

As a nurse specialist in anesthesiology as well as suffering from ME myself I would like to give my comments to the P2P draft report

1. PEM, not fatigue, is the cardinal symptom of ME

The term 'fatigue' is confusing and misleading and does not describe the symptoms of ME. Focusing on fatigue alone may identify some ME cases, but mainly include patients of other diseases in which fatigue dominates.

The professional organization IACFS/ME (International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis) says this:

"The key feature of the syndrome, post-exertional malaise, is the exacerbation of symptoms following minimal physical or mental activity, which can persist for hours, days or even weeks."

By recognizing PEM as the cardinal symptom, we can improve both the research field and clinical care for ME patients.

2. Definitions

You recognize that multiple case definitions for ME/CFS has been a problem, and your recommendation that the Oxford definition should be retired is welcoming news. I think the Fukuda definition should be retired too, given that a person could qualify under Fukuda without having the cardinal symptoms of ME, but actually has an medically unexplained fatigue, or CFS.

This is why we should separate the name ME from CFS. And this is why we should use either the CCC or the ICC criteria in both the research field and clinical care for ME patients.

Thank you for your work.

Kind regards,
Annette Ståhlstrøm