QUOTABLE QUOTES ABOUT ME/CFS

Myalgic Encephalomyelitis / Chronic Fatigue Syndrome

also known as PVFS (Post-Viral Fatigue Syndrome)

sometimes known as CFIDS (Chronic Fatigue & Immune Dysfunction Syndrome) in the USA

compiled by Margaret Williams on behalf of the charity Invest in ME

Registered Charity Number 1114035

April 2007

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Telephone: 01603 701980 or 02392 252365

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or from Mrs Sue Waddle, 18 Claremont Gardens, Purbrook, Waterlooville, PO7 5LL, UK

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Introduction

The following quotations are but examples of the many that exist in the international literature on ME/CFS. The quotations are in two sections.

SECTION I consists of quotations demonstrating the biomedical aetiology of ME/CFS. ME has been classified by the World Health Organisation in the International Classification of Diseases as a neurological disorder since 1969; since 1992, a synonymous listed term is Chronic Fatigue Syndrome (CFS), hence the use of the term ME/CFS (which refers to the WHO ICD-10 G93.3 code). **SECTION I provides credible evidence that ME/CFS is a serious multi-system organic disorder, the impact of which is greater than that of late-stage AIDS, end-stage renal disease or chemotherapy.**

SECTION II consists of quotations from psychiatrists of the "Wessely School" about what these psychiatrists assert is the same disorder. They refer to it as "CFS/ME" and they maintain it is a behavioural (mental) disorder. These psychiatrists work for the medical insurance industry and act against claimants with ME/CFS. Some also act as medical advisers on "CFS/ME" policy to UK Departments of State, including the Department for Work and Pensions.

Section II is in three parts: the first part provides illustrations of the published beliefs of Professor Simon Wessely (London) about ME/CFS; the second part provides illustrations of the published views of Professor Michael Sharpe (Edinburgh) on ME/CFS and the third part summarises the published beliefs of Professor Peter White (London) on ME/CFS.

It is widely believed that, between them, these three psychiatrists have exerted significant control over the perception of the disorder throughout the UK for almost twenty years, including over the funding bodies such as the Medical Research Council (where the disorder comes under the aegis of its Mental Health Board: the MRC's Mental Health Board Strategy and Portfolio Overview report of January 2005 confirms at paragraph 6.2: "**Mental health research in this instance covers CFS/ME**").

In 2000, the UK WHO Collaborating Centre for Mental Health at the Institute of Psychiatry misclassified the disorder as a mental (behavioural) disorder in its "Guide to Mental Health in Primary Care" by using Wessely's own material on "CFS/ME". The Guide was funded by the Department of Health. Despite strenuous complaints and despite ICD-10 classifications being mandatory in the UK, sales of the Guide were allowed to continue unabated until almost 30,000 copies had been sold. Eventually, an erratum was issued but this did not prevent the disorder being wrongly classified as a mental disorder in the NHS Mental Health Data Manual, nor did it prevent Ministers of State and Members of Parliament from receiving the impression that it was the WHO itself (not the WHO Collaborating Centre in the UK) that had re-classified the disorder as a mental disorder. In September 2001 the WHO issued a statement repudiating the unofficial re-classification by the UK Collaborating Centre. The matter was raised in Parliament on 22 January 2004, where Earl Howe noted the suggestion that Professor Wessely had **"effectively hijacked the WHO logo to give credence to his own view of ME as a mental illness"** *(Hansard [Lords] 23 January 2004:Vol 656:No 7:1192)*. The ME Association Newsletter of March 2004 stated: **"The issue mattered because the psychiatrists had stifled access to research funds for any UK researchers wanting to study organic causes".**

Undaunted, these psychiatrists then asserted that the WHO ICD-10 itself had classified the same disorder in two places, once in the Neurological Section and also in the Mental (Behavioural) Section. Yet again, their claims were repudiated by the WHO, who on 23rd January 2004 confirmed: **"According to the taxonomic principles governing ICD-10, it is not permitted for the same condition to be classified to more than one rubric".** Ministers were forced to correct their own misinformation and on 11th February 2004 the Health Minister formally confirmed that the correct classification for the disorder remains neurological.

SECTION II provides evidence of the apparent disregard by members of the Wessely School of the evidence-base on ME/CFS and of their dissemination of information that has successfully convinced many UK clinicians and Departments of State that ME/CFS is a psychogenic disorder.

SECTION I

Biomedical abnormalities demonstrated in ME/CFS

At the Press Conference held on 3 November 2006 at the National Press Club, Washington DC to launch the US Centres for Disease Control and Prevention (CDC) campaign to raise international awareness of the seriousness and economic impact of ME/CFS (between $22 billion and $28.6 billion annually in the US alone), Anthony Komaroff, Professor of Medicine at Harvard Medical School and acknowledged world expert on the disorder, said: **"There are now over 4,000 published studies that show underlying biological abnormalities in patients with this illness. It is not an illness that people can simply imagine that they have and it's not a psychological illness. In my view, that debate, which was waged for 20 years, should now be over".**

1956

"In nearly every patient there are signs of disease of the central nervous system. Hepatitis and splenomegaly may also turn out to be part of the picture." (A New Clinical Entity? Editorial: Lancet 26 May 1956; it was later conceded by Sir Donald Acheson -- who became Chief Medical Officer -- that it was written by him)

1977

"Objective manifestations of the disease can still be present over thirty years after the initial illness" (Iceland Disease [Benign Myalgic Encephalomyelitis or Royal Free Disease] AM Ramsay, EG Dowsett et al BMJ 1977: (May 21): 1350)

1978

"It became clear early on that there was organic involvement of the central nervous system. Bladder dysfunction occurred in more than 25% of all the patients. Objective evidence of brain stem and spinal cord involvement was observed" (An outbreak of encephalomyelitis in the Royal Free Hospital Group, London, in 1955. Nigel Dean Compston. Postgraduate Medical Journal 1978:54:722-724)

1981

"In 1969 it was suggested that ME should only be diagnosed if neurological and muscle signs were found. It is important that the title 'myalgic encephalomyelitis' should be restricted to patients who show some of each of the three major features of the disease: Firstly, symptoms and signs in relation to muscles, such as recurrent episodes of profound weakness and exhaustion, easy fatiguability, and marked muscle tenderness. Secondly, neurological symptoms or signs, especially affecting the eyes, or weakness of peripheral muscles, as demonstrated by the voluntary muscle test; or some loss of peripheral sensation; or involvement of the autonomic nervous system (orthostatic tachycardia, abnormal coldness of the extremities, episodes of sweating or pallor, [and] bladder disturbances). Thirdly, biochemical abnormalities, such as a raised urinary creatine, or an abnormal electrophoresis pattern with raised IgM". (Was it Benign Myalgic Encephalomyelitis? CS Goodwin. Lancet 1981:January 3: 37*)*

1983

"ME (is) a distressing and often prolonged illness. Many of the patients included in the study had been dismissed by hospital clinicians with the implication that there was no organic basis for their problems. As the study progressed, a pattern to the complexity of the symptoms developed (which included) malaise, exhaustion on physical or mental effort, chest pain, palpitations, tachycardia, polyarthralgia, muscle pains, back pain, true vertigo, dizziness, tinnitus, nausea, diarrhoea, abdominal cramps, epigastric pain, headaches, paraesthesiae and dysuria.The group described here are patients who have had miserable illnesses". (Sporadic myalgic encephalomyelitis in a rural practice BD Keighley EJ Bell JRCGP June 1983:339-341)

1985

"(In addition to the classic features), other features include a plethora of symptoms – usually involving multi-organ systems. The person may have a moist chest, headaches with sore muscles of the shoulders, neck and back. They may have frequency of urine or an irritable bowel. There is often oesophageal reflux with oesophageal tenderness and intermittent oesophegeal spasm. Chest pain may be intermittently prominent, and may be severe enough for hospital admission (and there may be) palpitations and a tight chest. Vision (is) often blurred, (with) stinging -- often burning -- pain behind the eyes (and) sensitivity to light. (There may be) sore joints". (Diagnostic Criteria and (Laboratory) Tests for ME. WR Gorringe ANZMES, 10th October 1985)

1986

"Eighty percent of patients demonstrate clinically significant IgE mediated allergic disease, including food and drug reactions. The data indicate that patients have a high association with hypersensitivity states. Percent positive responsiveness to allergens is consistent with the high degree of allergy observed in these patients" (Correlation between allergy and persistent Epstein-Barr virus infection in chronic active EBV infected patients George B Olsen James F Jones et al. J All Clin Immunol 1986:78:308-314. Note that in the 1980s (ME)CFS was known as Chronic EBV Disease)

1987

"Relapses are precipitated by undue physical or mental stress. However compelling the evidence for an hysterical basis may be, there is further, equally compelling, evidence of organic disease" (The postviral syndrome: a review. MI Archer. JRCGP 1987:37:212-216)

1987

"Two hundred patients fitting the criteria were seen between January 1985 and December 1986. The most common (symptoms) were irritability, lack of concentration, short-term memory problems, vertigo, visual upset, recurrent sore throat, difficulty with breathing, palpitations, abdominal distension and diarrhoea. On examination there were two important common findings – the presence of acute tenderness in the muscle bulk and a positive Romberg's sign, indicating vestibular upset. This syndrome has about the same prevalence as Parkinson's disease and is more prevalent than multiple sclerosis. In addition, nuclear magnetic resonance revealed abnormal muscle metabolism. Such patients become immunocompromised. That ME patients are immunocompromised is beyond question. Surely the underlying message is that patients with this syndrome need not await the solving of this puzzle before they are accorded the sick role (and) in the interim, it is our duty to care for them as sick". (Myalgic encephalomyelitis (ME) syndrome – an analysis of the clinical findings in 200 patients. J Campbell Murdoch The New Zealand Family Physician 1987:14:51-54)

1988

"Any kind of muscle exercise can cause the patient to be almost incapacitated for some days afterward. In severe cases, the patient is usually confined to bed. What is certain is that when one reviews (the) clinical features and laboratory results, it becomes plain that this is an organic illness in which muscle metabolism is severely affected". (Postviral fatigue syndrome PO Behan WMH Behan Crit Rev Neurobiol 1988:4:2:157-178)

1988

"We have shown that muscle fatigue and weakness for which there has previously been no explanation is indeed in the muscle rather than in the mind". (Transmissible disease and psychiatry. RP Yonge JRSM 1988:81:322-325)

1988

"Allergies are a common feature of patients with the chronic fatigue syndrome. Among the features of this syndrome is a high prevalence of allergy, an allergy that appears to be substantial" (Stephen E Straus et al: National Institutes for Allergy and Infectious Diseases: Allergy and the Chronic Fatigue Syndrome. J Allergy Clin Immunol 1988:81:791-795)

1989

"Our investigations suggest that (ME)CFS is characterized by objective laboratory abnormalities and that the currently used names for the syndrome are inappropriate. A more appropriate name for this syndrome would be chronic fatigue-immune dysfunction syndrome (CFIDS), since immune dysfunction appears to be the hallmark of the disease process". (Natural Killer Cell Activity in the Chronic Fatigue-Immune Dysfunction Syndrome. Nancy Eby, Seymour Grufferman et al. In: Natural Killer Cells and Host Defense. Ed: Ades EW and Lopez C. 5th International Natural Killer Cell Workshop. Pub: Karger, Basel, 1989:141-145)

1989

"Many of the immunological and physical features of ME/CFS cannot be explained by mental illness" (Stephen E Straus of the National Institutes for Allergy and Infectious Diseases, USA, Progress toward an answer to Chronic Fatigue: an interview with "USA Today", 13th April, 1989: reported in CFIDS Chronicle, Spring 1989, pp77-78)

1989

"It is a real organic problem and people who have it don't need the additional stress of hearing doctors tell them they are crazy" (John Esdale, Rheumatologist, Montreal General Hospital; Chronic Fatigue Syndrome wreaks havoc with victims' lives: The Gazette (Montreal, Canada) 15th November 1988; reported in CFIDS Chronicle, Spring 1989, p 79)

1989

"The most obvious factor is of course the severity of CFIDS" (David S Bell: Instructor in Paediatrics, Harvard Medical School: CFIDS in Children. CFIDS Chronicle, Spring 1989, pp34-37)

