Quotable quotes on ME/CFS from Dr Michael Sharpe

Margaret Williams 12 May 2001

On Wednesday 9 May 2001 psychiatrist and much-published author on myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS) Michael Sharpe appeared before the Cross Party Group on ME of Members of the Scottish Parliament in Edinburgh. Throughout, he talked about CFS, not about ME, but all his slides were entitled "CFS/ME" as though the two syndromes were one seemingly unified condition. When asked about his models of care, Sharpe informed MSPs that cognitive behaviour therapy (CBT) for CFS is the "evidence-based" treatment and said that the Cochrane findings support this view. *(The Cochrane Collaboration, originally based in Oxford, is an internationally available meta-analysis of what its members consider to be the most effective treatment / management regimes for all medical and psychiatric conditions; its recommendations are intended to become the definitive database of "evidence-based" treatment approaches. Simon Wessely is believed to be in charge of the section on recommended treatment / management of ME/CFS).* It was pointed out to Sharpe that this is not the case (indeed, the systematic review team advising the UK Chief Medical Officer's Working Group on CFS/ME makes the point that there is a limited range of good research evidence available in the field of CFS/ME). Sharpe did, however, concede that CBT does not help all patients with "CFS".

The root of the present problem lies both in the current case definition of CFS (including as it does such a wide spectrum of psychiatric disorder) and in the determination of some psychiatrists to deny the existence of ME --- which has a long history in the medical literature – and to amalgamate the two syndromes. This is bad science: the medical literature is replete with references to the limitations of previous research, especially the failure by researchers to distinguish between ME and CFS and / or between subgroups of CFS This is exemplified by an article in the current issue of the Annals of Internal Medicine which states the problem quite clearly: "Most studies are limited by methodological problems such as case definition and the selection and recruitment of case-patients and controls." (*A Review of the Evidence for Overlap among Unexplained Clinical Conditions. Aaron LA, Buchwald D. Ann Int Med 2001:134(9):868-881*).

During the summer of 2000, the US Department of Health and Human Services Chronic Fatigue Syndrome Coordinating Committee appointed a Name Change Workgroup to consider a name other than CFS on the basis that it is necessary to have a name which more accurately reflects both the severity of the disease and the organ systems affected by it, as there is evidence of dysfunction of the neurological, neuro-endocrine and immunological systems.

Nonetheless, Sharpe informed the meeting that the disorder is <u>*not*</u> a neurological one (as that term is generally understood).

In the interests of accuracy, ME appeared in the standard textbook of Neurology as long ago as 1962 (*Diseases of The Nervous System. Lord Brain. Oxford University Press, Sixth Edition, 1962*).

MSPs were not informed that ME is formally classified as a neurological disorder in the International Classification of Diseases (*ICD10:G 93.3; WHO 1992*), and that the ICD separately classifies fatigue syndromes as a behavioural (psychiatric) disorder (*ICD 10:F 48*), a fact of which Sharpe and his colleagues are well aware.

Both the ME Association and AfME were set up to promote and protect the interests of their members ie. those suffering from ME, and the term "ME" (not "CFS") is incorporated into their charitable status. It is thus incumbent upon these patients' organisations effectively to collate and disseminate up-to-date, comprehensive international research information (especially that which describes findings in various sub-groups) and to refute incorrect assumptions of a psychiatric aetiology, however forcefully held and promulgated. A recent Co-Cure web posting by Jill McLaughlin expresses the nature of the problem succinctly: *"It is because our medical community, professional societies and public health officials have not adequately gathered together, assimilated, integrated and made public the strong body of research pointing to the serious physical (not psychological) nature of this illness."*

Only by assembling and distributing the great wealth of scientific evidence which shows unequivocally that Sharpe and his group of like-minded psychiatrists are wrong is there any hope of refuting their erroneous assumptions and of limiting the damage which flows from them. By not doing so, the UK patients' associations seem to be open to a charge of failing in their duty. By comparison with the US patients' associations (especially the CFIDS Association of America), the UK patients' groups fare spectacularly badly and membership numbers have dropped significantly. It is to fill this void (ie. to provide education about ME) that the most recent ME charity (MERGE) has been set up in Perth, Scotland. Until such information is at the forefront of public awareness, psychiatrists like Michael Sharpe and his close colleague Simon Wessely will continue not only to delude themselves but also to mislead government departments and insurance companies, and will thereby continue to damage and even destroy some extremely sick people. Sharpe himself believes that **" Suicide is the only cause of death in CFS"** (*Chronic Fatigue Syndrome: A Practical Guide to Assessment and Management. M Sharpe et al Gen Hosp Psychiat 1997:19:3:185-199*).

