DENIGATION BY DESIGN?

A REVIEW, WITH REFERENCES, OF THE ROLE OF

Dr Simon Wessely

IN THE PERCEPTION OF MYALGIC ENCEPHALOMYELITIS

1987 - 1996

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## CONTENTS

Dedication and Acknowledgment........................................................................................................... 3  
Note...................................................................................................................................................... 4  
Introduction......................................................................................................................................... 5  
Background......................................................................................................................................... 10  
Terminologies....................................................................................................................................... 11  
Definition Difficulties.......................................................................................................................... 18  
Introducing Dr Wessely.......................................................................................................................... 20  
Wessely’s Status................................................................................................................................... 20  
Wessely’s Tactics.................................................................................................................................. 33  
Others Involved.................................................................................................................................... 45  
Research Findings and Opinions about ME with which Wessely Disagrees........................................... 46  
Some Illustrations of Same 1955 - 1996............................................................................................... 47  
Wessely’s Words................................................................................................................................... 87  
Lack of Balance...................................................................................................................................... 179  
Wessely’s Role in the “Organic” versus “Functional” Debate............................................................... 184  
Questions which Wessely might usefully be required to address......................................................... 185  
Harm done to ME Sufferers................................................................................................................... 189  
Losses Sustained by ME Sufferers......................................................................................................... 199  
Conclusion........................................................................................................................................... 201  

Appendix I  (Suggested reading on ME).............................................................................................. 203  
Appendix II (“Remarkable Coincidences” by Doris Jones)...................................................................... 205  
Appendix III (Book Review: Toxic Psychiatry) by Doris Jones................................................................. 209  
Appendix IV (Report on ME / CFS and the Press).................................................................................. 212  
Appendix V (Summarised History of ME: source unavailable).............................................................. 218  
Appendix VI (Mini-Review of Dr Anthony David’s work on CFS / ME)............................................... 224
DEDICATION AND ACKNOWLEDGMENT

Special gratitude is extended to Dr Betty Dowsett, Honorary Consultant Microbiologist and former President of The Myalgic Encephalomyelitis Association. Like the late Dr Melvin Ramsay (whom she knew well), Dr Dowsett has devoted her professional life to the study of ME and above all, to the care and support of those unfortunate enough to succumb to it. Her untiring dedication to and understanding of those with ME are unequalled.
NOTE

1. There is widespread concern that Dr Wessely’s published articles do not present a balanced or accurate picture of the available world literature on myalgic encephalomyelitis (ME).

2. The aim of this review is to provide a factual record of Dr Wessely’s involvement in the perception – both medical and public – of ME.

3. No personal animosity whatsoever is directed at Dr Wessely.

4. It is anticipated that it will be clearly recognised that this review in no way constitutes any kind of vendetta against Dr Wessely: even the hint of such a notion would be unacceptable and unprofessional.

5. The exposing of a genuine problem (with which Dr Wessely is closely associated) is, however, essential.
**Introduction**

This referenced review attempts to document the role of a UK psychiatrist, Dr Simon Wessely, in the perception of myalgic encephalomyelitis (ME) over the last decade.

There are case reports which indicate that a whole professional community may be unable to observe a problem with a calm professional eye, thus tending to delete or abolish the problem, **even though existing professional knowledge indicates that a different professional approach is available** (The Professional Historical Error: A. Levy, Arch. Gen. Psychiatry 1993:50:319-320). Has this happened in ME? If so, is Dr Wessely responsible in any way?

It is known that all scientists make mistakes and that some become obsessed by publicity in the endless fight for funds, and that the more egotistical exaggerate their findings to claim more than their fair share of attention (Daily Telegraph, 22nd November 1994).

Clinical psychologists know that the person you are is the sum total of your ideas. When someone wants to wipe out those ideas and replace them with their own, they threaten the very core of our being. According to Dr Dorothy Rowe, “people who know absolutely that they are right are very dangerous” (Observer, 14th November 1993).

People suffering from ME are able to observe that Dr Wessely threatens the concept of their illness as a nosological reality, which implies that their suffering has no reality: Wessely’s insistence that what they are suffering from is simply a belief that they are suffering threatens them on a fundamental level.

People who have been diagnosed as having ME find it increasingly hard to tolerate medical disbelief and patronising scepticism; they have repeatedly challenged Wessely’s insistence that his judgment and opinions are correct and that everyone who disagrees with him is wrong; their challenges have been to no avail.

One distinguished Canadian ME expert (Dr Byron Hyde) observed that those doctors who disbelieve in ME “treat their prejudices as if they were knowledge (and) hide behind their own myths as though they were a veritable and supported position. Yet the myths are their own, neither based upon scientific inquiry nor upon the astute observation and questioning of their patients. The lack of compassion of these physicians was quite incredible and the potential damage done by them to patients with ME was immeasurable” (Nightingale Research Foundation vol.1, No. 8, 1992).

It is the reasons behind the continued propagation of such myths, in the UK most notably by Dr Simon Wessely, which require investigation.

This review came into being as a result of lawyers’ needs to have an accurate over-view of the international perspective about ME; solicitors and barristers were being required to act in personal injury (PI) cases for clients with a diagnosis of ME, and the information most readily available to them in the UK (mostly by means of searches on Medline, which is the computerised version of the Index Medicus) did not accord with the information which clients and their medical advisers had obtained.

These PI lawyers could see for themselves that the lives of their ME clients had been substantially damaged by symptoms which, to experienced members of the Association of Personal Injury Lawyers (APIL) certainly did not seem to be psychogenic in origin, yet the UK medical literature on ME repeatedly produced overwhelming amounts of articles written mostly by the same group of psychiatrists; these articles all said in effect that ME did not exist as a separate illness, and that it was nothing more than “a belief” by a person that they had such a condition.
In a nutshell, APIL lawyers were confronted with a massive amount of published information which declared that not only did ME not exist, but that the belief which their clients and the medico-legal experts who were supporting them all held constituted nothing more than “dysfunctional” and “aberrant” thinking patterns which the psychiatrists claimed resulted in a form of avoidance behaviour by the patients; these psychiatrists claimed that the problem was much confounded by the “altered medical perception” of some naïve doctors who were simply pandering to the demands of their more suggestible patients.

It was not only in the medico-legal field that there were problems; indeed, the picture surrounding ME in general in the UK was disturbing. Many patients so diagnosed were obviously having a raw deal; many doctors, especially general practitioners, were confused. The medical journals which doctors read were saying that ME was largely a psychiatric condition and that 50 -75% of patients with a diagnostic label of ME have a mental illness; their patients, however, came to the surgery with information obtained from the mainstream world literature which showed evidence of lesions in the brain, a chronically up-regulated immune system and far lower levels of psychiatric morbidity.

It soon became apparent that medical journals in the UK were frequently failing to distinguish between ME and general chronic fatigue, and it was clear that editors of the UK journals had a preference for psychiatric explanations. This was borne out by the fact that so many of them published articles which emphasised the role of depression in ME but which ignored the evidence of on-going organic pathology such as neuroimmune dysfunction, including autonomic (particularly cardiac) abnormalities, the development of marked hypersensitivities to previously tolerated substances, (especially to prescribed medication), pancreatic and gut dysfunction and a clear pattern of post-exertional muscle fatigue accompanied by excruciating pain in the muscles, together with marked malaise.

The ME patients’ organisations were dismayed at the blatant way in which so much information about ME was being ignored, trivialised or dismissed as being of little consequence; their efforts to achieve more balanced reporting were not very successful and the biased reporting continued.

Published evidence of similar illness in horses was ignored: a paper entitled “Equine fatigue syndrome” (Ricketts SW, Young A, Mowbray JF, Yousef GE and Wood J: Veterinary Record 1992:131:3:58-59) found that 70% of horses examined with histories of persistent and marked lethargy had serum samples with haematological abnormalities containing detectable enterovirus protein (VP1). This paper states: “Recent studies at St Mary’s have confirmed the presence of RNA indistinguishable from that of human enteroviruses in the blood of all...equine cases tested, using Coxsackie B oligonucleotide primers and the polymerase chain reaction. These findings add weight to the hypothesis that an enterovirus exists in the blood of these horses which may be associated with the defined clinical syndrome. This report is the first indication that enteroviruses may affect equids”.

Equally, enteroviral particles were found in the blood, stools, muscle tissue and (post mortem) in the brain of ME patients, but these findings were assiduously dismissed as irrelevant by the same group of psychiatrists, whilst continuing to publish their own work proclaiming their own views about the aetiology of ME.

Other diagnostic markers were yielding results which clearly indicated that ME was an organic condition: SPECT scans (single photon emission computerised tomography) revealed a unique pattern of hypoperfusion in the brain stem of ME patients, with exacerbation after exercise, but these findings were at once dismissed as being “premature” by the same psychiatrists.

The documented failure of antidepressants and graded exercise in ME were also repeatedly ignored by this group of psychiatrists.

Patients were not believed and were regarded as being simply unfit, depressed or lacking in motivation.
Some severely affected people who had been clinically assessed as qualifying for state benefits were duly awarded them, only to find that these benefits were then withdrawn.

The patients’ organisations were accused by this same group of psychiatrists of being anti-psychiatry when in reality they were not; they were, however, anti bad science, for example, they were against changing the facts about ME; they were against the ignoring of important research from other parts of the world (and indeed from within the UK); they were against the mis-representation of others’ research and they were certainly against trivialising ME as nothing more than “tiredness” with a few aches and pains (Interaction: 1994:15:15-16).

When one reads in a broadsheet newspaper that patients with ME are ganging up on their doctors and are mounting a campaign against everyone who disagrees with them, one tends to think it might be true. The truth, however, is that this is a myth, cleverly orchestrated by a handful of ambitious and influential doctors in order to get rid of an illness which no-one wants and which the country cannot afford.

The story about ME is not about prejudice and manipulation by patients, but about the abuse of science, power and politics by medical practitioners.

In 1993 an article in The Times claimed that patients suffering from ME had invented the disease in order to avoid the stigma of mental illness (An illness that starts in the mind. Dr Thomas Stuttaford, The Times, 14th September 1993). Stuttaford, medical correspondent for The Times, re-wrote the history of ME and portrayed the illness in a way which no medical expert would recognise. Anyone reading Stuttaford’s article would find it impossible to relate what he was describing to the clear descriptions of ME which have appeared in the medical literature for over 40 years.

This medical literature made it plain that ME was a syndrome (i.e. a collection of associated symptoms) which commonly follows a virus and that the most striking characteristic is incapacitating dysfunction of the nervous system, accompanied by problems relating to cardiac, skeletal muscle, liver, lymphoid and endocrine organs (Dr Betty Dowsett, Medical Matters, Perspectives, ix, June 1995).

One of the patients’ organisations complained to the Press Complaints Commission, but the Commission was unmoved: it ruled that as long as an article made it clear that what is written is one person’s opinion, then doctors and journalists can write what they like (Interaction, 1994:15:15). Apparently there is no need to be medically accurate.

In 1994, an article in The Daily Telegraph alleged that ME patients were involved in a “highly venomous” campaign which threatened free speech: it claimed that any journalist who suggested that ME may have a psychological cause could expect a tirade of abusive phone calls throughout the night (So don’t argue with ME. Dr Rodney Silver: The Daily Telegraph, 30th March 1994).

The author of the Telegraph article wrote under the pseudonym of Dr Rodney Silver; it is, however, widely believed (and confirmed by a source at a national newspaper) that the true name of the author is Dr Anthony Daniels, one time psychiatrist at All Saints Hospital, Winson Green, Birmingham, who writes also for Medical Monitor (and indeed for The Telegraph) under another of his pseudonyms of Dr Theodore Dalrymple.

The Telegraph article was classic Dalrymple and the following extracts convey the tone quite accurately: “Most people suppose that the greatest threat to freedom of the press comes from the Government......sufferers from a condition now known to most doctors as Chronic Fatigue Syndrome, but to themselves as myalgic encephalomyelitis (ME), have organised themselves into an effective pressure group which has successfully restricted the open discussion of the condition in the lay press. In an age of outraged groups, their methods could easily serve as a model for others......Most doctors, however, believe
that it is of psychological origin.....sufferers from ME tend to be from the higher social classes..... a debilitating illness of supposedly viral origin fits their bill perfectly.....it enables them to retire from life without having to admit to their unhappiness.....most doctors find this group of people intensely difficult and irritating to deal with.....For many sufferers, ME appears to be an all-consuming political cause and a way of life.....It gives purpose to an existence otherwise emptied of meaning.....sufferers achieve that modern state of unassailable beatitude, victimhood”.

The article continues for five columns in the same vein: “there is a limit to the pressure which such a minority group can exert. Nevertheless it is able, by exacting a personal toll on journalists, doctors and others, significantly to distort public discussion of the matter.....Monomaniacs wish simultaneously to suppress others’ opinions and raise the ideological temperature of the argument (how else are they to persuade themselves of its importance?).....The greatest threat to our freedom, however, comes.....from the monomaniacs in our midst”.

Daniels is no stranger to malicious and inaccurate cheap journalism at the expense of defenceless patients. In February 1992 he wrote an exceptionally nasty piece on ME in Medical Monitor (Myalgic encephalomyelitis ---my eye. Dr Theodore Dalrymple, Medical Monitor, 14th February 1992, page 28). Not surprisingly, patients and even other doctors were upset and angered by his allegations that ME is “an escape route for the middle classes” and that patients “suffer triumphantly”. Daniels described the self-help groups as “pestilential”: this may have been tongue-in-cheek, as Daniels subsequently claimed after his true identity had been revealed, but it nevertheless did harm in that it undoubtedly contained undercurrents to which many ill-informed doctors subscribed.

It is generally held to be a true maxim that a sign of maturity is to learn by experience; sadly, some doctors, including Daniels, seem unable to benefit from their experience. For Daniels, it seems that he needs to demean people whom he regards as being inferior to himself.

In yet another unpleasant essay published in Monitor Weekly (Dining on troubled waters, 30th March 1994:55), Daniels wrote a derogatory and wholly inaccurate account of a woman with total allergy syndrome who, via her GP, had successfully appealed to The Secretary of State for Health about her medically confirmed need for bottled water. Not only did Daniels get this information from intemperate gossip at a dinner party by the woman’s contemptuous former GP but he made no attempt to check the truth of it before rushing into sadistic print; the woman was identified from his article and successfully sued Daniels, forcing an apology and correction to be published in the journal; the retraction was published in Medical Monitor on 9th August 1995 on page 30.

Stuttaford and Daniels were by no means lonely voices: elsewhere other doctors (mostly the same group of psychiatrists) were claiming that patients’ groups had pressurised the World Health Organisation (WHO) into classifying ME as an organic neurological condition; the psychiatrists who were most opposed to this classification also claimed that there was no scientific evidence indicating physical disease in ME.

Misrepresentation continued, especially about the contentious issue of exercise in ME. Neither of the two UK patients’ associations promotes total rest: the place where such advice was appearing was in the increasing number of articles in UK medical journals which stated that the support groups were advocating complete rest, and in doing so were responsible for keeping patients ill. Many of those articles were written by Simon Wessely or by people with whom he collaborated.

Despite a meeting between one of the support groups and Dr Wessely at which it was made plain that the groups did not advocate total rest, the allegations continued, yet despite all the insinuations and outright condemnation, the patients’ organisations have continued to urge patients to seek psychiatric help if they suffer from co-existing depression.
Whilst there was increasing frustration at being misrepresented and annoyance at the one-sided accounts of international ME research findings, there was certainly no vicious campaign by patients, even though Wessely in particular continued to exaggerate the role of psychiatric morbidity: studies which found a low rate of affective disorder in ME were downplayed and those studies which challenged a psychiatric approach to treatment were ignored; Minerva (columnist in the British Medical Journal) noted that an (uncontrolled and seriously flawed) trial of cognitive behavioural therapy (CBT) had found this to be helpful in chronic fatigue syndrome (note: not in ME), but did not mention that controlled studies had produced less favourable results (Immunologic and psychologic therapy for patients with chronic fatigue syndrome. Lloyd AR et al; Am J Med 1993:94:197-203).

The ME patients’ organisations, however, continued to discuss these other studies in their literature and press releases, so the psychiatrists began to cast doubt on the competence of the organisations’ medical advisers (Bookshelf: Simon Wessely: Lancet 23rd October 1993:1039). A letter challenging Wessely’s statement was rejected for publication and an editorial in the BMJ of 19th March 1994 implied that the advice given by patient groups was associated with a poor outcome.

Also in March 1994, Wessely et al stated that “The infective characteristics...may be the result of ...illness behaviour”. (Population based study of fatigue and psychological distress. T.Pawlikowska, T.Chalder, SR Hirsch, P Wallace, DJM Wright, SC Wessely: BMJ 1994:308:763-766); the previous year, Wessely had asserted that “there is no evidence of an inflammatory process affecting the central nervous system” (Chronic fatigue, ME and ICD 10. Anthony David, Simon Wessely, Lancet  November 13th 1993:342:1247-1248), yet the previous year Buchwald et al had concluded “Neurologic symptoms, MRI findings and lymphocyte phenotyping studies suggest that the patients may have been experiencing a chronic, immunologically mediated inflammatory process of the central nervous system” (A chronic illness characterised by fatigue, neurologic and immunologic disorder and active herpesvirus type 6 infection. Dedra Buchwald, Paul Cheney, Robert Gallo (co-discoverer of HIV), Anthony Komaroff et al, Ann Int Med: 1992:116:103-113).

Such findings do not seem to support Wessely’s views about the condition, but it must be remembered that Wessely does not accord significance to, or discuss the incidence of, many symptoms which others have documented as occurring in ME. Further, despite their many problems, patients with ME do not exhibit a loss of interest in life, which is commonly the case in depression, yet Wessely and his colleagues repeatedly claim ME as a form of depression, even though the neurological symptoms seen in ME are not listed amongst the Diagnostic and Statistical Manual (DSM) diagnostic criteria for affective disorder (see below).

Such selectivity on Wessely’s part would seem to be deliberately misleading and hence harmful to patients.
Background

A comprehensive historical documentation of recorded outbreaks of ME, both epidemic and sporadic, is beyond the scope of this review but in any event, such information is already in the public domain and those wishing to read it might consider papers such as the one by the UK former Chief Medical Officer, Donald (now Sir Donald) Acheson, entitled “The Clinical Syndrome variously called Benign Myalgic Encephalomyelitis, Iceland Disease and Epidemic Neuromyasthenia”. E.D. Acheson. American Journal of Medicine, April 1959: 569 - 595; additionally, the major 723 page textbook on ME would prove illuminating (The Clinical and Scientific Basis of Myalgic Encephalomyelitis Chronic Fatigue Syndrome, edited by Byron M. Hyde, published by The Nightingale Research Foundation, Ottawa, 1992).

This review gives merely a brief outline of relevant background to the present situation.

The medical literature shows that a condition very like the one currently known interchangeably but erroneously as chronic fatigue, chronic fatigue syndrome (CFS), chronic fatigue and immune dysfunction syndrome (CFIDS), postviral fatigue syndrome (PVFS) and myalgic encephalomyelitis (ME) was first described by Sir Richard Manningham in 1750 in a book called “The symptoms, nature, causes and care of the Febricula or Little Fever” (2nd edition, J. Robinson, London, 1750); the term “myalgic encephalomyelitis” was first introduced in the UK in 1956 in a leading article in The Lancet (A new clinical entity? Lancet, 26th May 1956: 789-790).

On 7th April 1978, a symposium on ME was held at the Royal Society of Medicine, London; it was entitled “Epidemic Neuromyasthenia 1934 - 1977: current approaches” and was a comprehensive attempt to encourage systematic study of the epidemiology, clinical findings and possible causes of this condition. The symposium was reported as a leading article in the BMJ in November 1978 (Epidemic Myalgic Encephalomyelitis. BMJ: 1978:1436) and in November 1978, the Postgraduate Medical Journal devoted a complete issue to documenting the entire symposium (Postgraduate Medical Journal, 1978:54:637:705-774). Tellingly, the Foreword concludes with a familiar phrase: “It is hoped that as a result of the meeting, sufferers from this miserable illness will, in future, be more sympathetically managed”.

Almost twenty years later, that hope is not yet fulfilled.


Further outbreaks occurred worldwide, and the idea that mass hysteria might account for these outbreaks was fashionable at one time (postulated by two UK psychiatrists some twenty years after the outbreak at The Royal Free Hospital in London, even though they had never examined a single patient and chose the topic simply as a vehicle for a PhD thesis), but like the majority of illnesses for which a psychiatric aetiology has been put forward, this hypothesis lacked all scientific merit and now, with the emergence of hard data, can be totally rejected (Diagnostic and Clinical Guidelines for Doctors: Peter O. Behan, published by The ME Association, 1991, pages 5-6).

ME was first listed as a neurological disorder in the WHO International Classification of Diseases in 1969. In July 1992, along with other organic neurological conditions, it remained in the chapter on Diseases of the Nervous System (ICD-10:G93.3, page 423), which was some considerable time after the distinguished neurologist Lord Brain had included it in the standard textbook on diseases of the nervous system in 1962 (Diseases of the Nervous System. Lord Brain; Oxford University Press, 6th Edition, page 355).
**Terminologies**

In his book about ME, a leading American physician who specialises in children with ME lists about 50 names for the syndrome, wryly observing that the number of names given to an illness is inversely proportional to the amount of knowledge about that illness. (ME: The Disease of a Thousand Names. Dr David S. Bell. Pollard Publications, Lyndonville, New York 1991).

In this review, mention will be made of only the most common terminologies now in current use.

**Myalgic Encephalomyelitis (ME)**

This was in common use in the UK from its introduction in 1956 by Sir Donald Acheson and colleagues including the late Dr Melvin Ramsay; it described an illness with three absolutely cardinal features:

i. a characteristic muscle fatiguability whereby after even a minor degree of physical effort, there is a marked delay (sometimes of several days, weeks or even months) before muscle power is restored

ii. a remarkable variability of symptoms and physical signs from episode to episode, and within each episode

iii. an extended relapsing and remitting course lasting for months or years, culminating in many cases becoming severe and chronic


Other significant problems found in “true” ME include the following, and all have been documented in the literature:

---malaise (often severe and incapacitating)
---exhaustion
---exquisite muscle tenderness on palpation
---muscle spasm
---intractable pain in certain groups of muscles, especially the neck, shoulder and pelvic girdles, leading to an inability to stand unsupported for more than a few minutes
---vertigo
---blurred and double vision
---observable nystagmus
---ataxia
---dysequilibrium
---impaired co-ordination of fine finger movements
---photophobia
---hyperacusis
---parasthesia
---tinnitus
---headache
---excessive somnolence
---reversed sleeping patterns
---vivid and disturbing dreams
---unrefreshing sleep
---nausea (often chronic)
---diarrhoea
---abdominal pain
---ovarian-uterine dysfunction
---relentless frequency of micturition (day and night)
---cardiac arrhythmias, especially pronounced orthostatic tachycardia with concurrent inverted T waves
---orthostatic hypotension
---dyspnœa on minimal effort
---drenching sweats, followed rapidly by shivering
---vascular problems
---spontaneous periarticular bleeds in the fingers / thumbs
---coldness in the extremities
---purple discolouration of the extremities, including (in females) the breasts
---severe recurrent mouth ulcers
---pancreatic exocrine insufficiency
---palindromic arthropathies
---swelling of the eyelids (and difficulty opening them)
---multiple hypersensitivities to normal foods and household chemicals, including perfumes such as scented deodorants, aftershave, hair mouse, make-up, washing powders, petrol and agricultural chemicals etc
---marked hypersensitivity to many medicinal therapeutic substances (this has been particularly noted, and is considered by some world-class experts to be almost pathognomonic)
---intolerance to alcohol
---sexual dysfunction
---there may be seizures
---hair loss (assessed as occurring in about 20% of patients by Dr Bell, his book mentioned above).

There appear to be distinct differences between those who experience frequent sore throats with swollen tender lymph nodes and those who rarely get sore throats but who have predominantly bowel problems.

In all presentations of this condition, the overwhelming fatigue is a totally incapacitating exhaustion, rendering the patient in need of full time care.

Some doctors, including Dr Wessely, insist on equating this physiological exhaustion with “tiredness”; other doctors do not have Wessely’s difficulty in distinguishing between the two: “the disabling weakness and exhaustion a patient with chronic fatigue syndrome experience is so profound that ‘fatigue’ is probably an insult” (Chronic Fatigue. Cuozzo J, JAMA 1989:261:5:697).

Although extensive, the above list is by no means comprehensive; in addition to those problems, there are numerous neuropsychological problems, but it is imperative not to assess the neuropsychological dysfunction on its own, without taking proper account of the other symptoms.

The neuropsychological problems include:

---forgetfulness
---irritability
---confusion
---difficulty in thinking
---inability to concentrate
---neurocognitive dysfunction (especially with words and numbers)
---anxiety
---depression  (note that this is usually *atypical* depression, with no anhedonia)
---emotional lability (often very marked, with typically out of character weepiness)
---panic attacks
---some degree of personality change

(CFIDS Chronicle, 1987 to date).

It is the co-existence of these psychological problems which seem to pose a significant problem of discernment for Wessely and his like-minded colleagues.

**Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS)**

This is an American term, designed to incorporate the immune abnormalities commonly found; it is virtually synonymous with the UK term ME.

**Chronic Fatigue Syndrome (CFS)**


The background to that paper makes compelling reading; the following information is taken from Osler’s Web by Hillary Johnson, published by Crown Publishers Inc, New York, 1996, to whom grateful acknowledgement is made.

According to Scientific Literature Index, Institute for Scientific Information, Philadelphia, the 1988 paper by Holmes et al became one of the most cited papers published in clinical medicine, but all is not as it seems.

In 1985, Gary Holmes (lead author of 16 listed on this paper) was employed at the Epidemic Intelligence Service Division of the US Centres for Disease Control (CDC) based in Atlanta, when Dr Daniel Peterson of Nevada contacted the CDC because he was convinced there was a singular medical crisis in his town, Incline Village, near Lake Tahoe; Peterson’s medical partner was Dr Paul Cheney.

The physical symptoms which many of his patients were reporting were seemingly without end; they included bouts of dizziness, rashes, abdominal pain and diarrhoea, rapid pounding heartbeat and chest pain, shortness of breath, blurred vision, acute photophobia, pain in the joints, loss of sensation in the fingers, numbness in the face, swelling of ankles, feet and eyelids, and patients reported that their hair was falling out.

This same symptom complex was not just limited to Nevada; epidemics of the same illness were being observed in other parts of the USA: additional symptoms included nightmares, intolerance of alcohol, loss of memory, trouble concentrating; many patients developed allergies to substances which had never previously triggered an allergic reaction. Many were quite unable to stand; above all, there was fatigue which was virtually paralysing.

Eventually, after much persuasion, the CDC agreed to investigate this supposedly mysterious illness; Gary Holmes was assigned to the job, along with Jonathan Kaplan.

Holmes’ efforts to establish a consensus case definition met with repeated fierce criticism and opposition from senior US scientists and clinicians: some were openly unwilling for Holmes to publish any such case definition at all.
Holmes was warned that should the US government’s diagnostic criteria be published and widely disseminated, then “the field could change from an epidemiological investigation into a health insurance nightmare” (Osler’s Web, page 218).

Holmes was seemingly coerced into forming his case definition according to the dictates of top US government scientists, so in reality, it was US Government scientists rather than clinicians who were defining the disease (Osler’s Web, page 638).

The 1988 paper was to take the form of a working case definition: as such, Holmes needed to choose a name for the syndrome he had been investigating. He wrote to his collaborators saying “Names we feel to be descriptive... include myalgic encephalomyelitis (the British term)”. His collaborators were apparently unwilling to concur; they did not wish to confer credibility by using such a name in case psychiatric illness might turn out to be the cause, thus the term “chronic fatigue syndrome” (CFS) triumphed over other suggestions which had been postulated by Holmes (Osler’s Web, page 219).

American patients were enraged at this terminology, not least because the definition was seriously flawed. Virtually every sign of organic illness had to be ruled out before the diagnosis of CFS could be made (Osler’s Web, page 268).

Because of the determination to suppress the true symptomatology, the view that CFS was a serious neuroimmunological disease was downplayed for many years and the publication of Holmes’ paper became the turning point in the deliberate attempts to make ME disappear.

In Holmes’ paper, the cardinal features of “CFS” were documented as severe fatigue, weakness, sore throat and painful lymph nodes, together with confusion and depression.

The symptoms complex which was supposedly being defined had previously been known as the chronic Epstein-Barr syndrome (also known as chronic mononucleosis or glandular fever).

Holmes’ paper stipulates that in order to fulfil the criteria for “CFS”, patients must exhibit palpable or tender anterior or posterior cervical or axillary lymph nodes documented by a physician on at least two occasions at least one month apart.

Such a definition bears little relationship to the symptoms which had caused Dan Peterson to contact the CDC; moreover, in ME (the name originally preferred by Holmes) the characteristic features have always been documented as severe muscle pains and “in nearly every patient there are symptoms and signs of disease of the central nervous system” (Leading article: A new clinical entity? Lancet, 1956: May 26: 789-790).

In addition, there have long been clear clinical differences between glandular fever (GF) and ME: for instance, in GF caused by Epstein-Barr virus the spleen is always enlarged, but it is almost never enlarged in ME; the sex ratio is different; in GF there may be high fever for 7 - 10 days but in ME there is low fever; in GF there is a major increase in the white blood count (WBC), mainly lymphocytes, the majority of which must be atypical (ie. have an enlarged nucleus), and neurological involvement is rare in GF but is invariably present in ME.

Unbelievably, at no point in the text or references did the final version of Holmes’ paper mention myalgic encephalomyelitis, but Holmes was minded to point out that the term “CFS” was merely an operational concept designed for research purposes.

Regrettably, the term “CFS” has been adopted as a term used by some doctors when referring to anyone who feels tired for more than one month (Tired, weak, or in need of a rest: fatigue among general practice
attenders. Anthony David et al. BMJ 1990:301:1199-1202). Notably, Dr David is a close colleague and co-author with Dr Wessely, who has been so indefatigable in causing ME to become subsumed under “CFS”.

The term “CFS” now encompasses other pathologies such as the Postviral Fatigue Syndrome (PVFS); by definition, any virus has a post-viral phase but it does not necessarily incapacitate the patient. The late Dr Melvin Ramsay wrote of this designation as follows: “The wrongful assumption that ME and PVFS are synonymous, now prevalent in the world literature on the subject, serves to blur the true clinical identity of the myalgic encephalomyelitis syndrome. This can only be remedied when the term PVFS is restored to its rightful context” (Myalgic Encephalomyleitis and Postviral Fatigue States: The Saga of Royal Free Disease. A. Melvin Ramsay, 2nd edition, Gower Medical Publishing, London 1988).

Further, confusion arises due to the fact that, despite the above caveat, some eminent ME researchers, including Professor Peter Behan of Glasgow, now tend to refer to ME as PVFS; this is somewhat surprising, given that Professor Behan’s own research has revealed convincing evidence that some cases of ME are not precipitated by a virus but are precipitated by certain toxins. Behan has found that organo-phosphate poisoning precipitates an identical illness to ME, and that following an initial exposure to OP toxins, on second exposure to OPs, patients do not require the same dose of toxin: a miniscule whiff of the chemical will cause deterioration (Transcript of video of lecture given by Professor Behan, 23rd November 1995, Coventry & Warwickshire Postgraduate Centre). Whilst OPs do not cause ME (ie. they do not reproduce the hypothalamic, neurological, cognitive, digestive, myalgic, hepatic, endocrine or musculo-skeletal problems of ME, which are specific to the tissue tropism of the infectious agent, OPs are immunosuppressive and can therefore trigger any normally harmless or latent microbe into action.

Patients themselves abhor the term CFS, believing that it implies a benign condition of trivial significance, and that it suggests that people with CFS lack motivation or the ability to get on with life.

Moreover, whilst the term myalgic encephalomyelitis is classified by the World Health Organisation in the International Classification of Diseases as a neurological condition (ICD 10 G 93.3), “chronic fatigue” is classified in ICD 10 under Mental and Behavioural Disorders; it comes under the sub-heading of Other Neurotic Disorders, which include neurasthenia, which in turn specifically includes Fatigue Syndrome (ICD 10, vol 1, F 48.0, page 351). Of importance, the term “Fatigue/syndrome/chronic” (ie. Chronic Fatigue Syndrome or CFS) is indexed to ME at G93.3 as a colloquial term specifically for ME.

Hence, some doctors who are very supportive of ME patients tend to use the term “CFS”, apparently being of the view that, as in multiple sclerosis, there are degrees of affliction, and that “ME” is at the most severe end of the spectrum which encompasses all chronic fatigue states. Whether or not this can be supported aetiological cannot yet be determined, as there is no definitive diagnostic test for ME, although there are clear patterns emerging.

Perhaps of most concern is that the name chronic fatigue syndrome is frequently confused with chronic fatigue, but the two are not synonymous. In 1990, the American Medical Association was forced to issue a correction, having published an article in JAMA which failed to make any such distinction: the correction accepted that the two conditions were not the same, and regretted any confusion caused (JAMA issues correction. Journal of the American Medical Association 1990, referring to JAMA dated 4th July 1990).

This clear clinical distinction has not, however, prevented Dr Wessely from continuing to use “CFS” as an umbrella term for anyone who experiences tiredness which he cannot ascribe to an organic pathology.

The various terminologies which may or may not be describing the same condition have long confounded doctors and patients alike. Being acutely aware that the several terminologies commonly used remain a minefield for the unwary, the Committee which produced the Report of the UK National Task Force on CFS / PVFS / ME (Westcare, Bristol, supported by the UK Department of Health, 13th September 1994) made valiant efforts at intelligible nomenclature.
This Task Force consisted of “individuals, clinicians and clinical scientists with a wide range of expertise and experience in the care of patients with chronic fatigue syndromes and of research into these problems”; the twelve medical members came from backgrounds which included molecular pathology, immunology, pharmacology and therapeutics, cancer epidemiology, psychological medicine, general practice and neurology; it included a physician who specialises in infectious diseases and who runs an NHS clinic specifically for ME patients.

This Task Force report made it plain that whilst the whole arena of idiopathic severe chronic fatigue (ISCF) had been considered, particular attention was directed to the sub-group known as ME, which the report refers to as “CFS / ME”; this sub-group is recorded as being the most severely afflicted sub-group.

The report notes that: “the most severely affected are bed-ridden with malaise, exhaustion and pain, together with other distressing symptoms, for example, inability to think clearly, loss of balance, painful hypersensitivity to the touch of bedclothes, daylight, or to the sound of a human voice, and profound fatigue and weakness such that the individual may not even be capable of feeding him/herself. This situation causes isolation and deep distress”.

Notably, the Task Force Chairman, Dr David Tyrell CBE. FRS. DSc. FRCP. FRCPath, when referring to the problem of nomenclature, felt obliged to state that this is not just a semantic problem, but that it “encompasses serious disagreements which have sadly led to ill-will and abusive remarks on such questions as whether the syndrome exists”.

The persistent and seemingly deliberate failure by Wessely and his close colleagues to distinguish between true ME and other chronic fatigue syndromes has caused considerable concern; this concern has been expressed in the international literature on many occasions, but for illustrative purposes, just five examples are provided here:


   “The importance of correctly identifying patients with this syndrome, who may otherwise be labelled neurotic, is emphasised”.

   “Once again, we stress the importance of recognising this relatively common illness, which may easily be mistaken for psychoneurosis”.


   “The all-embracing American term chronic fatigue syndrome or CFS includes many syndromes, some of organic and some of non-organic nature”.

   “The postviral fatigue syndrome (PVFS), with profound muscle fatigue on exertion and slow recovery from exhaustion seems to be related specifically to enteroviral infection.....the changes seen with chronic persistent enteroviral infections may be due to...viral infection in brain or muscle which are not usually present with other viruses which produce a fatigue syndrome”.


   Cheney and Lapp, two of the most experienced US ME specialists, state: “Over the past ten years a considerable and diverse medical literature has arisen concerning CFS.....Systemic errors exist among the
tools used to discern differences between CFS cases and ‘healthy’ controls.....the central problem is case selection. Some investigators, aware or unaware of bias, attract or include in their studies patients who best fit their view of CFS. This.....selection bias can markedly affect the observations of a study”.

4. **UK National Task Force Report, 1994** (see above): the Task Force report clearly recognises that “the picture is further complicated by slection and observer bias.....the observations made about these patients will depend.....on the focus.....of the specialist in question”.

The Task Force report concluded that “progress in understanding chronic fatigue syndromes is hampered by.....the use of study groups which have been selected using different definitions of CFS (and by) the invalid comparison of contradictory research findings stemming from the above”.


In this study, US neurologist Ben Natelson (a recipient of two National Institutes of Health CFS Research Center grants) removed all patients with possible confounding psychiatric disorders; he then found that CFS / ME patients were far more similar to patients with MS than to those with depression, and that their level of physical disability greatly surpassed *either* population. Dr Natelson is convinced that lack of careful patient selection for groups studied has produced the popular and well-documented myth that CFS is simply another form of depression.

Heedless of many such warnings, and having so publicly nailed his colours to his personal mast, Wessely has sailed on undaunted.
**Definition Difficulties**

Differential diagnosis is critical in medicine. Regrettably, there exists in the UK a group of doctors who all collaborate with each other and who are mostly but not exclusively psychiatrists, and all seem to experience profound difficulty when it comes to making a differential diagnosis involving ME. From the evidence available (see below), it almost seems as if this group is determined to ignore and even to suppress data on ME which does not accord with their own fixed concept of the syndrome, which they invariably refer to simply as “CFS”. The most prominent of this group is Dr Simon Wessely; he and his colleagues remain immutable in their view that the longer the list of physical symptoms of which a patient complains, the more unequivocal is the psychiatric diagnosis.

Herein lies an impasse, because Dr Wessely and his colleagues who claim a special interest in and knowledge of “chronic fatigue states” drew up their own definition for selection of patients in their future study groups; this definition would seem to exclude patients experiencing many of the symptoms commonly found in true ME. This group of doctors, however, expressly advocate that: “other psychiatric disorders (including depressive illness, anxiety disorders and hyperventilation syndrome) are not necessarily reasons for exclusion” (A Report – chronic fatigue syndrome: guidelines for research: Report of a consensus meeting held at Green College, Oxford, 23rd March 1990: MC Sharpe et al. JRSM 1991:84:118-121).

Not surprisingly, these new “guidelines” caused concern amongst those who live and work with ME, because they seemed to indicate an in-built selection bias in favour of a psychiatric outcome in future studies. It was believed that any such future studies that relied upon the Oxford guidelines would consequently further obfuscate the distinction between ME and chronic fatigue and that patients who did not have “CFS” but true ME would therefore be further harmed.

The major concern expressed about the Oxford criteria by those involved with true ME was, however, that they encompassed all categories of “fatigue”, and that “fatigue” is too vague a symptom on which to base any case definition. Sadly, and probably due to the input of the psychiatrists, ME definitions now centre on the sole symptom of chronic, “medically unexplained” fatigue instead of on the original definition by Ramsay. Undeniably, for those whose aim is to link ME to a primary psychiatric aetiology, such dilution of critical definitions can only serve to further their cause.

Indeed, Professor Peter Behan of the Department of Neurological Sciences at Glasgow says of the Oxford guidelines: “The recent attempt by Oxford psychiatrists ...has not taken us any further” (Myalgic Encephalomyelitis: Postviral Fatigue Syndrome: Diagnostic and Clinical Guidelines for Doctors. Peter O. Behan. The ME Association, 1991, page 9).

This persistence by Wessely et al in not differentiating between important sub-groups is the prime bone of contention expressed by those who suffer from true ME, and indeed of the many medical practitioners who disagree with Wessely. It is not surprising that those who have to struggle daily with the enormity of their physical problems become outraged when they read that studies purporting to discuss their condition fail to acknowledge – or even mention – the life-wrecking symptoms which engulf them.

Again, it is not surprising that patients with ME maintain that their illness is not psychiatric in origin: they do so because their history and symptoms clearly indicate this, and because they know from experience that symptoms which they clearly exhibit are so frequently ignored because of ignorance or bias.

Equally, they know that the deterioration of some patients with ME who have tried their utmost to keep mobile and independent is unacknowledged by Wessely.
It needs to be stated that psychiatrists use certain measures known as the Diagnostic and Statistical Manual of Mental Disorder (referred to as the DSM); there are various editions and revisions, for example, DSM IIIR refers to the revised third edition.

Psychiatric patients are assessed using DSM criteria. Depression, for instance, requires the presence of four symptoms from a shortlist, which includes the presence of fatigue, concentration difficulties, changes in eating pattern, and changes in sleeping patterns. Using these criteria alone, by definition, many patients with ME immediately become confirmed psychiatric patients.

This much-used practice is exceedingly dangerous when assessing patients with multiple sclerosis, ME, or other neurological disorders (OND), or patients receiving chemotherapy: this is because the DSM criteria rely heavily on the presence of symptoms which are common in such illnesses, but as secondary factors (ie. as a consequence), not as a primary aetiological factor.

Notwithstanding, Wessely seems determined to cling tenaciously to these limited and inappropriate measures of mental assessment in his dealings with ME patients. This is baffling, as he is an epidemiological psychiatrist, which means that he has a particular interest in studying the links between the environment and psychiatric illness. The aim of epidemiology is to find means of illness control and future prevention, so it is imperative to ensure accuracy in the selection of the patient cohorts studied.

There is abundant evidence to show that Dr Wessely has failed to study patients with true ME, but that those patients have then been incorporated as part of his conclusions under his guise of incorporating all fatigue states as “CFS”.

Unsurprisingly, this practice has caused Wessely to receive what he claims is hate mail (New Scientist, 18th August 1990, page 39).
Introducing Dr Wessely


Currently, he is Reader in Psychological Medicine at The institute of Psychiatry, University of London; this is a joint appointment in that he is also Reader in Psychological Medicine at King’s College School of Medicine and Dentistry, London, and carries the title of Reader in Liaison Psychiatry at both establishments.

He is Director of the Chronic Fatigue Syndrome Research Unit at The Raynes Institute, King’s College School of Medicine and institute of Psychiatry, London.

He is an honorary Consultant in Psychological Medicine at King’s College Hospital.

He is review editor for the journal Psychological Medicine, published by Cambridge University Press.

He is a member of Council of The Royal Society of Medicine Section of Psychiatry.

Wessely’s Status

As at June 1996, Wessely’s status seems formidable; he has undoubtedly become extremely powerful and influential. He is relentlessly and awesomely assiduous, and unquestionably dominates the CFS/ME literature.

It is all the more worrying that someone of such phenomenal influence is propagating what many believe to be inaccurate and misleading information which is hindering progress in medical understanding (see below).

1. Wessely has had connections with the drug company Wellcome (now combined with Glaxo) over many years. He has often been funded by Wellcome and was the Wellcome Research Fellow in Epidemiology at the Institute of Psychiatry. He appears to subscribe to the Wellcome strategy of profitable enterprise documented by Brian Deer in The Sunday Times Review on 27th February and 6th March 1994: one learns from Deer that the Wellcome strategy is not only curative medicine but commercial success; most certainly, Wessely advocates the use of antidepressant drug therapy in CFS/ME, in that he advises general practitioners that this is a treatment of choice in CFS even though until recently there have been no randomised double blind placebo-controlled studies showing the effectiveness of antidepressant drug therapy in CFS. The one such study undertaken found convincing evidence that although antidepressant therapy is commonly used in CFS, it “does not have a beneficial effect on any characteristic of CFS” (Randomised, double blind, placebo-controlled study of fluoxetine in chronic fatigue syndrome. Jan HMM Vercoulen et al. Lancet 30 March 1996:347:858-861). This same study also found that a larger than usual percentage of patients was forced to withdraw from the study because of side effects of the drug, and the study also found that Fluoxetine (Prozac) was no better than a placebo in treating depression; the study concluded that the use of Fluoxetine in CFS is unwarranted, as "it does not lead to improvement in any area of the patient’s functioning”.

It needs to be noted that Wellcome were promoting Prozac on behalf of the American producers, and that Wessely has been very actively involved in that promotion.

As Wellcome Research Fellow, Wessely is, of course, paid by Wellcome.
NOTES ON WELLCOME

Wessely's connections with Wellcome invite special interest, as does the company itself. In early 1994 Brian Deer, writing for The Sunday Times (Hard Sell by Brian Deer; The Sunday Times News Review: 27th February 1994) produced a two part in-depth article on Wellcome and its ramifications.

The headquarters of the Wellcome Trust are at 183 Euston Road, London; it is the world's biggest private medical research fund, a charity with assets worth more than £6 billion. The Trust alone distributes more money to institutions than even the British government's Medical Research Council: it gives some £400 million annually to doctors and scientists in Britain and around the world.

From the headquarters in Euston Road, the Trust controls a commercial drug company, the Wellcome Foundation (housed at 160 Euston Road), one of the top pharmaceutical manufacturers in the world, and through this, the Trust also controls Burroughs Wellcome, its giant US offshoot. At 183 Euston Road is also housed the Wellcome Institute, a multi-million pound centre that researches and shapes medicine's history, politics and ideology.

From all these - through grants and sponsorship - government agencies and hospitals are influenced everywhere: in offices in Euston Road, decisions have been reached that have affected lives and health on a scale that compares with minor wars (ibid). It is likely that Wessely is an assessor for the Wellcome Trust.

According to Deer, 183 Euston Road is the creation of the late Sir Henry Wellcome, architect of the modern pharmaceutical industry. It opened in 1932 and its aim was that it would be a flagship for profit-making enterprises, which today trade under the name of The Wellcome Foundation Ltd. In a memorandum written at the end of his life, Henry Wellcome set out detailed plans of how his empire would continue long after he was gone. "With the enormous possibility of development in... pharmacy and allied sciences", he predicted, "if my desires and plans are carried out in the way of research cooperation...there are likely to be vast fields opened for productive enterprises for centuries to come" (ibid).

Wellcome's strategy appears to be drawn towards an ever-increasing market and there is evidence which suggests that the biggest gainer may be Wellcome's accounts rather than public health. Even though powerful doubts have been raised about its products, Wellcome remained loyal to Henry's ideas and sharpened its marketing, raising questions about whether its greater commitment is to fighting sickness or to maximizing commercial success. Deer questions how it is that a giant organisation that is granted charitable status to relieve human suffering can be financially rooted in the sale of drugs which may be of trivial use, and may be inappropriate or even dangerous (ibid).

In his second article (The Money Spinners, The Sunday Times News Review 6th March 1994), Deer shows how medical research and company profits are inextricably linked. He documents how Dr George Hitchin, chief biochemist at Burroughs Wellcome, even now chortles as he states: "Now we've got the drugs, all we've got to do is find the diseases that go with them". Deer re-iterates that three of Wellcome's big four drugs - septrin, AZT and acyclovir - have all been promoted beyond the best medical opinion, and that much of these drugs' financial yield has come from use by patients for whom they may be of trivial or inappropriate use, and for whom they may even be a danger.

In a structure devised to distribute the profits of pharmaceuticals to the research work of doctors and scientists, there may be anxieties about Wellcome's wider impact.

In 1993, 19 of the 21 members of the UK Government's Committee on the Safety of Medicines either worked in institutions which received funds from Wellcome or they were granted a share of the drug revenues in their own right (ibid).
Both the Wellcome Foundation and the Burroughs Wellcome company make major contributions to swell the medical merry-go-round; unrestrained by charitable rules and regulations, such contributions can be channeled to where it counts - to where they bring the greatest reward (ibid).

Of particular note is the fact that in 1992, the minutes of the Campaign Against Health Fraud (now known as Healthwatch) annual general meeting disclosed that in the year 1991-2, it received a grant from the Wellcome Foundation (Dirty Medicine. Martin J. Walker. Slingshot Publications 1993, page 334). In this respect, it may be judicious to reflect that Wessely is also a member of the inner cell of Healthwatch.

2. Wessely has had connections with Healthwatch from its inception in 1989; soon after the press launch, he was one of the leading campaign activists and the majority of the early core activists had some financial connection with Wellcome (ibid page 335). From the beginning, the Campaign had a practice of restricting membership to those who endorsed the use of pharmaceuticals (ibid page 385). By the time the first newsletter was published, it was evident how the Campaign members were to go about prosecuting their complaints against non-pharmaceutical treatments: anything which challenges the monopoly hold of the chemical companies on food production and pharmaceuticals, or on the professional status of doctors, should be attacked (ibid page 340).

It may be pertinent to note here that many people with ME have an up-regulated immune response, which means that they react badly to common substances, and particularly to medicinal drugs (see (i) CFS Diagnosis and Treatment: Medical Training Video. Jonathan Rest: CFIDS Foundation 1995; (ii) The Presentation, Assessment, Investigation and Diagnosis of Patients with Post-viral Fatigue Syndrome in an Infectious Diseases Clinic: WRC Weir. In: Post-Viral Fatigue Syndrome, ed: Rachel Jenkins and James Mowbray; John Wiley & Sons, 1991; (iii) Educating the Educators. David Bell: CFIDS Chronicle, Spring 1995). Such patients may of necessity turn to “alternative” and/or complementary practitioners, in particular to clinical ecologists or allergy practitioners, who tend to advocate non-drug therapies and so have become the target of Healthwatch members.

A natural progression has been the attacking by Healthwatch of natural remedies, vitamins, food supplements and the health food shops in which these products are sold (Dirty Medicine pages 340-347).

Such attacks appear in the free journals sent to most doctors, for example “GP”, whose contents reinforce the fact that it is subsidised by drug company advertising (ibid page 342).

Indeed, in its literature, Healthwatch (as the Campaign Against Health Fraud) clearly states its aims, which include promoting “Better understanding by the public and the media that valid clinical trials (ie. drug trials) are the best way of ensuring public protection”, whilst the aims it opposes include “Diagnoses that are misleading or false, or that may encourage unnecessary treatment for non-existent diseases” (CAHF subscription form, valid to May 1990). It must be remembered that Dr Wessely teaches that ME is a non-existent disease.

It should also be remembered that there is accumulating evidence to incriminate organo-phosphates (OPs) in human ill-health and that Professor Peter Behan’s ME research has found a worrying similarity between people such as farmers who have been exposed to OPs and those who have been diagnosed with true ME.

In this context, it should also be noted that Wellcome’s involvement with OP products can be established by glancing at an old Ministry of Agriculture, Fisheries and Food (MAFF) “Guide to Veterinary Products” (HMSO 1977): perhaps it should also be noted at this point that in 1989, Wellcome sold Coopers Animal Health, a company it had set up in 1985 in partnership with ICI to produce organo-phosphates (Dirty Medicine, page 219).
Not only was Wellcome involved with OP sheep dips, it was also involved with warble fly treatment for cattle, which is also an OP: this compulsory warble fly treatment has been implicated in Bovine Spongiform Encephalopathy (BSE) and thus there may be the possibility that it is associated with Creutzfeldt Jakob Disease (CJD) in humans (Channel 4 Dispatches: Purdy’s Proof, 12th June 1996).

Wellcome’s commercial development has been uniquely shaped by its special relationship with both the British and US governments: the history of Wellcome’s alignment with the most powerful and long-established sectors of British and American power puts it in a unique position when dealing with governments. Unlike other pharmaceutical companies, Wellcome plays a commanding role in the British industrial military complex (Dirty Medicine page 221). Exhibiting their monopoly interests, Wellcome is able to dip in and out of a complex network which exists between doctors, their professional societies, chemical companies and government agencies such as the Department of Health and MAFF (Dirty Medicine page 240).

Equally, since its foundation, the UK Medical Research Council (MRC) has been close to Wellcome: by the late 1980s, medical research in Britain was controlled by a partnership between Wellcome and the government (Dirty Medicine page 259); indeed, the Wellcome Trust also finances the Wellcome Parliamentary Fellow who is paid entirely by a Wellcome bursary.

Is it purely by chance that Wessely, with his long connections with Wellcome, should be listed as a Healthwatch activist (one of whose stated aims being to attack those who challenge the monopoly hold of the pharmaceutical companies)?

Is it also by chance that Wessely should be so unrelenting in his efforts to ensure that ME is nothing more than a belief that one is ill? (see below).

Is it also pure chance that the devastating effects of ME have produced a host of desperate people who are turning more and more to alternative therapies and away from powerful drug therapies to which they frequently have an adverse reaction?

Is it possible that there might be a chemical neurotoxic factor in the aetiology of ME, and that Wellcome is anxious to categorise ME as psychological in order to avoid possible future litigation?

Only time will tell.

Another long-time member of Healthwatch, Dr James le Fanu, frequently promotes the Healthwatch ideology in his regular column in The Daily Telegraph, most recently in his piece on 18th June 1996 in which he mentions that a forthcoming report from the Department of Health finds the evidence linking foods with cancer so unconvincing that there are no grounds for giving the public advice on the matter. The evidence dismissed by Dr le Fanu and the government asserts that: “experts agree that a third of all cancers are diet-related” and was published by the Cancer Research Campaign in a press release earlier in June 1996. Many people are concerned at the amount of chemicals in our food, and some are more susceptible than others to these chemicals. Healthwatch is determined to suppress any such fears.

This suppression may not be achieved as easily as once thought and two recent conferences have brought this sharply into focus. The first was a public lecture given in London on 31st March 1996 by Dr James Braly, an allergist of 25 years’ experience and medical director of Immuno-Laboratories in Florida, USA, one of the most highly respected laboratories in the world for allergy testing. Braly’s lecture confirmed what many ME sufferers know for themselves from personal experience: food allergies and chemical sensitivity are very common causes of human suffering.
There are countless additives to food which can cause adverse reactions; these include flavourings and preservatives, and people who are food-allergic are also chemically sensitive because these are not separate entities. Once a person is allergy-prone, they are liable to recurrent episodes from many sources by virtue of having a "leaky gut". Alarmingly, Braly said that it had been shown that radioactive allergenic foods given to animals with a leaky gut could be detected by radioactivity in the brain. This implies that, despite the existence of the blood brain barrier, whatever is in the blood reaches the brain.

Leaky gut syndrome starts with large food molecules which pass into the blood stream and form immune complexes; assays can determine whether leakiness is present in an individual and some UK medical schools now make such assays available. Increased permeability of the gut due to inflammation can be caused by aspirin and by NSAIDs (non-steroidal anti-inflammatory drugs, for example, ibuprofen).

Leaky gut syndrome is well-documented in ME; it comes from a microbe (whether virus, bacteria, protozoa etc) which damages the gut lining by adhesion.

The second event was a conference on 26th - 28th July 1996 entitled "Human Health and Toxic Chemicals" arranged by the Green Network at the University of Warwick. A most forceful lecture was given by Professor Samuel Epstein and the conference brought together eminent researchers in toxicology. Epstein himself is Professor of Occupational and Environmental Medicine at the School of Public Health, University of Illinois Medical Centre. He said that the petrochemical industry's growth has been phenomenal: in 1940 it was worth $1 million per annum but by the 1980s this had risen to $600 billion per annum.

Consumers have a right to know all the ingredients in the food they eat and Epstein named key food manufacturing companies; he also named some of their products and the powerful neurotoxins which they contain: he said beef frankfurters (Oscar Mayer Foods) contained unlabelled toxic ingredients including benzene hydrochloride, dacthal, dieldrin, DDT, heptachlor, hexachlorobenzene, lindane, hormones and antibiotics.

Clairol's "Nice’Easy" permanent hair colour contains, he said, quaternium-15 (formaldehyde releaser), diethanolamine (DEA), phenylene-diarnines and propylene glycol.

Dr Charles Vyvyan Howard, senior lecturer in Infant Pathology, University of Liverpool, discussed foetal susceptibility to toxic insult, in particular, the effects of organo-chlorines. A man-made chemical used in many pesticides, it is completely alien to life and persists, accumulating in fat stores in living creatures. Pregnant mothers pass organo-chlorines to the foetus in the placenta, where they affect myelination; they are transferred to breast-fed babies, suppressing the thyroid gland and reducing muscle tone.

David Pimental, Professor of Ecology and Agricultural Science at Cornell University, Ithaca, New York, has published over 400 scientific papers and 18 books; his lecture was on the cost of pesticides in agricultural economics, and chemicals used in the environment. Two and a half million tons of insecticides/pesticides are used every year at around $26 billion worldwide, but less than 0.1% actually gets to the target pests.

About 35% of human food is contaminated with pesticides and at 1-3% above tolerance level.

73% of the global market is controlled by ten companies, including Ciba Geigy and Zeneca (Zeneca, the pharmaceutical arm of ICI, recently provided funding for Action for ME’s "Help ME" appeal, donating £10,000 to start off the appeal - Interaction, 1996: Spring: 20: 9).

At the Green Network conference, chronic illness, including ME and multiple chemical sensitivity (MCS), came up time and time again; it was stressed that such conditions are the first indication of problems due to chemicals and that if this is ignored or mis-handled, such neurological illnesses, including multiple sclerosis (MS) and motor neurone disease (MND), may result in cancer - in other words, there is a
progressive process (grateful acknowledgment to Doris Jones MSc for making available her transcripts of these two conferences).

It is hardly surprising that Healthwatch members, with their close association to major pharmaceutical companies, are not too keen to consider any possible role of chemicals in damaging the immune system.

3. It is widely believed by people involved with ME that Wessely is peer-review referee on all matters relating to ME for a number of British medical journals and magazines. Normally, the identity of referees is never revealed for obvious reasons, but there has been such concern at referees' powers to wield undue influence that colleagues of some referees have been letting their own unease be known (personal communication).

A referee for a particular subject can comprehensively block publication of any submitted papers or responses to previously published articles which express views or reveal results with which the referee disagrees. Thus it is clear that the role of referee on any particular subject carries enormous responsibility because s/he decides what gets published and what gets rejected.

If enough articles on a subject continually flood the medical journals, all reinforcing supposed current concepts of a particular condition, and with many of those articles being written by one particular author or by close collaborators of that author, then two things happen. One is that the ideas and conclusions repeatedly put forward in the journals become taken on board as facts in medical thinking; the other is that the prolific author becomes thought of as an expert merely by virtue of the sheer volume of his or her published work. It would then be natural for such an author to be sought out as the expert of choice by lawyers, for instance. Unashamed self-promotion serves to enhance such a view, whether deserved or not.

Most laymen and possibly many doctors are probably of the opinion that well-written articles published in major medical journals are both sound in principle and accurate in content: the long-established peer-review system is designed to ensure such high standards. Any medical article published in a non-peer reviewed journal is rarely taken seriously by medical practitioners, being deemed not even worthy of reading, unless as a useful target for mockery.

Sadly, the peer review system is now of necessity under scrutiny: Professor Peter Sleight, Head of Cardiology at the John Radcliffe Hospital, Oxford, speaking at a Royal Society of Medicine meeting, stated: “Peer review is 50% garbage, 50% malice, and 10% good advice”. He told the RSM meeting that for his own part, he prefers writing his own press releases rather than relying on the discredited peer review system (Can GPs trust what they see in academic journals? Jane Feinmann. GP; November 1993:53).

Information obtained suggests that Wessely is involved with articles on CFS/ME for the following publications: the British Medical Journal; The Lancet; Psychological Medicine; Journal of Neurology, Neurosurgery and Psychiatry; The British Journal of Psychiatry; Medical Monitor; Pulse of Medicine; Doctor; GP; Trends in Psychiatry and numerous other publications.

It is known that, under the editorship of Richard Smith, important papers on the nature of ME have been repeatedly turned down by the BMJ on the grounds that they were (quote) "not of sufficient interest" (personal communication); those papers had been submitted by senior medical consultants with much experience of ME. Such dismissive comments do not appear to apply to papers submitted by psychiatrists claiming that ME is a behavioural disorder. Blocking by the BMJ of non-psychiatric ME issues extended even to the official obituary of Dr Melvin Ramsay, who had done so much to get the true nature of ME recognised. It is also known that a senior NHS consultant physician who specialises in ME submitted a very sound article to The Lancet, but this, too, was rejected.
If referees perpetuate bias by suppressing the publication of valid information, they surely thereby subscribe to a major distortion of the truth.

4. Wessely is an official advisor on ME to the UK Department of Social Security (DSS), confirmed by a letter dated 7th April 1992 from the Disability Living Allowance Advisory Board (DLAAB) Secretariat; this is despite the fact that he does not believe in the existence of a disease called ME. He believes that patients only think they suffer from a disease called ME and that are actually suffering from psychiatric illness and he has advised the DSS accordingly. The result is that the Handbook for Examining Medical Practitioners has been adapted to include the views of Wessely and his close colleagues who share his own view on ME; as a result, payment of Mobility and Attendance Allowance (now combined as Disabled Living Allowance or DLA) to people diagnosed with ME has been widely halted, no matter how severely affected or disabled they might be. This withdrawal of benefit has occurred even in cases where the recipient had been awarded the allowance for life.

In the 1988 edition of the Handbook for Examining Medical Practitioners (HMSO), the entry on page 61 on myalgic encephalomyelitis is short; it includes the following:

“The symptoms do not persist beyond a few weeks” (17.1)

“The fact that much help is expected and often given does not necessarily indicate that it is reasonably required” (17.2)

“Claims for the need for attention on the grounds of myalgic encephalomyelitis or post-viral debility will not normally be expected to satisfy the criteria” (17.3).

When the Handbook entry on ME was being updated, on 28th February 1992 Michael Meacher, Shadow Secretary of State for Health, wrote to the Rt. Hon. Tony Newton MP, Secretary of State for Health, as follows:

"I am disturbed to learn of your failure to respond in any meaningful way to the many representations made during the last six months to revise the distressingly inadequate entry on ME in the first draft of your Disability Living Allowance Handbook....in the case of ME.....there is evidence of the cynical way in which these benefits are being manipulated in order to exclude individuals from eligibility".

The DLAAB having confirmed in their letter of 7th April 1992 that Wessely was an official adviser raises the matter of exactly what advice Wessely had given to the Department. In his letter to them dated 10th January 1992, the advice given in an official capacity by Wessely stated the following:

"It is certainly true that I and my colleagues consider that anxiety about the consequences of activity is one factor perpetrating disability in CFS patients......the evidence of normal muscle dynamic function in controlled conditions is indeed incompatible with theories of a primary neuromuscular origin to CFS symptoms......research shows a considerable overlap between depression and CFS.....I have previously been involved in advising the DSS that CFS should not be grounds for permanent disability" (letter dated 10th January 1992 from Wessely to Dr Mansel Aylward, Department of Social Security, The Adelphi, 1 John Adam Street, London WC2 6NT).

The UK ME Association was and is very concerned about the situation: in 1992 the Association sent out flyers inserted into their magazine "Perspectives"; these inserts point out that the Association has made, and is continuing to make, representations to the DSS about the published statement on ME, which will be used to assess entitlement to the DLA. The insert states:
"At our invitation, ME Action, IFMEA (the International Federation of ME Association) and Westcare are joining with the Association to actively protest to the Secretary of State for Health and to the relevant Government Departments about their continuing apathy and lack of understanding when presented with irrefutable facts about the illness. Our concerns are underlined by the description of ME in current publications available to GPs, Consultants, and lay adjudicators within the local offices of the DSS".

