

Letters to the Editor

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Simon Wessely Follow-up (to article in CFIDS Chronicle Spring 1994 "The Views of Dr. Simon Wessely on M.E.: Scientific Misconduct in the Selection and Presentation of Available Evidence?")

I was deeply saddened by the article that you carried in the Spring 94 issue of The CFIDS Chronicle devoted to my work on CFS/ME (myalgic encephalomyelitis). I do not intend to reply to the distasteful personal comments in the first half of the article. Instead I would simply ask your members to obtain the actual copies of my papers and read them from start to finish. I would be surprised if, having read them, they do not come away with a rather different opinion of my views on CFS. I think an impartial observer would conclude I treat CFS with great seriousness and CFS patients with compassion and dignity. I would only ask them to read the articles in full and not rely on misrepresentation and selective quotations.

What concerns me more is the view that I am "waging a war" against patients with CFS/ME. I run a small, but active, research unit concerned solely with CFS. At the moment we are carrying out inquiries into the endocrinology, epidemiology, immunology, neuropsychology, psychiatry, treatment and virology concerning this condition. I frequently act on behalf of CFS/ME sufferers in their dealings with insurers and the courts -- indeed, I was the principal expert witness in two recent medico legal cases concerning CFS. In the first, the sufferer was awarded £160,000 and the second £320,000. These are the only two cases of their kind in the U.K.

Most important of all is that I run the only free service solely dedicated to the needs of patients with CFS/ME that operates between the River Thames and the Coast. I personally see between 2 and 3 new patients with ME every week, free of charge. Because of our efforts our Health Authority is, as far as we know, the only Health Authority that has now made a contract. Research has shown that our rehabilitation programs are proving successful in decreasing the suffering and improving the general health of CFS/ME patients. If I am indeed "waging a war," as your correspondents put it, this is a very funny way of going about it.

Dr. Simon Wessely
Senior Lecturer in Psychological
Medicine, King's College; London

(The CFIDS Chronicle does not have "correspondents." Each article represents the opinion of the author, as stated in each issue. With the exception of the Association's professional staff all authors are volunteer contributors and are not paid for their services.

It should be noted that many people in England differentiate between "CFS" which, in their view, describes the common symptom of unexplained fatigue, and "ME" which they feel is synonymous with the U.S. term CFIDS. -- Editor.)

Eileen Marshall and Margaret Williams were invited to respond to Dr Wessely's letter:

Having been afforded the opportunity to respond to Dr. Simon Wessely's letter, we wish to make the following points in response. We read his letter with interest, and we hope people will read his published works in full and let his articles speak for themselves. In addition, we recommend that readers compare the articles he references in those works with a comprehensive search of the available literature.

Wessely states that he was "principal expert witness in two recent medico legal cases concerning CFS." In fact, he was 1 of 3 medical expert witnesses in both cases and the £320,000 was an out-of-court settlement. The £162,500 was awarded in the High Court in December 1992. It was subsequently withdrawn by three appeal court judges who accepted Dr. Wessely's testimony, in which he suggested that the plaintiff (a diagnosed ME patient) was "suffering from at least some degree of psychological disorder." This statement was prepared based only on a review of medical records, and not from an examination of the plaintiff. The statement that "these are the only two cases of their kind in the UK" is misleading, as there are at least seven other such cases which have been or currently are going through the British legal system. Apart from the legal system itself, it is important to note that patients with "psychological illnesses" are barred from receiving the higher rates of sickness benefit (*InterAction* 1994:15:55).

Wessely writes "most important of all is that I run the only free service solely dedicated to the needs of patients with CFS/ME." In the UK, there is a National Health Service; this means that *all* patients can receive treatment "free of charge". We wish to point out that there are numerous other NHS consultants who run clinics specifically for ME patients in many regions through the UK, including the area "between the River Thames and the Coast."

Dr. Wessely states that "at the moment we are carrying out inquiries into the endocrinology, epidemiology, immunology, neuropsychology, psychiatry, treatment and virology concerning this condition." To our knowledge, there have been no endocrinologists, immunologists or virologists co-authoring papers with Wessely, but we await with interest the results of this collaboration.

He also claims that "research has shown that our rehabilitation programs are proving successful in decreasing the suffering and improving the general health of CFS/ME patients" but he admits that he does not recognize ME/CFIDS as a distinct entity, but includes all people with unexplained chronic fatigue under the single label of CFS. Therefore we have no accurate idea of how many of his patients actually have ME as distinct from unexplained chronic fatigue. Thus his statement about the effectiveness of his rehabilitation programs needs to be questioned, since patients who do not have ME may well improve with his treatment strategy of cognitive behavioural therapy (CBT), graded exercise and antidepressants. In his paper "Chronic fatigue syndrome: a follow-up study" (*Journal of Neurology, Neurosurgery and Psychiatry* 1994:57: 17-21) Wessely neglects to refer, in either the text or his references, to the Lloyd, et al. study on CBT and graded exercise, which failed to find that such a "rehabilitation program" was of any benefit whatsoever to ME patients (Lloyd, et al.: *Immunologic and psychologic therapy for patients with CFS: a double-blind, placebo-controlled trial. American Journal of Medicine* 1993;94:197-203). There has yet to be a published controlled study which has shown this type of rehabilitation program to be beneficial in ME. While his own (uncontrolled) study suggests that his program is helpful to people with chronic fatigue, the unusually large drop-out rate means that his results are difficult to interpret. Furthermore, it would be normal practice for Wessely to get his patients via a psychiatric referral from a primary care physician. In our view, such patients are not necessarily representative of ME patients. Also, we know that many ME patients have been referred to other psychiatrists and have come out with a clean bill of mental health despite remaining severely ill.

