# What is ME? What is CFS?

## INFORMATION FOR CLINICIANS AND LAWYERS

**December 2001**

**E.P. Marshall (1)**
**M. Williams (1)**
**M. Hooper (2)**

**(1) ME Research (UK)**
**(British Library Registered)**
**c/o The British Library**
**Science Reference & Information Services**
**Boston Spa, Wetherby,**
**West Yorkshire LS 23 7BQ, UK**

**(2) Emeritus Professor of Medicinal Chemistry**
**Department of Life Sciences**
**University of Sunderland**
**SR2 7EE, UK**

# CONTENTS

**History and Classification of Myalgic Encephalomyelitis (ME)……..3**

**Description of ME…….4**

**Symptoms Documented in ME……6**

**Evidence of Abnormalities in ME……10**

**Precipitating Factors in ME…….13**

**Physical Signs Found in ME…….15**

**Changing Definitions: History of Chronic Fatigue Syndrome (CFS)…….. 17**

**How "CFS" Displaced ME in the UK……..18**

**The UK Chief Medical Officer's Report on "CFS/ME"……27**

**Caution needed by Lawyers…….. 29**

**Conclusion……30**

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## History and Classification of Myalgic Encephalomyelitis

Myalgic Encephalomyelitis (ME) has been documented in the medical literature from 1934. [1] The Wallis description of ME (not Chronic Fatigue Syndrome, known as CFS – *see below*) was in 1957. [2] Sir Donald Acheson's (a former UK Chief Medical Officer) major review of ME was in 1959. [3] In 1962, the distinguished neurologist Lord Brain included it in the standard textbook of neurology. [4] ME has been formally classified by the World Health Organisation as a neurological disorder in the International Classification of Diseases (ICD) since 1969 (ICD-8: Vol I: code 323, page 158; Vol II (Code Index)
page 173). On 7th April 1978 the Royal Society of Medicine held a symposium on ME at which ME was accepted as a distinct entity. The symposium proceedings were published in The Postgraduate Medical Journal in November that same year. [5] The Ramsay case description was published in 1981. [6] Since 1989, the Medical Information Service of the British Library has produced quarterly updates on the disorder: these updates (known as CATS, or Current Awareness Topics) compile published international research and clinical evidence about the condition and contain abstracts of published articles. The Centres for Disease Control (the US federal agency charged with the containment of diseases and known internationally as the CDC) designates it for funding status as "A serious legitimate diagnosis CDC PRIORITY 1 disease of public health importance".

ME remains classified in the current ICD as a neurological disorder (ICD 10. G.93.3) and the World Health Organisation has confirmed that there are no plans to reclassify it as a psychiatric disorder in the next revision of the ICD (due in 2003).

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[1] Epidemiological study of an epidemic diagnosed as poliomyelitis occurring among the personnel of Los Angeles County General Hospital during the summer of 1934. Gilliam AG *Public Health Bulletin, US Treasury Department No.240, 1938*

[2] An investigation into an unusual disease in epidemic and sporadic form in general practice in Cumberland in 1955 and subsequent years. Wallis AL. *University of Edinburgh Doctoral Thesis 1957*

[3] The Clinical Syndrome Variously Called Benign Myalgic Encephalomyelitis, Iceland Disease and Epidemic Neuromyasthenia. ED Acheson. *Am J Med 1959:569-595*

[4] Diseases of the Nervous System. Lord Brain. Sixth Edition. *Oxford University Press 1962*

[5] Epidemic Neuromyasthenia 1934-1977: current approaches. Ed: WH Lyle and RN Chamberlain. *Postgraduate Medical Journal 1978:54:637:705-774* *pub: Blackwell Scientific Publications, Oxford*

[6] Myalgic Encephalomyelitis: A Baffling Syndrome with a Tragic Aftermath. A.Melvin Ramsay *pub: The ME Association, November 1981*

Chronic Fatigue Syndrome (CFS) is listed in ICD-10 as a term by which ME is also known, as is the term Postviral Fatigue Syndrome (PVFS). The term "CFIDS", or Chronic Fatigue and Immune Dysfunction Syndrome, is used by some groups in the US.

**Description of Myalgic Encephalomyelitis**

ME / ICD-CFS is a serious, disabling and chronic organic (ie. physical not mental) disorder: 80% of patients do not get better.[7] According to US statistics provided by the Centres for Disease Control (CDC), only 4% of patients had full remission (not recovery) at 24 months.[8] International expert Daniel Peterson is on record as stating about ME / ICD-CFS:

> "In my experience, (it) is one of the most disabling diseases that I care for, far exceeding HIV disease except for the terminal stages". [9]

American researchers found that the quality of life is particularly and uniquely disrupted in ME / ICD-CFS and that all participants related profound and multiple losses, including loss of jobs, relationships, financial security, future plans, daily routines, hobbies, stamina and spontaneity. Activity was reduced to basic survival needs for some subjects. The researchers found that the extent of the losses experienced by sufferers was devastating, both in number and intensity. [10]

Australian researchers found that patients with this disorder had more dysfunction than those with multiple sclerosis, and that in ME / ICD-CFS the degree of impairment is more extreme than in end-stage renal disease and heart disease, and that only in terminally ill cancer and stroke patients was the sickness impact profile (SIP) greater than in ME /ICD-CFS. [11]

The incidence of ME / ICD-CFS is known to be rising: in April 1994, the insurance company UNUM (one of the largest disability insurers) reported that in the five years from 1989 - 1993, mens' disability claims for CFS increased 360%, whilst womens' claims for CFS increased 557%. **No other disease category surpassed these rates of increase.**
**In order of insurance costs, ME/ICD-CFS came second in the list of the five most expensive chronic conditions, being three places above AIDS**. At the Fifth American

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[7] Presentation to the Scottish Parliament on 4th April 2001 by Dr A.Chaudhuri, Senior Clinical Lecturer in Neurology, University of Glasgow

[8] US CDC CFS Programme Update, 29th August 2001

[9] Introduction to Research and Clinical Conference. Daniel L Peterson. *Journal of CFS 1995: 1:3-4:123-125 (Previously presented at the AACFS International Research and Clinical Conference on CFS held at Fort Lauderdale, Florida, 7th-10th October 1994, co-sponsored by the National Institutes of Health and the Centres for Disease Control)*

[10] The Quality of Life of Patients with Chronic Fatigue Syndrome. JS Anderson, CE Ferrans *J Nervous and Mental Diseases 1997:185:6:359-367*

[11] Quality of Life in Chronic Fatigue Syndrome. R Schweitzer et al *Soc Sci Med 1995:41:10: 1367-1372*

Association of Chronic Fatigue Syndrome International Research and Clinical Conference held in January 2001 in Seattle, the Associate Director of the University of Washington's CFS Research Centre (Dr N Afari) confirmed that the incidence is indeed rising.

Of potential significance is the fact that American researchers have demonstrated that in ME / ICD-CFS, a particular pathway in the body which is affected by viruses **can also be affected by chemicals.** [12]

The strike rate is higher than multiple sclerosis. Comparisons have been made between the prevalence of ME /ICD-CFS and MS in the UK, in the USA [13] and in Australia [14] and have been estimated to be three times, twice and equivalent respectively. Prevalence estimates in Britain vary by a factor of 8, which is a reflection of the problem of definition.
In the UK it is generally believed that at least 300,000 suffer from the disorder; some psychiatrists, however *(see below)*, having themselves broadened the case definition to include psychiatric disorders, claim that there are over one million "CFS" sufferers in the UK, of which they assert 75% have a psychiatric disorder. [15]

Estimated direct NHS costs are said to be from £180 million to just over £1 billion *per annum*, depending on the choice of prevalence estimates, with total costs ranging from £879 million to nearly £16 billion. [16]

ME/ ICD-CFS is a multi-system disorder, one form of which can be associated with enteroviruses related to the poliomyelitis virus [17]. Virally-induced ME used to be known as "atypical poliomyelitis". There are acknowledged similarities and overlaps between ME and the post-polio syndrome (PPS), particularly concerning the nature and source of the pathophysiology, including virological evidence that enteroviruses persist in the human central nervous system. Specifically, the mechanism of the incapacitating exhaustion is identical in the two conditions (ie. in ME and PPS). [18] In ME there are

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[12] Interferon-induced proteins are elevated in blood samples of patients with chemically or virally induced chronic fatigue syndrome. Vojdani A, Lapp CW. *Immunopharmacol Immunotoxicol 1999:21: (2):175-202*

[13] Estimating rates of Chronic Fatigue Syndrome from a community-based sample. Jason LA et al *American Journal of Community Psychology 1995:23:557-568*

[14] Prevalence of Chronic Fatigue Syndrome in an Australian Population. Lloyd AR et al *Medical Journal of Australia 1990:153:522-528*

[15] Chronic Fatigue Syndrome. Report of a Joint Working Group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners (CR 54) *pub. RCP, London 1996*

[16] The Organic Basis of ME / CFS. EG Dowsett, DM Jones. Information and Statistics presented to the Chief Medical Officer in person at a meeting on 11th March 1998

[17] Review by JF Mowbray, Emeritus Professor of Immunopathology, Imperial College School of Medicine, London: Enteroviral and Toxin Mediated Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and other Organ Pathologies. John Richardson. *The Haworth Press Inc. New York, 2001 ISBN 0-7890-1128-X*

[18] The Post-Polio Syndrome: Advances in the Pathogenesis and Treatment. Proceedings of the First International Scientific Conference on the Post-Polio Syndrome. ed: Dalakas MC, Bartfeld H & Kurland LT. *Annals of the New York Academy of Science 1995:753:1-409*

chronic sequelae and the effects may be neurological, hormonal, autoimmune and myalgic, which may include the myocardium. [19]

**Symptoms documented in Myalgic Encephalomyelitis**

In ME, symptoms are seemingly without end. There is a remarkable variability of signs and symptoms from day to day and even from hour to hour: Hyde and Jain [20] (quoting Pellew) describe this variability:

> "A patient examined in the morning might have nystagmus, which would disappear at midday, recur later, disappear later and recur the next day".

