

Professor Simon Wessely's award of the inaugural John Maddox Prize for his courage in the field of ME and Gulf War Syndrome

Professor Malcolm Hooper (with members of the ME community) **12th November 2012**

On 6th November 2012 it was announced that: *“Two strong-minded individuals are the first winners of an award for standing up for science....The prize rewards individuals who have promoted sound science and evidence on a matter of public interest, with an emphasis on those who have faced difficulty or opposition in doing so”*. The award is the inaugural John Maddox Prize and it was awarded jointly to the British psychiatrist Professor Simon Wessely for his courage in facing opposition to his views about ME and Gulf War Syndrome and to the Chinese science writer Shi-min Fang. The Kohn Foundation contributed to the prize. The initiative for the prize was shared between the journal Nature and the charity Sense about Science, a sibling of the Science Media Centre (on both of whose Advisory Councils Wessely himself is a member). The presentation can be viewed at <http://www.nature.com/news/courage-for-sound-science-wins-john-maddox-prize-1.11760>

Given that Wessely's belief that ME is a somatoform disorder has been comprehensively invalidated by the scientific evidence, for him to have received a prize for *“standing up for science”* for his work on ME/CFS has resulted in deserved derision, not least because it does not accord with the Declaration of Helsinki: section B11 requires that *“Medical research involving human subjects must conform to generally accepted scientific principles (and) be based on a thorough knowledge of the scientific literature”*, but Wessely's work ignores the existing scientific literature.

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.

International clinicians and medical scientists have repeatedly shown that Wessely has not produced *“sound science and evidence”* about either ME or Gulf War Syndrome and his work is widely referred to as “pseudoscience” by patients and professionals alike. Indeed, 21 years ago Peter Behan, Professor of Neurology at Glasgow, stated that the psychiatric hypothesis: *“lacked all scientific merit and now, with the emergence of hard data, can be totally rejected”* (Myalgic Encephalomyelitis: Postviral Fatigue Syndrome: Diagnostic and Clinical Guidelines for Doctors. The ME Association, 1991).

What the “Wessely School” (Hansard: Lords: 9th December 1998:1013) refer to as “CFS/ME” is, according to them, a “functional somatic syndrome” (ie. a behavioural disorder) in which medically unexplained fatigue is perpetuated by inappropriate illness beliefs, pervasive inactivity, current membership of a self-help group and being in receipt of disability benefits (PACE Trial Identifier, section 3.9 – see below). They insist that it should be managed by behavioural interventions (cognitive behavioural therapy/CBT and graded exercise therapy/GET) to “reverse” and “cure” the patients' mis-perceptions. Simon Wessely believes that attribution by patients to a virus is somatisation *“par excellence”* (J Psychosom Res 1994:38:2:89-98). According to the Wessely School's beliefs, to their teaching of students and other clinicians, and to their recommendations to Government departments to

which they are official advisors on “CFS/ME”, there are no physical signs of disease and there is no pathology causing the patients’ symptoms, and patients are merely “*hypervigilant*” to “*normal bodily sensations*”.

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*”.

Moreover, Professor Luc Montagnier (who in 2008 won the Nobel prize for discovering the AIDS virus), Honorary Member of the European Society for ME, is on record thus: “*Scientists have already uncovered a lot about ME, but this information does not reach professional healthcare personnel, and the disease is not taken seriously. It is about time this changes*” (<http://esme-eu.com/home/experts-launch-think-tank-for-mystery-disease-article37-6.html>).

This is an important point: it is not that accurate information and knowledge are unavailable; it is that in the UK, the information and knowledge are being systematically blocked by the extremely efficient and effective networking of the Wessely School who ensure that the gap between bench and bed is filled with their own views about “CFS/ME”.

Additionally, Professor Ian Lipkin, Director, Centre for Infection and Immunity, Columbia University, said on the record that patients with ME have a particular pattern of immunoreactivity, indicating a persistent disease process: “*Back in the mid to late 1990s...I looked at these Chronic Fatigue Syndrome patients, many of them coming out of a clinic that was run in the Karolinska, which at that point was one of the best clinics for CFS in the world....I said these patients are clearly sick in some way. They have some kind of immunological activation...I am convinced, after working in this field for a very long time, that this is a bona fide syndrome*”. ME/CFS was described as “*this crippling disease*” (transcript of podcast with Professors Vincent Racaniello and Ian Lipkin, 18th September 2012, This Week in Virology).

At a press conference on 18th September 2012 at Columbia University, Professor Lipkin emphasised the enormous amount of immune activation he had uncovered in ME/CFS patients, with two-thirds to three-quarters of the patients exhibiting polyclonal B-cell activation. ME/CFS, he said, “*is not a psychosomatic disorder*”. Professor Lipkin specifically encouraged patients with ME to be active in the political arena, remarking that advocacy and political leadership made “*a huge difference*” in obtaining significant funding (<http://www.prohealth.com/library/showarticle.cfm?libid=17220>). In the New York Times, David Tuller reported that Professor Lipkin said that he viewed ME/CFS as “*a major illness*” (NYT 18th September 2012).

At the AGM of the UK charity Action for ME held on 30th October 2012, Professor Julia Newton, Associate Dean at the University of Newcastle, UK, presented evidence using MRI scans to show brain, cardiac and muscle abnormalities in people with ME, as well as the relationship between cognitive impairment and autonomic dysfunction.

International experts have shown beyond doubt that Wessely's beliefs about ME/CFS are erroneous: there are over 6,000 peer-reviewed papers demonstrating the biomedical underpinnings and these comprehensively disprove Wessely's "aberrant behaviour" model (for illustrations, see "Magical Medicine: How to Make a Disease Disappear", pages 11-13 and Section II, pages 98 – 211:<http://www.meactionuk.org.uk/magical-medicine.htm>).

In March 2003 the "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Clinical Working Case Definition, Diagnostic and Treatment Protocols" (known as the Canadian Guidelines) were published, with 237 references (BM Carruthers et al. JCFS 2003:11(1):7-115). They represented evidence-based clinical practice and research provided by a panel of world experts with extensive experience of the disorder; its distinguished authors were critical of Wessely's psychosomatic model, stating that there was "*much that is objectionable*" about it and that it was "*far from being confirmed...Nevertheless, the assumption of its truth by some has been used to influence attitudes and decisions within the medical community....To ignore the demonstrated biological pathology of this illness, to disregard the patient's experience and tell them to ignore their symptoms, all too often leads to blaming the patients and (the) withholding medical support and treatment....Care must be taken not to classify patients experiencing chronic fatigue as ME/CFS patients....The question arises whether a formal CBT and GET programme adds anything to what is available in the ordinary medical setting. A well-informed physician empowers the patient...and helps them achieve optimal activity levels within their limits in a common sense, non-ideological manner, which is not tied to deadlines or other hidden agenda*". The Canadian Guidelines set out the defining features of ME/CFS, notably the cardinal feature (post-exertional exhaustion and malaise) and the criteria necessary for a diagnosis of ME/CFS (ie. the measurable and reproducible dysfunction of the immune, neurological, autonomic, neuroendocrine, musculo-skeletal, cardiovascular, respiratory and gastrointestinal systems).

