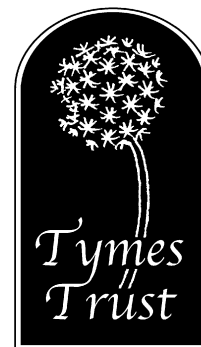


Professional Guides

Back to School?

First published Special Children April/May 2003
Reprinted with kind permission of Questions Publishing



Jane Colby

Former Head Teacher

Member, National Association of Educational Inspectors, Advisers and Consultants

Executive Director, The Young ME Sufferers Trust

Member, Chief Medical Officer's Working Group on CFS/ME

Abstract

This Guide analyses how relapses in children with ME are being caused by inappropriate programmes of reintegration arrived at through misinterpretations of the statutory guidance Access to Education for Children and Young People with Medical Needs.

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).

educational, medical and social work fields and included consultant paediatricians, parents and representatives of patient groups. We considered direct evidence from families and children, evidence from scientific studies and the clinical experience of physicians. The report, published by the Department of Health and endorsed by the Department for Education and Skills states:

- 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.

In his book *Enteroviral and Toxin Mediated ME/CFS and other Organ Pathologies* Dr John Richardson noted that 'isolation stress gravely interferes with immune resistance.' *Access to Education* states that 'generally' children do best in a group. So are the two publications

from the DOH and the DfES in conflict with one another?

In fact, both go hand in hand. Dr Richardson points out: 'Until such time as more specific treatment is available, empathy and support are undoubtedly potent agents in combating disease.' This means providing for the whole child. The holistic approach means we should neither attempt to meet the need for friendship and

A home tutor trained in CFS/ME can be key to building contact between the two worlds of school and home

company by forcing children into school even if it makes them worse, nor attempt to meet their need to learn by delivering education in total isolation.

The provision of home tuition, distance learning, part-time attendance at a home-and-hospital unit or school, flexibly adjusting these according to severity and stage of the illness, can include visits from friends and/or staff to the child's home. In this way, the child is supported and cared for, relapses minimised and educational achievement maximised.

Home teaching

A home tutor trained in CFS/ME



can be key to building contact between the two worlds of school and home; indeed, *Access to Education* clearly states that 'home teaching should be available for those who need it'.

Access to Education makes the following helpful points:

- A child with CFS/ME may be too sick to access education and should not be inappropriately pressurised
- Information Communications Technology can help to combat isolation and facilitate learning
- Support after 16 years of age may be needed
- Continuing support after the child returns to school may be needed

Some LEAs request a consultant's letter before deciding on provision. In practice, it is usually impossible to see a consultant within the 15 days by which an LEA is now bound to initiate provision. Therefore the GP should not be cut out of the loop; otherwise the LEA will fail in its duty to put suitable education in place within the prescribed time. The GP is best placed to monitor the child frequently and advice can be sought more quickly than from a consultant. A GP is qualified to make a diagnosis, to prescribe treatment and to recommend suitable education.

The medical profession is still in discussion about how best to manage CFS/ME in the long term. There is as yet no cure. It may be helpful for the school to contact the Tymes Trust, who can put them in touch with specialists who worked on the Department of Health report and who will explain in more detail.

Reintegration plans

Access to Education states: 'An LEA is responsible for ensuring that an individually tailored reintegration

plan is in place for all pupils before they return to school.'

This statement should be interpreted literally. It does not say that all pupils should have an individually tailored reintegration plan. It does say that before the pupil returns to school, such a plan should be in place, as this will of course ease the transition, both practically and emotionally.

The average bout of CFS/ME takes around four-and-a-half years to resolve and many children are too fragile to attend school for at least half of that time. They will therefore not need a reintegration plan until



return to school is envisaged. In practice, plans put in place typically include the reintegration element from the very beginning, putting pressure on chronically sick children and their families, who continually feel they are failing by not managing to meet the demands of the plan. This leads to frustration on the part of the school, as the plan is visibly seen to be failing.

A broad and balanced curriculum

Many LEAs try hard to provide this 'entitlement' to children with CFS/ME, whose brains cannot hold such a volume of information. Attention and cognition are both affected. Brain scans show that blood levels (and therefore oxygen levels) typically fall after effort, resulting

in extreme malaise and confusion. A child's face may blanch a short while before being taken ill.

Children with such serious brain dysfunction and physical fragility can sadly achieve nothing if they study many subjects at once, or try to take examinations in a large cohort. Ironically, they are educationally disadvantaged by a broad, balanced curriculum. They

The average bout of CFS/ME takes around four-and-a-half years to resolve

are also commonly made more unwell and this means that the LEA is failing in its duty to care.

