MYALGIC ENCEPHALOMYELITIS: ARE WESSELY'S WORDS OF WISDOM SUPERIOR TO SCIENCE?
The On-going Effects of the Role of Regius Professor Sir Simon Wessely in the Perception of ME

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Psychiatrists do not have a good track record in medicine. Wrongful attribution of an organic pathology to a psychogenic one by psychiatrists and those they advise is by no means uncommon; in the past, there simply was not the knowledge, but today, this is not the case. Despite the advanced investigative procedures which are now available and despite the resultant scientific confirmation that myalgic encephalomyelitis (ME) is a complex neuroimmune disorder, a group of UK psychiatrists persist in stark denial of the biomedical science which disproves their intransigent belief that ME is a behavioural (ie. mental), not physical, disorder.

In 1948, Booth described Parkinson's Disease as an "*illness of the ambitious, moralistic man*" and ascribed the cause of the characteristic tremor to "*conflict resulting from the wish to masturbate*" (Psychodynamics in Parkinsonism. Booth G. Psychosom Med 1948:10:1-14).

It was not until 1978 that multiple sclerosis lost its psychogenic status of hysteria in recognition that it is an autoimmune disease (Immunoregulation in multiple sclerosis. Weiner, HE & Hauser, SL. In: Immunology of Nervous System Infections: Progress in Brain Research vol. 59. Ed. P.O.Behan, V. ter Meulen & F. Clifford Rose. Elsevier Science Publications BV 1983:339-343).

Sadly, some psychiatrists appear not to learn from experience. Their determination to claim complex medical conditions without a definitive diagnostic test – such as ME -- as mental disorders (referred to as *"functional somatic syndromes*" or *"somatoform disorder"*) has not abated. In 2001, a UK psychiatrist wrote in the BMJ: "*Functional somatic syndromes…are not so much the remnants of medicine's deficiencies, but instead represent its future".* That is an alarming statement, as it indicates the intention to restrict biomedical research into such disorders.

That ME (sometimes referred to as "ME/CFS" or "chronic fatigue syndrome") is a serious neuroimmune disorder cannot be in doubt. There is incontrovertible published evidence that there is multi-systemic dysfunction, with the vascular endothelium as the target organ, causing a plethora of distressing symptoms. It is not unusual for it to be fatal.

Numerous experts in ME are on record about the biomedical reality of it, for example:

"Every time you look closely at someone with this disease, you see immense suffering….there appears to be no limits to the human toll that this disease is capable of exacting on patients" (Professor Emeritus Alan Cocchetto, Medical Director of The National CFIDS Foundation, 2005)

"***Our patients are terribly ill, misunderstood and suffer at the hands of a poorly informed medical establishment"*** (Nancy Klimas, Professor of Medicine and Immunology, University of Miami: one of the world's foremost AIDS and ME/CFS physicians; Incoming Presidential Address, AACFSME, 21st March 2005)

"It's not an illness that people can just imagine that they have, and it's not a psychological illness. In my view, that debate, which has raged for 20 years, should now be over" (Professor Anthony Komaroff, Harvard Medical School, Press Conference 2006

"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" (Nancy Klimas, Professor of Medicine and Immunology, University of Miami; New York Times, 15th October 2009)

"The whole idea that you can take a disease like this and exercise your way to health is foolishness. It is insane" (Dr Paul Cheney; Medical Director of the Cheney Clinic; Invest in ME Conference, London, May 2010)

Since 1988, one UK psychiatrist in particular denies the existence of ME other than as a "*myth*" and has been on a self-confessed mission to "*eradicate*" ME by re-naming it "CFS/ME" then dropping the "ME" when expedient and re-classifying "CFS" (chronic fatigue syndrome) as a mental/behavioural disorder, with "chronic fatigue" already being classified as such a disorder in ICD 10 at F48.0. Importantly, "chronic fatigue syndrome" is not the same as "chronic fatigue", a distinction that has become blurred because of that psychiatrist's personal interpretation and interchangeable use of the terms. It appears to be inescapable that his well-publicised beliefs about a devastating physical disorder have resulted in iatrogenic harm to countless people.

That person is Simon Charles Wessely, born on 23rd December 1956 in Sheffield, who has risen to the very top of the tree of prestige in the UK. He even has a group of mental health practitioners named after him, known as the "Wessely School" (Hansard: Lords: 9th December 1998:1013).

How could such a distinguished and revered expert with such unassailable status possibly be wrong about ME by insisting that it is but a *"myth"* which he wishes to *"eradicate"?*

That ME often deals unimaginable blows upon both adults and children cannot be disputed: for Wessely to deny the reality of its existence has been described as a medical scandal in urgent need of exposure.

In late October 2003, Wessely gave vent to his true feelings about sufferers from ME who disagree with him: he said that those who believe that ME is an organic disorder – to whom he referred as "***the radicals"*** -- are (quote): ***"crazy"*** and that they are "***engaged in fantasies, lies and gross distortions"***, that the ***"radicals"*** are left ***"fighting yesterday's battles"*** because he believes he has established that ME does not exist except as a false illness belief. He said that they need a ***"reality check"*** and that "***their behaviour is outrageous"*** (personal communication).

His words hardly concur with his frequent claims to be a caring clinician who has looked after people with ME all his professional life.

As clinical psychologist Dr Joseph Lenz commented: "*Science has no greater enemies than those who seek to confuse an issue, and those who create the most confusion are invariably those who believe that they already know the truth"* (The Scotsman: 9th January 2004).

What is ME?

ME is a serious, disabling, chronic, organic, multi-systemic disorder that is increasingly being shown to be an autoimmune disorder. 80% of patients do not get better (Presentation to the Scottish Parliament on 4th April 2001 by Dr A Chaudhuri, Senior Clinical Lecturer in Neurology, University of Glasgow). International expert Dr Daniel Peterson is on record as stating about ME: *"In my experience, (it) is one of the most disabling diseases that I care for, far exceeding HIV disease except for the terminal stages"* (Daniel L Peterson: JCFS 1995:1:304:123-125).

Researchers found that the quality of life is particularly and uniquely disrupted in ME and that all participants related profound and multiple losses including loss of jobs, relationships, financial security, future plans, daily routine, stamina and spontaneity. Activity was reduced to basic survival. The extent of the losses experienced by sufferers was devastating, both in number and intensity (JS Anderson CE Ferrans: J. Nervous and Mental Diseases 1997:185:6:359-367).

Australian researchers found that patients with ME had more dysfunction than those with multiple sclerosis and that the degree of impairment is more extreme than in end-stage renal disease and heart disease, and that only in terminally ill cancer and stroke patients was the sickness profile greater than in ME (R. Schweitzer et al: Soc Sci Med 1995:41:10:1367-1372).

The exhaustion experienced by patients is extreme: "*The disabling weakness and exhaustion a patient with ME experiences is so profound that 'fatigue' is probably an insult"* (Vojani A, Lapp CW: Immunopharmacol Immunotoxicol 1999:21: (2):175-202).

ME has been recognised and described in the medical literature since 1934 (the Los Angeles outbreak), with the seminal paper being the one by Wallis in 1957 (An Investigation into an Unusual Disease seen in Epidemic and Sporadic Form in a General Practice in Cumberland in 1955 and subsequent years. Andrew Lachlan Wallis. Doctoral Thesis, University of Edinburgh, 1957). Sir Donald Acheson's (a former Chief Medical Officer) major review of ME was published in 1959 (Am J Med 1959:26:569-595) and in 1962 the distinguished neurologist Lord Brain included ME in the standard textbook of neurology (Diseases of the Nervous System. Lord Brain; Oxford University Press, 6th Edition, page 355). In 1969 ME was formally classified as a neurological disorder by the WHO in its International Classification of Diseases (ICD10 G93.3) and in 1978 the Royal Society of Medicine accepted ME as a nosological entity. In November 1987 the Department of Health recognised ME as an organic disorder. In 1988 the British Medical Association officially recognised it as a legitimate and distressing physical condition. On 16th August 1992 the then-Minister of Health (Stephen Dorrell) confirmed that "***ME is established as a medical condition".*** In its 1993 update of ICD 10, the WHO recognised the term "Chronic Fatigue Syndrome" as one by which ME might sometimes be known and includes it with ME at G93.3. All this is a matter of public record.

No bodily system is exempt: all systems are adversely affected by it. There is a substantial literature base documenting significant abnormalities primarily in the immune system, but also in the neurological, cardiovascular, endocrine, musculo-skeletal and gastro-intestinal systems, with emphasis on an autoimmune vasculitis.

In ME/CFS there is an abundance of published evidence of:

- disrupted biology at cell membrane level
- abnormal brain metabolism
- reduction in grey matter
- cerebral hypoperfusion
- central nervous system inflammation and demyelination
- neutrophil apoptosis
- abnormal vascular biology, with disrupted endothelial function
- significantly impaired NK cell activity
- significantly elevated levels of isoprostanes (a marker for oxidative stress, which increases with exercise)
- cardiac insufficiency
- neuroendocrine dysfunction (notably HPA axis dysfunction)
- respiratory dysfunction, with reduced lung function in all parameters tested
- autonomic dysfunction (dysautonomia, with labile blood pressure, frequency of micturition with nocturia; thermodysregulation and POTS)
- haemodynamic instability
- recovery rates for oxygen saturation that are 60% lower than those in normal controls
- mitochondrial metabolic dysfunction
- a sensitive marker of muscle inflammation (inflamed tissues should not be exercised)
- conclusive evidence of delayed muscle recovery after exercise
- abnormal gene expression (there are more abnormal genes in ME than there are in cancer)
- multiple allergies, with adverse reactions to medicinal drugs
- sometimes profound cognitive impairment

There is no evidence that ME is a psychiatric or behavioural disorder.

References:

- The references can be found in "Magical Medicine: How to Make a Disease Disappear" February 2010; in "Concepts of Accountability", August 2001, and in "Illustrations of Clinical Observations & International Research Findings from 1955 to 2005 that demonstrate the organic aetiology of ME/CFS" by Malcolm Hooper www.margaretwilliams.me and www.oneagleswings.me.uk/margaretwilliams/
- Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: the biology of a neglected disease: Hayley Arron, Benjamin D Marsh, Douglas B Kell, M Assad Khan, Beate Jaeger & Etheresia Pretorius: Frontiers in Immunology: 3rd June 2024: 15.1386607. doi:10.3389.fimmu.2024.1386607 (593 references)
- The Clinical and Scientific Basis of ME/CFS. ed: BM Hyde; The Nightingale Press, Ottawa, Canada 1992.

The Oxford Criteria

The Wessely School constructed their own case definition of “chronic fatigue syndrome” which was published in 1991 (the “Oxford criteria”, named after a meeting they held in Oxford to compose what they considered to be a diagnostic tool (JRSM 1991:84:118-121). There is an important clinical difference between the inversion of the terms “ME/CFS” and “CFS/ME”: the former describes people classified in ICD10 at G93.3 under Neurological Disorders, whereas the latter was constructed by Wessely et al, who insist that it is a somatoform disorder and thus can be included with other “fatigue” disorders that are classified in ICD10 at F48.0 under Mental and Behavioural Disorders.

Post-exertional malaise, or PEM, is virtually pathognomonic of ME, but the Oxford criteria do not include it. Another key issue is that the Oxford criteria specifically include psychiatric disorders with “fatigue” as a symptom but specifically exclude anyone with any neurological signs or symptoms.

From the available statistics, it seems that only about 5% of those diagnosed with ME/CFS using the Oxford criteria meet the more robust diagnostic criteria such as the Canadian Consensus, or the even more stringent International Consensus Criteria (ICC). A major study of the Oxford criteria with over 6,000 participants who had been diagnosed with ME/CFS found that 85% were healthy subjects, with only mild “fatigue”, not ME/CFS, and that they had been inappropriately labelled (Baraniuk JN. Fatigue 2017:5:215- 230).

The Oxford case definition states: “*There are no clinical signs characteristic of the condition”*, yet the well-documented signs seen in ME (many of which are neurological) include sluggish visual accommodation; irregular pupil movement; nystagmus; positive Romberg; abnormal tandem stance; abnormal gait; abnormality of vestibular function; coarse hand tremor; cogwheel movement of leg on testing; fasciculation; hyper-reflexia without clonus; diaphragmatic incoordination; irregular bounding pulse; flattened or inverted T-waves; cyanotic nail beds; secondary Raynaud’s; vasculoid rash; neurally-mediated hypotension; recurrent mouth ulcers; hair loss and disturbed bladder and bowel function; there may also be an enlarged liver and spleen. How can any medically qualified practitioner disregard such signs? Could the answer be because the medical practitioner does not look for them?

Evidence from autopsies of people with ME/CFS

Wessely is on record as asserting ***“Most important of all, ME is not, and cannot be, fatal”*** (The Times, 14th September 1993).

There is a substantial body of evidence from autopsies of people who died from ME/CFS which leaves no possible doubt that it can be fatal.

The evidence is chilling: it includes viral infection of the heart, with fibrosis, indicating the presence of long-standing infection. Autopsies have provided evidence of oedema of the lower limbs; alveolar spaces of the lungs filled with inflammatory cells; small emboli scattered throughout the arteries; marked congestion of the liver and spleen; evidence of an ischaemic bowel; inflammation of the kidneys; evidence of rhabdomyolysis (the breakdown of muscle fibres resulting in the release of muscle fibre contents into the circulation, some of which are toxic to the kidney); hyperplastic bladder epithelium; thyroid with colloid filled follicles, with scattered dystrophic calcifications and calcification of the small arterial walls; degeneration of the right occipital lobe of the brain; degenerated astrocytes, with puckered white matter surrounding this defect.

The case of Sophia Mirza is well-documented: this 32 year-old was sectioned by psychiatrists, who alleged that she was suffering from a mental disorder. She was kept in a locked ward and denied basic care. Although she died in 2005, the inquest was not held until 13th June 2006. There was evidence of severe inflammation throughout 75% of her spinal cord, affecting the dorsal root ganglia, which are the gateway for all sensation going to the brain through the spinal cord.

At the inquest, one of the pathologists stated: *“ME describes inflammation of the spinal cord and muscles. My work supports the inflammation theory because there was inflammation in the basal root ganglia”* and that “*It lies more in the realms of neurology than psychiatry, in my opinion”.*

Evidence was provided at the inquest that Sophia had a "*fatty"* liver. (This was one of three such autopsies spoken about by Dr Abhijit Chaudhuri at the Royal Society of Medicine meeting on 11th July 2009). There are reports of hepatic involvement in ME going back to 1977. Published evidence shows infiltration of the splenic sinuses by atypical lymphoid cells, with reduction in white pulp, suggesting a chronic inflammatory process (Coincidental Splenectomy in Chronic Fatigue Syndrome. BJ Miller et al: JCFS: 1998:4(1):37-42).

On 18th June 1995, consultant radiologist Eric Booth died from ME aged 48 (Obit: BMJ 28 October 1995:311). The death certificate stated "*cardiac dysrhythmia, cryptogenic myocardial fibrosis*". The autopsy findings were disturbing and were suppressed: Booth's partner was warned by the Official Solicitor that action would be taken against her if she divulged all the *post-mortem* findings.

Another tragic and well-publicised case is that of 27-year-old Maeve Boothy O'Neill, whose inquest was held in July/August 2024, with an additional day of evidence on 27th September 2024. On 7th October 2024 it was necessary for the Devon Coroner Deborah Archer to serve a Coroner's Regulation 28 (Prevention of Future Deaths) Notice issued under Coroners' (Investigations) Regulations 2013, a Notice applicable to the NHS and local authorities regarding prevention of deaths from ME.

A hospital consultant physician stood before that Coroner and attempted to explain Maeve's death, and why vital tube feeding was withheld: in accordance with Wessely's teaching, senior medical staff did not want to "*medicalise*" her condition by accepting that she was suffering from a genuine organic disorder instead of a self-induced psychogenic condition as they believed to be the case.

These cases are not rare: coroners continue to provide incontrovertible evidence that ME can be fatal. The UK authorities keep no statistics, so the actual number of deaths from ME remains unknown. There have been numerous deaths in the UK where the cause of those deaths is recorded on the death certificate as ME. Could this perhaps be because over 90% of the UK medical profession fails to recognise ME as a serious biomedical disease (An Audit of UK Hospital Doctors' Knowledge and Experience of Myalgic Encephalomyelitis. Hng KN, Geraghty K, Pheby DFH: Medicina 2021:57(9): 885)? It is estimated that the suicide rate in ME is as high as 12%, driven not only by relentless suffering but also by medical abuse and NHS abandonment, and by financial destitution because essential benefits have been withdrawn or refused on advice provided to Departments of State by the Wessely School, in particular by Wessely himself and by his close psychiatrist colleague Peter White.

