

The HUMMINGBIRDS' FOUNDATION for M.E. (HFME)

Fighting for the recognition of Myalgic Encephalomyelitis based on the available scientific evidence, and for patients worldwide to be treated appropriately and accorded the same basic human rights as those with similar disabling and potentially fatal neurological diseases such as Multiple Sclerosis.

The WHO ICD in relation to M.E. and 'CFS' – Short version

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For more information and further discussion, please see the [long version](#) of this paper.

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1. Introduction

The World Health Organization (WHO) classifies all known diseases in its International Classification of Diseases (ICD). The WHO states:

‘The ICD is the international standard diagnostic classification for all general epidemiological, many health management purposes and clinical use.’

- ‘International Classification of Diseases (ICD)’

<http://www.who.int/classifications/icd/en/>

Myalgic Encephalomyelitis (M.E.) has been recognised and classified by the ICD since 1969. In the version of the ICD currently in use in most of the world except the US, ICD-10, M.E. is classified as a neurological disease.

M.E. is often denied or discredited by doctors, policy-makers and the general public. It is important for our ongoing efforts to have M.E. taken seriously as a neurological disease that the WHO recognises it as such.

It is possible that the current entries for M.E. and Chronic Fatigue Syndrome ('CFS') may be subject to change in the next revision of the ICD, ICD-11. If the classification of M.E. as a neurological disease is threatened, we should oppose this as forcefully as possible. This paper gives the basics of the ICD, which may be useful when considering the issues involved in revision.

2. Facts and Issues

Sections 3 and 4 below present the basic facts about the ICD versions, for reference. In particular section 4 containing the codes gives bald statements of fact. I have tried to be clear and neutral in presenting these facts, and the facts should be uncontroversial.

Sections 5 to 10 discuss issues arising from the ICD. Differences of opinion exist on these issues, and what I say differs from the views of many others. Perhaps most of these differences arise from the basic premise of this paper:

M.E. is not the same as 'CFS.' M.E. is a neurological disease, whereas 'CFS' defines a heterogeneous patient group suffering from various conditions which involve the symptom of 'fatigue.'

3. Versions of the ICD: summary

ICD-10 is currently used in the UK, Australia, Europe, Canada and other countries. ICD-10 is the responsibility of the WHO, Geneva.

ICD-11 will be used in future in the UK, Australia, Europe, Canada and other countries. Planned first draft 2010, publication 2014 and implementation 2015. Responsibility of the WHO, Geneva.

ICD-9 is currently used in the US. Responsibility of the US National Center for Health Statistics (NCHS) within the Center for Disease Control (CDC), and the Centers for Medicare and Medicaid Services.

ICD-10 CM (USA) will be used in future in the US. Planned implementation 2013. Responsibility of the US NCHS within the CDC, and the Centers for Medicare and Medicaid Services.

Please note that this information reflects the situation at the time of writing (July 2009), but may change in future.

4. Codes

The ICD is presented as a 'tabular list,' i.e. a list of codes, with disease terms organised under categories, along with an index to the tabular list. Other information may also be published, such as the instruction manual for ICD-10.

The following are excerpts from the full ICD listings. I have quoted only the relevant items with all levels of categories to which they belong, omitting any intervening listings which are irrelevant to this discussion.

For additional codes for terms such as Encephalopathy, Somatoform disorders, Somatization and Neurasthenia, please see the long version of this paper at <http://www.hfme.org/wlicdcodes.htm>.

Please note that I have put some terms in bold to call attention to them; these terms are not in bold in the ICD. I have added the notes in square brackets; these notes are not in the ICD.

'NOS' indicates 'not otherwise specified.'

As of July 2009:

ICD-10 (currently used in UK, Australia, Europe, Canada and other countries)

ICD-10 is published in three volumes:

- *Volume 1 is the Tabular list, i.e. the main listing of diseases, disease categories and codes*
- *Volume 2 is the Instruction manual*
- *Volume 3 is the Alphabetical index.*

An anomaly of ICD-10 is that while the Tabular list and the Instruction manual are published online on the WHO website, the Alphabetical index is not, being only available in book and CD-ROM form.

Listings below are from the Tabular List, with the exception of the listing for 'CFS,' which is from the Alphabetical index.

G00-G99 Diseases of the nervous system (Chapter VI)

G90-G99 Other disorders of the nervous system

G93 Other disorders of brain

G93.3 Postviral fatigue syndrome

Benign myalgic encephalomyelitis

'CFS' has no listing in the Tabular list of ICD-10. 'CFS' is only listed in the Alphabetical index, as follows:

Syndrome

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

...

