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This is the latest document from Professor Malcolm Hooper et al. It is long (75 pages in total but these include 23 pages of quotations from the published works of Simon Wessely and Michael Sharpe, all of which are relevant and topical). No progress will be made unless everyone helps to publicise the facts contained in this document to all health professionals, to Members of Parliament and to the media.

THE MENTAL HEALTH MOVEMENT: PERSECUTION OF PATIENTS?

A CONSIDERATION OF THE ROLE OF PROFESSOR SIMON WESSELY AND OTHER MEMBERS OF THE "WESSELY SCHOOL" IN THE PERCEPTION OF MYALGIC ENCEPHALOMYELITIS (ME) IN THE UK

Background Briefing for the House of Commons Select Health Committee

Is it the case, as demonstrated in a TV documentary, that multi-national corporations and not governments now control the world? Are powerful and influential psychiatrists who work within the Mental Health Movement linked to the multi-national corporations that now dominate and control medical and research institutions and whose life-blood is profit? (*Politics isn't working: the End of Politics. Cambridge academic Noreena Hertz presented evidence that multi-national corporations are taking the place of elected governments. ITV Channel 4, 13th May 2001)*

To the detriment of the sick, the deciding factor governing policies on medical research and on the management and treatment of patients is increasingly determined not by medical need but by economic considerations.

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December 2003

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EXECUTIVE SUMMARY

Evidence is presented in this document to show that

- In the UK, patients with myalgic encephalomyelitis (ME, also known as Chronic Fatigue Syndrome or CFS), particularly children, have suffered gross and barbaric abuse and persistent denigration as a consequence of the beliefs of certain psychiatrists who are attempting to control the national agenda for this complex and severe neuro-immunological disorder

- These psychiatrists are shown to be clearly in breach of the first tenet of medicine --- first do no harm--- in that by their words and deeds they have wreaked havoc in the lives of ME/CFS patients and their families by their arrogant pursuit of a psychiatric construct of the disorder which ignores the abundant clinical and scientific evidence (widely presented in the international medical and scientific literature) of the organic nature of ME/CFS

- There have been persistent and frequently covert attempts by these psychiatrists to subvert the international classification of this disorder, with destructive consequences for those affected

- To the serious disadvantage of patients, these psychiatrists have propagated untruths and falsehoods about the disorder to the medical, legal, insurance and media communities, as well as to Government Ministers and to Members of Parliament, resulting in the withdrawal and erosion of both social and financial support

- Influenced by these psychiatrists, Government bodies such as the Medical Research Council have continued to propagate the same falsehoods with the result that patients are left without any hope of understanding or of health service provision or delivery. As a consequence, Government funding into the biomedical aspects of the disorder is non-existent

- This coterie of psychiatrists has proven affiliations with corporate industry and has insidiously infiltrated all the major institutions, directing funding for research into an exclusively psychiatric model of the disorder, focusing on "management strategies" involving psychiatric techniques, even though such techniques have been shown to be at best of no lasting value and at worst to be harmful to patients with ME/CFS

- The same psychiatric model has been extended by these psychiatrists to a number of other disorders including Gulf War Syndrome, fibromyalgia, multiple chemical sensitivity and chronic low-dose organo-phosphate poisoning, leaving many other people without the help and support they so urgently need.

THE MENTAL HEALTH MOVEMENT -- PERSECUTION OF PATIENTS ?

A consideration of the role of Professor Simon Wessely in the perception of myalgic encephalomyelitis (ME): A matter for the Select Committee on Health

NB. ***For brevity, not all references are cited in the text but all are available on request from the Countess of Mar, House of Lords, London SW1A 0PW***

Brief Introduction

The matter for scrutiny by the Select Committee on Health concerns myalgic encephalomyelititis (ME) and is straightforward:

(i) is the Department of Health's current and proposed policy on the management of patients with ME as provided and promoted by psychiatrists of the "Wessely School" *(see below)* harmful to patients and

(ii) are such patients being abused as a consequence of scientific misconduct?

ME has been formally classified by the World Health Organisation (WHO) in the International Classification of Diseases (ICD) as a neurological disorder since 1969, but psychiatrist Simon Wessely advises Government that the disorder does not exist other than as an "aberrant belief" that one has a disorder called ME. He refers to "chronic fatigue syndrome" (CFS) and asserts that CFS is a somatoform (psychiatric) disorder in which patients produce physical symptoms as a means of expressing emotional distress.

This is at variance with the WHO classification of the disorder: Chronic Fatigue Syndrome is listed in the ICD as a term by which ME is also known and according to the ICD, the two terms are synonymous, thus "CFS" does not represent a psychiatric disorder even though Wessely School psychiatrists assert that it does.

Of potential significance is the fact that American researchers have demonstrated that in ME/CFS, a particular pathway in the body which is affected by viruses can also be affected by chemicals and it is known that ME/CFS can be either virally or chemically induced (Interferon-induced proteins are elevated in blood samples of patients with chemically or virally induced chronic fatigue syndrome. Vojdani A; Lapp CW. Immunopharmacol Immunotoxicol 1999:21: (2):175-202)

For at least a decade, questions about possible scientific misconduct and flawed methodology by Dr (now Professor) Wessely and his group of co-psychiatrists have been raised and published in international medical journals but it is only relatively recently that his long-time involvement as medical adviser to commercial bodies having a vested interest in his publications on ME has been exposed *(see below).*
There is no question that many millions of pounds sterling are at stake and that the vested interest groups for whom these psychiatrists act as medical advisers would like to prevent insurance cover for ME patients (those with a psychiatric label are denied medical insurance cover); prevent disability payments to them; prevent successful liability lawsuits and maintain the supremacy of their industries *(see below)*.

Increasingly, it is now "policy-makers" and Government advisers, not experienced clinicians, who determine how a disorder is classified and managed in the NHS: the determination of an illness classification and the provision of policy-driven "management" is a very profitable business.

The situation is admirably set out in a letter dated 29th December 2003 to the e-British Medical Journal from Angela Kennedy, Social Science Lecturer at the Open University:

"I suspect that psychiatry, if it is not careful, will eventually become most ridiculed over its adherence to one theme: that of 'somatization'. Presently, sufferers of Myalgic Encephalitis (sic) (also called Chronic Fatigue Syndrome) are increasingly subject to medical negligence or even abuse because the huge body of international bio-medical evidence is ignored, especially in Britain, in favour of an unfortunately incomprehensible, incoherent and empirically inadequate theory.

"The categorization of an illness as being psychosomatic also means a further categorisation of an individual as 'deviant' rather than 'ill', so that they are denied sympathy, support, and even benefits they are entitled to. Categorised as 'deviant', the ill then suffer increasing social exclusion and material inequalities.

"The main problem with somatization theories is that they cannot be either proven or disproven and therefore are not very 'scientific' at all.

"In relation to ME/CFS at least, flawed, unsubstantiated theories have been uncritically adopted and treated as 'fact', even against the already substantial (and substantiated) body of bio-medical evidence which continues to grow.

"The material effects of such sloppy 'science' have had two main consequences for ME sufferers: firstly, the medical impairments of the illness have often been ignored and left untreated, and many sufferers therefore become severely disabled, their physical health absolutely devastated and their chances of a restoration to good health uncertain at best. Secondly, children in particular end up victims of institutional abuse (though this can happen to adults too). In the case of children, they may be forcibly removed from their concerned parents and subjected to draconian 'treatments' that could, quite easily, be termed abuse.

"The capacity for abuse of institutional power appears to have increased enormously, and this is becoming most evident in the fields of health care and particularly psychiatry. How such problems are addressed will determine the future of such disciplines, as far-reaching demands for justice from those who are faced with or survive such institutional abuse are inevitable, and this will lead to a critical review of medical practice, both from other disciplines, and society at large".

The Mental Health Movement

In 21st century medicine the Mental Health Movement is politically correct and immensely powerful: it is backed by the giant chemical, pharmaceutical and insurance industries which are now the funders and controllers of both undergraduate and post-graduate medical education. In the UK, these industries have known links to research funding bodies such as the Medical Research Council (MRC) and as a result, a vast amount of public money is presently being provided in an attempt to strengthen the currently weak psychiatrically-driven research evidence that behaviour-modifying "chronic illness management strategies" are effective.

As a consequence, the MRC has decided not to fund urgently needed biomedical research into complex and devastating disorders such as myalgic encephalomyelitis (ME).

Also relevant may be the Council of Europe Strasbourg Convention on Human Rights and Biomedicine, which confers rights including provision for drug and other medical trials on human beings which in certain circumstances could be carried out without the individual's consent: this applies to three groups of people in particular:

(i) those who are deemed to be mentally ill
(ii) those for whom no other known treatment is effective
(iii) children

The Convention (not yet ratified by the UK) specifically states that in certain situations, "general interests" will take precedence over those of the individual.

Concurrently, in the UK, proposals for the Reform of the Mental Health Act were drawn so widely that they would give psychiatrists far greater powers to enforce compulsory psychiatric treatment upon both adults and children: proposals included provision for

psychiatrists to be able to drug people (including children against the wishes of their parents) if they have "*any disability or disorder of the mind or brain, whether permanent or temporary, which results in an impairment of mental functioning*".

Mental Health Movement advocates claim that disorders such as ME and CFS come into what they call the "medically unexplained symptoms" category (known as MUS or MUPS, which stands for "medically unexplained physical symptoms") and that such disorders are psychogenic in origin; contrary to established principles of scientific investigation and discovery, these psychiatrists assert that "*if all you look for are biomedical explanations, you're missing the whole picture"* and that if Government wants to solve the waiting-list dilemma (which it does, for political reasons), "*they will have to channel serious money at this problem*" by funding psychiatric management regimes (http://www.thes.co.uk/search/story.aspx). The implications of the implementation of this policy are already spiralling out of control.

On 4th May 2000, a letter from the Office of the Minister of State at the Department of Health (signed by John Hutton) seemed not to rule out the re-classification of ME/CFS as a "mental" disorder, stating it was unlikely that the proposed reforms to the Mental Health Act would affect such patients *(quote) "**even if (ME/CFS) were reclassified as a mental rather than a physical disorder***".

In October 1999 Dr Michael Sharpe (a psychiatrist and prominent member of the Wessely School) gave a lecture at the University of Strathclyde at which he said: ***"Purchasers and health care providers with hard-pressed budgets are understandably reluctant to spend money on patients who are not going to die and for whom there is controversy about the 'reality' of their condition (and who) are undeserving of treatment".***

Are those with other classified neurological disorders also ***"undeserving of treatment"***?

Infiltration of institutions by vested interest groups was the subject of an article by George Monbiot published on 9th December 2003 in the Guardian (*Invasion of the Entryists*), from which the following extracts are taken and to whom acknowledgement is made:

"One of the strangest aspects of modern politics is the dominance of former left-wingers who have swung to the right. The "neo-cons" pretty well run the White House and the Pentagon, the (UK) Labour party and key departments of the British government. But there is a group which has travelled even further to the extremities of the pro-corporate right. Its tactics (involve) entering organisations and taking them over. Research published for the first time today suggests that members of this group have colonised a crucial section of the British establishment. The organisation began in the late 1970s as a Trotskyist splinter; it immediately set out to destroy competing oppositional movements. In 1988 it set up a magazine called Living Marxism (known as) LM. By this time it had moved to the far right and was led by the academic Frank Furedi who started writing for the Centre for Policy Studies (founded by Keith Joseph and Margaret Thatcher) and who

contacted the supermarket chains, offering, for £7,500, to educate their customers 'about complex scientific issues'. In the late 1990s the group started infiltrating the media, with remarkable success. In 2000, LM was sued by ITN after falsely claiming that (its) news journalists had fabricated evidence of Serb atrocities against Bosnian Muslims. LM closed, and was resurrected as the web magazine Spiked.

"All this is already in the public domain. But now, thanks to the work of researcher Jonathan Matthews, what seems to be a new front in this group's campaign has come to light. Its participants have taken on key roles in the formal infrastructure of public communication used by the science and medical establishment.

"Its participants (work) for the PR firm Regester Larkin, which defends companies such as the biotech giants Aventis, Bayer and Pfizer against consumer and environmental campaigners.

"(One of its participants) is Fiona Fox, who is the director of the Science Media Centre (which) is funded, amongst others, by the pharmaceutical companies Astra Zeneca, Dupont and Pfizer. Fox has used the Science Media Centre to promote the views of industry and to launch fierce attacks against those who question them.

"Are we looking at a group which wants power for its own sake, or one following a political design? The scientific establishment appears unwittingly to have permitted its interests to be represented to the public by the members of a bizarre and cultish political network. Far from rebuilding public trust in science and medicine, this group's repugnant philosophy could finally destroy it".

Of significance to the ME community is the fact that Spiked's health writer is Dr Michael Fitzpatrick, well-known for presenting and promoting the views of Professor Simon Wessely and for his perverse and immoderate attacks on those with ME. One such article can be found at http://www.spiked-online.com/Articles/00000002D3B6.htm (SPIKED: Health: 17th January 2002: "ME: the making of a new disease"). Referring to the then newly published Chief Medical Officer's Working Group report on CFS/ME *(see text)*, Fitzpatrick roundly derided the CMO, Professor Liam Donaldson: *"The CFS/ME compromise reflects a surrender of medical authority to irrationality. The scale of this capitulation is apparent when Professor Donaldson claims that CFS/ME should be classified together with conditions such as multiple sclerosis and motor neurone disease. The effectiveness of the ME lobby reflects its middle-class base."*

Also of significance is the fact that in its NOTES FOR EDITORS, Spiked states that Professor Simon Wessely is available for comment or interview and can be contacted through Sandy Starr at Spiked (0207-269-9234).

Of relevance to the ME community is that fact that Lord (David) Sainsbury (Science Minister –*see text*) is a keen supporter of the Science Media Centre. It is Lord Sainsbury's Linbury Trust that since 1991 has financially supported studies of chronic fatigue by psychiatrists of the Wessely School.

Information on the GMWATCH website (www.gmwatch.org) is also important to the ME community. By 2003, Lord Sainsbury had donated over £11 million to the Labour Party. Mark Seddon, a member of Labour's National Executive Committee, told the BBC *"In any other country, I think a government minister donating such vast amounts of money and effectively buying a political party would be seen for what it is, a form of corruption of the political process"*.

For some, the choice of an unelected biotech investor and food industrialist to be Science Minister is more than emblematic of the UK's corporate-science culture.

In a recent Financial Times article, Lord Sainsbury cites the following statistics: British universities spun off 199 companies in 2000, up from an annual average of 67 in the previous five years. The UK's ratio of companies to research spending is now more than six times higher than the US. *"It's a dazzling record*", Lord Sainsbury is quoted as saying.

Not everyone shares Sainsbury's enthusiasm. Professor Stephen Rose of the Open University Biology Department is among those who have commented critically on this emerging corporate science culture: *"The whole climate of what might be open and independent scientific research has disappeared"*.

What is the problem?

The problem is that the Mental Health Movement does not restrict itself to mental disorders and ME has been the subject of unremitting psychiatric spin since the late 1980s: although ME is not classified by the WHO in the ICD as "mental", in the UK it is being high-jacked and covertly re-classified as "mental" by a small but influential group of psychiatrists known colloquially as the "Wessely School" (Hansard: Lords: 19th December 1998:1013 – *see below*) who have their own vested interests in casting their net of illness control ever wider. They have proposed a hypothetical model that cannot be tested experimentally and it is this group of psychiatrists who are the most assiduous advocates of the Mental Health Movement in the UK, to the extent that, in the case of ME, they have been shown to have created their own conclusions before generating the data which would support such conclusions.

The prevalence of ME/CFS is higher than for multiple sclerosis, which in the UK affects about 83,000 people; in January 2002 the Report of the Chief Medical Officer's Working Group *(see below)* gave a UK population prevalence of 0.2 – 0.4% (ie. up to 240,000 affected people). Certainly the incidence is known to be rising: as long as a decade ago, UNUM (one of the largest disability insurers) reported that in the five years from 1989 – 1993, disability claims for this disorder increased by 460%. In terms of insurance costs, ME/CFS came second in the list of the five most expensive conditions, being three places above AIDS.

At the publication of the UK Chief Medical Officer's Working Group Report on "CFS/ME" *(see below)*, the Chief Medical Officer (CMO) went on public record on BBC News on 11th January 2002 stating that the treatment of "CFS/ME" must improve and that it should be classed as a chronic condition with long-term effects on health, alongside other illnesses such as multiple sclerosis and motor neurone disease. It was not only Dr Fitzpatrick of Spiked who disagreed with the CMO: the week after the CMO made his announcement, the British Medical Journal (BMJ) highlighted the view of a prominent member of the Wessely School (psychiatrist Michael Sharpe) that doctors would not accept a particular strategy just because the CMO's Report recommended it.

Whether ME and CFS represent the same disorder or are two different entities has engaged many health care professionals, especially certain psychiatrists, in an often hostile political battle. These psychiatrists advise Government that ME does not exist as a separate entity; that "CFS/ME" is one and the same disorder and that it is a mental disorder which must be "managed" by mind-altering psychotherapy, despite the fact that, accepting that CFS equates with ME, international non-psychiatrist experts consider it to be a physical (ie. organic) neuro-immunological disorder and that there is a significant literature which supports an organic pathoaetiology.

In the UK, the primary duty of care for the sick has been displaced in the fierce battle for supremacy waged by this group of psychiatrists. Because personal status, competing personal interests, commercial interests and massive funding issues are involved, battle lines remain drawn and it is the patients who are caught in the cross-fire. As Shakespeare noted: *"As flies to wanton boys are we to the gods; They kill us for their sport"* (King Lear, Act IV Scene I).

What is the "Wessely School"?

UK policy concerning ME is based on the intransigent beliefs of a group of psychiatrists led by Simon Wessely, for years an adviser to various Government Departments including the Ministry of Defence and who is now Professor of Epidemiological and Liaison Psychiatry at Guy's, King's and St Thomas' Medical School (GKT) based at King's College Hospital (KCH) and at The Institute of Psychiatry (IOP); he is also Director of the Chronic Fatigue Syndrome Research Unit and of the Gulf War Illnesses Research Unit, both at King's. Other leading members include psychiatrists Michael Sharpe (formerly of Oxford and now at Edinburgh, where Alan Carson now collaborates with him); Peter White (of St Bartholomew's Hospital, London); Anthony David, Anthony Cleare, Stephen Reid and Matthew Hotopf of The IOP and KCH and Richard Mayou, Keith Hawton and Christopher Bass of Oxford. Trudie Chalder, a former Registered Mental Nurse, works with Wessely and her name often appears on their publications and in funding applications. Other supporters include Elena Garralda, Professor of Child and Adolescent Psychiatry at St Mary's, London; Tony Pelosi of Glasgow; Stephen Lawrie of Edinburgh; Alison Weardon and Leonie Ridsdale, Senior Lecturer in General Practice at Guy's, King's and St Thomas', London.

