



The Brief

They do say that it is only when the man in the pub repeats your own words back to you, that you know you are getting somewhere.

Well, we are getting somewhere, albeit slowly. I admit to being pleased when people tell me the results of research that I carried out myself, or start explaining to me the educational principles that I developed, as if I might not yet know of them!

Doctors have announced that school subjects should be reduced, journalists routinely write that ME is the biggest cause of long term sickness absence from school (Dowsett and Colby 1997). The Royal College of Paediatrics and Child Health has included information on virtual education in its guidelines for paediatricians. 'GP' magazine has just used the heading 'Exercise not for children with CFS/ME' alongside the new feature I wrote with Dr Nigel Hunt, now on the Trust's website. So some key messages we have fought for are taking hold.

Yet the true effect of ME on a child is still not widely appreciated and we cannot for a moment claim that the battle is won.

Teachers need training in the needs of children with ME. I have now given evidence on this to the Parliamentary Select Committee on Special Educational Needs, which we have been given permission to publish in full.

Not long ago, I was privileged to be in the Chamber of the House of Lords for Question Time, and was able to hear Education Minister Lord Adonis respond to Peers' questions. Our meeting with the Minister and Lord Clement-Jones has led to a very helpful offer to take matters further and I hope to have more news in the next issue of The Brief.

We must all be vigilant so that children with ME are taken

proper account of. Taking part in the consultation on the Essex Children and Young People Plan, I unfortunately found it necessary to write: 'Having looked carefully at your Plan and also at the categories of need you have identified, we were rather shocked to find no place at all for the children whom we support and we are therefore asking if the plan can be amended in this respect.'

Excerpts from my evidence to the Select Committee:

There is now abundant research evidence that this is an organic illness and not a psychological disorder, yet many children with ME are still not being offered education suitable for their needs, and to enable them to perform to their ability in examinations. They suffer widespread discrimination against their disability.

Section 19 of the Education Act 1996 requires Local Education Authorities to make suitable provision for all children and young people who cannot attend school by reason of illness. But there is a significant overlap between medical and special educational needs in this illness and it is often virtually impossible to separate the two. Schools have a Duty of Care as well as a duty to provide suitable education for children with special educational needs. In ME these two overlap, since too much mental concentration can produce physical relapse and physical relapse means that the child can no longer study. School attendance or inappropriate educational demands are a key cause of relapse; this results in further educational disadvantage.

New : British National Formulary for Children

Co-operation between the British National Formulary (BNF) and Medicines for children teams has led to this new publication for doctors. It aims to provide guidance on the use of medicines, both licensed and unlicensed, in children up to the age of 18 years. The scope of the information given on each drug is similar to that in the standard BNF but as yet the basis for using these products 'off-label' (eg extrapolation

from data in adults) is not always explained. Response to medicines is not necessarily the same as in adults. In general practice, at least one in 10 medicines prescribed for children are unlicensed or used 'off-label'. As always, if you have any concerns over medication, discuss them with your doctor. The pharmacist in your local prescribing chemist may be another good source of information.

Yellow Card Scheme

People with ME are, in the main, particularly sensitive to drugs. The Medicines and Healthcare products Regulatory Agency (MHRA) have launched a pilot scheme so that members of the public may now directly report their experiences of suspected side effects from medicines through its Yellow Card reporting system.

Patient Yellow Card reporting forms are being placed in pharmacies, GP surgeries and other NHS outlets across the UK. Reports on suspected side effects can also be made on the Yellow Card website at www.yellowcard.gov.uk or by freephone to the

Yellow Card hotline on 0808 100 3352.

Disabled Students

Under the Disability Discrimination Act (DDA), universities and colleges must now make 'reasonable' changes to their premises to make them more user-friendly for Britain's disabled students. A failure to do so could result in disabled students taking court action.

Campuses now have to ensure that lecture halls, libraries, ICT suites and halls of residence are more user-friendly. This includes altering steps, providing lifts, dropping kerbs, and making sure better lighting and clear signage are provided where it is reasonable to do so.

This is the final part of provisions for post-16 education under the DDA. In 2002, the Act introduced a fairer admissions process for disabled students and since 2003 universities and colleges have had a duty to provide, for example extra equipment and note takers.

From September 2002 it became unlawful to discriminate against disabled students or prospective students by treating them less favourably than others.

From September 2003 further and higher education institutions have been required to make reasonable adjustments to provide auxiliary aids, such as appropriate software and other services.

