# Table of contents

**Practical tips for living with M.E.**

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Table of contents</td>
<td>1</td>
</tr>
<tr>
<td>Treating and living with M.E.: Overview/introduction</td>
<td>3</td>
</tr>
<tr>
<td>Treating and living with M.E. – Part 2</td>
<td>6</td>
</tr>
<tr>
<td>Practical tips for living with M.E.</td>
<td>13</td>
</tr>
<tr>
<td>Tips for coping with M.E. emotionally</td>
<td>20</td>
</tr>
<tr>
<td>Assisting the M.E. patient in having blood taken for testing</td>
<td>34</td>
</tr>
<tr>
<td>Assisting the M.E. patient in managing bathing and hair-care tasks</td>
<td>36</td>
</tr>
<tr>
<td>Assisting the M.E. patient in managing toileting tasks</td>
<td>42</td>
</tr>
<tr>
<td>Tips for M.E. patients that are parents</td>
<td>44</td>
</tr>
<tr>
<td>Assisting the M.E. patient in the use of computers and technology</td>
<td>46</td>
</tr>
<tr>
<td>Assisting the M.E. patient in managing relapses and adrenaline surges</td>
<td>53</td>
</tr>
<tr>
<td>Assisting the M.E. patient in managing relapses and adrenaline surges: Summary</td>
<td>65</td>
</tr>
<tr>
<td>Tips on resting for M.E. patients: part 1</td>
<td>67</td>
</tr>
<tr>
<td>Tips on resting for M.E. patients: part 2</td>
<td>71</td>
</tr>
<tr>
<td>Deep healing in M.E.: An order of attack!</td>
<td>76</td>
</tr>
<tr>
<td>Buying, cooking and preparing food is so hard (or impossible) and makes me so much more ill, how can I try to minimise this?</td>
<td>84</td>
</tr>
<tr>
<td>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?</td>
<td>87</td>
</tr>
<tr>
<td>Finding a good doctor when you have M.E.</td>
<td>90</td>
</tr>
<tr>
<td>Finding a good doctor when you have M.E. – Part 2</td>
<td>99</td>
</tr>
<tr>
<td>Anaesthesia and M.E.</td>
<td>103</td>
</tr>
<tr>
<td>The HFME reminders and cognitive tips list</td>
<td>115</td>
</tr>
</tbody>
</table>
For more information about M.E. treatment, history, diagnosis and more, please see the HFME website or browse the other HFME printed or digital books available from Amazon or Lulu. The book by Jodi Bassett ‘Caring for the M.E. Patient’ is highly recommended for all M.E. patients.

For more information on the treatment of M.E. and improving symptoms please visit Jodi Bassett’s new Health, Healing & Hummingbirds website.

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**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.

“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

“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

‘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.

“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

“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
Treating and living with M.E.: Overview/introduction

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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 ways as powerful as 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 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.
1...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.
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 on M.E. treatment by HFME or HHH 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.
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 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 the Health, Healing & Hummingbirds website.

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 the Health, Healing & Hummingbirds website.

8...Look into treatments for M.E.: More information
For a detailed look at treating and reversing symptoms of disease please visit the Health, Healing & Hummingbirds website.

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
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
- General and M.E. specific treatment cautions given on the Health, Healing & Hummingbirds website.
- XMRV, 'CFS' and M.E.

10...Learn to avoid and minimise stress: More information
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.

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 the section on treating mental health problems with nutrition see the Health, Healing & Hummingbirds website 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 a very high carb diet 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.
The single most important tip for living with M.E. is to avoid overexertion. This is just so important. There is nothing to be gained by pushing yourself to perform above your limits except unnecessary relapses and perhaps disease progression. Avoiding overexertion doesn't guarantee a quick recovery or any recovery at all, there are other factors at work too (luck mostly), but overdoing it physically is a sure way to ensure that you remain more severely ill and for longer than would otherwise have been the case.

Please see the Treating M.E. – Avoiding Overexertion page for more information.

See also the Health, Healing & Hummingbirds website and the Practical Tips pages on HFME for more information on a wide variety of important issues for those with M.E., particularly the newly diagnosed. These texts discuss how to:

- Make sure you have been correctly diagnosed with M.E. (and note that qualifying for a ‘CFS’ misdiagnosis does not mean that you have M.E. nor any distinct illness named ‘CFS’)
- Avoid overexertion
- Work towards learning to accept your illness
- Educate yourself (and those around you) about M.E. and seek appropriate support
- Try to find a knowledgeable doctor
- Modify your diet
- Modify your environment
- Look into useful treatments for M.E.
- Learn how to avoid inappropriate or harmful treatments and scams
- Avoid and minimise stress
- Learn strategies to help with the cognitive symptoms of M.E.
- Consider becoming involved in M.E. activism and advocacy

The Health, Healing & Hummingbirds website is an essential guide to some of the basics you NEED to know to live with, cope with and to treat M.E. (or to help your child with M.E. do the same).

I hope some of the following hints might be helpful, they are taken from various sources and also include many of my own. A list of references follows the list of tips.

Also, some hints and tips are tips are only suitable for the very severely ill while others are inappropriate for the severely ill and will only be useful for those with moderate or mild versions of the illness so you need to just take the ones that are useful for you and ignore the rest as not all tips will be suitable for everyone.

**Beds and pillows**

- If you’re sore and achy all over in the morning and you have a bed that’s more than 10 years old, the pain might not all be M.E. related. My morning pain levels were cut in half when I just got rid of my 15-year-old saggy bed! Worth a thought anyway. Old beds can REALLY hurt. Not everything is the (just nearly everything.) (HUMMINGBIRD)
- There are some kind of air mattresses with holes in it which you can just lay on your mattress. Such an air mattress is very comfortable, since then I have no/less pressure pain. There are pillows, also called body pillows. You can use these in many different ways like for back support and meantime as pillow between your knees and/or (depending on the size) to support your arms and shoulders etc. I use it to support my arms and shoulders, this way I lay more relaxed. They are with different

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fillings like sand, foam, hard or soft etc. My mom made mine herself with soft foam, because I hurt a lot. (INGEBORG)

- Having at least 3 layers on a bed lets you deal with the hot/cold/hot/cold thing somewhat easier. A sheet, then a thin blanket and then a thicker blanket or doona on top of the bed lets you throw off the heavier top layers if you don't need them (that minute!) (HUMMINGBIRD)

**Bedroom**

- If you’ve spent years in the same room, having a selection of vases, ornaments and pictures that you can rearrange every now and then really helps. Stops you going completely insane (if you’re lucky). Repainting a wall or 2 with a different colour every now and then is great if you can get someone to do it as well. It really stops everything being quite so samey. Make sure you use a low VOC (volatile organic compound) paint though and choose a colour that won’t be too overstimulating to look at all day. Colours really can affect your mood. Reducing clutter also really helps your brain feel somewhat less overstimulated. (HUMMINGBIRD)

- Avoid ionisers as they can produce dangerous gases as well as ions. (According to ‘A Treatment Guide’ by Verillo & Gellman). (HUMMINGBIRD)

- An air filter with a HEPA filter is a good idea if you have a big dust allergy. They’re also meant to be able to remove mould spores as well and some even have carbon filters to remove chemicals from the air too to a certain extent. Just make sure you don’t get a really noisy one! (HUMMINGBIRD)

**Buzzers**

- If you have trouble speaking on an intercom, you could work out codes: 1 beep means I am well enough to eat my lunch now while 2 beeps might mean something else. Working out an emergency signal is probably also a good idea. (HUMMINGBIRD)

**Clothes**

- Use a folding laundry rack which stands on the floor. Hanging the laundry above your head is often much too exhausting and with such a laundry rack you can even hang on your laundry while sitting. (INGEBORG)

- I find wearing shiny fabrics in bed helps me turn over just that bit easier. I am unable to turn myself at all if I wear flannelette or have flannelette sheets! The right fabric choice can sometimes just make the difference between being able to turn yourself or not - worth a try anyway! (HUMMINGBIRD)

**Computer**

- Get printed address labels if you can afford them. (HUMMINGBIRD)

- If you have NMH and are struggling to sit up to use a computer, get a laptop or notebook computer if you possibly can so you can use the computer lying down in bed. Sitting up is just a waste when you could so easily lie down. I’ve also found that the glare from the computer screen is greatly reduced on a laptop. You can get reconditioned laptops for not too much money. If you can afford it – do it! (HUMMINGBIRD)

- NEW!!!! I have finally found a stand that lets me use my laptop/notebook computer lying completely flat in bed! Click here for more information. It's brilliant. The stand isn't cheap but it might be well worth it if you find it difficult (or impossible) to have to use your computer in the upright position. (HUMMINGBIRD)

- Did you know that (in Windows XP etc.) you can adjust some of the settings on your computer to make it easier to use? Things like making the text or cursor bigger and even changing the size of your scroll bars (which I would *really* recommend) and lots more. Even if you aren't that disabled it just makes working on your computer that much less effort. To make changes, go into Start, then All Programs, then Accessories, then Accessibility - then just follow the prompts on the Accessibility Wizard. You can undo any changes you make by running the wizard again incidentally. (HUMMINGBIRD)

- Online support groups are a must and there are so many now online. You can’t and shouldn’t have to go through this alone. It can take a while sometimes to find a group that suits you, it helps if you have illness severity in common among other things and sometimes you might have to join more than one group to find the right one for you. (HUMMINGBIRD)

- Becoming educated about M.E. really is a must too if you are at all able. Understanding your symptoms lets you deal with them better and knowing a bit about the politics of the whole thing
means you can argue your case better if you need to. You really need to be selective about what you read though – there’s a whole lotta crap out there! Click here to read some book reviews of some really great M.E. books. (HUMMINGBIRD)

- If you can’t sit behind the computer, print your replies on paper and let someone type them and send them. If you have a laptop with no internet then use a disk to download your emails on and write also on this disk your email so someone then can put the emails on a computer with internet-connection and send them. (INGEBORG)

- I have a new computer system; a 19 inch TFT-monitor which is placed with an arm against the wall. The desktop is a few meters away in the tv cabinet. I use a trackball, you have them in different kinds and I have tried them all. The one I have now works best, the ball feels good and rolls real flexible and light. The keyboard I use is small and light, so light that even I can lift it! I turn on my pc by pushing the space-bar. With this system I am no longer dependent on other to use the computer (INGEBORG)

- If you have trouble with your vision I got the following tip from someone. You can adjust the font size on your computer to the size which is easy for you to read. I use this tip for several years now; it's so common for me that I don't see it as a tip anymore, but maybe some of you didn't know this tip yet. You can also adjust the screen of your computer (for example in word, outlook, excel etc) in for example a soft colour. White hurts my eyes and makes reading even more difficult. That's why I always have a soft window colour like soft yellow or soft grey. Of course it's also possible to get it in negative. I also got the following great tip from someone to disable all animated images and banners on all websites [which can cause huge problems in M.E.!!] => start Internet Explorer and Go to:
  - Extra
  - Internet Options
  - choose tab Advanced
  - scroll down to Multimedia
  - uncheck "play animations on web pages" (3rd option, it can have another name, I'm using the Dutch version of IE) (INGEBORG)

- I always loved making jigsaws, but since I am fully bedridden in 1998 isn't that possible for me anymore. You must be able to sit at a table or sit/lay on the floor. But now I have found a site where you can make jigsaws on your pc (online, but also offline). They have over 800 jigsaws and you can make each jigsaw in 32 different ways, for example easy 6 pieces or pieces in the shape of stars or lizards and even hard 247 pieces. If you want to make them offline you have to do it as follow: download the jigsaws you want to make, click each jigsaw down to your taskbar, leave your pc on when you want to make the jigsaws the next day. If you become a member you will get every day an e-mail with the link to the jigsaw of that day. They have really nice jigsaws, take a look at www.jigzone.com. (INGEBORG)

Drinking
- Put a jug or bottle with water in it next to you so you don’t need to walk that often. If you have trouble holding for example a glass, get a bottle little children use, it’s not as heavy as a glass. Or use a water bottle or a so-called camelback. [A bag of water which sits above you with a straw which comes down for you to drink from] Nowadays there are even special mugs with which you can lay completely flat on your back, so you even don't need to lift up your head a bit. (INGEBORG)

- I like to have 3 1.5 litre water bottles on one table, and 4 glasses of water on another closer one. It means my carers don't have to be getting me water all the time, they just refill the bottles every 2 or 3 days. It also means that when I (or someone else) pours me a glass of water they or I can pour 4 at once which saves effort as well as reduces the amount of time I have to hear water being poured!! (One of the WORST things ever for hyperacusis - it's the tone *shudder*) (HUMMINGBIRD)

Dust
- An air filter with a HEPA filter is a good idea if you have a big dust allergy. They’re also meant to be able to remove mould spores as well and some even have carbon filters to remove chemicals from the air too to a certain extent. Just make sure you don’t get a really noisy one! (HUMMINGBIRD)

Eating
- If you're using that line about "I’ve had to give up so much, I’m not giving up nice food as well" why not just TRY a healthier diet for a few weeks or months (taking out the processed food, preservatives, wheat and dairy, yeasty and mouldy foods, foods from the nightshade family, and the
sugar and white flour for example). You might notice such an improvement it’d be worth it - feeling a bit better really does ‘taste’ so much better than mere food ever could! See Treating M.E. – The Basics for more information. (HUMMINGBIRD)

- If you have trouble swallowing food, mix it and do some soup with it so it’s easier to swallow. This way you still get your vitamins and minerals. (INGEBORG)
- Always have a variety of foods at hand near your bed for emergencies; nuts, peanut paste and a spoon, protein bars, fruit - whatever you can handle. (HUMMINGBIRD)

**Funerals**

- Funerals can sometimes be arranged to be viewed over the internet on a live feed or via DVD if you can't make it in person. It is also good to talk to people who did go to the funeral if you can, get them to tell you in detail what it was like. (HUMMINGBIRD)

**Hair**

- If you can’t shower and you don’t have a bath but you want to wash your hair then lay down on bed with your head over the side. Lay some kind of plastic on the floor before the bed, put a big bucket before the bed and fill a small one with warm water. It’s more comfortable if you lay on your belly; if you lay on your back you get cramp in your neck because of holding your head up, that's also why I can’t let my hair wash in those **inflatable hair wash basins** for in bed. Lay a pillow underneath your chest with plastic over it so it can’t get wet. Lie down on bed and let someone flush water over your head with a big jug or something, let her/him wash your hair and flush again water over your hair while hanging with your head above the big bucket. (INGEBORG)

**Household**

- At my bed I have a connector with power-points and an on/off-switch. In the connector sits 1 plug on which the 2 lights I have are connected. If I want the lights on I push the switch to 'on' (meaning power available), if I want them off I of course push the switch to 'off' (no power). With the heating I have the same problems as with the lights and beside that the control for the heating hangs too high for me to reach it from my wheelchair (this is also with the controls of the big lamps like the spots hanging down from the ceiling). This is solved with a bell thermostat and of course it has been put lower in wheelchair-height. The bell thermostat is now been put on 2 stand (it has a max. of 8 stands); the first stand is the time I usually just about awake and the 2nd stand is when I go to sleep, both of course with a different temperature. You can also operate the thermostat with the telephone or computer, but this has still to be sorted out for me. (INGEBORG)

**Ironing**

- Learn to live with wrinkled clothes - the ones you have from pre-illness, then ONLY buy things from then on that don't need ironing! I think even healthy people should do this - life is too short to be wasted ironing!!! (HUMMINGBIRD)

**Light Sensitivity**

- If you can’t tolerate light very well, put on your sunglasses, this is also more relaxing when you watch TV. If you can’t tolerate light at all, get an eye mask. (INGEBORG)

**Memory**

- If you have a M.E. affected brain, notebooks can be kind of like little spiral-bound external brains - if you don't use them already, get some!!! I have one beside my bed, 2 beside my daybed as well as 2 whiteboards and a few lists on the computer too. I do still forget lots of things but I wouldn't remember to do anything at all without them! (HUMMINGBIRD)
- Try to get into the habit of putting things back in the same place after you use them - even if it does make you look like a control freak to those around you - it really is the only way to remember where all your stuff is if you don't have a memory anymore. (HUMMINGBIRD)
- Get a pill box with at least enough compartments that it’ll last you a week. Life is just too short to mess with pills more often than you have to! Mine last me for a fortnight, it’s so much easier than doing all your meds one by one each day – you’ll never go back! Monthly pill boxes are also available. (HUMMINGBIRD)

**Neurally Mediated Hypotension**
You can get a wedge of foam custom cut at any custom foam shop to put under your legs and raise them up to help with NMH. They really help. Mine is 60cm x 60cm x 17cm. Make sure you get firm foam. (HUMMINGBIRD)

Compression socks/stockings help with NMH too. (HUMMINGBIRD)

If you have NMH and are struggling to sit up to use a computer, get a laptop or notebook computer if you possibly can so you can use the computer lying down in bed. Sitting up is just a waste when you could so easily lie down. I’ve also found that the glare from the computer screen is greatly reduced on a laptop. You can get reconditioned laptops for not too much money. If you can afford it – do it! (HUMMINGBIRD)

