

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.

'CFS' and M.E. comparison chart

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Chronic Fatigue Syndrome and Myalgic Encephalomyelitis are *not* the same, or similar, as this chart illustrates.

The many differences between CFS and M.E.

Chronic Fatigue Syndrome	Myalgic Encephalomyelitis
CFS was created in the late 1980s.	M.E. has existed for centuries. The first well-documented outbreak was in 1934. The name M.E. was coined in 1956.
CFS is characterised by chronic fatigue.	M.E. is characterised by damage to the brain and brain stem (which is observable on brain scans, and is similar to the CNS damage seen in M.S.). M.E. is primarily neurological and secondarily a vascular disease.
The symptoms associated with CFS can be caused by many different viruses, bacterial infections, trauma, physical or emotional stress, toxic exposures, nutritional issues and many other causes.	M.E. is caused by a virus. Significant evidence shows that M.E. is caused by an enterovirus. The major M.E. experts (Drs Hyde, Dowsett, Ramsay and Richardson) <i>all</i> consider M.E. to be an enteroviral disease.
CFS cannot occur in outbreaks.	M.E. occurs sporadically and in outbreaks. Over 60 M.E. outbreaks have been recorded worldwide since 1934.
Patients do not have to have neurological damage of any kind to qualify for a diagnosis of CFS. Most CFS diagnosed patients <i>do not have</i> CNS damage.	The term M.E. means muscle pain and brain/spinal cord inflammation. The neurological damage suggested by these terms is an essential M.E. feature, confirmed by testing.
CFS cannot be said to have any distinct incubation period, as it defines a heterogeneous patient group. (Many viruses previously considered causes of CFS, such as EBV and HHV6, have longer incubation periods of over 40 days).	M.E. has as an incubation period of 4 - 7 days.
CFS cannot be contagious.	M.E. can be passed on to others in the early stages.
CFS describes a gradual onset fatigue syndrome. Symptoms may appear gradually over many weeks or months.	M.E. onset is dramatic and sudden and the severe symptoms begin on day one of M.E. Most patients can tell you not only the day, but the <i>hour</i> they became ill.
CFS is not associated with a prodromal (or early symptom) phase.	The prodromal phase of M.E. most often involves: a respiratory illness, gastrointestinal upset, vertigo and/or a moderate to severe meningitic type headache.
CFS has a set of criteria (a checklist) that patients must fit to be given the diagnosis. This checklist is not a description of an actual disease; patients must merely meet certain criteria to qualify for the diagnosis.	M.E. has a distinct and testable definition, which describes the main features of this disease and how it presents in patients.
CFS is not a distinct disease with a distinct cause and pathology, it is a diagnosis of exclusion.	M.E. is not a diagnosis of exclusion. It is a distinct disease with a distinct definition, symptomatology and pathology.
CFS can not be diagnosed until after 6 months have passed.	M.E. can be diagnosed within just a few weeks if a physician is familiar with the disease. M.E. is an easily recognisable and diagnosable neurological disease.

