

## The HUMMINGBIRDS' FOUNDATION for M.E. (HFME)

Fighting for the recognition of Myalgic Encephalomyelitis based on the available scientific evidence, and for patients worldwide to be treated appropriately and accorded the same basic human rights as those with similar disabling and potentially fatal neurological diseases such as Multiple Sclerosis.

### Where to after a 'CFS' misdiagnosis?

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The paper [The misdiagnosis of CFS](#) explained why 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 patient has Myalgic Encephalomyelitis (M.E.), and (b) does not mean that the patient has any other distinct and specific illness named 'CFS.' In other words, why a diagnosis of CFS – based on these or any of the other CFS definitions – *can only ever be a misdiagnosis*.

So where does that leave you if you have been misdiagnosed with CFS, or you have diagnosed yourself with CFS? What should you do if CFS is the only diagnosis you have?

It is far easier said than done, but what your number one priority needs to be is getting a correct diagnosis. Every patient deserves the best possible opportunity for appropriate treatment for their illness, and for improved quality of life or recovery – including YOU – and this process must begin with a correct diagnosis if at all possible. A correct diagnosis is half the battle won.

#### So where do I start?

Before you can get a new diagnosis, you must first be willing to let go of your 'CFS' misdiagnosis. This is easy for some, but understandably somewhat harder for others who have become deeply involved in the CFS community (perhaps even for many years or decades) or who have had to fight or work very hard for a long time just to get a CFS (mis)diagnosis. It might even feel better (or less scary) to cling to this wrong diagnosis, than to have no diagnosis at all for a period of time.

This is understandable, but it is truly NOT in your long-term best interests (despite popular opinion). You deserve better than to be thrown into the 'CFS' wastebasket and left there without any real appropriate medical support or help, and subject to all sorts of abuse, inappropriate interventions and unfounded accusations of malingering.

Make no mistake, there really is no distinct disease called 'CFS.' There is no disease that is defined by prolonged fatigue, is extremely variable from one case to the next, is very 'mysterious' and 'medically unexplained' and that can be caused by any number of different viral or bacterial infections, stress, trauma, chemical exposure or vaccinations (or numerous other things) and which first appeared in the 1980s. The vague and hard to diagnose fatiguing illness described by the various 'CFS' definitions, a large body of flawed 'CFS' research and many different 'CFS' websites, books and 'advocacy' groups simply doesn't exist as a discrete entity.

The bogus disease category of 'CFS' is made up of people with all sorts of different and unrelated conditions, both psychological and non- psychological, that have been unscientifically lumped together due to the vague and inclusive 'CFS' diagnostic criteria. 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 (Hooper et al. 2001, [Online]) (Dowsett n.d.a, [Online]) (Hyde 2007, [Online]). As [Dr Byron Hyde MD](#) 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 (2006, [Online]).

This is why being diagnosed with any of the definitions of CFS is not a meaningful or useful diagnosis and why a diagnosis of CFS should never be accepted – by doctor or by patient – as an end point of the process of diagnosis. Each of the patient groups involved must be correctly diagnosed and then treated as appropriate based on legitimate and unbiased science involving the SAME patient group. People with M.E. must be diagnosed with M.E. and treated for M.E. Patients with depression must be diagnosed with depression and treated for depression.

Patients with Fibromyalgia must be diagnosed with and treated for Fibromyalgia. Patients with cancer should be treated for cancer, and so on. Lumping these disparate patient groups together under a vague and meaningless category of 'fatiguing illnesses' or 'CFS' only hinders each of the patient groups involved in their battle to regain their health (Dowsett 2001b, [Online]) (Hooper 2006, [Online]) (Hyde 2003, [Online]).

What a diagnosis of 'CFS' actually means is that the patient has a gradual onset fatigue syndrome which is usually due to a missed major disease; the patient has:

- a. Missed cardiac disease, b. Missed malignancy, c. Missed vascular disease, d. Missed brain lesion either of a vascular or space occupying lesion, e. Missed test positive rheumatologic disease, f. Missed test negative rheumatologic disease, g. Missed endocrine disease, h. Missed physiological disease, i. Missed genetic disease, j. Missed chronic infectious disease, k. Missed pharmacological or immunization induced disease, l. Missed social disease, m. Missed drug use disease or habituation, n. Missed dietary dysfunction diseases, o. Missed psychiatric disease. (Hyde 2006, [Online])

Some of the illnesses commonly misdiagnosed as 'CFS' (or even as CFS/ME, ME/CFS, CFIDS or M.E. depending on the physician) include:

- Various post-viral fatigue states/post-viral fatigue syndromes (eg. following glandular fever/mononucleosis, hepatitis, Q fever, flu, measles, chickenpox, herpes and many other infections)
- Fibromyalgia
- Candida
- Athlete over-training syndrome
- 'Burnout'
- Multiple chemical sensitivity syndrome (MCSS)
- Multiple Sclerosis
- Thyroid illness
- Adrenal insufficiency
- Localised and metastatic malignancies
- Brain tumours, including astrocytomas and gliomas
- Transverse Myelitis
- Myopathic illnesses including: myasthenia gravis, mitochondrial myopathies, post-infectious polymyositis
- Vitamin B12 deficiency disorders: pernicious anaemia, intentional dietary deprivation, intestinal disease
- Rheumatoid illness or lupus (SLE)
- Sarcoma
- Renal or liver disease
- Infectious illnesses including: Toxoplasmosis, AIDS, Lyme disease (*Borrelia burgdorferi*), Tuberculosis and Brucellosis
- Various psychiatric and social psychiatric states including: anxiety neurosis, uncomplicated endogenous or reactive depression, clinical depression, psychopathic personality disorder, post-traumatic stress disorder (PTSD), Schizophrenia and other psychiatric disease (Ramsay 1986, [Online]) (Hyde 1992, p 22) (Dowsett n.d.a, [Online]) (Hooper et al. 2001, [Online]) (Hyde 2003, [Online]) (Hyde 2006, [Online])

This is of course not a comprehensive list. It should also be remembered that although none of the CFS definitions define M.E., the majority of M.E. patients will unfortunately be given a CFS misdiagnosis by default (due to the ignorance surrounding M.E., and the confusion between M.E. and 'CFS'). Therefore the possibility that a patient misdiagnosed with CFS has authentic Myalgic Encephalomyelitis should also be investigated, along with these myriad other possibilities. (See [Testing for Myalgic Encephalomyelitis](#) for more information).

### **What is the good news and the bad news about trying again to get an accurate diagnosis?**

Learning that you don't actually have CFS (because *there is no such disease as 'CFS'*) is good and bad news. It's good because you might be about to finally get a correct diagnosis, and the correct treatment AND the enormous (or at least significant) improvement in your condition which comes with that or you might even be about to get a CURE for your illness. These are all real possibilities.

The bad news is that getting a correct diagnosis can be difficult, and this task may well feel even more overwhelming when you thought you'd already dealt with the issue of diagnosis once and for all. It can be really hard to find a good doctor that is willing to carefully listen to you and to examine you and do what it takes to find out what is really wrong with you, unfortunately (as many of you will know only too well).

But the potential for good really does outweigh the bad here. The other good news about rejecting your 'CFS' misdiagnosis is that you'll also be able to leave behind all the propaganda, psychobabble and mistreatment that is so inextricably linked with 'CFS.' All the nonsense about malingering, or about 'CFS' being somatisation or being able to be cured by 'positive thinking' or exercise or simple supplements, the false accusations of psychological or

behavioural illness, and all the claims that there is no proof that you are ill, or that you are supposedly 'enjoying the sick role.' You'll be able to leave behind forever the lack of respect, ridicule, bad treatment and abuse that comes with a 'CFS' misdiagnosis – something that can only be positive, in many different ways.

*(To clarify, even that percentage of you that do actually have a serious psychological condition misdiagnosed as 'CFS' do not deserve to be subjected to the sort of mistreatment and abuse commonly thrown at people with 'CFS,' of course. Nobody does. People with any disabling illness deserve to be treated humanely and based on the facts – and not treated unfairly or blamed for an illness that is not in any way under their control. Serious psychiatric illnesses are every bit as biological as multiple sclerosis or cancer; they can't be cured by mere positive thinking no matter how hard you try, and of course people with these conditions deserve at least as much respect and medical help as anyone else.*

*People with a 'CFS' diagnosis are NOT just mistakenly treated as if they had a psychological illness however; that is not what is happening here. It is far worse than that. They're treated as if they were deviants, as if they were beneath contempt and not worthy of even basic respect or consideration or medical care, or even any level of kindness or compassion. People with a 'CFS' misdiagnosis are often persecuted and vilified, discriminated against and lied about... and their physical suffering is very often ridiculed, trivialised and made fun of... like no other patient group I'm aware of. The level of abuse and neglect is sometimes so high that it has actually resulted in a number of deaths. (This high level of potentially life-destroying or fatal abuse seems to be on the increase; see [What is M.E.?](#) for more information.) It is not in the best interest of any of us to stay in this 'CFS' nightmare voluntarily, which is exactly what so many of us are doing. Any diagnosis, so long as it is accurate, is far better than keeping a 'CFS' misdiagnosis. Mental illnesses are just illnesses like any other. What is important is that we get a correct diagnosis and the appropriate treatment, whatever that may be.)*

### **What other reasons are there to reject a CFS misdiagnosis?**

Without trying to scare you unnecessarily, some of you *will* have very serious and life-threatening conditions causing your illness. Many serious illnesses, including various cancers, cause significant fatigue and are commonly misdiagnosed as 'CFS.' Every month you delay getting diagnosed and treated could really make an enormous difference to your long term health, or even to your survival. How quickly you reject your CFS misdiagnosis could literally be a matter of life and death for you. People have actually DIED because they had cancer and got no treatment for it because they were absolutely certain that they had a classic case of 'CFS' for example. Such misdiagnoses are not uncommon. This is not scaremongering; it's a fact, unfortunately.

