

A Good Practice Guide to Education for Children with ME for GPs, Schools and Families



The Queen's Award
for Voluntary Service

The MBE for volunteer groups

Jane Colby FRSA

Executive Director, Tymes Trust

Former Head Teacher

Co-author with consultant microbiologist Dr Elizabeth Dowsett: Long Term Sickness Absence due to ME/CFS in UK schools; An epidemiological study with medical and educational implications *Journal of Chronic Fatigue Syndrome* 1997. Comprising a school roll of 333,024 pupils and 27,327 staff, this is the largest study of its type. Key findings: ME/CFS is the biggest cause of long term sickness absence from school; it is often found in clusters.

Jane was a member of the Department of Health Chief Medical Officer's Working Group on CFS/ME and contributed key recommendations on education to Chapter 5 of its 2002 report.

The Department for Education included Jane's recommendations in its 2013 statutory guidance for local authorities on the education of children unable to attend school normally due to illness.

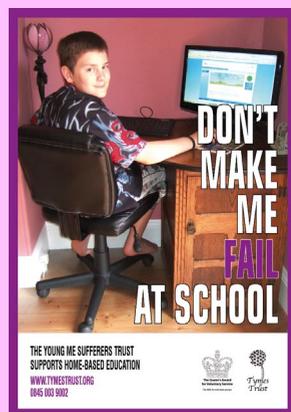
There is no cure for ME (full name myalgic encephalomyelitis, WHO classification ICD10 G93.3). The Department of Health uses the term Chronic Fatigue Syndrome (CFS) alongside ME.

The National Institute for Health and Care Excellence (NICE) states: "There is no known pharmacological treatment or cure for CFS/ME'.

The NICE Quick Reference Guide states: 'Be aware that people with CFS/ME have the right to

refuse or withdraw from any component of their care plan without this affecting the provision of other aspects of their care, or future choices about care'. The full Guideline refers to the 'patient's preferences and views firmly driving decision making'. In the child's case this is mainly the parent.

Despite this injunction, there is frequent conflict over how the child should be allowed to recover. Part of this appears to be down to a basic



"It can be next to impossible to study effectively after struggling into school."

**Lord Clement-Jones
CBE, Founder Patron
TYMES Trust**

misunderstanding about NICE recommendations over education.

What does NICE recommend?

There is frequent confusion between 'education' and 'school'. NICE uses the term 'education' rather than school. It talks of a flexible approach with home tuition and equipment that allows a gradual reintegration to education. *Not school.* This is frequently

misinterpreted by hospitals, leading to plans being made which schools feel they have to adhere to; these plans typically aim to increase the child's *attendance at school*, rather than the provision of suitable education, which may be in the home. This commonly leads to relapse, and unnecessary conflict between home and school.

Our Advice Line Records and the clinical experience of paediatricians we have worked with both confirm

that school attendance is a key source of relapse in pupils and students. In many cases it is the main source. Attending is too demanding physically, even part-time in many cases. It drains what little strength the pupil has, aggravating nervous system dysfunction and cognitive deficits and undermining the recovery process.

We have known children become bedridden for long periods after inappropriate school

GP Dr Nigel Hunt : *Everything needs to be tailored specifically to the individual young person*

One of the important skills one should learn early on in one's career as a doctor is to know one's limitations. Thus it was that I recognised that to achieve a holistic approach to ME I could extend the team around the child to encompass the educational dimension. In this way there was the potential to bring about real achievements

educationally as well as in terms of medical care. Thus my collaboration with former head teacher Jane Colby was born.

One of my young patients was a member of Tymes Trust for many years. At one time she was severely ill. Her success illustrates the importance of an open-minded collaborative approach so that the professions can work

together to maximise the potential for young people with ME.

Everything needs to be tailored specifically to the individual young person. Any plan needs to be flexible and must adapt to the changing and often fluctuating clinical condition whilst at the same time empowering the young person on the road of lifelong learning.

attendance. NICE warns doctors against using attendance as a sole marker of recovery; children can sometimes make huge efforts to put in time at school as instructed, only to end up more ill as a result when this proves unsustainable.

Unsuitable educational demands therefore:

- undermine the doctor's medical management
- deprive pupils and students of their legal right to education suitable for their medical and special educational needs. ME is recognised as a disability under equality legislation.

