4 December 2012

Dear Professor Wessely

I note from recent correspondence arising from the report in the Independent on Sunday on 25 November 2012, that you believe me as guilty of harassing you. Perhaps it is not surprising that I regard this belief with something less than amusement.

I wonder whether you recall the time when you were just getting your initial research into Gulf War Illnesses off the ground in mid-1998? I had given evidence to the Royal College of Physicians and Royal College of Psychiatrists Inquiry on Low Level Exposure to Organophosphate Sheep Dip which was published in November 1998. Your colleague, Professor Anthony David, was a member of the inquiry. I recall receiving a letter from you both to the effect that you were sorry that I had had reason to criticise your Gulf War research in the course of my evidence when, in fact I had not mentioned Gulf War research. You also asked to meet me. I recall correcting you on the facts and stated that I had no desire to meet you. I then received a number of telephone calls and letters, both to my office and my home, demanding that I meet you. I have to say that I regarded this as harassment at the time, though I did not see the need to contact the police. Eventually I agreed to accept your invitation to lunch at Gordon's Wine Bar behind Charing Cross Station.

I brought with me Ms Emily Green, an eminent scientific journalist, with your agreement. I shall never forget being astounded to find that, when we arrived at the appointed time, 12.30 pm, you had arrived early; bought your own lunch, and presented us with a bottle of water. Prior to the meeting you were very firm

about the time, as you had patients to see at 2.00 pm. We discussed a number of topics, including whether you knew Elaine Showalter and whether you had ever advised the Department of Social Security on subjects such as ME. Some of your responses we found were economical with the truth to put it mildly. It was very shortly before 3.00 pm that you finally got to the point – you wanted me to help persuade the Gulf War Veterans to complete your questionnaire!

I think you need to understand that this encounter left a rather enduring and nasty taste in my mouth, not least because I had to buy my own lunch when you had invited me to lunch. Neither was I impressed by your deviousness in response to straightforward questions. This caused me to look more deeply into what you were doing and into your associations, most of which are now public knowledge. This, in part, helps to explain why I have reason to criticise some of your work.

I have also attended some of your lectures and have read reports of others. I have heard and read the extraordinary way in which you and some of your colleagues have denigrated people with ME and have tried (and to some extent succeeded) to persuade others that people with ME are not really ill at all; they merely have 'aberrant illness beliefs'. You have deliberately obfuscated the terminology surrounding ME by linking it with chronic fatigue and attempting surreptitiously to reclassify it as a psychological condition under the WHO ICD classifications. In doing this you appear to have totally ignored the first exhortation to doctors – "First do no harm". Yet when this beleaguered population has reason to look at your work critically you deny what you have said and written and plead persecution and harassment from the very people you purport to be helping. I would have thought that any thinking person would ask themselves why this is happening; would ask the individuals who are clearly angry what is angering them, and try to put things right. You are in an exalted position – a Professor of Psychiatry with all sorts of awards. Why on earth do you need to play the victim?

My personal experience with organophosphate poisoning taught me that there are members of the medical profession who are not prepared to "listen to the patient for they will probably tell you the diagnosis". I am fortunate in that I am articulate and determined and I have been put into a position where I can speak for others less fortunate than I am. If that means offering honest criticism of individuals who, I believe, are hurting others who are not in a position to speak for themselves I am prepared to take any brickbats that come my way.

So much of the friction comes from people not knowing what you think because you are so inconsistent. For example, in your presentation to the full Board Meeting of the DLAAB on 2 November 1993 which was considering those with ME/CFS you said: “Benefits can often make people worse”, yet in your letter to Dr Mansell Aylward at the DSS you wrote: “CFS sufferers should be entitled to the full range of benefits”. Given that, in 1990 you had written: “A number of patients diagnosed as having myalgic encephalomyelitis …… were examined ……..in many of them, the usual findings of simulated muscle weakness were present” (Recent advances in Clinical Neurology, 1990, pp 85 – 131), I am wondering how a genuine condition can also be simulated and am curious to know what your position is regarding benefits for people with ME.

I note that you do not hesitate to condemn statements from your critics as “the same old stuff that they have been saying about me for years”. People with ME could be equally justified in their belief that you perpetuate the beliefs that you have long held that ME is a psychosocial behavioural problem and that you have totally failed to embrace the vast body of peer reviewed scientific literature that demonstrates damage to neurological, cardiac, endocrine and other systems in people with ME. I believe it was you who recommended that GPs should not indulge patients with too many investigations. This has meant that people with conditions that could have been treated have been misdiagnosed and neglected.

I have spoken strongly in defence of people with ME who have been traduced by you and your colleagues who have embraced the psychosocial behavioural model. I am not ashamed of having done so for they have few who will defend them publicly. The scientific evidence is heavily weighted against ME being ‘all in the mind’ so, by deduction it must be the economic argument that prevails, to the disadvantage of the estimated 250,000 people who have ME. have you ever considered the savings to the exchequer and to the insurance industry if people with ME were properly investigated and treated so that they could return to work or education?

I take no pleasure in asking “bogus” questions and making speeches in the Lords. I would very much sooner your profession got its act together and spent some time studying the real effects of ME on patients and looking for solutions. We all recognise that chronic illness, whatever it may be, presents with psychological aspects. CBT can only be a management tool and GET reportedly does more harm than good for patients with ME/CFS as opposed to chronic fatigue.

Patients must be able to trust doctors and scientists. You have betrayed this trust. A scientist should be able to accept honest criticism. You have misconstrued criticism and turned it into harassment. You have much to answer for, so it ill behoves you to employ diversionary tactics in an attempt to portray yourself as the injured party.

I have written this as an open letter because so much of this debate has been in the open. It would be helpful if you would make your position with regard to people with ME/CFS utterly clear. Do you still believe the ME/CFS is "perpetuated by dysfunctional beliefs and coping behaviours" as you wrote in your 2002 CBT Manual for Therapists? If you do, please will you explain why no one got better with your model. If you do not, would it not be sensible for you to withdraw it instead of continuing to make the facts fit your theories as they appear to have been in the PACE statistics where you were in charge of the Clinical Trial Unit.

I look forward to hearing from you.

Yours sincerely

Countess of Mar