

# **Notes on the involvement of Wessely et al with the Insurance Industry and how they deal with ME/CFS claims**

Attached as Appendix I to these notes are extrapolations from a formal Statement by Kevin Robinson, a university-educated person with ME/CFS (PWME) who has had an intimidating battle with his Permanent Health Insurance (PHI) company. The original statement is available. These notes may provide some insight as to why a genuinely sick man had to take on the mighty insurance industry.

Attached as Appendix II is a Statement from another ME sufferer, Robert Sclater, about his nine-year and still on-going dealings with *his* PHI company.

Attached as Appendix III are quotations from the published works and spoken views of psychiatrist Michael Sharpe, who acts for insurance companies against claimants with ME/CFS.

Much of the controversy about ME seems to stem from multi-national industry, especially the chemical / pharmaceutical industry and the insurance industry, and from the activities of those whom these industries employ, especially psychiatrists who act as medical officers to the insurance companies and who appear to be employed to deny legitimate claims, most particularly the claims of those with ME/CFS.

A decade ago, the insurance company UNUM (one of the largest disability insurers) reported that in the years from 1989-1993, disability claims for ME/CFS had increased by an average of 460% and in order of insurance costs, ME/CFS came second in the list of the five most expensive conditions, being three places above AIDS.

## **Brief background**

In 1988 the giant American insurance industry realised that the incidence of ME was increasing rapidly and became concerned about the rise in claims for long-term chronic illness due to the disorder. There is no NHS in the US, so insurers orchestrated the creation of a “new” disorder which was named “Chronic Fatigue Syndrome”, with “fatigue” being the dominant symptom. They chose this name because “fatigue” is ubiquitous and it afforded them an expedient way to deny claims which could be said to be arising from such a non-specific symptom as “fatigue”. World class experts in ME who had been on the case revision panel resigned from it because the newly constructed “CFS” bore little relationship to the ME with which they were so familiar and which had unequivocal neurological signs with incapacitating post-exertional exhaustion, whereas “CFS” focused on “fatigue” or “tiredness” (a totally different symptom).

Following the 1988 US criteria for “CFS”, in 1991 UK psychiatrists Michael Sharpe, Simon Wessely and Peter White were instrumental in the formulation of new “guidelines” (known as the “Oxford” case definition) in which they deliberately widened the case definition so that it expressly included psychiatric disorders (specifically depressive disorders and anxiety disorders).

In 1994, the US Centres for Disease Control (CDC) produced yet more “guidelines” for the case definition of “CFS”, this time making sure that **all** physical signs were removed from the case definition. (“Signs” are observable by doctors, whilst “symptoms” are described by patients). Both Michael Sharpe and Simon Wessely were involved in this 1994 re- definition of “CFS”.

## Current situation

Evidence exists which confirms the association of these psychiatrists with the insurance industry. The ME community is well aware of the long-time involvement of Michael Sharpe with the insurance company UNUM, of his association with Allied Dunbar and of his recommendation to insurers that claimants with a diagnosis of ME/CFS should be subject to covert video surveillance. The ME community is also aware that on 17<sup>th</sup> May 1995 Mike Sharpe and Simon Wessely were the main speakers at a UNUM-supported symposium held in London entitled “Occupational Health Issue for Employers” (where ME was described as “*the malingerers’ charter*”) at which they advised employers how to deal with employees who were on long-term sickness absence with “CFS”. Moreover, in UNUM’s “Chronic Fatigue Syndrome Management Plan”, ME/CFS is described as “*Neurosis with a new banner*” and the same document states “*UNUM stands to lose millions if we do not move quickly to address this increasing problem*”.

The insurance companies known to be involved in ME/CFS claims include, in addition to UNUM, Swiss Life, Canada Life, Norwich Union, Allied Dunbar, Sun Alliance, Skandia, Zurich Life and Permanent Insurance, and as Re-insurers, the massive Swiss Re (not the same as Swiss Life). Swiss Re are currently building a huge circular eyesore in London which has been dubbed the “gherkin”. These insurance companies all seem to be involved in RE-INSURANCE; for example, Norwich Union uses Swiss Re and psychiatrist Peter White is one of the Chief Medical Officers for Swiss Re. Their other “CFS experts” are Michael Sharpe and Simon Wessely, and they also use psychiatrist Anthony Cleare (a frequent co-author with Wessely who works in the same department) for the insurers. There seem to be two ways in which claims are underwritten between insurers and re-insurers: either the insurers agree to pay claims up to a pre-determined cut-off limit, after which the re-insurer becomes liable, or else the insurer and the re-insurer agree from the outset to share the costs of a claim.

This means that there is little hope of an ME claim succeeding, because both the insurers and the re-insurers all use the Wessely School psychiatrists to inter-refer claimants with ME/CFS. Given that insurers can refuse to pay out on claims until the claimant with ME/CFS has undergone a “rehabilitation” programme arranged by the insurer, this must surely result in a major conflict of interests because Peter White, Michael Sharpe and Wessely’s assistant Trudie Chalder (a former mental nurse who obtained a PhD and who seems often to be used as a grant front by Wessely) are the beneficiaries of the MRC’s latest £2.6 million grant to “strengthen” the very weak evidence that cognitive behavioural therapy (CBT or “brain-washing”) and forced “rehabilitation programmes” (graded exercise therapy or GET) actually work for those with ME/CFS, but the clear evidence is that they do not, and are in fact harmful.

Given that research funds are said to be so limited and particularly in view of the scathing criticism of the work of the MRC detailed in the recent (March 2003) Report of the House of Commons Science and Technology Select Committee (reference: “The Work of the Medical

Research Council” HC132), what is the MRC’s explanation for funding a four-year project by these psychiatrists on yet more psychosocial research into “CFS/ME” in preference to funding soundly-based projects on the known biological abnormalities which underpin this disorder? The Select Committee Report constituted an unprecedented attack on the workings of the MRC, finding that research funding was wasted on useless projects, but Wessely seems unperturbed (and has now left the Boards on which he served).

