

THE POWER OF PROPAGANDA ?

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For the last 48 years, myalgic encephalomyelitis (ME) has been formally classified by the World Health Organisation as a neurological disorder but for the last 29 years a group of UK psychiatrists (known as the Wessely School) have denied it exists other than as an aberrant belief; they insist that it is a mental (behavioural) disorder that can be cured by graded exercise and “cognitive re-structuring”.

“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)

“It is one of the most disabling diseases that I care for, far exceeding HIV disease except for the terminal stages” (Dr Daniel Peterson, ME/CFS Research & Clinical Conference, Florida, October 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)

“Our patients are terribly ill, misunderstood and suffer at the hands of a poorly informed medical establishment and society” (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)

“ME/CFS feels like you’ve been run over by a truck – pain, inflammation, utter exhaustion....I have been caring for patients with ME/CFS for 26 years now. It’s heartbreaking seeing them struggle and suffer from this serious illness that has been trivialised by science and society” (Professor Nancy Klimas, Nova Southeastern University Newsroom: 24th January 2013)

SUMMARY

1. ME is a neuro-inflammatory (sometimes fatal) disease that affects every bodily system.

Classification of Myalgic Encephalomyelitis / Chronic Fatigue Syndrome

In 1969 the World Health Organisation formally classified myalgic encephalomyelitis (ME) as a neurological disorder in its International Classification of Diseases (ICD 8: approved in 1965 and published in 1969: alphabetical Code Index Volume II, page 173). Volume II is the Index which alphabetically lists all the phrases and names of conditions commonly used by doctors, together with the appropriate code. ME was included as a neurological disorder in ICD 9 (approved in 1975 and published in 1977: alphabetical Code Index Volume II, page 182: code 323.9). In 1992, the current version (ICD-10) added the term “Chronic Fatigue Syndrome” as synonymous with ME and it is coded in the alphabetical Index to the same code (G93.3), as is Post-Viral Fatigue Syndrome.

On 10th September 2002 NICE Special Health Authority issued a Communications Progress Report: ***“The ICD-10 classification is used for the recording of diseases and health related problems (and) ICD-10 is the latest version...the classification codes are mandatory for use across England”***.

2. Wessely School psychiatrists do not accept the existence of ME as a neurological disorder

"You are only ill when someone says you are ill....The new societal syndrome of syndromatic diseases requires a new speciality, a syndromologist. Fortunately, one is to hand. His name is Professor Simon Wessely...Wessely has been arguing that ME is a largely self-induced ailment that can be cured by the exercise programme on offer at his clinic...Wessely occupies a key position in our socio-medical order (and...) denies the existence of ME. Clearly, he is a follower of Groucho Marx: 'Whatever it is, I deny it'. Not surprisingly, lots of people hate him... If Wessely is our syndromologist-in-chief, who has chosen and vetted him for that post, and by what criteria and procedures? When will we have the first officially sponsored study of such a problem which sufferers do not have the occasion to call a whitewash?" Ill-defined notions. Ziauddin Sardar. New Statesman, 5 February 1999

A group of UK doctors known as the Wessely School -- mostly psychiatrists and occupational health physicians who work for the permanent health insurance industry and who have undisputed vested interests -- disagree with the WHO classification of ME and, in defiance of the significant and established evidence-base of its organic nature, have spent their professional life trying to eradicate "ME" and get "CFS" re-classified as a mental disorder which, if so classified, would mean that the policy-holder is not entitled to benefit payments.

They claim "CFS" is a syndrome of "fatigue" (chronic fatigue being classified as a mental disorder in ICD-10 at F48.0) and that "CFS/ME" has dual classification. They do so despite the formal warning from the WHO on 23rd January 2004 that dual classification is not permitted: *"This is to confirm that according to the taxonomic principles governing the Tenth Revision of the World Health Organization's International Statistical Classification of Diseases and Related Health Problems (ICD-10) it is not permitted for the same condition to be classified to more than one rubric as this would mean that the individual categories and subcategories were no longer mutually exclusive".*

Doctors, including psychiatrists, are required to keep up-to-date but the Wessely School's views have remained intransigent (i.e. they continue to insist that ME/CFS is a behavioural disorder and that patients who believe they suffer from a physical disease perpetuate their own "perceived" ill-health).

3. Quotations show the Wessely School's ideology results in patients with a diagnosis of ME being called mad, lazy, liars, malingerers and fraudsters, with no hint of proof; they are accused of harassing and threatening psychiatrists; they often have to endure prejudicial taunts and dismissal. They suffer iniquitous abuse and they are harmed by such insults, but they have no redress.

SECTION 1

ME is a neuro-inflammatory (sometimes fatal) disease that affects every bodily system

There can be no credible dispute about the existence of ME/CFS as a chronic, whole-body disease, thought to be an autoimmune disease, with the vascular endothelium being the target organ. There are over 9,000 peer-reviewed articles describing the complex pathology. Basic screening results are often within the normal range, but advanced investigations (proscribed in the UK by the NICE Guideline on CFS that was produced in conjunction with the Wessely School) demonstrate significant dysfunction in many organs and systems: MRI scans show evidence of brain, cardiac and muscle abnormalities; the immune, gastro-intestinal, neuroendocrine and cardiovascular systems are particularly involved, with evidence of dysfunctional natural killer (NK) cells and increased apoptosis; dysautonomia is a significant component of the disorder and there is evidence of impaired cardiac function including reduced cardiac mass and blood volume; a key finding is dysfunction in cellular energy metabolism and ion transport.

Classic symptoms of ME (as distinct from other post-viral syndromes) include physiological exhaustion after minimal physical or mental effort (known as PEM, or post-exertional malaise); sufferers often feel profoundly ill and are frequently unable to stand unsupported for more than a few minutes. There is muscle and joint pain (which may be extreme); dizziness and loss of balance; breathlessness; visual problems including double vision; nausea; gut dysmotility; frequency of micturition (with nocturia); chest pains; tachycardia; spontaneous bleeding; rashes; poor co-ordination; multiple hypersensitivities; cognitive problems and un-refreshing sleep. There is frequently emotional lability, with episodes of unexpected weeping and overwhelming fear. Unlike people with other post-viral fatigue states, people with classic “Ramsay” ME (ie. with evidence of Coxsackie enterovirus) rarely suffer from colds or a sore throat.

Deaths from ME

Professor Wessely is on record as asserting: ***“Most important of all, ME is not, and cannot be, fatal”*** (The Times, 14th September 1993) but UK Coroners provide incontrovertible evidence that ME/CFS can lead to death. The UK authorities keep no statistics, so the actual number of deaths from ME/CFS remains unknown, especially as those with ME who are driven to commit suicide are not recorded as having died from ME.

More than one MP has died from ME: Brynmor John was diagnosed with ME (Hansard 23rd February 1988:167-168); on 13th December 1988 he collapsed and died on leaving the House of Commons gym, having been medically advised to exercise back to fitness.

In 1992, a 30 year old woman in the UK who had suffered from ME/CFS for five years committed suicide; **the post-mortem study showed enteroviral sequences**

in samples from her muscle, heart, the hypothalamus and the brain stem. No enteroviral sequences were detected in any of the control tissues. The researchers stated: *“The findings further support the possibility that hypothalamic dysfunction exists in the pathogenesis of (ME)CFS (and) they suggest that **the chronic fatigue syndrome may be mediated by enterovirus infection and that persistent symptoms may reflect persistence in affected organs**”* (McGarry et al. Ann Intern Med: 1994;120:11: 972-3).

On 18th June 1995, Consultant Radiologist Dr Eric Booth died from ME/CFS aged 48 years, having had ME/CFS for 16 years. Four years before he died, Booth wrote: *“**I have been very seriously ill for the last five years, being totally bedridden (but) am unable to convey this to my medical colleagues. I have come to believe that physicians suffer from compassion fatigue**”* (BMJ 28 October 1995:311).

In 1998 Joanna Butler aged 24 died from ME/CFS. **She was nursed at home by her parents and was bed-bound for the last two years of her life and required tube-feeding.** Her parents were suspected of having caused her death by administering too high a dose of a medically-prescribed morphine-related compound and the County Coroner (Michael Coker) ordered a police investigation. This investigation cleared them of blame but they were hounded to such an extent that they were forced to move away from the area (see The Observer, 19th March 1998: “Tragic death of young ME victim” and the reports in the local Warwickshire “Courier”, which carried a report on the ‘*many who die each year*’ of ME).

In January 2003 the wife of Richard Senior died of ME/CFS; **the North Wales Coroner entered CFS as the cause of death on the death certificate.**

On 4th July 2005 Casey Fero died of ME/CFS at the age of 23 in the US. The autopsy showed viral infection of the heart muscle. **The pathologist was shocked at the state of Casey’s heart, which showed fibrosis indicating the presence of a long-standing infection.**

In November 2005 Sophia Mirza died of ME/CFS in the UK and the death certificate of 19th June 2006 gives CFS as the cause of death, with acute renal failure.

Another UK death from ME/CFS occurred in May 2008 when a severely affected woman died in the North of England; **her death certificate gives “Myalgic encephalomyelitis” as the cause of death.**

The exceptionally tragic death of Lynn Gilderdale, aged 31, on 4th December 2008 was well-reported, as was the equally tragic death of Emily Collingridge, aged 30, on 21st March 2012: both these young people suffered beyond endurance, as did their families, **and both died from ME.**

Evidence from autopsies of people who have died from ME/CFS is chilling. **In Sophia Mirza’s case (a 32 year old woman sectioned by psychiatrists who alleged that she was suffering from a mental disorder so she was kept in a locked ward and denied basic care), there was evidence of severe inflammation**

throughout 75% of her spinal cord. This was one of three such autopsies spoken about by neurologist Dr Abhijit Chaudhuri at the Royal Society of Medicine meeting on 11th July 2009.

A 2005 autopsy in the US is particularly shocking: it showed oedema of the lower limbs; the alveolar spaces of the lungs were filled with inflammatory cells and there were small emboli scattered throughout the arteries; there was marked congestion of the liver and spleen; the bowel was ischaemic; there was mild inflammation of the kidneys; there was also 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); the bladder showed a hyperplastic epithelium; the thyroid showed colloid filled follicles, with scattered dystrophic calcifications and calcification of the small arterial walls; the right occipital lobe of the brain showed areas of degeneration and degenerated astrocytes, and the white matter surrounding this defect appeared puckered. The Medical Director of The National CFIDS Foundation (chronic fatigue immune dysfunction, a commonly-used US term for ME/CFS), Dr Alan Cocchetto, commented: ***“Every time you look closely at someone with this disease, you see immense suffering. There appears to be no limit as to the human toll that this disease is capable of exerting on patients”*** (<http://www.ncf-net.org/forum/Autopsy.htm>).

SECTION 2

Wessely School psychiatrists do not accept the existence of ME as a neurological disorder

Despite the plethora of evidence that vitiates their belief, the Wessely School -- including the three PACE Trial Principal Investigators (Professors Peter White, Michael Sharpe and Trudie Chalder) and the Director of the PACE Clinical Trial Unit (Professor Simon Wessely) -- continue to believe and assert that ME/CFS is an “*aberrant illness belief*” and **that all patients with ME/CFS are really suffering from the same mental illness, ie. somatisation; as such, their symptoms will never be medically explained, therefore there is no point in wasting health service resources in seeking a biomedical explanation.**

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”* (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”* (2011)
- *“I am delighted to have been elected as President of this very distinguished organisation (The RSM)I am also proud that I am the first psychiatrist to have received this honour”* (2016) (www.margaretwilliams.me/2017/quatable-quotes-continued.pdf)

but countless sick people hold him responsible for the denial and dismissal of their suffering.

It is possible that, as a result of the Wessely School’s activities, the forthcoming revision of both the WHO International Classification of Diseases (ICD-11) and the American Psychiatric Association’s Diagnostic and Statistical Manual (DSM-V) will reclassify ME/CFS as “Medically Unexplained Symptoms” (MUS); other terms include Functional Somatic Syndrome (FSS) and Bodily Distress Syndrome (BDS), these being the proposed replacement names for somatisation disorder, with the result that patients with an organic disorder will be managed as though they suffer from a mental disorder.

Many people not only in the UK but internationally attribute this deplorable situation to the undisputed influence of the Wessely School and in particular of psychiatrists Professor Sir Simon Wessely (currently President of The Royal College of Psychiatrists and whose influence extends to the USA and Australia); Professor Peter Denton White OBE and Professor Michael Sharpe, but not forgetting their colleague Professor Trudie Chalder.

Ms Chalder is a registered mental nurse who is highly esteemed by Sir Simon and to whom he handed over his chronic fatigue clinic at King's College Hospital, London.

She completed her PhD thesis at The Institute of Psychiatry, King's College, on "Factors contributing to the development and maintenance of fatigue in primary care" in 1998 but it is not listed in the King's College repository nor in the British Library EThOS (UK E-Theses Online Service).

In a book she co-authored (Overcoming Chronic Fatigue in Young People) that was published in June 2015 she is described as a "*health psychologist*" but it is understood that "Health Psychologist" is a [protected title](#) under Article 39(1) of the Health and Social Work Professions Order 2001 and that it is an offence for a person to [use a designated title protected by the Order to which they are not entitled](#). Further legislation on the regulation of psychologists [was introduced on 1 July 2009 and the Health and Care Professions Council \(HCPC\) register of practitioner psychologists opened](#). Ms Chalder is not registered as a psychologist on either of the two public registers.

She is, however, registered with the cognitive behavioural therapy organisation BABCP (British Association for Behavioural and Cognitive Psychotherapy) which, unlike the British Association for Counselling and Psychotherapy, is not just for practitioners; it is described as "*an interest group for people involved in the practice and theory of cognitive behavioural therapy*", an interest group of which Ms Chalder is a past-President.

