



IN THE HIGH COURT OF JUSTICE
QUEEN'S BENCH DIVISION
ADMINISTRATIVE COURT

BETWEEN

R (on the application of
DOUGLAS FRASER (1)
KEVIN SHORT (2))

Claimants

-and-

THE NATIONAL INSTITUTE
FOR HEALTH AND CLINICAL
EXCELLENCE (NICE)

Defendant

WITNESS STATEMENT OF
JANE COLBY

I, Jane Colby, Executive Director of The Young ME Sufferers Trust PO Box 4347 Stock Essex CM4 9TE, will say as follows:

1- I am Executive Director of The Young ME Sufferers Trust (also known as the TYMES Trust) and a former head teacher. I make this statement in support of the Claimants' application for judicial review. In particular, I make this statement to address the impression, given by the Witness Statement made by Mary-Jane Willows on behalf of the Defendant, that the views expressed by the Claimants are those of a disaffected minority. Insofar as the facts within this statement are within my direct knowledge they are true. Insofar as they are not, they are true to the best of my knowledge and belief. I am authorised to make this statement on behalf of The Young ME Sufferers Trust.

Personal Experience and Background

2- I am co-author of the largest study of ME/CFS to date (Dowsett and Colby, *Journal of Chronic Fatigue Syndrome* 1997). This study first established that ME/CFS is the biggest cause of long term sickness absence

from school in both children and staff. I have been published in many professional journals including

The Journal of Clinical Pathology, The Lancet, The British Medical Journal, the British Journal of Special Education, Special Children and Physiotherapy Frontline, and I was commissioned by Birmingham University School of Education to produce guidance on ME/CFS for Special Educational Needs Co-Ordinators.

3- I took a prominent role on the children's section of the Chief Medical Officer's Working Group on CFS/ME from 1997-2000 and made a major contribution to the subsequent Department of Health Report of 2002. I was a member of the Delphi Group consulted by the Royal College of Paediatrics and Child Health on the compilation of their guidance for Paediatricians and was also consulted over the content of *Access to Education for Children and Young People with Medical Needs* (DFES 2002). I have been invited to give training lectures to GPs and consultants, including two GP Forum Conferences at the Royal Pharmaceutical Society and Birkbeck College, London, a Paediatric Refresher Course for GPs at Imperial College Faculty of Medicine, Hammersmith Hospital, London, the Medical Education Programme for Doctors, Doncaster Royal Infirmary and at many hospitals including those in Lincolnshire and Kent. In 2004 I was invited to address the Scottish Parliamentary Cross Party Group on ME and earlier this year I was invited to address the Westminster All Party Group on ME on the subject of mistaken Child Protection procedures taken against families of children with ME. I was also invited by Canadian ME specialist Byron Hyde MD to assist in the creation and editing of the Nightingale ME Definition for the Nightingale Research Foundation, and was also requested to edit

the work of the late paediatric consultant Dr Alan Franklin, and of Dr Nigel Hunt, GP and Associate Director of Postgraduate Education, Eastern Deanery, for publication in medical journals.

The Young ME Sufferers Trust

4- The Young ME Sufferers Trust is the longest established service for children and young people with ME, their families and the professionals who care for and educate them. The Trust's Patrons are Lord Clement-Jones CBE, Earl Howe, Lady Elizabeth Anson, The Countess of Mar, Princess Helena Gagarin Moutafian MBE, Terry Waite CBE, Shirley Conran OBE, and Barbara Windsor MBE.

5- The organisation began in 1989 as the inspiration of two young people with ME. Due to increasing demand in the 1990s it grew, obtaining charitable status in 2000, and becoming the national charity it now is. Our work has been praised and supported by former Prime Minister Tony Blair and by David Cameron MP, Leader of Her Majesty's Opposition (see www.tymestrust.org) and we have the support of many well-known figures in public life. The Trust's website has been chosen by the Wellcome Trust for archiving in the national interest.

6- The Trust is a member of the ME Alliance and has Partner Groups throughout the UK. We are an entirely voluntary organisation with 35 volunteers, many of whom are, like myself, qualified professionals. Our Professionals Referral Service represents the fields of Education, Social Services, General Practice, Paediatrics, Psychiatry, Public Examinations, Nursing, Pharmacy, Educational Psychology and Welfare Rights. The numbers helped by the Trust include a present database of between 1600 and 1700 taking into account the many young people and their families, professionals and others who are registered with or who approach the Trust for assistance; there are also those who access the free publications on our website and the total number helped every year runs into many thousands. The Trust has run a training session for the ME Association (the leading adult ME charity) to help MEA volunteers in responding to calls about children. As the Trust's Executive Director I produced a specialist patient information leaflet for the MEA on ME/CFS

during childhood and adolescence.

7- The Government has recently thanked the Trust for its input into the new Education White Paper *Back on Track : A strategy for modernising alternative provision for young people*. We have taken part in giving advice to many government departments including the Department for Work and Pensions, the Department of Health and the Department for Children Schools and Families.

The NICE Guideline

8- The Trust's extensive and lengthy experience of assisting young people with ME and their families through our Advice Line puts us in the position of being able to convey the general reaction to the NICE Guideline on CFS/ME which we believe to be not fit for purpose. In this, our view is echoed by the great majority of ME support organisations.

9- An extremely serious fault with the NICE Guideline is the blanket recommendation for Graded Exercise Therapy and Cognitive Behaviour Therapy which our knowledge and experience informs us can be detrimental to many young people suffering with ME.

10- We feel that the reason this recommendation was accepted by NICE was the imbalance in the Guideline Development Group, which we believe was improperly constituted. One of the patient representatives on this Group resigned rather than endorse the finished Guideline.