1989

"The abnormalities we found provide evidence for central nervous system and neuromuscular involvement" (Carolyn L Warner: Neurology, March 1989:39:3: Suppl 1: 420; Presentation at the American Academy of Neurology Conference, Chicago, April 1989)

1989

"The disabling weakness and exhaustion a patient with ME/CFS experiences is so profound that 'fatigue' is probably an insult" (J Cuozzo: Chronic Fatigue: JAMA 1989:261:5:697)

1989

"A population of (ME)CFS patients was tested neuropsychologically over a period of three years. The age range was 16 to 65. All patients had multiple physical symptom complaints that are typical of this condition. (Patients) reported problems with memory, concentration, sequencing, spatial relations, calculation, word-finding, comprehension, visual discrimination, and motor ability. Many of these individuals were observed to have significant motor and balance problems. The pattern of focal and lateralised impairments in these patients is consistent with an atypical organic brain syndrome". (Neuropsychological Deficits in Chronic Fatigue Syndrome. Sheila Bastien. Paper presented at the International Conference "Epstein-Barr Virus: The First 25 Years", Oxford University, UK, April 1989; also published in CFIDS Chronicle, Summer / Autumn 1989: 24-26)

1989

"The crucial differentiation between ME and other forms of postviral fatigue syndrome lies in the striking variability of the symptoms not only in the course of a day but often within the hour. This variability of the intensity of the symptoms is not found in post viral fatigue states" (Dr Melvin Ramsay, President, UK ME Association. ME Association Newsletter, Winter 1989: 20-21)

1990

"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" (John Hammarley: AMA Science News Editor, JAMA 1990)

1990

"The subgroup of patients with immunological abnormalities may have a prolonged illness. It has been suggested that a new approach to the treatment of patients with postviral fatigue syndrome would be the adoption of a cognitive behavioural model *(Wessely S, David A, Butler S, Chalder T. Management of chronic (postviral) fatigue syndrome. JRCGP 1989:39:26-29)*. Those who are chronically ill have recognised the folly of the approach and, far from being maladaptive, their behaviour shows that they have insight into their illness". (Patient management of the postviral fatigue syndrome DO Ho-Yen JRCGP 1990:40:37-39)

1990

"The results of the present study suggest that (ME)CFS is a form of acquired immunodeficiency" (Nancy Klimas, Professor of Medicine, University of Miami School of Medicine: Director of Immunology; Director of AIDS research and Director of the Allergy Clinic at Miami: Immunologic Abnormalities in Chronic Fatigue Syndrome. Journal of Clinical Microbiology, June 1990:1403-1410)

1990

"Patients with the chronic fatigue syndrome have reduced aerobic work capacity compared with normal subjects. We found that patients with the chronic fatigue syndrome have a lower exercise tolerance than either normal subjects or patients with the irritable bowel syndrome. Previous studies have shown biochemical and structural abnormalities of muscle in patients with the chronic fatigue syndrome" (Aerobic work capacity in patients with chronic fatigue syndrome MS Riley DR McClusky et al BMJ:1990:301:953-956)

1991

"The NK (natural killer) cell is a very critical cell in (ME)CFS because it is clearly negatively impacted. The most compelling finding was that the NK cell cytotoxicity in (ME)CFS was as low as we have ever seen it in any disease. This is very, very significant data. In (ME)CFS the actual function was very, very low --- 9% cytotoxicity: the mean for the controls was 25. In early HIV and even well into ARC (AIDS related complex, which often precedes the fully developed condition), NK cytotoxicity might be around 13 or 14 percent. (ME)CFS patients represent the lowest cytotoxicity of all populations we've studied" (Nancy Klimas, Professor of Medicine, University of Miami School of Medicine; Director of Immunology; Director of AIDS research and Director of the Allergy Clinic at Miami. Presentation: Immunological Markers in (ME)CFS. The CFIDS Association Research Conference, November 1990, Charlotte, North Carolina. Reported in CFIDS Chronicle, Spring 1991; pp 47-50)

1991

"Once one is familiar with the concept of post-viral fatigue syndrome (ME/CFS), such patients are in practice not too difficult to differentiate from those with true psychiatric illnesses. The physical symptoms should be an aid to diagnosis, although they may be wrongly attributed to primary psychological illness unless care is taken in eliciting them". (Professor Rachel Jenkins: Assessment and Diagnosis of ME in the Psychiatric Clinic. In: Postviral Fatigue Syndrome; British Medical Bulletin 1991:47:4:241-246)

1991

"(ME)CFS is associated with physical, psychological and social distress. The illness cannot be defined using just one of these dimensions. Such a unilateral approach has resulted in unnecessary controversy over the nature of the 'real' core of (ME)CFS. Wessely and Powell (*JNNP 1989:52:940-948*) found the total psychiatric morbidity in (ME)CFS was 72% -- other studies have found it to be 21%. (Our) study finds a variable prevalence depending on the criteria used. This emphasised the ease with which psychiatric rating scales may lead to false positive diagnoses in patients with physical symptoms. It is unnecessary and indeed unproductive to force patients into unsuitable diagnostic categories as a condition of treatment". (Biopsychosocial aspects of Chronic Fatigue Syndrome. JDL Yeomans SP Conway J Inf 1991:23:263-269)

1991

"Despite the broad divergence of opinion in the medical community, there is little doubt that classic allergy and atopy are inexplicably prevalent in (ME)CFS. In a recent study, a high proportion (50%) of patients were found to be reactive to a variety of inhalant or food allergens when innoculated epicutaneously in the classic manner. Certainly patients with (ME)CFS differ immunologically from their healthy counterparts and it is this observation, more than any other today, that is evoked in support of the organic hypothesis of disease causation". (History of Chronic Fatigue Syndrome Stephen E Straus Review of Infectious Diseases 1991:13: Suppl 1: S2-S7)

1992

"Whatever name is used, the syndrome most often consists of neurological symptoms, immunological abnormalities, cognitive impairments (and) disabling fatigue in a variety of other symptoms reflecting involvement in some if not all body systems. (We looked at) over 200 patients and over 200 controls and evaluated the data for each of 25 (ocular) symptoms. Statistical analysis shows that the increased rate at which patients with CFIDS report ocular symptoms is not explained by chance alone. Many CFIDS patients experience very troubling and disabling symptoms. It appears that the ocular symptoms of CFIDS are genuine". (Ocular manifestations of Chronic Fatigue and Immune Dysfunction Syndrome. Walter Potaznick, Neil Kozol. Optometry and Vision Science 1992:69:10:811-814)

1992

"57% of patients were bed-ridden, shut in or unable to work. Immunologic (lymphocyte phenotying) studies revealed a significantly increased CD4 / CD8 ratio. Magnetic resonance scans of the brain showed punctate, subcortical areas of high signal intensity consistent with oedema or demyelination in 78% of patients. Neurologic symptoms, MRI findings, and lymphocyte phenotyping studies suggest that the patients may have been experiencing a chronic, immunologically-mediated inflammatory process of the central nervous system". (A chronic illness characterized by fatigue, neurologic and immunologic disorders, and active human herpes Type 6 infection. Dedra Buchwald, Paul Cheney, Robert Gallo *(co-discoverer of the HIV virus)*, Anthony L Komaroff et al Ann Intern Med 1992:116:2:103-113)

1992

"A patient examined in the morning might have nystagmus, which would disappear at midday, recur later, disappear later and recur the next day". (A. Jain: Clinical Observations of Central Nervous System Dysfunction in Post-Infectious Acute Onset ME/CFS. 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)

1992

"The neuro-opthalmological manifestations of (ME)CFS are myriad and common. Two thirds of the patients complained of blurred vision. The most obvious objective sign was nystagmus; it was even more astonishing that approximately one quarter of the patients had a primary nystagmus,

since such nystagmus is always pathological". (Neuro-opthalmological Manifestations of Chronic Fatigue Syndrome. Alfredo A Sadun and Pravin U Dugel. In: The Clinical and Scientific Basis of Myalgic Encephalomyelitis Chronic Fatigue Syndrome Ed: Byron M Hyde, Jay Goldstein and Paul Levine. The Nightingale Research Foundation, Ottawa, Canada 1992)

1992

"Other disease associations such as irritable bowel syndrome, polycystic ovarian disease, thyroiditis and endometriosis are probably part of (ME)CFS. It is a rare woman with (ME)CFS who has not had hair loss, usually diffuse". (How do I diagnose a patient with Chronic Fatigue Syndrome? J Goldstein. In: The Clinical and Scientific Basis of ME CFS. Ed: BM Hyde, J Goldstein, P Levine. Pub: the Nightingale Research Foundation, Ottawa, Canada, pp247-252)

1992

"CFIDS has an organic basis; it is not a psychiatric illness. Our Surveillance Study does not support the notion that (ME)CFS is a psychiatric illness, and in fact, suggests that it has an organic basis" (Dr Walter Gunn, Principal Investigator of (ME)CFS studies at the US Centres for Disease Control: CFIDS Chronicle, February 1992, page 1)

1993

"The performance of the CFIDS patients was sevenfold times worse than either the control or the depressed group. These results indicated the memory deficit in CFIDS patients was more severe than assumed by CDC criteria. A pattern emerged supporting neurological compromise in CFIDS" (Curt Sandman, Professor of Psychiatry and Human Behaviour, University of California School of Medicine: Memory deficits associated with chronic fatigue immune dysfunction syndrome: Biol Psych 1993:33:618-623)

1993

"(ME)CFS can last for years and is associated with marked impairment. (It is) a terribly destructive illness. The tenacity and ferocity of the fatigue can be extraordinary. On past medical history, the only clearly striking finding is a high frequency of atopic or allergic illness in approximately 50-80%, in contrast to a background prevalence of about 10% in the population at large. As for the symptoms that accompany the fatigue, it is striking that these symptoms are experienced not just occasionally but are present virtually all the time. In our experience, 80% of patients with (ME)CFS have an exceptional post-exertional malaise. (Physical examination findings) include abnormal Romberg test (and) hepatomegaly (and) splenomegaly. Anyone who has cared for patients with (ME)CFS will recognize that (the) description of the patient with lupus eloquently describes many patients with (ME)CFS as well". (Clinical presentation of chronic fatigue syndrome. Anthony L Komaroff. ~~In: Chronic Fatigue Syndrome, John Wiley & Sons, Chichester, 1991~~ Ciba Foundation Symposium 173: 43-61)

1993

"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" (Paul Cheney, Professor of Medicine, Capital University, USA: Testimony Before the FDA Scientific Advisory Committee, 18 February 1993)

1994

"The spectrum of illnesses associated with a dysregulated immune system must now include (ME)CFS" (Paul H Levine, Research Professor of Epidemiology and Biostatistics, George Washington University, Washington DC: Summary and Perspective: Epidemiology of (ME) Chronic Fatigue Syndrome: Clin Inf Dis 1994:18: (Suppl 1):S57-S60)

1994

"Abnormalities of immune function, hypothalamic and pituitary function, neurotransmitter regulation and cerebral perfusion have been found in patients with (ME/CFS). Recent research has yielded remarkable data. The symptoms of (ME)CFS have long been viewed as a neurologic pattern, as confirmed by other names such as myalgic encephalomyelitis. A link is being forged between the symptoms pattern of (ME)CFS and objective evidence of central nervous system dysfunction. The view that (ME)CFS is a primary emotional illness has been undermined by recent research" (Dr David S Bell: Instructor in Paediatrics, Harvard Medical School: Chronic fatigue syndrome update: Findings now point to CNS involvement: Postgraduate Medicine 1994:98:6:73-81)

1995

"In my experience, (ME/CFS) is one of the most disabling diseases that I care for, far exceeding HIV disease except for the terminal stages" (Dr Daniel L Peterson: Introduction to Research and Clinical Conference, Fort Lauderdale, Florida, October 1994; published in JCFS 1995:1:3-4:123-125)

1995

"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" (Dr Daniel Peterson: [a Diplomate of the American Board of Internal Medicine who first identified CFIDS during an outbreak in Incline Village, Nevada, in 1984] JCFS 1995: 1:3-4:123-125). At the Second World Congress on ME/CFS and related disorders, held in Brussels in September 1999, Peterson said he was amazed at the misconceptions that existed about ME/CFS; he said that ten years ago, he believed ME/CFS would be resolved by science; he had now changed his mind and believed it could only be resolved by politics)

