

*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' – Long version**

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## 1. Introduction

The World Health Organization (WHO) classifies all known diseases in its International Classification of Diseases (ICD). The ICD is used in reporting diseases to the WHO from around the world.

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)’

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

Whereas those who deny the reality of M.E. work to muddy the water and obscure the medical reality, the ICD should clarify it. Clarity should help us, and the ICD is in theory an instrument of clarity. Unfortunately, the ICD is in practice not always as clear as it should be. Classification of diseases should be a means of clarification and disambiguation; where the ICD is not perfect, we can work to improve it.

It is possible that the current entries for M.E. and Chronic Fatigue Syndrome (‘CFS’) may be subject to change in the next version of the ICD, work on which is currently underway. Some M.E. patients and advocates foresee trouble ahead, although proposals for revision have not yet been made public. 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.

The ICD is not enforced as we might wish. Despite the classification of M.E. as a neurological disease, patients continue to encounter disbelieving or disrespectful doctors who trivialise the condition, confuse it with the very different entity ‘CFS’ or view it as psychological, and offer inappropriate treatments. Some of us look at the gap between the theory of the ICD and the practice of medical treatment and government policy, and wonder whether the ICD has any effect on reality.

Despite the problems, the ICD classification of M.E. as a neurological disease is very important, as it indicates official recognition of the disease by the medical and scientific establishment. It may benefit M.E. patients to be aware of the facts regarding ICD classification; it may strengthen our confidence in the facts established by decades of scientific research, to know that we have the authority of the World Health Organization behind us.

## 2. Facts and Issues

Sections 3 to 6 below present the basic facts about the ICD versions, for reference. In particular sections 5 (codes) and 6 (facts about the codes) are bald statements of fact. I have tried to be clear and neutral in presenting these facts, and the facts should be uncontroversial.

Sections 7 to 22 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

(This paper does not discuss the history of the ICD, as its focus is the current situation and prospects for the future. See references for history of the ICD.)

There have been various versions of the WHO ICD. Currently most of the world with the exception of the US uses ICD-10 (i.e. 10<sup>th</sup> Revision).

The revision of ICD-10 is currently underway, and it is anticipated that the WHO will issue the first draft of the next version, ICD-11, in 2010. Publication is planned for 2014, with implementation from 2015 onwards.

The US uses ICD-9 in relation to morbidity (i.e. disease). (The US also uses parts of ICD-10 that relate to mortality (i.e. death) and statistics, but those parts are not relevant to this discussion.)

Some countries add extensions to distinguish the ICD version used in that country. For example, Australia uses ICD-10-AM and Canada uses ICD-10-CA. These differences do not affect the listings discussed in this paper (i.e. those relating to M.E. and 'CFS'), so for the purposes of this discussion they are equivalent and I will refer to 'ICD-10' for all country extensions.

Individual countries may make clinical modifications to the version of the ICD used in that country, which are then labelled 'CM' followed by the country name. For example, the version of ICD-9 with clinical modifications used in the US is 'ICD-9 CM (USA)'. In practice however, and especially when discussion of the ICD version takes place not internationally but within that country (so that the country is assumed), the suffix indicating the country is often omitted. For example, the version of the ICD with clinical modifications used in US should strictly be referred to as ICD-9 CM (USA). However, it is frequently referred to simply as ICD-9 CM (especially within the US).

While the WHO, based in Geneva, is responsible for the current ICD (i.e. ICD-10), it is no longer responsible for ICD-9 (now only used in the US). The US Government agencies The National Center for Health Statistics (NCHS) within the Center for Disease Control (CDC), and the Centers for Medicare and Medicaid Services are now responsible for ICD-9 CM (USA).

The USA has applied clinical modifications to ICD-9 in ICD-9 CM (USA). This CM version is the one currently used in the US, and ICD-9 is now obsolete elsewhere.

The distinction between ICD-10 and ICD-10 CM (USA), however, is relevant to this discussion. In the US, where ICD-9 is currently used, there has been much debate over the version of ICD-10 to be implemented in future. The debate is relevant to M.E. and 'CFS,' and is discussed below. ICD-10 CM (USA) is the version of ICD-10 that is planned for the future, i.e. it is not currently in use. Clinical modifications to ICD-10 have been made in ICD-10 CM (USA) which concern M.E. and 'CFS,' i.e. the version of ICD-10 for future use in the US is not the same as the version of ICD-10 currently in use in the rest of the world.

As with ICD-9 CM (USA), the NCHS in the US, authorised by the WHO, is responsible for ICD-10 CM (USA). It is currently planned that ICD-10 CM (USA) will be implemented in the US on 1 October 2013.

#### **Note on terminology used for ICD versions:**

Where I refer to 'the ICD' in this paper, I am referring to any or all versions of the ICD. Where I am referring to a specific version, I refer to it by name (e.g. ICD-10).

Since ICD-9 CM (USA) is the only version of ICD-9 used anywhere in the world, for the purposes of this discussion there is no need to distinguish between different versions of ICD-9. For simplicity, in this paper I refer to the current US version as 'ICD-9.' (However, readers who want to research this matter further should remember that there have been different versions of ICD-9, and that the current version in use in the US is actually ICD-9 CM (USA).)

Please note that the ICD version for use in the US in future is usually referred to as 'ICD-10 CM' (i.e. without the suffix '(USA)'). However, I refer to it as 'ICD-10 CM (USA)' in this paper, even though this is unusual, to remind readers that it is the version for future use in the US – especially when comparing it with ICD-10, used in the rest of the world.

#### **Summary of different ICD versions:**

- ICD-10 is currently used in the UK, Australia, Europe, Canada and other countries
- ICD-11 will be used in future in the UK, Australia, Europe, Canada and other countries (planned implementation 2015)
- ICD-9 is currently used in the US

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

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

#### 4. Classification Methods of the ICD

The ICD is organised as a classification hierarchy, i.e. items are organised within categories, which are organised within larger categories, and so on.

Every disease classified in the ICD is given a unique code, in addition to the disease name. As indicated by the code, diseases are listed under categories of diseases, which are listed under larger categories of diseases.

However, not all of the versions of the ICD are equally clear in coding so that the disease categories are easily apparent from the disease code. ICD-10 is wonderfully clear, making the meaning of the codes very easy to understand for readers. For example, 'G' is the letter code of the category 'Diseases of the nervous system'; the letter 'G' at the start of a disease code indicates that that condition is a neurological disease. Similarly with code numbers. For example, 'G93' is the code for 'Other disorders of the brain'; all codes starting with 'G93,' such as 'G93.3,' are other disorders of the brain. This coding system is intuitive for users, and probably already familiar, as it is the convention we see all the time.

Unfortunately, things are not so easy with codes in ICD-9, the current US version. Disease categories are not always aligned so conveniently with the numbering system. For example, ICD-9 has the category '320-389 Diseases of the nervous system.' Thus codes within this category may start with '32...' or '33...' up to '38...' Even more confusing is the category '320-319 Mental disorders' which may contain both codes in the 200s and codes in the 300s. Users of ICD-9 should be aware of this, as it is easy to mistakenly assume that codes will follow the convention of aligning within the same number, so that all codes starting with the same number (at any level, hundreds, tens or single units) will be within the same category. Beware; they may or may not be.

#### 5. 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 listings relevant to M.E. and 'CFS' from the various ICD versions are given below. These 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.

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

G93.4 Encephalopathy, unspecified

*Excludes:* encephalopathy:

- alcoholic ( G31.2 )

- toxic ( G92 )

...

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)]

Asthenia NOS

Debility:

· NOS

· chronic

· nervous

General physical deterioration

Lethargy

Tiredness

*Excludes:* debility:

- congenital ( P96.9 )

- senile ( R54 )

**exhaustion and fatigue (due to)(in):**

- combat ( F43.0 )

- excessive exertion ( T73.3 )

- exposure ( T73.2 )

- heat ( T67.- )

- **neurasthenia ( F48.0 )**

- pregnancy ( O26.8 )

- senile asthenia ( R54 )

**fatigue syndrome ( F48.0 )**

- **postviral ( G93.3 )**

...

F00-F99 Mental and behavioural disorders (Chapter V)

F40-F48 Neurotic, stress-related and somatoform disorders

F45 Somatoform disorders

F45.0 Somatization disorder

F45.8 Other somatoform disorders

F45.9 Somatoform disorder, unspecified

Psychosomatic disorder NOS

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.']

Use additional code, if desired, to identify previous physical illness.

*Excludes:* asthenia NOS ( R53 )

burn-out ( Z73.0 )

**malaise and fatigue ( R53 )**

**postviral fatigue syndrome ( G93.3 )**  
 psychasthenia ( F48.8 )

ICD-10 General Notes:

- Benign ME is classified with PVFS at G93.3 in the Tabular list (published online as well as in book and CD-ROM form)
- ICD-10 does not have an entry for 'CFS' in the Tabular list of codes
- 'CFS' is only in the Alphabetical Index, indexed to G93.3 (not published online; published in CD-ROM and book form only)
- 'CFS' is not the same as 'Fatigue syndrome' under F48.0 Neurasthenia, under 'Mental and behavioural disorders.'
- ICD-10 mentions 'fatigue' within the Tabular list at:  
     R53 Malaise and fatigue, and  
     'Fatigue syndrome' under F48.0 Neurasthenia.

**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**

*M.E. is not listed in the Tabular list of ICD-9. However, M.E. is listed in the index, as follows:*

**Encephalomyelitis** (chronic) (granulomatous) (**myalgic, benign**) (see also Encephalitis) 323.9

...

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]

...

