antiviral, and these substances very often make M.E. patients very ill. Thus starting very slowly and taking only a very low dose of medicinal garlic to start with is highly recommended.

Garlic can also be a gastric irritant at high doses. This is another reason for M.E. patients to perhaps stick to the lower doses.

It is recommended that garlic be taken in 2 - 4 daily doses, rather than all at once.

**Taking or eating garlic cloves medicinally**

Garlic can be crushed or finely chopped and added to a spoonful of yogurt, applesauce or raw honey or a small glass of fruit or vegetable juice.

When taking garlic cloves like pills, with water, make sure to always finely chop them or cut them up into small pill-sized pieces before swallowing them. Trying to swallow whole cloves is NOT recommended and is a very real choking hazard.

Garlic cloves can also be eaten as, or with, food. Garlic cooked at too high a temperature or for too long loses its benefits however. For this reason, garlic is best added to dishes close to the end of cooking time.

To make garlic easier to peel and less strongly flavoured, while still retaining all its health benefits, immerse it in boiling water for 40 seconds and then place it in a small bowl of cool water. (To stop the cooking process). Wait a few minutes for it to cool, then peel and use as desired.

**Garlic recipes**
Garlic zinger recipe: Juice 4 carrots, 2 stalks of celery, some parsley and 1 - 2 garlic cloves. Drink immediately.

Garlic vegetable mash recipe: Cook and mash 4 potatoes (or a similar quantity of sweet potatoes, pumpkin or other suitable vegetable), then add a few pinches of unrefined sea salt (to taste) plus some coconut oil (to taste). Immerse 4 garlic cloves in boiling water for 40 seconds and then place them in a small bowl of cool water. Wait a few minutes, then peel, chop finely and add to the mash. Mix well and serve immediately, sprinkled with fresh chopped parsley, if available.

To find more garlic recipes, Google 'garlic recipes' or '40 clove chicken' or refer to the books listed in the references section, or any of the other books featuring garlic recipes.

**Garlic cautions**

Very large doses of raw or lightly cooked garlic can cause gastrointestinal problems. When garlic is taken in overly generous doses, nausea, vomiting, and diarrhea could result.

Garlic is a mainstay of treatment for a leaky gut, but only at lower doses as high doses are a gastric irritant.

High doses of garlic can cause insomnia.

As with all foods, there is a possibility that a person can become allergic to or intolerant of garlic. Garlic supplementation can also cause some unpleasant symptoms due to various detoxification processes being instigated or accelerated. These symptoms are not side-effects or signs of an allergy, but signs that the compounds in the garlic are doing what they are supposed to. Unfortunately it can be difficult to tell which symptoms are caused by an allergy and which by a detoxification (or 'die off') reaction. The best way to minimise any symptoms caused by a detoxification reaction is to raise the dose very slowly and to build up your tolerance to garlic and its effects very gradually.

You must tell your doctor you are taking garlic if you are about to have surgery as garlic is a well-known blood thinner. Garlic has the potential to react with prescription drugs such as warfarin (or any other anticoagulant), antihypertensives and antiplatelets. Talk to your doctor before adding significant amounts of garlic to your diet or taking garlic capsules if you are taking any of these drugs. Avoid garlic if you have a bleeding disorder or an ulcer.

Avoid making your own garlic oil, by combining garlic and oil in a jar and using it in cooking over time. If you do make and use such an oil, make sure to keep it refrigerated and ALWAYS discard it after 2 weeks. (When raw garlic is stored in oil, *Clostridium botulinum* bacteria can grow. Needless to say, botulism can make you VERY ill and homemade garlic oil it is just not worth the risk.)
Make sure to read as much as possible before starting an anti-Candidiasis regime involving garlic. (See the Candida and M.E. page for more information.)

Note that raw garlic cloves should not be taken on an empty stomach.

References and additional recommended reading list:
- **GARLIC: THE BOUNTIFUL BULB** by Carmia Borek, Ph.D.
- **The Garlic Cure** by James F. Scheer, Lynn Allison, and Charlie Fox
- **The Garlic Book: Nature's Powerful Healer** by Stephen Fuller
- **Garlic Natures Super Healer** by Joan Wilen and Lydia Wilen
- **Possible Garlic Side Effects, Caution and Contraindications** by All 4 Natural Health.com

‘Garlic is as effective a medicine as some modern drugs.’ The Garlic Book

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The book *Salt your way to health* by holistic medicine expert Dr. Brownstein explains that the 3 main myths about salt are that low salt diets are healthy, that there is no difference between table salt and unrefined sea salt and that low salt products are good for you.

**Table Salt vs. Unrefined Sea Salt**

Refined salt or table salt doesn't provide the body with the 80 or so different trace minerals and elements that unrefined sea salt does. The overuse of table salt can lead to adrenal problems and can stop recovery from adrenal exhaustion as well as promote acidity. Table salt causes excess fluid in body tissue, which can contribute to cellulite, rheumatism, arthritis, gout and kidney and gall bladder stones. To make salt easier to pour or shake onto food aluminum hydroxide is often added, despite the fact that this light alloy deposits in the brain and is a possible cause of Alzheimer's disease. Table salt may also contain fluoride and chlorine. Dried at over 650 °C (1200 °F) the excessive heat alters the natural chemical structure of the salt, which in turn adversely affects the human body.

Not only does table salt not benefit your health it damages health by depleting the body of valuable minerals, which makes us more susceptible to diseases. The body also sacrifices tremendous amounts of energy (and intercellular water) to try to metabolise highly refined salt crystals.

Table salt is not necessary for good health and should be eliminated from the diet completely or as much as is possible. It is an unnatural and highly refined product. This includes iodised table salts. (Iodised table salts contain very small amounts of iodine which are not very available to the body. It is enough to prevent goiter, but nowhere near enough to provide the optimum levels of iodine the body needs.)

Unrefined sea salt, however, is vital for good health. Unrefined sea salt contains all of the minerals and trace minerals necessary for optimal functioning of our bodies.

This distinction between unhealthy and healthy salt is particularly important for M.E. patients (as well as patients with primary POTS). M.E. patients are often recommended to significantly increase salt intake or to make electrolyte drinks containing salt but it is not always made clear that the type of salt chosen for these purposes is important, and that increasing the use of highly refined salt can be problematic rather than helpful.
Why is table salt so commonly used?
Table salt provides big benefits for manufacturers over unrefined sea salt. Table salt contains only chloride and sodium, plus up to 2% toxic additives used in the bleaching and drying processes etc. which ensures the product has an almost indefinite shelf life. Refined salt is bleached white to make it more attractive to consumers, and more saleable. Refined salt can be produced from contaminated sources and the contaminants removed with the use of harsh chemicals such as chlorine, which saves money.

How can you tell which salts are unrefined?
Unrefined sea salt may be light brown, grey or pink but is never pure white. Unrefined sea salt form different areas contains slightly different amounts of each mineral, so there is some colour variation. Unrefined sea salt also dissolves in water. Products labelled 'sea salt' are almost always highly refined and unhealthy salts. (Most salt came from the ocean originally, so the label of 'sea salt' is meaningless.) Rock salt is also not the same as unrefined sea salt, and does not provide the same benefits.

Look for products such as Celtic sea salt or Himalayan sea salt which contain around 80 trace minerals and elements. These salts are often slightly moist and not fully dry. They are free of additives, chemicals and have been sun-dried.

The role and benefits of unrefined sea salt
- Dr Brownstein explains that it is impossible to have an optimum immune system or nervous system where salt is deficient.
- Optimal salt intake is vital for proper adrenal function (and as part of an adrenal exhaustion recovery program). The adrenal cortex produces the hormones that regulate many vital bodily functions such as blood sugar levels, blood pressure, water and salt distribution, as well as muscle strength and energy. Hormones produced in the adrenal cortex include cortisone, DHEA, progesterone, the estrogens, testosterone, pregnenolone and aldosterone.
- Adrenal problems cause thyroid problems, and vice versa, so optimal salt intake is also necessary for proper thyroid function. Table salt does not supply the nutrition needed by the thyroid and leads to a poor conversion of inactive (T4) thyroid hormone to active (T3) thyroid hormone. Unrefined sea salt helps this conversion.
- Salt regulates electrical activity in the body, along with potassium, calcium and magnesium
- Salt also aids the absorption of food particles through your intestinal tract, supports respiratory and sinus health, can help to prevent muscle cramps and promote bone strength and helps to regulate and promote sleep.
• Unrefined salt in water lowers acidity. This is important, as various enzymes can become deactivated with too acidic or too alkaline an environment. Refined foods are acidic and minerals are alkalis. The more ill a person is, the more acidic their body is, generally speaking. Reducing acidity can help to reduce food intolerances as well as any problems tolerating certain vitamin supplements.

• Salt can facilitate detoxification of various harmful chemicals in the body. Increased chloride in the diet means more bromide is released by the kidneys for excretion. (Note that adequate salt and iodine levels are very important where there is high bromide exposure. Bromide is in many different foods and drugs. Bromide is more toxic where there is iodine deficiency.)

• The lymph system functions better with adequate unrefined sea salt intake.

**How much unrefined sea salt do we need each day?**

The adult body contains roughly 250 grams of salt. Dr Brownstein comments that how much salt we need to take in each day depends on how much water we drink and recommends ¼ teaspoon of unrefined sea salt for every litre (or quart) of water. (A litre of water and a quart of water are very nearly the same. 1 litre = 1.056688 quarts.) Generally, Dr Brownstein recommends in his book that people with serious health issues drink 2 litres of water daily, and between ½ to 1 teaspoon of salt daily.

Electrolyte drinks taken to increase blood volume in M.E. should always be made with unrefined sea salt, and never table salt. (The salt in these drinks should count towards the ideal daily salt intake of up to 1 teaspoon, rather than taken in addition to this amount. See the 'Quick start' paper for an electrolyte drink recipe.)

Mix ¼ teaspoon of salt and the same amount of bicarb/baking soda with 240 ml/8 oz of pure water to treat a runny nose, and to lubricate the nasal passages and provide antibacterial and antihistamine benefits. Salt can also be inhaled to help treat various respiratory problems such as asthma.

**Salt cautions**

Those with renal failure need a low salt diet. If you have kidney disease, you must consult with your doctor before adding salt to your regimen.

It turns out the studies showing the supposed benefits of a low-salt diet for all of us, were wrong. The studies were flawed. (Read Dr Brownstein's book or article on salt for details on the flaws in some of these studies.) Dr Brownstein explains that, 'There is enough evidence to discount the myth that salt = hypertension. Good salt, unrefined sea salt, does not cause hypertension. In fact, its use can actually help prevent and treat hypertension.'
Dr Brownstein explains that while a low salt diet may modestly lower blood pressure in salt sensitive individuals, this comes at the price of causing other serious problems involving a lack of salt. A low salt diet can lead to a build-up of toxic elements in the body (eg. bromide, pesticides, heavy metals etc.). He also makes the comment that, ‘There are a few salt-sensitive individuals out there who need to use caution with any form of salt. However, they are few in number.’

Dr Brownstein writes that food tastes better with salt, because we NEED salt! Salt is essential for life and we cannot live without it.

Reference and recommended extra reading list

- The book *Salt your way to health* by holistic medicine expert Dr David Brownstein.
- The article *Shattering the myths about one of nature's most necessary nutrients* by Dr David Brownstein.

Note that in all the books and articles listed here, where ‘CFS’ is referred to, what is being discussed is not M.E., nor any other neurological disease. Some doctors refer to general miscellaneous chronic fatigue sufferers while others refer to patients with adrenal exhaustion, MCSS or post-viral fatigue syndromes caused by glandular fever/mononucleosis etc. when the term ‘CFS’ is used.

Other references

- New USDA Food Guidelines Strike Out Again! by Sean Croxton of UndergroundWellness.com
- The 13 amazing health benefits of Himalayan crystal salt (and why you want to avoid conventional salt) by Dr Mercola
- Articles on unrefined sea salt collated and quoted on the MyWellnessHouse.com website.
- Water and Salt, The Essence of Life by Dr Barbara Hendel and biophysicist Peter Ferreira
- Salt deficiency by Martin J. Lara

“Systematic reviews of the evidence, whether published by those who believe that salt is responsible for hypertension or by those who don’t, have inevitably concluded that significant reductions in salt consumption – cutting our salt intake in half, for instance, which is difficult to accomplish in the real world – will drop blood pressure by perhaps 4 to 5 mm Hg in hypertensives and 2mm Hg in the rest of us.” – Gary Taubes, Good Calories, Bad Calories

Just 4 to 5 mm Hg? How motivating…Okay, let’s say I did decide to follow Uncle Sam’s recommendations and lowered my salt intake to almost nothing. Yeah, my blood pressure would drop a bit (4 to 5 mm Hg) at first. But I’d eventually become weak and develop digestive challenges. It’s like trading one problem for two! Salt contains chloride, which is essential for the production of hydrochloric acid (HCl).
HCl is produced in the stomach and is responsible for the breakdown of proteins. When HCL is low (also known as hypochlorhydria), it can throw off the entire digestive process, as it is the acidity of the food leaving the stomach that initiates the proper function of the gallbladder and pancreas in the small intestine. New USDA Food Guidelines Strike Out Again! by UndergroundWellness.com

“Unrefined salt is an excellent, traditional source of nearly 80 trace minerals. In fact, this natural bacteria-inhibiting preservative can be considered a mineral “supplement” that is essential to life. On the other hand, pristine white refined varieties are heated to excessive temperatures (some up to 1200 degrees F), stripped of all nutrients, and combined with a myriad of undesirable substances, such as aluminum, sugar and anti-caking agents. Replace these over-refined varieties with mineral-rich, properly harvested salts, such as Celtic, Himalayan, RealSalt and Lima. They offer an abundance of healing qualities and their high moisture and trace mineral content are evident by their subtle grey to pink mineral hues.15 Most health food stores stock one or more of these selections.” WAPF

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It is important that M.E. patients stay well hydrated and also that they avoid the ‘nasties’ such as heavy metals, chlorine, fluoride and other chemicals that are present in standard tap water.

**A good water filter is essential!**
People with M.E. should particularly be careful to avoid the chlorine and fluoride in water. Drinking chlorinated water kills the good bacteria in the gut and may also increase your cancer risk. Fluoride added to drinking water is also very detrimental to health.

**Water filter options**
Water filtration options include:
- A 3-4 stage reverse osmosis water filter (which includes a carbon filter and a sediment filter)
- A water distiller (which includes a carbon filter)
- An alkaline water machine
- A carbon filter
- Filtered spring water delivered in bulk and stored in a ceramic dispenser

**Which type of filter is best?**
Opinions vary widely about which type is best so you need to do your own reading and make up your own mind. Reverse osmosis filters and water distillers are generally regarded as the two choices for when you want a very pure water. High quality models usually come with a carbon filter as well.

Some claim that these types of water filter are dangerous and not suitable to be used for more than 6 months, if at all, because they ‘are so low in minerals that they leach minerals out of the body.’ However, these are just *myths*. The vast majority of our mineral intake comes from our diet, not from water. (For example, drinking two litres of slightly to very hard water a day will provide your body with about 14 - 200 mg of calcium. That translates to a maximum of about 1.2% to 17% of the daily recommended 1000 to 1200 mg of calcium.)
Making sure your dietary and supplemental regime contains the appropriate amount of each mineral is essential to good health, but this applies whether very pure water is used or not. That being said, raising your calcium and magnesium intake slightly (10% or so) to make up for the slight difference probably couldn’t hurt and it is important to monitor your own body’s reaction to any change including drinking distilled or reverse osmosis water.

If serious problems are seen due to a sudden lack of intake of the very small amount of minerals in water, then the individual is likely to have been severely malnourished to begin with. Very cautious patients may be best advised not to use these types of water filters until they have started making sure they aren’t deficient in the major minerals.

There seems to be no convincing proof whatsoever that low-mineral water is unhealthy and there is at least some evidence that high-mineral water is unhealthy. As one book on the Gerson therapy explains, ‘The minerals in water are generally inorganic and are therefore poorly absorbed or downright harmful.’

Alkaline water machines by High Tech Health are recommended by Dr Sherry Rogers.

Carbon filters alone still leave lots of contaminants in the water but are absolutely better than nothing.

The filters must be changed as often as needed for any water purifier using filters to be effective.

If at all possible you want to make sure the chlorine, fluoride, VOCs, infective agents and any sediment and heavy metals are filtered out of your water. The addition of fluoride to water is based on terrible science. If you are unsure about the quality of your drinking water you may like to buy a water testing kit.

Water filters can be installed in the kitchen or can be set up to filter all of the water used in the house including that used for bathing. Where water for bathing is not filtered, products such as the Rainshower Dechlorination Crystal Bath Ball filter can be useful for reducing the chlorine in your bathwater, and models suitable for shower use are also available.

**How should I store filtered water?**

Store water in glass, ceramic or stainless steel bottles and use cups made out of these materials as well as much as possible. Avoid plastic cups and water bottles as these leach harmful chemicals into your water.

A short article on the main issues and facts on avoiding plastic contamination in food and drink is available here: Avoiding Plastic Toxins.
How much water should I drink each day?

Drinking around 2.4 litres of water daily is also important. Dr Cheney says while it is common for M.E. to cause excessive thirst (in a bid by the body to increase blood volume and improve cardiac insufficiency) that water intake should not exceed two litres unless there is a lot of sweating. Some of us may need an extra glass of water daily on top of this amount, and feel very unwell without this extra intake, but be very careful adding much more than that (and make sure you read the section on adding electrolytes to your water).

Taking high dose vitamin C and many other supplements that aid in detoxification may raise your daily water requirements.

You CAN drink too much water, and this can be dangerous or even fatal; it is up to you to carefully work out how much water you need to function optimally. As a general rule, if your urine is deep yellow, orange or brown you need significantly more water. Urine should be straw coloured/pale yellow, some say even colourless. If your lips are dry and painful, this can also be a sign that you need more water.

Some doctors recommend that for optimum digestion of food, water (and cold water especially) should not be consumed for 10 minutes before, and 2 hours after meals. Following this recommendation would mean taking tablets that need to be taken with food 10 – 15 minutes before meals. (Taking tablets with food means taking them during a meal, or 15 minutes before or after a meal.)

There is disagreement over whether or not avoiding water consumption during and after meals makes any difference to digestion. If digestion problems are significant, this idea may be worth a try however.

Further reading:
- The Choice is Clear by Allen E. Banik
- The Dangers of Dehydration by Natural News
- Detoxify or Die by Sherry Rogers MD
- Our Toxic World: A Wake Up Call by Doris J. Rapp
- Dietary Healing & Detoxification: A simple reference guide for those with chronic degenerative disease or cancer choosing the Gerson Therapy by Kathryn Alexander.
- Fluoridation / Fluoride Toxic Chemicals In Your Water
- The Fluoride Deception by Christopher Bryson, a review
- Fluoride: The Deadly Legacy by Gary Null
- 100 published studies illustrating fluoride's harm to the brain, plus 24 published studies directly linking fluoride exposure to reduced IQ in children from Dr Mercola.
- NoFluoride.com (Statements by Scientific and Medical Experts)
- CDC adjusts fluoride poisoning of America's water supply to a lower level on
Natural News

- Fluoride's Role in Thyroid Disease and Iodine Deficiency
- Collection of articles on fluoride at Shirleys Wellness Cafe.com
Section E: Other food topics
After writing so much about diet and reviewing so many diet books recently I'm often asked by patients what I eat each day. This short paper is my time-saving answer to this question.

I think that working out the best diet to work towards improving your health is an ongoing process. As you read more you slowly improve your diet bit by bit. My diet is always changing, and hopefully, improving.

**Recommended diet books**

It would be a lot simpler if I could recommend just one perfect diet book for my fellow patients, but unfortunately so far I haven't found one book that has all the important information and cautions in it, with nothing left out. I've worked out my own - whole food, nutrient dense, easily digested, allergen and irritant free, high fat, moderate protein and lowered carbohydrate but high vegetable content - diet based mostly on information from the following books:

1. **Eat Fat, Lose Fat** by Sally Fallon, **Deep Nutrition: Why Our Genes Need Real Food** by Catherine Shanahan, **Know Your Fats** by Mary Enig PhD and **Nourishing Traditions: The Cookbook that Challenges Politically Correct Nutrition and the Diet Dictocrats** by Sally Fallon and Mary G. Enig PhD. These books explain the importance of eating good-quality animal foods, avoiding soy foods and processed foods, ample healthy fats including saturated fats and eating lots of traditional foods including organ meats, bone broths and raw cultured vegetables. The first book describes a high fat, moderate protein and limited carbohydrate diet. The books by Sally Fallon also talk about the importance of soaking and drying seeds and nuts and of similarly properly preparing all grains and legumes. Unfortunately these books talk little about food allergies, the importance of supplements or gut issues or the fact that many do better avoiding grains and dairy - at the very least until a lot of healing of the gut has taken place.

2. **The Primal Blueprint** by Mark Sisson. This book explains that a healthy way to maintain your weight and have good health is to eat whole foods, avoid grains and legumes and dairy foods, eat healthy fats and proteins until satiety but to limit carbohydrates to around 50 - 100 grams a day if you need to lose a bit of weight and 100 - 150 grams if you need only to maintain your weight. The book describes a high fat, moderate protein and limited carbohydrate diet. This book explains the importance of eating good-quality animal foods, ample healthy fats including saturated fats and eating lots of traditional foods including organ meats and lots and
lots of vegetables. Unfortunately this book places little emphasis on cultured foods, the need for cooked foods, food allergies or gut issues.

3. **The Schwarzbein Principle** This book explains that a healthy way to maintain your weight and have good health is to eat whole foods, eat healthy fats and proteins until satiety but to limit carbohydrates to around 60 grams a day if you need to lose a bit of weight. These carbohydrate grams should be spread throughout the day, and not eaten all at once. Unfortunately this book places little emphasis on cultured foods, the need for cooked foods, food allergies or gut issues.

4. **No More Heartburn: The Safe, Effective Way to Prevent and Heal Chronic Gastrointestinal Disorders and Wellness Against All Odds** (and other books) by Sherry A. Rogers. This book recommends a whole foods diet containing no nightshade foods, no yeast foods, and eating in a relaxed state to aid digestion. Dr Rogers also recommends that for some patients with very poor digestion, eating only cooked fruits and vegetables may be necessary as well as Betaine and digestive enzyme supplements.

5. **GAPS Diet** by Natasha Campbell-McBride (plus to a lesser extent Breaking the Vicious Cycle: Intestinal Health Through Diet by Elaine Gloria Gottschall.) This book explains the importance of eating good-quality animal foods, eating cooked foods exclusively while the gut heals, having vegetables juices, having ample healthy fats including saturated fats and eating lots of traditional foods including organ meats, bone broths and raw cultured vegetables. This book also explains that avoiding certain fibrous foods and sticking to certain types of carbohydrates can help heal the gut and prevent fermentation in the gut leading to digestive and Candida problems.

**My average daily diet -2011**

**Brunch:**

400 - 600 ml of freshly made carrot juice/green juice or just green juice (beetroot tops, celery, lettuce, zucchini, parsley, broccoli etc.)

100 g of homemade 24 hour coconut yogurt with cinnamon (made with the VSL#3 probiotic).

100 ml of homemade coconut kefir (made from coconut water).

A serve of cooked vegetables, or of homemade vegetable soup cooked in bone broth or (every third day at most due to allergies) 3 scrambled eggs cooked with vegetables. Eggs are free range and organic or come from the farms of relatives and all fruits, vegetables and seeds are organic where possible and all water used for cooking and drinking is distilled and then carbon filtered.

1 teaspoon of fermented cod liver oil with 1 teaspoon of virgin coconut oil and 2 teaspoons of apple cider vinegar (to aid digestion of the oils).
Dinner:

A serve of chicken (free range and organic or at least free range - with skin on and cooked with bones in usually) or red meat (grass-fed, organic and local as much as possible - cooked with the fat on but then trimmed of most fat) or occasionally, fish or other seafood. Serving size is more than 90 grams and less than 250 grams (with a quarter of this meat put aside for my late-night meal). It varies. Meats are cooked where appropriate with generous amounts of healthy oils and with some Celtic sea salt added.

Two or three ½ - 1 cup serves of cooked vegetables, cooked where appropriate with generous amounts of healthy oils and with some Celtic sea salt added, including:

- Cauliflower mash (made in food processor) with olive oil and leeks
- Spinach mash (made in food processor) with lemon juice and avocado and olive oil
- Cooked onions, brussel sprouts, broccoli or broccolini, asparagus or beetroot etc.

1 teaspoon of virgin coconut oil and 1 tablespoon of extra virgin olive oil (if olive oil wasn't used much in cooking the meats and vegetables already).

1/4 to 1/2 a cup of homemade raw fermented vegetables (half ginger carrots, half sauerkraut)

5 Betaine HCl capsules and 2 digestive enzyme tablets.

Late night meal:

Leftover meat and vegetables from dinner.

90 gram tin of sardines in extra virgin olive oil - if the serve of meat at dinner was too small to have leftovers from. I eat about 2 or 3 tins a week.

1 teaspoon of virgin coconut oil

1/4 to 1/2 a cup of homemade raw fermented vegetables (half ginger carrots, half sauerkraut)

4 Betaine HCl capsules and 2 digestive enzyme tablets.

Snacks:

60 grams (a big handful) of seeds or sometimes nuts; pumpkin or sunflower with maybe small amounts of chia or flax. Seeds and nuts are soaked overnight and then dried to increase their digestibility.
I piece of lightly cooked fruit. Usually low sugar varieties such as berries, pineapple or Granny Smith apples or rhubarb, although the rhubarb is cooked with a little honey to sweeten it.

Occasional foods:
Caramel bananas (bananas, maple syrup and ghee), fruit crumble (pumpkin seeds, ghee and honey plus fruit), fruit sorbet (fresh fruit juice with honey), 70% cocoa organic fair trade chocolate and coconut cream hot chocolate.