1996

"The occurrence of autoantibodies to a conserved intracellular protein like lamin BI provides new laboratory evidence for an autoimmune component in (ME)CFS. 52% of patients with (ME)CFS develop autoantibodies to components of the nuclear envelope (NE), mainly nuclear lamins. These findings suggest that in addition to the other disturbances of the immune system, humoral autoimmunity against polypeptides of the NE is a prominent immune derangement in (ME)CFS. 67% of (ME)CFS patients were positive for NE reactivity, compared with 10% of normal subjects. These results confirm that the NE reactivity of some (ME)CFS sera is against lamin B. Autoantibodies to NE proteins are relatively infrequent in routine ANA serology, and most of these fall into the broad category of an unusual connective tissue disease subset characterised by brain or skin vasculitis". (Autoantibodies to Nuclear Envelope Antigens in Chronic Fatigue Syndrome. K.Konstantinov D.Buchwald J.Jones et al. J.Clin Invest 1996:98:8:1888-1896)

1996

"Compared with controls, patients with ME/CFS showed a significant reduction in all lung function parameters tested" (Lung function test findings in patients with chronic fatigue syndrome. De Lorenzo et al Australia and New Zealand Journal of Medicine 1996:26:4:563-564)

1997

"The most seriously affected individuals may be bed-ridden most or all of the time and can do little or nothing for themselves. Recent research has made it clear that the view that there were no specific changes demonstrable in patients with ME/CFS has become untenable" (Dr Derek

Pheby: Director, Cancer Epidemiology Research Unit, Bristol University: CFS: A Challenge to the Clinical Professions. Physiotherapy 1997:83:2:53-56)

1997

"The signal abnormalities in ME/CFS patients most closely resemble those seen in AIDS encephalopathy. Patients often experience rejection by family, friends and physicians. The illness is hardly 'imaginary' " (Anthony Komaroff, Assistant Professor of Medicine, Harvard Medical School: Clinical Crossroads: Conference Report: JAMA 1997:278:14:1179-1185)

1997

"Previous studies from this laboratory have demonstrated a statistically significant dysregulation in several key components of the 2' 5'A synthetase / RNase L and PKR antiviral pathways in (ME)CFS. The 2-5A synthetase *I* RNase L pathway is part of the antiviral defence mechanism in mammalian cells. An accumulating body of evidence suggests that (ME)CFS is associated with dysregulation of both humoral and cellular immunity, including mitogen response, reactivation of viruses, abnormal cytokine production, diminished natural killer (NK) cell function and changes in intermediary metabolites. Marked and striking differences have been observed in the molecular mass and RNase L enzyme activity of 2-5A binding proteins in extracts of PBMC from individuals with (ME)CFS compared with healthy controls. The biochemical and immunological data presented in this paper have identified a potential subgroup of individuals with (ME)CFS with an RNase L enzyme dysfunction that is more profound than previously observed in (ME)CFS, and which the authors believe is related to the severity of (ME)CFS symptoms". (Biochemical Evidence for a Novel Low Molecular Weight 2-5A-Dependent RNase L in Chronic Fatigue Syndrome. Robert J.Suhadolnik Daniel L.Peterson Paul R.Cheney Kenny de Meirleir et al Journal of Interferon and Cytokine Research 1997:17:377-385)

1997

"We believe that it is crucial for (ME)CFS research to move beyond fuzzy recapitulations of the neurasthenia concept and clearly delineate precise criteria for diagnosing pure (ME)CFS". (Politics, Science, and the Emergence of a New Disease. Leonard A Jason et al. American Psychologist 1997:52:9:973-983)

1997

"The findings suggest that quality of life is particularly and uniquely disrupted in (ME)CFS. 90% of the sample group experienced frequent feelings of isolation, alienation and inadequacy due to (ME)CFS. All participants stated that (ME)CFS had had a profound impact on every aspect of their lives in ways they had never imagined possible. All participants related profound and multiple losses, including the loss of jobs, relationships, financial security, future plans, daily routines, hobbies, stamina and spontaneity, and even their sense of self because of (ME)CFS. Activity was reduced to basic survival needs in some subjects. Symptoms were reported to be multiple, diverse, variable and pervasive. Symptom variability also made it impossible for those with (ME)CFS to predict their level of functioning, which interfered with efforts to plan activities. For this reason, symptom variability was regarded as an especially frustrating aspect of (ME)CFS, and the uncertainty was one of the most difficult aspects to deal with. All participants (100%) felt that (ME)CFS had devastated social relationships and activities. The extent of the losses experienced in (ME)CFS was devastating, both in number and in intensity. Participants described a sense of hopelessness that was integral to the illness due to symptom variability, length of illness and repeated relapses. Over time, those who were initially optimistic became emotionally exhausted. The impact of (ME)CFS on patients' life was so total and so devastating that participants had difficulty in accepting their illness and its consequences. (ME)CFS is a poorly understood and often trivialized illness, which in reality causes marked disruption and devastation". (The Quality of Life of Persons with Chronic Fatigue Syndrome. JS Anderson CE Ferrans. The Journal of Nervous and Mental Disease 1997:185:5:359-367)

1998

"The results showed that in (ME)CFS patients, a lower stroke volume was highly predictive of illness severity: across three different postures, the most severely affected (ME)CFS patients were found to have a lower stroke volume and cardiac output compared with those with more moderate illness. These findings suggest a low flow circulatory rate in the most severe cases of (ME)CFS; this may indicate a defect in the higher cortical modulation of cardiovascular autonomic control. In the most severely affected, situations may arise where a demand for blood flow to the brain may exceed the supply, with a possibility of ischaemia and a decrement of function". (CFS severity is related to reduced stroke volume and diminished blood pressure responses to mental stress Arnold Peckerman Benjamin Natelson et al. Presented at the Fourth International AACFS Research & Clinical Conference on CFIDS, Mass. USA 1998: Abstract page 47)

1998

"(ME)CFS is a severely disabling illness. Regional brain perfusion impairment (mainly hypoperfusion) was found in 83.9% of (ME)CFS patients. This study confirmed previous reports of brain perfusion impairment in (ME)CFS, providing objective evidence of central nervous system dysfunction". (Brain SPET in Chronic Fatigue Syndrome D.di Giuda D.Racciatti et al Presented at the Fourth International AACFS Research & Clinical Conference on CFIDS, Mass. USA: 1998: Abstract page 112)

1998

"The purpose of this study was to investigate the relationship between immunologic status and physical symptoms in (ME)CFS patients. The findings suggest that the degree of cellular immune activation is associated with the severity of (ME)CFS physical symptoms. Specifically, elevations in the T-helper / inducer cells, activated T-cells, activated cytotoxic / suppressor T-cells, and CD4 / CD8 ratio are associated with greater disease severity". (Immunological Status Correlates with Severity of Physical Symptoms in Chronic Fatigue Syndrome Patients. S Wagner N Klimas et al Presented at the Fourth International AACFS Research & Clinical Conference on CFIDS 1998: Mass. USA. Abstract page 28)

1999

"The most important thing is not to have (patients) do aerobic exercise. I believe that even progressive aerobic exercise is counter-productive. If you have a defect in mitochondrial function and you push the mitochondria by exercise, you kill the DNA" (Paul Cheney, Professor of Medicine, Capital University, USA: Presentation in Orlando, Florida, February 1999 at the International Congress of Bioenergetic Medicine)

1999

"Complaints of muscle weakness and pain are common, and abnormal muscle metabolism has been reported to occur in (ME)CFS. (ME)CFS patients had recovery rates for oxygen saturation that were 60% lower than those for recovery of oxygen saturation in normal subjects. The present study has demonstrated direct impairments in oxygen delivery in (ME)CFS patients compared with normal controls. These impairments were more clearly seen after exercise".
(Impaired oxygen delivery to muscle in chronic fatigue syndrome. Kevin K McCully Benjamin H Natelson Clinical Science 1999:97:603-608*)*

1999

"The use of 31 P-nuclear magnetic resonance (31 P-NMR) has now provided positive evidence of defective oxidative capacity in (ME)CFS. Patients with (ME)CFS reach exhaustion more rapidly than normal subjects, in keeping with an abnormality in oxidative metabolism and a resultant acceleration of glyolysis in the working skeletal muscles. When the rate of resynthesis of phosphocreatinine (PCr) following exercise is measured, this abnormality is confirmed. (This) provides a conclusive demonstration that recovery is significantly delayed in patients with (ME)CFS. The results demonstrate that patients with (ME)CFS fail to recover properly from fatiguing exercise and that this failure is more pronounced 24 hours after exercise".

(Demonstration of delayed recovery from fatiguing exercise in chronic fatigue syndrome. Lorna Paul Leslie Wood Wilhemina M.H.Behan William M.Maclaren European Journal of Neurology 1999:6:63-69)

1999

"Within the homogenous group of severe (ME)CFS patients, the prognosis for recovery was poor". (Natural History of Severe Chronic Fatigue Syndrome. NF Hill, LA Tiersky, BH Natelson et al. Arch Phys Med Rehab 1999:80:1090-1094)

2000

"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" (Anthony Komaroff: Professor of Medicine, Harvard Medical School: Editorial: Am J Med 2000:108:2:169-171)

2000

"Our patients with (ME)CFS had an average ~~VO_2~~ VO2 max just below 20 mL/kg per minute, representing significant impairment relative to the controls. Comparing the exercise capacity in our patients with data from other studies shows a functionality similar to that of individuals with chronic heart failure, patients with chronic obstructive pulmonary disease, and those with skeletal muscle disorder". (Exercise Capacity in Chronic Fatigue Syndrome. Pascale de Becker Neil McGregor Kenny De Meirleir et al. Arch Intern Med 2000:160:3270-3277)

2000

"(ME)CFS has been proposed to be a disease of autoimmune aetiology and it is interesting to note that the decreased populations of ~~naïve~~ naïve T cells are also seen in the peripheral blood of patients with autoimmune disease". (Comparative Analysis of Lymphocytes in Lymph Nodes and Peripheral Blood of Patients with Chronic Fatigue Syndrome. Mary Ann Fletcher Nancy Klimas et al JCFS 2000: 7:3:65-75)

2001

"In ME, there are chronic sequelae and the effects may be neurological, hormonal, autoimmune and myalgic, which may affect the myocardium" (Dr John Richardson: Enteroviral and Toxin Mediated Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and Other Organ Pathologies. The Haworth Press Inc, New York, 2001)

2001

"There is considerable evidence already that the immune system is in a state of chronic activation in many patients with (ME)CFS" (Anthony Komaroff, Assistant Professor of Medicine, Harvard Medical School: American Medical Association Statement, Co-Cure, 17 July 2001)

2001

"New Survey reveals Chronic Fatigue Syndrome (ME) is as disabling or debilitating as lupus, multiple sclerosis and rheumatoid arthritis. Many medical professionals are acknowledging it as a seriously disabling condition. Three quarters of medical professionals responding to the survey believe that (ME)CFS, also known as CFIDS, is as or more disabling than other chronic diseases" (Press Release, CFIDS Association of America, 15 November 2001)

2001

"In ME/CFS, convincing evidence of cardiovascular impairment can be demonstrated". ("Research Update on ME/CFS". Behan WHM. Professor of Pathology, Glasgow. Extracts from Over-view of the Alison Hunter Memorial Foundation ME/CFS Clinical and Scientific Meeting, December 2001, Sydney, Australia. For the complete over-view, see http://listserv.nodak.edu/cgi-bin/wa.exe?A2=ind0207c&L=co-cure&T=0&F=&S=&P=3579)

2002

"For me as a clinician, (ME)CFS is no longer a mystery. We have given it a place between lupus, Type I diabetes and multiple sclerosis. We explain all the symptoms of (ME)CFS, which we now call 'AFS' (autoimmune fatigue syndrome) by cellular and immune abnormalities" (Professor Kenny De Meirleir, Brussels, personal communication, 9 February 2002. See also the book "Chronic Fatigue Syndrome: a biological approach" edited by Patrick Englebienne and Kenny De Meirleir, CRC Press, 2002; pp291)

