

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.

The misdiagnosis of 'CFS' - Summary

Copyright © Jodi Bassett December 2006. This version updated March 2009.
Taken from www.hfme.org



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.' **A diagnosis of CFS – based on these or any of the other CFS definitions – can only ever be a misdiagnosis.**

The reason for this is that despite the fact that the new name and definition of CFS were created in a response to an outbreak of what was unmistakably M.E., this new name and definition did not describe the known signs, symptoms, history and pathology of M.E. It described a disease process which did not, and could not exist. (Hooper et al. 2001, [Online]) (Dowsett n.d.a. [Online]) (Hyde 2006, [Online]) As M.E. expert Dr Byron Hyde explains:

Do not for one minute believe that CFS is simply another name for Myalgic Encephalomyelitis. It is not. The CDC 1988 definition of CFS describes a non-existing chimera based upon inexperienced individuals who lack any historical knowledge of this disease process. The CDC definition is not a disease process. It is (a) a partial mix of infectious mononucleosis /glandular fever, (b) a mix of some of the least important aspects of M.E. and (c) what amounts to a possibly unintended psychiatric slant to an epidemic and endemic disease process of major importance. Any disease process that has major criteria, of excluding all other disease processes, is simply not a disease at all; it doesn't exist. The CFS definitions were written in such a manner that CFS becomes like a desert mirage: The closer you approach, the faster it disappears and the more problematic it becomes (2006, [Online]).

As Professor Malcolm Hooper explains, 'As a basis for sound scientific research, [CFS] has been a disaster.' (2001, [Online]) Today there are more than nine different CFS definitions. Just like the original definition of CFS produced in 1988 however, none of these definitions defines any distinct illness, including Myalgic Encephalomyelitis. (Hyde 2006, [Online]) All each of these flawed definitions 'define' is a heterogeneous (mixed) population of people with various misdiagnosed psychiatric and miscellaneous non-psychiatric states which have little in common but the symptom of fatigue. (Hooper et al 2001, [Online]) (Dowsett 2001b, [Online]) This is why being diagnosed with any of the definitions of CFS is not a useful or meaningful 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.

The creation of the flawed disease category of 'CFS' (and the equally flawed government policies that have gone along with it) have had a devastating effect on hundreds of thousands of M.E. sufferers around the world, including young children. These very ill patients are often denied appropriate medical treatment and care, denied appropriate insurance entitlements and other medical benefits and are often accused of malingering by doctors, welfare agencies and the media (and in turn even their own friends and family). M.E. patients are also routinely recommended or forced to participate in inappropriate or harmful psychologically based interventions while basic appropriate medical care is withheld. These harmful interventions (and the lack of basic medical care) have had disastrous and long-term physical effects on many sufferers. In some cases this has resulted in death. (Hooper et al. 2001, [Online]) (Hyde 2003, [Online])

Patients with M.E. are not the only patient group to be negatively affected however. Other patient groups misdiagnosed as CFS are also denied appropriate diagnosis and treatment. They may also be subjected to inappropriate psychological interventions. Doctors, researchers and the general public are also negatively affected in various ways by this subterfuge (As explained previously in Smoke and Mirrors). 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.

The only way forward for every group involved is that the disease category of 'CFS' must be abandoned.

(Hooper 2006, [Online]) 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 and treated for M.E. Patients with depression should be diagnosed and treated for depression. 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*. i.e. 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' include:

- Various post-viral fatigue states/post-viral fatigue syndromes (eg. following glandular fever/mononucleosis, hepatitis, Ross river virus, 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, gliomas
- Transverse Myelitis
- Myopathic illnesses including: Myasthenia gravis, Mitochondrial myopathies, Post-infectious polymyositis
- Vitamin B12 deficiency disorders: Pernicious anaemia, Intentional dietary deprivation, Intestinal disease associated with or independent of M.E.
- Rheumatoid illness or lupus (SLE)
- Sarcoma
- Renal or liver disease
- Infectious illnesses including: Toxoplasmosis, AIDS, Lyme disease (*Borrelia burgdorferi*), Tuberculosis, 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]) (Ramsay 1988) (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. M.E. expert Dr. Elizabeth Dowsett explains that, 'There are actually 30 well documented causes of 'chronic fatigue.'" (n.d.a. [Online]) It should also be remembered that although none of the CFS definitions define M.E., the majority of those with M.E. will be given a CFS diagnosis by default (due to the ignorance surrounding M.E., and the confusion with 'CFS'). Therefore the possibility that a patient misdiagnosed with CFS has authentic Myalgic Encephalomyelitis should also be investigated, along with these myriad other possibilities.

Today patients with all sorts of different illnesses are commonly misdiagnosed as having 'CFS.' Under cover of the bogus disease category of CFS, this diverse mix of patients are treated as if they each suffered the exact same specific illness. This is clearly unscientific, and unethical. These patients must be given the opportunity to be diagnosed correctly if they are to have any chance of appropriate treatment or recovery, not given a meaningless 'CFS' misdiagnosis. Patients with M.E. need this same opportunity. Treating this diverse and heterogenous 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 heterogenous patient group, many (likely the vast majority) of those with the diagnosis are not mentally ill, and do not suffer from behavioural problems. (This includes of course, those patients with authentic M.E.) (Hooper 2006, [Online]) (Hyde 2006, [Online]) (Hooper et al. 2001, [Online])

For the benefit of all of the patient groups involved, doctors must return to the age-old medical principals of correct diagnosis (a) careful history, (b) detailed physical examination and (c) appropriate investigation. (Hyde 2006, [Online]) As Dr Byron Hyde explains:

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])

Physicians who diagnose 'CFS' in any patient experiencing new onset fatigue without looking and testing for the true cause of the symptoms do their patients – and themselves – a great disservice. As [Dr. Elizabeth Dowsett](#) explains, 'There is no such disease(s) as CFS' (n.d.a. [Online]) 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.

