

Tuesday, 18th April 2006.

Oral Evidence Hearing
The Gibson Group on ME/CFS
House of Commons
Room E
7 Millbank
London SW1P 3JA
United Kingdom

Statement to Parliamentary ‘Inquiry’ into ME/CFS

By

The One Click Group

I am Angela Kennedy from the One Click Group, and this is my colleague Jane Bryant. One Click is a pressure group providing opposition to the psychiatric paradigm, for patients suffering from diseases such as Gulf War Syndrome, Lyme disease, Borreliosis and the neurological disease ME/CFS.

Our children, previously diagnosed with ME/CFS, have both been subsequently diagnosed with Borreliosis, a chronic spirochaete bacterial infection.

We carry breaking news, information and archive resources on our website, read by people in over 70 countries, often receiving in excess of 4,000 hits per day. We are read by Ministers, MPs, the Department of Health, the medical establishment, researchers, the media, patients and carers.

We bring to the attention of the Group that neither of our children can attend today because of the severity of their respective conditions, an all too common feature of this illness. We therefore are acting on their behalf and with their approval.

We give this presentation with the essential qualification that the enormous range and depth of problems related to British policies on ME/CFS is so great that it cannot possibly be done justice in 10 minutes.

Therefore what follows is a mere summary of some of the major problems facing sufferers both before and after the Chief Medical Officer’s Report: During which, it must be noted, psychiatrists, led by Peter White of the PACE Trial, walked out because they objected to the biomedical facts of this disease.

A reasonable appraisal of the situation facing sufferers cannot take place in a historical vacuum, with an arbitrary ‘cut-off’ point at the year of the CMO’s Report. The injustices facing sufferers began well before this time, and remain yet to be resolved.

We bring to the Group’s attention the issue of Borreliosis. The links between ME/CFS and Borreliosis have been known for some time, both by the National Health Service

and the ME/CFS charities. Research by Dr. John Gow shows that the gene expression in ME/CFS and Borreliosis is identical, as he has stated in public. Despite this, no research is being funded by the British government into this vital issue, and patients have had terrible difficulties in getting any treatment on the NHS. For some it has been impossible. One particular Borreliosis specialist in the UK has stated that some 95% of his ME/CFS patients have tested positive for Borreliosis.

We also bring to the Group's attention the large amount of international research evidence of organic, multi-system physiological abnormalities within this disease entity. This has been consistently ignored in various reviews, including the CMO's Working Group Report, and the recent Bagnall et al review for the NICE Guidelines. There also appears to have been a deliberate flooding of the literature with repetitive psychiatric papers consisting of conjecture and prejudiced opinion masquerading as 'science'.

There are broadly two contesting paradigms of ME/CFS: the neurological (biomedical) paradigm, and the psychiatric paradigm. The psychiatric paradigm in Britain is supported by various researchers such as Simon Wessely, Peter White, Michael Sharpe, and Elena Garralda, among others. It has been demonstrated to have serious theoretical, methodological and ethical flaws.

Proponents of this paradigm refuse to recognise the WHO ICD-10 neurological classification of ME/CFS. Indeed, they unilaterally misrepresented the term Chronic Fatigue Syndrome as being classified as a mental disorder in the ICD-10, wrongly advising the British government. This was corrected by the Countess of Mar during a House of Lords debate in 2004, with confirmation by the World Health Organisation.

Despite the overwhelming evidence to the contrary, proponents continue to assert the notion that the illness is caused and/or perpetuated by 'psychological' or 'behavioural' factors. They consistently portray sufferers as mentally and socially deviant.

They illogically and incorrectly describe ME/CFS as 'Medically Unexplained'. Ironically, they then promote a state of 'cultivated ignorance' about the illness by discouraging all but the most limited of biomedical investigations/treatments for sufferers.

They promote the use of Cognitive Behavioural Therapy, NOT as a strategy of coping with illness, but as a 'cure' for a neurological disease they do not even recognise, an irrational position. They claim that multi-system physiological abnormalities can be improved to the point of 'recovery', merely by challenging the illness beliefs and behaviour of the sufferer.

They promote Graded Exercise, even though their own research in this area has been criticised for the high drop out rate of patient samples and the patients excluded from such research. They continue to ignore the documented harmful effects and therefore potential dangers of 'Graded Exercise' for ME/CFS sufferers.

Their research design is highly flawed, as will be demonstrated by my colleague.

JANE BRYANT:

Professor Simon Wessely stated in public at the Eliot Slater Memorial Lecture: "There is a phenomenon known as myalgic encephalomyelitis - or ME. I will argue that ME is simply a belief - a belief that one has ME," he said.

