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A TRAVESTY OF SCIENCE AND A TRAGEDY FOR PATIENTS: QUOTABLE QUOTES CONTINUED 2006 – 2016

This document is in 4 sections: Professors Wessely, White, Sharpe and the PACE Trial

Compiled by Margaret Williams December 2016

To assist the reader, as this document is quite lengthy, notable sentences have been highlighted in yellow.

In his power-point presentation on 29th June 2011 about the PACE Trial for the "Forward ME" meeting at The House of Lords, Professor Malcolm Hooper referred to the ME situation in the UK as: "The 3 Ts – Travesty of Science; Tragedy for Patients and Tantamount to Fraud".

The tragedy for ME patients in the UK existed long before the PACE Trial: it has existed for the last three decades. Can it be attributed to the zealous proselytizing by certain psychiatrists – all of whom are involved with the medical insurance industry and who deem themselves "experts" on ME/CFS – to convert non-believers to their own beliefs about the nature of it?

As in "Quotable Quotes Updated" (which provided examples of unhelpful comments about people with ME/CFS from 1988 to 2005 emanating from psychiatrists Professors Simon Wessely, Peter Denton White and Michael Sharpe and can be accessed at www.margaretwilliams.me), this continuation provides more illustrations of their published views on ME/CFS from 2006 to 2016. It is not comprehensive but merely representative.

In order to understand the effect on patients with ME of the Wessely School's beliefs and their total disregard of the mainstream biomedical evidence-base that has been shown to underpin the disorder (evidence which vitiates their beliefs), it is essential to be aware of that evidence-base, particularly of the widespread inflammation and the proven immunological, cardiovascular, endocrine, gastrointestinal and musculoskeletal dysfunction, summaries of which can be accessed at www.margaretwilliams.me

One would have expected that these psychiatrists would have kept up-to-date (which doctors are required to do) but their views have remained intransigent (ie. they continue to insist that ME/CFS is a behavioural disorder and that patients who

believe they suffer from a physical disease perpetuate their own "perceived" ill-health).

Although some of these quotations are from ten years ago, they were published during the planning/execution of the PACE trial, whose interventions of CBT and GET were predicated on these psychiatrists' beliefs.

Introduction

At a lecture in May 1994, Wessely publicly denied the existence of ME, referring to it as nothing but a "belief" and a "myth". He seemed to enjoy mocking very sick people and the ensuing mirth of his medical audience; he even named and was openly scornful of a severely affected woman (who later died from ME). His lecture was audio-recorded, so cannot be denied (see below).

On 6th October 2003, an article in The Scotsman (Doctor's Notes: ME sufferers have found an enemy in Wessely – so they need friends) by Dr Margaret Cook, former wife of the late Robin Cook MP, portrayed the significance of Wessely's role in the misperception of ME/CFS. She referred to Wessely's belief that ME does not exist at all; to his downplaying of the need for research into diagnostic markers; to his insistence that no state funding should be granted for research other than psychiatric studies and to the resultant closing down of the portals, thereby reducing the chance of the broad and open perspective needed to break through the barriers of prejudice and ignorance.

In her article, Dr Cook also referred to an article in the BMJ (May 2003) about doctors' lavishly-generous sponsors, the pharmaceutical companies, and how the medical profession now prostituted itself for funding, and how both treatment and research are distorted as a result. She noted Wessely's response to that article, in which he refused to countenance the possibility of his judgment being swayed by any such paymaster, about which Dr Cook commented:

"You can tell from every sentence of his letter that he is used to dictating principles and having everyone in his orbit humbly accept his gospel. If I needed persuading that the ME community merited my support, this letter and its author would convince me. When you have enemies like him, you need a powerful lot of friends".

On 8th October 2003 Wessely wrote a letter to The Scotsman in response, in which he said: "Margaret Cook's article shows the real battle is not between myself and sufferers of ME but between your correspondent and the facts. I have never suggested that CFS does not exist. Unlike Margaret Cook, I have spent the last 15 years of my life looking after sufferers from this condition. Quite how Margaret Cook thinks that I could block research into this condition is beyond me, but if she had read the recent Lancet editorial I co-wrote with the chief executive of Action for ME, she would have seen a plea for more, not less, research into all aspects of CFS/ME".

An interesting development then occurred: on 11th October 2003 Wessely wrote to a journalist who had published articles on ME/CFS, asking his opinion about Dr Cook's article: "This was published in The Scotsman on Monday. Do you think this is fair comment? I don't think I need to tell you my feelings. This seems to be rapidly spiralling out of control. Your views / advice?"

The journalist replied to Wessely, saying: "You are obviously a hate figure (and) it might be interesting to enquire as to whether hate figures have any responsibility for the way they are perceived. The inescapable take-home message (that has been reinforced by newspaper headlines) is that this condition has a large psychological component, that these people are imagining it, making it up, being hysterical, suffering from neurasthenia etc. And that is not only seen as downgrading the reality of their condition but also has practical implications as far as benefits go.

"Whilst I take your point that you have looked into the physiological side and found nothing, it does seem to be the case that a number of other equally erudite careful scientists have looked there and found something that they do think is significant.

"I have to admit that when you set that body of work against the conclusion of the MRC that the biological area was not worth major funding, it is hard to escape the conclusion that you and the MRC are not taking the biological side seriously and that you do regard this as a psychological condition.

"You may say that you do take on board the biological aspect but the inescapable fact is that you are getting £2 million plus to research more aspects of the psychological side, a degree of funding that is not matched in any way by the funding from the MRC going to the biological side.

"The public perception of what is going on is that your actions on the issue of definition have tended to reinforce the psychosocial basis of the disorder rather than the biological one, which is at the heart of the reason why you have been so vilified.

"My opinion is that you would not improve anything by attempting to take any legal or other steps – you would be further seen as a major establishment figure attempting to silence / muzzle some poor powerless and chronically ill patients.

"A very simple step to change the perception of your position would be for you to give encouragement for a similarly sized grant to the one you have recently received, to look into some of the biological factors.

"It seems rather unlikely that there is something about CFS patients that makes them especially hostile and unreasonable, as opposed to people suffering from heart disease or multiple sclerosis (which) means the level of disagreement over CFS must reflect some underlying issue.

"I'm sure there is a lot of psychiatric literature on how denying another person's reality triggers all sorts of deep hostile responses".

In his response to the journalist, Wessely failed to address the legitimate points raised, but what he did say was astounding. Wessely said he was prepared to sue The Scotsman (Dr Cook's contract was soon terminated). He asserted that he had looked, but had found no abnormalities; he claimed that he had carried out the same tests as the Dundee team (ie. vascular endothelial experiments) and had found nothing. It was not hitherto known that Wessely had carried out studies on ME/CFS patients using a highly sophisticated scanning laser Doppler flowmeter such as that used by the Dundee team, the central point being that if a study has not been published, it effectively has not been done.

Wessely also said he had done work on genes and that all his results were negative. He said he was against the Canadian case definition and claimed the authors were not unbiased scientists (as he was); he said there was no need for any more poor quality science.

He said the whole field had moved forward and that the "radicals" were left fighting yesterday's battles and there was now a remarkable rapprochement between the psychiatrists and the ME charities. Wessely said that it was only a coterie around the Countess of Mar who do not support his views, and that the cause that the radicals are fighting is over. He said the radicals needed a reality check and their behaviour was outrageous; he said that the radicals were crazy and were engaged in fantasies, lies and gross distortions.

The opinion of the journalist was that what Wessely was saying was "bizarre".

Nothing seems to have changed the Wessely School's beliefs about ME/CFS since they came on the scene in 1988 (ie. that there are no physical signs of disease and that there is no pathology causing the patients' symptoms: it is simply that patients are "hypervigilant" to "normal bodily sensations" (The Cognitive Behavioural Management of the Post-viral Fatigue Syndrome; S Wessely, T Chalder et al; In: Post-Viral Fatigue Syndrome, ed. Rachel Jenkins and James Mowbray, John Wiley & Sons, 1991, page 311). That Wessely believes patients' ascription of the disease to a virus is "somatisation par excellence" is a matter of record (J Psychosom Res 1994:38:2:89-98).

Section I: Professor Sir Simon Wessely

Simon Charles Wessely (born on 23rd December 1956) was knighted in the 2013 New Year's Honours List. He is currently President of The Royal College of Psychiatrists and to celebrate his 60th birthday The Royal College adopted a book from the College's antiquarian collection to mark the occasion and to reflect how greatly he is esteemed within his own fraternity: the book is called "Observations on the nature, causes and cure of nervous, hypochondriac and hysterical (patients)".

In July 2017 Wessely assumes Presidency of The Royal Society of Medicine. Commenting on becoming President-Elect, Sir Simon said: "I am delighted to have been elected as President of this very distinguished organisation….I am also proud that I am the first psychiatrist to have received this honour - confirming that psychiatry is literally and symbolically at the heart of medicine." (RSM 22nd November 2016).

Despite the fact that it has long been Wessely's goal to entrench psychiatry into the body of general medicine, many people disagree that psychiatry can ever be at the heart of medicine: given that there are no scientific biomarkers for psychiatric disorders and that diagnosis depends on the psychiatrist's subjective opinion, it cannot rationally be claimed to be an objective science at the heart of medicine.

2006

The act of diagnosis: pros and cons of labelling chronic fatigue syndrome Marcus JH Huibers & Simon Wessely. Psychological Medicine 2006:36:7:895-900

"The ways in which CFS patients perceive themselves, label their symptoms and appraise stressors may perpetuate or exacerbate their symptoms, a process that involves psychological, psychosocial and cultural factors".

"The act of diagnosis therefore seems to be a trade-off between empowerment, illness validation and group support, contrasted with the risk of diagnosis as self-fulfilling prophecy of non-recovery".

"There is compelling evidence that a pessimistic illness perception is an important perpetuating factor in CFS….Several studies found that stronger physical attributions (assuming illness has a physical origin)…predict worse outcome".

"CFS is a mirror of society….Like it or not, CFS is not simply an illness, but a cultural phenomenon and metaphor of our times".

"Labelling physical symptoms as an illness carries the risk of the symptoms becoming self-validating and ….reinforcing illness beliefs".

"CFS…appears to have started from small groups and then spread along the lines of communication and exposure to information, in a similar fashion to infectious diseases".

"Many CFS patients, particularly in hospital settings, share a strong conviction that their symptoms are physical in nature. A plausible explanation is that biological illness attributions provide legitimacy, alleviate personal responsibility and protect against stigma, as opposed to psychological illness attributions. As a result, CFS patients will seek doctors who offer explanations in keeping with their own illness beliefs".

"Without doubt, some doctors are annoyed by the perception of a patient-initiated transgression into the sick role and qualified doctors…judge CFS primarily to be a psychological or psychiatric problem. Patients who present with a self-diagnosis of CFS are regarded as difficult and time-consuming. Consequently, many CFS patients encounter doubts, disbelief and rejection when consulting their physician".

"Diagnosis can provide a refuge that preserves self-esteem (and) offers a socially accepted reason for failure to cope".

The authors conclude by stating their expectation that definitive data which confirms organic pathology in ME/CFS will never appear; they acknowledge the help given by Professors Peter White and Michael Sharpe and, significantly, by Chris Clark of the UK charity Action for ME.

2006

Commentary: Symptoms not associated with disease: an unmet public health challenge
Jane Walker, Michael Sharpe & Simon Wessely. International Journal of Epidemiology 2006: March 1.

"Modern medicine is based on pathological diagnosis. But many patients present with symptoms that lack any identifiable pathology".

"How should their 'medically unexplained' complaints be understood and categorised?"

"Within psychiatry medically unexplained symptoms have been classified under the somatoform disorder label".

"One approach is to treat them as if there is organ symptom pathology and to give 'medical' diagnoses….Another is to assume that they represent the physical presentation of a psychological or psychiatric illness…(mental illness in somatic form)".

"This approach has the potential to lead us to a better understanding of the prevalence of such symptoms unbiased by consulting behaviour".

"These syndromes have a number of associated non-symptom factors in common: female gender, high levels of health anxiety (and) increased symptom reporting".

"Our current classification system and medical-system-based management of these patients must change. Using our current classification system such patients will continue to be referred to multiple specialist clinics"

"This paper reminds us of the value of…research in highlighting the shortcomings of categorising patients to fit with medical specialisation".

Seven references are provided, six of which are self-references.

2006

Chronic fatigue syndrome: an update focusing on phenomenology and pathophysiology Hyong Jin Cho, Anna Skowera, Anthony Cleare & Simon Wessely. Current Opinion in Psychiatry (Personality disorders and neuroses): 2006:19:67-73

"Chronic fatigue syndrome (CFS) is best understood as one of the medically unexplained or functional somatic syndromes (FSSs) (which) include irritable bowel syndrome, fibromyalgia, CFS, multiple chemical sensitivity …(and) more recently Gulf War illness".

"The overall evidence suggests hyperserotonergic state and hypoactivity of the HPA axis. Nevertheless, the question of whether these alterations are a cause or consequence of CFS remains unanswered".

"Immune system involvement in the pathogenesis of CFS is reflected via abnormal cytokine productions, perturbation of natural killer cells, and indication of Th-2-type responses (but)…a couple of recent studies could relate to the alternative hypothesis regarding the relationship between CFS and other FSSs….Recent findings suggest that further investigation is needed on…the overlaps and boundaries among various functional somatic syndromes".

2007

Incidence, Prognosis and Risk Factors for Fatigue and Chronic Fatigue Syndrome in Adolescents: A Prospective Community Study. Katharine A Rimes, Robert Goodman, Matthew Hotopf, Simon Wessely, Howard Meltzer & Trudie Chalder. Pediatrics 2007:119:3: E603-E609

(The synonymous use of the different terms "fatigue", "chronic fatigue" and the "chronic fatigue syndrome" is notable).

"The objective of this study was to describe the incidence, prevalence, risk factors and prognosis of fatigue, chronic fatigue and chronic fatigue syndrome in 11 – 15-year olds".

"This … study provides evidence for an association between emotional/behavioural problems and subsequent onset of fatigue/chronic fatigue".

2007

Handbook of Liaison Psychiatry edited by Geoffrey Lloyd & Elspeth Guthrie. Cambridge University Press 2007. Contributors include Richard Mayou, Simon Wessely, Keith Hawton, Alan Carson, Michael Sharpe, Matthew Hotopf, Christopher Dowrick and Peter Salmon.

The promotion and reviews of this book are glowing: "Medical libraries should stock it" (BMJ); "It will be essential reading for liaison psychiatrists…and service managers. It enthusiastically conveys the excitement and breadth of this developing subspecialty" (Clinical Medicine Journal of the Royal College of Physicians); "It is the first really comprehensive textbook of liaison psychiatry by authors predominantly working in the UK….Were I asked to recommend a single liaison psychiatry textbook…it would be this one" (The British Journal of Psychiatry).

The chapter on "Functional Somatic Syndromes" (pp 125-136) was written by Lisa Page and Simon Wessely.

"Functional somatic syndromes (FSS) refer to a number of related syndromes that have been characterised by the reporting of somatic symptoms and resultant disability rather than on the evidence of underlying conventional disease processes (and) all share the feature of a disconnection between subjective symptomatology and objective biomedical pathology".

"Chronic fatigue syndrome, irritable bowel syndrome and fibromyalgia have been more extensively researched than most other FSS…nevertheless it remains the case that the similarities between the different FSS are sufficiently striking for there to be a compelling case for considering them together".

"Patients with FSS have been rated as one of the three most common types of patients that are 'difficult to help'".

"The tendency of those with FSS to turn to alternative medicines for treatment is likely to be…because alternative remedies often endorse the FSS patient's own physical illness attributions".

"In chronic fatigue syndrome, observations concerning structural brain changes have been inconsistent and will not be discussed here".

2007

The relationship between prior psychiatric disorder and chronic fatigue: evidence from a national birth cohort study. SB Harvey, M Wadsworth, S Wessely & M Hotopf. Psychological Medicine 2007
Doi:10.1017/S0033291707001900

(Note that in the title, the authors refer to "chronic fatigue" but in the text they refer to "CFS/ME").

"There has been a consistent finding of a strong association between CFS/ME and psychiatric disorder…Possible explanations… include… psychiatric disorders having a causal role in the aetiology of CFS/ME".

"The relationships between personality measures, parental psychiatric disorder and a later diagnosis of CFS/ME are shown in table 3….parental psychiatric disorder was more common among those who later reported CFS/ME….It seems likely that psychiatric disorders…have an aetiological role in some cases of CFS/ME".

2007

The South London and Maudsley NHS Trust R&D annual reports by NHS organisations in England for 2007 (Section 2A: Overview of R&D year and examples of impact on health and social care)

"IMPACT OF OUR RESEARCH ON HEALTH AND SOCIAL CARE – SOME EXAMPLES: The examples that follow have been selected to illustrate the breadth of our portfolio of research and evidence-based practice:

"Chronic Fatigue Syndrome: In October 2006 NHS Plus published Occupational Aspects of the Management of Chronic Fatigue Syndrome: a National Guideline. It was accompanied by two leaflets, one for Health Care professionals and one for employers. This report was heavily influenced by research carried out by our Chronic Fatigue Unit.

"The NICE Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) guideline in development also includes priority recommendations to which our research, led by Trudie Chalder and colleagues has contributed: 'When the adult or child's main goal is to return to normal activities then the therapies of first choice should be CBT or GET because there is good evidence of benefit for this condition in mild to moderately affected adults and some evidence in mild to moderately affected children'….We have developed our chronic fatigue syndrome service to include treatment at home (and) we now offer telephone treatment routinely after demonstrating its effectiveness".

2008

'Health for me': a sociocultural analysis of healthism in the middle classes. Trisha Greenhalgh and Simon Wessely. http://bmb.oxfordjournals.org/cgi/content.full/69/1/197

"In this paper, we address what many health professionals see as a common, increasingly uncontainable and personally stressful problem: the beliefs, behaviour and expectations of the articulate, health-aware and information-rich middle classes".

"Writers on healthism…have addressed the various effects of the healthism phenomenon – such as its potential to distort public health priorities…its potential to increase health anxiety through media hype and risk inflation, the potentially huge economic implications of escalating demands for tests and referrals…and its threat to the morale and well-being of health professionals".

"One of us (Wessely) has a long history of engagement with the problem of chronic fatigue and its syndromes".

"Power has long been a critical theme in … the clinician-patient relationship. In the early 1950s, Talcot Parsons argued that the sick individual is granted certain privileges, such as an exemption from usual duties…The doctor is granted the privileges of professional dominance".

"This image prevailed unchallenged for a generation, but sits oddly against contemporary notions of empowerment, enablement, patient choice … and the challenging images and metaphors created by disability rights campaigners and patient-led pressure groups".

"Patient empowerment is a popular theme in both government policy and the health services research literature".

