

IS PROFESSOR SIMON WESSELY GUILTY OF MISLEADING MEDICAL PROFESSIONALS AND OTHERS?

A Call for a Parliamentary Select-Committee of Inquiry into UK ME/CFS Policy

Myalgic Encephalomyelitis (ME) has been recognised by the World Health Organisation (WHO) as a physical/neurological disease since 1969[1] and there is good scientific reason why the WHO does not conflate it with psychiatric 'fatigue syndrome'. Professionals and patients in the ME community are deeply worried about the ongoing influence of Professor Simon Wessely. There is justification in being pedantic about correct disease taxonomy and a full and fair representation of the scientific evidence-base. Both are vital to ensure correct diagnosis and genuine science-based research and treatment. Many believe that Professor Wessely has abandoned such basic professional principles and that abandonment has contributed to the mistreatment of many people with ME and to the death of at least one patient in the UK[2].

A leading international consensus panel of some of the world's most experienced ME specialists, including three of the longest-serving NHS specialist consultants (Drs Terry Mitchell, Nigel Speight, Anne Gerken), have recently reaffirmed both the WHO ME disease classification and the serious biomedical nature of the disease[3]. They have also called for abandonment of the inaccurate term 'Chronic Fatigue Syndrome' (CFS) that is favoured by the permanent-health insurance industry and so-called 'Wessely-School' psychiatrists linked to it. Contrary to Wessely's views, the International Consensus Panel also heavily criticised the UK National Institute for Health and Clinical Excellence (NICE) Clinical Guideline-53 (CG53) on 'CFS/ME' and the flawed evidence-base used. NICE itself took the extraordinary stance of attempting to brush aside earlier criticisms that CG53 did not conform to basic guideline standards outlined in the international 'AGREE Instrument' by stating they were not legally obliged to meet such standards[4].

In spite of receiving millions of pounds of public research funding over many years, the Wessely and Medical Research Council (MRC) associated 'PACE Trial' on 'CFS/ME', and its flagship cognitive behavioural and graded exercise therapies (CBT/GET) have, in reality, proved to be a spectacular failure. If CBT/GET treatments worked, patients would be actively seeking them out in their droves, not eschewing them. Wessely's reasoning that poor patient CBT/GET uptake is due to skewed information on the treatments from allegedly malign patient-activists does not stand up to scrutiny: especially when most patients receive far more pro-CBT/GET information from every government agency imaginable compared to the much smaller counter-efforts of under-funded activists. The truth is that the 'fear of activity causing muscle-deconditioning' premise of Wessely-School CBT is increasingly shown to be false by science. Moreover, many patients trying GET have reported considerable harm and the scientific basis underpinning why GET is likely to be harmful for ME patients is also growing relentlessly. The bigger picture is that questionable scientific practices surrounding the PACE Trial have led to widespread concern and erudite complaints from professionals[5]. Scientific malpractice and abuse of significant public funding is alleged.

NHS consultants, international specialists, senior UK parliamentarians and others have long warned that genuine evidence-based policy and research on ME may have been eclipsed in the UK by the politics of vested-interest[6]. Take for example the fact that the 2007 NICE 'CFS/ME' clinical Guideline Development Group (GDG) excluded from its membership all NHS specialists experienced in treating adult ME patients. This is shocking by any standards: imagine the media outrage if a NICE guideline on infectious disease excluded all virologists from its production or a

guideline on breast-cancer excluded all oncologists? Or take the alarming comments from a senior parliamentarian inquiry group on ME in 2006:

“There have been numerous cases where advisers to the DWP [Department of Work and Pensions] have also had consultancy roles in medical insurance companies. Particularly the Company UNUM Provident. Given the vested interest private medical insurance companies have in ensuring CFS/ME remain classified as a psychosocial illness there is blatant conflict of interest here. The Group find this to be an area for serious concern and recommends a full investigation of this possibility by the appropriate standards body.”^[7]

In the case of said NICE GDG, not only were all NHS adult specialists excluded (as indeed was the country's most experienced consultant ME paediatrician, Dr Nigel Speight), the GDG included the senior medical advisor to three permanent-health insurance companies.