Many of you will also have conditions that are very negatively affecting your quality of life – but that may be very easily treated once you've been correctly diagnosed. Many people who have had vitamin deficiencies or dietary issues that were causing their symptoms that once diagnosed and treated completely resolved (or at least greatly improved) their illness. What an absolute waste for all those people out there who have something that is very treatable but who don't get this treatment because of their 'CFS' misdiagnosis. Many of you may well be suffering *needlessly*, perhaps even for many long months or years.

There will also be some of you in-between these two extremes. You may not get a cure with your correct diagnosis and it may not be exactly a matter of life and death, but you may well find there are treatments out there for your condition – once it is correctly diagnosed – which can significantly improve your quality of life. (For example; antibiotics for sufferers of Lyme disease, and certain drugs developed to treat the symptoms of MS.)

What all this means is that it is not just vital that you get rid of your 'CFS' misdiagnosis and get an accurate diagnosis, but that it is very important you do so **AS SOON AS POSSIBLE**. It really could be a matter of life or death, or of prolonging your high level of suffering and reducing your quality of life needlessly.

### **Conclusion**

The only groups which gain from the 'CFS' confusion – the 'CFS' insurance scam – are insurance companies and various other organisations and corporations which have a vested financial interest in how these patients are treated, including the government. People with Myalgic Encephalomyelitis have a real fight on their hands to have the name and historically and scientifically correct definition of M.E. renewed – and to have M.E. separated once and for all from the bogus disease category of 'CFS.' But everyone who has been misdiagnosed as CFS who *doesn't* have M.E. is also harmed just as much by the man-made 'CFS' disease category.

The only logical way forward for every patient group involved is that the fictional disease category of 'CFS' must be abandoned. We all need to work together to stop this 'CFS' scam continuing any longer (Hooper 2006, [Online]). These vested interest groups have made ENOUGH extra millions of dollars for themselves *at our expense*.

Every diagnosis of 'CFS' – based on any of the CFS definitions – *is* a misdiagnosis. Everyone misdiagnosed with 'CFS' must stand up and refuse this wastebasket diagnosis starting now. This *isn't* just about politics, or semantics, or terminology. It isn't about who is sicker or more important than anyone else, or about one patient

group trying to sneakily gain advantages for itself at the cost of another. It is about big business manipulating science and REALITY to suit their own vested political and financial interests with a blatant disregard for ethical concerns or the violation of basic human rights; no matter what the enormous cost to some of our most ill and vulnerable members of society. It is about preventing needless suffering, abuse, neglect and countless needless deaths of hundreds of thousands of children and adults with M.E. *and* all those millions of people misdiagnosed with 'CFS' who have other illnesses. Needless suffering and death is needless suffering and death. We need to work together to stop this happening for the benefit of all of us. Nobody is going to do it for us, unfortunately.

There *is* a bigger picture that you are a part of, but at the same time, even if only for your own sake – please don't be apathetic or complacent about rejecting 'CFS' and getting a correct diagnosis, and don't delay the process unnecessarily either. A 'CFS' misdiagnosis can only hinder your efforts to get some or all of your health back.

If you think that there really is something seriously wrong with you physically, you are very probably right. ***Trust your instincts.*** Don't take 'I don't know' or 'I don't know but I think you maybe have CFS' or 'there is nothing wrong with you' for an answer. Keep pushing and pushing until you get the answers you need. If you come up against a brick wall; get a second opinion, or a third, or a fourth – or as many as it takes until you find a doctor that understands and practices the age-old medical principals of correct diagnosis: (a) taking a full and careful history, (b) detailed physical examination and (c) appropriate investigation and testing (Hyde 2006, [Online]). You need and deserve a correct diagnosis and appropriate medical care and a chance at improved health just as much as anyone else. Again, a correct diagnosis is half the battle won.

All the best to you all with obtaining a correct diagnosis as quickly – and as painlessly – as possible. (Far easier said than done though such a task is.) Hopefully your correct diagnosis will be one of the less scary prospects listed here too; but even if it isn't, the only thing worse than having a serious or life-threatening disease is having a serious or life-threatening disease and not getting the appropriate diagnosis or any of the correct treatment for it. (Not to mention getting mistreated and abused and denied appropriate support due to a 'CFS' misdiagnosis.) Best wishes and the very best of luck – and medical care – to you all.

#### **For more information on this topic:**

- The paper [The misdiagnosis of CFS](#) is essential additional reading. For details on the symptoms listed in the most commonly used CFS definitions, and how these compare to the symptoms of many of the illnesses commonly misdiagnosed as CFS (as listed above), see part 2 of [The misdiagnosis of CFS](#).
- For some hints and tips on getting a correct diagnosis, see the [Questions and Answers](#) section (below).
- For more information on why the bogus disease category of 'CFS' must be abandoned, including the use of confusing and misleading umbrella terms such as 'CFIDS' 'ME/CFS' 'CFS/ME' and others, see: [Who benefits from 'CFS' and 'ME/CFS'?](#) and [Smoke and mirrors plus Why the disease category of 'CFS' must be abandoned, Smoke and Mirrors](#) and [What is Myalgic Encephalomyelitis?](#)
- Also highly recommended are the excellent papers by Dr Byron Hyde,, a doctor with over 20 years experience with M.E. see: [A New and Simple Definition of Myalgic Encephalomyelitis and a New Simple Definition of Chronic Fatigue Syndrome & A Brief History of Myalgic Encephalomyelitis & An Irreverent History of Chronic Fatigue Syndrome](#) and [The Complexities of Diagnosis](#) (which mentions several case studies of people who died from cancer and other illnesses because of a 'CFS' misdiagnosis) and Dr Hyde's [M.E. textbook](#).
- There are a number of post-viral fatigue states or syndromes which may follow common infections such as mononucleosis/glandular fever, hepatitis, Q fever, Ross river virus and so on; but M.E. is an entirely different condition to these self-limiting fatigue syndromes. People suffering with any of these post-viral fatigue syndromes *do not have M.E.* Myalgic Encephalomyelitis is not the correct term for these illnesses, any more than is 'CFS' (or any other combination/variation of these terms). For more information see: [What is Myalgic Encephalomyelitis?](#)
- None of the CFS definitions is a description of any distinct disease, including Myalgic Encephalomyelitis. M.E. is not defined by fatigue and is not merely a diagnosis of exclusion or 'medically unexplained.' M.E. can be extremely severe and disabling and in some cases the disease is fatal. M.E. is an acute onset organic neurological disease which also causes significant cardiac and cardiovascular problems and which occurs in epidemic and sporadic forms and is initiated by a virus, most likely an enterovirus. M.E. is similar in a number of significant ways to illnesses such as multiple sclerosis, Lupus and poliomyelitis (polio). M.E. is a distinct, recognisable (and testable) entity that can be diagnosed relatively early in the course of the disease, providing that the physician has some experience with the illness. [The Nightingale Definition of M.E.](#) now also makes diagnosis easier than ever before even for those with no experience with the illness. For

information on how authentic neurological M.E. is characterised and diagnosed see: [Testing for Myalgic Encephalomyelitis](#) and [What is Myalgic Encephalomyelitis?](#)

- This website has become so large that its features can no longer all be taken in at a glance. In order for site visitors to find the information they need more quickly, the [Information Guides](#) page features guides relevant to each of the different types of visitors to the site including M.E. patients, doctors, 'CFS' misdiagnosed patients, friends and family of patients and so on.