In 2005 a 27-page "Overview of The Canadian Consensus Document: A Clinical Case Definition and Guidelines for Medical Practitioners" was published (BM Carruthers et al), which stated that ME/CFS "*is an acquired organic pathophysiological multi-system illness...classified as a neurological disease*" and detailed the symptoms and signs (including abnormalities in resting heart rate; maximum oxygen uptake; cardiac output; cerebral blood flow; respiration; cognitive functioning; gait kinetics; abnormalities of gene expression; temperature and blood pressure control and oxygen delivery to muscles). The authors noted that structural and functional neuroimaging show disruption in the normal coordination between the brain and the body, and the presence of muscle weakness and fasciculation, breathing dysregulation, intestinal irregularities, bladder dysfunction, cardiac dysfunction and vasculopathy, together with dysautonomia and marked immune system dysfunction.

In 2011 the "International Consensus Criteria" were published as a Review in the Journal of Internal Medicine (BM Carruthers et al. 2011:270:4:327-338), which was limited to the criteria of ME and their application, all of which are supported by research. The authors stated: "*Myalgic encephalomyelitis (ME), also referred to in the literature as chronic fatigue syndrome (CFS), is a complex disease involving profound dysregulation of the central nervous system and immune system, dysfunction of cellular energy metabolism and ion transport, and cardiovascular abnormalities....Individuals meeting the International Consensus Criteria have myalgic encephalomyelitis and should be removed from...the NICE criteria for chronic fatigue syndrome*".

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.

Also in 2012, because research and clinical experience strongly point to widespread neuro-inflammation and multisystem pathology, the best clinicians and scientists in the field (from 13 countries, with 400 years of both clinical and academic experience between them, and having treated approximately 50,000 patients with ME, as well as having authored hundreds of peer-reviewed publications) also published a primer for clinicians (“Myalgic Encephalomyelitis – Ault and Paediatric: International Consensus Primer for Medical Practitioners” supported by 154 references (BM Carruthers et al: The National Library of Canada; ISBN 978-0-9739335-3-6). The authors were succinct: “*Misperceptions have arisen because the name ‘CFS’ and its hybrids ME/CFS, CFS/ME and CFS/CF have been used for widely diverse conditions. Patient sets can include those who are seriously ill with ME, many bedridden and unable to care for themselves, to those who have general fatigue...There is a poignant need to untangle the web of confusion caused by mixing diverse and often overly inclusive patient populations in one pot called ‘chronic fatigue syndrome’*”.

In the Medical Research Council’s PACE Trial (see below), the Wessely School intentionally sought to include as many people with “fatigue” as possible: by letter dated 14th July 2006 to the West Midlands MREC, the Chief Principal Investigator (PI), Professor Peter White, requested permission to advertise (his word) the PACE Trial to GPs. The wording of the

advertisement to GPs is significant: “*If you have a patient with definite or probable CFS/ME, whose main complaint is fatigue (or a synonym), please consider referring them to one of the PACE Trial centres*”. **Just how scientifically rigorous the inclusion of patients with “fatigue (or a synonym)” might be is a matter for speculation.** It seems that the PIs’ intention was clear: “*Subjects will be required to meet operationalised Oxford criteria for CFS... We chose these broad criteria in order to enhance generalisability and recruitment*” (PACE Trial Identifier Section 3.6), and at the International Science Festival held on 9th April 2004 in Edinburgh, Michael Sharpe, one of the PACE Trial’s PIs, spoke in a debate entitled “Science and ME” and was specifically asked if patients with fibromyalgia (FM), a completely separate disease classified in the WHO ICD-10 at M79, were to be included in the PACE Trial of “CFS/ME”. Sharpe replied in the affirmative, implying that patients with FM needed to be included in order to reach the recruitment target. He said (*verbatim*): “*We want broadness and heterogeneity in the trial*”. Moreover, Section 3.17 of the Trial Identifier states that there is no intention to perform subgroup analyses of “fatigued” participants.

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*”.

The PACE Trial fiasco

Despite all the scientific evidence which completely disproves the Wessely School's assertions about the nature of ME/CFS, from 2004 – 2011 Wessely and his colleagues received £5 million of tax-payers' money in order to try to prove definitively their own beliefs that people with ME can recover with "cognitive re-structuring" (ie. brain-washing) and incremental graded exercise in a trial known as The Medical Research Council's "PACE" Trial. Wessely himself oversaw the PACE Clinical Trial Unit (which was primarily responsible for design and management of the trial).

The Patient Leaflet (<http://pacetrial.org/trialinfo.html>) that encouraged patients to become PACE Trial participants states: "*Chronic fatigue syndrome*" is "*also known as post-viral fatigue syndrome (and) myalgic encephalomyelitis (ME)*"; the same leaflet also states: "***Medical authorities are not certain that CFS is exactly the same illness as ME, but until scientific evidence shows that they are different they have decided to treat CFS and ME as if they are one illness***".

Thus there can be no doubt that the Wessely School are referring to ME, a classified neurological disorder (WHO ICD-10 G93.3) and not a psychiatric (somatoform or behavioural) disorder.

Prior to publication of selected results in The Lancet online in February 2011, the Principal Investigators deviated from the statistical analysis described in the Trial Protocol, with the result that a participant could deteriorate on both primary outcome measures (physical function and fatigue) following treatment and still fall within the redefined "*normal range*" (interpreted as "normal" health). **It cannot be acceptable to describe a PACE Trial participant at the end of the trial as having attained levels of physical function and fatigue "within the normal range" and to consider the same participant sufficiently disabled and symptomatic, as judged by the same recorded levels of physical function and fatigue, to have qualified for entry into the PACE Trial in the first place.**

Notwithstanding, on 17th February 2011 a press conference was held at the Science Media Centre (SMC) and, to a not inconsiderable fanfare, the PACE Trial article in The Lancet – due to be published the following day -- was launched as being "successful".

The emanations from the Science Media Centre are generally accepted by informed observers to be suspect because it represents only one narrow section of the scientific community (<http://ngin.tripod.com/020602c.htm>) and there was certainly profound mis-reporting about the PACE Trial by committed Wessely School adherents (some of whom, like many members of the Wessely School, work for the Permanent Health Insurance industry).

At the press conference, a number of grossly inflated and quite unjustified claims were made because, although no recovery statistics had been published, one of the PIs (Professor Trudie Chalder) said on the record: "*twice as many people on graded exercise therapy and cognitive behaviour therapy got back to normal*"; this was reported *verbatim* the following day in The Guardian, whose health correspondent stated: "*More people recover if they are helped to try to do more than they think they can*" ("Study finds therapy and exercise best for ME". Sarah Bosely. The Guardian, 18th February 2011).

