

# The Brief by Jane Colby

Third in a series of information  
pullouts for parents and older readers



Jane Colby FRSA

## NEW : ME/CFS GUIDELINES FOR EDUCATIONAL PSYCHOLOGISTS

As a former head teacher, I am delighted that the first ME/CFS Guidelines for Educational Psychologists are now available from the Trust.

The author, educational psychologist Naomi Burgess, has been working with me for some time, during which the improvement in recognition for children with ME at government level has not always translated into practice in LEAs and schools.

An educational psychologist is consulted, amongst other reasons, when special educational needs are formally assessed. Accurate knowledge about ME is vital to ensure that the assessment takes full account of a child's needs and is carried out in a sympathetic way.

The Guidelines give reminders about sensory difficulties *eg* photophobia (light sensitivity); hyperacusis (sound sensitivity); temperature regulation problems; heightened sensitivity to smells and touch; food intolerances.

They cover the illness, the assessment procedure, curriculum, examinations, short and long-term planning, educational methods such as virtual education and other aspects. They are also very practical.

'It is [...] universally helpful to identify practical solutions; for example, it is possible to tackle isolation in such a way that the child's health is not threatened (ways in which friends and school can keep contact with the child who cannot attend) and to find practical solutions to other problems in a similarly pragmatic way.'

### ***PUSHING THE BOUNDARIES***

The great majority of the Trust's Advice Line calls cite educational difficulties as a cause of distress, worry, discrimination or even relapse. Lynne Kersh, mother of member Daliany,

recently wrote:

'I bought a copy of the magazine *Special Children*. Your article *Pushing the boundaries in ME/CFS* is exceptional. To teaching staff new to the condition it sets out very clearly the damage caused by educational institutions' misconceptions about ME as well as being very positive as to what is desperately needed right now, for the good of the child.

'For me, it reopened very painful scars of what we personally had to go through 6 years ago when ME was seen, at best, as a 'behavioural problem' and, at worst, 'all in the head'.

'In our case, home tuition was refused by our school because my daughter was "so bright she would pass her GCSEs without even finishing the school year". A sentiment which did nothing to placate a very ill child whose only wish was to return to school, continue 'normal' life alongside her peers but, most importantly, eventually be examined, without being prejudiced in any way, so that all her hard work to date would not have been in vain.

'Congratulations on what I am sure will turn out to be not only the definitive article on the provision for children with ME in schools but also a life saver for thousands of anguished youngsters caught in the education v health conflict.'

Questions Publishing immediately granted permission to turn the full feature into one of the Trust's Professional Guides for Teachers.

*Pushing the boundaries in ME/CFS by Jane Colby and Guidelines for Educational Psychologists by Naomi Burgess are at [www.tymestrust.org](http://www.tymestrust.org) A presentation copy of the Guidelines is available.*

# FACTS AT YOUR FINGERTIPS

## A Persistent Viral Infection

Recent reports state that British scientists have found firm evidence that ME/CFS leads to clear biological changes in the blood, and may be caused by a viral infection. Dr Kerr's results are published in the *Journal of Clinical Pathology*. The online British Medical Journal wrote: 'While the new research is not incompatible with the long-held belief that the illness is psychological in origin, it suggests that a physical cause, such as a viral infection, is

more likely.' This statement can be quoted to your doctors.

In VISION March/April 2005 we interviewed Dr Vance Spence of MERGE, whose own research has also shown vascular changes.

The Trust has allocated £14,000 of its research funds to the first biomedical study in children, about to begin.

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## Overprescription of SSRI Antidepressants

David McCoy, specialist registrar in public health for the NHS, states in the *RSA Journal* that leading pharmaceutical corporations, driven by the need for profit, have been encouraging over-consumption and over-prescription of medicines.

Many people with ME are prescribed SSRI antidepressants (selective serotonin reuptake inhibitors) such as Prozac, Seroxat and Zoloft. The new RCPCH guideline on ME/CFS for paediatricians recommends fluoxetine – the drug in SSRIs.

However, McCoy writes: '...their benefit was exaggerated while their harm was minimised. It took years of patient experience and advocacy and a vigilant media to show that

SSRIs were addictive, caused a chemical dependency and came with serious side effects including increased risk of suicide.

GlaxoSmithKline reached a 2.5 million dollar settlement with the attorney general of New York over charges of withholding negative information about their drug. GSK revised their estimate of the risk of withdrawal symptoms from 0.2% to 25%. [...] Hundreds of thousands of children were put on SSRIs in the US during the 1990s.'

As always, if you have concerns over any medicines, discuss them with your own doctor and a pharmacist.