When the *Access to Education* guidance superseded a listing of medical conditions in the Code of Practice for the Identification and Assessment of Children with Special Educational Needs, it was recommended that schools link their policies for sick children with their SEN policies. By virtue of central nervous system dysfunction and muscular abnormalities, children with CFS/ME have special educational needs and should be notified to the SENCO.

A modified curriculum will need to be part of the child's Individual Education Plan. Once the child is able to access school, PE will need to be omitted for a considerable

time, since effort is the commonest cause of relapse. The delayed deterioration after effort, characteristic of CFS/ME, can give the erroneous impression that the child is putting it on after the event.

Many children find that their IEPs are insufficiently supportive. In *Access to Education* the example demonstrating that frequent adaptations can be made also demonstrates that adaptations were continually made *after* the child had experienced a worsening of illness, rather than predicting problems. A setback can mean weeks or even months, and should be avoided when possible.

Rehabilitation

The effect of rehabilitation courses varies in CFS/ME, probably because the term Chronic Fatigue Syndrome encompasses different types of illness under one umbrella, as highlighted by the Medical Research Council. The neurologically defined 'ME', listed by the World Health Organisation, is potentially severe and chronic. It is a polio-like illness and in polio, twice the level of paralysis occurred in children who returned to school too soon.

The Department of Health report notes that: 'no treatment has been found universally beneficial – indeed, all may cause harm to some patients'. Many people have relapses and some become bedridden or wheelchair-bound as a result.

It would not therefore be defensible to withdraw home tuition from a child with CFS/ME because the child 'ceases to follow a therapeutic programme [...] as part of a rehabilitation and reintegration package'. Whilst this policy example from *Access to Education* is perhaps reasonable in a general context, it could not be enforced in CFS/ME.

In chronic illness, the government wants patients to become experts in managing their own condition. Perhaps most encouragingly, CFS/ME eventually improves without treatment in most people, given support and a conservative lifestyle. But the time-scale is typically years, not weeks or months.

Any guidance is only as effective as those who put it into practice. Some of the best practice has been found in schools where staff work in partnership with families on a genuinely collaborative basis.

Jane Colby was a member of the Government Chief Medical Officer's Working Group on CFS/ME and co-wrote the Children's Chapter of its Report, published in Jan 2002 by the Dept of Health. She is a former head teacher, medical and educational author and journalist, Consultant for the Education of Children with ME and Executive Director of Tymes Trust (The Young ME Sufferer).

Access to Education for Children with Chronic Fatigue Syndrome/ME

126 families with children with Chronic Fatigue Syndrome/ME were surveyed about their experiences of the state education system and how helpful their LEAs had been.

These were their responses:

Educational provision

- **76% were not satisfied with their education provision**

- 22% were satisfied but some said they provided it themselves
- 2% did not answer this question

- **87% had had to struggle for recognition of their needs**

- 13% had not had to struggle for recognition of their needs

- **81% had moved school to get recognition of their needs**

- 14% had not moved school to get recognition of their needs
- 4% did not answer this question

- **63% had left state education**

- 31% had not left state education
- 6% did not answer this question

- **65% had paid for private tuition or distance learning**

- 33% had not paid for private tuition or distance learning
- 2% did not answer this question

- **62% had felt threatened or bullied by attitudes from other children**

- 35% had not felt threatened or bullied by attitudes from other children
- 3% did not answer this question

- **84% had felt threatened or bullied by attitudes from professionals¹**

- 15% had not felt threatened or bullied by attitudes from professionals
- 1% did not answer this question

- **72% did not give a vote of confidence to state education for children with CFS/ME**

- 14% did give a vote of confidence to state education for children with CFS/ME
- 14% abstained from this question; some explained that they could not give an opinion as they were using private educational facilities.

Help from LEAs

- 10% of families rated their Local Education Authority *'as helpful as possible'*.
- 5% of families rated their Local Education Authority *'very helpful'*.
- 25% of families rated their Local Education Authority *'helpful'*.
- 28% of families rated their Local Education Authority *'not helpful'*.
- 21% of families rated their Local Education Authority *'very unhelpful'*.
- 11% of families did not answer this question. Some said this was because they were not using LEA facilities.

¹ It was noticeable that in most cases, this applied to both medical and educational professionals, but in some cases only one profession was referred to, commonly either the medical or the educational profession.