

Facts about Myalgic Encephalomyelitis (ME)

(Also called chronic fatigue syndrome or CFS)

What is it?

- In medical terms, ME is an acquired, debilitating, multi-system disease that causes significant immune and neuroendocrine abnormalities; brain dysfunction and neurocognitive defects; cardiovascular and autonomic disturbances and abnormalities in energy production.
- In layman's terms, it is a disease that causes unrelenting exhaustion, brain fog, and muscle and joint pain. It can be so debilitating that it forces a person to stop working and stop socializing due to the persistent and extreme fatigue.
- ME is characterized by an exacerbation of all symptoms following even trivial amounts of physical or cognitive exertion. It may require days or weeks to recover. Other symptoms include memory impairment, confusion, nonrestorative sleep, dizziness, light and sound sensitivity, headaches, muscle weakness, and problems with coordinating movement.

How do people get ME?

People from all walks of life can be suddenly struck down with ME. The cause of the disease remains unknown, although in many cases ME is preceded by a viral or flu-like illness from which the patient never recovers. The small amount of research that exists suggests the illness is the result of an abnormal immune response to a triggering event.

Who does ME affect?

ME/CFS affects between 1-2.5 million Americans. The disease is more prevalent in women than men, affects all races and has been seen in children as young as five. The average onset is in the 30s although one study found another peak between 10 and 19 years old.

How is ME treated?

There are no FDA-approved treatments for ME, although some medications may be able to help with dizziness, sleep and cognitive problems, and pain. Experimental therapies have helped some patients, including antivirals and immunomodulatory drugs.

How serious is ME and how long will it last?

Patients with ME are more functionally impaired and have a lower quality of life than patients with many chronic illnesses. Some patients are able to work but spend all their time away from work recovering. 75-85% of patients are not able to work and 25% are bedbound or housebound. Recovery is rare, estimated at just 5%, leaving patients sick for years, even decades. Studies have suggested patients are more likely to die of cancer, cardiovascular disease and suicide than the general population. Patients are susceptible to suicide because of a society-wide disbelief about their disease and because of widespread medical neglect.

What does ME cost our country?

ME has a large personal and societal cost, estimated at \$17 to \$24 billion in medical expenses and lost productivity due to patients' inability to work.

For more information, see <http://www.meaction.net/about/what-is-me/>