

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.: The medical facts - Super summary

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Taken from www.hfme.org



- Myalgic Encephalomyelitis (M.E.) has been recognised by the World Health Organisation since 1969 as a distinct organic neurological disorder.
- M.E. occurs in epidemic and sporadic forms, over 60 outbreaks have been recorded worldwide since 1934. M.E. is similar in a number of significant ways to multiple sclerosis, Lupus and poliomyelitis (polio).
- Myalgic Encephalomyelitis is a systemic *acute onset* neurological illness initiated by an enteroviral infection which is 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 Myalgic Encephalomyelitis was coined in 1956 in the UK (using evidence from a number of M.E. autopsies), it means: My = muscle, Algic = pain, Encephalo = brain, Mye = spinal cord, Itis = inflammation.
- More than 60 different neurological, cognitive, cardiac, vascular, immunological, muscular, metabolic and other symptoms have been documented in M.E.
- M.E. affects all vital bodily systems and causes a loss of normal internal homeostasis. People with M.E. have severe limits post-illness with physical and cognitive activity, sensory input and orthostatic stress (being upright). Being active above these limits even in a minor way causes increased symptom severity (immediately and/or often with a 24-48 hour delay), prolonged relapse (lasting months, years or even longer), disease progression or death.
- A series of tests can confirm a suspected M.E. diagnosis (e.g. MRI and SPECT brain scans). If all tests are normal, if specific abnormalities are not seen on certain of these tests, then a M.E. diagnosis cannot be correct.
- M.E. is a chronic/lifelong disease that can be extremely severe and cause a profound level of disability and suffering. It can impose severe restrictions on all aspects of daily living including basic communication. More than 25% of patients are wheelchair-bound, bed-bound and/or housebound and in some cases M.E. is fatal.
- Myalgic Encephalomyelitis affects many thousands of children (as young as five) and adults all over the world.

See the full-length (or extended) version of [Myalgic Encephalomyelitis: The Medical Facts](#) for more information, and for a full list of references.

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What is M.E.? Super summary

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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. 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.). Every diagnosis of CFS can only ever be a misdiagnosis. 'CFS' is made up of people with a vast array of unrelated illnesses. 2.54% of the population qualify for a 'CFS' (mis)diagnosis.

- **Myalgic Encephalomyelitis** is a systemic neurological disease initiated by an enteroviral infection which is characterised by (scientifically measurable) damage to the brain stem which results in dysfunctions and damage to almost all vital bodily systems and a loss of normal internal homeostasis.

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 instead only be severely 'fatigued.'

Far fewer than 0.5% of the population has the distinct neurological disease known since 1956 as Myalgic Encephalomyelitis.

See the full-length (or extra extended) version of [What is Myalgic Encephalomyelitis? A historical, medical and political overview](#) for more information, and for a full list of references.

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- 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.
- 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.

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