Ms Chalder is described as a "*world expert in chronic fatigue and CFS/ME*" and is now Professor of Cognitive Behavioural Psychotherapy at King's College, London.

Professor Chalder features in a 2007 Training Video for Physicians ("The Management of Chronic Fatigue in Primary Care - Training Physicians in Mental Health Skills Series"; £60 per teaching package). The video lasts 45 minutes and is co-presented by Professor Andre Tylee (a GP specialising in mental health); it claims to demonstrate how not to get into arguments with the patient with ME/CFS and how to carry out a plan of treatment aimed at the restoration of normal function.

The video does not make it clear that Ms Chalder is not a GP; it is based on the Wessely School's belief of what constitutes ME/CFS: "*...It can be very frustrating working with patients with chronic fatigue syndrome particularly as you can get into arguments about their pre-set ideas about what causes the problem.....this video is going to help you to manage these patients*".

In vignette 2, Tylee asks: "*Is it important to sort of put somebody right if they believe it's due to a virus?*" and Chalder replies: "*people think that there's something lurking in the cupboard as yet undiscovered that is creating the problem and of course that's I think in their mind a bit silly*" (sic).

In vignette 3 Chalder says: "***It's really important that the patients keep a detailed diary so that you can re-order the activities***".

In vignette 5, the role of the GP is played by Wessely's wife (Dr Clare Gerada), who says to the patient:

"...what we're trying to do here as I've said to you is to break this association between activity and your symptoms...if you feel rotten I still want you to do that activity...even if you're absolutely exhausted I still want you to do your ten minute walk in the morning and the ten minute walk in the evening after work.....it will be safe -- all the evidence that we've put together and all the research literature shows that is absolutely safe, you will not do yourself any harm".

Tylee says: *"Now the other situation that myself and my partners at my practice often find is that people go to the ME Association and they get lots of advice...and things and they come in with a whole wealth of different agencies that they'd like to be referred to but presumably it's more appropriate really to contain it?"* at which point Chalder emphatically states: *"Yes, absolutely"*.

Apparently trying to justify patients not being sent for investigations, Tylee says: *"People can be taught how to re-learn or to change their behaviour and their sort of physiological processes in a way that can actually control chronic fatigue syndrome, is that correct?"* to which Chalder replies: *"That's absolutely right.... we know that the degree of pathology is not necessarily correlated with the degree of disability you know"*.

Tylee asks: *"What percentage would you expect to get better?"* and Chalder responds: *"About 70% in hospital populations which is actually very good....left untreated patients certainly don't get better and they deteriorate"*. (There is no evidence that about 70% of people "get better" ie. recover).

The video title refers to "The Management of Chronic Fatigue" but then purports to deal with ME/CFS but it was in 1990 that the American Medical Association issued a correction: *"A news release in the July 4 packet confused chronic fatigue with chronic fatigue syndrome; the two are not the same. We regret the error and any confusion it may have caused"*.

It is of concern that such harmful misinformation about ME/CFS has been provided for doctors who deal face-to-face with ME/CFS patients. Dr Clare Gerada is very influential; she has been a Senior Policy Advisor at the Department of Health; she became Chair of the Council of The Royal College of General Practitioners and is a close friend of Simon Stevens (currently Chief Executive of NHS England).

There has been a massive drive to dismiss ME/CFS as an organic disorder and Wessely in particular has been ceaseless in his efforts to discredit ME and its unfortunate sufferers. Ignoring the substantial evidence that disproves their ideology, he and his adherents relentlessly teach, lecture and disseminate their own beliefs to an unprecedented degree, to the extent that their beliefs have become established fact in the mind of most UK medical practitioners, politicians and decision-makers.

How is it possible for clinicians who are so dismissive about such very sick people to exert such wall-to-wall control but to be so monumentally wrong about ME/CFS? To whom are they accountable? The answer is that they are accountable

to no-one: not to the GMC; not to the Royal Colleges; not to Ministers of State; not to Departments of State; not to the NHS as their employers and certainly not to their patients. There is no recourse to the Law, as Judges do not rule on divergent medical opinion.

Enter Simon Wessely

In 1988, a young psychiatrist named Simon Wessely leapt into the limelight (a position he has sought and in which he appears to have revelled for the last 29 years) by supporting the forcible removal from his home – on a Sunday and in the presence of police – of a 12 year old boy named Ean Proctor who was very severely affected by ME. Although he did not obtain his MRCPsych until 1986, Wessely claimed expertise in the disorder; on 3 June 1988 he wrote to the Principal Social Worker at Douglas, Isle of Man; without having seen the child, he asserted:

*“Ean presented with a history of an ability (sic) to use any muscle group which amounted to a paraplegia, together with elective mutatism (sic). **I did not perform a physical examination** but was told that there was no evidence of any physical pathology...**I was in no doubt that the primary problem was psychiatric** (and) that his apparent illness was out of all proportion to the original cause. I feel that Ean’s parents are very over involved in his care. **I have considerable experience in the subject of ‘myalgic encephalomyelitis’** and am absolutely certain that it did not apply to Ean. I feel that Ean needs a long period of rehabilitation (which) will involve separation from his parents, providing an escape from his “ill” world. For this reason, I support the application made by your department for wardship”.*

Wessely’s assertion that Ean suffered from elective mutism was subsequently shown in an examination under anaesthetic to be untrue, as the child’s vocal cords were affected.

In this “care”, the sick child was forced into a hospital swimming pool with no floating aids because psychiatrists wanted to prove that he could use his limbs and that he would be forced to do so to save himself from drowning. He could not save himself and sank to the bottom of the pool. The terrified child was also dragged out of the hospital ward and taken on a ghost train because psychiatrists were determined to prove that he could speak and they believed he would cry out in fear and panic and this would prove them right. Another part of this “care” included keeping the boy alone in a side-ward and leaving him intentionally unattended for over seven hours at a time with no means of communication because the call bell had been deliberately disconnected. The side-ward was next to the lavatories and the staff believed he would take himself to the lavatory when he was desperate enough. He was unable to do so and wet himself but was left for many hours at a time sitting in urine-soaked clothes in a wet chair.

Another part of the “care” involved the child being raced in his wheelchair up and down corridors by a male nurse who would stop abruptly without warning, supposedly to make the boy hold on to the chair sides to prevent himself from being tipped out; he was unable to do so and was projected out of the wheelchair onto the

floor, which on one occasion resulted in injury to his back. This was regarded as a huge joke by the staff.

In a further medical report dated 5th August 1988 for Messrs Simcocks, Wessely wrote:

“It may assist the Court to point out that I am the co-author of several scientific papers concerning the topic of “ME”...I have considerable experience of both (it) and child and adult psychiatry (and) submit that mutism cannot occur (in ME). I disagree that active rehabilitation should wait until recovery has taken place, and submit that recovery will not occur until such rehabilitation has commenced”.

Thus began Wessely’s mission to “eradicate” ME and to claim “chronic fatigue/chronic fatigue syndrome” as a behavioural disorder. Indeed, his mission became an unending onslaught on patients suffering from ME and on their alleged need for an “acceptable” diagnosis.

In 1998 Wessely wrote in The Lancet: *“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”* (Myalgic encephalomyelitis, or what? Anthony David Simon Wessely Anthony Pelosi. Lancet 1988:July 9: 100-101).

In 1990, Wessely wrote that ME exists “only because well-meaning doctors have not learnt to deal effectively with suggestible patients” (Psychol Med 1990:20:35-53).

That same year he wrote: ***“It is regrettable that ME has become a fad”*** (The chronic fatigue syndrome -- myalgic encephalomyelitis or postviral fatigue. S. Wessely P.K. Thomas In: Recent Advances in Clinical Neurology Ed. Christopher Kennard.No.6. Churchill Livingstone 1990: 85-132)

In his letter dated 10th January 1992 to Dr Mansel Aylward, CMO 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 CFS should not be grounds for permanent disability".***

Following publication of the handbook for decision-makers which prompted a person with ME to write to the DSS, on 6th April 1992 a letter was sent from C G Blake, Head of Litigation, The Office of The Solicitor, DSS, Department of Health, which was uncompromising: *“I am instructed not to provide you with a list of persons who have been involved in the production of this handbook....You ask for details of the clinical trials referred to in the handbook...This information will not be provided at this stage”.*

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, as payments to people with ME/CFS were specifically targeted and widely withdrawn, even when the benefit had been awarded for life.

On 16th April 1992 a further letter to the same person with ME was sent from The Office of The Solicitor, DSS, Department of Health and was equally brusque: *“It has been made clear to you that the Secretary of State takes responsibility for the publication of the handbook and is satisfied as to the propriety of its contents. **It will not be withdrawn or modified**”.*

On 1st October 1993 Wessely wrote to Dr Mansel Aylward, CMO and 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**”.*

In May 1994 at the Eliot Slater Memorial Lecture, Wessely dismissed ME as nothing but *“a belief”* and a *“myth”* and in 1995 he again stated that ME was merely a *“belief”* (Clin & Exp Allergy: 1995;25: 503-514).

On 4th April 1995 Dr A E Furniss, a Medical Officer at the Benefits Agency Medical Service (BAMS) wrote a BAMS Advice about ME: ***“The weight of medical opinion regards this as a psychoneurotic disorder (and) the majority of these cases are somatisersRest will compound and prolong problems. Gradually increasing exercise programme would likely have a significant impact on fitness and ability within weeks...As regards treatment of a somatisation or behavioural disorder, strong encouragement of more normal behaviour is important, with avoidance of anything that rewards, acknowledges or enables continued mal-adaption...ME is a fashionable label and not pathology in its own right”.***

On 18th August 1995 he followed this up: ***“ME is a rag bag label...The DLA advisory board does not accept a physical basis is proven as regards ME”.***

On 19th October 1995 the same doctor wrote another BAMS Advice: ***“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...and such behavioural treatment would be as important if not more important than any antidepressant medication. The DLA advisory board has expressed a strong opinion as regards such labels”.***

(Subsequent handbooks for decision-makers emphasised the necessity for mental health assessment in ME/CFS, for example, in 2000 the handbook was clear: ***“A mental health assessment will almost always be appropriate. You will find it quicker and easier in the long run to approach the assessment on the basis that the mental health section will need to be completed. If you do not complete the mental health assessment you must fully explain your reasons for not doing so. The approved doctor will need to be aware that there is a developing consensus on the medical management of (ME)CFS which emphasises gradually increasing activity together with cognitive behavioural therapy. Indicators of a good prognosis (include) a management regime which concentrates on lifestyle modification”.***

In October 1996 the Joint Royal Colleges' Report (CR54) on ME/CFS was published, in which Wessely was instrumental:

- ***“The Royal Colleges have stressed that approaches to these patients should not be based on simple biomedical models”***
- ***“Some would prefer to continue to use the term ME. Patients may wish to keep (it) because only with that label are they eligible to call upon the welfare state for help”***
- ***“The term ME may mislead patients into believing they have a serious and specific pathological process”***
- ***“The possibility that abnormalities of immune function play a role in the pathogenesis of CFS has attracted considerable attention. Such abnormalities should not deflect the clinicians from the biospsychosocial***

(psychiatric) approach and should not focus attention towards a search for an 'organic' cause"

- *"Research suggests that dysfunctional illness beliefs are common in CFS patients. Such inaccurate beliefs might fuel avoidance of activity"*
- *"No investigations should be performed to confirm the diagnosis".*

In 2002, the BMJ ran a ballot asking doctors to vote on which diseases they considered to be "non-diseases" that are best left medically untreated: Wessely proposed ME. The result was that **along with ear-wax accumulation, nail-chewing and freckles, ME was voted a non-disease**, and in April 2002 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 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"*.

On 5th January 2004, Wessely wrote to The Scotsman: *"Finding anything in CFS/ME will be seized upon by some as further proof that the disorder is genuine"*, which clearly conveys his belief that it is not a "genuine" disorder.

The denigration and dismissal of people with ME did not diminish: in 2011, Dr Byron Hyde reported:

"Dr Wessely was speaking and he gave a thoroughly enjoyable lecture on M.E. and CFS. He had the hundreds of staff physicians laughing themselves silly over the invented griefs of the M.E. and CFS patients who according to Dr Wessely had no physical illness what so ever but a lot of misguided imagination...His message was very clear and very simple. If I can paraphrase him: 'M.E. and CFS are non-existent illnesses with no pathology what-so-ever. There is no reason why they all cannot return to work tomorrow'" (Hysteria and Myalgic Encephalomyelitis Byron Hyde MD 13th September 2011. The Nightingale Research Foundation).

The result of Wessely and colleagues' strident and public dismissal of ME as a valid medical entity has, from the outset, had profound and continuing repercussions on innumerable very sick people and their equally desperate families. **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 available evidence of the biomedical underpinnings of the disorder**; in 2007 NICE produced its Clinical Guideline (CG53) on CFS which totally ignored the substantive evidence-base which contradicted its content and which promoted the Wessely School dogma.

Some consequences of the Wessely School's dismissal of ME as a legitimate neurological disorder

In 1989, "InterAction", the magazine of the charity ME Action Campaign (now called Action for ME) carried the results of 1500 professionally conducted questionnaires:

Comments of doctors to ME patients:

- "Throw away your crutches – it's your head that needs them, not your legs"
- "Women of your age imagine aches and pains – are you sure you're not attention-seeking?"
- "I'm not prepared to do any tests, they cost money"
- "Shut up and sit down"
- "You are a menace to society – a pest. I wish you'd take yourself away from me"
- "You middle class women have nothing else to worry about"
- "It's one of those things you silly young women get"
- "Hypochondriac, menopausal, you have the audacity to come here and demand treatment for this self-diagnosed illness which does not exist"
- "Stop feeling sorry for yourself – I have patients with real illnesses, patients who are dying from cancer"
- "ME is a malingerer's meal ticket"
- "Your inability to walk is in your mind"
- "I'm not going to further your career of twenty years of being ill"
- "Nothing at all wrong with this woman – Put her on valium" (to GP from Consultant).

