

## **SINISTER SCIENCE?**

**Margaret Williams**

**5th June 2004**

On 3rd June 2004 Christine Hunter from Australia, whose daughter Alison died of severe ME aged just 19, was moved to ask where is the response of the worldwide ME community to the CDC International CFS Study Group's proposed refinement of the 1994 CFS criteria (published on 31st December 2003).

The CDC Study Group relies heavily on the work of those who support the views of UK psychiatrist Simon Wessely and Wessely is listed as a member of the International Study Group that produced the 1994 CDC criteria. The UK representative is currently listed as Anthony Cleare, who is one of the psychiatric lobby that withdrew in pique and publicity from the UK Chief Medical Officer's Working Group before publication of the Report, apparently because they did not succeed in their obsession to get "CFS/ME" unequivocally defined in that Report as a psychiatric disorder. Cleare has often co-authored papers on "CFS" with Wessely (a self-proclaimed expert on "CFS/ME" and a Government adviser internationally known for his well-published personal belief that ME does not exist other than as an "aberrant belief" and that "CFS/ME" is a behavioural disorder that is amenable to his own brand of psychotherapy).

Chris Hunter drew renewed attention to the fact that the CDC International Study Group recommends reliance upon the SPHERE mental health instrument for determining the new research case definition of "CFS" and pointed out that the SPHERE mental health instrument specifically encapsulates dimensions of neurasthenia and somatisation.

One would have anticipated a world-wide response that required a credible explanation as to why such an instrument has any place in deliberations about the WHO ICD-classified neurological disorder ME, but none seems to have materialised, and the major ME charities have been notably silent on this important issue.

Certainly, those clinicians and researchers who support the organic nature of ME are not likely to put their head above the parapet because if they do, it is likely that they would be instantly targeted and vilified by the Mental Health Movement and its powerful global sponsors.

It seems that the Mental Health Movement is not to be deflected by the evidence of mere medical science from its crusade of establishing psychiatry as underpinning not only service provision for those with ME but also the whole of medicine (and of its sibling, the health insurance industry).

Given its supporters' stated reliance on "evidence-based medicine", it is curious that the Movement shows such disregard and contempt for the evidence that ME is not a psychiatric disorder, for example, the evidence that is listed on the website of MERGE ([www.mererearch.org.uk](http://www.mererearch.org.uk)) as recently posted in the e-BMJ by Doug Fraser. Such evidence includes documented biochemical, metabolic, vascular, neurological and muscle

abnormalities in ME/CFS patients, but this evidence seems not to be to the liking of certain psychiatrists.

Despite the fact that the Health Minister, Lord Warner, confirmed in a letter dated 11th February 2004 to the Countess of Mar that the UK Department of Health and the WHO Collaborating Centre at the Institute of Psychiatry have now agreed on the classification of ME/CFS and that such classification is undoubtedly neurological, in a letter dated 28th May 2004 from the Department of Health signed by Robert Harkins (ref: TO1056746) is to be found the following: "In May 2003 we announced that £8.5 million would be made available for people with Chronic Fatigue Syndrome / Myalgic Encephalomyelitis. This is an important step in the development of NHS services and means that we can start making improvements in the care and treatment of people with CFS/ME. This investment will enable the NHS to set up centres of expertise to develop clinical care and clinical research (and) expand education and training programmes for health care professionals. The centres will be headed up exclusively by psychiatrists".

From this letter, it seems that the DoH is full of self-congratulation over its generous commitment to those with "CFS/ME" and sees no incongruity that all the centres are to be "headed up exclusively by psychiatrists".

Why should this be? There is no published evidence as opposed to opinion that ME (as distinct from chronic fatigue) is a psychiatric disorder.

Why do the influential adherents to the Mental Health Movement so persistently disregard the now-abundant evidence of physiological abnormalities that are seen in ME? Is it because they choose not to look? How can any qualified physician ignore common problems found in ME and rationally conclude that such problems are psychogenic in origin, with never a mention of the inordinate losses sustained by those who are afflicted with such problems?

Such problems include hair loss, double vision, quantifiable liver dysfunction, pancreatic dysfunction, vertigo, shortness of breath, inability to stand unsupported, severe myalgia, disrupted temperature regulation with marked intolerance to heat and cold and alternate sweating and shivering, nocturia, swollen glands, recurrent mouth ulcers, recurrent nausea, lack of bowel control, observable muscle spasm including "jelly knees" not brought about by deconditioning, oophoritis, prostatitis, intractable headache, demonstrable cardiac problems, vasculitis, definable hypersensitivities (especially to medicinal drugs and anaesthetics), alcohol intolerance, and a degree of incapacitating exhaustion about which in a statement posted on Co-cure on 3rd June 2004 Charles Lapp, Professor of Community and Family Medicine at Duke University, North Carolina (and a world expert on the disorder) says "there is no word in the English lexicon that describes the lack of stamina, the paucity of energy (and) the absolute malaise that accompanies this illness".

