

## Wessely's Wisdom?

### Some more open questions for Professor Wessely

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**16<sup>th</sup> January 2005**

Professor Wessely, in your reply to John Sayer's open letter to you of 5<sup>th</sup> January 2005 you made some interesting statements that have raised important issues concerning what you refer to as "CFS/ME", so perhaps you would be good enough to clarify your current position with specific reference to the issues set out below.

It is to be hoped that you will understand the reason you are being asked to address these issues: it is because the ramifications are of such crucial and fundamental importance to many sick people. You are therefore asked to give the matters raised here your very serious attention.

By way of introduction, you must surely be aware that many well-informed people consider the real stumbling block to the advancement of medical understanding of the discrete disorder myalgic encephalomyelitis (ME) to be the various non-homogenous case definitions currently in use, especially the 1991 Oxford criteria (which you helped to formulate) and the 1994 Fukuda criteria (with which you were also involved).

This is because both these case definitions expressly exclude those with physical signs (as distinct from symptoms), thereby excluding those with Ramsay-described ME but automatically including anyone with what you choose to call "medically unexplained" tiredness or fatigue --- as distinct from post-exertional incapacitating exhaustion and malaise that are the cardinal features of ME --- for longer than six months.

Such dilution of the case description of ME has resulted in uncountable numbers of people being included in a distorted, grossly inflated and heterogenous construct now known as chronic fatigue syndrome ("CFS") which also includes those with psychiatric disorders in which "fatigue" is a feature.

Flowing from this is the disunity and confusion generated by the fact that the alternative name for ME listed in the WHO ICD-10 is CFS: the problem is that although the name is identical, "CFS" means different things to you and your psychiatrist colleagues in the so-called "Wessely School" than it does to other, non-psychiatrist, researchers and clinicians.

This has resulted in considerable unrest about the inclusion criteria to be used in the forthcoming Medical Research Council trials on "CFS", especially as the MRC itself confirmed (on 19<sup>th</sup> March 2004, in writing) that: "The Oxford criteria are to be used since they are perceived to be broader and more inclusive", and indeed the Trial Identifier itself states: "We chose these broad criteria in order to enhance recruitment" (para 3.6). Although not an issue arising from your reply to John Sayer, perhaps you would explain how the intentional inclusion of different disorders will be of benefit to sufferers from a specific disease such as ME/ICD-CFS that you claim will be included in those MRC studies on "CFS/ME"?

On this important issue of scientific exactitude and rigorousness, did you know that Nancy Klimas, Professor of Medicine at Miami, is on record as stating “The research effort is hampered by poorly conceived, constantly changing, even non-existent standards” (CFS Research: the Need for Better Standards: Co-Cure 5<sup>th</sup> August 2002)?

The issues arising from your reply that require your clarification are itemised below.

### **1. The concept of ME/ICD-CFS as a nosological entity**

In your reply to John Sayer you state: “When we make a diagnosis of CFS/ME we are merely making a descriptive diagnosis”. On what evidence do you rely to substantiate such an assertion that flies in the face of so much published evidence to the contrary?

Why do you persistently reject the evidence that since 1969 ME has been listed by the World Health Organisation as a neurological disorder in the ICD and that ME has been accepted by The Royal Society of Medicine as a nosological entity since 1978?

In your Joint Royal Colleges’ Report on CFS (CR54, 1996) why did you entirely dismiss ME as an entity and assert that “Previous studies have counted people with ME, but these studies reflect those who seek treatment rather than those who suffer the symptoms” (13.3)? How curious that the WHO overlooked this.

Can you really be unaware that ME/ICD-CFS is a multi-system disorder of extraordinarily incapacitating dimensions from which complete recovery is unlikely?

Are you not aware that Professor Leonard Jason from De Paul University, Chicago, states that (ME)CFS can affect virtually every major system in the body and that for years, investigators have noted many biological abnormalities in ME/ICD-CFS, including an over-activated immune system, biochemical dysregulation in the 2-5A synthetase/RNase L pathway, cardiac dysfunction, EEG abnormalities, abnormalities in cerebral blood flow in certain areas of the brain and autonomic dysfunction (Subtypes of Chronic Fatigue Syndrome: A Review of Findings. Leonard Jason et al. JCFS:2001:8:3-4:1-21).

