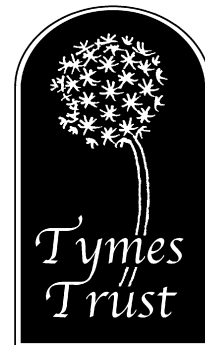


# *Professional Guides*

## **Implications for Schools of the Chief Medical Officer's Working Group Report on CFS/ME**



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**On 11th January, the Department of Health published a report on treatments for what is now termed CFS/ME. For some LEAs it could mean fundamental changes in education for children with the condition.**

Based on an older report authored mainly by psychiatrists, prompt re-integration to school has often been emphasised and home tuition discouraged. Family therapy and rehabilitation courses have sometimes been made conditions of receiving home tuition, due to a conviction that family dynamics perpetuate the illness and that graded exercise and/or cognitive behaviour therapy will bring the child back to fitness.

With the report's new information that "no management approach to CFS/ME has been found universally beneficial, and none can be considered a *cure*" it has become untenable to impose such conditions. The government now "endorses the view of the CFS/ME Working Group report that there should be no doubt this is a chronic illness and that Health and social care professionals should recognise it as such". Education professionals are also affected.

It was once thought that children did not get CFS/ME. When this belief was recognised as unfounded, the numbers were thought to be insignificant. The Dowsett/Colby study of UK schools (1997) in the Journal of Chronic Fatigue Syndrome - a key reference in the report - found that in the studied population of 333,000

schoolchildren, CFS/ME caused over half of all long term sickness absence, and more than any other condition. The report now acknowledges CFS/ME as a relatively common condition from which children of all ages do suffer. Early recognition with an authoritative, positive diagnosis is cited as key to improving outcomes.

Key quotes affecting education are:

- "Nearly all children who are severely affected and many who are moderately affected will require the provision of home tuition and/or distance learning. A critical element of the child's management is assessment and provision of educational needs."
- "Some young people will be too severely affected by their illness to participate in any form of education, even at home."
- "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."

What is, in an educational context, "severely disabled"? CFS/ME is listed as a neurological disease, and many of its severely disabling

effects are hidden in the brain and central nervous system. They are as real as those of a child whose disabilities may be seen and frequently result in relapse due to the physical demands of school attendance. This may be considered “severely disabled”. Information and communications technology (ICT) is suggested as a suitable solution, with work and social messages being faxed or emailed.

Wheelchairs and other equipment are also approved aids. When the child is eventually strong enough for attendance on a limited basis, quiet areas are recommended, and being allowed to rest or work “as their ability to concentrate fluctuates through the day.” In practice, if the child is made unwell by combining work with social contact, an interim plan could incorporate friendship visits to school with quiet study at home.

The report identifies a classic sign of CFS/ME as the deterioration of the patient after even minimal physical or mental effort. Brain blood flow often falls and this abnormal pattern only ameliorates after rest. The report explains: “Activity beyond the level that an individual can usually tolerate will prompt a delayed worsening of symptoms.” Teachers may not witness such a deterioration, since by then the child is at home again.

Insufficiently adapted education is a key cause of relapse, and pulls down the child’s achievement. Taken in conjunction with the DfES guidance *Access to Education for children and young people with medical needs* and the new Code of Practice for the identification and assessment of children with special educational needs, this report emphasises that a child with CFS/ME should have educational opportunities without exacerbating their illness.

Behind these recommendations is the recognition of the serious physical nature of this illness by mainstream doctors. In the past it was often considered a mental health problem, as were MS, tuberculosis, and other diseases before their causes were established.

The belief that home-based education should be quickly phased out has been eroded with the sobering recognition that: “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. Progressive deterioration can occur in some patients with CFS/ME. A minority of those with CFS/ME remain permanently severely disabled and dependent on others.”

Schools may be able to help in minimising the numbers who fall into this category.

***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).