

# Description of Myalgic Encephalomyelitis

ICD-9CM—323.9 Neurological Disease; WHO ICD-10—G 93.3

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Myalgic Encephalomyelitis is a neuroimmune disease, which is precipitated by multiple viral assault.

While there is yet no one definite test, the following tests indicate abnormalities in patients with ME. (The standard battery of tests are most often inadequate to reveal abnormalities in ME patients):

**Abnormal objective tests:** abnormal brain SPECT & PET scan neuroimaging (hypoperfusion in several regions of the brain), dysfunction of the immune system - either inadequate immune response or auto immune response), upregulation of 2-5A synthetase, RNase-L viral enzyme pathway—test: "RNase L Protein and Activity Assay" and "Protein Kinase Assay" to determine abnormal status of the Interferon Inducible 2-5A, RNase L, PKR (Protein Kinase R) Antiviral Pathway, low natural killer cell function, abnormal capillary flow and low circulating blood volume, abnormal function of muscles or dysfunction of the peripheral nerve system or of the spinal cord, Pituitary Thyroid Axis (changes in serum TSH, FT3, FT4, Microsomal b., PHT, calcium and phosphor). Vascular dysfunction (seen in brain SPECT scans), abnormal T-helper 1/T-helper 2 Function Panel, blood rheology (abnormal red blood cell shape---80% flat instead of discoid and/or often low level of white blood cells).

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**Dr. Melvin Ramsay, pioneer UK researcher and clinician,** posits this **short description of Myalgic Encephalomyelitis:** 1) Muscle myopathy, which Ramsay describes as a delay in muscle recovery after exercise. 2) Circulatory impairment including intolerance to temperature extremes, and exacerbated by low pressure weather systems. 3) Cerebral (brain) dysfunction including problems with memory and concentration, sleep disturbances, noise intolerance, palpitations and tachycardia. 4) Loss of stamina or rapid depletion of motor, sensory, intellectual and cognitive abilities. 5) Fluctuation of symptoms over the day, days, weeks, months - even over years.

**Dr. Melvin Ramsay, 1986 longer definition:** A syndrome initiated by a virus infection, commonly in the form of a respiratory or gastrointestinal illness with significant headache, malaise and dizziness sometimes accompanied by lymphadenopathy or rash. Insidious or more dramatic onsets following neurological, cardiac or endocrine disability are also recognized. Characteristic features include:

- 1 A multisystem disease, primarily neurological with variable involvement of liver, cardiac and skeletal muscle, lymphoid and endocrine organs.
- 2 Neurological disturbance - loss of stamina or rapid depletion of motor, sensory, intellectual and cognitive abilities during mental or physical exertion due to dysfunction of the central nervous system which may also be delayed and require several days for recovery; an unique neuro-endocrine profile which differs from depression in that the hypothalamic/pituitary/adrenal response to stress is deficient;

- dysfunction of the autonomic and sensory nervous systems; cognitive problems.
- 3 Musculo-skeletal dysfunction in a proportion of patients (related to sensory disturbance or to the late metabolic and auto immune effects of infection)
  - 4 Fluctuation of symptoms over the day, over days, weeks, months - even over years.
  - 5 A characteristically chronic relapsing course
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**Dr. Byron Hyde, a Canadian specialist in Myalgic Encephalomyelitis offers this 2004**

**definition of Myalgic Encephalomyelitis:** "Myalgic Encephalomyelitis is a measurable, diffuse post-encephalitic illness. The illness is characterized by (1) its acute onset, (2) the diffuse, non-focal persisting nature of the encephalopathy, and (3) the chronicity of the resulting symptoms. These symptoms consist of the rapid depletion or loss of stamina of motor, sensory, intellectual, and cognitive abilities. M.E. is of infectious/autoimmune origin and less commonly, a toxic/autoimmune origin. M.E. occurs in epidemics and sporadic cases."

Myalgic Encephalomyelitis starts with an inflammation of the brain that occurs rather suddenly. This initial inflammation usually results from an infectious/autoimmune process, but it can also be caused by a toxic/autoimmune process. This sudden, short-term inflammation is followed by a disorder of the brain that continues over time. This chronic disorder of the brain is not localized to a small part of the brain, but is spread out over large regions of the brain, and it leads to chronic symptoms that can involve essentially all the normal functions of the brain. The primary injury in Myalgic Encephalomyelitis is the diffuse CNS encephalopathy, the illness may cause or be associated with measurable dysfunction in end organs and various body systems. The most commonly injured end organs and systems are (1) the thyroid gland, (2) the cardiovascular system and (3) the immune system. The CNS dysfunctions are caused by widespread, measurable, diffuse micro-vasculitis affecting normal cell operation and maintenance.

