



# School Nurses Can Improve the Lives of Students With Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome

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*Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a chronic illness that is defined and diagnosed by its symptoms: extreme fatigue made worse by physical and mental activity, pain and decreased mental stamina, among others. A long-held, erroneous belief that ME/CFS is not a physiological illness has persisted among some clinicians, leading to the denial of a patient's physical illness and attributing the symptoms to other causes. The debilitating effects of ME/CFS in the pediatric population*

*can affect all aspects of academic, social, emotional, and physical development. ME/CFS has been diagnosed in children younger than 10 years. Therefore, the school nurse is likely to encounter one or more students in the various stages of this disease, putting the school nurse in a position to ameliorate the impact of this potentially devastating chronic condition.*

**Keywords:** myalgic encephalomyelitis; chronic fatigue syndrome;

ME/CFS; chronic illness; other health impairment

## **Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome in School-Age Children**

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), the newer name for chronic fatigue syndrome, may be the most frequent cause of long-term student absence from school (Crawley, Emond, & Steme, 2011). It is a complex,

disabling condition affecting multiple systems and is characterized by extreme fatigue made worse by physical and mental exertion (see Table 2 for a list of symptoms). By definition, it lasts minimally 4 to 6 months, and, if not managed properly, becomes a chronic illness with lifetime disabilities which makes accomplishing the tasks of daily living difficult or impossible. Although a rigorous epidemiological study reporting the frequency of this disease among school-age children and adolescents does not exist, one study found that the incidence of chronic fatigue syndrome for young people between the ages of 13 and 17 years to be 181 per 100,000 (Jordan et al., 2006). Current estimates report there are 38,363 young people with ME/CFS between the ages of 13 and 17 years (Dimmock, Mirin, & Jason, 2016). ME/CFS has been diagnosed in children younger than 10 years (Jordan et al., 2006). School nurses are, therefore, likely to encounter one or more students in the various stages of this disease (Rowe et al., 2017).

### **Cause of ME/CFS and the Controversy**

Although an outbreak of ME/CFS or an ME/CFS-like illness was investigated and reported by the U.S. government Public Health Service in the 1930s (Gilliam, 1938), progress in identifying the cause of the disease, developing specific treatments that reduce the severity of, or shorten the course of the disease, and developing curative or preventative measures has been disappointing. The Institute of Medicine (2015) report on ME/CFS focused new attention on this disease. The report has increased interest in discovering the cause of ME/CFS, encouraged the development of new treatment strategies, and encouraged clinicians to provide appropriate medical care for patients of all ages.

With regard to causes, initial and some subsequent investigations of ME/CFS describe “cluster outbreaks” suggestive of an infectious etiology (Underhill, 2015). However, the failure to identify an infectious agent, find any standard, disease-specific, clinical laboratory

abnormality in these patients, along with the occurrence of many, apparently, “isolated,” cases, have led a component of the healthcare community to be doubtful of a physiological cause of the disease. Often these studies conclude that the illness is psychological or psychosomatic in nature (Penfold, St. Denis, & Mazha, 2016). For years, studies have been published demonstrating the psychological or psychosomatic causation of ME/CFS (Penfold et al.). More recently, the data analyses used in these studies have been questioned calling for the withdrawal of these papers (Rehmeyer & Tuller, 2017; Wilshire et al., 2018). Further challenging the psychological or psychosomatic causation of ME/CFS are recent studies using more sophisticated laboratory research techniques demonstrating unique abnormalities associated with ME/CFS at the gene and gene-expression levels (de Vega, Herrera, Vernon, & McGowan, 2017; Tomas & Newton, 2018).

Despite these more recent research findings, the long-tenured, false belief that ME/CFS is an illness without an identifiable physiological abnormality persists, leading to the stigmatization of this illness as a psychological illness and causing delay in a correct diagnosis (Institute of Medicine, 2015). The school nurse, knowledgeable about the stigma, the clinical research, and the life-saving advantages of instituting early and appropriate care for young people with ME/CFS, may need to educate others who are unfamiliar with the disease or who are reluctant to accept ME/CFS as a valid, physiological illness within his or her workplace. When stigmas persist, providing for the medical needs and welfare of a sick student is challenging.