2002

"The main source of the exercise-induced IL-6 production appears to be exercising muscle. Exercise-induced modulations in cytokine secretion may contribute to allergies" (Cytokine response to physical activity, with particular reference to IL-6: sources, actions and clinical implications. Shepherd RJ. Crit Rev Immunol 2002:22:3:165-182)

2002

"Several cardiopulmonary and neurological symptoms in the present investigation occurred with higher frequency and uniquely differentiated the (ME)CFS group from the controls. Shortness of breath, chest pain, dizziness after standing, skin sensations, general dizziness, dizzy moving the head, and alcohol intolerance uniquely differentiate those with (ME)CFS from controls. Results of the current investigation also indicated that muscle weakness differentiated the (ME)CFS group from controls. Furthermore, it appeared that the muscle weakness in the (ME)CFS group occurred at multiple sites, with weak legs being the most frequently reported form of weakness. These findings concur with those of Hartz et al (1998), and therefore provide further support for the inclusion of muscle weakness in the case definition of (ME)CFS". (Symptoms occurrence in persons with chronic fatigue syndrome. LA Jason et al. Biological Psychology 2002:59:1:15-27

2002

"The impact of ME/CFS on the patients' lives was very profound. It can be concluded that the quality of life of the (ME)CFS group is particularly and uniquely disrupted" (Quality of Life of Patients with Chronic Fatigue Syndrome. Gus L van Heck and Jolanda de Vries. JCFS 2002:10(1):17-35)

2003

"This study provides indication of reduced cardiac function in some patients with (ME)CFS. Some patients may be explained and potentially treated as a problem with left ventricular function" (Press Release: 9th April 2003: American Physiological Society)

2003

"Findings indicative of a problem with circulation have been reported in patients with (ME)CFS. (Our) results provide evidence of reduced cardiac output in severe (ME)CFS. They suggest that in some patients with (ME)CFS, blood pressure is maintained at the cost of restricted flow, possibly resulting in a low circulatory state. Thus there may be periods in daily activities when demands for blood flow are not adequately met, compromising metabolic processes in at least some vascular compartments. Several deficiencies capable of affecting cardiac output have been reported in (ME)CFS, including lower blood volume, impaired venous regulation, and changes in autonomic, endocrine and cardiac function. The abnormalities causing a reduction in cardiac output in (ME)CFS thus may be dispersed over multiple systems. (Further research) should be

directed at conditions that may not be overtly expressed in symptoms of (ME)CFS, such as underperfusion in the kidneys and the gut, as the organs in which the initial conservation of cardiac output takes place. The patients with severe (ME)CFS had significantly lower stroke volume and cardiac output than the controls and less ill patients. In summary, this study provides indication of reduced cardiac output in some patients with (ME)CFS". (Abnormal impedance cardiography predicts symptoms severity in Chronic Fatigue Syndrome. Peckerman A Natelson BH et al. Am J Med Sci 2003:326:2:55-60)

2003

"The patients with (ME)CFS (indicated) profound physical impairment. These scores tended to be below the published norm for patients with Type II diabetes, cancer, congestive heart failure and myocardial infarction" (Functional Status, Neuropsychological Functioning and Mood in Chronic Fatigue Syndrome. LA Tiersky, Benjamin Natelson et al. J Nerv Ment Dis 2003:191:324-331)

2003

"ME in adults is associated with measurable changes in the central nervous system and autonomic function and injury to the cardiovascular, endocrine and other organs and systems. The patient with the diagnosis of ME/CFS is chronically and potentially seriously ill. These ME/CFS patients require a total investigation and essentially a total body mapping to understand the pathophysiology of their illness and to discover what other physicians may have missed. A patient with ME is a patient whose primary disease is central nervous system change, and this is measurable. The belief that ME/CFS is a psychological illness is the error of our time". (The Complexities of Diagnosis. Byron Hyde. In: Handbook of Chronic Fatigue Syndrome. Leonard A Jason et al. John Wiley & Sons, Inc. 2003)

2004

"CFS/ME patients are sensitive to the endothelium-dependent acetylcholine. Such sensitivity is unusual if not unique and it is clear that the sensitivity is specific to CFS/ME patients" (Vance Spence: Senior Research Fellow in Vascular Medicine, University of Dundee; Julian Stewart, Professor of Paediatrics and Physiology, New York Medical College: Standing up for ME: Biologist 2004:51:2: 65-70)

2004

"These findings are consistent with an activated inflammatory response. Shockingly, the mean QOL (quality of life) scores as regards limitations on physical functioning were very, very low, similar to those found in people with AIDS and multiple sclerosis" (Advances in biomedical understanding of ME. Neil Abbot. Vance Spence. InterAction May 2004)

2004

"In comparison with other chronic illnesses such as multiple sclerosis, end-stage renal disease and heart disease, patients with (ME)CFS show markedly higher levels of disability" (Quality of Life and Symptom Severity for Individuals with Chronic Fatigue Syndrome: Findings from a Randomised Clinical Trial. RR Taylor. American Journal of Occupational Therapy 2004:58:35-43)

2004

"CDC researcher Dr William Reeves, Chief of the (ME)CFS research programme, reported that (ME)CFS patients 'are more sick and have greater disability than patients with chronic obstructive lung or cardiac disease, and researchers found that the strongest predictor of the development of (ME)CFS is the severity of the acute illness at onset, and that psychological factors played no role' ". (Press Release: AACFS, 7 October 2004)

2004

"There is no word in the English lexicon that describes the lack of stamina, the paucity of energy (and) the absolute malaise that accompanies this illness" (Charles Lapp, Professor of Community and Family Medicine at Duke University, USA. Co-Cure, 3 June 2004)

2005

"Our patients are terribly ill, misunderstood, and suffer at the hands of a poorly informed medical establishment and society" (Professor Nancy Klimas, University of Miami, AACFS Incoming Presidential Address: Co-Cure, 21 March 2005: http://www.co-cure.org)

2005

"There is mounting evidence that oxidative stress and, more specifically, lipid peroxidation, contribute to the disease process and to some of the symptoms in (ME/CFS). The novel findings in this study are that patients with (ME)CFS have significantly elevated levels ~~of F_2~~ of F2 isoprostanes alongside other key markers of oxidative stress and that these correlate with various (ME)CFS symptoms. This is the first time that elevated levels of isoprostanes have been reported in patients with (ME)CFS. Isoprostanes have been shown to be powerfully vasoconstricting and are involved in endothelial injury. Research has demonstrated that incremental exercise challenge potentiates a prolonged and accentuated oxidant stress that might well account for postexercise symptoms in (ME)CFS patients. It could be suggested that (ME)CFS is an inflammatory condition (which) could explain many of the pathological manifestations that underlie the illness". (Oxidative stress levels are raised in chronic fatigue syndrome and are associated with clinical symptoms. Gwen Kennedy, Vance Spence et al. Free Radical Biology and Medicine: 2005:39:584-589)

2006

"Levels of serum acetyl-L carnitine, immunological abnormalities, DHEA and its sulphate, cortisol, prolactin, ACTH, serum metals, oxidative stress markers, plasma-free tryptophan and melatonin have been reported to be changed in (ME)CFS. (Our) findings indicate that Vis-NIR analysis for sera combined with chemometrics analysis of serum achieves complete separation of (ME)CFS patients from healthy controls. More importantly, these results suggest that unknown factor(s) in serum are commonly present in all (ME)CFS patients" (Spectropscopic diagnosis of chronic fatigue syndrome by visible and near-infrared spectroscopy in serum samples. A Sakudo, H Kuratsune et al. Biochemical and Biophysical Research Communications 2006:345:1513-1516)

2006

"There is evidence that the patients with this illness experience a level of disability that is equal to that of patients with late-stage AIDS, patients undergoing chemotherapy (and) patients with multiple sclerosis" (Professor Nancy Klimas, University of Miami, speaking at the launch of the US CDC campaign to raise awareness of ME/CFS, 3 November 2006, National Press Club, Washington DC)

2007

"Rates of orthostatic hypocapnia were significantly higher in (ME)CFS than in controls. This (ME)CFS group reported significantly more feelings of illness and shortness of breath than controls. The first occurrence of a hypocapnic value occurred in the first 3 minutes of standing (and) the magnitude of the hypocapnia increased over time. There are at least two explanations to account for orthostatic hypocapnia – hyperventilation or reduced delivery of CO2 to the lung secondary to reduced venous return to the right side of the heart. We found that the hypocapnia was sustained and progressive. Our data indicate that emotional factors related to anxiety or depression are not important. Our working hypothesis is that this phenomenon comes from a complex interaction among the baroreflex, chemoreceptors and thoracic blood volume" (Hypocapnia is a biological marker for orthostatic intolerance in some patients with chronic fatigue syndrome. Benjamin H Natelson, Julian M Stewart et al. Dynamic Medicine 2007:6:2)

2007

From presentations at the 8th International Association of Chronic Fatigue Syndrome (IACFS) Conference, Fort Lauderdale, Florida, held on 10 – 14 January 2007:

ME/CFS patients' ability to work is impaired, as shown by an abnormal exercise stress test. They do not recover in 24 hours. Serial testing points to a significant and confirmable physical abnormality. This test is 100% objective and can prove to the disability companies that ME/CFS is neither malingering nor faking (M Ciccolella and C Snell, Stockton, California)

70% of ME/CFS patients have low red blood cell volume (B Hurwitz, University of Miami)

The cardiac index of ME/CFS patients is so severe that it falls between the value of patients with myocardial infarction and those in shock (P Cheney, North Carolina)

Maximum aerobic capacity is reduced in ME/CFS patients compared with sedentary controls (Mark van Ness, University of the Pacific)

There are abnormally high levels of inflammatory markers that are significantly correlated with increased arterial stiffness (VA Spence, University of Dundee, UK)

ME/CFS patients have reduced blood flow to the brain and exercise exacerbates this reduced blood flow. This has been known for over a decade, but the new evidence is that elevated elastase and RNase-L levels correlate with reduced blood flow (H Kuratsune, Japan)

The proteomic biosignature of ME/CFS in the cerebrospinal fluid shows the (quote) "unbelievable" finding of unique markers that are completely absent from the control group; several proteins suggest amyloid deposition in the blood vessels of the brain, causing micro-haemorrhaging that occurs in conditions of chronic inflammation; another protein suggests increased rates of apoptosis (programmed cell death); another protein that was found suggests problems with vasoconstriction and endothelial damage; one protein that was found is associated with inflammation of the leptomeningeal cells in the membranes covering the brain and spinal cord (J Baraniuk, Georgetown University, Washington DC)

Some patients clearly have a persistence of virus in their brain (J Montoya, Stanford University School of Medicine)

Of 108 ME/CFS patients who underwent gastric biopsies, 100 revealed chronic inflammation and 80% were positive for enteroviral capsid antigen (VP1) (J Chia, California)

80% of ME/CFS patients experience problems with digestion (K De Meirleir, Brussels)

Increased levels of IL-6 correlate well with C-reactive protein and are proportionate to symptom severity in ME/CFS (B Gurbaxani and S Vernon, CDC, Atlanta)

The majority of ME/CFS patients have increased rates of RNase-L activity (83%), RNase-L fragmentation (88%) and a massive 95% had increased elastase levels (K De Meirleir, Brussels) (Elastase is a protease enzyme that degrades a number of proteins, including elastin, a substance that supports the structural framework of the lungs and other organs)

In ME/CFS, there are three main abnormalities in gene expression studies; these involve the immune system, mitochondrial function and G-protein signalling. There are seven genes upregulated in ME/CFS – those associated with apoptosis, pesticides, mitochondrial function, demyelination and viral binding sites (J Kerr, St Georges, London)

In ME/CFS, testing for elastase, RNase-L, C-reactive protein, selected cytokines and NK cell activity are recommended because they are objective markers of pathophysiology and severity. In addition, an exercise test/re-test of cardiopulmonary function is necessary because it is 100% objective and confirms reduced functional capacity as well as post-exertional malaise for

disability purposes. Further, lipid abnormalities and evidence of metabolic syndrome should be looked for (C Lapp, Charlotte, North Carolina)

For a summary of the IACFS conference, see http://www.meactionuk.org.uk/Facts_from_Florida.htm

SECTION II

Professor Simon Wessely

Wessely is renowned for his belief that (i) ME does not exist except as an aberrant belief held by people who think they suffer from ME and (ii) "CFS/ME" is a behavioural disorder that should be managed by a form of psychotherapy known as cognitive behavioural therapy, which includes graded exercise and "rehabilitation". Wessely himself created a form of CBT/GET that is being promoted throughout the NHS. This has raised concerns, firstly because he is a member of the Supervisory Board of a multi-national healthcare company (PRISMA) that works with insurance companies and the NHS to provide "rehabilitation" programmes for those with ME/CFS (so he may be recommending a management regime that is provided by a company of whose Supervisory Board he is a member) and secondly because there is substantial evidence that CBT/GET at best has very limited benefit and at worst is harmful. Even Wessely himself concedes: "**Many CFS patients do not benefit from these interventions"** (The act of diagnosis: pros and cons of labelling chronic fatigue syndrome. Marcus JH Huibers and Simon Wessely. *Psychological Medicine 2006:36: (7):895-900*).

