

The rewards of science in the UK

The inaugural John Maddox Prize

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 John Maddox Prize, awarded jointly to 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 initiative for the prize was shared between the journal Nature and Sense about Science (a charitable trust claiming to change public discussion about science and a sibling of the Science Media Centre, on both of whose Advisory Boards Wessely sits).

The press release referred to “*the courage*” of the recipients “*for communicating sound science and evidence*”.

The Problem

There is abundant evidence that Wessely’s views and influence have necessitated extraordinary courage, 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 despite it having been classified by the World Health Organisation as a neurological disorder since 1969.

Given that Wessely’s belief that ME is a somatoform (ie. behavioural) 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.

World experts have repeatedly shown that Wessely has not produced “*sound science and evidence*” about ME. Indeed, 21 years ago Peter Behan, Professor of Neurology at Glasgow, showed that the psychiatric hypothesis: “*lacked all scientific merit and now, with the emergence of hard data, can be totally rejected*” (1).

Psychiatrists of the “Wessely School” are lead advisors on “CFS/ME” to Government Departments and agencies of State. According to them, “CFS/ME” is a “functional somatic syndrome” (ie. a behavioural disorder) in which medically unexplained fatigue is perpetuated by inappropriate illness beliefs, pervasive inactivity, membership of a self-help group and being in receipt of disability benefits (2). They assert that there are no physical signs of disease and there is no pathology causing the patients’ symptoms, and that patients are merely “*hypervigilant*” to “*normal bodily sensations*” (3). They insist that CFS/ME should be managed by behavioural interventions including “*cognitive re-structuring*” (ie. brain washing) and graded exercise therapy to “reverse” patients’ “*mis-perceptions*”.

They state that they *“have decided to treat CFS and ME as if they are one illness”* (4), so there can be no doubt that they are referring to ME and not to a separate psychiatric disorder.

Over the last 25 years Wessely has written extensively about “CFS/ME”. He believes that attribution by patients to a virus is somatisation *“par excellence”* (5); that patients acquire *“secondary gain”* by *“adopting the sick role”* such as State and insurance benefits, which he states *“may be contingent upon their remaining unwell”* (6); he argues that ME is simply a belief that one has an illness called ME and that it is not a real disease but *“part of the world of myth”* (7); that patients prefer the label “ME” because it is *“better for their self-esteem”* (8); that symptoms *“have no anatomical or physiological basis”* (9); that no investigations should be performed to confirm the diagnosis (10); that ME *“has become a fad”* (11); that patients *“believe their symptoms are the result of an organic disease process (but) many doctors believe the converse”* (12); indeed the Wessely School have advised that the first duty of the doctor is to avoid legitimisation of symptoms (13). In 2002 the British Medical Journal ran a poll of what readers considered *“non-diseases”* in which Wessely was instrumental: it concluded that, along with big ears and freckles, ME is a *“non-disease”* best left medically untreated (14).

Wessely trivialises a devastating disorder from which people die: the recent tragic deaths from ME of three young women in the UK, all in their 30s (Sophia Mirza, Lynn Gilderdale and Emily Collingridge) should shame all “non-believers”.

Wessely’s influence also extends to the insurance industry. PRISMA is a multi-national healthcare company working with insurance companies; it arranges “rehabilitation” programmes (ie. graded exercise therapy) for people with ME claiming on their policies. In the PRISMA company information, Simon Wessely was listed as a Corporate Officer and was a member of the Supervisory Board (ie. higher than the Board of Management).

In 1995 the insurance industry complained that it: *“stands to lose millions if we do not move quickly to address this increasing problem”* (15) and in 2002 said: *“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”* (16).

Could there be a more clearly expressed reason for Wessely School members who work for the insurance industry to deny that ME/CFS exists and to oppose the evidence that it is a serious organic disease from which full recovery is unlikely?

If objective evidence of organic pathology were to be acknowledged, it would undermine the insurers’ assertion that it is a psychosocial disorder and therefore ineligible for benefit payment.

The “Real” Science

In contrast, Dr Harvey Alter (who discovered the hepatitis C virus), 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: *“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”* (17)

Professor Luc Montagnier (who in 2008 won the Nobel prize for discovering the AIDS virus and Honorary Member of the European Society for ME) said: *“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”* (18).

