

The CFIDS Association of America

Recognition of myalgic encephalomyelitis/ chronic fatigue syndrome (ME/CFS) in young people can be difficult because they are physically, emotionally and socially different from adults.

Failure to make a proper diagnosis of pediatric ME/CFS may lead to isolation, insecurity, sense of failure and family stress. Here are some things that are important to know if you think your child may have ME/CFS:

Symptoms

- The symptoms of ME/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 ME/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, preadolescent children and is defined by the appearance of symptoms over several months or longer.

Diagnosis

- ME/CFS is diagnosed when symptoms persist for more than six months and cannot be explained by any other medical or psychological disorders.
- Pediatric ME/CFS is frequently misdiagnosed as a behavioral or emotional problem, in particular school phobia. Unlike children with school phobia, children with ME/CFS are typically ill on weekends as well as during the school week.
- Many children with ME/CFS also have orthostatic intolerance, which causes the inability to tolerate upright posture.

Pediatric vs. Adult CFS

- Children with ME/CFS are more likely than adults to report symptoms such as dizziness, abdominal pain, rash, fever and chills.
- ME/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. They 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 ME/CFS (up to 94%) experience worsening of their school performance due to the physical and cognitive symptoms.
- Many children with ME/CFS must be homeschooled because they are too ill to attend classes.
- Children with ME/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 ME/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.
- Children may have unusual responses to medications, so low dosages should be tried first and gradually increased as appropriate.
- Chronic illnesses such as ME/CFS are traumatic for the child's family as well as the child, and support from school officials, physicians and friends is important.

Recovery

• Children with CFS often experience an alternating pattern of relapses and remission. The majority do not report a progressive worsening of their symptoms.

Cause

- Despite an intensive search, the cause of ME/CFS remains unknown. Much of the ongoing research into a cause now centers on the roles the brain and the immune endocrine, cardiovascular and autonomic nervous systems play in ME/CFS.
- 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; more research is needed.