

**Comparison of the American Report for Physicians on CFS with
the UK Joint Royal Colleges' Report on CFS**

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In October 1996 the UK Joint Royal Colleges published their report on CFS (Chronic Fatigue Syndrome. Report of a joint working group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners, CR 54, 58pp. Published by the Royal College of Physicians, London). The President of the Royal College of Physicians at the time was Professor Sir Leslie Turnberg.

Key authors of the report were psychiatrists Dr Anthony David, Dr Sean Lynch, Dr Anthony Pelosi, Dr Simon Wessely and Dr Peter White.

Of the non-psychiatrist authors, Sir Richard Bayliss believed that: 'Many of the symptoms in the chronic fatigue syndrome are identical to those seen in psychiatric diseases...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' (Medical Report. RIS Bayliss, 8th July 1991, Royal Courts of Justice).

Professor Richard Edwards believed: "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 (AJM Wagonmkaers, JH Coakley RHT Edwards. Ergonomics 1988:31:11:1519-1527).

Dr Tim Peto believed: "Illness beliefs and coping behaviour previously associated with a poor outcome changed more with cognitive behaviour therapy (which) leads to a sustained reduction in functional impairment" (Michael Sharpe, Tim Peto et al. BMJ 1996:312:22-26).

Dr Leonie Ridsdale believed: "Doctors may help some patients reattribute symptoms which may prevent unnecessary referrals" (Pulse: 24th September 1994:15).

There was a justified outcry about CR 54, especially when it was compared with the US Report on (ME)CFS published just one month earlier (Chronic Fatigue Syndrome. Information for Physicians. 16pp. National Institute of Allergy and Infectious Diseases / National Institutes of Health. Public Health Service. US Department of Health and Human Services, September 1996).

When asked to compare the US report with the UK report, Professor Turnberg wrote about the US report: "This seems to be helpful confirmation of the views expressed in our report" (personal communication). He was therefore publicly asked some questions.

Those questions were followed by illustrations of differences in the two contemporaneous reports on the same disorder.

There are various unhelpful similarities in both these reports; overall, however, the American report acknowledges viral, immunological and neurological considerations in (ME)CFS, whereas the UK report dismisses these findings as inconsequential.

Questions for Professor Turnberg about the UNHELPFUL aspects of the US report

1. The American report states on page 1: *"The clinical descriptions of CFS...and fibromyalgia...overlap considerably"*. Would Professor Turnberg be kind enough to tell us in which medical publication the following are listed as forming part of the case definition for fibromyalgia, and is he aware that all are documented in ME: vertigo; disequilibrium; ataxia; pancreatic exocrine dysfunction leading to malabsorption; frequency of micturition; alopecia; altered T4:T8 ratio and NK cell depletion?

2. The American report states on page 2: *"There is no evidence linking encephalomyelitis to the pathology of the illness"*. Does Professor Turnberg agree and, if so, is he aware of the following: *"Neurological symptoms, MRI findings and lymphocyte phenotyping studies suggest that the patients may have been experiencing a chronic, immunologically mediated inflammatory process of the central nervous system"* (Buchwald D et al. Ann Intern Med 1992:116:103-113)?

3. The American report states on page 2: *"No published data indicate that CFS...can be transmitted...by blood transfusion"*. If such is the case, would Professor Turnberg be kind enough to explain why patients with CFS/ME are **permanently excluded** from donating blood, as per the "Guidelines for the Blood Transfusion Service in the United Kingdom" 1989: chapter 5: paragraphs 5.313; 5.42 and 5.410.

4. The American report states on page 2: *"Outbreaks of CFS are unusual"*. We agree that outbreaks of CFS are unusual, as are outbreaks of depression, but is Sir Leslie aware that outbreaks of **ME** have been comprehensively documented by a former UK Government Chief Medical Officer (Sir Donald Acheson) in his paper "The Clinical Syndrome Variously Called Benign Myalgic Encephalomyelitis, Iceland Disease and Epidemic Neuromyasthenia" (Am J Med April 1959:569-595)? Does he consider that Sir Donald's paper misled the world medical community?

5. The American report states on page 6 that positive reports of neuroimaging techniques *"are preliminary and unconfirmed...and cannot be justified"*. Is Sir Leslie aware that Tavio et al have replicated Costa's findings and that these findings were presented at the San Francisco Conference on CFS, 13th 16th October 1996?

Illustrations of DIFFERENCES in the two reports

The American report states on page 3: *"It is important to note that about 20-40% of carefully evaluated CFS patients do not have depression or another psychiatric illness"*. This is substantially different from the UK report, which claims that **75% of all ME/CFS patients DO have psychiatric illness** (page 45).