"But…the downside of empowerment can be demanding and manipulative behaviour by individuals for whom 'health for me' takes precedence over any notions of equity, fairness or citizenship".

"Whilst the scientific literature linking stress and the immune system remains speculative (stress affects immune parameters, but there is relatively little evidence that this affects any disease outcomes), the link has become firmly established in popular thinking".

"The common features underlying popular explanations of conditions such as chronic fatigue syndrome…multiple chemical sensitivity, food intolerances and so on, are via the immune system".

"A few decades ago, many of these conditions were more likely to be explained by reference to the endocrine system…but the prevailing folk models have moved on".

"These new 'illnesses of modernity' play a large part in what we call the culture of health".

"Healthism is a well-recognised socio-cultural phenomenon in the western (and westernised) middle classes, characterised by high health awareness and expectations, information-seeking….distrust of doctors and scientists…and a tendency to explain illness in terms of …invisible germ-like agents and malevolent science".

"Healthism…is a common source of irritation and stress to health professionals".

"It has the potential to distort health care provision and effect unnecessary investigations and treatments".

2008

Can talking make you better? Simon Wessely The New Statesman 1st May 2008

"Cognitive behaviour therapy does represent a genuine advance in the treatment of many conditions".

"CBT is directive – it is not enough to be kind or supportive".

"Randomised controlled trials, which remain the gold standard of evidence, have shown that CBT is effective…even (in) disorders such as chronic fatigue syndrome".

2008

'Physical or psychological?' – a comparative study of causal attribution for chronic fatigue in Brazilian and British primary care patients. HJ Cho, D Bhugra, S Wessely. Acta Psychiatr Scand 2008:1-8

(Note that the title refers to chronic fatigue but the text refers to "chronic fatigue syndrome (CFS), sometimes also known as myalgic encephalomyelitis").

"Despite similar levels of current disability, unexplained chronic fatigue patients from two different cultural settings significantly differed in their causal attribution and illness perception".

"There are several possible explanations as to why British patients with chronic fatigue tend to hold physical attributions and also perceptions of longer illness duration".

"In the UK, most media and self-help material provided by patient organisations are more likely to promote physical rather than psychological explanations (and) more British patients were members of a self-help group".

"The health care system, which recognises and labels fatigue as a medical condition, may further reinforce this tendency".

"The greater public and medical sanctioning of CFS/ME and the more favourable economic climate in the UK may lead to greater access to sick leave/benefits for patients with chronic fatigue".

"Previous studies …have reported that social support provided in a way which fosters dependency can help maintain chronic fatigue".

"There is also evidence of an association between so-called 'secondary gain' and health outcomes"

"Therefore the higher availability of sick leave/sickness benefit because of CFS in the UK may both contribute to and reflect the greater 'legitimisation' of chronic fatigue as a medical disorder".

"The findings of this study lend some support to the evidence on the important role of sociocultural factors in shaping illness attribution and perception around chronic fatigue and CFS".

2009

Interview with Simon Wessely by Clare Wilson New Scientist 11th March 2009

"Such symptoms only become a problem when people get trapped in excessively narrow explanations for illness".

"(Patients) can get trapped in vicious circles of monitoring their symptoms (and) restricting their activities beyond what is necessary. This causes more symptoms (and) more physical changes, so much so that what started it off is no longer what is keeping it going".

Asked by Clare Wilson: "How successful is your treatment?", Wessely replied: "Roughly a third of people completely recover and a third show good improvement".

Asked about people who have such severe CFS that they are bedridden, Wessely replied: "In that kind of disability, psychological factors are important and I don't care how unpopular that statement makes me".

Asked: "What is it like to receive hate mail?", Wessely replied: "There have been times when it is pretty unpleasant. But it goes with the territory….What matters is that the research we do is good quality. That's what you stand or fall by".

(This published interview occasioned at least 27 pages of online comments, one of which by Sheila Campbell captured the issue: "It is ironic to read Professor Wessely stating that 'people get trapped in exceedingly narrow explanations for illness' when his theory of the cause of ME/CFS does exactly that").

On 18th March 2009 Wessely provided his response in the New Statesman, in which he drew attention to the (failed) judicial review of the NICE Guideline on CFS/ME:

"One day after publication of the NS interview with myself, Mr Justice Simon handed down his judgment in the judicial review of the NICE Guidelines on CFS/ME. The NICE Guidelines concluded that the treatments with the best evidence of effectiveness for the treatment of CFS are at present CBT and graded exercise. Two patients had challenged the guidelines in court, claiming they were flawed and that those who had created them were biased. Mr Justice Simon unequivocally rejected these claims, adding 'unfounded as they were, the allegations were damaging to those against who *(sic)* they were made, and were such as may cause any health professional to hesitate before they involve themselves in this area of medicine. A perception that this is an area of medicine where contrary views are not to be voiced, and where scientific inquiry is to be limited, is damaging to science and harmful to patients'".

What Wessely failed to mention is that 60% of the claimants' significant evidence was withdrawn at the 11th hour by the claimants' own lawyers because they had been personally threatened by NICE's solicitors with a massive and career-destroying wasted costs order against them or that notwithstanding, Mr Justice Simon imposed a massive £50,000 fine on them.

The claimants' evidence was not allowed to be heard and leave to appeal was refused by Mr Justice Simon, a situation which many continue to believe was a serious miscarriage of justice.

2009

Interview with Simon Wessely by Jeremy Laurance: "What's wrong with you? It depends where you live" The Independent 28th April 2009

"Simon Wessely, professor of psychiatry at Kings College, London, who has studied cultural trends in illness, says: 'People will always seek explanations when they feel under the weather or not quite right. Much of it depends on what is hot in medicine. Each age and each culture has its own answers. Doctors use many different labels to describe patients with unexplained symptoms – somatisation, burn-out, chronic fatigue syndrome, multiple chemical sensitivity, subclinical depression, post-traumatic stress disorder, low blood pressure, spasmophilia – despite no evidence that any of these are distinct or separate entities. Our belief is that most of these labels refer to similar clinical problems' ".

2009

The relationship between fatigue and psychiatric disorders: Evidence for the concept of neurasthenia
Harvey SB, Wessely S, Kuh D, Hotopf M. Journal of Psychosomatic Research 2009: 66(5):445-454

"Fatigue and psychiatric disorders frequently occur comorbidly and share similar phenomenological features. There has been debate as to whether chronic fatigue, or neurasthenia, should be considered an independent syndrome distinct from psychiatric disorders".

"Previous studies have shown that as additional somatic symptoms are added to the diagnostic criteria for fatigue syndromes, the association with psychiatric disorders increases".

"Our results confirm the significant overlap between fatigue and psychiatric disorders".

2009

Chronic fatigue syndrome: identifying zebras amongst the horses Samuel B Harvey & Simon Wessely
BMC Medicine 2009:7:58

"There are currently no investigative tools or physical signs that can confirm or refute the presence of chronic fatigue syndrome….As a result, clinicians must decide how long to keep looking for alternative explanations before settling on a diagnosis of CFS".

"(Compared with a Dutch study, NICE Guidelines) recommend…a more extensive list of blood and urine investigations. Such lists of physical investigations should not detract from the need to consider psychological causes of fatigue".

"A number of prospective studies have given us some knowledge of those at high risk, and which pathways to fatigue seem to be important….This suggests that CFS results from a combination of pre-morbid risk, followed by an acute event leading to fatigue, and then a pattern of behavioural and biological responses contributing to prolonged severe fatigue syndrome".

"Based on this model, the initial cause of the fatigue has a limited impact on the eventual course of the illness. Rather, it is the maintaining factors…that need to be addressed if recovery is to occur".

2009

Tired all the time: Can new research on fatigue help clinicians? Harvey S, Wessely S. British Journal of General Practice 2009: 59:93-100

"The success of interventions like CBT suggests that behavioural patterns…may be particularly important in maintaining fatigue symptoms".

2010

British Medical Journal podcast: http://podcasts.bmj.com/2010/03/05/chronic-fatigue-syndrome
5th March 2010

In this podcast, Wessely said: "We're not going to go doing more and more tests to find out what was the virus because, frankly, even if we found it there's nothing we're going to do about it. We're in the business of rehabilitation".

2010

Conversing with Professor Simon Wessely 29th August 2010 (by cfssufferer)
This correspondence is in three parts: parts 1,2 and 3

http://livingwithchronicfatiguesyndrome.wordpress.com/2010/08/29/conversing-with-professor-simon-wessely-part-2/

Replying to his correspondent, Wessely wrote: "We have not found the divisions of CFS into some of the categories that are proposed by the Canadian criteria to be helpful. In other words they do not seem to create a homogenous group of patients, nor can they be usefully applied in clinical practice. That is the reason why virtually no clinician nor researcher actually uses them".

"I simply do not accept that those who put together the Canadian definition had seen and see a different type of patient to those that we someone *(sic)* mysteriously overlook. Not so".

"I can say that I remain very content and indeed proud of the contribution that I and my many colleagues have made in improving the management of this condition".

"I am afraid that I am no longer involved in the politics of CFS research, and haven't been for many years. I no longer sit on any committees/workshops/conference etc about definitions, grants, research etc….I have handed over the research unit to someone else, and my involvement in research is largely either helping to recruit

patients for other peoples' research studies, or giving advice to PhD students/supervising juniors"

"So my ability to influence the areas that you wish influenced are practically zero – you may perhaps be relieved to hear that".

The same correspondent responded to Wessely, who wrote back: (part 3)

"(re: the Canadian criteria): I don't regard them as a step forward, I don't think they identify a homogenous group of patients, I don't think they are evidence-based, and I don't think they can be operationalised to be used in either clinical or research practice".

"It is essential in any study to make it clear exactly where your subjects come from – without that it is impossible to generalise from any report/paper/treatment….You will see that…we have continued in all our papers to make that distinction abundantly clear".

"If you look at consistency, then the two main findings are an immune activation (the NK cell story doesn't seem to have stood the test of time) and the low cortisol/HPA abnormalities, which definitely have stood the test of time".

"What CBT depends upon is that what starts this off, whatever it is, is not the same as what is continuing to long-term disability….We know that issues such as deconditioning, poor sleep, anxiety, demoralisation, depression and so on all play important roles, and all are potentially treatable/reversible".

"I outlined all that in the very first paper I wrote 21 years ago in which I first proposed that a cognitive behavioural model was a better explanatory model for chronic CFS than the chronic viral paradigm that dominated back then".

"In the intervening 21 years I have seen an awful lot of evidence that supports that model, and not much that doesn't".

2010

Does hypocortisolism predict a poor response to Cognitive Behavioural Therapy in Chronic Fatigue Syndrome? Roberts ADL, Charler M, Papdopoulos AS, Wessely S, Chalder T, Cleare AJ
Psychological Medicine 2010:40:515-522

"Low cortisol is of clinical relevance in CFS, as it is associated with a poorer response to CBT".

"CBT is individually tailored, but important components include changing unhelpful patterns of rest and activity… increasing exercise capacity (and) identifying unhelpful cognition about the illness".

"Not all patients respond to CBT, and several factors are associated with poor response to therapy, including physical illness attributions…and focusing on bodily symptoms".

"We suggest that the additional effects of lowered cortisol make CBT either less efficient or more difficult to implement in these patients. This might imply that such patients require a longer duration of therapy".

2010

Press Release from The Institute of Psychiatry: King's Award for Professor Simon Wessely
24th September 2010 (iop-pr@kcl.ac.uk)

"Professor Simon Wessely was presented with the King's Award for Media Personality of the Year 2010 last night at a reception in the Weston Room, Maughan Library, Strand Campus.

"Professor Wessely said: 'I am pleased and touched by this recognition from King's. It is very important for scientists to engage with the media – to ensure the public has access to accurate, evidence-based scientific information, to keep us ever-present in the minds of policy makers and funders, and to inform public debate' ".

The press release continued:

"Professor Simon Wessely is a trusted port of call for journalists who need an honest and reliable source of information delivered in a way which is meaningful for their audience. He is committed to science communication and sits on the Science Advisory Panel of the Science Media Centre – an independent organisation dedicated to facilitating scientists to engage with the media and improve public access to accurate, evidence-based scientific information.

"Professor Wessely is an asset to King's in its endeavour to disseminate cutting-edge science to the wider public".

2011

Two sides of the same coin? On the history and phenomenology of chronic fatigue and burnout Leone SS, Wessely S, Huibers MJ, Knottnerus JA, Kant I. Psychol Health 2011:Apr:26(4):449-464 (Epub 2010:Apr 29:1-16)

"The origins of CFS lie within medicine, whereas burnout developed in a psychological setting".

"As well as symptoms, burnout and CFS also share similar themes such as…external causal attributions".

"It has been argued that seeking (an organic) illness label, as seen in functional somatic syndromes such as CFS, provides a guard against a psychiatric label for all sorts of reasons: the stigma attached to a psychiatric label, being perceived as a malingerer and the associated illness benefits (eg. disability pensions)".

"Our findings suggest that culture (and) illness perceptions are important issues in both burnout and CFS".

2011

The Foundation for Science and Technology hosted a Dinner and Discussion at the Royal Society on 4th May 2011, the topic being The Future Strategy for the Management of Mental Health in the UK

Simon Wessely's presentation was entitled Health in mind and body: bridging the gap

"50% of all new hospital outpatients have physical symptoms unaccounted for by physical disease".

"Illness is not the same as disease: disease according to medical science is present only when it is medically explained. This difference needs to be recognised".

"Physical symptoms are an ESR/CRP for psychological distress".

"CFS: what do we know? It is perpetuated by behavioural and psychological factors; there is no evidence for chronic infection".

"Why the gap exists: separate commissioning of mental health and physical healthcare services; separate NHS trusts provide physical and mental healthcare; stigmatisation of mental disorders".

2011

Nature online: Ewan Callaway 3rd June 2011

"Wessely says although he is used to being subject to abuse, other researchers were 'absolutely appalled' by their treatment. (He says): 'This will convince another large group of decent scientists to say: oh no, I would rather go find the gene for homosexuality or do work on images of the prophet Mohammed than do this" (ie. than work on ME/CFS research).

2011

Dangers of research into chronic fatigue syndrome. Nigel Hawkes BMJ 22nd June 2011

In an invited Feature article, freelance journalist Nigel Hawkes wrote:

"There are jobs that carry a risk, such as volunteering as a human cannon ball at a funfair….And then there is the job of trying to conduct research into CFS/ME….Patients are incapacitated for years, unable to move, sometimes bedridden and fed through a tube. Yet it doesn't prevent some people, who claim to be its victims, from conducting a relentless personalised attack on doctors and academics who are trying to discover its cause and improve its treatment. Simon Wessely, professor of epidemiological and liaison psychiatry at King's College School of Medicine in London, has been the target of such attacks for years.

" 'It is a relentless, vicious, vile campaign designed to hurt and intimidate', Professor Wessely says. 'For some years now all my mail has been x-rayed. I have speed dial phones and panic buttons at police request and receive a regular briefing on my safety….Since PACE was published, this has become more intense' ".

Hawkes continued:

"The personalised nature of the campaign has much in common with animal rights activists….While the campaigners have stopped short of the violent activities of the animal rights groups, they have another weapon in their armoury – reporting doctors to the GMC….Professor Wessely says: 'With these people, it isn't that they don't want to get better but if the price is recognising the psychiatric basis of the condition, they'd rather not get better' ".

Hawkes concluded his article:

"As for Professor Wessely, he gave up active research on CFS/ME 10 years ago. He now specialises in the problems of war veterans. 'I now go to Iraq and Afghanistan, where I feel a lot safer', he says".

For the avoidance of doubt, from 2001 to December 2016 PubMed lists 71 papers on chronic fatigue syndrome bearing Wessely's name.

He was also involved in the PACE trial, as confirmed in the PACE Trial Identifier, which is unequivocal:

"Section 4. TRIAL MANAGEMENT 4.1 WHAT ARE THE ARRANGEMENTS FOR THE DAY TO DAY MANAGEMENT OF THE TRIAL?

"The trial will be run by the trial co-ordinator who will be based at Barts and the London, with the principal investigator (PI), and alongside two of the six clinical centres. He/she will liaise regularly with staff at the Clinical Trials Unit (CTU) who themselves will be primarily responsible for randomisation and database design and management (overseen by the centre statistician Dr Tony Johnson), directed by Professor Simon Wessely, in collaboration with Professor Janet Darbyshire at the MRC CTU.

"4.4. WHAT WILL BE THE RESPONSIBILITIES OF THE NAMED COLLABORATORS?

"Prof Simon Wessely will oversee the CTU".

It also needs to be recalled that the post of Statistician Clinical Trials Unit Division of Psychological Medicine Ref No: 06/A09 was described as the "Johnson_Wessely_Job" (07/07/2006) at The Institute of Psychiatry where: "The team works under the direction of Professor Simon Wessely, the Unit Director. The team is supported by the regular input of a Unit Management Group from within the Institute of Psychiatry. The statisticians within the Unit also have regular supervision meetings with Dr Tony Johnson from the MRC Clinical Trials Unit. The post holder will be directly responsible to the CTU Manager (Caroline Murphy), supervised by the CTU Statistician (Rebecca Walwyn) and will be under the overall direction of the Head of Department, Professor Simon Wessely".

Ethical approval for the PACE Trial was sought in 2001 and was granted in 2002; recruitment began in 2004 and the trial closed in 2009, with the first (selective) results being published in The Lancet in 2011**. In recent years, Wessely has written a great deal in defence of the PACE Trial in the lay media, including on the internet (see below), so the impression that he left the field in 2000/2001 is inaccurate).**

2011

Chronic fatigue syndrome: understanding a complex illness Holgate S, Komaroff A, Mangan D, Wessely S.
Nat Rev Neurosci. 2011 Jul 27;12(9):539-44. doi: 10.1038/nrn3087.

"Adding more symptoms, such as sensitivity to noise or light, to the current case definition makes the association with recognised psychiatric disorders stronger, not weaker as some mistakenly believe".

2011

BBC Radio 4 Today programme Tom Feilden interview with Simon Wessely 29th July 2011

Feilden seemed excessively eager to inform the nation about Wessely's claims of how he, a genuine scientist, is harassed and threatened by patients with ME to the extent that his mail has to be routinely scanned before he is allowed to access it and how he needs police protection as he has received death threats.

Feilden seemed unaware that claiming vilification and abuse by ME patients is a regular pattern of behaviour exhibited by Wessely over the years, usually when yet more published evidence further disproves his belief that ME is perpetuated by patients wrongly attributing their symptoms to a physical disease. At such times, Wessely often appears to deflect media attention away from the emerging biomedical science by portraying himself as the victim of endless harassment from vicious and intimidating ME patients.

