

## Treating M.E.: The basics - Summary

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Myalgic Encephalomyelitis (M.E.) is 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. Some ideas for where to start include to:

### **Make sure you have been correctly diagnosed**

The fact that a person qualifies for a diagnosis of Oxford Chronic Fatigue Syndrome (CFS), Fukuda (CDC) CFS, or either of the Australian CFS definitions (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.' A diagnosis of CFS – based on these or any of the other CFS definitions – can only ever be a misdiagnosis.

The reason for this is that 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. 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.' In other words:

1. **Chronic Fatigue Syndrome** is an artificial construct created in the US in 1988 for the benefit of various political and financial vested interest groups. It is a mere diagnosis of exclusion (or wastebasket diagnosis) based on the presence of gradual or acute onset fatigue lasting 6 months. If tests show serious abnormalities, a person no longer qualifies for the diagnosis, as 'CFS' is 'medically unexplained.' A diagnosis of 'CFS' does not mean that a person has any distinct disease (including M.E.). The patient population diagnosed with 'CFS' is made up of people with a vast array of unrelated illnesses, or with no detectable illness. According to the latest CDC estimates, 2.54% of the population qualify for a 'CFS' (mis)diagnosis. Every diagnosis of 'CFS' can only ever be a misdiagnosis.
2. **Myalgic Encephalomyelitis** is a systemic neurological disease initiated by a viral infection. M.E. is characterised by (scientifically measurable) damage to the brain, and particularly to the brain stem which results in dysfunctions and damage to almost all vital bodily systems and a loss of normal internal homeostasis. Substantial evidence suggests 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, a specific series of tests may also be necessary to help confirm the diagnosis. 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.

### **Avoid overexertion**

The single biggest factor determining recovery and remission from M.E. 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. 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.

This can *only* result in unnecessary relapses and so be counterproductive. Permanent damage (eg. to the heart) and disease progression may also be caused.

### **Work towards learning to accept your illness**

Acceptance of the limitations of the illness at as early a stage as possible is crucial. 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 and/or that there is no quick fix or 'miracle cure' available and that it is something you will have to deal with and adjust to – at least for now.

### **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 and seek appropriate physical, financial and emotional support. You'll need to do things such as:

- ❑ Educate yourself as much as you can medically and politically about M.E. Educate those around you so that they will know better than to believe the baseless propaganda surrounding the illness
- ❑ 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 M.E. sufferers probably will be initially) and make your application.
- ❑ Find out about other services in your area that might be appropriate or that you might need.
- ❑ Support yourself emotionally; 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.
- ❑ Join a 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.)

### **Try to find a knowledgeable doctor**

Of course this is absolutely vital, and very much easier said than done. Perhaps the best way to find a reputable doctor who is knowledgeable about the illness (aside from just trying your luck with as many different doctors as you can find) is to ask fellow sufferers in your area who they would recommend. Some M.E. charities may also be able to help with recommendations (although the quality of the doctors recommended here of course may be far more variable, or even abysmal).

A knowledgeable doctor will make sure you have been correctly diagnosed, monitor your condition for any treatable and/or other concerning abnormalities, provide symptomatic (and other) treatments, monitor new symptoms and much more. It is also very important that you are able to have some of the tests which can be used to confirm a M.E. diagnosis, to remove all doubt that this truly is the only correct diagnosis for you. If your doctor has been misinformed about M.E. or does not understand the world of difference between genuine M.E. and 'CFS' and is unwilling to do expensive tests such as MRI or SPECT brain scans, perhaps you could try to start with some of the cheaper tests and work up. (See: [Testing for M.E.](#) for more information.)

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. It may also be helpful to write a detailed medical history before your first visit, and indeed to make written notes about what you would like to discuss before every consult as an aid to (or a replacement for) memory.

### **Modify your diet and environment**

Most M.E. sufferers will experience food allergies and/or food intolerances as part of the illness and so will have to avoid certain foods. A rotation diet may also be necessary for some sufferers (where particular foods are eaten only every 4 days). Foods which may cause intolerances (and various other problems) include: stimulants (coffee, tea, caffeinated soft drinks, some herbal teas which contain ginseng, lomatium, mate and ma huang), sweeteners (sugar, dextrose, glucose, fructose, splenda, aspartame and saccharin), high levels of animal fats (may not be digested easily), additives (artificial colours, flavours, preservatives, MSG), foods from the nightshade family (potato, capsicum, eggplant and tomato), dairy products, gluten, fruit (may be difficult to digest and the high levels of fructose can trigger hypoglycaemia and other problems), gas producing foods (onions, cabbage, brussels

sprouts, broccoli), spicy foods, raw foods (may be difficult to digest), fermented and mouldy foods and foods containing yeast or wheat, acid foods, nuts and soy.

