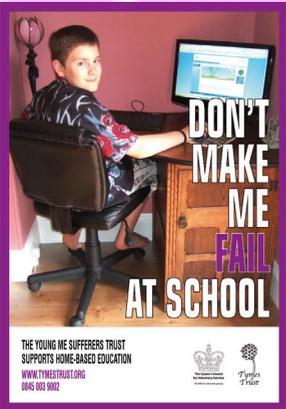


# ME Briefing : not NICE



**“It is our view that certain hospitals and paediatricians are misinterpreting the NICE Guideline by insisting on school attendance.”**



**“It can be next to impossible to study effectively after struggling into school.”**  
*Lord Clement-Jones  
CBE, Founder Patron  
TYMES Trust*

On 14 September I visited Richmond and Kingston ME Group with our Executive Director Jane Colby, who is a former head teacher. She spoke robustly on how doctors are increasingly influencing the education of children with ME. I have at times heard her refer to this as a ‘land grab’!

I asked Jane to open her presentation with an important fact that she has often emphasised: it would seem that doctors are using time spent in school as a measure of recovery from ME. They try to put in place a plan for graded school attendance, which is often unsustainable, and schools seem to think it their duty to follow it, leading to unnecessary conflict between school and family and causing distress to children.

To use one of Jane’s phrases, ‘let’s deconstruct this situation’...

The doctors’ guideline from the National Institute for Clinical Excellence (NICE) states: ‘do not use time in education as a sole marker of progress of CFS/ME’. (This was a strong recommendation by The Young ME Sufferers Trust when the guideline was being written.)

Not only that, but NICE also uses the term ‘education’ rather than ‘school’ (also at our recommendation) and says the approach should be flexible, with home tuition and equipment that ‘allows a gradual reintegration to education’. Not school. Education. The two are not the same.

It is our view that certain hospitals and paediatricians are misinterpreting the NICE Guideline by insisting on school attendance. Schools and education authorities should be using the 2013 guidance for Local Authorities from the Department for Education

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on sick children. This document makes it quite clear that they, and not doctors, are responsible for the child's education, and may thus be held to account themselves if it is not 'suitable' (a legal term).

The local authorities' guidance explains that reintegration plans for attendance at school should not be put in place until the child is

sufficiently recovered. Other forms of education should be used.

You can watch a 25 minute webinar on these new education guidelines at [www.tymestrust.org](http://www.tymestrust.org) (click on the link in the green box). There are 10 slides and we strongly suggest that ALL parents, schools and local authorities make time available as it is a real eyeopener.

Inside this booklet you will also find the Trust's appraisal of the NICE Guideline *The Good, The Bad and The Ugly* which was originally published in 2007. It is clearly necessary to reissue this appraisal and draw it to everyone's attention.

Kind regards



Keith Harley  
Chair of Trustees

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## Jane Colby : A briefing on our child protection work



Over the years we have publicised the fact that many families whose children have ME face child protection investigations. We thought you would like an overview.

### Campaigning and casework

**2002** As a member of the children's panel of the Chief Medical Officer's Working Group on CFS/ME, I worked with doctors to get information into the Dept of Health Report of 2002. It stated: 'In cases of CFS/ME, evidence clearly suggestive of harm should be obtained before convening child protection procedures or initiating care proceedings in a family court. Neither

the fact of a child or young person having unexplained symptoms nor the exercising of selective choice about treatment or education constitutes evidence of abuse.' Unfortunately, the DOH did not circulate the report.

**2006** I presented a briefing to Dr John Sentamu, Archbishop of York, who was very concerned. It was entitled *Guilty Without Trial*.

**2008** I made a presentation to the All

Party Parliamentary Group on ME on child protection issues. I presented two proposals: that social services be alerted to the frequency of investigations (a statistical anomaly) and that families should be alerted to their rights and the duties of the authorities.

**2011** At my suggestion, the new APPG held a further meeting at which I presented an update, explaining that the number of families whom we had helped with erroneous child protection investigations (ie the investigation was dropped) had risen to 70. By September 2013 it had risen to 108.

I listed three misperceptions which I thought partially explained these cases:

- a) the misperception that ME is a mental health disorder
- b) the misperception that treatments recommended by NICE can always be expected to 'cure' or substantially improve the

condition

c) the misperception that the illness is neither long lasting (chronic) nor severe.

I explained that as a result, parents are unjustly suspected of harm or neglect, with all the trauma for the family that a child protection investigation produces. This was brought to the attention of the then Children's Minister, by the APPG.

### **In the media**

In the 1990s I co-authored a piece for the press about a case where a severely ill child was seized from her home, with police in attendance. The piece was scheduled to appear in the *Mail on Sunday* three weeks running but it was pulled at the last minute each time. The child was later allowed home again after the hospital failed to effect an improvement. The child then improved over time, at home.

At the end of the 1990s I co-authored a

questionnaire for BBC *Panorama* showing how prevalent these investigations against families are (the figures are republished in my book *Zoe's Win*).