Comments of ME patients about their doctors:

- "I was told I was lazy and laughed at"
- "(he said) the illness was a load of trollop, he laughed me out of the surgery"
- "(he) laughed when I told him I could only visit him if I felt fit enough"
- "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"
- "My illness started with a sudden, severe collapse. The doctor said that it was due to 'attention seeking'"
- "(I was) told that I was a nutter"
- "(I was) told I was selfish and introverted and it was nothing but hysteria"
- "(the) doctors said to me 'if you go on like this you will be struck off the register'"
- "(the doctor) said my symptoms/signs 'didn't exist'"
- "It was suggested 'a good man' was all I needed".

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 and accused of abusing the NHS (despite the fact that she had worked for the NHS for longer than the GP).

In the 1980s and 1990s, whenever Wessely published a paper dismissing ME as a legitimate disorder, a journalist named Caroline Richmond simultaneously published a supportive piece in the widely-distributed medical trade magazines promoting his articles and from 1988 onwards she continued to vilify ME patients.

Together with Wessely, she was a founder member of the Campaign Against Health Fraud (which became known as HealthWatch), whose literature proclaimed its aims were *“to oppose...unnecessary treatment for non-existent diseases”* and the same document lists Simon Wessely as a *“leading member of the campaign”*. He is on record as regarding ME as a *“non-existent disease”*. HealthWatch has received funding from the pharmaceutical and health insurance industries, the latter persistently refusing to accept ME as a physical disorder and insisting that it is a mental disorder (mental disorders being excluded from benefit payments).

Illustrations of Miss Richmond’s disparaging comments about people with ME include:

- *“Many patients arrive in the consulting room with a firm attachment to a dramatic diagnosis”* (Pulse, 2nd April 1998)
- *“Myalgic encephalomyelitis is a new name for an old disease....hysteria was originally a disease of spinsters, whose dry wombs wandered round their bodies in search of moisture...Then, as now, ladies suffering from the vapours retired to their boudoirs...a boudoir is a lady’s sulking room...The illness behaviour of patients and the diagnostic behaviour of doctors is subject to fashion....Neurasthenia, melancholy, the vapours, hysteria, hypochondria...have lost their organic associations and imply states of personality or mind”* (BMJ 13 May 1989:298:1295-6)
- *“Whatever the patients have, it is not inflammation of the brain and spinal cord....There is no evidence to suggest that ME patients are immunocompromised and they don’t succumb to more infections than other people, although they are more likely to regard them as life events...Advice should be given to enable them to cope with their symptoms, gradually increase exercise tolerance and return to normality”* (Pulse, 14 October 1989). It is interesting that Miss Richmond was not in any way qualified to be giving advice to doctors, so could one hear Wessely speaking?
- *“Myalgic encephalomyelitis...sounds really serious and is guaranteed to impress friends and relatives of sufferers....Patients wanted to be referred to neurologists, who didn’t like seeing them...None of them seemed to find it remarkable that they are suffering from a disease called me”* (The Oldie, November 1992:26-27).

In 1991, researchers at Southampton University asked 140 local GPs to refer patients with ME/CFS to take part in a trial; only 60 bothered to reply, of which 40 made it clear that they did not believe in ME/CFS (GP Magazine, 6th April 1991).

On 20th July 1993 a GP, Dr P J Lefley of the Castle Mead Medical Centre, Hill Street, Hinckley, Leicestershire, wrote to one of his severely sick ME patients: ***"I have received nothing in any of the literature which is more than pseudo-scientific hype. It is interesting that out of the dozens of GPs and consultants whom I know personally I know of no-one who believes in ME as a syndrome...but (I) feel that like...numerous other medical fashions, ME will no doubt in a few years go the same way"***.

As a consequence of that letter, the Medical Advisor to the ME Association, Dr Charles Shepherd, wrote politely to Dr Lefley's senior partner Dr R A Yardley; he received the following reply: ***"I have to say that your conviction that a specific condition of 'ME' exists has led you to adopt the arrogant view which, unfortunately, one sees from time to time in the medical world, where a particular lobby lays claim to the high moral ground with evangelical fervour....I can assure you that in this practice there is no requirement for partners to subscribe to stereotyped and uniform viewpoints on medical matters....I think this is the straight-jacket in which you would like to see constrained all those with views which differ from your own....My own view, which I may say I feel no obligation to justify, is that I remain unconvinced of the existence of a separate disease category irrespective of the views of a former Junior Minister of Health or the success of the 'ME' lobby in achieving its recognition as such by the WHOFortunately, there are an increasing number of efficient antidepressants"***.

On 25th July 1993 a consultant neurologist at Newcastle General Hospital, Dr Peter Hudgson, spoke on national television (Frontline: Channel 4) about people with ME who presumably were hoping to receive help from him:

- *"The one, absolutely clear cut clinical feature of the disease is the personality profile of the people who develop it ----many of them have profound psycho-sexual difficulties"*
- *"I do not believe for one moment that (that) reflects organic dysfunction of any aspect of the nervous system: I think it is bound to be 'in the mind' "*
- *"I don't know what ME is, but what I'm absolutely certain is that it is NOT an organic illness"*
- *"Something like four-fifths, if not more, of the people I deal with are women in early middle age who have unsatisfactory marriages"*.

How could it be that an in-post NHS consultant like Dr Hudgson could be so proudly ignorant of all the valid peer-reviewed literature on ME and how could it be that doctors like him could be permitted, through ignorance and arrogance, to dispense such unnecessary suffering to his unfortunate ME patients?

His behaviour 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: what, then, is the purpose of having a formal WHO classification system -- the use of which is mandatory throughout England -- if it can be disregarded with impunity?

In April 1994, GP magazine carried an article entitled "GPs despise the ME generation" and the article stated that nationwide, only 10 to 30% of GPs believe that ME is a real disease.

In Doctor magazine on 12th January 1995 in the section entitled "Bluffer's Guide", Dr Douglas Carnall wrote: *"Yesteryear's neurasthenias: Investigations have their own hazards – it is possible to reinforce the patient's somatising behaviour. This has all kinds of risks, especially that the patient will run off to join a self-help group, membership of which is itself an adverse prognostic factor. Modern bluffers prefer the term chronic fatigue syndrome. If they 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"*.

It was in September 1995 that Dr Charles Shepherd wrote in "Perspectives": *"The ME Association now has evidence that the fashionable theory of abnormal illness behaviour linked to somatisation is being used by a number of agencies as a convenient excuse for turning down financial support benefits or for putting pressure on vulnerable patients to undergo highly speculative 'rehabilitation' programmes"*.

On 5th May 1996, in the section on America (Foreign News), the Sunday Express published a piece by Jonathan Miller, who stated: *"the absolutely most fashionable disease here is Chronic Fatigue Syndrome – CFS for the initiated"*. The headline was "Chronic Bandwagon Disease".

On 18th February 1999, Adrian Furnham, Professor of Psychology at University College, London, wrote an article in the Daily Telegraph in which **he suggested that there was "a wealth of conditions that can be fashionable excuses for lack of success" in which he included ME/CFS.**

On 6th April 2000, commenting on a paper in the Journal of the Royal Society of Medicine about children with ME/CFS, Dr Keith Hopcroft, a GP in Basildon, Essex, wrote in Update, page 522: *"In more than three-quarters of a group of children with chronic fatigue syndrome, the illness began at the start of the school year. An adult version of this – recurrent brief chronic fatigue—affects me every Monday morning"*.

In 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”***.

The tradition of shameful diatribes and invective against ME sufferers still abounds. Doctors seem to vie amongst themselves to produce jibes at ME sufferers’ expense. Why do they not jibe with equal disdain and offence at those with other classified chronic conditions such as lupus or multiple sclerosis?

Nothing has changed in practice: not only are people with ME still being refused blue badges for disabled parking but they are being refused State and permanent health insurance benefits unless they have undergone a “rehabilitation” programme of CBT and GET, even though, when the raw data from the much-acclaimed PACE Trial was independently re-analysed, those very interventions were clearly shown to be ineffective and even though evidence from 5,000 patients shows their potential for harm, as documented by various ME/CFS charities.

It is unacceptable that vulnerable and desperate patients should still be forced to justify their illness because of influential doctors who so egregiously ignore the biomedical evidence and who so persistently dismiss the reality and severity of ME/CFS and assert that it is a behavioural disorder.

The fact that, on the basis of Wessely's personal view, including his belief that in ME/CFS, there is no need to know the cause before initiating treatment (“New research ideas in Chronic Fatigue”: RSM Press 2000), so many people have been refused all support, both medical and financial, makes it imperative to distinguish the correct aetiology of ME, but above all, to distinguish genuine ME from chronic fatigue. The voluminous works of Wessely are proof that this is not happening, despite the WHO formal classification.

Concern about the situation expressed in 2005 by the UK’s Chief Medical Officer

On 22nd September 2005 The Royal Commission on Environmental Pollution (RCEP) published its report on crop spraying and health. As noted by Alison Craig, project co-ordinator of Pesticide Action Network, in its response the Advisory Committee on Pesticides (ACP) asserted that there was no need for precautionary measures to reduce public exposure to pesticides because the risk that these toxins cause illnesses such as ME/CFS are “minor” and it went on to imply that ME and CFS should be regarded primarily as psychiatric disorders.

The RCEP, however, advocated that sophisticated techniques should be used to investigate the physical basis of ME/CFS and in his oral evidence to the RCEP, the UK’s Chief Medical Officer, Sir Liam Donaldson was clear:

“I am always very concerned to hear about patients being unhappy, dissatisfied and frustrated in having their symptoms denied. That was the case and probably still is the case...with CFSME, as you know. Next to MMR, in the six years that I have

been Chief Medical Officer, I have received more letters on CFSME than any other subject, and I have read them all....At conferences...often people come up to me who have a history of the kind that you have described and sometimes they have been professional colleagues, retired doctors or even doctors who have been forced to retire because of their problem. So I do not for a minute think that this group of people are psychologically disturbed. I am very sympathetic and if you are telling me that there are people across the board who are being obstructed or denied access to proper treatment or proper assessment, then I think that we would like to try and do something about that”.

Despite such words from the CMO, nothing has been done. That patients with ME/CFS have been obstructed and denied proper treatment and/or proper assessment and that -- twelve years after the CMO's promise to the RCEP -- the same situation prevails is beyond dispute.

There can be no doubt that the Wessely School have substantial conflicts of interest as they are involved with and work for the permanent health insurance industry, whose aim is well-known to be not to pay out on a policy if they can possibly avoid doing so (“*UNUM stands to lose millions if we do not move quickly to address this increasing problem*”: UNUM's CFS Management Plan; Dr Carolyn Jackson, 4th April 1995). Their aim is to ensure that people with ME/CFS are removed from disability payment: UNUM's CFS Management Plan clearly states: “*Diagnosis: Neurosis with a new banner*”; “*Attending physicians (must) work with UNUM rehabilitation services in an effort to return the patient/claimant back to maximum functionality with or without symptoms*”.

Tactics of Denial

It is salutary to examine the similarities in the tactics and methods used by “deniers” and “revisionists” of whatever discipline. Deniers take liberties with facts, and what is omitted is often more significant than what is included. A falsifier uses many different means but all these techniques have the same effect --- falsification of the truth and denial of reality.

Other tactics include the following:

- deniers aggressively challenge others' views, claiming that others have no proof, and challenge them to validate the established facts and to produce proof to standards specified by the deniers themselves but to which they do not require their own “evidence” to subscribe
- deniers claim that “pressure groups” are active against them and are attacking both them and the truth
- deniers claim that there are “orchestrated campaigns” against them
- deniers agree, prepare and organise as a matter of policy a systematic strategy amongst themselves

- deniers show a readiness to jump to conclusions on every occasion
- deniers endeavour to rationalise their own ideology and for their own ideological reasons they persistently and deliberately misrepresent and manipulate the established evidence
- deniers fly in the face of the available evidence
- deniers engage in “complete deniability” which has nothing to do with genuine scholarly research.

Tactics of denial used in relation to ME/CFS as a physical disorder

Revisionism and denial of established evidence in medicine is nowhere more apparent than in the case of ME/CFS, where the choice of Government medical advisers is a matter of great economic impact.

To policy-makers and commissioning officers in a cash-strapped NHS, the advantages of denial must seem attractive. The last thing needed is a chronic disease which affects hundreds of thousands of people, so accepting advice which promotes the view that the condition in question is neither new nor particularly disabling (and that the disorder is largely self-perpetuated) makes instant economic sense, especially if the advice also recommends that granting state benefits to those affected would be not only inappropriate but counter-productive.

In ME/CFS, denial is directed at undermining the experience and expertise of doctors who hold different views from Wessely School psychiatrists.

In medicine, denial ought to be very rare due to the peer-review system but in the case of ME/CFS many peer-reviewers and editors of journals appear to share the same views as the deniers, so that articles and research papers which show a lack of objectivity, which misrepresent the existing literature and which make unsubstantiated claims abound, with the consequence that readers are misled.

In the UK ME/CFS literature (mostly as a result of the assiduous activities of psychiatrists of the Wessely School), there is evidence of a systematic attempt to deny the severity of the symptoms, the role of external causes and the nature of the illness. Such is the profusion of articles, reports and research papers produced by this group that there is now a widespread belief that ME/CFS is not a disorder which requires money to be spent on specialist tests or on expensive virological, immunological, vascular or gene research, let alone on long-term sickness benefits.

