

M.E., NEW INTERNATIONAL CRITERIA AND THE END OF  
'FATIGUE' AND 'OPATHY' TERMINOLOGY?

In the light of recent clarifications and expert findings I believe that use of the terms '*Chronic Fatigue Syndrome/CFS*', '*Fatigue Syndrome/FS*', '*Fatigue*', '*CFS/ME*', '*Myalgic Encephalopathy* and the like in reference to *Myalgic Encephalomyelitis* patients is clearly unjustified, harmful and needs to cease.

The new '*Myalgic Encephalomyelitis: International Consensus Criteria*'[1] by Dr Bruce Carruthers *et al* was published online in the Journal of Internal Medicine in July 2011 – doi: 10.1111/j.1365-2796.2011.02428.x.

This landmark document is an outstanding evidence-based patient diagnosis and research subject selection guideline that warrants widespread application. It was produced by an erudite international expert panel that between them have seen many thousands of ME patients in 13 countries and have engaged with both long-established and cutting-edge evidence from clinical practice and research settings. The document is designed for adult and paediatric clinical and research use and it is to be followed up with further supportive resources from the consensus panel as specified.

Set against a context of unhelpful, opaque and profound international medico-political controversy on disease terminology and related matters, the new international consensus document brings much needed clarity; stating:

***“The label “chronic fatigue syndrome” (CFS) has persisted for many years because of lack of knowledge of the etiological agents and of the disease process. In view of more recent research and clinical experience that strongly point to widespread inflammation and multisystemic neuropathology, it is more appropriate and correct to use the term “myalgic encephalomyelitis”(ME) because it indicates an underlying pathophysiology. It is also consistent with the neurological classification of ME in the World Health Organization’s International Classification of Diseases (ICD G93.3).”***[2]

The new international consensus document then goes on to cite evidence in the scientific literature underpinning myalgic encephalomyelitis terminology and its ICD classification and sets out problems with various broad-ranging patient selection criteria that give misplaced emphasis to 'fatigue':

***“The problem with broadly inclusive criteria is that they do not select homogeneous sets of patients. The Centers for Disease Control prevalence estimates increased tenfold from 0.24% using the Fukuda criteria to 2.54% using the Reeves empirical criteria. Jason et al suggest there are flaws in Reeves’ methodology because it is possible to meet the empirical criteria for ME without having any physical symptoms and it does not discriminate ME/CFS patients from those with Major Depressive***

***Disorder. Patient sets that include people who do not have the disease lead to biased research findings, inappropriate treatments, and waste scarce research funds.”***[3]

***“Using “fatigue” as a name of a disease gives it exclusive emphasis and has been the most confusing and misused criterion. No other fatiguing disease has “chronic fatigue” attached to its name – e.g. cancer/chronic fatigue, multiple sclerosis/chronic fatigue – except ME/CFS.”***[4]

The current revision/edition of the WHO International Classification of Diseases that most countries subscribe to, including the UK, is the tenth one (ICD-10). A few countries use their own 'clinical modification' version of the WHO ICD. The standard/unmodified WHO ICD-10 primary tabular list uses the term '*Postviral Fatigue Syndrome/PVFS*' as the primary disease label with '*Benign Myalgic Encephalomyelitis/ME*' as its synonym. *PVFS/ME* is classified in ICD-10 under '*Diseases of the Nervous System*' at section G93.3 (*Other disorders of brain*) and nowhere else. In doing so the WHO implicitly recognises the history of viral involvement in the disease and specifically excludes the disease from mental and behavioural disorders such as '*Fatigue Syndrome*' - which is classified separately and exclusively in ICD-10 under '*Mental and behavioural disorders*' at section F.48.0 (*Other neurotic disorders*). The WHO have confirmed on many occasions that such disease classification is always exclusive and that listed disease entities are not classified under more than one rubric and are not interchangeable.

Taxonomical confusion has arisen in this field for three main reasons. Firstly, certain psychiatrists have made and published widespread claims that are factually incorrect and at odds with the WHO (see below). Secondly, because a few countries, including the USA, use their own unique “clinical modification” version of the WHO ICD which is different from the world standard. Thirdly, because the WHO did not put all of the details of their ICD 10th Revision in their online website summary. For accuracy on ICD-10 classification therefore, full reference needs to be made to the three-volume published/book version[5].

The term '*Chronic Fatigue Syndrome/CFS*' (not to be confused with ICD-10-F.48.0 '*Fatigue Syndrome/FS*') is in fact not entered/categorised anywhere in the ICD-10 tabular list whatsoever and is not therefore an ICD-10 disease classification/term in its own right. It is merely listed in the ICD-10 alphabetical index as a term by which *PVFS/ME* (ICD-10-G93.3) may be referred to but crucially, in clarifying this point to members of the UK ME community, the WHO unequivocally stated:

***“ME is classified at G93.3 and is a specific disorder. The term CFS covers many different conditions, which may or may not include ME. The use of the term CFS in the ICD index is merely colloquial and does not necessarily refer to ME. It could be referring to any syndrome of chronic fatigue, not to ME at all. The index (i.e. volume iii) cannot be taken as definitive.”*** [Dr Robert Jacob, Medical Officer (ICD), Classifications, Terminologies and Standards, WHO HQ, Geneva. 4th February 2009].

