

Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome in the ICD-10-CM

*ICD-10-CM Coordination & Maintenance Committee
September 14-15, 2021*

Mary Dimmock on behalf of:

International Association for CFS/ME

#MEAAction

Open Medicine Foundation

Solve M.E.

Massachusetts ME/CFS & FM Association

Minnesota ME/CFS Alliance

Pandora Org

What is ME/CFS?

References: Bateman, Hickie, Jason, Komaroff,, NAM

- **A “serious, chronic, complex, and multisystem disease”**
 - Causes neurological, immunological, energy metabolism impairment
 - Not a psychological/ psychiatric condition, malingering, or deconditioning
- **Epidemiology**
 - 1-2.5 million Americans of all ages, genders, races, ethnicities, in more women
 - Significant impact on functioning - 25% home/bedbound, 75% not working
 - Can last for decades. US economic impact: \$36–51B/year
- **Etiology being researched, most often follows infection**
 - Seen following e.g. EBV, Ross river virus, enterovirus, Coxiella, Giardia, others
 - Studies have estimated 10% meet ME/CFS criteria across range of infections
- **Clinical Care**
 - Most not diagnosed. Can see many clinicians, take years to get diagnosed.
 - Outdated or inadequate coverage in student and continuing med ed
 - Misunderstood, stigmatized, and neglected by doctors

Pivotal 2015 Institute of Medicine Report

- **Extensive review of evidence multisystem pathologies**
- **Recommended new criteria focused on key features**
 - Hallmark symptom intolerance to exertion (post-exertional malaise)
 - Plus profound fatigue, sleep and cognitive impairment, orthostatic intolerance, substantial functional impairment, other symptoms

They concluded not all previously diagnosed CFS cases meet these criteria
- **Recommended new name - “ME/CFS” adopted instead**
 - SEID recommended but not adopted.
 - Recommended no longer use “chronic fatigue syndrome”
- **Recommended new ICD code**
 - Separate from “chronic fatigue”

Progress since 2015

(References: CDC, Bateman, Komaroff)

- **ME/CFS term adopted by federal agencies**
- **IOM criteria and ME/CFS term in new clinical guidance**
 - CDC
 - US ME/CFS Clinician Coalition recs in Mayo Clinic Proceedings
 - UpToDate, Kaiser (Healthwise), Cleveland Clinic, Medscape
- **Advances in understanding disease pathology**

Key theories being pursued include:

 - Pathogen triggered autoimmunity
 - Abnormal immune response to infection or other trigger
 - Autonomic dysregulation
 - Neuroinflammation and neurological changes
 - Metabolism impairment, especially energy metabolism

Issues with ICD-10-CM Coding

G93 Other disorders of brain
G93.3 Post-viral fatigue syndrome
Benign myalgic encephalomyelitis

R53.8 Other Malaise and fatigue
R53.82 Chronic fatigue, unspecified
Chronic fatigue syndrome, NOS

- **ME/CFS not in the ICD-10-CM**
- **Most US doctors use CFS - equated to chronic fatigue**
 - Doctors may be unwilling to use G93.3 if viral illness not proven
 - Only the US equates CFS to the symptom of chronic fatigue, not in ICD-10 or ICD-11
- **ME/CFS mortality/morbidity not being tracked**
 - Effectively lost in bucket of “chronic fatigue, unspecified”
- **ME/CFS cases not identifiable in EHR-based research & analysis**
 - CDC study: not able to identify ME/CFS cases in EHR records without manual chart review. ICD codes alone not sufficient

Changes Requested by ME/CFS Organizations

- **Expand G93.3 title to accommodate other related nonviral causes**
- **Remove “benign” from “myalgic encephalomyelitis”**
- **Provide separate subcodes for postviral fatigue syndrome and myalgic encephalomyelitis**
- **Add ME/CFS as an inclusion of myalgic encephalomyelitis**

References

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