

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.

M.E. is not 'fatigue' or 'CFS'

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Myalgic Encephalomyelitis (M.E.) is not synonymous with being tired all the time. If a person is very fatigued for an extended period of time this does not mean they are having a 'bout' of M.E. To suggest such a thing is no less absurd than to say that prolonged fatigue means a person is having a 'bout' of multiple sclerosis, Parkinson's disease or Lupus.

If a person is constantly fatigued this should not be taken to mean that they have M.E. no matter how severe or prolonged their fatigue is. Fatigue is a symptom of many different illnesses as well as a feature of normal everyday life – but it is not a defining symptom of M.E., nor even an essential symptom of M.E.

There are a number of post-viral fatigue states or fatigue 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 self-limiting fatigue syndromes however (and is *not* caused by the Epstein Barr virus or any of the herpes or hepatitis viruses), the science is very clear on this point. People suffering with any of these post-viral fatigue states or fatigue syndromes do not have M.E.

M.E. is also not the same condition as Lyme disease, athletes over-training syndrome, burnout, depression, somatisation disorder, candida, multiple chemical sensitivity syndrome or Fibromyalgia, or indeed any other illness. 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, 2007, [Online]) (Hooper 2006, [Online]) (Hooper & Marshall 2005, [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]).

M.E. is also not defined by 'fatigue following exertion which can last up to 24 hours' as the bogus definitions of 'CFS' describe. Fatigue following activity (or post-exertional fatigue or malaise) is a common symptom of a large number of different illnesses – but what is happening in M.E. is quite different. Overexertion does not cause fatigue in M.E. but instead a worsening of the severity of the illness generally and of various neurological, cognitive, cardiac, cardiovascular, immunological, muscular and gastrointestinal (and other) symptoms. The severity of these symptoms can range from mild to severe to life-threatening. The effects of overexertion can last for hours, days, weeks or even many months in M.E., or can even be permanent. The onset of these post-exertional effects are very often significantly delayed so that very often the worsening of the illness caused by overexertion has not even *begun* within 24 hours in M.E., let alone been completely resolved in that time.

The reaction people with M.E. have to physical and mental activity, sensory input and orthostatic stress not only has nothing to do with mere fatigue (or 'malaise') but is in fact unique to M.E. in a number of ways. This reaction is so abnormal in fact that exercise testing is one of the series of tests which can be used to help confirm a M.E. diagnosis, as are various tests which measure the abnormal responses to orthostatic stress seen in M.E. This is simply not the case in post-viral fatigue syndromes, Lyme disease, Fibromyalgia and so on. These patient groups do not exhibit the same measurable pathological abnormalities as M.E. patients in these (and other) tests.

Recent research has also shown that postural stress exacerbates cardiac insufficiency in M.E. and that this cardiac insufficiency is the cause of many of the symptoms and much of the disability of M.E. This pathology is also not seen in any of those illnesses causing fatigue after exertion which are commonly misdiagnosed as 'CFS.' The way people with M.E. respond to physical and mental activity, sensory input and orthostatic stress is profoundly different than in these other illnesses; it is an entirely different problem, of a much greater magnitude (Cheney 2006, [video recording]) (Hooper & Marshall 2005, [Online]) (Hyde 2003, [Online]) (Dowsett 2001, [Online]) (Hooper et al. 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]) (Dowsett et al. 1990, pp. 285-291) (Ramsay 1986, [Online]).

What does define Myalgic Encephalomyelitis?

What defines M.E. is not 'chronic fatigue' but a specific type of acquired damage to the brain. Myalgic encephalomyelitis is an acutely acquired illness initiated by a virus infection with multi system involvement which is characterised by post encephalitic damage to the brain stem; a nerve centre through which many spinal

nerve tracts connect with higher centres in the brain in order to control all vital bodily functions – this is always damaged in M.E. (Hence the name Myalgic Encephalomyelitis.) Central nervous system (CNS) dysfunction, and in particular, inconsistent CNS dysfunction is undoubtedly both the chief cause of disability in M.E. and the most critical in the definition of the entire disease process.

