

Oh Lord, please don't let me be misunderstood

Margaret Williams 16th January 2012

Professor Simon Wessely has recently published his own account of his involvement since the late 1980s with what he refers to as Chronic Fatigue Syndrome but does not clarify that he and his colleagues regard CFS as synonymous with ME and that they regard – and treat—it as a behavioural disorder (“CFS Personal Story”: simonwessely.com/faq.html).

His story as published on his new website makes a smooth and impressive read, at least for the uninitiated, as it refers to numerous biomedical studies with which Wessely says he was involved during his “CFS” career.

What he fails to make clear is the number of those biomedical studies that had negative findings, or that he uses the Oxford case definition that specifically excludes those with a neurological disorder such as ME, so he may be studying only those with unexplained “fatigue”.

Equally, he claims “*considerable success*” with cognitive behavioural therapy but again he does not explain the cardinal importance of case definition.

Wessely states that he is “*proud*” of having contributed to neuroendocrine studies and seems to be claiming the honour for having discovered HPA axis dysfunction in “CFS”, whereas this was first demonstrated by Mark Demitrack in the US (Journal of Clinical Endocrinology and Metabolism 1991;73:6:1224-1234; Biol Psychiatry 1992;32:1065-1077). Wessely specifically mentions Professor Tony Cleare (a member of Wessely’s group) and his work on neuroendocrine aspects of CFS, but does not explain that Cleare regards the disorder as being “*most likely of biopsychosocial origin*”, concluding that there is “*no evidence for a specific or uniform dysfunction of the HPA axis*” and that confounding factors such as inactivity and psychiatric comorbidity may influence the observed endocrine changes (Endocrine Reviews 2003;24:236-252). Cleare is also on record as stating that “*HPA axis changes can be reversed by modifying behavioural features of the illness, such as inactivity (and) deconditioning*” and that “*current evidence suggests that neuroendocrine changes are not a central core of the condition, but occur...at least partly as a response to certain features of the illness such as ...physical deconditioning*” (TRENDS in Endocrinology and Metabolism 2004;15:2). Notably, Wessely fails to report his own view on the cortisol abnormality: “*I will argue that this line here represents not the line between low and high cortisol responses...but the line between real and unreal illness*” (Microbes, Mental illness, the Media and ME: The Construction of Disease; 9th Eliot Slater lecture given at The Institute of Psychiatry, 12th May 1994).

Wessely mentions the immunological studies with which he has been involved, but again he does not explain that his group failed to find the immunological abnormalities documented by experts such as Professor Nancy Klimas, nor that he argues against immunological testing, for example: “*Though disordered immunity and persisting viral infection have recently attracted attention, it is important that immunologists do not deflect attention away from the wider (ie. psychiatric) aspects of the chronic fatigue/postviral syndrome*” (Anthony David, Simon Wessely, Anthony Pelosi. Lancet 1988; July 9th: 100-101). Notably, in his “CFS Personal Story” Wessely says: “*We showed that immune dysfunction didn't relate to clinical outcomes*” but experts have found the exact opposite, for example: “*We demonstrated changes in different immunological parameters, each of which correlated with particular aspects of disease symptomatology*” (Hassan I, Weir WRC et al. Clin Immunol & Immunopathol 1998;87:1:60-67); “*The findings suggest that the degree of cellular immune activation is associated with severity of physical symptoms*” (Immunological Status Correlates with Severity of Physical Symptoms in Chronic Fatigue Syndrome Patients. S Wagner, N Klimas et al; Fourth International AACFS Research & Clinical Conference 1998; abstract page 28) and “*Among (ME)CFS subjects, those who had been sick longer had higher rates of autoantibodies*” (S Vernon et al. Journal of Autoimmune Diseases 2005: May 25th: 2:5).

Wessely mentions his work looking at HLA phenotypes but does not reveal that his team found no association with any specific phenotype, whereas others have shown direct linkage: *"A significant association between CFIDS and the presence of HLA-DQ3 was noted"* (RH Keller, N Klimas et al. Clin Inf Dis 1994;18: (Suppl 1): S154-S156) and *"The frequency of the HLA-DQ1 antigen was increased in patients compared to controls. This association between (ME)CFS and the HLA-DQ1 antigen translates into a relative risk of 3.2"* (RS Schacterle, Anthony L Komaroff et al. JCFs 2004;11(4):33-42).