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**Noise Sensitivity or Hyperacusis**

- Hyperacusis (severe noise sensitivity) is a huge problem for me (as you’ll know if you’ve read my ‘Day in the life of severe M.E.’ and about the only thing I’ve found that helps is my noise-cancelling headset. It plays white noise – the sound you hear between songs when you listen to cassette tapes. They don’t block out really loud noises but they do make a huge difference. They are pretty expensive but well worth it if your hyperacusis is really severe. I can’t tolerate normal headphones or earplugs at all but these ones are very comfortable to wear. You can get them from www.bose.com and last time I looked they have a deal where you can try them for free at your home for 21 days. See also: www.sony.com They can also be attached to your Walkman or computer for really clear sounding music and double the noise blocking capabilities! If noise is very severe and the headset isn’t blocking it all out (or you don’t have one) playing music over the top of it can help. If you are really neurologically overstimulated and not well enough for normal music I find certain types of classical music can be much better tolerated. You need to make sure you get a CD of really slow and mellow ones though - no crashing cymbals and marching music! The other thing that’s helped the hyperacusis is installing thick solid doors internally and externally and attaching rubber seals to them as well so that the room is kind of airtight. They block out quite a bit of the noise but of course, are fairly expensive as well so not for everybody. I also keep a small stereo with a remote control near my bed so that if I’m woken up by loud noise I can lessen the impact by putting the radio or a CD on straight away. Of course the noise is still there, but nicer noise over the top of it does seem to help the hyperacusis a little bit somehow. Plus, just knowing you have some option, some action to take when agonising noise hits, can help somehow too. Stops you feeling so powerless to the pain. (HUMMINGBIRD)

- If you can tolerate noise sometimes but no music, there are also relaxing-cd’s without music with only rain for example. This is really relaxing, as far as you can relax. If you can't tolerate noise at all, you can try ear plugs. The earplugs I use now are so called swimming/water-earplugs which are being adjusted to your ear. They do it at home, at least they did with me. You first lye on 1 ear while they put some kind of liquid rubber into your ear. This has to harden before they can pull it out of your ear and then the other ear will be done. Normal swimming/water-earplugs are kind of small, but my earplugs also cover the ear-entrance. This way less sound can come in. You sometimes have to maintain the earplugs by putting them in a bit oil (olive oil for example), this way they don't dry out and don't break in 2 that easily. If you also use the earplugs when sleeping as I do, then ask for the softest rubber... the harder the rubber, the less comfy to lie on, but it may still take a while to get used to. (INGEBORG)

- I like to have 3 1.5 litre water bottles on one table, and 4 glasses of water on another closer one. It means my carers don't have to be getting me water all the time, they just refill the bottles every 2 or 3 days. It also means that when I (or someone else) pours me a glass of water they or I can pour 4 at once which saves effort as well as reduces the amount of time I have to hear water being poured!! (One of the WORST things ever for hyperacusis - it's the tone *shudder*) (HUMMINGBIRD)

**Opticians**

- See if you can find an optometrist that can test your eyes in your home. (HUMMINGBIRD)

**Pacing and rest**

- It is really important that if you get the flu on top of your M.E. that you rest. Even 'normal' people have had fatal heart attacks because they exercised/overexerted themselves while they had the flu. Those of us with pre-existing M.E. related heart problems may be at an even greater risk so if you have the flu, rest is not optional - do not exercise or exert yourself at all! Why take the risk? This
whole marketing message we're continually being fed to 'take drugs and keep going through the flu' is just plain dangerous. (HUMMINGBIRD)

Pain
- Electric heat packs are BRILLIANT!! They are around half the size of a pillow and they are good for period pain, cold fevers, cold feet, pain and just for warming you up! They're also very handy for when it gets colder suddenly and you can't get up to get another blanket …and they just feel nice and any part of you feeling ‘nice’ when you have M.E. is pretty rare! I think they’re a must have. (HUMMINGBIRD)

Pets
- A cat needs less cleaning and care and still you get attention, they love to lay on your bed beside you. (INGEBORG)

Shopping
- If you’re trying to buy appliances or anything substantial over the phone or in person, don’t forget to try to bargain (or get someone else to do it on your behalf if you can’t). Very often they’ll reduce the price by quite a lot, they want your business and are quite happy to reduce the price to get it if you just ask. I recently just saved 130$ on my air filter and 125$ on a new stereo just by asking!! I didn’t even have to talk them into it or offer reasons – it really surprised me. Their advertised prices really aren’t what they expect you to pay sometimes. It can’t hurt to try. (HUMMINGBIRD)

Talking Books
- Lots of books are available in audio versions and many classic books are available in free audio versions. (HUMMINGBIRD)

Teeth
- Get an electric toothbrush! You may even be able to use it to brush your teeth lying down in bed or in the bath. (HUMMINGBIRD)

Telephone
- If you are able to telephone but you can’t hold the phone for long, get a phone with intercom. (I have a Swatch telephone and if I want to call someone I lay the phone on my belly, the intercom stands further away because of the noise. With this phone you also can call internal if you have a second handset, so if you need help you can phone to someone downstairs. It is expensive, but really worth it. (INGEBORG)

Toilet
- There are urinals for women; you have them for sitting or standing use and you have them for lying down use only. (INGEBORG)

Vertigo
- If you can’t close your eyes when you are resting because the room spins with vertigo, putting a wheat bag or something else heavy over your eyes can help. It not only blocks the light out, but the weight of it lets your body know where ‘up’ is so you can get some rest hopefully without having to hold onto the side of the bed to stop yourself falling off! (HUMMINGBIRD)

Writing
- A pencil always writes and costs less strength. If you really want or need to write with a pen choose a gelpen, these are more comfortable in your hand and write lighter. I have bought the so-called dr.grip-peg pen at Medifix (only Dutch) and I am really very happy with it. The pen is perfectly balanced, lightweight and soft in your hand and you just need to touch the paper and the pen already writes… you absolutely don't need to put any pressure. There are also special scissors which don't hurt you to use and which cost no/less strength', spring assisted scissors. (INGEBORG)

A second list of tips which deals with how to cope with M.E. emotionally is also available: Tips for coping with M.E. emotionally.

If you’d like to share some of your own tips please submit them by email

I hope you have found a few things here that will help you in some way with living with M.E. Best wishes to you all in your battle with M.E.
Four of the most important ways to cope with M.E. are to:

- Once you are sure of having a M.E. diagnosis educate yourself as much as you possibly can about the illness so that you can explain it to those around you and give yourself a much greater chance of getting some of the support you need (not to mention the best treatments and chance for recovery). Knowledge is POWER!

(The paper A Million Stories Untold might be useful in explaining M.E. to your friends and family.) See also the new paper: M.E. vs MS: Similarities and differences. To read a list of all the articles on this site suitable for M.E. patients, carers, friends and family or severe M.E. patients and so on, see the Information Guides page.

- Join a support group either online or one which meets in person. It really just helps so much (more than almost anything) 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 really suits you but when you do it will likely be well worth it. (Finding groups which match your own severity level is really important; if you are sicker than everyone in a group it can make you feel like nobody really understands what YOU are going through; if everyone is much, much sicker than you, you may find the group depressing.)

Hopefully you will make yourself some new friends who will really help you cope with every stage of your illness, and who will support you in turn.

- Stop accepting the blame for getting ill in the first place (or for remaining ill) if ignorant friends, family or Doctors have been telling you that this is the case (and even though you know it isn’t true have in some ways started to believe it a tiny bit). It is just nonsense! Nobody causes themselves to get M.E. through anything that they did such as; overwork, ‘stress,’ perfectionism, not ‘eating right’ or childhood abuse or trauma or anything else. M.E. is not a form of burnout and with the most positive attitude in the world you CANNOT will yourself well from M.E. It just doesn’t work like that unfortunately.

Management strategies do have an important role to play in M.E.: making sure you avoid overexertion as is appropriate, avoiding all the foods and chemicals you may now be intolerant or allergic to etc. but so long as you are trying your best with all of these things – NOBODY can ask more of you than that. Don’t let stupid and ignorant comments get to you, you have more than enough to deal with just dealing with the REALITIES of M.E. let alone having to deal with things people have just made up about the illness!

- Remember to cut yourself some slack when you need to, and to always be kind to yourself. Accept that sometimes you will overdo it and cause yourself relapses/blow up at someone out of frustration at being ill/make silly mistakes about things because of your M.E. affected brain, and a million other things – nobody is perfect and doing these things and constantly making mistakes are all just part of being HUMAN.

Coping with M.E. emotionally is very much linked to coping the best way you can with the illness physically, so see the Practical tips for living with M.E. section on HFME as well as the Health, Healing & Hummingbirds website. These are essential guides to some of the basics you NEED to know to live with, cope with and to treat M.E. (or to help your child with M.E. do the same) and are highly recommended.

You might also like to read: What it feels like to have Myalgic Encephalomyelitis: A personal M.E. symptom list and description of M.E. Again, knowledge about your illness and your symptoms is POWER!
What do you say when people tell you ‘you look well’ when you are really ill? How do you deal with getting abusive or nasty comments related to M.E.?

N writes: I know everyone out there will have had to deal with this at some point. You know the one - you are sitting there feeling like utter crap, and someone says to you in an extra chirpy way, usually with a touch on the leg "You're looking well!", What is your response?

I've had my inlaws do this to me a few times lately, and I'm always at a loss for words. I don't want to be an ungracious grump and say "Well I'm not!!" because I really know that they do mean well. But I really really hate it.

It's like the implication is there that you got better, and somehow didn't notice it, so they had to tell you. Or that you're not as sick as you think you are.

I need a nice answer, that very politely tells them that the way I look has nothing to do with the way I feel. Any ideas?

N, Australian M.E. patient

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Depends upon the source how I react. There are "some people" who just want to believe that I could be "cured" if I "would just make the effort". They believe this because it relieves them, in their mind, from any moral obligation to care, offer assistance, offer kindness, or focus on anything in life beyond their own needs.

I try to not have anything to do with them, and don't really engage on any meaningful level with them if I can help it. Just tune out until they stop making noise LOL

Sometimes I am just too worn down by it all and will snap at them, though, and then I am angry with myself because it was a waste of energy.

But other people really do mean well, and they can't deal with the immensity or scariness or injustice or futility or having challenged all of their illusions about Life, Fairness, and the Medical and Social Systems.

Maybe they also want to help and don't know how. With those people, the ones whose hearts and intentions I know are good, I just skip their words and address their feelings.

I just say something like "I know you really care and would like to help and that means a lot to me. Thank you."

Sometimes that is all that is needed. Then I can go back to fantasising about throttling the others :) (especially the "if you only would really TRY ..." ones !!!!) Jo

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When I hear this (and I hate it, too!), I find myself responding with "I wish I felt CLOSE to as good as you say I look" ... Or something similar like "WOW looks can be deceiving, can't they?" Roseanne

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All these are such great responses! Then there's always the classic: 'Oh good, I'm glad I don't look as ill as I feel!' or 'Oh good, I'd hate to look as ill as I feel!'

Maybe with variations: '...I'd hate to look as bad as I feel - that would be really scary!' or '... if I looked as
bad as I feel, I'd be really hideous!

Best wishes, Lesely (oh no! We all know about ME-wooky-spelling-disease, but I don't want to catch 'Wessely'-spelling disease.) I mean, (typing very carefully) Lesley

To see the other replies made to this question, see the Group Comments page.

If family members are pressuring you to participate in scams such as the Lightning process, Reverse therapy, Mickel therapy, EFT and so on, see the new The Lightning Process scam page.

Email to fellow group member about coping with M.E., from Aylwin (long-time M.E. patient) November 2009

Coping with M.E. is a very fine balancing act. I think one trick is not to project into the endless future, it is totally overwhelming. As none of us really knows what will happen, you may well get real improvement over time. One day at a time is best. (When I'm feeling blue I remind myself that it's just a feeling I'm having right now.) Also, I take immense pleasure now in the tiniest things, seeing a bird through the window, a streak of sun on the trees, a funny joke. I'm lucky that I can watch some movies & more or less follow along, though I have no access to TV.

And it may be that you are not up to contributing, but I find a lot of relief & enjoyment hanging out & interacting here where we all understand. If you were able, it really would help you feel less isolated. In fact, I do most of my socialising online now & find it much less impactful than in-person or phone. It's just a different way.

As to meaning, well each of us works on that one (human being not human doing), but I suppose my spiritual beliefs have helped me there. We many not understand fully now, but some happy day we will (not a Christian but do believe in meaning, afterlife etc.). I have my ideas about it.

Anyway the majority of people in the world live in terrible circumstances, hungry, homeless, horrible violence, & I think us "first-world"-ers have been led to expect safety & happiness through some obscure virtue, when most do not have those silly expectations that life will go just as they want it to. Life is hard however you slice it, & I do not know one person who has not had major grief, illness, or other disasters to deal with. How is just the luck of the draw is all.

Cancer is also terrible, yet they get the red carpet of the latest treatments, counselling, & lotsa public recognition, parades even, while we languish in the backwaters of medicine, virtually ignored <sigh>. I think that makes a big difference as well. Again, here is a remedy, & I am so glad that at least you did get to see Dr. H & have that validation.

I think of the Kubler-Ross stages of grief & I must say that I feel I've mostly, finally reached the stage of acceptance. It is what it is. Although I am also not a Buddhist I find some of the philosophies very helpful. A good author (if you could handle books on tape, I think hers are all available) an excellent writer is Pema Chodron, she has brought me so much comfort, especially *When Things Fall Apart* (Heart Advice for Difficult Times), though she also has one called *The Wisdom of No Escape* I'd love to read. She writes in short, simple essays which helps. BTW someone recently told me that she suffers from poor health that is very limiting too.

I have been through that discouragement & sense of hopelessness so often in these 23 long years. My heart goes out to you & though there are no big answers I hope these wee tips can help just a tad.

Email to the same fellow group member about coping with M.E., from Lesley (M.E. patient) November 2009

22 PRACTICAL TIPS FOR LIVING WITH MYALGIC ENCEPHALOMYELITIS: COMPENDIUM
Welcome to the group. Sorry you're suffering with the terrible deprivation caused by this illness.

As for meaning in life, you're asking a profound question about finding meaning in the limited life that illness imposes.

In a way, I think ill people are forced to confront this question of meaning which confronts all human beings, but well people can distract themselves with work achievements, meeting people and falling in love, travelling, etc. We can't do all that.

We can't find meaning in 'doing,' and it can be a challenge to find meaning in just 'being.' As Aylwin said, we're human beings not human doings. I think the Buddhist orientation toward ways of being, rather than achievements in the world, has a lot of wisdom.

On a practical level though, we all need things that help up get through the day. It can be hard to think of meaningful or enjoyable things to do or experience with our limited health.

You mentioned that you can't read. Can you listen to recorded books? I don't know where you are, but in the UK the public libraries lend books on tape or CDs. Also, libraries have large print books, which can be visually easier to read (doesn't help with cognitive difficulties, though).

If you can read and type enough for the Internet, online groups like this one can help so much. I get such comfort and inspiration from this group. Although you can't tolerate live conversation (as many of us can't, and I often can't), online communication can feel very supportive and meaningful. Isolation is terrible - but if you have a computer, you can be in a community like this group.

It may not seem like much, but by your honesty in posting here you may have helped others - we all struggle with the issues you are dealing with. Reading your post is helpful to others who struggle to find meaning, but feel they're alone with this.

One last thing - terrible as it is, it may be that your suffering has given you the empathy and insight to understand the suffering of others. I'm often amazed at the wisdom and warmth shown by MEites.

Big hugs and best wishes,

Lesley

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Meditation and breathing and relaxation exercises can be such an important part of coping with M.E. Nutrition can also have a massive impact on mental health and wellbeing. For more information on these two topics please see the Health, Healing & Hummingbirds website.

Sara Douglass’s comments on chronic illness, death and dying made on her blog are so spot on and are recommended reading. Sara Douglass is a brilliant fantasy writer (I’m a huge fan) and has cancer. I hope Sara wont mind if I quote parts of her ‘The Silence of the Dying’ article a little bit here:

Modern society cannot deal with death. We just have no idea. We are terrified of it. We ignore it and we ignore the dying. Recently I’ve had it hammered home on a couple of occasions how much the dying are supposed to keep silent, that ‘dying well’ in today’s society means keeping your mouth firmly closed and, preferably, behind closed doors.

Never shall a complaint pass your lips. How many times have we all heard that praise sung of the dying and recently departed, “They never complained”?

Death in pre-industrial society was a raucous and social event. There was much hair-tearing, shrieking and breast beating, and that was just among the onlookers. Who can forget the peripatetic late-medieval Margery Kempe who shrieked and wailed so exuberantly she was in demand at all the death beds she happened across? Suffering, if not quite celebrated, was at least something to which everyone could relate, and with which everyone was at ease. People were comfortable with death and with the dying. Death was not shunted...
away out of sight. Grief was not subdued. Emotions were not repressed. If someone was in pain or feeling a bit grim or was frightened, they were allowed to express those feelings.

