



The CFIDS Association of America, Inc.

CHRONIC FATIGUE AND IMMUNE DYSFUNCTION SYNDROME
Publishers of *The CFIDS Chronicle*

*Advocacy, Information, Research and Encouragement
for the CFIDS Community*

Dear School Nurse:

Have you ever been concerned about a student struggling with exhaustion, flu-like symptoms, and difficulty concentrating, who did not have a medical diagnosis? Did you wonder whether that child might have chronic fatigue syndrome (CFS), and if so, what that would mean for his or her education and future? Volunteers that care about CFS are distributing the enclosed article from *School Nurse News*, which introduces pediatric CFS and a tool to help differentiate between normal activity levels and those seen in CFS. We hope you will incorporate knowledge of CFS in the many ways you support the school community.

As a school nurse, you witness the course of children's illnesses and have the opportunity to help families and pediatricians reach appropriate diagnoses and implement treatment plans. A recent DePaul University community-based CFS prevalence study found that less than 10% of adults with CFS have been diagnosed. The other more than 90% remain ill with little or no medical care for their illness. Children with CFS and their families report similar experiences of months or years of undiagnosed (or misdiagnosed) illness as do adults. As the enclosed article indicates, a careful, appropriate diagnosis of pediatric CFS can alleviate the child and parents' fears and allow them to begin coping constructively, by planning ways to maintain educational progress, encourage socialization, and manage symptoms. School nurses and primary care providers are equipped to help children and parents cope with chronic illness, if that illness is recognized and diagnosed.

Resources are available to help you recognize CFS in children and adolescents, provide a supportive school environment, and encourage positive coping strategies. The CFIDS Association of America, the nonprofit organization providing the enclosed materials, is the leading organization dedicated to conquering CFS and related disorders. The Association's publications, *The CFIDS Chronicle* and *The CFS Research Review*, are the world's most authoritative and widely read sources of information about CFS. The Association provides many resources for those that care about pediatric CFS:

- Free subscriptions to health care providers requesting our quarterly publication, *The CFS Research Review*;
- An extensive pediatric CFS web site addressing the educational, medical, and social issues facing young patients and their families (<http://www.cfids.org/youth>);
- A free pen-pal program for youth with CFS, their parents, and their siblings;
- Referrals to local CFS support groups and special Internet lists for youth and parents dealing with CFS;
- and print educational materials, including a Pediatric CFS Packet, medical journal articles on CFS, brochures, and back issues of *The CFIDS Chronicle* and *The CFS Research Review*.

To request a free subscription to *The CFS Research Review*, or to speak with me about our education and youth programs, please contact me at the address or phone number below. The CFIDS Association of America wants to help the medical and educational communities care for those with CFS. We're here to support you as you learn about this condition.

Sincerely,

Terri Lupton, BSS, RN
Coordinator, Educational Opportunities

TREATING CFS

By David S. Bell, MD, FAAP, Chief, Department of Pediatrics,
Medina Hospital, Medina, New York

Chronic fatigue syndrome (CFS) is a complex, multi-symptom illness with an unknown cause and no known cure. Treatment is based on symptoms. The illness is greatly misunderstood by both the medical community and general public, often creating feelings of invalidation and frustration for persons with the illness as well as their loved ones. CFS is widely recognized in adults, but it is not as well known that children and adolescents can have the illness. The following article provides an overview of CFS in the pediatric population.

CFS has been found in children as young as age five. An Australian study reported 5.5 CFS cases per 100,000 children up to age 9, and 47.9 per 100,000 in ages 10-19 (Lloyd et al., 1990).

Early practical intervention for pediatric CFS is well within the training and ability of primary care physicians; however, the illness can and often does appear differently in children than in adults and it can be difficult to diagnose.

Symptoms

There appear to be two onset patterns of pediatric CFS: gradual, or insidious, onset of symptoms, usually in children 5 to 12 years of age, and acute onset of symptoms, more common with cases beginning in adolescence. As in adult CFS, symptoms may include sore throat, joint pain, migraines, irritable bowel syndrome, postexertional malaise, sleep disorders, photosensitivity and impaired concentration and memory. Symptoms of CFS in young children most often have their onset with headache or irritable bowel syndrome.