It is also important that M.E. patients eat a varied diet full of nutritious whole foods, and low in sugar and processed foods. All food should be organic wherever possible, or at least very well washed or peeled where appropriate. Avoid aspartame and MSG. Many sufferers will also do better on a higher protein and controlled carbohydrate diet (and by eating small meals every 2-4 hours). High carbohydrate diets and low salt or fat diets are not appropriate for M.E. sufferers, generally speaking. Try to have some protein, fat and carbohydrate with each meal or snack. If you're at a loss as to how to start, you could go to a website like [www.nutritiondata.com](http://www.nutritiondata.com) and try to put together a diet where your calories are made up of 30% protein, 30% (healthy) fats, and 40% (low glycaemic index/ load) carbohydrates. (If you want a more detailed quick start guide, see 'The Zone' website.)

*Diet is so important in M.E.* It has such a strong effect on the immune system, our hormones, our gut health and our level of neurological and cognitive problems and our ability to detoxify and so on. Treating the gut problems of M.E. is the first step to treating M.E. itself and cannot be ignored. The health of the gut affects our neurological health to a significant degree. **Food is not merely fuel, it is MEDICINE.**

Chemical sensitivities are also common in M.E. as are allergies or sensitivities to various airborne allergens and personal care products. People with M.E. also need to avoid high levels of EMF radiation. Air and water filters may also be useful.

### **Look into treatments for M.E.**

Whilst there is no cure as yet, or treatments which can dramatically influence the natural course of the illness (due to the appalling lack of funding for legitimate research); intelligent nutritional, pharmaceutical 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.

M.E. is an illness known for its variability from each hour, day, week or month to the next. It is an illness where natural spontaneous remissions and relapsing of both the general severity of the illness and of particular symptoms are common. ('Spontaneous' means that these changes are natural, and not the result of treatment.) This means that when trying any new treatment it is important to:

- ❑ Try only one new thing at a time
- ❑ Take the treatment until it works (set a reasonable time limit for this to occur and cease treatment past this point if you notice no benefit), then stop treatment for at least 6 – 8 weeks to see if the effect disappears, then start taking the medication again and monitor the effect. This may need to be done several times. You'll be surprised just how often many medications you initially were sure were helping do not pass this test. If a treatment does pass, you know that you are definitely not wasting your precious money on it.
- ❑ Never spend more than you can afford on treatments in the hopes that this will be 'the one' or because amazing claims have been made about it by the people selling it or through testimonials by other sufferers. There is no 'one' for M.E. as yet unfortunately.

Both traditional and complementary therapies can be useful in treating M.E. However, it is important to ensure that any practitioner treating you for this illness must know what this illness actually is to be able to be useful in any way – and most importantly – to know how to avoid causing you harm (they must be aware that M.E. is not 'fatigue' or 'tiredness' and treating it as if it were will be DISASTROUS).

### **Learn how to avoid inappropriate or harmful treatments and scams**

Some of these treatments may do nothing, some may be harmful and some may have a modest beneficial effect which doesn't match up to the amazing claims made about the product, or justify how much you were persuaded to spend on the product. The biggest 'cost' from being taken in by misleading claims about treatments is not usually the financial cost however, but the emotional one; the high emotional price of false hope. Getting your hopes up that you have found the answer and that things will soon be so much better for you and then having your hopes completely shattered when the treatment doesn't live up to the claims made about it can be truly devastating. The best recommendations for treatments will come from: respected M.E. experts, reputable books on M.E., legitimate research, your own doctor (if your doctor is knowledgeable about M.E.) and perhaps also from well-read fellow M.E. sufferers.

### **Avoid and minimise stress**

Stress unequivocally does not cause M.E. but as with most illnesses, stress can exacerbate the symptoms of M.E. Try to learn 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.

