

## **ME: WHY NO ACCOUNTABILITY?**

### **A synopsis for the UK Parliamentary Inquiry**

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The continued manipulation of the facts surrounding ME is now well-known and has been widely disseminated in the public arena. Also in the public arena is the knowledge that Dr Ian Gibson MP, former Chairman of the House of Commons Science and Technology Select Committee, intends to convene a Parliamentary Inquiry in an attempt to untangle what has become a maze of constructed intrigue in relation to this disorder.

We believe it is time for those who have constructed this unnecessary intrigue to be held publicly accountable and that this accountability must include everyone entrusted with the diagnosis, management and care of patients with ME since the 1980s, especially those whose influence has resulted in the astonishing non-provision of appropriate clinical care for its unfortunate sufferers.

As in the case of Professor Sir Roy Meadow and the matter of sudden infant death, so in the case of Professor Simon Wessely and the matter of ME, medical “certainty” resulting in medical arrogance would seem to be a significant problem. As Professor David Taylor so cogently said in a letter to the Daily Telegraph on 22<sup>nd</sup> July 2005: “even the best experts can be wrong. The answer is that expert witnesses must be treated like any others and be subject to challenge”.

In his article in the Daily Telegraph on 15<sup>th</sup> July 2005 (“How could an expert like Roy Meadow get it so terribly wrong?”), Tom Utley was equally cogent: “There comes a point when a man, however well-meaning, must take responsibility for his conduct and beliefs, and he must be brought to account when his beliefs are shown to be stupid and false, and his conduct causes dreadful suffering to others. Experts who have pet theories like this are a menace”.

What follows is a synopsis of some of the issues that we believe a Parliamentary Inquiry needs to understand and address.

### **The Problem**

The problem is significantly related to one particular disorder (myalgic encephalomyelitis or ME, also listed in the World Health Organisation’s International Classification of Diseases as Chronic Fatigue Syndrome or CFS and as Postviral Fatigue Syndrome or PVFS) and to one particular person, namely psychiatrist Professor Simon Wessely from Guy’s, King’s and St Thomas’ Medical School, London and The Institute of Psychiatry. The problem relates to the sheer extent and degree of his denigration of very sick people suffering from the organic disorder ME/ICD-CFS, denigration that he has perpetrated since 1987 and which is clearly documented, so there can be no dispute or denial of the facts (see: “Denigration by Design?” Volume I (1987-1996); Volume II (1996-1999) Marshall and Williams (pp 488). Bound copies are available at cost price from either The Countess of Mar, House of Lords or from Mrs D. Jones, telephone 0208-554-3832. Some of it is online at: <http://www.btinternet.com/%7Esevereme.group/contents.htm> ).

Also of relevance is Wessely's intransigence in trivialising, dismissing or ignoring the significant published evidence that shows him to be wrong in relation to the nature and management of ME. He is not, however, alone: he leads a group of like-minded psychiatrists that has become colloquially known as the "Wessely School", other prominent members being Professor Michael Sharpe, formerly of Oxford but now at Edinburgh, and Professor Peter White of St Bartholomew's Hospital, London.

Because Wessely is exceptionally influential and has been an adviser to various Government departments, his views (even though unsubstantiated) have been given undue respect throughout the medical fraternity (as in the case of the now notorious Roy Meadow). With unmistakable disparagement, Wessely has disseminated his belief that the disorder affects mostly females (he seems to ignore the fact that all autoimmune disorders have a female preponderance due to hormonal influences); he has flooded the medical literature with his belief that patients with the disorder focus too much on misinterpretation of normal "bodily sensations" and he regards "personality" as a "perpetuating factor". He is known to have been involved with various campaigns of deliberate denigration of ME patients in the British Medical Journal, for example, the "Non-Diseases" poll that was carried out in 2002, which listed ME as a non-disease, giving rise to media headlines such as "When a disease is not a disease" (Metro, 11<sup>th</sup> April 2002) and "Obesity and ME are not diseases, say doctors" (Daily Telegraph, 11<sup>th</sup> April 2002). Wessely is on record as asserting that the disorder should not be "dignified" by its own case definition (see: "Consideration of some issues relating to the published views of psychiatrists of the 'Wessely School' in relation to their belief about the nature, cause and treatment of ME", M. Williams and V. Broke-Smith, March 2000, online at <http://www.meactionuk.org.uk/consideration.htm> ) and that it is simply "learned helplessness" as a result of faulty thought processes and a lack of motivation that results in de-conditioning brought about by lying around. He asserts that ME/ICD-CFS is a psychiatric disorder that should be "managed" by psychiatric interventions, especially cognitive behavioural therapy (CBT), particularly a version formulated by him that includes compulsory graded exercise therapy (GET), even though the evidence is that at best, CBT is of no lasting value and at worst, GET is positively harmful to those with authentic ME (see: "The Severely Affected. Preliminary Report: Action for ME, 28<sup>th</sup> February 2001, which on page 6 states: "Graded exercise was reported to be the treatment that had made most people worse". Note that one of the named authors of this report was Chris Clark, Chief Executive of Action for ME, but see below for Clark's apparent change of mind and his current position of active collaboration with Wessely School psychiatrists in the promotion of GET for those with ME).