Tests cannot confirm a suspected CFS diagnosis. If testable causes of symptoms are found then a person no longer qualifies for the CFS diagnosis.	A series of tests (including brain scans) can confirm a M.E. diagnosis with a high degree of accuracy. If all tests are normal, then a diagnosis of M.E. cannot be correct.
Abnormalities on physical exam are not associated with CFS.	Abnormalities are always seen on physical exam in M.E.
If a patient with a CFS diagnosis is then found to have medical reasons for their fatigue, such as cancer or vitamin B12 deficiency, they would no longer qualify for a CFS diagnosis.	If a patient with M.E. is also diagnosed with other diseases this makes no difference to their status as an M.E. patient as a patient can have other conditions alongside M.E. M.E. is not a diagnosis of exclusion or wastebasket diagnosis.
The fatigue of CFS is medically unexplained.	The many dysfunctions caused by M.E. are not medically unexplained. Much is known about the viral cause of the disease and of its symptoms and other characteristics.
CFS does not have unique features or symptoms. Patients must merely have a small number of vaguely defined symptoms to qualify for a CFS diagnosis.	M.E. has several unique features and symptoms and is virtually identical in presentation from one patient to the next.
CFS is not associated with neurological damage (to the central and autonomic nervous systems) or a loss of homeostasis.	Consequences of neurological damage in M.E. such as loss of homeostasis are an essential feature of the disease, as is damage to the CNS and ANS.
Fatigue is the defining and essential symptom of CFS. Patients <i>must</i> have fatigue lasting more than 6 months to qualify for a CFS diagnosis.	Fatigue is not a defining feature of M.E. and is not essential for the diagnosis. Some M.E. patients may have this minor symptom while many others will not.
CFS is associated with patients being constantly fatigued (or tired all the time) for longer than 6 consecutive months.	Part of what defines M.E. is the striking variability of many different neurological and other symptoms over the course of an hour, day or week. M.E. is not a stable disease.
While exercise may be <i>tiring</i> , CFS is not associated with a delayed <i>relapse</i> following overexertion.	M.E. causes a delayed relapse following overexertion. (The delay is typically 24 - 72 hours or more.)
Patients do not have to have seizures, paralysis, cardiac abnormalities, cognitive problems, vestibular problems or a sleep disorder to qualify for a CFS diagnosis.	<p>Core features of M.E. include:</p> <ol style="list-style-type: none"> Different types of seizures (e.g. absence seizures) Muscle weakness or paralysis (affecting all muscles including the heart, eyes and digestive system). Vascular/cardiac abnormalities have been reported in M.E. since the earliest M.E. outbreaks and are a major cause of the inability to complete basic daily tasks that M.E. causes; <i>the virus that causes M.E. has an affinity for the heart</i>. Problems include: Reynaud's phenomenon, reduced circulating blood volume and cardiac output, low blood pressure and postural orthostatic tachycardia (POTS). Significant cognitive dysfunction is always seen in M.E. Vestibular problems (e.g. abnormal Romberg test). M.E. includes a serious and testable sleep disorder. <p>Core features of M.E. also include pain issues (e.g. heart pain and extreme pain at the back of the head), sensitivity to alcohol/drugs/chemicals and intolerance of temperature extremes, etc.</p>
Overexertion may cause post-exertional malaise or fatigue in patients who qualify for a CFS diagnosis, but they do not have to worsen seriously with overexertion or suffer long-term or serious effects from overexertion to qualify.	Physical, mental or sensory overexertion causes a worsening of symptoms, serious relapse or disease progression, cardiac events or possibly death in the M.E. patient.

Patients that qualify for a CFS diagnosis may improve with exercise or treatments such as graded exercise therapy (GET), or at least suffer no long-term adverse effects from exercise.	Patients that improve with exercise therapies do not qualify for a diagnosis of M.E. Exercise therapies can and do leave M.E. patients far more severely ill and bedbound than they were before and in need of emergency care, or can be fatal. M.E. patients that are able to rest adequately in the early stages have the best prognosis. M.E. patients must avoid overexertion to have any quality of life.
Mild symptoms are adequate to qualify for a CFS diagnosis. Some patients may be so mildly affected as to not even be aware that they are in any way ill and/or may no longer qualify for this diagnosis after one to two years as the symptoms will often naturally resolve. CFS is not associated with fatalities.	M.E. is a severe, life-altering, long-term or lifelong disability which in some cases results in death.
The CFS criteria is similar to descriptions of Candida, burnout, EBV infections, glandular fever/mono, various nutritional deficiencies, influenza, clinical depression, and many other common fatiguing conditions.	M.E. is similar to diseases such as M.S. and Polio.
According to CDC estimates, 2.54% of the population qualify for a CFS diagnosis.	Far fewer than 0.5% of the population has the distinct neurological disease known since 1956 as M.E.