From September 2005, Further and Higher Education institutions have been required to make reasonable adjustments to physical features of premises, such as steps, where these put disabled people at a substantial disadvantage.

A person who believes that a Further or Higher Education body has discriminated against him or her may bring civil proceedings. Court action must be brought within six months of the alleged discrimination.

Care of CFS/ME in Children

A major feature on ME in children and young people, by Dr Nigel Hunt and Jane Colby, was published in GP (the General Practitioners' professional magazine) on 28 October 2005.

Key extracts:

"The first biomedical study in children is imminent."

"Vascular imaging has identified biochemical abnormalities in the circulation of adults, suggesting that CFS/ME could involve a continuing challenge to the immune system such as a persistent viral infection."

"With no laboratory test, diagnostic confusion has arisen between the physically disabling CFS/ME and the similarly named 'chronic fatigue', which could be of psychological origin or part of the presentation of other organic diseases."

"Over-enthusiastic activity management programmes can provoke relapse, while provision of wheelchairs, stairlifts and other equipment, together with conservation of energy, have been found to aid mobility and support recovery."

"In children and young people, educational demands are a key cause of relapse, so tuition in the home or virtual education is usually needed."

"Good patient self-management and a positive doctor / patient relationship are the ideal."

GP magazine chose to use 'chronic fatigue syndrome' in their headline, but accepted our use of 'CFS/ME' (the Department of Health term) in the text of the article.

Differences between how people with 'chronic fatigue' and those with CFS/ME react to exertion are clearly explained for your doctor.

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Quick Tour of ME Symptoms, Management, and Tymes Trust Services

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

ME - A Persistent Viral Infection?

Back in 1996 in *ME - The New Plague*, I argued that ME is a persistent viral infection. Evidence is now piling up to suggest that this is correct.

For the book, I interviewed consultant microbiologist Dr Elizabeth Dowsett. I asked her if one of the reasons why people slowly get stronger in ME is that they are learning to live with the virus and the virus is learning to live with them.

Dr Dowsett answered: 'Yes. Both sides make adjustments.'

I went on: 'And you can tell - because these viral particles are still there many years later - that this is what's been happening?'

'Right,' answered Betty. 'A marvellous example is the chicken pox virus, which simply zips itself into your genetic code. It does you no harm whatsoever. It never leaves your body.' Cold sore viruses are another example. When immunity is low, another cold sore can erupt.

Studies have already shown that some people with 'Chronic Fatigue Syndrome' have particles of enteroviruses in their tissues.

These 'gut' viruses are very versatile, easily spread, and each can cause different upsets, from cold and flu symptoms, to glandular fever symptoms, to polio myelitis, against which we now vaccinate children. Decades ago enteroviruses were known triggers for ME.

So why do only some people with CFS have these particles in their tissues? When the term Chronic Fatigue Syndrome was invented, great confusion ensued because it covered such a wide group of symptoms. It pulled in people with ME and people

with depressive illness. Even now, CFS is not as tightly defined as ME was and the confusion continues.

Further exciting evidence on Enteroviral RNA has come from the American Society for Microbiology. Researcher Dr Chia writes that his data 'suggest that enterovirus can initiate and perpetuate the immunological response often seen in patients with CFS.'

He goes on: 'Smouldering viral infection of various cells of the body with continuous expression of double stranded RNA and viral antigens could result in a chronic inflammatory state in the local tissues and account for the diverse symptoms reported by these patients.'

What is more, he emphasises that 'The mechanism of viral persistence reconciles the two seemingly opposing observations of the past two decades: absence of live virion in chronically infected patients and animals and the finding of enteroviral RNA in the blood or other tissues.'

Commenting on the relapsing nature of the illness, and the adverse effects of exercise, he writes. 'In most of the patients with CFS, the cyclic nature of low grade febrile illness [low fever] and severe exacerbation after physical activity would be consistent with a cyclical pattern in the viral replicative activity.'

Like Dr Dowsett and I in our 1997 study in the *Journal of Chronic Fatigue Syndrome*, Dr Chia recommends 'early virological testing' during the typical flu-like illness that can usher in ME. This would give evidence of a disease process, which children need in order to get proper recognition from doctors and schools.

Dr Dowsett reminds us that the chicken pox virus can also cause shingles later on. The parallel message in ME is that we should all take care not to provoke relapse through overdoing it, thus undermining our immune system's ability to achieve and maintain a balance.

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