

The RSM Protest Group

**An open letter to the President of the Royal Society of Medicine,
The Dean, Council Members, Fellows and Members of the RSM,
Conference Organisers as well as attendees at the RSM Conference
on "Chronic Fatigue Syndrome" at the RSM on 28th April 2008**

**The President,
The Royal Society of Medicine,
1 Wimpole Street,
London W1G OAE.**

Date: 28th April 2008

Dear Prof. The Baroness Finlay of Llandaff

Re: The RSM on April 28th on "Chronic Fatigue Syndrome"

We are individual members of the Myalgic Encephalomyelitis, or ME community of sufferers and carers for those with ME which also include those with positions of responsibility in various organisations. We few who are present at this demonstration here today represent many people from our community who were unable to attend due to the profound disability and debility produced by ME.

We want to convey to you that the CFS conference has caused a great deal of concern to our community because of :-

The marginalisation of a physically descriptive name

The name of the Conference is given as "Chronic Fatigue Syndrome". The name of our illness is Myalgic Encephalomyelitis, ME, which is an abbreviation of the WHO's full name of Benign Myalgic Encephalomyelitis and not Chronic Fatigue Syndrome, CFS.

The World Health Organisation's International Classification of Diseases version 10 which is currently in force, WHO ICD 10, categorises ME as a physical neurological condition which is why it is listed in the Neurological Chapter of the ICD under diseases of the brain and spinal cord beneath the heading Post Viral Fatigue Syndrome, PVFS at G93.3.

The WHO Classification System categorises PVFS and ME to be synonyms that are different names for the same aetiological diagnostic entity, and recognition is given to the fact that the preferred name in the UK is ME. CFS for viral onset is indexed to PVFS at G93.3.

It is therefore clear what the WHO state about the nature and nomenclature of ME, that it is a physical neurological disease produced by viral attack on the brain and spinal cord.

There are no double or dual entries in the WHO Classification System for ME and it is not classified or categorised as a mental disorder in addition to being a physical neurological disease, as the only entry is at G93.3 and neither are there any such entries for PVFS or CFS for viral onset.

There is no linked or corresponding entry for ME, PVFS and CFS in the American Psychiatric Association's Diagnostic and Statistical Manual of mental disorder in the current version DSM IV or any previous version of DSM. These two classification systems are interlinked and interleaved showing that ME, PVFS and CFS are a physical disease and not a mental disorder or mental illness.

There have been a long series of Parliamentary Questions asked of Health Ministers in both Houses of Parliament concerning the status of ME and how the WHO Classification System applies in the UK which culminated in the Spring of 2004 with Lady Mar asking Lord Warner to confirm that the WHO Classification was mandatory and binding on the UK Government and therefore on the NHS and other government agencies and organisations, and that there was only one single code used for ME, CFS, PVFS etc which is located at G93.3, which Lord Warner did.

Over the past couple of years leading clinicians and researchers who were an integral part of the American CFS initiative through the CDC, Centre for Disease Control in Atlanta, Georgia, who produced the CDC 1988 & 1994 Case Criteria for CFS which gave rise to the Fukuda Criteria have changed their view of CFS.

Some of them have stated in public that they were wrong to have used the term Chronic Fatigue Syndrome to describe the illness they were investigating. They now believe that the term CFS does not do justice to the profound debility and disability produced by the illness which they consider has the same or greater impact on a sufferer than Multiple Sclerosis.

Some of them have gone as far as to say that the label CFS minimises the seriousness of the illness and is therefore degrading and humiliating to patients in response to criticism that one would not re-define Alzheimer's disease as 'Chronic Forgetfulness Syndrome'.

Psychological / psychiatric bias

The conference is billed as having the objective of being able to "take a broad look at chronic fatigue syndrome, examining its nature and definition, pathophysiology, epidemiology, clinical assessment and diagnosis, the patient perspective, and various approaches to treatment. This is a scientific conference and there will be an emphasis on an evidence-based approach throughout".

We believe that this is simply not the case as the vast majority of speakers at the conference are from a psychiatric or psychological background and/or work for medical institutions of a psychiatric nature like the Institute of Psychiatry and are known to the ME community for their psychological view of ME, its causation and most particularly the psychological factors, that in their view, perpetuate our illness.