Is it the case that these psychiatrists do not have patients' best interests at heart, but only their own status and influence and that of their paymasters, with all the accolades and rewards that accompany such status? Or is it the case that the liability issue must never, ever, be officially recognised, as in the case of the Chinook helicopter crash on the Mull of Kintyre ten years ago and as in the case of Gulf War syndrome?

Whatever the reason, attempts by these psychiatrists to eradicate ME continue to abound.

In an Editorial on somatoform disorders in the current British Journal of Psychiatry (2004:184:465-467), psychiatrists Michael Sharpe of Edinburgh and Richard Mayou of Oxford (where Sharpe used to work) present what they clearly perceive to be an appealing alternative classification and terminology for disorders including what they refer to as chronic fatigue syndrome (but which bears little resemblance to Ramsay-described ME). Sharpe and Mayou do not like the present somatoform disorder classification: they think the main limitation is that the psychogenic implication of the diagnosis is "unacceptable to many patients, making it a poor basis for collaborative management" and that such a diagnosis "may lead to the underdiagnosis of depression and anxiety". They also point out something that many ME patients know for themselves only too well, namely that a label of somatoform disorder is "often taken simply to indicate a need to minimise access to medical care".

The authors state that somatoform disorders could readily be re-housed within the existing classification system and that such disorders are better considered as a combination of a personality disorder and an anxiety / depressive syndrome.

However, Sharpe and Mayou want a new classification that could accommodate "behaviour" disturbances and they state that "mere tinkering" with classification and terminology of disorders such as CFS is unlikely to be adequate, urging the need for "more radical revision". They then reveal their hand by stating "The ambitious programme to prepare for the forthcoming DSM-V and ICD-11 offers an opportunity to reconsider the somatoform disorders".

This seems to accord with a recent letter from the UK Chief Medical Officer written in response to a request for confirmation that in the light of Lord Warner's letter of 11th February 2004, the UK Department of Health will not seek to change the ICD classification of ME/CFS from neurological to psychiatric: in his reply, the CMO made it plain that involvement with changes in ICD classification is not within his remit as the UK WHO representative but is the responsibility of the WHO Collaborating Centre at the Institute of Psychiatry.

It is at the IOP that Professor Wessely exerts such influence amongst his like-minded psychiatrist colleagues; it is the Dean of the IOP who co-edited a psychiatric textbook with Wessely's wife, and the Dean's opinion about Wessely is on record in a letter he sent to the Countess of Mar on 27th August 2003 in which he stated "Professor Wessely must be judged one of the outstanding medical researchers in the UK, and indeed internationally. (He) has been awarded a Research Medal by the Royal College of Physicians (specially for work on CFS) and he has served on many prestigious scientific committees further attesting to the high regard in which he is held by the scientific community. The Institute of Psychiatry thus has every reason to have confidence in the quality and integrity of Professor Wessely's research".

The letter from the CMO confirmed the worst fears of the UK ME community, namely that the issue of reclassification of ME lies in the hands of Wessely and his psychiatrist friends: concern about this is growing, as there is plentiful evidence of the psychiatrists' determination to succeed in what they have worked so tirelessly for the last 17 years to achieve, namely the re-categorisation of "medically unexplained" disorders (including "CFS/ME") as "functional" disorders.

From Sharpe's Editorial, changes that would harm those with ME seem inevitable. True to the Mental Health Movement mantra, Sharpe and Mayou state "In the 'post-somatoform' world we envisage that there will be a renewed interest by all parts of medicine in an integrated approach to patients' symptoms. Such a development will require that psychological assessment and intervention are fully integrated into medical care".

Do the authors envisage that it is logistically possible for every single patient presenting with complex and chronic illness for which medicine does not yet understand the cause to be subjected to "psychological assessment and intervention" as a necessary component of medical care? Will such psychological assessments be mandatory for those with multiple sclerosis and other neurological disorders for which the cause, if not the effects, remains unknown, or is there to be special pleading only for ME/CFS?

Many informed people would doubtless concur with Alan Gurwitt MD, who put the matter concisely in a Co-cure post on 27th May 2004: "It is not well-trained psychoanalysts who are making wild generalisations about 'somatisation' (and) 'functional' symptoms etc. Psychoanalysts depend on a carefully gained understanding of each individual rather than cursory evaluations that are often inaccurate and misleading yet pass for 'science' ".

What passes for "science" is of great relevance to those with ME, for example, on what rational basis can the Medical Research Council persist in ignoring the evidence of organic pathoetiology in the world literature on ME/CFS that has been provided for its use?