Despite denials from Dr Sharpe that he has ever harmed "CFS" patients, there is mounting evidence that such is not the case; documented and detailed evidence of the consequences of inappropriate psychiatric intervention has been put before the Chief Medical Officer and is also variously recorded in Hansard (for example *Hansard (Lords) 19 December 1998:1013; Hansard 21 December 1999 147WH-166WH*).

Patients with ME/CFS have even been threatened with being sectioned under the Mental Health Act unless they agree to psychiatric interventions.

Not only have many patients been made physically worse by inappropriate psychiatric intervention but quite often CBT is simply ineffective, as has been shown by four major surveys; the statistics speak for themselves. Both Action for ME in their survey of 2,338 respondents (*Preliminary Report: The Severely Affected. AfME. 28 February 2001; an amended version entitled Severely Neglected: ME in the UK was publicly released on 21 March 2001)* and Dr Lesley Cooper in a separate survey jointly sponsored by the ME Association and AfME (*Report on Survey of Members of Local ME Groups; Perspectives, Spring 2001)* found graded exercise – a

component of CBT – to be the treatment which made more people worse than any other. A detailed survey and analysis by independent ME researcher DM Jones MSc confirmed the same results (*Follow-up Survey of ME/CFS/MCS Patients, 5 April 2001)* and a survey carried out by the 25% ME Group for the Severely Affected (*The 25% ME Group Questionnaire, July 2000)* found that CBT /GE caused a chronic and severe condition. Moreover, the Medical Director of the UK ME Association has published the fact that he continues to receive more adverse reports about graded exercise than any other form of treatment and there is clear confirmation that that many people with ME/CFS are suffering relapses through such programmes. He reminds people that doctors have now been warned by their medical defence insurance companies that any form of exercise treatment needs to be prescribed with just as much care as drug treatments, otherwise doctors could be taken to court. *(Dr Charles Shepherd, Medical & Welfare Bulletin, ME Association, Spring 2001).*

Other kinds of harm include the refusal and / or withdrawal of state benefits; difficulty amounting to the impossibility of obtaining insurance payments, with policy holders being refused benefits; the withdrawal of cover by private health companies for those with ME/CFS (often on the grounds that no cover is available for 'psychiatric' illness); an almost total lack of suitable provision or care by the NHS, with no facilities for specialist referral other than to a psychiatrist; an overtly hostile and unfavourable attitude being shown by doctors and other health professionals to those with ME/CFS and special problems for children and adolescents, with increasing numbers of young people being threatened with being removed from their parents and put into care (which has led to litigation).

Perhaps a unique form of harm is to be found in the persistent recommendation from this group of psychiatrists that no investigations (or only limited investigations) are necessary and appropriate in patients with ME/CFS. No-one can object to unnecessary investigations, but what constitutes "unnecessary"? Is it the case that such patients are often found to have "no abnormalities" on laboratory testing *only* because the right tests are not being conducted in the first place? Why are these doctors so insistent that patients should not be comprehensively investigated? As the Countess of Mar pointed out, where is their natural curiosity about this condition? Why should sufferers and those doctors who *observe* their suffering accept the limitations of scientific knowledge? If medical practitioners of the time had simply accepted the limitations of scientific knowledge, smallpox would never have been eradicated, nor would the link between asbestos and lung disease have been established. These psychiatrists refer to a lack of proven causality, yet they actively advise that no investigations should be performed on patients with ME/CFS and that no research into its organic nature should be undertaken. Is it because they do not wish to know? *(Hansard,Lords,19 December 1998:1011-1024).*

Those concerned about the plight of people with ME have long been asking that suitable provision, including specialist units, be made within the National Health Service for sufferers; the response is to be found in the 1996 joint Royal Colleges' Report on CFS (CR54), which goes so far as to state "Appropriate clinical practice is not to be defined by special interest groups" *(paragraph 12.4)*.