We believe that these speakers will make their presentations to the conference from a psychological and psychiatric viewpoint, and that these views will not be balanced by opposing views from the biomedical point of view. We also believe that the known psychological / psychiatric standpoint of speakers will draw an audience for the conference that will follow the speaker's lead and that those clinicians and researchers of a biomedical viewpoint will be discouraged from attending and participating in the conference to put forward the opposing biomedical point of view.

We therefore believe that the psychological view of ME will dominate proceedings despite evidence and argument to balance the conference in a way that would

achieve the stated objectives of the conference. We are therefore concerned that we will continue to be denied recognition of our physical illness by the medical profession, and consequently we will continue to be denied Incapacity Benefit and Disability Living Allowance and Insurance Benefits from, for example, Unum Provident that we would be entitled to if we suffered from any other disease with the same level of debility and disability.

We are also concerned that we will continue to receive a substantially worse level of health and social care than those who are equally debilitated and disabled from the NHS and private providers of healthcare services and social care services provided by Local Authority Social Services Departments.

Psychological treatments and rehabilitation

The Cognitive Behaviour Therapy "CBT" used at the "Fatigue Services" or "CFS Clinics" around the country is based on three conceptual elements, that of fear avoidance, in that the patient fears an increase in the number and severity of symptoms that they experience as a result of increased activity or exercise, which is held to be "an abnormal illness belief" which is the second component of the triad, and therefore it is the job of the CBT therapist to challenge these presumed "false beliefs" held by patients.

The presumption is that the patient is unduly anxious and/or depressed by the prospect of an increase in their symptoms and so "unreasonably" avoids any activity or exercise as a rationale for being "lazy".

CBT & GET, Graded Exercise Therapy, are part of the Biopsychosocial Model" of CFS which describes ME as being either some kind of psychosomatic disorder generated by psychological and social factors which when combined with anxiety and depression are then translated into physical bodily symptoms through the process of somatization. Therefore, the patient's illness is perceived to be "all in the mind" or in which there is a large psychological component and a minimal biological or physical component which it is perceived can be basically eliminated by addressing the presumed psychological and social factors involved through CBT and GET.

A consequence of these presumptions is a perception that the patient may be presumed to want to occupy the sick role" in order to achieve secondary psychosocial gains of not having to work or to shoulder their normal burden of responsibility as a parent, for example.

There are some 20 or more Case Criteria, Research Definitions and Clinical Definitions for CFS, ME, PVFS and all of them describe a physical illness in physical terms through the use of physical and not psychological or psychiatric criteria.

A very strong theme which runs through each and every one of them is that the patient will experience a pathologically slow recovery from minimal physical or mental effort and Post Exertional Malaise that accompanies this characteristically slow recovery, showing that symptoms are exacerbated by exercise.

The majority of them state in one way or another that if this is not the case for the individual patient, then the diagnosis ought not to be made.

This vast clinical and research evidence base which produced these Case Criteria or Definitions validates the experience of ME sufferers and carers that ME

sufferers are made worse by activity and exercise which produces and intensifies ME symptoms.

Therefore, ME sufferers and carers are accurately reporting their own experience in a reliable and credible way. Consequently, ME sufferers do not hold "abnormal illness beliefs" and any concerns that ME sufferers have about increasing their activity level or exercising are justified.

The presumptions that underlie CBT and GET are also unacceptable as they undermine our experience in being able to manage our own illness and also presume that we do not want to get better or that we have psychological blocks, phobias, anxieties and other psychological problems as opposed to genuine physical debility and disabilities and that we are not credible witnesses in the case of our own illness which is degrading, humiliating and offensive. It also presumes that ME patients and their carers do not know or understand the nature and extent of the physical debility and disability produced by the physical illness of ME which we have to live with each and every day and so it is a denial of our experience and our voice because it is a refusal by the medical profession to listen to us, let alone accept what we are telling you.

This is why there is a point of friction between ME sufferers and carers and healthcare professionals.

