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The incalculable contribution to medical science of Regius Professor Sir Simon Wessely: a thirty year retrospective.

Margaret Williams 28th December 2017

There can be no doubt that Simon Charles Wessely MA, BA, BM BCh (Oxon) 1981; MRCP 1984; MRC Psych 1986; MSc 1989; MD (Oxon) 1993; FRCP 1997; FRCPsych; FMed Sa (Psychiat) is an esteemed and influential figure in the top echelons of the British Establishment, being regarded by Government bodies and the medical insurance industry as an expert on his specific interests of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Military Health, subjects upon which he has been a prolific author, forcefully expressing his belief that neither ME/CFS nor Gulf War Syndrome exists except as mental (behavioural) disorders.

Amongst his many accomplishments he has been a member of various Medical Research Council Boards, a Member of Council of the Royal Society of Medicine Section of Psychiatry, a founder member of the industry-funded Science Media Centre and a co-author of an influential Cochrane Review.

Born on 23rd December 1956, he has risen to great heights. On 27 August 2003, Dr George Szmukler, Dean of Psychiatry, Institute of Psychiatry, King's College Hospital, London, wrote to the Countess of Mar: *"Professor Wessely must be judged one of the most outstanding researchers in the UK, and indeed internationally. Professor Wessely has been awarded a Research Medal by the Royal College of Physicians specifically for his work on CFS and he has served on many prestigious scientific committees, further attesting to the high regard in which he is held by the scientific community".*

Wessely oversaw the Clinical Trials Unit for the £5 million PACE Trial on ME/CFS that was funded by the MRC, the Department of Health, the Department for Work and Pensions and the Scottish Chief Scientist's Office (about which he wrote in The Journal of the Foundation for Science and Technology in December 2011: *"For those who appreciate these things, the trial is a thing of beauty"* but which has since been exposed as what many people regard as fraud. Wessely summarised his reaction to the independent re-analysis that proved the Principal Investigators' claims of recovery using his own behavioural modification interventions as false: *"OK folks, nothing to see here, move along please*" https://www.statnews.com/2016/09/21/chronic-fatigue-syndrome-pace-trial/).

In 2012 he was jointly awarded the inaugural John Maddox prize for "*standing up for sound 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"*; it was awarded to Wessely for his *"courage*" in facing opposition to his views about ME and Gulf War Syndrome. Given that his 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 resulted in international derision.

In 2013 he was knighted for his services to military healthcare and psychological medicine despite (i) his insistence that Gulf War Syndrome does not exist except as a mental disorder (but US researchers found that it affects about 25 -32% of veterans deployed in the 1991 Gulf War; that exposure to pyridostigmine bromide and pesticides in the theatre of war are causally associated with GWS; that exposure to sarin/cyclosarin also affected the health of Gulf War veterans; that neurological, neuroimmune, neuroendocrine and mitochondrial mechanisms underlie GWS and that it was not caused by combat stressors and cannot be explained by post-traumatic stress disorder or by other mental health disorders: http://www.sciencedirect.com/science/article/pii/S0010945215003329) and (ii) his advice to UK The Ministry of Defence (to whom he is honorary civilian consultant psychiatrist) that ME/CFS be categorized under psychiatric or mental disorders on the army recruitment form, a situation that pertained until direct communication with the Surgeon General resulted in clarification that the MOD's position has been corrected: *"there is today only one ICD-10 code used for CFS/ME…which is G93.3"* (personal communication from the Surgeon General, 26th September 2012).

In 2014 Wessely was named in the Health Service Journal Top 100 Clinicians.

In 2016, to celebrate his 60th birthday The Royal College of Psychiatrists adopted a book from the College's antiquarian collection to mark the occasion and to reflect how greatly he is esteemed within his own fraternity: the book is called "Observations on the nature, causes and cure of nervous, hypochondriac and hysterical (patients)".

In February 2017 he was appointed as Regius Professor of Psychiatry at Kings College, London (ie. a holder of a university chair founded by a sovereign or filled by Crown appointment).

On 14th February 2017 he was chosen as the subject of the BBC's Radio 4 programme "The Life Scientific" (the broadcast being notable for the singular lack of science discussed).

Until June 2017 he was President of the Royal College of Psychiatrists.

