

25% ME Group & Stonebird Submission re: DSM-V and ME/CFS

Greg Crowhurst July 12th 2011

(This joint submission is being made further to the previous submission by the 25% ME Group on 20th March 2010 re: DSM-V and ME/CFS)

“The PACE trial paper refers to chronic fatigue syndrome (CFS) which is operationally defined; it does not purport to be studying CFS/ME”.

Professor Peter White, response to Professor Malcolm Hooper. <http://www.meactionuk.org.uk/Hoopers-initial-response-to-PDW-letter.htm>

Executive Summary:

The inappropriate involvement of psychiatry, particularly the Wessely School, in ME in the UK, promoting a psychosocial agenda and even denying the definition and existence of ME as a neurological disease, would make it wrong for the DSM to validate CSSD and SSSD, until such time as ME is properly recognised as a neurological disease with the development of proper biomedical ME pathways and treatments established, to safe guard this extremely vulnerable group.

Because of the disregard, shown by the Wessely School of the WHO classification of ME as a neurological disease and its alternative term, CFS, patients with Myalgic Encephalomyelitis currently have no safe pathways through the UK Health Service.

They are likely to be quite wrongly treated as if they have a mental health disorder.

Because the specific elements of DSM5 are so closely linked to the way ME can be wrongly described by the Wessley school and because the term CFS has been widely adopted in the UK to mean ME, a neurological disease, and because CFS has been deliberately called a mental health disorder by the Wessley school, patients with an assessment of CFS have been wrongly exposed to psychiatric treatments and interpretations.

If the DSM validates CSSD and SSSD then patients with a current CFS diagnosis in the UK will be further wronged by potentially changing this diagnosis to these newly created somatoform categories. And a person with ME is in great danger of being shifted from an appropriate neurological disease categorization to a legitimate - but made up - category of mental health.

Because ME is currently so open to mental health misinterpretation, it would make it even more likely that people with ME will be mistreated; the DSM will have inadvertently given greater permission and validation for this to happen.

CSSD and SSD, the Simple and Complex Somatic Symptom Disorder categories, must not be given formal legitimacy, because they are profoundly unsafe for people with ME.

1.Introduction

The 25% ME Group for the Severely Affected is a registered UK charity representing people who are profoundly disabled by Myalgic Encephalomyelitis (ME). Stonebird is a website dedicated to raising awareness of the lived experience of Severe Myalgic Encephalomyelitis. This is our first joint submission.

The *Diagnostic and Statistical Manual of Mental Disorders* (DSM), strives to create an empirically sound source of diagnostic information on which clinicians can rely to plan treatments and predict outcome. We note that "*the formation of classes of disorders and the putative disorders within those classes are developed primarily by committee in the DSM.*"Pileki et al (2011).

Given how essential it is then, to identify non-theoretical or non-scientific biases that may be corrupting the way that the DSM conceptualises mental illness; we are greatly concerned about the involvement in the DSM-V Somatic Symptom Disorder Work Group of Professor Michael Sharpe, a member of the "Wessely School" (Hansard; Lords, 9th December 1998:1013) and Francis Creed, because according to existing evidence, they intend to ensure that ME, which is misnamed "CFS/ME" by the Wessely School, will fall within the purview of the new category of CSSD, because they wrongly assert that ME is a functional somatic syndrome (ie. a mental disorder) (cf Hooper and Williams 2010)ⁱ

2.The damaging influence of the Wessely School in the UK

For many years, the Wessely School, which has immense influence over Government policy, has been aggressively promoting a conceptualization of Myalgic Encephalomyelitis as a mental illness, a conceptualization that also fits the needs of the medical insurance industry (cf. Pileki et al 2011).