From the scientifically unproven belief system of this psychiatrist and the group that surrounds him, over £11.1m of British taxpayers money has flowed to set up the methodologically and ethically flawed psychosocial PACE and FINE trials being conducted at these 'CFS/ME' Centres primarily run by the psychiatrists for psychiatric benefit. These are the 'CFS/ME' Centres that have been thoroughly condemned by ME/CFS patients' right around the United Kingdom as has been evidenced, as just one example, by the many letters from patients sent to RiME – the group for Research into Myalgic Encephalomyelitis.

What was the purpose of setting up the Chief Medical Officer's Working Group, preparing a complex report, taking into account at least some of the patients' views and then to all intents and purposes, ignoring them completely?

Psychiatric interventions over ME/CFS have been forced on patients for the last fifteen years or more and are STILL the only treatments consistently available. If these had been in any way efficacious, where are the lost legions of the recovered to show this? Just where are they?

The enormous irony and scientific fraudulence of the PACE trial is the way that it has been deliberately structured using the outdated and superseded Oxford criteria for patient inclusion into this trial purely to enhance the numbers recruited and to include patients suffering from Idiopathic Chronic Fatigue, a mental disorder classified as such under F48 that is entirely different from ME/CFS. The Oxford criteria specifically EXCLUDE patients suffering from a neurological disorder that ME/CFS IS as defined by many international experts and the World Health Organisation. How has it come about that millions of pounds of British taxpayers money, agreed by the Medical Research Council, are being spent on a trial that is actually excluding the very patient population that it is supposed to be studying by use of the Oxford criteria for entry to the PACE trial? ME/CFS must be the only illness in the world where the most severe sufferers are never properly studied.

There is also massive controversy surrounding the bolt on inclusion of the Fukuda and London criteria in the PACE trial. The so called London criteria have never been peer reviewed, published, operationalised or validated.

This makes these criteria unusable in any clinical trial and that, together with the use of the aforementioned Oxford criteria, makes the structure of the PACE trial a scientific nonsense from the outset.

Furthermore, the charity Action for ME, that has no mandate or remit to act for ME/CFS patients at government level or any other since it has not held an Annual General Meeting that involved its members/subscribers for the last TEN YEARS is heavily involved in the PACE Trial protocol and has been given money by Section 64 government grant to promote this trial to their members. It clearly states in the PACE Trial Identifier produced by the psychiatrists for the Medical Research Council that: "Compliance with both the treatments and the study will be maximized by the COLLABORATION and SUPPORT of AfME."

The PACE trial, as delineated in The PACE Report produced by One Click, is a deceit and scandal of massive proportions as has indeed been written up in the Independent national newspaper in 2004. The PACE and FINE trials are clearly little more than job providers for the psychiatrists that are running them who operate on the basis of a misguided but entrenched illness belief system for which there is absolutely no scientific basis, that ME/CFS is a mental disorder, not the neurological illness that it

is, as defined by the World Health Organisation. Is it ethical for people with proven commercial interests in these studies to be designing and running these trials, give the proven evidence of their personal commercial interests in the desired outcome of these trials?

ANGELA KENNEDY:

Documented iatrogenic effects of the Psychiatric Paradigm of ME/CFS on patients include:

1. Lack of appropriate bio-medical investigation, treatment and support, contributing to deterioration in health.
2. Denial of benefits, insurance or pension payments to sufferers, even though the extent of their disabilities would, in other organic illnesses, entitle such sufferers to these.
3. Hostility, disbelief and lack of empathy from doctors, families, communities and society at large, who are frequently led to believe that the illness is a result of deviance.
4. Forced treatment of patients, including forced incarceration of children.

We bring to the Group's attention the TYMES Trust Dossier 'The Forgotten Children', the Panorama Survey, and the Ean Proctor Scandal, in which a semi-paralysed 11 year old ME/CFS diagnosed child was thrown into a swimming pool to see if his paralysis was genuine. The child sank. These are just a few examples of the mistreatment that sufferers, especially children, have had to endure as a result of the psychiatric paradigm.

5. There is adverse impact on quality of life to such a degree that some sufferers have committed suicide.
6. Progressive relapse into severe illness has resulted from Graded Exercise Regimes.

No other organic disease has had so much attention on 'psycho-social factors' while biological factors are consistently ignored and trivialised in the UK: and this special pleading about ME/CFS has thwarted the progress of biomedical research and clinical care.

In summary, we bring to the Group's attention that British health, social and research policy on ME/CFS in recent years has been based on fundamentally flawed conjecture, and prejudiced opinion masquerading as 'science', causing endangerment and disenfranchisement to sufferers. It is imperative that the British Government rectifies this wrong immediately.

This must include the urgent funding of biomedical research untainted by psychiatric vested interests, but also an overhaul of all social security and NHS practice, to reflect the already available evidence demonstrating serious disease processes, and it must move away from the erroneous and discredited claims that this illness is a result of deviance.

- ENDS -

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