www.margaretwilliams.me

OBSERVATIONS ON THE JOINT REPORT OF THE UK ROYAL COLLEGES OF PHYSICIANS, PSYCHIATRISTS AND GENERAL PRACTITIONERS ON CHRONIC FATIGUE SYNDROME, OCTOBER 1996 / CR 54 / RCP

Eileen Marshall Margaret Williams 17th November 1996

In September 1994 a report of the UK National Task Force on Chronic Fatigue Syndrome (CFS), Postviral Fatigue Syndrome (PVFS) and Myalgic Encephalomyelitis (ME) was published; it was partially funded by the Government and it concluded that ME is a distinct and particularly severe sub-group of the chronic fatigue syndrome (1). Such a conclusion was unsurprising, given that this specific sub-group of ME (known as chronic fatigue and immune dysfunction syndrome (CFIDS) in the USA) had already been formally classified by the World Health Organisation (WHO) in the International Classification of Diseases as a neurological disorder in July 1992 (2).

Notwithstanding, a recent joint report, ostensibly from the Academy of Medical Royal Colleges, disagrees (3) and seems to have as its main agenda an attempt at official "derecognising" of ME as a nosological entity; indeed, two members of this present working group have already tried to get the WHO neurological classification revoked (4).

At the press release to launch this joint report, a clear indication of its findings was given by Dr Robert Kendell, recent successor to Fiona Caldicott as President of the Royal College of Psychiatrists, when he was quoted as saying: "To try to distinguish between a physical illness and a psychological illness is not just wrong, it's meaningless" (5); this fallacy was encapsulated in a letter to The Guardian newspaper three days later: "Try telling that to someone with terminal cancer" (6).

Despite claims that this report was prepared at the request of the UK Chief Medical Officer and that it was the Presidents of the three Royal Colleges who nominated the expert committee, refutations are legion: it is widely believed that the prime mover was psychiatrist Simon Wessely, notorious for his views that those who have CFIDS/ME simply have a belief that they are suffering (7). Certainly Wessely is an Advisor on CFS to the UK Government Department of Social Security, and what is also certain is Wessely's close relationship with virtually all the other members of this "expert committee". Indeed, out of the 16 members, eight are psychiatrists well-known for their published views which deny the reality of ME (as distinct from chronic fatigue, which they accept as a psychological disorder), and most of the other members also publicly subscribe to this view. What is also

certain is that six of these members were also signatories to the much-criticised Oxford consensus criteria on CFS in 1991 (8).

Expert committees are usually held to be just that; complete impartiality is required as de rigueur: in this present case even the most cursory appraisal reveals that this expert working group might not be quite as impartial as is usual.

Of the psychiatrists involved:

<u>Dr Anthony David</u>, close colleague and frequent collaborator of Wessely, believes:

a) "A diagnosis of depressive illness would be appropriate. Unfortunately this is not good enough for the

patient" (9)

b) "Doctor behaviour, such as sick certification, emerged as a significant contributor to the risk of chronic

fatigue" (10).

Note that Dr David does not differentiate between chronic fatigue, chronic fatigue syndrome, postviral fatigue or ME and that his own papers rely heavily on Wessely's work as references.

<u>Dr Sean Lynch</u> believes:

a) "The original criteria for the chronic fatigue syndrome would exclude patients with any concurrent

psychiatric symptoms...but as few patients would then meet this definition...these criteria are

widened to include psychiatric morbidity"

b) "Symptoms of depression are not infrequent in the chronic fatigue syndrome....there are anecdotal

reports of 'cure' of all symptoms of the chronic fatigue syndrome using antidepressant therapy"

c) "There is no evidence to date of a higher than normal risk of adverse drug reactions in this group of

patients" (11).

Dr Anthony Pelosi believes:

a) "The closer cases fulfil the definition of chronic fatigue syndrome the stronger the association with

emotional morbidity....the only significant prognostic predictors.....were a primary psychiatric

diagnosis.....and a strong convictions that the illness represented a physical disease"

b) "Recovery from syndromes of chronic fatigue has now been shown to be independent of virology and

immunological measures, and a poor outcome to be related to psychological morbidity" (12)

c) "The myalgic encephalomyelitis societies should not try to set the research agenda or shout down

views with which they disagree" (13).

<u>Dr Simon Wessely</u> believes:

a) "There is a strong association between CFS and psychiatric disorder.....it is unlikely that psychiatric

disorder is solely the consequence of physical disability.. A history of depression may predispose an

individual to CFS.....perpetuating factors include.....illness beliefs and fears about symptoms,

symptom focusing, and emotional states"

b) "There lies at the heart of CFS not a virus, immune disorder or depression, but a distortion of the

doctor-patient relationship" (14)

Dr Wessely's views on CFS/ME are set out in more detail in an article entitled The Views of Dr Simon Wessely on ME: Scientific Misconduct in the Selection and Presentation of Available Evidence?" (CFIDS Chronicle, Spring 1994: 14-18).