Members of Parliament are on record as being gravely concerned about the difficulties which their constituents with ME/CFS suffer at the hands of the disability insurers, as recorded in the House of Commons debate chaired by Sir Alan Haselhurst on 21<sup>st</sup> December 1999 (reference: Hansard 147WH-166WH). In particular, Members of the Scottish Parliament are very aware of the involvement of Mike Sharpe with the insurance industry and with the processing of claims due to ME/CFS and are extremely concerned about the situation.

It is known that insurance company tactics are firstly to **deny** ME/CFS claims, then to **delay the processing** of those claims which they have not managed to destroy, then to **discredit** the claimant by such ploys as covert video surveillance, supported by the supposedly independent opinion of the insurers’ medical officers (ie. this group of UK psychiatrists). The primary aim of the insurance companies is known to be to avoid paying out on claims. Recently there has been much international publicity about UNUM, with the exposition in Courts of Law of their strategy not to pay the valid claims of their policyholders (including those with ME/CFS). Most vulnerable are policyholders with so-called “subjective illnesses” like ME/CFS.

In just one case alone (a claim brought by Dr Joanne Ceimo from Arizona, who was unable to work as a cardiologist following a neck injury), UNUM faces \$84.5 million damages for “mistreating an injured policy holder”, including \$79 million in punitive damages. Steve Dawson, Dr Ceimo’s attorney, said that evidence from previous policyholder cases against UNUM helped pave the way for this verdict.

In another case, it was revealed that UNUM had set up a system that appeared to put more emphasis on boosting company profits than on policyholders’ rightful claims by brushing aside legitimate claims. It was shown that this was part of a long-running campaign, and a judge in California (Judge O’Malley Taylor) criticised UNUM, saying “There is clear and convincing evidence that (UNUM’s) bad faith was part of a conscious course of conduct firmly grounded in established company policy”

A federal lawsuit filed in New York seeks to represent tens of thousands more UNUM policyholders as part of a class action against the company, and there have been hundreds of policyholder lawsuits already against UNUM, with the state of Georgia recently fining UNUM \$1 million over its claims handling practices. The company’s own former medical director has stated that UNUM’s primary purpose and policy was to deny disability claims and that company medical advisers were encouraged to use language in their patient reports that would support claim denials. If too many medical opinions favoured the policyholder, the doctors would be reprimanded or sacked.

In another claim against UNUM, a Florida federal court awarded \$36.7 million to ophthalmologist John Tedesco when UNUM refused to pay his benefits after he was diagnosed with Parkinson’s disease.

The case which is probably of most interest and relevance to the ME/CFS community is that of Dr Judy Morris versus UNUM (December 2002). Just before filing her lawsuit against UNUM, Dr Morris, an ME/CFS sufferer who can no longer work in the field of Accident and Emergency (ER) medicine, attended a conference in Boston and spoke to Dr Mike Sharpe in person, having found out that it is Sharpe's research on "CFS" which UNUM uses to support the view that CFS is a psychiatric condition and upon which UNUM relies to support the contention that psychotherapy could effectively cure it. She told Sharpe that his research was being used by UNUM to deny CFS claims. Later, she received an email from Sharpe telling her that UNUM's employees were not the monsters she was making them out to be, whereupon she wrote back asking him how much UNUM paid him for his "in-service". He did not reply.

Dr Morris, on her own, obtained two further opinions from experts about her condition, one of whom (Dr Richard Glew, an infectious diseases specialist) concluded that Dr Morris certainly is unable to pursue full-time, high pressure ER work. The other expert was Professor Nancy Klimas, an immunologist from the University of Miami in Florida and a leading researcher in ME/CFS, who tested Dr Morris' blood, concluding that there was marked T-cell activation, abnormal CD4 subsets, decreased NK cell function and markedly increased general immunological activity, and that such results were "completely consistent with (ME)/CFS, clinically, historically and immunologically".

UNUM was sent this objective evidence and in addition was informed by Dr Morris' GP Dr McIlvaine that **the US Centres for Disease Control (CDC) does not consider ME/CFS a psychiatric problem**, but all this was completely ignored by every defendant at UNUM, who maintained that if she would just have cognitive behavioural therapy (ie. a psychiatric intervention), Dr Morris "can begin focusing on her many accomplishments rather than on her perceived failures (and) she will begin the path to recovery and return to work" (Exhibit #13-6).

Michael Sharpe's close involvement with UNUM and what he states about ME/CFS in the UNUM company Report entitled "Trends in Health and Disability 2002" was brought to the direct attention of the UK Medical Research Council, including Sharpe's confirmation of the involvement of PRISMA (see below) in the delivery of psychotherapy in the form of cognitive behavioural therapy for those with "CFS/ME". In that UNUM Report, Sharpe advises that a psychiatric classification provides an alternative diagnosis of somatoform (psychiatric) disorder for patients with "medically unexplained symptoms" such as (ME)/CFS and that such a classification has important treatment implications. Of interest is the fact that in other areas of medicine, experts believe that the concept of "somatisation" (which rests on the assumed translation of repressed emotion and psychological conflicts into bodily symptoms) is fundamentally flawed and should be abandoned, because a diagnosis of somatisation will become a non-psychiatric diagnosis once the symptomatology is adequately explained by disordered physiology (well-known examples being Parkinson's Disease and multiple sclerosis).

PRISMA stands for Providing Innovative Service Models and Assessments. It is a multi-national healthcare company which is especially concerned with long-term disability from the perspective of governments, service providers and insurance companies. It claims to have developed a "unique treatment programme" for "hopeless" patients (in which it specifically includes those with ME/CFS) and it claims that such patients "avoid physical exercise and social activities, as they fear these may trigger new bouts of complaints". The PRISMA

programme places heavy emphasis on training people with ME/CFS to regain a “normal life again, with exceptional (*sic*) good results”. At PRISMA, they believe that the medical system in many countries has difficulty in providing the kind of treatment they promote: in the PRISMA Round Table, they discuss these issues with “leading experts in medical care, the insurance industry and government officials and provide recommendations to healthcare policy makers”. Many people are now aware that Simon Wessely is a Corporate Officer of PRISMA (and is ranked higher than the Board of Management, being a member of the Supervisory Board) but for some considerable time he failed to declare this significant interest. In the UNUM Report Sharpe confirms that PRISMA has already begun funding “rehabilitation” of UNUM policyholders with programmes of CBT on behalf of the NHS. Of special significance is the fact that UNUM is advising the UK Benefits Agency doctors on how to deal with chronically ill ME patients.