ME patients, they assert, complain of physical symptoms that do not result from underlying physical disease but are the consequence of abnormal illness beliefs, and those abnormal beliefs are responsible for the perpetuation of their perceived disability). (cf Hooper and Williams 2010)ⁱⁱ

The involvement of the medical and permanent health insurance industry, who have a vested interest in ensuring that ME is regarded as a mental health disorder, to enable it to be excluded from insurance coverⁱⁱⁱ has been repeatedly raised in the House of Commons, including the 2006 Report of the Gibson Inquiry and Members of the Scottish Parliament have written to Allied Dunbar about their concerns over Michael Sharpe's suitability to give an unbiased view when assessing people with ME; Sharpe has asked MSPs to withdraw their statements to Allied Dunbar about him.^{iv}

For almost two decades , the Wessely School , despite the failure of scientific research to reveal any specific biological marker for any psychiatric diagnostic category, has dismissed the international biomedical evidence, over 5000 published papers, that ME is an organic (not psychiatric) disorder through :

- i. their repeated failure to distinguish between "chronic fatigue" , a mental health disorder and ME, a neurological disease that affects multiple systems of the body.
- ii. their demonstrable bias that has resulted in the deliberate suppression of the biomedical evidence on ME by UK medical journals, these include: population choice bias; severity of illness bias (patients with a mild form of an illness may not respond in the same way as those with a more severe form); comparison choice; outcome choice bias; withdrawal bias; bias introduced by inappropriate handling of withdrawals, drop-outs and protocol violations; missing data bias; publication bias; moral bias; values bias; printed word bias (when a study is overrated because of undue confidence); prominent author bias (when the results of studies published by prominent authors are overrated, including esteemed author bias and esteemed professor bias); multicentre collaborative trials (when the results are overrated); vested interest bias; cherished belief bias and empiricism bias ^v
- iii. their selective manipulation of others' published papers (by claiming other authors' findings support their own view when such is not the case)
- iv. their unscrupulous determination to "eradicate" ME by asserting that it is nothing more than an "aberrant illness belief" and their tactics of denial (for referenced evidence and illustrations of such tactics of denial, see "The Mental Health Movement: Persecution of Patients" available online at http://www.meactionuk.org.uk/SELECT_CTTEE_FINAL_VERSION.htm and "Consideration of Some Issues Relating to the Published Views of Psychiatrists of the 'Wessely School' in relation to their belief about the nature, cause and treatment of ME" at <http://www.meactionuk.org.uk/consideration.htm>
- v. their focusing on the single symptom of chronic "fatigue" in ME and ignoring of other significant symptoms and signs, especially cardiovascular, neurological and immunological .
- vi. their deliberate dilution of the case description to include any "medically unexplained" fatigue, ie. their obfuscation of the case definition so that it specifically includes somatisation disorders (which instantly greatly increases the numbers of patients with an alleged diagnosis of "CFS/ME" who can be coerced into enrolling in the Wessely School management regime); if those with ME are physically unable to continue and have no option but to withdraw from these regimes, they immediately risk losing their State benefits and their medical insurance payments)
- vii. their advice to Government that no tests should be performed on those with ME to confirm the diagnosis (other than the most basic screening, which is universally known to be normal in ME and will not show up the complex dysfunction. These need highly specific ME tests and scans.)
- viii. their advice to Government that the reported biomedical abnormalities "should not deflect the clinician from the biopsychosocial approach and should not focus attention towards a search for an 'organic' cause" (*ref: Joint Royal Colleges' Report on CFS, CR54, 1996*)
- ix. their influence and functioning in areas of medicine in which they have no expertise: as psychiatrists, it follows that areas of complex medical science such as immunology, vascular biology and muscle pathology which underpin ME are not within their remit of expertise.

A direct comparison can be made between the situation of UK ME Patients and that of the women who were persecuted under the 1486 treatise entitled *The Malleus Maleficarum* (The Hammer Against Witches), written to assist in the detection and persecution of witches; it is important to note how both situations arise out of a fantasy story promulgated by those in power.

Dr John Soboro (2010) ^{vi} comments, "*The DSM as a scientific text and almost every diagnosis found within it suffer from the same sort of problem as the concept of someone actually being a witch: Validity*".

If you see ME patients, based upon their number of "medically unexplained symptoms", as having a somatoform disorder, you have a method of identification which is 100% reliable, in the context of the fantasy – but not in the real world; it is a relative view which perpetuates as an absolute view. It is simply not anchored in truth.

We believe that the Wessely School are engaged in a deliberate campaign to negate ME all together; the extraordinary revelations of the recent PACE Trial appear to confirm this.