This waxing and waning in the same patient in the same day is typical of almost all findings in ME / ICD-CFS and may lead to medical scepticism.

The most apparent features are extreme post-exertional muscle fatiguability, which is quite distinct from chronic "fatigue" or tiredness, together with recurrent nausea and profound, incapacitating malaise. It is striking how consistent are the symptoms that characterize this condition. [21] The exhaustion experienced by patients is extreme:

> "the disabling weakness and exhaustion a patient with ME / ICD-CFS experiences is so profound that "fatigue" is probably an insult". [22]

ME commonly starts with abdominal pain and diarrhoea, together with a persistent headache and / or vertigo, with a stiff neck and back, together with generalised myalgia, described as intense and burning. Muscles are tender to palpation and muscle spasm is not uncommon. There may be severe, intractable pain in particular groups of muscles, most notably in the neck and in the shoulder and pelvic girdles: the more severely affected are unable to stand unsupported for more than a few minutes. There is sometimes segmental pain in the chest wall.

In the more severely affected, dizziness is a particularly striking and chronic feature, as is persisting dysequilibrium and ataxia, with patients frequently bumping into things and becoming bruised. There is impaired neuromuscular coordination, particularly with fine finger movements. In the severely affected, there may be difficulty with swallowing; choking fits are not infrequent. There may be difficulty with voice production, particularly if speaking is sustained.

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[19] Enteroviral and Toxin Mediated Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and Other Organ Pathologies. John Richardson *The Haworth Press Inc, New York 2001*

[20] Clinical Observations of Central Nervous System Dysfunction in Post-Infectious Acute Onset ME / CFS. B Hyde A Jain. In: The Clinical and Scientific Basis of Myalgic Encephalomyeltis Chronic Fatigue Syndrome. ed: BM Hyde, J Goldstein, P Levine *pub: The Nightingale Research Foundation, Ottawa, Canada, 1992*

[21] as reference 19

[22] Chronic Fatigue. Cuozzo J. *JAMA 1989:261:5:697*

There may be seizures, although these are found only in the most severe cases.

In the most severe cases, photophobia and hyperacusis are common, as is tinnitus; often there is parasthesia.

Hypersomnia is prevalent, especially in the early stages of the disorder; this may be replaced by reversed sleeping patterns, with vivid and disturbing dreams; unrefreshing sleep is common.

Abdominal pains often recur; especially in the severely affected, there are usually chronic problems with diarrhoea and frequency of micturition, including nocturia. Bladder and bowel control may be insecure.

Cardiac arrythmias are very common, with pronounced tachycardia and an uncomfortably pounding heart; there may be paroxysmal attacks of angina-like chest pain. Cardiac pain is a recognised feature: patients may be convinced they are suffering a heart attack. Myocarditis was a common symptom in an analysis of 1,000 ME/ ICD-CFS patients seen in Glasgow, where clinicians were struck by the often-occurring association of patients
with ME/ICD-CFS with acute chest pain resembling coronary thrombosis.[23] A significant number of cases of Syndrome X strongly resemble ME / ICD-CFS clinically, and nuclear magnetic resonance spectroscopy studies of skeletal muscle in patients with Syndrome X show abnormalities that are identical to those found in patients with ME / ICD-CFS.[24] Syndrome X is characterised by typical anginal pain with a normal coronary angiogram:[25] in both Syndrome X and ME / ICD-CFS, blood supply to the heart muscle seems to be going haywire, but in Syndrome X there is desensitivity of the cell endothelium, whilst in ME / ICD-CFS there is heightened sensitivity of the cell endothelium. Syndrome X has been defined as a cluster of symptoms secondary to resistance of insulin-mediated glucose uptake; [26] it has been seen in association with increased risk for coronary heart disease due to enhanced growth and proliferation of arterial smooth muscle cells and highly elevated levels of cholesterol.

In the more severely affected, palindromic arthropathies regularly recur; spontaneous periarticular bleeds are frequent, especially in the fingers, which become swollen and painful, making the patient appear even more clumsy.

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[23] Arguments for a Role of Abnormal Ionophore Function in Chronic Fatigue Syndrome. A Chaudhuri, WS Watson, PO Behan. In: Chronic Fatigue Syndrome. ed: Yehuda and Moldofsky, *pub Plenum Press, New York 1997*

[24] Phosphocreatine turnover and pH balance in forearm muscle of patients with Syndrome X. Soussi B et al *Lancet 1993: 341:829-830*

[25] Chronic Fatigue Syndrome in Overlap Syndromes. A Chaudhuri, PO Behan. *CNS: Summer 1998:1:2:16-20*

[26] Lukaczer D. Syndrome X. *Inst Functional Med, Gig Harbor, Washington 1998*

Pancreatitis is not uncommon and may cause acute, severe pain: pancreatic exocrine insufficiency leads to malabsorption, which is a well-recognised feature found in the more severely affected; some patients have almost non-existent pancreatic exocrine function. Some patients have been shown to have achlorhydria.

Food intolerance is a prominent feature across all degrees of severity: multiple sensitivities to normal foods and household chemicals (including perfumes, chemical treatments of furniture and carpets such as flame-retardants and glues in chipboard), petrol and agricultural chemicals are frequent. Intolerance to alcohol and to medicinal drugs, particularly to antidepressants, is virtually pathognomonic.[27] Patients have to be cautious about all drugs but especially those acting on the central nervous system (ie. anaesthetics), as there is an increased occurrence of adverse reaction. [28]

ME affects not only the central nervous system but the autonomic and peripheral nervous systems as well. Sympathetic nervous system dysfunction is integral to ME / ICD-CFS pathology [29] and includes blurred and double vision, with difficulty in focusing and visual accomodation; eyes may be dry and eyelids are often swollen and painful. Typical autonomic symptoms include alternate sweating and shivering, with marked thermodysregulation. Patients experience orthostatic hypotension and symptoms of hypovolaemia, with blood pooling in the legs and insufficient blood flow to the brain: patients may feel faint, shaky and nauseous; they can be tearful and observably pale and they may experience severe distress.

Heightened sensory input awareness might be called an "acid test" for ME / ICD-CFS: one world expert claims that it is possible to make a diagnosis by taking a patient into a shopping mall (he calls it the Mall Test) because with all the lights, noise, echoes, smells, movement and confusion, a sufferer would be ready to explode. [30]

In the more severely affected, commonly there is difficulty with breathing, with sudden attacks of breathlessness and dyspnoea on minimal effort; the administration of oxygen may be necessary.

Rashes may occur; mouth ulcers may be recurrent and may be painful and severe to the extent that speaking and eating may be affected.

Hands and feet are frequently cold, blanched and / or purple, with painful vascular spasms seen in the fingers.

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[27] Presented at the Dublin International Meeting on ME / ICD-CFS by Professor Charles Poser of the Department of Neurology, Harvard Medical School and the Neurological Unit, Beth Israel Hospital, Boston, Massachusetts, 18th -20th May 1994 (under the auspices of The World Federation of Neurology)

[28] Allergy and the chronic fatigue syndrome. Stephen E Straus et al *J All Clin Immunol 1988:81:791-795*

[29] Sympathetic Dysfunction Demonstrated by Isometric Hand-grip Response in Chronic Fatigue Syndrome. JN Baraniuk et al. *Presented at the AACFS Conference, Seattle, Jan 2001 # 126*

[30] Lecture given by David Bell, Christie's Auction Rooms, London, 25th August 1998

Vascular headaches are common and recurring. [31]

In females, ovarian-uterine dysfunction is not uncommon; in males, prostatitis and impotence may occur.

Many patients can walk only very short distances and require a wheelchair. There is difficulty with simple tasks such as climbing stairs and dressing.

Problems with short-term memory are common:[32] cognitive impairment is significant and includes difficulty with memory sequencing, processing speed, word searching; dyslogia, spatial organisation, calculation (dyscalculia), and particularly with decision-making. In relation to the degree of cognitive impairment, American researchers found that

> "the performance of the CFIDS patients was sevenfold worse than either the control or the depressed group. These results indicated that the memory deficit in CFIDS was more severe than assumed by the CDC criteria. A pattern emerged of brain behaviour relationships supporting neurological compromise in CFIDS". [33]

Uncharacteristic emotional lability is very common; there may be an increased irritability.
Patients are often understandably anxious and afraid.

There may be significant and permanent damage to skeletal or cardiac muscle as well as to
other end-organs including the liver, pancreas, endocrine glands and lymphoid tissues, [34] with evidence of dysfunction in the brain stem. Injury to the brain stem results in disturbance of the production of cortisol (required for stress control) via damage to the hypothalamus and to the pituitary and adrenal glands, and patients react extremely adversely to stress.

Cycles of severe relapse are characteristic and common, together with the evolution of further symptoms over time. ME is rarely listed as the cause of death, although after decades of illness, death from end-organ damage (mainly cardiac or pancreatic failure)

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[31] Cardiac and Cardiovascular Aspects of Myalgic Encephalomyelitis. BM Hyde A Jain. *In: The Clinical and Scientific Basis of Myalgic Encephalomyelitis Chronic Fatigue Syndrome. Ed: BM Hyde, J Goldstein, P Levine. pub: The Nightingale Research Foundation, Ottawa, Canada 1992*

[32] Myalgic Encephalomyelitis – Then and Now. AM Ramsay EG Dowsett. *In: The Clinical and Scientific Basis of Myalgic Encephalomyelitis Chronic Fatigue Syndrome. Ed: BM Hyde, J Goldstein, P Levine. pub: The Nightingale Research Foundation, Ottawa, 1992*

[33] Memory Deficits Associated with Chronic Fatigue Immune Dysfunction Syndrome. CA Sandman, JL Barron et al *Biol Psychiatry 1993:33:618-623*

[34] Enteroviral and Toxin Mediated Myalgic Encephalomyellitis / Chronic Fatigue Syndrome and Other Organ Pathologies. John Richardson. *The Haworth Press Inc. New York, 2001*

is known to occur.