It is not only the evidence revealed at autopsy that proves neurological pathology; there is indisputable evidence that patients living with ME/CFS show signs of neurological dysfunction, for example:

"Neurologic symptoms, MRI findings, and lymphocyte phenotyping studies suggest that the patients may have been experiencing ***a chronic, immunologically mediated inflammatory process of the central nervous system****" (*Buchwald, Cheney, Peterson D, Komaroff, Gallo et al; Ann Int Med: 1992:116:103-113).

"As with any chronic inflammatory condition affecting the central nervous system*, the T2-bright foci on MRI in (ME)CFS may represent a perivascular cellular infiltrate and/or reactive demyelination of the surrounding white matter. Alternatively, these abnormalities may reflect the results of a vasculopathy specifically involving the small vessels of the cerebral white matter. Specifically, on the basis of our observations, the white matter abnormalities seen on MRI images may represent foci of gliosis or chronic demyelination, which appear to be irreversible"* (Schwartz RE et al; Am J Roentgenology:1994:162:935-941).

"It is now evident that this illness is not simply an imaginary one, nor the result of anxiously amplifying normal bodily sensations. Substantial objective evidence of abnormalities in the central nervous system is now available. Magnetic resonance imaging has revealed punctate areas of high signal in the white matter more often in patients with (ME)CFS than in healthy controls. They may represent areas of ***inflammation*** *or demyelination"* (Komaroff AL (JAMA:1997:278:14:1179-1184).

"These findings are consistent with an activated inflammatory response*. Shockingly, the mean QOL (quality of life) scores as regards limitations on physical functioning were very, very low, similar to those found in people with AIDS and multiple sclerosis*" (Advances in biomedical understanding of ME. Neil Abbot. Vance Spence. InterAction May 2004).

Wessely's beliefs about ME and the resultant effects of his beliefs

A current article shows that when doctors dismiss patients' symptoms as "all in the head", patients are traumatised and suffer serious psychological harm:

"This dismissive phrase from healthcare professionals triggers a cascade of harmful consequences. Research reveals the devastating impact when doctors invalidate patients' symptoms…This phenomenon, recently termed 'symptom invalidation' by researchers…occurs when doctors explicitly or implicitly communicate that patients are wrong about their own bodies…The review found such dismissal creates profound emotional harm…This problem disproportionately affects conditions that are difficult to diagnose through standard testing…The researchers conducted a systematic review of qualitative studies examining symptom invalidation across 11 difficult-to-diagnose conditions, including…myalgic encephalomyelitis/chronic fatigue syndrome…They screened 3,357 records (and) identified four broad themes of harm from symptom invalidation…including self-doubt, shame, and even suicidal thoughts" (https://studyfinds.org/medical-gaslighting-can-wreck-oatients-health-for-years/ Ignored, Dismissed, and Minimized: Understanding the Harmful Consequence of Invalidation in Health Care – A Systematic Meta-Synthesis of Qualitative Research. Allyson Bontempo et al. Psychological Bulletin 2025:151:4:399-427).

It cannot be denied that Wessely dismissed the symptoms shown by a 12 year old boy with severe ME and was closely involved in the forcible removal of the child from his parents because Wessely believes that ME is simply a "*myth"* to which he refers as an *"aberrant illness belief"* and as a *"non-disease".*

Just two years after he obtained his MRCPsych, Wessely considered himself an expert in ME and was first involved in this practice in 1988, when on 3rd June he wrote about Ean Proctor: "*I did not perform a physical examination but was told there was no evidence of any physical pathology".* Ean had lost the ability to speak, which Wessely asserted was *"elective mutatism" (sic).* Wessely wrote to Social Services: *"I have considerable experience in the subject of 'myalgic encephalomyelitis'. I feel that Ean needs a long period of separation from his parents. For this reason, I support the application made by your department for wardship".* On 10th June 1988 Wessely provided another report on Ean Proctor, in which he wrote: "*I did not order any investigations. Ean cannot be suffering from any primary organic illness, be it myalgic encephalomyelitis or any other. Ean has a primary psychological illness (and) requires skilled rehabilitation to regain lost function. I therefore support the efforts being made to ensure Ean receives appropriate treatment".* After his signature, Wessely wrote: "Approved under Section 12, Mental Health Act 1983". That same month, without ever having spoken to Ean's parents, social workers supported by psychiatrists, armed with a Court Order that had been specially signed on a Sunday, and in the presence of police officers, forcibly removed the severely sick child from his desperate parents.

Ean was subjected to utter terror by being placed face-downwards in the hospital swimming pool with no aids because the staff believed his inability to move was psychogenic and that he would have to move in order to save his life (he was unable to move and had to be rescued). He was also put on a ghost train in the belief that he would be so scared that he would cry out (thus proving that his inability to speak was psychogenic). He was raced in a wheelchair pushed at speed by a nurse along hospital corridors who, without warning, suddenly stopped, ejecting Ean of the wheelchair because he was unable to save himself, another unforgivable and barbaric incident in which Ean sustained physical injuries. He was left to lie in a urine-soaked bed in the belief that he would take himself to the toilet, which he was unable to do.

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 forcible removal of another child with ME was being discussed, when asked by the presenter Sheena McDonald if there can ever be a case for the coercive approach in situations involving the forcible removal of a child with ME/CFS from the parents, Wessely replied: "*I think it's so rare. I mean, it's never happened to me"*. Wessely's elective amnesia was broadcast on national television for all to see: that programme was recorded, providing evidence that Wessely is not always truthful. Unfortunately, such actions are far from rare.

Nothing seems to have been learnt from the appalling case of Ean Proctor. Twenty-six years ago, the grave issue of forcibly removing children with ME from their parents was raised by Dr Nigel Speight, then a consultant paediatrician at the University Hospital of North Durham with 20 years' experience of children with ME. In April 1999 Dr Speight reported to the Chief Medical Officer's Working Group on CFS/ME that the frequency of psychiatrists diagnosing the parents of children with ME/CFS as suffering from Munchausen's Syndrome by Proxy – and consequently placing these children into State "care" -- amounted to an epidemic.

These atrocities continue: not only are children with ME being taken from their parents, but also adults with severe ME are being threatened with being sectioned – ie. involuntary commitment to, and detention in, a psychiatric unit under the Mental Health Act 1983 – in the misguided belief that their inability to care for themselves is simply "attention-seeking". These extremely sick people are often intentionally neglected in hospital in the belief that they have a "non-existent" illness and on the false premise that if left for long enough, they will be so hungry that they will sit up and move, which they cannot do.

Wessely's campaign to get ME recognised as a "non-existent" disease

In 1989 Wessely was a Founder Member of The Campaign Against Health Fraud, where he was listed as a "*leading member of the campaign".* The campaign's literature states that its aim was *"to oppose unnecessary treatment for non-existent diseases".* For the following three decades Wessely has unceasingly campaigned to promote his belief that ME is a "*non-disease"* that does not exist except in the mind of those who believe it exists. He urges that no investigations should be performed to confirm the diagnosis and he has published over 900 papers – as well as contributing to numerous textbooks – in support of his own ideology that ME is not a neurological disorder but a psychiatric disorder. He appears to believe that people with ME/CFS can "recover" by following his own "treatments" of graded aerobic exercise therapy (GET) and by restructuring their "faulty" cognitions using his own directive cognitive behavioural therapy (CBT).

Wessely's efforts to get ME re-classified by the WHO as a mental disorder

Wessely does not accept the WHO classification of ME as a neurological disorder and he has worked assiduously to change that classification. In 2000, the UK WHO Collaborating Centre for Mental Health at the Institute of Psychiatry (Wessely's place of work) intentionally 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 adherence to 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 gaining the impression that it was the WHO itself (not the WHO Mental Health Collaborating Centre at the Institute of Psychiatry) that had re-classified the physical disorder as a mental disorder. In September 2001 the WHO issued a statement repudiating the unofficial re-classification by the UK Mental Health Collaborating Centre. The matter was raised in Parliament on 22 January 2004, where Earl Howe observed 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, Wessely then asserted that the WHO itself had classified the same disorder in two places in the ICD and thus it had dual classification, once in the Neurological Section and also in the Mental (Behavioural) Section. Yet again, his claim was 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 John Reid formally confirmed that the correct classification for the disorder remained neurological.

The issue at stake was of such importance that on 18th August 2003 the Countess of Mar had written to Dr George Szmukler, Dean of Psychiatry at the Institute of Psychiatry, in terms (for brevity, extracts only):

"In the Guide to Mental Health in Primary Care, Professor Wessely includes ME as a mental disorder, whilst on the King's College website it asserts that 'CFS has officially replaced the term ME', when such is not the case under the auspices of the WHO (and) Collaborating Centres are not permitted to change classifications without the approval of the World Health Assembly.

"I myself have raised the issue of Professor Wessely's continued denial of important biomarkers of the organic pathoaetiology of ME/CFS (all recorded in Hansard) and have provided Ministers with abundant documented concerns about Professor Wessely, who consistently dismisses, trivialises or ignores the published scientific evidence about the nature of ME, which is now considerable. I have also obtained an opinion from a leading Queen's Counsel and I quote from that advice: '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'.

"You will doubtless be aware of the major legal action currently before the High Court (claim number HQ02X02679) in which Professor Wessely, Kings College Hospital NHS Trust Corporate Legal Services and the South London and Maudsley NHS Trust are Defendants and of the fact that Legal Aid has been granted to pursue the action. You will know that it is an action for damages arising from the Defendants' alleged clinical negligence and from their alleged breach of duty in connection with the non-investigation of disease, the non-provision of medical facilities for diagnosis and/or sufficient testing necessary to provide adequate pathophysiological information on which to base a rational treatment programme. You may also be aware that the High Court Master assigned to the case (Master Yoxall) has made it clear that he will not permit the action to be struck out.

"For the avoidance of doubt, may I set out a few salient facts, all of which are readily verifiable.

"The truth about ME/CFS is still being suppressed and denied by Professor Wessely and his supporters and by those whom they control and influence: their dogma is that 'CFS' is an 'abnormal illness belief' resulting in deconditioning which must not be comprehensively investigated, treated or validated; those claiming to suffer from it must not be 'pandered' to by 'naïve' physicians and must not be given social services support, state benefits or insurance payments. In contrast, in the US Professor Anthony Komaroff states: '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 (Am J Med 2000:108:99-105).

"It is my opinion that this is not ignorance but deliberate misrepresentation and determined suppression by Professor Wessely of the available international medical and scientific evidence for over 16 years. For psychiatrists of the 'Wessely School' to continue to insist that they are relying on 'evidence-based medicine' and repeatedly to recommend psychotherapy as the best management strategy is a wholly deplorable situation which I intend to raise once again in the House.

"Without doubt, patients have been harmed by Professor Wessely's endless assertions that ME does not exist and by his unsubstantiated claim that previous studies of ME 'reflect those who seek treatment rather than those who suffer the symptoms' and that 'there lies at the heart of CFS not a virus (or) immune disorder, but a distortion of the doctor-patient relationship'.

"One immediate practical example is that the NHS Information Authority has confirmed in writing that 'the source of the coding for Chronic Fatigue Syndrome in the Mental Health Minimum Data Set (MHMDS) Data Manual is the WHO guidance on Mental Health for Primary Care' (sic). As this 'information' has been distributed throughout the NHS, the harm flowing from it is unquantifiable but entirely preventable and consequently it is expected that further legal actions will follow.

"I look forward to receiving your assurance that you will address the issues I have brought to your attention".

On 27th August 2003 Dr Szmukler replied to Lady Mar:

"Thank you for your letter of 18th August 2003 in which you ask me to address issues relating to the classification of ME and CFS, and the work of Professor Simon Wessely.

"I would like to say a few things about Professor Wessely. Questions about CFS/ME should be resolved through research, with rigorous scrutiny of the methods, findings and conclusions by the community of scientists devoted to the field. By these standards, Professor Wessely must be judged one of the outstanding medical researchers in

the UK, and indeed internationally. His research has been regularly and continuously funded by bodies such as the Medical Research Council and the Wellcome Trust which exercise the most demanding levels of peer review. Similarly, the publication of Professor Wessely's research findings has consistently and predominantly been in journals in which submissions are again subject to the most exacting scrutiny by his scientific peers. Professor Wessely has been awarded a Research Medal by the Royal College of Physicians (specifically for 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.

"The Institute of Psychiatry thus has every reason to have confidence in the quality and integrity of Professor Wessely's research".

On 2nd September 2003 Lady Mar responded to Dr Szmukler's letter:

"Your response of 27th August 2003 exactly typifies the problem that ME/CFS patients have to contend with: plainly, you chose to see only what you wanted to see instead of the reality of the situation.

"Apart from the anticipated eulogy of Professor Wessely, you have not addressed the central issues which I specifically asked you to deal with, namely the incorrect inclusion of ME/CFS in the UK Guide to Mental Health in Primary Care, and the need to distinguish between ME/CFS and the chronic fatigue found in somatoform disorder, when those are the very issues which fuel this furore.

"You state that 'the area remains somewhat controversial' but there can be no controversy about the fact that ME/CFS is classified by the WHO under 'Diseases of the Nervous System'. The controversy to which you refer is between the minority view of some psychiatrists and the majority view of the international research community: the latter accepts the biomedical science and the clinical signs exhibited in ME/CFS as being consistent with organic disturbance of the neuro-endocrine, immunological and cardiovascular systems, not somatisation disorder, whilst the former does not. It is Professor Wessely who has sought deliberately to usurp the authority of the WHO by departing from its clearly written classification as set out in the ICD, despite the fact that the WHO has confirmed that the present classification will not be subject to any revision in the foreseeable future and, specifically, that there is no intention to move ME from a neurological to a psychiatric classification.

You claim that 'amongst the scientific community there is less disagreement than your letter suggests': whilst I am aware that this may be so amongst certain self-proclaimed and vociferous 'experts' in the UK psychiatric community, it is certainly not the case amongst the biomedical community and I drew the international concern about this to your attention in my letter of 18 August 2003.

"The reason I wrote to you was because ME/CFS is not classified by the WHO as a mental disorder yet it is included in the UK Guide to Mental Health in Primary Care. Significantly, the Guide clearly states in its Introduction that it contains a list of categories of mental disorders from the ICD-10 classification consistent with the main ICD-10 classification (ie. each diagnosis and diagnostic category is claimed to correspond to those in ICD-10). This being so, on what credible grounds was ME/CFS included in the Guide? Its inclusion is seen as outright deception which provides false guidance for GPs, many of whom express concern about this situation far in excess of that shown in your letter.

"It is notable that, notwithstanding his assertion about the classification of ME in the Guide to Mental Health, Professor Wessely has acknowledged in writing that ME/CFS is not classified by the WHO at section F48 as a mental disorder. What is the explanation for this discrepancy? Clearly the issue with which I asked you to engage remains to be addressed: ME/CFS is wrongly included in the Guide to Mental Health compiled by the Institute of Psychiatry of which you are Dean. Is it the case that you see expediency and the funding it can bring as being more important than clinical accuracy?

"This matter of correct classification is of supreme importance to patients, not only because of the resultant financial consequences (because those with a psychiatric label are denied certain state benefits as well as medical insurance payment) but also because if their disorder has a 'mental' label, they can be (and are being) forcibly coerced into inappropriate management regimes which have been shown to be harmful and which are at variance with their own experience as expert patients.

"It is also important to researchers in the biomedical community, because if a condition is designated as 'mental', there is no funding available to undertake any biomedical research (as is currently the case in this disorder), with the result that patients continue to be denied alleviation of their suffering.

"Turning to your paean of praise for Professor Wessely, I believe this is misplaced. Whilst he is undoubtedly influential and is acclaimed within his own circle, in the wider sphere he is seen as showing a total lack of both

understanding and compassion. There is now a vast amount of published evidence which shows that his beliefs are wrong, yet he persists in rejecting that evidence.

