

## Wessely's Words Revisited

Malcolm Hooper 30<sup>th</sup> July 2011

**with acknowledgement to members of the ME community**

Tom Feilden's notably excited introduction to his interview with Professor Simon Wessely about the disorder ME on the BBC's Today programme on 29<sup>th</sup> July 2011 exemplified a failure to exercise the requisite journalistic neutrality when reporting a "story" ([http://news.bbc.co.uk/today/hi/today/newsid\\_9550000/9550947.stm](http://news.bbc.co.uk/today/hi/today/newsid_9550000/9550947.stm)).

Feilden seemed excessively eager to inform the nation about Wessely's claims of how he, a genuine scientist, is harassed and threatened by patients with ME to the extent that his mail has to be routinely scanned before he is allowed to access it and how he needs police protection as he has received death threats.

A dramatic and disturbing story by Wessely, but is it true or is it, as some people believe, an attempt to denigrate sick people and direct attention away from the ever-growing body of biomedical evidence which invalidates his own now-disproven beliefs about the disorder?

When challenged in the past to provide actual evidence – corroborated by the police -- of such threats to his life, did Wessely produce any evidence? The police take death threats seriously so each would be allocated a crime incident number. Have any of these alleged death threats been substantiated? Have there ever been any prosecutions and have they ever been reported in the press?

What must Wessely's "protection" cost the nation in the currently straightened economic climate, and do a few immoderate emails and postings on the internet by desperate patients pushed to the brink by Wessely's consistent denial of the very existence of the disease from which they suffer warrant such costly "protection"?

As for the "threats" allegedly suffered by Professor Myra McClure and Dr Esther Crawley, it seems they may be a matter of interpretation. Quite certainly, it is known that Professor McClure has dealt with a correspondent's valid concerns about her work by sending a receipt six weeks later which said "*Your message was deleted without being read*" (<http://tinyurl.com/3pftbt1>) and Dr Crawley has admitted that she has not received explicit death threats but has interpreted one email in particular to constitute a death threat (<http://www.bbc.co.uk/iplayer/console/b012nlcv>).

Feilden seemed unaware that claiming vilification and abuse by ME patients is a regular pattern of behaviour exhibited by Wessely over the years, usually when yet more published evidence further disproves his belief that ME is perpetuated by patients wrongly attributing their symptoms to a physical disease. At such times, Wessely often appears to deflect media attention away from the emerging biomedical science by portraying himself as the victim of endless harassment from vicious and intimidating ME patients.

Is such behaviour not one of the tactics of denial used by "deniers" and "revisionists" of whatever discipline? It is common practice for "deniers" to claim that "pressure groups" are active against them and are attacking both them and the truth and to claim that there are "orchestrated campaigns" against them ("The Mental Health Movement: Persecution of Patients? Background Briefing for the House of Commons Select Health Committee". Professor M. Hooper; December 2003: [http://www.meactionuk.org.uk/Select\\_CTTEE\\_FINAL\\_VERSION.htm](http://www.meactionuk.org.uk/Select_CTTEE_FINAL_VERSION.htm)).

Can it be co-incidence that this latest well-orchestrated campaign of media coverage of the alleged threats to Wessely and his colleagues who share his views about ME has been mounted hard on the heels of the publication by Carruthers et al of the International Consensus Criteria for diagnosing ME compiled by 26 researchers and clinicians from 13 countries (Journal of Internal Medicine; Accepted Article: doi:10.1111/j.1365-2796.2011.02428.x)?

The sound biomedical evidence upon which those criteria are based completely vitiates the belief of Wessely and colleagues about the psychiatric nature of ME, so what does he do?

He once again claims he is being vilified and threatened by patients with ME and he publicly denigrates and "attacks" them by asserting that they would rather have a disease caused by a retrovirus than admit they suffer from a mental disorder.

There are many who hold that it is Wessely et al who are orchestrating a media campaign against patients with ME, not the other way round.

The campaign to “eradicate” ME by Wessely et al cannot be denied and the documented referenced evidence can be accessed at <http://www.meactionuk.org.uk>

In 1990 Wessely asserted that ME exists “*only because well-meaning doctors have not learnt to deal effectively with suggestible patients*” (Psychological Medicine 1990:20:35-53).

In 1991, he cited medical comments made between 1880 and 1908 on patients with neurasthenia, with the very clear implication that such descriptions apply equally well to today’s ME patients: “*always ailing, seldom ill; a useless, noxious element of society; purely mental cases; laziness, weakness of mind and supersensitiveness characterises them all; the terror of the busy physician*” (BMB 1991:47:4:919-941).

His dismissal and rejection of the biomedical evidence on ME has continued unabated.

On 6<sup>th</sup> October 2003 in her regular column “Doctor’s Notes”, Dr Margaret Cook, former wife of the late Robin Cook MP, wrote an article about Simon Wessely in The Scotsman entitled “ME sufferers have found an enemy in Wessely – so they need friends”, commenting: “*It seems that he has been central to the psychiatric perspective that ME does not exist at all, and that the related “Chronic Fatigue Syndrome” is a mental condition best managed by a psychiatric therapeutic approach....He has downplayed the need for research into diagnostic markers...and such is his influence that no state funding is forthcoming to support any other research than his own....You can tell...that he is used to dictating principles and having everyone in his orbit humbly accept his gospel...When you have enemies like him, you need a powerful lot of friends*”.

