

# Proposal for modifications to the G93.3 terms in ICD-10-CM to the National Center for Health Statistics

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In 2015, the Institute of Medicine (IOM), now called the National Academy of Medicine, published an extensive evidence review of “myalgic encephalomyelitis/chronic fatigue syndrome” (ME/CFS) and recommended new diagnostic criteria.<sup>1</sup> The CDC, disease experts, and many clinical guidance and medical education providers have already adopted the IOM criteria along with the term “myalgic encephalomyelitis/chronic fatigue syndrome.”<sup>2</sup> But the term ME/CFS does not exist in the ICD-10-CM and thus cannot be coded. Instead, the ICD-10-CM code most often used is the one for “chronic fatigue syndrome,” which uses the same code as the symptom of “chronic fatigue.”

As a result, it is impossible to accurately track the mortality and morbidity of ME/CFS separate from the symptom of chronic fatigue. This could also have secondary effects on healthcare resource planning, appropriate reimbursement for clinical care, use of medical records in future research, provisioning of workplace/ school accommodations, and determination of disability benefits.

The need to accurately track ME/CFS is more urgent than ever because of the emergence of prolonged illness following acute COVID-19. According to NIH’s Dr. Fauci, some post-COVID patients are experiencing a post-viral syndrome that is “highly suggestive” of ME/CFS.<sup>3</sup> This is not surprising given that ME/CFS is known to often follow a viral infection. The US ME/CFS Clinician Coalition, a coalition of internationally recognized experts in ME/CFS, has encouraged medical providers to consider ME/CFS in the differential diagnosis of these post-COVID patients.<sup>4</sup> Some post-COVID patients have already reported being given a diagnosis of ME/CFS.

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<sup>1</sup> Institute of Medicine. Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness. *The National Academies Press*; May 2015.

<https://www.nap.edu/catalog/19012/beyond-myalgic-encephalomyelitischronic-fatigue-syndrome-redefining-a-n-illness>

<sup>2</sup> In addition to the US ME/CFS Clinician Coalition, examples of medical education and clinical guidance providers that use the ME/CFS term and the IOM criteria include

- CDC ME/CFS website – <https://www.cdc.gov/me-cfs/index.html>
- Medscape 2019 ME/CFS CME - [https://www.medscape.org/viewarticle/907632?src=acdm-part\\_cdc](https://www.medscape.org/viewarticle/907632?src=acdm-part_cdc)
- Kaiser Permanente. ME/CFS medical information.

<https://healthy.kaiserpermanente.org/health-wellness/health-encyclopedia/he.myalgic-encephalomyelitis-chronic-fatigue-syndrome.hw32907>

Content provided by Healthwise which provides content to a number of other sites as well

- Cleveland Clinic -

<https://my.clevelandclinic.org/health/diseases/17720-myalgic-encephalomyelitischronic-fatigue-syndrome-mecfs>

<sup>3</sup> Rubin R. As Their Numbers Grow, COVID-19 “Long Haulers” Stump Experts. *JAMA*. Sept 23, 2020.

<https://jamanetwork.com/journals/jama/fullarticle/2771111>

Also see the following report from NIH staff

- Nath A, Smith B. Neurological issues during COVID-19: An Overview. *Neuroscience Letters*. 2020. 135533. <https://doi.org/10.1016/j.neulet.2020.135533>.

<sup>4</sup> US ME/CFS Clinician Coalition letter to medical providers. October 30, 2020

[https://drive.google.com/file/d/15Z1pPMsTvXKe\\_eJtNG3XyXNxx9gB2xxU/view](https://drive.google.com/file/d/15Z1pPMsTvXKe_eJtNG3XyXNxx9gB2xxU/view)

To rectify this problem, we recommend the following changes to the ICD-10-CM terms at G93.3:

- a) Add “myalgic encephalomyelitis/chronic fatigue syndrome” as a new term, listed as an inclusion (synonym) to the term “myalgic encephalomyelitis” at G93.3
- b) Modify the title of G93.3 from “Postviral fatigue syndrome” to “Postviral and related fatigue syndromes” because ME/CFS and ME can be precipitated by both viral and nonviral infections and also by non-infectious causes.
- c) Add separate G93.3n sub-codes for the terms “postviral fatigue syndrome” and “myalgic encephalomyelitis”

We are requesting this proposal be discussed at the March 2021 NCHS meeting and the changes be expedited with implementation no later than the next release of ICD-10-CM in October 2021. Expedited implementation is warranted because the term “ME/CFS” has already been broadly adopted clinically and because of the urgent need to track all ME/CFS cases, including those that may develop following an acute COVID-19 infection.

