

**Myalgic Encephalomyelitis/
Chronic Fatigue Syndrome (ME/CFS)**

**School Fact Sheet
For Parents, Educators, and School
Nurses**

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Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) School Fact Sheet

SYMPTOMS

- Post-exertional malaise characterized by the loss of both physical and mental stamina
- Sleep Dysfunction - non-refreshing/disturbed sleep
- Lack of cognitive focus (Brain fog)
- Chronic joint/muscle pains and aches
- Headaches of new onset or severity
- Swollen glands, recurrent sore throat, recurrent flu-like symptoms, new sensitivities to food and/or medications
- Neurological/Cognitive Manifestations: confusion, impairment of concentration and short-term memory consolidation, disorientation, difficulty with information processing, categorizing and word retrieval, and perceptual and sensory disturbances
- *Neuroendocrine Manifestations:* loss of thermoregulation stability – subnormal body temperature and marked diurnal fluctuation, sweating episodes, recurrent feelings of feverishness and cold extremities; intolerance of extremes of heat and cold;
- *Autonomic Manifestations:* orthostatic intolerance - neurally mediated hypotension (NMH), postural orthostatic tachycardia syndrome (POTS).

ABOUT THE ILLNESS

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a disabling, chronic disease characterized by the body's inability to produce sufficient energy for normal everyday activities. As many as 1 million Americans, many of them children, suffer from this disease.

As an illness diagnosed by exclusion, and with no known cause, there is no single, confirming test. ME/CFS is not a psychological illness, however, though depression and anxiety can occur as it does in other chronic illnesses.

Children with ME/CFS experience debilitating fatigue and malaise (feeling ill) after minimal mental or physical exertion, unexplained by any other underlying medical condition. Symptoms and levels of fatigue change unpredictably from day to day or week to week; all can be exacerbated by stress or exertion; persist for hours, days or weeks; and are not relieved by rest.

Post-exertional malaise is characterized by the loss of physical and mental stamina, substantially reducing the ability to take part in personal, educational, or social activities. Children suffer from lack of cognitive focus and confusion ("brain fog"); non-refreshing or disturbed sleep; light-headedness; and a multitude of painful conditions.

Additional symptoms may include orthostatic intolerance (changing from a standing or sitting position results in becoming light-headed and/or passing out), dizziness, light-headedness and extreme pallor. Students may have difficulty regulating body temperature, and develop intolerance to heat and/or cold; some develop new allergies or have a change in the status of old ones, experience gastrointestinal symptoms, non-refreshing sleep, and pain (myofascial, joint, and/or abdominal) including swollen glands, a sore throat, and headaches.

Neurological and cognitive symptoms ("brain fog") include confusion; difficulty with concentration and processing information; short-term memory deficits; and impaired word retrieval. Many individuals also experience hypersensitivity to light, noise, touch, and/or odors.

There is no single treatment for ME/CFS. Treatment is for symptoms only, and that differs from individual to individual. Many children do not look ill, but they may appear very pale. (ME/CFS in Children and Adolescents, 2017)

[Dr. Faith Newton, Delaware State University, 2017](#)

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EDUCATIONAL IMPLICATIONS

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) almost always affects the child's attendance in school. Some can attend school daily, some attend part-time, and others are bed-bound. A child appearing fine one day may wake up the next unable to go to school, sometimes for weeks or even months or years. There may be long periods during which the child is incapable of completing any schoolwork. Young, ME/CFS patients will most likely need personalized school schedules to accommodate their medical condition (i.e. homebound services; arriving to school late or leaving early; or only attending school for one or two periods of classes a week).

ME/CFS does not affect intellectual reasoning or language ability. Children should take classes that meet their intellectual needs and, if otherwise qualified, should be encouraged to take Gifted & Talented, Honors, and/or Advanced Placement classes.

Several neurological issues may impact the student's ability to learn. "Brain fog," a state of acute mental confusion or forgetfulness, is one symptom often seen in classrooms. Students also experience difficulty concentrating, have much shorter attention spans, and exhibit slower processing speed. Working memory may also be significantly compromised. Poor physical and cognitive stamina (that cannot be improved) limits the length of time students can spend on activities/tasks.

These issues may manifest in the classroom in several ways. Asked to complete a task and then interrupted, the student may not remember the instructions, or even being asked to do something. The child may take twice as long as healthy peers to answer a question or complete an assignment, and may temporarily lose the ability to retrieve information learned the day before. Increased distractibility from the illness often results in teachers perceiving the student as disinterested, immature, or inattentive. Classroom noises, or even the teacher's voice can be distracting.

These students are particularly at risk for Dyscalculia (inability to handle simple math calculations). They might correctly complete the steps to solve a complex equation, but consistently make simple mathematical mistakes. Dyscalculia should be considered when grading assignments, tests and projects of students with ME/CFS.