Suicide rates are high [35] and are said to be the most common cause of death in ME and to be related to the current climate of disbelief and rejection of welfare support. [36]

**Evidence of abnormalities in ME**

Despite beliefs and assertions to the contrary, in ME there ***is*** evidence of inflammation of the central nervous system (CNS); that is what helps to differentiate ME from other forms of CFS. There are many references in the medical literature to inflammation of the CNS in ME and in ICD- CFS [37 38 39 40 41 42] but such CNS inflammation is not found in all variants of CFS. It is incorrect to deny the existence of CNS inflammation in ME / ICD-CFS. In some cases of ME, as in multiple sclerosis, there is evidence of oligoclonal bands
in the cerebrospinal fluid. [43 44]

It is accepted by the most experienced ME clinicians that some degree of encephalitis has occurred both in patients with ME and in those with post-polio syndrome: the areas chiefly affected include the upper spinal motor and sensory nerve roots and the spinal nerve networks traversing the adjacent brain stem (which is *always* damaged). [45] In nearly every patient there are signs of disease of the central nervous system. [46] Recent research continues to support neurological involvement. [47 48 49 50 51 52 53]

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[35] Reporting the high suicide risk. Ian Franklin. *Perspectives, Summer 2001:12; pub by The ME Association, Stanford le Hope, Essex, UK*

[36] The Epidemiology of Myalgic Encephalomyelitis (ME) in the UK. Evidence submitted to the All Party Parliamentary Group of Members of Parliament. EG Dowsett J Richardson. 23 Nov 1999

[37] A clinical description of a disease resembling poliomyelitis seen in Adelaide. Pellew RAA. *Med J Aust 1955:42:480-482*

[38] A chronic illness characterized by fatigue, neurologic and immunologic disorders. D.Buchwald, PR Cheney, DA Ablashi, RC Gallo, AL Komaroff et al. *Ann Intern Med 1992:116:103-113*

[39] Detection of intracranial abnormalities in patients with chronic fatigue syndrome. RE Schwartz et al. *Am J Roentgenology 1994:162:935-941*

[40] A 56 year old woman with CFS. AL Komaroff. *JAMA 1997: 278:14:1179-1184*

[41] Encephalomyelitis resembling benign myalgic encephalomyelitis. SGB Innes *Lancet 1970: 969-971*

[42] Prevalence in the cerebro-spinal fluid of the following infectious agents in a cohort of 12 CFS subjects: Human Herpes Virus 6 & 8; Chlamydia Species; Mycoplasma Species, EBV; CMV and Coxsackie B Virus. Susan Levine *JCFS 2001:9: 91-2):41-51*

[43] Neuromuscular Abnormalities in Patients with Chronic Fatigue Syndrome. Carolyn L.Warner,Reid R.Heffner, D Cookfair. I*n: The Clinical & Scientific Basis of ME / CFS. ed: BM.Hyde, J Goldstein, P Levine. pub. The Nightingale Research Foundation,Ottawa 1992*

[44] The Differential Diagnosis between Multiple Sclerosis and Chronic Fatigue Postviral Syndrome. Charles M.Poser. *ibid*

[45] Polio Encephalitis and the Brain Generator Model of Post-Viral Fatigue. Bruno RL et al

There is a substantial literature on the neuroendocrine dysfunction which has been demonstrated in ME / ICD-CFS, particularly the known dysfunction of the hypothalamic-pituitary-adrenal axis (HPA axis), leading to a disordered stress response.

There is mounting international evidence that ME / ICD-CFS is an autoimmune disorder, with similarities to systemic lupus erythematosus.[54 55] Evidence of antilamin antibodies has been found in the blood of ME / ICD-CFS patients: antibodies against this protein are proof of autoimmunity and of damage to brain cells. The occurrence of autoantibodies to an intra-cellular protein like lamin B1 provides laboratory evidence for an autoimmune component in ME / ICD-CFS. [56 57]

In the UK, patients with autoimmune features and neurological signs and symptoms are usually the most sick and as such they are excluded from studies of "CFS" or chronic fatigue undertaken by psychiatrists, so the results of UK studies from which such patients are excluded are not representative of the true situation.

A particularly important piece of research in these patients has demonstrated sensitivity of the vascular endothelium to acetylcholine (a major neurotransmitter and vascular dilator) and this finding may have implications for many other cholinergic pathways (which are extensive throughout the body). [58]

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*Journal of Chronic Fatigue Syndrome. 1996:2: (2,3):5-27*

[46] A new clinical entity? Editorial: *Lancet 26 May 1956*

[47] Detection of intracranial abnormalities in patients with chronic fatigue syndrome: comparison of MR imaging and SPECT. Schwartz RM, Komaroff AL et al. *AmJ Roentgenol 1994:162: (4):35-41*

[48] Enterovirus in the chronic fatigue syndrome. McGarry F, Gow J and Behan PO *Ann Intern Med 1994:120:972-973*

[49] Chronic Fatigue Syndrome – Findings now point to Central Nervous System Involvement. DS Bell *Postgrad Med 1994:96:6:73-81*

[50] Brainstem perfusion is impaired in patients with chronic fatigue syndrome. Costa DC, Tannock C and Brostoff J. *Quarterly Journal of Medicine 1995:88:767-773*

[51] Brain positron emission tomography (PET) in chronic fatigue syndrome: preliminary data. Tirelli U et al. *Am J Med 1998:105: (3A): 54S - 58S*

[52] Neurological dysfunction in chronic fatigue syndrome. Chaudhuri, A and Behan PO. *JCFS 2000:6: (3-4):51-68*

[53] Relationship of brain MRI abnormalities and physical functional status in chronic fatigue syndrome. Cook DB, Natelson BH et al *Int J Neurosci 2001:107: (1-2):1-6*

[54] A multi-centre study of autoimmunity in CFS. K Sugiura, D Buchwald, A Komaroff, E Tan et al *AACFS # 037, Seattle, January 2001*

[55] Presentation by Dr Paul Cheney. Chronic Fatigue Syndrome National Consensus Conference, Sydney, Australia, 1995

[56] Autoantibodies to Nuclear Envelope Antigens in Chronic Fatigue Syndrome. K Konsintinov, Dedra Buchwald, J Jones et al *J Clin Invest 1996:98:8:1888-1896*

[57] Antinuclear Envelope Antibodies – Clinical Associations. Nesher G, Margalit R, Ashkenazi YJ *Semin Arthritis Rheum 2001:30: (5):313-320*

[58] Enhanced sensitivity of the peripheral cholinergic vascular response in patients with Chronic Fatigue Syndrome. Vance A Spence, Faisal Khan, Jill JF Belch. *Am J Med 2000:108:736-739*

In ME / ICD-CFS there is evidence of disruption in ion channels in the cell membranes; changes in ion channel function from time to time offer a rational basis to explain the fluctuating symptoms, and such ion channel changes are known to be induced by physical activities, stress and fasting. If sodium channels are blocked in the open mode, this causes entry of sodium into neural tissues and muscles. This ingress of sodium is followed by water, which in turn leads to swelling of the neural tissues, a phenonmenon observed both electron microscopically and by laser scanning microscopy. Acquired ion channel abnormalities in the myocardium could explain the pathogenesis of Syndrome X and may form the basis of cardiac dysfunction in both Syndrome X and in ME / ICD-CFS. [59]

Australian researchers have found that total body potassium (TBK) is significantly lower in patients with ME / ICD-CFS; they suggest that abnormal potassium handling by muscles in the context of low overall body potassium may contribute to muscle fatigue in this disorder. [60] Burnett reports that there is a reduced flux of potassium across the cell membrane (which fits in with a channelopathy) and that patients will feel more ill the lower the potassium levels. TBK results for ME / ICD-CFS patients have also been shown by others to be significantly lower than those for controls; this fits with other metabolic abnormalities in these patients, such as impaired water metabolism. [61]

There is convincing evidence that patients with ME / ICD-CFS reach exhaustion more rapidly that normal subjects: the use of 31 P-nuclear magnetic resonance (31 P-NMR) has now provided positive evidence of defective oxidative capacity in such patients. [62] These findings show that there is a *continued* loss of post-exertional muscle power (giving an *additional* loss of power), with delayed recovery for at least 24 hours, whereas sedentary controls recovered full muscle power after 200 minutes.

A genetic component to ME / ICD-CFS is strongly suggested by HLA phenotyping analysis in the laboratory of Paul Terasaki at UCLA School of Medicine. Terasaki is one of the world's leading experts in HLA typing and he found 46% of ME / ICD-CFS patients were HLA-DR4 positive. [63] However, in a small study of only 58 patients, Wessely (a UK psychiatrist – *see below*) found no association between HLA genotype and CFS and claims there is no significant difference in HLA frequencies between patients and controls. [64]

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[59] Chronic Fatigue Syndrome is an Acquired Neurological Channelopathy. A Chaudhuri, P Behan. *Hum Psychopharmacol Clin Exp 1999:14:7-17*

[60] Chronic Fatigue Syndrome: is total body potassium important? Burnett RB et al *Medical Journal of Australia 1996:164:6:384*

[61] Arguments for a role of abnormal ionophore function in Chronic Fatigue Syndrome. A Chaudhuri, WS Watson, PO Behan. *Chronic Fatigue Syndrome. ed: Yehuda & Mostofsky pub: Plenum Press, New York, 1997*

[62] Demonstration of delayed recovery from fatiguing exercise in Chronic Fatigue Syndrome. Paul LA et al *European Journal of Neurology 1999:6:63-69*

[63] Chronic Fatigue Syndrome. JA Goldstein. *pub: The Chronic Fatigue Syndrome Institute, Beverly Hills, California 1990 ISBN 0-9625654-0-7*

[64] Lack of association between HLA genotype and chronic fatigue syndrome. Underhill JA, Wessely S et al *Eur J Immunogenet 2001:28 (3):425-428*

In the February 2000 issue of *The American Journal of Medicine*, Anthony Komaroff (Assistant Professor of Medicine at Harvard and a world expert on this disorder) summarised key points in an Editorial:

