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The European ME Alliance was established in 2008 and consists of 11 European national charities/non profit organisations campaigning for better diagnosis and understanding of myalgic encephalomyelitis (ME or ME/CFS - also referred to in some countries as CFS) as defined by WHO-ICD-10-G93.3. These countries are Belgium, Denmark, Germany, Holland, Ireland, Italy, Norway, Spain, Sweden, Switzerland and UK,

The Alison Hunter Memorial Foundation was established in 1998 through the initiative of the Public Interest Advocacy Centre, Sydney. The Foundation has a primary interest in the medical, legal and social needs of people with ME and the clinical documentation of severity.

This letter represents both organisations.

We have previously commented on the DSM-V revisions in June 2011. Our views have not changed since and we feel the proposed amendments to DSM-V now will make it even easier for people to be diagnosed with Somatic Symptom Disorders alone or the suggested DSM-V Somatic Symptom Disorders can now be added to almost any disease as an additional diagnosis. The amendments which have now been suggested make the APA suggestions even more divorced from reality and from any sense that they are really serving patients' needs.

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 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 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 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 SSD 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 - experiences across Europe and Australia - 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.

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Supporting patients with ME (Myalgic Encephalomyelitis) and CFS (Chronic Fatigue Syndrome) in Europe



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In fact, ME 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 SSD criteria to diagnose.

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

In our experience specialist ME clinics get as many as 40 % of patients referred with a ME diagnosis who turn out to have been misdiagnosed.

The patients we are concerned with suffer from myalgic encephalomyelitis and chronic fatigue syndrome 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 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 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 European ME Alliance

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Alison Hunter Memorial Foundation

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