ME/CFS: TERMINOLOGY

Margaret Williams 27th April 2009

Terminology is confusing. Although it may seem merely pedantic, inverting the initials "ME/CFS" and "CFS/ME" may have far-reaching implications for patients: "CFS/ME" (Chronic Fatigue Syndrome / Myalgic Encephalomyelitis) is not the same as "ME/CFS" because in "CFS/ME", the "CFS" refers to (chronic) "fatigue syndrome", not to **the C**hronic **F**atigue **S**yndrome (which is an officially recognised synonym for myalgic encephalomyelitis, hence the use of the term "ME/CFS").

The WHO International Classification of Diseases (ICD) consists of different volumes: Volume I is the Tabular List of diseases / disorders; Volume II is the Instruction Manual and Volume III is the Alphabetical Index (Codex) containing terms that the WHO considers synonymous with diseases / disorders listed in the Tabular List; there are many terms in the Alphabetical Index that are not included in -- but are coded to -- the Tabular List.

ME has been classified by the WHO in the ICD as a disease of the nervous system since 1969. In ICD-10 (the current Revision published in 1992 which has undergone numerous updates but is still the tenth Revision, hence it is referred to as "ICD-10") ME is classified in Chapter VI (code G) under Diseases of the Nervous System at G93.3 (Other disorders of brain).

Since 1992, the term "Chronic Fatigue Syndrome" (CFS) has been included in the Alphabetical Index (Codex) -- but not in the Tabular List -- and indexed to G93.3 Post Viral Fatigue Syndrome (PVFS) / ME in the Tabular List as a recognised synonym, and the use of the term "ME/CFS" denotes the neurological disease G93.3.

Chronic Fatigue Syndrome appears in the Alphabetical Index (Codex) under:

Syndrome -
-- fatigue F48.0
---- chronic G93.3
---- postviral G93.3.

This clearly indicates that **F**atigue **S**yndrome is coded to F48.0 and that the **Chronic F**atigue **S**yndrome (CFS) is not coded to F48.0 but to G93.3. Fatigue syndrome (sometimes referred to as "chronic fatigue") is not the same as the Chronic Fatigue Syndrome (American Medical Association: CFIDS Chronicle: Summer 1990:144).

Chapter V (Code F) of ICD-10 covers Mental and Behavioural Disorders. F40-48 covers Neurotic, stress-related and somatoform disorders; F48.0 (Other neurotic disorders)

includes Neurasthenia and Fatigue syndrome. This section (F48) specifically excludes the disease ME/PVFS/CFS that is coded to G93.3.

The term "CFS/ME" is an ambiguous term: it is not recognised by the World Health Organisation (WHO) which refers to its use as "*unfortunate*". The WHO Medical Officer (ICD Classifications, Terminologies and Standards) has confirmed in writing that it may be a term that does not fit into the ICD scheme (as it can mean anything that anybody wants it to mean). The WHO confirmed (*verbatim quote)*: ***"It is unfortunate that NICE uses a terminology that is not specific. 'CFS/ME' is a broad umbrella. This needs to be clarified. It is not possible to make a deduction from 'CFS/ME' ".***

Confusion has arisen because certain UK psychiatrists known as the Wessely School (Hansard, Lords: 19th December 1998:1013), many of whom work for the medical and permanent health insurance industry and who are influential at the Medical Research Council (MRC), have concocted the term "CFS/ME" to denote all states of what they believe to be "medically unexplained" chronic "fatigue" as a behavioural (somatoform) disorder. For decades, they have assiduously but wrongly attempted to subsume the quite separate neurological disease ME/CFS (G93.3) into F48.0 as a behavioural disorder.
The insurance industry for which Wessely School psychiatrists and their supporters work excludes mental disorders from cover (both medical expenses policies and permanent health insurance policies exclude psychiatric disorders from cover). Furthermore, people with mental disorders are excluded from higher rates of some State benefits.

The stated intention of the Wessely School psychiatrists who use the term "CFS/ME" is to eradicate ME entirely – they intend to drop the "ME" component from "CFS/ME" as soon as they deem it to be expedient ("Eradicating myalgic encephalomyelitis (ME)". Simon Wessely. Pfizer Invicta Pharmaceuticals 1992; "Managing patients with inexplicable health problems". B Fischoff, Simon Wessely. BMJ 2003:326:595-597). "CFS/ME" would then become just Chronic Fatigue Syndrome or CFS, which can (and inevitably will) be written as "chronic fatigue syndrome" or chronic "fatigue syndrome" (ie. a syndrome of chronic fatigue), which is classified as a somatisation disorder. Chronic fatigue is not the same as the Chronic Fatigue Syndrome but by such means, the Wessely School psychiatrists would achieve their long-held goal of eradicating the serious neuroimmune disease ME from the medical lexicon.

