

The Brief

by Jane Colby

First in a series of information pullouts
For parents and older readers



Jane Colby FRSA

TWENTY YEARS ON

The year 2005 marks my twentieth ‘ME anniversary’. A Head Teacher during the 1980’s, I was struck by a virus related to polio, and developed severe ME. This was part of the six-year pandemic of ME which occurred in that decade. When, in 1990, I left teaching to rebuild my health, I was asked by consultant microbiologist Dr Elizabeth Dowsett to help guide the professionals caring for children with ME.

Little did I realise that this task would be open-ended! Formal training for teachers and doctors in managing ME has been virtually non-existent, a situation which urgently needs addressing.

Many of you have heard that up to 25,000 UK children may have ME. This figure comes from my first book *ME – The New Plague* (1996) analysing the link between polio (a neurological disease) and many cases of ME such as my own.

Unfortunately, ME is often muddled together with other types of illness. The name Chronic Fatigue Syndrome (invented for research) hasn’t been good to people with ME - it is as if we invented a disease called ‘sneezing syndrome’ and then wondered why we couldn’t find a single cause or a single helpful treatment. It also belittles the seriousness of the condition.

A step forward is that the Department of Health now uses CFS/ME and the World Health Organisation also uses both terms and makes it quite clear that this *is* a neurological disease of the brain and nervous system having widespread effects upon the whole body.

For five years from 1991-1996 I worked with Dr Dowsett on the largest study of ME that

anyone has ever attempted. We might never have begun if we had truly envisaged the amount of work it would entail or how much resistance we would face.

Called *Long Term Sickness Absence due to ME/CFS in UK schools* it was published in 1997 in the Journal of Chronic Fatigue Syndrome. It hit the front pages and all the major TV news networks because it revealed that ME is the biggest cause of long term sickness absence in schools. No-one could ignore ME in children after the furore it caused in the medical press.

Nowadays my time goes on campaigning, writing, advising families and running The Young ME Sufferers Trust. This work has starkly revealed the lack of support still endured by children and their families.

As we move into a new year, my aim is for *The Brief* to be a serious source of less widely publicised information that will also focus on publications, available free and online from the Trust, to help you obtain that support.

Being appointed to the Steering Group of the PRIME project (Patient Research Into ME) run by the GUS Charitable Trust is very encouraging. Like my work on the children’s section of the Chief Medical Officer’s Working Group on CFS/ME, I see this as a real opportunity to work with others to promote change for the better. For change is most definitely needed.

For a slim binder in which to keep your copies of The Brief, please send your cheque for £1.50 (which includes post and packing) made out to The Young ME Sufferers Trust to: The Brief, PO Box 4347, Stock, Ingatestone, CM4 9TE.

FACTS AT YOUR FINGERTIPS

The Report of the Chief Medical Officer's Working Group on CFS/ME, in which The Young ME Sufferers Trust played a key role, was published by the Department of Health in 2002. The children's section (chapter 5) stated that education in the home is needed for many children with ME and this can be for a long period.

The Department for Education and Skills endorses this Report.

In the statutory guidance *Access to Education for children and young people with medical needs*, also published in 2002, the DfES states that education in the home must be provided for those who are not well enough to attend a school or special unit.

Children are legally entitled to education suitable for their needs, whether or not they are able to attend school.

If a child is absent due to sickness for more than 15 days, alternative education must be offered.

It is illegal to cite cost as a reason for declining to provide suitable education.

Linda Haines, Principal Research Officer at the Royal College of Paediatrics and Child Health told The Young ME Sufferers Trust:

'The college is absolutely delighted to have been able to lead the project to develop this evidence based guideline. We hope that the guideline will lead to improved care for all children with this debilitating illness.'

The Trust's commentary and analysis of the RCPCH guideline will be published in 2005.

The National Association of Head Teachers Statement of Policy 2004 - 2005

NAHT believes that the children now in our schools are the most tested generation in this country's history, and calls upon the Westminster Government to reduce drastically this culture of testing everything that moves.

NAHT congratulates the Welsh Assembly Government for accepting the Daugherty Report, signalling the end of external Key Stage 2 and Key Stage 3 tests in Wales and welcomes the fact that in this part of the UK, tests will now be formative and diagnostic rather than focussed on providing data for a damaging education market place. NAHT calls upon the Westminster Government to adopt similar measures for England and to re-direct the money saved directly into school budgets in order to raise standards further.

