



PEDIATRIC CHRONIC FATIGUE SYNDROME Fact Sheet

What is Chronic Fatigue Syndrome?

Chronic Fatigue Syndrome (CFS) is a disabling and complex illness characterized by incapacitating fatigue (loss of energy and stamina) and multiple symptoms in all body systems. The symptoms are made worse by physical and mental activity and are not relieved by rest. Patients' functional ability is substantially limited.

CFS is also known as Myalgic Encephalomyelitis (ME), Chronic Fatigue Immune Dysfunction Syndrome (CFIDS), or Chronic Epstein Barr Virus Syndrome (CEBV). Chronic Fatigue Syndrome is an unfortunate name, because fatigue occurs in many chronic illnesses and the name does not differentiate the pathological exhaustion of CFS from the normal fatigue felt by healthy people after exertion. The name CFS trivializes the severity and ignores the multi-system abnormalities found in this serious illness.

CFS in Children and Adolescents

Nearly one million Americans have CFS, but only 15% have been diagnosed. A substantial number of patients are under the age of 18 years. Adolescents between 12 and 17 years old are more likely to develop CFS than younger children, but children as young as four years old have developed the disease. In adults, three to four times as many women as men have CFS, but the gender ratio is almost equal in affected children. CFS usually occurs as sporadic (isolated) cases of the disease, but in 20% of patients it affects more than one family member. Outbreaks, or clusters of cases have been found worldwide and in several of these outbreaks the disease has been prominent in schoolchildren.

Diagnosis

There is no diagnostic test for CFS. The diagnosis is made clinically from the characteristic fatigue, the pattern of other symptoms and the exclusion of other fatiguing illnesses. A case definition, for diagnosing CFS in adults has been established by the CDC for research purposes. This case definition has also been used in children, because, a pediatric case definition has not yet been published. However using the adult case definition will exclude some children with genuine CFS, who do not exactly fit the criteria. It can be especially difficult to diagnose CFS in a young child,

because children may not recognize fatigue and may not realize that their non-painful symptoms are abnormal. The diagnosis is often made retrospectively when the child is older.

Symptoms

CFS in adolescents often resembles CFS in adults. It usually starts suddenly with a fever and flu-like symptoms. Sometimes the onset is gradual. In younger children, a gradual onset over some months or years is more likely. The first sign of the illness may be the child's marked limitation of activity, noticed by a parent or teacher. The pattern of symptoms experienced by a child may change from time to time and vary in severity during the day or from day to day. Children with CFS often do not look ill. Listening to the child and believing him/her are important. Only the child knows the severity of the symptoms.

The main symptoms are:

- pathological, incapacitating, fatigue, which is both physical and mental. It is not the result of exertion and is not relieved by rest
- malaise and increased fatigue following exertion. The exertion-induced malaise and fatigue require more than 24 hours to resolve
- non-refreshing sleep, nighttime insomnia and/or daytime hypersomnia (excessive sleep)
- skeletal pain particularly in the muscles, or the joints (without redness or swelling); abdominal pain; onset of a new type, or dramatic increase in severity of headaches. Rarely is pain absent
- difficulty in concentration; inability to recall words or numbers; poor short term memory.

The following symptoms have each been reported in more than 50% of children with CFS:

- muscle weakness, which is worse after exertion
- eye pain and sensitivity to light
- dizziness, lightheadedness, palpitations or shortness of breath
- nausea, diarrhea, or constipation
- recurrent sore throats
- tender lymph glands in the neck or armpits

- low grade fever or low body temperature, night sweats, cold extremities
- allergies, new sensitivities to foods, medicines or chemicals.

Mood changes, reactive depression and anxiety often result from the illness.

To diagnose CFS, the fatigue and symptoms must:

- be of new onset (not life long)
- have persisted or relapsed for at least six months
- result in a substantial reduction in previous level of activities
- be unexplained. Other fatiguing illnesses must be excluded by clinical examination and medical tests.

Children with CFS may also have the symptoms of Juvenile Fibromyalgia (pain and tender spots in muscles) and/or Orthostatic Intolerance (dizziness and marked changes in pulse and/or blood pressure on standing). It may be difficult to distinguish CFS from Infectious Mononucleosis, Rheumatoid Arthritis, Lyme disease, psychiatric disorders or other illnesses. CFS has sometimes been misdiagnosed as School Phobia, or Munchausen's syndrome by proxy (a parent is blamed for fabricating the disease in the child).

Progress and Recovery

Children with CFS may be very ill at the onset of the disease. The diagnosis is often uncertain, because although no other illness may be found, by definition the diagnosis of CFS cannot be established for six months. Sometimes a provisional diagnosis can be made sooner. Early diagnosis may lessen the impact of the disease, provided that the child is allowed adequate rest. The severity of CFS varies. Some children are severely or partly disabled and housebound, while others can go to school and a few even do sports. Most are between these extremes. Over time, slow improvement is likely. Remissions and relapses are common. Relapses may be caused by other bacterial or viral illnesses or over-exertion. Recovery rates are uncertain but rates of up to 40% have been reported. Recovery is more likely in the first four years. Recovered patients often find that they need more rest than their contemporaries.

Management

Establishing the diagnosis of CFS usually gives much relief to both the patient and parents. Adequate rest is the mainstay of treatment as there is no medication, which will cure the disease. Medication can be very helpful in the relief of individual symptoms. CFS patients commonly respond to much lower than

expected dosages of many medications. Advice on nutrition can be helpful. Patients should also be advised to adapt their lifestyle and live within their capabilities. Children with CFS may be isolated at home, miss their friends and may have had to give up their favorite activities. They should be encouraged to socialize with friends when possible and take up hobbies, which are within their capabilities.

Education

Most students with CFS fall behind in their education due to cognitive problems and fatigue. Many are too sick to attend school. In a British study ME/CFS was found to be the most common cause of long-term absence from school. Students with CFS may qualify for Special Services under the Individuals with Disabilities Education Act (IDEA) and/or Section 504 of the Rehabilitation Act, 1973. Eligible students receive an Individual Educational Plan (IEP) and the school can provide reasonable accommodations and/or home tutoring.

Causes

The cause of CFS is unknown, but several factors may be involved. In some families, where two or more genetic relatives have CFS, genetics may produce a susceptibility to the disease. Frequently the disease follows an acute infection, and immune system changes found in CFS are similar to the changes found subsequent to viral infections. In spite of much research, no known infectious agent has been shown to be the cause. Less frequently, CFS can be triggered by toxins, immunization, or major trauma. CFS is **not** a psychological illness. Depression and anxiety may occur secondary to CFS, but CFS and Major Depression can be distinguished from each other by contrasting results of hormonal and immunological testing.

For more information

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References

- Bell DS. Chronic Fatigue Syndrome in children and adolescents: A Review. *Focus and Opinion: Pediatrics* 1995, 1(5):412-420.
- Carruthers BM, Jain AK, et al. ME/CFS Clinical working case definition, diagnostic and treatment protocols. *J. Chronic Fatigue Syndrome* 2003, 11(1):7-115.