

**Brief comments on the collaborative report from Westcare / Action for ME
“Chronic Fatigue Syndrome / ME. Trusting Patients’ Perceptions of a
Multidimensional Physical Illness” by Richard Sykes and Peter Campion**

Margaret Williams 24th August 2003

This document first appeared in draft form in 2000 and many people were invited to provide their informed views; throughout 2001 it went through various modifications but even so, key people were so dismayed by it that they insisted their name be removed from the list of “consultants” to the report. Dr Vance Spence was one of those who wrote to Richard Sykes asking that his name should not be associated in any way with the report.

Although it makes some useful points, overall the report does not move things forward as Sykes clearly hoped it would.

As Westcare has now been subsumed within Action for ME, as a charity tasked with representing its members, AfME should be producing reports which actively push for **biological** research instead of acquiescing with yet more psychological / psychiatric studies and it should be representing the best interests of its members instead of ignoring and even denying them.

There was no need for this report. It further dilutes the evidence of physical causation and it unjustifiably emphasises the effectiveness of psychological support, even though the documented evidence for biological abnormalities is now massive (so why won't Sykes and Chris Clark **accept** that evidence?). Not to do so is merely reiterating the preferred assertions of the Wessely School, and a charity really should not get away with such deplorable practice when it flies so directly in the face of so much credible evidence.

There are many pages of discussion and arguments in the report in which a plea is made for a change in attitude by the medical and healthcare professions towards “CFS/ME” patients, but the report still offers only psychosocial support, CBT, graded exercise therapy (GET) and counselling, when at least four important surveys have shown that GET very clearly makes at least 50% of sufferers worse.

It uses the term “CFS/ME” **without definition of “CFS”**, which is unscientific and therefore of no practical use or help.

It uses the term “biopsychosocial” but there is no published evidence whatsoever that **ME** is a biopsychosocial disorder.

Doctors need robustly de-programming from all the psychobabble they have been drip-fed by Wessely et al but this report fails to do so.

Psychological aspects are NOT “key factors” in influencing the progress of ME/ICD-CFS.

Given the amount of significant published evidence of an organic pathoaetiology, there should be **NO ISSUE** that ME/ICD-CFS is a serious, chronic, physical disorder (which, like all severe illness, undoubtedly has some psychological overlay in some patients, but that is not the same as claiming that it is a primary psychological /psychiatric disorder).

This report will do nothing to encourage doctors to LISTEN to their ME patients because it downplays the biomarkers of organic pathology.

One would have expected that an ME charity would have got the basic facts right, but this report did not, and it is simply **wrong** in what it states about the ICD classification of ME and CFS: on page 45 at section 12.5 the report states ***“there is no specific mention of CFS in ICD-10”*** when the term CFS is clearly listed as one by which ME or postviral fatigue syndrome may be known:

Syndrome
 -Fatigue F48.0
 --chronic G93.3
 --postviral G93.3

The number of “--“ indicate the correct title and classification of the disorder in question.

This means that “fatigue syndrome” is classified as a mental disorder under F48.0 **but that chronic fatigue syndrome is classified under G93.3 with ME and so is PVFS** (in Volume II, which is the alphabetical list).

It also means that the whole collaborative report is constructed on an error and this basic error is fundamental to the report’s existence. Had the report been accurate, much of its deliberations would be unnecessary. It may be worth noting that Richard Sykes was funded by Wellcome (with which Professor Simon Wessely has long been associated) to spend a term at St John’s College, Cambridge in order to compile this report.

Concerning the view of AfME itself, at one point the charity even changed its logo from “Action for ME” to “Action for ME and chronic fatigue”, but was forced to remove the words “chronic fatigue” by the Charities Commission since that was not how the charity was registered with the Commission.

Further, it should be noted that in August 2001 Professor Hooper attended a talk given by Chris Clark to the Sunderland and South Tyneside ME Support Group and made detailed, accurate and careful notes of exactly what Chris Clark said. A few quotations from Professor Hooper’s notes follow:

- “He (Chris Clark) was quite happy with the confusions surrounding the use of both ME and CFS and insisted that there was no value in debating the best term to describe ME. The use of ME, CFS-ME, ME/CFS seemed to him to be a matter of choice and of no great significance. The terms could be used interchangeably.
- He expressed his hope about what might be included in the (CMO’s) Report and went on to list the kind of treatments that he was looking for: pacing, graded exercise, cognitive behavioural therapy and counselling
- I found the address extremely disturbing for the following reasons:
 - a) ME is classified in WHO ICD-10 (at) section G93.3 as a neurological disorder with clear clinical correlates and organic origins. In the Alphabetical index, the term chronic fatigue syndrome is listed as referring to G93.3 so, following the WHO, it is correct to use either ME or CFS to describe the disorder. **IT IS NOT A PSYCHIATRIC CONDITION**
 - b) ME/CFS is specifically excluded from section F48. The controversy arises because in the UK (but not generally in the USA or Australia) psychiatrists of the “Wessely School” have attempted to move CFS into this section and effectively reclassify it as a fatigue syndrome and therefore a psychiatric disorder. This amounts to a calculated deception (which) has far-reaching consequences for understanding and investigating both the diagnosis and treatment of ME. The sleight of hand practised in the UK to convert an organic disorder into a psychiatric one lies, in my judgment, behind the espousal by Chris Clark of the psychiatric/psychological treatments he described.
- There was no mention of any biochemical, immunological, rheumatological or endocrinological studies that have been widely reported and offer new insights into the nature and treatment of ME. There was no mention of the science that lies behind nutritional and food supplements that many people have found helpful, (nor of the fact that) viral infections and /or chemical exposure clearly play an important part in many cases of ME.
- Overall, very depressing. Action for ME appears to be committed to a psychiatric model of ME for both treatment and diagnosis. Of even greater concern is the thought that what Chris Clark described in this address reflects something of the content of the final report to the CMO.”

After Professor Hooper placed his notes in the public domain, AfME issued an angry denial, claiming that Professor Hooper was wrong and that Chris Clark’s speech had been “misinterpreted”; AfME called for Professor Hooper’s “remarks” to be withdrawn but Professor Hooper declined to do so because he is very secure about his facts and he refuses to be intimidated.

Although AfME took strong exception to Professor Hooper's reporting that "Action for ME appears to be committed to a psychiatric model of ME for both treatment and diagnosis", it is worth pointing out that in his contribution entitled "Functional Symptoms and Syndromes: Recent Developments" to the UNUMProvident Insurance company report "Trends in Health and Disability 2002, psychiatrist Michael Sharpe states about CFS:

" The majority will meet criteria for depressive or anxiety disorders and most of the remainder of those for the so-called somatoform disorders of which hypochondriasis and somatisation disorder have most clinical utility. Psychiatric classification has important treatment implications. There is strong evidence that symptoms and disability are shaped by psychological factors. Especially important are the patients' beliefs and fears about their symptoms. Obstacles to recovery (are) the current system of state benefits (and) insurance payments (which are) potentially major obstacles to effective rehabilitation. As the authority of medicine to define what is a legitimate illness is diminished (and as) privatised doctors will collude with the patients' views that they have a disabling and permanent disease, it may be difficult for those who wish to champion rehabilitation and return to work to 'hold the line'. However, there are glimmers of progress. An example is recent developments in the politics of CFS: one of the major patients charities (Action for ME) is aligning itself with a more evidence-based approach (and) if this convergence of rehabilitation-oriented clinicians and a patient advocacy group is successful, there could be very positive implications for insurers".

Before being appointed as Chief Executive Officer of AfME, Chris Clark had been an administrator and knew nothing about ME. It was, therefore, a matter of astonishment that so soon after introducing himself in May 2000 he was chosen to be an adviser to the team at the NHS Centre for Reviews and Dissemination at York who were to carry out a "Systematic Review" of the literature upon which the conclusions of the CMO's report on "CFS/ME would be based. To this end, on 28th June 2000 Margaret Williams wrote to Rachel Richardson at York in the following terms:

"I and others remain concerned that, on his own admission, one of the chosen advisers to your review team (Chris Clark) has absolutely no knowledge of the CFS / ME literature (or even about ME itself): what, then, can be his input as an adviser to your review team? How could someone with no knowledge or experience of the subject contribute to the outcome of your systematic review of the literature on treatment / management of the condition? Would someone with no knowledge be able to supply an informed and balanced contribution? On what grounds was he selected to assist you?"

In a reply dated 7 July 2000 Rachel Richardson answered those concerns as follows:

"We wish to make no comment regarding Chris Clark's knowledge or experience of cfs/me".

Other members of that advisory panel to the York Systematic Review team included Professor Simon Wessely and Professor Tony Pinching, who at the time he was appointed deputy Chair of the CMO's Working Group on CFS/ME had not published anything on ME: he subsequently authored a paper published by the Department of Health (Chronic fatigue Syndrome. Anthony J Pinching. Prescribers' Journal 2000;40:2:99-106) in which he asserted

“Over-investigation can be harmful....causing (patients) to seek abnormal test results to validate their illness”.

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

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

In his article, he does not even mention ME or the key manifestations of it and he expressly states that the fatigue found in CFS is “*not related to ongoing exertion*”. In ME, there is **always** post-exertional muscle fatigue, without which a diagnosis of ME is unsustainable.

Professor Pinching is now Medical Adviser to AfME.

24th August 2003