A further communication from the ME Association was also sent to all members of the Association; this read:

"Having received the ‘flyer’ in the Winter edition of ‘Perspectives’ you will now know of the new Disability Living Allowance which will replace the old Mobility and Attendance Allowance in April of this year. What you may not know is that the instructions to your doctor and to the civil servants who will assess individuals for the new benefit will imply that any disability experienced by people with ME is 'all in the mind'. When we first heard about the wording of the text, we approached the DSS (and) gave the DSS information on current research which proves ME is a serious organic illness and asked them to think again. The results were negligible.....you should be prepared, for the foreseeable future, to be accused of malingering”.

Driven to take quite desperate measures, some very severely affected ME sufferers wrote to the DSS Principal Medical Officer in 1992 asking why the DSS was relying only on the input of a psychiatrist (Dr Wessely); they also queried the legality of the Handbook.

The Principal Medical Officer at the DSS, Dr Mansel Aylward, did not reply. Instead, patients received a series of letters from the office of the DSS Solicitor saying:

“I am instructed not to provide you with a list of persons who have been involved in the production of this handbook....I reject your suggestion that there is or has been anything improper in the way that the Department has dealt with your representations....You ask for details of the clinical trials referred to in the handbook....this information will not be provided at this stage...Further correspondence before proceedings are commenced will not be conducted....It has been made clear to you that the Secretary of State takes responsibility for the publication of the handbook and is satisfied as to the propriety of its contents. It will not be withdrawn or modified”.

This threat of legal proceedings is a far cry from the usual bland reassurances churned out by the Government computers and sent to anyone who asks anything about ME, whether through a Member of Parliament or by writing directly to a Government department: the official reply almost always contains the standard sentence which is designed to reassure:

“Both this Department and the NHS recognize CFS as a debilitating and distressing disease affecting many thousands of people”.

In the 1994 update of the Handbook, the entry is now on Chronic Fatigue Syndrome and states:

“The Disability Living Allowance Advisory Board (DLAAB) has consulted widely with all shades of opinion and has concluded that there is no firm evidence to date to identify Myalgic Encephalomyelitis as a distinct entity. In addition, the Board has concluded that the case for any of the conditions listed under the general heading of Chronic Fatigue Syndrome being a physical disease is, at present, unproven” (1.1).

A question needs to be asked: if the DLAAB has “consulted widely”, why has it ignored (i) the findings of the UK National Task Force that was co-funded by the UK Department of Health (Westcare, September 1994); (ii) the 1969 classification of ME by the WHO in ICD-10 as a neurological disease; (iii) the published textbooks on the disorder, including the compendium of the Cambridge (UK) Symposium on ME held in 1990: (iv) the US Centres for Disease Control; (v) the American Academy of Family Physicians; (vi) the
published findings of countless scientific studies carried out by international eminent ME researchers, and the accumulated experience and knowledge of the national patients’ organisations, who certainly made due representation to the DLAAB?

The answer lies in the DLAAB’s advice on treatment, which states:

“The general consensus of informed opinion at present is that treatment should be by graded exercise and rehabilitation....antidepressant drugs may be helpful”.

The only people to continue to recommend graded exercise are those doctors who do not believe in ME as a clinical entity, the most prominent proponent being Dr Wessely.

It is obvious that the DLAAB has allowed itself to be unduly influenced by this group of psychiatrists and their colleagues, who have a vested interest in keeping ME and other chronic fatigue syndromes within the psychiatric field (Richmond & Kingston ME Group Newsletter No. 31, March 1995 pages 2-3).

It should perhaps be stated here that patients with “psychological” illnesses are barred from receiving the higher rates of state benefit (InterAction 1994: 15:55, published by Action for ME).

Additionally, if “ME” can be securely listed as psychological, this would establish a firmer dissociation from any putative chemical neurotoxicity as a possible aetiological factor, which would be in accordance with the aims of the drug companies and of the agencies who licensed the products.

In the June 1994 issue of Perspectives, the ME Association ran a headline which read: “‘Turned down for the DLA?’: the ensuing article revealed that the Association is receiving an increasing number of disturbing reports that members are being turned down when they apply for the DLA. According to one report, a local Adjudicating Officer stated: ‘Recent evidence published in the British Medical Association Journal (sic) states that the consensus of opinion classified ME as a psychological disorder”.

Of interest are three internal memoranda from the Benefits Agency Medical services (BAMS) concerning ME. All are signed by a Dr A.E. Furniss; the first dated 4th April 1995, states: “ME.....is a fashionable label and not a pathology in its own right......the weight of medical opinion regards this as a psychoneurotic disorder”.

The second BAMS memorandum, dated 18th August 1995, states: "Numerous opinions might be obtained, as ME is a rag-bag label......the DLA Advisory Board does not accept a physical basis is proven as regards ME and similar labels”.

The third BAMS memorandum, dated 10th October 1995, states: "The label ME is a rag bag representing no proven pathology. Encouraging illness behaviour is likely to prolong and aggravate this type of behaviour......most treatments would involve reinforcement of self-coping strategies as opposed to reliance on others and such behavioural treatment would be as important (as) antidepressant medication".

It would therefore seem that Dr Wessely’s views and publications have indeed done harm to some very sick and vulnerable people whose diagnosis is ME.

Clearly, the DLAAB is making sure that ME follows in the footsteps of many other organic disorders which were previously designated as "psychological"; these include conditions such as Dupuytren's contracture, diabetes mellitus, Graves disease (hyperthyroidism), glaucoma, asthma, peptic ulcer, ulcerative colitis, arthritis, angina, hypertension, kidney disease and eczema (Case Histories in Psychosomatic Medicine: HHW Miles & HC Shands, 1959: Norten & Co Inc, New York, page 9).

Wrongful attribution of an organic pathology to a psychogenic one by psychiatrists and those they advise is by no means uncommon; in the past, there simply was not the knowledge, but today, this is not the case; it is outright denial of such realities as SPECT scans, EMGs and virus isolation etc.

5. Wessely has yet more influence with the UK Government: in 1992, the Medical Research Council (MRC) granted funding for 'research' into CFS/ME. This grant was available only to The Institute of Psychiatry, and significantly, all applications for funding had to be made via Dr Simon Wessely (personal communication + public announcements).

6. Wessely has seemingly open access to the British media. By 16th June 1994, it was common knowledge in the ME world that TV companies who are licensed to broadcast had been warned off producing anything which might go against the current 'psychiatric' view of ME because of the sheer cost of all the benefits if ME were accepted as an organic condition (personal communication). Certainly, those people who wrote pleading with the BBC to do an in-depth documentary on ME received very short shrift (personal communication).

Wessely writes regularly for The Times (not only on CFS/ME); he writes for The Guardian and he broadcasts on BBC radio about the nature of CFS/ME (for example, The World Tonight, BBC Radio 4, 29th April 1994). In this broadcast (commenting on a study with which he had not been involved) he said: "We've recent work on changes in blood flow in the brain. This happens, apparently, in chronic fatigue syndrome. It certainly happens in many of the so-called psychiatric disorders, such as depression".

Wessely was commenting on work which, on 31st March 1994, ITN News at Ten had highlighted: ITN had broadcast an interview with Dr Durval Campos Costa of the Institute of Nuclear Medicine at The Middlesex and University College Hospitals; slides were shown which clearly demonstrated differences in the brain of people suffering from ME and those suffering from depression; the differences were apparent even to the inexpert eye. The reporter said: "Scanning the brain, researchers have established tangible proof that patients (ie. those with ME) share one physical symptom. A normal scan has a pink circle at the centre the brain stem. This shows a lot of blood flowing. The scans for depressed patients are the same, but in ME sufferers, there is very little blood at the centre".

Wessely, however, managed to convey misleading information to the listening nation by constructing what he said in such a manner that listeners would think that the changes in blood flow in the brain are the same in ME and in depression, thereby manipulating facts so that a false impression was given. This impression accorded with his own personal view of ME, but what he neglected to point out was that the brain scans of normal controls and of depressives are the same but brain scans of those suffering from ME are visibly different from both other groups (video and audio tapes available). In particular, brain scans of those with ME and those with depression show diminution of blood flow in the frontal lobes, but only in ME is there a particular pattern of hypoperfusion in the brain stem.

7. Wessely is a British representative on CFS/ME at the prestigious American Centres for Disease Control, which influences world medical concepts.
8. Wessely offered himself to and was accepted by the Cochrane Collaboration, initially Oxford-based but now international: this body is partly funded by the UK Government under the Department of Health; it was set up to prepare a database (with everything available on disc) to encompass the results of all clinical trials, so that there will be an internationally available meta-analysis of the most effective treatments in all medical disciplines; these results will thus become the definitive medical database worldwide.

Wessely is in sole charge of the working party on CFS/ME on this collaboration; the overall Director is Dr Iain Chalmers, who, incidentally, is a long-term member of Healthwatch (Dirty Medicine. Martin J Walker. Slingshot Publications 1993, page 334.)

9. To the intense chagrin of some participant researchers, Wessely got himself co-opted onto the 1995 Brussels international protocol on CFS/ME under Professor Kenny de Meirleir of the University of Brussels; this is an on-going collaboration and Wessely is in charge of the epidemiology of CFS/ME.

10. Wessely promotes himself as "principle expert witness" on CFS/ME in High Court cases (CFIDS Chronicle Summer 1994 page 77-79); in reality, he was one of three medical expert witnesses in the case to which he refers. Damages of £162,000 initially awarded by the High Court were subsequently withdrawn after The Court of Appeal accepted Wessely's testimony that the Plaintiff, a diagnosed ME patient, was "suffering from at least some degree of psychological disorder".

Media coverage of the Page v Smith case merits some scrutiny: when the original award of £162,000 was made in the High Court in December 1992, there was considerable coverage in both the broadsheets and the tabloid press; not unnaturally, when Mr Page was subsequently stripped of the award by the Court of Appeal on 30th March 1994, there was again intense media interest. The case was then referred to the House of Lords, and when their Lordships' Judgment was handed down, there was once again great media coverage; in addition, the case was written up in both legal and medical journals. In particular, on 12th May 1995, The Times' legal correspondent, Frances Gibb, wrote on page 6: "The law lords yesterday cleared the way for accident victims to sue for damages over 'nervous shock'"; she then went on to describe Mr Page's ME as a "mental illness".

A researcher into ME (the holder of an MSc degree in the epidemiology of ME) duly wrote to Frances Gibb, pointing out that her reference to ME as a "mental illness" was misleading, given that on page 25 of their Lordships' Judgment, Lord Lloyd of Berwick, having discussed all aspects of the case in detail, described ME as "the physical illness that the plaintiff undoubtedly suffered as a result of the accident". The ME researcher also sent a copy of her letter to the Editor of The Times, in case the one to the legal correspondent might be inadvertently 'lost'. An acknowledgment dated 6th June 1995 was received from Ivan Barnes, the Letters Editor, upon receipt of which the researcher wrote back saying "You will agree that false reporting of this type is due to either misrepresentation or negligence. In either case a newspaper of such national reputation as The Times should ensure an early and prominent correction".

The Times declined to print any such correction, whereupon the researcher wrote to the Deputy Managing Editor (from whom the refusal had come) pointing out that "It may be expedient for some to ignore (the) facts, but it does not change them".

It may be worth reflecting here that Simon Wessely often writes articles on ME and related topics for The Times.

After the House of Lords judgment in 1995, the Page case was yet again referred to the Court of Appeal on the short point of causation: on 12th March 1996, the Master of the Rolls, (then Sir Thomas Bingham), together with Lord Justice Auld and Lord Justice Morritt, unanimously found in favour of the Plaintiff (Page v Smith: Supreme Court of Judicature in The Court of Appeal (Civil Division) on Appeal from The High
Court of Justice. 12th March 1996: OBENF 93/0098/D. Trans. John Larkin). Perhaps significantly, the crown copyright transcript of this momentous judgment was subsequently lost, and has never been reported in the media, not even in the Law Reports.

There was, however, one snide mention written by Dr Theodore Dalrymple (the pseudonym of a consultant psychiatrist, referred to above) which was published in The Daily Telegraph on 1st April 1996, page 18: it was headed "Chronic Litigation Syndrome", and was sub-headed “By equating psychological and physical damage, courts help to create a nation of writ-happy inadequates”. The writer, well known for his immoderate and unjustified attacks on sufferers from ME, wrote: "It takes even well-paid people quite a long time to accumulate £162,000, but that was the sum awarded recently to a man suffering at the time from chronic fatigue syndrome......the legal doctrine that physical and psychiatric injury are not to be distinguished seems to me either astonishingly naive or else a conspiracy by lawyers to inflate the volume of their work......To view psychological damage in precisely the same way as physical damage is a throw-back to the crude 19th-century metaphysics of Vogt and Moleschott, who believed that the brain secretes thought as the liver secretes bile.......The dictum that psychiatric damage should be assessed no differently from physical damage fails utterly to recognise the complexity of human existence. It reduces Man to the level of an amoeba.......If one were actually trying to create a population of litigious, querulous, self-absorbed people without the slightest resilience or self-reliance, one could not do better than to make it widely known".

Do these examples from The Times and the Telegraph reflect the much-admired standard of unbiased and quality reporting in the British broadsheets?

11. Wessely is currently Reader in Psychological medicine; as such, he is instrumental in training medical students, so his input and influence can be expected to be far-reaching for future generations of doctors. In this respect, it is surely of critical importance that his teaching is accurate, and that it should reflect true awareness of current concepts in medicine.

12. Wessely lectures for the Industrial Relations Services (IRS) on CFS/ME. These are Conferences designed for personnel managers, occupational physicians, lawyers specialising in Personal Injury (PI) and employment law; the Conferences deal with the insurance implications of long-term sickness and absence from work. At a Conference held on London on 17th May 1995 at the London Business School, Wessely was listed as chief speaker; he was speaking on "Stress and chronic fatigue syndrome; issues for employers". The programme stated: "This Conference examines what Chronic Fatigue Syndrome is and looks at how employers can best deal with employees who are on long-term sickness absence...whilst keeping within the law. Chronic Fatigue Syndrome "ME" has also been called ‘malingering’s excuse’ ”.

13. As mentioned earlier, it is likely that Wessely is an Assessor for the Wellcome Trust; if so, it would be on his recommendations that applications to Wellcome for funding of prospective studies on ME would be granted or rejected.

14. On 20th May 1996, the London Times ran an article by Jeremy Laurance entitled "US funds study of Gulf War illness in British troops". This is claimed to be the definitive study which will establish the patterns of illness in Gulf War veterans; it is being funded by the Pentagon and will cost $1 million. This study is to be led by Dr Simon Wessely. It must be remembered that Wessely has already published his views on the Gulf War Syndrome in The Times on 27th May 1995; that article was sub-headed "Despite all they went through, Gulf veterans are healthier than average says Dr Simon Wessely". Wessely concludes the interview by recommending: "We should resist the temptation to subject those few soldiers who have come forward for testing to ever more complex investigations in the hope that 'something will turn up' ".

Wessely’s views about CFS are already well known so it may not auger well for those Gulf War veterans who might be seeking due compensation from the Government or from the drug companies when the person in charge of the joint UK / US study has already declared his hand.

This survey of Wessely’s status on matters relating to ME is not comprehensive, but it serves to illustrate how broad is his canvas: broad though it certainly is, Wessely has endeavoured to broaden it further.

It is known for instance, that he attempted to join two ME strongholds in the UK; the first was the Ramsay Society, which is a small group of dedicated doctors named in honour of the late Dr Melvin Ramsay: many people were relieved when Wessely’s attempts to join were rejected by the members.

Secondly, it is quite widely known that Wessely was eager to become Medical Advisor to the charity Action for ME; to many people’s surprise and dismay, some of their officers were happy for him to hold this position as they apparently felt that if they could work more closely with him, they could ensure that he was more stringently monitored in what he wrote about ME, and that they could even get him to change his mind about the nature of ME. However, this liaison suffered somewhat following the publication by Wessely of a particularly unhelpful article in The Times; plainly, such a hope was forlornly naive.

Having considered some areas of Wessely’s status in which his influence about ME is undeniable, the next section looks at his tactics.
**Wessely’s Tactics**

Wessely's tactics include strategies which, to the un_critical eye, are not always immediately recognisable as such.

This section presents examples; it is not a comprehensive appraisal of Wessely's methodology.

1. **Obfuscation of patient populations studied (ie. selection bias)**

Without doubt the most far-reaching consequence of Wessely's involvement with ME is his consistent selection bias, ie. his failure to include in his study cohorts patients who actually have ME as distinct from those whose primary complaint is fatigue, so it follows that his conclusions are inherently misleading.

Any review of his published works reveals that patients in his studies probably do not have true ME: it requires but minimal perusal of his papers to discover that the classic symptoms of ME rarely, if ever, feature in the problems presented by his study participants. Nonetheless, Wessely seems to believe that he is discussing "ME", which he includes under "CFS".

This seemingly deliberate obfuscation is unjustified both medically and morally. Critics believe that Wessely’s failure to distinguish between two entities prolongs the controversy and is positively harmful to patients, in that treatment such as cognitive behavioural therapy (CBT) and anti-depressant therapy may well be helpful for those with chronic postviral fatigue who may indeed have become trapped in a vicious circle of inactivity; that same therapy, however, is definitely contra-indicated for those whose diagnosis is ME.

The report of the UK National Task Force was especially critical of such obfuscation.

Dr Elizabeth Dowsett, a former President of the UK ME Association, laments: "One can only deplore the current fashion in...the UK to redefine and rename a disability which has been clearly described in the literature for at least 100 years" (Dowsett EG & Welsby PD. Conversation Piece. Postgraduate Medicine 1992:68:63-65).

For an epidemiologist not to define his patient cohorts accurately and within established medical paradigms is remarkable. Given that there is an ever-present risk of study findings being distorted by misdiagnosed patients taking part in clinical studies, it is the usual aim of an epidemiologist to ensure that this does not happen; in Wessely's case, such a scientific aim cannot readily be identified. What can be identified is that Wessely’s studies so often attempt to demonstrate a link between ME and psychiatric disorder; his stated view is intransigent: "Until proven otherwise, I will argue that fatigue syndromes such as CFS and neurasthenia are arbitrarily created syndromes that lie at the extreme end of the spectrum of fatigue" (Neurasthenia and Chronic Fatigue Syndrome: Theory and Practice. Wessely S. Transcultural Psychiatric Review 1994:31:173-209)

Is this good science?

2. **Flooding the medical journals with his own beliefs about ME**

As referred to earlier, in support of his personal opinion about ME, Wessely assiduously and continually floods the medical journals, both mainstream and medical trade papers, with articles which reinforce his own ideas of ME as a non-existent condition.
3. **Contrived collaboration that promotes his own beliefs**

A related strategy is Wessely's repeated collaboration with the same small group of like-minded colleagues. Certain of these colleagues have no difficulty in getting their papers published; these are psychiatrists whose findings would appear to provide independent corroboration of Wessely's own findings about ME. In reality, it is Wessely's views which are being re-presented. For example, one of Wessely's closest and long-term collaborators is psychiatrist Dr Anthony David, also of The Institute of Psychiatry; David's published work would appear to be overly-reliant upon Wessely's published papers and acknowledged opinions, in that in his paper "Postviral Fatigue Syndrome and Psychiatry", David uses no less than eleven of Wessely's papers as references (BMB: 1991:47:4:966-988) and in "Chronic fatigue in primary care attenders", eight works of Wessely are used as references (Psychological Medicine 1993: 23 November: 987-998). In his paper "Tired, weak, or in need of a rest" (BMJ 1990:301:1199-1202), the help given by Dr Wessely is specifically acknowledged.

(It is this same Dr David who, together with Wessely, will be in charge of the Pentagon-funded study on Gulf War Syndrome).

Apart from instances where David names Wessely in his references, it would be easy to miss those instances where David names only the first author in a reference, and thereafter writes "et al" (a customary practice in listing a lengthy list of co-authors); only those with quite detailed knowledge of the literature would be aware that not infrequently, the "et al" includes Wessely.

Such camaraderie helps to ensure that an unbalanced and unrepresentative view of ME is regularly put before medical practitioners at all levels of seniority.

Again, one must ask if this is good medical practice.

3. **Over-reliance on self-references**

Another related, but separate, strategy used by Wessely is his heavy reliance in his papers upon his own opinions. In one chapter in a neurological textbook, he uses no less than 31 self-references. ("The chronic fatigue syndrome, myalgic encephalomyelitis or postviral fatigue". Wessely S, Thomas PK. In: C.Kennard (ed) Recent Advances in Clinical Neurology no.6. Churchill Livingstone 1990:85-132). Most mainstream journals used to permit no more than two self-references.

4. **Generating his conclusions before he has the data to support them**

The extrapolations which Wessely makes from his own research findings simply do not have the weight to support his conclusions; for the most part, it seems he has reached his conclusions before he has generated his data and his conclusions are open to alternative interpretation.

One study which he carried out numbered only 47 patients, yet from this small sample, Wessely's major conclusion is that "an alternative hypothesis is that all cases of CFS can be explained by disorder of mood" ("Fatigue syndromes: a comparison of chronic 'postviral' fatigue with neuromuscular and affective disorders". S. Wessely, R. Powell. JNNP:1989:52). In truth, this study is too small to be of any practical use, and on his own admission Wessely's methodology was flawed, so his conclusions carry very little reliability, yet this paper continues to be quoted by Wessely as a paper of substance in the CFS/ME literature. This paper was published in the prestigious Journal of Neurology, Neurosurgery and Psychiatry, which would undoubtedly have conveyed a certain acumen had not one of Wessely's own (dissenting) colleagues let it be known that Wessely himself is closely connected with editorial decisions for this journal.
5. Altering historical records and omitting facts

Regrettably, Wessely alters and omits facts; some examples include the following:

(a) In his paper "Mass Hysteria: Two Syndromes?" (Wessely S. Psychological Medicine 1987:17:109-120) Wessely retrospectively altered the time scale of the 1955 Royal Free epidemic of ME; he changed it from the actual three months (from July to October), and in this paper he places it in the category of one day to one month. This seems a clear but curious distortion of the truth.

(b) Also, in this same paper Wessely argues that there had been pre-existing tension amongst those afflicted in the Royal Free outbreak, but this is not mentioned in any other contemporaneous or subsequent report of that epidemic at the Royal Free and it is robustly denied by those who were actually involved in that outbreak.

(c) In 1970, two now notorious psychiatrists named McEvedy and Beard published a paper concluding that the 1955 Royal Free outbreak of ME was in reality nothing more than mass hysteria. The authors did not interview or see a single patient; they based their conclusion only on their study of carefully selected old case notes. (Royal Free Epidemic of 1955: A Reconsideration. Colin P McEvedy, AW Beard. BMJ 1970: 1:7-11). It is said that one of these authors has subsequently admitted that they had no interest in ME: their paper was simply the vehicle for a PhD thesis. Referring to this McEvedy and Beard paper in "Mass Hysteria: Two Syndromes?", Wessely states that McEvedy and Beard felt that the name "benign myalgic encephalomyelitis" had served to reinforce the outbreak. That name, however, was not even used until 1956, by which time the 1955 outbreak had ended, so such terminology could not have influenced the course of the 1955 epidemic. Further, McEvedy and Beard themselves make no such reference.

(d) Yet again, in "Mass Hysteria", Wessely makes claims which are unsupported: he links the 1955 Royal Free outbreak to a fear of polio. There was and is no evidence of this: those affected in the Royal Free outbreak were hospital staff who were accustomed to looking after polio patients; furthermore, Wessely neglects to mention that the index cases had been diagnosed as glandular fever, not polio.

Indeed, in his seminal review, Acheson (later to become Sir Donald Acheson, Chief Medical Officer to the UK Government) unequivocally states: "At the Royal Free Hospital no patient with poliomyelitis had been admitted to the hospital prior to the outbreak, nor was the diagnosis entertained in the initial cases. There was no undue apprehension about poliomyelitis among this hospital staff" (The Clinical Syndrome Variously Called Myalgic Encephalomyelitis, Iceland Disease and Epidemic Neuromyasthenia. E.D.Acheson. Am. J. Med. 1959:569-595).

(e) In his paper "History of Postviral Fatigue Syndrome" (BMB 1991:47:4) Wessely writes: "alleged parallels between CFS and AIDS are frequently drawn by most of the popular books". This statement is not supported by the evidence. Dr Anne Macintyre's book on ME (ME. Post-Viral Syndrome: how to live with it: Unswin Hyman, London 1989) contains references to AIDS on only four out of 320 pages and Dr Macintyre actually writes: "the disease is quite different" (page 52). Dr Charles Shepherd's book "Living with ME" (Cedar, London 1988, with a second edition in 1992) mentions AIDS on only two pages out of 232 pages (1st edition), and draws no such parallels. Steve Wilkinson's book "M.E. and You" (Thorsons, 1988) does not mention AIDS once. Mike Franklin and Jane Sullivan ("ME. What is it?" Century 1989) specifically state "ME is not AIDS" (page 50). Dr Celia Wookey (Myalgic Encephalomyelitis Croomhelm 1986, reprinted Chapman and Hall 1989) does not mention AIDS at all. Drs Belinda Dawes and Damien Downing ("Why M.E.?" Grafton (Collins) 1989) mentions AIDS on only one page out of 182 pages and makes no such parallel. Wessely seems to be making wild claims which tend to serve the aims of his own agenda, but which are simply untrue.
(f) In this same paper Wessely asserts that neurological signs were "not found in sporadic cases", but a paper written specifically about the sporadic cases by Dr Melvin Ramsay (Lancet, 1957:1196-1200) listed a number of neurological signs.

(g) Wessely is dismissive about what he refers to as "medical fashions" and "altered medical perception"; he claims that the character of ME has changed during the last thirty years. This is not so when cases of "true" ME are studied, and it is noteworthy that according to Dr Elizabeth Dowsett, Honorary Consultant Microbiologist and former President of the ME Association, the symptoms of both the sporadic and epidemic forms of ME depend on which strain of which virus is most active. For instance, ECHO viruses are associated with more neurological complications than Coxsackie B, while Coxsackie A is more likely to cause paralysis, hand, foot and mouth disease. All, however, can cause meningitis, tonsillitis, gastroenteritis and mild hepatitis as well as damage to the posterior roots of the spinal cord. Thus Wessely's sweeping presumption (and it must be remembered that he is not a microbiologist) about the "changing character" of ME can be explained in terms of virology; it does not necessarily reflect "medical fashions" or "altered medical perception".

(h) In his article entitled "The neuropsychiatry of chronic fatigue syndrome" (In Chronic Fatigue Syndrome. Bock & Whelan. John Wiley & Sons, Chichester 1993) Wessely states that the "rates of psychiatric disorder in CFS are higher than by chance alone". This may be true for CFS but the rates for ME are not generally higher than those found in other medical conditions (see Tables 1, 2 and 3):

Table 1
Depression in patients, all or the majority of whom have ME/CFS (defined using Holmes and Australian criteria or equivalent).

<table>
<thead>
<tr>
<th>Depression %</th>
<th>Measures used</th>
<th>Authors</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>HAD</td>
<td>Ho-Yen et al.</td>
</tr>
<tr>
<td>0</td>
<td>RS+Interview</td>
<td>Peterson et al</td>
</tr>
<tr>
<td>13</td>
<td>Interview</td>
<td>Yeomans and Conway</td>
</tr>
<tr>
<td>14</td>
<td>BDI</td>
<td>Peterson et al</td>
</tr>
<tr>
<td>20*</td>
<td>POMS</td>
<td>Millon et al</td>
</tr>
<tr>
<td>22</td>
<td>Interview</td>
<td>Riccio et al</td>
</tr>
<tr>
<td>45</td>
<td>Interview</td>
<td>Hickie et al</td>
</tr>
</tbody>
</table>

Mean 16.29 (SD 14.20)
Mean (taking out first two estimates) 22.8 (SD 11.7)

(RS = various rating scales)
(* = middle of three estimates)

Table 2
Depression in patients, all or the majority of whom have chronic fatigue or CFS as defined by Oxford criteria or equivalent.

<table>
<thead>
<tr>
<th>Depression %</th>
<th>Measures used</th>
<th>Authors</th>
</tr>
</thead>
<tbody>
<tr>
<td>10.2</td>
<td>Interview</td>
<td>Katon et al</td>
</tr>
<tr>
<td>23.5</td>
<td>Interview</td>
<td>Wood et al</td>
</tr>
<tr>
<td>47</td>
<td>Interview</td>
<td>Wessely &amp; Powell</td>
</tr>
<tr>
<td>47*</td>
<td>Interview</td>
<td>Manu et al</td>
</tr>
</tbody>
</table>
Table 3
Depression in patients suffering from other medical conditions

<table>
<thead>
<tr>
<th>Depression %</th>
<th>Measure</th>
<th>Group</th>
<th>Authors</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.2</td>
<td>Interview</td>
<td>RA</td>
<td>Katon et al 1991</td>
</tr>
<tr>
<td>11</td>
<td>Interview</td>
<td>SLE</td>
<td>Hay et al 1992</td>
</tr>
<tr>
<td>12.5</td>
<td>Interview</td>
<td>muscle disease</td>
<td>Wood et al 1991</td>
</tr>
<tr>
<td>19</td>
<td>Interview</td>
<td>MI</td>
<td>Forrester et al 1992</td>
</tr>
<tr>
<td>28</td>
<td>RS</td>
<td>stroke</td>
<td>Wade et al 1987</td>
</tr>
<tr>
<td>38</td>
<td>BDI</td>
<td>chronic pain</td>
<td>Blakely et al 1991</td>
</tr>
<tr>
<td>40</td>
<td>Various</td>
<td>Parkinson’s</td>
<td>Cummings 1992</td>
</tr>
<tr>
<td>40</td>
<td>HAD</td>
<td>Breast cancer</td>
<td>Greer et al 1992</td>
</tr>
<tr>
<td>40</td>
<td>BDI</td>
<td>MS</td>
<td>Minden et al 1987</td>
</tr>
<tr>
<td>74</td>
<td>BDI</td>
<td>Diabetes *</td>
<td>Leedom et al 1991</td>
</tr>
</tbody>
</table>

Mean 30.57 (SD 19.5)
Mean (without last estimate) 25.7 (SD 13.8)
* = with complications

(source of tables: Dr E M Goudsmit, co-ordinator, International Federation of ME Associations (IFMEA) London TW11 9QX, 1994).

Tables 1 and 2 give the rate of depression found in the published studies on ME and chronic fatigue at the time of compilation; Table 3 summarises the rates of depression in ten other conditions. All assessments were made using standard rating scales. Means were calculated twice. The first figure covers all the studies; the second excludes the lowest figures for ME and the highest figures for CFS and other conditions. Even omitting the extreme estimates, there is a clear difference between rates of depression in ME and in CFS.

The mean for the ME plus CF groups together (omitting the two lowest estimates for ME) is 31.8%, which is well below the figure of 47% found by Wessely.

It is noteworthy that Wessely and his colleagues seem to record rates of depression which are much higher than those recorded by most other ME researchers.

Given the above figures, how can Wessely fairly claim that the rates of psychiatric disorder in ME really are "higher than by chance alone"?

In this same article (ibid) Wessely maintains that this high rate of psychiatric disorder cannot be explained as a "reaction to physical disability", since two studies found lower rates of emotional distress in people with other medical conditions (arthritis and neuromuscular disease). However, what Wessely did not say...
is that in the first study, the results upon which he draws indicated that the arthritis patients did not feel as ill and impaired as the CFS group, while in the second study he quotes, there is no information to enable one to judge whether the two groups were matched for level of impairment. This is important, since anecdotal reports from study participants have suggested that the neuromuscular controls were not as ill as the people with ME.

Another relevant point is that the incidence of depression found in the patients with rheumatoid arthritis is markedly lower than most estimates published by other researchers.

There are few studies on ME which have looked at the relationship between emotional distress and the level of impairment, but in two such studies, Landay et al (Clinical Condition Associated with Immune Activation. Lancet 1991:338:707-712) showed a clear association between the incidence of depression in ME and the severity of symptoms, and Sharpe et al (Follow-up of patients presenting with fatigue to an infectious diseases clinic. BMJ 1992:305:147-152) reported that the severely affected group suffering from CFS had higher rates of emotional distress than those who were not so severely affected. Both these findings contradict Wessely’s claim.

(i) Still referring to Wessely’s paper "The neuropsychiatry of chronic fatigue syndrome" (ibid), Wessely makes gravely misleading and sweeping claims about viral infection and central nervous system (CNS) disturbance. He states that cognitive deficits associated with viral infections last "days rather than months". Research by A. Smith et al (Cognitive changes in myalgic encephalomyelitis. In: Postviral Fatigue Syndrome. ed. Rachel Jenkins and James Mowbray, John Wiley & Sons Chichester 1991) and by Daugherty et al (Chronic Fatigue Syndrome in Northern Nevada. Rev. Inf. Dis. 1991:13 (Suppl.1): S39-44) found cognitive deficits in ME patients who had most certainly been ill for far longer than "days".

These researchers, together with Smith et al (Chronic Fatigue Syndrome and Performance. In: AP Smith & D.Jones (eds). Handbook of Human Performance vol. 2. Academic Press, London 1992) found the pattern of cognitive abnormalities to be similar to those found in patients with other infections; Wessely, however, implies that the cognitive disturbances are nothing more than "mental fatigue". He fails to mention the studies by Smith et al 1992 (ibid) which found that these cognitive deficits were still present when tests were repeated six months later and were therefore reliable over time.

Smith's findings are consistent with those of Daugherty et al (ibid) and also with those of DeLuca et (Information processing efficiency in Chronic Fatigue Syndrome and Multiple Sclerosis. Archives of Neurology. 1993:50:301-304), yet Wessely does not refer to these published findings (which were published in the same year as his own work under discussion).

Neither does Wessely mention the findings of Millon et al (A psychological assessment of chronic fatigue syndrome/Epstein-Bar virus patients. Psychology and Health. 1989:3:131-141), nor those of Sandman et al (Memory deficits associated with Chronic Fatigue Immune Dysfunction Syndrome. Biol.Psychiatry April 15 1993:33: (8-9):618-623), all of whom have reported deficits which are unlike those found in patients with depression. The specific deficits in ME which were also reported by Smith et al contrast with the more global deficits documented in patients with depression, but Wessely dismisses Smith's work on the basis that Smith used selective patients: it must be noted that Smith tested both a general sample and selective patients, using different tests and different laboratories.

Wessely states that Smith’s patients fared well in tests of free recall: this is particularly significant, because Smith himself says that as far as free recall tests were concerned: "the patients with ME were very poor at recalling the first few items" (page 191). How remarkable, then, that Wessely so specifically denies Smith's own findings.
Smith also notes that the recognition memory patterns in ME resemble those of patients with Korsakoff's syndrome, yet Wessely claims that the results of patients with ME are quite different from those with organic brain syndromes.

Despite the evidence found in all these studies that there is a difference between the cognitive dysfunction found in ME and that found in depression which cannot be explained, Wessely endeavours to explain it away as being mediated by mood disorder; this is in absolute contradiction to the findings of Dr Sheila Bastien, a world expert on neuropsychometric testing (Patterns of Neurological Abnormalities and Cognitive Impairment in Adults and Children. In: The Clinical & Scientific Basis of Myalgic Encephalomyelitis. ed: B.M. Hyde, Nightingale Research Foundation 1992, Ottawa pp 453-460).

One exceptional omission on the part of Wessely is his apparent failure to accept that there have been no recorded epidemics of depression, whereas very many such epidemics of ME have been documented.

Such frequent distortion of facts inevitably leads to an overall misrepresentation of the available evidence on ME; indeed, an independent report by a medical doctor found clear evidence of bias in the coverage of ME in the medical press (ME/PVFS and the Press. Dr Cathy Read. Action for ME. 29.10.1993). Dr Wessely features in this report, and one must conclude that it is inescapable that Wessely is a prime contributor to this bias.

6. Exaggerated claims of success for his own interventions

Wessely makes repeated assertions that psychological treatment in the form of cognitive behavioural therapy is the treatment of choice in ME, claiming that "Research has shown that our rehabilitation programmes are proving successful in decreasing the suffering and improving the general health of CFS/ME patients" (letter from Dr Wessely, CFIDS Chronicle, Summer 1994, page 77-79). The rehabilitation programmes to which he is referring include not only CBT but graded exercise and anti-depressant therapy.

Given that Wessely frequently admits he does not recognise ME as a distinct nosological entity, there is no accurate idea of how many of his patients actually have ME: thus his claim about the effectiveness of his regime needs to be closely questioned. Certainly in relation to those patients known to have ME, such claims have been found to be false, notwithstanding Wessely's claim in The Times (ME: is this the answer? 9th January 1996) that researchers in the Department of Medicine and Psychiatry at Oxford had published a randomised controlled trial of a structured rehabilitation programme for CFS, and that one year later, 73% of those receiving active treatment had done well, having attained near normal functioning. Wessely claimed that this compared with only 23% of those receiving standard medical care, and that the Oxford programme of CBT is the same as his own treatment in London. He wrote that the Oxford findings indicate that disability in patients with the condition is not fixed, and that a return to normal functioning is possible for the majority. He concluded by saying that it would be encouraging to think that the Oxford study findings will help to overcome prejudices about the condition.

Of particular note is the fact that the Oxford study in question was carried out by his psychiatrist colleague Dr Michael Sharpe, who was the instigator of the "Oxford" definitions referred to earlier.

Assiduous as always, after the piece in The Times, the psychiatrists ran another spread about this same trial in The Independent on 26th March 1996, entitled "Feeling tired and confused"; what was not pointed out was that the author's wife was one of the therapists in the Oxford trial.

Interestingly, on 30th March 1996 the Independent published a letter from someone who had been a participant in the Oxford trial (Doubts on ME therapy trial, page 16) which said that there are facts about the trial which throw into doubt how successful it had been. The writer (Catherine Rye) pointed out that it
had been stated that patients in the control group received "standard medical care"; she herself had been in that group, but received nothing. She also made the valid point that those on the trial had to attend hospital on a weekly basis, thus excluding the most severely affected sufferers. She noted that patients who "improved significantly" in fact had only increased their score from 70 to 80 on a scale of general functional ability.

Also on the same day, the Independent published another letter questioning the accuracy and efficacy of the Oxford trial; it was written by Dr Charles Shepherd, Honorary Medical Adviser to the ME Association, and his view was that claims about the success of such trials would continue to be viewed "with a healthy degree of scepticism".

7. Ignoring, trivialising or dismissing work of other ME researchers with which he disagrees

Wessely ignores, trivialises or dismisses evidence from other ME researchers which does not accord with his own views (see below). However, one such example is apparent in his paper "Chronic Fatigue Syndrome: a follow-up study" (JNNP 1994:57:17-21) in which Wessely did not mention the one properly conducted trial by Lloyd et al (Immunologic and psychologic therapy for patients with CFS: a double blind, placebo-controlled trial. Am.J.Med. 1993: 94:197-203); this trial by Lloyd found that a rehabilitation programme such as the one advocated by Wessely was of no benefit whatsoever to ME patients. Notably, Wessely's own study which he claims shows that his programme is helpful to people with chronic fatigue was an uncontrolled study, from which there was an unusually high drop-out rate; this means that Wessely's conclusions from that study are open to question.

Strangely, Wessely continues to make his claims about the efficacy of his treatment even after the publication of the elegant study which provided incontrovertible evidence that such programmes do not work in ME.

A further illustration of Wessely's policy of dismissal tactics was provided in 1990, when an important landmark research paper on ME was published (Sensory and cognitive event-related potentials in myalgic encephalomyelitis. Deepak Prasher, Alison Smith, Leslie Findley. JNNP. 1990:53:247-253). This was a completely authentic, double blind controlled trial performed at The National Hospital, Queen Square, London. It found that ME is not psychogenic and that patients are not suffering from a form of depression: Wessely, however, dismissed this by claiming that all laboratory data is meaningless because it is open to subjective interpretation (personal communication).

Another example can be found when Wessely discusses the persistence of viruses: he writes that even if the immune system does not remove antigens and the virus manages to evade the host response, "the immune system still responds in such a fashion as to indicate the presence of the virus. Evidence of any of these processes has not been provided in CFS" (The neuropsychiatry of chronic fatigue syndromes. S.Wessely. In Chronic Fatigue Syndromes. Bock & Whelan. Wiley & Sons1993. CIBA Foundation). The fact that Wessely chooses to ignore the very real and extensive evidence in ME does not mean that there is none; it means only that Wessely, as usual, restricts his reference to a biased and personal selection of the evidence which is available; for instance he ignores the following research findings, all of which document immune abnormalities in ME:


Interestingly, Wessely, not himself a specialist in immunology, attempts to assure his readers of just how immunologically sophisticated he is when he mentions the immune abnormalities found by others: by his use of carefully chosen phrases such as "the immunologically naive reviewer", he perhaps hopes to convey that he is not naive enough to be taken in by "meaningless" and "mild" immunological abnormalities which he considers of no significance (Chronic fatigue syndrome: current issues. S. Wessely. Reviews in Medical Microbiology 1992:3:211-216).

8. Denigration and mockery of patients with ME

Sadly, Wessely seems to denigrate patients with ME who belong to self-help groups and national ME patient associations (see below).

9. Contempt of medical practitioners who accept that ME is an organic disease

He is openly contemptuous of those medical practitioners who do believe in the existing medical evidence which shows that ME is an organic disease: Wessely claims there is no such disease as ME, only "altered medical perception" and he suggests that such doctors have not learnt how to deal with their suggestible patients effectively; that these doctors encourage somatisation, and that they pander to their patients by having invented a new disease (Old wine in new bottles: neurasthenia and 'ME'. Simon Wessely. Psychological Medicine 1990:25:35-53).

After the publication of this contemptuous article, someone who had held a senior post in the NHS for many years before developing severe ME wrote to Wessely as follows:

"Is it realistic to assume that doctors worldwide, from the US, Russia, South Africa, Australia, New Zealand, Japan and Holland, as well as from Great Britain, have anything to gain by encouraging somatisation in suggestible patients, and is it not offensive to criticise so many doctors for having pandered to their patients by having 'invented' a 'new' disease, and to suggest that such doctors have not learnt to deal with their suggestible patients 'effectively'?"

"Why do you assume (always a dangerous practice in medicine) that patients with ME stand to gain from the illness in some way? You write 'since once neurasthenia was viewed as psychiatric, a principal social function was lost'. What about the many single, isolated, financially insecure people who have no-one to impress or manipulate emotionally, nor have they anyone to witness their daily struggle to keep going at all costs? What about academics and professionals who actively grieve for their lost careers? Do you really
believe that so many people worldwide are opting out in favour of some masochistic fulfillment?" (letter to Dr Wessely).

Wessely's reply was revealing: "Your letter puzzles me. I am particularly puzzled because the answers to most of the questions you ask which are answerable are contained in the published literature" (personal communication, letter from Dr Wessely).

10. Misleading claims of his own importance

Wessely makes misleading claims; for instance, he writes "Most important of all is that I run the only free service solely dedicated to the needs of patients with CFS/ME that operates between the River Thames and the Coast" (CFIDS Chronicle, Summer 1994 pages 77-79). For some reason, Wessely entirely fails to state that in the UK, there is a national health service: this means that all patients can receive treatment free of charge. Furthermore, it must be pointed out that there are numerous other NHS consultants who run clinics specifically for ME patients in many regions throughout the UK, including "the area between the River Thames and the Coast".

In the same letter, Wessely makes another inflated claim: he says he was "principal expert witness in two recent medico-legal cases concerning CFS. These are the only two cases of their kind in the UK". The facts are, however, that Wessely was but one of three expert witnesses, and there are at least seven other such cases which have been or currently are going through the British legal system; all are known to the present authors.

11. Patronising and supercilious behaviour

Wessely is patronising about ME patients: a consultant psychiatrist wrote in a personal communication as follows: "I've just got your letter enclosing the report on Simon Wessely's talk to the Royal College of Psychiatrists. I actually attended that talk, and I thought it was awful. He talked of the patients he had studied in a patronising and supercilious way….he should refrain from giving advice until he has done an adequate controlled study with long term follow-up...Wessely's neo-McEvedy & Beardism may undermine Ramsay's massive contribution to the understanding of this disease".

A further illustration of Wessely's mocking attitude toward patients with ME is to be found in his Eliot Slater Memorial Lecture given in 1994 (see below).

12. Inconsistency in his published papers

Wessely is inconsistent: for example, in two papers in 1994 which came out at about the same time, Wessely said two completely opposite things:

"A firm belief that symptoms are related to solely physical factors is the strongest association of poor prognosis in CFS" (A cognitive behavioural approach to chronic fatigue syndrome. Alicia Deale, Simon Wessely. The Therapist, Spring 1994:2:1:11-14).

He also stated: "Attribution of illness to a physical cause does not appear to be as important a prognostic factor in the long term" (Chronic fatigue syndrome: a follow up study. D. Bonner, M. Ron, T. Chalder, S Butler, S. Wessely. JNNP 1994:57:617-621).
13. Threats of legal action against those who quote his own work

Wessely is seemingly not averse to resorting to legal threats when something is published about his work which, strangely, he does not like. It has been confirmed (personal communication) that Richard Sykes, the Director of Westcare, a Bristol-based charity supporting people with ME, felt obliged to take legal advice when Wessely threatened to serve an injunction upon Westcare to stop them distributing the CFIDS Chronicle Spring 1994 edition (published in the USA but distributed worldwide) which contained an article questioning whether or not Wessely is guilty of scientific misconduct, in that he so persistently ignores, dismisses or trivialises findings by international ME researchers which do not support his own views and claims about CFS/ME (CFIDS Chronicle, Spring 1994:14-18).

On 17th June 1994, Sykes telephoned the Chronicle Editor in America and told her he had received a telephone call that morning from Wessely, and that Wessely was very, very upset about the article, which had been written by two British authors based in the UK.

Sykes informed the Editor that he would be writing to her requesting that the Chronicle publish an apology to Dr Wessely for publishing the article; the Editor told Sykes that she would not do so: she said that she and her colleagues had spent considerable time on the article before deciding to publish it; that she and they felt it stood up on its own merits, and that under United States law, the article was fine.

Sykes' response to this was interesting: he informed the Editor that he did not want anything published which could harm the profits of his company; the Editor took this to be referring to the profits of Westcare.

Wessely's "request" that Westcare remove the article from the copies which they distributed in the UK was speedily complied with by Sykes, although not before some copies had already been sent out.

Westcare's remaining copies duly had that article removed before distribution; each such copy contained an insert dated 22nd June 1994 in the form of a letter signed by Sykes, which read:

"It is regretted that an article has had to be removed from this issue since it could possibly be held to be defamatory by the British Courts. As Westcare circulates CFIDS Chronicles in Britain it is possible that Westcare could be held to be a "distributor" and hence liable to prosecution. This is a risk which Westcare cannot entertain".

Those UK subscribers who received defaced copies were most annoyed, and some queried whether or not it was legal for Westcare to deface copies of a journal for which they had been required to pay in advance, without the existence of an actual injunction.

This whole episode drew spectacular attention to the article in question: people were quick to point out that they wondered what Wessely had to fear, since he must surely believe in the accuracy of his own published work and thus should have been happy for it to be so widely quoted, even to the extent that it was put onto the Internet.

People were puzzled that Wessely seemingly felt it necessary to try to suppress an article about him and his work, when that article quoted at length from his own published articles.

Also, it was deemed significant that Wessely could so easily prevent the legitimate circulation of one single article about him which he apparently did not like, whilst those with ME have had to endure for almost a decade very many articles about them which they did not like, written by Wessely.
It is known that Wessely took Counsel's advice under the auspices of the Medical Defence Union (MDU); it is understood that Counsel advised that the CFIDS Chronicle article was nothing more than fair comment; certainly, no legal proceedings were instituted against the authors.

It is known that on 4th July 1994, Wessely wrote a letter to the CFIDS Chronicle Editor denying that he had threatened Westcare with any legal action and confirming that he had no interest in any law suit.

Notwithstanding, Marc Iverson, President of the Board of Directors of the CFIDS Association of America, was very annoyed that copies of the Chronicle had been defaced by Sykes.

Perhaps it needs to be recollected that Sykes' instant acquiescence might possibly have been linked to the fact that the Wellcome Trust, with which Wessely is closely associated, was giving financial support to the UK Task Force on CFS/ME, and that this was run from Westcare, and of which Sykes was the secretary.

It is of interest that Sykes himself did write a letter to the Editor of the CFIDS Chronicle defending Wessely; this was published in the Summer 1994 Edition on pages 77-79 and asked that "an appropriate apology to Dr Wessely" be printed in the next issue. Sykes wrote:

"one-sided views are common in medicine....failure to achieve a balanced view...does not imply professional misconduct".

Considering that Sykes has a PhD on Wittgenstein, this was a surprising error on his part, as the authors of the article at no point suggested or even mentioned "professional" misconduct, which is not the same as "scientific" misconduct. The article did postulate that Wessely has an unbalanced and one-sided view of ME, because in the authors' opinion (which is shared by many others), Dr Wessely does hold and often proclaims such a view.

Sykes' letter continued:

"even if Dr Wessely's views are one-sided, it is not appropriate...to make the much more serious accusation of 'scientific misconduct'".

Again, Sykes was perhaps over-enthusiastic in his defence of Wessely, because the authors' title contained an unmistakable question-mark: this conveyed that they were asking a question as distinct from making a statement, let alone an accusation.

All in all, Sykes' letter seemed to infer that he accepts that Wessely's views on CFS/ME are one-sided, but that no-one should dare to question the ethics of Wessely's stance.

The CFIDS Chronicle editors published their own response to Sykes' letter in the same journal (CFIDS Chronicle, Summer 1994:77-79), in which they said: "You maintain that one-sided views are common and acceptable in science and medicine, and in so doing, you seem to miss the authors' point. How has Dr Wessely reached his "one-sided view"? With an open mind, honest investigation and authentic use of the scientific method? The authors contend not. And, if they are correct, he may indeed be guilty of scientific misconduct".
Others involved

It is not, of course, Dr Wessely alone who has figured in the acrimony about ME; he is, however, the most vociferous and prominent member of a particular coterie of non-believers in ME: this includes several of the attendees at the Consensus meeting at Green College, Oxford, on 23rd March 1990.

Most notable, apart from Wessely himself, are psychiatrists Michael Sharpe of Oxford and Anthony David of the Institute of Psychiatry. Also present was Dr David J. Pearson, Senior Lecturer from the Department of Medicine at the University of Manchester; Pearson is a dedicated member of Healthwatch and is powerfully active in medico-legal personal injury cases, where he acts as expert witness for major insurance companies against plaintiffs with a diagnosis of ME or of multiple chemical sensitivities.

His reports are designed, apparently, to decimate the plaintiff, and by no stretch of imagination can they be considered to be a reasoned attempt at justice. Most certainly, he imparts opinions which do not conform even to standard textbooks of medicine, which for a Senior Lecturer in Medicine, is a cause for concern.

Another signatory of particular note is Professor Richard Edwards of the Muscle Research Centre, Department of Medicine, University of Liverpool: his views on ME are illustrated in the following extract:

"Activities of mitochondrial enzymes have been measured in per-cutaneous muscle biopsies obtained from 23 patients with non-specific muscle pains (eg. effort syndromes and post-viral fatigue syndromes).

"In most of the 23 patients...exercise precipitated or exacerbated the pain and they, therefore, had reduced their habitual activity....the adaptive changes to reduced habitual activity...would consist of a high degree of exercise stress at low exercise intensities, decreased endurance, tachycardia and an increased dependence on glycolysis leading to a high lactate production at low exercise intensities'.

"These patients have a constellation of symptoms which fits the description of myalgic encephalomyelitis...as specified by the ME Association. The ME Association is publishing substantial amounts of information on the "disease" and its advice to patients is to rest as much as possible.


This view is one to which Wessely is passionately committed (see below). Although not a signatory to the Oxford Consensus, psychiatrist Dr Anthony Pelosi of Edinburgh is also a staunch supporter and frequent co-author with Wessely.

When one considers the power vested in this group, and the extent of their influence, it is little short of miraculous that ME researchers and clinicians have succeeded in getting papers published in the UK at all during the last decade.
Research findings and opinions about ME with which Wessely disagrees

In order to present a fair and balanced exposition of the role of Dr Wessely in the current perception of ME, it is necessary to present an equally fair and balanced exposition of the published literature on ME which Wessely dismisses, discredits or ignores.

There has been such a wealth of evidence on abnormal muscle pathology, persisting virus activity, immunological, neurological and endocrinological abnormalities documented in ME that even a barely-representative review is beyond the scope of this text; it must, therefore, be most strongly urged that Wessely's papers and pronouncements should not be judged unless one has read widely from the list of suggested reading on ME in Appendix I.

For illustrative purposes, however, there follows in this section a selection in chronological order of some of the published papers which document an organic aetiology for ME.

It is reasonable to state that Dr Wessely is very much aware of the extent of the published work on ME which has appeared over the last few decades, as he told a colleague he believes he has a greater collection of the published work on ME than anyone else.

For Wessely et al so repeatedly to deny the separate existence of the syndrome, and its relevance in terms of human suffering, seems to defy all reason. To many people involved with ME, Wessely's on-going attempts to side-line such a well-documented and serious condition convey an image not of erudite medical sophistication, but of someone dangerously unbalanced. Not to accord proper significance to the distressing multisystem symptoms which are invariably present in ME cannot be anything other than deliberately selective; if so, this may indeed amount to scientific misconduct: if nothing else, it is certainly a modifying of reality.

As mentioned earlier, the WHO has formally classified ME as a neurological disease (ICD 10 G93.3, page 423); it is beyond dispute that Wessely and Anthony David are trying to get this classification reversed: to this end they published a letter in The Lancet (Chronic Fatigue, ME and ICD 10. David A, Wessely S. Lancet 13 November 1993:1247-8) which read as follows:

"The inclusion in the tenth revision of the International Classification of Diseases (ICD 10) of benign myalgic encephalomyelitis as a synonym for postviral fatigue syndrome under Diseases of the Nervous System seems to represent an important moral victory for self-help groups in the UK....it is unlikely to lead to advances in our understanding of the condition....The nineteenth century term 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....We believe this latest attempt to classify fatigue syndromes will prevent many people from seeing the world as it actually is".

One would be justified in asking “In whose eyes?”

(Note: the authors refer to the tenth revision of the International Classification of Diseases and speak of “an important moral victory for self-help groups in the UK” but appear unaware that the WHO first classified ME as a neurological disorder in the ICD in 1969).
Illustrations of research findings with which Wessely disagrees

1955

Outbreak at the Royal Free  ED Acheson (who later became Sir Donald Acheson, UK Chief Medical Officer) Lancet 1955:394-395

“All outbreaks have been remarkable for the relatively long active course of the disease and for marked muscular pain and spasm. Sensory symptoms and signs are additional features”.

1956

A new clinical entity?  Editorial (although at the time this Editorial was anonymous, it was later conceded by Sir Donald Acheson that he had written it) Lancet 1956 (May 26);789-790

“In spite of perplexing variations in the clinical picture from case to case it soon became clear that a new clinical entity had appeared”

“Relapses are frequent”

“Among the more characteristic features are the severe muscular pains, often accompanied by exquisite tenderness. Most commonly they affect the neck, back or limbs but there may also be Bornholm-like chest and abdominal pains”

“In nearly every patient there are symptoms or signs of disease of the central nervous system”

“Hepatitis and splenomegaly may also turn out to be part of the picture”

“The term ‘benign myalgic encephalomyelitis’ does describe some of the striking features by (1) symptoms and signs of damage to the brain and spinal cord; (2) protracted muscle pain with paresis and cramp; (3) emotional disturbances in convalescence; (4) normal cerebrospinal fluid; (5) involvement of the reticuloendothelial system; (6) a protracted course with relapses in severe cases”

“We believe that its characteristics are now sufficiently clear to differentiate it from, need it be said, hysteria”.

1959


“Pain in the muscles was an almost constant feature. In severe cases it was agonizing and unresponsive even to opiates”

“Definite parasthesia occurred. Diplopia (was noted)”

“It would be manifestly erroneous to consider as hysteria the emotional instability associated with this illness. The disorder is not a manifestation of hysteria”
“Other sensory disturbances consisted of loss of memory and difficulty in concentration”

“It is concluded that the disease is recognizable in its epidemic form on clinical and epidemiological grounds and therefore may properly be considered a clinical entity”.

1969

“This entity is in danger of becoming a ‘wastebasket’ diagnosis because of its variable signs and symptoms. Almost every conceivable neurologic sign has been described under the heading of epidemic neuromyasthenia”.

1970
Encephalomyelitis resembling benign myalgic encephalomyelitis   SGB Innes   Lancet 1970: (May 9):969

“Motor weakness may not be confirmed on formal testing since it appears to take the form of an incapacity for sustained muscular effort”.

1977
Iceland Disease  (benign myalgic encephalomyelitis or Royal Free disease)   AM Ramsay, EG Dowsett et al   BMJ 1977: (May 21):1350

“Physical findings may include hepatitis”

“Objective manifestations of the disease can still be present over thirty years after the initial illness”.

1978
Epidemic myalgic encephalomyelitis   Editorial   BMJ 1978: (3 June):1436-1437

“The features common to every epidemic include headache, unusual muscular pains (which may be severe), lymphadenopathy and low grade fever. In a minority of cases frank neurological signs can be detected by careful clinical examination: there may be nystagmus, diplopia, myoclonus, bulbar weakness, motor weakness, increased or decreased tendon reflexes, disturbances of the sphincters and extensor plantar responses”

“Fasciculations, cranial nerve lesions and extrapyramidal signs have also been reported”

“One characteristic feature of the disease is exhaustion, any effort producing generalised fatigue. Often there (is) emotional instability and lack of concentration. The clinical outcome may take any of three courses: some patients recover completely, some follow a relapsing course and some are permanently incapacitated”

“At a symposium held recently at the Royal Society of Medicine to discuss the disease and plan research there was clear agreement that myalgic encephalomyelitis is a distinct nosological entity”
“Other terms that have been used to describe the disease were rejected as unsatisfactory for various reasons: the cardinal clinical features show that the disorder is an encephalomyelitis...indeed, the exhaustion and tiredness are similar to that described by patients with multiple sclerosis”

“From the patient’s point of view the designation ‘benign’ is misleading, since the illness may be devastating”

“Some authors have attempted to dismiss this disease as hysterical, but the evidence now makes such a tenet unacceptable. The organic basis is clear --- from the detection of an increased urinary output of creatine, the persistent findings of abnormal lymphocytes in the peripheral blood of some patients, the presence of lymphocytes and an increased protein concentration in the cerebrospinal fluid and the neurological findings. Immunological studies showed a high incidence of serum anticomplementary activity and the presence of ill-defined aggregates on electron microscopy of acute-phase sera”. (The Editorial was fully referenced).

1978


“It became clear early on that there was organic involvement of the central nervous system. There was objective evidence of involvement (of the CNS)”

“The most characteristic symptom was the prolonged painful muscle spasms”

“Bladder dysfunction occurred in more than 25% of all the patients”

“Objective evidence of brain stem and spinal cord involvement was observed”

“McEvedy and Beard’s (psychiatric) conclusions ignore the objective findings”.

1979


“Ten patients were investigated for blood levels of myoglobin and various enzymes. The biochemical pattern bears a close similarity to that found in Duchenne muscular dystrophy (DMD). These findings are discussed with particular reference to the recent suggestion that the permeability of cell membranes may be impaired by changes in intracellular energy mechanisms”

“The dominant clinical features could be classified as follows: (1) abnormal muscle fatigability (with severe pain, particularly in the legs and back) (2) circulatory impairment was a feature of all cases, suggestive of hypothalamic damage and (3) impairment of memory and inability to concentrate was common in all patients”

“The duration of illness in the ten cases was 35 years, 9 years, 6 years, 3 years, 2 years, 23 years, 17 years, 2 years, 5 years and 17 years respectively. A tendency to severe relapse was a feature of (four) cases”
“If the aetiological factor in benign myalgic encephalomyelitis impairs the permeability of the muscle cell membrane as a result of changes in the intracellular energy content, this could be followed by a differential loss of intracellular proteins”.

1981


“In 1969 it was suggested that ME should only be diagnosed if neurological and muscle signs were found. Parish has described the neurological signs and the symptoms of involvement of the autonomic nervous system”

“It is important that the title ‘myalgic encephalomyelitis’ should be restricted to patients who show some of each of the three major features of the disease: Firstly, symptoms and signs in relation to muscles, such as recurrent episodes of profound weakness and exhaustion, easy fatigability, and marked muscle tenderness. Secondly, neurological symptoms or signs, especially affecting the eyes, or weakness of peripheral muscles, as demonstrated by the voluntary muscle test; or some loss of peripheral sensation; or involvement of the autonomic nervous system (orthostatic tachycardia, abnormal coldness of the extremities, episodes of sweating or pallor, [and] bladder disturbances). Thirdly, biochemical abnormalities, such as a raised urinary creatine, or an abnormal electrophoresis pattern with raised IgM”.

1983

Sporadic myalgic encephalomyelitis in a rural practice BD Keighley EJ Bell JRCGP June 1983:339-341

“ME (is) a distressing and often prolonged illness. Many of the patients included in the study had been dismissed by hospital clinicians with the implication that there was no organic basis for their problems. As the study progressed, a pattern to the complexity of the symptoms developed (which included) malaise, exhaustion on physical or mental effort, chest pain, palpitations, tachycardia, polyarthralgia, muscle pains, back pain, true vertigo, dizziness, tinnitus, nausea, diarrhoea, abdominal cramps, epigastric pain, headaches, paraesthesias and dysuria”

“The group described here are patients who have had miserable illnesses. There is a large number of ill and unhappy patients in the community”.

1984

Myalgic encephalomyelitis and the general practitioner JC Murdoch New Zealand Family Physician 1984:11:127-128

“Recent reports have shown an association with infection with the Coxsackie (sic) and two authoritative editorials have pointed to an entirely physical basis for the disorder”

“Most sufferers had monumental problems with work, family and personal life and with their doctors. They should be warned to expect a long illness characterised by relapses. They should be certified as unfit for work”

“In the long-term sufferer, patients are often anxious to identify food and chemical allergies”.

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1984

Myalgic encephalomyelitis  Cory Matthew  New Zealand Medical Journal 1984: 14th November:782

“It has been my consistent observation that activity requiring physical exercise or mental concentration exacerbates the condition”

“Many ME patients also experience food and chemical intolerances, and are often therefore unusually sensitive to the side effects of drugs”.

1984

Myalgic encephalomyelitis  AJ Brook-Church  ibid

“An attempt to recover normal fitness and activity levels can exacerbate the condition and bring about a relapse”.

