

CHRONIC FATIGUE SYNDROME AND SCHOOL EDUCATION GUIDELINES FOR STUDENTS

WHAT IS ME/CFS?

Myalgic encephalomyelitis (ME) or chronic fatigue syndrome (CFS) as it is more commonly known, is a chronic and disabling illness affecting the immune and central nervous systems. It is characterised by profound fatigue which is accentuated by physical and mental effort. It occurs in all sections of the community including children and adolescents. This can result in major disruption to education, social, physical and emotional development for many months or years.

ME/CFS has received most attention for its devastating effects on previously healthy adults, but children also contract the disorder and the consequences can be just as devastating. Living with ME/CFS is difficult for everyone involved, particularly children and adolescents who suffer from this debilitating illness at such a crucial phase of life.

DIAGNOSIS OF ME/CFS

Even though there are no specific diagnostic tests for ME/CFS, it is very important that an accurate diagnosis of ME/CFS be made, by excluding other illnesses and by assessing the sufferer's symptom history. Although a diagnosis may not cure sufferers, it is essential for the healthy emotional development of a child/adolescent.

Despite the fact that no cause or cure has been found for this illness, research into ME/CFS has developed worldwide at a rapid rate over the last decade. By keeping up to date with the most recent research, a range of treatment options may be found.

Due to the variation in symptoms and their intensity, symptoms of ME/CFS may be misdiagnosed in children/adolescents as being school phobia, an emotional disorder, or lack of motivation or laziness on the part of the child. This misdiagnosis may also occur because with a developing less articulated child it is much more difficult to identify a change in a physical or behavioral pattern not associated with normal growth.

SYMPTOMS

Symptoms can and do vary between individuals and may vary in intensity from day to day or even hour to hour. There is often a variability and inconsistency in physical abilities. For example, a young person might be able to swim but not be able to run.

In most cases the onset of symptoms is sudden, yet for some the onset is gradual. Children with a gradual onset of symptoms are often not able to describe the precise amount of fatigue or the difficulties they experience because they cannot remember a time period without them. Although children and adolescents may look well, they can be suffering severe pain and discomfort.

The hallmark of the condition is a prolonged and disabling physical and mental exhaustion out of proportion to the level of activity and often unrelieved by sleep. This goes far beyond the bounds of a healthy person's idea of fatigue. One of the indicators of this illness is the sufferer's desire to perform but inability to do so.

In a person with ME/CFS every system in the body can be affected to some degree. Although this is not an exhaustive list, people with ME/CFS may experience four or more of the following symptoms.

- Unrefreshing sleep
- Flu-like symptoms including sore throat, fever and sore lymph glands
- Persistent pain in muscles and joints
- Headaches varying from dull to intense and an excessive number migraines
- Dizziness, nausea, and fainting
- An inability to tolerate extremes of heat and cold, bright light or sound, for example, a noisy classroom
- A sensitivity to various agents which may be found in food or in common chemicals such as paints, glues and gas or kerosene heating
- Weight gain or weight loss
- Depression or anxiety may develop in individuals as a result of this chronic illness
- Cognitive problems such as poor concentration and difficulty with short-term memory

HOW IS THE STUDENT AFFECTED?

The process of ME/CFS can be very traumatic because many children/adolescents do not want to be stigmatised because of their condition. Students may suffer severe cognitive difficulties resulting in short-term memory, inability to maintain concentration, as well as problems in visual/spatial perception. Mathematics is likely to cause the most problems for students with ME/CFS due to the logical and sequential nature of the subject, but difficulties with reading comprehension and writing are also common. These cognitive symptoms can profoundly affect the student resulting in school work becoming challenging, if not impossible. It has been reported that high achievers may find this aspect of the illness the hardest to cope with because of the loss of academic ability.

Children and adolescents with ME/CFS also miss other childhood activities that healthy children experience. As a consequence of this chronic illness, children/adolescents may miss schooling making it difficult to plan for the future. They may also be isolated from friends, experience family disruption and be deprived of formerly enjoyable activities, such as socialising and playing sport. For this reason, it is not unusual for them to grieve over the loss of their former lives and suffer from a lowered self-esteem and altered self-image.

EDUCATIONAL ISSUES FOR STUDENTS

People are affected by ME/CFS to different degrees and in different ways.

Although no-one knows the entire spectrum of illness in the school-age child, it appears that it ranges between almost normal activity with no obvious cognitive difficulties to children who are bedridden with severe cognitive impairment. All grades of disability exist and the degree of impairment usually fluctuates with time. Students might improve, but the symptoms may still persist over time.