Wessely's views are in direct contrast to the now substantial amount of international published research that confirms the organic basis of the disorder (for just some of the issues and references, see [http://www.meactionuk.org.uk/Wesselys\\_Wisdom.htm](http://www.meactionuk.org.uk/Wesselys_Wisdom.htm) ).

This has not deflected Wessely from his obsession to "eradicate" ME and to subsume it within other psychiatric states of "on-going fatigue" that are already classified as "mental or behavioural", nor from his intention formally to have ME re-classified by the World Health Organisation (WHO) as a primary mental disorder: indeed, in about 1999 Wessely successfully effected such a reclassification by supplying information on ME (taken from his own guidelines for GPs) to those at the Institute of Psychiatry WHO Collaborating Centre who produced "The WHO Guide to Mental Health in Primary Care"; he did this knowing that the Guide was intended specifically as a guide to mental (not physical) disorders. It is quite legitimate for a WHO Collaborating Centre to use the WHO title (the IoP had become a

designated Collaborating Centre on mental health issues in 1993 after Wessely joined it), so the incorporation of the initials “WHO” in the Guide’s title implied that the contents of the Guide carried the approval of the WHO, yet such was not the case: unsurprisingly, this resulted in great confusion amongst Ministers of State who were deceived into believing that ME had been reclassified as a mental disorder by the World Health Organisation itself. With the assistance of the WHO headquarters in Geneva, certain individuals within the ME community forced the issuing of an erratum as well as a public retraction by obtaining written confirmation from the WHO that such re-classification was (quote) “at variance with the WHO’s position”, as well as confirmation from the WHO that no disorder could have dual listing in the International Classification of Diseases (a necessary clarification because Wessely asserted and advised that “CFS” had dual listing in the ICD – once in the neurological section and again in the mental and behavioural section). Following a debate in the House of Lords, this clarification eventually resulted in written confirmation from the Minister of Health, Lord Warner, that the UK Department of Health does accept that the correct WHO classification for ME is neurological, not psychiatric.

Professor Sharpe is no less involved in the “eradication” of ME and is on record as advising that patients suffering from this disorder are “undeserving of treatment”, stating: “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” (lecture given in October 1999 hosted by the University of Strathclyde).

Regrettably, there is now evidence that Wessely School views and aims have been adopted whole-heartedly by one of the major ME charities (Action for ME), and for many years there has been evidence that the other major ME charity (The ME Association) has also been compliant with certain of the Wessely School aims (specifically the view published in its magazine that ME might indeed be a psychiatric disorder – see below). This presents potential problems for the ME community as there is evidence that the influence of the Wessely School has permeated the All Party Parliamentary Group on ME (APPGME), for which these charities have succeeded in providing the secretariat and over which they have undisputed influence. Despite the inevitable denials, the evidence speaks for itself and has been collated by Paul Davis of RiME (Research into ME), who has also collated many moving case histories (see: <http://www.erythos.com/RiME/> ).

Wessely’s role in all this cannot be denied: see “The Mental Health Movement: Persecution of Patients? A Consideration of the Role of Professor Simon Wessely and Other Members of The “Wessely School” in the Perception of Myalgic Encephalomyelitis (ME) in the UK”. M. Hooper et al, December 2003; online at [http://www.meactionuk.org.uk/SELECT\\_CTTEE\\_FINAL\\_VERSION.htm](http://www.meactionuk.org.uk/SELECT_CTTEE_FINAL_VERSION.htm)

## **The facts**

ME has been documented in the medical literature for over 60 years. It has been formally recognised and classified by the World Health Organisation as a **neurological disorder** since 1969. It used to be called both “atypical polio” and “atypical multiple sclerosis”. Other, non-specific, fatigue states are currently classified by the WHO as **mental and behavioural disorders**. Those who have a psychiatric disorder are ineligible for certain state benefits and for permanent health insurance payments.

Because there are two names in common use for the same disorder (ME and CFS), international non-psychiatric studies referring to CFS are very likely to be describing those with ME, and the identified biomarkers of an organic pathology in CFS are likely to be referring to ME, but care is needed because the term “CFS” has been highjacked by Wessely School psychiatrists to mean what they want it to mean, ie. a state of chronic unexplained “fatigue” that is a somatoform or “functional” (psychiatric) disorder in which emotional distress is expressed via physical symptoms.

