



## Chronic Fatigue Syndrome (ME/CFS)

### What is Chronic Fatigue Syndrome?

Chronic Fatigue Syndrome (CFS) is a serious, complex and disabling disease, which causes incapacitating fatigue coupled with a wide variety of immune, neurological, autonomic, and other symptoms. The patient's ability to function is substantially reduced. A key feature of the disease is malaise and exacerbation of symptoms following normal activity or mild exercise. This can persist for days or weeks and is not relieved by rest or sleep.

CFS is recognized by the Centers for Disease Control and Prevention (CDC) as an organic syndrome, not a psychiatric/psychological disorder. Any psychological symptoms are secondary to the disease, as happens in many other chronic illnesses.

Chronic Fatigue Syndrome is an unfortunate name for this serious condition. Fatigue is universal in healthy people, but the pathological loss of energy and stamina with CFS is very different from the fatigue felt by healthy people following vigorous exercise or who are living under stress. Chronic fatigue is a symptom in numerous other diseases, which must be distinguished from CFS. The name CFS ignores the multi-system abnormalities found in the disease and trivializes the severity of the symptoms. In many parts of the world, CFS is known as Myalgic Encephalomyelitis (ME) or Myalgic Encephalopathy (also ME). The acronym ME/CFS is currently gaining in popularity worldwide. The disease is also sometimes known as Chronic Fatigue Immune Dysfunction Syndrome (CFIDS).

### Who gets ME/CFS?

At least one million Americans have ME/CFS; but research has shown that 80% of patients are undiagnosed. ME/CFS affects all races, all socio-economic groups and all ages, from young children to the elderly. The most common age of onset is between 20 and 50 years of age. Four times as many women have ME/CFS as men, but the gender ratio is almost equal in affected children.

### What causes ME/CFS?

The cause of ME/CFS is uncertain and both genetic and environmental factors may contribute to the

disease. ME/CFS usually occurs as sporadic (isolated) cases, but clusters of cases or outbreaks (epidemics) have occurred worldwide. Some outbreaks have affected large numbers of individuals in a particular community, hospital or school. In sporadic cases, 20% of patients have another family member with the disease.

ME/CFS frequently starts with acute, "flu-like" symptoms and the immune system changes found in ME/CFS are similar to those found in some viral infections. A number of infectious agents (pathogens) have been found to occur more frequently in patients with ME/CFS than in the general population. No known pathogen has been proven to be the cause of the disease and the presence of these pathogens may result from the illness (opportunistic infections). For the safety of the blood supply, patients with ME/CFS should refrain from donating blood. Occasionally, ME/CFS has been triggered by environmental toxins, the receipt of an immunizing injection or surviving a major trauma. Depression and anxiety may occur, secondary to the disease, but Major depressive disorder can be distinguished from ME/CFS by behavioral, immunological, and hormonal testing.

### Main symptoms and diagnosis

Diagnosing ME/CFS is difficult. ME/CFS is not covered in the curriculum of most medical schools. There is currently no specific diagnostic test for the disease and so the diagnosis is often missed or delayed. The diagnosis is made clinically from the pattern of symptoms and the exclusion of other fatiguing illnesses. Although the pattern of symptoms differs in different patients, a diagnosis can be made if the patient's symptoms meet the criteria of one of several case definitions. The 1994 International research case definition (Fukuda<sup>(1)</sup>) is the most commonly used. However, this case definition was intended as a research tool and excludes some patients who genuinely have ME/CFS but do not precisely satisfy this case definition's criteria. The newer Canadian clinical case definition<sup>(2)</sup> overcomes this problem by including more of the symptoms commonly found in patients with ME/CFS.

**Both case definitions require:**

1. the new onset of unexplained, persistent, or relapsing physical and mental fatigue that has lasted for at least six months, and has substantially reduced activity levels. The fatigue is not the result of ongoing exertion and not relieved by rest.
2. that the patient's clinical evaluation include a medical history, a clinical examination, and medical testing that excludes other fatiguing illnesses.

**The 1994 International research case definition**<sup>(1)</sup> also requires the presence of four of the following eight symptoms:

Post-exertional malaise lasting more than 24 hours; non-refreshing sleep; difficulty in concentration or short-term memory; muscle pain; painful joints devoid of redness or swelling; a new type or dramatically increased severity of headache; tender lymph glands in the neck or armpits; sore throat.

**The Canadian clinical case definition**<sup>(2)</sup> also requires the following symptoms:

1. Malaise and worsening of other symptoms, occurring after exertion, with recovery being delayed by more than 24 hours
2. Unrefreshing sleep, nighttime insomnia, and/or daytime hypersomnia (excessive sleep)
3. Widespread, migratory or localized pain in muscles or joints (without swelling), or headache of a new type or of increased severity
4. At least two neuro-cognitive symptoms including: confusion, impaired concentration, impaired short-term memory, disorientation, difficulty finding words and/or numbers, disturbed balance, photophobia, hypersensitivity to noise, or hypersensitivity to emotional overload
5. At least one symptom from two of the following three categories:
  - a. Autonomic manifestations including orthostatic intolerance (OI), neurally mediated hypotension (NMH), postural orthostatic tachycardia (POTS), dizziness, facial pallor, palpitations, irritable bowel syndrome, urinary frequency, or shortness of breath
  - b. Neuroendocrine manifestations including low body temperature, intolerance to heat and/or cold, feeling feverish, sweating, abnormal appetite, or symptoms that worsen with stress
  - c. Immune manifestations including tender lymph nodes, recurrent sore throats, recurrent flu-like symptoms, or new sensitivity to food, medications or chemicals

Symptoms characteristically vary in severity both during the day and from day to day.

By definition, the diagnosis of ME/CFS cannot be established for six months. A provisional diagnosis can often be made earlier. Early diagnosis can lessen the impact of the disease, by ensuring that the patient has adequate rest.

**Progress and Recovery**

ME/CFS usually starts suddenly with "flu-like" symptoms, but in some patients, the onset is gradual, over months or years. Patients may be very ill at the onset of the disease. Later on, many patients improve slowly until they reach a plateau. At this time, the severity of their disease varies between the extremes of some patients who are completely bedbound and others who are able to go out to work. Most patients are between these extremes. Patients with ME/CFS who work may require reasonable accommodations and often need extra rest. Remissions and relapses are common. Relapse is frequently caused by over-exertion or an infectious disease. A few patients slowly get worse. The recovery rate is uncertain and varies from 10% to 30% in the first five years. After five years, recovery is less likely to occur. Recovered patients often find that they need more rest than their contemporaries.

**Treatment**

Establishing the diagnosis of ME/CFS will usually give the patient much relief. There is no medication that will cure the disease, but medications can be helpful for symptomatic relief. Management is directed towards educating the patient about the disease, encouraging patients to alter their lifestyles to live within their existing capabilities (resting and pacing of activities) and giving advice on nutrition. Joining a support group for patients with ME/CFS can be helpful.

Sometimes there is an overlap of symptoms between ME/CFS and the following: Fibromyalgia, Multiple Chemical Sensitivities and Gulf War illness. It can also be difficult to distinguish ME/CFS from Lyme disease, Rheumatoid Arthritis, Lupus, Multiple Sclerosis, psychiatric disorders and many other diseases.

**For more information:**

[www.njcfsa.org](http://www.njcfsa.org). (888) 835-3677

**References:**

- (1) Fukuda, K., et al., *Annals of Int. Med.* 1994; 121:953-959.
- (2) Carruthers, BM, et al., *J. Chronic Fatigue Syndrome* 2003; 11(1):7-115.

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