

# New IOM report identifies five symptoms to diagnose chronic fatigue syndrome

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Myalgic Encephalomyelitis/Chronic Fatigue Syndrome—commonly referred to as ME/CFS—is a legitimate, serious, and complex systemic disease that frequently and dramatically limits the activities of affected individuals, says a new report from the Institute of Medicine. The committee that wrote the report developed new diagnostic criteria for the disorder that includes five main symptoms. In addition, it recommended that the disorder be renamed "Systemic Exertion Intolerance Disease" and be assigned a new code in the International Classification of Diseases, Tenth Edition.

"Diagnosing ME/CFS often is a challenge, and seeking and receiving a diagnosis can be frustrating due to the skepticism of [health care providers](#) about these patients and the serious nature of their disease," said committee chair Ellen Wright Clayton, Craig-Weaver Professor of Pediatrics and professor of law at Vanderbilt University. "The new diagnostic criteria will make it easier for clinicians to recognize and accurately diagnose patients in a timely manner, as well as allow a large percentage of currently undiagnosed patients to receive appropriate care."

Between 836,000 and 2.5 million Americans suffer from ME/CFS, and an estimated 84 percent to 91 percent of people with ME/CFS are not diagnosed. The disease's symptoms can be treated, even though a cure does not exist. Its cause remains unknown, although in some cases symptoms have been triggered by an infection. Less than one-third of medical schools include ME/CFS-specific information in the

curriculum. Sixty-seven percent to 77 percent of patients said it took more than a year to receive a diagnosis; about 29 percent of these patients said it took more than five years. The direct and indirect economic costs of ME/CFS to society have been estimated at \$17 billion to \$24 billion annually, \$9.1 billion of which has been attributed to lost household and job productivity.

The committee recommended that physicians diagnose ME/CFS if the diagnostic criteria are met following an appropriate history, physical examination, and medical work-up.

Diagnosis of ME/CFS requires that a patient have the following three core symptoms:

- A substantial reduction or impairment in the ability to engage in pre-illness levels of activities that persists for more than six months and is accompanied by fatigue—which is often profound—of new or definite onset, not the result of ongoing excessive exertion and not substantially alleviated by rest
- The worsening of patients' symptoms after any type of exertion—such as physical, cognitive, or emotional stress—known as post-exertional malaise
- Unrefreshing sleep

At least one of the two following manifestations is also required:

- Cognitive impairment
- The inability to remain upright with symptoms that improve when lying down—known as orthostatic intolerance

These symptoms should persist for at least six months and be present at least half the time with moderate, substantial, or severe intensity to distinguish ME/CFS from other diseases.

The proposed criteria will not improve the diagnosis and care of patients unless health care providers use them, the committee recognized.

Therefore, it recommended that the U.S. Department of Health and Human Services develop a toolkit for screening and diagnosing patients with ME/CFS in a wide array of clinical settings, including primary care practices, emergency departments, and mental health clinics.

To convey the complexity and severity of ME/CFS, the committee recommended that the disorder be renamed "Systemic Exertion Intolerance Disease" (SEID). The committee, along with many ME/CFS patients, believed the term "chronic fatigue syndrome" perpetuates misunderstanding of the illness and dismissive attitudes from health care providers and the public. The term "myalgic encephalomyelitis" was deemed an inappropriate name by the committee, because myalgia, or muscle pain, is not a core symptom of the disease and because there is inconclusive evidence of brain inflammation in ME/CFS patients. SEID captures the central characteristic of the disease that exertion of any sort can adversely affect several organ systems and many aspects of patients' lives, often seriously and for long periods. Individuals who meet the proposed criteria, whether or not they have already been diagnosed with ME/CFS, should be diagnosed with SEID, the committee said.

In addition, research on ME/CFS is urgently needed, especially given the number of people affected, because too little is known about the causes, development, and progression of the disease, or about effective treatment. Future research could lead to findings that refine the diagnostic criteria and understanding of ME/CFS subtypes. Therefore, the committee recommended that a multidisciplinary group re-examine the proposed criteria after five years or sooner if firm evidence supports the need for modification.

"This disorder is often devastating for those who suffer from it," said Victor Dzau, president of the Institute of Medicine. "The [diagnostic](#)

criteria offered in this report are intended to promote prompt diagnosis for patients and enhance treatment, as well as improve public understanding of the disease."

**More information:** [www.nap.edu/catalog/19012/beyo ... edefining-an-illness](http://www.nap.edu/catalog/19012/beyo..._edefining-an-illness)

Provided by National Academy of Sciences

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