For years, these psychiatrists have asserted that “ME” is simply one end of a continuum of “medically unexplained fatigue” or “tiredness” and, in extraordinary defiance of the published evidence, they describe it as a disorder with no pathology, as Professor Sharpe asserted in his inaugural lecture given in Edinburgh on 12<sup>th</sup> May 2005 (see [http://www.meactionuk.org.uk/Evidence-based\\_Psychiatry.htm](http://www.meactionuk.org.uk/Evidence-based_Psychiatry.htm) ). These psychiatrists have subsumed ME within their own definition of “CFS”. This financially expedient but unscientific “lumping together” of all cases of “unexplained fatigue” has hindered medical progress and understanding of the quite distinct and identifiable disorder ME/ICD-CFS; as a result, confusion is rife within the medical fraternity in respect of case definition, criteria, diagnosis, management, and appropriate investigation and service provision. As always when there is a division of medical opinion, it is the patient who is transformed into the unwilling victim.

In both the psychiatrists’ own 1991 (Oxford) case definition and in the 1994 US Centres for Disease Control definition, “CFS” has no physical signs, whereas ME cannot be diagnosed without physical (neurological) signs, yet the psychiatrists persistently and illogically refer to the disorder as “CFS/ME”.

Importantly, there is increasing published evidence that ME/ICD-CFS (ie. non-psychiatric “CFS”) may be either virally or chemically induced, not least the recent findings by Kerr and Holgate et al from the UK (see “Gene expression in peripheral blood mononuclear cells from patients with chronic fatigue syndrome”. N Kaushik, ST Holgate, JR Kerr et al. J Clin Pathol 2005;58:826-832). These researchers have demonstrated reproducible alterations in gene regulation in ME/ICD-CFS, notably in genes involved with immune, neuronal and mitochondrial function, observing that this effect is known to be linked to organophosphate exposure. Significantly, the neuronal component is associated with central nervous system hypomyelination and encephalopathy. Of practical significance is the fact that NTE (neuropathy target esterase) is inhibited by several OP pesticides, lubricants and the now ubiquitous plasticisers (as well as chemical warfare agents), leading to OP-induced delayed neuropathy in people. The ramifications of this are monumental: these include the cost implications for the NHS of providing suitable medical care and respite services and for the Government that granted product licences for such chemicals, as well as for the medical insurance industry to whom Wessely School psychiatrists are advisers (see: [www.meactionuk.org.uk/Notes\\_on\\_the\\_Insurance\\_issue\\_in\\_ME.htm](http://www.meactionuk.org.uk/Notes_on_the_Insurance_issue_in_ME.htm) ).

There is now evidence that ME/ICD-CFS is likely to be an autoimmune disorder at cell membrane level: on 9<sup>th</sup> February 2002 Professor Kenny De Meirleir of Brussels wrote: “For me as a clinician, “CFS” is no longer a mystery but a treatable auto-immune disorder. We have given it its place between lupus, diabetes Type 1 and multiple sclerosis. We explain all the symptoms of “CFS”, which we now call “AFS” (autoimmune fatigue syndrome) by cellular and immune abnormalities” (private communication, but see the book “Chronic

Fatigue Syndrome: a biological approach” edited by Patrick Englebienne and Kenny De Meirleir, CRC Press 2002, pp291).

There is also evidence that the vasculature is uniquely affected (see: [http://www.meactionuk.org.uk/A\\_FINAL\\_FAREWELL\\_TO\\_THE\\_PSYCHIATRIC\\_FALL\\_ACY.htm](http://www.meactionuk.org.uk/A_FINAL_FAREWELL_TO_THE_PSYCHIATRIC_FALL_ACY.htm) ) thus consequently affecting the tissues and organs supplied by that vasculature, and that many patients currently diagnosed with the disorder could have an inflammatory condition that would be worsened by exercise, since incremental exercise challenge induces a prolonged and accentuated oxidative stress that might well account for the post-exercise symptoms in such patients.

Of crucial significance is the fact that it has been shown by US clinicians and researchers that patients with the disorder are in fact in cardiac failure, not through occlusion of the coronary vessels but because of mitochondrial dysfunction that affects muscles, including the cardiac muscle (see: [http://www.meactionuk.org.uk/The\\_MRC\\_Profits\\_before\\_Patients.htm](http://www.meactionuk.org.uk/The_MRC_Profits_before_Patients.htm) ).

