

Submitted by	Proposal	Status of proposal	Notes
Suzy Chapman December 30, 2014	Add exclusion for <i>(Benign) myalgic encephalomyelitis</i> under Fatigue	Implemented March 26, 2017	ICD-10 " <i>Malaise and fatigue</i> " entity is revised to " <i>Fatigue</i> " for ICD-11.
	Add exclusion for <i>Chronic fatigue syndrome</i> under Fatigue	Implemented March 26, 2017	
	Add exclusion for <i>Postviral fatigue syndrome</i> under Fatigue	Implemented April 15, 2019	
Suzy Chapman March 29, 2017	Add exclusion for <i>Fatigue</i> under Postviral fatigue syndrome; BME; CFS	Implemented February/March 2019	
Suzy Chapman March 02, 2017	<p>Proposal for Deletion of the Entity: Bodily distress disorder</p> <p>[Proposal summary] The proposed ICD Entity Title "<i>Bodily distress disorder</i>" should be rejected. Since 2007, this term has been used interchangeably for the differently conceptualized diagnostic construct, "<i>Bodily distress syndrome</i>" (Fink et al. 2010), which has very different criteria and captures a different patient population to ICD-11's <i>BDD</i>. If the S3DWG working group is unprepared to reconsider the nomenclature and recommend an alternative name for its proposed disorder, then the current proposal to replace the ICD-10 somatoform disorders with a single "<i>Bodily distress disorder</i>" diagnostic category should be abandoned.</p> <p>Rationale: http://wp.me/pKrrB-4dc</p>	<p>Rejected February 26, 2019</p> <p>Rationale for decision: "This proposal has been extensively discussed by WHO and its advisory committees. There is no new scientific evidence to support this proposal and will not be further processed." Team 2 WHO 2019-Feb-26 - 23:04 UTC</p>	<p>This is an inadequate response from WHO Admins. It fails to address the points raised in my submission.</p>
Suzy Chapman March 28, 2017 Update: Proposal re-submitted on December 02, 2019	<p>Add exclusions for <i>Postviral fatigue syndrome; fatigue syndrome postviral; Benign myalgic encephalomyelitis; Chronic fatigue syndrome</i> under Bodily distress disorder</p> <p>Rationales: http://bit.ly/2XOLCxl http://bit.ly/2ERovtw</p>	<p>Proposal submitted March 28, 2017 Rejected February 2019.</p> <p>New rationale for proposal submitted December 02, 2019: http://bit.ly/2NL0IX5</p>	<p>No Rationale was provided by WHO Admins for this decision to reject.</p> <p>Proposal submitted December 02, 2019 Approved and Implemented January 17, 2020.</p>
Suzy Chapman March 29, 2017	<p>Add exclusion for <i>Bodily distress disorder</i> under Postviral fatigue syndrome; Benign myalgic encephalomyelitis; Chronic fatigue syndrome</p> <p>Rationales: http://bit.ly/2XOLCxl http://bit.ly/2ERovtw</p>	<p>Rejected March 04, 2019</p> <p>Rationale for decision: "In response to the many proposals on <i>Chronic fatigue syndrome</i>, the WHO Secretariat has conducted a vast amount of research.</p> <p><i>Findings: The condition is characterized by chronic, profound, disabling, and unexplained fatigue and coinciding symptoms such as sleep problems or post-exertional malaise. There is no agreement on a reliable diagnostic symptom pattern. The etiology is still being discussed and there is no uniform treatment approach with reliable outcomes. The only constant is the lead symptom 'fatigue' that persists over time.</i></p> <p><i>Decision: As a result of this study, the category 'postviral fatigue' that is the indexing target, will not be changed as currently there is no evidence to suggest a better place. The entity will retain its name and remain within the Nervous system chapter. The Medical and Scientific Advisory Committee and the Classification and Statistics Advisory committee supported this decision."</i> Team3 WHO 2019-Mar-04 - 22:52 UTC</p>	<p>This rationale text merely reiterates the Rationale posted on November 19, 2018, when WHO Admins rejected the proposal submitted by Dr Tarun Dua in November 2017. [See pink panels, on p3]</p> <p>Whilst the decision to reject Dr Dua's proposal was welcomed, this is an inadequate response from WHO Admins.</p> <p>It does not provide a rationale for rejecting the specific proposal for adding an exclusion for <i>Bodily distress disorder</i> under <i>Postviral fatigue syndrome, Benign myalgic encephalomyelitis; Chronic fatigue syndrome</i>.</p>