Now we ignore death. We shunt it away. Children are protected from it (and adults wish they could be protected from it). The dying are often not allowed to express what they are really feeling, but are expected (by many pressures) to be positive, bright and cheerful as ‘this will make them feel better’ (actually, it doesn’t make the dying feel better at all, it just makes them feel worse, but it does make their dying more bearable for those who have to be with them). When it comes to death and dying, we impose a dreadful silence on the dying lest they discomfort the living too greatly.

By the mid-nineteenth century, if not earlier, the lesson was clearly implanted in our society’s collective subconscious. Death should be silent. Confined. Stoic. All this silence and stoicism scares the hell out of me.

Now, with death lurking somewhere in the house, I have begun to notice death all about me. I resent every celebrity who ‘has lost their long battle with cancer’. Oh God, what a cliché. Can no one think of anything better? It isn’t anything so noble as a ‘battle’ gallantly lost, I am afraid. It is just a brutal, frustrating, grinding, painful, demoralizing, terrifying deterioration that is generally accomplished amid great isolation.

Let me discuss chronic illness for a moment. As a society we don’t tolerate it very well. Our collective attention span for someone who is ill lasts about two weeks. After that they’re on their own. From my own experience and talking to others with bad cancer or chronic illness, I’ve noticed a terrible trend. After a while, and only a relatively short while, people grow bored with you not getting any better and just drift off. Phone calls stop. Visits stop. Emails stop. People drop you off their Facebook news feed. Eyes glaze when you say you are still not feeling well. Who needs perpetual bad news?

This is an all too often common experience. I described once it to a psychologist, thinking myself very witty, as having all the lights in the house turned off one by one until you were in one dark room all alone; she said everyone described it like that. People withdraw, emotionally and physically. You suddenly find a great and cold space about you where once there was support. For me there has been a single person who has made the effort to keep in daily contact with me, to see how I am, how I am feeling, and listen uncomplainingly to my whining. She has been my lifeline. She also suffers from terrible cancer and its aftermath, and has endured the same distancing of her friends.

The end result is, of course, that the sick simply stop telling people how bad they feel. They repress all their physical and emotional pain, because they’ve got the message loud and clear.

People also don’t know how to help the sick and dying. I remember a year or so ago, on a popular Australian forum, there was a huge thread generated on how to help a member who was undergoing massive and life-changing surgery that would incapacitate her for months. People asked what they could do. I suggested that if one among them, or many taking it in turns, could promise this woman two hours of their time every week or fortnight for the next few months then that would help tremendously. In this two hours they could clean, run errands, hang out the washing, whatever. And they had to do all this while not once complaining about how busy their own lives were, or how bad their back was, or how many problems they had to cope with in life. Just two hours a fortnight, with no emotional-guilt strings attached. Whatever she wanted or needed. Freely given.

Bliss for the incapacitated or chronically ill.

But that was too difficult. Instead the poor woman was buried under a mountain of soft toys, dressing gowns, bath salts and bombs, daintily embroidered hankies, a forest’s worth of Hallmark cards, chocolates and flowers and exhortations that everyone was ‘thinking of her’.

None of which helped her in any way, of course, but all of which assuaged the guilt of the gift-givers who mostly promptly forgot her and her daily horrific struggle through life.

Modern attention spans for the chronically ill are horribly short, probably because chronic or terminal illness in today’s society is horribly tedious. Tedious, because we are all so uncomfortable with it.

Instead, too often, it is up to the sick and the dying to comfort the well and the un-dying.
Just take a moment to think about this, take a moment to see if you have ever experienced it yourself. The dying — sweet, stoic, silent — comforting those who are to be left behind. I know I experienced it when first I was diagnosed with cancer. I found myself in the completely unreal situation of having, over and over, to comfort people when I told them I had cancer. In the end I just stopped telling people, because almost invariably I was placed into the bizarre situation of comforting the well by saying everything would be all right (which, of course, it won’t, but that’s what people needed to hear to make them comfortable about me again).

The dying have been indoctrinated from a very young age into this sweet, stoic and silent state. They earn praise for always being ‘positive’ and ‘bright’ and ‘never complaining’. Perhaps they are bright and positive and uncomplaining, but I am certain they lay in their beds with their fear and anger and grief and pain and frustration completely repressed while modern expectation forces them, the dying, to comfort the living. I am sick of this tawdry game. I am sick to death of comforting people when all I want is to be comforted. I am sick of being abandoned by people for months on end only to be told eventually that ‘I knew they were thinking of me, right?’ I am sick of being exhorted to be silent and sweet and stoic. I know I face a long and lonely death and no, I don’t think I should just accept that. I don’t think I should keep silent about it.

Click here to view the Sunday Times article on Sara Douglass.

An excerpt from ‘It’s not personal’ by Clytie, an Australian severe M.E. patient. This amazing piece speaks for so many of us with severe M.E. It gives our extreme isolation and suffering a voice. This is true very severe M.E., and nothing to do with mere ‘fatigue’ or tiredness.

…. (Warning: temporarily disabling ‘Brave and Cheerful™ mode) …

....My family is perfectly willing to travel across the country to see me. They care, and they want to help. So they don't visit me.

Anyone who has had or dealt with a virulent chronic disease is probably getting the point by now: contact makes me sicker ... permanently. Early on, I would trade days or weeks of being much sicker, just to spend some time with friends or family, until I learnt that I never quite got back to my previous level of capability. As the disease "progresses", each time you lose more and more of your rapidly-vanishing capability. It's rather like borrowing money at very high interest, then not being able to repay it. However, this disease is even more extortionate than our banks: it doubles and triples the interest rate whenever you overdraw. You end up with nothing, which probably wouldn't be so bad if the process weren't so drawn-out and agonizing.

So, how do you feel if your much-loved relative asks you not to come and visit her? By the sound of my daughter's voice on the phone today, you feel disappointed, rejected and unappreciated. She tried very hard not to show it, but I know her. In the same way, she probably sees through my determined cheerfulness in other calls. The fact is, we're separated by this disease, and we both hate it. Do I feel abandoned by my family because they don't visit me? No, but I feel resentful and miserable that my condition prevents them from doing so. Who do I blame? I really wish I had something I could hammer or lambast. My grandchildren are toddlers, and I've never seen them, apart from photos. I couldn't be with my daughter when she gave birth, or help her afterwards. I'm really angry about that. Unfortunately, I have nowhere to direct my anger. I'm no longer able even to punch pillows or scream. I end up being a quiet victim, and in many ways that is the greatest humiliation.

My daughter had made a great effort. Even though she and her partner are very short of money, they planned to spend it on bringing the kids to see me, over thousands of kilometres, with all the difficulties of travelling with children on a strained budget. After that, they were going to move even further away, to improve their work opportunities and the environment for their children. But first they wanted me to have this chance.

God, I appreciate it so much. I am crying as I write this. It hurts so much to say "No". I wish, desperately, that there were some way we could do this. Actually to hug my daughter again, to meet her partner, to be in the same room with their beautiful kids ... why isn't there a way?

I want this article to stand as a public declaration to my daughter, that I love her so much and appreciate
what she tried to do. I don't want her to doubt her self-worth, or feel unwanted in any way. I value her, and her efforts, more than I can possibly say.

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**Art therapy**

If you are an artist, you may find that your preferred ways of working are no longer possible. These may have to be modified or you may have to think about becoming involved in different types of art. The types of materials you use might have to change to those that are less toxic or less time-consuming or less requiring of physical strength. If you can, try and find something that you can still do, even if it isn’t what you would most like to do and you can’t do it very often or have the same quality levels as you used to.

Art has so many different benefits. It can make you feel as if you haven’t lost absolutely everything and help you feel reconnected to your pre-illness self. It can also help you vent negative emotions and work through various issues.

You might like to share your finished works with friends online via email or Facebook, so that you can continue to get feedback from fellow artists and friends. Artwork can also be sold online fairly easily (although getting sales is anything but easy!).

If you have some good friends and family around you and supporting you, exhibitions may be able to be organized from home with no need for you to attend if you are housebound.

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**Craft projects as therapy**

If you don’t see yourself as an artist and whether or not you feel you have some talent or not much at all, craft projects can be a really great way to spend some of your time when you are ill with M.E. If you want to do a craft project, then you can, enthusiasm is all that is necessary. You can build you skill level as you go.

Decorating a room or a table or putting together clothes and accessories involves artistic skill, you may be more artistic and have more of an eye for colour and textures etc. than you think.

Always having a ‘project’ on the go is so great for keeping positive and taking your mind off your daily struggle. There is also the sense of accomplishment when you finish something and the joy of giving some of the things you have made to friends and family.

If you make you own cards and letter writing paper you could even save yourself a bit of money.

**Craft ideas:**

- Buy some lightweight card and fold it down the middle to make a greeting card. Then decorate the front of it using water-colour paints, pastels, pencils, or acrylic paints or even oil paints. (When using oil paints, avoid traditional turps and buy odourless turps instead.) You might choose to just use colours that you’d like to see together to form abstract designs.
- Buy some (cheap) canvasses or water-colour paper and do a painting. You might choose to just use colours that you’d like to see together to form abstract designs. If you don’t know where to start, there are books on abstract painting available.
- Cross-stitch projects are enjoyed by some M.E. patients, along with beadwork and jewellery making, mosaicing, knitting and so on. If you still don’t know where to start, perhaps find a food online craft shop and just browse until something takes your interest. There are also how-to books on most craft topics available.

You might also choose to be creative through writing poetry or composing music, or anything else that you have an interest in.
**Pet therapy**

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.

Cats are generally less work than dogs, although they can still be too much for some people. Fish, birds and mice are probably less work than cats.

If fish, birds or mice etc. don’t appeal, you may consider taking on a quieter people-loving older cat that needs a new home.

You may be surprised how different it feels to be home alone (or in bed alone) with a pet, as compared to truly alone.

That little animal presence can make such a big difference and pets can make you laugh a lot too. They can also provide a constant topic of conversation that is non-illness related and positive, and that everyone in your household can join in with.

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**Barbara writes:**

- Something I have done that keeps me visualizing; I make scrapbooks (not the new fad scrapbooking) from magazine articles/pictures...I put quotes and ideas in this book. When I am so lost and hurting that my dreams won't ever come true..I pull out my book and even if it inspires me for one more nano-second of hope for tomorrow it is worth it. Even if it is delusional....sometimes it can lift my spirit.

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**Ingeborg, on her website 'Borg of Space' recommends:**

Most importantly: try to enjoy the small things in life and ask for help if you need it and of course pay attention to your body and don't overdo it.

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**Some strategies and thoughts on coping from a ME sufferer (to give you some ideas maybe):**

THOUGHT: I am still better off, in many ways anyway than 2/3rds or people who have no reliable access to food, water and shelter and a war and violence-free life.

THOUGHT: I think just to be lucky enough to be born in Australia you (almost!) don’t get to complain about anything else, no matter what horrible things happen to you after that. No matter what happens to us here we are still better off than most people in this world. (Insert your own country here) We are so lucky; so many people will never have and couldn’t even dream of having lots of the things we take for granted every day.

THOUGHT: To not compare my life with my peers but instead with people around the world and of all types. The comparisons tend to come out more favourable that way! Yes I may have the crappest life of all my ‘well’ friends and family and every other person I know that doesn’t have M.E., but on a wider/world scale, I'm not doing so bad!!! You just have to pick the right people to compare yourself to so you come out on top is the trick - it makes you feel so much less unlucky!

THOUGHT: I just have to get through today and by tomorrow it wont matter so much how horrible it was as I will have forgotten it almost completely (oh the joys of memory loss!)

THOUGHT: I cling to the fact I will get better, I tell myself that this is not forever, all the time (even though it very well may be, and its much more likely I'll never recover than that I will). But I tell myself that anyway, even though the facts don’t back it up, just because I need to believe it and without the hope of getting better life isn’t worth living. It’s a necessary delusion that lets me keep going every day. (I believe it because I have to, not because I really believe it.)
THOUGHT: I feel so grateful I got to be healthy for 16 whole years before I got sick, many people never have that and are ill from birth. At least I have been healthy and know what that’s like to a certain extent — even if I don’t remember it much! At least I got to have my basic education before I got sick too, I couldn’t imagine having to struggle through primary school or high school with this thing.

THOUGHT: I feel lucky I was born healthy/average or whatever. I have the right number of fingers and arms etc and a 'normal' appearance and intelligence, so many people don’t have these things ever. Yes I feel mad I can’t use these things because I am ill but at least I was lucky enough to have them in the first place to lose! If I ever get better I can DO things with my life. I also feel lucky I have had the opportunity for a good education. Many people don’t get even half as much education as I have had.

If people choose to believe I am not ill it is their ignorance and hang-ups that are the issue, it really is nothing to do with me. I try to do all I can to convince others close to me (by giving them copies of my essays and research and things) but if they choose to still stay ignorant after that then I will know at least that I have done all I can and that I can do no more but accept their decision however hard that is.

I try to resist the urge to plead with 'disbelievers' about my illness being legitimate and severe as it makes them even more sceptical as they seem to see it as me being really interested in trying to get sympathy. I refuse to put myself in a position of having to justify my illness to someone else. It’s b***shit and makes you feel like dirt and I refuse to do it any more. I’ve done it for such a long time already and it’s got me nowhere. It is so obviously a legitimate illness and if they just opened their eyes they’d see that. They really are much more likely to come around if you just try to get on with dealing with your symptoms as best you can without saying anything and if they don’t then they obviously have their heads up their..... and can just get stuffed anyway!! Harsh but fair *grin*

THOUGHT: I look forward to the fact that if I ever get well and get back into the world, I will deal with it so much better than I ever would have had I not got ill. There’s no way I will worry about small things going wrong when I know what its like to live in hell for years. If I get even a bit more well I will lead a great life, I’ll make it great. (Not that I wouldn’t swap all this personal growth for recovery of any kind in a SECOND – I would! But you have to do the best with what you’ve got)

THOUGHT: I look forward to visiting all the friends I've met online if I ever get well too. I've made some great friends I'd never have known existed otherwise.

I also live almost totally in the moment. Partly because I have the attention span of a fly, partly because life is so monotonous, but mostly because it’s the least stressful way to be - and life is so difficult sometimes with the M.E. symptoms you can only get through it one second at a time too.

It’s a good idea to try to have some nice event planned and on the calendar so I can focus on that when I feel down, I always like to have something to look forward to. It’s usually only small things like a visit from a friend or something. Or Christmas or a Birthday, or someone else’s Birthday. If I have no fun things I choose a minor one like something on TV and try to focus on that.

If I am going through a real rough patch I like to always leave myself with something good for the next day. Anything. Right before I go to bed I'll paint my toenails purple, or move my flowers and things around a bit so the room looks less samey. Or I'll have some TV show I like on tape all ready to play. Something, anything! No matter how small, just one positive thing to cling to for the next day because I know I'll need it. I save any new clothes I’m given on my Birthday or whatever for really bad days when I need the cheering up the most.

THOUGHT: I tell myself that I'm dealing with a worse life than all but 2% or less of people will ever have to deal with and so I should give myself a break, as anything short of suicide is showing brilliant coping skills! I think you have to let yourself fall apart occasionally too. We are only human after all and perfection isn't actually a good thing, or anything you really want to be aiming for.

A note on avoiding and minimising stress
Stress unequivocally does not cause M.E. but as with most illnesses, stress can exacerbate the symptoms of M.E. 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) 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 a 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.

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 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.

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. 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).

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 …well that and of course, your illness level (unfortunately!).

- See Problems with ‘our’ M.E. (or CFS, CFIDS or ME/CFS) advocacy groups 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
An excellent article to give to friends and family to help them understand the limits imposed by illness is 'The Spoon Theory' by Christine Miserandino www.Butyoudontlooksick.com © 2003. Christine has Lupus, but the article translates fairly well to some M.E. sufferers too. (although it is less appropriate for severely affected sufferers, who have no 'spoons').

"As I went to take some of my medicine with a snack as I usually did, she watched me this time, with a kind of stare, instead of continuing the conversation. She then asked me out of the blue what it felt like to have Lupus and be sick. I was shocked not only because she asked the random question, but also because I assumed she knew all there was to know about Lupus. She came to doctors with me, she saw me walk with a cane, and throw up in the bathroom. She had seen me cry in pain, what else was there to know? I started to ramble on about pills, and aches and pains, but she kept pursuing, and didn't seem satisfied with my answers. I was a little surprised as being my roommate in college and friend for years; I thought she already knew the medical definition of Lupus. Then she looked at me with a face every sick person knows well, the face of pure curiosity about something no one healthy can truly understand. She asked what it felt like, not physically, but what it felt like to be me, to be sick".