Despite the ever-increasing international evidence of serious organic pathology, and despite numerous petitions from patients and their despairing families, it seems that no Government funding into the organic basis of ME is planned in the UK, yet in excess of £11.1 million has recently been granted for “Centres of excellence” for what Wessely School psychiatrists refer to as “CFS/ME” (see below) which will offer only psychiatric regimes, and for yet more psychiatric studies funded by the Medical Research Council (MRC) that are designed to show that psychiatric interventions such as cognitive behavioural therapy (described in the 2002 report for the Chief Medical Officer [CMO] as “a tool for constructively modifying attitude and behaviour”), together with forced graded exercise, are the management regimes of choice.

Perhaps it is coincidental that Wessely is a member of the Supervisory Board of the commercial company (PRISMA) that is now delivering such “rehabilitation” regimes to the NHS for those with “CFS” (see: “What is ME? What is CFS? Information for Clinicians and Lawyers”. M. Hooper et al, December 2001; available online at: [http://www.meactionuk.org.uk/What\\_Is\\_ME\\_What\\_Is\\_CFS.htm](http://www.meactionuk.org.uk/What_Is_ME_What_Is_CFS.htm) and see also: “Functional Symptoms and Syndromes: Recent Developments”. Michael Sharpe. In: Trends in Health and Disability: UNUM Provident, 2002).

ME is a multi-system disorder of extraordinarily incapacitating dimensions from which complete recovery is unlikely. It can be a devastating condition, with some patients being unable to speak or swallow and needing to be tube-fed for years; at least 25% of sufferers are severely affected, yet patients are accused of malingering. On the advice of Wessely School psychiatrists, state benefits are refused or withdrawn, even in cases of ME where they have been awarded for life. Many with ME commit suicide: in the UK, figures are said to run at one ME suicide per month. This is not because patients are psychiatrically ill: it is because they are completely unable to look after themselves and are too sick to survive without the necessary support, both medical and financial.

The hall-mark of ME (post-exertional exhaustion with incapacitating malaise) is largely ignored by Wessely School psychiatrists, even though it does not equate in any way with “de-conditioning” as these psychiatrists are wont to claim. Just focusing, as they do, on “unexplained fatigue” and “aberrant illness beliefs” and “personality” as a perpetuating factor, with the determined dismissal or ignoring of other devastating and life-wrecking

problems such as vertigo and balance problems, severe myalgia, neuro-muscular incoordination, cardio-pulmonary problems, liver and gut problems, pancreatic problems, hair loss, mouth ulcers, intolerance to everyday household chemicals and foods, and to medicinal drugs, especially those acting on the central nervous system (a feature that in May 1994 at the Dublin International Symposium on the disorder held under the auspices of The Ramsay Society and The World Federation of Neurology, the internationally renowned neurologist Professor Charles Poser of Harvard described as pathognomonic of the disorder) and the invariably present (and measurable) parasympathetic neuropathy is a significant part of the problem.

The Opinion of a Leading Queen's Counsel from the House of Lords has been obtained by the Countess of Mar, advising that, from the evidence before him, there is very real doubt if the psychiatric approach of Professor Simon Wessely towards ME/ICD-CFS accords with good and safe medical practice, and that there *must* be an urgent independent inquiry.

If such an inquiry were to be convened, it would be imperative that panel members should provide evidence of their independence and impartiality, and that it be chaired by a prominent civil rights lawyer: in the UK, patients with ME continue to be denied their civil rights because since the 1980s they have never had appropriate medical care that is accorded to sufferers from other organic diseases such as multiple sclerosis and lupus, with both of which there is considerable clinical overlap. As far as the transparent independence of the Inquiry panel members is concerned, it is important to recall that in 2002 the UK ME community was deceived by the MRC when its RAG (Research Advisory Group) was set up to advise on the direction of future research into "CFS/ME" to much publicity that the RAG members were "fresh and independent" to the issue of ME, when this was not the case at all: some of the members had previously co-authored published papers with both Wessely and Sharpe, and in a letter dated 15<sup>th</sup> July 2002, Professor Sir George Radda, then Chief Executive of the MRC, was compelled to acknowledge this.

### **The issues**

We believe that the core issues of the ME "problem" that any Inquiry must address are widely acknowledged to be:

**Heterogeneity**: the lack of progress and provision would seem to come down to the confusion by Wessely School psychiatrists of ME with "chronic fatigue", and their determination to convince Government and the medical insurance industry (with which their involvement is now well-known and well-documented) that there is no such disorder as "ME" except in the aberrant beliefs of sufferers and in the mind of those few naïve and misguided doctors who support them. The repeated insistence by these psychiatrists *and* by the medical advisers to the two major adult ME patients' charities that there is no need for sub-grouping of the heterogeneous label "CFS" would seem to defy rationality, if not to reflect vested interests, and flies in the face of calls from acknowledged international (non-psychiatrist) experts that such sub-grouping is an urgent priority (see Professor Leonard Jason's paper entitled "Chronic Fatigue Syndrome: The Need for Sub-types" in *Neuropsychology Review* 2005:15:1:29-58). Specifically, whilst Deputy Chair of the CMO's Working Group on "CFS/ME", Professor Anthony Pinching advised that sub-grouping was unnecessary and "may be considered a matter of semantics and personal philosophy" and, indefensibly, this view is contained in the final Report of January 2002 on "CFS/ME" for the Chief Medical Officer.