The cognitive disturbances in CFS can produce reduced concentration, short-term memory loss, and confusion and may be confused with attention deficit disorder in children. These symptoms may be hard to recognize, because children do not have as much experience as adults in judging their own cognitive abilities.

Pediatric CFS patients will often have numerous symptoms at equally severe levels, but the symptoms will migrate. For example, a child may complain of sore throat and headache, followed the next day by lymph node and abdominal pain. By recording the symptoms during office visits, an overall pattern can be established.

PEDIATRIC



CENTERS FOR DISEASE CONTROL AND PREVENTION CASE DEFINITION OF CHRONIC FATIGUE SYNDROME*

CFS is a syndrome characterized by fatigue that is:

- Medically unexplained
- Of new onset
- Of at least six months' duration
- Not the result of ongoing exertion
- Not substantially relieved by rest
- Causing a substantial reduction in previous levels of occupational, educational, social or personal activities

In addition, there must be *four* or more of the following symptoms:

- Impaired memory or concentration
- Sore throat
- Tender neck (cervical) or armpit (axillary) lymph nodes
- Muscle pain (myalgia)
- Headaches of a new type, pattern, or severity
- Unrefreshing sleep
- Postexertional malaise (lasting more than 24 hours)
- Multi-joint pain (arthralgia without swelling or redness)

Conditions that would exclude a diagnosis of CFS include other medical disorders known to cause fatigue, major depressive illness, medication that has fatigue as a side effect, and alcohol or substance abuse.

*Fukuda et al, The chronic fatigue syndrome: a comprehensive approach to its definition and study, *Annals of Internal Medicine*, 121:953-959, 1994.

However, establishing a pattern may be complicated by the fact that children sometimes have difficulty recognizing changes in energy, and very young children in particular are unable to verbalize what they are experiencing. Some children with CFS do not perceive themselves as being ill because they have no clear reference for normal health.

Diagnosis

The diagnosis of CFS is entirely clinical: a characteristic pattern of somatic symptoms (see CDC case definition) dominated by unexplained fatigue limiting normal activity. Laboratory testing should be used to exclude other possible causes for the symptoms, but by far the most effective tool to use when CFS is suspected is an activity scale or daily diary that measures a child's overall normal activity levels.

A child with CFS will have substantially reduced activity levels, but may appear to others to have a normal activity level. For example, a child with CFS may be able to participate in sporting activities on the weekend (i.e., playing in a soccer game), giving the appearance that he or she is healthy. On closer examination, however, the child with CFS who participated in the soccer game would have to rest for the remainder of the day and usually the next day.

School attendance is the most important indicator of both severity and prognosis of pediatric CFS. If the CFS symptoms are mild, the child can make it through a full day of school, perhaps even with gym class, but will have increased fatigue and may need to rest often. Moderate CFS permits part-time school without gym or sports, and requires the child to get extra rest every evening. With severe forms of CFS, school attendance may not be possible, and home tutoring should be used to maintain an appropriate grade level.

Comparing the child's activity levels on weekends and during the summer to activity during the school week is also important. Children often report that they feel better in the summer, which is often considered an indication of school phobia. However, it may actually be because fewer sustained activities are required.

Measuring activity levels helps to rule out school phobia or depression. Depressed children do not feel overly tired and weak. A child with CFS will be just as inactive on the weekend as during the school week or may actually exhibit even less activity during unrestricted times.

Treatment

In longitudinal studies, 8% to 47% of children with CFS become well; 27% to 46% improve; 12% to 29% remain unchanged, and 6% to 17% become worse on follow-up evaluation (Bell, 1995).

In pediatric CFS, it is important to develop long-term treatment plans that address all issues, including maximizing the child's activity levels, alleviating anxiety, and maintaining grade-level school work. Children with CFS who cannot attend school or have reduced participation in school activities are missing important developmental opportunities and should be encouraged to combine social contact with exercise or play whenever they are physically able. For CFS patients who cannot remain upright for more than 4 hours in a 24-hour period, it is important that they learn coping skills for school and social activities.

The pediatric patient's fears should also be addressed. Children with CFS may believe that they have AIDS or cancer, or that they are dying. They may also fear that any increased activity level will worsen their condition, causing them to avoid social and other activities important to their development. Putting these fears to rest can help children cope with their illness better.