> "Many controlled studies have compared patients with age-matched and gender-matched healthy control subjects. Objective biological abnormalities have been found significantly more often in patients with the syndrome than in the comparison groups. The evidence indicates pathology of the central nervous system and immune system. What is the evidence of central nervous system pathology? Magnetic resonance imaging has revealed areas of high signal in the white matter. Single photon emission computed tomography (SPECT) signal abnormalities also are found more often in patients, abnormalities like those seen in patients with encephalopathy due to the acquired immunodeficiency syndrome (AIDS) and unlike the findings in patients with depression. Autonomic nervous system testing has revealed abnormalities of the sympathetic and parasympathetic systems that are not explained by depression or physical deconditioning. Studies of hypothalamic and pituitary function have revealed neuroendocrine abnormalities not seen in healthy control subjects and opposite to those found in depression. There is considerable evidence from different investigators, using different technologies and studying different groups of patients, of a state of chronic immune activation. In summary, there is now considerable evidence of an underlying biological process in most patients (which) **is inconsistent with the hypothesis that (the syndrome) involves symptoms that are only imagined or amplified because of underlying psychiatric distress. It is time to put that hypothesis to rest".** [65]

## Precipitating Factors

Precipitating factors are acknowledged to include stress, [66 67 68] exposure to toxic chemicals, [69 70] and physical trauma - particularly a motor vehicle accident. [71 72]

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[65] The Biology of the Chronic Fatigue Syndrome. Anthony L Komaroff *Am J Med 2000:108: 99-105*

[66] Epidemiological Advances in Chronic Fatigue Syndrome. Paul H Levine *J psychiat Res 1996:31:1:7-18*

[67] Neuroendocrinology of Chronic Fatigue Syndrome. TG Dinan. *Presented at the First World Congress on CFS and Related Disorders, Brussels, 9-11 November 1995*

[68] Critical life events, infection and symptoms during the year preceding CFS. Theorell T et al *Psychosom Med 1999:61:3:304-310*

[69] Chronic fatigue syndrome following a toxic exposure. D Racciatti et al *Sci Total Environ 2001:1-3:27-31*

[70] Chronic Fatigue Syndrome as a Delayed Reaction to Chronic Low-dose Organophosphate Exposure. PO Behan *J Nutr & Environ Med 1996:6:341-350*

[71] Precipitating Factors for the Chronic Fatigue Syndrome. Irving E Salit. *J psychiat Res 1997:*

There is convincing evidence that when combined with physical trauma, chemical or biological insult, stress potentiates the condition and that the disorder may be due in part to multiple chemical and / or biological exposures which have been shown to increase the permeability of the blood brain barrier (BBB), leading to a significant brain injury. [73] [74] [75] Evidence of BBB breakdown in ME / ICD-CFS was presented at the international conference held in London in April 1999: scientists in Israel have shown that severe stress (physical or mental) can produce breakdown of the BBB; if that barrier is broken, small amounts of substances which are normally outside the brain could produce brain injury. It is postulated that in the case of ME / ICD-CFS, a person already under physical or mental stress is exposed to an agent (viral or chemical) which crosses the BBB, enters the brain, and produces long-term dysfunction.[76]

John Dwyer, Professor of Medicine at the University of New South Wales, Australia, states that his team has seen ME / ICD-CFS stimulated by vaccination and that they have seen it both with vaccinations such as those for influenza and also with the use of material which is not live, such as that in a tetanus toxoid injection. [77] [78]

The disorder is known sometimes to occur or worsen after anaesthetics, [79] [80] [81] and to be related to some infections (both viral and bacterial). There is a considerable literature on the viral aspects of the disorder, the most implicated viruses being Coxsackie B [82] [83] and

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*31:1:59-65*

[72] Medical Aspects of Delayed Convalescence. LE Cluff. *Rev Inf Dis 1991:13: (Suppl 1): S138- S40*

[73] Diagnosis and treatment of multiple chronic bacterial and viral infections in Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia Syndrome and Gulf War Illness. GL Nicolson et al *Presented at The Alison Hunter Memorial Foundation Third International Clinical and Scientific Conference, 1st-2nd December 2001, Sydney, Australia*

[74] Stress and Combined Exposure to Low Daily Doses of Pyridostigmine Bromide, DEET and Permethrin in Adult Rats Causes Blood Brain Barrier Disruption and Neurochemical and Neurohormonal Alterations in the Brain. MB Abou-Donia. *ibid*

[75] Objective Evidence of Brain Impairment in the Chemical Syndrome. KH Kilburn. *ibid*

[76] Blood Brain Barrier Breakdown in Myalgic Encephalomyelitis. Behan W, Gow JW, Curtis F Presented at "Fatigue 2000" Conference, London 23rd-24th April 1999, arranged by The National ME Centre, Harold Wood, Essex, in conjunction with the Essex Neurosciences Unit

[77] personal communication (10 February 1992) from John Dwyer, Professor of Medicine, University of New South Wales, Australia

[78] Is CFS linked to Vaccinations? Charles Shepherd. *The CFS Research Review 2001:2:1:6-8*

[79] New light on the causes and management of postviral fatigue syndrome. Charles Shepherd. *Modern Medicine 1988:287*

[80] Environmental Medicine in Clinical Practice. H Anthony, S Birtwhistle, K Eaton, J Maberly. *pub: BSAENM 1997. ISBN 0-9523397-2-2*

[81] CFIDS and Anaesthesia: what are the risks? EA Crean. *CFIDS Chronicle Winter (Jan) 2000:11-13*

[82] 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 et al *J Gen Virol 1990:71:6:1399-1402*

[83] Evidence for Enteroviral Persistence in Humans. DN Galbraith et al *J Gen Virol 1997: 78:307-312*

Human Herpes Virus 6 (HHV6). [84] [85] HHV-6 has been found in patients suffering from ME / ICD-CFS and also in MS; it has also been linked to other autoimmune conditions such as systemic lupus erythematosus (SLE or lupus).

**Physical signs found in ME**

In cases of severe ME there are definite physical signs indicative of physical illness and not of abnormal illness behaviour. Some of these signs are often present in less severely affected cases but in the UK are dismissed or trivialised in order to comply with the currently-favoured psychiatric definition of CFS. Not all patients have all signs, but throughout the ME literature, the following are common in the sickest patients.

Observable signs include a typically swinging low-grade temperature, nystagmus; sluggish visual accommodation; abnormality of vestibular function with a positive Romberg test; abnormal tandem or augmented tandem stance; abnormal gait; hand tremor; incoordination; cogwheel movement of the leg on testing; muscular twitching or fasciculation; hyper-reflexia without clonus; facial vasculoid rash; vascular demarcation which can cross dermatomes with evidence of Raynaud's syndrome and / or vasculitis; [86] mouth ulcers; [87] [88] hair loss; [89] [90] [91] [92] [93] a labile blood pressure (sometimes as low as 84/48 in an adult at rest); flattened or even inverted T-waves on 24 hour Holter monitoring [94] (a standard 12 lead ECG is usually normal); orthostatic tachycardia; shortness of breath (patients show significant reduction in all lung function parameters tested); [95] abnormal glucose tolerance curves; liver involvement [96] [97] [98] [99] [100]

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[84] Frequent HHV-6 reactivation in multiple sclerosis (MS) and chronic fatigue syndrome (CFS). DV Ablashi et al *J Clin Virol 2000: (3):16:179-191*

[85] Evidence of Active HHV6 Infection and its Correlation with RNase L Low Molecular Weight Protein (37 kDa) in CFS Patients. D Ablashi, S Levine et al *Presented at The Alison Hunter Third International Clinical and Scientific Conference, 1st-2nd Dec 2001, Sydney,Australia*

[86] The Clinical and Scientific Basis of Myalgic Encephalomyelitis Chronic Fatigue Syndrome *pp. 42, 62, 70, 73, 87, 89, 91, 268, 376, 427-430. ed: BM Hyde, J Goldstein, P Levine. pub: The Nightingale Research Foundation, Ottawa 1992*

[87] Outbreak at The Royal Free. ED Acheson. *Lancet 20 August 1955:304-305*

[88] M.E. Post-Viral Fatigue Syndrome. Dr Anne Macintyre. *Unwin Hyman 1989*

[89] Chronic Fatigue and Immune Dysfunction Syndrome: a Patient Guide. *CFIDS Assn. 1989*

[90] The Disease of a Thousand Names. DS Bell. *Pollard Publications, New York 1991*

[91] How do I diagnose a patient with CFS? J.Goldstein. *In: The Clinical and Scientific Basis of ME/CFS ed: BM Hyde, J Goldstein, P Levine. pub: The Nightingale Research Foundation, Ottawa, 1992*

[92] Chronic Fatigue Sydrome: evaluation of a 30-criteria score and correlation with immune activation. Hilgers A, Frank J. *JCFS 1996:2:4:35-47*

[93] Viral Isolation from Brain in Myalgic Encephalomyelitis (A Case Report). John Richardson *Journal of CFS 2001:9: (3-4):15-19*

[94] Cardiac involvement in patients with CFS as documented with Holter monitor and biopsy data AM Lerner et al *Infectious Diseases in Clinical Practice 1997:6:327-333*

[95] Lung function test findings in patients with chronic fatigue syndrome, De Lorenzo et al. *Australia & New Zealand Journal of Medicine. 1996:26:4:563-564*

[96] Icelandic Disease (Benign Myalgic Encephalomyelitis or Royal Free Disease). AM Ramsay EG Dowsett et al. *BMJ May 1977:1350*

(an enlarged liver or spleen may not be looked for in ME, so missed) and destruction of fingerprints: (atrophy of fingerprints is due to perilymphocytic vasculitis and vacuolisation of fibroblasts [101]).

In his Testimony before the FDA Scientific Advisory Committee on 18th February 1993, Dr Paul Cheney (Professor of Medicine at Capital University; Medical Director of the Cheney Clinic, North Carolina and one of the world's leading exponents on ME /ICD-CFS) testified as follows:

> " I have evaluated over 2,500 cases. At best, it is a prolonged post-viral syndrome with slow recovery. At worst, it is a nightmare of increasing disability with both physical and 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".