A key factor in UK medical politics is that Professor Simon Wessely widely misrepresented authoritative Myalgic Encephalomyelitis (ME) WHO classification and nomenclature as merely being patients' own "lay label". In his own words, he did this in order to pursue a "constructive labelling" "strategy" of increasingly having ME subsumed into the rubric of mental disorders by "gradually expanding understanding of the condition to incorporate the psychological and social dimensions." Thus Professor Wessely tellingly stated in the British Medical Journal:

“One challenge arises when patients have named their condition in a way that leaves doctors uncomfortable, as occurred with chronic fatigue syndrome. It may seem that adopting the lay label endorses the implicit causal theory and reinforces the perceived disability. For better or worse, the medical profession has lost the monopoly on naming conditions, and rejecting lay terms can needlessly alienate patients. A compromise strategy is “constructive labelling,” expanding on the lay name. It would mean treating chronic fatigue syndrome as a legitimate illness, acknowledging that it may have a viral trigger (as many patients report), while gradually expanding understanding of the condition to incorporate the psychological and social dimensions. The recent adoption by the UK Medical Research Council and the chief medical officer’s report of the term chronic fatigue syndrome/myalgic encephalitis reflects such a compromise, albeit an uneasy one.”^[8]

It is astonishing that, because of such misrepresentation, so many medical professionals, policy-makers and journalists erroneously believe that the long-established WHO classification of Myalgic Encephalomyelitis (ME) is merely the “lay label” of patients. Such misrepresentation and subsequent confusion has done untold harm: as is indicated for example by the International Consensus Panel.

In the face of unrelenting growth of biomedical evidence, Professor Wessely has attempted to claim that he has not stated that ME, which he conflates with Fatigue Syndrome and CFS, is primarily a behavioural illness, but rather that he views such illness as having psychiatric components. Such an assertion was again made for example in 'The Independent' newspaper on 25 November 2012 in an article warning of the possibility of Wessely being stripped of his recent scientific award:

“I have never said that CFS is all in the mind. I do not believe that, and have never written that.”^[9]

This claim by Professor Wessely however appears to contradict earlier alleged statements made by him^[10] as, for example, that noted in his own writing from his 1994 Elliot Slater Memorial Lecture:

“I will argue that ME is simply a belief, the belief that one has an illness called ME”^[11]

Whatever one's views on Professor Wessely and his claims surrounding ME or CFS, it is clear that he has had a major impact upon the views and actions of UK medical professionals and policy-makers. He has also had a major impact on certain sections of the British Media: much of which seems content to parrot somewhat one-sided assertions of Wessely being both a champion of honest science and innocent victim of unscientific angry activists. Many patients have a contrary view and tell harrowing stories of neglect and persecution arising in no small part because of views advanced by Professor Wessely. The impression given by much of the media however that only ME patients oppose Professor Wessely's views is highly misleading: as, for example, a simple viewing of the recent International Consensus Panel documents reveal[12]. One can only hope that when Lord Leveson produces his forthcoming report into media standards[13] he will warn the media of the dangers and unfairness of favouring powerful lobbies: in much the same way that parliamentary standards committee chairman, Sir Christopher Kelly, recently warned Parliament concerning the same[14]? The simple truth in my view is that, for many years, the UK establishment has drowned-out, misrepresented and effectively ignored the voice of ME patients and professionals who do not hold to the questionable view of the disease being psychosocial.

One such common establishment misrepresentation comes for example from Professor Colin Blakemore. In his former role as MRC chairman, Professor Blakemore presided over what was a virtual monopoly of public 'CFS/ME' research funding by the Wessely-associated PACE and FINE Trials. In August 2011 Professor Blakemore stated the ME community was angry at researchers:

“...for doing “the wrong kind of research”. Professor Simon Wessely, of King’s College London, has been a particular target — not so much for what he did as where he did it: in a department of psychiatry.”[15]

This is singularly misleading. Any long-term chronic physical illness has patients that sometimes require the input of psychiatric services for secondary/co-morbid complications. Such psychiatry is necessary and welcomed. What ME patients and ME professionals are objecting to is not psychiatric research per se, but that being done on the basis of misrepresented disease taxonomy, misrepresented evidence-bases, confusion of primary physical illness with co-morbid secondary complications, unscientific patient selection criteria, and highly questionable scientific methodology. In effect, what ME patients and professionals object to is disingenuous psychiatric 'research' they believe is bent to suit the pre-determined conclusions of vested-interests.