3. The failure to operationally define ME

In a letter to the Lancet, Professor Peter White, the Lead Investigator, stated that "***The PACE trial paper refers to chronic fatigue syndrome (CFS) which is operationally defined; it does not purport to be studying CFS/ME***".

What can be inferred from a major study, supposedly for ME, yet excluding it, only "operationally" defining "CFS" patients for the study? Why was "ME" not operationally defined? Could it be because the intention to negate ME, as a physical disease, has always been the Wessely School's intention?

Myalgic Encephalomyelitis (ME), has been classified by the World Health Organisation (WHO) as a neurological disorder since 1969. Currently it is listed in the International Classification of Diseases (ICD), chapter 6, under Disorders of Brain at ICD-10 G 93.3. In the 1992 revision of the ICD, the WHO approved the term "Chronic Fatigue Syndrome" (CFS) as a term by which ME may be known. The term CFS is coded only to ME at ICD-10 G93.3, hence the composite term "ME/CFS" is often used to denote the disorder. A synonymous term also sanctioned by the WHO is "postviral fatigue syndrome".

The WHO by affirming the CFS label, have inadvertently given the Wessely School the power to misuse the name CFS, which the Wessely School have wrongly equated with Chronic Fatigue, coded at Section F48 - a mental health section, confusing practitioners specifically in the UK into thinking that CFS and therefore ME, by association, is a mental health condition, rather than the serious disease that it actually is.

It is this shifting of the use of the name into the mental health field that has caused such havoc in the lives of genuinely physically ill ME patients.

In this light, when the WHO term "CFS" is used it can be considered another name for ME, but when the Wessely School use the term CFS they mean something completely different, they mean a mental health disorder, which has no business being equated with ME. This is how the confusion has arisen and where the danger lies in validating CSSD.

The PACE Trial by its failure to operationally define "CFS/ME" – defining only "CFS", has, in effect, negated ME; apparently deliberately, rather than scientifically, making it "unexplained".

4. The deliberate ambiguity of the term CFS

Because the boundaries have been moved and two separate conditions, one physical and one mental health, have been wrongly equated under the same name, there needs to be a formal separation and respect for "ME" and psychiatrically-labelled "CFS". Until this difference is clarified and medically honoured, people with ME will continue to be misinterpreted, misrepresented and abused by the psychosocial method.

To do that, you have to accurately define "ME" and "CFS"; which the Wessely School of psychiatrists refuses to do, presumably because of their apparent agenda to reclassify ME, a neurological disease, as a mental health issue – ultimately as CSSD, which appears to be at least a seven step process :

1. First they changed the name to CFS.
2. Then they mislabelled CFS as a mental health condition, as opposed to the intention of the WHO for CFS to be another name for ME, a physical, neurological disease.
3. Having empirically changed the meaning of CFS they saw ME patients under the guise of the CFS label, which then had dual interpretation of either a physical disease or a mental health disease.
4. Then they denied access to proper testing, by not advising and by actively proscribing the tests that will show up the physical dysfunction in ME and moved the treatment of ME into a mental health, therapy-led framework, denying patient's physical, underlying disease process.
5. Then, as the PACE Trial so extraordinarily shows, they chose not to formally define the disease "ME", in the biggest ever government funded research programme, that was supposed to be for "CFS/ME".
6. They used the PACE Trial to validate their Oxford Criteria as an operational definition of CFS, to give it more authenticity.
7. Finally, using only the term CFS but working, as Sharpe and Creed appear to be doing, they are now seeking to have CFS formally defined as CSSD; ultimately a clever way of invalidating a WHO classified neurological disease, by deliberate exclusion and formally categorising a complete fantasy.

The PACE Trial has made ME not only medically unexplained, but also medically undefined; a steep slippery slope, away from the truth, with dire implications. This is very serious.

If the DSM validates CSSD somatisation criteria for CFS in the UK, it endangers patients with ME who are being wrongly labelled as having CFS and already being wrongly treated, under the psychosocial model by CBT and GET; fulfilling the Wessely School mission, but bringing about profound suffering, denying patients access to proper biomedical care.

