



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 examinedin 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

From: Wessely, Simon
Sent: 04 December 2012 17:23
To: MAR, Countess
Subject: your letter

Dear Lady Mar

I received your letter.

You state that “ 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”.

You are referring to the letter published in the Independent on Sunday on Dec 2nd from 25 leading clinicians and academics that was a response to the article of 25th November. I am not an author of that letter, and did not have sight of it before it was sent. I am however informed today by one of the authors that the letter published in the newspaper was not the same as the letter submitted, and that some editorial changes were made. I can see that you might make the inference that you do from the published version, but I am told that was not in the original. I understand that a

correction may be requested. It is anyway a little harsh to blame me for a letter that I neither saw nor signed.

I think we will have to differ on our recollections of our lunch engagement over ten years ago. What I am certain about however is that I have never written to you at your home address, and never called you on the telephone. I have no idea where you live, and no record of your phone number. I do however have the letter that I did write to you before the meeting, which are addressed to the House of Lords. If you are interested I am happy to forward a copy, but I think that anyone reading it would conclude that it was written in a polite and respectful manner. If it was otherwise, I doubt that you would have agreed to meet me. I am afraid that I have not the slightest memory of what we ate or drank, nor who picked up the bill – oddly enough I usually have the reputation of being a rather generous host, but if my manners failed me back then, then I apologise.

If we are going over history, then I wonder what you now think of your speeches in the Upper House reported in Hansard 16 April 2002, and 22 Jan 2004. I attach the transcripts to refresh your memory. By now I hope you realize that you were seriously misquoting and misrepresenting me, although I suspect this was on the basis of inaccurate material provided to you by a third party, and that you would not have access to the relevant sources to be able to check for yourself. If you are still in doubt, then you will find many of these highlighted in a statement on my website in which I point out just some of the significant distortions and misrepresentations in the material you were supplied with.

<http://www.simonwessely.com/misund.html>

Some of your language about me in that debate was also distinctly unparliamentary, and again I suspect was not your voice. I note that Lord Addington speaking after you remarked that that the debate “would make libel lawyers feel like dieters looking in a cake shop window” . I wonder if you in turn regret some of what you said that day, looking back in time as we are.

Yours sincerely

Professor Simon Wessely

Professor Simon Wessely
Vice Dean, Institute of Psychiatry
Head, Department of Psychological Medicine
Director, King’s Centre for Military Health Research
King’s College London

From: MAR, Countess

Sent: 05 December 2012 18:40

To: 'Wessely, Simon'

Subject: RE: your letter

Dear Professor Wessely

Thank you for replying to my letter of 4 December 2012.

I found your response unsatisfactory in that you chose not to answer my questions and instead made derogatory comments about me, about which I will simply say that I am sorry your long-term memory is so selective. However, I can tell you that regarding the letter in the Independent on Sunday signed by 27 of your colleagues, I have received a very gracious apology from Professor White for any inference that may be drawn from it, which I have accepted.

I have no wish to enter into an unproductive and personalised correspondence with you because the issue of how people with ME are treated is far too important to be side-tracked by such diversions.

Instead I will ask you again: the data from the FINE and PACE trials strongly suggest that the psychosocial model of ME/CFS, which you first proposed, is wrong. These were large trials involving several hundred people and which cost the UK taxpayer several million pounds.

In the light of these results, do you still believe that ME/CFS is “perpetuated predominantly by dysfunctional beliefs and coping behaviours”?

If not, do you not have a duty to say this clearly, in plain language, so that other, more productive lines of research can be pursued?

When data suggest a model is wrong it must either be amended or discarded and the data is clear, so what is your intention? The harm that may result from pursuing wrong ideas in medicine cannot be overstated.

In your reply you ask if I regret some of the things I said about you. I have seen and heard nothing that alters what I said in my speech of 16 April 2002 and anything I might have said on the subject subsequently.

What I said does not hold a candle to the scorn and derision that you have poured on people with ME and on the doctors who do not subscribe to the psychosocial model.

Yours sincerely

Mar

See also: "**Bringing in the quacks**".

<http://www.meactionuk.org.uk/Bringing-in-the-Quacks.htm>

In this latest correspondence with the Countess of Mar, Professor Wessely raises the issue of libel: "I note that Lord Addington speaking after you remarked that that the debate "would make libel lawyers feel like dieters looking in a cake shop window" ."

My recollection is that the Countess's remarks were repeated on the BMJ website - and then hastily removed. Apparently she was protected by Lords' privilege, but anyone repeated her words outside Parliament would not be immune from a libel suit.