It may be informative to compare the tactics of denial listed above with a selection of methods and tactics used by those engaged in denial relating to ME/CFS:

- Deniers consistently ignore existing evidence which contradicts their own preferred theories: they disregard evidence, they misconstrue findings, they distort figures and they speculate

- Deniers apply a double standard to the evidence --- they support their own claims with a select choice of studies, with flawed research (ie. with research which has been shown to be flawed in the medical literature), and with a mass of generalisations, whilst insisting that the opposition provides irrefutable proof. These authors down-play and attempt to overlook inconsistencies in their own research. (Indeed, on one notable occasion, when challenged, Simon Wessely actually blamed his peer-reviewers for allowing his own indisputable “mistake” to evade rectification)
- Deniers challenge the expertise of those with whom they disagree, implying that their own claims are based on balanced scientific scholarship whilst those of others are based only on myth
- Deniers portray sufferers as victimisers, claiming that it is *patients* who are guilty of targeting *psychiatrists*; the psychiatrists then portray themselves as the vulnerable and wronged group. There is reference to “vicious campaigns” organised by “pressure groups” and to unreasoned hostility on the part of the patients
- Deniers minimise or trivialise the distress and suffering of those with ME/CFS, alleging that patients exaggerate their symptoms and suffering
- Deniers promote the view that patients have only themselves to blame, and that the problem is therefore not external but internal
- Deniers often include a totally reasonable and uncontroversial supposition (for instance, that decisions must be based upon the best evidence), which gives the impression that their other arguments must be equally reasonable and valid
- Deniers often suggest or imply that patients are motivated by financial or secondary gain (even though there is not a shred of evidence to support such a claim), and that their claims for state benefits are unjustified
- Any negative characteristics of a minority of patients are typically generalised and ascribed to all ME/CFS patients, without any supportive evidence
- Deniers suggest or imply that patients have formidable powers, for instance that they are able to influence certain institutions; that they get the media on their side and even that they have managed to influence the World Health Organisation. It is also alleged that patients use such tactics to misrepresent the situation to lead others astray
- Deniers even re-write medical history and alter it so that it appears to support their own claims (this is certainly demonstrable in the psychiatrists’ interpretation of the early ME literature)

- Deniers may attempt to rename or reclassify the condition, for example claiming it as a modern form of an old (psychiatric) illness
- Deniers make inappropriate comparisons between syndromes, suggesting that they are all simply the same (psychiatric) syndrome, ignoring or downplaying any specific features which are present.

SECTION 3

Illustrations of the harm resulting from the implementation of the Wessely School's ideology

There are about 9,000 published academic papers contradicting the Wessely School's beliefs about ME/CFS.

The following quotations come from the grey literature but they accurately portray the reality for people struggling to survive the life-wrecking disorder that is ME/CFS.

1997

*“The current trendy line to psychologise disease, to implicitly blame sufferers for not being ‘positive’ enough, to accuse them of causing their own misfortunes, has gone far enough. Obviously, it is desirable to be positive, but **those who continue to malign and demoralise already vulnerable people are guilty of unforgivable ignorance and arrogance.** No doubt they think it terribly clever and far sighted and intellectually probing of them to blame everything on the psyche, but it isn’t; it is actually now a facile, tired, clichéd out-tray, into which they can toss anything too complex or challenging for them” (Joanna Ewing, ME Association Perspectives, September 1997:16).*

2001

*“ME is a severe, organic, utterly debilitating chronically relapsing illness which affects men, women and children from all walks of life. **Research has shown that the quality of life is particularly and uniquely disrupted and that only in terminally ill stroke and cancer patients is the sickness impact profile (SIP) greater than in this illness....There are now many biomarkers which support multi-system involvement, particularly the immune, endocrine and cardiovascular systems, as well as the neurological system...(The term) CFS means different things to different people and has several case definitions, all of which specifically exclude the neurological features seen in ME, focusing instead on a central complaint of fatigue. Yet ‘fatigue’ is a symptom, not an illness. To elevate a symptom to the status of a disease is absurd...(but) because ‘fatigue’ is a prominent feature of psychiatric illness, modern psychiatry has sought to claim ‘CFS’ as its own and to eradicate ME from neurological textbooks, replacing it with the all-embracing term CFS....The misguided obsession by some psychiatrists with ‘fatigue’ has led to the bizarre argument as to whether the fatigue in ME is...real or imaginary...It may be ‘central fatigue’ which physiologists now recognise as an important mechanism in the preservation of damaged muscles from further exercise. This central ...fatigue does not equate with a heightened perception of normal bodily sensations leading to such demeaning terms as ‘dysfunctional illness beliefs and ‘aberrant illness behaviour’. These latter terms, favoured by psychiatrists, underlie their own obsession with CFS and a form of***

*psychotherapy known as CBT, the aim of which is to change the way patients **think about their illness***” (Dr Vance Spence, formerly Senior Research Fellow, Vascular and Inflammatory Diseases Research Unit, Institute for Cardiovascular Research, Medical School, University of Dundee; Submission to the Scottish Cross Party Group on ME, 6th September 2001).

2001

*“A member of the Edinburgh ME Self-Help group found out yesterday that the almost negligible services for ME sufferers in Edinburgh are to be slashed to almost nothing....ME has always clearly been an inconvenience to the Edinburgh medical establishment (and the) ME clinic will close....Patients in Edinburgh, the Lothians and Fife are therefore going to lose nearly all of the very small service they had....We are encouraged to write to the Consultant who has administrative responsibility...to ask why he took this decision....I have just learned that...Scotland’s Health Minister is a guest on tomorrow’s...Radio Scotland (and) **the Minister deserves to be asked if she stands by this apparent act of aggression against ill people**....My own, ill, son has in three years been totally unable to get any diagnosis...ME – at least in children – truly does not exist. There is a big blind spot here, which just seems to have got a lot bigger”* (Nick Stroud: by email: 13th September 2001).

2002

“At the end of the day it is the patient who will suffer through misrepresentation, mistreatment and abuse, not only in day to day clinical practice but also through the social security system and attitudes in society as a whole” (Stephen Ralph, DCR (R) Retired: MEActionUK: 16th July 2003)

2002

“I am a physician who has fallen victim to not only a disease which resembles an agonising living death but also to a medical system that has minimised and ignored a devastating medical condition. I, too, am embarrassed and ashamed to say I have (ME)CFS because the horror of dealing with the medical realities of this illness is only surpassed by the horror of dealing with an uninformed physician and general population. I believe that by calling this derangement of what is most likely numerous biologic systems ‘fatigue’ only enables the stigma, trivialisation and lack of adequate delegation of research money to not only be supported, but – what is even more appalling – justified” (Un-named Physician: Co-Cure ACT: 3rd October 2002).

2002

“ ‘Chronic Fatigue Syndrome is a way of expressing a sense of ill being that has been medicalised and transformed by a small group of activists, both physicians and patients, into a proposal for a new disease’. Thus does psychiatrist Peter Manu, who is reported to have been hired by insurance companies to intercept disability payments, offer his trademark demeaning attributions of ME/CFS in Kim Snyder’s new film ‘I Remember Me’ ” (Maryann Spurgin PhD: Co-Cure ACT:13th October 2002).

2002

In his Address to the NE MEG (Clwyd) Conference on 13th September 2002, immunologist Professor Anthony Pinching acknowledged that unfortunately, the rate of learning about ME/CFS has been much slower than in HIV. He spoke about the Chief Medical Officer’s 2002 Report, saying that the point had been made that ME/CFS is relatively widespread, is profound and often prolonged, with major impact on sufferers and on all their circumstances: ***“There has existed great misunderstanding about the condition and the patient’s plight in the past, even from professionals (and) this situation (has existed) over many years. ME/CFS is complex and devastating in its many personal and social consequences”***. He said this was not about ‘special pleading’ but about simply bringing ME/CFS up to the level that already exists in healthcare elsewhere and which is provided for in other medical conditions. He said: ***“It really isn’t a question of whether a practitioner ‘believes’ in ME/CFS or not – they don’t have a choice about that”***. He went on to say: ***“We are not capturing all the evidence, the data or observation in a systematic and collective way”***, which could and should be done. He confirmed that ***“ME/CFS is complex. The sense that many clinicians here have is that they do not have the knowledge or the skill to treat the condition, or that the patient knows more about ME/CFS than they do, and so this is often a problem”***. He drew attention to ***“the difficulty with ‘disability’...and all the issues that flow from that, (including) the benefits system, the insurance companies and so on are all contingent on the ME/CFS patient. And lastly here perhaps we must raise the question of the stigma associated with ME/CFS and false or even denigrating beliefs about the problem that some people, or aspects of the media, still entertain”*** (Karl Krysko, NWW MEG [Chair], Welsh Association of ME & CFS Support [WAMES]: 31st October 2002).

2002

“After two decades the psychiatrists have tried their utmost to psychologise ME. They’ve systematically altered the case definition, the name, the symptoms and anything they possibly can to make ME theirs. They’ve even tried to delete it from the World Health Organisation ICD10 index where it lists CFS to Neurological Diseases (G93.3)....They have failed to prove their claims, taking millions of pounds and dollars of funding with them along the way. There are neurological issues to do with brain damage, neurochemical abnormalities including choline, creatine and glycine. We already know that there are cardiac problems...and that some people with ME have abnormally low blood volume (and) often have gut dysfunction...(and) liver problems, in fact, multi-system problems

that add up to severe degrees of pain, suffering and disability” (Stephen Ralph DCR (R) Retired: MEAction UK: 3rd December 2002).

2002

*“The Belfast Telegraph ran a good review of New York doctor Derek Enlander’s CFS Handbook. Enlander warns that **there are powerful vested interests at work in making ME appear as a ‘joke disease’.** Employers, government organisations and insurers may all have a part to play in this, as well as insensitive media” (ME Essential: Winter 2002:19).*

2003

“The LHB (Local Health Board in Wales) will only fund treatment for Chronic Fatigue Syndrome and Myalgic Encephalomyelitis where the prime focus is either Cognitive Behavioural Therapy and/or Graduated Exercise Therapy” (Christine Llewellyn: MEAction UK: 29th June 2003).

2003

*“There is abundant scientific evidence...that explains patients’ symptoms. This includes well-documented central nervous system, immune, endocrine, cardiovascular and autonomic nervous system abnormalities, which indicate that it is biologically, not psychologically, determined....**Many patients are unable to obtain basic medical care or services and benefits routinely accorded other sick patients....There has been significant prejudice, neglect and discrimination by the medical profession, the community and even family members. Many patients are still subjected to uninformed, demeaning attitudes and comments from those who do not ‘believe’ in the illness or assume that patients could ‘think and exercise themselves well’.** This denigration of the illness greatly contributes to abandonment, isolation, despair and, too often, suicide” (Jill McLaughlin, Co-Cure ACT: 25th August 2003). In the same Co-Cure post, Jan van Roijen observed about this comment: **“This crying abuse is particularly produced by the misinformation and denial of the scientific research and the biomarkers of the organic pathoaetiology of this unbearable disease by the adherents of the psychiatric Wessely School”.***

2003

“In the case of ME/CFS, there are powers at work forcing ME/CFS to be formally recognised as a mental health disorder, thus making psychiatrists the primary care specialists for anyone and everyone with ME/CFS. And because this process is well advanced, there are also forces at work preventing people with ME/CFS from having clinical investigations that will almost certainly highlight the very specific neurological abnormalities in people with G93.3 ME/CFS ICD-

10 that psychiatrists are trying to deny exist....As we know, Professor Wessely has been the key individual trying for years to effectively reclassify ME/CFS into a mental health disorder known as a functional somatic syndrome....There is a whole wealth of research information out here in the real world outlining so many neurological, immunological, cardiological, endocrinological and other abnormalities totally contradicting the current forced agenda of classifying and treating ME/CFS as a mental health disorder, yet it is being ignored” (Stephen Ralph DCR(R) Retired: MEAction UK: 12 September 2003).

2003

Replying to a derogatory item in the BMJ by general practitioner Michael Loudon (30th November 2003), one respondent was blunt: ***“As someone whose life has been totally destroyed by ME...I take great exception to Michael Loudon’s smug assertion that that this is a psychological illness to which some people are vulnerable because of ‘psychiatric co-morbidity’ and ‘personality construction’...About 15 years ago a small clique of undemocratic, unaccountable, self-serving psychiatrists managed to monopolise most of the research funding in this field and it’s been downhill ever since. One of their first decisions was to change the name of the illness from ME to CFS. This breathtakingly arrogant decision was taken without any consultation with patients whatsoever”*** (N Portman, Tunbridge Wells, 3rd December 2003).

2004

“There are still many physicians, healthcare providers and healthcare facilities that do not regard (ME/CFS) as a valid medical condition and provide inadequate care as a result...CBT and GET are being touted as the treatment interventions of choice for (ME/CFS) when they are of limited value to some, of no value to most, and harmful to many” (Nancy Hall, Co-Cure ACT: 16th January 2004).

2004

An item in the Derry Journal (Northern Ireland) entitled “The ME Scandal” quoted Dr Vance Spence, formerly Senior Research Fellow, Vascular and Inflammatory Diseases Research Unit, Institute for Cardiovascular Research, Medical School, University of Dundee, who has published many papers on the vascular dysfunction demonstrated in ME/CFS: ***“I can think of no other illness where such a powerful schism exists between those who suffer from it and those whose responsibility is to care for them. How can it be that an illness that affects between 100,000 and 200,000 persons of all ages in the UK...is no longer referred to in medical textbooks, is not cited in medical research indexing systems and rarely features in the syllabus of undergraduate education in medical schools? Why have the experiences of these patients been largely ignored, their testimonies...undervalued, even ridiculed, and their requests for assistance met often with prejudice and disbelief?”*** (Co-Cure RES ACT:25th May 2004)

2004

“The following is an article I wrote in 1997. Seven years later so little has changed. It just goes to show how profoundly the rhetoric has permeated the very foundation of the CFS/ME arena.