In the interview, Wessely said about people with ME/CFS: "People seem to prefer to be diagnosed with a retrovirus, a potentially incurable, maybe even fatal illness, rather than an illness for which we do have some reasonable but not perfect treatment. That really attests to the strength of feeling here – I would rather have an incurable virus than a potentially curable disorder if the cure was treatment involving any acknowledgement of the social or psychological".

2011

Essay: Mind the gap Simon Wessley The Spectator 26th August 2011

"In 1987 I went to work as a trainee psychiatrist at The National Hospital for Neurology in Queen's Square, London….One of my jobs was to see a group of patients who were not popular with the neurologists who ran the place….The found it irritating that the patients insisted they had an illness called ME….The more I saw, the more convinced I became that the condition was a genuine, serious, debilitating illness".

(For the avoidance of doubt, this should be compared with what Wessely said at his 1994 Eliot Slater Memorial Lecture and with what he said in British Columbia -- see below).

"I started…to try to do better….Our two approaches were named Graded Exercise Therapy and Cognitive Behaviour Therapy. The evidence soon showed that they worked".

"I am proud of what we achieved".

"Three things here anger me. First, the repeated claim that we don't think our patients have an illness. They do, and to say otherwise is insulting. Second, even if you don't think that the treatments we pioneered are for you, it is wrong to try to stop others from benefitting from them…And last, the malign tactics of the minority have helped to delay scientific progress: numerous scientists in other fields, including neurology, immunology and virology, have dipped their toes in the water of CFS, been scalded and given up".

2011

Protesters have got it all wrong Max Pemberton Daily Telegraph 26th August 2011

"It might seem strange that a group of doctors would be subjected to harassment, bullying and death threats for attempting to help people…Yet earlier this month Prof Simon Wessely, a doctor and pioneering researcher into ME, disclosed that he and other scientists working on the condition had received death threats from a small group of protesters who have ME. In addition, the protesters have made complaints to the General Medical Council, universities and ethics committees – all of which have been proved to be baseless – in an attempt to disrupt further work".

"The reason for their behaviour is that research is focusing on the psychological basis of the condition; as a result of the findings, ME is now considered to have a significant psychiatric component".

"Years of research (have) produced underwhelming and inconclusive results to support a bio-medical cause".

"It wasn't until psychiatrists such as Prof Wessely started treating the condition as a mental illness that real progress was made".

"Microbiologists and immunologists have been unable to help ME patients, so psychiatrists have become involved. But that is considered outrageous. People have refused to go to outpatient appointments and refuse treatment, despite evidence that (supervised exercise and talking therapies) work(s)".

"For me, a psychological explanation is a very real one….It is testament…that the mind is capable of such stark physical symptoms. As a model for understanding a condition, it's as valid as any other".

(Note that after three days, this article was amended: "It wasn't until psychiatrists such as Prof Wessely started treating the condition as a mental illness that real progress was made" was changed to: "It wasn't until psychiatrists such as Prof Wessely started treating the condition psychologically that real progress was made").

2011

Hysteria and Myalgic Encephalomyelitis Byron Hyde MD 13th September 2011 (accessed 17th September 2011)
The Nightingale Research Foundation

"Several years ago I was lecturing in British Columbia. Dr Wessely was speaking and he gave a thoroughly enjoyable lecture on M.E. and CFS. He had the hundreds of staff physicians laughing themselves silly over the invented griefs of the M.E. and CFS patients who according to Dr Wessely had no physical illness what so ever but a lot of misguided imagination. I was appalled at his sheer effectiveness, the amazing control he had over the minds of the staid physicians….His message was very clear and very simple. If I can paraphrase him: "M.E. and CFS are non-existent illnesses with no pathology what-so-ever. There is no reason why they all cannot return to work tomorrow".

"The next morning I left by car with my crew and arrived in Kelowna British Columbia that afternoon. We were staying at a patient's house who had severe M.E. with dysautanomia and was for all purposes bed ridden or house bound most of the day. That morning she had received a phone call from her insurance company in Toronto. (Toronto is approximately 2742 miles from Vancouver). The insurance call was as follows and again I paraphrase:

> "Physicians at a University of British Columbia University have demonstrated that there is no pathological or physiological basis for M.E. or CFS. Your disability benefits have been stopped as of this month. You will have to pay back the funds we have sent you previously. We will contact you shortly with the exact amount you owe us".

"That night I spoke to several patients or their spouses came up to me and told me they had received the same message. They were in understandable fear".

"What is important about this story is that at that meeting it was only Dr Wessely who was speaking out against M.E. and CFS and how … were the insurance companies in Toronto and elsewhere able to obtain this information and get back to the patients within a 24 hour period if Simon Wessely was not working for the insurance industry… I understand that it was also the insurance industry who paid for Dr Wessely's trip to Vancouver".

2011

Meta-analysis and meta-regression of HPA axis activity in functional somatic disorders Tak L, Cleare A, Ormel J, Manoharan A, Kok I, Wessely S, Rosemalen J. Biological Psychiatry 2011:87:183-194

"Functional somatic disorders (FSDs) are syndromes of related physical complaints without known underlying conventional organic pathology. The main three disorders are chronic fatigue syndrome (CFS), fibromyalgia (FM), and irritable bowel syndrome (IBS)".

2011

Health in mind and body Simon Wessely. The Journal of the Foundation for Science and Technology Dec 2011:20:7:9-11

"CFS is a multi-factorial illness….To understand why some people do not get better as the months and years go by, one has to look at behavioural and psychological factors. The illness is then a complicated mixture of predisposition, precipitation and perpetuation".

"A landmark trial on the management of CFS, known as the PACE trial, was published recently in The Lancet".

"For those who appreciate these things, the trial is a thing of beauty and the results confirm previous smaller studies and follow ups. We now have two treatments that we can recommend with confidence to our patients".

"However, the story does not quite end there. Patient groups rejected the trial out of hand, and the internet was abuzz with abuse and allegations. The main reason for this depressing reaction was the stigma that attaches to disorders perceived …to be psychiatric in origin".

"If one obtained identical results to the PACE trial, but this time with anti-viral drugs, the reaction would have been totally different. This is exactly what did happen when a very small trial of a drug that modulates the immune system (and which has some nasty side effects) was greeted with acclaim from the same sources that tried to discredit the PACE trial, which tested interventions with an impeccable safety record".

For the avoidance of doubt, there is abundant evidence from numerous surveys by ME/CFS charities of almost 5,000 patients that in such patients CBT is ineffective and GET can be positively harmful.

Those surveys include one sponsored jointly by the ME Association and Action for ME ("Report on a Survey of Members of Local ME Groups". Dr Lesley Cooper, 2000). Cooper found that "Graded exercise was felt to be the treatment that made more people worse than any other" and that it had actually harmed patients.

Another survey of 2,338 ME/CFS sufferers ("Severely Neglected: M.E. in the UK") was carried out in 2001 by Action for ME; its preliminary report stated: "Graded exercise was reported to be the treatment that had made most people worse"; in the final

report, this was changed to stating that graded exercise had made 50% of patients worse.

The 25% ME Group for the Severely Affected carried out a further survey in 2004 which found that 93% of respondents found GET to be unhelpful, with 82% reporting that their condition was made worse.

In 2005, a report ("Our Needs, Our Lives") published by The Young ME Sufferers Trust found that 88% had been made worse by exercise.

In October 2006 the ME Association secured an acknowledgement by NHS Plus – a Government-funded project -- that GET (recommended in the NICE Guideline as part of CBT) can be harmful to people with ME/CFS.

The NHS Plus Guidance leaflets say: "Although some RCTs show evidence of improved functional capacity for work, and reduced fatigue, some patients experience a significant deterioration in symptoms with this intervention". The ME Association noted: "This is a significant acknowledgment by the NHS that GET has dangers to people with ME/CFS".

In 2008, Action for ME published a survey of over 2,760 patients ("M.E. 2008: What progress?") which found that one third had been made worse by GET and that at their worst, 88% were bed/housebound, being unable to shower, bathe or wash themselves, and that 15% were unable to eat unaided. The Press Release of 12th May was unambiguous: "Survey finds recommended treatment makes one in three people worse".

Professor Crawley, a member of the GDG that drew up the NICE Guideline, dismissed the AfME / AYME report's findings, saying the survey was unreliable: "This survey is based on a biased sample of people who have had an issue with treatment and we cannot deduce who had graded exercise therapy delivered by a specialist, as NICE recommends". Her dismissal was notable, given that she was -- and still is -- Medical Adviser to the charity AYME.

On 15th May 2008 a Joint Statement about CBT and GET by the ME Association and The Young ME Sufferers' Trust noted their "serious concern for the safety of patients given this controversial approach to management. Put simply, the illness worsens as a result of physical and mental effort. Advocating progressive exertion is to show a worrying lack of knowledge about the nature of the illness. Any treatment that causes an adverse reaction in 33% - 50% of those using it cannot be recommended as a blanket form of treatment…. We consider this is likely to result in iatrogenic damage to some patients".

In 2009, the Norfolk and Suffolk ME Patient Survey of 225 respondents stated: "Respondents found the least helpful and most harmful interventions were Graded Exercise Therapy and Cognitive Behavioural Therapy".

Hence there is an abundance of patient reports of harm (which are analogous to Yellow Card reporting of adverse drug reactions) from ME/CFS patients and charities (and indeed from NHS Plus) confirming that GET makes people with ME/CFS, including children, worse).

2011

Chronic Fatigue Syndrome: A Personal Story Simon Wessely
www.simonwessely.com/index.php/cfs-personal-story

"Overall, I think that we…achieved quite a lot for the benefit of medicine and patients".

"In 1991 …I set up what was one of the first NHS services exclusively devoted to CFS patients"

"The research and clinical unit was handed over to the more than capable hands of Professor Chalder and her team, and I am pleased to say goes from strength to strength".

"I remain proud of the work myself and colleagues did in the early days of CFS".

"I think that with all my colleagues we made a very positive contribution to improving patient care".

"I still see CFS patients to this day".

"But there has been a downside"

"I do not blame those who repeat some of the things they have read about me, and can understand why they might get angry and upset. Most people do not have the time or access to check each and every quotation for accuracy or context".

"I feel however very differently towards those who originally extracted or altered the quotes, and persist in doing so over the years despite knowing that these are wrong".

"So next time you come across something that purports to be an unfavourable or unflattering quote from myself or one of my colleagues, make sure you check it out first with the actual article. By all means feel free to disagree – that's fine".

"Because in the end science proceeds by debate, discussion and disagreement. What it doesn't do is proceed by distortion".

For the avoidance of doubt, references to the originating source of all quotations from Sir Simon and his colleagues are always provided precisely so that people can check with the actual article.

Where disagreement remains, however, is over the refusal of Wessely and colleagues to consider over 9,000 peer-reviewed papers that prove them wrong about the nature of ME/CFS and which clearly support its organic basis.

2012

The function of "functional": a mixed methods investigation Richard A Kanaan, David Armstrong, Simon C Wessely

(Under "Contributors" it states: "Simon Wessely designed the study and edited the manuscript").

"The term 'functional' has a distinguished history…but has increasingly come to mean 'hysterical'.

"The DSM-V working group proposes to use 'functional' as the official diagnostic term for medically unexplained neurological symptoms (currently known as 'conversion disorder').

"The interviews (with all neurologists in the UK on their use of the term 'functional') revealed four…uses -- 'not organic'; a physical disability; a brain disorder and a psychiatric problem".

"The ambiguity was also seen as useful when engaging with patients".

"Its diversity of meanings allows it to be a common term while meaning different things to different people, or at different times, and thus conceal some of the conflict in a particularly contentious area".

" 'Functional' is a common term for medically unexplained symptoms….It has retained some popularity among neurologists as a medical term for conversion disorder and been found less offensive than some of the alternatives to patients".

"It can, for example, be used to mean a disturbance of body function or it can be used to denote conversion disorder, and by telling a patient they have a 'functional disorder' they may encourage them to contemplate the former meaning, without being aware of the latter…allowing neurologists to use the same term to mean one thing to colleagues and another to patients".

2012

A modern perspective on some of the most highly cited JNNP papers of all time
Simon Wessely
JNNP 2012:83:4-5 (Simon Wessely revisits his own 1989 paper "The nature of fatigue: a comparison of chronic 'Postviral' fatigue with neuromuscular and affective disorders")

"In 1987 I was a senior registrar on the Maudsley psychiatry training scheme when I was moved at short notice up to the National Hospital for Neurology, London….I soon expressed an interest in seeing one group of patients who … were not popular with the neurologists who ran the place".

"I was struck not by the overlaps with muscle disorders but with some of the symptoms I had seen in depressed patients…It dawned on me that I had a wonderful opportunity to test this out".

"There was no instrument available to measure subjective fatigue, so I simply invented one, which would later get modified into the Chalder Fatigue Scale, which also became a citation 'hit' ".

"What we showed was clear….The pattern of fatigue in the CFS patients was different to that seen in …neuromuscular diseases, and instead was similar to those in the affective controls".

"The CFS patients did not show core cognitive features of depression, such as guilt or self-blame. We wondered if this was a reflection of their different pattern of attribution (blaming an external cause, namely a virus)".

"The paper was accepted without revision – 600 papers later that still hasn't happened again. I wasn't aware of citation indices back then, and it was many years before I was aware that it was indeed a citation success".

"Papers were published showing abnormalities in the muscle, but these were most likely secondary rather than primary findings".

"No compelling viral or immunological biomarker has been found …. as we were doing the interviews for the JNNP paper we also collected samples for a blinded study of the VP1 antigen, which had been claimed to be a specific enteroviral marker and a test for 'ME'. That would prove to be one of many false dawns in the story of CFS". (**It was Wessely himself who dismissed it as "unsuitable for routine clinical use":** Lancet 1989:1:1028-9).

"How have I stood the test of time? I had really enjoyed doing the research that led to the JNNP paper….I continued for the next decade to work on problems like CFS and had some success. We showed…that it was not untreatable".

"It wasn't plain sailing though, since it was impossible to get rid of the stigma of being a psychiatrist, which transferred itself to the patients. I found, and still find,

that hard to accept, but it was a fact of life, and I became identified with the 'all in the mind' view of CFS, which was ironic since my interest in the condition was triggered by the fact that I did not think this was an imaginary or non-existent disorder, as many did at the time".

(For the avoidance of doubt, in his 1994 Eliot Slater Memorial Lecture "Microbes, Mental Illness, The Media and ME: The Construction of Disease", Wessely was audio-recorded; moreover, his own lecture notes – annotated in his own handwriting – are clear on the first page: "I am going to talk not about an illness, but about an idea….I will argue that ME is simply a belief , the belief that one has an illness called ME" and on page 5 they state: "I will argue that this line here represents not the line between low and high cortisol responses… but the line between real and unreal illness", whilst on page 6 he mocked people with ME: "There is another condition with which ME might easily be confused and it is hysteria. Hysteria, the mention of the word in the context of ME brings me palpitations and makes me worried about the safety of my family". On page 8 Wessely continued: "How do you prove that you are not hysterical? You must convince the doctor that you really are ill – organically ill – so…the arm becomes more floppy – the leg weaker – the sensory changes more bizarre, yet what is the result of this…the neurologist, who is not a fool, is now more convinced that the problem is functional. How…can you prove the doctor wrong? Well the one thing you might not do is get better, since that might be interpreted…as proof that it was all in the mind after all". On page 11 Wessely said: "No matter how bad doctors are, … sufferers still need to keep going – doctors are still the main passport to acceptance and validation of suffering, not least because we control access to support and benefits", whilst on page 12 Wessely concluded: "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….Each generation will find it necessary to discover its own ME") .

2012

Don't let the implacable few determine what you study View from the top. Simon Wessely
Research Fortnight 28th November 2012

"Since my first publication, back in 1988, on chronic fatigue syndrome, also known as myalgic encephalomyelitis or ME, I and many of my colleagues have been subjected to relentless attacks on our science, conduct and integrity. These have ranged from claims of scientific misconduct, abuse of patients, corruption, theft, conspiracy and much else that would have kept numerous libel lawyers busy, had we been so inclined".

"The rewards, however, have far outweighed the costs".

"Most recently, I was honoured and surprised to be one of two recipients of the first John Maddox Prize for Standing Up for Science".

"Workers in controversial fields need the support of their employers….. If there have been times when either my Trust or university wished I concentrated on a less visible area, they have never shown it. Mine have, for example, instructed lawyers….(and) when a member of The House of Lords used parliamentary privilege to make false allegations about me, they helped me brief other parliamentarians to set the record straight".

"We all have a duty to stand up for science".

Indeed so, thus many people, including scientists, questioned the justification of the award to Wessely. The Declaration of Helsinki requires that "Medical research involving human subjects must …be based on a thorough knowledge of the scientific literature", **but Wessely's work ignores the existing scientific literature on ME/CFS and has been widely described as pseudoscience and "psychobabble".**

On 6th November 2012 it was announced that the inaugural john Maddox prize "rewards individuals who have promoted sound science on a matter of public interest, with an emphasis on those who have faced difficulty or opposition in doing so".

Expressing his opposition to Wessely's model of ME/CFS, Dr Harvey Alter, Chief of Clinical Studies and distinguished investigator at the US National Institutes of Health (one of the world's foremost medical research centres) said in 2010 at an FDA Blood Products Advisory Committee meeting: "I'm absolutely convinced that **when you define this disease by proper criteria, this is a very serious and significant medical disease, and not a psychological disease. It has the characteristics of a viral disease".**

In 2012 the International Association for CFS/ME published its "Primer for Clinical Practitioners" (www.iacfsme.org), the collected wisdom of many experienced clinicians and scientists, with 121 references and contributions by undisputed world experts in ME including Anthony Komaroff, Professor of Medicine at Harvard; Professor Fred Friedberg (New York); Professor Leonard Jason (Chicago) and Professor Nancy Klimas, formerly at the University of Miami and now at the Neuro-Immune Institute on ME/CFS at Nova Southeastern University.

In his Foreword, Professor Komaroff wrote: "What has 25 years of research taught us? Twenty-five years ago we had no idea of the underlying pathophysiology of this illness…Indeed, some clinicians and scientists argued that the illness was probably psychological, and some even argued that it was fabrication: patients were imagining symptoms that had no physiological basis". Komaroff went on to list the proven neurological abnormalities, the impaired energy metabolism, the immune activation, the gene sequencing studies showing the genetic component, and the implications of all these abnormalities for medical practice.

The Primer covers Nomenclature, Epidemiology, Diagnosis, Presentation and Course of Illness, Aetiology, Pathophysiology and Management and states: "The pathophysiological consequences of ME/CFS are multi-systemic and may include: immune and neuroendocrine abnormalities; brain dysfunction and neurocognitive defects; cardiovascular and autonomic disturbances; abnormalities in energy production including mitochondrial dysfunction, and changes in the expression of certain genes".

