

Letter to educators & agencies regarding young people with myalgic encephalomyelitis (ME)

Educators may be perplexed by the many symptoms and degree of disability in students who have ME. A long-term study of absence of students in 1,098 schools indicated that 51% of students absent had ME [Dowsett E, Colby J. JCFS 1997]. In a long-term follow-up study, the average loss of school was 1.8 years per child [Speight N]. It is hoped that this letter will enhance your understanding of ME and its educational implications. Educators have an opportunity to support these young people, accommodate their educational needs, and make a positive difference in their delicate lives.

My = muscle
algic = pain
Encephalo = brain
mye = spinal cord
itis = inflammation

ME affects all age groups, including young children, all ethnic/racial groups, and all socioeconomic strata. Currently there is no curative treatment. Prognosis for an individual cannot be predicted with certainty.

ME: WHO ICD G93.3
neurological disease

Myalgic encephalomyelitis (ME) is a severe, complex neurological disease that affects all body systems. The initial infection may damage the brain and cause profound dysregulation of the nervous and immune systems, impair cellular energy production, and cardiovascular function. ME is more debilitating than most diseases. Symptom severity and hierarchy of symptoms in children can fluctuate rapidly and may appear to be erratic.

Hallmark feature: The **body is unable to produce sufficient energy on demand**, like a furnace that has its pilot light on but it cannot be turned up to address the need for additional heat.

They can't produce the energy they need. Simple activities are exhausting.

- **Neuroimmune exhaustion:** Physical or mental exertion, which can be minimal such as activities of daily living, causes rapid exhaustion and worsening of symptoms.
- **Post-exertional exhaustion and flare of other symptoms** can be immediate or delayed by hours or days.
- **Recovery period is long**, taking 24 hours to several days. A relapse can last days, weeks or much longer.
- **The lack of physical and mental stamina** results in a substantial reduction in pre-illness energy and activity levels.

Cognitive and central nervous system impairments: Children may have

- **Difficulty processing information:** slowed thought and speech, poor concentration, confusion, disorientation, difficulty making decisions, difficulty absorbing information, dyslexia that may only be evident when fatigued, difficulty sequencing words and numbers, cannot multi-task
- **Short-term memory loss:** difficulty remembering what one wanted to say, what one was saying, retrieving words, recalling information, poor working memory
- **Headaches:** severe and chronic headaches are often debilitating; migraine can be accompanied by rapid drop in temperature, shaking, severe weakness, vomiting
- **Pain:** muscles, joints, chest, abdomen, etc. Pain can be widespread, and quickly fluctuate and migrate.
- **Sleep disturbances:** In the acute stage, patients typically have prolonged sleep, sometimes extreme, and cannot stay awake. This often evolves into sleep reversal – insomnia and sleeping much of the day. When patients “crash” (immobilizing exhaustion), they revert to being unable to stay awake. No matter how long they sleep, they awaken feeling very tired physically and mentally.
- **Motor impairments:** muscle weakness, twitching, “pins and needles”, poor balance, poor coordination and fine motor skills, may appear clumsy, joint hypermobility
- **Sensory/perception disturbances:** inability to focus vision, hypersensitivity to light, sound, vibration, odour (including perfume & paint), taste, some foods, chemicals, medications; poor depth perception

Messages between the brain and the other body systems are miscommunicated and are misinterpreted.

Other prominent symptoms

- **Immune:** flu-like symptoms frequently reoccur or activate with exertion
- **Digestive/gastro-intestinal disturbances,** urinary urgency or frequency
- **Cardiovascular:** inability to tolerate an upright position, light-headedness/dizziness, periods of heart racing
- **Body temperature:** fluctuates, cold hands and feet, periods of feeling feverish without fever, shivery
- **Temperature:** cannot tolerate extremes in temperature

ME is like having the flu every day. Symptoms worsen with mental or physical exertion.