290-319 MENTAL DISORDERS (Chapter 5)  
 300-316 Neurotic disorders, personality disorders and other nonpsychotic mental disorders  
 300 Anxiety, dissociative and somatoform disorders

300.5 Neurasthenia

Fatigue neurosis

Nervous debility

Psychogenic:

asthenia

general fatigue

Use additional code to identify any associated physical disorder

Excludes: Anxiety state (300.00-300.09)

Neurotic depression (300.4)

Psychophysiological disorders (306.0-306.9)

Specific nonpsychotic mental disorders following organic brain damage (310.0-310.9)

300.8 Somatoform disorders

300.81 Somatization disorder

Briquet's disorder

Severe somatoform disorder

300.82 Undifferentiated somatoform disorder

Atypical somatoform disorder

Somatoform disorder NOS

300.89 Other somatoform disorders  
 Occupational neurosis, including writers' cramp  
 Psychasthenia  
 Psychasthenic neurosis

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

340-349 OTHER DISORDERS OF THE CENTRAL NERVOUS SYSTEM

348 Other conditions of brain

348.3 Encephalopathy, not elsewhere classified

348.30 Encephalopathy, unspecified

348.39 Other Encephalopathy

Excludes: encephalopathy:

alcoholic (291.1)

hepatic (572.2)

hypertensive (437.2)

toxic (349.82)

ICD-9 General Notes:

- ICD-9 has an entry for 'CFS'
- The entry for 'CFS' does not say 'NOS,' whereas the entry for 'CFS' in ICD-10 CM (USA) (below) does say 'NOS'
- ICD-9 does not have an entry for M.E. in the Tabular list of codes
- The index of ICD-9 does have an entry for M.E. indexed to 323.9 (although M.E. is not currently in the Tabular list at that code)

**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]

G93.4 Other and unspecified encephalopathy

Excludes1 : alcoholic encephalopathy (G31.2)

hypertensive encephalopathy (I67.4)

toxic (metabolic) encephalopathy (G92)

G93.40 Encephalopathy, unspecified

G93.49 Other encephalopathy

Encephalopathy NEC

...

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)**

...

F01-F99 Mental and behavioral disorders (Chapter 5)

F40-F48 Anxiety, dissociative, stress-related, somatoform and other nonpsychotic mental disorders

F45 Somatoform disorders

F45.9 Somatoform disorder, unspecified

Psychosomatic disorder NOS

F48 Other nonpsychotic mental disorders

## F48.8 Other specified nonpsychotic mental disorders

### Neurasthenia

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.' Please see section 'Confusion about the ICD,' subsection "'Fossils' of previous versions" below.

#### ICD-10 CM (USA) General Notes:

- There is a classification listing for 'CFS' in ICD-10 CM (USA), whereas in ICD-10 'CFS' is only listed in the index
- Although 'CFS' has a classification listing in ICD-10 CM (USA), it is not mentioned in the index. In other words, it seems that the index was not updated when 'CFS' was added to ICD-10 CM (USA). 'Postviral fatigue syndrome' and 'Benign myalgic encephalomyelitis' are mentioned the index
- The entry for 'CFS' in ICD-10 CM (USA) says 'NOS,' whereas the entry for 'CFS' in ICD-9 does not.
- There is no longer any listing for 'Chronic fatigue syndrome, post-viral' in ICD-10.

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See references section 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 given in the references section for current versions.

## 6. Facts about Codes

Since there is so much potential for confusion about the ICD versions, it might be useful to state the following facts clearly:

#### M.E. and the ICD:

- ICD-10, used in UK, Australia, Europe and other countries, has M.E. listed at G93.3 Postviral fatigue syndrome / Benign myalgic encephalomyelitis
- ICD-10 CM (USA), to be used in the US in future, also has M.E. listed at G93.3 Postviral fatigue syndrome / Benign myalgic encephalomyelitis (the same as ICD-10)
- ICD-9, currently used in the US, does not mention M.E. in the Tabular list of codes (It lists Unspecified cause of encephalitis, myelitis, and encephalomyelitis as 323.9.)
- ICD-9 has an entry for M.E. in the index, indexed to 323.9, although M.E. is not in the Tabular list at that code
- ICD-10 & 10 CM (USA) both classify M.E. as a neurological disease, i.e. under Diseases of the nervous system. (ICD-9 has Unspecified cause of encephalitis, myelitis, and encephalomyelitis under Diseases of the nervous system and sense organs.)

#### 'CFS' and the ICD:

- ICD-10, used in UK, Australia, Europe and other countries, has 'CFS' in the index only, indexed to G93.3 (published in CD-ROM and book form only, not available online); 'CFS' does not appear in the Tabular list, i.e. the main body of the classification listings, at that code
- ICD-10 has R53 Malaise and fatigue but no code R53.82 (the code for 'CFS' in ICD-10 CM (USA))
- The Tabular list of ICD-10 mentions 'fatigue' only as R53 Malaise and fatigue, and 'Fatigue syndrome' listed under F48.0 Neurasthenia
- In ICD-10 'CFS' is not the same as 'Fatigue syndrome,' which is classified at F48.0 Neurasthenia under Mental and behavioural disorders
- ICD-9, currently used in the US, has 'CFS' listed as 780.71 Chronic fatigue syndrome
- ICD-10 CM (USA), to be used in future in the US, has 'CFS' listed as R53.82 Chronic Fatigue Syndrome (NOS)



- In ICD-10 CM (USA) 'CFS' is not classified as a neurological disease. It is not listed under diseases of the nervous system (as it is in ICD-10) but under 'Symptoms, Signs and Abnormal Clinical and Lab findings, not elsewhere classified.'

### The relationship of M.E. and 'CFS,' and the ICD:

- ICD-10 has 'CFS' in the Alphabetical index, indexed to G93.3. Thus it has a relationship with the diseases at this code, PVFS and Benign M.E. See section "ICD-10 and 'CFS'" below for discussion of the nature of this relationship.
- ICD-10 CM (USA) excludes R53.82 Chronic fatigue syndrome (NOS) from its listing for G93.3 Postviral fatigue syndrome/ Benign myalgic encephalomyelitis, and vice-versa. In other words, according to ICD-10 CM (USA), CFS is not the same disease as M.E.

## 7. ICD-10 and M.E.

Probably the most important thing for M.E. patients, supporters and advocates is the fact that the WHO ICD classification of M.E. exists. 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.

Professor Malcolm Hooper says of the classification of M.E. as a neurological disease in ICD-10: 'It cannot be emphasised too strongly that this recognition emerged from meticulous clinical observation and examination.' (Hooper, M., 'Myalgic Encephalomyelitis (ME): a review with emphasis on key findings in biomedical research,' J. Clin. Pathol. Published online 25 August 2006, available at: <http://www.hfme.org/whooper.htm>)

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.

## 8. 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.

(Regarding the online invisibility of 'CFS,' 'CFS' is not found by the search facility on the WHO website (as of July 2009), even though the default 'full search option' includes a search of the index. Thus the index entry for 'CFS,' not in the Tabular list and also not found by search, is doubly hidden from online users. Please see section 'Confusion about the ICD' subsection 'Index of ICD-10 not available online on the WHO website' below.)

'CFS' in the index is indexed to G93.3. What does this mean? Clearly the indexing of 'CFS' indicates that 'CFS' has a relationship to the diseases at G93.3, i.e. PVFS and Benign M.E., 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 in the index, and PVFS and Benign ME in the Tabular list.

In general terms, 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. For example:

- the Index term may be a synonym, omitted from the Tabular list for reasons of space; the Tabular is the 'primary coding tool,' but is 'not exhaustive' (Introduction to ICD-10 Vol.3, 2<sup>nd</sup> Edn.)
- the Index term may be 'a diagnostic term currently in use,' (Introduction to ICD-10 Vol.3, 2<sup>nd</sup> Edn.)
- the Index term may be an 'imprecise and undesirable term' or 'a rubric for ill-defined conditions.' Its presence in the Index 'should not be taken as implying approval of its usage' (Introduction to ICD-10 Vol.3, 2<sup>nd</sup> Edn.)

- the index term may be 'a best coding guess' for the 'coding of a disease that is described by a physician with term that does not fit into the ICD scheme' (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.

This lack of specificity in ICD-10, which is not clear about the status of 'CFS' and states only that 'CFS' has some relationship to M.E., makes it difficult to assess the classification. 'CFS' is not a neurological disease, so it should not be classified in that category; it is not the same thing as M.E., so it should not be classified as a synonym. However, it is not clear that ICD-10 does classify 'CFS' in that way; 'CFS' may be in the index indexed to G93.3 as an imprecise term, an ill-defined condition, or a best coding guess.

For further discussion of the lack of clarity on this issue please see section 'Confusion about the ICD' below.

For further discussion of 'CFS' in the index, please see section "Implications of 'CFS' in the Index of ICD-10" below.

Please note that 'Chronic fatigue syndrome' in the index, indexed to G93.3 (i.e. a code indicating neurological disease) is not the same as 'Fatigue syndrome' classified under F48.0 Neurasthenia under Mental and behavioural disorders. On this issue please see sections 'Past Threat: Attempt by King's Group to Subvert ICD-10' (describing events in which confusion on this issue was exploited) and 'Confusion about the ICD,' subsection 'Unfortunate wording' below.

## 9. 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 are being strenuously promoted, particularly in the UK where they have become official terms used by the Department of Health and the National Health Service. They are increasingly used internationally.

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

The combined terms are problematic for many reasons. M.E. and 'CFS' are not the same, so the combined terms are meaningless; they only increase confusion, which helps the vested interest groups trying 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 there is no such disease; 'CFS' does not exist. The definitions of 'CFS' describe a mixed group of patients suffering from a vast array of different diseases which cause fatigue.

Another problem with the term 'CFS' is that because it describes a mixed patient group, research based on patients diagnosed with 'CFS' yields results that are not true of M.E. (e.g. 'muscle weakness is due to de-conditioning and should be overcome by exercise,' a 'research result' which is very damaging to M.E. patients). M.E. patients treated for 'CFS' may be harmed by the treatment.