“While people debate and speculate about...CFS/ME, lives are being destroyed by it....Speculation... is not science. Throwing forth theories of psychiatric causations of CFS/ME just because there isn’t enough understanding of the physiology and aetiology of CFS/ME isn’t science. Science, hard science, is objective...Psychiatric research is observational and highly interpretive, but it lacks the concrete evidence of biologic research. Because psychiatric research must rely singularly upon subjective observation and theory...it can become tainted (and) can be driven by its original theories instead of more concrete evidence....Why is anyone listening to self-proclaimed experts who have direct connections with corporate entities that only wish to protect their financial assets? Why must people with CFS/ME still be forced to jump through hoops of fire to prove they are disabled?” (John Herd, Co-Cure ACT: 1st August 2004).

2004

“To imply that studying ‘fatiguing illnesses’ is to be studying ME/CFS is as appropriate as saying that studying elevated body temperature or headache is to be studying Severe Acute Respiratory Syndrome... Fatigue is not a causative agent of ...ME/CFS. Inferring an overlap of ‘fatiguing illnesses’ and ME/CFS is to lead science away from finding the aetiology of ME/CFS...and finding effective treatments” (John Herd, Co-Cure RES: 26th September 2004).

2004

“A typical quote from one physician (at the September 2004 CFSAC meeting): ‘CFS is a lay diagnosis. I will not legitimise an illness that is not backed up by fact. CFS is not a fact’ ” (Rita Sanderson; reported on Co-Cure 6th July 2005)

2004

“More and more doctors have become entrenched in an ‘all in the head’ bias about ME/CFS that is not founded upon evidentiary science. Instead of welcoming advancements of science, their minds have become ever more closed to objective laboratory findings that conflict with their belief systems....Doctors who are uninformed about the illness and those firmly entrenched in flawed ideologic bias may not even bother to read new research articlesIn turn, many patients see no improvement in accessibility to adequate clinical care....Proponents of the idea that ME/CFS is a psychosocial phenomenon have been getting more and more of their articles in the medical journals. They hold a powerful and influential position in the World Health Organisation and in many influential

government/medical committees....We must find ways to remove ideology and speculation from the equation” (John Herd, Co-Cure ACT: 19th October 2004).

2004

“We know that ‘CFS’ is not viewed as a legitimate disease by most physicians and medical institutions, resulting in the universal experience of ME/CFS patients receiving inattentive and poor medical care once the name ‘CFS’ is spoken or appears in a medical record...Even aware GPs do not recognise the gravity and truly disabling nature of this disease” (Steven Du Pre, Co-Cure ACT: 29th September 2004).

2004

“Too often, we have seen ‘multidisciplinary’ and ‘integrated approach’ twisted to mean ‘psychiatric’ and ‘behavioural’. We have seen ‘centres of excellence’ turned into generalised ‘fatigue’ centres. We’ve seen research funding diverted towards studies of perceptions and beliefs. We’ve seen networks of collaborators taken over by psychiatrists. We’ve seen... research workshops and physician training sessions all turned into excuses to psychologise our disease. And there is nothing we fear more than watching all of that happen again” (Elsie Owings, Co-Cure ACT: 26th October 2004).

2004

“According to a recent report by Sheffield Hallam University, (ME)CFS costs the UK a staggering £3.5 billion a year in benefit payments, lost earnings and healthcare....Sufferers are frequently left bed-or housebound, unable to work and in chronic pain, sometimes for decades. Indeed, perhaps the horrors of (ME)CFS are not more widely known because the people who suffer are, by the very nature of their condition, hidden away....Clearly some medical advice doesn’t help – Alison Watson’s sister was told by her GP to join the gym, as ‘you don’t have to have ME if you don’t want it’. Months later she collapsed, was hospitalised and has remained bedbound since” (Mind the hidden illness; Ed Halliwell: The Independent on Sunday (Review): 14th November 2004).

2004

“...‘Theories that diseases (illnesses) are caused by mental states...are always an index of how much is not understood about the physical terrain of a disease’. Susan Sontag understood illness” (Kate Duprey, Co-Cure NOT: 29th December 2004)

2005

“The disgrace of taking a seriously ill group of people and constructing psychological theories about why they are ill was bad enough back when the Royal Free was closed, but it is still going on in the face of significant medical research proving it irrelevant” (Hayley Klinger; 25% ME Group; Co-Cure NOT ACT: 25th July 2005).

2005

“The ME Association (is) fully behind the view that psychiatrists of the ‘Wessely School’ should take note of present developments and re-think their obviously outdated and potentially damaging approach to those with ME/CFS” (Christine Llewellyn, The ME Association, Co-Cure ACT: 18th August 2005).

2005

“Over the years, and contrary to all I once believed, one glaring fact has emerged: a career in medicine and in particular psychiatry, offers protection to the incompetent and to those with sadistic and criminal tendencies. People of this ilk misuse their power to denigrate the intelligence and integrity of others; to deliberately cause harm and to deny ill people the essential assistance they need to survive” (Gurli Bagnall: Before the Light Dies. October 2005).

2006

“There are plenty of hospital doctors and GPs who think this is some sort of malingering, but in my experience people who are out to gain benefit by feigning ill health are actually very rare in the context of (ME)CFS... For the vast majority of people I see, this is a devastating state of affairs. They’re often people with good jobs, who are suddenly unable to deliver that level of work and lose their employment, suffering a catastrophic decline in their personal affairs. One of the things that makes me very angry is that doctors tend to dismiss things they can’t explain. I think that’s a serious error....It’s the duty of doctors to help (ME)CFS patients, not to just dismiss them as time wasters....Accessing benefits is one of the things that causes most aggravation....Patients have actually been told their claims have been rejected because they haven’t been seen by a consultant....So many patients are out there with their chronic disability without support or guidance as the GP doesn’t feel there’s much they can do” (Interview with Dr Gavin Spickett, Consultant Immunologist, Royal Victoria Infirmary, Newcastle; InterAction 55, March 2006:16-19).

2006

“Three quarters of ME sufferers have lost their jobs because of their illness, costing the nation £6.4 billion a year, according to new research. About 55,000 people in Britain are so severely affected by myalgic encephalomyelitis...that they are bed-bound or house-bound....Published as part of an awareness campaign by

Action for ME, it provides the most detailed analysis of the illness ever carried out”
(Joanna Bale, The Times 8th May 2006).

2006

“The Department of Health’s commitment to advancing research into ME has, so far, come to nothing. Dr Jonathan Kerr (from) St George’s Hospital, University of London, says: ‘It seems extraordinary and very sad that there is no Government support for biomedical studies of ME. We have applied for funding from the MRC and been turned down’....Trish Taylor, chairman of Action for ME...says: ‘People are essentially being left to cope on their own. This must be the only condition where the more seriously you are affected, the less care you receive....ME is much more than feeling a ‘bit tired’: it devastates lives, robs people of their ability to work and destroys relationships’”

(Copyright of Telegraph Group Ltd 2006; filed 15th May 2006).

2006

Given the long-time involvement of so many people involved in the UK PACE Trial (especially the Principal Investigators) with the permanent health insurance industry and with Government agencies whose intention is known to be to target people with ME/CFS in order to remove them from benefits, there was legitimate concern that such conflicts of interest would direct the outcome of the PACE Trial. The Gibson Report of November 2006 (Inquiry into the Status of CFS/ME and Research into Causes and Treatment) expressed concern about these competing financial interests at page 31, section 6.3:

“At present, ME/CFS is defined as a psychosocial illness by the medical insurance companies. We recognise that if ME/CFS remains defined as psychosocial then it would be in the financial interests of the medical insurance companies.

“There have been numerous cases where advisors to the DWP have also had consultancy roles in medical insurance companies, particularly the company UNUMProvident.

“Given the vested interest private medical insurance companies have in ensuring CFS/ME remains classified as psychosocial illness, there is blatant conflict of interest here.

“This Group finds this to be an area for serious concern and recommends a full investigation by the appropriate standard body”
(http://erythos.com/gibsonenquiry/Docs/ME_Inquiry_Report.pdf).

Those parliamentarians who expressed this concern included the former Chairman of a House of Commons Science and Technology Select Committee and former Dean of Biology; a member of the Home Affairs Select Committee; a Minister of State for the Environment; a former President of the Royal College of Physicians;

the Deputy Speaker of the House of Lords, and a former Health Minister and Honorary Fellow of the Royal College of Physicians.

Over ten years later, nothing whatever has been instituted to remedy this unacceptable situation.

2007

“Question: My daughter, 33, has been diagnosed with ME but the doctors seem to be treating her as if the illness isn’t physical but all in her mind. She’s not getting better.

“Answer: There has been fierce argument about the nature of this debilitating condition for several decades. Some psychiatrists claim it’s a psychosomatic condition where patients imagine they have an illness, but increasing numbers of scientists worldwide state that it’s a genuine physical (or organic) condition....Sadly the £11 million NHS budget has, to date, gone into centres where ME is treated as a psychiatric condition” (Healthnotes. Sarah Stacey. You. 14th January 2007).

2007

*“We, the undersigned, petition the Prime Minister to get the Health Service and medical profession to accept the WHO classification of ME/CFS as an organic neurological disorder and not as a psychosocial syndrome...**The latest DWP Guidelines...are still directing the Health Service to treat ME sufferers with GET and CBT (a tool used for mental illness) despite mounting evidence from a vast amount of research proving that ME is an organic not a psychosomatic disease and that the treatments forced onto those affected do in fact cause more harm than good and can worsen the condition of patients....Patients should not be forced into becoming psychiatric cases or lose their benefits”** (Co-Cure ACT: NOT: UK Government website online petition: 26th January 2007).*

2007

*“The record of the medical profession in this area is not a terribly good one. **There has been a long 30-year period of semi-denial of its reality....Medicine...allowed it to be taken over by the psychiatrists....In many places it’s still an unofficial disease. Medical students aren’t taught about it and medical textbooks include it in the psychiatry section....It’s a life-threatening condition at its worst. If it had been researched better for the last 30 years we might have had a cure by now....Within the medical profession there is controversy about whether it exists....A lot of doctors prefer to call it Chronic Fatigue Syndrome – often those who don’t quite believe in it as an organic syndrome”** (Dr Nigel Speight, Consultant Paediatrician, speaking on Radio Ulster: 20th February 2007).*

2007

“For some time now we have been aware that the reform of the mental health act could affect members of the ME community should it be deemed that people with ME have a mental health disorder. The new act states that people could in theory be forced to undergo treatment if it was thought that a refusal of treatment was unacceptable to those prescribing such treatments” (MEActionUK 23rd February 2007).

2007

“It is crystal clear that those who expound the Wessely School’s ‘CFS/ME’ psychosocial model have worked very very hard to gain the position they hold currently. It is also crystal clear that they wish to cling tightly to it and not even consider other ideas or options....It’s unclear how they have managed to continue this fantasy for so long” (LK Woodruff: Help ME Circle: 1st March 2007).

2007

“Wessely and his followers feel that clean distinctions and subgroups for emerging illnesses are actually counterproductive to effective scientific methodology. In a paper published in 1998, Wessely urged researchers to avoid classifying patients according to symptoms, claiming he and his associates in the UK have discovered novel proof that classifying clinically differing patients is ‘outdated’ and ‘misguided’. He strongly feels that treating and researching patients...by clinical differences can lead to a ‘risk of over-investigation’ and increase the ‘potential for iatrogenic harm’” (Craig Maupin: Co-Cure 11th March 2007).

2007

“I was diagnosed 30 years ago with acute onset myalgic encephalomyelitis by a tenured Harvard MD...I have suffered and still suffer from the confusion that the creation of CFS causes my medical providers....Part of the consequences of this is that all the research into CFS has been, as far as ME patients are concerned, a tragic waste of our time and our money. The data are invalid due to the lack of specificity of the inclusion criteria” (Charles Stafford: Co-Cure MED ACT: 28th March 2007).

2007

“Simon Lawrence pulls no punches when he says ‘Public money is being wasted on research that will be of no help to ME patients. It is about time serious money

was spent on research into the pathology, not the psychology, of this devastating illness and high time that psychiatrists retreated to their own field of mental health and left ME well alone’” (Hayley Klinger: 25% ME Group: Help ME Circle: 29th May 2007)

2007

“ ‘You can’t go after a health care system under the control of the insurance companies and pharmaceutical corporations. That system is immune’ warns Noam Chomsky in his latest book (Interventions; Hamish Hamilton, 2007).....The consequences for people with ME are dire indeed....The financial system underpinning the new market model of healthcare is Payment by Results (PbR); no other country in the world is moving faster than the UK to implement it. In April 2006 PbR was rolled out to cover over 80% of hospital activity, placing them in competition with each other....Clinical decision-making will increasingly come under the control of commercial managers and shareholders...The great bane of the ME sufferer’s life, the medical insurance industry which since the mid 1980s has lobbied hard, with great success, to have ME classified as a psychiatric behavioural disturbance in order to avoid massive payouts, makes no secret of its intention to take over the UK health market....All of this is taking place against a wider picture of increasing social control and state repression, as ‘the new rulers of the world’ (Pilger 2003), the corporations, aided and abetted by media and government, take over and implement health and social policies consistent with their own strategic and economic interests (Noam Chomsky, Failed States, 2003)....What can be done?...It means incredible courage and determination and above all, a complete refusal to compromise on the truth that ME is a physical, neurological disease” (Greg Crowhurst: <http://carersfight.blogspot.in/2017/02/be-trouble-maker.html> 13th August 2007).

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:

- 1. ME patients are given a psychiatric label.*
- 2. As a result, they are regarded as irrational and their opinions are not taken seriously.*
- 3. 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.*
- 4. By silencing patients, their opposition is neutered and psychiatric dominance in ME continues unchallenged. (Horace Reid: LocalME: 13th August 2007).*

2007

“From Sickness Impact Assessments, Professor Komaroff (Harvard University) states that ME is rated as being more severely disabling than type 2 diabetes, congestive heart failure and MS. The degree of impairment is more extreme than untreated hypothyroidism, end-stage renal disease and heart disease, with only terminally ill cancer and stroke patients being more impaired. Low support from medical professionals is often the case, with many viewing ME as a psychosomatic illness requiring a change in the patients’ ‘attitude’ to allow recovery....Recovery to pre-illness level of functioning is rare” (Joan Crawford: MEActionUK: 2nd November 2007).