A 25 minute webinar (10 slides with quotes) on the Department for Education statutory guideline on education for children unable to attend school (full or part-time) due to ill health can be accessed at www.tymestrust.org.

What can the GP do?

Teachers may not write prescriptions for medication, yet doctors are expected to 'write prescriptions' for education. Clearly some principle is necessary on which to base such decisions.

Energy efficient education assists recovery: recommendations can be made that are commensurate with pacing life carefully.

School attendance is not energy efficient and the government makes clear that there is no requirement for a plan to reintegrate to *school* until it is likely to be sustainable.

If a child is thought to need home tuition, or interactive virtual education (a successful innovation, promoting both recovery and achievement) or needs to be excused from physical education for an extended period of time, the school will require medical confirmation of this.

The GP is the doctor who is most accessible to the family and will often find him or herself in the position of being able to help by supporting such modifications; schools cannot insist on a consultant's recommendation.

GPs can have a positive influence on the educational demands made on the child so that progress towards recovery is enhanced rather than set back.

Curriculum

Every child is entitled to a broad, balanced curriculum, but unfortunately, with the effects of this condition on the brain (lowered oxygen perfusion after effort) this 'entitlement' is in many cases prejudicial to achievement; studying too many subjects at once often has the added effect of militating against physical recovery.

Medical recommendations are usually crucial to the school's acceptance of the need for a modified

curriculum.

The GP may need to lend support to a reduction in the number of subjects over a spectrum: from nil (where education may need to be entirely stopped for a while due to the severity of the condition) through a period of studying very few subjects, and finally to a full curriculum, if the child's recovery proves to be sufficiently robust.

During this progression, which may take some years, flexibility is important, with adjustments made whenever necessary.

Recovery is not likely to be a smooth upward curve.

Examinations

A whole spectrum of modifications can be made to examination procedures, including extra time, rest breaks, and even sitting the exam at home.

Any such modifications are not intended to confer an advantage, but to help

level the playing field, so that the student has a chance to show their knowledge and produce the standard of work of which they are capable. This is the purpose behind all examinations.

The provisions allowable are subject to change so up to date guidance needs to be obtained.

Timescales

In 2013 the Department for Education issued statutory guidance for Local Authorities entitled *Ensuring a good education for children who cannot attend school because of health needs*.

As soon as it is clear that a child will be away from school for *15 days or more (whether consecutively or cumulatively)* other provision should be made. Since the child is unlikely to have seen a paediatrician within this timescale, *schools cannot insist on a consultant's recommendation before making provision*. The guidance makes this clear.

The GP's prompt support for the family is therefore not only needed, but crucial to proper education provision.

The guidance applies to children in all types of school and those not on the roll of a school. It is the Local Authority's responsibility to ensure that these children receive a *good* education. It applies equally, whether a child cannot attend school at all or can only attend intermittently.

The whole document is based on the consideration of what is best for each individual child. It is made clear that the child should not feel it is their fault that they cannot get to school in the normal way. They are ill. It is very easy for a child to feel a failure when it is the system that is failing them.

The guidance also makes clear that reintegration into school may take a long time and it may be necessary to mix education at home with education in school during this period.

Stages of the illness

There is a spectrum of severity in ME.

Cases range from what has been termed ‘mild’ to ‘very severe’; however, ME is not in itself a mild condition but a potentially severe and chronic disability that has become included under the wider concept of fatigue.

Milder cases can become severe and chronic unless carefully managed.

The late consultant microbiologist and ME expert Dr Elizabeth Dowsett advocated an extended period of convalescence from ME. Her principles of management have stood the test of time:

- *conservation of energy*
- *reduction of stress*
- *simplification of work*

It can be helpful to think in terms of stages.

Stage One (more obvious in severe cases): the patient feels ill all the time. Apparent

improvements are fragile. Exercise is counterproductive. As in all acute illnesses, a drastic reduction in cognitive activity is usually indicated. However, this need for reduction in physical and intellectual activity will typically persist for far longer than in many other illnesses.

Stage Two consists of stabilisation. Any excess activity may cause relapse to Stage One. Great caution is needed. Patients may remain in this fluctuating stage for years and progress may be slow.

Stage Three has been called recovery but remission may be more accurate. Activities can be gradually increased with confidence.

The GP is the doctor who is most accessible to the family. A student says: ‘Our GP was always there for us. It was he who opened the education doors.’