1985

Diagnostic Criteria and (Laboratory) Tests for ME  WR Gorringe  ANZMES, 10th October 1985

“The following features are commonly represented: atopy, history of food reactions and allergies”

“ME can be indistinguishable from multi-allergy syndrome”

“(There is) a tendency to a relapsing course”

“(In addition to the classic features), other features include (a) plethora of symptoms – usually involving multi-organ systems. The person may have a moist chest, headaches with sore muscles of the shoulders, neck and back. They may have frequency of urine or an irritable bowel. There is often oesophageal reflux with oesophageal tenderness and intermittent oesophageal spasm. Chest pain may be intermittently prominent, and may be severe enough for hospital admission (and there may be) palpitations and a tight chest. Vision (is) often blurred, (with) stinging -- often burning -- pain behind the eyes (and) sensitivity to light. (There may be) sore joints”

“The commonest mistake doctors make is failing to take a wide enough view (with) an adequate systems review when encountering apparently unconnected complaints”

1985

Persisting Illness and Fatigue in Adults with Evidence of Epstein Barr Virus Infection

(Nota that in the US, the condition was at that time thought to be associated with the Epstein Barr (glandular fever) virus and so was known as chronic EBV disease)

“By all regards, including formal evaluations, many of these patients appeared to be neurotic. However, our detailed studies have uncovered a series of subtle, yet objective, organic abnormalities in these patients”
“This disorder is not rare”

“It is of immeasurable benefit to patients with this disorder to document an organic basis for their complaints”.

1985

The postviral fatigue syndrome – an analysis of the findings in 50 cases  PO Behan, WMH Behan, E J Bell
Journal of Infection 1985:10:211-222

“Our data confirm the organic basis of the illness (and) suggest that it is associated with disordered regulation of the immune system and persistent viral infection”

“The illness was severe, with a high morbidity and a disastrous effect on their lives”.

1985

Electrophysiological studies in the post-viral fatigue syndrome  Goran A Jamal  Stig Hansen
JNNP 1985:48:691-694

“The post-viral fatigue syndrome, also known as ME, has been recognised recently as a distinct neurological entity with increasing evidence of the organic nature of the disease”

“The most important findings were type II fibre predominance, subtle and scattered fibre necrosis and bizarre tubular structures and mitochondrial abnormalities”

“About 75% of the patients had definitely abnormal single fibre electromyography results. This was regarded as evidence of abnormality in the peripheral part of the motor unit”

“We conclude that we have shown clear electrophysiological evidence of an abnormality in the peripheral part of the motor end unit in patients with post-viral fatigue syndrome”.

1986

Correlation between allergy and persistent Epstein-Barr virus infection in chronic active EBV infected patients  George B Olsen  James F Jones et al  J All Clin Immunol 1986:78:308-314

(Note that in the 1980s (ME)CFS was known as Chronic EBV Disease)

“Eighty percent of patients demonstrate clinically significant IgE mediated allergic disease, including food and drug reactions”

“The data indicate that patients have a high association with hypersensitivity states”

“Percent positive responsiveness to allergens is consistent with the high degree of allergy observed in these patients”.
The postviral fatigue syndrome: a review  MI Archer  JRCGP 1987:37:212-216

“Relapses are precipitated by undue physical or mental stress”

“However compelling the evidence for an hysterical basis may be, there is further, equally compelling, evidence of organic disease”

“Some patients do have frank neurological signs”

“Muscle biopsies showed necrosis and type II fibre predominance”.


“Two hundred patients fitting the criteria were seen between January 1985 and December 1986... All had other symptoms, the most common of which were irritability, lack of concentration, short-term memory problems, vertigo, visual upset, recurrent sore throat, difficulty with breathing, palpitations, abdominal distension and diarrhoea”

“On examination there were two important common findings – the presence of acute tenderness in the muscle bulk and a positive Romberg’s sign, indicating vestibular upset”

“17% of patients had a positive smooth muscle antibody and a further 11% had a weakly positive SMA. 4% had anti-nuclear antibody and two patients had weakly positive thyroid autoantibody”

“This syndrome has about the same prevalence as Parkinson’s disease and is more prevalent than multiple sclerosis”

“The clinical findings strongly suggest that the musculature and the central nervous system are the main sites of disorder in these patients”

“In addition, nuclear magnetic resonance revealed abnormal muscle metabolism”

“Such patients become immunocompromised. That ME patients are immunocompromised is beyond question”

“Surely the underlying message is that patients with this syndrome need not await the solving of this puzzle before they are accorded the sick role (and) in the interim, it is our duty to care for them as sick”.


“These studies show that a majority of patients with (ME)CFS have low numbers of NKH1 T3-lymphocytes”
“When tested for cytotoxicity against a variety of different target cells, patients with CFS consistently demonstrated low levels of killing”

“In this study we demonstrate that a majority of patients with (ME)CFS have abnormally low numbers of NKH1+T3- cells that result in a distinct NK subset abnormality, as well as a deficiency of cytotoxicity against both standard and viral-infected targets”

“(This study) will hopefully improve our understanding of the immunopathogenesis of this illness”.

1987

ME Fact Sheet  ME Action Campaign: 1987

“Drug therapy is not recommended in general, and there are some drugs, particularly anaesthetics, that can have disastrous effects”.

1988

Anaesthetics and ME/CFS
A Consultant Anaesthetist (Dr F.L.M of the McNeil Centre for Research in Anaesthesia, Philadelphia)

“When there may be neural involvement by a disease, spinal or epidural anaesthesia is not recommended because of the risk of worsening symptoms”

“Normally, a depolarizing muscle relaxant is used, (but) in persons with neuromuscular disease such as demyelination, which has been described for (ME/CFS), this drug has a known risk of causing potassium release from muscle, which can lead to cardiac arrest”

“Because of chronic muscle weakness, breathing may be impaired (and) muscle weakness increases the risk of respiratory failure”

“More care than usual is appropriate in the case of (ME/CFS)”.

1988


“Any kind of muscle exercise can cause the patient to be almost incapacitated for some days afterward. In severe cases, the patient is usually confined to bed”

“Psychiatric diagnoses abound: many patients will already have been labeled as neurotic, neurasthenic, or depressed...it should be possible to make the correct diagnosis, however, based on the...story of typical fatigue or exhaustion made worse by exercise, with myalgia”

“What is certain is that when one reviews PFS with its epidemic and endemic data, clinical features and laboratory results, it becomes plain that this is an organic illness in which muscle metabolism is severely affected”.
1988

Myalgic encephalomyelitis, or what? A. Melvin Ramsay  Lancet 1988: July 9

“The mistaken assumption that ME and PVFS are synonymous has given rise to a lot of unnecessary confusion. Used in its correct context, PVFS covers several conditions such as post-influenzal debility or the more severe post-infectious mononucleosis fatigue state, which are clinically in complete contrast to the three cardinal features of ME”.

1988


“Enteroviral syndromes range from trivial to severe and many are unrecognised or under-investigated”

“Myalgic encephalomyelitis has been the cause of more than 50 epidemics. Serious (neurological) sequelae are common. Enteroxiral infections in humans, as in animals, may be persistent”

“The main features (of ME) are prolonged fatigue following muscular exercise, an extended relapsing course which, unlike other postviral fatigue, lasts for months or years”

“An association with neurological, cardiac and other characteristic enteroxiral complications (including) pancreatitis has long been recognised as part of severe generalised enteroxiral infection”.

1988


“These data show that enterovirus RNA is present in skeletal muscle of some patients with postviral fatigue syndrome up to 20 years after onset of disease and suggest that persistent viral infection has an aetiological role”

“These results provide further evidence that Coxsackie B virus plays a major role in ME, either directly or by triggering immunological responses which result in abnormal muscle metabolism”.

1988

Transmissible disease and psychiatry  RP Yonge  JRSM 1988:81:322-325

“This was the first time that it was possible to show unequivocally that there was an organic basis for the fatigue experienced by a patient diagnosed as having postviral syndrome”

“Nuclear magnetic resonance (imaging) has shown a metabolic basis for the fatigue experienced by some patients diagnosed as suffering from postviral fatigue syndrome”

“We have shown that muscle fatigue and weakness for which there has previously been no explanation is indeed in the muscle rather than in the mind”.
1988

**Chronic fatigue syndromes: relationship to chronic viral infections**  
Anthony L Komaroff  
Journal of Virological Methods 1988:21:3-10

“The fatigue and associated symptoms are debilitating in all patients and can be fully disabling in some”

“There are a group of conditions which go by different names but which may share a final common pathogenic pathway. (These include) true chronic mononucelosis; another, much less frequent group have apparent severe chronic active EBV infection; another chronic, fatiguing illness is called myalgic encephalomyelitis; another illness characterized by chronic fatigue is fibromyalgia (and) finally, there are patients with what we now call chronic fatigue syndrome”

“One simple piece of evidence that these ("CFS") patients are suffering from an ‘organic’ illness is the sudden onset of the illness in 85% of the patients”

“A few of the individuals in our group had acute neurologic events: primary seizures (7%); acute, profound ataxia (6%); focal weakness (5%); transient blindness (4%) and unilateral parasthesias not in a dermatomal distribution”

“On past medical history, the only clearly striking finding is a high frequency of atopic or allergic illness in approximately 50%”

“On physical examination, unusual and abnormal findings are observed in up to 50% of patients, (including) hepatosplenomegaly”

“Because of the neurologic and cognitive symptoms, (some) patients have had lumbar punctures. In 45% of the patients, there was pleocytosis (the presence of an abnormally large number of lymphocytes in the cerebrospinal fluid). In several patients, the lymphocytes were described as ‘atypical’ ”

“It is the judgment of the neuropsychologists that the pattern of test performance suggests an ‘organic’ deficit, rather than cognitive dysfunction secondary to mood disorder”.

1988

**Allergy and the chronic fatigue syndrome**  
Stephen E Straus et al  

“Many patients report inhalant, food or drug allergies (and) this article emphasizes our assessment of one of (the syndrome’s) more common manifestations, allergy”

“Allergies are a common feature of patients with the chronic fatigue syndrome”

“Attempts to avoid all the allergens further isolate the victims of ‘total allergy’ ”

“A variety of immunologic abnormalities can be detected in patients with the chronic fatigue syndrome, abnormalities that suggest that the immune system may participate in the pathogenesis of this disease”

“It is possible that individuals with a heightened reactivity to allergens also respond more vigorously to certain infectious antigens. Inherent hyper-responsiveness would be the initiation by certain infectious agents of a level and duration of lymphokines and interleukin release that would in themselves perpetuate the reactive symptoms of the syndrome”
“Among the features of this syndrome is a high prevalence of allergy, an allergy that appears to be substantial”.

1988

The chronic fatigue syndrome (myalgic encephalomyelitis) – myth or mystery?

“The frequency of this condition is demonstrated by the increasing number of ME associations being founded around the world”

“The strength of the ME lobby in the UK is illustrated by the fact that the Member of Parliament for Clydesdale, Jimmy Hood, drew attention to ME with the first reading of a Bill on 23rd February 1988 and the second reading on 15th April 1988. This was used to attract public attention and counter the suffering and injustice caused by this terrible illness”

“Hood requested an annual report on progress made in investigating the causes, effects and treatment of ME”

“A promise was given by the Parliamentary Under-Secretary of State for the Department of Health and Social Services, Mrs Edwina Curry, that ME was recognized under the NHS and would be treated correctly in all NHS hospitals”

“The difficulty in understanding (ME)CFS is that one is probably dealing with several different entities, all of which can result in the Ramsay triad of (i) muscle fatigability, where even after a minor degree of physical effort, three or more days may elapse before muscle power is restored; (ii) an extraordinary variability or fluctuation of symptoms even over 24 hours; and (iii) an alarming chronicity”

“In Mowbray’s opinion, 62% of cases are due to persistent infection with enteroviruses, especially when muscle fatigue occurs only on exertion”

“Mowbray stresses that pericarditis is found in 10% of patients”

“Reflecting British thinking, Dowsett has stated that the evidence for persistent enteroviral infection is so strong that the use of the term CFS as opposed to ME is to be deplored”

“There is no question that fatigue is worsened by exercise”

“It seems unlikely that the neuropsychiatric symptoms described in this syndrome are causative”

“Attempts to invoke concepts like mass hysteria (and) psychosomatic illness seem unwarranted”

“Two-thirds of patients report respiratory or gastro-intestinal symptoms”

“While the onset in 20% of cases may be insidious, the remainder follow acute vertigo, Bornholm’s disease, pericarditis, herpangina, thyroiditis, parotitis, viral meningitis or acute visual disturbances”

“Electron microscopy has shown increased mitochondria and ‘bizarre tubular structures’ ”

“Periods of physical stress should be avoided”
“Since exertion and physiotherapy are known to aggravate symptoms, rest is probably the most important treatment”.

1989


“We believe there is another disorder, the chronic fatigue syndrome, that is likely to be an organic disorder”

“A critical question has not been addressed: are patients fatigued because they have a primary mood disorder, or has a mood disorder developed as a secondary component of a chronic organic illness?”

“We are concerned about the interpretation of data: many of the instruments base the diagnosis of psychiatric disease on the presence of symptoms that could well reflect an underlying organic illness”

“It would be inappropriate to conclude that patients with chronic fatigue had only a primary psychiatric disorder”.

1989

Statement to the (USA) House Appropriations Subcommittee, 25th April 1989
James F Jones, National Jewish Center for Immunology, Denver CFIDS Chronicle: Spring 1989:28-30

“For the patients, there is no question that the illness exists. For the physicians who see these patients, the similarities among them allow ready identification of a distinct clinical illness. For those who scoff at this concept, one can only query as to what happened to their curiosity and their ability to listen to patients”.

1989

Natural Killer Cell Activity in the Chronic Fatigue- Immune Dysfunction Syndrome
Nancy Eby, Seymour Grufferman et al

“Our investigations suggest that (ME)CFS is characterized by objective laboratory abnormalities and that the currently used names for the syndrome are inappropriate. A more appropriate name for this syndrome would be chronic fatigue-immune dysfunction syndrome (CFIDS), since immune dysfunction appears to be the hallmark of the disease process”.

1989

Progress towards an answer to Chronic Fatigue: an interview with ‘USA Today’, 13th April 1989
Stephen E Straus, National Institutes for Allergy and Infectious Diseases CFIDS Chronicle: Spring 1989:77-78

“Many of the immunological and physical features of ME/CFS cannot be explained by mental illness”.

58
1989

Chronic Fatigue Syndrome wreaks havoc with victims’ lives  John Esdale, Rheumatologist, Montreal General Hospital.  CFIDS Chronicle: Spring 1989:79

“It is a real organic problem and people who have it don’t need the additional stress of hearing doctors tell them they are crazy”.

1989


“We have found that many people with this clinical picture have concomitant food and chemical sensitivities”

“We were therefore greatly surprised to learn from Dr Holland (ibid: 706) that ‘it would be non-therapeutic to offer such a patient empathy’ and that we must not condone a belief in a ‘non-existent disease”

“These statements are difficult to reconcile with the immunologic abnormalities, disorders of muscle metabolism and abnormal results of muscle biopsies found in such patients”.

1989

Presentation at the American Academy of Neurology Conference, April 1989  Carolyn L Warner


“The abnormalities we found provide evidence for central nervous system and neuromuscular involvement”.

1989


“The finding of significantly increased numbers of peripheral blood mononuclear cells that express class II histocompatibility antigens (HLA-DR) in our patients implies immunological activation of these cells”

“These cell-surface antigens may have been induced by interferons or other cytokines.  Once activated, these cells may continue to produce the cytokines which may mediate the symptoms of CFS”.
1989

“Similar immunological and metabolic disturbances in myalgic encephalomyelitis may also result from chronic infection, usually with enteroviruses, providing the organic basis of the postviral fatigue syndrome”

“This condition is characterised by severe fatigability and recuperation through rest. The myocardium, however, cannot rest --- except terminally”.

1989

“I believe that postviral fatigue syndrome is a distinct entity with a precise definition. In only a few patients is there confusion with psychiatric illness”

“As I understand the article (referring to an article by Wessely), graded exercise has been suggested but has not ‘led to improvement in patients’. This article’s suggestion of exercise until symptoms cease is the reason why a patient may be hospitalised”.

1989
Neuropsychological Deficits in Chronic Fatigue Syndrome  Sheila Bastien
Paper presented at the International Conference “Epstein-Barr Virus: The First 25 Years”, Oxford University, UK, April 1989; also published in CFIDS Chronicle, Summer / Autumn 1989: 24-26

“A population of (ME)CFS patients was tested neuropsychologically over a period of three years. The age range was 16 to 65. All patients had multiple physical symptom complaints that are typical of this condition”

“(Patients) reported problems with memory, concentration, sequencing, spatial relations, calculation, word-finding, comprehension, visual discrimination, and motor ability”

“Many of these individuals were observed to have significant motor and balance problems”

“Verbal memory was 68% below the mean T score on the immediate condition and 68% below the mean T score on the delayed condition”

“The pattern of focal and lateralised impairments in these patients is consistent with an atypical organic brain syndrome”.

1989
Chronic Fatigue and Immune Dysfunction Syndrome: A Patient Guide
CFIDS Association, Charlotte, North Carolina, 1989

In addition to the commonly known symptoms such as profound fatigue, low grade fever, sore throat, painful lymph nodes, muscle weakness, myalgia, sleep disturbance, headaches, migratory arthralgia, photophobia, transient visual scotoma, forgetfulness, confusion and cognitive difficulties, the following
form part of the clinical picture: “spacial disorientation, blurring of vision, sensitivity to light, eye pain, frequent (spectacle) prescription changes, emotional lability, chills and night sweats, shortness of breath, dizziness and balance problems, sensitivity to heat and cold, irregular heartbeat, abdominal pain, diarrhoea, numbness of face or extremities, burning in hands or feet, hearing sensitivity, menstrual problems, hypersensitivity of the skin, chest pain, rashes, allergies and sensitivities to odours and chemicals, weight changes without changes in diet, feeling ‘in a fog’, fainting, muscle twitching, seizures, and hair loss”.

1990

The diagnosis of postviral syndrome  DJD Perrins JRSM 1990:83:413

“The clinical pattern of myalgic encephalomyelitis has much in common with multiple sclerosis”.

1990

Chronic Fatigue Syndrome and the Psychiatrist  Susan E Abbey Paul E Garfinkel
Can J Psychiatry 1990:35:625-632

“The number of patients having (ME)CFS has increased. Research has demonstrated that cognitive (and) affective symptoms are prominent (and) psychiatrists are being asked to participate in the assessment and management of patients with this syndrome”

“Two patterns of illness have been recognized: relapsing and remitting, and continuous”

“All of the findings regarding psychopathology are descriptive and do not allow for conclusions about the direction of the relationship --- ie. whether the psychopathology is secondary to (ME)CFS or is the cause of (it)”

“Findings related to psychopathology may be artifactual”

“The pathophysiology of fatigue attributable to psychiatric disease remains unclear (and) it is premature to make aetiological assumptions”.

1990

Clinical and General Research Findings in CFIDS  Paul Cheney

“I believe this is a disease that affects the central nervous system and I’ll show you some slides to help convince you of that. We are going to explore what evidence there is for neurologic disease.”

“This is a study done by Dr Carolyn Warner from the Dent Neurologic Institute in Buffalo, New York, which specializes in multiple sclerosis. Some people think that (ME)CFS can look like MS and there are clinical features that are overlapping”

“I think this study is important because this is an MS specialist looking at (ME)CFS and seeing they are not MS, and then looking at them neurologically”
“Here are a number of symptoms. You can see that the great majority of these (ME)CFS cases have neurologic symptoms”

“The most specific neurologic symptoms that I find in (ME)CFS is dysequilibrium”

“These patients have a balance disturbance and on certain simple neurologic tests they fall over”

“On more sophisticated tests of vestibular function they are often grossly abnormal”

“Nearly every patient had something abnormal within the central nervous system”

“Our evidence of central nervous system involvement can be demonstrated by tests looking directly at the CNS”

“These inflammatory and/or demyelinating plaques can be seen in the white matter, in the cerebellum and white matter tracks throughout the high cerebral convexities and in the frontal lobes”

“These lesions are not specific, they could be inflammation, they could be demyelination, there could be an element of destruction. What it says is that there is something going on in the brain”.

1990

The chronic fatigue syndrome: a return to common sense AM Denman

“It is salutary to reflect how many sufferers from infectious mononucleosis (glandular fever) may in the past have been maligned for their allegedly ‘functional’ illness before appropriate laboratory tests became available. Similar considerations apply to chronic fatigue following enteroviral infection, particularly by Coxsackie B virus”

“In some patients, muscle pain and easy fatiguability may be so prominent as to suggest a separate diagnostic category ‘myalgic encephalomyelitis’. This is also a point of practical importance if a form of the syndrome existed in which active physical rehabilitation were contra-indicated”

“Progress will only be achieved if the different categories of chronic fatigue are dissected with scientific objectivity and therapeutic reason”.

1990

Patient management of the postviral fatigue syndrome DO Ho-Yen
JRCGP 1990:40:37-39

“The subgroup of patients with immunological abnormalities may have a prolonged illness”

“It has been suggested that a new approach to the treatment of patients with postviral fatigue syndrome would be the adoption of a cognitive behavioural model (Wessely S, David A, Butler S, Chalder T: Management of chronic (postviral) fatigue syndrome. JRCGP 1989:39:26-29). Those who are chronically ill have recognised the folly of the approach and, far from being maladaptive, their behaviour shows that they have insight into their illness”.
1990

Objective measurement of personality variables in epidemic neuromyasthenis patients
A. Sricklin et al  South African Medical Journal 1990:77:31-34

“Too often only one aspect of the illness is treated, with little attention to other symptoms”.

1990

The psychiatric status of patients with the chronic fatigue syndrome  Ian Hickie et al

“We conclude that psychological disturbance is likely to be a consequence of rather than an antecedent risk factor to the syndrome. Our results suggest that patients are no more psychologically disturbed before the onset of their illness than members of the general population”

“There is no evidence from our well-defined sample to support the hypothesis that CFS is a somatic presentation of an underlying psychological disorder. In particular, there is no evidence that CFS is a variant or expression of a depressive disorder”.

1990

Myalgic encephalomyelitis: an alternative theory  CWM Wilson
JRSM 1990:83:481-483

“In his discussion paper on myalgic encephalomyelitis (April 1989 JRSM), Wessely suggested that a new term should be used to describe the observed symptoms. In his definition of CFS, he did not refer to any of the somatic symptoms which are always present”

“Evidence of biochemical and neurological changes have been reported in the brain. These symptoms are resistant to tranquillisers and antidepressant therapy in ME. Indeed, patients are often allergically sensitive to these drugs”

“The identification of viral antibodies in the tissues confirms the existence of a previous viral challenge”.

1990

CD8 Deficiency in patients with muscle fatigue following suspected enteroviral infection (myalgia encephalitica)  JR Hobbs, JA Mowbray, JE Monro et al  In: Protides of the Biological Fluids 1990:36:391-398

“Postviral states have been shown to be associated with acquired (secondary) T-cell deficiencies, particularly with CD8 dysfunction, and even immune paresis”

“It is also clear that the acquisition of T-cell deficiency, particularly the CD8 subset, can itself impair immune regulation and predispose to atopy not previously experienced by the patient”

“It is known that psychological disturbance can influence immunity. We, ourselves, have undertaken extensive T-cell subset measurements in normal subjects subjected to psychological stress, and would point out that in none of these did we see CD8 levels as low as in some 40% of our ME patients”
“It seems unlikely that the severe CD8 deficiency found could be due to psychological disturbance”.

1990

Immunologic Abnormalities in Chronic Fatigue Syndrome  Nancy Klimas et al  (Nancy Klimas is Professor of Medicine, University of Miami School of Medicine; she is also Director of Immunology, Director of AIDS research and Director of the Allergy Clinic at Miami)  J Clin Microbiol 1990:28:6:1403-1410

“(ME)CFS is a clinical state of some complexity. In order to characterize in a comprehensive manner the status of laboratory markers associated with cellular dysfunction in patients with this syndrome, 30 patients were studied”

“All the subjects were found to have multiple abnormalities in these markers”

“The most consistent immunological abnormality detected was low natural killer (NK) cell cytotoxicity”

Lymphocyte phenotypic marker analysis of peripheral blood lymphocytes showed that there were significant differences between patients with (ME)CFS and controls”

“The pattern of immune marker abnormalities observed was compatible with a chronic viral reactivation syndrome”

“Depression of cell-mediated immunity was noted in our study population, with over 80% of patients having values below the normal mean”

“The values obtained were closely similar to those we observed in a group of human immunodeficiency virus type I-seropositive (HIV) intravenous drug users”

“Result from the present study indicate that there is an elevation in activated T-cells”

“A strikingly similar elevation in CD2+ CDw26+ cells has been reported in patients with multiple sclerosis”

“Functionally, the CD45RA+ CD4 cells, also termed Tinf, for inflammatory CD4 cells, can transfer delayed-type hypersensitivity”

“Selective depletion of CD4+ CD45RA+ cells was noted during the active phases of multiple sclerosis, but not in patients in remission or with inactive multiple sclerosis or other neurological diseases. Deficiencies quantitatively similar to those observed in patients with (ME)CFS were also reported in patients with other autoimmune diseases”

“The results of the present study suggest that (ME)CFS is a form of acquired immunodeficiency”.

1990

Persistence of enteroviral RNA in chronic fatigue syndrome is associated with the abnormal production of equal amounts of positive and negative strands of enteroviral RNA  L Cunningham  NE Bowles  RJM Lane V Dubowitz  LC Archard  J Gen Virol 1990:71:1399-1402

“This suggests that enteroviral persistence in muscle is due to a defect in control of viral RNA synthesis”
“These data are the first demonstration of persistence of defective virus in clinical samples from patients with (ME)CFS”.

1990

Myalgic encephalomyelitis --- a persistent enteroviral infection? EG Dowsett AM Ramsay et al

“Myalgic encephalomyelitis is a common disability but frequently misinterpreted”

“This illness is distinguished from a variety of other post-viral states by a unique clinical and epidemiological pattern of characteristic enteroviral infection”

“Advice to avoid over-exertion is mandatory”

“In our opinion, two major errors are responsible for the present confusion surrounding the case definition, aetiology and diagnosis of ME. First, there has been a failure to distinguish the syndrome from postviral debility following Epstein Barr mononucleosis, influenza and other common fevers. Second, there has been a failure to recognise the unique epidemiological pattern of ME”.

1990

Aerobic work capacity in patients with chronic fatigue syndrome MS Riley DR McClusky et al

“Patients with the chronic fatigue syndrome have reduced aerobic work capacity compared with normal subjects”

“We found that patients with the chronic fatigue syndrome have a lower exercise tolerance than either normal subjects or patients with the irritable bowel syndrome. The main reason for the impaired exercise performance seems not to be diminished motivation”

“Previous studies have shown biochemical and structural abnormalities of muscle in patients with the chronic fatigue syndrome”

“Patients with (ME)CFS invariably indicated an aspiration to return to (their) previous level of activity”.

1991

Immunological Markers in ME/CFS

Presentation at the AACFS Research Conference, November 1990. Professor Nancy Klimas (reported in CFIDS Chronicle: Spring 1991:47-50)

“The most compelling finding was that the NK (natural killer) cell cytotoxicity in (ME)CFS was as low as we have ever seen in any disease. This is very significant data. (ME)CFS patients represent the lowest cytotoxicity of all populations, including HIV AIDS, we have ever studied”.
In addition to the standard symptoms such as exhaustion, headache, malaise, short term memory loss, muscle pain and abdominal pain, included in his list of 50 commonly presented symptoms in ME/CFS are the following: double vision, balance disturbance, dizziness, palpitations, shortness of breath, easy bruising, swelling of extremities and eyelids, incontinence, and hair loss.

"Kendell seeks to draw together similarities between (ME)CFS and depression but ignores important differences. Patients with typical depression are characterised by clinical features such as anhedonia, weight loss, suicidal ideation, psychomotor retardation or agitation that are notably absent in (ME)CFS”

“Patients with (ME)CFS lack many essential characteristics of patients with primary depression; their symptoms more closely resemble those seen with depression complicating primary medical disorders”.

“Despite (the) clinical findings, some physicians question whether there is such a syndrome”

“Immunological disorders such as those seen in viral infections have been described in (ME)CFS – eg. decreased function of NK cells and macrophages, reduced mitogenic response of lymphocytes, B-cell subset changes, and activation of CD8 cells”

“These findings further support the notion that (ME)CFS involves immune disorders due most likely to an infectious agent”

“We found that patients could be placed into three groups according to their symptoms. Group A consisted of patients whose illness was so severe that they had less than 25% of their normal daily activity and also had multiple symptoms; group B had reduced physical activity and group C initially had many symptoms but had substantially improved”

“Three cell surface markers gave noteworthy results. These data point to a high probability (90%) of having active (ME)CFS if an individual has two or more of the CD8 cell subset alterations”

“Evaluation of CD8 cell subsets in control subjects with a diagnosis of depression showed no significant differences compared with healthy controls”

“Laboratory findings have shown low level autoantibodies which may reflect an underlying autoimmune disease”

“When all (ME)CFS patients were considered, we found a state of immune activation specifically among the CD8 lymphocyte population. Moreover, the suppressor subset of CD8 (CD11b) was reduced in many patients, significantly so in patients with multiple symptoms and severe incapacitating illness (group A)”
“Our findings suggest that the CD8 CD11b population is reduced, and the CD38 and HLA-DR markers remain persistently raised.”

“The immune disorder in CFS does not seem to reflect depression”.

1991


“The findings described here provide the first evidence that PFS may be due to a mitochondrial disorder precipitated by a virus infection”

“The pleomorphism of the mitochondria in the patients’ muscle biopsies was in clear contrast to the findings in the normal control biopsies”

“Diffuse or focal atrophy of type II fibres has been reported, and this does indicate muscle damage and not just muscle disuse”.

1991


“Several lines of evidence suggest that the various components of the hypothalamic pituitary adrenal axis (the HPA axis) merit further study in these patients, for instance, debilitating fatigue, and abrupt onset precipitated by a stressor, arthralgias, myalgias, post-exertional fatigue, exacerbation of allergic responses and disturbances of mood and sleep are all characteristic of glucocorticoid insufficiency”

“A deficiency of CRH (cortico-releasing hormone) could theoretically contribute to the lethargy and fatigue that are the cardinal symptoms of (ME)CFS”

“Identification of psychological illness by standard diagnostic criteria includes many symptoms that are an inherent part of the definition of (ME)CFS”

1991

Biopsychosocial aspects of Chronic Fatigue Syndrome  JDL Yeomans  SP Conway  J Inf 1991:23:263-269

“(ME)CFS is associated with physical, psychological and social distress. The illness cannot be defined using just one of these dimensions. Such a unilateral approach has resulted in unnecessary controversy over the nature of the ‘real’ core of (ME)CFS”

“Psychiatric case definition is central to a psychiatrist’s work and deserves careful attention in discussions of (ME)CFS with medical colleagues”

“It was hoped (that our present study) would avoid selection biases favouring the presence of psychiatric illness as might occur with selection by specialised fatigue clinics”
“A single item on the HAD depression scale refers to ‘feeling slowed down’. Not surprisingly, this was cited by all patients. When this single item was removed from analysis, no patient retained a rating of depression. This emphasised the importance of possible false positive diagnosis of depression on the basis of somatic symptoms”

“Wessely and Powell (JNNP 1989:52:940-948) found the total psychiatric morbidity in (ME)CFS was 72% --other studies have found it to be 21%. (Our) study finds a variable prevalence depending on the criteria used. This emphasised the ease with which psychiatric rating scales may lead to false positive diagnoses in patients with physical symptoms”

“It is possible that studies of (ME)CFS have had a tendency to over-estimate the prevalence of depression”

“The absence of (biological markers) has been interpreted as support for a psychogenic aetiology for (ME)CFS. It is important to diagnose such syndromes correctly, and (our) study suggests that questionnaires alone may over-emphasise psychiatric syndromes”

“It is unnecessary and indeed unproductive to force patients into unsuitable diagnostic categories as a condition of treatment”.

1991

Postviral fatigue: current neurobiological perspective  PGE Kennedy

“It is clear that there is now a widespread consensus that postviral fatigue syndrome (PVFS) is a definite disease entity. Recent intense research has made it no longer acceptable to dismiss PVFS as non-organic”

“Molecular viral studies have proved to be extremely useful. They have confirmed the likely important role of enteroviral infections, particularly with Coxsackie B virus”

“The PVFS has now come of age as a definite organic entity”.

1991

The management of Post Viral fatigue Syndrome in General Practice  David G Smith  ibid:265-279

“In the absence of any coherent move in Britain to develop criteria for the disease, the medical profession has had to fall back on the American Working Case definition of chronic fatigue syndrome, Holmes et al 1988, although this is not synonymous with ME”.

1991

Assessment and Diagnosis of ME in the Psychiatric Clinic  Rachel Jenkins  ibid 241-246

“Once one is familiar with the concept of post-viral fatigue syndrome, such patients are in practice not too difficult to differentiate from those with true psychiatric illnesses such as depressive illnesses, anxiety, hypochondriasis or hysteria”
“The classic diurnal variation of mood in severe depressive illnesses is not seen: the patient with ME will relate their depression to the frustration felt at not being able to do the active things they enjoy doing”

“The depressed patient feels fatigued and will be unmotivated to exercise, but can do most activities if required and sustain them, including climbing a hillside, standing upright for two hours or carrying a heavy object. The sufferer with ME, on the other hand, cannot do more than a fraction of these activities”

“There are also subtle differences between the impairment of concentration in depression and that in ME; in ME, the impairment of concentration tends to be associated with the timing and severity of the fatigue”

“In addition, specific cognitive abnormalities are present in ME, including difficulty in marshalling material, difficulty in finding the correct words in a sentence, and in appropriate syntax; speech is sometimes slurred, and the patient appears more clumsy than usual. They tend to bump into doorways and furniture more frequently, may display old bruises, and may complain of a feeling of disequilibrium”

“The physical symptoms should be an aid to diagnosis, although they may be wrongly attributed to primary psychological illness unless care is taken in eliciting them”

“Under a regime of pushing beyond physical limits, severe relapses occur and physical limits decrease. This is the exact opposite of what happens in a depressed person who is otherwise physically well, where steady pushing beyond physical limits will extend those limits and increase physical fitness”

“People with this illness do not tolerate antidepressants well”

“Patients with postviral fatigue syndrome are often very scared and in considerable pain”.

1991


“Despite the broad divergence of opinion in the medical community, there is little doubt that classic allergy and atopy are inexplicably prevalent in (ME)CFS. In a recent study, a high proportion (50%) of patients were found to be reactive to a variety of inhalant or food allergens when innoculated epicutaneously in the classic manner”

“Because neurologic symptoms have dominated in certain of the case clusters (and even in some sporadic ones), the syndrome has been called benign myalgic encephalitis (sic)”

“Certainly patients with (ME)CFS differ immunologically from their healthy counterparts and it is this observation, more than any other today, that is evoked in support of the organic hypothesis of disease causation”.

1991

Defining the Chronic Fatigue Syndrome Gary P Holmes ibid S53-S55

“Preferably, patients with (ME)CFS who have such immune abnormalities might be considered a subset of the larger group: ie. persons with (ME)CFS who have immune dysfunction”.
“Those most consistently reported include depressed natural killer cell function and reduced numbers of natural killer cells; low levels of circulating immune complexes; low levels of autoantibodies, particularly antinuclear antibodies and antithyroid antibodies; altered levels of immunoglobulins; abnormalities in number and function of lymphocytes”

“Enlargement of the spleen and liver is not unusual”

“The striking distortion of cognitive function along with the abnormal results of the MRI scans observed in these patients suggests a pathologic process in the brain”

“The pattern of focal and lateral impairments in these patients is more consistent with that of an atypical organic brain syndrome”

“This is not the pattern seen in depression, psychosis, anxiety or situational stress”.

“(Kennedy states that in (ME)CFS the) ‘fatigue is the decline in performance that occurs in any prolonged or repeated task’ ”

“We remain cautious in attributing the cause of (ME)CFS in the vast majority of cases to an underlying psychiatric conflict. The tendency towards such an attribution is currently popular”.

“Allergies are a common feature of patients with (ME)CFS”.
1991

Postviral Fatigue Syndrome and the Cardiologist, RG Gold

*ibid*: 227-231

“The patient suffering from PVFS (ME) is referred to a cardiologist almost always because of chest pain. The usual cause of the chest pain in these patients is chronic benign pericarditis. When we reviewed this condition in 1967, we felt then that the pericarditis was the final common pathway in an abnormal immunological response.”

“The pain of pericarditis has some highly characteristic features which suggest the diagnosis to the clinician who is aware of these”

“(The) chest pain is variable in character. It is sometimes severe, sharp and stabbing, or it may be dull and aching. The pain may last for several hours or even days. It frequently occurs centrally but even in the same patient may recur on a different occasion in the right or left chest or back. It is commonly aggravated by sudden movement, change of posture, respiration, or swallowing”

“The patient may complain of shortness of breath”

“Palpitations are frequent, with sinus tachycardia being a common and at times distressing symptom”

“The presence of the pericardial rub is independent of the intensity of pain”

“The diagnosis of the cause of chest pain as a complication of ME rests almost entirely on careful clinical evaluation”

“Chronic benign pericarditis may continue or recur for many years and, like ME, be a distressing and debilitating illness. There is, alas, no way of predicting how long the condition will persist, and no reliably successful means of treating it”

“The main role of the clinician is to provide symptomatic relief and sympathetic support”.

1991


“Exposure to trace amounts of chemicals in indoor air or common foods has been said to produce symptoms such as headaches, memory loss, dizziness (etc)”

“There is no specific treatment for MCS, whose existence is widely acknowledged”

“Treatment usually consists of avoidance of the offending substance (by special diets, for example)”

“Some governments will not wait for questions to be answered through research. The Bush administration is already requiring special accommodation for the chemically sensitive in its housing policy”

“The Chemical Manufacturers Association’s senior officials are concerned about the mounting litigation”.
“Many different neurological and psychiatric syndromes follow viral infections. Recently, attention has been focused on (a) common postviral neurological syndrome, ie. the postviral fatigue syndrome, termed myalgic encephalomyelitis”

“Guidelines from the Medical Research Council may be unhelpful, since they suggest that “CFS” is a better term”

“The chief organ affected is skeletal muscle and severe fatigue, with or without myalgia, is the main symptom. The fatigue appears clinically to be of central origin in most patients but a peripheral component, ie. muscle involvement, has also been demonstrated by biochemical, electrophysiological, pathological and virological studies”

“Muscle metabolism is undoubtedly disturbed, but other organs, particularly the brain, heart, endocrine system and immune system are also affected”.

“The idea that mass hysteria might account for these outbreaks was fashionable at one time, but like the majority of illnesses for which a psychiatric aetiology has been put forward, this hypothesis lacked all scientific merit and with the emergence of hard data, can be totally rejected”

“Some patients never exhibit any psychiatric manifestations whatsoever”

“It is quite clear to anyone who has experience in dealing with these patients that their symptoms differ considerably to those (with) endogenous depression”

“Gastro-intestinal symptoms are often made worse by certain foods and antibiotics”

“Patients who present with labyrinthitis often have a dysequilibrium syndrome, so that they are uncertain of their balance when walking”

“The recent attempt by Oxford psychiatrists to formulate (another case definition) has not taken us any further”

“It should be pointed out that there are definite subgroups who will have signs and symptoms of myocarditis”

“We have seen a large number of patients who presented with classical postviral fatigue syndrome and who continue to have intermittent but definite abnormalities in liver enzymes”

“Some patients exhibit all the symptoms of irritable bowel syndrome in addition to PVFS”

“We have demonstrated mitochondrial abnormalities on electronmicroscopy”

“75% of patients were found, using single fibre EMG, to have prolonged jitter values”

“Our experience with patients who have had the illness for one year or more and in whom there continues to be fluctuation in symptoms intensity but no remission, is that the prognosis is poor for recovery”. 
“Many patients have a history of allergies years before the onset of (ME)CFS, and allergic symptoms may worsen after these patients become ill. Allergies are so prevalent in (ME)CFS patients that it is important to differentiate those symptoms that are allergy-related”

“(ME)CFS symptoms overlap with those of many well-recognised illnesses, for example, lupus erythematosus (SLE) and multiple sclerosis”

“Psychiatric evaluations fail to identify any psychiatric disorders in some patients”

“Many people with (ME)CFS have neurologic symptoms, including parasthesias, dysequilibrium and visual blurring. A few patients have more dramatic neurologic events such as seizures, periods of severe visual impairment, and periods of paresis”

“Many investigators believe that the illness involves a constant antigenic challenge to the immune system and, as a consequence, a constant immunologic response to that challenge”

“Evidence suggests that several latent viruses may be actively replicating more often in (ME)CFS patients that in healthy control subjects”

“Most investigators believe that reactivation of these viruses is probably secondary to some immunologic challenge”

“For many patients, it is important to avoid situations that are physically stressful”

“A balanced diet and rest enhance well-being”

“For now, physicians do not have all the answers, but in treating people with (ME)CFS, they can offer guidance with compassion”.

“Whatever name is used, the syndrome most often consists of neurological symptoms, immunological abnormalities, cognitive impairments (and) disabling fatigue in a variety of other symptoms reflecting involvement in some if not all body systems”

“(We looked at) over 200 patients and over 200 controls and evaluated the data for each of 25 (ocular) symptoms”

“Statistical analysis shows that the increased rate at which patients with CFIDS report ocular symptoms is not explained by chance alone”

“Many CFIDS patients experience very troubling and disabling symptoms”

“It appears that the ocular symptoms of CFIDS are genuine”.
“It is important for psychiatrists to familiarise themselves with the complexities of this syndrome and to be aware of the rapidly expanding body of new literature on this illness”

“Wessely’s work on depression and (ME)CFS is methodologically flawed; (his patients) were not diagnosed using the full diagnostic criteria and therefore included many ‘non-pure’ (ME)CFS cases”

“Psychiatrists need to utilise such terminologies as ‘the sick role’ and ‘abnormal illness behaviour’ with great caution when discussing chronic illness. Not only will they alienate their medical colleagues, but, more importantly, the patients they are trying to help”

“Our surveillance study does not support the notion that CFS is a psychiatric disease and, in fact, suggests that it has an organic basis”.

“Evaluation of the psychiatric status of patients with (ME)CFS does not support the contention that (ME)CFS is simply a depressive equivalent”

“Although depression is common in patients with (ME)CFS, the disturbance in cell-mediated immunity in this disorder differs in prevalence and magnitude from those associated with major depression”

“It is likely therefore that this disorder is generated and maintained by an immunopathological process within the central nervous system”.

“57% of patients were bed-ridden, shut in or unable to work”

“Immunologic (lymphocyte phenotyping) studies revealed a significantly increased CD4 / CD8 ratio. Taken together, the controlled studies cited above and many others, seem to indicate an immune system chronically responding to a ‘perceived’ antigenic challenge”

“Magnetic resonance scans of the brain showed punctate, subcortical areas of high signal intensity consistent with oedema or demyelination in 78% of patients”
“Neurologic symptoms, MRI findings, and lymphocyte phenotyping studies suggest that the patients may have been experiencing a chronic, immunologically-mediated inflammatory process of the central nervous system”.

1992

Possible up-regulation of hypothalamic 5-hydroxytryptamine receptors in patients with postviral fatigue syndrome  AMO Bakeit, PO Behan, TG Dinan et al  BMJ 1992:304:1010-1012

“In the past few years evidence which shows the organic nature of this condition has accumulated”

“The results suggest upregulation of the hypothalamic 5-hydroxytryptamine (5-HT) receptors in patients with PVFS but not in those with primary depression”

“Most of these patients had objective evidence of muscle damage, as shown by mitochondrial changes and the persistence of enteroviral RNA sequenced in muscle”

1992


“(SPECT scans have demonstrated) significant deficits in brain perfusion, particularly in the hypothalamus and pons”.

1992

The postviral fatigue syndrome  WRC Weir  Current Medical Literature (Royal Society of Medicine) 1992:6:1

“In more acutely affected individuals the advice to ‘exercise back to fitness’ is a recipe for disaster”.

1992

Neuro-opthalmological Manifestations of Chronic Fatigue Syndrome  Alfredo A Sadun and Pravin U Dugel

In: The Clinical and Scientific Basis of Myalgic Encephalomyelitis Chronic Fatigue Syndrome  Ed: Byron M Hyde, Jay Goldstein and Paul Levine  Pub: The Nightingale Research Foundation, Ottawa, Canada 1992

“The neuro-opthalmological manifestations of (ME)CFS are myriad and common”

“Two thirds of the patients complained of blurred vision; one patient (complained of) binocular diplopia”

“The most obvious objective sign was nystagmus; it was even more astonishing that approximately one quarter of the patients had a primary nystagmus, since such nystagmus is always pathological”.

“Other disease associations such as irritable bowel syndrome, polycystic ovarian disease, thyroiditis and endometriosis are probably part of (ME)CFS. It is a rare woman with (ME)CFS who has not had hair loss, usually diffuse”.

“Since about 1986, clinicians in the San Francisco area have seen an upsurge of (ME)CFS in their practice”

“In the majority of cases, the onset of depression occurred six months after the onset of the illness”

“Three (immune) markers were found to be highly significant: the data indicate a high (90%) probability that an individual with two or more of the CD8+ cell subset changes will have active (ME)CFS”

“We expect that when the clinical data on these individuals are tabulated, severe illness will again correlate with significantly abnormal lymphocyte phenotypic findings”

“Our observations strongly suggest that a large population of (ME)CFS patients have immunologic disorders and that their symptoms could be explained by a chronic immune activation state”

“We speculate that (ME)CFS represents a type of autoimmune disease. Because of the known higher prevalence of (ME)CFS in women, the 3:1 female/male ratio would not be unexpected: autoimmune syndromes are more common in women”

“Because of the autoreactive nature of this condition, it might also lead to other immune disorders, such as well recognized autoimmune diseases and multiple sclerosis”.

“At the present time, the term ME is viewed as probably the most satisfactory in encompassing all the features of this distressing illness”

“The acute presentation in all patients followed a similar pattern”

“Muscle pain was common after even trivial attempts at exercise”

“All patients reported difficulty in concentration which was often profound”

“All reported an inability to socialize because of exhaustion”

“Few controversies in modern medicine have raged so fiercely as that over the syndrome which has been called ME”
“(This) study offers an insight into the nature of the central nervous system component of the disorder. The results presented here may point to the presence of an organic aetiology for the neuropsychiatric abnormalities which have been noted clinically in some patients”

“The neuropsychological abnormalities we have shown are not accountable wholly in terms of depression”

“In the presence of evidence of organic memory impairment, it seems reasonable that the patients should consider themselves to be ill”

“In conclusion, the present study provides evidence that, in some patients with operationally defined ME, cognitive abnormalities which may be compatible with an organic cause can be detected”

1993

Clinical presentation of chronic fatigue syndrome  Anthony L Komaroff
In: Chronic Fatigue Syndrome, John Wiley & Sons, Chichester; Ciba Foundation Symposium 173: 43-61

“Many diseases that today are well-established -- for example, multiple sclerosis, systemic lupus erythematosus and rheumatoid arthritis -- were at one time controversial until definitive objective abnormalities were identified”

“(ME)CFS can last for years and is associated with marked impairment”

“(ME)CFS is) a terribly destructive illness”

“The tenacity and ferocity of the fatigue can be extraordinary”

“On past medical history, the only clearly striking finding is a high frequency of atopic or allergic illness in approximately 50-80%, in contrast to a background prevalence of about 10% in the population at large”

“As for the symptoms that accompany the fatigue, it is striking that these symptoms are experienced not just occasionally but are present virtually all the time”

“In our experience, 80% of patients with (ME)CFS have an exceptional post-exertional malaise”

“(Physical examination findings) include abnormal Romberg test (and) hepatomegaly (and) splenomegaly”

“Anyone who has cared for patients with (ME)CFS will recognize that (the) description of the patient with lupus eloquently describes many patients with (ME)CFS as well”.

1993

Information Processing Efficiency in Chronic Fatigue Syndrome and Multiple Sclerosis
John DeLuca  Susan Johnson  Benjamin Natelson  Arch Neurol 1993:50:301-304

The objective of this study was to compare the cognitive performance of subjects with (ME)CFS, MS, and healthy controls.
“The MS group was added so that the performance of the (ME)CFS group could be compared with a population presenting with a symptoms cluster similar to that of patients with (ME)CFS, but of known organic cause”

“The results of this study clearly demonstrate that subjects with (ME)CFS and MS exhibit difficulties in information processing efficiency compared with matched controls”

“These results indicate that subjects with (ME)CFS and subjects with MS show significant impairment when compared with appropriate controls”

“The results of our study indicate that depression alone cannot account for the deficits observed in the (ME)CFS and MS groups”.

1993

Biochemical and muscle studies in patients with acute onset postviral fatigue syndrome

“Patients with acute onset PVFS lose muscle protein synthesis potential, but not muscle bulk. Histopathology is consistent with these observations. These perturbations may contribute to the apparent feature of perceived muscle weakness associated with the persistent viral infection in the muscles themselves”.

1993

Persistence of enterovirus RNA in muscle biopsy samples suggest that some cases of chronic fatigue syndrome result from a previous, inflammatory viral myopathy NE Bowles, LC Archard et al Journal of Medicine 1993:24:2:145-160

“The term PVFS has been widely misused to describe all forms of chronic fatigue”

“Investigation with strand-specific riboprobes demonstrated that in each of the PFS cases found positive for virus RNA, enterovirus persisted in these non-inflammatory muscle biopsies as a replication defective mutant”

“Our data confirm that enterovirus infection of muscle is not a general feature of the population”

“This association of enterovirus infection is compatible with what is often considered an autoimmune disease”

“We propose that in PFS patients, a mutation affecting control of viral RNA synthesis occurs during the initial phase of active virus infection and allows persistence of replication defective virus which no longer attracts a cellular immune response”.

1993

Testimony before the US FDA Scientific Advisory Committee, 18th February 1993
Paul Cheney, Professor of Medicine, Capital University, USA; Medical Director of the Cheney Clinic, North Carolina, USA (one of the world’s leading exponents on ME/CFS)
“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 neurocognitive 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. 40% have impaired cutaneous skin test responses to multiple antigens. 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”.

1993

Memory deficits associated with chronic fatigue immune dysfunction syndrome
Curt Sandman (Professor of Psychiatry and Human Behaviour, University of California School of Medicine)
Biol Psychiat 1993:618-623

“The performance of the CFIDS patients was sevenfold times worse than either the control or the depressed group. These results indicated the memory deficit in CFIDS patients was more severe than assumed by CDC criteria. A pattern emerged supporting neurological compromise in CFIDS”.

1994

Summary and Perspective: Epidemiology of Chronic Fatigue Syndrome
Paul H Levine

“Epidemiologists play a number of roles in the study of diseases; the functions of these specialists include case definitions, descriptions of disease patterns, identification of risk factors, and analysis of clinical trials. In the study of a complex illness such as (ME)CFS, for which no definitive diagnostic test exists, the most important aspect is case definition – all other areas of investigation depend on this standard for appropriate interpretation of results”

Most patients affected in a cluster of ‘epidemic neuromyasthneia’ do not fit the 1988 case definition of (ME)CFS”

“It has been noted for a number of years that a history of allergies appears to be an important risk factor for (ME)CFS”

“The spectrum of illnesses associated with a dysregulated immune system must now include (ME)CFS”

“The precipitating factors leading to (ME)CFS were also an important focus of this symposium. In addition to a history of allergy, other factors such as exposure to chemicals and noxious agents were noted to be possible triggers”

“It is likely that host response, due to genetic predisposition, contributes to the development of (ME)CFS as an outcome of the exposure”.

1994

Association between HLA Class II Antigens and the Chronic Fatigue Immune Dysfunction Syndrome
RH Keller, MA Fletcher, N Klimas et al Ibid S154-S159
“The chronic fatigue immune dysfunction syndrome (CFIDS) is a major subgroup of the chronic fatigue syndrome (ME/CFS). We and other investigators have reported a strong association between immune dysfunction and a serological viral reactivation pattern among patients in this group. This finding appeared similar to that for a variety of conditions such as chronic active hepatitis, juvenile rheumatoid arthritis and systemic lupus erythematosus (SLE or lupus), in which a definite association between a particular HLA-DR/DQ haplotype and increased disease frequency has been reported.”

“It is possible that DR4 (relative risk for CFIDS 1.6) and DR5 (relative risk for CFIDS 1.8) are also associated with an increased risk of developing CFIDS.”

“The data presented herein suggest that CFIDS, together with a variety of immune-mediated diseases, may share similar sequences of pathogenic mechanisms.”

“It may be speculated that in a particular sub-population, a genetic predisposition may be triggered immunologically by any of a number of potential stimuli, resulting in a state of chronic immune dysequilibrium.”

“This model could easily explain the recent findings with regard to acute viral infection, allergies or other mechanisms that are obscured by the process of chronic immune activation”.

1994
Decreased Natural Killer Cell Activity is Associated with Severity of Chronic Fatigue Immune Dysfunction Syndrome  EJ Ojo-Amaize et al  *ibid* S157-S159

“Our results confirm and extend previous reports that low NK cell cytotoxicity is a pronounced immunologic abnormality found in some patients with CFIDS.”

“The fact that NK cell activity decreases with the increased severity and duration (of the disorder) suggests that measurement of NK cell function could be useful for stratification of patients and for monitoring the progression of CFIDS.”

1994
Immunologic studies of CFS  Andrew R Lloyd  *ibid* S134-135

“Circumstantial evidence suggests that (ME)CFS may result from a disordered immune response to a precipitating infection or antigenic challenge”

“Findings from several case reports and one controlled study have suggested that serum levels of IgG subclasses (especially IgG1 and IgG3) may be reduced in patients with (ME)CFS”

“The three most prominent and reproducible findings are (1) impaired lymphocyte proliferation in response to stimulation by mitogens has been repeatedly documented and has also been shown to be dissociated from the potential effect of concurrent mood disturbance on this response; (2) investigators have reported increased number of peripheral blood lymphocytes bearing activation markers such as HLA-DR and interleukin-2R in these patients; (3) impaired cell-mediated immune function”

“It is likely that conflicting data may arise because of the heterogeneity of the sample populations studied.”
1994

Upregulation of the 2-5A Synthetase/ Rnase L Antiviral Pathway Associated with Chronic Fatigue Syndrome  Robert J Suhadolnick  Daniel L Peterson  Dharam Ablashi et al  *ibid* S996-104

“The object of this study was to measure key parameters of the 2-5A synthetase/Rnase L antiviral pathway in order to evaluate possible viral involvement in (ME)CFS”

“The data presented suggest that the pathway is an important indicator of the antiviral state in (ME)CFS”

“Evidence that this pathway is activated in (ME)CFS was identified in the subset of severely disabled patients as related to virological and immunological status”.

1994

Closing Remarks of the Symposium  Anthony L Komaroff and Nancy Klimas  *ibid* S166-167

“Few studies by psychiatrists are presented in this symposium. Many investigators who have argued that (ME)CFS is primarily a psychiatric disorder chose not to present their work”.

1994


“Of the 14 enteroviruses tested for, (only) those to Coxsackie B1 and B4 were present at significant titres in cases versus controls at a percentage significantly higher than that of controls”.

1994

Chronic Fatigue Syndrome Up-date: Findings now point to CNS involvement  David S Bell (Instructor in Paediatrics, Harvard Medical School)  *Postgraduate Medicine* 1994:98:73-81

“Abnormalities of immune function, hypothalamic and pituitary function, neurotransmitter regulation and cerebral perfusion have been found in patients with (ME)CFS. Recent research has yielded remarkable data. The symptoms of (ME)CFS have long been viewed as a neurologic pattern, as confirmed by names such as myalgic encephalomyelitis. A link is being forged between the symptoms of (ME)CFS and objective evidence of central nervous system dysfunction. The view that (ME)CFS is a primary emotional illness has been undermined by recent research”.

1994


“(ME)CFS affects the ocular system in many ways”
“Every patient seen with (ME)CFS presented with at least one ocular symptom”

“There were three major prevalent ocular findings in patients with (ME)CFS: all patients presented with ocular symptoms; (some) patients had reduced accommodation (and some) patients had objective abnormalities of preocular tear film and ocular surface”

“In the past, the ocular signs and symptoms of (ME)CFS have not been considered to be a major component of the disease process. However, it appears that the ocular system may be very much affected by this systemic disease”

“The objective findings of the anterior segment suggests an organic aetiology”

“The number of patients presenting with tear film and ocular surface abnormalities was remarkable”

“There are histological studies that demonstrate lacrimal gland invasion by inflammatory cells in Sjogrens syndrome. One could speculate that there may be similar histological findings in patients with (ME)CFS”

“The ocular neurological symptoms that presented in such a large number of (ME)CFS patients suggests a neurological basis of the disease. The visual symptoms combined with the reduced motor skills of these patients might lead some clinicians to entertain the diagnosis of multiple sclerosis”.

1994


“SPECT scans showed more abnormalities than MR scans did in patients with (ME)CFS”

“The complaints of afflicted patients, particularly those involving the central nervous system, can be misdiagnosed or even considered by some to be factitious. The finding of abnormal neuroimaging studies in the vast majority (94%) of patients with (ME)CFS indicates that this condition is associated with physiologic changes that can be observed objectively”

“As with any chronic inflammatory condition affecting the central nervous system, the T2-bright foci on MR in (ME)CFS may represent a perivascular cellular infiltrate and / or reactive demyelination of the surrounding white matter”

“Alternatively, these abnormalities may reflect the results of a vasculopathy involving the small vessels of the cerebral white matter; indeed, the distribution of lesions on MR in ME/CFS is similar to that observed in occlusive arteriolar disease of any origin”

“The cortical defects measured with SPECT likewise may result from direct infection of neurological elements, from cellular dysfunction due to circulating cytokines, or from decreased flow through cortical arterioles owing to vasculitis”

“Specifically, on the basis of our observations, the white matter abnormalities seen on MR images may represent foci of chronic demyelination which appear to be irreversible”.
1994

Anaesthesia in CFIDS  Patrick L Class  CFIDS Chronicle, Summer 1994:82

“There is a group of commonly-used anaesthetic agents which are known histamine-releasers and are best avoided by CFIDS patients”

“Since so many of these histamine-releasing agents are commonly used during emergency surgery, it would be advisable (for patients with (ME)CFS) to wear a medical alert bracelet”

1995

SPECT Imaging of the Brain: Comparison of Findings in Patients with Chronic Fatigue Syndrome, AIDS Dementia Complex and Major Unipolar Depression  RB Schwart, AL Komaroff et al

“This study demonstrates that (ME)CFS shares some similarities on SPECT imaging with AIDS Dementia Complex (ADC). By this objective standard, the pathophysiologic processes in the central nervous system of patients with (ME)CFS would seem more similar to that in patients with ADC than in patients with unipolar depression”

“The similarity in MCUI data between patients with ADC and (ME)CFS suggests a similar origin for the neurologic dysfunction in these conditions (and) the similarity in appearance on SPECT suggests the possibility of similar underlying abnormalities in ADC and (ME)CFS”.

1995

Introduction to Research and Clinical Conference, Fort Lauderdale, Florida, October 1994
Daniel L Peterson  JCFS 1995:1:3-4:123-125

“In my experience, ME/CFS is one of the most disabling diseases that I care for, far exceeding HIV disease except for the terminal stages”.

1995

Immunology  Roberto Patarca  Ibid: 195-202

“Several groups have been working on defining immune status variables of relevance to the nosology and follow-up of (ME)CFS patients”

“One rationale for the immunological approach stems from the experience accumulated with similar syndromes of heterogeneous presentations such as autoimmune and environmentally-triggered diseases”

“The hypothesis was entertained that (ME)CFS may be associated with certain HLA class II antigens, as are some forms of environmental disease”

“Viruses are frequently reactivated in association with immune system dysregulation in (ME)CFS and may contribute indirectly to the symptomatology”
“These observations underscore the distinction between (ME)CFS and psychiatric maladies”

1995

‘Abnormal’ Illness Behaviour in Chronic Fatigue Syndrome and Multiple Sclerosis
Peter Trigwell Simon Hatcher BMJ 1995:311:15-18

“Those who see (ME)CFS as primarily a psychiatric disorder regard it as a variety of somatisation. The concept of somatisation overlaps with that of ‘abnormal illness behaviour’. There is an explicit judgment to be made in concluding that a patient is exhibiting abnormal illness behaviour: it is that the doctor does not think that the patient’s objective pathology entitles him to be placed in the sick role he expects”

“If (ME)CFS is a variety of somatisation, then we should expect to find evidence of abnormal illness behaviour with the syndrome”

“We wanted to confirm whether patients with (ME)CFS have abnormally high levels of disease conviction and if so, whether it is associated with other elements of abnormal illness behaviour or is, indeed, merely a corollary of chronic disease”

“We draw two conclusions from our study. Firstly, the illness behaviour questionnaire seems to be unsatisfactory as a measure of abnormal illness behaviour in (ME)CFS. Secondly, we have confirmed that disease conviction is common in (ME)CFS”

“Scores on illness behaviour questionnaires cannot be taken as evidence that (ME)CFS is a variety of abnormal illness behaviour because the same profile occurs in multiple sclerosis”.

1995

Exercise response and psychiatric disorder in chronic fatigue syndrome
Russell JM Lane Leonard C Archard et al BMJ 1995:311:544-545

“In previous studies patients with (ME)CFS showed exercise intolerance in incremental exercise tests, which seemed to be related to an increased perception of effort”

“We examined venous blood lactate responses to exercise at a work rate below the anaerobic threshold in relation to psychiatric disorder”

“Our results suggest that some patients with (ME)CFS have impaired muscle metabolism that is not readily explained by physical inactivity or psychiatric disorder”.

1995

Brainstem perfusion in chronic fatigue syndrome DC Costa C Tannock J Brostoff

“Patients with (ME)CFS have a generalised reduction of brain perfusion, with a particular pattern of hypoperfusion of the brain stem”.

Detection of Enterovirus-specific RNA in Serum: the Relationship to Chronic Fatigue

“In the study described here, enteroviral sequences were found in significantly more (ME)CF patients than in the two comparison groups. The presence of the enteroviral sequences in a significant number of patients points to some role in (ME)CF”

“A variety of immunological disturbances have been reported for (ME)CF patients which may relate in some way to the enteroviral persistence”

“This study provides evidence for the involvement of enteroviruses in just under half of the patients presenting with (ME)CF and it confirms and extends previous studies using muscle biopsies”

“We provide evidence for the presence of viral sequences in serum in over 40% of (ME)CF patients and also in some buffy coat cells and stool samples”.

