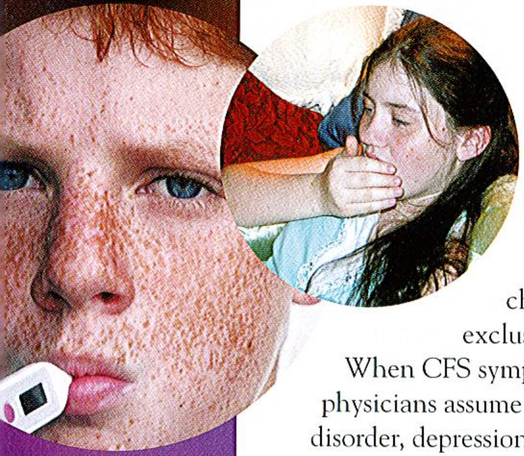
ASPECTS OF THE ILLNESS

Pediatric CFS

We still know remarkably little about CFS in children and teens. Research has been limited, and few clinicians specialize in pediatric CFS. Here, two of the most respected American experts share their perspectives.

By Pamela Young, Director of Publications, CFIDS Association of America



Although awareness of pediatric CFS has increased in recent years, too many researchers and health care professionals still believe chronic fatigue syndrome is almost exclusively a disease of adulthood. When CFS symptoms are seen in children, most physicians assume it's school avoidance, anxiety disorder, depression or an undiagnosed illness.

"Studies have established the validity of pediatric CFS and that it's neither a psychiatric problem nor a benign illness, as earlier suggested," says David Bell, MD, who treats children from across the United States and Canada. "Despite these findings, there is still tremendous misunderstanding in the medical community."

Peter Rowe, MD, a researcher at Johns Hopkins University, agrees that we know too little about CFS in children: "There have been only a handful of published pediatric research studies on CFS, largely due to the lack of adequate funding opportunities for researchers in the field."

> **"A strong support system from family, school officials, health care professionals and peers can help children with CFS cope better. It's not a cure-all, but it helps."**
>
> —DR. PETER ROWE, JOHNS HOPKINS CHILDREN'S CENTER

What's unique about pediatric CFS?

Although CFS affects children and adolescents in many of the same ways it affects adults, there are some significant differences. From a clinical standpoint, one major difference is in onset. In adults, gradual onset occurs in up to 75% of cases. In children with CFS, most of whom are adolescents, it's reversed, with around 75% experiencing acute onset. (Gradual onset, however, is more common in young children.)

There is variability of the illness in symptoms, which tend to migrate. For example, a child may experience sore throat and headache, followed the next day by lymph node pain. There is also considerable variability in symptom severity. In adults, there are often a few symptoms that are worse than others. In children, certain symptoms may be worse one day, only to be replaced by other severe symptoms a few days or weeks later. This dynamic can be further complicated by the fact that children may have more difficulty recognizing and verbalizing their symptoms.

Bell believes, "The most striking thing about pediatric CFS is the ability of children to adapt to their symptoms. Yet that fact makes it more difficult to detect and treat the problem." A teen may come home and sleep for three hours after school every day, but may not complain of tiredness because it has become the norm. Similarly, "young children who grow up with CFS have become accustomed to the symptoms and are able to function despite persistent and sometimes severe discomfort."

The psychosocial aspects of the illness are another important difference for pediatric patients. Says Rowe, "One of the biggest challenges to pediatric patients results from the fact that the illness affects them before they've truly had an opportunity to identify what their aptitudes and strengths are in life, and to have established strong emotional relationships with a significant other. The accountant who develops CFS as an adult knows she was a capable, functioning contributor to society, and that the illness doesn't define her as a person."

What do we know from research?

In spite of the paucity of research, studies have shed light on various aspects of pediatric CFS. The main studies show the following findings:

▶ CFS occurs in children and adolescents, though less frequently in children younger than age 10. The age at onset of Bell's pediatric CFS patients ranges from 11-18; for Rowe the age range is 10-21, with the average age at onset of 15. Both have seen younger CFS patients, but not frequently. This suggests age of onset may be connected to hormonal changes as children approach puberty, but this isn't confirmed.