**Future diet goals and proposed changes**
I'm pretty happy with my current diet and feel it is really working for me, finally. In the future I aim to also try sprouting some seeds and nuts, growing some of my own greens for juicing maybe, having bone broths more often, buying a higher percentage of grass-fed and organic meats, to switch from using powdered kefir grains to the real thing and to add some cultured garlic to my daily meals.

**Final comments**
Adding Betain HCl, lots of raw cultured foods and digestive enzymes to each meals as I have recently has made a big difference to my digestion. So has avoiding (uncultured) raw vegetables and fruits. No longer does food just sit in my stomach like a lump after meals.

Making your own sauerkraut and kefir is so easy and cheap and I'd highly recommend it. I'd also recommend buying organic and free range meats and eggs as much as possible, trying to eat some liver and bone broths now and then, making sure you don't skimp on unrefined sea salt and the healthy fats such as coconut oil and buying a good water filter.

If you are going to spend money on food you may as well make it all work for you and be health improving! There is also little point spending lots of money on treatments and supplements if you aren't doing what you need to with your diet and if your diet is so poor that it prevents healing from occurring.

Note that all dietary changes need to be made very slowly and cautiously if you have M.E. and that rushing in and changing huge parts of your diet too fast could leave you feeling absolutely terrible. Food is medicine and has lots of different effects on the body and so all changes need to be considered carefully.

For more information please see: [Food as medicine and M.E.](http://www.hfme.org) and the book review pages.
The information on this page is taken primarily from:

- Diet for Pregnant and Nursing Mothers and FAQ on Diet for Pregnancy on WAPF
- The Vitamin C Foundation website
- The Vita-Nutrient Solution book by Dr Atkins.
- The Doctor Yourself website page on vitamin C by Andrew Saul
- The Doctor Yourself website page on pregnancy by Andrew Saul
- The Vitamin Update: Pregnancy webpage.
- Probiotics in pregnancy prove beneficial for both mom and baby Natural News
- Fetal programming: Gene transformation gone wild (Part I and II) Dr Sears
- More bad news on Toxic Fat with a glimmer of hope Dr Sears
- Good thing I listened to Dr. Sears

Recommended books:


Books for those very interested in nutrition and theories of nutrition:

- Deep Nutrition: Why Your Genes Need Traditional Food by Catherine Shanahan
- Nourishing Traditions by Sally Fallon
- Eat Fat, Lose Fat: The Healthy Alternative to Trans Fats by Sally Fallon

These books and articles are highly recommended further reading.

Reading in-depth information before taking or stopping any medication or supplement is vital if you are pregnant or there is even a small chance of you becoming pregnant. Double check every fact! It should also not be assumed that every important nutrient deficiency has been mentioned here. This is just a brief and basic summary of the topic I have put together for a family member.

Some extra comments specific to pregnant M.E. patients are included at the end of the paper.

**Before conception**

Deficiencies of vitamins B1, B2, B6, folic acid, zinc, iron, calcium and magnesium
can cause problems with the foetus. If at all possible it is best to treat any of these deficiencies before becoming pregnant. Deficiencies can be tested for using sophisticated tests such as the Cardio-ION from Metametrix, and others.

It is also advisable if at all possible for the father and mother to do an intensive detoxification before conception. This should involve FIR sauna use, among other methods. Avoiding using chemical-filled personal care and cleaning products is also important before, during and after pregnancy. For more information see the HFME papers Toxin avoidance and M.E. and FIR saunas and M.E.

**Pre-natal diet**

Optimum nutrition is vital as soon as you begin to try for a baby or are pregnant. It is just as important as avoiding drugs, alcohol and cigarettes. Women who eat well during pregnancy have larger healthier babies with fewer complications.

Caloric needs go up by around 15% when you are pregnant but needs for some nutrients may actually double. Pregnancy is not the time to try to lose weight. You need lots of good whole foods, with lots of variety. Avoid processed food, artificial flavourings and colours as much as possible, and buy organic if you can.

Adequate protein is essential during pregnancy too, and you’ll need to consume at least 50 – 60 grams daily. Meats that contain bones and are slow cooked with the bones in are a very nutritious choice. Trust your instincts, if you feel like eating more fish or eggs, then maybe that is because you need to.

Healthy fats include extra virgin olive oil, coconut oil and coconut cream, cod liver oil, butter (if dairy does not cause problems), palm oil, expeller-expressed sesame and peanut oils and expeller-expressed flax oil (in small amounts).

If you have a real interest in nutrition you may wish to read books on nutrition such as ‘Deep Nutrition’ and ‘Nourishing Traditions’ and ‘Eat Fat, Lose Fat: The Healthy Alternative to Trans Fats.’ If you want to check which nutrients you are getting through your diet, you may like to use websites such as www.nutritiondata.com

For those that would like further information on diet, the lists below can also be used:

**Healthier choices**

- Eat lots of fresh vegetables and fruits each day. As many different types and colours as possible is ideal, including lots of different leafy greens. (Vegetables should be emphasised far more than fruits but both are important.)
- Eat at least 50 – 60 grams of protein daily from fish, chicken and red meat and eggs etc. (An egg, 30 grams of chicken or red meat and around 45 grams of fish all contain around 7 grams of protein.)
- Unroasted and unsalted nuts and seeds. (Sesame, pumpkin, sunflower and chia
• Whole grains are a better choice than highly processed grains. (Steel cut oats, or as a second best, rolled oats, are better than instant or quick oats; brown rice is better than white rice; traditional sourdough bread or sprouted Essene bread or even basic rye or wholemeal bread is better than plain white bread.)

• Eat plenty of good fats such as virgin or extra virgin coconut oil and olive oil, palm oil, plus expeller-expressed sesame, peanut and flax oils (in small amounts). Choose olive oil when adding oil to a salad but use coconut oil for cooking as coconut oil is a more stable oil at higher temperatures. A little bit of fat from butter and animal products is also okay.

• Eat 7 or more eggs weekly. Choose organic free-range eggs if possible.

• Full-fat pot set yogurts made traditionally using whole milk are a far better choice than low-fat, sugary yogurts made using gelatine, thickeners and preservatives.

• Add half a teaspoon of unrefined sea salt to food each day. Unrefined salt is full of trace minerals.

• Make sure you at least buy/use a carbon water filter. This cuts down chlorine by a high percentage and removes some of the toxic fluoride from the water.

Extra super-healthy additions

• Drink a glass of freshly made green juice or carrot juice, or both, daily or at least weekly.

• At least once a week eat a dish made using a traditional stock (a bone broth) or a slow-cooked meat dish made using a cut of meat that has the bones still in.

• Eat 1 – 3 tablespoons of coconut oil daily, especially when breastfeeding.

• Eat small oily fish high in Omega 3 oils 3 times a week or more. This includes sardines, mackerel, herring and anchovies. (Tuna and other carnivorous fish are probably best avoided due to high mercury content.)

• Take a small amount of liquid cod liver oil each day as a food; preferably fermented cod liver oil. Cod liver oil contains vitamins A, D and K and also all the natural co-factors that are absent from supplemental forms of these vitamins. It is also a good source of Omega 3 fatty acids. It is usually recommended to keep overall daily vitamin A intake from all sources under 5000 – 6000 IU, however. Cod liver oil is best taken mixed with a bit of water in a glass as a ‘shot.’

• Drink water that has been filtered to remove a high percentage of contaminants; far more than is removed just by the use of a carbon filter. Choose between a water distiller (the best choice in my opinion), a reverse osmosis water filter and a water alkaliser. Check to make sure it removes almost all fluoride.

• Make sure you get some of the extra calcium and magnesium you need by eating extra leafy green vegetables, nuts and seeds, bone broths and whole
small fish with bones in.

- Eat seaweed and sea vegetables at least once a week, if possible. These foods are rich in iodine.

**Foods to avoid**

- All heavily processed foods, many of which contain dangerous trans fats.
- All packaged breakfast cereals; even if they claim to be healthy or organic or whole grains.
- All cured meats and dried fruits containing nitrates.
- All soy products, except small amounts of traditionally brewed soy sauce or similar.
- All foods modified to be low fat or which contain artificial sweeteners.
- All table salt including iodised salt and standard sea salt.
- Products containing sugar, corn syrup, glucose and fructose.
- Avoid eating too much carbohydrate, or too little. Too much carbohydrate can cause weight gain, moodiness, excessive hunger and tiredness, or insulin resistance or type 2 diabetes/gestational diabetes. Eating too little carbohydrate means that some of the protein you eat has to be converted into glucose instead of being used for other more specialised protein-specific tasks, which is just a waste of good protein. 150 grams of carbohydrate a day is too much, while 60 grams a day is unlikely to be enough. People do well on different amounts of carbohydrate in the diet, so you need to find out what works for you. It may be best to start with around 100 grams of carbohydrate a day and see how you feel (and how your weight changes) and move a little bit up or down from there.
- Minimise canned foods as much as possible.
- All products containing trans fats and processed vegetable oils (soy, corn, safflower, cottonseed and canola). This includes margarine and almost all baked goods and processed foods containing fat including biscuits, crackers, pies, cakes, breakfast cereals and so on.
- Margarine with added sterols.
- Avoid coffee. If you can’t give coffee up, restrict coffee to one cup daily, maximum.
- Anything that you are allergic to or which causes any sort of negative reaction after you eat it including indigestion, a racing pulse, irritability, a headache or a foggy head.
- Make sure you also check out the most up-to-date list of foods that should be avoided by pregnant women. You’ll need to avoid soft cheeses, wash fruit and veggies well, seafood which contains mercury, raw or undercooked animal products and some other common foods.

*For the very dedicated*
• Choose only grass-fed, organic red meat and milk products made from organic grass fed animals as well. When these types of products are chosen it is very healthy to eat lots of butter and animal fat.

• Choose only organic and free range poultry and eggs. Eggs contain choline; choline is a B vitamin needed for foetal development.

• Try to source some wild-caught fish or other wild game meats.

• Read up about the benefits of soaking all grains, nuts and seeds before you eat them in books such as ‘Nourishing Traditions’ or online and put this information into practice.

• Read up about the benefits of sprouting seeds (and also possibly grains) in books such as ‘Nourishing Traditions’ or online and put this information into practice. Sprouted Essene bread can also be purchased from some health-food stores, and is kept in the freezer section.

• Read up about the benefits of making your own fermented foods such as sauerkraut, beet kvass and kefir in books such as ‘Nourishing Traditions’ and put this information into practice. Some fermented products such as sauerkraut can also be found at health-food stores, but make sure they are made using traditional methods.

• Start your own veggie patch outside in the garden, or grow some vegetables or micro herbs in trays. Picking the vegetables you need to make green juices or other vegetable dishes just minutes before you need them means they will be many times more nutritious than those you buy at the supermarket.

• Use your juicer every day and make both a glass of green juice and of carrot juice. To make green juices more palatable; add lemon juice, or have a ¼ teaspoon honey as a chaser, or some carrot juice or the juice of an apple.

• Drink only distilled, reverse osmosis or alkaline water and use this water for all cooking purposes as well.

• Try eating some organ meats each week, sourced from free-range or grass fed animals. Brains are very rich in Omega 3 oils and hearts and kidneys also provide health benefits, if you can manage to eat them. Liver may be best avoided while pregnant due to the high vitamin A content although a daily intake of up to 5000 – 6000 IU is considered by most experts to be very safe. Food source vitamin A is also considered to be much safer than synthetic supplements of vitamin A.

• Avoid microwave cooking entirely, as this reduces the nutritional content of food.

• Read the section on vitamin C and plan to supplement baby’s diet with vitamin C after birth and beyond, as well as during your own pregnancy.

• Eat a 100% healthy diet free of processed foods.

Pre-natal nutrition and supplements
It is best to take small amounts of all the important nutrients, rather than large
amounts of just a few of them. Balance is important. You probably don’t want or need to take a huge dose of anything while you are pregnant. Deficiencies should be fixed before pregnancy, and not during. It is also important to add in all new supplements gradually, the body prefers gradual change. Work up to a full dose of supplements over a few weeks, rather than taking a full dose of everything all at once.

Synthetic vitamin A should be restricted to 4000 - 6000 IU daily during pregnancy or if there is a chance you may become pregnant. This restriction does not apply to beta carotene. Products containing high amounts of vitamin A such as liverwurst and other liver products should be restricted to small infrequent servings. A vitamin A deficiency can also cause problems for the foetus and so avoiding vitamin A entirely is not a good idea. Andrew Saul explains that vitamin A deficiency during pregnancy is a far more likely risk than excess.

Taking omega 3 fatty acids before, during and after pregnancy is essential. The minimum dose is 1 g of DHA daily and a similar amount of EPA, according to Dr Atkins. Doses higher than 4 – 5 g of DHA and EPA combined daily should be avoided.

The need for vitamin B1 is increased during pregnancy and lactation.

There is an increased need for vitamin B12 during pregnancy, as well as vitamin B6. At least 30 mg of B6 daily is recommended during pregnancy by Dr Atkins and Patrick Holford. Vitamin B6 may help reduce nausea during pregnancy.

The B vitamin folic acid is very important to take before and during the pregnancy. The best type is the activated form of folate as this form can be used by the body even if you are one of the people that has problems converting the standard folic acid supplements to the active form. The dosage should be at least 800 - 1000 mcg (1 mg). Dr Atkins recommends 4 mg of folic acid daily for pregnant women and writes that this amount is safe to take and helps to prevent some birth defects and miscarriages.

Pregnancy increases the need for vitamin C. At least 2 grams daily should be taken before, during and after pregnancy. See the section below for more information on vitamin C dosage during pregnancy.

Vitamin D levels should be checked and optimised with sun exposure or supplements before pregnancy if possible. It may not be safe to take high levels of vitamin D while pregnant such as 4000 – 10 000 IU or more. Getting a little bit of sun a few times a week or every day is probably a good idea.

Vitamin E contributes to the health of new cells developing in your baby and may help the mother deal with toxins. Mothers pass vitamin E to their babies in the last 12 weeks of pregnancy (about 20 mg in total). Vitamin E has been prescribed by some doctors (in combination with vitamin C) to prevent high blood pressure during pregnancy and premature birth. Taking 800 – 1600 IU of vitamin E daily is not
appropriate if you are pregnant. Very high doses of vitamin E can increase the risk of bleeding, which is particularly dangerous for pregnant women. For this reason it is probably best to add no extra vitamin E in supplemental form in addition to the small amount of 50 - 200 IU or so in your basic prenatal vitamin product.

Ideally every prenatal vitamin product would contain a small amount of all 8 types of vitamin E, although few actually do. To make sure you’re getting some of all 8 types of vitamin E make sure to add some almonds, sunflower seeds and spinach to your diet. Small amounts are also available in foods such as collard greens, parsley, kale, papaya, olives, brussels sprouts, kiwifruit, tomato, blueberries, and broccoli.

**Calcium** helps prevent pre-term labour and is important for the baby for many different reasons, as is magnesium. **Magnesium** treats pre-eclampsia and a dosage of 400 – 600 mg daily is essential. Holford recommends a minimum of 300 mg calcium daily and 200 mg magnesium. Calcium and magnesium should always be taken in balance, in either a 1:1 ratio or slightly more calcium or magnesium – depending on which health expert you listen to!

Low **zinc** levels can cause miscarriage. Dr Atkins writes that a dose of 15 – 25 mg of zinc daily is safe for pregnant women.

**Selenium** is usually restricted during pregnancy, and most prenatal vitamins contain only 50 – 100 mcg. As brazil nuts are VERY high in selenium it would also make sense to restrict their intake to some extent while pregnant.

**Vitamin C in pregnancy – a special case**

Taking vitamin C before, during and after pregnancy has many advantages for mother and baby. A conservative dose during pregnancy is 3 – 4 grams daily and a very conservative dose is 2 grams daily. At the very least 2 g daily should be taken.

The Vitamin C Foundation write:

> Vitamin C is essential for the health of both mother and fetus. When vitamin C is in short supply, nature favors the baby. The Foundation strongly advocates that pregnant women ingest sufficient (at least 6000 mg) vitamin C during pregnancy. 
> An early pioneer, Fred Klenner, MD, has stated that Vitamin C has definite "Primary and lasting benefits in pregnancy."
> "Observations made on over 300 consecutive obstetrical cases using supplemental ascorbic acid, by mouth, convinced me that failure to use this agent in sufficient amounts in pregnancy borders on malpractice. The lowest amount of ascorbic acid used was 4 grams and the highest amount 15 grams each day. (Remember the rat-no stress manufactures equivalent "C" up to 4 grams, and with stress up to 15.2 grams). Requirements were, roughly, 4 grams first trimester, 6 grams second trimester and 10 grams third trimester. Approximately 20 percent required 15 grams, each day, during last trimester. Eighty percent of this series received a booster injection of 10 grams, intravenously, on admission to the hospital. Hemoglobin levels were much easier to maintain." - Fred Klenner, MD
More than 99.99% of animal species synthesize vitamin C (ascorbic acid) on average, adjusted for body weight, 5400 mg daily. In animals, their ascorbic acid (vitamin C) is transmitted directly into the blood stream. They also obtain a little more in their diets.

Irwin Stone believed that most humans are born with scurvy. Stone is not alone in blaming Sudden Infant Death Syndrome (SIDS) on the lack of vitamin C in baby diets. It is wise for the mother to consume all orthomolecular vitamins, especially 1 to 5 mg of folic acid. Dr. A. Hoffer, MD, Ph.D.:

The recent studies showed that folic acid supplementation decreased Neural Tube Defects’s by 75 percent. If all the other vitamins were used as well I am certain that figure would be closer to 100 percent. I can not recall in the past 40 years a single female patient of mine on vitamins giving birth to any child with a congenital defect. I have been able to advise them all that they not only would not harm their developing baby by taking vitamins, but that their chances of giving birth to a defective child would be greatly diminished. I was frequently asked this by my patients who had been told by their doctors that they must stop all their vitamins while pregnant. They looked upon vitamins as toxic drugs.

So in a nutshell:

- **The most conservative dose:** 2 grams daily during and after pregnancy
- **The best ‘playing it safe’ yet moderate dose for most people:** 3 - 5 g daily during and after pregnancy.
- **The vitamin C Foundation recommendation:** 6 g daily during and after pregnancy
- **Klenner’s recommendations:** Roughly 3-4 grams first trimester, 6 grams second trimester and 10 - 15 grams third trimester – depending on the patient’s need. If this route is taken, it is essential that the baby be given 50 mg of vitamin C each day after birth to prevent rebound scurvy (and because this will have many other health benefits for the baby). The usual recommendation by Klenner for vitamin C in childhood is to give 1 gram per year of life up to the age of 10 at which point the dose is kept at 10 g daily (if the child is in good health). Thus a 5 year old child would be given 5 grams of vitamin C each day.

Which option you choose will depend on what your current needs are for vitamin C, how conservative you want to be and how much you are willing to go with scientific facts over what is just popular, how much you’ve read about the benefits and need for vitamin C and whether or not you want to give your child a small amount of vitamin C daily after birth. **If this last task does not appeal then the best choice is probably to take 3 to 6 grams of vitamin C daily throughout the pregnancy.**

Make sure to make any changes to how much vitamin C you are taking daily gradually. Very high doses of vitamin C such as 30 – 50 grams or more daily are usually not recommended for this reason; the child’s levels would drop too steeply after birth unless the child was given vitamin C every day.
For more information on vitamin C see High-dose vitamin C and M.E. or any of the following books and articles:

- Ascorbate: The Science of Vitamin C by Dr Hickey and Dr Roberts
- The Ascorbate Effect in Infectious and Autoimmune Diseases by Robert F. Cathcart, M.D.
- VITAMIN C, TITRATING TO BOWEL TOLERANCE, ANASCORBEMIA, AND ACUTE INDUCED SCURVY by Robert F. Cathcart, III, M.D.
- VITAMIN C: The Real Story by Steve Hickey, PhD and Andrew Saul
- Orthomolecular Medicine For Everyone: Megavitamin Therapeutics for Families and Physicians by Abram Hoffer,
- Fire your doctor! : how to be independently healthy by Andrew W. Saul
- The healing factor: Vitamin C against disease by Irwin Stone
- How to live longer and feel better by Linus Pauling
- Curing the Incurable by Dr T. Levy

Preventing stretchmarks
To help prevent stretchmarks the most important nutrients are zinc, vitamin C and vitamin E. Vitamin E creams can also be used.

Dealing with nausea and morning/all-day sickness
Ginger tablets or teas can help with nausea as can making sure you have adequate vitamin B6.

Probiotics can also help with nausea and constipation, and also decrease the likelihood that the child will have allergy problems such as eczema. One article adds,

The researchers at Turku University are now reporting that probiotic supplements may reduce the frequency of gestational diabetes by 20 per cent, according to data published in the British Journal of Nutrition. As well as the above mentioned benefits to the mother, the study’s findings may also have benefits for the baby, with fewer births of larger babies.

The Natural News site explains,

The skin is our first line of defense from infection. However, many people are unaware that 60-70% of our immune system lies within our intestines. Pregnancy causes the immune system to work harder, and increased intake of probiotics may decrease the risk of colds and respiratory infections. Research shows that probiotics also help prevent urinary tract infections, yeast infections and skin inflammations like dermatitis; all of these complaints are common during pregnancy.

The use of essential oils and herbal oils and other herbal products should be stopped entirely during pregnancy, unless you have read enough to be absolutely sure each of
them is safe. Assume products should be avoided until you know for sure otherwise. This is also true for all over-the-counter drugs and products.

**Which pre-natal vitamin product is best?**
The best pre-natal vitamin might be the product by Thorne, as it contains the activated forms of vitamins B2, B6, B12 and folate. Extra vitamin C, calcium, magnesium and EPA/DHA are required however plus also possibly some low-dose B complex and a daily probiotic.

**Pregnancy and M.E. patients**

**Diet**
Patients with M.E. that are pregnant may do best to avoid grains (especially wheat and gluten grains), legumes and perhaps also dairy, if intolerances exist. A water distiller that removes almost all fluoride is also far more important for the M.E. patient.

**Starting supplements gradually**
While it is important for every pregnant women to start taking new supplements gradually this is absolutely essential for the M.E. patient. Starting supplements at a full dose right away could make you feel very ill and could even cause problems with the pregnancy potentially. Ideally you’ll have worked up to a reasonable dose of all the basic nutrients before becoming pregnant, and so will only need lower maintenance doses while you are pregnant.

**Feeling less ill while pregnant**
Many, and perhaps even most, M.E. patients report feeling far less ill when they are pregnant. This may be due to the blood volume increase of around 50% which occurs during pregnancy, the decrease in a certain type of immune system function (which lets the baby stay in the body and not be attacked as a ‘foreign object’) or other factors.

**Resting while pregnant**
Whether you feel better while pregnant or not, one piece of advice is has been given to me over and over again, for me to pass on, from M.E. patients that have been through pregnancy. Use the time while you are pregnant to REST as much as possible, as when the baby is born you’ll need to be as well rested and as physically well as possible to cope with all the extra work and sleeplessness! Rest as much as you can, while you can! This applies to all pregnant women to some extent of course, but is crucially important when the mother has M.E.

M.E. patients that are pregnant are likely to be moderately affected at most, but even
so, the recommendation of rest before the birth should be taken no more lightly because of this. Relapse is always possible with M.E. unfortunately.

**Relevant quotes**

"Are megadoses of vitamin C safe for the baby?" I knew that Frederick R. Klenner, MD (the trailblazer of vitamin C quacks) gave large doses to over 300 pregnant women and reported virtually no complications in any of the pregnancies or deliveries (Irwin Stone, *The Healing Factor*, chapter 28). Indeed, hospital nurses around Reidsville, North Carolina, the region where Dr. Klenner practiced, noted that the infants who were healthiest and happiest were in Klenner's care. The hospital staff dubbed them the "Vitamin C Babies." Abram Hoffer, MD, has similarly reported that he has observed a complete absence of birth defects in babies born to his vitamin-C taking mothers-to-be.

Specifically, Klenner gave: 4,000 milligrams during the first trimester, 6,000 mg during the second, and 10,000 milligrams of vitamin C a day - or even 15,000 mg - throughout their third trimester. This was his routine prescription for healthy women. He would respond to any sickness with daily vitamin C injections totaling many times that. Over a nearly 40 year practice, Klenner (and previous animal studies) rigorously ascertained the safety and effectiveness of vitamin C during pregnancy. Specifically, there were no miscarriages in this entire group of 300 women. There were no postpartum hemorrhages at all. There was no cardiac distress and there were no toxic manifestations (Stone, p. 191). Among Klenner's patients were the Fultz quadruplets, who, at the time, were the only quads in the southeastern U.S. to survive. Upon admission to the hospital for childbirth, Klenner gave all mothers-to-be "booster" injections of vitamin C. So my answer to Marta's question of safety was an unfettered "yes." Additionally," I added, "For the ladies who had all the vitamin C, labor was both shorter and less painful."

The Doctor Yourself website page on vitamin C by Andrew Saul

"Rebound scurvy, or the rebound effect, is when a person takes a lot of vitamin C, usually with great success, and then abruptly stops taking it. At that instance, symptoms come back, sometimes including a few classic vitamin C deficiency signs. Research shows that such an effect does not occur in the vast majority of situations. However, pregnancy is a special case. If the mother takes a lot of C while pregnant, Klenner and others confirmed that her labor and delivery will be shorter, easier and free of complications. If the vitamin helped while Mommy was pregnant, it should most certainly be given to the baby. During gestation, the baby got all the C he needed. But now, baby is on his own: no more C through the placenta and umbilical cord. If the baby is used to, and benefiting from, abundant vitamin C, it obviously should be provided for him individually after birth. Klenner gave newborns about 50 milligrams a day. Not doing that results in a scorbutic baby.

