

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