The first stage of the eradication of ME has already happened: the meaningless term "CFS/ME" was used in the UK Chief Medical Officer's Working Group Report of 2002; in the MRC's CFS/ME Research Strategy Report of 2003, and most recently in the NICE Clinical Guideline 53 of 22nd August 2007.

Largely controlled by – and certainly influenced by – Wessely School psychiatrists, the MRC Neurosciences and Mental Health Board is on record as stating that the PACE trial on "CFS" ---which uses the 1991 Oxford / Wessely School criteria that expressly exclude neurological disorders but expressly include states of psychiatric fatigue-- <u>does</u> include people with ME (because according to the Wessely School psychiatrists who are leading the MRC trial, ME is not a recognised neurological disorder).

By letter dated 16th June 2005, Dr Sarah Perkins, Programme Manager of the MRC Neurosciences and Mental Health Board, asserted: "*The main entry for the PACE trial are the Oxford Criteria. Used successfully in both research and clinical practice for many years, they have been the entry criteria for almost all the leading UK CFS/ME published trials of treatment to be compared in the PACE trial. Their use will ensure that the results of the trials will be applicable to the widest range of people who receive a diagnosis of CFS/ME* (this accords with the Trial Identifier, where Professor Peter White states at section 3.6: "*We chose those broad criteria in order to enhance generalisability and recruitment"*). *The exclusion criteria criterion of 'proven organic brain disease' will be used to exclude neurological conditions.* ***It will not be used to exclude patients with a diagnosis of ME"***. This is in defiance of the fact that the WHO classifies ME as a neurological disorder.

In January 2005 the MRC Portfolio in Mental Health Research was unequivocal: section 6.2 stated: ***"Mental health research in this instance covers….CFS/ME".*** This is contained in the MRC's Neurosciences and Mental Health Board Scoping Study, which also states: "*Mental health represents a vast potential market for pharmaceutical companies"* and that mental health research funding links with industry *"are weak in the UK in relation to those in the USA"*.

Influenced by Wessely School psychiatrists (who have boasted about their influence on the NICE Guideline) and those who support them, NICE wrongly uses the meaningless term "CFS/ME".

A single NICE Guideline (CG53) cannot cover two discrete entities with mutually exclusive WHO classifications (the neurological disease ME/CFS <u>and</u> Neurasthenia / Fatigue syndrome, a classified behavioural disorder) on the incorrect assumption that they are one syndrome of medically unexplained chronic fatigue which is deemed to be a somatisation (mental) disorder.

Moreover, it is mandatory for NICE to use the WHO International Classification of Diseases (ICD) codes. NICE's own Communications Progress Report 8 of 18th September 2002 from Anne Toni Rodgers is clear: "*The ICD-10 classification has been used as a basis for the new Institute classification directed at the informed reader. ICD-10 is used within the acute sector of the NHS* ***and classification codes are mandatory for use across England"***. The Progress Report also states: "*The Board is asked to note the Progress Report"*.
Furthermore, NICE's Taxonomy of May 2007 (three months before CG53 was published) is also clear: (ME)CFS is listed as a disease of the Central Nervous System, not as a behavioural disorder.

By letter dated 16th October 2001, Dr B Saraceno from the WHO Headquarters in Geneva provided clarification: "*I wish to clarify the situation regarding the classification of neurasthenia, fatigue syndrome, post viral fatigue syndrome and benign myalgic encephalomyelitis. Let me state clearly that the World Health Organisation (WHO) has*

not changed its position on these disorders since the publication of the International Classification of Diseases, 10th Edition in 1992 and versions of it during later years. Post viral 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 is included within this category. However, post viral fatigue syndrome is explicitly excluded from F48.0".

