

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>