On 12 May 1994, Dr. Wessely gave a lecture at The Institute of Psychiatry called "Microbes, mental illness, the media and ME: the construction of disease." Some of Wessely's comments, which clearly express his views on ME, follow:

"I am going to talk not about an illness, but about an idea ... I will argue that ME is simply a belief that one has an illness called ME. ... The label [ME/CFIDS] spread with even greater alacrity in the States and it is now firmly established. Why?"... "What lies behind all this talk of viruses and immunity?... In consequence, talk of viruses and the immune system is now deeply embedded in popular consciousness ... these links are made entirely explicitly in the States." ... "Does it really matter if the 5-HT neurotransmission is enhanced (that's CFS) or suppressed (that's major depression) ... what's a little up- or down-regulation among friends?" ... "Depression is not the only threat facing the self-esteem of the ME patient ... there is another condition with which ME might easily be confused, and it is hysteria." ... "Viruses are an attribution free from blame ... there's no blame, no shame and no stigma ... and here is the virus research doctor himself to protect us from that shame ... and what is it he delivers? Respect! ... We can therefore understand the delight when another sufferer found out she had a low IgG, probably of no significance, but she knew that the difference between a crazed neurotic and a seriously ill person is simply a test ... Nancy Kaiser [the first Ampligen patient] also rejoiced [when diagnosed], but before

then she had to visit 211 doctors ... you think she might have given up, don't you -- after 100 ... doctors are still the main passport to acceptance and validation of suffering, not least because we control access to support and benefits ... so Nancy Kaiser got her respect, but at what price?" ... "Doctors are entitled to express their scepticism about the status of the diagnosis, and even to suggest that these illnesses are already adequately covered in the psychiatric classifications."

Our own experiences with ME have led us not to share Dr. Wessely's views about it. In addition, Wessely's own colleagues at the Institute of Psychiatry disagree with his view that "viral attribution [reflects] somatization *par excellence*." The state: "We found no evidence to support the somatization hypothesis." (Both quotes from Cope H, David A, Mann A: Maybe it's a virus?: Belief about viruses, symptom attributional style and psychological health. *Journal of Psychosomatic Research* 1994;38(2):89-98)

Furthermore, it is sadly true (and we believe it can be readily demonstrated) that Dr. Wessely has indeed changed the facts about ME, that he has indeed misrepresented the valid findings of other ME researchers and that he does ignore important findings which do not support his own views. Bearing this in mind, we felt justified in querying whether or not this amounts to scientific misconduct.

Eileen Marshall
Margaret Williams

Letter of support for Dr Wessely from Richard Sykes, Director of Westcare (who complied with Wessely's demand and threat of an injunction that the original article be removed from all copies of the Chronicle distributed in the UK by Westcare):

I am writing to express my concern over "The Views of Dr. Simon Wessely on ME" in the Spring '94 issue of The CFIDS Chronicle and to ask you to print an apology.

My concern is that the article goes beyond the bounds of responsible journalism by accusing Dr. Wessely of "scientific misconduct." It is one thing to criticize his views, quite another to make accusations which could be implying professional misconduct.

The article suggests that Dr. Wessely has an unbalanced and one-sided view of ME and that his views and publications have done much damage to ME/CFIDS patients. Extensive evidence is produced purporting to show that Dr. Wessely's views are one-sided.

Whether or not these contentions are true, The CFIDS Chronicle certainly has the right to publish them. If they are true, then the Chronicle is providing a valuable service both to science and to ME/CFIDS patients by publishing them. If they are not true, then it is up to Dr. Wessely or others to rebut them.

Had the article been content to draw the line there, this letter would not have been written. But the article goes on to accuse Dr. Wessely of "scientific misconduct." This is a quite different and, in my view, completely inadmissible accusation. One-sided views are common in science and medicine, also in philosophy, religion, the arts and most areas of human endeavor, especially where there is still much uncertainty. Balanced views are always the ideal, but not all practitioners manage to attain them. Failure to achieve balanced views is not a crime, nor does it imply professional misconduct. Hence, even if Dr. Wessely's views are one-sided, it is not appropriate or admissible to make the much more serious accusation of "scientific misconduct"

There is a further serious aspect to this matter. It is possible that the article could be considered by the British courts as defamatory under British laws. Hence, it is unlikely that any British publisher would be willing to publish it unless they were willing to go to court. It also means that Westcare, which has been circulating The CFIDS Chronicle in Britain, could risk liability to prosecution -- a risk which Westcare as a small, independent charity cannot entertain.

I write, therefore, to express my concern and to ask that you print an appropriate apology to Dr. Wessely in your next issue.

Richard Sykes; Director, Westcare

CFIDS Chronicle Editors' reply to Richard Sykes:

Dear Mr. Sykes:

Please understand that we have not taken your letter or its implications lightly. We do regret any hardship this has caused you as an independent distributor of 35-40 copies of each issue of the Chronicle in England, but we offer no apology.

All articles in the Chronicle represent the opinion of the author(s); this is clearly stated in the disclaimer on the inside front cover of each issue. Further, we believe that the authors of this article made articulate arguments when drawing their conclusions.

You maintain that one-sided views are common and acceptable in science and medicine and, in so doing, you seem to miss the authors' point. How has Dr. Wessely reached his "one-sided View"? With an open mind, honest investigation and authentic use of the scientific method?

The authors contend not. And, if they are correct, he may indeed be guilty of scientific misconduct.

We appreciate that you took the time to express your opinion. If Westcare feels that it will be unable to distribute the Chronicle in the future, we will miss your support. However, we do offer foreign memberships in the Association and encourage all our British readers to join so that they may continue to receive uncensored information. - ***The editors***