On 6th February 2009, Dr Robert Jakob from the WHO in Geneva re-confirmed the WHO's classification as specified by Dr Saraceno, adding: *"Again, there is no evidence for any change of the above to be made for ICD-11".*

Wessely School psychiatrists have a long track record of attempting to re-classify ME/CFS as a mental disorder, for example, the UK WHO Collaborating Centre for Mental Health at the Institute of Psychiatry, London, misclassified the disorder as a mental (behavioural) disorder in the first edition of its "Guide to Mental Health in Primary Care", using Wessely's own material on "CFS/ME" (30,000 copies of which were sold in the UK).

The letter dated 16th October 2001 from the WHO (referred to above) addressed the psychiatrists' confusion: "***It is possible that one of the several WHO Collaborating Centres in the United Kingdom presented a view that is at variance with the WHO's position".***

An erratum was eventually issued over the Guide to Mental Health in Primary Care, whereupon the Wessely School psychiatrists then asserted that the WHO itself had classified the same disorder in two places, once in the Neurological section and also in the Mental (behavioural) section of the ICD. This misinformation was fed to Government Ministers, who in turn fed it to Members of Parliament, who then provided it as "evidence-based" fact to their constituents and others.

Yet again, the Wessely School's claims were repudiated by the WHO: on 23rd January 2004 Andre l'Hours from the WHO in Geneva provided further written clarification: "*This is to confirm that according to the taxonomic principles governing the Tenth Revision of the World Health Organisation's International Statistical Classification of Diseases and Related Health Problems (ICD-10)* ***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".***

Notwithstanding, the NICE Guideline Development Group (GDG) refused to accept the ICD classification of ME/CFS as a neurological disease (thus placing itself as a higher authority than the WHO) and it is the Wessely School's beliefs about the nature of "CFS/ME" that underpin the NICE Guideline's recommendations of behavioural management (cognitive behavioural therapy or CBT and graded exercise therapy or GET) for "CFS/ME".

CBT is described in the Chief Medical Officer's Working Group Report of 2002 as *"a tool for constructively modifying attitude and behaviour"* (Annex 6, page 8); in the Medical Research Council's PACE trial on CFS/ME, CBT *"will be based on the illness model of fear avoidance"*; in the Guide to Mental Health in Primary Care it is described in the following terms: *"This is used to change a patient's thought processes and behaviour"*, while the NICE Guideline itself describes CBT as *"a psychological therapy"*. Why would a psychological therapy be the primary (indeed the only) recommended management intervention for a classified neurological disease? Is multiple sclerosis henceforth also to be managed only by behavioural modification?

GET is described in MRC PACE trial on CFS as being *"based on the illness model of both deconditioning and exercise avoidance"*, whilst the CG53 graded exercise plan specifies that the intensity of GET should be incrementally increased (with the patient's agreement), leading to aerobic exercise, which is in direct contradiction to the advice given in 1999 by international ME/CFS expert Professor Paul Cheney: *"The most important thing about exercise is not to have them do aerobic exercise. If you have a defect in the mitochondrial function and you push the mitochondria by exercise, you kill the DNA"* (International Congress of Bioenergetic Medicine, Orlando, Florida, February 1999).

Over 5,000 papers in the international medical literature confirm the organic nature of ICD-10 G93.3 ME/CFS. It is important to be aware that many international research papers refer not to "ME" or to "ME/CFS" but to "CFS", a term that was invented in 1988 in the United States when ME was erroneously renamed CFS (Osler's Web. Hillary Johnson. Crown Publishers Inc., New York, 1996).

This means that the ambiguous and heterogeneous label "CFS" may be referring to ME (ICD-10 G93.3) or to chronic fatigue syndrome (ICD-10 F48.0), an impossibly confusing situation for both patients and practitioners that the Wessely School seems to have exploited to its own and its insurance industry paymasters' advantage.

ME/CFS has been included in the UK National Service Framework (NSF) as a chronic neurological condition since the NSF was launched on 10th March 2005.

ME/CFS is classified in the UK Read Codes as a neurological disorder at F286. (The Read Codes, used by UK GPs, use the prefix "F" to denote diseases of the nervous system, which to the uninformed may be confusing in that WHO ICD "F" codes relate to mental disorders).

The evidence that the NICE Clinical Guideline 53 on "CFS/ME" cannot apply to both the neurological disease ME/CFS (G93.3) and to mental and behavioural fatigue states of neurasthenia / fatigue syndrome (F48.0) was provided to the Claimants' lawyers for the Judicial Review of the NICE Guideline CG53 heard in February 2009 in the High Court in London but was not used. The challenge failed.