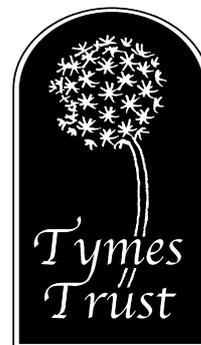


Professional Guides

Pushing the Boundaries in ME/CFS

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Abstract

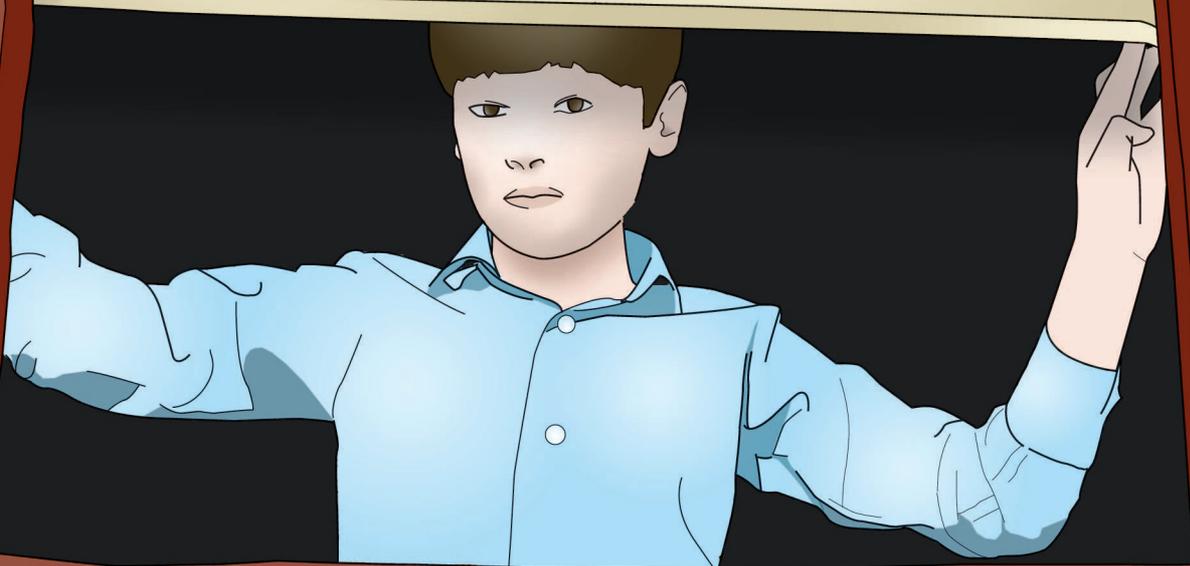
Ever more research is showing that ME/CFS is a physical illness. As the first ever biomedical research project into childhood ME begins, Jane Colby discusses the implications for education professionals.

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).

What are the underlying causes of ME/Chronic Fatigue Syndrome? **Jane Colby** reports on new research that may help to provide answers



Pushing the boundaries in **ME/CFS**

Peter Ustinov once said, “We are united by our doubts and divided by our convictions.” When it comes to the best way to treat and educate children with ME that is certainly true. Disagreements over school attendance, curriculum, special educational needs, medical needs, school examinations, home tuition, virtual education, all arise because of conflict between strongly held beliefs among professionals.

Now The Young ME Sufferers Trust has announced the first ever biomedical study in children with ME, also called Chronic Fatigue Syndrome. The Trust has co-funded the study with the research group MERGE and a contribution from a Scottish charity, Search ME.

Using sophisticated vascular imaging techniques, previous work by the researchers has already shown biochemical abnormalities in the circulation of adult ME patients, suggesting that ME could involve a continuing challenge to the immune system, such as a persistent viral infection.

The aim of the new study is to investigate a group of children with well-defined ME/CFS (in whom there is the possibility of long-lasting chronic ill-health) to see, for the first time, if similar biochemical abnormalities exist. If they do, children with ME/CFS may have a chronic inflammatory disorder associated with increased risk factors for cardiovascular disease, but encouragingly, the findings might

become the basis for future treatment interventions.

