

Notes for UK Members of Parliament about ME/ICD-CFS

Margaret Williams

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In the light of what might soon appear as a revision of the BBC website on ME by the ME Association, it may assist Members of Parliament to be reminded that, contrary to what may be claimed or implied in that revision, certain facts about myalgic encephalomyelitis (ME) remain irrefutable and readily verifiable:

1. It is misleading to state that the controversy as to whether or not ME/CFS is a real disease or is “all in the mind” was effectively ended following the release of a Report on “CFS/ME” from the Chief Medical Officer in January 2002 which concluded that ME/CFS is a genuine and disabling condition without making it clear that:
 - (i) ME has been recognised by the UK Department of Health (then the Department of Health and Social Services) as a physical (organic, not psychosocial or psychiatric) disorder since November 1987 (see Hansard, 27th November 1987:353)
 - (ii) since March 1992 the then Disability Allowance Board recognised a physical cause for ME
 - (iii) since March 2000, the Social Security Ruling (SSR 99-2p), titles II and XVI (Fed Regist 1999 Apr 30; 64 (83)23380-4) determined that “in accordance with 20 CFR 402.35(b)(1), the Commissioner of Social Security gives notice of Social Security Ruling SSR 99-2p. This Ruling clarifies disability policy for the evaluation and adjudication of disability claims involving Chronic Fatigue Syndrome (CFS). This Ruling ensures that all adjudicators will use the same policies and procedures in evaluating disability claims involving CFS”. This was reported in the Disability Rights Bulletin, Summer 2000, in the following terms: “In assessing Disability Living Allowance higher rate mobility component for people with ME, recent guidance advises decision makers to assume in the vast majority of cases that the claimant has a physical disablement. Guidance (DMG Memo Vol 10-3/00) advises that if a doctor says the claimant has ME or CFS then that can be taken as an opinion that they have a physical disablement”.
2. It is also misleading to state that CFS and ME are “now” classified by the World Health Organisation (WHO) as neurological disorders because ME has been so classified for the last 36 years: the WHO has classified ME as a neurological disorder since 1969 and the terms “chronic fatigue syndrome” (CFS) and “post-viral fatigue syndrome” (PVFS) are listed as synonymous, not as being in any way different. Indeed under the WHO rules, they could not be different: on 23rd January 2004 the WHO confirmed in writing 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”.
3. The information about prognosis in the revision of the BBC’s website would seem to be attractive to the psychiatric lobby because the ME Association advises that obtaining an early diagnosis and “appropriate medical advice” are important factors in reducing prolonged and severe incapacity. There seems to be no clarification that the only “medical advice” obtainable within the NHS is related to financial inducement for doctors to enrol patients with ME/CFS and fibromyalgia in rehabilitation regimes of cognitive behavioural therapy and

graded exercise which have been shown to be at best ineffective and at worst actively harmful to those with ME as distinct from “chronic fatigue”. Thus, the issue of what constitutes “appropriate medical advice” remains to be addressed.

4. This revision of the BBC website may possibly be designed to relate to research being undertaken by psychiatrists and others of the so-called “Wessely School” (specifically to the current MRC PACE trials). This research is likely to be flawed from the start by the deliberate design of the study that was compiled by the psychiatrists involved. The Trial Identifier expressly states that the “Oxford” case definition will be used as entry criteria, but the Oxford criteria were published in 1991 by the same psychiatrists **and expressly EXCLUDE those with any neurological disorder**, yet the psychiatrists claim that ME **will** be included because they do not accept the WHO classification of it as a neurological disorder. The **reason** that the psychiatrists want to use their own definition is explained by them in the Trial Identifier: **“We chose these broad criteria in order to enhance recruitment”**. That is hardly good or accurate science. The **reason** the psychiatrists want to pull in as many people as possible might be because the outcome is seemingly a forgone conclusion, namely that such people are a hefty drain on NHS resources and so they must be “managed” by the currently favoured psychiatric intervention of cognitive behavioural therapy (defined in the CMO’s Report 2002 as “a tool for modifying attitudes and behaviour”).
5. There seems to be an undeclared competing interest here and the MRC trial results could be suspect because psychiatrist Professor Simon Wessely is named as a Corporate Officer in the PRISMA Company Information and is a member of the Supervisory Board (ie. he is higher than the Board of Management of PRISMA), which is a multi-national healthcare company working with insurance companies by arranging compulsory “rehabilitation” programmes (ie CBT and GET) for claimants with “medically unexplained symptoms”. Wessely is described as a “world expert” in the field of such symptoms. His colleague, psychiatrist Mike Sharpe, is on record as confirming that PRISMA is now working with Action for ME to provide CBT programmes throughout the NHS (ref: “Functional Symptoms and Syndromes: Recent Developments” in the UNUMProvident Report 2002 “Trends in Health and Disability”). Can it be that Wessely is recommending and promoting a management programme and trials of the same management programme that is known to be harmful for those with ME/ICD-CFS but is provided by a company of whose Supervisory Board he is a member?
6. “Wessely School” adherents are not persuaded by the abundance of medical science that has already demonstrated an organic pathology for ME/ICD-CFS and they continue to assert that it is a “medically unexplained syndrome”, known as MUS. They are trying to get a new category of MUS in the next edition of the WHO ICD (ICD-11). Importantly, **the definition of MUS is already published: “Physical symptoms without organic basis will be referred to as ‘medically unexplained or functional symptoms’”. These terms are used synonymously with somatization**” (ref: Assessment and Treatment of Functional Disorders in General Practice: the Extended Reattribution and Management Model. Per Fink et al. Psychosomatics, March-April 2002:43:2:93-131).
7. Control of funding for research into “CFS/ME” as the psychiatrists now refer to it (purely to placate patients, claiming that patients prefer the term “ME” but that *doctors* never use it--in fact, when asked by an interviewer in a magazine if CFS and ME were the same thing, the Medical Adviser to the ME Association, Dr Charles Shepherd, replied that yes, they *were* the same thing but that patients preferred the term ME because it sounded more serious) would seem to be in their own hands: Wessely was a member of three Boards at the MRC, including the Monitoring and Evaluating Steering Group which conducts evaluations of the MRC’s research funding policies; the Neurosciences and Mental Health Board and the Health Services and Public Health Research Board. In March 2003 the House of Commons Select Committee on Science and Technology produced its Report “The Work of The Medical Research Council” (HC 132) in which MPs issued a damning judgment on the MRC, lambasting it for wasting funds and for introducing misguided strategies for its research. MPs found evidence of poor planning and of focusing on “politically-driven” projects that have diverted money away from top-quality proposals. The unprecedented attack was the result of a detailed probe into the workings of the MRC.