Myalgic Encephalomyelitis is a loss of the ability of the CNS (the brain) to adequately receive, interpret, store and recover information which enables it to control vital body functions (cognitive, hormonal, cardiovascular, autonomic and sensory nerve communication, digestive, visual auditory balance etc). It is a loss of normal internal homeostasis. The individual can no longer function systemically within normal limits. This dysfunction also results in the inability of the CNS to consistently programme and achieve normal smooth end organ response. There is also multi-system involvement of cardiac and skeletal muscle, liver, lymphoid and endocrine organs. Some individuals also have damage to skeletal and heart muscle.

This diffuse brain injury is initiated by a virus infection which targets the brain; M.E. represents a major attack on the central nervous system (CNS) by the chronic effects of a viral infection. M.E. is an infectious and primarily neurological disease process which occurs in epidemic and sporadic forms. There is a history of recorded outbreaks of M.E. going back to 1934, when an epidemic of what seemed at first to be poliomyelitis was reported in Los Angeles. A review of M.E. outbreaks found that clinical symptoms were consistent in over sixty recorded epidemics of M.E. spread all over the world. M.E. has been linked to Poliomyelitis (Polio) since 1934 and for a number of years M.E. was referred to as 'atypical Polio.' There is ample evidence that M.E. is caused by the same type of virus that causes polio; an enterovirus. The evidence which exists to support this theory is compelling, for example: M.E. epidemics very often followed Polio epidemics, M.E. resembles Polio at onset, serological studies have shown that communities affected by an outbreak of M.E. were effectively blocked (or immune) from the effects of a subsequent polio outbreak, evidence of enteroviral infection has been found in the brain tissue of M.E. patients at autopsy, and so on. (See: [The outbreaks \(and infectious nature\) of M.E.](#) and for more information.)

M.E. is primarily neurological, but because the brain controls all vital bodily functions virtually every bodily system can be affected by M.E. Again, although M.E. is primarily neurological it is also known that the vascular and cardiac dysfunctions seen in M.E. are also the cause of many of the symptoms and much of the disability associated with M.E. – and that the well-documented mitochondrial abnormalities present in M.E. significantly contribute to both of these pathologies. There is also multi-system involvement of cardiac and skeletal muscle, liver, lymphoid and endocrine organs in M.E. Some individuals also have damage to skeletal and heart muscle. Thus Myalgic Encephalomyelitis symptoms are manifested by virtually all bodily systems including: cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, gastrointestinal and musculo-skeletal dysfunctions and damage.

M.E. is an infectious neurological disease and represents a major attack on the central nervous system (CNS) – and an associated injury of the immune system – by the chronic effects of a viral infection. There is also transient and/or permanent damage to many other organs and bodily systems (and so on) in M.E. M.E. affects the body systemically. Even minor levels of physical and cognitive activity, sensory input and orthostatic stress beyond a M.E. patient's individual post-illness limits causes a worsening of the severity of the illness (and of symptoms) which can persist for days, weeks or months or longer. In addition to the risk of relapse, repeated or severe overexertion can also cause permanent damage (eg. to the heart), disease progression and/or death in M.E.

M.E. is not stable from one hour, day, week or month to the next. It is the combination of the chronicity, the dysfunctions, and the instability, the lack of dependability of these functions, that creates the high level of disability in M.E. It is also worth noting that of the CNS dysfunctions, cognitive dysfunction is one of the most disabling characteristics of M.E.

M.E. is a distinct, recognisable disease entity which contrary to popular belief is not difficult to diagnose and can in fact be diagnosed relatively early in the course of the disease (within just a few weeks) – providing that the physician has some experience with the illness. Although there is (as yet) no single test which can be used to diagnose M.E. there are a series of tests which can confirm a suspected M.E. diagnosis. If all tests are normal, if specific abnormalities are not seen on certain of these tests (eg. brain scans), then a diagnosis of M.E. cannot be correct (Hyde 2006, 2007, [Online]) (Hooper 2006, [Online]) (Hooper & Marshall 2005, [Online]) (Hyde 2003, [Online]) (Dowsett 2001, [Online]) (Hooper et al. 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]) (Hyde 1992 p. xi) (Hyde & Jain 1992 pp. 38 - 43) (Hyde et al. 1992, pp. 25-37) (Dowsett et al. 1990, pp. 285-291) (Ramsay 1986, [Online]) (Dowsett n.d., [Online]) (Dowsett & Ramsay n.d., pp. 81-84) (Richardson n.d., pp. 85-92).

