



# Solve M.E.

## **Solve M.E. Patient and Caregiver Resource Guide: Children and Young Adults with ME/CFS**

Pediatric ME/CFS is most common in children between the ages of 10 and 18 years old, although it has been reported in children as young as five years old as well. Research indicates that adolescents are more likely to acquire the disease after an illness, especially the Epstein Barr Virus (EBV), mononucleosis (which is caused by EBV), or an intense case of the flu. Although basic symptoms of the disease are the same in children as adults, there are some differences in presentation.

Orthostatic intolerance (feeling weak or lightheaded when standing/sitting upright, also referred to as postural orthostatic tachycardia syndrome or POTS) is often one of the most problematic symptoms for pediatric patients. In addition to being more severe, OI seems to occur more often in children and adolescents than it does in adults.

Cognitive impairment, specifically slowed information processing and an inability to concentrate during school activities, can be particularly troubling for children and adolescents who are still in their formative years. Research suggests that this is one of the more prominent symptoms in pediatric ME/CFS.

Sleep problems may be harder to recognize due to changing sleep habits as children grow, especially during the teenage years. Parents/guardians might notice daytime sleepiness, intense dreaming, difficulty falling asleep, difficulty sleeping through the night, and an overall lack of energy.

Pain in the muscles and joints is less common in children than it is in adults with the disease. Stomachaches, headaches and flu-like issues (e.g. tender lymph nodes, sore throat) are the most commonly reported types of pain in children with the disease.

### **Management and Treatment of Pediatric ME/CFS**

In 2017, a key resource entitled “[Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Diagnosis and Management in Young People: A Primer](#)” was authored by the International Writing Group for Pediatric ME/CFS. According to the primer, “Successful management is based on determining the optimum balance of rest and activity to help prevent post-exertional symptom worsening. Medications are helpful to treat pain, insomnia, OI and other symptoms.”

As with adults, ME/CFS experts suggest that medical treatments and therapies be aimed at addressing the child's most problematic symptoms first. The primer also emphasizes that "careful avoidance of overexertion can help to both avoid deterioration and facilitate improvement." As such, parents/guardians should work with their children and the other adults in their lives to establish a schedule which lets the child remain as active as possible without triggering the PEM response. Activities should be prioritized and non-essential items should be delayed, delegated or eliminated. Ample rest time should be planned. Above all, the schedule should remain flexible in order to accommodate the child's varying needs.

### **Impact of Pediatric ME/CFS**

It is important for family members and caregivers to know enough about the disease to understand what is happening and help guide the child's activities in order to prevent worsening of symptoms. Although it may be challenging to participate in family outings or social events, activities that allow the child to participate without exacerbating symptoms are important to the overall well-being of the child. Healthy interaction with others benefits the child's development in many ways by strengthening learning skills, enhancing communication and interpersonal capabilities, and building self-esteem.

As with adults, the degree to which a child's life is impacted by the disease depends on a number of things, including disease severity. If the child is mildly affected, he or she might benefit from a slightly modified school schedule and a reduction in social activity as long as parents and guardians recognize the need to avoid triggering PEM and worsening symptoms. If the child is moderately ill, the school and parent/guardian will need to work together to establish a substantially modified plan of education which might include private tutoring, remote learning, or some type of home-schooling. Children who fall into the moderate-to-severe range are generally unable to attend school at all and need help with even the most basic personal care.

### **Emotional and Psychological Reactions**

Adults often experience anger, frustration, grief, anxiety, and depression when faced with chronic illness. For children with ME/CFS, these emotions are just as real. However, children generally lack the coping skills and intellectual abilities that adults can draw upon to get through their most difficult times. Additionally, they may be more adversely impacted by negative responses from friends and family. It is therefore important that the adults in their lives acknowledge their struggles and offer comfort, support and guidance regarding the many challenges associated with the disease.

Adults should also be aware that psychological illness may develop in children who are living with the debilitating consequences of ME/CFS. When this occurs, the psychological illness is considered “secondary” to ME/CFS. The most common secondary illnesses in children with ME/CFS are anxiety and depression, although symptoms may look more like behavioral problems than the traditional symptoms associated with these illnesses. The pediatric primer is a valuable resource regarding common emotional responses in children and the behaviors that might be associated with psychological illness.

If you suspect that your child is struggling with mental health issues as well as the emotional and physical challenges of the disease, be sure to see a mental health professional. As indicated in the pediatric primer, “It is important to distinguish: (a) normal emotional reactions to ME/CFS from (b) clinically significant psychiatric symptoms such as depression or anxiety secondary to ME/CFS and from (c) a primary psychiatric illness such as Major Depressive Disorder (MDD) or an anxiety disorder without co-existing ME/CFS.”

### **Educational Accommodations**

Research suggests that the waxing and waning nature of ME/CFS (whether diagnosed or not) may be a major cause of school absence in children. There is also evidence to suggest that children with ME/CFS have been frequently mislabeled with school phobia or other issues. However, ME/CFS experts have made it clear that the behavior of children with the disease compared to children who are avoiding school is usually quite different. Specifically, children with ME/CFS do not suddenly “feel all better” on weekends, holidays and vacations, a phenomenon that is often observed in children who are avoiding school. Additionally, moderate to severe patients will be unable to enjoy the extracurricular or social activities that were once such an important part of their lives.

ME/CFS can impact the school experience in ways far beyond attendance. Problems with memory, concentration, and information processing all affect a student’s ability to participate, complete assignments, take tests, and more. As such, parents/guardians of children with ME/CFS will need to work with the school to get appropriate accommodations put in place. According to the pediatric primer, this might include “testing accommodations, homework modifications, limiting physical activity, splitting time between school and home tutoring, and permission to have fluids and salty snacks available, if needed.”

The Individuals with Disabilities Education Act requires that schools work with parents/guardians (and older students) to create an individualized education program (IEP) that meets the individual needs of the particular student when deemed necessary. A child with ME/CFS will likely qualify for an IEP if it can be shown that the disease affects their strength, energy or alertness and/or impedes their ability to learn and/or communicate. For those who don't meet the standard for the IEP, the alternative 504 Plan (named after Section 504 of the Rehabilitation Act of 1973) might be an option. The Center for Parent Information & Resources, which exists to help parents participate in their child's education, has more information on the resources that may be available: <https://www.parentcenterhub.org/me-cfs/>. Additionally, although not specific to IEP or 504 plans, the Centers for Disease Control offers a "Fact Sheet for Education Professionals" which can be printed and used as a starting point for discussion with school personnel: <https://www.cdc.gov/me-cfs/me-cfs-children/factsheet-educational-professional.html>.

### **Further Reading:**

#### **GENERAL INFORMATION/MEDICAL CARE**

- [CDC's ME/CFS in Children](#)
- [CDC's ME/CFS in Children: Fact Sheet for Parents/Guardians](#)
- [CDC's Pediatric ME/CFS: Fact Sheet for Healthcare Professionals](#)
- [Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Diagnosis and Management in Young People: A Primer](#)

#### **SCHOOL ACCOMMODATIONS**

- [CDC's ME/CFS in Children: Fact Sheet for Education Professionals](#)
- [Center for Parent Information & Resources' ME/CFS page](#)
- [Environmental accommodations for university students affected by Myalgic Encephalomyelitis/Chronic Fatigue Syndrome \(ME/CFS\)](#)