SATS are not taken in Scotland either. The Young ME Sufferers Trust recommends that children with ME do not use their precious energy on SATS, which were invented to provide data for school league tables.

Quotes From: Standards for Children in Hospital

Drawn up as part of a National Service Framework intended to raise standards of care across the NHS and social services.

- Children and young people should receive care that meets their individual needs.
- You and your child should be treated with respect at all times.
- You and your children should be encouraged to contribute to making decisions about what treatment they should have and be given as much choice as appropriate.
- Hospital staff should take account of guidance that the Government has issued on giving consent to treatment. (www.doh.gov.uk/consent)

Department of Health 2003

PUBLICATIONS AVAILABLE

at www.tymestrust.org

FOCUS ON: Professional Guides

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

by Dr Alan Franklin FRCPCH DCH
Consultant paediatrician and ME specialist

The sad loss of Dr Alan Franklin in no way diminished the value of his work. To commemorate him and to coincide with the production of the new RCPCH guideline for paediatricians, the Trust has re-issued his timeless advice to doctors treating ME in children.

If Alan were still with us, he would have been in the thick of it, contributing to the new guideline from his years of specialist experience.

Key quotes from Dr Franklin's guide include:

- It is startling how little wasting is seen in young people with ME who also have an intact CNS [*Central Nervous System*] even after prolonged bed rest and how quickly this is restored when they recover.
- Clinical experience shows that recovery is slow but spontaneous and does not require exercise programmes.

Your own doctor may welcome this pithy Professional Guide, with its easy-reference list of symptoms and signs.

Get it free at
www.tymestrust.org/publications.htm

National Institute for Clinical Excellence

The first stakeholders' meeting was held in November. Representing the Trust with me was Sally Player, Trustee and mother of two teenagers with ME. All existing guidelines will be used as references in preparing NICE Guidelines on CFS/ME. The process should take a maximum of three years, patients will be consulted, and the document will be disseminated throughout the NHS.

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

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

Information Pack for Schools £3.75.

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.

Whispered Words Study of severe child cases. Highlights their needs. £1.55.

ARE INJECTIONS SAFE FOR CHILDREN WITH ME/CFS?

Many people with ME have reported getting worse, having a relapse, or even developing their very first dose of ME, after injections of various types. This has been reported in both adults and children.

The injection may perhaps have been for an immunisation, leading the patient to suspect that they have had a reaction to a vaccine.

Although this can happen it is rare, so is something else happening?

When your body is fighting an ongoing infection (and despite rumours to the contrary, this may well be happening in ME) any extra demand on the immune system – such as responding to an immunisation – can provoke relapse from ME because there is too much overall demand. Doctors have instructions not to immunise children with an active infection because of this well-known fact.

But other injections have also been reported to make people worse, or to trigger ME in the first place.

Have injections affected other illnesses? In other countries, where antibiotics have been given by injection, some children have developed paralysis afterwards. The antibiotics didn't cause it, so what did? It turned out that the children had poliovirus in their bodies and the virus was tracking up nerves that had been disturbed by the needle and getting into the brain.

Can the polio experience help us in deciding how to deal with ME?

Microbiologists and virologists still maintain that 'true ME' cases (as opposed to other types of illness trapped under the same CFS umbrella) are caused by viruses in the same family as polio, to which we have not been immunised. The implication

is that injections, especially when you have active ME are not to be taken lightly as these viruses, if present in the body tissues, could track up the nerves after an injection and get to the brain, making you worse.

In 1993, a paper was published describing a 'case control' study to identify the role of intramuscular injection as a 'provoking factor' for poliomyelitis. In case control studies, healthy patients are studied alongside sick ones, and are matched for age and sex. These patients were all children attending an outpatient department and the study was done at the Institute of Child Health in Madras. The total number of cases studied was 257, and the total number of controls was 515 (two controls for every case).

The overall risk of paralysis developing after an intramuscular injection was increased and the odds of it happening were 2 to 1. Multiple injections did not produce a higher risk. Just one could do it.

As H V Wyatt wrote in his article *A view from the West*, 'everyone wants injections'. He pointed out that this well-accepted procedure is not without risk: 'The muscle into which the injection is made can be paralysed if the child already has the polio virus in his body.'

In this day and age, in Britain, polio is thought of as a disease of the past. But as long as we do not have immunisations against the viruses *related to polio*, we will continue to see cases of illness caused by them. If ME can be one of these illnesses, we should not lightly subject children (or adults) with active ME to unnecessary procedures involving injections, such as some of the treatments that have been promoted.

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