

## Information sheet for Teachers of children with ME/CFS

**Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME)** is a serious illness that can affect all age groups. It leaves sufferers exhausted after minimal activity, and is characterised by many different symptoms.

Children and young people do get this illness, which will usually come on following a viral infection (such as influenza or glandular fever). The immune system is activated, as expected, to fight off infection, and instead of settling after the infection is controlled, it remains abnormally affected, leading to ongoing symptoms, which may be very severe. This initial illness may have been particularly aggravated by pushing exercise hard, or suffering undue stress in the lead up or during the recovery phases. Teenagers are particularly vulnerable, as **they** will have been often studying hard, participating in sport, suffering undue stress or not sleeping well.

**Diagnosis:** is made from the typical story and set of symptoms experienced according to a set of medical diagnostic criteria. There is as yet no blood or other test used to confirm the diagnosis. Research is progressing to help us understand the underlying causes of the syndrome. Changes have been shown in the immune, neurological and endocrine systems, and there is a complex interaction occurring within these systems resulting in this illness.

**Severity:** there are all levels of illness from those who are seriously afflicted and bed bound to those who are well enough to attend school, but with very limited energy or capacity to study or participate in sport.

**Typical symptoms include:** Fatigue, muscle aches and pains, headaches, poor concentration and memory, feelings of faintness/light headedness and an inability to exercise more than minimally. Pushing exercise tends to lead to what is known as “Post-Exertional Malaise” (PEM), and these ill effects may be delayed often until the next day. The feelings of faintness are due to the effects of upright posture as most with CFS/ME do have very low blood pressure and sluggish brain blood flow. This is known as POTS. Some have a lot of gastro-intestinal symptoms such as nausea and diarrhoea.

**Variability of illness:** The illness is variable and typically “up and down”. So that on some days the student may look well, and be able to cope – on other days they may look pale and exhausted, and need “time out” to rest or even go home. There may be phases when they cannot attend school at all. The illness is totally unpredictable, with no set time frame. With careful management, recovery is possible, although the student may remain vulnerable for a long time. Because those with the illness are not usually depressed, motivation is good, but then there is a tendency to easily overdo things and risk relapse.

**Guidelines for Teachers:** The more the teacher understands the complexities of this illness, the better the student will do. Care and understanding do count for a lot. Stress due to pressure can aggravate the symptoms and lead to relapse. However it is important for the student to continue to attend school if at all possible, even if for only one period a week. Interaction with friends, and feeling “normal” are vital for young people.

Teachers need to be very flexible regarding the demands put on these students.

The student needs to know that they can go and lie down in the school sick bay if they feel ill.

Arrangements to contact the parents should be in place in case they need to go home.

There may be long phases when a child cannot attend school. Work can then be sent home so that they can work in their own time, and not feel they are falling behind their peers. Social interaction should always be encouraged, and maybe friends can visit at home.

School attendance may be **erratic**. It may be necessary to have short days with later start-times.

Sometimes parents do not have transport readily available to get their child to and from school at different times, but a taxi service may be available through the local health board. Parents can sometimes get help from Work and Income towards costs of the extra care and arrangements needed for a sick child.

**Sport:** Although highly motivated, most with CFS/ME will find it difficult to participate in sport. Pushing too hard physically can easily lead to relapse, as muscle and brain chemistry cannot sustain the effort required. The student may also begin to feel ill or even faint due to standing for long periods, particularly in the heat. Sometimes swimming is more suitable and achievable as being horizontal means less likelihood of developing the typical postural symptoms. The child must be watched carefully however for undue fatigue/exhaustion.

Competitive sport is best avoided.

**Exams:** Special consideration may be needed to enable the student to cope with exams. **A?** Longer time may be required or tests/exams could be spread over separate days, rather than too much on any one day. It may be necessary to make provision for drinks and snacks to be readily available during these times. Sometimes it is best to have a separate room available with minimal disturbance. Those with CFS/ME are often very sensitive to bright light, noise and other sensory stimulation, so a quiet environment can be helpful.

**Special assessments:** Students with long-term conditions or learning difficulties which they believe will significantly impair their performance in specified external assessments and in particular written examinations, may apply to The New Zealand Qualifications Authority for special assessment conditions. For example a time allowance, modifications to question and answer booklets, or the use of an examination assistant such as a reader/writer. The student must have been diagnosed as requiring special assessment conditions by a suitably qualified and registered medical professional, **as** schools must make online applications for special assessment conditions each year by the date notified by NZQA, liaising with the parents of the student is important.

**Medical needs:** Medication may be needed, and arrangements need to be in place so that this is available at the correct time. The school records need to keep this documented. If there is a school nurse or counsellor, she should be provided with all necessary information about this health condition. Counselling may be needed to help cope with socialisation, peer pressure, isolation etc.

Some with CFS/ME may need to use the toilet more often and need easy access to be available, without embarrassment. Girls with CFS/ME often feel worse at period time, and may need someone with whom they can confide in about such sensitive issues.

With correct management, care and understanding there is a good chance of recovery for a young person. They are particularly vulnerable when they are nearly better, and then tend to push themselves too hard too soon, either at sport or study. This can risk relapse. A cautious, paced approach is always recommended.

**Health schools:** Schooling may be available through the local "Health School" (a division of the Correspondence School). Contact can be made by the parent through the regular school or through the Education Department. Arrangements can then be made for enrolment. Usually part-time attendance at regular school is encouraged, with other works/subjects being done at home. Some, who are too ill to attend school at all, may do all their education at home. If health improves, they can be gradually re-introduced to regular schooling part time. Liaison between regular school and the Health School will be in the child's best interests. The G.P. will need to complete the form with recommendations for the Health school involvement. The results from this approach to educational management are usually excellent, and most students manage to keep up well. Personalised approach with a visiting teacher is very appropriate for all ages.