People with ME are permanently excluded from being blood donors.[102]

Twenty-five per cent of sufferers are severely affected and are either house or bed bound; they are invisible and for the most part, they are ignored and abandoned to their own fate. A major Report by the charity Action for ME [103] found that 77 % of sufferers experienced severe pain; over 80% had felt suicidal as a result of the illness; 70% are either never able, or are sometimes too unwell to attend a doctor's clinic; 65% (nearly two out of three) have received no advice from their GP on managing this illness; 80% of those who are currently bedridden by ME report that a request for a home visit by a doctor has been refused; many people do not receive state benefits to which they are clearly entitled.

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[97] The 'chronic mononucleosis' syndromes. Komaroff AL *Hosp Pract 1987 (May):71-75*

[98] Chronic Fatigue Syndrome in Northern Nevada. SA Daugherty et al *Rev Inf Dis 1991:13: S39-S44*

[99] Chronic Fatigue Syndrome and Depression: Biological Differentiation and Treatment CM Jorge, PJ Goodnick. *Psychiatric Annals 1997:27:5:365-386*

[100] Symptom patterns in long-duration chronic fatigue syndrome. F.Friedberg et al *J Psychosom Res 2000:48:59-68*

[101] Presentation by Dr Paul Cheney. CFS National Consensus Conference, Sydney, Australia,1995

[102] Guidelines for the Blood Transfusion Service in the UK *1989:5.42 / 5.44 / 5.410; Department of Health; pub. HMSO*

[103] Severely Neglected: ME in the UK. Report from Action for ME. *March 2001*

Despite all this verifiable and authenticated international research, much of the current perception of ME, both medical and lay, is beset by confusion and misinformation.

**There are still doctors who dismiss the condition as non-existent and too many sick children are still being forcibly removed from their parents and placed in institutional care where they are forced to undergo inappropriate exercise regimes under the care of psychiatrists.**
Very recently, there have been two tragic ME cases involving children: in one case social workers, accompanied by uniformed police officers, appeared unannounced on the doorstep to take away a child under a Child Protection Order; the other child had been made a Ward of Court.

In July 2001, the appalling treatment of children with ME / ICD-CFS was the subject of a major feature written by the Countess of Mar in The Daily Telegraph. [104] Cases such as these have been only too common since the late 1980s: support for families in such situations is available from the mother of a child who was compelled to go to the High Court to stop the local Council and NHS Healthcare Trust from using child protection procedures to force her sick son into psychiatric treatment without his parents' consent and in disregard of competent but differing medical opinion (telephone: Val Broke Smith: 01564 - 778649).

Refusal by some doctors to accept what is known about ME /ICD-CFS may raise the question of whether or not such doctors are in breach of their contract of employment if that contract requires them to keep abreast of advancing medical knowledge. Guidance issued by the General Medical Council (GMC) requires that doctors "*must observe and keep up to date with the laws and statutory codes of practice which affect your work.*" [105] The law cannot be used to enforce alternative treatment on a patient already receiving competent medical treatment just because doctors disagree.

The fact that so many doctors do not keep reasonably up-to-date about ME / ICD-CFS has enormous implications for patients. [106]

## Changing Definitions: History of Chronic Fatigue Syndrome (CFS)

In the US in the late 1970s and 1980s there seemed to be a remarkable rise in incidence of a condition indistinguishable from ME, with manifestations of serious neuro-immune disease and profound incapacity, to the extent that the powerful insurance industry became alarmed. The insurance industry was concerned that, because there is no National Health Service in the US:

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[104] How the Law is being abused to force treatment on children: parents of ME sufferers are being victimised by the Children Act. The Countess of Mar *Daily Telegraph 11th July 2001*
[105] Good Medical Practice. *pub The General Medical Council, UK*
[106] The position of Australian psychiatry in the CFS debate. N Phillips. *Presented at The Alison Hunter Memorial Foundation Third International Clinical and Scientific Conference, 1st-2nd December 2001, Sydney, Australia*

> "the field could change from an epidemiological investigation into a health insurance nightmare". [107]

The result was a determination to suppress the true symptomatology and to construct a new case "definition" for which insurers could not reasonably be liable: the condition was henceforth to be called 'chronic fatigue syndrome' or CFS and emphasis was to be on chronic "fatigue" as the primary symptom. The case definition required every sign of organic illness to be excluded before the diagnosis of "CFS" could be made. As a result, the view that patients were clearly afflicted by serious neuro-immune illness was to be strenuously down-played for many years. [108]

"CFS" did not come into existence until 1988. As a basis for sound scientific research, it has been a disaster. "CFS" is not a single diagnostic entity and "fatigue" is not a disorder, it is a symptom. The term "CFS" is now applied to a heterogeneous group as a non-specific label which embraces many different medical and psychiatric conditions in which tiredness and fatigue are prominent.

The first definition of CFS (1988 Holmes et al) concentrated on "fatigue" persisting for at least six months; it expressly excluded the cardinal features of ME which had been documented for decades despite the fact that ten years earlier, the UK Royal Society of Medicine had accepted ME as a distinct nosological entity. In 1988 in the US, the eighteen strong panel of medical scientists and clinicians charged with formulating a new case definition and new name could not agree: two of the most experienced members refused to sign the final document and withdrew from the panel because the proposed definition and new name were too different from the ME with which they were so familiar.[109] Those two members were Dr Alexis Shelokov from the US and Dr Gordon Parish from the UK. Dr Parish now lives in Scotland and is curator of the Ramsay Archive, which is possibly the world's largest collection of medical papers on ME which pre-date 1988.

## How "CFS" displaced ME in the UK

At about the same time (1988) in the UK, psychiatrist Simon Wessely rose to prominence.
Wessely leads a group of UK doctors, mostly but not exclusively psychiatrists, who have colloquially become known as the " Wessely School".[110] Wessely is now Professor of Epidemiological and Liaison Psychiatry at Guy's, King's and St Thomas' School of Medicine, London and at The Institute of Psychiatry, where he is Director of both the CFS Research Unit and the Gulf War Illness Research Unit. He is well-known for his

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[107] Osler's Web: Inside the Labyrinth of the Chronic Fatigue Syndrome Epidemic. Hillary Johnson. *Crown Publishers Inc, New York, 1996 (page 218)*
[108] *ibid (page 268)*
[109] *ibid (page 218)*
[110] Hansard (Lords) 19th December 1998:1013

strongly-held beliefs that neither ME nor Gulf War Syndrome exists, [111] and that such patients are mentally, not physically, ill.

Since the late 1980s he and his close colleagues have assiduously attempted to obliterate recorded medical history by insisting that there is no such disorder as "ME", claiming that previous studies of ME *"reflect those who seek treatment rather that those who suffer the symptoms*", [112] even though those studies were published in peer-reviewed prestigious medical journals and span over sixty years.

Despite the fact that the International Classification of Diseases is approved by all the countries who are part of the World Health Assembly, Wessely believes the WHO got it wrong about ME, writing in the *Lancet*:

> "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. 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". [113]

In the ICD classification the section entitled "Mental and Behavioural Disorders" (section F-48.0 subtitled "Other Neurotic Disorders") includes "neurasthenia" and "fatigue syndrome". **ME, CFS and PVFS are specifically excluded from the psychiatric section F-48.**

Wessely's views of those afflicted by ME / ICD-CFS are well-known, and may be summarised in just two illustrations:

> "The description given by a leading (doctor) at The Mayo Clinic remains accurate: 'the doctor will see that they are neurotic and he will often be disgusted with them' **"** [114]

> "There lies at the heart of CFS not a virus (or) immune disorder, but a distortion of the doctor-patient relationship" [115]

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[111] Ill-defined notions. Ziauddin Sardar. *New Statesman, 5th February 1999*
[112] Chronic Fatigue Syndrome. Joint Royal Colleges' Report CR54. *RCP Publications Unit, 1996*
[113] Chronic Fatigue, ME, and ICD-10 David A, Wessely S. *Lancet 1993:342:1247-1248*
[114] Chronic fatigue and myalgia syndromes. Wessely S. *In: Psychological Disorders in General Medical Settings. ed: N Sartorius et al pub: Hogrefe & Huber, 1990*
[115] Chronic fatigue syndrome: an update. Anthony J Cleare, Simon C Wessely. *Update (Recent Advances): 14th August 1996:61-69*

Wessely's determination to eradicate ME as a legitimate medical entity seems never to cease. Perhaps his most blatant attempt to change the WHO classification from neurological to psychiatric can be found in his contribution to the WHO *Guide to Mental Health in Primary Care (November 2000)* in which ME is notoriously re-classified as a mental disorder. Psychiatrists at King's College Hospital and The Institute of Psychiatry are designated as one of the WHO Collaborating Centres and as such are entitled to use the WHO logo. Use of the WHO logo implies that contributions carry WHO sanction, but in this particular instance, such is not the case and Wessely's actions brought forth international condemnation. The WHO has confirmed that what Wessely published about the classification of ME in the *Guide to Mental Health in Primary Care* did not carry WHO approval, stating

> "It is possible that one of the several WHO Collaborating Centres in the United Kingdom presented a view that is at variance with WHO's position". [116]

The present confusion has been compounded by the fact that the term "CFS" has been included by the WHO in the latest revision of the International Classification of Diseases as one of the terms by which ME has become known. In practice, this has come to mean that when referring to "CFS", some doctors (mostly some UK psychiatrists led by Simon Wessely) are talking about psychiatric illness involving "chronic fatigue", whilst international experts are talking about ICD- CFS, which is synonymous with ME.

**It is important to be aware that published international research on CFS (as distinct from UK psychiatric research on CFS) reflects patients who are likely to have ME rather than psychiatric disorder.**

The essence of the confusion concerns the use in the UK of the combined term "CFS/ME", given that "CFS" means different things to different people.