▶ Pediatric CFS has quite a variable duration, from months to many years. Although many children get better, the illness can be more chronic than we first thought. For instance, a 13-year follow-up study of 35 pediatric cases by Bell indicated that as many as 20% don't recover, and of the 80% who reported a good functional outcome, only 37% considered themselves fully recovered.

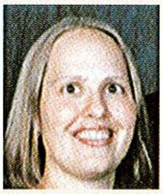
▶ Comorbid psychiatric disorders such as anxiety and depression are not uncommon, but they are generally mild when present and often secondary to the effect of being ill. Many kids with CFS have no anxiety or depression, in contrast to prior views of CFS as a form of generalized anxiety disorder or atypical depression.

▶ There is a strong association between adolescent CFS and related circulatory disorders that are characterized by intolerance of prolonged upright posture. Rowe reports that in 90% of untreated pediatric patients, this worsening of CFS symptoms with standing is associated with abnormalities in the regulation of heart rate and blood pressure. The most common of these problems is neurally mediated hypotension (NMH), but postural tachycardia syndrome (POTS) is also common. These disorders are treatable, which has opened up new avenues for the rehabilitation of patients with CFS.

▶ A physical examination of children with CFS may not be normal, as was once claimed. In addition to the orthostatic intolerance just mentioned, adolescents with CFS are more likely to have joint hypermobility, a physical trait that is present before they become ill. Children with CFS are also more likely to exhibit movement restrictions such as restricted prone knee bend, ankle dorsiflexion and straight leg raise during the physical exam.

▶ Preliminary evidence suggests that certain treatments such as cognitive behavioral therapy and graded exercise may help pediatric patients manage CFS.

Teen Advocacy Spurs Research



In the story of pediatric CFS, the kids themselves played a major role in spurring research. **Rebecca Moore**, just 17 at the time, was part of the team that led the charge for action in the mid-1990s.

"For a long time, it was easy for people to dismiss pediatric CFS as being school phobia, a behavioral problem or simply prolonged fatigue," Moore recounts. "They didn't know about the neurological, cardiovascular and immune-related problems youth with CFS experience."

In fact, she remembers, "There were many people in the CFS community who had never spoken to kids with CFS, and who therefore felt this was a rare problem. And if the CFS community wasn't attuned to pediatric CFS, you know that the rest of the world certainly was not." She recalls how it didn't occur to most CFS researchers to include pediatric cohorts in their studies and how the CDC didn't even analyze the pediatric CFS prevalence data from their earliest studies. That is, not until young people themselves stepped up and made the push to be counted.

Over several years, a network of young people—some bedridden with the illness—put a face and a voice to pediatric CFS and presented policy suggestions to help stimulate research. This eventually led to new pediatric-specific studies. It also led to a greater sense of community and support among the young people suffering with the illness.

"Most of the kids were isolated from peers, dependent on parents and unable to pursue independence the way a typical teen would do," explains Moore. "Then they found each other and stood up to say, 'We exist and so do our friends. We speak for ourselves and for those who are too ill to participate.' The icing on the cake was that kids with CFS got to help solve their own problems, instead of waiting for someone else to do so."

What's needed next?

The variability of the illness in children makes it difficult to diagnose and identify treatments that would be beneficial. In the short run, this points to the critical need for individualized care for children with CFS. In the long run, it emphasizes the need for a much larger research initiative.

Rowe and Bell agree on the vital need to focus more research on pediatric CFS, not only because of the debilitating nature of the disease itself, but because of the critical period of life it disrupts. As Rowe puts it, "Chronic illness and its limitations on activities constrain a young person's ability to determine identity, discover skills and form strong emotional relationships with others. There is an inability to engage in the normal activities of adolescence that help with the healthy transition to adult life." ■