

Comments on statements of Professor Peter Denton White at the RSM on “CFS” on 28.04.08

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Evidence as to why the NICE Guideline Development Group (GDG) that produced the NICE Guideline CG53 on “Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis” (CFS/ME) failed to accept the WHO ICD-10 classification may be found in the presentation of psychiatrist Professor Peter Denton White on 28th April 2008 at the Royal Society of Medicine in London.

Significantly, the WHO has confirmed that the use of the term “CFS/ME” by the GDG is unfortunate: *“It is unfortunate that NICE uses a terminology that is not specific. ‘CFS’ is a broad umbrella. This needs to be clarified. It is not possible to make a deduction from ‘CFS’ ”* (4th February 2009; personal communication). The WHO does not recognise the term “CFS/ME” as used by NICE in CG53.

On 4th February 2009 the WHO further clarified the position in writing: *“Terms that are listed in the (ICD) Index (Volume II) may be a synonym to the label (title) of a category of ICD (for example, ‘CFS’ is coded to ME/PVFS at G93.3 in Volume I); they may be a sub-entity to the disease mentioned in the title of a category, or they may be a best coding guess”* (in other words, the use of the term “CFS” in the ICD Index is merely colloquial and does not necessarily refer to the specific disorder ME, which is why the WHO described NICE’s term “CFS/ME” as *“unfortunate”*. Thus the WHO has clarified that the term “CFS” as listed in the ICD-10 Index may or may not be referring to ME. “CFS” could be referring to any syndrome of chronic fatigue, not to ME at all. That is why the WHO said: *“It is not possible to make a deduction from ‘CFS’ ”*.

The WHO correspondence of 4th February 2009 continued: *“I wish to clarify the situation regarding the classification of neurasthenia, fatigue syndrome, postviral fatigue syndrome and benign myalgic encephalomyelitis. Let me state clearly that the WHO has not changed its position on these disorders. Postviral fatigue syndrome remains under the diseases of the nervous system as G93.3. Benign myalgic encephalomyelitis is included within this category. Neurasthenia remains under mental and behavioural disorders as F48.0 and fatigue syndrome (note: not THE CHRONIC FATIGUE SYNDROME) is included within this category. (ME)PVFS is explicitly excluded from F48.0. There is no evidence for any change of the above to be made for ICD-11”*.

The WHO has also confirmed – in writing – that under the taxonomic principles governing the ICD, it is not permitted for the same condition to be classified to more than one rubric as this would mean that the individual categories were no longer mutually exclusive. Leading Wessely School members, however, seem to believe that they know better than the WHO.

PDW: *“I’m going to review the ICD-10 criteria for the illness and see if they’re helpful. The answer will be they are not helpful”*. The WHO ICD-10 classification is disease-specific and bodily system-specific. Peter White and the Wessely School do not like the WHO’s rigorous classification and do not abide by it. Furthermore, in the production of CG53 for “CFS/ME”, the NICE Guideline Development Group (GDG) was obliged to abide by it but in defiance of NICE’s own taxonomy, did not do so (NICE’s own policy that dates from 18th September 2002 as set out in its Communications Report 8 sent by Anne Toni Rodgers clearly states: *“the (ICD) classification codes are mandatory for use across England”*).

PDW: *“ I’m going to look at research criteria to see if they help us to try and define this illness. And the answer is, the research criteria are pretty useless at defining the illness clinically”*. Here we have Peter White clearly stating that the research criteria (used in the RCTs that NICE relied upon for its recommended behavioural interventions) are *“pretty useless at defining the illness clinically”*.

PDW: *“We then come to the three clinical criteria to see if they’re useful and two of them do help us, so there will be some good news, where there are two particular clinical criteria: the NICE Guidelines and the Royal College of Paediatrics and Child Health criteria I would commend to you as a useful way of starting the process of diagnosis and management of your patients”*.

