

**WITHOUT PREJUDICE      FOR INFORMATION**

**CONCEPTS OF ACCOUNTABILITY ?**

Following the release of the Montague / Hooper document of 1<sup>st</sup> May 2001 entitled Concerns about the forthcoming UK Chief Medical Officer's Report on Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS), notably the intention to advise clinicians that only limited investigations are necessary, the Medical Director of the UK ME Association (Dr Charles Shepherd) continues to press for a formal investigation by the Vice Chancellor of the University of Sunderland into the "conduct" of Professor Hooper. The present document outlines some of the background which lies behind the writing of the original Montague / Hooper paper.

This present document should be read in conjunction with the amended original Montague / Hooper paper (which was amended on 30 July 2001 in order to clarify issues raised by Dr Shepherd and by HealthWatch) and with the Response to criticisms about their paper by Montague and Hooper also dated 30 July 2001.

Sally Montague  
Malcolm Hooper  
and associates

25 August 2001

## CONCEPTS OF ACCOUNTABILITY ?

### FOREWORD

On 1<sup>st</sup> May 2001 Professor Malcolm Hooper and Sally Montague produced a paper entitled “Concerns about the forthcoming UK Chief Medical Officer’s Report on Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS), notably the intention to advise clinicians that only limited investigations are necessary”.

As is customary, Professor Hooper’s mail address at the University of Sunderland was provided as the contact for correspondence. ‘Sally Montague’ is a composite pseudonym for a group of medical scientists, researchers, clinicians and others, some of whom are themselves severely affected by ME and who for professional reasons and reasons of ill-health do not at present wish to reveal their identity. The document was not submitted to any journal for publication and no deceit took place.

The release of the original Montague/Hooper document brought forth poignant worldwide gratitude from researchers and patients alike; it also brought forth an immediate barrage of letters which essentially amounted to a threatening campaign against the authors; these letters were written almost entirely by Dr Charles Shepherd, Medical Director of the UK ME Association and member of the CMO’s Key Group charged with preparing the forthcoming report, whose membership of HealthWatch was mentioned by Montague and Hooper in their paper. On his own written admission Dr Shepherd caused the Chairman of HealthWatch (solicitor Malcolm Brahams of Messrs David Wineman, Craven House, 121 Kingsway, London WC2B 6NX) to send official letters to Professor Hooper.

The issues raised by Dr Shepherd and Malcolm Brahams were addressed in a written response to the solicitors on 30 July 2001 by Montague and Hooper. Dr Shepherd, however, refuses to accept the evidence and clarification provided in the authors’ response. Because of this, and because Dr Shepherd’s campaign shows no sign of abating, Montague and Hooper and their associates have set out in more detail in this present document some of the background to their original paper.

The authors would like to confirm again that they did not put their original document on the internet. No responsibility is accepted by the authors for any amendments or alterations which have not been authorised by them. The authors have no responsibility for or connection with any website. The authors point out that any criticisms levelled against their paper must relate to their authorised document and to no other.

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## **The need for the Montague / Hooper document**

Montague and Hooper and their associates are aware that the matters addressed in their document are of substantial public interest. Specifically they are concerned that in the UK Chief Medical Officer's forthcoming Report on Chronic Fatigue Syndrome / Myalgic Encephalomyelitis, advice is to be given to UK clinicians that CFS and ME are entirely synonymous and that in cases of CFS/ME, only limited investigations are necessary. Such advice may have long-term consequences for many very sick people and their families who have already suffered for too long from what has been called by the Bristol-based ME charity Westcare the "psychiatric fallacy".

Since the late 1980s, the use by some UK researchers of heterogeneous patient cohorts has hampered progress in understanding this group of complex disorders. There has been too much reliance placed upon the results of studies which have used different case definitions of chronic fatigue syndrome (CFS) whilst not even looking at those with ME, resulting in the invalid comparison of contradictory research findings, and there has been a lack of standardised laboratory tests (1).

In light of these problems, Montague and Hooper and their associates believe it is time to challenge advice that only limited investigations are necessary in CFS/ME.

## **Brief historical summary**

Crucial to understanding the complexity which underlies the entire problem is the question of case definition and related nomenclature.

Myalgic encephalomyelitis (ME) has been documented in the medical literature since 1934 (2); the Wallis description was in 1957 (3); Sir Donald Acheson's (a former UK Chief Medical Officer) major review of ME was in 1959 (4); the disorder used to be known as "atypical poliomyelitis" but was given the term benign myalgic encephalomyelitis in 1956 (5); in 1962 the distinguished neurologist Lord Brain included ME in the standard textbook of neurology (6); the Royal Society of Medicine held a symposium on ME on 7 April 1978, at which ME was accepted as a distinct entity; the symposium proceedings were published in The Postgraduate Medical Journal in November 1978 (7) and the Ramsay case description was published in 1981 (8).

ME was formally classified as a disease of the nervous system in the World Health Organisation International Classification of Diseases in ICD 8 (which was approved in 1965 and published in 1969): it is listed both in the tabular list and in the Code Index as Code 323, page 173.

ME continued to be classified as a disease of the nervous system in ICD 9 (approved in 1975 and published in 1979), both in the tabular list and in the Code Index, where it is coded as 323.9, page 182.

ME continues to be listed as a neurological disorder in the current ICD 10 at section G.93.3.

By direct communication with the WHO in Geneva, the authors have been informed that when considering the correct classification of ME, the syndrome should be regarded as neurological and not as psychiatric; moreover, there are no plans to reclassify ME in the psychiatric section in the next ICD revision (Version 10.2) which is due in 2003.

Specifically, the authors were advised that the fatigue states including neurasthenia which are currently classified in the ICD at section F 48 as “Behavioural and Mental Disorders” **do not refer to ME**. This information clearly counteracts the claim made frequently by psychiatrists of the Wessely School (*see below*).

“Chronic Fatigue Syndrome” is now included in the Code Index in ICD 10 as one of the many names used by some when referring to ME.

Here a difficulty arises, because “Chronic Fatigue Syndrome” (CFS) means different things to different people. There are currently two different interpretations of “CFS”, one used by international researchers and clinicians which relates to a clearly organic (ie. physical) disorder which is the same as or very similar to ME, the other used by a group of UK psychiatrists led by Simon Wessely, now Professor of Epidemiological and Liaison Psychiatry at Guy’s, St Thomas’ and King’s School of Medicine, London, which relates to a clearly psychiatric disorder. These psychiatrists have become known colloquially as the “Wessely School” (9).

Wessely heads the CFS Research Unit at King’s College Hospital, as well as the Gulf War Illness Research Unit. He is renowned for his belief that ME does not exist other than as a *belief* that it exists (*see below*), and for his published belief that there is no such thing as Gulf War Syndrome (10). He is also renowned for his belief that the symptoms reported by the residents of Camelford (Cornwall) as a result of the drinking water disaster in 1988 (when 20 tonnes of aluminium sulphate were accidentally pumped into the town’s drinking water supplies) were due to heightened perception of normal bodily sensations being attributed to an external cause such as poisoning, and that such behaviour was due to anxiety and preoccupation with the state of the environment over chemical toxins. Writing about this catastrophe in the Journal of Psychosomatic Research (11), Wessely and his frequent co-author Anthony David (a psychiatrist who supports the Wessely School view of ME) claimed that such fears often appear in controversial fields such as environmental medicine and clinical ecology; they stated that individuals with long histories of multiple physical complaints divert their symptoms to fall in line with the prevailing issue (in that case, water pollution).

In an article in the BMJ based on a re-assessment of the Wessely and David paper in the Journal of Psychosomatic Research, Bernard Dixon wrote that “mass hysteria was largely responsible for the furore” (12). In the Camelford incident, seven people died, 25,000 suffered serious health effects and 40,000 animals were affected (13); a study commissioned by lawyers acting on behalf of the Camelford plaintiffs and funded

through Legal Aid (as opposed to the Department of Health) showed conclusively that those residents who were exposed to aluminium sulphate-contaminated drinking water suffered considerable damage to cerebral function which was not related to anxiety, and that there is objective evidence of organic brain damage which is compatible with the known effects of exposure to aluminium (14).

In a BBC Radio 4 interview on 14 August 2001 on the “Today” programme (the day when, after thirteen years, a further independent enquiry into the episode was announced), the lead author of that study (Paul Altman from Oxford) made the salient point that when studied *in detail*, abnormalities were found. Speaking on television on the same subject, Paul Tyler, Member of Parliament for the area, said that having to suffer the ill-health was bad enough, “but the cover-up is the real disaster”.

Professor David sat on the Royal College of Physicians and Royal College of Psychiatrists’ Working Party which produced the report on organophosphate sheep dip (15); the report suggested that the ill-health suffered by farmers and others after chronic exposure to OPs was possibly due to “severe anxiety or depression, which have intuitively been attributed by the sufferers to OP exposure”.

On 5 February 1999 the New Statesman carried an article by Ziauddin Sardar entitled “Ill-defined notions” which featured Wessely and which commented on his dismissal of such illnesses as ME and Gulf War syndrome; “Even though 400 veterans have actually died and some 5,000 are suffering from illnesses related to Gulf War Syndrome, the syndrome does not officially exist ... Wessely has been arguing that ME is a largely self-induced ailment that can be cured by the exercise programme on offer at his clinic.... Wessely, who occupies a key position in our socio-medical order, denies the existence of Gulf War Syndrome, just as he denies the existence of ME. Clearly, he is a follower of Groucho Marx: ‘Whatever it is, I deny it’. Not surprisingly, lots of people hate him”.

In 1991, the Wessely School of psychiatrists and supporters re-defined ME and adapted the US 1988 Holmes et al “Chronic Fatigue Syndrome” (CFS) case definition (16) (*see below*) to include psychiatric illness of which on-going fatigue is a prominent symptom. The 1991 definition is known as the Oxford criteria (17). When used by these psychiatrists, the term CFS is often referring to other fatigue states in which the primary symptom is tiredness or “fatigue”. The Oxford 1991 case definition specifically states ***“There are no clinical signs characteristic of the condition”***.

In 1994 the US Centres for Disease Control (CDC) produced another revision of the working case definition of CFS; that revised definition specifically states ***“We dropped all physical signs from our inclusion criteria”*** (18).

Notably, in correspondence dated 26 February 2001 Dr Charles Shepherd (Medical Director of the UK ME Association) denies this outright, writing “It’s just not true that the 1994 criteria specifically exclude patients who have physical signs”, yet the 1994 CDC criteria document plainly says this (page 957).

As with the formulation of the Oxford criteria for CFS, UK psychiatrists Simon Wessely and Michael Sharpe were involved with the 1994 US revision. Notwithstanding Shepherd's assertion, the two case definitions of CFS emphasise that there are no physical signs; by comparison, those with ME *always* have observable physical signs (*see below*).

This confusing state of affairs was noted in the 1994 UK National Task Force report (1), which states unequivocally that "ME" and "CFS" do not represent the same patient populations (*see below*).

However, in the US the term "CFS" has come to represent patients with what is probably "ME", and much of the international research literature refers to "CFS". This dichotomy has been encapsulated by Fred Friedberg, Clinical Professor in the Department of Psychiatry at the State University of New York (19):

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

Disturbingly, the prime authors of the UK Chief Medical Officer's report on CFS/ME are apparently determined to equate ME with "CFS" as one single entity, which they refer to as "CFS/ME" (*see below*). To do so takes no account of the different interpretations of the undifferentiated term "CFS" and it is likely to perpetuate the existing confusion to the detriment of those with *non-Oxford* defined CFS. It is already known that the CMO's Report on CFS/ME will recommend psychiatric management approaches: such approaches may be appropriate when considering the Oxford definition of CFS but may be harmful when considering the international interpretation of "CFS" which more closely equates with ME.

Montague and Hooper believe that by seeking to equate one specific syndrome or subgroup with another syndrome or subgroup which does not have the same features, the CMO's Working Group may be doing a grave disservice to both patients and medical science: they believe it is scientifically unacceptable that one name should refer to two different case definitions, each of which having different symptom profiles. Montague and Hooper are concerned at the repeated refusal by the CMO's Key Group to acknowledge the clinical difference between ME and other forms of CFS, a difference which many believe has important implications for management and treatment outcomes, as well as for service provision.

## What is ME?

ME is a multi-system disorder sometimes associated with enteroviruses related to the poliomyelitis virus (20); it occurs in both epidemic and sporadic form. There are acknowledged similarities and overlaps between ME / non-Oxford CFS and the post-polio syndrome (PPS), particularly concerning the nature and source of the pathophysiology, including virological evidence that enteroviruses persist in the human central nervous system. The mechanism of the incapacitating exhaustion is identical in the two conditions (ie. in ME and PPS). (21).

In ME, different people have different symptoms but the general pattern and evolution of major symptoms are remarkably coherent. Organ systems may be differentially affected and within organ systems there may be a mosaic of affected and unaffected cells, the sum of which defines the degree of organ dysfunction.

The chronicity and severity of ME, together with the degree of disablement, the disruption of the family unit and the inevitable social isolation make this disorder a nightmare.

The most striking feature is overwhelming and incapacitating post-exertional muscle fatigueability, which is quite distinct from “fatigue”, “tiredness” or “sleepiness”, together with extreme malaise. All muscles are affected, including the heart. Cardiac symptoms often mimic coronary thrombosis and it can seem to patients that they are having a heart attack but the usual cause of chest pain is chronic benign pericarditis. The presence and behaviour of the pericardial rub is independent of the intensity of the pain (22).

Research from Glasgow has provided firm laboratory evidence demonstrating delayed muscle recovery from fatiguing exercise and it shows convincingly that in ME/CFS there is *continued* loss of post-exertional muscle power (giving an *additional* loss of power), with recovery delayed for at least 24 hours, whereas sedentary controls recovered full muscle power after 200 minutes (23).

ME commonly starts with diarrhoea, together with a persistent headache and or vertigo (dizziness is a particularly striking and chronic feature), with a stiff neck and back, together with generalised muscle pain. It affects not only the central nervous system but the autonomic and peripheral nervous systems as well. Sympathetic nervous system dysfunction is integral to ME and “core” CFS pathology (24).

There may be significant and permanent damage to skeletal or cardiac muscle as well as to other end-organs including the liver, pancreas, endocrine glands and lymphoid tissues (25), with evidence of dysfunction in the brain stem. Injury to the brain stem results in disturbance of the production of cortisol (required for stress control) via damage to the hypothalamus and to the pituitary and adrenal glands. The later effects include not only muscle but joint pain; many patients can walk only very short distances and require a wheelchair.

There is difficulty with breathing, with sudden attacks of breathlessness, problems with swallowing and voice production, thermodyregulation with sweating and shivering, and low blood pressure. There is difficulty with simple tasks such as climbing stairs and dressing, and with short-term memory (26). Cognitive impairment includes difficulty with memory sequencing, processing speed, word searching, spatial organisation and calculation.

Sleep is characteristically unrefreshing. Uncharacteristic emotional lability is prevalent. There are usually chronic problems with diarrhoea and frequency of micturition, including nocturia. Vascular headaches are common and recurring (27). Patients have to be cautious about drugs, especially those acting on the central nervous system ie. anaesthetics, as there is an increased occurrence of adverse reaction (28). (*see also Appendix 1 to the Response dated 30 July 2001 by Montague and Hooper*).

Pain is often extreme and intractable: in his three-day CFS/ME intensive Workshop for practitioners given in Australia in August 1995, world expert Dr Paul Cheney emphasised that the control of pain in very sick patients can easily be the most challenging problem in ME/CFS management

ME is a potentially severe, chronic and disabling disorder from which complete recovery is unlikely. Cycles of severe relapse are common, together with characteristic evolution of further symptoms over time. Death occurs almost entirely from end-organ damage, mainly from cardiac or pancreatic failure. Suicide is not uncommon and is related to the current climate of disbelief and rejection of welfare support (29).

Despite claims from some quarters to the contrary, in ME there *is* evidence of inflammation of the central nervous system (CNS); that is what helps to differentiate ME from other forms of CFS. There are many references in the medical literature to inflammation of the CNS in ME and in “core” CFS (30,31,32,33,34) but such CNS inflammation is not found in all variants of CFS. It is incorrect to deny the existence of CNS inflammation in at least some forms of CFS (ie. in ME), even though such inflammation is by no means universal in all forms of CFS.