### References (and recommended additional reading list)

All of the information concerning Myalgic Encephalomyelitis on this website is fully referenced and has been compiled using the highest quality resources available, produced by the world's leading M.E. experts. More experienced and more knowledgeable M.E. experts than these – [Dr Byron Hyde](#) and [Dr. Elizabeth Dowsett](#) in particular – do not exist. Between Dr Byron Hyde and Dr. Elizabeth Dowsett, and their mentors the late Dr John Richardson and Dr Melvin Ramsay (respectively), these four doctors have been involved with M.E. research and M.E. patients for well over 100 years collectively, from the 1950s to the present day. Between them they have examined more than 15 000 individual (sporadic and epidemic) M.E. patients, as well as each authoring numerous studies and articles on M.E., and books (or chapters in books) on M.E. *These doctors have also dealt with a vast number of patients misdiagnosed as 'CFS.'* Again, more experienced, more knowledgeable and more credible M.E. (and 'CFS') experts than these simply do not exist.

This paper is merely intended to provide a brief summary of some of the most important facts of M.E., and the difference between M.E. and 'CFS.' It has been created for the benefit of those people without the time, inclination or ability to read each of these far more detailed and lengthy references created by the world's leading M.E. experts. The original documents used to create this paper are essential additional reading however for any physician (or anyone else) with a real interest in this topic. For more information see the [References](#) page. A partial reference list follows:

- Dowsett, Elizabeth MBChB. n.d. a, Differences between ME and CFS, [Online], Available: <http://www.hfme.org/wdowsett.htm>
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- Hyde, Byron M.D. 2007, The Nightingale Definition of Myalgic Encephalomyelitis [Online], Available: <http://www.hfme.org/whydepapers.htm#390403648>
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For a full list of references, see: [What is Myalgic Encephalomyelitis?](#)

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This paper will be continue to be updated regularly (at least annually). Please check back at the website periodically to make sure that you have the most up-to-date version of this paper available.

*'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*

*"People in positions of power are misusing that power against sick people and are using it to further their own vested interests. No-one in authority is listening, at least not until they themselves or their own family join the ranks of the persecuted, when they too come up against a wall of utter indifference.' Professor Hooper 2003*

**Additional questions and answers section:**

1. Some groups are working on renaming, redefining or sub-grouping CFS. Won't this fix the problem? Isn't that at least a step in the right direction?
2. How can I assist my doctor in giving me a correct diagnosis?
3. Point by point, what is the difference between M.E. and CFS? I'm still not entirely sure.
4. Are M.E. advocates saying that 'CFS' is made up of people who have M.E. and people who are – as Wessely, Sharpe, Lloyd and the CDC and others say – malingering, 'enjoying the sick role' or exaggerating their symptoms and so on? That we either have M.E. or else we fit the psychological or behavioural model of CFS?
5. How and why did this mess start? Why was CFS created?
6. There is a lot of information out there about people with M.E. being harmed and suffering abuse because of the confusion between M.E. and CFS, and so on. Are people misdiagnosed with 'CFS' but who don't have M.E. affected by this too?
7. I'm worried...what if I have tests done, and M.E. is ruled out?
8. What about all those 'CFS' (and 'CFIDS' 'ME/CFS' and Myalgic 'Encephalopathy' etc.) advocacy groups out there, why haven't they been telling me this information? Why haven't *they* told me that CFS is a misdiagnosis?
9. I'm still confused about terminology, what are the correct terms to use?
10. Are M.E. advocates saying that every single article or piece of research which uses the term 'CFS' is completely irrelevant with regard to authentic M.E. patients?
11. M.E. advocates have an interest in the actions of CFS groups and people misdiagnosed with CFS and so on; they're affected by our actions to some extent. Is the information here (and in similar papers) designed to gain advantages for people with M.E. at the expense of people misdiagnosed with CFS who don't have M.E.?
12. I seem to fit the 2003 Canadian definition of 'ME/CFS' does this mean that I definitely have M.E.?
13. I have a post-viral fatigue syndrome, that's basically the same thing as M.E. isn't it?
14. But don't 'CFS' and M.E. at least have severe fatigue in common?
15. I'm absolutely appalled by this 'CFS' scam and all the abuse and neglect of so many very ill people. What else can I do to help improve things?

**Question 1:** Some groups are working on renaming, redefining or sub-grouping CFS. Won't this fix the problem? Isn't that at least a step in the right direction?

**Answer:** No, it most definitely isn't. Sub-grouping different types of 'CFS,' refining the bogus 'CFS' definitions further or renaming 'CFS' with some variation on the term M.E. would achieve nothing and only create yet more confusion (which the corporations involved would no doubt continue to take advantage of, to the continued detriment of patients).

The problem is not that 'CFS' patients are being mistreated as psychiatric patients; some of those patients misdiagnosed with CFS actually do have psychological illnesses. CFS is made up of people with depression (and various other psychological illnesses), multiple sclerosis, athletes over-training syndrome, Fibromyalgia, various post-viral fatigue syndromes, Candida, chronic Lyme disease, burnout, cancer and many more entirely unrelated and already well-defined conditions. To say that these conditions are all subgroups of 'CFS' is just absurd. Sub-grouping 'CFS' would only waste another 20 years or more. There is no such distinct disease/s as 'CFS' – that is the entire issue, and the vast majority of patients misdiagnosed with CFS (an estimated 75% at least) do not have M.E. and so have no more right to that term (or a variation of it) than to 'cancer' 'diabetes' or 'multiple sclerosis.'

The distinction must be made between terminology and definitions. The terminology is often used interchangeably, incorrectly and confusingly and new ill-defined umbrella terms such as 'ME/CFS' 'ME-CFS' 'CFS/ME' 'CFIDS' and others just increase this confusion. However, the DEFINITIONS of M.E. and CFS are very distinct, and it is these definitions which are of primary importance.

Changing the name of the bogus disease construct of 'CFS' to some variation on the term M.E. is not at all a step in the right direction. This move will actually be a huge step BACKWARD for everyone with M.E. and all those patients misdiagnosed with CFS. It will make it harder than ever for anyone to distinguish between 'CFS' and authentic M.E., and for those misdiagnosed with CFS to be able to receive a correct diagnosis and treatment. The 'CFS name change proposal' seems nothing more than a political stunt; designed to appease (justifiably) angry patients and make them feel like something is being done and that progress is being made finally – but not to actually effect any real change. The proposal that the name of 'CFS' should be changed to a variation on the term M.E. – despite the fact that the term is completely scientifically inaccurate for the vast majority of the patients involved and that this term has already been TAKEN by a very well-defined (and scientifically sound)

patient group for over 50 years – merely because it ‘sounds a lot more serious’ makes a mockery of legitimate advocacy, and of science, logic and ethics.

- For more information see: [Who benefits from 'CFS' and 'ME/CFS'?, 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' by M.E. advocates, Why the disease category of 'CFS' must be abandoned and What is Myalgic Encephalomyelitis?](#)

**Question 2:** How can I assist my doctor in giving me a correct diagnosis?

**Answer:** There are a number of things you can do to help your doctor understand your illness better. You could:

1. Write down your medical history and your family medical history in detail (including mentioning any pre-existing illnesses you may have had) for your doctor.
2. Write down a description of the onset of your illness for your doctor. (Was it acute or gradual? This could be very important. You could also write a list of anything that happened just before you became ill that may or may not be relevant potentially; did you have a chemical exposure, tick bite, car accident, head and neck trauma, vaccination, viral infection, surgery, overseas travel or a blood transfusion just before you became ill, for example.)
3. Write a detailed description of all of your symptoms, taking care to be as specific as you can.
4. You could keep an activity diary for a week, to show your doctor exactly how your symptoms affect your life and what things you can and can't do since you became ill.
5. Write a list for your doctor of any physical signs of illness that you have noticed (eg. rashes).
6. Show your doctor copies of any relevant test results you have

This way your doctor gets as much information as possible about your illness, and you aren't left struggling to remember everything in detail when you're put on the spot (which can be very difficult or even impossible depending on what sort of illness you have and how it affects your thinking and memory). Make sure you keep copies of everything you write too, in case you need to use them again for future appointments.

If you have problem with memory, you might like to take a recording device into the appointment (or a friend or family member) or to take notes during or directly after the appointment.

If the only doctor you have access to is often inappropriate or even abusive in the way they deal with you – for example telling you that you should just ‘get over it and try harder’ or that ‘you don't have anything more willpower and exercise couldn't fix’ or ‘the only thing wrong with you is your attitude, and your false belief you are ill’ – then you might like to consider taking another person with you to your appointments. Many people have commented that this has made an enormous difference in the way the doctor speaks to them; that these bullies are far less comfortable being so nasty when there is another person there who can see exactly what they are doing and how cruel and unfair it is. You might also like to print out some legitimate information on M.E. (for example the Nightingale Definition of M.E.) for them.

Again, if you think that there really is something seriously wrong with you physically, you are very probably right. *Trust your own instincts.* Be as calm and as assertive as you can, but keep pushing until you get the answers you need.