PDW: *“So, does the ICD-10 help us? Unfortunately not; there are at least five ways of classifying Chronic Fatigue Syndrome using the ICD-10 criteria. You get a virally triggered chronic fatigue syndrome – that’s your diagnosis. Or is it? What if a viral illness is not a clear trigger for the illness? Well, you’ve got alternatives: in the Mental Health chapter, you’ve got neurasthenia. There’s five possible diagnoses you can use (and) you have to somehow guess that psychological factors have an important role to play in their aetiology – how on earth can you guess that when someone may be presenting five years after the illness started? The “alternatives” shown on White’s power point slide are all explicitly forbidden by the WHO; they include not only neurasthenia (which White points out includes “fatigue syndrome”), but also at F45.1 “Undifferentiated somatoform disorder”; at F45.3 “Somatoform autonomic dysfunction” and at F45.9 “Somatoform disorder, unspecified”. White pays no heed whatever to the WHO directive that **ME** (and the NICE Guideline refers throughout to “CFS/ME”) **is not permitted to be classified to more than one rubric**. If he does not include ME within “CFS/ME”, then he is correct about “fatigue syndrome”, but clearly he uses the term “CFS/ME” and that term is designed to include ME, which is impermissible.*

PDW: *“So ICD-10 is not helpful and I would not suggest, as clinicians, you use ICD-10 criteria”*.

PDW: *“So we come to the clinical criteria”*. Peter White listed three: the Canadian criteria, the NICE criteria and the RCPCH criteria. He dismissed the Canadian Guidelines and focused on the two UK criteria that do not distinguish between ME/CFS and

“CFS/ME”. White said about the Canadian criteria: *“The Canadian criteria are popular in some quarters so I’m going to review them to see if they are useful to us. Start off well -- you’ve got to have these four symptoms, now take a deep breath – it gets worse, because you’ve got to have two of any of this lot, so you’re up to six symptoms already to meet the Canadian clinical criteria. Look at the symptoms: disorientation? A symptom of this illness? Ataxia? As a psychiatrist, I would have problems defining emotional overload, so is this really useful? You need six symptoms already to make the definition and some of these symptoms are very hard to define and therefore how can you use them clinically? It gets worse again, because not only do you need those two symptoms --I don’t expect you to read the list, don’t worry -- you need at least one from two of the following: autonomic manifestation, neuroendocrine manifestation or immune (manifestation). New sensitivity to food: is that really an immune manifestation?”*

White effectively advised his audience that because as a psychiatrist he finds it difficult to recognise an ME patient’s physical symptoms, there is no need even to consider those symptoms. He made it plain that the less symptoms a definition of CFS/ME has (and he does refer to “CFS/ME”), the better. To back up his claim, and using a graph from a study by Professor Simon Wessely, White said: *“You notice a fairly straight line showing the more physical symptoms you have, the more likely you are to meet the criteria for psychiatric distress. The cut-off for CIS (Clinical Interview Schedule, revised in 1990 by psychiatrist Anthony Pelosi) for psychiatric morbidity is about 12. So once you get above 4 symptoms – you can see once you get 5,6,7,8 symptoms as the Canadian criteria suggest, you are more likely to find someone with a psychiatric disorder and not CFS/ME. So I would suggest you do not use the Canadian criteria”.*

Is this the reason why the Wessely School supporters on the GDG refused to recommend the use of the Canadian criteria in the UK?

Having praised the NICE new case definition, which requires only fatigue plus one other symptom (*“You might argue with some of these symptoms such as palpitations – is that really part of CFS/ME -- but at least the good news is that we’re going for less symptoms to define the syndrome rather than more”*), White then told his audience that the RCPCH criteria got the *“gold star for me – I think these are the best. So here we are -- generalised fatigue causing significant impairment, they say for three months, and I would commend these criteria to you as probably the best to use clinically”*. This is a guideline for children, not adults, and it states: *“Children and young people with CFS/ME should be considered for graded exercise or activity programmes”*; contributors referred to the *“emotional dimensions of the illness”* and stated: *“The overarching aim of CBT is to help patients modify their behaviour for their own benefit”*.