Yet another problem with the term 'CFS' with its mixed-bag definitions is that it serves the purposes of those who claim the disease should be understood, classified and treated as a mental disease. 'CFS' is defined to include patients with fatigue due to psychiatric illness (as well as patients with fatigue due to all sorts of physiological diseases). Psychiatrists such as Professor Simon Wessely and his colleagues state that 'CFS' and M.E. are the same psychosomatic disease. We should not do the Wesselyites' work for them by combining the terms as though they refer to the same disease.

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 Alphabetical index, indexed to the same code as PVFS and Benign ME, but what does this mean? 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: the index term may be a synonym, an ill-defined condition, a best coding guess, etc. ICD-10 says that 'CFS' has some relationship with M.E., but it does not say what this relationship is.

Some people use the term 'ME/CFS' intending to refer to a biomedical disease, while viewing the term 'CFS/ME' as indicating the psychological view. However, this distinction does not hold; both combined terms are used with various meanings so that it is not clear what either term means. Both combined terms harm patients by confusing the medical issue and equating M.E. with 'CFS.'

The WHO Medical Officer (ICD Classifications, Terminologies and Standards) has explicitly disapproved of the term 'CFS/ME,' commenting on the use of the term in the UK's NICE Guidelines:

'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.'

- Margaret Williams, 'ME/CFS: TERMINOLOGY,' 2009

Even though the WHO does not classify 'CFS/ME,' senior figures in the UK Department of Health make erroneous and confused statements such as 'The WHO... [has] now agreed a position on the classification of CFS/ME.' (Professor Anthony Sheehan, Professor of Care Services at the Department of Health, on behalf of Sir Liam Donaldson, Chief Medical Officer). Such statements are wrong and should be challenged - and ridiculed! - by those who are familiar with the WHO ICD.

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.

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.

## 10. 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. However, there is an entry for M.E. in the index, reflecting the fact that M.E. was formerly present in the Tabular list; it was removed in an update to the Tabular list, but was left behind in the index where it remains as a 'fossil.'

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.

Although the US will have an ICD classification for M.E. from 2013, to what extent doctors in the US will recognise and diagnose M.E. is another matter. M.E. goes largely unrecognised throughout the world, more so in the US than in other countries. Nonetheless, it is positive that the ICD version to be used in the US in future does classify M.E. It may indicate official recognition of M.E., which may be a first step towards appropriate medical policy.

### '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 (the office responsible for the US versions of the ICD) 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:

'The Centers for Disease Control and Prevention (CDC), of which NCHS is a component Center, has still not determined the etiology of CFS. A virus may be the cause in some cases, but not all. For this reason 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. Please see the following website:

<http://www.cdc.gov/cfs/cfscauses.htm>

(email to me, 9 July 2009)

'CFS' is coded in a completely different category from M.E. in the US. In ICD-9, currently used, 'CFS' has code 780.71 under category 780-799 Symptoms, signs, and ill-defined conditions; M.E. has no listing in ICD-9, but the nearest listing is 323.9 Unspecified cause of encephalitis, myelitis, and encephalomyelitis under category 320-389 Diseases of the nervous system and sense organs.

In ICD-10 CM (USA), to be used in the US in future, 'CFS' is coded as R53.82 Chronic Fatigue Syndrome (NOS) under category R00-R99 Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified, far from M.E. G93.3 under G00-G99 Diseases of the nervous system. The listings for 'CFS' and M.E. each exclude the other, reflecting the fact that they are classified as different diseases.

It is worth noting that the clinical modifications to the US versions of the ICD were written by US Government agencies and not by the WHO. It is interesting that the US versions of the ICD differ from the WHO version in their treatment of 'CFS.' The US versions do not associate 'CFS' with M.E., and they give 'CFS' the definite status of a real disease with its own classification.

The difference between the WHO and CDC versions of the ICD is surprising (to an outsider) given that the CDC is a funding donor to the WHO and has considerable influence.

For further discussion please see section "Implications of 'CFS' Classification in the US" below.

### **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. ICD-9, currently used, does not classify M.E. as such, and the nearest equivalent is classified at a code far from that of 'CFS' (323.9 and 780.71), as discussed above. ICD-10 CM (USA), for use in future, classifies M.E. at a completely different code from that of 'CFS' (G93.3 and R53.82).

The combined terms, which equate 'CFS' with M.E., are not supported by the US ICD versions. This reflects the fact that as Amy Blum of the NCHS has stated, 'ME is not considered a synonymous term for chronic fatigue syndrome in the United States.'

## **11. The ICD and 'ICD-CFS'**

The term 'ICD-CFS' is sometimes used by those who are aware of the psychological connotations of 'CFS' and who want to refer to it without any such connotations, i.e. wanting to make clear that by the term 'CFS' they mean a real, biological disease. While this intention might at first glance seem good, it is misguided. The term 'ICD-CFS' is problematic and harmful to the cause of M.E. in a number of ways.

Firstly, the 'psychological versus physiological' debate in relation to 'CFS' misses the point. It distorts the facts about 'CFS' and M.E. M.E. is a neurological disease, while 'CFS' is a false disease category whose definitions are so vague that they include patients suffering from many different conditions, including patients with ME as well as those with psychological illnesses.

Secondly, it is not clear what the yoking of the term 'CFS' to the term 'ICD' means. It seems to imply something like "'CFS" as classified by the ICD.' However, this means different things in different places.

In the version of the ICD used in most of the world except the US, ICD-10, 'CFS' is only in the index, indexed to G93.3. As discussed above, this might indicate that 'CFS' is a synonym of PVFS and Benign ME which are classified at that code, i.e. a neurological disease. On the other hand it might not. It might indicate that 'CFS' is a term used in practice to refer to those diseases. 'CFS' might be an ill-defined or imprecise term for PVFS and Benign ME. Thus it is not clear what "'CFS" as classified by the ICD' means.

In the version of the ICD used in the US, 'CFS' is classified differently; in ICD-9 'CFS' is classified in the category Symptoms, signs, and ill-defined conditions, whereas in ICD-10 used in the rest of the world, 'CFS' is indexed to – but not classified as – a neurological disease.

It is unfortunate that the authority of WHO classification was lent to the concept 'CFS' by the classification of 'CFS' in ICD-9 and ICD-10 CM (USA), and the entry of 'CFS' in the Alphabetical index of ICD-10. This unfortunate association of the WHO with 'CFS' only undermines the authority of the WHO and thereby the authority of its classification of M.E.

- For further discussion of the term 'ICD-CFS,' particularly in relation to research, see the section 'What does the term ICD-CFS mean?' in: Jodi Bassett, 'What is M.E.? Extra extended version' <http://www.hfme.org.com/whatismeextraextended.htm>

## 12. The ICD and 'Myalgic Encephalopathy'

'Myalgic Encephalomyelitis' identifies a specific neurological disease, which has an ICD classification. There is no such disease as 'Myalgic Encephalopathy,' and no ICD classification for it.

Benign ME is classified with PVFS at G93.3 in ICD-10. Encephalopathy, unspecified is classified at G93.4. There is no such disease as 'Myalgic Encephalopathy' in ICD-10.

The so-called 'Fair Name' campaign proposes that there should be a disease category 'ME/CFS'; to be as inclusive as possible, the 'ME' part is to refer to either Myalgic Encephalomyelitis or Myalgic Encephalopathy.

It has been claimed that this would help those making insurance or welfare claims. This is not true. In fact the reverse is true. Claims under such a name would be rejected if submitted to institutions which require valid WHO ICD codes, such as health insurance companies, Medicare and Medicaid in the US.

'M.E.' standing for either 'Myalgic Encephalomyelitis' or 'Myalgic Encephalopathy' could never be given an ICD code, as it contravenes a basic rule of ICD classification. One disease cannot be classified in two places. This principle has been repeatedly stated by the WHO, for example by Andre l'Hours of the WHO Headquarters on 23 January 2004:

'it is not permitted for the same condition to be classified under more than one rubric as this would mean that the individual categories and subcategories were no longer mutually exclusive.'

Myalgic Encephalomyelitis is classified at G93.3. Encephalopathy is classified at G93.4. Thus the rules of ICD classification do not allow the two to be the same disease.

## 13. The ICD and 'Somatization'

Professor Simon Wessely and his colleagues use various terms such as 'CFS,' 'ME/CFS' and 'CFS/ME' seemingly interchangeably. Wessely has also said, "'CFS" is also referred to as M.E.'

With the characteristic ambiguity that seems to be their hallmark, members of the Wessely School have also made many statements associating 'CFS' with the concept of somatization, in which mental distress is manifested as physical symptoms.

However, this group of psychiatrists never demonstrate fancier footwork than when making statements about whether or not 'CFS' is in fact psychosomatic. They cannot be definitely pinned down on this issue. Wessely has said 'I don't classify CFS as a somatoform disorder' ('Wessely Answers Questions,' CAME, 10 April 2002). He has also said 'Functional somatic syndromes include Chronic Fatigue Syndrome' (Rev Bras Psiquiatr 2005;27:3).

For every statement that says that 'CFS' is psychosomatic, there is one that says it is not, and vice versa. It is fruitless to try to get clear what the stance of the Wessely School is on 'CFS' and somatization disorder; suffice it to say that they talk a lot about both in the same breath. Whatever they do and/or don't say about the relationship between 'CFS' and somatization, they are certainly responsible for the association of the two.

Let's take Wessely's statement 'Functional somatic syndromes include Chronic Fatigue Syndrome.' Whether or not there will be changes relating to somatization in the future ICD-11 version (see below), let's look at what current ICD versions have to say about 'CFS' and somatization.

ICD-10 has the following listings:

F00-F99 Mental and behavioural disorders  
 F40-F48 Neurotic, stress-related and somatoform disorders  
 F45 Somatoform disorders  
 F45.0 Somatization disorder  
 ...  
 F45.8 Other somatoform disorders  
 F45.9 Somatoform disorder, unspecified Psychosomatic disorder NOS

'CFS' is in the Alphabetical index of ICD-10, indexed to G93.3, and is not classified within category F45. Thus ICD-10 does not accord with Wessely's claim that 'CFS' involves somatization.

