



The Brief

This summer I have been increasingly concerned at the muddle in medical circles between 'ME', 'Chronic Fatigue Syndrome,' and 'chronic fatigue'.

Chronic fatigue is a symptom of many illnesses that may or may not turn out - in any particular case - to be ME as originally defined.

ME itself, in which exhaustion to the point of disability clearly plays a part, is classified by the World Health Organisation as a neurological disease. Fatigue can be a sign of a serious physical illness, or it can indicate a psychological disorder. In the rush to embrace the woolly concept of Chronic Fatigue Syndrome (CFS), the medical establishment has been slow to accept that there are, of course, subgroups within the various wide criteria for CFS. A proportion of 'CFS' patients display the pattern of ME.

My concern has increased with the recent discovery that on the website of a London hospital which runs a specialist ME/CFS service, an advertisement for a member of staff explains: *Anorexia nervosa (AN) and chronic fatigue syndrome (CFS) are classical psychosomatic disorders where response to social threat is expressed somatically [...]. Other similarities between these disorders include strong female preponderance and overlapping personality characteristics, such as being introverted and anxious/avoidant.*

The staff at this hospital are involved in GP training and in a conference for the staff of specialist clinics. They may be sympathetic to people with CFS/ME (the composite term now used by the Dept of Health) but the fact that such statements are on their website reveals the beliefs they are likely to hold.

This would perhaps help explain the fact that, in the past months, the Trust has been

contacted by a number of families, worried about 'programmes' of activity

being imposed on their children (some of whom are very ill) by 'new' CFS/ME paediatricians, who have grown up in the 'biopsychosocial' era and seem to swallow that model uncritically. Families say that the graded increases in activity expected in these programmes are unrealistic for their children and make them worse.

With regard to the apparent success of such programmes as claimed by some paediatricians; I have been told personally by some families that, due sometimes to a feeling of intimidation, and sometimes to a perceived need to have a doctor 'onside', they keep the paediatrician happy by saying they are following the programme, when in fact they are not. They are, instead, 'pacing' their child. When the child improves, the paediatrician and the GP think the programme is working and their use of it is reinforced.

Another problem is, of course, the woolly concept of 'CFS' which means that the programmes will probably be suitable for some patients, who either don't have 'true' ME at all, or who are in the process of recovering already and can manage the level of increases in activity required. Nevertheless, only two families have contacted me to report that such a programme was really helpful for their child, and no long-term feedback is as yet available to indicate lasting benefit.

In this climate of muddle and diagnostic uncertainty, parents should be careful not to suspend their own judgement about what is helping their child. Please feel free to send me your frank and open feedback about treatment.

Facts At Your Fingertips

Centre for Policy Studies warning on state funding and charity independence

For some years The Young ME Sufferers Trust has expressed concern about the influence over policies pursued by some voluntary organisations and charities, which may follow from obtaining funds from official bodies. An organisation's readiness to challenge unhelpful official policies or medical treatment could be affected.

It now appears we are not alone in our concerns. A report from the Centre for Policy Studies warns that state funding for charities is now threatening their independence, having outstripped public donations through traditional fundraising methods.

While donations from the public grew by 7% in the three years to 2004, government funding over the same period increased by 38%. For larger charities, the document says, the state is now the 'most important paymaster'.

The report, 'Charity: The spectre of over-regulation and state dependency', says the independence of charities is being put at risk by the profile of their funding streams, and criticises charities for the way they spend their money.

It attacks large charities for paying an average salary of £83,000 to the sector's most senior executives and criticises increased spending on fundraising. It deems the function of the Charity Commission 'confused', being both a regulator and an advisor to the charity sector, and calls on the Commission to relinquish its advisory role.

'As the charitable sector becomes more dependent on the state, and further distanced from its voluntary donor base, there is a danger that the vitality and voluntary nature of the sector could be irretrievably undermined', the report's authors, Richard Smith and Philip Whittington, warned.

It recommends that where a charity is delivering a public service, the direct financial link between the state and charity should be broken wherever possible.

www.charitytimes.com

With thanks to Duncan Cox for alerting us to this via IMEGA-e.

Funding of The Young ME Sufferers Trust

The Young ME Sufferers Trust is almost wholly funded by donation from members like yourselves, with occasional grants for specific projects. None of the Team, including myself, are paid for our services. In order to support these services to the

families of children with ME, regular donations are required. Your help in this mammoth task would be genuinely appreciated. If you would like to set up a standing order, please phone for details or use the Contact Us form at www.tymestrust.org

Post-exertional symptom exacerbation

A study by The American College of Sports Medicine has concluded that 'CFS patients suffer symptom exacerbation' following physical stressors. Post-exertional symptom exacerbation 'appears to be both a real and incapacitating feature of the syndrome'. They comment on 'the delayed recovery response evoked by a single bout of exercise' and say that it is 'distinctly different from that of sedentary controls'.