<p>Suzy Chapman January 19, 2018</p>	<p>Delete chronic fatigue, unspecified from the Synonyms list for Postviral fatigue syndrome</p> <p>Rationale: <i>chronic fatigue, unspecified</i> is a term imported from the U.S. ICD-10-CM. The entity is specific to the U.S. clinical modification and does not appear in the WHO's unmodified ICD-10. In ICD-10-CM, <i>Chronic fatigue, unspecified</i> is coded under Chapter 18: Symptoms, signs etc. under R53 <i>Malaise and fatigue</i> > R53.82 <i>Chronic fatigue, unspecified</i> with an Excludes1 for postviral fatigue syndrome (G93.3).</p>	<p>Approved January 29, 2018 Implemented March 15, 2019</p>	
<p>Suzy Chapman and Mary Dimmock March 27, 2017</p>	<p>[Proposal summary] For ICD-11, the ICD-10 G93.3 entities should be retained under their legacy chapter: Diseases of the nervous system under parent: Other disorders of the nervous system.</p> <p>Remove Postviral fatigue syndrome as the Concept Title.</p> <p>Deprecate the term "Benign." Create new Concept Title: Myalgic encephalomyelitis. For backward compatibility, add "Myalgic encephalomyelitis (benign)" under Synonyms list for new Concept Title: <i>Myalgic encephalomyelitis</i>. Rationale: http://bit.ly/2NXt9dW</p> <p>Relocate Postviral fatigue syndrome under Synonyms to new Concept Title: <i>Myalgic encephalomyelitis</i>.</p> <p>Create new Concept Title: Chronic fatigue syndrome.</p> <p>Assign unique sequential codes to new Concept Titles: Myalgic encephalomyelitis; and Chronic fatigue syndrome.</p> <p>Add reciprocal exclusions for Bodily distress disorder for new Concept Titles: <i>Myalgic encephalomyelitis</i>; and <i>Chronic fatigue syndrome</i>.</p> <p>Add reciprocal Exclusions for Fatigue for new Concept Titles: <i>Myalgic encephalomyelitis</i>; and <i>Chronic fatigue syndrome</i>. Full proposal: http://bit.ly/2NS8sQo</p>	<p>Rejected March 04, 2019</p> <p>Rationale for decision: <i>"In response to the many proposals on Chronic fatigue syndrome, the WHO Secretariat has conducted a vast amount of research.</i></p> <p>Findings: <i>The condition is characterized by chronic, profound, disabling, and unexplained fatigue and coinciding symptoms such as sleep problems or post-exertional malaise. There is no agreement on a reliable diagnostic symptom pattern. The etiology is still being discussed and there is no uniform treatment approach with reliable outcomes. The only constant is the lead symptom 'fatigue' that persists over time.</i></p> <p>Decision: <i>As a result of this study, the category 'postviral fatigue' that is the indexing target, will not be changed as currently there is no evidence to suggest a better place. The entity will retain its name and remain within the Nervous system chapter. The Medical and Scientific Advisory Committee and the Classification and Statistics Advisory committee supported this decision."</i> Team3 WHO 2019-Mar-04 - 22:58 UTC</p>	<p>Again, this rationale text reiterates the Rationale posted on November 19, 2018, when WHO Admins rejected the proposal submitted by Dr Tarun Dua in November 2017.</p> <p>It does not provide any specific rationales for rejecting the various recommendations within this Chapman and Dimmock proposal.</p> <p>Although a blanket Rejection has been applied, exclusions for <i>Myalgic encephalomyelitis</i>; and <i>Chronic fatigue syndrome</i> under Fatigue had already been approved by WHO and implemented on March 26, 2017.</p> <p>An exclusion for Fatigue under Concept Title: Postviral fatigue syndrome had also been recently approved and implemented, though neither of those decisions has been acknowledged in the Rationale that accompanies the Rejection of this proposal. This joint submission with Mary Dimmock had garnered over 320 comments from stakeholders, including the support of over 30 international patient orgs and this is a cavalier response from WHO.</p> <p>I have submitted a request for the WHO's rationale for rejecting the recommendation that the term "Benign" should be deprecated. Rationale: http://bit.ly/2NXt9dW</p>
<p>Lily Chu, MD on behalf of IACFS/ME www.iacfsme.org March 31, 2017</p>	<p>[Proposal extract] We recommend the following:</p> <ol style="list-style-type: none"> 1) The continued classification of these three terms in the neurological chapter, as was done in ICD-10, until such time that research provides the evidence for a more appropriate classification. 2) The retention of the term "postviral fatigue syndrome" (PVFS) as a concept title along with the elevation of the terms "chronic fatigue syndrome" (CFS) and "myalgic encephalomyelitis" (ME) to concept titles at the same level, with each of the three terms given a unique code. 3) Modify the ICD-10 term "benign myalgic encephalomyelitis" to "myalgic encephalomyelitis" as the disease is not benign. 4) Add back the reciprocal exclusions between these terms and the word "fatigue" (as was done in ICD-10) and also between these terms and bodily distress disorder. 	<p>Rejected March 04, 2019</p> <p>Rationale for decision: <i>"In response to the many proposals on Chronic fatigue syndrome, the WHO Secretariat has conducted a vast amount of research.</i></p> <p>Findings: <i>The condition is characterized by chronic, profound, disabling, and unexplained fatigue and coinciding symptoms such as sleep problems or post-exertional malaise. There is no agreement on a reliable diagnostic symptom pattern. The etiology is still being discussed and there is no uniform treatment approach with reliable outcomes. The only constant is the lead symptom 'fatigue' that persists over time.</i></p> <p>Decision: <i>As a result of this study, the category 'postviral fatigue' that is the indexing target, will not be changed as currently there is no evidence to</i></p>	<p>Again, this rationale text reiterates the Rationale posted on November 19, 2018, when WHO Admins rejected the proposal submitted by Dr Tarun Dua in November 2017.</p> <p>It does not provide any specific rationales for rejecting the various recommendations within this IACFS/ME proposal.</p>

