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Open letter to the WHO

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### **Health care for people with myalgic encephalomyelitis (ME) in Sweden**

I am writing because there are huge problems in my country in all levels of care and knowledge of ME (WHO ICD-10 G93.3 – also known as CFS or ME/CFS). I hope WHO can do something to require that one of its member states does not systematically disregard one disease in the healthcare system. At the end of the letter I have attached a personal account of the situation for ME suffers in my country.

Yours sincerely,

Kasper Ezelius, Örebro, Sweden

## **Can WHO do anything to improve the situation?**

Does membership in WHO require the member country to include all the diagnosis in the WHO ICD-10 list, when performing diagnosis and treatment?

Is a country allowed to systematically disregard one entry of the ICD list?<sup>1</sup>

Is it acceptable that WHO member states do not have primary care units with knowledge about the primary symptoms and primary concerns for one ICD list entry, and do not have any specialist (when primary care does not have enough knowledge) that have up-to-date knowledge (diagnosis, treatment, clinical experience) about the disease condition?

I would wish that the medical system in my country has ME in mind when doctors perform a diagnosis. This means that:

- ME should be on the schedule in the education of new doctors (during medical university studies),
- the present medical staff would need additional training/education, and
- diagnostic and treatment guidelines are readily available to the doctors.

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<sup>1</sup> <http://www.un.org/disabilities/convention/conventionfull.shtml> - see article 25 Health

Furthermore, I wish for the medical system to work together to be able to perform an early diagnosis. ME should be suspected after, at the most, 3 months after onset and be confirmed after 6 months.

ME also strikes children. For children the time for diagnosis can be set shorter. The medical services at school and teachers should be aware of ME. They should also be aware of the special characteristics of ME among children. Usually ME expresses itself a bit differently in children.

Is it possible for the WHO to recommend their member states to use for example the Canadian diagnosis criterion<sup>2</sup> for ME?

## **Suggestions for improvement of the regional health governments in my country**

It is of fundamental importance to diagnose ME early, because it is the most important way to reduce the risk of a life-long invalidity. Patients with ME stay alive for decades, but with such limited abilities that they are mostly dead.

I would like this to happen in the health care system:

- that primary caregivers are aware and attentive about ME, and that preliminary diagnosis is made within 3 months of onset.
- that primary caregivers know the symptom-picture of ME and include it early in a differential diagnosis
- that at least one neurologist in each region of my country has special knowledge about ME
- that biomedical research is performed on ME with the objective to find a cure
- that the Canadian consensus report is used in the clinical work for diagnosis and care
- that the RNase L test is used as a complement in diagnosis, but not as a sole means because the test only detects 95% of the ME cases. Possibly some individuals can have an earlier diagnosis with an early use of the RNase L test.

## **Change proposal for WHO ICD-10**

Doctors in my country feel very uncertain how to use ICD-10 for coding a ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome) diagnosis. In the tabular list<sup>3</sup>, the term "chronic fatigue syndrome" does not exist. In the index the term "chronic fatigue syndrome" indeed exists, but it would be helpful that "chronic fatigue syndrome" is also present in the tabular list.

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<sup>2</sup> [http://www.mefmaction.net/documents/me\\_overview.pdf](http://www.mefmaction.net/documents/me_overview.pdf)

<sup>3</sup> <http://www.who.int/classifications/apps/icd/icd10online/>

The widely used term in research articles CFS (chronic fatigue syndrome) can not be found anywhere in the tabular list, which also makes doctors quite confused. The closest they can come is F48.0 "neurasthenia", which has "fatigue Syndrome" below the describing text.

The word "benign" before "myalgic encephalomyelitis" in the code of G93.3 makes them to feel insecure, as to whether it is the same thing as "myalgic encephalomyelitis".

So my proposal for a less confusing ICD-10 is:

- Add the term chronic fatigue syndrome to G93.3 in the tabular list.
- Avoid using terms, that can be confused with chronic fatigue syndrome, for other conditions. For example the terms "chronic fatigue" and "fatigue syndrome", are easily confused with chronic fatigue syndrome. (Another solution could be to make researchers stop to use chronic fatigue syndrome and skip that term altogether for G93.3, but that would probably take a lot of time and lead to a lot of confusion in the research area).
- Add the term Myalgic Encephalomyelitis to G93.3, or simply put the word "benign" in parenthesis before Myalgic Encephalomyelitis.

So my wish is to have a text in the tabular list of ICD-10 for the code of G93.3 as in the example below in italics:

*G93.3 Postviral fatigue syndrome, benign myalgic encephalomyelitis, myalgic encephalomyelitis, chronic fatigue syndrome.*

*Condition that is defined by the Canadian consensus document: "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols" (Carruthers et al, ISBN 0-7890-2207-9, year 2003).*

Would it be possible to make such an update? I think it would straighten out a lot of confusion among professionals in their clinical practice.