Pathophysiology of a Central Cause of Post Polio Fatigue
Richard L Bruno et al

“These relationships and recent empirical comparisons between post polio and chronic fatigue will be described”

“Beginning in Los Angeles in 1934 and continuing for more than 20 years, a dozen outbreaks occurred of a disease that was at first diagnosed as poliomyelitis, then as ‘atypical’ poliomyelitis and finally named myalgic encephalomyelitis (ME)”

“Most patients were left with a marked exhaustion and fatigability that were always made worse by exercise and emotional stress”

“A more direct association between the polio virus and ME was seen in 1948”

“More recent support for a relationship between poliovirus and ME came in 1989 when a dangerously rising titre to type III poliovirus was documented in a patient who did not have polio but who had been diagnosed with ME”

“A constellation of symptoms resembling ME was termed ‘chronic fatigue syndrome’ (CFS) --- like ME and post-polio fatigue, CFS is characterized by complaints of chronic fatigue and impaired concentration that are triggered or exacerbated by physical exertion and emotional stress”

“Hyperintense signal imaged along white matter tracts may have resulted from damage to the brain parenchyma by a local, tissue-toxic effect of the poliovirus”

“Notably, periventricular and deep white (but not grey) matter HS have been imaged in between 40 and 100% of (ME)CFS patients and have been suggested to represent either enlarged, fluid-filled spaces around arterioles, or demyelination”

“Neuroradiologic and neuroendocrine data have indicated damage to brain areas responsible for cortical activation and attention in polio survivors and others with chronic fatigue”
“Word-finding difficulties are reported by 82% of polio survivors with fatigue, and appear similar to word-finding problems reported by (ME)CFS patients”.

1996

Prognosis in chronic fatigue syndrome: a prospective study on the natural course
JM Vercoulen et al JNNP 1996:60:489-494

“Comprehensive assessment of (ME)CFS entails measurement on all dimensions simultaneously”

“The finding that on three out of seven outcome measures these patients did not show improvement underlines the importance of multidimensional assessment in studies on prognosis”

“Psychological well-being (including depression) did not predict improvement in this study, although others (Wessely et al) have suggested that this factor plays a part in the perpetuation of complaints”

“Avoidance of physical activity is also thought to play a part in the perpetuation of complaints (Wessely et al) but the present study is not conclusive on this issue”

“The improvement rate in patients with a relatively long duration of complaints is small”.

As noted above, the above quotations are entirely randomised and are for illustrative purposes only.

Many more examples of the organic nature of ME, and of its nosological existence, can be found in the list of suggested reading in Appendix I.
Wessely's Words

This section is inordinately long; this is because it reflects the extent of Wessely's denigratory pronouncements on those with a diagnosis of ME. The quotations are listed in annual chronology.

1987


The various inaccuracies and distortions which Wessely makes in this paper have already been mentioned in the section above devoted to Wessely's tactics.

1988

Postviral fatigue syndrome: time for a new approach.   Anthony S David, Simon Wessely, Anthony J Pelosi

(Note: the authors promote themselves as having personal experience in the care and investigation of patients with what they call "the postviral fatigue syndrome"; they suggest that the "organic versus functional" dichotomy should be replaced by a multifactorial approach, but then proceed to denigrate both other researchers and patients alike).

"Flaws detected in certain aspects of recent research included in particular failure to define fatigue, (and) inadequate assessment of psychological features"

"Unfortunately, it has been inferred in some quarters that the concepts of suggestibility, imitated behaviour, and altered medical perception amount to an accusation of fakery"

"Hysteria itself is an outmoded diagnosis and is being replaced by the concept of ‘abnormal illness behaviour’….in a desperate search for recognition patients may resort to...‘unacceptable patterns of behaviour’….this is a manifestation of the patient's need for an acceptable diagnosis....the difference between a crazed neurotic and a seriously ill person is simply a test”.

"If a single virus were to be implicated this would greatly enhance the validity of the syndrome"

"(Immunological research) found…suppressor cell abnormalities….there has been…criticism of this type of (immunological) research, as it disregards the psychological dimension"

"The failure of more psychiatrists…to contribute leaves a yawning gap in this research"

"Future investigations and clinical practice must take into account the similarities between the symptomatology of the postviral fatigue syndrome and that of common psychiatric disorders…when the somatic symptoms of depression are compared with those of the postviral fatigue syndrome not only are they similar…but the frequency with which they occur is also remarkably concordant"

"Valid and reliable methods of assessing and quantifying psychiatric symptoms have been established, for example…the general health questionnaire - which ought now to be applied to patients with the postviral fatigue syndrome"

"Why have sufferers and their doctors been so vigorous in rejecting the possibility that these ubiquitous psychological factors may be aetiological in the postviral fatigue syndrome?"
"Well-designed studies are required...these must incorporate...clearly defined operational criteria...perhaps using our suggestions as a framework with emphasis on...psychological symptoms...and standardised instruments with proved validity and reliability for assessing symptoms"

(Martin Lev of ME Action Campaign wrote to the editor of the BMJ; in a letter dated 14th March 1988, Lev took issue with the authors, asking why a single viral aetiology would greatly enhance the validity of the syndrome and pointing out that other immune disorders are recognised as perfectly valid despite the absence of any single determining factor. Lev correctly stated that multiple sclerosis is a valid entity, yet no causative factor has been identified).

1988


Referring to an article on ME by Lloyd et al published in the Lancet on June 4th 1988, Wessely et al asserted:

"Though disordered...immunity and persisting viral infection have recently attracted attention...inclusion of these laboratory findings in a case definition presupposes that immunological dysfunction is of primary aetiological relevance. It is important that immunologists do not deflect attention away from the wider aspects of the chronic fatigue /postviral syndrome"

1988

The case of Ean Proctor

Wessely leapt into notoriety in 1988 by becoming involved in the appalling and much-reported case of Ean Proctor, then a twelve year old boy from the Isle of Man: against his parents' wishes and with no prior warning, Ean (then an extremely sick child) was -- on a Sunday -- forcibly taken into care; a policeman was standing by, and a court order had been obtained. This was carried out by social workers who unquestioningly complied with the forceful urging of Dr Bryan Lask, a psychiatrist at Great Ormond Street Hospital to whom Ean had been referred and who did not accept the diagnosis of severe ME which had been made by Dr J. Morgan-Hughes, a senior consultant neurologist at The National Hospital, Queen Square, London.

Before being referred to doctors in London, Ean had been subjected to a terrifying ordeal on more than one occasion whilst he was under the care of doctors on the Isle of Man: these doctors did not believe in ME; they were certain that Ean was suffering from a psychiatric illness and so they devised activities which were designed to prove that his symptoms were simply simulated. One such "therapy" entailed forcibly taking the petrified child on a ghost train: they were determined to terrify him into crying out, as they believed his mutism to be "elected": it should be recorded that in a report dated 17th July 1988 written by Dr D.M. Lewis, consultant paediatrician at Aberystwyth (written at the request of solicitors), Dr Lewis noted that Ean's "loss of speech was not sudden as in elective mutism, but a gradual fading out".

Ean's parents turned for help to the Tynwald, whose Report documents even more horrors: (Report of the Select Committee of Tynwald on the Petition for Redress of Grievance of Robin and Barbara Proctor, 19th April 1991): "At the time, Ean could not keep his balance, his legs were getting weak, his speech was much slower, he found it difficult to read and he could not keep his concentration" (ibid page 4.2.2). He could not feed himself because he could not move his arms; he could not stand, and was suffering terrible
headaches (ibid page 4: 2.3). He was subsequently unable to speak”. The Tynwald report documents that, during one admission to Nobles Hospital on the Isle of Man, whilst "paralysed, (Ean was) put in the swimming pool with no floating aids whatsoever. Mrs Proctor said that at this time Ean could not move a finger and could not speak. Ean sank under the water" (ibid page 14: 3.15).

During one of the visits to Dr Morgan-Hughes at the National Hospital in London, the Proctors were asked by Dr Morgan-Hughes if they would be willing to speak to Simon Wessely, who, they were told, was doing research into ME: wanting to help, they agreed.

The Tynwald report confirms that "a psychiatrist called Dr Wessely briefly saw Ean and then informed the Proctors that 'children do not get ME' ". Wessely then wrote three medical reports on Ean Proctor.

In the first of his three reports, dated 3rd June 1988, which was written to the Principal Social Worker in Ean's case, Wessely wrote that he "was requested to see Ean by Dr Morgan-Hughes" but Mrs Proctor stoutly refuted this interpretation, maintaining that they agreed to see Wessely only because they wished to help his "research". In this first report, Wessely admits that he did not physically examine Ean, yet his report states that Ean presented with a history of "elected mutatism" (sic) and that "I was in absolutely no doubt that the primary problem was psychiatric. My initial impression was that Ean's condition was a form of hysteria". Wessely then stated that "Ean's apparent illness was out of all proportion to the original cause". He continued: "I feel that Ean's parents...are very over-involved in his care". Remarkably, having been qualified for such a relatively short time, Wessely then asserted: "I have considerable experience in the subject of 'myalgic encephalomyelitis' and am absolutely certain that whatever the status of that diagnosis, it did not apply to Ean". Wessely continued: "I feel that Ean needs a long period of rehabilitation, part of which will involve very skilled management of separation from his parents...providing an escape from his 'ill' world. For this reason I support the application made by your department for wardship" (letter dated 3rd June 1988 from Dr Simon Wessely to Mrs Jean Manson, Principal Social Worker (Child Care) at The Department of Education, Bucks Road, Douglas, Isle of Man).

On 10th June 1988 Wessely wrote a second report on Ean, this time at the request of Messrs Simcocks & Co., Solicitors for the Child Care Department, the Isle of Man Department of Education, which he claimed "summarises my involvement with Ean and his parents...between 22nd March 1988 and 6th April 1988". In this report, Wessely stated: "Ean cannot be suffering from any primary organic illness...The question of the existence of a disease called 'ME' is irrelevant as...Ean does not have it"....Ean has a primary psychological illness causing him to become mute and immobile...I support the efforts being made to ensure Ean receives appropriate treatment" (Report dated 10th June 1988 from Dr Wessely to Messers Simcocks, reference JW/APB/211).

Messrs Simcocks then requested a supplementary report on Ean, which Wessely wrote on 5th August 1988; in this he boasted: "It may assist the Court to point out that I am the co-author of several scientific papers concerning the topic of 'ME'. I am currently conducting three research projects at the National Hospital for Nervous Diseases, concerning...treatment of patients with this condition. I have been invited to present these results at an International Conference...organised by the W.H.O....I submit that (my) experience is more relevant to the case of Ean". Wessely then made a somewhat wild and unsubstantiated claim; he wrote: "Scientific teams in this country and also in the USA and Australia are studying this illness. None of these teams would accept Ean's current condition as being due to 'ME' and all would search for an alternative explanation". Curiously, Wessely seems to have overlooked the fact that an eminent and experienced consultant neurologist at his own hospital (the National) had already made such a diagnosis and confirmed it in writing in a report dated 12th August 1987 to Dr N.J. Birkin, consultant paediatrician at Douglas, Isle of Man. Dr Morgan Hughes listed some of Ean's problems as "persistent nausea and intense mental and physical fatigue in that he is now unable to stand or support himself and needs help with washing, dressing and feeding; recurrent bouts of sore throat and ulceration of his mouth and tongue; hypersensitivity to both light and noise; post-exertional aches and pains in his muscles; reduced concentration span; diffuse...weakness in the limbs and trunk".
Dr Morgan Hughes then wrote: "I would agree that this young man's symptoms are all compatible with the postviral syndrome, which...is a very poorly understood condition" (letter from Dr J Morgan-Hughes to Dr N.J. Birkin, Douglas, Isle of Man, reference NJB/CP).

Wessely, however, sweepingly ignored the symptoms established by Dr Morgan-Hughes and in his own report mentioned only "fatigue", writing: "Not everyone with fatigue has 'ME' ", yet indisputably, Ean had far more than just fatigue.

This tactic of Wessely's (ie. ignoring vital evidence which does not accord with his own chosen construct) has become his absolute hallmark, and is frequently employed by him to patients' detriment.

In this third report on Ean Proctor, Wessely resumed his own self-promotion, stating: "I have considerable experience of both the post-viral fatigue syndrome and child and adult psychiatry, and would submit that mutism does not and cannot occur in a true chronic fatiguing illness".

(For the record, just as there is a bulbar form of poliomyelitis which attacks the vital breathing, vomiting and heart-regulating brain centres, leading often to death, there is a bulbar form of ME which attacks similar centres, leading to nausea, vomiting, inability to swallow and problems with the voice: this results in weakness).

Wessely then wrote: "I disagree that...active rehabilitation should wait until recovery has taken place, and submit that recovery will not occur until such rehabilitation has commenced. I would emphasis that delay may lead to further psychological complications....It may help the Court to emphasise that...we now have increasing expertise in the management of individuals presenting with fatigue...I would emphasis that active management, which takes both a physical and a psychological approach, is the most successful treatment available...I am sure that...Ean is now anxious for a way out of this dilemma with dignity".

The Report of the Tynwald disagreed with Wessely: on page 18 at paragraph 4.8 it stated: "It seems to be generally agreed among those who have made a study of ME that patients should never exceed their physical or mental limitations. Attempting more active exercise or active physiotherapy (which is recommended by some doctors) will only exacerbate the condition".

The Tynwald Report concludes "This Committee...cannot find that the case conference was acting appropriately or in the best interests of Ean (page 17:4.6).

Despite the sobering fact that the Select Committee of Tynwald found in favour of the Proctors and did not find in favour of the psychiatrists involved, Dr Wessely continues unabated to promote himself as an expert on "CFS" and to maintain that "ME" is nothing more than a belief that one is ill.

1988

**Exercise is the Key to Fighting ME**  
GP. 2nd December 1988:35 Weekly Briefing  Caroline Richmond

Caroline Richmond, not a doctor but a journalist who, together with Wessely, was one of the founder members of Healthwatch and never lost a single opportunity to promote Wessely's views on ME. Her full page article served to promote awareness of Wessely's forthcoming paper in the Journal of the Royal College of General Practitioners which appeared the following month (ie. January 1989). Richmond's article carries an illustration of a jogger and a sub-heading saying: "Gradually expose them to hard activity".

"Dr Simon Wessely believe(s) it is important to give GPs a handy guide to management of what can be difficult cases"
"(Dr Wessely) regards chronic fatigue syndrome -- a term he and others prefer to myalgic encephalomyelitis or postviral fatigue syndrome -- as a debilitating state in which symptoms are perpetuated by inactivity, deterioration in exercise tolerance, and further symptoms. In many patients this is compounded by depressive illness, leading to a self-perpetuating cycle of exercise avoidance that makes the depression worse"

"Some will have embarked on a struggle to find an acceptable diagnosis"

"Patients with chronic fatigue syndrome have normally functioning muscles that are neither weak nor fatiguable"

"Many sufferers have read advice leaflets saying that physical and mental exertion are to be avoided. Wessely and colleagues regard this as counter-productive"

"The patient's treatment programme will probably include...cognitive therapy...(and) no further visits to specialists or hospitals....As for formal psychotherapy, Dr Wessely and colleagues consider that insight-orientated treatment may be undesirable as chronic fatigue syndrome patients are already highly introspective. However, many will benefit from antidepressants"

Richmond's published response to the criticisms evoked by her article stated:

"ME is...a dramatic name for a group of...conditions including post-viral fatigue, nervous exhaustion and chronic neurasthenia. The first two groups are treatable because they have the courage and motivation to participate in their own recovery. The third group...appear to have a vested interest in being invalids".

Note: as usual, Richmond adopted Wessely's tactics of ignoring the facts, for example, that a diagnosis of ME should never be made unless there are signs of neurological involvement, and she conveniently failed to mention any of the published evidence from neurologists, virologists and immunologists that there is an organic basis for this illness).

1989


"This paper...is intended to offer treatment guidelines to general practitioners, neurologists, physicians and psychiatrists, all of whom may be faced with people with the chronic fatigue syndrome"

"Many patients referred to a specialised 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 concerned with the condition”

“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'...the process is therefore 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"

"The cognitive-behavioural model...can explain the continuation of symptoms"
"This has led to a vicious circle of increasing avoidance, inactivity and fatigue.... Many sufferers have been told that 'physical and mental exertion is to be avoided'.... in general, such advice is counter-productive.... ideally, a behavioural programme... is likely to involve the following... regular exercise... a gradual increase in exercise, encouragement of exercises... cognitive strategies.... no further visits to specialists or hospitals unless agreed with the therapist"

"Occasionally patients 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... sexual problems occur in the majority of patients referred to hospital"

"The notion of allergies further alienates the patient from the illness, which exacerbates and extends it"

"Such ideas reinforce the view that the sufferer is under attack from outside elements which have nothing to do with himself or herself"

"There is no clinical evidence that allergies exist in anything but a small number of sufferers, and their existence may be coincidental".

1989

Myalgic encephalomyelitis -- a warning: discussion paper. Simon Wessely.
JRSSM 1989, April: 82:215-217

"...the strongest factors associated with fatigue were depression, anxiety and lack of exercise. Depression as a symptom is not synonymous with depression as a syndrome, but this highlights the need to consider the relationship between affective disorder and CFS"

"...patients with profound fatigue on physical and mental exertion... could easily be classified as CFS or major depression"

"It can be concluded that affective disorder is a common condition which shows symptomatic overlap with CFS.... Sadly, few of the current workers in the field of CFS seem aware of this problem"

"It is now time to include, either as cases or controls, those patients who... have diagnoses such as affective disorders".

1989

VP-1 Antigen in Chronic Postviral Fatigue Syndrome. David Halpin, Simon Wessely
Lancet May 6 1989:1028-1029

"Yousef et al reported that an enterovirus group specific protein, the VP-1 antigen, was found in 51% of a series of patients with the postviral fatigue syndrome.... The clinical relevance of these findings has been questioned.... The selection of patients from members of a self-help organisation for people with postviral fatigue may also have led to overestimation of the association.... We conclude that... VP-1 antigen status remains of research interest but its sensitivity and specificity are unsuitable for routine clinical use".
"My local bookshop has just given ‘ME’ (myalgic encephalomyelitis) the final seal of approval, its own shelf...five books on the subject appeared in almost as many weeks and there was no space left between meditation and menopause....certain themes are common to all five and are revealing about the whole phenomenon that is ME"

"The heroes are those few enlightened doctors who have supported the cause...and the villains are the rest of the medical profession, but especially the psychiatrists"

"The dislike and distrust of psychiatry that run through these pages are a...product of the illogical medical world that has given rise to ME"

"...we all suspect...that ME is not one disease but a collection of diseases and syndromes with varied causes"

"A little more psychology and a little less T cells would be welcome".

This mocking piece called forth near-despair from sufferers and their hard-pressed clinicians alike; one severely affected sufferer, formerly an NHS consultant radiologist, wrote to Wessely saying: "those patients who have severe neurological and other physical sequelae (whether or not they have psychological problems) must surely be allowed to have their immunological profile measured...it would be a Luddite view indeed if the emerging evidence that viral particles have contributed to the aetiology of the illness were to be suppressed. Would it have been of any value and to whom if the aetiological mechanisms and pathogenesis of poliomyelitis...had not been elucidated thus far? The function of doctors (not least psychiatrists) should not be to try to debunk this complex syndrome as being caused by psychological factors, but to attempt to help those patients in the best way possible. Some patients do not and could not be expected to respond positively to merely a psychological approach. It makes them worse" (letter dated 3rd June 1989 from Dr Eric Booth to Dr Wessely).

On 16th June 1989, Wessely replied to Dr Booth, saying: "As you realise, the piece was a review, for the benefit of a medical audience....If we look at the studies published of such populations, we find that the majority have normal serology and immune systems....at the moment, the only symptoms of ME that can be treated are anxiety and depression....I disagree with some of the books reviewed because of balance....You say that such patients will respond badly to a purely organic approach....they will also respond badly to a purely psychological approach.... I have absolutely no time for those books...from the psychogenic movement saying that UC (ulcerative colitis), MS, cancer etc were "psychogenic" or the result of repression etc. Such approaches are foolish, inaccurate and unhelpful. So are some of the books I reviewed".

"Two weeks ago I reviewed the current books on 'ME'....since then two more have appeared....what on earth is happening?....ME is fast being incorporated into a religion, dependent on faith, with prophets and devils...like a religion, these books cover most forms of misery.... I have considerable doubt that all such distress can be explained by any combination of a virus, allergy, intolerance or immune deficit....these ideas explain everything, and thus nothing".
Fatigue syndromes: a comparison of chronic "postviral" fatigue with neuromuscular and affective disorders  S Wessely  R Powell  JNNP 1989:52:940-948

"Seventy two percent of the CFS patients were cases of psychiatric disorder using criteria that excluded fatigue as a symptom"

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

"The symptoms of 'postviral' fatigue had little ability to discriminate between CFS and affective disorder"

"The clinical problem of patients with severe fatigue without obvious cause has received renewed attention in the professional literature, accompanied by intense media interest... a patients' organisation, the Myalgic Encephalomyelitis ('ME') Association has become Britain's fastest growing charity"

"(In the current study) all cases of fatigue... without an acceptable diagnosis were... included.... The aims of the study were to establish ... the role of psychiatric disorders in 'postviral' fatigue"

"Fatigue precipitated by mental effort is ubiquitous in CFS and affective disorder, but only occurs in neuromuscular disease in the presence of psychiatric disorder"

"Any abnormalities in muscle structure or function may... result from physical inactivity... The results confirm that fatigue is a frequent accompaniment of major depression, but also suggest a considerable overlap between CFS and affective disorder"

"An alternative hypothesis is that all cases of CFS can be explained by disorder of mood... CFS is a heterogeneous condition: depressive illness is a sufficient... explanation"

"Viruses may not be either necessary nor sufficient for the development of CFS.... Instead, (our results) suggest(s) that the link, if any, between virus and fatigue operates via recognised psychiatric disorder"

"The current study demonstrates the importance of psychiatric illness in fatigue states of longer duration".

(Note: although none of the patients in the CFS group had been diagnosed as having ME or postviral fatigue syndrome, many of the subjects in this group stated that they became ill after an infection. Of those, 33% had evidence of a previous infection in their blood).

In their papers, Wessely and Powell state: "the link, if any, between a virus and fatigue operates via recognised psychiatric disorders in the majority of cases", but whilst Wessely and Powell stress the importance of psychiatric illness in chronic fatigue states, this is in stark contrast to the conclusions of Lloyd et al (Med J Aust) who used the Australian diagnostic criteria for ME to select their subjects. Of 100 people in the patient group, only two were deemed to be suffering from endogenous depression. Instead, Lloyd et al found a number of immune abnormalities, including reduced levels of IgG1 and IgG3 (thought to play a major role in virus neutralisation). It is not clear how many of the Wessely and Powell patients would have fulfilled the Australian criteria.

Other findings in the Australian study were that the mean lymphocyte count was significantly lower in patients compared with controls, as were the CD2 (total T cells), CD4 (T helper cells) and CD8 (suppressor) counts.
As a group, the Australian patients also had significantly elevated numbers of peripheral blood mononuclear cells displaying HLA-DR antigens. The authors state that the latter implies "immunological activation". These surface antigens may have been induced by interferon or other cytokines; once activated, these cells may continue to produce cytokines which may mediate the symptoms of "CFS/ME". The results support the authors' view that disordered immunity is an important factor in the aetiology of ME (Immunological abnormalities in the Chronic Fatigue Syndrome. Lloyd, A R, Wakefield D, Boughton CR and Dwyer J M. Medical Journal of Australia 1989:151:122-124).

1989

Worry to blame for yuppie flu Dr James Le Fanu. Sunday Telegraph 20th August 1989
(It will be recalled that Le Fanu is a member of Healthwatch)

"Most sufferers from the illness...known as ME, or more popularly as "yuppie flu", are in fact psychologically depressed, research workers at the National Hospital for Nervous Diseases in London have found"

“The findings cast further doubts on the nature of the disease”

“Some doctors...argue that it is a malingerer's charter....Dr Simon Wessely...added "many patients are likely to improve with antidepressant drugs".

1989

ME is 'all in the mind' Kathryn Bingham. GP. November 4th 1989
(GP magazine is sent to every GP in the country)

"Findings from a new study suggest that ME is a psychological and not a physical disorder”

“According to study leader, Dr Simon Wessely, ME sufferers do not have a virus and there is nothing wrong with their muscles....(patients) 'end up adopting the sick role completely, assume they have an incurable disease and avoid any type of activity, even taking to wheelchairs-- which of course makes them worse', he said. 'These patients are very well informed and we have big difficulties getting over that' said Dr Wessely. Speaking at last week's autumn meeting of the Royal College of Psychiatrists in London, Dr Wessely admitted that his study was unscientific in that it was uncontrolled and unrandomised".

Once again, Dr Eric Booth (a consultant radiologist with ME) wrote to Wessely; his letter was dated 26th November 1989 and he wrote: "I read with incredulity the article in GP Magazine of 4th November 1989. I cannot believe that a Maudsley trained doctor could be so ignorant of the facts....The clinical features of true myalgic encephalomyelitis can readily be differentiated from depression. Of course depressed patients may well respond to cognitive therapy and graduated exercise but patients with persistent virus infection have been made worse....Would you not agree that one of the cardinal features of ME is that patients do not improve with exercise because they cannot. In the same way...you would not expect patients with active paralytic polio to improve with exercise".

Wessely replied on 28th November 1989, saying: "I am afraid there are still some points of disagreement. The point of my JNNP paper...was to show how difficult it is to separate out severe depression from ME on a clinical basis". On 30th November 1989 Dr Booth rose yet again to the occasion, and responded to Wessely's reply as follows: "You didn't answer any of my questions in your letter....There are many causes of "chronic fatigue" as you know....A persistent virus infection with viral particles in muscle and brain is a very specific cause --not some airy-fairy, nebulous, non-specific concept. Viral heart disease and viral
pancreatitis are also pretty specific and the heart and pancreas are two other target organs which have been shown to be involved in some patients....There is a JNNP paper in the pipeline which might clarify some things for you, which will enable you to differentiate very well indeed between ME and depression, if you have had trouble with this so far”.

(Note: in 1991, in a plea for physicians to listen to him, Dr Booth wrote: "Over the last few months ...I feel that I do not wish to go on living while being forced to endure such unbearable suffering. Despite my feeling this way, I am unable to convey this to my medical colleagues. It is a very sad state of affairs that the people on whom I ought to be able to rely the most are the very people who do not wish to hear (me). What they were hearing is that ME is due to disordered thinking and that the aetiology of this is psychological”. Although a consultant physician, Dr Booth was treated accordingly, ie. with disparagement and medical dismissal; tragically, he died -- of cardiomyopathy -- on 18th June 1995, aged 48. Only a few people knew that his partner was formally warned by the UK Government’s Official Solicitor not to discuss the autopsy findings).

1990


"We read with interest Dr Ho-Yen’s thoughtful paper...written in response to our previous paper on the subject” (The Management of chronic post-viral fatigue syndrome JRCGP 1989:39:26-29)

"Many of the apparent differences between our approach and that of Dr Ho-Yen are, as he states, due to sample differences"

"Simple...conditioning suggests that such a powerful experience of failure will lead to persistent avoidance, perhaps when the original need for it is no longer present"

"We also suggest that...repeated exposure to uncontrollable...and mysterious symptoms, such as the profound muscle pain that characterises the syndrome, is (a) potent cause of the...helplessness so frequently found (Powell R, Wessely S, manuscript submitted for publication) and may in turn explain the high rates of mood disorder"

"It is increasingly accepted that fibromyalgia may indeed be the same condition as post-viral fatigue"

"Our conclusion was that the advice currently offered to these patients (ie. by other doctors such as Ho-Yen who advocate rest in the initial stages) may not be accurate, and the therapeutic nihilism in this condition may be unduly pessimistic".

1990

Possible ME The Practitioner 8th March 1990:234:195-198

This series of articles entitled "How I treat...." affords common scenarios met by GPs, and asks various doctors how they would treat each case; this particular exercise asks how the doctors would approach a female university lecturer complaining of fatigue and lack of energy for two months; she is unable to play regular squash or go walking; she acknowledges that she is under a lot of stress, and says "I think I've got ME".
Three doctors publish their various approaches; two are GPs, the other is Simon Wessely. His answer states: "I suspect that most doctors are likely to experience a sense of dread when a patient like Mrs Green tells them her diagnosis....it is threatening when the patient produces her own diagnosis"

"The field of 'ME' is messy, difficult and controversial. The doctor can anticipate arguments and quarrels"

"ME is a description, not a diagnosis, and there are no pathognomonic signs, symptoms or tests for it"

"I would not refer for 'investigation' unless something has turned up that needs further investigation"

"I would accept her ME as a real problem (which it is), but start to redefine what it means"

"The quality of the doctor-patient relationship may be a more important influence on eventual outcome than allergy or virus".

1990

**Attributions and Self-Esteem in Depression and Chronic Fatigue Syndromes**
R. Powell, R Dolan and S. Wessely  

"Recent work has shown that the symptomatology of CFS overlaps with that of operationally defined depressive disorders. Several studies (Wessely here refers to his own work) have shown that between 46 and 67% of CFS patients seen in hospital practice have met diagnostic criteria for depressive illness. These figures suggest that much affective illness in patients with a primary symptom of fatigue is unrecognized not only by referring doctors but also by those with an interest in CFS".

"In contrast to depressed controls, depressed CFS sufferers experienced very little self-blame or lowered self-esteem"

“This research shows that in longstanding CFS, those with major depression having an external attributional style experience less guilt and have preservation of their self-esteem....Such an external style of attribution has certain advantages....external attribution....protects the patients from being exposed to the stigma of being labeled psychiatrically disordered....Such an external attribution of cause in CFS...may lead to helplessness, increased fatigue, lack of self efficacy and diminished responsibility for ones own health"

"Our results are close to those predicted by the 'learned helplessness' theory of depression"

"....'inappropriate' referrals to physicians can lead to extensive physical investigation that may perpetuate the symptom pattern of physical attribution".

1990

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

(Note: this is one of Wessely's seminal papers; it is urged that people read it in its entirety. Wessely's theme is that neurasthenia remained popular as long as it was viewed as non-psychiatric illness which affected successful people and for which the cure was rest; he argues that similar factors are associated with the current interest in myalgic encephalomyelitis).
"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"

"The concept of ME has shifted from an acute paralytic state to one of chronic fatigability"

"As in neurasthenia, the emphasis is on muscle fatigability"

"Sufferers from neurasthenia often time wonder and complain that they have so many symptoms; that their pain and distress attack so many parts and organs' (Beard, 1880). Beard listed over 70 with special attention being paid to...cardiac, gastrointestinal, temperature regulation, paraesthesiae and pain syndromes....Identical symptom lists will be found in the current literature"

"There is no doubt that neurasthenia began as a disease of the upper social classes... All current work on the postviral fatigue syndrome acknowledges a positive socio-economic gradient, with an over-representation of upper social classes"

"The relationship of chronic fatigue and depression is fundamental to our understanding of the condition"

"In a current leading neurology textbook, chronic fatigue, neurasthenia and depression are seen as synonymous (Adams and Victor, 1985)"

"Mood disorder is thus found in many cases of ME but it is not the only psychiatric disorder...some patients do satisfy criteria for anxiety and phobic disorders"

"Oppenheim (1908) wrote that great harm resulted from patients meeting in sanatoriums and 'spreading the mental infection by constant conversation and comparison of their complaints'. Such patients would now be considered as 'somatizers'. Recent studies report that between 10 and 15 % of hospital patients with chronic fatigue syndrome fulfil diagnostic criteria for somatization" (Wessely is referring here to his own papers).

"Beard's neurasthenia began as a physical disease... 'the diagnosis proved as satisfactory to the patient as it is easy to the physician (Sicherman 1977)...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"

"One of the reasons for the rapid rise of ME...lies in the nature of the principal alleged aetiological agent. Viruses are among the commonest explanations....Such attribution has many features relevant to ME. The agent is external, and is beyond the subject's control...There is no...guilt or self-blame. External attributions of illness to entirely organic causes distinguish ME patients from matched psychiatric controls (Wessely & Powell, 1989)"

"The conviction that exhaustion will follow any amount of effort, physical or mental, is already a guarantee that it will result (Waterman 1909)"

"It was clear that neurasthenia was shifting from being the concern of neurology to psychiatry. This change was of critical importance, since once neurasthenia was viewed as psychiatric, a principal social function was lost"

"It remains to be seen whether the same process happens in the UK"
"This essay has traced the history of ME, and drawn parallels with...neurasthenia. Evidence is presented of the striking resonances between neurasthenia and ME"

"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, and may create more severe and persistent morbidity than the initial illness which led to the consultation (Wessely,1989)".

(NB. Throughout his text, Wessely uses no less than 21 self-references).

1990

The chronic fatigue syndrome -- myalgic encephalomyelitis or postviral fatigue

"There has been a recent upsurge of interest in both the medical literature and the media in the problems of people with excessive fatigue. Patients are usually described as suffering from 'myalgic encephalomyelitis'....Even its nosological existence is subject to dispute" (note: ME has been formally classified by the WHO in ICD as a neurological disorder since 1969)

"The original literature...described an acute neurological disease....Gradually the emphasis changed....Finally, interest in the conventional neurological features waned, and attention shifted to the importance of fatigue as the central symptom"

"There is now a consensus that physical signs are few or absent....The reader will note the non-specificity (and changeability) of many of the features of the condition"

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

"Single fibre EMG performed in CFS patients at the National Hospital, London, has been consistently normal"

"...post-exercise myalgia occurs in the majority of patients with major affective disorder"

"...there is no doubt that psychological symptoms are strongly associated with chronic fatigue"

"Not only is fatigue found in most depressed patients, so are all the other symptoms characteristic of CFS, both in nature and frequency" (note: this is untrue; the cardinal features of ME -- which Wessely refers to as "CFS" -- are found only in ME/CFS)

"Many physicians may not be familiar with the range and severity of the symptoms of major depression"

"As in the assessment of neuromuscular abnormalities, it is essential that investigators cease relying on normal controls, and instead use controls with equivalent...psychiatric disability"
"...studies...have shown that past psychiatric history is significantly associated with post-infectious fatigue" (Wessely lists his own study here)

"Of particular relevance is that many immunological variables...are very influenced by such factors as physical inactivity (and) depression"

"Psychiatric disorder is associated with immune dysfunction...and the findings reported in CFS have also been found in psychiatric patients....The relevance...of the observed (immunological) changes are unclear....and perhaps simplistic....One may anticipate considerable overlap between the minorities of CFS and depressed patients who demonstrate immune dysfunction"

"It was the epidemic of an unexplained illness at the Royal Free Hospital in 1955 that resulted in the labeling of a supposedly new disease entity called benign myalgic encephalomyelitis....McEvedy & Beard (1970) re-analyzed the epidemic....It had spread down a social hierarchy in a closed community that was at the time expecting an outbreak of poliomyelitis. The signs and symptoms were inconsistent, the tests normal, or could be simulated"

"Case to case spread is suggestive of infection, but also occurs in psychological epidemics (Wessely 1987)"

"(The Royal Free) controversy is whether the contagion was of emotional distress or an infectious agent"

"The (Lake Tahoe) epidemic may have resulted from...altered medical perception"

"...a physical diagnosis...implies the illness has an external (physical) cause, usually a virus”

“Such attribution always conveys certain benefits, irrespective of accuracy....In other words there is an avoidance of guilt and blame....Perhaps it is no coincidence that the germ theory of non-specific illness is gaining popularity among patients at the expense of a decline in the acceptance of personal responsibility for illness"

"Patients who fail to respond (to antidepressants) should be treated along similar lines to those proposed for treatment-resistant depression....Adding a second antidepressant agent, especially lithium...may be beneficial"

"In recent years...psychiatrists have come increasingly to rely on cognitive behavioural therapies....The purpose is to question the vicious cycle between symptoms, stopping activity and further fatigue....Symptoms may no longer be viewed as an inevitable reason for...cessation of activity"

"...exercise is necessary...as a specific therapy. 'Fatigue is a physiological disturbance, and should be treated by physiological means, ie. exercise' (Edwards 1986)"

" 'there is no evidence that...physical activity worsens the underlying process' "

"...many reputable authors have in the past accepted minor variations as evidence of...organicity....Similar efforts are often made to over-interpret laboratory findings"

"It is...regrettable that ME has become a disease of fashion, even a 'fad'...along with such disorders as...total allergy syndrome"

"Suggestible patients with a tendency to somatize will often be found among the ranks of sufferers from disease with ill-defined symptomatology and external causation, until doctors learn to cope with them more effectively"
"Over enthusiastic espousal of new illnesses can...be harmful. It may legitimize some of the maladaptive
behaviour already described"

"No relationship has been found between any laboratory findings and clinical status in CFS"

"Few risk factors have been identified other than previous psychiatric illness"

"Future work must spread the net wider to....psychiatric facilities".

NB. Throughout this text, Wessely uses no less than 32 self-references.

Clearly, Wessely and Powell see encephalitic symptoms as “fatigue”, not as manifestations of an
inflammatory process in the brain. Indeed, they find the evidence for a physical/immunological basis
inconsistent and unconvincing.

They believe that more attention should be paid to factors such as psychiatric morbidity, coping strategies
and what they regard as the misattribution of symptoms, which they believe may prolong the illness.

1990

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

"Physicians working in the general medical field frequently encounter patients with excessive fatigue for
which no simple explanation can be found. These continue to attract diagnoses such as effort
syndrome...fibromyalgia...or environmental allergy syndrome, the exact label depending more on the
medical specialty than on any clinical differences....Recently several new diagnoses have been introduced,
including postviral fatigue...and myalgic encephalomyelitis.... Despite the variety of names, all of the above
illnesses have the following characteristics....absence of abnormalities on conventional medical
investigations. For the remainder of this chapter the term "Chronic fatigue syndrome (CFS) will be used to
refer to all such illnesses, as this term is accurate"

"It is premature to describe CFS as a ‘common, discrete and easily diagnosable clinical illness’ (Bell & Bell,
1988)"

"Most CFS patients fulfil diagnostic criteria for psychiatric disorder"

"Wessely and Powell (in press) also used the Schedule for Affective Disorders and Schizophrenia to study
47 referrals with unexplained fatigue to a specialist neurology hospital. Of these 72% had a psychiatric
diagnosis"

"Intensive efforts have been made to identify specific causes of chronic fatigue states, but have largely
been unrewarding"

"At present there is no reason to differentiate fatigue states according to any specific associated infection"

"Other symptoms include muscle pain and many somatic symptoms, especially cardiac, gastrointestinal
and neurological. Do any of these symptoms possess diagnostic significance? The answer is basically
negative"
"This suggests that, despite frequent claims to the contrary, these are not immunodeficiency syndromes, nor is active viral infection a likely factor"

"...altered medical perception has resulted in a coalescing of many different entities"

"Psychological vulnerability was a risk factor for duration of illness and fatigue"

"The conclusion is that...past psychiatric history predisposes to fatigue states of longer duration"

"The description given by a leading gastroenterologist at the Mayo Clinic remains accurate: 'The average doctor will see they are neurotic, and he will often be disgusted with them'"

"A new explanatory model for CFS has recently been proposed (Wessely et al 1989) which combines cognitive and behavioural principles"

"Avoidance behaviour continues, as does the conviction that further activity will increase fatigue...a self-perpetuating vicious circle of avoidance, depression, fatigue and a conviction of continued pathology is established"

"Patients who think, or whose diagnosis has established, that they are suffering from 'ME', 'postviral fatigue'...believe -- with varying degrees of conviction -- that they have a physical illness, ascribed to a physical cause, as do those making the diagnosis....Such an attribution is an integral part of the clinical presentation"

"The similarities between the symptoms of viral infection and depression may lead to misattribution and misdiagnosis"

"...it is of interest that the "germ theory" of non-specific illness is gaining popularity...at the expense of a decline in the acceptance of personal responsibility for illness....Such attribution conveys certain benefits, irrespective of accuracy....in other words, there is an avoidance of guilt and blame (unless the germ is sexually transmitted)"

"In the National Hospital Study the symptoms of guilt and self-blame were usually absent in the chronic fatigue patients"

"It is this author's belief that the interaction of attributional, behavioural and affective factors is responsible for both the initial presentation to a physician and for the poor prognosis"

(NB. Throughout this text, Wessely uses no less than 25 self-references).

This article discusses the similarities between chronic fatigue states and affective disorders. Wessely believes that CFS results from a lack of activity, inaccurate symptom attribution and abnormal illness behaviour. He concludes by criticising doctors for missing treatable psychiatric illness and for creating new diagnoses which may legitimise ME patients’ “abnormal” illness behaviour.

1990

Mass Sociogenic Illness by Proxy: Parentally Reported Epidemic in an Elementary School

(Note: This article is not directly about CFS/ME, but it is relevant to this text).
"In a cluster of illness reported among students at an elementary school parents mentioned many signs and symptoms including headache...nausea and vomiting--which they attributed to recurrent leaks of natural gas at the school. It is likely that the parents spread among themselves the notion of toxic exposure at the school. The possibility of an epidemic from toxic exposure at the school caused intense parental concern’ " . The summary above is from an article by Philen et al in The Lancet 1989:ii: 1372-1376 upon which Wessely was asked to comment and his views are quoted as follows:

"This paper demonstrates that parental concerns are a potent cause of outbreaks of "illness", and especially the group episodes often called "mass hysteria". I...am pleased to see it in a prestigious journal such as The Lancet"

"In 1987, I reviewed 52 episodes of mass hysteria....Participants no longer talked about demons and possession states, but now about viruses, mystery gases, and toxins.... We are no longer oppressed by devils, but by allergies, pollution and viruses"

"Fashions in illness change, but will always reflect the preoccupation of the age"

"The preoccupation behind this and other outbreaks...are worries about...a wider belief about the deteriorating quality of the environment in which we live....How often are such factors a direct cause of ill-health? Very rarely"

"If social validation is granted to those affected, and is continued, then the transient disturbances may become serious and severe....What if the school authorities contacted not the sensible researchers represented here, but a less critical specialist in a field such as 'clinical ecology'....The same symptoms that the authors ascribe to the general level of non-specific illness in the community could then have become proof of 'environmental hazard' and susceptible children (which really means susceptible parents) would be on the way to a lifetime of ill-health....Imagine the effect of media coverage of this episode if the doctors had accepted the parental explanation".

1990

New Scientist  18th August 1990

"There are two ways of being well known: fame or notoriety....Simon Wessely, of the Institute of Psychiatry in London, does research into the controversial area of ME -- myalgic encephalomyelitis, or sometimes "yuppie flu". In this area the scientist does not need to make any effort to meet the media -- journalists come knocking on the door. 'One article in the national press can have more influence on public attitudes than any number in professional journals' says Wessely".

1990

Briefing  The Lancet 1990:336:619

"The Royal Society does its best to educate medical and science journalists by organising press briefings on topics of wide public interest. Last week it was the turn of chronic fatigue syndrome (CFS), popularly known as myalgic encephalomyelitis"

“With a frightening name and a self-help group run by a few articulate members ‘ME’ (a label spurned by the medical profession) is often in the news. Any new finding is good for a story"
"A common finding in epidemiological surveys is that what seems in the clinic to be a discrete disorder proves to be one end of a spectrum of a complaint that merges into milder and transient forms seen in the general population. And so, suggested Professor Anthony Mann (Institute of Psychiatry), (note: often a co-author of Wessely) it is with CFS"

"The majority of CFS patients have a psychiatric disorder (most commonly depression), but many actively avoid a psychiatric diagnosis"

"Localised epidemics do not necessarily indicate an infectious cause, and the attribution of sporadic cases to a viral infection is generally based on self reporting of non-specific symptoms....enteroviruses and human herpes virus-6 have been considered as candidates...but no definite association has been established"

"The successful use of antidepressant drugs...to relieve fatigue in patients with post-viral fatigue syndrome may be a foretaste of (future approaches in CFS)"

"Contrary to the advice to rest offered by the ME Association, Professor Richard Edwards (University of Liverpool) recommended that CFS patients should be given a graded exercise programme....he attributed the reduced mitochondrial enzyme activity seen in the muscles of some CFS patients to inactivity"

"Most of the assembled journalists found the meeting instructive".

Response from Dr Charles Shepherd, Medical Adviser to the ME Association 1st September 1990

TO: Members of the Association of British Science Writers who attended the 'forum for discussion' on myalgic encephalomyelitis at the Royal Society on August 31st 1990

"As you probably gathered, I was far from happy that the organisers of this meeting which was called to discuss a very controversial medical topic, decided to avoid including at least one of the ME Association's medical or scientific advisors on the panel of speakers. (Eight of our scientific advisors hold academic posts in UK teaching hospitals and four of them are professors of medicine).

"As a result I believe that most science writers went away with an unbalanced view of current thinking on the subject....I would also argue that the psychiatrists' decision to rename ME as chronic fatigue syndrome and then include under that umbrella a vast group of heterogeneous patients suffering from a mixture of physical, psychological and physiological problems resulting in fatigue is a great mistake which only adds to the confusion.

"I asked if I could place an information sheet on the table outside the meeting describing...current research...but this was refused.

"Dr Archard is a virologist who has shown that persisting enteroviral RNA in the muscle biopsies is a mutant strain which may explain why it is evading normal immunological surveillance.

"Next time the Association of British Science Writers holds a 'forum for discussion' on myalgic encephalomyelitis (or chronic fatigue syndromes) I hope that a representative from the ME Association could be invited onto the platform".

(Note: Caroline Richmond, Wessely's ardent co-activist on Healthwatch, is associated with the British Association of Science Writers, to which the Ciba Foundation plays host: the steering committee meeting of Healthwatch -- originally called the Campaign Against Health Fraud -- was held at the Ciba Foundation on 3rd April 1989 (Dirty Medicine by Martin J Walker, Slingshot Publications, 1993 pp 292 & 334).
"In his review of PVFS...Dr Wessely lists several disadvantages in allowing patients to assume that they may have a continuing problem with 'a virus'......The psychiatrist's model of depression leading to a perpetuating cycle of inactivity may well be valid for some patients with chronic fatigue, but many of those with classic PVFS are not depressed....Other findings...support the hypothesis that intracellular virus may be interfering with muscle function"

Wessely responded: "...explanation involving viral infection of muscle as a basis for symptoms must be regarded in a less positive light. First, the evidence is thin, consisting of a few, small, selected studies using extremely sensitive techniques...second, studies of muscle function...have been consistently normal".

"Although emotional and psychological symptoms have been frequently noted in patients with CFS...research measurement of psychiatric disturbance has only recently been undertaken. A consensus is emerging that depression is the commonest associated diagnosis"

"Having established the high prevalence of psychiatric disorder, particularly affective disorder, in patients with CFS...it is well established that fatigue is common in depressive illnesses"

"...two conclusions can be drawn at this stage. First, fatigue is a common complaint....Second, the incidence of CFS is relatively small"

"Previous psychiatric illness can be a significant risk factor for long-term morbidity"

"As each new infective agent is discovered one must anticipate an initial enthusiasm to find an association with CFS, which almost inevitably will later be modified in the light of more cautious research"

"Given the well-known links between...depression and the immune system, it is not surprising that a host of immune abnormalities continue to be reported in association with CFS...In particular, altered ratios of T lymphocyte subpopulations...have not been replicated"

"Although there were preliminary well-publicised reports by some workers of increased levels (of interleukin 1) in the serum of some CFS patients, this could be accounted for by elevations known to rise following exertion in normal unfit subjects"

"In summary, research into hypothetical immune mechanisms and CFS...must take account of both psychological and physical influences on the immune system. As Straus (1988) says: 'Unfortunately, the present generation of scientists is ill equipped to explore this aspect of the hypothesis' "

"Another sophisticated technique which has not lived up to its promise is nuclear magnetic resonance spectroscopy....Physical inactivity impairs ATP generation and hence is an important confounding variable in such studies"
"Non-specific abnormalities of muscle biopsy specimens continue to be reported...but are of little diagnostic value"

"Various antidepressant medications have been used and there are several uncontrolled studies...suggesting their efficacy"

"By...encouraging a gradual increase in activity, much of the severest morbidity of CFS can be prevented and even reversed"

"We and many others believe...that many of the reported biochemical and structural changes could be secondary to inactivity"

"The importance of psychiatric illness in CFS is now clear".

1991

Myalgic encephalomyelitis Letter Simon Wessely JRSM 1991:84: 182

Referring to Professor Wilson’s article (see above), Wessely replied:

"I am pleased that Dr Wilson...has paid me the compliment of giving my article on the vexed topic of 'myalgic encephalomyelitis' serious attention, and echoes our call for a 'new approach' to the problem, based on the absence of prejudice....I only wish I could follow the rest of his arguments so clearly. Dr Wilson states that I failed to realize that 'about 100%' of patients have an allergic diathesis and an allergic family history. I was indeed unaware of this remarkable finding. Unfortunately, I have been unable to trace the two sources cited for this observation....In my defence I would not...have known that the two references quoted...are actually about chronic fatigue syndrome....Dr Wilson advocates treatment of ME based on exclusion of 'dietary, chemical or environmental challenges'....Such treatments have not found support amongst specialists in allergy...and indeed may lead to more serious disabilities than the diseases they purport to cure".

Professor Wilson was afforded the right to respond to Wessely's letter and his reply stated:

"Different paradigms are often incommensurable which means they cannot be reduced to a common vocabulary...(this) is aptly confirmed in Dr Wessely's statement that he is not familiar with relevant modern literature in psychiatric, or clinical ecology and allergy fields. Information about allergic diathesis and allergic family history is obtainable from standard textbooks on allergic disease.... In clinical allergy and ecology, as in biological psychiatry, there are differing opinions about its practice and philosophy. It would be of value to Dr Wessely to read the references cited in my original paper....The objective of biological psychiatry, and of clinical allergy and ecology ...is to provide improved therapy for the patient....Dr Wessely apparently agrees with my request for a new kind of approach based on absence of prejudice...in patients having ME"

In October that same year, another letter on ME was published, from Dr L.O. Simpson of New Zealand (JRSM 1991:84:), who wrote "The exchange of views between Drs Wessely and Wilson... highlights the divergence of opinion concerning the nature of ME....A disappointing aspect of ME research is the apparent lack of cooperation among investigators. While immunologists, virologists and behavioural scientists continue to retain entrenched positions, those who suffer the problems and frustrations of ME seem to have been dismissed to the sidelines".
"Mr Cox and his colleagues (March 30 p 757) correctly note that antidepressants may help the treatment of depression and anxiety in chronic fatigue syndrome. Nevertheless, Cox et al state that such treatments 'may be counterproductive' because they are associated with psychogenic illness. By the same token, magnesium, which according to the Nottingham health profile scores has altered energy, emotional reactions, sleep and social isolation, must also be seen as psychogenic, and thus counterproductive".

In this same issue, Caroline Richmond, writing officially on behalf of Healthwatch, wrote as follows:

"Biolab, the private laboratory that did the magnesium analyses in Mr Cox and his colleagues' study, has twice been the subject of investigative journalists; on both occasions the laboratory was shown to be unable to measure magnesium accurately or consistently. Why did not Cox et al use the analytical facilities of Southampton University...for more direct comparison of measured magnesium concentrations?"


"Ms Richmond wonders why we did not use the facilities of Southampton University for determining magnesium. We stated in the paper that for the clinical trial...the measurements were done in the department of clinical biochemistry at Southampton General Hospital, and the staff were acknowledged"

"Dr Wessely picks on one sentence to revive discussion of the unhelpful distinction between 'organic' and 'psychogenic'...we referred to a publication, of which Wessely is a coauthor, that highlights the issue"

"It is one of the reassuring features of the trial that it was double blind and it was the treated group alone who had increased red cell magnesium".

"Ms Richmond's comments display a journalist's inadequate grasp of the technical aspects of the issues under discussion....In the past six years our laboratory has done over 50,000 estimations of magnesium levels...with perfectly adequate performance in an external quality control scheme for serum magnesium"

"I cannot allow Ms Richmond's apparent determination (May 4, p 1095) to undermine the credibility of Biolab's technical competence to obscure the very real good that that organisation has done for many patients and in promoting nutritional medicine....This subject stands now on the fringes of orthodox medicine, but already some its ideas and concerns are permeating orthodoxy".

1991

The Cognitive Behavioural Management of the Post-viral Fatigue Syndrome
(Note: this lengthy chapter aims to discuss the pragmatic management of patients with PVFS. Of note is the fact that Wessely et al specifically state that it is necessary to define the groups of patients they are attempting to treat).

"It is probable that delayed recovery coinciding with a liability to mood disorder is the most likely beginning to PVFS"

"The relationship between depression and PVFS is complex. Helplessness is a symptom of depression, and contributes to the expectation that fatigue and pain will follow exertion. Alternatively, myalgia and fatigue fulfil the description of stimuli that are associated with the genesis of depression in the 'learned helplessness' model....It is probable that both explanations are relevant to PVFS, forming the first of many self-perpetuating cycles that contribute to the clinical picture"

"The consequences...may be that the patient (and doctor) blames all ills on continuing viral infection, unaware of other competing influences. The word 'blame' is used deliberately, as issues of guilt, blame and responsibility affect both patients with PVFS and doctors making the diagnosis....Blaming symptoms on a viral infection conveys certain advantages, irrespective of its validity....It is also beneficial to self-esteem by protecting the individual from guilt and blame. The germ has its own volition and cannot be controlled by the host....The victim of a germ infection is therefore blameless....Continuing to attribute symptoms to an external cause continues to maintain self esteem, and avoids guilt and self-blame"

"Many patients...become over-sensitised to physical sensations"

"Dysfunctional cognitions are not sufficient to account for prolonged disability; their importance is linked to the development of maladaptive behavioural patterns"

"Behaviours that fall short of complete avoidance may also contribute. For example, many patients modify their activity to prevent exacerbation of symptoms.... Others may take precautions, such as keeping a wheelchair handy even when not necessary, further limiting activity"

"The behaviour of family and friends may inadvertently reinforce the sick role"

"Fear of illness is an important part of PVFS"

"It is not untypical to find a patient who is relatively free of symptoms, but on enquiry this is because they are leading an astonishingly restricted life"

"A breakdown in the doctor-patient relationship seems to be part of the experience of ME"

"Over 50 years ago a consultant physician at the Mayo Clinic....in an article entitled 'What to do with the patient who feels tired, weak and toxic' (Alvarez, 1935) wrote: 'The average doctor may feel the patient is neurotic, and will be disgusted with them. Often he sends them away with as little ceremony as possible...yet these poor creatures suffer the tortures of the damned'. Nothing has changed"

"Many PVFS patients have a great deal of information about the condition"

"There are very few absolute contra-indications to the (cognitive therapy) programme"

"Treatment refusal is the major obstacle we have encountered....Those refusing treatment were more likely to attribute all their symptoms to a purely physical problem"

"Some (patients) develop an intense commitment to the 'cause' ".
1991

**Cognitive behaviour therapy in chronic fatigue syndrome**  S Butler  T Chalder  M Ron  S Wessely  
JNNP 1991 54 (2):153-158

(Note: in the abstract, it states that 50 patients with CFS were offered cognitive behaviour therapy in an open trial: the principal problems encountered were a high refusal rate, and that advice currently offered to chronic patients -- i.e. to avoid physical and mental activity -- is counterproductive).

"Recently attention has been given to the role of cognitive distortions....Looking specifically at CFS...the initial symptoms, in particular fatigue and myalgia, engender a state of 'learned helplessness'"  
"Continuing attribution of all symptoms to a persistent, untreatable 'virus' continues to increase helplessness, although it preserves self-esteem"

"Instead of antiviral agents, therapeutic success should result from reducing avoidant behaviour....In practice this can involve using the techniques of cognitive behaviour therapy"

"The...variable associated with a poor outcome was the strength of attribution to a physical cause"

"There was a trend for patients positive for this group specific enteroviral antigen (ie.VP1) to do worse, although this did not reach conventional statistical significance"

"We have shown that for patients suffering from CFS.....many were able to resume their occupations or...return to previous levels of functioning"

"The balance between physical, psychological and social factors changes over time.... Our results are compatible with current theories on either a viral or immune precipitant"

(Note: in the above paper, a slight sea-change on the authors' part will not go unnoticed: not only was there an admission that those with a positive VP1 did not do as well in the study, (which is entirely in accordance with Professor Mowbray's dictum that those with a positive VP1 are more chronically ill -- personal communication 1989) but it is accepted that a viral or immune precipitant, as distinct from an aetiological psychiatric one, is possible. Whilst Wessely has often argued that even if a virus were to be the precipitating cause, he has previously argued that a virus is not the perpetuating cause of long-term illness in ME).

1991


"The role of neuromuscular disorder in the pathogenesis of CFS is becoming clearer, although areas of disagreement remain"

"Studies of dynamic muscle function have demonstrated essentially normal muscle strength, endurance and fatigability, other than as a consequence of physical inactivity....despite claims to the contrary, it has been impossible to find evidence of delayed fatigability"

"Wessely and Powell...found that 72% of a consecutive series of chronically fatigued patients seen at the National Hospital in London fulfilled Research Diagnostic Criteria for psychiatric disorder even if fatigue
was excluded as a symptom....The diagnoses vary, but depression is the commonest, followed by anxiety disorders...and somatisation disorders"

"There is an increasingly complex literature on possible serological abnormalities in CFS....It is now clear that these require re-evaluation....as many believe that any such association in chronic illness are...artefactual"

"A recent case control study demonstrated the unreliability of serology, and concluded that enteroviral serology has little place in the diagnosis of CFS. The implication is that a number of previous reports linking exposure to Coxsackie virus in CFS are unreliable....Serdipity continues to play a role in medical research"

Referring to virological studies: "Few details are given of psychiatric status in any of these studies (so) the clinical relevance of such findings can also be questioned"

"Why have there been such efforts to find a microbiological cause of CFS?"

"Other mysterious illnesses have been established as of infective origin, whilst the concept of an external agent is familiar one for both the doctor and patient, and can serve to preserve the patient's self-esteem and protect them from stigma"

"Potential immunological abnormalities in CFS are now attracting increasing attention, particularly in the USA....such as raised circulating immune complexes and decreased natural killer cells...(but) problems included poor attention to methodological detail, especially the control of confounding factors such as inactivity and psychiatric morbidity"

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

"Promising lines of inquiry include the role of antidepressants"

"Over investigation should be avoided...it may reinforce maladaptive behaviour".

1991


(Note: this is yet another lengthy essay which re-presents Wessely's -- by now somewhat stale -- views on the similarities between neurasthenia and CFS/ME).

"The similarities between neurasthenia and PVFS are inescapable, and authors are now beginning to draw on this legacy" (Wessely includes himself among these authors)

"...such observations demonstrate a familiar theme, how social prejudice influences medical thinking"

"As Shorter points out, 'physicians in these competitive profit making clinics were happy to comply with the patients' desire for face saving (organic) diagnoses'"

"It became increasingly difficult to deny the role of suggestion, of the doctor-patient relationship, upon which 'everything depends'"
"Neurasthenia was never accepted by the neurological establishment. The giants of the profession declared themselves against an organic view of neurasthenia, and in favour of psychological interpretations"

"The diagnosis (of neurasthenia) was made 'for the comfort of relatives and peace of mind of the patient', since it avoided the stigma of psychiatric illness"

"Statements such as...neurotic, neurasthenic, hysterical and hypochondriacal are, on the lips of the majority of clinical teachers, terms of opprobrium"

"30 years later the Spectator observed, neurasthenia was no longer 'interesting', it was 'discredited and disgraceful...shameful to confess'"

"In place of overwork came laziness, fecklessness, degeneration....Neurasthenia, once almost a badge of honour, was now considerably less praiseworthy -- in place of the hard-pressed businessman came the stereotype of the workshy labourer or the pampered hypochondriacal upper class female invalid"

"The view became widespread that 'all neurasthenic states are in reality depression'"

In his section on "The Emergence of Post Infective Fatigue Syndromes", Wessely states: "systematic studies first disproved persistence of the bacteria, and then provided evidence for a high rate of psychiatric illness in those affected. Sufferers were described as combining a high degree of conviction of physical illness with a reluctance to discuss emotional issues"

"One of the most popular characteristics of neurasthenia was of the body giving way under attack from outside....All these ideas reappear in the popular current theories on immune disorganisation, in which the new 'overload' is from viruses, pollution, stress..."

"Theories of immune dysfunction have achieved prominence in the USA, and alleged parallels between CFS and AIDS are frequently drawn by most of the popular books and the occasional professional"

(Nota: the popular books to which Wessely's reference in this text refers do not draw such parallels; this aspect has been addressed in more detail in the section above on Wessely's tactics).

"Just as neurasthenia highlights the perpetual battle between the organic and the psychological views, so does the story of ME"

"In 1970 two psychiatrists published a re-analysis of...the Royal Free outbreak...and reached an opposite conclusion-- the illness was contagious, but the contagion was an example of mass hysteria...McEvedy and Beard provided the most coherent account"

"Meanwhile, the nature of the illness was changing....Altered medical perception rather than a true increase in rates, was soon added to the list of explanations"

"The result, largely unnoticed, was a gradual, but profound, change in the character of the illness....Instead, persistent severe fatigue...increased in importance...to become the hall mark of the disease"

"Media coverage of ME became linked to other themes...and popular conditions like multiple allergy....Neither development was likely to attract professional support....This required serious research, which appeared from the Glasgow group, and a team at St Mary's Hospital Medical School....Their...significance lay in the respectability given to the condition"
"Indignation with the implications of a psychiatric label remains a motive for many professionals involved in ME....The difference is simply the status to be accorded to ME/PVFS"

"After dissent came dismissal....Clark called neurasthenics 'always ailing, seldom ill’ (and Urquhart said) 'the wealthy neurasthenic will be a useless, frivolous, noxious element of society'....At the Johns Hopkins Hospital 'the patient is treated by physicians....with ridicule or a contemptuous summing up of his case in the phrase 'there is nothing the matter, he is only nervous'....Jelliffe...a neurologist...described them as 'purely mental cases. Laziness, indifference, weakness of mind and supersensitiveness characterise them all. They are...ill because of lack of moral courage'"

"The story of PVFS...is a story of...how doctors view patients".

1991

The psychological basis for the treatment of CFS Simon Wessely. Pulse: Dec 14 1991 page 58. “Simon Wessely argues that the psychological approach is the only effective treatment for chronic fatigue syndrome”

"What exactly is CFS?...There is no proof that viruses cause the disability"

"We know the majority of patients fulfil criteria for various psychological disorders, mainly, but not only, depression.... We know fatigue is...not due to neuromuscular pathology....We...know the placebo response for any treatment in CFS is extremely high....Most people call antidepressants psychological....However they are viewed, they work (and are) effective...and they should be used"

"Many use other psychological treatments, such as cognitive behaviour therapy, that involves treating mood disorder, cognitive distortions and behavioural avoidance. Among these distortions is the belief CFS is untreatable and muscle pain means further damage"

"Psychological treatments...are sensible, safe and offer real hope...The future also lies with psychological therapy"

"The prognosis may depend on variables like mood disorder, maladaptive coping strategies, fitness, helplessness, and the attitude of family, friends and the medical profession".

