M.E.: The medical facts - Summary

Myalgic Encephalomyelitis (M.E.) is a debilitating (acute onset) neurological disease which has been recognised by the World Health Organisation 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 illnesses such as multiple sclerosis, Lupus and poliomyelitis (polio). M.E. can be extremely severe and disabling and in some cases the disease is fatal.

Is Myalgic Encephalomyelitis a new/modern illness? The illness we now know as Myalgic Encephalomyelitis is not a new illness. M.E. is thought to have existed for centuries. The name M.E. was coined in 1956 in the UK.

What is Myalgic Encephalomyelitis? What is its symptomatology? M.E. is characterised primarily by damage to the central nervous system (the brain) – initiated by an enteroviral infection – which results in dysfunctions and damage to many of the body's vital systems and a loss of normal internal homeostasis.

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. 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. These symptoms are exacerbated by certain levels of physical and cognitive activity, sensory input and orthostatic stress. 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. 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, gelling of the joints, hypoglycaemia, hair loss, nausea, vomiting, vertigo, chest pain, cardiac arrhythmia, resting tachycardia, orthostatic tachycardia, orthostatic fainting or faintness, circulatory problems,

opthalmoplegia, eye pain, photophobia, blurred vision, wavy visual field, and other visual and neurological disturbances, hyperacusis, tinnitus, alcohol intolerance, gastrointestinal and digestive disturbances, allergies and sensitivities to many previously well-tolerated foods, drug sensitivities, stroke-like episodes, nystagmus, difficulty swallowing, weight changes, paresthesias, polyneuropathy, proprioception difficulties, myoclonus, temporal lobe and other types of seizures, an inability to maintain consciousness for more than short periods at a time, confusion, disorientation, spatial disorientation, disequilibrium, breathing difficulties, emotional lability, sleep disorders; sleep paralysis, fragmented sleep, difficulty initiating sleep, lack of deep-stage sleep and/or a disrupted circadian rhythm.

Neurocognitive dysfunction may include cognitive, motor and perceptual disturbances. Cognitive dysfunction may be pronounced and may include; difficulty or an inability to speak (or understand speech), difficulty or an inability to read or write or to do basic mathematics, difficulty with simultaneous processing, poor concentration, difficulty with sequencing and problems with memory including; difficulty making new memories, difficulty recalling formed memories and difficulties with visual and verbal recall (eg. facial agnosia). There is often a marked loss in verbal and performance intelligence quotient (IQ) in M.E.

What causes Myalgic Encephalomyelitis? Are there outbreaks? There is a history of over 60 recorded outbreaks of the illness worldwide going back to 1934. M.E. is an acutely acquired neurological illness (with systemic effects) initiated by a virus infection; a virus with an incubation period of 4-7 days. This point of view is supported by history, incidence, symptoms, similarities with other viral illnesses and a large body of medical research. The evidence which exists to support the concept of M.E. as an enteroviral disease is compelling.

How common is Myalgic Encephalomyelitis, who gets it and how? Although M.E. has existed for centuries, for much of that time it was a relatively uncommon disease. It wasn't until the late 1970s that M.E. began (for reasons as yet not fully understood) its dramatic increase in incidence worldwide. M.E. has a similar strike rate to multiple sclerosis, and is now estimated to affect roughly 0.2% of the population. M.E. affects children as young as 5 as well as adults, all ethnic and socio-economic groups and has been diagnosed all over the world.

M.E. expert Dr Byron Hyde explains that: "[The] prodromal phase is associated with a usually short onset or triggering illness. This onset illness usually takes the form of either, or any combination, of the following, (a) an upper respiratory illness, (b) a gastrointestinal upset, (c) vertigo and (d) severe

meningitic type headache." The main period of infectivity of M.E. peaks at the time just before symptoms appear through to the initial acute phase of the illness (which lasts for several months or in some cases years). Modes of transmission are thought to include: casual contact (respiratory), salivary transmission (eg. kissing), sexual transmission and transmission through blood products. There is also evidence that asymptomatic carrier of the illness may be able to pass the illness on to others for a brief period following their exposure to the illness. (During the recovery and/or chronic stages of the illness however M.E. does not appear to present a significant infective risk).

