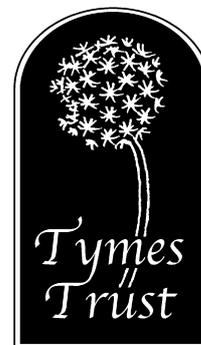


Professional Guides

Ten Points on the Education of Children with ME



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Abstract

This Guide is a complete, practical "How To" - it sets out principles that enable a child with ME to achieve educationally whilst preserving health as much as possible. They have been developed through years of personal experience and study of the illness, and have proven consistently effective.

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).

Ten Points on the Education of Children with ME

When a formerly fit child suddenly develops a severe case of ME, the decline into ill health can be dramatic. Myalgic Encephalomyelitis or 'Chronic Fatigue Syndrome' is a neurological disease of the brain and central nervous system which has existed under various names for centuries. It is becoming increasingly prevalent and can be found in clusters in schools, families and communities.

Potentially long-lasting (an average bout lasts four and a half years, relapsing over decades) it can be very disabling and is known to be virally triggered. Microbiologists suspect that it is a variation on poliomyelitis not covered by vaccination; many children suffer similar symptoms to polio, including breathing difficulties and partial paralysis or muscle weakness, particularly after effort.

Effects come on up to 48 hours after the effort was made. Children can lose the ability to swallow and, in some cases, tube-feeding may be necessary.

Exhaustion and pain can be extreme, but because of the typical delayed effect, teachers will not witness this and may find it hard to believe that the child is really as ill as parents may say.

1 Autumn Awareness

ME often starts in the Autumn term, just when new physical and intellectual demands are placed on children beginning a new school year or entering a new establishment. Staff may suspect stress, and the child may be considered psychologically troubled, but summer/autumn onset is just one of many known epidemiological features of this disease, no matter what the patient's age.

Entering a new social group gives maximum opportunity for spread of organisms and staff themselves are not immune; teaching is the highest risk occupation for developing ME.

Children's absence from school has led to parents being suspected of neglect, of condoning truancy, or even of Munchausen's Syndrome by Proxy [*recently renamed Factitious Induced Illness*], where a person harms another to gain attention. School phobia or anorexia are common misdiagnoses and a survey by the BBC's *Panorama* team found that 59% of families were told their children's illness was due to psychological problems. The cluster pattern means that a school with one case of ME may have more; it is not uncommon for a vigilant teacher to be the first to spot a case.

2 Educational Deficit

ME has a devastating effect on education, causing more long-term sickness absence than

any other illness. A five-year study of six widely spaced LEAs revealed it as responsible for 51 per cent of such absences [1]. No other disease came close to this figure; cancer and leukaemia, the next most common, scored only 23 per cent.

For a child, the key factor in recovery is often the way in which education is managed. By law, the child must be educated, and is entitled to the best education possible, but educational demands often turn a mild case into a severe one. Teachers have a huge responsibility to avoid this, while still enabling the child to achieve as much as possible.

How do we reconcile these apparently conflicting aims? Personal experience and study of this illness over the years has enabled me to develop principles which, if applied, work consistently from case to case and do enable the child to achieve educationally whilst preserving health as much as possible.

3 Sickness versus Special Educational Needs

A sick child can receive home tuition in the short-term, with the aim of returning to school as soon as possible. A child with special educational needs is typically the subject of long-term plans to enable learning to take place as effectively as possible. The child with ME unfortunately falls into both categories at once and should always be drawn to the SENCO's attention, firstly because inappropriate education can worsen the illness and secondly because brain function is damaged; conditions such as dyslexia and dyspraxia may develop.

An Individual Education Plan is useful, whether or not statementing is contemplated. The increasing use of Home and Hospital services enables many sick children to attend a setting suitable for their needs instead of having tuition at home, but attendance at a unit of any kind is not always right for a pupil with ME. Where health is put first, the family will be eternally grateful and a true teacher-parent partnership can develop.

4 Health before Work

Paradoxically, putting education second actually achieves the best educational results in this illness. A child who is recovering is a child who can achieve educationally. Parents of children with ME typically care most about their child's physical well-being and they are right to do so, since learning can take place at any age, whereas inappropriate education actively exacerbates the illness and delays recovery.

Causing harm or failing to provide suitable education may make the LEA legally liable and parents are starting to take authorities to court - and winning. Pressure on children with ME to attend school is applied because of a conviction that this is where children belong. But they only belong there if attendance threatens neither their health nor their educational achievement. In addition, any potential social benefits are negated for a child who has continually to watch their friends doing everything that they cannot do.

5 The Yo-Yo Pattern

After recuperating from a bout of ME, the child may return to school having apparently recovered or begun to recover. Everyone is hopeful that the illness is over. Then relapse occurs. Many years of yo-yoing between attendance and absence may follow, during which the ME becomes chronic.

Parents and child become increasingly distressed by the persistence of the disease, and teachers and doctors may suspect that school phobia has taken over from physical illness. During this time, children commonly underachieve, having little to show for their sporadic attendance at lessons. This is because the energy expended on getting to school, carrying bags and walking around the building has been at the expense of cognitive function.

Many youngsters leave school with few or no qualifications, still not properly well, and unqualified for college or university.