1992


"At the turn of the century fatigue was almost an obsession....now, of course, fatigue and fatigue syndromes are undergoing a renaissance......a rapidly growing literature is emerging on all aspects of these 'new' diseases"

"Our views of this elusive, but disabling, condition, are currently in flux"

"At least seven studies have now confirmed that high rates of operationally defined mood disorders exist in hospital samples of CFS patients"

"Interestingly, evidence from other sources is...showing that although CFS does resemble major depression in many ways, and symptomatically may be indistinguishable, there are also biological
differences, including neuroendocrine function and event-related potentials. Previous views that CFS is simply a form of somatized depression are no longer tenable

(Note: another small sea-change by Dr Wessely seems apparent in the above Editorial).

1992

Eradicating 'Myalgic Encephalomyelitis' (ME) Report of the meeting held on 15th April 1992 at Belfast Castle, Belfast, Pfizer/Invicta Pharmaceuticals: pp4-5

(Note: the report of the promotion by the Royal College of Psychiatrists and Pfizer Pharmaceuticals to educate the public about mental disorder and its treatment (LINC-UP) carried an illustration of Dr Wessely delivering his speech standing at a LINC-UP podium at the Belfast meeting. Pfizer/Invicta Pharmaceuticals are the manufacturers of sertraline [Lustral], an antidepressant much advocated for use in CFS/ME).

"From the start the media has been intimately involved with the ME story...in fact for a long time most of what has been published on the subject has been found in the lay press and not in scientific journals, said Dr Wessely"

"...it seems that ME sufferers prefer to feel that they have a 'real' physical disease -- it is better for their self-esteem"

"The label ME helps legitimise their dealings with doctors"

"What is the pragmatic approach? Firstly, said Dr Wessely, the depression should be treated and inactivity should be addressed through a graded exercise programme".

1992


"Michael Sharpe and colleagues' paper (ref Sharpe, M et al: Follow up of patients presenting with fatigue to an infectious diseases clinic. BMJ:1992:305:147-152 18 July) suggests that membership of a self-help organisation is associated with a poor outcome"

"What are the possible explanations for these disturbing findings? Sharpe and colleagues suggest that patients' beliefs are an important mediator of disability, a view I share"

"It now seems that the evidence on which these beliefs (that persistence of enteroviruses in muscles is the cause...) is based is less than convincing"

"Previous work on enteroviral serology is now known to be unreliable"

"Most importantly, it seems increasingly unlikely that this condition results from any neuromuscular disorder, viral or otherwise"

"I hope that this more optimistic research (ie. that of Sharpe et al) will be publicised with the same vigour".
"The observation that...(some patients) were worse as a result of antidepressant treatment...brings into question Sharpe et al’s conclusion that 'such patients may be suffering from a depressive illness, of which physical fatigue is a somatic manifestation'....The problem with...research into the chronic fatigue syndrome is that...it covers a large heterogeneous group of patients....Researchers should therefore not be surprised to find that the outcome varies considerably when the aetiology is not more clearly defined"

"Michael Sharpe and colleagues...conclude that for patients with the chronic fatigue syndrome membership of a self-help organisation is associated with a poorer outcome”

“...a belief in the persistence of a viral infection (is) also associated with continuing disability”

“Unfortunately, such advice (to rest) continues to be offered to patients with the syndrome, particularly by self help organizations”

“It is to be hoped that all those caring for patients will take note of Sharpe and colleagues' conclusions”

“Work with fatigued patients in primary care suggests that general practitioners have a central role...by limiting investigations and referrals to specialist centres (and) prescribing antidepressants".

"The British organisations have long been unhappy with the way the media have portrayed the illness, and it is often extremely difficult to get erroneous or biased information corrected”

“The main reason why our beliefs tend to differ from those of Wessely and H. Cope and A.S. David is that the authors do not distinguish between myalgic encephalomyelitis and chronic fatigue and we do”

“We see (it) as more than 'mental and physical fatigue’”.

"...it is hard to avoid agreeing with the conclusion that the term ME 'was originally proposed by an unusually uncritical Lancet editorialist’

"I shall follow the international consensus and use the term...CFS"

"More attention is now being devoted to the illness that represents a more likely origin for ME/CFS: neurasthenia. The parallels...are striking"
"Mild immunological disorders are...encountered, but their significance is unknown...The immunologically naive reviewer is faced with...claim and counter claim"

"...the role of confounders remains relatively unexplored...there is nothing yet to allow distinction between cause and effect"

"Unless the undoubted technological brilliance of many of the studies now underway is matched by an equal attention to study design and interpretation, the result will not be clarification but more confusion"

(Note: it has long been Wessely's failure to select and study cohorts of patients with 'true' ME that has led to much animosity and consequent harm to patients).

"The precursor to CFS, neurasthenia, was eventually almost completely replaced by a variety of psychiatric diagnoses"

(In CFS) "the risk of psychiatric morbidity was at least twice that of comparison groups of patients with neuromuscular fatiguing illness or rheumatoid arthritis suggesting that the observed morbidity was not simply a reaction to physical ill health"

"It is possible that the division between the psychiatrist's mood disorder and the neurobiologist's CFS will be found to be more semantic than real, and there is an increasing consensus that there is a considerable overlap between severe depression and CFS"

"What is...important (to the patient) is the acknowledgment...that they are not malingering, or displaying low moral fibre"

“To do that, validation is needed from the doctor, and then social security, family, employers and so on”

“Once that is granted the patient may assume the privileges of the sick role (sympathy, time off work, benefits etc)"

"...it is my own impression that most patients now take some form of magnesium supplementation" (on what evidence does Wessely feel confident to make such a sweeping statement?)

"Two therapeutic approaches are successful. The first (is) antidepressants, and the second is...increasing physical activity"

"For patients presenting with chronic fatigue in primary care...psychiatric disorder is the commonest diagnosis".

1992

The epidemiology of fatigue: more questions than answers     G Lewis, S Wessely

"This paper reviews the epidemiology of fatigue in the general population and in primary care and examines potential sources of bias in hospital based studies"

(Referring to another author) "This paper promised to be a more direct and honest investigation of the previous 'bias in hospital based studies', but such initial hope was unfortunately not fulfilled”

"Fatigue, like many medical conditions, is best viewed as a continuum"
"We suggest that many patients currently labeled as having ‘chronic fatigue syndrome’ may not be cases of a discrete disorder, but instead may lie at the extreme end of a continuum that begins with the common feeling of tiredness"

"The probability of a psychiatric diagnosis increases with both the duration of fatigue and the number of associated symptoms"

"...there remain genuine contradictions in the literature. How have these arisen? Selection factors are probably the most important bias in these studies" (Note: the patient self-help organisations have been pointing this out for a decade)

"...studies...usually find a high prevalence of psychiatric disorder among those with CFS, confirming that physicians are poor at detecting such disorders"

"There is now a growing realisation that attempting to tease out multifactorial aetiologies will not be aided by excluding the psychiatrically ill from samples of CFS"

1993

Machines and diets can't help ME victims. Dr Simon Wessely. Evening Standard 18th May 1993, page 47

"Restrictive and expensive diets have never been shown to help the illness....There is no link between ME and...diseases of the joints such as arthritis -- ME sufferers certainly experience pain in their joints, but that is not arthritis. There is no evidence that ME has anything to do with diseases that cause permanent memory loss"

(Note: there certainly is evidence that the removal of antigenic challenges from the diet of someone with 'true' ME results in clinical improvement -- see Appendix I; moreover arthralgia -- pain in a joint without signs of arthritis -- is extremely common in ME, as Wessely accepts).

1993

Is cancer all in the mind? Simon Wessely. The Times, 22nd June 1993 page 17

Although not about CFS/ME, this article demonstrates Wessely's conviction that psychotherapy is paramount.

"There is little new in the suggestion that cancer has psychological origins. For many years it was thought that depression was a cause of cancer, although a recent...study...found no evidence for this, suggesting instead that depression is an early sign of cancer”

“(A researcher undertook) a clinical trial, in which people identified as having the cancer-prone personality were divided into two groups. One received a form of psychotherapy designed to alter their personality....Group therapy...seemed to prevent cancer”

“The literature on the psychological causation of cancer is complex and contradictory”

“Of greater concern is that this affair has drawn attention away from the real progress that has been made in the psychological management of cancer....British psychiatrists...have shown the effect of coping strategies on the prognosis of breast cancer”
“It may be more rewarding to concentrate on providing better psychological care for those with cancer”.

1993

Why ME is not all in the mind  Simon Wessely. The Times, 27th July 1993 page 15

sub-headed: "Doctors get an unfair press when treating chronic fatigue syndrome"

"Sunday's edition of Frontline (Channel 4)...concerned the illness known to sufferers as ME, to doctors as CFS and to journalists as 'yuppie flu' “

“Viewers were told the awful story of a young boy with ME, unable to speak or move, taken from his family by social workers on medical advice, and subjected to such indignities as being thrown into a swimming pool to see if he would swim”

“There is another version which throws a different and more complex light on these matters. The programme failed to mention that the events surrounding the boy had been subject to an enquiry, summoned by the Manx government, to investigate the same allegations so graphically described by Channel 4”

“The enquiry published a 164-page report a year ago….The enquiry said that all the professionals involved (including, on one occasion, myself) had acted correctly, indeed, with care and compassion. Doctors and social workers were praised, rather than criticised” (note: as mentioned above, this does not accord with the written evidence, which was that: “It seems to be generally agreed among those who have made a study of ME that patients should never exceed their physical or mental limitations. Attempting more active exercise or active physiotherapy (which is recommended by some doctors) will only exacerbate the condition….This Committee...cannot find that the case conference was acting appropriately or in the best interests of Ean”. Report of the Tynwald page 17:4:6).

"It is far from proven that (ME) is due to a virus, and extremely unlikely to be due to an allergy"

“IT is true that many doctors feel that psychological factors are of considerable importance, confirmed by a surprisingly unanimous research literature”

“The rates of psychiatric disorder in those with physical illness are three times higher than in those without”

"In Britain, five clinical trials are in progress, led by psychiatrists”

"It is ironic that critics of medicine frequently call for doctors to be better listeners and better able to empathise with their patients...These are precisely the skills necessary for a successful psychiatrist”.

The following responses to Wessely's article were published by The Times on 2nd August 1993

(i) From Mr Hugh Faulkner

"It is understandable that Dr Simon Wessely...in referring to the Channel 4 programme 'Frontline' (July 24) which discussed myalgic encephalomyelitis, should seek to defend the doubtful action of the social services in one case in which he was involved, but sufferers from this devastating disease have in the past been given a bad time by the medical profession. Persistent virus disease has been recognised as an organic disease by our Department of Health and by the World Health Organisation".
(ii) **From Dr Charles Shepherd**

"Dr Simon Wessely errs if he assumes that the ME Association's criticism of psychiatrists and strange forms of behaviour therapy (eg. throwing a patient into a swimming pool to see if he sank or swam) is...intended to stigmatise people with psychiatric illness. Our dispute is principally with those doctors...who continue to deny the genuinely debilitating and distressing nature of this syndrome".

(iii) **From Mr Nicholas Anderson**

"ME is a distinct clinical entity recognised as such by the World Health Organisation...and is not the same as chronic fatigue syndrome (CFS). Medical research may be 'surprisingly unanimous' in detecting depression in a high proportion of CFS patients but it is equally surprisingly unanimous in recording relatively low rates of depression in ME sufferers...If only 50 per cent of Dr Wessely's psychiatric colleagues believe that ME has an organic basis...presumably the remaining 50 percent are either 'don't knows' or wedded to the psychiatric hypothesis".

(iv) **From Mrs P. O'Connor-Lintott**

"By the time I was diagnosed, by a consultant virologist...I had lost all that was dear to me in terms of job, home and mental security, family and friends. Now, at 49 years old, I am reduced to living in warden-controlled pensioners' accommodation.... From being a successful teacher...I now manage a few sessions a week of voluntary work. I am convinced that it would have been a different picture had my original GP taken me seriously at first when I was happy, secure and stable but felt so dreadfully ill nonetheless".

(v) **From Ms Sarah David**

"I have had ME for twenty years and have yet to meet a DSS doctor who doesn't advise me to go to yet another psychiatrist or make me feel like a parasite. I spent five years in my bedroom, barely able to move. In my experience, most doctors listen but do not believe. Sadly, nothing in Dr Wessely's article suggests that things are about to improve".

1993

*The power of the placebo*  Simon Wessely.  *The Times*  3rd August 1993  page 13

This article is not directly about ME, but is relevant to this text.

"Boots yesterday launched a new range of over-the-counter homeopathic remedies....Conventional doctors remained sceptical. John Garrow, Professor of Nutrition at St Bartholomew's Hospital and Chairman of Healthwatch, pointed out that none of these preparations had been tested in a clinical trial"

"Scientific wisdom remains that homeopathy is itself a placebo"

"If homeopathy is a placebo, why is it increasingly popular? There are several reasons. Placebos work"

"As a psychiatrist I have one further concern. Research has consistently shown that patients who turn to homeopathy are likely to...have below average emotional health. Perhaps the main attraction of homeopathy is that it enables such people to seek help free from the stigma of mental illness"
(It will be recalled that the Queen and members of the Royal family have used homoeopathic remedies for many years; it is said that both the Queen and Princess Anne always take a homoeopathic emergency kit on their foreign tours).

1993

Stand up and be healed  Simon Wessely  The Times  24th August 1993 page 13

Again, this article is not directly about CFS/ME, but Wessely's theme runs unmistakably through it.

"Last week I went to the Earl's Court exhibition centre to hear Morris Cerullo, the American evangelist whose posters promising miraculous healing have been spread around London....The most common explanation for miraculous cures is that the person who was cured never had that particular disease in the first place....The interpretation of a shadow on a X-ray, or of cells under a microscope, is a matter of judgment....In my clinical practice I see patients whose notes and letters state that they have been diagnosed as suffering from a variety of serious diseases....On reading the file in detail one finds the diagnosis was often made many years ago by a busy junior doctor and never subsequently challenged....These patients may experience genuine symptoms such as chest pain or palpitations, the results not of chest or heart disease, but psychological disorders such as depression or anxiety"

“Classic Freudian teaching calls this hysteria”

“Modern neurology cannot cure those with hysterical symptoms”

“A condition which, like hysteria, depends upon an idea of illness, could respond to Mr Cerullo's exhortation”.

1993

Camera lights, action for ME  Anthony David  BMJ 1993:307:688

This is not written by Wessely but by psychiatrist Anthony David, his co-author and collaborator; it is of interest because the BMJ chose a reviewer who has not yet published any research on ME (fatigue is not ME), and who has shown a clear preference for psychiatric explanations postulated by his close associate. The article purports to review the programme called “Wide-eyed and Legless” shown on BBC 1 (Screen One) on 5th September 1993, which was about Diana Longden: Dr David's piece contains numerous inaccuracies and the disparaging approach is inescapable.

Don't swallow the myth  Simon Wessely  The Times 14th September 1993 page 16

This item formed part of a full page spread devoted to ME; the sub-heading of Wessely's article is “Too much ME propaganda spreads despair, argues Simon Wessely”

As in the item by Dr David in the BMJ, Wessely is giving his opinions about the same TV programme (Wide eyed and Legless).

"As is usual when anyone deviates from the party line on ME, I spent a sleepless night anticipating the inevitable hostile barrage of letters”
"I needn't have worried. Points of View ignored my comments, preferring instead letters praising the production....It was a bleak portrayal of relentless disability. Epilepsy has nothing to do with ME....claw hands...are not part of ME"

“There is no evidence of inflammation of the brain or spinal cord”

Most important of all, ME is not, and cannot be, fatal”

“The only cause of death in sufferers is suicide”

“The play (contained) the obligatory swipe at psychiatrists who, in the world of ME, are always ignorant, insensitive and only interested in imaginary diseases”

“Studies are emerging that suggest that antidepressants are effective even in sufferers who are not depressed”

(Note: seizures are in fact documented as part of the symptom complex, as are claw hands in severe cases; patients with ME have certainly died as a result of cardiomyopathy and pancreatitis; indeed, Brynmor John, MP for Pontypridd, who had been diagnosed as having ME (Hansard, 23rd February 1988:167-168) collapsed on Westminster Bridge after exercising in the House of Commons gym that same morning; he died in St Thomas’s Hospital at 17.35 on 13th December 1988, having been following advice given to him by a Cardiff consultant that he should exercise back to fitness).

An illness that starts in the mind  Dr Thomas Stuttaford. The Times (ibid)

"In the case of ME it is the patients with an intense interest and knowledge of their own symptoms...who have fought to have ME acknowledged”

“They have done so with no scientific foundation on which to rest this knowledge”

“Even before ME became a fashionable diagnosis, it was difficult for doctors to persuade patients that depressive illness is often associated with bodily symptoms”

“Many patients who are depressed prefer...to attribute their problems to the worsening of any physical signs or symptoms...rather than to acknowledge that they have a psychiatric problem”

Depression and ME  Nicholas Anderson, Director, Action for ME (response published in The Times on 21st September 1993 page 17)

"Since Dr Stuttaford prefers the "depression" theory of ME...and Dr Simon Wessely specialises in chronic fatigue, the reader may be left with the impression that ME 'starts in the mind' as the headline to Dr Stuttaford's article put it. However, several recent research studies have shown that the level of depression found in ME sufferers is no greater than in those suffering from cancer or multiple sclerosis”

“That Simon Wessely has apparently not encountered ME patients who have had epileptic fits or 'claw hands' perhaps demonstrates that being expert in chronic fatigue is not the same as being expert in ME”.

A further letter which was sent to The Times by Mrs Doris Jones MSc was not published; this letter made the point that a true scientist should always question the correctness of his knowledge and judgment, and that he should also be aware of continually changing findings, especially in medicine. The letter also said:
"Dr Wessely's comments on the 'myth' which in his view is now spread about ME are merely an extension of his favoured belief that ME in essence is just another depressive disorder, treatable and curable with antidepressant drugs....He is incorrect in saying that the fate of the heroine in "Wide-eyed and Legless" does not represent a true picture. I know several who are as badly affected. It seemingly does not occur to Dr Wessely that the very drugs he so fervently advocates as a treatment for ME may in fact make the condition worse for some subjects. Perhaps it is time for Drs Stuttaford and Wessely to upgrade their information".

1993

The psychology of multiple allergy   Louise M Howard   Simon Wessely

(Note: allergies, hypersensitivities and widespread intolerances are recognised and well-documented feature of 'true' ME although not of fatigue; although not an immunologist, Wessely takes a different view of these symptoms).

"Many people present to their doctors with multiple unexplained symptoms which they attribute to allergy. Such subjects develop symptoms in response to many substances including foods and chemicals and therefore avoid contact with them"

"Those at the extreme end of this range often attract a diagnosis of total allergy syndrome, multiple chemical sensitivity, or environmental illness --diagnoses that most allergists or immunologists repeatedly reject"

"These patients have no consistent...immunological abnormalities"

"If the problem is not one of allergy, then what are the possible causes? Research has shown the relevance of psychological disorder"

"A recent study...confirmed that...psychological symptoms were a central component of chemical sensitivity"

"...the high prevalence of psychiatric disorder suggests that psychological factors must be relevant. A history of psychiatric morbidity predating exposure to chemicals...and the onset of sensitivity to chemicals has been found to predict the development of multiple chemical sensitivity"

"The overlap between psychiatric disorder and environmental illness is unsurprising. Almost by definition, patients who claim multiple allergies suffer from multiple somatic symptoms that conventional medicine cannot explain"

"One of the strongest findings in psychiatric epidemiology is that the risk of psychiatric disorder increases linearly with the number of symptoms with which patients present"

"Possible aetiological factors include...over-protective parents"

"Simon et al suggest that patients with "allergies" may have an underlying trait of symptom amplification"

"A subculture seems to have developed around these ‘allergies’....This subculture may be psychologically important to patients for many reasons, such as legitimising distress, avoiding stigma, allowing escape from an intolerable situation"
"Self-diagnosis frequently changed between multiple chemical sensitivity, the total allergy syndrome, the chronic fatigue syndrome, candidiasis and food allergy"

"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 any moral sanction"

"Sufferers from mysterious conditions 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"

"Total allergy syndromes may be regarded as cultural syndromes"

"Several reasons exist for concern about the increased prominence afforded environment illness and clinical ecology. Treatment usually entails some form of avoidance"

"Treatments for such conditions as depression and anxiety may be neglected"

"Whereas a diagnosis of allergy leads to avoidance, modern psychological treatments are...based on exposure"

"If symptoms result from anxiety, panic or phobia but patients are treated as if they are sensitive to some aspect of their environment...the unintended result may be to reinforce maladaptive behaviour"

(see Appendix II: "Remarkable Coincidences, Scientific Antics or Deliberate Diversionary Tactics?"; see also Appendix III "Book Review: Toxic Psychiatry").

Whilst Wessely et al are confidently dismissive about any possibility that unexplained "allergic" symptoms might well be due to a silent but organic pathoaetiology, others are rather more judicious. Perhaps of some relevance in this context is a paper which was published in The Lancet entitled "Does cryptic gluten sensitivity play apart in neurological illness?" (M Hadjivassiliou, AGibson, G A B Davies-Jones et al: Lancet February 10th 1996:347:369-371). This paper, by doctors from the Royal Hallamshire Hospital, Sheffield, reports data which suggest that an undiagnosed allergy to wheat, barley, oats and rye (ie. gluten) is common in patients with neurological disease of unknown cause, and that it may well have aetiological significance.

Many neurological manifestations are known to be associated with coeliac disease; such symptoms include muscle weakness, poor co-ordination, poor balance, and peripheral neuropathy. The Sheffield study found that nearly three fifths of the patients with unexplained neurological symptoms had antigliadin antibodies to gluten in their blood, yet none had been diagnosed with overt coeliac disease (symptoms of which include diarrhoea, flatulence and bulky stools). However, on biopsy, when samples of tissue were removed from the gut, more than a third of these undiagnosed coeliacs showed clear evidence of the disease, including inflammation of the gut. The presence of antigliadin antibodies are now believed to be directly involved in the neuropathological process, possibly as markers of autoimmune activity.

Without testing for these antigliadin antibodies, it would not be unimaginable that an unwary psychiatrist might ascribe the unexplained muscle weakness and poor balance and incoordination as being due to aberrant thought processes or to altered medical perception, or even as being due to "anxiety, panic or phobia", because the search for causes of neurological dysfunction in coeliac disease have largely ignored the immunological aspect.
As far as ME is concerned, it will be recalled that Wessely et al are strongly against any immunological investigations, preferring instead to prescribe antidepressants, yet ME has many unexplained neurological manifestations and also shares many features of gut disturbance with coeliac disease; in ME, for instance, there is known pancreatic exocrine insufficiency, which is an established consequence of enterovirus persistence.

Also of relevance is the reply by Michael J Radcliffe, Pamela Ashurst and Jonathan Brostoff to Howard and Wessely's article on the psychology of multiple allergy, which was published in the Journal of the Royal Society of Medicine, although not until 1995 (Unexplained illness: the mind versus the environment Michael J Radcliffe, Pamela Ashurst, Jonathan Brostoff: JRSM 1995:88:678-679). Professor Brostoff has long taken issue with views which are overly dismissive of immunological deficits, and his reply contained the following:

"In psychiatric practice, the mere absence of an organic cause of disease is often regarded as adequate reason to invoke a psychological mechanism"

"This action precludes the possibility of any other diagnosis, and thus constricts therapeutic management to the psychiatric realm"

"Such psychologisation of illness is commonplace, overworked and infrequently challenged. This highlights the longstanding controversy over multiple allergy and the role of psychiatric disorder"

"The medical profession tends to dismiss the patient's reality if it doesn't fit in with currently accepted medical wisdom"

"This psychological language ....tends to preclude the possibility of any somatic or environmental explanation"

"The influence of food on organ systems has...been clearly shown in a number of studies where the definitions and application of a compatible diet by rigorously applied methods of dietary elimination...has reproducibly secured remission in irritable bowel syndrome, Crohn's disease, hyperactivity, migraine and rheumatoid arthritis"

"Many of the common diseases which respond (to dietary elimination) do so with resolution also of many of the 'soft' symptoms (which lead to the application of concomitant psychiatric labels) as well as the... 'organic' symptoms (which define the organic condition). This observation tends to raise serious doubts about the intrinsic validity of...psychiatric labels in such cases"

"Man's capacity to make dramatic technological advances has created an illusion of power and control over environmental forces which increases our problems of understanding"

"Our failure fully to appreciate the role of the environmental factor in disease, and to conceive that this may potentially contribute to ill-health and frank disease may well be a source of wonder to future generations of medical practitioners".

Unsurprisingly, Howard and Wessely responded to the above reply; their response was published in Journal of The Royal Society of Medicine: Unexplained illness: Louise Howard, Simon Wessely: March 1996:89:180)

"We agree with Radcliffe et al...that there is a tendency within the medical profession to dismiss a patient's reality if it does not fit in with medical knowledge"
"Radcliffe and colleagues might argue that depression or anxiety disorders arise secondary to a disorder provoked by an environmental agent, but our point is that what is most important is that these psychological problems respond well to treatment largely irrespective of the initial trigger"

"This observation leads us to our principle objection to the thesis proposed by Radcliffe and colleagues. When working with patients with multiple symptoms and long durations, our biopsychosocial perspective emphasizes that what starts a disorder may not be what perpetuates it"

"In those conditions that lie in the area between medicine and psychiatry, be it multiple chemical sensitivity...or chronic fatigue syndrome, the evidence to date supports a model that treating perpetuating factors (such as depression, activity avoidance) is usually more successful than treating any presumed trigger factor"

"Psychological factors such as mood and anxiety are important, but perhaps even more important are the cognitive, interpersonal and behavioural responses"

"Furthermore, treating patients using interventions derived from these empirical observations appears safe and cost effective".

This correspondence continued to be run by the JRSM, and a valid contribution was made by Dr V Rippere, whose letter was published in the July 1996 edition (volume 89: 419):

"The debate on whether mind or environment causes unexplained illness...takes the categorization of illness as 'unexplained' for granted"

" 'Unexplained illness' arises less from patients' minds or environments than from the conjunction of clinicians' diagnostic nihilism with lax quality standards for diagnosis that permit its indulgence"

"Quality standards are as necessary for excluding an organic diagnosis as they are for making one"

"Having to provide...an explicit, objective, accountable basis for excluding an organic diagnosis would wonderfully concentrate clinicians' minds. Statements would expose shortcomings in their diagnostic performance and enable patients to challenge premature relegation to diagnostic limbo"

"A further standard could do the same for less obvious medical -- including environmental -- causes that are commonly overlooked"

"If such standards were combined with quality standards for psychiatric diagnosis, specifying that these be made on positive grounds, not by exclusion, and that primary symptomatology be clearly distinguished from secondary symptoms reactive to illness...there would be little 'unexplained illness' and less to debate."

1993

Don't Dismiss Exercise   Trudie Chalder and Alicia Deale. Nursing Times
20 October 1993:89:42:22-23

The authors are both Registered Mental Nurses who work and co-author papers with Wessely; their letter in the Nursing Times states: "There is no convincing research which shows that ME differs from CFS"
“The World Health Organization has classified ME as an organic brain syndrome. However, reviews of laboratory-based research have yielded little conclusive evidence to support this” (note: one reference quoted here is by Wessely)

“To suggest that rest gives a degree of recovery ... in patients with ME is frankly misleading”

“It has been suggested, even in patients with a recognised muscle disease, that two or three hours of standing and walking should be carried out daily”.

Gill Dakin’s reply was published (ibid)

"The World Health Organisation did not base its decision on the research on fatigue syndrome, which it decided to classify under psychiatric disorders”

“The US and UK criteria for CFS do not insist on evidence of CNS involvement or the presence of marked fluctuations, both of which are considered characteristic of ME”

“As for the evidence of ongoing disease, the last six issues of the IFMEA Medical Update... indicate that since January 1992, there have been over 30 separate published studies in medical journals giving details of abnormalities consistent with an organic aetiology”

“Most of those studies were controlled, and many revealed significant differences between ME and major depression”

“In terms of therapy, an elegantly designed controlled trial from Australia revealed that graded exercise and cognitive therapy were no better than clinic attendance”

“The London and Oxford studies have not limited themselves to patients with ME”.

1993


"Just as chronic fatigue syndrome is one of the successors of neurasthenia, so is Jay Goldstein a successor of the Victorian neurasthenia specialists"

"Goldstein is committed to a biological reductionism that has always pervaded the world of chronic fatigue"

"Unlike some chronic fatigue syndrome specialists, who seem to regard antidepressants as suitable only for the morally infirm, Goldstein has a detailed knowledge of their psychopharmacology"

"Like many Victorian physicians, Goldstein knows in his heart that his success in treating patients with chronic fatigue syndrome depends not upon his cornucopia of remedies, but on a far older drug-- himself"

"Goldstein uses the jargon and concepts of neurobiology and immunology (and)... links... the popular concept of stress with the current obsession with immunology”.

A clinical psychologist who specialises in ME sent a letter to The Lancet:
"I was astonished to read (Bookshelf) that 'some chronic fatigue syndrome specialists...seem to regard antidepressants as suitable only for the morally infirm'. I have been studying ME and chronic fatigue syndrome for ten years and I have yet to come across a health care professional who holds such...views. If Dr Wessely's claim is based on accurate information, then perhaps he should notify the relevant authorities and allow them to check these specialists' competence. However, if he cannot substantiate these allegations, then Dr Wessely owes his colleagues an apology".

Naturally, the letter was not published, but it did bring the valid points it contained before Assistant Editor level.

1993


(Note: this letter has been referred to above but deserves more detailed consideration. It is a determined attempt to pour scorn on the WHO's formal classification of ME).

"Sufferers pleased to avoid the imagined stigma that a psychiatric diagnosis might carry will nevertheless balk at the inclusion of benign in the title"

"There is no evidence of an inflammatory process affecting the central nervous system"

"Instructions urge clinicians to record whether the syndrome develops in the aftermath of physical illness, especially viral infection, yet postviral fatigue syndrome is given as an exclusion criterion. Thus, the two definitions, though identical, are mutually exclusive"

"CFS avoids artificial separation between mental and physical symptoms"

"The WHO may have made use of converging case definitions from both the Centers for Disease Control in the US and the Oxford criteria from the UK, which have proven reliability as well as clinical and research usefulness"

"Considerable research effort has yet to identify any grounds for separating postviral...fatigue, including ME, from the broader CFS other than what sufferers call their condition".

(It will be recalled that in their published letter, Drs David and Wessely also stated:

"The inclusion in the tenth revision of the International Classification of Diseases (ICD 10) of benign myalgic encephalomyelitis as a synonym for postviral fatigue syndrome under Diseases of the Nervous System seems to represent an important moral victory for self-help groups in the UK...it is unlikely to lead to advances in our understanding of the condition....The nineteenth century term 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....We believe this latest attempt to classify fatigue syndromes will prevent many people from seeing the world as it actually is".

A member of the UK ME Association, Mrs Sandra Howes, wrote a letter which challenged Wessely's overzealous assertions, writing to the Editor of The Lancet (Lancet 1994:Jan 22:343:243) as follows:
"I would challenge David and Wessely's statement that the Oxford criteria have 'proven reliability'. I am not aware of any research which supports this view and indeed, the only published report on the subject concluded that it had 'relatively poor predictive validity' "(Definition of chronic fatigue syndrome. Lynch S, Main J and Seth R. Br.J.Psychiat 1991:159:439-440).

Of particular interest is the fact that IFMEA contacted the American Psychiatric Association (APA), who confirmed that ME has not been added to their updated list of psychiatric disorders contained in DSM IV. The APA's refusal to add ME to DSM IV means that none of the officially recognised classification systems regard ME as a psychiatric disorder.

1994

A cognitive behavioural approach to Chronic Fatigue Syndrome. Ms Alicia Deale, Principal Nurse Therapist and Dr Simon Wessely, Senior Lecturer in Psychological Medicine, King's College Hospital School of Medicine. The Therapist: 1994:2:1:11-14. Sub-headed: "In 10-20 sessions of therapy, most ME sufferers are well on the road to recovery say authors."

(An immediate question arises: how many sufferers of ME are there in the UK and what percentage of them are simply too ill to participate in such 'therapy'? )

"Cognitive behavioural therapy (CBT) has been used successfully in many such conditions...more recently, the approach has been applied specifically to CFS, with encouraging results" (a Wessely self-reference is provided at this point)

"...some believe the cause to be a persistent viral infection, or a disorder of the immune system....Others view it as a depressive illness, best treated with antidepressant drugs....Behavioural, attributional and cognitive factors are central to the perpetuation of fatigue"

"Illness beliefs and fears about symptoms can influence disability....In CFS, unhelpful illness beliefs include fear that any activity which causes an increase in fatigue is damaging....Increased concern leads to heightened awareness...and 'body watching', which in turn can intensify...the experience and perceived frequency of symptoms, thereby confirming illness beliefs"

"In particular, depression and anxiety produce physiological changes including increased fatigue and muscle pain....It has also been suggested that the...apparently uncontrollable symptoms of fatigue and myalgia engender a state of 'learned helplessness' (a further self-reference by Wessely)

“It is important to note that the rates of depression and anxiety in CFS are far too high to be explained solely as a reaction to chronic illness"

"Cognitive behavioural understanding of CFS...suggests ways in which (perpetuating factors) may interact in self-perpetuating vicious circles of fatigue, behaviour, beliefs and disability" (another self-reference)....Increasingly we find that many patients also gain considerable benefit from antidepressant medication"

"The process of rationale giving may take place over several sessions, as few clients are 'converted' immediately" (a consultant NHS psychiatrist has likened this technique to "brainwashing")

"Clients and their families often read widely on their condition-- it is therefore useful...to correct any misinformation"

“Family and friends...may...act as powerful reinforcers of dysfunctional illness beliefs"
"The client may also need reassurance that there is now little doubt that neuromuscular function is normal in CFS -- ie. that the fatigue is not due to muscle disease"

"The final phase of therapy involves transferring more responsibility for treatment to the client”

“For many sufferers, it is a road back to normal life".

1994

Neurobiological aspects of the chronic fatigue syndrome   J Bearn & S Wessely

(Note: this is another very lengthy essay which again relies on Wessely's often repeated personal view. The extent of his repeated statements is crushing; in order for the effect of this 'brain washing' to be fully appreciated, it is vital that the articles are read in full. As is customary in papers by Wessely, this paper contains many self- references).

"Most of the difficulties in this difficult subject can be traced back to a key issue -- that of case definition"
(note: Wessely repeatedly highlights this problem correctly, yet in his own work he continually departs from the WHO classification, confounding the problem)

"It has been argued elsewhere (self-reference) that the origins of chronic fatigue syndrome lie in the condition known to the Victorians as neurasthenia"

"Chronic brucellosis was another common neurasthenic diagnosis.....Systematic studies first disproved persistence of the bacteria, and then provided evidence for a high rate of psychiatric illness in those affected. Sufferers were described as combining a high degree of conviction of physical illness with a reluctance to discuss emotional issues. Once this evidence became widely disseminated, chronic brucellosis disappeared” (another a self-reference)

"Nevertheless, the tendency to link formerly neurasthenia and latterly CFS with each new organism is unstoppable"

"In the United Kingdom initial attention was given to the enteroviruses...as the original evidence implicating the enterovirus family is now seen as faulty, these latest sophisticated studies, if correct, must be considered serendipitous"

“Another problem preventing acceptance of the role of infective agents in the aetiology of CFS is the absence of conventional signs of inflammation and tissue damage....Even if the cell appears intact (when the virus evades the normal immune response) it remains essential to show its function is altered”

“Decrease in muscle protein synthesis (has) been demonstrated, but the significance is unclear”

"It is now beyond dispute that patients with severe chronic fatigue are at high risk of psychosocial morbidity. It is a matter of regret that each generation of physicians appears to need to discover this afresh"

"The greater the number of associated symptoms, and the greater the severity of fatigue, the stronger the link with psychiatric disorder" (another self-reference)
"Studies using Single Photon Emission Computed Tomography (SPECT) reveal a range of abnormalities including frontal and temporal hypoperfusion and basal ganglia abnormalities...from which no clear pattern emerges"

"Cortical evoked potentials...were normal in patients diagnosed as suffering from 'ME'"

"It is notable that the HPA dysfunction described in patients with CFS contrasts with that found in depressed patients, and so fails to support the hypothesis that CFS is fundamentally a clinical variant of depression....It is hard to acknowledge that depression and CFS are categorically completely distinct"

"The increasingly complex literature on immune function and CFS is fraught with inconsistencies"

"The concept of immune dysfunction is, however, a popular one with many cultural resonances, especially in the USA"

"A recent report of immune activation in major depression had many similarities with findings in CFS -- the most notable difference between the studies was the publicity accorded to the latter and not the former"

"There is increasing evidence for a neurobiological basis to CFS, accruing from neuroendocrine, neurochemical and immune studies, which corroborate the close link between CFS and depression"

“These confirm a close link between disorders of chronic fatigue and disorders of mood...one implication is that antidepressants might have a role in the management of CFS"

"It is still unclear whether or not CFS is a different nosological entity from extreme fatigue (another self reference)....In whatever setting patients with fatigue syndromes present...psychiatric disorder is the commonest diagnosis"

"Over-investigation should be avoided. Not only is it a waste of resources, it may not be in the patients' interest, and may reinforce maladaptive behaviour in a variety of ways"

"Some of the current research into CFS...is...motivated less by a desire to understand the illness, and more by a need to establish a spurious organic authenticity".

(Note: this paper is of some interest, as it admits and accepts what are clearly "organic" malfunctions in this group of patients, but then every effort is made to dismiss the significance of these findings; it is not difficult to ascribe to each author the relevant sections in this paper).

1994


(Note: This study illustrates particularly well how determinedly Wessely obfuscates case definitions: it would appear that the patients studied did not suffer either from ME or even from CFS).

"Establishing the clinical relevance of hyperventilation to CFS is...important... We studied 31 consecutive attenders...to a clinic specialising in chronic fatigue syndrome run by SW”

“53% belonged to a self-help organization"
"Seventeen (77%) of these patients had no other apparent medical conditions and reported no symptoms other than chronic fatigue" (note: in which case the patients did not suffer from ME)

"Our results suggest that the link between hyperventilation and chronic fatigue syndrome is weak"

"Our results do not support a role for hyperventilation in the aetiology of CFS as previously suggested" (Note: while this is an unsurprising result, the study clearly demonstrates that Wessely, an epidemiologist, fails to make any attempt at case differentiation).

1994

**Chronic fatigue syndrome: a follow up study**  D Bonner, M Ron, T Chalder, S Butler, S Wessely  JNNP 1994:57:617-621

"Forty six of 47 patients diagnosed as having chronic fatigue and offered treatment four years previously were followed up. Twenty nine patients were interviewed.... These patients were initially assessed before the current criteria for chronic fatigue syndrome became available, but most would have satisfied the criteria retrospectively....Treatment (had) followed cognitive behavioural principles”

"Ten of 29 patients interviewed continued to fulfil the criteria for chronic fatigue syndrome at the four year follow up. Of these seven also had an RDC (research diagnostic criteria) psychiatric diagnosis"  

"Of the five patients who did not successfully complete treatment, none had spontaneously improved at the four year follow up....Nine out of the ten patients with chronic fatigue syndrome attributed their illness to a physical cause"

"One patient had recently been seen at the National Hospital for Neurology and Neurosurgery for a disability allowance appraisal...Her original diagnosis of somatisation had been changed to one of hysterical conversion disorder”

"(In the case of one non-responder) the general practitioner had asked for the patient to be removed from his practice because of non-compliance with treatment. The patient was still confined to a wheelchair when the general practitioner last saw him two years previously"

"It is hoped that the findings presented here will shed some light on the long-term prognosis of chronic fatigue syndrome and the long-term effects of treatment of a kind which is now commonly used in these patients"

"The issue of disability payments for patients with chronic fatigue syndrome is currently receiving attention and is the subject of controversy. Our results highlight the long-term benefits that may result from treatment"

"The prognosis of severe chronic fatigue syndrome appears to be associated with psychiatric morbidity and in particular depression"

"It has been postulated that in some patients persistent fatigue may be initiated by an acute viral infection”

“Symptoms...are then perpetuated in the psychologically vulnerable by relevant psychological factors”
"Those who had a good response to treatment did not change their attribution over the years. In other words patients still believed they had postviral fatigue syndrome/chronic fatigue syndrome/myalgic encephalomyelitis even after their recovery".

1994

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

“Most doctors in hospital medicine will be familiar with patients who complain...about a wide variety of symptoms but whose physical examination and investigations show no abnormality. Numerous and mainly perjorative terms to describe these patients and their symptoms will be found in their notes, eg. difficult, factitious, functional, heartsink, hysterical, hypochondriacal, Munchausen, malingering and supratentorial"

"Patients with medically unexplained symptoms or syndromes...lack a natural constituency as regards classification"

“Their 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"

"Care of these patients is hampered by the attitudes of both clinicians and patients....Patients with inexplicable physical symptoms are usually strongly resistant to any psychological interpretation....Many doctors share the same prejudices, as witnessed by the following recent referral from a consultant physician: 'Please see this patient with ME. There is nothing wrong with her' "

Patients with FSS (functional somatic symptoms) will frequently not only be seeing their GP and several different NHS specialists but also consulting private doctors and practitioners of alternative medicine"

"The management of a 54-year-old woman with chronic FSS was co-ordinated by a consultant psychiatrist...who contained her 'doctor shopping' and requests for investigations"

"A controlled study in the USA showed a significant reduction in health care charges...when physicians were advised by a psychiatrist on appropriate management along the lines that we have described"

"Patients with FSS ...are generally viewed as an unavoidable, untreatable and unattractive burden".

1994

A way out of great despair     Simon Wessely.   The Times 8th March 1994  page 17

"In this country there are many studies to show that general practitioners fail to diagnose correctly about half of their depressed patients. This is because most sufferers present not with obvious signs of low mood, such as...excessive guilt, but with...symptoms such as insomnia, pain, headache and exhaustion"

"The first step is for both sufferers and doctors to recognise the possibility of depression. The diagnosis is usually easy, provided the doctor remembers to ask the relevant questions. The Royal College of Psychiatrists and The Royal College of General Practitioners, together with the Department of Health, who
are leaders in the Defeat Depression Campaign, are working to help doctors improve their skills in detecting depression"

"Many patients will be prescribed anti-depressants. There are now thousands of studies showing they are effective"

"No single treatment has ever been shown to be superior. Like all drugs, anti-depressants have side effects, but the benefits more than outweigh them"

"Fortunately psychological therapies…such as cognitive or brief psychotherapies are also effective"

"Why then do we need a campaign at all? The answer is that the public remains ignorant about most basic…facts of depression and its treatment"

"Most damaging of all is the stigma that surrounds depression”.

1994


(Note: once again, this paper is a clear example of how the authors refer to "fatigue" and “chronic fatigue syndrome” interchangeably, with inevitably confounding results).

"In recent years fatigue has attracted renewed attention, largely because of the prominence given to the chronic fatigue syndrome"

"The infective…characteristics may, however, be the result of referral patterns and illness behaviour and not intrinsically related to the chronic fatigue syndrome”

“Fatigue was assessed with a self-reported questionnaire which was developed for a hospital study of the chronic fatigue syndrome"

"In four practices a random sample of 100 persistent non-responders was followed up….Telephone numbers were taken from notes within the practice"

"Studies of the chronic fatigue syndrome have been based in either general practice or tertiary referral centres”

“We conducted a large community survey of fatigue”

“The results supported the concept of a continuum of fatigability”

“The chronic fatigue syndrome…may represent a morbid excess of fatigue rather than a discrete entity…hence the definition may have arisen as a result of referral patterns to specialists"

"Although this is not a study of the chronic fatigue syndrome, it does give some information about it, (this)…confirms that increasing the number of restrictions in the definition of chronic fatigue syndrome does not reduce the association with psychological morbidity but has the opposite effect".
Professional and popular views of chronic fatigue syndrome

Gael MacLean    Simon Wessely


"We had the impression that coverage is different in peer reviewed literature and the popular press....We identified all scientific papers on the chronic fatigue syndrome published in the United Kingdom from 1980 by a systematic search of Medline, Current Contents (from 1986), the British Library Abstracting Service, and hand searching key journals....We then searched for articles on the same subject appearing in the professional trade journals (Hospital Doctor, Pulse etc), national newspapers, and women's magazines over the same period....Although our coverage is not complete, we do not believe any systematic bias was introduced"

"We restricted our study to British journals and articles"

"Most research papers did not favour organic causes" (note: it must be remembered just how insurmountable are the obstacles presented to British ME researchers and clinicians who do submit high quality papers for publication; not infrequently their papers are rejected on the grounds that they are not of sufficient interest, yet the journals are bursting with papers on the psychiatric aspects of the condition, which on the surface, certainly lends support to the above observation: it is, however, critical to look carefully below the surface when considering the UK ME peer-reviewed literature).

"By contrast, all three sections of the press surveyed were more likely to favour organic causes"

"The ratio of organic to non-organic opinions increased with increasing distance from the medical community"

"Although the British press does not directly link the syndrome with AIDS (unlike the American press, where the analogy is common), many noted the parallels between the two "new conditions"....The journalists noted that the syndrome had caused a genuine difference of opinion within the medical profession and had led to frequent disputes between patients and doctors"

"Much of the press coverage of the chronic fatigue syndrome shows a lack of understanding of psychological medicine and its practitioners"

"Many stories were fuelled by, but also contributed to, the stigma of psychological disorder".

The glass cage

Clare Flemming   BMJ 19th March 1994:308:797

(Note: this short article by a former general practitioner who was forced to abandon her career because of ME is a useful comparison with the usual theme presented by Wessely).

"Words can lie comfortably on the page, distanced by medical terminology....Medical training had not equipped me to understand myalgic encephalomyelitis"

"Illness cost me my job, my social life, my role in the family, my access to activity and my ability to rely on my body to function predictably"

"Research has confirmed that myalgic encephalomyelitis is a disorder of the immune system and central nervous system, yet many doctors continue to be skeptical"
"I encountered undermining attitudes and hurtful words. Thankfully...for the most part my professional advisers, family and friends believed and supported me. Sadly, many others with myalgic encephalomyelitis are not so lucky".

1994

Look at ME Tony Delamothe ibid:798

(Note: this is a review of the study commissioned by Action for ME of ME/PVFS and the press by Dr Cathy Read (see Appendix IV). The tone of the review is unmistakable).

"The supporters of myalgic encephalomyelitis as a discrete entity with an organic cause have brought off some spectacular coups....They have landed a Myalgic Encephalomyelitis Act on to the British statute books"

“They succeeded in getting the latest revision of the International Classification of Diseases to include myalgic encephalomyelitis under diseases of the nervous system”

“Only doctors now remain sceptical about the condition"

"Doctors sometimes believe what they read in medical journals. Could journals be partly to blame for their doubts? Action for ME, a patient support group, thinks so. After reviewing the coverage of the illness in the BMJ, The Lancet, and three weekly newspapers sent to British general practitioners for the 18 months up to August 1993, it concluded that 'medical journals keep doctors in the dark' with their 'biased reporting'. The main complaints were that journals confused the chronic fatigue syndrome, myalgic encephalomyelitis, and the post-viral fatigue syndrome, and that they preferred psychological explanations of patients' symptoms"

"The report is best understood as part of a marketing exercise to separate myalgic encephalomyelitis from a rag bag of chronic fatigue syndromes and to 'brand' it as the one with an organic cause"

"Complaints about...'important omissions' (of mentions of papers suggesting an organic basis for the condition) lie at the heart of the report....Simon Wessely...was castigated for displaying similar prejudice in a six page article in Pulse"

"In 27 articles appearing in the weekly newspapers only one reported on a neurological abnormality and only one concentrated on immune dysfunction in the chronic fatigue syndrome"

“Although journals regularly promote 'graded exercise'...they failed to notice a paper published in the American Journal of Medicine reporting no benefit from it"

"Undoubtedly, the report raises question about the conduct of medical journals and those who write reviews and news stories for them. They are clearly less receptive to papers that challenge their beliefs than they are to papers that confirm them....But things aren't as simple as that"

"For example, the report makes much of...a letter published in the BMJ suggesting decreased cerebral blood flow in patients (with ME).Two years on, however, no more detailed account of this study...has appeared" (note: the authors of this particular study met with solid opposition when their further paper was submitted in the UK).

"Attempting to censor the encephalomyelitically incorrect is more likely to alienate than convert".
"I suspect...some members of the audience may have come not so much out of interest in Eliot Slater, but perhaps to find out more concerning CFS....I regret they are going to be disappointed. I am going to talk about something that is only tangentially related to the condition of chronic fatigue syndrome—instead I am going to talk not about an illness, but about an idea" 

"There is a condition that we currently call chronic fatigue syndrome. It can be operationally defined” 

"There is also a phenomenon known as myalgic encephalomyelitis -- or ME. This is not open to simple definition. ICD-10 now discourages its use" (note: the WHO later confirmed in writing that it does not discourage use of the term myalgic encephalomyelitis and has no plans to do so). 

"Instead, I will argue that ME is simply a belief, the belief that one has an illness called ME" 

"CFS is not very common....Believing you have ME is very rare, and the two rarely overlap" 

"In general when there is a dramatic change in the incidence of any diagnostic label it reflects not any change in the world itself, but a change in the way we view the world....So what has changed to give us ME?“ 

"Right from the start ME has been identified with...a refusal to accept the doctor's verdict" 

"Let us start with neurasthenia -- nervous exhaustion -- the precursor of modern ME" 

"What about now?....Neurasthenia was the disease of modern life, so is ME....Nowadays the overload is due to what? Not the wireless telegraph, but pesticides (toxic sheep dip), dental amalgam (mercury fillings), allergies, electromagnetic radiation...chemicals...over-refined diet, pollution, not to mention new viruses, antibiotics, immunisations, candida and so on....here are all of them brought together to cause ME" 

“ME thus reflects what may be our appropriate concerns with the state of the food we eat, the water we drink and the air we breathe, translated into a disease idiom” 

"What lies behind all this talk of viruses and immunity? The rise of ME followed behind the rise of that other disease in which viruses do affect the immune system with catastrophic results -- HIV. In consequence, talk of viruses and the immune system is deeply embedded in popular consciousness. These links are made entirely explicitly in the States" 

"...prolactin responses (in this study)...indicate...that 5-HT neurotransmission is reduced in depression, normal in controls and are enhanced in CFS in the absence of depression....Outside the world of psychopharmacology, who will get excited about these results? Does it really matter of the 5-HT neurotransmission is enhanced (that's CFS) or suppressed (that's major depression)....What's a little up or down regulation among friends? Everything -- I will argue that this line here represents not the line between low and high cortisol responses...but the line between real and unreal illness"
"Depression is not the only threat facing the self esteem of the ME patient....there is another condition with which ME might easily be confused...it is hysteria"

"McEvedy and Beard suggested that certain epidemics were due to mass hysteria”

“It is sad that they did, since the passion that their paper injected into the almost dormant subject might be said to have given it a new lease of life”

"The Royal Free disease is itself part of the world of myth"

"It is a tragedy that the label of ME has...brought with it its burden of hysteria, and what a burden it is....a diagnosis which, accurate or not, dare not speak its name. As Tony David has called it, it is the H word, never spoken, but always present"

"Organic diagnoses lose their credibility as their psychological causes are recognised"

"How do you prove that you are not hysterical? You must convince the doctor that you are really ill--organically ill, so...the arm becomes more floppy, the leg weaker...yet what is the result of this--- it is exactly the opposite -- the neurologist, who is not a fool, is now convinced that the problem is functional"

"How...can you prove the doctor wrong? Well, the one thing you might not do is get better, since that might be interpreted by the unsympathetic...as proof that it was all in the mind after all...thus the mere existence of the word...condemns the sufferer to a life time of non-recovery, if only to prove the doctor wrong"

"Viruses are an attribution free from blame...there's no blame, no shame and no stigma...and here is the virus research doctor himself to protect us from that shame...white coat, microscope, the lot--- and what is it he delivers -- respect"

"The test is therefore crucial to respectability and legitimate occupation of the sick role"

"We can therefore understand the delight when (a sufferer) found out she had a low IgG, probably of no significance, but she knew that 'the difference between a crazed neurotic and a seriously ill person is simply a test' "

"Nancy Kaiser also rejoiced, but before then she had to visit 211 doctors---you think she might have given up, don't you, after 100 ----but sufferers still need to keep going --- doctors are still the main passport to acceptance and validation of suffering, not least because we control access to support and benefits"

"Nancy Kaiser got her respect, but at what price"

"Hence our virus doctor exists not to hold out hope of cure -- but to give legitimacy to distress"

"Doctors are entitled to express their scepticism about the status of the diagnosis, and even to suggest that these illnesses are already adequately covered in the psychiatric classifications"

"Each generation will find it necessary to discover its own ME".

(note: tape and transcript of this lecture are available).
1994

As a consequence of the various articles published in the BMJ on 19th March 1994, many concerned people wrote to the journal: the issue of 14th May 1994 published 14 items of correspondence about the ME controversy, for example:

*Distinguish between syndromes*.... Ellen M Goudsmit, Director, Information Unit, IFMEA BMJ 14th May 1994:308:1297-1298

"People writing in the BMJ are still confusing myalgic encephalomyelitis with the chronic fatigue syndrome. The 'Oxford' criteria used in Britain (catch) all patients whose severe, unexplained fatigue that been present for at least half of the time and for at least six months....Unlike the strict Australian definition, no immunological criteria have to be met....Most patients who fulfil the Oxford criteria suffer not from myalgic encephalomyelitis but from more common conditions, notably depression, anxiety states, sleep disorders, and fibromyalgia. None of these disorders occur in epidemics, and most are not associated with the neurological and immunological abnormalities found in myalgic encephalomyelitis"

"Does the distinction between the chronic fatigue syndrome and myalgic encephalomyelitis matter? It depends. According to recent research, treatments such as graded exercise which are helpful for the chronic fatigue syndrome do not generally benefit those with myalgic encephalomyelitis. On the other hand, combining all the fatigue syndromes together, implying that they share a common aetiology, and treating them in the same way would probably save the NHS and Medical Research Council some much needed money"

"If authors of editorials do not start to distinguish between myalgic encephalomyelitis and the other fatigue syndromes (the confusion) is unlikely to improve".

*....and study them separately* Nick Anderson, Director, Action for ME *ibid*:1298

"Both sides in this debate accept that most illnesses combine organic and psychological factors. The struggle is about methodology and definition"

"Until the various chronic fatigue syndromes are each studied in their own right rather than as one huge 'dustbin' syndrome we shall make little progress. Findings from research studies that are allegedly of the chronic fatigue syndrome but that use study groups that are not comparable...will continue to contradict each other".

*Preliminary report misrepresented* Charles Tannock, Durval Campos Costa, Jonathan Brostoff *ibid*

"We wish to point out an inaccuracy in Tony Delmothe's review of ME/PVFS and the Press. Delmothe dismissively describes the preliminary report...as not worthy of carrying equal weight with every other publication as no further details have been forthcoming....Further details of the findings were published as abstracts of presentations (referred) to scientific societies in two specialist journals of nuclear medicine at the same time, giving the report the status of more than a letter"

"Our findings show clear differences in brain stem perfusion between patients with myalgic encephalomyelitis...and depressed controls, strongly suggestive of an abnormality that can be shown objectively with single photon emission tomography".
Self help groups give valuable support  D.O. Ho-Yen, A. Grant  *ibid*:1298-1299

"Delmothe questions whether 'medical journals keep doctors in the dark'. We believe that the (BMJ) editorial was not even-handed"

"Irrespective of the cause of their illness, patients require support. This...is probably best provided by the doctor and a self help group, a combination that has been found useful in other illnesses, such as diabetes and multiple sclerosis"

"Delmothe states 'only doctors now remain sceptical about the condition'. We believe that this may be true for the rest of Britain, but in the highlands of Scotland 71% of general practitioners accept the existence of myalgic encephalomyelitis. Our example shows that doctors are being given different advice".

Prevalence study overlooked  D.O. Ho-Yen, M. Shanks  *ibid*

"It is sad that, in an issue in which Tony Delmothe considers biased reporting of the chronic fatigue syndrome, S.M. Lawrie and A.J. Pelosi's editorial on the subject should be so one-sided....The editorial states that 'the closer cases fulfil the definition of chronic fatigue syndrome the stronger the association with emotional morbidity'"

"Our study used a strict definition of the syndrome (and found that) the prevalence of psychiatric disorder is close to that found in studies of patients with other medical conditions. This is quite different from stating that three quarters of hospital patients with the chronic fatigue syndrome have an associated psychiatric illness".

Immunological findings may vary between populations  Neil C Abbot, Vance A Spence et al  *ibid*

"Our most unexpected finding was a positive relation...between CD38 activation markers in patients and their close family contacts....In view of the association of these markers with progression of HIV infection...they may also have potential in predicting outcome in patients with the chronic fatigue syndrome".

Stop bickering about labels  Cathy Read  *ibid*

"As an independent medical journalist...I reject Tony Delmothe's assertion that my report is 'best understood as part of a marketing exercise to separate myalgic encephalomyelitis from a rag bag of chronic fatigue syndromes and to 'brand' it as the one with an organic cause'....The report did point out...that the medical press as a whole preferred psychiatric explanations rather than organic explanations for the entity we call myalgic encephalomyelitis"

"Rather than being an attempt to 'censor the encephalomyelitically incorrect' the report was intended to highlight the imbalance and open the issue for debate....Patients with myalgic encephalomyelitis and other types of chronic fatigue are not helped by ignorance and bias".

ME Association is honest about prognosis  Sandra Howes, Member of Board of Directors, ME Association  *ibid*:1299-1300

"The chronicity of myalgic encephalomyelitis was documented as long ago as 1956...Thirty two years later a re-examination...showed that the recovery rate was no more than 20%....Thus the criteria used by
Lawrie and Pelosi in defining the differences between realism and nihilism seem to require re-examination"

Keep an open mind and listen to patients   Karen Price   ibid

"What is really at issue is whether this illness is real or imaginary"

"These people cope at a reduced level of activity because of ill health, not fear of ill health"

"They may gain in insight and coping skills, but they lose far more in family, career, social and financial terms. I know, because, like Fleming, this happened to me. After a documented myocarditis due to Coxsackie B virus infection I developed the chronic fatigue syndrome and had to leave my general practice partnership"

"We read that a 'disease conviction' is found to be associated with a poor outcome....Until the aetiology and pathophysiology of the chronic fatigue syndrome have been established, doctors should remember the maxim 'absence of evidence is not evidence of absence'. When there are...wide gaps in clinical knowledge doctors should return to a basic tool-- the clinical history. Let us listen to, and believe, our patients".

Editorial bias affects patients' benefits   Charles Shepherd   ibid

" 'We should try to keep an open mind on the condition ' concludes Editor's Choice in an issue of the BMJ that seeks to clarify the controversy over whether myalgic encephalomyelitis is a physical or mental illness.Sound advice, but does the BMJ practice what the editor preaches?"

"On one side of this debate are those who believe that myalgic encephalomyelitis is nothing more than a psychosocial disorder. During the past five years their views have been expressed in three editorials in the BMJ. On the other side are doctors who believe in a more complex pathoaeetiology, possibly involving persisting or reactivated viral infection(s),or both; disordered immunoregulation; mitochondrial abnormalities and dysfunction of the hypothalamic-pituitary axis....Those who put forward an organic hypothesis have never been granted any editorial space during the same period"

"One particularly disturbing result of this editorial bias concerns practical care of patients, with some of our most severely affected members now being refused the mobility component of the disabled living allowance, because, to quote one adjudicating officer, ' Recent evidence published (in the BMJ) states that the consensus of opinion classified (ME)as a psychological disorder rather than physical' ”

"Contrary to the impression given in Tony Delmothe's review of media coverage...it is untrue to state that no evidence has been published that shows inflammation of the central nervous system"

"The ME Association is more than willing to participate in fair, open, and informed debate on both pathology and management. Unfortunately, this will take place only when the BMJ provides equal opportunities for both points of view to be expressed".

Take a holistic viewpoint   Clare Fleming   ibid

"As the journalist quoted by Gael MacLean and Simon Wessely states, 'Balance isn't interesting: it doesn't make a story'. It seems that even the medical press takes this line"
"If you are disabled by pain and exhaustion it would be strange if you did not exhibit psychological symptoms....there is nothing unique to myalgic encephalomyelitis here"

"Psychiatrists are more at ease with psychological explanations and treatments and physicians with the physiological....Such slants were clear in the editorial by psychiatrists S.M. Lawrie and A.J. Pelosi. This does a disservice to patients and doctors alike, as well as to the standing of a reputable medical journal".

Give physical symptoms equal prominence  Vicki Aires et al  ibid:l301

"Care must be taken with the nature of the current debate to ensure that the patients are not discriminated against and disadvantaged any more than they are already....Resolution of 'bitter conflict' will never come about until the physical aspects of this illness are given equal prominence in the debate"

"We challenge the statement by Tony Delmothe about there being a Myalgic Encephalomyelitis Act on the British statute book; this is not true"

"Neither were we, other organisations of patients, or other groups of supporters involved at any level in the World Health Organisation's decision to add myalgic encephalomyelitis to the 10th edition of the International Classification of Diseases"

"Finally, S.M. Lawrie and A.J. Pelosi are clearly confused....Our advisers are not lay people but qualified medical professionals, who no doubt will resent, as we do, the assumption that any advice is based on speculation and anecdotal reports or even wishful thinking".

(Note: following the considerable response outlined above, in the issue of 23rd July 1994 the BMJ gave the last word to psychiatrists S.M. Lawrie and Tony Pelosi who had written the Editor's Choice' in the issue of 19th March which had aroused such ire)

Chronic fatigue syndrome and myalgic encephalomyelitis  S.M. Lawrie, A.J. Pelosi

"Many of our critics show that the editor of the BMJ is wrong to state in the 'editor's choice' of 14 May that 'only the naivest medical students think that diseases have some independent, objective reality'. Medical students show greater intellectual sophistication in tacking the classification of ill-defined illnesses than many patients and doctors --- and particularly medical practitioners with self-diagnosed myalgic encephalomyelitis."

"The repeated criticism of our editorial and the scientific medical journals -- that they are biased towards psychiatric and away from 'organic' aetiological theories -- is based on isolated reports of results of brain imaging and neuroendocrine findings, which have not been replicated and have not controlled for depression and inactivity"

"Accusations of bias arise from a misunderstanding of the nature of progress in medical research"

"Replicated, peer reviewed findings ensure that doctors and well informed patients are not misled by preliminary reports of research or exaggerated claims in the media, examples of which are numerous concerning...myalgic encephalomyelitis"

"The myalgic encephalomyelitis societies should not try to set the research agenda or shout down views with which they disagree"
"The editors of medical journals could equally be accused of bias towards the self-appointed patients' representatives in printing their simplistic criticism".