On 27 August 2003, Dr George Szmukler, Dean of Psychiatry, Institute of Psychiatry, King's College Hospital, London, wrote to the Countess of Mar about Professor Simon Wessely: **"Professor Wessely must be judged one of the most outstanding researchers in the UK, and indeed internationally. Professor Wessely has been awarded a Research Medal by the Royal College of Physicians specifically for his work on CFS and he has served on many prestigious scientific committees, further attesting to the high regard in which he is held by the scientific community".**

However, not all share that view.

The work of the Wessely School on "CFS/ME" has been stringently criticised in the international literature for flawed methodology; for use of a heterogeneous patient population (studies using mixed populations are not useful unless researchers disaggregate their findings); for selective manipulation of others' work, claiming it supports their own findings when such is not the case; for their focus on the single symptom of "fatigue" whilst ignoring other significant signs and symptoms associated with abnormalities of the central and autonomic nervous systems, neuroendocrine, cardiovascular, respiratory and immunological systems; for generating conclusions before generating the data to support such conclusions and for their recommendation that no advanced tests should be carried out on "CFS/ME" patients when it is those very tests that reveal the unequivocally organic nature of the disorder.

When dealing with "CFS/ME", these psychiatrists are regarded by Government bodies and the medical insurance industry as "experts", yet their adverse influence over the lives of people with ME/CFS is phenomenal, and Wessely's personal published output is prodigious.

There is inevitable overlap amongst members of the Wessely School, who often co-author papers on "CFS/ME". Professor Anthony David from the Institute of Psychiatry is one such co-author; his beliefs about ME/CFS are unequivocal: **"A diagnosis of depressive illness would be appropriate. Unfortunately this is not good enough for the patient"** (Post-viral fatigue syndrome and psychiatry. AS David. *British Medical Bulletin 1991:47:4:966-988*)

1988
Myalgic encephalomyelitis, or what? Anthony David Simon Wessely Anthony Pelosi
Lancet 1988:July 9, 100-101

“Though disordered immunity and persisting viral infection have recently attracted attention, it is important that immunologists do not deflect attention away from the wider (ie. psychiatric) aspects of the chronic fatigue / postviral syndrome”.

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

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

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

“Many patients referred to a specialized hospital with chronic fatigue syndrome have embarked on a struggle. One of the principal functions of therapy at this stage is to allow the patient to call a halt without loss of face”.

“The patient should be told that it is now time to ‘pick up the pieces’ (and) the process is a transfer of responsibility from the doctor to the patient, confirming his or her duty to participate in the process of rehabilitation in collaboration with the doctor”.

“The notion of allergies reinforces the view that the sufferer is under attack from outside elements which have nothing to do with himself or herself”.

1989
Fatigue syndromes: a comparison of chronic ‘postviral’ fatigue with neuromuscular and affective disorders S Wessely R Powell *JNNP 1989:52:940-948*

“Attribution of symptoms to physical rather than psychological causes was the principal difference between matched CFS and psychiatric controls”.

“An alternative hypothesis is that all cases of CFS can be explained by disorder of mood”.

1990
Attribution and self-esteem in depression and Chronic Fatigue Syndrome.
R Powell R Dolan S Wessely *J Psychosom Res 1990:34:6:665-67.*

“This research shows that in CFS, (patients) experience less guilt: such an external style of attribution has certain advantages; external attribution protects the patient from being exposed to the stigma of being labelled psychiatrically disordered, (affording) diminished responsibility for one’s own health”.

“Our results are close to those predicted by ‘learned helplessness’ ”

“Inappropriate referrals to physicians can lead to extensive physical investigation that may then perpetuate the symptom pattern of physical attribution”.

1990

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

"Most CFS patients fulfil diagnostic criteria for psychiatric disorder"

"Symptoms include muscle pain and many somatic symptoms, especially cardiac, gastrointestinal and neurological. Do any of these symptoms possess diagnostic significance? The answer is basically negative"

"It is of interest that the 'germ theory' is gaining popularity at the expense of a decline in the acceptance of personal responsibility for illness"

"Such attribution conveys certain benefits, in other words, there is avoidance of guilt and blame"

"It is this author's belief that the interactions of the attributional, behavioural and affective factors is responsible for both the initial presentation to a physician and for the poor prognosis".

1990

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

"Mood disorder is found in many cases of ME but it is not the only psychiatric disorder. Beard's neurasthenia began as a physical disease -- it provided the most respectable label for distressing, but not life-threatening complaints, one that conferred many of the benefits -- and fewest of the liabilities -- associated with illness. It was preferable to the alternatives --- hypochondria, malingering and insanity. There is little evidence of any change in the current era"

"Suggestible patients with a tendency to somatize will continue to be found among sufferers from diseases with ill-defined symptomatology until doctors learn to deal with them more effectively"

"The social processes that govern the creation of such illnesses remain obscure but one may argue that they represent culturally sanctioned expressions of distress"

"It has been shown that some patients have always preferred to receive, and well-meaning doctors to give, a physical rather than a psychological explanation for ill-defined illnesses associated with fatigue"

"Such uncritical diagnoses may reinforce maladaptive behaviour".

1990

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

"A number of patients diagnosed as having benign myalgic encephalomyelitis who complained of persistent muscle weakness were examined neurologically by one of the authors of this chapter. In many of them, the usual findings of simulated muscle weakness were present"

"A physical diagnosis implies the illness has an external (physical) cause"

"Such attribution always confers certain benefits, irrespective of accuracy. In other words, there is avoidance of guilt and blame"

"Exercise is necessary as a specific therapy. There is no evidence that physical activity worsens the underlying process"

"Efforts are made to over-interpret laboratory findings"

"It is regrettable that ME has become a disease of fashion, even a 'fad' "

"Suggestible patients with a tendency to somatise will often be found among the ranks of sufferers from disease with ill-defined symptomatology until doctors learn to cope with them more effectively"

"Over-enthusiastic espousal of new illnesses can be harmful. It may legitimize some of the maladaptive behaviour already described".

1990
Chronic Fatigue and Myalgia Syndromes Simon Wessely
In: Psychological Disorders in General Medical Settings Ed: N Sartorius et al Pub: Hogrefe & Huber, 1990

"Most CFS patients fulfil diagnostic criteria for psychiatric disorder"

"Other symptoms include muscle pain and many somatic symptoms, especially cardiac, gastrointestinal and neurological"

"Do any of these symptoms possess diagnostic significance? The answer is basically negative"

"The description given by a leading gastroenterologist at the Mayo Clinic remains accurate:

'The average doctor will see they are neurotic and he will often be disgusted with them' ".

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

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

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

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

1991
Cognitive behavioural management of the Post-viral Fatigue Syndrome Simon Wessely, Sue Butler, Trudie Chalder, Anthony David. *In: Post-Viral Fatigue Syndrome; Ed: Rachel Jenkins and James Mowbray. Pub: John Wiley & Sons, Chichester, 1991*

"Helplessness contributes to the expectation that fatigue and pain will follow exertion, forming the first of many self-perpetuating cycles that contribute to the clinical picture"

"The patient (and doctor) blames all ills on continuing viral infection. The word 'blame' is used deliberately, as issues of guilt, blame and responsibility ~~affects~~ affect both patients with PVFS and doctors making the diagnosis"

"Blaming symptoms on a viral infection conveys certain advantages, irrespective of its validity"

"It is also beneficial to self-esteem by protecting the individual from guilt and blame. The germ has its own volition and cannot be controlled by the host. The victim of a germ infection is therefore blameless"

"Patients may think 'I am going to find this impossible' before attempting any activity. This will lead to an upsurge in symptoms on attempting any activity. All this will be reinforced by the advice currently available ~~advice~~ from the self-help literature"

"Many patients become hypervigilant and over-sensitised to physical sensations"

"Dysfunctional cognitions are not sufficient to account for prolonged disability; their importance is linked to the development of maladaptive behavioural patterns"

"A vicious circle of pain, misery, avoidance and inactivity is established"

"The behaviour of family and friends may inadvertently reinforce the sick role"

"Fear of illness is an important part of (the disorder)"

"The approach we favour is provided by professionals whose training and background is in mental health"

"There is no doubt that many patients are hostile to such an approach. Treatment refusal is the major obstacle we have encountered".

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

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

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

"Studies usually find a high prevalence of psychiatric disorder among those with CFS, confirming that physicians are poor at detecting such disorders".

1992
Eradicating myalgic encephalomyelitis (ME) Simon Wessely
Report of meeting held on 15 April 1992 at Belfast Castle; Pfizer Invicta Pharmaceuticals, pp4-5

"It seems that ME sufferers prefer to feel that they have a 'real' disease – it is better for their self-esteem (and) the label 'ME' helps legitimise their dealings with doctors".

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

"Many people present to their doctor with multiple unexplained symptomatology which they attribute to allergy. Those at the extreme end of this range often attract a diagnosis of total allergy syndrome, multiple chemical sensitivity, or environmental illness"

"Inherent in the concept of allergy is the avoidance of any blame"

"Sufferers from allergies feel no guilt about their condition and are not subject to moral sanction"

"Sufferers from mysterious conditions that lie outside conventional medical practice no longer consider themselves to be oppressed by spirits and demons but by mystery gases, toxins and viruses. This is particularly visible in the changing nature of mass hysteria".

1993
Chronic Fatigue, ME, and the ICD-10 David A Wessely S *Lancet 1993:342:1247-1248*

"The inclusion in the tenth revision of the International Classification of Diseases (ICD-10) of benign myalgic encephalomyelitis as a synonym for postviral fatigue 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 subgroup 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".

(The authors seemed curiously unaware that ME was first classified and included as a neurological disorder by the WHO in 1969 -- MW).

1994
Microbes, Mental Illness, The Media and ME: The Construction of Disease Simon Wessely
9th Eliot Slater Memorial Lecture, Institute of Psychiatry, London, 12 May 1994

"I will argue that ME is simply a belief, the belief that one has an illness called ME"

"The Royal Free Disease itself is part of the world of myth".

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

"Most doctors in hospital practice will be familiar with patients who complain about a wide variety of symptoms but whose physical examination and investigations show no abnormality"

"(Such) symptoms have no anatomical or physiological basis"

"Patients at the severe end of the spectrum exert a disproportionately large and avoidable financial burden on the health and social services"

"Patients with inexplicable physical symptoms are usually strongly resistant to any psychological interpretation (and) are generally viewed as an unavoidable, untreatable and unattractive burden".

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

"The infective characteristics may be the result of referral patterns and illness behaviour"

"The definition may have arisen as a result of referral patterns to specialists"
"Muscle pain was related to psychological morbidity".

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

"Many doctors are frequently consulted by patients with persistent unexplained symptoms attributed to allergy or chemical sensitivity. When patients are told there is no evidence of any underlying immunological or allergic cause, they can be difficult to manage"

"The illness is usually sporadic but epidemics have been described. Such epidemics overlap with the related subject of mass psychogenic illness, a term which has partly replaced mass hysteria"

"The epidemiology of environmental illness is reminiscent of the difficulties encountered in distinguishing between the epidemiology of myalgic encephalomyelitis (ME), a belief, and chronic fatigue syndrome, an operationally-defined syndrome"

[***Note: The World Health Organisation does not regard ME as " a belief", but as a neurological disorder*** --- MW].