8. Despite the evidence to the contrary, the MRC regards “CFS/ME” as a psychiatric disorder: at a meeting with the Countess of Mar at the House of Lords in 2004, the MRC CEO (Professor Colin Blakemore, who was accompanied by Elizabeth Mitchell of the MRC) made it clear that the MRC is very happy with Wessely and his views. Earl (Freddie) Howe was also present and was very disturbed by the stance taken by Blakemore. This might explain why proposals submitted to the MRC for funding for biomedical projects on ME are always rejected (the usual excuse being that the quality of the proposal was not good enough).
 9. Wessely is on record as referring to ME as a “myth” (at the symposium on Occupational Health Issues for Employers” held on 17th May 1995 at the London Business School). At that Symposium, ME was described and promoted as (quote) “**neurosis under a new banner**” and described as a “**malingerer’s charter**”. Wessely is also on record as claiming that ME is nothing but a “belief”: (quote) “I am going to talk not about an illness, but about an idea. I will argue that ME is simply a belief” (Microbes, Mental illness, the Media and ME: The Construction of Disease”: Lecture at the Institute of Psychiatry, 12th May 1994).
 10. Wessely School psychiatrists base their paradigm on the construct of “CFS/ME” as possibly being initiated by a trigger, but maintained and perpetuated by “aberrant” and “dysfunctional” beliefs and by “avoidant” behaviour that must be “managed” by compulsory exercise and by substitution of such “dysfunctional” beliefs by their own beliefs. Wessely is on record as asserting that ME exists only because (naïve) doctors have not learnt to deal adequately with their “suggestible” patients (Old wine in new bottles: neurasthenia and ‘ME’: Psychological Medicine 1990:20:35-53). This was written in 1990, yet despite the wealth of published evidence of biological anomalies that has been discovered in ME/ICD-CFS since then, Wessely’s views have hardly changed, as is apparent from his more recent papers.
 11. Much misinformation initially propagated by Wessely et al has been perpetrated (in writing) in letters sent to various people by Dr Stephen Ladyman MP, Parliamentary Under Secretary of State at the Department of Health. Given what is now known about the disorder, that is inexcusable (for example, see the letters dated 18th August 2003 and 2nd September 2003 sent by the Countess of Mar to Professor George Szmuckler, Dean of the Institute of Psychiatry where Wessely works (http://www.meactionuk.org.uk/Mar_Szmukler_Correspondence.htm). Clearly nothing changes in Dr Ladyman’s mind, because his letter of 17th December 2004 to Annabelle Ewing MP fails to clarify that the WHO classification of ME/ICD-CFS is as a **neurological** disorder and his letter is disingenuous because the “strategy” and “initiatives” he mentions are simply psychiatric, which are completely misplaced as far as ME/ICD-CFS is concerned. Whilst to the uninformed, the letter seems to list much support for sufferers, in reality it merely replays the psychiatric paradigm. It does not address the crucial issue of ME at all, because the new Centres that Dr Ladyman extols will provide only psychiatric interventions for those with “unexplained fatigue” lasting longer than six months. This bears no relationship to the multi-system complex neuro-immuno-vascular disorder that is ME.
 12. Annabelle Ewing MP is entirely correct when she says in her letter of 9th December 2004 that “We will never move forwards with respect to ME unless we understand the causes of this debilitating illness”, but it is now Government policy **that it is not necessary to look for the cause** (based on Wessely’s advice because he believes it is **a functional somatic syndrome** and that it is neither appropriate nor necessary to carry out diagnostic investigations in search of the pathology of “CFS/ME”). He and his colleagues are on record as advising Government that (quote) “No investigations should be performed to confirm the diagnosis, which is a clinical one” (Joint Royal Colleges’ Report, CR 54, October 1996), whilst the same view prevails in the more recent report to the Chief Medical Officer of January 2002 and the MRC also seems to believe this.
 13. In the light of the evidence available it is suggested that it is the duty of MPs to be asking some very probing questions.
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The following documents provide a more in-depth exposition of the problem and are available at <http://www.meactionuk.org.uk>

What is ME? What is CFS? Information for Clinicians and Lawyers.
EP Marshall, M Williams, M Hooper. December 2001
http://www.meactionuk.org.uk/What_Is_ME_What_Is_CFS.htm

The Mental Health Movement: Persecution of Patients?
M Hooper. December 2003 http://www.meactionuk.org.uk/SELECT_CTTEE_FINAL_VERSION.htm

Wessely's Wisdom? Some more open questions for Professor Wessely.
M Williams. 16th January 2005 http://www.meactionuk.org.uk/Wesselys_Wisdom.htm