RESOURCES

Chronic Fatigue Syndrome in Children and Adults U.S. Centers for Disease Control and Prevention (<https://www.cdc.gov/cfs/pediatric/index.html>)

Parent Information Center
<http://www.parentcenterhub.org/find-your-center/>

Massachusetts CFIDS/ME & FM Association
<https://www.masscfids.org/pediatric>

International Association for CFS/ME (<http://iacfsme.org/Home/tabid/36/Default.aspx>)

Solve ME/CFS
<http://solvecfs.org/mecfs-resources/patient-resources/youth/>

Teach-ME: A sourcebook for Teachers of Young People with ME/CFS and Fibromyalgia
<http://mefmaction.com/images/stories/Support/TEACH-ME2edition.pdf>

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Diagnosis and Management in Young People: A Primer
<http://journal.frontiersin.org/article/10.3389/fped.2017.00121/full>

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CLASSROOM ACCOMMODATIONS AND INSTRUCTIONAL STRATEGIES

MATERIALS

- Provide two sets of textbooks – one for school and one for home, online, or eBooks.
- Allow work to be completed and submitted online.
- Teach the student to use an assignment book and online calendar to record assignments and work completed to help with organization
- Allow use of electronic devices in the classroom (e.g. laptop or tablet)

INSTRUCTION

- Review the students 504 Plan or IEP to determine activities that are suitable for the child's medical condition
- Use multi-sensory instruction to focus on child's learning style.
- Address attention/organizational deficits with preferential seating; frequent checks that assignments are recorded and completed; clear directions with frequent feedback, monitoring of on-task behavior
- Teach internal memory aids – including rehearsing information
- Use checklists to break larger tasks down into smaller ones
- Teach tasks serially instead of having the student multi-task
- Support/facilitate social relationships; often the classroom is the only place these students can socialize with other children their own age
- Use visual aids such as graphic organizers and non-linguistic representations

LOGISTICAL/ADMINISTRATIVE

- Examine the daily physical demands: school attendance, distance between classes, number of stairs, availability of an elevator
- Shortened day – Students may need to come in late or leave early. Some students may only be in school partial days two or three times a week or on complete homebound instruction. Procedures to keep accurate track of attendance will need to be put in place
- Flexible scheduling – e.g. the student can attend Tuesday's 8th grade math lesson during any scheduled section of that class.
- Plan a place to rest if fatigue is evident
- Provide tutorial or homebound instruction for work missed or if child is too sick to attend school
- Dietary restrictions may need to be monitored
- Hydration – provide water for the student
- Support and facilitate social relationships within the school when possible.
- Tutoring and Homebound may need to be provided.

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CLASSROOM ACCOMMODATIONS AND INSTRUCTIONAL STRATEGIES

ASSESSMENT

- Work needs to be divided into manageable segments
- Buddy system for notes; teacher outline of material taught
- Alternative ways to test knowledge of material (e.g. providing oral performance instead of written performance or PowerPoint)
- Extra time for assignments, modification of the number of problems and/or assignments completed, no time limit on assignments
- Provide significantly extended time to complete assignments

CURRICULUM

- Focus on mastery of skills rather than completion of assignments
- Essential content needs to be identified/prioritized to shorten the number and length of assignments, projects, quizzes and tests.
- Short frequent projects are preferable to long-term projects
- Tests/Final Exams may need to be given over several days and/or sessions. It may take a student with ME/CFS double the amount of time to complete an assignment or test.

SUGGESTED PSYCHOLOGICAL TESTS AND PROCEDURES

When testing a student with ME/CFS, one must be aware that the fatigue may have an effect or may confound the results of any educational psychological assessments that are administered. Dr. Robert Sedgwick (Bell, et. al, 2005) cautions psychologists and suggests that the student be tested “during their window of opportunity.” If the student’s symptoms are in the early morning hours, testing the student during that time may yield very different test results than if perhaps you tested the student at 2 p.m. in the afternoon. Testing is not required for a student with ME/CFS but if administered correctly can support the student in obtaining the appropriate school accommodations.

- Wechsler Intelligence Scale for Children ages 6 - 16 (WISC) and the WAIS is used for children 16 and older and adults. Achievement measures academic functioning; it does not measure working memory or processing speed. The digit span subtest measures attention, short-term memory and concentration. The test can be used to indicate whether there is a significant discrepancy between a child’s intelligence and their performance at school.
- The WAIS-R can be used to measure the auditory span of attention.
- The Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) Form A or B can also be used. To determine if there are deficits in working memory, the psychologist can administer the digit span forward and backwards.
- The Test of Written Language (TOWL) can be used to compare contextual writing, writing an essay and the time comparison and some free thought writing
- Woodcock Reading Mastery Test (WRMT) tests reading skills.
- Computerized Continuous Performance Test (CPT) to evaluate processing speed, simple reaction time and vigilance, and executive function specifically multi-tasking.