



Solve ME/CFS Initiative

Leveraging patient-centered research to cure ME/CFS

FORMERLY KNOWN AS THE CFIDS ASSOCIATION OF AMERICA

What Is ME/CFS?

Myalgic encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS), also known as chronic fatigue and immune dysfunction syndrome (CFIDS), is a complex and debilitating chronic disease with a serious impact on one's quality of life.

What are the symptoms of ME/CFS?

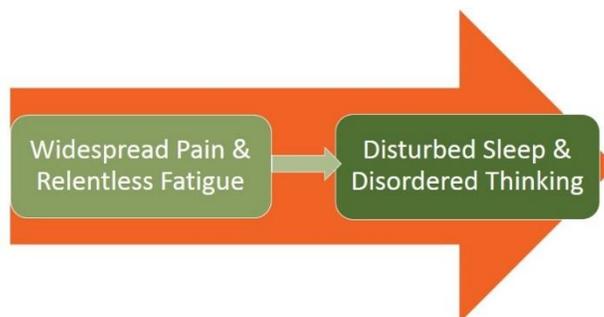
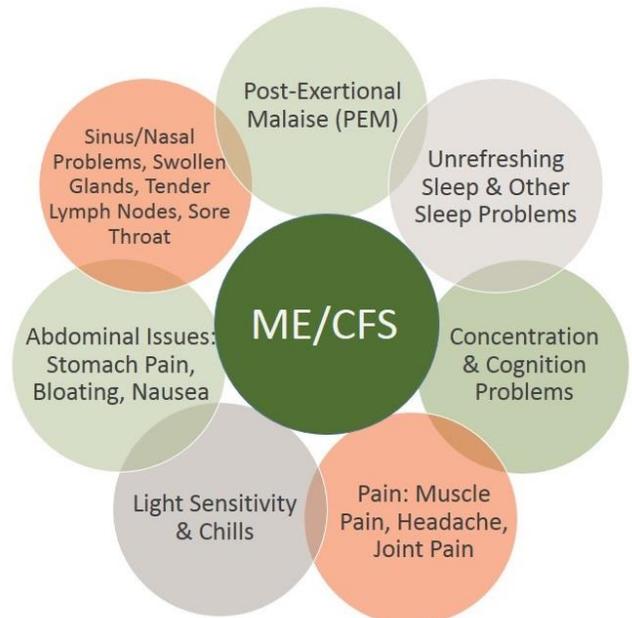
The most common symptoms of ME/CFS include post-exertional malaise (PEM), unrefreshing sleep, concentration problems and muscle pain, typically lasting at least six months.

Post Exertional Malaise (PEM) – PEM is a cardinal symptom of ME/CFS. PEM occurs following mental or physical exertion and is described as worsening symptoms lasting 24 hours or more.

Unrefreshing Sleep - Disrupted and unrefreshing sleep is another hallmark of ME/CFS that causes patients to wake up feeling tired even after periods of rest, to experience excessive daytime sleepiness and to have difficulty falling asleep and staying asleep.

Concentration Problems - Many ME/CFS patients consider concentration problems to be the most serious and debilitating symptom. They experience difficulties with attention, concentration and memory that have been linked to problems in how the brain processes information – particularly processing speed and complex information processing.

Pain - For a long time pain was not thought to be a prominent symptom in ME/CFS, but muscle pain, joint pain and headache are common in ME/CFS patients. It is likely that these four major symptoms of ME/CFS are intertwined, each affecting the other and potentially exacerbating the disease. This is why physicians who understand ME/CFS try to treat pain and sleep disturbances with medications in an attempt to relieve the severity of the overall ME/CFS symptom complex.



The severity of ME/CFS varies greatly from patient to patient, with some people able to maintain fairly active lives. For others, ME/CFS has a profound impact. Many with ME/CFS are severely disabled by the illness and there's often a pattern of relapse and remission. *Most symptoms are invisible to others, which makes it difficult for family members, friends and the public to understand the challenges of the condition.*

It is not uncommon for people with ME/CFS to have some of these symptoms:

- visual disturbances (blurring, light sensitivity, eye pain)
- Difficulty maintaining upright posture, dizziness, balance problems and fainting
- Chills and night sweats
- Gastrointestinal disturbances
- Allergies and sensitivities to foods, odors, chemicals, medications
- Brains fog and cognitive impairment
- Gynecological problems including PMS
- Irritability, depression and mood swings

Because these symptoms are shared with many other illnesses—and because many of these conditions lack a diagnostic test or biomarker—unraveling which illnesses are present can be difficult. Some patients actually receive diagnoses for multiple conditions.

Common conditions that occur along with ME/CFS:

- Fibromyalgia
- Orthostatic intolerance
- Irritable bowel syndrome
- Interstitial cystitis
- Temporomandibular joint disorder
- Chronic pelvic pain
- Multiple chemical sensitivity

Who gets ME/CFS?

At least one million people in the United States have ME/CFS and the condition affects millions more worldwide. Although research has shown that ME/CFS is about two to four times as common in women as men, ME/CFS strikes people from every age, racial, ethnic, and socioeconomic group.

How is ME/CFS diagnosed?

Studies show that fewer than 20 percent of ME/CFS patients in the United States have been properly diagnosed. Diagnosing ME/CFS is a challenging process because there is no diagnostic test or biomarker and other medical conditions must be ruled out before a diagnosis of ME/CFS can be established.

Diagnosis can also be complicated by the fact that the symptoms and severity of ME/CFS vary considerably from person to person. Seek care first from the health care provider who knows you best and will work with you to rule out other possible causes of symptoms and identify other conditions.

How is ME/CFS treated?

Since no cause or cure for ME/CFS has been identified, treatment is directed at relieving symptoms. Although there's no single treatment that fixes the illness at its core, there are treatments that can improve symptoms, increase function, and allow people with ME/CFS to engage in activities of daily living. Sleep problems, pain, heart rate irregularities, gastrointestinal difficulties, allergies, and depression are some of the symptoms that can be relieved treated.

Alternative therapies are often explored in an attempt to relieve symptoms. Acupuncture, hydrotherapy, yoga, tai chi, and massage therapy have been found to help and are often prescribed for symptom management.