R00-R99 Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (Chapter XVIII)

R50-R69 General symptoms and signs

R53 Malaise and fatigue

[note: no R53.82 Chronic fatigue syndrome, as there is in ICD-10 CM (USA)]

Excludes: debility:

exhaustion and fatigue (due to)(in):

- **neurasthenia (F48.0)**
- **fatigue syndrome (F48.0)**
- **postviral (G93.3)**

...

F00-F99 Mental and behavioural disorders (Chapter V)

F40-F48 Neurotic, stress-related and somatoform disorders

F48 Other neurotic disorders

F48.0 Neurasthenia

[long paragraph of descriptive text giving symptoms of neurasthenia...]

Fatigue syndrome [note: this is the only occurrence of 'fatigue syndrome' (not 'postviral') in ICD-10. Note that it is not 'chronic,' i.e. not 'CFS.']

Excludes: ...

malaise and fatigue (R53)

postviral fatigue syndrome (G93.3)

ICD-9 (currently used in the US)

320-389 DISEASES OF THE NERVOUS SYSTEM AND SENSE ORGANS
(Chapter 6)

320-326 INFLAMMATORY DISEASES OF THE CENTRAL NERVOUS
SYSTEM

323 Encephalitis, myelitis, and encephalomyelitis

323.9 Unspecified cause of encephalitis, myelitis, and encephalomyelitis

...

780-799 SYMPTOMS, SIGNS, AND ILL-DEFINED CONDITIONS
(Chapter 16)

780-789 SYMPTOMS

780 General symptoms

780.7 Malaise and fatigue

780.71 Chronic fatigue syndrome

[note: not 'NOS']

[note: no exclusions]

ICD-10 CM (USA) (to be used in the US in future, planned implementation
2013)

G00-G99 Diseases of the nervous system (Chapter 6)

G89-G99 Other disorders of the nervous system

G93 Other disorders of brain

G93.3 Postviral fatigue syndrome [note: same as ICD-10]

Benign myalgic encephalomyelitis

Excludes1: chronic fatigue syndrome NOS (R53.82) [note: not in ICD-10]

...

R00-R99 Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (Chapter 18)

R50-R69 General symptoms and signs

R53 Malaise and fatigue

R53.8 Other malaise and fatigue

R53.82 Chronic fatigue, unspecified [note: not in ICD-10]

Chronic fatigue syndrome NOS [note: 'NOS' is new; the listing for 'CFS' in ICD-9 does not say 'NOS']

Excludes1: postviral fatigue syndrome (G93.3)

There used to be a listing for 'Chronic fatigue syndrome, post-viral' under G93.3 along with PVFS and Benign ME in a previous version of ICD-10 CM (USA). It was removed in 2007, when the new code R53.82 was created for 'CFS.'

See the references section of the long version of this paper at <http://www.hfme.org/wlicdcodes.htm> for online listings of the different versions of the ICD Classifications.

Please note that the details given above were correct at the time of writing (July 2009), but may change. Refer to the online listings for current versions.

5. ICD-10 and M.E.

M.E. has been classified in the ICD since 1969 following the seminal work of Dr. Melvin Ramsay and others. The WHO recognises M.E.

ICD-10 classifies M.E. under Diseases of the nervous system, i.e. the WHO states that M.E. is a neurological disease.

In a world where the reality of M.E. is denigrated and denied on all sides, the ICD-10 classification of M.E. as a neurological disease is an important instance of the disease being given appropriate official recognition by the medical and scientific establishment.

6. ICD-10 and 'CFS'

'CFS' is not classified in the Tabular list (the main body of the code listings) of ICD-10. 'CFS' is present in the Alphabetical index, published only in CD-

ROM and book form, not online. 'CFS' has been listed in the index of ICD-10 since it was published in 1994.

'CFS' in the index is indexed to G93.3. What does this mean? Clearly it indicates that 'CFS' has a relationship to the diseases at G93.3, i.e. PVFS and Benign ME, but what is this relationship?

ICD-10 does not say that 'CFS' is synonymous with M.E. ICD-10 is silent as to the relationship between CFS, and PVFS and Benign ME.