Prior to this clarification there was understandable use of the compromise term '*Myalgic Encephalomyelitis/Chronic Fatigue Syndrome*' or '*ME/CFS*'[6] (as opposed to '*CFS/ME*' - see below) by many ME activists given that so many genuine ME patients have unfortunately been labelled and studied as CFS patients. Now that the WHO and the new Myalgic Encephalomyelitis International Consensus Criteria have added clarity to matters, use of the compromise *ME/CFS*

terminology is no longer justified in my view: It is far better to simply stick to ICD-10 recognised 'Myalgic Encephalomyelitis' terminology in our literature and relegate to a caveat or footnote the fact that many genuine ME patients and research subjects have been labelled as CFS. Surely the best way for ME activists to assist fellow patients that are inappropriately labelled with CFS is to refuse to adopt the latter terminology any longer and insist that patients are examined, diagnosed and included in biomedical research studies on the scientifically justifiable basis set out in the new Carruthers *et al* international consensus criteria?

Alongside the problem of various "fatigue" labels diverging from WHO-ICD-10 *Myalgic Encephalomyelitis* taxonomy, in the UK, we have the added problem of the use of *Myalgic Encephalopathy* by Dr Charles Shepherd and his associated charity. This wholly unclassified label was subsequently taken up by *The National Institute for Health and Clinical Excellence (NICE)* in production of its psychosocial 'CFS/ME' clinical guideline 53. The "encephalopathy" terminology is very broad-ranging and, given that most medical dictionaries state something along the lines of **"the hallmark of encephalopathy is an altered mental state"**[7] is wide open to psychosocial misattribution in my view. Moreover, to reiterate the views of the expert international consensus panel, the encephalomyelitis terminology is evidence-based and entirely justified:

***"In view of more recent research and clinical experience that strongly point to widespread inflammation and multisystemic neuropathology, it is more appropriate and correct to use the term "myalgic encephalomyelitis"(ME) because it indicates an underlying pathophysiology"***[8]

With regard to the encephalopathy matter therefore, Dr Bruce Carruthers, lead author of the international consensus criteria, earlier cautioned:

***"The Politics around this are horrendous, and the motive for any name change would seem to have less than the good of mankind at heart. I would not favour any kind of name change, since -itis is well established in the name ME, and there is no good reason for changing it, since -opathy would not reduce our state of ignorance re ME but serve to further confuse everyone- perhaps that is one of the motives behind the suggestion."***[9]

Even if the reason for the '-opathy' name change at the UK *ME Association* was well-meaning it is clear that Dr Carruthers' concerns on motives behind terminology change are broadly justified. Consider for example the case of Professor Simon Wessely who, in spite of the tenth edition of the International Classification of Diseases and a large body of biomedical evidence claimed **"that ME is simply a belief, the belief that one has an illness called ME"**[10]. Wessely then went on to misrepresent Myalgic Encephalomyelitis in a various professional fora as mental illness and misrepresent WHO ICD-10 taxonomy as merely patients' own **"lay label"**. He did this, by his own admission, in order to pursue a **"constructive labelling" "strategy"** of having physical ME gradually subsumed into the rubric of mental disorders - by **"gradually expanding understanding of the condition to incorporate the psychological and social dimensions."** Thus, in *The British Medical Journal* Professor Wessely tellingly stated:

***"One challenge arises when patients have named their condition in a way that leaves doctors uncomfortable, as occurred with chronic fatigue syndrome. It may seem that***

***adopting the lay label endorses the implicit causal theory and reinforces the perceived disability. For better or worse, the medical profession has lost the monopoly on naming conditions, and rejecting lay terms can needlessly alienate patients. A compromise strategy is “constructive labelling,” expanding on the lay name. It would mean treating chronic fatigue syndrome as a legitimate illness, acknowledging that it may have a viral trigger (as many patients report), 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 chronic fatigue syndrome/myalgic encephalitis reflects such a compromise, albeit an uneasy one.”***[11]

Myalgic Encephalomyelitis is WHO ICD-10 disease classification, not the ***“lay label”*** that Professor Wessely misleadingly claims. ME is rightly classified in ICD-10 as neurological/physical disease and accompanied by a large body of biomedical evidence. ME is not ***“simply a belief”*** as Wessely disgracefully asserts. Caveat Emptor therefore: the psychiatrists’ ***“constructive [re]labelling” “strategy”*** gradually moves 'PVFS/ME' to 'ME/CFS' to 'CFS/ME' to 'CFS' to 'FS' to 'F' etc in disregard of a growing body of biomedical evidence and all in aid of ***“gradually expanding understanding of the condition to incorporate the psychological and social dimensions.”*** In my view such a questionable shift is aided by changing to an ‘encephalopathy’ label ***“the hallmark of [which] is an altered mental state”***

