

What is M.E.? Summary

COPYRIGHT © JODI BASSETT 2004. UPDATED JUNE 2011. TAKEN FROM WWW.HFME.ORG



Myalgic Encephalomyelitis (M.E.) is a debilitating acquired neurological disease that has been recognised by the World Health Organisation (WHO) since 1969 as a distinct organic neurological disorder. M.E. can occur in both epidemic and sporadic forms; over 60 outbreaks of M.E. have been recorded worldwide since 1934. M.E. is

similar in a number of significant ways to Multiple Sclerosis, Lupus and Poliomyelitis (Polio). It can become extremely severe and disabling and in some cases is fatal.

Is M.E. a new illness?

No. The illness has been documented as an organic (physical) neurological disease for centuries. The name Myalgic Encephalomyelitis was coined in 1956 in the UK.

M.E. has nothing to do with 'fatigue'

Unlike 'Chronic Fatigue Syndrome' (CFS) M.E. is a neurological illness of extraordinarily incapacitating dimensions that affects virtually every bodily system. Fatigue is not a defining (or essential) symptom of M.E. M.E. and 'CFS' are not at all the same thing.

Why do some groups claim that M.E. and 'CFS' are synonymous terms?

This new name and case definition of 'CFS' was created in the United States by a board of 18 members, few of which had either looked at an epidemic of M.E. or examined *any* patients with the illness.

Why? Money! In the late 1970s and 1980s there was an enormous rise in the reported incidence of M.E. causing alarm among American medical insurance companies. It was at this time when, in order to side-step the financial responsibility of the many new incoming claims, those involved in the medical insurance industry (on both sides of the Atlantic) began their campaign to reclassify this severely incapacitating and discrete neurological illness as a psychological or 'personality' disorder. As Professor Hooper explains:

A political decision was taken to rename M.E. as "CFS", the cardinal feature of which was to be chronic or on going "fatigue", a symptom so universal that any insurance claim based on "tiredness" could be expediently denied. The new case definition bore little relation to M.E.: objections were raised by experienced international clinicians, but all objections were ignored.

Public, medical and governmental understanding of M.E. is a huge mess, that is for certain – but it is not an *accidental* mess. (For more information see: [Who benefits from 'CFS' and 'ME/CFS'?](#))

What does a diagnosis of 'CFS' actually mean?

Those diagnosed using the flawed 'CFS' definitions are from a heterogeneous (mixed) population with various misdiagnosed psychiatric and miscellaneous non-psychiatric states that have little in common except the symptom of fatigue. The fact that a person qualifies for a diagnosis of 'CFS' based on any of the 'CFS' definitions (a) does not mean the patient has M.E., and (b) does not mean she or he 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 *misdiagnosis*.

What is M.E.? What is its symptomatology?

M.E. is characterised primarily by damage to the central nervous system (the brain) initiated by an enteroviral infection that results in dysfunctions and damage to many of the body's vital systems as well as a loss of normal internal homeostasis.

M.E. symptoms are manifested by virtually all bodily systems including: cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, gastrointestinal and musculo-skeletal dysfunctions and damage. These symptoms are exacerbated by physical and cognitive activity, sensory input and orthostatic stress beyond the individual's limits. In addition to the risk of relapse, repeated or severe overexertion can also cause permanent damage (e.g. to the heart), disease progression and/or death. Symptoms of M.E. include:

Sore throat, chills, sweats, low body temperature, low grade fever, lymphadenopathy, muscle weakness (or paralysis), muscle pain, muscle twitches or spasms, hair loss, nausea, vomiting, vertigo, cardiac arrhythmia, orthostatic tachycardia, orthostatic fainting or faintness, photophobia and other visual and neurological disturbances, hyperacusis, alcohol intolerance, gastrointestinal and digestive disturbances, allergies and sensitivities to many previously well-tolerated foods, drug sensitivities, stroke-like episodes, nystagmus, difficulty swallowing, myoclonus, temporal lobe and other types of seizures, an inability to maintain consciousness for more than short periods at a time breathing difficulties, emotional lability and sleep disorders. Cognitive dysfunction may be pronounced and can include: difficulty/loss of ability in speaking or understanding speech; difficulty in reading, writing or performing basic mathematical tasks as well as having problems with memory including difficulty making new memories and recalling formed memories; difficulties with visual and verbal recall.

What does cause M.E.? Are there outbreaks?

A review of early outbreaks in the history of M.E. shows clinical symptoms were consistent in over 60 recorded epidemics spread all over the world as far back as 1934. M.E. is an acutely acquired neurological illness initiated by a viral (enteroviral) infection with a 4-7 day incubation period. This point of view is supported by history, incidence, symptoms and similarities with other viral illnesses as well as a large body of research.

So what do we know about M.E. so far?