The stated aim of Simon Wessely is to "eradicate" ME from the medical lexicon and to re-classify CFS as a mental disorder which does not need biomedical research or explanation and which is to be managed by a version of cognitive behavioural therapy which he claims to have developed. His own commercial involvement in such a management regime has been established *(see below).*

The certainty of these psychiatrists that they are right whilst other researchers of international repute who disagree with them are wrong, their power and their influence are destroying countless lives, yet they continue to fly unscathed even in the face of substantial evidence that calls their views into question.
Wessely School psychiatrists have built their careers and reputations on denying the physical nature of ME/CFS, with the result that untold numbers of chronically and seriously ill patients are bullied, derided, threatened and driven to suicide by being told that they are not physically ill but are suffering from "aberrant illness beliefs".

The constant theme running through the work of this group of psychiatrists is that CFS is a somatoform disorder and that factors such as female gender, too much focus on normal bodily sensations, specific personality traits, avoidance behaviour, learned helplessness, faulty thought processes, lack of motivation, inadequate coping strategies, interpersonal conditioning and contagious sociological hysteria play an important role in the perpetuation of the disorder.

Wessely School psychiatrists have been described in the eBMJ (N Portman, 3rd December 2003) as *"a small clique of undemocratic, unaccountable, self-serving psychiatrists who have managed to monopolise most of the research funding in this field and, thanks to their prejudices, have been its downfall ever since"*.

Without doubt, the influence of Simon Wessely has resulted in a cascade of horrors which most people in the UK do not know about and when they do, they find scarcely believable.

It has taken 25 years for the notorious Professor Sir Roy Meadow to be exposed and discredited as "world expert" on Munchausen's Syndrome by Proxy, whose views Lord Howe described as "*one of the most pernicious and ill-founded theories to have gained currency in childcare and social services in the past 10 to 15 years. It is a theory without science. It rests instead on the assertions of its inventor*". The downfall of Meadow, who is finally to appear before the Professional Conduct Committee of the General Medical Council, serves to prove that a so-called "medical expert" whose views apparently portray incontrovertible medical judgment and certainty may, in fact, be wrong, but the damage done cannot be undone. So it is with ME. It must not be allowed to take 25 years before the views of the Wessely School on ME are subjected to similarly rigorous public examination and exposure.

Many doctors and their non-medical managers still have misguided ideas about medical negligence and believe that doing one's best is all that matters or is required. This is not

so in law and the legal profession is about to become less deferential to the medical profession. (http://bmj.bmjjournals.com/cgi/eletters.327/7424/1118#41799)

The Opinion of an eminent Queen's Counsel has been obtained

A leading QC and member of the House of Lords was asked for an Opinion on the Wessely School approach to ME: that Opinion is unequivocal; it states: "*On the document you have sent me there is an overwhelming case for the setting up of an immediate independent investigation as to whether the nature, cause and treatment of ME as considered by the Wessely School is acceptable or consistent with good and safe medical practice. There is substantial doubt as to whether such could be the case. A formal request should be made to set up an enquiry. It is essential that a reputable firm of solicitors should be instructed*".

Are psychiatrists cruel?

Based in New York, Dr John Diamond is a founding member of The Royal College of Psychiatrists. In an extract from his recent book (Facets of a Diamond 2003) in the October 2003 issue of the journal "What Doctors Don't Tell You", Diamond says "*I am no longer a psychiatrist. I renounce it because I believe cruelty is at the core of the profession (and) I believe that there is something inherent in the profession that tends to bring out any cruelty lurking within. I have long wondered why this profession --- which ought to be so compassionate – has, it seems to me, turned its back on humanity*".

A recent article in The Sunday Telegraph ("Trust me, I'm a psychopath" by Alasdair Palmer, 30th November 2003) quotes Dr Robert Hare, a Canadian professor of psychology, as saying "*The psychiatric profession and its associates are very reluctant to admit they are wrong or that they have made a mistake*".

Yet psychiatrists have powerful positions of control and ever more credibility in so many areas: Simon Wessely and Anthony David were funded by the US Pentagon (and came to the conclusion that Gulf War Syndrome does not exist) and Wessely is involved with advising NATO. Add to this the errors of mis-diagnosis made by psychiatrists in the past (Parkinson's Disease, multiple sclerosis, epilepsy, diabetes, thyrotoxicosis and many other disorders with a physical causation have all been asserted by psychiatrists to be "mental" disorders until medical science revealed their true aetiology) and one has a right to despair at the current situation facing ME patients.

Two illustrations of the implementation of Wessely School policy

Out of the many known cases of patients being persecuted as a result of the implementation of Wessely's policy on ME, just two are mentioned here: details of

many others have been put before the Chief Medical Officer, who has made it known that he receives more letters about ME than on any other medical issue. There are numerous records relating to this matter in Hansard (both Lords and Commons) and on 23rd November 1999, the House of Commons Select Committee on Health produced its Report looking at adverse clinical incidents, unexpectedly poor outcomes to treatment, failures in medical care and poorly-performing doctors: that Committee took representations from at least eight people about ME.

1. <u>The case of Ean Proctor</u>

In 1988, a formerly healthy 12 year old boy named Ean Proctor from the Isle of Man had been suffering from ME since the autumn of 1986; his symptoms included total exhaustion, feeling extremely ill, abdominal pain, persistent nausea, drenching sweats, headaches, recurrent sore throat, heightened sensitivity to noise and light and loss of balance; he was also dragging his right leg. In 1987 his condition had rapidly deteriorated; he had gradually (not suddenly as may occur in hysterical disorders) lost his speech and was almost completely paralysed (which lasted for two years). He had been seen by Dr Morgan-Hughes, a senior consultant neurologist at the National Hospital in London, who had reaffirmed the diagnosis of ME and advised the parents that ME patients usually respond poorly to exercise until their muscle strength begins to improve; he also advised that drugs could make the situation worse.

Although he did not obtain his MRCPsych until 1986, during one visit by the Proctors to the National Hospital in 1988, Wessely (then a Senior Registrar in Psychiatry) entered the room and asked Ean's parents if he could become involved in his case; desperate for any help, they readily agreed. Wessely soon informed them that children do not get ME, and unknown to them, on 3 June 1988 he wrote to the Principal Social Worker at Douglas, Isle of Man (Mrs Jean Manson) that *"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".*

On 10 June 1988 Wessely provided another report on Ean Proctor for Messrs Simcocks & Co, Solicitors for the Child Care Department on the Isle of Man. Although Wessely had never once interviewed or examined the child, he wrote *"I did not order any investigations….Ean cannot be suffering from any primary organic illness, be it myalgic encephalomyelitis or any other. Ean has a primary psychological illness causing him to*

become mute and immobile. Ean requires skilled rehabilitation to regain lost function. I therefore support the efforts being made to ensure Ean receives appropriate treatment". Under his signature, Wessely wrote "Approved under Section 12, Mental Health Act 1983".

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

In this "care", the sick child was forcibly thrown 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 expressed a diametric opinion from that of Dr Morgan-Hughes, writing: *" A label does not matter so long as the correct treatment is instituted. 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……..it may help the Court to emphasise that…active management, which takes both a physical and psychological approach, is the most successful treatment available. It is now in everyone's interests that rehabilitation proceeds as quickly as possible. I am sure that everyone, including Ean, is now anxious for a way out of this dilemma with dignity".*

Ean Proctor was kept in "care" and away from his parents for over five months.

Although this took place in 1988, such brutality is still happening in the UK: the continued barbaric "treatment" of sick children by certain psychiatrists who profess to specialise in ME was the subject of a Panorama programme transmitted on 8th November 1999 and was profoundly disturbing (a videotape recording is available). Nothing seems to have been learnt from the appalling case of Ean Proctor and there is no question that children with ME continue to be forcibly removed from their parents and home; this issue was raised by Dr Nigel Speight, a consultant paediatrician at the University Hospital of North Durham with 20 years experience of children with ME, who in April 1999 reported to the Chief Medical Officer's Working Group on "CFS/ME" that the frequency of psychiatrists diagnosing the parents of children with ME as having Munchausen's Syndrome by Proxy now amounted to an epidemic. Jane Colby, Executive Director of The Young ME Sufferers Trust (TYMES Trust) says *"To have your sick child taken from you, to be suspected of damaging them yourself, just when they most need your care, is an appalling experience".*

2. <u>The case of Child X:</u> Some ten years after her own nightmare experience, Mrs Proctor answered a knock at her door on the Isle of Man and was surprised to find herself confronted by a police officer who had been directed to question her by the Metropolitan Police. Although at the time she did not know it, another child with ME in southern England was being threatened with forcible removal from his home if his parents did not agree to his being admitted to a psychiatric hospital: in an effort to protect the child from inappropriate treatment and medical harm, his father had surreptitiously taken him abroad. When police officers broke into the house, it seems they found Mrs Proctor's name and address and she was therefore suspected of assisting the boy's parents in his disappearance and of harbouring him, which was untrue. Believing his son to be safe, the father returned to the UK where he was arrested and sentenced to two years imprisonment, a sentence he was happy to endure, thinking that his son was safe. However, the child's mother was then targeted and threatened with imprisonment if the boy was not handed over to a particular psychiatrist at a Teaching Hospital. The physically sick child was forced to spend seven months under the "care" of this psychiatrist and was subjected to "active rehabilitation", during which time his condition deteriorated considerably. He is now severely ill and terrified of health professionals.

The lengths to which these psychiatrists who have focused their careers on "eradicating ME" will go in order to obtain parental obedience, and the control they wield, is extremely disquieting.

Professor Wessely, though, seems to be curiously affected by elective amnesia over the compulsory removal of children with ME from their parents: his involvement with the wardship of Ean Proctor is incontrovertibly established, yet in a Channel 4 News programme on 26th August 1998 in which the case of Child X was being discussed, when asked by the presenter Sheena McDonald if there can ever be a case for the coercive approach in situations involving forcible removal of a child with ME from the parents, Wessely stated *(verbatim quote) "You know very well I know nothing about these cases"* and when Sheena McDonald asked *"So you would agree that unless there is criminal*

abuse, there is never a case for a coercive approach to take children away from parents?", Wessely replied *(verbatim quote) "I think it's so rare. I mean, it's never happened to me"*. Despite this denial on national television, there is unequivocal evidence that Wessely had been personally involved in Ean Proctor's wardship and that he had advised the local authorities to take the action they did. (Copies of Wessely's letters and reports and a videotape recording of the Channel 4 News item are available).

The formal international classification of ME by the World Health Organisation

Although formally classified by the World Health Organisation in the International Classification of Diseases (ICD) as a neurological disorder since 1969 (currently to be found at ICD-10: G93.3), Wessely School psychiatrists have succeeded in a gradual but consistent distortion of the clinical entity ME, by denying its very existence and by subsuming it within the heterogeneous label of "CFS". The term CFS was first coined in the US in 1988 and at the time, it was indicated that it was intended to replace the older term ME or to be considered equivalent to it, but Wessely School psychiatrists have increasingly equated "CFS" with other chronic fatigue states (especially neurasthenia) which are formally classified in the ICD as Mental and Behavioural Disorders (ICD-10 F48.0).

It is important to be aware, however, that ME remains classified as a neurological disorder in the ICD (with CFS listed as an alternative term for ME) and that the WHO has confirmed it has no plans to re-classify the condition as a psychiatric disorder.

Current Government policy concerning ME/CFS

Whereas the American Medical Association has issued a Statement addressing the fact that basic laboratory tests are insufficient for ME/CFS patients because it is known that routine screening is normal in 90% of such patients and that more complex investigations (such as immunological assays, nuclear medicine screening and gene expression profiling) are essential to demonstrate the underlying biological and physiological basis of ME/CFS, in the UK current and future policy dictates the non-investigation of ME/CFS patients other than by routine screening; it dictates that no special provision or facilities other than psychiatric clinics need be provided for the care of ME/CFS patients; it dictates that no special training for doctors about the disorder is necessary; it dictates the denial of appropriate medical care; it dictates that there is no need for respite care (and commissioning officers are advised accordingly); it dictates that State benefits for those with ME be withdrawn unless patients agree to psychiatric intervention, whereupon (as for all psychiatric disorders) a lower rate of benefit is payable; it approves the use of Court Orders for the compulsory removal from their home of both children and adults with ME under the auspices of the Mental Health Act if patients decline psychiatric

intervention and it dictates that no biomedical research is necessary into the disorder and that such research should not be publicly funded by Government bodies.

What is ME and is it the same as Chronic Fatigue Syndrome (CFS)?

Myalgic Encephalomyelitis (ME): ME is not a new disorder; there are many reports in the medical literature spanning at least 70 years and in April 1978 the Royal Society of Medicine accepted ME as a distinct entity. It is a serious and complex disorder which can affect virtually every major system in the body, with neurological, immunological, cardiovascular, respiratory, hormonal, gastrointestinal and musculo-skeletal manifestations.

The cardinal features of ME are post-exertional muscle fatigability (this bears no comparison with ordinary "tiredness" or "fatigue" or TATT ("tired all the time", which is a feature of many psychiatric disorders); profound malaise; intractable muscle pain in specific groups of muscles (myalgia); variability of symptoms from day to day and even from hour to hour, and chronicity.

Non-psychiatric research into ME is impressive. It is funded in the UK almost entirely by small charities such as MERGE (www.meresearch.org.uk) but not by the larger charity Action for ME, which has now chosen to support Government policy and as a result has received significant Government funding, This research deals with scientific facts, not with beliefs, and there is an ever-increasing body of evidence from international centres of excellence of a variety of biomarkers for ME, some of the most significant being inflammatory markers. The following evidence exists:

neurological deficits - these are demonstrated by nuclear medicine techniques such as SPECT scans (single photon emission computed tomography, a type of radionuclide scanning) and MRS scans (magnetic resonance spectroscopy) which demonstrate cerebral hypo-perfusion, and PET imaging (positron emission tomography) which shows brain areas of hypo-metabolism

endocrine dysfunction - there is evidence of disturbance of the HPA axis (hypothalamic-pituitary-adrenal axis) and of central adrenal insufficiency, with evidence of an impaired stress response in that both the right and left adrenal gland bodies are reduced by over 50%, indicative of significant adrenal atrophy

immune dysfunction - there is abundant evidence of an unusual and inappropriate immune response, with evidence that changes in different immunological parameters correlate with particular aspects of disease symptomatology and with measures of disease severity

vascular disturbances – there are specific disturbances peculiar to patients with ME/CFS, characterised in particular by orthostatic intolerance (this is not the same as postural hypotension, stated by some psychiatrists to be related to de-conditioning).

There is evidence of very extensive damage to the endothelium which lines all blood vessels; it was found to be swollen and stiffened as a result of severe damage: damage of this kind would compromise the blood supply to the deep capillary beds in all tissues, including nerve cells

mitochondrial abnormalities in muscle - there is convincing evidence that ME/CFS patients reach exhaustion more rapidly than normal subjects. The use of ^{31}P NMR (^{31}P nuclear magnetic resonance) has now provided positive evidence of defective oxidative capacity: oxidative activity involves production of ATP (adenosine triphosphate, the main energy releasing source of the cell) which can be seen and monitored in tissues. The findings show that there is a continued loss of post-exertional muscle power (giving an additional loss of power), with delayed recovery for at least 24 hours, whereas sedentary controls recovered full muscle power after 200 minutes. Further evidence shows that some ME/CFS patients have persistent enterovirus within skeletal muscle tissue; these are also findings consistent with delayed recovery of muscle power after exertion.

There is also evidence of increased neutrophil apoptosis (programmed cell death) in ME, whilst evidence of higher levels of TGF β1 (transfer growth factor beta 1), indicative of a persistent viral infection or of a toxic state has been presented at international conference proceedings on ME/CFS.

In health, the cells of endothelium that line every blood vessel of every organ and which provide the all-important blood-brain barrier have tight cell junctions that prevent many compounds from crossing these membranes. Some chemicals are known to open these normally tight cell junctions, allowing free transport of compounds that are toxic to the central nervous system. When the gut wall, for instance, has increased permeability, the opioid peptides (casomorphin and gliadomorphin) which would normally be excluded are absorbed into the blood stream, giving rise to diffuse symptomatology and systemic dysfunction. Hypersensitivity reactions are common in ME/CFS patients, especially to cow's milk and gluten, as well as to many medicinal drugs, particularly to anti-depressants. The compromised gut facilitates the development of a gut dysbiosis which in turn can give rise to autoimmune disease, with very significant and chronic damage to health.

Studies from both Israel and the US have shown that ME/CFS has components of autoimmune disease: immunohistochemistry has shown a high percentage of reactors in these patients as in patients with lupus (another autoimmune disorder) which is a known overlap condition.

Studies performed in the US on ME/CFS patients have shown prominent RNA not observed in normal controls. RNA bands so far sequenced show homology with human genes which are noted for their tendency for gene rearrangement under severe physiological stress: environmental stresses which researchers are investigating include the frequent and well-documented linking of this disease with food and chemical sensitivities. In the UK, a pilot study (funded by a small charity, the CFS Research Foundation) has found changes in 50 or so genes in patients with ME/CFS, from which it

can definitely be concluded that many of the genes that show up are involved with the immune system.

The exhaustion experienced by patients is extreme, being described in the Journal of the American Medical Association in the following terms: *"The disabling weakness and exhaustion that a patient with (ME) CFS experiences is so profound that "fatigue" is probably an insult"* (J. Cuozzo: JAMA 1989:261:5:697).

Other distressing symptoms commonly arising in the more severely affected are:

- multi-systemic dysfunction including vertigo, dysequilibrium and ataxia
- difficulty with swallowing (choking fits are not uncommon and both adults and children may require tube-feeding) and voice production (particularly if speaking is sustained)
- episodic cardiac pain indistinguishable from myocardial infarction (heart attack) and segmental chest wall pain
- pancreatitis
- frequency of micturition, including nocturia (bladder and bowel control may be insecure)
- pronounced vascular disturbance (leading for example to an inability to use the fingers and to the "ME headache")
- inability to stand unsupported for more than a few moments with the ability to walk only very short distances, requiring the use of a wheelchair
- difficulty with simple tasks such as climbing stairs and dressing
- difficulty with breathing, with sudden attacks of breathlessness requiring the administration of oxygen (lung function studies have demonstrated a significant reduction in all parameters tested)
- in females, ovarian-uterine dysfunction is not uncommon, whilst in males, prostatitis and impotence may occur
- cognitive impairment may be profound
- hair loss is a recognised and documented finding
- an adverse reaction to medicinal drugs, especially to anaesthetics, is virtually pathognomonic.

