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DENIGRATION BY DESIGN?

A REVIEW, WITH REFERENCES, OF THE ROLE OF

Dr Simon Wessely

IN THE PERCEPTION OF MYALGIC ENCEPHALOMYELITIS

1987 - 1996

by

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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 (see later) 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,number 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 overview 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 perturbing. 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 some psychiatrists, whilst these same psychiatrists continued to publish their own work proclaiming their own views about the aetiology of ME (see later).

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 a certain group of psychiatrists (see later).

The documented failure of antidepressants and graded exercise in ME were also repeatedly ignored by the same proponent psychiatrists (see later).

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 (see later).

The patients' organisations were accused by this same group of psychiatrists of being anti-psychiatry (see below), 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 men 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.

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 with no knowledge of ME who read 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 (ie. 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: 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 a group of psychiatrists – see later) 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 (see later) 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, which is not synonymous with CFS – see later), 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 (see later) 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 in 1992 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 (see later). 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 later).

Such selectivity on Wessely's part would seem to be deliberately misleading.

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 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 the condition 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.

Although cases had been well documented by the end of the last century (Epidemic Neuromyasthenia: the sporadic form: Holt GW, Am J Med: 1965:250:98), doctors did not take the condition seriously until 1934, when a major outbreak occurred among the staff of the Los Angeles County Hospital (Epidemiological Study of an Epidemic Diagnosed as Poliomyelitis, occurring among the personnel of the Los Angeles County General Hospital during the Summer of 1934, US Public Health Bill

No.240, Public Health Science,US Government Printing Office, Washington DC:1:90).

Further outbreaks occurred worldwide, and the idea that mass hysteria might account for these outbreaks was fashionable at one time (postulated by two psychiatrists some twenty years after the outbreak at The Royal Free Hospital in London, even though they had never examined a single patient), 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).

Indeed, in July 1992 the WHO finally and formally listed ME under Diseases of the Nervous System, along with other organic neurological conditions (International Classification of Diseases (ICD): 10:G93.3, page 423), which was some considerable time after the distinguished neurologist Lord Brain had listed ME 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 “ME: The Disease of a Thousand Names”, 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 by the late Dr Melvin Ramsay and colleagues in 1956; 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) 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

(Myalgic Encephalomyelitis and Postviral Fatigue States. 2nd edition
A.Melvin Ramsay,Gower Medical Publications,London, 1988).

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
- dyspnoea 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, see his book above, page 5).

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 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, and 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 close, like-minded colleagues (see later for illustrations).

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 most commonly used term at present is CFS; it was coined in 1988 by a group of United States scientists and physicians in a paper entitled Chronic Fatigue Syndrome: a working case definition, by Gary Holmes et al (Ann Int Med: 1988;108:387-389).

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, Institutue 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 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 reluctant that Holmes should 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; in reality, it was 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 /GF).

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 Encephalomyelitis 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), CFS 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).

Notwithstanding, 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 aetiologically cannot yet be determined, as there is no definitive diagnostic test for ME, although there are clear patterns emerging (see later).

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 who

produced the Report of the UK National Task Force on CFS / PVFS / ME (Westcare, Bristol, 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 certain 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, we supply just five examples:

1. Coxsackie B viruses and the postviral syndrome: a prospective study in general practice. BD Calder, PJ Warnock, RA McCartney, EJ Bell
JRCF **1987**:37:11-14

“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”.

2. Immunology of Postviral Fatigue Syndrome. JF Mowbray, GE Yousef
In: British Medical Bulletin **1991**:47:4:886-894

“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”.

3. The Diagnosis of Chronic Fatigue Syndrome: an assertive approach
Paul R.Cheney Charles W.Lapp. CFIDS Chronicle Physicians’ Forum,September
1992:13-19

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**”.

5. Reducing heterogeneity in chronic fatigue syndrome: a comparison with depression and multiple sclerosis. Natelson BH, Johnson SK, DeLuca J et al
Clin Inf Dis **1995**:21:1204-1210

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.