Further, 'Functional somatic syndrome' is not classified at all in ICD-10.

ICD-10 also does not accord with the claim sometimes made by members of the Wessely School that M.E. is a somatization disorder. M.E. is classified at G93.3, and not F45.0 Somatization disorder.

ICD-9, used in the US, has the following listing:

290-319 Mental disorders  
 300-316 Neurotic disorder, personality disorders, and other nonpsychotic mental disorders  
 300.8 Somatoform disorders  
 300.81 Somatization disorder

ICD-9 classifies 'CFS' at 780.71, and not at 300.81 Somatization disorder.

Thus in both current versions of the ICD, 'CFS' does not involve somatization. In ICD-10, M.E. does not involve somatization. ICD-9 does not mention M.E., but in ICD-10 CM (USA), as in ICD-10, M.E. does not involve somatization.

(I follow the WHO spelling of 'somatization' in the discussion above.)

#### **14. Past Threat: Attempt by King's Group to Subvert ICD-10**

The Institute of Psychiatry at King's College, London, is the home of a group of psychiatrists headed by Professor Simon Wessely who promote the concept of 'CFS' as a psychiatric illness. The Institute is a 'WHO Collaborating Centre for Research and training for Mental Health,' and as such was commissioned by the WHO to adapt an existing WHO publication for use in the UK, producing the handbook 'The WHO Guide to Mental Health in Primary Care.'

The Guide contains the outrageous and erroneous statement:

"The terms 'Post-viral fatigue syndrome' and '(benign) myalgic encephalomyelitis' (classified under G93.3 'neurological disorders') have been used where there is excessive fatigue following a specific trigger such as a viral disease. 'Fatigue syndrome', both chronic and not, has been classified under 'neurasthenia', F48.0."

The King's group thus rewrote the WHO ICD without any authorisation from the ICD to do so. Using the WHO logo and using the name 'WHO' in the title of the Guide, they falsely implied WHO status for this rewriting of the ICD as it concerns ME, 'CFS' and neurasthenia. In doing this, the adapters of the Guide were exploiting the fact that, for the purposes of the (relatively minor) task of adapting a guide on primary care for mental health, they were working for the WHO. As a 'WHO Collaborating Centre for Research and training for Mental Health,' the King's group spuriously claimed WHO authority for their re-writing of the ICD.

The Guide went on to make the inappropriate and harmful recommendation of the psychiatric treatment Cognitive Behavioural Therapy (CBT) plus Graded Exercise Therapy (GET), treatments which have been proven to be not only inappropriate and useless, but also probably damaging and potentially fatal to M.E. patients.

Connie Nelson, an alert, diligent and forceful campaigner, brought the situation to light and fought for it to be rectified. Despite protests, the authorities were very slow in correcting the egregious and harmful work of the King's group. Tens of thousands of copies of the Guide were bought – to be referred to by medical practitioners - before an erratum slip was sanctioned. (An erratum slip is a tiny piece of paper, often ignored or lost, slipped into

a book to announce an error – in other words, the error is not corrected as it occurs on the page.) Too little too late; the Guide has done its work.

The mistaken notion that the WHO associates 'CFS' with M.E., and classifies it as F48.0 Neurasthenia, now permeates the medical profession, particularly in the UK. These 'facts' are repeated and quoted widely.

The WHO itself was moved to refute the attempt by the King's group to subvert ICD-10. On 28 June 2001 Andre L'Hours of the World Health Organization Headquarters in Geneva, the WHO Technical Officer with overall responsibility for the ICD, stated that it was 'unacceptable for the same disorder to be classified in two places in the ICD'. Thus 'CFS' cannot be indexed to G93.3 and classified under F48.0, and M.E. cannot be classified under F48.0 as well as at G93.3

Dr. B. Saraceno of the WHO made the following statement on 16 October 2001:

'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 Organization (WHO) has not changed its position on these disorders....

'Post-viral fatigue syndrome remains under the diseases of 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 in this category. However, post-viral fatigue syndrome is explicitly excluded from F48.0.'

Dr. Saraceno went on to make it clear that the WHO guide which the King's group had been asked to adapt did not associate G93.3 with F48.0:

'The WHO ICD-10 Diagnostic and Management Guidelines for Mental Disorders in Primary Care, 1996, includes fatigue syndrome under neurasthenia (F48.0) but does not state or imply that conditions belonging to G93.3 should be included here.'

Dr. Saraceno then presumably referred to the King's group in the following masterpiece of understatement:

'It is possible that one of the several WHO Collaborating Centres in the United Kingdom presented a view that is at variance with WHO's position.'

It seems that the WHO could not have been more clear in refuting the statements made by the King's group. Unfortunately this had little effect; the false statements made by the King's group, spuriously claiming WHO authority, were more widely noted than the WHO refutations of them.

The idea that 'CFS' and M.E. were synonymous, and that 'CFS' was classified under F48.0 Neurasthenia, persisted. Andre l'Hours issued a further clarification on 23 January 2004:

'This is to confirm that according to the taxonomic principles governing the Tenth Revision of the World Health Organization'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 and subcategories were no longer mutually exclusive.'

Apparently in response to the King's group's flagrant flouting of the procedures of the WHO ICD (i.e. re-writing the ICD without any authorisation to do so from the WHO), Andre l'Hours also emphasised the obligation of the UK as a member of the WHO to abide by the ICD classification. He stated clearly that that if a country accepts the WHO Regulations concerning nomenclature (which the UK does) then that country is obliged to accept the ICD classification (which the King's group did not). The UK has registered no reservations about the ICD-10 and therefore formally accepts it. With his statement, Andre l'Hours clarified that there is no basis on which any group within a country which is a member of the WHO and accepts its regulations is allowed to disregard or rewrite the WHO ICD, as the King's group had done.

In the UK House of Lords in 2004, the Countess of Mar raised the issue, and Lord Warner made a speech which included the following masterpiece of misunderstanding:

'The current version, ICD-10, classifies CFS in two places: as neurasthenia in the mental health chapter, F48.0; and also as myalgic encephalomyelitis in the neurology chapter, G93.3. The diagnostic criteria used in

the ICD shows that the WHO has essentially put the same condition in both places. That is the WHO's formal position.'

- Hansard, Column 1195 [Hansard is the record of the proceedings of the UK House of Lords]

[My underlining: apparently both Andre L'Hours and Dr. Saraceno wasted their time in making crystal-clear statements on the basic principle of ICD classification that the same condition cannot be classified twice.]

Confusion continued to spread; Professor Anthony Sheehan, Professor of Care Services at the Department of Health, made the following confused statement on behalf of Sir Liam Donaldson, at the time Chief Medical Officer:

'The WHO; the WHO Collaborating Centre [i.e. the King's group]; and the Department of Health have now agreed a position on the classification of CFS/ME. It has been agreed that the second edition of the WHO Guide to Mental Health and neurology in primary care will have only one ICD-10 code for CFS. This is G93.3. ... I can only say that the Department of Health has no plans to seek a reclassification of CFS within ICD-10.'

This statement, while ostensibly claiming agreement between the WHO, the King's group and the Department of Health, in fact uses the term 'CFS/ME' which the WHO does not classify. The WHO does not sanction the use of the term 'CFS/ME' and the term 'CFS/ME' has no classification in the ICD; the term 'CFS/ME' is not even mentioned in ICD-10. It is therefore both false and ridiculous to claim that 'The WHO... [has] agreed a position on the classification of CFS/ME.' Such confusion at the highest levels of the UK medical establishment might be funny if it were not so tragic.

Despite the WHO's unequivocal and repeated statements making it clear that the King's group had been wrong, I am not aware of any retraction or apology published by Wessely or his colleagues. They did not resign and were not fired. Their careers continue to prosper as they continue to promote the false and meaningless concept of 'CFS,' to associate it with ME, and to associate both with neurasthenia.

The confusion created by the King's group about M.E., 'CFS' and neurasthenia continues to spread like a stain through the fabric of the medical establishment as well as popular opinion, both in the UK and internationally.

## **15. Future Threat: Concerns about Possible Re-classification in ICD-11**

The revision of ICD-10 (currently used in most of the world except the US) is currently underway for the future version, ICD-11; the first draft of ICD-11 is planned for 2010, 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. The DSM-ICD Harmonization Coordination Group is a joint initiative of the WHO and the APA, whose task is 'to facilitate the achievement of the highest possible extent of uniformity and harmonization between ICD-11 mental and behavioural disorders and DSM-V disorders and their diagnostic criteria.' This task will in particular aim to make the information which is currently in ICD-10 Chapter V on Mental and behavioural disorders (containing the F codes) consistent with DSM-V.

Many people in the M.E. and 'CFS' communities fear that the Wesselyite notion of M.E. and 'CFS' as psychosomatic may yet again exert its influence; there is concern that the revision process may result in 'CFS' (and possibly M.E.) being classified as mental disorder in ICD-11.

The 'Conceptual Issues in Somatoform and Similar Disorders' (CISSD) project was convened by Dr. Richard Sykes (Ph.D.) to inform the revision process of ICD-10 and DSM-IV on 'CFS' and somatoform disorders. The project, for which the UK charity Action for ME acted as principal administrator, had no official status in relation to either the WHO or the APA; its proposals were advisory only. The CISSD project operated from 2003-2007, and did not reach consensus in all areas.

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



The DSM-V Task Force has set up thirteen Work Groups; the Work Group reviewing the classification of somatic disorders is the DSM-V Somatic Symptom Disorders Work Group (SSD Work Group, initially called the 'Somatic Distress Disorders Work Group'). Many influential members of the CISSD project now serve on the DSM-V Task Force and the SSD Work Group.

