

Title: Education Children with Pediatric CFS/ME

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Recently an increasing awareness of the impact of pediatric CFS/ME on education has emerged, leading to two important realizations. First, the conversion of what clinicians know about the symptoms and treatments for CFS/ME into workable strategies for teachers to help children suffering from this disease is only in its earliest stages. Most educators across the globe have little if any understanding of the disease, and know less about how helping affected children in their classrooms. The second key realization is that the clinicians treating these children have a critically important role to play in remedying that problem. Success in school is a recognized clinical component affecting the long-term prognosis of children with CFS/ME. Not only do clinicians need to become more involved in educational issues in Pediatric CFS, but they also need to make student success a priority in ongoing treatment plans.

Most children and their families spend more time and endure more stress dealing with education than in visiting the doctor's office. "Try this new medication for the next six to ten weeks and we'll see if it's more effective, or if there are problematic side effects" often translates into another quarter of a school year passing by, with the student falling further and further behind his or her peers. When the weight of trying to help their son or daughter get an education that might allow him or her to become independent as an adult is added to the pressure of raising a chronically ill child, the results are often crushing. This is especially true when families deal with a school system that is completely unprepared to educate a student suffering from such a debilitating condition. This is why the clinician's input is critical to the child's success, because in almost every country the school system needs medical professionals to help them figure out what to do for these children. That is why it is necessary for clinicians to become aware of at least the basic educational research with regard to successfully educating children suffering from CFS/ME.

Current education research suggests that children suffering from CFS/ME can be successful when schools focus on strategies dealing with their lack of stamina and cognitive deficits. To deal with high absentee rates and the inability to complete a full school day, children with CFS/ME can be given abbreviated schedules, a reduced course load, and—often most critically—tutoring support at home. Most students suffering from CFS/ME have the capability to work at least an hour or two each day, and if homebound tutoring is scheduled in that "sweet spot," students will continue to advance in their studies even when too sick to attend school.

Within the classroom, distractibility, and slower processing speeds often impair the ability of students suffering from CFS to keep pace with their peers. Teachers can reduce the number of assignments, modify the remaining assignments/tests, and provide supports like graphic organizers to keep the student on-task. In education parlance, this is known as "mastery over completion," a strategy which focuses on learning required knowledge and skills rather simply counting assignments completed. A wider body of specialized accommodations and modifications for these students are now finally emerging (see resource list below), and

educational literature is in the early stages of communicating them to teachers around the world.

At this moment, however, such dissemination is sporadic and has yet to reach a great many schools. This is an important understanding for clinicians, who are usually requested by the schools to file a “physician’s letter” documenting their patient’s diagnosis, symptoms, treatment, and prognosis. The letter can be an important vehicle in advocating for such necessary services and alerting school officials to the availability of information on successful classroom strategies. Physicians should consider direct recommendations for abbreviated schedules, attendance requirements waived, homebound instruction, additional completion time for tests/assignments, and other strategies because such specific language carries great weight with educators. Likewise, the greater the detail in which the letter describes the student’s individual symptoms, the more effective parents and teachers can be in managing the child’s education.

Managing the education of any child with a chronic illness is always best handled via a team approach. The clinician is rarely in the room when parents and teachers sit down to go over the details of schedules, assignments, and/or transportation, but the clinician’s information and recommendations set the stage for an effective process and a positive outcome. Even after an initially successful agreement is reached on instructional strategies, the clinician should take the time at each subsequent visit to inquire about school, and to determine if additional information and/or recommendations about education should be provided. Qualitative data (reports from physicians who have become more attuned to, and involved in, supporting education) is scattered but consistent: clinicians who take an active role in making educational recommendations for their pediatric CFS/ME patients generally report that these children and their families experience less stress and have a much more positive attitude toward learning to cope with this chronic disease.

The items below represent resources which clinicians can consult for a more comprehensive but still concise listing of potential recommendations to support the education of children suffering from CFS/ME. They are also excellent resources to recommend to teachers and school officials dealing with such a student for the first time.

Resources

1. Faith Newton (2015): Improving academic success for students with myalgic encephalomyelitis/chronic fatigue syndrome, *Fatigue: Biomedicine, Health & Behavior*, DOI: [10.1080/21641846.2015.1004831](https://doi.org/10.1080/21641846.2015.1004831)
2. Chronic Fatigue Syndrome page on the National Association of Special Education Teachers website <http://www.naset.org/otherimpairments2.0.html>
3. Chronic Fatigue Syndrome in Children and Adolescents <https://www.cdc.gov/cfs/pediatric/index.html>
4. Institute of Medicine. Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness <http://www.nationalacademies.org/hmd/Reports/2015/ME-CFS.aspx>