On what basis do you still disregard and dismiss the significance of the published findings of such an eminent and experienced expert, given that such abnormalities as he documents cannot be psychosocial in origin?

Will you explain why (apart from expediently relying on the fact that the 1991 Oxford criteria that you helped to formulate specifically exclude neurological signs and symptoms from your version of “CFS”) you reject the documented evidence of neurological signs and symptoms in ME such as vertigo, nystagmus, ataxia, positive Romberg, abnormal tandem, abnormal gait, fasciculation, neuromuscular incoordination and autonomic dysfunction (especially frequency of micturition and nocturia) that are so frequently present in ME/ICD-CFS?

Despite claims from you and your associates (and despite what you stated in your reply to John Sayer that “no-one has yet provided compelling evidence that there is a subgroup of CFS which is ‘neurological’), there is indeed published evidence (if you look for it) of inflammation of the central nervous system. Just a few examples include Pellew RAA (Med J Aust:1955:42:480-482); Innes SGB (Lancet:1970:969-971); Buchwald, Cheney, Peterson

D, Komaroff, Gallo et al (Ann Int Med: 1992;116:103-113); Schwartz RE et al (Am J Roentgenology:1994;162:935-941); Komaroff AL (JAMA:1997;278:14:1179-1184). There are other more recent papers such as Tirelli U, Chierichetti F, Tavio M, Simonelli C, Bianchin G, Zanco P et al. Brain positron emission tomography (PET) in chronic fatigue syndrome: preliminary data. Am J Med 1998;105:54S–58S; Chaudhuri A, Behan PO. In vivo magnetic resonance spectroscopy in chronic fatigue syndrome. Prostaglandins, Leukotrienes and Essential Fatty Acids 71 (2004) 181–183; Yamamoto S et al. Reduction of serotonin transporters of patients with chronic fatigue syndrome. NeuroReport 2004;15:2571-2574. What is your own explanation for such findings?

Why do you refuse to acknowledge the existence and significance of other well-documented problems in ME/ICD-CFS, including delayed muscle recovery that has been shown not to be due to “deconditioning” (as you claim), cardiovascular symptomatology, particularly vasculitis (with convincing laboratory evidence of disruption of microvascular integrity), respiratory problems, gastro-intestinal dysfunction, pancreatic dysfunction, an enlarged liver with disruption of liver enzymes, severe and recurrent mouth ulcers, hair loss, adrenal and thyroid dysfunction (including low free T3), the many visual problems that are documented as occurring in ME/ICD-CFS and the well-documented increased incidence of allergies and hypersensitivities, none of which is present in your version of “CFS” or in other, non-specific, states of chronic fatigue in which “fatigue” is the predominant complaint?

Despite the published evidence of organic pathology that has been demonstrated in ME/ICD-CFS, you are on record as asserting that ME is nothing more than a “belief system”.

And then there is your article in which you categorically assert that “there lies at the heart of CFS not a virus (or) immune disorder, but a distortion of the doctor-patient relationship” (Chronic fatigue syndrome: an update. Anthony J Cleare, Simon C Wessely. Update (Recent Advances): 14<sup>th</sup> August 1996:61-69).

Compare your own view with that of Professor Komaroff: “The report by De Meirleir, Bisbal and their colleagues is another strong piece of evidence that is consistent with the hypothesis that the immune system is under attack. Furthermore the report is inconsistent with the hypothesis that (ME)/chronic fatigue syndrome involves symptoms that are only imagined or amplified because of underlying psychiatric distress. It is time to put that hypothesis to rest” (Editorial: The Biology of the Chronic Fatigue Syndrome: Am J Med 2000;108:99-105).

By contrast, you and your colleagues proclaim (frequently) that ME is perpetuated by “dysfunctional illness beliefs” (specifically, the belief that the disorder is a physical illness) and by “avoidant coping”, these precise quotations being taken from the Presentation of Dr Peter White to the Scientific Workshop sponsored by the National Institutes of Health that was held at Bethesda, Maryland on 12<sup>th</sup>-13<sup>th</sup> June 2003.