In some cases of ME there is evidence of oligoclonal bands in the cerebrospinal fluid (35,36). It is accepted by the most experienced ME clinicians that some degree of encephalitis has occurred both in patients with ME and in those with post-polio syndrome: the areas chiefly affected include the upper spinal motor and sensory nerve roots and the spinal nerve networks traversing the adjacent brain stem, which is *always* damaged (37). In nearly every patient there are signs of disease of the central nervous system (38). Recent research continues to support neurological involvement (39,40,41,42,43).

**In the UK, patients with neurological signs and symptoms are usually the sickest and as such they are excluded from studies of “CFS”. The results of studies from which such patients are excluded are not representative of the true situation.**

## **Physical signs found in ME**

In cases of severe ME there are definite physical signs indicative of physical illness which cannot credibly be ascribed to abnormal illness behaviour. Some of these signs are often present in less severely affected cases but are dismissed or trivialised in order to comply with the definition of CFS.

Not all patients have all signs, but throughout the ME literature, the following are common in the sickest patients. Observable signs include nystagmus; sluggish visual accommodation; abnormality of vestibular function with a positive Romberg test (in his 1995 Australian Workshop, Cheney said that more than 90% of patients have an abnormal Romberg versus 0% of controls); abnormal tandem or augmented tandem stance; abnormal gait; hand tremor; incoordination; cogwheel movement of the leg on testing; muscular twitching or fasciculation; hyper-reflexia without clonus; facial vasculoid rash; vascular demarcation which can cross dermatomes with evidence of Raynaud's syndrome and / or vasculitis (44) and spontaneous periarticular bleeds in the digits; mouth ulcers (45,46); hair loss (47,48,49); a labile blood pressure; flattened or even inverted T-waves on 24 hour Holter monitoring: a standard 12 lead ECG is usually normal (50); orthostatic tachycardia; shortness of breath: patients show significant reduction in all lung function parameters tested (51); abnormal glucose tolerance curves, liver involvement (an enlarged liver is not always looked for and can be missed) (52,53,54,55) and destruction of fingerprints: atrophy of fingerprints is due to perilymphocytic vasculitis and vacuolisation of fibroblasts (56).

## **What is CFS?**

The term "chronic fatigue syndrome" (CFS) did not come into existence until 1988. In the late 1970s and 1980s there seemed to be a remarkable rise in incidence of a condition virtually indistinguishable from ME, to the extent that the powerful American medical insurance industry became alarmed. The result was a new case definition and from 1988 "ME" was henceforth to be called chronic fatigue syndrome.

As a basis for sound scientific research, the new definition has been a disaster. "CFS" is not a single diagnostic entity: it has become a heterogeneous and non-specific label embracing many different medical and psychiatric conditions in which tiredness and fatigue are prominent. The first (1988 Holmes et al) definition of CFS (16) concentrated on "fatigue" as the primary symptom occurring as a post-viral effect and persisting for at least six months, with a sore throat and tender lymph glands in the neck.

The new "CFS" case definition focused on the symptoms of glandular fever and indeed, the disorder was at that time called the Chronic Epstein-Barr Virus Disease (the virus responsible for glandular fever). The Holmes et al definition was obliged to exclude the cardinal features of ME which had been documented for decades, distinguishable by post-exertional muscle fatiguability, extreme fluctuation and variability of symptoms and chronicity.

In the United States in 1988, the eighteen strong panel of medical scientists and clinicians charged with formulating a new case definition and new name could not agree: two of the most clinically experienced members refused to sign the final document and withdrew from the panel because the proposed definition and new name were too different from the ME with which they were so familiar (57). Those two members were Dr Alexis Shelokov (USA) and Dr Gordon Parish (UK). Dr Parish is the custodian of possibly the world's largest reference library of the pre-1988 literature on ME, known as the Ramsay Archive, which is now housed in Scotland.

Notwithstanding the position of the Royal Society of Medicine in 1978, the case definition of CFS expediently ignores the overt features of neurological disease seen in ME, a disorder which is often confused with multiple sclerosis (36). There is an increasing literature on the issue of ME/CFS being frequently diagnosed as multiple sclerosis: as recently as 1<sup>st</sup> August 2001 an internet posting listed the similarity of signs and symptoms (numbering 28) and discussed the similarities of magnetic resonance imaging (MRI) scans in ME/CFS and MS. Dr S.Blair noted that in ME, the 'unidentified white spots' tend to be punctate but in MS they tend to be more ovoid. While the MRI scans are similar, those of ME patients show increased signal intensity in the white matter near the white=gray delineation rather than in the white matter of the periventricular area (58).

The case definition of CFS also ignores the evidence that ME / non-Oxford CFS has features of autoimmune disorder (eg lupus 59,60) and features of allergy and multiple chemical sensitivity (MCS) (61,62,63,64,65,66), which is now officially recognised in the International Classification of Diseases (67). Data presented at the American Association for Chronic Fatigue Syndrome (AACFS) Fifth International Research and Clinical Conference in Seattle in January 2001 showed that MCS was present in 42.6% of ME/CFS patients compared with 3.8% of controls (68).

The evidence speaks for itself. Other postviral fatigue states are clinically in contrast to the three cardinal features of ME (69). Other fatigue states which may follow flu, measles, chickenpox, herpes or mononucleosis lack not only the clinical but also the laboratory features of ME (70).

Montague and Hooper again draw attention to the fact that both the Oxford 1991 and the CDC 1994 case definitions of CFS unequivocally state that those with CFS have no physical signs, yet patients with ME always have physical signs. The overriding difficulty is that some clinicians in some medical disciplines apparently fail to see them or have no desire to look for them.

It is a matter of record that those who favour a psychiatric aetiology and who wish to eradicate the classification and even the existence of ME were unhappy about the Report of the UK National Task Force on CFS / PVFS / ME published by Westcare (Bristol) in 1994: indeed, that Report itself acknowledges this, stating "*People who gave us their much-valued help are not necessarily in agreement with the opinions expressed*". Being known to be in disagreement with the Report from the National Task Force (which did

not have a psychiatric bias), the proponents of the psychiatric view responded to the Task Force Report by producing their own report (that of the 1996 Joint Royal Colleges (71), in the Preface to which it confirms that the authors of the Joint Royal Colleges' Report are not in agreement with all the findings of the National Task Force report) and indeed the Joint Royal Colleges' report on CFS presented the views of the psychiatrists and supporters of the Wessely School to the virtual exclusion of all other credible explanations.

### **The 1996 Joint Royal Colleges' Report on Chronic Fatigue Syndrome (CR54)**

Ostensibly claimed to have been prepared at the request of the UK Chief Medical Officer as a response to the 1994 UK National Task Force Report on CFS/PVFS/ME and that it was the Presidents of the three Royal Colleges who nominated the expert committee, it is widely believed that Wessely was the instigator and prime mover in the joint Royal Colleges' report. Out of the fifteen members of the Working Group, eight (53%) are psychiatrists well known for their published views which deny the reality of ME and six were signatories to the 1991 Oxford CFS case definition (which denies any physical signs).

Two members of that Working Group (psychiatrists Anthony David and Simon Wessely) had already made their views very clear, writing in the British Medical Journal (72)

“ The inclusion in the tenth revision of the International Classification of Diseases (ICD 10) of benign myalgic encephalomyelitis ...under Diseases of the Nervous System seems to represent an important moral victory for self- help groups in the UK...it is unlikely to lead to advances in our understanding of the condition....The nineteenth century term neurasthenia remains in the Mental and Behavioural Disorders chapter under Other Neurotic Disorders... neurasthenia would readily suffice for ME....Applying more stringent criteria for CFS in the hope of revealing a more neurological sub-group succeeds only in strengthening the association with psychiatric disorders. We believe this latest attempt to classify fatigue syndromes will prevent people from seeing the world as it actually is”.

In the Joint Royal Colleges' Report, ME is dismissed. Throughout the report is the relentless assertion that the more severe subgroup (ie those with ME) does not exist as a disease entity, and that antidepressant drugs together with cognitive behavioural therapy is an effective measure which should be used to modulate sufferers' maladaptive perception of their suffering.

Specifically, the Report recommends that antidepressants should be tried in CFS sufferers even in the absence of depression; it advises of the need to remove children forcibly from their parents and home if this is “in the best interests of the child”, and it stipulates that“ no investigations should be performed to confirm the diagnosis”.

The Report virtually ignored the available literature which describes physical anomalies: it cited 256 references, of which half were by the same or associated group of authors (the Wessely School), with 10% of the references being by Wessely himself; nine had not been published or reviewed.

The Report was heavily criticised on both sides of the Atlantic; in one cogently argued critique, Dr Terry Hedrick ( a psychologist and former Assistant Comptroller General for the US Government's Senior Executive Service) exposed just why it was insidiously biased and potentially harmful (73)

In the Joint Report, the authors mention a paper by Buchwald, Gallo (co-discoverer of the HIV virus), Komaroff et al (reference 128 in the Report) but dismiss it, stating

“White matter abnormalities occur in a number of settings, and their significance remains to be determined”

However, the paper itself concludes that patients with ME/CFS

“may have been experiencing a chronic, immunologically mediated inflammatory process of the central nervous system”

and that the MRI scans revealed a punctate, subcortical area of high signal intensity consistent with oedema or demyelination in 78% of cases. This is a clear illustration of the biased and misleading personal interpretation of the available evidence by the authors of the Joint Royal Colleges' Report.

In that Report, the authors mention a paper by Bombadier and Buchwald (reference 173 in the Joint Report), conveying that it supports their own stance, whereas the paper itself actually states the exact opposite of what is claimed by the authors of the Joint Report:

“The fact that the same prognostic indicators were not valid for the group with CFS challenges the assumption that previous outcome research on chronic fatigue is generalizable to patients with chronic fatigue syndrome”.

Another illustration from the Joint Royal Colleges' report can be found where the authors mention a paper by Sandman (reference 153 in the Joint Report) in apparent support of their own view that the results of neuropsychological testing have been “inconsistent”: the paper referenced in fact concludes that

“the performance of the CFIDS (ME/CFS) patients was sevenfold worse than either the control group or the depressed group. These results indicated that the memory deficit in CFIDS was more severe than assumed by CDC criteria. A pattern emerged of brain behaviour relationships supporting neurological compromise in CFS”.

As has been commented on in the international medical literature (74), Wessely et al often rely upon a mischaracterisation of the facts: some believe that the frequent use of such practice may even amount to scientific misconduct (75).

As far as the CMO's forthcoming report on CFS/ME is concerned, as Medical Director of the UK ME Association, ought not Shepherd to be pointing this out and questioning the accuracy of the Wessely School instead of condoning and positively supporting such mis-representation, which he seems to be doing by virtue of recommending the model of evaluation favoured by the Wessely School (ie. only limited investigations are necessary in CFS/ME)?

### **The Petition "Fighting for Truth"**

Because the published criticisms and the many informed critical responses to the Joint Royal Colleges' report were ignored and / or were met with dismissive and patronising rebuttal by the Presidents of the three Royal Colleges, the UK ME community organised a petition for it to be withdrawn; the petition was called "Fighting for Truth" (ForT) and was signed by 12,500 people. On 26 November 1997 it was presented in the House of Lords by the Countess of Mar to the Minister of State for Health but was rejected, and the unquestionably biased report was not withdrawn.

### **The inclusion of ME in the World Health Guide to Mental Health in Primary Care**

It is perhaps worth drawing attention to the fact that Wessely's determination to classify ME as a mental illness apparently remains undiminished: in the WHO Guide to Mental Health in Primary Care (2000) is to be found the following (Disk 2: 6.2, 6.3):

"What is Chronic Fatigue Syndrome? (It) is an illness in which people experience extreme fatigue and muscle pain from activity. As a result they do much less than they used to....It is often known as ME.  
What makes people develop chronic fatigue syndrome? The pressures of life; lifestyle; personality style. What can keep fatigue going? Too much rest. Avoiding activity. Demoralisation and depression. Various methods of rehabilitation have been shown to be helpful. These include cognitive behavioural therapy and.. graded programmes of exercise..... What is negative thinking? Sufferers often feel...that any attempt to do more...may lead to an increase in symptoms, which the sufferer may believe means they are doing themselves permanent damage".

The Guide to Mental Health in Primary Care states that it is adapted from the patient management package by Dr Trudi Chalder (a registered Mental Nurse and behaviour therapist), Dr Alicia Deale (a behaviour psychotherapist), both of whom work with Wessely, and Professor Simon Wessely himself, amongst others. It has the benefit of

being promoted by the website of the University of Oxford Department of Psychiatry (www.psychiatry.ox.ac.uk), long known as a fervent supporter of the Wessely School, and whose website is mirrored on www.whoguidemhpcuk.org

Referring to the WHO International Classification of Diseases, the Oxford website specifically states

“CHRONIC FATIGUE AND CHRONIC FATIGUE SYNDROME - F48.0  
(Known internationally as neurasthenia, may be referred to as ME)

“Presenting complaints: patients may report...feeling tired easily...lack of energy...Chronic fatigue syndrome is diagnosed when substantial physical and mental fatigue lasts longer than six months...and where there are no significant findings on physical examination or laboratory investigation...  
A behavioural approach, including cognitive behavioural therapy (and) a graded programme of exercise can be helpful. *Guide developed by the WHO Collaborating Centre for Research and Training for Mental Health, Institute of Psychiatry, Kings College, London*”.

The Oxford Department of Psychiatry website recommends another website:

“The Institute of Psychiatry’s website includes a full patient management package...it is a useful resource for the practitioner who is working with the patient to overcome the condition”.

Clearly, the website of the University of Oxford Department of Psychiatry is informing people that the approved WHO classification of ME is as a mental disorder under ICD 10 section F48; the WHO, however, has confirmed by e-mail dated 22 August 2001 that those responsible for the website are in fact the Institute of Psychiatry, King’s College, London (ie.where Wessely works) and that it is not a WHO publication. Moreover, associates of Montague and Hooper were advised by the editor of the ICD that it was unacceptable for there to be two differing categorisations of ME under the WHO banner (one in a neurological classification and one a mental classification), and that this is something which will be looked into by the WHO. The advice from the WHO is that for legal purposes, the ICD takes precedence over the Guide to Mental Health in Primary Care. This is because the classification in the ICD has been approved by the World Health Assembly, whereas the Guide to Mental Health in Primary Care has not been approved by the World Health Assembly. Moreover, the ICD 10 itself specifically mentions at section F48 (Mental and Behavioural Disorders) **that ME / postviral fatigue syndrome is excluded from section F 48.**

From the University of Oxford Department of Psychiatry website, it indeed appears that the Wessely School at King’s College Hospital, London have managed to get the name and logo of the World Health Organisation linked to their own beliefs about ME by portraying the WHO logo in a prominent position, but this would seem to be deliberate

and calculated deception because the website is carrying incorrect and misleading information which is not condoned by the WHO at all.

As an ME sufferer points out in an internet posting, this is an important issue which ME patients should be able to look to the ME charities to sort out, but most members know that any such intervention is unlikely. An internet posting makes another valid point, namely that the Chief Medical Officer should be alerted to the incorrect inclusion of ME at section F 48 under Mental and Behavioural Disorders: crucially, however, it is members of the CMO's own Working Group who are *responsible* for the promotion of this misinformation.

It is remarkable that psychiatrists of the Wessely School apparently see no need to observe the internationally approved classification: the WHO Guide to Mental Health (available from November 2000) will be on all GPs' desks, and GPs will yet again be subject to more deliberate mis-information about ME, which in turn will undoubtedly cause more inappropriate management and more unnecessary iatrogenic suffering for the unfortunate patients who attend with ME.

### **The evidence that ME/CFS may be virally and chemically induced**

One reason why HealthWatch and at least four of its members have mounted such a campaign against Montague and Hooper could be that in their original paper, the authors referred to research which has demonstrated that an antiviral pathway (the RNase L pathway) is dysfunctional in ME/CFS, and it has been shown that this same pathway is also affected by chemicals (76). The authors also cite researchers in the US who have demonstrated a link between toxic exposure and chronic diseases such as ME/CFS and other autoimmune disorders, they suggest that the huge increase in chemical usage is chronically stimulating the immune system (77).