The Wessely School's strategy seems to be to ultimately negate ME as a genuine disease through a deliberate policy of exclusion, characterised, as the PACE Trial shows, by a refusal to define the disease.

ME is easily defined by the Canadian Criteria, however because the Wessely School, which exercises such extraordinary international influence, does not accept the Canadian Criteria, they do not give people with ME anywhere else to go, because they have already taken over the ME Clinics in the UK; offering inappropriate treatments, which are causing harm or just simply excluding people with ME, through the Oxford Criteria, while pretending to offer an ME service. It is not hard to see where the Wessely School is heading with CFS.

5. Conclusion

While the term "CFS" is used instead of clearly identifying who has neurological ME and who has psychiatric fatigue and who has an undiagnosed illness or who has Post Viral Fatigue, then it is dangerous for the DSM to uncritically allow Wessely School psychiatrists to label patients' illness as "undefined" .

People with ME desperately want to be separated from CFS, but not to be excluded from existence under a tragically wrong CSSD label. It is fine to get rid of the hopelessly ambiguous term CFS, as long as ME is formally acknowledged as a neurological disease and the people who are currently labelled as having CFS are properly tested and diagnosed using the Canadian Criteria and appropriate medical services are set up to meet their physical needs.

Until this happens it is not safe to validate CSSD or SSSD because people with ME are already wrongly included in the term CFS. CFS will then be presumably placed and validated totally as a mental health disorder and people with ME will have been utterly wronged and caught in the middle; misdiagnosis and mistreatment is already happening but will be awarded, by the DSM, formal justification.

The Wessely School have so compromised the current situation, that it would be utterly wrong to consolidate their power base until this issue is resolved, fairly, adequately, and honestly, with biomedical integrity and they are held to account.

Appendix

Complex Somatic Symptom Disorder

(From the perspective of a Severe ME patient)

To meet criteria for CSSD, criteria A, B, and C are necessary.

Without adequate biomedical testing being available for people with ME, these criteria are not justifiable or safe.

The symptoms of ME are absolutely physically debilitating and impact your daily living from moment to moment. This can be so easily misinterpreted as a “preoccupation” with your symptoms if you do not believe in a physical cause for ME.

There is no safe diagnosis process currently for people with ME, because of the direct influence of the psychosocial lobby . All these CSSD Criteria will do is give them more power and authority to misinterpret ME and endanger people’s lives.

A. Somatic symptoms:

One or more somatic symptoms that are distressing and/or result in significant disruption in daily life.

B. Excessive thoughts, feelings, and behaviours related to these somatic symptoms or associated health concerns:

At least two of the following are required to meet this criterion:

(1) High level of health-related anxiety.

The informed patient has much to be concerned about, which could be misinterpreted as anxiety, given the psychiatric mistreatment that already exists within the current system.

The uninformed or unaware patient will approach the health system expecting to be treated with respect, to be given the appropriate biomedical tests and an accurate diagnosis. As the system continues to fundamentally fail them, it would not be surprising if a person became genuinely and reasonably anxious, for justifiable reasons.

Without a much needed biomedical pathway; the more likely a person could be perceived as fitting these vague CSSD criteria, because they little or no medical proof of their illness.

If you have neurological ME, it would be reasonable to have some level of anxiety about how the system might abuse you where:

- **doctors can already choose whether they believe ME is a physical disease or a mental health disorder,**
- **a range of diagnostic criteria are used, including the extremely vague and inappropriate Oxford Criteria,**
- **ME is already perceived, quite wrongly, to be a Fatigue condition rather than a neurological disease**
- **the biomedical tests and treatments needed, to prove the physical dysfunction, are proscribed by NICE and more specific tests are not available on the NHS**

While this ambiguity of definition and interpretation of ME symptoms exists, it would be wrong to give psychiatrists more power to misdiagnose ME, under Somatisation Disorder.

Anyone would be understandably anxious in a situation where they are not being treated properly or biomedically.

(2) Disproportionate and persistent concerns about the medical seriousness of one's symptoms.