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## Free Over 16 Virtual Education for members of The Young ME Sufferers Trust

Following the launch in the House of Lords of our partnership with Nisai Education, the Trust arranged this new opportunity for members over 16 or approaching the age of 16. At the last count there were 35 places remaining.

In September 2003 provision was made by the Learning and Skills Council for students with medical needs to continue their GCSE courses in sixth forms with funding secured by the Local Education Authority. Although Further Education Colleges may suggest that they provide open access, the reality is that some students are unable to secure a place, where their medical needs determine that they require continuing home-based education. We hope that this scheme will assist them.

## **FOCUS ON:**

### **YOUNG HEARTS**

#### **Television Interview**

*We are grateful to ITV Central for donating this interview.*

View it at [www.tymestrust.org](http://www.tymestrust.org)

On the eve of the launch by Terry Waite CBE of the book *Young Hearts* in Warwick Castle, Trust member Lucy Hayes, a contributor, was interviewed by ITV Central News.

Also interviewed were: Lucy's father; Karen Scarrott (mother of Jade, who inspired the book); and Jane Colby. Jane explained that we now know that viruses trigger the illness.

Mark Gough: 'Jane, why is it so misunderstood?'

'Because people see you when you're feeling well enough to get out and they don't see you when you're not. [...] They don't see the children when they're bedridden and really sick. [...] They may be in terrible pain and people are saying, "Isn't it nice to have some time off school?"'

Everyone who reads *Young Hearts*, even those who previously knew nothing about ME, learns from these poems. If you have a doubter in your family, ask them to watch this TV interview.

*You can purchase Young Hearts for £7.95 directly from the Trust by credit card (01245 401080) or send us a cheque. If buying through Amazon please go to [www.tymestrust.org](http://www.tymestrust.org) first and click on the link. Amazon will then make a donation.*

*'The courage of your young authors is both humbling and inspiring.'*

**Julia Malin**

### **Online Free**

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

*In The Spotlight : The Tymes Trust View*

### **Self-Help**

*ME – and my Friends : leaflet for friends*

*The Tymes Trustcard : 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*

*Experiences – Whispered Words : severely affected*

### **Professional Guides**

*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*

Presentation copies of our Reports are also available. Details are on the website or contact the Advice Line.

# 50 000 youngsters learning at home

**Advocates of home schooling believe that children achieve more educationally and lead a well-adjusted adult life. Several years ago, Australian research revealed higher academic results in those not attending school, but learning instead via the school of the air.**

In the UK, concern over bullying, dislike of the incessant testing regime, or personal choice means that up to 50,000 youngsters are now believed to be receiving home education in the UK.

The conventional view that children with ME learning at home are isolated because they are not at school is incorrect. It is the illness that isolates them. They are often not well enough to attend special interest clubs, swimming pools, museums etc and make friends with others being home educated.

Studies show that healthy children learning at home are not isolated, but have a circle of acquaintance of all ages, rather than solely of their own age, as typically happens in the artificial environment of school.

Education Otherwise reports enrolling 200 members a month. Ninety per cent of calls to their helpline concern children who have been bullied at school. At The Young ME Sufferers Trust a similar percentage of calls report the unsuitability of educational demands on children with ME, often amounting to institutional bullying.

Along with many paediatricians, the Trust finds that educational demands are a key cause of relapse from ME. Some parents find they need to take their children out of the state system to help them get well. Others are not in a position to do this and should not have to. Under the law, the state system should offer suitable education to all children.

A half-way house between attempting to comply with unsuitable demands or

taking the drastic action of complete withdrawal from the state system is to persuade the Local Education Authority to provide education at home.

The government states in *Access to Education for Children and Young People with Medical Needs* that children off school due to illness for more than 3 weeks should receive other provision and that those needing home schooling should receive it. But it regards this as temporary. Children with ME often have a need for home-based education in the longer term. You will need medical support for this.

You may find that your GP is not listened to. The LEA may insist on a consultant's recommendation. But as this cannot normally be obtained within the statutory 3 weeks, you can challenge any LEA who makes this a condition.

Last year, the Departments of Health and Education jointly published *Megan's Journey*, a fictional child's journey through ME. In some respects this Exemplar is not representative of a typical case, but it clearly shows the LEA giving home-based education on the recommendation of a GP. You can use this as evidence of the government's expectations.

If your child needs educating at home for longer than some notional minimum period, the following documents from the Trust may help.

*GPs Good Practice Guide to Education for Children with ME*

*Back to School?* by Jane Colby First published in *Special Children*.

*Pushing the Boundaries in ME/CFS* by Jane Colby First published in *Special Children*

*Succeeding with ME* : Virtual Education for Children with ME/CFS

All at [www.tymestrust.org](http://www.tymestrust.org)

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