

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

Key Facts

What is the prevalence of ME/CFS?

- ME/CFS affects 836,000 to 2.5 million Americans.
- An estimated 84 to 91 percent of people with ME/CFS have not yet been diagnosed, meaning the true prevalence of ME/CFS is unknown.
- ME/CFS affects women more often than men. Most patients currently diagnosed with ME/CFS are Caucasian, but some studies suggest that ME/CFS is more common in minority groups.
- The average age of onset is 33, although ME/CFS has been reported in patients younger than age 10 and older than age 70.

What are the symptoms and other effects of ME/CFS?

- There are five main symptoms of ME/CFS:
 1. Reduction or impairment in ability to carry out normal daily activities, accompanied by profound fatigue;
 2. Post-exertional malaise (worsening of symptoms after physical, cognitive, or emotional effort);
 3. Unrefreshing sleep;
 4. Cognitive impairment; and
 5. Orthostatic intolerance (symptoms that worsen when a person stands upright and improve when the person lies back down).
- Other common manifestations of ME/CFS include pain, failure to recover from a prior infection, and abnormal immune function.
- At least one-quarter of ME/CFS patients are bed- or house-bound at some point in their illness.
- Symptoms can persist for years, and most patients never regain their pre-disease level of health or functioning.
- ME/CFS patients experience loss of productivity and high medical costs that contribute to a total economic burden of \$17 to \$24 billion annually.

What are the challenges in improving diagnosis and care for ME/CFS?

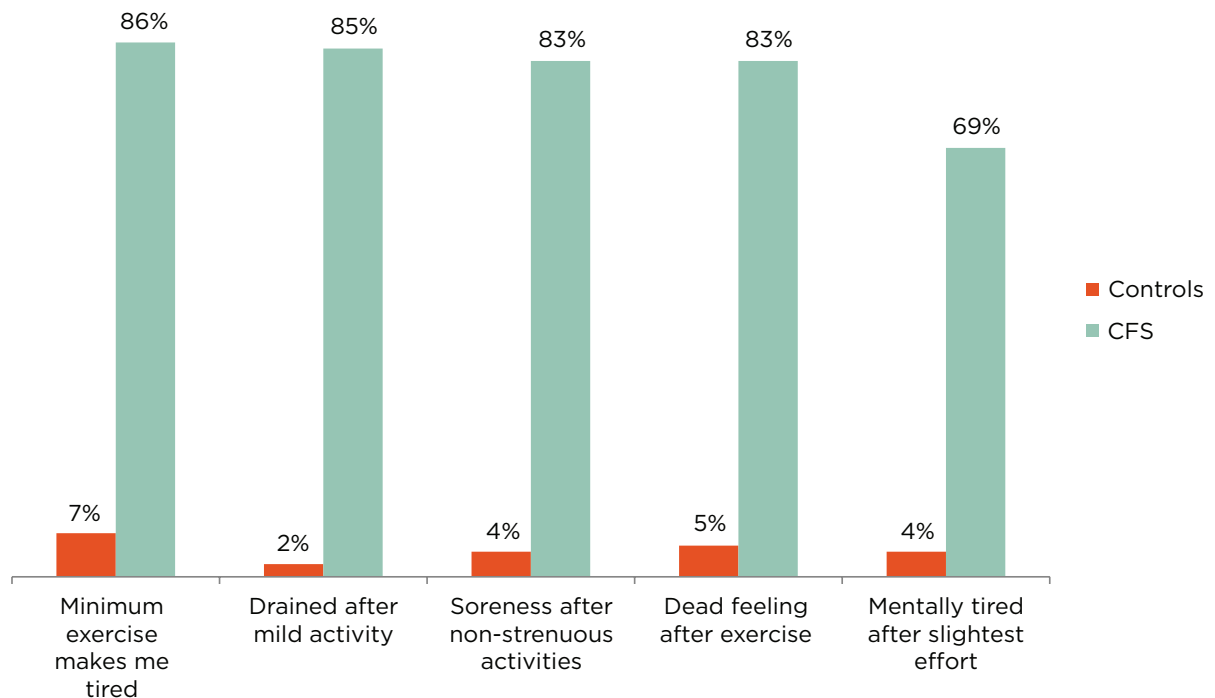
- The cause of ME/CFS remains unknown, although symptoms may be triggered by certain infections.
- Although there are therapies available to manage symptoms of ME/CFS, their efficacy is not known. There is no existing cure for ME/CFS.
- There is an urgent need for more research to discover what causes ME/CFS, understand the mechanisms associated with the development and progression of the disease, and develop effective diagnostic markers and treatments.

Why is a new name for ME/CFS needed?

- Several studies have shown that the term “chronic fatigue syndrome” affects patients’ perceptions of their illness as well as the reactions of others, including medical personnel, family members, and colleagues. This label can trivialize the seriousness of the condition and promote misunderstanding of the illness.
- The term “myalgic encephalomyelitis” is not appropriate because there is a lack of evidence for encephalomyelitis (brain inflammation) in patients with this disease, and myalgia (muscle pain) is not a core symptom of the disease.
- The Institute of Medicine (IOM) committee recommends the name **systemic exertion intolerance disease (SEID)** for this disease. This new name captures a central characteristic of this disease—the fact that exertion of any sort (physical, cognitive, or emotional)—can adversely affect patients in many organ systems and in many aspects of their lives.

To learn more, and to access the IOM committee’s proposed diagnostic criteria for ME/CFS, visit www.iom.edu/ME/CFS. 

FIGURE 1 Percentage of ME/CFS patients and healthy controls reporting post-exertional malaise symptoms of at least moderate severity that occurred at least half of the time during the past 6 months.



NOTE: See the complete report for note and source information (available at www.iom.edu/ME/CFS).