In 2004 I authored a report *The Forgotten Children* based on information from families registered with the Trust. A main theme was how the education system was failing children with ME and page 12 restated the *Panorama* statistics. This report made national news. Soon afterwards, the Trust's report *Our Needs Our Lives* revealed that 25% of families who took part said doctors or other professionals had suggested their illness was caused by parents.

Erroneous child protection investigations are still causing many families of children with ME great trauma, often sparked because treatments do not work and because the child is not well enough to get into school.

# NICE - the CFS/ME Guideline

## the Good, the Bad, and the Ugly

**On 22nd August [2007] the National Institute for Clinical Excellence published its guidance for doctors on CFS/ME, entitled *Chronic fatigue syndrome / myalgic encephalomyelitis (or encephalopathy) : diagnosis and management of CFS/ME in adults and children***

The NICE remit was to prepare guidance for the NHS in England and Wales on ‘the assessment, diagnosis, management of adjustment and coping, symptom management, and the use of rehabilitation strategies geared towards optimising functioning and achieving greater independence for adults and children of CFS/ME’.

The *Guideline, Quick Reference*, patient / carer booklet and related documents can be downloaded from [www.nice.org.uk/CG53](http://www.nice.org.uk/CG53).

Some doctors may only read the *Quick*

*Reference* which does not include this (from the Introduction):

*The World Health Organisation (WHO) classifies CFS/ME as a neurological illness (G93.3), and some members of the Guideline Development Group (GDG) felt that, until research further identifies its aetiology and pathogenesis, the guideline should recognise this classification. [the Trust concurs with this view] Others felt that to do so did not reflect the nature of the illness, and risked*

*restricting research into the causes, mechanisms and future treatments for CFS/ME.*

This disagreement within NICE indicates that even the WHO’s expertise is unlikely to be heeded by some medical professionals until classic ‘ME’ (the neurological illness) is unscrambled from ‘CFS’ (a collection of symptoms too imprecise for a unique diagnosis).

We believe this makes our stand in advocating the separation of ME and CFS even more important; we will continue to highlight this issue.

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## Press Release Excerpts

### **On diagnosis:**

*If a child or young person under 18 years old has symptoms of possible CFS/ME they should be referred to a paediatrician within 6 weeks of first seeing their doctor about the symptoms.*

*After other possible causes have been excluded, a CFS/ME diagnosis should be*

*made after symptoms have persisted for 4 months in adults, and after 3 months in a child or young person (in consultation with a paediatrician).*

### **On management:**

*An individualised management plan should be developed with the person with CFS/ME and they are in charge of the aims*

*and goals of the overall management plan.*

### **On Education:**

*Follow guidance from the Department for Children, Schools and Families [now the Department for Education] on education for children and young people with medical needs, or equivalent statutory guidance.*

## The Good

NICE has acted on a number of the Trust's recommendations and those of other ME organisations (our recommendations are in *Vision 2007-1* p14-15 at [www.tymestrust.org/tymesmagazine.htm](http://www.tymestrust.org/tymesmagazine.htm); printed copies available).

NICE emphasises prompt diagnosis and doctors are urged to 'acknowledge the reality and impact of the condition and symptoms'.

NICE prescribes 'shared decision-making' between

health professionals and patients and emphasises the individual's 'right to refuse or withdraw from any part of their treatment plan without it affecting future care.'

Quote this if you feel coerced into management plans that are unsuitable for you. NICE advises that the doctor is not 'in charge' - you are. Use your own judgement; this is a difficult illness for someone to appreciate from outside.

NICE recommends a flexible approach to education, with home tuition and equipment that 'allows a gradual reintegration into education'. This does not say 'reintegration to school', reflecting our recommendation that education should not necessarily mean school attendance. There are other means of learning which may be more suitable, such as the interactive online schemes for which the Trust is in

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partnership with Nisai Virtual Academy.

NICE advises doctors: 'do not use time in education as a sole marker of progress of CFS/ME [this was a

strong recommendation by the Trust], and ensure a balance between education and home and social activities.' We know that school attendance has unfortunately been used

as a marker of recovery without reference to whether symptoms are provoked, or whether attendance is hindering academic progress.

## The Bad

NICE discourages daytime naps in the name of 'sleep hygiene' a dreadful term (who invented that?) with overtones that someone who cannot sleep in the prescribed way is dirty. It flies in the face of evidence from ME experts that daytime napping promotes health and ignores the Mediterranean siesta tradition as if that were abnormal.

NICE advocates management plans based on the outdated concept that the muscles are merely 'deconditioned' from lack of use. We disagree: physical disability and illness require time for healing before demands are made on the muscles. Inappropriate exercise

is a recipe for relapse. Patients made worse by such treatment may take legal action or report the therapist in order to help protect other patients.