"But doesn't that just mean that the baby is dependent on vitamin C?" Marta said. "No," I answered. "No more than the baby is dependent on oxygen, or water, or food."

The Doctor Yourself website page on vitamin C by Andrew Saul
“This is a tough order, but try to put your spouse FIRST so your baby will have two parents even after the novelty wears off. Fortunately, almost all authorities indicate that sex during pregnancy does not harm the baby. Common sense is needed, certainly, during the times immediately before and immediately after giving birth. But make a point do not neglect each other.” Andrew Saul.

“A new idea is first condemned as ridiculous and then dismissed as trivial, until finally, it becomes what everybody knows.” William James (1842-1910), American Philosopher

"The medical profession itself took a very narrow and very wrong view. Lack of ascorbic acid caused scurvy, so if there was no scurvy there was no lack of ascorbic acid. Nothing could be clearer than this. The only trouble was that scurvy is not a first symptom of a lack but a final collapse, a premortal syndrome and there is a very wide gap between scurvy and full health. "- Albert Szent-Gyorgyi, Nobel-prize winner for his discovery of vitamin C

"There are more than ten thousand published scientific papers that make it quite clear that there is not one body process (such as what goes on inside cells or tissues) and not one disease or syndrome (from the common cold to leprosy) that is not influenced -- directly or indirectly -- by vitamin C." Dr Emanuel Cheraskin, Dr Ringsdorf and Dr Sisley in THE VITAMIN C CONNECTION.

“Modern medicine is not scientific, it is full of prejudice, illogic and susceptible to advertising. Doctors are not taught to reason, they are programmed to believe in whatever their medical schools teach them and the leading doctors tell them. Over the past 20 years the drug companies, with their enormous wealth, have taken medicine over and now control its research, what is taught and the information released to the public.” Abram Hoffer MD

“Modern drug based medicine is as incomplete as a novel written with three vowels. As discordant as a symphony constructed using only some of the notes. High dose nutritional therapy is the much needed missing part of our vocabulary of healthcare. The fight against disease needs all the help it can get.” Andrew Saul PhD in ‘Fire your doctor: How to be independently healthy’ 2005

‘Vitamin C is the world’s best natural antibiotic, antiviral, antitoxin and antihistamine. This book’s recurring emphasis on vitamin C might suggest that I am offering a song with only one verse. Not so. As English literature concentrates on Shakespeare, so orthomolecular (megavitamin) therapy concentrates on vitamin C. Let the greats be given their due. The importance of vitamin C cannot be overemphasised.’ Andrew Saul PhD in ‘Fire your doctor: How to be independently healthy 2005

“What you eat has more power over disease and aging than any other medicine your doctor can prescribe. Food is awesomely powerful.” Dr Sherry Rogers.
“Good nutrition and vitamins do not directly cure disease, the body does. You provide the raw materials and the inborn wisdom of your body makes the repairs. Someday healthcare without megavitamin therapy will be seen as we today see childbirth without sanitation or surgery without anaesthetic.” Andrew Saul PhD in ‘Fire your doctor: How to be independently healthy’ 2005

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Further reading on diet, healing and gut health

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For more information on eating a nutrient dense diet and improving gut health and health generally, see the following excellent books:

- Eat Fat, Lose Fat by Sally Fallon
- Nourishing Traditions by Sally Fallon
- Deep Nutrition: Why Your Genes Need Traditional Food by Catherine Shanahan
- Good Calories, Bad Calories: Fats, Carbs, and the Controversial Science of Diet and Health or The Diet Delusion: Challenging the Conventional Wisdom on Diet, Weight Loss and Disease (or the shorter version, Why We Get Fat: And What to Do About It) by Gary Taubes
- Breaking the Vicious Cycle (The SCD diet book) by Elaine Gottschall
- The GAPS diet book by Natasha Campbell-McBride
- The Primal Blueprint by Mark Sisson or Primal Body, Primal Mind: Beyond the Paleo Diet for Total Health and a Longer Life by Nora T. Gedgaudas
- The Coconut Oil Miracle by Bruce Fife and Jon J. Kabara (or any other Fife book on coconut oil).
- No More Heartburn: The Safe, Effective Way to Prevent and Heal Chronic Gastrointestinal Disorders by Sherry A. Rogers
- Salt your way to health by Dr Brownstein

These books are the main references used in “Food as Medicine’

The authors of most of these books, with the exception of Dr Rogers and some others, also have websites where you can get much of the information for free.
Treating M.E.: The Basics – Part 3: Avoiding Overexertion
The importance of avoiding overexertion in M.E.

The single biggest factor determining recovery and remission from Myalgic Encephalomyelitis (M.E.) at this point is undoubtedly appropriate rest in the early and/or severe stages of the illness. The importance of avoiding overexertion in M.E. can not be overestimated.

M.E. patients that are newly diagnosed, or still in the acute stages especially must be given their best possible chance for recovery and be enabled to REST appropriately. Improvements in symptoms and stability of the illness can also be positively affected at every stage of the illness by appropriate activity management/reduction. Limiting activity levels to only as much as the patient is capable of dealing with may well be the single most important factor in the patient’s M.E. improving over time.

It is vital that patients avoid physical over-exertion and are never encouraged to exercise (or be active) beyond their individual limits particularly in the early and acute stages of the illness, but also at any stage of the illness. There is nothing to ever be gained by people with M.E. pushing themselves beyond their limits physically as this can only cause unnecessary relapses. Permanent damage (eg. to the heart) and disease progression may also be caused and there have also been reports of sudden deaths in M.E. patients following exercise.

Avoiding overexertion doesn't guarantee a quick (partial) recovery or any recovery at all, there are other factors at work too, but overexertion is a sure way to ensure that the patient remains more severely ill and for longer than would otherwise have been the case. For those with M.E., resting as much as is needed is not just 'doing nothing' - it is an active and vital disease management process.

What is meant exactly by the term 'resting'?

Resting means completely different things at different severity levels of illness. For the mildly ill resting may mean watching TV or perhaps sitting in a chair reading a book or having a quiet night in with friends. For the severely ill, these activities are not at all restful and indeed would provoke severe relapses.

For the very severely ill, resting means lying down in a dark room, in silence and with no sensory input at all (such as TV or radio or light) and not moving at all physically or engaging in any type of cognitive activity. Clothing must also be comfortable and the room must be neither too warm nor too cold. For the very severely ill a better term would be ‘complete incapacitation,’ rather than ‘resting.’
The term ‘resting’ implies that the inactivity is optional and this is often not the case in the severely ill who are often ‘resting’ (i.e. incapacitated) because it is physically impossible for them to do anything else.

For moderately ill patients resting means something somewhere between the two extremes, and so on.

Of course for the very severely ill there will be no safe or symptom-free activity limit. Concepts of pacing or of keeping activity at a level which does not cause immediate or delayed symptoms are useless. Indeed, a sizeable proportion of the very severely ill may well be so severely affected in the first place BECAUSE of overexertion in the early stages of their illness, because they were not told how important it was to rest or were not allowed to rest adequately. This is extremely common in M.E. It is a tragedy and an absolute disgrace.

Note that I have never heard of anyone with M.E. who is too restrictive with their activity levels; the problem is always the opposite, if anything. It is human nature to want to do things and to want to live and experience life as much as possible. It is very difficult for the person with M.E. to be unable to do so many things and it requires enormous discipline to avoid overexertion. Severe M.E. restricts life to a degree that healthy people might find hard to imagine, but patients have learnt from bitter experience many times over the extreme negative consequences of overexertion. Patients are reminded of this every week if not every day as even with careful control, limits can be misjudged or tasks can take a greater toll than expected.

For most if not all patients it is much harder to rest adequately than it is to keep pushing yourself to do things even to the point of worsening the illness. It is often much easier to just keep doing things and suffer the dire consequences in the short- and long-term, rather than stand up to extreme pressure from friends, family and medical staff for these activities to be completed as they were before the patient’s illness, unfortunately.

Resting so endlessly for many years on end is much harder than you can imagine. (It has been commented many times that learning to walk again, or speak again after a stroke or accident would be so much easier than having to just rest endlessly and do almost nothing and to have no distraction from the extreme pain. People with M.E. would give anything to be able to work hard to improve their illness, and to be improving every day instead of staying the same or getting worse.) The problem of M.E. patients under-reporting or underestimating their ability levels just does not exist.

This is not about patients being as inactive as possible. Of course a person with moderate M.E. of course does not need to live with the same restrictions as does someone with severe M.E. The point here is just that patients must stay within their individual post-illness limits. No more and no less than that is necessary.
Increasing the activity levels of someone with M.E. beyond their individual limits can only ever be harmful. It really doesn’t matter if this is done gradually or all at once.

The evidence which shows that some ‘CFS’ patients are merely deconditioned and can be restored to health through graded exercise programs is based on patients who DO NOT have M.E. None of the various cardiac, cardiovascular, immunological, neurological, cognitive, muscular, and other abnormalities present in M.E. sufferers – which together cause the high level of disability associated with M.E. – can be explained by mere ‘deconditioning.’ Patients who improve with graded activity programs do not have M.E. It should go without saying that treatment of one disease cannot be determined by studying a completely different and unrelated (and mixed) patient group. Yet this essential medical and logical guideline is all too often ignored when it comes to M.E. unfortunately. In this case, money speaks louder than logic, science or ethics. Please don’t fall for this nonsense about ‘deconditioning’ or about ‘CFS’ supposedly being just another term for M.E. and so on. It has nothing to do with M.E. For more see: Smoke and Mirrors. To summarise:

- No one with M.E. is too restrictive with their activity levels and M.E. patients do not underestimate their activity levels
- It is very difficult for M.E. patients to restrict their activity levels, and requires a high level of discipline
- M.E. patients know from bitter experience the negative consequences of overexertion
- The appropriate activity level depends on the severity of each patient’s illness
- The symptoms of M.E. are not caused by deconditioning
- Graded exercise does not help M.E.; if a patient improves with graded activity, they do not suffer from M.E.
- Some patients that qualify for a ‘CFS’ diagnosis may improve with graded exercise, but these patients do not suffer from M.E.

What is Myalgic Encephalomyelitis?

Myalgic Encephalomyelitis (M.E.) is a debilitating neurological disease which has been recognised by the World Health Organisation (WHO) since 1969 as a distinct organic neurological disorder. It can occur in both epidemic and sporadic forms, over 60 outbreaks of M.E. have been recorded worldwide since 1934.

What defines M.E. is a specific type of damage to the brain. Myalgic encephalomyelitis is an acutely acquired illness initiated by a virus infection with multi system involvement which is characterised by post encephalitic damage to the brain stem; a nerve centre through which many spinal nerve tracts connect with higher centres in the brain in order to control all vital bodily functions – this is always damaged in M.E. (Hence the name 'Myalgic Encephalomyelitis'). Central nervous system (CNS) dysfunction, and in particular, inconsistent CNS function is undoubtedly both the chief cause of disability in M.E. and the most critical in the definition of the entire disease process. Myalgic Encephalomyelitis also causes a loss
of normal internal homeostasis. The individual can no longer function systemically within normal limits.

M.E. is primarily neurological, but because the brain controls all vital bodily functions virtually every bodily system can be affected by M.E. Again, although M.E. is primarily neurological it is also known that the vascular and cardiac dysfunctions seen in M.E. are also the cause of many of the symptoms and much of the disability associated with M.E. – and that the well-documented mitochondrial abnormalities present in M.E. significantly contribute to both of these pathologies.

There is also multi-system involvement of cardiac and skeletal muscle, liver, lymphoid and endocrine organs in M.E. Some individuals also have damage to skeletal and heart muscle. Thus Myalgic Encephalomyelitis symptoms are manifested by virtually all bodily systems including: cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, gastrointestinal and musculo-skeletal dysfunctions and damage.

M.E. is an infectious neurological disease and represents a major attack on the central nervous system (CNS) – and an associated injury of the immune system – by the chronic effects of a viral infection. There is also transient and/or permanent damage to many other organs and bodily systems (and so on) in M.E. M.E. affects the body systemically.

What characterises M.E. every bit as much as the individual symptoms however is the way in which people with M.E. respond to physical and cognitive activity, sensory input and orthostatic stress, and so on. The way the bodies of people with M.E. react to these activities/stimuli post-illness is unique in a number of ways. Along with a specific type of damage to the brain (the CNS) this characteristic is one of the defining features of the illness which must be present for a correct diagnosis of M.E. to be made. The main characteristics of the pattern of symptom exacerbations, relapses and disease progression (and so on) in M.E. include:

A. People with M.E. are unable to maintain their pre-illness activity levels. This is an acute (sudden) change. M.E. patients can only achieve 50%, or less, of their pre-illness activity levels post-M.E.

B. People with M.E. are limited in how physically active they can be but they are also limited in similar way with; cognitive exertion, sensory input and orthostatic stress.

C. When a person with M.E. is active beyond their individual (physical, cognitive, sensory or orthostatic) limits this causes a worsening of various neurological, cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, muscular, gastrointestinal and other symptoms.

D. The level of physical activity, cognitive exertion, sensory input or orthostatic stress needed to cause a significant or severe worsening of symptoms varies from patient to patient, but is often trivial compared to a patient’s pre-illness tolerances and abilities.

E. The severity of M.E. waxes and wanes throughout the hour/day/week and month.
F. The worsening of the illness caused by overexertion often does not peak until 24 - 72 hours (or more) later.

G. The effects of overexertion can accumulate over longer periods of time and lead to disease progression, or death.

H. The activity limits of M.E. are not short term: a gradual (or sudden) increase in activity levels beyond a patient’s individual limits can only cause relapse, disease progression or death in patients with M.E.

I. The symptoms of M.E. do not resolve with rest. The symptoms and disability of M.E. are not just caused by overexertion; there is also a base level of illness which can be quite severe even at rest.

J. Repeated overexertion can harm the patient’s chances for future improvement in M.E. M.E. patients who are able to avoid overexertion have repeatedly been shown to have the most positive long-term prognosis.

K. Not every M.E. sufferer has ‘safe’ activity limits within which they will not exacerbate their illness; this is not the case for the very severely affected.

This is not simply theory, but is based upon an enormous body of clinical information and mutually supportive research. Confirmation of this hypothesis is supported by electrical tests of muscle and brain function (including the subsequent development of PET and SPECT scans) and by biochemical and hormonal assays. M.E. is neither ‘mysterious’ nor ‘medically unexplained.

M.E. affects all races and socio-economic groups and has been diagnosed all over the world with a similar strike rate to multiple sclerosis. Children as young as five can get M.E., as well as adults of all ages. M.E. is similar in a number of significant ways to illnesses such as multiple sclerosis, Lupus and Polio. 25% of M.E. sufferers are severely affected and housebound and/or bedbound. In some cases Myalgic Encephalomyelitis can also be progressive, or fatal. M.E. is an infectious neurological illness of extraordinarily incapacitating dimensions that affects virtually every bodily system – not a problem of unexplained ‘fatigue.’

- See The M.E. Symptom List for references and for more detailed information.
- See The misdiagnosis of CFS for information on some of the illnesses which are commonly misdiagnosed as ‘CFS’ and what a diagnosis of ‘CFS’ based on any of the CFS definitions actually means.
- See Who benefits from 'CFS' and 'ME/CFS'? Smoke and Mirrors and Why the Discussion of M.E. and Why the disease category of ‘CFS’ must be abandoned for a discussion of the lack of evidence (and financial and political motivations) behind the 'behavioural' model of M.E. and why the bogus disease category of 'CFS' must be abandoned.
- See M.E. is not defined by 'fatigue' and Myalgic Encephalomyelitis is not fatigue, or 'CFS' for more information on why ‘fatigue’ does not define M.E.
- A significant number of the world’s leading M.E. experts believe that M.E., like Polio, is caused by an enterovirus, and the evidence which exists to
support this theory is compelling. See: The outbreaks (and infectious nature) of M.E. and for more information.

- What is Homeostasis? Homeostasis is the property of a living organism, to regulate its internal environment to maintain a stable, constant condition, by means of multiple dynamic equilibrium adjustments, controlled by interrelated regulation mechanisms. Homeostasis is one of the fundamental characteristics of living things. It is the maintenance of the internal environment within tolerable limits.

Research and articles on this topic
An abundance of research and articles support the importance of avoiding overexertion in Myalgic Encephalomyelitis. A small collection of sample articles is reproduced below.

For more information on this topic see:
- The effects of CBT and GET on patients with Myalgic Encephalomyelitis This paper looks at the physical effects of CBT (psychotherapy) and GET (exercise) on patients with M.E.
- See the paper Smoke and Mirrors for information on why patients with M.E. are being treated based on theories (such as CBT and GET) motivated by financial and political considerations as opposed to the available medical evidence. This text forms the introduction to a 100 page + CBT and GET database. The database contains excerpts and links to literally hundreds of articles and research studies which expose the lack of scientific legitimacy (and the hidden financial and political motivations) underlying the 'behavioural' paradigm of M.E. and the use of CBT and GET on M.E. patients – as well as a large number of patient accounts of CBT and GET.
- For more articles on this topic see: General Research and Articles, Cardiac and Cardiovascular Research, Exercise Research, Metabolic research, and Muscle Research, and Research and articles which expose the lack of scientific legitimacy (and the hidden financial and political motivations) underlying the 'behavioural' paradigm of M.E. and the use of CBT and GET (graded exercise therapy) on M.E. patients.

MYALGIC ENCEPHALOMYELITIS: A Baffling Syndrome With a Tragic Aftermath. By A. Melvin Ramsay, Hon Consultant Physician, Infectious Diseases Dept, Royal Free Hospital. [Published 1986]

The degree of physical incapacity varies greatly, but the [level of severity] is directly related to the length of time the patient persists in physical effort after its onset; put in another way, those patients who are given a period of enforced rest from the onset have the best prognosis.

Those who are given complete rest from the onset do well and this was illustrated by the aforementioned three patients admitted to hospital in an unconscious state; all
three recovered completely. Those whose circumstances make adequate rest periods impossible are at a distinct disadvantage, but no effort should be spared to give them the all-essential basis for successful treatment. Since the limitations which the disease imposes vary considerably from case to case, the responsibility for determining these rests upon the patient. **Once these are ascertained the patient is advised to fashion a pattern of living that comes well within them.**

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**Myalgic encephalomyelitis--a persistent enteroviral infection?** Dowsett EG, Ramsay AM, McCartney RA, Bell EJ. Basildon Hospital, Essex, UK. 1990 [edited for brevity]

Myalgic encephalomyelitis is a common disability but frequently misinterpreted. Amongst 6,000 patients referred for general microbiological diagnosis between 1975 and 1987, 420 cases were recognized. This illness is distinguished from a variety of other post-viral states by an unique clinical and epidemiological pattern characteristic of enteroviral infection. **Prompt recognition and advice to avoid over-exertion is mandatory.**

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**The book:** The Clinical and Scientific Basis of Myalgic Encephalomyelitis edited by Dr Byron Hyde

Dr Byron Hyde in his M.E. textbook, explains that it has been found that those patients with M.E. who returned to work soon after becoming ill or while they were still seriously or severely ill – instead of having an extended period of rest and recovery – are at risk of causing an abnormal increase in damage ‘to a heart muscle already vulnerable and under attack from an acute viral infection.’ He also writes that:

This is not just clinical supposition, there is a strong basis for this belief of work or exercise potentiated heart damage in the literature. It is well known that enteroviruses may cause chronic cardiac disease as well as major neurological injury. Kandolf states that “enteroviruses are capable of causing dilated cardiomyopathy of sudden onset or lead to a variety of common arrhythmias.” Utilizing mouse models, Wilson and again Reyes demonstrated that Coxsackie infected [enterovirus infected] mice, forced to swim to the point of exhaustion during the acute phase of infection, developed chronic heart disease whereas Coxsackie infected mice who were allowed to rest during the acute phase, did not develop chronic heart disease.

M.E. represents a possibility of serious cardiac injury primarily in patients who exercise or maintain exhaustive work efforts during the onset of their illness. It is possible that some of these patients who die and others that develop major cardiac changes are never recognised as M.E.
Those who do not, or cannot, rest in the early stages of M.E. potentially create, says Dr Hyde, ‘a physical injury to the myocardium, cardiac pacemaker cells or their autonomic control,’

M.E. is an infectious neurological disease and represents a major attack on the central nervous system (CNS) by the chronic effects of a viral infection. A significant number of the world’s leading M.E. experts believe that M.E., like poliomyelitis, is caused by an enterovirus. Dr Hyde explain that enterovirus infections are able to cause:

a. a chronic host infection
b. major or no cardiac disease depending on the virulence of the subtype
c. cardiac injury dependent upon the sex of the patient and of the level of physical activity of the patient during the acute or infectious stage
d. cardiac disease depending upon the immunological variability of the host.

An enterovirus would also explain the; age variation, sex variation, obvious resistance of some family members to the infection and the effect of physical activity (particularly in the early stages of the illness) in creating more long-term/severe M.E. illness in the host.

Dr Hyde also writes that;

‘With both CNS and CVS disease, chronicity may be provoked by maintaining strenuous exercise and work levels during the acute and recovery stage of the viral illness. Early patient activation may represent serious cardiovascular danger to patients [with M.E.]. The strange concept of waiting 6 months to diagnose a classical case of M.E. is unnecessary and fraught with potential danger to the patient. Such a diagnostic delay may create legal consequences for the physician. Physicians who take an early aggressive approach in physically activating these acute stage patients may do so at both their and their patient’s peril.’

From 'The Myalgic Encephalomyelitis symptom list' on this site:
‘Only being able to achieve 50% or less of your pre-illness activity level immediately upon becoming ill is very common – if not universal – in Myalgic Encephalomyelitis. (Although a small percentage of sufferers may possibly be somewhat less severely affected at onset.) This is not a gradual change in ability levels which occurs over weeks, months or years; it is an acute change. The onset of M.E. is frequently very dramatic, M.E. patients can very often tell you not just the day that they became ill, but the exact hour they became ill.’

‘The types of symptoms produced in response to certain levels of physical activity, cognitive activity, sensory stimuli or orthostatic stress may or may not vary depending on the type (and severity) of the activity or stimuli involved. But very often the types of symptoms worsened or produced by overexertion are fairly similar
regardless of which exertion or input was involved. Overexertion can sometimes cause just one or two symptoms to worsen (eg. cardiac problems) but often a large cluster of symptoms are worsened. The cluster of symptoms made worse by excessive exertion or stimulus is often very similar from patient to patient, as generally it is a worsening of the most common symptoms of the illness. Patients commonly experience a combination of the following symptoms:

- Profound cognitive dysfunctions (and various other neurological disturbances), muscle weakness (or paralysis), burning eye pain or burning skin, subnormal temperature or low-grade fever, sore throat or painful lymph nodes (and/or other signs of inappropriate immune system activation), faintness, weakness or vertigo, loss of co-ordination, dyspnea, an explosion of sensory phenomena (low level seizure activity), cardiac and/or blood pressure disturbances, facial pallor and/or a slack facial expression, widespread severe pain, nausea or feeling as if ‘poisoned,’ feeling cold and shivering one minute and hot and sweating the next, anxiety or even terror (as an organic part of the attack itself rather than as a reaction to it) and hypoglycaemia. Often the patient will feel an urgent need to retreat from all homeostatic pressures. The types of symptoms triggered vary widely from patient to patient, but some combination of these is common. There may also be an accompanying exacerbation of other symptoms. These symptoms often combine to create an indescribable and overwhelming experience of terrible illness that is unique to M.E, and can be profoundly incapacitating. At its most severe, the patient feels as if they are about to die.’

‘Each of the symptoms caused or exacerbated by overexertion can be clearly articulated without difficulty whether they be; seizures, cardiac events, labile blood pressure, tachycardia, shortness of breath, muscle pain, muscle weakness or muscle paralysis, facial paralysis, black outs, flu-like symptoms, nausea, inability to speak or to understand speech, problems with memory, and so on. It makes no scientific or logical sense to subsume these very specific symptoms, and very specific and varied combinations of symptoms, under a vague and inaccurate label of mere ‘fatigue.’ To say that all of these very different and very specific – and in some cases very serious – symptoms can be accurately summarised as being a problem of mere ‘fatigue,’ ‘malaise’ or ‘exhaustion’ is absurd.’

‘A large number of illnesses cause significant fatigue or malaise after activity (for example post-mononucleosis or glandular fever fatigue syndromes, Lyme disease and Fibromyalgia and so on) but what is happening in M.E. is simply not the same; the symptomatology and pathology – and the effect of physical, cognitive and orthostatic overexertion on long-term prognosis – is very different in M.E.’

‘The severity of M.E. is not stable over the course of a day, or even from one hour (or even one minute) to the next: it also isn’t stable from one week or month to the next. This waxing and waning of the severity of the illness can be very unpredictable. The severity of M.E. also waxes and wanes from one minute/hour/day/week etc. due to the acute and delayed effects of overexertion.’
‘Because of the lack of stability in M.E. you simply cannot know a M.E. sufferer’s usual ability level or severity level unless you have observed them over a very long period of time, or actually asked the person detailed questions about what their average daily activity limits, abilities and symptoms are. Just observing someone with M.E. do a certain task should not be taken to mean; (a) that they can necessarily repeat the task anytime soon, (b) that they would have been able to do it at any other time of day, (c) that they can do the same task every hour, day or even every week, or month, or (d) that they won’t be made very ill afterwards for a considerable period because they had to really push themselves (and make themselves ill) to do the task. Most importantly, because the worsening of the illness caused by overexertion very often does not even begin until 48 or more hour afterwards you also can’t tell by looking if a particular activity was so far beyond a M.E. patient’s individual limits that they will end up having made themselves severely or permanently more ill by completing the task.’