On the one hand there is an extensive published record by the UK "psychiatric CFS" school promoting their view that ME no longer exists and that CFS (a term they use interchangeably with chronic or long-term "fatigue" [117 118]) is a psychiatric (behavioural) disorder with no physical signs which is perpetuated by aberrant *"illness beliefs"* and "*personality"* [119] which is best managed by a form of psychotherapy known as cognitive behavioural therapy (CBT) and delivered according to a *"management plan"* administered by psychotherapists. Wessely himself has published over 200 papers mostly on his own view of CFS but his beliefs are not supported by international experts and there is stringent criticism of his papers in the peer-reviewed medical literature *(see below).*

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[116] Letter from Dr B Saraceno, Director, Department of Mental Health *16 October 2001*

[117] A Research Portfolio on Chronic Fatigue. ed. Robin Fox for The Linbury Trust. *pub. The Royal Society of Medicine Press 1998*

[118] New research ideas in Chronic Fatigue. ed. Richard Frackowiak and Simon Wessely for The Linbury Trust. *pub The Royal Society of Medicine Press 2000*

[119] Final draft of CMO's Report on CFS/ME, *November 2001*

On the other hand, ME /ICD-CFS is formally classified as a neurological disorder in the WHO International Classification of Diseases. The whole area of terminology has become a minefield for the unwary, to the serious detriment of patients.

This dichotomy has been summarised by Fred Friedberg, Clinical Professor in the Department of Psychiatry at the State University of New York:

> "descriptive studies of CFS patients in England, the US and Australia suggest that the CFS population studied in England shows substantial similarities to depression, somatization and phobic patients, while the US and Australian research samples have been clearly distinguished from depression patients and more closely resemble fatiguing neurological illnesses". [120]

**It is important to be familiar with the fact that "chronic fatigue" and chronic "fatigue syndromes" do not equate with chronic fatigue syndrome (CFS) or with ME**.

Following an erroneous News Release in 1990 about this point, the American Medical Association was forced to issue a correction which said: *"A news release in the July 4 packet confused chronic fatigue with chronic fatigue syndrome; the two are not the same. We regret the error and any confusion it may have caused. AMA Science News Editor: John Hammarley"* [121]

Wessely's beliefs, however, have flooded the UK literature; he is adviser to the UK Government and to the Ministry of Defence and his wife (psychiatrist and GP Dr Clare Garada) is Senior Policy Adviser to the Department of Health.

Specifically, Wessely and those who agree with him officially advise that no investigations should be performed to confirm the diagnosis; [122] particularly, they emphasise that immunological abnormalities (documented by worldwide researchers as underlying the disorder) should not *"deflect the clinician from the (psychiatric) approach….and should not focus attention towards a search for an 'organic' cause"*. In this respect it is notable that it has been convincingly demonstrated that changes in different immunological parameters correlate with particular aspects of ME / ICD-CFS symptomatology and with measures of disease severity, lending further support to the concept of immunoactivation of T- lymphocytes. [123] Such findings seem to be

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[120] A Subgroup Analysis of Cognitive Behavioural Treatment Studies. Fred Friedberg. *Journal of CFS 1999:5:3-4:149-159*

[121] JAMA issues correction. *Journal of the American Medical Association 1990 (referring to the issue dated 4th July 1990 and article entitled Chronic fatigue: A prospective clinical and virologic study by Deborah Gold et al:264:1:48-53)*

[122] Chronic Fatigue Syndrome. Report of a Joint Working Group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners (CR54) *pub RCP October 1996*

[123] A study of the immunology of the chronic fatigue syndrome: correlation of immunological parameters to health dysfunction. IS Hassan, W Weir et al *Clin Immunol Clin Immunopathol 1998:87:60-67*

intentionally diverted by Wessely and his colleagues, who officially advise Government that the performing of medical investigations on patients with ME or CFS is neither necessary nor appropriate and that doing so merely reinforces sufferers' "dysfunctional belief" that they are physically ill,
from which they seek to obtain secondary gain in the form of sickness benefits and from the relinquishing of personal responsibility for their imagined ill-health.

Wessely and his associates ignore the fact that ME is often confused with multiple sclerosis. [124] They also ignore the evidence that ME /ICD-CFS has features of autoimmune disorder and features of allergy and multiple chemical sensitivity (MCS), [125] [126] [127] [128] [129] [130] which is now officially recognised in the International Classification of Diseases, (*ref: ICD 10: SGBV:3.1:code T78.4: Chemical Sensitivity Syndrome, Multiple).* Data presented at the American Association for Chronic Fatigue Syndrome (AACFS) Fifth International Research and Clinical Conference in Seattle in January 2001 showed that MCS was present in 42.6% of patients compared with 3.8% of controls. [131] Wessely, however, asserts that MCS does not exist and that along with fibromyalgia (in apparent contempt of the fact that FM is formally classified as a legitimate physical disorder in the International Classification of Diseases under Soft Tissue Disorders *ref ICD-10 M.79.0* ), conditions such as irritable bowel syndrome, pre-menstrual tension, globus hystericus, tension headache and chronic fatigue syndrome should all be classed as one entity because, he claims, all occur more frequently in women and all are associated with unnecessary expenditure of medical resources and are afforded unjustified credibility largely because of *"an artefact of medical specialisation"*: Wessely believes this one entity to be a psychiatric disorder which he terms a "functional somatic syndrome". [132]

Psychiatrists who do not subscribe to the "Wessely School" doctrine point out that "somatic syndromes" are simply assumed to be without a physical cause, but this assumption is never tested or validated; they advise that it is a mistake to diagnose mental illness in people with ME / ICD-CFS because of the unproven and incorrect assumption that their physical complaints are of psychological origin. [133]

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[124] The Differential Diagnosis between Multiple Sclerosis and Chronic Fatigue Postviral Syndrome. Charles M Poser. *In: The Clinical and Scientific Basis of ME / CFS. ed: BM Hyde, J Goldstein & P Levine. pub: The Nightingale Research Foundation, Ottawa,1992*

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

[126] The Myalgic Encephalomyelitis Syndrome. JC Murdoch. *Family Practice 1988:5:4:302-306. pub: Oxford University Press*

[127] Allergy and the chronic fatigue syndrome. Stephen E Straus, Janet Dale et al *J All Clin Immunol 1988:81:791-795*

[128] History of the chronic fatigue syndrome. Stephen E Straus. *Rev Inf Dis 1991:13:1:S2-S7*

[129] Epidemiology of Chronic Fatigue Syndrome. Paul Levine. *Clin Inf Dis 1994:18:1:S57-S60*

[130] Comparison of patients with chronic fatigue syndrome,fibromyalgia and multiple chemical sensitivities. D Buchwald, D Garrity. *Arch Intern Med 1994:154:2049-2053*

[131] Multiple Chemical Sensitivity in CFS. JN Baraniuk et al. *AACFS Seattle, Jan 2001 # 124*

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

[133] How to differentiate CFS from psychiatric disorder. E.Stein. *Presented at The Alison Hunter Memorial Foundation Third International Clinical and Scientific Cnference, 1st-2nd December*

Wessely and colleagues also dismiss the evidence that immune abnormalities documented in ME/ ICD-CFS follow a recognisable, consistent and reproducible pattern, with clear evidence of an immune activation state.

It is true that the immune system dysfunction is not reflected in any of the currently used case definitions, hence the international support for a name change. Currently, the favoured choice supported by the internationally renowned immunologist and ME /ICD-CFS expert Professor Nancy Klimas (of the University of Miami) is for NEIDS or Neuro-Endocrine-Immune Dysfunction Syndrome or for CNDS (Chronic Neuroendocrineimmune Dysfunction Syndrome), both of which accurately reflect the nature of the underlying organic pathoaetiology.

It may well be the case that ME is one of the recognised conditions which are characterised by chronic post-exertional fatiguability, but ME is different in clinical presentation from other chronic fatigue syndromes. The evidence speaks for itself. Other postviral fatigue states are clinically in contrast to the three cardinal features of ME.[134] Other fatigue states which may follow flu, measles, chickenpox, herpes or mononucleosis lack not only the clinical but also the laboratory features of ME. [135]

There are no less than nine case definitions of CFS. [136] The two most commonly used (the UK 1991 Oxford case definition which was drawn up by Wessely and his associates and the US 1994 CDC case definition, in the formulation of which Wessely participated) both unequivocally state that patients with CFS have no physical signs. In the US, in Australia and on the Continent, such a stipulation is now accepted as being unsatisfactory and apart from the UK (where the forthcoming Chief Medical Officer's Report on CFS/ME *(see below)* is likely to state that *"on present evidence, (subgrouping CFS) may be considered a matter of semantics and personal philosophy"),* there is an increasing clamour within the medical fraternity for the urgent need to study sub-groups of "CFS" [137 138 139 140 141 142] because those with ME / ICD-CFS always do have observable physical signs and abnormal immunological laboratory results.

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*2001, Sydney, Australia*

[134] Myalgic encephalomyelitis or what? AM Ramsay. *Lancet 1988:100*

[135] ibid: *101*

[136] Report from The National Task Force on Chronic Fatigue Syndrome, Post Viral Fatigue Syndrome, Myalgic Encephalomyelitis. Westcare, Bristol, 1994

[137] Editorial: Roberto Patarca- Montero *Journal of Chronic Fatigue Syndrome 2000:7:4:1*

[138] Politics, Science, and the Emergence of a New Disease: the case of Chronic Fatigue Syndrome. Jason LA et al *Am Psychol 1997:52:9:973-983*

[139] Conference calls for serious research. T Lupton *CFIDS Chronicle 2001:14:1:12-13*

[140] Cytokine Levels in CFS Patients with a Different Immunological Profile. K de Meirleir et al *AACFS, Seattle, January 2001 # 017*

[141] A Definition-based Analysis of Symptoms in a Large Cohort of Patients with CFS. P de Becker et al *AACFS, Seattle, January 2001: # 019*

[142] Use of Factor Analysis in Detecting Subgroups (of CFS patients). Paul H Levine et al *AACFS, Seattle, January 2001 # 052*

The overriding difficulty is that some clinicians in some medical disciplines apparently fail to see them, have no desire to look for them or even deny their significance and existence.
It is the case that some of those doctors have been funded for many years by sources with links to the same industry which manufactures the chemicals which may be contributing to the rise in incidence of chemically-induced ME / ICD-CFS. They have also been funded by the insurance industry and by private interests such as The Linbury Trust which belongs to the Sainsbury (supermarket) family.

Since 1991, the Linbury Trust has funded over £4 million for research into CFS (which they call "chronic fatigue"), almost all of it by Wessely and his psychiatrist colleagues.