The Science Media Centre press release included the following:

- Dr Alastair Miller from Liverpool: ***“This trial represents the highest grade of clinical evidence – a large randomised clinical trial, carefully designed, rigorously conducted and scrupulously analysed and reported. It provides convincing evidence that GET and CBT are safe and effective and should be widely available for our patients with CFS/ME”.***

It should be noted that Dr Miller was one of the three “independent” assessors of trial safety data for the PACE Trial.

As the PACE Trial was not a controlled trial, Dr Miller was in error to refer to it as ***“the highest grade of clinical evidence”***, and it cannot be described in such terms.

- Dr Brian John Angus: ***“The study should reassure patients that there is an evidence based treatment that can help them to get better.... It was extremely rigorous... (and) was carefully conducted....As a trial this involved a huge amount of checking and cross checking....This should mean that GET and CBT should be widely available throughout the country....The trial was conducted to a high ethical standard... It was rigorously performed”.***

Dr Angus was Centre Lead for the PACE Trial in Oxford.

- Professor Derick Wade from Oxford: ***“The trial design of this study was very good, and means the conclusions drawn can be drawn with confidence. This is a very significant finding. It identifies that one commonly used intervention (by which he meant pacing) is not effective (and therefore should not be used), and it confirms the effectiveness of two treatments, and their safety. The study suggests that everyone with the condition should be offered the treatment, and every patient who wishes to be helped should be willing to try one or both of the treatments”.***

Professor Wade has written to the DWP advising that, despite the WHO classification, ME/CFS is not a neurological disorder but a ***“non-medical illness”*** (letter dated 22nd August 2005 to Dr Roger Thomas, Senior Medical Policy Advisor in the Benefit Strategy Directorate at the DWP). He has also written to an ME/CFS patient: ***“it is wrong to fit ME/CFS into a biomedical model of illness”*** (letter dated 7th July 2006).

- Dr Willie Hamilton: ***“This study matters. It matters a lot....It sends a powerful message to PCTs – and the soon-to-be-formed GP consortia – that they must fund CBT or GET. NICE proposed this before the study came out – the evidence is stronger now”.***

Dr Hamilton is Chief Medical Officer for three permanent health insurance companies -- Exeter Friendly Society, Liverpool Victoria and Friends Provident – and he categorises ME/CFS as a functional disorder. (People diagnosed as having this disorder will thus be excluded from payments under a permanent health insurance policy with these companies, since psychiatric disorders are not covered). He was a member of the NICE CG53 Guideline Development Group which recommended CBT/GET as the only intervention for people with ME/CFS.

Thus the Science Media Centre obtained quotations only from people with known and indisputable biases.

On 18th February 2011 The Lancet online published selected results of the PACE Trial which allegedly showed that CBT and GET “*moderately improve outcomes for chronic fatigue syndrome*” (PD White et al; “Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial”). **It made no mention of any of the biomedical evidence, thereby implying that the premise upon which the PACE Trial was based is scientifically valid.**

An accompanying Comment in The Lancet claimed that “*the recovery rate of cognitive behaviour therapy and graded exercise therapy was about 30%*”, about which Zoe Mullan, Senior Editor at the Lancet, confirmed in response to a complaint: “*Yes, I do think we should correct the Bleijenberg and Knoop Comment, since White et al explicitly state that recovery will be reported in a separate report*” (personal communication, 8th June 2011).

That Comment has not been withdrawn or corrected even though no recovery or return to employment rates have been published.

It is known that, despite previous assurances from the Investigators that those results were to be published at a later date, the results on both recovery and return to employment are so bad that the Chief Principal Investigator, Professor Peter White, is reluctant to publish them and they will not be published (personal communication, 12th November 2012).

This is despite the fact that (i) the Trial Protocol specified the precise statistics which would define “recovery”; (ii) in his letter of March 2011 to the editor-in-chief of The Lancet (Richard Horton), Peter White stated: “*We are planning to publish a paper comparing proportions meeting various criteria for recovery or remission, so more results pertinent to this concern will be available in the future....Future papers...are in preparation including reports of economic outcomes, different definitions of recovery and remission...and long-term follow up*” and (iii) in his reply published in The Lancet to complaints about his paper (online 17th May 2011), Peter White stated: “*It is important to clarify that our paper did not report on recovery; we will address this in a future publication*”.

Twenty-one months later, he has not done so. What sort of (publicly funded) scientists refuse to produce their outcome data?

It is notable that the British Medical Journal (BMJ) will refuse to publish research papers unless all clinical trial data is made available for independent scrutiny (The Times Health, 31st October 2012) and signatories to the campaign to end the “*on-going secrecy*” surrounding clinical trials include Dr Clare Gerada, President of the Royal College of GPs and wife of Simon Wessely.

The ultimate proof of the failure of Wessely’s work is to be found in the PACE Trial, and by normal scientific standards, the results of that Trial should be the death of the Wessely School model of ME.

Accolades for Professor Wessely for his work on ME/CFS

Given the abundance of the biomedical evidence-base that exists about ME, it is incomprehensible how any scientist could support the award of the John Maddox Prize to Simon Wessely, yet the accolades from these pillars of the Establishment are there for all to see.

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....in the words of his friend Walter Gratzer (John Maddox): ‘wrote prodigiously on all that was new...in scientific discovery, denouncing fearlessly what he believed to be wrong, dishonest or shoddy’”* and she referred to *“the courage and responsibility that people are taking for communicating sound science and evidence”*.

The journal Nature said it congratulates 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, 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, 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, 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”*.

On one of the blogs relating to the John Maddox Prize
(<https://noodleamaz.wordpress.com/2012/11/07/john-maddox-prize-2012/#comment-3033>,

noting Wessely's frequent resorting to the press in order to demonise the entire ME patient population who disagree with him, people have commented on the inappropriateness of the award, for example:

- *“Giving the award to Wessely makes science a laughing stock”*
- *“ in the case of Simon Wessely, the arguments are poor and the methodology is poor”*
- *“(his) actions over the years seem to have epitomised the term ‘anti-science’ (and) I can think of few people less worthy than Prof Simon Wessely.....real science is exploding the myths that he has created”.*

On the MEActionUK group site are the following comments:

- *“We have become used to people in the entertainment industry giving each other meaningless incestuous awards for the purpose of self-aggrandising puffery, but we expect better from serious scientists. Simon Wessely should be an embarrassment to the scientific community.....His ill-mannered dismissals of the patients’ plight as being in effect ‘all in the mind’ is bad enough, but he has somehow acquired friends in high places....Quite simply, on the say-so of one not-particularly-specialist academic, research into a serious illness blighting the lives of a huge number of people has been stopped in its tracks. Furthermore, even the serious press seems to have been ‘got at’, dismissing criticisms of Wessely’s views as the work of loonies. It is hard to know where to go with this when there appears to be such determined stonewalling by a group of cronies in the scientific community, but as we have seen with the Savile revelations, corruption always gets exposed eventually, even if there’s a very long wait”.*
- *“I, too, am dismayed that this prize was awarded to Simon Wessely. He has done much harm to people who are seriously ill by focusing attention away from biological research into this hellish disorder and by trivializing their suffering in claiming it is about “beliefs”... Perhaps he helps some people, but they cannot have the serious physical disorder of ME/CFS, which I have studied – and observed first hand in a very severely ill family member – for nearly three decades and which, I can assure you, is not amenable to any change in belief structure.....Before leaping to support someone so universally disliked by the patient community, it would have been advisable for those making the award to speak with knowledgeable researchers about the actual physiology underlying the illness. Wessely’s detractors are not in any way a minority, the questions they raise are not “bogus” and their complaints are not mischievous. (Lynn Royster JD, PhD).*
- *“Where is the science in the views that Simon Wessely has promoted over a long and profitable career? The constant reiteration of a fallacy does not prove it, no matter how many times it is referenced”.*
- *“I think the widespread disdain, if not outright contempt, that Prof Wessely’s work is shown by the patient communities that this (prize) claims he helps is entirely deserved and will be shown to be so in history’s 20/20 vision. Rather than, or as well as,*

awarding Prof Wessely for being so 'strong minded' in the face of such voluminous criticisms, perhaps it might be worth investigating the subject to find out why such criticism exists in the first place”.

At <http://www.the-scientist.com/?articles.view/articleNo/33211/title/Awarding-Science-Defense/> can be found the following comments:

- *“Perhaps equally courageous are the numerous biomedical researchers whose...sound science does not validate Dr Wessely’s – in part because they do not use the same definition or study the same patients. And who soldier on despite a historic lack of funding and universities demanding they stop their research or be fired”.*
- *“Simon Wessely’s efforts to psychologise a devastating physical illness have outraged pretty much the entire population of people affected with “CFS” and are decried by every single patient group....There is far more (and stronger) research supporting a physical origin for CFS than there is supporting Wessely’s view, and this body of research is growing every day. Virtually every CFS expert outside the UK treats this as a physical disease...Wessely is far from a hero of science, nor a bold defender of good science...he is one who wilfully ignores scientific advances in ‘his own’ field (though, since he is a psychiatrist, the important research isn’t in his own field)...The award is an outrage....The time will come when Nature magazine, sponsor of the prize, will regret its part in championing this man and his quack ‘science’”.*

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...One of the judges, Professor Colin Blakemore – also on the advisory council – said earlier this week in the Times: ‘If scientists are silent, loony ideas will win’. Why reward the loony ideas then?”* (Nasim Marie Jafry, 8th November 2012).

Evidence of professional concern about Wessely’s work on ME

That there is profound professional concern and dismay about Wessely’s work on ME is typified by the following:

“The belief that ME/CFS is a psychological illness is the error of our time” (The Complexities of Diagnosis. Dr Byron Hyde. In: Handbook of Chronic Fatigue Syndrome. Ed: Leonard A Jason et al. John Wiley & Sons Inc. 2003).

“...to assign someone to the wrong category on the basis of a false understanding of the nature of the illness and its context is an example of a well-known phenomenon which psychologists term ‘fundamental attribution error’ “ (Dr Derek Pheby: InterAction 2009:69:16-17).

“I hope you are not saying that (ME)CFS patients are not as ill as HIV patients. I split my clinical time between the two illnesses, and I can tell you that if I had to choose between the two illnesses (in 2009) I would rather have HIV” (Nancy Klimas, one of the world’s

foremost AIDS and ME/CFS physicians; Professor of Medicine and Immunology, University of Miami; New York Times, 15th October 2009).

It was in 2000 that Anthony Komaroff, Professor of Medicine at Harvard, said: *“There is now considerable evidence of an underlying biological process which is inconsistent with the hypothesis that (ME/CFS) involves symptoms that are only imagined or amplified because of underlying psychiatric distress. It is time to put that hypothesis to rest”* (The Biology of the Chronic Fatigue Syndrome. Am J Med 2000:108:99-105).

Twelve years later, Wessely has been rewarded for continuing to promote exactly that hypothesis, which is described as “sound science”.

What, then, is all this about?

The influence of industry

The permanent health insurance industry does not like the disease ME/CFS.

An article in 2002 by Peter Pallot on health insurance gives examples of the risks of chronic illnesses such as ME/CFS for medical insurance companies: referring to the Chief Medical Officer’s recognition of ME/CFS as a genuine disorder, Pallot said:

“Official recognition has not brought clarity for insurers. Take for instance a 30 year old who succumbed aged 30 when earning £75,000 a year. The policyholder might be in line to get two-thirds salary -- £50,000. Over 35 years, if the condition never resolved, the insurer would be paying out £1.75 million. Re-naming the condition CFS and discarding earlier labels including ME was helpful. ‘Syndrome’ implies a range of causes and symptoms. The company’s exposure to chronic fatigue claims has pushed it into a very proactive approach. We get Prisma to talk to the individual and also to the partner; Prisma will work out a programme. Until recently, the role of IP (income protection) providers stopped at paying claims. Now they are initiating intervention” (<http://www.hi-mag.com/healthinsurance/article.do?articleid=20000081634>).

PRISMA is a multi-national healthcare company working with insurance companies; it arranges “rehabilitation” programmes (ie. GET) for those claiming on their insurance policies and it claims to be especially concerned with long-term disability from the perspective of Government, service providers and insurance companies. **In the PRISMA company information, Simon Wessely was listed as a Corporate Officer; he was a member of the Supervisory Board, and in order of seniority, ranked higher than the Board of Management.**

Could there be a more clearly expressed reason for the determination of Wessely School members who do so much work for the medical insurance industry to deny that ME/CFS exists and to oppose the evidence that it is a serious, multisystem organic disease from which full recovery is unlikely? If objective evidence of pathology were to be acknowledged, that would remove the insurers’ assertion that “CFS/ME” is a psychosocial disorder.

Despite the fact that the WHO has classified ME as a neurological disorder since 1969, the permanent health insurance industry for which many of the Wessely School psychiatrists

work is known internationally not to pay out on a policy if they can possibly avoid doing so: “*UNUM stands to lose millions if we do not move quickly to address this increasing problem*” (UNUM’s CFS Management Plan; Dr Carolyn Jackson, 4th April 1995). Certainly, the Wessely School has worked assiduously for the last quarter of a century to change the WHO classification and they have exerted significant control over the perception of the disorder throughout the UK for over twenty five years, including over the funding bodies such as the Medical Research Council (where the disorder comes under the aegis of its Mental Health Board: the MRC’s Mental Health Board Strategy and Portfolio Overview report of January 2005 confirms at paragraph 6.2: “*Mental health research in this instance covers CFS/ME*”).