- All of the above advice may well be unhelpful for people with M.E. as the vast majority of doctors wouldn't recognize the disease no matter how textbook perfect your case was and how perfectly you described it (unlike many of the illnesses misdiagnosed as ‘CFS’ which are very well known). There are almost no doctors available who are aware of even the most basic facts about M.E., and the vast difference between M.E. and ‘CFS.’ You might have no choice but to try to bring your own doctor up to speed about M.E. yourself. Perhaps a good way to start (after showing them some of the legitimate information on M.E. out there created by genuine M.E. experts such as Dr Hyde or Dr Dowsett) might be to get some of the tests done that can help confirm (or rule out) a M.E. diagnosis. If your doctor refuses to give you any of the more expensive tests such as MRI or other brain scans, perhaps you could ask to begin with some of the more simple and inexpensive tests: a Romberg test, tests of the immune system (eg. tests of your natural killer cells etc.), the ESR test, sitting/standing and lying down pulse and blood pressure readings and so on, and then try to move forward from there. See [Testing for Myalgic Encephalomyelitis](#) for more information.
- It must be noted here that a significant number of sufferers (with M.E. and with many other illnesses) will not be able to make practical use of any of this advice, unfortunately. They will have no access to appropriate medical care or testing at all; either due to being severely ill and housebound and/or bedbound, or simply because the medical care available to them is of such a low standard (or so acutely influenced by the financially and politically motivated propaganda surrounding M.E. and ‘CFS’ as to be of a very low standard solely in this area). This is a human rights travesty and is the reason we desperately need some REAL activism for people with M.E., and all those misdiagnosed with ‘CFS’ who have other illnesses. This is a worldwide disgrace, especially in wealthy ‘first world’ countries such as the US, UK, Canada, the Netherlands, New Zealand and Australia, and so on. This desperately needs to change. (For everyone who is in this terrible situation, hopefully it will change for you in the near future.)

- *A note on alternative practitioners:* While many different types of alternative practitioners (naturopaths, acupuncturists, iridologists and so on) may often be helpful in treating different conditions to a certain extent, this does not mean that they are equally skilled when it comes to the initial diagnosis of your condition. Such practitioners may have very little knowledge about different illnesses or training in diagnosis (or at all), and will also not have access to any of the appropriate tests which are so important in this field. (You're more than likely to get 5 different *wrong* diagnoses from 5 different practitioners, or to be told by all 5 of them that you have a simple dietary problem that is easily treated by over-the-counter remedies – when in reality you have a serious neurological or cardiovascular condition that is nowhere near so easily treated. You might then also be blamed by the practitioner for your lack of improvement and accused of 'not wanting to be well' which is of course very unfair and inappropriate.) Be very wary of any diagnosis (or advice) given by an alternative practitioner especially after a very short and superficial consultation, and without the appropriate testing. If it sounds too good to be true it probably is. Use alternative therapists only once you have a correct diagnosis and you are confident that they have sufficient knowledge about your illness to be of use, and not to cause you harm. (For example, it is a rare practitioner who understands the difference between M.E. and 'CFS/fatigue' and this could lead to a very negative outcome if you do have M.E. Despite popular opinion, 'natural' therapies are not without significant risk.)

**Question 3:** Point by point, what is the difference between M.E. and CFS? I'm still not entirely sure.

**Answer:** The terminology of M.E. and 'CFS' is often used interchangeably, incorrectly and confusingly. However, the DEFINITIONS of M.E. and CFS are very different and distinct. In a nutshell:

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

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

Dr Byron Hyde MD also explains that:

Although the authors of these definitions have repeatedly stated that they are defining a syndrome and not a specific disease, patient, physician, and insurer alike have tended to treat this syndrome as a specific disease or illness, with at times a potentially specific treatment and a specific outcome. This has resulted in much confusion. (2006, [Online]) Thirty years ago when a patient presented to a hospital clinic with unexplained fatigue, any medical school physician would have told the students to 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. (2003, [Online])

- For more information see: [What is Myalgic Encephalomyelitis?](#)

**Question 4:** Are M.E. advocates saying that 'CFS' is made up of people who have M.E. and people who are – as Wessely, Sharpe, Lloyd and the CDC and others say – malingering, 'enjoying the sick role' or exaggerating their symptoms and so on? That we either have M.E. or else we fit the psychological or behavioural model of CFS?

**Answer:** Of course not! A million times NO! These groups and individuals are motivated by vested political and financial vested interests, rather than scientific or ethical concerns. All of their claims about M.E. or 'CFS' patients should be taken with an enormous grain of salt, if not rejected outright and ridiculed because of this bias. Their work has very little – if anything – to do with legitimate science or REALITY.



It is possible that some of their theories about 'CFS' are accurate to some extent with some of those patients misdiagnosed with 'CFS' who have very mild fatigue as a result of very mild and transient behavioural or psychological illnesses, but to say that the nonsense they have produced relates to everyone, or even most people misdiagnosed with 'CFS' is just ridiculous. Studies on people with mild fatigue and no visible or testable organic abnormalities cannot be legitimately used to determine the aetiology and treatments for people with a vast array of different illnesses including multiple sclerosis, cancer and various post-viral fatigue syndromes, nor M.E.

It is absolute nonsense to suggest that every person misdiagnosed with CFS has a psychological or behavioural illness, or has an illness that will respond well to psychological interventions such as cognitive behavioural therapy (CBT), graded exercise therapy (GET) or antidepressants. Unsurprisingly, the vast majority of patients DO NOT fit this scientifically unsupportable – but very politically and financially convenient – illness model.

What is true however is that some proportion of those misdiagnosed with 'CFS' *will* have serious organic psychological illnesses. (This is why arguing that 'CFS' is not psychological is so absurd; for one thing, there is no such distinct disease as 'CFS' and for another, some percentage of the ragbag of different illnesses misdiagnosed as 'CFS' are psychological in nature.) Many psychological illnesses, including clinical depression, can cause a variety of 'physical' symptoms along with the more well-known psychological symptoms. This very often includes very severe – and significantly disabling – fatigue. Illnesses such as clinical depression, PTSD, schizophrenia (etc.) are every bit as real and as biological as cancer or diabetes, and just as much not your fault or something you can merely 'positive think' your way out of. *If you think that you may have a psychological illness, you must pursue this diagnosis as you would any other.* The only thing that is important is that you get a correct diagnosis, and correct treatment; and you cannot get the correct treatment without the correct diagnosis.

**Question 5:** How and why did this mess start? Why was CFS created?

**Answer:** The disease category of CFS was created in a 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.

So why were the renaming and redefining of the distinct neurological disease Myalgic Encephalomyelitis allowed – indeed intended – to become so muddled? Indeed why did Myalgic Encephalomyelitis suddenly need to be renamed or redefined at all? **Money.** There was an enormous rise in the reported incidence of Myalgic Encephalomyelitis in the late 1970s and 1980s, alarming medical insurance companies in the US. So it was at this time that certain psychiatrists and others involved in the medical insurance industry (on both sides of the Atlantic) began their campaign to reclassify the severely incapacitating and discrete neurological disorder known as Myalgic Encephalomyelitis as a psychological or 'personality' disorder, in order to side-step the financial responsibility of so many new claims (Marshall & Williams 2005a, [Online]). As Professor Malcolm Hooper explains:

In the 1980s in the US (where there is no NHS and most of the costs of health care are borne by insurance companies), the incidence of ME escalated rapidly, so a political decision was taken to rename M.E. as "chronic fatigue syndrome", 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 and medical scientists, but all objections were ignored... To the serious disadvantage of patients, these psychiatrists have propagated untruths and falsehoods about the disorder to the medical, legal, insurance and media communities, as well as to government Ministers and to Members of Parliament, resulting in the withdrawal and erosion of both social and financial support [for M.E. patients]. Influenced by these psychiatrists, government bodies around the world have continued to propagate the same falsehoods with the result that patients are left without any hope of understanding or of health service provision or delivery. As a consequence, government funding into the biomedical aspects of the disorder is non-existent. (2003a, [Online]) (2001, [Online])

For example, the psychiatrist Simon Wessely – arguably the most powerful and prolific author of papers which claim that M.E. is merely a psychological problem of chronic fatigue – began his rise to prominence in the UK at the same time the first CFS definition was being created in the USA (1988). Wessely, and his like-minded colleagues – a small group made up mostly but not exclusively of psychiatrists (colloquially known as the 'Wessely School') has gained dominance in the field of M.E. in the UK (and increasingly around the world) by producing vast numbers of papers which purport to be about M.E. For at least a decade, serious questions have been raised (and published) in international medical journals about possible scientific misconduct and flawed methodology in the work of Wessely and his colleagues. It is only relatively recently however that his long-term involvement as medical adviser – and board member – to a number of commercial bodies having a vested interest in how M.E. (and 'CFS') is managed have been exposed. As Professor Malcolm Hooper goes on to explain:

Increasingly, it is now "policy-makers" and Government advisers, not experienced clinicians, who determine how a disorder is classified and managed in the NHS: the determination of an illness classification and the provision of policy-driven "management" is a very profitable business. To the detriment of the sick, the deciding factor governing policies on medical research and on the management and treatment of patients is increasingly determined

not by medical need but by economic considerations. There is a gross mismatch between the severity and complexity of M.E. and the medical and public perception of the disorder (2003a, [Online]).