11- We believe that the composition of the Guideline Development Group did not reflect the true state of knowledge of this controversial illness. Treating ME as if it were synonymous with the artificial construct called Chronic Fatigue Syndrome in the Guideline that emerged was a fundamental flaw in the process that would not have happened had ME experts been included along with those who are presently promoting 'CFS'. Earlier this year, I prepared a Judge's briefing at the request of the Official Solicitor who was acting as a Litigation Friend for a young person, which clarifies the difference between ME and CFS. I attach a copy of this document as Exhibit JC1. [*the document submitted as Exhibit JC1 is available at www.tymestrust.org/pdfs/metheillness.pdf*]

12- We further believe that it was incorrect to

relegate patient experience to a low level of priority. The Chief Medical Officer's Working Group gave equal weighting to evidence from patients and evidence from the medical profession, which we believe would have been the correct way for NICE to proceed. With the Government promoting the idea of Expert Patients as being authorities in their own management, it was, in our opinion, perverse and wrong of NICE to then treat their evidence as of less value than that of medical professionals who can offer no cure.

13- We believe that it is as a result of this Guideline's misguided and blanket recommendation for Graded Exercise/Activity that we are now seeing paediatricians treating attendance at school as if it were part of a Graded Activity Programme, thus depriving children of their rights under the law to suitable education.

14- The result of insisting on school attendance is often further illness, and even where the child can manage it physically, low or non-existent educational attainment often results from the effect of such efforts upon brain function. The statutory guidance *Access to Education for Children and Young People with Medical Needs* makes it clear that the child should be educated in the manner and in the venue that enables them to perform to the best of their ability. A school attendance register is not the measure of whether the child is performing to the best of their ability. Serious injustice is being perpetrated and magnified, in our opinion, by the use of the NICE Guideline to justify and promote these potentially illegal practices by paediatricians.

15- Furthermore, there are problems with chronic fatigue clinics that have been set up around the country and which appear to follow the same approach, often replacing existing consultants' clinics so that patients have been diverted from their care to the new services. We have been contacted by parents begging us not to support these clinics, which are promoting the same flawed therapies, therapies that are undermining their children's health. One parent was absolutely distraught in case the Trust might be going along with the approach of AYME in supporting these clinics 'as then I shall have no-one to turn to'.

Quick Tour of ME Symptoms, Management and Trust Services
Email Alerts and Trust Statements
Special Problems of Children with ME and the Enteroviral Link

Self-Help

ME ~ and My Friends (*a leaflet for your friends*)
The Tymes Trustcard (*a pass card for school*)
Explain Your Abilities
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

Speech to the Royal Society of Medicine
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

16- The notion that these therapies are effective in general is to equate children with ME, who may be severely affected and respond badly to any kind of activity or exercise until substantially recovered, with others who may have a different, perhaps psychologically based illness. They are all trapped together in the CFS net and are now widely expected to respond to the same treatment as a direct consequence of the way in which the NICE Guideline Development Group was set up.

17- It also seems to us anomalous for a Guideline Development Group to major on advice that would appear to be intended for those who do not have neurological disease. Cases of ME were already known, in the mid-1900s, to be triggered by enteroviruses, which are in turn known to attack the nervous systems of the body. To set up a Guideline Development Group that appears to exclude those who can bring this fundamental knowledge to the task cannot be correct.

Mary-Jane Willows & AYME

18- I also wish to address certain points made by Mary Jane Willows, Chief Executive of AYME, in her Witness Statement.

19- In paragraph 6 of her Statement, Ms Willows states that there was ‘one co-opted expert’ on the Guideline Development Group. Although she does not in fact say so, this ‘expert’ was AYME’s own founder and Chair of Trustees. In my view, this calls into question the whole of Ms Willows’ Statement as there is a clear conflict of interest.

20- The Trust has not seen evidence that young patients’ views resemble Ms Willows’ account with regard to the Guideline. We are certainly not aware of young patients ‘fighting for years’ for the treatments recommended by NICE. Quite the contrary. One young man recently resigned publicly from AYME, severely criticising AYME’s promotion of graded exercise therapy and stating publicly: ‘What worries me now is how one sided your stance has become.’ I attach as Exhibit JC2 a copy of that statement.

21- In paragraph 8 of her Statement Ms Willows states that, if the NICE Guideline were withdrawn, she feels it ‘highly probable’ that the patients that AYME represents would be deprived of ‘highly effective’ treatments. However, it is AYME’s own Medical Advisor who a) is providing this treatment and b) took a prominent role, as a member of the GDG, in writing the Guideline recommending it. In our view, this calls into question any objectivity in Ms Willows’ Statement. In practice, a number of our young members have not found this treatment effective and have had to withdraw from it, whereupon, in several cases, a psychiatric diagnosis was mooted to account for its lack of success. The medical literature states that the psychiatric diagnosis in question (Pervasive Refusal Syndrome, where a child refuses to interact with the world) can develop due to parental abuse and can lead to forcible admission to psychiatric units.

22- In summary of these points, Ms Willows’ description of the benefits of this Guideline bears little resemblance to the reality with which we come into contact in our work. In common with NICE Guidelines generally, this Guideline is widely regarded by the medical profession as binding; in one of the worst cases a consultant wrote to a young patient’s GP recommending that Child Protection procedures be considered if the family continued to decline the treatments recommended by NICE.

Conclusion

23- There are some recommendations in the NICE Guideline which are not in our view unhelpful. But this fact serves only to underline the strength of our concern that the Guideline should not stand in its present form. It is not worth preserving that which is good if it means propping up that which is monumentally bad.

Statement of Truth

I believe that the facts in this statement are correct.