Dr Peter White believes:

"Psychiatric diagnoses were particularly associated with a duration of symptoms longer than four

months.....the commonest diagnosis...was major depressive disorder in half the

patients, with a further

15% having a somatisation disorder....if symptoms persist, treatable psychiatric disorders will be found

in two-thirds of patients" (15).

Of the non-psychiatrists:

<u>Sir Richard Bayliss</u> believes:

"Many of the symptoms in the chronic fatigue syndrome are identical to those seen in psychiatric

diseases, notably a depressive illness. Furthermore many patients with the chronic fatigue syndrome

improve in response to anti-depressive pharmacological therapy.....about 70% of those treated in this way

return to work with a good quality of life" (16).

<u>Professor Richard Edwards</u> believes:

"Many of the symptoms of these patients could be a consequence of their reduced habitual

activities.....the dizziness and disturbances ... of vision and the gastro-intestinal problems experienced

by ... patients after relatively mild exercise are also experienced by normal controls ... and by athletes

during competitive sports events" (17).

<u>Dr Tim Peto</u> believes:

"Illness beliefs and coping behaviour previously associated with a poor outcome changed more with

cognitive behaviour therapy adding cognitive behaviour therapy to the medical care of patients with

the chronic fatigue syndrome is acceptable to patients and leads to a sustained reduction in functional

impairment" (18).

Dr Leone Ridsdale believes:

"Doctors may help some patients reattribute symptoms which may prevent

unnecessary referrals" (19).

At least five members of this working group all have connections with Wellcome, the pharmaceutical giant who in 1989 sold Coopers Animal Health, a company it had set up in 1985 in partnership with ICI to produce organo-phosphates (OPS) (20). Perhaps of note is the fact that Peter Behan, Professor of Neurological Sciences at Glasgow, has found farmers who have been exposed to OPS to have a neurological condition indistinguishable from CFIDS/ME (21, 22).

Wellcome has financial connections with Healthwatch (formerly known as The Campaign Against Health Fraud) and Healthwatch exists to attack anything and anyone who challenges the monopoly hold of the chemical companies on food production and pharmaceuticals (23). From its inception in 1989, Wessely has been a leading activist (24).

Many people with CFIDS/ME have an up-regulated immune response, which means that they can react badly to common substances, particularly to medical drugs (25, 26). Such patients may of necessity turn to "alternative" and/or complementary medicine and to dietary advisors, in particular to clinical ecologists or allergy practitioners who tend to advocate non-drug therapies and who thus have become the target of Healthwatch members (27).

Members of this present joint committee who have links with Wellcome are, for example, Wessely himself, not only via Healthwatch but as Wellcome Research Fellow in Epidemiology, whilst Professor Leszek Borysiewicz was formerly Wellcome Trust senior lecturer at the Department of Medicine at Cambridge; Tim Peto and Richard Edwards have both been funded by Wellcome, and Tony Pelosi was the holder of a Wellcome Training Fellowship in Epidemiology.

Is it purely by chance that these particular doctors who are known to have links with Wellcome should be so unrelenting in their efforts to ensure that CFIDS/ME is nothing more than an aberrant belief held only by suggestible sufferers and accepted by only those doctors who have not learnt to deal with them effectively (28), or is it possible that there might be a neurotoxic factor in the aetiology of ME, perhaps in genetically pre-disposed individuals? Could it be that Wellcome is anxious to categorise CFIDS/ME as psychological in order to pre-empt possible future litigation?

For the record, it is two prominent members of this joint working group whose report has just been published (Drs Simon Wessely and Anthony David) who have been appointed to lead the Pentagon-funded \$1 million study of Gulf War veterans (29, 30): this study will be the definitive one which will establish patterns of illness in Gulf War veterans; it is not due to report until 1999, yet Wessely has already declared his hand about the Gulf War Syndrome: "We should resist the temptation to subject those few soldiers who have come

forward for testing to ever more complex investigations in the hope that 'something will turn up' " (31).

It is perhaps significant that this "expert committee" did not include Professor Peter Behan from the Depatrment of Neurological Sciences, University of Glasgow, who is undoubtedly the most prestigious researcher on ME in the UK and who is of international acclaim, and nor did it include any member of the Task Force on ME, which comprised medical experts from disciplines including molecular pathology, immunology, neurology and infectious diseases.

In a letter dated 14th October 1996 submitted for publication to the British Medical Journal, Dr Charles Shepherd, Medical Adviser to the ME Association, pointed out that many of the disagreements about this joint report could have been resolved if the Royal Colleges' working party had agreed to meet with representatives of the National Task Force during the preparation of the report, but this was not the case, so an opportunity to create a real consensus was lost.

One is obliged to ask why the Chief Medical Officer requested this latest report on CFS, and why those particular people were appointed to provide this report: to construct an enquiry solely on the views of participants whose views have already been challenged (32, 33), and when evidence of physical anomalies has already been extensively published worldwide, raises the spectre of a personal agenda on the part of those involved.

