



The Brief

In July, I went to London to the Palace of Westminster with Joanna Smith, who is one of our parents and also a Welfare Rights Advisor for Brunel University, to give a presentation by invitation of the All Party Parliamentary Group on ME concerning Child Protection Issues.

Our presentation addressed what happens in Child Protection procedures, gave details of misunderstandings over parental or carer influence where children with ME are concerned, and chronicled the personal experiences of a parent of a Trust member.

I also presented the Trust's recommendations to help stop the misapplication of Child Protection measures to the families of children with ME. As I said at the time, we cannot just continue to discuss this problem and wring our hands over such injustices. I have been fighting this since the 1990s and indeed, I did the survey for the BBC Panorama programme which revealed the statistics of the problem at that time. Now these cases seem to be escalating again.

I have reopened my discussions with Dr John Sentamu, the Archbishop of York, where cases have taken place, and he has asked me to keep him apprised of developments and report to him the eventual outcome of the APPG meeting.

It's important that families who feel they may be affected by suspicions about how they are caring for their child to remember that things move quickly once procedures are underway. The Social Services Manager on the Trust's Professionals Referral Panel explains that if a family is suspected of neglect or of harming their child, an initial decision is made within 24 hours about whether to pursue a Child Protection Section 47 investigation. Within 7 days an initial assessment must be done which involves

seeing the family and within 30 days a core assessment must be done.

Thus the process moves swiftly and parents are usually unprepared as to how to fight it.

In terms of Action, both I and the Trust have recommended that The Department of Children Schools and Families should urgently alert Social Services professionals to the frequency of misunderstandings in cases of ME.

In addition, a leaflet clarifying the procedures that should be adhered to by professionals in Child Protection investigations should be given to families under suspicion, and they should be informed of their rights.

Joanna Smith's presentation covered her personal experience of an erroneous Child Protection investigation. She concluded: 'The overall picture shows two children with complex neurological disease, in London, in the 21st century, without access to adequate medical assistance and without access to education. Furthermore, the level of ignorance is so shocking, that despite the wealth of knowledge about ME, Child Protection measures are still brought against families like mine. I am sure you will agree, it is an appalling situation. I would just like to add that without the support of The Young ME Sufferers Trust I don't know how we would have coped so far.'

Joanna has now joined the Trust's Professionals Referral Panel as our own Welfare Rights Advisor. My heart goes out to anyone suffering from injustice in the way she has suffered.

The full presentation is at www.tymestrust.org/pdfs/childprotectionissues.pdf.

Appeals President Criticises DWP and ATOS

The President of Appeal Tribunals has criticised the Department of Work and Pensions for having made no improvement in the standard of decision making in the last 10 years and criticised ATOS doctors for failing to listen to claimants.

Robert Martin, the final President before the November reforms abolish his position, used his last report to look back at changes introduced by the Social Security Act 1998, which was supposed to revolutionise DWP decision making. The introduction of a reconsideration stage was intended to ensure that all necessary evidence was collected and carefully looked at by the decision maker. The intent was that only the most complex legal issues would end up at tribunals, rather than disputes about facts or medical evidence.

In reality, the President revealed that the number of appeals has gone up from 217,000 a year to 229,000 and the proportion of appeals that succeed has remained at around 37% - and the success rate at DLA and incapacity oral hearings is considerably higher. †

The President said that the same problems and errors are repeated year after year. Failings of the DWP included: failure to collect all necessary

evidence, especially by talking to the claimant; failure to carry out proper reconsiderations when a decision is challenged; medical reports underestimating the severity of the claimant's disability; failure to listen, or give credibility, to the evidence provided by claimants; failure to set up systems that allow people with particular disabilities to make effective use of the claims and appeals process.

In relation to DLA, out of a sample of 365 successful appeals, medical evidence was supplied by ATOS in 302 cases. Sixty one of the medical reports were considered to have underestimated the severity of the disability whilst thirty eight did not address all the issues. Tribunal chairs also criticised medical reports that 'did not coincide with reality' and considered that it was the fact that tribunals took time to question appellants about their history and care and mobility needs which led them to a different conclusion from the decision maker's.

Tribunal chairs told the President that the major problem was the refusal by examining doctors and decision makers to believe evidence given by the claimant.

† *bear this in mind if your claim is turned down*

Oxygen Deprivation During Exercise Confirmed

It has been noted that when people with ME/CFS undertake exercise, brain perfusion with oxygen decreases instead of increasing. A new study by Neary et al confirms this finding. The authors refer to the 'inadequate oxygen delivery to the brain' and note that the study provides evidence of

physiological differences between those with CFS and the control subjects.

Prefrontal cortex oxygenation during incremental exercise in chronic fatigue syndrome

Journal Clin Physiol Funct Imaging 2008 Jul 29

www.cfids-cab.org/rc/Neary.pdf

Universities and the Disability Discrimination Act

University websites often provide specific advice on the Disability Discrimination Act. The Open University, which is generally helpful to students with ME, states: 'Under this legislation disabled people have equal opportunities to benefit from and contribute to the learning services available in higher education institutions.'

All aspects of teaching and learning are covered

including lectures, lab work, field work, distance learning, examinations and assessment, learning resources (such as libraries and computer facilities), catering, residential and leisure facilities, and access to the 'built environment and its facilities'.