Additional notes on this text and more information

- The terms and concepts of ‘CFS,’ ‘CFS/ME,’ ‘CFIDS’ and ‘ME/CFS’ should not be used interchangeably with M.E. and the term M.E. should be used *only* in the context of being included with genuine M.E. facts. For more information about all aspects of M.E., and how M.E. and the bogus disease category of ‘CFS’ came to be erroneously linked, please see: [What is M.E.?](#)
- The most commonly used CFS criteria are described in [The misdiagnosis of ‘CFS’](#) paper. For practical information on rejecting a CFS non-diagnosis see also: [Where to after a 'CFS' \(mis\)diagnosis?](#)
- [The Nightingale Definition of M.E.](#), a *testable* definition of M.E., now makes diagnosis easier than ever before even for those with no experience with M.E. See also: [Testing for M.E.](#)
- Newer criteria which mix together CFS with a few minor M.E. symptoms, such as the Canadian ME/CFS Criteria (or the updated version, the ICC), are at least equally unhelpful and as unscientific as the earlier CFS definitions. These mixed definitions only worsen the problems faced by patients seeking correct diagnosis and appropriate care. The fact that some patients may fit these definitions does not mean that these patients can be correctly diagnosed with M.E. These are not definitions of M.E. and *many* patients can and do fit them that have diseases other than M.E. See: [Canadian Guidelines Review](#) and [Testing for M.E.](#)

References

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.’ 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. Please see the ‘What is M.E.?’ paper on the [HFME website](#) (or the *Caring for the M.E. Patient* book) to view a full reference list for the information contained in this paper. The ‘What is M.E.?’ paper also provides similar information as is included in this paper in an extended and fully referenced (intext) format.

Acknowledgements

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Relevant quotes

‘The differences [between M.E. and CFS] are so significant that they would exclude M.E. patients from the CDC diagnoses of CFS.’

DR. BYRON HYDE

‘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.’

DR BYRON HYDE

CFS IS A CREATION OF THE CDC IN THE US. BUT EVEN THE RECENTLY UPDATED CDC WEBSITE ADMITS:

‘The name myalgic encephalomyelitis (M.E.) was coined in the 1950s to clarify well-documented outbreaks of disease; however, M.E. is accompanied by neurologic and muscular signs and has a case definition distinct from that of CFS.’

‘Simple fatigue can signal a small cancer in the body or a pending heart attack. However, most doctors, faced with this common complaint, do little or no testing to find out if something deeper is amiss. Instead, they may advise the patient with fatigue to exercise more, take a nap, take a vacation or worse, have a cup of coffee or tea. By following this advice, however, the patient often masks or obscures the original symptom of fatigue. This often leads to worse problems in the following months or years.’

DR LAWRENCE WILSON

‘In terms of the patients whose illness is consistent with the various CFS definitions, none of these patients I have ever seen have been seriously examined and as far as I am concerned, CFS is simply a missed diagnosis in which we have uncovered missed malignancies, missed MS, missed cardiac and cardiovascular disease, missed autoimmune disease. The CFS diagnosis is largely indefensible and since it can represent so many different pathologies and illnesses, it is absurd to consider a uniform treatment whether this treatment is graded exercise or some theoretical pharmaceutical. It is essential to first discover the underlying pathologies before one considers treatment by any modality.’

DR BYRON HYDE

‘To the very few physicians still practicing today who began seeing patients with this illness some 40 years ago and who have continued to record and publish their clinical findings throughout, the current enthusiasm for renaming and reassigning this serious disability to subgroups of putative and vague “fatigue” entities, must appear more of a marketing exercise than a rational basis for essential international research. It was not always so unnecessarily complicated!’

DR ELIZABETH DOWSETT

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

ME is a systemic disease (initiated by a virus infection) with multi system involvement characterised by central nervous system dysfunction which causes a breakdown in bodily homeostasis (The brain can no longer receive, store or act upon information which enables it to control vital body functions, cognitive, hormonal, cardiovascular, autonomic and sensory nerve communication, digestive, visual auditory balance, appreciation of space, shape etc). It has a UNIQUE Neuro-hormonal profile.’