American and Australian research has shown that the quality of life in this disorder is lower than for any other chronic illness group apart from terminal cancer and that the quality of life is uniquely disrupted on all levels.

A major report by an ME charity (Severely Neglected: ME in the UK; Action for ME, March 2001) found that 77% of sufferers experienced severe pain; over 80% had felt suicidal as a result of the illness; 70% are either never able, or are sometimes too unwell, to be able to attend a doctor's clinic; 65% (ie. nearly two out of three) have received no advice from their GP on managing this illness; 80% of those who are currently bed-ridden by ME report that a request for a home visit by a doctor has been refused, and many people do not receive the State benefits to which they are clearly entitled. (This report is apparently no longer used by Action for ME, who have seemingly now joined forces with the Wessely School in endorsing psychiatric interventions).

Suicide rates are very high, not necessarily because patients are psychiatrically disturbed, but because the unavoidable isolation and the physical suffering are simply unbearable without adequate support. The losses are many, including loss of career, loss of marriage, loss of ability to be self-supporting and loss of independence. Although frequently told that they do not look ill, patients may be severely incapacitated and quite unable to fend for themselves. Their suffering is compounded if, as is often the case, their means of financial survival by way of State benefits is withdrawn because of Wessely's dictum that ME is a "non-disease" *(see below)*. Many patients are simply too sick to be forced to attend psychiatric units and to participate in compulsory "management strategies" which involve exercising, but if they fail to attend, they are deemed not to want to get better and their State benefits are withdrawn because of Wessely's dogmatic advice to Government that ME is nothing more than an "aberrant illness belief". There are many such known cases, including those in which ME patients have been threatened with being sectioned (ie. compulsorily detained under the Mental Health Act) unless they comply with psychotherapy.

In his Testimony before the US FDA Scientific Advisory Committee on 18th February 1993, Paul Cheney, Professor of Medicine and Director of the Cheney Clinic, North Carolina and one of the world's leading experts on ME/CFS, testified as follows:

"I have evaluated over 2,500 cases. At best, it is a prolonged post-viral syndrome with slow recovery. At worst, it is a nightmare of increasing disability with both physical and neuro-cognitive components. The worst cases have both an MS-like and an AIDS-like clinical appearance. We have lost five cases in the last six months. The most difficult thing to treat is the severe pain. Half have abnormal MRI scans. 80% have abnormal SPECT scans. 95% have abnormal cognitive-evoked EEG brain maps. Most have abnormal neurological examination. Most have evidence of T-cell activation. 80% have evidence of an up-regulated 2-5A antiviral pathway. 80% of cases are unable to work or attend school. We admit regularly to hospital with an inability to care for self".

In the February 2000 issue of the American Journal of Medicine, Anthony Komaroff, Assistant Professor of Medicine at Harvard, summarised key points in an Editorial:

"Many controlled studies have compared patients with age-matched and gender-matched healthy control subjects. The evidence indicates pathology of the central nervous system and the immune system. There is considerable evidence from different investigators, using different techniques and different groups of patients, of a state of chronic immune activation. In summary, there is now considerable evidence of an underlying biological process in most patients (which) is inconsistent with the hypothesis that (the syndrome) involves symptoms that are only imagined or amplified because of underlying psychiatric distress. ***It is time to put that hypothesis to rest***".
As long ago as 1994, Professor Paul Levine from the US National Cancer Institute stated *"the spectrum of illnesses associated with a dysregulated immune system must now include (ME)CFS"* and the Centres for Disease Control now take the disorder so seriously that it has been designated a ***"serious legitimate diagnostic Priority One disease of public health importance"***.

In the UK, the very existence of ME is denied: psychiatrist Simon Wessely advises that ME is a "non-disease" and he has personally re-classified CFS as a mental disorder in UK reference manuals *(see below)*. He asserts that the disorder exists only because of "*artefacts of medical specialisaton"* and he advises that such disorders *"should not be dignified by their own formal case definition and body of research"* (Functional somatic syndromes: one or many? S Wessely, C Nimnuan, M Sharpe Lancet 1999:354:936-939).

What is CFS?: In the 1980s in the US (where there is no NHS and most of the costs of health care are borne by insurance companies), the incidence of ME escalated rapidly, so a political decision was taken to rename ME as "the chronic fatigue syndrome", the cardinal feature of which was to be chronic or on-going "fatigue", a symptom so universal that any insurance claim based on "tiredness" could be expediently denied. The new case definition bore little relation to ME: objections were raised by experienced international clinicians and medical scientists, but all objections were ignored. In 1991 in the UK, Wessely and Sharpe were amongst a group which produced their own criteria for "CFS" and this definition became known as the Oxford criteria. In 1994 these same psychiatrists were instrumental in yet another revision of the criteria known as the CDC or the Fukuda criteria because they were produced under the auspices the US Centres for Disease Control. Of great significance is the fact that both the Oxford and the CDC criteria specifically include psychiatric conditions which are known to feature prolonged "fatigue" or "tiredness" and, crucially, they specifically exclude **all physical signs** from the case definition of CFS, including the signs of neurological disease which had been noted in the ME medical literature for many years. Thus the quite specific neuro-immunological disease ME became subsumed within the heterogeneous label of "CFS".

This marked a turning point in the "eradication" of ME by psychiatrists and of the campaign to designate CFS as a "mental" disorder.

Are both camps studying the same disorder?

Disconcertingly, the editors of both the CMO's Report of January 2002 and the Medical Research Council's subsequent document setting out its preferred strategy for the direction of future research in "CFS/ME" (released on 1st May 2003, the editor being Dr Chris Watkins, whose position at the time was MRC Programme Manager for Research on Mental Illness) persistently refused to heed repeated calls for accuracy: when draft copies of both Reports were studied, the same important error appeared in both documents and was pointed out but was deliberately retained in the final version of both reports. That error relates to the classification of ME and of CFS in the ICD and it reads: *"Currently, CFS and ME are classified as distinct illnesses in the World Health Organisation's International Classification of Diseases" (CMO's Report 2002:1.4.1).*

As this error was pointed out to the editors of both reports long before they were published, it cannot have been an over-sight that the error appeared in the final versions of the reports and it may well have been expedience on the part of the Wessely School psychiatrists who dominated both reports *(see below)*.

This error is easily shown to be erroneous: CFS is clearly listed at G93.3 as a term by which ME is also known, whilst other syndromes of chronic fatigue are listed under Mental and Behavioural Disorders at F48.0, **a category from which ME/CFS is expressly excluded by the WHO.** Moreover, the WHO has confirmed that it is *"unacceptable"* for the same disorder to be classified in two different places and does not accept this to have occurred.

It is necessary to be aware that the patients studied by Wessely are largely obtained from either his own 1991 Oxford criteria or from the 1994 CDC criteria which he helped to develop, neither of which selects those with ME.

It is increasingly accepted that it is inappropriate to synthesize results from studies of this illness which use different definitions to select study populations (A Comparison of Diagnostic Criteria. Jason et al: Evaluation and the Health Professions: in press December 2003), but Wessely is well-known for using the terms "fatigue"; "chronic fatigue"; "CFS" and "ME" interchangeably, even though they may represent totally different patient populations. He has been stringently criticised for this in, for example, the Quarterly Journal of Medicine (QJM 1997:90:723-727), where Hedrick succinctly pointed out his mischaracterisation of the facts and noted that it is unacceptable for him to summarise a wide variety of studies, in this case drawing conclusions across seven studies which were based on different patient populations -- from simple fatigue of 30 days to severe chronic fatigue of decades – without addressing the adequacy of the analysis performed. (In his article, Wessely even left out findings from cited studies which did not support his own pre-determined conclusions). To quote Hedrick: *"Studies and review articles on psychiatric factors and CFS need to be subject to the same standards of scientific inquiry as studies investigating organic factors, lest the theoretical*

stance of the researchers / authors turns out to be the most powerful predictor of results".

Wessely is always at pains to point out that only "patients" refer to the disorder as ME and that those with superior knowledge (ie. doctors) refer to it as "CFS".

Until the issue of case definition is accurately addressed and is beyond doubt, it seems to serve Wessely's purpose very well indeed to ensure that clinical obfuscation continues to abound around ME and CFS.

The published views of the Wessely School on ME

Wessely continues to be overtly patronising in his encounters with ME/CFS patients whilst continuing to mock and denigrate them in print and in his behaviour with his colleagues, where those with ME are the subject of his ill-concealed ridicule and contempt, as exemplified when he gave the 9th Eliot Slater Memorial Lecture at the IOP on 12th May 1994 (of which an audiotape recording exists). The title of his lecture was revealing: "Microbes, Mental Illness, The Media, and ME: the Construction of Disease".

The sheer cumulative extent of Wessely's denigration of ME patients as set out in his published works over 16 years has to be read for oneself to be believed.

For convenience, attached as an appendix to this document is a short compilation of referenced quotations from the published works on ME/CFS of both Simon Wessely and Michael Sharpe, which speak for themselves.

Extracts from many of Wessely's published papers from 1987 to 1999 have been compiled in two spiral-bound volumes for ease of access and are available at cost price on request *(see Further Reading)*.

Wessely is well-known for his published views on ME. One of the best known dates from 1993 when, together with Anthony David, he wrote in the Lancet (Lancet 1993:342:1247-1248) in unmistakable terms: "*The inclusion in the tenth revision of the ICD of benign myalgic encephalomyelitis under Diseases of the Nervous System seems to represent an important moral victory for the self-help groups in the UK (but) neurasthenia remains in the Mental and Behavioural Disorders chapter under Other Neurotic Disorders. Neurasthenia would readily suffice for ME. Applying more stringent criteria for CFS in the hope of revealing a more neurological sub-group succeeds only in strengthening the association with psychiatric disorders*". What is strange is that the authors seemed not to know that in 1993, ME had already been classified under Diseases of the Nervous System for almost a quarter of a century.

Wessely believes that "*There lies at the heart of CFS, not a virus or immune disorder, but a distortion of the doctor-patient relationship*" (Chronic fatigue syndrome: an update. Anthony J Cleare Simon C Wessely. Update 14th August 1996:61-69).

In another paper, Wessely claims that ME exists "*only because well-meaning doctors have not learnt to deal effectively with suggestible patients*" (Psychological Medicine 1990:20:35-53).

Wessely concluded his major Review of the Post-viral Fatigue Syndrome (yet another ICD term for ME/CFS) in the prestigious British Medical Bulletin by citing medical comments on patients between 1880 and 1908, with the clear implication that such descriptions apply equally well to today's ME sufferers: "*always ailing, seldom ill; a useless, noxious element of society; purely mental cases; laziness, weakness of mind and supersensitiveness characterises them all; the terror of the busy physician*" (BMB 1991:47:4:919-941).

In one medical textbook, Wessely wrote about ME/CFS patients that "*the description given by a leading (doctor) at the Mayo Clinic remains accurate: 'the doctor will see that they are neurotic and he will often be disgusted with them' "* (Chronic fatigue and myalgia syndromes. Wessely S. In: Psychological Disorders in General Medical Practice. eds: N Sartorius et al Hogrefe & Huber 1990)

In relation to patients with ME/CFS in a paper on "medically unexplained symptoms", Wessely states *" Patients with functional somatic symptoms are generally viewed as an unavoidable, untreatable and unattractive burden"* (Patients with medically unexplained symptoms. Alcuin Wilkie Simon Wessely. British Journal of Hospital Medicine 1994:51:8:421-427).

Such has been Wessely's "help" to ME/CFS patients over the last sixteen years of almost supreme reign over their fate that they are frequently abused by busy physicians whose views are based upon the misinformation with which they have been targeted and bombarded by the journals and the medical trade press (over which Wessely exerts so much editorial control) to the virtual exclusion of opposing views. Busy practising clinicians rarely have time to study the international medical literature which presents a very different picture.

Wessely's own literature output is prodigious; he has authored well over 200 papers, so it is necessary to be aware that a database search on "ME/CFS" is dominated by his publications and that he promotes himself as a world expert in "medically unexplained symptoms", a category in which he and his adherents firmly place "CFS"; it is easy, therefore, for the uninformed and disinterested to be misled about what is actually known and published in (non-UK) peer-reviewed journals about ME/CFS.

Wessely does not hesitate to refer to himself as a medico-legal expert, in one instance claiming *"I frequently act on behalf of CFS/ME sufferers in their dealings with insurers (see below* for his involvement with insurance companies*) and the courts ---indeed, I was*

the principal expert witness in two recent medico-legal cases concerning CFS. In the first, the sufferer was awarded £160,000 and the second £320,000. These are the only two cases of their kind in the UK". The published response pointed out that in the two cases to which Wessely referred, he was one of three medical expert witnesses in both cases and the £320,000 was an out of court settlement. The £162,000 was awarded in the High Court in December 1992 but was withdrawn by three appeal court judges who accepted Wessely's testimony that the plaintiff (a diagnosed ME sufferer) was "*suffering from at least some degree of psychological disorder*", evidence which was given without Wessely ever having examined the appellant. In claiming that there were only two such cases in the UK, Wessely was misleading, to say the least: in reality, at that time seven similar cases either had been or were going through the British legal system. (CFIDS Chronicle Spring 1994:14-18 and Summer 1994:77-79).

Wessely is ceaseless in his efforts to discredit ME and its hapless sufferers: in early 2002, at his instigation the British Medical Journal ran a ballot asking doctors to vote on which diseases they considered to be "non-diseases" which are best left medically untreated: Wessely proposed ME. 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"*. He appears indifferent to the fact that the stigma of having a "non-disease" could not fail to make things worse for sufferers; certainly it is the case that since the BMJ poll, many more ME patients have been removed without notice from their GP's list, in one specific case, a very sick ME patient was brusquely informed that *"This practice does not treat non-diseases"*.

As a direct result, an unknown number of ME patients are simply left to suffer and die at home without any medical care or support.

Illustrations of Wessely's influence over the national perception of ME/CFS

The WHO Guide to Mental Health in Primary Care: Wessely's determination to eradicate ME as a legitimate medical disorder seems never to cease. In 1997 he deliberately included ME in the WHO Guide to Mental Health in Primary Care. This Guide, available to all GPs in the UK, was produced by the UK WHO Collaborating Centre at the IOP, so it legitimately bore the WHO logo. However, Wessely's covert re-classification of ME was effected without the approval of the World Health Assembly and the WHO has confirmed in writing that what Wessely published about the classification of ME in the UK Guide to Mental Health in Primary Care did not carry WHO approval, stating: "*It is possible that one of the WHO Collaborating Centres in the UK presented a view that is at variance with WHO's position"*. When on 18th August 2003 the Countess of Mar wrote to Wessely's Dean at the Institute of Psychiatry (Professor George Szmukler) raising concerns about the erroneous inclusion of ME as a mental disorder, his reply of 27th August 2003 failed to address the issues raised and instead consisted of a paean of praise for Wessely, describing him as *"one of the most outstanding medical researchers in the UK, and indeed internationally (and he) has been*

awarded a Research Medal by the Royal College of Physicians (specifically for work on CFS). The Institute of Psychiatry has every reason to have confidence in the quality and integrity of Professor Wessely's research". It later transpired that the Dean had co-edited a psychiatric text book with Wessely's wife, also a psychiatrist and a Senior Policy Adviser to the Department of Health.

The NHS Information Authority (NHSIA): this is a body which was set up in 1999 to disseminate approved information throughout the NHS. The fact that the WHO so unequivocally distanced itself from the UK Guide to Mental Health in Primary Care did not prevent Government Ministers and the NHSIA from relying upon the Guide in their own database of mental disorders, both as a source of information from Ministers to Members of Parliament and also for distribution throughout the entire NHS, with dire results for ME sufferers. In various letters to MPs, the Parliamentary Under Secretary of State for Health (Stephen Ladyman MP) refers to the UK Guide to Mental Health in Primary Care as *"the WHO Guide"*, mistakenly conveying the notion that he was referring to a Guide produced by the WHO itself in Geneva (whereas he ought to have been referring to the UK WHO Collaborating Centre at the IOP) and stating about the Guide *"Although WHO were initially keen to use the term 'neurasthenia', they eventually decided to call the section "Chronic Fatigue and Chronic Fatigue Syndrome (may be referred to as ME)"*. In one letter dated 29th August 2003, Stephen Ladyman provided false information for Dr Liam Fox MP, erroneously stating that the current version of the ICD classified CFS in two different places: *"as Neurasthenia / Fatigue Syndrome in the mental health chapter (F48.0) and as Post Viral Fatigue Syndrome / Benign Myalgic Encephalomyelitis in the neurology chapter (G93.3)"*. This is quite unacceptable, because, as mentioned above, the WHO itself has confirmed that this is not the case, and that ME/CFS is expressly excluded from F48.0. It took until 2003 before "patient power" finally succeeded in securing an erratum on the website of the Royal Society of Medicine (publishers of the Guide) but to date (December 2003), the NHSIA has still not corrected its website and continues to classify ME/CFS as a mental disorder.

The House of Commons Library: it is known that MPs are provided only with information on ME/CFS which endorses a psychiatric aetiology, in particular with a Research Paper prepared for MPs by Dr Alex Sleator of the Science and Environment Section of the House of Commons Library (98/107, December 1998) which is simply a re-hash of the discredited Joint Royal Colleges' Report of 1996 *(see below)*. Many letters exist from MPs which testify to this. This is despite the fact that medical textbooks, papers, journals and international conference reports which demonstrate an organic basis for the disorder are known to have been placed in the House of Commons Library for the use of MPs. It has been ascertained that the information supporting an organic basis has been removed to the Library archives, so unless an MP was sufficiently well informed to know what s/he was asking for by name, it is difficult for them to access such material.

The Official Secrets Act: During the life (1998-2002) of the Chief Medical Officer's Working Group on ME/CFS, members were ordered not to discuss the deliberations and were even threatened with the Official Secrets Act (documents available). If the psychiatric lobby which dominated that Working Group is so confident that they are

right, why the need to force the suppression of opposing views by resorting to threats of prosecution under the Official Secrets Act in a Working Group that had nothing to do with State security but was supposed to be acting simply in the best interests of sick people? This is in marked contrast to the "Key working principles" set out in the first Briefing Note of March 1999, which states *"The Group must have maximum 'transparency' ie. as much information about its activities to be distributed as possible to all potential interested parties"*.

The Media: The UK national newspapers frequently run headlines such as *"ME's mainly in the mind---Study reveals yuppie flu can be cured by positive thinking*" (Daily Express, 5th January 1996, about one of Mike Sharpe's studies) and "*ME is just a myth, sufferers told*" (Sunday Telegraph, 20th November 1994, about the conclusions of 150 British psychiatrists attending a pharmaceutical conference in Jersey). On 5th May 1996 the Daily Express carried an article by Jonathan Miller from America, which ran with the headline *"Chronic Bandwagon Disease"* in which he referred to CFS as *"Completely Fictitious Syndrome"*.