Many psychiatrists find the concept of 'somatoform disorders' problematic, and call for alternatives; the SSD Work Group is discussing concepts not previously classified in ICD-10, such as 'Functional Somatic Syndrome' (FSS) as well as 'Somatic Symptom Disorder' (SSD).

Revision proposals for ICD-11 have not been finalised and made public. It is not yet clear whether it will be proposed that 'CFS' should be classified as a mental disorder. It is also not yet known whether the proposal will be that M.E. (and/or PVFS) should accompany 'CFS' and be re-classified under mental disorders.

Those who are concerned about the revision process for DSM-V as it affects ICD-11 are not helped by the difficulty of obtaining information. On the issue of 'transparency' in the DSM-V process, Dr. Allen Frances, who was the chair of the DSM-IV Task Force, has stated:

'DSM-V has had an inexplicably closed and secretive process.... It is completely ludicrous that the DSM-V Workgroup members had to sign confidentiality agreements that prevent the kind of free discussion that brings to light otherwise hidden problems... The secretiveness of the DSM-V process is extremely puzzling.'  
- Allen Frances, MD, 'A Warning Sign on the Road to DSM-5: Beware of Its Unintended Consequences', Psychiatric Times, 26 June 2009

We know little more at this stage than that the changes to be recommended by the DSM-V Task Force could be far-reaching, due to 'its stated ambition to effect a "paradigm shift" in psychiatric diagnosis' (Frances, as above).

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. The TAG for Neurology is listed here. A WHO presentation in June 2009 lists the TAG for Neurology as 'in formation': see slide 12 here.

If there is any proposal that M.E. should be removed from a neurological code, it is hoped that the TAG for Neurology will work to resist this.

(Note: this was written in July 2009. The situation will change. Please refer to sources given in the references section for the current situation.)

## **16. Implications of 'CFS' in the ICD: General**

The following general comments in this section apply to all current and future versions of the ICD.

### **a) 'CFS' in the ICD and patient welfare**

(The following general comments apply to all current and future versions of the ICD.)

Patients whose disease is M.E. should be so diagnosed and classified, and should be eligible for insurance and welfare benefits when claiming for M.E. Those who suffer from other diseases should be given the appropriate diagnosis and classification, and should be able to claim for the disease they have. (Patients misdiagnosed with 'CFS' may in fact suffer from a whole range of undiagnosed conditions, including fibromyalgia, Lyme disease, Multiple Chemical Sensitivity, Multiple Sclerosis or cancer.)

With accurate diagnosis rather than the meaningless 'CFS' label, patients should also be able to seek and claim for appropriate treatment (which is denied patients diagnosed with 'CFS').

Accurate diagnosis would require the cooperation of the medical profession with the ICD in recognising M.E. and learning the basic facts of the disease, and the willingness of doctors to investigate patients properly to discover what disease they suffer from, rather than abandoning them to the wastebasket of 'CFS.'

'CFS' is a false and meaningless disease category, and it injures the interests of the ill to be given a diagnosis of 'CFS.' It prevents accurate diagnosis and appropriate treatment. It is unfortunate that the ill should be forced into

accepting a meaningless diagnosis, and trapped within a disease category that harms their interests, by fear of losing their insurance or welfare benefits

## **b) 'CFS' in the ICD and M.E. advocacy**

The concept of 'CFS' is used to obscure the reality of M.E. Many institutions and groups such as the CDC in the US and the Wessely School in the UK promote the concept of 'CFS.' Those who seek the recognition of the reality of M.E. oppose the concept of 'CFS.'

The presence of 'CFS' in the ICD harms the cause of M.E. in various ways. It inappropriately promotes a false and meaningless disease category. Every diagnosis of 'CFS' is a misdiagnosis. 'CFS' is often used to misdiagnose M.E. patients, to their serious detriment. It similarly harms sufferers from a variety of other illnesses, misdiagnosed with 'CFS.'

ICD classification is an important issue for M.E. advocates. The classification of M.E. is important in achieving and maintaining recognition of M.E. It is similarly important that the concept of 'CFS' should not be promoted by ICD classification. The fact that 'CFS' has an ICD classification casts doubt on the credibility of the ICD in general, and this undermines the authority of the ICD classification of M.E.

## **17. Implications of 'CFS' in the Index of ICD-10**

### **a) Background on National Health Service**

In the UK, where ICD-10 is used, the National Health Service (NHS) is responsible for provision of free universal healthcare. The Department of Work and Pensions (DWP) is responsible for income support (or 'welfare') for those who are unable to work. Thus in theory the state provides healthcare and income support for those who cannot work due to ill health. In practice, however, patients encounter difficulties.

The NHS used to recognise M.E. In previous decades, doctors who were aware of the work of Drs. Ramsay, Acheson (subsequently Sir), Richardson, Dowsett and others understood M.E. as a neurological disease and recognised and diagnosed it in patients. However, following the US CDC's definition of 'CFS' in 1988, the NHS in the UK gradually began to adopt that term for M.E. and indeed for any fatiguing illness. In recent years the combined terms 'ME/CFS' and 'CFS/ME' have been increasingly used, 'CFS/ME' now seeming to be the official term used in the UK.

The Guidelines on 'CFS/ME' published by the NHS's National Institute for Health and Clinical Excellence (NICE) recommended only two treatments: Graded Exercise Therapy (GET) and Cognitive Behavioural Therapy (CBT).

Influenced by increasingly Wesselyite Government policy, many UK doctors now view M.E. as 'CFS' or 'CFS/ME,' and view it as a 'psychosocial' illness.

Those who are too ill to work need a doctor's report in claiming benefits from the DWP. The fact that some doctors do not believe in the biological reality of M.E. may cause problems, as may the view of many doctors that the illness is psychological. The DWP pays benefits for psychological illnesses at a lower rate.

Europe, Australia and Canada, which also use ICD-10, have different systems. However, they all have systems of government-funded universal healthcare, and income support/welfare for those who cannot work. Many countries follow the lead of the UK in adopting the concept of 'CFS' or 'CFS/ME,' and are influenced by UK Wesselyite psychiatrists.

### **b) Does ICD-10's listing of 'CFS' in the index protect patients?**

'CFS' is in the Alphabetical index of ICD-10, indexed to G93.3. The code G93.3 is listed under Other disorders of brain, under Diseases of the nervous system. Thus 'CFS' is indexed to a neurological code. Are patients who are diagnosed with 'CFS' in the UK treated as though they suffer from a neurological condition?

As described above, it is official policy that patients diagnosed with 'CFS' in the UK should be offered only GET and/or CBT. GET is clearly no treatment for neurological illness, being based on the notion that weakness is

caused by de-conditioning, and may damage the health of M.E. sufferers irreparably. CBT is a 'talking therapy,' a psychological treatment based on the notion that 'CFS' is a psychosomatic and not a neurological condition.

Thus the fact that 'CFS' is indexed to a neurological code has no effect on the treatment of patients so diagnosed in the UK. For NHS, DWP, Social Services and official policy in relation to 'CFS' in the UK, it is as though ICD-10 does not exist.

For many patients, 'CFS' is treated as a mental illness. Patients are denied medical testing which would 'reinforce their aberrant illness beliefs.' Not only are patients commonly offered only psychological treatment, but they may be coerced into it; the income support/welfare payments on which patients depend for survival may be conditional on undergoing 'appropriate treatment.'

Horrifyingly, there have been cases where patients diagnosed with 'CFS,' mistakenly viewed as suffering from mental illness by medical and social services, have been 'sectioned' (i.e. forcibly incarcerated in a mental institution). Sophia Mirza was severely ill when she was removed by force from her home and imprisoned in a mental institution where she did not receive the care she needed. This treatment contributed to her subsequent death. (See <http://www.sophiaandme.org.uk/>)

The fact that 'CFS' is indexed to G93.3 in the Alphabetical index of ICD-10 does not protect patients at all.

## **18. Implications of 'CFS' Classification in the US**

### **a) Background on insurance and welfare claims**

Whereas the UK, Australia, Europe and Canada provide healthcare and income support for those unable to work due to ill health, the US provides little support. Thus the situation of US citizens is very different from that of citizens of other countries. Government-funded health and income support systems in the UK are very far from perfect, but without such systems, people in the US who suffer from serious diseases are particularly vulnerable.

In the US many patients rely on insurance companies for healthcare and income support. Many others, who do not have health insurance, rely on the Government Medicare and Medicaid programs. Medicare, Medicaid and most health insurers may require ICD codes for health claims. This means that diagnosis according to an ICD code is crucial for US patients.

The US Department of Health and Human Services (HHS) and the Centers for Medicare and Medicaid Services plan to replace the old ICD-9 codes with the new ICD-10 CM (USA) codes as of 1 October 2013.

With this transition in prospect, the issue of ICD coding has been fraught for those in the US who had been diagnosed with 'CFS' under ICD-9 and who were afraid that loss of an ICD classification for 'CFS' in the new ICD version would invalidate their claims.

There has been a concerted campaign for the inclusion of 'CFS' in the tabular list of ICD-10 CM (USA), as it was in ICD-9. An extra code, R53.82, was created for 'CFS' and inserted under the existing listing R53 Malaise and fatigue.

Those who are currently classified as 780.71 Chronic fatigue syndrome under ICD-9 will have their code updated to R53.82 under ICD-10 CM (USA). (Those few who are currently classified as 323.9 Unspecified cause of encephalitis, myelitis, and encephalomyelitis will have their code updated to G93.3.)

Many in the US feel that the inclusion of 'CFS' in the tabular list of the future version of the ICD is a victory, feeling that it will protect patients. (Please see next section.)

### **b) Does the US's ICD classification of 'CFS' protect patients?**

The practical considerations of insurance and welfare claims are a survival issue for many in the US. The 'CFS' listing in ICD-10 CM (USA) may seem to allow those diagnosed with 'CFS' to continue to claim under an ICD classification.

