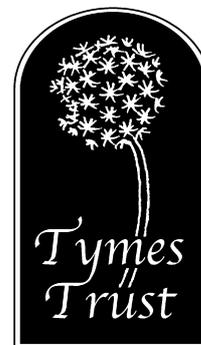


# *The Young ME Sufferers Trust* Professionals Referral Service



The Young ME Sufferers Trust, the longest running national organisation supporting children with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and their families, operates a Professionals Referral Service.

Faced with a case, or a suspected case, of ME/CFS, doctors, teachers, social workers and other professionals can telephone the Trust to consult an ME/CFS expert who is also a fellow professional of their own standing.

*I am pleased to assist this service. GPs can find it hard to believe that ME/CFS can mimic a brain tumour or stroke. I have dealt with extremely severe cases.*

Dr Nigel Hunt, General Practitioner  
Associate Director, Post Graduate GP Education, Eastern Deanery

The service can put professionals in touch with, among others, hospital consultants, paediatricians, educational consultants, social workers and examinations officers, all with expertise in ME/CFS.

## **Education is key cause of ME relapse in children**

The Tymes Trust Advice Line finds that educational demands are a key cause of relapse in children. Over 90% of callers report education as being the main problem or the main pressure. The Trust is often asked to run teacher training sessions for Local Education Authorities. The Trust regularly advises schools, home tutors, examinations officers and LEAs.

ME/CFS is the biggest cause of long-term sickness absence from schools. It is thought to affect 25,000 children in the UK. Tymes Trust's Executive Director, former headteacher Jane Colby, co-authored the world's biggest study of ME/CFS (*Journal of CFS, 1997*).

## **The Tymes Trustcard**

The Trust has created a Passcard system endorsed by Education Minister Baroness Ashton and the Secondary Heads Association for pupils and students with ME/CFS in school, to protect their health needs. For more information see the Trust website.

**ME/CFS is classified 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.**

**Tymes Trust played a major role in the Chief Medical Officer's Working Group on CFS/ME and its Report (DOH 2002). The Trust is endorsed by the Prime Minister, the Leader of the Opposition and the Leader of the Liberal Democrats.**

## **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.

**Further specialist publications for education and medical professionals are available from  
[www.tymetrust.org](http://www.tymetrust.org)**