The reliance by insurance companies upon these psychiatrists in cases of ME/CFS has resulted in an insurance scandal of epic proportions. Underlying and sustaining this scandal in the UK are psychiatrists Simon Wessely, Michael Sharpe and Peter White, together with other psychiatrist colleagues such as Anthony Cleare. Their power, control and influence are seemingly without limit.

Examples of the control exerted by this group of psychiatrists include the “official” view about ME/CFS, not only within medicine itself [encompassing as it does the medical education of undergraduates; post-graduate medical education; editorial policy of medical journals; the peer-review system of many medical journals (not limited to UK journals); national and international medical and scientific conferences; the policy on ME/CFS of the various medical Royal Colleges (where the psychiatric view prevails, as exemplified by (i) the 1996 Joint Report on CFS of the Royal Colleges of Physicians, Psychiatrists and General Practitioners, in which Wessely and Peter White were prime movers (ii) the

document produced by The Royal College of Paediatrics and Child Health entitled “The Next Ten Years”, which is a joint training project with the Royal College of Psychiatrists and which categorises children with ME/CFS as having mental health problems and (iii) the production by the Royal College of Psychiatrists of a series of Fact Sheets entitled “Mental Health and Growing Up: Fact Sheets for parents, teachers and young people”, with Fact Sheet 33 listing CFS as a mental illness); the policy on ME/CFS adopted by the Royal Society of Medicine and its publishing arm; the policy on ME/CFS adopted by Government departments and agencies; the funding of medical research into ME/CFS (dominated in the UK by psychiatric studies); the control of supposedly independent Working Groups such as the Chief Medical Officer’s Working Group on “CFS/ME”; the research strategies on ME/CFS favoured by the Medical Research Council (MRC), where Wessely was on three important Boards including the Health Service and Public Health Research Board, the Neurosciences and Mental Health Group and the Monitoring and Evaluating Steering Group etc] but also the within the law and medico-legal issues, where Wessely is keen to promote himself as a medico-legal expert on ME/CFS. His influence also extends to the involvement of industry and politics in medicine, particularly his involvement with the Linbury Trust which belongs to the Sainsbury supermarket family: since 1991 it has funded over £4 million for research into “chronic fatigue”, almost all of it by Wessely and his psychiatrist colleagues. Lord (David) Sainsbury of Turville is currently Minister for Science in the Labour Government and as such, he has nominal control of the Medical Research Council. Wessely is an adviser to the Ministry of Defence and he recently acted against Gulf War veterans in a Court case over compensation; further, he is very proud of the fact that he has been funded by the US

Pentagon in respect of GWS. He is involved in NATO. His wife, also a psychiatrist and GP, is Senior Policy Adviser to the UK Department of Health. This group of powerful and influential psychiatrists has a perfect set-up: by allowing no-one to oppose them and by discrediting and intimidating (with threats of legal action) those who try, they ensure that nothing changes in the perception of ME which they wish to promote.

The truth about ME/CFS is being suppressed by these psychiatrists and those whom they control and influence: their dogma is that ME/CFS is merely an “abnormal illness belief” resulting in de-conditioning which must not be investigated, treated or validated, and those claiming to suffer from it must not be “pandered to” by “naïve” clinicians and must not be given social services support, state benefits or insurance payments. Instead, those claiming to be ill with ME/CFS must be brain-washed into altering their “mis-perception” that they are physically ill. If the motive is not financial, what can it be? What is so appalling is that this is not ignorance, but the deliberate and determined suppression of the available international medical and scientific evidence which has demonstrated organic pathology in what is a very serious and complex disorder.

Since 1987, Wessely has been unceasing in denying the existence of ME and in asserting that “CFS” is a somatoform (psychiatric) disorder which should be managed by cognitive behavioural therapy delivered by psychotherapists according to his own specification.

An illustration of Wessely’s blatant determination to get ME re-classified as a psychiatric disorder is to be found in the WHO Guide to Mental Health in Primary Care (November 2000), which is a clear attempt to subvert and manipulate the whole issue surrounding ME, with the aim of allowing both Government and the insurance companies to evade paying benefits to many extremely sick people. Use of the WHO logo implies that contributions carry WHO sanction, but in this particular instance, this is not the case and the WHO has confirmed in writing that what Wessely published about the re-classification of ME as a mental disorder did not carry WHO approval and that what had been claimed about ME by Wessely was “*at variance with WHO’s position*”.

For the avoidance of doubt, six illustrations of Wessely’s control over the national perception of ME/CFS are provided here:

1. when a constituent or someone on their behalf such as the Citizens’ Advice Bureaux requests information on ME/CFS from a Member of Parliament, the MP usually turns to the House of Commons library for that information: however, it is known that an MP is provided with information selected for him by House of Commons Library staff and that MPs are provided **only** with information endorsing a psychiatric aetiology of ME/CFS, even though medical textbooks / books / journals / reports etc which demonstrate the organic nature of the disorder are known to have been placed in the Library for the use of MPs. When the reason for this selectivity was legitimately queried, an MP’s constituent received an angry and intimidating letter from the Head of the House of Commons Library (original letter available). This seems to indicate the immediate State / Government control response when people dare to ask how an MP is provided with information about ME/CFS. The same control of information seems also to apply in the House of Lords, because it has been ascertained that the information supporting an organic basis for ME/CFS has been removed to the Library archives, so is not available unless specifically requested.

