WHAT IS ME/CFS?

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a distinct biological disease which impacts the immunological, neurological, cognitive, autonomic, and energy production systems of the body.

Although the cause of the disease has yet to be discovered, ME/CFS seems to be triggered by an infection or other precipitating event (e.g. injury, trauma, exposure to environmental hazards). There is a subset of patients for whom symptoms seem to have emerged over a period of time without any clear triggering event. However, most people with the disease were leading healthy and productive lives when they first became ill.

ME/CFS is not psychiatric in nature and it is not synonymous with “chronic fatigue.” For decades, mischaracterization of the disease has profoundly impacted scientific research and medical care, leaving patients misunderstood and without the support they need.

Symptoms of ME/CFS

Due to the chronic and multi-systemic nature of the disease, people with ME/CFS experience a variety of symptoms on a daily basis. Symptoms wax and wane unpredictably, making life with the illness challenging. The core symptoms for a diagnosis of ME/CFS (experienced at least half of the time with moderate to severe intensity) are as follows:

- **Substantial Reduction in Energy**: People with ME/CFS experience a significant reduction in their energy levels, often described as complete exhaustion or fatigue. Depending on severity of the disease, this symptom makes it difficult (and sometimes impossible) to engage in activities that were once part of a person’s normal life. With ME/CFS, school, work, social activity and even personal care can become extremely challenging.
- **Post Exertional Malaise (PEM)**: Considered the hallmark of ME/CFS, PEM is a worsening of symptoms after seemingly minor exertion of any kind (physical, cognitive, or emotional). PEM is a delayed response (often 12-48 hours after the activity) and can last hours, days, weeks, or longer. PEM symptoms are far worse than the term “malaise” implies. In addition to debilitating fatigue, people with ME/CFS can experience flu-like symptoms (fever, chills, sore throat, headache, muscle aches), muscle weakness, sensory overload (to light, sound, odors); nausea and other GI issues; new or worsening allergies and sensitivities; depression and anxiety; sleep disturbances, vertigo, and more. PEM is often described as a relapse, a collapse, or a “crash” by those who experience it.
- **Sleep Abnormalities**: Unrefreshing or nonrestorative sleep is one of the most common symptoms reported. Other symptoms include insomnia, sleep disturbances and daytime sleepiness.

Additional core symptoms required for diagnosis include at least one (although many patients experience both) of the following:

- **Cognitive Impairment**: Confusion, short-term memory loss, slowed information processing, and an inability to concentrate are common symptoms of the disease. Many patients report difficulty doing simple tasks or finding the right words to use. Patients often describe this problem as “brain fog.”
- **Orthostatic Intolerance**: Feeling weak or lightheaded upon standing (or sitting upright) for a period of time is common. Other symptoms include blurred vision, confusion, nausea, heart palpitations, sweating, and in some cases, fainting.

Although not considered to be “core” symptoms for diagnostic purposes, the following are common among people with
ME/CFS:

- **Pain**: Pain is almost universal among patients, although it varies widely in location and severity. The most common types of pain reported are headaches, muscle pain, sore throat, joint pain (generally without swelling), and GI pain.

- **Neurological issues**: Muscle weakness and twitching, physical instability, sensitivity (or intolerance) to light, noise and touch and changes in vision, hearing, smell and taste are among the most reported neurological symptoms. Problems with balance and coordination are reported as well.

- **Other Common Symptoms**: People with ME/CFS may experience some or all of the following: susceptibility to infection; perpetual flu-like symptoms; recurring sore throat; tender lymph nodes; sensitivities to certain substances (foods, odors, medications, chemicals); gastrointestinal and/or genitourinary issues; neuroendocrine issues (e.g. cold extremities, excessive sweating, weight change, high/low temperature, chills/shivers, loss of appetite, alcohol intolerance).

**ANYONE CAN GET ME/CFS**

ME/CFS can strike anyone at any time and is arguably one of the most unaddressed and clinically misunderstood public health issues in the world. According to the CDC, ME/CFS affects people of every age, race, ethnicity and socio-economic group. More than one million Americans currently have the disease.

**IMPACT OF ME/CFS**

ME/CFS not only impacts a person's health, but it also impacts careers, education, finances, relationships, family life, and quality of life. Although patients don't always “look sick,” the Centers for Disease Control (CDC) has found that ME/CFS “can be as disabling as multiple sclerosis, lupus, rheumatoid arthritis, heart disease, end-stage renal disease, and similar chronic conditions.” At least one-quarter of patients are bedbound or housebound at some point in the illness, and most never regain their pre-disease level of functioning. Compounding the personal harm caused by the disease is the effect on our country's economic well-being. ME/CFS drains our workforce and costs our country an estimate $17-24 billion annually. Yet the general public and much of the medical community remain unaware of its impact on lives.

**But there is hope.** New technologies are being used by scientific researchers to gain a better understanding of the disease. Studies are being funded by the Centers for Disease Control and the National Institutes of Health. Scientific laboratories across the country and around the world are making visible progress towards better identification of the disease and its effects. At the Solve ME/CFS Initiative, we are working hard to do our part to accelerate research, strengthen scientific collaboration, and make the disease widely understood, diagnosable, and treatable.

**FURTHER READING:**


American Myalgic Encephalomyelitis and Chronic Fatigue Syndrome Society “What is ME/CFS?”

https://ammes.org/what-is-mecfs/

New York State Department of Health ME/CFS Webpage

https://www.health.ny.gov/diseases/conditions/me-cfs/

Massachusetts ME/CFS & FM Association “The ME/CFS Initiation – A Primer for New Patients”

https://www.massmecfs.org/for-new-patients

**Disclaimer:**

The Solve ME/CFS Initiative Inc. serves as a clearinghouse for information on Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS). Ideas expressed within the Solve ME/CFS Initiative website, print publications or materials, or monthly e-newsletters are strictly those of the authors or quoted individuals. The Solve ME/CFS Initiative assumes no liability for any medical treatment or other activity undertaken by individuals and encourages you to seek advice from a licensed health care professional before beginning any new medication, supplement, treatment, therapy, or exercise regime. The Solve ME/CFS Initiative does not recommend, endorse, make any warranties or representations with regard to any of the materials, products or services provided by companies or organizations referred to in this website, print publications or materials, or e-newsletters.