### **Distinguishing ME/CFS From Other Conditions**

Adding to the difficulty of providing appropriate care for a young person with ME/CFS is the confusion that exists between ME/CFS and two other, serious, medical conditions: major depressive disorder (MDD) (Jason, 2015), and Munchausen’s syndrome by proxy

(MSBP) (Van Hoof, De Becker & De Meirleir, 2011). MSBP is now referred to as factitious disorder imposed by another (FDIA) (Selekman, 2013). Any child who develops a serious, long-term illness, and is, therefore, withdrawn from school and previous social contacts, is placed in a situation in which a depressive mood disorder is more likely to occur (Boulard, Quertemont, Gauthier, & Born, 2012). Depression does not cause the symptoms of ME/CFS (Rowe et al., 2017). A formerly active child, who suddenly becomes severely ill and is bedridden or housebound for several months, may exhibit some symptoms of depression, but these symptoms do not constitute MDD. Briefly, to distinguish ME/CFS from MDD, one needs to observe the child. If the child has the desire, but lacks the energy or physical ability to perform, the child may have ME/CFS. If the child has the physical ability but lacks the desire to perform or participate, then the child may have MDD. On the other hand, FDIA is a condition in which the parent or guardian of the young person claims the child is ill, or makes the individual in his or her care ill, in order to bring attention to that caregiver. Because a young, ME/CFS patient may be too ill to articulate or advocate for him or herself, a parent or guardian speaking on behalf of or instead of a sick child may appear to the healthcare provider as a parent or guardian exhibiting FDIA (Rowe et al., 2017).

### **Role of the School Nurse**

The role of the school nurse in assisting a student with ME/CFS falls into three main categories: (1) being informed about the disease, (2) recognizing the signs and symptoms of the disease in the student, and educating school staff and families about the disease and its impact, and (3) advocating for accommodations and modifications in the school setting, and assisting the student in managing what is most likely to be a modified educational program on his or her return to school (Centers for Disease Control and Prevention [CDC], 2017b).

**Table 1. Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Resources**

Professional and government publications	
ME/CFS Diagnosis and Management in Young People: A Primer	<a href="https://www.frontiersin.org/articles/10.3389/fped.2017.00121/full">https://www.frontiersin.org/articles/10.3389/fped.2017.00121/full</a>
CDC ME/CFS for Healthcare Providers	<a href="https://www.cdc.gov/me-cfs/healthcare-providers/index.html">https://www.cdc.gov/me-cfs/healthcare-providers/index.html</a>
CDC ME/CFS in Children	<a href="https://www.cdc.gov/me-cfs/me-cfs-children/index.html">https://www.cdc.gov/me-cfs/me-cfs-children/index.html</a>
New York Department of Health ME/CFS	<a href="https://health.ny.gov/diseases/conditions/me-cfs/">https://health.ny.gov/diseases/conditions/me-cfs/</a>
Parent Information Center	<a href="http://www.parentcenterhub.org/me-cfs/">http://www.parentcenterhub.org/me-cfs/</a>
Solve the ME/CFS Initiative	<a href="https://solvecfs.org/">https://solvecfs.org/</a>
State organizations	
Massachusetts	<a href="https://www.masscfids.org">https://www.masscfids.org</a>
Michigan	<a href="https://pandoraorg.net/">https://pandoraorg.net/</a>
New Jersey	<a href="http://www.njcfsa.org/">http://www.njcfsa.org/</a>
Vermont	<a href="http://ImmuneDysfunction.org">ImmuneDysfunction.org</a>
Wisconsin	<a href="https://www.wicfs-me.org/">https://www.wicfs-me.org/</a>

**Being Informed**

Several resources exist to increase school nurse knowledge regarding ME/CFS. A definitive work on the subject of young people with ME/CFS, targeted to healthcare providers, has recently been published (Rowe et al., 2017). The document, titled “ME/CFS Diagnosis and Management in Young People: A Primer,” is approximately 50 pages in length and contains a fact sheet for schools that provides a brief overview of what school personnel should know about students with ME/CFS. To be clear, there is no test to diagnose ME/CFS. Next, the CDC (2017a) has made available an online ME/CFS resource page for healthcare providers. A third suggested resource is the New York Department of Health (2018) ME/CFS information page. It describes ME/CFS, its symptoms, who gets it, how it is diagnosed, and how it is treated. A recent documentary, “Unrest” has gained attention for demonstrating the struggle of a young woman as she discovers and adjusts to the limitations imposed by the onset of ME/CFS (Brea, 2017). The film depicts a patient with moderately severe disease. See Table 1 for the list of resources.