It then goes on to detail these serious organic abnormalities and the supportive evidence (including brain scans and echocardiography), especially the fact that the immune system abnormalities are associated with symptom severity. It covers management, and notes in particular the problems with Wessely's model: "CBT is a much publicised and debated psychotherapeutic intervention for ME/CFS….The premise that cognitive therapy (eg. changing 'illness beliefs') and graded activity can 'reverse' or cure this illness is not supported by post-intervention outcome data. In routine medical practice, CBT has not yielded clinically significant outcomes for patients with ME/CFS". The Primer discusses gastrointestinal problems, urinary problems, allergies, multiple chemical sensitivity, infections, dietary management, special considerations (including patients who are so disabled that they cannot attend a surgery or hospital, and the need for home-based care-givers as well as support for those care-givers) and follow-up.

The biomedical evidence cannot be ignored by any credible scientist or clinician: the International Consensus Panel Primer is clear: "Activated immune complexes, including elevated levels of various cytokines, cause chronic inflammation….The underlying pathophysiology produces measurable abnormalities in physical and cognitive function and provides a basis for understanding the symptomatology". The Primer includes a concise summary of current pathophysiological findings. It selects patients "who exhibit explicit multi-system neuropathology and have a pathological low threshold of physical and mental fatigability in response to exertion... Cardiopulmonary exercise test/ retest studies have confirmed many post-exertional abnormalities….Myalgic encephalomyelitis is the most accurate and appropriate name because it reflects the underlying multi-system pathophysiology of the disease….Not only is it common sense to extricate ME patients from the assortment of conditions assembled under the CFS umbrella, it is compliant with the WHO classification rule that a disease cannot be classified under more than one rubric….It is counter-productive to use overly inclusive criteria (and) there is an urgent need for ME research using patients who actually have ME….Overly inclusive criteria have created misperceptions, fostered cynicism and have had a major negative impact on how ME is viewed by the medical community…with the result that very significant advances and appropriate diagnostic protocols and treatment protocols have not reached many busy medical practitioners. Some doctors may be unaware of the complexity and serious nature of ME".

The Primer is unambiguous: "Structural and functional abnormalities within the brain and spinal cord are consistent with pathological dysfunction of the regulatory

centres and communication networks of the brain, the central nervous system, and autonomic nervous system….consistent with demyelination or inflammation".

As in the Canadian Guideline, the Primer makes it plain that in ME: "profound dysfunction/dysregulation of the neurological control system results in faulty communication and interaction between the central nervous system and major body systems, notably the immune and endocrine systems, dysfunction of cellular energy metabolism and ion transport, and cardiac impairments…(ME/CFS) is characterised by an inability to produce sufficient energy on demand". These impairments "increase the risk of cardiovascular events".

As with any evidence that disproves Wessely's behavioural model of ME/CFS, this has been consistently ignored in the UK and peons of praise for Wessely flood the literature and the media: accolades included the following:

In a press release about the John Maddox Prize issued by Sense about Science, Tracey Brown (one of the judges), said: "The John Maddox Prize recognises the work of individuals who promote sound science and evidence on a matter of public interest, facing difficulty or hostility in doing so" and she referred to "the courage and responsibility that people are taking for communicating sound science and evidence".

The journal Nature said it congratulated Simon Wessely: "Simon Wessely is a psychiatrist at the Institute of Psychiatry, King's College, London, who has specialised in two areas above all – the mental health of military personnel and veterans, and chronic fatigue syndrome….He subsequently developed a treatment approach using cognitive behavioural therapy techniques…This treatment…can now be found in the guidelines of the United Kingdom's National Institute for Health and Clinical Excellence. 'All along the way', says the individual who nominated him (Wessely's fellow psychiatrist, Professor Anthony David) 'Wessely has had to suffer continued abuse and obstruction from a powerful minority of people who, under the guise of self-help organisations, have sought to promote an extreme and narrow version of the disorder….Hostile letters, emails and even death threats have been directed at Professor Wessely over two decades. Mischievous complaints have been made against him and his clinical team, and bogus questions raised in the Houses of Parliament'".

Writing in support of the award to Wessely, the Editor of Nature and one of the judges, Philip Campbell, said: "We looked beyond communicating for a more unusual degree of courage. The winners of the prize demonstrated the kind of sustained resilience and determination to communicate good science that John Maddox personified" and at the presentation he spoke of the "acute hostility" that Wessely had endured and said he was "a very worthy winner".

Professor Colin Blakemore, a former Chief Executive of the Medical Research Council and one of the judges, said: "…the two winners stood out….Simon Wessely and Fang

Shi-min have worked with courage and dignity to uphold the standards of science and evidence against the forces of prejudice and greed".

Professor Sir John Beddington, then-Government Chief Scientific Advisor, said: "Given the importance of science…it is more important than ever for scientists to speak up and make their views heard. This always requires conviction but often requires real courage too, and I welcome the John Maddox Prize as recognition of that".

Sir Paul Nurse, then-President of The Royal Society, said: "The John Maddox Prize is an exciting new initiative to recognise bold scientists who battle to ensure that sense, reason and evidence base play a role in the most contentious debates. The winners will be an inspiration to us all".

As one UK author, herself an ME sufferer, has commented about the award to Wessely: "It is a dangerous absurdity to reward him – it only perpetuates the damage and nonsense of conflating ME with 'chronic fatigue syndrome'….It's an act of appalling scientific ignorance to give him this prize (and) the continued blinkered back-patting is frankly terrifying" (Nasim Marie Jafry, 8th November 2012).

There is abundant evidence that Wessely's views and influence have necessitated extraordinary courage and determination, not by Wessely, but by ME patients in the face of his orchestrated opposition to the acceptance of their disease as a legitimate medical entity.

As the Countess of Mar commented, the John Maddox prize was "awarded to the defender of a hypothesis with no evidence-base rather than to someone who was upholding true scientific inquiry".

2012

Unity of opposites? Chronic fatigue syndrome and the challenge of divergent perspectives in guideline development Charlotte Smith Simon Wessely JNNP 17th November 2012 Epub ahead of print

"Guideline development by its nature is a process and method of integration and synthesis of information….however it is possible that that the objective and subjective cannot be synthesised".

"An example of where this might be the case has been analysed: a report published by the Scottish Public Health Network (ScotPHN), a Health Care Needs Assessment of Services for people living with ME/CFS".

"We propose that, if followed, this document would lead to the adoption of dangerous diagnostic criteria for ME/CFS…as well as discouraging clinicians from

following evidence-based medicine and recommending proven treatments for ME/CFS".

"This (report's) formal review of healthcare needs was commissioned by the Scottish Government to undertake a review of the scientific literature…and to establish the needs of people with ME/CFS….This has potentially important implications for subsequent commissioning and funding of services by NHS Scotland. The ScotPHN's aim was to complete a national project of needs assessment that would incorporate the views of clinicians and patients from across Scotland".

"Unfortunately, it is our view that this report does not help resolve the controversy and may further confuse both patients and clinicians….We argue that the results are unsustainable conclusions, with implications that are at best misleading and at worst harmful for patients and clinicians".

"The ScotPHN report has recommended that Scotland uses two separate categories for diagnosis, one diagnosis of ME/CFS based on the NICE 2007 criteria, and a separate diagnosis of ME based on the Canadian Consensus Document Criteria….(which) 'emphasises the neurological features of the condition and the post-exertion fatigue/malaise which more psychiatrically-based definitions under emphasise' ".

Wessely and his co-author then devote much space to robustly dismissing the Canadian Criteria and the international experts who formulated them, asserting that: "Many of the recommendations …made in the document are not supported by published or peer-reviewed evidence….The process of developing (them) is in itself flawed, a result of patient group pressure on politicians…leading to a one-sided document".

Wessely then draws on the input of the Scottish Neuroscience Council: "The Scottish Neuroscience Council takes the view that the 'hard' neurological signs of ataxia or fasciculations never occur in ME". Wessely supports this assertion by relying on a reference from his own wife, Dr Clare Gerada, who wrote to the Council condemning the ScotPHN report.

"If one accepts, as most neurologists do, that some of the signs and symptoms that are held by the Canadian consensus criteria to be incompatible with a diagnosis of ME/CFS, then the adoption of those same criteria by the ScotPHN Health Care Needs Assessment Group encourages poor practice and would, if implemented, have a detrimental impact on patient care".

Wessely and Smith then go on to extol the virtues and safety of CBT and GET, claiming there is no evidence to overturn their own observations: " 'CBT and GET can safely be added to specialist medical care'….The issue of safety is now resolved beyond reasonable doubt – all four management approaches (in the PACE trial) had an excellent safety profile".

"We think there is a case that…the ScotPHN did not reflect a fair and balanced summary of the evidence….The conclusions drawn in this report would also deprive Scottish clinicians who wish to follow evidence-based medicine the ability *(sic)* to access these treatment for their patients by hindering their commissioning".

"The ScotPHN appear to have marginalised psychiatric and psychological perspectives of ME/CFS".

"When making recommendations regarding the multi-disciplinary teams, the report states that consultant clinicians for a specialist ME/CFS service could be recruited from 'clinical neurology, rehabilitation medicine or infectious diseases specialists', with no mention of psychological medicine".

"If the guidelines were to be implemented and/or widely disseminated, Scottish sufferers from ME/CFS would not be able to make an informed choice about treatment, let alone access the same treatments as patients in other parts of the UK".

Then, in ironic denial of the fiasco that resulted in the production of the 2007 NICE Guideline on CFS/ME (from whose Guideline Development Group the Medical Advisor to the ME Association was expressly excluded), Wessely and Smith state: "Guidelines and assessment should be focused on what benefits patients".

"Although guidelines should attempt to integrate…subjective experience into the literature, this should not skew or outweigh the scientific evidence base".

"There has been an apparent exclusion of a large and helpful wealth of literature, and this cannot be a basis for a review of an impartial evidence-base".

Wessely and Smith conclude that there has been "a less than helpful interaction between politics and science, and one in which the former has outweighed the latter".

2013

Research in Chronic Fatigue Syndrome – ups and downs; Bristol Medico-Chirurgical Society; 13th March 2013: Simon Wessely (approved as a Continuing Professional Development module for doctors).

At a medical meeting in March 2013 held in Bristol, staring with a photograph of himself as a young psychiatrist outside the National Hospital for Nervous Diseases in 1987, Wessely described his personal experience of researching, treating and thinking about CFS. He claimed that he played a significant role in identifying CFS/ME patients as actually "being ill", as opposed to "making it all up". To make his story more persuasive, he left out all reference to the developments in biomedical research.

He informed attendees that ME has been caused almost entirely by what he called the "shockingly" negative way in which some ME charities, in particular the ME Association (but also the media) portray it as a viral illness, saying that this had harmed patients as it encouraged them to focus too much on symptoms and to be fearful of activity, resulting in a vicious cycle of deconditioning. He was especially critical of patients being advised to rest, claiming that this led to patients being over-attentive to symptoms and becoming afraid of activity and therefore avoiding it.

He emphasised that the more symptoms a patient had, the greater the likelihood that s/he had psychological problems.

Speaking about children with ME/CFS, Wessely said he didn't need to see children, as he could treat them just by talking to the parents.

Making no distinction between chronic "fatigue" and ME/CFS, the audience of medical doctors was assured by Wessely that all patients with CFS – including the severely ill -- would benefit from the same management regime, namely behavioural therapy and exercise.

The talk ended with an old student friend of Wessely's singing a ridiculing and lewd song which seemed to have been written by Wessely and seemed to be about people who were considering sex change surgery and joking that Wessely should know better how to hold a microphone, demonstrating "as if he was going to fellate it".

At least some attendees found the whole experience deplorable and some doctors themselves were embarrassed by what had occurred.

It is inescapable that, despite Wessely's overt support for people with ME/CFS when it suits him, in reality he continues to denigrate them.

(A similar talk was given by Wessely in Brighton).

2013

Hate Campaign Michael Hanlon The Sunday Times 5th May 2013

"The most high profile combatant of the ME war in Britain is Wessely….It is perhaps his impiety that has got him into trouble. 'It is a religion, they have saints and apostates' he says. As for the 2009 XMRV paper, Wessely snorts with derision".

It is Wessely's often-unconcealed "derision" directed towards people with ME -- a disease from which people die and which appears on Coroners' death certificates as the cause of death -- which arouses such anger, an anger that is not confined to

patients in the UK but encompasses medical scientists in other countries whose decision-makers have come under Wessely's thrall.

2014

The Maudsley Handbook of Practical Psychiatry Paperback 11th September 2014
Editors: Gareth Owen, Simon Wessely and Robin Murray

"Somatisation is the expression of emotional distress in physical terms, with medical help-seeking".

"Always take a history of previous contacts with the medical profession….If the patient receives an endless series of negative physical investigations, it is only a matter of time before s/he develops a chronic form of somatisation disorder. Patients attending specialist clinics with labels such as ME or chronic fatigue syndrome…have a gloomy outlook associated with the strength of their physical illness convictions and the degree of avoidance behaviour".

"Further investigations will reinforce the sense that something organic is wrong".

"Management has several purposes: first, to engage the patient in some form of dialogue (and) secondly, to reduce further doctor visits and medical investigations".

"You are not taking a history for diagnostic purposes, but so that the patient feels you have listened".

"Supportive psychotherapy involves seeing the patient regularly, but not in response to symptoms".

"The guiding principle is to empower patients to take back responsibility for their illness and recovery…but without harbouring any guilt or blame for becoming ill in the first place".

"If the patient has a specific illness belief ('ME')…do not question this…Do not dispute the condition by saying 'This illness doesn't exist'!".

As one informed scientist observed on reading this, since when was it considered OK to encourage doctors to openly manipulate patients and dismiss the physical reality of their suffering?

2016

Bad science misled millions with chronic fatigue syndrome. Here's how we fought back

Julie Rehmeyer https://www.statnews.com/2016/09/21/chronic-fatigue-syndrome-pace-trial/

(Selective results of the PACE Trial were published in February 2011 but attempts to obtain the raw data from the PACE trial for independent professional analysis were unsuccessful until autumn 2016, when the data were released only after a UK court order. The PACE Investigators initially published results based on thresholds that deviated substantially from their published protocol, claiming "recovery" rates of 22% for GET and 22% for CBT. However, when re-analysed independently according to the Investigators' published protocol, 13% of participants at baseline simultaneously met the trial entry criteria for "significant disability" and the revised "recovery" criteria; importantly, the rates for GET were in fact 4% and for CBT 7%. This means that the Investigators had inflated their results by an average of four-fold. It also means that "recovery" rates for CBT and GET were not statistically significant, as the substantial changes made by the Investigators once the trial was well under way resulted in the "recovery" criteria becoming too lax to allow conclusions about the efficacy of CBT and GET as rehabilitative treatments for ME/CFS. The independent analysts commented: "The PACE trial provides a good example of the problems that can occur when investigators are allowed to substantially deviate from the trial protocol without adequate supervision of scrutiny").

"Simon Wessely, president of the UK Royal College of Psychiatrists, defended the trial in an email exchange with me. He argued that some patients did improve with the help of cognitive behavior therapy or exercise, and noted that the improvement data, unlike the recovery data, was statistically significant. "The message remains unchanged," he wrote, calling both treatments "modestly effective."

"Wessely declined to comment on the lack of recovery. He summarized his overall reaction to the new analysis this way: "OK folks, nothing to see here, move along please."

A comment on the STATSNEWS site on 25th September 2016 said: "Simon Wessely is at pains to distance himself from involvement with the PACE trial, but once again he seems to have overlooked the facts".

The comment provided evidence of Wessely's role in overseeing the trial statisticians and observed:

"Despite the fact that the post-hoc changes showed reported results that were up to five times better than those derived from the original protocol, you continue to defend what has been described by many as "fraud" in the PACE trial. Can it be said that the President of The Royal College of Psychiatrists condones what is widely considered to be scientific fraud?" http://www.margaretwilliams.me/2016/comment-statnews-sep2016.pdf

Section II: Professor Peter Denton White OBE

In 2004, Professor Peter Denton White was awarded an OBE for "services to medical education"; notices circulating at the time proclaimed him as leading the research into "CFS/ME" and said his OBE was "a well-deserved honour and acknowledgement of his contribution to work on CFS/ME".

He was born in November 1952: aged only 64, he suddenly retired from clinical practice just before he was compelled by a court order to release the raw data from the PACE trial, so any investigation by the General Medical Council for alleged professional misconduct is unlikely to be pursued, but is he guilty of misfeasance in public office?

According to the Crown Prosecution Service (CPS) website, misfeasance in public office is a cause of action in the civil court against the holder of public office, the allegation being that the office-holder has misused or abused their power: such misuse or abuse is an affirmative act that causes harm to another party without reasonable justification. The NHS is a State body as it provides public health care, so this matter is one in which the public has a significant interest.

Facts to be considered

1. Peter White has used his own money, as well as charitable money and public money, in order to lobby support for his belief that ME/CFS is a psycho-behavioural disorder that can be overcome through "cognitive restructuring" and graded aerobic exercise

2. he has egregiously used large sums of public money (£250,000) to prevent the disclosure of data that would falsify his belief

3. for nearly 30 years, he has ignored evidence that disproves his belief, including evidence from his own clinical trials

4. he has failed to correct errors of fact after being alerted to them

5. he has consistently failed to disclose significant financial, institutional and ideological conflicts of interest

6. he has been in breach of his NHS contractual obligations in that he has persistently ignored mandatory directives and has wilfully encouraged other clinicians to do the same

7. as a consequence of his actions:
    - money which should have been used for biomedical research into the aetiology of ME/CFS has been diverted to fund studies into therapies which were already known to be ineffective and even harmful

- patients have been stigmatised as sociopaths and malingerers who refuse to accept that they have a behavioural disorder
- patients have been denied financial support from private insurers for whom Peter White and his colleagues work (for example, he was Chief Medical Officer for the giant re-insurer Swiss Re and was also CMO to Scottish Provident) and from the Department for Work and Pensions (where he was lead advisor on "CFS/ME" and was a prominent member of the group who re-wrote the chapter on "CFS/ME" in the DWP's Disability Handbook used by Examining Medical Practitioners, by DWP decision-makers and by members of the Appeals Services Tribunals); he also works for the US Centres for Disease Control, and for defendants in legal actions (BMC Health Services Research 2003:3:25)
- patients with ME/CFS have been wrongfully sectioned and detained under the Mental Health Act
- clinicians who oppose his views about ME/CFS have been sanctioned by the General Medical Council and prevented from working.

On 11th January 2002 the Chief Medical Officer's Working Group (from which Peter White and Trudie Chalder – another PACE Principal Investigator – resigned because they did not get their own way about classifying "CFS/ME" as a behavioural disorder) published its Report. Speaking in support of those with ME/CFS at the launch of the Report, Professor Sir Liam Donaldson, Chief Medical Officer, said on the record: "CFS/ME should be classed as a chronic condition with long term effects on health, alongside other illnesses such as multiple sclerosis and motor neurone disease" (BBC News / Health: 11th January 2002).

