



The Brief

Voices from the past usually come out of the blue - an email or letter from someone I advised years ago. Knowing ME from first hand experience, and knowing how impossible it is for children and young people to study the usual number of subjects to the usual timetable, I have spent much time developing strategies to overcome this in so far as it can be overcome. So it is valuable to hear from families who make practical use of these strategies, which are designed not just to help with educational achievement, but also to preserve health.

Alison Isaacs writes: 'It is many years since I have been in touch with you. You were my main support for a time when my son, David, was ill from age 12 to age 16. With your advice, we cut his school work right down - he took 6 GCSE's and got A* for all of them.

'He then went on to get 3 A's at A level and a distinction in the AEA in English. He is now 19 and on a gap year, but has just won a place at Cambridge to read English. I felt you should know because he would never have achieved all that without the support you gave me when I was trying to work out what was right for him, and indeed to survive the trauma of such a cruel illness.

'He does seem well now, and enjoyed the last two years in the 6th Form. He sometimes seems to get more tired than he should, but has taken full part in all sorts of music activities and has a very full social life. All a far cry from when he was ravaged with ME. As a Mum, I seem to always be on the lookout for a relapse, but he does seem to cope very well at the moment.'

This story, and David Loxley-Blount's (*Vision* page 21) are successes not just in

educational terms, but in medical terms too. Yet my work brings me into conflict with psychiatrists who still insist on regular school attendance, just as they did in 1996 in their 'Royal Colleges' Report that influenced so many.

A recent study, *A Follow-up Study of CFS in Children and Adolescents: Symptom Persistence and School Absenteeism* published in *Clinical Child Psychology and Psychiatry* concludes: 'Maintaining school attendance [...] is also vital if long-term morbidity is to be reduced.' In other words, the children will remain ill if they don't go to school! My experience disproves this.

Of course that study used the wide 'Oxford criteria' for CFS, which include people with psychological disorders along with others who have the true neurological ME. So the results reflect sub-groups, ignored in its recommendation.

Alison finishes: 'So, thank you Jane, for your vision to do the wonderful job you do and for opening the eyes of the education establishment.' It was a lovely thought, but there is still so much inertia in the system, despite individual good practice, that I can't yet claim all that Alison generously credits me with. Such psychiatric 'studies' do not help.

For strategies to modify education for someone with ME, read the Professional Guide 'Ten Points on the Education of Children with ME' and the report 'Succeeding with ME (The Virtual Classroom)', both at www.tymestrust.org.

Remember the key principle: Health Before Work. Putting education second achieves better results in the end. Convalescence is the number one priority.

Medicines for children not fully tested

A House of Lords report on the European Commission's proposals for paediatric medicines has stated that 50% of all medicines given to children of all ages are not fully tested.

The report by the Lords EU Sub-Committee on Social Policy and Consumer Affairs, praised the Commission for attempting to set up a common EU-wide procedure for testing and approving medicines for use in children and incentives to encourage manufacturers to develop or adapt medicines specifically for children.

Chair Baroness Thomas of Walliswood said: 'We are pleased that the European Commission has taken the lead on this important issue. It is worrying that so many of the medicinal products used by our children have not been properly tested to ensure the appropriateness of their use. Children are not simply small adults and it cannot be right that 90% of the medication given to new born babies has only ever been tested on adults. This will be a concern for all parents.

'We were satisfied that the basic framework proposed by the Commission was right and gave the Government the go-ahead to accept them, which they have done. But a lot of care has to be given to the guidelines that will be needed to carry out the procedures for testing and authorising drugs to make sure that ethical considerations are fully considered and clearly explained. The Government has promised to give us progress reports on this.'

Conclusions of the report include:

- ◆ Too many children's prescriptions and over-the-counter drugs have not been properly tested on children prior to launch.
- ◆ Children are not simply small adults and their medication should not be treated as if they were. There is an overwhelming and urgent need to take action at a European level to promote and govern clinical trials of medicines on children.
- ◆ Guidelines covering medical trials must take into account the vulnerability of children. They will need to consider ethical issues around consent to trials by children, the effects of different drugs on children of different ages and access to research databases.
- ◆ Medical products should be properly labelled to indicate their suitability for children.
- ◆ It is impossible to judge at this stage how well the incentives designed to stimulate the development of drugs for children will work. The Government must press the Commission to carry out a full economic review of the incentive arrangements after a few years of operation.

Available from The Stationary Office: Paediatric Medicines: Proposed EU Regulation, House of Lords, EU Sub-Committee on Social Policy and Consumer Affairs, 20th report of session 2005/06, HL paper 101, ISBN 010 400809 1, Price £15.50.

Respite Care

Families whose children suffer from severe ME may wish to consult the Department of Health about its new Guide on palliative care options, *which include the right to be treated at home*.

The Guide is for professionals but may help parents to obtain services they are entitled to or want.

The DoH states: 'The Department is determined that choice for children is kept as wide as possible

[...] It considers hospices as integral to delivering better services to sick children in need of palliative care. Palliative care for children and young people with life-limiting conditions should focus on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care.'