"Are you aware that Professor Wessely has repeatedly been criticised in the mainstream literature for his bias, his methodological flaws, his lack of objectivity and his manipulating of others' published research findings so as to make them appear to support his own conclusions when they do not? He has become notorious for ignoring the published work of those whose findings do not accord with his own beliefs, and also for his theories about the omnipresence of somatisation disorder. He has been severely criticised over his Gulf War studies by eminent experts in that field, including Professor Robert Haley in the US and Professor Malcolm Hooper in the UK.

"It is indeed the case that for much of his career, Professor Wessely has been closely associated with both the MRC and Wellcome. You say that the MRC exercises 'the most demanding levels of peer-review': why, then, did a House of Commons Select Committee Report (The Work of the Medical Research Council Third Report of the Science and Technology Select Committee of the Session 2002-2003. HC 132. ISBN 021 500 896 0. March 2003) lambast the MRC for introducing misguided strategies, wasting research funding on projects of second-rate quality and for mismanagement? MPs found that there were serious questions about the way the MRC has operated over the last few years. They warned that the MRC had failed to win the full confidence of both the public and the research community and that 'Something has gone badly wrong at the MRC. Our report shows why scrutiny of British science is so badly needed'. Are you not aware of this unprecedented attack and damning judgment on the MRC ?

"I look forward to receiving a reasoned and comprehensive reply".

On 8th September 2003 Dr Szmukler replied to Lady Mar:

"I am sorry I am unable to help you further".

Of particular note is the fact that Dr George Szmukler and Dr Clare Gerada (Professor Simon Wessely's wife, now Professor Dame Clare Gerada, who was to become President of the Royal College of General Practitioners) had co-edited a book entitled "Mental Illness – A Handbook for Caregivers", RCP 2001. Also, Clare Gerada is mentioned in the acknowledgements page of the intentionally misleading "WHO Guide to Mental Health in Primary Care" for which, after an intense battle, an erratum had to be issued.

Does this explain why Dr Szmukler defended Wessely so fervently?

Without doubt, Wessely is indeed revered.

Wessely's influence in UK Departments of State

Despite what many people consider to be his iniquitous behaviour, Wessely's influence over UK Departments of State appears to be unmatched, especially over the Department for Work and Pensions and the Department of Health and Social Care, the Medical Royal Colleges and the Medical Research Council, where Wessely was a member of three Boards: the Monitoring and Evaluating Steering Group which conducts evaluations of the MRC's research funding policies; the Neurosciences and Mental Health Board, and the Health Services and Public Health Research Board.

During the MRC's Public Consultation period for ME/CFS in 2002-2003, more members of the Wessely School were appointed to MRC Boards, including Trudie Chalder (a psychiatric nurse who became a behaviour therapist, now Professor of Cognitive Behavioural Psychotherapy at the Institute of Psychiatry), Anthony Cleare (Senior Lecturer in Affective Disorders and Director of the National Affective Disorders Unit at the Institute of Psychiatry, specialising in "CFS/ME"), Anthony David (Professor of Cognitive Neuropsychiatry at the Institute of Psychiatry and Consultant Psychiatrist), Anne Farmer (Professor of Psychiatric Nosology at the Institute of Psychiatry), Michael Sharpe (who for a short time held a Personal Chair in Psychological Medicine and Symptoms Research at Edinburgh but then returned to Oxford and is now Professor Emeritus of Psychological Medicine), Til Wykes (Professor of Clinical Psychology at the Institute of Psychiatry), and Peter White (now Professor Emeritus of Psychological Medicine, Barts & Queen Mary's School of Medicine).

As the late Dr Jonathan Kerr (formerly at the Department of Cellular and Molecular Medicine at St George's University of London, whose grant application for gene research in ME/CFS was rejected by the MRC) said on the record at the Invest in ME International Conference in May 2007 held in London, as long as psychiatrists control the MRC, it will never fund biomedical research into ME/CFS.

Wessely's influence extends beyond medicine into the judicial system. On 1 September 2017 he was appointed to the Judicial Appointments Commission (JAC)—the body responsible for selecting candidates for judicial office in England and Wales—and was reappointed on 1st September 2020.

This may be a matter of concern, because in one High Court case involving ME, a claimant was told: *"Judges regard ME as psychological self-indulgence."* Such a remark from within the very system meant to protect the rights of vulnerable people may reflect the Wessely School's influence on institutional attitudes.

Wessely influences the (non)-payment of long-term benefits for people with ME and it seems he may influence NHS Research funding: for example, it was known that Long Covid was listed as a top priority for research funding, but very soon after Wessely was appointed to NHS England Board of Directors (who control funding) in January 2023, Long Covid no longer appeared on that list.

It is now widely accepted by many medical scientists and clinicians that some people with Long Covid fulfil the diagnostic criteria for ME. Indeed, the Joint Statement for World ME Day on 12th May 2025 issued by combined ME groups states that an estimated one in two people with Long Covid meet the diagnostic criteria for ME.

Wessely's importance and involvement in UK institutions cannot be equalled.

Wessely's involvement with The Science Media Centre

Wessely is a Founder Member of the Science Media Centre and is listed as a member of its Scientific Advisory Panel. The SMC began work in 2002 and is funded by, amongst others, the pharmaceutical and chemical industries. Its nominal purpose is to explain science in briefings to the media to help them understand the intricacies of a scientific story, but there are those who believe that its actual purpose is to control how science is reported in the media so that it accords with government policy, a ploy which is successful. For example, the Health Editor of The Daily Telegraph refused to report a story about the biomedical basis of ME, saying that they only accepted items about ME when they came from the SMC (personal communication).

Wessely's involvement with the insurance industry

Wessely's close involvement with the insurance industry is undeniable.

On 17th May 1995, Wessely and his close colleague and co-author, psychiatrist Michael Sharpe (who claimed to be a specialist in "CFS"), were the main speakers at a symposium entitled "Occupational Health Issues for Employers" held at the London Business School, at which they advised employers how best to deal with employees on long-term sickness absence with ME. Attendees were informed that "CFS" is known as "*the malingerers' excuse".* Another speaker was Dr John Lo Cascio, Vice President of UNUM, a major permanent Health Insurance company. Attending physicians were told that they must "*work with UNUM rehabilitation services in an effort to return the claimant back to maximum functionality with or without symptoms".*

Another insurance area with which Wessely was known to be actively involved was PRISMA ("Providing Innovative Service Models and Assessments"), funded by the European Commission's Information Society Technologies Programme. In the early 2000s, PRISMA claimed to analyse services identifying "best practice" models and was known to be especially concerned with long-term disability from the perspective of governments, service providers and insurance companies. It claimed to have developed a "*unique treatment programme"* for "*hopeless"* cases, in which ME was included. The PRISMA programme placed heavy emphasis on training such cases to regain a "*normal life"* again, with *"exceptional (sic) good results".* In the PRISMA Round Table, discussions take place with "*leading experts in medical care, the insurance industry and government officials and provide recommendations to healthcare policy makers".* In the PRISMA company information

Wessely was listed as a Corporate Officer and as a member of the Supervisory Board. In order of seniority, he was higher than the Board of Management and listed as a world expert in the field of medically unexplained illnesses, including ME/CFS. In response to a parliamentary question in the House of Lords, Lord Falconer of Thoroton, Minister of State in the UK Cabinet Office, confirmed that the PRISMA findings would be taken into consideration by the UK Government.

Note: Wessely says that he resigned after about a year because they were not interested in research (CFS Myths. Simon Wessely). **"PRISMA" is an EU acronym for a small German company. Confusingly, "PRISMA" also stands for "Preferred Reporting Items for Systematic reviews and Meta-Analyses" (which used to be called QUORUM), which is the healthcare acronym.**

Wessely's influence on the NICE Guidelines on ME/CFS

It is widely believed that Wessely was unofficially involved with the production of the 2007 NICE Guidelines on "CFS/ME" (CG53), Guidelines which were a veritable travesty of the truth. It is also widely believed that it was Wessely who ensured that not one of the Guideline Development Group (GDG) members regarded ME as an organic disorder, and this obviously resulted in the recommendations of directive (as distinct from supportive) cognitive behavioural therapy (CBT) and increasingly strenuous graded exercise therapy (GET), no matter how ill the patient.

The outcome was inevitable when, despite his requests to be included, the Medical Adviser to the UK ME Association was not allowed to be on the GDG. For the Medical Adviser to a charity for the disorder in question to be refused membership of the GDG was a "first" for NICE.

Those damaging Guidelines held sway until they were revised in October 2021 (NG206) when, in a momentous *volte face,* NICE stated that ME is recognised as a serious, chronic medical condition, not a psychological or behavioural disorder. NICE specifically advised that GET must not be used for people with ME. It is notable that the Medical Royal Colleges opposed the revised Guidelines: they expressed significant concerns and were particularly critical of the removal of GET and of the down-grading of CBT to supportive therapy from a so-called curative treatment. As at May 2025 there is still no joint statement from the Medical Royal Colleges endorsing the revised Guidelines.

It is, however, unsurprising that certain members of the Medical Royal Colleges still adhere to the behavioural model, as their whole careers have been built upon such a model. There is strong circumstantial evidence that Wessely and his close colleagues Peter White and Michael Sharpe have influenced the Medical Royal Colleges' views on the revised NICE Guidelines, primarily through their historical shaping of ME policy and their on-going promotion of the behavioural model of ME. Indeed, Wessely's influence as a former President of the Royal College of Psychiatrists cannot but leave a lasting impact. The perpetuation of the behavioural model of ME is evident in the Wessely School's continued defence of GET and CBT, their influence on medical education and upon institutional attitudes. It is thus inevitable that the Medical Royal Colleges appear to remain unquestioningly supportive of Wessely's disproven dogma.

Paeans of praise for Wessely

Honours and praise have been unceasingly bestowed upon Wessely: he was knighted in 2013 by the late Queen Elizabeth II. In February 2017 he was appointed Regius Professor of Psychiatry at King's College, London, an honour bestowed by the Crown to recognise his exceptional contributions to the field of psychiatry and his leadership in advancing mental health research and practice, making him a distinguished figure in the field. He is England's first and only Regius Professor of Psychiatry. He is Founder and Director of the King's Centre for Military Health Research. He was elected President of the Royal College of Psychiatrists from 2014 to 2017 and became the first psychiatrist to be elected as President of the Royal Society of Medicine in 200 years. He is a Fellow of the Royal College of Physicians, Royal College of Psychiatrists, and Academy of Medical Sciences, and in 2021, he became a Fellow of the Royal Society. He has won numerous awards, prizes and accolades. In September 2010 he was presented with the King's Award for Media Personality of the Year (at which he said: "*It is very important for scientists to engage with the media – to ensure the public has access to accurate, evidence-based scientific* *information"*). In 2012 he was awarded the inaugural John Maddox prize for his "*courage"* in "*standing up for science*" against those who consider ME to be an organic disease, and for *"communicating sound science and evidence".* As this became known, there was utter incredulity throughout the ME community. Malcolm Hooper, Professor Emeritus of Medicinal Chemistry, said that Wessely is "*responsible for trying to make ME into a psychiatric condition when it's not".* When in December 2012 the Independent on Sunday ran an article which noted that both the Countess of Mar and Consultant Physician Dr William Weir opposed the award to Wessely, the IoS quoted Professor Wessely himself: *"I have published several hundred papers on this over the last 20 years. These have been published in world-class journals…and subject to rigorous peer-review.* ***I have never said that CFS is all in the mind. I do not believe that. I have said repeatedly the exact opposite"*** **(a statement that does not accord with the fact that the Wessely School assert that ME and CFS are synonymous and Wessely has dismissed ME as nothing but a "belief")**. Awards and honours continue to be heaped upon Wessely: on 26th June 2019 he was awarded an Honorary Doctorate of Science by the University of Oxford.

Without doubt, as such a distinguished expert of unassailable status, Wessely must be believed. The problem is that he believes ME is a "*non-disease*" that exists only as an *"aberrant illness belief".* Science has disproved his beliefs, but Wessely is apparently unmoved by science.

Some consequences of Wessely's disbelief in ME

No matter that Wessely's beliefs about ME are not supported by medical science, his beliefs have resulted in patients with a diagnosis of ME being dismissed by doctors, especially GPs and neurologists, the latter being especially disdainful toward people with ME. Those sick people are called mad, lazy, liars, malingerers and fraudsters, with no hint of proof by their accusers. They have to endure derision and prejudicial taunts, and they suffer shocking abuse and insults; they are ridiculed and mocked, but they have no redress.

In 2002, the British Medical Journal ran a ballot asking doctors to vote on which diseases they considered to be "non-diseases" that are best left medically untreated. It was widely believed that **Wessely proposed ME as a "non-disease" because he had made his views so well-known**. The result was that, **along with ear-wax accumulation, nail-chewing and freckles, ME was voted a non-disease;** both broadsheet and tabloid newspapers ran banner headlines proclaiming: "*Obesity and ME are not diseases, say doctors".*

That the stigma of having a "non-disease" could not fail to make things worse for ME sufferers seems not to have troubled Wessely. Certainly, it is the case that after the BMJ poll, many ME patients were removed without notice from their GP's list, including a very sick ME patient who was informed that: "*This practice does not treat non-diseases*".

In what was probably an unofficial survey of neurologists organised by Wessely about the validity of ME as a neurological disease, he reported that not one of those he contacted accepted ME as a *bona fide* disease. The triumphalism with which he conveyed his findings was inescapable.

Wessely's dismissal of Gulf War Syndrome

Not only does Wessely dismiss the existence of ME, he is on record as asserting that there is no such thing as Gulf War Syndrome either. In their official report (Unwin, Hotopf, David, Wessely et al: Lancet 1999:353:169-178), despite having performed no clinical examination or laboratory investigations on the veterans, the authors concluded that Gulf War Syndrome does not exist. They advised that one pathway of subsequent illness could be the "*perceived"* risk of chemical attack, and that the "*psychological*" effect of this fear might be contributing to the increased level of ill-health in Gulf War veterans. In his evidence given on 10th August 2004 to the Lord Lloyd of Berwick Inquiry into Gulf War Syndrome, when questioned, Wessely said: "*A man has got to know his limitations and my limitations are immunology".* Such an admission, given with flourish, ought to have rung danger bells about the safety and reliability of Wessely's assertion that there is no such thing as Gulf War Syndrome, but a Parliamentary Early Day Motion (EDM) 880 in 2004 is clear: *"The Ministry of Defence accepted Professor Wessely's advice…that Gulf War Syndrome does not exist".*

Note: the significance of Wessely's statement given to the Lord Lloyd Inquiry is addressed in more detail later in this document.

Science, however, comprehensively demolished Wessely's beliefs and proved that GWS does indeed exist. In 2008 Wessely et al were conclusively shown to be wrong by a Report commissioned by the US Congress (Gulf War Illness and the Health of Gulf War Veterans: Scientific Findings and Recommendations: Washington DC; US Government Printing Office 2008: www.va.gov/RAC-GWV1) which demonstrated that GWS is causally related to veterans' exposure to organophosphates and pyridostigmine bromide (PB/NAPPS tablets). This is another proven example of misattribution by Wessely.

Wessely's dismissal of the Camelford water poisoning

Another of Wessely's well-publicised assertions which turned out to be wrong is the Camelford mass water poisoning episode. In July 1988 twenty tonnes of aluminium sulphate were pumped into the drinking water supplies of the Cornish town of Camelford (The Ecologist:1999:20:6:228-233). Ninety minutes later, a 140-square mile area was affected by Britain's worst water pollution. Residents and visitors immediately suffered distressing symptoms including nausea and vomiting, diarrhoea, stinging eyes, mouth ulcers that took weeks to heal, skin rashes, peeling skin and lips sticking together, followed by musculoskeletal pains, malaise and impairment of memory and concentration. In some cases, hair, skin and nails turned blue; bone showed stainable aluminium over six months later. At least seven people died, 25,000 suffered serious health effects and 40,000 animals were affected. It is since thought that at least twenty people died from drinking the contaminated water (Sue Reid, Daily Mail: 14th December 2007).

Wessely published his belief that the alleged ill-health was due to contagious mass hysteria and that the "*somatic"* symptoms were due to (i) *"heightened perception of normal bodily sensations being attributed to an external cause such as poisoning"* and (ii) irresponsible reporting by the press (J Psychosom Res 1995:39:1:1-9). Wessely failed to mention how mass hysteria affects animals.

In 1999 it was conclusively shown by Paul Altmann et al that there was objective evidence of considerable organic brain damage compatible with the known effects of exposure to aluminium and that it was this exposure, not anxiety or hysteria, which was the cause of the symptoms exhibited by those who had been exposed to the contaminated water (BMJ 1999:319:807-811).