Wessely also fails to mention that in the 1996 Joint Royal Colleges' Report on CFS his advice to Government bodies was that the reported biomedical abnormalities *"should not deflect the clinician away from the biopsychosocial approach and should not focus attention towards a search for an 'organic' cause"*, or his recommendation that no advanced tests should be carried out on these patients when it is those very tests that reveal the organic nature of the disorder (Joint Royal Colleges' Report 1996: CR54).

He refers to his work on vitamin levels without mentioning his disparaging dismissal of vitamin supplementation or his unsupported conclusion that *"many"* people with *"CFS"* are taking vitamin B supplementation with no evidence of benefit (JRSM 1999;92:183-185).

Wessely concedes that he has changed his *"writing style"* but does not appear to comprehend the extent to which his earlier published views are perceived almost universally as being denigratory and sometimes mocking (as is to be found, for example, in the audiotape and his own notes for his 1994 Eliot Slater lecture), nor does he mention the harm in the form of medical rejection and dismissal, as well as the financial hardship, that have resulted from the widespread adoption of his views by the medical fraternity, government departments and private health insurers.

Indeed, he entirely fails to mention his published views, for example: *"neurasthenia would readily suffice for ME"*; *"It seems that ME sufferers prefer to feel that they have a 'real' disease – it is better for their self-esteem"*; *"many patients become...over-sensitised to physical sensations"*; *"Blaming symptoms on a viral infection conveys certain advantages, irrespective of its validity...It is also beneficial to self-esteem by protecting the individual from guilt and blame"*; that patients obtain *"secondary gain"* by *"adopting the sick role"*; that *"fear of illness is an important part of (the disorder)"*; that patients are not suffering from any organic disorder because he believes their symptoms have no anatomical or physiological basis; that *"The term ME may mislead patients into believing they have a serious and specific pathological process"* and that *"Several studies (often Wessely's own) suggest that poor outcome is associated with social, psychological and cultural factors"*.

Wessely says in his account of his involvement with *"CFS"*: *"I remain proud of the work myself and colleagues did in the early days of CFS...But there has been a downside"*, and here he appears to seek sympathy from his readers by referring to alleged threats made to him by *"activists"*.

He continues: *"Right from the start, myself and all my colleagues had from the start (sic) been targeted by a small group of activists who (sic) mission was, and still is, to impede our work in as much as they are able. Thankfully... they haven't succeeded and won't"*.

He goes on to say: *"I do not blame those who repeat some of the things they have read about me....I feel however differently towards those who originally extracted or altered the quotes, and persist in doing so over the years despite knowing that these are wrong"*.

No, Professor Wessely: responsible people who quote your published or recorded spoken words can readily demonstrate that these are not wrong.

He continues: *"So next time you come across something that purports to be an unfavourable or unflattering quote from myself or one of my colleagues, make sure you check it out first with the actual article"*.

For those who wish to “*check it out first with the actual article*” and to verify for themselves the quotations from his own work to which attention needs to be repeatedly drawn but which Wessely now plays down, the full references can be accessed in “Quotable Quotes Updated” (www.meactionuk.org.uk/Quotable_Quotes_Updated.pdf) and in “Magical Medicine: how to make a disease disappear” (www.meactionuk.org.uk/magical-medicine.htm).

Readers of Professor Wessely’s website may not recognise his version of medical history but they may recognise a recurring theme, which is his apparent lack of self awareness.

He presents himself in a heroic role as a patient advocate determined to dispel unhelpful stereotypes whilst, many would argue, he is in fact the source of those stereotypes.

He seems unable to grasp why those suffering from a disease he regards as “*somatisation par excellence*”, whose symptoms he describes as being “*perpetuated predominantly by dysfunctional illness beliefs and coping behaviours*” and whose “[*negative automatic thoughts*] are explained as *distortions of reality*” (Manual of cognitive-behavioural treatment for CFS, Chalder T, Deale A, Sharpe M, Wessely S. 19/6/2002) should fail to be grateful for his interventions.

The essence of his *apologia* may perhaps amount to no more than two lines from a Nina Simone song:

*“But I’m just a soul whose intentions are good;
Oh Lord, please don’t let me be misunderstood”.*