What is known about Myalgic Encephalomyelitis so far? There is an abundance of research which shows that M.E. is an organic illness which can have profound effects on many bodily systems. Many aspects of the pathophysiology of the disease have, indeed, been medically explained in volumes of research articles. More than a thousand good articles now support the basic premises of M.E. Whilst there is as yet no *single* laboratory test which can diagnose M.E., there are a specific *series of tests* which enable a suspected M.E. diagnosis to be easily confirmed (MRI and SPECT scans of the brain for example). Various abnormalities are also visible on physical exam. If all tests are normal, then a diagnosis of M.E. cannot be correct. M.E. is a distinct, recognisable disease entity that is not difficult to diagnose and can in fact be diagnosed relatively early in the course of the disease – providing that the physician has some experience with M.E.

Abnormalities found in M.E. patients include: extremely low blood volume (up to an astounding 50%), enzyme pathway disruptions, punctate lesions in M.E. brains resembling those of Multiple Sclerosis patients, decreased cerebral blood flow, sub-optimal cardiac function and abnormal cardiovascular responses, persistent viral infection in the heart, increased numbers of activated cytotoxic T cells, low natural killer cell function, severe mitochondrial defects and significantly reduced lung functioning. One specialist found that in dual chromatography analyses, many M.E. patients actually had more derangement of the brain, on a biochemical level, than Parkinson's or Alzheimer's patients. (Of course this list of abnormalities is far from exhaustive.)

Strong evidence also exists to show that exercise can have extremely harmful effects on M.E. patients in many different bodily systems; permanent and severe damage/disability may be caused, as well as disease progression. Sudden deaths have also been reported in M.E. patients following exercise.

Are there any treatments for Myalgic Encephalomyelitis? Whilst there is no cure as yet, or treatments which can dramatically influence the course of the illness due to the lack of funding into research; intelligent nutritional,

pharmaceutical and other interventions can make a significant difference to a patient's life.

Recovery from and severity of Myalgic Encephalomyelitis M.E. 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. can be progressive, degenerative (change of tissue to a lower or less functioning form, as in heart failure), chronic, or relapsing and remitting. M.E. is a life-long disability where relapse is always possible. Symptoms are extremely severe for around 30% of the people who have M.E. (leaving many of them housebound and bedbound), and the illness can also be fatal.

One doctor found that: 'M.E. patients experienced greater "functional severity" than the studied patients with heart disease, virtually all types of cancer, and all other chronic illnesses.' An unrelated study compared the quality of life of people with various illnesses, including patients undergoing chemotherapy or haemodialysis, as well as those with HIV, liver transplants, coronary artery disease, and other ailments, and again found that M.E. patients scored the lowest. "In other words", said one doctor in a radio interview, "this disease is actually more debilitating than just about any other medical problem in the world."

An infectious disease specialist and head of an AIDS and M.E. Clinic testified that a M.E. patient, 'feels effectively the same every day as an AIDS patient feels two weeks before death.' But in M.E., this extremely high level of illness and disability is not short-term, it can instead continue uninterrupted for **decades**. **Truly Myalgic Encephalomyelitis can be one of the most devastating illness there is.** People with M.E. must be given the appropriate advice and support to ensure that they are given a chance at achieving their best possible prognosis.

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

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. 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 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
- Dowsett, Elizabeth MBChB. 2002a, *The impact of persistent enteroviral infection*, [Online], Available: http://www.hfme.org/wdowsett.htm
- Hyde, Byron M.D. & Anil Jain M.D. 1992, *Clinical Observations of Central Nervous System Dysfunction in 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. 38-65.
- Hyde, Byron M.D. 2007, *The Nightingale Definition of Myalgic Encephalomyelitis* [Online], Available: http://www.hfme.org/whydepapers.htm

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 homoeostasis (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

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."*

There is ample evidence that M.E. is primarily a neurological illness. It is classified as such under the WHO international classification of diseases (ICD 10, 1992) although non neurological complications affecting the liver, cardiac and skeletal muscle, endocrine and lymphoid tissues are also recognised. Apart from secondary infection, the commonest causes of relapse in this illness are physical or mental over exertion. Dr Elizabeth Dowsett

The body, its systems (such as the gastrointestinal system, the muscular system, the endocrine system, the cardiovascular and vascular systems) and its organs are dependent and their actions largely controlled by the brain. If the brain is physiologically injured, then so is the body. Depending upon which parts of the brain are physiologically injured different parts of the body will also be caused to malfunction. Dr Byron Hyde 2006

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.

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.