**The malign influence of Wessely School psychiatrists:** the extent of the influence of this group of psychiatrists is phenomenal: it extends not only to Government and its Departments of State but as noted above, to the medical insurance industry, as well as being rampant throughout the NHS and medical research establishments such as the MRC; it seems to encompass many medical journals and much of the media (including the BBC). Also as noted above, of concern is that this malign influence has now extended to the APPGME and to certain of the ME patients' charities, one of which (Action for ME) is actively colluding with the psychiatric studies being undertaken by Wessely School psychiatrists that are funded by the MRC. This collusion has given rise to substantial documented concern, primarily because if such Trials are to include those with authentic ME, the Trials may be dangerous because of the evidence that patients may already be in significant cardiac failure, so participation in the Trials may therefore result in irreversible deterioration. No compensation would be payable for such deterioration, since participants are likely to be required to sign a consent form containing a no-liability clause. That potential dangers exist has been highlighted by Dr Charles Shepherd, medical adviser to the ME Association, who more than once has drawn attention to the fact that doctors have now been warned by their insurance companies that any form of exercise treatment needs to be prescribed with just as much care as drug treatments, otherwise they could be taken to court (see: Perspectives Medical & Welfare Bulletin, issue number 2, Spring 2001, page 8).

A second point is that the MRC Trials are a gross misuse of tax-payers' money. Given the extent of the international evidence of serious organic pathology in ME/ICD-CFS, most recently the findings of Kerr and Holgate et al of acquired and reproducible abnormalities in genes involved with immune, neuronal and mitochondrial function in the disorder (mentioned above -- for a short consideration of this paper, see: [http://www.meactionuk.org.uk/ME\\_Organic\\_or\\_Psychiatric\\_-\\_Decision\\_Time.htm](http://www.meactionuk.org.uk/ME_Organic_or_Psychiatric_-_Decision_Time.htm) ), the question has to be asked why such vast sums have been allocated to Wessely School psychiatrists, especially given that these psychiatrists insist on "evidence-based medicine" (ie. abnormal results of laboratory tests, when they themselves dictate that such tests must not be carried out on ME/ICD-CFS patients) before they will permit ME/ICD-CFS to be "validated" as a "legitimate" disease, even though no psychiatric diagnosis can be thus validated. This being so, why is such undue weight and importance accorded to the pronouncements of psychiatrists? Is it because such influence emanates from the chemical, pharmaceutical and medical insurance industries, whose life-blood is profit? (for a summary of some of the evidence taken by the House of Commons Health Select Committee of concerns about this aspect, see "An Inquiry by the UK House of Commons Health Select Committee into the Influence of the Pharmaceutical Industry". M.Williams. 28<sup>th</sup> October 2004, available online at [http://www.meactionuk.org.uk/HoC\\_Select\\_Cttee\\_Inquiry\\_into\\_Pharma.htm](http://www.meactionuk.org.uk/HoC_Select_Cttee_Inquiry_into_Pharma.htm) ).

### **Some consequences of this influence:**

1. An indisputable consequence of Wessely School influence is the continued patronising of patients and the downplaying of the seriousness of the disorder by the use of the contrived term "CFS/ME", a label carefully crafted to placate patients by including the term "ME", this being the term most favoured by patients, who universally abhor the ludicrous and overly-simplistic term "chronic fatigue syndrome". According to Wessely, to refer to it as "CFS/ME" is "constructive labelling", which he describes as "a compromise strategy: it would mean treating chronic fatigue syndrome as a legitimate illness while gradually expanding understanding of the condition to incorporate the psychological 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" (see: "Managing patients with inexplicable health problems". B. Fischhoff, Simon Wessely: BMJ 2003:326:595-597).