6 Porridge Brain

The well-known term ‘porridge brain’ is a classic amongst people with ME. The sensation of trying to access information when attention and concentration are no longer possible is reminiscent of how Mother Hubbard felt when she went to the cupboard to get her poor dog a bone. When she got there, the cupboard was bare. Trying to recall information when brain fatigue has set in is like finding a set of empty neural shelves. No matter how hard the child tries, thinking is *impossible*, and trying to think produces unpleasant physical symptoms. Brain scans, both in children and adults with ME, show that when effort (physical or mental) is undertaken, blood flow to the brain decreases and the oxygen supply is reduced. Normally, effort results in an *increase* in blood flow to the brain because of the increased demands upon it.

7 The Goal-Oriented Environment

The goal of education is to educate; where this takes place is secondary to that aim. It should be the place that produces the best results. The most suitable environment for a child suffering with ME is

often the home as it involves no expenditure of energy in travel.

To function intellectually, energy has to be conserved for that purpose. A brain starved of oxygen cannot think clearly or remember anything. The child may collapse or feel faint; encouraging a child with ME to go on working for even a short time after symptoms arise is to invite a relapse [2]. Built-in mini-breaks can minimise symptoms, and using the home as the learning environment is energy-efficient; results can be far better than at school.

Home tuition and/or distance learning employed for longer than is customary can also produce much better examination scores, especially when special arrangements are put in place. Specialist home tutors or distance learning tutors knowledgeable about ME are needed.

8 The Focused Curriculum

Sadly, for the child with ME, the entitlement to a broad and balanced curriculum is an entitlement to fail. In addition to suffering a painful disease, these children frequently fail educationally - a double whammy that we can avoid. A broad and balanced curriculum is only useful to a child who can benefit from it.

ME causes not only serious cognitive dysfunction such as short-term memory loss, inability to process words and numbers into a meaningful structure, and a drastically shortened attention span, but the effort necessary for intellectual work often makes the child physically ill.

For the best results it is necessary to follow, not a broad and balanced curriculum, but a focused one, concentrating on a few subjects and minimising course-work. This leads to real achievement in those subjects. Achievement is the child’s entitlement. It raises morale and demonstrates that real success is possible.

9 End-on Exams

Once one or two subjects are identified for study (in mild cases one may consider more) the child is allowed to study them exclusively, right through to GCSE or another qualification. The idea is to take the examination as soon as the course has been covered, which may be at an earlier age than usual, and then go on to other subjects. Instrumental music examinations are traditionally taken as soon as the student is proficient at that level, whereas it is traditional for most pupils to take the majority of their GCSEs concurrently, at the same age as one another. This means sitting large numbers of papers within a few days. The ME brain cannot manage this without a marked deterioration in health which may set back recovery significantly. It also discriminates

against achievement, since the brain begins to be able to think less and less clearly. The pupil typically does less and less well as the days go by, eventually having to give up before completing the papers and suffering ill effects for a long time afterward.

10 Longitudinal Achievement

Taking GCSEs and other similar examinations in this way enables the child to progress to other subjects. Thus a *Portfolio of Qualifications* is built up, in spite of the intellectual and physical disability suffered by the child. By the time the school leaving age is reached, the pupil will hopefully be in at least partial remission and have a number of qualifications to show for all those years of work – just like other children. Thus we can level the playing field for them and help them towards a future.

One boy whose parents consulted me when he was eleven years old has followed these principles ever since; he achieved his first GCSE in history (his favourite subject) at the age of 13 and by 15 he had achieved 6 GCSEs, each graded either A or A*. For most of this time he was bedridden and almost always too ill to go out of the house. *[He has subsequently gained entrance to Cambridge University.]*

It is the child's right to be enabled to achieve qualifications. Idealism about studying a wide range of subjects needs to be tempered with realism and pragmatism. If approached in this way, the child with ME can still study a number of subjects - just not all at once.

∫ Conclusion

These are some of the principles of energy-efficiency in education. However, over and above energy-efficiency we must build in the flexibility to respond to the illness itself and its vagaries.

The illness typically varies during the day, so that each child will have a 'best time' when the brain is at maximum arousal. This is the most efficient time to deliver a lesson, and is often during the afternoon or early evening, due to defects in the brain's hypothalamus gland and its control of automatic functions like body temperature and sleep.

Relapses due to vaccinations, other infections, and any unusual demand upon the child are not predictable either.

The health status of the child (ie how far health has progressed towards stabilisation of the illness, so that efforts will not produce full relapse but only a short setback) must always determine the approach. This is what I have termed Status Responsive

Education and it is the overall guiding principle informing everything else.

Finally, we must allow these children to have a life. 'I saw him out on his bike' means 'I saw him trying to have a life'. ME is a soul-destroying illness and children have to learn about it; they must sometimes test the boundaries and learn from the relapse which ensues if they go too far.

References

- [1] *Long Term Sickness Absence due to ME/CFS in UK schools*; An epidemiological study with medical and educational implications Dowsett EG, Colby J Journal of Chronic Fatigue Syndrome May 1997 vol 3 (2)
- [2] *Zoe's Win* Colby J, SEN book on ME pub. Dome Vision 2000 price £7.95