It is known that the incidence of ME/CFS is rising: this evidence comes from UNUM, one of the largest disability insurers in the United States; in April 1994, UNUM reported that in the five years from 1989-1993, mens' disability claims for CFS increased by 360%, whilst womens' claims for CFS increased 557%. **No other disease category surpassed these rates of increase.** In order of insurance costs, CFS/ME came second in the list of the five most expensive chronic conditions, being three places above AIDS.

Recent studies have demonstrated circulating plasma RNA in Gulf War Syndrome, and at the American Association of Chronic Fatigue Syndromes Fifth International Research and Clinical Conference held in Seattle in January 2001, a study was presented which had been conducted to determine the presence or absence of RNA in ME/CFS patients and to determine if the amplified sequences of RNA were similar to or different from those found in Gulf War Syndrome. All chronic illnesses studied (including Gulf War Syndrome, CFS/ME, AIDS and multiple myeloma) show prominent RNA not observed in normal controls. Prominent RNA bands so far sequenced show homology with human

genes which are noted for their tendency for gene rearrangement under severe physiologic stress. The most amplified sequences appear to be disease specific. (78)

Dr N. Afari, Associate Director of the University of Washington's CFS Research Centre, stated that the disorder appeared to be increasing, and that genetic abnormalities may team up with environmental influences to produce ME/CFS, and that environmental influences which researchers are investigating include the frequent pairing of ME/CFS with food and chemical sensitivities.

### **Evidence that there is a need for careful subgrouping within "CFS"**

There is now an unmistakable recognition that sound research has strengthened the need for consideration of subgroups (79,80,81,82,83,84,85,86).

A recent Editorial in the Journal of Chronic Fatigue Syndrome (87) makes the point that

“the sorting of patients into subpopulations...is helping in the design and interpretation of clinical trials for therapeutic interventions aimed at particular disease manifestations”.

The 1994 CDC criteria for CFS (whilst referring only to CFS) themselves recommend that researchers use stratification techniques to identify subgroups of patients (18).

One clear message which emerged from the National Institutes of Health (NIH) State of the Science Conference on CFS held on 23-24 October 2000 in Arlington, Virginia was that CFS is heterogeneous and researchers must subgroup patients by features including chronicity, immunology and neuroendocrinology (88). Conference participants included Dr David Bell, Professor Dedra Buchwald and Professor Nancy Klimas, all world-renowned experts on ME/CFS.

Roberto Patarca-Montero, Assistant Professor of Medicine and Director of the Laboratory of Clinical Immunology, University of Miami School of Medicine (who is also Editor of The Journal of Chronic Fatigue Syndrome) emphasises the importance of subsets of patients in his paper “Directions in Immunotherapy” (89).

Experienced researchers and clinicians presented evidence at the Fifth International AACFS Conference held in Seattle, 27-29 January 2001 about the need for subgrouping. Some examples include the following:

--- Professor Leonard Jason from De Paul University, Chicago, concluded (90)

Subtype differences detected may account for some of the inconsistencies in findings across prior studies that have grouped CFS patients into one category.

Subtyping patients according to more homogeneous groups may result in more consistent findings which can then be used to more appropriately and sensitively treat the wide range of illness experience reported by different types of individuals with CFS

--- Professor De Meirleir from Brussels compared immunological profiles in three different subgroups of CFS patients; he found significant differences between the groups (91).

--- Dr Pascale de Becker from Brussels presented evidence that there is a need to assess the homogeneity of a large CFS population in order to establish those symptoms which can improve differentiation of CFS patients (92).

--- Dr Paul Levine from Washington demonstrated that factor analysis is an important tool for separating subgroups of CFS; he showed that it should be utilised in future attempts to develop case definitions for CFS to identify discrete patient groups, which may have different pathogeneses and responses to treatment (93).

--- Dr Katherine Rowe from Australia presented evidence showing that at least three distinct subgroups can be identified within the CFS syndrome (94).

--- A large international multicentre study of autoimmunity was presented by E.Tan with, amongst others, participants from The Scripps Research Institute, La Jolla, California; the University of Washington; Harvard Medical School, Boston; State University of New York and George Washington University, Washington DC. Of interest is that another participant was Simon Wessely from Kings College, London. This large study reflected the heterogeneity from one CFS centre to another; it emphasised the importance of subcategorising CFS studies (95).

In the light of current awareness of the overriding need for consideration of subgroups within CFS, there is concern that if the UK CMO's Report advises UK clinicians that any difference between ME and "CFS" is simply a matter of semantics and personal philosophy (*see below*), and if it advises that only limited investigations are necessary, the report may be immediately dismissed and be held in derision by well-informed clinicians and patients alike.

### **The views of the CMO's Key Group member Dr Derek Pheby on the need for subgroups**

In February 1999 a member of the CMO's Key Group (Dr Derek Pheby of The Unit of Applied Epidemiology, Frenchay Campus, Bristol) produced a discussion document for the Working Group to consider. In that document, Pheby is definite about the need for attention to be given to the existence of subgroups and he quotes from the Report of the UK National Task Force on CFS / PVFS / ME (1). The Task Force Report states

unequivocally that *“Although both the terms “CFS” and “ME” have a range of applications, they do not represent the same populations”.*

In his discussion document for the CMO’s Working Group, Pheby explicitly states (emphasis added ):

“ The National Task Force recommended that five main sets of issues should be addressed, i.e. **Clarify the difference between the various chronic fatigue syndromes...** areas where in the view of the Task Force research needed to be encouraged included: **clear definition of the various chronic fatigue syndromes**”

“ CFS is a **spectrum** of disease” [i.e. not a disease entity in itself (quoting Levine) who is emphatic that “It is clear that CFS is not a single entity”]

“Variations in prognosis may be attributable once again to the heterogeneity of the condition, **with different subgroups having different prognoses**”

“The heterogeneity of CFS has made it very difficult to interpret research results from different studies which may have been conducted in very dissimilar populations”

**“If progress is to be made, it is necessary to consider...the possible existence of subgroups within the population of patients with CFS / ME”**

“The increasing knowledge of pathological processes occurring in CFS / ME has led to a belief that it should be possible to define subgroups on the basis of biomarkers and thus to draw a distinction between CFS and ME”

**“It has been argued by many that not only can ME be differentiated from CFS by biological markers, but that its clinical features also differ”**

Under “Priority Areas for Research”, Pheby concludes

“Certain areas for research have been identified as being important in enabling the Working Group to achieve its objectives. These include... systematic reviews to consider **subgroups**”

### **The views of others involved on the need for subgroups**

On 24<sup>th</sup> August 2000 Helen Wiggins of the NHS Executive (who co-compiled chapters 1 and 2 of the CMO’s draft report version 6) e-mailed a correspondent as follows:

“I would also like to assure you that the CFS/ME Working Group is aware that treatment that works for one person does not necessarily work for another. Hence the fact that the team undertaking the Systematic Review will look at evidence that subgroups of patients respond differently to treatment”.

On 18<sup>th</sup> August 2000 the Deputy Chair of the CMO’s Working Group on CFS/ME, Professor Anthony Pinching, wrote to Mrs Anne Crocker of Okehampton:

“... there is no doubt in my mind that the CMO’s Group is well aware of the heterogeneity of CFS/ME....obviously “one size” will not fit all...I hope very much that the final product will adequately address these issues”.

In an e-mail to a correspondent dated 11<sup>th</sup> December 2000 Professor Pinching wrote:

“I am all too well aware of the fact that current treatment options are unsatisfactory and that there is a significant group of patients where our current very limited armamentarium is either ineffective or worse”.

On 11<sup>th</sup> January 2001 Pinching e-mailed a correspondent as follows:

“It may be that we can define subgroups that are useful and I would have no problem with the concept (I have done this on other disease entities (when) subgrouping has also been helpful)”.

### **The apparent change of mind by the authors the CMO’s draft report regarding the need for subgroups**

From what is known of the Working Group’s earlier intentions (examples of which are set out above), many people were hopeful that the matter of subgroups would be addressed, especially given their importance in relation to the implications for treatment outcomes. Seemingly this is not to be: Pheby’s contribution on the need for subgroups has apparently disappeared from the CMO’s report whilst those who wield the most influence appear to have made the decision to amalgamate ME and CFS as one single disorder without subgroups, despite all the evidence to the contrary.

This decision may have been approved by Professor Pinching, because to the consternation of a very considerable number people (not only in the UK but via the internet to a worldwide readership), in 2000 a paper on CFS appeared in Prescribers’ Journal (96). It was authored solely by Pinching whilst holding the position of Deputy Chair of the CMO’s Working Group and it caused an outcry.

It was deemed to be a forerunner of the CMO’s Report on the basis that even when wearing two hats, the same wearer could not credibly hold substantially divergent views. The article was seen as illustrating very clearly the extent of the problem of differentiation between the specific and the generic and just how easy it is for the unwary

(or those who are following a pre-determined agenda) to “lump together” ME with other fatigue states.

In the article, Pinching states (emphasis added):

“CFS ...is a clearer appreciation of a pattern of symptoms previously characterised in many different ways”

“**over investigation can be harmful** and counterproductive to the management of these patients...**causing them to seek abnormal test results to validate their illness**”

“patients may need guidance about claims.... from other practitioners”

“ (patients) ...avoid activity, fearing relapse, but then develop symptoms of deconditioning...or **excessive awareness of physiological changes**”

“cognitive behavioural therapy...can substantially optimise rehabilitation”

“Complementary therapists...sometimes reinforce unhelpful illness beliefs”

“**The essence of treatment is activity management and graded rehabilitation**”.

Pinching does not even mention ME or the key manifestations of it and he expressly states that the fatigue found in CFS is “*not related to ongoing exertion*”. In ME, there is always **post-exertional muscle fatigue**, without which the diagnosis of ME is unsustainable, yet the intention of the CMO’s report is to unite ME with CFS as a single entity as the following illustrations from the draft version 6 exemplify:

“we do not see that it is either practicable or appropriate to use the term ME to define a subgroup within CFS, or even distinct from it.....there is currently no clear evidence from the literature formally to differentiate ME from CFS on grounds of either pathophysiology or response to treatment”

“**The Working Group suggests... that the terms CFS and ME are used synonymously** as the composite CFS/ME for the purposes of this report”.

“For the meantime, it seems appropriate to regard CFS / ME as a single, albeit diverse, clinical entity.....on present evidence (subdividing categories of CFS) may be considered a matter of semantics and personal philosophy rather than a

matter of established fact”.

Montague/ Hooper and their associates believe that good science requires attention to detail and not the broad-brush approach, however politically expedient or financially attractive such an approach might be.

To the consternation of those who represent the subset of patients who *do* have evidence of central nervous system disturbance (including inflammation), the drafts of the CMO’s Report seem to ignore Pheby’s carefully prepared and accurate document and instead to accept Pinching’s personal view -- a view which clearly echoes that of the Wessely School (ie. the psychiatric lobby) as expressed in the 1996 Report of the Joint Royal Colleges (71), as did his article and choice of references in Prescribers’ Journal.

Can this really be called “evidence-based medicine” ?

Montague and Hooper believe that in the final version of the CMO’s Report, clinicians’ view of the impact of the illness will need to reflect both patients’ clinical reality and the established laboratory abnormalities found in the various subgroups, not just the prevailing misconceptions so widely promoted by the Wessely School of psychiatrists. Montague and Hooper and their associates believe those misconceptions to be as follows:

1. a psychological rehabilitation programme is the treatment of choice for those with ME / CFS
2. any differences between subgroups (or between ME and CFS) are of no clinical significance
3. brain imaging and / or laboratory abnormalities found in ME / CFS are merely inconsequential epiphenomena.

The information on the need for subgroups set out above has recently been strengthened: expert medical opinion is now unequivocal that there is a pressing need for the study of sub-groups of CFS, using a variety of investigative criteria. In July 2001 the American Medical Association issued a statement, explaining that **90% of CFS/ME patients show normal test results on basic investigations** and that studies designed for specific subgroups are needed. Professor Anthony Komaroff, an undisputed world expert on ME/CFS, said:

“Researchers are already using imaging technology to measure brain hormones and are examining the function of the immune system. There is considerable evidence already that the immune system is in a state of chronic activation in many patients with CFS” (97).

The response of members of the CMO’s Key Group (particularly that of both Dr Shepherd and Professor Pinching) to this developing international scientific opinion is therefore particularly disappointing.

**Implications for treatment if the CMO's final report continues to assert that there is no need for subgrouping.**

Montague and Hooper believe that in the pursuit of both medical science and medical practice it is necessary to be as specific as possible. Nowhere is this more true than in relation to the various categories of "CFS". Not only is a broad brush approach potentially harmful to those with mitochondrial damage (particularly the use of CBT involving aerobic graded exercise regimes) (98), but despite attempts to do so, the claimed success with the approach of just one group of UK psychiatrists and their colleagues has not been replicated in the US or in Australia (19).

As mentioned above, such disparate findings are likely to be the result of different authors studying different subgroups of CFS. Montague and Hooper believe it would reflect badly if the CMO's Working Group report failed to understand the importance of this concept. To imagine that one treatment modality (ie. the psychological approach of cognitive behaviour therapy with or without a programme of graded exercise) could apply to all cases of ME and "CFS" would indeed be inappropriate or worse, a fact which Professor Pinching appeared to appreciate in his e-mail of 11 December 2000 mentioned above.

**Other areas of concern about the CMO's forthcoming report on CFS/ME**

In addition to their concern that investigations be limited in cases of CFS/ME and their concern at the intention of the report to promote CBT as an appropriate management intervention, there are other areas in the CMO's report about which Montague and Hooper and their associates are concerned, particularly the sections which assert that factors which maintain the syndrome include mood disorder, inactivity and illness beliefs, illness behaviour and illness attributions; and that factors apparently unrelated to prognosis include the patient's immunological profile. In the opinion of many people, such assertions are not in accordance with the international published literature or with clinical experience or with the known biomarkers and are thus unacceptable.

In the US, physicians are concerned by abnormalities in cell biology in ME/CFS; the emphasis of their research is firmly placed on immunology and Th1 - Th2 shifts; on virology and RNase L abnormalities; on HPA axis dysfunction and neuro-endocrinology; on aberrant RNA amplicons, and on cell membrane dysfunction.

In the UK, attention to such findings seems to be intentionally diverted and instead emphasis is heavily placed on socio-psychological investigation and management.

It is a matter of concern that the CMO's report is intending to advise UK clinicians that neuroimaging investigations should not be carried out on patients with CFS/ME and that looking for specific immune markers should not be part of the clinical evaluation, yet it is

such screening procedures which are delivering evidence confirming serious abnormalities in patients with ME/CFS. If such abnormalities are present, then they impact significantly on management.

Research funded by the ME Association found convincing evidence that changes in different immunological parameters correlate with particular aspects of disease symptomatology and with measures of disease severity, lending further support to the concept of immunoactivation of T-lymphocytes (99).

How can it be in any patient's best interests to advise UK clinicians that such significant abnormalities should not even be looked for?

Having set out some of the background which influenced the Montague/Hooper paper, the authors now consider in more detail matters of relevance and concern.

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### **The actions of Dr Charles Shepherd after the release of the Montague / Hooper document**

The issues raised by Shepherd and by the Chairman of HealthWatch have been addressed by Montague and Hooper in their response dated 30 July 2001, but certain aspects are incorporated here as they are deemed worthy of closer consideration.

Following release of the Montague / Hooper paper, those associated with it have received much publicly circulated comment contained in letters from Charles Shepherd.

Dr Shepherd has also written many letters to the Vice Chancellor of Professor Hooper's University as well as many letters to the University's Head of Corporate Affairs; he has written to Professor Allen Hutchinson (Chairman of the CMO's Working Group on CFS/ME) and to the Chief Medical Officer (Professor Liam Donaldson). Further, Shepherd requested Malcolm Brahams, solicitor and currently Chairman of HealthWatch, to send letters from Messrs David Wineman of Kingsway, London, to Professor Hooper. In an apparent attempt to prevent Professor Hooper from fulfilling an invitation to address members of the Scottish Cross-Party Parliamentary group on ME, Shepherd has also written to Members of the Scottish Parliament about the document (which he describes as "scurrilous misinformation"). Shepherd has placed some of his own letters on the internet, including one he wrote on 17 July 2001 to the CMO and one he wrote on 1<sup>st</sup> August 2001 to the Head of Corporate Affairs at the University of Sunderland.