"These patient populations recruited from the environmental subculture are a subgroup of patients who can be expected to show unusually strong beliefs about the nature of their symptoms, associated with a high prevalence of psychiatric disorder"

"Somatization sufferers consume vast amounts of health resources for little benefit"

"The risk of psychiatric diagnosis is known to increase linearly with the number of symptoms with which the patient presents"

"Attribution of unexplained symptoms to a "virus", as happens in most patients with the label of ME, may preserve self-esteem and protect against the stigma of psychiatric disorder"
"These total allergy syndromes are akin to culture-bound syndromes afflicting modern developed societies where sufferers from unexplained symptoms no longer see themselves as possessed by devils or spirits but instead by gases, toxins and viruses"

"When a psychiatric disorder is not recognised, patients are often investigated extensively for organic disease; there are hazards in these inappropriate investigations, as patients' beliefs in organic pathology are reinforced"

"Further investigations will add nothing to the management but will reinforce the patient's beliefs in organic pathology".

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

"Chronic fatigue may be better understood by focusing on perpetuating factors and the way in which they interact in self-perpetuating vicious circles of fatigue, behaviour, beliefs and disability"

"The perpetuating factors include inactivity, illness beliefs and fear about symptoms, symptom focusing, and emotional state"

"CFS is dogged by unhelpful and inaccurate illness beliefs, reinforced by much ill-informed media coverage; they include fears and beliefs that CFS is caused by a persistent virus infection or immune disorder"

"Increased symptom focusing occurs in CFS sufferers; (this) increased concern leads to selective attention and 'body watching': this can intensify the perceived frequency of symptoms, thereby confirming illness beliefs and reinforcing illness behaviour".

1996
Chronic Fatigue Syndrome. Report of a Joint Working Group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners
October 1996 Simon Wessely, Anthony David, Peter White et al

"The Royal Colleges have stressed that approaches to these patients should not be based on simple biomedical models"

"Some would prefer to continue to use the term ME. Patients may wish to keep (it) because only with that label are they eligible to call upon the welfare of the state for help"

"The group within CFS with more symptoms, profounder fatigability, greater disability and longer illness duration is the subset with the strongest associations with psychological disorder"

"The term ME may mislead patients into believing they have a serious and specific pathological process"

"The possibility that abnormalities of immune function play a role in the pathogenesis of CFS has attracted considerable attention. Such abnormalities should not deflect the clinicians from the biospsychosocial (psychiatric) approach and should not focus attention towards a search for an 'organic' cause"

"Several studies suggest that poor outcome is associated with social, psychological and cultural factors"

"Chronicity is likely to be associated with 'perpetuating factors', which may include poor illness management or unaddressed psychosocial issues. We therefore urge that no-one should be regarded as permanently impaired until they have had the opportunity of participating in all sensible efforts at rehabilitation"

"We have concerns about the dangers of labelling someone with an ill-defined condition which may be associated with unhelpful illness beliefs"

"Research suggests that dysfunctional illness beliefs are common in CFS patients. Such inaccurate beliefs might fuel avoidance of activity"

"There is no compelling evidence linking immune dysfunction with disability"

"CFS in children covers a broad spectrum of problems, perhaps even involving the Munchausen's by Proxy syndrome"

"We discourage home tuition"

"We draw attention to the relevant statutory duties and the need to be prepared to act in the best interests of the child (*ie. by removing the child from its parents and home via the Courts ---MW*)

"Appropriate clinical practice is not to be defined by special interest groups, nor consensus conferences"

"Previous studies have counted people with ME, but these studies reflect those who seek treatment rather than those who suffer the symptoms"

"No investigations should be performed to confirm the diagnosis"

(The Joint Royal Colleges' Report provided the basis for the Research Paper 98/107 "Chronic Fatigue Syndrome/ ME" by Dr Alex Sleator (1st December 1998) of the Science and Environment Section of the House of Commons Library, which in turn supplied the misinformation that was provided for all Members of Parliament and Ministers and which informed Government response to "CFS/ME' issues---MW).

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

"The clinical problem we address is the assessment and management of the patient with a *belief* that he / she has an illness such as CFS, CFIDS or ME"

"The majority of patients seen in specialist clinics typically believe that their symptoms are the result of an organic disease process, and resent any suggestion that they are psychological in origin or psychiatric in nature. Many doctors believe the converse"

"It is particularly important to focus on factors which may be *perpetuating* the illness. A conviction of a solely physical cause for symptoms is the single most consistent predictor of poor outcome"

"(Patients') beliefs are probable illness-maintaining factors and targets for therapeutic intervention"

"Many patients receive financial benefits and payment which may be contingent upon their remaining unwell. Gradual recovery may therefore pose a threat of financial loss"

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

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

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

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

"An important task of treatment is to return responsibility to the patient for management and rehabilitation without inducing a sense of guilt, blame or culpability for his / her predicament".

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

"Many people suggest that the condition should be called ME, but doctors and the editors of journals have taken a firm stand against this label"

"The GP's response may be important. A sick note and unclear diagnosis are both associated with development of CFS".

1999

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

"We postulate that the existence of specific somatic syndromes is largely an artefact of medical specialization"

"Functional somatic syndromes pose a major challenge to medicine. Those symptoms are associated with unnecessary expenditure of medical resources"

"Chronic fatigue syndrome is associated with worse disability than conditions such as heart failure"

"Many of these (functional somatic) syndromes are dignified by their own formal case definition and body of research"

"We question this orthodoxy and ask whether these syndromes represent specific diagnostic entities (eg. irritable bowel syndrome, premenstrual syndrome, fibromyalgia, hyperventilation syndrome, tension headaches, globus hystericus, multiple chemical sensitivity, chronic fatigue syndrome) or are rather more like the elephant to the blind man --- simply different parts of a larger animal?"

"We have put forward the hypothesis that the acceptance of distinct syndromes as defined in the medical literature should be challenged. We contend that the patients so identified have much in common"

"We propose an end to the belief that each different syndrome requires its own particular sub-specialist".

2000

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

"Such outbreaks are not novel. In a previous era, spirits and demons oppressed us. Although they have been replaced by our contemporary concern about invisible viruses, chemicals and toxins, the mechanisms of contagious fear remain the same"

"The term 'psychogenic illness' and its predecessor 'mass hysteria' exemplify the problem"

"To the majority of observers, including most professionals, these symptoms are indeed all in the mind"

"How do you convey the message that the main mechanisms for the transmission of distress are psychosocial and behavioural? A firm public message that certain symptoms are probably psychological in origin will probably help prevent their spread".

2001

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

"Social, behavioural and psychological variables are important in both chronic fatigue and chronic fatigue syndrome"

"Compelling evidence of abnormal neuromuscular fatigability in patients with the chronic fatigue syndrome is lacking"

"Some of the desire to split the chronic fatigue syndrome into subgroups is driven by emotion. It is interesting to note how some of those who advance this argument assume that "their" condition (the one they suffer from, research or treat) will fall on the physical side of the divide"

"The greater the number of symptoms and the greater the perceived disability, the more likely clinicians are to identify psychological, behavioural or social contributors to illness"

"If the chronic fatigue syndrome did not exist, our current medical and social care systems might force us to invent it"

"Other symptoms identified in the chronic fatigue syndrome (include) increased symptom-monitoring".

(In correspondence arising from this paper, Wessely wrote: ***"I can sleep easy at night when it comes to treatment. I know that we have done more good than harm. All I know is that I am quietly proud of what our group has achieved over the years"****).*

<u>2003</u>

<u>Managing patients with inexplicable health problems</u> B Fischhoff Simon Wessely
BMJ 2003:326:595-597

"When a medical explanation is slow in coming, physicians, officials and companies often bear the brunt of (patients') anger, for example in chronic fatigue syndrome and Gulf war sickness, authorities who denied sufferers' claims met with scorn and contempt"

"It is only human for doctors to view the public as foolish, uncomprehending, hysterical or malingering"

"One challenge arises when patients have named their condition in a way that leaves doctors uncomfortable, as occurred with chronic fatigue syndrome"

"It may seem that adopting the lay label reinforces the perceived disability. A compromise strategy is 'constructive labelling': it would mean treating chronic fatigue syndrome as a legitimate illness while gradually expanding understanding of the condition to incorporate the psychological and social dimensions. The recent adoption by the UK Medical Research Council and the chief medical officer's report of the term CFS/ME reflects such a compromise, albeit it an uneasy one".

<u>2003</u>

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

"This paper proposes that well-intentioned actions by medical practitioners can exacerbate or maintain medically unexplained symptoms (MUS). This term is now used in preference to 'somatisation' "

"The medical specialties employ shorthand descriptions for particular clusters of MUS, including irritable bowel syndrome, fibromyalgia and chronic fatigue syndrome"

"The adoption of a label such as CFS affords the sufferer legitimacy --- in other words, it allows entry into the 'sick role' "

"The external acknowledgement that the condition is 'legitimate' is both reassuring and enabling"

"The conferring of a label is not a neutral act, since specific labels are associated with specific beliefs and attitudes. In CFS for example, use of this term or the alternative 'myalgic encephalomyelitis' implies underlying assumptions about aetiology and treatment for both patients and doctors"

"If sections of the media advocate an exclusively organic model, as has happened with CFS, the biomedical model may become firmly enshrined for patients and families at the expense of psychosocial models".

2003
The Guardian Saturday 1st March 2003 Simon Wessely

"Science is indeed socially controlled, and so it should be. You cannot sit on a scientific body in this country without knowing that decisions are strongly influenced by the priorities set by elected politicians".

2004
Unloading the trunk: neurasthenia, CFS and race A Luthra S Wessely *Social Science and Medicine 2004:58:2363-2369*

"Overall, CFS (or ME) is represented as a Western disease".

(*At the 8th International IACFS Conference held in Florida in January 2007 which Wessely did not attend, there were over 250 medical scientists and clinicians from 28 countries, including Japan, South Korea, Chile and Latvia, to name just some. In Japan, the economic cost of ME/CFS is over $10 billion annually. The Japanese Government recognises ME/CFS as a real threat not only medically but also economically and has initiated a large research programme into causation and treatment --- MW).*

2005
Chronic fatigue syndrome: an overview Hyong Jin Cho Simon Wessely
Rev Bras Psiquiatr. September 2005:27:3: Sao Paulo

"Functional somatic syndromes refer to groups of symptoms lacking demonstrable abnormalities of structure. They include chronic fatigue syndrome"

"Perpetuating factors have particular importance in understanding CFS"

"Many consider that amplification of somatic symptoms that happen in our daily lives is a core factor underpinning the perpetuation of many unexplained medical syndromes"

"Several factors have been reported to be associated with the perpetuation of CFS. These include a fixed somatic attribution, which may be associated with avoidance behaviour related to exercise or activity"

"Physical deconditioning as a consequence of reduced activity may contribute to towards greater experience of symptoms".

For more fully-referenced articles refuting Wessely's unfounded beliefs about the nature of ME/CFS, see http://www.meactionuk.org.uk

SECTION II

Professor Michael Sharpe

Michael Sharpe is heavily involved with the medical insurance industry, including UnumProvident. Unum's "**Chronic Fatigue Syndrome Management Plan**" dated 4 April 1995 (authored by Dr Carolyn L Jackson) is unequivocal: (i) "**Diagnosis: Neurosis with a new banner" (ii) "UNUM stands to lose millions if we do not move quickly to address this increasing problem".**

The incidence and prevalence of ME/CFS are known to be rising substantially. As long ago as 1994, UNUM reported that no other disease surpassed the rate of increase of ME/CFS. In order of insurance costs, ME/CFS came second in the list of the five most expensive chronic conditions, being three places above AIDS.

For an exposition of UNUM's involvement in the UK Benefits Service and of the numerous awards of punitive damages against UNUM for malpractice, together with Wessely School psychiatrists' continued attempts to influence the entry on ME/CFS in the Department of Work and Pensions Handbook, see "Concerns About A Commercial Conflict of Interest Underlying The DWP Handbook Entry on ME/CFS" by Hooper et al available online at www.meactionuk.org.uk/HOOPER_CONCERNS_ABOUT_A_COMMERCIAL_CONFLICT_OF_INTEREST.htm

On 17 May 1995 both Wessely and Sharpe were main speakers at a UNUM symposium entitled "Occupational Health Issues for Employers"; Wessely spoke about the "**myths**" of ME; Sharpe spoke about the use of CBT and their colleague Trudie Chalder spoke about "**selling the treatment to the patient**". Information presented including informing attendees that ME/CFS has been called "**the malingerer's excuse**".

