



European ME Alliance, Sønder Alle 5, st 3, 9500 Hobro, Denmark

Email: info@euro-me.org

web: www.euro-me.org

The European ME Alliance consists of 11 European national charities/non profit organisations campaigning for better diagnosis and understanding of myalgic encephalomyelitis (ME or ME/CFS) as defined by WHO-ICD-10-G93.3.

Even though we are not mental health professionals or represent people with mental health disorders we feel it important to comment on the draft proposal of DSM-V and its Complex Somatic Symptom Disorders proposal.

This response should be seen against the backdrop of the devastation caused by the misinformation within the medical profession regarding ME/CFS and the promotion of false perceptions about the disease to the public, healthcare authorities and government.

It is of paramount importance that the American Psychiatric Association are aware of the dangers inherent in establishing incorrect categories of disorders which are based on poor science, vested interests or which do not serve the patients. It is the patients who must surely be the priority in all healthcare provision.

We are especially concerned about the criteria described in the new category of Complex Somatic Symptom Disorder which seems to imply that anyone who has a chronic or incurable illness with somatic symptoms and 'misattributes' their symptoms could be given this label.

Who decides when someone misattributes their pain or fatigue?

How are these symptoms measured?

How long and vigorously is a patient allowed to complain about their symptoms before a doctor can decide to investigate further and determine if a headache is a brain tumour or irritable bowel syndrome colon cancer?

In the CSSD Criteria B there are terms used which are subjective and not measurable – such as "health concerns" and "catastrophising".

Based on our collective experiences with the treatment of an organic illness such as ME/CFS - experiences across Europe - our concern is that there is a great danger of mis- or missed diagnoses when looking at this category and its proposed diagnostic criteria.

The criteria are very vague and allow too much subjectivity.

In fact, ME/CFS could mistakenly be placed in this category if one were to ignore, or be unaware of, the huge volume of biomedical research and evidence which shows it to be an organic illness and if one were to use only the broad CSSD criteria to diagnose.

Such an action would be a major and costly mistake and would not serve the patients or the healthcare communities.



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In our experience specialist ME/CFS clinics get as many as 40 % of patients referred with a ME/CFS diagnosis who turn out to have other very serious and sometimes fatal illnesses.

The patients we are concerned with suffer from myalgic encephalomyelitis which is a neurological disease. Yet all too often these patients are being treated as if they had a somatoform illness.

Parents of children with ME/CFS are restricted in visiting their severely ill children in hospital or worse still the children are taken away from their families as the healthcare professional believes it is the family that is keeping the child ill by having 'wrong illness beliefs'.

Severely ill grown ups with this disease are denied normal medical care and threatened with being placed in mental hospitals if they are too ill to care for themselves and ask for help.

This not only sets patient against healthcare professional but also is a waste of resources and of lives.

A broad unspecific category such as the proposed Complex Somatic Symptom Disorder does not help patients who need an honest and clear diagnosis.

Any illness lacking a diagnostic test is in danger of being put into this non specific category which helps no one.

We hope and request that the APA listens to patients and avoids creating a category of mental illness that is meaningless.

Yours Sincerely,

The Chairman, Board and Members of the European ME Alliance
www.euro-me.org