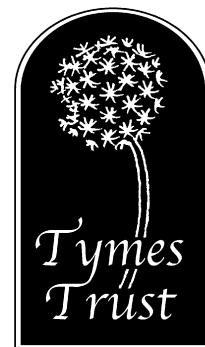


# *Professional Guides*

## **The SENCO's Key Role in Supporting Pupils With CFS/ME**



*First published SENCO Update October 2003*

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### **Abstract**

*This Guide has been produced to assist Special Educational Needs Coordinators to manage educational demands on children with ME to preserve health and help them achieve. It incorporates some of the best ideas and practice to come out of years of work in this field.*

### ***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).

## Supporting pupils with CFS/ME

In this article **Jane Colby** addresses the question “Why does a SENCO need to be alerted to children with Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME)?”

### **The children’s section of the Department of Health report (2002) on which I worked for three years as a member of the Chief Medical Officer’s Working Group on CFS/ME explains:**

- 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.
- Many of the symptoms of CFS/ME suggest dysfunction of the central nervous system.
- Activity beyond the level that an individual can usually tolerate will prompt a delayed worsening of symptoms.
- Nearly all children who are severely affected and many who are moderately affected will require the provision of home tuition and/or distance learning.
- An educational plan is not an optional extra but an integral part of therapy.
- 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.

From this we can see that CFS/ME is a disabling illness producing special educational needs. Health is vulnerable, often for many years. Children who need a manual wheelchair will also need someone to push it, because used energy, once expended, cannot be regenerated in the normal way.

A child who expends too much energy, whether physically or intellectually, may relapse, so the special educational needs of a child with CFS/ME overlap considerably with their medical needs.

### **A typical illness pattern for CFS/ME**

- (1) Viral infection mimicking flu, gastric flu, glandular fever, tonsillitis
- (2) The illness appears to abate
- (3) The child returns to school
- (4) Complications of the infection develop.

Sometimes the initial infection is mild and may not be obvious. A similar pattern occurred in poliomyelitis, to which CFS/ME may be related.

### **CFS/ME is the biggest cause of long-term sickness absence in schoolchildren**

A typical school attendance pattern:

- \* Absence during the initial infection
- \* Child returns to school
- \* Relapse occurs
- \* Child returns to school a second time
- \* Relapse occurs again
- \* Broken attendance punctuated by relapse becomes the norm
- \* Family seeks part-time attendance and/or home tuition
- \* Targets set for re-integration
- \* Targets prove unrealistic as recovery can take years
- \* Friction develops between school and family
- \* Disbelief and mistrust ensue
- \* Family change school, or withdraw from state education in despair.

Social services may become involved if non-attendance is misinterpreted and the parents are suspected of neglect or abuse.

A knowledgeable SENCO can take the lead in helping to adapt education so as to break this destructive pattern and re-establish trust. The key cause of relapse in children is generally education.

Find out how many children in your school already have CFS/ME. Clusters occur in schools, families and communities so one case may mean more.

### **Practical steps in the individual case**

- (1) Meet the child with their parents and develop a rapport.
- (2) Ask the family what makes the illness worse; cases are different.
- (3) Discover what subjects the child likes best. The curriculum usually needs to be drastically cut and children can achieve more in subjects they enjoy.
- (4) Play a key role at decision-making meetings.
- (5) Ensure that all coursework is limited to the minimum.
- (6) Consider formal assessment under the SEN Code of Practice.
- (7) Any Statement of Special Educational Needs will need to be flexible and should be monitored frequently as the illness fluctuates.

Children with CFS/ME lack the strength to study many subjects. If they do, they may achieve little to show for all that effort.

Soon they feel like failures. They already feel undermined by physical limitations. When they relapse or are unable to keep up with work, it is typically the system that has failed them, not the other way around. The entitlement to a 'broad, balanced curriculum' becomes a straitjacket restricting their achievement.

### **Post-activity deterioration**

When a child relapses at home after effort at school, parents may not be believed. 'She was all right in my class', is a typical observation from teachers who have not been trained in CFS/ME. A key clinical feature, observable in tests, is that the body responds to effort by declining afterwards. The deterioration may not be obvious for a day or so, but can then be dramatic.

Physical and/or intellectual over-demand can lead to the child becoming bedridden or even reverting to an earlier phase, such as partial paralysis or tube-feeding. Schools could be held accountable if they negligently cause such a relapse.

### **Systems can help**

Once you have identified the children with CFS/ME in your school:

- Initiate a red-flag procedure to alert the SENCO to any child diagnosed with CFS/ME.
- Meet with the families on a regular basis.
- Note specifics about each case. Neurological effects can differ.
- Watch for educational complications; eg dyslexia can result from ME.
- Monitor whether the pace of work is sustainable. If symptoms are abating, the body is healing. Increased demands from school can set back this progress.
- Consider daily schedules. Damage to the hypothalamus can result in sleep reversal and morning work can be counter-productive in many cases.
- Physical support needs to include minimising travel around buildings, stairs, carrying of bags.
- Consider a joint health and education plan for the child.

### **Pupils' other needs**

Some of these symptoms may seem eccentric, but just as in meningitis, they point to damage in the central nervous system. If the child has many symptoms or is in constant pain, they probably should not be in school.

