a series of information pullouts
for parents and older readers

Jane Colby

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I would like to congratulate Invest-in-ME (Sue Waddle, Richard Simpson, their families and others) who organised the successful Westminster Conference in May. My full lecture is now on DVD with those of the other speakers. I was then invited to submit a paper on children with ME to the *Journal of Clinical Pathology*, which was accepted. This is a major step forward in spreading knowledge amongst medical professionals, since the journal is part of the *British Medical Journal* stable. The paper is entitled *Special Problems of Children with ME/CFS and the enteroviral link*. Here is the Abstract:

Since 1997, it has been known that ME/CFS constitutes the biggest cause of long term sickness absence from school, in both staff and pupils. The scale of the problem in children is substantial, and the pattern of illness in schools suggests a prominent role for virus infection, for example, the clustering of cases. The Dowsett/Colby study of 1997, researching long term sickness, reported on a school roll of 333,024 pupils and 27,327 staff, and found a prevalence of 70/100,000 in pupils and 500/100,000 in staff; 39% of cases were in clusters of 3 or more. The peak age was 14-16 years. The illness is known to be potentially very severe and chronic. In addition, the Tymes Trust has reported that many affected children struggle for recognition of their needs and feel bullied by medical and educational professionals. Children should have time to recover sufficiently before returning to school; sustainable, energy-efficient and often home-based education is important here, to fulfil legal obligations. Research is needed into viruses that trigger childhood ME, for example, enteroviruses, and into the neurocognitive defects caused by ME. We should recognise the value of previous biological research and records of outbreaks and I recommend that ME be made notifiable due to the encephalitic nature of the effects commonly reported in this illness.

http://jcp.bmjjournals.com/onlinefirst.dtl

This is merely a summary. The full paper carries new medical information to which families can alert their doctors. Papers by Professor Malcolm Hooper, Dr Jonathan Kerr and other speakers appear in the same issue of the *Journal of Clinical Pathology*.

When reputable information is published for professionals, it really can make a difference. Parent Karon Mason wrote to me: ‘Bryony’s social worker told us about you. She printed off copies of your professional guide, *The SENCO’s Key Role in supporting pupils with CFS/ME*. I have to tell you, I had been at a very low ebb until I read those guides. Everything in them perfectly described what Bryony had been (and still was) going through, even down to the more seemingly “eccentric” symptoms of ME. In fact it was like reading something that had been written about Bryony. We wasted no time in handing them out to the school, and Integrated Support at the following review meeting and I couldn’t help but notice that the teacher in charge of Bryony’s case seemed to (quite visibly) sit up and take notice when he saw it was written by a former head teacher. Thanks to that report, they have a better understanding of just how much of an impact ME has on the life of a sufferer.’

Genetic Relationship and Close Household Contact are Possible Risk Factors for CFS

A questionnaire-based study by the New Jersey Chronic Fatigue Syndrome Association was published in the June 2006 issue of the *Journal of Chronic Fatigue Syndrome*. It found that CFS occurs in family members of physician-diagnosed CFS patients much more frequently than in the general population. This included both blood relatives, particularly children of adults with CFS, and unrelated spouses and partners sharing the same household.

Overall, 45 of the 219 patients whose families were studied (ie 20.5%) had one or more blood relatives and co-habiting spouses or partners who had been diagnosed with CFS by a physician using the CDC (Centres for Disease Control) diagnostic criteria. These criteria were developed for research. The unrelated spouses or partners were 8 times more likely to have CFS than the general population.

The most striking finding is perhaps that regarding offspring. The children of patients with CFS were 13 times more likely to suffer from it than the general population, whereas parents, brothers and sisters of CFS patients were three times more likely to have it than the general population.

The authors say that the greater incidence in children suggests that ‘close household contact may have more influence than genetics in accounting for the occurrence of CFS in the offspring.’ It is possible that this is further evidence for the role of infection in the disease process.

GP Services

Private companies are being encouraged into primary healthcare by the government. The British Medical Association believes that 10,000 more GPs are needed to maintain current service standards, because around 20% of GPs will retire during the next two years as 36% of practitioners are aged over 50. The Department of Health has announced that the number of separate GPs’ surgeries may reduce from 10,000 to 1,800 over the next few years as a result of the retirement of GPs in single and two-partner practices - an 80% reduction overall.

In 2005, a 42,800 person study called ‘Your Health, Your Care, Your Say’ revealed that 20% of UK residents have problems registering with a GP and 52% find it difficult to book an appointment, especially out of hours. GPs’ telephone lines may be frequently engaged (25% of people gave up according to a YouGov survey) and many people have unfortunately experienced ‘rude’ or ‘offhand’ receptionists. This may be partly explained by the stress the receptionists are under, trying to run the system in those areas.

Because around 90% of GPs have opted not to work out of hours and many Saturday morning clinics have closed, people are using the NHS Direct helpline, nurses, paramedics, pharmacists and A&E as GP substitutes. The Government is fast tracking nurses and paramedics into a new ‘Medical Care Practitioner’ position to help cover the shortage. Health Secretary Patricia Hewitt has introduced Independent Sector Treatment Centres (ISTCs) and ‘nurse-led’ treatment centres, while reversing some community hospital closures. Supermarkets such as Tesco and Sainsburys are being encouraged to open surgeries in their bigger stores.