From the outset, this working group has addressed inappropriate imperatives, and we here briefly provide illustrations.

Chapter 1 is entitled <u>Terms of Reference</u>, which have been addressed above.

Chapter 2 is entitled <u>Background</u>; at paragraph 2.1 the report states: "there is a tendency to over-investigate using laboratory and imaging techniques": the reality is that patients with ME frequently find it impossible to be taken seriously by their doctors, who often treat them without basic courtesy and with obvious disdain. Patients with ME are regularly struck off their doctor's list.

At paragraph 2.7, the report states "in clinical practice we have noted that the label of ME has been used by doctors and others for the following situations, emphasising an unacceptable diversity of use: severe, unexplained fatigue and exhaustion...". It should be noted that it was members of this same working party who formulated the Oxford criteria (8) and it is the Oxford criteria which stipulate that all categories of "fatigue" be encompassed in the case definition of CFS, so it was they themselves who advocated such dilution of critical definitions.

We agree however, that "CFS" is over-diagnosed, but believe it is the Oxford criteria which have contributed to this over-diagnosis.

If guidelines formulated by researchers into true CFIDS/ME were followed, over-diagnosis should not happen: as Dr David Bell (34) and Dr Rachel Jenkins (35) point out, a differential diagnosis is not difficult. It is not simply a matter of unexplained fatigue, rather that the pattern of symptoms is identical, reproducible and remarkably consistent. Dr Bell lists 50 symptoms, commenting that: "Physicians seeing a patient with CFIDS have been unable or unwilling to recognize this pattern of symptoms"; Dr Jenkins (like David and Wessely, a member of The Institute of Psychiatry, London) provides a detailed and impeccable formula for differential psychiatric diagnoses, and it is a matter of concern that the doctors responsible for this report repeatedly ignore good medical practice.

Chapter 3 is entitled <u>Definitions</u>. Paragraph 3.1 states: "The most appropriate term for the syndrome is chronic fatigue syndrome (CFS)". The name CFS, however, is neither appropriate, accurate nor descriptive, because for many sufferers, "fatigue" equated with "tiredness' is not the major symptom: the over-riding symptom is incapacitating exhaustion together with extreme post-exertional muscle fatigability, invariably accompanied by profound malaise. The term CFS excludes core symptoms and without doubt is abhorred by patients and physicians alike, who believe it implies a benign state of trivial importance, suggesting that people with CFS lack motivation or the ability to get on with life.

Paragraph 3.4 states: "Patients may wish to keep a particular term (ie. ME) because only with that label are they eligible to call upon the welfare state for help". In the UK, it is the very label "ME" which has stopped patients from getting state welfare benefits; even those who on clinical need have been awarded such benefits for life have had their benefits withdrawn on the grounds that ME "is not a pathology in its own right" (36) and "The label ME is a ragbag representing no proven pathology" (37). These directives come from the Benefits Agency Medical Services, to whom Wessely is Advisor on CFS/ME (38).

Paragraph 3.5. states: "the group within CFS with more symptoms, profounder (sic) fatigability, greater disability and longer illness duration is the subset with the strongest associations with psychological disorder".

Psychiatrists use certain scales known as The Diagnostic and Statistical Manual of Mental Disorder (referred to as the DSM); there are various editions and revisions, and psychiatric patients are assessed using DSM criteria.

Symptoms (of whatever duration) such as ataxia, diplopia, vertigo, rashes, easy bruising, palpable lymph nodes, severe and recurrent mouth ulcers, non-androgenous hair loss, pancreatic dysfunction, vascular changes and cardiac problems, together with a proven up-regulated immune response, abnormal jitter on EMG and hypoperfusion of highly specific areas of the brain stem are commonly found in CFIDS/ME in addition to autonomic dysfunction resulting in bladder and bowel insecurity. It is doubtful whether such symptoms could possibly form part of standard diagnostic criteria for "psychological"

disorder".

For this report to claim that the longer the duration of problems such as these, (but which the Report authors ignore), the stronger is the association with psychological disorder would seem to be approaching the realms governed by the General Medical Council's jurisdiction on fitness to practise.

Even though the report is at pains to point out that such association does not indicate that psychological disorder is the cause of the greater disability, the authors immediately negate the value of what they have acknowledged, because the very next sentence states that the greater the severity of symptoms, the more "misguided" is the "chance of finding an 'organic' aetiology' ".

A pertinent letter in CFIDS Chronicle (39) hits the nail squarely on the head: "Those who continue to assert 'depression' in the face of study after study to the contrary...are clearly acting politically, not scientifically".

Chapter 4 is entitled <u>Epidemiology</u>. Paragraph 4.2. states: "At least 25 studies exist concerning the prevalence of chronic fatigue in the community...chronic fatigue as a symptom is extremely common...only a minority of these will fulfil criteria for CFS". It is the constant and indiscriminate use of the various terminologies as interchangeable which has contributed to the present obfuscation of case definitions, and this factor is the one which so hinders research (1).

