

Pediatric CFS

CHRONIC FATIGUE SYNDROME

Chronic fatigue syndrome (CFS) is widely recognized in adults. But it is not as well known that children and adolescents can have the illness. Recognition of CFS in young people can be difficult because they are physically, emotionally and socially different from adults. For example, rather than saying their child is “fatigued,” parents may say that he/she is always sleepy, grumpy or cannot keep up with other children in school or at play. Failure to make a proper diagnosis of pediatric CFS may lead to isolation, insecurity, sense of failure and family stress.

Symptoms

- The symptoms of CFS in children are similar to those of adults. In addition to debilitating fatigue, they may include impaired memory or concentration, sore throat, tender lymph nodes, muscle pain and headaches.
- The majority of children with CFS, particularly adolescents, have an acute onset--symptoms appear suddenly within a few days or weeks, usually with a flu or mononucleosis-like illness.
- Gradual presentation occurs more often in younger, pre-adolescent children and is defined by the appearance of symptoms over several months or longer.

Diagnosis

- CFS is diagnosed when symptoms persist for more than six months and cannot be explained by any other medical or psychological disorders.
- Teenagers are more likely than younger children to fit the case definition created by the U.S. Centers for Disease Control and Prevention (CDC).
- Pediatric CFS is frequently misdiagnosed as a behavioral or emotional problem, in particular school phobia. Unlike children with school phobia, children with CFIDS are typically ill on weekends as well as during the school week.
- Many children with CFS also have orthostatic intolerance, which causes inability to tolerate upright posture.

Pediatric vs. Adult CFS

- Children with CFS are more likely than adults to report symptoms such as dizziness, abdominal pain, rash, fever and chills.
- CFS may be more difficult to identify in children, since they often use words to describe their symptoms that are different from those used to describe adult illness.
- Neurological symptoms in particular may be overlooked because children do not have as much experience with and are less sure of their cognitive abilities, and so are less able to recognize changes. Problems with memory and concentration may appear as progressive school difficulties.

- Long-term difficulties resulting from cognitive disorders may be more prevalent in children than in adults because symptoms occur during a period of rapid intellectual development.

Educational/social effects

- The majority of children with CFS (up to 94%) experience worsening of their school performance due to the physical and cognitive symptoms.
- Twenty to 44 percent of children with CFS must be home-schooled because they are too ill to attend classes.
- Children with CFS who cannot attend school miss out on important social development opportunities. They can be classified as disabled and may be entitled to educational services under the Individuals with Disabilities Education Act and/or Section 504 of the Rehabilitation Act of 1973.

Treatment

- Treatment for children with CFS is similar to treatment for adults, and is intended primarily to relieve specific symptoms, such as difficulty sleeping, pain, gastrointestinal difficulties, allergies and dizziness.
- Lifestyle changes, including increased rest, dietary restrictions and very light exercise, are also frequently recommended.
- Children with CFS may have unusual responses to medications, so low dosages should be tried first and gradually increased as appropriate.
- Chronic illnesses such as CFS are traumatic for the child's family as well as the child, and support from school officials, physicians and friends is important.

Recovery

- Many children (and adults) do recover from CFS. However, there is no standard duration for the illness.
- In the few published studies that have looked at outcomes of pediatric CFS, 8-27 percent of children with CFS “recovered,” 27-46 percent improved and 12-29 percent remained unchanged from the onset of the illness.
- Children with CFS often experience an alternating pattern of relapses and remission. The majority do not report a progressive worsening of their symptoms.

Cause

- The cause of CFS remains unknown. Many viral, bacterial and psychological causes have been considered and rejected, but the search continues.
- From 10-15 percent of people with CFS have a family member who also has the illness, leading researchers to speculate that genetics may play a role, but more research is needed.

Learn more by visiting the CFIDS Association of America at www.cfids.org/cfs