(Note: it would be fair comment to observe that it is these intransigent psychiatrists who powerfully insist on setting the research agenda and who shout the loudest against views with which they personally disagree).

1994

The devil you think you know Simon Wessely. The Times May 3 1994: page 15

(Note: this essay is not about ME; once again, however, Wessely's invariable theme is apparent).

"Satanic abuse does not exist. This is the leaked finding of a three year inquiry commissioned by the Department of Health"

"Satanic abuse thus joins other episodes of false collective beliefs in the psychiatric literature"

"Sad though these stories are, saddest of all is the way in which well-meaning professionals have become caught up in them"

"Such patients are actively searching for meaning and explanation for their symptoms, and are in an extremely suggestible state"

"How have intelligent people come to believe in a conspiracy of leading figures...? One reason is that it is not the role of the therapist to question a patient's beliefs"

"Nothing in the professional training of a psychiatrist...gives them any expertise, or any role, in determining the truth".

(Note: this last direct quotation from Dr Wessely is perhaps worth re-reading: certainly it might be prudent for Dr Wessely to engage in a little in-depth reflection about the meaning of what he has written here, and relate it appositely to the ME issue).

1994

On 11th July 1994, BBC Panorama broadcast a programme entitled “Poison in the mouth”, presented by Tom Mangold.

On 14th July 1994 The Times published Simon Wessely's article "A filling dose of doubts".

In it, Wessely once again used a stratagem which has served him well many times; this stratagem is his complete lack of reference to any of the factual evidence which Mangold uncovered, for example, the X-rays showing the diffusion of mercury throughout the body, and the vapour given off by the fillings in day-to-day use.

Wessely's policy of deliberately misrepresenting known facts, ignoring valid research findings which do not accord with his own agenda and trivializing important matters with which he happens to disagree are all evident in his critique of the Panorama programme, viz:
"Tom Mangold has few equals as a reporter....Unfortunately, Monday's Panorama (The Poison in your Mouth) (sic) was as disappointing as his previous programme (on the links between HIV and dentistry) had been illuminating"

"The programme concerned the possible health risk posed by dental amalgam...Over the past 20 years a considerable literature has developed on the subject, and little evidence has emerged to suggest any dangers. This doesn’t make for an exciting programme. Instead, Panorama put together a programme that told...the essential elements of good medical scare stories."

"The first element is a plausible villain. Mercury, which every medical student knows made the Mad Hatter mad...is perfect."

"Second, your villain should have a link with something near home....A danger from your own teeth could hardly be closer"

"Third, the threat must cause symptoms hard to verify, hard to disprove, but also extremely common"

"Fourth, frightening diseases of unknown aetiology should be part of the picture"

"The fifth element is an absence of published research that does not support your case."

"Sixth is the use of emotional language"

"Thus dental amalgam is a ‘time bomb’ and ‘a growing threat’....who could resist the pleas to ‘think what this might do to the brains of young children’?"

"A spokesperson for authority who can then be made to look complacent is element number seven....This role was played...by the chief executive and the scientific officer of the British Dental Association. They were confronted with new American research findings of unknown provenance and reliability. The credibility of the officials suffered merely because they had yet to consider this new work"

"Eighth, when another authority figure, on this occasion the Department of Health, refuses to take part (presumably because they can spot a mugging in advance), you can call this 'ignoring the evidence'"

"Ninth, cover yourself at the end. Many of my patients with ME (myalgic encephalomyelitis) have already heard of the amalgam controversy and have had their fillings removed at great expense and for little purpose"

However, if dental amalgam turns out to be without hazard, then one can envisage patients with a legitimate complaint against Panorama for the expense...they have endured in consequence"

"It would be better to acknowledge the real source of our unease, rather than resort to the tired cliches of the medical scare story".

On 19th July 1994, Tom Mangold was afforded the opportunity to respond to Wessely:

We did not ignore the good news --there was none   Tom Mangold. The Times 19.7.94

"A sour note was struck...with a feature...by Dr Simon Wessely. He came to praise our work but ended by plunging a knife through the shoulder blades of our research"
"His article accused Panorama of scaremongering by implying there was insufficient new scientific evidence to show amalgam’s implication in...potentially dangerous pre-clinical symptoms of low-level mercury poisoning"

"In the course of several allegations, he claimed we had ignored evidence that mercury in fillings was safe. However, not a single scientific study has ever been conducted which proves mercury in amalgams is safe, and the World Health Organisation certainly does not endorse this view."

"Dr Wessely referred to a Swedish study...that 'had found no link between the (poisoning) symptoms and mercury fillings'....We knew all about that work....The study in question is always quoted by the pro-amalgam lobby. We rejected it because it was based on a self-answering questionnaire and not a scientific study....There was no control group, and crucially, the whole study looked for symptoms which are not even related to low-level mercury poisoning symptoms....That is why the study is regarded as so scientifically flawed as to be worthless"

"Dr Wessely then attacks us for ignoring a survey of the pregnancies of 20,000 dental workers. We ignored this study because...it contained no controls and it was published in the journal of the American Dental Association, which is not independent"

"Dr Wessely alleged we had ignored the 'considerable literature’ (containing) 'little evidence' to suggest dangers. Once again, we did not ignore the good news, because there is none. Reviews are regularly published by the pro-amalgam lobby. These British Dental Association reviews are opinionated articles about other people's works, and with unsurprising regularity the reviewer usually criticises those studies which show amalgam in a bad light. These reviews are not science"

"Furthermore, the BDA is not fully conversant with all the latest science. When I asked its scientific adviser to comment on a key work by a scientist whose name we had already given the BDA a week earlier, he still had not heard of the paper. Nor had the study been published in an obscure house magazine, but in the journal of the Federation of American Societies for Experimental Biology, one of the most distinguished scientific journals in the world"

"The German federal health service...warns pregnant women and young children to avoid amalgam"

"Every piece of scientific evidence presented by Panorama in 'Poison in the Mouth' has been peer-reviewed and is already or about to be published in reputable science magazines"

"The Swedes, Germans and Austrians are getting rid of amalgams and mercury; that is why we ban mercury in paint, and why we are taking it out of batteries. Why then are we still leaving it deep inside our mouths as a lifetime’s implant?"

"Although Dr Wessely hedges his bets...his article shows how hard the pro-amalgam lobby is prepared to fight its corner in this important issue. But it doesn’t tell us why".

1994

The Patient with Chronic Fatigue

(Note: a conference on the patient with chronic fatigue was held at Southmead Hospital on October 3rd 1991; it was not reported until 9th October 1994 by the West of England Medical Journal Volume 108:52-56. The speakers included Simon Wessely).
In his Introduction, the Chairman, Professor HG Morgan, Professor of Mental Health, University of Bristol, said: "No evidence has been found of organic disease in CFS, and it should probably be considered to be a psychosomatic disorder".

Dr Wessely’s address was called “Cognitive Behavioural Management of Chronic Fatigue Syndrome”.

"It is possible that...viral infection is a direct precipitant of mood disorder"

"We have previously studied the clinical features of 50 patients consecutively referred to the National Hospital...with a complaint of severe fatigue”

“72% felt their illness had begun with a viral infection, and nearly all believed they had ‘ME’ and were members of the ME Association"

"All cases were offered a programme of cognitive behaviour therapy”

“The aims of treatment were to provide alternative explanations for symptoms”

“The methods chosen included standard cognitive therapy...and the use of established techniques to treat depression”

“The principle problem encountered was a high rate of treatment refusals"

"Distress and disability could have many causes...the majority considered themselves to be much improved by treatment, although many continue to have some somatic symptoms"

"We are unable to determine what led to improvement in the patients studied. It is possible it was simply due to the amount of...attention given".

1994

Dilemma of the editor: Who knows when researchers lie? Simon Wessely The Times 24th October 1994

"Since the 18th century, scientists have announced their discoveries by writing for a scientific journal....How did the journal decide to publish their paper? Perhaps it was wrong --- based on flawed data or faulty analysis. How could the editor decide?"

"There are approximately 25,000 biomedical journals, so no editor could hope to keep up with the pace and complexity of scientific investigation. Another problem is the pressure to publish. Academic preferment, reputation and promotion depend upon publication, and quantity matters more than quality"

"Decisions about what to publish are made through the peer review system. Papers submitted to a journal will be sent to one or more specialists in that field....the editor can be guided by technical advice and experience which no single person can possess"

“The peer review process itself remains unchallenged. Fundamentally, scientific research depends upon the integrity of the person reporting his own data and the referee reviewing it. It is for that reason that scientific fraud remains the ultimate professional sin".

As a result of the above feature by Wessely, several people wrote to The Times; mostly they were professionals who were well acquainted with the peer review system.
From Dr Chris Richards

"Are Simon Wessely's concerns about scientific fraud and the importance of the integrity of scientists reporting their own data in any way connected with the debate about his own scientific reputation in the pages of the Chronicle of the CFDS Association of America (Spring and Summer 1994) and his threatened injunction against the Bristol charity Westcare, the distributor of CFIDS Chronicle in the UK?"

From Eileen Marshall and Margaret Williams (authors of the CFIDS article mentioned in the above letter)

"Simon Wessely...claims that scientific research depends upon the integrity of both the person reporting it and the referee reviewing it. The peer review system does not, however prevent lies from reaching print. All it takes is for an editor to have a bias in favour of research which reaches particular conclusions, and for the editor to have access to peer reviewers who are known to him to share his own views. When a paper is submitted, the editor can easily send it a reviewer whose responses he can predict....Given that his own published work has recently been the subject of a review article and that serious questions have been raised about the validity of his findings, and about whether or not he himself has been guilty of scientific misconduct (CFIDS Association of America --Spring 1994 pp14-18; Summer 1994 pp 77-79) are we justified in asking quis custodiet ipsos custodes?"

Given Wessely's known association with The Times, unsurprisingly these letters were not published, but they were acknowledged.

Certain colleagues of Wessely were minded to postulate that his piece was either a disingenuous attempt at damage limitation, or perhaps even a clear case of pathological hysterical denial.

1994

Despite Wessely's known association with The Times, the following letters were published about herbal medicines and the safety factor on 22nd November 1994.

From Andrew Chevallier (President, National Institute of Medical Herbalists)

"Dr Simon Wessely is quoted as saying that if herbs ‘work, they must be drugs, and if they are drugs they must have side effects’. Obviously he has never come across camomile, a well known, well researched herb with...no known side effects. Herbal medicines are not the same as most pharmaceutical medicines; they are not isolated chemicals synthesised in laboratories, but dilute...mixtures of naturally occurring chemicals...This is one reason why herbal medicines...can have (a) powerful...effect without causing the side effects so common to conventional...treatment".

From Mrs Anne Baring

"Dr Simon Wessely's reported desire for academic control of research into herbal medicines (in the ostensible interests of safety) suggests that authoritarianism is still with us: no member of society can exercise his or her right to choose between different approaches to healing without the permission of a small but powerful clique. To attempt to destroy a method of treating illness which many people use and value is blatantly totalitarian".
From Ms Christine Steward

"Why the obsession with licensing? A medicines licence doesn't make a medicine safe -- if it did there would not be thousands of people occupying hospital beds suffering from serious side-effects caused by licensed pharmaceutical drugs prescribed by the medical profession".

1994

The Chronic Fatigue Syndrome: A Comprehensive Approach to its Definition and Study


"Clarification of the relationship between the chronic fatigue syndrome and the neuropsychiatric syndromes is particularly important"

"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 neuroimaging studies, can be recommended for the specific purpose of diagnosing the chronic fatigue syndrome. Examples of specific tests that do not confirm or exclude the diagnosis of the chronic fatigue syndrome include serologic tests for...enteroviruses; tests of immunologic function, including cell population and function studies; and imaging studies, including magnetic resonance imaging scans and radionuclide scans (such as single photon emission computed tomography and positron emission tomography) of the head"

Under the sub-heading "Essential Subgrouping Variables" is to be found the following: "The presence or absence, classification and timing of onset of neuropsychiatric conditions should be established using published or freely available instruments"

Under the sub-heading "Optional Subgrouping Variables" is to be found the following: "Examples of optional variables include...epidemiologic or laboratory features of specific interest to researchers. Examples include...the presence or level of a particular immunologic marker"

"With regard to the clinical psychiatric evaluation of fatigued persons, we consider a mental status examination to be the minimal acceptable level of assessment"

"Psychiatric conditions are highly prevalent in persons with chronic fatigue and the chronic fatigue syndrome, and the exclusion of persons with these (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 we agreed that their presence had been unreliably documented in past studies"

"Others argues that...a requirement for multiple symptoms biases the selection of cases toward those with psychiatric disorders"

(Note: once again it can be seen that certain lines of approach are being strongly advocated, whereas immunological investigation -- which has produced the most useful markers of ME/CFS to date -- plus brain imaging studies -- which have also produced clear patterns of hypoperfusion abnormalities -- are expressly to be rejected).
One can only surmise what those ME researchers who specialise in immunology and nuclear medicine might think of this "revised case definition": equally, given that the stated reason for dropping "all physical signs" from the criteria is that "their presence had been unreliably documented in past studies", could it not fairly be argued that, in very many studies, the presence of psychiatric manifestations have been "unreliably documented in past studies"?

1995

Neuroendocrine Responses to d-Fenfluramine and Insulin-Induced Hypoglycaemia in Chronic Fatigue Syndrome

Jenny Bearn, Theresa Allain, Patsy Coskeran, Neil Munro, Joan Butler, Alan McGregor and Simon Wessely


(Note: at last, Wessely is forced to concede there is indeed unequivocal 'organic' dysfunction in ME/CFS).

"Attention has shifted to the role of the central nervous system in CFS and neuroendocrine studies provide one means of exploring this"

"Because depressed patients have attenuated neuroendocrine responses to ITT (insulin tolerance test) confounded by insulin resistance...we confined the test to CFS patients who were not concurrently depressed"

"Neuroendocrine strategies have also been applied to estimate central serotonin (5-HT) neurotransmission...This strategy has recently been applied in CFS...because of the role of 5-HT in the regulation of sleep, appetite, pain and inflammation, all commonly disturbed in CFS"

"We sought to distinguish any specific changes in CFS by confining our study to non-depressed patients...in order not to confound or mask any specific changes attributable to CFS alone"

"We have shown that patients with CFS have a selective impairment of hypothalamo-pituitary responsiveness to the stress of hypoglycaemia, confined to the prolactin response...The impaired prolactin response cannot be accounted for by either depression or insulin resistance"

"Prolactin responses to d-fenfluramine are attenuated in depressed patients...and this potentially confounding factor was accounted for by the exclusion of depressed patients from the present study"

"In CFS patients, we have shown increased ACTH secretion in response to d-fenfluramine in the face of normal cortisol responses. This suggests that adrenal cortical function is impaired"

"A recent rigorous study (Demitrack et al 1989) has shown that CFS patients exhibit HPA dysregulation"

“Taken together these findings are most compatible with impaired hypothalamic function compromising CRH (corticotrophin releasing hormone) synthesis/secreetion"

"In conclusion, we have demonstrated impaired prolactin responsiveness to metabolic stress in chronic fatigue syndrome, which cannot be explained by any concurrent depression"

"This study provides further evidence for hypothalamic dysfunction in chronic fatigue syndrome".

(Note: This interesting paper makes two main points: (i) that the authors confined their study to patients who were carefully confirmed to be non-depressed and (ii) the study provides evidence for both pituitary and adrenal cortical impairment in CFS. Given the extent of Wessely's previously published work on the
nature of CFS/ME, this current paper would seem to invite three possibilities: first, that in his previous studies, Wessely must indeed have been looking at groups of patients described in the report of the UK Task Force on CFS/ME as having been (quote) 'selected using different definitions of CFS' which led to the 'invalid comparison of contradictory research findings stemming from the above'; however, as a Fellow in Epidemiology, it would seem unlikely that Wessely would have repeatedly made such a basic error of judgment in his selection of patients cohorts; second: that Wessely was simply wrong in his previous conclusions about ME, or third: that he has been forced to change his mind about the nature of CFS/ME, due to the accumulation of evidence which even he can no longer ignore, dismiss or trivialise).

**1995**

*How long should a sick leave last?*  Simon Wessely  The Times 23rd February 1995

"I run a clinical service that specialises in seeing patients with chronic fatigue. We see people with complaints ranging from general feelings of tiredness and lassitude that affects all of us from time to time, to those...who have often been diagnosed as suffering from chronic fatigue syndrome or ME"

"Not long after the initial appointment, a letter usually follows from the patient's employers, asking when, or if, their employee will be able to return to work"

Wessely then refers to "....nervous exhaustion (a wonderful term which deserves to be reintroduced to the medical textbooks)...."

"During (a take-over battle, a high-flying city lawyer) had been working 16 hour days without respite....Two weeks later he was almost unable to get out of bed"

"He recovered, until perhaps the next takeover bid"

"For those seeking further guidance, the bible has traditionally been Fitness for Work: The Medical Aspects produced by the Faculty of Occupational Medicine of the Royal College of Physicians. (It) is comprehensive, but not detailed. In particular, mental health deserves greater attention....Each year an estimated 80 million working days are lost because of overt mental health problems...(this estimates is) likely to be exceeded by the costs of covert psychological problems hidden under such labels as back pain (and) irritable bowel".

(Note: given that back pain and irritable bowel are two documented prominent symptoms of ME, could it be that Wessely's intentional, but subliminal, message to readers of The Times -- customarily regarded as 'the top peoples’ newspaper' and read by those who shape the country’s decisions -- is that ME is a mental health problem?).

**1995**

*Social and Cultural Aspects of Chronic Fatigue Syndrome  Simon Wessely*


(Note: a curious anomaly appears to be presenting itself with this paper: the findings described in the preceding study show quite clearly that CFS/ME has an organic aetiology: that paper was received by the journal (Biological Psychiatry) on 10th November 1993, so the conclusions must have been known to Wessely by that date, even though it was not published until 15th February 1995; in this chapter,
published in 1995, one would be forgiven for believing that Wessely has chosen to ignore his own previous work, which raises the question as to just how involved in the neuroendocrinological aspects he really was: it is possible that his involvement was limited to excluding depression in the subjects studied. The present chapter is yet another re-run of all the well-used Wessely doctrines, and cannot fail to be recognised as such).

"Patients with chronic exhaustion after minimal effort for which a medical explanation is lacking are not new...in recent years many will acquire the label of chronic fatigue syndrome (CFS) or fibromyalgia"

"This paper will consider the wider social and cultural aspects of the condition"

"There has been a tendency to neglect these aspects of CFS in favor of biomedical explanations, in the hope that some new discovery arising out of immunology or virology will explain the enigma of CFS"

"There are two aspects to CFS. The first is an operationally-defined condition, that can be measured and studied...We and others are making progress in determining the epidemiology of CFS...using the conventional methods of epidemiological research....The second problem of CFS...is the belief, whether self-or doctor-generated, that one is suffering from an illness with that label"

"Patients are appearing in increasing numbers who believe, often with passion and conviction, that they suffer from chronic fatigue and immune deficiency (sic) syndrome (CFIDS) in the USA, or myalgic encephalomyelitis (ME) in the United Kingdom"

(Note: "CFIDS" stand for Chronic Fatigue and Immune Dysfunction Syndrome: this is clearly displayed on their literature; perhaps "deficiency" is more in line with Wessely's personal agenda)

"As an observer of the social scene, I...know that ME or CFIDS is defined by the sufferers themselves"

"Untold confusion has arisen from the failure to distinguish between an operationally-defined epidemiological construct and a social belief system. This essay concerns the latter"

"Wherever CFS patients are studied, and however they are studied, psychological morbidity is conspicuous by its presence. It is a matter of regret that each generation of physicians appears to need to discover this afresh"

"The consequences of physical disease cannot alone account for the clinical features of CFS"

"Chronic fatigue syndrome and psychiatric disorder go together"

"Operational criteria will be unable to make a complete distinction between CFS and psychiatric disorders. To understand these differences, one must turn to the role of social and cultural factors"

"At the heart of CFS is the rejection of any form of psychological causation or treatment....Courtroom analogies are apt, since the atmosphere surrounding CFS is now an adversarial one....A typical headline is 'Justice for the neglected and maligned sufferers of ME'. Others speak of bitterness, anger and hate"

"The accusation is not just that the sufferer is guilty of being depressed...but of not being ill at all -- of having an imaginary disease"

"It is the search for validation that underlies the drive to find a test for CFS"

"Without a test, not just the CFS patient, but also the fibromyalgia and RSI sufferer, exists on the margins of sickness and disability"
"Why a virus (or immune defect, or allergy)? Why have there been such efforts to find a microbiological cause of CFS? ...Proof that CFS is associated with either a post or persistent viral state is far from compelling"

"Of more relevance are the social and cultural factors. The concept of an external agent is a familiar one for both doctor and patient....External attribution may protect the patient from the stigma of being labeled psychiatrically disordered"

"The absence of guilt and the preservation of self-esteem, even in the presence of mood disorder, has been noted in post-infectious syndromes"

"What many popular explanations have in common is that they are external to the patient, and are not accompanied by accusations of moral weakness or blame"

"...the rise of HIV has meant that the concept of a deadly virus that affects the immune system is now one deeply embedded in popular consciousness....The name adopted by the most vigorous of the campaigning organizations in the USA -- the Chronic Fatigue and Immune Deficiency (sic) Syndrome -- is a conscious attempt to draw upon the experience of AIDS"

"Much of the current information on CFS may also adversely influence prognosis"

"Rest is one part of the spectrum of avoidance behaviour that characterizes much of the popular management of chronic fatigue syndrome"

"A frequent theme is the need to avoid various agents, ranging from immunisations and pollution to a variety of foods and even sunlight....In its most extreme form CFS overlaps with such Western cultural syndromes as multiple chemical sensitivity or total allergy syndrome, where lives are ruined by fearful anticipation...."

"The consequences of lack of physical activity, and the changes in the neuromuscular system that result, have been known to clinicians for many years"

"One purpose of CFS is to give legitimacy to distress that would otherwise be unacceptable to the patient”

“...This has many benefits...(if) the label of CFS is seen to indicate a physical, and hence blameless, aetiology"

"As well as permitting changes to lifestyle, CFS serves as a conduit for social concerns, expressed via the metaphor of illness"

"Nowadays, the overload is due to pesticides, allergies, chemicals, neurotoxins, antibiotics, over-refined diet, pollution, electromagnetic radiation, candida and so on"

"Will CFS go the same way as neurasthenia? I suspect not”

"Once an agnostic, I am inclined to believe that an entity called CFS can be located in the community, although I suspect that, like fibromyalgia, it will be the arbitrary end of a spectrum of fatigue and exhaustion"

"Whether it exists or not, it is here to stay".
"On the basis of a small selected case series Rowe and colleagues report an association between chronic fatigue, chronic fatigue syndrome, and hypotension. Are there alternative explanations for Rowe and colleagues' findings? The first possible confounder is depression.

"One of the two epidemiological studies I mention showed that the association between fatigue and low blood pressure was related to low mood, which is a common finding in chronic fatigue syndrome.

"The second is inactivity, the essential feature of chronic fatigue syndrome.

"Simple rehabilitation and activity management programmes might...be more appropriate than further unproven pharmacological intervention"

Authors' reply (Rowe et al) *(ibid)*

"Prolonged bed rest might have been a more reasonable explanation for our findings if any of our patients had been confined to bed. They had not"

"Similarly, none was clinically depressed. Symptoms improved within two weeks...which is an improbably short time for physical reconditioning to occur or for there to be spontaneous recovery from depression"

"We did not describe an association between chronic fatigue and simple low blood pressure, as Wessely suggests, but between chronic fatigue and neurally mediated hypotension"

"Whether intentionally or not...Wessely implies that chronic fatigue syndrome is usually self-limited and that in some way patients could walk it off. There are no data suggesting that physical rehabilitation exercises are effective as primary treatments for neurally mediated hypotension or chronic fatigue syndrome. Indeed, patients with chronic fatigue syndrome typically feel much worse after modest physical exertion. Similarly, we are not aware of data suggesting a high rate of spontaneous resolution of chronic fatigue syndrome in the short term when patients satisfy strict criteria for this diagnosis. In a large study by Wilson and colleagues (BMJ 1994:308:756-759), the mean duration of illness was 9.2 years and a substantial proportion of patients continued to have impaired function with a further three years of follow-up. Against this background, the term self-limited loses meaning".

(Note: in 1993, a group of experienced Australian CFS/ME researchers published a paper in the American Journal of Medicine (Immunologic and psychologic therapy for patients with chronic fatigue syndrome: a double blind, placebo controlled trial: Am J Med 1993:94:197-203) which found that cognitive behavioural therapy was of no more value to patients with CFS/ME than simple clinic attendance. Wessely and his collaborators sent a lengthy reply, which was published in 1995):


"The study of Lloyd et al suggests that cognitive behaviour therapy (CBT) is no more effective than clinic attendance in the management of chronic fatigue syndrome. These results contrast with our uncontrolled study reporting substantial benefits of CBT"
"We have a number of observations concerning these different findings"

"Our principal question concerns the nature of the treatment employed....We have considerable doubts that the treatment used was comparable to CBT as we have described it for CFS"

"We...suggest that patients in the Lloyd et al study may have attended the sessions, but did not comply with the programme"

"We suspect that the patients were actually non-compliant with treatment"

"We feel that CBT may have failed for a number of reasons. First, the number of sessions was inadequate"

"Second, no rating or indication is given of the experience and training of the therapists"

"Third, the treatment rationale may have been compromised by the presence of an immunological trial"

"We have received extensive adverse criticism of our programme under the misguided apprehension that graded activity would be harmful in CFS. We are delighted that Lloyd and colleagues have shown these fears to be groundless"

"We agree that our study populations may well be different....Our impression is that we may see a more disabled group of patients with higher rates of psychiatric disorder than they do"

"We agree...that the benefits of CBT in our open study may still have reflected nonspecific effects of treatment, likely to be important in a condition with such a high placebo response as CFS"

"In conclusion, the authors state that their findings do not support the hypothesis that CFS could be adequately treated by CBT alone. We do not feel that this study is an adequate test of CBT in CFS".

(Note: as often seems to be the case, Wessely's coterie of like-minded psychiatrists also sent a lengthy rebuttal of the Australian study (ibid); the author in this case was Michael Sharpe of Oxford):

"Lloyd et al concluded that patients with CFS did not respond to psychological therapy. Specifically they claim to have found that...CBT was no more effective than ordinary medical follow-up. An examination of the design of this study, however, indicates that only limited conclusions can be drawn"

"There are strong arguments to suggest that CBT may be effective in patients with CFS" (here Sharpe refers to the paper by S Butler, T Chalder, M Ron and S Wessely in the JNPP 1991:54:153-158, a study of only 50 patients and from which there was a high drop-out rate; it was, moreover, an uncontrolled study)

"We have found that patients' belief that their symptoms are a result of physical disease...is an important factor in perpetuating illness....Not only did the patients' belief in physical disease appear to be unchallenged in this study, it may even have been unwittingly confirmed by the simultaneous administration of immunoglobulin injection"

"Furthermore, the 'dose' of CBT was far too small...to realistically expect much effect"

"The therapy failed even to achieve an increase in the patients' level of activity (suggesting non-compliance with the behavioral programme)"

"The type and dose of therapy given was inadequate".
The Australian authors’ reply was suitably trenchant (ibid: 421)

"The criticisms raised by Chalder (and Wessely) et al and Sharpe need to be examined within their proper context. Both groups have been strong advocates, largely on theoretical grounds, of non-pharmacological treatments for patients with CFS. Both have placed great emphasis on the initial study (ie. the one reported in the JNNP 1991 by Wessely et al)"

“Although that ‘trial’ consisted initially of 50 patients, only 32...actually accepted treatment. Outcome data was reported for treated patients only”

“Pardoxically for a ‘trial of CBT’, 20 patients also received tricyclic antidepressants”

“(the Wessely study) in their own words, was 'subject to all the deficiencies of a non-blind, non-randomised study'"

"Our study did not simply assess the efficacy...of therapy at the end of active treatment, but rather at follow-up after a 3-month intervention-free period"

"In the study of Butler et al (ie. Wessely: JNNP 1991) the mean number of therapist hours per treated patient was 7.5. After correction for the actual number of enrolled subjects, this drops to 4.8 hours per patient”

“In our study, therapists spent 4 to 6 hours with each patient"

“The duration of treatment (10 weeks) was as long as that encountered in most CBT programs for psychological disorders"

"The programme was designed by a psychiatrist"

"The treatment was administered by experienced psychiatrists"

"Patients' beliefs regarding key attitudes such as the possible negative outcome of physical activity were challenged"

"Clearly the therapy administered in our trial constitutes more than adequate CBT, and the lack of efficacy cannot simply be attributed to perceived ‘deficiencies’ with our treatment package"

"Both correspondents adhere to a model of CBT where it is necessary for patients to trade one unsubstantiated dogma ('that their illness is entirely physical') for another (that their disability is determined largely by 'psychological or social problems')"

"Sharpe castigates us for not challenging ‘the patients' belief in physical illness' and 'unwittingly confirming' this illness attribution....Within our model such dualism is firmly rejected in favour of an approach that is...acceptable to patients (unlike the approach of Butler, Wessely et al)"

"Had we also relied simply on an assessment at the end of the treatment...we too may have prematurely concluded that benefit was gained from CBT"

"In our study, self-reported measures...showed significant improvement in the CBT group...at the end of the treatment period....Nevertheless, this apparent change was not sustained through the follow-up period"

"We believe...that our patients did comply with the programme"
"This...trial should sound a warning to those who have espoused or promoted the virtues of various...expansive...psychologic treatments to a vulnerable patient group on the basis of limited data from uncontrolled assessments of 'clinical management' programmes. Our study suggests that (patients) might do equally well if they simply receive supportive care by regular attendance with their physician".

1995


(Note: although this study purports to be looking at CFS, it seems to be based on self-reports of fatigue among general practice attenders).

"The problem of excessive fatigue has attracted much interest in the past few years. Special attention has been paid to the possibility that the condition has an infective origin"

(Note: ME is not synonymous with simple fatigue; Wessely so often fails to acknowledge this crucial fact. Importantly, true ME is associated with enteroviruses, not merely any virus such as RSV).

"The majority of patients seen in clinics specialising in chronic fatigue syndrome report that their problems began with a viral infection....Difficulties with this simple story soon became apparent....There are psychological reasons why patients might attribute symptoms...to a viral cause"

"To overcome these difficulties, we carried out a study of chronic fatigue that...involved ascertainment of...psychological vulnerability”

“Fatigue was assessed by a self-report questionnaire”

“All general practice records were searched for records of any psychiatric admissions (or) prescriptions of psychotropic medication"

"The commonest symptoms in the exposed cohort were sore throat, cough, headache, aching muscles, runny nose, fever and chills"

"Previous fatigue...was the strongest independent predictor of fatigue after viral infection"

"Independent contributions were made by both fatigue and psychological distress before presentation with the clinical infection, and by psychological distress at the time of presentation"

"We found no evidence to suggest that in primary care common viral infections are associated with chronic fatigue syndromes”

"....general symptoms did predict chronic fatigue. These symptoms were also associated with both current and previous psychological distress"

"...the symptoms may pre-date viral exposure, but may be confused by the patient with the symptoms of viral malaise"

".....the symptoms may develop during an acute infection because of an underlying trait of somatisation"
"Can these results be applied to chronic fatigue syndrome outside primary care? We believe they can"

"We conclude that common infections play little part in the aetiology of chronic fatigue in primary care."

(Note: the above study has already been published under the title "Population based study of fatigue and psychological distress": BMJ 19th March 1994:308:763-766; curiously, these two papers (which both report the same study) have different lead authors; even more curious is that this very same study was later published in 1996 in the American Journal of Psychiatry with Wessely himself as the lead author).

Inevitably, Wessely's conclusions were widely disseminated throughout the medical trade papers.

1995

Chronic fatigue syndrome not linked to infection Monitor Weekly: May 31st 1995

"Postviral fatigue syndrome usually has little to do with viral infections according to a prospective study based in general practice"

"Dr Simon Wessely...said: 'Common viral infections in primary care do not pose a substantial risk of chronic fatigue syndrome"

“So-called postviral fatigue is not...due to a virus. It is associated with previous fatigue and...depression" "

"'most CFS is not linked to viral infection' added Dr Wessely"

"The causes of chronic fatigue syndrome lay in the patient’s history and lifestyle"

"Risk factors include...over-work."

1995

Mental ills linked to chronic fatigue Doctor: June 1st 1995

"The link between chronic fatigue syndrome and common infection is not substantiated by the latest study results. Instead, findings show there to be a link between previous fatigue and psychological disorder"

"Patients with previous fatigue were three times more likely than normal to develop subsequent episodes and patients with psychological distress were nearly twice as likely to do so"

"No correlation between infection and fatigue was found (Lancet 1995:345,1333-1338)"

1995

Study finds ME is not linked to viral infections GP News: June 2nd 1995

"Viral infection is not a major trigger of chronic fatigue syndrome, a general practice study has found"
"The findings contradict previous research which suggested chronic fatigue is a form of post-viral syndrome"

"The study was co-ordinated by researchers at King's College Hospital...Findings provided strong evidence that common infective episodes in primary care are not related to the onset of chronic fatigue"

"GPs were right to investigate physical causes of chronic fatigue first 'But if these lead nowhere, then thorough psychiatric assessment must be considered" 

1995

New evidence on chronic fatigue  Pulse: 3rd June 1995

"Chronic fatigue syndrome is not linked to common viral infections as previously believed, general practice-based research has shown"

"Dr Simon Wessely...found...patients...with a history of psychiatric distress were almost twice as likely to suffer post-viral chronic fatigue"

"Dr Wessely added that...the findings showed that common viral infections were not linked to post-viral fatigue"

Once again, Mrs Sandra Howes, a member of the Board of Directors of the ME Association, sent a response to the Editor of the Lancet, making valid observations:

"Wessely et al (Lancet 1995 345:1333) claim that chronic fatigue is often thought to have an infectious origin but give no reference in support. In fact, they may have difficulty finding one....Perhaps Wessely et al were thinking of the literature on chronic fatigue syndrome (CFS)?....To equate the two and to generalise from one to the other is premature. As their own study shows, the majority of patients with chronic fatigue do not fulfil any of the standard criteria for CFS"

"By including patients with a prior history of fatigue, it is possible that the data on psychological distress may have been confounded by the presence of affective disorders....Accordingly, it would have been interesting to know if the scores on the general health questionnaire also predicted fatigue in those without premorbid or concurrent psychiatric diagnoses. If the results matched those of the fatigued group as a whole, then the conclusions relating to psychiatric disorder and CFS are justified. If they do not, then the comments about the role of psychological distress in the aetiology of CFS must be reassessed"

"Excluding the patients with premorbid fatigue may have produced a purer sample, but with only 6 cases of CFS left in the analysis, the findings relating to infection should have been interpreted with more care".

The letter was rejected for publication.

1995


(Note: this is a remarkable paper because in it, Wessely unequivocally states [on page 662] that:
“Scott... argues that the DSM or ICD (are) the arbiters of psychiatric compensation, since if your illness is not in (them), you certainly will not be able to claim” (note: given that ME is classified in ICD-10 as a neurological disease, and given that Wessely knows this to be so, it is interesting that he here postulates that only if a disease is listed in DSM or ICD can it be considered an independent entity, yet he continues to deny the existence of ME).

However, Wessely is seemingly arguing that only psychiatric listings require to be accorded recognition as independent entities, but that other listings, (such as neurological entities, for example, ME) need not be accorded the same acknowledgment.

As he claims that ME is not an independent disease entity, but simply a belief that one is ill, and as he also claims CFS is a psychiatric illness (which presumably qualifies its sufferers as bona fide litigants for psychiatric compensation in appropriate cases), Wessely's logic throughout this article is somewhat challenging to follow.

This paper was delivered at a symposium at The Royal College of Physicians on 15-16 November 1994; it was organised by the Society for Psychosomatic Research and the Liaison Group of the Royal College of Psychiatrists. Importantly, some of the same topics were addressed in a consultation document on liability for psychiatric illness produced by the Law Commission.

"By failing to recognise the complex multifactorial models that operate in psychiatry, there is a risk of considerable increase in litigation for psychiatric injury, which in turn will have an adverse effect on the public health"

"The example of PTSD (Post Traumatic Stress Disorder) suggests that the Law Commission Report, despite its immense scholarship...sometimes gives......too little attention to the ambiguity of psychiatric diagnosis. The 'discovery' of PTSD was not the result of any careful hypothesis, epidemiological investigation or even serendipitous inquiry. It arose in response to America's own traumas associated with the Vietnam War”

“PTSD was created 'consciously and deliberately'....The history of nervous shock (and) traumatic neurasthenia......remain relevant....The Law Commission...appear less aware that psychiatry is....susceptible to such influences (as current social concerns)"

"...the law and social psychiatry sit uneasily together"

"Given the Commission's concern with not 'opening the floodgates' of litigation...they are surprisingly relaxed about the implication of extending liability for psychiatric disorder"

"It is axiomatic in the study of chronic disease to note that what starts an illness may not be what sustains it over the years"

"The example of RSI (Repetitive Strain Injury) should serve as another warning. It is now accepted that the dramatic epidemic of RSI that swept across Australia in the early 1980s was a...psychosocial phenomenon that resulted from the interaction of an ill-defined syndrome, conflicting medical opinions, alarmist media publicity and a compensation system that was too easy to access”

"When the scope of compensation was reduced, the episode ended"

"If physical and psychiatric injury are to be treated in similar fashion, then the eggshell personality argument should remain valid for as long as the eggshell skull argument is accepted in physical injury. However, as the Commission notes, this principle is already under review in the case of Page v. Smith. The current author (ie. Wessely himself) gave expert testimony in that case, which concerned a gentleman with a history of previous psychological disorder, who suffered a relapse of a chronic fatigue syndrome
after what was a relatively minor car crash. I made what I thought was the relatively uncomplicated observation that he had relapsed......not because of any virological, neurological or immunological process, but because of his vulnerability to psychiatric injury conveyed by his previous history"

"That this argument successfully surfaced in the context of a case concerning the already controversial subject of chronic fatigue syndrome was ironic....The Court of Appeal chose to reject that argument....The...verdict of the House of Lords was to restate the law in its original form --- eggsgell personalities remain"

"Myself and others who write on the subject of chronic fatigue syndrome/ME draw attention, with monotonous regularity, to the malign consequences of a hierarchy that places physical above mental disorders in terms of importance, but reverses the situation as regards moral culpability"

"The Commision wonders if treating psychiatric illness just like any other personal injury would open the floodgates. It is this author's belief that uncritical acceptance of the simple medical model would do just that".

1995

'Have you heard? We are being poisoned' Simon Wessely. The Times 4th July 1995 p.14

"The release of poisoned gas into a crowded Tokyo subway on March 20, which killed 12 people, was one of the most frightening acts of modern urban terrorism. Since then there have been several reports of sudden episodes of...panic among crowds of Japanese commuters"

"These were probably examples of mass hysteria, which occurs when a group of people believe themselves to be ill"

"It is far from rare. In 1989 a group of Alaskan schoolchildren reported a mystery gas with a smell like rotten eggs: within minutes 700 children had collapsed with acute breathing difficulties. A Rhode Island school also experienced a mass collapse in the first week of the Gulf War. This was blamed on a gas leak but...was later linked to the media coverage of the risks of chemical warfare"

"There have been similar British accounts of mass hysteria...nor are children the only victims...even when no cause is found the affected children or their parents may believe that they have been affected and embark on a lifetime of susceptibility to strange allergies and chemical sensitivities"

"Mass hysteria is far from new....All that has changed is the precise nature of the false explanation. In previous times mass hysteria would be blamed on demons, spirits and diabolic possession. Nowadays we are oppressed by equally invisible gases, viruses and toxins"

"So long as (the) true nature (of mass hysteria) is rapidly identified...little harm results. Things only go wrong when the nature of an outbreak is not recognised and a fruitless and expensive search for toxins, fumes and gases begins".

1995


"The small Cornish town of Camelford is the reputed site of Camelot in Arthurian legend"
But what of Camelford's other claim to fame - as the location of the water pollution incident on 6 July 1988, when a driver accidentally dumped 20 tonnes of aluminium sulphate into a reservoir at the local purification plant?"

"The aluminium sulphate made lots of people seriously ill, but mass hysteria was largely responsible for the furore"


"David and Wessely...write... 'Immediate symptoms included nausea and vomiting, skin rashes and mouth ulcers. Others noted that their hair, skin or finger nails had been stained blue or brown', yet few of those affected were sufficiently concerned to seek help from their general practitioners. Of 600 consultations at the time, only two were by people seeking help over health effects of the pollution"

"Nevertheless, when the first Clayton report in 1989 concluded that...there was little cause for concern about the longterm effects, some local residents suspected a cover up. Litigation was under way, and a pressure group grew in strength"

"The second and longer Clayton report of 1991...reached an unambiguous verdict: there was no evidence of long term adverse effects on health as a consequence of the water contamination"

"The report cited anxiety as the cause of the long term symptoms that had been claimed by up to 400 people"

"David and Wessely's wide ranging review contains nothing to alter this verdict"

"It was...non-medical features...which turned an incident into a legend --- the second legend of Camelot."

(Note: the David and Wessely "reassessment" of the Camelford incident bears no relationship to the facts. Douglas Cross, an Environmental Consultant and Forensic Ecologist, investigated the Camelford drinking water poisoning: his findings are published in "The Politics of Poisoning: The Camelford Aluminium Sulphate Scandal" (The Ecologist:1990:20:6:228-233). In a separate paper (Political and Industrial Pressure on Environmental Consultants), Cross explains that what the people of Camelford were exposed to was not simply an acidic aluminium sulphate solution, but a strong and dangerous cocktail of metals, particularly copper, mixed with a range of potentially chelating agents, such as tea or citric acid. In fact the water authority recommended that people should use orange juice to disguise the foul taste. Cross continues: "The highly acidic water was contained, and even stored at high temperatures, in modern copper pipework and hot water tanks, with soldered joints. With pH values of between 3 and 4 in the water, the resultant system closely remembled a primitive sulphuric acid battery and the electrolytic action across the soldered joints promoted active dissolution of metals into the water, most notably copper".In other words, what people were actually drinking was perhaps a weak solution of sulphuric acid.

In the Camelford catastrophe, seven people died and 25,000 suffered serious health effects; 40,000 animals were affected. Much evidence and information was collated very quickly and the local community co-operated. South West Water was taken to court: it was eventually convicted of being a nuisance).
"Many doctors, particularly immunologists and general practitioners, 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 prove difficult to manage. This article addresses these issues so that physicians know how to manage such patients...identify psychiatric diagnoses...and make referrals."

"A small proportion of those who believe they have allergies develop symptoms to numerous environmental substances, such as foods and their additives, and chemicals. In some cases patients claim allergy to almost all of the environmental products of the Western world and have attracted diagnoses such as total allergy syndrome, multiple chemical sensitivity or environmental illness."

"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 largely unknown...As such it 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: it may be useful to recall that the WHO does not regard ME as "a belief", but as a discrete neurological entity.)

"Orthodox physicians have found no consistent physical or immunological abnormalities to explain the multiple symptoms these patients experience...Nevertheless, patients often undergo large numbers of medical investigations (and) large amounts of resources are consumed in the process."

"One intriguing aspect of the new allergy diseases is their overlap with other so-called modern diseases. In some severe cases the symptoms of those claiming environmental sensitivity overlap with disorders such as chronic fatigue syndrome (CFS), myalgic encephalomyelitis (ME)...sick building syndrome and candida infection."

"Psychiatric research has demonstrated a high prevalence of psychiatric disorder in patients with 'environmental illness'."

"A history of psychiatric morbidity predating the onset of sensitivity to chemicals has been found to be a strong predictor of the development of multiple chemical sensitivity."

"Those who advocate environmental explanations...argue that such symptoms should be considered as further evidence of environmental sensitivity -- the psychological disorder as a consequence of allergic mechanisms...However it is still necessary to prove consistent abnormalities of immune dysfunction before it can be argued that these are the cause of any observed psychological morbidity."

(Note: it may be recalled that, in his capacity as UK representative to the US Centers for Disease Control, Wessely is a signatory to the definition paper on CFS and that this paper specifically advised that immunological investigation should not be carried out.)

"Weak (immunological) evidence was...provided by a 15 year follow up of subjects enrolled in an American Health Maintenance Organization (HMO)...Malaise at the start of the study was associated with a modest
increase in so-called 'hyperimmune' conditions (an odd collection including asthma, allergy, hay fever, osteoarthritis and autoimmune diseases) 15 years later" (Note: there is extensive evidence in the world literature that 'hyperimmune' status is regularly found in true ME; Wessely's deliberately casual and dismissive attitude is once again demonstrated by his almost perjorative use of the term 'an odd collection'; the illnesses he then lists are responsible for considerable morbidity).

"Those working in allergy clinics can expect to find high rates of psychological disorder in patients whose unusually strong beliefs of an allergic basis to distress are not confirmed by clinical investigation. These patient populations recruited from...the environmental illness 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"

"Somatisation...sufferers have long histories of unhelpful medical and surgical admissions with high rates of disability, yet 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, either receiving no diagnosis or one of (the) ill-defined and overlapping syndromes such as chronic fatigue syndrome"

"The risk of psychiatric disorder is known to increase linearly with the number of symptoms with which the patient presents"

"It may appear more acceptable to attribute allergy as the cause of symptoms than psychological problems"

"Attribution of unexplained symptoms to a 'virus', as happens in most patients with the label of postviral fatigue or ME, may thus 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"

"One example is the change in the nature of beliefs of those who fall victim to contagious episodes of emotional distress...(mass hysteria)"

"Recent examples have included complaints of toxic gases, solvents, air pollution, and pesticides"

"Similarly, patients with chronic fatigue and multiple system symptoms attribute their symptoms to ME"

"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 belief in organic pathology (and) add to the cost of the consultation"

"Patients...will benefit from...training in...cognitive coping skills"

"Other patients...should be treated with psychotropic drugs"
"The idea that 'stress' can influence the immune system is prevalent in modern western culture"

"All too often referral letters from physicians state: 'please see this patient who has nothing wrong with them'"

"Some clinical ecologists claim that suggestions of possible psychosocial aetiology can itself then cause the psychological disorders found in many patients"

"Although we do not yet fully understand how patients develop these new allergy diseases, research into related syndromes have suggested various possible treatment options...these include...cognitive behavioural therapy"

"Liaison between the physician and the liaison psychiatrist is necessary so that patient acceptance of psychiatric referrals can be facilitated".

(Note: significantly, Wessely refers critically and dismissively to ideas which he attributes to "Some clinical ecologists" (page 512) and gives a reference in support of his statement: the reference in question is in fact written by a clinical psychologist, and further, the reference quoted by Wessely is the wrong article from a series of articles in the Newsletters of the Society for Environmental Therapy 1992).

1995

What is this mystery illness which we call Gulf War Syndrome? Simon Wessely. The Times 27 July 1995 p.10  Despite all they went through, Gulf veterans are healthier than average, says Dr Wessely

(Note: this article was referred to above in the section on Wessely’s Tactics).

"In this country alone there have been more than 200 newspaper reports concerning Gulf War Syndrome, which has apparently left some ex-servicemen and women crippled with mysterious illnesses"

"Why might service in the Gulf have caused longterm illness?....Even if direct casualties were light, soldiers faced new threats. The most pressing was that Iraq would use chemical and biological weapons....it is not hard to imagine just how stressful this threat must have been"

"Since then other risk factors have surfaced -- a recent summary produced by the Institute of Medicine in Washington reads like a catalogue of 20th century demons -- 'biological and chemical warfare, depleted uranium, microwaves, chemical exposures, oil-well fires, pesticides, petrochemicals, physical stress, pyridostigmine, rape or sexual harassment, stress, vaccination and inoculation'.... Add to this a whiff of cover-up and one has a potent brew of modern illness fears"

"More than 2,000 American and 200 British personnel have been fully evaluated. No new illness or specific Gulf War Syndrome has been identified"

"Obviously something is wrong with the sick soldiers -- but one must not automatically assume it is the result of service in the Gulf....Do Gulf War veterans show increased rates of any known...psychiatric condition?"

"The latest report from the Department of Defense shows that 80 per cent of the sick soldiers were suffering from known conditions such as cancer. It is the remaining 20 per cent who are left with mysterious illnesses such as chronic fatigue syndrome or multiple chemical sensitivity which are controversial even in those who have never been near the Gulf"
"It is probably these ill-defined and poorly understood conditions that have given rise to many of the myths surrounding Gulf War Syndrome"

"Did these immunisations in some unknown way 'overload' the immune system and trigger conditions such as chronic fatigue syndrome? Vaccines can produce short-term discomforts...but there is no evidence linking them with long-term problems such as ME"

"Simply finding a serviceman who complains of depression, chronic fatigue syndrome, cancer or anything else and who also went to the Gulf proves nothing"

"In the meantime we should resist the temptation to subject those few soldiers who have come forward for testing to ever more complex investigations in the hope that 'something will turn up'"

On 29th July 1995, an ME researcher wrote to The Times:

"In the above article Dr Wessely states there is no evidence of any link of vaccines causing long-term problems such as ME or Chronic Fatigue Syndrome...He is either inordinately ignorant of the documented evidence or deliberately misleading your readers. I had no problem in finding 16 references to such links, including one emanating from a renowned professor in immunology and another from an equally renowned consultant neurologist from Harvard Medical School, not to mention the Government-funded National Task Force Report on CFS/PVFS/ME. It would be nice if The Times occasionally would publish a response to Dr Wessely's unique assertions". On 1st August 1995 a letter of rejection was sent by Ivan Barnes.

1995

Costing a bitter dispute over pills  Are the new antidepressants such as Prozac better than the older type? Dr Simon Wessely reports. The Times 3.10.95 page 14

"What happens when specialists disagree about the effectiveness of a new development? Psychiatrists are facing this question in the treatment of depression. Conventional antidepressants, introduced in the 1950s, are known as the tricycles because of their chemical structure...The precise way in which they act to relieve depression is still unclear but it is probably linked to the finding that tricycles increase the levels of several chemical messengers (neurotransmitters) in the brain"

"Fluoxetine, better known by its trade name Prozac, has a different action (and) is classified as a selective serotonin re-uptake inhibitor or SSRI"

"The arrival of SSRIs has led to predictable competition between manufacturers, but the differences between SSRIs are not fundamental, nor are costs, so most psychiatrists do not have very strong views on the matter"

"The same is not true of the wider struggle between SSRIs and tricycles. The stakes are high"

"One tricyclic alone...(Prothiaden) represents 30 per cent of all GP prescriptions for antidepressants....Many pharmaceutical company fortunes now rest on changing this"

"The debate is thus occasionally bitter, and there have been several angry exchanges in the letter columns of the British Medical Journal. Partisans have claimed that doctors who continue to prescribe the old
drugs are irresponsible and even negligent, while opponents say that the supporters of the SSRIs are in the pockets of the drug industry"

"Academic psychiatrists with strong connections with the pharmaceutical industry complained that some of the trials...were of poor quality. They re-analysed only those trials they regarded as being of adequate standard. This time, SSRIs did better than tricyclics"

"It is likely that a doctor's decision to stay with the old or switch to the new will remain a personal one, influenced by...the skills with which the drugs are marketed".

(Note: the above essay surely represents Wessely's subliminal tactics at their unequalled best).

1995

Contrasting neuroendocrine responses in depression and chronic fatigue syndrome

(Of particular note is the fact that this paper was received for publication on 5th January 1995, so its conclusions must have been known to Wessely by that date).

"These data confirm that depression is associated with hypercortisolaemia and reduced central 5-HT neurotransmission and suggest that CFS may be associated with hypocortisolaemia and increased 5-HT function"

"The opposing responses in CFS and depression may be related to reversed patterns of behavioural dysfunction seen in these conditions"

"These findings attest to biological distinctions between these disorders"

"Importantly, the CFS and depressed group differed on all three outcome measures (prolactin response, cortisol response and basal cortisol) after careful matching with controls"

"Our findings...support preliminary findings of hypocortisolism and increased 5-HT neurotransmitter function in CFS"

"The demonstration of healthy control responses that fall mid-way between depression and CFS suggests that the neuromodulators measured in this study, HPA axis function and 5-HT neurotransmission, may be pathologically altered in opposite directions in these two conditions"

"That HPA axis and/or 5-HT function may be causal in these reversed biological symptoms is suggested by preclinical evidence that CRH is an activating peptide giving rise to increased motor activity and general arousal and decreased feeding and sleep....There is animal evidence that the 5-HT re-uptake inhibitor antidepressants may work by reducing HPA axis function"

"These findings suggest that depression and CFS are characterised by an exaggerated and a deficient stress response respectively".

(Note: this study is yet another one showing that CFS/ME and depression are biologically distinct: [Interaction 1996:20:2]. The results also challenge the view that antidepressants which increase levels of 5-HT (eg.Prozac) are appropriate treatments for ME/CFS. According to the data contained in this study, many patients with CFS/ME probably have enough 5-HT and do not need their levels increasing, as people
with depression do. The findings also explain why the paper by Vercoulen et al, which was presented at Brussels in November 1995, found that Prozac was no better than a placebo for people with chronic fatigue/ME. Of note is that Prozac was found to be ineffective in 'pure' depression also.

1995

The Epidemiology of Chronic Fatigue Syndrome  S Wessely

"In recent years clinicians in many countries have been starting to report increasing numbers of patients presenting with complaints of profound exhaustion after minimal physical and mental effort, often accompanied by numerous other somatic symptoms such as muscle pain; headache, sleep disturbance and others"

"Clinicians have also noted that such patients are predominantly women and tend to come from higher social classes....Each of these features may give clues as to the aetiology"

"All might...be due to a combination of complex selection and referral biases"

" 'Yuppie flu' is a myth created by selection bias"

"Common infections seen in primary care are not related to CFS"

"Functional impairment is associated with CFS....Psychological morbidity is very common, and is related to functional impairment, and to the number of somatic symptoms"

"Being female remains a risk factor"

"It is essential to have a case definition, and in the last few years at least two working case definitions have been provided. This represents a major step forward"

(Note: Wessely was involved with both these case definitions, and both emphasise a psychiatric aetiology of CFS. Many non-psychiatrists who are involved with true ME regard these definitions are a major step backwards).

"Epidemiological studies continue to cast doubts on the validity of the CFS concept"

"It remains possible that, like fibromyalgia, CFS represents the arbitrarily defined end of a spectrum of symptomatic and functional impairment".

(Note: attention is drawn to other presentations at the Proceedings in Brussels which documented the aberrations in neuroendocrinology, the neuropharmacological tests that differentiate CFS from depression, neuroradiological abnormalities, immune aberrations, lesions in muscle mitochondria and disturbed metabolism).

In his Welcoming Remarks at the Brussels Congress, Professor Peter Behan of Glasgow said the following in his official capacity as Conference President:

"In the past, clinicians...became polarised into two groups, those who tried to explain all the symptoms as nothing but the manifestations of psychopathological processes and those who realised that patients had an organic illness....We have only to look at most diseases in which the aetiology was previously unknown,
to see that this psychobabble was commonly used as an explanation. The group...who realised that the patients were genuine, accorded them enough dignity and respect to believe what they said”

“In between attacks, the patients with epilepsy may be entirely normal on every imaginable test but this in no way changes the fact that there is something wrong with them. Fortunately there have always been physicians who have striven to be sympathetic to patients with CFS and to try and understand the mechanism for their symptoms”.

1995

Chronic fatigue, chronic fatigue syndrome, and fibromyalgia  Wessely S and Sharpe M
In: Treatment of Functional Somatic Syndromes; ed: Mayou R, Bass C and Sharpe M  (chapter 16); OUP 1995

On the issue of patients’ associations making medical research information available to members, Wessely and Sharpe state: “Such information may have a considerable and often unhelpful influence on patient attributions of illness”.

1996

ME: Is this the answer?  Dr Simon Wessely  The Times  January 9 1996  page 14

Sufferers from ME are usually ordered to do nothing but rest. Dr Simon Wessely describes an alternative showing good results

"Myalgic encephalomyelitis (ME) or chronic fatigue syndrome (CFS) as we should now call it is usually characterised as controversial, difficult to diagnose, debilitating and difficult to treat. The first three are true, but...at last doctors can report promising treatment"

"Rest remains at the centre of advice given to sufferers....Unfortunately...rest is not without its side-effects"

"About 50 per cent of the CFS patients we see in our specialist clinic are depressed --- I am sometimes surprised it is not more"

"Sufferers are told so emphatically to rest because in the short term rest works -- it reduces symptoms. The cost is long-term problems"

"But this week’s British Medical Journal brings some hope. Researchers at the Department of Medicine and Psychiatry at Oxford University have published a randomised controlled trial of a structured rehabilitation programme for CFS. One year later 73 per cent of those receiving the active treatment had done well...compared with only 23 per cent of those receiving standard medical care"

"The treatment (called cognitive behaviour therapy) is based on a very simple idea that regardless of what starts an illness...something else may be the reason why people fail to recover"

"This is not the first time cognitive behaviour therapy has been used to treat CFS, but Dr Michael Sharpe and his Oxford team have provided a randomised controlled trial. It is not a flash in the pan either --at King's College Hospital my colleagues and I have also completed a controlled trial of the same treatment with equally promising results"
"It is important to consider the psychological side of the illness -- are there emotional factors such as fear or depression which need treatment?"

"(CBT) does offer a realistic and safe method of improving the quality of life and starting sufferers on the road back to health"

"The BMJ report concludes that...disability in patients with the condition is not fixed"

"Given the controversial nature of chronic fatigue syndrome, not everyone will welcome this news"

""It would be encouraging to think that such prejudices will be overcome by the evidence of two randomised trials".

Studying chronic fatigue syndrome: Response from Dr Charles Shepherd, Honorary Medical Adviser to the ME Association, The Times  January 18 1996

"Far from sufferers with ME being usually ordered ‘to do nothing but rest’ as your heading states, the ME Association's Guidelines for the Care of Patients booklet, which has been distributed to well over 10,000 doctors in the UK, makes it clear that the best way forward is to pursue a programme of gradually increasing both physical and mental acitivity"

"Although 22 patients out of 30 in the Oxford...CBT trial achieved an improvement of approximately 10 per cent in their disability rating after a year, the only other two controlled trials of CBT to be published found no benefit from this fashionable form of short-term psychotherapy"

"The ME Association believes that...the results so far obtained...do need to be viewed with a considerable degree of caution".

Feeling tired and confused: A treatment for chronic fatigue syndrome has provoked a hostile reception from sufferers. By Rob Stepney  The Independent Section Two  26 March 1996

(Note: the author's wife is one of the therapists in the Oxford trial).

"A year ago Laura reached her lowest point...with permanent flu symptoms, panic-stricken and confined to a wheelchair, she was eventually diagnosed as having chronic fatigue syndrome, the term doctors now use instead of ME"

"Laura, a 30 year old marketing manager, has since made a remarkable recovery....She puts her newfound sense of wellbeing down to a technique called cognitive behaviour therapy"

"Research shows CBT can...help people with chronic fatigue syndrome. Yet many sufferers are bitterly opposed to the treatment, arguing that their condition is physical, not psychological"

"Laura says that CBT helped her to change the way she thought about her problems without implying she was to blame for them"

" 'Many people with chronic fatigue (sic) have a personality which hinders recovery' Laura says"

"Laura's experience of overcoming chronic fatigue (sic) does not stand alone. The British Medical Journal recently published results of a study that compared 30 patients given CBT with another 30 who received standard medical care. At the end of a year, more than 70 per cent of the CBT group had improved significantly, but this was true of fewer than 30 per cent of the controls"
"Results of the Oxford trial have been replicated by a second study...from King's College Hospital, London"

"Until CBT, no form of treatment had shown much promise, so the new evidence that helps should be widely welcomed. Surprisingly, it has received a luke-warm response from a source one might expect to be more enthusiastic. Last week's magazine published by the ME Association...is grudging at best. The magazine's medical editor is Stephanie Woodcock. She says of the Oxford study: 'The full weight of 'righteous zeal' exhibited by the therapists does not seem to have produced anything more than a perfunctory change at the margins of the illness' "

"Some doctors have clearly provoked hostility by denying a problem exists. 'ME is an escape route for the middle classes' claimed one psychiatrist, who writes under the pseudonym of Dr Dalrymple"

"At the other pole are those who will countenance nothing but a physical cause for CFS. 'This is an organic problem. There are clear disturbances of brain and hormone function' argues Peter Behan, professor of neurology at Glasgow University. 'To claim cognitive therapy tackles the underlying problem is bunkum' "

" Though they don't speak for the majority of sufferers, there are certainly some people who would rather see trials like that in Oxford fail,' says Dr Simon Wessely, whose CFS research unit at King's College Hospital works on both psychological and hormonal approaches to the disease"

"Dr Wessely has received dozens of hostile phone calls and letters, despite his broad range of research"

"Dr Richard Smith, editor of the British Medical Journal which published the Oxford trial, has also been bitterly criticised for its approach to CFS....'It is claimed we are biased against the idea that CFS is physical'"

"Sometimes, in struggling to get better, (patients) make things worse. Cognitive behaviour therapy can break the vicious circle"

(Note: Rob Stepney's article then promotes CBT even further: "Trudie Chalder's book 'Coping with Chronic Fatigue' (Sheldon Press)...is a good starting point for anyone interested in CBT". It is notable that Wessely himself wrote a most glowing and enthusiastic forward to this book).

Doubts on ME therapy trial Response from Dr Charles Shepherd, Honorary Medical Adviser, ME Association. Independent, 30 March 1996 page 16

"Having recently referred a patient with CFS to Dr Michael Sharpe's unit in Oxford for a course of CBT I was surprised to find Rob Stepney...inferring that the ME Association was provoking a hostile reaction to this form of treatment"

"We have no doubt that CBT can be of value where there is co-existent depression, panic attacks, or what is termed 'abnormal illness behaviour'....We will continue to review the often conflicting results of trials such as that at Oxford with a healthy degree of scepticism".

Response from Catherine Rye ibid

"I am a sufferer and participated in the Oxford trial you highlighted. The article...implies....that a new successful treatment has been found for ME but that sufferers and others 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"

"There is mounting research showing that ME is a complex neurological disease although Chronic Fatigue Syndrome is a broader term which probably encompasses a wider range of disorders".