Some young people are able to continue at school but with reduced activity, especially avoiding physical activity like Physical Education. Children with a moderate functional disability may be unable to complete a full day of school and might need rest periods during the day at school. Some children may only manage part days or alternative days and may benefit from a slower paced education at home. Sadly, a small number of young people are so severely affected that they are unable to attempt any kind of formal education at all for some time.

There is no single method of dealing with the situation. However, with co-operation between the sufferer, parents, medical and educational authorities, one can find the best possible form of management for each individual.

ALTERNATE EDUCATIONAL OPTIONS

A number of options that may assist students with ME/CFS are listed below.

- Attendance at school through part-time study, reduced subject load and reduced hours.
- Distance education could be considered if the student is too ill to attend school on a regular basis. This allows students to work at their own pace and avoids travelling. (A combination of Distance Education and part-time attendance at school may also be an option).
- TAFE HSC Pathway and Open Training and Education (OTEN) is a way of studying at home. Students can complete their School Certificate and Higher School Certificate along with many other courses by correspondence.
- Home schooling is a system in which parents take responsibility to teach their children at home.
- Self-tuition is where school students may take responsibility to tutor themselves either alone or with private tutors.
- The Board of Studies has a number of special provisions that may assist students with ME/CFS attempting either the School Certificate or Higher School Certificate.
- Some students may need to put formal education on hold until they are well enough to continue.

Please note that there may be certain eligibility requirements and restrictions that apply to the above options, particularly for students studying the School Certificate and Higher School Certificate.

Please contact the ME/CFS Society of NSW for further details on the above.

TIPS FOR SCHOOLS WITH STUDENTS SUFFERING FROM ME/CFS

Management of ME/CFS must be adapted to the individual needs of the sufferer due to the varying and fluctuating symptoms. This requires understanding and sympathetic handling by all those involved with the young person. Staff at schools should be encouraged to be innovative and find the best possible ways to help students manage their illness. Here are some suggestions to help students with ME/CFS:

Helping students with their intellectual needs:

- Students should be given clear boundaries regarding what work is absolutely necessary and what tasks need not be done. However, student's should make the ultimate decision about what, how much and when.
- Emphasise that educational opportunities are much broader now than in the past, with greater educational flexibility in areas such as TAFE and Distance Education.
- The cognitive symptoms of ME/CFS may result in the loss of academic ability, thus realistic goals and care should be taken.

Helping students with their social needs

- Encourage the student to remain at school during breaks to re-establish vital social links. Finding a quiet comfortable place for the student to sit with their friends may be helpful.
- Be aware that the student is missing a social, recreational and family life, as well as a school life.
- Be aware that other students may need help in understanding the condition.

Helping students with their psychological needs

- Talk with the student about what their experience of ME/CFS is like. In what ways does it prevent them from being able to manage school work and other activities?

- Having contact with the student at home or by phone can help the student feel supported and not left behind.
- Treat the student with sympathy and trust.
- Understand that the condition is relapsing and can vary from near normality to sheer exhaustion quite suddenly.
- Encourage students to access support networks such as the ME/CFS Society of NSW to make contact with other ME/CFS sufferers their own age.

Helping students with their physical needs

- All staff should be aware of a student's limitations, particularly in relation to exercise and sport, as well as the need for rest. ME/CFS sufferers are prone to relapse if they exceed their limits of physical or mental exertion.
- Be aware of the school environment and how it may adversely affect the child. For example, stairs to be negotiated. Are there any ways the student can avoid these things, for example, timetabling classes on the ground floor.
- Consider taping important lessons, or photocopying notes, with main points highlighted or in a larger font size.
- Consider the provision of two sets of texts - one for school and one for home, to avoid heavy bags.
- Place a special box in a designated place where teachers can leave school work for the student/guardian to pick up and return when completed. This way all parties concerned have a system in place for communicating effectively. Alternatively, establish one contact person at school such as the Year Advisor or Welfare Co-Ordinator and encourage all information and negotiations to be relayed through this person.
- Students can apply to the Board of Studies for special provisions such as rest breaks and separate rooms, when undertaking assessments.
- Allow flexibility in attendance at school, by minimising administrative requirements, for example, presenting notes for being late or leaving early.
- If an e-mail service is available, this can be a valuable tool in maintaining communication with the child at home.
- Allow the student free access to the sick bay.

HOW TO CONTACT THE ME/CFS SOCIETY OF NSW:

The Society has an extensive range of information on ME/CFS. Contact us for information kits, library access to videos and other resources.

Our Community Development Worker is happy to visit metropolitan schools wherever possible to discuss issues arising from ME/CFS in students.

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