

**Brief comments on the DWP proposed entry on “CFS/ME”**

**(version 8 of March 2006)**

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The letter of 24<sup>th</sup> March 2006 accompanying the revised guidance from the DWP Corporate Medical Group Directorate (CMG) states: “the CMG has been working with Professor Pinching to revise the CFS/ME guidance. As your agreed representative, Professor Pinching has deemed the revised guidance as fit for purpose. We are now issuing the revised CFS/ME guidance. Given Professor Pinching’s endorsement of the guidance, we expect you will be content that this represents a consensus view of this illness”.

To claim that Professor Pinching is an agreed representative of the UK ME community is to misrepresent the facts: Pinching is Medical Adviser to Action for ME but he does not represent the majority of people with ME in the UK, especially as AfME seems increasingly to speak for those with chronic “fatigue” as distinct from those with true ME (some years ago having even changed its logo to incorporate the words “chronic fatigue”). It is true that Pinching was Chairman of the Investment Steering Group that devised the process and the criteria for setting up the new Centres (about which there is now evidence of what might be deemed to be abuse of patients), that he oversaw the assessment of bids and that he allocated the funds. It is also true that he is the lead adviser for the Department of Health on “CFS/ME”. Despite his tenure of such positions, it is not the case that Pinching’s view represents a “consensus view” of ME/CFS. Within the ME community, Pinching is best known for his publication “Chronic Fatigue Syndrome” in Prescribers’ Journal (2000:40:2:99-106) in which he stated that the fatigue in “CFS” is “not related to on-going exertion”; that “over-investigation can be counter-productive, causing (those with ME/CFS) to seek abnormal test results to validate their illness”; that “it is helpful to establish with the patient a way of thinking about the illness” and that “The essence of treatment is activity management”. Such views do not reflect an informed knowledge of the disorder ME/CFS as demonstrated in the international literature.

The title of the DWP document refers to chronic fatigue syndrome and “myalgic encephalomyelitis / encephalopathy”: there is no such classified disorder in ICD-10 as “myalgic encephalopathy”. It was Simon Wessely who pointed out over a decade ago that: “Scott argues that the DSM or ICD take it for granted that the diagnoses contained therein exist as independent entities (and that) these are the arbiters, since if your illness is not in (them), you certainly will not be able to claim” (ref: Editorial: Simon Wessely. Journal of Psychosomatic Research 1995:39:6:659-669).

It is untrue that there is no evidence of inflammation in authentic ME/CFS: there is increasing evidence that ME/CFS is an autoimmune disorder (see for example Eng Tan; Kenny De Meirleir; Susan Levine and Charles Raison, amongst others); for example, the current 65 page issue “Science and Research of (ME)CFS” from the CFIDS Association of America states on page 30: “Autoimmune disorders like multiple sclerosis and lupus are being studied to determine the precise link with chronic inflammation. Illnesses like (ME)CFS and FM, with their documented immune irregularities, also merit further study to determine what role chronic inflammation may play”. See also Autoantibodies to Nuclear Envelope Antigens in

It is important to be aware that what Wessely School adherents, including Pinching, deliberately refer to as “CFS/ME” equates with “neurasthenia”, which is a mental disorder classified at ICD-10 F48.0 and is not the same as ME/CFS that is classified at ICD-10 G93.3. For clarification, see “More on the Myth” at [http://www.meactionuk.org.uk/More\\_on\\_the\\_Myth.htm](http://www.meactionuk.org.uk/More_on_the_Myth.htm) , which quotes from a World Psychiatric Association Report of 2002 on Neurasthenia (to which Wessely was a named contributor); on page 22 of that Report, “chronic fatigue syndrome / myalgic encephalomyelitis” is specifically named as one presentation of neurasthenia.

However, the key issue for those claiming DLA is that Pinching is categorical that what he calls “CFS/ME” is indeed a “physical” disorder for the purposes of the law relating to eligibility for this benefit (para 15 states: “For this purpose, CFS/ME is ‘physical’ ”), which is to be welcomed (although the use of inverted commas -- with the implications of such use in this context -- is noted).

That apart, there are errors of fact and misapprehensions that ideally should be addressed. Some of these include the following:

Para 1: In the “Definition”, many key symptoms and features of true ME/CFS are again omitted: since the Guidance is not limited to mild forms of the disorder (but covers the entire spectrum of severity), why have such symptoms as cardiac insufficiency, neuromuscular incoordination, respiratory dysfunction, vertigo /balance problems, inability to stand unsupported for more than a few moments, frequency of micturition / nocturia, pancreatic insufficiency, chest pain, parasympathetic enteropathy etc been omitted? This would seem to amount to deliberate disinformation.

Para 2: again, there is obfuscation about which disorder is being discussed. It is untrue that “most authorities consider the condition as CFS/ME”; the people who use that term are Wessely School adherents and UK Government bodies whom they have influenced. The term was coined by Wessely himself, who wrote in the BMJ: “It may seem that adopting the lay label (of ME) reinforces the perceived disability. A compromise strategy is ‘constructive labelling’: it would mean treating CFS as a legitimate illness while gradually expanding understanding of the condition to incorporate the psychological and social dimensions. The recent adoption by the UK Medical Research Council and the chief medical officer’s report of the term CFS/ME reflects such a compromise” (BMJ 2003;326:595-597). It must not be forgotten that Wessely’s version of “CFS/ME” equates with neurasthenia.