Once again, science proved Wessely's assertions to be erroneous: the evidence did not support his belief that the Camelford disaster was merely contagious mass hysteria.

Note: It is believed that Wessely does not apologise for his errors when he is shown to be wrong.

Some consequences of Wessely's refusal to accept the existence of ME

No matter that many of Wessely's assertions have been proved to be wrong, his doctrine that ME does not exist as a physical disorder still remains deeply embedded in the NHS. The resultant iatrogenic harm and the indescribable grief of parents whose children have died -- which appear to have resulted from his conviction that ME is a psychogenic disorder which must not be investigated -- is incalculable.

As long ago as 1989, "InterAction", the magazine of the charity ME Action Campaign (formerly called Action for ME) carried the results of 1500 professionally conducted questionnaires: the results were distressing. Some of the comments made by doctors to people with ME include: "*I'm not prepared to do any tests*"; *"Hypochondriac, menopausal, you have the audacity to come here and demand treatment for this self-diagnosed illness which does not exist"*; *"ME is a malingerer's meal ticket"*; *"You are a menace to society – a pest"*; *"Stop feeling sorry for yourself – I have patients with real illnesses"*; *"I'm not going to further your career of twenty years of being ill".*

Comments of ME patients about their doctors include: *"He said the illness was a load of trollop"; "I was called 'stupid' and shouted at on more occasions than I care to mention …one neurologist said he 'couldn't care less' whether I ever got better"; "I was told I was a disgrace"; "the doctor said it was 'attention seeking'"; "I was told that I was selfish and introverted and it was nothing but hysteria"; "the doctor said my symptoms/signs 'didn't exist' "; "the doctor said 'if you go on like this you will be struck off the register' ".*

That same year, a severely affected female patient was informed by her GP that ME *"is a condition developed by the patient for what they can get out of it".*

One woman who had held a senior clinical position in the NHS before succumbing to ME was sworn at by her GP, told that she should be ashamed of herself, and accused of abusing the NHS (despite the fact that she had worked for the NHS for longer than the GP himself).

In 2025, it is undeniable that nothing has changed in the derisive and disbelieving attitude of many NHS doctors, even though Wessely's dogma has been exposed as fallacious.

There have been representations to the General Medical Council (GMC) about the iatrogenic harm to defenceless patients with ME, but to no avail. One such incident in particular was reported to the General Medical Council, but on 6th October 1993 a reply was received from the Conduct, Health and Standards Division which was uncompromising: *"The members have asked me to stress that the Council cannot take action against groups of doctors on the grounds that they hold particular views on medical issues".*

Seemingly, the GMC is not concerned with medical evidence: use of the formal WHO classification system is mandatory throughout England, but the GMC can disregard it with impunity.

Wessely's involvement with the PACE Trial

Another major issue in which Wessely has been shown to be wrong is the notorious PACE Trial (2004 -2011), for which he was Director of the Clinical Trial Unit. The trial was partly funded by the MRC, the DoH, the DWP and the Scottish Chief Scientist's Office. It is the only clinical trial that the DWP has ever funded; it did so by the persuasion of the Wessely School's assurance that people would be cured and so the cost to the State would be reduced.

It was designed to prove that people with ME – rebranded by Wessely et al under the broader and more ambiguous term CFS -- could recover if they undertook graded aerobic exercise (based on the illness model of deconditioning), and if they re-structured their thinking by means of directive CBT (based on the illness model of fear-driven avoidance of activity).

This infamous clinical trial is now taught to medical students as how <u>not</u> to conduct a clinical trial. It has been condemned for serious methodological and ethical failings.

From the outset, there were difficulties in obtaining sufficient participants.

It was confirmed on 12th May 2004 by the then-Parliamentary Under Secretary of State at the Department of Health, Dr Stephen Ladyman, at an All -Party Parliamentary Group on Fibromyalgia (FM), that doctors were being offered financial incentives to persuade patients with FM to attend a "CFS" Clinic to aid recruitment to the PACE Trial (EIF: Spring/Summer 2004, page 19).

This caused written representations to be made to the MRC, because FM has a distinct biological profile that is different from ME/CFS and is classified as a distinct entity in ICD-10 at section M79.0 under Soft Tissue Disorders, so concern was expressed to the MRC as to how the intentional inclusion of disparate disorders could yield meaningful results, and if the inclusion of FM patients would evade detection by the MRC's allegedly rigorous monitoring process. The questions elicited no response from the MRC.

It was also established that people were coerced to take part in the trial: patients attending an ME/CFS clinic in London, for which Peter White was responsible, were threatened that unless they enrolled with the trial, they would no longer be provided with support from the clinic (necessary for the provision of sickness certificates).

Because of difficulty in obtaining enough participants, the Chief Principal Investigator (PI), Peter White, had to resort to contacting GPs asking them to refer anyone with any form of "fatigue" as a participant. The trial was funded to study ME/CFS, but such a wide inclusion of anyone with "fatigue" cannot be specifically studying those with ME/CFS and cannot constitute a scientific study. Studies using mixed populations are not useful and should not inform clinical policy.

The trial was heavily criticised because it used the Wessely School's own Oxford case definition, so people with confirmed psychiatric disorders were included, but anyone with any neurological symptomatology was expressly excluded. Additionally, the MRC confirmed that it does not accept ME/CFS as a neurological disorder. What, then, was the disorder being studied in the PACE trial?

Of particular concern was the fact that in 2004, the Chief PI, Professor Peter White, published a study proving that he had prior knowledge of the immunological abnormalities associated with exercise in people with ME: *"We designed this study to explore whether the illness was associated with alterations in immunological markers following exercise…Altered cytokine levels…could modify muscle and/or neuronal function…Concentrations of TGF-β1 (anti-inflammatory) were significantly elevated in CFS patients at all times before and after testing…We found that exercise induced a sustained elevation in the concentration of TNF-α (pro-inflammatory) which was still present three days later, and this only occurred in the CFS patients…These data replicate three out of four previous studies finding elevated TGF-β in subjects with CFS…The pro-inflammatory cytokine TNF-α is known to be a cause of acute sickness behaviour, characterised by reduced activity related to 'weakness, malaise, listlessness and inability to concentrate', symptoms also notable in CFS…These preliminary data suggest that…exercise may induce pro-inflammatory cytokine release (TNF-α) in patients with CFS"* (Immunological changes after both exercise and activity in chronic fatigue syndrome: a pilot study. White PD, Nye KE, Pinching AL et al. JCFS 2004:12: (2): 51-66).

Hence there is proof that the Principal Investigators and, presumably, the Director of the Clinical Trial Unit knew that people with ME/CFS have significant immune dysfunction (the TFG-β median values were approximately 18.1 times as high in patients versus controls), yet they still went ahead with a trial which compulsorily increased aerobic exercise.

Of note is the fact that Peter White later declared his 2004 paper to be a false positive due to an artefact, for which he blamed a laboratory anomaly (https://forums.phoenixrising.me/threads/cytokine-responses-to-exercise-and-activity-in-patients-with-chronic-fatigue-syndrome-case-control.53299/) even though he had confirmed that his own results had replicated three out of four previous studies that also found elevated TGF-β in ME/CFS patients.

Disturbingly, participants whose fatigue score was low at baseline and which went down further after the interventions used in the trial were then classified by the Principal Investigators as "recovered". The falsifying of data to obtain the desired and promised outcome is surely verging on the immoral, if not illegal, as it appeared to be misuse of over £5 million of taxpayers' money.

In her submission to a House of Commons Debate on ME, Carol Monaghan MP was explicit: *"I think that when the full details of the trial become known, it will be considered one of the biggest medical scandals of the 21st century"* (Hansard HC 20th February 2018).

That the PACE Trial Investigators, including Wessely as Director of the Clinical Trial Unit, were indeed aware that people with ME/CFS had significant immunological problems is further confirmed by the fact that another paper confirming immune dysfunction was published in 2004, and one of the co-authors was Wessely himself.

The paper is entitled "High levels of type 2 cytokine-producing cells in chronic fatigue syndrome"; it was published in Clinical & Experimental Immunology in February 2004:135:2L294-302 and the authors are Anna Skowera, Anthony Cleare, David Blair, Lisa Brevis, Simon Wessely and Mark Peakman. The investigators found increased production of Type 2 cytokines, indicating a shift towards a Th2 immune response in people with

ME/CFS. Such a shift would explain the classic exhaustion and severe debility after minimal exertion which is the hall-mark of ME/CFS, in that immune activation in a Th2 shift uses vast cellular energy (ATP) even at rest, and drains metabolic reserves.

The investigators found that even without stimulation, ME/CFS patients showed higher levels of T cells producing both IL-4 and IFN-ɣ, suggesting continuous low-grade immune activation.

These findings are highly significant and mean that there is immune dysregulation which could account for cardinal symptoms found in ME/CFS. The Th2 bias may contribute to the pathophysiology of ME/CFS by (i) impaired viral clearance; (ii) autoimmunity and (iii) chronic inflammation contributing to symptom persistence. Th2 cytokines (IL-4, IL-5, IL-13) drive IgE production and mast cell activation, leading to allergies that are commonly found in ME/CFS.

The paper supports ME/CFS as a biomedical disease and confirms that it is not a passing post-viral syndrome but an entrenched immune disorder. In the context of other studies such as those by Klimas, Hornig and Scheibenbogen, this paper defines ME/CFS as a serious multisystem immunological disease; without doubt it challenges Wessely's psychiatric model.

Is it possible that Wessely had too much professional, financial and reputational capital tied to his favoured model to accept immunological evidence which demolished his model, even if he co-authored that paper?

Even if his contribution was simply to provide a suitable patient cohort for the study, the fact that Wessely co-authored an important paper showing biomedical pathology in ME/CFS, yet continued to lead campaigns and clinical policies that denied such proven pathology, raises serious ethical concerns.

Could it be argued that continuing to promote harmful interventions used in the PACE Trial, (especially GET) while having knowledge of immune dysfunction that results in severe exhaustion, amounts to professional misconduct, or even gross negligence, or at the very least, wilful ignorance?

Could it be said that Wessely's continued promotion of CBT and GET in the face of such immunological proof that it could be potentially harmful appears to reflect either deliberate disregard for patients' welfare or a dangerous ideological rigidity?

A notable point is that despite being a co-author of such an important immunology paper just six months earlier, when giving evidence at the Lord Lloyd of Berwick Inquiry into Gulf War Syndrome on 10th August 2004, Wessely is on record stating: *"Now, please do not ask me what that means because I do not really know. A man has got to know his limitations and my limitations are immunology"*.

Is it acceptable for a medical practitioner to boast that he does not understand the content of a published paper which lists him as a co-author?

Wessely's pride in his work with ME

It is perhaps unsurprising that Wessely is unhesitating in claiming pride in his work with ME/CFS patients:

- *"I can say that I remain very content and indeed proud of the contribution that I and my many colleagues have made in improving the management of this condition"* ("Conversing with Professor Simon Wessely": 2010)
- *"Overall, I think that we…achieved quite a lot for the benefit of medicine and patients….I remain proud of the work myself and colleagues did in the early days of CFS...I think that with all my colleagues we made a very positive contribution to improving patient care"* (Chronic Fatigue Syndrome: A Personal Story Simon Wessely 2011).

Is Wessely in any way responsible for the fact that there is no appropriate support or medical provision for people with ME in the NHS? Policy-makers appear completely unaware of (or are forbidden to consider) the significant amount of evidence of the biomedical underpinnings of the disorder.

Medical science has proved that ME is a chronic life-wrecking multi-systemic inflammatory disease which shares features of an autoimmune response in which the immune system attacks the whole body. There is no cure and no treatment; the only option is to attempt individual management of the extensive and distressing symptomatology.

Not only is Wessely's published output phenomenally prolific, he has sought and obtained a strong media presence, portraying himself as a rational scientist combatting militant and deluded patient groups who reject his psychogenic model of ME as being anti-science. As mentioned above, he won the King's Award for Media Personality of the Year in September 2010.

In an article entitled "Defiance of Science" dated 12th July 2007 about Wessely's continued rejection of the proven organic pathology underpinning ME (www.margaretwilliams.me), the question was asked: at what point will the extensive body of scientific knowledge confirming the pathoaetiology of ME be so great that it will be considered serious professional misconduct to pretend that it does not exist?

Eighteen years later, that question remains unaddressed and Wessely's disproven doctrine remains entrenched throughout the NHS. Concern that there is no provision whatsoever on the NHS for those with severe ME go unheeded and disregarded; the current Labour Government has no plans to award any funding for ME research.

People are dying because of unspeakable mismanagement and neglect by ignorant and arrogant NHS medical practitioners who unquestioningly continue to believe what Wessely teaches; they adhere to his views and refuse to practice even the most basic tenet of medicine ("*first do no harm*" -- ascribed to the Hippocratic oath and historically sworn by graduating physicians but which, for the record, is no longer always sworn).

Should Wessely be held to account and required to justify his immutable beliefs, or to publicly renounce them?

Readers may wish to judge for themselves from the following examples of Wessely's words of wisdom.

Overview of the Wessely School's teaching about ME

In 1992, the Wessely School gave directions that in "CFS", the first duty of the doctor is to avoid legitimisation of symptoms (Medical Research Council Highlights of the CIBA Foundation Symposium on CFS, 12-14th May 1992).

In 1994, ME was described as merely "*a belief*" ("Microbes, Mental Illness, The Media and ME - The Construction of Disease". Simon Wessely; 9th Eliot Slater Memorial Lecture, Institute of Psychiatry, 12th May 1994 (transcript of lecture and Wessely's own working notes).

In 1996, recommendations were made that no investigations should be performed to confirm the diagnosis (Chronic Fatigue Syndrome. Report of a Joint Working Group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners; Royal Society of Medicine (CR54), October 1996.

In 1997, ME was referred to as a "*pseudo-disease diagnosis*" ("Chronic Fatigue Syndrome and Occupational Health": A Mountstephen & M Sharpe; Occupational Medicine 1997:47:4:217-227).

In 1999, patients with ME/CFS were referred to as "*the undeserving sick*" ("ME. What do we know - real physical illness or all in the mind?" Lecture given in October 1999 by Michael Sharpe, hosted by the University of Strathclyde: transcript of lecture).

When did the careful assessment of sick people stop being part of the practice of medicine, especially when the disorder in question is known to be a complex multi-system disorder?

Note: The following illustrations are but a small fraction of Wessely's prodigious output about the "non-existence" of ME, a stance which international experts believe to be in stark defiance of the abundant medical science that confirms the neuroimmune pathology.

Wessely often refers to ME as being a "*vicious circle*" of dysfunctional cognitions in the form of "*aberrant illness beliefs*" and maladaptive behavioural patterns such as avoidance of exercise exhibited by those affected.

Many believe that it is the Wessely School psychiatrists' stranglehold over what research is permitted to be carried out into ME and their advice that no laboratory investigations should be carried out that is the true "vicious circle" of ME.

Illustrations

1988

Myalgic encephalomyelitis, or what? Anthony David Simon Wessely Anthony Pelosi
Lancet 1988:July 9, 100-101

"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".

1989

What your patients may be reading Wessely S BMJ 1989:298:1532-1533

"Beard and Mitchell have returned to obscurity, but their disease (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".

1989

Management of chronic (post-viral) fatigue syndrome Simon Wessely Anthony David Sue Butler
Trudie Chalder Journal of the Royal College of General Practitioners 1989:39:26-29

"Many patients referred to a specialised hospital with chronic fatigue syndrome have embarked on 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".

"The patient should be told that it is now time to 'pick up the pieces' (and) the process is a transfer of responsibility from the doctor to the patient, confirming his or her duty to participate in the process of rehabilitation".

1989

Fatigue syndromes: a comparison of chronic 'postviral' fatigue with neuromuscular and affective disorders
S Wessely R Powell JNNP:1989:52:940-948

"Attribution of symptoms to physical rather than psychological causes was the principal difference between matched CFS and psychiatric controls"

"An alternative hypothesis is that all cases of CFS can be explained by disorder of mood".

1990

Attribution and self-esteem in depression and Chronic Fatigue Syndrome.
R Powell R Dolan S Wessely J Psychosom Res 1990:34:6:665-67.

"…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".

