

APPENDIX D

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Fact Sheet for Schools

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is characterized by the body's inability to produce sufficient energy for the normal range of human activity and the patient's energy reserves are substantially reduced. The main symptoms include:

- Severe, overwhelming fatigue with loss of mental and/or physical stamina and a substantial reduction in ability to take part in personal, educational and/or social activities.
- The cardinal symptom of worsening of symptoms and malaise (feeling ill) following minimal physical or mental exertion which can persist for hours, days, or weeks and is not relieved by rest
- Cognitive problems ("brain fog"), unrefreshing or disturbed sleep and a variety of painful conditions (rarely pain is absent). Cognitive problems may worsen with prolonged upright posture.

There is no medical test for the illness. The diagnosis is made from (a) the characteristic pattern of symptoms (b) some or all of the above symptoms must be present every day for at least 6 months, (c) symptoms must be moderate or severe, and (d) other fatiguing illnesses must be ruled out by history, physical exam, and medical testing

Additional symptoms are often present and include:

- Orthostatic intolerance, which is the development of symptoms due to prolonged upright posture (standing or sitting) that result in lightheadedness (and sometimes passing out), increased fatigue, cognitive worsening, headaches, and/or nausea.
- Hypersensitivities to light, noise, touch, odors, and/or medications.
- Problems with thermoregulation such as low body temperature, intolerance to heat and cold and/or cold hands, and feet.
- Gastrointestinal symptoms such as abdominal pain, nausea, and/or loss of appetite.

ME/CFS often starts suddenly following a viral illness, but it can start gradually. Symptoms can vary unpredictably in severity from day-to-day and from week-to-week. Students with ME/CFS often do not look ill, but can appear to be very pale. The cause of ME/CFS is unknown, but the disease is not thought to be transmitted by casual contact. There is currently no medication or intervention that will cure ME/CFS. Successful management is directed toward determining the optimum balance of rest and activity to help prevent post-exertional worsening of symptoms. Medications are helpful to treat pain, insomnia, orthostatic intolerance and other symptoms

Educational Implications

Myalgic encephalomyelitis/chronic fatigue syndrome is the most common cause of long-term absence from school due to illness. Absence from school is usually due to poor physical and cognitive

function, not behavioral factors. Some students can attend school daily, others can manage part-time, while others are homebound and some are confined to bed. Sometimes a student has enough energy for school at the start of the week, but is unable to manage school on Thursday and Friday. ME/CFS is unpredictable. A student might appear fine one day but the next day might be unable to come to school, sometimes for several weeks. There might also be long periods where she/he is unable to complete schoolwork at home.

Most students with ME/CFS experience worsening of their school performance as ME/CFS symptoms impact education. Cognitive problems include confusion, difficulty with concentration, slow information processing, short-term memory problems, impaired word retrieval, and easy distractibility. These problems can manifest in several ways. If the teacher has asked the student to complete a task and she/he is interrupted, she/he might not remember what the teacher asked her/him to do. The student might require extra time to answer questions or complete assignments. The student might temporarily lose the ability to retrieve information learned the day before. Classroom noise can worsen distractibility. This distractibility can result in teachers perceiving that the student is uninterested, or cannot pay attention. Students with ME/CFS may be unable to handle simple math calculations. They can often complete the steps to solve a complex calculus problem, but make simple addition or multiplication mistakes. Intellectual reasoning is usually retained in spite of cognitive problems, and many students are capable of taking academic classes with their peers, provided that the number of their classes is strictly limited.

Symptoms of ME/CFS worsen after physical exertion. Participation in sports can deplete the student's energy reserves. Some students may manage a short physical activity, but not an activity that requires stamina. The student needs to be able to recognize when she/he is experiencing the onset of fatigue, inform the teacher and *must* stop and rest. The student might want to participate, but failure to stop and rest at the onset of increased fatigue can cause a serious relapse of symptoms. Students with ME/CFS should never be pressured to push themselves to their limits.

Educational Accommodations

Students may need a personalized school schedule. The following accommodations can be helpful:

In the school:

- A single point of contact for teachers.
- A shortened day/week, the student might need to come in late, leave early, and/or attend school for only 2 or 3 days a week.
- A reduction in course load and flexible scheduling where only classes in selected subjects are attended.
- A quiet place for the student to rest if fatigue is evident to the student or the teacher.
- Use of the elevator to access different floors.
- Exemption from, or modification of, the physical education program.
- Provide homebound instruction or "Distance Education" for students who are partly or completely homebound.

In the classroom:

- Provide two sets of textbooks—one for school and one for home.
- Give clear directions with frequent feedback.
- Help the student to organize work with the use of an assignment book and/or online calendar to record assignments and work completed.
- Use the buddy system, so that someone can take notes in class, allow taping of classes, and/or give the student an outline of material taught.
- Use multi-sensory instruction, e.g., visual aids like graphic organizers and non-linguistic representations to better suit the learning style of the student.
- Teach tasks serially instead of having the student multitask, break work down into manageable segments—short frequent projects are better than long-term projects.
- Permit the use of electronic devices such as a laptop or tablet and allow work to be completed online.
- Permit a student with orthostatic intolerance to move around during classes and allow salty snacks and a water bottle in the classroom.
- Provide tutorial or homebound instruction, if the student is too sick to attend school.
- Allow flexibility with assignments and deadlines, and modifications of the number of problems and/or assignments to be completed.

Assessments/testing

- Test knowledge of material in multiple ways, e.g., oral instead of written tests, or course work instead of exams.

- Extended time and a quiet room might be needed for testing as well as adjusted time for assessments depending on the time of day when the student functions best.
- Tests/Final Exams may need to be given over several days or sessions, with water and snacks available.

Curriculum

- Identification/prioritization of essential content.
- Focus on mastery of skills rather than completion of assignments.
- Use of frequent short-term projects instead of long-term projects.
- A reduction in the number and length of assignments, projects, quizzes, and tests.

Social Development

The classroom and the school cafeteria might be the only place where the student with ME/CFS is able to socialize with her/his peers. When possible, this should be facilitated. Access to extra-curricular activities is also important for social reasons.

Resources

National Association of Special Education Teachers Chronic Fatigue Syndrome, www.naset.org/3349.0.html. Association of young people with ME, AYME www.ayme.org.uk. Association of New Zealand Myalgic Encephalopathy Society, www.azmes.org.nz.