

Chief Medical Officer,
Professor Liam Donaldson,
The Department of Health
Richmond House
79 Whitehall
London
SW1A 2NS

Dear Professor Donaldson,

Towards the end of August 2001 I inadvertently stumbled across a [website](#) hosting a "GUIDE to Mental Health in Primary Care" developed by the WHO Collaborating Centre for Research and Training for Mental Health, Institute of Psychiatry, Kings College, London. On reading through this website I was shocked to find Chronic Fatigue Syndrome & M.E. had been included as mental health disorders and given the incorrect classification of F48.0 (Mental & Behavioural, Neurotic disorders) and I quote from the site; "**Chronic Fatigue and Chronic Fatigue Syndrome - F48.0 (may be referred to as M.E)**"

Realising neither M.E nor CFS are classified as mental health disorders, with ME being classified in the [ICD-10](#) under [G93.3](#) (neurological) and Chronic Fatigue Syndrome being [index](#) linked to the same, myself and others contacted the Collaborating Centre and the WHO Headquarters in Geneva to voice our concerns. Due to these complaints some modifications have now been carried out. The main modification is that the aforementioned statement now completely omits CFS and ME and instead reads;

"CHRONIC FATIGUE, FATIGUE SYNDROME & NEURASTHENIA - F48.0"

However the modifications to date are insufficient and unfortunately seem to confound the issue. References to Chronic Fatigue Syndrome and M.E. have only partially been removed and CFS remains covertly within the following areas;

- 1) The index for self-help leaflets and the index to mental disorders on the website's Home page.
- 2) The Introduction page under the heading,
'A linked set of patient information and self-help leaflets.'
- 3) On page 21 of the WHO GUIDE book it still states;

**" Chronic Fatigue and Chronic Fatigue Syndrome - F48.0
(may be referred to as M.E) "**

4) Also under the Mental Disorders section with the new heading of, **CHRONIC FATIGUE, FATIGUE SYNDROME & NEURASTHENIA - F48.0** you will find under ' resources for patients and families ' the following book suggested; **Chronic Fatigue Syndrome: The Facts** by M Sharp and F Campling, 2000, Oxford University Press (self-help advice for more severe symptoms).

One is also directed to the following information; [The Institute of Psychiatry's website](#) includes a full patient-management package for more severe symptoms of **Chronic Fatigue Syndrome**. This includes information about the disorder and suggestions to aid self-management. It is a useful resource for the practitioner who is working with the patient to overcome the condition.

On following the internet link given to **The Institute of Psychiatry's website** you arrive at; A Practical Self Help Guide, [The Chronic Fatigue Syndrome Research and Treatment Unit New Medical School, Kings College Hospital, London SE5 7PJ](#)

As CFS / ME are not classified as mental health disorders by the World Health Organisation one must seriously question why these disorders are included in a WHO Guide to Mental Health in Primary Care and included on a psychiatric website.

Once again this Guide which is intended only to include disorders classified under F48.0 (Mental & Behavioural, Neurotic disorders) makes mention of CFS and ME under, **CHRONIC FATIGUE, FATIGUE SYNDROME & NEURASTHENIA - F48.0** 'resources for patients and families' by directing readers to;

[A review of the evidence for the full range of treatments for CFS/ME, see: Bagnall AM, Whiting T, Wright J, Sowden AJ, 2001 The effectiveness of interventions used in the treatment/management of CFS and/or myalgic encephalomyelitis in adults and children NHS Centre for Reviews and Dissemination, University of York, York.](#)

At this juncture it may be appropriate to look at the airmail letter I received from the WHO Headquarters in Geneva which states; (full copy attached)

“ The information posted on the website in question has recently been modified on the basis of advice provided by the Classification, Assessment, Surveys and Terminology Team here at WHO Headquarters.

You will see that there is now a clear distinction between chronic fatigue, fatigue syndrome and neurasthenia on the one hand and chronic fatigue syndrome and ME on the other. ”

I regret the clear distinction mentioned above has not yet been attained. I wish also to draw your attention to the unacceptable duplicity of the following paragraph which can be found under Mental Disorders preceding the heading 'Essential Information' for patient and family as follows;

“ Postviral fatigue syndrome and benign myalgic encephalomyelitis (classified under [G93.3](#) 'neurological disorders') are diagnosed where there is excessive fatigue following a viral disease and the symptoms do not fulfil the criteria for F48.0. '**Fatigue syndromes' both chronic and not**, both with and without an established physical precursor, may be classified under 'neurasthenia' F48.0. In practice, there is extensive overlap in symptoms (up to 96%). The choice of coding reflects different recording practices and *uncertainty about the aetiology* of these syndromes.

Although *classification is controversial*, treatment is similar whatever choice is made about coding ”

The authors, very astutely, may not have used the actual name ‘ Chronic Fatigue Syndrome’ within the above paragraph but I would suggest it is blatantly obvious what message the following sequence of words is intended to convey;

“ **Fatigue syndromes, both chronic and not** ” It is my opinion and that of many others that herein lies proof of the duplicity involved. The authors themselves have above made a very good case as to why these disorders should not be in this Guide, and that is, *a) uncertainty about the aetiology b) classification.*

To further support my comments please find below an extract of [Jo Paton’s reply](#) to complaints regarding the inclusion of CFS and ME or the classification given to it within this Guide. (Full copy attached.)