2. Perhaps the most serious consequence of this psychiatric influence is the rigorous rejection by the Establishment of the international published scientific evidence that has demonstrated unequivocally that ME/ICD-CFS is a complex neuro-immuno-endocrine and vascular disorder that has an extremely high SIP (Sickness Impact Profile): world expert Dr Dan Peterson from the US is on record as stating: "In my experience, it is one of the most disabling diseases that I care for, far exceeding HIV disease except in the terminal stages". Australian research has found that those with this disorder have more dysfunction than those with multiple sclerosis and that in ME/ICD-CFS the degree of impairment is more extreme than in end-stage renal disease and heart disease. American research has found that the quality of life is particularly and uniquely disrupted in ME/ICD-CFS, with multiple losses including jobs, relationships, financial security, future plans, daily routines and hobbies. Activity is reduced to basic survival needs. According to US statistics provided by the Centres for Disease Control, only 4% of patients had full remission (not recovery) at 24 months but in the UK, in defiance of the robust scientific evidence, Ministers and the MRC seem to believe what Wessely advises them to believe (for individual references, see: <http://www.meactionuk.org.uk/consideration.htm> ).

3. Equally important is the rigorous refusal to permit patients with ME/ICD-CFS to be suitably investigated, especially by nuclear medicine imaging and immune profiling (which are two areas that have revealed cardinal evidence of an organic pathoetiology). To the incredulity of the ME community, whilst Deputy Chair of the CMO's Working Group on "CFS/ME", Professor Anthony Pinching pre-empted the conclusions of the CMO's Report by publishing his views (see: "Chronic Fatigue Syndrome". Anthony J. Pinching. Prescribers' Journal 2000:40:2:99-106) in which he unequivocally stated: "CFS is not related to ongoing exertion" and, significantly, that what he chose to call "over-investigation" can be harmful, causing patients "to seek abnormal test results to validate their illness". True to the Wessely School paradigm, Pinching stated: "It is helpful to establish with the patient a way of *thinking* about the illness" and he concluded: "The essence of treatment is activity management". Even in the current (Summer 2005) magazine of the UK ME Association, the medical adviser, Dr Charles Shepherd, once again stated his resistance to investigations such as the RNase L immunoassay test (RNase L is an important anti-viral pathway that has been shown to be abnormal in ME/ICD-CFS), and he continues to argue against the Canadian Clinical Guidelines that recommend such a test. It is a matter of record that Shepherd is an active member of HealthWatch, a campaigning organisation whose own literature --- despite its Officers' vociferous denials --- clearly promotes the pharmaceutical industry and that has in the past accepted money from both the pharmaceutical and medical insurance industries; Simon Wessely is also listed as a "leading member". It is undeniable that Wessely, Pinching and Shepherd have argued strongly against full investigation of patients with ME and have advised that only the most basic screening tests should be performed; indeed, in the 1996 Joint Royal Colleges' Report on "CFS" (CR54: RCP), Wessely et al advised that *no* tests should be performed to confirm the diagnosis and even went so far as to state that the observed immunological abnormalities should not (quote) "deflect the clinician from the (psychiatric) approach and should not focus attention towards a search for an 'organic' cause". If a single sound-byte were required of Wessely School dogma, there could be no more explicit encapsulation than that statement. In comparison, in July 2001 the American Medical Association issued a statement confirming that 90% of ME/ICD-CFS patients will



have normal results on basic testing: why, therefore, are Wessely, Pinching and Shepherd advising only basic screening, when they must know that the result will be quite normal? Such a stance by Wessely, Pinching and Shepherd does not seem to equate with commitment to advancing medical understanding of the disorder, but when Professor Hooper et al brought this to public attention (together with Wessely and Shepherd's membership of HealthWatch, an interest that neither had declared), Shepherd immediately commenced a sustained and immoderate public attack on Hooper that included letters and emails to Hooper and to the Vice Chancellor of his University, demanding "disciplinary" action be taken. Shepherd's own innumerable letters were followed up by threatening letters from lawyers acting for HealthWatch. For the record, Hooper's University quickly concluded that no action was necessary because there was no case to answer. Shepherd's animosity towards Hooper is well-known: just one example is the fact that Shepherd did his utmost to prevent Professor Hooper from giving an invited address to the Scottish Parliament.