Unless people know what is in the archives by name, it is difficult for them to request such information.

2. During the life (1998-2002) of the Chief Medical Officer's Working Group on ME/CFS, members were ordered not to discuss the deliberations and were even threatened with the Official Secrets Act (documents available). If the psychiatric lobby which dominated that Working Group is so confident that they are right, why the need to force the suppression of opposing views by resorting to threats of prosecution under the Official Secrets Act in a Working Group that had nothing to do with State security but was supposed to be acting simply in the best interests of sick people?
3. During the life (2002-2003) of the MRC Research Advisory Group on strategies for future research into "CFS/ME" (this particular term was adopted in order to accommodate the psychiatrists), someone who is involved in High Court litigation over ME believed it was imperative for MRC RAG members to study the seminal international textbook on ME/CFS edited by Byron Hyde et al. At her own expense, she had previously spent £800 so that members of the CMO's Key and Children's Groups (see (2) above) could each have a copy of this 724 page textbook, arranging for 128 copies to be flown from Canada direct to the Department of Health Headquarters Disability Section at Quarry House in Leeds. She herself arranged with the Department of Health that out of the 128 copies, 20 copies should be sent from Leeds to London for the CFS/ME Working Group members; this meant that there were 108 copies left at the Department of Health HQ in Leeds, but she was informed that all would be put to very good use. When she subsequently wanted to make sure that each and every member of the MRC RAG should have a copy, she contacted Quarry House in Leeds to expedite this but was informed that the Department of Health had "lost" the remaining 108 copies of the textbook. She finally managed to track down a few copies, having been informed by someone called Sue Pemberton that they had been dumped at the Cystic Fibrosis Service at Seacroft Hospital in Leeds, but discovered that the majority were missing, believed to have been trashed. She then spoke to Elizabeth Mitchell at the MRC and asked her to ensure that RAG members should each have the opportunity to see one of the remaining copies of the textbook, but Elizabeth Mitchell insisted that the woman should herself arrange and pay for the two copies to be sent from Leeds to London, which she did. However, she discovered that Elizabeth Mitchell had made the two copies of the book available to RAG members only "before and after one meeting", which Elizabeth Mitchell said was sufficient. It is not difficult to realise that seven busy people could not study a 724 textbook if only two copies were available to them for a few brief moments before and after just one meeting. The woman wrote to the Chief Medical Officer about such a wholly unacceptable situation but the response she received was nothing more than an "I'm not interested" letter. When it finally appeared, the MRC RAG Report on the direction of future research and management in ME/CFS accepted the view of Wessely et al.
4. Last year, Wessely orchestrated a campaign in the British Medical Journal (BMJ) to identify "non-diseases", asking readers to vote in a poll of what they considered were not valid diseases. ME was nominated (apparently by Wessely himself), along with bags under the eyes. As a direct consequence, ME patients were removed from their GP's list, being tersely informed that the GP did not treat "non- diseases".

5. The UK national newspapers frequently run headlines such as “*ME’s mainly in the mind---Study reveals yuppie flu can be cured by positive thinking*” (Daily Express, 5<sup>th</sup> January 1996, about one of Mike Sharpe’s studies) and “*ME is just a myth, sufferers told*” (Sunday Telegraph, 20<sup>th</sup> November 1994, about the conclusions of 150 British psychiatrists attending a pharmaceutical conference in Jersey), whilst the medical trade magazines (widely distributed free to doctors, especially to GPs, and to hospital libraries by the drug companies) have made a point of promoting psychiatric interventions for those with “CFS” and of mocking and denigrating sufferers from ME/CFS in a way they would not dare do about patients with multiple sclerosis or other neurological disorders, yet ME is formally classified by the WHO as a neurological disorder. For example, on 1<sup>st</sup> April 1994 “GP Medicine” carried a bold banner headline proclaiming “*GPs despise the ME generation*”; on 12<sup>th</sup> January 1995 “Doctor” magazine ran a feature called “Bluffer’s Guide” by Dr Douglas Carnall, in which he wrote “*Modern bluffers prefer the term chronic fatigue syndrome....if they really insist on a physical diagnosis tell them 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. Or, if you’re feeling tired, you could always refer*”; “Doctor” magazine also ran a quiz by Dr Tony Copperfield (known to be the pseudonym of a GP in Essex) in which GPs were asked to choose from four possible answers to the question “*What would be your initial response to a patient presenting with a self-diagnosis of ME?*” The correct answer was “*For God’s sake pull yourself together, you piece of pond life*”. One of the worst and most damaging examples was published on 20<sup>th</sup> October 2001 in “Pulse” in a series called “Choices for the new generation of GPs”. The item on which three GPs provided their approach was entitled “*ME patient with litigation history demands inappropriate therapy*” and the approach provided by Dr Mary Church (this is her real name: she is a Principal in a practice in Blantyre, Scotland and most disturbingly of all, she is a member of the British Medical Association medical ethics committee) was particularly contemptuous but is not untypical: “*Never let patients know you think ME doesn’t exist and is a disease of malingerers. Never advise an ME patient to make a review appointment. At the end of the consultation, I say goodbye, not au revoir. Always refer ME patients to a local expert. It’s a wonderful way of passing the buck*”. Although some of these items are doubtless intended to be amusing, it is not appropriate for a doctor to write with such contempt about **any** illness, physical or psychiatric, which ruins lives and quite frequently causes death, and these items are damaging because they lend credence to what many doctors privately admit they still believe (ie. Wessely’s view that ME does not exist and that “CFS” is a psychiatric disorder).
6. As recently as Sunday 15<sup>th</sup> June 2003, Clare White, a woman in her early 60s who has been severely affected by ME for many years, was taken ill: being unable to contact her GP (because the surgery had only an answering machine telling patients to telephone NHS-Direct) she was forced to telephone 999 for an ambulance. She was taken to the A & E Department of a flagship London hospital. She was in great distress, suffering from acute renal colic and was vomiting. On arrival she was seen by a very helpful, polite, considerate and conscientious junior doctor who examined her and found that she had many abnormalities, including blood in her urine. She was given an injection of morphine. He asked her if she had any other diagnosis, so she told him she suffered from ME. He started to organise various investigations, including an IVP, informing her of what was proposed. The woman subsequently