Could the insistent recommendation not to investigate patients with ME/CFS be in any way related to the findings of Professor Vojdani and others, who have demonstrated that the 2-5A

RNase L antiviral pathway (abnormalities in which are considered by world researchers to underlie the pathology of ME/CFS) is also affected by *chemicals*?
(*Interferon-induced proteins are elevated in blood samples of patients with chemically or virally induced chronic fatigue syndrome. Vojdani A, Lapp CW. Immunopharmacol Immunotoxicol 1999:21 (2):175-202).*

Is it the case, as portrayed in a recent TV documentary, that multi-national corporations and not governments now control the world? *(Politics isn't Working: the End of Politics. Cambridge academic Noreena Hertz presented evidence that multi-national corporations are taking the place of elected governments. ITV Channel 4, 13 May 2001, 8pm).*

Are any of these powerful and influential psychiatrists linked in any way whatever to multi-national chemical and pharmaceutical industries who now dominate and control not only governments but also medical and research institutions and whose life-blood is profit?

It is certainly known that Simon Wessely is a Corporate Officer of PRISMA (which stands for Providing Innovative Service Models and Assessments) and that PRISMA is a pan-European organisation funded by the European Commission's Information Society Technologies Programme. PRISMA is especially concerned with the cost of long-term disability from the perspective of governments, service providers and insurance companies. It states that its analysis of services involves "identifying best practices" and that it is "developing long-term visions of desirable best practice models" (of patient management). PRISMA claims to have developed a "unique treatment programme" for chronically disabled patients including those suffering from CFS; that "unique" treatment is CBT. In the PRISMA round table, they discuss these issues with "leading experts in medical care, the insurance industry and government officials"; they also "provide recommendations to healthcare policy makers". Simon Wessely is a member of the Supervisory Board; in order of seniority, he is higher than the Board of Management. In the PRISMA literature, he is listed as a "world expert" in the field of medically unexplained illnesses, including Chronic Fatigue Syndrome. (*PRISMA address is www.prismahealth.com but part of its website seems now to have been closed down).*

In response to a question in the House of Lords by the Countess of Mar, Lord Falconer of Thoroton, Minister of State in the Cabinet Office, confirmed that **where relevant to the UK's e-government initiative, the PRISMA findings will be taken into consideration.**

<u>Some illustrations of what Dr Sharpe really believes about ME/CFS</u>

It is not just a matter of noting the more offensive statements but rather it is the relentlessness of the same message over more than a decade (and the fact that the message does not adapt to but actively dismisses the strength of emerging biological evidence) which shows it to be out of touch with international scientific knowledge.

<u>1991</u>

<u>Psychiatric management of PVFS. M Sharpe. British Medical Bulletin 1991:47:4: 989-1005</u>

"Psychiatric assessment distinguished factors that perpetuate the condition from those that may have precipitated it. Treatments are targeted at perpetuating factors.

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

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

"Multiple perpetuating factors may operate (and) the following have been suggested in CFS:

"Infection: viral infection is of theoretical interest but of minor importance in managing established cases

"Immune dysfunction: the possibility that immune function is impaired by psychosocial factors and may be improved by psychiatric treatment is a tantalising possibility

"Other physiological factors: Several physiological factors may perpetuate symptoms. These include the consequences of inactivity and hyperventilation.

"Psychiatric disorder: Syndromes conventionally termed "psychiatric" have been shown to occur in the majority of patients with CFS. Extensive physical investigation is unlikely to be fruitful and should be limited

"Other psychological factors: Personality factors (attitudes, beliefs and thoughts) and behaviour have been shown to perpetuate disability. These unhelpful or "dysfunctional" cognitions include the beliefs that recovery from the illness is not under personal control or that the illness is poorly understood. It has been suggested that dysfunctional cognitions and maladaptive behaviour interact with the physiological factors and psychiatric illness to perpetuate the disability that comprises CFS. Increasing physical deconditioning…may lead to helplessness