‘Another reason that short-term and superficial judgements of ability and disability levels in people with M.E. are ill-advised and often very misleading – and are in fact almost guaranteed to give a falsely more optimistic view of daily ability levels – is because the relapses caused by exertion very often do not appear until 48 or more hours afterward, when the average observer is long gone.’

‘Recent research shows that mitochondrial dysfunction (etc.) leads to diastolic dysfunction and reduced stroke volume/low cardiac output in M.E. – and that certain levels of orthostatic stress and physical and mental activity etc. exacerbate this cardiac insufficiency. Dr Cheney explained recently that because it takes more metabolic energy for the heart to relax and fill with blood than it does for it to squeeze and pump blood, the hearts of people with M.E. don’t fill with the proper amount of blood before they pump which is what causes the reduced cardiac output and many of the symptoms of M.E. (and much of the disability of M.E.) So the tachycardia – fast heart rate – often seen in M.E. in response to orthostatic stress and so on is actually compensating for low stroke volume to help increase cardiac output. The heart doesn’t fill with enough blood before each beat of the heart so it is forced to beat faster to try to make up some of the shortfall, but people with M.E. are still left with reduced cardiac output leaves them very ill and disabled. If this problem is severe enough it can also result in death. As one M.E. advocate explains: ‘Cardiac output is sometimes too low to meet the demands of movement, and any attempt to exert oneself beyond one’s own capacity for cardiac output - that is when demand exceeds cardiac capacity - would indeed result in death. Studies on dogs have shown that when the demands of the body exceed cardiac output by even 1%, the organism dies. M.E. patients [must] reduce demand and reduce their exertion level to stay within the bounds of their low cardiac output to stay alive.’”

From 'Smoke and Mirrors' on this site:
What is the effect of graded exercise therapy (GET) on Myalgic Encephalomyelitis (M.E.) patients?
As (bad) luck would have it, graded exercise programs are probably the single most inappropriate treatment that a M.E. sufferer could be recommended to undertake. This is because one of the unique features of authentic M.E. is exercise intolerance – that patients worsen with even trivial levels of activity or exercise. Exercise or exertion intolerance is one of the many things which separates Myalgic Encephalomyelitis so distinctly from various post-viral fatigue states or other illnesses involving 'chronic fatigue.’ People with M.E. do not improve with exercise. They cannot; exercise intolerance is a large and essential part of what M.E. is. Veteran M.E. expert Dr Ramsay explained that this unique characteristic: ‘is virtually a sheet-anchor in the diagnosis of Myalgic Encephalomyelitis and without it a diagnosis should not be made.’ (1986, [Online]).

This essential feature of M.E. is characterised by a unique form of paralytic muscle weakness whereby muscles perform normally to begin with but after even a minor degree of physical effort; three, four or five days, or longer, elapse before full muscle power is restored. This affects all muscles including the heart and is very different from mere ‘fatigue.’ (Ramsay 1986, [Online]) (Hyde 2003, [Online]) (Hyde 1992 p. xi) (Hyde & Jain 1992 pp. 38 - 43) (Dowsett 2001, 2000, 1999.b, b [Online])

Doctors who have experience with M.E. (and can tell the difference between authentic M.E. and various unrelated fatigue states) and the leading M.E. experts all concur; exercise can have many harmful effects on patients both in the short- and long-term. The following comments which illustrate this point are provided by some of the world’s leading M.E. experts, all of whom have been specialising in M.E. for many years and each of whom has seen literally thousands of M.E. patients;

a. Dr Melvin Ramsay a UK doctor who specialised in M.E. for more than thirty years, from the Royal Free Hospital M.E. outbreak of 1955 until his death in 1990, and who is credited with having written some of the most accurate description of the illness to date, explains; ‘The degree of physical incapacity varies greatly, but the [level of severity] is directly related to the length of time the patient persists in physical effort after its onset; put in another way, those patients who are given a period of enforced rest from the onset have the best prognosis. Since the limitations which the disease imposes vary considerably from case to case, the responsibility for determining these rests upon the patient. Once these are ascertained the patient is advised to fashion a pattern of living that comes well within them.’ (Ramsay 1986, [Online])

b. Dr. Elizabeth Dowsett, explains: ‘There is ample evidence that M.E. is primarily a neurological illness although non neurological complications affecting the liver, cardiac and skeletal muscle, endocrine and lymphoid tissues are also recognised. Apart from secondary infection, the commonest causes of relapse in this illness are physical or mental over exertion’ and ‘Prompt recognition and advice to avoid over-exertion is mandatory’ and ‘The prescription of increasing exercise can only be counter-productive.’ She also states that; ‘20% have progressive and frequently...
undiagnosed degeneration of cardiac muscle which has led to sudden death following exercise.’ (Dowsett & Ramsay et al. 1990) (Dowsett 2000, [Online]) (Dowsett a, [Online])

c. Dr Byron Hyde explains that: ’I have some ME patients with a circulating red blood cell volume less than 50% of expected and a very large number with the range of 60% to 70%. What this test means is that blood is pooling somewhere in the body and that this blood is probably not available for the brain. When blood flow to the heart decreases sufficiently, the organism has an increased risk of death. Accordingly, the human body operates in part with pressoreceptors that protect and maintain heart blood supply. When blood flow decreases, pressoreceptors decrease blood flow to noncardiac organs and shunt blood to the heart to maintain life. This, of course, robs those areas of the body that are not essential for maintaining life and means the brain, muscles, and peripheral circulation are placed in physiological difficulty.’ This physiological difficulty is exacerbated by physical and mental activity and orthostatic stress. Dr Byron Hyde goes on to say that: ‘In MRI spectography of arm muscle of ME patients, it has been shown that because of an abnormal buildup of normal metabolites, the muscle cell actually shuts down to prevent cell death.’ Dr Hyde explains that this is what is happening to the true M.E. patient’s cell physiology in the brain, and in muscle as a result of certain levels of physical and mental activity; there is ‘cell field shutdown’ to prevent the death of the cell. (Hyde 2003, [Online])

d. Dr. Paul Cheney explains that when disabled M.E. patients stand up, they are on the edge of organ failure due to extremely low cardiac output as their Q drops to 3.7 litres per minute (a 50% drop from the normal of 7 litres per minute). Without exception, according to Cheney, every disabled M.E. patient ‘is in heart failure’ and the disability level is exactly proportional to the severity of their Q defect, without exception and with scientific precision. (Marshall & Williams 2005, [Online].) Findings which showed mitochondrial metabolic dysfunction similar to mitochondrial encephalomyopathy also led Dr Cheney to comment, ‘The most important thing about exercise is not to have [patients with ME] do aerobic exercise. I believe that even progressive aerobic exercise is counter-productive. If you have a defect in mitochondrial function and you push the mitochondria by exercise, you kill the DNA.’ (Williams 2004, [Online]).

As these comments show, the adverse response to physical activity in M.E. patients is not ‘medically unexplained.’ It is also worth noting that none of these abnormalities can be explained by ‘deconditioning’ – the supposed reason for the recommendation of therapies such as GET.

The Nightingale Definition of M.E. by Dr Byron Hyde

Graduated Exercise and the Myalgic Encephalomyelitis Patient: Possibly due to the fact that some Fibromyalgia patients can be improved by a gradual increase in exercise, or possibly due to the so called protestant ethic that all
you have to do to get better is to take up your bed and walk, some physicians have extended the concept of passive or forceful increased exercise to Myalgic Encephalomyelitis patients. This is a common and potentially dangerous, even disastrous misconception.

If the M.E. patient conforms to the guidelines set out in this definition, the insurance company can only make the patient worse by instituting progressive aggressive forced physical and intellectual activity. M.E. is a variable but always, serious diffuse brain injury and permanent damage can be done to the M.E. patient by non-judicious pseudo-treatment.

**Question marks over evidential basis of claims for psychosocial therapies**

ME Research UK, The Gateway, Perth; and the Department of Medicine, University of Dundee

In response to an article in the British Medical Journal, we reviewed trials of the use of psychosocial therapies in ME/CFS. The total number of available trials is small, numbers are relatively low (6/8 trials have n<40 in the active groups), and 2 of the 5 cognitive behavioural therapy (CBT) trials do not show an overall significant effect. No trial contains a "control" intervention adequate to determine specific "efficacy": in only 2 trials are the treatment arms compared with an "active", though not indistinguishable, intervention. A number of non-specific effects could have accounted for the positive results, and the fact that the drop-out rate in the active arm of one of the trials was 40% may point in this direction, as discussed in one of the reviews. Again, the heterogeneity of the trials, the potential effect of publication or funding bias for which there is some evidence, and professional doubts about the evidence base for some behavioural therapies themselves give grounds for caution.

Abbot NC, Newton DJ
*Letter to the British Medical Journal* 2002

Sharpe and Wilks' review [1] contains an "evidence-based summary" with the statement, "graded exercise and cognitive behavioural therapies are effective in treating chronic fatigue syndrome". However, rigorous examination of the literature indicates that this remark is not itself evidence-based, a serious criticism since evidence-based summaries in the BMJ carry weight and are widely quoted. Again, the heterogeneity of the trials, the potential effect of publication or funding bias for which there is some evidence [4], and professional doubts about the evidence base for some behavioural therapies themselves [5] give grounds for caution. Indeed, if a similar evidence base existed for, say, Shamanic healing - which has no professional proponents - it would arouse little clinical interest. Neither of the review groups has commended GET or CBT as particularly effective for chronic fatigue syndrome patients. Whiting et al. [2] state, "all conclusions about effectiveness should be considered together with the methodological inadequacies of the studies."
Physiological responses to incremental exercise in patients with chronic fatigue syndrome. Inbar O, Dlin R, Rotstein A, Whipp BJ.

‘As a group, the CFS patients demonstrated significantly lower cardiovascular as well as ventilatory values at peak exercise, compared with the control group.’ ‘These results could indicate either cardiac or peripheral insufficiency embedded in the pathology of CFS patients.’ ‘We conclude that indexes from cardiopulmonary exercise testing may be used as objective discriminatory indicators for evaluation of patients.’

Chronic fatigue syndrome: assessment of increased oxidative stress and altered muscle excitability in response to incremental exercise. Jammes Y, Steinberg JG, Mambrini O, Bregeon F, Delliaux S

‘The response of CFS patients to incremental exercise associates a lengthened and accentuated oxidative stress together with marked alterations of the muscle membrane excitability. These two objective signs of muscle dysfunction are sufficient to explain muscle pain and postexertional malaise reported by our patients.’

Profits Before Patients? Eileen Marshall and Margaret Williams, 15th April 2005

The role of the Medical Research Council (MRC) is to fund projects on the basis of expertly written, peer-reviewed and approved proposals. Clearly, therefore, the role of peer-reviewers is of paramount importance as it is they who influence what research the MRC will fund. In the case of ME/ICD-CFS there are a limited number of peer-reviewers of psychiatric interventions of cognitive behavioural therapy and graded exercise apart from the PACE trial proponents themselves, so the favourable recommendation of the carefully selected peer-reviewers was not unexpected, nor was the decision to fund the trials on "CFS/ME" patients. The PACE trials involve compulsory aerobic exercise even though the deleterious effects of such exercise on those with ME/ICD-CFS are well documented in the medical literature.

Considering the rapidly increasing weight of available published data on organic pathology in ME/ICD-CFS (little of which is published in the UK medical literature), the MRC will inevitably have its hand forced eventually, as the time will come when such evidence can no longer continue to be ignored, but currently this seems to remain a forlorn hope. Surely this is a short-sighted policy, because it is well recognised that those who are correctly diagnosed and permitted to rest adequately in the initial stages are the ones who have hope of some recovery; moreover, if relevant research were to be instituted, it would lead to patients being investigated competently and treated correctly, thus offering the prospect of ME/ICD-CFS
Treating M.E.: The basics


Dr. Dowsett believes that the polio vaccine made room for other polio-like viruses (from the family of viruses called enteroviruses) to take over. According to Dr. Dowsett's research and other work, these other viruses may even hit some parts of the brain harder than in polio. So, even if people with ME don't have (permanent) paralysis and get as physically weak as people who had polio, they may be even more impaired in other ways.

This has VERY IMPORTANT implications for assessment of disability and for treatment.

Important Treatment Information: Dr. Bruno says pacing, NOT cognitive behavioural therapy and NOT graded exercise, is the cornerstone of treatment for people with PPS and ME. The key message is that people with ME and PPS have demonstrated brain stem dysfunction. This explains a multitude of symptoms because the brain stem controls so many physical and mental processes. Dr. Dowsett supports this view. Dr Bruno is admirable in his determination to get over to people the effects of PPS, ME, and what can be done to allow people to help themselves improve their quality of life.

Politically-modified Research Eileen Marshall and Margaret Willians, 26th June 2005

‘If only someone with sufficient influence would question where "Wessely School" psychiatrists get their opinions from. If this were to happen, then the rampant metastatic spread of their unproven beliefs would soon stop because their opinions are not -- and cannot be -- based on biomedical evidence. But then, "policy-based evidence" is not required to be based on biomedical evidence and that, of course, is its value to Government.’

Time to put the exercise cure to rest? by Dr Elizabeth Dowsett

There is ample evidence that M.E. is primarily a neurological illness. It is classified as such under the WHO international classification of diseases (ICD 10, 1992) although non neurological complications affecting the liver, cardiac and skeletal muscle, endocrine and lymphoid tissues are also recognised. Apart from secondary infection, the commonest causes of relapse in this illness are physical or mental over exertion. The prescription of increasing exercise is such a situation (or
in the early stage of the illness when the patient desperately needs rest) can only be counter-productive.

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**Theres no smoke without fire! Some comments on the tendency to relapse in ME**
by Dr Elizabeth Dowsett

WHAT IS A RELAPSE? It is an unexpected deterioration in the condition of a sick person after partial recovery. The commonest causes of such a reverse in ME appear to be mental and physical over exertion.

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**CONCERNS ABOUT A COMMERCIAL CONFLICT OF INTEREST UNDERLYING THE DWP HANDBOOK ENTRY ON MYALGIC ENCEPHALOMYELITIS / CHRONIC FATIGUE SYNDROME**
(THE GIBSON PARLIAMENTARY INQUIRY) Professor Malcolm Hooper, Eileen Marshall and Margaret Williams, December 2005

The information in this document is relevant to the Gibson Inquiry, specifically the continued ignoring by the Department of Work and Pensions (DWP) and its commercial advisers of the compelling scientific evidence that myalgic encephalomyelitis / chronic fatigue syndrome is not a primary psychiatric disorder. If eligibility for certain benefits becomes contingent upon the intended implementation of compulsory psychiatric "rehabilitation" regimes, in cases of authentic ME it is likely to result in serious relapse that may be life-long (and may in some cases even result in death).

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**Mobility problems in ME** by Dr Elizabeth Dowsett

The symptoms of this multi system disease are characterised by post encephalitic damage to the brain stem (1) (which contains major nerve centres controlling bodily homeostasis) and through which many spinal nerve tracts connect with higher centres in the brain. Some individuals have, in addition, damage to skeletal and heart muscle. SPECIFIC MOBILITY PROBLEMS INCLUDE THE FOLLOWING:

NEUROLOGICAL PROBLEMS.
Exhaustion, weakness and collapse following mental or physical exertion beyond the patients’ capacity. This arises from metabolic damage to the reticular activating system and to the hypothalamic control of the pituitary-adrenal axis (2). Whereas in healthy controls or in other illnesses (such as depression) there is an increased metabolic response to exertion, in ME this is diminished, leading to sudden collapse which requires several days or more for recovery. These complications (following even trivial exercise) are not recognised in short medical examinations for social benefits and no allowance is made for the delayed effects of exertion. Recent research indicates that these patients (3) have high resting energy requirements which further diminish their resources.
Problems with balance are common in ME due to involvement of spinal nerve tracts in the damaged brain stem.

**MUSCULO-SKELETAL PROBLEMS**
Over 70% of ME patients suffer from significant bone and muscle pain (due to disordered sensory perception – a further consequence of brain stem damage which seriously affects their mobility).

Other patients have (in addition) metabolic damage to muscle fibres resulting in abnormal early lactic acidosis as demonstrated by sub anaerobic exercise tests. 30% of patients with abnormal exercise tests have evidence of persistent infection in the muscle and of muscle infarcts (tender points on pressure affecting mainly limb and trunk muscles) and of jitter (due to incoordinated muscle fibre action) on slow leg raising for example, following damage to the neuromuscular junction. A rapid decline in thigh muscle tone can be demonstrated between 2 and 24 hours after exercise (3.)

**CARDIOVASCULAR PROBLEMS**

Patients with ME suffer a variety of symptoms arising from autonomic nervous system dysfunction (4.) including liability to a dangerous drop in blood pressure on standing for more than a few minutes, while some 20% have progressive and frequently undiagnosed degeneration of cardiac muscle which has led, in several cases, to sudden death following exercise.

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**CRITICAL CONSIDERATIONS by Margaret Williams**

Since as long ago as 1996 it has been known that those with ME have abnormal lung function tests, with a significant reduction in all lung function parameters tested (see "Lung function test findings in patients with chronic fatigue syndrome" De Lorenzo et al. Australia and New Zealand Journal of Medicine 1996:26:4:563-564), and Jo Nijs from Belgium presented evidence at the Wisconsin international conference of underlying lung damage in ME through intracellular immune dysregulation with impairment of cardiopulmonary function. How can forced aerobic exercise regimes be guaranteed to be harmless where there is existing underlying lung damage?

There is also evidence that many people with ME may have a serious heart problem. In April 2003, Arnold Peckerman MD from New Jersey reported findings to the annual meeting of the American Physiological Society that demonstrated via a sophisticated test that after exercise, the heart of those with ME pumped less blood than it did at rest. Peckerman is on record as saying: "Basically we are talking about heart failure. Chronic fatigue syndrome is a progressive disease". Cardiologist Joseph Miller MD from Emory University agrees that these patients have serious heart problems: "A drop in (blood pumped by the heart) during exercise is actually a marker of significant coronary artery obstruction".
What are the risks of forcing such patients to undertake aerobic exercise regimes and "push themselves back to fitness"? The ME community will recall the case of Brynmor John MP who had ME but who was advised to exercise back to fitness; he dutifully tried to do so but collapsed and died coming out of the House of Commons gym.

This excellent text from Verillo and Gellman gives a good starting point on how to start setting activity limits appropriate for your individual limits imposed by the illness. This is an excellent book and is very highly recommended – along with Dr Hyde’s M.E. textbook.

Taken from Verillo and Gellman's CFS: A Treatment Guide p. 267 - 285

Single-photon emission computed tomographic (SPECT) scans have shown that in patients with [ME] who exercise, brain blood volume is reduced 1 to 3 days after exercising. In patients who are acutely or seriously ill, this could have profoundly negative effects on immune and endocrine system regulation. In patients with [ME], exercise also lowers cortisol levels, which makes it more difficult for the body to control inflammation. In addition, it increases erratic breathing and leads to a rapid progression to anaerobic metabolism, which produces ammonia and lactic acid. These negative results are the opposite of what would normally be expected.

In short, a simple answer to the exercise question is, if you are severely or acutely ill, exercise can make matters worse—in some cases, much worse. The time to discuss an exercise program with your physician is only when the illness is stabilised and clear signs of recovery are noted.

Dr. Paul Cheney remarks that "patients with this disease must, for many of them for the first time, place limits on their workstyles and lifestyles. Proper limit-setting, which is always individualised, is the key to improvement." This comment comes after observation of thousands of patients, many of whom denied their illness for extended periods before adjusting to its limitations. Dr. Cheney has seen not only the successes inherent in making these adjustments, but the failures that resulted from attempting to ignore them. But first, we must address the question of what is meant by "proper limit-setting."

To set proper limits, we must start with a basic awareness of how [ME] affects the body and the [brain]. [ME] affects the ability to maintain homeostasis; that is, once the illness is established, it alters the body’s ability to adjust to changes in the environment. For example, a person with [ME] climbs a set of stairs and feels like he or she has just climbed Mount Everest. The out-of-breath, depleted feeling is the result of sluggish heart rate, which, in [ME] does not respond in time to greater demands for oxygen required by exertion. As a result, not enough oxygen is available, and a person with [ME] feels winded after even minimal strain. This type of delayed reaction also results from temperature changes. People with [ME] often remark that when they become
cold, "it takes forever to warm up." The same is true for heat. Both temperature extremes produce symptoms as the body attempts to adjust.

People with [ME] often comment that they are either "on" or "off." Once they stop, they can’t get going again; and once they start, they can’t stop. In the *Clinical and Scientific Basis of ME*, Dr. Byron Hyde, a well-known clinician and researcher of myalgic encephalomyelitis (ME) describes taking a walk with one of his patients. Dr. Hyde noticed when he stopped to look in a store window, his companion kept going. When asked why, Dr. Hyde’s companion replied that if he stopped, he would never get going again!

Once embarking on a project, a task, or a plan, it is difficult to stop. Even when performing easy activities such as taking a walk or balancing a chequebook, patients with [ME] often pass the point of endurance, and symptoms rapidly develop as a result.

Learning when we are "overdoing" it is how we define our own particular limits. This takes awareness, skill, and practice. Each person has limits that are defined by the severity of the illness. For a person who is bedbound, limits will be very different from those of someone who is able to work. Patients who are bedbound may find that extended telephone conversations, standing in the shower, or tackling stressful tasks such as filling out disability application forms produce exhaustion and a general exacerbation of symptoms. These patients may find that sitting in a plastic chair while showering, limiting conversations to 10 minutes, and resting before and after doing necessary paperwork [may help]. A patient who is mildly ill and able to work may wish to cut back on work hours, take naps, and forego activities that place excessive or inflexible demands on the body (such as team sports or other activities that do not allow the participant to "listen": to the body).

A former airline pilot refers to limit setting as living in a box. "As long as I’m in the box, I do alright. If I cross the margins of this box, I don’t do very well." **Defining the limits of your own particular box is the key to developing good coping strategies.** Whatever produces a symptom on any particular day or at any particular hour is where you would define your limits, not by any abstract assessment of what you think you should be doing or a comparison with former capacities.

Patient accounts of graded exercise therapy (GET)

These are just a small sample of many of the personal accounts available of M.E. sufferers being made very ill by exercise (GET is a specific type of exercise program often forced on M.E. patients due to studies which have shown benefit with it on ‘fatigued’ people who do NOT have M.E.). To read more patient accounts and surveys on this topic see: Section 6 of the CBT and GET database and the Case Studies section.
Name: Ruth Country: Ireland
I have been severely affected by M.E. for the past 14 years, completely bed bound for about 10 of those years, and had between 5% and 10% of my former health for the other 4. When I read headlines saying that an exercise regime was the answer to my ill health I couldn't understand it, as every time I tried to push myself physically even in small incremental steps I would deteriorate significantly. The last time I was able to walk I managed to convince myself that I was heading for a full recovery, and so increased my activity regardless of whether I was able for it, the result of this is that I have been unable to get out of bed for the past 6 1/2 years.

Graded Exercise is the worst possible thing for M.E (strictly defined). This is not to say that anybody with M.E. should not exercise, common sense tell us that it is preferable to be as active as possible, but in my experience it is critical to stay within your limits, whether that is a 20 minute walk or in my case a tightening and relaxing of my muscles 2 or 3 times a day. Having learned the hard way in future I will be allowing my body to dictate the amount of exercise I do even though that is one of the most frustrating things about this illness.

Regarding how exercise has come to be recommended by some medics, all I can assume is that they have not read the research behind the headlines, as even a cursory glance at the methodology reveals a sloppy scientifically lame approach biased towards a psychiatric model. This is wholly inappropriate for many reasons not least because M.E is classified as a neurological disease and upon closer inspection a proportion of these researchers may benefit financially from M.E being "treated" with graded exercise.

Name: Annette
I have done 2 GE programs under supervision, both were failures. They both left me far worse off than before for a long period. The first program was at a gym and involved low-impact exercises and then second was a walking program. The symptoms got much worse (sore throat, sinus infections, weakness, fainting) grew progressively worse and I had to abandon the exercise. The first one was early on in my illness (ME as per Ramsay) and probably led to the illness becoming permanent.

Name: Matthew* Country: UK
Exercise - handle with extreme care- ruined my life.

Before becoming ill, I was extremely sporty. Initially, after not being able to rest when having a virus on a school trip at an adventure centre and made do all the activities and never recovering, I was only very mildly affected. This I put down to giving up sport because of the muscle problems I developed so for the early years, I was able to go to school and then college full-time although I had to make cut-backs in most other areas of my life and, as my brain didn't work as well, struggled.
Anyway, my condition suddenly got much worse in the middle of my second year exams (a few hours after a tough 3-hour maths exam where I pushed myself hard to do questions (got a first, by the way), my throat swelled up and I felt feverish). Kept trying to exercise during the summer but developed more and more muscle problems - the physios said they never saw anything like it and x-rays of my back showed inflammation along my spine. I took a year out of college as felt I wouldn't have been able for my finals with the health problems I had and set about trying to get back to normal health by gradually trying to build up the exercise.

Instead of improving, I kept getting worse and worse until I virtually collapsed and have been chronically and severely affected ever since and need a wheelchair to go distances more than 50 metres.

As nobody went to bed when they were sick in my house, neither did I so my symptoms in the early years could not have been put down to deconditioning.

I get so annoyed reading all the rubbish that is written about exercise and M.E. Drugs which make a significant percentage of people worse are usually banned or have big warnings yet exercise ruins the lives of lots of people with ME, like it has done mine, yet most medical people often aren't told by the people advocating the approach how dangerous it can be for patients. It really is unbelievable.

I simply can't do this treatment now. I went to all this trouble to warn others - patients shouldn't have to wait until they are harmed by a treatment to learn it is a potentially dangerous treatment - they should be able to learn from other patients. If I had come across this information years ago, I might now be living a more normal life, rather than the life of a very disabled person.