**Recognizing and Reporting ME/CFS**

Early recognition that a child may have ME/CFS is of decided benefit to the child: The earlier appropriate treatment for ME/CFS is instituted, the more likely that child will be to recover from the illness (Rowe et al., 2017). Delayed recognition of ME/CFS or delayed symptom management reduces the probability of a favorable prognosis and increases the probability of chronic, lifelong disabilities. A student may be referred to the school nurse when the student exhibits a pattern of inattentiveness, being unwell, or feeling tired during the school day. Such signs may signal the onset of an illness which, if not treated appropriately, may precede ME/CFS. If a student returns to school after an illness and continues with symptoms that are ignored, a relapse of the illness is likely. That relapse may trigger the onset of ME/CFS. A prolonged absence from school for what was believed to be a routine illness should raise suspicion that the child may be developing ME/CFS. The school nurse may suspect a student of having ME/CFS if the student exhibits signs suggestive of the disease. A list of symptoms of ME/CFS is shown in Table 2. A student with

these symptoms should be encouraged to complete the questionnaire (Bell, 2013) found in Table 3. The school nurse may need to assist the student in completing the questionnaire which is designed to assess the likelihood of a student having ME/CFS.

If the answers to the questions suggest that the student may have ME/CFS, a referral to a health care provider is recommended. Prior to referring a student for evaluation for ME/CFS, the school nurse should consider identifying healthcare providers open to, and capable of, diagnosing and managing ME/CFS in young people (see Table 1 for a list of resources). Because ME/CFS is a stigmatized illness, underrepresented in health profession textbooks and health professions school curricula (Jason, Paavola, Porter, & Morello, 2010; Peterson, Peterson, Emerson, Evans, & Jason, 2013), not all healthcare professionals will be knowledgeable about, or supportive of, a ME/CFS diagnosis. Often adult and pediatric patients with ME/CFS can only find care for their disease at a distance from where they live (International Association for

**Table 2.** Symptoms of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)<sup>a</sup>

Symptoms that persist or recur during the past 6 months	
Impaired function	There is loss of mental and/or physical stamina and a substantial reduction in ability to take part in personal, educational, or social activities
Postexertional symptoms	Normal activity or mild/moderate exertion is followed by worsening of malaise, fatigue, and other symptoms. Recovery takes more than 24 hours
Fatigue	The fatigue is not the result of ongoing exertion, is not relieved by rest and is medically unexplained. Fatigue can worsen with prolonged upright posture
Sleep problems	Sleep is unrefreshing, with disturbed quantity or rhythm that can include daytime hypersomnia, nighttime insomnia, day/night reversal
Cognitive problems	Any of the following: difficulty in concentration or focusing, difficulty understanding information or expressing thoughts, difficulty retrieving words or numbers from memory, impaired short-term memory, absent mindedness, and/or slowness of thought. Cognitive problems can be provoked by, or worsen with, prolonged upright posture or physical or mental activity. Some patients do not recognize these problems, but they might be noticed by a parent or teacher.
Pain	Can be widespread or localized; commonly seen are: chronic daily headaches, myalgias, abdominal pain, joint pains, sore throats, painful lymph nodes. Pain can be worsened by prolonged upright posture. Rarely is pain absent
Other symptoms present in many, but not all, pediatric patients with ME/CFS	
Orthostatic intolerance	Prolonged upright posture can induce symptoms that can include lightheadedness, increased fatigue, worsening of cognitive symptoms, headaches, or nausea. Postural tachycardia syndrome (POTS), neurally mediated hypotension (NMH), or both are often present
Hypersensitivities	Light, noise, touch, odors, medications
Thermoregulatory imbalance	Low body temperature, intolerance to heat and cold, and cold hands and feet
Gastrointestinal	Abdominal pain, nausea, and anorexia

<sup>a</sup>Adapted from Rowe et al. (2017).