Please contact xxx with any questions or to discuss this or alternative approaches to achieving the objective of being able to accurately track patients with this devastating disease.

#### **Rationale for these recommendations:**

1. **Add the term ME/CFS as a new term, listed as an inclusion (synonym) to the term ME**  
Because the term “myalgic encephalomyelitis/chronic fatigue syndrome” has been broadly adopted by US federal agencies, disease experts and medical education providers, it must be available in the ICD-10-CM to ensure accurate coding of medical records.

The rationale for including ME/CFS as a synonym to ME is that the ME and ME/CFS criteria, including the IOM criteria, all require the hallmark symptoms of post-exertional malaise, unrefreshing sleep, profound fatigue, and significant impairment in function. These criteria all also include other symptoms such as cognitive impairment, orthostatic intolerance, pain, and sensory sensitivity. The US ME/CFS Clinician Coalition recommends the IOM criteria for diagnosis in the US but also acknowledges the similarities across these definitions and notes that some experts use the 2003 Canadian Consensus Criteria (labeled as ME/CFS) and the 2011 ME International Consensus Criteria (labeled as ME) to validate an IOM-criteria clinical diagnosis of ME/CFS.<sup>5</sup>

The potential alternative is to have coders separately apply the two codes for the terms “myalgic encephalomyelitis” and “chronic fatigue syndrome” when the doctor diagnoses ME/CFS. But this is far less preferable because it does not capture the name of the disease as specified by the doctor or in clinical guidance and medical education. Further, this alternative is not allowed by ICD-10-CM coding rules because an “Excludes1” rule exists between G93.3 (the code for PVFS and ME) and R53.82 (the code for CFS), specifying that the two codes “should never be

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<sup>5</sup> US ME/CFS Clinician Coalition Handout. July 2020.  
<https://drive.google.com/file/d/1SG7hJTCSDrDHqvioPMq-cX-rgRKXjfk/view>

used at the same time” and that the “conditions cannot occur together.”<sup>6</sup>

Finally, the IOM noted that not all people previously diagnosed with CFS using the Fukuda CFS definition, used in the US prior to adoption of the IOM criteria, would meet the new IOM criteria for ME/CFS.<sup>7</sup> This indicates that the IOM did not intend the term ME/CFS to be a replacement for the term “chronic fatigue syndrome” or an amalgamation of all ME and CFS diagnoses.

Accordingly, we recommend the term “myalgic encephalomyelitis/chronic fatigue syndrome” be added as a new term and be listed as an inclusion (synonym) to the term ME.

## 2. Establish a new title for G93.3

The title term for G93.3 is currently “postviral fatigue syndrome” and ME is an included term to G93.3. Because the G93.3 title specifies postviral illness, some doctors have declined to diagnose ME when viral illness is not proven. But ME, according to practice and established criteria, can be triggered by both viral and non-viral precipitants, including non-viral infections and non-infectious causes.<sup>8</sup> This is also true for the definitions that use the ME/CFS label, including the IOM criteria.

We recommend the G93.3 title, “postviral fatigue syndrome” be expanded to “postviral and related fatigue syndromes” to accommodate these other precipitants while still retaining the original words.

## 3. Add separate subcodes for PVFS and ME

By its name, the term “postviral fatigue syndrome” is intended only for post-viral illness. But as noted above, the terms ME and ME/CFS include both viral and nonviral precipitants. The ME and ME/CFS definitions further specify that symptoms should persist for 6 months while PVFS is reportedly used even if patients have not been sick for six months.

Given these differences in diagnostic criteria and usage, we recommend that PVFS and ME be given separate sub-codes, G93.30 and G93.31 respectively.

### The following minor changes are also recommended

#### 1. Remove the term “benign” from “benign myalgic encephalomyelitis:”

In the 2019 release of ICD-10<sup>9</sup>, the term “benign myalgic encephalomyelitis” was replaced by the term “myalgic encephalomyelitis.” The rationale for this change was that “benign” was originally added under the assumption that patients do not die. But research has demonstrated that patients can die of ME/CFS complications<sup>10</sup> and that ME/CFS results in a high disease burden.