heard him discussing her case with a more senior colleague just outside her cubicle and was dismayed to hear the senior doctor instruct the junior doctor to do nothing because ME was a “personality” problem which did not need further investigation. She definitely heard this said very clearly. The junior doctor repeated forcefully that the abnormalities he had found had nothing to do with ME and that she needed investigating. The two doctors had a heated argument, the outcome being that the junior doctor, although clearly very angry, was pressurised into not investigating further. In her own words, “a stop was put on the works” and she was lead to believe that investigations were complete. To his credit, the junior doctor, who was visibly uncomfortable, arranged a wheelchair and ambulance transport for the woman to be taken home. She lives alone and has no-one to look after her. The pain has now spread to the bladder region but she is receiving no medical care and no social support. No-one wants to know.

It can be seen that the power and influence of this group of psychiatrists is truly immense, so it is inevitable that their influence prevails throughout the insurance industry, since they are preaching what that industry wishes to hear. These psychiatrists follow their prejudices and their pay-masters rather than the medical science. Even though psychiatry is not an exact science and is riddled with pseudo-scientific jargon, Sharpe and Wessely et al are demanding positive “proof” before they will allow ME/CFS to be designated as a physical illness, yet they consider it perfectly acceptable that they themselves should designate ME/CFS as “psychiatric” on nothing more than the fact that there is as yet no single definitive test for ME/CFS and on the fact that routine laboratory tests are usually normal in ME/CFS --- significantly, it is these same psychiatrists who, knowing that routine screening will be normal, insist that only basic screening tests should be done in ME (asserting that other investigations would serve to reinforce patients’ mal-adaptive belief that they were physically sick and would thus prolong their pseudo-illness), whereas it is the more complex investigations which are delivering hard evidence of serious organic pathology. Disgracefully, in the UK such tests are denied to ME patients just because the Wessely School says so. These psychiatrists ignore the fact that in a person bed-bound and wholly dependant due to multiple sclerosis, basic tests would also come back negative and in our own lifetime, MS was designated by psychiatrists as “hysterical paralysis”. It should be recalled that on 11<sup>th</sup> January 2002 the UK Chief Medical Officer went on the record stating that ME/CFS should be classed as a chronic condition with long-term effects on health, alongside other illnesses such as multiple sclerosis and motor neurone disease (for which he was publicly castigated in the BMJ by Mike Sharpe).

Correct classification does matter, not only because it leads to correct investigation / treatment / management, but because for people who are severely sick with a serious neuro-immune disorder, to be wholly dependent on disability payments (either from an insurer or from the state) when both insurers and the state inappropriately classify an illness as “mental” and who therefore refuse to pay legitimate claims results in unspeakable distress, leading to very high rates of suicide in ME/CFS. Most insurers exclude psychiatric illness from eligibility and in the UK, state benefits are paid at a lower rate for those with a psychiatric label.

Of particular concern in this respect is the matter of the Strasbourg Convention and the reform of the UK Mental Health Act, proposals for which were drawn so widely that they would give psychiatrists far greater powers to enforce compulsory psychiatric treatment upon both adults and upon children even against the wishes of their parents.

It seems inevitable that as long as these psychiatrists reign unopposed by the establishment, then as far as ME/CFS is concerned, not only incalculable human suffering but also flawed studies and gross injustice will continue unabated in the UK and will even be promoted by Government agencies. It also seems inevitable that there will be a corresponding increase in insurance company profits, as a substantial number of very sick people with a complex neuro-endocrine-immuno-vascular disorder are not going to be allowed to stand in the way of those vested interests.

Bad science, bad “policy” and vested commercial interests deserve to be exposed and criticised.

## **SOME ARTICLES WHICH HAVE HIGHLIGHTED THE PROBLEM**

**ME sufferers forced to battle with insurers** Christine Stopp. *Independent on Sunday* 27<sup>th</sup> June 1993. This is about Michael Lever from Christchurch and his battles with UNUM: Lever worked with Dr Charles Shepherd over the insurance issue but Shepherd, who is close to Wessely, has just been sacked by the ME Association from his position as Medical Adviser and the Association (a charity) is about to disappear through gross financial mismanagement.

### **Life insurers tighten up on ME claims Gavin Lumsden. *Times, Sat 7<sup>th</sup> December 1996***

**Can a machine be fair?** Anjana Ahuja *Times*, 21<sup>st</sup> June 2001. This exposes how insurance companies use an organisation called **Managed Medical Care** to assess chronically ill claimants with ME, which uses a test called the Blankenship evaluation to decide whether ME claimants are genuine. (“Concern is growing over a computerised test used by insurers to decide whether ME claimants are genuine”). Unsurprisingly, the test shows that ME people are making only “sub-maximal effort”, so claims can be denied. These “functional capacity evaluations” or FCEs are used by several insurance companies. James Miller Craig, a solicitor with the London firm Royds Treadwell (tel: 0207-583-2222 or [jmc@royds.law.co.uk](mailto:jmc@royds.law.co.uk)), says that over the past decade he has represented dozens of patients whose insurance payments have stopped after FCEs. Swiss Life uses Managed Medical Care for its FCEs, whose manager is (or was) Andrew Pearce and whose managing director is (or certainly was) Tom Grant. **Database searches on FCEs have proved interesting.**

## **CONTACTS**

1. **Monica and Andrew Dale**, Greenwater, 86 Clarence Road, East Cowes, Isle of Wight, PO32 6HA. email: [monica@funfarm.demon.co.uk](mailto:monica@funfarm.demon.co.uk)

Monica is a former nursing sister and they run a support group for people with ME who have problems with insurance companies and with getting their occupational pension. They have an enormous database of information. They have been very politically active to the extent that they managed to force the NHS Pensions Agency to pay out about £20 million (200 of their cases were re-visited by the authorities and were then awarded what they had been denied). They have truly harrowing stories: one woman was sent to Wessely who diagnosed depression and had her Sectioned under the Mental Health Act. They know of many suicides, of course. Many sick people had to wait for 6 years to get their payments. They were involved with the All Party Parliamentary Group on ME (APPG -- see below). The Dales were harassed and were videoed and followed by people in cars. In other words, they were intimidated, but would not give up. They got an Early Day Motion supported by 170 MPs. They know what they are talking about.