In addition to UNUM, insurance companies known to be involved in ME/CFS claims include Swiss Life, Canada Life, Norwich Union, Allied Dunbar, Sun Alliance, Skandia, Zurich Life and Permanent Insurance, and as re-insurers, the massive Swiss Re. These companies also seem to be involved in re-insurance: for example, Norwich Union uses Swiss Re as re-insurer, whose "CFS experts" are Michael Sharpe and Simon Wessely, and Peter White is one of the Chief Medical Officers for Swiss Re. Swiss Re also uses psychiatrist Anthony Cleare, who is a colleague and frequent co-author on ME/CFS with Wessely.

This seems to mean that there is little hope of an ME/CFS claim succeeding, because both the insurers and the re-insurers all use Wessely School psychiatrists to inter-refer claimants with ME/CFS.

Members of Parliament are on record as being gravely concerned about the difficulties which their constituents with ME/CFS suffer at the hands of the disability insurers, as recorded in the House of Commons debate chaired by Sir Alan Haselhurst on 21 December 1999 (*Hansard: 146WH-166WH)* and Members of the Scottish Parliament are aware of and concerned about the involvement of Mike Sharpe with the industry's processing of claims due to ME/CFS. Sharpe has asked MSPs to retract their statements to Allied Dunbar regarding his suitability to give an unbiased view when assessing people who suffer from ME/CFS.

For more information on this issue, including extracts from signed Statements provided by ME/CFS claimants about the involvement of Wessely, Sharpe, Peter White and Anthony Cleare, see "The Mental Health Movement: Persecution of Patients? Background Briefing for the House of Commons Select Committee" at http://www.meactionuk/org.uk/SELECT_CTTEE_FINAL_VERSION.htm

1991

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

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

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

"Several physiological factors may perpetuate symptoms. These include the consequences of inactivity"

"Extensive physical investigation is unlikely to be fruitful and should be limited"

"Personality factors (attitudes, beliefs and thoughts) and behaviour have been shown to perpetuate disability"

"These unhelpful or "dysfunctional" cognitions include the beliefs that recovery from the illness is not under personal control or that the illness is poorly understood"

"Such symptoms are frequently regarded as revealing personal weakness and as not being a valid reason for exemption from daily demands"

"Physical disease, on the other hand, particularly if validated by a doctor, is rarely considered to be the responsibility of the afflicted, merits sympathy, and excuses the sufferer from meeting the demands of others"

"Patients without a "physical" disease label for their illness may consequently experience difficulty in explaining their disability to friends, family or employers. Hence they may request a 'physical diagnosis' from doctors"

"In response to the lack of acceptance of the "reality" of the symptoms of CFS, support has been sought for the existence of a disease called myalgic encephalomyelitis or 'ME' "

"The insistence that "ME" is an exclusively physical disease with a poor prognosis may have been unhelpful for sufferers (and) such a restricted conception of the problem may have perpetuated illness in some individuals"

"The use of extensive laboratory investigation may be psychologically harmful to the patient by reinforcing their beliefs about serious physical disease"
"Problems may arise if the patient requires a diagnosis the doctor feels is inappropriate or wants certification of permanent invalidity (ie) "ME".

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

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

"Psychosocial factors may maintain disability. Family members may reinforce both beliefs and avoidance"

"We suggest that the clinical assessment should consider mood, beliefs, avoidance of ~~inactivity~~ activity and the role of the family".

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

"In clinical practice, no additional tests, including laboratory tests and neuro-imaging studies, can be recommended"

"Examples of specific tests (*which should not be done*) include serologic tests for enteroviruses; tests of immunologic function, and imaging studies, including magnetic resonance imaging scans and radionuclide scans (such as single photon emission computed tomography (SPECT) and positron emission tomography (PET) of the head"

"We consider a mental status examination to be the minimal acceptable level of assessment"

"The exclusion of persons (*with psychiatric disorders*) would substantially hinder efforts to clarify the role that psychiatric disorders have in fatiguing illness".

"We dropped all physical signs from our inclusion criteria ".

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

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

1997
Chronic Fatigue Syndrome and Occupational Health A Mountstephen and M Sharpe
Occup Med 1997:47:4:217-227

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

(ME as a specific syndrome has been classified since 1969 as a neurological disorder by the World Health Organisation; it was accepted as a nosological entity by the Royal Society of Medicine in 1978; it was recognised by the UK Department of Health as an organic disorder in November 1987; it is a matter of public record that the Minister of Health (Stephen Dorrell MP) confirmed that ***"ME is established as a medical condition"*** *on 16 August 1992, so it is difficult to know on what evidence these authors rely to support their statement that "the existence of ME as a specific syndrome remains unestablished" --- MW).*

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

"Patients' beliefs and behaviour are often a prominent part of the clinical presentation"

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

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

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

"Psychiatric assessment is recommended in *every case*"

"Few laboratory investigations are necessary"

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

"Referral to 'specialists' should be avoided as they can entrench illness behaviour"
(*presumably the authors exclude referral to specialist psychiatrists ---MW)*

"A process of education to address inaccurate and unhelpful attitudes and beliefs may be a necessary preliminary step".

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

"Chest pain, back pain, headache, muscular pains, bowel symptoms, breathlessness, dizziness and fatigue often remain unexplained after medical assessment. Such cases may be referred to as functional syndromes of chronic fatigue or as somatoform disorders"

"When symptoms are found not to result from 'genuine physical illness', they are often attributed to mental illness"

"Evidence for the superiority of new ways of thinking about and managing such patients is growing"

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

"The small but conspicuous group of patients who present with recurrent and multiple physical symptoms will be given co-ordinated care aimed at limiting unnecessary medical interventions".

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

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

"CBT helps patients to re-evaluate their beliefs (and) encourages them to change their behaviour"

"Change in the belief is an important factor in recovery".

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

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

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

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

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

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

"Cognitive behavioural therapy has been shown to have substantial benefits for patients with CFS (and) can reduce disability in most patients"

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

“There is very clear evidence that a condition which appears identical caused similar concerns a hundred years ago (and) the causes were thought to lie in the concerns of that time namely, the changing role of women; in our time it is allergy and toxins”

“The vehemence with which many patients insist that their illness is medical rather than psychiatric has become one of the hallmarks of the condition”

“Over-solicitousness and the reinforcement of unhelpful illness beliefs can have an unhelpful effect on patients’ attitude and coping”

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

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

2000
Chronic Fatigue Syndrome (Myalgic Encephalomyelitis) Michael Sharpe
NETDOCTOR.CO.UK February 2000

“Special ~~investigation~~ investigations such as brain scans do not help the diagnosis of this condition”.

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

“Psychosocial factors are important in CFS. Prognostic factors include family factors and social factors”

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

2001
Interpretation of symptoms in chronic fatigue syndrome Dendy C Cooper M Sharpe M
Behaviour Research and Therapy 2001:39(11):1369-1380

“It has been suggested that patients with CFS tend to interpret their symptoms as indicating physical illness”

“The tendency to interpret symptoms in terms of physical disease rather than emotion is potentially of clinical importance as it has been shown to predict a poor outcome”

“A cognitive model of ME/CFS has been proposed (Sharpe et al, 1991)”

“According to this model, the interpretation of symptoms predominantly in terms of physical illness, and not in terms of emotional states, plays a particularly important role in the maintenance of the disorder”

“Patients with ME/CFS may have had experiences of being told by others, including medical staff, that their symptoms are best explained by physical illness. It seems likely that such experience will contribute to the development of beliefs”.

2001

Unexplained somatic symptoms, functional syndromes and somatisation: do we need a paradigm shift?
Michael Sharpe Alan Carson *Ann Intern Med 2001:134:9:2:926-930*

"Although there is a research literature suggesting the presence of biochemical and physiological abnormalities in many of these disorders, they share a lack of pathologically defined changes that dignify medical conditions (such as cancer) as disease"

"It does seem that the neglect of the psychological impact can be harmful, for example, by suggesting to the patients that they are sick when they are not".

2002

The English Chief Medical Officer's Working Parties' report on the management of CFS/ME: Significant breakthrough or unsatisfactory compromise? Michael Sharpe
Journal of Psychosomatic Research 2002:52:6:437-438

"In 1998, the UK Chief Medical Officer took the unusual step of commissioning a special working group (on CFS). What does it say?"

"Some recommendations are controversial. The first of these is about a matter as basic as what to call the illness. The report comes down on a compromise term CFS/ME"

"The name CFS/ME symbolizes the fudge adopted regarding the issues of psychiatric care and of the choice of treatment"

"My own view has long been that the issues around CFS/ME are the same as those surrounding the acceptance and management of (patients) who suffer conditions that are not dignified by the presence of what we call disease".

2002

Clinical Review: ABC of psychological medicine Michael Sharpe David Wilks
BMJ 2002:325:480-483

"Fatigue can refer to a subjective symptom of malaise and aversion to activity"

"Patients generally regard fatigue as important, whereas doctors do not"

"Predisposing factors include being female"

"Perpetuating factors include physical inactivity (and) emotional disorders"

"Other factors such as immunological abnormalities are not of clinical value"

"Chronic fatigue syndrome is a useful descriptive term for prominent physical and mental fatigue"

"A preoccupation with medical causes seems to be a negative prognostic factor"

"Perpetuating causes (are) excessive inactivity, unhelpful beliefs, avoidance of activity"

"While patients may be concerned about the need for medical investigation, it can be explained that no disease has been found".

2002

Functional Symptoms and Syndromes: Recent Developments   Michael Sharpe
In: Trends in Health and Disability 2002, Report of UNUM Provident Insurance Company

"It is becoming increasingly clear that the problem of patients who have illness that is not clearly explained by disease is a large one"

"There is a great deal of confusion about what to call such illness. A wide range of general terms has been used including 'hysteria', 'abnormal illness behaviour', 'somatisation' and 'somatoform disorders' "

"Recently the terms 'medically unexplained symptoms' (MUS) and 'functional' symptoms have become popular amongst researchers"

"The psychiatric classification has important treatment implications. Because patients may not want a psychiatric diagnosis, this may be missed"

"There is strong evidence that symptoms and disability are shaped by psychological factors"

"Especially important are the patients' beliefs and fears about their symptoms"

"**Possible causal factors in chronic fatigue syndrome:**

"Psychological: personality, disease attribution, avoidant coping style.

"Social: information patients receive about the symptoms and how to cope with them; this information may stress the chronicity and promote helplessness. Such unhelpful information is found in 'self-help' books. Unfortunately doctors may be as bad.

"Obstacles to recovery:

"**The current system of state benefits, insurance payment and litigation remain potentially major obstacles to effective rehabilitation"**
"As the authority of medicine to define what is a legitimate illness is diminished, increasingly consumer oriented and privatised doctors will collude with the patient's views that they have a disabling and permanent illness"

"It will be imperative that health and social policy address this problem"

"Both health services and insurers now need to take a more positive approach".

2004

Somatoform disorders --- new approaches to classification, conceptualization and treatment
Winfried Rief   Michael Sharpe
Editorial: Journal of Psychosomatic Research 2004:56:387-390

"Every medical specialty has its own syndrome of 'medically unexplained' or 'functional' somatic symptoms. Fibromyalgia, irritable bowel syndrome, chronic fatigue syndrome, pelvic pain syndrome and non-cardiac chest pain are just some examples"

"Many patients with somatoform disorders manifest a tendency to interpret benign bodily complaints as signs of disease"

"Abnormal illness behaviour was described as seeking verification of a medical diagnosis by multiple doctors ('doctor-shopping'), urging doctors to do unnecessary investigations, inability to go working, and many others"

"Modern psychiatry is based on the concept of psychopathology. That is, patients are assumed to have 'mental disease' "

"Hence, somatoform disorders serve both medicine and psychiatry by providing a disposal for the patients who would otherwise challenge the theoretical models upon which practice is based".

2004

Somatoform disorders: a help or hindrance to good patients care? Michael Sharpe Richard Mayou
British Journal of Psychiatry 2004:184:465-467

"The value of somatoform diagnoses is often taken simply to indicate a need to minimize access to medical care".