Key Quotes from the Report of the Chief Medical Officer’s Working Group on CFS/ME (Department of Health 2002)

“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.”

“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.”

“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.”

“Neither the fact of a child or young person having unexplained symptoms nor the exercising of selective choice about treatment or education constitutes evidence of abuse.” *We especially include this quote because the Trust sees frequent cases where families whose children have ME have been erroneously suspected of causing and/or maintaining their illness.*

Recent Research Findings

In 2010, researchers at Dundee university found an abnormal level of inflammatory chemicals in the blood of a proportion of children with CFS, and an abnormal rate of white blood cell death (apoptosis)^[1].

Professor Jill Belch, Professor of Vascular Medicine at the university, confirmed that this was consistent with a reactivating or persistent viral infection, echoing the findings of virologist John Chia in America who has found evidence

of chronic enterovirus infection in samples of stomach lining^[2].

Dr Chia also found evidence that such infection persists over many years.

The Dundee researchers also found that the children’s quality of life was significantly worse than children suffering with other illness (type 1 diabetes mellitus and asthma) with only one child out of 25 able to attend school full time^[3].

CFS is known to be a heterogeneous condition, with the more tightly defined ME having been subsumed under its umbrella. This has implications for treatment and research.

References

- [1] Kennedy, G. et al. (2010a) Biochemical and Vascular Aspects of Pediatric Chronic Fatigue Syndrome, *Arch Pediatr Adolesc Med.* 2010; 164(9):817-823
- [2] Chia JK, Chia AY. Chronic fatigue syndrome is associated with chronic enterovirus infection of the stomach. *J Clin Pathol.* 2008 Jan;61(1):43-8. PMID: 17872383
- [3] Kennedy et al. Physical and Functional Impact of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis in Childhood. *Pediatrics* 2010; 125:e1324-e1330.

In some cases, the child’s health needs may make it advisable to use only virtual education for a time.

Ensuring a good education for children who cannot attend school because of health needs
Department for Education 2013

Statement on virtual education

Jane Colby FRSA

Executive Director, Tymes Trust

Speaking at the House of Lords

As a former Head Teacher, I was author of the first specialist article on ME in schoolchildren (*The School Child with ME* was published in the *British Journal of Special Education* Vol 21 No 1 in March 1994). I also co-authored the largest ever study of ME in schools. This 5-year survey comprised 1098 schools, 333,024 pupils and 27,327 staff - the largest epidemiological survey of this type made to date. It revealed that ME is the biggest cause of long-term sickness absence from school in both pupils and staff.

Although we have created resources to help with education in-school, my personal and professional experience and also my research have shown that for young people with ME the most effective form of

education is home-based, with interactive virtual education producing grades equivalent to, or higher than, healthy students at school.

Social contact is provided by online student groups, and where possible, interaction with the local school.

Such a protocol enables very sick students to achieve, when otherwise they are typically condemned to a recurring pattern of school attendance and subsequent relapse with little to show for it. They often feel they are failures, when in reality it is the educational system that has failed them.

Such a protocol has also been shown to promote the student's health and recovery, in contrast with misguided pressure to get

back to school too early in what is a chronic, seriously disabling disease. Pressure of this kind is counter-productive, typically producing further illness and further interruption to achievement.

Finally, such a protocol is usually far less expensive than traditional home tutoring. It has, over time, not only produced success, but enabled many to get back to school or college again when their physical and intellectual stamina have recovered sufficiently to benefit, with far less detriment to their health.



About The Young ME Sufferers Trust

2014 is our 25th anniversary year. Started by two youngsters reaching out to offer companionship, TYMES grew into a national charity, honoured in 2010 with the Queen's Award for Voluntary Service: the MBE for volunteer groups. It was for pursuing the educational rights of children with ME and advancing their care.

The Tymes Trustcard

Launched by Lord Adonis, when Parliamentary Under-Secretary of State for Schools. Endorsed by the Association of School and College Leaders. A 'pass card' signed by the child's Head Teacher, carrying the child's photograph. It states that the child has permission to use the school's disabled facilities (eg lifts) or obtain other assistance. Application forms require confirmation of diagnosis. Please support the use of the Tymes Trustcard by young ME patients.

Free publications : www.tymestrust.org

Advice Line : 0845 003 9002



**The Queen's Award
for Voluntary Service**

The MBE for volunteer groups