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**Name:** Ina

Having had this DD for 30 years, nothing set me back so far as graded exercise. I have still not regained the little strength I had prior to this exercise and it has been several years.

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**SEVERELY AFFECTED ME (MYALGIC ENCEPHALOMYELITIS)**

**ANALYSIS REPORT ON QUESTIONNAIRE** (Word document) ISSUED JANUARY 2004 Analysis Report by 25% ME Group, 1st March 2004

Results of survey:
Graded exercise therapy: 95% found it unhelpful
Cognitive behavioural therapy: 93% found it unhelpful
By far the most unhelpful form of treatment was considered to be \textit{Graded Exercise Therapy (GET)}. This is a finding that may surprise some readers, given the current medical popularity of this approach. However, these patients' perceptions are supported by data from previous experience: of the 39\% of our members who had actually used Graded Exercise Therapy, a shocking 82\% reported that their condition was made worse by this treatment. It is worth noting that some patients were \textbf{not severely affected before trying GET}. Thus, it is not only people with severe ME who may be adversely affected by this form of treatment.

\textbf{SOME FACTS AND FIGURES ON CBT, GET AND OTHER APPROACHES}
\textit{Directly from the 'Horses' Mouths:} written by Doris M Jones MSc.

In July 1998 the then Chief Medical Officer, Sir Kenneth Calman, announced the setting up of a Working Group on CFS/ME, to include patients, carers, patient group representatives as well as medical experts, including Psychiatrists. The aim was to find out what really worked in treating these conditions and based on findings, to then compile Guidelines on Diagnosis and Treatment for Clinicians and other Health Care Professionals. Over 80 people took part in this 3 year exercise, including myself. Eventually details were available on 3074 patients, and the summarized results showed very clearly that:

1. \textbf{The most helpful strategies were}:  
   a) Pacing activity with rest (2300/2568 cases = 90\%)  
   b) Bed rest (2165/2426 cases = 89\%)  
   c) Dietary changes (1496/2226 cases = 67\%)

2. The least effective strategy was: \textbf{CBT}  
3. The most harmful strategy was: \textbf{Graded exercise}

Surely it is time that psychiatrists took some notice and actually listened to what patients tell them. I have yet to come across a patient who complains about any treatment which works, whether this is allopathic, psychological methods (like CBT) or exercise regimes (like Graded Exercises). If it works, no-one will complain; the problem is these approaches very often don’t, and this is the one and only reason why patients are so persistent in their demands for other options and are determined to get to the real causes of their ill health. One thing is certain: psychiatrists have made things worse for many, in more ways than one.

\textbf{Conclusion}  
It is vital that patients avoid physical over-exertion and are never encouraged to exercise (or be active) beyond their individual limits particularly in the early and acute stages of the illness, but also at \textit{any} stage of the illness. There is nothing to ever be gained by people with M.E. pushing themselves beyond their limits physically as this can \textit{only} cause unnecessary relapses. Permanent damage (eg. to the heart) and
disease progression may also be caused and there have also been reports of sudden deaths in M.E. patients following exercise.

- See What is M.E.? for more information on all aspects of M.E. See: The effects of CBT and GET on patients with Myalgic Encephalomyelitis for more information on the negative effects of exercise on patients with M.E.
- A note on M.E. and other illnesses: It is sometimes claimed that while exercise programs are not safe or appropriate for the severely affected, that mild or moderately affected M.E. sufferers can benefit from such interventions. But this assertion is NOT supported by the evidence. (Some miscellaneous ‘fatigue’ sufferers have been shown to benefit from graded exercise programs, but the results of these studies are no more relevant to mild M.E. sufferers than they are to severe M.E. sufferers; people with ‘fatigue’ do NOT have mild M.E. any more than they have mild multiple sclerosis, mild Lyme disease, mild cancer or any other illness.) Recent studies have shown that graded exercise programs are the actual reason many with M.E. are so severely affected in the first place, thus exercise programs should not be considered safe for M.E. sufferers of any severity. Graded exercise cannot improve authentic M.E.; disabled patients who improve with exercise do not qualify for a diagnosis of authentic M.E.

Additional notes on this text

1. A note about Myalgic Encephalomyelitis and ‘CFS’:
The various definitions of ‘CFS’ do not define M.E. Myalgic Encephalomyelitis is an organic neurological disorder as defined at G.93.3 in the World Health Organization’s International Classification of Diseases (ICD). The definitions of ‘CFS’ do not reflect this. The ‘CFS’ definitions are not ‘watered down’ M.E. definitions, as some claim. They are not definitions of M.E. at all.

However, ever since an outbreak of M.E. in the US was given the label ‘CFS,’ the name/definition ‘CFS’ has prevailed for political reasons. ‘CFS’ is widely though wrongly applied to M.E. as well as to other diseases. The overwhelming majority of ‘CFS’ research does not involve M.E. patients and is not relevant in any way to M.E. patients. However, a very small amount (a minuscule percentage) of research published under the name ‘CFS’ clearly does involve a significant number of M.E. patients as it details those abnormalities which are unique to M.E. (see the end of the references section for more on this topic.)

It is important to be aware that M.E. and CFS are not synonymous terms. For more information see What is M.E.? See also Smoke and Mirrors for a discussion of why the bogus disease category ‘CFS’ must be abandoned. In short:

1. Chronic Fatigue Syndrome is an artificial construct created in the US in 1988 for the benefit of various political and financial vested interest groups. It is a mere diagnosis of exclusion (or wastebasket diagnosis) based on the presence of gradual or acute onset fatigue lasting 6 months. If tests show serious abnormalities, a person no longer qualifies for the diagnosis, as ‘CFS’ is
‘medically unexplained.’ A diagnosis of ‘CFS’ does not mean that a person has any distinct disease (including M.E.). The patient population diagnosed with ‘CFS’ is made up of people with a vast array of unrelated illnesses, or with no detectable illness. According to the latest CDC estimates, 2.54% of the population qualify for a ‘CFS’ (mis)diagnosis. Every diagnosis of ‘CFS’ can only ever be a misdiagnosis.

2. Myalgic Encephalomyelitis is a systemic neurological disease initiated by a viral infection. M.E. is characterised by (scientifically measurable) damage to the brain, and particularly to the brain stem which results in dysfunctions and damage to almost all vital bodily systems and a loss of normal internal homeostasis. Substantial evidence indicates that M.E. is caused by an enterovirus. The onset of M.E. is always acute and M.E. can be diagnosed within just a few weeks. M.E. is an easily recognisable distinct organic neurological disease which can be verified by objective testing. If all tests are normal, then a diagnosis of M.E. cannot be correct.

M.E. can occur in both epidemic and sporadic forms and can be extremely disabling, or sometimes fatal. M.E. is a chronic/lifelong disease that has existed for centuries. It shares similarities with MS, Lupus and Polio. There are more than 60 different neurological, cognitive, cardiac, metabolic, immunological, and other M.E. symptoms. Fatigue is not a defining nor even essential symptom of M.E. People with M.E. would give anything to be only severely ‘fatigued’ instead of having M.E.’ Far fewer than 0.5% of the population has the distinct neurological disease known since 1956 as Myalgic Encephalomyelitis.

Of course this ‘CFS’ and M.E. confusion must be stopped. It is unbelievable in this day and age that studies on a vague mixed patient group be used to determine the treatments and aetiology of an entirely different and unrelated and distinct patient group! The only way forward, for the benefit of society and every patient group involved, is that:

1. The bogus disease category of ‘CFS’ must be abandoned completely. Patients with fatigue (and other symptoms) caused by a variety of different illnesses need to be diagnosed correctly with these illnesses if they are to have any chance of recovery; not given a meaningless Oxford or Fukuda ‘CFS’ misdiagnosis. Patients with M.E. need this same opportunity. Each of the patient groups involved must again be correctly diagnosed and then treated as appropriate based on legitimate and unbiased science involving the SAME patient group.

2. The name Myalgic Encephalomyelitis must be fully restored (to the exclusion of all others) and the World Health Organization classification of M.E. (as a distinct neurological disease) must be accepted and adhered to in all official documentations and government policy. As Professor Malcolm Hooper explains:

The term myalgic encephalomyelitis was first coined by Ramsay and Richardson and has been included by the World Health Organisation (WHO in their International Classification of Diseases (ICD), since 1969. The current version
ICD-10 lists M.E. under G.93.3 - neurological conditions. It cannot be emphasised too strongly that this recognition emerged from meticulous clinical observation and examination. (2006, [Online])

People with M.E. must also be given access to basic medical care, financial support and other appropriate services (including funding for legitimate M.E. research involving 100% M.E. patient populations finally) on an equal level to what is available for those with comparable illnesses (eg. multiple sclerosis or Lupus). The facts about M.E. must again be taught to medical students, and included in mainstream medical journals, and so on.

References
All of the information concerning Myalgic Encephalomyelitis on this website is fully referenced and has been compiled using the highest quality resources available, produced by the world's leading M.E. experts.

More experienced and more knowledgeable M.E. experts than these – Dr Byron Hyde and Dr. Elizabeth Dowsett in particular – do not exist. Between Dr Byron Hyde and Dr. Elizabeth Dowsett, and their mentors the late Dr John Richardson and Dr Melvin Ramsay (respectively), these four doctors have been involved with M.E. research and M.E. patients for well over 100 years collectively, from the 1950s to the present day. Between them they have examined more than 15 000 individual (sporadic and epidemic) M.E. patients, as well as each authoring numerous studies and articles on M.E., and books (or chapters in books) on M.E. Again, more experienced, more knowledgeable and more credible M.E. experts than these simply do not exist.

This paper is merely intended to provide a brief summary of some of the most important facts of M.E. It has been created for the benefit of those people without the time, inclination or ability to read each of these far more detailed and lengthy references created by the world’s leading M.E. experts. The original documents used to create this paper are essential additional reading however for any physician (or anyone else) with a real interest in Myalgic Encephalomyelitis. Click here to read the reference list for this paper. For more information see the References page.

Before reading this research/advocacy information, please be aware of the following facts:
1. Myalgic Encephalomyelitis and ‘Chronic Fatigue Syndrome’ are not synonymous terms. The overwhelming majority of research on ‘CFS’ or ‘CFIDS’ or ‘ME/CFS’ or ‘CFS/ME’ or ‘ICD-CFS’ does not involve M.E. patients and is not relevant in any way to M.E. patients. If the M.E. community were to reject all ‘CFS’ labelled research as ‘only relating to ‘CFS’ patients’ (including research which describes those abnormalities/characteristics unique to M.E. patients), however, this would seem to support the myth that ‘CFS’ is just a ‘watered down’ definition of M.E. and that M.E. and ‘CFS’ are virtually the same thing and share many characteristics.
A very small number of ‘CFS’ studies/articles and books refer in part to people with M.E. but it may not always be clear which parts refer to M.E. The A warning on ‘CFS’ and ‘ME/CFS’ research and advocacy paper is recommended reading and includes a checklist to help readers assess the relevance of individual ‘CFS’ studies (etc.) to M.E. (if any) and explains some of the problems with this heterogeneous and skewed research.

In future, it is essential that M.E. research again be conducted using only M.E. defined patients and using only the term M.E. The bogus, financially-motivated disease category of ‘CFS’ must be abandoned.

2. The research referred to on this website varies considerably in quality. Some is of a high scientific standard and relates wholly to M.E. and uses the correct terminology. Other studies are included which may only have partial or minor possible relevance to M.E., use unscientific terms/concepts such as ‘CFS,’ ‘ME/CFS,’ ‘CFS/ME,’ ‘CFIDS’ or Myalgic ‘Encephalopathy’ and also include a significant amount of misinformation. Before reading this research it is also essential that the reader be aware of the most commonly used ‘CFS’ propaganda, as explained in A warning on ‘CFS’ and ‘ME/CFS’ research and advocacy and in more detail in Putting Research and Articles on Myalgic Encephalomyelitis into Context.

“People in positions of power are misusing that power against sick people and are using it to further their own vested interests. No-one in authority is listening, at least not until they themselves or their own family join the ranks of the persecuted, when they too come up against a wall of utter indifference.” Professor Hooper 2003

‘Do not for one minute believe that CFS is simply another name for Myalgic Encephalomyelitis (M.E.). It is not. The CDC definition is not a disease process. It is (a) a partial mix of infectious mononucleosis /glandular fever, (b) a mix of some of the least important aspects of M.E. and (c) what amounts to a possibly unintended psychiatric slant to an epidemic and endemic disease process of major importance’ Dr Byron Hyde 2006

The term myalgic encephalomyelitis (means muscle pain, my-algic, with inflammation of the brain and spinal cord, encephalo-myel-itis, brain spinal cord inflammation) was first coined by Ramsay and Richardson and has been included by the World Health Organisation (WHO) in their International Classification of Diseases (ICD), since 1969. It cannot be emphasised too strongly that this recognition emerged from meticulous clinical observation and examination. Professor Malcolm Hooper 2006

M.E. is a systemic disease (initiated by a virus infection) with multi system involvement characterised by central nervous system dysfunction which causes a breakdown in bodily homoeostasis. It has an UNIQUE Neuro-hormonal profile. Dr Elizabeth Dowsett
M.E. appears to be in this same family of diseases as paralytic polio and MS. M.E. is less fulminant than MS but more generalized. M.E. is less fulminant but more generalized than poliomyelitis. This relationship of M.E.-like illness to poliomyelitis is not new and is of course the reason that Alexander Gilliam, in his analysis of the Los Angeles County General Hospital M.E. epidemic in 1934, called M.E. atypical poliomyelitis. Dr Byron Hyde 2006

Dr Melvin Ramsay on Myalgic Encephalomyelitis: "The degree of physical incapacity varies greatly, but the [level of severity] is directly related to the length of time the patient persists in physical effort after its onset; put in another way, those patients who are given a period of enforced rest from the onset have the best prognosis."

The vested interests of the Insurance companies and their advisers must be totally removed from all aspects of benefit assessments. There must be a proper recognition that these subverted processes have worked greatly to the disadvantage of people suffering from a major organic illness that requires essential support of which the easiest to provide is financial. The poverty and isolation to which many people have been reduced by ME is a scandal and obscenity. Professor Malcolm Hooper 2006

‘Thirty years ago when a patient presented to a hospital clinic with unexplained fatigue, any medical school physician would search for an occult malignancy, cardiac or other organ disease, or chronic infection. The concept that there is an entity called chronic fatigue syndrome has totally altered that essential medical guideline. Patients are now being diagnosed with CFS as though it were a disease. It is not. It is a patchwork of symptoms that could mean anything’ Dr Byron Hyde 2003

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Disclaimer: The HFME does not dispense medical advice or recommend treatment, and assumes no responsibility for treatments undertaken by visitors to the site. It is a resource providing information for education, research and advocacy only. Please consult your own health-care provider regarding any medical issues relating to the diagnosis or treatment of any medical condition.
Myalgic Encephalomyelitis (M.E.) patients have strict limits on how active they can be. If these limits are breached, symptoms worsen immediately and there is also a further deterioration 24 – 48 hours later, as well as the very real potential for repeated or severe overexertion to prevent significant recovery, cause disease progression or even death.

It is very important that M.E. patients stay within their limits. Unfortunately, M.E. patients may find staying within these limits all of the time very difficult for a number of reasons.

This paper explains how carers, doctors, and also friends, family members and partners of M.E. patients, can help patients to avoid overexertion, ensuring their best possible long-term health outcome. It also describes the characteristics and signs of adrenaline surges and relapses in M.E. for the benefit of these individuals, as well as for newly ill M.E. patients themselves.

This paper is designed to be read together with the more detailed Hospital or carer notes for M.E. paper.

**What is an adrenaline surge and how does this affect M.E. patients?**

People with M.E. can sometimes operate significantly above their actual illness level for certain periods of time thanks to surges of adrenaline – albeit at the cost of severe and prolonged worsening of the illness afterward.

Adrenaline is often referred to as the ‘fight or flight’ hormone as it kicks into action in situations of potential danger. However, adrenaline also kicks in when the body is in physiological difficulty, which is very often what is happening to severe M.E. sufferers. Adrenaline surges make the heart pump faster and raise the blood pressure, forcing blood around the body with greater force to supply the muscles with more oxygen, so that they can make a greater effort. Surges of adrenaline increase the metabolism. They also relax and dilate the airways so that more oxygen than usual can be taken in. Adrenaline surges can also decrease the amount of pain felt. As a result of all of these factors, adrenaline surges – while they last – have the ability to increase physical speed, strength and other physical abilities.

Unfortunately, when these bursts of adrenaline wear off – as they must – people with M.E. are left far more ill as a result for many days, weeks, months or even years of
overexertion. People with M.E. are harmed by adrenaline surges, both by the physiological stress to the body of the changes caused by adrenaline, and by the extra activity which adrenaline enables, which may be far beyond the body’s normal limits so that such activity causes damage. For every short term ‘gain’ there is a far greater loss overall.

Surges of adrenaline can last hours, days, weeks or even months at a time.

These adrenaline surges are a bit like owning credit cards. They allow patients to do things that they could never otherwise do, or ‘afford.’ But the interest rate is extortionate, sky high, a killer. Clytie, a very ill M.E. patient, explains her adrenaline surges “in terms of money.” In the same way that a financially limited person could purchase a Ferrari, she says, only to be plagued by debt and potentially resorting to desperate measures to settle the score, a seriously ill M.E. patient can overspend in order to perform some activities. But sooner or later the loan sharks are going to show up at your door. Paying that debt, Clytie explains, “could take you a lifetime.”

M.E. expert Dr Melvin Ramsay explains:

The degree of physical incapacity varies greatly, but is directly related to the length of time the patient persists in physical effort after its onset; put in another way, those patients who are given a period of enforced rest from the onset have the best prognosis. Since the limitations which the disease imposes vary considerably from case to case, the responsibility for determining these rests upon the patient. Once these are ascertained the patient is advised to fashion a pattern of living that comes well within them.

Why do M.E. patients sometimes overexert themselves, considering the severe consequences?

There are many reasons why this occurs, including the following:

- Once a patient gets going, stopping can be very difficult. This is due to neurological problems with stopping and starting new tasks easily, and also because once an adrenaline surge has occurred, it takes a long time to wear off.
- When a patient has become very ill from overexertion or is in the middle of an adrenaline surge, judgement can be affected, and the patient may be lost in the moment and not realize how important it is for them to stop what they are doing as soon as possible.
- Resting after a relapse is often very difficult for the M.E. patient emotionally. It can be very difficult to lie in a dark quiet room in extreme pain and worse, with no distraction from it. It can be tempting to keep the adrenaline surge going in a small way, to put off the crash. (A bit like drinking more alcohol the day after a night of heavy drinking to delay the inevitable hangover.)
Many patients with M.E. have been treated appallingly in the earlier stages of their illness. Medical abuse is very common. Patients have often been told or forced to keep pushing through their limits and that this is what they must do if they ever want to recover. This ignorant advice has forced many patients to develop a very high tolerance for pain and discomfort – and this can be a real obstacle when it comes to training oneself to rest appropriately when experiencing minor symptoms. Patients have often become very used to paying a high price afterwards for every little bit of fun they have or every task they do, and have had to accept this as a way of life for so long that change can be difficult.

Many patients, along with much of the general population, have a strong work ethic and at times find not pushing themselves to do things very difficult. M.E. patients need a level of discipline as high as the average Olympic athlete to control and restrict all their activities so completely for years.

M.E. is an acute onset disease which means that patients go from healthy to very disabled from one day to the next. Being so disabled so suddenly is shocking and takes a long time to get used to. Particularly in the early years of M.E., patients often feel the need to constantly push at the boundaries to work out where their limits are. This is sometimes tied to denial of the realities of the disease, and a desire to keep ignoring physical limits in the madly optimistic hope that this will make them go away as quickly as they came.

Other reasons include:

- Due to the brutal severity of M.E., some M.E. patients must overexert just to live or to have a little bit of basic human contact.
- Many M.E. patients overexert themselves as they have no other choice, and do not have the appropriate financial or practical support they need due to the political situation facing M.E. patients. Patients with M.E. are also often forced to overexert themselves in order to get the welfare payments they are entitled to (and need to have to survive) and to try and get some basic medical care.
- Many M.E. patients are told that ‘everyone recovers, it is just a matter of when, and at most you will be well in 5 years’ by ignorant doctors, websites and patients that do not understand the massive difference between the neurological disease M.E. and mere post viral fatigue syndromes. They have no idea that there is a big long-term cost with every short-term relapse, and by the time they do get this information it is often far too late and they have become severely affected and greatly harmed their chances of future recovery.
- Many M.E. patients are told that they are not ill, and that they cannot do things simply because they believe they can’t. This abusive brainwashing can lead many patients to try again and again to push past their limits in a brave but misguided effort towards a ‘mind over matter’ approach to the disease. Unfortunately, many patients have so much faith and trust in their doctors that they ignore what they know to be true about their own bodies and their disease for many months or even years, often ending up severely affected and disabled as a result.
What signs may indicate a relapse or an adrenaline surge?

Signs that an M.E. patient is overexerting and/or running on adrenaline may include the following:

- Very fast and continuous talking is a sure sign of an adrenaline burst. Speech may also become very loud as the patient becomes unable to modulate their volume level. This may also be accompanied by fast and jittery movements. Speech may make evident feelings of euphoria, over-excitability or wild optimism and will often be less well-considered than normal. The patient may also sit up or stand for longer than usual (without realising they are doing so) or get fired up to undertake tasks that they would usually be too ill to do. (Big cleaning or organisational tasks for example.)

- After or during an adrenaline surge, sleeping and resting is very difficult as the patient feels ‘wired’ and very un-fatigued or sleepy. Sleep onset may be delayed for many hours, perhaps leaving the patient unable to sleep. The patient may also only be able to sleep for one or two hours at a time, awaken for a few minutes many times during the night, and/or may experience very light sleep where the slightest noise wakes them up.

- Particularly in the first few years of the disease, patients may sleep, or be unconscious, for much longer than usual after overexertion, perhaps 12 – 16 hours or more. In extreme cases, the patient may be unable to maintain consciousness for more than a few hours a day.

- When suffering an acute neurological episode M.E. patients may be mistaken for being drunk or high on drugs. They may slur their words, talk very fast and ramble, seem euphoric and have very poor balance.

Other signs of an adrenaline surge include:

- A lack of facial expression and ‘slack’ facial muscles and/or extreme facial pallor.
- A burning sensation in the eyes and/or an inability to tolerate visual stimulus and to keep the eyes open.
- Excessive water drinking (to try to boost blood volume).
- Excessive hunger and a desire for sugar- or carbohydrate –rich foods. Even after eating, the patient may feel as if they have very low blood sugar and may need to eat far more often than usual.
- Sweating or shortness of breath after minor exertion.
- Visible shaking of the arms or legs or twitching facial muscles.
- Paralysis and weakness in the muscles or an inability to move, speak or understand speech.
- Sudden loss of ability to walk.
- Very sore throat and/or painful and tender glands in the neck (and possibly other flu-like symptoms).
- Distinctly pink, purple or blue feet or legs, with white blotches, after standing or sitting for too long.
- Patients may complain of a severe headache or feeling of pain or pressure at the base of the skull. This may also be accompanied by pain behind one or both eyes or ears, or blackouts.
- Sudden onset ringing in the ears or loss of hearing.
- During and after overexertion, a patient’s pulse will often become much faster (150 bpm or more), their blood pressure will become lower and their temperature may rise and they may feel very hot (or alternating hot and cold). Pulse and/or temperature measurements may be useful in determining when a patient is overexerting. As blood pressure readings tend to be abnormal only when the patient is standing or sitting upright – which in itself causes relapse - this test will often be counter-productive and inappropriate.

Other things to be aware of:

- Sometimes when the patient is running on adrenaline, it is very obvious that this is what is happening. The patient is able to do more than usual but feels very unwell and wired; a bit like they haven’t slept in days but have had a LOT of coffee (or other stimulants). At other times, particularly where the adrenaline surge is long-lasting, the adrenaline effects can be more subtle and can easily be mistaken for genuine wellbeing for a period of time.

- When a patient declares that they are improving and suddenly able to do tasks again which they have not been able to do for many months or years – and this occurs right after a very big task has been completed such as a house move or a very taxing trip to the doctor, it is almost certainly an adrenaline surge and not a real improvement. The big task was well beyond their limits and so the body has released a surge of adrenaline just to cope.

  Unfortunately, this type of lower-level but prolonged adrenaline surge will often be less easily recognised for what it is by the patient, especially where there are problems with memory and placing events which occurred weeks ago in the appropriate timescale. (Events which occurred more than a few days ago may be forgotten, or seem to have occurred much longer ago than they actually did.)

  This type of adrenaline surge can sometimes fool even the most experienced M.E. patients. Having hope of improvement replaced with the realities of a severe relapse can be very disheartening, to say the least.

- When a patient regularly pays a big price for doing small tasks but then suddenly pays only a small price for a big task, suspect an adrenaline surge. There is just no such thing as a free lunch with M.E. (When a relapse is expected and doesn’t
occur, that indicates use of the ‘credit card’ or that the patient’s body is ‘writing cheques it can’t cash’ as it were.)

- Often a considerable rest period is needed before and after a task, which may be hours, days, weeks or months long. For example, someone may need 2 weeks rest before an outing, and may then spend 3 weeks extremely ill afterwards recovering from it. The need for a long rest period before a task is a sign that this task is not within usual limits and will probably require an adrenaline surge to be completed and so be detrimental to the patient’s long-term health.

  Ideally, a patient will only complete tasks which can be done daily or every second or third day without causing relapse. The goal is to do only 80% of the activity that can be done sustainably each day.

- Thanks to adrenaline surges, a moderately ill patient may spend several hours a day, one day a week studying or working and then 6 days extremely ill and disabled, or be able to struggle through study or work part-time and spend the rest of their time extremely ill and disabled. This type of schedule can only be kept up for a few years at best, as the patient becomes sicker and sicker and less able to bounce back from relapses.

