www.margaretwilliams.me

Dysfunctional beliefs in ME/CFS?

Margaret Williams 27th March 2004

Anthony J Cleare is a psychiatrist who is well-known to the UK ME community. He works in the Section of Neurobiology of Mood Disorders at the Institute of Psychiatry and has co-authored numerous papers on "CFS" with Professor Simon Wessely. Along with psychiatrist Peter White and other members of the "Wessely School", Cleare was one of the five members of the Chief Medical Officer's "independent" Working Group on "CFS/ME" who resigned from the group before the publication of the Report because they wanted that Report to state conclusively that "CFS/ME" is a psychiatric disorder and that cognitive behavioural therapy /graded exercise therapy (CBT / GET) is an effective measure that should be used to modulate patients' maladaptive perception that they are suffering from a physical disorder. Cleare et al were not happy with what they considered to be "pandering to patients" so, to media publicity, they walked out.

Now, however, Cleare believes he has solved the problem of ME/CFS. In his article "The HPA axis and the genesis of chronic fatigue syndrome" (Anthony J Cleare: Trends in Endocrinology and Metabolism, March 2004:15:2:55-59), Cleare presents his belief that there is no specific change to the HPA axis in CFS and that the observed HPA axis changes occur as a consequence of the illness and can be reversed by modifying "behavioural features" of the illness such as inactivity and deconditioning. He states:

"when certain maintaining factors of the illness are targeted, the HPA axis changes can be reversed"

"there is no specific change to the HPA axis in CFS"

"the aetiology of HPA axis disturbance relates to the many factors that might impinge on the HPA axis in CFS, such as inactivity (and) psychiatric comorbidity"

"modifying cognitive behavioural components of the illness leads to a normalisation of the HPA axis"

"a vicious cycle is set up in the later stages of CFS, in which certain features of the illness can precipitate HPA axis changes, which can in turn lead to propagation and maintenance of fatigue and other symptoms"

"psychological and social factors can act as a maintaining factor in CFS"

"These perpetuating HPA axis changes do seem to be responsive to CBT, which appears to be the most appropriate means of addressing them at present, given the much more favourable evidence base for graded exercise and CBT in CFS (and) the evidence of long-term benefit".

These are momentous claims, but before indulging in universal rejoicing, some questions spring to mind. Since Cleare's paper is a REVIEW and not the result of a new study he has carried out, what were the entry criteria for participants in the studies he has reviewed? Bearing in mind the fact that ME/CFS can be differentiated from chronic fatigue by biological markers and by differences in clinical features, is he talking about patients with a classified neurological disorder (ME/CFS) or about patients with long-term fatigue?

A glance at the cited references provides the answer. Why does Cleare refer to "CFS" patients, given that "CFS" formally equates with ME (confirmed by the Health Minister to have only one coding, which is that ME/CFS is a neurological disorder)? This recent confirmation clearly post-dated Cleare's submission of his article, but the facts were merely confirmed by Lord Warner, not changed in any way and in medical science it is imperative to be precise.

How can seeking to equate one specific syndrome with another that does not have the same features (or using the same name to refer to two different case definitions, each with differing symptom profiles) lead to the advancement of medical understanding? Failure to be precise has important implications for management outcomes, as well as for service provision.

In contrast to Cleare's assertions about the "favourable evidence" for the "long-term benefit" of CBT, international attempts in Australia and America to replicate the claimed success of the Wessely School psychiatrists for those with ME/CFS have not been successful.

By analogy, is Cleare claiming that the physical symptoms of multiple sclerosis can also be reversed by psychiatrically "corrected" cognition processes and exercise?

Does Cleare believe that the established laboratory abnormalities seen in ME/CFS are simply inconsequential epiphenomena? Is he confident that in terms of restoring ME/CFS patients to asymptomatic pre-morbid levels of functioning, CBT/GET can restore damaged mitochondria; that CBT/GET can address the confirmed (published) vascular abnormalities – specifically the blood vessel sensitivity to acetylcholine which affects only those with ME/CFS and not other groups (such as Gulf War Syndrome and those with Organophosphate-exposed illness) who are equally disabled and who fulfil criteria for chronic fatigue syndrome; that CBT/GET can restore a leaky gut and a non-intact blood brain barrier; that CBT/GET can prevent the prominent immune derangements seen in ME/CFS such as humoral autoimmunity against polypeptides of the nuclear envelope (the occurrence of autoantibodies to an intracellular protein like

lamin β1 provides **laboratory evidence** for an autoimmune component in ME/CFS); that CBT/GET can modulate increased neutrophil apoptosis; that CBT/GET can restore maximum oxygen delivery and optimum lung function tests; that CBT/GET can restore an increased CD4-CD8 ratio; that CBT/GET can restore an up-regulated antiviral pathway and that CBT/GET can reverse recurrent pancreatitis, cardiomyopathy and hair loss and that it can control vertigo and observable nystagmus, double vision, nausea, bladder and bowel dysfunction, neuromuscular incoordination and intractable pain, all of which may occur in ME/CFS?

If so, where is his evidence?