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<sup>6</sup> ICD-10-CM Official Guidelines for Coding and Reporting. FY2020  
[https://www.cdc.gov/nchs/data/icd/10cmguidelines-FY2020\\_final.pdf](https://www.cdc.gov/nchs/data/icd/10cmguidelines-FY2020_final.pdf)

<sup>7</sup> Institute of Medicine 2015 report. Page 210.

<sup>8</sup> Institute of Medicine 2015 report. Page 1. Also see the 2003 Canadian Consensus Criteria and the 2011 ME International Criteria which use the terms ME/CFS and ME respectively.

- Carruthers B, Jain A, De Meirleir K, Peterson D, Klimas N, et al. Myalgic encephalomyelitis/chronic fatigue syndrome: Clinical working case definition, diagnostic and treatment protocols (Canadian case definition). *Journal of Chronic Fatigue Syndrome*. 2003 11(1):7-115.

- Carruthers B, van de Sande M, De Meirleir K, Klimas N, Broderick G, et al. Myalgic encephalomyelitis: International consensus criteria. *Journal of Internal Medicine* 2011. 270(4):327-338.

<sup>9</sup> World Health Organization ICD-10: Version 2019 . <https://icd.who.int/browse10/2019/en#/F48.0>

<sup>10</sup> International Association of CFS/ME Chronic fatigue syndrome/myalgic encephalomyelitis Primer for Clinical Practitioners Primer. 2014. [http://iacfsme.org/portals/0/pdf/Primer\\_Post\\_2014\\_conference.pdf](http://iacfsme.org/portals/0/pdf/Primer_Post_2014_conference.pdf)

The IOM concurred, stating ME/CFS “frequently and dramatically limits the activities of affected patients.”<sup>11</sup>

This change has already been implemented in the clinical modifications of ICD-10 implemented by Germany (ICD-10-GM) and Australia (ICD-10-AM) and is also being implemented in ICD-11. To align with these standards, we recommend its implementation in ICD-10-CM.

## 2. Establish needed exclusions

Recognizing that ME/CFS had been equated to mental illness and that it “entails much more than the chronic presence of fatigue”, the IOM recommended creation of an ICD code not linked to neurasthenia or chronic fatigue.<sup>12</sup> ICD-10-CM currently includes an exclusion between G93.3 and the term “chronic fatigue syndrome” but not the term “chronic fatigue.” The ICD-10 includes an exclusion between G93.3 and neurasthenia, coded at F48.8, but this has not yet been implemented in ICD-10-CM.

We recommended that an “Excludes1” be added between F48.8 and G93.3 and also between R53.82 and G93.3.

Note: The submitted proposal also included requests to clean up existing exclusions to revise codes and remove the term “benign.”

### **Background: What is myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)?**

In its 2015 report, the Institute of Medicine concluded that ME/CFS is “*a serious, chronic, complex, and multisystem disease,*” characterized by the hallmark symptom of post-exertional malaise (PEM) in which even small amounts of cognitive and physical exertion can exacerbate symptoms that can last for days, weeks or sometimes months. ME/CFS is debilitating with an estimated 25% of patients homebound or bedbound and as many as 75% unable to work or go to school.

The IOM report established new diagnostic criteria that include PEM and also substantial impairment in functioning, profound fatigue, unrefreshing sleep, and either cognitive issues or orthostatic intolerance. Other common but non-required symptoms include joint and muscle pain, headaches, and sensitivity to noise and light. Published peer-reviewed studies have demonstrated neurological, immunological, autonomic, and energy metabolism impairment associated with these symptoms.<sup>13</sup> In addition to the new clinical diagnostic criteria, the IOM also recommended a new name, “Systemic exertion intolerance disease (SEID).” However, this recommendation was never adopted. Instead, federal agencies including CDC and NIH, disease experts, and medical education and clinical guidance providers have adopted the term “ME/CFS” along with the new clinical diagnostic criteria recommended by the IOM in the 2015 report.

## References

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<sup>11</sup> Institute of Medicine 2015 report. Page 5

<sup>12</sup> Institute of Medicine 2015 report. Page 8, 77

<sup>13</sup> See the evidence review in the Institute of Medicine report. Also see

- Komaroff A. 12th International IACFS/ME Conference Emerging Science & Clinical Care. October 2016.

<http://iacfsme.org/Conferences/2016-Fort-Lauderdale/Agenda/Dr-Komaroff-s-2016-Summary-Slides/IA-CFSME-Komaroff-Slides.aspx>