2. **Robert Sclater** He contacted Malcolm Hooper with information he wanted to be used. His address is 98 Forker Avenue, Rosyth, Fife KY11 2UG. Vance Spence knows him also. His PHI insurer wanted to send him to Mike Sharpe in his claim against Allied Dunbar but knowing of Sharpe's involvement with them, he refused to be seen by Sharpe. His Statement is explicit.

3. **Ian Woodcroft** (APPG) He is Tony Wright's Parliamentary Assistant and is new to the post. Tony Wright is the MP for Gt Yarmouth who runs the All Party Parliamentary Group on ME; they have a huge amount of information on the problems of people with ME and their fights with insurance companies. Ian's email is [ianwoodcroft@hotmail.com](mailto:ianwoodcroft@hotmail.com) and his direct line phone number at the House of Commons is 0207-219-3447. He would be able to provide the Minutes of the APPG on ME of their meeting on 25<sup>th</sup> January 2000 in Committee Room 18; it was chaired by Tony Wright and was entitled "Presentation and Discussion: Permanent Health Insurance" and speakers included Clive Efford MP, Alison Whitely, Monica Dale and John Sharpe. John Sharpe has been in contact with the Consumers Association and with the OFT who both recognise the problem. Tony Wright has a very large postbag about it.

4. **Kevin Robinson** - his Statement is also explicit.

5. **Clare White** is a university graduate who taught French. She is a long-term severely affected ME sufferer.

## **APPENDIX I: EXTRACTS FROM STATEMENT OF KEVIN ROBINSON**

**re: Peter White, Chief Medical Officer of the world's second largest re-insurer**

In 1999 Peter Denton White was Chief Medical Officer for Swiss Re and worked for them on Thursday mornings. (He appears to have been one of four doctors holding this title). I also have one piece of evidence that Michael Sharpe worked for them at about the same time, but I cannot confirm any position or title. The letter obtained has a name obscured, but the person is described as a CFS expert, who had recommended Anthony Cleare as a medical

examiner, and the penultimate letter of his name is clearly a “p” – the stem below the line is unmistakable and cannot be any other letter. In this obscured form his name appears twice on the letter.

Re-insurance may seem irrelevant, because customers, and even abused policyholders are often unaware of the name of the re-insurer who may be re-insuring their policy, but re-insurers may be carrying more than half of the insurance industry’s exposure to ME. I would encourage any PHI claimants to make a subject request under the Data Protection Act from both the insurer **and** re-insurer since one may disclose documents that the other has held back.

There are two common arrangements between insurer and re-insurer, which I have previously found on Swiss Re’s website but have been unable to find again: one in which they split the cost of the claim and one in which the insurer pays everything up to a certain limit and the re-insurer pays everything beyond the limit. In the latter case PHI claims from PWME (*persons with ME*) would be very expensive because the claims would normally be so long term because PWME rarely die: i.e. the majority of the claim would be beyond the agreed limit.

Though most people haven’t heard of Swiss Re they are actually the second largest re-insurer in the world with assets of 86 billion Swiss Francs (about £40 billion sterling). (See Summary of Financial Statements). They are a Swiss company but judging by the extravagance of their new building in London, they do much business in the UK. I note that in 2002, Life and Health Benefits accounted for 10,000 billion Swiss Francs out of total expenses of 34,000 billion SF.

I see it as a conflict of interest for research scientists (such as Peter White and Michael Sharpe) to work for a re-insurer with exposure to ME claims, and believe that it totally undermines the credibility of their research. I wrote and spoke to the MRC about this and was told by Elizabeth Mitchell that doctors did not need to disclose this. I think that they should do so, in the same way that MPs have declared interests.

Peter White and Anthony Cleare advised that my claim should be paid but Michael Sharpe must have advised against.

Whereas insurance companies need to use doctors as medical examiners, re-insurers do not see patients but see the reports produced by the insurers. I was very surprised at the extent that the re-insurer was involved with the processing of my claim and how there was so much correspondence between the two. John Sharpe, leader of UNUM consumers PHI group, seemed mind-blown about this.

The insurers proposed firstly Michael Sharpe and secondly Peter White as joint experts (in the pre-action protocols of the Civil Procedure Rules) on my PHI case, but being warned about both, I refused to be examined by them. I understand that a joint expert is a bit like an arbitrator. At the time we were unaware of their relationship with the re-insurer. I have no evidence that Michael Sharpe knew that he was proposed but I do have evidence that Peter White knew that we had rejected him as joint expert.

I now know that immediately before the insurer had proposed Michael Sharpe as a joint expert, the insurer had got him to write a report about me based upon medical reports and surveillance reports but without ever meeting me. **My main concern is not that he wrote a**

**report without seeing me, but the fact that when he was proposed as a joint expert, the insurer already knew that he believed that I should not be paid.** I see this as judge selection on the part of the insurer. However, I have no evidence that Michael Sharpe was complicit in this arrangement, but would presume that he was. The only reason that the existence of Michael Sharpe's report came to light was that it is listed in the sources for the report of Anthony Cleare, who I did eventually see for the insurer, but as expert for their sake rather than as joint expert. The insurer had refused to disclose Cleare's report but the re-insurer **did** disclose it. The insurer has refused to disclose Michael Sharpe's report and the re-insurer claims that they do not have a copy, but its contents are referred to in other places.