The resulting 'confusion' between the distinct neurological disease M.E. and the man-made bogus disease category of 'CFS' has caused an overwhelming additional burden of suffering for those who suffer from neurological M.E. and their families, as well as the many millions of people with various mild, moderate and severe psychiatric and non-psychiatric illnesses who are also lumped together with a 'CFS' misdiagnosis. It's a human rights travesty and a huge mess, that is for certain – but it is not an *accidental* mess – that is for certain too (Hyde 2006a, [Online]) (Hooper 2006, [Online]) (Hyde 2003, [Online]) (Hooper 2003a, [Online]) (Dowsett 2001a, [Online]) (Hooper et al. 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]).

**Question 6:** There is a lot of information out there about people with M.E. being harmed and suffering abuse because of the confusion between M.E. and CFS, and so on. Are people who are misdiagnosed with 'CFS' but who don't have M.E. affected by this too?

**Answer:** Yes, they are. Patients with M.E. are not the only patient group to be negatively affected in this way. Other patient groups misdiagnosed as CFS are also denied appropriate diagnosis and treatment. They may also be subjected to inappropriate psychological interventions such as CBT and GET, as well as serious neglect and abuse. Some of the conditions commonly misdiagnosed as CFS are very well defined and well-known illnesses and very treatable – but only once they have been correctly diagnosed. Some conditions are also very serious or can even be fatal if not correctly diagnosed and managed, including Myalgic Encephalomyelitis.

Treating this diverse and heterogeneous patient group as if their illnesses each shared the same symptoms, aetiology, pathology and response to treatment is inappropriate and highly unlikely to benefit the health and wellbeing of any of the patient groups involved. Treating this 'CFS' group as if they each shared a specific psychological or behavioural illness is also clearly inappropriate. Aside from representing a heterogeneous patient group, many (likely the vast majority) of those with the diagnosis are not mentally ill, and do not suffer from behavioural problems (Hooper 2006, [Online]) (Hyde 2006, [Online]) (Hooper et al. 2001, [Online]).

Doctors, researchers and the general public are also negatively affected in various ways by this subterfuge (As explained previously in [Smoke and Mirrors](#)). Truly, the only groups which gain from the 'CFS' confusion are insurance companies and various other organisations and corporations which have a vested financial interest in how these patients are treated, including the government.

**Question 7:** I'm worried... what if I have tests done, and M.E. is ruled out?

**Answer:** Discovering that you don't have M.E. is NOT bad news! It's true it would mean you having to start the process of getting a correct diagnosis again... but it also means that you could be about to be diagnosed with an illness that has treatments available, and which is not subject to so much abuse and misunderstanding from friends and family, the media and medical professionals as M.E. There are potentially a lot of positives in other words.

When looking at what diagnosis is correct for you, the worst thing you could do is to be determined to have a M.E. diagnosis – and to skew and warp everything you read about M.E. to incorrectly fit your own case study – if that isn't what you have. There are as many downsides to sticking to an incorrect M.E. diagnosis as a 'CFS' misdiagnosis. It won't help you. Surely what is important is that your diagnosis is correct; not how serious a name it has, or what sort of reputation or history it has (or what history YOU have with it), or anything else.

**Question 8:** What about all those 'CFS' (and 'CFIDS' 'ME/CFS' and Myalgic 'Encephalopathy' etc.) advocacy groups out there, why haven't they been telling me this information? Why haven't *they* told me that CFS is a misdiagnosis?

**Answer:** That is a very good question.

Unfortunately, for various reasons the vast majority of 'CFS' (and 'ME/CFS' 'CFS/ME' 'CFIDS' and ME'opathy etc) 'advocacy' groups are now so bad, so committed to spreading and supporting the same propaganda and pseudo-scientific nonsense they were created to FIGHT AGAINST and supporting the status quo, that we'd actually all be far better off if they closed completely. Many of these groups are now working directly AGAINST what is in our best interests. Whether through ignorance or ineptitude, or selling us out to the highest bidder, these groups help nobody; not people with M.E. nor all those patients misdiagnosed with 'CFS' who have other illnesses ...except maybe themselves. These groups should not be trusted as sources of legitimate and unbiased scientific or political information on M.E., nor on 'CFS.' Very often the 'information' supported and created by these groups does not contain even a SINGLE fact!

It is a nightmare. Legitimate activism and advocacy for M.E. patients and all those misdiagnosed with 'CFS' who have other illnesses is (with a small number of notable exceptions) almost non-existent. This is why things are so bad for patients, and we are subject to so much abuse. In a perfect world what might happen would be that:

1. Many of these 'CFS' groups (or whichever term they use) would soon choose to become *anti-CFS* groups; dedicated to eradicating the bogus disease category of CFS and all the abuse and neglect and harm it causes, and helping all those misdiagnosed with 'CFS' to reject this misdiagnosis and to find their correct diagnosis and get appropriate treatment and support finally.
2. Some of these groups would become genuine Myalgic Encephalomyelitis advocate groups; dedicated to eradicating the bogus disease category of 'CFS' (and the confusion between M.E. and 'CFS') and fighting for the rights of people with M.E. and for M.E. patients to be treated based on science, and for the serious neurological disease they have (in the same way others with comparable neurological illnesses are treated).
3. These two types of groups would also work together to eradicate the fictional disease category of 'CFS,' while at the same time respecting the rights of each distinct patient group equally.

(We would all respect the fact that we all equally deserve a chance at a correct diagnosis, appropriate treatment and regaining our health no matter what the aetiology or the severity of the illness, and so on. For example, people with post-viral fatigue syndromes, Lyme disease, Candida, MCSS, Fibromyalgia and others would respect the fact that M.E. is a distinct neurological illness and that these illnesses do not cause M.E. and are not at all the same as M.E., and that M.E. research should ONLY contain people who have authentic M.E. etc. There would be no more media reports of people with psychological illnesses misdiagnosed as 'CFS' claiming that just because they seem to have been helped by the latest psychological fad – CBT/Lightening therapy/Mickel therapy or Reverse therapy etc. – that this is at all relevant to other patients groups be they M.E. patients or various other illnesses misdiagnosed as CFS, for example. *We would all take the appropriate care not to make things WORSE for other patient groups in other words; either out of ignorance or self interest.*)

People with M.E. and people with all those different illnesses misdiagnosed as 'CFS' – and our respective M.E. and anti-CFS advocacy groups – would unite together to fight our shared political battle in eradicating 'CFS' but be equally careful to retain the scientific separation of each distinct illness. This is exactly what these vested interest groups are hoping that we WON'T do – and the exact opposite of what is happening all too often now.

As I said, this is all just a fantasy... but in a perfect world, perhaps this is what would happen... It is what needs to happen, so desperately. These tainted groups (and individuals) must again start working and fighting to actually HELP their members and to do what is scientifically sound, logical and ethical... what is in their best interests, and will help to effect real positive change. How else will progress ever be made?

Nobody is ever going to give us what we need and do what is right and ethical just because we have asked our abusers nicely to stop (or drowned them in unearned flattery in the hopes it will make them treat us better) or because we have mere facts and reality on our side. *We have always had the facts, reality and ethics on our side.* We will only ever make as much progress as we are prepared to fight for. This 'CFS' nightmare is NOT just an innocent misunderstanding we can reason our way out of. We have to be realistic. Nobody is going to concede anything to us without a fight when it means an enormous loss to powerful political and financial concerns.

- Don't be fooled into thinking that groups and individuals who support the CDC, or Wessely or Lloyd, or CBT or GET, or renaming or subgrouping 'CFS' or who claim that M.E. and 'CFS' are the same, or who support any of the other myths surrounding M.E. are being helpful. They are not, whatever their claimed (or actual) intentions and no matter how *superficially* caring and 'nice' they may seem. We must stop supporting these ignorant/inert/sell-out groups and individuals if we are ever to get anywhere. As one severely ill M.E. sufferer commented recently, 'What they are doing is not just stupid and corrupt, it is murder.' Supporting groups and individuals who support the same propaganda that is the cause of our problems, and who support our abusers... is even sicker than we are, truly. Don't let these useless groups and individuals waste another 20 years for us, don't let things continue to get WORSE for us; as is happening now. Knowledge is power.

For more information see: [Problems with 'our' M.E. \(or 'CFS' etc.\) advocacy groups](#). This paper is also available as (animated) video, see the [Audio and Video](#) page for details. See also [Who benefits from 'CFS' and 'ME/CFS'?](#), [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' by M.E. advocates](#).

- See also: [Activism and Advocacy](#). (Also note that while these problems do sadly affect the vast majority of 'advocacy' groups, of course there are a very small number of genuine M.E. advocacy groups out there that are worthy of our support; the 25% M.E. Group for example, and the Nightingale Research Foundation.)