Chapter 5 is entitled <u>Virology</u>. Paragraph 5.8 states: "One study of 250 general practice patients suggests that a definable fatigue syndrome exists after glandular fever...symptoms include...reduced interest (and) social withdrawal". Reduced interest is not a feature of CFIDS/ME (35).

Chapter 5 Summary states: "Studies..have found that psychological distress..and.. attributional style prior to clinical viral infection are risk factors for the subsequent development of CFS".

The chapter on Virology in CFS is only 2.5 pages long; within it are no less than 12 self-references of the report authors, who have long been known for studying "chronic fatigue" as distinct from CFIDS/ME and then to be ascribing their results to all chronic fatigue syndromes, including CFIDS/ME.

Chapter 6 is entitled <u>Muscle dysfunction and immunology</u>. It consists of less than one full page and contains six self-references by the report authors. Muscle pathology and immunology are two very important areas in CFS/CFIDS/ME but are treated by the Report authors as inconsequential.

Chapter 7 is entitled <u>Psychiatry and neuropsychiatry</u>; unsurprisingly, this is a much longer

chapter. Paragraph 7.3 states: "Approximately half of those seen in either primary or specialist care with a diagnosis of one or other form of CFS fulfil criteria for other psychiatric disorders, chief amongst which are anxiety and somatisation disorders". The same concern arises, ie. the authors are not being careful enough and are not controlling for selection bias. Not discussed is the possibility that the diagnostic criteria used may have significant shortcomings in that the measures relied upon do not make the necessary discrimination. In other words, psychologists have not yet devised measures which are appropriate for the current task.

Depression, for example, requires the presence of four symptoms from a shortlist which includes fatigue, concentration difficulties, changes in eating pattern and changes in sleeping patterns: using these criteria alone, many people with CFIDS/ME immediately become confirmed psychiatric patients.

This much used practice is unsuitable when assessing patients with multiple sclerosis, ME, or other neurological disorders, or patients receiving chemotherapy; this is because the criteria rely on the presence of symptoms which are common in such conditions, but as a secondary factor (ie. as a consequence) and not as a primary aetiological factor. Notwithstanding, some doctors cling tenaciously to these inappropriate scales of mental assessment, to the detriment of good science.

Paragraph 7.5 states: "The possibility that both psychiatric disorder and CFS have a common neurobiological origin is appealing". To whom? This is another indication of the authors' obvious preference for a psychiatric ascription.

Paragraph 7.7 states: "Psychological disorders are thus one component ... of the aetiology of CFS. Other factors..include..altered health perception (and) deconditioning". The authors seem to have overlooked the abundant evidence (not least in their own published work) which documents that the pre-morbid life-style of many sufferers gives the lie to any possibility of "deconditioning"; if people become seriously ill, it is normal for them to "perceive" their health status differently because it different. By what mode can normal perception figure in the aetiology of the disorder?

Paragraph 7.9 states: "Patients with long histories of multiple somatic symptoms (such as) unexplained abdominal pain, headaches, chest pain, food allergies, chemical sensitivities (and) unresolved gynaecological problems ... may fulfil ... established criteria for somatisation disorder": paragraph 7.11 expressly states: "In CFS ... the greater the number of somatic symptoms, the greater the probability of psychiatric disorder". As these authors themselves earlier point out at paragraph 3.5, correlation does not imply causality.

It is perhaps worth noting that multi-symptomatic patients who may well be victims of medical ignorance or arrogance, not to mention medical prejudice, would be abnormal if they were not despondent: diagnostic uncertainty is itself associated with increased anxiety (40) and the present authors are here confounding the predictor and the criterion

of psychiatric disorder.

By including "food allergies" and "chemical sensitivities" in this paragraph, the authors appear to be conferring their view that such symptoms are in reality evidence of somatisation, which would be in accordance with the unstated conflict of interest, which again raises the question of just how scientifically objective is the Report.

Paragraph 7.13 states: "Findings of white matter abnormalities require careful interpretation, since it is a sensitive technique and may reveal 'abnormalities' of little consequence". In this attempt at discussing the value of neuroimaging in CFS, the authors adopt their usual dismissive stance; they seem to imply (7.15) that to date, neuroimaging studies are of limited value on the grounds that confounding factors such as depression and anxiety have not been taken into account in the interpretation of the findings.

Overall, the authors are unequivocal that "there is no justification" for the use of neuroimaging studies other than as part of "carefully conducted" research, but do not most researchers believe that they conduct their work "carefully"?

Significantly, at the recent AGM of the UK ME Association held in London on 5th October 1996, Dr D.C. Costa of the Institute of Nuclear Medicine at UCL Medical School, London, the foremost ME researcher in nuclear medicine in the UK, gave a lecture in which he explained that hypo-perfusion of the brain stem is the main characteristic apparent on neuroimaging in ME, and that it is more severe in ME than in AIDS encephalitis, or indeed in any other brain disease he has examined since 1985 in some hundreds of patients (it is well known that Dr Costa experienced opposition to getting his findings published).