1990

Old wine in new bottles: neurasthenia and ME Simon Wessely Psychological Medicine 1990:20:35-53

"Suggestible patients with a tendency to somatise 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 for ill-defined illnesses associated with fatigue"

"Such uncritical diagnoses may reinforce maladaptive behaviour".

1990

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 pp85-131

"A number of patients diagnosed as having benign myalgic encephalomyelitis who complained of persistent muscle weakness were examined neurologically by one of the authors of this chapter. In many of them, the usual findings of simulated muscle weakness were present"

Note: Wessely's assertion that the muscle weakness was "simulated" (ie. not genuine) may have had far-reaching consequences and may explain why people with ME who had been awarded disability benefits had those benefits withdrawn, even when they had been awarded for life.

"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"

"Efforts are made to over-interpret laboratory findings"

"It is regrettable that ME has become a disease of fashion, even a 'fad' "

"Over-enthusiastic espousal of new illnesses can be harmful. It may legitimize some of the maladaptive behaviour already described".

Note: ME is not a new illness.

1990

Chronic Fatigue and Myalgia Syndromes Simon Wessely In: Psychological Disorders in General Medical Settings Ed: N Sartorius et al Pub: Hogrefe & Huber, 1990

"Most CFS patients fulfil diagnostic criteria for psychiatric disorder"

"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' ".

"Symptoms include muscle pain and many more 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"

"Such attribution conveys certain benefits, in other words, there is avoidance of guilt and blame".

1991

Cognitive behaviour therapy in chronic fatigue syndrome. Butler S, Chalder T, Ron M, Wessely S.
JNNP 1991:54:153-158

"Continuing attribution of all symptoms to a persistent 'virus' preserves self-esteem".

1991

Chronic Fatigue Syndrome Simon Wessely Editorial: JNNP 1991:54:669-671

"(Since 1988) there have been many welcome changes, including the name, which has shifted to the more appropriate label of chronic fatigue syndrome (CFS)"

"In the United Kingdom similar enthusiasm greeted reports of an association with the Coxsackie virus… A recent case control study…concluded that enteroviral serology has little place in the diagnosis of CFS"

"Choosing to incorporate, rather than ignore, the links between CFS and psychiatric disorder, research gains in credibility"

"Previous overzealous counselling of rest as the mainstay of treatment has little to commend it"

"Over-investigation should be avoided. Not only is it a waste of resources, it may not be in the patients' interest, and may reinforce maladaptive behaviour…As patients undergo more tests, they will focus on a laboratory abnormality and subsequently find researchers interested in studying these abnormalities"

"It is still possible to encounter such comments as ' this suggests an organic cause for their complaints, and means the syndrome should not be dismissed out of hand as a psychiatric entity'. Armon and Kurland provide wiser counsel – 'psychosocial disability is real, significant and worthy of treatment even when there are no biochemical or immunologic abnormalities present'".

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

"Helplessness contributes to the expectation that fatigue and pain will follow exertion, forming the first of many self-perpetuating cycles that contribute to the clinical picture"

"Blaming symptoms on a viral infection conveys certain advantages, irrespective of its validity"

"It is also beneficial to self-esteem by protecting the individual from guilt and blame. The germ has its own volition and cannot be controlled by the host. The victim of a germ infection is therefore blameless"

"Many patients become hypervigilant and over-sensitised to physical sensations"

"Dysfunctional cognitions (are) linked to the development of maladaptive behavioural patterns"

"A vicious circle of pain, misery, avoidance and inactivity is established"

"Fear of illness is an important part of (the disorder)"

"The approach we favour is provided by professionals whose training and background is in mental health".

1992

Note: For some years, the late Professor Sir Mansel Aylward CB was closely involved in the campaign to "cancel" ME as a neurological disorder but to embrace "CFS" as a somatoform disorder, thought to be because of his known involvement with the permanent health insurance industry. In 1993 Aylward and his wife were investigated and exposed in a national newspaper for having major conflicts of interest between private insurance companies and the UK government social security department. From 1996 to 2005 he was Chief Medical Adviser, Medical Director and Chief Scientist to the DSS/DWP. He was a member of the PACE Trial Steering Committee. He was funded by UNUM when in 2005 he became Director of the Cardiff University Centre for Psychosocial Research. Aylward was knighted in the UK 2010 New Year Honours.

In his letter dated 10th January 1992 to then-Dr Mansel Aylward at the Department for Social Security (now the Department for Work and Pensions), Wessely wrote: *"It is certainly true that I and my colleagues consider that anxiety about the consequences of activity is one factor perpetuating disability in CFS patients....research shows a considerable overlap between depression and CFS....I have previously been involved in advising the DSS that as CFS is undoubtedly a genuine condition and is as legitimate an illness as any encountered in the field of both medicine and psychiatry, CFS sufferers should be entitled to the full range of benefits…On the other hand I have also advised that CFS should not be grounds for permanent disability".*

Wessely's status as official advisor to the DSS on ME/CFS is on record in a letter dated 7th April 1992 from the DLAAB (Disabled Living Allowance Advisory Board). This appears to have had a major influence on the handbook for decision-makers because, as noted above, payments to people with ME/CFS were specifically targeted and widely withdrawn.

1992

In April 2002 Wessely was on record stating: "*I don't classify CFS as a somatisation disorder*" (written answer to questions posed by Trevor Wainwright on April 10, 2002).

That he did regard "CFS" as a somatoform disorder, and "ME" as nothing more than a belief, is not in doubt, and letter dated 7th April 1992, Dr Adrian Furness of the DLA Advisory Board/Benefits Agency Medical Services confirmed Wessely's status as an official advisor and on Wessely's advice he informed doctors that: "*The weight of medical opinion regards this as a psychosomatic disorder (and) the majority of these cases are somatisers".*

1992

Chronic fatigue syndrome: current issues Wessely S Reviews in Medical Microbiology 1992:3:211-216

"Validation is needed from the doctor. Once that is granted, the patient may assume the privileges of the sick role (sympathy, time off work, benefits etc)".

1992

Eradicating "Myalgic Encephalomyelitis" (ME) Report of a LINC UP meeting held on 15th April 1992 at Belfast Castle. Pfizer Invicta Pharmaceuticals pp 4-5.

There were two speakers: Simon Wessely and Peter White.

Simon Wessely:

"*It seems that ME sufferers prefer to feel that they have a 'real' physical disease: it is better for their self-esteem (and) the label 'ME' helps legitimise their dealings with doctors".*

Referring to his study of graded exercise for "CFS/ME" patients, Wessely said that there were *"a very large number of drop-outs, largely related to the fear these patients had, albeit inappropriately, that their disorder was 'all in the mind'"* (Fatigue syndromes: a comparison of chronic "postviral" fatigue with neuromuscular and affective disorders. S. Wessely R. Powell. JNNP 1989:52:940-948). Nothing could be clearer: the report of the meeting records that Wessely stated that patients' fear of accepting that their disorder was "all in the mind" was "inappropriate"; in other words, he was saying that it is "all in the" mind".

Peter White:

Echoing Wessely's views on the danger of the ME label, White said that ME is a misnomer. "*There has never been any evidence that the condition is associated with inflammation of the central nervous system…In particular, there is no evidence of any physiological muscle fatigue….(only) an exaggerated perception by patients of the effort they are experiencing".*

Note: Peter White's sweeping statements are readily proved to be untrue: he himself said in his lecture at the Royal Society of Medicine on 28th April 2008 that 74% of people with ME showed objective involvement of the central nervous system in the 1955 outbreak (see below)**. He went on to say that ME then was different from ME now. This is contradicted by the numerous *post-mortems* of people who died from ME since 1987/8 when Wessely began his campaign to "eradicate" ME.**

1993

Letter dated 13th October 1993 to Dr Simon Wessely from Dr Mansel Aylward's Office but signed by Dr M McGrath

Based on Wessely's input to policy regarding ME/CFS, the Department's position was set out by Dr McGrath: *"It seems likely that the greater the disability, the more likely is the disorder to be associated with either misdiagnosed psychiatric disorder or poor illness management….It is a treatable disorder but its management is deplorable at present, the worst thing to do is to tell them to rest. Rehabilitation is essential, exercise is good for these patients, prolonged inactivity causes adverse physical and psychological consequences. Most cases can be expected to improve with time. As regards benefits – it is important to avoid anything that suggests that disability is permanent, progressive of unchanging. Benefits can often make patients worse".*

1993

Letter dated 10th November 1993 sent by Dr Peter White to Dr Mansel Aylward at the DSS

"I was worried to learn that the Disability Handbook 'will probably conclude that myalgic encephalomyelitis is a separate entity within the group of disorders encompassed by the chronic fatigue syndromes and that affected people remain disabled, make little or no progress, or even deteriorate over time'. I am a psychiatrist who has been studying fatigue (and) I would not agree that there is a consensus that 'ME' and the chronic fatigue syndrome are separate conditions…I suggest that separating the two conditions may enhance disability. The reason for this is that those who believe in the separate existence of 'ME' believe this is a totally physical condition, probably related to immune dysfunction or persistent viral infection (for) which no treatment is available. On the contrary, I think present evidence suggests that the chronic fatigue syndrome is…a discrete syndrome and treatments and rehabilitation programmes are available which address both the physical (and) psychological factors that maintain this syndrome. For this reason, I would ask you to reconsider separating the two conditions".

1993

Chronic Fatigue, ME, and the ICD-10 David A Wessely S 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".

Note: The authors seem unaware that ME was first classified and included as a neurological disorder by the WHO in 1969, so there was no new "important moral victory".

1993

In one of his most chilling interventions with potential to inflict considerable harm on people with ME, on 1st October 1993 Wessely wrote again to Dr Mansel Aylward, then-Head of Medical Services Policy and Business Development at the Department of Social Security: *"You may recall we corresponded last year over the ever controversial subject of chronic fatigue syndrome, or ME as it is sometimes known. I wrote to express some dissatisfaction with the then DLA entry, feeling it did not accurately reflect the state of medical knowledge on the subject. I am afraid I feel obliged to write again following the receipt of the enclosed leaflet from the ME Association, which triumphantly states that CFS/ME will now be listed under 'Other Neurological Disorders'….I am disturbed that this disorder should be listed as a neurological disease….I feel that this decision represents the triumph of an effective lobby over scientific evidence….It is also a most unfortunate message to send sufferers. It colludes with the erroneous belief that this is a severe disorder of neurological functioning, for which there is little effective treatment, and a poor prognosis. It will discourage any sensible efforts at rehabilitation. 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 this is the intention of the Department, if only on grounds of cost!….I believe that the Department is making an error if it accepts the partisan views put forward by pressure groups as a basis for making medical decisions. I also believe that it is a decision the Department will come to regret, since it seems likely the result will be an ever increasing stream of claims for permanent benefits in people who might otherwise have had a chance of recovery….I know all too well how your spirits may well sink at receiving another letter on the topic".*

On 13th October 1993 Dr Aylward replied to Wessely: "*Very many thanks for your welcome letter of 1st October…. I welcome your letter….Some of your comments and advice, far from depressing one's spirits, provides an alternative view to those which have bombarded me, my colleagues in the Department and members of the Disability Living Allowance Advisory Board (DLAAB) and I am most grateful for your bringing our attention to the various points you raise in your letter*…. *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".*

1993

Summary of Talk Given On 2nd November 1993 by Professor PK Thomas CBE DSc MD FRCP and Dr S Wessely BM Bch MRCP MRCPsych to a Full Board Meeting in Richmond House -- the Department of Health)

Dr Simon Wessely: "*There is no evidence of primary muscle dysfunction ie. it is not a neuromuscular disorder or a neurological disorder. There is no evidence of inflammation of the CNS. There is no evidence of hysterical or feigned origin to symptoms"*

Note: re: the last sentence above: this statement by Wessely does not accord with what he and Professor Thomas stated in their chapter entitled "The chronic fatigue syndrome – myalgic encephalomyelitis or postviral fatigue" in Recent Advances in Clinical Neurology 1990: pp 85 – 131: "*In many of them, the usual findings of simulated muscle weakness were present"*

"It is associated with high rates of psychiatric disorders…There is little evidence that it is due to a persistent virus".

1994

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

"The Royal Free Disease itself is part of the world of myth".

Note: The author of this document possesses a copy of Wessely's own annotated lecture notes.

On the first page he states: *"I am going to talk not about an illness, but about an idea….I will argue that ME is simply a belief, the belief that one has an illness called ME"*

On page 6 he mocked people with ME: *"There is another condition with which ME might easily be confused and it is hysteria. Hysteria, the mention of the word in the context of ME brings me palpitations and makes me worried about the safety of my family"*

On page 8 Wessely continued: *"How do you prove that you are not hysterical? You must convince the doctor that you really are ill – organically ill – so…the arm becomes more floppy – the leg weaker – the sensory changes more bizarre, yet what is the result of this…the neurologist, who is not a fool, is now more convinced that the problem is functional. How…can you prove the doctor wrong? Well, the one thing you might not do is get better, since that might be interpreted…as proof that it was all in the mind after all".*

On page 11 Wessely said: *"No matter how bad doctors are, … sufferers still need to keep going – doctors are still the main passport to acceptance and validation of suffering, not least because we control access to support and benefits"*

On page 12 Wessely concluded: *"Doctors are entitled to express their scepticism about the status of the diagnosis and even to suggest that these illnesses are already adequately covered in the psychiatric classifications".*

1994

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

"Patients with inexplicable physical symptoms are usually strongly resistant to any psychological interpretation (and) are generally viewed as an unavoidable, untreatable and unattractive burden".

1995

Psychiatry in the allergy clinic: the nature and management of patients with non- allergic symptoms.
LM Howard   S Wessely   Clinical and Experimental Allergy 1995:25:503-514

"The epidemiology of environmental illness is reminiscent of the difficulties encountered in distinguishing between the epidemiology of myalgic encephalomyelitis (ME), a belief, and chronic fatigue syndrome, an operationally-defined syndrome".

Note: The World Health Organisation does not regard ME as "a belief", but as a neurological disorder. Both ME and CFS are classified together in the same Neurology section G93.3.

1995

Numerous in-house medical trade publications joined in supporting Wessely's views about ME, for example:

GPs despise the ME generation: GP Medicine: 1st April 1994

"Most see ME sufferers as heartsink patients….Almost half (of a nationwide survey of GPs on ME) feel that ME patients take up excessive amounts of time"

The Hypochondriac's Medical Dictionary: YOU magazine: 24 July 1994

"Can't be bothered to get up: ME"

Bluffers' Guide: Chronic Fatigue   Dr Douglas Carnall: Doctor: 12 January 1995

"Yesteryear's neurasthenia….modern bluffers prefer the term chronic fatigue syndrome (Wessely's name for ME)….If (striving middle class professionals) insist on a physical diagnosis, tell them chronic fatigue syndrome is a complex disorder in which multiple biopsychosocial factors are mediated via the anterior hypothalamus -- in other words it's all in the mind".

Note: Damaging articles such as these cannot but reinforce physicians' dismissive attitudes to patients who are genuinely sick and in distress; as such, these patients deserve to be treated with basic respect, and it is abhorrent that vulnerable and desperate patients should be forced to justify their illness because of ill-informed but influential doctors who so persistently deny the severity (and indeed, the existence) of ME.

1995

Three internal memoranda from the UK Benefits Agency Medical Services (BAMS) about ME, all signed by Dr Adrian E Furniss, reflect Wessely's beliefs and Wessely was closely involved in advising BAMS. The first, dated 4th April 1995, states: "*ME.....is a fashionable label and not a pathology in its own right......the weight of medical opinion regards this as a psychoneurotic disorder";* the second, on 18th August 1995, states: "*The Disability Living Allowance Advisory Board does not accept a physical basis is proven as regards ME"* and the third, dated 10th October 1995, states: *"The label ME is a rag bag representing no proven pathology. Encouraging illness behaviour is likely to prolong and aggravate this type of behaviour......most treatments would involve reinforcement of self-coping strategies as opposed to reliance on others".* It would therefore seem that Wessely's self-sought involvement with BAMS and his persuading BAMS to implement his own views have indeed done harm to some very sick and financially vulnerable people whose diagnosis is ME.

1996

Chronic Fatigue Syndrome. Report of a Joint Working Group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners (CR54) October 1996 Simon Wessely, Anthony David, Peter White et al

"The term ME may mislead patients into believing they have a serious and specific pathological process"

"No investigations should be performed to confirm the diagnosis"

"CFS is frequently associated with somatisation symptoms".