The ME community has said it many times: the long-term interests of the permanent-health insurance industry and the UK state do not coincide and the relationships between the two need close scrutiny. Whilst it may be advantageous for profit-driven insurers to advance highly questionable money-saving psychiatric 'treatments', the same cannot be said of the UK state. Mistreatment and neglect of ME patients can only result in prolonged illness, greater disability and greater long-term burdens upon public funding. British taxpayers deserve better: especially those with ME who paid national insurance contributions for years before becoming ill. It is about time that ME science and ME welfare policy was taken out of the realm of vested-interest. This can only begin when public policy is determined to be genuinely evidence-based and the utter mess that is present UK 'CFS/ME' policy is fully, independently and openly inquired into. I now call for such an inquiry by a parliamentary select-committee with a broad remit and full powers of subpoena.

Anglia ME Action, November 2012.

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www.angliameaction.org.uk/docs/wessely-misleading.pdf

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REFERENCES:

[1] 'ME/Myalgic Encephalomyelitis (benign)' is classified along with 'PVFS/Postviral Fatigue Syndrome' by the World Health Organization (WHO) in the tenth revision of 'The International

Statistical Classification of Diseases and Related Health Problems' (ICD-10) in chapter VI, diseases of the nervous system, other disorders of the nervous system, other disorders of the brain (G93.3) – ICD-10-G93.3.

'Fatigue Syndrome is categorised as a mental and behavioural disorder at ICD-10-F48.0 and not to be conflated with ME/PVFS at ICD-10-G93.3.

This is easily determined by a visit to the World Health Organisation ICD website at the following web-links:

<http://apps.who.int/classifications/icd10/browse/2010/en>

<http://www.who.int/classifications/icd/en>

Please note the WHO website colour-coding rules by clicking on the blue-help icon next to the search box at the top of the web-page (green = main disease title in ICD-10 volume-1; blue = included disease title in ICD-10 volume-1; orange = broad indexed term in ICD-10 volume-3). Searching for 'Postviral Fatigue Syndrome' gives main/green G93.3 volume-1 coding; searching for 'Benign Myalgic Encephalomyelitis' gives included/blue G93.3 volume-1 coding; searching for 'Chronic Fatigue Syndrome' gives index/orange reference in volume-3).

For authoritative WHO ICD-10 disease classification, full reference needs to be made to the published ICD book versions:

- International Statistical Classification of Diseases and Related Health Problems - Tenth Revision – Second Edition: Volume 1 – Tabular List – ISBN: 92 4 154649 2.
- International Statistical Classification of Diseases and Related Health Problems - Tenth Revision – Second Edition: Volume 2 – Instruction Manual – ISBN: 92 4 154653 0.
- International Statistical Classification of Diseases and Related Health Problems - Tenth Revision – Second Edition: Volume 3 – Alphabetical Index – ISBN: 92 4 154654 9.

Note, in harmony with the Carruthers et al International Expert Panel, the WHO have repeatedly clarified to various lay and professional members of the ME community that diseases cannot be encoded under more than one rubric in ICD-10 volume-1, and that broad and colloquial terms in the ICD-10 index (volume-3) are NOT to be taken as authoritative WHO disease classification terminology. For example, on 4th February 2009, Dr Robert Jakob, Medical Officer (ICD), Classifications, Terminologies and Standards, WHO Headquarters, confirmed:

“CFS is a broad umbrella. This needs to be clarified. It is not possible to make a deduction from CFS. Volume 1 is the relevant volume for ME. ME is classified at G93.3 and is a specific disorder. The term CFS covers many different conditions, which may or may not include ME. The use of the term CFS in the ICD Index is merely colloquial and does not necessarily refer to ME. It could be referring to any syndrome of chronic fatigue, not to ME at all. In its Guideline, NICE has used an ambiguous term. The WHO does not recognise the term ‘CFS/ME’ and refers to it as ‘unfortunate’ ”.