1996

Sickness of the century. Patients may grumble about modern ills, but Simon Wessely sees a connection to fears of the past. The Guardian May 28 1996 page 13

"The film ‘Safe’ tells the story of...a normal...Californian housewife whose life disintegrates as she develops increasingly debilitating reactions to everyday household objects, starting with her sofa....Critics are uncertain if the film is...a parody on the odd health beliefs of Americans or an attempt to awaken us to the perils of another health hazard. On one thing only are all the critics agreed -- it is a story of contemporary life. But they are wrong"

"Like many hospital specialists, during the past few years I have seen a steady stream of patients with many mysterious symptoms that other doctors cannot explain. The sufferers usually blame their ill health on a variety of factors such as solvents, pesticides, pollution, candida, car exhaust fumes, food additives or dental amalgam. Many report exquisite sensitivity to such everyday substances as perfumes, deodorants, tap water and hairspray"

"I recall one patient, who would only leave his house wearing a mask...who still dramatically collapsed when he realised that one of our medical students was wearing aftershave"

"Such people are sometimes labeled as suffering from 'total allergy syndrome'"

"I also remember a highly educated city lawyer...He had read about the hazards of electromagnetic radiation, and believed that was the cause of his illness. As a result he had gone round his house and had placed tin foil over all his electrical appliances and plugs to reduce electromagnetic emissions"

"All of these explanations, superficially very different, have much in common. First, there is no personal blame. It is not the sufferer, but the dentist, or estate agent, or furniture manufacturer who can be blamed"

"All are linked by another modern theme-- the immune system in trouble. Why is the immune system the new zeitgeist?...Immunologists make it clear that these links do not explain these new '20th century' illnesses, which are not immunological disorders" (note: many clinical immunologists do believe these are manifestations of an immune system which is permanently up-regulated, and there is substantial published evidence of this in the international peer-reviewed literature; see Appendix I).

"I doubt it is coincidence that multiple chemical sensitivity, and total allergy, rose to prominence in parallel with the rise of HIV. The idea that the immune system might give way because of an invisible external agent is now embedded in popular consciousness"
"By calling these conditions 20th century illnesses we make implicit both their link with modern conditions, and their newness. Doctors, and particularly immunologists, are therefore easily blamed as being either ignorant of, or hostile to, their existence. But just how new are these modern illnesses?

"As far back as 1891...a French neurologist published his book on a new modern illness, called neurasthenia, or nerve weakness"

"Parisian public health specialist Dr Adrien Proust...claimed that neurasthenia was 'the disease of the century'....It is ironic that his claim to fame is as the father of the novelist Marcel....From a child (Marcel) was labeled as having various 'allergies'....His symptoms became so incapacitating that he rarely ventured out of his cork-lined room. On the few occasions he did so he would be wrapped up...to prevent him catching any new allergies -- just like my aftershave-sensitive patient"

"The things that we blame for making us feel ill change over the years. Medieval man was oppressed by spirits and demons....Nowadays we blame similar ills on mysterious viruses, and allergies"

" 'Modern' illness is far from modern".

(Note: it is sometimes difficult to separate fact from assertion; without being fully aware of the international literature which shows Wessely's opinionated views to be comprehensively wrong, it would not be difficult to find his endlessly repeated ideology to be plausible; it is, therefore, essential that one is aware of and conversant with world literature on this aspect, otherwise one cannot even begin to assess Wessely's immense output with any degree of realism).

Allergy danger. Response to the above article: letter from Mrs Elizabeth Girling, Chairperson of the Lothian Allergy Support Group, Guardian 1 June 1996 page 26

"Simon Wessely's idenitifation of food and chemical allergies with fears about contemporary society...makes me angry. Eleven years ago our son died as a result of psychiatrists' refusal to believe that his mental symptoms always followed certain food and most psychiatric drugs"

"Growing numbers of hospitals now test and treat allergies...but we have yet to hear of a psychiatrist who would not choose to give drugs, however harmful their side-effects".

1996

Chronic fatigue syndrome: a stress disorder? Anthony J Cleare, Simon C Wessely
British Journal of Hospital Medicine 1996:55:9:571-574
(note: this paper is in the section of the Journal headed Psychiatry: Chronic fatigue syndrome and contains nine self-references).

"CFS affects about 1% of the population....This article describes the complex relationship between stress and CFS, including viral infections and psychological factors"

"The role of viral infection in CFS remains controversial"

"Predictors of this fatigue included somatic attribution styles...and the issuing of a sick note"

"In a carefully controlled prospective study, Wessely et al (1995) found no increase in fatigue in those suffering from a symptomatic viral infection compared to those without infection"
"The predictors of CFS were previous psychiatric disorder and prolonged convalescence"

"Taken together, this suggests that common viral infections do not trigger CFS, but severe infections do -- acting, we presume, as a stressor rather than by any specific molecular process"

"It is interesting that psychological stress, before or at the time of infection...is a powerful predictor of fatigue persisting after viral infection (Wessely et al 1995)"

"It can be concluded that psychological symptoms (1) may predict the development of CFS (2) are part of the syndrome of CFS itself (3) may be present as co-morbid illnesses (4) act as maintaining factors in fatigue chronicity"

"CFS sufferers may possess personality types more liable to generate stress than non-sufferers"

"Recent research has revealed intriguing abnormalities of the HPA axis in CFS sufferers...It may be that previous episodes of depression or chronic stress leave so-called 'endocrine scars', increasing the risk of subsequent CFS or depression"

"The link between CFS and stress suggests several possible modes of therapy. On a biological level, the rationale for using antidepressants is provided by...the presence of comorbid depression in around 50% of cases"

"More convincing evidence...relates to the benefit of psychological and rehabilitative treatments. Cognitive-behavioural therapy attempts to overcome the behavioural avoidance...using a graded exposure model. At the same time, illness attribution, negative conditions, maladaptive coping strategies and links to personality traits can be identified, challenged and modified....There is now controlled evidence for the effectiveness of this therapy (Sharpe et al, 1995)".

1996

Memory, attention and executive function in chronic fatigue syndrome
Eileen Joyce, Stephen Blumenthal, Simon Wessely JNNP 1996:60:495-503

"Patients with chronic fatigue syndrome often complain of poor concentration and memory. Several studies have looked for objective evidence of cognitive dysfunction...but have found only mild deficits, if any" (Note: papers listed in Appendix I clearly contradict this statement)

"Two studies have examined memory and information processing while measuring evoked potentials...One study found distinct abnormalities in the P300 cognitive evoked response whereas the other did not"

"One explanation of these discrepant findings concerns sample selection"

"The role of expectancy...might also exert an influence"

"A total of 2376 patients aged 18 to 45 were recruited from primary care after a consultation with a general practitioner for a viral infection"

"Of these, 1985 were followed up at six months...to establish the criteria for chronic fatigue syndrome....These patients were spread across five general practices in the south of England"
"Most of the fatigued patients did not consider themselves to have chronic fatigue syndrome or myalgic encephalomyelitis and were not seeking help under these labels"

(Note: this raises the question of whether or not these patients actually had ME/CFS despite the title of the paper).

"In this study we have examined the cognitive function of a group of patients with chronic fatigue syndrome prospectively identified in a primary care setting"

"The patients with chronic fatigue syndrome were most impaired on tests of spatial span and spatial working memory....Patients with chronic fatigue syndrome made more between-search errors than controls....They were also deficient in using a search strategy"

"The patients with chronic fatigue syndrome were impaired only when they had to retain some pattern locations in memory while learning.... others also showed impaired verbal fluency"

"In summary, we have shown that patients with chronic fatigue syndrome have cognitive deficits predominantly in the domain of memory....The profile of deficits suggests an attentional problem.....We propose that in chronic fatigue syndrome, the subjective experience of both central fatigue and impaired concentration and memory is a reflection of reduced attentional capacity which is manifest objectively as impaired performance on effortful memory tasks"

"In our study, patients with chronic fatigue syndrome were not clinically depressed"

"Relative to their own control groups, patients with chronic fatigue syndrome were more impaired than depressed patients on the spatial working memory task and the attentional set shifting task"

"Thus there is little evidence from these parallel studies to support the contention that the cognitive deficits in chronic fatigue syndrome reflect a depressive illness"

1996

Chronic fatigue and minor psychiatric morbidity after viral meningitis: a controlled study
Matthew Hotopf, Norman Noah, Simon Wessely JNNP 1996:60:504-509

"Enteroviral infection has been suggested as a cause of fatigue and chronic fatigue syndrome, sometimes called...ME"

"We hypothesised that if enteroviral infection is a true risk factor...then this effect will be strongest in a sample of patients exposed to enteroviral infection of the CNS. Patients with viral meningitis represent such a sample"

"If enteroviruses cause chronic fatigue syndrome we would expect patients recovering from viral meningitis to be at increased risk of abnormal fatigue"

"There were no statistically significant differences in outcome between the group who had viral meningitis compared with other viral infections. This suggests that there is little to support enterovirus infection as a specific risk factor for chronic fatigue syndrome"

"The variables which best predict chronic fatigue syndrome at follow-up are previous psychiatric morbidity and a prolonged convalescence"
"This was a postal survey and a response rate of 77% leaves the results open to response bias...because those with fatigue may be more inclined to respond"

"A history of previous consultation for psychiatric disorder predicted chronic fatigue syndrome"

"The relation between psychiatric morbidity and chronic fatigue syndrome is well established" (a self-reference is given in support of this claim)

"Previous psychiatric morbidity might be a risk factor by leading to prolonged convalescence, or alternatively may act directly due to the considerable overlap between depression, anxiety and fatigue....It may be possible to predict those at risk of poor outcome after physical illness, and to plan early intervention".

1996

The rise of counselling and the return of alienism  Simon Wessely

(Note: This essay mentions chronic fatigue syndrome only in passing; it is an attempt to preserve psychiatrists' autonomy over the rise of counselling, thereby ensuring psychiatrists' opportunity to prescribe antidepressant and cognitive behavioural therapies).

"'Worried well force aside the mentally ill' ....At issue is a fundamental question about mental health services.....Who is really in need?....Who to meet that need? Should patients always get what they want anyway?"

"The rise of counselling has attracted both attention and criticism....Having joined the ranks of others who noted the lack of evidence for the efficacy of counselling, (the authors of a recent editorial) concluded that 'all counsellors in primary care should be properly trained, supervised and supported'....However...a properly trained and supervised person who delivers an ineffective treatment is hardly a sign of progress"

"The evidence in support of counselling is scarce for several reasons....General descriptions such as 'providing an opportunity for the client to work towards living in a more satisfying and resourceful way' are more mission statements than descriptions of treatment (and) adverse effects are rarely considered"

"Data from randomised controlled trials suggest that specific psychological treatments, such as cognitive therapy, behaviour therapy...can be effective for these disorders"

"Some claim that counselling is effective because it reduces the use of antidepressants....In a recent study one of the claimed benefits was a 60% reduction in the use of antidespressants (ref: J R Soc Med 1995: 88: 97-102) Such claims have not been confirmed"

"Replacing an intervention of proved efficacy with one whose efficacy is much in doubt is not a satisfactory outcome measure"

"Even if a therapy works in a randomised controlled trial that does not mean it will work elsewhere"

(Note: that is exactly the point made in response to the Oxford trial of CBT for ME).

"Cognitive behaviour therapy given by a skilled clinical team is effective in the management of chronic fatigue syndrome"
"The evidence is that CBT is not effective in chronic fatigue syndrome, but as ever, Wessely simply dismises or ignores any evidence which does not accord with his own views and agenda."

"The effectiveness of modern drug treatment...is beyond dispute, and there is increasing recognition of the effectiveness of non-drug treatments in preventing relapse"

"Patients with chronic somatisation disorders have few equals in terms of...cost to the health service"

"The obsession with severe mental illness means that psychiatry is in danger of withdrawing from the care of non-psychotic patients with mental disorder....withdrawing such services may reduce any influence the profession might have across the range of mental disorder"

"We must ensure that the growth in counselling does not divert resources away from access to such treatments as behaviour therapy...or cognitive therapy"

"The consequence of these changes will be an inevitable reduction in the scope of psychiatry...and indeed the attraction of a psychiatric career"

"Current policy has increased the pressures on the profession, as shown by the seemingly endless stream of public inquiries (15 are currently in progress) into the 'failures' of that policy, despite a lack of evidence of any change in the risk to the public posed by mentally ill people" (Wessely here supplies another self-reference in support of his last sentence: Wessely S, Castle D, Douglas A, Taylor P: The criminal careers of incident cases of schizophrenia. Psychological Medicine: 1994:24:483-502).

(Note: most people would be profoundly in disagreement with Wessely's claim: the appalling case of Jane Zito's husband, who was stabbed to death through his eye on the London underground by a mentally ill patient who had been delegated to community care is just one case in point).

1996

Psychological Symptoms, Somatic Symptoms, and Psychiatric Disorder in Chronic Fatigue and Chronic Fatigue Syndrome: A Prospective Study in the Primary Care Setting
Simon Wessely, Trudie Chalder, Steven Hirsch, Paul Wallace and David Wright

(Note: this is the third time that this study has been presented to different journals; (references: Population based study of fatigue and psychological distress. BMJ 1994, 19 March: 308:763-766 and Postinfectious fatigue: prospective cohort study in primary care. The Lancet 1995 May 27:345:1333-1338).

"The nature of chronic fatigue syndrome remains subject to controversy. Perhaps the most contentious area is the relation between chronic fatigue syndrome and psychiatric disorder"

"Thirty two somatic symptoms were measured by self-report in the case-control study....These symptoms were not specific to chronic fatigue syndrome"

"Subjects with...chronic fatigue syndrome were significantly more likely than subjects without fatigue to complain of 37 out of 38 somatic symptoms....there was a linear correlation between the mean number of somatic symptoms and various measures of psychological symptoms"

"The study had several limitations. First, we merged the two study cohorts (viral and non-viral illness) for this analysis. This was done to increase the power of the study...(but) results of all of the analyses reported are the same when the analyses are performed with either cohort"
"Third, we did not carry out all of the laboratory screening tests recommended in the latest CDC criteria. We only performed tests of liver and thyroid function, haemoglobin, urea, electrolytes and C-reactive protein. This was for reasons of cost. We feel that few, if any, alternative physical diagnoses would have been made if more extensive screening had been undertaken"

"Whether or not psychological vulnerability predisposes to chronic fatigue or chronic fatigue syndrome remains controversial"

"It remains possible that studies of the minority of chronic fatigue syndrome patients without co-morbid psychiatric disorder may reveal a different pattern of associations from that of the majority, as is beginning to emerge from studies of neuroendocrinology"

"Despite the current interest in chronic fatigue syndrome among the public and professionals, the nosological status of the disorder remains uncertain. Is it an independent entity or, alternatively, does chronic fatigue syndrome simply reflect an arbitrarily defined end of a spectrum of severity? Is there a particular symptom profile that serves to distinguish chronic fatigue syndrome? Our study suggests that the answer is no"

"One of the strongest findings of this study was the linear relationship between the experience of somatic and psychological symptoms"

"We... found no epidemiological justification for stating that certain symptoms are characteristic of chronic fatigue syndrome... solely because they resemble those of an infective or immunological disorder held to underlie chronic fatigue syndrome. Most symptoms may instead reflect... psychological distress"

"Only postexertional malaise, muscle weakness, and myalgia were significantly more likely to be observed in chronic fatigue syndrome than in chronic fatigue... None of the other 35 symptoms distinguished chronic fatigue, idiopathic chronic fatigue, or chronic fatigue syndrome"

"Case definitions are obligatory for many types of research... However, at present all such definitions must not be taken as verification of a specific nosological entity."

(Note: the most striking issue in the above paper is that Wessely et al do not comment appropriately in the text and conclusions on the significance of their own table 5 (which lists 38 somatic symptoms).

1996

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

"Persistent fatigue is a common complaint... Some with the most extreme symptoms and disability may be diagnosed as suffering from chronic fatigue syndrome (CFS) or, as it is more popularly known in the UK, myalgic encephalomyelitis (ME)"

"The treatment of CFS has been a mess. For many years sufferers have received no advice or help except exhortations to rest"

"There is no evidence that such advice is helpful and to offer it is to ignore a mass of publications stretching back over many years that testify to its adverse effects"
“However, there are signs of a return of common sense, and the situation may be improving”

"The strongest predictor of poor outcome is strong attribution of symptoms to a solely physical cause"

"Outcome studies to date describe the natural history of CFS without treatment, as they...used ineffective treatments"

"We can anticipate the publication this year of more encouraging studies that will prompt reassessment of previously cherished beliefs"

"Fatigue was predicted by a tendency to somatize emotional distress, imprecise diagnosis by the general practitioner, and the issuing of a sick note"

"We found no link between CFS and common viral illnesses"

"Triggering and perpetuating factors must be distinguished"

"Viral meningitis is a definite risk factor for subsequent CFS".

(Note: this would seem to be in total contradiction to what Wessely stated in his paper “Chronic fatigue and minor psychiatric morbidity after viral meningitis: a controlled study”. Matthew Hotopf, Norman Noah, Simon Wessely. JNNP 1996:60:504-509 in which the authors stated: "This suggests that there is little to support enterovirus infection as a specific risk factor for chronic fatigue syndrome").

"There is a strong association between CFS and psychiatric disorder"

"It is unlikely that psychiatric disorder is solely the consequence of physical disability"

"Psychiatric disorder affects the outcome of CFS, and requires treatment if present"

"Post-infectious fatigue that would otherwise be self-limiting may be exacerbated and perpetuated by the high levels of psychological distress it induces in such (type-A) personality types"

"A history of depression may predispose an individual to CFS. Depression is associated with...chronic social stress...(which) may cause perturbation of the HPA axis long after the stress has resolved. It may be that episodes of depression leave 'endocrine scars' that increase the risk of subsequent CFS or depression"

"The most widely publicized neuroimaging study of CFS found widespread abnormalities, in particular lowered perfusion of the brainstem....This finding must be interpreted with caution" (note: here Wessely relies on a reference written by his close collaborator Anthony David; see Appendix VI).

"Routine referral to a physician or neurologist is rarely indicated"

"Several groups have suggested a new model for understanding CFS" (here Wessely uses a self-reference and another from Michael Sharpe of Oxford)

"At its heart is the message that whatever triggers CFS may not perpetuate it"

“Perpetuating factors such as psychosocial stressors rapid loss of physical fitness...or concurrent depression may delay or impede recovery. Fatigue then becomes chronic, persisting long after the original trigger and being maintained by new variables"
"Chronic fatigue may be better understood...by focusing on...perpetuating factors, and the many ways 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, re-inforced 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...increased concern leads to...selective attention and 'body watching'; this can intensify both the experience and perceived frequency of symptoms, thereby confirming illness beliefs and re-inforcing illness behaviour"

"New models of CFS have prompted development of two styles of rehabilitation. The first...is graded exercise...the other treatment strategy is cognitive behaviour therapy (CBT)" (note: who decided to introduce “new models” of CFS, which Wessely asserts is the same as ME? ME remains a classified neurological disorder in the ICD).

"CBT seems to be a promising method of reducing disability in what is otherwise a chronic and intractable condition"

"CFS becomes less of an enigma with each passing month"

"A new report from the three Royal Colleges highlights that there lies at the heart of CFS not a virus, immune disorder or depression, but a distortion of the doctor-patient relationship".

Note (i): the report to which Wessely refers is the long-awaited joint report of the Royal Colleges of Physicians, Psychiatrists and General Practitioners on "CFS"; given that the joint report was compiled because Wessely et al strongly disagreed with the 1994 UK Task Force Report on ME/CFS/PVFS, such an outcome was a foregone conclusion, bearing in mind who the committee members were; they included Wessely. It is still in press at the time of writing but Wessely gives it as a reference.

Note (ii): on the very day on which the above article was published (14th August 1996), Stephen Dorrell MP, Secretary of State for Health, wrote a letter to one of his constituents who had contacted him about ME; in that letter he wrote:

“I think most would agree that, until such time as science is able to provide us with a diagnostic test for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), doctors will need to explore and consider both the possible organic as well as psychological causes of this illness. Concentration on one, at the expense of the other, may not always be helpful....Furthermore, I think that in considering the possible cause of ME/CFS, opinion may have been somewhat polarized around the origins of the illness....This is one of the reasons why the Chief Medical Officer has asked the Academy of Medical Royal Colleges for its expert advice on the nature and wider clinical aspects of ME/CFS to help towards the development of a professional consensus about this condition”.

Given that Wessely has already published the conclusion of this in-press report (as set out in his article immediately above), we can be in no doubt about the “expert advice” of this forthcoming report from the Academy of Medical Royal Colleges.

Our information is that the Royal College of General Practitioners was initially excluded from participation until after the report had been drafted by the other two Royal Colleges; this situation was apparently a source of unease to the Royal College of General Practitioners.
Given the strong motivation of Wessely to secure a joint report which fits his own agenda and that no-doctor experienced in ME was involved in any way with the joint report, no-one should be surprised at the outcome, least of all Stephen Dorrell MP, even though the American Psychiatric Association has confirmed that there are no plans to include ME as a psychiatric illness in the next revision of the DSM.

The quotations from Wessely's extensive output are not by any means comprehensive; they do, however, illustrate how remarkably assiduous he is in support of his own agenda.

Although it has been previously urged that one should read his papers in their entirety, this is once again emphasised, so that his papers can speak for themselves.

It is also emphasised that unless one is adequately familiar with the literature listed in Appendix I, it would be improper to attempt to formulate an opinion about Wessely's role in the current perception of ME.
Lack of balance

There can be no dispute about the authenticity of the quotations from Wessely's work contained in the preceding section because they are taken from his own published works.

Given that in his review of some 'popular' books on ME, Wessely was contemptuously dismissive about them on the grounds that they lacked balance (which he clearly stated in his letter of 16 June 1989 to the late Dr Eric Booth), it is quite remarkable that his own work should be so singularly lacking in balance.

This lack of balance which his own papers reflect has long been one of the underlying complaints levelled at Dr Wessely and at those whom he influences. Reading the opinions and research findings of other ME clinicians and researchers is like reading about a completely different syndrome, and, due in no small measure to Wessely, doctors in the UK have been grossly misled about an illness that has been totally misrepresented. Just one such example is about the demographics of the disease: contrary to Wessely’s assertions that ME is only found in the developed Western countries, there have been epidemics in Sierra Leone, Botswana and Papua New Guinea, but receive no mention.

Far more importantly, UK doctors have been misled about the nature, signs and symptomatology of ME.

In his lecture given in London on 18 November 1995, Professor Anthony Komaroff, Director and Professor of Medicine at Harvard Medical School, said the following:

"Depression is a serious illness, just as ME is, but I don’t think they are the same thing. These are the reasons why.

"First, there is a group of symptoms in ME --- sudden onset, lymph gland swelling, this post-exertional malaise, and night sweats. None of these symptoms reflect psychiatric illness.

"Secondly, there is a whole series of good studies that find abnormalities of the brain in the hypothalamic-pituitary axis, different to what one sees in major depression or other psychiatric illness.

"Third, there is the failure of this illness to resolve fully with psychiatric therapy.

"Not once has anyone’s illness gone away with psychiatric therapy. There was an important paper presented at the Brussels conference that used a treatment for depression called Prozac; in a randomised trial they found absolutely no benefit to ME from Prozac.

"And then there is the failure to find evidence of psychiatric disease, either before or after the onset of ME, in a large fraction of our patients.

"In ME/CFS, what you see is the opposite from major depression...this objective measure in ME is different from healthy people and even more different from major depression.

"So the simple answer to the question 'why isn’t it all just depression or some other psychiatric illness' is because it’s not.

"When we looked with our psychiatric colleagues we could not find evidence of psychiatric illness in the majority of ME patients.

"Now let’s turn to other objective laboratory studies. This is a paper published three months ago, in which we basically summarised 10 years of laboratory studies, conducted on over 700 patients with ME....All blood samples were tested by technicians who did not know if a sample came from a healthy or an ME person.
"We found very striking increased frequencies of abnormalities:

- immune complexes were found nearly 27 times more often in ME patients than in healthy controls
- elevated levels of Immunoglobulin G were found nearly nine times more often in the ME patients
- unusually shaped white blood cells were found 11 times more often…also several other abnormalities.

"So these tests are saying there is, in the ME patient, an activation of the immune system. The unusual white cells are typically taken to mean evidence of a virus infection.

"There is more evidence in the literature that the immune system in ME is chronically turned on. I think the body of evidence overwhelmingly says there is a chronic state of immune activation in these patients - as if they're fighting against something ---what are they fighting?

"Now what is the evidence of abnormalities in the brain?

"This part of the brain, the cerebellum, is important for balance, and there in the cerebellum are those white spots. In a large study…we found nearly 80% had these spots, compared to only 20% of healthy age and sex matched people….These spots don't always indicate a current abnormalities (but) what's striking was the much higher frequency of these abnormalities in the patients….Three other research groups have reported similar results.

"Another way of taking a picture of the brain is called SPECT scan. Look at the outer part of the brain in this ME patient (slide). You can see holes where it should all be smooth.

"We subsequently did SPECT scans of a large number of ME patients, patients with AIDS encephalopathy, major depression and healthy individuals. The computer counted how much signal was coming from the brain. Here (slide) is the signal in healthy people, and in major depression which is essentially the same. But here was the signal in patients with AIDS involving the brain, and here in ME involving the brain. Both statistically significantly lower: so there's something impairing the blood flow to the brain in these two groups (AIDS encephalopathy and CFS) compared with these two groups (depression and healthy controls).

"Two kinds of abnormal brain waves, called sharp waves or spike waves, are seen more often in patients with ME than in patients with major depression or healthy people. Yet another objective measure that says 'there's something wrong in the brain'.

"Recently a group from Johns Hopkins medical school looked at the autonomic nervous system, part of the brain that controls blood pressure, heart rate, breathing and other basic processes….They used tests of the autonomic nervous system…and found this test was abnormal by very stringent criteria in 70% of ME patients and none of the healthy control people. We have also been doing similar studies for the past four years.

"We published a paper a few months ago, on balance, or dysequilibrium, in patients with ME. On objective tests of the balance centre of the brain and the inner ear, we found very abnormal results.

"So the answer comes back 'there is something wrong with the brain'."

The Harvard researchers are not alone: in the UK, Peter Behan, Professor of Neurological Sciences at Glasgow, and perhaps the most eminent UK researcher into ME, is adamant that it is an organic as
opposed to psychogenic illness; he says that although it remains essentially a diagnosis by exclusion, there are now laboratory techniques which will confirm the diagnosis. He and his team believe there is a lesion at DNA level, hence the multisystem symptomatology. They have demonstrated what they believe to be a toxic or stress phenomenon in the mitochondria (the site of the cell's energy production), together with an abnormality of the lactic/pyruvic ratio (glycolysis is the conversion of glucose to lactic acid, which process involves the production of energy; during strenuous exercise, pyruvic acid--a compound derived from carbohydrates -- is reduced to lactic acid, which then accumulates in the muscles causing cramp and pain).

These studies have also been done in Oxford, in Canada and in Belgium, and the abnormal findings cannot be dismissed.

Professor Behan has also found evidence that ME is a metabolic abnormality, as demonstrated by reduced levels of acylcarnitine in ME, together with grossly abnormal lipid metabolism (carnitine is an amino-acid used in mitochondrial oxidation for transporting fatty acids across the membrane).

The Glasgow team, too, have found abnormalities on SPECT scans of ME patients, and, unsurprisingly, they have found major differences in immune function between ME patients and controls.

Behan has done thallium scans on patients with ME (thallium scans are a measure of studying blood flow through the heart muscle using an injection of the radioisotope thallium-201), and in 100% of ME cases, these scans are abnormal, showing what Behan described as gross abnormalities of the myocardium.

Another test used by the Glasgow team in ME patients is the water-loading test, which is given in the morning: the urinary output is measured over the next three hours, and in ME patients, again, the results are grossly abnormal.

Particular interest has been aroused by Behan's findings of disordered prolactin response, demonstrating that there is something wrong between the 5-HT axis and the production of cortisol (the hormone required for normal response to any stress).

Behan’s current thinking is that in genetically susceptible people, there is fundamental damage which is almost certainly at an enzyme level, affecting the subtle metabolism of the cell.

Behan is characteristically scathing about those doctors who dispute the organic reality of ME; he says that these tests bring home the fallacy of simply examining someone in a clinic with a tendon hammer and a stethoscope and pronouncing the patient to be normal (Lecture by Professor Behan at the Coventry & Warwickshire Post-graduate Centre on 23 November 1995; transcripts of this lecture are available from the present authors).

That this lack of balance (earlier documented by Dr Cathy Read in her 1993 report, Appendix IV) has infected the UK medical journals is readily shown: particularly notable was the fact that the BMJ did not report the findings of the UK Task Force on ME, nor has its Minerva column mentioned any research which supports an organic aetiology for the syndrome. Moreover, four leading articles in the BMJ were all written by people who are known to be strongly anti-ME as a nosological entity.

One can only wonder if such people ever read the available literature for themselves, or if they are content to be spoon-fed.

As an epidemiologist, it is beyond belief that Wessely cannot accept the need for rigorous case definition, and that such definition is paramount; despite his protestations that such rigorous case definition is essential in groups studied, he persistently fails to employ such a definition, or to provide a balanced
selection of the available references, and he often mis-reports and/or disparages others’ published findings, especially when those findings disprove his own entrenched beliefs.

For instance, minimal application of basic logic to just one of Wessely's papers (Fatigue syndromes: a comparison of chronic "postviral" fatigue with neuromuscular and affective disorders: S Wessely R Powell JNNP:1989:52:940-948) immediately raises a host of differential possibilities from those so strongly adopted by the authors:

(i) they start with a subjective introduction, and write "postviral" in quotes, thereby putting the whole illness in doubt from the outset

(ii) Wessely himself devised the fatigue questionnaire used in this study and he relies heavily upon it, yet by any standard it seems a vague and ambiguous measure. He divides fatigue into 'physical' and 'mental', but under 'physical' fatigue lists the sentences "I get tired easily" and "I can no longer start anything"

(iii) the second sentence quoted above could well be referring to 'mental' fatigue

(iv) all his questions could easily be answered in the affirmative by someone who was depressed

(v) the first five questions out of eight could be answered in the affirmative by someone with no muscle fatigue after exercise, yet post-exertional muscle fatigue is the cardinal feature of ME

(vi) Wessely fails to elicit what is meant or understood by 'exercise': is this a 100 metre struggle using two walking sticks and with several rests, or is it a two mile jog? Wessely proposes to equate the two

(vii) an even more important point is that Wessely seems to be claiming that sharing one symptom (ie. sleep or appetite disorder) is enough to classify the person as having a mood disorder: from an epidemiological perspective, it may be worth recalling that not everyone with a headache has a brain tumour.

Despite its obvious shortcomings, this study is often used by Wessely as a self-reference of importance and substance.

It is surely the duty of scientists to check that what they write is accurate, and it is the duty of editors to make sure that those who submit papers do not present their own opinion as fact.

When, on one of countless occasions, Dr Charles Shepherd of the ME Association wrote with concern to the BMJ about inaccurate representation of ME, he received a reply dated 23 June 1989, signed by the Secretary, which said: "Publication in any journal neither implies...that the facts and opinions in the articles are necessarily truth". Some saw this remarkable letter as confirmation of the lack of efficacy of the peer-review system.


Equally curious is the inconsistency contained in the same issue. Editor Richard Smith's "Conflict of interest and the BMJ" (ibid:4-5) declares: "We avoid asking anybody who has a strong conflict of interest to write us an editorial or referee a paper for us". According to Smith, the BMJ relies on the definition of conflict of interest defined as 'a set of conditions in which professional judgment concerning a primary interest (such as...the validity of research) tends to be unduly influenced by a secondary interest (such as financial gain)....Other sources of conflict are personal, political (and) academic and we believe that these may be just as potent as financial conflicts".
One can hardly disagree; sadly, one is obliged to raise an eyebrow nevertheless. Such inconsistency apparently relates only to the topic of ME.

In other papers, for instance, Wessely claims that any initiating virus in ME is long gone and that abnormal illness behaviour is responsible for the continuing morbidity. So far however, he has not succeeded in demonstrating that a virus has gone, nor has he proved that it has not gone. Polio virus goes away, but there are many after-effects apart from any obvious paralysis, yet Post Polio Syndrome (PPS) is not denied credibility. This is relevant, because ME used to be called Atypical Polio: its similarities are well recognised and documented by international experts such as Dr Richard Bruno (The Post Polio Syndrome: Advances in Pathogenesis and Treatment. Proceedings of the First International Scientific Conference on the Post Polio Syndrome, April 27-30, 1994: eds: Dalakas MC, Bartfeld H and Kurland L C. Annals of the New York Academy of Sciences 1995:1-409).

Wessely’s continued refusal to consider a balanced approach to the assessment and investigation of people with ME has long been the subject of professional disquiet.

He, however, is certain that he is right, so he sees no need to heed others’ concerns, from whatever source those concerns have come.
Wessely’s role in the “organic” versus “functional” debate

Over the last decade Wessely has repeatedly claimed that he does not want to get into the 'organic' versus 'functional' debate; for example:

in 1988 he wrote: "the fruitless dichotomy of 'organic' versus 'functional' should be replaced by a multifactorial approach" (BMJ 5 March 1988:296:696)

in 1991 he wrote: "much of the controversy surrounding the syndrome arose through a breakdown in the doctor-patient relationship exacerbated by a facile separation of mind and body" (BJ Hosp Med March 1991:45:158)

also in 1991 he wrote: "such observations continue to inspire the same futile 'organic versus psychological' polemics" (JNNP 1991:54:669-671)

again in 1991 he wrote: "Although obituaries of Cartesian dualism are frequent, the controversy surrounding ME proves such dualism to be alive and well" (BMB 1991:47:4:919-941).

Notwithstanding the above, many believe that Wessely has done perhaps more than anyone else to fan this particular flame, to the great detriment of patients with ME, and as such, he has done much to prevent ME attaining disease legitimacy in the UK.

Even though more latterly Wessely may acknowledge in his text that there are several distinct neurobiological differences between "CFS" patients and depressives, these are not acknowledged in any way in his Conclusions. As a psychiatrist with knowledge of psychology, Wessely must be well aware that what readers remember best of any article are the conclusions.

Is this a further strategy in his mission to convince readers that CFS/ME in reality is psychogenic and is therefore amenable to "appropriate treatment" (ie. correction of patients’ “cognitive distortions")?
Questions which Wessely might usefully be required to address

Do Wessely's views and published opinions about CFS/ME actually matter? Are they of concern to anyone other than those who have to deal with this illness?

Will Wessely's seeming determination to destroy the reality of ME alter the course of medical history?

Is there a Government-backed agenda to save money on state benefits, or is it perhaps nothing more than (to quote Dr "Rodney Silver" in a reversed context) a simple case of monomania?

Is it perhaps true that, having built his entire career and academic reputation on extinguishing the concept of ME as a separate entity, Wessely cannot possibly now contemplate a volte-face? Having so assiduously carved his personal reputation on his own view of ME, how can he acknowledge that he might have been wrong all along?

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.

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.

It would be informative and relevant if Wessely were to answer some questions:

1. Why does he not accept the formal WHO ICD-10 classification of ME as a neurological disorder?

2. On what grounds can he justify his personal selection of patients for his own studies, when his own criteria (the Oxford criteria) do not include the diagnostic criteria necessary for a diagnosis of ME as categorised by the WHO?

3. Does he not consider it important that the Oxford criteria he favours are constructed so as to anticipate a psychiatric outcome (because they expressly include patients with psychiatric illness)?

4. Why does he challenge the WHO’s classification of ME as a neurological disorder?

5. Why does he ignore the world-wide literature on the severity and chronicity of ME?

6. Is it acceptable to draw conclusions across different studies of different patient populations?

7. Why is he so confident that his views are correct and others are wrong?

8. What is the average drop-out rate from his studies on “CFS”

9. Where is his follow-up evidence?

10. What are his views on the fact that patients with diagnosis of ME are not permitted to donate blood, whereas patients with a psychiatric diagnosis are not excluded? (Reference: Guidelines for
11. Why has he not attempted to visit the more severely afflicted in their own homes so that they, too, can be included in his trials and written up in his published papers?

12. Where is his evidence of secondary gain that he asserts is part of the ME picture?

13. In how many of his patients with "CFS" has he asked for their pancreatic exocrine function to be tested? In what percentage were these abnormal?

14. In what percentage of his "CFS" patients has he carried out a water-loading test?

15. How many of his "CFS" patients have had a SPECT scan?

16. How many have had a copper response test to ascertain liver function?

17. What percentage of his "CFS" patients have demonstrated unequivocally abnormal vestibular function on formal assessment?

18. In what percentage of his "CFS" patients has he documented (or noticed) nystagmus?

19. In how many of his "CFS" patients has he documented blurred and double vision?

20. What percentage of his "CFS" patients have a positive Romberg test?

21. What does he understand the significance of a positive Romberg test to be?

22. How many of his "CFS" patients have noticeably slurred speech?

23. What percentage of his "CFS" patients has he referred to a cardiologist for investigation of pericarditis or cardiomyopathy?

24. In what percentage of his "CFS" patients have vascular changes been noted?

25. What percentage of his "CFS" patients have palpable lymph nodes?

26. How many patients have observable severe mouth ulcers?

27. In what percentage of his "CFS" patients has he obtained the results of 24 hour urinary output measures?

28. What percentage of his female "CFS" patients have shown clear and unmistakable non-androgenous hair loss?

29. In what percentage of his "CFS" patients has he obtained the results of a Doppler vascular scan, and how many of his patients so referred have results which confirm greatly reduced levels of oxygenation, perfusion and pulsatilities?

30. In what percentage of his "CFS" patients has he measured their T4:T8 ratio?

31. In what percentage of his "CFS" patients has he carried out HLA phenotyping, and how many were HLA DR positive?
32. What percentage of his "CFS" patients have abnormally low NK cell counts?

33. What percentage of his "CFS" patients have raised IgE levels?

34. What percentage of his "CFS" patients have changes in IgG3?

35. How many have immune complexes?

36. In how many has he measured their auto-antibodies?

37. What percentage of his “CFS” patients have increased mast cells?

38. In how many of his "CFS" patients has he measured sIgA levels?

39. Has he ever, in any of his "CFS" patients, run a cohort study to ascertain the percentage of VP1 positive tests in the chronically affected?

40. What percentage of his "CFS" patients have undergone muscle biopsies subjected to polymerase chain reaction investigation?

41. What percentage of his patients have demonstrated abnormal jitter on EMG?

42. Why does he so frequently exaggerate the role of depression and abnormal illness behaviour in ME?

43. Given the extent of the biomedical evidence-base on ME, what are his reasons for continuing to argue that "CFS" is a better name for the syndrome of ME over and above the simplistic one that the term CFS denotes no specific aetiology?

44. Why is he so denigratory about patients with ME, and why does he mock them as he clearly did in his Eliot Slater Memorial lecture in London on 12 May 1994? (tape and transcript available from present authors) and in his address to the Royal College of Psychiatrists?

45. Why does he assume that there are invariably benefits in the sick role? If he wishes to claim that there are benefits of “adopting the sick role”, then he needs to ascertain in each individual case that patients are benefitting from adopting the sick role for what they can get out of it: this needs to be proved before it can be stated as fact. No expensive tests would be required to ascertain whether or not patients do benefit in any way, but this should not be stated as a universal fact merely on Wessely's assertion that it is so. Even a cursory attempt to discuss their losses with ME patients would rapidly demonstrate the absurdity of Wessely's claims about this aspect.

It is, of course, far simpler not to have any of these tests carried out, but just to sit at a computer looking at and re-interpreting patients’ GP records.

One must not forget that Wessely is the UK representative at the CDC, which formulates guidelines advising that over-investigation in CFS/ME should not be recommended.

In the short term, the cheaper option from a health economics point of view clearly is preferable, but when the long-term health economic costs of ME are considered, it is a very different story.
The ME Association has published a report on the cost of the disease to the nation ("How much is ME costing the country?" Report summary (press release) 30 April 1996); this shows that direct and indirect costs to the community are £2,138 million per annum. The data were processed and analysed by Sheffield Hallam University's Survey and Statistical Research Centre (grateful acknowledgment to Tim Heatly of the Leicestershire ME Group for this information).

Whatever the short or long-term health economic cost, the prescribing of antidepressants to the ME sufferer who does not have concurrent depression is not good for the patients, but it is undeniably good for company profits, which in turn is good for medical research that -- inevitably -- will find that pharmacological interventions are the intervention of choice in ME.

Is this the true self-perpetuating "vicious circle"?
Harm done to sufferers of ME

Is there any evidence that people with a diagnosis of ME have suffered in any way as a result of Wessely's opinions and published papers? One can but list examples, so that readers can form their own judgment.

Wessely's journalist ally and promoter Caroline Richmond (see above) certainly seems to enjoy poking fun at people with ME, who have been the butt of her derisory jibes on numerous occasions; the following examples are illustrative.

**Finding a new approach in practice to the postviral fatigue syndrome**  
Caroline Richmond. Pulse 2 April 1988

"Many patients arrive in the consulting room with a firm attachment to a dramatic diagnosis made, not by a neurologist or a virologist, but by themselves"

"Many patients have...read some ill-thought-out advice leaflets"

"Fortunately, this deadlock has now been broken by two recent papers which argue for a...more constructive approach" (then followed promotion of Wessely et al's paper “Postviral fatigue syndrome: time for a new approach” BMJ 1988:296:696-698).

**Myalgic encephalomyelitis, Princess Aurora and the wandering womb**: Caroline Richmond: BMJ 13 May 1989:298:1295-1296

"Myalgic encephalomyelitis is a new name for an old disease...it's a British disease, unknown in the new world"

"The attraction of allergy to the hypochondriac is its personal uniqueness"

"...the dedicated hypochondriac...scenting a new career as a patient...wants to see the 'top man' on the subject"

"Hysteria was originally a disease of spinsters, whose dry wombs wandered round their bodies in search of moisture....Then, as now, ladies suffering from the vapours retired to their boudoirs. Taken from the French verb bouder, to sulk, a boudoir is a lady's sulking room"

"The illness behaviour of patients and the diagnostic behaviour of doctors are susceptible to fashion, and they are a part of it"

"Neurasthenia...melancholy, the vapours, hysteria...hypochondria...the names emphasised that the diseases were organic. Now they have lost their organic associations and imply states of personality or mind. Will the same thing happen to...total allergy syndrome (and) myalgic encephalomyelitis?"

Other vitriolic swipes at those with ME followed from Richmond:

**Yours disgustedly**  
Caroline Richmond. Medical Monitor 16 June 1989 page 36

"All but two of the hostile letters were from patients, lay people who would not normally see the journal"

(it will be recalled that Ms Richmond is herself a "lay" person)
"Most live in Gloucestershire, Coventry or Avon. Either it is something in the water or someone is orchestrating them. One person sent me a magazine article with a photo of a sufferer. She was sitting in a wheelchair and she described how she was getting progressively weaker. And she looked fulfilled, happy, healthy, attractive and well-presented."

Myalgic encephalomyelitis: a new name for old symptoms?  
Caroline Richmond  
Pulse October 14 1989:92

"Whatever the patients have, it is not inflammation of the brain and spinal cord. Often it resembles a nervous breakdown"

"72% of fatigue patients at The Institute of Neurology in Queen Square had psychiatric symptoms" (Wessely at this time was working there).

"There is no evidence to suggest that ME patients are immunocompromised and they don't succumb to more infections than other people, although they are more likely to regard them as life events"

"Many patients have succeeded in getting disability pensions"

"Advice should be given to enable them to cope with their symptoms, gradually increase exercise tolerance and return to normality".

Interestingly, Ms Richmond is not in any way qualified to be giving doctors such advice: can one hear Wessely speaking?

When Wessely published one of his studies in a journal, Richmond would frequently give his findings a prominent write-up in the medical trade papers. On 3 June 1989 Wessely wrote in the BMJ "What your patients may be reading" (see above) and he was critical of the popular books on ME that he was reviewing for 'Bookshelf': one did not have to wait too long for Richmond to add her support for Wessely by supposedly reviewing the very same books:

Supplying facts that ME sufferers will buy  
Caroline Richmond  
Doctor July 27 1989

"There is a ready market for the rash of books that have been published on ME"

"These books give much the same view of the history and aetiology of ME – the 'official' version of the ME activists"

"Unconventional procedures, such as alternative allergy diagnosis...are advocated" (Healthwatch in action again here)

"A checklist of irrationalities...shows Mr Wilkinson's and Dr Macintyre's books giving the highest scores...the others are little better".

There is more:

What is ME?  
Caroline Richmond  
The Oldie  
November 1992:26-27

“Myalgic encephalomyelitis...sounds really serious and is guaranteed to impress the friends and relatives of sufferers"
"Dr Ramsay was specialising in infectious diseases when his wife fell victim to the new epidemic. She was one of the few who took it with her to her death in 1990"

"While the patient groups funded research into possible organic origins of the disease, more and better research was emerging from psychiatric departments"

"Patients...wanted to be referred to neurologists, who didn't like seeing them"

"None of them seemed to find it remarkable that they are suffering from a disease called ME".

Richmond, vitriolic as ever, made numerous factual errors in this piece: the Royal Free Hospital outbreak did not take place in 1956 but in 1955, and her disparaging remarks about Mrs Ramsay were wholly untrue: Mrs Ramsay was never a "victim" of ME and her death was not in any way related to it as Richmond claimed. These uncalled for fabrications by Richmond caused dismay to those who knew and loved the Ramsays.

However, what Ms Richmond wrote about neurologists not wanting to see patients with ME was certainly borne out by Dr Peter Hudgson, consultant neurologist at Newcastle General Hospital who on 25 July 1993 spoke on national television as follows, saying about people with ME who presumably were hoping to receive help from him:

"The one, absolutely clear cut clinical feature of the disease is the personality profile of the people who develop it --- many of them have profound psycho-sexual difficulties"

"I do not believe for one moment that (that) reflects organic dysfunction of any aspect of the nervous system: I think it is bound to be 'in the mind'"

"I don't know what ME is, but what I'm absolutely certain is that it is NOT an organic illness"

"Something like four-fifths, if not more, of the people I deal with are women in early middle age who have unsatisfactory marriages" (Channel 4 Television: Frontline: 25 July 1993: videotape available from present authors).

How can it be that in-post NHS consultants such as Dr Hudgson can be so proudly ignorant of all the valid literature on ME in his own speciality of neurology, and how can it be that doctors like Hudgson can be permitted, through ignorance and arrogance, to dispense such unnecessary suffering to his unfortunate ME patients?

For someone in his position so wilfully to refute the existence and nature of ME is surely as negligent and as culpable as his saying he does not believe in multiple sclerosis, or myasthenia gravis, or motor neurone disease, or Parkinson's disease.

What effective measures can concerned patients and their families take, bearing in mind that many senior doctors, including those in supervisory posts, regard ME as a yuppie joke about which they snigger at patients' expense, thus ensuring that normally accessible channels of complaint are rendered wholly ineffective?

These questions were sent in a letter to the GMC on 26 July 1993; on 6th October 1993 a reply was sent from the Conduct, Health and Standards Division of the GMC which said: "The members have asked me to stress that the Council cannot take action against groups of doctors on the grounds that they hold particular views on medical issues".

So, like the BMJ, the GMC seemingly is not concerned with medical truth: what, then, is the purpose of having a formal WHO Classification of Diseases? Do in-post NHS doctors not have an obligation to keep themselves up-to-date about ME? They do about other conditions.

It is also entirely possible that Wessely's views have influenced such doctors as Dr P.J. Lefley of the Castle Mead Medical Centre, Hill Street, Hinckley, Leicester who, on 20th July 1993, wrote to Dr Charles Shepherd, Medical Adviser to the ME Association, as follows:

"I must express wondrous amazement at the tirelessness and vigour of the 'ME' lobby, a paradox indeed don't you think?...Of the dozens of doctors whom I know professionally, both in general practice and in hospital, I know none who believe in 'ME' as a clinical condition and I think it is self-evident that the indefatigable lobbying of your Association has...distorted the public perception of what little support your cause has amongst the medical profession....You may find these opinions offensive but I would ask you to reflect on how widely they are held".

On 24th July 1993 Shepherd replied to Lefley, saying:

"I suspect that you have not...read any of the peer-reviewed published research which indicates that there may well be a complex interaction between persisting or reactivated viral infection, immune system dysfunction and neuromuscular pathology (particularly changes in the response of the hypothalamic-pituitary axis, cerebral blood flow and mitochondrial enzyme function). Have you ever taken the trouble to read my advice on patient management?....Adopting a dogmatic and hostile attitude is not a very satisfactory way of helping such patients".

On 3rd August 1993, Lefley again wrote to Shepherd:

"I am pleased that I have received your latest letter as your true character shines through far more clearly than in your first communication. Given the scientific evidence that you peddle, I am not at all surprised at the intellectual fascism and bully boy techniques which you use. They would seem to be the only methods that you have of supporting your cause....I am afraid that if I am looking for intellectual rigour I would do better to watch children's television....I am glad you will make regular use of my letter, I would be grateful if you could give it all the publicity possible. It shows that there are still people of an independent mind in this country who are capable of rejecting your propaganda".

On 20th July 1993, Lefley had also written to a patient severely ill with ME, saying:

"I have received nothing in any of the literature which is more than pseudo-scientific hype. It is interesting that out of the dozens of GPs and consultants whom I know personally I know of no-one who believes in ME as a syndrome...but (I) feel that like...numerous other medical fashions, ME will no doubt in a few years go the same way".

When on 24th July 1993 Dr Shepherd wrote a polite note to Dr Lefley's senior partner Dr R.A. Yardley asking if it were true (as stated by Dr Lefley) that no doctors in his practice believe in ME and asking whether or not they issue sick notes for their patients who have been diagnosed as having ME by another GP or specialist, Dr Yardley wrote a three-page letter back to Dr Shepherd dated 3rd August 1993 in which he said:

"I have to say that your conviction that a specific condition of 'ME' exists has led you to adopt the arrogant view which, unfortunately, one sees from time to time in the medical world, where a particular lobby lays claim to the high moral ground with evangelical fervour....I can assure you that in this practice
there is no requirement for partners to subscribe to stereotyped and uniform viewpoints on medical matters....I think this is the straight-jacket in which you would like to see constrained all those with views which differ from your own....My own view, which I may say I feel no obligation to justify, is that I remain unconvinced of the existence of a separate disease category irrespective of the views of a former Junior Minister of Health or the success of the ‘ME’ lobby in achieving its recognition as such by the WHO....Fortunately, there are an increasing number of efficient antidepressants”.

Knowing how commonly major pharmaceutical companies fund GPs’ practice requirements (for example, by furnishing them with new computers on the understanding that the practice’s prescribing of certain drugs manufactured by the company does not fall below a given plateau, otherwise the computer system would be recalled), it might merit investigation as to whether or not the Castle Mead Medical Centre has any such agreement in operation, and if so, with whom.

Other damaging reports abound, for example:

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

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

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

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

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

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

"Or of you’re feeling tired, you could always refer".

All amusing, lighthearted stuff, of course, but damaging nevertheless, as articles such as these tend to re-inforce dismissive attitudes to patients who are genuinely sick and in distress; as such, these patients deserve to be treated with basic respect, and it is abhorrent that vulnerable and desperate patients should be forced to justify their illness because of ill-informed but influential doctors who so persistently minimise the severity of ME.

Probably due to the influence of Wessely et al, genuine research on ME which points towards an organic aetiology is ignored, and not just in the journals: a large international conference on CFS/ME, held in Dublin from 18-20th May 1994 did not merit any coverage in any of the UK major newspapers but it did merit snide editorial mention in a subsequent issue of GP:

"Hundreds of hangers-on joined dozens of researchers for a conference which gave ME a little more credibility. Most of the papers were from those who measured and pampered the afflicted".

Such editorials are widely circulated by the drug companies and are widely read; they are implicitly damaging and insulting, and they inevitably do far-reaching harm.
Patients with a diagnosis of ME are called mad, lazy, liars, malingerers, fraudsters etc, with no hint of proof, yet in our civilised country, do we not have laws about the undesirability of promoting prejudice, as in racial prejudice? Why, then, do patients with ME have to endure prejudicial taunts and dismissal so often? They do indeed suffer such abuse, and they are harmed by such insults, but they have no redress.

This was admirably picked up by Dr Leonie Sweeney, herself a consultant psychiatrist, who wrote:

"Critics seem quite sanguine about putting forward the hypothesis that the syndrome is of psychological or psychiatric origin without a hint of an opinion regarding the basis of the hypothesis, far less evidence to support it....Some patients are appropriately seen at psychiatric clinics for various problems secondary to their illness, not the least of which is their experience of not being believed" (BMJ: 11 May 1991:302:1153).

Patients have a right to be believed when they are telling the truth.

In a letter to InterAction (Summer 1994:16:25-26) Darren Guymer stated the views of many people:

"I find it frustrating that Dr Wessely is still so prominent a voice....It is clear from his comments in the media and his papers that despite Dr Ramsay's criticisms, he is still unable or unwilling to differentiate ME from PVFS and CFS. He also seems unable to differentiate the consequences of inactivity from the muscle fatigue/pain of ME and thus portrays the illness as psychological, explaining the symptoms in terms of a "self-perpetuating cycle of exercise avoidance" (1) and how "genuine symptoms arise from the frequent combination of physical inactivity and depression rather than continuing infection".

"I consider it absurd to suggest deconditioning/inactivity to be wholly or even partly responsible for the many variable symptoms of ME such as muscle twitching/spasms, severe head pains, mental confusion, blurred vision, sore throats, disturbed bladder function etc. In addition, and this is crucial, the cardinal muscular symptoms of ME are not only more severe but inherently different and thus distinguishable from the consequences of inactivity....To say that such consequences are even remotely similar to the muscle symptoms of ME belittles those symptoms and shows a fundamental lack of understanding of them....Patients immobilized for long periods, for example...through accidents, do not acquire the many symptoms of ME.

"I believe that Dr Wessely....rather than being sympathetic, is actually increasing the frustrations and suffering of ME patients. When struggling to adjust to and accept severe pain, disability and limitations, it is not sympathetic when someone states that using a wheelchair (something it took me personally a long time to accept) "of course only makes matters worse" (3) or to be described as experiencing "learned helplessness" (4), as being "highly introspective", or implies one has "fragile self-esteem" (3). Such comments, and there are many other examples which are offensive, are further evidence that clearly reinforce what is clear: Dr Wessely continues to confuse ME with other conditions and thus confuses causes and treatment/management.

"I have seen no indication that his views have changed....His confusion simply cuts across the truth about ME: that it is an organic disease....Doctors with this view (eg. Ramsay, Dowsett) seem not to have gained such extensive media and medical journal coverage as those such as Dr Wessely".

(References: (1) Management of Chronic (Postviral) Fatigue Syndrome. S Wessely et al. JRCGP January 1989; (3) GP Magazine 1990; (4) Am I Sick or Just Tired? by Adele Chorreson).

Other documented areas of harm concern the refusal of benefits to those with ME: the Spring 1994 issue of the Singles Newsletter of the ME Association carried the following report: "Other members might be
interested in problems experienced...over renewing my Orange Badge....Having obtained...agreement from my doctor, I was refused as ‘ME/PVFS is no longer recognised as a permanent disability by (the) medical establishment and Department of Transport’.

Not only are those diagnosed with ME being refused orange badges for disabled parking, they also are being refused Disabled Living Allowance on the grounds that ME is not a physical illness. The UK Task Force report on ME (see above) clearly states: "These syndromes are real. They pose a significant health problem both to society and to affected individuals and this problem needs to be addressed" (page 1: Main Findings: Task Force Report), yet within one month of the Task Force report, the Disabled Living Allowance Advisory Board (DLAAB) brought out their own new Guidelines, which stated: "There is no firm evidence...to identify ME as a distinct entity. The Board has concluded that the case for any of the conditions included under the general heading of Chronic Fatigue Syndrome being a physical disease is...unproven" (Section 12.1.3).

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

Earlier, in the June 1995 issue of Perspectives on page 21, Kevin Short raised the issue of Government agencies insisting on inflicting damaging treatments before eligibility for state benefits would be considered: "I have heard of...ME sufferers being told to undertake a course of intensive physiotherapy, with the implication of refusal being (the) loss of DSS benefits....Presumably such abuse of ME patients by BAMS (Benefits Agency Medical Services) doctors is likely to increase....Given that brain scans...revealed lesions in the brain tissue of 80% of ME sufferers tested, proving the illness is not just 'all in the mind', I wonder if there may be a legal defence against BAMS doctors, or any medical practitioner who, through crass ignorance or prejudice, try to inflict damaging treatment applicable only to psychiatric illness".

As it is known (see above) that Wessely, on his own admission, is an adviser to the DSS on CFS/ME, his assertions that any distinction between "physical" and "psychological" illness is futile can quickly be seen for what they are: from a practical consideration, there is a difference in benefit eligibility.

Not only that, but it could be actively dangerous for Wessely to persist in claiming that a unified approach is justified, since inappropriate active therapy during acute viral illness, and indeed during reactivation periods of viral illness, can have devastating life-long effects, as is the case with poliovirus.

There would seem to be a most curious anomaly about Wessely's position as adviser to the UK Government: certainly the text of his own letter to Dr Mansel Aylward of the Department of Social Security is authentic (letter dated 10th January 1992, see above), and certainly a reply to an ME sufferer dated 7th April 1992 from the DLAAB Secretariat clearly stated that Wessely had written to them in an official capacity, yet in another official letter, this time dated 21st November 1994 from Dr Hugh Nicholas, Senior Medical Officer at The Department of Health, it unambiguously states: "Your letters speak of the undue influence of a particular psychiatrist. I think I should point out that this doctor does not advise the Department directly on CFS/ME". Can it be true that there is no inter-departmental co-operation and liaison about such a contentious issue as ME?

Also in this same letter from Dr Hugh Nicholas is a sentence which is surprising; he writes: "There is no UK representative to the CDC in Atlanta". This is surely incompatible with the fact that Wessely is clearly listed as a member of the International Chronic Fatigue Syndrome Study Group from the Centers for Disease Control, Atlanta (see above).

Also relevant to the area of refusal of benefits, is the fact that Wessely does not, to our knowledge, go on to study further those who have had antidepressants and who have become unequivocally worse, nor
those who have undergone his programme of CBT and still have not recovered: he merely ascribes a convenient psychiatric label to such people. In particular, he makes little mention of those who are just too ill for his programme.

The fact that so many people, on the basis of Wessely's personal views, have been refused all support, both medical and financial, makes it imperative to distinguish the correct aetiology of ME, but above all, to distinguish genuine ME from chronic fatigue. The voluminous works of Wessely are proof that this is not happening, despite the WHO formal classification.

That intemperance and intolerance abound about ME was shown in the recent TV programme "The Rantzen Report" on BBC 1 (5\textsuperscript{th} August 1996) and in the ensuing media madness. Esther Rantzen, whose 18 year old daughter Emily has ME, introduced the programme by saying that ME is an illness that wrecks lives and destroys careers, that sufferers can lose their speech, and that they cannot walk or work, that the illness is sneered at and dismissed, and that there is hardly any research being done.

Unfortunately, although there was much to recommend in the programme, particularly the contributions of Dr Charles Shepherd and Dr William Weir, it lost direction and did not seriously address the main issues. Certainly there were rumbles of dissent when Dr Thomas Stuttaford (medical correspondent of The Times) repeatedly claimed that ME was indeed a form of depression (odd, this, since Wessely himself has now conceded that it is not, and that ME is in fact biologically the opposite of depression),

Interestingly, we are told that Wessely was due to appear on the programme but he withdrew at the last moment, saying that he did not want to miss the England versus Germany match which was taking place on the day of filming.

The ensuing hysteria in the UK press was truly remarkable: the prize for the nastiest review must go to Victor Lewis-Smith of the London Evening Standard, who wrote that the show was driven by malice on the part of Miss Rantzen and served merely to belittle and indoctrinate in an ill-considered, inconsiderate, manipulative and unscrupulous manner: "she seems to be holding the corporation to Rantzen. She puts the network to shame" (A paid up member of the ME generation: Victor Lewis-Smith: Evening Standard: 6 August 1996 page 27).

Peter Paterson in the Daily Mail said: "I was sorry to see the great and good Dr Thomas Stuttaford placed in the ducking stool for suggesting that ME may be a form of depression".

Matthew Bond in The Times naturally supported his colleague Dr Stuttaford, saying: "As you would expect from a Times man, Dr Stuttaford went down fighting, but it was still a dreadful sight to behold".

Anita Chaudhuri in The Guardian said: "...a studio full of sufferers and supporters, all of whom were programmed to boo and heckle the moment any medical expert mentioned the words 'form of depression' did make for good television. The trouble with ME is that, now Esther Rancid's got on the bandwagon, it's going to be very difficult to get her off. Boo, hiss". This was infantile and offensive.

The review in the BMJ was hardly more accurate (Taking "ME" too seriously: Richard Morriss: BMJ 10 August 1996:313:369): "This time the big campaign is 'ME' because unfortunately her daughter has ME"

"Typically, there is no attempt to give a balanced perspective, only exposure of the evil as if it were an open and shut case"

"Esther's specific accusations are that (a) most doctors view ME wrongly as malingering (or) a psychiatric disorder... (b) some doctors are intentionally or mistakenly cruel to some patients with ME and their families... and (c) insufficient research has been carried out"
"She paraded a series of severely ill, often atypical, patients...focusing on their degrading 'psychological' treatment...(which) included throwing patients into swimming pool....I (have not) heard of any doctor treating patients with ME in this way" (the programme told how Ean Proctor and Michelle Golding had both been thrown into swimming pools).

"Unfortunately Esther Rantzen is affected too personally and is too aggrieved to produce a programme that would persuade more doctors to take ME seriously".

The most media space was secured by Dr Stuttaford, who seems to have worked journalistic overtime since transmission of the programme. The day after it was shown, he wrote: "Politics have prepared me for difficult, noisy meetings and audiences with inflexible opinions. However...I don't think that I have ever met such aggression and stubborn refusal to listen to, let alone understand, any opinion that was contrary to their own".

"It was interesting how many of those taking part in the programme --- relatives as well as ME sufferers -- had a history of psychiatric illness themselves".

"People still have to learn that psychiatric diseases can often produce very severe physical symptoms" (Why a diagnosis of ME can be a danger to patients: Dr Thomas Stuttaford: The Times. 6th August 1996 page 4).

(Dr Stuttaford is far from being a "medical expert": when he was directly asked at the recording session how many patients with ME he had personally seen, he became abusive. This was not transmitted).