Chapter 8 is entitled <u>Presentation</u>, assessment, investigation and prognosis. At paragraph 8.9 the authors state: "detailed laboratory investigation is largely unhelpful in anyone with fatigue (sic) lasting more than six months" and they advise that there is little point in looking at parameters of antinuclear factor, immune complexes, cholesterol levels or immune subsets, since "revealed changes" are "rarely substantial".

Quite incredibly, in Appendix 4 (Summary of the report) they authors spell this out again: they direct that: "No diagnostic test exists for CFS and no investigations should be performed to confirm the diagnosis".

That "revealed changes" are "rarely substantial" is simply incorrect: Professor Behan and his team at Glasgow, for example, have found that patients with ME have raised cholesterol levels; when they did a study of 30 well-defined cases, looking not only at cholesterol levels but at the full lipid profile, they found that of the 30 patients, 27 showed not only gross but (quote) "grotesque" abnormalities. Exactly the same abnormalities have also been observed by Professor Anthony Komaroff at Harvard Medical School (21). Professor Behan states that not only is there abnormal carnitine metabolism in ME, but abnormal lipid metabolism as well.

At paragraph 8.12, in "aims of assessment", the Report authors include the following:

"To ... consider alternative diagnoses.....to elicit the beliefs and fears of patient and family......to identify psychological distress......to formulate the problem in terms of predisposing (and) perpetuating factors".

There is little acknowledgement of the need for adequate clinical screening but, inevitably, over-emphasis on mental health screening.

In many illnesses, patients present with multiple non-specific symptoms such as fatigue, joint pains, irritable bowel, altered micturition; such symptoms may well be due to hypothyroidism, SLE, MS, Addison's disease, chronic brucellosis, rheumatoid arthritis or to other autoimmune overlap syndromes, so contrary to what the Report authors advise, it is imperative to carry out detailed laboratory investigation and not to rely on the personal assumptions of the examining doctor.

In paragraph 8.16, the authors state: "several studies suggest that poor outcome is associated with social, psychological and cultural factors. These include the strength of belief in a solely physical cause for symptoms....and the use of avoidant coping strategies". The report then states "Chronicity is likely to be associated with perpetuating factors which may include....unaddressed psychosocial issues."

Would the authors look at perpetuating factors or unaddressed psychosocial issues in multiple sclerosis, or SLE, or post-polio syndrome or AIDS? If not, why the special pleading in CFS/ME? Could it be that if patients are not investigated, then no evidence will ever come to light which challenges the authors' stance, so their position will thus be maintained?

The authors appear to be counting on their readership being unaware of how far removed from world mainstream opinion their highly psychologised interpretation actually is; most CFIDS/ME research scientists and clinicians, and indeed patients themselves, are better acquainted with the literature, so the Report authors are likely to attract yet more opprobrium. Can they really believe that they are of sufficient stature to presume superior knowledge over 80 of the world's leading ME/CFS authorities? (41).

Of particular note is that one of the authors of this joint report (Professor Richard Edwards) himself contributed a chapter to the major 724-page textbook on ME/CFS (41) and thus cannot claim ignorance of the clinical and scientific evidence which the Joint Report neglects.

This arbitrary (or possibly expedient) rejecting of the significance of parameters found by others to be abnormal in CFIDS/ME requires detailed explanation.

On every front except the psychological, the authors urge against "over-interpreting the abnormalities described to date" (6.5). Not only do they urge this in relation to muscle pathology, but to immunological abnormalities (8.9), to virological evidence (5.5) and to neuroimaging abnormalities also (7.13).

They even advise that: "The possibility that previous depressive illness alters the reactivity of the HPA axis to subsequent infection or psychosocial stress is intriguing" (7.18); indeed, Simon Wessely, whose hand seems to be heaviest on every page of this report, has previously expressed this as follows: "It may be that episodes of depression ... leave 'endocrine scars' that increase the risk of subsequent CFS or depression" (14). Do the authors think that depression-induced 'endocrine scars' precipitated polio or glandular fever or AIDS or leukaemia? How do they explain the fact that many people with CFIDS/ME never had any episodes of previous depression? Always, always there is special pleading only in CFIDS/ME: is this a scientific approach?

It seems that such is the authors' fanaticism to secure a primary psychological aetiology for this syndrome that they will stop at nothing in their determination to dismiss any possibility of an organic aetiology; their message is clear: only the ill-informed or the naive would allow themselves to be influenced by "premature" indications of organic causality. Few will readily admit to being naive or ill-informed, so the authors are using a powerful psychological tool to effect their own ends.

Chapter 9 is entitled <u>Management</u>. Again, the authors declare themselves: We have concerns..about the dangers of labeling someone with an ill-defined condition which may be associated with unhelpful illness beliefs" (9.2). ME is hardly "ill-defined" and it is formally classified by the WHO as a neurological disease, so it is hardly an "unhelpful illness belief".