Myths

Doubts are more important than convictions, and science needs to ask questions. Too little biomedical research into ME has been done, too little confirmed about biological mechanisms involved, and about potential treatments and harm to the body when the illness is badly managed.

With doctors arguing about medical management, how can teachers decide what's best for their pupil? Teachers need to go back to the source – the children themselves – to devise a way out of this dilemma. We expect children to learn, so we too must be open to learning, not only from families about what, in their experience, is safe for their child to do without threatening relapse, but also from the latest research showing physical damage, potentially from viral causes.

Gene abnormalities, cell death abnormalities, brain function abnormalities, muscle metabolism abnormalities, spinal fluid abnormalities – serious physical dysfunctions are being uncovered. They receive little publicity in the general media.

Unfortunately, myths die hard. Some seem to have a life of their own and rule everything we do: “The Myth is dead; long live the Myth.” What is the main myth about ME? Surely, it is that ME is mainly psychological, or that even if it isn’t, psychological therapies will enable normal function to return in a few months or a year, enabling children to participate in school as they did before they were ill.

That path is fraught with bear-traps. It has resulted in parent-teacher wars with the child caught in the middle, tribunals, suspicions of child neglect or abuse, and even the threat of court cases where the duty of care is breached and illness is exacerbated.

This is all so unnecessary. When, as a headteacher, I opened a new primary school in 1982 (the height of the Project era) the local inspector criticised me for obtaining a set of large, beautifully illustrated and imaginative history books for the children to pore over. Children could not understand history, I was told, because they “were not there at the time”. By that reasoning, no generation can learn from the previous one and we are all condemned to repeat the same mistakes. Whilst there may be some truth in this, it is surely a counsel of nihilism and despair.

I countered his argument. By comparing the lives of people of yesteryear with their own lives, children can grasp differences, and should be encouraged to do so. There is danger in knowing nothing of the consequences that flow from ignorance, danger in acting on conviction and belief instead of actively seeking new knowledge and keeping our minds open.

In centuries past, it was normal practice to “bleed” patients. It was also normal to beat pupils who could not remember their lessons. We find such things unthinkable today, yet still many young folk with ME are pushed beyond their limits, tragically to the point of cruelty, by those who genuinely believe it is “right” for them. The result is often further disability and distress.

In LEA training sessions, I sometimes run an exercise where teachers internalise the potential impact of ME on their own lives and ability to care

for themselves. Like the child who “was not there at the time”, this is hard, but a teacher who has not personally suffered from ME/CFS (rather than chronic fatigue with its differing causation) cannot be expected to know how little effort it takes by body or brain to have a deleterious effect. Because of the classic “latent period” between cause and effect in this illness, they may not witness it in a pupil and may have to rely – and should rely – on the testimony of an observing third party, usually the parent.

Guidance

The recent report from the Royal College of Paediatrics and Child Health highlights “the devastating impact that CFS/ME can have on the education of the more severely affected child/young person.”

It accepts that “these children and young people are likely to require the provision of home tuition and/or distance learning although at times some may be too ill for any education.” It suggests that consideration be given to virtual education and states that paediatricians should liaise with the school “as soon as the diagnosis is made”, with a designated contact being identified within the school, with whom the paediatrician can establish an ongoing dialogue. It quotes the DfES guidance that when and if the child is deemed to be ready for re-integration to school, this process should be “slow and cautious”, for it is known that this is a key cause of relapse.

Unfortunately, while progress has been made in guidance for paediatricians, the RCPCH guideline is not all that was hoped for. Unlike the Department of Health’s approach in the Chief Medical Officer’s Working Group Report, the Royal College used a system placing low weighting on patient experience and a resulting emphasis on psychological therapies about which patients “in the field” report very differing results. This approach seems out of step with the government’s Expert Patient scheme in which those with chronic illnesses are themselves used as experts in how to manage their condition.