"Social factors: because of their possible importance in CFS (social factors) deserve discussion. One such factor is our cultural attitude to symptoms occurring in the absence of demonstrated physical disease. Such symptoms are frequently regarded as revealing personal weakness and as not being a valid reason for exemption from daily demands. Physical disease, on the other hand, particularly if validated by a doctor, is rarely considered to be the responsibility of the afflicted, merits sympathy, and excuses the sufferer from meeting the demands of others. Patients without a "physical" disease label for their illness may consequently experience difficulty in explaining their disability to friends, family or employers. Hence they may request a "physical diagnosis" from doctors. In response to the lack of acceptance of the "reality" of the symptoms of CFS, support has been sought for the existence of a disease called myalgic encephalomyelitis or "ME"…..the insistence that "ME" is an exclusively physical disease with a poor prognosis may have been unhelpful for sufferers (and) such a restricted conception of the problem may have perpetuated illness in some individuals".

Under Assessment of CFS, Sharpe again states: "the use of extensive laboratory investigation may be psychologically harmful to the patient by reinforcing their beliefs about serious physical disease.

" Even if shown to be beneficial, such (immunological) treatment is unlikely to be feasible on a wide scale because of cost

"There are many anecdotal reports (of the efficacy of antidepressant drugs) in CFS

"Cognitive behaviour therapy is a development of Behaviour Therapy in which emphasis is placed on changing the patients' cognition as well as their behaviour. The aim is to show that the patient can regain control of their lives and that their illness is not so mysterious as to be untreatable".

Under Guidelines for Management, Sharpe yet again states: "Excessive investigation should be avoided. Problems may arise if the patient requires a diagnosis the doctor feels is inappropriate or wants certification of permanent invalidity (ie) "ME"

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

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

"There is anecdotal evidence that (antidepressants) can reduce disability in CFS.

"Psychsocial factors may maintain disability. Family members may reinforce both beliefs and avoidance. We suggest that the clinical assessment should consider mood, beliefs, avoidance of inactivity and the role of the family".

1992

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

"Because of its suspected viral aetiology, CFS is becoming an increasingly frequent presentation seen by specialists in infectious diseases. Current thinking *(here Sharpe quotes a self-reference)* does not require the presence of a viral aetiology in defining the syndrome

"(Patients') higher levels of depression serve to reinforce the now widely current notion that such patients may be suffering from a depressive illness, of which physical fatigue is a somatic manifestation."

1994

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

"The use of tests to diagnose the chronic fatigue syndrome should be done only in the setting of protocol-based research. In clinical practice, no additional tests, including laboratory tests and neuro-imaging studies, can be recommended. Examples of specific tests (*which should not be done*) include serologic tests for enteroviruses; tests of immunologic function, and imaging studies, including magnetic resonance imaging scans and radionuclide scans (such as single photon emission computed tomography (SPECT) and positron emission tomography (PET) of the head. We consider a mental status examination to be the minimal acceptable level of assessment.

"The exclusion of persons (*with psychiatric disorders*) would substantially hinder efforts to clarify the role that psychiatric disorders have in fatiguing illness. We dropped all physical signs from our inclusion criteria (because) their presence had been unreliably documented in past studies."

1995

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

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

On 17 May 1995, Sharpe was one of the main speakers at a symposium entitled "Occupational Health Issues for Employers" held at the London Business School; the advice presented included informing attendees that ME/ CFS has also been called (quote) "the malingerer's excuse"; Wessely spoke on the "myths" of ME; Sharpe spoke about anti-depressants and CBT and Trudie Chalder (a Registered Mental Nurse who works with Wessely) spoke about "Selling the treatment to the patient". Another speaker at this symposium was the Vice President of UNUM, the UK's largest disability insurer, whose Chronic Fatigue Syndrome Management Plan dated 4 April 1995 states about ME/CFS

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

[In February 2000 a Conference on Insurance Medicine was held at The Royal College of Physicians in London, attended by Simon Wessely and Michael Sharpe, at which it is believed Sharpe advised that he was recommending to insurance companies that claimants with ME/CFS should be subject to covert video surveillance. See below for Conference report.]