When your physical health is impacting upon every aspect of your life, yet you are being denied tests, treatments, respect, validity, to prove you are physically ill, as is the case with ME, then you could easily be misinterpreted as having “*disproportionate and persistent concerns about the medical seriousness of one's symptoms*”.

You will have persistent concerns all the time your symptoms go unrecognised and untreated and yet continue to disable you, for decades on end. This situation does not justify a mental health label; this criterion is ridiculous within the current context of ME. In ME this would not be a symptom of mental health dysfunction but of the system dysfunction that fails to recognise and treat ME honourably.

Given there is so much misinformation in the medical world, about ME, these criteria are dangerously open to the beliefs of the person making the assessment; it is a lottery dependent solely on the beliefs underpinning the views of the assessor as to how they will interpret ME. This is unacceptable.

If you have Myalgic Encephalomyelitis, then you have a serious disease with symptoms that are currently negated, neglected and denied because of the influence of the psychiatric lobby and are not tested for adequately, using appropriate, specific biomedical ME tests.

To only use these categories, to give a somatoform diagnosis is at best naïve and at worst a deliberate attempt to further mistreat people with ME.

(3) Excessive time and energy devoted to these symptoms or health concerns.*

A person with a physical illness which is chronic and disabling, which is denied its truth, which is covered up by a blanket of psychiatric fatigue and where the first-line treatment offered is therapy described as treatment, could so easily be wrongly interpreted as having CSSD.

While it remains optional, whether you view ME as a psychiatric disorder or a physical disease, people with ME will be exposed to a great danger of being wrongly diagnosed and having their human rights infringed. If these criteria are validated by the DSM and are allowed to become a standard interpretation of ME symptoms, the wrong interpretation of ME as a psychiatric disorder will be further consolidated.

- C. Chronicity: Although any one symptom may not be continuously present, the state of being symptomatic is chronic (at least 6 months).**

In ME symptoms are not necessarily continuously present and may vary in degree and severity, making this category particularly dangerous and open to misinterpretation, for the person with ME.

Linking CSSD with six months chronicity is a great concern, because that happens to be the exact amount of time one needs to be ill, to receive an ME diagnosis highlighting yet again the dangers for people with ME and the risk of misinterpretation, which would be enhanced if this somatoform disorder is allowed to be validated.

Given the dearth of biomedical consultants, with biomedical ME specialism in the UK this categorization makes the diagnosis of ME, a neurological disease, as even less likely in the future and endangers people with ME from receiving a fair and adequate health service.

For patients who fulfill the CSSD criteria, the following optional specifiers may be applied to a diagnosis of CSSD where one of the following dominates the clinical presentation:

XXX.1 Predominant somatic complaints (previously, somatization disorder)

The Wessely School, quite wrongly, considers ME to be a somatoform disorder, despite ME being a WHO classified, physical neurological disease, with multi-system dysfunction.

Anyone who has ME in the UK, who sees a Wessely School –influenced clinician or therapist, is likely to be given a mental health label, therefore this criteria is extremely concerning; it raises the question of how CSSD can be safely applied to anybody and how the DSM can ensure that patients with ME are not misdiagnosed and mistreated.

XXX.2 Predominant health anxiety (previously, hypochondriasis). If patients present solely with health-related anxiety with minimal somatic symptoms, they may be more appropriately diagnosed as having Illness Anxiety Disorder.

Without proper physical testing, alongside the powerful influence of the psychiatric lobby in the way ME can be regarded and treated as a mental health disorder, associated with wrong thought belief, this criteria gives greater validation and power to those misinterpreting patients with ME, as having an anxiety disorder.

Without the safeguard of proper biomedical ME tests and treatments, separating ME from Chronic Fatigue states, people with ME are in danger of being psychiatrically abused, with the blessing of the DSM.

XXX.3 Predominant Pain (previously pain disorder). This classification is reserved for individuals presenting predominantly with pain complaints who also have many of the features described under criterion B. Patients with other presentations of pain may better fit other psychiatric diagnoses such as adjustment disorder or psychological factors affecting a medical condition.

The psychiatric view in CSSD appears to be that certain physical pain is not valid, unless medically explained; “medically unexplained” is open to interpretation.

In ME, there is complex system dysfunction and patients experience severe levels of pain that in many people is completely uncontrollable by current pain medication.

