Communication from the Countess of Mar
9 April 2018

Forward-ME would like to clarify its position on proposed changes to the ICD that will affect ME patients, including “bodily distress disorder” in the general ICD, and “bodily stress syndrome” in the ICD for primary care.

Before we go any further, I would gently remind people why I formed Forward-ME nearly ten years ago. My purpose was to establish an organisation under an independent Chairman which can work together for the common good, and I believe that our overall aim is why we have made progress.

I hope that the following analysis will explain our current understanding of this situation and that you will feel able to endorse the joint conclusion we came to.

Summary of key points

- There are two versions of the International Classification of Diseases (ICD), the standard international diagnostic tool published by the World Health Organisation: the general ICD, and the primary care ICD.

- The general ICD may be revised to replace the “somatoform disorders” with a new category, “bodily distress disorder” (BDD). We have previously set out our concerns about this.

- The primary care ICD may be revised to replace the “medically unexplained symptoms” (MUS) with a new category, “bodily stress syndrome” (BSS).

- Our current understanding is that BSS would be set up in such a way that it does not allow doctors to conclude that ME is a biological disease. Instead, it ensures that ME patients will be captured with a psychiatric diagnosis.

- If BSS is included in the next revision of the ICD, this would override any guidance, including the UK guideline published by the National Institute of Health and Care Excellence, that recognises ME as a biological disease. This could have serious implications for treatment and symptom management.

- We understand that the news about BSS is a worrying development, but it is essential that we understand the situation in as much detail as possible before moving forward, and Forward-ME will keep the M.E. community updated as soon as it has learnt more by engaging with the WHO in the appropriate way.

Further information

Bodily distress disorder

First, we would like to acknowledge the excellent work that has been done by advocates to clarify the implications of "bodily distress disorder" (BDD), the new diagnosis that's been recommended to replace "somatoform disorders" in ICD-11. Their hard work has facilitated understanding of this construct by sharing their detailed research with the M.E. community.

We recognise that BDD is problematic for ME, because it gives physicians the latitude to conclude that ME patients are suffering from a psychiatric condition.

Second, we would like to clarify that we are concerned about the new diagnosis that's been recommended to replace "medically unexplained symptoms" (MUS) in the primary care version of the new ICD, called "bodily stress syndrome" (BSS).

How BDD is different from BSS

BDD is threatening because it allows physicians to diagnose ME as a psychiatric condition. However, if a physician or a national health system were to conclude that ME is a biological disease, BDD criteria would not conflict with that conclusion. While BDD does give physicians the freedom to construe ME as psychiatric, there is nothing in BDD criteria that actually *demands* that they do so.

BSS is more threatening because *it does make that demand*. Symptom cluster criteria were specifically designed to capture ME patients and route their care through psychiatry. If a physician or national health system were to conclude that ME is a biological disease, that conclusion would conflict with physicians' directives for BSS. This is a serious problem. Symptom cluster criteria do not allow physicians to conclude that ME is a biological disease. They ensure that ME patients will be captured with a psychiatric diagnosis.

Will the new Primary Care ICD be used?

The current ICD for primary care (called ICD-10-PHC) is mostly an abridged version of the general ICD, with limited use.

For many years, however, the WHO has been developing a more substantial ICD for primary care. Most importantly, they have developed a manual for mental health disorders in primary care that has its own unique diagnostic constructs and criteria, many of which are designed to cut expenditures for national health systems. It seems unlikely that the WHO would have spent so much time and money on this endeavour if they did not imagine that the new primary care

mental health manual would have widespread use. Research suggests that this is its intent.

It is also important to note that BSS has been developed to replace “medically unexplained symptoms” (MUS). Back in 2013, the DSM-5 recommended that the term MUS should be retired, but many countries, such as the UK, continue to rely heavily on the term. When the new mental health manual for primary care is published, it will communicate to the world that global leaders in psychiatry have fully retired the term MUS.

Regardless of which countries make use of the primary care ICD, researchers across the globe will no longer be able to use the construct of MUS. Health care systems too will be pressed to accept that psychiatry has rejected the term MUS. It is hard to imagine how researchers or health systems could develop an alternative to the replacement that’s been recommended by world leaders in psychiatry, that is, BSS.

In the UK we have not just maintained use of the term MUS. There have been national programmes developed around long-term plans for managing MUS. The Improving Access to Psychological Therapies (IAPT) programme, for example, aims to develop psychiatric care within the primary care setting for patients with MUS, with the understanding that ME patients should be diagnosed with MUS.

When the new ICD for primary care establishes that the term MUS is no longer in use, the IAPT programme will have to choose another term, and it is hard to imagine them developing a construct of their own rather than adopting the recommendation of global authorities in mental health.

On this point, we note that symptom cluster criteria were originally developed to implement the idea of Wessely, Nimnuan and Sharpe, in 1999, that functional somatic syndromes are an “artefact of specialisation”. There are very strong ties, in other words, between symptom cluster criteria and the UK professionals who developed PACE and the current NICE guideline.

Our goals

For these reasons, Forward-ME has taken a strong stand against the recommendation to include symptom cluster criteria with Bodily Stress Syndrome in the new ICD for primary care. We feel it is very important for the ME community to present a clear, unified objection to any criteria in ICD-11 that will ensure physicians diagnose ME as a psychiatric condition.

We are not happy with BDD criteria in the general ICD, but we do see that if NICE were to recognise ME as a biological disease, BDD criteria would not stand in the way of that recommendation. If the symptom cluster criteria were to be

implemented, however, they would directly conflict with a NICE guideline that might see ME as a biological disease. Because symptom cluster criteria would be recommended for use in primary care, we are concerned that, in practice, those criteria would override a NICE guideline that would recognise ME as a biological disease.

We recognise that this is an extremely complex issue. Because the *core criteria* for BSS in primary care (based on BDD in the general ICD) do not *demand* that a GP labels ME as psychiatric, we would encourage a general objection to the addition of *symptom cluster criteria* to the construct of BSS in primary care: it is these which do not allow physicians to construe ME as biological. Unity on this difficult issue would be appreciated.

Next steps

We know from experience that a carefully considered, strategic approach is the only effective way to engage with decision-makers at this level. Forward-ME is now undertaking work to clarify the situation, by engaging with the WHO in an appropriate way.

Forward-ME's member charities and I will discuss forthcoming information arising from this when we next meet on 1 May, and agree next steps.

We understand that the news about BSS is a worrying development, but it is essential that we understand the situation in as much detail as possible before moving forward.

The WHO has very clearly defined parameters for how it engages with stakeholders, and any approaches outside of this are likely to be ineffective, if not counter-productive.

For this reason, I ask you to be patient, and not undertake any action, especially letter writing and petitions just yet. With the support of Forward-ME's member charities, I will share an update as soon as it is feasible to do so.

In the meantime, if you have any questions or comments, please email info@forward-me.org.uk. The group will endeavour to respond as soon as we are can.

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