1996

Chronic fatigue syndrome: an update Anthony J Cleare Simon C Wessely
Update 1996: 14 August:61

"Chronic fatigue may be better understood by focusing on perpetuating factors and the way in which they interact in self-perpetuating vicious circles of fatigue, behaviour, beliefs and disability"

"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".

1997

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 clinical problem we address is the assessment and management of the patient with a belief that he/she has an illness such as CFS or ME".

"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".

1997

Wessely's close colleague, psychiatrist Professor Michael Sharpe, supports Wessely's beliefs. Sharpe's focus was on occupational medicine and he was closely involved with medical insurance companies. From Sharpe's own declarations of his conflicts of interest, a senior lecturer in medicine calculated from the charge Sharpe declared he made for each report and from the number of reports he said he supplied per week that he earned at least an additional £4,000 per week from writing reports for a permanent health insurance company denying people unable to work due to ME the payments to which they were legitimately entitled.

Chronic Fatigue Syndrome and Occupational Health A Mountstephen and M Sharpe
Occup Med 1997:47:4:217-227

"(The term myalgic encephalomyelitis) has been used to define a supposedly specific disease associated with viral infection. Despite this, the existence of ME as a specific syndrome remains unestablished. Use of the term is best avoided".

Note: Given that ME as a specific syndrome has been classified since 1969 as a neurological disorder by the World Health Organisation, it is difficult to know on what evidence these authors rely to support their statement that *"the existence of ME as a specific syndrome remains unestablished".*

"The label of CFS avoids the connotations of pseudo-disease diagnoses such as ME"

"Cognitive behavioural therapy offers patients (with CFS/ME) a new way to think about their illness. The first application of CBT to chronic fatigue syndrome was by Wessely and colleagues (who proposed) a vicious circle model of the perpetuation of chronic fatigue whereby patients' beliefs about the illness lead to avoidance of activity and thus to chronic disability. Our group (i.e. the Wessely School) wanted to develop the behavioural approach. CBT helps patients to re-evaluate their beliefs (and) encourages them to change their behaviour. Change in the belief is an important factor in recovery. The trials of CBT have shown that 'psychological' treatment is effective in patients with CFS" (Sharpe referred to his own article in "A Research Portfolio on Chronic Fatigue". Ed: Robin Fox. Published by The Royal Society of Medicine for The Linbury Trust, 1998).

PULSE: 20th June 1998:86-88

Psychiatrist Peter White advised all UK doctors that exercise helps "CFS" and that: "*Most patients with CFS will also have a psychiatric disorder*". White stated that increasing exercise is important, "*aiming at a total of half an hour of exercise, five days a week"*. He continued: "*cognitive behavioural therapy has already been shown to be a useful treatment for patients with the chronic fatigue syndrome and can particularly help to challenge unhelpful illness beliefs and coping strategies"*

1999

In support of Wessely, Michael Sharpe was unambiguous in his lecture given in October 1999, hosted by the University of Strathclyde:

"In my lecture this evening, I would like to talk to you about myalgic encephalomyelitis (ME)"

"The vehemence with which many patients insist that their illness is medical rather than psychiatric has become one of the hallmarks of the condition"

"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."

1999

Somatoform Disorders: In Current Opinion in Psychiatry 1999:12:163-168 Steven Reid Simon Wessely

Wessely was unequivocal that CFS/ME is a somatisation disorder in which patients *"may selectively perceive bodily sensations and misinterpret them as pathological".*

2001

A short biography of psychiatrist Peter White (in Insurance Medicine, 3rd July 2001) stated: "*The first claim for Permanent Health Insurance (income protection) because of CFS or ME arose around 1987. CFS/ME is now one of the four commonest reasons for claiming income protection. Poor prognosis with CFS/ME has been found to be precipitated by certain illness beliefs and receiving a disability pension"*.

2001

Dr Tony Copperfield (known to be a pseudonym of a GP in Essex who wrote a regular column in Doctor magazine) posed a question: *"What would be your initial response to a patient presenting with self-diagnosed ME?"* Out of four possible answers, the correct one was stated to be*: "For God's sake pull yourself together, you piece of pond life".*

2001

Chronic fatigue syndrome: Symptom and Syndrome Wessely S Annals of Internal Medicine 2001:134: 9S:838-843

"The greater the number of symptoms and the greater the perceived disability, the more likely clinicians are to identify psychological, behavioural…contributors to illness".

Note: In a personal communication 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".*

2001

Choices for the new generation of GPs Pulse 20th October 2001 Dr Mary Church (Principal GP and a member of the BMA medical ethics committee)

"*Never let patients know you think ME doesn't exist and is a disease of malingerers. Never advise an ME patient to make a review appointment".*

2002

After the publication of the English Chief Medical Officer's Report on ME/CFS, the CMO himself, Sir Liam Donaldson, went on public record on BBC News on 11th January 2002 stating that treatment must improve and that it should be classed as a chronic condition with long-term effects on health, alongside other illnesses such as multiple sclerosis and motor neurone disease.

Wessely School psychiatrists disagreed: the week after the CMO made his announcement, the British Medical Journal highlighted psychiatrist Michael Sharpe's pronouncement that doctors would not accept a particular strategy just because the CMO's Report recommended it (BMJ:2002:324:131).

2002

Sharpe afforded yet more support to Wessely in his criticism of the English Chief Medical Officer's Report on ME: The English Chief Medical Officer's Working Parties' report on the management of CFS/ME: Significant breakthrough or unsatisfactory compromise? Michael Sharpe Journal of Psychosomatic Research 2002:52:6:437-438

"My own view has long been that the issues around CFS/ME are the same as those surrounding the acceptance and management of (patients) who suffer conditions that are not dignified by the presence of what we call disease".

2002

Clinical Review: ABC of psychological medicine   Michael Sharpe   David Wilks   BMJ 2002:325:480-483

"Factors such as immunological abnormalities are not of clinical value".

2002

Functional Symptoms and Syndromes: Recent Developments   Michael Sharpe
In: Trends in Health and Disability 2002: report of UNUM Provident Insurance Company

"The current system of state benefits (and) insurance payment remains potentially major obstacles to effective rehabilitation"

"As the authority of medicine to define what is a legitimate illness is diminished, increasingly consumer oriented and privatised doctors will collude with the patient's views that they have a disabling and permanent illness"

"Funding of rehabilitation by commercial bodies has begun in the UK with organisations such as PRISMA and is likely to continue".

2003

Managing patients with inexplicable health problems   B Fischhoff   Simon Wessely
BMJ 2003:326:595-597

"It is only human for doctors to view the public as foolish, uncomprehending, hysterical or malingering".

2003

Medically unexplained symptoms: exacerbating factors in the doctor-patient encounter.
LA Page   S Wessely   Journal of the Royal Society of Medicine 2003:96:223-227

"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".

"The adoption of a label such as CFS affords the sufferer legitimacy – in other words, it allows entry into the 'sick role' ".

Note: Wessely focused on what he called the "secondary gains" of the sick role without equally considering the losses.

2004

Somatoform disorders – new approaches to classification, conceptualisation and treatment   Winfried Rief   Michael Sharpe   Editorial: J Psychosom Res 2004:56:387-390

"Modern psychiatry is based on the concept of psychopathology. That is, patients are assumed to have 'mental disease' ".

2005

The Science of the Art of Medicine Michael Sharpe Inaugural Lecture, University of Edinburgh, 12 May 2005

In his inaugural lecture, attended by Simon Wessely, Sharpe spoke about *"functional medicine"* and how to treat diseases with "*no pathology*" in which he included ME, claiming to highlight medicine's "*blind spot*" in dealing with symptoms that are not expressions of disease.

2005

Chronic fatigue syndrome: an overview Hyong Jin Cho Simon Wessely
Rev Bras Psiquiatr. September 2005:27:3: Sao Paulo

"Functional somatic syndromes refer to groups of symptoms lacking demonstrable abnormalities of structure. They include chronic fatigue syndrome"

"Perpetuating factors have particular importance in understanding CFS"

"Several factors have been reported to be associated with the perpetuation of CFS. These include a fixed somatic attribution, which may be associated with avoidance behaviour related to exercise or activity"

"Physical deconditioning as a consequence of reduced activity may contribute towards greater experience of symptoms".

2006

"Dysfunctional assumptions of the CFS patient" Chronic Fatigue Syndrome (Disorders with Somatic Presentations) Trudie Chalder Tess Browne (Institute of Psychiatry)
PSYCHIATRY: 1st February 2006: vol 5: issue 2, pp 48-51,

"CFS is generally considered as a syndrome of somatic symptoms"

"The current international consensus favours the term CFS. Some patients, however, still prefer the term ME, probably because it implies the condition has a biological cause"

"Many patients diagnosed with CFS also meet the criteria for common psychiatric disorders"

"Diagnosis depends on whether the symptoms are interpreted as medical or psychological, the preference depending on the clinician"

"This 'boom and bust' pattern worsens the symptoms, further reinforcing their belief that they have a serious illness"

"Eventually, patients become increasingly preoccupied with their symptoms and illness, intensifying the experience and frequency of symptoms"

"Unhelpful illness beliefs and fear about symptoms further influence disability. For some, the belief that they have an on-going incurable illness results in chronic disability"

"An alternative means of understanding CFS is the de-conditioning paradigm"

"Cognitive strategies help combat unhelpful beliefs and assumptions that may be disturbing the rehabilitation process"

"An objective of this treatment (CBT) is to establish a consistent level of activity every day regardless of symptoms"

"Predictors of poor response to CBT include focusing on physical symptoms"

"Membership of a self-help group (and) receiving sickness benefit… are associated with poor response".

2007

Cognitive Behavioural Treatment for Chronic Fatigue Syndrome Trude Chalder (Institute of Psychiatry) Trondheim lecture: 25th May 2007.

Trudie Chalder made unsubstantiated assertions, for example, that the Oxford criteria are *"consensus criteria*", when such is not the case: those criteria have no predictive value. As usual, she used the terms "chronic fatigue", "chronic fatigue syndrome" and "ME" interchangeably. The following quotations are taken from her overhead slides:

"(There is a) close link between CFS and clearly defined psychiatric disorder"

"GET is based on the illness model of both deconditioning and exercise avoidance"

"CBT addresses the way thoughts and behaviours affect physiological and emotional processes"

"Precipitating factors (include) advice to rest in response to virus"

"Perpetuating factors (include) symptom focusing and physical illness attributions"

"Social and cultural factors (include) misinformation in the media".

2007

Functional Somatic Syndromes Lisa Page Simon Wessely In: Handbook of Liaison Psychiatry Edited by Geoffrey Lloyd and Elspeth Guthrie pp 125-136

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

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

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

Note: Wessely's disregard of proven structural brain changes appears to typify his failure to heed anything that disproves his own belief about ME/CFS.

2007

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

Note: In the title, the authors refer to "chronic fatigue" but in the text they refer to "CFS/ME".

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

2007

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

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

"The NICE Chronic Fatigue Syndrome/Myalgic Encephalomyelitis guideline in development also includes priority recommendations to which our research, led by Trudie Chalder and colleagues has contributed: 'When the adult or child's main goal is to return to normal activities then the therapies of first choice should be CBT or GET'".

2008

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

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

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

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

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

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

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

2009

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

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

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

Asked about people who have such severe CFS that they are bedridden, Wessely replied:

"In that kind of disability, psychological factors are important and I don't care how unpopular that statement makes me".

Note: Such a seemingly callous statement might reflect Wessely's certainty that he is right, despite the fact that his views have been consistently discredited.

2010

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

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

Note: Wessely focuses on "rehabilitation" as if the biomedical evidence does not exist. Is such a mindset not just misguided, but dangerous? A Leading Queen's Counsel considered it to be so (see above in the Countess of Mar's correspondence with Dr George Szmukler).

2010

Conversing with Professor Simon Wessely 29th August 2010 (by cfssufferer)
http://livingwithchronicfatiguesyndrome.wordpress.com/2010/08/29/conversing-with-professor-simon-wessely-part-2/

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

Note: Given that the PACE Trial, for which Wessely was Director of the Clinical Trial Unit, failed spectacularly to make clear exactly where the subjects came from, one can but wonder at Wessely's statement.

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

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

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

Note: There is abundant evidence that ME is a neuroimmune disorder which disproves Wessely's own model. What is not looked for will not be found, and it seems that he does not look for what he does not wish to see.

2010

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

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

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

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

2011

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

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

2011

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

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

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

2011

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

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

2011

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

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

Note: Wessely does believe that "ME" (as CFS/ME) is a "real" disease, but he believes that it is a somatoform disorder, not a neurological disorder, and that it is curable by his own particular forms of psychotherapy.

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

"I am proud of what we achieved"

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

Note: For years, Wessely has sought sympathy and support by claiming that he has been harassed and threatened by the ME community; in this essay, he is blaming the ME community for frightening away biomedical researchers, which is untrue.

The reason biomedical researchers cannot carry out their research is because their applications for funding are rejected in favour of psychiatric research.

2011

Hysteria and Myalgic Encephalomyelitis   Byron Hyde MD   13th September 2011
The Nightingale Research Foundation

"Several years ago I was lecturing in British Columbia. Dr Wessely was speaking and he had the hundreds of staff physicians laughing themselves silly over the invented griefs of the M.E. and CFS patients who, according to Dr Wessely, had no physical illness what so ever but a lot of misguided imagination

"I was appalled at his sheer effectiveness, the amazing control he had over the minds of the staid physicians….His message was very clear and very simple. If I can paraphrase him: "M.E. and CFS are non-existent illnesses with no pathology whatsoever. There is no reason why they all cannot return to work tomorrow".

2011

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

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

2011

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

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

"For those who appreciate these things, the trial is a thing of beauty"

"We now have two treatments that we can recommend with confidence to our patients"

"…the PACE trial…tested interventions with an impeccable safety record".

Note: the PACE trial has been comprehensively discredited and NICE has forbidden the use of GET for people with ME. There is abundant evidence from numerous surveys by ME/CFS charities of almost 5,000 patients that in such patients, CBT is ineffective and GET can be (and been shown to be) harmful.

2012

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

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

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

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

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

Note: Once again, Wessely is being misleading: he does not believe that ME is a neurological disorder; he does believe that "CFS" is a "real" disorder – but a psychiatric one which is amenable to his own forms of psychotherapy. His frequent interchange of terminology seems designed to confuse.

2012

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

"Since my first publication, back in 1988, on chronic fatigue syndrome, also known as myalgic encephalomyelitis or ME, I and many of my colleagues have been subjected to relentless attacks on our science, conduct and integrity"

"Workers in controversial fields need the support of their employers….. Mine have, for example, instructed lawyers….(and) when a member of The House of Lords used parliamentary privilege to make false allegations about me, they helped me brief other parliamentarians to set the record straight".

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

Note: Indeed so. What was said by Lady Mar in her letters to Dr George Szmukler personified standing up for science.

2014

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

"Patients attending specialist clinics with labels such as ME or chronic fatigue syndrome…have a gloomy outlook associated with the strength of their physical illness convictions and the degree of avoidance behaviour"

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

Note: "Something organic" is definitely wrong and there is substantive evidence of organic pathology which Wessely refuses to accept because it disproves his own model upon which he has built his career and for which he has received considerable funding.

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

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

Note: Is such deception in patients' or doctors' best interest?

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

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

Note: Is it acceptable for Wessely to encourage doctors to deceive and manipulate patients and to dismiss the organic cause of their suffering, seemingly in order to preserve Wessely's own reputation?

2016

Bad science misled millions with chronic fatigue syndrome. Here's how we fought back
Julie Rehmeyer https://www.statnews.com/2016/09/21/chronic-fatigue-syndrome-pace-trial/

Note: Selective results of the PACE Trial were published in February 2011 but attempts to obtain the raw data from the PACE Trial Principal Investigators for independent professional analysis were unsuccessful until autumn 2016, when the data were released only after the Chief PI was legally ordered to release them. The repeated refusal of the PACE Chief PI, Peter White, to release the data (obtained at tax-payers' expense, so not his own material) was widely known to be because he feared that the data would expose fraud, which indeed was the case.

The PACE Investigators initially published results based on thresholds that deviated substantially from their published protocol, claiming "recovery" rates of 22% for GET and 22% for CBT.

However, when the data were re-analysed independently according to the Investigators' published protocol, the rates for GET were in fact 4% and for CBT 7%.

