The M.E. symptom list - Summary

Myalgic Encephalomyelitis (M.E.) has been recognised by the World Health Organisation since 1969 as a distinct organic neurological disease. It can occur in both epidemic and sporadic forms.

M.E. is not medically unexplained or untestable and is not the same thing as the wastebasket disease category of 'CFS' (or 'ME/CFS'). Fatigue is a symptom of many different illnesses – but it is not a defining symptom of M.E., or an essential symptom of M.E. What defines M.E. is a specific type of viral damage to the brain.

M.E. is a multi system disease which is characterised by post encephalitic damage to the brain stem; a nerve centre which controls all vital bodily functions – this is always damaged in M.E., hence the name M.E. Inconsistent CNS function is undoubtedly both the chief cause of disability in M.E. and the most critical in the definition of the entire disease process. M.E. represents a major attack on the CNS by the chronic effects of a viral infection which targets the brain: an enterovirus.

M.E. has a sudden/acute onset that is often very dramatic. Many patients can tell you not just the day they became ill but the *hour*. M.E. is primarily neurological, but because the brain controls all vital bodily functions virtually every bodily system can be affected by M.E. M.E. is a loss of normal internal homeostasis. M.E. is secondarily a vascular disease and the vascular and cardiac dysfunctions seen in M.E. are also a major cause of much of the disability associated with M.E. More than 60 symptoms have been authentically documented in M.E.

M.E. is associated with signs and symptoms including (but not limited to):

Neurological signs and symptoms:

- Inconsistent central nervous system function
- Vertigo, disequilibrium and proprioception difficulties (e.g. lack of sense of 'up' and 'down' with eyes closed)
- Temperature dysregulation and poor tolerance for hot or cold environments
- Hyperacusis (sensitivity to noise) and photophobia (pain/relapse on exposure to light)
- Pain and pressure at the back of the head (where the head meets the neck) and behind the eyes
- Blurred vision, blacked-out vision, nystagmus, wavy visual field, and other visual disturbances
- Stroke-like or coma-like episodes
- Seizures and 'sensory storms' (while conscious)
- Sleep paralysis, fragmented sleep, difficulty initiating sleep, lack of deep-stage sleep and/or a disrupted circadian rhythm
- Many other varied neurological symptoms and abnormalities

Vascular and cardiovascular signs and symptoms:

- A very high heart rate, chest pressure, heart pain and a fluttering/straining heart
- Very low blood pressure particularly when upright (e.g. 84/48 or less in an adult at rest), orthostatic tachycardia/POTS and reduced circulating blood volume (up to 50%)
- Feet burning painfully and turning blue/purple on standing (Reynaud's phenomenon)
- Pain/discomfort/poor digestion following meals

Muscular signs and symptoms:

- Muscle weakness and paralysis (affecting all muscles including the heart, eyes, digestive system etc.)
- Muscle pain, twitching and uncontrollable spasms
- Difficulty breathing and air-hunger, difficulty swallowing/chewing
- Paresthesias, polyneuropathy or myoclonus

Cognitive signs and symptoms:

- Word-finding difficulty, scanning or disjointed speech, speech reversals, difficulty or an inability to speak
- Difficulty comprehending speech or delayed speech comprehension
- Handwriting changes, difficulty writing or comprehending text
- Difficulty with even basic mathematics (dyscalculia)
- Difficulty with simultaneous processing, concentration, spatial perception and with sequencing
- Difficulty making new memories, recalling formed memories and with immediate and delayed visual and verbal recall (e.g. facial agnosia). There is often a marked loss in verbal and performance IQ

Other signs and symptoms:

- Nausea, vomiting and feeling 'poisoned' and very ill
- Throat and gland pain/tenderness, chills and low grade fevers
- Food allergies, alcohol intolerance, hypoglycaemia and sensitivity to common drugs/chemicals
- Ghastly pallor of face with frequent lupus-like submaxillary mask or facial vasculoid rash
- Parkinsonian rigidity of facial expression

What characterises M.E. every bit as much as the individual symptoms is the way in which people with M.E. respond to physical and cognitive activity, sensory input and orthostatic stress, and so on. It is unique in a number of ways and must be present for a correct diagnosis of M.E. to be made, and includes the following:

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 ways with cognitive exertion, sensory input and orthostatic stress.
C. When a person with M.E. is active beyond their individual limits, there is 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 (being upright) that is needed to cause significant relapse varies from patient to patient, but is often trivial compared to 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 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, causes relapse, disease progression or death.
I. The symptoms of M.E. do not resolve with rest. 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.

30% of M.E. patients are housebound and/or bedbound and are severely limited with even basic movement and communication. Cognitive disability can be very pronounced in M.E., just as much as can physical disability.

This information is based upon an enormous body of clinical information and research. Although M.E. can cause many different symptoms the major features of epidemic and sporadic M.E. are distinct and almost identical from one patient to the next. M.E. is a severely disabling, distinct, easily recognisable and testable disease entity.

- See the full-length Ultra-comprehensive M.E. symptom list for more information and for references.
- For more information about M.E. (and why every diagnosis of 'CFS' based on any of the 'CFS' or 'ME/CFS' definitions is a misdiagnosis or non-diagnosis) see: What is M.E.? plus The misdiagnosis of CFS, Why the disease category of 'CFS' must be abandoned and Who benefits from 'CFS' and 'ME/CFS'?

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. From the 1950s to the present day, Dr Byron Hyde and Dr.Elizabeth Dowsett along with their mentors, the late Dr John Richardson and Dr Melvin Ramsay (respectively). Collectively, these four doctors have been involved with M.E. research and M.E. patients for well over 100 years. Among them they have examined more than 15 000 individual (sporadic and epidemic) M.E. patients as well as each authoring numerous studies and articles and books (or chapters in books) on M.E. As stated previously, 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. See: What is M.E.? or the References page. A partial reference list follows:

- Dowsett E., Ramsay A.M., McCartney A.R., & Bell E.J. 1990, '*Myalgic Encephalomyelitis: A persistent Enteroviral Infection?' in The Clinical and Scientific Basis of Myalgic Encephalomyelitis,* B. Hyde (ed.), The Nightingale Foundation, Ottawa, pp. 285-291.
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- 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
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- Hyde, Byron M.D., Bastien S Ph.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, pp. 25-37.

"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 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.

- 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 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 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.)