A list of known letters to date sent by Dr Shepherd and other members of HealthWatch was provided as Appendix 3 to the authors' response to the letters from the HealthWatch solicitor (acting in his dual capacity as Chairman of HealthWatch) dated 30 July 2001.

### Issues raised by Dr Shepherd in correspondence

Shepherd comprehensively rejects the authors' factual response and continues to insist that the Vice Chancellor of the University of Sunderland should carry out an investigation into Professor Hooper's "conduct".

In copious correspondence, Shepherd insists that his complaints about the Montague / Hooper document were justified and that sufficient evidence has been provided by him for the University of Sunderland to instigate a formal investigation into the conduct of Professor Hooper (even though he now appears to accept that there are unauthorised versions in circulation).

Notably, Shepherd makes no attempt to retract any of his own statements which were erroneous, for example:

- a) Shepherd asserts that the book Dirty Medicine on which Montague and Hooper relied in their paper had "rightly" been withdrawn from sale: such an assertion is untrue and was clearly refuted in the response dated 30 July 2001 by Montague and Hooper.
- b) Shepherd repeatedly refers to the book Dirty Medicine as being "unreliable". That may be Shepherd's opinion, but it is not the opinion of others. The book was meticulously referenced and many of the issues it addressed are public knowledge, including such matters as the attack by members of HealthWatch upon Dr Jean Monro which bankrupted her private hospital specialising in allergy treatment; the attack by members of HealthWatch upon Dr Keith Mumby (publicly shown on television) and the involvement of some members of HealthWatch in the attack upon the Bristol Cancer Help Centre which almost caused it to close (*see below*).
- c) On several important matters, Shepherd mis-represents what the original document actually stated and he continues to do so in a manner which in the authors' opinion is irrational and unacceptable.
- d) In his letter of 1 August 2001 to the University of Sunderland, Shepherd makes a fundamental error; he states

"Just because HealthWatch received a donation from the Wellcome Foundation ( a registered charity linked to a drug company) back in 1991 does not mean that the organisation is currently **"funded by drug companies"**.

The Wellcome Foundation *is* a drug company, it was never a registered charity, nor is the Wellcome Trust (to which one presumes Shepherd is referring) a registered charity: that is why it is called a "Trust".

In correspondence, Shepherd states that the Montague / Hooper document contains a number of false or misleading allegations relating to the preparation of the CMO's report

on CFS/ME. What was stated about the preparation of the CMO's forthcoming Report on CFS/ME was taken from documents prepared by members of the Working Group and the NHS Executive.

In correspondence, Shepherd claims that he is now being accused of acting in ways which are unprofessional and detrimental to those with ME/CFS, and that the Montague / Hooper document is resulting in

“ a growing amount of sometimes quite unpleasant and nasty feedback aimed in my direction”.

The Montague / Hooper paper does not incite anyone, including ME/CFS sufferers, their families or friends to behave in an aggravating manner towards Dr Shepherd or towards anyone else. The authors of a paper cannot be held in any way responsible for the actions of other people. By encouraging ME/CFS sufferers to contact their Member of Parliament and the media, the authors believe that far from being irresponsible, they acted in a legitimate and sensible manner, given that many people believe that what is happening to the UK ME community is a national scandal which requires public exposure.

In correspondence, Shepherd makes it plain that he regards the Montague / Hooper paper as being “*seriously flawed*” as far as the “*scientific conclusions are concerned*”. Shepherd states in his letter of 17 July 2001 to the CMO that

“much of the scientific argument being put forward by Hooper and ‘Montague’ to justify the use of investigations they advocate (eg immunological, endocrine and virological screening) is very seriously flawed. They rely on statements from a highly selective use of references along with omission of references which fail to support their case....Exactly the same type of flawed logic can be found when they argue for various other tests to be routinely carried out in the assessment of these patients”.

The irony of this seems to have escaped Shepherd entirely, because it is precisely that argument which has been levelled at the Wessely School for many years.

Currently, there is no treatment modality which is wholly effective in ME/CFS and the medical profession has nothing much to offer these patients. Until the cause or causes are established, management of the disorder is necessarily somewhat speculative. For Shepherd (in his role as Medical Director of the UK ME Association) to advise UK clinicians not even to *look* for abnormalities of the immunological or endocrine system (when such abnormalities are well documented as occurring in the disorder) is mystifying.

Far from cherry-picking the available references as Shepherd intimates in his letter to the CMO, Montague and Hooper have instead put forward a broad selection of references which support an organic pathoetiology for the condition. Such references, even though

available, have for too long been either ignored, dismissed or trivialised by those in the UK who prefer a psychiatric model of the illness. Montague and Hooper firmly believe that it is necessary to consider a more balanced approach than one which is limited to the psychiatric literature which has dominated the UK medical journals for so many years.

In support of his opinion that the research relied upon by Montague and Hooper is “*seriously flawed*”, Shepherd makes the following statement in his letter of 17 July 2001 to the Chief Medical Officer:

“ I acknowledge that I have opposed the inclusion of testing for RNaseL activity (an antiviral marker) and CFS urinary markers...one of the major problems with both of these tests is that all the published information so far comes from researchers who have a financial interest in their promotion – a situation which involves a clear conflict of interest”.

That seems to be an extremely serious allegation by Shepherd which appears to cast substantial doubt on the integrity of leading ME/CFS researchers, including those of professorial status in America, Belgium and Australia. Despite Shepherd’s claim to the CMO, in the opinion of Montague/Hooper, the integrity and status of these eminent researchers is not open to question.

Concerning the RNase L pathway, in a Workshop given in February 1999 at the International Congress of Bioenergetic Medicine in Orlando, Florida, world expert Dr Paul Cheney explained that there are three phases of the illness and each phase has to be dealt with differently: in phase one, the RNase L is significantly elevated (for about the first five years), after which time there is a progressive loss of this enzymatic upregulation, and by phase three, it is not seen anymore. It is therefore not a diagnostic marker for the condition, but it does mean that patients need to be fully investigated within the first years of onset.

According to Cheney, in phase two there is a significant down-regulation of RNase L, so patients do not have the underlying protein synthesis disruption that RNase produces. However, patients in phase two cannot do as much as they could in phase one (even though they were in fact more sick in phase one) but they are more limited and are still very sick. Phase two is primarily a toxicity issue, as the RNase activity dysregulates the body’s detoxification system, so patients start getting toxic.

In phase three, patients have no RNase activity but are really locked into their boundaries and are limited by the damage done to deep brain structures, particularly in the hypothalamic region. They are grossly limited by substantial damage to the mitochondrial DNA. It is the loss of mitochondria and (most importantly) the loss of dynamic hormone response which causes the limitations so universally experienced by these patients -- they are *severely* affected by their low dynamic response to any stressor and it is this hypothalamic injury which is so limiting. According to Cheney, that is the end-point of the disease. He made the chilling observation that there is an end-stage which is resistant to all therapeutic intervention, in that any intervention simply makes

the patient even more ill, and that in phase three, because of the injured brain, there will be things which these patients will never be able to do again and they will be locked into significant impairment.

It seems that in the UK those charged with helping patients with ME/CFS have no time for such science: in correspondence dated 26 February 2001 Dr Charles Shepherd wrote

“You are being completely unrealistic if you expect that the docs on the CMO WG might accept Paul Cheney’s ideas....They won’t.”

Referring to the Montague / Hooper paper, in his letter to the CMO Dr Shepherd wrote:

“Professor Allen Hutchinson (Chairman of the Working Group) has offered to communicate with the Vice Chancellor (of Professor Hooper’s University) to discuss the problems which this type of scurrilous misinformation creates for the Working Group”.

The authors of the Montague / Hooper paper cannot agree that by setting out the known facts, they are guilty of “*scurrilous misinformation*”. For Shepherd to use such language in place of reasoned argument is a matter of concern.

Robust disagreement between differing factions of opinion is not uncommon in medicine. As has been stated many times by many people, the root of the present disagreement would appear to lie in the great difference of patient populations being studied using varying criteria for CFS, different disciplines and a variety of methodologies.

Uppermost in the mind of those who are being inundated by letters from Dr Shepherd (Medical Director of the charity The ME Association) are two questions:

- (i) On the instigation of Charles Shepherd, HealthWatch has employed the professional services of its own solicitor, so why is Charles Shepherd continuing to send out copious letters in defence of that organisation and trying to drive the situation himself? Even before the solicitor had a chance to consider the response, Shepherd continues to send out letters (assiduously copied to many others) in which he continues to quote passages from the original paper, even though those exact issues have been addressed in the response to the HealthWatch solicitor and are supported by impeccable evidence (including Hansard) which does not rely on distortion or misrepresentation, about which Shepherd states

“this pathetic and unconvincing defence of their position will inevitably diminish their credibility still further”

Given that the reference to HealthWatch in the original Hooper paper made no deleterious assertions whatsoever ( it merely pointed out that the most influential members of the CMO’s Working Group are members of or involved with HealthWatch and it set out the aims of HealthWatch which were taken

directly from the organisation's own literature), why does Shepherd find it necessary to react in a way which has drawn far more attention to this issue than did the original paper?

People are particularly incensed at Shepherd's blatant attempts to prevent Professor Hooper from fulfilling an invitation to address the Scottish Parliamentary Cross Party Group on ME. MSPs, however, are not intimidated by Shepherd and believe they should hear what Professor Hooper has to say.

- (ii) Why does Shepherd not address the central issue, rather than resorting to tactics which seem so obviously diversionary? The central and crucial issue is that Shepherd gave advice to the CMO's Key Group that only limited investigations are necessary in ME/CFS.

Shepherd's advice on this point has been perceived not only as a betrayal of the ME community but as being against the weight of considerable international evidence and medical opinion which is continuing to accumulate.

In correspondence, Shepherd fails to address the evidence put forward by Montague and Hooper which clearly supports the need for more advanced investigations in this group of complex disorders; instead he states

“Montague and Hooper raise a number of completely irrelevant points about the scientific content of the paper but make no attempt to respond to my view that their overall conclusions regarding extensive testing of ME/CFS patients are seriously flawed, are not supported by the current weight of evidence, and are not advocated by the overwhelming majority of physicians with expertise in this illness”.

One can only wonder who in the UK constitutes this “overwhelming majority of physicians with expertise in this illness”.

Given that Shepherd was funded by the UK ME Association to attend the AACFS Fifth International Research and Clinical Conference in Seattle in January 2001, his professional advice that investigations should be limited in cases of ME/CFS is all the more bewildering.

### **Government Advisory Committees**

All those associated with the Montague / Hooper paper are concerned about the manner in which government consultative groups are organised, particularly those on subjects relating to chemicals and health. The lack of facilities for public presentation and cross examination leaves this system wide open to the influence of vested interests be they from the medical profession or the chemical and pharmaceutical industries. Those associated with the Montague / Hooper paper believe that if any members or associates of

HealthWatch are appointed to advisory committees, then it should also be the case that an expert in the appropriate field who supports complementary and nutritional medicine should be appointed in order to achieve the necessary balance.

There is real concern at the way in which those with ME have been treated by various Government departments, and specific evidence of cases of abuse was presented in person to the former Chief Medical Officer Sir Kenneth Calman on 11 March 1998 by the Countess of Mar and Doris M Jones MSc.

In her Chairman's Comments in The Environmental Medicine Foundation Newsletter March 2000, the Countess of Mar said:

"I continue to pursue various avenues in the House of Lords. Gulf Veterans, sheep dip victims and ME sufferers seem to take up much of my time. I continue to be concerned about the appalling way in which Government treats those individuals and will not let go until they are treated as they should be".

In her Chairman's Comments in the October 2000 issue, the Countess of Mar wrote:

"I am increasingly incredulous at the extraordinary refusal of anyone in authority to take very genuine reports of illness and complaints about the way matters are handled seriously. It matters not whether it is ME, MCS, Gulf War illness, pesticide poisoning or Munchausen's Syndrome by Proxy that is under the spotlight. It does not matter whether it is adults or children who are affected. If one does get a response from a Department of State it is calculated not to relate to any of the matters raised or questions asked.....I find this situation intolerable ... I am very concerned about the way in which the Department of Health is deferring any action on people with ME until after the Task Force (*ie. the CMO's Working Group*) has reported. Many of the questions that I ask, and that I know sufferers and their carers ask, are not dependent upon the outcome of the report. The effect of this is to increase the sense of isolation and the suffering of a large number of sick people.....Perhaps you should bring this to the notice of your elected representatives".

Given the recent track-record of the British Government, the Department of Health, DEFRA (the Department of the Environment, Food and Rural Affairs, formerly MAFF) and the Ministry of Defence in the areas of medicine and health, particularly with respect to such subjects as Gulf War Syndrome, organophosphate pesticides (OPs), BSE and most recently the foot and mouth epidemic, Montague and Hooper believe transparency demands that all interests of members of Government advisory committees should be made public.

If any member of the CMO's Working Group on ME/CFS (or any member of any other public body) is a member of any organisation which is known to be (or to have been) backed by vested interests, then the authors believe such information should be brought to public attention and that such an association should be declared, as is the case with Members of Parliament.

In this particular instance, the CMO's advisory committee (the Working Group on CFS/ME) is known to contain members who have associations with at least three powerful vested interest organisations, namely (i) the Linbury Trust, (ii) PRISMA and (iii) HealthWatch, but the original Montague/Hooper document made no mention of the Linbury Trust or of PRISMA, and mentioned HealthWatch only briefly.

### **Note on Cognitive Behaviour Therapy and Professor Simon Wessely**

As noted above, the Wessely School of UK psychiatrists and their supporters are known to hold the belief that ME does not exist; that it is better termed "Chronic Fatigue Syndrome" and that CFS is treatable by a psychotherapeutic intervention known as cognitive behavioural therapy together with a programme of graded exercise.

For over a decade, criticism of this approach has been levelled at these UK psychiatrists but they remain impervious and intransigent. Since the late 1980s, this group persistently and assiduously dismisses, trivialises and ignores the now substantial evidence that ME/CFS has an organic pathoaetiology with supportive biomarkers; such a view does not accord with their own preferred psychiatric model of the disorder nor does it accord with their chosen treatment regime of cognitive behavioural therapy (CBT) and graded exercise (GE).

Wessely's influence in particular is phenomenal: not only does he teach medical students his own views of ME/CFS (so future generations of doctors will be influenced by his teachings) and work as a hospital consultant, he is a most prolific and assiduous author of medical textbooks and medical papers (having published in excess of 200). He has been / is adviser to various Government departments (notably the Department of Social Security) and the Ministry of Defence, where he advises on the non-existence of Gulf War Syndrome. He is associated with insurance companies and is known to have advised them on "Occupational Health Issues for Employers" on ME/CFS; he lectures to the Industrial Relations Services on ME/CFS. He joined a Board of the Medical Research Council in 1998; he refers to himself as an expert witness in Court cases involving ME/CFS; he is a member of the Cochrane Collaboration (*see below*); he is the British representative at the US Centres for Disease Control and is a member of the International Chronic Fatigue Syndrome Study Group. He is a Member of Council of The Royal Society of Medicine Section of Psychiatry. He appears to have unassailable influence over what gets published and what gets rejected by the UK medical journals, having been review editor and referee in matters concerning ME/CFS. He has seemingly open access to the British media.

A detailed and fully referenced though not comprehensive compendium of Wessely's published works on ME/CFS and related disorders is to be found in "Denigration by Design? A Review, with References, of the Role of Dr Simon Wessely in the Perception of Myalgic Encephalomyelitis (1987-1996)" by Eileen Marshall and Margaret Williams, August 1996; Volume II (Update) covers the period 1996 - 1999; pp 488. Copies of both volumes are available at cost price from DM Jones MSc, telephone 0208-554-3832.

The preferred management approach of the Wessely School is aimed at altering patients' beliefs that they have a physical illness, described by these psychiatrists as "aberrant" beliefs; a similar technique used to be called "brain washing".