At paragraph 9.6 the authors allude to "pre-existing personality": clinicians are instructed that the best way to modulate such attitude problems is by using cognitive behaviour therapy (CBT) (9.8), even though there is no evidence of phobic avoidance of activity in CFIDS/ME and even though evidence superior in construct to Wessely's own confirms that CBT is of no benefit whatever in CFIDS/ME(42).

Notwithstanding, the report eulogises that: "CBT is a promising and cost-effective approach that has been recommended for the..management of CFS...the treatment is safe and acceptable" (9.9).

Inevitably, these authors declare "We have concerns about the use of complementary therapy and dietary interventions" (9.20). It might be prudent to reflect that Healthwatch states its aims as being to promote publicly the view that "valid clinical trials (ie. drug trials) are the best way of ensuring public protection" and to oppose "diagnoses that are misleading or false, or that may encourage unnecessary treatment for...non-existent diseases". (43)

Chapter 10 is entitled <u>Children and CFS</u>. The authors state that: "CFS in children covers a broad spectrum of problems..perhaps even..Munchausen's by Proxy syndrome" (10.2). The authors are firmly against home tuition, and advocate "immediate return to school" (10.12). Crucially, they advise of the need to remove children forcibly from their home and parents if this is "in the best interest of the child" (10.14). As expected, school phobia and school refusal feature in this chapter, and the paediatricians who support children with this syndrome are themselves advised that they need to "interact closely with multidisciplinary teams so that the appropriate range of..psychiatric..skills can be used in the child's management" (10.19).

Chapter 11 is entitled <u>Future research</u>. Readers are assured that the authors "are satisfied that the normal processes of supporting sound research are adequate...the Medical Research Council and the major medical charities have supported and continue to support CFS research" (11.1).

Wellcome is not mentioned by name, nor is the fact that in 1992, the MRC granted a substantial amount for research into "CFS"; this grant was available only to The Institute of Psychiatry and all applications for funding had to be made to Dr Simon Wessely, and this was announced publicly at medical meetings (44).

Chapter 12 is entitled <u>Facilities and services provision</u>. Predictably, the authors state: "We see no reason for the creation of specialist units" (12.1), and "we do not think that specific guidelines on the management of CFS should be issued for general practitioners" (12.4).

Chapter 13 is entitled <u>Conclusions</u>. The authors concede that "CFS" is a substantial problem, but they define CFS as "an operationally defined syndrome characterised by a minimum of six months of severe physical and mental fatigue made worse by minor exertion". The only other symptoms which are mentioned are "muscle pain, sleep disorder and mood disturbance".

ME is dismissed: "Previous studies have counted people with the ME, but these studies reflect those who seek treatment rather than those who suffer the symptoms" (13.3). How curious that the WHO overlooked this.

The report concludes that it recommends "controlled clinical trials of antidepressants for CFS sufferers without symptoms of depression" (Appendix 4:12).

Is it not bizarre that the Report authors insist on absolute laboratory proof of organic abnormalities in CFS/ME, yet psychiatric disorders, arrived at by reference to the DSM criteria, incorporate no such laboratory proof?

Given that the case definition of "CFS" has been revised by the Report's authors so that it now specifically includes psychiatric morbidity, and given the authors involved in the

preparation of the Joint Report, the whole exercise has no more value than a charade, played out at the expense of desperately sick people.

CONCLUSION

No-one, patients least of all, is against the use of pharmacological therapeutic intervention to relieve suffering and to improve the quality of life of those suffering from CFIDS/ME if such measures work and if they do not cause further problems, but the evidence is that such measures do <u>not</u> work (45, 42).

What is particularly objected to is the constant assertion in this Report that the more severe sub-group (ME as distinct from CFS) does not exist as a disease entity and that antidepressant therapy, together with CBT, is an effective measure which should be used to modulate sufferers' maladaptive perception of their suffering.

This onslaught has been unremitting for the last 10 years from this group of doctors, so no matter how disingenuously they use their Report to promote the view that psychiatric illness is just as legitimate as "organic" illness (which no-one except the Government Benefits Agency denies, in that higher rates of benefit are awarded only to those suffering from a physical disablement, and "CFS" is not accepted as a physical affliction) (46), people are not deceived, because the published evidence of what they really think about people with CFIDS/CFS/ME is there for all to see (32).

Over the last decade these same doctors have assiduously and relentlessly denigrated patients with this syndrome, some of whom are so sick that they have to be fed via a nasogastric tube. Many cannot look after themselves and require 24 hour care.

We believe that sufferers from no other illness apart from multiple sclerosis (that, too, was known as "the faker's disease" (47)) have had to endure such a lengthy orchestrated attack upon their credibility.

Despite their lip-service about the need for strict operational case definitions and for care in the selection of patients studied (48), these doctors do not heed their own advice in that they do not study those who are the most severely affected, preferring instead to study patient cohorts who will not disrupt their own analyses and to whose malady can safely be ascribed the label "chronic fatigue".

