

The Brief by Jane Colby

Second in a series of information
pullouts for parents and older readers



Jane Colby FRSA

THE RCPCH GUIDELINE

In January the Royal College of Paediatrics and Child Health launched *Evidence based guideline for the management of CFS/ME in children and young people*. This document is for paediatricians and I was not part of the team that wrote it, but I was consulted on certain matters as a member of the Delphi Panel (individual experts consulted by the Royal College). This enabled me to make recommendations, some of which were accepted and others not.

The 'Executive Summary and Guideline Recommendations' are what many doctors will read. Unfortunately, the Recommendations on Cognitive Behaviour Therapy (CBT) and Graded Exercise Therapy (GET) are likely to prove problematic for many young patients and their families.

Theoretically, the Recommendation that 'Children and young people with CFS/ME should be considered for graded exercise or activity programmes..' just means that these therapies 'should be considered'. In practice, it could well produce a knee-jerk referral despite the detailed discussion in the full document.

Regarding school, 'poor attendance' (even after changes that I requested were made) is twice referred to as a psychological symptom. Absence from school may continue to be misinterpreted despite more helpful comments elsewhere in the guideline.

On the plus side, my recommendation that the term 'Special Educational Needs' be inserted was accepted. I also alerted the Principal Research Officer at the Royal College to how the statutory guidance from the Dept for Education and Skills, *Access to Education for Children and Young People with Medical Needs*, affects doctors. This was included, together with my recommendations

for virtual education as a possibility for some young people with ME. The guideline *detail* gives potential for more help with education generally, but the Summary less so.

The Dowsett/Colby study of long-term sickness absence in schoolchildren is in the references, plus two of my other papers.

The Trust itself engaged strongly in the Stakeholders consultation that took place later in the production of the guideline. Our representations achieved 21 changes in wording together with a number of amplifications of information.

Doctors are now advised that (when making the diagnosis) '...unless there are immediate concerns regarding the psychological wellbeing of the patient, a detailed exploration of family dynamics or the taking of a full psychiatric/psychological history is not necessary at this point.'

Nevertheless, we still have a number of serious reservations. The responsibility on the paediatrician will be to diagnose correctly within the spectrum of conditions where debilitating 'fatigue' is a symptom. The Clinical Algorithm (a flow-chart) is there to assist.

This flow-chart displays a box advising that where investigations are abnormal, the condition is not CFS/ME. Another box advises that if all results *are* normal, it is likely to be CFS/ME. *But that depends on tests used.* Tests not included in the guideline (despite our drawing attention to these) may well be abnormal. If a doctor uses, for example, a rapid PCR to identify enteroviruses – known triggers of CFS/ME – and gets a positive result, will the doctor think he is not seeing CFS/ME? How confusing is that?

More inside

FACTS AT YOUR FINGERTIPS

RCPCH Guideline : The ‘evidence-based’ process and its snags.

This guideline is described as ‘evidence based’. Recommendations on treatments therefore reflect the choice of evidence consulted and its rating.

Randomised Controlled Trials (RCTs) have been given a higher rating than evidence from patients describing their own experiences. Yet RCTs largely depend, in their evaluation of treatment, on patients describing their experiences! This anomaly has not in the Trust’s view been resolved.

Some RCTs have not included the experience of patients who dropped out. This skews results. The report’s Executive Summary states: ‘there is no evidence for the efficacy or otherwise of pacing as an effective management strategy for children and young people with CFS/ME’.

This sidelines evidence from patient surveys of people of all ages that indicate ‘pacing’ is, for the majority, the most helpful form of self-management.

When the Trust requested that: ‘A warning should be given about the potential for harm that over-zealous physiotherapy or occupational therapy can cause’ we were told: ‘we were unable to include this suggestion as we had no evidence on which to base such a statement.’

A young person who considers putting their hand on a hotplate does not need a Randomised Controlled Trial to tell them they will be burned. ‘Evidence’ must surely include common sense and the general experience of patients.

We are informed that patient surveys indicating damage that can be caused by inappropriate exercise had been offered to the group writing the guideline but this offer was not taken up.

In a piece commissioned by the Trust for VISION Nov/Dec 2004 (available at www.tymestrust.org) Linda Haines, Principal Research Officer at the RCPCH wrote: ‘The guideline has been written by a group of experts who have a lot of experience of looking after young people with CFS/ME, after considering all the available research evidence.’

However, from its own records of patient experiences over five years, the Trust believes that some of this report’s Recommendations demonstrate the inadequacies of the evidence-based process.

Despite this, the RCPCH made a welcome recommendation - that childhood cases of ME/CFS should be diagnosed ‘as soon as possible’.

RCPCH Guideline : The strictures of the time-line and its snags

The guideline, finally launched on Thursday 3 February 2005 at Westminster, began overrunning its original timetable early on in the process, but the College nevertheless decided to publish almost on time.

This meant a dramatic contraction of the consultative process, including a summer holiday period. A number of the Delphi Group of experts were not able to contribute.

The Trust strongly advised that the timetable be allowed to slip so that the Delphi and Stakeholder consultative processes could be given the originally allotted span of time.