Suppression of any view other than the psychiatric, combined with efficient dissemination of the rigid beliefs of the "Wessely School" has adversely affected the attitude of an unknown but extensive number of healthcare professionals, to the great detriment of some severely sick people.

In contrast, Montague and Hooper rely on compelling research evidence which has been carried out by the foremost international experts on ME/CFS. Such competent and credible research from world-class centres has informed international medical opinion about ME/CFS. The references relied upon in the Montague / Hooper paper are appropriate and relate to this significant research which has mostly been done overseas and which has uncovered discrete physical anomalies in the disorder. Those associated with the Montague / Hooper paper are concerned that UK patients will continue to be denied such investigations if Shepherd's advice on this issue (which accords with the advice of the Wessely School) is accepted. They believe that the only way to advance medical understanding of this complex group of disorders is by investigation, not only in centres of research but in clinical practice also.

If such investigations are comprehensively denied to those UK patients who are deemed likely to have the disorder, then progress and advancement will be obstructed. In the view of Montague and Hooper, that cannot be in sufferers' best interests. For certain doctors persistently to recommend that no investigations (or only limited investigations) are necessary does not, in the authors' view, accord with best medical practice, as it would be likely to lead to the continuation of inappropriate psychiatric interventions such as cognitive behavioural therapy and graded exercise, the hazards of which have been reported in the magazine of the UK ME Association (100).

That CBT is *not* the best "evidence-based medicine" for ME/CFS is the subject of recent robust correspondence in the *Lancet* (101).

In the Spring 2001 edition of the *Medical and Welfare Bulletin* issued by the UK ME Association which accompanied their "Perspectives" magazine (102), Shepherd himself published the fact that he continues to receive more adverse reports about graded exercise (a component of CBT) than any other form of treatment and that there is clear confirmation that many people with ME/CFS are suffering relapses through such exercise programmes.

The same results have been found by the three patient support groups in three separate surveys: both Action for ME in their survey of 2,338 respondents (February 2001) and also the ME Association in a separate survey carried out by Dr Lesley Cooper (November 2000) which was jointly sponsored by the ME Association and Action for ME revealed that graded exercise was felt to be the treatment which made more people worse than any other. A survey carried out in July 2000 for the 25% ME Group for the Severely Affected found that graded exercise / CBT caused a chronic and severe condition. Additionally, a detailed survey carried out in April 2001 by an independent ME researcher (DM Jones MSc) has confirmed the same results.

In all these surveys, it was found that not only did graded exercise / CBT make most participants worse, but even for those who were not made worse by such programmes, graded exercise was not helpful.

Further, scientists in Adelaide, Australia, have found evidence that such exercise programmes commonly undertaken by patients with ME/CFS (in many instances by compulsion) may actually make the condition worse: the study was conducted by the Exercise and Physiology Research Unit at the University of Adelaide; Associate Professor Garry Scroop said *“The exercise programme really destroys these patients”* (103).

Such findings add to the mounting evidence that CBT has been shown to be of no long-term benefit even in disorders other than ME/CFS: as mentioned in the Montague / Hooper document, researchers from the Department of Psychiatry and Behavioural Sciences at the Royal Free and University College Medical School found in a multi-centre study that there are no differences in clinical outcome between CBT and the usual general practitioner care at 12 month follow-up for patients suffering from depression and from those with depression and co-existing anxiety (104).

Why then is CBT, including graded exercise, being inflated to the status of “evidence-based medicine” and why is it being recommended by the CMO’s Working Group in their forthcoming report on CFS/ME?

As mentioned above, despite ME being formally and separately classified as a neurological disorder in the International Classification of Diseases (ICD10:G93.3), supporters of the Wessely School do not recognise the existence of it, claiming that it is nothing more than a dysfunctional belief that the sufferer has an illness called “ME” and that such beliefs, together with other “medically unexplained” illnesses such as tension headache should form part of a single, unified psychiatric disorder which they have called a “functional somatic syndrome” (105). These psychiatrists and their supporters strongly promote CBT for all patients whom they deem to be suffering from a “medically unexplained” disorder.

Montague and Hooper understand from documents they have seen that the CMO's Report on CFS/ME will advise that cognitive behaviour therapy should be given to "all adults able to attend outpatients".

### **HealthWatch**

It is not in doubt that Dr Shepherd and Professor Wessely are members of HealthWatch.

More information concerning the known activities of some members of HealthWatch is included below but in relation to Shepherd's behaviour, it appears to be a common strategy of HealthWatch and its members on reading material critical of themselves to inundate authors with letters, e-mails and faxes, threatening censure and demanding retraction of views with which they disagree.

Montague /Hooper and their associates find it a matter of concern that following the release of a paper of international interest, an academic whose contact address appeared on the paper should receive threatening legal letters from the Chairman of a charity.

By resorting to solicitors, those members of the CMO's group critical of the paper further obscure and devalue the important issues it addresses. In the opinion of those associated with the Montague / Hooper paper, such stratagems and objectives are not those which should occupy either a charity or members of the CMO's Working Group on CFS/ME.

There is substantial evidence that members, associates and participants in HealthWatch have a common position in support of orthodox allopathic medicine and are opposed to alternative and complementary therapies, to forms of non-pharmaceutical intervention and to ideas about environmental and chemically induced illness. Whether these views are incorporated into a HealthWatch perspective, or whether individual members of the charity personally adhere to similar positions, there are reasonable grounds for suggesting that those associated with HealthWatch represent certain collective interests. In support of this view, it is noted that on the campaign's own 1990 literature it unequivocally states:

“ The Campaign Against Health Fraud ('Quackbusters') exists to combat the growing problems of quackery. It was formed by a group containing doctors, lawyers, journalists and others who are worried that quackery has acquired a veneer of respectability and has worked its way into otherwise respectable news media. It plans a programme of public information”.

Montague and Hooper and all those associated with their paper believe they have an irrefutable right to voice the concerns expressed in their paper and that material written with serious academic intent is a matter for ongoing public debate.

They further believe that having given specific professional advice to the CMO's Key Group, Shepherd is both responsible and accountable for that advice, especially as it may have far-reaching effects upon patients' future welfare.

They also believe it is unacceptable for their legitimate enquiry and their expectation of accountability to be mis-represented by Shepherd as a "personal attack" upon him. Shepherd's persistent refusal to accept the accurate, reasonable and credible evidence upon which the authors based their opinion is noted.

It is also notable that Dr Shepherd focuses not on refuting he has advised that only limited investigations are necessary in ME/CFS but on defending what he perceives as unfounded allegations about HealthWatch. Specifically, he seems concerned about the need to assure Professor Allen Hutchinson (Chair of the CMO's Working Group on ME/CFS) that his membership of HealthWatch is entirely separate from any advice given in his role on the Working Group.

In a letter (listed in Appendix 3 to the response dated 30 July 2001), Shepherd states:

"there really is no evidence to support these highly derogatory allegations about HealthWatch".

Nowhere in the Monague / Hooper paper do the authors make "*highly derogatory allegations about HealthWatch*" nor does the paper state that HealthWatch is "*running*" the CMO's Working Group on CFS/ME as Shepherd claims. The paper simply notes that in the authors' opinion, the Working Group's most influential members are members of or have been involved with HealthWatch.

### **The Founding of HealthWatch in the UK**

HealthWatch was founded in London as the Campaign Against Health Fraud in 1988 by Caroline Richmond, a medical journalist. It was originally called the Council Against Health Fraud, thus following the lead of the American quackbusting organisation known as The National Council Against Health Fraud which has links to the industrially funded American Council for Science and Health (106). The UK organisation, now a charity, is known for its zealous views which are antagonistic towards alternative and complementary medicine and its practitioners, and towards those who believe in environmental illness and chemical sensitivity. It is a campaigning organisation which in the past has accepted funding from pharmaceutical companies.

In 1990, its own subscription form listed its aims as being "*to OPPOSE diagnoses ...that may encourage unnecessary treatment for non-existent diseases*" and "*To PROMOTE ...better understanding by the public and the media that valid clinical trials (which are generally accepted as being pharmaceutical (drug) trials) are the best way of ensuring public protection*".

The same HealthWatch document lists Simon Wessely as a “*leading member of the campaign*”. Also listed (among others) as a *leading member of the campaign*” are Professor (now Sir) Iain Chalmers, former Chairman of the Cochrane Collaboration (*see below*); Professor Vincent Marks (*see below*), psychiatrist Dr Chris Bass from Kings College Hospital and Dr David Pearson (*see below*). Duncan Campbell (*see below*) is listed as their “*Writer*”

As noted in the response of 30 July 2001, to mention in a document that Charles Shepherd and Simon Wessely are members of HealthWatch does not, in the authors’ view, constitute a “*very personal accusation*”, especially when that information is already in the public domain. Wessely’s name is clearly on the HealthWatch literature, whilst the fact that Shepherd has been a long-time member is documented in the book Dirty Medicine (*see below*).

HealthWatch has its own website: <http://www.healthwatch-uk.org/> Links to other internet sites include, amongst others, the Advertising Standards Authority, a body which regulates advertising and which HealthWatch members have used to discipline alternative practitioners and therapy producers; the American Council on Science and Health, a powerful group which is sponsored by multinational industry (including in large measure the pharmaceutical companies); the Association of Broadcasting Doctors; the British Association for the Advancement of Science; the Food and Agriculture Organisation; Medline; Medscape; Net Doctor; NHS Direct Online; the United Nations; the World Health Organisation; the UK Department of Health, and the Cochrane Collaboration.

The Cochrane Collaboration is an organisation which was set up to prepare a database encompassing the results of all clinical trials in order to compile an internationally available meta-analysis of what Cochrane Collaboration members consider to be the most effective treatments in all medical disciplines. The results of this collaboration are intended to become the definitive worldwide medical database on all medical conditions. Professor Simon Wessely is said to be responsible for collating and including all trials relating to the treatment and management of ME/CFS.

The Centre for Reviews and Dissemination (the York-based body which carried out the systematic review of the literature on management on ME/CFS for the CMO’s Working Group) is a sibling of the Cochrane Collaboration.

### **HealthWatch Founder Caroline Richmond’s views on ME**

From its early days when it was known as the Campaign Against Health Fraud, Caroline Richmond was indefatigable in her attacks upon those suffering from chemical sensitivity, now well documented in the medical literature as being a prominent component of ME/CFS; indeed at the Dublin International Meeting presented under the auspices of The World Federation of Neurology on 18-20 May 1994, Professor Charles Poser of the Department of Neurology, Harvard Medical School, said such sensitivity to chemicals is virtually pathognomonic of ME/CFS. In the late 1980s however, Richmond

launched her ferocious attacks upon environmental medicine and against those claiming to suffer from ME. She seemed determined to show that the illness had no organic basis and that sufferers were simply malingerers. Many people with ME/CFS have a chronically up-regulated immune response and react badly to common substances including medicinal drugs, so of necessity they have turned to non-drug treatments offered by complementary medicine and as such they became the targets of HealthWatch, which exists to attack anything and anyone who challenges the monopoly hold of the chemical industry on food production and pharmaceuticals (106 page 340). When Simon Wessely published articles in the mainstream medical journals on ME/CFS claiming psychiatric attributions, Caroline Richmond gave them maximum publicity in the medical trade papers.

So that people can form their own judgement, some illustrations are provided here.

“Myalgic encephalomyelitis is a new name for an old disease....it’s a British disease, unknown in the new world.....The attraction of allergy to the hypochondriac is its personal uniqueness.....The dedicated hypochondriac... scenting a new career as a patient...wants to see the ‘top man’ on the subject.....Hysteria was originally a disease of spinsters, whose dry wombs wandered round their bodies in search of moisture. Then, as now, ladies suffering from the vapours retired to their boudoirs. Taken from the French verb *bouder*, to sulk, a boudoir is a lady’s sulking room. The illness behaviour of patients and the diagnostic behaviour of doctors are susceptible to fashion, and they are a part of it.....neurasthenia, melancholy, the vapours...now they have lost their organic associations and imply states of personality or mind. Will the same thing happen to...total allergy syndrome (and) myalgic encephalomyelitis?”. (107)

“One person sent me a magazine article with a photo of a sufferer. She was sitting in a wheelchair and she described how she was getting progressively weaker. And she looked fulfilled, happy, healthy, attractive and well-presented”. (108)

“ Whatever the patients have, it is not inflammation of the brain and spinal cord. Often it resembles a nervous breakdown. 72% of fatigue patients at The Institute of Neurology in Queen Square...had psychiatric symptoms”. (*at the time Richmond wrote this, Simon Wessely had been working at Queen Square*). “There is no evidence to suggest that ME patients are immunocompromised and they don’t succumb to more infections than other people, although they are more likely to regard them as life events.....many patients have succeeded in getting disability pensions..... Advice should be given to enable them to cope with their symptoms, gradually increase exercise tolerance and return to normality”. (109)

As a journalist, Richmond was not qualified to be advising clinicians about the medical advice which should be given to patients.

“Many patients arrive in the consulting room with a firm attachment to a dramatic diagnosis made, not by a neurologist or a virologist, but by themselves.....many patients have... read some ill-thought out advice leaflets.....Fortunately this deadlock has now been broken by two recent papers which argue for a...more constructive approach”.(110)

Richmond is there promoting Wessely’s paper Postviral fatigue syndrome: time for a new approach. *BMJ 1988;296:696-698*.

On 3<sup>rd</sup> June 1989 Wessely wrote an article in the BMJ for the “Bookshelf” slot entitled “What your patients may be reading” in which he was very critical and mocking of ME sufferers. It was not long before Caroline Richmond added her support for Wessely by supposedly reviewing the same books:

“there is a ready market for the rash of books which have been published on ME...these books give much the same view of the history and aetiology of ME -- the ‘official’ version of the ME activists.....unconventional procedures, such as alternative allergy diagnosis...are advocated.....a checklist of irrationalities...shows Mr Wilkinson’s and Dr Macintyre’s book giving the highest score...the others are little better”. (111)

“Myalgic encephalomyelitis...sounds really serious and is guaranteed to impress the friends and relatives of sufferers....while the patients groups funded research into possible organic origins of the disease, more and better research was emerging from psychiatric departments.....Patients wanted to be referred to neurologists, who didn’t like seeing them.....None of them seemed to find it remarkable that they are suffering from a disease called ‘me’”. (112)

Richmond made numerous factual errors and her journalistic ambition allowed her to fabricate complete untruths, but the damage was done.

The HealthWatch perspective on ME owes much to Caroline Richmond’s prejudice against sufferers. Some of Richmond’s articles are extremely offensive about very sick people. Had she been insulting those with cancer or multiple sclerosis, there would have been an outcry. Instead, doctors seemed to vie amongst themselves to produce jibes at ME sufferers’ expense. Dr Douglas Carnall wrote in *Doctor*, 12 January 1995 a piece entitled “Bluffers’ Guide” in which he said

“Yesteryear’s neurasthenia....modern day bluffers prefer the term chronic fatigue syndrome....if (patients) insist on a physical diagnosis, tell them that chronic fatigue syndrome is a complex disorder in which multiple biopsychosocial factors are mediated via the anterior hypothalamus --- in other words, it’s all in the mind”.

The tradition of shameful diatribes and invective against ME patients which Richmond began in the medical trade press in the late 1980s continues to the present day. *Doctor* magazine recently published a “Question and Answers” (supposedly humorous) quiz by “Dr Tony Copperfield” (said to be a GP in Essex) in which the question was

‘What would be your initial response to a patient presenting with a self-diagnosis of ME?’.

The correct answer was said to be

“For God’s sake pull yourself together, you piece of pond life”.

All amusing, light-hearted stuff of course, but damaging nevertheless, as articles such as these tend to reinforce dismissive attitudes to patients who are genuinely sick and in distress, and it is abhorrent that vulnerable and desperate patients should be forced to justify their illness because of ill-informed but influential doctors who so persistently minimise the severity of ME.

Another example of harm flowing from such offensive views is to be found in a recent article in *GP* magazine written by an academic registrar in Oxford (Dr Bogdanovic), who in his review of management wrote

“The provision of disability services and benefit payments is a controversial issue because (a) illness beliefs may be reinforced (b) services and benefits constitute a secondary gain”.