In this environment, it seems that the Trust was forward-looking to negotiate in 2005 a discount for its volunteers, members, their families and friends to register with GP Line (for our own personal experience of the service, see *Vision 2006-2* page 15). The service gives unlimited telephone access to a qualified, practising GP around the clock - not just in daytime surgery hours. To gain a prompt answer to a question in the middle of the night, I found it a great help. You should always remain registered with a GP so that a surgery appointment can be sought if necessary.

Focus On

School Examinations and ME - Special Assessment Arrangements

Special examination arrangements are intended to enable candidates who might not otherwise be able to do so to demonstrate their attainment.

For many years this document was at the Colby site www.youngactiononline.com. In early August I modified it and it is now in the Self-Help section of the Publications Page at www.tymestrust.org.

Special Arrangements is the term used for making arrangements in advance of the exam. Due to the effects of ME on brain function, appropriate special arrangements should be requested as a matter of course, well in advance if possible.

They include:

- extra time
- supervised breaks or rest periods
- modifications of visual presentation such as enlarged print or if the candidate's eyes are light sensitive, use of a colour filter over the paper, or use of different coloured paper
- taking the exam at home (any responsible adult not related to the candidate may invigilate)

If candidates have multiple disabilities, staff should consider all the possibilities for meeting their assessment needs. Whilst it would be unfair for a pupil to gain advantage over others, no pupil should be disadvantaged by exam arrangements.

Special Considerations is the term for what may be done at the marking stage. If the pupil is suddenly much worse on the day, special consideration can be given at the marking stage in exams leading to an external certificate (GCSE, A-level).

This does not apply to National Curriculum tests (SATS) but those with ME may be well advised not to attempt these tests, which are used to compile school league tables for comparison between schools. They do not confer a qualification. Conserving energy for healing and other necessary or desirable activities is recommended.

If the exam has to be cancelled, it is not the end of the world. There is no age by which any particular qualification has to be obtained, although many people assume that there is. There is no such thing as 'too late'.

Publications Available @ www.tymestrust.org

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)*

School Examinations and ME - Special Assessment Arrangements

The Essex ME Companion

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

If you haven't yet visited our website, you are in for a treat. Multi-coloured dandelion clocks float down the screen (no, they don't get in the way of the text!) and it's easy to navigate. You can also see Vision in vibrant full colour.

Opathyitis

The ‘opathy’ v ‘itis’ debate has been much on my mind. After a glorious Shakespeare evening, I recently wrote a column For Stock Press summarising my own experience and stressing the need to champion children with ME:

The Young ME Sufferers Trust Would Like To Thank...

...Sir John and Lady Carter for their spendid Shakespeare Evening in aid of the Trust, and the wonderful Citizens of Stock and others, for attending! The total raised was £700. Thank you all so much, on behalf of the children we support. What a great evening it was - and also for me personally. In 1985 I was so weak from ME that I could scarcely comb my hair or chew my food. I was an Essex headteacher when, at the age of 40, I caught a virus related to polio. My mother had to look after me, just as she did when I was a child. The pain and weakness were beyond description. They went on day by day, week by week, month by month - and year by year. My heart rhythms were all over the place. When I moved to Stock in 1991 (I can’t believe that 15 years have gone by since then!) I had to be moved along with the furniture - I was plucked from one sofa and plonked on another. Our local doctors have always been caring and supportive and have always taken an interest in the Trust since I began running it in 2000. The Trust is run by a small team of dedicated volunteers. We have political support at the highest level, but volunteers and funds are always needed. I still have some limitations and can’t do too much at one time, but the body has a way of healing itself if we let it, though sadly, not everyone becomes strong again. Children with ME need love, kindness, they need a voice (read their words in *Young Hearts* and in *Vision*, both from the Trust). And they need someone to champion their cause with the authorities when they don’t understand. To find out more about us, please go to www.tymestrust.org and enjoy the pretty dandelion clocks floating down the screen!

Re-living those graphic effects, I recalled my profound disagreement with the unofficial renaming of ME by some organisations, downgrading it to ‘Myalgic Encephalopathy’, when the name listed by the World Health Organisation is Myalgic Encephalomyelitis.

The aim - for medical professionals to accept the term ME - hasn’t worked. Most doctors still use the unsatisfactory and hopelessly muddled name ‘chronic fatigue syndrome’. The only outcome has been to downgrade ME. Where ‘opathy’ just means that something’s wrong, ‘itis’ specifies inflammation, which is typically caused by infection. The word ‘Encephalomyelitis’ means ‘inflammation of the brain and spinal column’. The ‘opathy’ dogma has now got into ME literature for schools. Denial of inflammation flies in the face of the symptoms and the work of those who first coined ‘ME’. Thank goodness polio myelitis was not called ‘chronic weakness syndrome’.

Research such as *Spinal Fluid Abnormalities in Patients with Chronic Fatigue Syndrome* by Natelson et al shows that something nasty has indeed occurred. Along with Professor Malcolm Hooper, Dr Byron Hyde, Dr Elizabeth Dowsett, the late Dr Richardson and others, I consider that the original name is correct, as case records and other evidence indicates. I was very moved when Dr Dowsett called to say that my feature in the *Journal of Clinical Pathology* which calls for ME to be made notifiable was ‘the best birthday present I’ve ever had!’