PDW: *“Simon Wessely and Michael Sharpe’s Lancet (1999) paradigm-shifting paper suggested that what we should be doing is lumping them all together (CFS/ME, irritable bowel syndrome, fibromyalgia) rather than trying to isolate CFS. Reactionary diehards like me disagreed with this; I think we shouldn’t be lumping, we should be splitting, so actually CFS/ME is more than one illness. Let’s just show you the data to suggest that this is the case....just looking at the symptoms and demographics alone*

without looking at laboratory abnormalities, you can define these two separate subgroups: when you start to look at the symptoms and demographics, you get separate illnesses coming out however you analyse it". Here White refers to "laboratory abnormalities" (the existence of laboratory abnormalities is denied by the GDG) and he is saying that "CFS/ME" is not a single disorder, so on what evidence did the GDG lump them together as one (somatoform) disorder?

PDW: *"So diagnosis --- what is the point of making the diagnosis? I would suggest that it is useful to make the diagnosis of CFS/ME to lump as far as that..... there's a final common pathway (for) several different disease processes with the same clinical presentation. It may be in the future the PACE trial – which I lead – may show that actually heterogeneity could help us define which treatment to give our patients (but) at the moment it can't, so certainly (as far as treatment is concerned) keep it lumped as CFS/ME".*

There in the clearest terms seems to be the rationale behind the blanket management interventions recommended in CG53.

In the last few minutes of his talk, White spoke about ME as described by Acheson and Ramsay from the 1950s and he stressed that it was a different illness from what is now called "CFS/ME". Disturbingly, he misled his audience by manipulating the clinical presentation of the Royal Free outbreak, which seemed to be an attempt to distinguish between the "original" ME cases and what is now called "CFS/ME". He was at pains to emphasise that in 1955 at the Royal Free, "74% showed objective involvement of the central nervous system" but implied that in "CFS/ME" there is no such CNS involvement, which is 100% incorrect. It is important to recall that when the term "CFS" was coined in the USA in 1988, it was made known that "CFS" was simply a new name for what was known as ME, so White is incorrect to imply that "CFS/ME" is not based on the earlier and more clinically accurate descriptions of it. People die from ME, and there is irrefutable evidence of CNS involvement, as shown in the autopsy of Sophia Mirza, where 75% of her spine showed dorsal root ganglionitis (a severe inflammation of the nerves in her spinal cord).

PDW: *"How did this happen? I'm afraid we're responsible (laughter from the audience). We transmogrified, we changed, transposed epidemic ME into endemic ME. So actually we've got a definition of a different illness that we have transposed onto this illness, which I think is where our problem comes from. What message? This is organic. What does that word mean? Incurable neurological disease. OK, it might be right, it might be wrong. But what message does this give our patients? 'You have an incurable neurological disease'. Is it a more useful message for our patients to say that, or to say 'graded exercise therapy is a safe and effective treatment if it's done properly', because the two statements cannot be at this moment joined together".*

This seems to be paternalism *par excellence*, in that Peter White is saying that patients with an incurable organic neurological disease must not be allowed to know the reality about their condition but must be patronised by being given GET, not least because GET

is known not to be “*safe and effective*” (evidence which the Wessely School and the GDG had no compunction in denying).

PDW: “*I would commend to you the broad-based definitions* (ie. the ones that pull in patients with chronic “fatigue”) *rather than the one with lots of* (specific and characteristic) *symptoms*”.

This whole presentation at the RSM was irresponsible and damaging to many very sick people who suffer from a serious and complex neuro-immune disorder, but it does seem to provide the explanation for the inappropriate stance taken by NICE in its Guideline on “CFS/ME”.