(Click the link in the title to read the whole article)

**ME sufferer Pat Mathewson** has written a short account of how ME has affected her life for the past 25 years. How restricting it is and how few people have any real understanding of the severity of the illness. Pat is wheelchairbound due to M.E.

Click here to read Pat's piece 'This is what M.E. means'

This is a brilliant post written by M.E. sufferer Johnno, in response to a question from another group member about grief and sadness and coping with M.E.

Hi ________,

I wanted to respond to your question about when does one ever come to terms with this illness?

My experience after 20 years of it is that you sort of come to terms with what you are able to do and not do, the symptoms are probably the easiest thing to accept and just put up with, and you invent ways to make your day interesting and worthwhile, which to some might be trivial but it means that you can go to bed knowing that you have done something with the day.

Then suddenly out of the blue all of this acceptance stuff gets turned upside down, this can happen quite regularly, and at times like this you experience the full force of your loss.

At times I still grieve my inability to participate in life like normal people, and such participating covers a lot of levels: social, financial, physical, and emotional.

Then there's sex, beer, parties, shopping malls, decorating and repairing the house, feeling awful that my dogs don't get walked regularly, the isolation both physical and internal that comes from being unable to "share" what you are really going through, having to think about what you can eat, having to do the "must-do" things in a day which might be all you can achieve for that day, dealing with people close to you who put down your illness rather than acknowledge it.......bumping into things all day, having to drive home when you know you can neither focus your thoughts or your eyes, and yet you have to get home!!!!!!!!

And then things change again, and one seems to be able to wear it all more easily, you notice the birds in the trees, the sunshine, the flowers, and can acknowledge that you cooked a great meal, cleaned up, or even supported someone else whilst overlooking your own pain.
It is I fear a roller coaster, that seems to get easier the more often you ride it, but not because anything about the ride changes, it will always have those plummeting falls that take your breath away, but because something within you acknowledges that you have been here before, and that somehow makes recovery quicker.

_____ said in a recent post that anger is a very necessary and natural thing, and in many ways so is grieving. To lose so much and not grieve would be un-natural, and I belong to that school which believes in acknowledging those feelings rather than denying them, or chasing distractions to avoid confronting them. When feelings of loss arise they have a reason and purpose and need to be acknowledged, even perhaps allowed to sit centre stage for a while, for in the same way that an incomplete grieving procedure at the loss of a loved one leads to relapses of emotion at a later stage, much can be said about incomplete grieving for what might have been in our lives if only....................

It is my experience that people with M.E. are amongst the bravest people I know, committed to survival, and have amazing skills in finding ways of coping. They are willing and able to push themselves to extremes if somebody else is depending on them, even though there will be a "cost" to themselves at a later date.

Most of all they have this wonderful quality of "hope", generating a whole new way of living, and even managing to create light in a world that on some days seems to be very dark!

I guess what I am getting at is that I don't believe there really is an end stage of acceptance, as someone or something will always come along and remind you of your awful reality from time to time. Therefore accepting the inevitable nature of the "roller-coaster" with its highs and lows is probably a more useful goal than expecting yourself to be able to learn to "accept" this illness.

IMHO

Johnno (Melbourne)

On reality, distraction and resting in M.E. (from the Yahoo discussion group)

We all struggle to make a life with what we can, and look for meaning and pleasure where they can be found.

I would guess that for all of us, there are also times when cheerfulness fails. Then we feel faced with a reality that is stark and brutal and possibly frightening.

Jodi recently told us of her spell of sadness, feeling painfully keenly the loss of being out and about. Others here have shared bleak times when the reality of the illness seems overwhelming.

While it's good to stay positive where possible so that life can go on, I think it's brave to confront the harsh reality of having ME. I also think it's necessary - MEites have to be ruthlessly realistic in order to protect themselves from the overexertion that comes from making mistakes about the possibilities in our lives. We have to know when we can't go out, can't socialise, or can't go dancing or travelling. We can't afford dreams that are really delusions.

At the moment, I feel very aware of the emotional difficulty of facing reality - and well as the need to do so, in order to deal with it.

I think we're all admirable as we find ways to go on living and laughing. But I also think we're showing a courage which is necessary for survival when, at times, we face the stark reality of having ME.

Best wishes, Lesley
Note 1: It's wonderful, the creativity and imaginativeness that we MEites show in finding meaning or purpose or pleasure or humour or distraction. In my first 'Reality' post, I didn't mean that we should sit around in doom & gloom all the time.

Yes, as ______ said, it's a natural human response not to want pain all the time, and to take a break from the whole ME thing.' Absolutely! We're human beings, as well as ME patients.

What I meant was that there are some times (not all the time!) when we're very aware of the reality of our condition. This can feel so bad, like a long dark night of the soul / being in the belly of the beast / being forced up against the sharp jagged edges of a painful reality.

It can take bravery to live through those difficult times when we confront our reality, and not try to run away from it. Awareness of the reality of our illness makes us stronger and wiser. In practical terms, it makes us better able to manage our illness, which is so important.

I completely agree with _____ that 'a balance is needed but hard to acquire.' As Bea also said 'it is not easy to really face our reality. and it is important to do; maybe then we can put it in the back of our mind and do the days but we need to be honest.'

Note 2: This confronting reality business is easier said than done! I have to admit that this is the main difficulty I have with periods of 'aggressive resting,' and with going to bed long before I can sleep. As Jodi described, when I'm alone in the silence and dark with no distraction, I'm vulnerable to painful or fearful thoughts and feelings.

This is one of the big challenges of deliberate rest periods, I think - not just the boredom or physical pain, but being alone with one's thoughts and feelings.

I think Jodi identified something important. In practical terms, when planning a programme of deliberate rest periods, it's useful to be aware of the possibility that some of the motivation for keeping busy may be to keep these bad feelings at bay, so it might be harder than expected to stop 'being busy.'

It's also good to anticipate the possibility of these bad feelings during rest periods, and to recognise them if/when they come. Perhaps if these feelings are a challenge foreseen, they won't seem so overwhelming.

Note from Jodi Bassett (typing errors intact!): What I really hate, and get a lot..is where you are resting in dark quite room, and the thoughts start to come in, fear and legitimate worry about life with ME and your future....so you have that to deal with, but also, lots of pain AND a heart rate that is way too fast, or is beating painfully or erratically or feels as if struggling to beat. It is dealing with BOTH at saem time that makes it so horrible...

It's silly, and illogical...thouihh it makes sense when you consider these things...that i find it fear far easier to rest extremely, when I am not so ill! When u are really ill is whej u need it most...but mostly I cannot cope with it, and its when I feel better tgan usual that I am most likely to rest.

It was actually feeling better than 8sal the last few months that prompted my desire to rest extremely in januray 2010...NOT a deterioration of my health as many have very kindly comiderated with me on. (Thanks thought!)

It seems illogical, but isn't! So much easier to rest and cope with scary real feeling...cope with reality of situation really, really realise it.....when your body isnt screaming at you that you are v ill and SHOULD be worried! Musings:)

ps. This is such a great discussion, so wonderful and helpful to me::) Its so core to ME yet so seldom discussed, hwo HARD resting is physcailly, with our social ideas and idess about productiveness but also emotionally and just phdcially. With eeryones permission, and maybe some identifying/perosnal info removed...this mght be another chat that could go on the iste to help others:) many too ill to join a group like this:( But need this info!
An important question to ask when you are dealing with M.E. and having trouble coping is, is it depression or grief?

The distinction between true organic depression, and natural grief and sadness which comes with having your life torn apart by something like Myalgic Encephalomyelitis is an important one as normal emotional responses do not require medical and diagnostic labels! We have enough bogus psychiatric labels applied to us already surely?

If you’d like to share some of your own ways of coping please submit them by email

Again, coping with M.E. emotionally is very much linked to coping the best way you can with the illness physically, so see the Practical tips for living with M.E. section on HFME as well as the Health, Healing & Hummingbirds website which is highly recommended for anyone with M.E., but particularly the newly diagnosed.

For more information about all aspects of M.E. see What is M.E.?

I hope you have found a few things here that will help you in some way with coping with M.E. emotionally. Best wishes to you all in your battle with M.E.
Assisting the M.E. patient in having blood taken for testing

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Myalgic Encephalomyelitis (M.E.) patients may experience significant difficulties in having blood taken. Problems may be caused by low blood pressure, blood clotting abnormalities (blood that clots too quickly), reduced circulating blood volume and an inability to maintain an upright posture.

These problems may be minimised in the following ways:

Pre-blood test tips

- M.E. patients should be advised to drink 1 – 2 glasses of water before blood tests, to help boost blood volume and raise blood pressure slightly. It may also help to improve hypercoagulation of the blood. A glass or two of an electrolyte drink will be even more effective than plain water. (The drink is made by adding ¼ teaspoon of unrefined sea salt to water, and also possibly a small amount of potassium or magnesium powder or liquid. At a pinch, some patients use a product similar to ‘Gatorade’ although these products are unfortunately very high in sugar and relatively low in salt and potassium. An unsweetened bottle of organic coconut water may be a better substitution, if available.)
- Very severely ill M.E. patients may benefit from a saline IV being given to them the day of, or the day before, blood is taken for testing, or both. The IV will help to reduce the relapse caused by the interaction with medical staff and also slightly improve circulating blood volume and blood pressure and make the task of collecting the blood samples easier also.
- As much as possible, M.E. patients should be given blood tests at their best time of day and always while lying down. This will minimise the detrimental effect on severely ill patients and also make the task of collecting the blood samples easier.
- M.E. patients that have deep veins or very thin veins that are difficult to take blood from should be advised to apply a heat pack to the appropriate arm (or both arms) for 10 – 25 minutes before blood is taken. The heat dilates the blood vessels and makes the veins easier to see and to take blood from. If veins are very difficult to take blood from, having a 15 minute warm bath before blood is taken can help, although this isn’t always practical.

Blood test tips

- The medical staff collecting the blood samples should always be advised beforehand that the patient has low blood pressure and low blood volume and/or blood that clots easily.
- The medical staff collecting the blood samples should always listen to the patient or their carer about which vein or veins are the best to use. (Often there will be a significant difference in one arm being used over another.)
- Severely ill M.E. patients should always be given blood tests in their own home, wherever possible. Even short trips out of the house can cause severe relapses which can last days, weeks, months or longer.
- As puncture sites from blood draws will take longer to heal in M.E. patients, medical staff should be advised to use a different vein if possible, where tests are repeated within a short period of time.
- Some M.E. patients will bruise very easily and may feel pain from blood draws (or minimal movement or flexing of limbs) more than might be expected in other patients. Where appropriate, medical staff
should be advised to be very gentle in handling the arms of M.E. patients. Younger patients with M.E. in particular may also benefit from the use of anaesthetic cream spread on the puncture site some time before blood is taken. Some adults may also prefer that anaesthetic cream be used. (This may reduce pain and also bruising and swelling at the site and so speed up the healing process.)

- Light pressure should be applied for two minutes to all puncture sites directly after the needle is removed. This helps to prevent bruising and applies to all types of needle puncture sites whether they were successful or not.
- If children (or adults) are afraid or uncomfortable around needles, slowly counting as blood is taken can help.
- Patients or carers may want to advise medical staff to use smaller bore needles in M.E. patients due to the fragility of the veins which often occurs.
- When many vials of blood are taken at one time, very severely affected M.E. patients may feel weak, dizzy or faint. This may be due to severely reduced circulating blood volume or the patient being too ill to cope with the interaction between themselves and medical staff over such a period of time – or a combination of the two. Extra electrolyte drinks are essential for these patients.

Unfortunately, even after following some or all of these guidelines, blood flow into the tube can stop after less than a minute in some severely affected M.E. patients due to very low blood pressure and reduced circulating blood volume.

**Blood test aftercare tips**

- Many people are sensitive to the wound dressing and if this is the case a hypoallergenic dressing should be used. Micropore tape (or even sellotape) and cotton wool are preferable to the more typically used coloured sticking tape.

**Other problems to be aware of with testing M.E. patients**

- **Fasting and glucose solutions:** M.E. patients will often be unable to fast for tests or drink glucose containing solutions without it making them very ill for some time afterwards. Tests which require fasting or ingestion of a glucose solution should not be given to M.E. patients unless there is a real need that justifies the relapse it will cause, because this relapse may last for some time.
- **Blood pressure monitors:** M.E. patients will sometimes have such low blood pressure that it comes up as an error message on some blood pressure monitors. If this occurs a different type of monitor should be used, if possible, and the test redone.
- **Intravenous medications:** M.E. patients often need smaller bore needles for use with IVs. Very chemically sensitive patients may also benefit from the use of glass IV flasks. As with blood draws, patients may benefit from careful handling of the arm and the use of anaesthetic creams.
- **Tests which involve standing upright for periods of time:** Standing upright for even a few minutes can be too much for many M.E. patients and can cause a severe worsening of symptoms or even a severe cardiac event. When the M.E. patient says that they have to lie down right away, this request should NEVER be ignored. See Testing for M.E. for more information. For more information on M.E. treatment, electrolyte drinks and supplements which help to thin the blood see the Health, Healing & Hummingbirds website.

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Assisting the M.E. patient in managing bathing and hair-care tasks

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Bathing can at times be very difficult for patients with Myalgic Encephalomyelitis (M.E.) Problems faced by the M.E. patient can include the following:

1. Problems tolerating very warm temperatures and problems tolerating very cool temperatures, or sudden changes in temperature, and difficulty warming up once a certain level of coldness is reached. Becoming very cold or hot can cause relapse.
2. Problems being upright for more than very short periods of time, or at all (e.g. standing, sitting or even lifting the head from the bed).
3. Problems with balance, vertigo, dizziness and faintness.
4. Poor flexibility, grip and muscle strength.
5. Poor muscle strength in regard to completing repetitive tasks. (e.g. tooth brushing or lifting body weight in and out of the bath).
6. The recovery period after certain tasks, or after a period of overexertion is often days or weeks or longer. (It may take longer than a day for a patient to recover from having a shower or a bath and so this task may not be able to be done daily.)
7. Problems tolerating many commonly used chemicals in personal care or cleaning products.
8. Problems tolerating sensory inputs such as noise, light, movement and touch.
9. Problems completing complex tasks or small tasks with many individual steps.
10. Ability to do tasks changes markedly with time of day and from one day to the next; this can depend on how active the patient has been in the hours, days, weeks and months previous.

To complete these tasks, special equipment or other items may need to be purchased, minor or major assistance from a carer may be necessary and/or tasks may need to be modified in certain ways or done less often. The following suggestions and tips come from people who have been ill with M.E. for a considerable time and who would like to share some of the solutions they have found with their fellow patients, in the hopes that others may benefit from their years of experience and (many) experiments. Some tips are aimed at M.E. patients themselves, while others provide information appropriate for carers and parents of M.E. kids.

Tips on showering

- A shower chair can be useful where the patient is shaky and has a fear of falling while in the shower. It can be used everyday or just on those days where it is needed. Shower chairs can be freestanding or wall mounted.
- Where standing can only be tolerated for a few minutes at a time a patient may wish to have a 1 minute shower as follows; turn on the water and while it’s heating up, get undressed; step into the shower and spend about 20 seconds washing your face and then your underarms and crotch with some liquid soap; get out of the shower, quickly dry off and get dressed in clothes you’ve brought with you into the bathroom.
- Some patients find it easier to lie or sit on the floor of the shower, and use the shower hose to bathe.
A warm bathroom can make undressing for a bath or shower easier. (Patients that become too cold, even for just a few minutes, may be unable to become warm again for many hours afterwards and this may trigger a relapse.)

Some patients cannot tolerate showers and need baths as they find they need the immersion in heat to be able to bathe. Others, who cannot shower due to the need to be upright for too long, can bathe lying down in a bath. A patient’s tolerance for baths or showers can also change over time.

Non-slip shower mats, non-slip flooring in the bathroom and shower rails may be helpful for some patients.

Patients that feel painfully cold after a shower may benefit from using an electric blanket to warm their bed before they shower. Where Electromagnetic Field Sensitivity is severe, the blanket can be put under the quilt, tuned on for a few hours and then turned off and pulled out of the bed before the patient gets in bed. (This is easier where the bed slept in at night is different to the bed used in the daytime.)

Tips on having a bath

- A very hot bath can cause dizziness, heart-pounding and weakness. It is not recommended that patients ever just get into a very hot bath as a healthy person might.

- Some patients that have problems tolerating the heat of baths may well be able to tolerate a warm bath if the bath is done a certain way which minimises the stress on the body and only exposes the body to the heat very gradually. Instead of just getting into a warm bath and shocking the body with a huge temperature change all at once, using the following steps may help: Get into the bath at the stage that there is only 1 inch or 2 cm of warm water in it. Then fill the bath slowly (at the normal speed) with water just a bit over lukewarm or as warm as one needs to not feel shivery. Then, when bath is about 3/4 filled or a bit more, put straight hot water in until it’s nice and warm. If possible, mix the water with the legs to even up the water temperatures. It is also very important to have only half (or a bit over half) the ribcage submerged, and never the full chest so that the warmth from the bath isn’t too much for the body to cope with.