What are some of the real hallmark symptoms and characteristics of Myalgic Encephalomyelitis?

What characterises M.E. every bit as much as the individual neurological, cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, muscular, gastrointestinal and other symptoms is the way

in which people with M.E. respond to physical and cognitive activity, sensory input and orthostatic stress, and so on. In other words, the pattern of symptom exacerbations, relapses and of disease progression.

The way the bodies of people with M.E. react to these activities/stimuli post-illness is unique in a number of ways. Along with a specific type of damage to the brain (the central nervous system) this characteristic is one of the defining features of the illness which must be present for a correct diagnosis of M.E. to be made. The main characteristics of the pattern of symptom exacerbations, relapses and disease progression etc. in Myalgic Encephalomyelitis include:

- A. People with M.E. are unable to maintain their pre-illness activity levels. This is an acute (sudden) change. M.E. patients can only achieve 50%, or less, of their pre-illness activity levels.
- B. People with M.E. are limited in how physically active they can be but are also limited in similar way with; cognitive exertion, sensory input and orthostatic stress.
- C. When a person with M.E. is active beyond their individual (physical, cognitive, sensory or orthostatic) limits this causes a worsening of various neurological, cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, muscular, gastrointestinal and other symptoms.
- D. The level of physical activity, cognitive exertion, sensory input or orthostatic stress that is needed to cause a significant or severe worsening of symptoms varies from patient to patient, but is often trivial compared to a patient's pre-illness tolerances and abilities.
- E. The severity of M.E. waxes and wanes throughout the hour/day/week and month.
- F. The worsening of the illness caused by overexertion often does not peak until 24 - 72 hours (or more) later.
- G. The effects of overexertion can accumulate over longer periods of time and lead to disease progression, or death.
- H. The activity limits of M.E. are not short term; an increase in activity levels beyond a patient's individual limits, even if gradual, can only cause relapse, disease progression or death.
- I. The symptoms of M.E. do not resolve with rest. The symptoms and disability of M.E. are not caused only by overexertion; there is also a base level of illness which can be quite severe even at rest.
- J. Repeated overexertion can harm the patient's chances for future improvement in M.E. Patients who are able to avoid overexertion have repeatedly been shown to have the most positive long-term prognosis.
- K. Not every M.E. sufferer has 'safe' activity limits within which they will not exacerbate their illness; this is not the case for very severely affected patients (Bassett 2010, [Online]).

When a person with M.E. is active beyond their individual post-illness limits, the result is not tiredness, fatigue or even exhaustion – nor is 'malaise' an accurate word to describe what occurs. There simply is no one symptom caused by overexertion in M.E. What does happen is that there is a worsening of all sorts of different symptoms and of the severity of the illness generally with overexertion. (Repeated or severe overexertion can also cause disease progression, permanent damage, or death in M.E.) It is an entirely different problem of a much greater magnitude.

Overexertion causes an exacerbation of all sorts of combinations of neurological, cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, muscular, gastrointestinal and other symptoms which can be mild, moderate, severe, or even life threatening (eg. seizures and cardiac events). Many of the symptoms involved are present at a lower level at rest, but overexertion causes them to worsen. (Although some patients may also have some symptoms that only appear after overexertion.) Anywhere from one symptom to a large cluster of symptom can be made worse, or produced, by overexertion. The cluster of symptoms made worse by excessive exertion or stimulus is often very similar from patient to patient, as generally it is a worsening of the most common symptoms of the illness. M.E. patients commonly experience a combination of the following:

Profound cognitive dysfunctions (and various other neurological disturbances), muscle weakness (or paralysis), burning eye pain or burning skin, subnormal temperature or low-grade fever, sore throat or painful lymph nodes (and/or other signs of inappropriate immune system activation), faintness, weakness or vertigo, loss of co-ordination, dyspnoea, an explosion of sensory phenomena (low level seizure activity), cardiac and/or blood pressure disturbances, facial pallor and/or a slack facial expression, widespread severe pain, nausea or feeling as if 'poisoned,' feeling cold and shivering one minute and hot and sweating the next, anxiety or even terror (as an organic part of the attack itself rather than as a reaction to it) and hypoglycaemia. Often the patient will feel an urgent need to retreat from all homeostatic pressures. The types of symptoms triggered vary widely from patient to patient, but some combination of these is common. There may also be an accompanying exacerbation of other symptoms. These symptoms often combine to create an indescribable and overwhelming experience of terrible illness that is unique to M.E, and can be profoundly incapacitating. At its most severe, the patient feels as if they are about to die.

Each of the symptoms caused or exacerbated by overexertion can be clearly articulated without difficulty whether they be; seizures, cardiac events, labile blood pressure, tachycardia, shortness of breath, muscle pain, muscle weakness or muscle paralysis, facial paralysis, black outs, flu-like symptoms, nausea, inability to speak or to understand speech, problems with memory, and so on. It makes no scientific or logical sense to subsume these very specific symptoms, and very specific and varied combinations of symptoms, under a vague and inaccurate label of mere 'fatigue.' To say that all of these very different and very specific – and in some cases very serious – symptoms can be accurately summarised as being a problem of mere 'fatigue,' 'malaise' or 'exhaustion' is absurd.

Repeated or severe overexertion can also cause disease progression, permanent damage (eg. to the heart), or death in M.E. patients. Again, to suggest that these very serious and long-term effects – including fatalities – could be accurately summarised as being a problem of mere 'fatigue' is clearly absurd (Hyde 2006, 2007, [Online]) (Hooper 2006, [Online]) (Cheney 2006, [video recording]) (Hooper & Marshall 2005, [Online]) (Hyde 2003, [Online]) (Dowsett 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]) (Dowsett 1996, p. 167) (Hyde 1992 p. xi) (Hyde & Jain 1992 pp. 38 - 43) (Hyde et al. 1992, pp. 25-37) (Dowsett et al. 1990, pp. 285-291) (Ramsay 1986, [Online]) (Dowsett n.d., [Online]).

What is 'Chronic Fatigue Syndrome'?

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. All each of these flawed CFS 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 (a symptom seen in many illnesses but not a defining feature of M.E. nor even an essential symptom of M.E.).

The disease category 'CFS' has undoubtedly been used to impose a false psychiatric paradigm of M.E. by allying it with various unrelated psychiatric fatigue states and post-viral fatigue syndromes (etc) for the benefit of various (proven) financial and political interests (Hyde 2006, [Online]) (Hooper 2006, [Online]) (Hyde 2003, [Online]) (Hooper 2003, [Online]) (Dowsett 2001, [Online]) (Hooper et al. 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]).

The fact that a person qualifies for a diagnosis of CFS (a) does not mean that the patient has Myalgic Encephalomyelitis, and (b) does not mean that the patient has any other distinct and specific illness named 'CFS.' A diagnosis of CFS – based on any of the CFS definitions – can only ever be a wastebasket diagnosis, in other words, a *misdiagnosis*. Despite popular opinion, M.E. and CFS are not synonymous terms. All 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*. As Dr Byron Hyde explains, 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 (2006, [Online]).

The only groups which gain from this 'CFS' confusion are insurance companies and other organisations and corporations which have a vested financial interest in how these patients are treated, including the government. Under the cover of 'CFS' these vested interest groups have assiduously attempted to obliterate recorded medical history of Myalgic Encephalomyelitis; even though the existing evidence has been published in prestigious peer-reviewed journals around the world and spans over 70 years. This is clearly unscientific, and unethical. The only way forward for M.E. patients and all of the diverse patient groups commonly misdiagnosed with 'CFS' (both of which are denied appropriate support, diagnosis and treatment) is that the bogus disease category of 'CFS' must be abandoned. (See: Who benefits from 'CFS' and 'ME/CFS'?)