ICD-10 gives various possible relationships between a term in the Alphabetical index, and the term in the Tabular list to which it is indexed. It may be:

- a synonym
- 'a diagnostic term currently in use'
- an 'imprecise and undesirable term' or 'a rubric for ill-defined conditions' (all from Introduction to ICD-10 Vol.3, 2nd Edn.)
- 'a best coding guess' (correspondence from the WHO).

However, ICD-10 does not specify which of these possible relationships applies in the case of 'CFS.' Thus ICD-10 does not specify what relationship 'CFS' has with M.E.

Nor has the WHO issued any statement which specifies the relationship between 'CFS' and M.E. (as far as I know), despite requests for clarification.

Please note that despite the similarity of the terms, 'Chronic fatigue syndrome' which is indexed to G93.3, a code indicating neurological disease, is not the same as 'Fatigue syndrome' classified under F48.0 as a mental disorder.

7. ICD-10 and Combined Terms 'ME/CFS' and 'CFS/ME'

No version of the WHO ICD classifies the terms 'ME/CFS' or 'CFS/ME.' Nor do any past or currently planned future versions of the ICD classify either of these terms. Not only does the ICD not classify these terms, it does not mention them at all. Thus according to the ICD, 'ME/CFS' and 'CFS/ME' do not exist.

The combined terms equate M.E. with 'CFS.' This harms M.E. patients.

M.E. and 'CFS' are not the same, so the combined terms are meaningless; they only increase confusion, which helps those who try to deny the medical reality of our disease, and give the impression that M.E. is 'mysterious.'

The main problem with the term 'CFS' is that 'CFS' does not exist. The definitions of 'CFS' describe a heterogeneous group of patients suffering from a vast array of different diseases which cause fatigue. The mixed-bag definitions of 'CFS' lend themselves to psychiatric interpretation, and yield meaningless research results.

The term 'ME/CFS' does the same harm to the cause of M.E. as the term 'CFS/ME,' by equating M.E. with 'CFS.' Equating the two, so M.E. patients are subsumed into the ill-defined morass of 'CFS,' is one of the most important strategies of those who deny the biomedical reality of M.E.

Neither combined term is justified by ICD-10. The combined terms imply that 'CFS' and 'M.E.' are alternative names for the same disease, but ICD-10 does not say that 'CFS' is the same as M.E.

'CFS' is in the index, indexed to the same code as PVFS and Benign ME, but this does not mean it is synonymous with those diseases. As discussed above, there are several possible relationships between a term in the index and the term at the code to which it's indexed. Thus ICD-10 does not justify joking the two terms as though they are synonyms.

The ICD does not recognise either 'ME/CFS' or 'CFS/ME.' The absence of the combined terms from the ICD may be useful in our efforts to resist them.

8. US ICD versions, M.E., 'CFS' and Combined Terms

M.E.

M.E. is hardly recognised in the US. The disease formerly described as 'epidemic neuromyasthenia' in the US is now more likely to be diagnosed as 'CFS.'

Unfortunately there is currently no classification for M.E. in the Tabular list of ICD-9 used in the US. The closest to a classification of M.E. in ICD-9 is Unspecified cause of encephalitis, myelitis, and encephalomyelitis, which is in practice seldom used. The lack of a listing for M.E. will be rectified in ICD-10 CM (USA) to be used in the US from 2013, which has a classification for M.E. as a neurological disease.

'CFS'

Unlike ICD-10, the US versions of the ICD are quite clear about the relationship between 'CFS' and M.E.: there is none. Amy Blum, Medical Classification Specialist at the National Center for Health Statistics has stated:

'ME is not considered a synonymous term for chronic fatigue syndrome in the United States.'

Ms. Blum has also made the following illuminating statement:

'...it is not clinically valid to classify all cases of CFS to code G93.3. The default will be R53.82 except in those cases where the cause is determined to be of viral origin.'

(email to me, 9 July 2009)

'CFS' is coded in a completely different category from M.E. in the US. ICD-9, currently used, does not classify M.E. as such, and the nearest equivalent is at 323.9 under Diseases of the nervous system and sense organs while 'CFS' is at 780.71 under Symptoms, signs, and ill-defined conditions.

ICD-10 CM (USA), for use in future, classifies M.E. at G93.3 under Diseases of the nervous system, while 'CFS' is at R53.82 under Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified.

Combined terms 'ME/CFS' and 'CFS/ME'

The combined terms are not supported by ICD-10; still less are they supported by the US ICD versions. As discussed above, M.E. and 'CFS' are at completely different codes within different categories. Thus the combined terms, which equate 'CFS' with M.E., are not supported by the US ICD versions.