- Some patients will manage their limits very carefully but still exhibit signs that they are running on a low level of adrenaline most or all of the time. This is likely an indication that more rest is needed and that more challenging tasks should, if possible, be scaled back or discontinued.

- When the adrenaline surge starts to wane, the patient will often feel very irritable. Part of this is due to problems with blood sugar and so eating a substantial meal can help the patient feel better both physically and emotionally. Cravings for sugar and carbohydrate-rich foods are common at this time, but a meal containing some protein, fat and some low glycaemic load carbohydrate foods is a better choice. Part of this is also an emotional response, as coming down form an adrenaline high is very difficult emotionally. A patient has just had a reminder of how it might be if they were not as ill and disabled, and also has a significant worsening of their symptoms and disability level.

  The patient may also feel very cold and shaky and even more sensitive than usual to light and noise as an adrenaline surge starts to wane.

- When a person with M.E. starts to rest after an adrenaline surge, it takes a little while for the adrenaline to wear off, so the patient will start resting and gradually begin to feel more and more unwell. Unfortunately the patient will have to go through a period of feeling much worse, in order to feel better. Starting to feel worse shows that the adrenaline is wearing off and that the patient is resting properly. The period of feeling very ill may last for hours, days, weeks or longer, depending on how ill the patient is and how much they overexerted.

  In contrast, when an M.E. patient who has not overexerted rests they will feel better right away and this improvement may continue to build over time. Thus feeling much more ill after a period of resting is another sign that the patient has been running on adrenaline and overexerting.
**What can you do to help?**

- When you notice fast talking, and other signs of an adrenaline burst or surge, encourage the patient to slow down. Perhaps remind them that the sooner they rest, the better off they will be.

- When a patient is talking very fast and very loudly, subtle reminders to speak more quietly may be helpful. (Remember that slow talking may in fact be a very good sign of health and of living within limits!)

- When you notice a patient sitting or standing when they do not need to, or for longer than they can usually cope with, a reminder to lie down may be helpful as the patient may not realise that they are standing up for too long.

- When, out of necessity, the patient has completed a big task that was far beyond their, be aware from the outset that this will cause a surge of adrenaline to be released. This surge will affect the patient during the event but probably also for some days, weeks or months afterwards. The patient may feel somewhat less ill and be able to do some tasks which they haven’t managed for some time. But tasks done using adrenaline surges come at a very high cost long-term and so must be strongly discouraged and absolutely never encouraged.

  Making sure that the patient is aware of this characteristic of M.E. before a big task is completed - and before they misinterpret these signs of overexertion and illness as an improvement in their condition - can only be helpful.

- When a big adrenaline surge has occurred, the only way to stop it is to make sure that the body is no longer placed in physiological difficulty. For the severe M.E. patient, this will mean at least 3 days of complete rest. (The time period of rest needed will vary with how severe and prolonged the surge is and how ill the patient is.) Adrenaline will stop being released when the body is at rest and time has passed allowing the adrenaline in the system to wear off.

  Severely affected patients will need almost complete rest constantly, to avoid adrenaline surges and relapses in symptoms.

- Do not instigate conversations with a patient when they are trying hard to come down off an adrenaline surge. You may ruin hours of solid resting by asking a question that forces the patient’s body to have to rely on adrenaline again in order to reply. If possible, write down any questions you have so that the patient can answer them in their own time and in the way easiest for them. When patients are severely affected and can’t speak often, you may want to devise a system whereby they can reply to yes and no questions, or questions with 2 options using hand signals or printed cards.

- If possible, if you are a carer who visits the patient’s home for a few hours a day, make a set time to talk to the patient so that they do not have to be ‘switched on’ and ready to talk the whole time you are there. Staying ‘switched on’ may require an adrenaline burst and leave the patient very ill afterwards even if you only spoke to them very briefly. Having to be ‘switched on’ in case of interaction is almost as taxing as actually talking, for many patients.
• When you speak to an M.E. patient who is very ill or relapsing, speak slowly, calmly and somewhat softly. Do not speak loudly or shout. Do not ask stressful or difficult questions when the patient is at their most ill or if it is not their ‘best’ time of day.

• Don't repeat things unless you are asked or indicated to do so. M.E. patients often have a significant time delay in understanding spoken words, and they may rely on a period of silence after each statement in order to understand what you have said.

• For more information on how to appropriately treat M.E. patients and help them to avoid relapse please see the following two essential papers: Hospital or carer notes for M.E. and Why patients with severe M.E. are housebound and bedbound.

How should you use this information?

This paper largely focuses on patients who are at the severe end of the moderate continuum and severely affected patients who are almost entirely bedbound. It will have to be adjusted somewhat for patients who are more moderately affected, or extremely severely affected.

How much assistance and guidance you give an M.E. patient to help them minimise relapses depends on several factors. These include how close you are to the patient, how receptive they are to input from you, how ill the patient is and how well they are managing their symptoms and relapses themselves.

M.E. patients understand their own limits very well almost all of the time. All they may need from you is the occasional verbal reminder to lie down or to rest.

Perhaps in most cases, just the fact that you have a desire to help and have read this paper and that you both have a solid understanding of the challenges they face and the nature of M.E. relapses will be enough. Knowledge is power.

Conclusion

It may seem obvious that M.E. patients would always do what is best for their long-term outcome, but this is not always the case. M.E. is a very difficult disease to manage. M.E. patients are very often sick to death of all the resting, caution and explanation required of them and so anything that you can do to help is very welcome. Thank you for taking the time to read this paper.

More information
• If you know someone with M.E. and want to know how to deal with it, and what you can do to help, then please read So you know someone with M.E.?

• M.E. patients and those involved in determining treatment for M.E. patients may wish to look at the Treating M.E. paper which discusses treatment for M.E. generally, and also treatments which may support normal adrenal function. (This includes extra B complex and vitamin B5, high-dose vitamin C, vitamin A, low dose cortisol and unrefined sea salt.)

• For tips for M.E. patients on avoiding overexertion see: A quick start guide to treating and improving M.E. with aggressive rest therapy, diet, toxic chemical avoidance, medications, supplements and vitamins plus the important new paper: Tips on resting for M.E. patients.

• All M.E. patients need to have their cortisol levels checked regularly. Low cortisol levels are well documented in M.E. In some cases testing may indicate very low cortisol levels and a prescription for low dose cortisone may be required. See Testing for M.E. for more information.

Acknowledgments
Thanks to Caroline Gilliford for editing this paper. Thank you to Victoria for suggesting the topic of this paper. Thank you to Victoria, Frir, Clytie and everyone else who contributed to this paper.

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References note
The foundations of the pathology and symptomatology described in this text are well documented. For referenced information on the importance of avoiding overexertion in M.E., cardiac insufficiency in M.E., deaths in M.E. patients caused by overexertion, circulating blood volume being reduced to 50% or less and very low blood pressure readings in M.E., severely reduced cortisol levels in M.E. and the delayed effects of overexertion in M.E. etc. please see: What is M.E.? Extra extended version, Testing for M.E. and The effects of CBT and GET on patients with M.E.

What is not as well documented, however, is the exact nature of the relapses and adrenaline surges in M.E. The details on adrenaline surges included in this paper have been taken largely from hundreds of patient accounts shared with me both privately and in various online groups over the last 10 years or so, as well as my own experiences as a long-term M.E. patient. Further comments and suggestions from knowledgeable patients or doctors are always welcome.

Relevant quotes
‘M.E. is a systemic disease (initiated by a virus infection) with multi system involvement characterised by central nervous system dysfunction which causes a breakdown in bodily homoeostasis (The brain can no longer receive, store or act upon information which enables it to control vital body functions, cognitive, hormonal, cardiovascular, autonomic and sensory nerve communication, digestive, visual auditory balance, appreciation of space, shape etc). It has an UNIQUE Neuro-hormonal profile.’

DR ELIZABETH DOWSETT

‘There is ample evidence that M.E. is primarily a neurological illness. It is classified as such under the WHO international classification of diseases (ICD 10, 1992) although non neurological complications affecting the liver, cardiac and skeletal muscle, endocrine and lymphoid tissues are also recognised. Apart from secondary infection, the commonest causes of relapse in this illness are physical or mental over exertion.’

DR ELIZABETH DOWSETT

‘This illness is distinguished from a variety of other post-viral states by a unique clinical and epidemiological pattern characteristic of enteroviral infection. Prompt recognition and advice to avoid over-exertion is mandatory.’

DR MELVIN RAMSAY & DR ELIZABETH DOWSETT

‘[Legitimate descriptions of the illness are] a far cry from the hopelessly inadequate description of M.E. as ‘chronic fatigue.’ The distinction between fatigue and M.E. needs emphasising. If you are tired all the time, you do not have M.E. If you are feeling drained following a viral illness but are recovering over weeks or months, you do not have M.E. A central problem is the word ‘fatigue’ which doesn’t come close to describing how sufferers can feel – comatose might be better.

Like most people with M.E. I have acquaintances who say, ‘Oh I feel tired at 4pm too, and would love a snooze.’ But that’s not it. Minds and bodies do not function. This is nothing like fatigue.’

LYNN MICHELL IN ‘SHATTERED: LIFE WITH M.E.’ P 6

‘If patients draw down their lifestyle to live within the means of the reduced cardiac output, then progression into congestive cardiac failure (CCF) is slowed down, but if things continue to progress, a point will be reached where there is no adequate cardiac output, and dyspnoea will develop, with ankle oedema and other signs of congestive cardiac failure.

In order to stay relatively stable, it is essential for the patient not to create metabolic demand that the low cardiac output cannot match.’

DR PAUL CHENEY [VIDEO LECTURE]

‘Dr Paul Cheney explained how the bodies of patients are choosing between lower energy and life, or higher energy and death. On a physiological level, patients live in a near-death suspension, making patients feel much like they are dying, not tired.’

PEGGY MUNSON 2003
‘There is a difference between diastolic dysfunction and diastolic failure: in diastolic dysfunction there is a filling problem but the body is compensating for it and achieving enough cardiac output to match metabolic demand. Diastolic failure begins when the body can no longer compensate and there is a reduction in cardiac output. This is seen in 80% of patients. In order to stay relatively stable and avoid heart failure, it is essential for the patient not to create metabolic demand that the low cardiac output cannot match.’
DR PAUL CHENEY [VIDEO LECTURE]

‘Patients have a high heart rate but a low cardiac output. There is a cardiac dimension that is independent of (but not excluding) autonomic function or blood volume. It’s hard to talk about a low cardiac output without talking about the involvement of the brain and the adrenal glands. A mismatch between metabolic demand and cardiac output, even very briefly, will kill. If the cardiac output goes down, in order not to die, there is a rise in noradrenergic tone (also involving the adrenal glands) to bring the output back up. This is a serious problem, because when the adrenals are exhausted, there will be low cardiac output. There is no such thing as an [M.E.] patient who is NOT hypothyroid: this has nothing to do with thyroid failure, but everything to do with matching metabolic demand and cardiac output.’
DR PAUL CHENEY [VIDEO LECTURE]

‘Order of sacrifice in cases of declining microcirculation: First is the skin; second is the muscles and joints; third is the liver and gut (patients can usually only tolerate a few foods); fourth is the brain; fifth is the heart; sixth is the lung and lastly is the kidney.’
DR PAUL CHENEY [VIDEO LECTURE]

‘Among the major causes of death in [M.E.] is heart failure: 20% die of heart failure. There are two types of heart failure: systolic (which is a failure to eject) and diastolic (which is not a failure to eject, but a failure to fill properly). There are two types of diastolic heart failure: primary relaxation deficit giving rise to decreased cellular energy as seen in [M.E.] and secondary relaxation deficit as seen in hypertension, diabetes and the elderly over age 75. Primary relaxation deficit is a disorder that seems to have gone right under the radar of most cardiologists (who focus on the secondary relaxation deficit). Diastolic heart failure was first described in the 1980s but there was no significant literature until the 1990s, and no significant way to measure it until 2001. One is just as likely to die of diastolic heart failure as from systolic heart failure.’
DR PAUL CHENEY [VIDEO LECTURE]

‘If your illness is M.E., the main thing you can do to help yourself is not push beyond your limits. I seriously damaged my health by pushing myself to continue at work after I became ill. I bitterly regret that now. I wish I had had access to Jodi’s Hummingbird website at that time, which gives the all-important message that we must not push beyond our limits.’
LESLEY, M.E. PATIENT
‘ME "old-timers" all say the same thing. Please take really good care of yourself, and don't get into the mindset of "needing" to push yourself because of things you want to do in the future.

When you have M.E., it's important to NOT push yourself, so you'll still be able to do those things in the future! You deserve to take really, really good care of yourself, especially right now, in the beginning.

I did the same thing too (pushing through, and over-exerting), and I regret every moment of it. If you are still within the first few years, and it IS really M.E., please slow down the pace of your life - you still have a chance of a meaningful recovery if you're very careful. I wish I could go back and do it all over, but since I can't, I wanted to tell you that you can avoid the mistake we've made. I am now totally disabled, and during my "healthy times", I am doing good to leave the house for a couple hours 2 times a week (and there are a LOT of M.E. patients much worse off than me!).

I also go through periods when I deal with a worsening of my symptoms (like now) and these periods are especially difficult to deal with (bed bound, house bound, etc for extended periods).'

SARAH, M.E. PATIENT

‘i feel sick,foggy, achy, weak, dizzy, jangly but not yummy old fatigue: like you get when you have walked to the beach, or dug a garden bed, or shopped til you dropped..’

BARBARA, M.E. SUFFERER

‘It is as if someone has frayed the ends of every nerve in the body and left them raw and exposed. It brings an overwhelming need to close down sensory input and, for many, to retreat from everyday ordinary stressors - conversation, noise, light, movement, TV - since they are agonising to deal with. Everyone said that they were not fatigued.’

LYNN MICHELL, DISCUSSES HER M.E. PATIENT INTERVIEWS FOR HER BOOK (P.24)

‘i try to xplain this one in terms of money
ok, you could buy a ferrari, couldn't you?
no, i don't have the money
oh, but you could borrow lots of money, sell your house, take up dealing drugs, gamble, and in the end you'd have your ferrari
<blank look>
maybe for a day or so, before the loan sharks shoot your kneecaps off, and the gangs blackmail you, and you have to find a way to repay all that money... could take you a lifetime
<rather frightened look>
yeah. you get the point’

CLYTIE, M.E. PATIENT

‘My worst acceleration in symptoms was when I was trying to work and go to
university at the same time. I really wish I had listened to my body and stopped earlier (although I know this is really hard to do). I might have been able to go back and work part-time or something. As it is, I'm pretty sure the damage is permanent now. I don't think I will ever be able to work again. On the other hand I am so glad that I did not keep going. I'm sure that I would be a lot worse (scary thought!) if I had.’

N, M.E. PATIENT

‘If it is M.E. & you continue to overdo, you may well end up sooooooo much worse than you are now. It happened to Jodi, it happened to me, this determination that we are suffused with in our culture of soldiering through & mind over matter & good people get well...& then we do "fight the good fight"...& with this disease the price is very, very high & can be permanent. Hate to be a harbinger of doom, I know it is hard to imagine being more ill, but you do have an opportunity here to avoid our fate. Hard choices I know.’

AYLWIN CATCHPOLE, M.E. PATIENT

‘I am a ghost in the land of the living - forgotten, ignored and drifting on the edges of life, whispering my message in the ears of the lucky ones who can participate in life and community. But they don't hear me. And mine is all too often the fate of those of us existing with a disabling chronic illness.

I have M.E., or Myalgic Encephalomyelitis, that most ridiculed entity, downgraded to something called Chronic Fatigue Syndrome by most of the medical profession.

I call it paralysis, muscle and cardiac failure, brain injury, a living plague that kills only slowly but does kill, that has planted me on the sidelines of life, incapacitated and waiting for the Telethon, Walkathon, ANYthing-a-Thon in recognition of this insidious and infectious plague that has rendered millions worldwide house and bed-bound. I get so jealous when I see the pink-clad hordes out supporting others, who already have better support than I can ever hope for.’

AYLWIN CATCHPOLE, M.E. PATIENT

A dedication

This paper is dedicated to my dear friend Aylwin (Jennifer) Catchpole. Aylwin was the first fellow M.E. patient I met that really understood that the 'adrenaline surge' was a part of M.E. and was suffering with the problems associated with it as much as I was.

Over many (short) emailed conversations over a period of years she helped me more fully understand this phenomenon, and so very much was a contributor to this paper. Aylwin died in 2010 (before this paper was completed), but I am sure she would have been very happy to know that this paper had been written and that hopefully many M.E. patients will get this information at the start of their disease when it can do the most good, rather than many years or decades in – like most patients do, and like we both did, unfortunately.
For more information on Aylwin see the Aylwin Catchpole memorial page on the HFME website.
As explained previously in HFME papers such as A quick start guide to treating and improving M.E. with aggressive rest therapy, diet, toxic chemical avoidance, medications, supplements and vitamins and The importance of avoiding overexertion in M.E. plus Assisting the M.E. patient in managing relapses and adrenaline surges, Myalgic Encephalomyelitis (M.E.) patients have strict limits on how active they can be and must strictly avoid overexertion.

If these limits are breached, symptoms worsen immediately and there is also a further deterioration 24 - 48 hours later, as well as the very real potential for repeated or severe overexertion to prevent significant recovery, cause disease progression or even death.

It is very important that M.E. patients stay within their limits. Unfortunately, M.E. patients may find staying within these limits all of the time very difficult for a number of reasons. This paper gives M.E. patients some practical tips and guidelines on resting and on avoiding overexertion.

**Follow the 80% rule**
The idea of the 80% rule is to work out how much you can do every day without becoming in any way sicker, and then do only 80% of that. To have each day the same activity-wise is the goal. Avoid adrenaline surges and crashes where you can operate outside your normal ability levels for a hour or a day or even weeks or months but then spend a long time after much sicker; weeks, months or years or longer.

Avoiding overexertion is essential, but it is not enough. Getting some real rest is important too. Your body needs energy to heal and without any metabolic energy to spare, healing will be very slow.

**Forced overexertion and the M.E. patient**
Patients with M.E. are also often forced to overexert themselves just to get through each day and in order to get the welfare payments they are entitled to (and need to have to survive) and to try and get some basic medical care.

If you are absolutely forced to operate outside your limits sometimes, or quite often, due to not having the basic care and support you need, my sincere commiserations.
Just do the very best you possibly can and all the best with your support level improving in the future.

**Tips on avoiding overexertion and resting as much as necessary**

Instead of doing a task until you become too ill to do it anymore, try doing the same task for smaller periods of time, interspersed with rest periods. You might find that you can read for an hour all at once, or if you read for 15 minutes and then rest for 15 minutes you might find that you can read for an hour and a half, and you may feel less ill afterwards and even remember more of what you read. Stopping a task regularly for significant rest breaks also makes it less likely you’ll build up a big adrenaline surge to accomplish a task.

Switch tasks often. Instead of reading all day, and then spending the next day on physical tasks, try to alternate different types of tasks. Of course in M.E. avoiding overexertion is not just about physical overexertion. Cognitive, sensory and orthostatic overexertion (being upright) can cause the exact same, or worse, problems. Too much bright light and noise, sitting, thinking or reading can make you just as ill as too much physical activity and so these types of activities must be kept within your own strict limits also.

Modify tasks, and get help with tasks if you can. Lie down to use the computer, lie down to watch TV or read, chop your vegetables lying down, lie down when you go outside the house to be in the garden, lie down when you travel by car, and so on. Even if you can do something standing up, do it lying down and use the extra cardiac function you save on something more fun or necessary.

Choose comedies, dramas and documentaries when you watch TV, rather than shows designed toexcite and get adrenaline pumping. If you can, listen to TV shows but don’t watch them, or close your eyes now and then while you have the TV on and always mute the ads.

Spend some time each day listening to a meditation or relaxation CD, or just relaxing and doing some simple breathing exercises if you can. Slowing your heart rate and breathing right down reduces the workload of your heart and so can count as a kind of ‘double rest.’

Ask your doctor if he will consider letting you have some or all of your consults by phone. Switch to online banking and shop online as well if going out makes you more ill.

Think about all your priorities, and realise that if you have been overexerting something WILL have to give and you will have to save your abilities for just those few things highest on the list, at least for now. This might also mean stopping work or study or stopping leaving the house for appointments now, rather than waiting a bit longer until you utterly collapse and have no choice but to remain at home in bed. This is very difficult to do but it will be worth it in the end if you can manage it.
Doing otherwise unfortunately means you will have to give up even more in the long term.

**What is an adrenaline surge and how does this affect M.E. patients?**

People with M.E. can sometimes operate significantly above their actual illness level for certain periods of time thanks to surges of adrenaline released when the body is put in physiological difficulty – albeit at the cost of severe and prolonged worsening of the illness afterward. These adrenaline surges are a bit like credit cards. They allow patients to do things that they could never otherwise do, or ‘afford.’ But the interest rate is extortionate.

Signs that you are overexerting or running on adrenaline may include the following:

- Very fast, loud and continuous talking is a sure sign of an adrenaline burst. You may also sit up or stand for longer than usual (without realising you are doing so) or get ‘hyper’ and fired up to undertake tasks that you would usually be too ill to do. Sleeping and resting is very difficult as one feels ‘wired’ and very ‘unfatigued.’

- A lack of facial expression and ‘slack’ facial muscles and/or extreme facial pallor.

- A burning sensation in the eyes and/or an inability to tolerate visual stimulus and to keep the eyes open.

- Excessive water drinking (to try and boost blood volume) and excessive hunger and a desire for sugar- or carbohydrate –rich foods.

- Sweating or shortness of breath after minor exertion or a sudden loss of the ability to walk.

- Visible shaking of the arms or legs or twitching facial muscles.

- Paralysis and weakness in the muscles or an inability to move, speak or understand speech.

- Very distinctly pink, purple or blue feet or legs, with white blotches, after standing or sitting for too long.

- Severe headache or feeling of pain or pressure at the base of the skull. This may also be accompanied by pain behind one or both eyes or ears, or blackouts.

- Sudden onset ringing in the ears or loss of hearing or sore throat and painful glands in the neck.

- During and after overexertion your pulse will very often become much faster (150 bpm or more), your blood pressure will become lower and your temperature may rise and you may feel very hot.

When you are sure you are improving and are suddenly able to do tasks again which you have not been able to do for many months or years – and this occurs right after a
very big task has been completed such as a house move or a very taxing trip to the
doctor, it is almost certainly an adrenaline surge and not a real improvement.
Improvements just do not occur after overexertion in M.E. this way. The big task was
well beyond your limits and so the body has released a surge of adrenaline just to
cope. Unfortunately, this type of lower-level but prolonged adrenaline surge can often
be less easily recognized for what it is.

Tasks done using adrenaline surges come at a very high cost long-term and so must
be strongly discouraged and absolutely never encouraged. Friends, family members
and carers should be advised not to instigate conversations with a patient when they
are trying hard to come down off an adrenaline surge as this can undo hours of
resting. If possible, they make a set time to talk to the patient so that they do not have
to be in ‘on’ and potentially ready to talk for hours at a time as this is almost as taxing
as actually talking for many patients.

The only way to stop an adrenaline surge is to make sure that the body is no longer
placed in physiological difficulty. This often means 3 days or more of absolute rest.
While some of the effects of overexertion are immediate there are also secondary
relapses that are delayed by 24 – 72 hours.

Ideally we need to try to live long-term only completing tasks which can be done
daily or every second or third day without causing relapse.

• For more information on adrenaline surges in M.E. see: Assisting the M.E.
  patient in managing relapses and adrenaline surges

How do I know if I am resting enough?
Try resting significantly more for a week and see which symptoms improve, if any. If
you feel a lot better, you may still be doing too much in your usual routine and may
need to cut back.

You may also choose to have an extra intensive rest period lasting a day, or three
days or a week to try and give your health a boost if you’ve been having a very bad
time of it recently. Intensive rest therapy in M.E. is not fun, or easy. It’s anything but,
as anyone with M.E. will tell you. But it is unfortunately absolutely necessary.

Can I do stretching exercises? What about deconditioning?
Stretching exercises may be beneficial for the M.E. patient as they help improve
circulation and can help to reduce pain and stiffness and increase flexibility, but only:
• If you aren’t wasting ability you could use on something far more useful or
  fun, and:
• If you are not severely affected and are well enough to do it without any
  payback. If you can’t then it is counter-productive.
For patients that have experienced significant recovery light weightlifting may also be useful, but again, only if the two conditions listed above are met.

Stretching exercises even if they seem mild and fairly effortless can still cause severe relapse and disease progression in the M.E. patient that is not well enough to cope with them.

Remember that it is absolutely true (as Dowsett and others have said) that just doing the basic tasks of living IS ENOUGH by itself to stop significant deconditioning. This includes walking to the bathroom a few times a day, getting dressed and eating your food and so on – all those little tasks use all sorts of different muscles.

Do not worry about deconditioning as when you can do more you will do more but trying to do things that you aren’t well enough to do to avoid deconditioning is a sure way to make your condition worse. The extreme scaremongering about deconditioning in M.E. is about politics subverting science. It is an unscientific sham involving ‘medically unexplained fatigue patients’ and not actual M.E. patients at all!

M.E. patients can’t do things because they are ILL, and they have serious metabolic, homeostatic and cardiac insufficiency issues. It is not because they are merely ‘deconditioned.’ M.E. is also an acute onset disease and the idea that deconditioning could happen from one day to the next is unscientific to say the least.

What happens when my condition improves and I can start doing a bit more?

Over time, when/if you are able to do a little more in a day with no payback, you will just know, and can then adjust your activity levels accordingly. You will know because you will feel much healthier and find tasks which used to cause a small amount of strain, now cause no problems at all and you’ll start doing tasks for longer and longer periods before you’re even aware that you are able to do so.