That same month, on 31st January 2002, a company called One Health (company number: 04364122) was incorporated to act as a lobby group in order to achieve Professor Peter White's lifetime goal. He was Chairman of One Health and his fellow Directors included Trudie Chalder. It was described as a company that (quote): "was established in order to promote a system of healthcare based on the biopsychosocial model of ill-health".

Of significance is that One Health's registered address was 100 Fetter Lane, London, the same address as the company's lawyers -- Messrs Beachcroft, the same lawyers who acted for NICE in the 2009 Judicial Review of the NICE Clinical Guideline on "CFS" and who threatened the Claimants' lawyers with a massive wasted costs order unless most of the Claimants' evidence was withdrawn. (The evidence was that members of the Guideline Development Group were carefully selected because of their support for the psychosocial model of ME/CFS, even to the point that the Medical Advisor to the ME Association was rejected as a member, so the outcome – the recommendation of CBT and GET -- was a foregone conclusion).

One Health was supported to the tune of at least £100,000 by the Andrew Mitchell Christian Charitable Trust, based at The Grange, St Peter Port, Guernsey (a significant financial interest which it seems Peter White has never declared).

The Memorandum of Association of One Health stated:

1. The name of the Company is 'One Health'
2. The registered office of the Company will be situated in England and Wales
3. The objects for which the company is incorporated are to carry on all business associated with the establishment and promotion of a system of healthcare based on a biopsychosocial model, being a model that incorporates thoughts, feelings and behaviour with a physiological approach to health and illness; such establishment to include, without limitation:

3.1 research into the biopsychosocial model of healthcare by active promotion of the biopsychosocial model amongst healthcare professionals, patients and others, using evidence and influence;

3.2 the education of healthcare professionals in relation to the biopsychosocial model; and

3.3 publicising, through any medium thought appropriate by the Company, the biopsychosocial model.

Members of the One Health company are on record as being actively involved in social engineering via the deliberate creation of "psychosocial" illness. They believe that the biomedical approach to healthcare is "*a blind alley*" and that the correct approach to illness – whatever its provenance -- is the psychosocial one, in which thoughts, feelings and behaviour can be modified by cognitive behavioural therapy with graded exercise, resulting in restoration of health and productivity.

Many people believe it to be a retrograde step to reject the hard-earned scientific evidence -- gained over centuries -- that ill-health is directly caused by disease and its pathological processes and to revert to blaming ill-health on aberrant beliefs instead of pathogens.

The proceedings of the One Health conference held in 2002 were published in a book entitled "Biopsychosocial Medicine: An integrated approach to understanding illness" edited by Peter White, Professor of Psychological Medicine at St Bartholomew's and the London, Queen Mary School of Medicine, published by Oxford University Press (2005).

The reviewer (Craig Jackson, Professor of Occupational Health Psychology at Birmingham City University) commented about Wessely's Foreword to the book: "Wessely's foreword uses the local geography around Denmark Hill, with the Maudsley Hospital and the Institute of Psychiatry situated across the road from King's College Hospital as a good metaphor concerning the opposition of the soma from the psyche. He almost completes it without a dig at the Chronic Fatigue fraternity – succumbing in the end".

One contribution in particular stands out: that of Professor Trudie Chalder (to whom, it will be recalled, Simon Wessely handed over his Chronic Fatigue Unit at King's College Hospital); her words were chilling. Following a question from Douglas

Drossman (Professor of Medicine and Psychiatry, University of North Carolina, USA) who asked about the best ways of indoctrinating people with the psychosocial model of illness: "Is there a way to communicate these ideas to the people involved with running medical schools? Often, the problem is in changing the behaviours of physicians at practice who are 50 years old. It may be much easier to start with new medical students. We want to begin with them", Trudie Chalder made a truly disturbing contribution: "Rather than start with the physicians, which might be quite a difficult task, we could make a start with youngsters in schools. My experience is that they are much easier to educate. The only barrier is the parents. Once we have the child on our side we are in a very good position".

Professor Chalder is a committed devotee of the psychosocial model of all illness and fervently believes that CBT is a cure-all. For example, she believes that CBT has a role to play in the control of diabetes: CBT "is showing promise in more unlikely fields. Several studies have shown that it can improve the prognosis for some cancers and this week, Professor Trudie Chalder, of King's College, London, announced that it can help people with type I diabetes. Though her study has not yet been peer-reviewed or published, Professor Chalder described the results as positive" (The Times, 15th September 2007).

Professor Chalder's beliefs about "CFS/ME" are unambiguous: in 2007 the newly convened Biomedical Research Unit at the Institute of Psychiatry funded a project called "Emotional Processing in Psychosomatic Disorders". The Section of General Hospital Psychiatry at the IoP advertised for a psychology graduate to work on the project, which would "involve working across the Section on Eating Disorders and the Chronic Fatigue Research and Treatment Unit". The closing date for applications was 13th July 2007. The job reference was 07/R68. The advertisement said: "The post holder will work under the immediate supervision of Professors Ulrike Schmidt (AN) and Trudie Chalder (CFS)".

The study literature stated: "The comparison with CFS will allow (researchers) to gauge whether any social cognition deficits are unique to anorexia, or reflect more global symptoms of psychiatric illness with marked physical symptoms". So, according to one of the MRC PACE Trial Principal Investigators, "CFS" is "a psychiatric illness with marked physical symptoms". Applicants were informed that: "Aberrant emotional processing is a strong candidate as a maintaining factor for these disorders" and the background to the project stated: "Anorexia Nervosa (AN) and chronic fatigue syndrome (CFS) are classical psychosomatic disorders where response to social threat is expressed somatically".

An Action Plan for one of Chalder's patients is unambiguous about the proposed intervention: "We expect XX to protest, as well as the activity causing a lot of pain. This may result in screams".

Other IoP job advertisements for "CFS" that can be found on the website include one for a "Cognitive Behavioural Psychotherapist", accountable to Professor Trudie

Chalder, which requires the applicant to possess "an understanding of the needs of people with mental health problems".

Peter White's influence encompasses the General Medical Council; the Medical Research Council; the Department of Health; the Department for Work and Pensions; the Scottish Chief Scientist's Office, NICE; the Medical Royal Colleges (in the 2005 Update for the MRCP examination, chronic fatigue syndrome is listed under "Psychiatry"); the Royal Statistical Society; the Royal Society; the Science Media Centre; The Lancet and other medical journals; the mainstream media; the (supposedly impartial) Cochrane Review (that found in favour of GET, a review which Peter White appears to have partly funded himself, just as he part-funded the Oxford criteria used in the PACE trial) and The Houses of Parliament, where there is a misleading record in Hansard about the outcome of the PACE trial: on 6th February 2013 there was a "debate" on the PACE trial in the House of Lords for which, on his own admission, Peter White briefed all those who spoke in support of it, with the intended result that the study was enshrined in Hansard as an officially-recorded success story:

"I have had to provide responses to Parliamentary Questions from members of both Houses of Parliament to allow them to understand the nature and findings of the PACE trial. In particular, I had to recently brief several members of the House of Lords so that they might speak in a critical debate about the Pace trial held on 6th February this year (exhibit C)" (Peter White's evidence to FOI Tribunal on 28th June 2013).

Knowingly misleading Members of Parliament is a serious offence.

Peter White received over £5 million to carry out the PACE Trial but he was already aware that ME/CFS patients without a comorbid psychiatric order do not have an exercise phobia: "Fatigue was not caused by current level of inactivity" (J Psychsom Res 2005:58:4:367-373) and furthermore, he knew that there are serious immunological disturbances in ME/CFS patients that are related to inflammation and exercise:

"Immunological abnormalities are commonly observed in CFS…Concentrations of plasma transforming growth factor-beta (TGF-β) (anti-inflammatory) and tumour necrosis factor-alpha (TNF-α) (pro-inflammatory) have both been shown to be raised….Abnormal regulation of cytokines may both reflect and cause altered function across a broad range of cell types…..Altered cytokine levels, whatever their origin, could modify muscle and or neuronal function.

"Concentrations of TGF-β1 were significantly elevated in CFS patients at all times before and after exercise testing.

"We found that exercise induced a sustained elevation in the concentration of TNF-α which was still present three days later, and this only occurred in the CFS patients.

"TGF-β was grossly elevated when compared to controls before exercise (and) showed an increase in response to the exercise entailed in getting to the study centre.

"These data replicate three out of four previous studies finding elevated TGF-β in subjects with CFS.

"The pro-inflammatory cytokine TNF-α is known to be a cause of acute sickness behaviour, characterised by reduced activity related to 'weakness, malaise, listlessness and inability to concentrate', symptoms also notable in CFS.

"These preliminary data suggest that 'ordinary' activity (ie. that involved in getting up and travelling some distance) may induce anti-inflammatory cytokine release (TGFβ), whereas more intense exercise may induce pro-inflammatory cytokine release (TNF-α) in patients with CFS" (Immunological changes after both exercise and activity in chronic fatigue syndrome: a pilot study. White PD, KE Nye, AJ Pinching et al. JCFS 2004:12 (2):51-66).

It seems that Professor White chose to ignore the significance of his own research findings in order to pursue his ideological goal of embedding his "psychosocial" model of illness/disability into the medical, social and welfare policies in the UK.

2006

During the consultation period for production of the NICE Guideline on CFS/ME (September 2006), Professor Peter White submitted his views and recommendations, some of which are included here. The first quotations are what the draft Guideline originally said, followed by Peter White's disagreement with them:

On Disability aids and equipment:

"6.3.6.8 For adults and children with moderate or severe symptoms, provision of equipment and adaptations (for example, a wheelchair, blue badge or stairlift) to allow individuals to improve their independence and quality of life should be considered, if appropriate and as part of an overall management plan"

On behalf of St Bartholomew's Hospital Chronic Fatigue Services, Professor White said about this recommendation:

"We disagree with this recommendation….Where is the warning about dependence being encouraged and expectation of recovery being damaged by the message that is given in this intervention? We are in no doubt that it is a powerful message for a therapist of any sort to provide such aids. Our view is that such aids should only be considered by a multi-disciplinary therapeutic team as a whole, and usually in the context of providing a temporary means for a patient to increase their activity levels.

An example would be providing a wheelchair for a bed-bound patient as part of their active rehabilitation programme. In our opinion, such aids should never be seen as a permanent solution to disability in this illness….Equipment and aids may hinder recovery as much as help it".

Bowel symptoms and CFS/ME:

"6.4.5.5 Prescribing of gut anti-spasmodics (such as mebeverine, alverine, and peppermint oil) should be considered for adults and children with bowel symptoms, such as cramp or bloating".

Professor White said about this recommendation:

"..gut anti-spasmodics.." are not treatments of CFS/ME since bowel symptoms are not part of CFS/ME".

(This was untrue, and there is a substantive evidence-base documenting that bowel symptoms are an integral component of ME/CFS").

On Drug Intolerance and CFS/ME:

"6.4.5.2 Adults and children with CFS/ME may experience greater intolerance and more severe adverse/side effects from drug treatment. Where appropriate, drug treatment used for symptom control should therefore be initiated at a lower dose than in usual clinical practice, and should be increased gradually".

Professor White said about this recommendation:

"We are not aware of any reliable and replicated evidence to support the statement that patients with CFS/ME are more intolerant or have more severe adverse effects; and "more intolerant" than whom? We do not agree that drug treatment should be initiated at lower dose than in usual clinical practice. This possible myth is repeated within the guideline at various points…"

On Recovery times:

"6.3.6.16 When planning a programme of GET the healthcare professional should:

• discuss with the patient ultimate goals with the patient that are important and relevant to them. This may be, for example a 2 x 15 minutes daily brisk walk to the shop, a return to previous active hobby such as cycling or gardening, or, if more severely affected, sitting up in bed to eat a meal

• recognise that it may take weeks, months, or even years to achieve goals, and it is essential that the therapy structure takes this pace of progress into account.

Professor White said about this recommendation:

"These goals should include recovery, not just exercise and activity goals. If it takes "years" to achieve goals, then either the goals are wrong or the therapy is wrong. What other treatment in medicine would take years to work? We suggest "or even years" is deleted. If a therapy is not helping within a few months, either the therapy or the diagnosis or both should be reviewed and changes considered. We suggest that this advice is pertinent to all treatment approaches, not just for GET".

On Multiple Chemical Sensitivity (MCS):

"Family life may also be affected as people with severe CFS/ME are often sensitive to sounds and smell. For example, the person may be unable to tolerate light or cleaning products whilst they are often unable to control their body temperature, thus impacting on the living environment….Those caring for an individual with severe CFS/ME professionally need an understanding of the illness and the needs of the individual to meet the challenges of, for example, cooking or cleaning for an individual who is sensitive to the smell of food or of cleaning materials or bathing an individual who finds touch painful. Therefore proper training should be given about the condition with the involvement of the patient for any particular problems."

Professor White said about this recommendation:

"A patient with increased sensitivity to the smell of various chemicals may be suffering from multiple chemical sensitivity, but you would be making a dubious assumption to state this is part of or even characteristic of severely disabling CFS/ME".

"It should not be considered as a part of CFS/ME".

These comments by Professor White reveal the depth of his lack of knowledge of the evidence-base on ME/CFS.

2006

Occupational Aspects of the Management of Chronic Fatigue Syndrome: A National Guideline October 2006
NHS Plus Evidence based guideline. External Assessors: Professor Michael Sharpe & Professor Peter White.
Guideline Development Group member: Professor Trudie Chalder.

(For the avoidance of doubt, the main speaker at the All Party Parliamentary Group meeting held on 17th May 2007 at the House of Commons was Dr Ira Madan, an Occupational Health Consultant and Director of Clinical Standards for the NHS Plus project that produced the guidance and who since 1999 was Chief Medical Advisor to Houses of Parliament. She said the Guideline Development Group deliberately chose not to approach Professor Simon Wessely because they realised his appointment would be contentious, but that she did not consider the appointment of the two psychiatrists as the external assessors to be biased and she confirmed that one of the psychiatrist assessors had been recommended by Chris Clark of AfME and that Mr Clark had signed the guidance in March 2006).

The Report states: "Limitations of the Literature Review: The two external assessors are experts in the field of CFS and they indicated that they were content that all relevant research had been identified in the review".

Under "Conflicts of interest", the NHS Plus Guideline states: "none declared", yet the two external assessors (Sharpe and White) were long-time medical advisers to the insurance industry and White did consultancy work for the Department for Work and Pensions, so there was a blatant failure to declare such obvious conflicts of interest.

This was a serious issue, because there is written evidence that Professors Peter White, Michael Sharpe and Trudie Chalder appeared to have been less transparent than was required of them.

On 20th November 2008 the Department of Health confirmed (in writing) in relation to the NHS Plus Guideline about Professors White, Sharpe and Chalder: "I can confirm that the guideline contributors gave written confirmation that they had no conflicts of interest".

Since it was known that Professors White, Sharpe and Chalder all did have significant conflicts of interest and since any such conflicts had been denied by them, representations were made questioning why their known conflicts of interest had been denied.

Following these representations, on 23rd December 2008 a remarkable revelation was made – in writing – by Dr Ira Madan:

"The Department of Health have asked me to investigate your concern that one of the guideline development group members, Professor Trudie Chalder, and the two external assessors, Professor Michael Sharpe and Professor Peter White, had conflicts of interest whilst involved in the production of the guideline. I can confirm that I was aware of the potential for competing interests that you have stated. The roles that Professor White, Professor Sharpe and Professor Chalder have undertaken for the agencies and companies that you stipulate (i.e. the DWP and the medical and permanent health insurance industry) were in the public domain prior to the publication of the NHS Plus guideline. I am content, as the Director of that guideline,

these potential competing interests did not in any way influence the synthesis of the evidence or the guideline recommendations".

There is thus written confirmatory evidence from Dr Ira Madan that Professors White, Sharpe and Chalder all did have what she referred to as "competing interests" that were undeclared, but that she was "content" about the situation.

This illustrates how the normal rules of independent peer review and conflicts of interest are suspended when it comes to the "evidence-base" for CBT/GET in people with ME/CFS, because in relation to the NHSPlus Guidelines, two researchers were allowed to sit in judgment on their own publications, with the prior knowledge and permission of Dr Ira Madan.

Furthermore, they were not required to make conflict-of-interest declarations, even though their conflicts were known about by Dr Madan. This is not peer-review as the rest of the scientific world understands it.

Quotations from the full report include the following:

"In the past 20 years, the medical profession has increasingly come to believe that symptoms of individuals with CFS are not readily explained by recognisable organic disease".

"One model that has been used to consider the possible contributing factors to the condition, and hence an approach to managing it, is the 'biopsychosocial' model….**B**iological: consequences of inactivity; **P**sychological: attributional style, fear of making symptoms worse, coping by avoidance of activity; **S**ocial: personal conflicts".

"Poor outcome was predicted by membership of a self-help group; being in receipt of sickness benefit at the start of treatment".

It concluded that the two treatments for which there is the greatest weight of evidence are CBT and GET and its "Key priority for implementation" states: "Ill health retirement should be deferred until CBT/GET has been explored".

NHS Plus issued three leaflets promoting its Policy Document, all claiming to be "evidence-based"; they are intended for employers, employees and healthcare professionals.

The Policy Document itself and the three promotional leaflets all fail to present a balanced view of ME/CFS and reflect unequivocal support for the Wessely School psychosocial model of the disorder.

All failed to state that the correct WHO classification for ME/CFS is neurological.

The leaflet for healthcare professionals stated:

"This leaflet summarises the findings of a review of the scientific evidence on the occupational management of CFS…It summarises the evidence-based guidance on how to support individuals back into, and to remain in, work".

"The perpetuation of CFS may be attributed to an individual's response to an illness".

"Factors may include inactivity; deconditioning, weakness and fatigue brought on by excessive rest after an acute viral illness; inappropriate avoidance of activity (and) fears about the condition itself".

The "Management" is CBT and GET which are "supported by good quality evidence", but the leaflet concedes that: "Not everyone responds well to CBT", stating that factors which may limit its effectiveness include "excessive focus on bodily symptoms and taking …disability-related benefit during treatment".

Under "Predicting Work Outcomes", the leaflet stated that factors identified as predictors or poorer work outcomes include a "higher number of physical complaints" and a "higher number of physical signs, such as lymphadenopathy".

It continued: "Patients who are still working should be advised to stay at work, even if they feel tired".

The leaflet for employers was categoric: "Ill-health retirement…should only be considered if appropriate treatments such as CBT or GET have been explored"

"Many individuals who develop CFS can be rehabilitated back to work with a combination of the appropriate treatment and good management".

The leaflet for employees directed them to stay at work even if they feel tired.

The advice was clear: "When we have time off work from work, it is easier to lose our 'work hardiness' and that ill-health retirement is "not a first choice….CBT and GET increase the likelihood of people with CFS returning to work".