In 2000, the UK WHO Collaborating Centre for Mental Health at the Institute of Psychiatry misclassified the disorder as a mental (behavioural) disorder in its “Guide to Mental Health in Primary Care” by using Wessely’s own material on “CFS/ME”. The Guide was funded by the Department of Health. Despite strenuous complaints and despite WHO ICD-10 classifications being mandatory in the UK, sales of the Guide were allowed to continue unabated until almost 30,000 copies had been sold. Eventually, an erratum was issued but this did not prevent the disorder being wrongly classified as a mental disorder in the NHS Mental Health Data Manual, nor did it prevent Ministers of State and Members of Parliament from receiving the impression that it was the WHO itself (not the WHO Collaborating Centre in the UK) that had re-classified the disorder as a mental disorder. In September 2001 the WHO issued a statement repudiating the unofficial re-classification by the UK Collaborating Centre. The matter was raised in Parliament on 22 January 2004, where Earl Howe noted the suggestion that Professor Wessely had “*effectively hijacked the WHO logo to give credence to his own view of ME as a mental illness*” (Hansard [Lords] 23 January 2004:Vol 656:No 7:1192). The ME Association Newsletter of March 2004 stated: “*The issue mattered because the psychiatrists had stifled access to research funds for any UK researchers wanting to study organic causes*”.

Undaunted, these Wessely School psychiatrists then asserted that the WHO ICD-10 itself had classified the same disorder in two places, once in the Neurological Section and also in the Mental (Behavioural) Section. Yet again, their claims were repudiated by the WHO, who on 23rd January 2004 confirmed: “*According to the taxonomic principles governing ICD-10, it is not permitted for the same condition to be classified to more than one rubric*”. Ministers were forced to correct their own misinformation and on 11th February 2004 the Health Minister formally confirmed that the correct classification for the disorder remains neurological.

In their determination to supplant sound science with their own ideology, the Wessely School resolutely dismiss the international biomedical evidence-base and continue to target “*the attitudes and beliefs of doctors*” in order to further their own disproven beliefs that ME is a behavioural disorder and thus does not qualify for insurance payments (Cognitive and behavioural treatments for functional somatic syndromes; Presentation by Professor Peter White; Royal Society of Medicine; International Forum on Disability Management, 10th-12th September 2012).

Industry’s role

The aim of Sense about Science seems to be to “educate” the public so that it unquestioningly accepts industry’s agenda for ever-tighter control of the nation’s health.

Its Director, Tracey Brown, is known for a Discussion Paper extolling the peer review system in the alleged protection of the public (The Times, 18th June 2005). Given the wide and long-standing acknowledgement of how seriously the peer-review system is flawed, the unquestioning public acceptance of the secret peer-review process continues to raise legitimate concerns (False positives: fraud and misconduct are threatening scientific research; The Guardian, 13th September 2012:<http://www.guardian.co.uk/science/2012/sep/13/scientific-research-fraud-bad-practice>); Scientific fraud is rife: it’s time to stand up for good science; The Guardian, 4th November 2012: <http://www.guardian.co.uk/science/blog/2012/nov/02/scientific-fraud-good-science?cat=science&type=article>). Other members of the Sense about Science Working Group that produced the Discussion Paper on peer review included Professor Colin Blakemore (a former Chief Executive of The Medical Research Council, whose views on ME appear consistent with Wessely’s views, namely that it is a behavioural disorder, and one of the judges for the John Maddox Prize) and Fiona Fox, Director of the Science Media Centre.

As Director of the Science Media Centre (which is funded by industry), Fiona Fox has used the charity to promote the views of industry and to launch fierce attacks against those who question them (Invasion of the Entryists; George Monbiot; The Guardian, 9th December 2003).

The Science Media Centre has links to the online magazine “spiked” whose health writer Dr Michael Fitzgerald -- who sits on the Board of Sense about Science – derided the UK Chief Medical Officer when he stated that ME/CFS “*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, Friday 11th January 2002), asserting that it reflected “*a surrender of medical authority to irrationality. The scale of this capitulation is apparent when Professor Donaldson claims that CFS/ME should be classified together with conditions such as multiple sclerosis and motor neurone disease*”; (ME: the making of a new disease: <http://www.spiked-online.com/Articles/0000002D3B6.htm>). Supporting Fitzpatrick, Professor Michael Sharpe (one of the PIs of the PACE Trial), said that doctors would not accept a particular strategy just because the CMO’s report recommended it (BMJ:2002:324:131).

On learning of the award and of these glowing tributes to Wessely, one eminent Parliamentarian commented that it was “*incest*”(personal communication, 7th November 2012).

Given that the Science Media Centre and Sense about Science are so inter-connected, such a view is entirely understandable, but it is far more than self-congratulatory support of industry because it perpetuates the suffering being perpetrated upon extremely sick people, which is why this whole issue is of major importance.

How can such eminent scientists be unaware of the damage and distress that Wessely has imposed on countless sick and defenceless people over the last 25 years? How can they remain unaware of the significant evidence base demonstrating that Wessely is wrong about the nature of ME? How can these top-ranking scientists have such closed minds that they ignore or reject the freely accessible biomedical science about the nature and severity of ME?

If it is the case that Wessely's work on both ME and Gulf War Syndrome has been shown to be wrong, it must also be wrong that what many believe to be pseudoscience in a null field should be acclaimed as "sound science" when to do so is a travesty of sound science (Ioannidis; PLoS Medicine 2005:2:8:e124), because it has been shown that the Wessely School may well have spent their careers in a "null field" in relation to their efforts to designate ME/CFS as a behavioural disorder.

Is there a "cover-up" about ME/CFS?

So great is the extent of the refusal by successive UK Governments and their agencies of State (especially the Department for Work and Pensions, with which the PHI insurance industry has been deeply involved since 1993) to engage with the sound biomedical science which underpins ME that comparisons are now being drawn with the Hillsborough disaster "cover-up" by the Police; with the Jimmy Savile paedophile investigation, in relation to which numerous public bodies including the NHS, the Police and the BBC are apparently to be investigated for what can only be described as being involved in a 40-year "cover-up". Comparisons are equally being made with the North Wales care home scandal in which Clwyd County Council's insurers threatened the Council that it must not publicly release what it knew to be the truth (Channel 4 News, 7th November 2012), thereby condoning the continued ruination of so many people's lives. That powerful men cover up for other powerful men means that they continue to escape justice (Channel 4 News, 8th November 2012).

Equally, that people with ME have been and continue to be intimidated and abused both mentally and physically by the imposition of harmful interventions cannot be in dispute: the evidence is overwhelming and patients' testimonies are plentiful. Such patients are also abused financially and their means of livelihood are compromised, since if they refuse to take part in Wessely's "rehabilitation" programmes, they are deemed not to want to get better, so they can expect their State benefits to be withdrawn or refused, leaving extremely sick people to face destitution.

Written evidence exists of a "cover-up" with regard to ME (personal communication, 19th September 2004) and public opinion is mounting that all those who did not speak out are themselves culpable and must be held to account.

Twelve years ago, the Opinion of a Leading Queen's Counsel (Lord Campbell of Alloway, 2, King's Bench Walk, Temple, London EC4Y 7DE) obtained on 6th April 2000:

- *"On the document you have sent me there is an overwhelming case for the setting up of an immediate independent investigation as to whether the nature, cause and treatment of ME as considered by the Wessely School is acceptable or consistent with good and safe medical practice.*
- *There is substantial doubt as to whether such could be the case in view of the clear division of medical opinion.*
- *The document and a copy of this Opinion should be sent to the NHS by the good offices of Lord Hunt of Kingsheath with whom informal contact should be made and it*

could well be that the Department would wish to send an observer to the enquiry and (if so advised) participate.

