



WHAT IS MYALGIC ENCEPHALOMYELITIS?

Myalgic encephalomyelitis is a neurological and immunological disease (with an infectious component and/or etiology) appearing in epidemic and sporadic forms. The illness typically has an acute onset of a viral or bacterial infection or toxin/chemical exposure.

The disease strikes about one million American men, women and children and about 17 million worldwide. Most patients are disabled and cannot work and about 25% are bedbound and cannot care for themselves.

The key feature of ME is a post-exertional exacerbation of symptoms including immune dysfunction and cognitive impairment. The symptoms of ME are numerous and can include but are not limited to the following:

- difficulty processing information, aphasia, short term memory loss, etc.
- significant muscle and joint pain
- headaches/migraines
- sleep dysfunction, unrefreshing sleep
- extreme muscle fatiguability, poor coordination, weakness (including paralysis)
- sensitivity to light, sound, noise, vibrations, and impaired depth perception
- **profound immune dysfunction (reactivated viruses and opportunistic infections)**
- nausea and bloating
- urinary frequency
- sensitivities to food, medications, molds, odors or chemicals
- orthostatic intolerance and vertigo
- air hunger, labored breathing, fatigue of chest wall muscles
- subnormal body temperature, chills, low-grade fever, cold extremities
- cardiovascular abnormalities including low blood volume



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Patients with ME need to be screened for infectious agents including viruses and bacteria often associated with ME that are reactivated or opportunistic infections that develop due to an impaired immune system. The International Classification of Diseases (ICD) code for ME is G93.3 under diseases of the nervous system – other disorders of the brain.

Patients with ME must remain inside a safe activity window to prevent exacerbation of symptoms and deterioration of baseline functionality. Graded exercise or pushing to gradually increase activity is dangerous and medical professionals should encourage patients to rest as much as necessary to avoid post-exertional neuroimmune exhaustion (PENE).

SEVERE ME

Severe ME patients are suffering from a harsh, disabling form of ME. These patients are isolated due to the severity of their symptoms and are often unable to leave their home even to seek medical care.

IS IT LIKELY I HAVE ME?

If you have been diagnosed with CFS, ME/CFS, Fibromyalgia, Chronic Lyme or other immune dysfunction diseases, it is important to be evaluated for ME. Finding a qualified expert to definitively diagnose myalgic encephalomyelitis is difficult.

Most doctors have not been educated on diagnosing ME using the International Consensus Primer (ME-ICC).

MEadvocacy has an easy to use questionnaire on the resources page found on website at www.MEadvocacy.org that can help patients and doctors have more confidence in identifying a suspected ME diagnosis. Then doctors can follow the International Consensus Primer (IC Primer) to definitively diagnose myalgic encephalomyelitis and pursue symptom treatments to help improve quality of life. A link to the IC Primer is also provided on MEadvocacy's Resources page.

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