However, patients' safety does not lie in a classification of 'CFS.' Consider the following:

- One aspect of this false disease category which recommends it to insurers is that it is characterised as a psychological illness, increasingly so with each succeeding CDC definition. Many insurers exclude psychological illnesses from health insurance policies, or limit the term of cover, typically to two years.
- The future version of the ICD for use in the US, ICD-10 CM (USA), newly includes the designation 'NOS' (not otherwise specified) at the 'CFS' classification. This may mean that the situation becomes more difficult for 'CFS' claimants in future, as 'NOS' may cause problems with claims. For example, Medicare is allowed to refuse claims for non-specific codes.
- Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET), proven to be harmful to M.E. patients, are increasingly regarded as appropriate treatments for 'CFS.' Some insurers require that claimants undergo such treatment. If the patient refuses treatment, either because s/he knows it to be potentially harmful or because of physical inability (in the case of graded exercise), 'non-compliance' is grounds for the insurer to stop payment.
- The policy of many health insurers is to be increasingly tough on 'CFS' claims (which are an expensive and increasing liability for insurance companies). Some insurers employ doctors who will supply medical evidence that undermines claims. Some insurers give their claims handlers (i.e. insurance company employees who process and assess claims) financial incentives to discontinue claims. Some insurers have a policy of stopping benefits, putting the onus on sick patients to litigate to reinstate payments, in the knowledge that many patients are too ill and disabled, as well as lacking the financial resources, to fight such a battle.

Patients who feel their security lies in their 'CFS' classification may be in a very vulnerable position.

The position of patients in the US with a 'CFS' classification may grow yet worse. It seems that the US is set to follow the lead of the UK in dealing with 'CFS' as a psychological illness. At the CDC's CFS Stakeholders Meeting in Atlanta on 27 April 2009, Dr. William Reeves spoke approvingly of the UK model and of the work of Professor Peter White (a leading Wesselyite psychiatrist).

Patients would be on stronger ground in relation to insurance and welfare claims if they had an accurate diagnosis and ICD classification of a testable and scientifically recognised condition.

### c) 'CFS' as a 'wastebasket' category

'CFS' is a 'wastebasket' diagnosis - or perhaps 'garbage bin' diagnosis in the US - which is sometimes applied to those with M.E. and sometimes to those with various other fatiguing illnesses. 'CFS' harms the interests of all patients so diagnosed by obscuring the reality of their disease; this applies to those with M.E. as well as those with other illnesses.

In both ICD-10 and ICD-10 CM (USA), the category 'R00-R99 Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified' is described by three paragraphs of text. In ICD-10 this text is obviously of no relevance to 'CFS' since 'CFS' is not classified in the R codes. In ICD-10 CM (USA) this text is relevant to 'CFS,' which has the new listing 'R53.82 Chronic fatigue syndrome NOS' inserted within this category. I quote this text below, as it illustrates how 'CFS' is clearly a 'wastebasket' category. (The underlining is mine, and I have added the notes in square brackets).

'This chapter includes symptoms, signs, abnormal results of clinical or other investigative procedures, and ill-defined conditions regarding which no diagnosis classifiable elsewhere is recorded.'

'Signs and symptoms that point rather definitely to a given diagnosis have been assigned to a category in other chapters of the classification. In general, categories in this chapter include the less well-defined conditions and symptoms that, without the necessary study of the case to establish a final diagnosis, point perhaps equally to two or more diseases or to two or more systems of the body. Practically all categories in the chapter could be designated "not otherwise specified", "unknown etiology" or "transient". The Alphabetical Index should be consulted to determine which symptoms and signs are to be allocated here and which to other chapters. The residual subcategories, numbered .8, are generally provided for other relevant symptoms that cannot be allocated elsewhere in the classification.

[note: R53.82 is one of these 'residual subcategories']

'The conditions and signs or symptoms included in categories R00-R99 consist of: (a) cases for which no more specific diagnosis can be made even after all the facts bearing on the case have been investigated; (b) signs or symptoms existing at the time of initial encounter that proved to be transient and whose causes could not be determined; (c) provisional diagnosis in a patient who failed to return for further investigation or care; (d) cases referred elsewhere for investigation or treatment before the diagnosis was made; (e) cases in which a more precise diagnosis was not available for other reasons; (f) certain symptoms, for which supplementary information is provided, that represent important problems in medical care in their own right.'

[note: assuming that (c) and (d) do not apply, it is interesting to consider whether (a), (b), (e) or (f) is intended to apply to R53.82 Chronic fatigue syndrome]

## 19. Confusion about the ICD

There are many sources of confusion about the ICD, such as:

### Different versions of the ICD in use in different countries

The fact that different versions of the ICD are used in different countries is problematic. It introduces a level of complication for those who are aware of the different versions. For those who are unaware of the different versions, the situation can get very confusing. Research and articles which refer to the ICD may be at odds with the reader's understanding. Conversations and correspondence particularly between those who are and who are not in the US may be at cross purposes.

When people mention 'the ICD' it may not be clear whether they are referring to ICD-10, ICD-9 or possibly ICD-10 CM (USA).

As outlined above, there are two enormous differences relevant to this discussion between ICD-10 used in most of the world and ICD-9 used in the US:

- M.E. is classified in ICD-10 but does not appear in ICD-9, and
- 'CFS' in ICD-10 has some relation to M.E.: it is listed only in the index and indexed to the same code, which might indicate a synonym or a coding guess or one of various other relationships. ICD-9 on the other hand classifies 'CFS' as a completely different disease from M.E. at a completely different code.

### Ambiguity such as status of 'CFS in index of ICD-10

There is also confusion caused by areas of ambiguity in the coding and structure of ICD-10 which have not been clarified by the WHO.

An example of this is the listing of 'CFS' in the Alphabetical index and not in the Tabular list of ICD-10. As discussed above in section "ICD-10 and 'CFS,'" a good deal of confusion and conflict arises from the fact that ICD-10 does not specify the relationship of 'CFS' and M.E., and does not say whether or not they are synonymous.

### Index of ICD-10 not available online on the WHO website

The fact that not all of ICD-10 is available on the WHO website causes confusion. The ICD page on the WHO website does not explain this, nor does the page which is referred to as 'ICD-10 ONLINE / current version' in the link to it from the UCD page. The link is misleading. Users may well assume that they are being shown the current version of ICD-10, rather than only part of it.

Crucially, the WHO website does not show the Alphabetical index, which is the only place 'CFS' is mentioned in ICD-10. This fooled me initially. It also fooled Dr. Richard Sykes of the CISSD project, informing the ICD revision process for ICD-11, whose initial report to Action for ME in December 2007 stated that ICD-10 does not mention 'CFS.' It also fools many other users of the WHO website.

As of July 2009, the search facility on the WHO website page giving the Tabular list of ICD-10, labelled 'search ICD-10,' strangely does not find 'CFS,' even though the default 'full search option' includes a search of the index. Thus the index entry for 'CFS,' not in the Tabular list and also not found by search, is doubly hidden from online users.

This is unfortunate, since many M.E. patients are unable to afford the expensive CD-ROM of ICD-10 or the astronomically expensive books, and are not physically able to travel to a library to consult the books. Many M.E. patients, and patients with other disabling diseases, are housebound and rely on the Internet for information. It is a pity that the WHO does not make the complete ICD-10 available online.

### **Misinformation**

There is a good deal of misinformation on the ICD available, particularly on the Internet. Not all sources are reliable; many are misleading or make statements which are simply not true.

Many misleading claims are made based on ICD classification. The confusion might be genuine, as many people are genuinely baffled by the different ICD versions. This is understandable (!). It may also be that people were misinformed; this is also understandable, as their informants may themselves have gathered information from an unreliable source. Unfortunately, it may also be that some people are deliberately trying to mislead. Confusion serves the ends of those who promote the concept of 'CFS.'

Readers are urged not to believe everything they read about the ICD. If in doubt, refer to the official listings, where these exist, as given in the references section below.

### **Unfortunate wording**

While 'Chronic fatigue syndrome' is listed in the index of ICD-10 and indexed to a neurological code, 'Fatigue syndrome' is classified with Neurasthenia under Mental and behavioural disorders. Despite the similarity of the two terms, the conditions are completely different, and are given completely different codes, 'CFS' being indexed to G93.3 while Fatigue syndrome is listed at F48.0.

As well as being confusing, the similarity of the two terms facilitated a Wesselyite attempt to create slippage around the semantics of 'Fatigue syndrome' and declare that 'CFS' is classified under Neurasthenia as a mental disorder (see section 'Past Threat: Attempt by King's Group to Subvert ICD-10' above, and subsection below).

The similarity of the terms 'Chronic fatigue syndrome' and 'fatigue syndrome' continues to cause confusion.

### **Attempt to subvert ICD-10**

As discussed in the section 'Past Threat: Attempt by King's Group to Subvert ICD-10' above, a group from King's College, London claimed WHO authority for a statement, in a guide to mental health in primary care, that 'CFS' is referred to as M.E., and is classified as a mental illness under F48.0 Neurasthenia.

Dr. Saraceno of the WHO made a statement which thwarted this attempt, but nonetheless much damage was done and continues to be done.

Tens of thousands of copies of the guide containing this statement were sold. They remain on bookshelves, to be consulted by medical practitioners and policy-makers.

Many members of the medical profession in the UK had their opinions formed by this false statement, whether they currently consult the guide or not. Some senior NHS consultants still believe that M.E. is neurasthenia. This belief persists, unaffected by the erratum slip placed in later editions of the guide.

### **'Fossils' of previous versions**

Many 'fossils' litter the landscape, particularly on the Internet; many research and discussion papers still exist which were written based on previous ICD versions.