People with M.E. must be diagnosed with Myalgic Encephalomyelitis, and treated for M.E. based on information gained solely from studies involving authentic M.E. patients. People with depression must be diagnosed and treated for depression. People with cancer must be diagnosed with cancer and then treated as appropriate for the type of cancer they have, and so on. Physicians who diagnose 'CFS' in any patient experiencing fatigue without looking and testing for the true cause of the symptoms (and who choose not to familiarise themselves with the scientific facts about Myalgic Encephalomyelitis) do their patients – and themselves – a great disservice. 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 can become 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 and this process must begin with a correct diagnosis if at all possible. *A correct diagnosis is half the battle won*

(Hyde 2006, 2007, [Online]) (Hooper 2006, [Online]) (Hyde 2003, [Online]) (Hooper 2003, [Online]) (Dowsett 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]) (Dowsett n.d., [Online]).

Conclusion

All of this is not simply theory, but is based upon an enormous body of mutually supportive clinical information which has been published in prestigious peer-reviewed journals all over the world and spans over 60 years. Confirmation of this hypothesis is supported by electrical tests of muscle and of brain function (including the subsequent development of PET and SPECT scans) and by biochemical and hormonal assays. Newer scientific evidence is increasingly strengthening this hypothesis. M.E. is neither 'mysterious' nor 'medically unexplained'. Many aspects of the pathophysiology of the disease have, indeed, been medically explained in volumes of research articles. These are well-documented, scientifically sound explanations for why patients are bedridden, profoundly intellectually impaired, unable to maintain an upright posture and so on.

Despite popular opinion, there simply is no legitimate scientifically motivated debate about whether or not M.E. is a 'real' illness or not, or whether or not it is 'behavioural' or has a biological basis. The psychological or behavioural 'theories' of M.E. are no more scientifically viable than are the theories of a 'flat earth.' They are pure fiction.

The reality is that anyone, whether medically qualified or not, who looks at the worldwide published medical evidence on M.E. could not fail to recognise that the psychological or psychiatric theories could not possibly explain the many different and profound physical abnormalities seen in M.E. (nor the many other characteristics of the disease which are not consistent with psychological or behavioural illness). There are only two ways that a person could reach a different conclusion:

1. Bias due to vested political or financial (or other) interests
2. Lack of access to a truly representative selection of the evidence (ie. an individual has only availed themselves of the pseudo-science provided by financial stakeholders and not a representative selection (or indeed *any*) of the legitimate and unbiased science.)

Myalgic Encephalomyelitis is a debilitating autoimmune disease which has been recognised by the World Health Organisation (WHO) since 1969 as an organic neurological disorder. M.E. is similar in a number of significant ways to illnesses such as multiple sclerosis, Lupus and Polio. M.E. affects all ethnic and socio-economic groups and has been diagnosed all over the world with a similar strike rate to multiple sclerosis. Children as young as five can get M.E., as well as adults of all ages. M.E. can be extremely disabling, and is not a self-limiting or short term illness. 25% of M.E. sufferers are severely affected and housebound and bedbound. In some cases Myalgic Encephalomyelitis can also be progressive, or fatal. Governments around the world are currently spending \$0 a year on M.E. research.

The name and authentic definition of Myalgic Encephalomyelitis must be fully restored (to the exclusion of all others) and the WHO classification of M.E. must be accepted and adhered to in all official documentations and government policy. People with M.E. must be diagnosed with M.E. and treated for M.E. again, finally.