Since 1996, David Sainsbury (now Lord Sainsbury of Turville) has donated £7 million to the UK Labour Party. He is currently Minister for Science; as such, he has responsibility for the Office of Science and Technology and the Chemical and Biotechnology industries, as well as all the Research Councils, including the Medical Research Council.

The MRC, itself often now funded by partnership schemes with industry, is on record as regularly funding research into "chronic fatigue" by psychiatrists and others who subscribe to Wessely's views (who then claim that their results relate to "CFS"), whilst regularly declining to fund applications for research submitted by suitably qualified non-psychiatrists into the physical basis of ME, claiming of those applications: *"none have been of sufficiently high scientific quality to merit funding".* [143]

This is notable, given that the psychiatric research done by Wessely's close colleagues and co-authors which the MRC has funded has been rigorously criticised on the grounds that it is methodologically flawed and biased and that it relies on a highly selective and misrepresentative choice of references, including citing too many of their own studies as references. [144] [145] [146] [147]

In a letter to Wessely (made widely available), the Countess of Mar brought to his personal attention the fact that questions have been asked about his methodology, the selection of evidence he utilises, the obvious bias, and the lack of balance and objectivity.[148] That same letter continued

> "You *must* recognise that you and your colleagues have an enormous influence on the treatment meted out to a very large group of sick people.

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[143] Written reply from the Parliamentary Under-Secretary of State for Health, *18 January 1996 reference POH (6) 4139/192*
[144] The Royal Colleges' Report on CFS: Insidiously Biased and Potentially Harmful. T Hedrick *CFIDS Chronicle 1997:10:1:8-13*
[145] Editorial: Frustrating Survey of Chronic Fatigue. *Lancet 1996:348:971*
[146] Why doctors are failing ME sufferers. Richard Horton (Editor of *The Lancet*): *Observer Life,23rd March 1997:p 54*
[147] Chronic Fatigue Syndrome. TE Hedrick *Quarterly Journal of Medicine 1997:90:723-727*
[148] Letter to Professor Wessely from the Countess of Mar *18th February 2000*

How you managed to achieve this influence is a matter for conjecture".

The Office of Science and Technology monitors all government funding of research grants and controls official science policy and it is "policy" which determines the research which
is funded: *"The Department funds research* ***to support policy****"*. [149]

It is the case that in 1998, Wessely joined a Board of the Medical Research Council but it is unthinkable that he would be asked to read, report on or referee anything to do with his own work. It is also the case, however, that from 1989 to 1992 the MRC granted the Institute of Psychiatry £92,000 for research on "chronic fatigue".

Since 1988, psychiatrists of the "Wessely School" have been funded not only by the MRC but by Wellcome Training Fellowships in Clinical Epidemiology; by a Wellcome Research Fellowship in Epidemiology; by the Wellcome Trust; by ICI Pharmaceuticals; by Pfizer UK; by Duphar Pharmaceuticals; by The Linbury Trust; by the Medical Policy Group of the Department of Social Security; by the Department of Health; by Private Patients Plan by BUPA and by the US Department of Defense.

If influential doctors can succeed in portraying ME as non-existent and CFS as psychiatric in origin, then the chemical companies and the governments who granted them product licences would not be at risk of being accountable should there turn out to be a provable link with the synergistic effects of so many chemicals, daily exposure to which is now impossible to avoid due to the huge increase in chemical usage. It is this prevailing use of so many chemicals which is thought to be chronically stimulating the immune system. [150]
In the shadows is also the massive insurance industry, which cannot ever face liability for chemical injury or environmental illness without considerable strain and even collapse.

Accountability becomes more remote if all research which demonstrates the link between chemicals and the present upsurge in chemically-induced ME / ICD-CFS is blocked, dismissed, trivialised, ignored or discredited.

As well as being advisors to the UK Government, some of this same group of doctors are also known to have indisputable long-term commitment to the insurance industry and have acted as advisors to it, notably Professor Wessely and his close colleague and co-author Michael Sharpe, also a psychiatrist who claims to be a specialist in "CFS". Many illustrations could be provided; only one is mentioned here. On 17 May 1995 both Wessely and Sharpe were the main speakers at a symposium held at the London Business School entitled "Occupational Health Issues for Employers" at which they advised employers how best to deal with employees who are on long-term sickness absence with

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[149] Hansard 11th May 2000: 461W - 462W
[150] Human endogenous retrovirus: nature, occurrence and clinical implications in human disease. Urnovtiz HB *Clin Microbiol Rev 1996:1:72-99*

"ME". Information presented included informing attendees that ME/CFS has also been called "the malingerer's excuse". Another speaker at this conference was Dr John le Cascio, Vice President of UNUM.

Just three extracts from a copy of UNUM's "Chronic Fatigue Syndrome Management Plan" seem significant:

*(i) Diagnosis: Neurosis with a new banner*
*(ii) UNUM stands to lose millions if we do not move quickly to address this increasing problem*
*(iii) attending physicians (must) work with UNUM rehabilitation services in an effort to return the patient / claimant back to maximum functionality* ***with or without symptoms****.*

Apart from those mentioned, there are other areas related to ME / ICD-CFS in which Wessely is known to have special interests, none of which he usually declares.

One of these is PRISMA, which stands for Providing Innovative Service Models and Assessments. It is based in Germany and is a multi-national healthcare company working with insurance companies; it arranges rehabilitation programmes for those with "CFS" and its recommended management is cognitive behavioural therapy, placing heavy emphasis on training sufferers to *"regain a normal life again"*. PRISMA claims to be especially concerned with long-term disability from the perspective of government, service providers and insurance companies. It claims to have developed a *"unique treatment programme"* for *"hopeless"* cases (it specifically includes those with ME /CFS), claiming that such patients *"avoid physical exercise and social activities, as they fear these may trigger new bouts of complaints"*. In the PRISMA Company Information, Professor Simon Wessely is listed as a Corporate Officer. He is a member of the Supervisory Board; in order of seniority, he is higher than the Board of Management. He is listed as a "*world expert"* in the field of *"medically unexplained illnesses, including Chronic Fatigue Syndrome"*. [151] Is it possible that Wessely is recommending to the Chief Medical Officer a management programme for "CFS" which is known to be harmful for those with ME / ICD-CFS [152] and which is provided by a company of whose Supervisory Board he is a member?

Another area with which Wessely is known to be involved is the organisation now called HealthWatch, but which used to be called The Campaign Against Health Fraud. This UK organisation, now a charity, is known for its zealous views which are antagonistic towards alternative and complementary medicine, and towards those who believe in environmental and chemically-induced illness, including multiple chemical sensitivity. It is a campaigning organisation which in the past has accepted funding from both

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[151] PRISMA Company Information, *2001 (Internet)*
[152] Medical and Welfare Bulletin. *2001:2:8 pub by The ME Association, Essex, UK*

pharmaceutical companies and the health insurance industry. [153] [154] In the Campaign's own literature, it states that it plans a programme of public information and that its aims are *"to oppose…unnecessary treatment for non-existent diseases"*. The same document lists Simon Wessely as a *"leading member of the campaign"*, together with other doctors including other psychiatrists and Dr David Pearson of Manchester. [155] It is the case that Wessely asserts that ME is a "non-existent" disease. [156] [157]

Pearson became notorious [158] for his evidence for the Defence in the High Court in London in 1991 [159] in which he relied upon an unauthorised draft report from the Royal College of Physicians entitled *Allergy: Conventional and Alternative Concepts* despite a letter from solicitors for the Royal College of Physicians (Field Fisher Waterhouse) forbidding him to use it; the letter, dated 18th October 1991, stated "*The College is not in a position to endorse the contents or conclusions of the draft you have seen…we must ask that this letter be brought to the attention of the Judge"*. The draft report upon which Pearson relied in evidence was subsequently subjected to stringent critical review and was withdrawn; it was substantially amended on the grounds that Fellows of the College found it to be wildly inaccurate and misleading, but the Judge (Mr Justice McPherson) did not know this and found against the Plaintiff (who could not obtain Legal Aid to mount an appeal). It is difficult to know how significantly the Judge was influenced by the inaccurate draft report, but it is likely that he would have been influenced by an apparently prestigious report supposedly backed by the Royal College of Physicians.

The HealthWatch website has links to other Internet sites, including amongst others the Advertising Standards Authority, a body which regulates advertising and which HealthWatch members have used to discipline alternative therapy practitioners; the American Council on Science and Health, a powerful group which is sponsored by multinational industry including pharmaceutical companies; the Association of Broadcasting Doctors; the Food and Agriculture Organisation; Net Doctor; NHS Direct Online; the UK Department of Health and the Cochrane Collaboration (a sibling of the Centre for Reviews and Dissemination based at the University of York, which carried out the review of the literature for the Chief Medical Officer's forthcoming report and which recommended cognitive behavioural therapy as "best practice" management of CFS/ME. The Chief Medical Officer has himself confirmed in writing [160] that it was Wessely's own database which formed the basis of that literature review; it is a matter of record that Wessely himself was adviser to the team which carried out the review).

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[153] Hansard (Lords), *28th April 1993:364-382*
[154] Hansard (Lords), 10th May 1995:66-68
[155] Subscription Form for CAHF (now HealthWatch), 1990
[156] Microbes, Mental Illness, the Media and ME: The Construction of Disease. Simon Wessely. The 9th Eliot Slater Memorial Lecture, The Institute of Psychiatry, London, *12th May 1994*
[157] Eradicating ME: Report of a meeting held on 15th April 1992 at Belfast Castle. *Pfizer / Invicta Pharmaceuticals: 1992:4-5*
[158] Dirty Medicine. Martin J Walker *pub: Slingshot Publications, BM Box 8314, London 1993*
[159] Taylor - v - Airport Transport Warehouse Services, *21 October 1991; Osmond Gaunt & Rose for the Plaintiff; Wilde Sapte for the Defendant*
[160] Letter from Professor Liam Donaldson, CMO, *September 1999, ref PO319/99*

**The Chief Medical Officer's Working Group on CFS/ME**

In 1998 the UK Chief Medical Officer (CMO) set up a Working Group to produce an official Report on ME and CFS: many people hoped and believed that the aim was to produce accurate information about the condition so that UK clinicians would be brought up to date with current scientific knowledge. In reality, the remit of the CMO's advisory group was narrow: it was restricted to just one single aspect, namely to advising UK clinicians as to the best way of managing the disorder, it being acknowledged that currently, there is no effective treatment.