### **Some views of HealthWatch**

Not everyone accepts the rosy picture of a small charity staffed by volunteers struggling to promote reliable information about health care as stated by its Chairman Malcolm Brahams in his letter of 13 July 2001 to Professor Hooper, or as implied by Simon Wessely in his e-mail to Professor Hooper of 6 July 2001. In that e-mail, Wessely wrote:

“clearly the fake author knows sod all about Healthwatch. I am not sure it even still exists, to be frank....As I recall it consists of about half a dozen rather nice, well-meaning people largely retired from the health service. Your doppelganger makes it sound like some sinister cabal with links to the Mossad and CIA. What utter rubbish! Someone has some seriously paranoid thinking here!”

However, as briefly mentioned in the response dated 30 July 2001, the Earl Baldwin of Bewdley (who served on the Research Council for Complementary Medicine and was Chairman of the Parliamentary Group for Alternative and Complementary Medicine) made these points in a debate in the House of Lords:

“The influence of drugs companies, with their multi-billion pound turnover, now reaches into every corner of mainstream medicine. It is not possible that so much money should be put in and that outcomes should not, however subtly, be influenced ... (Drug company funded research) is product-orientated research...and other kinds of research are being squeezed out. Drugs company money has gone into Healthwatch, the body that has set itself up to expose unacceptable practice in medicine (but unacceptable, one may ask, according to whose agenda?) ... The chief implication of this is that we suffer the dangers of a virtual monoculture. And one of the principal dangers of a monoculture is that you are not even aware that you are in it ... I know of examples where highly promising lines of research into complementary medicine are being stifled by the influence of drugs company funding.... Vitamins and minerals cannot be patented”. (*ref: Hansard (Lords) 28 April 1993:364-382*).

Also as noted in the response of 30 July 2001, HealthWatch was again mentioned in Hansard two years later. The accountability of registered charities was under scrutiny when the Countess of Mar asked Her Majesty’s Government:

“What powers the Charity Commissioners have to ensure that registered charities are accountable for their activities ...Is the noble Baroness (*the then Minister of State, Home Office, Baroness Blatch*) aware of the activities of an organisation - formerly the Campaign against Health Fraud and now called HealthWatch- which has been systematically destroying the reputations of people working in complementary medicine, particularly those in nutritional medicine? ... The information which Health Watch has provided to the media has been subsequently proved false ... Can the noble Baroness say what recourse the organisations and individuals concerned can take in order to restore their reputations?”

The Minister of State replied:

“The noble Countess is right in saying that HealthWatch has been subject to investigation...if any organisation uses its funds in order to campaign against another organisation on the basis of flawed research, the Charity Commission will be concerned”.

The Countess of Mar:

“Does the noble Baroness appreciate that many of the people who have been damaged by Health Watch are not very well off? Does she approve of the fact that the organisation is supported by the Wellcome Foundation and Private Patients Plan, among other pharmaceutical and insurance companies?”.

The Minister replied:

“If there is a suggestion that that or any other organisation is acting improperly and inconsistent with its aims and objectives, that must be a matter for the Charity Commission”. (*ref*:: Hansard (Lords): 10 May 1995:66-68).

### **The known views of HealthWatch as related to ME/CFS**

In his letter of 13 July 2001 to Professor Hooper, HealthWatch founder member and current Chairman (solicitor Malcolm Brahams of Messrs David Wineman) states

“We have looked (but) cannot find the phrases represented as if a quotation ‘Diagnoses...that may encourage unnecessary treatment for non-existent diseases’,

yet these exact words appear on the campaign’s own 1990 literature.

As far as HealthWatch’s “leading member” Simon Wessely is concerned, it cannot be in any doubt that he is most influential on matters relating to ME/CFS. Wessely is a named member of the Working Group; whether or not he has physically attended any meeting of the Working Group is immaterial to the effect of his influence concerning ME/CFS. It is a matter of public record that it was Wessely’s own personal database of the ME/CFS literature which formed the basis of the literature review carried out by the Centre for Reviews and Dissemination on behalf of the CMO’s Working Group; this is confirmed in a letter dated September 1999 from the Chief Medical Officer, which unequivocally states that “*for the Working Group’s reference library... much of the database was provided by Professor Wessely*”.

Despite ME being formally classified since 1969 in the WHO International Classification of Diseases as a neurological disorder ( ICD 8: 1969: code 323, page 173), Wessely (“leading member” of HealthWatch) promotes his belief that ME is a non-existent disease, and the HealthWatch literature clearly states that its aim is to oppose diagnoses which may encourage unnecessary treatment for non-existent diseases. Those who suffer from ME, he teaches, only *think* they suffer from a disease called ‘ME’ (113,114).

As mentioned above, it is widely believed that Simon Wessely was the prime mover in the 1996 Joint Royal Colleges Report on CFS (71), in which ME is dismissed completely: paragraph 13.3 states:

“Previous studies have counted people with ME, but these studies reflected those who seek treatment rather than those who suffer the symptoms”.

As far as Dr Shepherd (Medical Director of the UK ME Association) is concerned, in a recent article in the magazine Top Sante (July 2001) he was asked “Is ME the same as

chronic fatigue syndrome (CFS)?" to which he replied "Yes, but patients prefer the term myalgic encephalomyelitis (ME) because it sounds serious".

In reply to the question "Are there any drug treatments?", Shepherd advised low doses of antidepressants, and to the question "What else helps?", he replied "Accepting these major changes in lifestyle can be difficult, and some people benefit from a course of cognitive behavioural therapy, in which a therapist helps them change the way they think about their condition". Asked "What about alternative therapies?", Shepherd replied "...beware of quacks who charge a lot of money for strange treatments. Although some people find them helpful, there's no evidence that special diets, large amounts of food supplements or anticandida treatments will help cure this disorder".

### **The known views of ME/CFS experts who are also HealthWatch members concerning vitamins and nutritional therapies**

On this matter, one paragraph in the Joint Royal Colleges' Report (71) stands out, namely paragraph 9.20 which states:

"We have concerns about the use of complementary therapy and dietary interventions".

In his paper about the status of vitamin B in CFS patients (115), Wessely found a functional deficiency of the B vitamins, particularly pyridoxine, but also of riboflavine and thiamine. The study involved only 12 patients, yet the conclusion states: "But clearly, many patients with CFS are currently taking vitamin and other supplements with little evidence of benefit". If the study involved only twelve patients, to conclude that "many" patients show "little evidence of benefit" from taking supplements is remarkable.

To compare Dr Shepherd's different approach to pharmaceutical trials (*see below*) with the use of alternative, complementary and nutritional medicine, Montague and Hooper rely on his January 1991 article in *GP* magazine entitled "'Natural health' pills can be lethal"; subheaded "Many of the remedies can have bizarre and disturbing toxic effects". According to Martin Walker in the book "Dirty Medicine, this article "is one of the most climactic anti-vitamin articles ever published" (Dirty Medicine, page 341). The article attacks vitamin and mineral supplements without giving any supporting evidence for alleged damaging effects.

As there are known to be deficiencies of certain vitamins and minerals in some patients with ME/CFS, those associated with the Montague / Hooper paper believe it may be appropriate to attempt to restore micronutrient status and to regain baseline values in those patients who have demonstrated a deficiency. They also believe that dietary modulation can be helpful. However, as was pointed out in the Montague / Hooper paper, it is possible for patients to have "normal" laboratory measurements yet to be deficient at

intracellular level, and this is a particular trap for the inexperienced, dismissive or unwary practitioner.

It is the case that since his involvement with the ME Association, Charles Shepherd has often advised against “complementary and alternative” interventions and his views have been published over the years in *Perspectives*. Just three examples are quoted here:

“Alternative allergy treatments are once again causing controversy and concern...the current boom in private and alternative services (has resulted in) GPs having to cope with patients armed with the knowledge that they have ‘multiple allergies’ “ (Get out of the allergy maze. Dr Charles Shepherd. *Perspectives, Summer 1990*). The article was reprinted from *General Practitioner*.

“There is no reliable data to indicate that these supplements will provide any benefit” (*Perspectives Spring 1992*). In this item Shepherd refers to selenium, which is discussed in detail in the Montague / Hooper paper: in patients who have reduced T3 levels, selenium levels should be monitored, because selenium (as selenocysteine) is an integral component of two important enzymes (glutathione peroxidase and iodothyronine deiodinase): it is expressed in the liver and regulates the conversion of T4 to T3.

“Many people with ME believe that allergies and chemical sensitivities form an important part of their illness. This belief is particularly strong amongst those who consult alternative or complementary practitioners, although the evidence is not always based on sound scientific principles ... Similar concerns have now been expressed by the Royal College of Physicians ...for anyone who is considering making use of alternative therapies, (the RCP report) could save a great deal of time and money in the alternative allergy maze” . (Allergy: Conventional and Alternative Concepts. Dr Charles Shepherd. *Perspectives, Summer 1992*).

*(for further reference to this same report, see below)*

After the Montague / Hooper paper was released, Dr Shepherd’s stance on nutritional intervention was commented upon in an internet posting on 2<sup>nd</sup> July 2001:

“I have always found the ME Association’s hostility to nutritional approaches unreasonable”.

Shepherd’s antagonism to nutritional medicine was demonstrated when he joined forces with Duncan Campbell on a critical television item about Dr Stephen Davies.

Davies, a qualified medical doctor, is regarded by many as the 'father' of nutritional medicine in Britain. He is founder of the Journal of Nutritional Medicine and of Biolab, the major London laboratory which has pioneered a number of advanced assays to produce a wide variety of human nutritional data.

Shepherd's most recent writings seem to indicate that his stance on nutritional medicine has not changed. In a booklet sent to members of the UK ME Association, Shepherd says:

“there is no evidence from clinical trials to indicate that vitamin and mineral supplementation is of value” (116).

In fact, while there might be few clinical trials using nutritional supplements, the results of four independent surveys of patients with ME/CFS showed that 67% of 2,226 patients found dietary modulation to be helpful, and 61% of 1,953 patients found nutritional supplements to be helpful (117).

In the same ME Association publication by Shepherd and Chaudhuri, Shepherd states categorically on page 10 that

“There is no evidence of disturbed thyroid gland function in ME/CFS”

and in a letter to the British Medical Journal (118), Shepherd had earlier stated:

“During the last six months I have become aware of an increasing number of patients with normal results of thyroid function tests who are being treated with...thyroxine ---mainly as a result of publicity being given in the lay media to a hypothesis put forward by Gordon RB Skinner and colleagues....In the absence of any reputable evidence to support the hypothesis that clinical hypothyroidism can exist in biochemically euthyroid patients, I believe that this entirely speculative use of thyroxine should be restricted....In the meantime I have sent all my information to the Department of Health in an attempt to persuade the chief medical officer to issue clear guidelines”.

Some UK clinicians have successfully treated ME/CFS patients with thyroid replacement therapy including natural thyroid hormone (119), which contains all five constituents (ie. T4, T3, T2, T1 and T), and when deemed necessary with very low dose adrenal support. One such clinician was Dr Barry Durrant Peatfield. Despite hundreds of letters of support from patients and others, he was suspended from the practice of medicine by the GMC on 11 May 2001. Dr Peatfield described the decision as “*an extraordinary piece of injustice*”. A spokesman for the GMC said that Dr Peatfield had been suspended in order to protect his patients. On 25 May 2001 a Reference Group member of the CMO's Working Group sent to all members of the Key Group a proposal for more comprehensive thyroid and adrenal testing in ME/CFS. The only reply received was from Dr Shepherd, who in a letter dated 25 May 2001 acknowledged that

“As far as thyroid function testing (ie TSH, T4, T3) is concerned, this is one aspect of screening that everyone on the Working Group agrees must be carried out in **all** cases of possible ME/CFS...I would point out that I very rarely see patients under the age of 50 who have any laboratory abnormalities (including T3) involving thyroid function. I cannot therefore agree that there is a justifiable case for prescribing low doses of thyroxine to people with ME/CFS who have normal thyroid function tests.....I have serious concerns about (Dr Peatfield) and believe that the GMC decision to suspend him from medical practice is quite correct. I will be forwarding this information to the GMC in due course.....There doesn't seem any point in routinely testing adrenal function”.

A detailed reply dated 27 May 2001 was sent to Shepherd which reiterated the various problems with routine thyroid function tests (including non-compliance with requests for T3 by NHS laboratories if the TSH levels were deemed to be within normal limits, conversion problems and receptor blockage). To date, this remains unanswered.

In fact, the Montague / Hooper paper discussed the issue of clinically hypothyroid but biochemically euthyroid patients and the authors relied upon papers published in the *Journal of Clinical Endocrinology and Metabolism* and in *Postgraduate Medicine* (references 59,60 and 61 in the original paper). The evidence which was relied upon suggests that such patients may not really be euthyroid, especially at tissue level.

HealthWatch members were amongst the most supportive of an article entitled “Alternative allergy and the General Medical Council” written by Professor Barry Kay in the BMJ in 1993 (120) in which he attacked clinical ecology and sensitivity to chemicals:

“This is based on the idea that some patients are unusually susceptible to their environment ...Clinical ecologists ... attempt to diagnose and treat a disease which conventional doctors believe does not exist.... The GMC must face the issue of alternative allergy practice, particularly when a diagnosis is given of an illness which conventional doctors believe does not exist....The GMC should consider censoring all forms of diagnosis and treatment which, by reasonable standards, have failed to show clinical efficacy. There should be a close dialogue between the GMC and the royal colleges to ensure ...clinical trials using generally accepted procedures”.

Foremost in their published support of this article were HealthWatch members Charles Shepherd, Simon Wessely, Caroline Richmond and Professor John Garrow (121). Writing as the then Chairman of HealthWatch, Garrow said:

“Even if an ineffective treatment does not in itself cause damage, it may harm patients by...deflecting them from a better treatment.

The... strategy is to inform patients...so that they can make an informed choice. This task is being undertaken by HealthWatch.... (so that) the public need not be deceived by quacks...”

Simon Wessely wrote:

“ I and many of my colleagues who work in general hospital psychiatry often see patients (who are) seeing alternative allergy practitioners... Such patients are often suffering from various psychological disorders, in particular depression, anxiety or somatisation disorder. Formal studies confirm that most patients who have been labelled as having... ‘environmental illness’ fulfil criteria for psychiatric disorders. .... Once diagnosed, many of these disorders are easily treated...on the other hand, providing a false diagnosis...reinforces maladaptive behaviour and ensures that what might have been a brief illness becomes refractory to treatment.....some of the techniques used by clinical ecologists, which centre on avoiding environmental stimuli, can worsen psychological distress and physical disability”.

Wessely goes on to state that a key goal for public health is the improvement of “medical recognition of depressive disorders”.

Charles Shepherd wrote:

“ AB Kay deserves support in his attempt to persuade the General Medical Council to provide far more effective protection for members of the public in relation to doctors who publicise treatments of unproved efficacy ....Unfortunately, through gullible journalists...grossly exaggerated claims can be made for ‘natural’ health supplements, herbal remedies, allergy treatments etc... (The GMC) must issue some clear guidelines on the manner in which doctors involve themselves in promoting unproved remedies to the general public”

Caroline Richmond wrote:

“People with such symptoms...are convinced that their symptoms are caused by organic illness...Many find their way to alternative allergists... many behave like members of cults....doctors must educate the profession and the public that inchoate multiple symptoms of psychological origin are curable at little or no expense if doctor and patient collaborate in treatment”.

In the interests of balance, it is noted that on this same issue, Sir Robert Kilpatrick (then President of the GMC) wrote:

“Many qualified members of the profession now practise, or refer patients to others who practise, treatments whose scientific validity is considered by some doctors, to be questionable. Acupuncture and homoeopathy are only two examples of many. Few medical procedures carry no risk of any kind”.

### **Dr Shepherd and the journalist Duncan Campbell**

Shepherd has supported Duncan Campbell in a number of his campaigns and Campbell has written in Perspectives (the newsletter of the UK ME Association (*ref*: Autumn 1991, pages 18-19). Shepherd was Campbell’s expert witness in a Court action.

