New Jersey Chronic Fatigue Syndrome Association, Inc

Chronic Fatigue Syndrome in Children and Adolescents

Rosemary Underhill, MB BS.

What is Chronic Fatigue Syndrome?

Chronic Fatigue Syndrome is a debilitating 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' ability to function is substantially less than before the illness.

Chronic Fatigue Syndrome (CFS) is an unfortunate name for this illness, because fatigue occurs in many other 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 also ignores the multi-system abnormalities found in this illness and trivializes its severity. Although the illness is called CFS in the USA, it is a global illness and in other parts of the world it is known as Myalgic Encephalomyelitis (ME). Current medical definitions of the illness now use the acronym ME/CFS (1-2). ME/CFS is also known as Chronic Fatigue Immune Dysfunction Syndrome (CFIDS) and was previously known as Chronic Epstein Barr Virus Syndrome (CEBV).

CFS in Children and Adolescents

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

Causes

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

Symptoms, Diagnosis and Case Definition

There is no diagnostic test for ME/CFS. The diagnosis is made from the characteristic fatigue, the pattern of other symptoms and the exclusion of other fatiguing illnesses. The main diagnostic features of the illness have been incorporated into a number of different case definitions for adults (2) and more recently a case definition for children (1). An adult case definition (3) has often been used to diagnose children, but it excludes some children with genuine ME/CFS, who do not exactly fit the adult criteria. Key symptoms of the recommended pediatric case definition for ME/CFS (1) are as follows:

- Clinically evaluated, unexplained, persistent, or relapsing fatigue for at least three months, which is not the result of exertion, is not relieved by rest, and results in a substantial reduction in previous activities
- The concurrent presence of the following symptoms:
  1. Malaise, fatigue, or worsening of other symptoms after exertion, with loss of mental and/or physical stamina, and delayed recovery of more than 24 hours
  2. Un-refreshing sleep, day/night reversal, nighttime insomnia and/or daytime hypersomnia (excessive sleep), Disturbance of sleep quantity or rhythm
  3. Widespread or migratory pain. The pain can be located in the muscles and/or joints (without signs of inflammation), in the abdomen, in the chest, or it can be a new type, or an increase in severity of headaches
  4. Two or more neuro-cognitive manifestations, including impaired short term memory, difficulty in concentration or focusing, difficulty finding words or numbers, absent mindedness, slowness of thought, difficulty understanding information and expressing thoughts, educational difficulties
  5. At least one symptom from two of the following three subcategories:

     a. Autonomic manifestations, including neurally mediated hypotension, postural hypotension, postural orthostatic tachycardia, shortness of breath, disturbed balance

b. Neuro-endocrine manifestations, including feeling of feverishness, cold extremities, low body temperature, sweating, intolerance to heat or cold, change of appetite or weight

c. Immune manifestations, including recurrent flu-like symptoms, sore throats, fevers and sweats, tender lymph nodes, new sensitivities to food, medicines, odors, or chemicals

- Other fatiguing illnesses must be excluded by clinical examination and medical tests. Routine tests are frequently normal, but specialized testing may show various abnormalities in some patients' immune systems, nervous systems, cardiovascular systems and/or in cellular energy production.
- The pattern and severity of the symptoms experienced by a child may change markedly from day to day or during the day. Children with ME/CFS often do not look ill, so it is important to listen to what the child has to say about the severity of his/her symptoms. Mood changes, reactive depression or anxiety may result from the illness. Many children also have the symptoms of Juvenile Fibromyalgia (pain and tender points, or areas, in muscles when they are touched). It may also be difficult to distinguish ME/CFS from Infectious Mononucleosis, Rheumatoid Arthritis, Lyme disease, psychiatric disorders or other illnesses. ME/CFS has often been misdiagnosed, as School Avoidance Behavior, or as Munchausen's syndrome by proxy (a condition in which, a parent fabricates their child's illness).

Progress and Recovery

ME/CFS in adolescents usually starts suddenly with a fever and flu-like symptoms. Sometimes the onset is gradual. In younger children, a gradual onset over months or years is more likely. It can be especially difficult to diagnose ME/CFS in younger children, because they may not recognize that their fatigue and their other symptoms are abnormal. The diagnosis is often made retrospectively when the child is older. The first sign of the illness may be the child's marked limitation of activity, noticed by a parent or teacher.

Children with ME/CFS may be very ill at the onset of the illness and the diagnosis is often uncertain, because routine blood tests are frequently normal. By definition the diagnosis of ME/CFS cannot be made for three months, even if no other illness is found. Sometimes a provisional diagnosis of ME/CFS can be made sooner. Early diagnosis may lessen the impact of the illness by ensuring the child gets adequate rest. The severity of ME/CFS varies. Some children are severely disabled and bedridden, while others can go to school and a few even do sports. Most are between these extremes. Remissions and relapses are common. Relapses may be caused by over-exertion or by other infectious illnesses. Over time, slow improvement is likely. Recovery rates are uncertain but rates of up to 40% have been reported. Dramatic improvement is more likely to occur in the first four years. Children whose health improves to near pre-illness levels are likely to find that they need more rest than their contemporaries.

Management

Establishing the diagnosis of ME/CFS and confirming that the child has a recognized illness will relieve uncertainty in the minds of the patient and the parents. There is no medication, which will cure the illness, but medication can be helpful in the relief of individual symptoms. ME/CFS patients commonly respond to lower than expected, dosages of many medications. Adequate rest is the mainstay of treatment. Patients should be advised to adapt their lifestyle to live within their capabilities. Advice on nutrition can be helpful. Children with ME/CFS who are unable to attend school will be isolated at home, miss their friends and often need to give up their favorite activities. They should be encouraged to see their friends when possible and take up hobbies, which are within their capabilities.

Education

Most students with ME/CFS fall behind in their education due to cognitive problems and fatigue. Many are too ill to attend school. A British study found that ME/CFS was the most common cause of long-term absence from school. Students with ME/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 should provide reasonable accommodations and/or home tutoring.

References

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

For more information

http://njcfsa.org.   E-mail: njcfsa@njcfsa.org.
Phone; (888) 835 3677 (help line).

Revised 2007