**Question 9:** I'm still confused about terminology, what are the correct terms to use?

**Answer:** 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:

Miscellaneous psychological and non-psychological fatigue states (including somatisation disorder) 2. A self limiting post-viral fatigue state or syndrome (eg. following glandular fever/mononucleosis) 3. A mixed bag of unrelated, misdiagnosed illnesses (each of which feature fatigue as well as a number of other common symptoms; poor sleep, headaches, muscle pain etc.) including Lyme disease, multiple sclerosis, Fibromyalgia, athletes over-training syndrome, depression, burnout, systemic fungal infections (Candida) and even various cancers, and 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 are of primary importance. The distinction must be made between terminology and definitions. (See above for a brief definition of M.E., and of 'CFS'.)

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 60 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/s as "CFS.") M.E. is not a primarily fatiguing condition, nor is it a wastebasket diagnosis or 'medically unexplained' as 'CFS' is. Sub-grouping different types of 'CFS,' refining the bogus 'CFS' definitions further or renaming 'CFS' with some variation on the term M.E. would achieve nothing and only create yet more confusion and mistreatment. The problem is not that 'CFS' patients are being mistreated as psychiatric patients; some of those patients misdiagnosed with CFS actually do have psychological illnesses. There is no such distinct disease/s as 'CFS' – that is the entire issue, and the vast majority of patients misdiagnosed with CFS do not have M.E. and so have no more right to that term than to 'cancer' or 'diabetes.'

There is no such disease/s as 'CFS' – the name CFS and the bogus disease category of CFS must be abandoned (along with the use of other vague and misleading umbrella terms such as 'ME/CFS' 'CFS/ME' 'ME-CFS' 'CFIDS' and 'Myalgic Encephalopathy' and others), for the benefit of all the patient groups involved. In other words, Myalgic Encephalomyelitis must be referred to as Myalgic Encephalomyelitis. Lyme disease must be referred to as Lyme disease. Fibromyalgia must be referred to as Fibromyalgia. Post-viral fatigue syndromes must be referred to as post-viral fatigue syndromes, and so on.

- For more information on the name Myalgic Encephalomyelitis (and the problems with some of these other terms including ME'opathy) see: [Meitis? A slender string to our bow](#), and [ME and CFS, The Definitions. See On the name MEitis](#) for more articles.
- The main goal of M.E. advocacy is not to have it understood that 'CFS' is a real serious non-psychological illness; there is no such disease/s as 'CFS' that is the entire point. The real issue is the fact that M.E. is not at all the same thing as 'CFS.' It is hard to see how this goal could be achieved using ridiculous and counterproductive terms such as 'ME/CFS' which imply that the two terms and patient groups are interchangeable; they are not. Despite its popularity with some groups, the term ME/CFS makes no more sense scientifically than made up terms such as cancer/diabetes or headache/broken leg. It only makes it harder for us to achieve our goals. For more information on why the bogus disease category of 'CFS' must be abandoned, (along with the use of other vague and misleading umbrella terms such as 'ME/CFS' 'CFS/ME' 'CFIDS' and 'Myalgic Encephalopathy' and others), see: [Why the disease category of 'CFS' must be abandoned](#) and [The Terminology Explained](#) and [Smoke and Mirrors](#).

**Question 10:** Are M.E. advocates saying that every single article or piece of research which uses the term 'CFS' is completely irrelevant with regard to authentic M.E. patients?

**Answer:** No, certainly not. (I am not aware of anyone who does have this view in the M.E. community.)

The definitions of CFS do not define M.E. but because an outbreak of M.E. in the US was labelled as being 'CFS' at the time (and for other reasons to do with political considerations), some researchers have undoubtedly produced valuable research on M.E. under the name 'CFS.' The overwhelming majority 'CFS' research however, does not involve M.E. patients and is not relevant in any way to M.E. patients, and the vast majority of patients with a 'CFS' diagnosis do not have M.E.

It would be foolish to throw the baby out with the bathwater and to reject everything that uses the term 'CFS' as being irrelevant to M.E. no matter how much it does clearly relate to neurological M.E. and the unique features of M.E. and not any other illness. But it is also extremely important that we don't go too far the other way and claim ALL of the 'CFS' research out there as relating to M.E. when this is very far from being the case. (This is why terms such as 'ME/CFS' are so counter-productive, illogical and dangerous; as they incorrectly imply that M.E. and 'CFS' are synonymous terms and that every article or piece of research that uses the term 'CFS' relates to authentic neurological M.E.)

Sometimes the term 'ICD-CFS' is used in those studies and articles which, while they use the term 'CFS,' do relate to some extent to authentic M.E. General problems with the term 'ICD-CFS' include the following:

- 1) The main problem is that the term 'ICD-CFS' implies that 'CFS' has a WHO ICD classification as a neurological disease. 'CFS' has no ICD listing as a neurological disease. Indeed, in the version of the ICD in use in most of the world, 'CFS' has no classification at all. Myalgic Encephalomyelitis was classified as a distinct neurological disease in the WHO ICD in 1969 based on a large body of compelling scientific evidence. To imply that 'CFS' research and the definitions of 'CFS' have been properly evaluated by the WHO and classified as neurological is erroneous. Of course 'CFS' can never be classified as a neurological illness because none of the 'CFS' definitions define a neurological disease, or any distinct disease.
- 2) It is also erroneous to imply that the WHO has deemed 'CFS' to relate to Myalgic Encephalomyelitis in any way. The term ICD-CFS incorrectly suggests that 'CFS' and M.E. are synonymous terms for a single entity.
- 3) The term also implies a lack of scientific rigour in the ICD, suggesting that definitions as vague and as problematic as those of 'CFS' would be accepted by the WHO as the basis for a neurological classification. If this were to be believed, it would weaken the authority of Myalgic Encephalomyelitis's ICD classification.
- 4) In addition to its use in relation to research, some people use the term 'ICD-CFS' to refer to the disease generally. The term is usually used by people who are aware of the psychological paradigm of 'CFS,' and who want to indicate a real, biological disease rather than a psychological one. However, which exact disease or diseases are being referred to with this term varies considerably from one author to another. As with terms such as 'ME/CFS' the term 'ICD-CFS' only increases confusion as it has no agreed definition and many different groups use it to refer to very different, often very mixed, patient groups.

The overwhelming majority of 'CFS' research does not involve M.E. patients and is not relevant *in any way* to M.E. patients. A small number of 'CFS' studies refer in part to people with M.E. but it may not always be clear which parts refer to M.E. Unless studies are based on an exclusively M.E. patient group, results cannot be interpreted and are meaningless for M.E. Thus while it is important to be aware of the small amount of research findings that do hold some value for M.E. patients, using the term 'ICD-CFS' to refer to this research is misleading and in many ways just damaging as using terms and concepts like 'ME/CFS' or 'CFS/ME.'

- For further details of the WHO ICD classifications of M.E. and 'CFS' worldwide (and why terms such as 'ICD-CFS,' 'ME/CFS' and Myalgic Encephalopathy' must be avoided) please see the new paper by patient advocate Lesley Ben entitled: The World Health Organization's International Classification of Diseases (WHO ICD), ME, 'CFS,' 'ME/CFS' and 'ICD-CFS'
- For more information about the WHO classifications of M.E. and 'CFS' worldwide please see the articles by patient advocate LK Woodruff.
- Virtually all of the research which does relate to M.E. (at least in part) but which uses the term/concept of 'CFS' (or ME/CFS, or CFIDS etc.) is also contaminated in some way by 'CFS' misinformation. Most often these papers contain a bizarre mix of facts relating to both M.E. and 'CFS.' For more information on some of the most common inaccuracies and 'CFS' propaganda included in this research, see the paper: Putting research and articles on Myalgic Encephalomyelitis into context

Often the research that really offers a glimmer of genuine hope to Myalgic Encephalomyelitis patients is research into diseases that share significant similarities with M.E. including Alzheimer's, Polio, Parkinson's, AIDS, Lupus, Multiple Sclerosis and so on. (Alzheimer's, Parkinson's and Multiple Sclerosis are listed along with M.E. under 'Diseases of the nervous system' in the ICD Classifications.) These studies have far more relevance to M.E. patients than almost all of the 'CFS' studies produced which lack scientific merit and use exclusively or almost exclusively non-M.E. patient groups. In future, however, it is essential that M.E. research again be conducted using only M.E. defined patients and using only the term M.E.

**Question 11:** M.E. advocates have an interest in the actions of CFS groups and people misdiagnosed with CFS and so on; they're affected by our actions to some extent. Is the information here (and in similar papers) designed to gain advantages for people with M.E. at the expense of people misdiagnosed with CFS who don't have M.E.?

**Answer:** The advice and information given here aimed at all those misdiagnosed with 'CFS' who do not have M.E. would be exactly the same even if there were no such illness as M.E.