This is an important point: it is not that accurate information and knowledge are unavailable; it is that in the UK, the evidence is being systematically blocked by the networking of the Wessely School who promote their own views about “CFS/ME”.

World-renowned virus-hunter, Professor Ian Lipkin, Director, Centre for Infection and Immunity, Columbia University, said 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 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.....these patients...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”* (19). ME/CFS, he said, *“is not a psychosomatic disorder”* (20) and he viewed it as *“a major illness”* (21).

The US Food and Drug Administration has confirmed that ME/CFS is *“a serious complex disease that lacks treatment and suffers from the unwillingness of the insurance companies”* to address it (22).

International experts have shown comprehensively that Wessely’s beliefs about ME/CFS are erroneous: there are over 6,000 peer-reviewed papers demonstrating the biomedical underpinnings (23).

In 2003, the “Canadian Consensus Guidelines” were published, supported by 237 references (24); in 2011 the International Consensus Criteria for ME were published (25); in 2012, two Primers for Clinicians were published (26; 27); these were all produced by the leading clinicians and scientists in the field, from 13 countries, with 400 years between them of clinical and academic experience, having authored hundreds of peer-reviewed publications and having treated about 50,000 ME patients.

Their message is unequivocal:

ME “*is characterised by an inability to produce sufficient energy on demand*”; it is an acquired complex organic multi-system disease whose diagnostic feature is post-exertional exhaustion and malaise, with measurable and reproducible dysfunction of the neurological, immunological, endocrine, musculoskeletal, cardiovascular, respiratory, genitourinary and gastrointestinal systems and dysfunction of cellular energy metabolism and ion transport

signs and symptoms include 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, and the presence of allergies and multiple chemical sensitivity

structural and functional neuroimaging show profound disruption in the normal coordination between the brain and the body

special consideration is necessary for patients who are so disabled that they cannot attend a surgery or hospital, and there is need for home-based care-givers as well as support for those care-givers

individuals meeting the 2011 International Consensus Criteria have myalgic encephalomyelitis and should be removed from the UK NICE’s own criteria for “chronic fatigue syndrome” published in 2007 (the 2003 Canadian Consensus Guidelines having been rejected for use in the UK on the Wessely School’s advice).

The distinguished authors state about Wessely’s model that there is: “*much that is objectionable*” about it and that it is “*far from being confirmed...Nevertheless, the assumption of its truth by some has been used to influence attitudes and decisions within the medical community*”. They state: “*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*”.

They are clear: “*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*”.

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

Dr Byron Hyde, the clinician with perhaps the widest clinical experience of ME, said: “*The belief that ME/CFS is a psychological illness is the error of our time*” (28) and

one of the foremost AIDS and ME specialists in the world, Professor Nancy Klimas, said: “*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 I would rather have HIV*” (29).

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”* (30).

Twelve years later, Wessely is honoured for his *“courage”* in continuing to promote exactly that hypothesis, which is described as *“standing up for sound science”*.

Wessely’s work appears to be based on an ideological commitment to ME as a somatoform disorder and the recent Medical Research Council’s PACE Trial with which he was involved exemplifies serious deficiencies and is considered by many people to have no credible scientific, clinical or ethical foundation: 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 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.

Wessely is on record as saying about the PACE Trial: *“For those who appreciate these things, the trial is a thing of beauty”* (31).

The editor of the journal Nature should be concerned about clinical trials and how they are run and reported, because this *“thing of beauty”* had no control group, was unblinded, and committed the cardinal sin of trial design by altering the outcome measures at the end of the trial so as to give the impression that an unsuccessful intervention favoured by the investigators was a success when in fact the results were so bad that 21 months later, no recovery rates have been (nor, it is understood, are they to be) published.

One can only assume that those awarding the prize and proffering acclaim are unaware of the scientific evidence which disproves Professor Wessely’s view about ME.

Professor Colin Blakemore, former CEO 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, 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”*.

The real problem is that the top echelons of the UK scientific community appear to have failed in their duty to the memory of John Maddox and to the innumerable patients world-wide who are suffering from ME.

That is a travesty of science, truth and justice.

