# Recognizing and assisting students with CFS

Most students with ME/CFS fall behind in their schoolwork due to cognitive problems and fatigue.

*by Dr. Kenneth Friedman and Rosemary Underhill*

Many times, it is the classroom teacher who first realizes that a student's behavioral changes indicate a serious problem. Teachers often spend more time with their students than the students spend with their parents. The classroom teacher may be the best person to determine if the problem is physical or psychological in nature. One illness, Chronic Fatigue Syndrome (CFS), may appear to be a behavioral problem in the classroom, but in actuality, is a serious medical condition. CFS, if left unrecognized and untreated, may result in lifelong disability. Would you be able to recognize a student with CFS in your classroom?

## What is CFS?

CFS is an illness. It is *not* the same thing as "chronic fatigue." Chronic fatigue may be due to overexertion, stress, or the presence of some other illness that has the symptom of fatigue. CFS is a debilitating and complex illness in which the incapacitating fatigue (loss of energy and stamina) is accompanied by a variety of symptoms in multiple body systems. The fatigue and other symptoms of CFS are not reduced by rest or sleep and are typically made worse by physical and mental activity. The person's ability to function is substantially less than before the illness. The Centers for Disease Control and Prevention (CDC), recognizes CFS as a physical illness and not a psychological or psychiatric disorder. CFS can be clearly differentiated from depression by medical testing.

CFS is the name used in the United States for this illness. In Europe and elsewhere, the name Myalgic Encephalomyelitis (ME) is used. To be inclusive, the acronym ME/CFS is gaining popularity worldwide. The illness is also known as Chronic Fatigue Immune Dysfunction Syndrome (CFIDS) and was previously known as Chronic Epstein Barr Virus Syndrome (CEBV).

## Who gets ME/CFS?

The number of persons suffering from ME/CFS in the U.S. is not known with certainty. Recent studies suggest that somewhere between one and four million Americans have ME/CFS. It is also estimated that only 15 percent have been diagnosed. In adults, teachers and nurses have a higher prevalence of ME/CFS than people who are not exposed to infections. Adolescents 12 to 17 years old are much more likely than younger children to develop ME/CFS, but children as young as four years of age have developed the illness. In adults, four times as many women as men have ME/CFS. In children, equal numbers of boys and girls contract the illness up until puberty.

## What causes ME/CFS?

The cause of ME/CFS is unknown. Several factors may be involved. ME/CFS usually occurs as sporadic (isolated) cases. In 20 percent of patients, more than one family member is affected. This latter finding suggests a genetic or an environmental link. There is evidence to suggest that CFS is caused by a viral infection. Frequently the illness follows an acute infection. Clusters of cases or outbreaks of the illness have been found worldwide. In many of these outbreaks, the illness has been prominent in schools. In spite of much research, no known infectious agent has been shown to be the cause of ME/CFS. Occasionally, ME/CFS is triggered by a toxin, an immunization, or major trauma. ME/CFS is *not* a psychological illness. Depression and anxiety may occur secondarily to ME/CFS. It is possible to distinguish major depression from ME/CFS by thorough testing.

## How is ME/CFS diagnosed?

Diagnosing ME/CFS is difficult because there is no clinical test for it. The diagnosis of ME/CFS in adults depends upon the patient meeting the criteria of the generally accepted "International Case Definition" (ICD). Not all adults with ME/CFS meet the criteria of the ICD and even fewer children and adolescents can be diagnosed using these criteria.

To better identify children and adolescents with ME/CFS, a new pediatric case definition has been developed. It was developed by an international working group of the International Association for Chronic Fatigue Syndrome (IACFS/ME).

The full definition appears in print in the *Journal of Chronic Fatigue Syndrome* and is available on the IACFS/ME website (*www.iacfs.net*).

## Symptoms of Pediatric CFS

For a child or adolescent to be diagnosed with Chronic Fatigue Syndrome (ME/CFS) using the new pediatric case definition, the following symptoms need to be present:

- Pathological fatigue and at least seven other symptoms (see chart on next page).
- The fatigue and the symptoms persist or remain for at least three months.
- They result in a substantial reduction in previous activities.
- The symptoms cannot be explained by another illness. Other fatiguing illnesses must be excluded by the history of the illness, by physical examination or by medical tests.

Patients with ME/CFS also suffer from a variety of other symptoms, which are not in the case definition. Mood changes, reactive depression or anxiety may result from the illness, but do not cause it.