Every patient deserves the best possible opportunity for appropriate treatment for their illness, and for recovery. This process must begin with a correct diagnosis if at all possible. **A correct diagnosis is half the battle won.**

For more information:

- PART 2 of this paper (included in the full-length version of this text) lists the symptoms of some of the illnesses commonly misdiagnosed as CFS, and compares them with the CFS definitions. If you have been misdiagnosed with 'CFS' and aren't sure what to do next, see the new must-read paper: [Where to after a 'CFS' \(mis\)diagnosis?](#) and [Additional question and answer session on the text.](#)
- M.E. is a distinct, recognisable entity; an acute onset organic neurological disease that can be diagnosed relatively early in the course of the disease, providing the physician has some experience with the illness. [The Nightingale Definition of M.E.](#) – a testable definition of M.E. finally – now also makes diagnosis easier than ever before even for those with no experience with the illness. For information on how authentic M.E. is characterised and diagnosed see: [Testing for Myalgic Encephalomyelitis](#) and [What is Myalgic Encephalomyelitis?](#) The excellent papers by Dr Byron Hyde, a doctor with over 20 years experience with M.E. (and who is also very knowledgeable about 'CFS' and has seen a vast number of patients misdiagnosed with 'CFS') and regarded by many as today's leading M.E. expert are also essential extra reading, 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](#) and his newest paper: [The Nightingale Definition of M.E.](#)
- The terminology is often used interchangeably, incorrectly and confusingly. However, the DEFINITIONS of M.E. and CFS are very different and distinct, and it is the definitions of each of these terms which is of primary importance. *The distinction must be made between terminology, and definitions.* In summary:
 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.

M.E. is not synonymous with 'CFS' and 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 as 'CFS'* – that is the entire issue, and the vast majority of patients misdiagnosed with CFS *do not* have M.E. and so for them that term is as incorrect as 'cancer' or 'diabetes.' 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: [What is Myalgic Encephalomyelitis?](#), [Myalgic Encephalomyelitis is not fatigue, or 'CFS' or '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](#), plus [Why the disease category of 'CFS' must be abandoned](#) and [Smoke and Mirrors](#)

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. Again, more experienced, more knowledgeable and more credible M.E. experts than these simply do not exist.

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

- Dowsett, Elizabeth MBChB. 2001a, *THE LATE EFFECTS OF ME Can they be distinguished from the Post-polio syndrome?* [Online], Available: <http://www.hfme.org/wdowsett.htm>
- Dowsett, Elizabeth MBChB. 2001b, *A rose by any other name* [Online], Available: <http://www.hfme.org/wdowsett.htm>
- Dowsett, Elizabeth MBChB. n.d. a, *Differences between ME and CFS*, [Online], Available: <http://www.hfme.org/wdowsett.htm>
- 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>
- 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://jcp.bmjournals.com/cgi/content/abstract/jcp.2006.042408v1> The PDF is also available at: http://www.hfme.org/Other/ME_A_Review_by_Hooper.pdf
- 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 [Online], Available: <http://www.hfme.org/whydepapers.htm>
- 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>
- Hyde, Byron M.D. 2007, *The Nightingale Definition of Myalgic Encephalomyelitis (M.E.)* [Online], Available: <http://www.hfme.org/whydepapers.htm>
- Hyde, Byron M.D. 1992, *Preface* in Hyde, Byron M.D. (ed) 1992, *The Clinical and Scientific Basis of Myalgic Encephalomyelitis*, Nightingale Research Foundation, Ottawa
- Hyde, Byron M.D., Bastien, Sheila M.D. & Anil Jain M.D. 1992, *General Information: Post Infectious, Acute Onset M.E.* in Hyde, Byron M.D. (ed) 1992, *The Clinical and Scientific Basis of Myalgic Encephalomyelitis*, Nightingale Research Foundation, Ottawa
- Hyde, Byron M.D. & Anil Jain M.D. 1992, *Clinical Observations of Central Nervous System Dysfunction in Post Infectious, Acute Onset M.E.* in Hyde, Byron M.D. (ed) 1992, *The Clinical and Scientific Basis of Myalgic Encephalomyelitis*, Nightingale Research Foundation, Ottawa
- Ramsay, A. 1988, *Myalgic Encephalomyelitis and Postviral Fatigue States: The saga of Royal Free Disease*, Gower Medical Publishing, London.
- Ramsay, Melvin A. 1986 *MYALGIC ENCEPHALOMYELITIS : A Baffling Syndrome With a Tragic Aftermath.* [Online], Available: <http://www.meactionuk.org.uk/ramsey.html>

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.

Disclaimer: The HFME does not dispense medical advice or recommend treatment, and assumes no responsibility for treatments undertaken by visitors to the site. It is a resource providing information for education, research and advocacy only. Please consult your own health-care provider regarding any medical issues relating to the diagnosis or treatment of any medical condition.

The 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.

Copyright © Jodi Bassett, January 2009. This version updated May 2009.
Taken from 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.