The Hansard record of the 2002 debate is still available at:

http://www.publications.parliament.uk/pa/ld200102/ldhansrd/vo020416/text/20416-19.htm#20416-19_head0

The 2004 debate is at:

http://www.publications.parliament.uk/pa/ld200304/ldhansrd/vo040122/text/40122-12.htm#40122-12_head0

Lord Addington was in no way supportive of Professor Wessely:

22 Jan 2004 : Column 1190

"Lord Addington: My Lords, one thing is clear: the noble Countess's historical basis for complaint is solid. There is a tremendous tradition, when we do not know the medical or physical causes of something, of bringing in the quacks, to put it bluntly. That has happened on numerous occasions."

"I shall give the House an example to add to the one that the noble Countess gave. Dyslexia is the one that I know most about. I can remember being told in the mid-1970s that my inability to read and write at the same rate as others was due to the fact that I came from a single-parent family. There are others examples, so I suggest that we take a sceptical look at things. With regard to the noble Countess's speech, I suspect that there are many libel lawyers who, on hearing our debate,

will react in the same way as someone on a diet looking at a cake shop window. It is a lovely feast that they cannot get at."

<http://www.meactionuk.org.uk/Bringing-in-the-Quacks.pdf>

From: MAR, Countess

Sent: 12 December 2012 10:36

To: 'Wessely, Simon'

Subject: [My letter of 5 December 2012](#)

Dear Professor Wessely

I am sure you will appreciate the importance of my letter of 5 December 2012. Please will you answer the central question: do you still believe that ME/CFS is "perpetuated predominantly by dysfunctional beliefs and coping behaviours"?

The rancour that persists seems to result from the incompatible and, seemingly, irreconcilable views about why patients with ME/CFS continue to experience exercise intolerance, fatigue, pain and other incapacitating symptoms for long periods following a viral infection or other environmental exposure.

The psychological model, which you first proposed, argues that these symptoms result predominantly from physical deconditioning secondary to fear of activity. Almost without exception, this model is not consistent with the experience of patients with a diagnosis of CFS/ME; nor is it consistent with the data from the FINE and PACE trials, as well as a significant bio-medical evidence base, which all suggest that the patients are correct.

It is my hope that we can find a way out of the current impasse; that we clarify where we agree and disagree, and that we find the means to advance the science of ME/CFS to the benefit of millions of patients worldwide who are now living their lives in the shadows of despair.

I look forward to hearing from you soon.

Yours sincerely

Mar

From: Wessely, Simon
Sent: 12 December 2012 10:50
To: MAR, Countess
Subject: RE: My letter of 5 December 2012

Dear Lady Mar

May I ask, genuinely respectfully, am I writing to you, or am I writing to all the internet?

When you wrote to me, you said it was an “open letter”, and indeed, it appeared on the internet as you sent it me

Personally, I don't particularly like that way of communicating. If I write to a newspaper, or have a paper in a journal, then clearly that is public. But if I write to a private individual, then that is private, unless I indicate otherwise (as you did in your letter to me) or the other person asks for permission to repost, I think the word is.

So if we are to pursue this, can I first of all establish what is the basis of our correspondence. Is it private, or is it public? I can cope with either, but I think it's only fair to both of us to establish which it is.

Simon Wessely

From: MAR, Countess
Sent: 12 December 2012 17:12
To: 'Wessely, Simon'
Subject: RE: My letter of 5 December 2012

Dear Professor Wessely

Thank you for responding to my letter of 12 December 2012.

As this correspondence began with an open letter I believe that it should continue as such. Unless you can give very good reasons why it should not, I can see no reason why your private response should be any different from your public response. Your answer to my question should be the same to whomever you reply.

Much of this debate has been conducted in the public arena, but a public arena from which people with ME/CFS are largely excluded. I am sure that you are aware that they do not have the same

access to press, radio and television as you do. As we are concerned with their health, they should be privy to your honest opinion.

Do you still believe that ME/CFS is “perpetuated predominantly by dysfunctional beliefs and coping behaviours”?

I still look forward to your reply.

Yours sincerely

Mar

From: Wessely, Simon
Sent: 15 December 2012 10:02
To: MAR, Countess
Subject: your letter.

Dear Lady Mar

Thank you for your last letter and the accompanying clarification. I am happy to confirm that I am in agreement that you may publish this correspondence where you see fit.