In summary, the case definition allows the diagnosis of ME/CFS primarily on the basis of pathological fatigue, the pattern of other symptoms, and the exclusion of other fatiguing illnesses by medical history, physical examination, and appropriate tests.

## What happens to children and adolescents who develop ME/CFS?

In adolescents, ME/CFS usually starts suddenly with a fever and flu-like symptoms. A gradual onset is less frequent, but is more common in younger children. In young children, the onset may take several months or even years. Diagnosing ME/CFS in younger children is further complicated by their inability to appreciate that their fatigue and other symptoms are abnormal. In such cases, the diagnosis of ME/CFS may be made retrospectively when the child is older. Children and adolescents with ME/CFS are occasionally extremely pale. More often, however, they look completely well. The lack of obvious signs of illness may mean that the first sign of ME/CFS will be a marked limitation in either physical or mental activity. These limitations are usually first noticed by a parent or teacher. The outwardly normal appearance of a ME/CFS child may lead to the accusation of School Avoidance Behavior (school phobia) or the citing of a parent for Munchausen's syndrome by proxy.

The severity of ME/CFS varies. Some children are severely disabled and bedridden. Others can go to school. A few are capable of playing sports. Most children fall between the two ends of this spectrum. As a rule, ME/CFS is more disabling than other chronic illnesses. The pattern and severity of the symptoms experienced by a child may change markedly from day to day or during the day. It is important to listen to what the child has to say about the severity of his/her symptoms. Remissions and relapses are common. Relapses may be caused by over-exertion or by other infectious illnesses. Over time, slow improvement is likely, especially in the first four years. Recovery rates are uncertain but rates of up to 40 percent have been reported. Children whose health improves to near pre-illness levels are likely to find that they need more rest than their peers.

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A student who becomes chronically ill may develop the additional problem of emotional conflict. The emotional conflict by itself can impinge upon a student's education. A teacher can better assist a chronically ill student once he/she realizes that the student is exhibiting one of the four behaviors associated with the emotional conflict:

1. **Denial**—I am not sick. I want to be like everyone else. (The student overdoes on good days, followed by severe relapses.)
2. **Isolation**—I cannot keep up with my peers. My peers ridicule me because some days I can keep up and other days I can do nothing.
3. **Depression/Anxiety**—I will never get well. I will never do what I want to do. I will never be who I want to be.
4. **Resiliency**—I am who/what I am. I will do what I can. My illness has taught me special things. I will be a different person than I imagined.

Psychotherapy can be helpful in working through the phases of this emotional conflict both for the patient and the family. For psychotherapy to be successful, the therapist needs to understand and be experienced with treating patients with illnesses like ME/CFS.

## What are educators' responsibilities to students with ME/CFS?

New Jersey State law requires that every child receive a thorough and efficient education regardless of the severity of symptoms of his/her chronic illness. Most students with ME/CFS fall behind in their schoolwork due to cognitive problems and fatigue. Many are too ill to attend school. Students with ME/CFS may qualify for special services under the Individuals with Disabilities Education Act (IDEA) and/or Section 504 of the Rehabilitation Act, 1973. Eligible students receive an Individual Educational Plan (IEP), which requires the school to provide reasonable accommodations and/or home tutoring. The child's pediatrician should be able to give a written explanation about the child's health, advise the school concerning the severity of the illness, and support a recommendation for an evaluation by the school for an IEP or home instruction.

## What accommodations can your school offer?

Accommodations that schools and school systems can offer a student with ME/CFS that will permit him/her to continue with school include:

- Relax the attendance and tardiness policies; permit the student to attend school either part-time or for half days; allow for rest breaks in the student's class schedule; permit the student to be dismissed early from classes; permit the student to take a modified physical education program or exempt the student entirely from physical education classes; exempt the student from loud assemblies that may exacerbate his/her symptoms; issue the student an elevator pass so that the student's limited energy is not expended climbing up and down stairs; issue an extra set of books for home use so that the student does not expend his/her limited energy carrying heavy books to and from school; provide copies of missed work; provide tutors for home-schooled students.
- For medical treatment: Permit medications to be kept in the school nurse's office; allow the student to assume a comfortable position during class as needed.