Chronic Fatigue Syndrome/Myalgic Encephalomyelitis, 2018; Sunnquist, Nicholson, Jason, & Friedman, 2017). The CDC recognizes the paucity of qualified ME/CFS healthcare providers and propose that basic care for a patient with ME/CFS be provided by a local health practitioner with referral to specialists as needed (Brimmer et al., 2008). Although this has been the model of care for more than fifteen years, ME/CFS patient satisfaction with the specialized care they receive remains low (Sunnquist et al.).

### Treatment

Currently there are no treatment options to cure ME/CFS. Treatment is focused on managing the symptoms based on individual need (Rowe et al., 2017).

ME/CFS can be a devastating illness and a parent/legal guardian may be frightened to learn that their child has this disease. On the other hand, a

diagnosis of ME/CFS may come as a relief to the parent or legal guardian, as it offers an explanation for their child's apparent, atypical behavior (Association of Young People With ME, 2013; Rowe et al., 2017). The school nurse's ability to provide assurance and suggest resources is invaluable for obtaining a positive outcome for the affected student. For example, the school nurse could inform parents that the average duration of the illness of those who report having "recovered" was 4 to 5 years with a range from 1 to 15 years. By 5 years, 60% reported recovery, and by 12 years, 88% reported recovery (Rowe et al.).

### Support the Student with ME/CFS at School

The symptoms and levels of fatigue in a student with ME/CFS can fluctuate from day to day or week to week making his or her attendance at school

and participation in classes unpredictable. This lack of predictability of student attendance and participation in school can be frustrating to school administrators and staff. Staff and administrators may not understand why a student may appear well on Tuesday but cannot get out of bed on Wednesday. The school nurse can play a pivotal role in reassuring colleagues that the waxing and waning of this illness is normal and needs to be accepted (Newton, 2018). Accurate information and resources about the illness will benefit the student, the family and school personnel. When the student is well enough to attend school, even on a limited basis or with an abbreviated schedule, the school nurse should serve as an advocate for the student and assist the student through the modified school program. Because all aspects of a student's life may be affected, an Individual

**Table 3.** ME/CFS: A Checklist for School Nurses by David S. Bell, MD<sup>a</sup>

<input type="radio"/> Did the illness begin suddenly with a flu or mono-like infection?
<input type="radio"/> Has there been a single week since the onset that you felt entirely well?
<input type="radio"/> Does the fatigue go away with a good night's sleep?
<input type="radio"/> Do you have difficulty getting a restful night's sleep?
<input type="radio"/> Do you have fatigue every day?
<input type="radio"/> Is the fatigue made worse by exertion or activities?
<input type="radio"/> Do you have a sore throat at least once a week?
<input type="radio"/> Are the glands under your neck frequently sore?
<input type="radio"/> Does light hurt your eyes?
<input type="radio"/> Are you uncomfortable with noise?
<input type="radio"/> Do odors bother you?
<input type="radio"/> Do you have stomach pain more than once a week?
<input type="radio"/> Do your muscles hurt?
<input type="radio"/> Do your muscles feel weak?
<input type="radio"/> Are your joints (fingers, knees, etc.) sore?
<input type="radio"/> Do you have a headache several times a week?
<input type="radio"/> Is it difficult to concentrate?
<input type="radio"/> Do you have a hard time remembering simple things?
<input type="radio"/> Do you get light-headed or dizzy frequently?
<input type="radio"/> Do you feel like you have a fever frequently?
<input type="radio"/> Do you wake up at night sweating?

Note: ME/CFS = myalgic encephalomyelitis/chronic fatigue syndrome.

<sup>a</sup>Reprinted by permission of Dr. David Bell and Solve the ME/CFS Initiative. Although this is not a diagnostic algorithm for ME/CFS, a student answering “yes” to a significant number of the following questions indicates the need for further evaluation by an ME/CFS-knowledgeable physician.

