The CFIDS Association of America

Working to conquer chronic fatigue and immune dysfunction syndrome

What is CFIDS in Youth?

Chronic fatigue and immune dysfunction syndrome (CFIDS), also known as chronic fatigue syndrome (CFS), is widely recognized in adults. But it's not as well known that children and adolescents can have CFIDS.

In children and adults, CFIDS is a complex illness characterized by incapacitating fatigue, neurological problems and a constellation of symptoms that can resemble many other disorders (including mononucleosis, childhood migraine syndrome and Lyme disease).

How is CFIDS diagnosed?

Despite a decade of research, there is still no definitive diagnostic test for CFIDS.

The diagnosis is made by identifying a characteristic pattern of symptoms and excluding other possible causes for them. The Centers for Disease Control's 1994 case definition requires at least six months of fatigue which interferes with daily activities and four of eight listed symptoms.

The Definition of CFS

From "The Chronic Fatigue Syndrome: A Comprehensive Approach to its Definition and Study," *Annals of Internal Medicine*, 12/15/94.

A thorough medical history, physical examination, mental status examination and laboratory tests must be conducted to identify underlying or contributing conditions that require treatment. Diagnosis or classification cannot be made without such an evaluation. Clinically evaluated, unexplained chronic fatigue cases can be classified as chronic fatigue syndrome if the patient meets both the following criteria:

1. Clinically evaluated, unexplained persistent or relapsing chronic fatigue for at least six months that is of new or definite onset (i.e., not lifelong), is not the result of ongoing exertion, is not substantially alleviated by rest, and results in substantial reduction in previous levels of occupational, educational, social or personal activities.
2. The concurrent occurrence of four or more of the following symptoms: substantial impairment in short-term memory or concentration; sore throat; tender lymph nodes; muscle pain; multi-joint pain without joint swelling or redness; headaches of a new type, pattern or severity; unrefreshing sleep; and post-exertional malaise lasting more than 24 hours. These symptoms must have persisted or recurred during six or more consecutive months of illness and must not have pre-dated the fatigue.

In general, children's symptoms are similar to those of adults: substantial impairment of short-term memory and/or concentration, sore throat, tender lymph nodes, muscle pain, multi-joint pain, headaches, unrefreshing sleep and fatigue lasting more than 24 hours following exertion. CFIDS is diagnosed when these symptoms persist for at least six months and cannot be explained by any other medical condition.

What are the differences between adult and pediatric CFIDS?

A prominent difference between adults and children with CFIDS is that children more commonly report symptoms such as dizziness, light-headedness, abdominal pain, rash, fever and chills. The illness' relapsing and remitting pattern is a primary reason for frequent misdiagnosis of pediatric CFIDS as a behavioral or emotional disorder, in particular school phobia.

While the physical symptoms may be similar in children and adults, differences in defining the symptoms can make it more difficult to identify CFIDS in children. Parents (who are usually responsible for talking to doctors about their children's illnesses) and children may use different words to describe the child's symptoms than those used to describe an adult's illness. For example, rather than saying their child is "fatigued," a parent might say that the child is always sleepy, grumpy or can't keep up with other children in school or at play.

Because the CFIDS diagnosis is made by excluding all other possible causes of the symptoms, it's recommended that parents request extra time with the doctor when making appointments. Experts recommend that the physician listen carefully, ask appropriate questions and talk with the child alone. Scheduling longer appointments may allow the doctor to spend enough time to investigate the patient's complaints.

Another difference between adults and children with CFIDS exists in the recognition of neurological symptoms. Adults have a clear perception of their mental abilities, so memory loss and concentration difficulties are easily recognized. Because children don't have as much experience with and are less sure of their cognitive abilities, these symptoms may appear as progressive school difficulties.

Because these memory and concentration symptoms occur during a period of rapid learning and intellectual development, youth with CFIDS may be at greater risk for long-term difficulties.

How does CFIDS develop in children?

The majority of children, particularly adolescents, have an acute onset of symptoms that marks the beginning of CFIDS. An acute onset is characterized by the sudden appearance of symptoms within a few days to weeks, usually with a flu-like or mononucleosis-like illness in a child who had previously been healthy.

Children who experience an acute onset can clearly describe their symptoms, such as the degree of fatigue or impairment in cognitive abilities, in comparison to their pre-illness state. These children may accumulate a bewildering array of diagnoses from their pediatricians, including childhood migraine syndrome, Crohn's disease, atypical epilepsy, school phobia, attention deficit disorder, rheumatoid arthritis, chronic rheumatic fever, irritable bowel syndrome and others.