Professor Malcolm Hooper and members of the ME community
15th November 2012

References

Myalgic Encephalomyelitis: Postviral Fatigue Syndrome: Diagnostic and Clinical Guidelines for Doctors. The ME Association, 1991

The Medical Research Council's PACE Trial Identifier, section 3.9

The Cognitive Behavioural Management of the Post-viral Fatigue Syndrome. Simon Wessely, Sue Butler, Trudie Chalder and Anthony David. In: Post-viral Fatigue Syndrome. Ed: Rachel Jenkins and James Mowbray. John Wiley & Sons, Chichester, 1991

The Patient Leaflet for the PACE Trial (<http://pacetrial.org/trialinfo.html>)

Maybe it's a virus? Beliefs about viruses, symptom attributional style and psychological health. Cope H David A Mann A. Journal of Psychosomatic Research 1994:38:2:89-98

Chronic fatigue syndrome: a practical guide to assessment and management. Sharpe M, Chalder T, Wessely S et al. General Hospital Psychiatry 1997:19:3:185-199)

Microbes, Mental Illness, The Media and ME: The Construction of Disease. Simon Wessely. 9th Eliot Slater Memorial Lecture, Institute of Psychiatry, London, 12 May 1994

Eradicating myalgic encephalomyelitis (ME). Simon Wessely. Report of meeting held on 15 April 1992 at Belfast Castle; Pfizer Invicta Pharmaceuticals, pp 4-5

Patients with medically unexplained symptoms. Alcuin Wilkie, Simon Wessely. British Journal of Hospital Medicine: 1994:51:8:421-427

Joint Report on Chronic Fatigue Syndrome (CR54); The Royal Colleges of Physicians, Psychiatrists and General Practitioners, 1996

The chronic fatigue syndrome—myalgic encephalomyelitis or postviral fatigue. S.Wessely PK Thomas. In: Recent Advances in Clinical Neurology. Ed: Christopher Kennard. Pub: Churchill Livingstone 1990 pp 85-131

Chronic fatigue syndrome: a practical guide to assessment and management. Sharpe M, Chalder T, Wessely S et al. General Hospital Psychiatry 1997:19:3:185-199

The MRC's own summary of the CIBA Foundation Symposium on CFS that was held on 12-14th May 1992

In search of non-disease. British Medical Journal 2002:324:883-885

UNUM's CFS Management Plan; Dr Carolyn Jackson, 4th April 1995

An article in 2002 by Peter Pallot on health insurance:

<http://www.hi-mag.com/healthinsurance/article.do?articleid=20000081634>

Transcript of FDA Blood Products Advisory Committee, 2010:

<http://www.fda.gov/AdvisoryCommittees/CommitteesMeetingMaterials/BloodVaccinesandOtherBiologics/BloodProductsAdvisoryCommittee/ucm239304.htm>

<http://esme-eu.com/home/experts-launch-think-tank-for-mystery-disease-article37-6.html>

Transcript of podcast with Professors Vincent Racaniello and Ian Lipkin, 18th September 2012, This Week in Virology

Press conference on 18th September 2012 at Columbia University:
<http://www.prohealth.com/library/showarticle.cfm?libid=17220>

David Tuller, New York Times, 18th September 2012

www.fda.gov/downloads/Drugs/NewsEvents/UCM320310.pdf; 13th September 2012

“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>

“Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Clinical Working Case Definition, Diagnostic and Treatment Protocols” (known as the Canadian Guidelines). BM Carruthers et al. JCFS 2003;11(1):7-115

The International Consensus Criteria for ME. BM Carruthers et al. Journal of Internal Medicine; 2011;270:4:327-338

The International Association for CFS/ME “Primer for Clinical Practitioners” (www.iacfsme.org)

“Myalgic Encephalomyelitis – Adult and Paediatric: International Consensus Primer for Medical Practitioners”. BM Carruthers et al: The National Library of Canada; ISBN 978-0-9739335-3-6

The Complexities of Diagnosis. Byron Hyde. In: handbook of Chronic Fatigue Syndrome. Ed: Leonard A. Jason et al. John Wiley & Sons Inc. 2003

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

The Biology of the Chronic Fatigue Syndrome. Anthony Komaroff. Am J Med 2000;108:99-105.

Health in mind and body. Simon Wessely. The Journal of the Foundation for Science and Technology, Volume 20, Number 7, December 2011
http://www.foundation.org.uk/journal/pdf/fst_20_07.pdf