4. A further and most disturbing effect of Wessely School influence has been on the ME charities themselves, whose charter requires them to act in the best interests of those with ME. In the early days of their foundation, both charities produced excellent leaflets and information for both patients and physicians but gradually, possibly as a result of Wessely School influence, things changed and turned sour. In 1997, for example, members of the ME ForT campaign (Fighting for Truth) who produced a petition of over 14,000 signatures calling for the withdrawal of the 1996 Joint Royal Colleges' report --- a petition that was presented in the House of Lords by the Countess of Mar --- were threatened with legal action by the ME Association. In 2001, the ME Association's revised Guidelines that members were asked to pass on to their health professionals was a document that (a) denied ME as the condition recognised by the late Dr Melvin Ramsay and as included in the ICD; (b) blurred the distinction between ME and chronic "fatigue"; (c) blocked the very investigations that many patients sought; (d) dismissed the continuing deterioration that occurs in ME and (e) advocated management by GPs with no further education or training about the disorder: in other words, this was a betrayal of ME patients' best interests and welfare. In October 2002, a male representative of the ME Association went on record as stating: "The ME Association's opinion is that it has been shown that people who want to get better do, and people who have negative expectations do not get better". In its Research & Scientific Bulletin, issue number 9, Winter 2002, the ME Association formally backed the Wessely School belief that ME is a functional somatic syndrome (ie. a primary psychiatric disorder): on page 4 it reproduced some of the text of its application for funding for a project entitled "How best to conduct research in ME/CFS" and the application stated: "These problems are not unique to CFS. There are a number of these so-called functional syndromes (including) irritable bowel syndrome, fibromyalgia, pre-menstrual syndrome, dyslexia and autism. None have a defined pathology or demonstrable biochemical changes, and arguments continue as to their hysterical origin". In November 2002, in an article entitled "The saboteurs of ME research", the ME Association launched what seemed to be a public attack on Professor Hooper and his colleagues (who had placed in the public domain their concerns about the MRC's Report on the direction of future research into ME/ICD-CFS that favoured the Wessely School views): in its Research and Scientific Bulletin issue number 10 (note that the November 2002 and the Spring issue 2003 are *both* designated "Issue No 10), a Dr Margaret Macdonald (the ME Association's "Research Manager") wrote: "The name of the disease is NOT of any importance" and "The conviction that ME is a 'physical disease' and not a 'mental disease' is another meaningless 'opinion', showing those who insist it is the truth to be ignorant and bigoted. We do not know whether ME is psychological". On page 16 of the ME Association's Research and Scientific Bulletin of November 2002, the same Dr

Macdonald published her view that those who challenge the psychiatric view are “troublemakers”. In February 2003, for those seeking further information and contacts, the ME Association had a link on its website directly to Wessely’s website at King’s College Hospital. In May 2003, an item on the ME Association Research website was unequivocal: “Is ME a mental or physical illness? The ME Association knows there are ME patients who are radically opposed to any suggestion that ME is ‘all in the mind’. The ME Association holds no opinion on this”. In June 2003, the British Medical Journal carried an item about the ME Association, noting that it had “adopted some of the arguments of that section of the medical establishment that believes the condition to be a somatisation disorder”. As recently as January 2005, the ME Association’s medical adviser (Dr Charles Shepherd) was of the opinion that there is “no need” to seek research on the issue of a diagnostic marker for ME: this would seem to be at variance with his more supportive statements and it may reflect profound internal divisions with the Association’s leadership. Such actions as those listed above do not accord with the founding aims of the ME Association and have caused deep and lasting concern to many of its members. There are, however, presently welcome signs of a more robust opposition to the psychiatric stranglehold being adopted by the current Chairman and of the ME Association returning to its roots.

As for Action for ME (AfME), on 1<sup>st</sup> September 1993 in a disturbing development, the ME Action Campaign (as it used to be known) changed its name and logo to “Action for ME and chronic **fatigue**”, but following complaints to the Charity Commission, it later removed the words “chronic **fatigue**”. During the various campaigns of denigration of ME/ICD-CFS patients that were run by the British Medical Journal, it is understood that AfME made no submission to correct the misrepresentation about and mockery of ME/ICD-CFS patients. Without doubt, Chris Clark (Chief Executive of AfME) is not an admirer of Professor Hooper: in August 2001 Clark gave a talk to the Sunderland and Tyneside ME Support Group which Hooper attended and at which he took careful notes. During his talk, Clark was quite happy with the confusion surrounding the terminology and insisted that there was no value in debating the best term to describe ME – he maintained the various names could be used interchangeably (including chronic “fatigue”). He expressed his hopes about what might be included in the then-awaited CMO’s Working Group report and listed the kind of treatment that he was looking for: notably, this included graded exercise and cognitive behavioural therapy. Clark made no mention of any of the biochemical, immunological or endocrinological studies that had been widely reported and seemed openly committed to the psychiatric model of ME. On 21<sup>st</sup> August 2001 Hooper published his notes of Clark’s talk, which were immediately refuted by AfME, followed on 17<sup>th</sup> September 2001 AfME by a detailed rebuttal of Hooper’s notes. Hooper, however, stood his ground and declined to withdraw them. Almost two years later, following Hooper’s critique of the MRC RAG strategy report, on 4<sup>th</sup> February 2003 Chris Clark published a statement in which he said: “We do not subscribe to the views expressed in some forums that the MRC expert group was dominated by a “psychiatric school” and regard a recent attack on named individuals included in a paper by Hooper, Marshall and Williams as disgraceful”, to which Hooper responded as follows: “In response to the Statement put out by Chris Clark on behalf of Action for ME, Hooper et al are happy to let the ME community judge the accuracy and value of their respective responses to the MRC RAG draft document of 17<sup>th</sup> December 2002. Hooper et al believe that there is nothing “disgraceful” in drawing attention to important and relevant factual issues which are the outstanding concerns of the ME community and which are too often neglected or distorted by those intent upon establishing a counter-view of the scientific evidence about this significant organic disorder”.