Now let me address the specific question that you ask. As a part of a programme of research over many years, colleagues and I have shown that perpetuating factors are different from those that trigger the illness. So, when you ask "do you still believe that ME/CFS is "perpetuated predominantly by dysfunctional beliefs and coping behaviours"? my answer is that I think the evidence is compelling that symptoms, disability and distress can indeed be perpetuated by what people believe about their illness and how they manage it. This is true of very many disorders, and says little about what causes illness, but about why some people improve more than others. Turning to CFS I say to patients that having this illness is like being given a certain hand of cards. With that hand, there are better and worse ways of playing the hand. What we can do is help you play that hand better. Continuing the analogy I often add that what we can't do at the moment is give you a new set of cards. And so I say that in my opinion as a researcher and clinician, either CBT or GET are the two ways in which we can currently help you. I share with them that these are currently the best treatments that we have, that they are not perfect, but are safe, and that if it was me, I would try one or the other, but of course it is their choice. This view says nothing about what causes the illness, but speaks to how we can best help patients improve their quality of life now.

In clinical practice I repeatedly see that this approach helps patients. Since there are no other treatments currently available that have been reliably and repeatedly shown to be both safe and effective, I think that opposing their use is unhelpful to patients and their families. And for avoidance

of doubt, and mindful of the communication error with which we began this exchange, may I make it clear that I know that you are not one of those who have opposed making CBT available within the NHS to assist CFS sufferers improve their quality of life, and have indeed supported this. I do believe that this is an area in which there is indeed common ground between us. Likewise, your recent raising in the Upper House concerns about the clinical networks that were established by the last CMO in 2008 but whose future is now in doubt reflects similar concerns that are held by the vast majority of NHS clinicians working in this field and will no doubt be appreciated by patients and practitioners alike.

So this is what I tell patients about CBT and GET at the moment. Like any decent doctor, I will change my views and hence advice when the evidence changes - for example when a different treatment approach proves to be as safe but more effective than either CBT or GET , and indeed would be delighted to so.

Yours sincerely

Professor Simon Wessely
King's College London.

From: MAR, Countess
Sent: 17 December 2012 12:03
To: 'Wessely, Simon'
Subject: RE: your letter.

Dear Professor Wessely

Thank you for your letter of 15 December 2012.

I have read your letter several times and it is still not clear to me whether you believe that ME/CFS can be reversed fully by CBT or GET, as set out in the models described in the PACE trial, published in the Lancet in February 2011, or whether you consider them to be palliative interventions only, to be offered in the hope that they will increase functionality.

You may recall from the Lancet report:

CBT was done on the basis of the fear avoidance theory of chronic fatigue syndrome. This theory regards chronic fatigue syndrome as being reversible and that cognitive responses (fear of engaging in activity) and behavioural responses (avoidance of activity) are linked and interact with physiological processes to perpetuate fatigue.

GET was done on the basis of deconditioning and exercise intolerance theories of chronic fatigue syndrome. These theories assume that the syndrome is perpetuated by reversible physiological changes of deconditioning and avoidance activity.

There is abundant evidence on the record that you did believe ME/CFS to be a somatoform disorder. Is this still the case?

I look forward to a definitive answer.

Yours sincerely

Mar

-----Original Message-----

From: Wessely, Simon

Sent: 21 December 2012 09:15

To: MAR, Countess

Subject: RE: your letter.

Dear Lady Mar,

Thank you for your letter of Dec 17th 2012.

In general I think that CBT/GET improves outcomes in CFS but does not make the majority of sufferers symptom free. I don't particularly like the word palliative in this context, but I think we mean the same thing.

However, on the basis of my extensive clinical experience and the published literature I do know that rehabilitative treatment can in a smaller proportion lead to a resolution of the illness. My hypothesis would be that in these instances the original factors have resolved, but the secondary handicaps of chronic illness remained. I emphasise again that this is not the reason that I recommend CBT or GET to patients.

CFS is not classified as a somatoform disorder. Nor do I believe it should be. In addition, like many of my colleagues in liaison psychiatry, I think that the classification of somatoform disorders is unsatisfactory.

May I take this opportunity to wish you the compliments of the season.

Yours sincerely

Professor Simon Wessely

Professor Simon Wessely
Vice Dean, Institute of Psychiatry
Head, Department of Psychological Medicine Director, King's Centre for Military Health Research
King's College London

-----Original Message-----

From: MAR, Countess
Sent: 21 December 2012 17:41
To: 'Wessely, Simon'
Subject: RE: your letter.

Dear Professor Wessely

Thank you for making your position on CBT and GET clear.

In the spirit of the last full paragraph of my letter to you of 12 December 2012, there is more that I would like to be able to discuss with you. I suggest that we follow-up after the New Year?

I hope you have a peaceful Christmas and New Year.

Yours sincerely
Mar

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