- *On the basis of such information, if the formal request were to be refused it could be possible to seek declamatory relief against the GMC”.*

Given how much evidence has been presented to them over the years, it is beyond doubt that the Prime Minister, the DWP, the NHS, the DoH, the MRC, NICE and other agencies of the State do indeed know that ME is a serious, chronic, multi-system neuro-immune disease and not a behavioural disorder as asserted by Simon Wessely, but they refuse to act.

Is it possible that in time they, too, will all be investigated for refusing to listen to very sick people, for denying them appropriate medical investigation and care, and for imposing upon them psychological interventions which cannot help but only harm them?

Evidence that Wessely's management interventions do not work in ME/CFS

There is abundant evidence from numerous surveys by ME/CFS charities of almost 5,000 patients that in such patients, Simon Wessely's favoured psychological interventions of “cognitive restructuring” (CBT) is ineffective and that GET is unacceptable and sometimes 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**(<http://www.afme.org.uk/res/img/resources/Group%20Survey%20Lesley%20Cooper.pdf>).

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**(<http://www.afme.org.uk/res/img/resources/Severely%20Neglected.pdf>).

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**(<http://www.25megroup.org/Group%20Leaflets/Group%20reports/March%202004%20Severe%20ME%20Analysis%20Report.doc>).

In 2005, a report (“Our Needs, Our Lives”) published by The Young ME Sufferers Trust found that **88% had been made worse by exercise** (<http://www.tymestrust.org/pdfs/ourneedsourlives.pdf>).

In June 2007, through Section 16b funding from the Scottish Government, Action for ME produced a report “Scotland ME/CFS Scoping Exercise Report”, which found that **74.42% were made worse by GET**.

In 2008, Action for ME published another 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*” (<http://www.afme.org.uk/news.asp?newsid=355>).

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*”(<http://www.norfolkandsuffolk.me.uk/surveylink.html>).

There is thus an abundance of empirical evidence from ME/CFS patients and charities that GET can result in high rates of adverse effects, and this evidence was conveyed to the Medical Research Council and other agencies but has been comprehensively ignored in their support of Wessely’s belief that ME is a behavioural disorder.

Despite the evidence of abnormalities in the immune system, the central nervous system, the endocrine system, the cardiovascular and respiratory systems, the musculoskeletal system, the gastrointestinal system and the ocular system, all of which have been credibly demonstrated in ME, over the years Wessely has consistently dismissed or denied it, yet he has produced no evidence of his own to disprove the biomedical evidence.

Alleged threats claimed by Wessely, and evidence of threats made by him

Whilst frequently seeking the support of his colleagues and the media by mentioning the alleged threats he claims to have received, it is appropriate to consider how many threats Wessely himself has issued to those who have opposed him, including the written evidence of his threats. It is perhaps notable that although he has consulted the Medical Defence Union and has threatened injunctions, to date he has not brought any legal action against those who have reported what he has said or written about ME, but his threats have been sufficiently intimidating to have resulted in the loss of professional employment by senior clinicians/researchers and in the defacing of a journal before it was distributed because he was incensed that the authors of an article about his published work on ME had the temerity to quote him, and he was self-admittedly panicking about his resultant public image (personal communication).

No right-minded person would condone threats of any kind, certainly not death threats, to Wessely (of which as yet there is no hard evidence, nor reports of any action by the Police), but given the dire circumstances of people with ME, expression of frustration and despair are to be expected.

Illustrations of Wessely’s published views about people with ME/CFS

Wessely makes statements about ME that are not supported by evidence (for example, he has never produced any evidence of “*secondary gain*” by ME patients “*adopting the sick role*”) and he has often stated that he does not want to get into the “organic” versus “functional” debate (BMJ 1988:296:696; Brit J Hosp Med March 1991:45:158; JNNP 1991:54:669-671; BMB 1991:47:4:919-941) but many people accept that he has done more than anyone else to fan this particular flame, to the great detriment of patients with ME, and as such he has done much to prevent ME attaining disease legitimacy in the eyes of the majority of UK doctors.

For example:

On 3 June 1988 Wessely wrote to the Principal Social Worker at Douglas, Isle of Man (Mrs Jean Manson) about a young boy named Ean Proctor who had been diagnosed with severe ME by a senior consultant neurologist at The National Hospital for Nervous Diseases in London: *“I did not perform a physical examination...I was in no doubt that the primary problem was psychiatric (and) that his apparent illness was out of all proportion to the original cause... I have considerable experience in the subject of ‘myalgic encephalomyelitis’ (Wessely had obtained his MRCPsych barely two years earlier) and am absolutely certain that it did not apply to Ean. I feel that Ean needs a long period of rehabilitation (which) will involve separation from his parents, providing an escape from his “ill” world. For this reason, I support the application made by your department for wardship”*.

On 10th June 1988, at the request of Messrs Simcocks & Co, Solicitors for the Child Care Department, The Isle of Man Department of Education, Wessely wrote another letter about Ean Proctor: *“I did not perform a physical examination on Ean....I did not order any investigations....Ean cannot be suffering from any primary organic illness, be it myalgic encephalomyelitis or any other....I therefore support the efforts being made to ensure that Ean receives appropriate treatment”*. (It is notable that in June 1988, Wessely accepted ME to be a “*primary organic illness*” but then spent the rest of his professional career denying it to be so).

The result of that letter was that in that same month (June 1988), without ever having spoken to his parents, social workers supported by psychiatrists and armed with a Court Order specially signed by a magistrate on a Sunday, removed the child under police presence from his distraught and disbelieving parents and placed him into “care” because Wessely believed his illness was psychological and was being maintained by an “*over-protective mother*”. Everything possible was done to censor communication between the child and his parents, who did not even know if their son knew why they were not allowed to visit him.

Wessely’s involvement with the wardship of Ean Proctor is incontrovertibly established, yet in a Channel 4 News programme on 26th August 1998 in which the case of Child X (another child with ME whose parents were facing wardship) was being discussed, when asked by the presenter Sheena McDonald if there can ever be a case for the coercive approach in situations involving forcible removal of a child with ME from the parents, Wessely stated (verbatim quote) *“You know very well I know nothing about these cases”* and when Sheena McDonald asked “So you would agree that unless there is criminal abuse, there is never a case for a coercive approach to take children away from parents?”, Wessely replied (verbatim quote) *“I think it’s so rare. I mean, it’s never happened to me”*. Despite this public denial on national television, there is unequivocal evidence that Wessely had been personally involved in Ean Proctor’s wardship and that he had advised the local authorities to take the action they did.

(Copies of Wessely's letters and reports and a videotape recording of the Channel 4 News item are available).