Medical Trade Journals: The medical trade magazines (widely distributed free to doctors, especially to GPs and to hospital libraries by the drug companies) have made a point of promoting psychiatric interventions for those with "CFS" and of mocking and denigrating sufferers from ME/CFS in a way they would not dare do about patients with multiple sclerosis or other neurological disorders, yet ME is formally classified by the WHO as a neurological disorder. For example, on 1st April 1994 "GP Medicine" carried a bold banner headline proclaiming *"GPs despise the ME generation"*; on 12th January 1995 "Doctor" magazine ran a feature called "Bluffer's Guide" by Dr Douglas Carnall, in which he wrote *"Modern bluffers prefer the term chronic fatigue syndrome….if they really 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. Or, if you're feeling tired, you could always refer*"; "Doctor" magazine also ran a quiz by Dr Tony Copperfield (known to be the pseudonym of a GP in Essex) in which GPs were asked to choose from four possible answers to the question *"What would be your initial response to a patient presenting with a self-diagnosis of ME?"* The correct answer was *"For God's sake pull yourself together, you piece of pond life"*. One of the worst and most damaging examples was published on 20th October 2001 in "Pulse" in a series called "Choices for the new generation of GPs". The item on which three GPs provided their approach was entitled "*ME patient with litigation history demands inappropriate therapy*" and the approach provided by Dr Mary Church (this is her real name: she is a Principal in a practice in Blantyre, Scotland and most disturbingly of all, she is a member of the British Medical Association medical ethics committee) was particularly contemptuous but is not untypical: "*Never let patients know you think ME doesn't exist and is a disease of malingerers. Never advise an ME patient to make a review appointment. At the end of the consultation, I say goodbye, not au revoir. Always refer ME patients to a local expert. It's a wonderful way of passing the buck*". Although some of these items are doubtless intended to be amusing, it is not appropriate for a doctor to write with such contempt about **any** illness, physical or psychiatric, which ruins lives and quite frequently

causes death, and these items are damaging because they lend credence to what many doctors privately admit they still believe (ie. Wessely's view that ME does not exist and that "CFS" is a psychiatric disorder).

Disgraceful treatment of ME patients: On Sunday 15th June 2003, Clare White, a woman in her early 60s (a graduate who taught French during her professional academic career but who has been severely affected by ME for many years) was taken ill: being unable to contact her GP (because the surgery had only an answering machine telling patients to telephone NHS-Direct) she was forced to telephone 999 for an ambulance. She was taken to the A & E Department of a flagship London hospital in great distress, suffering from acute renal colic and vomiting. On arrival she was seen by a very helpful, polite, considerate and conscientious junior doctor who examined her and found that she had many abnormalities, including blood in her urine. He asked her if she had any other diagnosis, so she told him she suffered from ME. He started to organise various investigations, including an IVP (intravenous pyelogram), informing her of what was proposed. The woman then heard him discussing her case with a more senior colleague just outside her cubicle and was dismayed to hear the senior doctor instruct the junior doctor to do nothing because ME was a "personality" problem which did not need further investigation. She definitely heard this said very clearly. The junior doctor repeated forcefully that the abnormalities he had found had nothing to do with ME and that she needed investigating. The two doctors had a heated argument, the outcome being that the junior doctor, although clearly very angry, was pressurised into not investigating further. In her own words, "a stop was put on the works". To his credit, the junior doctor, who was visibly uncomfortable, arranged a wheelchair and ambulance transport for the woman to be taken home. She lives alone and has no-one to look after her. The pain has now spread to the bladder region but she is receiving no medical care and no social support. No-one wants to know and no-one cares.

Medical Insurance: In December 2003 a professional woman telephoned SAGA with a view to taking out private health insurance; she was asked if she suffered from any chronic physical disorder, to which she replied that she suffered from ME. The reflex response of the clerk was "Oh, that's not a physical disorder".

Illustrations of Wessely's influence over the international perception of ME/CFS

Wessely's influence is not restricted to the UK; of many available, just two illustrations (one from Australia and New Zealand and one from Canada) are presented here.

The Australian CFS Report 2002 (Chronic fatigue syndrome: Clinical practice guidelines ---2002. Report of a Working Group convened under the auspices of the Royal Australasian College of Physicians. Medical Journal of Australia 2002:176: S17-S55). This Report virtually echoed the UK Joint Royal Colleges' Report of 1996 and was comprehensively condemned as seriously flawed. One typical review is that of Dr Abhijit Chaudhuri, DM, MD, MRCP(UK), Clinical Senior Lecturer in Neurology,

University of Glasgow and Consultant Neurologist who specialises in ME/CFS: *"This document contains many flawed statements and observations (and) the accounts appear biased and inaccurate. I have deep concerns about the selectivity of the literature review. The document has over-emphasised the behavioural model and has failed to review the appropriate literature on the neurology. The paper has devoted much of its clinical discussion on the comparison of psychiatric disorders with CFS. The quality of references and review on the neurological aspect of CFS is very poor, with omissions of research carried out by international groups in the past three or four years. The cited references show a skewed representation of a group of psychiatrists. The guidelines show a preference for cognitive behaviour therapy and graded exercise therapy and ignore criticisms and the flawed designs of the trials upon which their success has been claimed. Many areas of the text appear highly opinionated in favour of the psycho-behavioural model of CFS. The document cannot be recommended since it does not reflect the cumulative base of knowledge on CFS".*

Notwithstanding intense international criticism, it was this same Australian Report that formed the basis of the MRC's 2003 Report on the direction of future research in ME/CFS from its Research Advisory Group *(see below)*.

A Canadian reference book: Whiplash and Other Useful Illnesses (a medico-legal reference book by Andrew Malleson, published in 2003 by McGill-Queen's University Press, Montreal and London). This supposed reference book is one of the worst in existence and is a shameful display of ignorance on the part of its author. He cites Wessely in his references and in the chapter headed "Finessing Whiplash: Copycats and Fashionable Illnesses" vents his undisguised venom on ME/CFS patients :

"Somatizers had dropped neurasthenia like a hot brick, Fatigued somatizers needed a new diagnosis (so) they developed "chronic fatigue syndrome" (CFS) in North America and "myalgic encephalomyelitis" (ME) in the United Kingdom. Chronic fatigue syndrome has gone from strength to strength. In Britain in the mid 1950s, an apparent viral illness featuring muscle pains and severe fatigue hit 292 members of the staff at the Royal Free Hospital in London. The illness was well-publicized by the media and, in a familiar pattern, people all over the country soon came down with it; many are still doing so. The Royal Free epidemic was first christened "encephalomyelitis" but because no-one died, the illness was re-named "benign myalgic encephalomyelitis". Its victims soon dropped the "benign" so the condition is now known simply as "myalgic encephalomyelitis". Shorter comments "The disease label alone was a triumph of the longing for organicity over science". At the end of the 1980s, conventional medicine focused on the acquired immunodeficiency syndrome of AIDS. AIDS left its victims in a chronic state of exhaustion. In the typical way that fashionable illnesses have of acquiring serious-sounding pathology, CFS quickly incorporated this concept. The chronically fatigued promptly renamed their illness "chronic fatigue and immune dysfunction syndrome (CFIDS), a condition satisfactorily endowed with all the pathological glamour of AIDS, but respectable. From the medico-legal point of view (lists produced by itemizers of symptoms) are a goldmine. They provide lawyers with

symptoms over which they can litigate and healthcare practitioners with the ability to charge insurance companies for treating practically any symptoms of which a patient might choose to complain. Victims of CFS and ME, like the neurasthenics before them, are mostly young to middle-aged women from the middle and professional classes. Epidemics of ME, CFS (and) environmental hypersensitivity do not occur in the industrially underdeveloped countries. Fashions and affluence go together. Before the days of the welfare state, only the well-off could afford a fashionable illness, although as sickness benefits and compensation payments have made the luxury of pseudo-illnesses more accessible, these illnesses have trickled down the social pyramid. I have used the word "victim" to designate the sufferers of fashionable illnesses. I have done so deliberately, because these sufferers are quick to adopt the victim role. They often see themselves being harmed by members of the medical profession who inflexibly refuse to recognize the validity of their suffering. As well-educated members of the middle and professional classes, these victims are often vocal advocates for their own anguish. Despite their fatigue, literate victims of fashionable illnesses have displayed inexhaustible energy writing, arranging meetings and proselytising on behalf of their particular fashionable illness. Victims aim much of their copious literature at the unbelieving doctors and their callous disregard for such illnesses (because) in order to provide compensation or support, insurance companies and government social services require medical validation of the illness. Some doctors, perhaps out of a sense of scientific integrity, out of bloody-mindedness, or even, as the claimants for fashionable illnesses sometimes maintain, because of payments from insurance companies, refuse to validate these pseudo-illnesses. Responsible members of the medical profession have difficulty providing authentication when no evidence of any disability exists".

Andrew Malleson was born and brought up in England but is now a psychiatrist with Toronto University Health Network; he is also psychiatric consultant to the Canadian Government Occupational Health and Safety Agency; his particular interest is in the uses and abuses of illness, especially illnesses that are intentionally or unconsciously feigned. He has done medico-legal work for the last 15 years.

Malleson seems entirely unaware of a well-recognised problem in modern medicine, namely, that medicine does not listen to patients any more, nor does it pay any regard to symptoms: it only respects laboratory results. Clinical practice (the very foundation of medicine) is now ignored. In a nutshell, there is a current misconception that evidence-based medicine means laboratory-based medicine, wherein objective clinical observation is accorded lower evidential weight than laboratory measurements. If no cutting-edge laboratory investigations are to be permitted (as is currently the case for ME/CFS patients), then the politically desired *status quo* will prevail and the advancement of medical science will continue to be actively obstructed by corporate control.

Tactics of denial

It is not only upon ME/CFS patients that Wessely School psychiatrists seek to impose their preferred but unproven psychotherapy regimes; other related conditions for which these particular psychiatrists promote their own regime include almost any syndrome for which medicine does not yet have an explanation of the exact, confirmed pathoaetiology, for example, fibromyalgia, multiple chemical sensitivity, chronic low-dose organophosphate poisoning, Gulf War syndrome, pre-menstrual tension, irritable bowel syndrome, and atypical chest pain. Psychiatrists of the Wessely School deny the physical reality of all these conditions, asserting that they are all one and the same psychiatric condition. (In the case of irritable bowel syndrome (IBS), it has now been shown not to be a "psychological" disorder at all: American researchers have demonstrated molecular alterations in serotonin signalling in the gastro-intestinal tract and that IBS is caused by altered gut biochemistry).

In relation to Gulf War syndrome, Wessely claims that Gulf War veterans have a three-fold increase in somatoform disorders: despite the fact that in the UK alone, over 500 formerly healthy, tough young men have died, Wessely denies the existence of any such syndrome and has advised the Ministry of Defence that one of the biggest risk factors for a soldier to develop ill-health following deployment to the Gulf is the fact that s/he knows another deployed person who has developed a similar illness.

Denial of the known and available evidence

Denial of existing evidence is currently popular by those who see themselves as "revisionists", and such people are extremely dangerous, as they seem to believe that they and their like-minded colleagues alone have the prerogative to define reality.

On 29th April 2000 Channel Four transmitted a programme entitled "Denying the Holocaust" which revealed the tactics used by "deniers" of the truth (in that case, the reality of the Holocaust).

Whilst in no way comparing the suffering and atrocities imposed upon Holocaust victims with the suffering imposed upon those with ME/CFS by doctors who do not believe in it, it may nevertheless be salutary to examine the similarities in the tactics and methods used by "deniers" and "revisionists" of whatever discipline.

Referring to David Irving (the subject of the lengthy legal action involving Penguin Books and Professor Deborah Lipstadt, who was also the subject of the programme). Lipstadt branded Irving *"one of the most dangerous of the men who call themselves revisionists"*. The narrator said *"familiar with (the)…evidence, he bends it until it conforms to his ideological leanings and political agenda"*.

Such allegations have been made about Wessely in relation to what he publishes about ME/CFS.

Tactics used by "deniers" were identified in the programme as including the following:

manipulation, distortion, deliberately portraying things differently from what is known, falsifying facts, invention, misquotation, suppression, illegitimate interpretation, political re-modelling, exploiting public ignorance and intimidation.

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

To policy makers and physicians in a cash-strapped NHS, the advantages of denial must seem attractive. The last thing needed is a disease which threatens the health of hundreds

of thousands if not millions world-wide, 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 and which misrepresent the existing literature and which make unsubstantiated claims abound, with the consequence that readers are deliberately 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 profundity of articles, reports and research papers produced by this group of psychiatrists 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 or immunological research, let alone on long-term sickness benefits.

It may be informative to compare the tactics of denial listed above as identified in the TV programme with a selection of methods and tactics used by those engaged in denial activity relating to ME:

- 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.

- 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 targetting ***psychiatrists***; who 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 psychiatric interpretation of the 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 and / or unusual features which are present.

In the case of ME/CFS, it seems apparent that the tactics of denial which were exposed in the Channel Four programme mentioned above are indeed being implemented by the psychiatrists of the Wessely School; out of the many available illustrations, just the following are provided:

- On 25th April 2000, Dr Michael Sharpe of Edinburgh wrote a letter to Mrs Ann Crocker in which he stated *"I understand your desire to have the condition classified as a Neurological Disorder (but) trying to change doctor's (sic) behaviour by altering classification probably will not work and might even provoke a paradoxical response"*. The reality is that ME is already formally classified by the World Health Organisation in the ICD as a neurological disorder,

and it is Wessely School psychiatrists (not patients) who are actively trying to "alter the classification" ***<u>from</u>*** neurological ***<u>to</u>*** psychiatric.

- On 18th January 2000 Simon Wessely wrote to the Countess of Mar that the *"ad hominen (sic) attacks"* upon him *"may have the unforseen outcome of re-inforcing unhelpful stereotypes of sufferers held by some in high office"*. Again, this seems to be nothing less than a threat, with the use of an intimidation technique made, it must never be forgotten, to very sick human beings who have been trying since Wessely came to such prominence in 1987 to redress the wrongs perpetrated upon them by these powerful medical deniers.

- In the Joint Royal Colleges' Report on CFS *(see below)*, the authors mention a paper by Buchwald, Gallo and Komaroff et al (reference 128 in the Joint Report) but dismiss it, stating *"White matter abnormalities occur in a number of settings and their significance remains to be determined"*, whereas the paper itself concludes that patients with ME/CFS *"may have been experiencing a chronic, immunologically mediated inflammatory process of the central nervous system"* and that the MRI scans revealed a punctate, subcortical area of high signal intensity consistent with oedema or demyelination in 78% of cases. This is a clear illustration of the biased and misleading personal interpretation of the available evidence by Wessely School psychiatrists.

- Also in the Joint Royal Colleges' Report, the authors mention a paper by Bombadier and Buchwald (reference 173 in the Report) and convey that this paper supports their own stance, whereas the paper itself actually contradicts the Joint Report and clearly states *"The fact that the same prognostic indicators were not valid for the group with CFS challenges the assumption that previous outcome research on chronic <u>fatigue</u> is generalizable to patients with chronic fatigue <u>syndrome</u>"*.

- Another illustration is found in the Joint Royal Colleges' Report: the authors rely on a paper by Sandman et al (reference 163 in the Joint Report) in apparent support of their own view that the results of neuropsychological testing have been inconsistent, but the paper in fact concludes *"the performance of the CFIDS patients was sevenfold worse than either the control or the depressed group. These results indicated that the memory deficit in CFIDS was more severe than assumed by the CDC criteria. A pattern emerged of brain behaviour relationships supporting neurological compromise in (ME)CFS"*. One would never know this from the way the authors of the Joint Royal Colleges' Report deliberately downplayed, misrepresented and manipulated the references which they cited in supposed support of their own views.

<u>The Joint Royal Colleges' Report on CFS, October 1996</u>

Like its successors from the same stable (the CMO's Working Group Report of January 2002 and the MRC's Strategy document of May 2003 – *see below*), this Report erroneously refers to CFS as being classified by the WHO in the ICD under "Mental and Behavioural Disorders" (F48.0), whereas in fact CFS is one of the terms by which ME is listed and is classified under Diseases of the Nervous System at G93.3.

It is worth noting that out of the 15 medical members of the joint working group, 12 were committed adherents of the Wessely School well-known for their entrenched views on ME/CFS, illustrations of which include the following:

Anthony David: *"Doctor behaviour, such as sick certification, emerged as a significant contributor to the risk of chronic fatigue*" (Predictors of chronic "postviral" fatigue. Lancet 1994:344:864-868).

Sean Lynch: *"The original criteria for the chronic fatigue syndrome would exclude patients with any concurrent psychiatric symptoms, but as few patients would then meet this definition, these criteria were widened to include psychiatric morbidity*" (Antidepressant therapy in the chronic fatigue syndrome. British Journal of General Practice 1991:41:339-342).

Anthony Pelosi: "*The myalgic encephalomyelitis societies should not try to set the research agenda or shout down views with which they disagree*" (Chronic fatigue syndrome and myalgic encephalomyelitis. BMJ 1994:309:276), It seems to be perfectly acceptable for ***psychiatrists*** to set the research agenda and to shout down views with which ***they*** disagree,

It is enlightening to compare Wessely School views as set out in the Joint Royal Colleges' Report on CFS (CR54) of October 1996 (known to have been dominated by Wessely) with an American Report of the same time (Chronic Fatigue Syndrome: Information for Physicians. NIH Public Health Services, US Department of Health and Human Services, September 1996).

For example, with regard to children, the American Report states on page 7 that it advocates a "*supportive approach*" but the UK Report states that children may need to be forcibly removed from their parents, stating "*CFS in children covers a broad spectrum of problems, even Munchausen's by Proxy Syndrome*" (10.2).

The American Report states on page 8 that "*the physician should work with the school to limit class time, if necessary, and to resume school attendance gradually*", but the UK Report urges "*an immediate return to school*" (10.12).

The American Report advises "*Home tuition may be an alternative*" but the UK Report states "*School phobia is important as a complication of CFS*" (10.8) and "*We discourage home tuition"* (10.12).

The American Report points out (on page 3) that *"It is important to note that about 40% of carefully evaluated CFS patients do not have depression or other psychiatric illness*", but the UK Report asserts that 75% of all CFS patients do have psychiatric illness (Summary for commissioners, page 45).

The American Report states (on page 3) that "*some studies have found a significantly greater prevalence of allergy in CFS patients (and) patients report a worsening of allergic symptoms or the onset of new allergies after becoming ill with CFS*"; on page 9 it refers to "*the high prevalence of allergies in the CFS population*", but the UK Report describes CFS patients who have "food allergies (or) chemical sensitivities" as fulfilling the criteria for somatisation disorder (7.9); significantly, the authors refer to "food allergy" in inverted commas, thereby indicating their disdainful non-acceptance of food allergy as legitimate.