### **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).

**If you were to create a top 10 list of basic, important M.E. treatments, it would have to include:** CoQ10 (ubiquinol), vitamin B12 (as hydroxocobalamin), Essential fatty acids, a good quality multivitamin and multimineral supplement (without iron, copper or stimulants), Probiotics/prebiotics, Magnesium/Calcium/Potassium/Salt, Hawthorn extract, an antioxidant complex (containing adequate vitamin A, vitamin C, vitamin E, Selenium and Zinc – if there isn't enough of each already in your multivitamin, as well as Pycnogenol and grape seed extract), digestive enzymes and L Carnitine/Acetyl L Carnitine.

**If you were to create a top 20 list of basic, important M.E. treatments, you'd probably also add:** Silymarin, Carnosine, Vitamin C, NADH, Undenatured WPI, Ashwagandha, Inosine, Armour thyroid, extra B2 and B3 and Lipoic acid.

Of course this is not a comprehensive list of treatments or treatment cautions, it is just a list of some of the basics. Information given on dosages in this paper is only a very general guide. This paper is designed to be merely a starting point in your research on dosages and treatments, not by any means the last word.

Remember to *always check with your doctor* before trying any new treatments (and to always monitor yourself for the effects of each new treatment to help you and your doctor decide what is working and what is not.) Before you start any new treatment remember too to always start with a very very small dose, try only one new thing at a time and to do as much research on the new treatment as possible (online and in reputable M.E. books) before you start taking it. [Click here](#) to download a free M.E. medication chart in Word format.

### **Are there other tests that I can have done privately that can help with determining the best treatments?**

A number of tests are available privately (ie. not covered by health funds or government etc.) that can help you and your doctor learn more about how best to treat your illness and how it has affected your body, and just as importantly; which treatments to avoid. *Note that these tests are not at all useful for the diagnosis of M.E. and abnormalities in these tests are seen in many different illnesses. They are to help with determining treatment only.* Tests which may be useful include:

- [Hair mineral analysis](#) (including testing for heavy metals such as mercury).
- [IgG food allergy tests](#) test for around 100 different IgG food allergies, by blood test. There is also the [ALCAT - Food Allergy & Chemical Sensitivity/Intolerance Test](#).
- [SpectraCell](#) blood tests can identify missing vitamins and minerals for targeted nutritional replacement.
- [Comprehensive Detoxification Profile](#); and [Standard Detoxification Profile](#); [Comprehensive digestive stool analysis](#), [Urinary organic acids test](#) and [Urine toxic metals test](#) and [Oxidative Stress Analysis, Blood & Urine](#):
- You might also want to look into genomic testing for [methylation problems](#) and how appropriate the [Yasko protocol](#) might be for you. (Although as this test is so expensive, some suggest trying the protocol and just seeing if it works for you. It includes a stone age diet, a good multi-vitamin and mineral supplement with no copper or iron in it, essential fatty acids, vitamins C and D, D-ribose, CoQ10, Acetyl L-carnitine, NAD, [Phosphatidyl serine complex](#), probiotics, and help for methylation with 5mg of B12 daily as [cyanocobalamin](#) and [hydroxocobalamin](#) and 800mg folic acid as [methyltetrahydrofolate](#) although M.E. patients in particular need to start at much, much lower doses and may only ever be able to tolerate far lower doses than this.)

### **What if I only have a tiny bit of money to spend on treatment, or almost none?**

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

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

If you had \$15 a week to spend, perhaps you could also add 1000mcg B12 as hydroxycobalamin (91c), 200mcg folate as L-5-methyl tetrahydrofolate (50c), 1.8g of EPA/DHA from fish oil (\$3.30), 50mg CoQ10 as ubiquinol (\$2.80), 400 IU natural vitamin E (49c), a daily probiotic capsule (\$2.50), 100mg Silymarin (98c), 1000mg vitamin C powder with bioflavonoids (35c) and 1000mg Hawthorn (\$1.80). If you had a bit more money you could add a few more things, and if you had less money to spend you'd have to take off a few things (obviously). If you only have a small amount to spend, it's more important than ever to see what really works best for you. If there are gaps in your supplement regime it is also more important than ever that you try to fill them with your diet. Make everything you eat work for you and avoid empty calories.

