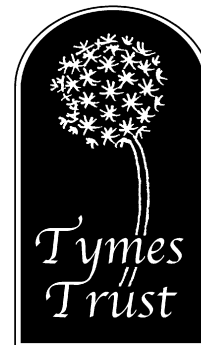


# *Professional Guides*

## Teacher Information on CFS/ME



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**This Guide concerns the neurological condition classified under the names ME and CFS by the World Health Organisation as a disease of the brain and nervous system (ICD 10; G93.3). Unlike other chronic fatigue, with which it can be confused, it is a disabling, relapsing illness; minimal physical or mental effort can produce serious deterioration, typically 24-72 hours after the event.**

Thank you for supporting your pupils with ME. Symptoms they may experience include:

- Sudden exhaustion - the pupil may need to lie down in a quiet place.
- Inability to concentrate.
- Generalised pain and weakness.
- Difficulty with recall, both verbal (temporary loss of spoken vocabulary, pronunciation difficulties, switching the order of words) and numeric.
- Difficulty in assimilating new information.
- Reversal of sleep rhythms (hyperactivity and wakefulness by night, somnolence and unresponsiveness by day, mediated by a malfunctioning hypothalamus gland).
- Emotional lability *eg* depression, anger, emotional highs and hyperactivity followed by exhaustion.
- Disturbances of appetite, taste and smell. The pupil may be obliged to avoid certain foods. Hypersensitivity to chemical smells can mean caution is necessary with lab work to avoid dizziness, malaise and headaches.
- Disturbance of balance and clumsiness due to defects in spatial orientation.
- Hypersensitivity to sound and light - the pupil may need dark glasses or a shade and to avoid direct sunlight.
- Impaired body temperature regulation - the pupil may need extra clothing to keep warm, or the reverse.
- Impaired blood sugar regulation - the pupil may need a snack immediately if feeling unwell.
- Abnormal response to exercise - **pushing a child with ME too far physically is dangerous**. Depending on the strain of infecting virus, up to 30% of patients may suffer from cardiac complications such as palpitations and tachycardia (racing pulse) and disturbances in blood pressure, leading to faintness or falling over. Inappropriate exercise typically results in relapse.

Tests demonstrate reduced brain blood flow after effort leading to oxygen starvation (only returning to normal after rest) and lowered brain cortisol (the opposite of depression) as a result of which pupils can become ill in any stressful situation, even just a normally challenging one. It is therefore inappropriate to encourage a child to do "just that little bit more" or to use the usual challenges to motivate the child. Most people with ME do not lack motivation. They are simply too ill to achieve what a well person can do.

*Relapses often follow onslaughts on the immune system such as secondary infections, immunisations, stress or other extra demands upon the body. There is no cure for CFS/ME; interventions such as Cognitive Behaviour Therapy and Graded Exercise can also produce relapse and great care needs to be taken. A modified curriculum and special arrangements for examinations should be put in place in order for the pupil to fulfil potential. Statutory guidance provides for home-based education when appropriate (please refer to our publication Back to School?).*

**The pupil's health is fragile and even normal social situations can exhaust the brain and body.**

**Use of the Tymes Trustcard helps schools comply with the DFES statutory guidance *Access to Education for Children with Medical Needs*. For details see the Trust website.**

## **Excerpts from the Report of the Chief Medical Officer's Working Group on CFS/ME (Department of Health 2002)**

### **Treatment/Management**

- No management approach to CFS/ME has been found universally beneficial, and none can be considered a “cure”. Patient responses suggest that [...] all can cause harm if applied incorrectly.
- As with many chronic conditions, the emphasis should be on improvement and adjustment rather than “cure”. The goal of rehabilitation or re-enablement will often be adjustment to the illness.
- Experience suggests that provision of a wheelchair or other mobility aid does not stop patients working towards mobility without the equipment in the long term; indeed, such aids probably assist remobilisation, with suitable supervision.
- The notion of “once in a wheelchair, never out” is prejudicial: each case must be assessed according to clinical and functional need.
- Although there is no cure for CFS/ME, the condition has been found to improve in most patients both with and without\* treatment; it is good practice to encourage patients to become experts in self-management and to choose between treatment options. [*\* patients may therefore decline active treatment*]
- Most children who are missing school can be cared for and managed in their homes, with follow-up in primary care or by a specialist such as a community paediatrician.
- Careful listening and respect for parents/carers' opinions are important factors.

### **Educational Management**

- Nearly all children who are severely affected and many who are moderately affected will require the provision of home tuition and/or distance learning. Some young people will be too severely affected by their illness to participate in any form of education, even at home.
- An educational plan is not an optional extra but an integral part of therapy.
- A young person who is likely to have special needs, including home tuition, should be identified early in the diagnostic process, preferably by a GP or paediatrician.
- Specifically, a young person with CFS/ME should never be forced to study but instead should be encouraged to set a pace that is likely to be sustainable, then have their progress regularly reviewed.
- Some more severely disabled children may need home tuition and/or distance learning on a longer-term basis. In addition to the time of a tutor or therapist, this may require information and communications technology, which can also help improve social contact.

### **Child Protection**

- In cases of CFS/ME, evidence clearly suggestive of harm should be obtained before convening child protection conferences or initiating care proceedings in a family court.
- Neither the fact of a child or young person having unexplained symptoms nor the exercising of selective choice about treatment or education constitutes evidence of abuse.

### **Prognosis**

- Overall, there is wide variation in the duration of the illness, with some people recovering in less than two years, while others remain ill after several decades.
- A minority of those with CFS/ME remain permanently severely disabled and dependent on others.
- Most people with CFS/ME can expect some degree of improvement with time and treatment, so a positive attitude towards recovery needs always to be encouraged.

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