



## Simple Facts About Myalgic Encephalomyelitis (ME)

Although ME is recognized as a neuroimmune disease around the world, in the US, governmental health agencies redefined ME as “chronic fatigue syndrome”. Patients who fit the criteria for ME also fit the criteria for CFS. But patients who fit the *overly broad criteria* for CFS may not fit the criteria for ME.

- Appears worldwide in epidemic and endemic forms.
- Chronic neuroimmune disease that affects many systems in the body including the neuroendocrine, autonomic and immune systems.
- Symptoms include: fatigue, sleep dysfunction, pain, headaches, post exertional neurological exhaustion (PENE) [aka post exertional malaise (PEM)], muscle weakness, cognitive dysfunction, orthostatic intolerance, and sensory disturbances.
- Defined in 1955 outbreak at London’s Royal Free Hospital and labeled myalgic encephalomyelitis.
- Redefined by CDC with overly broad criteria and renamed chronic fatigue syndrome, following cluster outbreaks in Nevada and New York in the mid 1980’s.
- 1 million men, women and children suffer with ME in the U.S. alone, 17 million worldwide.
- Majority are disabled: unable to work, attend school or participate in activities of daily life.
- 25% bedbound/housebound due to severity of symptoms, unable to care for themselves.
- Shortened 20 year life span/premature death from complications of ME.
- Frequent suicides due to the severity and length of suffering without proper palliative care, understanding from medical community, and effective treatments.
- 17 to 25 billion dollar burden to the economy.
- Cause is unknown. Suspected immune deficiencies, chronic viral/microbial infections, autonomic/sympathetic/central nervous system dysfunction and genetic factors, among others.
- No cure and no approved FDA treatments for the disease.
- NIH has flatlined research spending at just \$5 million a year for 30 years. A similarly prevalent disease, HIV/AIDS receives \$3 billion.
- Negligent medical school training results in poorly and erroneously trained physicians. Broad CFS criteria, a deficient disease description, and the recommendation of ineffective treatments comprise the curriculum if it is even taught at all. Nothing is taught on ME.
- High percentage of Chronic Fatigue Syndrome Advisory Committee (CFSAC) recommendations have been ignored by HHS. [Note: CFSAC is a federally chartered advisory committee charged with advising and recommending to the Secretary of HHS on issues relating to patient care, clinical, research and educational issues.]

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