Particularly pernicious are the documents which still exist referring to the erroneous statement made in the guide produced by the King's group (i.e. that 'CFS' is also known as M.E. and is classified under Neurasthenia); although that original guide has been corrected, other documents have not.

Another fossil which causes confusion is 'Chronic fatigue syndrome, post-viral' which was formerly listed in ICD-10 CM (USA) at G93.3 along with PVFS and Benign ME. It is no longer there, having been removed in 2007 when the new code R53.82 was created. (In other words, this was a past version of a plan for the future; it was never and will never be implemented.) However, although 'CFS, P-V' no longer exists in ICD-10 CM (USA) - nor in any version of the ICD - many references to it still exist.

A fossil within the ICD itself is the entry for M.E. in the index of ICD-9, indexed to a code from which M.E. has been removed.

### Difficulties of version control

In addition to the different versions of the ICD such as ICD-9 and ICD-10, there are also periodic updates. Members of a meeting of WHO Collaborating Centres in Cologne in 2003 were admirably honest in noting 'difficulties in dissemination and version control,' observing that 'ICD-10 users around the world are using different versions of the classification, and not all are aware of updates to rules, terms and classes.' (No longer available [here](#): HTML version still available when a Google search is done on this URL)

### The 'CFS' quagmire

As noted above, the WHO has not clarified the status of 'CFS' in the index of ICD-10. Then there is the fact that the ICD used in the US says something different about 'CFS' from the ICD used in the rest of the world. There is also the fact that there are inconsistencies between the ICD and other official classifications such as that of the CDC in the US. All in all, it's a mess.

For example, an editing discussion of the issue on Wikipedia Talk includes the following comments from various contributors:

- What we would really need is an explicit statement saying "the WHO considers CFS and ME to be different"
  - I interpret this to mean CFS is a synonym for ME.
  - I interpret this to mean CFS is not a synonym for ME.
  - If you can find an *explicit* discussion of this... ideally *from the WHO itself*, that'd not only clarify things, it would immensely help the page. I find it curious that the WHO would not have any documentation if it was truly controversial
  - I think we're still waiting for an explicit discussion
- [http://en.wikipedia.org/wiki?title=Talk:Controversies\\_related\\_to\\_chronic\\_fatigue\\_syndrome#Naming](http://en.wikipedia.org/wiki?title=Talk:Controversies_related_to_chronic_fatigue_syndrome#Naming)

## 20. Structural Problems of the ICD

The ICD is not exactly a 'classification' in the usual meaning of the word; this may cause problems for those who approach it assuming that it is.

A classification is a taxonomic structure (usually a hierarchy) which organises a set of things (usually within categories or classes). In other words, the classifier surveys the set of things, and imposes order on them by means of the classification which expresses the concept of their natural order. Famous examples of classification include Linnaeus's classification of plants and Darwin's classification of animals.

ICD-10 both is and is not a classification in this sense. It is a classification in the sense that the WHO provides a structure for disease terms it considers valid. However, the ICD is used for the reporting of diseases from around the world, and thus the WHO is obliged to include disease terms used in practice, even if the WHO does not consider them to be valid. (A fanciful comparison might be imagining that Darwin had been obliged to include mermaids and unicorns in his classification of animals, because these creatures had been reported to him.)

In other words, the ICD is both top-down and bottom-up. (I'm using the terms here in the conventional sense: 'top-down' meaning starting with the concept or theory, and bottom-up meaning starting with the things found in the world.) Being both top-down and bottom-up simultaneously is an uneasy straddling of roles. ICD-10 is top-down in that it imposes the WHO's concept of the organisation of diseases on the diseases occurring in the world. However, it is also bottom-up in that it accommodates diseases reported to the WHO, whether or not the WHO considers them valid.

A related problem is that the ICD has no listing of what the WHO considers to be the set of valid terms for diseases. This is an important and surprising omission.

The Tabular list is too exclusive; we are told that many valid terms are excluded from it for reasons of space, and can be found in the index. The Alphabetical index is too inclusive; as well as the valid terms excluded from the

Tabular list, it also includes invalid terms such as the 'imprecise and undesirable term[s]' of which the WHO does not approve, as mentioned in the Introduction to Volume 3, the Alphabetical Index.

There is no way of inferring the set of valid disease terms from the information given in ICD-10. As discussed in section "ICD-10 and 'CFS'" above, there are many reasons why a term may be in the Alphabetical index and not in the Tabular list, and there is no indication which reason applies in each case, i.e. whether the WHO considers a particular term valid or invalid.

Some of the problems discussed in section 'Confusion about the ICD' above arise from these structural problems. For example, those who assume that ICD-10 is a classification in the usual sense may think that the presence of 'CFS' in the index indexed to G93.3 means that the WHO says that 'CFS' is correctly classified at that code. However as discussed above, ICD-10 does not specify whether or not this is true.

## 21. Enforcement of the ICD

Despite the problems of the ICD, it is very important to M.E. patients and those who support them. ICD-10 (currently used in the UK, Australia, Canada and most of the world except the US) classifies M.E. as a neurological disease. What does this mean in practice for M.E. patients?

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/>

Thus although the primary function of the ICD may be the reporting of diseases to the WHO from around the world, the diagnostic function of the ICD also has a clinical role. In other words, the ICD is used to diagnose patients.

As discussed above, following the King's group's attempt to subvert ICD-10, Andre l'Hours of the WHO pointed out that there is an obligation for WHO member countries to abide by the ICD classification.

M.E. is classified by the WHO ICD. Why then do M.E. patients continue to encounter doctors and officials who deny the biomedical reality of their disease? M.E. is classified by the ICD specifically as a neurological disease, so why do we continue to encounter doctors and officials who see it as interchangeable with a vast array of other illnesses, such as various fatigue conditions, fibromyalgia and so on, which may be far more easily treated, or resolve naturally? M.E. is classified in ICD-10 as a neurological disease and not as a mental disorder, so why do the Wessely School in the UK and the Nijmegen group in the Netherlands treat the disease as a somatization disorder? Why do we continue to encounter doctors and officials who characterise our disease as a psychiatric illness?

The meaningless terms 'CFS/ME' and 'ME/CFS' continue to gain ground despite the fact that they have no ICD classification.

M.E. patients and advocates frequently quote the WHO ICD; doctors and officials frequently ignore it. Many people, observing the US CDC and UK NHS continually seeming to 'trump' the WHO, wonder about the authority of the WHO. They wonder if the WHO has teeth.

Perhaps one day the authority of the WHO ICD will be put to the test by a legal challenge to those who flout it.

What is sorely needed is an ICD which is not merely a theoretical classification and a framework for reporting diseases to the WHO, but a classification which guides policy and action.

## 22. 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.

PVFS was introduced as the 'proper term' for M.E., but it is inaccurate and misleading. Dr. Melvin Ramsay opposed it.

Dr. Elizabeth Dowsett has stated that the first 'major error... responsible for the present confusion surrounding the case definition, aetiology and diagnosis of M.E.... [is] a failure to distinguish the syndrome from post-viral debility.'

- Dowsett, Ramsay et al, 'Myalgic Encephalomyelitis (M.E.) - A Persistent Enteroviral Infection?' in *The Clinical and Scientific Basis of Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome*, eds. Hyde, Goldstein and Levine, 1992

Fatigue following viral infection, i.e. the 'post-viral debility' mentioned by Dr. Dowsett, 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 was used to indicate 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. Those who are not aware of the medical meaning of 'benign' may interpret it 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. A proposal for dealing with this situation follows:

'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 a valid disease category.

The ICD already accepts that patients are in practice diagnosed with 'imprecise and undesirable term[s]' for 'ill-defined conditions,' and the ICD acknowledges that such terms are recorded, without 'implying approval of [their] usage.' (Introduction to ICD-10 Vol.3 Alphabetical index, 2<sup>nd</sup> Edn.) Given that the principle of including invalid terms used in practice is already established in the ICD, it would not be an enormous step to move such terms from the index to the Tabular list, to create a category specifically for such invalid terms.

Such a category would make explicit what is already implicit in categories such as 'Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified' (Chapter XVIII of ICD-10 containing the R codes): 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.

As discussed above, the false 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 is an important issue for M.E. advocates. The classification of M.E. is important in achieving and maintaining recognition of M.E. It is also important that the concept of 'CFS' should not be promoted by ICD classification. 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. Currently (as of July 2009) the search facility for ICD-10 misleadingly fails to find 'CFS' which is present in the Alphabetical index.
- All rather than only part of the current WHO ICD should be published on the WHO website. The WHO should publish the Alphabetical index of ICD-10 online. If this is impossible for some reason, the WHO website should call attention to its omission.

If ICD-11 (the future version, details of which are unknown at present) also comprises multiple volumes, then all should be published on the WHO website. Again, if this is not possible, the website should call attention to the fact that material is omitted.

Sales of the CD-ROM and book editions of ICD-10 generate income for the WHO. However, it is hoped that financial considerations do not override the WHO constitution. The WHO states: 'The WHO constitution mandates the production of international classifications on health so that there is a consensual, meaningful and useful framework which governments, providers and consumers can use as a common language.' (My underlining)  
- 'The WHO Family of International Classifications'  
<http://www.who.int/classifications/en/>

Surely ill people and doctors are 'consumers' of the ICD. Ill people, as well as doctors in countries with inadequate medical funding, may not be able to afford the CD-ROM or book editions of the ICD. Not everyone has access to a library, the seriously ill being physically unable to travel to one.

If the WHO ICD is truly to serve its worldwide constituency, it must be available online in its entirety.

## 23. References

There is a huge amount of misinformation about the WHO ICD out there, particularly on the Internet. For example, while researching this paper I came across many online listings of ICD codes, and references to them, which were wrong. Beware!

It is important to know where to look for reliable information on the ICD.