The American report states on page 3: *"Some studies have found a significantly greater prevalence of allergy in CFS patients....Many CFS patients have a history of allergy years before the onset of the syndrome. Sometimes patients report a worsening of allergic symptoms or the onset of new allergies after becoming ill with CFS"*. Also, on page 9, the American report refers to *"the high prevalence of allergies in the CFS population"*. The UK report, however states: *"Patients with long histories of...food allergies (and) chemical sensitivities may fulfil...established criteria for somatisation disorder"* (page 16: 7.9) and expressly states: *"In CFS, the greater the number of somatic symptoms, the greater the probability of psychiatric disorder"* (page 16:7.11). Also, the UK report refers to "food allergy" in inverted commas (page 3:2.7), thereby conferring the authors' non-acceptance of food allergy as legitimate.

The American report states on page 6: *"Patients with CFS should be treated with compassion and evaluated carefully....people with CFS usually do not look as sick as they feel"*. "Compassion" in the UK involves the withdrawal of state benefits due to the ascription held by the reports' authors that CFS is a psychiatric diagnosis, for which category state benefits are not paid at the higher rate and for some benefits not at all.

The American report states on page 7 that *"a reasonable laboratory workup"* should be performed in cases of CFS; this differs from the UK report, which categorically states: *"No investigations should be performed to confirm the diagnosis"* (page 45).

The American report, in discussing children with (ME)CFS, states on page 7 that it advocates a *"supportive approach"*, whereas the UK report authors state that children may need to be forcibly removed from their parent and home. The American report further states on page 8 that for children and adolescents, *"the physician should work with the school to limit class time, if necessary, and to resume normal attendance gradually"*, whereas the UK report stipulates *"an immediate return to school"* (page 31:10.12). Also, the American report states: *"Home tutoring may be an alternative"*, but the UK report states: *"We discourage home tuition"* (page 31:10.12).

The American report recognises and accepts that: *"Some patients benefit from participation in CFS support groups"* (page 8) but the UK report authors are well-known for their often-repeated view that membership of such support groups is a prognostic indicator of a poor outcome and that advice given by patient support groups is unhelpful (Outcome in the CFS. Simon Wessely. BMJ 8th August 1992:365).

The American report states on page 8: *"Referrals to professionals who can help patients with practical matters, such as applying for disability and obtaining home health care... can help some patients and their families better"*

manage this illness". This contrasts markedly with the UK report authors' advice that the way to manage this illness is to alter patients' (and their families') view about it and in particular, to brain-wash them into accepting that the illness does not have an organic aetiology.

The American report states on page 9: "*CFS patients often report that antidepressants given in full therapeutic doses exacerbate their fatigue*" and that "*Many CFS patients are extremely sensitive to these drugs*" but the UK report unambiguously and vigorously urges the use of "*antidepressants for CFS sufferers (even those) without symptoms of depression*" (page 45).

The American report states on page 10: "*A variety of common viruses can be reactivated in some CFS patients....Most investigators believe virus reactivation could be occurring secondarily to some immunological disturbance*" but the UK report states: "*The symptoms of infection overlap and include those of mood disorder*" (page 10:5.3) and the authors are dismissive about the immunological abnormalities: "*Some use the results of immunological tests as evidence for a so-called 'organic' component in CFS....Such abnormalities should not deflect the physician from the biopsychosocial approach...and should not focus attention solely towards a search for an organic' cause*" (page 13:6.4).

The American report states on page 11 that "*CFS patients were found to have a subtle deficiency of the stress hormone cortisol....Because cortisol is a potent suppressor of immune responses, this finding may also explain the immune disturbances seen in some people with CFS*" and it goes on to state that central nervous system research, if confirmed, would support the theory that "*CFS is a multisystem illness with prominent CNS involvement*". The UK report, however, concludes that "*chronicity is likely to be associated with...unaddressed psychosocial issues*" (page 21:8.17) and states: "*Many of the current findings may be epiphenomena relating to...psychological distress ...or...inactivity*" (page 37:13.7).

The American report concludes that physicians treating ME/CFS should draw on practices "*that have always made medicine a valued art: ameliorate symptoms and offer guidance with compassion*".

The UK report states that "*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*" but it is the very label "ME" which has stopped patients from receiving vital welfare benefits: even those with confirmed ME who have been awarded such benefits for life have now had them withdrawn on the grounds that "*ME is not a pathology in its own right*" (internal memorandum from Dr AE Furniss, Medical Officer to the Benefits Agency Medical Services, 4th April 1995) and "*The label ME is a ragbag representing no proven pathology*" (internal memorandum from Dr AE Furniss, Medical Officer to BAMS, 10th October 1995; the Benefits Agency was an executive agency of the Department of Social Security (now called the Department for Work and Pensions) and it is noteworthy that Dr Simon Wessely was advisor on "CFS" to the UK Department of Social Security). In the UK report, ME is referred to as an "*unhelpful illness belief*" (9.2) and its existence is dismissed (13.3).

The above illustrations are just some examples of the differences in approach to the understanding of ME/CFS by American and UK clinicians, as evidenced by their respective reports.

The message from Professor Sir Leslie Turnberg that the American report (quote): *“seems to be helpful confirmation of views expressed in our report”* does not withstand scrutiny.