

Tracking of ME/CFS Cases in the Revised US ICD-10-CM

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Since 2015, the 1-2.5 million Americans with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) have been effectively nonexistent, at least as far as US disease tracking systems are concerned. Americans don't experience any morbidity (suffering, impairment) from ME/CFS. They can't die with ME/CFS. Nobody develops ME/CFS following an acute COVID-19 infection - despite all the evidence that shows they can and do. And ME/CFS cases don't show up in research using electronic health records. The reason? ME/CFS is effectively nonexistent simply because ME/CFS is not being coded in US health records.

This coding problem is finally being fixed in the 2023 release of the ICD-10-CM, being implemented October 1, 2022. Going forward, Americans diagnosed with ME/CFS, including any new cases following COVID, will no longer be invisible.

The ICD-10-CM is the US version of the International Classification of Diseases used to track diseases globally. When the US implemented the ICD-10-CM in 2015, the term "chronic fatigue syndrome," the term almost always used by US doctors for ME/CFS, was assigned the same ICD code as the symptom of "chronic fatigue, unspecified." At the same time, the term "myalgic encephalomyelitis/chronic fatigue syndrome," the name adopted by US federal agencies and in clinical guidance, was never added to the ICD-10-CM.

As a result, virtually all US cases of ME/CFS have been effectively lost in a bucket of unspecified chronic fatigue due to any cause. This impacts tracking of ME/CFS disease mortality and morbidity and assessment of its disease burden and healthcare utilization and cost. It impacts insurance billing and reimbursement. And it also impacts research using electronic health records, including plans by NIH and CDC to undertake such research to understand Long COVID and its sequelae. More information on the coding issue and its impact is available [here](#).

This is a uniquely American problem as only the US has reclassified CFS in its ICD-10-CM to be equivalent to the symptom of chronic fatigue, unspecified. The World Health Organization and other countries classify both CFS and ME together with postviral fatigue syndrome in the neurological chapter.

To fix this coding problem in the ICD-10-CM, the term ME/CFS has been added and the term "postviral fatigue syndrome" expanded to "postviral and related fatigue syndromes" to account for non-viral infections and other causes. "Chronic fatigue syndrome" has been moved back to the neurological chapter and the term "systemic exertion intolerance disease" added because some US healthcare providers use this term. Importantly, a note has been added to also code post-COVID condition (U09.9) when ME/CFS is associated with COVID. The full set of ICD-10-CM changes for ME/CFS, CFS and postviral fatigue syndrome is summarized [here](#). Note that this change impacts only newly created health records, not existing ones. Correcting existing records would be challenging as they have been coded comingled with the symptom of "chronic fatigue, unspecified."

This update is the result of multiple proposals by the ME/CFS community since 2011, most recently in 2021 by seven ME/CFS organizations: #MEAction, Open Medicine Foundation, Solve ME/CFS Initiative, International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis, Massachusetts ME/CFS & FM Association, Pandora Org and Minnesota ME/CFS Alliance. Their proposal to add the term ME/CFS and expand postviral fatigue syndrome is available [here](#). The additional changes recommended by the National Centers for Health Statistics, responsible for ICD-10-CM, can be seen [here](#) and in the final updates [here](#).

If you have any questions or comments, please contact Mary Dimmock at medfeb@yahoo.com