Source: Professor Malcolm Hooper:

<http://www.meactionuk.org.uk/COMPLAINT-to-Lancet-re-PACE.htm>

[2] See for example the case of Sophia Mirza in 2005, a young ME patient who was accused of exaggerating and misattributing her illness, was forcibly removed into psychiatric 'care' and died shortly after from renal failure. The subsequent autopsy revealed considerable damage to her central nervous system along with other serious physical pathologies long associated with ME:

<http://www.sophiaandme.org.uk/>

<http://www.sophiaandme.org.uk/docsindex/212.jpg>

[3] Myalgic Encephalomyelitis: International Consensus Criteria [ME-ICC], Carruthers et al, Journal of Internal Medicine, 2011. Doi:10.1111/j.1365-2796.2011.02428x:

<http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2796.2011.02428.x/abstract>

<http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2796.2011.02428.x/pdf>

Also see the important 2012 follow-up document from the International Consensus Panel: Myalgic Encephalomyelitis – Adult & Paediatric: International Consensus Primer for Medical Practitioners, Carruthers et al, International Consensus Panel, 2012. ISBN 978-0-9739335-3-6:
www.angliameaction.org.uk/docs/ME-ICC-Primer-2012.pdf

[4] Since its original release in 2003, the 'Appraisal of Guidelines for Research and Evaluation (AGREE) Instrument' has advanced the science of practice guidelines (PG) appraisal and quickly became the international gold standard for PG evaluation and development. See:
<http://www.agreetrust.org/resource-centre/the-original-agree-instrument/>
<http://www.agreetrust.org/>

Also see:

http://www.meactionuk.org.uk/Comments_on_the_NICE_Guidelines.htm

[5] Such as, for example, Professor Malcolm Hooper's concerns with the widely criticised MRC-funded 'PACE Trial into CFS/ME' – see:

<http://www.meactionuk.org.uk/COMPLAINT-to-Lancet-re-PACE.htm>

<http://meactionuk.org.uk/Update-on-the-PACE-Trial-110712.htm>

http://meactionuk.org.uk/Further_Articles.htm

[6] See for example:

Dr Terry Mitchell, witness statement to the UK High Court, 23 June 2008:

http://www.angliameaction.org.uk/NICEJRdocs/Terry_Mitchell_WS.pdf

Dr Ian Gibson MP, witness statement to the UK High Court, 21 July 2008:

http://www.angliameaction.org.uk/NICEJRdocs/Ian_Gibson_WS.pdf

Dr Neil Abbot, witness statement to the UK High Court, 2008:

http://www.angliameaction.org.uk/NICEJRdocs/Neil_Abbot_MERUK_WS.pdf

And see: Inadequacy of the York (2005) Systematic Review of the CFS/ME Medical Evidence Base: Comment on Section 3 of The diagnosis, treatment and management of chronic fatigue syndrome (CFS)/(ME) in adults and children Work to support the NICE Guidelines carried out by Anne-Marie Bagnall, Susanne Hempel, Duncan Chambers, Vickie Orton and Carol Forbes Centre for Reviews and Dissemination, University of York, October 2005 - Comment by Professor Malcolm Hooper & Horace Reid, January 2006:

http://meactionuk.org.uk/Final_on_NICE_for_Gibson.html

<http://www.investinme.org/Documents/Hooper%20Inadequacy%20of%20the%20York%20%20Review.doc>

[7] Parliamentary Group on the Scientific research into ME (GSRME) Report, Page 30, November 2006:

<http://www.erythos.com/gibsonenquiry/index.html>

[8] Managing patients with inexplicable health problems. BMJ Volume 326, 15 March 2003. Baruch Fischhoff, Simon Wessely. BMJ 2003;326:595–7:

www.hss.cmu.edu/departments/sds/media/pdfs/fischhoff/BMJ-F-W.pdf

[9] ME: bitterest row yet in a long saga. Sanchez Manning, The Independent newspaper (UK), 25 November 2012:

<http://www.independent.co.uk/news/science/me-bitterest-row-yet-in-a-long-saga-8348389.html>

See also: Professor Simon Wessely's award of the inaugural John Maddox Prize for his courage in the field of ME and Gulf War Syndrome. Professor Malcolm Hooper (with members of the ME community), 12th November 2012:

http://www.meactionuk.org.uk/Wessely_John_Maddox_Award.htm

And see: Ruffled feathers? Margaret Williams, 18th November 2012:

<http://www.meactionuk.org.uk/Ruffled-feathers.htm>

[10] See: QUOTABLE QUOTES ABOUT ME/CFS - Myalgic Encephalomyelitis / Chronic Fatigue Syndrome also known as PVFS (Post-Viral Fatigue Syndrome) sometimes known as CFIDS

(Chronic Fatigue & Immune Dysfunction Syndrome) in the USA - compiled by Margaret Williams on behalf of the charity Invest in ME Registered Charity Number 1114035, April 2007:

[www.meactionuk.org.uk/Quotable Quotes Updated.pdf](http://www.meactionuk.org.uk/Quotable_Quotes_Updated.pdf)

And see: Professor Simon Wessely's award of the inaugural John Maddox Prize for his courage in the field of ME and Gulf War Syndrome. Professor Malcolm Hooper (with members of the ME community), 12th November 2012:

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And see: Ruffled feathers? Margaret Williams, 18th November 2012:

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[11] See: "Microbes, Mental Illness, The Media and ME: The Construction of Disease"; Simon Wessely; 12th May 1994; 9th Eliot Slater Memorial Lecture, Institute of Psychiatry, London. A copy of Professor Wessely's own 12th May 1994; 9th Eliot Slater Memorial Lecture notes, along with comment, is available here:

http://www.meactionuk.org.uk/wessely_speech_120594.htm

http://www.meactionuk.org.uk/wessely_speech_120594.pdf

Also cited in 'Submission re: DSM-V and ME/CFS', Compiled by Professor Malcolm Hooper and Margaret Williams for submission by The 25% ME Group, 20 March 2010:

<http://www.meactionuk.org.uk/DSM-V-submission.htm>

<http://www.meactionuk.org.uk/DSM-V-submission.pdf>

[12] Myalgic Encephalomyelitis: International Consensus Criteria [ME-ICC], Carruthers et al, Journal of Internal Medicine, 2011. Doi:10.1111/j.1365-2796.2011.02428x:

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www.angliameaction.org.uk/docs/ME-ICC-Primer-2012.pdf

[13] The Leveson Inquiry is an ongoing public inquiry into the culture, practices and ethics of the British press following the News International phone hacking scandal. On 6 July 2011, Prime Minister David Cameron announced to Parliament that an inquiry would be established under the Inquiries Act 2005 to further investigate the affair. On 13 July, Cameron appointed Lord Justice Leveson as Chairman of the inquiry, with a remit to look into the specific claims about phone hacking at the 'News of the World', the initial police inquiry and allegations of illicit payments to police by the press, and a second inquiry to review the general culture and ethics of the British media:

http://en.wikipedia.org/wiki/Leveson_inquiry

<http://www.levesoninquiry.org.uk/>

[14] Big money is poisoning British democracy, warns anti-sleaze watchdog: Chairman of the Committee on Standards in Public Life says public faith is collapsing. Andrew Grice, The Independent newspaper [UK], Monday 19 November 2012:

<http://www.independent.co.uk/news/uk/politics/big-money-is-poisoning-british-democracy-warns-antisleaze-watchdog-8327305.html>

[15] Professor Colin Blakemore: from The Times newspaper (UK): today's columnists, 2 August 2011:

www.meassociation.org.uk/?p=7430

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