In 1989 Wessely wrote in the BMJ: 298:1532-1533:

- *“(neurasthenia) is back with a vengeance. My local bookshop has just given ME the final seal of approval, its own shelf. A little more psychology and a little less T-cells would be welcome”.*

Also in 1989 Wessely wrote:

- *“Many patients referred to a specialised hospital with chronic fatigue syndrome have embarked in a struggle. One of the principal functions of therapy at this stage is to allow the patient to call a halt without loss of face” (JRCGP 1989:39:26-29).*

In 1990, blaming “naïve” doctors for the growing numbers of people diagnosed with ME, Wessely wrote:

- *“Suggestible patients with a tendency to somatize will continue to be found among sufferers from diseases with ill-defined symptomatology until doctors learn to deal with them more effectively...It has been shown that some patients have always preferred to receive, and well-meaning doctors to give, a physical rather than a psychological explanation...Such uncritical diagnoses may reinforce maladaptive behaviour” (Psychological Medicine 1990:20:35-53).*

In another article in 1990, Wessely wrote:

- *“This research shows that in CFS, (patients) experience less guilt: such an external style of attribution has certain advantages; external attribution protects the patient from being exposed to the stigma of being labelled psychiatrically disordered, (affording) diminished responsibility for one's own health...Our results are close to those predicted by 'learned helplessness' ...Inappropriate referrals to physicians can lead to extensive physical investigation that may then perpetuate the symptom pattern of physical attribution” (J Psychosom Res 1990:34:6:665-667).*

Also in 1990, Wessely wrote about people with ME:

- *“A physical diagnosis implies the illness has an external (physical) cause....Such attribution always confers certain benefits, irrespective of accuracy. In other words, there is avoidance of guilt and blame...Exercise is necessary as a specific therapy. There is no evidence that physical activity worsens the underlying process...It is regrettable that ME has become a disease of fashion, even a fad” (The chronic fatigue syndrome – myalgic encephalomyelitis or postviral fatigue. In: Recent Advances in Clinical Neurology; Ed: Christopher Kennard; Churchill Livingstone 1990; pp 85-131).*

Again in 1990, Wessely wrote about people with ME:

- *“The description given by a leading gastroenterologist at the Mayo Clinic remains accurate: ‘The average doctor will see they are neurotic and he will often be disgusted with them’ ” (Chronic Fatigue and Myalgia Syndromes. Simon Wessely. In: Psychological Disorders in General Medical Settings Ed: N Sartorius et al. Pub: Hogrefe & Huber, 1990). For the avoidance of doubt, Wessely often claims that this quotation from what he published has been deliberately reversed in order to demonise him, but the extent and content of his other publications on patients with ME robustly counter his proffered “explanation”.*

In 1991 Wessely wrote:

- *“Continuing attribution of all symptoms to a persistent ‘virus’ preserves self-esteem” (JNNP 1991:54:153-158) and “The prognosis may depend on maladaptive coping strategies and the attitude of the medical profession” (Pulse of Medicine 1991:14th December:58).*

In 1992 Wessely said:

- *“It seems that ME sufferers prefer to feel that they have a ‘real’ disease – it is better for their self-esteem (and) the label ‘ME’ helps legitimise their dealings with doctors” (Eradicating myalgic encephalomyelitis (ME). Simon Wessely. Report of meeting held on 15 April 1992 at Belfast Castle; Pfizer Invicta Pharmaceuticals, 4-5).*

In 1992, the Wessely School gave directions that in ME/CFS, the first duty of the doctor is to avoid legitimisation of symptoms (the MRC’s own summary of the CIBA Foundation -- in 1996, CIBA became Novartis -- Symposium on CFS that was held on 12-14th May 1992).

In 1993, following the publication in 1992 of the Tenth Revision of the WHO International Classification of Diseases (ICD-10) in which ME remained in the Neurology section, Wessely and his colleague Anthony David – seemingly unaware that ME has been classified as a neurological disorder since 1969 -- wrote to The Lancet (1993: 342:1247-1248):

- *“The inclusion in the tenth revision of the International Classification of Diseases (ICD-10) of benign myalgic encephalomyelitis as a synonym for postviral fatigue under Diseases of the Nervous System seems to represent an important moral victory for self-help groups in the UK...Neurasthenia remains in the Mental and Behavioural Disorders chapter under Other Neurotic Disorders...Neurasthenia would readily suffice for ME....Applying more stringent criteria for CFS in the hope of revealing a more neurological subgroup succeeds only in strengthening the association with psychiatric disorders....We believe this latest attempt to classify fatigue syndromes will prevent many people from seeing the world as it actually is”.*

on 12th May 1994, giving the 9th Eliot Slater Memorial Lecture at The Institute of Psychiatry, Wessely talked about ME in terms of hysteria, and said:

- *“I will argue that ME is simply a belief, the belief that one has an illness called ME....Neurasthenia was the disease of modern life, so is ME....Talk of viruses and the immune system is deeply embedded in popular consciousness....Does it really matter if the 5HT neurotransmission is enhanced (that’s [ME]CFS) or suppressed (that’s major depression) -- what’s a little up or down regulation among friends? 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...Royal Free Disease itself is part of the world of myth...As Tony David has called it, it is the H (hysteria) word, never spoken but always present in the ether between doctor and patient...The mere existence of the word (hysteria) might condemn the sufferer to a lifetime of non-recovery, if only to prove the doctor wrong...viruses are an attribution free from blame...there's no blame, no shame, and no stigma....Hence our virus doctor exists not to hold out hope of cure – but to give legitimacy to distress....Each generation will find it necessary to discover its own ME”.

Also in 1994, Wessely wrote:

- *“Most doctors in hospital practice will be familiar with patients who complain about a wide variety of symptoms but whose physical examination and investigations show no abnormality”*
- *“(Such) symptoms have no anatomical or physiological basis”*
- *“Patients at the severe end of the spectrum exert a disproportionately large and avoidable financial burden on the health and social services”*
- *“Patients with inexplicable physical symptoms are usually strongly resistant to any psychological interpretation (and) are generally viewed as an unavoidable, untreatable and unattractive burden” (British Journal of Hospital Medicine 1994:51:8:421-427).*

In 1996 Wessely wrote:

- *“The perpetuating factors include inactivity, illness beliefs and fear about symptoms, symptom focusing, and emotional state”*
- *“CFS is dogged by unhelpful and inaccurate illness beliefs, reinforced by much ill-informed media coverage; they include fears and beliefs that CFS is caused by a persistent virus infection or immune disorder”*
- *“Increased symptom focusing occurs in CFS sufferers; (this) increased concern leads to selective attention and ‘body watching’: this can intensify the perceived frequency of symptoms, thereby confirming illness beliefs and reinforcing illness behaviour” (Update 14th August 1996:61).*

Also in 1996 the Joint Report on Chronic Fatigue Syndrome of The Royal Colleges of Physicians, Psychiatrists and General Practitioners was published, with which Wessely was instrumental; it advised UK clinicians and Government agencies that:

- *“The Royal Colleges have stressed that approaches to these patients should not be based on simple biomedical models”*