Many people noted that the NHS Plus Guidance was published before the NICE Guideline (which was not published until August 2007) and asked how those who produced it knew in advance what NICE would advise.

A contributor to the MEActionUK group (Mike) commented: "The timing of this document makes a complete nonsense of the efforts we have been making to register our thoughts with NICE" (23rd October 2006).

2007

How common is chronic fatigue syndrome; how long is a piece of string? Peter D White
Population Health Metrics 2007:5:6

"If the disease in question has no biological marker and is difficult to define clinically, the problem of working out the accurate prevalence becomes esoteric. CFS is just such an illness".

"It is therefore no great surprise that half of all doctors do not even believe it exists".

"Doctors don't understand things they can't see or measure, and patients mistrust doctors who don't understand them".

(This statement by Professor White raises the issue of how psychiatrists diagnose mental disorders which have no biomarkers, often cannot be seen and certainly cannot be measured).

"Our current criteria for diagnosing CFS are arbitrary, and we need to widen the net to capture all those people who become so chronically tired and unwell that they can't live their lives to their full potential".

(Unlike psychiatrists, medical scientists prefer to study as homogeneous a group of patients as possible, not to widen the net to capture everyone who might share a single symptom).

2007

Is a Full Recovery possible after Cognitive Behavioural Therapy for Chronic Fatigue Syndrome?
Hans Knoop, Gijs Bleijenberg, Peter White et al Psychother Psychosom 2007:76:171-176

"The objective of this study was to find out whether recovery from CFS is possible after CBT".

"If the therapist suggests that recovery is possible, the patient expectations are raised, which in turn may lead to a change in the perception of symptoms as well as disability".

"For complete recovery the perception of the patient has to change".

"Healthy adults without a chronic condition were used as the norm group, with a mean score of 93.1 (on SF-36). A patient had to score 80 or higher to be considered as recovered".

(This score of 80 needs to be compared with the fact that in the PACE Trial, Professor White reduced the SF-36 score to 60 for a participant to be deemed "recovered").

"The percentage of recovered patients was determined for all criteria and ranged between 23 and 59%".

"Improvement and not meeting research criteria for an illness are different from recovering. To examine if recovery was possible we used different definitions of recovery that encompassed three elements: no longer being severely fatigued, being able to resume all activities, and a perception of health and fatigue that is similar to the perception of healthy persons".

"Depending on the definition used, up to 59% of patients recovered".

"Even if we used the most conservative definition of recovery, 23% fully recovered".

"The first clinical implication of the present study is that a therapist delivering CBT can tell the patient that substantial improvement is likely to occur and that full recovery is possible".

2008

The Royal Society of Medicine: Conference on "Chronic Fatigue Syndrome" 28th April 2008 Peter White
What is Chronic Fatigue Syndrome and what is ME?

Of note is the fact that Professors White and Wessely were members of the RSM's Planning Committee for this "CFS" conference.

After notices announcing the conference appeared, many people wrote to the Chief Executive of the RSM, Mr Ian Balmer, expressing their concern and dismay that the conference was clearly being hijacked by the Wessely School in an attempt to influence non-psychiatrists. One reply from Ian Balmer dismissed patients' rightful concerns:

"Our conference on CFS…has been set up to contribute to health practitioners' understanding of (CFS)…The causes of CFS are not clear and our agenda was drawn up to reflect current thinking on its diagnosis and treatment, as outlined in the NICE guidelines….The content of the meeting is..well-grounded in evidence-based medicine".

On 10th September 2002 the Communications Director (Anne-Toni Rodgers) of the National Institute for Clinical Excellence Special Health Authority issued a Communications Progress Report which, at section 2.7.1.5 is clear: **"The ICD-10 classification is used for the recording of diseases and health related**

problems…The WHO produces the classifications and ICD-10 is the latest version…the classification codes are mandatory for use across England". Although the WHO ICD-10 classifies ME/CFS as a neurological disorder and although adherence to that classification is mandatory in England, in his lecture Peter White was unequivocal in advising clinicians not to use the ICD-10 classification of ME/CFS as a neurological disease; his words *(verbatim*) were:

"I'm going to try to define what Chronic Fatigue Syndrome is. By doing so, I'm going to review the ICD-10 criteria for the illness and see if they're helpful. The answer will be, they are not helpful…..This meeting is about clinicians making the diagnosis and helping patients…..Then we come the three clinical criteria to see if they're useful, and two of them actually do have help to us: the NICE Guidelines criteria and the Royal College of Paediatrics and Child Health criteria I would commend to you".

The NICE Guideline CG53 recommends CBT/GET and very limited investigations, whilst the RCPCH Report of December 2004 (Evidence-based Guidelines for the Management of CFS/ME in Children and Young People) bears little relationship to children and young people with ME/CFS. The College's view of ME/CFS was that it is a behavioural disorder. The RCPCH report emphasised behavioural interventions: "Children and young people with CFS/ME should be considered for graded exercise or activity programmes" and contributors referred to the "emotional dimensions of the illness" and stated: "The overarching aim of CBT is to help patients modify their behaviour for their own benefit".

White then said that there was another important clinical point that he was going to make: "that is – the diagnostic labels we choose to use influence our patients and influence prognosis…One of our problems is: labels do count".

"So, does the ICD-10 help us? Unfortunately not; there are at least five ways of classifying CFS using the ICD-10 criteria. What are they? We start off well: myalgic encephalomyelitis is in the neurology chapter of ICD-10…and helpfully, "chronic fatigue syndrome, postviral". So it starts off well. What if the viral illness is not a clear trigger for the illness? Well, you've got alternatives: in the Mental Health Chapter, you've got Neurasthenia…if you think that somehow, psychological factors have some role to play".

The "alternatives" shown on White's power point slide are all explicitly forbidden by the WHO; they include not only neurasthenia (which White pointed out includes "fatigue syndrome"), but also at F45.1 "Undifferentiated somatoform disorder"; at F45.3 "Somatoform autonomic dysfunction" and at F45.9 "Somatoform disorder, unspecified". White paid no heed whatever to the WHO directive that ME (and the NICE Guideline refers throughout to "CFS/ME") is not permitted to be classified to more than one rubric. If he does not include ME within "CFS/ME", then he is correct about "fatigue syndrome", but clearly he uses the term "CFS/ME" and that term is designed to include ME, which is impermissible.

He said: "It's confusing, isn't it?….ICD-10 is not helpful and I would not suggest, as clinicians, you use ICD-10 criteria. They really need sorting out, and they will be in due course, God willing".

That was a clear instruction to clinicians to disregard the ICD-10 classification of ME/CFS as a neurological disorder.

White discussed the various somatoform classifications for chronic fatigue before saying: "the trouble with these diagnoses is, you somehow have to guess that psychological factors have an important role to play in their aetiology".

White then dismissed the Canadian Guidelines and focused on the two UK criteria that do not distinguish between chronic fatigue and ME/CFS. White said about the Canadian criteria: "The Canadian criteria are popular in some quarters so I'm going to review them to see if they are useful to us. Start off well -- you've got to have these four symptoms, now take a deep breath – it gets worse, because you've got to have two of any of this lot, so you're up to six symptoms already to meet the Canadian clinical criteria. Look at the symptoms: disorientation? A symptom of this illness? Ataxia? As a psychiatrist, I would have problems defining emotional overload, so is this really useful? You need six symptoms already to make the definition and some of these symptoms are very hard to define and therefore how can you use them clinically? It gets worse again, because not only do you need those two symptoms --I don't expect you to read the list, don't worry -- you need at least one from two of the following: autonomic manifestation, neuroendocrine manifestation or immune (manifestation). New sensitivity to food: is that really an immune manifestation?"

White advised his audience that, because as a psychiatrist he finds it difficult to recognise an ME patient's physical symptoms, there was no need even to consider those symptoms. He made it plain that the less symptoms a definition of CFS/ME has, the better.

To back up his claim, and using a graph from a study by Professor Simon Wessely, White said: "You notice a fairly straight line showing the more physical symptoms you have, the more likely you are to meet the criteria for psychiatric distress. The cut-off for CIS (Clinical Interview Schedule, revised in 1990 by psychiatrist Anthony Pelosi) for psychiatric morbidity is about 12. So once you get above 4 symptoms – you can see once you get 5,6,7,8 symptoms as the Canadian criteria suggest, you are more likely to find someone with a psychiatric disorder and not CFS/ME. So I would suggest you do not use the Canadian criteria".

Having praised the case definition that was created by the NICE Guideline Development Group (which requires only fatigue plus one other symptom), White continued: "You might argue with some of these symptoms such as palpitations – is that really part of CFS/ME -- but at least the good news is that we're going for less symptoms to define the syndrome rather than more".

White then told his audience that the RCPCH criteria got the "gold star for me – I think these are the best. So here we are -- generalised fatigue causing significant impairment, they say for three months, and I would commend these criteria to you as probably the best to use clinically" (this is a guideline for children, not adults).

Peter White then went on to say: "Simon Wessely and Michael Sharpe's Lancet (1999) paradigm-shifting paper suggested that what we should be doing is lumping them all together (CFS/ME, irritable bowel syndrome, fibromyalgia) rather than trying to isolate CFS".

"Reactionary diehards like me disagreed with this; I think we shouldn't be lumping, we should be splitting, so actually CFS/ME is more than one illness".

"Let's just show you the data to suggest that this is the case….just looking at the symptoms and demographics alone without looking at laboratory abnormalities, you can define these two separate subgroups: when you start to look at the symptoms and demographics, you get separate illnesses coming out however you analyse it".

It is notable that White referred to "laboratory abnormalities" (which are proscribed by NICE) and that he said "CFS/ME" is not a single disorder, so on what evidence did the NICE Guideline Development Group combine them into one single somatoform disorder?

He continued: "So diagnosis --- what is the point of making the diagnosis? I would suggest that it is useful to make the diagnosis of CFS/ME to lump as far as that….. there's a final common pathway (for) several different disease processes with the same clinical presentation. It may be in the future the PACE trial – which I lead – may show that actually heterogeneity could help us define which treatment to give our patients (but) at the moment it can't, so certainly (as far as treatment is concerned) keep it lumped as CFS/ME".

There, in the clearest terms, seemed to be the rationale behind the blanket management interventions recommended by NICE.

In the last few minutes of his talk, White spoke about ME as described by Acheson and Ramsay from the 1950s and he stressed that it was a different illness from what is now called "CFS/ME". Disturbingly, he misled his audience by manipulating the clinical presentation of the Royal Free outbreak, which seemed to be an attempt to distinguish between the "original" ME cases and what is now called "CFS/ME". He was at pains to emphasise that in 1955 at the Royal Free, "74% showed objective involvement of the central nervous system" and implied that in the current "CFS/ME", there is no such CNS involvement, which is 100% incorrect.

It is important to recall that when the term "CFS" was coined in the USA in 1988, it was made known that "CFS" was simply a new name for what was known as ME, so White is incorrect to imply that "CFS/ME" is not based on the earlier and more clinically accurate descriptions of it. People die from ME, and there is irrefutable

evidence of CNS involvement, as shown in the autopsy of Sophia Mirza, where 75% of her spine showed dorsal root ganglionitis (a severe inflammation of the nerves in her spinal cord).

White joked with his audience: "How did this happen? I'm afraid we're responsible (laughter from the audience). We transmogrified, we changed, transposed epidemic ME into endemic ME. So actually we've got a definition of a different illness that we have transposed onto this illness, which I think is where our problem comes from".

"What message? This is organic. What does that word mean? Incurable neurological disease. OK, it might be right, it might be wrong. But what message does this give our patients? 'You have an incurable neurological disease'. Is it a more useful message for our patients to say that, or to say 'graded exercise therapy is a safe and effective treatment if it's done properly', because the two statements cannot be at this moment joined together".

It is clear that Peter White was saying that patients with an incurable organic neurological disease must not be allowed to know the reality about their condition but must be patronised by being given GET, not least because GET is known <u>not</u> to be ***"safe and effective***" (evidence which the Wessely School still have no compunction in denying).

Having earlier said he personally was not a "lumper", Professor White concluded his presentation by saying: "I would commend to you the broad-based definitions (ie. the ones that pull in patients with chronic "fatigue") rather than the one with lots of (specific and characteristic) symptoms".

The whole presentation at the RSM was pernicious, irresponsible and damaging to many very sick people who suffer from a serious and complex neuro-immune disorder, but it does seem to provide the explanation for the inappropriate stance taken by NICE in its Guideline on "CFS/ME".

(Professor White gave a lecture with the same title on 18th September 2008 at the RSM West Region meeting held at the UHBT Education Centre, Upper Maudlin Street, Bristol, earning medical attendees a CPD of 5 credits. Dr Esther Crawley was the Chair for Session Two and also spoke on "The Practical Management of CFS").

<u>2008</u>

<u>Chronic Fatigue Syndrome</u> Letters to the Editor Lucy V Clark and Peter D White J Rehabil Med 2008:40:883-885

"There is no scientific evidence that properly delivered GET causes harm (to ME/CFS patients)".

"The aim of setting a baseline of activity is that that it is possible to undertake it even on a 'bad' day".

"It is recommended that duration is increased by less than 20% at any increment up to 30 minutes per day, and then intensity is increased by 10-20% at any increment".

"A central concept of GET is that patients maintain their level of exercise…even after a CFS/ME setback".

2008

The Essentials of Neuropsychiatry Chronic fatigue syndrome: neurological, psychological, or both? Peter White

In December 2008 Peter White gave a presentation at a Neurology and Psychiatry Teaching weekend (12th-14th December).

It was organised by the British Neuropsychiatry Association (BNA) at St Anne's College, Oxford. His presentation is summarised in the event Handbook.

Extracts from the Handbook show that White remains resolutely unmoved by biomedical science and by the taxonomic rules governing the WHO ICD classification:

"The clinical taxonomy for CFS is a mess. The ICD-10 classification defines CFS within both the neurology chapter and mental health chapters".

"Myalgic encephalomyelitis, the alternative name for CFS, is classified as a neurological disease (G93.3) (a.k.a. post-viral CFS), whereas neurasthenia (a.k.a. CFS not otherwise specified) is classified with mental health (F48").

"Reversing maintaining factors should lead to improvement…(these) include…illness beliefs such as believing the whole condition is physical, pervasive inactivity, avoidant coping, membership of a patient support group, and being in receipt of or dispute about financial benefits".

"Few pathophysiological findings in CFS have been replicated in independent studies".

"Those that have been include…physical deconditioning, and discrepant reports between perception of symptoms and disability and their objective tests".

"The discrepancy between subjective states and objective tests…may be related to interoception (the perception of visceral phenomena)".

"The two approaches with the greatest evidence of efficacy are CBT and GET (and) about 25% report full recovery, which lasts".

2009

Risk markers for both chronic fatigue and irritable bowel syndrome: a prospective case-control study in primary care. WT Hamilton, PD White et al. Psychological Medicine 15th April 2009

(Note that despite having categorically denied the existence of bowel problems in ME/CFS in 2006 – see above – Professor White is a co-author of this paper).

"Fatigue syndromes and irritable bowel syndrome (IBS) often occur together".

"A strong relationship between CFS and psychiatric, particularly mood, disorders is a constant finding in population-based studies".

"The common predisposing risk markers were symptoms such as dizziness and menstrual symptoms, in addition to diagnoses such as atopy, mood and other symptom-based disorders, and immunisations".

"Specific predisposing diagnoses included infections in general, particularly systemic viral infections, for fatigue syndromes".

"Mood diagnoses are more specific risk markers for CFS/ME".

"Future research into the role of immunisations…are unlikely to yield useful data".

"These data suggest that…CFS/ME and PVFS should be considered as separate conditions, with CFS/ME having more in common with IBS than PVFS does. This requires revision of the ICD-10 taxonomy, which classifies PVFS with ME".

2010

Chronic fatigue syndrome: is it one discrete syndrome or many? Implications for the 'one vs many' functional somatic syndromes debate Peter D White Journal of Psychosomatic Research 2010:68:455-459

"The example of one particular 'functional somatic syndrome', namely, chronic fatigue syndrome, provides insights into the difficulties of trying to define the phenotype in the absence of … biomarkers".

"Why is CFS strongly associated with both chronic widespread pain ('fibromyalgia') and irritable bowel syndrome? Could it be that there is only one general functional somatic disorder?".

"Kato et al …found that perceived stress and 'emotional instability' are risk factors for later CFS".

"Chronic fatigue syndrome can be considered as a discrete functional somatic syndrome….At the same time, CFS shares common risk factors with other FSS".

2010

Is there a better term than 'medically unexplained symptoms'? Francis Creed, Michael Sharpe, Peter White et al
Journal of Psychosomatic Research 2010:68:5-8

"It has become apparent that the term 'medically unexplained symptoms' is itself a barrier to improved care…because the term is not acceptable to some patients and doctors".

"Terms suggested as alternatives for 'medically unexplained symptoms': Functional somatic syndromes; Bodily distress syndrome/disorder; Somatic symptom disorder; Psychophysiological disorder; Psychosomatic disorder; Somatoform disorder".

"The term 'functional somatic disorder or syndrome' fulfils most criteria….demonstrating that the symptoms are 'real' and yet changeable by alteration in thinking and behaviour as well as by a psychotropic drug".

The authors then discuss "the implications for DSM-V and ICD-11", from which it is clear that the authors wish to re-classify ME/CFS as a chronic somatic symptoms disorder in future editions of these major classification manuals.

As Joe Bouch, Editor of Advances in Psychiatric Treatment (2010:16:1) pointed out about classification:

"Clinicians need to think about…the forthcoming revisions".

"There are many vested interests at stake: not just clinicians but governments, NGOs, lawyers, researchers, public heath practitioners, Big Pharma and patient groups. Vast sums are at stake – everything from welfare benefits and compensation claims to research budgets".

"Like Sartorius, Thornicroft singles out chronic fatigue syndrome, bitterly contested in terms of its status as a physical, psychiatric or psychosomatic condition and viewed by healthcare staff as a less deserving category".

2011

Although not authored by Professors Wessely, White or Sharpe, the FINE Trial (Fatigue Intervention by Nurses Evaluation) of "pragmatic rehabilitation" (which incorporated graded exercise) and "supportive listening" for those severely affected by ME/CFS (BMJ 2010:340:c1777) produced what was effectively a null result.

Of significance is the paper published in 2011 which appeared to blame the participants: (Challenges of nurse delivery of psychological interventions for long-term conditions in primary care: a qualitative exploration of the case of chronic fatigue syndrome/myalgic encephalitis *(sic)* Sarah Peters, Alison Wearden et al. Implementation Science 2011:3:10)

"The evidence base for a range of psychosocial interventions and supporting patients with long-term conditions (LTCs) is now well-established…The purpose of this study was to examine the challenges faced by non-specialist nurses when delivering psychological interventions for an LTC (CFS/ME) within a primary care setting".