1996

Cognitive behaviour therapy for the chronic fatigue syndrome: a randomised controlled trial. Michael Sharpe, Tim Peto et al BMJ 1996:312:22-26

"Cognitive behaviour therapy offers a novel approach to the treatment of the chronic fatigue syndrome…(it) aims at helping patients to re-evaluate their understanding of the illness….it was both acceptable and more effective than medical care alone."

(One of the trial participants (Catherine Rye) had a letter published in the Independent on 30 March 1996 in which she made valid points: "I participated in the Oxford trial…the article implies that a new successful treatment has been found for ME but that sufferers do not want to accept it. There are facts about the trial that throw into doubt how successful it is. It is stated that patients in the control group received standard medical care. I was in that group but I received nothing. Also, patients receiving treatment had to attend weekly hospital visits, thus excluding the most severely affected sufferers. Patients who "improved significantly" only increased their score from 70 to 80 on a scale of general functional ability.")

1997

Treating medically unexplained symptoms. EDITORIAL (Editor's Choice). Richard Mayou and Michael Sharpe. BMJ 1997:3:15:561-562

"Evidence for the superiority of new ways of thinking about and managing 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."

Chronic Fatigue Syndrome: A Practical Guide to Assessment and Management Sharpe M. Wessely S et al Gen Hosp Psychiatry 1997:19:3:185-199

"The only treatment strategies of proven efficacy are cognitive behavioral ones.

"The clinical problem we address is the assessment and management of the patient with a *belief* that he / she has a fatiguing illness such as CFS, chronic fatigue and immune deficiency syndrome (CFIDS) ---*CFIDS in fact stands for chronic fatigue and immune dysfunction syndrome* --- or myalgic encephalomyelitis (ME). The patients who cause the greatest clinical difficulty are those with both severe symptoms and strong beliefs. The majority of patients believe that their symptoms are the result of an organic disease process. Many doctors believe the converse.

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

"Beliefs are probable illness-maintaining factors and targets for therapeutic intervention

"Many patients receive financial benefits and payments which may be contingent on their remaining unwell. Recovery may therefore pose a threat of financial loss

"Personality is important….the account of an informant *(about the patient's personality)* is often helpful

"Most sufferers are seeking confirmation of their own intuition that they are suffering from a particular condition, rather than reassurance that they are not

"Abnormal physical signs should not be accepted as compatible with a diagnosis of CFS

"In our experience, postural hypotension usually resolves with increased activity

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

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

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

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

"An important task of treatment is to return responsibility to the patient for rehabilitation without inducing a sense of guilt

"(CBT) is acceptable to patients, safe and more effective than standard medical care
(*"standard medical care" is not defined*)

"It is usually possible to persuade these patients to try antidepressants

"Disability systems and insurance agencies are sceptical about CFS. When asked to comment in benefits or insurance claims, we do not support claims for permanent disability until all reasonable efforts at rehabilitation have been tried."

Chronic fatigue syndrome and occupational health. A Mountstephen and M Sharpe Occup Med 1997:47:4:217-227

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

"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 (which) is most commonly diagnosed in young and middle aged females

"the evidence for an association between immunologic abnormalities and CFS remains unclear

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

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

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

"psychiatric assessment is recommended in *every case*

" in most cases of chronic fatigue, few laboratory investigations are necessary

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

"Exercise therapy may be considered for patients who are physically inactive

"the only psychological treatment supported by the evidence is cognitive behavioural therapy (which) is well fitted to the task of helping patients achieve a more helpful view of the illness

"referral to 'specialists' should be avoided as they can entrench illness behaviour

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

Under "Eligibility for benefits", the authors state "The DSS's Handbook advises adjudication officers that in CFS there is unlikely to be a need for assistance with attending to bodily functions or with mobility. It will be unfortunate if the (Disability Discrimination) Act leads to an undue focus on long term disability at the expense of efforts directed at rehabilitation and recovery."

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

"Chest pain, back pain, headache, muscular pains, bowel symptoms, breathlessness, dizziness and fatigue often remain unexplained after medical assessment. Such cases may be referred to as functional syndromes of chronic fatigue or as somatoform disorders. When symptoms are found not to result from "genuine physical illness", they are often attributed to mental illness. Evidence for the superiority of new ways of thinking about and managing such patients is

growing. These new treatments, often referred to as cognitive behavioural therapies, take an approach in keeping with the evidence that perpetuation of unexplained somatic symptoms is best understood in terms of an interaction between physiological processes, psychological factors and social context.

