**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).
Early in 2002, the Department for Education and Skills published statutory guidance for schools under the title *Access to Education for Children and Young People with Medical Needs*. It was hoped that it would significantly assist children with Chronic Fatigue Syndrome/ME, since in 1997 a study of a school roll of 333,000 pupils over six widely spaced local education authorities revealed that 51 per cent of children on long-term sickness absence had the condition, making them the biggest group. The nearest was cancer and leukaemia, with 26 per cent.

One year on, local interpretation of the national guidance has forced many families to change schools, to pay for tuition privately, or even to leave state education altogether (see page 31).

The intention is for all sick children to receive their entitlement to education promptly and with comparable continuity to their friends. What could have gone wrong?

**Appropriate education**

The overall aim of *Access to Education* is to enable ‘children and young people to access education appropriate to their medical condition’.

In practice, re-integration is often elevated above this main aim, with some LEAs renaming their provision ‘reintegration’ services. The sample LEA policy included in *Access to Education* may be being confused with the guidance itself. That policy aims ‘to reintegrate these [sick] pupils back into full-time education at the earliest possible opportunity.’ Unfortunately it does not explain how that objective will achieve the overall aim of enabling all children to access education ‘appropriate to their medical condition’.

Whilst early re-integration might work well in some illnesses and enable the child to carry on ‘normally’, in CFS/ME the central nervous system is too badly affected for this to be successful. One medical specialist has declared that we should regard the child as brain injured. The dysfunction, comparable to the effects of a stroke, can be so severe that some may no longer recognise their own parents.

When *Access to Education* was being written, the government Chief Medical Officer’s Working Group on CFS/ME was in the throes of a three-year process culminating in the publication of its own report by the Department of Health in January 2002.

The panel that produced the recommendations for children comprised experienced practitioners from the
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 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.

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

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 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

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
The average bout of CFS/ME takes around four-and-a-half years to resolve. A modified curriculum will need to be enforced in CFS/ME. 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.

**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.