Can you be unaware that your view that ME/ICD-CFS is a functional somatic syndrome that is amenable to compulsory psychotherapy regimes has had a catastrophic impact, not only on adults but especially on children and young people with ME, which as far as children are concerned is certainly unproven, since there have been no trials on children?

Does it not trouble you that (quote) “every school system in the nation seems to be more familiar with the phrase ‘Munchausen’s Syndrome By Proxy’ than ‘Chronic Fatigue

Syndrome'. The situation for children and adolescents with the disease – and their families – is grim. The stories are so horrible, frightening, terribly sad. Threatening to take a sick child away from his / her parents because the school system doesn't 'believe' in a disease that the CDC calls 'a major life-altering illness' is too obviously wrong" (acknowledgment to Mary Schweitzer, Co-Cure ACT: 16<sup>th</sup> January 2005).

Will you explain how such abnormalities as those mentioned above can possibly be the consequence of aberrant beliefs?

For you to have dismissed ME as an aberrant belief is surely gravely erroneous yet you once wrote that you are proud of your own contribution to the advancement of understanding about the disorder. Are you still proud of yourself?

The researchers whose work is mentioned here are not quacks and they did not rely on "subjective questionnaires, theories, personal feelings or sociological musings to support their ideas" (M.E.Advocacy. Maupin C: <http://cfidsreport.com> ).

Do you know what Dr Peter Rowe, paediatric cardiologist of Johns Hopkins University, Baltimore, said about the somatisation theory of ME/ICD-CFS in his invited presentation to the CFS Advisory Committee on 10<sup>th</sup> January 2005? At that meeting, Professor Charles Lapp noted that when he went to the international body of literature on paediatric (ME)/CFS, he found that much of the research claimed that children with (ME)/CFS were "psychosomatic" and he asked Rowe what he thought of that. Rowe was emphatic: "When there is depression or anxiety, it is co-morbid". Lapp said that one quarter of articles found on paediatric (ME)/CFS were from the United Kingdom and that of these, 62% insisted that it was purely a psychiatric problem or one that would be outgrown. Lapp concluded that a paediatrician who went to the world literature for information on (ME)/CFS would get the wrong impression. Rowe's reply was "With information, good doctors will pick up (the correct facts). On the other hand, the psychiatrists have gotten very good at picking out the patients...so what we need are good psychiatrists" (with acknowledgment to Mary Schweitzer: Co-Cure ACT: 12<sup>th</sup> January 2005). Would you be good enough to comment on this?

Have you ever read Osler's Web by Hillary Johnson? Perhaps you prefer not to read it, but you may have seen Johnson's recent reminder on the internet (Back to the Future, 14<sup>th</sup> January 2005) about how other well-respected physicians regard ME/ICD-CFS, for example, as long ago as the late 1980s Philip Peterson, Professor of Infectious Diseases at the University of Minnesota, found by using a morbidity scale first published in JAMA in 1989 (the Medical Outcome tool) that whilst healthy controls scored on average 75 and those with rheumatoid arthritis scored in the 40s range, those with ME/ICD-CFS scored an average of only 16.

Also in the late 1980s, Mark Loveless, an HIV expert from Oregon, found that ME/ICD-CFS patients whom he saw had far lower scores on the Karnofsky performance scale than his HIV patients even in the last week of their life.

By 1990, Peterson was unequivocal: "It is, potentially, an immunologic disease".

Then there is world expert Professor Klimas herself on this same issue, who has described this disorder in very specific terms: it is "a form of acquired immunodeficiency, with natural

killer (NK) cell dysregulation being the most consistent abnormality” (Immunologic Abnormalities in chronic fatigue syndrome. J Clin Microbiol 1990:1403-1410).

Do you recall that in 1992, international experts including Cheney, Komaroff and Gallo et al found that “neurologic symptoms, MRI findings and lymphocyte phenotyping studies suggest that the patients may have been experiencing a chronic, immunologically mediated inflammatory process of the central nervous system” (Ann Int Med 1992:116:103-113).

And on the same issue, do you remember that in 1994, Professor Paul Levine (from the National Cancer Institute in Bethesda) is on record as advising that “the spectrum of illnesses associated with a dysregulated immune system must now include (ME) CFS”? (Clin Inf Dis 1994:18: (Suppl 1):557-560).