There is an abundance of research that shows M.E. is an organic illness that can have profound effects on many bodily systems. Many aspects of the pathophysiology of the disease have been medically explained, and to date there are volumes of articles written, from which more than a thousand good articles support the basic premise of M.E. While there is yet no single laboratory test able to diagnose M.E., there *are* a specific *series of tests* which enable an M.E. diagnosis to be easily confirmed; i.e. MRI and SPECT scans of the brain.

Some of the abnormalities found in M.E. patients include: extremely low circulating blood volume (up to an astounding 50%), enzyme pathway disruptions, punctate lesions in M.E. brains resembling those of Multiple Sclerosis; sub-optimal cardiac function and abnormal cardiovascular responses; persistent viral infection in the heart, severe mitochondrial defects and significantly reduced lung functioning.

Also, strong evidence exists to show (even mild or moderate) exercise can have extremely harmful effects on M.E. patients; permanent damage may be caused as well as disease progression and even death. For this reason, danger exists when medical professionals recommend (and sometimes insist on or even *force*) M.E. patients, including children, to partake in exercise as a treatment to their diagnosis of 'CFS.' Under these harmful circumstances, the M.E. patient is undergoing what amounts to actual legalized torture. Patient accounts of exiting exercise programs much more severely ill than when they entered them, *being wheelchair-bound, bed-bound or needing intensive care* are common. *Deaths have also been reported in M.E. patients following exercise.*

How common is M.E. and who gets it?

M.E. has a similar strike rate to Multiple Sclerosis. M.E. affects more than one million children as young as five, as well as teenagers and adults. It affects all ethnic and socio-economic groups, and has been diagnosed all over the world.

Recovery from and severity of M.E.

M.E. can be progressive, degenerative (change of tissue to a lower or less functioning form, as in heart failure), chronic, or relapsing and remitting. It can also be fatal. Patients who are given advice to rest in the early stages of the illness (and who avoid overexertion thereafter) have repeatedly been shown to have the most positive long-term prognosis. M.E. is a life-long disability where relapse is always possible. Symptoms are extremely severe for at least 30% of sufferers leaving many of them housebound, bedbound and severely disabled.

Truly M.E. can be one of the most devastating and horrific illness there is, yet many with M.E. are subject to repeated medical abuse and neglect because of the way the illness has been dishonestly 'marketed' to the public as being psychological or 'behavioural,' or as being a problem of mere 'fatigue' or a 'fatigue syndrome.'

Sub-grouping or refining or renaming 'CFS' will only waste another 20 years. *There is no such distinct disease/s as 'CFS.'* For the benefit of all the patient groups involved, the bogus disease category of 'CFS' must be abandoned and patients with M.E. must again be diagnosed with M.E. and treated for M.E. Due to an overwhelming amount of compelling scientific evidence, in 1969 the World Health Organization correctly classified M.E. as a distinct organic neurological disease. This classification/definition and name must be accepted and adhered to in all official documentations and government policy.

PLEASE help to spread the truth about Myalgic Encephalomyelitis. This appalling abuse and neglect of so many severely ill and vulnerable people on such an industrial scale is inhumane and has already gone on far too long. This will only change through education. People with M.E. desperately need your help.

- For more information, and for references, see the full-length (or extra extended) version of *What is M.E.?*
- Permission is given for this document to be freely redistributed by e-mail or in print for any not-for-profit purpose provided that the entire text (including this notice and the author's attribution) is reproduced in full and without alteration. Please redistribute this text widely.

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, Elizabeth MBChB. 2001a, *THE LATE EFFECTS OF ME* [Online], Available: <http://www.hfme.org/wdowsett.htm>
- Hyde, Byron M.D. 2007, *The Nightingale Definition of Myalgic Encephalomyelitis* [Online], Available: <http://www.hfme.org/whydepapers.htm>

Acknowledgments: Edited by Roseanne Schoof.

“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

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. It cannot be emphasised too strongly that this recognition emerged from meticulous clinical observation and examination. Professor Malcolm Hooper 2006

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. It has a UNIQUE Neuro-hormonal profile. .Dr Elizabeth Dowsett

M.E. appears to be in this same family of diseases as paralytic polio and MS. Dr Byron Hyde 2006

Dr Melvin Ramsay on Myalgic Encephalomyelitis: *“The degree of physical incapacity varies greatly, but the [level of severity] is directly related to the length of time the patient persists in physical effort after its onset; put in another way, those patients who are given a period of enforced rest from the onset have the best prognosis.”*

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

‘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.

COPYRIGHT © JODI BASSETT JANUARY 2009. FROM WWW.HFME.ORG



- 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, 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 (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 more than one million 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.

For more information on all digital and printed HFME books please visit the *HFME Books* page on www.hfme.org