The Quick Tour

‘Mum uses your leaflet to explain the illness to people, like my care manager. It's the best leaflet on ME we've seen!’

We have recently updated our *Quick Tour of ME Symptoms, Management and Tymes Trust Services*.

At just two pages, giving someone a copy of the Quick Tour is the simplest way to help them understand. We recommend keeping a small pile available to hand out. It saves you having to give long explanations, or hand over a long document.

Excerpts from the Quick Tour:

- ◆ Even minimal exertion (cognitive or physical) can trigger exhaustion; the delayed effect is a classic sign of ME, differentiating it from other types of fatigue.
- ◆ Inappropriate educational demands impede recovery and are a key cause of relapse in children. Energy Efficient Education (home tuition, distance learning) can maximise achievement whilst protecting health.
- ◆ Children with ME are legally entitled to education suited to their medical and special educational needs.
- ◆ There is no known cure. The body needs energy to heal, so personal energy management is a safe way to live with ME without provoking side-effects.
- ◆ Some treatments may be harmful, such as overzealous physiotherapy. The condition naturally fluctuates, and may improve despite, rather than because of, treatments.
- ◆ If treated inappropriately, the patient can become much worse. In extreme cases, children can suffer fits or collapse. Some go through periods of partial paralysis and may have to be tube-fed.

You can download the pdf and print your own (it's at the top of the Publications Page at www.tymestrust.org) or we can send you a holder with six leaflets for £2.60 (includes post and packing).

Quick Tour of ME Symptoms, Management, and Tymes Trust Services (*updated*)

In the Spotlight : The Tymes Trust View

Self-Help

ME ~ and My Friends (*a leaflet for your friends*)

The Tymes Trustcard (*a pass card for school*)

Reports

ME Diagnosis : Delay Harms Health †

Children and Young People : The Key Points

The Forgotten Children : A Dossier of Shame †

Succeeding with ME (*the Virtual Classroom*) †

Our Needs Our Lives (*on CFS/ME clinics*) †

Whispered Words (*the severely affected*)

† *presentation copies available*

For Professionals

Professionals Referral Service

Teacher Information on CFS/ME

Back to School?

Pushing the Boundaries in ME/CFS

10 Points on the Education of Children with ME

The SENCO's Key Role in Supporting Pupils with CFS/ME

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

GPs Good Practice Guide to Education for Children with ME

Physios Urged to Go Cautiously

Implications for Schools of the Chief Medical Officer's Working Group Report on CFS/ME

ME/CFS Guidelines for Educational Psychologists

Care of CFS/ME in Children

We have all seen conflicting theories about the causes of ME. It is often not possible to isolate the exact time at which the disease began, and to remember if there was an infection shortly beforehand. Some infections even take place subclinically - that is, they cause no immediate symptoms, though they may lead to complications later if a chronic effect is triggered.

Not everyone reacts to viruses in the same way, so what we call 'host factors' come into play, and here there is more scope for confusion. If you get an infection, you are playing 'host' to it. How will your body react? Many different things can affect someone's 'host response' - genetic susceptibility, great physical effort, shocks to the body - anything that affects the ability to produce a satisfactory immune response at the time. One of the many contributory factors to ME, or even one of the many effects, can become isolated from the whole picture. Researchers may say - 'Aha.' They think they have found the cause.

One subject that has caused a lot of 'Aha' is stress. Was the patient very stressed when ME took hold? 'Aha, ME must be a stress-induced disease.' ME became seen as psychological. This is now known to be an unsatisfactory explanation on its own. Disease is a complex process. Stress affects immune function and is just one of the many 'host response' factors that may affect our ability to fight infection.

A very demanding lifestyle, great stress at work, personal trauma or accident can all undermine immune response and can trigger a much worse reaction to what might otherwise be a trivial infection. Doing something physically demanding in the first week or two, such as sport, can

affect how our body deals with a foreign invasion - which is what an infection is. A vaccination demands the attention of our immune system to deal with it and distracts the body from fighting other invasions that we are exposed to at the same time; schools are supposed to wait until an actively sick child recovers before immunising them.

We may not even possess the necessary antibodies to cope with a particular bug. ME often follows a foreign holiday, one of the known risk factors, especially where polluted beaches are concerned. Did we meet viruses we had never met before and against which we had built up no natural immunity? The list of possible links with infection goes on and on.

In the absence of a straight cure for ME, researchers have focused on psychological therapies, touted as cures by irresponsible practitioners and reported as such in the media. Like Invest in ME and The Young ME Sufferers Trust, I believe that enough is enough. It is time to focus attention on the physical nature of the illness, and particularly in my opinion, on the microbiology as well as the host factors and the effects. Early identification of infecting organisms, especially in children, who are the epicentre of this illness, is vital.

There are three Holy Grails:

- 1) a biological marker for diagnosis
- 2) remedial treatment for the effects
- 3) preventative measures; this last could happen now, with early use of rapid PCR tests in GPs' surgeries.

A longer version of this feature is at www.investinme.org in the Guest Speaker Column.

To learn how clusters of ME occur in schools, read 'Does ME Cluster in Schools?': www.youngactiononline.com/docs/doesme.htm.