2007

“The ‘elephant in the room’ – ever-present but rarely alluded to in the media or the mainstream scientific literature – concerns the overarching influence of the psychosocial model of the illness, which emphasises ‘beliefs, coping styles and behaviours’....It colours the perception of the illness across the board – from official reports such as the 2007 NICE Guideline, to policy of government agencies such as the Department for Work and Pensions and NHS Plus. But it also impacts on research....In ME/CFS, psychosocial investigation seems to have hoovered up attention and funding at the expense of hard-core biomedical investigation. Take the Medical Research Council for example: the vast bulk of its £3 million ME/CFS grant-spend since 2002 has gone towards research into psychological management strategies, while around 30 other applications, some from established biomedical research groups with a track record in the field have been rejected....Moving basic scientific and clinical research centre-stage, into the spotlight presently occupied by psychosocial models in the mind of opinion-formers and healthcare professionals, is one of the greatest challenges” (Dr Neil Abbot, ME Research UK: Co-Cure RES:MED: 14th December 2007).

2008

“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?”

(Greg Crowhurst: The Year of No Compromise. 8th March 2008:
<http://carersfight.blogspot.in/2017/01/the-year-of-no-compromise.html>).

2009

“ME has been classified as a physical, neurological illness...by the World Health Organisation since 1969. Instead of receiving biomedical treatment, ME sufferers are mixed up with sufferers of other fatigue-causing conditions, including mental ones, under the meaningless umbrella term ‘chronic fatigue syndrome’. In the UK no other neurological condition is treated solely by psychological interventions. All UK taxpayers’ research and treatment millions have gone to the psychiatric profession that insists, against all scientific evidence, that it is an ‘abnormal illness belief’.... The parliamentary Gibson report recommended that these psychiatrists be investigated for a possible conflict of interest in also working for large insurance companies. This has never been done. Is health care here also, in President Obama’s words, ‘working better for the insurance companies’ than for ME sufferers?” (H Patten; The Times: 17th August 2009).

2009

“People with (ME)CFS, adults or children, suffering from multiple symptoms, with varying degrees of severity, are dismissed and improperly diagnosed or treated.... There is now a wealth of good information available from research and clinical experience. Is skepticism as to the realities of (ME)CFS... still so prevalent that there is little or no motivation to learn about these illnesses? Well, sadly, yes....The lack of correct diagnosis, treatment steps not taken, disdainful and dismissive attitudes do hurt people. Are the skepticism and ignorance simply the result of individual physician decisions? Not at all. The CDC and NIH in the USA, the NHS in the UK, medical societies and medical schools, and prestigious journals, no matter what is said, if anything, shout, by means of their silence or lack of effective action, their disinterest and disbelief.... These skeptics predominate in government, medical school and journal hierarchies so they have, in effect, blocked and can continue to block the research and clinical teaching necessary to change the picture...(There) is a kind of "old boy bias", opinions formed many years ago, passed on by a form of group-think as the proper and prevailing views, untouched, unexamined, unchanged, and driven by an unwillingness to learn about the new research....When is enough ignorance enough? When the evidence is there, but the will to study it is not, and then harm is done out of this ignorance, does that become an ethical issue, rather than a scientific one?” (Dr Alan Gurwitt; Psychiatrist: Co-Cure ACT: 20th August 2009).

2010

(In December 2008, Kay Gilderdale, unable to cope with the extreme suffering that severe ME caused her 31 year-old daughter Lynn, helped her to commit suicide -- which Lynn intended but was so severely ill that she was unable to carry it out herself -- and was arrested; two years later Kay Gilderdale was cleared of her daughter's attempted murder).

“The death of Lynn Gilderdale and the humane verdict in the trial of her mother brought home to many people for the first time what a devastating illness myalgic encephalomyelitis (ME) can be. Many of the estimated quarter of a million people with ME in Britain experience not only extreme pain and disability, but also incomprehension, ignorance, lack of sympathy and at times outright hostility, not only from the public but also from professionals responsible for their care. Such lack of understanding even extends to blaming parents for the severity of their child's illness. It is time the nation began to take ME seriously....Above all, we should fund biomedical research to resolve the enigma of the underlying pathology of this illness. We should build on recent scientific advances to develop effective treatments, so that no-one in future need experience the pain, isolation and despair that were Lynn Gilderdale's fate” (The Countess of Mar and 19 others; Daily Telegraph Letters: 6th February 2010).

2010

“ME is definitely a harrowing condition to have to live with....A typical example of the disease and its perception was discovered by Nicola (Weiss) when she...became ill and had long-term disability insurance coverage. ‘My claim was turned down on technical grounds and a lawyer advised me that it was useless trying to pursue it. This is extremely common with cases of ME. Now I’m living a nightmare – too ill to work, no income, no cure, no understanding. I am totally dependent on my ageing parents who are both well into their eighties’” (Gerald Fenech: Malta Today, 30th May 2010).

2010

“What do you think of Acheson’s suggestion that diagnosis of ME should be reserved for those with (virally induced) evidence of CNS damage?”

‘If not, the syndrome will become a convenient dumping ground for non-specific illnesses characterised by fluctuating aches and pains, fatigue and depression’, exactly the situation that exists in the UK 50 years after Acheson’s prophecy: ED Acheson. American Journal of Medicine, April 1959:569-595” (Connie Nelson: LocalME: 31st May 2010).

2011

“Simon Molesworth AM QC said...family, social breakdown and isolation are common with devastating impacts on families and individuals....Medical research in the US shows that ME/CFS patients are sicker with a far greater disability than patients with cardiac disease, HIV, MS, chronic lung disease or depression, but many Australians are bearing the burden of this disease in isolation....It can take up to seven years to be diagnosed....When we consider the ongoing social impact of this condition the real costs of this disability are frightening.... Dr Nicole Phillips said that ‘ME/CFS is ...not just fatigue...it is not a psychological condition but a real physical neurological condition’” (ME/CFS Australia Media Release 9th May 2011).

2011

“(The name CFS) has allowed governments and psychiatrists, especially in Britain, to sweep a plethora of psychological diagnoses into the tent...while diverting government funding away from serious biomedical research....You might have...stretches of almost total helplessness....The brutal loneliness is always there...I have heard from a lot of men, including a medical doctor and a young man who was thrown out by his father who accused him of malingering. His plight is terrible....Insurance companies drop coverage routinely, and many doctors misdiagnose or are influenced by psychiatric arguments” (Llewellyn King – executive producer of The White House Chronicle: Co-Cure 3rd June 2011).

2011

Dr Jeremy C Gibson, lead author of “New GP Guidelines for Chronic Fatigue Syndrome” (http://www.oxfordjournals.org/our_journals/innovait/about.html) stated: ***“In this article, we outline GP management of CFS, the condition also known colloquially in the UK as ‘ME’. The paper is based on NICE guidelines”,*** to whom the Chairman of Invest in ME wrote the following: ***“ME is not a colloquial term for CFS. It is the official term used by the WHO in its classification of ME as a neurological illness in ICD-10 at G93.3. The NICE guidelines ignored all biomedical evidence on the pretence that looking at the biomedical research on ME was outside their remit....The Royal College of GPs, with this guidance, is spreading misinformation...and Invest in ME would like to ask you to request that the RCGP removes ME from the mental health section in the GP curriculum and places it in its correct section of neurological illness...By continuing to classify ME incorrectly the RCGP is not only compromising the health of patients – it is also compromising the work of healthcare staff and is guilty of extreme negligence”*** (Kathleen McCall; Invest in ME: July 2011).

2012

“Like millions of others, I have seen ME through the eyes of the medical establishment, the Government and the media. The picture has not been good. Here is what I previously understood about ME and those who have it. ME sufferers are workshy malingerers. They whine, constantly, about feeling tired. They are annoying sympathy seekers....ME is ‘all in the head’ and can be overcome with a bit more determination and a little less of the ‘poor me’ attitude. That, generally, is what I thought about ME...until a reader sent me a DVD of a British-made film titled ‘Voices from the Shadows’...that stopped me in my tracks....The more I began to delve into the subject, the more curious it all became. Why are records pertaining to ME locked away in our national archives at Kew for 75 years? The normal period would be 30 years. 75 years, the period generally used for documents of extreme public sensitivity and national security, is excessive. The reason given, that of data protection, is a nonsense. ME ruins peoples’ lives even if the patient is not entirely bedbound....According to figures obtained from the Office of National Statistics, there have been five deaths listed (from) ME in recent years. ME sufferers are subject to a battery of controversial fit-to-work assessments. The anxiety and physical exertion this requires generally worsens the condition. When the ME sufferer is unable to work because of their illness, they are removed from disability benefit and are plunged into poverty. The fact that it is still so widely misunderstood is a modern day travesty that must be addressed without further delay. Or is it convenient that we still view ME as being ‘all in the mind’? I believe that we, as a nation, deserve to know the truth. Not only for those still battling the disease, but for those poor souls who have already been lost to it” (All in the mind? Why critics are wrong to deny the existence of chronic fatigue. Sonia Poulton, Daily Mail journalist: MailOnline 8th May 2012).

2012

“People with ME face enormous obstacles to access health care. Among the impediments over past decades has been research which has shifted emphasis to fatigue and fatigue states with scant regard for the myriad yet distinguishing neurological, autonomic and gastrointestinal features of ME. Semantics and biased attributions continue to deny the severely ill, both child and adult, the right to care which addresses their acute and chronic medical needs without fear” (Christine Hunter AM; ME/CFS Clinical Autoimmunity Working Group Meeting, 30th-31st May 2012, Invest in ME, London; Welcome Address by Dame Bridget Ogilvie AC DBE FRS).

2012

*“Over the past year there has been a rise in the number of articles published on ME, all fed through the Science Media Centre who are giving a grossly unbalanced view on the disease and I feel that journalists have no right in portraying severely ill patients as anything other than severely ill....**There is a... smear campaign designed specifically to abuse and ridicule ME patients and I call on you to make this public in your inquiry....Not one article in the mainstream press concerning biomedical research has been published since October 2009. The Invest in ME Conference 2010 went unreported....**Patients’ concerns over editorial bias in the media with regards to ME stories are not a new issue. **All mainstream media articles on ME/CFS over the past two years have specific quotes from either Professor Wessely or his colleagues...which either (denigrate) or vilify patients or promote their skewed psychosocial school of thought....It is time that the Press Complaints Commission looked into how the media is effectively being controlled by Professor Wessely through the Science Media Centre”** (Gabiella Lewis; letter to The Leveson Inquiry, Royal Courts of Justice, 8th February 2012).*

2012

*“Ever since I first wrote on the subject of ME...I have been overwhelmed by the responses from patients and their loved ones....**For decades, people who have suffered the debilitating – and sometimes fatal – condition of ME have been forced into a type of denial. They have been told that their illness doesn’t really exist on the scale that they claim to experience it....They have been told, repeatedly, to ‘pull themselves together’....**And the myth of it ‘being in the mind’ has been perpetuated worldwide....It may surprise you to know that I have detractors....These people troll me on the internet (and) will be making comments like ‘get the violins out – here comes a sob story’. **Well, ME is a sob story. And the way patients have been portrayed is grossly wrong and that injustice must be recognised as such....People die from MEBut there have been powerful forces at play that have served to maintain the status quo...and they have proved more than a challenge to be reckoned with...The illness has been hijacked by the psychiatric community as one of ‘theirs’....This wholesale insistence of it being something that can be overcome with the right attitude has been highly detrimental to those who actually matter in this debate: the people who are***

suffering with it....What we are dealing with here is a systematic neglect of ME patients – and we should be under no illusion about that....ME is a modern-day scandal. The way it has been portrayed is shocking” (Sonia Poulton; ME is no more in the mind that Multiple Sclerosis; MailOnline 19th September 2012).

2012

Following her above article, Sonia Poulton received a communication from Wessely, about which she blogged: *“Woke to find a long email from Professor Simon Wessely...for those who don’t know, he is the big State cheese when it comes to ME...for many people, his name represents years of their personal misery....I have been repeatedly warned that I can expect a communication from him...well it came....He didn’t like me blaming psychiatry for standing in the way of research and treatment...he didn’t like that I didn’t give him credit for his ‘contribution to the debate’ and he most definitely did not like the idea that I say graded exercise is detrimental to the patient....The truth is this: I have done my research and he knows it....there comes a point when you know what you know and no amount of sharp words can change that”* (Sonia Poulton; 20th September 2012: <http://bit.ly/2l8dqcv>).

2012

“I have had ME for 15 years...I no longer have the energy...to keep my house the way I used to and cook for my family....My worst problems are headaches, cramps, all sort of tummy problems (and) I feel like I’m crawling through a fog in the dark carrying an elephant on my back ... I have hot and cold pins and needles and I have breathing problems...I waited six months to see a neurologist last year...I was with him for just five minutes when he said ‘You ME people should stop looking for a diagnosis and get on with your lives’. I cried all the way home....I had to pay £120 to see a specialist who told me I had ME in 1997. My GP would not fund it and I was at my wits end as to what was wrong with me....I had to give up full time employment because I was falling over...it got to the point where I could not walk upstairs anymore. I was getting vertigo and sickness attacks and was unable to drive; within a few months I was in a wheelchair...I live with constant pain and sickness...I still feel isolated, trapped, useless and misunderstood. I have had to fight for everything and it’s been a long hard struggle for the last 15 years” (Nicola Cousins; Independent blogs: LocalME 4th October 2012).

2012

On 6th November 2012 it was announced that the inaugural John Maddox prize had been awarded to Professor Wessely for his *“courage”* in *“standing up for science”* and for *“communicating sound science and evidence”*.