Perusal of this Joint Report and its references (many of which are self-references of the report contributors) reveals disregard of the available world literature: such selectivity is a well-established hall-mark of many members of this particular coterie of colleagues.

The British Medical Journal offered a Leader to Dr Stephen Straus, Chief of the Laboratory of Investigation, National institute of Allergy and Infectious Diseases, Bethesda, USA (43),

published for maximum effect just three days after the launch of the report, in which Straus describes this report as "arguably, the finest contemporary position statement in the field".

Interpreting this as yet more evidence of the current trans-Atlantic mutual support between Drs Straus and Wessely (50), the more perspicacious readers turned to The Lancet, whose common-sense Editorial (51) saw straight through the fabric of this Report: "The sixteen-strong committee was top-heavy with psychiatric experts, so the emphasis on psychological causes and management ... is no surprise. Charles Shepherd, Medical Director for the ME Association, told us that 'the committee was rigged, with dissenting voices excluded'. Certainly, the expert committee describes no attempt to collect external opinions.....Psychiatry has won the day for now.... We believe that the report was haphazardly set up, biased, and inconclusive, and is of little help to patients or their physicians".

Nevertheless, this latest report will have some impact, not least on those who allow themselves to be spoon-fed. Even the Medical Adviser to the ME Association himself is now on public record as concurring with at least one tenet of this Joint Report when he affirmed: "factors that maintain ME/CFS are far more likely to involve a combination of physical, psychological and social influences" (52). As a long-term sufferer himself, one wonders exactly what psychosocial factors he believes are perpetuating his own illness? Shepherd, however, is a member of Healthwatch (53).

It is no wonder that some psychiatrists are despised and mistrusted when they refuse to accept that a conviction of physical disease in CFIDS/ME may not be dysfunctional thinking or psychosocial denial but may arise from severe physical symptoms which are indeed organic in origin.

Doctors who have set views regardless of the facts might themselves qualify as dysfunctional thinkers, the effect of which is their determination to psychologise illnesses which they do not understand.

On what logic should the unprovable opinions of psychiatrists be held to be superior to the reproducible research findings of neurologists or immunologists or virologists?

CFIDS/ME sufferers' iatrogenic distress will end only when truth becomes as important as power and politics, and when inaccurate diagnostic labelling no longer serves as a cloak for ignorance, prejudice and misguided beliefs (54).

Eileen Marshall Margaret

Williams

Warwickshire,

UK

REFERENCES

- 1. Report from the National Task Force on Chronic Fatigue Syndrome (CFS), Postviral Fatigue Syndrome (PVFS) and Myalgic Encephalomyelitis (ME); Westcare, Bristol, September 1994
- 2. International Classification of Diseases (ICD)10:1992: ref.G93.3:423: WHO
- 3. Chronic Fatigue Syndrome. Report of a joint working group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners. October 1996/CR54; published by The Royal College of Physicians, London
- 4. Chronic Fatigue, ME, and 1CD 10. Anthony David, Simon Wessely. Lancet 1993;342:1247-1248
- 5. Press Release, Royal College of Physician, London, 2nd October 1996
- 6. Letter: H.J.H. Berger, Guardian, 5 October 1996, page 16
- 7. The Eliot Slater Memorial Lecture; Simon Wessely; Institute of Psychiatry, London, 12 May 1994, entitled 'Microbes, Mental Illness, the Media and ME: The Construction of Disease'
- 8. A report chronic fatigue syndrome: guidelines for research. M.C. Sharpe et al. Journal of The Royal Society of Medicine 1991:84:118-121
- 9. Postvira1 fatigue syndrome and psychiatry. A.S. David. British Medical Bulletin 1991:47:4:966-988
- 10. Predictors of chronic "postviral" fatigue. Helen Cope, Anthony David, Anthony Pelosi, Anthony Mann. Lancet 1994;344:864-868
- 11. Antidepressant therapy in the chronic fatigue syndrome. Sean Lynch, Ram Seth, Stuart Montgomery. British Journal of General Practice 1991;41:339-342
- 12. Chronic fatigue syndrome: prevalence and outcome. Psychological factors are important for management. S.M. Lawrie A.J. Pelosi BMJ 1994;308:732-733
- 13. Chronic fatigue syndrome and myalgic encephalomyelitis. S.M.Lawrie A.J.Pelosi BMJ 1994:309:275
- 14. Chronic fatigue syndrome: an update. Anthony J Cleare Simon C. Wessely Update 14 August 1996:61-69
- 15. Fatigue syndromes: neurasthenia revived -- psychiatric illnesses are worth considering. Peter White BMJ 1989;298:1199-1200
- 16. Medical report prepared for a High Court action in the Royal Courts of Justice, London; R.I.S.Bayliss. 8 July 1991
- 17. The metabolic consequences of reduced habitual activities in patients with muscle pain and disease. Anton J.M. Wagenmakers, John H Coakley, Richard H.T. Edwards. Ergonomics 1988;31:11:1519-1527
- 18. Cognitive behaviour therapy for the chronic fatigue syndrome: a randomised controlled trial. Michael Sharpe, Tim Peto et al. BMJ 1996;312:22-26
- 19. GPs and patients disagree over the causes of fatigue. Pulse, 24 September 1994:15