You can save a lot of money on supplements by buying high dosage capsules or tablets and then splitting them, and by buying supplements in powder form and either making your own capsules or drinking them in water or in a protein shake. Supplements widely available in powder form include: the B vitamins, vitamin C, Carnitine and Acetyl L Carnitine, Lecithin, various amino acids, prebiotics (FOS), Chlorella, Calcium and Magnesium. You can save up to 50% by buying pure powders, you also avoid synthetic fillers.

**Note:** Many of the links given in the full-length treatment section are to VRP or iHerb products; see the full-length text to read about the VRP and iHerb affiliate programs and how up to 15% of the total cost of some of your supplements and vitamins could be donated towards funding M.E. research and advocacy!

#### **For more information:**

- If at all possible, please the full-length [Treating M.E.: The Basics](#) for more information about all of the subjects discussed here (and much more).
- If you are about to have surgery, read: [Anaesthesia and M.E.](#) and [Hospital or carer notes for M.E.](#) first. See also: [Why patients with severe M.E. are housebound and bedbound](#)
- Before trying any of the treatments listed here, you MUST read the treatment cautions section in the full-length version (and check with your doctor first, if possible). Some of these treatments must be taken with caution and can cause adverse effects if not taken in very low doses to start with, or if the wrong form is taken, and so on. There are also treatments that you need to know about to AVOID. Always take only one new treatment at a time.
- 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: [Who benefits from 'CFS' and 'ME/CFS'?](#), [Why 'CFS' must be abandoned](#) and [What is M.E.?](#) 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](#) and [Where to after a 'CFS' \(mis\)diagnosis?](#)
- For information on how authentic M.E. is characterised and diagnosed see: [Testing for Myalgic Encephalomyelitis](#) and [What is M.E.?](#) See also: [The Nightingale Definition of M.E.](#) by Dr Byron Hyde.
- The paper '[A Million Stories Untold](#)' is also recommended for use in explaining M.E. to your friends and family. See also the new paper: [M.E. vs MS: Similarities and differences](#). For general information for carers and hospital staff or family members on how to appropriately care for someone with M.E. see the new paper: [Hospital or carer notes for M.E.](#)
- To read a list of all the articles on this site suitable for different groups such as M.E. patients, carers, friends and family, the 'CFS' misdiagnosed, doctors or severe M.E. patients and so on, see the [Information Guides](#) page.
- See also [Practical tips for living with M.E.](#) and [Tips for coping with M.E. emotionally](#) and [M.E. and children](#) .....and the best of luck to all of you in your battle with M.E., or with your child's battle with M.E.

**‘Information’ sources to avoid:**

Unfortunately when it comes to information on M.E. there is always far more bad than good available and so it is just as important that you are aware of what information to avoid as well as what is useful. The ME books best avoided section contains a list of books which are not recommended because they; do not distinguish appropriately (or at all) between mere fatigue and the neurological disease M.E., offer inappropriate medical advice which may help some fatigue sufferers but is inappropriate or dangerous for people with M.E., offer unrealistic expectations of recovery based on confusion with mere fatigue sufferers, or they propagate many of the myths and propaganda about the illness which do M.E. patients so much harm.

Add to this list of resources to avoid, any book, website, newsletter, TV segment, radio segment, newspaper article, research – or anything else that; uses the term ‘chronic fatigue’ in the title, or which uses the term ‘chronic fatigue’ interchangeably with CFS or CFIDS or M.E. anywhere in the text, which claims that the illness is a new 21<sup>st</sup> Century disease caused by the ‘busy stressful modern world’ or which claims that the illness can be easily cured with exercise, psychotherapy, stress reduction, an anti-Candida diet, various vitamins and other treatments or anything else. (Titles like ‘From Fatigued to Fantastic’ should set all your alarm bells ringing!)

Also avoid anything which talks about M.E. being: ‘mysterious’ or ‘medically unexplained’ or ‘an amazing illness which crosses the boundaries between the body and the mind,’ of having no tests which can aid diagnosis, of even being an illness where ‘no tests have ever shown anything,’ or which claims that the illness is a problem of fatigue following glandular fever, or that the illness is caused by the Epstein-Barr virus, herpes, glandular fever or Candida, can be caused by stress or trauma, or is the same illness as Fibromyalgia or Lyme disease anything else. These are all just useless and harmful ‘CFS’ myths and propaganda; they have nothing to do with authentic M.E. and legitimate science.

For more on some of the most common myths of M.E. see [The myths about M.E.s](#) and [Research and articles in context](#).

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