Do you remember that from his first hand experience of ME/ICD-CFS patients, Dr Dan Peterson confirmed that “In my experience (ME)CFS is one of the most disabling diseases that I care for, far exceeding HIV disease except for the terminal stages” (JCFS 1995:1:3-4:123-125).

Moving on to 2001, do you recall the work of Cook et al? You can hardly overlook that they demonstrated that brain abnormalities detected by MRI are significantly related to low physical function in ME/ICD-CFS, and that the abnormalities were grouped into five categories: (i) lateral ventricular enlargement (ii) grey matter and / or brain stem hyperintensities (iii) subcortical white matter hyperintensities (iv) cerebral atrophy and (v) L – R cerebral hemisphere asymmetries. 52% of patients examined showed abnormalities that fell into one of the five categories and the authors suggest that the brain abnormalities in ME/ICD-CFS are “as functionally significant as has been shown in the case of multiple sclerosis” (Intern J Neuroscience 2001:107:1-6).

However, you are on record as advising ardently that people with ME/ICD-CFS should receive only the most basic routine screening and you specifically advised Government that “no investigations should be performed to confirm the diagnosis, which is a clinical one” (Joint Royal Colleges’ Report, 1996: Summary for Commissioners, page 45).

And then there is your advice to the CMO: were you content that the advice contained in the CMO’s Working Group Report was that it is inappropriate and unnecessary even to look for such pathology in those who are thought to have the disorder?

Unless such abnormalities as those demonstrated by Cook et al are looked for, how can they be found? You might argue that even if abnormalities are found, they would not change the management or outcome, but how can you justify this argument in the light of such data as that mentioned in this document?

Do you recall that in 2001, Susan Levine found indisputable evidence of infectious agents in the spinal fluid of ME/ICD-CFS patients? (JCFS 2001:9: (1-2):41-51). Some of the infectious agents found have previously been shown to invade the central nervous system. The author commented that it was surprising to obtain such a relatively high yield of infectious agents on cell free specimens that had not been centrifuged. What is your view on these findings?

Then we move right up-to-date: as a self-proclaimed expert on this disorder, you would be expected to be at the forefront of knowledge on your speciality, so you will know that Ben Natelson et al from New Jersey have published some very interesting and important results supporting the view that some patients with ME/ICD-CFS have a neurological abnormality and that immune dysregulation within the central nervous system may be involved in this process (Clinical and Diagnostic Laboratory Immunology. January 2005;12:1:52-55). It is noteworthy that Natelson says about the disorder: “Some think that it is an example of symptom amplification indicative of functional or psychogenic illness, while our group thinks that some (ME)CFS patients may have brain dysfunction”. By testing spinal fluid, Natelson found that 30% of those with (ME)CFS had protein levels that were higher than controls (all of whom had normal levels), with some patients having levels that were higher even than the laboratory norms. Significantly, those with the highest protein levels had a lower rate of comorbid depression than the controls. Natelson concludes that this confirms a neurological cause for the disorder. Would you explain why you disagree?

What is your interpretation of Jonathan Kerr’s finding from Imperial College, London that supports a genetic basis for this disorder, as reported by James Le Fanu in The Sunday Telegraph on 9<sup>th</sup> January 2005? Do you regard it as significant that the identified genetic abnormality is present in no less than 15 genes involved in the functioning of “the nerves and the ‘batteries’ that provide the energy for the cells”?

Despite all this (and what is mentioned here barely scratches the surface of what is known and published about ME/ICD-CFS), you are seemingly determined to deny reality in that you ride rough-shod over such findings as those illustrated above. Why is this so?

From your own published (and audio-recorded) views on people with ME/ICD-CFS, it would be unreasonable to expect you to show compunction, but does it not concern you at all that the ME community is understandably outraged by your statement that ME is simply a “belief system”?

Why are you so opposed to looking diligently and relentlessly for evidence of disrupted biological processes in ME/ICD-CFS patients? What drives your resistance?

You are on record as stating that it is not necessary to know the *cause* of a disorder before treating it, but what countless people find so unacceptable is the denial by you and your group of psychiatrists of the need even to look for the cause, as well as your denial and dismissal of the very existence of the symptoms that so comprehensively wreck so many lives.