Of special concern is the fact that the remit specifically dictated that ME and CFS should be considered as one entity: this has been particularly problematic, because the most influential members of the Working Group are Simon Wessely and his psychiatrist colleagues. Psychiatrists and those who agree with Wessely's beliefs are heavily represented on the Working Group and it is known that their beliefs about the nature and management of the disorder have dominated the proceedings.

To the concern of many researchers and clinicians, advice that only the most basic screening should be carried out on patients with CFS/ME is likely to be enshrined in the CMO's forthcoming Report, the final draft of which specifically advises that no immunological tests and no nuclear medicine scans should be carried out on patients suspected of suffering from "CFS/ME" (even though it is these two areas which are delivering the strongest evidence of organic pathoaetiology).

Also of concern is the fact that whilst Deputy Chair of the CMO's Working Group on CFS/ME, Professor Anthony Pinching of St Bartholomew's Hospital, London published an article in Prescribers'Journal in which he asserted that *"over-investigation can (cause patients) to seek abnormal test results to validate their illness"*. [161] Such views are in stark contrast to those expressed by international researchers, whose clear message is that **basic laboratory testing is not sufficient for patients with ME / ICD-CFS, and that more advanced immunological and neurological tests are necessary.** [162]

As long ago as 1994, world-renowned ME/ ICD-CFS clinician and researcher Daniel Peterson stated in his Introduction to an International Research and Scientific Conference: [163]

> "I take great issue with the current recommendations that no additional testing should ever be done. I believe there are indications for more advanced testing".

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[161] Chronic Fatigue Syndrome. Anthony J Pinching *Prescribers' Journal 2000:40:2:99-106*

[162] Immunological studies on the blood of patients with Gulf War Syndrome. A.Vojdani. *AACFS # 076, Seattle, January 2001*

[163] Introduction to Research and Clinical Conference. Daniel L Peterson. *Journal of CFS 1995: 1:3-4:123-125 (Presented at the AACFS International Research and Clinical Conference held at Fort Lauderdale, Florida, 7th - 10th October 1994, co-sponsored by the National Institutes of Health and the Centres for Disease Control*

As recently as July 2001, the American Medical Association issued a statement, explaining that 90% of ME / ICD-CFS patients show normal test results on basic investigations, and that studies designed for specific subgroups are needed. Anthony Komaroff, Associate Professor of Medicine at Harvard and an undisputed world expert on the disorder, said:

> "Researchers are already using imaging technology to measure brain hormones and are examining the function of the immune system. There is considerable evidence already that the immune system is in a state of chronic activation in many patients with CFS". [164]

In the UK, it seems that clinicians are to be advised that it is inappropriate and unnecessary even to look for such pathology in those who are thought to have this disorder.

The final draft of the CMO's forthcoming report states that management is to be psychiatric (cognitive behavioural therapy and graded exercise), and that future NHS services for "CFS/ME" patients *"ideally would adopt a biopsychosocial model of care--- The components of such a service are facilities for activity management"*.

In the final draft of November 2001, there is no recommendation (nor even any acknowledgment of the need) for the urgent establishment of centres of excellence which would provide facilities to look at the underlying immunology, neurology, endocrinology or the molecular biology of ME / ICD-CFS, but only for more psychiatric services; the need for provision of in-patient care or suitable respite care for such very sick people is notable by its absence.

## Caution Needed by Clinicians and Lawyers

It is essential to be ever mindful of the fact that it is unsafe to assume that the most prolific published author on a subject is necessarily the unquestioned expert on that subject. This is especially true in relation to ME / ICD-CFS, where Wessely is keen to promote himself as a medico-legal expert.[165]

In any medical discipline, the selective or multiple reporting of studies as if they were different trials, sometimes by "shifting first authorship", makes it difficult to detect duplicate publications in different journals: examples of this practice in psychiatry include one trial which had been published (in one form or another) in 83 separate publications. [166]

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[164] American Medical Association Statement, Co-Cure: *17th July 2001*
[165] Letters. Simon Wessely. *The CFIDS Chronicle, Summer 1994:77*
[166] Publication bias and the integrity of psychiatric research. Editorial: SM Gilbody, F Song *Psychological Medicine 2000:30:253-258*

Once again, however, medical science is seeking to expose such deliberate manipulation of the facts. Undeclared competing interests which in reality underlie numerous published biomedical studies are again in the spotlight, with editors of JAMA (Journal of the American Medical Association) and the BMJ Publishing Group now looking for ways to ensure that the studies which they publish are free from hidden bias. [167] This supports the acknowledgment by medical science that the problem not only exists but is considerable, and that it is essentially a form of scientific misconduct. [168] In an Editorial in 2000 in the journal *Psychological Medicine* entitled "Publication Bias" [169] Gilbody and Song state

> "Despite psychological researchers being the first to recognize the importance of publication bias (Sterling, 1959), this issue has been all but ignored in the sphere of mental health. Publication bias needs to be dealt with if psychiatry is going to become more 'evidence-based'. The continued existence of publication bias represents an abuse of the trust that patients give and is essentially a form of scientific misconduct. The recognition of the potential consequences of publication bias has led to important advances in its minimization and detection. However, these methods are rarely employed when they should be in psychiatry. This is unfortunate when, compared to other specialities, psychiatry is likely to be especially prone to publication bias.
>
> "The cornerstone of evidence-based medicine is the belief that good quality research should form the basis of clinical practice and decision-making. It is largely published research that forms the 'knowledge base' of the evidence movement. A fundamental difficulty arises when published research results are a biased sample of all research results.
>
> "A consequence is the danger that readers of journals are more likely to see studies showing results in a certain direction".

In the UK, nowhere is this more pertinent than in the field of ME / ICD-CFS.

## Conclusion

Clinicians and lawyers need to be fully aware of the political undercurrents surrounding the reality of ME, ICD-CFS and CFS.

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[167] Biomedical Journals Ponder the Failures and Remedies of Peer Review. Joan Stephenson JAMA 2001 (December 19):286:23

[168] Under-reporting research is scientific misconduct. Chalmers I. *JAMA 1990:253:1405-1408*

[169] Publication bias and the integrity of psychiatric research. SM Gilbody, F Song. *Psychological Medicine 2000:30:253-258*

They need to come to their own conclusions about what might motivate a group of doctors to disassemble a formally classified neurological disorder and endeavour to replace it by a much larger category of psychiatric "behavioural" illness.

They need to consider how, despite there being such an extensive worldwide literature on the organic nature of ME / ICD-CFS, a group of UK doctors has come to exert such influence over the rest of the UK medical community to the extent that discussion of the biomarkers of serious organic pathology is rarely published in the UK medical journals, with the result that UK clinicians are effectively being deprived of the opportunity to obtain an informed and balanced over-view of the reality of their patients' suffering, as the literature they are most likely to see reflects only the views of Wessely and his associates.

Lawyers may wish to reflect on some of the practical consequences of the denial of ME / ICD-CFS; these include:

--- refusal and denial of state benefits: those with a psychiatric diagnostic label are denied the higher rates of some state benefits and do not usually qualify for the Disability Living Allowance (DLA), which requires that the recipient has a physical disability

--- difficulties in obtaining insurance benefit if unable to work through ill-health (some health insurance companies expressly exclude psychiatric illness)

--- difficulties in obtaining private health care insurance (again, some companies do not provide cover for psychiatric disorders)

--- difficulties in obtaining early retirement on health grounds

--- unfit patients are forced to return to work

--- inappropriate treatment (some ME sufferers have been threatened with being sectioned
under the Mental Health Act unless they comply with psychiatric treatment)

--- withdrawal of Out of Area Treatment / Transfers for those with ME / ICD-CFS
(necessary if no suitable clinician is available within the patient's own Health Authority
area; there is a marked lack of appropriate referrals, eg to neurologists, immunologists endocrinologists etc )

--- lack of appropriate service provision within the NHS

--- special problems for children and young people with ME.

Lawyers may wish to consider that on 23rd November1999 the House of Commons Select Health Committee produced its report looking at adverse clinical incidents, unexpectedly

poor outcomes to treatment, failures in medical care, poorly-performing doctors and the NHS complaints procedures; the Select Committee took evidence and representations from at least eight people about ME. [170]

It may also be of interest to lawyers to know that the opinion of an eminent Leading Counsel (a member of the House of Lords) has been obtained and that this Opinion is unequivocal. It states:

> " On the document you have sent me there is an overwhelming case for the setting up of an immediate independent investigation as to whether the nature, cause and treatment of ME as considered by the Wessely School is acceptable or consistent with good and safe medical practice.
>
> " There is substantial doubt as to whether such could be the case in view of the clear division of medical opinion.
>
> "A formal request should be made to set up such an enquiry, at which interested parties could be represented by Counsel. It is all but essential that a reputable firm of solicitors should be instructed: an approach to Lord Mishcon would be well advised". [171]

Lawyers may wish to consider if a small group of exceptionally influential doctors should be allowed to determine public policy without there being some external moderation.

They may wish to consider why disease definition has become socially constructed, resulting in political tensions between sufferers, medical science and the modern State, a consequence of which is the intentional construction of "mental illness" by some groups of medical professionals resulting in stigma caused by the on-going denial. [172]

If clinicians and lawyers are unaware of this background and accept the readily proffered psychiatric explanations as if objective and based on sound scientific research, they will be unable to support their patients / clients with ME / ICD-CFS and will risk failing in their professional duty in this difficult area.

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[170] Sixth Report: Procedures Related to Adverse Clinical Incidents and Outcomes in Medical Care. *Stationary Office, 23 November 1999*

[171] Written Opinion from Leading Counsel (2, Kings Bench Walk) Temple, London) *6th April 2000*

[172] A sociological gaze on ME/CFS: a modern malady in need of humane medicine. NT Millen *Presented at the Alison Hunter Memorial Foundation Third International Clinical and Scientific Conference, 1st - 2nd December 2001, Sydney, Australia*