Indeed, in the most recent issue of Medical and Welfare Bulletin (sent out with the ME Association’s newsletter *Perspectives* Summer 2001) there is an item by Shepherd referring to the decision of the General Medical Council to remove the name a doctor from the Medical Register. Whilst Montague and Hooper have no comment upon that decision, they draw attention to what Shepherd writes :

“On February 20 the General Medical Council’s Professional Conduct Committee found Dr Michael Kirkman guilty of serious professional misconduct and recommended that his name should be immediately removed from the Medical Register. This followed a two day hearing in which Duncan Campbell, the investigative journalist with whom I worked on an undercover TV programme, and myself gave evidence about Dr Kirkman’s involvement in an unproven and potentially dangerous therapy.... (the therapy in question contained herbs and other substances).....**The result of the Kirkman case will have important implications for doctors who decide to become involved in alternative therapies** (*emphasis added*) .....Following the GMC decision to remove Dr Kirkman from the Medical Register, I gave several interviews to BBC radio and local television on the subject of ME/CFS and unproven alternative therapies”.

One of the expert witnesses against Dr Kirkman was Vincent Marks, Emeritus Professor of Chemical Pathology, University of Surrey, who has been an important member of HealthWatch and who on its website is listed as a member of the HealthWatch committee.

### **HealthWatch, Dr Shepherd and support for pharmaceutical intervention**

Dr Shepherd argues in one of his letters concerning the Montague/Hooper paper:

“It is untrue to state that membership is only open to those who promote the pharmaceutical industry”.

In their paper, Montague and Hooper relied upon the fact that despite HealthWatch being a charity, it chooses carefully those to whom it sends its newsletters and it has been known to refuse membership to those involved in 'natural medicine'. Indeed, on its own literature (the 1990 subscription form) it clearly states "*Applications are subject to approval by a Membership committee*". Its literature now states its aims as being:

"The advancement for the public benefit of medical knowledge, training and care in all its branches and, in particular, the development of good practices in the assessment and testing of treatments and the conduct of clinical trials generally... In brief: **HealthWatch - for treatment that works**".

One of the claims made by Shepherd in his correspondence is

"It is untrue to say that the clearly- stated aims are to promote pharmacological interventions.....No such statement exists".

As pointed out in the response dated 30 July 2001, in support of what was written in the Montague / Hooper paper the authors relied on the CAHF (HealthWatch) 1990 subscription form previously mentioned, which clearly sets out its aims as being " To promote...better understanding by the public and the media that valid clinical trials are the best way of ensuring public protection".

Certainly both Dr Shepherd and HealthWatch appear committed to double blind placebo-controlled trials of pharmaceutical products but not to trials involving alternative, complementary or nutritional medicine.

In 1997, Dr Shepherd gave notice in *Perspectives* (December 1997) of a trial involving galanthamine hydrobromide, suggesting that ME patients who lived near one of the trial centres would be getting a letter from him inviting them to participate.

This trial was a large national multi-centre study involving about 15 hospitals in London, Manchester, Bristol, Bath, Leeds, Cardiff, Bradford, Cornwall, Oxford and Preston. Galanthamine is a powerful long-acting cholinesterase inhibitor. Organophosphate (OP) compounds are also powerful anticholinesterase agents ie. both galanthamine and OPs are inhibitors of cholinesterase, an enzyme which regulates acetylcholine, which is a major neurotransmitter in both the central and autonomic nervous systems, and in muscle.

A young farmer of 31 who had been exposed to sheep dip since childhood and who had been diagnosed with ME became a trial subject and was given galanthamine by a psychiatrist whose patients were participating in the drug trial. Tragically, the man's symptoms worsened, culminating in his agonising death by suicide after he was driven to take strychnine.

In a subsequent issue of *Perspectives* (June 1998), Shepherd wrote of the tragedy, saying "The only way forward if we are ever going to discover a successful drug

treatment for ME/CFS is to carry out properly controlled clinical trials....This is the purpose of the current multicentre trial into galantamine” (*sic*).

It is understood, however, that the results of the trial (by Shire Pharmaceuticals) were such that the efficacy of galanthamine for those with ME/CFS was not demonstrated.

However much Shepherd assures everyone that his membership of HealthWatch has nothing to do with the advice he has given to the CMO’s Working Group on CFS/ME, it is surely unreasonable to imagine that the views for which certain doctors have become so well-known will be changed or abandoned during their membership of the CMO’s Working Group on CFS/ME.

### **HealthWatch members and another report**

HealthWatch associates and members have been involved in other Reports, most notably they were involved in the premature release of a draft version of a report entitled “Allergy: Conventional and Alternative Concept” (the Report which Charles Shepherd praised in Perspectives as mentioned above). Dr David J Pearson (also listed in the HealthWatch literature as a “leading member of the campaign”) and HealthWatch founder Caroline Richmond seized an opportunity to attack allergy, food intolerance and chemical sensitivity practitioners and patients alike when, in 1989, the Royal College of Physicians (RCP) agreed to write a report on the subject. Pearson was instrumental in the production of this report. Also on this report committee was Dr Anthony Pinching. Richmond secured the job of writing the report, despite her lack of medical training or membership of the Royal College of Physicians.

By the autumn of 1991, the Report committee had produced a first draft. In October of that year there was a High Court action taking place in London; it was the case of Taylor - v - Airport Transport Warehouse Services (21 October 1991: Osmond Gaunt & Rose for the Plaintiff and Wilde Sapte for the Defendant) and David Pearson was acting as expert medical witness for the Defence. Lorraine Taylor, a van driver for ATWS, claimed that her health had been seriously damaged by the spillage of a highly volatile chemical in the back of the van she drove for the company. Taylor’s solicitor had approached Dr Jean Monro to act as an expert witness on her behalf. The year before, in October 1990, the Campaign Against Health Fraud (HealthWatch), working with ITV’s *World in Action* team, had mounted a devastating media assault on Dr Monro, bankrupting her small private hospital; both Pearson and Caroline Richmond featured in the programme.

Pearson and Caroline Richmond used Lorraine Taylor’s case as another opportunity to attack Dr Monro and her alternative approach to chemical sensitivity. In his evidence to the High Court Dr Pearson argued that the Plaintiff’s symptoms were not a sign of any physical damage caused by chemicals but were evidence only of anxiety attacks. Further, he argued that the chemicals in question were not toxic to a healthy person and Taylor must have been idiosyncratically vulnerable to them.

Giving evidence against Dr Monroe, rather than *for* the transport company, Dr Pearson claimed that clinical ecology (Dr Monroe's area of medical expertise) was actually a cult which harmed patients who were drawn into it. To add an edge to his evidence and to influence the judge, on the first day of the trial (ie. long after the last opportunity to enter evidence) Pearson entered the draft RCP report, even though it had not been approved by its committee.

When it became known that Pearson was entering the draft report in evidence, a letter dated 18 October 1991 was sent by solicitors for the Royal College of Physicians (Field Fisher Waterhouse) forbidding Pearson to submit the draft to the Court. The letter stated: "The College is not in a position to endorse the contents or conclusions of the draft you have seen ... we must ask that this letter be brought to the attention of the Judge". Notwithstanding, the draft report *was* tendered to the Court by Caroline Richmond in answer to a subpoena obtained by the Defence for whom Pearson was acting.

When its contents became public, the draft version of the RCP report on which Pearson had relied in his evidence came under massive critical review and had to be re-written; Fellows of the RCP described it as "wildly inaccurate" and misleading.

It is difficult to know how significantly the judge was influenced by the inaccurate draft report, which was scathingly critical of allergy and chemical sensitivity. However, it is likely that the Judge would have been influenced by an apparently prestigious report supposedly backed by the Royal College of Physicians: in the event he accepted the "devastating critique" of Dr Pearson and he found against Lorraine Taylor. He said that she had been harmed by the "suggestion" that she was affected by chemicals.

Caroline Richmond (who had attended court with Pearson each day of the trial) was jubilant at the verdict and wrote a number of articles following the case. In one article (122) she wrote

"Dr David Pearson at Manchester University has warned that many clinical ecology patients end up as... psychological cripples".

Her article continued with a quotation from a Manchester University psychiatrist Professor David Taylor, who said:

"What is absolutely critical is that physicians should recognise this sort of sickness from the very outset and refuse absolutely to be drawn into the web of...delusion that some people need to protect themselves from unpalatable truths".

Richmond was supported in her attack on clinical ecology by barrister Diana Brahams, a founder member of HealthWatch and wife of Malcolm Brahams (HealthWatch solicitor of Messrs David Wineman). In her *Lancet* article (123) Diana Brahams wrote:

"The judge accepted the evidence given by the defendant company's experts – namely Dr D. J. Pearson...whose "careful and impressive" evidence

persuaded the judge that there was no scientific basis for the ‘spreading phenomenon’ of chemical sensitisation”.

David Pearson had published no specialised clinical or other research on chemical sensitivity and experts who have done so do not share his views: his view is at odds with the reputable evidence extensively documented, where the “spreading phenomenon” of chemical sensitivity is fully supported. (124).

### **HealthWatch and the Bristol Cancer Help Centre**

There seems to be a very real continuity in the tactics of HealthWatch members and associates. One well-known example is that of the Bristol Cancer Help Centre, whose complementary approach underpins their philosophy of care for those suffering from cancer. HRH Prince Charles is known publicly to support this Centre.

In 1983 the BBC “Forty Minutes” team made a series of documentaries and one programme featured the BCHC. At the time, Dr Alex Forbes was medical adviser to the BCHC. During the making of the film, a doctor informed the team that Dr Forbes had been struck off the Medical Register. This was not true. Dr Forbes had been an orthodox consultant physician for twenty years.

The BCHC agreed that their approach should be looked at by “orthodox” doctors and scientists. They did not then know that there were those in orthodox medicine who were looking for an opportunity to destroy them. The result of the research was the Chilvers report (125). One of the main authors of that report was HealthWatch (then called the Campaign Against Health Fraud) member Professor Tim McElwain from the Institute of Cancer Research and the Royal Marsden Hospital.

The Chilvers report concluded that those women with breast cancer who sought help from the BCHC were more likely to die than those who did not. This finding very nearly obliterated the BCHC and the staff who supported it.

HealthWatch member Dr James Le Fanu (currently a columnist for the Daily Telegraph) positively revelled in the results of the Chilvers report, writing in The Times (126)

“There is a grim satisfaction in learning that women with breast cancer seeking the help of alternative medicine at the Bristol Cancer Help Centre fare worse –relapse earlier and die sooner - than those who put their trust in conventional medicine”.

Supporting the attack upon the BCHC, consultant radiologist Dr Jeffrey Tobias wrote in the BMJ (127):

“The very fact of the existence of these centres with their strong message to patients that there really is a reasonable and realistic alternative to

conventional medicine represents a very real threat to the health of a patients with cancer”.

The beleaguered staff of the Bristol Cancer Help Centre were crushed but they fought back with tenacity. The result was that the Chilvers report was found to be seriously flawed and was retracted by the authors (128).

On 26 November 1990, only two weeks after he put his name to the retraction of the report in the Lancet, Professor McElwain, one of the founder members of HealthWatch, cut his throat in the bathroom of his home in Clapham.

### **HealthWatch and Dirty Medicine**

Dr Shepherd is correct in assuming that some of the information about HealthWatch upon which Montague and Hooper relied comes from the book *Dirty Medicine; science, big business and the assault on natural health care* by Martin J Walker. This was stated in the original document and was clearly referenced. Published in 1993, it remains the only account of orthodox medicine’s war against alternative and complementary medicine in Britain in the late eighties and early nineties. Described by Jerome Burne in the Guardian Saturday magazine as a “remarkably detailed book” and an “exhaustive chronicle”, the book is a meticulously researched and well-written history of the contemporary struggle between orthodox and alternative medicine. The book contains a number of chapters on HealthWatch and its members.

“Dirty Medicine”, for example, confirms that Dr Shepherd at one time held the position of Clinical Adviser to the Media Resources Service of the CIBA Foundation, an offshoot of the drug company which used to be Ciba Geigy.

In correspondence Shepherd states that “Dirty Medicine” is “*a book which has now quite rightly been withdrawn from further sale*”. This statement is not true, a fact which Montague and Hooper pointed out in their response of 30 July 2001.

In his letter dated 12 July 2001 to the Head of Corporate Affairs of the University of Sunderland, Shepherd says of the book ‘*This is a scurrilous publication which should have no place in the referencing of a scientific paper*’.

After the book was published, a campaign was mounted against it by journalist and one time HealthWatch supporter Duncan Campbell. The campaign entailed threats of legal action - but no actual action - against the author of the book, its wholesalers, distributors, retailers and even its printers in Finland. Campbell’s campaign was partially successful because, due to the fear of litigation, the book was sold by few retailers. Nonetheless the book sold over 7,000 copies while it was in print and gathered outstanding reviews in a number of influential journals and papers.

## **POINTS FOR CONSIDERATION**

The authors and all those associated with the Montague / Hooper document believe their paper makes fair comment on a number of issues. Whilst there is some talk about the CMO's forthcoming Report on CFS/ME being intended to be only *guidelines* for UK clinicians, nevertheless much depends on it, for example Health Boards are known to be putting off making far-reaching decisions related to ME/CFS pending the appearance of the Report. In reality, the CMO's report on ME/CFS will in the long term be translated into NHS policy.

If the advice of Dr Shepherd and of those who share his views about an important aspect of ME/CFS is accepted (ie. that only limited investigations are necessary), then surely this would indicate a clear preference for the maintenance of the *status quo*, which the editors of the draft Report themselves acknowledge is most unsatisfactory.

Whilst not detailed in this present document, the authors have in their possession certain exchanges of correspondence with members of the CMO's Key Group, some of it with Dr Shepherd and Professor Pinching about Pinching's article in Prescribers' Journal.

Attempts were made to persuade Pinching to understand better the patients' perspective and to ensure that their interests were represented in the forthcoming report for the CMO. Both Shepherd and Pinching reacted immediately and very defensively: whilst Pinching adopted a more moderate tone, Shepherd was more aggressive, dismissing outright many of the points made in a jointly-signed letter of concern sent to all members of the Key Group; Shepherd described some of the contents as "plain daft". One of the recipients wrote back saying

"Please forgive me if you think I am being 'daft', but I think the ME community and especially the severely affected have been 'sold down the river' many times over the last 2-3 decades by certain groups of people and we are fed up with it".

The correspondence exchanges clearly indicate that Shepherd and his like-minded fellow 'experts' have no intention of including more comprehensive investigations for those with CFS/ME in their recommendations to the CMO.

All those associated with the Montague / Hooper paper believe that it is legitimate to question whether or not the best interests of those with ME/CFS are being properly presented by some members of the CMO's Working Group in respect of the need for comprehensive investigation of such very sick people. Given the harrowing plight of so many of those affected by ME/CFS, especially those most severely affected, when such advice comes from the Medical Director of the UK ME Association, it is surely a matter which requires exposure and explanation.

It is difficult to convey the truly monumental degree of anger, fear and frustration experienced by so many affected patients and carers over these issues, in part at least

because they feel (with justification) that the representatives of the main UK ME charities have not been sufficiently assertive in representing the interests, views and concerns of their members to the appropriate authorities.

Many letters have been sent expressing such concerns, including to the CMO himself, to the NHS Executive in Leeds, to Pinching and to Dr Timothy Chambers (Chairman of the CMO's Childrens' Group). This means that key people in the CMO's Working Group must have been aware of these concerns, yet they disregarded them long before the release of the Montague / Hooper document.

Montague and Hooper and their associates believe it is necessary to accumulate data on all aspects of the disorder and that this can only be done as a result of multi-system in-depth investigation, in the clinical as well as the research setting.

Without such investigation, medical understanding of ME/CFS will not move forward. As the Countess of Mar observed:

“Why should the doctor and patient accept the limitations of scientific knowledge? Who is to say that their searches are likely to be futile? They may well, between them, come up with the answer. I simply ask whether we would have been able to cure TB, eradicate smallpox, prevent infectious diseases of childhood or establish the link between asbestos and lung disease if the medical practitioners of the time had accepted the limitations of scientific knowledge”. (ref: Hansard (Lords) 9 December 1998:1011-1024).