There is much unrest about AfME's close liaison with the Wessely School psychiatrists: that such liaison exists was spelled out by Michael Sharpe in his report entitled "Functional Symptoms and Syndromes: Recent Developments" in which he included "CFS" (for the reference, see above). Sharpe was unambiguous about AfME's position: "Benefits and medical services need to be more rehabilitation orientated. One of the major patient charities (Action for ME) is aligning itself with a more evidence-based approach. If this convergence of rehabilitation oriented clinicians and a patient advocacy group is successful, there could be very positive implications for insurers".

It is of interest that it is Professor Anthony Pinching who is AfME's Principal Medical Adviser. Currently, AfME takes the view that as a charity, it should not raise money to fund research into ME. Quite certainly, AfME is not only supporting but is closely involved with the MRC psychiatric trials, as well as the new "Centres of excellence" that will deliver CBT and GET. It is of note that it is Professor Pinching who is Chairman of the Investment Steering Group that devised the process and criteria for the setting up of these Centres and who allocated the funds. Pinching is also lead adviser for the Department of Health on "CFS/ME".

**The manipulation of the scientific process:** the MRC current PACE trials on "CFS/ME" run by psychiatrists of the Wessely School are selecting participants by means of the psychiatrists' own 1991 "Oxford" criteria for "CFS", yet those 1991 criteria expressly include those with psychiatric fatigue and expressly exclude those with neurological disorders (and therefore those with neurological signs such as occur in ME). Further, the MRC trials will include those with fibromyalgia, a distinct disorder with different laboratory findings that is separately classified in the ICD at M79, with ME being classified at G93.3 (for some of the laboratory differences between fibromyalgia and ME/ICD-CFS, see: "Science or Semantics?" online at <http://listserv.nodak.edu/cgi-bin/wa.exe?A2=ind0412b&L=co-cure&F=&S=&P=488> ). The MRC Trial Identifier is clear; at paragraph 3.6 it states: "We chose these broad criteria in order to enhance recruitment", which seems a remarkably unscientific reason. Despite written requests to the MRC, no-one has explained how the intentional inclusion of different disorders will be of benefit to sufferers from a specific disorder such as ME/ICD-CFS, but these MRC trials (the design of which has already been criticised) will undoubtedly catch many thousands with psychiatric fatigue, and this may inevitably be used as "evidence" to support the current Government "policy" to deal with troublesome and costly disorders by the implementation of cognitive behavioural therapy throughout the NHS. To intentionally include from the outset different disorders in these trials but to claim that the results will relate to "CFS/ME" would seem to be a blatant abuse of the scientific process. In reality, if people with authentic ME are included as the psychiatrists intend, as noted above, these MRC trials of exercise "therapy" may endanger participants' lives because of the well-documented adverse effects of such exercise on the cardiac and other muscular problems that are known to prevail in ME.

**The continued forcible removal of both young people and adults from their home:** for desperately sick people with ME/ICD-CFS to be removed by means of a Court Order and under Police escort from their own home and locked up in "secure" units at the instigation of psychiatrists is a national scandal, but it has, according to Consultant Paediatrician Dr Nigel Sleight, become an "epidemic".

**Conclusion**

The human rights of people suffering from ME/ICD-CFS are being conspicuously denied without any justification whatever, and an independent inquiry is required as a matter of extreme urgency. It is completely unacceptable that the unsubstantiated personal beliefs of a few immensely influential psychiatrists with indisputable vested interests should continue to indoctrinate UK medicine and the media regarding ME/ICD-CFS and that these psychiatrists should be permitted to impose inappropriate management regimes upon sick and defenceless patients on pain of having their benefits withdrawn if they do not comply, a situation that has continued unabated for far too long.

The matter of potential scientific misconduct by Wessely in his selection and presentation of the available evidence relating to ME was first raised in public in 1994 (see: *The CFIDS Chronicle*, Spring 1994:14-18). It is now time that he and his like-minded colleagues be held accountable for their published beliefs about ME and for the consequences of those beliefs upon many thousands of sick people suffering from a well-established organic disease, including the prevention of informed medical understanding and the loss of the provision of appropriate and compassionate care.