



Chronic Fatigue Syndrome

What is Chronic Fatigue Syndrome?

Chronic Fatigue Syndrome (CFS) is a devastating and complex illness that affects at least a million Americans. The pathological loss of energy and stamina of CFS is very different from the fatigue felt by healthy people following strenuous exercise or who are living under stress. The incapacitating fatigue of CFS is coupled with multiple symptoms in many of the body's organs and systems. These symptoms are made worse by physical and/or mental activity and are not relieved by rest. Therefore, a CFS patient's ability to function is substantially reduced. CFS is recognized by the Centers for Disease Control and Prevention (CDC) as an organic syndrome, not a psychiatric disorder.

Chronic Fatigue Syndrome (CFS) is an unfortunate name because fatigue is common in many other illnesses. The name ignores the multi-system abnormalities found in CFS. The name trivializes the severity of the symptoms. CFS is also known by several other names including: Chronic Fatigue Immune Dysfunction Syndrome (CFIDS), Myalgic Encephalomyelitis, Myalgic Encephalopathy, (both are abbreviated ME), and Chronic Epstein Barr Virus Syndrome (CEBV). The acronyms ME/CFS and CFS/ME are currently gaining in popularity worldwide (1-2).

Who gets ME/CFS?

At least one million Americans have ME/CFS; research shows that only 15% of them have been diagnosed. ME/CFS affects all races, all socio-economic groups and all ages. The most common age of onset is between 20 and 50 years of age. Four times as many adult women have ME/CFS as adult men. In children an equal number of boys and girls have the illness.

What causes ME/CFS?

The cause of ME/CFS is unknown. Several factors may be involved. ME/CFS usually occurs as sporadic (isolated) cases, but 20% of patients have another family member with the illness. This suggests that genetic and/or environmental factors may contribute to the illness. Clusters of cases or

outbreaks of ME/CFS have been found worldwide. Some outbreaks have affected large numbers of individuals in a particular community, hospital, or school. Frequently, the illness follows an acute, 'flu-like' infection and the immune system changes found in ME/CFS are similar to the immune system changes associated with some viral infections. In spite of much research, no known infectious agent has been identified as the unique cause of ME/CFS. Occasionally, ME/CFS has been triggered by: environmental toxins, the receipt of an immunizing injection, or surviving a major trauma. ME/CFS is distinct from major depressive disorders. Depression and anxiety may occur secondary to ME/CFS, but Major Depression and ME/CFS can be distinguished by behavioral, immunological, and hormonal testing.

Main symptoms and diagnosis

Diagnosing ME/CFS is difficult. There is no clinical or laboratory test for this illness. The diagnosis depends upon the patient's symptoms meeting the criteria of one of several "case definitions." The 1994 International case definition (3) 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 the case definition's criteria. The newer Canadian clinical case definition (1) was produced to overcome this problem. The Canadian clinical case definition includes more symptoms commonly found in patients with ME/CFS.

Both case definitions include:

1. The onset of new, 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 is not relieved by rest.
2. The taking of a medical history, a clinical examination and medical testing to exclude other fatiguing illnesses.

The International case definition also requires the presence of four of the following eight symptoms: Post-exertional malaise lasting more than 24 hours; non-refreshing sleep; muscle pain; painful joints

without redness or swelling; a new type or dramatically increased severity of headache; difficulty in concentration or short-term memory; sore throats; tender lymph glands in the neck or armpits.

The Canadian clinical case definition also includes the following:

1. Malaise and worsening of other symptoms occurring after exertion. Recovery is 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 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 subcategories:
 - a. Autonomic manifestations such as 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 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.

The pattern of symptoms differs in different patients and symptoms may vary in severity from day to day or during the day. In summary, the diagnosis is made clinically from the pattern of symptoms and the exclusion of other fatiguing illnesses.

Progress and Recovery

In most patients ME/CFS starts suddenly with a 'flu-like' illness. Sometimes the onset is gradual, over months or years. Although patients may be very ill at the onset of the illness, the diagnosis is usually delayed because by definition, the diagnosis of adult ME/CFS cannot be established for six months. A provisional diagnosis can often be made

earlier, and early diagnosis may lessen the impact of the disease, by ensuring that the patient has adequate rest.

Patients with ME/CFS tend to improve slowly and then reach a plateau. At this time, the severity of their illness varies between the extremes of some patients who are homebound, and others who are able to go to work. Patients, who work usually require extra rest and may require reasonable accommodations. Most patients are between these extremes. Remissions and relapses are common. Relapse is frequently caused by over-exertion or another infectious illness. A few patients slowly get worse. Recovery rates are uncertain and vary from 10% to 30% in the first five years. After five years, recovery is less likely to occur. The prognosis is better in children (up to 40% may recover). Recovered patients often find that they need more rest than their contemporaries.

Treatment

Establishing a firm diagnosis of ME/CFS will usually give the patient much relief. Management is directed towards the relief of individual symptoms, giving advice on nutrition and encouraging patients to adapt their lifestyle to live within their existing capabilities. There is no curative medication. Joining a support group for ME/CFS patients can be helpful.

In some patients there is an overlap of symptoms between ME/CFS and one or more of the following syndromes: Fibromyalgia (FMS); Gulf War Syndrome (GWS); and Multiple Chemical Sensitivities (MCS). It can also be difficult to distinguish ME/CFS from Lyme disease, Rheumatoid Arthritis, Lupus, Multiple Sclerosis, psychiatric disorders or other illnesses.

For more information

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References

1. Carruthers BM, et al. ME/CFS Clinical working case definition, diagnostic and treatment protocols. *J. Chronic Fatigue Syndrome* 2003; 11(1):7-115.
2. Jason LA, et al. A pediatric case definition for Myalgic Encephalomyelitis and Chronic Fatigue Syndrome. *J. Chronic Fatigue Syndrome* 2006; 13 (2/3):1-28.
3. Fukuda K, et al. The Chronic Fatigue Syndrome: A comprehensive approach to its definition and study. *Annals of Int. med.* 1994; 121:953-959.