In July 2017 he became the first psychiatrist to be elected as President of The Royal Society of Medicine.

In October 2017, UK Prime Minister Theresa May chose him to conduct a review of the Mental Health Act.

Surely a record of which anyone could rightly be proud and about which Wessely himself has stated: *"I can sleep easy at night…. 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".*

But is his pride justified, or is he suffering from self-delusion?

He is certain that he is right about the non-existence of both ME and Gulf War Syndrome as organic disorders, but according to the leading clinical psychologist Dr Dorothy Rowe, *"people who know absolutely that they are right are very dangerous"* (Observer, 14th November 1993).

Perhaps tellingly, in 1996 Wessely wrote in the BMJ about the "*attraction*" of a career in psychiatry and how he does not want to lessen the control of psychiatrists over sick people (BMJ 1996:313:158-160).

"*OK folks, nothing to see here, move along please"* seems to have been his standard response to everything he has investigated when he has been proved wrong, for example, ME/CFS, Gulf War Syndrome, the potential dangers of mobile phones, and the Camelford poisoning disaster, a stance which seems to have made him useful to UK Governments of whatever party and he has been rewarded accordingly: a knighthood and a Regius professorship are not awarded for speaking inconvenient truths that may expose vested interests and the incompetence and liability of Departments of State. Indeed, Ian Biggs' comments about how low an institution will sink to protect the pseudoscience from which it benefits financially for maintaining the status quo could not be more apposite: http://www.iainbiggs.co.uk/2017/12/the-great-stink-and-the-russell-group-of-universities/

Dismissive of the fact that the WHO has formally classified ME/CFS as a neurological disorder since 1969, Wessely has spent the last 30 years denying the existence of ME and striving to get "CFS/ME" re-classified as a mental (somatisation) disorder. He is renowned for his unfounded belief that ME does not exist except as an aberrant belief held by people who think they suffer from it and for his unassailable belief that ME is somatisation *"par excellence"* (J Psychosom Res 1994:38:2:89-98).

Not only has he consistently denigrated people with ME, but he has dismissed, ignored or ridiculed the substantial body of international biomedical evidence published over the last 30 years that proves him wrong. The vast number of his own publications provides irrefutable proof of such denigration and dismissal, but it worth noting that the Medical Research Council itself now acknowledges that there is evidence of immune dysfunction and inflammatory mechanisms in the brain and spinal cord of people with ME.

From his early days as a psychiatrist, Wessely was a member of The Campaign Against Health Fraud (now known as HealthWatch), where he was listed as a *"leading member of the campaign".* Although now denied, the aims of that campaign were *"to OPPOSE diagnoses that are misleading or false, or that may encourage unnecessary treatments for non-existent diseases"* (CAHF subscription form, valid to May 1990) and Wessely has been assiduous in promoting his belief that ME is a non-existent disease.

All this information is already in the public domain, but it may be worth re-considering just a few examples illustrating Wessely's campaign to "eradicate" ME as an organic disorder.

In 1989 Wessely wrote dismissively about ME/CFS in the BMJ: *"A little more psychology and a little less T-cells would be welcome"* (BMJ 1989:298:1532-1533).

Much was already known at that time about the role of dysfunctional T cells in ME/CFS but such was Wessely's influence that his personal beliefs prevailed throughout the NHS: important research findings were ignored, with Government and other institutions such as the medical insurance industry gratefully and uncritically accepting as fact Wessely's assertions that ME/CFS is a behavioural disorder, thus depriving claimants of financial support to which they were legitimately entitled. Indeed, in October 1993 Wessely wrote in strong terms to Dr Mansel Aylward, then Head of Medical Services at the Department for Social Security: *"As we, and now many other groups, have shown that the only determinant of outcome in this condition is strength of belief in a solely physical cause, then it will also itself contribute to disability and poor outcome. I cannot believe that is the intention of the Department, if only on grounds of cost!"* In reply, Aylward wrote*: "Very many thanks for your welcome letter of 1st October…. You can well imagine how we now feel when reading the ME Association's leaflet which you kindly enclosed with your letter. That disturbing leaflet is a glowing expression of what the lobby would like to be the truth rather than what is the truth".*

The truth was that in January 1990 Professors JR Hobbs and J Mowbray had published convincing evidence of T cell abnormalities in ME/CFS:

"Postviral states… have been shown to be associated with acquired (secondary) T-cell deficiencies, particularly with CD8 dysfunction, and even immune paresis….It is also clear that the acquisition of T-cell deficiency, particularly the CD8 subset, can itself impair immune regulation and predispose to atopy not previously experienced by the patient…It is known that psychological disturbance can influence immunity. We, ourselves, have undertaken extensive T-cell subset measurements in normal subjects subjected to psychological stress, and would point out that in none of these did we see CD8 levels as low as in some 40% of our ME patients" (CD8 Deficiency in patients with muscle fatigue following suspected enteroviral infection (myalgia encephalitica) JR Hobbs, JA Mowbray, JE Monro et al In: Protides of the Biological Fluids: Jan 1990:36:391-398).

John Hobbs was at the forefront of clinical immunology and protein biochemistry and James Mowbray was an immunopathologist whose team developed the VP1 test/Viral Protein 1 for classic ME. In his Medical Address at the AGM of the ME Association on 25th April 1987, Professor Mowbray said: *"we have been able to find a very large fraction of the ME patients have got an enterovirus antigen….Just because you find virus proteins in the blood, does that mean they are infected? Yes, it does….The virus is present in the intestine. It is also shown to be present in the muscle...What does it do in the muscle?….(It) does the thing that viruses usually do, they infect the cell and take over....."*. In 1988 the ME Association was offering the VP1 test to its members for an administration fee of £3 but Wessely succeeded in getting the VP1 test withdrawn, asserting that it was *"unsuitable for routine clinical use*" [Lancet 1989:1:1028-9] and it is no longer available in the UK. Referring to the VP1 test, in 1998 Dr Byron Hyde said: *"ME patients with a positive VP1 test become chronic, whilst those with a negative VP1 test recover*".

It was twenty eight years after Wessely successfully called for "*more psychology and less T-cells"* that on 27th December 2017 The Open Medicine Foundation announced the First T cell Project Meeting for the ME/CFS Collaborative Research Centre at Stanford:

"The team will follow up on Dr. Mark Davis' observations of T cell activity in ME/CFS, to study a new cohort of patients and figure out what this T cell activity means for the understanding and treatment of the disease. Some of the best technologies out there for sequencing the RNA and DNA of single T cells have been developed by this team! This was achieved through a collaboration between Drs. Mark Davis (Professor of Immunology & Microbiology) and Lars Steinmetz (Professor of Genetics), who will now apply these technologies to achieve new understanding of the role of T cells in ME/CFS. The team discussed which experiments they will perform in 2018 with the new funding from OMF, and developed plans to analyze and interpret the data. They are all excited to get started on this important project!" (https://www.omf.ngo/2017/12/27/first-t-cell-project-meeting-cfs-collaborative-research-center-stanford/).

On 21st December 2017 the Solve ME/CFS Initiative published highlights of important advances in ME/CFS research during 2017; these include the unprecedented commitment by the US National Institutes of Health to fund a consortium of collaborative centres dedicated to ME/CFS, as well as the fact that the US Centres for Disease Control recently removed inaccurate information about ME/CFS from their webpages (ie. the CDC has archived its previous advice about using CBT and GET for people with ME/CFS).

The Solve ME/CFS Initiative's summary covers not only major collaborative efforts, but also the accepted need for improved study design, noting that the heterogeneity of people with the label "ME/CFS" may be the greatest obstacle to identifying the underlying pathology (again, this is counter to the Wessely School's practice of including in their studies anyone with diagnosis of unexplained chronic fatigue and then claiming that their results applied to "CFS/ME", although – curiously -- after

selective results from the PACE Trial were published in The Lancet in 2011, given that the PACE Trial documentation referred to "CFS/ME", the PACE Trial Chief Principal Investigator Professor Peter Denton White wrote to the Editor-in-Chief of The Lancet: *"The PACE trial paper refers to chronic fatigue syndrome (CFS) which is operationally defined; it does not purport to be studying CFS/ME").*

Other topics in the summary include immunity and inflammation, noting amongst other things that:

- Montoya et al found the blood levels of 17 cytokines correlated with disease severity (13 of the cytokines being pro-inflammatory)
- Horning et al found distinct immune cytokine signatures in the cerebrospinal fluid in both "classical" and atypical patients groups, with suggestions of autoimmunity apparent in the "classical" group
- Nguyen et al found a different gene expression pattern in patients that indicates impaired B cell differentiation and increased viral immune response and inflammation.