You are also on record many times as expressing the need to control NHS costs, in particular for what you regard as the substantial and costly problem of “non-existent” and “medically unexplained” syndromes (in which you include “CFS/ME”), but is there something perhaps more self-serving than cost control involved?

On the matter of “medically unexplained syndromes”, did you know that in his item in the current BMJ (A new era of psychospiritualism), Abhijit Chaudhuri, Senior Lecturer in Neurosciences at the University of Glasgow, writes that Medically Unexplained Syndromes (MUS) is an artificial construct that is entirely synthetic; that it is created by psychiatrists and lies outside the natural territory of medicine? How do you respond to this?

## **2. Cognitive Behavioural Therapy and the Mind-Body Movement**

In the CMO's Working Group Report of January 2002, cognitive behavioural therapy is described as "a tool for modifying attitudes and behaviour".

It is known that it is Government policy to promote CBT as widely as possible for conditions for which medicine currently has no answer. After all, in 2002 the BMJ made the position clear: "The trend started with the 1996 NHS Strategic Review 'Psychotherapy Services in England'. This set out a programme for coordinated, evidence-based, comprehensive, safe and equitable provision of psychotherapy. Psychological therapies increasingly form an integral part of government planning for mental health care and cognitive behavioural therapy tends to be seen as the first line treatment for many psychiatric disorders....for most diagnoses, cognitive behavioural therapy tends to get the accolade of 'level 1' evidence ....a similar theme emerges in the Department of Health's guidelines: cognitive behavioural therapy comes first for depressive disorders, panic disorder and chronic fatigue" (All you need is cognitive behavioural therapy. Jeremy Holmes et al BMJ 2002;324:288-294).

However, correctly delivered CBT is very expensive and time consuming, as one of your named collaborators in the current MRC PACE trial (Tony Johnson from the MRC Biostatistics Unit at Cambridge) has previously confirmed when he challenged the validity and cost effectiveness of CBT in a critical analysis of the methodology of psychiatric trials: you will doubtless be aware that he found that a course of psychotherapy typically lasted for 12 weeks and a major limitation is its cost (Clinical trials in psychiatry: background and statistical perspectives. T. Johnson. Statistical Methods in Medical Research 1998;7:209-234). As you know, the trial statistician is named as Dr Tony Johnson in the PACE Trial Identifier, which says: "Prof. Simon Wessely will oversee the CTU (Clinical Trial Unit), with the support of Dr Tony Johnson" (para 4.4).

In your reply to John Sayer on the issue of cognitive behavioural therapy for those with ME/ICD-CFS, you write: "what I know is that these are treatments that have a reasonable chance of helping you irrespective of the cause. I can say from the evidence of the randomised trials that more people who receive them do better than those who do not. I am entitled to say that because that is what the trials, reviews and meta analyses show".

How many meta-analyses have there been? How can there be a secure evidence-base of "best practice" for the cost-effective benefit of CBT when not enough attention has been given to the fact that in the systematic review of the literature that was commissioned for the CMO's Working Group (the York review) there were only three randomised controlled trials (RCTs) of graded exercise therapy and five RCTs of CBT that were of sufficiently acceptable standard to have been included?

Those RCTs that were included in the York Review found the possibility of **some** benefit to **some** patients in broadly-defined cohorts, not that CBT was specifically or universally efficacious.

The Review is unequivocal: "overall, sufficient research evidence was lacking and the quality was not optimal".

Would you accept so low a figure of RCTs as a viable evidence base for "best practice" in support of homoeopathy, for example? As Abbot and Newton say, if a similar evidence base

existed for Shamanic healing, it would arouse little clinical interest (<http://bmj.bmjournals.com/cgi/eletters/325/7362/480>).

Given the prolific evidence that ME/ICD-CFS is not a primary psychosomatic disorder (which you cannot deny but only reject), why were you and your colleagues so specific in your recommendations in the 1996 Joint Royal Colleges' Report on CFS (CR54), about which in regard to the provision of future services in the UK for those with "CFS" you (a liaison psychiatrist) said: "such services could arise out of existing liaison psychiatry provision" (CR54:13.10)?