2005

The Science of the Art of Medicine Michael Sharpe
Inaugural Lecture, University of Edinburgh, 12 May 2005

In his inaugural lecture, attended by Simon Wessely, Sharpe (who now ~~hold~~ holds a Personal Chair in Psychological Medicine and Symptoms Research) spoke on "functional medicine" and how to treat diseases with "no pathology".

Sharpe highlighted medicine's 'blind spot' in dealing with symptoms that are not expressions of disease, including patients with controversial syndromes such as chronic fatigue syndrome or ME.

In summary, it can ~~fairly be~~ be fairly said that Michael Sharpe regards ME/CFS as having ***"no pathology"*** *and sufferers as being the "**undeserving sick of our society and our health service**".*

It seems he is unaware of – or simply dismisses – the evidence of multi-system pathology (illustrations of which are set out above) that has been demonstrated in ME/CFS.

SECTION II

Professor Peter White

White and the Department for Work and Pensions

Peter Denton White is lead adviser on "CFS/ME" to the Department of Work and Pensions. He is involved in the production of the latest DWP Disability Handbook, which includes a section on the entitlement or otherwise of patients with "CFS/ME" to receive State disability benefits. That section has already undergone nine revisions because it was deemed by the ME/CFS charities to be unfit for purpose. Representations from the ME/CFS charities and from the patient community have been consistently disregarded. Whilst the biomedical aspects are largely ignored, inappropriate emphasis is placed on the psychosocial model of the disease, which effectively excludes those with ME/CFS from receiving the benefits on which they depend in order to survive. It is understood that the seemingly insurmountable problems of dealing with the DWP has led to countless suicides by people with ME/CFS, the statistics (according to the ME Association) being one ME/CFS suicide per month in the UK.

The undeniable conflict of interest arising from White's close involvement with the insurance industry and his position within the DWP has caused deep concern to such an extent that Parliamentarians involved in the production of the Gibson Report of 2006 have called for an official inquiry:

"There have been numerous cases where advisors to the DWP have also had consultancy roles in medical insurance companies, particularly UNUMProvident. Given the vested interest private medical insurance companies have in ensuring CFS/ME remains classified as a psychosocial illness, there is blatant conflict of interest here. The Group finds this to be an area for serious concern and recommends a full investigation by the appropriate standards body".

(see "Summary of Key Points in the Report of the Gibson Parliamentary Inquiry" at http://www.meactionuk.org.uk/Summary_of_Key_Points_in_Gibson_Inquiry_report.htm

White and the MRC PACE trials

Together with Michael Sharpe, White is also ~~Principle~~ Principal Investigator in the Medical Research Council's trial known as the PACE trial (Pacing, Activity and Cognitive Behaviour Therapy; a randomised Evaluation) for those with "CFS/ME". The CBT (cognitive behaviour therapy) component of the PACE trial is based on the illness model of fear avoidance, whilst the GET (graded exercise therapy) component is based on the illness model of both deconditioning and exercise avoidance.

This trial has been heavily criticised because it is using an un-validated and outdated case definition that has no predictive value to select patients (the 1991 Oxford criteria, formulated by Wessely School psychiatrists, which expressly includes those with psychiatric disorders but expressly excludes those with neurological disorders, and the MRC has confirmed that it does not accept ME/CFS as a neurological disorder). The trial has also been criticised because it intentionally includes different patient populations from the outset (which will inevitably skew the results). Of further concern is the fact – confirmed by Minister of State Dr Stephen Ladyman -- that doctors are being offered financial incentives to persuade those who do not have ME/CFS to take part in the PACE trial.

No evidence of long-term benefit from CBT/GET

There is no evidence of long-term benefit from CBT/GET: as mentioned above, Wessely himself concedes that it does not help many patients with ME/CFS, and there is further acknowledgement from others:

- at the AACFS International Conference at Cambridge, Massachussets on 10-11 October 1998, Mike Sharpe went on record stating that the benefits of CBT faded with time
- in a personal communication dated 12 October 1998 to Professor Fred Friedberg, Mike Sharpe stated about his often-quoted 1996 study (BMJ 1996:312:22-26) that outcome measures have begun to decline 17 months after treatment termination (quoted in JCFS 1999:5:3/4:149-159)
- on 3 November 2000, Sharpe again confirmed "There is a tendency for the difference between those receiving CBT and those receiving the comparison treatment to diminish with time due to a tendency to relapse in the former" (www.cfs.inform/dk)
- the very modest benefit in only some patients who have undergone CBT has been shown to last for only 6-8 months and *"***observed gains may be transient***"* (Long-term Outcome of Cognitive Behavioural Therapy Versus Relaxation Therapy for Chronic Fatigue Syndrome: A 5-Year Follow-Up Study. Alicia Deale, Trudie Chalder, Simon Wessely et al. Am J Psychiat 2001:158:2038-2042)
- in his Summary of the 6th AACFS International Conference in 2003, Charles Lapp, Associate Clinical Professor, Duke University and Director, Hopkins-Hunter Centre, NC, stated about CBT that Dr Daniel Clauw (who had studied 1,092 patients) found that at 3 months there were modest gains, but at follow-up at 6 and 12 months, those modest gains were lost.
- Wessely himself is on record stating that CBT doesn't work for all: in his Editorial (JAMA 19 September 2001:286:11) he stated that CBT and GET are only "**modestly effective**" and that neither is "**remotely curative**"

This existing knowledge calls into question the scientific rationale for the MRC PACE trial that is led by Peter White and Mike Sharpe.

White and Social Engineering

Like other members of the Wessely School, Peter White has intransigent views about ME/CFS and, with them, is actively involved in social engineering via the deliberate creation of "psychosocial" illness.

The evidence is contained in a book entitled "Biopsychosocial Medicine: An integrated approach to understanding illness" edited by Peter White, Professor of Psychological Medicine at St Bartholomew's and the London, Queen Mary School of Medicine, published by Oxford University Press (2005).

It arose out of a conference held in London in 2002, which was a joint venture between the Novartis (pharmaceutical) Foundation and a company called One-Health, of which Peter White is Chairman. The company was established in order to promote a system of healthcare based on the biopsychosocial model of ill-health.

In his Preface, Peter White states that the conference concentrated on examining the relevance of the biopsychosocial approach to chronic "medically unexplained" symptoms, which include Chronic Fatigue Syndrome.

Peter White states that the book was written because **"some people believe that medicine is currently travelling up a 'blind alley' (and) this 'blind alley' is the biomedical approach to healthcare. The biomedical model assumes that ill-health and disability is directly caused by diseases and their pathological processes (but) there is an alternative approach -- the biopsychosocial approach is one that incorporates thoughts, feelings, behaviour, their social context and their interactions with pathophysiology".**

Many people believe it is a retrograde step to reject the hard-earned scientific evidence gained over centuries that ill-health is directly caused by disease and its pathological processes; further, they reject the notion that the correct approach to healthcare should be the psychosocial one, in which "aberrant" thoughts, feelings and behaviour can be "modified" by the Wessely School's own brand of cognitive behavioural therapy with graded exercise (CBT/GET), resulting in restoration of health and productivity.

For more information on social engineering by the Wessely School, and for quotations from chapter 12 of White's book, see http:// www.meactionuk.org.uk/Proof_Positive.htm

White and Government Policy

White and Sharpe also collaborated in a Government Policy Document that was released with little publicity in 2006.

To be added to the reports that fail the ME/CFS community is the new Guideline (now a published Policy Document) from NHS Plus for the Department of Health that will have a devastating impact upon those with ME/CFS who are of working age ("**Occupational Aspects of the Management of Chronic Fatigue Syndrome: a National Guideline**" DH Publication 2006/273539).

The External Assessors for the National Guideline were psychiatrists Professors Michael Sharpe and Peter White, who both believe that "CFS/ME" is a behavioural disorder.

Under "Conflicts of interest", the NHS Plus Guideline states: "none declared", yet the two external assessors (Sharpe and White) are long-time medical advisers to the insurance industry and White does consultancy work for the Department for Work and Pensions, so failure to declare such obvious conflicts of interest would seem to be a serious matter.

Also of concern is that the searches upon which so much reliance is placed are limited to those that will deliver the desired outcome: "**Due to time and resource limitations, the "grey literature" on CFS** (*do they mean the biomedical literature? ---MW*) **was not comprehensively searched. The two**

external assessors are experts in the field of CFS and they indicated that they were content that all relevant research had been identified in the review".

Unsurprisingly, this National Guideline states: "**In the past 20 years, the medical profession has increasingly come to recognise that the symptoms of individuals with CFS are not readily explained by recognisable organic disease"**.

It concludes that the two treatments for which there is the greatest weight of evidence are CBT and GET and its "**Key priority for implementation**" states: "**Ill health retirement should be deferred until CBT/GET has been explored".**

The timing of the appearance of this Policy Document to coincide with the publication of the heavily criticised draft Guideline on "CFS/ME" by the National Institute for Health and Clinical Excellence (NICE) seems to indicate a co-ordinated tactical strategy by the psychiatric lobby to achieve its aim of widespread implementation of psychotherapy for patients with "CFS/ME" via national guidelines.

White and Medical Education

Together with Anthony Clare, Professor of Clinical Psychiatry at Trinity College, Dublin, Peter White contributed the section on Psychological Medicine in the medical textbook that is likely to be on the desk of every GP in the UK as it won the 'Highly Commended' British Medical Association Award (Clinical Medicine: Kumar and Clark, 2004, 5th edition: published by Saunders: ISBN 0 7020 25798).

It is promoted as "**one of the most highly respected textbooks of medicine in the world. It is used by medical students and practising doctors, as well as by many other health professionals. It has been translated into several languages**". One of the editors is Parveen Kumar, Professor of Clinical Medical Education at Barts and The London, Queen Mary School of Medicine (ie. the same institution as Peter White).

The entry for Myalgic Encephalomyelitis directs the reader to the entry for CFS, which in turn directs the reader to Section 21 (Psychological Medicine) where CFS/ME is listed under "Functional or Psychosomatic Disorders: Medically Unexplained Symptoms". White and Clare assert that the psychiatric classification of these disorders is "**somatoform disorder**", which the authors state were previously known as " **'all in the mind', imaginary and malingering"**.

White and Clare state that "CFS" has two classifications (ie. in the International Classification of Diseases): one as neurasthenia in the psychiatric section and the other as myalgic encephalomyelitis in the neurological section (a statement that is insupportable and which has been repudiated by the WHO); perpetuating factors are said to include inactivity, avoidant behaviour and maladaptive illness beliefs.

Clare himself is known for his disparaging comments about those with ME/CFS: when he chaired the meeting that was convened to formulate the Oxford criteria for "CFS", there was, he said, only one reason for calling the meeting and that was **"a group of patients with a cluster of symptoms who get a lot of publicity**" (BMJ:1990:300:832).

That disparaging comment reflects the apparent denigration that has for so long been the hallmark of Wessely School psychiatrists towards those with ME/CFS and which they have imposed upon countless people who are incredibly sick.

At the Alison Hunter Memorial Foundation International Conference on ME/CFS held in Adelaide, Australia in March 2007, calls were made for an autopsy protocol and an international tissue bank.

Following the tragic death from ME/CFS of a 32 year-old woman in 2005 in the UK, Sophia Mirza, who was forcibly removed from her home under Police presence and who was detained against her will under the Mental Health Act, and the discovery at the autopsy of indisputable evidence of severe inflammation and cell damage in her spinal cord, there is concern that brain and spinal cord tissue which might shed light on the disorder are being lost because pathologists do not appreciate their significance.

Before medical science discovered the aetiology of multiple sclerosis and Parkinson’s Disease, people afflicted with those disorders were subjected to medical dismissal and to charges of hysteria. Those with ME/CFS are suffering the same fate, because even though so much is now known about the pathology, precise causation remains elusive.

Causation will continue to remain elusive as long as Wessely School psychiatrists advise the UK Government that no tests should be performed on those with ME/CFS, especially immunological and neuro-imaging investigations which, when carried out elsewhere, have already delivered evidence of the organic nature of the disorder.

It is the psychiatrists’ stranglehold over what research is permitted to be carried out into ME/CFS and over the with-holding of laboratory investigations in the UK, not patients’ “aberrant illness belief”, that is the true “vicious circle” of ME/CFS.