Para 4: To which “consensus” does this refer? The Canadian Guidelines do not support the Wessely School view of the disorder.

Para 7: It is untrue that there is no evidence of persisting infection, nor is it true that “beliefs and coping strategies” are implicated in the perpetuation of ME/CFS.

Para 8: there is no evidence whatever that “personality” is a factor in ME/CFS (although it may be so in cases of psychiatric “fatigue”).

Para 13: Pinching seems to be confusing “postural hypotension” (which is as described in the document) with “orthostatic hypotension” which occurs in ME/CFS; the two are not the same – orthostatic hypotension is an abnormal change in heart rate and blood pressure accompanied by signs and symptoms over time: it does not occur immediately on moving from supine to upright as in postural hypotension and is characteristic of the autonomic dysfunction seen in ME/CFS.

Para 17: It is untrue (re: graded exercise) that “Research suggests that this approach is helpful in the majority of adult ambulant patients”. It may well help those suffering from psychiatric fatigue states, but these are not the same as ME/CFS. The evidence is that GET is actively harmful in true ME/CFS because of a degree of cardiac failure in such patients. No less than four American physicians who all specialise in (ME)CFS (note: not in neurasthenic states) do not share Pinching’s view as stated in this DWP document:

Professor Charles Lapp:

"In my opinion, CBT is widely but unfairly maligned because of the British approach, which presumes that (ME)CFS has no organic basis, and is therefore contradictory to current science. This type of CBT assumes somatic symptoms are perpetuated by errant illness beliefs and maladaptive coping".

Professor Nancy Klimas:

"I don't take the British point of view that CBT is the one thing you can do to effectively treat (ME)CFS (but) it's a tool that can help some patients cope with the illness (and) create a support system within the confines of the illness".

Dr David Bell:

"It won't suddenly make patients better. I don't refer (ME/CFS patients) to outside CBT therapy".

Dr Daniel Peterson:

Peterson is not convinced of the efficacy of CBT: "Sending patients to therapists who don't understand (ME)CFS isn't something I'd comfortably do".

Simon Wessely himself has conceded that his therapies are “not remotely curative” and are only “modestly effective” and that “these interventions are not the answer to ME/CFS” (*Trials and Tribulations: JAMA 2001:286:11*).

Wessely is also on record as stating: “cognitive behaviour therapy has been shown to improve functional impairment and fatigue for up to eight months after treatment. Observed gains may be transient” (*Am J Psychiatry 2001:158:2038-2042*).

Para 18: (re: CBT) Again, it is untrue that “Research suggests that this approach is helpful in the majority of adult and adolescent outpatients”: it is unknown what such outpatients were suffering from; most of the three RCTs that claim some benefit from CBT (and such benefit is only temporary) were not studying those with true (severe) ME/CFS because if the Oxford criteria were used, those with ME/CFS are excluded by definition.

Para 20: It is misleading to claim “Antidepressants may be very helpful in treatment of co-morbid conditions such as depression or insomnia” because (i) the statistics of alleged psychiatric co-morbidity in ME/CFS are widely divergent (due to the use of non-standard case definitions) and (ii) in true ME/CFS there is a well-documented hypersensitivity to such drugs and such drugs are poorly tolerated. It is particularly misleading to promote fluoxetine for those with ME/CFS because the literature is quite clear: it is poorly tolerated because of adverse side effects; it does not work and should not be used: “Fluoxetine in a 20 mg daily dose does not have a beneficial effect on any characteristic of CFS. We conclude that fluoxetine in CFS is unwarranted” (ref: Randomised, double-blind, placebo-controlled study of fluoxetine in chronic fatigue syndrome. Jan HMM Vercoulen et al. Lancet 1996: 347:858-861).

Para 22: It is misleading to state: “Most people who are able to attend hospital for treatment will make a significant improvement with appropriate treatment” because, yet again, the population to which this might refer has not been defined, so it is unknown how many of such patients actually had true ME/CFS. Such a statement seems to disregard the actual statistics: according to the US Centres for Disease Control, only 4% of (ME)CFS patients had full remission (not “recovery”) at 24 months (ref: US CDC Programme Update, 29<sup>th</sup> August 2001) and even Wessely’s own 2005 chapter states the full recovery rate to be only 5% (ref: Ruud Vermeulen: in chapter 5: “Chronic Fatigue and Neurasthenia: A Review” by Michael Sharpe and Simon Wessely; in: Somatoform Disorders (Volume 9), ed. Mario Maj et al; John Wiley & Sons, 2005, ISBN 13978-0-01612-1).

For further information and more references, see the 174 page document “Illustrations of Clinical Observations and International Research Findings in ME/CFS from 1955 – 2005” by M Hooper, E. Marshall and M Williams; 12<sup>th</sup> December 2005 (prepared for the Gibson Parliamentary Inquiry into ME/CFS).