In January 2003 I checked out Peter Denton White's GMC registration. I rang the local library but they could not find him listed on the Medical Register. I rang the GMC twice and they could not find him listed on either occasion. I then rang the MRC who told me that they had checked it out with the GMC and found that he was listed. This did seem a bit strange and might merit a bit more research.

Re: Insurer uses 'pseudo Part 36 offer' to put pressure on policyholder to see Michael Sharpe

When the insurer proposed Michael Sharpe as a joint expert under the Civil Procedure Rules (CPR), they did something else which put us under great pressure to agree to see him. Looking at it another way, they gave me great fear of not agreeing to see him. They were very determined that I should see him.

They made what they alleged was a Part 36 offer under the CPR. Their "offer" consisted of saying to us "If you agree to see Dr Michael Sharpe, we will agree to be bound by his opinion". Though I can now see very clearly that this is not a material offer like money paid into Court, I could not see this at the time. Thus I was afraid that if I turned down this offer, the Court might see me as having behaved unreasonably in turning down a reasonable offer.

I was very fortunate in that I had a solicitor who was well capable of arguing that this did not meet the criteria for being a Part 36 offer. However, if I had not known about Michael Sharpe or not had the legal backup, I would have been very pressured into agreeing.

In the end, the insurer said that our refusal to accept this would be presented in any Court proceedings and my solicitor said he would be quite happy for it to be presented before any Judge.

The (out of house) solicitor for the insurance company was Rona Doyle. John Sharpe of the UNUM consumers' group told me that she has worked for UNUM.

I wonder if the idea came from her and if it was a widely used ploy used by insurers.

So in addition to using a doctor who was not independent because he worked for the re-insurer, and getting his opinion *before* proposing him as a supposedly independent joint expert, the insurer put great pressure on me to accept this "expert". There is no doubt that they were very determined that they wanted me to see Dr Sharpe.

When I rejected seeing Dr Sharpe as joint expert they again asked me to see Dr Sharpe, but then proposed Dr Peter White, and my seeing him was made part of a Part 36 offer.

*(signed)*

Kevin Robinson

June 4<sup>th</sup> 2003

## **APPENDIX II: STATEMENT OF ROBERT SCLATER**

I have suffered from ME/CFS for over 10 years now and have an insurance policy with Allied Dunbar Insurance Company which covers me for benefit payments till age 60 years. During the course of my illness I have been asked by them to attend medical examinations about every two years which has never been a problem until now.

On this occasion I was asked to see Dr Michael Sharpe ( Psychiatrist ) who I know, through my dealings with the Cross Party Group on ME in the Scottish Parliament, to have opinions which could prove harmful to me when being assessed.

My concerns regarding the medical are due to Dr. Sharpe's well publicised opinions on ME/CFS and his relationship with insurance companies in an advisory capacity. I fear that because of his views I will not receive a fair, impartial and independent medical examination to ascertain my present state of health.

It is well documented that Dr. Sharpe has on many occasions lectured to insurance companies, business schools and employers. He advises that those with ME/CFS who are seeking payment of benefit under their policies "should not qualify for such payments." He also advises employers that ME/CFS can also be called "the Malingerers Excuse." At a meeting at the Royal College of Physicians in February 2002 Dr. Sharpe is believed to have advised that he was recommending to insurance companies that claimants with ME/CFS should be subject to covert video surveillance. These comments do not appear to me to be those of an impartial medical assessor. These sadly are only a few of the denigrating and ungrounded statements he is reported to have uttered to date.

It seems unjust to me that Dr. Sharpe should be paid by an insurance company who he directly or indirectly advises the non-payment of claims for people with ME. This is surely a conflict of interest and the legality of such an appointment must be in question. It is for these reasons that I fear I will not receive a fair hearing.

For this reason I contacted the MSPs that I knew would be interested in my case. I am happy to say that they shared my opinion that I could not be certain that I would receive an impartial and unbiased medical assessment. They wrote letters of support for me which along with my own prompted Dr Sharpe to state that "under the circumstances, it would not be appropriate for him to assess your condition."

I still await a satisfactory conclusion to this matter.

Dr Sharpe has asked the MSPs to retract their statements to Allied Dunbar regarding his suitability to give an unbiased view when assessing people who suffer from ME/CFS.

When will people like Dr Michael Sharpe and his partner in crime Dr Simon Wessely be shown in their true colours?

Robert Sclater

## **APPENDIX III: ILLUSTRATIONS OF MICHAEL SHARPE'S VIEW ON ME/CFS**

1. "Psychiatric management may be defined as the treatment of the mentally ill....Personality factors (attitudes, beliefs and thoughts) and behaviour have been shown to perpetuate disability...these 'dysfunctional' cognitions include the belief that recovery from the illness is not under personal control...it has been suggested that dysfunctional cognitions and maladaptive behaviour perpetuate the disability that comprises CFS...Even if shown to be beneficial, such (immunological) treatment is unlikely to be feasible on a wide scale because of cost....The aim (of cognitive behavioural therapy) is to show that the patient can regain control of their lives ...There is evidence that psychiatric treatment can reduce disability in CFS. In some patients it can be 'curative' "

(ref: Psychiatric management of PVFS. M Sharpe. British Medical Bulletin 1991:47:4:989-1005).

2. "(Patients') higher levels of depression serve to reinforce the now widely current notion that such patients may be suffering from a depressive illness".

(ref: Fluctuations in perceived energy and mood among patients with chronic fatigue syndrome. C Wood, M Sharpe et al JRSM 1992:85:195-198)

3. "In clinical practice, no additional tests, including laboratory tests and neuro-imaging studies, can be recommended.....We consider a mental state examination to be the minimal acceptable level of assessment....The exclusion of persons (with psychiatric disorders) would substantially hinder efforts to clarify the role that psychiatric disorders have in fatiguing illness".

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

[Note that this is the "1994 CDC" criteria].

4. "Evidence for the superiority of new ways of thinking about such patients is growing. These new treatments, often referred to as cognitive behavioural therapies, take a new approach (which) is in keeping with the evidence that the perpetuation of unexplained somatic symptoms is best understood in terms of psychological factors (such as) misinterpretation of bodily sensations and unhelpful coping behaviour".