Moving forwards by six years, why do the recommendations to the Chief Medical Officer about the necessary direction of health service planning (CMO's Report, January 2002) say: "Government investment in research on CFS/ME should encompass behavioural and social science (and) the research programme should include sufficient resource allocation for investigator-generated studies on the condition". Is it only by chance that in the UK, "investigator-generated studies" are firmly in the psychiatric domain?

Why do you disregard the substantial evidence that CBT stops being effective when the sessions with the therapist end?

Is there perhaps even more at stake? For instance, is it because of your allegiance to and involvement with the Mind-Body movement which, as you will know, arose in Germany and Austria, its aim being to counteract laboratory-based medicine by emphasising mental and behavioural aspects of disease management?

You will be aware that under a \$50 million initiative, the US National Institutes of Health established 10 centres around the country in just two years (between 1999 and 2001) for the promotion of behavioural management strategies. Could the recent funding of £8.5 million by the UK Government for the setting up of new centres to deliver CBT regimes for "medically unexplained syndromes" have anything to do with this growing movement that seems to have access to unlimited corporate funds?

In the light of the research findings mentioned in this document, have you any regrets that the report by the CMO's Working Group states that the management of "CFS/ME" is to be psychiatric and that future NHS service provision (quote) "ideally would adopt a biopsychosocial model (and that) the components of such a service are facilities for activity management"?

Would you be good enough to comment on the fact that CBT has been shown to be at best ineffective and at worst actively harmful for those with ME/ICD-CFS (it is unnecessary for you to claim that the MRC trials are intended to resolve this issue, since the obfuscation of the trial entry criteria referred to above precludes any such resolution).

### **3. The classification issue: is it also connected to the Mind-Body Movement?**

There can be no doubt that you and your colleagues have worked assiduously to effect the reclassification of ME/CFS from its present category of neurological to psychiatric, even to the extent of misclassifying ME/ICD-CFS as a mental disorder in the WHO Guide to Mental Health in Primary Care without the WHO sanction or approval--- a fact that was unacceptable



to the WHO (who on 16<sup>th</sup> October 2001 confirmed in writing that such a view (quote) “is at variance with WHO’s position”).

It was eventually also unacceptable to the UK Government, as Health Minister Lord Warner’s letter of 11<sup>th</sup> February 2004 to the Countess of Mar made clear: “The Department (of Health) accepts that it might have been clearer to say that chronic fatigue syndrome is indexed to the neurology chapter and fatigue states to the mental health chapter”.

Even the CMO’s Working Group Report of 2002 (with which you were involved) was misleading on this point, because it stated: “Currently, CFS and ME are classified as distinct illnesses in the World Health Organisation’s International Classification of Diseases”. Given that the Working Group was notified of this error on more than one occasion before the final report was published, to have included such an erroneous statement in a report of such significance was either inexcusable editorial carelessness or it was deliberate promulgation of misinformation in accordance with what appeared to be a pre-determined agenda.

The whole issue of correct classification is a serious matter, yet you are on record as being dismissive about it, referring to it in a statement entitled “What’s in a classification?” on your King’s College website as nothing more than “a storm in a teacup”. Your comments were also reported in the newsletter of the UK ME Association (ME Essential, March 2004, page 10).

On the troubled issue of the correct ICD classification code for ME/ICD-CFS, in your reply to John Sayer you refer to the letter that you and Tony David wrote to the Lancet about the classification of ME (and for the sake of accuracy, it was in November 1993, not in 1992 as you state in your reply to Sayer), in which you said “neurasthenia would readily suffice for ME”: Chronic fatigue, ME and ICD 10. David A, Wessely S. Lancet 1993;342:1247-1248).

As you will know, Charles Shepherd, Medical Adviser to the UK ME Association, commented on the letter you and Tony David sent to the Lancet in the following terms: “Despite (Wessely’s) view that (the inclusion of ME/CFS in ICD-10 as a neurological disorder) was a ‘moral victory’ for self-help groups, there was a very strong and growing campaign at this time, mainly involving psychiatrists on both sides of the Atlantic, to completely eradicate the term myalgic encephalomyelitis from medical language. And they had a considerable degree of success as it became almost impossible to use the term ME in the medical journals” (Co-Cure 26<sup>th</sup> July 2002).