The gradual presentation of CFIDS is slightly different and seems to occur more often in younger (pre-adolescent) children. It is defined by the appearance of symptoms over several months or longer, or by mild symptoms suggestive of CFIDS (frequent sore throats, headaches or joint pains, relative inactivity, sleeping more than other children of the same age) prior to an acute episode.

It is often difficult for children who experience a gradual onset to describe their degree of fatigue or cognitive difficulties because they don't recall a time period without them. Interestingly, these children may not perceive themselves as being ill, most likely because they have been growing up with their symptoms and have no clear reference to normal health.

Do children recover?

Many children (and adults) do recover from CFIDS. However, there is no standard duration of the illness. Some people get better over a period of a few years, while others cycle through periods of illness and improved health. Fortunately, most don't report a progressive worsening of symptoms.

In the few published studies that have looked at outcomes of pediatric CFIDS, 8 to 27% of children with CFIDS "recovered," 27 to 46% improved, and 12 to 29% remained unchanged from the onset of the illness.

Is there a treatment for children with CFIDS?

The first step in properly treating children with CFIDS is making the diagnosis. There is a great body of knowledge available about how children cope with chronic illness, and identifying a reason for their poor health will help them cope with it in an emotionally healthier way.

Failure to establish the diagnosis and lack of cooperation between professionals may lead to inaccurate impressions that the child is malingering or "faking." This may result in isolation, insecurity, sense of failure, family stress and even legal action against the family by school authorities. Further, an unresolved diagnosis may leave the child with uncertainty as to whether he or she is really experiencing the symptoms, or whether they are "all in the mind," as skeptics claim.

Otherwise, treatment for children varies little from that for adults and is intended primarily to relieve specific symptoms. Treatment must be carefully tailored to meet the needs of each patient. Sleep disorders, pain, gastrointestinal difficulties, allergies, dizziness, light-headedness, blood pressure irregularity and depression are some of the symptoms which physicians commonly attempt to relieve with prescription and over-the-counter medications. Persons with CFIDS may have unusual responses to medications, so extremely low dosages should be tried first and gradually increased as appropriate.

Lifestyle changes, including increased rest, reduced stress, dietary restrictions, nutritional supplementation and light exercise (such as walking) also are frequently recommended. These changes will likely impact a young person's educational and social experiences, and their long-term impact must be considered. Supportive therapy, such as counseling, can also help a young person with CFIDS identify and develop effective coping strategies.

New treatments for CFIDS are currently under investigation that may not only improve symptoms, but also help the underlying condition.

Is CFIDS related to other illnesses?
There are a host of illnesses that share many of the symptoms of CFIDS. Fibromyalgia is a common condition that causes widespread muscular pain. Neurally mediated hypotension (NMH) is a condition in which the blood pressure falls when it should rise, resulting in dizziness or feeling faint. Chronic Lyme disease, multiple chemical sensitivities (MCS), food allergies and interstitial cystitis are just a few of the many other syndromes which can co-exist with CFIDS. If you would like information about any of these related disorders, please visit www.cfids.org or contact The CFIDS Association directly.

My child seems depressed. Is this common?
Many persons with CFIDS (PWCs) become depressed as a result of -- rather than as a cause of -- CFIDS. Depression is common in all chronic illnesses; it results from numerous losses, life changes and brain chemistry irregularities. In some cases, depression becomes very severe. The good news is that, with good medical care, it is one of the easiest-to-treat symptoms caused by CFIDS. CFIDS-related depression is properly managed with medication and/or supportive counseling.

Is exercise helpful or harmful?
One hallmark of CFIDS is an intolerance of previously well-tolerated levels of physical activity. Most PWCs' symptoms worsen severely, sometimes for days, following even minor exertion. Physicians generally recommend that PWCs perform limited physical activity (such as walking or yoga) to guard against the negative consequences of deconditioning, but that they listen to their bodies and not push beyond their limits.

Students with CFIDS may be exempted from or obtain adaptations to physical education requirements with a note from their physicians and the understanding of school administrators.

How does CFIDS affect school performance?
A child with CFIDS must often work harder to maintain the same grades he or she was earning prior to becoming ill. In many cases, grades drop because of the physical and cognitive impairments caused by CFIDS. Children with CFIDS often miss a good deal of school. A reduced school schedule supplemented by home tutoring can lead to a positive educational experience.