(ref: Treating medically unexplained symptoms. EDITORIAL (Editor's Choice).

Richard Mayou and Michael Sharpe. BMJ 1997;3:15:561-562)

5. "The only treatment strategies of proven efficacy are cognitive behavioural ones. The clinical problem we address is the management of the patient with a BELIEF that he/she has a fatiguing illness such as CFS or ME. The patients who cause the greatest clinical difficulty are those with strong beliefs. The majority of patients believe that their symptoms are the result of an organic disease process. Many doctors believe the converse....Beliefs are targets for therapeutic intervention....Abnormal physical signs should not be accepted as compatible with a diagnosis of CFS...Perpetuating factors (include) reinforcement of sick role by mother and doctor".

(ref: Chronic Fatigue Syndrome: A Practical Guide to Assessment and Management.

Sharpe M, Wessely S et al Gen Hosp Psychiatry 1997;19:3:185-199)

6. "The label of CFS avoids the connotations of pseudo-disease diagnoses such as ME...Patients' beliefs and behaviour are often a prominent part of the clinical presentation...CFS may serve as a culturally defined function which allows a socially acceptable expression of distress...psychiatric assessment is recommended in EVERY CASE (and) few laboratory investigations are necessary".

(ref: Chronic fatigue syndrome and occupational health. A Mountstephen and M Sharpe.

Occup Med 1997;4:217-227)

7. "CBT helps patients to re-evaluate their beliefs (and) encourages them to change their behaviour. Change in the belief is an important factor in recovery".

(ref: Cognitive Behaviour Therapy. Michael Sharpe. (In): A Research Portfolio on Chronic Fatigue. Ed. Robin Fox for The Linbury Trust. pub. The Royal Society of Medicine 1998)

8. "In my lecture this evening, I would like to talk to you about ME, also known as CFS. We know that in the majority of cases CFS can be effectively treated (with CBT). I shall argue that patients themselves have played a part in denying themselves this type of treatment...reinforcement of unhelpful illness beliefs can have an unhelpful effect on patients' attitude and coping".

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

9. "Psychosocial factors are important in CFS....The belief that there is no treatment is incorrect...correcting misconceptions about the disease process and avoiding unnecessary investigations all help patients....The problem of communication between doctors and insurance or benefit agency personnel were discussed throughout the meeting, which was an excellent first step towards improved links between the Royal College and doctors working in insurance and benefit agencies".

(ref: Insurance Medicine: Chronic fatigue syndrome and its management. Dr Michael Sharpe. Conference Raporteur: Ian Cox, Chief Medical Officer, Prudential UK

JRCP 2000:34:394-396)

10. In his contribution to the UNUM Report entitled "Functional Symptoms and Syndromes: Recent Developments" (2002), Sharpe includes "post-viral fatigue syndrome / CFS" as demonstrated by the following extracts:

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

**There is a great deal of confusion about what to call such illness. A wide range of general terms has been used including 'hysteria', 'abnormal illness behaviour', 'somatisation' and 'somatoform disorders'. Recently the terms medically unexplained symptoms (MUS) and 'functional' symptoms have become popular amongst researchers.**

**Classification is also confusing as there are parallel medical and psychiatric classifications. The psychiatric classifications provide alternative diagnoses for the same patients.**

**The majority will meet criteria for depressive or anxiety disorders and most of the remainder for somatisation disorders of which hypochondriasis and somatoform disorder have most clinical utility.**

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

**There is strong evidence that symptoms and disability are shaped by psychological factors. Especially important are the patients' beliefs and fears about their symptoms.**

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

**PSYCHOLOGICAL:** personality, disease attribution, avoidant coping style.

**SOCIAL:** information patients receive about the symptoms and how to cope with them; this information may stress the chronicity and promote helplessness. Such unhelpful information is found in 'self-help' books.

**Unfortunately doctors may be as bad.**

**Obstacles to recovery:**

**The current system of state benefits, insurance payment and litigation remain potentially major obstacles to effective rehabilitation.**

**Furthermore patient groups who champion the interest of individuals with functional complaints (particularly chronic fatigue syndrome) are increasingly**

**influential; they are extremely effective in lobbying politicians. The ME lobby is the best example.**

**Functional symptoms are not going to go away. However, the form they take is likely to change. Possible new functional syndromes are likely to include those associated with pollution (chemical, biological and radiological).**

**As the authority of medicine to define what is a legitimate illness is diminished, increasingly consumer oriented and privatised doctors will collude with the patient's views that they have a disabling and permanent illness.**

**In other words, it may be difficult for those who wish to champion rehabilitation and return to work to 'hold the line' without seeming to be 'anti-patient'.**

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

**This will not be easy. However, there are glimmers of progress. An example is recent developments in the politics of CFS. One of the major charities (Action for ME) is aligning itself with an evidence-based approach. These are early days but if this convergence of rehabilitation oriented clinicians and a patient advocacy group is successful, there could be very positive implications for insurers.**

**Funding of rehabilitation by commercial bodies has begun in the UK (with organisations such as PRISMA) and is likely to continue.**

**..an increased availability of rehabilitative treatment facilities is highly desirable. The NHS is not likely to pay for these.**

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

Serving as confirmation of the influence of these psychiatrists, also in Trends in Health and Disability 2002 is a contribution by Mansel Aylward, Medical Director for The Department of Work and Pensions, who sets out some of the Labour Government "planned initiatives" in the areas of Health and Welfare:

**"There is a common interest across several Government Departments in measures which would reduce the high costs of sickness absence and improve the quality and availability of ...rehabilitation.**

**The Government shares an interest...in the public, private and voluntary sectors which have a stake in the development of more effective models of rehabilitation.**

**Growth in benefit recipients due to mental and behavioural disorders has been rapid during the last five years....Another interpretation might be a migration in the diagnostic label from other medical conditions to 'mental health problems' "**

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