This was despite the fact that as far back as 2003, the Canadian Consensus Guidelines stated about his “behavioural” model of ME/CFS that there is: *“Much*

that is objectionable” about it and that it is “far from being confirmed...Nevertheless, the assumption of its truth by some has been used to influence attitudes and decisions within the medical community”, so it was not surprising that people questioned the award of the John Maddox Prize to Wessely for his work on ME/CFS and the criticisms were picked up by the media (who, via the auspices of the Science Media Centre of which Wessely is a founder member, are ever-supportive of him by vigorously promoting the psychosocial model of ME/CFS whilst suppressing dissemination in the UK press of the biomedical evidence that disproves the behavioural model).

On 25th November 2012 The Independent on Sunday published an article entitled **“ME: bitterest row yet in a long saga”** by Sanchez Manning, who wrote: *“Critics protested against the decision...They said the professor’s work perpetuates the idea that myalgic encephalomyelitis, also known as chronic fatigue syndrome, is a mental health problem, trivialising what they claim is a largely physical illness. Malcolm Hooper, emeritus professor of medicinal chemistry at Sunderland, said: ‘He’s responsible for trying to make ME into a psychiatric condition when it’s not. He has done very poor science’”*. The article also quoted the Countess of Mar and Consultant Physician Dr William Weir, both of whom opposed the award to Wessely and then it 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 he is on record as asserting that ME and CFS are synonymous and he has dismissed ME as nothing but a “belief”).

The article resulted in the publication on 2nd December 2012 of a letter in the Independent on Sunday from Dr Esther Crawley that was signed by 27 others, including Professors Michael Sharpe, Peter White (who orchestrated it), Stephen Holgate, Mansel Aylward and Trudie Chalder, as well as by other firm supporters of the psychosocial model of ME/CFS.

The letter accused the Countess of Mar, Professor Malcolm Hooper and Dr William Weir of *“allegations against Simon Wessely, one of the few UK clinicians with a specialist interest in treating CFS/ME and someone who has done pioneering research in the field. Such harassment risks undermining research, preventing the development of new treatments and discouraging specialist clinicians from entering the field. We fear that this may have resulted in patients not receiving the best treatments or care”*.

This generated much internet traffic, including correspondence from Wessely himself in which he wrote about the article of 25th November 2012: *“...that really is too much. Have u read what the countess says about me?”* to which his correspondent replied: *“That isn’t harassment”*.

The next development was a letter of apology written by Professor Peter White and sent individually to the Countess of Mar, Professor Hooper and Dr William Weir, in which he said: *“As you know, I was a co-author of a letter criticising your and others’ reported statements about Professor Simon Wessely being co-awarded the*

John Maddox award. Unfortunately the final version of the letter which was published was revised by the IoS (Independent on Sunday) without our prior knowledge or agreement, such as to change its meaning, so as to imply that we were accusing you and others mentioned of personally being responsible for harassing Professor Wessely. That was not our intention, nor was it that which we wrote. On behalf of the co-authors I am in the process of contacting the IoS to ask them to publish our original unrevised letter on their website and to ask them to publish a clarification. Although this was neither my doing nor intention, I regret that this has occurred and hope that you will accept my apology for any harm or upset this may have caused you”.

What those signatories wrote was very seriously improper: it was almost inevitable that, as the article referred to Lady Mar, Professor Hooper and Dr Weir by name, people would link the three of them as being involved in what the article referred to as the “*fanatical fringe*” that allegedly harasses, stalks and intimidates Simon Wessely, so it became important to find out what, if any, was the role of the editor of Independent on Sunday.

Communication with the Deputy Editor resulted in receipt of a copy of the original letter from Professor White et al, with observations from the Deputy Editor about the matter: “*I’d be grateful if Peter White could tell me in what way we have substantially altered what he wrote...The editor...quite understandably...asked for a minor clarification for legal reasons, so that the reader would not infer that it was the paper that was making the allegations, but (the Countess of Mar, Professor Hooper and Dr Weir)...I’d be intrigued to know what he apologised for, or is he suggesting that we were entirely to blame?*”

Professor White’s original letter was duly posted on the IoS website and, if anything, it was more defamatory than the published version. It referred to “*false allegations*” and included the sentence: “*Ironically, it was because of accusations like this that Professor Wessely received the award in the first place*”.

One of the resultant letters which was sent on 21st December 2012 to the IoS and written by Yvonne Foss said: “***Professor White’s letter appears to be part of a campaign orchestrated by the Science Media Centre....It surely cannot be ethical for members of the medical profession to be involved in a campaign of negative publicity about patients to whom they owe a duty of care....It is indeed hard to believe the authors’ claim of concern about research being undermined by threats....The long history of inadequate medical research into ME is paralleled by a long history of mockery of patients by the media and by medical professionals. If research has been discouraged, the cause is more likely to be the psychiatric paradigm that has led to widespread misconceptions that ME is not a physical disease but results from ‘dysfunctional beliefs’....It is this misinformation that has precluded proper clinical and scientific investigation into the disease***”.

On 24th December 2012 Professor White wrote again to the Countess of Mar: “*The IoS were unwilling to publish a correction or clarification in the hard copy newspaper. This was in spite of mediation by the Science Media Centre on our behalf*”

On 1st January 2013 a letter was sent to the IoS, extracts of which are provided here:

“In the IoS article of 25 November 2012 we were criticising the award of the Maddox Prize to Professor Wessely because it is axiomatic that the progress of scientific understanding depends upon sound evidence. Sir Paul Nurse, President of the Royal Society, has said: “The John Maddox Prize is an exciting new initiative to recognize bold scientists who battle to ensure that sense, reason and evidence base play a role in the most contentious debates.

“We are in complete agreement with Sir Paul. We would wish the scientific process to prevail. Whereby the extensive peer reviewed biomedical evidence base on ME/CFS is acknowledged and used by all researchers on the field to advance the understanding of the disorder, and we have been calling for this for many years.

“Both Professor White and Sir Simon Wessely have promoted an hypothesis that ME/CFS is due to an abnormal illness belief (and) that it is perpetuated by dysfunctional beliefs and coping behaviours.

“In our view, the idea that ME/CFS owes its origins to a dysfunctional psyche is an hypothesis that lacks a scientific evidence base. We are therefore at a loss to understand why the Maddox Prize was awarded to the defender of that hypothesis rather than to someone who was upholding the spirit of true scientific enquiry.

“Our main interest is in advancing the scientific understanding of the cause of a frequently devastating and debilitating condition which blights the lives of many thousands of people. We do not believe that personal attacks directed against Professor Wessely will advance this cause, but reserve the right to direct criticism at the hypothesis”.

It was deemed too long for publication but a shorter version was published on 13th January 2013.

This whole episode illustrated the willingness of the British establishment to give uncritical support to an evidentially flawed model of ME/CFS and to use their influence to discredit dissenting voices.

2012

A medical scientist who entered medicine as a mature student but who became too ill with ME to qualify wrote: “When I took really sick I was forced to go to hospital by my friends...I remember a doctor telling me he wanted to admit me, then coming back into the room after he had reviewed my notes which flagged up ME and he said something like ‘Haven’t you been here before to A&E? We have a shortage of beds and you are wasting your own time and our time by keep coming back here’...The other time I went to A&E with heart problems, the doctor kept me in A&E all night on a trolley but then sent me away telling me it was anxiety. I later paid for a private consultation with a heart scan and was told I had atrial ectopic beats, which was causing the problem....The specialist said it was most

likely viral....All the way along I have come across specialists who basically know nothing about ME (and) a few dismiss it as an illness. My biggest concern is my GP; I have spent years...trying to get him to recognise ME is a real illness, not a mind and belief problem....I was sent to a consultant psychiatrist (who) sent a letter to King's College Group seeking a referral but got a response back saying I was not a serious case and I'd be better treated (locally). I went along with this (and) was offered CBT and given a booklet about GET...I told (the psychiatrist) over and over I was suffering from a viral illness, not a mental health problem....One time while waiting to see him, I was sitting on a chair in the waiting area, I was so weak and feeling so sick I couldn't actually sit up, so I lay down over two chairs, and he came out and stood over me and said 'What are you doing?' – I replied 'I am very weak'; he then said 'Why? There is nothing wrong with you'....(Re) the doctor-patient interaction: the doctor first believes, runs tests, then questions the patient's mental health status; this is then verified by biased psychiatrists applying a flawed model of somatisation, then we are left with no help because we are categorised into a block of 'medically unexplained symptoms' (and diagnosed) with somatisation and hypochondria" (personal communication; 8th December 2012).

2013

"Despite ME/CFS being an illness so severe that it has been found to cause a poorer quality of life than any major illness including cancer, its sufferers continue to be disbelieved, shamed, and abandoned by doctors, friends and family. It is an illness that affects every major bodily system including the heart, nervous system, immune system and the production of energy. These patients are poorly served by contemporary medicine and die from heart failure and commit suicide in greater numbers and at far younger ages than the general population. Why is this illness so stigmatised?....The fact that this illness impacts every major bodily system means it generates a wide variety of symptoms. This in itself undermines credibility....One of the medical criteria for the diagnosis of hypochondria is 'presenting a large number of symptoms'. Once a suggestion of hypochondria enters a patient's record, prejudice is engendered which can destroy the patient's chance of getting care indefinitely (and) every encounter with a new medical provider raises concern about being believed....Patients continue to suffer widespread misunderstanding, prejudice and stigma....The medical establishment, which could protect patients from stigma, instead perpetuates it....The failure of the medical establishment to respond appropriately to ME/CFS has been widespread....Often families and friends are taking their cue from the medical establishment....The absence of validation alone is profoundly worsening the suffering of these patients who already suffer so much....There are no specialists for this highly complex life-destroying illness....This irresponsible neglect by the medical establishment points to a failure to honour its social contract...A fundamental problem lies with the failure to educate doctors in this illness. It is indefensible that they are still so uninformed regarding an illness so serious, complex and widespread" (The ME/CFS Stigma. Carol Schmid. Phoenix Rising, 19th March 2013).

2013

Mindful of the fact that Professor Wessely's wife, Dr Clare Gerada, was at that time Chair of the Council of The Royal College of General Practitioners, it is notable that the first e-training course on ME/CFS was launched by The Royal College of General Practitioners on 31st May 2013: *"It aims to demystify CFS/ME by highlighting common misconceptions and challenges that GPs may encounter when assessing adults presenting with fatigue"*.

The e-learning training course was supported by the National Institute for Health and Research, about which is stated: *"The National Institute for Health Research (NIHR) is funded by the Department of Health to improve the health and wealth of the nation through research....The NIHR plays a key role in the Government's strategy for economic growth"*.

Given that the GP e-learning programme appears to have been written by the same people who were behind the FINE Trial, quotations from the FINE Trial patients' hand-outs are instructive:

- *"We know that there is no disease in CFS (but there is severe deconditioning)*
- *We know that graded aerobic exercise reverses these problems*
- *There is no disease – you have a right to full health*
- *This is a good news diagnosis*
- *From the moment you walk out of this room, your recovery is beginning*
- *Every exercise is strengthening your body*
- *There is no disease*
- *Go for 100% recovery*
- *The medical research evidence shows no virus persists; no sign of muscle disease; no underlying serious disease*
- *Activity can do no harm when performed at a level matching your present fitness"*.

2013

"Its impact is horrific; confiscating lives, wrecking homes, sundering love affairs and grinding down caregivers and families. For the most part, the sick are sick until they die. Some are bedridden for years. Advocacy groups say suicide is high. I have received many letters from patients who say they can't take the pain, the helplessness and the stigma any longer, and beg for a quick release" (Llewellyn King, The White House Chronicle, June 2013).

2013

"Myalgic encephalomyelitis, the disease... recognised by the World Health Organisation since 1969, has disappeared. In its place, we have the catchall term

‘CFS’, which has been associated in the literature with depression, deconditioning, medically unexplained chronic fatigue and, for some researchers and clinicians, fatigue due to...’false illness beliefs’” (Mary Dimmock; Co-Cure ACT: 6th June 2013).

2013

In its Report “The Voice of the Patient” released in September 2013 (following a meeting held by the FDA on 25th April 2013 to hear perspectives from patients with CFS and ME and the impact on their daily life), the overview found that it is a complex and serious debilitating disease; that many patients experience a prolonged course of illness and that there are no approved therapies to treat it. Key themes were identified.

“Patients struggle daily with their symptoms. Of over 50 symptoms identified, the most frequently mentioned included severe fatigue or exhaustion, impairments in cognitive function, chronic pain, sleep difficulties, blood pressure drops and dizziness, sensitivity to light, sound and temperature and susceptibility to infection....A ‘crash’ can result from even minimal mental or physical exertion, can happen without warning, and can last for days, weeks, months or even years....CFS and ME takes a devastating toll on the lives of many patients and their families, including loss of careers, decreased quality of family life, social isolation and feelings of hopelessness. Patients are desperate for research and treatments that can (a) better relieve their most significant symptoms and (b) address the underlying cause(s) of their disease.

The Conclusion of the Report states: *“CFS and ME is a serious disease. It is a highly variable disease and may manifest in different ways from person to person. It severely affects day-to-day functioning and some patients struggle with the simplest tasks of daily life. CFS and ME has had devastating effects on many patients’ lives”.*

2013

In his Keynote Address on 8th November 2013 at the Action for ME Research Conference, Professor Stephen Holgate gave a brief overview of ME/CFS research, noting how little contribution it has made to patient benefit. He said *“There is hardly an organ in the body not affected by this disease, and yet there is still an enormous lack of knowledge, disagreement over diagnostics, and perceptions of ME/CFS vary enormously....Times have got to change”* (Co-Cure NOT: AfME research conference: 12th November 2013).