This means that the Investigators had inflated their results by an average of four-fold. It also means that "recovery" rates for CBT and GET were not statistically significant.

The independent analysts commented: *"The PACE trial provides a good example of the problems that can occur when investigators are allowed to substantially deviate from the trial protocol without adequate supervision or scrutiny".*

In her article, Julie Rehmeyer wrote: *"Simon Wessely, president of the UK Royal College of Psychiatrists, defended the trial in an email exchange with me. 'The message remains unchanged', he wrote"*

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

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

2023

Anomalies in the review process and interpretation of the evidence in the NICE guideline for chronic fatigue syndrome and myalgic encephalomyelitis Peter White et al JNNP 2023: doi:10.1136/jnnp-2022-330463. There were 51 signatories, including Trudie Chalder, Anthony David, Paul Garner, Alastair Miller, Michael Sharpe and Simon Wessely

Note: In an extraordinary and resentful diatribe about the revised NICE Guideline on ME/CFS published in October 2021, these 51 signatories revealed a disturbing refusal to concede the superiority of science over their own entrenched beliefs

"This U-turn in recommendations from the previous 2007 guideline is controversial. We suggest that the controversy stems from anomalies in both processing and interpretation of the evidence by the NICE committee"

"CFS/ME is not a fatal disease"

Note: This demonstrates a disturbing denial of reality

"It suggested that CBT should focus primarily on support for managing symptoms…This is not what CBT was developed to do"

"The primary intention of CBT in the context of CFS/ME is to improve fatigue and function. Suggesting that CBT should only be used to manage symptoms and reduce distress associated with having a chronic illness implies that there is a 'core illness' that CBT cannot change"

Note: Such is indeed the case

"In the current guideline, NICE described GET as incorporating fixed increments of exertion that are pursued irrespective of how the patient feels…There are no 'fixed increments of exercise' in GET"

"The pain of CFS/ME is not neuropathic pain…The category of nociplastic pain…is the correct category for the pain of CFS/ME"

Note: Nociplastic pain is a type of chronic pain that arises from altered pain processing even in the absence of tissue or nerve damage

"*It is difficult to understand the disconnect between the initial 2007 guideline that recommended CBT and GET, which the research evidence has strengthened over the following decade, and the recent guideline that removes GET, qualifies CBT and replaces them with 'energy management' "*

Note: The international research evidence has strengthened the biomedical pathoaetiology, which NICE could not ignore

"We are concerned that this new guideline will effectively deny clinicians the ability to offer GET and evidence-based CBT…and risks perpetuating chronic ill health and disability"

Note: No evidence exists which supports the effectiveness of the Wessely School's own GET/CBT "therapy" for ME/CFS

"In the meantime, both patients and clinicians may wish to remember that NICE guidelines are advisory, not mandatory".

<u>**2024**</u>

<u>NICE guideline on ME/CFS: robust advice based on a thorough review of the evidence</u> Peter Walter Barry et al JNNP: 2024 doi:10.1136/jnnp-2023-332731

Note: The Chair of the Guideline Committee, Peter Barry, demolished the Wessely School's petulant tirade with imperturbability; he drew attention to the Medical Royal Colleges' failure to distinguish fact from fiction:

"*A recent opinion piece…suggested that there were anomalies in the processing and interpretation of the evidence when developing the guideline…We outline how these opinions are based on a misreading or misunderstanding of the guideline procedure process"*

"The committee's criteria for diagnosing ME/CFS are more restrictive than in the previous guideline…The committee agreed that papers that had used diagnostic criteria that did not include PEM (post-exertional malaise) *would be downgraded"*

"*<u>Data on treatment harm</u>. In studies relating to GET…participants reported that following the exercise programme was 'hard work' and in some, this led to worsening of symptoms after each session. For others, trying to persist with the exercise programme led to a worsening of their symptoms in the longer term. Debilitating* *exacerbation of their symptoms was a reason for discontinuation. In one study, up to 74% of patients have reported experiencing harms after GET"*

In direct response to the Wessely School's assertion that "*There are no fixed increments of exercise' in GET"*, Barry et al were blunt: "*The GET therapists' manual from the PACE Trial instructs practitioners to 'negotiate meaningful goals' and then, as its next step, to increase the duration of exercise by a fixed increment, such as 'add 20% duration, up to 30 min'. If people have exacerbation of their symptoms, they are encouraged to maintain the same level of exercise that led to their deterioration and told that 'hurt does not equal harm'.*

"Others report that GET…is still used and that has caused significant harm".

"Exercise in individuals with ME/CFS can exacerbate both fatigue-related and pain-related PEM"

"Criticisms of the guideline discussed in this paper are misplaced".

The marked opposition of the Medical Royal Colleges to the revised NICE Guideline on ME/CFS and their refusal to co-operate in its implementation resulted in no surprise throughout the international ME community. Of particular note is that this opposition appeared not to be grounded in concern for patients' welfare but was concerned primarily with the preservation of the Wessely School's own reputation.

To quote Professor Brian Hughes' dry humour: *"In other words, the new guideline was creating anxiety among providers because they* (the Wessely School) *felt that some of their services — CBT, GET, and anything else the new guideline dispensed with — **might no longer be wanted"*** (The Science Bit: 31st October 2021).

Could the refusal of the Medical Royal Colleges to accept the revised NICE Guidelines have anything to do with Wessely et al's long-term close involvement with the medical insurance industry, which must now be quaking in its boots at the prospect of having to accept that, if NICE designates ME as an organic disorder and disallows Wessely's form of psychotherapy as a management strategy, it can no longer be excluded from cover?

Wessely commandeered the ME scene in 1988 and has been exerting his influence and control over what is published about it in UK medical journals, as well as by NICE, for decades.

That he has had control over what is published about ME/CFS is confirmed in a letter dated 20th November 1989 sent by Dr Melvin Ramsay (who was involved with the outbreak at The Royal Free Hospital between July and November 1955) to someone named "Edith":

"For many months we have been in difficulty by the influence exerted by a psychiatrist, Dr. Simon Wessly [sic] who has secured for himself the position of referee to the BMJ whose Assistant Editor has been strongly anti-ME and we cannot get anything published in British medical journals in our favour. Simon Wessly cuts right across my fundamental tenet of "rest" for chronic M.E. cases and tries to get them admitted to Psychiatric Units where they are immediately put on vigorous exercise" (https://x.com/rfh1955/status/1427702364908175366?s=61).

Despite the medical evidence which comprehensively disproves his doctrine, Wessely is certain that he is right and that "CFS/ME" is a somatoform disorder. According to the late Dr Dorothy Rowe, a world-renowned clinical psychologist, "*people who know absolutely that they are right are very dangerous*" (Observer, 14th November 1993).

Notwithstanding, it seems that the Wessely School have new enthusiasts, one being Professor Emeritus Paul Garner, Evidence Synthesis in Global Health, Liverpool School of Tropical Medicine, who has joined forces with a long-time proponent, Dr Alastair Miller, Consultant Physician in the Tropical & Infectious Disease Unit at the Royal Liverpool University Hospital. Dr Miller is well-known for his glowing praise of the discredited PACE Trial: in a press release issued in 2011 by the Science Media Centre (with which Wessely is closely involved), he said:

"*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"*.

Note: Dr Alastair 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.

NICE did not agree with him: their detailed analysis of the evidence-base upon which the Wessely School relied proved that those studies were of *"low"* or "*very low"* quality (NG206). Moreover, Professor Emeritus Jonathan Edwards of University College, London (an expert in clinical trials) concluded that those trials of GET and CBT upon which the Wessely School psychiatrists built their careers were deeply flawed and do not support their claim that their own version of CBT (directive as opposed to supportive CBT) or GET are effective treatments for ME.

Despite the unfavourable reviews, it seems that the Wessely School has no intention of succumbing to science.

2025

Patients with severe ME/CFS need hope and expert mulitidisciplinary care Alastair Miller, Fiona Symington, Paul Garner, Maria Pedersen BMJ 2025:389:r977

"*These disabilities, and the patients' belief that they won't recover, can harm their mental well-being"*

"*Recovery is possible, but patients need help to find their path"*

"Neither somatic pathology nor specific physiological disturbance has been reliably and consistently identified"

"Functional impairment may lead to malnutrition and dehydration"

The article refers to the need to avoid *"continuous sensory deprivation and total bed rest, both of which are likely to harm health"*

"Fatigue after activity doesn't necessarily mean that this is dangerous…A gradual, controlled approach to increasing activity is an important part of rehabilitation"

"Emerging evidence suggests that psychoeducation about the stress response can help reduce hypervigilance"

"The UK is following an outdated model, leading NICE to disallow cognitive approaches to help recovery or bespoke programmes designed to increase activity"

"*The unproved narrative of a disease with no cure, improvement, or recovery can be harmful and is erroneous".*

"Multidisciplinary, tailored approaches based on a biopsychosocial understanding can help patients and are urgently needed"

"Above all, we must remind patients, their relatives, and doctors that even those with severe ME/CFS can recover".

As Suzy Evans pointed out in a BMJ rapid response, there is "*growing biomedical evidence implicating immune dysregulation, neurological impairment, and metabolic dysfunction. The article's framing of ME/CFS as largely driven by maladaptive beliefs and functional dysregulation is outdated and directly conflicts with the 2021 NICE guidelines, which specifically caution against GET and other interventions aiming to 'recondition' patients or reframe their thinking as a route to recovery… This kind of narrative has long contributed to medical gaslighting, delayed diagnosis, and denial of appropriate care… It risks causing harm, particularly if it leads clinicians to push treatments that worsen symptoms or invalidate patient experiences."*
(https://www.bmj.com/content/389/bmj.r977/rr).

As another rapid respondent observed: *"In their article, Garner et al have opted for the 'psychological theory', based on dogma, rather than the scientific truth which requires observation, correlation and deduction"* (rapid response submitted by Dr WRC Weir, Consultant Physician specialising in ME/CFS; it was rejected for publication).

Garner seems to be an unduly enthusiastic member of the Wessely School: on Saturday 17th May 2025 he spoke at a SIRPA (Stress Illness Recovery Practitioners' Association) conference held at King's in London where his message was clear:

- NICE should be ashamed
- ME/CFS Activist Societies should be CHALLENGED
- DHSC should be told that government policy is causing disability

It might be said that the Wessely School should be ashamed and challenged for their relentless defiance of science.

Yet another rapid response was published: **"**Patients with severe ME/CFS need hope in the form of evidence-based interventions, not opinions" BMJ: 2025:389:r977 David Putrino, Binita Kane et al

"Miller et al suggest that patients with severe ME/CFS are hindered in their recovery by a 'belief' that they will not get better, and advocate for the use of CBT to 'change their illness narrative'. As clinicians, researchers and advocates with expertise in ME/CFS, we strongly disagree with this framing. It misrepresents the disease, revives discredited psychosomatic theories, and risks harm to patients"

"Miller et al continue to promote the unsubstantiated claims that ME/CFS is deeply rooted in psychosomatic aetiology and occurs due to a combination of deconditioning and 'unhelpful illness beliefs'. When clinicians believe that severe ME/CFS stems from 'unhelpful illness beliefs', life-saving interventions may be withheld, on the basis that they 'reinforce' these beliefs in patients. The withholding of life-saving care is not a theoretical concern: it is a documented, devastating outcome of misapplying psychosomatic models to a serious organic illness.

"Fatigue is a symptom; ME/CFS is a disease with specific diagnostic criteria"

"There is now a substantial and growing body of evidence pointing to measurable abnormalities in immune, metabolic, neurological and cardiovascular function in people with ME/CFS. These findings are incompatible with psychosomatic explanations and underscore the importance of biomedical approaches to diagnosis and care"

"Guidelines from NICE, the CDC, the National Academies of Medicine, and others, now advise clinicians to screen for PEM before recommending any exercise. Ignoring this guidance increases the risk of serious, potentially irreversible, deterioration".

Note: The above rapid response is fully referenced.

Medical concern about the Wessely School's dissemination of their own ideology

Perhaps the most cogent concern about the Wessely School's decades-long control over all aspects of ME/CFS is to be found in the article "Why the Psychosomatic View of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome is Inconsistent with Current Evidence and Harmful to Patients" is the one published on 31st December 2023 by Professor Carmen Scheibenbogen et al (Journal of Clinical Medicine 2023:12(24)8345 https://doi.org/10.3390/jcm122483345). She is Professor of Immunology and Deputy Chair, Institute of Medical Immunology, at the University Hospital Charité in Berlin.

"A vocal minority of researchers remains convinced of a psychosomatic…causation of ME/CFS despite the frequently demonstrated organic abnormalities and the simultaneous lack of evidence for relevant psychosomatic factors. The striking discrepancy between the strong conviction among proponents of a psychosomatic aetiology of ME/CFS and the simultaneous lack of evidence for this view has also been observed in other scientific fields.

Research shows that…individuals who strongly disagree with the scientific consensus are, on average, less knowledgeable about the topics than others but are more convinced of their knowledge (97).

The reference 97 refers to: Light, N.; Fernbach, P.M.; Rabb, N.; Geana, M.V.; Sloman, S.A. "Knowledge overconfidence is associated with anti-consensus views on controversial scientific issues" Sci. Adv. 2022, 8, eabo003. It accords with Dunning, D., & Kruger, J. "Unskilled and Unaware of It: How Difficulties in Recognizing One's Own Incompetence Lead to Inflated Self-Assessments" (Journal of Personality and Social Psychology 1999: 77(6), 1121-1134. doi: 10.1037/0022-3514.77.6.1121). This study found that the most ignorant people are the most confident in their mistaken opinions and lack the metacognitive ability to realise their incompetence.

Professor Scheibenbogen continues: *"Contrary to psychosomatic hypotheses, replicable organic abnormalities are evident in ME/CFS. The most important replicated abnormalities include a significant reduction in cerebral blood flow, endothelial dysfunction, a reduction in systemic oxygen supply, a reduced peak oxygen consumption, an increase in ventricular lactate levels, hypometabolism and increased levels of autoantibodies against G-protein-coupled receptors. Many organic abnormalities found in ME/CFS correlate with symptom severity, indicating a relevant role in the disease process.*

"In addition to ME/CFS itself, the lack of medical care and social support is particularly burdensome for those affected. In the health care system, patients with ME/CFS have to reckon with medical gaslighting and sometimes severe maltreatment – physicians convince patients…that they are psychosomatically ill. When admitted to hospital or rehabilitation programmes, patients with ME/CFS who are wrongly classified as having a psychosomatic illness are threatened with mistreatment, including activity-increasing therapies like GET that can seriously harm them".

Professor Scheibenbogen emphasises the importance of educating physicians and the public about the incorrect and harmful psychosomatic model, as this misdiagnosis can lead to mistreatment, stigmatisation and difficulty in receiving appropriate care and benefits.

Note: the article is fully referenced.

EXACTLY WHAT DISORDER ARE WESSELY et al LOOKING AT?

In the opinion of many people, this question is central to the debate that has raged for decades at the expense of very sick people suffering from the neuroimmune disorder ME.

Wessely's known intention is to "eradicate" ME by dropping "ME" from "CFS/ME" when expedient and then to reclassify "CFS" as a behavioural disorder under Mental and Behavioural Disorders (BMJ 2003: 326:595-597). Can there be any credible doubt that his ruthless but so far unsuccessful efforts to reclassify "CFS/ME" as a psychiatric disorder have resulted in much unnecessary confusion, hardship and suffering?

One of the underlying reasons for the confusion is the Wessely School's use of their own criteria, which have been shown to be virtually useless and bear no comparison with the International Consensus Criteria (ICC).

The ICC were published in October 2011 in the Journal of Internal Medicine by a panel of 26 international experts in ME from 13 countries. The Journal of Internal Medicine was founded in 1863 and is a monthly peer-reviewed medical journal covering all aspects of internal medicine. A person will meet the criteria for myalgic encephalomyelitis if they have PEM plus at least one neurological impairment symptom out of four categories including neurocognitive impairments, pain, sleep disturbance and neurosensory, perceptual and motor disturbances; at least one immunological/gastro-intestinal/genito-urinary impairment out of three categories including sensitivities to food, medications, odours and chemicals, and at least one energy metabolism/ion transport impairment symptom including cardiovascular, respiratory or dysautonomia symptom. The ICC were designed for both clinical and research settings. The authors state that the name myalgic encephalomyelitis is the most accurate and appropriate name because it reflects the underlying multi-system pathophysiology of the disease. Without doubt, the ICC identifies a more impaired cohort than those studied by Wessely et al (MEpedia).