9. Concerns about Possible Re-classification in ICD-11

The revision of ICD-10 is currently underway for the future version, ICD-11. The first draft of ICD-11 is planned for 2010, with publication is planned for 2014 and implementation from 2015.

The 'Diagnostic and Statistical Manual of Mental Disorders' (DSM), published by the American Psychiatric Association (APA), is the US 'bible' on psychiatric diagnostic criteria. The current version is DSM-IV. The revision process for the future version, DSM-V, is underway with publication planned for 2012.

The WHO and the APA are collaborating on the revision process for ICD-11 and DSM-V to ensure consistency where possible, and in particular to achieve 'harmonization between ICD-11 mental and behavioural disorders and DSM-V disorders and their diagnostic criteria.'

There is concern among many people in the M.E. and 'CFS' communities that the revision process may result in 'CFS' (and possibly M.E.) being classified as mental disorder in ICD-11.

The revision of ICD-10 is currently advised by 'Topic Advisory Groups' (TAGs). The TAG for Mental Health is working on mental disorders, and the TAG for Neurology is 'in formation.'

Given the amount of psychiatric attention being brought to bear in the revision process from the DSM side, it is crucial that neurological expertise from the ICD side should be focussed on the diseases at G93.3. The Topic Advisory Group for Neurology may have an important role to play.

(Note: this was written in July 2009. The situation will change. For the current situation, please refer to sources given in the references section of the long version of this paper at <http://www.hfme.org/wlicdcodes.htm>.)

10. Recommendations for Future

- The classification for M.E. should be G93.3 Myalgic Encephalomyelitis under Diseases of the nervous system.
- The name currently given first at G93.3 in ICD-10 and ICD-10 CM (USA), 'Postviral fatigue syndrome,' should be removed. It is not correct: M.E. is not a syndrome. Fatigue is not a defining symptom of M.E.; it is frequently but not necessarily present, and when present it may be only a minor symptom.

Fatigue following viral infection is not a neurological disease and should be classified elsewhere as appropriate.

- The current term 'Benign' should be deleted from before 'Myalgic encephalomyelitis.' It is not correct.

The term 'benign' (meaning 'not fatal') was originally introduced in the context of the WHO's efforts to categorise epidemic diseases, and indicated that a disease did not kill more than a certain percentage of its victims. However, this usage is not consistent throughout the ICD.

The term misleadingly obscures the fact that M.E. can be fatal.

The term also contributes to the public misunderstanding of M.E. Some people interpret 'benign' to mean that M.E. is not a serious illness. This is unfortunate considering the degree of severe disability and suffering which may be experienced by M.E. patients.

- There should be no ICD listing for 'CFS' as a valid disease term. 'CFS' does not exist and should not be given the status of a real disease.

However, many patients are diagnosed with 'CFS' and need the protection of an ICD listing.

'CFS' could be classified in the ICD within a new category containing invalid disease terms. This would acknowledge that while patients are in practice diagnosed with the term, it is not valid.

The ICD-10 already accepts that patients are in practice diagnosed with 'imprecise and undesirable term[s]' for 'ill-defined conditions,' in that such terms are given in the index.

A category of invalid disease terms would make explicit what is already implicit in categories such as 'Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified': not that the disease is not real, but that the patient requires a better diagnosis.

- Failing the proposal above or similar, 'CFS' should not be classified in the ICD.

The false disease category of 'CFS' does not serve the best interests of patients. All patients would be better off with an accurate classification of a real disease, whether they suffer from M.E. or from another condition. Accurate classification would facilitate not only insurance and welfare claims, but also appropriate treatment.

ICD classification of 'CFS' as a valid disease is not the way forward; it harms M.E. patients as well as those suffering from undiagnosed conditions who have been falsely classified with 'CFS.'

- The fault in the online search facility for ICD-10 should be corrected so that the default 'full search option' which is supposed to include a search of the index, should indeed find terms in the index.
- All rather than only part of the WHO ICD should be published on the WHO website. The WHO should publish the Alphabetical index of the current ICD-10 online. If this is impossible for some reason, the WHO website should call attention to its omission. All of the future ICD-11 should be published online. If the WHO ICD is truly to serve its worldwide constituency, it must be available online in its entirety.

11. References

Please see the long version of this paper at <http://www.hfme.org/wlicdcodes.htm> for references, including official and alternative online listings of the ICD codes.