The Neuroendocrine Biology section notes increasing evidence supporting the involvement of the nervous system and the relevance of neuroinflammation.

The Energy System Defects section highlights irregularities in various metabolic pathways, including disturbances in fatty acid and lipid metabolism, with 35 metabolites being significantly altered in patients.

The Gut Microbiome section is categoric that ME/CFS is associated with gastrointestinal disturbances (vehemently denied by Professor Peter White), with evidence of a proinflammatory environment, potentially leading to damage of the intestinal lining and hence influencing immune function in ME/CFS patients.

The Solve ME/CFS Initiative summary can be found at http://solvecfs.org/2017-research-highlights-study-developments-on-our-radar/

Although the research mentioned above was published in 2017, there have been thousands of biomedical papers published over the last 30 years which, intent on promoting his own belief that ME/CFS is a mental (behavioural) disorder, Wessely has ignored.

Wessely is renowned for his damaging assertions about ME/CFS, some of the more memorable ones being:

- *"Though disordered immunity and persisting viral infection have recently attracted attention, it is important that immunologists do not deflect attention away from the wider (ie. psychiatric) aspects of the chronic fatigue / postviral syndrome"* (Lancet 1988: July 9, 100-101)

- *"Most CFS patients fulfil diagnostic criteria for psychiatric disorder….Other symptoms include muscle pain and many somatic symptoms, especially cardiac, gastrointestinal and neurological. Do any of these symptoms possess diagnostic significance? The answer is basically negative….It is of interest that the 'germ theory' is gaining popularity at the expense of a decline in the acceptance of personal responsibility for illness….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' "* (In: Psychological Disorders in General Medical Settings Ed: N Sartorius et al Pub: Hogrefe & Huber, 1990)

- *"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"* (Report of meeting held on 15 April 1992 at Belfast Castle; Pfizer Invicta Pharmaceuticals, pp4-5)

- *"I will argue that ME is simply a belief, the belief that one has an illness called ME"* (9th Eliot Slater Memorial Lecture, Institute of Psychiatry, London, 12 May 1994)

- *"Patients with inexplicable physical symptoms…are generally viewed as an unavoidable, untreatable and unattractive burden"* (Brit J Hosp Med 1994:51:8:421-427)

- *"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….No investigations should be performed to confirm the diagnosis"* (Joint Royal Colleges Report on CFS, October 1996)

- *"The majority of patients seen in specialist clinics typically believe that their symptoms are the result of an organic disease process…. Many doctors believe the converse....Many patients receive financial benefits and payments which may be contingent upon their remaining unwell* (Gen Hosp Psychiatry 1997:19:3:185-199)

- *"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"* (Ann Intern Med 2001:134:9S:838-843)

- *"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 (ME) reinforces the perceived disability. A compromise strategy…would mean treating chronic fatigue syndrome as a legitimate illness while gradually expanding understanding of the condition to incorporate the psychological and social dimensions" (BMJ 2003:326:595-597)

- *"Functional somatic syndromes…include chronic fatigue syndrome"* (Rev Bras Psiquaitr Sept 2005:27:3: Sao Paulo).

There are a vast number of similar papers and chapters in medical textbooks by Wessely. Why would he write for three decades in such terms about people with a devastating neuro-immune disorder if his intention was not to ensure that clinicians and Government Departments also accept that such descriptions apply to people with ME/CFS?

Some people may ask what is the point of looking back over old ground, saying that we must now move forward; however, the point is that so much harm has been done to such very sick people and they have endured so much suffering, including medical dismissal, ridicule, contempt and neglect that it is necessary to be adequately informed about the cause of such 30 year harm in order to prevent it happening again by holding those responsible publicly accountable.

In October 2011 Bjorn Guldvog, Deputy Director General of the Norwegian Director of Health, apologised for failing to provide necessary and proper health care facilities for people with ME in Norway: *"I think that we have not cared for people with ME to a great enough extent. I think it is correct to say that we have not established proper health care services for these people, and I regret that".*

Such an apology by the UK Government is long over-due.