- \* Temperature regulation is often impaired. One child, persuaded back to school too soon, collapsed unconscious and had to be rushed to hospital by emergency ambulance. She had overheated.
- \* Some children may need coats on warm days and may need to take off clothing on colder days – the reverse of normal.
- \* Some may need to eat immediately they start feeling ill, much as a diabetic needs a biscuit; blood sugar levels can drop suddenly.
- \* Fumes, the smell of paint or the perfume from flowers, can cause dizziness and malaise.
- \* The child may need to visit the toilet frequently.
- \* Dark glasses and even a peaked hat may be needed because of over-sensitivity to light.
- \* Rests may be needed in a sanctuary or quiet place.

### **The spectrum of the illness**

Some cases are more severe than others and a mild case can become severe if mishandled. When a child returns to school, lack of co-ordination between teachers can mean over-demand to 'catch up'.

Some children are more affected physically. Some are unable to walk but their thinking processes are less affected.

Some suffer panic attacks, distress or even bouts of over-activity, due to imbalance of brain chemicals. Adrenalin may surge, forcing the child to behave as if on amphetamine. Then they will be ill or just totally exhausted.

Pulse may speed up or slow down. There may be flutters at the heart, extra (ectopic) beats and frightening bouts of tachycardia (racing pulse) which are not controllable. The muscles may twitch visibly due to incoordination of muscle fibres and exercise may be unwise.

The SENCO can give the child's teachers the salient facts. Do not assume that someone else has performed this task. The Young ME Sufferers Trust produces a simple Teacher's Information Sheet; copies can be given to the children to show temporary teachers, dinner staff and others.

### **Falling into two categories**

These children are sick but also have special educational needs, so the government statutory guidance *Access to Education for Children and Young People with Medical Needs* is as relevant to your work with them as the SEN Code of Practice.

However, misunderstandings have led LEAs to, for example, impose re-integration plans on children who will not be fit enough to attend school for a long time.

The instruction is to ensure that children have such a plan in place before they re-attend. The plan does not have to be in place long before it will be

needed. To put it in place far too early puts pressure on sick children, and sets them unachievable targets. A sense of failure results if the targets are unrealistic.

### **Work with the school examinations officer**

Special Arrangements (*eg* taking the exam at home, rest breaks, an amanuensis) redress the balance and level the playing field a little. They enable the child to try and demonstrate what they are capable of and what they have learned. Taking exams at home can maximise the grade achieved, as energy is not used in getting to the examinations centre.

A child with CFS/ME is severely disadvantaged in exams. Attention and cognition are both affected. Coupled with the other neurological problems, this can lead to a child being unable to complete a paper, being unable to sit more than one, or even becoming very ill through intellectual over-demand.

Special Consideration can come into play at the marking stage if the child became ill during the exam or was generally unwell on the day and has not achieved a representative result.

SATs are controversial for children with CFS/ME. Exams of any kind take a toll on the child's health. Since SATs confer no qualifications but are there for other reasons, the usual advice is to put health to the top of the agenda and to avoid taking them. The school's duty of care is paramount.

### **Primary school issues**

Fewer primary age children suffer from CFS/ME, which peaks in the mid-teens. This is thought to be due to hormonal factors and factors related to the activity of the developing immune system. Because fewer teachers are involved with the child, it is vital that all key staff understand the fragility of the child's health. Project work produces subject overlap and curriculum issues differ from those at secondary level, but the smaller building and grounds, lack of stairs, and the involvement of parents as a routine part of school life are all advantages. Having supportive parents as assistants for their own children deserves consideration and an informed SENCO can facilitate this.

### **Secondary school issues**

A knowledgeable SENCO can help make decisions that will not overstretch the pupil, particularly at the 'options' stage. Because of the number of teachers and the size of the building, use of the Tymes Trustcard can be helpful. Careers advice and the involvement of Connexions earlier than usual may be appropriate. Families may be stressed, not knowing that accommodations can be made for sick and disabled children by colleges and universities. Early liaison with Disability Officers in any prospective college or university can reassure the family that their child can access a course without the usual complement of exams.

### **Where does responsibility end?**

Not all relapses are your personal failure. Do not be tempted to assume such a huge weight of responsibility. Relapses can follow other infections, immunisations, stressful events that undermine the immune system, over-activity at home - in short, events that you cannot control.

When The Young ME Sufferers Trust collected information from 126 families of children with CFS/ME, 81% reported having to uproot their child and change school in order to find support. This is a drastic step to feel forced to take when your child is ill.

These were not fussy, overdemanding parents, they were just parents whose children had been denigrated in school, called 'lazy', 'skiver', and other cruel words. These words had come from teachers; phrases like 'It's not as if she had cancer,' or 'I get tired too, you know' were frequent. Children had been told that social services would take them from their parents.

A SENCO can work in partnership with the family as a knowledgeable, influential friend and can make sure that the state education system helps and supports and empowers the child with CFS/ME rather than the reverse.

**The SENCO is not just the key person whom the family can approach when things go wrong. SENCOs can do more than trouble-shoot – they can make sure that things go right.**