"The evidence would suggest that Myalgic Encephalomyelitis is caused primarily by a diverse group of viral infections that have neurotropic characteristics and that appear to exert their influence primarily on the CNS arterial bed."

**10 Diagnostic Criteria for Myalgic Encephalomyelitis according to Dr. Byron Hyde (2006):**

- 1 **A variable and biphasic acute onset disease.**
- 2 **Primary Infection Phase:** The first phase is an epidemic or endemic infectious disease generally with an incubation period of 4 to 7 days, where in most, but not all cases, an infection is evident.
- 3 **Chronic Phase:** The second and chronic phase follows closely on the first phase, usually within two to seven days, and is characterized by a measurable diffuse change in the function of the CNS. This is the persisting disease that most characterizes M.E. and is demonstrated by the following:
- 4 **Testable Brain Changes:** This second phase becomes chronic and is characterized by various measurable and clinical dysfunctions of the cortical or cortical and sub cortical brain. If the patient's illness is not persistently measurable using SPECT, PET or QEEG and/or Neuropsychological changes then it is not M.E. These changes can be

roughly characterized as to severity:

- **Type 1:** where one side of the cortex is involved. These patients have the best chance of spontaneous recovery.
  - **Type 2:** where both sides of the cortex are involved: These patients have the least chance of spontaneous recovery.
  - **Type 3:** where both sides of the cortex, and either one or all of the posterior chamber organs, the Pons and Cerebellum, the sub cortical and brain stem structures are involved. Type 3 are the most severely affected patients and the most likely to be progressive or see little or no improvement with time.
- 5 **Pain Syndromes:** The pain syndromes associated with the acute and chronic phases of M.E. may include (a) severe headaches of a type never previously experienced, (b) often associated with neck rigidity and occipital pain, (c) retro-orbital eye pain, (d) migratory muscle and arthralgia pain, (e) cutaneous hypersensitivity and (f) fibromyalgia type pain. These pain syndromes tend to decrease over time.
- 6 **Neuropsychological Changes:** There are neuropsychological changes that are measurable and demonstrate short-term memory loss, cognitive dysfunctions, increased irritability, confusion, and perceptual difficulties. There is usually rapid decrease in these functions after any physical or mental activity. This feature may improve over a period of years in patients with adequate financial and social support.
- 7 **Major Sleep Dysfunction:** including all forms of sleep dysfunction and day time alertness and sleep reversals.
- 8 **Muscle Dysfunction:** This feature may be due to vascular dysfunction or peripheral nervous or spinal dysfunction and includes both pain and rapid loss of muscle strength after moderate physical or mental activity. This feature tends to improve over years.
- 9 **Vascular Dysfunction:** This is the most obvious dysfunction when looked for and probably is the cause behind a significant number of the above complaints. Vascular change is most evident in patients with:
- **POTS:** severe postural hypotension.  
**Cardiac irregularity:** on minor positional changes or after minor physical activity, including inability for the heart to increase or decrease in speed and pump volume in response to increase or decrease in physical activity.  
**Raynaud's Disease:** vasoconstriction, blanching, coldness and pain of extremities. This is in part the cause for temperature dysfunctions seen in M.E.  
**Bowel Dysfunction:** vascular dysfunction may be the single most causal basis behind bowel dysfunction when it occurs.
- 10 **Endocrine Dysfunction:** This feature is common and tends to be a late appearance and is most obvious in the:
- **Pituitary-thyroid axis:** This is common. Changes in serum TSH, FTI, FT4, Microsomal Ab., PTH, Calcium and phosphorus rarely occur until one or more years after illness onset and usually only after several years. This can be followed by ultrasound of the thyroid gland where a steady shrinking of the

thyroid gland occurs with or without the development of non-serum positive Hashimoto's thyroiditis (a seeming contradiction of terms) and a significant increase in thyroid malignancy. Serum positive changes occur only after years.

**Pituitary-adrenal axis changes:** this finding is infrequent.

**Pituitary- (adrenal)-Bladder dysfunction:** occurs frequently in the early disease in some people. It is unknown if the cause is due to this link.

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This Edinburgh Definition, with modifications by Dr. Melvin Ramsay is available at Nightingale Research Foundation's website [www.nightingale.ca/](http://www.nightingale.ca/)

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