## Internet links

- UN Convention on the Rights of Persons with Disabilities: <http://www.un.org/disabilities/convention/conventionfull.shtml> — see article 25 Health
- An overview of the Canadian Consensus Document: [http://www.mefmaction.net/documents/me\\_overview.pdf](http://www.mefmaction.net/documents/me_overview.pdf)
- Canadian consensus document : [www.mefmaction.net/documents/journal.pdf](http://www.mefmaction.net/documents/journal.pdf) — see "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols"
- RED laboratories performs the RNase L test: <http://www.redlaboratories.be/2/index.php>

## **Situation for people that suffer from ME/CFS in my country**

I live in Sweden and I have discovered that almost no doctor knows about ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome). This causes people that have acquired this devastating disease to go around for years with a disease that impacts their life in a profound manner without knowing what causes them to be handicapped. Many people aggravate their ME disease during this time because they do not know what it is and because the doctor does not know what it is. Some doctors prescribe anti-depressive medication, but this can aggravate ME because of the toxic load. Many ME patients do not tolerate alcohol, chemicals and medication well. ME can also be aggravated by stress. If the onset of anti-depressive medicine causes the patient to have anxiety for a few days, then the body will be in a state of emergency and the ME patient will not be able to sleep for 72 hours, then it is likely that the ME disease will be aggravated permanently.

Many patients are not believed about their disease. Many patients are classified as hysteric, hypochondriac, psychosomatic, tired from not being at work, depressed, phobic, anxious or with a personality disorder. ME is also confused with burn-out.

Patients in Sweden try to make their doctor read "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols" (Carruthers et al, ISBN 0-7890-2207-9, year 2003, [www.mefmaction.net/documents/journal.pdf](http://www.mefmaction.net/documents/journal.pdf)), but doctors refuse to learn anything about the disease. So patients end up trying to treat themselves. The doctors do not understand that they should be careful with medication. The doctors do not know how to interpret their patient's descriptions of symptoms. Because they know nothing about the characteristics of ME, they interpret them as being psychological. Patients quickly learn to be very careful when explaining things because things can very easily be interpreted in the wrong way by a person without any knowledge of the ME symptom complex.

For example, doctors may say: "Now, the summer is coming and then there is more light so things will feel better". This is probably relevant to a depressed person, but for an ME person it might be the opposite! Many ME patients are intolerant to heat or cold! So the summer with high temperatures may very well be unbearable to an ME person. If you tell the doctors that you sleep all the time because of the anti-depressive medication, they do not react. They simply think you are still depressed and need stronger medication. But in fact many (most) ME patients are intolerant of medication and have to be monitored very carefully when receiving medication so their ME symptoms will not get worse.

Some patients develop problems with social insurance coverage because the doctors simply do not know enough about ME. Many doctors say they have not found anything wrong so the patients can go back to work. Some patients end up without social insurance coverage and have to sign up to search for a job in order to get unemployment aid.

Doctors violate ME patients when they do not believe that the patient is severely disabled by this disease. It is a form of violation to be disbelieved. I think a person normally feels dishonoured when somebody disbelieves him. Instead of giving a person with ME credit for doing such a good job in struggling with her disease, doctors violate patients by, for example, saying: "I think you are only tired because you do not work anymore. I will end your sick leave so you will get back on your feet again." It would be great progress if the doctors would support the patients instead in order to keep the ME patients self-esteem high in spite of a severely disabling illness.

The history could be very long for how ME patients have been treated by the medical system. I believe that some people that do not know they have ME, and get treated in a maladapted manner may commit suicide. If a doctor says "there is nothing wrong with you. You have only become so tired because you do not work any more", a person with ME may believe it and feel totally worthless because he has "sunken so deep". The patient may feel it is all his own fault that he has sunken so deep, that he let himself to get pulled down and that he did not fight back enough. He may feel he is not able to struggle back to the surface again. He blames himself. He gets depressed. He becomes anxious because he "realizes" he has dug his own pit. This can really happen. It happens all the time according to the ME patients I have contact with. The details of the story change from person from person, but it is basically always the same.

It is quite common for ME persons to be left by their partners. Of course! Who would like to be with someone that is not well enough to have a normal relation? Without energy to speak at times. Bedridden most of the time. Unable to care for the most basic household duties such as cleaning, making or buying food. In some cases, ME persons are even disbelieved by their own families (parents, brothers and sisters). Very sad stories exist where people have been disbelieved by the medical system and in addition have been excluded by their families. If one adds this on top of the fact that a person does not have knowledge about what kind of disease she is suffering from, then one has a very bad cocktail. A person unable to care for oneself due to the disabilities from ME, excluded from any help or support, and in addition accused from all sides of being a malingerer. The person may in fact end up believing that she is worthless, because she does not understand that she is actually struck by a severe illness.

Here in Sweden the medical system is, to a very high degree, in hands of the state (public). There exists no public unit for diagnosis and care of ME patients. All there is, is a private clinic in Gothenburg that gives a diagnosis and does research on a vaccine treatment for ME patients. They do not take patients from the whole country for care. Not even the capital, Stockholm, has a unit for ME patients.

The medical system in Sweden should have primary care doctors that know enough about ME that they can recognize it in a patient with typical ME symptoms. We also need ME specialists at the regional level (landsting) as most ME patients can not travel very far.

I think it is a human right to have a medical system that does not exclude any disease when making a diagnosis. Any patient attending a medical unit expects that he will be evaluated for all possible diseases when going to a doctor. He does not expect that some disease will be excluded. In Sweden this is a fact. The medical system systematically excludes ME as a possible diagnosis, but the patients are not informed of this. People with several years of post-exertional fatigue, should of course have ME considered when making a diagnosis! In fact, ME should be considered much earlier if one would like to increase the probability that the patient can return to health, to decrease the risk of aggravation and to decrease human suffering. By understanding the disease, the patient is able to use self-help strategies. If the doctor knows it can be ME, he can avoid treatments that may aggravate the disease.