The bogus disease category of 'CFS' harms both patient groups, and destroying it will benefit all of us. It really would be win/win... and at the moment it is lose/lose. Please don't make the mistake of dismissing all of this information as some covert attempt by the M.E. community to try to put you down or to gain advantages for

ourselves at your expense because we think 'we're sicker than you' or 'more important than you' or because we are just 'mean' – that is not what is happening here.

Severity just isn't the point at all! It's true that many of the illnesses misdiagnosed as 'CFS' are far less severe than M.E. and that many of these illnesses resolve on their own within a few years, we know that for a fact. For example, the most recent study of 'CFS' patients conducted by the CDC showed that on average the average combined workload (employment and chores) of those diagnosed with CFS by the CDC research definition was close to 48 hours per week. This same research discovered that these 'CFS' patients illnesses were so mild that 84% of people who qualified for the diagnosis, didn't even know they were sick at all until the CDC told them they had 'CFS' ([click here](#) for more information).

In contrast, people with M.E. are reduced to only being able to do 50% of what they could do pre-illness AT BEST, and at least 25% of M.E. sufferers are bedbound and/or housebound for many months, years or even decades at a time. M.E. is always a severe and chronic/lifelong illness.

But it's also undeniably true that many people misdiagnosed with 'CFS' are significantly disabled by their illness, and that some of these people are equally as disabled as some M.E. patients, and that others are even more seriously ill than most M.E. sufferers or even than the most severely affected M.E. sufferers. So the severity of the illness really is irrelevant; it's about each of us all deserving a correct diagnosis. No more and no less. (It is *not* the case that those who are mildly affected have CFS, and those who are severely ill have M.E. – 'CFS' is *not* some kind of 'M.E.-lite.')

The issue is not that M.E. is more severe, more serious, more credible, or has a longer history than 'CFS' – and so we're trying to gain superiority over you because of that – but that the disease category of 'CFS' does not exist.

The creation of 'CFS' has harmed people with M.E. in many different ways. Because of mistreatment, many are bedbound and housebound (who would not have been otherwise), and there have even been many needless deaths. But non-M.E. sufferers misdiagnosed with 'CFS' are harmed in similar ways very often, and there continue to be needless deaths among these sufferers too. It is absolutely for the benefit of all the patient groups involved that 'CFS' must be abandoned. We all deserve our best chance for our most positive prognosis and 'CFS' denies all of us this chance. We all equally deserve this chance, and the best way there is of both of us getting what we want and need is to unite together to fight against 'CFS' – that is our common enemy (that and the vested interest groups involved) not each other.

- *A note on non-M.E. patients misdiagnosed with CFS:* I am primarily a M.E. advocate, but for years I've gotten almost as many emails from people misdiagnosed with 'CFS' who don't have M.E. as I do people who do have M.E., and they're often just as desperate for help and have just as sad and tragic stories to tell. This paper is a sincere attempt to help all those people misdiagnosed with 'CFS' who don't have M.E. I wrote it so that I would have something to send to these people that might be helpful (and that I don't have to type from scratch each time). I hope this is to be the first of a series of papers aimed NOT at people with M.E. but at those patients who have been lumped into a 'CFS' misdiagnosis who have other illnesses for which they do not yet have an accurate diagnosis, and who are also harmed immeasurably by the creation of the fictional disease category of 'CFS' and so on. Needless suffering and death is needless suffering and death.
- If you fit into this category and have any suggestions on any extra information you'd like to see in this paper, please send them by [email](#). Please be as brief and as 'to the point' as you can. I'm also after 'from CFS misdiagnosis to accurate diagnosis' stories, for future inclusion on this page. (Let me know; how long did it take you to get a correct diagnosis? How did this new diagnosis affect you and your health? What was your correct diagnosis in the end? Do you have any tips for other sufferers, any useful advice on getting a correct diagnosis? Are there any books or articles in particular that you'd like to recommend? Etc.)

**Question 12:** I seem to fit the 2003 Canadian definition of 'ME/CFS' does this mean that I definitely have M.E.?

**Answer:** No, it doesn't. As the name suggests, this is a mixed M.E. and 'CFS' definition. It is essentially yet another redefinition of CFS, but with some of the symptoms (and other features) of M.E. tacked on.

The Canadian 'ME/CFS' definition should not be considered a pure M.E. definition as it is possible to qualify for the diagnosis without having the unique and essential features of M.E. M.E. is defined by measurable damage to the central nervous system; the brain, as well as various other cardiac, cardiovascular and metabolic dysfunctions and damage – and not by mere (medically unexplained or other form of) 'chronic fatigue' or 'post-exertional fatigue or malaise.'

The fact that some (or all) post-viral fatigue syndrome or Lyme disease patients, and others, may fit the symptoms listed in the Canadian criteria does not mean that these patients can be correctly diagnosed with authentic neurological M.E. – as per Ramsay/Richardson/Dowsett and Hyde and the long history of M.E. and the outbreaks of M.E. – nor that these illnesses are the same or 'virtually the same' as M.E. They are not.

The Canadian 'ME/CFS' guidelines are not a pure/accurate M.E. definition. They are, as the name suggests, a 'ME/CFS' definition, a bizarre mix of two entirely different entities; M.E. and 'CFS.' Because of the flaws in this definition, it seems entirely possible that one could conduct research on a Canadian 'ME/CFS' patient group, which did not contain even one genuine M.E. sufferer. Despite the good parts of this definition, this has to be cause for enormous concern and caution regarding the use of these guidelines (Hyde 2006, [Online]).

- *An additional note on the Canadian guidelines:* Like the Fukuda and Oxford 'CFS' definitions, the Canadian 'ME/CFS' guidelines also selects a heterogeneous (mixed) patient group; although it has been shown that the Canadian patient group is less likely to have a psychiatric illness as the cause of their symptoms, and more likely to be more seriously disabled by their illness. Despite its many imperfections however, the Canadian guidelines remain overall vastly superior to each of the definitions of 'CFS' (for the diagnosis and study of M.E.) which are not M.E. definitions in any part. Read more about the benefits and the limitations of the Canadian Guidelines at: [Canadian Guidelines Review](#), [The Definitions of M.E.](#) and [Testing for M.E.](#)
- See also: [The Nightingale Definition of M.E.](#) by Dr Byron Hyde, a TESTABLE M.E. definition. (M.E. must not be diagnosed solely based upon symptomatology as this seems very open to misinterpretation; the tests which can distinguish M.E. from other conditions must also be utilized if at all possible. eg. MRI brain scans.)
- *An additional note on 'fatigue':* Just as some M.E. sufferers will experience other minor and non-essential symptoms such as vomiting or night sweats some of the time, but others will not, the same is true of fatigue. The diagnosis of M.E. is determined upon the presence of certain neurological, cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, muscular, gastrointestinal and other symptoms (and so on) – the presence or absence of mere 'fatigue' is irrelevant. The symptoms and disability associated with M.E. are also not 'mysterious' or 'medically unexplained.' See: [What is Myalgic Encephalomyelitis?](#)

**Question 13:** I have a post-viral fatigue syndrome, that's basically the same thing as M.E. isn't it?

**Answer:** No, it isn't. They're apples and oranges. There are a number of post-viral fatigue states or syndromes which may follow common infections such as mononucleosis/glandular fever, hepatitis, Q fever, Ross river virus and so on. M.E. is an entirely different condition to these post-viral fatigue syndromes however. People suffering with any of these post-viral fatigue syndromes do not have M.E. any more than they have other distinct neurological diseases such as multiple sclerosis or motor neurone disease.

An abundance of evidence spanning over 70 years shows that it is simply not possible that M.E. could be caused by the Epstein-Barr virus, any of the herpes viruses (including HHV6), glandular fever/mononucleosis, Cytomegalovirus (CMV), Ross River virus, Q fever, hepatitis, chicken pox, influenza or any of the bacteria which can result in Lyme disease (or other tick-borne bacterial infections). The symptoms, pathology and incubation periods, and so on, simply do not fit. M.E. is also not a form of chemical poisoning. We know for a fact that M.E. is caused by a virus, a virus with an incubation period of 4-7 days – and there is very good evidence to suggest that the culprit is an enterovirus (Hyde 2006, [Online]) (Hyde 2007, [Online]) (Hooper 2006, [Online]) (Hooper & Marshall 2005a, [Online]) (Hyde 2003a, [Online]) (Dowsett 2001a, [Online]) (Hooper et al. 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]) (Ryll 1994, [Online]).