"Tensions existed for nurses when attempting to deliver psychological interventions for patients with CFS/ME in this primary care trial".

"A substantial evidence base now exists as to the most effective ways of managing the condition, with CBT and GET having the most robust evidence base".

Various sections were analysed, and were revealing and disturbing:

(i) being a novice therapist
(ii) engaging patients in the therapeutic model
(iii) dealing with emotion
(iv) complexity of primary care.

Under "Being a novice therapist", one nurse was blunt: "As a nurse…I would have just turned up and said 'right get on the bike. I will talk you through it' and that is something I have had to restrain myself with…I really had to teach myself to step back…..There was nought wrong with her".

Under "Engaging patients in the therapeutic model", a nurse was advised by her supervisor that "You might have a little bit of a tussle for the first couple of weeks while they are getting their head around the concept".

"An unresolved mismatch between patient's illness and treatment beliefs was a key source of tension".

Under "Dealing with emotion", a significant theme was "A particularly difficult challenge of interacting with patients for the nurses and their supervisors was managing patients' resistance to treatment. This arose from patients not accepting the rationale of the treatment".

A supervisor noted about the nurses under her guidance: "There have been one or two times where I have been worried because they (the nurses) have got angry at the patients…that anger has been communicated to the patients….There is a sort of feeling that the patient should be grateful and follow your advice, and in actual fact, what happens is the patient is quite resistant and there is this thing, like, you know, 'The bastards don't want to get better' ".

Under "Complexity of primary care" is listed "Issues of personal security" for the nurse-therapist.

"Managing patients' illness beliefs to psychotherapy was a consistent theme across nurse, supervisor and patient interviews".

"Over half of the trial sample reported one or more medical conditions that did not explain their fatigue, with the most common being musculoskeletal, gastrointestinal or cardiovascular conditions".

"Expanding the role of non-specialist primary care nurses to include delivering psychological interventions for patients with …CFS/ME creates a number of challenges".

2012

Time to end the distinction between mental and neurological illnesses PD White et al BMJ 24th May 2012

"As…classification systems are currently under revision…we propose… that psychiatric disorders should be reclassified as disorders of the central nervous system. This will…foster the integration of psychiatry into the mainstream of medicine, where it belongs".

"The requirement that conditions should be classified under either mental or physical chapters causes particular difficulty in the context of functional somatic syndromes…For example, chronic fatigue syndrome may be classified as myalgic encephalomyelitis (ME) within the neurology chapter (G939) if ICD-10, or as neurasthenia, a psychiatric disorder (F48.0)"

This again is in contradiction to the rules of the ICD, which forbid dual classification of the same disorder; it also shows a remarkable lack of medical knowledge about the differences between chronic fatigue and ME.

"Beliefs, feelings, and consequential behaviour are important in maintaining ill health and disability once an illness is established".

"The change in the classification of disorders will help psychiatrists and neurologists to promote a biopsychosocial model of illness".

(**It is worth pointing out that a change in classification of ME from neurological to psychological would trigger an automatic limit on insurance claims and would save the industry millions of pounds in payments; it is also worth reiterating that Professor White works for that industry, being CEO of Swiss Re, a massive re-insurance company**. In his item for Swiss Re entitled "Managing claims for chronic fatigue the active way", he is clear: *"A final point specific to claims assessment, and a question we're often asked, is whether CFS would fall within a mental health exclusion, if one applies to a policy. The answer to this lies within the precise exclusion wording. If the policy refers to functional somatic syndromes in addition to mental health, then CFS may fall within this exclusion….The point made is that a diagnosis of ME (a term used colloquially instead of CFS) is considered a neurological condition according to the ICD diagnostic codes, whereas CFS can alternatively be defined as neurasthenia which is in the mental health chapter of ICD-10"*).

Section III: Professor Michael Sharpe

As noted in "Quotable Quotes Updated", Michael Sharpe is heavily involved in the medical insurance industry, especially with UNUMProvident. In 2005 he held a Personal Chair in Psychological Medicine and Symptoms Research at the University of Edinburgh and on 12th May 2005 he delivered his inaugural lecture (attended by Simon Wessely) entitled "The Science of the Art of Medicine" in which he spoke on "functional medicine" and on how to treat diseases with "no pathology". He highlighted medicine's "blind spot" in dealing with symptoms that are not expressions of disease, including patients with ME/CFS. This was reminiscent of his 1999 lecture at the University of Strathclyde ("ME. What do we know – real illness or all in the mind?"), where he said: "Purchasers and Health Care providers with hard pressed budgets are understandably reluctant to spend money on patients who are not going to die and for whom there is controversy about the 'reality' of their condition (and who) are in this sense undeserving of treatment….Those who cannot be fitted into a scheme of objective bodily illness yet refuse to be placed into and accept the stigma of mental illness remain the undeserving sick of our society and our health service".

In June 2005, thinking that he was sending his lecture notes to an ME patient who had contacted him about his lecture on 12th May 2005, Sharpe sent a file containing about 120 of his patients' clinical notes; those notes contained his patients' name, date of birth and address and included Sharpe's own adverse comments on his patients. His clinical notes were embedded into his power point presentation file. Those personal details could have been forwarded to anyone and were indeed on Google (but were not put there by the ME patient to whom they had been sent). The essence of Sharpe's comments could be summarised as "These idiots need to change their attitude". The comments included such words as: "putting it on"; "mad"; "imagining symptoms"; "examination was a waste of time"; "It's been a waste of time because the reports from Psych aren't here". The file also contained deeply

private comments made by patients to Professor Sharpe about their feelings. Because of his work for the insurance industry, Sharpe's notes had an adverse impact on his patients who were in receipt of insurance benefits because they were informed that their benefits were to be stopped.

Following a complaint about Sharpe's substantial breach of patient confidentiality, on 19th August 2005 journalist Ian Johnston reported it in The Scotsman, reporting that the University of Edinburgh accepted the leak by Professor Sharpe: "An unfortunate, inadvertent error has led to a breach of confidentiality and will be subject to a full investigation conducted in partnership with the proper NHS authorities". Johnston's article continued: "The university spokeswoman said that Prof Sharpe had been made aware of the situation, but was on holiday". It is understood that no disciplinary action was taken against him.

Sharpe's notes on patients were made during his work on a report for the Scottish Neurological Symptoms Study that was published on 28th March 2005, which Sharpe co-authored with Dr Alan Carson. The study ran from December 2002 to February 2004 and the authors' findings were that:

"Many physical symptoms such as pain, weakness and fatigue are …unexplained by disease…There is now increasing evidence that such medically unexplained symptoms (MUS) …place a very substantial burden on both the NHS and on the economy in general".

"Patients whose symptoms were less explained by organic disease had increased health anxiety….They also found it harder to believe their doctor when he/she told them there was nothing to worry about. This pattern of beliefs has been termed hypochondriasis".

2007

Revising the Classification of Somatoform Disorders: Key Questions and Preliminary Recommentations
Kurt Kroenke, Michael Sharpe, Richard Sykes Psychosomatics 2007:July-August: 48:4

"As the DSM-V process unfolds, Somatoform Disorders are a diagnostic category for which major revisions seem warranted….A large-scale revision is planned".

"The Conceptual Issues in Somatoform and Similar Disorders (CISSD) was launched several years ago by Richard Sykes to stimulate a multidisciplinary dialogue about the taxonomy of somatoform disorders and the medical diagnoses of functional somatic syndromes eg. irritable bowel syndrome; chronic fatigue syndrome, fibromyalgia".

"Patients often resist having somatic problems labelled as a psychiatric disorder, with the consequent stigma and negative financial implications".

"It was strongly argued that we should change the currently used terms such as Somatoform, Somatisation and Hypochondriasis, and pay more attention to their acceptability to patients….Furthermore, it was anticipated that the stigma will simply re-attach to any new name unless the concept of mental causation – and therefore personal responsibility -- is changed".

"Terms such as 'functional', 'medically unexplained' and 'psychosomatic' are currently less satisfying to many patients than the diagnosis of a particular medical disorder".

"Multi-system diseases usually have objective manifestations…and are not commonly misdiagnosed as somatoform disorders".

"Patients with poorly explained somatic symptoms are often sensitive to disease labels and language, making it important to carefully amend potentially perjorative language".

2008

Chronic fatigue syndrome Michael Sharpe
Psychiatric Aspects of General Medicine: Medicine 2008:36:9:452-454

"Illness perpetuating factors include inactivity, a fear of making oneself worse and belief that the illness is permanent…. Management should be directed at the perpetuating factors".

"CFS shares symptoms, aetiological factors and treatment response with other so-called 'functional somatic syndromes' ".

"Ensure it is clear that you accept the reality of the patient's symptoms and that you do not think they are imagined or 'all in the mind' ". (**This clearly advocates duplicity and deception of patients by the clinician).**

2009

Neurology out-patients with symptoms unexplained by disease: illness beliefs and financial benefits predict
1-year outcome M. Sharpe, A Carson et al. Psychological Medicine 2009:40(4):689-698

"We …aimed to determine predictors of poor subjective outcome for new neurology out-patients with symptoms unexplained by disease one year after the initial consultation".

"On the univariate analysis, poor outcome … was predicted by…not attributing symptoms to psychological factors and the receipt of health-related financial benefits".

"In the multivariate analysis, the only strong independent predictors of a poor outcome were the patients' beliefs in expectation of non-recovery, non-attribution of symptoms to psychological factors, and the receipt of health related financial benefits at the time of the initial consultation".

"The finding that being in receipt of financial benefits…predicted poor outcome will perhaps not come as a surprise to many clinicians".

"Hence it is possible that payment consequent on having symptoms and disability acts to perpetuate them".

"The finding of an association of poor subjective outcome with specific beliefs and being in receipt of health-related financial benefits in patients with symptoms unexplained by disease…may point the way to a greater understanding of the psychological and social mechanisms that determine poor outcome".

"Interventions which change these variables…emphasise that those policies that determine health-related benefits may need to be amended if we are to maximise the chance of recovery".

2011

Disability, distress and unemployment in neurology outpatients with symptoms 'unexplained by organic disease' A Carson, C Warlow, M Sharpe et al JNNP 2011:82:810-813

(Of note is the fact that Michael Sharpe -- one of the PACE Trial Principal Investigators -- co-authors papers with Professor Charles Warlow who, at the time of the PACE Trial fiasco, was Complaints Ombudsman for The Lancet where the misleading results were published, making it impossible to seek his intervention in The Lancet's failure to address the formal complaints submitted because he was conflicted).

"We know that one-third of neurology out-patients have symptoms…that are not explained by recognised 'organic' disease".

"But are these patients really ill?...Are such symptoms actually associated with disability…and is this reflected in their…receipt of disability-related state financial benefits?"

"New neurology patients with symptoms unexplained by organic disease have more disability, distress, and disability-related state financial benefits than patients with symptoms explained by disease".

2012

Healthcare costs incurred by patients repeatedly referred to secondary medical care with medically unexplained symptoms: a cost of illness study Burton C, Sharpe M et al Journal of Psychosomatic Research 2012:72(3):242-247

"Some patients are repeatedly referred from primary to secondary care with medically unexplained symptoms. We aimed to estimate the healthcare costs incurred by such referrals".

"The repeated referral of patients with MUS to secondary medical care incurs substantial healthcare costs".

2014

Medically unexplained symptoms including chronic fatigue syndrome can be accurately identified and treated
Research Excellence Framework 2014 Impact Case Studies Submitting Institution: University of Edinburgh
Team led by Alan Carson and Michael Sharpe

"Up to 1 in 300 people in the UK have CFS".

"Moreover, more than a quarter of all individuals presenting to a GP in the UK – in excess of 100 million consultations per year – have pain, paralysis, bowel symptoms of chronic fatigue for which no adequate medical explanation can be found".

"In 2011, Sharpe and colleagues published the first definitive randomised controlled study (n = 641) showing superior efficacy of CBT for CFS …and the inefficacy of the very widely recommended (at the time) intervention of 'pacing' at 52 weeks follow-up (the PACE trial)".

"By showing the benefits of accurate identification and targeted treatment of chronic fatigue syndrome, UoE research has influenced worldwide medical practice….Guidelines and policy debate have resulted in improved patient treatment, with associated economic benefit".

"These medically unexplained symptoms…cost the NHS £14K per annum per patient. The cost to the UK economy is up to £3.5 billion per annum for CFS alone".

"The UoE challenged the once popularly held view that CFS is an organic disorder".

(It is surely ironic that it was the University of Edinburgh who in 1957 awarded Dr Andrew L Wallis a PhD for his 143 page doctoral thesis, in which Wallis unambiguously set out one of the best descriptions of ME ever formulated, leaving no doubt of its organic nature. One paragraph in Wallis' thesis particularly stands out: "Consultant medical opinion rather clearly showed disinterest, an implication being that a hypothetical mountain was being erected on an imagined molehill, and that the cases could readily be explained on conventional grounds by a competent person". It seems that medical arrogance was prevalent then as now).

"The work has been presented at international meetings and published in high-impact journals with global reach accompanied by UoE and Medical Research Council press releases".

"The work has also led specifically…and directly to changes in what is considered best clinical practice".

"The work has fed into the development of the International Classification of diseases (ICD-11) and the Diagnostic and Statistical Manual of the American Psychiatric Association (DSM-V)".

Section IV: the PACE Trial

The PACE Trial inhabits a unique and unenviable position in the history of medicine. It is believed to be the first and only clinical trial that patients and the charities that support them have tried to stop before a single patient could be recruited and is the only clinical trial that the UK Department for Work and Pensions (DWP) has ever funded. It did so because Professor White, who was lead advisor on "CFS" to the DWP, convinced Dr (now Professor Sir) Mansel Aylward, Chief Medical Adviser, Medical Director and Chief Scientist of the DWP, that his favoured interventions of CBT and GET would reduce the number of benefit claimants.

The three Principal Investigators (PIs) were Professor Peter Denton White (the Chief PI, with whom all responsibility lies) and Professors Michael Sharpe and Trudie Chalder.

Although Peter White has denied it in writing, it seems undeniable that the PIs broke almost every rule concerning the conduct of a clinical trial:

- Because of serious recruitment difficulties, patients attending a "fatigue" clinic of which Peter White was in overall charge have provided a statement

confirming they were coerced onto the PACE trial on pain of being discharged from a consultant's care at the clinic if they declined to enrol (support from a consultant being necessary to authorise claims for state benefits). **No patient must be coerced to take part in a clinical trial.**

- **Selection of participants was based on criteria that excluded patients with ME** (the "Oxford" criteria, which Professor White part-funded himself) but there was to be a "secondary" analysis using the "London" criteria. It is a straightforward fact that if those with a classified neurological disorder are excluded from the outset by correct application of the Oxford entry criteria, no amount of "secondary analysis" will reveal those with a classified neurological disorder. The "London" criteria have never been published in any medical journal and are not on PubMed so are not available for scrutiny or comparison. There is no methods paper which specifically describes them as a "case definition"; they have never been approved nor have they even been finally defined (there are various versions). **This meant that Professor White was able to (and did) create his own version of the "London" criteria as evidenced on page 188 of the Full Protocol.** In fact, Professor White amended the Protocol and he substituted his own version of the "London" criteria for the Ramsay definition (Professor White's "version 2" is dated 26.11.2004). The original intention of the PIs was to use the Ramsay definition of ME and this was date-stamped by the MREC as received on 21st March 2003. The Ramsay definition of ME as approved by the MREC required the following: fluctuation of symptoms from day to day or within the day; headaches; giddiness; muscle pain; muscle cramps; muscle twitchings; muscle tenderness; muscle weakness; pins and needles; frequency of passing water; blurred vision; double vision; increased sensitivity of hearing; increased sensitivity to noise; feeling generally awful, and muscle weakness after exercise. Whilst the Ramsay definition does exist (Postgrad Med J 1990:66:526-530), the "London" criteria do not in fact exist and the reference cited in the Lancet paper is to the 2004 Westcare Report, which simply said that they were "proposed" criteria**. Professor White's own version of the "London Criteria" specifically states on page 188 of the Full Protocol that neurological disturbances "are not necessary to make the diagnosis" and they further state that: "the usual precipitation by 'physical or mental exercise' should be recorded <u>but is not necessary to meet criteria</u>". Put another way, Professor White's "London Criteria" do not require the cardinal feature of ME to be present in his subgroup of patients in a trial that purported to be studying "CFS/ME".**

- "CFS/ME" as created by the Wessely School is very different from ME/CFS. The former is believed by them to be a behavioural disorder, whilst the latter is known (and scientifically proven) to be a biomedical disorder and has been classified in the ICD since 1969 as a neurological disorder.

- The PIs failed to use as homogeneous a cohort as possible (a basic tenet of clinical trials), making the results meaningless: (i) **on 12th May 2004 the**

Parliamentary Under Secretary of State at the Department of Health, Dr Stephen Ladyman, announced at an All Party Parliamentary Group on Fibromyalgia that doctors were being offered financial inducements to persuade patients who did not have ME/CFS to take part in the PACE Trial in order to aid recruitment; (ii) the Trial Identifier is clear at section 3.6: "Subjects will be required to meet operationalised Oxford criteria for CFS. **We chose these broad criteria in order to enhance generalisability and recruitment"** and (iii) on 14th July 2006 Peter White sought approval from the West Midlands Multicentre Research Ethics Committee (MREC) to write to GPs asking them to refer patients with "fatigue" to the PACE trial ("If you have a patient…whose main complaint is fatigue (or a synonym)…please consider referring them to…one of the PACE trial centres").

- **The PIs obtained ethical approval and financial funding to study CFS/ME (and all the Trial documentation referred to it as such), yet once the trial was over, Peter White wrote to Richard Horton, Editor-in-Chief of The Lancet stating**: "The PACE trial paper refers to chronic fatigue syndrome (CFS) which is operationally defined; it does not purport to be studying CFS/ME".

- They ignored the existing evidence-base on ME/CFS (which contravenes the Declaration of Helsinki).

- They failed to declare their vested financial interests until 2007 (and then incompletely): in the Minutes of the Joint Trial Steering Committee and Data Monitoring Committee held on 27th September 2004, there are no conflicts of interest recorded by the three PIs (who all worked for the PHI industry and Peter White also worked for the DWP, so they all did have vested financial interests but none was declared, including the fact that they chose to use their own "Oxford" criteria [which Peter White had partly funded himself] and despite the fact that one of the PIs (Michael Sharpe) stated in 1997 that the Oxford criteria *"have been superseded by international consensus"* (Chronic fatigue syndrome and occupational health. A Mountstephen and M Sharpe. Occup Med 1997:47:4:217-227); Peter White also used his own money to fund the Cochrane Review of GET which, unsurprisingly, given that he was instrumental in the outcome, found that it was effective. Moreover, some members of the MRC Trial Steering Committee also failed to declare their significant conflicts of interest.