The following day, Natalie Clarke wrote in the Daily Mail that: "Medical columnist Dr Thomas Stuttaford complained he was subjected to trial by television when he appeared on the BBC's Rantzen report....'It was like Daniel walking into the lions' den' he said" (Doctor's trial by television on the Esther Ranting Show: Natalie Clarke: Daily Mail August 7 1996 page 7), whilst Stuttaford himself, in The Times, said: "I was set up, no doubt about that". He complained that rather than being invited to represent the 75% of GPs who did not believe that ME was an illness in its own right, he was used as a scapegoat (BBC defends Rantzen over TV 'shout-in' claim : Carol Midgley and Lin Jenkins. The Times August 7 1996 page 5)

His feathers obviously still ruffled, Stuttaford had another attempt the next day, under a sub-heading of "Dr Thomas Stuttaford on...psychiatric disorders"; his item on ME was entitled "When it's all in the mind" (The Times 8 August 1996, page 14). Stuttaford continued unmoved on his usual track: "The greatest difficulty is often in making a diagnosis when the physical symptoms...have resulted from psychological disorder....Depression frequently results in physical symptoms....The standard advice given to patients with chronic fatigue syndrome is that as some sufferers will improve with antidepressant treatment, this should be prescribed....All the patients should be encouraged to take physical exercise, for there is well-documented evidence that it is important to persuade patients...to avoid (relying) on wheelchairs" (note: it is Wessely who so advises, and Wessely also writes for The Times). "In discussing the physical symptoms which are often seen in psychiatric disease it is of fundamental importance to explain to patients...the physical symptoms which afflict psychologically disordered patients are very real and can be totally disabling".

On and on it rumbled, with Jessica Davies of The Mail on Sunday having a swipe: "Rantzen's shameful episode of victim TV" August 11 1996 page 35).

The only reviewer not to be disparaging was Stafford Hildred in The Sun, who showed perspicacity sadly lacking in others when he wrote: "The smug doctors were a lot less convincing than the people whose lives had been wrecked by ME (The Sun 6 August 1995).
Inevitably and quite properly, people were outraged, and wrote to the Press Complaints Commission about Stuttaford, making three broad points:

(i) as the WHO has classified ME as a disease of the nervous system, Stuttaford should not have the option of self-indulgence to re-classify it as a psychiatric disorder

(ii) his assertions that antidepressant therapy helps many ME sufferers are at best spurious and at worst, such treatment is contra-indicated, as has been amply documented in clinical trials

(iii) his statement that many ME sufferers and their relatives present at the recording session had a history of psychiatric illness is wholly unsupportable: in any event, he certainly did not question those present at the recording session, so he must have been fabricating.

Letters were also sent to The Times, to the Director General of the BBC, to the Broadcasting Complaints Commission, and letters were sent by recorded delivery to the Editor of the Evening Standard about Victor Lewis-Smith's article.

The outcome of these various assays is not yet known, but past experience of the Press Complaints Commission invites little expectation of accuracy being upheld or required.
**Losses sustained by people with ME**

Another aspect of harm to patients which, whilst somewhat less closely aligned to Wessely and his views, but which nevertheless flows in some measure from him, concerns the extent of the losses experienced by people with ME.

It is surely bad enough feeling permanently ill, not just off-colour, and having to live daily with extreme malaise; in addition, patients must cope with vertigo and loss of balance, with bladder and bowel dysfunction, with intractable pain and exhaustion, together with visual problems, and indeed with the full panoply of problems that have been documented in ME (see above).

On top of that is the fact that so many are severely disabled, as distinct from feeling ill. Many have less than 25% of their pre-morbid level of function.

They cannot work; they frequently cannot look after themselves, and there is crucial need for practical help with housekeeping, shopping, driving, maintenance of the car and garden etc.

One of the saddest losses is that severely affected parents cannot look after their own children; they certainly cannot attend school functions such as sports day or drama productions.

Not only can there be a breakdown of the usual support networks, with loss of family, friends, job, income and independence, but after initial involvement, neighbours offer less and less support. Many marriages of ME sufferers are known to have failed.

Sufferers have also to contend with the fear that their increased needs might overburden their partner; single people severely affected by ME are in a veritable nightmare situation. Many have had to give up their home and move back with elderly parents, who are far from able to cope. In one case known to the present authors, a single middle-aged woman was denied state invalidity/incapacity benefit and also income support because she was unable to register as available for employment; she then was forced to live with her elderly mother, who was over 60, and the mother, who herself had cancer, was forced to go out to work to support her sick daughter.

The plight of children with ME can be disastrous: some schools do not accept the diagnosis and many parents have been threatened with having the child removed from them and put into care if they do not make them attend school.

All involved need emotional support in dealing with the consequences of the illness, but, unsurprisingly, Wessely does not dwell on such aspects: in fact he doesn’t mention them at all.

We contend that as a result of Wessely's massive out-put on the subject of ME, there is no Government-funded research into the organic causes of the syndrome; furthermore there is no Government-funded research into possible treatment, nor into diagnostic procedures, nor into the numbers of those severely and chronically afflicted who are housebound.

The only such epidemiological survey is CHROME (Case History Research on ME), which is an independent 10 year project with charitable status whose preliminary results were presented at the Brussels conference in November 1995; these results suggest that there is a group of patients in the UK who have been rendered so chronically disabled by CFS/ME that they cannot leave home unassisted, and that chronicity of a scale not previously documented is a significant feature of the disease.

The Department of Health refuses to send out accurate information to health care providers, who thus remain uninformed about the true nature of the condition. As a consequence, those who are too
incapacitated to work experience major problems in convincing bodies such as permanent health insurers to honour their policies.

More universally, patients experience the ill-concealed contempt of their doctors on whom they are so dependent.

A fundamental but related area of concern which could lead to future harm is that the reduction in Government funding has eroded independent medical research; as a result, such research has passed into the control of multinational pharmaceutical companies such as Wellcome, which in turn has affected the type of research projects being selected for funding. Under this commercial control, these companies and their agents not only select their research programmes, but they control their progress and own the results.

Many research projects are thus in jeopardy of being turned down due to low profit potential.

Science and medicine have increasingly become commercially orientated and it is very difficult for the honest and unbiased scientist to obtain funding (Green Network Petition on behalf of Farming and Livestock Concern, June 1996).
Conclusion

Our objective in this review has been to promote wide scrutiny of Wessely's work which we hope will lead to serious questioning as to whether his undoubted influence is justified in the light of so much conflicting evidence to the contrary.

We believe we have provided examples of how Dr Wessely ignores, alters or dismisses much of the evidence of other ME specialists which conflicts with and contradicts his own theories about the syndrome of ME and its causation.

We also maintain that Wessely frequently omits relevant information which might put a completely different interpretation on his own findings.

We further submit that most of his articles on CFS/ME do not present a balanced or even an accurate picture of the available published findings and evidence on ME.

We and many others involved with ME who are known to us find Wessely's view wholly unacceptable and we therefore ask if it is not time for a multidisciplinary appraisal of his published views and public statements on this devastating condition.

We maintain that for Wessely to claim that nearly all patients with CFS/ME resort to the same maladaptive, ineffective coping strategies (so all end up helpless and hopeless) is plainly ludicrous, and over-simplifies patients' experience.

We are strongly opposed to the diminution of the long-established ME criteria as formulated by the late Dr Melvin Ramsay, with the result that the diagnostic label of "CFS" can be applied to anyone who feels tired for one month, and the nosological entity of ME has all but disappeared.

We believe that Wessely and his close associates have set back the cause of ME in the UK by almost a decade.

We contend that many of the quotations from his work which are set out above are unquestionably derogatory, damaging and disparaging, and that if such comments, based as they are on myth and unacknowledged personal bias, were to be applied to patients with Post-Polio Syndrome, or leukaemia or multiple sclerosis or cancer, they would be deemed comprehensively unacceptable, yet in the ME literature, they seem to go unchallenged.

Patients themselves cannot usually challenge the dishonesty surrounding ME because the UK medical press rarely grants them a right of reply.

Psychological factors affect all diseases and ME is no exception; they influence the onset and outcome of cancer, as is well known, but cancer is not deemed to be psychosomatic.

Psychiatrists should be looking at ways of minimising psychological distress instead of adding to it by repeatedly drawing parallels with psychiatric disorders.


It is curious that Wessely cannot see how opposite this is to himself.
The much-advocated CBT has been found not to be an effective or appropriate therapeutic approach in ME and nor would it substantially improve MS, Parkinson's disease or motor neurone disease; as there is no evidence of phobic avoidance of activity in ME, CBT can have little to offer, but Wessely seems overly reluctant to accept the evidence of brain dysfunction in ME, preferring instead to believe patients have an attitude problem. Seemingly, his own contradictions perpetually escape his attention and the attention of his peers.

He rarely discusses concepts such as the fact that the presence of many illnesses is unproven until autopsy, nor can one prove the existence of depression, given that psychometric tests may not be answered truthfully.

It is no wonder that some psychiatrists are despised and mistrusted when they seem unable to accept that a conviction of physical disease in ME may not be dysfunctional thinking or psychosocial denial as Wessely et al so regularly promulgate. Patients' convictions may arise from severe physical symptoms which are indeed organic in origin.

More accurately, doctors who have set views regardless of the facts might themselves qualify as dysfunctional thinkers, the result being manifest as a determination to psychologise illnesses which those doctors do not understand.

Whether or not membership of an ME patients' organisation results in a poor outcome is hardly a provable point, so it should not be tossed about as a possibility or claimed as a perpetuating factor.

Powerful minority groups such as the clique of psychiatrists to which Wessely belongs should not be allowed to determine public policy without there being some external moderation. It is a cause for concern that UK Government departments so willingly and uncritically accept Wessely's views on ME as sacrosanct, but not those of Professor Behan.

On what logic should the unproven views of a psychiatrist be held to be superior to the proven views of a neurologist, or an immunologist, or a virologist, especially when it is so easy to demonstrate how misplaced are the views of that psychiatrist.

As a psychiatrist, Wessely is hardly best qualified to claim expert knowledge of, or to give expert advice about, a most complex postviral neuro-immune-endocrine syndrome such as ME.

Patients' distress will end only when truth becomes as important as power and politics, and when inaccurate diagnostic labeling no longer serves as a cloak for ignorance, prejudice and misguided beliefs.

Eileen Marshall
Margaret Williams
August 1996
APPENDIX I

1. MEDLINE  Updates on Myalgic Encephalomyelitis 1984 to date. (Current Awareness Topics Search) 
(CATS): British Library Medical Information Service: Boston Spa, Wetherby, West Yorkshire LS 23 7BQ. 
Tel: 01937 - 546039

2. CFIDS Chronicle 1987 to date. (Chronic Fatigue and Immune Dysfunction Syndrome Association of America Inc.) PO Box 220398, Charlotte, North Carolina 28222-0398 Tel: 001 - 704 - 3640016

3. InterAction (Journal of Action for ME) 1988 to date. PO Box 1302, Wells, Somerset BA5 2 WE 
Tel: 01749 - 670577

4. Perspectives 1987 to date. (Magazine of the ME Association)

5. The Clinical and Scientific Basis of Myalgic Encephalomyelitis / Chronic Fatigue Syndrome. Ed. B M Hyde, J Goldstein, P Levine. Nightingale Research Foundation, Ottawa 1992. (Contains contributions from 80 of the world’s leading ME experts and includes sections on history, epidemiology, children with ME, investigations, virology, immunology, muscle pathology, host response, food intolerance, brain mapping, neurophysiology, neuropsychology, psychiatry, treatment and management of the condition)


13. The Body at War. John Dwyer (Professor of Clinical Immunology). Unwin Hyman 1988


16. Although the British Library Medical Information Service carries details of virtually all papers published worldwide on ME (see item 1 above), two special Supplements deserve particular mention, as both are entirely devoted to ME/CFS:

(i) Review of Infectious Diseases 1991: 13: Supplement 1; published by The University of Chicago Press

17. Proceedings of the International Meeting on Chronic Fatigue Syndrome, Dublin, 18-20 May 1994 (under the Auspices of The Ramsay Society and The World Federation of Neurology (University of Glasgow, UK)

APPENDIX II

REMARKABLE COINCIDENCES, SCIENTIFIC ANTICS or DELIBERATE DIVERSIONARY TACTICS?

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The recent announcement by the Minister for Agriculture on continued use of organophosphate (OP) pesticides in sheep dipping procedures by qualified farmers has focused attention anew on the question whether human and animal health take second place to commercial interests. The Minister said there was no scientific justification for banning the use of these dips. However, hides from undipped sheep have lower commercial values, due to damage from parasites (1). The similarities between problems experienced by subjects exposed to such pesticides and by M.E. sufferers also raise the question whether these and other potentially noxious chemicals and substances could generally be involved in the aetiology of this disorder (2,3).

Hot disputes surround the issue of food and chemical allergies or sensitivities in M.E./C.F.S. and in other disorders; some believe these or allergic reactions in general may lie at the root of the M.E./C.F.S. phenomenon (3,4,5). By contrast, some psychiatrists argue that multiple chemical sensitivities (MCS) in many cases can be explained in terms of somatization disorders (6).

Let us assume for a moment that the entire issue goes beyond medical and scientific squabbles such as those described above and in the 'Alternative Allergy and the GMC' dispute (7), and even beyond the idea that a 'flat earther approach' by orthodox medicine proponents may be responsible (8). Most M.E. sufferers will have heard of an infamous 1970 article written by 2 psychiatrists, in which the 1955 Royal Free Hospital outbreak was reassessed and attributed to 'mass hysteria' (9). It is this article which is forever reported and disputed. Few people know that the same authors wrote a companion article (10); in this they describe case study reports from a different London outbreak and explain other less localized epidemics as being recorded due to a changed medical perception of the community. The authors state: 'It would be wrong to term this an iatrogenic epidemic, for in our view there was no epidemic at all; the basic phenomenon was an altered medical perception of the community' (10: p.14). This article is rarely mentioned nowadays and the nature of such an 'iatrogenic epidemic' can only be a matter of conjecture. However, publication of these two articles coincided with increased use of many common drugs, antibiotics and corticosteroids in particular, plus an increased range of routine vaccination. In addition, pesticides were widely used, as were many chemicals in disinfectants, solvents, fertilizers, food additives and preservatives and in many other substances, apart from increased air and water pollution. During the 1960s and well into the 1970s, reports were accumulating of severe and hitherto unknown problems associated with the use of the above and other drugs. Two professors in pharmacology summarized these in an enlightening book entitled 'Iatrogenic Diseases' (11). None other than the Senior Lecturer in Bacteriology at the London School of Hygiene and Tropical Medicine and former Director of the Public Health Laboratory Service for England and Wales wrote an equally enlightening book, entitled 'The Hazards of Immunizations' (12). Important as these books may be, they are unlikely to adorn the bookshelves of the average GP. In 1969 a complex article was published by C.M. Poser, a now well known Professor in Neurology, in which he reviewed post-infectious and post-vaccinal neuropathies, concluding that these were allergic phenomena and that clinical and pathological manifestations in these disorders were indistinguishable (13). Professor Peter Behan recently confirmed that the neurological complications of whooping cough vaccines are identical to those of natural whooping cough, in a Channel 4 programme on batches of vaccines containing a pertussis (whooping cough) component with excess toxicity. A huge compensation award was made in one Irish case (14). Poser in his 1969 paper states that such hyperergic (or allergic) reactions result in vasculopathy and ischaemia (bloodlessness of certain body parts),
inflammation, oedema and other complications. In chemically sensitive subjects blood vessel constriction, inflammation or leakage in multiple organ systems may explain the varied symptomatology (15). Scientists in the forefront of research into M.E. are now rediscovering an impaired cerebral blood flow, can illustrate it using SPECT scanning techniques (16) and are beginning to relate these findings to the diverse symptomatology seen in these patients (17).

Are all these remarkable coincidences or are we looking at scientific antics, or even deliberate diversionary tactics, especially from the psychiatric sector? Maybe, and maybe not. Perhaps we should have a closer look at Dr. Wessely's 'History of postviral fatigue syndrome'(18), which I read with interest, noticing some remarkable facts. This chapter discusses the similarities between M.E. and neurasthenia. One is led to believe that M.E. is the successor of neurasthenia, which was first reported between 1860 and 1880, then affecting male professionals, including doctors and 'captains of industry'. Shortcomings and flaws in this paper were discussed (19). However, in my view several interesting and perhaps revealing comments in the text and/or the given references may offer clues to the possible underlying aetiology of this disorder, if Dr. Wessely's assumption is correct. These include the following: Central (CNS) exhaustion in neurasthenia was thought to be brought about by a failure of cerebral blood flow, a deficiency in energy sources, a genetic fault, or by excessive demands on the body, arising from overwork, toxic, metabolic or infective insults (based on papers published between 1868 and 1904). Neurasthenia was considered to have a physical origin until Freudian views gained popularity. Pharmacological treatment was unsatisfactory; patients were exquisitely sensitive to side effects; the principal treatment was rest. Early in the 20th Century the illness affected mainly labourers, including garment workers, and an increasing number of females. It was associated with infections, weakness and toxicity, but now the main emphasis was increasingly placed on psychological causes, especially in the U.K. Later descriptions and/or references link in vaccinations and observations that any infective agent can cause states of chronic exhaustion. Dr. Wessely comments on a growing list of bona fide post-infective conditions, especially in the neurological field, from the 1940's. He mentions an experimental animal model, recorded in 1947, where adjuvants (i.e. chemical substances contained in some inactivated adsorbed vaccines to enhance antibody responses) were injected into brain tissue of a rhesus monkey, resulting in rapid production of disseminated encephalomyelitis. Such a model was lacking in neurasthenia he states. His account of M.E./P.V.F.S. runs along similar lines, emphasizing that investigations into a common viral aetiology were largely futile. He agrees that the over-representation of health workers amongst sufferers from neurasthenia and its various successive forms, including M.E. is striking and difficult to explain epidemiologically. He also states that M.E. is linked to dissatisfaction with orthodox medicine and with popular conditions like multiple allergy and candidiasis, neither of which would attract professional support. Through most of his chapter he capitalizes on the lack of understanding of this condition by orthodox medical practitioners, on the growing influence which psychiatry had in medicine, and on how dissent led to dismissal and the current dilemma. Cartesian dualism is alive and well he states.

My principal objection to Dr. Wessely's account concerns his emphasis on and endorsement of psychological aspects. He fails to query the possibility of an iatrogenic aetiology, which perhaps he should have done in view of the examples which I extracted from his own description and references and which indicate a possible environmental link. Doctors and professionals were the first to use vaccines and medications, as were and are health care workers and most were/are exposed to many potentially toxic chemicals in their working environment. 'Exquisite sensitivity to pharmacological treatment' equals adverse drug reactions now and is indicative of chemical sensitivity. Garment workers and labourers most probably came in contact with potentially toxic chemicals and substances. He omitted the second McEvedy & Beard paper from his references. Instead he concludes his chapter, which he said would attempt both chronological description and social analysis, by citing comments on neurasthenic sufferers from papers published between 1880 and 1908. These include the following: 'always ailing, seldom ill'; '...a useless, frivolous, noxious element of society'; 'purely mental cases'; 'laziness, indifference, weakness of mind and supersensitiveness characterize them all'; 'the terror of the busy physician' etc. It is well known that the concluding comments of an article are best remembered. The BMB is read by doctors, specialists
and appropriate Government officials. One can only deduce that Dr. Wessely wishes M.E. sufferers to be viewed in the same way by these people.

Quoted examples from Dr. Wessely's account and the earlier references could all be mere coincidence, but the smallprint acknowledgements in Dr. Wessely's paper and in certain other articles (not necessarily by Dr. Wessely) add an extra dimension to the saga, i.e. the interests of the pharmaceutical industry.

Underlying reasons for the incredible battles and wrangles which rage between the complementary sector and opponents in orthodox medicine, in liaison with drug companies, have now been documented more fully in a revealing new book 'Dirty Medicine' (20). Some patients with suspected OP poisoning, who are referred to the National Poisons Unit at Guys Hospital, are now given long psychiatric questionnaires (21). And last, but not least, if longterm use of many psychoactive drugs, including antidepressants, may cause brain dysfunctions in some subjects (22), then evidence of such dysfunctions could ultimately be the same in patients suffering from depression and in M.E./C.F.S. sufferers, if such patients were treated with these drugs. Reflecting on these aspects, one is left with the options of considering whether the above are remarkable coincidences, scientific antics or deliberate diversionary tactics, where the latter serve one major purpose: commercial benefit. Readers may wish to judge for themselves. The Government is dragging its heels over the OP pesticide issue. If M.E. is even in part an iatrogenic disease due to drug involvement, this is a far bigger fish. Their reluctance to face the problem thus becomes much clearer, as does a tendency to give credance to the views expressed by some psychiatrists.

'Divide a nation into parties, or set your enemies at loggerheads, and you can have your own way.'

[Machiavelli, Florence, 1469-1527](23).

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31.12.1993
Appendix III


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Peter R. Breggin is a maverick American psychiatrist and psychotherapist. In this landmark 578 page tome he relates his lifetime experiences and observations in practices of his profession. He confronts most of his colleagues and the medico-pharmaceutical establishment, arguing persuasively that there is no convincing evidence that 'mental illnesses', such as schizophrenia, depression, manic-depression, panic, obsessive-compulsive or attention-deficit disorders are physical or genetic, curable by drugs or ECT [electroconvulsive therapy]. The real reasons for these claims are that such treatments fund, justify and lend medical authority to a huge industry, i.e. psychiatry. Millions of unsuspecting people, including schoolchildren, housewives, the elderly, childhood abuse victims and 'problem adolescents', are lured into resorting to 'miracle' cures, not realizing that many prescribed drugs are less effective and sometimes much more dangerous than they are led to believe.

Breggin outlines the history of 'mental illness'. Starting in the 1960s, 'biopsychiatry' maintains that a 'broken brain' or 'biochemical imbalance' causes personal unhappiness; this cannot be cured, but can be managed by psychoactive drugs and ECT. Yet, he says, the only biochemical imbalance which can be found is that produced by psychoactive treatment. Psychiatrists' main function is not treatment, but control, and their role resembles that of the police. They are agents of the State, can prescribe drugs or electroshock to hospital patients, treat people against their will, lock them up, talk about them behind their backs to relatives and even plan their future. ECT and lobotomies are surgical mutilations to the highest centres of the brain, he states. A revolution has occurred in psychiatry: Freud's and Jung's views are no longer of interest; instead psychiatrists are trained to methodically ask questions, make a diagnosis and prescribe appropriate drugs. Yet the public still thinks of them as psychotherapists and therefore holds grossly outdated views on modern psychiatrists. Those in the profession who disagree with the mainstream approach are ostracized or threatened with dismissal. Toxic Psychiatry has not been reviewed in any professional journals.

Schizophrenics make up a high proportion of psychiatric patients. Onset of their problems is invariably precipitated by a personal crisis. They are often highly sensitive and capable of symbolic and abstract thought. Brain damaged people (e.g. Alzheimers, stroke or tumour) display memory difficulties and may get confused and disoriented. Modern treatment for schizophrenics consists of highly toxic neuroleptic drugs (e.g. Haldol, Thorazine, Stemetil and others) and sometimes ECT, leading to a marked deterioration over years. Prolonged use of such drugs is said to induce a chemical lobotomy, traditionally implying the surgical severance of nerves between the frontal lobes and the remainder of the brain. Frontal lobes are the seats of higher human functions, such as love, empathy, self-insight, judgment etc. Lobotomy turns the individual into a simpler, more dependent and emotionally blunted human being. Breggin stresses that if a patient already suffers from a real brain dysfunction, caused by hormones or viral infection for instance, then psychoactive drugs, ECT or surgery will worsen or compound the effect.

Tardive dyskinesia, i.e. delayed abnormal involuntary movements akin to those seen in advanced Parkinson's Disease, is frequently caused by prolonged use of neuroleptics. Pioneers of these drugs in the early 1950s noticed that small doses of Thorazine produced a neurological disease almost identical to a special type of virulent post-war world one flu, known as encephalitis lethargica, or von Econemos disease [which is often quoted as a forerunner of M.E.]. But the psychiatric literature has expurgated [removed] this important information; hence most young psychiatrists are unaware of it. A worldwide epidemic of
brain disease similar to lethargic encephalis, with symptoms finally progressing to Parkinsonism, brought about by these drugs, was predicted by one early pioneer (p.91).

In 1988 'manic depression' was declared to be a physical disorder and renamed 'bipolar disorder'. Serotonergic sluggishness is said to lie at its root, which is amenable to drug intervention. In reality, Breggin states, this causes great imbalances in the system, including a relative compensatory shut-down of serotonergic neurotransmission, especially with PROZAC, which has recently been implicated as a potential cause of murderous and suicidal acts. Antidepressants are the 'jack-of-all-trades' drug, used for a host of problems, including eating disorders and PMT. Tricyclic antidepressants are the best studied and widely used. They have a dulling effect on the mind and in effective doses produce lethargy, disinterest and a feeling of being 'zoned'. They result in generalized mental dysfunctions, can cause severe withdrawal symptoms, have numerous side effects, and are lethal in overdose. In many ways they are neuroleptics in disguise. Side effects are due to suppression of cholinergic rebounds, and include blurred vision, dry mouth, suppressed function of the gut, bladder and sexual organs, low BP, weight gain, seizures, impaired cardiac function and others. Withdrawal symptoms are invariably attributed to mental illness, stresses, allergies or viral infections. Tricyclics are addictive. Animal studies suggest that longterm use produces hyper-reactivity of the neurotransmitter system in the brain, or chronic subsensitivity or reduced reactivity. These findings are wholly ignored. Tardive dyskinesia has also been found to occur, but less frequently. Breggin is concerned about unexplored dangers of permanent cognitive dysfunction and brain atrophy, which has been found in patients diagnosed as having affective disorders [i.e. depression, manic depression and schizophrenia], when treated with such drugs. Antidepressants are now often associated with successful suicides, but enthusiasm for their use has skyrocketed amongst psychiatrists at the same time as research has cast more doubt on their efficacy.

MAOIs [Monoamine Oxidase Inhibitors], including Marplan, Nardil, Parnate and others, are amongst the most dangerous agents in medicine. Diet must be watched very carefully to avoid severe and life-threatening cardiovascular reactions. Many foods must be avoided.

PROZAC, introduced in January 1988, is the most recent 'miracle drug', heralded as a breakthrough drug for depression. It has been feverishly promoted by the drug industry and the media, purportedly acting selectively on the neurotransmitter serotonin. Breggin states that serotonin nerves spread throughout most of the brain, including the limbic system and frontal lobes and hence are involved in multiple functions. The biochemical imbalance, caused by blocked serotonin re-uptake, would affect many other related neurotransmitter systems and result in widespread disruptions. Reported side effects include headaches, nausea and somnolence, sometimes bizarre dreams, loss of appetite, diarrhoea, dry mouth, sweating, dizziness, impotence, seizures, rash and others. Hypoglycaemia, chills, cold sweats, confusion, weakness and other symptoms of low blood sugar have been observed, and occasionally a severe rash with fever, joint pains and swollen lymph nodes. Combinations with other drugs can be dangerous. Prozac can act as a stimulant, a little like amphetamines. Breggin suspects that Prozac is associated with amphetamine-like psychosis; it is now referred to as the 'Yuppie-Upper' in the American popular press. Its longterm effects are still unknown.

Shock treatment [ECT] is described as a 'controlled type of brain damage', often consistent with that seen after a head injury. It causes grand mal convulsions. 100,000 or more Americans are shocked every year, and numbers are rising.

The minor tranquillizers, including Xanax, Valium, BuSpar, Ativan, Halcion and the antidepressant Anafranil are CNS depressants, with similar effects to alcohol and barbiturates, classified as sedative-hypnotics. Breggin describes their addictive properties, tolerance and withdrawal symptoms, memory - and some cognitive dysfunctions. Patients are often unaware of their impairment. Brain shrinkage has likewise been reported after prolonged use.
Breggin also discusses hyperactivity, attention-deficit disorders, learning disabilities, dyslexia, autism and other problem diagnoses. The overwhelming number of people involved in writing editorial and top management functions of the Archives of General Psychiatry for instance are male (43 men and 2 women), but most patients treated with psychoactive drugs are women.

The book draws to a close by discussing the dangerous liaison between psychiatry and the pharmaceutical industry, best summarized perhaps by an editorial in the American Journal of Orthopsychiatry, Oct. 1990: 'In bed together at the market: psychiatry and the pharmaceutical industry'.

Throughout the book Breggin spices his accounts with anecdotes and case histories, but nevertheless backs everything up with many references and a supporting list of recommended reading. He also describes some resounding successes which have been achieved with more humane alternatives for the treatment of mild and severe psychological distress over the past twenty years.

Toxic Psychiatry is a frightening revelation to anyone with M.E. or other organic disorder, particularly if treated with any of the drugs which Breggin discusses. It should be compulsory reading for all psychiatrists, especially those who write prolifically and dogmatically about M.E.

11.9.1994
APPENDIX IV

ME/PVFS and the Press: A report for Action for ME on the coverage of myalgic encephalomyelitis and postviral fatigue syndrome in the medical press

Dr Cathy Read  29.10.1993

A review of recent coverage of ME/PVFS in selected mainstream medical press.

Controversy still surrounds the diagnosis of myalgic encephalomyelitis (ME) and related fatigue syndromes. This point was recently highlighted by the television screening of 'Wide-Eyed and Legless', the story of Diana Longden, labelled hysterical by her doctors during life and posthumously considered by some to have suffered ME.

This review looks at the coverage of the illness in the mainstream medical press over an eighteen month period from March 1992 to August 1993. The publications reviewed include the British Medical Journal (BMJ), The Lancet, General Practitioner (GP), Pulse, and Doctor.

Among the findings:

1. CFS, ME and PVFS are often used interchangeably although they often describe different problems.

2. Sufferers of ME, PVFS and CFS are often portrayed in a bad light or not taken seriously.

3. There is a tendency to confuse patients with CFS, ME and PVFS with 'TAT', patients who are 'tired all the time'.

4. Despite growing evidence of abnormal brain and immune function in many patients with ME and PVFS there is a tendency to 'psychologise' the illness.

Background

There are many reasons why the diagnosis of ME, PVFS and CFS is so controversial. Many different terms are used interchangeably to mean the same thing. Labels range from 'Royal Free Disease' and 'Tapanui Flu' to 'myalgic encephalomyelitis'(ME) and 'post-viral fatigue syndrome' (PVFS). Five years ago American researchers suggested chronic fatigue syndrome (CFS), a 'catch-all' term which focuses attention on one symptom- fatigue. All these diagnoses are controversial; there have been many attempts to identify a single disease entity but no consensus exists, there is no diagnostic test, a range of treatments have been recommended but none is very effective and many are scientifically untested.

Despite the lack of any overall agreement doctors have made many attempts to define ME, CFS and PVFS. The definitions are described more fully in the appendix. Briefly, CFS is an umbrella term used to describe fatigue lasting six months or more and which is severe enough to reduce a person's daily activity to half the normal level. The definition of ME is much narrower and includes the following three features: generalised or localised fatigue following minimal exertion with prolonged recovery time, a variety of neurological disturbances, marked variability of symptoms in the course of a day. If there is clear evidence of infection at onset the term PVFS is used.
The terminology

Both the American and British criteria for CFS have been widely used but it is now generally agreed that the term CFS covers a number of conditions and that it is not synonymous with ME or PVFS.

Even though the definitions in use for ME and PVFS are not equivalent to those for CFS there is a tendency for people writing on the subject to ignore the distinctions.

Articles often mentioned the different terms but concluded that the American label, CFS, was preferable. The majority of articles (70% or 19 out of 27) either referred to CFS alone or used it interchangeably with ME and/or PVFS. Different terms were used interchangeably in one third of the articles reviewed. Most articles which did this and adopted CFS as the preferred terminology then proceeded to assume it was a single disease entity. So, Dr Moin Subhani's article on the chronic fatigue complex in Doctor reads: 'chronic fatigue syndrome seems to be the most suitable name and has been widely adopted' (1). In a BMJ editorial Professor Peter Thomas, Emeritus professor of neurology at the Royal Free Hospital School of Medicine, uses the common terms ME, PVFS and CFS interchangeably but concludes: 'the chronic fatigue syndrome seems the most acceptable label (2).

An article on 'Yuppie Flu' in Doctor was one of the few to point out the differences: 'it seems likely that chronic fatigue represents a mixture of pathologies rather than one specific entity' wrote Dr Keith Hopcroft (3).

The term ME was used almost as often in the trade press as the term CFS but ME was more likely to be used when reporting information linked to a patient group such as Action for ME. None of the articles in the trade medical press attempted to define whichever term they chose to use.

Although general reviews might be expected to present a balanced picture this does not seem to be the case here. Four out of four general articles (two in Doctor, one in Pulse and one BMJ editorial) used different terms interchangeably. Three of these articles recommended antidepressants and one stressed the high incidence of depression among patients. Half this sample advised graded exercise, a recommendation which is highly controversial.

The psychologisation of illness

In many articles psychological features were exaggerated over others. Professor Thomas illustrates this well in his BMJ editorial. Although he writes: 'the cause of the chronic fatigue syndrome remains a highly controversial and emotive issue', it is clear he favours a psychological explanation:

'in most cases it is an inescapable conclusion that a psychiatric disorder is involved....The search for a physical cause outside the patient highlights the current unfortunate attitudes towards psychiatric illness, recalling the social stigma attached to tuberculosis or epilepsy in former generations,' he says.

To back this conclusion Professor Thomas cites two studies which identified a psychiatric disorder in three quarters of the patients studied. Both studies used a broad definition for CFS and were not restricted to ME and PVFS. Elsewhere, but not mentioned in this editorial, studies of patients with ME or well-defined CFS have found clinically significant depression is probably no more common than among patients with multiple sclerosis or cancer (4) (5) (6). When depressive symptoms occur in people with ME, PVFS and CFS they differ markedly from symptoms in people suffering predominantly from depression (7), a point this editorial alludes to only briefly.
Although the editorial says strenuous efforts have been made to identify a non-psychiatric explanation for chronic fatigue syndrome it does not mention most of them.

Two studies of abnormal brain function, both reported in the BMJ within the lifetime of this review, were not mentioned. One study found reduced blood flow to the brain stem in patients with ME (8) and another identified abnormalities in the functioning of the hypothalamus in patients with post viral fatigue syndrome but not in patients with depression (9).

Pulse's extensive six page feature on CFS which appeared in February this year also favours the psychiatric axis. The magazine chose Dr Simon Wessely, senior lecturer in psychological medicine at King's College School of Medicine, for its regular '10 Questions Answered' slot:

'Perhaps three-quarters of patients referred to specialists with a possible diagnosis of chronic fatigue syndrome fulfil criteria for psychiatric disorders,' says Dr Wessely.

While Dr Wessely admits there are 'one or two papers showing some sophisticated abnormalities of cerebral function', he does not go into detail (10). There is no mention of a number of other studies which found, on average, only 19% of patients with ME and strictly defined CFS suffered depression (11).

Another report in Pulse, headed 'Psychiatric diagnosis and chronic fatigue link' covers a study by Dr Peter Manu, a psychiatrist at the University of Connecticut and presented at a London symposium. The report says four out of five patients diagnosed as having chronic fatigue syndrome responded to treatment for depression. It does not give the criteria used to define CFS in these patients, suggesting they may be a broad group with long term unexplained fatigue. Nevertheless Dr Manu suggests: 'GPs refer fatigued patients for a psychiatric evaluation before trying other treatments for their condition (12).

Doctors have often 'psychologised' illnesses which are well not understood. Diabetes, Parkinson's disease and multiple sclerosis, diseases now recognised as having an organic basis, have all been 'psychologised' in the past (13).

Perpetuating the controversy

Coverage suggests ME/PVFS/CFS has fallen into the perpetual controversy trap. Doctors have fallen into one camp or another and careers and vested interests are at stake. Controversy makes better news than general agreement and it can run and run.

The letters pages of medical journals often reflect more accurately the entrenched views of some doctors than the articles. Some of these were flushed out after the publication in the BMJ of a study of 200 patients referred to an infectious diseases clinic in Oxford with unexplained fatigue (14).

Patients tended to have a poor immediate prognosis but most had recovered two years after initial clinic attendance. Functional impairment at follow-up was significantly associated with belief in a viral cause of the illness, limiting exercise, avoiding alcohol, changing or leaving employment, belonging to a self help organisation, and current emotional disorder. The authors said the patient group was almost certainly heterogenous. In a balanced argument they pointed out that, due to the design of the study, the connections between functional impairment and certain factors such as limiting exercise did not indicate cause and effect.

The Oxford findings were leapt on by Dr Simon Wessely, senior lecturer in psychological medicine at King's College Hospital Medical School, as evidence of the failure of doctors and self-help organisations to relieve the disability associated with CFS (15).
Wrongly interpreting a causal link between poor outcome and membership of a self help organisation he says: 'I fear that the self help organisations may interpret this as another attack on their credibility, which will further sour relations between the organisations and the profession'.

In a subsequent letter Melanie Hume of the ME Association took issue with Dr Wessley, pointing out that neither the ME Association nor Action for ME interpreted the Oxford paper as an attack on its credibility:

'The main reason why our beliefs tend to differ from those of Wessley is that the authors do not distinguish between myalgic encephalomyelitis and chronic fatigue and we do. We see myalgic encephalomyelitis as more than 'mental and physical fatigue' and we have evidence that treatments that seem to help patients with chronic fatigue do not always benefit people with myalgic encephalomyelitis,' says Mrs Hume (16).

Failure to distinguish between ME, PVFS and CFS is clearly prolonging the controversy. Dr Subhani, writing in Doctor, found only a single common thread: 'Fatigue is the key symptom and the only one common to all sufferers '. The article is referenced as 'Fatigue'. What hope, then, of finding a common cause or a common cure? This is a point Dr Charles Shepherd, Medical Director to the M.E. Association, made on the BMJ letters pages. He emphasised that people with chronic fatigue syndrome were a large and varied group: 'Researchers should therefore not be surprised to find that the outcome varies considerably when the aetiology is not more clearly defined' (17).

**Yuppie flu and heartsink patients**

Several of the articles in the medical trade press adopted unhelpful and sometimes derogatory tones when covering ME. Dr Keith Hopcroft did not beat about the bush in his weekly column in Doctor. In an article entitled 'Yuppie Flu' he says: 'Yuppie flu is one of a number of names given to a state of persistent fatigue. Others include myalgic encephalomyelitis (ME) and effort syndrome. The generally accepted term nowadays is chronic fatigue syndrome'.

Dr Hopcroft's exhortations in the final paragraph to be sympathetic and non-judgemental came too late for Dr Graham Palmer of Stockton Heath who replied, expressing his disgust:

'... use of this derogatory term is highly offensive and set the tone for the rest of the article, which was unhelpful and superficial,' wrote Dr Palmer (18).

In his defence Dr Hopcroft replied that use of the offensive term had: 'enabled this important condition to be included in an A-Z series under Y.'

Dr Shepherd employed the same tactics to reply: 'By the same logic his (Dr Hopcroft's) next A-Z series ought to classify AIDS under the letter G (for gay plague) and mental subnormality under the letter I (for imbeciles). I very much doubt this would occur' (19).

There is little in the medical press to lift the image of ME, PVFS or CFS sufferers. So, in Pulse, Dr Melanie Wynne-Jones's review of the Oxford study reported in the RMJ is entitled: 'The tiring legacy of chronic fatigue'. 'Do patients with chronic fatigue make your heart sink?' Dr Wynne-Jones asks her readers (20).

Another headline in Pulse asked: 'Are fatigued patients worth investigating?' (21). This article reviewed a paper carried in the BMJ in July which followed up patients presenting with tiredness in general practice. Although it did not specifically deal with ME or PVFS it illustrates doctors' distaste for patients who are tired: 'These patients strike a familiar chord and frequently trigger feelings of frustration or 'heartsink' in their doctors,' says Dr Neil Snowise, a GP from Bath.
Important omissions

Of 27 articles on CFS/ME/PVFS carried in Pulse, Doctor and GP over the last eighteen months, only one specifically reported on a neurological abnormality. The article in GP ('Clue to ME found in the brain') described an American study which found inflammatory changes on the brain scans of ME patients (22).

One article out of 27 concentrated on immune dysfunction in CFS and also reported on American research (23).

While there have been relatively few new scientific papers on immune system dysfunction and ME/PVFS/CFS over this period, at least five papers have appeared in the scientific literature on the link with brain dysfunction.

Two significant reports on the link with brain dysfunction were published in the BMJ during this period. One identified reduced blood flow to the brain stem in 14 patients diagnosed with ME. Although this was a letter, several full papers were published in other medical journals, all showing abnormalities in blood flow (24).

A second report found upregulation of 5-hydroxytryptamine receptors in the brains of patients diagnosed as having post viral fatigue syndrome. This last change was not found in patients who were depressed.

Neither of these reports was carried in the medical trade press. These publications did, however, pick up on two other papers reported in the BMJ. Pulse ran an article on 'The tiring legacy of chronic fatigue', describing the follow up of fatigued patients presenting to an infectious diseases clinic. GP concluded: 'Chronic fatigue syndrome may simply be poor sleep' after a team of psychiatrists reported findings of sleep abnormalities in patients with chronic fatigue syndrome (25).

Whether or not people with ME and PVFS should exercise is a highly controversial issue. The main psychiatric theory for CFS, based on a cognitive-behavioural model, considers symptoms are due to mistaken perceptions about the illness and lack of activity. The theory argues that a downward spiral ensues; people become less fit as they take less and less exercise, in addition, they may then become depressed. This theory won credibility with a study published in 1991 which found a combination of graded exercise, cognitive therapy and antidepressants helped 81% of patients who completed treatment. Although the fluctuating symptoms experienced by many people with ME seem to conflict with this model, some doctors now consider graded exercise to be a cornerstone of treatment.

This view is typified in Dr Hopcroft's article in Doctor: 'Most doctors now believe the most appropriate action is graded exercise aimed at improving muscle function, increasing mobility and raising morale.'

The counter view argues that restricting activity is a normal coping strategy for people who are ill and beneficial rather than detrimental. If patients with ME and PVFS exercise beyond their personal limits (for example, while feeling very tired) they may feel worse and could suffer increased anxiety (26). Doctors who hold this view are not against all exercise but advise gentle exercise dictated by the patients' symptoms. They are supported by the only controlled trial to include graded exercise, published in the American Journal of Medicine this year but not picked up by the medical press under review (27). Patients allocated to the 'psychologic' arm of the trial saw a psychiatrist in a series of outpatient sessions and were given a schedule of home-based graded exercise.

There was no benefit from psychologic therapy, which included graded exercise, or immunologic therapy, the other treatment evaluated in the trial.

The medical press readily picked up unpublished and sometimes esoteric work on ME and CFS. So: 'Doctors pour cold water on bath cure' GP revealed after reading a report in The European newspaper...
The European was apparently the preferred outlet for researchers at the Thrombosis Research Institute in London to publicise their finding that daily cold baths could boost levels of T-lymphocytes and some hormones in people with poor circulation and fatigue syndrome (29).

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APPENDIX V

MYALGIC ENCEPHALOMYELITIS

There is a tendency to regard Myalgic Encephalomyelitis as a "new" disease which has only come to light since the 1980s. In fact, even allowing for the difficulties of interpreting ancient medical texts it seems clear that ME has been a cause of ill-health for many centuries.

The first known description of a disease complex resembling the clinical entity we now call ME is to be found in a fragment of an Egyptian papyrus dated to 1900 BC, which is an obvious copy of a much older document. This information is repeated in the Ebers papyrus, a complete rather than partial record, dating from c 1400 BC.

Galen, in the second century AD, not only describes a similar disease, but makes it clear that he regards this as a physical illness rather than a disease of the spirit, the concept of any unexplained illness emanating from the mind having been passed to the Greeks by the Egyptians, and from the Greeks right down to the present day, with lamentably few attempts at serious scrutiny.

In the 16th century, the army of Henry VIII brought what may have been the first recorded epidemic of an illness resembling ME back to England from a campaign in Holland. Called the English sweat, many of those at court were affected, including Ann Boleyn, but it was not until the mid-seventeenth century that medical descriptions became clear enough for us to be relatively certain that it was ME that was being referred to.

In the 1650s the renowned physician Thomas Sydenham described what was clearly ME. Called "muscular rheumatism" by physicians, it was commonly known as "the English Disease." Sydenham prescribed a preparation he called Balm of Gilead for the relief of muscle pain, the recipe for which is still extant, and it may well have been effective.

A post-infectious disorder which clearly resembled ME was described by the diagnostician Sir Richard Manningham in c 1750, and was called by him "febricula", and from this time onwards there are more and more references to instances of an illness which, whatever the nomenclature in use at the time, was virtually indistinguishable from ME. The incidence appears to have been on the increase during the Victorian period, and it seems at least possible that this is the illness that afflicted Florence Nightingale in 1854, when following an infection she became chronically ill with muscle fatigue and persistent pain in the chest and back. Miss Nightingale's illness persisted for at least 25 years.

From the 1850s, epidemics also began to be reported. There were two in Iceland, in 1856 and 1865, and another in America, during the Civil War. This last, called "Soldiers' Disease", was the subject of a book published in 1877 by the neurologist-in-chief for the Union Army, Silas Weir Mitchell.

From the 1880s another disease, paralytic polio, also began to be recorded as occurring in epidemics, and physicians who had until then not believed in the theory of infection by microbes, had to at least consider the concept. Progress in this was slow, and as late as 1901 some physicians were still insisting that paralytic polio was due to psychological factors, an all too familiar story, and one that later became well known to the victims of ME, as well as to those suffering from, among other things, tuberculosis, diabetes, and what was formerly known as disseminated sclerosis, now multiple sclerosis.

It was during this period that those documenting the polio epidemics also noticed cases which were not typical in that the patient did not go on to become paralysed - abortive poliomyelitis or where the polio was recurrent, or caused muscle pain and weakness rather than paralysis. However the possibility that there was another, separate, if possibly related agency at work was not recognised until the 1934
Californian polio epidemic during which an epidemic of a different type occurred involving 198 ancillary and medical staff of the Los Angeles County General Hospital.

This epidemic was investigated by Dr A G Gilliam, Past Assistant Surgeon of the US Public Health Service, who at first referred to it as "An Epidemic Diagnosed as Polio." The symptoms recorded were those typical of ME, including relapsing muscle weakness, muscle pain, memory loss, aphasia, fatiguability, all to the classic fluctuating pattern. Gilliam published a report of the epidemic in 1938, in spite of considerable opposition from the health authorities, and one of the points made was that this was a disease causing lasting ill-health, since many of the staff had not returned to full employment after six months.

There were many other ME epidemics, often associated with outbreaks of polio, during the 1930s, 1940s and the early 1950s, such as that in Wisconsin in 1936, and outbreaks in Switzerland. In 1948 there was an outbreak involving 1,116 people in Iceland, an outbreak in Adelaide in Southern Australia between 1949-51, outbreaks in upper New York State in 1951, in Copenhagen and Coventry in 1953, and at the Addington Hospital, Durban, in 1955.

Two epidemics in the UK in 1955, that in Dalston, Cumbria, and that at the Royal Free Hospital, were not associated with outbreaks of polio, and the association dies after the advent of polio vaccine in the mid-1950s. ME, however, continues to occur in both epidemic and sporadic form, and remains a disease of unknown aetiology, although a link with viral infection at onset in most cases is beyond doubt.

**NOMENCLATURE**

One thing that has not changed is the plethora of names attached to the illness, and it is nomenclature which is now proving to be the greatest cause of confusion and confounding in research and in clinical practice. A brief list of names and their association is given below:

**ATYPICAL POLIOMYELITIS - 1934**

Used by Gilliam in his report of the Los Angeles outbreak.

**A DISEASE SIMULATING POLIOMYELITIS - 1948**

Sigurdsson used this term to describe the outbreak in Iceland.

**AKUREYRI DISEASE - ICELAND DISEASE -1948**

Names also used for the Icelandic outbreak, referring to the town and country of occurrence.

**EPIDEMIC NEUROMYESTHENIA - 1953**

Shelokov used this term to describe an outbreak amongst student nurses in Maryland. The term "Epidemic" was used to signify the infectious nature of the illness.

**ROYAL FREE DISEASE -1955**

Used in referring to the outbreak at the Royal Free Hospital, also called in various publications
The word "benign" was used to signify low mortality.

MYALGIC ENCEPHALOMYELITIS -1956

Drs Ramsey and Richardson independently modified the last two names to Myalgic Encephalomyelitis since they felt that to call the illness benign detracted from its serious effects. This name was adopted by both physicians and patient groups in the UK.

POST-VIRAL FATIGUE SYNDROME -1980

This name was coined in the UK to point up the link at onset to an infectious process. Unfortunately, it has also led to confusion with common self-limiting post-viral debility.

CHRONIC EPSTEIN BARR VIRUS DISEASE - 1984

Used by some physicians in the USA until it was shown that the EBV was not the only virus associated with this illness.

CHRONIC FATIGUE AND IMMUNE DYSFUNCTION SYNDROME - 1984

This name was suggested by Grufferman from a study of an outbreak involving musicians in the North Carolina Symphony Orchestra, which reported a decrease in both the number and activity of natural killer cells in the patients. This name is used by American patient groups.

CHRONIC FATIGUE SYNDROME - 1988

This name was coined by Dr Gary Holmes of the Centers for Disease Control in Atlanta as a replacement for the term Chronic Epstein Barr Virus disease. It was based on a single symptom found in those affected by the outbreak of ME at Lake Tahoe, Nevada, in 1984, but has since become an umbrella term used to describe many illnesses where there is an element of unexplained chronic fatigue. It has given rise to much confusion, and given added impetus to the attempted psychologisation of ME.

THE PSYCHOLOGISATION OF ME

There has always been a tendency to psychologise illnesses of uncertain aetiology, over and above the all too frequent misdiagnosis of individual cases of known organic illness as being of psychiatric origin. Medical history shows us all too clearly that very few people, including doctors and scientists, seem able to understand that the absence of unequivocal evidence of organic dysfunction does not necessarily mean that there is no evidence, since it can equally well mean that there are as yet no techniques with which to find it.

In the early years of this century it was perhaps understandable that those engaged in the new discipline of psychiatry should be looking for illnesses to which they could direct their curative skills. There is no doubt that (unlike in the epidemics which showed the connection between infectious agents and onset), in many of the sporadic cases of ME, physicians dealing with single cases in the community would be unlikely to have enough information on the diagnostic criteria to make the correct diagnosis.
This situation should have begun to change, indeed, was changing, in the 1950s and 60s, as more reports of outbreaks and sporadic cases were reported in the medical literature, particularly those studies referring to the outbreak amongst the staff at the Royal Free Hospital in 1955 which resulted in the closure of the hospital from 25 July to 5 October.

No-one involved at the time had any doubt that this outbreak was precipitated by an infectious agent, probably a virus, brought into the hospital by the admission since the spring of a number of cases from the surrounding community, and this was reflected in the literature.

This changed in 1970, when two psychiatrists, Drs McEvedy and Beard, published papers purporting to show that the Royal Free outbreak was due to mass hysteria, and despite the fact that their examination of the evidence was demonstrably flawed, the deliberate movement towards the psychologisation of ME on the part of some psychiatric and other health professionals and researchers began to gain momentum. This in time affected the thinking of a great part of the medical community who, without time or inclination to investigate the literature, could see no reason to doubt what became a more and more vocal lobby for psychologisation.

If some of those who became involved in the debate had studied the literature for themselves, the myth of "all in the mind" could not have gained ground to the extent that it has, as a mere glance at the "evidence" for mass hysteria being the cause of the Royal Free outbreak would have shown the fallacy of such a theory.

McEvedy and Beard had confined themselves to a study of records only, and instead of studying the 200 cases which other researchers had used as a patient group because those case records were complete and there was no doubt that this was an homogenous group, they studied the remaining 92 cases where the picture was not so clear.

Of these 92 cases, case records were incomplete for 37 patients, who were either nursed at home or in other hospitals, and the 55 other cases had presented with symptoms which were not as clear-cut as those of the cohort of 200. It may well be that these patients were suffering from a less severe form of the illness, from another type of infection, or indeed, from the understandable effect of anxiety and stress on the patients or the examining doctors who were seeing colleagues struck down all around.

However, when the 200 cases with clear homogeneity are examined, a very clear profile emerges, and it is a profile which has nothing in common with the accepted profile of mass hysteria.

**MASS HYSTERIA**

Takes place in closed community, no connection with cases with similar symptoms elsewhere.

Usually involves adolescent, poorly educated females.

There may be a "trigger", an illness frightening to those involved.

A duration of around 10-20 days, often less.

No objective signs on examination, or from laboratory tests.

Symptoms do not endure beyond the duration of the outbreak.
ROYAL FREE OUTBREAK

There were cases in the local community and outbreaks in Cumbria, and at the Addington Hospital in Durban, South Africa, all to the same pattern and time-span.

Very few staff members under 20 were affected, and those who were affected included consultants, two Matrons, several senior sisters, and junior doctors, as well as ancillary staff. Of staff in residence, 20% of males were affected and 19% of females.

There was no trigger, and index cases were thought to be glandular fever, of no concern.

Duration was over 4 months, from 13 July to 24 November.

Abnormalities were detected in lymphocytes: 74% showed signs of CNS involvement, with fever in 89%, and generalised lymphadenopathy in 79%. Facial paralysis was present in 19%, ocular palsy in 20%, while the now familiar symptoms of ME at onset from vertigo to problems with hearing and micturation were also present.

It is estimated that at least 75% of Royal Free patients have yet to make a full recovery.

It is therefore obvious that an infective agent was at work at the Royal Free, and the theory of hysteria should never have been entertained, much less presented for publication in a scientific journal. Much of the later and current literature putting forward psychiatric theories as to the aetiology and prolongation of ME is equally flawed, and promulgates equally specious theories, yet it continues to appear and to take precedence over studies into organic causes in the mainstream medical journals.

Another major factor in the advance of psychologisation is the use of the term Chronic Fatigue Syndrome, which has led to the loss of specificity. Researchers fail to differentiate between chronic fatigue states caused by depression, anxiety, psychosocial causes, and those by illnesses such as ME.

Rather than acknowledge that there are different groups within the umbrella of CFS, and that it is necessary to define each of these groups since different causes will require different treatments, there is now a trend to go beyond that group of conditions first defined as CFS, and to include the nebulous cases of fatigue which were once excluded.

Such poor science can only prolong the search for the causes, treatment, and cure of these illnesses for years to come, as the physical versus psychosocial debate continues to impede progress.

It seems incredible that this should be so, given the vast number of sound scientific studies showing abnormalities in the immune system, the endocrine system, the central nervous system, and the muscles of those affected by ME.

Not only are these studies ignored, or misquoted, by the increasingly vociferous psychiatric lobby, but the patients themselves and the patient organisations are sneered at and stigmatised.

Figures on prognosis given by patient groups are "nihilistic", notwithstanding the fact that these figures are taken from published studies, and are less pessimistic than those quoted by (a) particular researcher: patients are people who "suffer triumphantly... their claim that the disease has ruined their lives is not to be believed".
No-one with any understanding of the illness would wish to deny that some patients also suffer concurrently from psychiatric conditions such as depression and anxiety, either as a result of CNS dysfunction, or as a reaction to chronic illness and disablement, such as occurs in other illnesses.

The mind/body division has always been artificial in the sense that what affects one will inevitably affect the other, but while it is not the patient who has polarised the debate, it is the patient who will continue to suffer from prejudice, misunderstanding, and out-right disbelief until the true picture is allowed to be shown.
APPENDIX VI

MINI-REVIEW OF SOME OF THE PUBLISHED WORKS OF Dr ANTHONY DAVID ON "FATIGUE" AND CHRONIC FATIGUE STATES

Note: "Fatigue" is not the same as chronic fatigue, neither is it the same as the chronic fatigue syndrome (CFS); the latter is an umbrella term, one subset of which is myalgic encephalomyelitis (ME).

1990

Tired, weak, or in need of a rest: fatigue among general practice attenders

(Note: this study was funded by the MRC; the help given by Dr Simon Wessely is specially acknowledged, and 3 of Wessely's own papers are relied upon in the text and are given as supportive references).

This study purports to determine the prevalence of “fatigue”: out of 611 subjects, only one was considered to have CFS, yet the authors conclude: “Despite the recent interest in chronic fatigue syndrome shown in the medical and lay press...this (study) counters the inflated claims of the frequency with which that syndrome occurs”.

(Note that the interchangeable obfuscation of terminologies serves to support the authors' own opinions).

1991

Postviral fatigue syndrome and psychiatry
A.S. David; British Medical Bulletin 1991:47:4:966-988

(Note: this was funded by the MRC; it is acknowledged that many of the ideas in this paper grew out of discussions with Dr Simon Wessely; it uses 11 Wessely papers as references and David refers to the British (Oxford) operational definition formulated by Sharpe, Wessely et al which requires the absence of physical neurological signs and myalgia, so the use of this overly-narrow case definition immediately leads to inherent selection bias).

“Psychological symptoms...are a major feature of the syndrome”

"Fatigue persisting beyond six months was predicted by psychiatric illness prior to the episode"

"Most cases of CFS do have psychiatric symptoms prominent enough to justify psychiatric caseness"

"Thirteen published reports are reviewed, all of which record psychiatric symptoms and diagnosis in chronically fatigued patients" (note that chronically fatigued patients do not necessarily have CFS or ME)

"A diagnosis of depressive illness would be appropriate. Unfortunately, this is not good enough for the patient"

"When PVFS patients are placed alongside suitable controls, they still stand out as especially prone to emotional problems"
"Powell and colleagues (ie. Wessely) found that... feelings of guilt and low esteem featured less prominently in PVFS. They interpreted this (as affording) protection from pathological guilt" (note: why should those with ME/PVFS be obliged to feel guilty about being ill, just because such feelings of guilt fit neatly with the unproven opinions of certain psychiatrists?)

"In short, there is little empirical support for... disability causing depression" (note: there is if an accurate search of the literature is performed and the results are utilised).

David is overly dismissive about the findings of a controlled study which do not support his own view and concludes: "In summary, there is considerable direct and circumstantial support for chronic fatigue being an aspect of psychiatric illness, especially depression".

(Note: David fails to mention the immense amount of peer-reviewed international work which does not support his own view, nor that even Wessely himself now has to concede that CFS is plainly distinct from depression).

1993

Chronic fatigue in primary care attenders
Elizabeth McDonald, Anthony David, Anthony Pelosi & Anthony Mann.

(Note: this study was funded by the MRC; it uses 8 works of Wessely as references).

"Epidemiological studies (reviewed by Lewis and Wessely 1992) have pointed to an association between fatigue and psychological symptoms"

"Many putative risk factors... for fatigue syndromes... have often been at odds with majority medical opinion. This is illustrated by the concept of myalgic encephalomyelitis or 'ME' (Ramsay, 1986)"

"Self-help organizations... have established 'ME' in the minds of the public"

The authors deliberately selected subjects who "specifically... would be less wedded to a physical explanation" (note: this raises the issue of outright selection bias)

The authors chose not to use the accepted American guidelines for selection of study subjects (Holmes et al, 1988), asserting that the American guidelines' insistence on multiple physical complaints (quote): "leads to the... inclusion of cases with lifetime psychiatric disorder" (note: in genuine ME, there are at least 64 physical complaints listed, so it could be legitimately claimed that this study is biased in favour of a psychiatric outcome).

One (perhaps inadvertent) pearl of wisdom: "More strict criteria for CFS (referring to the Oxford criteria drawn up by Sharpe and Wessely et al) succeed only in selecting those cases with more severe psychiatric disorders", which is indeed the case.

"The difference between patients with chronic fatigue in primary care versus those with chronic fatigue syndromes identified in secondary and tertiary care lies in the... patients' beliefs about the cause of their symptoms"

"It is conceivable that keeping patients within the ambit of primary care will prevent the development and adverse consequences of fixed physical attribution... We would predict that the long-term prognosis for
patients so managed would be favourable” (note: in other words, GPs should not send their fatigued patients for any further investigation or help).

1994

Predictors of chronic "postviral" fatigue
(Note: this study was funded by the MRC and contains six Wessely references).

"Chronic severe fatigue six months after GP-diagnosed viral illness is related to...doctor behaviour, rather than to features of the viral illness”

"A high prevalence of psychiatric disorders has been documented in patients with chronic fatigue syndromes"

"Personality and psychological functioning were predictive of prolonged sickness and disability"

"Our findings remain of considerable practical importance. Doctor behaviour, such as sick certification, emerged as a significant contributor to the risk of chronic fatigue"

(Note: some doctors were concerned that in concentrating on psychosocial risk factors for chronic fatigue, the authors might have underplayed physical ones [Lawrie &McHale, Lancet 1994, November 26]; the authors responded to these concerns):

"Despite Lawrie & McHale's suggestion that more attention be paid to symptoms and their severity as a measure of physical illness, these indices further support the influence of psychological factors in predicting chronic fatigue states....Work by Wessely has confirmed this finding".

1995

Cognitive Functioning and Magnetic Resonance Imaging in Chronic Fatigue
(Note: This work was supported by a grant from the Sainsbury (supermarket) family's Linbury Trust which has substantially funded Wessely et al to study chronic "fatigue").

The authors refer to "Subjects with chronic fatigue, most of whom met the criteria for chronic fatigue syndrome"

“Subjective cognitive dysfunction increased with psychopathology"

"An extensive battery of cognitive tests failed to reveal conspicuous differences between patients with severe, chronic fatigue or CFS and matched controls" (note: careful scrutiny of the text reveals that this "extensive battery" did not include a measure of sustained attention, which is a cardinal deficit in true ME).

“Some subjects focus excessively on benign cognitive errors and attribute them to neurological illness"

"Clinicians should...avoid re-inforcing unproven illness beliefs"
"Our data contrast with studies which have demonstrated irreversible cognitive decline...due to proven viral infection, despite continued use of the term myalgic encephalomyelitis (ME)"

"We are critical of what we regard as the misuse of neuropsychological test results to confirm or refute an 'organic' basis for CFS".

Notwithstanding their dismissive attitude throughout the text, the authors are forced to conclude their paper as follows: "Subtle morphological changes may not have been detected in this study, which did not employ quantitative volumetric measures" (note: why not, when the stated purpose of this study was to examine whether cognitive dysfunction in "chronic fatigue" may be due to brain pathology evident on magnetic resonance imaging?).

1996

Neuroimaging in chronic fatigue syndrome

Although other MRI studies in CFS have found areas possibly reflecting demyelination, these authors assert about those studies that they: "suggest that no abnormality evident on MRI is characteristic of chronic fatigue syndrome".

Despite the fact that neither author is a specialist in nuclear medicine, they positively conclude: "It is...premature to claim unique neuroimaging abnormalities in the chronic fatigue syndrome"

(Specialists in nuclear medicine at The Middlesex Hospital, using single photon emission tomography, clearly showed that compared with depressives and with controls, patients with ME had significant reduction of blood flow around the brain stem -- Costa DC, Brostoff J, Douli V, Ell PJ; Brainstem hypoperfusion in patients with myalgic encephalomyelitis- chronic fatigue syndrome. Eur.J.Nucl Med: 1992:19: 733).

Perhaps the above review gives some indication of the likely outcome of the Pentagon-funded GWS study, of which Drs Simon Wessely and Anthony David are to be in charge.

The persistent failure of David and Wessely to address or accept the valid findings of other worldwide ME researchers which point to an organic aetiology must surely border on scientific misconduct.

Margaret Williams
10th June 1996