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

"Implementation of this new approach will require changes in both medical practice and the organisation of services. Innovative service developments such as dedicated liaison psychiatry services will provide for patients who require more intensive treatment. The small but conspicuous group of patients who present with recurrent and multiple physical symptoms will be given co-ordinated care aimed at limiting unnecessary medical interventions

"If these changes in practice and service provision could improve patient care, why have they not been implemented? One reason is the widespread lack of awareness that effective evidence based treatments are available. There are welcome signs of change, as evidenced by the recent joint royal colleges' reports".

1998

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

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

"Our group (ie. the Wessely School) wanted to develop the behavioural approach and the fist step was to gain a systematic view of their beliefs and behaviour

(*No mention is made about obtaining a systematic view of patients' brain perfusion patterns, or of their immune status, or of their neuroendocrine function).*

"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.

"The trials of CBT have shown that 'psychological' treatment is effective in patients with CFS. (CBT) is currently the most effective treatment we have for CFS."

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

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

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

"Why are many physicians reluctant to provide a medical diagnosis? (Because) to make such a diagnosis, especially if it is suggested by the patient, may risk the censure of peers

"The application of (a psychiatric diagnosis) may give the physician the satisfaction of having applied a label of which most of his peers would approve. The problem is that many patients not only fail to accept this diagnosis but respond to it with frank hostility because a psychiatric diagnosis may offer lower financial benefits

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

1999

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

"Many different functional syndromes have been described….each medical speciality seems to have at least one *(the authors here equate non-ulcer dyspepsia, pre-menstrual syndrome, hyperventilation syndrome, tension headaches and globus hystericus with CFS).* We postulate that the existence of specific somatic syndromes is largely an artefact of medical specialisation.

"Many of these syndromes are dignified by their own formal case definition. We question this orthodoxy. Almost all functional somatic syndromes are more common in women than in men. If we accept that functional somatic syndromes are considered together, we open the way for more general strategies for their management. Functional somatic symptoms and syndromes are a major health issue. They are common and may be costly. We contend that the patients so defined actually have much in common. We propose an end to the belief that each 'different' syndrome requires its own particular sub specialist."

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

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

"We know that in the majority of cases CFS can be effectively treated. CBT has been shown to have substantial benefits for patients with CFS (and) can reduce disability in most patients.

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

"Despite a lot of media comment and much hypothesising relating CFS to modern concerns such as toxic exposures, there is very clear evidence that a condition which appears identical caused similar concerns a hundred years ago (and) the causes were thought to lie in the concerns of that time namely, the changing role of women….in our time it is allergy and toxins.

"The conventional wisdom is that illnesses are made real when they are legitimised by a doctor's diagnosis

"Does CFS have biology? Yes –not conventional disease pathology

"The majority of patients with CFS have no doubt how they prefer their conditions to be seen….the vehemence with which many patients insist that their illness is medical rather than psychiatric has become one of the hallmarks of the condition.

"Clinically, it appears that interpersonal stress appears to be a major factor giving rise to development of CFS

"Over-solicitousness and the reinforcement of unhelpful illness beliefs can have an unhelpful effect on patients' attitude and coping

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

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

2000

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

Psychosocial factors are important in CFS. Prognostic factors include family factors and social factors; work could also mitigate against a full recovery.

Reports from doctors for employers, insurance companies and benefit agencies could reinforce beliefs and behaviour to delay full recovery.

The belief that there is no treatment is incorrect; correcting obvious misconceptions about the disease process and avoiding unnecessary investigations all help patients.

Cognitive behaviour therapy caused improvement in 60% of patients with CFS

Secondary prevention (ie preventing chronicity) includes early identification and treatment; keeping the individual in contact with the workplace helps to reduce the chronic problems.

There was general agreement that all doctors have a responsibility to aid their patients' return to employment.

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

The problem of communication between doctors and insurers or benefits 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".