Although pharmacologic therapy may help with the symptoms of the illness, there is no evidence that it shortens its overall course. Healthcare practitioners should be aware that children with CFS often have unusual responses to medications, so low dosages should be tried first and gradually increased as appropriate.

If the child experiences difficulty initiating or maintaining sleep, small doses of antihistamines may help. More severe cases might require low doses of tricyclic antidepressants (Lapp, 1997). For headache pain, a mild analgesic, such as acetaminophen or ibuprofen, can also be effective.

There is increasing evidence that orthostatic intolerance (OI) plays a role in adult CFS, and this area is being studied in children. Research indicates that OI may be more common in children with CFS than in adults with CFS. Symptoms of light-headedness and postural syncope in children can often be managed by increasing

MEASURING ACTIVITY LEVELS

The following questionnaire can help health care practitioners measure children's activity limitations more objectively. Have parents record how many hours are spent engaged in each of the following activities (total number of hours should equal 24). Note: hours sleeping do not have to be all at once, but over a 24-hour period.

Activity	Number of Hours
Sleeping	_____
Resting, but not sleeping	_____
Light activities while sitting or lying down (watching TV, reading, etc.)	_____
Moderate activities around house (tutoring, studying, meals, etc.)	_____
Moderate activities outside of house (school, walking, shopping, etc.)	_____
Vigorous activity (exercise, sports, etc.)	_____
Total:	_____

A typical day for a healthy child is roughly 12 hours of activity and 12 hours of inactivity. For pediatric CFS patients, you usually see fewer than eight hours of activity, and none of it is vigorous. A severe case of pediatric CFS usually involves fewer than four hours of activity.

daily water and salt intake. In adolescents, mineral corticosteroids and beta-blockers can be effective (Stein, 1998).

Fatigue, which can be associated with reduced serotonin states, may be helped with selective serotonin re-uptake inhibitors (SSRIs) such as fluoxetine (Prozac) and sertraline (Zoloft).

Case Management

Pediatric CFS is often mistaken for school phobia, anxiety disorder or depression. Failure to make a proper diagnosis can lead to isolation, insecurity and family stress for the child. Examining the child's school attendance and activity levels, as well as establishing a symptom pattern through the office visits, can help diagnose CFS.

Validating the illness, providing symptomatic relief, and encouraging graded increases in activity are the most prudent paths to managing the illness (Lapp, 1997). Because many of the symptoms of CFS are present early in other disease states, periodic diagnostic reevaluation is essential.

As in other chronic illnesses, the physician is often called upon to act as patient advocate, managing both medical and psychosocial issues, and providing information and education to the patient, family and school personnel. Physician support during all phases of pediatric CFS will allow greater compliance with treatment suggestions. 🐾

REFERENCES

- Bell, D. Chronic fatigue syndrome in children and adolescents: a review. *Focus & Opinion: Pediatrics*, 1:412-420, 1995.
- Lapp, C. Management of chronic fatigue in children: a practicing clinician's approach. *Journal of CFS*, 3:59-76, 1997.
- Lloyd, A. et al. Prevalence of chronic fatigue syndrome in an Australian population. *Medical Journal of Australia*, 153:522-528, 1990.
- Stein, M. Twelve-year-old-girl with chronic fatigue; school absence, and fluctuating symptoms. *Journal of Developmental and Behavioral Pediatrics*, 19:196-201, 1998.

ABOUT THE AUTHOR

David Bell, MD operates the Primary Care Pediatrics and Family Practice in Lyndonville, New York. A clinical researcher in Chronic Fatigue Syndrome since 1979, Dr. Bell has published six books and numerous papers on CFS. He is a graduate of Harvard University and Boston University Medical School, and currently serves as Vice President of the American Association for Chronic Fatigue Syndrome, the Vice President of Medina Memorial Hospital Medical Staff in Medina, NY, Chairperson for the Department of Pediatrics, the Medina Memorial Hospital Advisor to the Chronic Fatigue Syndrome Coordinating Committee, National Institutes of Health.

Reprinted with permission. The CFIDS Association of America. *The CFS Research Review*, Fall 2000, Volume 1, Issue 4.