Cognitive problems, such as loss of ability to concentrate and difficulties with short-term memory, word-finding ability and visual/spatial perception can go unrecognized. As a result, the cognitive deficits may only be pinpointed through educational evaluation, which is provided by schools upon parental request.

What about my child's social needs?

It is important to consider the role school plays in the social development of a child or adolescent and the simple accommodations which can help young persons with CFIDS become happy, healthy adults. In addition to becoming proficient in math and reading, school is the place people learn to communicate, work with others and develop the social skills that are essential throughout life.

Schools should maintain an open door policy for students with CFIDS, helping them to feel welcome whenever they are healthy enough to come to school. Allowing students to come in for easier classes, such as art or music, and to be home tutored for more difficult subjects, such as math or science, will allow them to participate in school, while ensuring that their education does not suffer. Attendance requirements may be modified to prevent chronically ill children from feeling that they are being punished for being ill.

If these situations occur, the student's parents and health care team must step in and try to strike a compromise with schools to ensure that their children have opportunities to develop into well-adjusted, as well as well-educated, adults.

Does my child have educational rights?

Students disabled by CFIDS are entitled to special educational services under the Individuals with Disabilities Education Act (IDEA) and/or accommodations under Section 504 of the Rehabilitation Act of 1973.

IDEA mandates a free and appropriate public education for all children with disabilities. Young persons with CFIDS (YPWCs) may meet IDEA's disability classification of "other health impaired" defined by "...limited strength, vitality or alertness, due to chronic or acute health problems, which adversely affects a child's educational performance." If a YPWC is deemed to meet this criteria, the parents and school personnel will meet to develop an individualized education plan (IEP), which will be reviewed annually.

If YPWCs are achieving at their pre-illness level and are ineligible for services under IDEA, they may be entitled to accommodations under Section 504 of the Federal Rehabilitation Act of 1973. Section 504 assures equal opportunities for disabled youth in schools receiving federal funds, including colleges and universities. The school's 504 contact person can put modifications, accommodations or aids into a plan outlining what a YPWC needs to participate and benefit from the educational program.

NICHCY is a national resource center that provides information on disability-related issues, such as CFIDS. See below for more information.

How can I help my child with CFIDS?

Above all, believe your child. Children with CFIDS need to be taken seriously by parents, doctors, teachers and others, and not to be written off as manipulative, lazy, emotionally disturbed or school phobic. Parents must learn to listen to and accept what their children with CFIDS communicate about what they can and cannot do. Acknowledging and validating their illness relieves the pressure they feel to prove they are really sick. Children need advocates -- people who are willing to fight for them -- to educate the public, health care providers and educators about the physical and cognitive challenges faced by children with CFIDS.

For more information, read " Supporting the Child With CFIDS: The Rights and Needs of YPWCs."

How can I get more help?

The CFIDS Association of America is working to improve the lives of young persons with CFIDS by providing emotional and educational support, coping tips and medical information to them and their families. The CFIDS Association is committed to helping pediatricians, family practitioners, school nurses and teachers learn how to recognize pediatric CFIDS and how to help kids who have it.

Please join us as an advocate for CFIDS patients of all ages, and support our efforts to provide hope and help to them by joining The CFIDS Association of America today.

Other resources
The CFIDS Association of America offers many resources on its Web site (http://www.cfids.org), including a special section on youth-related issues.

Pediatric CFIDS information is available from The CFIDS Association of America to help children and adults with specialized questions about educational, medical and social/coping issues. Please call the Association's Resource Line at 704/365-2343 for information.

The National Information Center for Children and Youth with Disabilities (NICHCY, PO Box 1492, Washington DC 20013, 800/695-0285, http://www.nichcy.org) provides resources, referrals to other national and local organizations, free information packets and lists of publications.

The CFIDS Association of America, Inc. is the nation's leading 501(c)(3) charitable organization dedicated to conquering CFIDS by supporting education, public policy and research programs. The Association has invested over $14 million in CFIDS education, public policy and research in its efforts to bring an end to the suffering caused by this devastating illness.

Our mission is to conquer CFIDS. We work toward our mission by:

- Building recognition of CFIDS as a serious, widespread medical disorder;
- Securing a meaningful response to CFIDS from the federal government;
- Stimulating high quality CFIDS research;
- Improving health-care providers' abilities to detect, diagnose and manage CFIDS; and
- Providing information to persons with CFIDS and enabling the CFIDS community to speak with a collective voice.

For an excerpt from the CFIDS Association of America's Annual Report providing financial and operations results from the previous calendar year, please make a written request to the address below.

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