The UK Report authors are adamant that "*We see no need for the creation of specialist units"* (12.1); that "*We do not think that specific guidelines on the management of CFS should be issued for general practitioners*" (12.4) and that "*In CFS, the greater the number of somatic symptoms, the greater the probability of psychiatric disorder*" (7.11)

The UK Report authors are unequivocal that "*there is no justification" for the use of neuroimaging studies because 'abnormalities' require careful interpretation (and may be) of little consequence"* (7.13); this might be compared with what the foremost UK researcher in nuclear medicine, Dr DC Costa of UCL Medical School, believes about the abnormalities found in ME, namely that the hypo-perfusion of the mid-brain seen in ME is more severe than in AIDS encephalitis, or indeed in any other brain disease he has examined since 1985.

The UK Report authors specifically advise against looking at immunological parameters since "*revealed changes (are) rarely substantial*" (8.9), and in their Summary for commissioners they conclude that "*No investigations should be performed to confirm the diagnosis"*.

Predictably, the authors state that the "*aims of assessment*" should *"elicit the beliefs and fears of patient and family (and) identify psychological distress"* (8.12).

The UK Report authors state *"We have concerns about the dangers of labelling someone with an ill-defined condition which may be associated with unhelpful illness beliefs"* (9.2): ME is classified by the WHO as a neurological disorder, so it is hardly an "unhelpful illness belief" as these psychiatrists claim it to be.

The American Report states on page 6 that *"Patients with CFS should be treated with compassion"*, but the message of the UK Report is clear --- ME does not exist; CFS patients must not be gratified on any level and their aberrant beliefs that they are physically sick must be corrected by compulsory psychotherapy.

Of note is that out of the 256 cited references, almost half were by the same or associated group of authors and included nine which had not been published or reviewed.

Requests that the flawed Joint Royal Colleges' Report be withdrawn were made at the highest level but were refused. The damage done by the Joint Royal Colleges' Report is still reverberating on the UK ME community, but it is notable that at a "CFS" event at the Royal College of Physicians in January 2003, the current President (Professor Carol Black) indicated that more had been learnt since the publication of the Joint Report. Informed attendees refrained from pointing out that much had been learnt long before the 1996 Joint Report was published but that the available knowledge base was comprehensively rejected by the report's authors.

The CMO's Working Group Report on "CFS/ME"

It was as a result of the obvious bias and mis-information which the Joint Royal Colleges' Report contained that the CMO set up the supposedly "independent Working Group" in 1998, whose Report was published in January 2002. Sadly, its membership was far from "independent" and was dominated by the Wessely School psychiatric lobby including Simon Wessely himself, Peter White, Anthony Cleare and Trudie Chalder, supported by child psychiatrist Elena Garralda and Harvey Marcovitch (a paediatrician and editor of Archives of Disease in Childhood and well-known for his article in the BMJ following the Panorama programme in November 1999, in which he wrote "*BBC's Panorama performed a hatchet job on Dr Michael Prendergast, a child psychiatrist (who) uses active rehabilitation as a treatment for chronic fatigue syndrome. It's about time the (medical) profession hit back at those who are vilifying our colleagues*").

The Working Group was partly funded by the Linbury Trust, which since 1991 has financially supported the Wessely School psychiatrists and their studies of "chronic fatigue". The Linbury Trust is one of the Sainsbury supermarket family trusts: since 1996 David Sainsbury (now Lord Sainsbury of Turville) has donated over £11 million to the UK Labour Party and he became Minister for Science, responsible for the Office of Science and Technology as well as for the chemical and biotechnology industries, and for the Research Councils, including the Medical Research Council. The Office of Science and Technology monitors all government funding of research grants and controls official science policy, and it is "policy" which determines the research to be funded.

Undeclared competing interests relevant to the CMO's Working Group Report

The involvement of the Linbury Trust with the CMO's Working Group was made public from the outset but apart from Wessely's close association with the Linbury Trust, there are other areas related to ME/CFS in which he is known to have special interests which he usually does not declare; certainly none of his other competing interests was made public in the CMO's Working Group Report documents:

The disability insurance industry

Wessely School psychiatrists who claim to be specialists in "CFS" (especially Wessely himself, Mike Sharpe, Peter White and Anthony Cleare) are known to have indisputable commitment to the insurance industry and act as medical advisors to it. Many illustrations could be provided. On 17 May 1995 both Wessely and Sharpe were the main speakers at a symposium held at the London Business School entitled "Occupational Health Issues for Employers" at which they advised employers how best to deal with employees who are on long-term sickness absence with "ME". Wessely spoke on the "*myths*" of ME; Sharpe spoke about the use of anti-depressants and cognitive behavioural therapy, and Trudie Chalder spoke about "*selling the treatment to the patient*". Information presented included informing attendees that ME/CFS has also been called "the malingerer's excuse". Another speaker at this conference was Dr John le Cascio, Vice President of UNUM.

Three extracts from a copy of UNUM's "Chronic Fatigue Syndrome Management Plan" seem significant: *(i) Diagnosis*: *Neurosis with a new banner (ii) UNUM stands to lose millions if we do not move quickly to address this increasing problem (iii) attending physicians (must) work with UNUM rehabilitation services in an effort to return the patient / claimant back to maximum functionality* ***with or without symptoms***.

Other insurance companies known to be involved in ME/CFS claims include, in addition to UNUM, Swiss Life, Canada Life, Norwich Union, Allied Dunbar, Sun Alliance, Skandia, Zurich Life and Permanent Insurance, and as Re-insurers, the massive Swiss Re (not the same as Swiss Life). These insurance companies all seem to be involved in re-insurance; for example, Norwich Union uses Swiss Re as re-insurer and psychiatrist Peter White is one of the Chief Medical Officers for Swiss Re. Their other "CFS experts" are Michael Sharpe and Simon Wessely, and they also use psychiatrist Anthony Cleare (a frequent co-author with Wessely).

This means that there is little hope of an ME claim succeeding, because both the insurers and the re-insurers all use the Wessely School psychiatrists to inter-refer claimants with ME/CFS. Given that insurers can refuse to pay out on claims until the claimant with ME/CFS has undergone a "rehabilitation" programme arranged by the insurer, this must surely result in a major conflict of interests because Peter White, Michael Sharpe and Wessely's assistant Trudie Chalder are the beneficiaries of the MRC's latest £2.6 million grant to them *(see below).*

The reliance by insurance companies upon these psychiatrists in cases of ME/CFS has resulted in an insurance scandal of epic proportions. Just two illustrations are provided here, taken from signed Statements of ME patients:

(i) Extract from Statement of Kevin Robinson

"In 1999 Peter Denton White was Chief Medical Officer for Swiss Re and worked for them on Thursday mornings. I also have evidence that Michael Sharpe worked for them. I see it as a conflict of interest for Peter White and Michael Sharpe to work for a re-insurer with exposure to ME claims, and believe that it totally undermines the credibility of their research. The insurers proposed firstly Michael Sharpe and secondly Peter White as joint experts, but being warned about both, I refused to be examined by them. I now know that immediately before the insurer had proposed Michael Sharpe, the insurer had got him to write a report about me without ever meeting me. My main concern is not that he wrote a report without seeing me, but the fact that when he was proposed as expert, the insurer already knew that he believed that I should not be paid. The only reason that the existence of Michael Sharpe's report came to light was that it is listed in the sources for the report of Anthony Cleare, who I did see for the insurer. The insurers were very determined that I should see Michael Sharpe. In addition to using a doctor who was not independent because he worked for the re-insurer, and getting his opinion <u>before</u> proposing him as a supposedly independent expert, the insurer put great pressure on me to accept this "expert". There is no doubt that they were very determined that they wanted me to see Dr Sharpe".

(ii) <u>Extract from Statement of Robert Sclater</u>

"I have suffered from ME/CFS for over ten years and have an insurance policy with Allied Dunbar. During the course of my illness I have been asked by them to attend medical examinations about every two years which has never been a problem until now. On this occasion I was asked to see Dr Michael Sharpe who I know, through my dealing with the Cross Party Group on ME in the Scottish Parliament, to have opinions which could prove harmful to me when being assessed. It is well-documented that Dr Sharpe has on many occasions lectured to insurance companies (and) that he advises that those with ME/CFS who are seeking payment of benefit under their policies should not qualify for such payments. At a meeting at the Royal College of Physicians in February 2002 Dr Sharpe is believed to have advised that he was recommending to insurance companies that claimants with ME/CFS should be subject to covert video surveillance. These comments do not appear to me to be those of an impartial medical assessor. It seems to me that Dr Sharpe should not be paid by an insurance company who he directly or indirectly advises the non-payment of claims for people with ME. This is surely a conflict of interest. For this reason, I contact the Members of the Scottish Parliament that I knew would be interested in my case. I am happy to say that they shared my opinion (and) they wrote letters of support for me. Dr Sharpe has asked the MSPs to retract their statements to Allied Dunbar regarding his suitability to give an unbiased view when assessing people who suffer from ME/CFS".

Members of Parliament are on record as being gravely concerned about the difficulties which their constituents with ME/CFS suffer at the hands of the disability insurers, as recorded in the House of Commons debate chaired by Sir Alan Haselhurst on 21st December 1999 (reference: Hansard 147WH-166WH). In particular, Members of the

Scottish Parliament are very aware of the involvement of Mike Sharpe with the insurance industry and with the processing of claims due to ME/CFS and are extremely concerned about the situation.

Another such competing interest in which Wessely is involved is PRISMA, which stands for Providing Innovative Service Models and Assessments. There are two such bodies with the identical title, but one is based in Germany and is a multi-national healthcare company working with insurance companies; it arranges rehabilitation programmes for those with "CFS" and its recommended management is cognitive behavioural therapy, placing heavy emphasis on training sufferers to *"regain a normal life again"*. PRISMA claims to be especially concerned with long-term disability from the perspective of government, service providers and insurance companies. It claims to have developed a *"unique treatment programme"* for *"hopeless"* cases (it specifically includes those with ME/CFS), claiming that such patients *"avoid physical exercise and social activities, as they fear these may trigger new bouts of complaints"*. In the PRISMA Company Information, Professor Simon Wessely is listed as a Corporate Officer. He is a member of the Supervisory Board; in order of seniority, he is higher than the Board of Management. He is listed as a *"world expert"* in the field of *"medically unexplained illnesses, including Chronic Fatigue Syndrome"*. Is it possible that Wessely recommended to the Chief Medical Officer a management programme for "CFS/ME" which is known to be harmful for those with ME/CFS and which is provided by a company of whose Supervisory Board he is a member?

In his contribution entitled "Functional Symptoms and Syndromes: Recent Developments" in UNUM's Report "Trends in Health and Disability 2002", Mike Sharpe stated about (ME) CFS:

"The majority will meet the criteria for depressive or anxiety disorders and most of the remainder for somatisation disorders of which hypochondriasis and somatoform disorder have most clinical utility. The psychiatric classification has important treatment implications. The current system of state benefits, insurance payment and litigation remain potentially major obstacles to effective rehabilitation. Patient groups who champion the interests of individuals with functional (psychiatric) complaints are extremely effective in lobbying politicians. The ME lobby is the best example. It may be difficult for those who wish to champion rehabilitation and return to work to 'hold the line' (but) it will be imperative that health and social policy address this problem. This will not be easy. However, there are glimmers of progress. One of the major charities (Action for ME) is aligning itself with an evidence-based approach. Funding of rehabilitation by commercial bodies has begun in the UK with organisations such as PRISMA and is likely to continue. An increased availability of rehabilitative treatment facilities is highly desirable. Both health services and insurers need to take a more positive approach".

Another area with which Wessely is known to be involved is the organisation now called HealthWatch, but which used to be called The Campaign Against Health Fraud. HealthWatch is a campaigning organisation which in the past has accepted funding from

both pharmaceutical companies and the health insurance industry. In the Campaign's own literature, it states that it plans a programme of public information and that its aims are *"to oppose…unnecessary treatment for non-existent diseases"*. The same document lists Simon Wessely as a *"leading member of the campaign"*, together with other doctors and psychiatrists who are members of the Wessely School. It is the case that Wessely asserts that ME is a "non-existent" disease. This UK organisation, now a charity, is known for its zealous views which are antagonistic towards alternative and complementary medicine, and towards those who believe in environmental and chemically-induced illness, including ME and multiple chemical sensitivity. One of its founders, medical journalist Caroline Richmond, has a long track record of publishing her contempt for those with ME and of denying the reality of the disorder. Nick Ross of Crimewatch is another founding member. To some people's surprise, Dr Charles Shepherd, formerly Medical Adviser to the ME Association, is also an active member: when Professor Malcolm Hooper made this known in the context of querying undeclared competing interests by those on the CMO's Working Group, Shepherd launched a furious and protracted onslaught upon Hooper and his co-authors, which involved intimidating letters from the HealthWatch lawyers and the sending of endless tirades to the Vice Chancellor of Hooper's university.

Professor Anthony Pinching

One of those who supported the Wessely School view was the Deputy Chair of the Working Group, Anthony Pinching, who at that time was Professor of Immunology at St Bartholomew's Hospital, London. He became notorious for the publication during his tenure of an article (Chronic fatigue syndrome. Anthony J Pinching. Prescribers' Journal 2000:40:2:99-106 published by the Department of Health itself, but now discontinued) which caused great distress to the ME community, in which he made his views clear:

- *"over-investigation can be harmful and counter-productive to the management of these patients, causing them to seek abnormal test results to validate their illness"*
- *"patients avoid activity but then develop symptoms of deconditioning or excessive awareness of physiological changes"*
- *"cognitive behaviour therapy can substantially optimise rehabilitation"*
- *"complementary therapists sometime reinforce unhelpful illness beliefs"*
- *"the essence of treatment is activity management and graded exercise"*.

Pinching did not even mention ME or the key manifestations of it and he expressly stated that the fatigue found in CFS is "*not related to ongoing exertion*": this was a particularly odious statement because in ME, there is always post-extertional muscle fatigue, without which the diagnosis of ME is untenable.

To the consternation of many people with ME, Pinching is now Medical Adviser to the charity Action for ME, which even changed its logo to include "chronic fatigue" but was compelled to remove the words and revert to "Action for ME" by the Charity Commission.

Anthony Komaroff, (who as mentioned above is Associate Professor of Medicine at Harvard and an undisputed world expert on the disorder) is on record confirming that "*Researchers are already using imaging technology to measure brain hormones and are examining the function of the immune system. There is considerable evidence already that the immune system is in a state of chronic activation in many patients with (ME)/CFS"* (American Medical Association Statement, 17th July 2001), but in the UK, clinicians are advised by the CMO's Working Group Report that it is inappropriate and unnecessary even to look for such pathology in those who are thought to have the disorder: the Report states that the management is to be psychiatric and that future NHS service provision for "CFS/ME" patients "*ideally would adopt a biopsychosocial model of care (and that) the components of such a service are facilities for activity management".*

The York Systematic Review of the literature

During the life of the Working Group, a systematic review of the literature was commissioned from the NHS Centre for Reviews and Dissemination (CRD) by the Working Group; the CRD is based at the University of York and is a sibling of the UK Cochrane Centre (part of the international Cochrane Collaboration), whose Director at the time was Professor Iain Chalmers, who, with Simon Wessely, was a member of HealthWatch. Set up in 1994, the NHS Centre for Reviews and Dissemination aims to provide the NHS with important information on the effectiveness and cost-effectiveness of treatments and the delivery and organisation of healthcare and it plays an important role in disseminating politically correct information throughout the NHS.

To no-one's surprise, the CMO confirmed in writing that it was Wessely's own database of over 3000 papers which formed the substance of that review upon which the CMO's Report would depend for its "evidence".

The team which carried out the systematic review of the literature had another team to advise them, since none of them had any clinical experience of "CFS/ME"; again, to no-one's surprise, the key adviser on this "advisory" team was Simon Wessely, assisted by Anthony Pinching and Christopher Clark. At the time, Clark was the new Chief Executive of the charity Action for ME, who on his own admission knew nothing whatever about either ME, CFS or about the literature. It was for this reason that on 28th June 2000 a letter was sent to the CRD asking what could be his input as an "expert adviser" to the review team, and how could someone with no knowledge or experience of the subject contribute to the outcome of a systematic review of the literature on the management of the disorder? Would someone with no knowledge be able to supply an

informed and balanced contribution to a review upon which so much depended for so many very sick people?

A reply was sent on 7th July 2000; it said *"The expert panel was carefully chosen to provide a balanced and representative group……We wish to make no comment regarding Chris Clark's knowledge or experience of cfs/me"*.

Inevitably, the conclusion of the systematic review, published in September 2001, was that the best "evidence-based" management option for CFS/ME was cognitive behavioural therapy and graded exercise therapy. However, it did find that the "evidence" was "weak" and it advised that further research was required.

The Medical Research Council agrees and has granted £2.6 million to psychiatrists of the Wessely School *(see below)*.

The conclusions of the CMO's Working Group Report

Right from the outset, when it became known who were the behind-the-scenes players on the CMO's Working Group, the ME community was disappointed but unsurprised to learn that the remit of the Group was notably narrow: it was restricted to just one aspect, namely, to advising UK clinicians as to "best management practice" of "CFS/ME". Thus the conclusions of the report were widely expected to be disappointing, which was the case. The report side-stepped the vital issue of definition, classification and terminology, stating *"We recognise that no current terminology is satisfactory, so in line with our original terms of reference, we have used the composite CFS/ME, acknowledging that CFS is widely used among clinicians and ME among patients and the community"*. As noted above, the CMO's Report repeated the erroneous information in the Joint Royal Colleges' Report, asserting that CFS and ME are classified as distinct illnesses in the International Classification of Diseases, which is not the case.

This was yet another lost opportunity to set the record straight. That it was lost has been widely acknowledged to be due to the domination of the Group by the same Wessely School psychiatric lobby. No less than five of that psychiatric lobby walked out because they were not getting their own way sufficiently in that the final report failed to agree with them that "CFS/ME" is entirely a primary psychiatric disorder and they were strongly opposed to what they considered to be pandering to the patients.

At the final meeting of the CMO's Working Group, Consultant Paediatrician Dr Alan Franklin, a compassionate clinician with great experience of children with ME, stood squarely in demanding the restoration of the policy of home tuition into the final Report after psychiatrists had removed it and he did much to protect families from unjustly having their sick children taken from them by inappropriate Child Protection procedures. Nevertheless, the CMO's Working Group Report makes the point very clearly that *"Social Services should be made aware that medical opinion in this area is divided"* (5.2.8 Child Protection).