NICE advocates that Cognitive Behavioural Therapy (CBT) and/or Graded Exercise Therapy (GET) should be offered to people with mild or moderate CFS/ME and provided for those who choose it, saying that there is the clearest evidence of benefit for these approaches, and that 'sleep hygiene' should also draw on the principles of CBT and GET. The Trust's information is that only those who do not have classic ME are helped by graded exercise, unless the body has healed sufficiently to withstand

progressive increases in effort.

NICE states that the Graded Exercise Therapist should discuss ultimate goals that are important to the person eg a 'twice daily short walk to the shop, a return to cycling or gardening or, for people with severe CFS/ME, sitting up in bed to eat a meal'. Increases of up to 20% in effort are recommended with advice to the therapist to 'explain symptoms and the benefits of exercise'. We would like to hear any such explanations you are given.

NICE recommends that the intensity of Graded Exercise should be increased in stages, leading to aerobic exercise. This puts up the heart

rate. It contravenes advice from experts such as Professor Paul Cheney: ‘The most important thing about exercise is not to have them do aerobic exercise. I believe that even progressive aerobic exercise [...] is counter-productive. If you have a defect in the mitochondrial function

and you push the mitochondria by exercise, you “kill” the DNA’ (1999, International Congress of Bioenergetic Medicine, Florida).

NICE advises: ‘Offer people with severe CFS/ME an individually tailored activity management programme

as the core therapeutic strategy,’ based on the same principles as Graded Exercise (above). Yet the Trust has formerly severely ill members who have greatly improved over time with no treatment at all, and others whose health has declined after accepting this treatment. We caution care.

## The Ugly

NICE published comments received on its 2006 Draft guideline (*we thank Tom Kindlon, Vice Chair, Irish ME Support Group, Partner Group to The Young ME Sufferers Trust, for researching the NICE website*). Many have caused concern. The following were submitted by St Bartholomew’s Hospital (Barts):

- *We emphasise that CBT and GET can also help those small number of patients who do not wish to return to normal health.*
- *Equipment and aids may hinder recovery as much as help it.*

- *In response to the NICE Draft text *For adults and children with moderate or severe symptoms, provision of equipment and adaptations (for example, a wheelchair, blue badge or stairlift) to allow individuals to improve their independence and quality of life should be considered, if appropriate and as part of an overall management plan*, Barts said: *We disagree with this recommendation. Why should someone who is only moderately disabled require any such equipment?**

There seems little recognition by Barts that people can be made more ill if such practical help is denied. We feel that their comment shows a serious misunderstanding of the illness as being perpetuated by psychological factors rather than physical limitations. We are not aware that children wish to depend on a wheelchair, a stair-lift or hoist for longer than necessary. Barts also states that CBT / GET can help the severely affected - discussed above.

- *We do not agree that drug treatment should*

*be initiated at lower dose than in usual clinical practice.*

This contradicts evidence on drug reaction given to NICE.

- *Weight loss is not part of CFS/ME at any age.*

The NICE Guideline Development Group itself disagreed: 'The view of the GDG is that some

children may lose weight and require nutritional support.'

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## Young Hearts Twitter Q&A, Friday 29 November 3pm-5pm GMT

Our next Twitter Q&A session is on Young Hearts Day. Tweet your questions to @JaneCColby and include hashtag #AskJCC.

Why have we changed the hashtag since last time? Because others started using it!



*Has your doctor or teacher been especially helpful? Why not award them a Tymes Trust Young Hearts certificate. One free per member. Send us details via the Contact Us form at [www.tymestrust.org](http://www.tymestrust.org).*

Here are some questions we answered earlier:

**Q Can school withhold home tutors, virtual ed etc if family decides to refuse so-called treatment plans?**

*A No. Watch My talk on statutory duty of LAuth to give 'good' + 'suitable' ed for sick children.*

**Q Just been diagnosed with CFS, finding it hard, worried about the future - need advice but don't know where to start?**

*A Start with something easy. Try Quick Tour of ME Symptoms, Management etc [www.tymestrust.org/pdfs/quicktour.pdf](http://www.tymestrust.org/pdfs/quicktour.pdf) Convalescence is helpful.*

**Q What info, if any, would you recommend giving to our new GP? He is very dismissive of the illness.**

*A Don't overload him. Give things targeted to yr specific problem eg he thinks it's psychological? Use [www.tymestrust.org/pdfs/ttmeisphysical.pdf](http://www.tymestrust.org/pdfs/ttmeisphysical.pdf)*

**Q I hear #TymesTrust is run entirely by volunteers - that's something special isn't it?**

*A Yes, totally voluntary including me. TT received Queen's Award for Voluntary Service 2010 (MBE for volunteer groups).*

**Q Where do you get all your boundless energy & enthusiasm from Jane? That's my question**

*A I focus my energy/enthusiasm on what matters (to me, and to ME). Energy's not really boundless! Lots of vegging out!*

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*Coming in December - your jolly Tymes Tidings!*