

# The Young ME Sufferers Trust

## Teacher Information on ME

*Some children may be diagnosed as 'CFS'*

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**The Queen's Award  
for Voluntary Service**

*The MBE for volunteer groups*



**This Guide concerns the neurological illness classified as ME and CFS by the World Health Organisation as a disease of the brain and nervous system (ICD10; G93.3). Unlike other chronic fatigue, with which it can be confused, ME is a disabling, relapsing illness; minimal physical or mental effort can produce serious deterioration, typically 24-72 hours after the event.**

*It is inadvisable for sufferers to return to school, college or work without adequate convalescence.*

Dr Elizabeth Dowsett, Consultant Microbiologist and ME Specialist

### Symptoms 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 distress/depression, anger, emotional highs/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 physically can be 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 (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 eg secondary infections, immunisations, stress or other extra demands upon the body. **There is no cure**; interventions such as Cognitive Behaviour Therapy, Graded Exercise or Graded School Attendance can produce relapse and great care is needed. A modified curriculum

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and special arrangements for examinations should be put in place to enable the pupil to fulfil potential. Statutory guidance provides for home-based education when appropriate. The pupil's health is fragile and even normal social situations can exhaust the brain and body.

**A succinct 25 minute webinar (10 slides) on the statutory guidance for Local Authorities (2013) concerning children unable to attend school due to health needs is available via the Trust's website [www.tymestrust.org](http://www.tymestrust.org).**

*Students with ME should always be offered modified procedures for examinations, as with any other disability.*

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## **From the Report of the CMO's Working Group on CFS/ME (Department of Health 2002)**

### **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."

"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." Since the publication of the Report, interactive virtual education has become widely available. The Young ME Sufferers Trust works with Nisai Learning.

### **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."

### **Child Protection**

"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. 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 [...] so a positive attitude to recovery needs always to be encouraged."

## **From the NICE Guideline on CFS/ME 2007**

NICE press release: "Follow guidance from the Department for Children, Schools and Families [now the Department for Education] on education for children and young people with medical needs, or equivalent statutory guidance."

NICE prescribes "shared decision-making" between health professionals and patients and emphasises the individual's "right to refuse or withdraw from any part of their treatment plan without it affecting future care."

NICE recommends a flexible approach to education, with home tuition and equipment that "allows a gradual reintegration into education". This does not say "reintegration to school", reflecting our recommendation that education should not necessarily mean school attendance. There are other means of learning which may be more suitable, such as interactive online schemes.

NICE advises doctors: "do not use time in education as a sole marker of progress of CFS/ME [this was a strong recommendation by the Trust], and ensure a balance between education and home and social activities." We know that school attendance has unfortunately been used as a marker of recovery without reference to whether symptoms are provoked, or whether attendance is hindering academic progress.

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