The MRC Research Advisory Group on CFS/ME

The outcome of the CMO's Working Group was an announcement that the Government had asked the MRC to '*develop a broad strategy for advancing biomedical and health services research on chronic fatigue syndrome CFS/ME'*. Speaking at a meeting of the All Party Parliamentary Group on ME, Dr Diana Dunstan, Director of the MRC Research Management Group, said the MRC Research Advisory Group on CFS/ME (known as the RAG) that had been chosen comprised leading experts from various fields "***who did not previously specialise in CFS/ME*** *because it was felt appropriate to get a wide range of specialties and to have* ***an independent and fresh look*** *at the issue"*.
The ME community does not consist only of "white whinging women" as so often portrayed in the press; both sexes are affected by ME and include clinicians, radiologists, medical scientists (including vascular biologists and neurobiologists), lawyers (including High Court judges and their families), university lecturers, academics, teachers, nurses, Members of Parliament, editors, journalists and social workers, amongst others, and although physically and cognitively impaired on various levels, their intelligence remains intact and many of them have an excellent professional knowledge of the literature. Within moments of this announcement it was realised that it was misleading if not false and that some of those appointed to the RAG were far from "fresh" to the field.

Two names particularly stood out: Professor Alan McGregor and Professor Philip Cowan.

Alan McGregor works at Kings College and has co-authored papers on CFS with Simon Wessely (Journal of Affective Disorders 1995:34:(4):283-289; Biological Psychiatry 1995:32:245-252) so is hardly "fresh" to the issue. Further, he is listed as a Member of the Linbury Trust Advisory Panel on CFS; it is the Linbury Trust that has granted Wessely School psychiatrists over £4 million for research into "chronic fatigue"; concerning "treatment", the Linbury Trust approach states that it *"deals only with graded exercise, cognitive behaviour therapy and antidepressants"* (A Research Portfolio on Chronic Fatigue. Edited by Robin Fox for the Linbury Trust. Published by The Royal Society of Medicine Press, 1998).

Philip Cowan has strong views on CFS and is co-author of a paper entitled "Abnormalities of Mood" published in the second Linbury Trust Portfolio on Chronic Fatigue, published in 2000, of which Simon Wessely was co-editor. Cowan has also co-authored papers on CFS with Michael Sharpe and other members of the Wessely School (Journal of Affective Disorder 1996:41: (1):71-76).

Another member of the RAG was Professor Til Wykes, who, like Simon Wessely, works at the Institute of Psychiatry and who is on record for believing about CBT that "*If you encourage them to do things as part of a treatment called cognitive behaviour therapy, then you do see improvement. It's a way of getting people to take control of their lives. It works"*.

Representations were therefore made to Professor Sir George Radda, then Chief Executive of the MRC, who in a written reply dated 15th July 2002 was obliged to concede that *"We are aware of Prof Macgregor's involvement with the Linbury Trust"*; then, somewhat weakly, he stated "*You cite papers from some years ago"*. Inevitably, Radda was forced to support the MRC, saying *"The inclusion of Profs Macgregor and Cowan is consistent with MRC's intention to select the working group from experts in various fields who do not specialise in CFS/ME"*. This unconvincing response failed to reassure the ME community that the legitimate concerns they had raised would be competently addressed.

With this knowledge, the outcome of the RAG Report was anticipated by the ME community and once again, their anticipation proved realistic. The MRC RAG Report was released on 1st May 2003 and baldly stated that *"There are separate entries in the WHO ICD for "chronic fatigue syndrome" and "myalgic encephalomyelitis"* yet before publication of the final version RAG members had had this error specifically pointed out to them, as had been the case with the CMO's Working Group Report. The repeated ignoring of the evidence on this issue must therefore be seen as deliberate, and reflects the determination of Wessely School psychiatrists to re-classify ME/CFS as a psychiatric disorder, no matter what the evidence to the contrary.

The MRC document refers to "*the effects of gender", "mood disorder", "the effects of suggestibility", "personality factors", "sickness behaviour syndrome*" and abnormalities induced by "*immobility*" in relation to ME/CFS and it stated that "*studies investigating causal pathways and mechanisms would not have immediate impact on increasing understanding of CFS/ME"*. This seemed to echo the Linbury Trust view as expressed by Simon Wessely that *"It is usual to try to discover the cause of an illness before thinking about treatment (but) some illnesses are treated without knowledge of the cause; examples include chronic fatigue syndrome"*(New Research Ideas in Chronic Fatigue. Edited by Richard Frackowiak and Simon Wessely for The Linbury Trust. Published by The Royal Society of Medicine Press, 2000).

Predictably, the MRC Strategy document recommended that there was no need for research into biomedical aspects of CFS/ME; it comprehensively dismissed the substantial and validated biomedical research on ME/CFS published in the international peer-reviewed literature which had been brought to its attention, stating that such research was not published in the peer-reviewed literature and that even if it was, it was "*not well-described…….the lack of methodological rigour and independent replication means that many of these claims find little support from the wider medical community but may have strong currency among some patients and practitioners"*. Having read the draft and before publication of the final report, several members of the ME community provided the names of 65 mainstream international journals which had published significant non-psychiatric papers on ME/CFS (including many high impact factor journals); these were submitted to the MRC but as was customary, this information was not acknowledged and was ignored; clearly, the agenda was pre-determined.

So indeed it turned out: the MRC document stipulated that the way forwards was to be further research into psychiatric interventions of cognitive behavioural therapy and graded exercise therapy and that *"there may be a need for specific measures to promote multidisciplinary collaborations (which would) offer established centres of excellence the kind of new scientific opportunities that are essential if (those existing centres) are to sustain their competitiveness internationally"*.

The only "centres of excellence" for "CFS" are psychiatric units, since clinics for ME patients have been summarily closed (for example, Preston).

Uninfluenced by hard evidence and undaunted by the criticism of the House of Commons Select Committee on Science and Technology about its misguided research strategies *(see below)*, the MRC is forging ahead with the Wessely School agenda.

Cognitive Behavioural Therapy: CFS/ME is regarded by these psychiatrists as a behavioural disorder and they advise Government Departments and the insurance industry that it must be "managed" by a behaviour-modifying technique known as cognitive behavioural therapy or CBT (now patronisingly referred to as "Lifestyle Management" in an attempt to disguise the fact that it is psychotherapy), accompanied by compulsory graded exercise therapy (GET) and anti-depressants. CBT aims to stamp out "irrational" thoughts and behaviour and to replace them with "*realism*". Who would compel those with motor neurone disease or multiple sclerosis to "exercise back to fitness" and who would condone the withdrawal of their state benefits when they simply could not do so?

In its Preliminary (Confidential) Report of 26th February 2001 containing the results of its survey of 2,338 respondents, the charity Action for ME stated ***"graded exercise was reported to be the treatment that made most people worse"*** (page 6). This was entirely omitted from the charity's final report. It is this strategy that is recommended in both the report of the CMO's Working Group and in the Medical Research Council's CFS/ME Research Strategy.

Such regimes have been shown to be at best ineffective and at worst extremely harmful, even to the point of death. One well-known MP with ME followed such advice: he collapsed and died coming out of the House of Commons gym.

The Medical Adviser to the UK ME Association wrote in the *Medical & Welfare Bulletin (published by the ME Association, Spring 2001)* that he continues to receive more adverse reports about graded exercise than any other form of intervention and that there is clear confirmation that many people with ME/ICD-CFS are suffering relapses through such programmes. He reminded people that doctors have now been warned by their insurance companies that any form of exercise treatment needs to be prescribed with just as much care as drug treatments, otherwise doctors could be taken to court.

At the 6th American Association of Chronic Fatigue Syndromes International Conference in January 2003, Charles Lapp, Associate Clinical Professor, Duke University; Director, Hopkins-Hunter Centre, Charlotte, North Carolina, quoted from Dr Daniel Clauw's very large study on the efficacy of CBT: after 3 months there were very modest improvements, but when followed up at 6 and 12 months, these modest gains were lost. This is but one of the numerous studies which have shown no benefit from CBT.

Despite the findings from the US that CBT is ineffective, in the UK Wessely School psychiatrists have just been granted a further £11.1 million (£2.6 million from the MRC plus £8.5 million from Government) in order to "strengthen" their own very weak evidence that such mind-altering management regimes are effective and are the best "evidence-based" management option; this sum is in addition to previous funding of over £4 million.

It is perhaps significant that Wessely has served on three Boards of the MRC, including the Monitoring and Evaluating Steering Group (MESG) which conducts evaluations of the MRC's research funding policies; the Neurosciences and Mental Health Board, and the Health Services and Public Health Research Board.

Report of the House of Commons Select Committee on Science and Technology

It is also notable that in March 2003 the House of Commons Select Committee on Science and Technology produced its Report, "The Work of The Medical Research Council" (HC 132) in which MPs issued a damning judgment on the MRC, lambasting it for wasting funds and for introducing misguided strategies for its research. MPs found evidence of poor planning and of focusing on "politically-driven" projects that have diverted money away from top-quality proposals. The unprecedented attack was the result of a detailed probe into the workings of the MRC.

A chemical link?

A major Report from the Royal Commission on Environmental Pollution under the Chairmanship of Sir Tom Blundell FRS, FMedSci was released in June 2003 (Chemicals in Products; pp 291, pub: The Stationery Office). It pointed out that thousands of chemicals are being used every day without proper safety tests. Only 40 of the 30,000 chemicals in large-scale use have been tested fully. It would take 50 years to check all commercial chemicals. Blundell said on the record that *"Given our understanding of the way chemicals interact with the environment, you could say we are running a gigantic experiment with humans and all other living things as the subject"*.

The World Wildlife Fund is on record as pointing out that "*The chemical industry is contaminating the nation and the Government is rolling over and allowing it to continue*" (Independent:25.11.03: Steve Connor).

It is this prevailing use of so many chemicals that is thought to be chronically stimulating the immune system, dysfunction of which (non-psychiatrist) world experts have demonstrated lies at the heart of ME/CFS.

If influential doctors can succeed in portraying ME as non-existent and CFS as psychiatric in origin, then the chemical companies and governments who granted them product licences would not be at risk of being accountable should there turn out to be a provable link with the synergistic effects of so many chemicals, daily exposure to which is now impossible to avoid due to the huge increase in chemical usage.

Accountability becomes even more remote if all research which demonstrates a link between chemicals and the present upsurge in chemically-induced ME is blocked from publication, trivialised, ignored or discredited, as is certainly the case with ME.

Those informed and brave enough to voice their legitimate concerns and who try to resist what they know to be inappropriate strategies are treated as "enemies of the State": they are berated, dismissed, ridiculed, threatened with injunctions, covertly videoed, harassed, subjected to phone taps, bullied, attacked on the Internet and denigrated; their universities are contacted with countless insistent demands for disciplinary proceedings; NHS Consultants are "warned off"; non-psychiatric ME clinics are closed virtually overnight; families are taken before the Courts and children are forcibly removed from their loving parents and placed into psychiatric "care" by those charged with healing the sick.

Wessely School psychiatrists have spent years defending the chemical industry. Two important examples are provided:

<u>The Camelford Drinking Water Contamination</u>

In July 1988 20 tonnes of aluminium sulphate were accidentally pumped into the drinking water supplies of the small town of Camelford in Cornwall. As a result, residents and visitors immediately suffered distressing symptoms; seven people died, 25,000 suffered serious health effects and 40,000 animals were affected. An article by Bernard Dixon in the BMJ on 5th August 1995, based on the work of psychiatrists Anthony David and Simon Wessely, stated that "mass hysteria" was largely responsible for the furore. David and Wessely had found that "anxiety" and "heightened perception of normal bodily sensations" were the cause of the long-term symptoms and that "sensational reporting" by the media had been a significant factor. It was not until 1999 that Paul Altmann from Oxford (commissioned by lawyers acting on behalf of the Camelford plaintiffs and funded by Legal Aid, not through the Department of Health) effectively rebutted the Wessely School view that anxiety was to blame and showed conclusively that Camelford residents had objective evidence of considerable organic brain damage which was compatible with the known effects of exposure to aluminium. Altmann demonstrated that many of those originally affected still had symptoms eleven years later.

The organophosphate (sheep dip) issue

In November 1998 the Royal Colleges of Physicians and Psychiatrists produced a Report (Organophosphate sheep dip: clinical aspects of long-term low-dose exposure / CR67); two of the authors were Professor Anthony David and Professor PK Thomas. This was the same Anthony David who co-authors with Wessely on ME/CFS and whose views on ME/CFS echo those of Wessely himself. It was Professor Thomas who, with Wessely, published a chapter on ME in a major textbook of clinical neurology which stated *"A number of patients diagnosed as having myalgic encephalomyelitis were examined. In many of them, the usual findings of simulated weakness were present. Over-espousal of new illnesses may legitimise maladaptive behaviour"* (The chronic fatigue syndrome --- myalgic encephalomyelitis or postviral fatigue. Wessely S, Thomas PK. In: Recent Advances in Clinical Neurology No. 6. ed: C Kennard: Churchill Livingstone 1990:85-132). Unsurprisingly, the Report concluded that "*possible explanations for the symptoms are naturally occurring illnesses, for example, severe anxiety and depression which have been attributed by the sufferers to OP exposure"*. The Report recommends "*a treatment trial of a cognitive behavioural approach (and) a randomised controlled trial of antidepressants"*.

Conclusion

Correct classification of a disorder does matter because it defines medical understanding and treatment of a disorder; it also impacts upon NHS service provision and upon the delivery of appropriate and necessary medical care.

Nothing eradicates or changes what has been published time and again by Simon Wessely about those with ME/CFS, or the untold harm that he and his group of psychiatrists have caused to such very sick people.

Wessely has published many articles denigrating those with ME, repeatedly claiming (whilst producing no supportive evidence) that there is "*secondary gain*" from "*adopting the sick role*", and that once their incapacity has been *"legitimised"* by being given a medical label, those with ME can then *"manipulate"* those around them to do their bidding, and that legitimising their "*tiredness*" absolves the sufferer from any sense of guilt for being a failure.

He never visits those who are house or bed-bound and he never considers those who have no-one at all even to speak to, let alone to attempt to "manipulate" to do their bidding, and who are reduced to a bare existence in truly dire circumstances.

He fails to consider that sufferers who have a conviction that they have a physical disorder may not be suffering from *"dysfunctional thinking"* or from "*psychosocial denial"*. Indeed, doctors who have set views regardless of the facts may themselves qualify as dysfunctional thinkers.

Powerful minority groups such as the Wessely School should not be allowed to determine public policy without there being some external moderation.

Merely to state that there is “medical disagreement” over ME/CFS is not enough: people in positions of power are misusing that power against sick people and are using it to further their own vested interests. No-one in authority is listening, at least not until they themselves or their own family join the ranks of the psychiatrically-persecuted, when they too come up against a wall of utter indifference.

Given that what Wessely promotes is contrary to the established scientific evidence, how does he manage to maintain such power and control? Many knowledgeable people believe he maintains it by singing the desired political tune; by scientific misconduct; by manipulation of other people’s published work; by flawed methodology; by deception and by the circularity of self-references. Such blatant use of the same self-references is a clear illustration of the abuse of the peer-review system (which is increasingly recognised and accepted as being flawed and discredited).

Substantial evidence clearly reveals that in pursuit of his personal ideology or, alternatively, that of his corporate masters, Wessely abuses the scientific process. The implementation of his personal philosophy is not based on medical science and has had devastating consequences, not just for sufferers of ME/CFS but for their families as well.

There is a gross mismatch between the severity and complexity of ME/CFS and the medical and public perception of the disorder, but until Simon Wessely is held to public account, and medical professionals and public alike are informed and educated about the reality of ME/CFS, this will continue.

Wessely School psychiatrists got it wrong about Camelford, about chronic OP poisoning and about irritable bowel syndrome; they have got it equally wrong about ME.

Also, despite their insistence that fibromyalgia is a functional somatic syndrome (ie. psychiatric), it is listed in the ICD as a legitimate medical disorder under “Soft tissue disorders: Rheumatism” at M79.0.

The danger is that the Wessely School belief system is so entrenched that no amount of explanation, demonstration or presentation of evidence will sway them from their belief in their own model of “CFS”.

It is a grave matter which deserves urgent and robust investigation by the Select Committee on Health.

Suggested Further Reading

1. Myalgic Encephalomyelitis Post-Viral Fatigue Syndrome and how to cope with it. Celia Wookey. Croom Helm 1986 (reprinted Chapman & Hall 1989)

2. Myalgic Encephalomyelitis and Postviral Fatigue States. A.Melvin Ramsay. Gower Medical Publishing, London. Second edition 1988

3. Post-Viral Fatigue Syndrome. pp 463. ed. Rachel Jenkins and James Mowbray. John Wiley & Sons, Chichester, 1991

4. The Disease of a Thousand Names. Chronic Fatigue/Immune Dysfunction Syndrome. David S Bell. Pollard Publications, New York, 1991

5. The Clinical and Scientific Basis of Myalgic Encephalomyelitis Chronic Fatigue Syndrome. pp 724. ed. Byron M Hyde, Jay Goldstein & Paul Levine. The Nightingale Research Foundation, Ottawa, Canada, 1992

6. Chronic Fatigue Syndrome: A Biological Approach. ed. Patrick Englebienne and Kenny de Meirleir. CRC Press, New York 2002

7. Canadian Clinical Working Case Definition: Diagnostic and Treatment Protocols on ME/CFS. Bruce M Carruthers et al. Journal of Chronic Fatigue Syndrome 2003:11(1):7-116

8. Denigration by Design? A Review, with references, of the role of Dr (now Professor) Simon Wessely in the perception of Myalgic Encephalomyelitis Vol I (1987-1996) pp 217; Vol II (1996-1999) pp 271. Eileen Marshall Margaret Williams. Available at cost price from the Countess of Mar, House of Lords, London SW1A 0PW

9. What is ME? What is CFS? Information for Clinicians and Lawyers. December 2001 EP Marshall M Williams M Hooper. Available @ £3.50 from Malcolm Hooper. Emeritus Professor of Medicinal Chemistry, Department of Life Sciences, University of Sunderland, SR2 7EE, UK

10. Engaging with ME: Towards Understanding Diagnosis and Treatment. pp 85 Malcolm Hooper. Available @ £4.55 from Professor Hooper as above

Appendix I:

Quotations from the published works of Professor Simon Wessely on ME/CFS

1988

Postviral fatigue syndrome: time for a new approach. David AS, Wessely S, Pelosi AJ

BMJ 1988:296:696-699

"Future investigations and clinical practice must take into account the similarities between the symptomatology of the post-viral fatigue syndrome and that of common psychiatric disorders in the community"

1989

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

"Beard and Mitchell have returned to obscurity, but their disease (neurasthenia) is back with a vengeance. My local bookshop has just given ME the final seal of approval, its own shelf. A little more psychology and a little less T-cells would be welcome".