  A half-filled bath with moderately warm water may be better tolerated than a full bath with luke-warm water – the amount of water in the bath and how quickly you’re immersed in the water make a difference too. Legs and arms may be prone to poor circulation and cold and so need warmer bath temperatures, and have a higher tolerance for them, than the torso (including the heart) and the head. Having only 50% of ones body exposed to the heat of the water makes it easier for the body to cope with.

  To make the bath last longer, let some water drain out and replace it with some more hot water when the water gets too cold.

  It is also important not to leave the bath while the water is still quite warm or too cold. Leaving when the water is too warm can leave ones heart pounding and overstimulated, while leaving when the water is too cold can cause a chill and an inability to get warm again.

  These precautions can allow even those with very severe heat sensitivity to take pain-relieving and warming baths, occasionally or even daily, with no problems. Baths should always be taken at the time of day when the patient is least ill and more able to tolerate temperature changes.

- Soaking in the bath for a time is recommended as this allows time for recovery from the effort of getting undressed and getting in. Resting or perhaps even reading a book or listening to music or an audio book for a while is also recommended so that the pain relief of the bath can be enjoyed fully. Exfoliation and the use of soaps should be left until just before the end of the bath so that the patient is only soaking in ‘clean’ water.

- If bath water temperature needs to be within a narrow range to avoid problems, buy a bath thermometer.

- In summer the bath might be kept filled with cold water and occasional dips or splashes taken throughout the day.

- Where strong scents can be tolerated, a few drops of essential oil added to the bath can be very pleasant, but a cheaper way to go about it can be to put two drops of oil, always combined with two or three drops of carrier oil, on the chest (right under the nose so that it can easily be breathed in). Only about a fifth as much essential oil is needed this way, and the bath doesn’t become hard to clean with essential oil residue. Try ginger, lavender or rose geranium oils.

- When the patient gets so seriously cold that only a warm bath can help, but the patient isn’t well enough for a bath, sometimes having a plastic bucket of warm water to soak the feet in (while lying in bed, with
legs hanging off the side) for 10 minutes can help, as can a hot water bottle. These warming up ideas can also be used to prepare the patient to be warm enough to undress for a shower.

- A bath with in-built jets or a spa bath mat put in a normal bath can be very soothing, if one can afford them and put up with the noise. They avoid the chemical/mould problems common with outdoor spas.
- Where the difficulty in bathing is being able to lift one's body weight into and out of the bath, a walk-in (and sit down) bath may be an option, albeit a very expensive one. There are also bath lifts, inflatable bath lifts, swivel bath seats and hydraulic/powdered seat baths which lower one into the bath automatically, in a seated position.
- Keep a dry handtowel draped over the side of the bath that can be gripped more easily when the patient is getting in and out of the bath. This towel can also be used to dry hands before reading a book in the bath. Make sure that there is a non-slip mat for the patient to step on when getting out of the bath.

**Tips on hair washing**

- Patients may want to wash hair quickly while leaning over the bathroom or laundry sink. Hair should be washed only at the time of day that cool temperatures can be best tolerated so that cold water straight from the tap can be used. A pump-pack of shampoo should be placed near the sink, ready to be used. This is also the best way to wash hair where there is a need to keep the ears completely dry.
- Patients may find it easiest to wash hair sitting in a chair and with the head laid back on the sink (as at a hair salon) with help from a carer. The back of the chair should be covered with plastic and a folded towel placed around the neck and also on the edge of the sink to rest the patient's head and neck on.
- Patients should make sure all soaps and shampoos and conditioners are pump packs so that valuable time and effort isn't used opening lids, turning bottles upside down and shaking them to get the product to come out and so on.
- Where hair really needs a wash but there is no time or ability to do so, consider just washing the front of the hair (the fringe) under the tap quickly.
- Hair can be washed (with the help of a carer) by swivelling your body until your head is leaning over one side of the bed over a bucket of water (doing this lying on your stomach may stress the neck less), or by using an inflatable hair washing basin for the bedbound.
- For use in emergencies, powdered shampoos may be useful. Some patients use oatmeal, cornstarch or talc powder.
- Dry hair while lying flat in bed to avoid overexertion. If hair is thick and the weather is cold, hair can be dried by lying on some pillows on the floor and laying the hair next to an electric heater for half an hour. Longer hair that is wet can be done into 2–4 rough plaits to let air circulate around the scalp a bit more if the patient starts to feel a serious chill.
- Micro-fibre towels are very light and small and dry hair quickly and thoroughly. On hot days, wet hair quickly under the tap and let dry naturally after towelling off briefly, to cool the whole body down.
- Hair can be washed while lying down in the bath. Perhaps where a full hair wash is not possible, the hair could just be given a water rinse between washes to help keep hair fresh longer.
- Once hair is dry, comb hair while lying down in bed using a big (and light) brush if possible, to minimise the number of strokes needed. Hair can also be brushed by a carer while the patient lies in bed.

**Tips on hair maintenance**

- Many patients with severe M.E. choose to cut their hair very short, for easier maintenance. This style means that there is no need for a hairdresser as hair can be cut with clippers, there is no need for hair styling before going out or having visitors, and hair is very easy to wash and also dries very quickly.
- Some M.E. patients prefer to keep their hair just long enough to tie back so that it can be easily pulled away from the face (and so easily styled for trips out of the house too). Hair on the face may make the skin on the face greasy and cause pimples, especially where hair washing isn’t done as often as it might be. It can also cause problems with concentration where the M.E. patient must have an entirely distraction free environment to do simple tasks such as walking. Hair this length can be quickly styled by twisting it into a bun and securing with a hair claw. Hair claws pull at the hair less than (even snagless) elastic hair bands.
Hair that is around shoulder length, and that is usually tied up in a bun with a hair claw or put in a ponytail can be trimmed easily by the patient either in a 2 minute standing-in-the-bathroom haircut, or in bed using a mirror placed by the side of the bed. Use a hair claw to tie back the back half of your hair and cut the front part first, then let all your hair down and brush it, then cut the other half. Tie hair into a ponytail to check for any missed longer hairs and trim any that you see.

Or, for a quicker if messier cut, just tie hair into a ponytail and chop off all hair longer than a hands-length from the hair tie. Another technique used by some M.E. patients is to position a beanie on your head and to then cut around it, perhaps using pinking shears to give a more interesting cut. The cut can be altered by parting the hair in different ways before cutting.

To cut a fringe/bangs which feathers hair (especially straight hair) around the face giving you a softer look, one patient recommends that you wet your hair and plaster it to your forehead then cut little Vs into the line of the fringe (preferably using pinking shears).

Mobile hairdressers may be available in your area and may be a good idea, if you can afford them and if you can sit up for the (very long for some) 10 minutes or more required. (Many M.E. patients would find sitting up so long impossible.) Some mobile hairdressers may also cut your hair for you while you lie in bed.

‘Bad’ hair or very short hair can be covered up with a bandana, scarf or hat where desired.

To shave legs, use an electric razor or epilator while lying down in bed, using a bath towel laid under you to catch the hair. If you have baths, you can also shave armpits and legs while lying down, just using a disposable razor. Don’t waste time upright shaving legs standing up in the shower!

Many patients with severe M.E. choose to keep their pubic hair trimmed to a very short length (with scissors or electric clippers) for reasons of improved hygiene and comfort. When using clippers, narrow clippers designed specifically for use on pubic hair may be best and your grip on them can be improved by wrapping a few rubber bands around the clippers. Clippers may be easier to use, but for some the noise of them and the effort needed to set them up may make scissors a better option.

To shape eyebrows with tweezers in bed, use a small mirror with at least 2 x magnification. Don’t waste upright time doing this standing up. If you’re able to sit up, prop a mirror on a lap desk or bed tray.

Tips on oral care

Get an electric toothbrush. (A cheap model is fine and you may want to look for cheap replacement head packs online.)

Brush teeth in the bath, lying down, just before getting out. Use tap water to rinse out your mouth, and then spit it into the bath (away from yourself!) just before you get out.

Patients should buy toothpaste that has a flip-top lid only, no screw tops. When tooth brushing is not possible, floss teeth and use mouthwash while lying down in bed.

Nursing homes and hospitals use products a bit like a large cotton bud or a small sponge on a stick to gently clean patients’ teeth or apply mouthwash.

Patients that have severe jaw pain and cannot open their mouths wide enough for teeth brushing may use a finger with some toothpaste on it to clean their teeth or, even better, a slip-on textured finger toothbrush. To find these products, search for ‘silicon finger toothbrush’.

Tips on hand washing

Liquid soaps save valuable time compared to bar soaps and they make lather far more quickly (and are also less tough on painful hands and body parts).

Some patients keep unscented baby wipes or a bottle of inexpensive vodka (!) or isopropyl alcohol next to the bed to use for hand washing so they don't have to get up to wash their hands. Other patients find these products too harsh and prefer to keep a small basin of water, washcloth and some simple liquid or bar soap by the bed for this purpose. Antibacterial products of any kind are not recommended as they contain unsafe chemicals. (All products containing triclosan should also be avoided.)

General tips

Buy a brush on a long handle to scrub your back, or a textured back scrubbing cloth to use in the bath. Scrubbing your back now and then is important if you spend a lot of time in bed.
- An exfoliating bath mitt or loofah can make bathing quicker and more thorough. A face scrub product may also be useful. Bedbound M.E. patients tend to need to exfoliate more often than healthy people. It is especially important to exfoliate before shaving to prevent itching and ingrown hairs. A foot file or pumice stone is also recommended to keep feet soft.

- A towelling robe (or just towels) can be worn after a bath or shower for 5 minutes or more, to dry off in.

- Trim nails after bathing when they are softer.

- Covering the whole body with thick white soap suds every day, despite what some advertisers would have us believe, is not only unnecessary but is very bad for your skin! Soaps containing harsh cleansers (such as Sodium Lauryl Sulfate) are not good for your skin, and mild soap is needed only on the face, armpits and crotch. M.E. patients need only very mild plant-based products or home-made/pure products if sensitivities are severe. (Some patients also report needing to change products often due to sensitivities developing.)

- Some patients find it helpful to have faucet levers attached instead of turn taps. Levers which set a temperature (like those used in hospitals) can also be useful. Some patients will also need easier to use taps, or for taps to be lowered to be more reachable.

- If you have M.E. and bathe alone, always keep a torch handy in case the power goes off (if like most M.E. patients you have no sense of up and down at all without light).

- Bamboo towels are very soft and may be a good choice for the very severely affected M.E. patient.

- Other problems commonly faced by M.E. patients to be aware of include dry skin and many different skin conditions, scalp infections and itching, night sweats, ingrown toenails and nail infections.

**Tips for when bathing isn’t everyday, or is more a sponge bath than a full shower or bath:**

- Keep a natural rosewater spray by your bed to spray onto face and legs and arms and anywhere else to feel cooler (or less ‘ugh’) for a short time afterwards. Use throughout the day or during long hot nights or fevers. Especially good in summer. (Avoid synthetic rose scented products. If smelling like a rose holds little appeal, try making your own very diluted ginger oil spray or other scented spray, or use plain water.)

- A bed bath can be given by a carer, or can be done by the patient using a bowl of warm, very mildly soapy water and a soft face washing cloth or sponge. It may not be possible to wash all areas in one attempt. Products such as pre-moistened body wipes may be used where the patients can tolerate the chemicals they contain. The advantage of these wipes is that no drying is needed afterwards. Some patients alternate the use of wipes with a soapy water and sponge bed bath.

- If you get up to go to the toilet, you could possibly do a ‘drive-by sponge-bath’ by washing a small part of yourself each time you go. One trip may include a quick face wash using a liquid soap, another toilet trip might include a quick underarm wash or tooth brushing.

- A warm soft and fluffy robe is a good idea for wearing on the trip from the bathroom to the bedroom, or for just after you have had a sponge bath or are changing clothes.

- Some patients recommend wiping under arms with hydrogen peroxide and then using a deodorant if you are unable to bathe every day.

- Talcum powder (if not allergic) or cornflour can be used on folds where skin cracks due to sweating and then doesn’t heal. Cornflour also helps somewhat where skin is reacting to seams or parts of clothes.

- Changing clothes and sheets more often can help offset the problem of non-daily baths.

**A note to M.E. patients:** If you are not well enough to bathe daily at the moment, know that many severely and even moderately affected M.E. patients can bathe ‘properly’ only once a week or so, due to severe illness. This is very common in M.E., even though it isn’t something that is often talked about. While it is not ideal, it is also nothing to be ashamed of.

Just do the best you can with your ‘birdbaths’ or sponge baths (and perhaps hair that sometimes looks like a birds nest!), hang in there and keep hoping for, and working toward, better health in the future, and know that you aren’t alone.
More information

- To find more disability equipment that may be useful for making bathing easier, patients or carers may like to do an internet search for terms such as ‘bathing disability equipment.’
- For more information on the severity of M.E. and caring for M.E. patients please see Hospital or carer notes for M.E., and Why patients with severe M.E. are housebound and bedbound.
- More tips on living with M.E. are available on the Practical tips for living with M.E. web page.

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This paper is included in the new Caring for the M.E. Patient book by Jodi Bassett.

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Assisting the M.E. patient in managing toileting tasks

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The problems with mobility and maintaining an upright posture previously described in ‘Assisting the M.E. patient in managing bathing and hair care tasks’ can also affect toileting in Myalgic Encephalomyelitis (M.E.) patients.

The physical exertion required to complete toileting tasks can at times be very difficult for moderately to severely affected patients with M.E. It may cause relapse or increased pain during and/or afterwards, and the tasks may have to be modified in some way to be completed or may require assistance from a carer.

M.E. patients may also face problems such as: loose stools or constipation (or both, at different times), urgency, frequency and urinary and/or faecal weakness or incontinence.

The following suggestions and tips come from people that have been ill with M.E. for a considerable time and would like to share some of the solutions they have found with their fellow patients, in the hopes that others may benefit from their years of experience.

Some tips are aimed at M.E. patients themselves, while others provide information appropriate for carers and parents of children with M.E.

Tips on devices that may assist the severely affected patient with toileting:

- If at all possible, the moderately to severely affected M.E. patients should have access to an ensuite bathroom, to save them wasting valuable time upright walking down a hallway etc. to the bathroom. This may also allow some patients to continue toileting themselves independently where this would otherwise not be possible.
- Some patients may find it helpful to have a bar attached to the wall of the toilet that can be used to help them lift their own body weight.
- Wheelchair using patients may need a wheelchair lift to be installed in order to help their carers place them on the toilet.
- Catheterisation carries a significant infection risk in M.E. patients and should be avoided unless there is no other choice.
- Some patients may require the help of a carer and the use of a bedpan for toileting.
- If patients are able to sit upright for a few minutes, a better choice than a bedpan may be a commode chair. This is a plastic or metal chair that can be used in the bedroom, and has a slide-out bedpan that can easily be removed for cleaning by a carer.
- Portable plastic containers designed for urinating in may be helpful for bedbound patients. Different designs are available for men and women (such as the Urifem). Patients may be able to use and rinse out the containers themselves (or with assistance from a carer) and save their valuable time upright for trips to the toilet to defecate. Avoiding all the daily trips to the toilet for urination could mean the difference between improvement and deterioration for the M.E. patient. Using a regular toilet for defecation minimizes cleanup afterwards enormously and can also save the patients dignity.
- Raised toilet seats are available for those patients that find lifting themselves up from lower seats difficult.
Patients that find regular toilet paper painful to use may benefit from having a bidet installed, or having a bidet attachment fitted to their regular toilet.

Some severely affected patients may require the use of adult diapers, fitted and changed often with the help of a carer. Disposable underpads or waterproof sheets for the bed may also be helpful, along with absorbent pads for use inside a patient’s underwear if incontinence is mild.

Additional notes:

- Kegel exercises may benefit many patients with urinary incontinence, as the exercises help to strengthen the pelvic floor muscles. However, Kegel exercises may be impossible for the M.E. patient to complete or even counter-productive due to muscle weakness and paralysis that occurs in M.E. when any muscle is used repeatedly. These exercises may in fact make the problem much worse unless the patient is well enough to tolerate mild exercise.

- If the patient is very ill and basic tasks such as walking to the toilet half a dozen times a day are almost all that can be done each day, and only then with great difficulty, it may well be worth considering the use of a Urifem or a portable male urinal. Giving up independent and unmodified toileting while still able is very difficult emotionally, but may really pay off in the long term. If the patient is overexerting each day then disease progression and deterioration becomes more and more a reality and so pre-empting a forced change of toileting habits may in fact be the best way to ensure independent toileting in the long term.

- It should be noted that patients very severely affected with M.E. may be in the terrible position of being too ill to tolerate any other form of toileting than constant diaper use, but also too ill to tolerate – without extreme pain and suffering from the noise, movement and the interaction with another person – the carer regularly changing and refitting the diapers. Some patients are also so ill that although they need this type of constant care, they do not qualify for it. M.E. patients in either or both of these positions are living in a situation more terrible than most people can even imagine and are a prime reason why some genuine advocacy is so desperately needed, right now. Please see What is M.E.? for more information.