This was not done. We feel this was very unfortunate. Quality is more important than time in a matter of such importance.

FOCUS ON:

Experiences

Whispered Words

The experiences and needs of young people severely affected by ME/CFS

Since The Young ME Sufferers Trust produced *Whispered Words* in 2001, it has proved its value to parents suspected of harming their children, and to doctors, who may not have seen severe ME/CFS. Misunderstandings between doctors, families and Social Services are described.

Severe ME can occur as a complication of an initial infection and it is unwise to get back to school too soon. Less severe cases can worsen due to inappropriate management *eg* over-demand on physical and mental energies.

Families are wise not to suspend their own judgement. Give feedback to doctors about treatment. You may wish to decline certain treatments if they seem unsuitable, or seem to be making your child much worse. Energy management (pacing) may be the best way for your child to proceed.

Key quotes from Whispered Words include:

- 'My head was fine until they messed with my legs.' *Child suffering severe cognitive difficulties after Graded Exercise Therapy*

- 'The physiotherapists didn't understand the illness and were determined that he should stand and walk – the after-effects were dreadful. When the physiotherapy was stopped, his condition did improve..' *Parent*

Releasing *Whispered Words* online has enabled these families to inform the wider world but it could be disturbing to some, as we explain on the website.

Get it free at

www.tymestrust.org/publications.htm

Online Free

Quick Tour of ME Symptoms, Management and Tymes Trust Services

In The Spotlight : The Tymes Trust View

GPs Good Practice Guide to Education for Children with ME

Report of the UK Government Chief Medical Officer's Working Group on CFS/ME : Children and Young People - The Key Points

The Forgotten Children : A Dossier of Shame

Succeeding with ME : The Virtual Classroom

Professional Guides : The SENCO's Key Role in Supporting Pupils With CFS/ME

Professional Guides : Back to School?

Professional Guides : Teacher Information on CFS/ME

Professional Guides : The Doctor's Guide to ME in Children and Young People

Experiences : *Whispered Words* Study of severe child cases. Highlights their needs.

Documents available only by post (prices include post and packing)

Information Pack for Schools £3.75

Quick Tour Pack of six leaflets in plastic carry wallet - the Quick Tour is also available here for you to download. £2.60

ME and My Friends Pack of six leaflets in plastic carry wallet - one for each friend to show them how to help. £2.60

Combined Leaflet Pack Three each of the My Friends leaflet and the Quick Tour leaflet in plastic carry wallet. £2.60

Doctor Still Knows Best?

The belief that doctor ‘knows best’ was never taken for granted by all, despite the myth. Doctors’ advice has been hotly disputed for centuries, and rival doctors would compete to secure royal or rich patrons.

For centuries, patients were ‘bled’; pints of it were taken from sick people at a time when wound infection by micro-organisms was unknown. Happily, there is now a larger body of specialist knowledge than ever before, which doctors can access. They have gone through years of training to use it appropriately; they have learned to take a history and to examine a patient for signs of disease. Despite controversial changes in medical training, doctors have knowledge and expertise that most of us would not claim to possess, simply because we have not gone through *any* medical training.

But doctors are fallible, just like anyone else. Doctor may well know best in certain circumstances, but by no means all. An attitude of superiority is misplaced and is fought against by the more progressive. Scientific knowledge is patchy; theories and therapies may become popular via a few proponents who are eventually proved wrong, for example, in the child abuse field and the field of infant heart surgery.

The best doctors work in partnership with patients, sharing knowledge and expertise and admitting areas of uncertainty, as in ME.

In VISION Nov/Dec 2004 (available at www.tymestrust.org) Linda Haines, Principal Research Officer at the Royal College of Paediatrics and Child Health’ said: ‘We hope that the [RCPCH] guideline will lead to improved care for all children with this debilitating illness.’ Sadly, against our advice, the language in the guideline still conveys the traditional doctor/patient power balance. A great opportunity for a break with

tradition has been missed. It would have detracted nothing from the content and would have added much, encouraging paediatricians to engage with the family, as intended, rather than using language that expects the reverse.

For example, one Recommendation reads: ‘The majority of children and young people with CFS/ME will not need hospital admission.’ But it continues: ‘...there may be some circumstances where an admission is helpful such as, for example, for assessment or the initiation of a management plan when the expertise is not available on an outpatient basis.’ The ‘initiation’ of inappropriate ‘management plans’ in severely ill children has already produced many adverse reactions.

There should be a clear expectation on paediatricians to explain to young patients and their families that they are *free to make their own choices* over how to manage their illness from a number of suggestions, or indeed, to manage it in their own way.

The phrase ‘when the expertise is not available on an outpatient basis’ is telling. Unless parents are completely unable to look after a severely ill child, how is it that ‘expertise’ in management of the illness can be considered to be *unavailable on an outpatient basis*?

The expertise of parents and/or carers seems to have been discounted in this sentence without the writer being aware that this has been done.

The guideline does recommend the involvement of the family at all stages of the management of this illness. Families are usually *the* experts on what their child can manage day to day, given that nothing is going to be curative and that the body must be supported and cared for while it heals.

The Brief