1989

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

"Many patients referred to a specialized hospital with chronic fatigue syndrome have embarked on a struggle. This may take the form of trying to find an acceptable diagnosis, or indeed any diagnosis and may involve reading the scientific literature. One of the principal functions of therapy at this stage is to allow the patient to call a halt without loss of face. [ME patients are in] a vicious circle of increasing avoidance, inactivity and fatigue. The patient should be told that it is now time to 'pick up the pieces' (and) the process is a transfer of responsibility from the doctor to the patient, confirming his or her duty to participate in the process of rehabilitation in collaboration with the doctor. Occasionally patients may say they cannot take drugs (but) there is no clinical evidence that allergies exist in anything but a small number of sufferers, and their existence may be coincidental. Anxiety is often part of the syndrome (and) sexual problems occur in the majority of patients referred to hospital. The notion of allergies reinforce the view that the sufferer is under attack from outside elements which have nothing to do with himself or herself".

1990

Attribution and self-esteem in depression and Chronic Fatigue Syndrome. R Powell, R Dolan, S Wessely. *J Psychosom Res 1990:34:6:665-673.*

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

1990

Chronic fatigue and myalgia syndromes. Wessely S. In: Psychological Disorders in General Medical Settings. eds: N Sartorius et al pub: Hogrefe & Huber 1990

"Most CFS patients fulfil diagnostic criteria for psychiatric disorder. Symptoms include muscle pain and many somatic symptoms, especially cardiac, gastrointestinal and neurological. Do any of these symptoms possess diagnostic significance? The answer is basically negative. It is of interest that the 'germ theory' is gaining popularity at the expense of a decline in the acceptance of personal responsibility for illness. Such attribution conveys certain benefits, in other words, there is avoidance of guilt and blame. It is this author's belief that the interactions of the attributional, behavioural and affective factors is responsible for both the initial presentation to a physician and for the poor prognosis".

1990

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

"It is assumed that ME is an organic disorder of the peripheral or central nervous system. In the initial reports this was indicated by frank neurological signs (but) the concept of ME has shifted…as in neurasthenia, the emphasis is on muscle fatiguability….in a current leading neurology text book (Adams and Victor, 1985) chronic fatigue, neurasthenia and depression are seen as synonymous. Mood disorder is found in many cases of ME but it is not the only psychiatric disorder (and) some patients do satisfy the criteria for anxiety and phobic disorders…Beard's neurasthenia began as a physical disease…it provided the most respectable label for distressing, but not life-threatening complaints, one that conferred many of the benefits - and fewest of the liabilities-associated with illness….it was preferable to the alternatives --- hypochondria, malingering and insanity. There is little evidence of any change in the current era. Suggestible patients with a tendency to somatize will continue to be found among

sufferers from diseases with ill-defined symptomatology until doctors learn to deal with them more effectively. The social processes that govern the creation of such illnesses remain obscure but one may argue that they represent culturally sanctioned expressions of distress. It has been shown that some patients have always preferred to receive, and well-meaning doctors to give, a physical rather than a psychological explanation for ill-defined illnesses associated with fatigue. Such uncritical diagnoses may reinforce maladaptive behaviour".

1990

Possible ME. Simon Wessely. *The Practitioner 8 March 1990:234:195-198*

"ME is a description, not a diagnosis".

1990

The chronic fatigue syndrome—myalgic encephalomyelitis or postviral fatigue.
S.Wessely PK Thomas. In: Recent Advances in Clinical Neurology. ed: Christopher Kennard. pub: Churchill Livingstone 1990 pp85-131

"There is no doubt that at least half of CFS patients have a disorder of mood. The management of affective disorders is an essential part of the treatment of CFS/ME. Numerous trials attest to the efficacy of tricyclic antidepressants in the treatment of fatigue states. Patients who fail to respond should be treated along similar lines to those proposed for treatment-resistant depression, especially (with) lithium".

1991

Editorial. Wessely S. *Journal of Neurology, Neurosurgery and Psychiatry 1991:54:669-671*

"Studies of dynamic muscle function have demonstrated essentially normal muscle strength, endurance and fatigability, other than as a consequence of physical inactivity. Advice that antidepressants may be counter-productive is misguided".

1991

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

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

1991

The psychological basis for the treatment of CFS. Wessely S. *Pulse of Medicine 14th December 1991:58*

"The prognosis may depend on maladaptive coping strategies and the attitude of the medical profession".

1992

The epidemiology of fatigue: more questions than answers. Lewis G, Wessely S. *Journal of Epidemiology and Community Health* 1992:46:92-97

"We suggest that many patients currently labelled as having 'CFS' may lie at the extreme end of a continuum that begins with the common feeling of tiredness. Studies usually find a high prevalence of psychiatric disorder amongst those with CFS, confirming that physicians are poor at detecting such disorders".

1992

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

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

On 10th January 1992 Wessely wrote a letter to Dr Mansel Aylward at the Department of Social Security in which he stated

"It is certainly true that I and my colleagues consider that anxiety about the consequences of activity is one of the factors perpetuating disability in CFS. I have previously been involved in advising the DSS that CFS should not be grounds for permanent disability".

Following Wessely's advice, the 1994 Disability Living Allowance Handbook entry on CFS states "The general consensus of informed medical opinion is that treatment should be by graded exercise and rehabilitation (and) antidepressant drugs may be helpful".

1993

The psychology of multiple allergy. LM Howard, S Wessely. *BMJ:1993:307:747-748.*

"Many people present to their doctor with multiple unexplained symptomatology which they attribute to allergy. Those at the extreme end of this range often attract a diagnosis of total allergy syndrome, multiple chemical sensitivity, or environmental illness. A recent study confirmed that psychological symptoms were a central component of chemical sensitivity. Inherent in the concept of allergy is the avoidance of any blame. Sufferers from allergies feel no guilt about their condition and are not subject to moral sanction. Sufferers from mysterious condition that lie outside conventional medical practice no longer consider themselves to be oppressed by spirits and demons but by mystery gases, toxins and viruses. This is particularly visible in the changing nature of mass hysteria".

1994

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

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

1994

Population based study of fatigue and social distress. Pawlikowska T, Chalder T, Wallace P, Wright DJM, Wessely S. *BMJ 1994:308:763-766*

"In recent years, fatigue has attracted renewed attention, largely because of the prominence given to the chronic fatigue syndrome. The infective characteristics may be the result of referral patterns and illness behaviour. The chronic fatigue syndrome may represent a morbid excess of fatigue rather than a discrete entity. The definition may have arisen as a result of referral patterns to specialists. Muscle pain was related to psychological morbidity".

1994

The patient with chronic fatigue. Simon Wessely et al *West of England Medical Journal*

"The aims of treatment were to provide alternative explanations for symptoms. The methods chosen included the use of established techniques to treat depression, namely, dothiepin".

1994

A cognitive-behavioural approach to chronic fatigue syndrome.
Alicia Deale Simon Wessely *The Therapist 1994:2;1:11-14*

"Behavioural, attributional and cognitive factors are central to the perpetuation of fatigue. It is important to note that the rates of depression and anxiety in CFS are far too high to be explained solely as reactions to chronic illness".

1995

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

"Many doctors are frequently consulted by patients with persistent unexplained symptoms attributed to allergy or chemical sensitivity…when patients are told there is no evidence of any underlying immunological or allergic cause, they can be difficult to manage. In some cases patients claim allergy to almost all of the environmental products of the Western world. The illness is usually sporadic but epidemics have been described. Such epidemics overlap with the related subject of mass psychogenic illness, a term which has partly replaced mass hysteria. The epidemiology of environmental illness is reminiscent of the difficulties encountered in distinguishing between the epidemiology of myalgic encephalomyelitis (ME), a belief, and chronic fatigue syndrome, an operationally-defined syndrome. **[** ***Note: The World Health Organisation does not regard ME as " a belief", but as a neurological disorder***]. These patient populations recruited from the environmental subculture are a subgroup of patients who can be expected to show unusually strong beliefs about the nature of their symptoms, associated with a high prevalence of psychiatric disorder. These patients typically resist any attempt to discuss the possibility of a psychological cause. Somatization sufferers consume vast amounts of health resources for little benefit. Between a quarter and a half of new patients attending medical clinics do not have an organic explanation for their symptoms, (receiving) a diagnosis of chronic fatigue syndrome. The risk of psychiatric diagnosis is known to increase linearly with the number of symptoms with which the patient presents. Attribution of unexplained symptoms to a "virus", as happens in most patients with the label of ME, may preserve self-esteem and protect against the stigma of psychiatric

disorder. These total allergy syndromes are akin to culture-bound syndromes afflicting modern developed societies where sufferers from unexplained symptoms no longer see themselves as possessed by devils or spirits but instead by gases, toxins and viruses. When a psychiatric disorder is not recognised, patients are often investigated extensively for organic disease; there are hazards in these inappropriate investigations, as patients' beliefs in organic pathology are reinforced. Further investigations will add nothing to the management but will reinforce the patient's beliefs in organic pathology (and) add to the cost of the consultation. Patients will benefit from training in cognitive coping skills; (and some) patients should be treated with psychotropic drugs. Liaison between the physician and the liaison psychiatrist is necessary so that patient acceptance of psychiatric referrals can be facilitated".

1996

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

" Chronic fatigue may be better understood by focusing on perpetuating factors and the way in which they interact in self-perpetuating vicious circles of fatigue, behaviour, beliefs and disability. The perpetuating factors include inactivity, illness beliefs and fear about symptoms, symptom focusing, and emotional state. CFS is dogged by unhelpful and inaccurate illness beliefs, reinforced by much ill-informed media coverage; they include fears and beliefs that CFS is caused by a persistent virus infection or immune disorder. Increased symptom focusing occurs in CFS sufferers; (this) increased concern leads to selective attention and 'body watching': this can intensify the perceived frequency of symptoms, thereby confirming illness beliefs and reinforcing illness behaviour".

1996

Chronic fatigue syndrome: a stress disorder? Anthony J Cleare Simon C Wessely
British Journal of Hospital Medicine: 1996:55:9:571-574

"Between half and two thirds of patients with CFS have a co-morbid psychiatric disorder".

1997

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

" The majority of patients seen in specialist clinics typically believe that their symptoms are the result of an organic disease process, and resent any suggestion that they are

psychological in origin or psychiatric in nature. Many doctors believe the converse. (Patients') beliefs are probable illness-maintaining factors and targets for therapeutic intervention. Many patients receive financial benefits and payment which may be contingent upon their remaining unwell. Gradual recovery may therefore pose a threat of financial loss. Abnormal physical signs should not be accepted as compatible with a diagnosis of CFS. The only treatment strategies of proven efficacy are cognitive behavioural ones. We have developed a more intensive (CBT) therapy (which) is acceptable to patients, safe, and more effective than either standard medical care or relaxation therapy. It has also been shown to be cost-effective. An important task of treatment is to return responsibility to the patient for management and rehabilitation without inducing a sense of guilt, blame or culpability for his / her predicament".

1998

Clinics in Controversy: Chronic Fatigue Syndrome.
Anthony J Cleare Simon C Wessely. *Update 20 May 1998:1016-1026.*

"CFS may be better understood as the extreme end of a spectrum that starts with 'feeling tired all the time'. Many people suggest that the condition should be called ME, but doctors and the editors of journals have taken a firm stand against this label. The GP's response may be important. A sick note and unclear diagnosis are both associated with development of CFS".

1999

Functional somatic syndromes: one or many? S Wessely, C Nimnuan, M Sharpe. *Lancet 1999:354:936-939*.

" We postulate that the existence of specific somatic syndromes is largely an artefact of medical specialisation. That is to say that the differentiation of specific functional (ie. psychiatric) syndromes reflects the tendency of specialists to focus on only those symptoms pertinent to their speciality, rather than any real differences between patients…Various names have been given to medically unexplained symptoms. These include somatisation, somatoform disorders…and functional somatic symptoms…we define a functional somatic symptom as one that, after appropriate medical assessment, cannot be explained in terms of a conventionally defined disease. Functional somatic syndromes pose a major challenge to medicine. Those symptoms are associated with unnecessary expenditure of medical resources. Chronic fatigue syndrome is associated with worse disability than conditions such as heart failure… three quarters of patients had symptoms more than 10 years after presentation. Thus, functional somatic complaints constitute a large…and costly health-care issue that urgently requires improved management. Many of these (functional somatic) syndromes are dignified by their own formal case definition and body of research. We question this orthodoxy and ask whether these syndromes represent specific diagnostic entities (eg. irritable bowel

syndrome, premenstrual syndrome, fibromyalgia, hyperventilation syndrome, tension headaches, globus hystericus, multiple chemical sensitivity, chronic fatigue syndrome) or are rather more like the elephant to the blind man --- simply different parts of a larger animal?….Such patients may have variants of a general functional somatic syndrome. If we accept that functional somatic syndromes are considered together, we open the way for more general strategies for their management….Functional somatic symptoms and syndromes are a major health issue. They are common, and may be costly. Most of the current literature pertains to specific syndromes. We have put forward the hypothesis that the acceptance of distinct syndromes as defined in the medical literature should be challenged. We contend that the patients so identified…have much in common…We propose an end to the belief that each different syndrome requires its own particular sub specialist…A previous generation of physicians noted overlaps between "psychosomatic syndromes". Unfortunately, none of these theories were accompanied by empirical support and consequently have disappeared from our current thinking. We argue that their re-instatement is overdue".

2000

Responding to Mass Psychogenic Illness. Editorial: Simon Wessely. *The New England Journal of Medicine 2000:342:2:129-130*

"Such outbreaks are not novel. In a previous era, spirits and demons oppressed us. Although they have been replaced by our contemporary concern about invisible viruses, chemicals and toxins, the mechanisms of contagious fear remain the same. The term 'psychogenic illness' and its predecessor 'mass hysteria' exemplify the problem. To the majority of observers, including most professionals, these symptoms are indeed all in the mind. It is now commonplace to blame our environment for many of our ills. Should we investigate at all? How do you convey the message that the main mechanisms for the transmission of distress are psychosocial and behavioural? A firm public message that certain symptoms are probably psychological in origin will probably help prevent their spread".

2001

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

"Social, behavioural and psychological variables are important in both chronic fatigue and chronic fatigue syndrome. The lack of congruence between the patient's report of feeling tired and exhausted and objective measures of fatigability further frustrate clinicians and investigators. Compelling evidence of abnormal neuromuscular fatigability in patients with the chronic fatigue syndrome is lacking. Fatigue can be related to psychological variables such as belief and expectation. Some of the desire to split the chronic fatigue syndrome into subgroups is driven by emotion. It is interesting

to note how some of those who advance this argument assume that "their" condition (the one they suffer from, research or treat) will fall on the physical side of the divide. The greater the number of symptoms and the greater the perceived disability, the more likely clinicians are to identify psychological, behavioural or social contributors to illness. The pressure to reify the chronic fatigue syndrome comes from the way in which the developed world organizes medical services and reimbursement systems. Some of the modern impetus to 'allow' a specific chronic fatigue syndrome arises from the various compensation and social insurance schemes operating in developed countries. If the chronic fatigue syndrome did not exist, our current medical and social care systems might force us to invent it. Other symptoms identified in the chronic fatigue syndrome (include) increased symptom-monitoring and increased anxiety".

In correspondence arising from this paper, Wessely wrote "I can sleep easy at night when it comes to treatment. I know that we have done more good than harm. You mention the views of Paul Cheney, but I must say I disagree profoundly with them – and more importantly, so does every neurologist I have ever met. All I know is that I am quietly proud of what our group has achieved over the years".

2001

How many functional somatic syndromes? C Nimnuan, S Rabe-Hesketh, Simon Wessely, Matthew Hotopf. *Journal of Psychosomatic Research 2001:51:4:549-557*

"Experiencing symptoms is part of normality. Most of these symptoms are not associated with clear-cut biomedical diagnosis and are then referred to as "medically unexplained" or "functional". Functional somatic symptoms are an important problem in general medicine on account of the high associated consumption of health service resources. Such symptoms may be elevated to the status of a syndrome to which a specific name is attached. These include irritable bowel syndrome, pre-menstrual pain, fibromyalgia and chronic fatigue syndrome. Physicians instinctively seek and treat only conditions they know well. Patients may be seen in several clinics, which increases the risk of over-investigation. We argue that such an approach is outdated. Instead, an appreciation of the fundamental unity of those syndromes may reduce the potential for iatrogenic harm ".

2002

Modern worries, new technology, and medicine Keith Petrie Simon Wessely
Editorial: *BMJ 2002:324:690-691*

" People's suspicion of modernity has increased to such an extent that it has increased their worries about environmental causes of poor health and fostered a migration to complementary medicine. We believe that these concerns have important implications for the way patients interact with health services. In clinical settings patients are reluctant to start medication for fear of putting 'unnatural chemicals' into their body. At the same

time the consumption of unproved herbal and alternative 'natural' remedies is increasing. This anxiety is reflected in the presentation of psychosomatic illness: the number of illnesses attributed to environmental factors --- for example, multiple chemical sensitivity, total allergy syndrome --- has increased. Normal everyday symptoms such as headache and fatigue are now more easily interpreted as signs of disease or ill health. Attributions made by patients about the cause of their illness often involve environmental pollution, and they see the effects of modern life as undermining the effectiveness of their immune system. Distrust of experts is now commonplace, and at its extreme it can merge into the conspiratorial thinking that is part of a modern paranoid style. Mismanaged environmental incidents add to the fear of the public. New and unsubstantiated health worries can be instantly transmitted to an internet audience eagerly seeking information on health, or to special interest networks such as illness support groups. We believe it is only a matter of time before a mass psychogenic illness is identified as being spread electronically".

2003

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

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

2003

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

"This paper proposes that well-intentioned actions by medical practitioners can exacerbate or maintain medically unexplained symptoms (MUS). This term is now used in preference to 'somatisation'. The medical specialties employ shorthand descriptions for particular clusters of MUS, including irritable bowel syndrome, fibromyalgia and

chronic fatigue syndrome. Examples of precipitating events include muscle ache after unaccustomed exercise. As one expert notes, 'It is a commonplace clinical observation that somatising patients --- more than any other group ---resent psychiatric referral'. Once a patient feels discredited, the opportunity to explore psychosocial factors is lost. For patients with MUS, the sensory experiences tend to outweigh the negative results of a doctor's examination or investigations. Thus one sees how the cycle of excessive investigation can begin. If enough investigations are performed, minor and irrelevant abnormalities will be detected and themselves become hypothesis-generating. Reassurance is particularly important in patients who have hypochondriasis or MUS. The adoption of a label such as CFS affords the sufferer legitimacy --- in other words, it allows entry into the 'sick role'. The external acknowledgement that the condition is 'legitimate' is both reassuring and enabling. However, the conferring of a label is not a neutral act, since specific labels are associated with specific beliefs and attitudes. In CFS for example, use of this term or the alternative 'myalgic encephalomyelitis' implies underlying assumptions about aetiology and treatment for both patients and doctors. (In relation to treatment), there is evidence to suggest that harm occurs at the hands of non-medical practitioners (who) colluded with patients' abnormal illness beliefs. If sections of the media advocate an exclusively organic model, as has happened with CFS, the biomedical model may become firmly enshrined for patients and families at the expense of psychosocial models. Clearly there are implications for the way doctors are taught to assess and treat these patients".