There were sound medical reasons for the creation of the name in 1956, and for the classification of the illness as a distinct organic neurological disorder by the WHO in 1969; neither of which has changed in the interim (Hyde 2006, 2007, [Online]) (Hooper 2006, [Online]) (Cheney 2006, [video recording]) (Hyde 2003, [Online]) (Dowsett 2001, [Online]) (Hooper et al. 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]) (Hyde 1992 p. xi) (Hyde & Jain 1992 pp. 38 - 43). As Professor Malcolm Hooper explains:

The term myalgic encephalomyelitis (means muscle pain, my-algic, with inflammation of the brain and spinal cord, encephalo-myel-itis, brain spinal cord inflammation) was first coined by Ramsay and Richardson and has been included by the World Health Organisation (WHO) in their International Classification of Diseases (ICD), since 1969. The currently version ICD-10 lists ME under G.93.3 - neurological conditions. It cannot be emphasised too strongly that this recognition emerged from meticulous clinical observation and examination (2006, [Online]).

Myalgic Encephalomyelitis is a distinct infectious neurological disease of extraordinarily incapacitating dimensions that affects virtually every bodily system – not a problem of medically unexplained 'fatigue.'

More information

- For more information about the medical and political facts of M.E. and the motivations behind the creation of 'CFS' see: [Who benefits from 'CFS' and 'ME/CFS'?](#), [Smoke and mirrors](#) and [What is Myalgic Encephalomyelitis?](#)

- 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: [Who benefits from 'CFS' and 'ME/CFS'?](#), [The misdiagnosis of CFS](#), [Why the disease category of 'CFS' must be abandoned](#) and [Smoke and Mirrors](#). M.E. and 'CFS' are not synonymous terms, and should not be used interchangeably. *The distinction must be made between terminology and DEFINITIONS*. The truth about the organic and distinct neurological illness M.E. must not be allowed to be buried under cover of 'fatigue' and 'CFS' for another 20 years!
- See [The outbreaks \(and infectious nature\) of M.E.](#) section for more information about the acute onset of M.E. (associated with a virus), and the links between outbreaks of M.E. and Polio outbreaks, and so on.
- The [Ultra-Comprehensive ME Symptom List](#) discusses the authentic symptomatology of M.E. and has been compiled using references from the world's leading M.E. experts.
- A new paper is available: [M.E. vs MS: Similarities and differences](#)
- See: [Testing for Myalgic Encephalomyelitis](#) for more information about the tests used to diagnose M.E.
- Many M.E. experts (and M.E. sufferers) have spoken out about against 'fatigue' being the defining features of M.E., see: [M.E. is not defined by 'fatigue'](#) and also the [Quotes](#) section for more information. (See also: [What it feels like to have Myalgic Encephalomyelitis: A personal M.E. symptom list and description of M.E.](#))
- [The effects of CBT and GET on patients with Myalgic Encephalomyelitis](#) looks at the serious physical effects of inappropriate interventions such as CBT (psychotherapy) and GET (exercise) on patients with M.E.
- The [Fatigue Schmatigue](#) paper explains how the fraudulent 'fatigue' construct came into being and how the M.E. community can and MUST play an active part in debunking this myth. **This paper is aimed not at the public but at M.E. sufferers and other members of the M.E. community and is highly recommended.**
- If you have been misdiagnosed with 'CFS' see: [Where to after a 'CFS' \(mis\)diagnosis?](#)

Additional notes on this text:

- The basic facts are that fatigue, 'CFS' and M.E. are not at all the same thing:
 - People with **chronic fatigue** may be tired because of cancer, MS, vitamin deficiency, a sleep disorder, depression or a large number of other reasons. Fatigue is a symptom of many illnesses. As fatigue has many causes, there can be no tests which can detect the symptom of fatigue. 20% of the population may currently suffer from some form of fatigue or chronic fatigue.
 - **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.
 - **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.

There is also no such disease as 'ME/CFS' or 'CFS/ME' or CFIDS and so on. The unadulterated scientific facts about M.E. are mind blowing and utterly compelling and credible, but the 'CFS' and 'ME/CFS' propaganda isn't. For more information see: [Who benefits from 'CFS' and 'ME/CFS'?](#), [What is Myalgic Encephalomyelitis? A historical, medical and political overview](#) and [The Terminology Explained](#)

- **A note on the high quality of the references used to compile this paper:** This paper has been compiled using the highest quality resources available. Not everyone was taken in by the 'CFS' insurance scam thankfully! A small but dedicated group of M.E. experts have made many remarkable discoveries about the pathology of

M.E. – as well as confirmed many times over what was already known about M.E. prior to 1988, before M.E. research became tainted by 'fatigue' and 'CFS.' Legitimate unbiased M.E. experts and researchers do exist, and their numbers continue to grow – albeit far more slowly than is needed, unfortunately.