More information

- To find more disability equipment that may be useful for making toileting easier, patients or carers may like to do an internet search for terms such as ‘toileting disability equipment’ or ‘urifem’ or ‘bidet attachment.’

- For more information on the severity of M.E. and caring for M.E. patients please see Hospital or carer notes for M.E. and Why patients with severe M.E. are housebound and bedbound.

Acknowledgments

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M.E. patients have strict limits on how active they can be physically and cognitively and also how much orthostatic stress and sensory input they can tolerate. 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.

M.E. is an overwhelming disease to have to cope with. M.E. patients that have small children to care for also face many additional challenges. Life does not get more difficult than having severe M.E. and small children!

By working with the M.E. patient to try to manage and minimise some of these problems the sensitive carer can have an enormously positive influence on the life of the patient, and the patient’s children. As much as is possible the needs of the patient for rest and avoiding overexertion must be sensitively balanced with the needs of the children.

As M.E. severely affected M.E. patient and mother Tatiana explains,

Sometimes the best care for a M.E. patient is good care for his/her kids, as any parent by nature thinks of his/her kids before himself/herself. And if the kids are not well looked after where is not much chance for heath improvement of the patient no matter how much care the M.E. patient receives. Worries for the little ones will work as a serious stress factor which is one of the worst heath hazards in M.E. as M.E. affects the ability to cope with stress and all strong emotions (and any type of cognitive or physical stress).

Carers can assist M.E. patients that have children in the following ways:

- Do not allow the children to play right next to the patient’s door, as the noise will cause pain and possibly relapse.
- Make sure the TV set is positioned as far as possible from the patient’s room, and always watched at a reasonable volume (and not too loudly).
- Children that can be given enough walks/exercises out of the home will be calmer and quieter at home. When the children are at a park/playground this allows the M.E. patient to have some quiet time off.
- Having the children well looked-after (fed, bathed, well dressed etc.) means that the patient doesn’t have to worry about basic care tasks but instead spends the little ‘well’ time he/she has for ‘quality fun time.’
- Help to teach the children about the illness and its consequences. It’s never too early to start and as children tend to forget things quickly they needed to be reminded all the time. This is a hard or even impossible task for the severe M.E. patient to do themselves.
- Do not allow the children to disturb the patient. It is impossibly hard for the patient to tell the children to leave the room, for a variety of reasons. If they do enter the room sometimes, it may be best to offer
them something interesting to look at or do so they leave the room willingly, instead of telling them off for entering.

**Tips for M.E. patients that have small children:**

1. Have a couch or mattress in every room, so that you can always lie down while you interact with your child. You could also drag around an air mattress for this purpose.

2. Always explain as best you can what is wrong with you. Depending on the age of the child, you may like to use some of the HFME leaflets and summarised papers for this purpose.

3. Have toys, books, paper and pencils next to your bed so that you can entertain your small child on the bed with you when you can’t get up.

4. With slightly older children, have safe foods within the child’s reach so he or she can get something to eat if you can’t get out of bed.

5. Buy the child or children a CD/mp3 player with headphones so that they can enjoy music, without you having to hear it too.

6. Make sure you have emergency phone numbers clearly listed on or near the phone so that children could call for help if you needed help and were unable to call yourself.

7. Wear earplugs or a noise-cancelling headset when you go out in public anywhere with the child such as a park.

8. Give the child rewards for keeping his or her room clean, from an early age.

9. Teach children to answer the phone.

10. One patient writes, ‘When I was feeling ok I would babysit my friend’s kids so they would have my daughter to give me a break when I really needed it.’

11. Have a chair or a bed next to the window so that you can see your child playing outside even if you can’t be there with him or her.

12. Make sure your house is very ‘child safe’ and has the appropriate locks and gates. One M.E. patient says, ‘Locks on every door of the house allow you to block yourself in the room so you don’t have to chase your kid all over or don’t need to get up to check on him/her. After the child gets bored with one room you move together to another. That is why the presence of a couch in each room is recommended. It could be an air mattress which you can drag along with you as well.’

13. A child-proof gate may be able to be places in the hallway to block children (and pets) from coming into, or even getting too close to the patient’s room, when the patient is trying to rest.

14. When you have small children and the severe orthostatic problems of M.E., eating while sitting at a small children’s table may be a good idea. It is easier to be ‘closer to the ground’ with OI/NMH/POTS and if pieces of food fall down they are easier to pick up at the end of the meal, before standing.

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**Acknowledgments**

Edited by Jodi Bassett.
Assisting the M.E. patient in the use of computers and technology

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The HFME video ‘Why everyone with M.E. needs a computer’ talked about the enormous benefits to be had with computer use by M.E. patients. Unfortunately, using a computer is one also of the things that M.E. patients have to be most careful with, in order to prevent serious relapse. This paper looks at some of the ways that M.E. patients can get the most out of their computers, TVs and HDD/DVD recorders, mobile phones and other electronic devices while also using them in the most M.E.-friendly ways.

Computer tips: adjusting the settings to make them more M.E. friendly

- Note that while the computer can be hard to use physically because of the arm movements needed to type and to move the mouse, the main problems with M.E. patients using a computer are often the severe restrictions patients have on cognitive activities such as thinking and doing tasks with several steps and also coping with neurological overload and inputs such as noise, light and also movement. A few minutes of cognitive or neurological overload can easily be more taxing than 30 minutes or more spent typing for some patients. Thus the physical exertion required may be very small in comparison to the level of neurological and cognitive exertion required, although of course individual tolerances in M.E. patients do vary.

- Changes that can be made to make the computer easier to use include making the cursor bigger, making the cursor flash more slowly, making the text bigger, making the scroll bar wider (very helpful!), making the colours used on text boxes etc. less jarring, making the background colour in the screen a pale grey, purple, blue or green rather than a glaring white, muting all sound effects, and so on. Sometimes these settings are found under ‘accessibility options’ or ‘appearance and personalisation.’ To find out where they are on your computer, google ‘increase text size on Microsoft XP’ for example to get detailed step by step instructions on how to adjust your settings.

- Many M.E. patients need to dim the computer screen as far as it goes or turn down the screen brightness severely to be able to look at the screen without pain.

- Some patients may prefer to have the computer speak the words on the screen rather than to read them and most computers have this option. Programs can also be bought which allow emails or documents to be written using your own voice input.

- It is highly recommended that M.E. patients disable animations from playing automatically on their computer as these can cause seizures, vertigo and severe relapse. (M.E. patients react so badly to these types of moving images that it is easy to tell a site isn’t a genuine M.E. site if it has any moving animations on it!) This is easily done when using Firefox (with Flashblock installed as an add-on). In Internet Explorer it is slightly more complicated, click here for information on how to change this setting in IE. A good pop-up ad blocking program is also important in M.E.

- Timer and alarm programs can be helpful to remind you to get off the computer after a certain amount or time or to remind you to do other tasks while on the computer. Alarm programs can also remind you of birthdays or other anniversaries and tasks.

- A free program is available which can disable the ‘caps lock’ key. It is easy to accidentally hit this key and to write all in capitals but one should never communicate with fellow patients in this manner as it is much harder to read than normal text. Stick to plain fonts and easy to read text colours too with no busy or moving backgrounds.

- To avoid having to read text in colours and font and sized that are not ideal for you, set your email...
program to view emails in ‘plain text.’ This lets all your emails come up as black 12 point Arial or TNR, or whatever you prefer, no matter how they were actually sent.

**Computer tips: different types of physical computer set-ups**

- The computer should always be used lying down if at all possible with M.E. Even where symptoms from using the computer upright are not obvious or severe it is still a good idea to save this needless exertion to benefit your health and also to save it for tasks which must be done in an upright position.
- Notepad or laptop computers are generally much easier to use lying down than standard computers.
- A laptop computer can be used in bed via the use of a stand called ‘The laptop laidback.’ The stand is very light and easy to use and can be very useful for the M.E. patient.
- A laptop computer can be used in bed via the use of a strong trolley slid over the bed.
- Where the patient can touch-type, a standard computer monitor can be placed on a table by the bed at the appropriate height and angle, or mounted on a swivel arm to the wall above the bed. The patient can then place a very lightweight keyboard and mouse/trackball on their lap and start using the computer.
- Special keyboards and mouses are available for those with disabilities. Some keyboards are designed to reduce the strength needed to type. The computer can also be voice controlled, or you can set it up to use a combination of keyboard, mouse and voice input.
- If money is very tight, look for free or subsidised computer or laptop programs in your area.
- An anti-glare screen can be fitted to the computer monitor to reduce eye strain.
- Where EMF sensitivity is severe, it is important to avoid wireless devices. Please read: Computers for the Electrically Sensitive (ES) for more information.

**Computer: different uses and important websites**

- Online support groups are a must and there are so many now online. You can’t and shouldn’t have to go through this alone. It can take a while sometimes to find a group that suits you, it helps if you have illness severity in common among other things and sometimes you might have to join more than one group to find the right one for you.
- Another way to get support from fellow patients and to stay in touch with friends and family is Facebook. Ignore all the games and quizzes and just use it to communicate in short and fun ways.
- Use the favourites bar or list so that you can easily access all your most frequently visited sites.
- Make sure you enlarge the text on websites so you never have to strain your eyes. In Firefox click on the ‘enlarge text size’ link and in IE use the controls at the bottom right of the screen.
- Learn to shop online and get a Paypal account and/or a debit card so that you can do so easily. You may want to check out eBay, iHerb, and bookshops such as Betterworld Books, The Book Depository and Amazon plus grocery delivering services in your area.
- Writing letters electronically lets you send the same email to lots of different friends and family members all at once, saving lots of writing time. If handwriting is easier for you, you can scan a letter and print it out and send multiple copies via snail mail.
- Becoming educated about M.E. online really is a must too if you are at all able. Understanding your symptoms lets you deal with them better and knowing a bit about the politics of the whole thing means you can argue your case better if you need to. You really need to be selective about what you read though – there’s a whole lot of crap out there!
- Some hobbies have computer versions which might be easier to do than the real thing. For example, jigsaw lovers (like Ingeborg, who suggested this tip) may like to visit the www.jigzone.com website.
- If typing is difficult, print your emails and write your replies on paper and let a carer type them and send them. If you have a laptop with no internet connection then download your emails from an internet-connected computer to the laptop via CD or USB, reply to the emails on the laptop (lying down) and then transfer them back to the other computer and send them.
- Join Yahoo so that you can join various support groups.
- Go to Yahoo, or Google or your internet provider to get a free email address for yourself.
- Sign up with your bank to do your banking online and pay bills online.
- Be aware of nasties, scammers and misinformation online. All warnings about new scary computer viruses passed on to you by friends are not genuine! Get good anti-virus software and never open attachments from people you don’t know.
- Get emails only infrequently if you are very ill, don’t check for new ones when you are online every few minutes.
- Google for help when you have computer problems or software problems. Most often you’ll find that someone else has had the same problem and that someone has offered them a solution already.
- Make some of your notes and to-do lists and medical and budget charts on the computer.

**Phones**

- Always put an answering machine on, or turn your answering service on, when you do not wish to take calls or are too ill for calls and need to be resting. Always ignore your mobile/cellular phone unless you are really up to texting or taking in new input etc. Nothing is more urgent or important than your own improvement!
- Mobile phones can be helpful to have for texting with friends, family members or carers and also for emergency use.
- Mobile phones can permanently be set to ‘silent’ and can just flash a small light for an hour or so when a text has come in. M.E. patients may also like to adjust the brightness of the phone’s screen to the lowest setting, and adjust the text size.
- Mobile phones with QWERTY keyboards are much, much more M.E.-friendly for texting than the standard buttons with 3 or more letters for each button, and are coming down in price finally. Where a QWERTY keyboard phone is not an option, it may be possible to write texts using your computer keyboard if your phone company has an online text sending programs available.
- Mobile phones with pre-paid credit may be the cheapest option where use is only occasional or very light. Often just $25 - $30 of credit can be bought at a time with an expiry period of 6 – 12 months.
- Touch-screen phones may not be ideal for M.E. patients and may be far more effort to use than regular phones. They may require far more cognitive and neurological resources to be used by the M.E. patient than a standard phone. With a touch screen phone, there is more need to actively look at the screen, the moving/changing screen, which chews up the brain's resources (oxygen, blood etc.) really fast compared to just pressing buttons which are always in the same place and kind of doing things on automatic pilot. With standard buttons you have either pressed them or not, but with touch-screens it can be more difficult and it may need to be done twice or a certain way, making doing tasks with several steps much harder. (It can ruin the 'flow' and that can make the task much more costly in brainpower.) Plus the way some of these phones scroll fast through images or emails etc. is seizure inducing in M.E., and it can hurt hands and leave them bent to have to touch the screen in certain ways, rather than just pressing buttons in the normal way where you can do it different ways to suit you. Simple is often best in M.E.
- Multi-media messages (MMS) such as text accompanied by an image may be useful where another person is shopping for items on your behalf.
- Phone calls made internationally may be much cheaper is the voice over internet protocol (VOIP) is used. This connects you to your friend or family member through your computer, rather than your phone. Some mobile phone handsets allow the handset to be used for VOIP calls.
- Some phones have the ability to amplify outgoing (or incoming) sound. Some two-handset phones can also be used as an intercom, to enable communication between the patient and a person in another room in the house.
- Where EMF sensitivity is severe, or holding a handset is difficult, phones can be used wearing a headset. Speakerphone can also be used for these reasons but it often requires loud talking and makes sound very
fuzzy due to distortion.

**Messenger and online chat rooms**
- Using online live chat features on the computer or the mobile phone may be too much for many patients, but a very useful and enjoyable tool for others.

**Television, VCR, DVD and HDD/DVD recorder tips**
- Make sure any TV or HDD/DVD recorder or player you buy has a MUTE button.
- If possible, buy a HDD/DVD recorder that has a 30 or 60 second ‘skip’ button. This allows you to skip through ads with a few button presses and most importantly, means there is NO NEED to watch the ads whizz by at high speed which can often cause seizure or neurological overstimulation problems in M.E. (Grand mal seizures occur in some patients but more minor types of seizures are far more common and also very unpleasant.) This button can make a huge difference to the M.E. patient.
- The TV can be linked to the VCR or HDD/DVD recorder using a cable. This allows TV shows to be listened to without the TV being turned on, for when sound well tolerated but images would be too much stimulation. It also allows much clearer sound, which can make voices more distinct at a lower volume.
- A HDD/DVD recorder can be very helpful to M.E. patients as it can allow the pausing of live TV for breaks when needed, the pausing or skipping of all ads breaks, and TV shows to be watched at the time most convenient or in several goes rather than all at once. The TV show can also be taken back a few minutes if you’ve drifted off for a while. Some models will also record your favourite TV shows each week automatically and remember your place of you stopped watching a recording partway through a few days or weeks previously.
- HDD recorders can be used to store dozens of your favourite recorded TV shows or movies on, that can be ready to watch with no need to get up and put discs on. It is less stimulating to watch things that have been seen several times before and so such shows can be a good choice when you are ill but want the comfort of a funny movie or TV show.
- Where watching TV causes neurological overload, the patient can turn their back on the TV and watch the TV screen in a small mirror. This reduces neurological overload significantly.
- HDTV may cause problems that watching SDTV may not, according to some patients. Bigger TVs may also cause far more problems with neurological overload.
- TV can be just listened to with the eyes closed on days where neurological overstimulation is severe, or when the show is very visually uninteresting.
- Where the dialogue is indistinct or the background music is awful and too-loud, it can be helpful to mute the TV and read the dialogue via teletext or subtitling, where available. This requires either a teletext TV or a digital TV or HDD/DVD recorder (with a digital tuner) and is only available on some shows. Sometimes it may help comprehension to have both sound and subtitling.
- A universal remote may or may not be less complicated than having 3 or 4 separate remotes. If the DVD recorder remote has a better design than your TV remote, then set your TV to the DVD recorder channel and just use the DVD recorder remote for everything except turning your TV on (unless your remote supports this function, as some do).
- YouTube can be a replacement for when there is nothing good on TV. It has lots of good free content. Do searches for your favourite stand-up comedians, clips from favourite TV shows from your childhood or more recent TV shows, your favourite music videos, and so on.
- Using a tape-head cleaning cassette may help reduce the fuzzy background noise made by the VCR. If upgrading to a HDD/DVD recorder, buy one which allows all your video cassettes to be easily digitized.

**Buzzers and intercoms**
- Portable doorbells can be used to communicate with carers. One beep or buzz may mean ‘Could you please bring me lunch now’ while two might be agreed to mean ‘I need help now, can you please come?’ and so on. Some portable doorbells (or baby monitors) also come with an intercom which allows
speech both ways.