It is notable that the Wessely School's views appear inconsistent: it is clear that they know and accept that people with ME do present with neurological dysfunction, yet they choose to disregard, dismiss and/or deny it.

As mentioned above, Peter White spoke at the Royal Society of Medicine Conference on CFS on 28th April 2008 and spoke about ME as described by Acheson and Ramsay from the 1950s: he stressed that it was a different illness then from what is now called "CFS/ME". Disturbingly, he misled his audience by manipulating the clinical presentation of the Royal Free outbreak, which seemed to be an attempt to distinguish between the "original" ME cases and what is now called "CFS/ME". He was at pains to emphasise that, as noted above, in 1955 at the Royal Free, ***"74% showed objective involvement of the central nervous system"*** and implied that in the current "CFS/ME", there is no such CNS involvement, which is 100% incorrect.

There appears to be a State-corporate insurance business collusion, both of which share the same concern: the unquantifiable cost to both parties if ME is allowed to become a recognised chronic, incurable physical disorder ("*Diagnosis: Neurosis with a new banner. 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).

For decades, Wessely et al have flooded the medical literature with their own theories dressed up as fact and their apparent mission to protect and benefit from the Permanent Health Insurance industry continues unchecked.

General Observations

1. No amount of evidence showing how wrong they are about ME/CFS seems to daunt the Wessely School.

In June 2004 Professor Peter White was awarded an OBE for his work on "CFS". The citation was: "*For services to medical education"*. Notices circulating at the time proclaimed him as leading the research into CFS/ME and said his OBE was a *"well-deserved honour and acknowledgement of his contribution to work on CFS/ME".* For someone to receive such an honour seems surprising if the person so honoured is apparently ignorant of the established facts pertaining to the subject of his research for which he was honoured.

Adherence to the WHO's ICD is mandatory in England, but at the Royal Society of Medicine's Conference on "Chronic Fatigue Syndrome" on 28th April 2008, Peter White was unequivocal in advising clinicians not to use the ICD classification of ME/CFS as a neurological disorder. His verbatim words were:

"I'm going to try to define what Chronic Fatigue Syndrome is. By doing so I'm going to review the ICD-10 criteria for the illness and see if they're helpful. The answer will be, they are not helpful".

"One of our problems is: labels do count. Does the ICD-10 help us? Unfortunately not. There are at least five ways of classifying CFS using the ICD-10 criteria. You've got alternatives (to the neurological chapter): in the Mental Health chapter, you've got neurasthenia".

The "alternatives" shown on White's power point slides are all explicitly forbidden by the WHO. They include not only neurasthenia (which White pointed out includes "fatigue syndrome"), but he also highlighted at F45.1 "Undifferentiated somatoform disorder; he highlighted at F45.3 "somatoform autonomic dysfunction" and at F45.9 he highlighted "somatoform disorder, unspecified". White paid no heed whatever to the WHO directive that ME/CFS is not permitted to be classified to more than one rubric. He clearly used the term "CFS/ME" and that term is included at G93.3, so any other designation is impermissible. There are not five ways of classifying ME, despite what White told his medical audience:

"*ICD-10 is not helpful and I would not suggest, as clinicians, you use ICD-10 criteria".*

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

Members of the Wessely School seem to pay scant attention to anything other than to their own beliefs and intentions.

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

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

Note: Knowingly misleading Members of Parliament is a serious offence.

3**.** Whilst it has proved impossible to place any credibility on the PACE Trial's official results, it appears it is likewise impossible to place reliance on Professor White himself, as just one example confirms: following a formal complaint to The Lancet, in 2011 he wrote to Richard Horton, the Editor-in-Chief, stating categorically and unambiguously: ***"The PACE trial paper refers to chronic fatigue syndrome (CFS) which is operationally defined; it does not purport to be studying CFS/ME"***. The PACE Trial was funded to study ME/CFS out of tax-payers' money and it was understood to be looking at ME/CFS.s

However, on 22nd September 2016 Peter White wrote in the BMJ: ***"The PACE trial was the largest clinical trial to date into Chronic Fatigue Syndrome (CFS), also sometimes referred to as Myalgic Encephalomyelitis (ME)"*** (http://blogs.bmj.com/bmj/2016/peter-white-et-al-releasing-patient-dara-from-the-pace-trial-for-chronic-fatigue-syndrome/). Professor White's two statements about the same issue contradict each other: in one, he says he was not studying CFS/ME but in the other, he says his PACE Trial was indeed studying CFS/ME. This is a matter of importance and there should be no room for any dissembling.

4. The Wessely School's influence about ME can be found in a book published in 2015 entitled "It's All in Your Head: True Stories of Imaginary Illness" by Dr Suzanne O'Sullivan, a neurologist at The National Hospital for Neurology and Neurosurgery in London where Simon Wessely began his illustrious career refuting the existence of ME other than as a false belief. Once again, ME is described as an "imaginary illness". The book won O'Sullivan the Wellcome Book Prize in 2016. The Sunday Times reviewer said: *"(People) in the West (are) stricken with irritable bowel syndrome and food 'intolerances' – which O'Sullivan clearly believes are psychosomatic illnesses. She thinks the same about ME".*

On 9th June 2015 the Countess of Mar wrote to Dr O'Sullivan listing some facts about ME that appeared to have escaped her and pointing out that in its Report "Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome" released on 10th February 2015, the US Institute of Medicine's primary message was that: " *'ME/CFS is a serious, chronic, complex systemic disease'. Patients with the disease have always known this and are, predictably, deeply hurt and offended by the denigration they receive from some medical practitioners….I am…disappointed that you appear to have failed dismally to keep abreast of current research into ME/CFS. Had people like you in senior positions really tried to discover what is at the root of the symptoms suffered by the patients that you see, more progress might have been made in the diagnosis and treatment of this dreadfully neglected disease….I really do think that if one is professing an expertise in a particular disease or illness, one should try to keep abreast of current research, don't you? ….The evidence is now so strong that ME/CFS is a serious multi-system neuro-immune disease that it becomes intellectually embarrassing for anyone to continue to consider it to be a psychosomatic disorder….I do hope that you will take my submission seriously and reconsider your belief that ME/CFS is a psychosomatic disorder. I look forward to receiving your considered response".*

Dr Suzanne O'Sullivan was discourteous enough not to reply to the Countess of Mar.

5. Instead of receiving medical support, ME sufferers are mixed up with sufferers from other fatigue-causing conditions. In the UK, no other classified neurological condition is treated solely by psychological interventions.

6. Simon Wessely believes that attribution by patients to a virus is somatisation "*par excellence*" (J Psychsom Res 1994:38:2: 89-98). According to the Wessely School's beliefs, in their teaching of others and in their recommendations to Government departments to which they are official advisers on ME, there are no physical signs of disease and no pathology causing the patients' symptoms: 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 at the US National Institutes of Health 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 one. It has the characteristics of a viral disease".*

Professor Luc Montagnier (who in 2008 won the Nobel prize for discovering the AIDS virus) is on record as stating that scientists have already discovered a lot about ME, but this information does not reach professional healthcare personnel, and the disease is not taken seriously.
(http://esme-eu.com/home/experts-launch-think-tank-for-mystery-disease-article37-6.html).

International experts have shown beyond doubt that Wessely's belief about ME/CFS is erroneous, but his belief, and the belief of his close colleagues, appear to be invincible. Aided and abetted by the Science Media Centre (to which Wessely is not only a Founder Member but, as he also sits on its Science Advisory Panel, he effectively controls its output about "CFS/ME"), he and his colleagues seem to ignore and dismiss world-class evidence that proves them wrong.

As someone wrote on 1st January 2013: "*Wessely has a lot to answer for, and the elements in the ME community that are hostile to him are not fringe cranks but mainstream advocacy organisations…(He) has caused enormous suffering with dubious science…Regardless of his titles and letters after his name…(the media) should stop airing Wessely's evasions and circumlocutions and his tales of persecution and ask him serious questions about the holes in his theories which are obvious…"* (Simon Wessely: more sinning than sinned against: www.blogistan.co.uk).

Physician Dr John Whiting FRACP was also succinct: "*I am thinking about ME/CFS as a burden that society is not ready to…even entertain as real….There are powers who support Wessely…The truth will hurt (but) the atmosphere is one of a dying paradigm, one that is eventually going to yield to overwhelming evidence that has been denied, unrecognised, suppressed and distorted by these 'unknown' powers behind the scenes….We are not burdens to society. We are not scientific trash. We are the forerunners of a new understanding of the physiology of man and its diseases. So I say RIP to those who have supported Wessely…A new age is coming"* (LocalME: 23rd November 2012).

As Natalie Boulton, mother of a severely affected daughter and, with her son Josh, author of the book "Lost Voices from a Hidden Illness" and producer of the acclaimed film "Voices from the Shadows" says: *"The illness that trapped my daughter and her friends has 'disappeared'… supported by government policy and the media, with the help of the mental health section of the Science Media Centre, which was doing an excellent job of trivialising the illness and denigrating patients. Nowhere in the public domain was there any sign of the terrible severity of the illness I saw driving many intelligent, creative, positive and courageous young people into lives of devastating dependency, social isolation, pain and steadily deteriorating health. Not only that, but the abuse suffered by some patients who were being harmed by professionals was going totally unrecorded and unnoticed. Patients were, and are, suffering and dying invisibly".*

On 3rd December 2012 Lydia Neilson, CEO of the National ME/FM Action Network, said in an open letter to Simon Wessely what many people have wanted to say for decades: "*It is…regrettable that you are insinuating that the scientific community and the health and social professionals working so diligently to understand, diagnose, treat and support ME/CFS and FM patients are all on the wrong path and only you know the correct approach. That is, to say the least, the height of arrogance"*
(www.facebook.com/MEFMActionNetwork/posts/516966931656588).

In the Open Medicine Foundation News for February 2017, Professor Ron Davis, Scientific Advisory Board Director, Metabolomics & Genetics Study, University of California, said about ME/CFS: "***It's a horrible disease. It's one of the most horrible diseases I've ever seen".***

7. Wessely's frequent attention-seeking behaviour claiming that he is being vilified and threatened by patients with ME/CFS is a matter of record. One such example was on 29th July 2011 when, in a notably excited introduction to his interview with Wessely about ME/CFS on the BBC's "Today" programme, journalist Tom Fielden informed the nation how Wessely, a "genuine scientist", is harassed and threatened by patients to the extent that his mail has to be routinely scanned before he is allowed to access it, and how he needs police protection, as he has received death threats. The "police protection" involves security briefings and panic buttons. The police take death threats seriously, so each threat would be allocated a crime incident number. Have any of these alleged death threats been substantiated? Have there ever been any prosecutions reported in the press? There are no reports of any action by the police, nor does Wessely provide any crime incident numbers. Wessely's boasts of police protection are not rare, so what must it be costing the nation in these straightened economic times? Do a few immoderate emails and internet postings -- by desperate patients pushed to the brink by Wessely's constant denial of the very existence of the disease from which they suffer -- warrant such costly "police protection"?

It is notable that Wessely's claims of harassment usually occur when yet more published evidence further disproves his belief that ME is perpetuated by patients wrongly attributing their symptoms to a physical disease. At such times Wessely appears to be deflecting media attention away from the latest biomedical evidence which vitiates his own belief about the psychiatric nature of ME/CFS by portraying himself as the victim of endless harassment by vicious and intimidating ME/CFS patients.

It is appropriate to consider how many threats Wessely himself has issued to those who oppose his views, and how often he has threatened injunctions. 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 work on ME had the temerity to quote what he had actually published, and he was self-admittedly panicking about his resultant public image (see The Scotsman, October 2003 to January 2004; also personal communication).

8. As the late Horace Reid, himself afflicted by ME, so aptly wrote on LocalME on 13th August 2007: *"Today's Daily Telegraph details how Russians often silence their dissidents – they give them a psychiatric diagnosis. There is some parallel with the treatment of ME patients in the UK:*

- ***ME patients are given a psychiatric label.***
- ***As a result, they are regarded as irrational and their opinions are not taken seriously.***
- ***Effectively they are silenced, since no-one will afford them credibility; not their GPs, not their MPs, not their employers, and sometimes not their friends.***
- ***By silencing patients, their opposition is neutered and psychiatric dominance in ME continues unchallenged.***

9. Another accurate summary of how people with ME are treated in the UK is the one produced on 8th March 2008 by Greg Crowhurst in "The Year of No Compromise". http://carersfight.blogspot.in/2017/01/the-year-of-no-compromise.html). Nothing has changed in the last 17 years.

"This is a simple summary of the inferred messages underpinning the psychiatric paradigm currently being heavily promoted in the UK:

The recommendations:

- ***do not investigate ME/CFS patients***
- ***do not provide special facilities for ME/CFS patients other than psychiatric clinics***

- ***do not offer special training to doctors about the disorder***
- ***do not offer appropriate medical care for ME/CFS patients***
- ***do not offer respite care for ME/CFS patients***
- ***do not offer State benefits for those with ME/CFS***
- ***do not conduct biomedical research into the disorder***

The tactics:

- ***the wreaking of havoc in the lives of ME/CFS patients and their families by the arrogant pursuit of a psychiatric construct of the disorder***
- ***the attempts to subvert the international classification of this disorder from neurological to behavioural***
- ***the propagation of untruths and falsehoods about the disorder***
- ***the building of affiliations with corporate industry***
- ***the insidious infiltration of all the major institutions***
- ***the denigration of those with ME***

The practices:

- ***the attempt to make 'ME' disappear in a sea of chronic fatigue***
- ***the refusal to see or acknowledge the multiplicity of symptoms***
- ***the ignoring and misinterpretation of the biomedical evidence***
- ***the suppression of published (biomedical) findings***
- ***the vested interests***

The impact:

- ***the arresting and sectioning of protestors***
- ***the silencing of ME patients through being given a psychiatric label***
- ***the suppression of dissent***
- ***the labelling of ME patients as the 'undeserving sick', as malingerers***
- ***the forcible removal of sick children and adults from their homes.***

The impact of the above strategy on peoples' lives is catastrophic. Who can measure the suffering?"

Conclusion

An as-yet unanswered question requires an answer from Wessely: what is his justification for rejecting the elementary rules of procedure which require clinical trials to build on what has already been established and published about the disorder in question?

Did this happen with the PACE Trial? If not, what was the reason for it not happening?

Investigators are always at liberty to take issue with established knowledge, but in order to do so, they need to provide a carefully reasoned critique of the established knowledge from which they propose to depart, which Wessely et al seemingly failed to do, since they have not overturned – indeed they cannot overturn -- the biomedical evidence-base that disproves their own beliefs about "CFS/ME".

Despite extensive biomedical evidence contradicting his claims that ME/CFS is a mental health disorder, Wessely has accrued considerable personal and professional esteem, whilst an incalculable number of people are suffering – and in too many cases, dying – from a neuroimmune disease whose very existence he denies.

Accolades continue to flow in: as recently as 10th March 2025 Wessely was appointed to the Board of The Advisory Council on National Records and Archives, one of six new ACNRA Board members. The ME community may discern a certain irony in this particular appointment, given their efforts to access documents about ME that are held in the National Archives, some of which are to remain inaccessible for the foreseeable future.

There are many people who believe that Wessely has set back medical progress in ME/CFS by a whole generation.

"It's absolutely retrogressive to suggest (ME)CFS is in the heads of patients. I have seen patients commit suicide, or have been otherwise destroyed, because some professor has diagnosed them as having a psychiatric illness" (Peter Behan, Professor of Clinical Neurology, University of Glasgow; New Scientist, May 1994)

(ME/CFS patients) "feel effectively the same every day as an AIDS patient feels two months before death; the only difference is that the symptoms can go on for never-ending decades" (Professor Mark Loveless, Head of AIDS & ME/CFS, Oregon Health Sciences University – Congressional Briefing 1995)

"Individuals are often stigmatized and told their illness isn't real…People with (ME)CFS face an incredible burden just getting doctors to take their symptoms seriously" (Dr Barry Hurwitz, University of Miami: Co-Cure MED: 30th July 2003)

"There is no word in the English lexicon that describes the lack of stamina, the paucity of energy, the absolute malaise …that accompanies this illness" (Dr Charles Lapp, Medical Director, Hunter-Hopkins Centre, North Carolina; Clinical Associate Professor, Duke University, Co-Cure: 3rd June 2004)