Returning to the new International Consensus Criteria, not only do the authors cite evidence against use of 'fatigue' terminology and in support of encephalomyelitis pathology, in their concluding remarks, Carruthers *et al* state:

***“Individuals meeting the International Consensus Criteria have myalgic encephalomyelitis and should be removed from the Reeves empirical criteria and the National Institute for Clinical Excellence (NICE) criteria for chronic fatigue syndrome.”***[12]

I could not agree more, but if the ME community want state agencies to properly use ICD-10 Myalgic Encephalomyelitis disease taxonomy then we need to consistently lead by example.

Kevin Short, July 2011.

[contact@angliameaction.org.uk](mailto:contact@angliameaction.org.uk)

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ENDNOTES:

[1] Myalgic Encephalomyelitis: International Consensus Criteria. Journal of Internal Medicine, 20 July 2011. Bruce M Carruthers, Marjorie I van de Sande, Kenny L De Meirleir, Nancy G Klimas, Gordon Broderick, Terry Mitchell, Don Staines, Peter Powles, Nigel Speight, Rosamund Vallings,

Lucinda Bateman, Barbara Baumgarten-Austrheim, Nicoletta Carlo-Stella, John Chia, Austin Darragh, Daehyun Jo, Don Lewis, Alan R Light, Sonya Marshall-Gradisbik, Ismael Mena, Judy A Mikovits, Kunihiisa Miwa, Modra Murovska, Martin L Pall, Staci Stevens. Please cite this article as; doi: 10.1111/j.1365- 2796.2011.02428.x Available online at: <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2796.2011.02428.x/abstract>

[2] Ibid.

[3] Ibid.

[4] Ibid.

[5] For accuracy in ascertaining WHO ICD-10 disease classification, full reference needs to be made to the three-volume published/book version. The bibliographic details of all three volumes are:

- *International Statistical Classification of Diseases and Related Health Problems - Tenth Revision – Second Edition: Volume 1 – Tabular List* – ISBN: 92 4 154649 2.
- *International Statistical Classification of Diseases and Related Health Problems - Tenth Revision – Second Edition: Volume 2 – Instruction Manual* – ISBN: 92 4 154653 0.
- *International Statistical Classification of Diseases and Related Health Problems - Tenth Revision – Second Edition: Volume 3 – Alphabetical Index* – ISBN: 92 4 154654 9.

[6] See, for example, *ME/CFS: TERMINOLOGY* by Margaret Williams at:

[www.angliameaction.org.uk/docs/me-cfs-terminology.pdf](http://www.angliameaction.org.uk/docs/me-cfs-terminology.pdf)

[http://meactionuk.org.uk/ME\\_CFS\\_TERMINOLOGY.pdf](http://meactionuk.org.uk/ME_CFS_TERMINOLOGY.pdf)

And *ME/CFS: Classification Issues* by Margaret Williams at:

[http://meactionuk.org.uk/ME\\_CFS\\_Classification\\_Issues.pdf](http://meactionuk.org.uk/ME_CFS_Classification_Issues.pdf)

[7] “*The hallmark of encephalopathy is an altered mental state.*” See:

<http://en.wikipedia.org/wiki/Encephalopathy>

[8] Carruthers *et al* op. Cit

[9] Dr Bruce Carruthers, in personal correspondence with Kevin Short in 2005 with a view to his comments being made public. Viewable on-line at:

[www.investinme.org/Article%20010-Encephalopathy%20Carruthers.htm](http://www.investinme.org/Article%20010-Encephalopathy%20Carruthers.htm)

[10] In “*Microbes, Mental Illness, The Media and ME: The Construction of Disease*”; Simon Wessely; 12th May 1994; 9th Eliot Slater Memorial Lecture, Institute of Psychiatry, London. A copy of Professor Wessely's own 12th May 1994; 9th Eliot Slater Memorial Lecture notes, along with comment, is available here:

[http://www.meactionuk.org.uk/wessely\\_speech\\_120594.htm](http://www.meactionuk.org.uk/wessely_speech_120594.htm)

[http://www.meactionuk.org.uk/wessely\\_speech\\_120594.pdf](http://www.meactionuk.org.uk/wessely_speech_120594.pdf)

Cited in 'Submission re: DSM-V and ME/CFS', Compiled by Professor Malcolm Hooper and Margaret Williams for submission by The 25% ME Group, 20 March 2010:

<http://www.meactionuk.org.uk/DSM-V-submission.htm>

<http://www.meactionuk.org.uk/DSM-V-submission.pdf>

[11] *Managing patients with inexplicable health problems*. Baruch Fischhoff, Simon Wessely. BMJ Volume 326, 15 March 2003. BMJ 2003;326:595–7.]

[12] Carruthers *et al* op. Cit.

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