It is also noted that on 3 July 2001 the Countess of Mar wrote a letter to the Chief Medical Officer, in which she stated:

“I continue to be amazed that world class evidence, which shows clearly, simply and indisputably that the psychiatrists are wrong, is consistently ignored by them and that they find it necessary to resort to bullying tactics to dominate the proceedings. I am sure that you must also agree that it is unacceptable that you are being advised by a small group of influential doctors whose personal records and vested interests are a matter of public record”.

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### **The Plight of ME/CFS Sufferers**

ME/CFS is a multi-system disorder: authentically documented symptoms number in excess of 64. Sufferers experience significant problems in virtually all bodily systems including not only the central, autonomic and peripheral nervous systems but also the immune system; the cardiovascular system; the respiratory system and the endocrine system as well as the musculo-skeletal system. In essence, it has been shown to have

features of autoimmune disorders (eg. lupus); features of allergy and multiple chemical sensitivity (MCS); features of neurological disease (multiple sclerosis) and it shares many features of infectious disorder and encephalopathy. The impact is difficult to describe. The influential doctors in the “Wessely School” have performed no research looking at the quality of life in these patients, but others have done so. An American paper found that the quality of life is particularly and uniquely disrupted in ME/CFS, and that all participants related profound and multiple losses, including the loss of jobs, relationships, financial security, future plans, daily routines, hobbies, stamina and spontaneity. Activity was reduced to basic survival needs for some subjects. The researchers found that the extent of the losses experienced in ME/CFS was devastating, both in number and intensity (129).

An Australian paper found that patients with this disorder had more dysfunction than those with multiple sclerosis, and that in ME/CFS the degree of impairment is more extreme than in end-stage renal disease and heart disease, and that only in terminally ill cancer and stroke patients was the sickness impact profile (SIP) greater than in ME/CFS (130).

It must never be overlooked that the aim of the CMO’s Report is to help patients. The draft version of the CMO’s Report of 19<sup>th</sup> June 2001 acknowledges that the most severely affected cannot access NHS services or care and that in any event, little provision exists.

The plight of the ME/CFS sufferer is dire but it is only since 1970 that such heated controversy about the reality of ME has existed. In that year, two psychiatrists named McEvey and Beard published a paper in which they asserted that the 1956 outbreak of ME at The Royal Free Hospital was nothing more than mass hysteria (131). Those psychiatrists did not interview or examine a single person who had been affected in the 1956 outbreak (those affected included experienced nursing and medical staff): the purpose of their paper was said to be nothing more than a vehicle for a PhD thesis and neither doctor had any interest in ME. They based their conclusions on nothing more than a perusal of carefully selected old case notes and it is commonly held that they excluded from study the notes of those who had clear evidence of neurological disturbance. That paper opened the door to rife speculation which a group of the succeeding generation of psychiatrists appears since to have exploited with expedience.

For the past 15 years at least, people suffering from ME/CFS (supported by experienced clinicians) have done their utmost to get the severity of their plight acknowledged within the NHS. State benefits are refused or withdrawn without justification from even the sickest sufferers and there are difficulties amounting to the impossibility of sufferers being able to obtain insurance policy benefits. This has even been reported in Hansard (132). There are difficulties in obtaining early retirement on health grounds, with unfit patients being forced to return to work.

Apart from psychiatric units such as Wessely’s own CFS unit at King’s College Hospital, London, most of the handful of NHS specialist ME clinics have now been closed or are in the process of being closed: according to the Chief Executive of the Royal Free Hospital

(Martin Else) even the Royal Free Hospital, with its long association with ME, apparently intends to refer patients from the ME clinic to “ a local GP practice where there is an interest in the subject (or) transfer patients to existing specialists at other centres” (said to be Wessely’s psychiatric unit): in correspondence dated 23 August 2001 Mr Else wrote

“ We are in particular currently exploring (the GP) option which it is believed would provide an innovative development for the benefit of ME patients”.

Given that there is currently much unrest amongst GPs even to the extent that they are threatening a mass exodus from the NHS because they are so over-burdened and have insufficient time to look after their patients adequately in the permitted seven minutes per patient, such a move can hardly auger well for patients of the Royal Free ME clinic.

ME/CFS sufferers have been compelled to undergo inappropriate psychiatric treatment which has caused a worsening of their condition. Cover has been withdrawn by some private insurance companies (sometimes on the grounds that the policy excludes “psychiatric” illness). Suicide in ME/CFS sufferers is not rare and despite discussions a few years ago with the Chief Medical Adviser to the Department of Social Security (Dr Mansel Aylward) about the possibility of DSS funding for research into suicide in ME/CFS cases, nothing resulted. The most recent edition of *Perspectives (Summer 2001)* carries a feature entitled “Reporting the high suicide risk”.

Rather than becoming more liberal, medical attitudes to patients have hardened. Many patients have been treated with disdain and contempt by doctors and those with ME/CFS are not uncommonly refused a home visit, no matter how sick they are. The number of patients with ME/CFS being summarily removed from their GP’s list continues to rise.

Abusive articles about those with ME/CFS continue to appear. Editors of UK medical journals are known to prefer to publish articles and research which supports a psychiatric aetiology and to reject for publication papers which refute this aetiology. Those with ME/CFS are continually discriminated against, denigrated and dismissed and are effectively abandoned.

The plight of young people with ME/CFS is harrowing indeed: too many sick children are still being removed from the parental home and placed in institutional care. This aspect has recently been the subject of a major feature by the Countess of Mar in *The Daily Telegraph* (133). Jill Moss of The Association of Young People with ME recently announced her disappointment at having to inform people that AYME is having to deal with two tragic cases, one where Social Workers, accompanied by uniformed police officers, appeared unannounced on the doorstep to take a child away under a Child Protection Order and one in which a child had been made a Ward of Court.

### **Testimony of Dr Paul Cheney**

All this is happening to people who are sick, and about whom on 18 February 1993

Dr Paul Cheney (one of the world's most experienced experts on ME/CFS) testified before the US FDA Scientific Advisory Committee as follows:

“I have evaluated over 2,500 cases...At best it is a prolonged post-viral syndrome with slow recovery. At worst, it is a nightmare of increasing disability with both physical and neurocognitive components. The worst cases have both an MS-like and an AIDS-like clinical appearance. We have lost five cases in the last six months. The most difficult thing to treat is the severe pain; half have abnormal MRI scans; 80% have abnormal SPECT scans; 95% have abnormal cognitive-evoked EEG brain maps; Most have abnormal neurological examination; 40% have impaired cutaneous skin test responses to multiple antigens. Most have evidence of T-cell activation; 80% have evidence of an up-regulated 2-5A antiviral pathway. 80% of cases are unable to work or attend school. We admit regularly to hospital.... with an inability to care for self”.

In the UK, the Medical Director of the ME Association and other members of the CMO's Key Group are intending to advise UK clinicians that only limited investigations are appropriate and necessary in this devastating disorder.

### **The known opinion of the Deputy Chief Medical Officer**

At the Sounding Board event held in London on 7 June 2000 (which was an opportunity for invited participants to meet some of the officials involved in the preparation of the CMO's report on CFS/ME), the Deputy Chief Medical Officer Dr Sheila Adams made it quite clear that there is a growing realisation within the Department of Health that in chronic illnesses, patients know more about their illness and how to handle it than do doctors. She was speaking specifically to an audience involved with ME/CFS, so this point is worth emphasising. Dr Adams informed those present that an Expert Patients' Task Force was being established by the CMO and that Modernisation Action Teams are developing a national plan for the NHS which aims to empower and inform patients.

Although not mentioned by Dr Adams, it is the case that in March 2000 the Association of British Pharmaceutical Industry (ABPI) produced a booklet written by John Illman entitled “The Expert Patient”, the key points of which emphasise that we are now living with a global medium – the internet – and that the self-help movement is the fastest growing component of the health service industry; it states that the Department of Health is inviting the patient to join the information revolution; that information and communication skills are the prerequisite for the informed patient of the 21<sup>st</sup> century and those who do not develop these skills could become the new underclass in a two-tier health system. Notably, it states that patients are increasingly reluctant to accept medical advice at face value and that this trend may become more pronounced in Britain after reports that doctors have told some patients that ‘nothing more could be done’ when in fact the NHS would not pay for treatment. Significantly, the ABPI booklet states “*many*

*patients with chronic conditions know more about their illness than the individual GP who treats them.”*

### **The known opinion of the Chief Medical Officer**

Although not speaking about ME/CFS, on BBC Radio 4's 'The World Tonight' programme on 18 July 2001, the UK Chief Medical Officer (Professor Liam Donaldson) quite clearly said that the NHS should revolve around the needs, views and wishes of the public who use it; he added that the NHS should not be centred anymore around the needs, views and wishes of the medical profession and his opinion was that doctors do not necessarily know best.

Currently, ME/CFS appears to remain excluded from this philosophy.

### **The patients' voice**

People need answers to their questions, and those questions include asking *why* the patients' voice is not being heeded, and *why* just one group of psychiatrists has got such a hold on this disorder, and *why* the evidence of physical abnormalities is being so resolutely and persistently disregarded.

They do not forget that at the Sounding Board event on 7 June 2000, Professor Pinching (Deputy Chair of the CMO's Working Group on CFS/ME) said (*quote*)

“our worries about names, causation...OK are *fun*...” and  
“There is no need for research to treat this illness”.

This echoes the information contained in Research Paper 98/107 “Chronic Fatigue Syndrome / ME” by Dr Alex Sleator (1<sup>st</sup> December 1998) which is to be found in the House of Commons Library specifically for the use of Members of Parliament, page 39 of which records that Baroness Hayman informed the House that

“The Department of Health has not commissioned any research in this area, and has no present plans to do so. We are, however, working with the Linbury Trust on issues related to the treatment and management of the problem.”

It also echoes the recommendations of the 1996 Joint Royal College's Report on CFS, which advises that future research for an “organic” cause is unnecessary: indeed, the Joint Report states that some people

“use the results of immunological tests as evidence for a so-called ‘organic’ component in CFS (but) such abnormalities should not deflect the clinician from the (psychiatric) approach endorsed below...and should not focus attention

towards a search for an ‘organic’ cause”.

It seems that Professor Wessely’s influential involvement with industry (the Sainsbury connection) determines who gets the financial grants and what research is done on ME/CFS in the UK, and that the Department of Health is content for this situation to continue.

In his book “Faces of CFS” (Lyndonville, New York, 2000), US expert Dr David Bell writes

“If one tenth of the money that has been applied to the psychological studies of people suffering from (ME)/CFS had been used to study (blood volume, blood flow and brain hormones) instead, we would have seen some progress in understanding this terrible disease” (page 76).

If clinicians, especially GPs, continue to be misled and misinformed about ME and “CFS” and if the available knowledge continues to be given virtually no coverage in UK medical journals, then clinicians will not be able to recognise it and patients will continue to be neglected. It is time for the tide to turn. The prevailing “psychiatric fallacy” must be effectively challenged. It is unacceptable that many very sick and disabled people should have to suffer such continued and unjustified denigration.

There can be no justification for requiring patients whose basic laboratory investigations are “within the normal range” but who are clinically very sick to undergo compulsory exercise regimes on the dictum that if routine tests come back “normal”, then the patients cannot be physically ill and if they are not physically ill then they must be psychologically ill. Due in no small measure to the internet, patients are much better informed than their doctors and if provoked, they will resist, if necessary through the Courts. There are too many horror stories of people who in the early stages of their illness were forced to undergo CBT and graded exercise and who are now house or even bed-bound yet *still* the patients’ representatives are giving advice that CBT is to be given to all patients with a diagnosis of ME/CFS who can physically attend a hospital outpatients department.

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### **Support for Professor Hooper**

Just after the Hooper document was released, an internet posting dated 3 July 2001 stated:

***“ Hooper is coming out in public saying that people with ME should be investigated properly....He is critical of Charles Shepherd and Pinching for going along with the ‘don’t investigate’ line. He argues why it is illogical***

*and not in patients' best interests.... Looks like he feels the Wesselyites will control the outcome, especially the 'don't investigate' line (just like the Royal Colleges report in 1996). Thank heaven, someone is prepared to nail their colours to the mast and take a principled position in support of proper investigation....it's so great having a leading medic coming out and saying it...this way the real debate will be out in the open and I for one would back Hooper all the way”.*

Another internet posting dated 7 July 2001 stated

*“Professor Hooper is the first...in this country of any eminence who has actually come out and said what so many of us have been saying in recent years. He's supporting the concerns of the severely ill and disabled....These issues are not being faced openly by either Dr Shepherd or Professor Pinching. The use of excuses, the negativity, the procrastination, the rejection of the scientific data no matter how significant, the failure to campaign effectively for urgent research for people who have been severely ill and disabled for decades is atrocious... Many other people agree....Thankfully, people of more influence are starting to come out and ask legitimate questions...it's been well overdue. I hope that both Professor Pinching and Charles Shepherd can start giving honest and full answers to the critics they've been ignoring for so long. Patients need doctors who are proactive, assertive, keen, focused and interested in seeking out the questions to help those who are in desperate need of the answers”.*

Another observer wrote a letter dated 9 July 2001 stating

*“I was pleased to see the Sally Montague / Malcolm Hooper paper published on the Co-cure website. Hopefully the truth is finally becoming too obvious for anyone to ignore. If only the CMO's Working Group would acknowledge that ME and CFS are two separate entities then we could really begin to build on the truth and start to help people with ME instead of cause them more harm. I will try to write to Malcolm Hooper to thank him and his associates for an extremely well-written document that will hopefully make many people reconsider their preconceived ideas about the illness we know as ME”.*

Professor Hooper has received much support, one correspondent on 10 July 2001 stating simply

*“ I applaud your courage...and your steadfast stance on these matters”.*

On 6 August 2001, yet another internet posting made some salient points:

*“Of course I have been unhappy with what the MEA has not done for us over the years, given that it was meant to be our right arm and mouthpiece. There have been so many unpleasant rumours about disbelief in the 'real' research and use of members' money to pay lawyers to threaten litigation.....Are we all*

*witnessing it happening...? So in essence if any of us question Shepherd's views or actions publicly he is likely to threaten us. So if "Sally Montague" represents all of us who support this report (the original Montague/Hooper paper), can we all be sued?"*

On 21 August 2001, Derek Peters of the Northern Ireland Campaign for ME/CFS, Gulf War Veterans and OP sufferers posted the following:

***"The N.I Campaign for ME/CFS, N.I. Gulf War Vets, N.I. Organophosphate Sufferers declare their support for the courageous efforts of Professor Malcolm Hooper in confronting the illness deniers in the medical establishment and his unflinching championing of the truth in support of patients' rights to medical investigation, proper diagnosis and treatment."***

Clearly, the views of Charles Shepherd about the "conduct" of Professor Hooper are not shared by everyone.

Despite Shepherd's contrived allegations, the Montague/Hooper paper did not mount a "personal attack" on Shepherd but it did require him to be publicly accountable for his professional advice, which in essence is the advice of Professors Wessely and Pinching; as all are members of the CMO's Working Group, all ought to be equally accountable.

Since 1987, countless ME sufferers and carers have travelled the "correct" route of putting their valid concerns before the ME charities, before at least two Chief Medical Officers and before the Presidents of the various Royal Colleges, but it seems that each and every approach has been met with dismissal. It seems that such dismissal is about to be officially perpetuated yet again, but this time there are those who, despite the threats and outright intimidation, will not be silenced.

Montague and Hooper and their associates believe, as does Dr Sam Etherington of the BMA Council, that doctors must be more personally accountable (134).

Montague and Hooper and their associates are encouraged to note that having received unfavourable comments on his draft Westcare report, Richard Sykes has recently amended it and they quote from Sykes' Preface, with which they concur:

*"These are changing times for doctors and other health practitioners. Having enjoyed for a long time considerable immunity from public inspection, they are now very clearly being held to public account. For many practitioners this transition to public accountability will be uncomfortable, particularly for those who do not meet the high standards that are expected of them...."*

Montague and Hooper believe that the prevailing culture which protects physicians from being held personally accountable is no longer tenable, because it means that the system of silence ensures that the beliefs and actions of doctors which need to be challenged are *not* challenged, and this is potentially harmful to vulnerable patients.

Sally Montague  
Malcolm Hooper  
and associates

25 August 2001

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