It would seem to defy reason for the MRC to maintain, as it does, that the publicly-funded PACE trials for "CFS" patients (described as such in the Trial Identifier, though not now on the MRC website, which refers to them as "CFS/ME" patients) will indeed use the broad-ranging Oxford entry criteria that were compiled by Sharpe and Wessely et al in 1990 and published in 1991.

It must be asked why the Oxford criteria were passed by the MRC reviewers in relation to studies of people with ME, because it is the case that the Oxford criteria specifically include those with psychiatric disorders and specifically exclude those with neurological disorders; the Oxford criteria never attained international consensus and have been superseded.

In apparent response to public disquiet about the use of the Oxford entry criteria, it was confirmed by the MRC that there will now be additional "secondary analysis" of the data, as such secondary analysis might identify the more severely affected, but there was no mention of any "secondary analysis" in the Trial Identifier.

It is a straightforward fact that if those with classified neurological disorder are to be excluded from the outset by virtue of the Oxford entry criteria, no amount of "secondary analysis" will reveal those with classified neurological disorder, and it is seen as offensive for the MRC to patronise desperately sick ME patients by such condescending and meaningless platitudes.

When concerns about the MRC trial entry criteria were made public, there were repeated assurances from both the MRC and the Department of Health that those with ME would not be excluded from the PACE trials. However, if this is so, then on what basis are those with ME to be included in the MRC trials, given that the Oxford criteria stipulate that patients with neurological or organic brain disease must be excluded?

Is it in fact the case that those with ME are to be included on the basis that "CFS/ME" is deemed by the MRC (and by the psychiatrists running the trial) to be a psychiatric disorder and therefore to come under the aegis of the Oxford entry criteria? It is a matter of published record that Wessely believes "neurasthenia would readily suffice for ME" and in the same item he pointed out that "the term neurasthenia remains in the Mental and Behavioural Disorders chapter under Other Neurotic Disorders". (Chronic fatigue, ME, and ICD-10 Anthony David, Simon Wessely. Lancet 1993;342:1247-1248).

It seems that these powerful psychiatrists whom the MRC holds in such esteem are still calling all the shots, apparently for no more scientifically robust a reason than that the very psychiatrists who are to carry out the trials have chosen to use their own criteria for "CFS" in the sure knowledge that those eligible to be enrolled do not suffer from Ramsay-described ME but from chronic fatigue, and may therefore stand some chance of gaining at least some benefit from the psychiatrists' favoured behaviour-modifying intervention.

This being so, the results of the trials may be anticipated to confirm that people with "CFS/ME" do improve with Wessely's brand of cognitive behavioural therapy, even though people with Ramsay-described ME would in reality be excluded by virtue of the trial entry criteria. Although unthinkable, could this be calculated deceit for financial gain?

The deliberately heterogeneous population that is to be studied in the MRC PACE trials on "CFS" is a matter of mounting concern. It is hardly what most people would regard as good science to include in the same study those who from the outset are known to suffer from a different disorder that is separately classified in the ICD, yet those with fibromyalgia (classified in the ICD-10 at M79 under Soft Tissue Disorders) are to be included in the MRC trials on "CFS", together with those who suffer from medically unexplained fatigue (classified in the ICD-10 at F48.0 under Mental and Behavioural Disorders) as identified by the Oxford criteria.

It is the case that at a meeting of the All Party Parliamentary Group on Fibromyalgia held on 12th May 2004 at the House of Commons, the Parliamentary Under Secretary of State at the Department of Health (Dr Stephen Ladyman MP) announced that GPs would be offered financial incentives and encouraged to identify patients with fibromyalgia and to refer them to the new "CFS/ME" centres, where these fibromyalgia patients would be included in the CFS study.

Despite such intentional heterogeneity, it seems that the results of the MRC PACE trials on "CFS" are likely to be claimed to relate to those with specific Ramsay-described ME (classified in the ICD-10 at G93.3 under Disorders of the Nervous System).

It remains to be explained how the lumping together of such a deliberately heterogeneous study population can yield accurate and meaningful scientific results that relate to those with ME when, by the Oxford case definition entry criteria, those with ME will have been excluded from the study.

To many knowledgeable and informed people, including medical scientists, this smacks of state control and of sinister science designed for purely political ends.

To whom can ME patients now turn? Despite initial interest, enthusiasm and commitment, even the Chairman of the House of Commons Select Health Committee, David Hinchliffe

MP, has declined to take the ME situation on board, now claiming that it is a matter of divergent medical opinion and is therefore not something with which the Select Health Committee could become involved. When she heard this, the well-informed ex-wife of a prominent Member of Parliament said that such an about-turn was "interesting", and wondered if those involved had been leant on "by people in high places".

Why will the usually rapier-sharp investigative media not pay proper and sustained heed to ME patients' quite desperate plight? Is that not their job? Or is it the case that, as in anything to do with ME, they, too, are being effectively controlled by sinister science and by Government? Some people think so.