Healthcare Plan should focus on supporting the student to find a balance between academic, social, emotional, and physical activity for optimal function with minimal symptoms (Rowe et al., 2017). As a member of the student's Child Study Team, the school nurse can be instrumental in developing an Individual Education Plan (IEP) or a 504 Plan to help the student succeed in school. The school nurse can represent the student's interests and, if necessary, interpret the medical concerns to the faculty and administrators who are not conversant with the signs and symptoms

of ME/CFS, or the language used by healthcare professionals. A student with mild to moderate cases of ME/CFS could qualify for a 504 Plan, providing accommodations to their educational environment. A student with moderate to severe ME/CFS could qualify for an IEP, with the classification of, “Other Health Impaired.” The IEP would provide both accommodations and modifications to his or her educational environment and allow the student to continue working for his or her high school diploma until they reach 21 years of age (Newton, 2018). Some suggested accommodations

and modifications that can be implemented with a 504 Plan or an IEP appear in Table 4. A balance of developmental activity is important for a student with ME/CFS. Accommodations and modifications to meet the academic and physical health needs of a student with ME/CFS must be balanced with social and emotional development as the student recovers.

The school nurse can help maintain the student's health by alerting the student and parent or legal guardian to outbreaks of infectious illnesses in the school. Clinicians report that ME/CFS patients have a more protracted course of illness with colds and the flu. Such illnesses exacerbate their symptom of fatigue. Parents may wish to consult with their child's healthcare provider regarding the prophylactic administration of Tamiflu. The school nurse should remind the student with ME/CFS of the CDC (2018) recommendations to avoid becoming infected: frequent hand washing, avoiding touching eyes, nose and throat with unwashed hands, and staying away from people who are sick.

## Conclusion

The ability of a school nurse to recognize the possible onset of ME/CFS in a student and to refer the student to one or more appropriate healthcare providers may lessen the likelihood of the student entering a downward spiral into a disabling, chronic illness. If the student is well enough to return to school, even on a part-time basis, the school nurse can assist the student in managing their educational program. While the severity of ME/CFS is different for each student, the school nurse can assist in addressing the individual needs of the student by educating school staff about the disease symptoms, the course of the illness and the necessary accommodations and/or modifications needed in the academic setting. This support from the school team will give the student an opportunity to successfully meet academic requirements and remain socially and emotionally engaged with peers. ■

**Table 4.** Suggested Accommodations/Modifications for a Student With Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)<sup>a</sup>

<p>In the school:</p> <ul style="list-style-type: none"> <li>○ Designate one person as the point of contact for both teachers and family.</li> <li>○ Allow a shortened day/shortened week. Permit the student to arrive late, leave early, attend school for only part of the day and/or only 2 or 3 days per week. Some students might not be able to manage morning classes while others cannot manage afternoon classes.</li> <li>○ Provide a quiet place to rest.</li> <li>○ Permit the student to use the elevator.</li> <li>○ Exemptions or modifications of the physical education program needed.</li> <li>○ Provide a flexible blend of alternative instructional services including homebound and online instruction for students who are able to attend school even on a part-time basis.</li> </ul>
<p>In the classroom:</p> <ul style="list-style-type: none"> <li>○ Provide two sets of textbooks—one for school, one for home, online texts, and/or eBooks.</li> <li>○ Allow extended time for work to be completed and submitted online.</li> <li>○ Use the buddy system—a fellow classmate can take and share class notes. Allow taping of classes, and/or provide the student with an outline of the material taught or mirroring software.</li> <li>○ Allow the student to Skype into the class if they are well enough.</li> <li>○ Provide an electronic device, such as a laptop or tablet, to permit work to be completed and submitted online.</li> <li>○ Permit a student with orthostatic intolerance to move around the classroom during classes.</li> <li>○ Allow the student to eat salty snacks and drink fluids (water or juice) to maintain blood pressure and cognitive function.</li> <li>○ Provide tutorial or homebound instruction for work missed or if the student is too ill to attend school, even if it is on a part-time basis.</li> <li>○ Allow flexibility with assignments and deadlines as well as modifications of the number of problems and/or assignments to be completed. Seek mastery over subject rather than completion.</li> </ul>
<p>Assessments and testing:</p> <ul style="list-style-type: none"> <li>○ Permit extended time for testing if needed. Adjust the time of day of testing so as to test the student when the student functions best.</li> <li>○ Allow testing with the tutor outside the classroom and in the home if possible.</li> <li>○ Permit and schedule longer exams, such as final exams, over several days and/or several sessions.</li> <li>○ Allow the student to eat salty snacks and drink fluids (water or juice) during testing to maintain blood pressure and cognitive function.</li> </ul>

<sup>a</sup>Adapted from Newton (2018) and Rowe et al. (2017). Any of the suggested accommodations/modifications can be recommended, depending on the student's physical condition.

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