

International News From the CFIDS Community: UK Task Force Report: CFS/M.E. is Real

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On September 13, 1994, the UK National Task Force on chronic fatigue syndrome (CFS), postviral fatigue syndrome (PVFS) and myalgic encephalomyelitis (ME) published its first report.

This Task Force consists of "individuals, clinicians and clinical scientists with a wide range of expertise and experience in the care of patients with chronic fatigue syndromes and of research into these problems." Although the Task Force is independent, the two-year project was financially supported by the UK Government Department of Health. The Chairman was Dr. David Tyrrell, former director of the Common Cold Research Unit. The 12 medical members represented a variety of disciplines including molecular pathology, immunology, neurology, paediatrics, pharmacology and therapeutics, cancer epidemiology, psychological medicine and general practice, as well as one dedicated ME researcher.

In his foreword, the Chairman, while stating categorically that "we have no doubt that such conditions exist," refers to the problems of nomenclature, stating that this is not just a semantic problem but that it "encompasses serious disagreements which have sadly led to ill-will and abusive remarks on such questions as whether the syndrome...exists." Indeed, the report spells out that "some doctors continue to believe that the chronic fatigue syndromes do not exist and that their patients simply need to 'pull themselves together'". The Task Force, however, clearly recognizes that "the picture is further complicated by selection and observer bias," and that "the observations made about these patients will depend...on the focus and experience of the specialist in question".

The report considers many aspects of chronic fatigue syndromes, including epidemiology, presentation, prognosis, aetiology and pathogenesis, assessment, management, drug and food sensitivities and CFS/ME in children. It lists 188 journal references and 14 book references, but it acknowledges that it should be considered rather as a "springboard" for further work and not as a comprehensive manual.

The report recommends that specific issues should be addressed and lists guidelines for areas such as information and training; management and services; and further research. It will be submitted to the Royal Colleges and other professional bodies including administrators, clinicians, scientists, funding agencies and patients. The Chairman states that it is important that those concerned identify the topics in their field on which action is needed.

The Task Force comes to 15 main conclusions in its report; two of these deserve special mention. First, the report states emphatically that there is not one all-embracing chronic fatigue syndrome as had previously been advocated by some researchers. There are numerous such syndromes which cover a wide spectrum of disease and are collectively known as "the chronic fatigue syndromes".

The report clarifies these various entities, which range from neurasthenia and chronic fatigue to idiopathic severe chronic fatigue (ISCF). This latter category is the subject of the report and it is further divided into the commonly recognized subgroups of CF(ID)S, PVFS and ME.

The Task Force directs particular attention to the subgroup of ME which includes many severe cases. The term "CFS(ME)" has been used throughout the report to differentiate this most severely afflicted subgroup, and mention is made that in the U.S. the term "chronic fatigue and immune dysfunction syndrome (CFIDS)" is the term of choice. The report makes particular note that in the subgroup CFS(ME) "the most severely affected are bed-ridden with malaise, exhaustion and pain, together with other distressing symptoms, for example, inability to think clearly, loss of balance, painful hypersensitivity to the touch of bedclothes, daylight or the sound of a

human voice and profound fatigue or weakness such that the individual may not even be capable of feeding him/herself. This situation causes isolation and deep distress”.

Despite valiant efforts by the Task Force at intelligible nomenclature, the various terminologies remain a minefield for the unwary; in recognizing this, the report notes that “what is really needed is a clear way of describing the illness which leads ... to effective management... regardless of the label they are given ... Whatever the origin of their disease or the views of their doctors, people with chronic fatigue syndromes are disabled. They need and deserve help and support”.

The second item of special note is that the Task Force is unequivocal in its conclusion that progress in understanding these syndromes is hampered by the use of heterogeneous study groups and definitions of CFS; the lack of adequate comparison groups and standardised laboratory tests, and the invalid comparison of contradictory research findings stemming from these factors.

Flowing from this conclusion, the report considers the role of depression and other psychological disorders in these syndromes. Mention is made of papers previously published (mostly by British psychiatrists like Dr. Simon Wessely) about which the report states: “The studies which have been done have used a variety of case definitions, some of which are very broad. However it appears that many CFS patients (*note: not CFS(ME) patients*) would additionally meet the criteria for psychiatric disorder, most commonly depression. Such findings might invite the conclusion that the fatigue experienced by patients is attributable...to depressive disorder. However, it should be noted that a proportion of CFS patients attract no psychiatric diagnosis ... furthermore, the relationship between CFS and a diagnosis such as depression can be interpreted in other and diverse ways... First, the depression could be a reaction to CFS and the limitation it poses. ...Second, mood disorder can be a constituent symptom of, or secondary to...systemic disease process. Third, methodological factors which could lead to rates of depression being over-estimated should also be considered”.

The Task Force report goes on to warn that “the status of fatigue as an indicator of depression in patients with various medical conditions has been questioned” and that “the role of depression and other psychiatric disorders in CFS is thus ambiguous ... given the evidence to date, we may conclude that it is unlikely that CFS is no more than a form of depression”.

The authors state: “where psychological factors are playing an important part in the disease process ... a vicious circle may then develop,” but they continue: “careful evaluation of this hypothesis is required in different subsets of patients. Therapies which benefit those in whom this kind of vicious circle has developed may be quite inappropriate for those whose chief difficulty is their inability to avoid overactivity”.

The Task Force concludes that: “No advantage has been reported for the use of ... cognitive behavioural therapy”. CBT was previously advocated as a viable treatment by British psychiatrists¹ but has since been shown to have little benefit in CFS(ME).² The report further states that there is no general agreement about the value of psychologically based therapies and warns that although results from such trials have been published in peer-reviewed journals, most of these studies have involved only small numbers of patients so the results should be viewed “with considerable caution” .

In Summary, this National Task Force Report is a balanced and most welcome document and it is to be hoped that its conclusions will be duly heeded. Such hopes may, however, be in vain given the amount of published papers on CFS previously written by British psychiatrists. It is remarkable that these same journals have almost wholly ignored the Report of the Task Force. Indeed, press coverage in general has been stunningly silent.

Despite the undoubtedly valuable contribution made by the Task Force Report, it seems that the Chairman was singularly accurate when he stated in his foreword that: “We should be prepared for the long haul. It will be years before the chronic fatigue syndromes are conquered comprehensively”.

Copies of the report may be obtained for £6.95 (British currency only) from The National Task Force on CFS/PVFS/ME, 155 Whiteladies Rd, Clifton, Bristol BS8 2RK.

References

1. Butler S, Chalder T, Ron M, Wessely S: Cognitive behavior therapy in the chronic fatigue syndrome. *J Neurol Neurosurg Psychiatry* 1991;54:153-158.
2. Lloyd, et al: Immunologic and psychologic therapy for patients with chronic fatigue syndrome. *Am J Med* 1993;94:1973203.