

# Professional Guides

## Care of CFS/ME in Children

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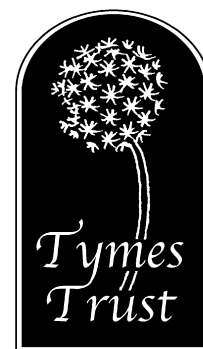
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*Early diagnosis and support are key to helping children with CFS/ME*

**A**round 25,000 people per year may be developing Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME). It is unknown whether its course and duration can be altered but a recent report incorporating diagnostic guidance suggests that diagnostic delays can lead to the patient's condition deteriorating without advice on how to self-pace. [1]

CFS/ME is classified as a neurological illness and can be particularly severe in children. Pain and exhaustion are key features. Seizures, breathing difficulties, temporary paralysis and lack of ability to swallow or tolerate solid food can necessitate nasogastric intubation or percutaneous endoscopic gastronomy (PEG). Very severe cases can mimic a brain tumour, the patient can be unable to recognise close family and may develop speech difficulties as in a stroke.

Abnormalities have been demonstrated in brain function, muscle metabolism and in spinal fluid, suggesting that "myelitis" is indeed a feature. The first biomedical study in children is imminent; vascular imaging has identified biochemical abnormalities in the circulation of adults suggesting that CFS/ME could involve a continuing challenge to the immune system such as a persistent viral infection. Patients may have a chronic inflammatory disorder associated with

increased risk factors for cardiovascular disease.

Post-exertional malaise and deterioration are diagnostic of CFS/ME. Thus over-enthusiastic activity management programmes can provoke relapse, while provision of wheelchairs, stairlifts and other equipment together with conservation of energy have been found to aid mobility and support recovery. Successful strategies help to keep up the patient's spirits without encouraging them to attempt too much.

Why do some patients appear to find cognitive behaviour therapy (CBT) or graded exercise therapy (GET) helpful while others report deterioration? One reason is that wide diagnostic criteria such as those often used for research pull in patients with differing aetiologies. Another is that the therapy was used at an inappropriate stage of the illness (see overleaf).

In children and young people, educational demands are a key cause of relapse, so tuition in the home or virtual education is usually needed. Many Local Education Authorities (LEAs) request a consultant's recommendation, but an exemplar of a child's journey through CFS/ME, published jointly by the Department of Health and the Department for Education and Skills (DfES), shows the GP's recommendations being used.

With no laboratory test, diagnostic confusion has arisen between the physically disabling CFS/ME and the similarly named "chronic fatigue", which could be of psychological origin or part of the

presentation of other organic diseases. Patients with fatigue of depressive origin can benefit from exercise, but those with CFS/ME are typically made worse by even minimal exertion.


DfES statutory guidance *Access to Education for Children with Medical Needs* states that a child too ill to attend school for over three weeks must be offered home education - insufficient time to obtain a consultant's recommendation. GPs may need to point this out to the LEA.

A possible diagnosis of CFS/ME can be considered at an early stage. The "rule" that it should not be diagnosed before 6 months is historical and arose from the need to define a study population. The report of the Chief Medical Officer's Expert Group, published by the Department of Health states: "Early recognition with an authoritative positive diagnosis is key to improving outcomes" and emphasises the urgency of early diagnosis in children. "When a child or young person has symptoms affecting school attendance for at least four weeks, active steps should be undertaken to identify the cause from a list that includes CFS/ME." [2] Local CFS/ME clinics may assist GPs with diagnosis and clinical diagnostic criteria have now been published in Canada and Australia. [3,4]

Severity and/or long-term school absences tend to arouse suspicions of neglect or abuse and child protection investigations have caused trauma to families. A multi-professional approach can be helpful. Good patient self-management and a positive doctor/patient relationship are the ideal.

### References

- [1] ME Diagnosis : Delay Harms Health, 2005  
From the ME Alliance and at [www.tymestrust.org](http://www.tymestrust.org)
- [2] Report to the Chief Medical Officer of an Independent Working Group, 2002  
At [www.doh.gov.uk](http://www.doh.gov.uk) Under CFS/ME.
- [3] Carruthers, B et al. ME/CFS: Clinical WorkingCase Definition, Diagnostic and Treatment Protocols  
J Chronic Fatigue Syndrome 2003; 11: 7-115
- [4] ME/CFS Guidelines: Management Guidelines for GPs 2004 ISBN 0 7308 9334 0  
At [www.co-cure.org/AU\\_CFS.pdf](http://www.co-cure.org/AU_CFS.pdf)

 ***Patients with fatigue of depressive origin may benefit from exercise, but those with CFS/ME are made worse***

**Milder cases of CFS/ME can become severe and chronic unless carefully managed. It can be helpful to think in terms of stages with fluctuations.**

**Initial Stage :** Particularly evident in severe cases. The patient feels ill all the time; any attempt at exercise is counterproductive.

Symptomatic support and physical aids are recommended. Any therapy encouraging an increase in exertion is inadvisable.

**Intermediate Stage :** Stabilisation, typically taking several years; excess activity can cause relapse to the initial stage.

Supported self-pacing is recommended to avoid yo-yoing between over-activity and relapse. Counselling or CBT may help reduce anxiety or post traumatic stress but should not be based on the assumption that pathology is no longer present. GET can be counterproductive for these CFS/ME patients (as opposed to those with chronic fatigue).

**Recovery/Remission :** Symptoms abate. Overdoing things usually leads only to a minor setback.

Activities can be gradually increased with confidence. GET is safer once this stage is reached.

### ***The Department of Health now refers to this condition as CFS/ME***

Many doctors use the term CFS (Chronic Fatigue Syndrome). Others prefer ME (Myalgic Encephalomyelitis) as originated in The Lancet.

This guidance 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)