Speaking as someone that is slowly improving month by month, it really is such a natural process to slowly start doing more and more small tasks that you can now ‘get away with.’ It isn’t something you have to plan, you just know when you are finally well enough to do something at a time when you would normally be resting. You can feel the difference in your body and the difference in how you feel after doing certain tasks. Listen to your body and remember to only do these new activities a few times a week to start with rather than every day, so as not to jeopardise your hard won improvements by accidentally overdoing it.

Nobody with M.E. will ever do far less than they are physically capable of doing. It would just go against basic human nature to do so, having lost so much dealing with such a life-destroying and life-limiting disease. Thus it is just NOT a problem. The problem is always patients doing too much, if anything, that is just human nature too sadly. Resting so much is incredibly difficult.
More information

- For more information on treating M.E. please see: A quick start guide to treating and improving M.E. with aggressive rest therapy, diet, toxic chemical avoidance, medications, supplements and vitamins and Symptom-based management vs. deep healing in M.E.
- For more information on the importance of avoiding overexertion in M.E. please see: Assisting the M.E. patient in managing relapses and adrenaline surges, Smoke and Mirrors plus The effects of CBT and GET on patients with M.E. and Treating M.E. - Avoiding Overexertion.
- See Hospital or carer notes for M.E. and Why patients with severe M.E. are housebound and bedbound for tips for carers and friends and family on how to help the M.E. patient avoid relapse.
- For more information about the medical and political facts of M.E. see: What is M.E.? Extra extended version and Who benefits from 'CFS' and 'ME/CFS'?
- For more tips on living with M.E. see:
  - Practical tips for living with M.E.
  - The HFME reminders and cognitive tips list
  - Tips for coping emotionally with M.E.
  - Assisting the M.E. patient in the use of computers and technology
  - Assisting the M.E. patient in managing bathing and haircare tasks and
    Assisting the M.E. patient in managing toileting tasks
  - Assisting the M.E. patient in having blood taken for testing
Avoiding overexertion is so important when you have M.E. Patients must limit physical overexertion but also cognitive and orthostatic overexertion and excessive sensory input. In addition to these, there are also other ways in which we can help to reduce the workload of the body and so increase the amount of extra cardiac function available to help our bodies work properly.

Paying attention to these other factors may result in a slight reduction in disability levels, reduced symptom severity, reduced pain and suffering as well as a greater chance that the body will be able to heal some of the damage inflicted by the disease.

The information in this paper is to some extent ‘controversial’ but is included for those patients with an interest in this type of medicine. The details of it are based on some conclusions I came to recently in quite an organic way due to my own knowledge of M.E. and all the many books and articles I have read on it as well as a lot of what I have read about the way the body burns calories as well as approaches to healing which focus on the ‘total load’ principle and holistic and environmental medicine generally.

**The theory**

It is well-known that being more active only increases our daily calorie expenditure a tiny amount. A man that weighs 250 pounds and has a base-level calorie expenditure of 2500 calories daily will only burn 3 extra calories if he one day climbs a flight of stairs in addition to his usual more-sedentary activities. If he climbs 20 flights of stairs he will only expend an extra 60 calories.

M.E. patients, many of them, would be made very ill by climbing one set of stairs, let alone 20 of them – if they were able to climb any stairs at all.

But if doing this small extra task can make us ill, and if it uses so little of our daily percentage of calories and energy, doesn’t it logically follow that in addition to trying to minimise voluntary physical, cognitive and orthostatic overexertion and sensory input we should also be trying to minimise the far larger load of all the involuntary tasks our body does each day just to keep us going?

In other words, if we don’t have the metabolic energy or cardiac output to cope with something that has a very small energy cost, then of course we don’t have enough for
all those other very energy intensive tasks the body does all by itself either. This is part of why we have poor liver function, reduced cardiac output and poor immune function and so on, with M.E. All of our bodily systems are not able to function properly in part due to a lack of metabolic energy (and also because of various other at least equally important homeostatic, CNS, ANS, endocrinological, neurological and other dysfunctions).

So the question becomes – can we reduce the load on the body further in addition to ‘just’ trying to minimise voluntary physical, cognitive and orthostatic overexertion and sensory input. I think we can and many experts in holistic and environmental medicine would agree.

**What are some basic principles of this type of medicine?**

There are 3 basic principles:

1. *Get the good stuff in.* Give your body the fuel and tools it needs to work at an optimum level. Good food, nutrients and all the proper vitamins, minerals and antioxidants. Make sure you aren't deficient in anything important as the different nutrients all work together.

2. *Get the bad stuff out.* Make sure your body can detoxify out all the toxic substances and toxic by-products of bodily processes properly. Stop as many toxins from getting in in the first place, and do a detoxification program to get rid of the ones you have. Stop doing or eating the things which cause inflammation and have a pro-oxidant effect, and so on.

3. *Reduce your body's total load.* The total load concept is that lessening the body's overall burden/work and stress level in one area, will improve health generally and improve the body's ability to heal because the body's total load (or burden) is lessened. Fixing one problem frees up bodily resources that can be then be used to help other parts of the body function getter or to heal.

As Andrew Saul PhD explains,

> Good nutrition and vitamins do not directly cure disease, the body does. You provide the raw materials and the inborn wisdom of your body makes the repairs. Someday healthcare without megavitamin therapy will be seen as we today see childbirth without sanitation or surgery without anaesthetic.

**Reducing the ‘total load’ of the body**

Ways we might start to reduce the burden on our bodies include the following:

1. An enormous amount of the energy our bodies use is focused on digesting our food. Taking digestive enzymes with meals reduces the workload of the pancreas and can also increase the amount of energy we get from the food we eat.

2. Taking Betaine HCl with meals, if your stomach acid levels are low, increases the
amount of energy you get from your food and makes fats and proteins less work for the body to digest.

For some people these supplements may be enough to improve digestion significantly, but if problems remain then they should be investigated further. Good gut health and the proper assimilation of food nutrients is essential to healing.

3. Eating foods that you can digest easily, as opposed to foods that your stomach has problems with, means that your body has to expend less energy digesting your meals. Cooked foods may be digested more easily than raw foods, soaked and dried nuts and seeds are digested more easily than raw nuts, meats that are not overcooked are easier to digest than overcooked meats that have become tough, and so on. If chewing is difficult one can also reduce the body’s digestive workload by whizzing foods up in a blender and/or taking in some of your daily vegetable intake in juice form.

Reducing chemical additives in foods is also important as these foods create extra detoxification work for the liver. If a person with M.E. spends the day resting as they know they need to but during the day also eats a packet of potato chips and a can of diet soda or soft drink then they are in effect giving with one hand and taking with the other. While doing this is better than overexerting and eating poor quality food, it amounts to only giving the body a partial rest at best.

4. Eat some of your daily fat intake as coconut oil as this oil is easily digested compared to other oils and does not have to be broken down by the liver.

5. Take probiotic supplements daily to improve your digestion and make sure you have as many good bugs as possible helping your body digest your food. It can also be very helpful to add fermented vegetable dishes such as sauerkraut to your meals as these foods are rich in enzymes and probiotics and are very easy to digest themselves as the fermenting process ‘pre-digests’ them in a way. A serve of probiotic rich kefir (a yogurt-like drink made from milk or coconut water) or homemade 24 hour yogurt can also serve the same purpose when added to a meal.

6. If your blood sugar levels can cope with it, don’t force yourself to eat if you don’t feel like eating until much later in the day than you would normally break your nightly fast. Missing a meal saves your body a lot of metabolic energy and lets your body use this energy for healing instead of digestion. Your body must have access to spare metabolic energy if it is to heal – healing is hard work!

7. Take the form of each supplement that your body has to work the least to absorb and assimilate. Your body has to work hard to convert many nutrients to their active forms. This process uses up bodily energy but also uses up bodily resources such as other vitamins and minerals. So when possible take the activated form of a nutrient or a real food sourced nutrient. For example, take activated folate instead of standard folate supplements, take a sublingual and coenzymated B complex product or a liposomal B complex product rather than a B complex tablet, take liposomal vitamin C instead of vitamin C tablets, take nascent iodine instead of iodine tablets, take
fermented cod liver oil instead of isolated vitamin A and D supplements. Where appropriate you may also take some supplements in powder form rather than in capsules, and squeeze out and ingest the contents of gel capsules rather than consuming the whole capsule.

8. Try to avoid nutrient deficiencies. Your body works best and most effortlessly when it has enough of all the basic components it needs to run properly. A deficiency in even one vital nutrient can place extra stress on all sorts of different bodily systems and set up a type of domino effect.

9. Cut right down on the amount of chemicals you are exposed to. The liver has to work harder every time you are exposed to or ingest a harmful chemical compound, and this process of detoxification also uses up valuable nutrients that the body has spent energy producing, such as glutathione.

This means changing the types of cleaning and personal care products you use and looking for less or non-toxic alternatives to many different products.

Remember that where you spend your time matters here as well. Chemicals can be taken in orally and through the skin but also through the nose. If you walk through a shopping centre of supermarket for 5 minutes you’ll have used up far more energy and nutrient reserves than if you’d walked for the exact same time period somewhere that isn’t overflowing with breathable toxic chemicals. If you can smell it, it is in your bloodstream Dr Sherry Rogers explains and your body has to then work hard to detoxify it.

10. Cut right down on the amount of allergens you are exposed to. Your body has to work harder every time you are exposed to or ingest something you are allergic to. This process of detoxification or inflammation also uses up valuable nutrients. Find out which foods you are allergic to and avoid them.

11. Buy a decent water filter. If you don’t your BODY will have to act as your water filter which again uses up a lot of metabolic energy and nutrients unnecessarily. Make sure to drink adequate water as well.

12. Start a detoxification regime to rid your body as much as possible of those substances that interfere with normal enzyme reactions in the body and other bodily processes. This might involve the use of various nutrients or the use of an FIR sauna.

13. Make sure to always avoid constipation. A long ‘transit time’ for faeces puts extra stress on the body and the body’s detoxification systems.

14. You might consider having a daily or weekly enema to reduce the load on your digestive system and reduce the amount of detoxification work the body has to do.

15. Don’t suppress symptoms unnecessarily if you are trying to heal. This is so important. Symptoms are your body’s attempts to heal and when you stop the
symptoms you also stop the healing.

For example, one might take a steroidal nasal spray to stop allergy symptoms such as runny nose, sneezing and watery eyes. But the sneezing and watery eyes and streaming nose are the body’s ways to try and get harmful substances out of the body as soon as possible and to water them down so they do less harm to sensitive tissues. The nasal spray may stop the symptoms but it does nothing at all to treat the actual cause of your symptoms. So using this drug creates a lot more work for the body as (a) Your body now has to cope with an allergen onslaught without using all the coping mechanisms it has developed to try and minimise the impact of the problem, (b) Your body now has extra work to do in detoxifying the drug you have taken and (c) Without the cues your body gives you of sneezing and watery eyes, you’re a lot more likely to have an even higher exposure to allergens than you would otherwise.

A better solution would be to first of all do all you can to minimise your exposure to the things you are allergic to. You might invest in an air filter or dust mite mattress protectors and dry your clothes indoors rather than outside where they would collect pollen. You might keep pets out of the room you sleep in at night and brush them often (or trim their hair to be shorter) so that they don’t shed so much hair all over the house, and wash your hands after touching them. You might make your bedroom an allergen free zone containing only the essential things you need to get through each night. You could also help by boosting your body’s supply of nutrients such as vitamin C, using a saline nasal spray throughout the day and using a netti pot to more quickly flush out your sinuses when allergy symptoms strike. Insufficient vitamin C makes suffering with allergy symptoms far more likely, as do other low nutrient levels.

Don’t automatically lower a fever with drugs, as fevers are one of the most common healing reactions that are seen and also play an important role in healing when we have the flu. Fevers should only be treated when medically necessary.

The body doesn’t just stupidly produce all sorts of symptoms for no reason. These symptoms have a cause and a purpose and may be playing an important role in stopping you from becoming more ill. The body can heal from all sorts of things if given the right tools and the right environment and this incredibly complex system – when properly resourced – is far more powerful than any drug.

If possible make yourself aware of the difference between the symptoms of a disease and healing reactions by reading papers such as: Symptom-based management vs. deep healing in M.E. and Recognising and managing healing reactions in M.E.

16. Take good care of yourself generally. Have good dental hygiene, eat good quality food (buy organic and free range chicken and eggs and organic grass-fed beef etc. if you can), minimise germ exposure as much as possible (by not seeing friends when they are ill, not by using toxic antibacterial sprays and wahses), don’t let your feet become cracked and prone to infections, practice good sleep hygiene, avoid hypoglycaemia, don’t use harsh and drying soaps, don’t smoke, don’t drink alcohol,
treat and clean any wounds you have properly, use good food hygiene, go outside and get some fresh air and sunshine for half an hour a day or more when you can, avoid sunburn, and so on. Don’t let your body waste any of its resources on anything that you could have avoided making it have to do, so it can put as much as possible into your healing from M.E.

17. Consider taking proteolytic enzymes systemically. Taken on an empty stomach these enzymes free up bodily energy and enzyme making ability for other healing related tasks.

18. Don’t go overboard on non-essential supplements. More is not better. Your body has to work to digest all those capsules and also to detoxify the substances in them. Take those supplements that your body needs to function before spending lots of time and money on herbs and other substances that are non-essential. It is no good taking extras like ginkgo or echinacea if part of why your body is having problems working well and healing is that you are severely deficient in vitamin B6 and magnesium and these deficiencies are stopping all sorts of important enzyme reactions from happening that are essential to good health, for example. The key to supporting the body's task of healing is not new and ever more exotic or specialised drugs or herbs, but a focus on all the nutrients we need to live and for our bodies to function optimally and to heal as much as is possible.

All these little things add up. It makes sense to do as many of them as you can in addition to working hard to minimise voluntary physical, cognitive and orthostatic overexertion and sensory input. It makes sense to at least do some of the easier ones, even if the idea of acting on all of the suggestions given feels very overwhelming.

Again, paying attention to these other factors may result in a slight reduction in disability levels, reduced symptom severity, reduced pain and suffering as well as a greater chance that the body will be able to heal some of the damage inflicted by the disease. Your body must have access to spare metabolic energy (and all the necessary nutrients) if it is to heal. Healing is hard work!

More information

- For more information on many of the topics discussed in this paper please see:
  o Symptom-based management vs. deep healing in M.E.
  o Recognising and managing healing reactions in M.E.
  o A quick start guide to treating and improving M.E. with aggressive rest therapy, diet, toxic chemical avoidance, medications, supplements and vitamins
  o Deep healing in M.E.: An order of attack
  o Food as medicine and M.E.
  o Toxin avoidance and M.E.
References
This paper is based on the information in books on orthomolecular, holistic or environmental medicine from experts such as Dr Sherry Rogers, Dr Lawrence Wilson, Dr Abram Hoffer and many others. To see lists of some of these books see the references list for the Symptom-based management vs. deep healing in M.E. or the book reviews pages titled Useful books on diet and nutrition and useful books on health, nutrition, supplements and vitamins.
Final comments and references
Useful sources of further information
- The book *The Clinical and Scientific Basis of M.E.* edited by Byron Hyde MD. Is absolutely essential for everyone who has M.E., or has an interest in M.E.

The Clinical and Scientific Basis of M.E. edited by Byron Hyde M.D.

This book contains the most comprehensive information available on the symptoms of M.E., the history of M.E. including a look at many of the outbreaks of the illness, epidemiology of M.E. (including the links with polio), issues of diagnosis, children with M.E., investigation, virology, immunology, muscle pathology, host response, food intolerance, brain mapping, neurophysiology, neuropsychology, sleep dysfunction and much more. This is a simply essential reference book for doctors, and M.E. patients, and easily surpasses all others of its type (as there really are no others of its type). All funds from the purchase of this 725-page encyclopaedia also benefit further research into the illness and assist in the promotion of greater understanding about M.E.

This book contains the accumulated knowledge of many of the worlds leading M.E. experts but the brilliant chapters written by Dr Hyde alone make this book worth the purchase price. This book cannot be recommended highly enough.

You may also like to read *A New and Simple Definition of Myalgic Encephalomyelitis* and *A New Simple Definition of Chronic Fatigue Syndrome & A Brief History of Myalgic Encephalomyelitis & An Irreverent History of Chronic Fatigue Syndrome* and *The Complexities of Diagnosis* by Byron Hyde M.D. (and more) available online. Dr Hyde’s latest paper is also a MUST-READ: *The Nightingale Definition of M.E.*
See the Book Reviews section for more information about both of these (and many other) books.

Other recommended sources of additional information include:

- If you are about to have surgery, read: Anaesthesia and M.E. and Hospital or carer notes for M.E. first.
- If you are severely disabled by M.E. you may like to read (or print out for your family, doctor or carer) the new paper: Why patients with severe M.E. are housebound and bedbound.
- To read a complete list of the articles and resources available on the site suitable for different groups – severe M.E. patients, M.E. patients, patients misdiagnosed with ‘CFS,’ doctors, friends and family of M.E. patients, carers and so on – see the Information Guides page.
- The papers by Dr Byron Hyde listed in the previous section, again, are all ESSENTIAL reading. Also highly recommended are papers by the brilliant Dr Dowsett (Both true M.E. experts in a world of ‘CFS’ and ‘ME/CFS’ and ‘subgroups of CFS’ compromise and selling out.) These two doctors are really the only ones listed on my recommended authors page that you can trust to be writing purely about M.E. in their various papers. Between them they have seen many thousands of individual M.E. patients, although unfortunately neither has created a publically available comprehensive guide to M.E. treatment as yet. Dr Hyde's latest paper however is a MUST-READ: The Nightingale Definition of M.E.
- Engaging with M.E. by Professor Malcolm Hooper contains an overview of some of the medical knowledge of M.E., including a detailed discussion of treatments for the illness. This is a valuable and useful resource for doctors and patients alike.
- Dr Paul Cheney in the US has over 20 years experience in treating M.E. and has seen thousands of M.E. patients. You can read about many of his theories and treatment recommendations for M.E. here. His latest lecture available on DVD – unfortunately not transcribed – includes an interesting section on treatment (although unfortunately, Dr Cheney cannot at all be recommended with regards to his grasp of the political situation surrounding M.E. and ‘CFS’ and so on. Nor on the aetiology of M.E. Much of the information Cheney produces on what he unfortunately calls ‘CFIDS’ relates to and refers to M.E. patients, but there are some significant exceptions, it seems). Cheney explains that like M.E., other neurodegenerative diseases such as Parkinson's, Alzheimer's and multiple sclerosis are also suspected of being driven partly by free radical formation. Cheney has recently made big changes to what supplements and drugs he recommends. He now DOES NOT recommend whey protein, D-ribose, glutathione, and CoQ10 (if you have been taking CoQ10 for some time with no noticeable benefit). Treatments recommended include: IM magnesium, B12 injections, Inosine, as well as Omega 3s from fish oil, plus Artesunate - an anti-malarial drug, cell signaling factors, gut dysbiosis treatments (probiotics, digestive enzymes, diet) and in some cases, stem cell infusion. Dr Cheney advises that
patients stop taking a supplement if it is not causing noticeable benefits as it may be causing harm.

- To learn more about the mitochondrial defects in M.E. see: United Mitochondrial Disease Foundation (go to the treatments page) and The Heart of the Matter: CFS and Cardiac Issues from Dr Paul Cheney. To see some of the abundance of M.E. mitochondrial research available see Mitochondrial Muscle Research.

- Click here to read about Dr Martin Pall’s protocol/products which aim to promote down-regulation of the NO/ONOO cycle, or see his most recent book etc. Supplements recommended include: CoQ10, DHLA, vitamin E, AL Carnitine, carotenoids, milk thistle extract, bilberry, ginkgo leaves, grape seed extract, green tea and hawthorn, as well as Omega 3s from fish oil.

  (It is important to note however that Pall should not be considered an M.E. expert and that when he refers to ‘CFS’ this information should not be assumed to apply in whole or in part to M.E. Some of what he is saying generally may possibly be relevant to M.E. patients to some extent (as regards treatment, rather than symptomatology or aetiology, as it does with multiple sclerosis for example), but this is as yet unclear due to the fact he unfortunately makes no distinction between fatigue and ‘CFS’ and the distinct neurological disease M.E. M.E. is NOT at all a medically unexplained illness, and has little in common with the conditions Pall claims ‘share many symptoms and often occur together’ such as PTSD and MCS and Fibromyalgia – unlike ‘CFS.’ As Pall claims, ‘CFS’ (or rather, those illnesses which are misdiagnosed as ‘CFS’) can be caused by many different things including bacterial infections, psychological stress and physical trauma but this makes it very clear that when Pall refers to ‘CFS’ he is not referring to genuine M.E. Anyone who describes an illness that is based on fatigue, is medically unexplained, has symptoms similar to Fibromyalgia or PTSD etc., and that can be caused by many different things such as trauma, physical and emotional stress and bacterial infection and common virus infections such as EBV or herpes etc., IS NOT REFERRING TO M.E. and is not knowledgeable about even the most basic facts of M.E. The research is very clear that M.E. is not (and cannot) be caused by stress, trauma or bacterial infections and so on. M.E. is caused by a virus, an enterovirus and is primarily a testable and measurable neurological disease with many distinct features and unique symptoms. For more information see the ‘What is M.E.?: Summary’ reprinted below.)

- You might find it useful to learn more about health and the role of nutrition, vitamins and antioxidants generally, rather than just sticking to purely M.E. based information. Books such as The NEW optimum nutrition bible, Dr Atkins Vita-Nutrient Solution: Nature's Answer to Drugs and Good Health in the 21st Century can provide useful simple overviews (although you should ignore 100% of anything they have to say about treating ‘CFS’ as this will be irrelevant or inappropriate with regards to M.E.). These books are also useful for letting you know which vitamins etc. are in which foods, and what is the safe amount of each vitamin and mineral etc. and so on.

- I’d also highly recommend: The Overlooked Role of Chronic Infection in Neurodegeneration and Its Reversal Using Nutraceutical Agents. For more on neurodegeneration see also: Metabolism Mitochondria and ME and Mitochondrial...
Treating M.E.: The basics

Muscle research and general muscle research and Neurological and cognitive research. For useful information about treating problems such as thyroid disease, neurological diseases such as MS, cardiac disease, candida etc. with nutritional and herbal medicine, you may find LEF’s Disease prevention and treatment book useful, although of course the section on ‘CFS’ is of a poor quality and is not recommended. This book also contains useful information about safety issues with certain supplements.

- Some of the best books which contain stories of the experiences of individual M.E. sufferers, and which really explain what living with M.E. is like from a patients point of view, are the books Stricken edited by Peggy Munson and Shattered: Life with ME by Lynn Michell. Both are highly recommended. See also In the Shadow of Memory and The Night Side by Floyd Skloot which detail the author’s own experiences with M.E.

- Some of the best sources of individual stories and opinions of M.E. sufferers available online are listed in the Case studies section.

- Myalgic Encephalomyelitis Research and Articles – A collection of literally HUNDREDS of some of the best M.E. research and articles, from some of the worlds leading researchers, doctors and M.E. advocates.

- For those that have trouble reading (and prefer listening) see the new Audio and Video page. This paper is now available in audio and video form, among others.


M.E. and children

Tragically, children as young as 5 (or in rare cases even as young as three) can be affected by M.E. There is a real need for more information and research on M.E. specifically geared to children as currently very little is available but some additional resources parents or carers of M.E. children may find useful, include: A Parents Guide to CFIDS by David S. Bell MD. Books which have a significant chapter on M.E. and children in them include: The Doctor's Guide to CFS by David S. Bell MD, The Clinical and Scientific Basis of M.E. edited by Byron Hyde MD., CFS: A Treatment Guide by Verillo and Gellman, ME: The New Plague by Jane Colby and Shattered: Life with ME by Lynn Michell. (Note that although incorrect and confusing terminology is bafflingly and unfortunately used in some of these books, these books do relate primarily if not totally to M.E.)

A small collection of relevant articles are also available on the: M.E. and Children page.
Note that information given in this paper on dosages (and amounts of water and food intake) are aimed at adults and are not suitable for children in many cases. Children will often require much lower doses compared to adults, or some supplements and drugs may not be suitable at all for children. If you are the parent of a child with M.E. you will need to look into what the appropriate dosages are for children for each supplement.

‘Information’ sources to avoid:
Unfortunately when it comes to information on M.E. there is always far more bad than good available and so it is just as important that you are aware of what information to avoid as well as what is useful. The ME books best avoided section contains a list of books which are not recommended because they; do not distinguish appropriately (or at all) between mere fatigue and the neurological disease M.E., offer inappropriate medical advice which may help some fatigue sufferers but is inappropriate or dangerous for people with M.E., offer unrealistic expectations of response to treatment and recovery based on confusion with mere fatigue sufferers, or they propagate many of the myths and propaganda about the illness which do the M.E. cause (and community) so much harm.

Add to this list of resources to avoid, any book, website, newsletter, TV segment, radio segment, newspaper article, research – or anything else that; uses the term ‘chronic fatigue’ in the title, or which uses the term ‘chronic fatigue’ interchangeably with CFS or CFIDS or M.E. anywhere in the text, which claims that the illness is a new 21st Century disease caused by the ‘busy stressful modern world’ or your supposed perfectionist personality (even if you happen to have one it’s irrelevant and didn’t cause you to get M.E.), or which claims that the illness can be easily cured with exercise, psychotherapy, stress reduction, an anti-Candida diet, various vitamins and other treatments or anything else. (Titles like ‘From Fatigued to Fantastic’ should set all your alarm bells ringing!)