- A front door buzzer and intercom can be used to talk to people at the door without getting up, until and unless it is necessary. An automatic door opener may also be useful, where after speaking to the person via intercom, a button is pressed to electronically unlock the door. Door locks which allow entry to the house when the correct code is keyed in can also be useful, and have the advantage over giving people keys to the house as the code can more easily be changed regularly.

**Voice recorders**

- Voice messages for carers can be recorded when the patient is feeling at their best and then left out for the carer to play back when they arrive. Many mp3 players, computers or mobile/cellular phones have a voice recorder function that could be used for this purpose.
- Ask your doctor if they mind if you record your appointment using a voice recorder, if your memory is poor. If you are housebound and asking for a phone or email consult (many times!) hasn’t worked, it may be possible to have a very well-briefed friend or carer attend your consult in your stead and to have them record the consult for you.
- Instead of writing letters or emails back and forth with fellow patients, some patients prefer to send voice recordings back and forth using digital voice recorders or tape decks with a voice record function.

**Music players and mp3 players**

- Portable music players can be used to play restful or classical music, mediation or relaxation recordings, audio books or even M.E. activism information from HFME in audio format. They can be listened to using headphones or earbuds, or can be attached to a mp3 player compatible stereo or set of speakers. Some speakers are also able to charge your player. A portable music player gives you access to all of your recordings in every room in the house.
- A more old-school alternative to a portable mp3 player is a 5 disc mp3 player. This type of player allows you to put all of your music (or at least lots of it, perhaps 60 mp3 albums) on the 5 discs meaning that there is never a need to get up and change discs.
- Mobile phones and voice recorders can also often be used as mp3 players, but they may not have a very good battery life if used for this purpose.

**Miscellaneous other useful gadgets and tips**

- Noise cancelling headphones can help with the sensitivity to sound in M.E. The best and most expensive kind are made by Bose, but Sony and other brands also make good quality models.
- A ZEM headset may also possibly help with the sensitivity to sound in M.E. The Hyperacusis Network says: ‘This headset is unique. The ZEM works by directing sound away from the ears. Sonically sealed chambers act as an extension of the ear canal. They form a vacuum that pulls harmful sounds away from the sensitive ear anatomy.’
- An air filter with a HEPA filter is a good idea if you have a severe dust allergy or problems with other airborne pollutants such as mould. Some even have carbon filters which help remove chemicals from the air too to a certain extent. If possible, check that the model you buy isn’t unnecessarily noisy.
- Environmental control systems can let a patient control lights, curtains, buzzers and the door and telephone while lying down in bed. These systems may be provided for severely disabled patients for free or at a reduced cost depending on which country you are in.
- Consider getting a dishwasher, if finances allow.
- Consider getting an electric blood pressure monitor, if finances allow.
- Consider getting an electric shaver and/or electric toothbrush, if finances allow. Electric blankets or heat pads can also be useful, and placed on the bed and then removed where EMF sensitivity is severe. Electric heaters may also be useful at times, along with portable airconditioners (or ducted heating and/or cooling systems).
Digital cameras can be useful for taking photos of pets or friends or family or if photography is a hobby. Many mobile phones contain a camera. Extras like ‘anti-shake’ technology can be useful, but really for most patients a cheaper model or a hand-me-down camera from a friend or family member that wants to upgrade will be adequate.

Lights that turn on and off with a touch may be less effort than standard switches. If the switches on lights or heaters or other items are difficult to use, or too far away to get to from bed, it may be preferable to attach a few items to a power board that has 4 or so individual sockets and switches, so you can turn any of the 4 items on or off from the one board, placed near your bed.

Lights with dimmers can be very useful where light sensitivity is very severe.

Electronic pill boxes are available which beep until the correct pills are taken and so remind you to take pills at a certain time. Alarms and timers can also be helpful to remind you to do certain tasks. Many mp3 players and mobile/cellular phones also feature a timer.

Some patients prefer to read books either using their computer or an e-reader.

Some patients are able to use electric wheelchairs or scooters. Check with the government in your country before purchasing to see if you qualify for some type of assistance with this purchase.

If possible, test the noise made by new gadgets, both in standby and when in use, before buying them. This can be done using your own ears, or those of a family member, or using a Sound Level Meter. Note that a SLM will only tell you how loud a product is, and not what pitch the sound is which can be a problem when high pitched noises cause far more pain than other noises as often occurs in M.E.

Read reviews about products online before purchasing and research what the price range is. If buying online, look around to find the best price from a reputable seller. If buying in person, try haggling and asking the sales person if they will accept a lower price.

**M.E. computer and telephone etiquette tips**

- It is easy to accidentally hit this key and to write all in capitals but one should never communicate with fellow patients in this manner as it is much harder to read than normal text. This is because there is no variation in the height of the letters, which makes deciphering them much more difficult to do at a glance. It is not uncommon for M.E. patients to be unable to read text done in all capitals, or without lots of line breaks or in anything but basic fonts and colours. (Avoid bright yellow, pink or aqua cursive or italicised text when writing to fellow patients, or anyone else! Stick to basic fonts like Arial and TNR and avoid the awfully spaced ‘Courier’ font as well.)

- Be forgiving and generous with your fellow M.E. patients online, and everyone else as well. Words are so easily misunderstood when there is no tone of voice or body language input to go with them. Sometimes a sentence is badly worded and gives a different meaning altogether, and sometimes a person may be very super-sensitive about an issue and may misread an ambiguous phrase as aggressive, sarcastic or mean when in fact it was written very kindly. Sometimes that person is you!

  It’s hard to understand sometimes that the email you wrote with a caring spirit and big friendly smile on your face could be taken the wrong way, but it does happen. If you think someone has said something mean to you and this is out of character for them, ask them to clarify (in a neutral way) before you maybe get very mad at someone and perhaps lose a good friend or upset everyone in your support group for no good reason.

  Cut your fellow M.E. patients some slack for making dumb or irritable sounding comments now and then (remember the tone of emails is easily misconstrued), or for not wording something right or forgetting things. These things are often just a part of the illness. Just as importantly - cut yourself some slack too! Nobody is going to be able to do or say everything perfectly ‘right’ all the time, particularly when dealing with so much physically and in so many other ways. What is important is that we all try and do the best we can, to try and help our fellow patients through this awful situation as best we can. Overall, we do an amazing job at this!

- Before you get angry about how you are being ignored or rejected by someone with M.E. (because they haven’t responded yet to your e-mail/phone message/invitation to visit) consider the thought that maybe the person just hasn’t had time to respond to you yet because of their illness. Just because YOU would have answered within the particular time frame (and if you hadn’t it would be because you are ignoring or snubbing the person), you have to remember that another persons ability level may be very different.
Getting no response does not mean that the person necessarily has any negative feeling towards you or what you’ve written at all. It just means they haven’t replied yet! Keep reminding yourself that we all work to different (and very unreliable) timetables. The last thing you want to do is get yourself all worked up over someone having the gall to do absolutely nothing to you!

- Try to stop yourself making assumptions about how well someone is based on their tone of voice or the fact they’ve called or visited or done a lot of emailing recently. We all know these things are not reliable indicators of our health status. Non-sufferers make these sort of assumptions all the time because they don’t understand what M.E. is like. But wouldn’t it be wonderful if at least our fellow sufferers didn’t do this to us? Remember that: (1) Sounding happy is not the same as sounding healthy. Feel free to comment on how happy someone sounds but don’t assume that this means that they are doing well health-wise (2) Also remember that just because someone did task A, it shouldn’t be assumed that they can necessarily also do task B, or even do task A again anytime soon! You just don’t know how easy or hard doing a certain task was for someone with M.E., or how long they had to pay for doing what they did (with a relapse) unless you ask them. A person may be emailing a lot and/or very active in a support group because they are very sad and fed-up and need the communication right now, even at the cost of relapse, for example.

   Appearances can be deceiving! If you want to know how someone is doing health-wise, or what they can and can’t do, just ask them!

- When more severely affected sufferers join a support or discussion group this can sometimes make other members feel a bit uncomfortable. But it is important to not assume that those who are severely ill will be entirely unsympathetic to the problems of anyone less ill than themselves. This (just plain wrong) assumption can leave the severely ill sufferer with considerably LESS support than others, which is of course really unfair! Please don’t be intimidated by severe sufferers – all they want is to give and receive the same support that all of us want, need and deserve. No more and no less than anyone else. We are all suffering and all need as much support as we can get. There simply is no aspect of ‘competition’ involved in this for most people and many severely affected patients still have a lot of sympathy for those who are less severely affected. Moderate M.E. is hell too, most of us know that very well!

- Always keep to the facts when discussing M.E. politics. (Generally those who resort to personal attacks only do so because they don’t have any actual facts to back up their opinion, but they refuse to accept what the other person is saying, for various reasons.)

- If you’re hosting any sort of event for M.E. sufferers always remember that this should always take into account the severely ill. If the severely ill cannot be accommodated you should explain why this is not the case and apologise if appropriate. (For example, wheelchair access may be necessary, or talks could be transcribed and made available in written format etc.)

More information
- For more information on the severity of M.E. and caring for M.E. patients please see Hospital or carer notes for M.E. and Why patients with severe M.E. are housebound and bedbound
- More tips on living with M.E. are available on the Practical tips for living with M.E. page.

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Assisting the M.E. patient in managing relapses and adrenaline surges

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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 from 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 Health, Healing & Hummingbirds website 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, Ashwaganda, low dose cortisol and unrefined sea salt.)
- For tips for M.E. patients on avoiding overexertion see 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. The feedback I have had so far from M.E. patients that have read this paper has been overwhelming and very positive. It has probably gotten the most positive feedback of almost any paper I have written, and the most responses as well. Further comments and suggestions from knowledgeable patients or doctors are always welcome.

Reference list:

- Dowsett, Elizabeth MBChB. in: Colby, Jane 1996, CONSULTATION
- Dowsett, Elizabeth MBChB. 2001b, Time to put the exercise cure to rest, [Online], Available: http://www.hfme.org/wdowsett.htm
- Dowsett, Elizabeth MBChB. n.d. a, Differences between ME and CFS, [Online], Available: http://www.hfme.org/wdowsett.htm
- Dowsett, Elizabeth MBChB. n.d. c, Brain problems in ME – is there a simple explanation? , [Online], Available: http://www.hfme.org/wdowsett.htm
Before reading any of the above links to research/advocacy information, please be aware of the following facts:

1. Myalgic Encephalomyelitis (M.E.) and ‘Chronic Fatigue Syndrome’ (CFS) 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 was 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. 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,’ ‘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 M.E. into Context.

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 homeostasis (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

‘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.’

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 arrythmias.” 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.’

JODI BASSETT, FROM ‘AVOIDING OVEREXERTION IN M.E.’

‘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
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.

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.

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.

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.

Adrenaline surges are one of the best and worst things about M.E. They provide a way for our bodies to cope with overexertion in the short term and they can allow us to attend events that are very important to us (such as funerals, weddings and medical appointments) which we would normally be too ill for. Unfortunately, they also let our bodies 'write cheques they can't cash' and are the reason why so many of us are severely affected. The payback for each adrenaline surge is just so enormous and so prolonged. It can be tempting to rely on them for a while especially when you are first ill, until the whole house of cards inevitably falls down and you are far more ill than when you started, possibly for months or years afterward. Adrenaline surges are also so often misunderstood by others.

For example, when I warn a friend that I am having a bad day and may not be up to much while we have our visit, the adrenaline surge phenomena of M.E. sometimes creates an illusion of good health. I get more and more ill as the evening wears on, and when it gets bad enough that my body is in real physiological difficulty, my body floods with adrenaline and I appear to suddenly become quite well. I talk a lot and very quickly. It is frustrating but of course quite understandable that so few people can see the difference between genuine health and vitality, and an adrenaline surge brought on by a health crisis, the latter of which is anything but a sign of good health in the M.E. patient. I don’t expect others to always recognise this sign of a pending relapse, but to have it misinterpreted as a sign of improvement can be hard to take!

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!).
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, DISCUSES 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, couln't you?
no, i don't have the money
oh, but you could borrow lots of money, sell your house, talke 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. yioyu 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.

This paper is included in the new Caring for the M.E. Patient book by Jodi Bassett.

The book also includes a Foreword by the world’s most experienced M.E. expert Dr Byron Hyde and is essential reading for anyone with an interest in M.E.

For more information on all digital and printed HFME books please visit the HFME Books page on www.hfme.org
It is very important that Myalgic Encephalomyelitis (M.E.) patients stay within their limits in order to prevent relapse and disease progression and so that chances for significant recovery are not destroyed. This paper explains how carers and loved ones of M.E. patients can help patients to avoid overexertion and so have their best possible long-term health outcome.

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 an M.E. patient is overexerting or running on adrenaline, may include the following:

- Very fast, loud and continuous talking is a sure sign of an adrenaline burst. The patient may also sit up or stand for longer than usual (without realising they are doing so) or get ‘hyper’ and fired up to undertake tasks that they would usually be too ill to do. Sleeping and resting is very difficult as the patient 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. 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 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.
- 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 or sore throat and painful glands in the neck.
- During and after overexertion, a patient’s pulse will often become much faster (150 bpm or more), their blood pressure will become lower, their temperature may rise and they may feel very hot.

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. Improvements just do not occur after overexertion in M.E. this way. 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.

Tasks done using adrenaline surges come at a very high cost long-term and so must be strongly discouraged and absolutely never encouraged. You might gently remind the patient to lie down and rest if they sit up for much longer than usual, or are talking very fast and far more than usual.
Do not 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, make a set time to talk to the patient so that they do not have to be ‘switched 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 at least 3 days 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, a patient will live long-term only completing tasks which can be done daily or every second or third day without causing relapse.

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.

Thank you for taking the time to read this paper. Please see the full-length version of the text for more information on adrenaline surges and M.E.

Permission is given for each of the individual papers in this book to be freely redistributed by email or in print for any genuine not-for-profit purpose provided that the entire text, including this notice and the author’s attribution, is reproduced in full and without alteration.
As explained previously in HFME papers such as *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 to excite 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 the [Health, Healing & Hummingbirds](#) website.
- 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 for tips for carers and friends 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’?
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 others 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 better 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, water 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 a 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 then 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 the Health, Healing & Hummingbirds website.

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 Health, Healing & Hummingbirds website.
Deep healing in M.E.: An order of attack!
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This paper examines in what order all the different treatments and management techniques are best implemented.

Before starting any new treatment, please read the safety notes given on the Health, Healing & Hummingbirds website. This site 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 main Health, Healing & Hummingbirds papers as listed at the top of the mini-site map on the site. This reading can be spread out over many months.

**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 M.E. 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 on treating acute M.E. on the Health, Healing & Hummingbirds website 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 M.E.

- 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.

| 1. 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.) | Date started | Date complete d | Notes |
| 2. Go on an elimination diet, so 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. | Date started | Date complete d | Notes |
| 3. Eliminate other possibly problematic food from the diet such as caffeine, fermented foods, mouldy foods and replace table salt with unrefined sea salt. | Date started | Date complete d | Notes |
| 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. | Date started | Date complete d | Notes |
| 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. | Date started | Date complete d | Notes |
| 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 | Date started | Date complete d | Notes |

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 the minimising exposures page on the Health, Healing & Hummingbirds website.

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 the Health, Healing & Hummingbirds website.
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 the vitamin C pages on the Health, Healing & Hummingbirds website.

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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 on the Health, Healing & Hummingbirds website. Coffee enemas can also be used for this purpose, if disability allows.

**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 the Health, Healing & Hummingbirds website.

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<td>Candida diet/testing/treatment</td>
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<td>Leaky gut investigation/treatment</td>
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☐ 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 basic supplement guide on the Health, Healing & Hummingbirds website 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.

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78  **PRACTICAL TIPS FOR LIVING WITH MYALGIC ENCEPHALOMYELITIS: COMPENDIUM**
from cod liver oil started complete

Extra B vitamins Date started Date completed Notes

Extra vitamin E (if needed) Date started Date completed Notes

Extra vitamin magnesium, calcium and potassium. Date started Date completed Notes

☐ 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.

☐ 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 vitamin page on the Health, Healing & Hummingbirds website.

Daily niacin flushing Date started Date completed Notes

☐ 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 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.

☐ 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 the vitamin D page on the Health, Healing & Hummingbirds website.

☐ 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 the page on treating adrenal and thyroid issues on the Health, Healing & Hummingbirds website.

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.)

Starting to take a sachet of liposomal glutathione (GSH) daily (or weekly) at this time is also recommended, if budget allows. For more information on GSH see the Health, Healing & Hummingbirds website.

<table>
<thead>
<tr>
<th>Vitamin C, 10-20 grams daily and/or liposomal vitamin C x 2</th>
<th>Date started</th>
<th>Date completed</th>
<th>Notes</th>
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</thead>
<tbody>
<tr>
<td>Liposomal GSH</td>
<td>Date started</td>
<td>Date completed</td>
<td>Notes</td>
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</table>

- 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 HHH basic supplements guide 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 the Health, Healing & Hummingbirds website.