Wessely was both hurt and angry by that article and he demanded its retraction and an apology from The Scotsman, which meekly complied and as a result of his threats of litigation duly dispensed with the services of Dr Cook as a columnist.

Of note in relation to Feilden’s broadcast is that in Wessely’s reply to Dr Cook published in The Scotsman, he stated he had spent 15 years of his life looking after sufferers from ME.

That does not chime with the fact that for the most part he has denied the very existence of ME – how many other “caring” doctors have amused themselves by orchestrating a campaign in the BMJ about “non-diseases” and proposed that ME be one of those “non-diseases”, along with freckles and big ears, as happened in 2002?

Patients with ME know what Wessely really thinks about them, as his published views leave no room for doubt or conjecture (for illustrations of his descriptions of ME/CFS patients, see “Quotable Quotes about ME/CFS”: [http://www.meactionuk.org.uk/Quotable\\_Quotes\\_Updated.pdf](http://www.meactionuk.org.uk/Quotable_Quotes_Updated.pdf)).

Later in October 2003, Wessely asserted that those who disagree with him and believe that ME is an organic disorder -- to whom he referred as “*the radicals*” -- are (quote) “*crazy*” and that they are “*engaged in fantasies, lies and gross distortions*”, that the “*radicals*” are left “*fighting yesterday’s battles*” (seemingly because he believes he has established that ME does not exist except as a false belief), that they need a “*reality check*” and “*their behaviour is outrageous*” (private communication).

Those words hardly concur with his claims to be a caring clinician who has looked after people with ME all his professional life.

Responding to Wessely’s claims of vilification and denigration by patients with ME that he made seven years ago, in his letter of 7<sup>th</sup> January 2004 to The Scotsman, Dr John Greensmith pointed out: “*It is deplorable if he has been so treated, no matter how controversial his views. It is instructive, however, to examine how Professor Wessely has raised passions to this level of fervour by, perhaps, more than any other single individual, being responsible for making the area as controversial as it is*”.

Referring to Wessely’s use of the term “*battleground*”, in a letter of 9<sup>th</sup> January 2004 to The Scotsman, DM Jones pointed out: “*It is astonishing that he seemingly is blind to the fact that that this situation has arisen almost entirely due to his own prolific output and that of his like-minded collaborators, denying the existence of ME on the one hand and reclassifying (his) preferred term ‘CFS’ as a mental and behavioural disorder in the ‘WHO Guide to Mental Health in Primary Care’ on the other....Professor Wessely should be held accountable for his own role in this controversy over CFS/ME, which provides the basis for this ‘battleground’ and which has had such disastrous consequences for so many patients*”.

Importantly, as Erik Johnson noted, Wessely has stated: “*Right from the start, ME has been identified with a refusal to accept the doctor’s verdict*” (Co-Cure EDU: 9<sup>th</sup> January 2004). Johnson drew attention to the dictum of

Sir William Osler: *"Listen to the patient. He is telling you his diagnosis"*, commenting that Wessely's name *"threatens to stand as the epitome of physicians who refuse to listen to their patients"*.

In another letter of 9<sup>th</sup> January 2004 to The Scotsman, Dr Joseph Lenz, a clinical psychologist, hit the nail on the head: *"Science has no greater enemies than those who seek to confuse an issue, and those who create the most confusion are invariably those who believe that they already know the truth"* (Co-Cure EDU: 10<sup>th</sup> January 2004).

This being so, can – or should -- one take at face value what Wessely says?

One moment Wessely states, as he did on 12<sup>th</sup> May 1994 in his 9<sup>th</sup> Eliot Slater Memorial Lecture: *"I will argue that ME is simply a belief, the belief that one has an illness called ME"* but ten years later he states, as he did in his article in the Scotsman on 5<sup>th</sup> January 2004: *"I have been saying for 15 years that this is a real illness"*.

Clearly both statements cannot be true.

Presently, Wessely has seized the opportunity to weave the theme of his alleged personal harassment into his responses in the current issue of Nature Reviews Neuroscience published online on 27<sup>th</sup> July 2011 (Viewpoint: Chronic fatigue syndrome: understanding a complex illness: doi:10.1038/nrn3087): in answer to the question *"What is the best way for the field to make progress?"*, his answer was: *"So long as decent clinical and basic scientists continue to engage with the field it will make progress, although sadly that no longer includes myself....The ongoing antagonism that has been directed towards so many of the scientists who failed to replicate the original (XMRV) finding and who thus came up with what the extremists see as the 'wrong answer' has alienated yet another group of scientists from getting involved in this area"*.

What Wessely and the media fail to acknowledge is that it was the utterly triumphant and contemptuous comments of certain of those scientists whose studies failed to replicate the original XMRV study published in Science (2009:326:585-589) that so incensed some people with ME, many of whom have daily to run the gamut of undisguised disdain amounting to abuse meted out by those who are supposed to be supporting and helping them cope with a devastating disease.

In the interests of common justice, Tom Feilden would do well to investigate the reasons why people with ME are so angry by checking the easily verifiable facts and then to redress the balance by reporting with equal enthusiasm the other side of the "battleground" because, compared with Wessely's 25-year campaign of dismissal and denigration of extremely sick people that has resulted in no appropriate healthcare provision and in the relentless harassment by the DWP of people with ME, there may be those who consider that, whilst abusive emails and death threats are never in any circumstances to be condoned, complaints to the GMC are entirely understandable and legitimate.