- ***A final 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. In addition to these other (far more serious) symptoms, some M.E. sufferers may also suffer with mild, moderate or severe fatigue some of the time, while others will not. Thus the symptom of fatigue is not an essential symptom of M.E. and does not define M.E. (Although the symptom of fatigue *is* essential to qualify for a misdiagnosis of 'CFS'). The point to be most aware of is not that M.E. is 'more than fatigue' – but that M.E. *ISN'T FATIGUE AT ALL*.

References (and an additional recommended 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 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.

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Before reading this research/advocacy information, please be aware of the following facts:

1. Myalgic Encephalomyelitis and 'Chronic Fatigue Syndrome' are not synonymous terms. The overwhelming majority of research on 'CFS' or 'CFIDS' or 'ME/CFS' or 'CFS/ME' or 'ICD-CFS' does not involve M.E. patients and is not relevant *in any way* to M.E. patients. If the M.E. community were to reject all 'CFS' labelled research as 'only relating to 'CFS' patients' (including research which describes those abnormalities/characteristics unique to M.E. patients), however, this would seem to support the myth that 'CFS' is just a 'watered down' definition of M.E. and that M.E. and 'CFS' are virtually the same thing and share many characteristics.

A very small number of 'CFS' studies/articles and books refer in part to people with M.E. but it may not always be clear which parts refer to M.E. The [A warning on 'CFS' and 'ME/CFS' research and advocacy](#) paper is recommended reading and includes a checklist to help readers assess the relevance of individual 'CFS' studies (etc.) to M.E. (if any) and explains some of the problems with this heterogeneous and skewed research.

In future, it is essential that M.E. research again be conducted using only M.E. defined patients and using only the term M.E. The bogus, financially-motivated disease category of 'CFS' must be abandoned.

2. The research referred to on this website varies considerably in quality. Some is of a high scientific standard and relates wholly to M.E. and uses the correct terminology. Other studies are included which may only have partial or minor possible relevance to M.E., use unscientific terms/concepts such as 'CFS,' 'ME/CFS,' 'CFS/ME,' 'CFIDS' or Myalgic 'Encephalopathy' and also include a significant amount of misinformation. Before reading this research it is also essential that the reader be aware of the most commonly used 'CFS' propaganda, as explained in [A warning on 'CFS' and 'ME/CFS' research and advocacy](#) and in more detail in [Putting Research and Articles on Myalgic Encephalomyelitis into Context.](#)

"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

'Do not for one minute believe that CFS is simply another name for Myalgic Encephalomyelitis (M.E.). It is not. 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' Dr Byron Hyde 2006

'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

The vested interests of the Insurance companies and their advisers must be totally removed from all aspects of benefit assessments. There must be a proper recognition that these subverted processes have worked greatly to the disadvantage of people suffering from a major organic illness that requires essential support of which the easiest to provide is financial. The poverty and isolation to which many people have been reduced by ME is a scandal and obscenity. Professor Malcolm Hooper 2006

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

M.E. 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 an UNIQUE Neuro-hormonal profile. .Dr Elizabeth Dowsett

M.E. appears to be in this same family of diseases as paralytic polio and MS. M.E. is less fulminant than MS but more generalized. M.E. is less fulminant but more generalized than poliomyelitis. This relationship of M.E.-like illness to poliomyelitis is not new and is of course the reason that Alexander Gilliam, in his analysis of the Los Angeles County General Hospital M.E. epidemic in 1934, called M.E. atypical poliomyelitis. Dr Byron Hyde 2006

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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



- 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 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, Itis = inflammation. This neurological damage has been confirmed in autopsies of M.E. patients.
- Myalgic Encephalomyelitis has been recognised by the World Health Organization'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.
- 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 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 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 barely pump 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 one 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.