The Biopsychosocial Model of CFS is not acceptable to the ME community because it does not recognise that ME patients are suffering from a genuine physical organic disease as defined by the WHO, because it presumes that ME patients are suffering from some kind of composite mental disorder combined with Somatization or Conversion Disorder, when this is simply not the case.

NICE

The National Institute for Clinical Excellence published its Guideline on the diagnosis and treatment of "CFS/ME" in August 2007. This document has been widely condemned by the ME community, ME sufferers and carers as well as almost all of the local and regionally based ME groups and organisations and national ME charities as being unfit for purpose.

The only major exception has been Action for ME who also support another Guideline for Occupational Health that the ME community also finds unacceptable.

The ME community believes that these Guidelines use criteria that are far too broad and would encompass whole swaths of other illnesses and mental health conditions because there is an inadequate testing and diagnostic protocol. More importantly, the Guideline fails to recognise ME as a physical multi-system organic neurological disease that affects all of the body's major systems in the way an International Consensus Panel described in the Canadian Guidelines, which represents the most modern and up to date international consensus on the nature of ME and its diagnosis.

The One Click Group, a web based campaigning group, has attracted considerable support for its Judicial Review of the NICE Guideline and has raised over £10,000 from public pledges / donations from within the ME community and further afield demonstrating that the ME community are willing to vote with their wallets and purses to try to overturn the NICE Guideline.

The ME community considers that in order to have confidence in any UK ME Guideline that the Guideline must rely on biomedical research of ME as a physical

illness, and not the flawed psychological research of psychologists and psychiatrists who have researched ME as if it were a psychological condition which can be "cured" or the patient rehabilitated" through psychological means and which attributes physical bodily symptoms to the expression of psychological distress through a presumed mind-body interaction.

The Patient Perspective

We are very concerned that "The Patient Perspective" presentation is not being given by ME patients and or carers themselves, and instead, the Chief Executive Officer of a highly undemocratic and controversial charity, Action for ME, which many in the ME community see as holding a psychological bias will be speaking for patients.

Yours Truly,

Mr. Ciaran Farrell, Steward
Mr. Augustine Ryan, Organiser
Ms. Annette Barclay, Steward

24th April 2008

Dr John Scadding, Dean
Royal College of Medicine
1 Wimpole Street
London W1G 0AE

Dear Dr Scadding

RSM Conference 28th April 2008

You will have received many letters from ME sufferers, and their carers, expressing dismay at the unbalanced list of speakers at this conference.

I am writing on a more personal level. My daughter, my only child, was a long term ME sufferer. She died by her own choice on her 27th birthday. She walked out of her flat in the middle of the night, the first time she had been out alone for eight years and took an overdose.

It was 9 days before her body was found behind a church, 250 yards from her flat. The police later admitted that they had failed to search there. It was 4 years later before an Inquest was heard and ME was not even mentioned as a cause of death. It was simply recorded as "she killed herself".

Nobody seemed interested as to why she took this action. It is impossible to ascertain just how many sufferers have taken such action as ME is not recorded on the Death Certificates. To my knowledge only two people in UK have had M.E. recorded as cause of death on their Death Certificates "Annabel Senior and Sophia Mirza, both of whom were long term sufferers and died in extremely tragic circumstances.

My daughter's health was, in fact, considerably better than it had been for years but she was no way at a stage where she could return to work. She would soon have to complete yet another application for DLA if she wanted to be able to maintain her flat and independence. She felt alone, isolated and with little hope for the future. Appealing for Benefits with an "invisible" illness puts sufferers in an impossible position. They are treated in such a horrendous manner by the Benefit Agency staff that my daughter said that she would never ever apply again. Her action meant that she never had to.

Her death has had a most devastating effect on our family. I have since discovered that she was the third ME sufferer in this area to take such action. I was contacted by hundreds of sufferers from all around the country who felt that they had little to continue to live for. They did not want to live for another 2 or 3 decades with such a cruel illness. Reading their e-mails was a most harrowing experience.

I believe that the actions of the psychiatric lobby to have ME classified as a psychiatric illness and to prevent research into the cause, and a diagnostic test were the major reason that my daughter chose to end her life

Yours faithfully

Sheila Barry