2013

“My doctors were not particularly interested in getting to the bottom of anything. Instead, after a few basic tests, they told me that my symptoms were not real. I was diagnosed with conversion disorder – a nicer, modern version of

‘hysteria’....Many patients who are eventually diagnosed with ME encounter doctors who do not believe they are ill. They tell them their symptoms cannot be medically explained. These beliefs are about professional training, not science....The disability is more severe than many types of cancer, or AIDS two months before death...It shortens your lifespan. It turns your body into a prison and locks you away for decades....It is similar in many ways to multiple sclerosis, but three times more prevalent....Twenty five percent cannot leave their homes. Many are bedridden for years...What happens when, for decades, the story among doctors is that a serious illness is psychosomatic?....What’s maddening is that science tells a different story entirely. Studies show severe immunological abnormalities – damage that...is unlikely to be caused by anything other than an infectious agent. They show distinct abnormalities in the spinal fluid, EEGs and SPECT scans; bodies ravaged by opportunistic infection; pathological alterations in the bacteria living in our guts....There is something elusive about this disease such that unless you live it, or live with and care for someone who does, it’s almost impossible to understand or describe” (Jennifer Brea; The Most Prevalent and Devastating Disease Your Doctor Has Never Heard Of: Co-Cure NOT: ACT: 20th November 2013).

2014

“For many of us with this condition, one of the greatest questions we have to answer is, how do we have some kind of life while dealing with this debilitating, corrosive disease?....How do we have family, relationships, work, pastimes, a social life...while living with something that makes normal life impossible?....This is the central conflict in a life shared with ME, the conflict between trying to stay well and living a life” (The Whole Damn Chronic Situation – A Life with Chronic Fatigue Syndrome: <http://thedamnchronicsituation.blogspot.co.uk> 16th June 2014).

2014

“Currently it is not safe for people with ME to use NHS services, due to a high risk of misunderstanding and ignorance....Why is ME still not treated medically in the UK as a neurological disease, despite being classified as such by the WHO since 1969? Why does the misinterpretation and mistreatment of ME as a psychiatric condition...continue under your government? Can the Minister explain why psychiatry is allowed to continue to interfere, control and wrongly influence the care and (lack of) treatment of people with ME?....Why is there still no biomedical treatment pathway on the NHS for people with ME, despite the overwhelming need for one and requests for one?Why is there no unified biomedical training programme within the NHS to make sure that all professionals from paramedics through to nurses and doctors/consultants have an accurate medical picture of the disease as a serious physical disease with multi-system dysfunction?....Why is there no national system for reaching the house and bed-bound... at home? ...Can the Minister explain why it is that the information on the NHS website says that ME can be caused by psychological factors...putting peoples’ lives and health at risk?...Can you make a specific commitment to stop

the abuse, the neglect, the misinterpretation and misrepresentation of ME and the mistreatment, particularly of the most seriously ill patients?”

(Pro-forma letter supplied by The 25% ME Group for the Severely Affected, Summer 2014).

2015

Perhaps the most damaging item about ME/CFS to appear in 2015 was the book **“It’s All in Your Head: True Stories of Imaginary Illness”** published in June by Suzanne O’Sullivan, a consultant neurologist at The National Hospital for Neurology and Neurosurgery in London.

Once again, ME is described as an “imaginary illness”.

The book was very well received: it was described as *“honest, fascinating and necessary”*; as *“extraordinarily compassionate”* and as *“beautifully intriguing”*; it was promoted by the Daily Mail and it won O’Sullivan the Wellcome Book Prize 2016.

The Times reviewer commented: *“There is an unusual tone that runs through this book ...the tone of someone who has spent quarter of a century carefully explaining to people...what they do not want to hear....This unwanted explanation is that the illnesses the patients have are simultaneously real but have no physical origins, and they are products of the mind....ME is just one of the possibly psychosomatic conditions that patients present with....(O’Sullivan) thinks that, for various reasons, our minds can express distress...through our bodies. If we cannot recognise this possibility, then we cannot deal with it...(O’Sullivan) notes that something like 70 per cent of patients who present with inexplicable conditions are female (and she) wonders whether we aren’t immensely vulnerable to our own suggestibility”.*

The Sunday Times reviewer noted: *“(O’Sullivan) reveals that doctors are reluctant to diagnose illnesses as psychosomatic, partly in case they missed something, but also because patients react angrily. They feel accused of fraud or madness. As a result, some search for any diagnosis except the right one, often at great cost to themselves and to the NHS....O’Sullivan...describes how psychosomatic illnesses arise....Some people ‘medicalise every sensation...and that in itself can lead to illness’....We can acquire the symptoms we learn about, it seems. The extraordinary evidence for this derives from so-called culture-specific syndromes....(People) in the West (are) stricken with irritable bowel syndrome and food ‘intolerances’ – which Sullivan clearly believes are psychosomatic illnesses. She thinks the same...about ME”.*

The Guardian reviewer (Tim Adams) said: *“By the time these patients come to O’Sullivan they have generally exhausted every scan and endoscopy the NHS can provide, as well as the patience of doctors and specialists in different fields....It is O’Sullivan’s contention that ‘psychosomatic disorders are physical symptoms that mask emotional distress’....The tendency to respond to every inexplicable bodily*

sensation may be ignored in most of us, but not in all of us, particularly if it becomes part of a pattern masking or deflecting some other stress”.

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.

2016

On 1st November 2016 the BBC repeatedly announced: “A *successful treatment for children with CFS is being trialled by the NHS*”, giving 24-hour non-stop promotion of a study of myalgic encephalomyelitis/chronic fatigue syndrome in children and adolescents by Professor Esther Crawley from Bristol (the £1 million FITNET trial, which stands for Fatigue In Teenagers on the interNET) and which claims success for a behavioural modification intervention when there is no objective evidence of any such success in either children, adolescents or adults. **Fatigue, whether chronic or not, is not the same as ME/CFS.**

Throughout the day, the reporting was inaccurate (66% of participants were said to be “cured”) because it grossly exaggerated and mis-represented the findings of a small Dutch study in young people upon which the FITNET trial relies as evidence of efficacy: whilst there was a significant difference in school attendance at six months in those who received internet CBT *versus* those who received “usual care” (75% vs 16%), the ultimate findings of the Dutch study showed no difference between the groups at 2-year follow-up.

On 3rd November 2016 The Countess of Mar wrote to Lord Hall, Director General of the BBC, from which the following extracts are taken:

“It seems that the BBC relies on briefings provided by the Science Media Centre (SMC) without bothering to verify the facts. Such lazy reporting is unacceptable

*because it is misleading and is harmful to the public. The Science Media Centre began work in 2002 to operate like a newsroom for national and local media when science stories hit the headlines. It is funded by, amongst others, the pharmaceutical and chemical industries. **The SMC's covert purpose is to ensure that journalists and the media report scientific and medical matters only in a way that conforms to Government and industry's 'policy' on the issues in question. To that end, the SMC provides 'training days' for journalists so that what they report on scientific and medical issues is effectively influenced and controlled by the SMC. Its founder member is psychiatrist Professor Sir Simon Wessely, whose life's work consists of asserting that ME/CFS is not an organic but a behavioural disorder that can be cured by 'cognitive restructuring' and graded aerobic exercise (ie. the interventions to be used in the FITNET study).***

*"It is not surprising that the 'experts' put forward by the SMC to support the news item were Professor Esther Crawley herself, her close friend Professor Stephen Holgate, and Professor Paul McCrone (who was involved with the now-discredited PACE trial of CBT/GET in adults), all of whom are known to be biased in favour of the SMC's agenda. **Professor Holgate referred to Professor Crawley's FITNET trial as 'high quality research', but one senior UK Consultant Physician who specialises in the multi-systemic pathology of ME/CFS asks how a study that is carried out on Skype and which does not even meet the patients face-to-face, let alone examine them over time, can be described as 'high quality research'.***

"I ask that you ensure that the BBC issues a prominent retraction of its endorsement of and support for the FITNET study and, to counter-balance its support for behavioural interventions for a proven and classified neuro-immune disorder, the BBC offers a commensurate right of reply to those with an understanding of the biomedical nature of the disease".

Her request was refused by Lord Hall.

This remains a matter of concern: the FITNET trial is funded by Health Technology Assessment (HTA) Programme (UK), which claims to fund "independent" research about the effectiveness, costs and broader impact of healthcare treatments; it is the largest of the programmes supported by the National Institute of Health Research (NIHR), which is the research arm of the NHS. The HTA Programme says: "*Our research serves a wide variety of key stakeholders, including decision-makers in local government (and) policy-makers (including NICE)*". Its Clinical Evaluation and Trials Board includes Professor Michael Sharpe, one of the PACE Principal Investigators and a staunch supporter of behavioural interventions for ME/CFS.

This support from the NHS presents a major discrepancy, because whilst one arm of the NHS is funding behavioural interventions to be used in the FITNET trial (CBT and GET), in October 2006 another arm of the same NHS (NHS Plus, a Government-funded project) warned of the dangers of graded exercise in ME/CFS: "*Although some RCTs show evidence of improved functional capacity for work, and reduced fatigue, some patients experience a significant deterioration in symptoms with this intervention*". The ME Association noted: "***This is a significant acknowledgment by the NHS that GET has dangers to people with ME/CFS***".

Professor Crawley's "information" leaflets – all headed: “**Dealing with Chronic Fatigue (CFS/ME) in Young People....Specialist help for ME**” – were produced by CFS/NHS/PAEDIATRICS/BATH and are lacking in any appreciation of what ME/CFS actually is.

The leaflets are deeply concerning because, first and foremost, “Chronic Fatigue” is not “CFS/ME” and they pay no attention to the reality of ME/CFS, for example:

The leaflet “Cognitive Behaviour Therapy” starts off by saying: “*Hassles and problems are part of everyday life...but sometimes...the problems seem to take over and you may end up feeling unhappy...People with problems often think in unhelpful ways....CBT will help you find the link between what you think, how you feel and what you do...(and) how to face and overcome your problems*”.

The “Exercise Chart for Severely Affected” requires one specified exercise **each hour**.

The leaflet entitled “Thinking Traps” says: “*This leaflet will help you find the negative trap you have fallen into. You will then be able to challenge your negative thoughts and fight back*”.

The “Thoughts and Feeling Diary” requires that at the end of each day, the young person must write down what they have done that day, naming the time, who was there, where they were, what was happening before, and what happened afterwards.

The “Managing Feelings and Emotions” leaflet says: “*If we feel angry and frustrated, we might shout or swear at someone....If we feel anxious and worried about something, we might avoid doing it, and make up excuses....**Don't worry – the trick is to do just a little bit more each time you do something.***”

The “Activity, Rest and Sleep Diary” is to “*help you use a graded activity programme to record what you do each week. This will help as you gradually increase the amount you do*”.

The “Energy Management” leaflet says: “*We have lots of ways to help you...including charts and cards...When you have managed **2 weeks** of the same activity daily, you can start to increase it by **10% a week***”.

As world expert Professor Anthony Komaroff from Harvard said at the IACFSME conference in Fort Lauderdale in October 2016, it is known that genes involved in signal transduction are hypomethylated but that genes involved in apoptosis are hypermethylated; that exercise triggers a characteristic gene expression signature involving 15 cytokines/adipokines/growth factor; that there is lower oxygen consumption leading to earlier conversion to anaerobic metabolism and that lactate levels are higher at all work effort; that most of the dysfunctional cytokines are pro-inflammatory and that there is evidence of chronic low-level inflammation. It is also known there is altered heart rate variability due to reduced cardiac vagal activity.

As a paediatrician with an interest in ME/CFS, why does Professor Crawley ignore this large body of science and persist in testing – yet again — a theory that has comprehensively and unarguably failed, and why did she make such insupportable assertions on BBC radio, demonstrating once again a fundamental lack of understanding of basic scientific principles?

Despite many trials that have attempted to cure ME/CFS by incremental physical exercise, none has demonstrated sustained objective improvement, let alone a cure for the disease.

Over the years, there has been abundant evidence from numerous surveys by ME/CFS charities of almost 5,000 patients that in such patients CBT is ineffective and that GET is unacceptable and sometimes positively harmful, for example, in 2008 Action for ME published a survey of over 2,760 patients (“M.E. 2008: What progress?”) which found that **one third had been made worse by GET and that at their worst, 88% were bed/housebound, being unable to shower, bathe or wash themselves, and that 15% were unable to eat unaided.** The Press Release of 12th May was unambiguous: *“Survey finds recommended treatment makes one in three people worse”*.

Why do those with responsibility continually deny and disregard so much evidence that disproves their own beliefs and authorise the waste of public money on trials of interventions that have been shown to be ineffective?

It is disturbing that the Wessely School baton has been passed to a new generation of seemingly prejudiced and ill-informed clinicians.

Conclusion

Is Professor Sir Simon Wessely guilty of misleading medical professionals, State policy-makers and decision-makers about ME/CFS?

He has certainly trivialised a devastating neuro-immune disorder from which people die by teaching that it does not exist other than as a “belief” that one suffers from something called ME, yet in his lecture to the Bristol Medico-Chirurgical Society on 13th March 2013 Wessely presented himself as a caring and compassionate saviour of patients who had been suffering neglect and ridicule at the hands of neurologists and the medical profession in general but, he said with pride, he himself knew even in 1987 that these patients had a “real” illness.

His own belief about the reality of ME/CFS is that it is a somatisation disorder (a belief shared by Professors Peter Denton White, Michael Sharpe and Trudie Chalder).

Their belief is invincible and is well-documented.

Aided and abetted by the Science Media Centre, he and his colleagues ignore and dismiss world-class evidence that proves them wrong.

As a result, instead of protecting and supporting people with ME/CFS, the State is manipulating them, with disastrous results.

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’. This was being 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/MEFMAActionNetwork/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”.*

History will judge the scientific legitimacy (or otherwise) of the Wessely School doctrine but for those whose suffering as a result of ME/CFS is unabated, there can be no doubt about the power of pride and propaganda.

www.margaretwilliams.me