Secondary symptoms

- **Mood:** When young people are trying to cope with this complex, poorly understood disease that can be very debilitating, they often have mood swings and become anxious or depressed. Temporary hyperactivity is followed by overwhelming exhaustion. They may become irritable or appear lazy when exhausted.
- **Secondary school phobia** may develop due to bullying and academic difficulties. Children with ME spend most of their out-of-school time resting, whereas those with primary school phobia are socializing and participating in activities.

The physician may stop the child's education until the child is stronger and his/her health has stabilized.

Educational considerations and recommendations: Ensure the child receives the education to which s/he is entitled. The pathophysiology of ME must be respected and reflected in all educational programs.

It is helpful for teachers to meet with the parents and student as soon as the student has been diagnosed with ME and at the beginning of each year if attending school. Liaise with the child's physician when appropriate.

Educational accommodations should be selected on an individual basis according to the patient's health status, capabilities, special educational needs, and in order to provide the best opportunity for recovery.

1. **Modes of education** to be considered include home education, tutoring, on-line and virtual learning, correspondence courses, part-time school attendance, or combinations of various modes.
2. **Location of learning environment for education: "What environment provides the best opportunity for this child to learn and become educated?"** In the past there has been too much emphasis on returning the child to school as quickly as possible. This strategy has failed because the fast paced school environment is too demanding, even on a part-time basis, and in many cases it has caused the child's fragile health to spiral downward.
 - **Energy Efficient Education:** Home educating is becoming the method of choice as it makes the most efficient use of the child's limited energy in a quiet environment without distractions, and is more conducive to recovery. It is easier to prioritize and streamline course work in the home setting. Not only does it accommodate pacing and rest periods as needed, but the mode in which information is given can be adjusted to the individual child. This ensures the child understands the information at each step and eliminates much of the stress. Ideally a teacher or tutor should be part of the program. On-line virtual tutoring, with the use of Skype or similar program, can be beneficial.
 - **School environment:** • usually very busy • fast-paced • multi-sources of input • several things may be going on simultaneously • requires social interaction • sensory overload - bright lights, noise, odours, etc. The physical, mental, sensory and emotional overload can cause exhaustion, symptom flare, anxiety, depression and relapse.
 - **Attending school part-time:** Is the child strong enough? Does school exacerbate symptoms?
 - **Combination of part-time school and home tutoring** may be considered in mild cases.
 - **Social contact** is secondary to the child's health and education. Visiting school for social contact may be beneficial when the child becomes strong enough.
3. **Curriculum must be modified, course-work streamlined, and submissions minimalized.**
 - **Prioritize** the essentials and focus on concepts.
 - **Begin a program at a level that will ensure success.** Short intervals on a daily basis are better than longer intervals that can cause exhaustion. After resting during the summer, children typically overestimate what they can do.
 - **Exams:** Focus on exams that are necessary for qualifications. Patients may need to write exams at home under the supervision of an invigilator. Marked cognitive impairments should entitle a minimum of a 25% increase in the allotted test time to reflect the work quality of which the patient is capable.

With patience, understanding and support, educators can help these children acquire the education they desire.

Sincerely,

International Consensus Panel for Myalgic Encephalomyelitis (physicians, researchers & an educator representing 12 countries)

References & helpful resources

- TEACH-ME: online in both English & French: http://www.mefmaction.com/index.php?option=com_content&view=article&id=288&Itemid=356
- Tymes Trust: most comprehensive information regarding education of young people with ME <http://www.tymestrust.org>
- Carruthers BM, van de Sande MI, De Meirleir KL, et al. Myalgic encephalomyelitis: International Consensus Criteria. *J Intern Med* 2011;270(4):327-38.

Access to Education School Pass: Simple accommodations that have been prearranged and agreed upon by the teacher and student, such as taking a rest, eating a snack to regain strength, wearing sunglasses due to light hypersensitivity, not standing in a cue, or being excused to the bathroom can be made without discussion or disruption of the class by showing the school pass.

Myalgic Encephalomyelitis International Access to Education School Pass	photo	student's name has permission to use disabled facilities and obtain other assistance.	teacher's signature principal/head teacher's signature Endorsed by: ME International Consensus Panel <i>(Physician's confirmation of diagnosis is required.)</i>
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