	<p>5) We oppose the classification and/or dual parenting of these terms in either the symptoms chapter or the mental health chapter in the ICD 11 Handbook.</p> <p>Full proposal: http://bit.ly/2Hleist</p>	<p><i>suggest a better place. The entity will retain its name and remain within the Nervous system chapter. The Medical and Scientific Advisory Committee and the Classification and Statistics Advisory committee supported this decision.” Team3 WHO 2019-Mar-04 - 22:54 UTC</i></p>	
<p>Dr Tarun Dua November 06, 2017</p>	<p>[Proposal extracts] “This proposal recommends to remove Myalgic encephalitis/Chronic Fatigue Syndrome (ME/CFS) [sic] from the nervous system diseases chapter. The rationale for the proposal is lack of evidence regarding any neurological etiopathogenesis of chronic fatigue syndrome.</p> <p>We suggest that ME/CFS be classified in the Signs and Symptoms Block of the ICD-11 as a child of Symptoms, signs or clinical findings of the musculoskeletal system. The classification in this position according to symptom patterns and severity would be consistent with existing evidence: the syndrome consists of a multitude of symptoms, has an ill-defined pathophysiological etiology, and is a diagnosis of exclusion requiring medical evaluation [1].</p> <p>When there is sufficient evidence and understanding of the pathophysiological mechanisms, diagnostic biomarkers, and specific treatments, the syndrome can be appropriately classified within the proper block.</p> <p>... ME/CFS is thus not a disease of the nervous system. It should be categorized in the Signs and Symptoms chapter given the lack of clear evidence pointing to the etiology and pathophysiology of this syndrome until evidence to organ placement is clarified in years to come.”</p> <p>Full proposal: http://bit.ly/2TBMwPQ</p>	<p>Rejected November 19, 2018</p> <p>Rationale for decision: “In response to the many proposals on Chronic fatigue syndrome, the WHO Secretariat has conducted a vast amount of research.</p> <p>Findings: <i>The condition is characterized by chronic, profound, disabling, and unexplained fatigue and coinciding symptoms such as sleep problems or post-exertional malaise. There is no agreement on a reliable diagnostic symptom pattern. The etiology is still being discussed and there is no uniform treatment approach with reliable outcomes. The only constant is the lead symptom ‘fatigue’ that persists over time.</i></p> <p>Decision: <i>As a result of this study, the category ‘postviral fatigue’ that is the indexing target, will not be changed as currently there is no evidence to suggest a better place. The entity will retain its name and remain within the Nervous system chapter. The Medical and Scientific Advisory Committee and the Classification and Statistics Advisory committee supported this decision.” Team3 WHO 2018-Nov-19 - 07:10 UTC</i></p>	<p>Dr Tarun Dua is a medical officer working on the Program for Neurological Diseases and Neuroscience, Management of Mental and Brain Disorders, Department of Mental Health and Substance Abuse, World Health Organization.</p> <p>Dr Dua had served as Lead WHO Secretariat and Managing Editor to the Topic Advisory Group (TAG) for Neurology.</p> <p>As TAG Neurology had ceased operations in October 2016, it was initially unclear whose opinions this proposal represented. Four weeks later, Dr Dua clarified that the recommendation was submitted on behalf of Topic Advisory Group (TAG) for Neurology and “reiterates the TAG’s earlier conclusions.”</p> <p>In February 2018, Chapman and Dimmock submitted a robust rebuttal to the Dr Dua proposal, which restated WHO’s general principles on consideration of potential chapter relocations:</p> <p>Extract: 4. Compliance with WHO standards and other considerations on relocation: http://bit.ly/2CdaypD</p> <p>Full response: http://bit.ly/2F1pfxQ</p>

ICD-11 Proposal Mechanism, status of processed proposals at 17.01.20 v5

Prepared by Suzy Chapman, *Dx Revision Watch*

Sources:

ICD-11 Mortality and Morbidity Statistics (ICD-11 MMS) Orange Maintenance Platform:

Foundation view: <https://icd.who.int/dev11/f/en#/>

Mortality and Morbidity Statistics Linearization: <https://icd.who.int/dev11/l-m/en#/>

Registration required for access to Proposal Mechanism:

Registration: <https://icd.who.int/dev11/Account/Register>

Proposals by ICD category: <https://icd.who.int/dev11/proposals/l-m/en#/>

Proposals List/Search: <https://icd.who.int/dev11/proposals/f/en/ProposalList>

ICD-11 for Mortality and Morbidity Statistics Version for preparing implementation (Version: 04/19):

<https://icd.who.int/browse11/l-m/en>