

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

Copyright © Jodi Bassett December 2007. This version updated March 2009.

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



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.

### **In 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, if you are reading the full-length text).
- 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>
- Hooper, M 2006, Myalgic Encephalomyelitis (ME): a review with emphasis on key findings in biomedical research J. Clin. Pathol. published online 25 Aug 2006; doi:10.1136/jcp.2006.042408 Available: <http://www.hfme.org/whooper.htm>

- Hooper, M. Marshall E.P. & Williams, M. 2001, What is ME? What is CFS? Information for Clinicians and Lawyers, [Online], Available: <http://www.hfme.org/wmarwillhoopwimewicfs.htm>
- Hyde, Byron M.D. 2007, The Nightingale Definition of Myalgic Encephalomyelitis [Online], Available: <http://www.hfme.org/whydepapers.htm#390403648>
- Hyde, Byron M.D. 2006, 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 [Online], Available: <http://www.hfme.org/whydepapers.htm#390405053>
- Hyde, Byron M.D. 2003, The Complexities of Diagnosis in (ed) Jason, Leonard at et al. 2003 Handbook of Chronic Fatigue Syndrome by Ross Wiley and Sons, USA. Available: <http://www.hfme.org/whydepapers.htm#390405053>

For a full list of references, see: [What is Myalgic Encephalomyelitis?](#)

**Permission is given for this document to be freely redistributed** by e-mail or in print for any not-for-profit purpose provided that the entire text (including this notice and the author's attribution) is reproduced in full and without alteration. Please redistribute this text widely.

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*