They warn that 'the debilitating effects experienced by these patients help to explain activity avoidance, which should be considered when prescribing exercise and activity management programs for CFS patients.'

Ref: *Medicine & Science in Sports & Exercise: Volume 39(5) Supplement May 2007p S445*

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

Following the 10th Anniversary feature (*Vision 2007-1*) on the Dowsett/Colby study, the Trust's website now carries a report by Dr Elizabeth Dowsett on the original research paper (*Journal of Chronic Fatigue Syndrome 1997*). Included is the original abstract and introduction.

This study is the largest epidemiological study of ME available to date. It gives vital evidence about the reality of ME in schools, many of whom still treat ME sufferers far from satisfactorily.

In my introduction to Dr Dowsett's report, I point out:

When, back in 1990, Dr Dowsett explained to me that 'the problem is, we have no statistics showing the pattern of ME in schools', I said 'So let's get them.' If I had realised then that it would take us five years, during which I was myself still ill with ME from a virus related to polio, I might not have considered it so readily. The exercise was hard, frustrating at times and involved accepting that due to political pressures on the education system (and the near chaos of its re-organisation into new types of institutions) schools were now overtly in competition with one another. Funds depended on pupil numbers, numbers depended on reputation and public image. They still do.

I go on to explain:

This meant that there was extreme reluctance to reveal statistics to us in some quarters. ME had a controversial image back then, more even than now, and in addition there was a perception that if schools admitted to clusters of cases, there would be a scare that children with ME could transmit it to others.

In the report Dr Dowsett states her continuing concern that 'there remains a sizeable proportion of professionals in Health Care, Education and Social Services who are still prepared to ascribe the numerous, disabling [...] symptoms of this illness in young people to anorexia, depression, school phobia or a dysfunctional family background.'

www.tymestrust.org/pdfs/dowsettcobly.pdf

Quick Tour of ME Symptoms, Management, and 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*)

School Examinations and ME - Special Assessment Arrangements

The Essex ME Companion

Reports

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

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

Pervasive Refusal Syndrome - What Is It?

About ten years ago, a magazine commissioned me to write on Pervasive Refusal Syndrome (PRS). I was disturbed by what I found. I am revisiting the subject because in this 'biopsychosocial' era, suspected PRS seems to be experiencing a new dawn amongst doctors treating youngsters with ME.

PRS is not an illness, but a collection of symptoms. The young patient is thought to be 'refusing' to interact with the world. Doctors try to help recovery by forcing children back to normality.

In very severe cases of ME (which is a physical illness) a child may be too weak to chew and may find swallowing hard, so a period of feeding by tube can help nutrition. Compare this with the definition of PRS by Lask et al in 1991 as 'manifested by a profound and pervasive refusal to eat, drink, walk, talk or care for themselves in any way over a period of several months.' Treatment can include tube-feeding. The difference? In a diagnosis of PRS, confirmed or suspected sexual abuse and/or domestic violence may play a part. Any parent whose child is thought to have PRS would be wise to check their own medical records for such comments.

Lask wrote that a diagnosis of PRS is not possible if organic illness can account for the symptoms. But as PRS is thought to reflect severe post-traumatic stress, any severe physical illness (such as ME) might also be considered a predisposing factor.

Clearly, a psychiatrically ill child who retreats from the world to the point of refusing to eat needs help. But the team treating a child with PRS is advised to stick together to avoid the family becoming close to any individual, who might reinforce the family's own view. A doctor or nurse who realised

that the child's illness was physical could therefore feel unwilling to go up against the majority view. How often have we heard of injustice resulting from a physician not standing out against his peers?

The literature on PRS talks of 'physical or chemical restraint' to protect the child and others from aggressive outbursts. In practice, studies of PRS warn that one of the main dangers of treatment in hospital is that staff can end up becoming punitive towards the child.

If your child were being punished for being ill, your reaction would probably be to take her home. However, in his report on PRS, Lask wrote: 'If the child expresses a clear wish to return home and [...] the parents are able to accept and work on the fact that there is a psychological explanation for their child's illness, then a gradual return to the family home is indicated.' The parent is required to agree the psychological diagnosis.

This instruction allows for no possibility of misdiagnosis. A report on the management of PRS in 1998 stated that removal of the child from therapy is a major problem (why am I not surprised?) and lists it as a 'specific problem behaviour' in the family. 'This is often the result of a failure to fully accept the diagnosis plus the overprotective nature of the parents' say the authors. So refusing to accept the diagnosis could actually confirm it in the professionals' eyes.

I have recently talked with a specialist who dismisses 'pseudo-diagnoses' like PRS and MSBP as unhelpful. That seems to me a polite understatement.

Refs: *Archives of Disease in Childhood*, 1991; 66: 866-9 and *Clinical Child Psychology and Psychiatry*, 1998; 3: 229-249

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