You specifically confirm to Sayer that what you said in that (1993) letter was true: (“nevertheless, what I wrote was true”). You then say to Sayer: “most doctors, even those involved in CFS/me (sic) research, are not bothered by the issue of F or G codes. I don’t myself think it does much good to get too hung up on the business of what code the WHO uses. Remember, if you look at the descriptions, you will see beyond a shadow of doubt that what is being described under the two headings is the same condition”.

This is clearly erroneous, because the WHO itself confirmed in writing (on 23<sup>rd</sup> January 2004) that “it is not permitted for the same condition to be classified to more than one rubric as this would mean that the individual categories and subcategories were no longer mutually exclusive”.

If you believe that ICD codes are not of significance, why are you so determined to get the existing classification of ME changed from neurological to psychiatric?

This being so, on what evidence-base do you maintain your view? Why do you persist in ignoring not only the distinguishing difference in symptomatology but also the enormous body of biomedical evidence that ME/ICD-CFS is not the same as medically unexplained idiopathic chronic fatigue to which you ascribe the term “CFS/ME” (and the F code) and assert that it is indistinguishable from ME (which carries the G code)?

In your reply to John Sayer, you mention depression. In your earlier work you seemed certain that ME/ICD-CFS was a form of depression and you are on record as advising the use of anti-depressants; indeed, despite the published evidence that anti-depressants do not work in ME/ICD-CFS and that those with ME/ICD-CFS have a high frequency of adverse reactions to such medication, you have argued for their use more recently even in people with ME/ICD-CFS who are not depressed.

This inevitably brings to mind the fact that the House of Commons Health Select Committee is currently holding an inquiry into the influence of the pharmaceutical industry: you will doubtless be aware that this industry has come under intense scrutiny and has been criticised for, amongst other disturbing things, “disease-mongering” and the creation of “life-style” illnesses, especially in the field of mental health. This is apparently with a view to creating a market for long-term dependence on prescribed medication. In view of your persistent efforts to reclassify ME/ICD-CFS as a mental disorder, could this be one of the reasons why you wish to reclassify ME/ICD-CFS from neurological to psychiatric?

The classification issue is important and correct classification does matter because it impacts on correct referral to an appropriate specialist, correct investigations, correct diagnosis, correct management and / or treatment, correct State benefit support, correct insurance policy payments and, as part of correct management, the provision of home tuition for young people.

Are you really unaware that ICD codes are used to plan the provision and delivery of NHS services? It is a fact that software systems in the NHS use ICD-10 to encode diagnostic data. For this reason alone, ICD codes matter very much, so it is hardly surprising that people find your views dismissive and patronising. Have you really no contrition about this, especially when the consequences of misdiagnosis and the imposition of inappropriate management regimes have been (and remain) so serious?

Do you promote the re-coding of ME as a mental disorder and the further funding of psychiatric services for “CFS/ME” in order to secure funding for the maintenance of what is described as your current status as world leaders and your Centre of Excellence in this field? Given the significant amount of evidence that ME/ICD-CFS is not a psychiatric disorder, how can recommending such resources for your own speciality be in the best interests of patients with ME?

## **CONCLUSION**

In the letter that you and Tony David wrote to the Lancet in November 1993 (to which you referred in your reply to John Sayer), you ended by affirming: “We believe that this latest attempt to classify fatigue syndromes will prevent many people from seeing the world as it

actually is". That seems remarkably arrogant and presumptuous. Although that letter was written over a decade ago, it is obvious from your subsequent publications that despite the ever-mounting evidence that shows you to be wrong in your belief about the nature of ME/ICD-CFS, you still hold such a view.

You claim to have read "Denigration by Design?" which as you know, documents your own involvement in the current perception of ME/ICD-CFS in the UK. You may therefore recall what the internationally respected psychologist Dr Dorothy Rowe states: "People who know absolutely that they are right are very dangerous" (Observer, 14<sup>th</sup> November 1993). You may not, however, be aware of what Cormac Rigby, former BBC Radio 3 announcer who became a Catholic priest has to say on the same issue: "The greatest enemies of truth are those who think they have a monopoly of truth" (The Lord be with you -- a book of sermons. Fr. Cormac Rigby. Family Publications, Oxford 2004). Do you agree with such a view?