- 20. Dirty Medicine. Martin J Walker. Slingshot Publications, London 1993 page 219
- 21. Transcript of Lecture by Professor Peter Behan given at the Coventry and Warwickshire Postgraduate Centre, 23 November 1995
- 22. Chronic fatigue syndrome as a delayed reaction to chronic low dose organo-phosphate exposure. Peter O Behan. Journal of Nutritional Medicine, December 1996 (in press)
- 23. Dirty Medicine. Martin J Walker. Slingshot Publications, London 1993, page 340
- 24. ibid page 334
- 25. The presentation, assessment, investigation and diagnosis of patients with Post- viral fatigue syndrome in an Infectious Diseases Clinic. W.R.C. Weir. (In) Post-Viral Fatigue Syndrome. Eds. Rachel Jenkins and James Mowbray. John Wiley & Sons 1991
- 26. Allergy and the chronic fatigue syndrome. Stephen E Straus et al J Allergy Clin Immunol 1988:81:791-795
- 27. Dirty Medicine. Martin J Walker. Slingshot Publications, London 1993 page 341
- 28. Old wine in new bottles: neurasthenia and 'ME' Simon Wessely Psychological Medicine 1990;20:35-53
- 29. US funds Gulf War illness. Jeremy Laurance. The Times (London) 20 May 1995
- 30. News Release: Office of Assistant Secretary of Defense (Public Affairs) Washington DC. June 20 1996 page 6
- 31. What is this mystery illness which we call Gulf War Syndrome? Despite all they went through, Gulf veterans are healthier than average. Dr Simon Wessely The Times (London) 27 July 1995 page 10
- 32. The Views of Dr Simon Wessely on ME: Scientific Misconduct in the Selection and Presentation of Available Evidence? Eileen Marshall & Margaret Williams CFIDS Chronicle Spring 1994:14-18
- 33. Simon Wessely Follow-up: Letters: CFIDS Chronicle Summer 1994: 77-79
- 34. The Disease of a Thousand Names David S. Bell. Pollard Publications, Lyndonville New York 1991 pages 4-5
- 35. Assessment and Diagnosis of ME in the Psychiatric Clinic. Rachel Jenkins. (In) Postviral Fatigue Syndrome (Eds) Rachel Jenkins & James Mowbray: chapter 16: 241-246. John Wiley & Sons 1991
- 36. Internal Memorandum from Dr A.E. Furniss, Medical Officer to the Benefits Agency Medical Services: 4 April 1995
- 37. Internal Memorandum from Dr A.E. Furniss, Medical Officer to BAMS: 10 October 1995
- 38. Letter dated 10 January 1992 from Dr Simon Wessely to Dr Mansel Aylward at The Department of Social Security, The Adelphi, 1 John Adam Street, London WCZ 6NT
- 39. Letter: Jean Linn, CFIDS Chronicle, Fall 1996, page 8
- 40. Diagnosis in chronic illness: disabling or enabling -- the case of chronic fatigue syndrome. Woodward R, Brown D, Legge D. Journal of the Royal Society of Medicine 1995;88:315-319
- 41. The Clinical and Scientific Basis of Myalgic Encephalomyelitis Chronic Fatigue Syndrome. (Ed) B.M. Hyde. The Nightingale Research Foundation 1992, Ottawa
- 42. Immunologic and psychologic therapy for patients with Chronic fatigue syndrome. Lloyd A, Hickie I et al. American Journal of Medicine 1993:94:197-203

- 43. Healthwatch (formerly known as The Campaign Against Health Fraud) subscription form valid up to 1st May 1990
- 44. Professor Peter Behan (personal communication)
- 45. Randomised double blind, placebo-controlled study of fluoxetine in chronic fatigue syndrome. Jan H.M.M. Vercoulen et al, Lancet 1996:347:858-861
- 46. UK Government (DSS) Disability Handbook (Annexe) September 1996:12.2.4. HSMO
- 47. Mysterious Maladies. Scientific American. September 1996227523:15
- 48. Postviral fatigue: time for a new approach. David A, Wessely S & Pelosi A. BMJ 1988:2962696-699
- 49. Chronic fatigue syndrome. Stephen E. Straus. BMJ 1996: (5 October): 313:831-832
- 50. The chronic fatigue syndrome: A comprehensive approach to its definition and study. Keiji Fukuda, Stephen E. Straus, Simon Wessely et al. Annals of Internal Medicine 1994: 15 December: 121;12:953-959
- 51. Frustrating survey of chronic fatigue. Editorial: Lancet 12 October 1996:348-971
- 52. Give ME a break. Dr Charles Shepherd. The Sunday Telegraph: 13 October1996
- 53. Dirty Medicine. Martin J Walker. Slingshot Publications, London 1993, page 277
- 54. Source acknowledged but unknown