- **The PIs failed to keep participants' data securely and some of it was stolen** (and thus was lost to analysis); the theft was reported to Southwark Police on 22nd March 2006 and the crime number was 3010018-06.

- During the trial, the PIs produced and disseminated Newsletters for participants, which contained glowing reports by other participants of how the interventions had helped them.

- In order to gain participants' co-operation and trust (thereby enhancing the likelihood of a more favourable outcome) CBT and GET therapists (but not therapists in the other arms of the trial) were trained to deceive participants by assuring them that they agreed CFS/ME was a physical disorder and that symptoms were real, when in fact the therapists were taught that it was a behavioural disorder.

- Once the raw data had been obtained, the PIs changed the outcome criteria and failed to report on protocol-specified primary outcome measures**; this meant that a participant could enter the trial with a baseline SF-36 score showing a higher level of physical functioning and a lower fatigue score; they could deteriorate and become more disabled during the trial with a lower SF-36 score than at baseline, but would then still be classed as "normal/recovered".**

- Having been funded to use actometers, the PIs decided not to use them at the end of the trial, but to rely on self-reported questionnaires.

- During the trial, the PIs changed their method of scoring from use of the bimodal Chalder Fatigue Scale to the 33 point Likert scale; the conversion is complex (a score of 4 on the Chalder Fatigue Scale equates to a Likert score of 8-19, but by using the Likert scale the PIs were able to produce scores that just reached a level of significance). This has been seen as manipulation of the figures to obtain a mathematical level of significance in order to achieve a pre-determined result of success.

- The PIs' re-definition of "recovery" was not specified in the statistical analysis plan (which was not published until two years after the selective (ie. adjusted) results had been published.

- The PIs chose a comparator which included the very old and the very ill, when the correct comparator should have been the healthy adult population.

- At the press conference to announce the alleged success of the PACE Trial (convened by the Science Media Centre of which Professor Sir Simon Wessely is a founder member and to which he is advisor), the PIs permitted grossly misleading press reports to abound, resulting in false reporting by the media.

Having published his selective results in 2011, Peter White obstructed the release of his raw data for independent analysis until 2016 but was finally compelled to release it by a court order. **Once it was re-analysed, it was obvious that the PACE Trial (which cost £5 million) had failed:** the following extracts are taken from "A preliminary analysis of 'recovery' from chronic fatigue syndrome in the PACE trial using individual participant data" by Alem Matthees, Tom Kindlon, Carly Maryhew, Phil Stark (Associate Dean, Mathematical and Physical Sciences; Professor, Department of Statistics, University of California, Berkeley) and Bruce Levin

(Professor of Biostatistics and Past Chair, Department of Biostatistics, Mailman School of Public Health, Columbia University, New York):

1. There was no (MREC) committee approval for the re-definition of “recovery”.

2. The PACE PIs originally reported “recovery” rates of 22% for CBT and GET.

3. In contrast to the published paper by the PIs, the recovery rates in the CBT and GET groups are not significantly higher than in the standard medical care group alone.

4. APT (adaptive pacing therapy) was a highly modified version of “pacing” (preferred by patients).

5. 13% of participants at baseline simultaneously met the trial entry criteria for “significant disability” and the revised “recovery” criteria.

6. The Investigators excluded drop-outs, which is not recommended practice in clinical trials.

7. Logistic regression (used by the PIs) has been shown to be an inappropriate method of analysis in randomised trials.

8. The figures originally given by the PIs for the four groups were:

- SMC 7% (but according to the protocol are 3%)
- APT 8% (but according to the protocol are 2%)
- CBT 22% (but according to the protocol are 7%)
- GET 22% (but according to the protocol are 4%)

9. “Our findings therefore contradict the conclusion of White et al (2013) that CBT and GET were significantly more likely than the SMC group to be associated with ‘recovery’ at 52 weeks”.

10. “The multiple changes to the recovery criteria had inflated the estimates of recovery by approximately 2.3 to 5.1-fold, depending on the group, with an average inflation of 3.8-fold”.

11. When using the revised recovery criteria, 8% of the “recovered” participants still met trial eligibility criteria for “significant disability”.

12. “The changes made by the PACE investigators after the trial was well under way resulted in the recovery criteria becoming too lax to allow conclusions about the efficacy of CBT and GET as rehabilitative treatments for CFS”.

13. “This analysis, based on the published trial protocol, demonstrates that the major changes to the thresholds for recovery had inflated the estimates of recovery by an average of approximately four-fold”.

14. “It is clear from these results that the changes made to the protocol were not minor or insignificant, as they have produced major differences that warrant further consideration”.

15. “The PACE trial provides a good example of the problems that can occur when investigators are allowed to substantially deviate from the trial protocol without adequate justification or scrutiny”.

16. “It seems prudent that the published trial results should be treated as potentially unsound, as well as the medical texts, review articles, and public policies based on those results”.

Investigators’ continued denial of the factual evidence

It will be recalled that Professor Sir Simon Wessely dismissed the significance of what appeared to amount to scientific fraud in a cavalier manner: “The message remains unchanged….OK folks, nothing to see here; move along please” (Bad science misled millions with chronic fatigue syndrome. Here’s how we fought back: Julie Rehmeyer: https://www.statnews.com/2016/09/21/chronic-fatigue-syndrome-pace-trial/).

Professor Peter White likewise refused to accept the importance of the re-analysis: “It makes not a ha’porth of difference” (BMJ 2016;354:i5053).

These comments should be compared with what Professor Michael Sharpe said on Australian Radio on 18th April 2011: “What this trial wasn't able to answer is how much better are these treatments than really not having very much treatment at all” (http://www.abc.net.au/rn/healthreport/stories/2011/3192571.htm).

The role of The Lancet

By publishing the (selective) results of the PACE Trial in 2011, there appear to be breaches of the Elsevier Ethical Guidance policy by The Lancet, specifically, **Ethical Duties of Authors** in relation to:

“Reporting Standards: *Authors of reports of original research should present an accurate account of the work performed as well as an objective discussion of its significance.* ***Underlying data should be presented accurately in the paper. Fraudulent or knowingly inaccurate statements constitute unethical behaviour and are unacceptable.***

"Fundamental Errors in Published Works: *If the editor or the publisher learn from a third party that a published work contains a significant error, it is the obligation of the author to promptly retract or correct the paper or provide evidence to the editor of the correctness of the original paper*

"Ethics in Publishing: Instructions to Authors: *Ethics and Procedures (General): Fundamental Principles:* ***the paper should….be placed in the context of prior and existing research".***

With specific regard to **Ethical Duties of Reviewers**, The Lancet was asked to consider whether the relevant criteria had been met:

"Standards of Objectivity*: reviews should be conducted objectively*

Several of the requisite criteria set out in the **Elsevier Publishing Ethics Resource Kit (PERK)** appear to have been violated. In particular, there would appear to be issues with regard to:

"Research Error and Fraud (PERK 5): *Fraud is publishing data or conclusions that were not generated by experiments or observations, but by data manipulation or invention.* ***Changing the data measurements to conveniently fit the desired end result is fraud, but excluding inconvenient results is deliberate research error, which, in effect, is the same result – fraud***

"Research Standards Violations (PERK 6): *Research standards violations normally come to light when a referee sees that there was no informed consent on human subjects …*

"Undisclosed Conflicts of Interest (PERK 7): *Financial relationships (such as employment, consultancies, stock ownership, honoraria, paid expert testimony) are the most easily identifiable conflicts of interest and the most likely to undermine the credibility of the journal, the authors, and of science itself. However, conflicts can occur for other reasons, such as… intellectual passion".*

Infringements of Professional Ethics Codes include breaches of the Declaration of Helsinki (which occurred in the PACE Trial) and which states:

"Article Retraction: *Reports of research not in accordance with the principles of this Declaration should not be accepted for publication".*

"Article Replacement: *"Identification of false or inaccurate data that, if acted upon, would pose a serious health risk".*

All Elsevier journals are members of the Committee on Publication Ethics (COPE) and are required to take valid complaints seriously, but a detailed formal complaint was ignored and mocked, with The Lancet's Editor-in-Chief, Richard Horton, making derisory remarks about it on Australian Radio on 18th April 2011, referring to it as: *"a*

43 page diatribe" (http://www.abc.net.au/rn/healthreport/stories/2011/3192571.htm).

The relevant papers on the PACE Trial are:

1. Protocol for the PACE trial: A randomised controlled trial of adaptive pacing, cognitive behaviour therapy, and graded exercise as supplements to standardised specialist medical care versus standardised specialist medical care alone for patients with the chronic fatigue syndrome/myalgic encephalomyelitis or encephalopathy.
Peter D White, Michael C Sharpe, Trudie Chalder, Julia C DeCesare, Rebecca Walwyn and the PACE trial group
BMC Neurology 2007:7:6 DOI: 10.1186/1471-2377-7-6

2. Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial. P D White, K A Goldsmith, A L Johnson, L Potts, R Walwyn, J C DeCesare, H L Baber, M Burgess, L V Clark, D L Cox, J Bavinton, B J Angus, G Murphy, M Murphy, H O'Dowd, D Wilks, P McCrone, T Chalder, M Sharpe, on behalf of the PACE trial management group.
Lancet 2011; 377: 823–36 Published Online February 18, 2011 DOI:10.1016/S0140-6736(11)60096-2

3. Adaptive Pacing, Cognitive Behaviour Therapy, Graded Exercise, and Specialist Medical Care for Chronic Fatigue Syndrome: A Cost-Effectiveness Analysis. Paul McCrone, Michael Sharpe, Trudie Chalder, Martin Knapp, Anthony L. Johnson, Kimberley A. Goldsmith, Peter D. White Published: August 1, 2012 http://dx.doi.org/10.1371/journal.pone.0040808

4. Recovery from chronic fatigue syndrome after treatments given in the PACE trial. P. D. White, K. Goldsmith2, A. L. Johnson, T. Chalder and M. Sharpe; PACE Trial Management Group. Psychological Medicine (2013), 43, 2227–2235. Cambridge University Press 2013 doi:10.1017/S0033291713000020

5. Rehabilitative therapies for chronic fatigue syndrome: a secondary mediation analysis of the PACE trial.
Trudie Chalder, Kimberley A Goldsmith, Peter D White, Michael Sharpe, Andrew R Pickles
Lancet Psychiatry 2015; 2: 141–52 Published Online January 14, 2015
http://dx.doi.org/10.1016/S2215-0366(14)00069-8

6. Rehabilitative treatments for chronic fatigue syndrome: long-term follow-up from the PACE trial.
Sharpe, Michael et al. The Lancet Psychiatry December 2015, Volume 2, Issue 12 , 1067 – 1074 Volume 2, No. 12, p1067–1074

Conclusion

The amount of published papers by the Wessely School promoting their own beliefs about the nature of ME/CFS is enormous (the above quotations are merely illustrative) and the extent of the incorporation of their beliefs into medical practice cannot be over-stated as it has become the default position.

This is illustrated by the outcome of a seminar (reported by Horace Reid, who was present) on 14th December 2016 at The School of Law, Queen's University, Belfast, where Dr Charlotte Blease from University College, Dublin, spoke on "Epistemic Injustice and the Ethics of Healthcare Encounters: Evidence from Chronic Fatigue Syndrome". Her analysis of NHS ethical failure was neutral, factual, rational and dispassionate.

She said: " 'Many doctors (and medical students) display uncertainty about whether or not CFS/ME is real…Patients with CFS/ME often experience suspicion by health professionals…The (often unintentional) marginalization of many CFS/ME patients represents a failure in medical professionalism, one that may lead to further ethical and practical consequences both for progressive research into CFS/ME and for ethical care'.

"With one exception, doctors attending the seminar were either defensive or silent. In their eyes, the ME patients present were conforming to stereotype (angry, unscientific, unreasonable) and therefore they – the doctors – would not engage with them. Paradoxically, these doctors were themselves conforming to another stereotype, as described by the speaker: 'Knowledge-formation is also influenced by social and cultural factors. Such encounters have an inherent power differential; there is significant potential…to be unjust from an epistemic point of view'.

"Why are ME patients widely stigmatised, and by the NHS? The answer is that for 30 years the NHS has operated on the false hypothesis that CFS/ME is – in whole or in part -- a psychiatric entity.

"This claim was successfully propagated by Professors Simon Wessely, Michael Sharpe and Peter White. They are charismatic, and for three decades they were universally persuasive. But they were monumentally wrong. 30 years of research effort and funding have been wasted.

"Charlotte Blease's thesis got to the heart of NHS failure with CFS/ME. Her proposition is well-founded, except in one respect. In July and August 2011 Simon Wessely ran a media campaign with the BBC and the broadsheets, successfully vilifying patients who had justifiably criticised his research. In his case, the marginalisation of ME patients was not 'unintentional'. It was active and deliberate". (Horace Reid; personal communication 05.01.2017)

It is important to be aware that:

(i) the vast amount of published "research" into ME/CFS emanating from the Wessely School psychiatrists and in particular, from the UK PACE Trial, does not accord with the extensive biomedical literature

(ii) it is widely believed that three decades of iatrogenic harm have resulted from the application of the Wessely School's beliefs about the nature of ME/CFS

(iii) the Institute of Medicine (IOM) of the National Academies produced a report "Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness" which was published on 10th February 2015; it stated: "ME/CFS is a serious, chronic, complex, multisystem disease that frequently and dramatically limits the activities of affected patients. In its most severe form, this disease can consume the lives of those whom it afflicts. It is 'real' " **(**https://iom.nationalacademies.org/Reports/2015/ME-CFS.aspx)

(iv) after publication of the IOM committee report, the CDC decided to archive its "CFS Toolkit" which had recommended the cognitive behavioural and exercise interventions so strenuously promoted by the UK psychiatric lobby. In its "Brief Report" of February 2015 that accompanied the full Report**, the IOM pointed out: "Many health care providers are skeptical about the seriousness of ME/CFS, mistake it for a mental health condition, or consider it a figment of the patient's imagination.** Misconceptions or dismissive attitudes on the part of health care providers make the path to diagnosis long and frustrating for many patients

(v) The National Institutes of Health (NIH), one of the world's foremost medical research centres, convened a "Pathways to Prevention" (P2P) working group which on 16th July 2015 published its Report "Advancing the Research on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome". **The Report is clear: "Strong evidence indicates immunologic and inflammatory pathologies, neurotransmitter signaling disruption, micorobiome perturbation, and metabolic or mitochondrial abnormalities in ME/CFS that are potentially important for defining and treating ME/CFS…Both society and the medical profession have contributed to ME/CFS patients feeling disrespected and rejected. They are often treated with skepticism, uncertainty, and apprehension and labeled as deconditioned or having a primary psychological disorder. ME/CFS patients often… treated inappropriately causing additional harm…It is not a primary psychological disease in etiology…**"fMRI and imaging technologies should be further studied as diagnostic tools and as methods to better understand the neurologic dysfunction of ME/CFS…Many clinicians do not fully understand ME/CFS…Specifically,

> continuing to use the Oxford definition may impair progress and cause harm. Thus, for needed progress to occur we recommend that the Oxford definition be retired" (https://prevention.nih.gov/programs-events/pathways-to-prevention/workshops/me-cfs/workshop-resources#finalreport).

It is impossible to place any credibility on the PACE trial's official results.

It seems it is likewise impossible to place reliance on Professor White himself, as just one example confirms: as noted above, following a formal complaint to The Lancet, in 2011 he wrote to Richard Horton, the Editor-in-Chief, stating categorically and unambiguously: **"The PACE trial paper refers to chronic fatigue syndrome (CFS) which is operationally defined; it does not purport to be studying CFS/ME"** (www.margaretwilliams.me).

However, on 22nd September 2016 he wrote in the BMJ: "**The PACE trial was the largest clinical trial to date into Chronic Fatigue Syndrome (CFS), also sometimes referred to as Myalgic Encephalomyelitis (ME)**" (http://blogs.bmj.com/bmj/2016/peter-white-et-al-releasing-patient-dara-from-the-pace-trial-for-chronic-fatigue-syndrome/).

Professor White's two statements about the same issue contradict each other: in one, he says he was not studying CFS/ME but in the other, he says his PACE Trial was indeed studying CFS/ME. This is a matter of critical importance and there should be no room for any dissembling.

Surely the stalwart determination of Professor White to defeat the court and prevent independent scrutiny of the trial's data, at a cost to his own university of over £250,000, strongly suggests that the published and reported results were in fact a distortion, and that CBT and GET are no more than elaborate placebos which confer no benefit.

There seems to be a similar problem in placing reliance on Professor Sir Simon Wessely himself.

He is on record as dismissing ME as nothing but a belief and a myth; as occurred during his 1994 lecture and as Dr Byron Hyde has documented, Wessely is known to mock and ridicule ME patients, yet in his 2013 lecture in Bristol he presented himself as a caring and compassionate saviour of patients who had been suffering neglect and ridicule at the hands of neurologists and the medical profession in general but, he said with pride, he himself knew even in 1987 that these patients had a "real" illness.

The facts are very different: from his published work it is clear that instead of being the "saviour" of patients, as he portrayed himself in his talk, it was he who helped establish the fundamental confusion which has bedevilled patients for decades.

Wessely portrayed himself as being genuinely upset that patients suffered from the "terrible negative image" of a severe illness for which no-one knew the cure, but that (quote) "getting better from ME" obviously was not important for patients. Prolonged cases of illness, he claimed, are generally perpetuated by emotional causes and people cannot risk getting better.

He emphasised that patients' thoughts had to change, which was all that was needed for patients to get better.

In support of this, he spoke of the PACE Trial, admiring it as a "truly beautiful piece of research" with which he was very proud to be involved.

Referring to the comment about the PACE Trial by Dr Charles Shepherd of the ME Association ("This is not a good day for people with ME/CFS"), Wessely said: "What more evidence do you need to show how destructive these charities can be and how patients are utterly determined to reject treatments that help them" (this being the explicit message to his audience of doctors).

In April 1990, the First World Symposium on ME/CFS was held at the University of Cambridge. The predominant view was of a persistent or chronic viral infection which either gave rise to, or was the result of, a continuing abnormal immune response and abnormalities of the muscle and central nervous system**. Evidence was presented of an infective vasculitis in ME/CFS. The conclusion of the Symposium was plain: ME/CFS is a true organic disease, with abundant evidence of its organic nature. Why has this been ignored for 26 years?**

Can there be any credible doubt that Professors Wessely, White and Sharpe have been responsible for years of suppression of the biomedical evidence about ME/CFS in the UK; for the wasting of many millions of pounds sterling in unwarranted "behavioural" research and for creating an environment which has caused suffering – both physical and financial – to patients with ME/CFS? As Professor Malcolm Hooper said, this is indeed a travesty of science and a tragedy for patients.