- *“Some would prefer to continue to use the term ME. Patients may wish to keep (it) because only with that label are they eligible to call upon the welfare of the state for help”*
- *“The term ME may mislead patients into believing they have a serious and specific pathological process”*
- *“The possibility that abnormalities of immune function play a role in the pathogenesis of CFS has attracted considerable attention. Such abnormalities should not deflect the clinicians from the biospsychosocial (psychiatric) approach and should not focus attention towards a search for an ‘organic’ cause”*
- *“We have concerns about the dangers of labelling someone with an ill-defined condition which may be associated with unhelpful illness beliefs”*
- *“Research suggests that dysfunctional illness beliefs are common in CFS patients. Such inaccurate beliefs might fuel avoidance of activity”*
- *“There is no compelling evidence linking immune dysfunction with disability”*
- *“No investigations should be performed to confirm the diagnosis”.*

In 1997 Wessely wrote:

- *“The majority of patients seen in specialist clinics typically believe that their symptoms are the result of an organic disease process, and resent any suggestion that they are psychological in origin or psychiatric in nature. Many doctors believe the converse”*
- *It is particularly important to focus on factors which may be perpetuating the illness. A conviction of a solely physical cause for symptoms is the single most consistent predictor of poor outcome”*
- *(Patients’) beliefs are probable illness-maintaining factors and targets for therapeutic intervention...Many patients receive financial benefits and payment which may be contingent upon their remaining unwell. Gradual recovery may therefore pose a threat of financial loss” (General Hospital Psychiatry 1997:19:3:185-199).*

In 1998 Wessely wrote:

- *“Many people suggest that the condition should be called ME, but doctors and the editors of journals have taken a firm stand against this label....The GP’s response may be important. A sick note and unclear diagnosis are both associated with development of CFS” (Update; 20th May 1998:1016-1026).*

In 1999 Wessely wrote:

- *“We postulate that the existence of specific somatic syndromes is largely an artefact of medical specialization...Functional somatic syndromes pose a major challenge to*

medicine. Those symptoms are associated with unnecessary expenditure of medical resources”

- *“Many of these (functional somatic) syndromes are dignified by their own formal case definition and body of research... We question this orthodoxy and ask whether these syndromes represent specific diagnostic entities (eg. irritable bowel syndrome, premenstrual syndrome, fibromyalgia, hyperventilation syndrome, tension headaches, globus hystericus, multiple chemical sensitivity, chronic fatigue syndrome) or are rather more like the elephant to the blind man --- simply different parts of a larger animal?”*
- *“We have put forward the hypothesis that the acceptance of distinct syndromes as defined in the medical literature should be challenged... We propose an end to the belief that each different syndrome requires its own particular sub- specialist” (Lancet 1999:354:936-939).*

In 1999 Professor Michael Sharpe of the Wessely School referred to patients with ME in terms:

- *“In my lecture this evening, I would like to talk to you about myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome or CFS (which) for convenience I will refer to as CFS”*
- *“Cognitive behavioural therapy has been shown to have substantial benefits for patients with CFS (and) can reduce disability in most patients”*
- *“I shall argue that patients themselves have played a part in denying themselves this type of treatment”*
- *“The vehemence with which many patients insist that their illness is medical rather than psychiatric has become one of the hallmarks of the condition”*
- *“Over-solicitousness and the reinforcement of unhelpful illness beliefs can have an unhelpful effect on patients’ attitude and coping”*
- *“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” (ME. What do we know (real physical illness or all in the mind? Lecture given in October 1999 by Professor Michael Sharpe, hosted by the University of Strathclyde*

In 2001 Wessely wrote:

- *“The greater the number of symptoms and the greater the perceived disability, the more likely clinicians are to identify psychological, behavioural or social contributors to illness”*
- *“If the chronic fatigue syndrome did not exist, our current medical and social care systems might force us to invent it”*
- *“Other symptoms identified in the chronic fatigue syndrome (include) increased symptom-monitoring” (Annals of Internal Medicine 2001:134:9S:838-843).*

(In correspondence arising from this paper, Wessely wrote: ***“I can sleep easy at night when it comes to treatment. I know that we have done more good than harm. All I know is that I am quietly proud of what our group has achieved over the years”***).

In February – April 2002, the BMJ ran a poll of what readers considered “*non-diseases*” in which Wessely was instrumental; it concluded that ME, along with big ears and freckles, was a “non-disease” that is best left medically untreated (BMJ 2002:324:883-885).

In 2003 Wessely wrote:

- *“When a medical explanation is slow in coming, physicians, officials and companies often bear the brunt of (patients’) anger, for example in chronic fatigue syndrome and Gulf war sickness, authorities who denied sufferers’ claims met with scorn and contempt”*
- *“It is only human for doctors to view the public as foolish, uncomprehending, hysterical or malingering”.*
- *“One challenge arises when patients have named their condition in a way that leaves doctors uncomfortable, as occurred with chronic fatigue syndrome....It may seem that adopting the lay label reinforces the perceived disability. A compromise strategy is ‘constructive labelling’: it would mean treating chronic fatigue syndrome as a legitimate illness while gradually expanding understanding of the condition to incorporate the psychological and social dimensions. The recent adoption by the UK Medical Research Council and the chief medical officer’s report of the term CFS/ME reflects such a compromise, albeit it an uneasy one” (BMJ 2003:326:595-597).*

Also in 2003 Wessely wrote:

- *“This paper proposes that well-intentioned actions by medical practitioners can exacerbate or maintain medically unexplained symptoms (MUS). This term is now used in preference to ‘somatisation’”.*
- *“The medical specialties employ shorthand descriptions for particular clusters of MUS, including irritable bowel syndrome, fibromyalgia and chronic fatigue syndrome”*
- *“The adoption of a label such as CFS affords the sufferer legitimacy --- in other words, it allows entry into the ‘sick role’”.*

- *“The conferring of a label is not a neutral act, since specific labels are associated with specific beliefs and attitudes. In CFS for example, use of this term or the alternative ‘myalgic encephalomyelitis’ implies underlying assumptions about aetiology and treatment for both patients and doctors”*
- *“If sections of the media advocate an exclusively organic model, as has happened with CFS, the biomedical model may become firmly enshrined for patients and families at the expense of psychosocial models” (JRSM 2003:96:223-227).*

In 2005 Wessely wrote:

- *“Functional somatic syndromes refer to groups of symptoms lacking demonstrable abnormalities of structure. They include chronic fatigue syndrome” (Rev Bras Psiquiatr: September 2005:27:3).*

There are many more examples of Wessely’s beliefs and published works about ME (including several textbooks) and the above are merely illustrative. Despite the advancement of medical science over the last quarter of a century, Wessely’s views about ME have remained intransigent. There is abundant evidence of his total disregard of the significant biomedical evidence base that has been shown to underpin ME, and despite his irrefutable indifference to the profound suffering of people blighted by ME, Simon Wessely is honoured with the inaugural John Maddox Prize for his courage in standing up for *“sound science”*.

That is a travesty of science, truth and justice.