Visit www.open.ac.uk and type *Disability Discrimination Act* into the search facility.

Explain Your Abilities

How do you explain to a teacher how ME affects your child? How do teachers gain a fair picture of what a child with ME can do?

The questionnaire was designed by Educational Psychologist Naomi Burgess and former Head Teacher Jane Colby as an initial tool to show up the extent of problems and to clarify how much a child can safely manage. It is presented in 'plain English' which means it's in simple, clear language suitable for young people.

Originally part of our *ME/CFS Guidelines for Educational Psychologists*, whose job includes assessing children's special educational needs, the questionnaire is now also available as a stand-alone publication in the Trust's Self-Help series.

Questions for the young person to answer include:

If you go to school sometimes, how do you feel after the journey? Say how you travel.

How do you feel if you have to get around the building? Say how you get around.

If you have any difficulties with the following, please write 'yes' or 'no' beside them. Don't give lots of details, but do indicate what the main problem is. [A list follows this question]

Is there anything your parents notice about how you look just before you feel ill? It will help for your teachers to have this information.

In some contexts the child is asked to consider 'what would need to change to make this manageable for me?' Perhaps some of the things under consideration aren't manageable at all just now, in which case they can explain this.

A vital piece of evidence for teachers will also be how long it takes to complete the questionnaire. If necessary, do it in stages according to individual limitations, to avoid exacerbating the illness.

Finally, other free Trust publications are recommended to give certain professionals, such as the SENCO's guide which is useful for the school's Special Educational Needs Co-Ordinator.

www.tymestrust.org/pdfs/explainyourabilities.pdf

Quick Tour of ME Symptoms, Management and Trust Services

In the Spotlight : The Tymes Trust View

Self-Help

Explain Your Abilities

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

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

School Examinations and ME - Special Assessment Arrangements

The Essex ME Companion

Diet in ME

Reports

Child Protection Issues

Long Term Sickness Absence due to ME/CFS in UK Schools

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*) †

† presentation copies available

Experiences

Mummies Aren't Supposed To Cry

Whispered Words (*the severely affected*)

For Professionals

ME - The Illness and Common Misconceptions: Abuse, Neglect, Mental Incapacity

The Nightingale Definition of Myalgic Encephalomyelitis (ME)

Professionals Referral Service

Teacher Information on CFS/ME

Back to School?

Pushing the Boundaries in ME/CFS

Ten 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

For decades the notion that ME was caused by viruses was widely dismissed. This in turn has caused ignorance of how it spreads. As this year's guest speaker at the Clywd ME Conference, I reviewed the evidence from my 1996 book *ME - The New Plague* and linked it with new evidence from a US virologist who is providing physical proof. I started with two newspaper headlines 10 years apart.

'Back in 1997, a study I did with Dr Betty Dowsett was published. This newspaper is from May 22nd 1997 and look at the headline: "Schools swept by ME plague". That was the front of *The Guardian*. This is the biggest study of ME that's ever been done and it did actually find that there were more cases of ME causing long term sickness absence from school than anything else. So I want to start my talk today, which is about ME and viruses - enteroviruses, which are linked in with polio as well - with another headline.

'When bird flu came along, a headline in *The Times* screamed: "Bird Flu? It's kids' stuff". The article starts: "If avian flu infects humans, it will be spread through schools." So, when it's an illness everybody's terrified of, people immediately understand that it is spread through schools. Betty Dowsett and I found out in 1997 that this illness - ME - spreads through schools.

'You may or may not have heard of Dr John Chia from California. He is a virologist and he writes this to me in an email - and after all the work I've been doing, it's wonderful to hear him say it: "You need to emphasise the need to develop new anti-viral drugs for enteroviruses. This is an old and yet newly characterised viral infection that affects more people than AIDS and hepatitis C in the US, and likely in the UK." That is quite a statement.

'When I wrote for the *Journal of Clinical Pathology* in September 2006, I stated:

"Suspicions among physicians that groups of children with ME are copying one another, rather than physically ill, has not only led to misunderstandings and obstacles to special educational needs provision, but also to the sidelining of an epidemiological phenomenon" - that means the behaviour of an illness in the community. "Children may well be the epicentre of this illness. The Dowsett/Colby study was conducted to determine whether the recognition of multiple cases of ME/CFS in one school is a unique experience." In other words, we wanted to see if something that we had heard about was being repeated all over the place.

'There had been an outbreak of 'summer flu' with gastroenteritis in a village school and that prompted our study, because that involved 70 out of 230 nine-to-eleven year old children and in the autumn term some 10% of those who'd been affected by that gastroenteritis in the summer complained of profound fatigue and cognitive disturbance that had not resolved on follow-up two years later. One child's encephalitic illness was shown to be due to an enterovirus infection in July but the investigations in the other cases were delayed and therefore they were unhelpful. Relapse in the same pupils occurred the following year.

'So when I gave evidence to the Gibson parliamentary inquiry, I proposed priorities for research and one of them was that an enteroviral study be set up, as John Chia has suggested in his review of the role of enteroviruses in Chronic Fatigue Syndrome, because this is the key to finding out what can actually be done about it. We don't just need to understand what's causing it, we need to know what we can actually do about it.'

The complete transcript of this talk will be in The Colby Report. To reserve an advance copy, phone, write or email me via the Trust.