Also avoid anything which talks about M.E. being: ‘mysterious’ or ‘medically unexplained’ or ‘an amazing illness which crosses the boundaries between the body and the mind,’ of having no tests which can aid diagnosis, of even being an illness where ‘no tests have ever shown anything,’ or which claims that the illness is a problem of fatigue following glandular fever, or that the illness is caused by the Epstein-Barr virus, herpes, glandular fever or Candida, can be caused by stress or trauma, or is the same illness as Fibromyalgia or Lyme disease anything else. These are all just useless and harmful ‘CFS’ myths and propaganda; they have nothing to do with authentic M.E. and legitimate science.

For more on some of the most common myths of M.E. see M.E. Activism and Advocacy, The myths about Myalgic Encephalomyelitis and Research and Articles in Context. See also: What is M.E.?, and M.E. books best avoided
Permission is given for this document to be freely redistributed by e-mail or in print for any not-for-profit purpose provided that the entire text (including this notice and the author’s attribution) is reproduced in full and without alteration.

Acknowledgments: A big thank you to all the M.E. sufferers who were kind enough to give me their feedback, opinions and advice on many of the subjects discussed in this text as I was writing it, you know who you are! A big thank you especially to Lesley, Jo and Peggy. If you have any further suggestions for this paper, please send them by email.

References: The following references have been used to compile the majority of the treatments section:

1. Papers and lectures by Dr Richardson, Dr Byron Hyde, Professor Malcolm Hooper, and Dr Paul Cheney. The United Mitochondrial Disease Foundation. Plus books such as: The Clinical and Scientific Basis of Myalgic Encephalomyelitis and Verillo and Gellman’s Treatment Guide.

2. General health books such as Good Health in the 21st Century, The NEW optimum nutrition bible, LEF’s Disease prevention and treatment, The Anti-Inflammation Zone, The Brainpower Plan, Dr Atkins Vita-Nutrient Solution: Nature’s Answer to Drugs, Orthomolecular Medicine For Everyone: Megavitamin Therapeutics for Families and Physicians by Abram Hoffer, Fire your doctor! : how to be independently healthy and Doctor yourself : natural healing that works by Andrew W. Saul, plus Ascorbate: The Science of Vitamin C by Dr Hickey and Dr Roberts, How to live longer and feel better by Linus Pauling and VITAMIN C: The Real Story by Steve Hickey, PhD and Andrew Saul.


Details about the VRP affiliate program
If you use one of the VRP links in this paper and make a purchase from the VRP site (or if you make a purchase from VRP and type in my affiliate number of 647871 when you order) 15% of the total cost of your order will be donated. Funds raised will go 100% to the HFME.

This offer applies to new VRP customers only. It applies to all VRP products, but only for one year from your first date of purchase (after one year I’ll no longer receive 15% of the cost of your order). It is probably best to type in the affiliate
number of 647871 in the appropriate box when you order, even of you have used one of the links here (just in case I’ve made a mistake with any of the links).

(Also note that VRP do discounts of up to 30% per order if you buy in bulk).

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If you are a new customer to iHerb, and you put in the HFME code when you order, you get $5 off your first order, and (as explained above) 4% of your order total for the next year will be donated. Funds raised will be split evenly between The Nightingale Research Foundation and HFME. iHerb sells everything from neti pots, to NADH, to ubiquinol and their international postage charges are very reasonable. The code is JOD573 and the website is www.iherb.com

**Affiliate program notes**
Of course patients must always buy the supplements from the store most appropriate and convenient to them, and with the best prices and range. To do otherwise is not recommended or even supported by the HFME. Details are included of these two affiliation schemes for the use of those patients who had chosen to use these companies anyway. It should also be noted that the information on HFME is never influenced in any way by these affiliation schemes, and that the monies raised by them are very small in comparison to the funds donated to HFME by the author (Jodi Bassett).

**Final comments:**
Living with and coping with M.E. is no easy feat and so of course it is impossible to cover everything you could need to know in these fifty or so pages (or even three hundred and fifty pages) but hopefully every M.E. sufferer and every parent of a child with M.E. reading this will have found something here that perhaps you were not aware of before, and that is helpful in some way.

The treatments listed here are not any type of miracle cure, and no promises can be made about outcomes; that treatment a, b and c together will always give you outcome d. The aim here is to give your body its best possible chance to at least partly heal itself by giving it some of the basic tools and materials it needs in order to heal. No level of improvement is guaranteed, just the best chance there is at achieving the level of improvement possible for YOU - and lowered risk of developing secondary diseases.

The message here is not to reject every part of mainstream medicine, and that you don’t need a doctor and can do everything yourself. It’s about coming at the problem of M.E. from all sides. It’s a huge problem and we need to throw everything at it that we can, all at once! We need to make sure we work in partnership with our doctors (if at all possible). Listening to what they say and getting any tests necessary and so on, while also making sure our bodies have all the extra vitamins and minerals they need.
to heal and to prevent secondary diseases, and that we also do all those things which are so important to our health but which are out of our doctor’s hands. In M.E. that means aggressive rest therapy, minimising stress, eating a good diet, avoiding toxic chemical exposures and so on.

Don’t let anyone tell you ‘there is nothing at all that can be done’ to treat M.E. What you do can have an enormous – positive or, unfortunately, negative – impact on the course of your disease. You are not completely powerless here, not at all.

The very best of luck – and health – to you all.

**Relevant quotes:**

In newspapers, magazines and on television, the public has been warned off the very vitamins and other supplements that have been repeatedly proven to reduce illness in practically every instance. The effective use of food supplements and natural diet saves money, pain and lives... and you have been told not to do it. If you want something done right you have to do it yourself. This especially includes your healthcare. One of the most common questions about vitamin therapy is, are huge doses safe? This book will help answer that question once and for all, and while we are at it, here’s the answer in advance. Yes. Megadoses of vitamins are very safe. Vitamins do not cause even one death per year. Pharmaceutical drugs, taken as directed, cause over 100 000 deaths annually. Still it is granted that we need access to all the tools that medicine and technology can provide, when used with caution. We must also fully use our natural resources of therapeutic nutrition and vitamins. To limit ourselves to pharmaceutical medicine is like going into the ring to fight the champ with one hand tied behind our backs. Andrew Saul PhD in ‘Fire your doctor: How to be independently healthy’ 2005

Most people’s fear of self-care centres on three common fallacies.

1. You are not educated enough to treat yourself, that is what doctors are for
2. Natural therapies are not powerful enough to cure real diseases
3. Megavitamin therapy is dangerous

These are not facts, these are beliefs, and they are all unfounded. Jazz musician Eubie Blake said it best “It is not what we don’t know that harms us, but what we do know that ain’t so”. If your doctor does not believe in using vitamins, not only is that doctor behind the times, that doctor is not being scientific. Therapeutic nutrition is not a matter of belief; it is a matter of confirmed clinical experience. Belief systems can be wrong.

Modern drug based medicine is as incomplete as a novel written with three vowels. As discordant as a symphony constructed using only some of the notes. High dose nutritional therapy is the much needed missing part of our vocabulary of healthcare. The fight against disease needs all the help it can get. Andrew Saul PhD in ‘Fire your doctor: How to be independently healthy’ 2005
“Modern medicine is not scientific, it is full of prejudice, illogic and susceptible to advertising. Doctors are not taught to reason, they are programmed to believe in whatever their medical schools teach them and the leading doctors tell them. Over the past 20 years the drug companies, with their enormous wealth, have taken medicine over and now control its research, what is taught and the information released to the public.” Abram Hoffer MD

“Modern drug based medicine is as incomplete as a novel written with three vowels. As discordant as a symphony constructed using only some of the notes. High dose nutritional therapy is the much needed missing part of our vocabulary of healthcare. The fight against disease needs all the help it can get.” Andrew Saul PhD in ‘Fire your doctor: How to be independently healthy’ 2005

I have seen the foolishness of conventional disease care wisdom. I have seen hospitals feed white bread to patients with bowel cancer and hospitals feed "Jello" to leukemia patients. I have seen schools feed bright red "Slush Puppies" to 7 year olds for lunch and I have seen children vomit up a desk-top full of red crud afterwards. And, I have seen those same children later line up at the school nurse for hyperactivity drugs.

I have seen hospital patients allowed to go two weeks without a bowel movement. I have seen patients told that they have six months to live when they might live sixty months. I have seen people recover from serious illness, only to have their physician berate them for having used natural healing methods to do so. I have seen infants spit up formula while their mothers were advised not to breast feed. I've seen better ingredients in dog food than in the average school or hospital lunch.

And I have seen enough. Andrew Saul PhD.

Good nutrition and vitamins do not directly cure disease, the body does. You provide the raw materials and the inborn wisdom of your body makes the repairs. Someday healthcare without megavitamin therapy will be seen as we today see childbirth without sanitation or surgery without anaesthetic. Andrew Saul PhD in ‘Fire your doctor: How to be independently healthy’ 2005

If we doctors threw all our medicines into the sea, it would be that much better for our patients and that much worse for the fishes. Oliver Wendell Holmes, M.D.

There is virtually no funding for pharmaceutical companies to fund vitamin research. Why is that? Because there is no money for them in a cheap, non-prescription cure which already exists and cannot be patented. For decades, nutritionists and dieticians have preached tat vitamin and mineral supplements are not needed if you just eat a balanced diet. It is a nice story, but it is only a story. Daily supplements are the only way Americans can possibly get the 800 IU of vitamin e per day, the amount that prevents most cardiovascular disease. Daily supplements are the only way to get several thousands milligrams of vitamin C per day, the amount that is protective against many forms of cancer. Nutritional deficiency is the rule not the exception in America. It is simply not enough to keep cholesterol and saturated fat out of your
diet, you have to put something good in. Andrew Saul PhD in ‘Fire your doctor: How to be independently healthy 2005

When pharmaceuticals are versatile, they are called ‘broad spectrum’ and ‘wonder drugs.’ When vitamins are versatile, they are called ‘faddish’ and ‘cures in search of a disease.’ Such a double standard needs to be exposed and opposed at every turn. People often ask, ‘if vitamin therapy is so good, why hasn’t my doctor told me about it?’ I do not know the answer to that question. Quite frankly, over time, I have grown to be less and less fired-up about even wanting to know. There are too many sick people that need positive help. Andrew Saul PhD in ‘Fire your doctor: How to be independently healthy 2005

Vitamin C is the world’s best natural antibiotic, antiviral, antitoxin and antihistamine. This book’s recurring emphasis on vitamin C might suggest that I am offering a song with only one verse. Not so. As English literature concentrates on Shakespeare, so orthomolecular (megavitamin) therapy concentrates on vitamin C. Let the greats be given their due. The importance of vitamin C cannot be overemphasised. Andrew Saul PhD in ‘Fire your doctor: How to be independently healthy 2005

The degree of physical incapacity varies greatly, but the [level of severity] is directly related to the length of time the patient persists in physical effort after its onset; put in another way, those patients who are given a period of enforced rest from the onset have the best prognosis. Dr Melvin Ramsay on M.E.

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This paper will be continue to be updated regularly (at least annually and often monthly). Please check back at the website periodically to make sure that you have the most up-to-date version of this paper available.
Myalgic Encephalomyelitis (M.E.) is a debilitating acquired neurological disease that has been recognised by the World Health Organisation (WHO) since 1969 as a distinct organic neurological disorder. M.E. can occur in both epidemic and sporadic forms; over 60 outbreaks of M.E. have been recorded worldwide since 1934.

M.E. is similar in a number of significant ways to Multiple Sclerosis, Lupus and Poliomyelitis (Polio). It can become extremely severe and disabling and in some cases is fatal.

Is M.E. a new illness?
No. The illness has been documented as an organic (physical) neurological disease for centuries. The name Myalgic Encephalomyelitis was coined in 1956 in the UK.

M.E. has nothing to do with ‘fatigue’
Unlike ‘Chronic Fatigue Syndrome’ (CFS) M.E. is a neurological illness of extraordinarily incapacitating dimensions that affects virtually every bodily system. Fatigue is not a defining (or essential) symptom of M.E. M.E. and ‘CFS’ are not at all the same thing.

Why do some groups claim that M.E. and ‘CFS’ are synonymous terms?
This new name and case definition of ‘CFS’ was created in the United States by a board of 18 members, few of which had either looked at an epidemic of M.E. or examined any patients with the illness.

Why? Money! In the late 1970s and 1980s there was an enormous rise in the reported incidence of M.E. causing alarm among American medical insurance companies. It was at this time when, in order to side-step the financial responsibility of the many new incoming claims, those involved in the medical insurance industry (on both sides of the Atlantic) began their campaign to reclassify this severely incapacitating and discrete neurological illness as a psychological or ‘personality’ disorder. As Professor Hooper explains:

A political decision was taken to rename M.E. as “CFS”, the cardinal feature of which was to be chronic or on going “fatigue”, a symptom so universal that any insurance claim based on “tiredness” could be expediently denied. The new case definition bore little relation to M.E.: objections were raised by experienced international clinicians, but all objections were ignored.
Public, medical and governmental understanding of M.E. is a huge mess, that is for certain – but it is not an accidental mess. (For more information see: Who benefits from 'CFS' and 'ME/CFS'?)

**What does a diagnosis of ‘CFS’ actually mean?**

Those diagnosed using the flawed ‘CFS’ definitions are from a heterogeneous (mixed) population with various misdiagnosed psychiatric and miscellaneous non-psychiatric states that have little in common except the symptom of fatigue. The fact that a person qualifies for a diagnosis of ‘CFS’ based on any of the ‘CFS’ definitions (a) does not mean the patient has M.E., and (b) does not mean she or he has any other distinct and specific illness named ‘CFS.’ A diagnosis of ‘CFS’ – based on any of the ‘CFS’ definitions – can only ever be a misdiagnosis.

**What is M.E.? What is its symptomatology?**

M.E. is characterised primarily by damage to the central nervous system (the brain) initiated by an enteroviral infection that results in dysfunctions and damage to many of the body’s vital systems as well as a loss of normal internal homeostasis.

M.E. symptoms are manifested by virtually all bodily systems including: cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, gastrointestinal and musculo-skeletal dysfunctions and damage. These symptoms are exacerbated by physical and cognitive activity, sensory input and orthostatic stress beyond the individual’s limits. In addition to the risk of relapse, repeated or severe overexertion can also cause permanent damage (e.g. to the heart), disease progression and/or death. Symptoms of M.E. include:

Sore throat, chills, sweats, low body temperature, low grade fever, lymphadenopathy, muscle weakness (or paralysis), muscle pain, muscle twitches or spasms, hair loss, nausea, vomiting, vertigo, cardiac arrhythmia, orthostatic tachycardia, orthostatic fainting or faintness, photophobia and other visual and neurological disturbances, hyperacusis, alcohol intolerance, gastrointestinal and digestive disturbances, allergies and sensitivities to many previously well-tolerated foods, drug sensitivities, stroke-like episodes, nystagmus, difficulty swallowing, myoclonus, temporal lobe and other types of seizures, an inability to maintain consciousness for more than short periods at a time breathing difficulties, emotional lability and sleep disorders. Cognitive dysfunction may be pronounced and can include: difficulty/loss of ability in speaking or understanding speech; difficulty in reading, writing or performing basic mathematical tasks as well as having problems with memory including difficulty making new memories and recalling formed memories; difficulties with visual and verbal recall.

**What does cause M.E.? Are there outbreaks?**

A review of early outbreaks in the history of M.E. shows clinical symptoms were consistent in over 60 recorded epidemics spread all over the world as far back as 1934. M.E. is an acutely acquired neurological illness initiated by a viral (enteroviral) infection with a 4-7 day incubation period. This point of view is supported by history,
incidence, symptoms and similarities with other viral illnesses as well as a large body of research.

**So what do we know about M.E. so far?**

There is an abundance of research that shows M.E. is an organic illness that can have profound effects on many bodily systems. Many aspects of the pathophysiology of the disease have been medically explained, and to date there are volumes of articles written, from which more than a thousand good articles support the basic premise of M.E. While there is yet no single laboratory test able to diagnose M.E., there are a specific series of tests which enable an M.E. diagnosis to be easily confirmed; i.e. MRI and SPECT scans of the brain.

Some of the abnormalities found in M.E. patients include: extremely low circulating blood volume (up to an astounding 50%), enzyme pathway disruptions, punctate lesions in M.E. brains resembling those of Multiple Sclerosis; sub-optimal cardiac function and abnormal cardiovascular responses; persistent viral infection in the heart, severe mitochondrial defects and significantly reduced lung functioning.

Also, strong evidence exists to show (even mild or moderate) exercise can have extremely harmful effects on M.E. patients; permanent damage may be caused as well as disease progression and even death. For this reason, danger exists when medical professionals recommend (and sometimes insist on or even force) M.E. patients, including children, to partake in exercise as a treatment to their diagnosis of ‘CFS.’ Under these harmful circumstances, the M.E. patient is undergoing what amounts to actual legalized torture. Patient accounts of exiting exercise programs much more severely ill than when they entered them, being wheelchair-bound, bed-bound or needing intensive care are common. Deaths have also been reported in M.E. patients following exercise.

**How common is M.E. and who gets it?**

M.E. has a similar strike rate to Multiple Sclerosis. M.E. affects more than one million children as young as five, as well as teenagers and adults. It affects all ethnic and socio-economic groups, and has been diagnosed all over the world.

**Recovery from and severity of M.E.**

M.E. can be progressive, degenerative (change of tissue to a lower or less functioning form, as in heart failure), chronic, or relapsing and remitting. It can also be fatal. Patients who are given advice to rest in the early stages of the illness (and who avoid overexertion thereafter) have repeatedly been shown to have the most positive long-term prognosis. M.E. is a life-long disability where relapse is always possible. Symptoms are extremely severe for at least 30% of sufferers leaving many of them housebound, bedbound and severely disabled.

**Truly M.E. can be one of the most devastating and horrific illness there is,** yet many with M.E. are subject to repeated medical abuse and neglect because of the way the illness has been dishonestly ‘marketed’ to the public as being psychological or ‘behavioural,’ or as being a problem of mere ‘fatigue’ or a ‘fatigue syndrome.’
Sub-grouping or refining or renaming ‘CFS’ will only waste another 20 years. There is no such distinct disease/s as ‘CFS.’ For the benefit of all the patient groups involved, the bogus disease category of ‘CFS’ must be abandoned and patients with M.E. must again be diagnosed with M.E. and treated for M.E. Due to an overwhelming amount of compelling scientific evidence, in 1969 the World Health Organization correctly classified M.E. as a distinct organic neurological disease. This classification/definition and name must be accepted and adhered to in all official documentations and government policy.

PLEASE help to spread the truth about Myalgic Encephalomyelitis. This appalling abuse and neglect of so many severely ill and vulnerable people on such an industrial scale is inhumane and has already gone on far too long. This will only change through education. People with M.E. desperately need your help.

- For more information, and for references, see the full-length (or extra extended) version of What is M.E.?
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References
All of the information concerning Myalgic Encephalomyelitis on this website is fully referenced and has been compiled using the highest quality resources available, produced by the world's leading M.E. experts. More experienced and more knowledgeable M.E. experts than these – Dr Byron Hyde and Dr. Elizabeth Dowsett in particular – do not exist. From the 1950s to the present day, Dr Byron Hyde and Dr. Elizabeth Dowsett along with their mentors, the late Dr John Richardson and Dr Melvin Ramsay (respectively). Collectively, these four doctors have been involved with M.E. research and M.E. patients for well over 100 years. Among them they have examined more than 15 000 individual (sporadic and epidemic) M.E. patients as well as each authoring numerous studies and articles and books (or chapters in books) on M.E. As stated previously, more experienced, more knowledgeable and more credible M.E. experts than these simply do not exist.

This paper is merely intended to provide a brief summary of some of the most important facts of M.E. It has been created purely for the benefit of those people without the time, inclination or ability to read each of these far more detailed and lengthy references created by the world’s leading M.E. experts. The original documents used to create this paper are essential additional reading however for any physician (or anyone else) with a real interest in Myalgic Encephalomyelitis. See: What is M.E.? or the References page. A partial reference list follows:

Acknowledgments: Edited by Roseanne Schoof.

“People in positions of power are misusing that power against sick people and are using it to further their own vested interests. No-one in authority is listening, at least not until they themselves or their own family join the ranks of the persecuted, when they too come up against a wall of utter indifference.’ Professor Hooper 2003

‘Do not for one minute believe that CFS is simply another name for Myalgic Encephalomyelitis (M.E.). It is not. The CDC definition is not a disease process. It is (a) a partial mix of infectious mononucleosis / glandular fever, (b) a mix of some of the least important aspects of M.E. and (c) what amounts to a possibly unintended psychiatric slant to an epidemic and endemic disease process of major importance’ Dr Byron Hyde 2006

The term myalgic encephalomyelitis (means muscle pain, my-algic, with inflammation of the brain and spinal cord, encephalo-myel-itis, brain spinal cord inflammation) was first coined by Ramsay and Richardson and has been included by the World Health Organisation (WHO) in their International Classification of Diseases (ICD), since 1969. It cannot be emphasised too strongly that this recognition emerged from meticulous clinical observation and examination. Professor Malcolm Hooper 2006

M.E. is a systemic disease (initiated by a virus infection) with multi system involvement characterised by central nervous system dysfunction, which causes a breakdown in bodily homoeostasis. It has an UNIQUE Neuro-hormonal profile. Dr Elizabeth Dowsett

Dr Melvin Ramsay on Myalgic Encephalomyelitis: "The degree of physical incapacity varies greatly, but the [level of severity] is directly related to the length of time the patient persists in physical effort after its onset; put in another way, those patients who are given a period of enforced rest from the onset have the best prognosis."

The vested interests of the Insurance companies and their advisers must be totally removed from all aspects of benefit assessments. There must be a proper recognition that these subverted processes have worked greatly to the disadvantage of people suffering from a major organic illness that requires essential support of which the easiest to provide is financial. The poverty and isolation to which many people have been reduced by ME is a scandal and obscenity. Professor Malcolm Hooper 2006

‘Thirty years ago when a patient presented to a hospital clinic with unexplained fatigue, any medical school physician would search for an occult malignancy, cardiac or other organ disease, or chronic infection. The concept that there is an

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entity called chronic fatigue syndrome has totally altered that essential medical
guideline. Patients are now being diagnosed with CFS as though it were a disease. It
is not. It is a patchwork of symptoms that could mean anything’ Dr Byron Hyde 2003
Myalgic Encephalomyelitis (M.E.) is a disabling neurological disease that is very similar to Multiple Sclerosis (M.S.) and Poliomyelitis. Earlier names for M.E. were ‘atypical Multiple Sclerosis’ and ‘atypical Polio.’

M.E. is a neurological disease characterised by scientifically measurable post-encephalitic damage to the brain stem. This damage is an essential part of M.E., hence the name M.E. The term M.E. was coined in 1956 and means: my = muscle, algic = pain, encephalo = brain, mye = spinal cord, tis = inflammation. This neurological damage has been confirmed in autopsies of M.E. patients.

Myalgic Encephalomyelitis has been recognised by the World Health Organisation’s International Classification of Diseases since 1969 as a distinct organic neurological disease. M.E. is classified in the current WHO International Classification of Diseases with the neurological code G.93.3.

M.E. is primarily neurological, but also involves cognitive, cardiac, cardiovascular, immunological, endocrinological, metabolic, respiratory, hormonal, gastrointestinal and musculo-skeletal dysfunctions and damage. M.E. affects all vital bodily systems and causes an inability to maintain bodily homeostasis. More than 64 individual symptoms of M.E. have been scientifically documented.

M.E. is an acute (sudden) onset, infectious neurological disease caused by a virus (a virus with a 4-7 day incubation period). M.E. occurs in epidemics as well as sporadically and over 60 M.E. outbreaks have been recorded worldwide since 1934. There is ample evidence that M.E. is caused by the same type of virus that causes Polio; an enterovirus.

M.E. can be more disabling than M.S. or Polio, and many other serious diseases. M.E. is one of the most disabling diseases that exists. More than 30% of M.E. patients are housebound, wheelchair-reliant and/or bedbound and are severely limited with even basic movement and communication.

Why are M.E. patients so severely and uniquely disabled? For a person to stay alive, the heart must pump a certain base-level amount of blood. Every time a person is active, this increases the amount of blood the heart needs to pump. Every movement made or second spent upright, every word spoken, every thought thought, every word read or noise heard requires that more blood must be pumped by the heart.
However, the hearts of M.E. patients only barely pump enough blood for them to stay alive. Their circulating blood volume is reduced by up to 50%. Thus M.E. patients are severely limited in physical, cognitive and orthostatic (being upright) exertion and sensory input.

This problem of reduced circulating blood volume, leading to cardiac insufficiency, is why every brief period spent walking or sitting, every conversation and every exposure to light or noise can affect M.E. patients so profoundly. Seemingly minor 'activities' can cause significantly increased symptom severity and/or disability (often with a 48-72 hour delay in onset), prolonged relapse lasting months, years or longer, permanent bodily damage (e.g. heart damage or organ failure), disease progression or death.

If activity levels exceed cardiac output by even 1%, death occurs. Thus the activity levels of M.E. patients must remain strictly within the limits of their reduced cardiac output just in order for them to stay alive. M.E. patients who are able to rest appropriately and avoid severe or prolonged overexertion have repeatedly been shown to have the most positive long-term prognosis.

- M.E. is a testable and scientifically measurable disease with several unique features that is not difficult to diagnose (within just a few weeks of onset) using a series of objective tests (e.g. MRI and SPECT brain scans). Abnormalities are also visible on physical exam in M.E.
- M.E. is a long-term/lifelong neurological disease that affects more than one million adults and children worldwide. In some cases M.E. is fatal. (Causes of death in M.E. include heart failure.)

For more information, and to read a fully-referenced version of this text compiled using information from the world’s leading M.E. experts, please see: What is M.E.? Extra extended version. Permission is given for this unedited document to be freely redistributed. Please redistribute this text widely.