DR ELIZABETH DOWSETT

‘It is increasingly obvious that too much importance is being placed upon the definitions of Chronic Fatigue Syndrome (CFS), and not enough upon the actual disease, Myalgic Encephalomyelitis (M.E.). These two illness spectrums are not the same and should not be considered to be the same. Nor is there any doubt in my mind that the various definitions of CFS actively impede physicians’ ability to make a rapid and rational diagnosis as well as a scientific confirmation of any testable illness.’

DR BYRON HYDE 2011

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

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- Myalgic Encephalomyelitis (M.E.) is a disabling neurological disease that is very similar to Multiple Sclerosis (M.S.) and Poliomyelitis. Earlier names for M.E. were 'atypical Multiple Sclerosis' and 'atypical Polio.'
- M.E. is a neurological disease characterised by scientifically measurable post-encephalitic damage to the brain stem. This damage is an essential part of M.E., hence the name M.E. The term M.E. was coined in 1956 and means: my = muscle, algic = pain, encephalo = brain, mye = spinal cord, tis = inflammation. This neurological damage has been confirmed in autopsies of M.E. patients.
- Myalgic Encephalomyelitis has been recognised by the World Health Organisation's International Classification of Diseases since 1969 as a distinct organic neurological disease. M.E. is classified in the current WHO International Classification of Diseases with the neurological code G.93.3.
- M.E. is primarily neurological, but also involves cognitive, cardiac, cardiovascular, immunological, endocrinological, metabolic, respiratory, hormonal, gastrointestinal and musculo-skeletal dysfunctions and damage. M.E. affects all vital bodily systems and causes an inability to maintain bodily homeostasis. More than 64 individual symptoms of M.E. have been scientifically documented.
- M.E. is an acute (sudden) onset, infectious neurological disease caused by a virus (a virus with a 4-7 day incubation period). M.E. occurs in epidemics as well as sporadically and over 60 M.E. outbreaks have been recorded worldwide since 1934. There is ample evidence that M.E. is caused by the same type of virus that causes Polio; an enterovirus.
- M.E. can be more disabling than M.S. or Polio, and many other serious diseases. M.E. is one of the most disabling diseases that exists. More than 30% of M.E. patients are housebound, wheelchair-reliant and/or bedbound and are severely limited with even basic movement and communication.
- *Why are M.E. patients so severely and uniquely disabled?* For a person to stay alive, the heart must pump a certain base-level amount of blood. Every time a person is active, this increases the amount of blood the heart needs to pump. Every movement made or second spent upright, every word spoken, every thought thought, every word read or noise heard requires that more blood must be pumped by the heart.
 However, the hearts of M.E. patients only 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 and cardiac insufficiency, is why every brief period spent walking or sitting, every conversation and every exposure to light or noise can affect M.E. patients so profoundly. Seemingly minor 'activities' can cause significantly increased symptom severity and/or disability (often with a 48-72 hour delay in onset), prolonged relapse lasting months, years or longer, permanent bodily damage (e.g. heart damage or organ failure), disease progression or death.
 If activity levels exceed cardiac output by even 1%, death occurs. Thus the activity levels of M.E. patients must remain strictly within the limits of their reduced cardiac output just in order for them to stay alive. *M.E. patients who are able to rest appropriately and avoid severe or prolonged overexertion have repeatedly been shown to have the most positive long-term prognosis.*
- M.E. is a testable and scientifically measurable disease with several unique features that is not difficult to diagnose (within just a few weeks of onset) using a series of objective tests (e.g. MRI and SPECT brain scans). Abnormalities are also visible on physical exam in M.E. M.E. is a long-term/lifelong neurological disease that affects hundreds of thousands of adults and children worldwide. In some cases M.E. is fatal. (Causes of death in M.E. include heart failure.)



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

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

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