<table>
<thead>
<tr>
<th>Cod liver oil/fish oil</th>
<th>Date started</th>
<th>Date completed</th>
<th>Notes</th>
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<tbody>
<tr>
<td>CoQ10/ubiquinone</td>
<td>Date started</td>
<td>Date completed</td>
<td>Notes</td>
</tr>
<tr>
<td>L carnitine</td>
<td>Date started</td>
<td>Date completed</td>
<td>Notes</td>
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<tr>
<td>vitamin D (as cod liver oil or D3)</td>
<td>Date started</td>
<td>Date completed</td>
<td>Notes</td>
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<tr>
<td>B12</td>
<td>Date started</td>
<td>Date completed</td>
<td>Notes</td>
</tr>
<tr>
<td>Lipoic acid</td>
<td>Date started</td>
<td>Date completed</td>
<td>Notes</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.

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 Klenner page on the Health, Healing & Hummingbirds website for more information.

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 the Health, Healing & Hummingbirds website for more information.

<table>
<thead>
<tr>
<th>Vitamin D test</th>
<th>Date taken</th>
<th>Result</th>
<th>Notes</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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</table>

☐ 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.

<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>
<th>Notes</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, but at the mid-range to high end of the dosages indicated, or as high as you feel is appropriate and necessary.

☐ 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 the Health, Healing & Hummingbirds website.
b. Consider regular coffee enemas and an annual gallbladder flush. Liver support is very important during an FIR sauna detoxification program.

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.

• 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?**
  
  - 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.
  
  - 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.
  
  - 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).
  
  - Increasing the doses of supplements gradually is important and it reduces the likelihood of problems. The body likes gradual change.
  
  - 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.
  
  - 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.
  
  - 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.
  
  - 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.
  
  - 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 the Health, Healing & Hummingbirds website.**
Buying, cooking and preparing food is so hard (or impossible) and makes me so much more ill, how can I try to minimise this?

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. Y

• 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?

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](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5490831/) recommends only pesticide-free whey protein produced solely by ion-exchange (yielding 25% glycomacropeptides 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](https://www.nutiva.com/), as the powder is only very minimally processed, while others say that [Alpha ENF](https://www.alphafactors.com/) 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.
Finding a good doctor when you have M.E.
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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.

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 spherocytosis, 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 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 Irving Spurr** in the UK may possibly be the only UK doctor that still diagnoses M.E. He refers to the disease as EvME and understands the disease to be caused by an enterovirus. Dr Spurr is Chairman of the John Richardson Research group.
- **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, and his political views on M.E. are in no way supported by HFME, 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 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 main articles on the Health, Healing & Hummingbirds website are essential reading.

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 the Health, Healing & Hummingbirds website 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](https://orthomolecular.org) on Orthomolecular.org
- [American College for Advancement in Medicine](https://acam.org) (ACAM)
- [The Center for Holistic Medicine](https://thecenterforswelness.com)
- [ACOEM’s Occupational Medicine Doctor Finder Service](https://www.acoem.org/memberfinder)
- [Patrick Holford’s website](https://www.patrickholford.com)
- [Institute for Functional Medicine: Find a Functional Medicine Practitioner](https://www.functionalmedicine.org/finding-a-physician)
• 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.
• www.biologicaldent.com and www.HugginsAppliedHealing.com provide information on dentists able to do a total dental revision.

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 Health, Healing & Hummingbirds website.

This a free 300 page + fully referenced resource created 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 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 [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 gettter 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 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.

For more information on this topic see the [Health, Healing & Hummingbirds](#) website.
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 the Health, Healing & Hummingbirds website.

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.
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. (e.g. 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 alllying 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 (e.g., 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 documents 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 may be 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.]

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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.’]

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"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 of 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 thiobarbiturates such as sodium pentothal, 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 emergency 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.]

Preoperative considerations in a patient with orthostatic intolerance syndrome 2000

CFIDS and anesthesia: what are the risks? by Elisabeth A. Crean

[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.

[Note that no other part of this site is necessarily recommended. The term ‘ME/CFS’ is not supported by this site, and note that this term should not be considered synonymous with M.E.]

CFS Patient 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.

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, ginkgo, 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.

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 affected 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 ‘

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

[This article is one of the worst there is for supporting the myths of ‘CFS’ and mixing a small amount of M.E. information with psychobabble about ‘CFS.’ This ‘CFS’ site is not recommended.]

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 described 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 meditation 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 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
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 they can do any of the blood work 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 intolerance, 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 oversimplification, 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 anaesthesia 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 hepatoxic 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
- 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]

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**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.]

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**Hospitalization for the Chemically Sensitive Patient**, in Loving Memory of Selene Anema, RN

**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]
The HFME reminders and cognitive tips list

- Things I need to do urgently:
- Things I need to do this week or month sometime:
- Things I need to do, sometime this year or next:
- Appointments I have over the next few months:
- Things I need or want to buy soon:
- Medications and supplements I need to reorder soon:
- Things I’ve ordered and am waiting to arrive in the post:
- Treatments I am thinking of trying soon:
- **My health focus this month is** (eg. resting more, eating better, meditating, taking vitamin C to bowel tolerance):
- **My health focus this month is to STOP** (eg. running on adrenaline so much, eating unhealthy foods when I feel terrible, forgetting to drink water for half the day):
- Friends I really owe an email, letter or call to:
- Birthdays coming up this month:
- Birthday present ideas for friends and family:
- Birthday present ideas for me, in case anyone asks:
- Books and movies I want to read/see/buy:
- Important web pages I want to read or reread when I’m having a good brain day:
- Documents I want to print next time I’m doing some printing (or having some done):
- **My last computer backup was on**:
- Food I need to buy more of:
- Food I have in the freezer that needs to be used soon:

The above list is a template for a computer reminder list for M.E. patients. List items should be deleted if not needed and new ones can easily be added. It can be helpful to make a computer shortcut to this file on the desktop of your computer, for easy access, and to keep this file always open when you are on the computer so you can jot down anything important that comes to mind.

*Other ways to remember tasks and recent events:*
Using a whiteboard to write down all important tasks as soon as you learn of them or remember them, and leaving it right near your day-bed (etc.) so that you will naturally look at it a few times a day. You might make permanent category headings on the whiteboard, with room underneath to add new listings, such as: things to do this month, last computer backup, things coming in the mail, birthdays coming up this month, and so on. Very urgent items can be marked with an asterisks or a different coloured pen.

Where time on the computer is very limited, the above reminders list featured in this document would be replaced with a whiteboard list. Where the patient is very ill, list-making is probably best restricted to this one whiteboard (or a notepad) to keep things very simple. Any other lists may have to be done with assistance from a carer, if at all.

The whiteboard should never be attached to the wall etc. as this would mean only being able to write on it while standing, which is no good in M.E. It needs to be placed leaning against something else to stand up, or have a string and hook at the back to hang it up by so you can easily take it down to write on it.

Keep a small notebook in both rooms, so that if you think of things to be added to your whiteboard or computer reminder list, you can write them down and then tear the page off and take it with you when you go into the other room the next day or have it near you when you go on the computer. You might like to also write a list of things to do for the next day, at night or when you thinking is at its most clear, when you have lots of things that need doing all at once.

Urgent notes for the day can be written on the hand, or written on notepaper and stuck with tape to a door or wall the night before, where you know you’ll see them when you get up.

A diary can be useful for keeping a food diary in, or a running commentary on which new treatments have been tried and any changes to how you’ve felt each day. An A4 or A5 notebook can also be used just as well for this purpose. Knowing exactly when you started a particular treatment can be very helpful in determining what is helping and what is not.

Any changes to your current weekly pillbox fill should be noted, but there is no need to list every item from scratch each time. So for example an entry might say ’2 weeks of pills done today, all as before except 500 mg Hawthorne raised to 2 daily instead of 1.’

Keeping a chart of all the medications you are taking, what each of them costs and where you buy them from is very helpful. Click here to download HFME’s free Budget/Medication chart in Word format.

Keep a separate notebook (or Word document if typing is easier for you) for writing down what is said in your medical appointments or phone consults. Try to fill it in as soon as possible afterwards so that you don’t forget anything.

If you do better with audio inputs than the written word, perhaps you might use a voice recorder to make copies of all your consults instead.

Add to this document a list of all your friends addresses and birthdays (if you don’t already have a birthday remembering system worked out). Make sure to list the birthdays separately and in order so you can easily see who has a birthday coming up. You may also wish to print out a copy of this information so that you’ll always have it close at hand.

Save shortcuts/links to all your favourite websites and support groups to your computer’s desktop. Try to keep it to your top 10 or so so it doesn’t become too cluttered.

Look for an A4 diary with a ‘year to an opening’ section and the front or back, as this can be very helpful to fill in every few days with all the big events that have happened to you and that you have coming up. This can be filled in as well as, or instead of, a standard diary. Having a view your whole year on one page can be immensely helpful and may be able to be done even where filling in any other sort of more involved diary is impossible.

(A calendar could also be used for this purpose. The boxes would be bigger, but it’d be far more awkward to flick through while lying down.)

This can be very quick to fill in if you work out some codes or symbols. For example:
KEY:

1. An underlined day number indicates a day that the disability pension is paid.

2. An asterisks or dot before a day number means that this is the day a period is due (an asterisks after the number indicates that the period has arrived, and the size of that asterisks or dot can be used to indicate the heaviness of the flow for each day of the period).

3. A visit received by a person with a name beginning with C is indicated by a ‘C’ being written on the left side of the box (a C with a line under it might indicate a phone call instead of a visit).

4. The middle of the box can be used to indicate facts or events such as a your current weight, when you’ve had a haircut or a medical consult, important anniversaries as well as important days to remember such as deaths and hospitalisations.

5. A diagonal line can be drawn on the right side of the box each day indicating how long you’ve spent on the computer. Decide first whether a full drawn line represents one or two hours of computer time. If it represents 2 hours, draw a full line if you’ve spent 2 hours on the computer that day, or just half a line if you only spent an hour.

If it is important for you to monitor and keep an eye on time spent on the computer each day, and memory is blurry on these facts past one or two days, this can be very helpful. Other lines in other positions, styles (dots or wavy lines) or colours can also be used to measure other things such as TV time, time spent meditating or your pain level or overall illness level. Make sure you write down exactly what a full line means in each case, on the year to a page sheet, in case you forget later.

*More cognitive tips and tricks:*

- If you haven’t done so already, set up phone or internet banking and automatic bill paying, where available.

- Keeping things in the same place each time saves time wasted always looking for the same things you’ve lost. Find a place for read and unread books from the library, incoming and outgoing mail, letters from friends, bills and so on. Important documents might be pinned to a corkboard so that they are never out of sight, and so out of mind.

- Keep your medication in one or more pill boxes with the days of the week on them so you will know whether or not you have taken your medication each day.

- Removing distractions such as noise or TV on in the background may help you think more clearly or complete a task more easily (or have a conversation more easily). Watching less TV and/or reading less and/or less time on the computer etc. may help increase your cognitive abilities for the rest of the day (you will likely have to choose between quality and quantity of brain-power).

- Save difficult tasks until the time of day when you are at your best mentally. Ask others to also only ask you if you are able to do the more challenging tasks you are capable of, at your best time of day.

- If a task is too difficult cognitively, and you are too overwhelmed to do it, try breaking it down into lots of smaller tasks. Many big tasks can be broken down into smaller tasks. Even if one of these smaller tasks is only done every few days or weeks, in time the seemingly impossible task may be able to be slowly completed.

- Timer programs can be used while on the computer to help you remember anniversaries, birthdays or to take your medication or get off the computer and rest at or after a certain time. See the new paper: ‘Assisting the M.E. patient in the use of computers and technology’ for more information.
Other tips papers available from HFME include: Practical tips for living with M.E., and Tips for coping emotionally with M.E. and Assisting the M.E. patient in managing relapses and adrenaline surges and Assisting the M.E. patient in managing bathing and haircare tasks and Assisting the M.E. patient in managing toileting tasks and also Assisting the M.E. patient in having blood taken for testing.

A note from the author: The cognitive symptoms of M.E. can often be some the most severe and disabling of the entire illness, as well as some of the most concerning and frustrating.

Any of the tips listed here can be used separately and may be helpful but they may be even more helpful in combination, particularly over time as you become used to using them. (Of course extremely ill patients may have far fewer tasks to attend to and may not need, or be up to keeping, so many lists.)

I find I need very much to use all of the tips listed here in order to do any of the things I need and want to do. If it isn’t on one of my lists I just won’t remember to do it, no matter how important it is. Being VERY organised in this way can really help to lessen the cognitive disability caused by M.E. The lists can serve as a replacement for memory to some extent.

All these lists etc. may seem excessive to some, but for me, I do find all of these things necessary unfortunately. To everyone else with M.E. in the same position, I hope these tips help! Jodi Bassett, 2010.
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 entero-virus.

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.)
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 Malcolm 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. ‘CFS’ is a wastebasket diagnosis; a mere diagnosis of exclusion.

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 spanning decades.

**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 legalised 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.

To read a fully-referenced version of the medical information in this text compiled using information from the world’s leading M.E. experts, please see the “What is M.E.?” paper on page 113 of this book or on the HFME website.

**Acknowledgments**

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‘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.’
DR BYRON HYDE 2006

‘Myalgic Encephalomyelitis is a clearly defined disease process. CFS by definition has always been a syndrome. M.E. and CFS are not the same.’
DR BYRON HYDE 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

In the mid 1980s, the incidence of M.E. had increased by some seven times in Canada and the UK, while in the USA a major outbreak at Lake Tahoe (wrongly ascribed at first to a herpes virus) led to calls for a new name and new definition for the disease, more descriptive of herpes infection. This definition based on “fatigue” (a symptom common to hundreds of diseases and to normal life, but not a distinguishing feature of myalgic encephalomyelitis) was designed to facilitate research funded by the manufacturers of new anti-herpes drugs. However, a “fatigue” definition (which also omits any reference to children) has proved disastrous for research in the current decade.
RESEARCH INTO M.E. 1988 - 1998 TOO MUCH PHILOSOPHY AND TOO LITTLE BASIC SCIENCE! BY DR ELIZABETH DOWSETT

‘Fatigue is immeasurable and largely indefinable. Fatigue is a normal phenomenon as well as being associated with almost all chronic disease states. Fatigue, which is simply one of the common features of healthy life and disease, neither defines M.E. nor clarifies the illness. The term ‘fatigue’ does cause disparagement to those who study this serious debilitating illness and those who suffer from it.’
DR BYRON HYDE

‘There are actually 30 well documented causes of ‘chronic fatigue’. To say that M.E. is a ‘subset’ of CFS is just as ridiculous as to say it is a ‘subset’ of diabetes or Japanese B encephalitis or one of the manifestly absurd psychiatric diagnosis, such as, ‘personality disorder’ or ‘somatisation.’’
DR ELIZABETH DOWSETT

‘The human rights of people suffering from M.E. are being conspicuously denied without any justification whatever. It is completely unacceptable that the unsubstantiated personal beliefs of a few immensely influential psychiatrists with indisputable vested interests should continue to indoctrinate UK medicine and the media regarding M.E. and that these psychiatrists should be permitted to impose inappropriate management regimes upon sick and defenceless patients on pain of having their benefits withdrawn if they do not comply, a situation that has continued unabated for far too long.’
PROFESSOR M. HOOPER AND E.P. MARSHALL IN M.E.: WHY NO ACCOUNTABILITY?

‘M.E. [is] a loss of the ability of the central nervous system (CNS) to adequately receive, interpret, store and recover information. This dysfunction also results in the inability of the CNS to consistently programme and achieve normal smooth end organ response. [It is a] loss of normal internal homeostasis. The neurochemical homeostatic events continue to be employed uselessly and to the detriment of the organism. This modulatory biochemical complex, biologically derived over the millennium to assist the organism, destabilises the autonomic neuronal outflow and the individual can no longer function systemically within normal limits.’
DR BYRON HYDE
Jodi Bassett is an Australian writer, fine artist, designer, patient advocate, and the founder of the international M.E. charity, The Hummingbirds' Foundation for Myalgic Encephalomyelitis (HFME).

Jodi contracted M.E. in 1995 when she was just 19. Due largely to misdiagnosis and inappropriate medical advice in the early stages of the disease, and because she was not told of the importance of avoiding overexertion in M.E., she is currently severely affected, housebound and largely bedbound.

For the same or similar reasons, the majority of HFME contributors are likewise disabled.

Very little advocacy exists for M.E. patients, and HFME contributors have determined that despite their high disability levels, they must do what they can for M.E. rights.

HFME contributors also aim to advocate for those non-M.E. patients who have been given the always meaningless ‘Chronic Fatigue Syndrome’ diagnosis, and subsequently denied correct diagnosis and treatment.

For more information on M.E. check out the *Caring for the M.E. Patient* book by Jodi Bassett.

The book includes a Foreword by the world’s most experienced M.E. expert Dr Byron Hyde and is essential reading for anyone with an interest in M.E.

For more information on all digital and printed HFME books please visit the HFME Books page on www.hfme.org