“What we have decided to do and why”

We are using the code: F48.0 because the 1996 ‘WHO Diagnostic and Management Guidelines for Mental Disorders in Primary Care: [ICD-10](#) Chapter V Primary Care Version’ of which our guide is an adaptation included a guideline on **neurasthenia (fatigue syndrome)** which is a broad inclusive category. **However, UK GPs do not use the terms ‘fatigue syndrome’ and ‘neurasthenia’.** **Instead they use the terms ‘Chronic Fatigue’ and ‘Chronic Fatigue Syndrome’.** Therefore we have used the term ‘Chronic Fatigue’ and made clear that our guideline refers both to fatigue that is mild / moderate and short-lived and to fatigue that is severe and chronic. ”

I am most concerned that a reasonable person reading this Guide to Mental Health in Primary Care would infer that the condition CFS / ME is synonymous with the condition Neurasthenia, chronic fatigue & Fatigue Syndrome classified by the WHO under F.48.0 (Mental, Behavioural & Neurotic disorders)

It is widely recognised that General Practitioners, the general public, the media, the DSS, and sufferers in the UK use the term Chronic Fatigue Syndrome as another name for M.E. ([G93.3](#)) and not as a new name for ‘**neurasthenia**’ (**Fatigue Syndrome**) It is also my experience that UK General Practitioner’s use the term chronic fatigue when referring to a troublesome symptom rather than as the name of a specific illness.

This paradoxical situation with the WHO Collaboration Centre’s Guide to Mental Health in Primary Care can only serve to mislead general practitioners, primary care workers, the public, the media. It could easily lead to irrevocable harm to sufferers whether it be with regards treatment, the obstruction of research into organic related research, difficulties with entitlement to DSS benefits especially Disability Living Allowance, complications with Insurance Policies, and could possibly affect sufferers rights or the right of parents to refuse certain medical treatments for their children.

I personally am appalled that the authors of this Guide should be seen to be allowed to play such games with words at the expense of clarity and accuracy not to mention

at the expense of vulnerable M.E and CFS sufferers. I am confident you will agree that it is wholly unacceptable for misleading information to be published and distributed by a U.K WHO Collaborating Centre to members of the medical profession.

We have been led to believe that the ME Association and Action for M.E. were unaware that CFS and ME had been included in this Guide to Mental Health in Primary Care or that Primary Care workers throughout the U.K were being informed that ME and CFS were Mental & Behavioural, Neurotic disorders (classified by the WHO as F48.0.) This compels me to ask, without accusation, if this situation was made known to either yourself or the 'Chief Medical Officer's Working Group on Chronic Fatigue Syndrome/Myalgic Encephalomyelitis.' which I believe first met in March 1999. If the answer to this is negative I would ask that you initiate rigorous enquiries to establish why. To assist I have attached a copy of the extensive list of individuals and organisations given mention in the **Acknowledgements** of this GUIDE and a copy of the stated **Mission of the WHO Collaborating Centre of the Institute of Psychiatry.**

May I mention that I have contacted the WHO Headquarters in Geneva twice and have attached a copy of their reply to my first communication. I have not as yet received a reply to my second e-mail voicing my dissatisfaction at the insufficient, incomplete nature of the amendments. Following the completion of these modifications I contacted Derek Flannery - administrator and Professor Rachel Jenkins - Director of the Collaboration Centre about my concerns but unfortunately have not as yet had the courtesy of a reply.

In summary, I respectfully put it to you that whilst ME and CFS are not officially classified as, or by any manner of means proven to be mental health disorders their inclusion within a Mental Health Guide stated to be specifically for disorders classified by the WHO as F48.0 (Mental, Behavioural & Neurotic disorders) is wholly unjustified and unacceptable.

I would therefore ask that you use whatever power is within your means and take whatever action is necessary to ensure all references to CFS and / or ME are removed from this Guide to Mental Health in Primary Care.

Due to the gravity of the misinformation published and distributed by this WHO Collaborating Centre in their WHO Guide to Mental Health in Primary Care I would ask if you would ensure, if even only as a damage limitation exercise, that the medical profession, the public, the sufferers, the media, insurance companies, the DSS and those internationally concerned are clearly informed of the correct World Health Organisation [ICD-10](#) classification for CFS and ME within your forthcoming report the 'Chief Medical Officer's Working Group on Chronic Fatigue Syndrome / Myalgic Encephalomyelitis.'

Thank you for your time and consideration on this matter and hope you will actively pursue and attain the removal of all reference to Chronic Fatigue Syndrome and ME from this 'WHO Guide to Mental Health in Primary Care.'

I look forward to your response.

Yours sincerely,

Connie Nelson

26th October 2001

Note: The WHO Guide to Mental Health in Primary Care is hosted on two websites. The links to these websites are listed below. Minor alterations to these sites has happened as a result complaints made but references to Chronic Fatigue Syndrome still exist throughout these websites.

<http://www.whoguidemhpcuk.org/>

<http://cebmh.warne.ox.ac.uk/cebmh/whoguidemhpcuk/>

Many thanks to Connie for your efforts.

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