The guideline does indicate, however, that the common myth that Cognitive Behaviour Therapy or Graded Exercise Therapy can “cure” a child is misplaced. Probably depending on the individual pathology or stage of their illness, together with the individual therapist, some patients do report progress, but many others report deterioration. Studies have given few, if any, details of why some had to discontinue the therapy.

Many young folk with ME are pushed beyond their limits, tragically to the point of cruelty, by those who genuinely believe it is “right” for them



Early diagnosis

Without a diagnosis at all, schools have difficulty in making special provision. Such is the concern over delays in diagnosis, during which deterioration can take place, that 2005 also sees another collaboration. The ME Alliance is a group of six charities, members of the Chief Medical Officer's Working Group on CFS/ME, who all contributed individually to the 2002 Department of Health Report. That report decisively recommended flexible education for these children. The Alliance is now planning its first joint campaign on early diagnosis, with its own report for doctors.

Teachers cannot make medical diagnoses but, as I wrote in the first *ME Guidelines for Schools* in 1991, it is not unknown for an alert teacher, seeing the child daily, to spot a pattern that could turn out to be ME/CFS. If a GP requests home tuition or other special arrangements, schools and LEAs should take serious note. No matter how desirable it is to obtain a consultant's diagnosis and recommendation, statutory guidance from the DfES in *Access to Education for Children and Young People with Medical Needs* states that sick children who have to miss school for over three weeks should have other provision made.

The *knowledge* boundaries in ME are starting to be pushed back, but we have a long way to go before there is full

understanding and an effective treatment. In the meantime, unrealistic expectations, pushing too hard at the boundaries of *recovery*, is unwise and a more realistic approach is necessary. Dr Darrel Ho-Yen, a well-known medical author, microbiologist and ME specialist, has pointed out that in this illness it is by *living within the boundaries* that the boundaries expand as the body heals. A fair parallel is the child who can reach further the higher he grows. Growth has to come first.

Whilst relieving psychological distress is good and encouragement is also good, an educationist's true job is to find a way – not from previously held conviction but from open-minded and careful experiment – to help each one of our children achieve, and enjoy that achievement, in whatever way works best for them.

Jane Colby is a former head teacher. She is Executive Director of The Young ME Sufferers Trust (www.tymestrust.org / 0845 003 9002) and a member of the ME Alliance. Her latest book, *Supporting Children with ME / CFS*, will be available from Questions Publishing Company next term. To register your interest email sales@questpub.co.uk

Young Hearts: Inspirational poetry by children with ME

On Hold

The cure you would like to have is currently unavailable. Please try again later.

The life you are trying to reach knows you are waiting. Please hold.

Your hopes are important to us – we will be with you shortly. Please hang on.

Victoria Flute

From *Young Hearts*

A poetry book is rarely a page-turner. This is the exception. "I honestly could not put it down," comments an educational psychologist who sees children with ME regularly. "I feel I am really starting to understand what it must be like." This remarkable poetry collection by over 40 children and young people with ME has been launched by Terry Waite CBE, former Special Envoy to the Archbishop of Canterbury and middle-east hostage.

Jade Louise Scarrott was 14 when a random road accident cut short her life. She had suffered with ME for four years. Her poems are published in *Young Hearts* along with contributions from children and young people aged seven to twenty-six. Jade conceived the project and its title to raise awareness; the shock of her death determined everyone involved to dedicate it to her memory.

Some of the poems are cries from the heart: "I'm no different to anyone else. I'm just ill." Some are funny (*The Spider in My Room*), some contemplative (*Snow Falling*). Not all are about illness. What they share is the ability to touch us and leave us different from before.

Children with ME can become isolated, lonely and forgotten: "I am the child who disappeared, passing like a shadow from your lives..." Despite such privations, the amazing spirit of these young people shines through their words. As Terry Waite says in his Foreword, "Suffering need not destroy."

My world's stopped, but life goes on – And I've time to drink in each new dawn.

Young Hearts is available for £7.95 (inc. P&P) from The Young ME Sufferers Trust, PO Box 4347, Stock, Ingatstone, CM4 9TE. Tel: 01245 401080. Further information at www.tymestrust.org