### a) Official listings of the ICD versions

#### ICD-10:

ICD-10 can be found online on the website of the WHO: <http://apps.who.int/classifications/apps/icd/icd10online/>

As discussed, only the Tabular list and the Instruction manual of ICD-10 are published on the WHO website; the Alphabetical index (containing the listing for 'CFS') is not published there. For this reason, in the next section I give references to alternative online listings of the Alphabetical Index of ICD-10.

#### ICD-9:

ICD-9 (which is actually ICD-9 CM (USA), as mentioned in the section 'Versions of the ICD'), can be found online at:

[ftp://ftp.cdc.gov/pub/Health\\_Statistics/NCHS/Publications/ICD9-CM/2008/](ftp://ftp.cdc.gov/pub/Health_Statistics/NCHS/Publications/ICD9-CM/2008/)

and open the fourth-listed zip file, 'Dtab09.zip'

then open the Word file 'Dtab09'

The index to ICD-9 contains a reference to M.E., although M.E. is not listed in the Tabular list. The index can be found at:

[ftp://ftp.cdc.gov/pub/Health\\_Statistics/NCHS/Publications/ICD9-CM/2008/](ftp://ftp.cdc.gov/pub/Health_Statistics/NCHS/Publications/ICD9-CM/2008/)

(as above)

and open the third-listed zip file, 'Dindex09.zip'

then open the Word file 'Dindex'

(Unofficial but more easily accessible version of ICD-9 given below under 'Alternative listings')

### **ICD-10 CM (USA):**

Note that Amy Blum, Medical Classification Specialist at the NCHS within the CDC, has said:

'Any 10-CM files currently on the internet are out of date. A new set of 10-CM files will be posted on the NCHS website in January 2010 and will be updated annually from then on in preparation for the implementation of 10-CM on October 1, 2013.'  
(email to me, 9 July 2009)

Thus the following files are out of date, but are the most recent listings of ICD-10 CM (USA) available on the CDC website, giving the 2009 update.

ICD-10 CM (USA) can be found online on the website of the [CDC](#):  
and click on 'ZIP' following 'Tabular,' 4<sup>th</sup> in the list under 'New Files' at the bottom of the page,  
then opening the last-listed zip-file 'tab2009.zip',  
then opening the pdf file 'i10tab2009.pdf'

Can also be accessed from  
[ftp://ftp.cdc.gov/pub/Health\\_Statistics/NCHS/Publications/ICD10CM/2009/](ftp://ftp.cdc.gov/pub/Health_Statistics/NCHS/Publications/ICD10CM/2009/)  
then opening the last-listed zip-file 'tab2009.zip',  
then opening the pdf file 'i10tab2009.pdf'

<http://www.cdc.gov/nchs/about/otheract/icd9/abtcd10.htm>  
- gives information about ICD-10 CM (USA)

[Click here.](#)  
- gives information on the files for the 2009 update of ICD-10 CM (USA)

The CDC website does not make access to the current or future ICD codes very user-friendly, so I have given references below to alternative listings of ICD-9 and ICD-10 CM (USA) codes.

### **b) Alternative listings of the ICD versions**

Please note that unofficial listings such as those found on Wikipedia or Scribd may contain errors. Please also be aware that copying material from these sources may involve copyright issues. See note on Wikipedia at end of references.

### **ICD-10, index:**

The Alphabetical Index of ICD-10 (2006 update) can be found online at:  
<http://www.scribd.com/doc/7350978/ICD10-2006-Alphabetical-Index-Volume-3>  
- 'CFS' is at page 528

Photocopied and scanned versions of the Alphabetical index of ICD-10 can be seen at  
[www.meactionuk.org.uk/G93-3-ICD-10-index-closeup.jpg](http://www.meactionuk.org.uk/G93-3-ICD-10-index-closeup.jpg) (close up)  
[www.meactionuk.org.uk/G93-3-ICD-10-index.jpg](http://www.meactionuk.org.uk/G93-3-ICD-10-index.jpg) (whole page)  
and [here](#) (close up)

I have not given an alternative listing for the ICD-10 codes, since the Tabular list is easily accessible on the WHO website, as under 'Official listings' above.

### **ICD-9:**

ICD-9 can be found online at:  
[http://en.wikipedia.org/wiki/List\\_of\\_ICD-9\\_codes](http://en.wikipedia.org/wiki/List_of_ICD-9_codes)  
(please see warning on Wikipedia at the end of references section)

ICD-9 search facilities:

<http://www.lumrix.net/icd-9.php>

and

<http://www.mays-systems.com/icd9cm/index.php>

- these websites give the classification of any disease entered, which is useful if one wants to locate a particular disease (or confirm its absence from ICD-9)

### **ICD-10 CM (USA):**

ICD-10 CM (USA):

<http://en.wikipedia.org/wiki/ICD#ICD-10-CM>

ICD-10 and ICD-10 CM (USA):

[http://uk.geocities.com/me\\_not\\_cfs/US\\_ICD\\_10\\_CM.html](http://uk.geocities.com/me_not_cfs/US_ICD_10_CM.html)

### **c) General discussion of the ICD**

As discussed above, a basic premise of this paper is that M.E. is not the same as 'CFS,' and for this reason I do not support concepts such as 'ME/CFS,' subgrouping of 'CFS' or 'ME/CFS' and so on. Some of the websites listed below support 'ME/CFS' and/or other problematic concepts; I include these links because of the relevant information available on these websites, without implying that I support everything said on these websites, or all of the papers published on them.

[http://en.wikipedia.org/wiki/ICD#WHO\\_official\\_ICD\\_sites](http://en.wikipedia.org/wiki/ICD#WHO_official_ICD_sites)

- gives links for many other sources of information on ICD listings  
(please see warning on Wikipedia at the end of references section)

<http://en.wikipedia.org/wiki/ICD#ICD9>

- gives an overview of the ICD and its different versions.

[http://uk.geocities.com/me\\_not\\_cfs/site\\_map.html](http://uk.geocities.com/me_not_cfs/site_map.html)

- this website is not specifically on the ICD, but is a useful list – with online links - of all the major official classifications, definitions, descriptions, and discussions of M.E., 'CFS,' 'ME/CFS' and 'CFS/ME.' Thus this site is a resource for putting the WHO ICD in context among other classifications.

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

- pdf file 'History of ICD' gives history

<http://www.mesite.dk/ME-CFShistory.htm#note6sym>

- gives history of the ICD within context of history of M.E. and 'CFS'

[http://www.meactionuk.org.uk/Corporate\\_Collusion\\_2.htm](http://www.meactionuk.org.uk/Corporate_Collusion_2.htm)

- this is a long document which ranges over many issues; readers specifically interested in the ICD can search within this document for terms such as 'WHO,' 'ICD,' 'ICD-10,' 'F48.0' etc.

[http://www.meactionuk.org.uk/SELECT\\_CTTEE\\_FINAL\\_VERSION.htm](http://www.meactionuk.org.uk/SELECT_CTTEE_FINAL_VERSION.htm)

- this is another long document. Readers can go to the section: 'The formal international classification of ME by the World Health Organisation,' or search as above

### **On the King's group's attempt to subvert the WHO ICD:**

<http://www.meactionuk.org.uk/cmoletter.htm>

<http://www.meactionuk.org.uk/whomisc.htm>

- Connie Nelson's correspondence

Also other papers on <http://www.meactionuk.org.uk/> such as [http://www.meactionuk.org.uk/ladyman\\_v2.htm](http://www.meactionuk.org.uk/ladyman_v2.htm)

'Who's kidding WHO' within:

[www.erythos.com/RiME/Docs/NL0309.rtf](http://www.erythos.com/RiME/Docs/NL0309.rtf)

### **On the ICD and DSM revision processes:**

<http://meagenda.wordpress.com/>

- for the 'The Elephant in the Room' series of reports by Suzy Chapman, a 'DSM-V and ICD-11 Directory' and related material at:

<http://meagenda.wordpress.com/dsm-v-directory/>

<http://www.meactionuk.org.uk/>

- See papers by Margaret Williams and Stephen Ralph

Note: Many people do not like to rely on Wikipedia, which is extremely biased and misleading in its information on M.E. and 'CFS.' However, I have given Wikipedia references above because they give some factual information as well as links to other websites. Readers may want to approach Wikipedia with caution, and not necessarily accept at face value all they read there.

## 24. Acronyms

APA - American Psychiatric Association

CBT - Cognitive Behavioural Therapy

CDC - Center for Disease Control, officially 'Centers for Disease Control and Prevention' (US Government agency)

DSM - Diagnostic and Statistical Manual of Mental Disorders

FSS - Functional Somatic Syndrome

GET - Graded Exercise Therapy

ICD - International Classification of Diseases, published as 'International Statistical Classification of Diseases and Related Health Problems'

NCHS - National Center for Health Statistics (US Government agency, part of CDC)

NHS - National Health Service (UK)

SSD - Somatic Symptom Disorder

WHO - World Health Organization (international, based in Geneva)

## 25. Note on Spelling

UK English and US English spelling are sometimes different. I have used UK spelling in this paper, except for:

- names of institutions: I use the name used by the institution, e.g. 'World Health Organization,' 'National Center for Health Statistics' and 'Centers for Medicaid and Medicare.'

- 'somatization': I use the US spelling because the ICD refers to it this way (and it might have been distracting to readers to keep switching between US and UK spelling in my text).

- 'harmonization': I use the US spelling because the WHO and the APA refer to it this way, in relation to ICD-11 and DSM-V.

I mention this because it is worth remembering that different spellings exist, particularly if doing an Internet search or search within a document for particular terms. For example, while the name of the WHO uses the spelling 'Organization,' many articles refer to it as the 'World Health Organisation.' Similarly, although the ICD mentions 'somatization,' some articles spell it 'somatigation.'

## 26. Acknowledgements

Many people have contributed to this paper.

The issues discussed here are contentious, and inevitably not everyone will share my point of view. Whether or not we agree on everything, I'm grateful for the help given by each of the generous contributors.