*(continued)*

- For neurocognitive problems: Refer the student for a consult concerning assistive technology; allow the student to use a calculator or spell checker; permit the student to use study guides; repeat or have repeated the instructions for an assignment; shorten the length of assignments; divide long tests into shorter sections that can be taken at different times; provide extra time for exams and assignments; be flexible with deadlines and scheduling.
- For visual problems: Provide an alternative to fluorescent lighting if fluorescent lighting is problematic to the student (natural lighting and incandescent lighting are less problematic for students with CFS); permit the student to wear dark glasses if photophobia is present; permit the use of books on tape and/or screen magnifiers if the student is having difficulty reading.
- For gastrointestinal difficulties: Permit the student to bring snacks to school as needed; permit the student to use the bathroom as needed without asking permission; provide advice from the school dietician if assistance with diet is needed.
- For immune dysfunction: Inform the parent when viral illnesses are in school; develop a plan for an extended absence from school in case need for such a plan develops.
- For difficulties getting to and from school: Arrange for the student's transportation to and from school so that the student does not spend his/her limited energy walking to and from school.
- For difficulties satisfying graduation requirements: Relax the elective requirements for graduation so that the student may graduate from school having satisfied alternative elective standards; relax the timeframe for graduation to permit the student to complete the necessary requirements for graduation.

## What resources exist?

Although ME/CFS is seldom taught in medical schools and many pediatricians are skeptical about ME/CFS, the Centers for Disease Control and Prevention now offers continuing medical education courses for physicians interested in learning about ME/CFS. A physician and/or other healthcare professional knowledgeable about ME/CFS should be part of any team determining the appropriate accommodations for a ME/CFS student.

The New Jersey Chronic Fatigue Syndrome Association, Inc. (NJCFSA) is a non-profit organization whose purpose is to support patients with ME/CFS and their families. NJCFSA disseminates reliable information about ME/CFS to the public and medical community. The organization sponsors both patient and healthcare professional conferences. It sponsors support groups, publishes a newsletter, and maintains a physician referral list. NJCFSA also includes a Youth Education Committee that advocates for children and adolescents with CFS and offers a High School Scholarship for graduating seniors. Further information about ME/CFS is available on the NJCFSA website, *www.njcfsa.org*, and from the helpline, 888-835 3677.

## Learn more at the NJEA Convention

Dr. Donnica Moore, MD. will speak about ME/CFS and her personal experience as the mother of a son with ME/CFS in her presentation at the NJEA Convention. She will present “CFS in Students: Are you missing the diagnosis?” on Thursday, Nov. 8, 9:30-11:30 a.m., in Room 405 of the Atlantic City Convention Center. Dr. Moore is a trustee of the NJCFSA.

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*Both Friedman and Underhill are trustees of the NJCFSA and contributed to New Jersey's* A Consensus Manual for the Primary Care and Management of CFS.

| Symptoms | Details of symptoms |
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| Pathological fatigue | The fatigue is not the result of ongoing exertion. It is not relieved by rest. |
| Post-exertional malaise | Mild or moderate exertion is followed by malaise, fatigue, or worsening of other symptoms, with loss of mental and/or physical stamina, and delayed recovery of more than 24 hours. |
| Sleep problems | Sleep is un-refreshing, with a disturbance of quantity or rhythm, including daytime excessive sleep, nighttime insomnia and/or, day/night reversal. |
| Pain (at least one symptom) | Pain can be widespread, migratory or localized. It may be located in the muscles, the joints (without signs of inflammation), the chest, the abdomen, the eyes (with or without a sensitivity to light), a new type of headache, or an increase in headache severity, or nausea or vomiting. |
| Two or more neuro-cognitive manifestations | These include impaired short term memory, difficulty in concentration or focusing, difficulty finding words or numbers, absent-mindedness, slowness of thought, difficulty understanding information and expressing thoughts, educational difficulties. |
| At least one symptom from from two out of these three subcategoties | 1. Autonomic manifestations: including postural hypotension, postural orthostatic tachycardia (POTS), neurally mediated hypotension (NMH), palpitations, dizziness, shortness of breath, disturbed balance.<br>2. Neuro-endocrine manifestations: including feelings of feverishness, cold extremities, low body temperature, sweating, intolerance to heat or cold, change of appetite or weight. Symptoms worsen with stress.<br>3. Immune manifestations: including recurrent flu-like symptoms, sore throats, fevers and sweats, tender lymph nodes, new sensitivities to food, medicines, odors, or chemicals. |