Only by assembling and distributing the great wealth of published medical and scientific evidence which shows unequivocally that Wessely and his like-minded psychiatrists are wrong is there any hope of refuting their erroneous assertions and of limiting the unquantifiable damage that flows from them.

Both the ME Association and Action for ME were set up as charities to promote and protect the interests of their members, ie. those suffering from ME (and the term is incorporated into their charitable status). Neither currently does so, since the Chief Executives of both charities seem only too happy to subscribe to the Wessely School view (which ensures continued Government funding).

A Co-cure (internet) posting by Jill McLoughlin expresses the nature of the problem succinctly:

"It is because our medical community, professional societies and public health officials have not adequately gathered together, assimilated, integrated and made public the strong body of research pointing to the serious physical (not psychological) nature of this illness".

Appendix II:

Quotations from the published works of Dr Michael Sharpe on ME/CFS

As with Wessely, it is not just a matter of noting the more offensive statements but rather it is the relentlessness of the same message over more than a decade (and the fact that the message does not adapt to, but actively dismisses, the strength of emerging biological evidence) which shows Wessely School psychiatrists to be out of touch with international scientific knowledge.

1991

Psychiatric management of Post Viral Fatigue Syndrome M Sharpe *British Medical Bulletin 1991:47:4:989-1005*

"Psychiatric assessment distinguished factors that perpetuate the condition from those that may have precipitated it. Treatments are targeted at perpetuating factors.

"To exclude (patients with a psychiatric diagnosis) is practically restrictive.

"Psychiatric management may be defined as the assessment and treatment of the mentally ill.

"Multiple perpetuating factors may operate (and) the following have been suggested in CFS:

"Infection: viral infection is of theoretical interest but of minor importance in managing established cases

"Immune dysfunction: the possibility that immune function is impaired by psychosocial factors and may be improved by psychiatric treatment is a tantalising possibility

"Other physiological factors: Several physiological factors may perpetuate symptoms. These include the consequences of inactivity and hyperventilation

"Psychiatric disorder: Syndromes conventionally termed "psychiatric" have been shown to occur in the majority of patients with CFS. Extensive physical investigation is unlikely to be fruitful and should be limited

"Other psychological factors: Personality factors (attitudes, beliefs and thoughts) and behaviour have been shown to perpetuate disability. These unhelpful or "dysfunctional" cognitions include the beliefs that recovery from the illness is not under personal control or that the illness is poorly understood. It has been suggested that dysfunctional cognitions and maladaptive behaviour interact with the physiological factors and

psychiatric illness to perpetuate the disability that comprises CFS. Increasing physical deconditioning…may lead to helplessness.

"Social factors: because of their possible importance in CFS (social factors) deserve discussion. One such factor is our cultural attitude to symptoms occurring in the absence of demonstrated physical disease. Such symptoms are frequently regarded as revealing personal weakness and as not being a valid reason for exemption from daily demands. Physical disease, on the other hand, particularly if validated by a doctor, is rarely considered to be the responsibility of the afflicted, merits sympathy, and excuses the sufferer from meeting the demands of others. Patients without a "physical" disease label for their illness may consequently experience difficulty in explaining their disability to friends, family or employers. Hence they may request a "physical diagnosis" from doctors. In response to the lack of acceptance of the "reality" of the symptoms of CFS, support has been sought for the existence of a disease called myalgic encephalomyelitis or "ME"…..the insistence that "ME" is an exclusively physical disease with a poor prognosis may have been unhelpful for sufferers (and) such a restricted conception of the problem may have perpetuated illness in some individuals".

Under Assessment of CFS, Sharpe again states "the use of extensive laboratory investigation may be psychologically harmful to the patient by reinforcing their beliefs about serious physical disease.

" Even if shown to be beneficial, such (immunological) treatment is unlikely to be feasible on a wide scale because of cost.

"There are many anecdotal reports (of the efficacy of antidepressant drugs) in CFS.

"Cognitive behaviour therapy is a development of Behaviour Therapy in which emphasis is placed on changing the patients' cognition as well as their behaviour. The aim is to show that the patient can regain control of their lives and that their illness is not so mysterious as to be untreatable".

Under Guidelines for Management, Sharpe yet again states "Excessive investigation should be avoided. Problems may arise if the patient requires a diagnosis the doctor feels is inappropriate or wants certification of permanent invalidity (ie) "ME".

"There is evidence that psychiatric treatment can reduce disability in CFS. In some patients it can be 'curative' ".

1991

Mania and recovery from chronic fatigue syndrome MC Sharpe, BA Johnson *JRSM 1991:84:51-52*

"There is anecdotal evidence that (antidepressants) can reduce disability in CFS.

"Psychosocial factors may maintain disability. Family members may reinforce both beliefs and avoidance. We suggest that the clinical assessment should consider mood, beliefs, avoidance of inactivity and the role of the family".

1992

Fluctuations in perceived energy and mood among patients with chronic fatigue syndrome C Wood, M Sharpe et al *JRSM 1992:85:195-198*

"Because of its suspected viral aetiology, CFS is becoming an increasingly frequent presentation seen by specialists in infectious diseases. Current thinking *(here Sharpe quotes a self-reference)* does not require the presence of a viral aetiology in defining the syndrome

"(Patients') higher levels of depression serve to reinforce the now widely current notion that such patients may be suffering from a depressive illness, of which physical fatigue is a somatic manifestation."

1994

The Chronic Fatigue Syndrome: A Comprehensive Approach to its Definition and Study. K. Fukuda, S.Straus, M Sharpe et al *Ann Int Med 1994:121:12:953-959*

"The use of tests to diagnose the chronic fatigue syndrome should be done only in the setting of protocol-based research. In clinical practice, no additional tests, including laboratory tests and neuro-imaging studies, can be recommended. Examples of specific tests (*which should not be done*) include serologic tests for enteroviruses; tests of immunologic function, and imaging studies, including magnetic resonance imaging scans and radionuclide scans (such as single photon emission computed tomography (SPECT) and positron emission tomography (PET) of the head. We consider a mental status examination to be the minimal acceptable level of assessment.

"The exclusion of persons (*with psychiatric disorders*) would substantially hinder efforts to clarify the role that psychiatric disorders have in fatiguing illness. We dropped all physical signs from our inclusion criteria (because) their presence had been unreliably documented in past studies."

1995

Chronic fatigue, chronic fatigue syndrome, and fibromyalgia. Wessely S and Sharpe M. In: *Treatment of Functional Somatic Symptoms. Ed: Mayou R, Bass C and Sharpe M. (chapter 16): OUP 1995*

On the issue of patients' organisations making medical research information available to members, Sharpe states "Such information may have a considerable and often unhelpful influence on patient attributions of illness."

1996

Cognitive behaviour therapy for the chronic fatigue syndrome: a randomised controlled trial Michael Sharpe, Tim Peto et al *BMJ 1996:312:22-26*

"Cognitive behaviour therapy offers a novel approach to the treatment of the chronic fatigue syndrome…(it) aims at helping patients to re-evaluate their understanding of the illness….it was both acceptable and more effective than medical care alone."

(One of the trial participants (Catherine Rye) had a letter published in the Independent on 30 March 1996 in which she made valid points: "I participated in the Oxford trial…the article implies that a new successful treatment has been found for ME but that sufferers do not want to accept it. There are facts about the trial that throw into doubt how successful it is. It is stated that patients in the control group received standard medical care. I was in that group but I received nothing. Also, patients receiving treatment had to attend weekly hospital visits, thus excluding the most severely affected sufferers. Patients who "improved significantly" only increased their score from 70 to 80 on a scale of general functional ability.")

1997

Treating medically unexplained symptoms. EDITORIAL (Editor's Choice).
Richard Mayou and Michael Sharpe. *BMJ 1997:3:15:561-562*

"Evidence for the superiority of new ways of thinking about and managing such patients is growing. These new treatments, often referred to as cognitive behavioural therapies, take a new approach (which) is in keeping with the evidence that the perpetuation of unexplained somatic symptoms is best understood in terms of psychological factors (such as) misinterpretation of bodily sensations and unhelpful coping behaviour."

1997

Chronic Fatigue Syndrome: A Practical Guide to Assessment and Management
Sharpe M. Wessely S et al *Gen Hosp Psychiatry 1997:19:3:185-199*

"The only treatment strategies of proven efficacy are cognitive behavioral *(sic)* ones.

"The clinical problem we address is the assessment and management of the patient with a *belief* that he / she has a fatiguing illness such as CFS, chronic fatigue and immune deficiency syndrome (CFIDS) *[CFIDS in fact stands for chronic fatigue and immune dysfunction syndrome]* or myalgic encephalomyelitis (ME). The patients who cause the greatest clinical difficulty are those with both severe symptoms and strong beliefs. The majority of patients believe that their symptoms are the result of an organic disease process. Many doctors believe the converse.

"It is particularly important to focus on factors which may be perpetuating the illness. A large number of somatic symptoms suggests a greater likelihood of psychiatric disorder. A conviction of a solely physical cause for symptoms is the single most consistent predictor of poor outcome.

"Beliefs are probable illness-maintaining factors and targets for therapeutic intervention

"Many patients receive financial benefits and payments which may be contingent on their remaining unwell. Recovery may therefore pose a threat of financial loss

"Personality is important….the account of an informant *(about the patient's personality)* is often helpful

"Most sufferers are seeking confirmation of their own intuition that they are suffering from a particular condition, rather than reassurance that they are not

"Abnormal physical signs should not be accepted as compatible with a diagnosis of CFS

"In our experience, postural hypotension usually resolves with increased activity

"Reports from specialist settings have shown statistically increased rates of abnormal results on tests for parameters such as antinuclear factor, immune complexes, cholesterol, immunoglobulin subsets and so forth. Their significance is for researchers rather than clinicians and we feel that testing for such variables is more likely to result in iatrogenic harm *(caused by doctors)* than good

"Many physicians are reluctant to make the diagnosis of CFS (because of) reinforcing unhelpful illness beliefs

"Patients need a diagnosis in order to organise their dealings with the world of benefits

"Perpetuating factors (include) reinforcement of sick role by mother and doctor

"An important task of treatment is to return responsibility to the patient for rehabilitation without inducing a sense of guilt

"(CBT) is acceptable to patients, safe and more effective than standard medical care ("*standard medical care" is not defined*)

"It is usually possible to persuade these patients to try antidepressants
"Disability systems and insurance agencies are sceptical about CFS. When asked to comment in benefits or insurance claims, we do not support claims for permanent disability until all reasonable efforts at rehabilitation have been tried."

1997

Chronic fatigue syndrome and occupational health A Mountstephen and M Sharpe *Occup Med 1997:47:4:217-227*

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

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

"Patients' *beliefs and behaviour* are often a prominent part of the clinical presentation (which) is most commonly diagnosed in young and middle aged females

"the evidence for an association between immunologic abnormalities and CFS remains unclear

"Both self help books and the media have tended to emphasise medical explanations at the expense of psychiatric conceptualisations

"CFS may serve as a culturally defined function which allows a socially acceptable expression of distress

"illness perpetuating factors are more important than predisposing or precipitating factors

"psychiatric assessment is recommended in *every case*

" in most cases of chronic fatigue, few laboratory investigations are necessary

"important aspects are the individual's beliefs about their illness

"Exercise therapy may be considered for patients who are physically inactive

"the only psychological treatment supported by the evidence is cognitive behavioural therapy (which) is well fitted to the task of helping patients achieve a more helpful view of the illness

"referral to 'specialists' should be avoided as they can entrench illness behaviour

"a process of education to address inaccurate and unhelpful attitudes and beliefs may be a necessary preliminary step
Under "Eligibility for benefits", the authors state "The DSS's Handbook advises adjudication officers that in CFS there is unlikely to be a need for assistance with attending to bodily functions or with mobility. It will be unfortunate if the (Disability Discrimination) Act leads to an undue focus on long term disability at the expense of efforts directed at rehabilitation and recovery."

1997

Treating medically unexplained physical symptoms. Effective intervention available.
EDITORIAL. EDITOR'S CHOICE. (press release). Richard Mayou. Michael Sharpe. BMJ 1997:315:561-562

"Chest pain, back pain, headache, muscular pains, bowel symptoms, breathlessness, dizziness and fatigue often remain unexplained after medical assessment. Such cases may be referred to as functional syndromes of chronic fatigue or as somatoform disorders. When symptoms are found not to result from "genuine physical illness", they are often attributed to mental illness. Evidence for the superiority of new ways of thinking about and managing such patients is growing. These new treatments, often referred to as cognitive behavioural therapies, take an approach in keeping with the evidence that perpetuation of unexplained somatic symptoms is best understood in terms of an interaction between physiological processes, psychological factors and social context.

"This integrative approach (consists of) identifying the principal factors that perpetuate illness, including misinterpretation of bodily sensations, abnormalities of mood and unhelpful coping behaviour.

"Implementation of this new approach will require changes in both medical practice and the organisation of services. Innovative service developments such as dedicated liaison psychiatry services will provide for patients who require more intensive treatment. The small but conspicuous group of patients who present with recurrent and multiple physical symptoms will be given co-ordinated care aimed at limiting unnecessary medical interventions

"If these changes in practice and service provision could improve patient care, why have they not been implemented? One reason is the widespread lack of awareness that

effective evidence based treatments are available. There are welcome signs of change, as evidenced by the recent joint royal colleges' reports".

1998

Cognitive Behaviour Therapy Michael Sharpe. *A Research Portfolio on Chronic Fatigue. Ed: Robin Fox; published by The Royal Society of Medicine for The Linbury Trust, 1998*

"Cognitive behaviour therapy offers patients a new way to think about their illness. The first application of CBT to chronic fatigue syndrome was by Wessely and colleagues (who proposed) a vicious- circle model of the perpetuation of chronic fatigue whereby patients' beliefs about the illness lead to avoidance of activity and thus to chronic disability

"Our group (ie. the Wessely School) wanted to develop the behavioural approach and the fist step was to gain a systematic view of their beliefs and behaviour
(*No mention is made about obtaining a systematic view of patients' brain perfusion patterns, or of their immune status, or of their neuroendocrine function)*

"CBT helps patients to re-evaluate their beliefs (and) encourages them to change their behaviour. Change in the belief is an important factor in recovery.

"The trials of CBT have shown that 'psychological' treatment is effective in patients with CFS. (CBT) is currently the most effective treatment we have for CFS."

1998

Doctors'Diagnoses and Patients' Perceptions: Lessons from Chronic Fatigue Syndrome
EDITORIAL Michael Sharpe. *Gen Hosp Psychiat 1998:20:335-338*

"For many patients, the more clearly 'biomedical' the diagnosis is, the more likely they are to welcome it

"These patients want a medical diagnosis for a number of reasons. First, it allows them to negotiate reduced demands and increased care from family, friends and employer. Without such a diagnosis, the patient is open to the social stigma of psychiatric illness. In short, (a biomedical label) admits them to a bona fide 'sick role'. Second, it may open the way for practical help in terms of financial and other benefits from government, employers and insurers

"Why are many physicians reluctant to provide a medical diagnosis? (Because) to make such a diagnosis, especially if it is suggested by the patient, may risk the censure of peers

"The application of (a psychiatric diagnosis) may give the physician the satisfaction of having applied a label of which most of his peers would approve. The problem is that many patients not only fail to accept this diagnosis but respond to it with frank hostility because a psychiatric diagnosis may offer lower financial benefits

"For many patients, obtaining an acceptable diagnosis becomes their main preoccupation."

1999

ME. What do we know (real physical illness or all in the mind?)
Lecture given in October 1999 by Michael Sharpe, hosted by the University of Strathclyde

"In my lecture this evening, I would like to talk to you about myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome or CFS (which) for convenience I will refer to as CFS.

"We know that in the majority of cases CFS can be effectively treated. CBT has been shown to have substantial benefits for patients with CFS (and) can reduce disability in most patients.

"I shall argue that patients themselves have played a part in denying themselves this type of treatment

"Despite a lot of media comment and much hypothesising relating CFS to modern concerns such as toxic exposures, there is very clear evidence that a condition which appears identical caused similar concerns a hundred years ago (and) the causes were thought to lie in the concerns of that time namely, the changing role of women….in our time it is allergy and toxins.

"The conventional wisdom is that illnesses are made real when they are legitimised by a doctor's diagnosis

"Does CFS have biology? Yes –not conventional disease pathology

"The majority of patients with CFS have no doubt how they prefer their conditions to be seen….the vehemence with which many patients insist that their illness is medical rather than psychiatric has become one of the hallmarks of the condition.

"Clinically, it appears that interpersonal stress appears to be a major factor giving rise to development of CFS

"Over-solicitousness and the reinforcement of unhelpful illness beliefs can have an unhelpful effect on patients' attitude and coping

"Purchasers and Health Care providers with hard pressed budgets are understandably reluctant to spend money on patients who are not going to die and for whom there is controversy about the "reality" of their condition (and who) are in this sense undeserving of treatment.

"Those who cannot be fitted into a scheme of objective bodily illness yet refuse to be placed into and accept the stigma of mental illness remain the undeserving sick of our society and our health service."

2000

Insurance Medicine. Chronic fatigue syndrome and its management. Dr Michael Sharpe, University of Edinburgh. Conference rapporteur: Ian Cox MA MRCP, Chief Medical Officer, Prudential UK, Reading. *JRCP 2000:34:394-396*

"Psychosocial factors are important in CFS. Prognostic factors include family factors and social factors; work could also mitigate against a full recovery.

"Reports from doctors for employers, insurance companies and benefit agencies could reinforce beliefs and behaviour to delay full recovery.

"The belief that there is no treatment is incorrect; correcting obvious misconceptions about the disease process and avoiding unnecessary investigations all help patients.

"Cognitive behaviour therapy caused improvement in 60% of patients with CFS

"Secondary prevention (ie. preventing chronicity) includes early identification and treatment; keeping the individual in contact with the workplace helps to reduce the chronic problems.

"There was general agreement that all doctors have a responsibility to aid their patients' return to employment.

"Social attitudes and differing health beliefs can slow down or even prevent a return to work and such beliefs are increasingly being promulgated through the media and doctors have to be aware of these issues.

"The problem of communication between doctors and insurers or benefits agency personnel were discussed throughout the meeting, which was an excellent first step towards improved links between the Royal College and doctors working in insurance and benefit agencies".