Myalgic Encephalomyelitis does have some limited similarities – to varying degrees – to illnesses such as multiple sclerosis, Lupus, post-polio syndrome (and polio), Gulf War Syndrome and chronic Lyme disease, and others. But this does not mean that they represent the same etiological or pathobiological process. They do not. M.E. is a distinct neurological illness with a distinct; onset, symptoms, aetiology, pathology, response to treatment, long and short term prognosis – and World Health Organization classification (G.93.3) (Hyde 2006, [Online]) (Hyde 2007, [Online]) (Hooper 2006, [Online]) (Hooper & Marshall 2005a, [Online]) (Hyde 2003a, [Online]) (Dowsett 2001a, [Online]) (Hooper et al. 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online])

While it is true that some of the definitions of 'CFS' do describe some of these post-viral fatigue syndromes to some extent – CFS is not the correct term for post-viral fatigue syndromes. (For a start, these post-viral fatigue syndromes are NOT medically unexplained, nor a mere diagnosis of exclusion, nor are they illnesses in which all tests will always be normal.) Terms such as CFS/ME, ME/CFS, Myalgic Encephalomyelitis, CFIDS or Myalgic Encephalopathy are also inappropriate and incorrect.

Post-viral fatigue syndromes must be studied under the name 'post-viral fatigue syndromes' (or post-infective fatigue syndromes perhaps?) and using legitimate definitions for these illnesses – and not the various flawed 'CFS' definitions which select a heterogeneous patient group – so as not to be confused with any other patient group. Studies on post-viral fatigue syndrome patients must only contain those patients who have the same post-viral fatigue syndrome for the benefit of these post-viral fatigue syndrome patients, M.E. patients, and people with other illnesses which may be misdiagnosed as 'CFS.'

It is not scientifically or ethically sound to claim that 'CFS' or M.E. is the same thing as all the post-viral fatigue syndromes, or that people with post-viral fatigue syndromes are a subgroup of 'CFS' (or of M.E.) or that post-viral fatigue syndromes can 'turn into' 'CFS' or M.E. It may well be true that post-viral fatigue syndrome patients

would benefit from these conditions being renamed or redefined in some way and that there is a need for greater advocacy attention and research spending – but to attempt to gain this at the expense of a far more seriously disabled and vulnerable group of patients who are already dealing with so much abuse from all sides (people with M.E.) is cruel to say the least and, again, not in any way scientifically or ethically sound. If there is to be a new name for this patient group, it must be one which is not already TAKEN by an entirely unrelated and already well-defined patient group. Post-viral fatigue syndromes (caused by glandular fever or mononucleosis, hepatitis, Ross River virus etc.) are not at all the same illness as neurological M.E. and so there is no more right to claim that name (and to the patient group and research it is legitimately linked with) than to 'diabetes' or 'cancer.'

- See: [The outbreaks \(and infectious nature\) of M.E.](#) section for more information.
- See [M.E. and other illnesses](#) for more information. See also [Who benefits from 'CFS' and 'ME/CFS'?, 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' by M.E. advocates.](#)

**Question 14:** But don't 'CFS' and M.E. at least have severe fatigue in common?

**Answer:** Myalgic Encephalomyelitis is not synonymous with being tired all the time.

Fatigue and feeling 'tired all the time' are not at all the same thing as the very specific type of paralytic muscle weakness or muscle fatigue 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 up to 50% (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, Reynaud's phenomenon, 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 post-illness limits leaving M.E. patients extremely disabled (Bassett 2007, [Online]).

M.E. expert [Dr Melvin Ramsay](#) explained that this unique characteristic: 'is virtually a sheet-anchor in the diagnosis of Myalgic Encephalomyelitis and without it a diagnosis should not be made' (1986, [Online]). This intolerance of certain levels of physical or cognitive activity, sensory input and orthostatic stress is one of the many things which separate Myalgic Encephalomyelitis so distinctly from various post-viral fatigue states or other illnesses involving chronic fatigue. M.E. expert [Dr Byron Hyde](#) also writes that: 'In MRI spectography it has been shown that because of an abnormal build-up of normal metabolites, the muscle cell actually shuts down to prevent cell death [in M.E.]' (Hyde 2003, [Online]). People with M.E. are experiencing a form of heart failure which can be exacerbated by even relatively low levels of activity. People with M.E. are made very ill and disabled by this problem with their cells (and their mitochondria, and so on); it affects virtually every bodily system, and has also led to death in some cases. Many patients are severely disabled and housebound and bedbound. People with M.E. would give anything to instead 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. These terms are not accurate or specific enough to describe what is happening in M.E. M.E. is a neurological illness of extraordinarily incapacitating dimensions that affects virtually every bodily system – not a problem of chronic fatigue (Hyde 2006, [Online]) (Hooper 2006, [Online]) (Hooper & Marshall 2005a, [Online]) (Hyde 2003, [Online]) (Dowsett 2001, [Online]) (Hooper et al. 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]) (Dowsett 1996, p. 167) (Dowsett et al. 1990, pp. 285-291) (Dowsett n.d., [Online]).

- For more information see [Myalgic Encephalomyelitis is not fatigue, or 'CFS'](#). Many of the worlds leading M.E. experts have spoken out strongly against 'fatigue' being claimed to be the defining/essential symptom of M.E. see [M.E. is not defined by 'fatigue'](#) to read some of their comments.
- For more information on the symptoms of M.E., including the unique reaction people with M.E. have to activity, see: [The Ultra-comprehensive Myalgic Encephalomyelitis Symptom List](#)

**Question 15:** I'm absolutely appalled by this 'CFS' scam and all the abuse and neglect of so many very ill people. What else can I do to help improve things?

**Answer:** The only way forward, for the benefit of society and every patient group involved, is that:

1. The bogus disease category of 'CFS' must be abandoned completely and each of the patient groups involved must again be correctly diagnosed and then treated as appropriate based on legitimate and unbiased science involving the SAME patient group.



2. The name Myalgic Encephalomyelitis must be fully restored (to the exclusion of all others) and the World Health Organization classification of M.E. must be accepted and adhered to in all official documentations and government policy. People with M.E. must again be diagnosed with and treated for M.E. based on unbiased research involving only authentic neurological M.E. patients.

We have only a tiny minority of the medical, scientific, legal and other potentially supporting professions (or the public) on our side. What is needed is for people from all over the world to stand up for the truth about 'CFS' and about Myalgic Encephalomyelitis; individual physicians, journalists, politicians, human rights campaigners, patients, families and friends of patients and the public. That is the only way change will occur, through education and through people refusing to accept what is happening any more; refusing to accept the 'CFS' insurance scam.

Despite the gross violation of human rights, the large human rights organisations and the media seem entirely disinterested in the truth about M.E. or in all those people who have been misdiagnosed with 'CFS' and subjected to serious abuse and neglect. They have been unable (or unwilling) to see past the 'CFS' propaganda, and have done nothing to help any of the hundreds of thousands of very ill and vulnerable patients who are being systematically abused by those in positions of power because it is politically and financially convenient; indeed very often they are strong and vocal *supporters* of some of the worst propaganda and pseudo-science.

**So what you can do to help is to PLEASE help to spread the truth about 'CFS' and about Myalgic Encephalomyelitis.** This appalling abuse and neglect of so many severely ill people on such an industrial scale is truly inhuman and has already gone on for far too long. Knowledge is power.

- For more information see: [What is Myalgic Encephalomyelitis?](#)

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**The HUMMINGBIRDS' FOUNDATION for M.E. (HFME)**

*Fighting for the recognition of Myalgic Encephalomyelitis based on the available scientific evidence, and for patients worldwide to be treated appropriately and accorded the same basic human rights as those with similar disabling and potentially fatal neurological diseases such as Multiple Sclerosis.*

**A one-page summary of the facts of M.E.**

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Taken from [www.hfme.org](http://www.hfme.org)



- Myalgic Encephalomyelitis is a disabling neurological disease that is very similar to multiple sclerosis (M.S.) and poliomyelitis (polio). Earlier names for M.E. were 'atypical multiple sclerosis' and 'atypical polio.'
- Myalgic Encephalomyelitis is a neurological disease characterised by scientifically measurable post-encephalitic damage to the brain stem. This is always damaged in 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, Itis = 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 with the ICD code G.93.3.
- Myalgic Encephalomyelitis 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.
- Myalgic Encephalomyelitis is an acute (sudden) onset, infectious neurological disease caused by a virus (a virus with a 4-7 day incubation period). M.E. occurs in epidemics as well as sporadically and over 60 M.E. outbreaks have been recorded worldwide since 1934. There is ample evidence that M.E. is caused by the same type of virus that causes polio; an enterovirus.
- Myalgic Encephalomyelitis can be more disabling than MS or polio, and many other serious diseases. M.E. is one of the most disabling diseases there is. 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 Myalgic Encephalomyelitis 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 pump barely 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 (eg. 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.*
- Myalgic Encephalomyelitis 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 (eg. MRI and SPECT brain scans). Abnormalities are also visible on physical exam in M.E.
- Myalgic Encephalomyelitis is a long-term/lifelong neurological disease that affects more than a million adults and children worldwide. In some cases M.E. is fatal. (Causes of death in M.E. include heart failure.)

For more information, and to read a fully-referenced version of this text compiled using information from the world's leading M.E. experts, please see: What is M.E.? Extra extended version. Permission is given for this unedited document to be freely redistributed. Please redistribute this text widely.