Patients are often too drug sensitive to tolerate the drugs themselves and may experience drastic side-effects, as a result of their multi-system dysfunction. However, without satisfactory biomedical testing and practices in the UK, patients with ME have little or no medical proof of the cause of their pain.

This does not mean their pain is not real, this does not mean it is not physically caused, it does not mean it is a psychological, it does not mean it is caused by wrong thoughts and beliefs; it means the NHS and the Government have not undertaken the commitment required to develop new tests and treatments based on proper and adequate biomedical research.

This leaves the door wide open, wrongly and frighteningly for the Wessely School of psychiatry to enter and use these bizarre and vague somatoform criteria to assert that the person has a somatic disorder, rather than the physical disease they actually have.

Given the disrespect shown to the WHO classification of both ME and CFS as neurological by the Wessely School alongside their refusal to even operationally define ME, then anyone with genuine ME, who is referred by a unaware physician to a psychosocial psychiatrist or therapist or other clinician, with a psychosocial understanding of ME, will not be considered to have a physical disease; despite actually having one.

A diagnosis of ME will not be an option for these people: if a patient comes with

- numerous symptoms that do not show up dysfunction on the standard NHS tests;**
- a concern about their health and the overwhelming nature of the symptoms that stop them from interacting in everyday life**
- an anxiety about their being able to sustain their jobs, careers, their social life, financial status, etc**
- a worry that their tests are not showing anything up, with pain that can so easily be interpreted as psychological, by the practitioner,**

they are likely to end up being mistreated by psychiatry and labelled as having a somatoform disorder according to these dangerous criteria.

This is the danger of wrongly associating a neurological physically disabling disease with psychiatry and completely, deliberately misinterpreting it as a mental health issue.

On this basis it would be a violation of human rights to validate these CSSD criteria, given the long-standing agenda of the Wessely School to deny ME as a physical disease and give it no opportunity to be properly tested and aided, biomedically.

Conclusion:

These criteria will further strengthen the misinterpretation of the symptoms of ME as a mental health disorder.

Just because the NHS, in the UK, has not developed proper testing or will not pay for the more expensive tests that can show up the underlying possible causes of ME, it is extremely dangerous to then make the jump to say that patients should be considered as either having psychological difficulties or an adjustment disorder.

On the basis of these minimal criteria, anyone newly ill with ME, going to an uninformed clinician is likely to be given a somatoform misinterpretation or be referred down a psychiatric pathway, away from the truth of their physical disease and exposed to potentially abusive treatments that deny their physical reality.

The category of CSSD could become a reason to openly abuse patients with ME.

CSSD is like a golden pass for the psychiatric lobby to block anyone from even receiving an ME diagnosis in the first place. Given the NHS does not offer the specific ME tests required to identify dysfunction, it is potentially a green flag to a mass abuse of people with a physical disease

ⁱ Hooper M & Williams M (2010) **Submission re: DSM-V and ME/CFS, 25% Group**
<http://www.meactionuk.org.uk/DSM-V-submission.htm>

ⁱⁱ Hooper M & Williams M (2010) **Submission re: DSM-V and ME/CFS, 25% Group**
<http://www.meactionuk.org.uk/DSM-V-submission.htm>

ⁱⁱⁱ http://erythos.com/gibsonenquiry/Docs/ME_Inquiry_Report.pdf.

^{iv} Hooper M (2011) REPORT: COMPLAINT TO THE RELEVANT EXECUTIVE EDITOR OF THE LANCET ABOUT THE PACE TRIAL ARTICLES PUBLISHED BY THE LANCET <http://www.meactionuk.org.uk/COMPLAINT-to-Lancet-re-PACE.htm>

^v Random Controlled Trials. A Jadad & M Elkin; Oxford, Blackwell 2007; first published in 1998.

^{vi} JOHN SORBORO, M.D.(2010) Prognosis Negative
Psychiatry and the Foibles of the Diagnostic and
Statistical Manual V (DSM-V) , Skeptic Magazine volume 15 number 3
2010 <http://www.psychiatry.freeuk.com/SorboroDSM.pdf>

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