

**Open letter to Margaret Cook from Margaret Williams about The Scotsman article
on Professor Simon Wessely**

Margaret Williams

18th October 2003

In his reply (Research goes on), Professor Simon Wessely said that your article “shows the real battle is not between myself and sufferers of ME but between (you) and the facts”.

It seems you have drawn upon yourself the usual threatening salvo which is fired on anyone who dares to doubt the gospel according to Wessely. However, you correctly and bravely identified a significant problem in UK medicine and the ME community is deeply grateful to you. To support your view, you may like to explore some of the “facts” about ME that Simon Wessely and his “school” have produced over the last 16 years. Many of those facts can be found on the website www.meactionuk.org.uk, including the most recent posting which contains Wessely’s own lecture notes from 12 May 1994 in which he spectacularly failed to exhibit any degree of “care” for those with ME, but instead ridiculed and mocked some extremely sick people.

His lecture was audiotaped by more than one person who attended. It is hoped that copies of the tape will soon be widely available as a CD on the Internet, so that those who wish may hear and judge for themselves the exact tone in which the lecture was delivered.

Should there be any discrepancy between his perception of the facts and reality, you might wish in a future article to remind Wessely of the following:

1. He knows he is a hate figure. It would be interesting to consider whether, from a psychiatric perspective, hate figures bear any responsibility for the way in which they are perceived. Given his published record on ME/CFS, he should not be at all surprised that he is hated. If he had written in those terms about people with other neurological disorders such as motor neurone disease or multiple sclerosis, he might well have been up before the GMC on grounds of disregard of personal responsibilities to patients for their care. As a doctor yourself, you know the public are entitled to expect that a registered medical practitioner will afford sufficiently thorough diagnostic investigation. The sheer volume of Wessely’s disparagement of ME is mountainous: much of what he published about ME/CFS between 1987 – 1999 is available as a two-volume compendium entitled “Denigration by Design? A Review, with References, of the Role of Dr (now Professor) Simon Wessely in the Perception of Myalgic Encephalomyelitis” (both volumes can be obtained from DM Jones, 176, Perth Road, Ilford, Essex, IG2 6DZ, UK). What he has published is a matter of factual record and cannot be denied. It is also a “fact” that Wessely is currently a named defendant in a High Court action on grounds which include his alleged breach of duty in connection with investigation of disease and provision of insufficient testing to provide

adequate pathophysiological information on which to base any rational treatment programme.

2. Wessely claims to have spent 15 years of his life “looking after sufferers” from ME yet for the most part, he has denied the very existence of ME: How many other “caring” doctors do you know who amuse themselves by orchestrating a campaign in the BMJ about “non-diseases” and who proposed ME as one of those “non-diseases”, as happened in April 2002? Not content with refusing to accept ME as an ICD-classified disorder, Wessely has hijacked “CFS” as a somatoform disorder which in the UK he has re-classified as a mental disorder in absolute defiance of the mandatory WHO classification of ME/CFS as a neurological disorder. Are these the actions of someone who is “looking after sufferers” ? The inescapable take-home message is that ME is nothing more than an aberrant belief held by those who are over-aware of normal bodily sensations and who are seeking validation of their inability to cope with the modern world. Not only is this seen as downgrading the reality of people’s suffering, but it also impacts forcibly on their ability to survive, because sufferers are denied State benefits as a direct result of Wessely’s “care” and compassion for them. Many have been driven to suicide, not because they were psychiatrically ill, but because they could not survive without support so had no other option. These are facts. The details of these facts have been put before the Chief Medical Officer in person.
3. Wessely claims to have looked for physiological abnormalities but has usually found none, yet other reputable scientists and clinicians have looked and *have* found significant markers of organic disease and have concluded that ME/CFS is a biological, not psychiatric, disorder which urgently requires biological research. When such findings are set against the conclusion of the MRC that there is no need for biological research and that biological research is not worth funding, it is hard to escape the conclusion that Wessely and the MRC are not taking the biological abnormalities seriously and that ME/CFS *is* held by the decision-makers to be a psychiatric disorder. That is an unacceptable level of care and is rightly infuriating to sufferers who are barely alive and to their desperate families who can only watch helplessly.
4. Wessely may claim to take on board the biological findings of others, but the inescapable fact is that his psychiatric lobby is getting £2.6 million to carry out yet more research which he hopes will strengthen his “evidence” (currently very weak) that “CFS” is a psychiatric disorder. Such a degree of funding is not matched in any way by the MRC for research into the biological basis of ME/CFS.
5. Wessely’s ubiquitous misrepresentation of ME/CFS as a psychiatric disorder rests on his own definition of the disorder, not on the facts: the public perception of what is going on is that Wessely’s actions have reinforced the currently prevalent belief that ME/CFS is a psychosocial disorder rather than a biological one, and

this is at the heart of why he is so vilified. This is entirely understandable, because it has been endlessly pointed out to him (supported by hard evidence) that he is wrong, yet he is unmoved. The fact that so many very sick children (and adults as well) with ME still continue to be forcibly removed from their loving parents and home and taken into psychiatric “care” as a result of his doctrine also seems to leave him unmoved, as does the fact that so many ME sufferers have been removed from their GP’s list because of his dogma that there is no such disorder as ME. A fact which seems to have escaped Wessely is that even doctors dare not acknowledge the reality of ME in case they themselves become targets of peer ridicule as a direct result of Wessely’s influence on the “politically correct” medical perception of ME/CFS.

6. You should be assured that if Wessely persists in seeking the withdrawal of your article and an apology from you, the “attacks” upon him would redouble. The ME community (and the Gulf War veterans) would welcome the opportunity to bring everything out into the open, where Wessely might be shown to be a bully who ruthlessly attempts to silence the chronically sick who are so often powerless in the face of power such as that which he wields.
7. If he really does “care” for the suffering sick, it would not be too difficult for him to change the perception which people have of him: all he needs to do is to support and secure the award of a similarly sized grant to the one his own discipline of psychiatry has just received from the MRC and award it to a national ME charity like MERGE to carry on with its work on the vascular disruption it has identified in those with ME. This would go a long way to convince Wessely’s opponents that he means it when he says he does believe there is a physical basis to this disorder even if, as a psychiatrist, he has been unable to verify it himself.
8. It seems unlikely that there is something about ME/CFS patients that makes them especially hostile and unreasonable as opposed to, for example, those with MS or MND. This must therefore reflect the fact that there is an underlying socio-politically driven agenda to deny their suffering, which patients rightly rail against. Wessely’s long-term denial that these patients have an organic disorder (which flies in the face of the now massive evidence that they do) essentially means that he does not believe them. And that does not help them. There is probably a large psychiatric literature on how denying the reality of another person’s suffering triggers deep hostility towards the perpetrator, particularly when the denial results in increased suffering.

The ME community looks forward to another article from you in which you will be able soon to announce that Wessely does, after all, really “care” for those with ME: the proof would be in a substantial award of funding for biological research into ME which he had succeeded in procuring.

We hope you will be able to continue your much-valued support.