

HEALTH

Institute of Medicine calls for renaming chronic fatigue syndrome

Report recommends calling illness systemic exertion intolerance disease to reflect severity of physical symptoms

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by [Natasja Sheriff](#)

Chronic fatigue syndrome, a disorder that has for decades been trivialized by an inappropriate name should be renamed systemic exertion intolerance disease (SEID), according to a [study released Tuesday by the Institute of Medicine](#).

Sufferers of chronic fatigue syndrome (CFS), also known as myalgic encephalomyelitis (ME), have been fighting for years to have the word “fatigue” dropped from the name of the disorder, which leaves many of them bedridden and unable to perform even simple tasks like putting on socks and brushing their teeth.

“‘Fatigue’ doesn’t begin to describe the suffering that is associated with ME/CFS,” said Suzanne Vernon, the scientific director at the Solve ME/CFS Initiative. “A new name will be very important for really legitimizing this debilitating disease that for too long has just been marginalized because of a very inappropriate name.”

The cause of the disease is unknown, and there is currently no blood test or brain scan that can be used to diagnose the disease. Many sufferers encounter skepticism from the general public and health care providers alike, making it difficult for them to access the care and support they need.

“It sort of strikes at the Achilles’ heel of modern medicine, which relies on bloodwork and so-called objective tests,” said Dan Troph, who contracted the illness 40 years ago after a bout of mononucleosis. He was 25 years old at the time and two years out of graduate school with an MBA from the University of Michigan.

The new Institute of Medicine (IOM) report, sponsored by several federal agencies, including the Department of Health and Human Services and the Social Security Administration, could help raise awareness in the medical community by providing physicians with the tools to more effectively diagnose the disease. According to an IOM press release, more than half of medical textbooks include ME/CFS, and the condition is covered in fewer than one-third of medical school curricula.

For the study, the 16 volunteer members of the [Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome](#) reviewed the available scientific evidence about the disease and heard testimony from patients, advocates and experts in the field of ME/CFS. They received over 1,000 public comments submitted online.

In its report, the committee describes ME/CFS as “a legitimate, serious and complex systemic disease that frequently and dramatically limits the activities of affected individuals.”

Estimates suggest that the disease afflicts 836,000 to 2.5 million Americans and about 17 million people worldwide, but as many as 91 percent of people with disease might be undiagnosed, according to the IOM report.

“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,” IOM committee chair Ellen Wright Clayton, a Craig-Weaver professor of pediatrics and a professor of law at Vanderbilt University, said in a statement.

In an attempt to address this problem, the IOM committee offered a set of criteria to help physicians diagnose the disease.

Most people with ME/CFS suffer from extreme exhaustion, made worse by even mild physical or mental effort. After a crash, known as postexertional malaise, recovery may take days or weeks, and sleep brings no relief. These symptoms are recognized as key defining characteristics of the disease, according to the new criteria. Problems with speaking, thinking and remembering, known as cognitive impairments, are also widespread among patients.

Some sufferers have good days and bad days; others are confined to bed for months or years. Many people with the disease experience severe headaches, muscle pain and sensitivity to light and noise.

“It really is a hidden illness,” said Troph. “A tricky point is that people tend to see you when you’re feeling your best. When you’re feeling crummy, you’re hopefully home in bed.”

Loretta Sheridan was a trial lawyer with a 2-year-old daughter when she became ill with ME/CFS in 1986. Bedridden for a year, she was eventually able to get up for a few hours a day, but she was never able to return to full-time work.

“I had to close my own law firm in midtown Manhattan. I had to turn over all my cases to other associates, and that was a big deal,” she said. “I put myself through law school when I was 30 years old. To have to shut it down after just six years — it was really hard.”

Her illness also took a toll on her family life.

“My daughter tells people, ‘My mother slept through my childhood,’” she said. Her marriage suffered under the strain of decades of illness.

Speaking before the report’s publication, Sheridan was very positive about the prospect of a new name for the disease.

“I stopped telling people what I had because in the beginning years, if I explained what I had, they’d go, ‘I know a chiropractor who can take care of anybody’ or ‘You need to take vitamin B,’” said Sheridan.

“The minute people hear ‘chronic fatigue syndrome,’ they lose their interest,” she said. “They could call it anything — it would be better than ‘chronic fatigue.’ Everybody has chronic fatigue sometimes.”

Names of diseases don’t require scientific accuracy, according to Leonard Jason, the director of the Center for Community Research at DePaul University, who [wrote in a blog post for Oxford University Press](#) that they are sometimes “offensive, victim blaming and stigmatizing.” ME/CFS patients aren’t the first to try to change a disease name that trivialized or misrepresented the severity of their condition; before multiple sclerosis was renamed, patients were diagnosed with “hysterical paralysis.”

According to the IOM report, “systemic exertion intolerance” captures how any kind of physical, cognitive or emotional exertion can affect the organ systems of ME/CFS patients and have an adverse impact on many aspects of their lives. “The committee intends for this name to convey the complexity and severity of this disorder,” the report reads.

Still, there has been strong opposition to the IOM study from patients, clinicians, researchers and advocates who argued that it should have been canceled and the funds channeled into research on the disease.

In a 2013 [open letter](#) to Kathleen Sebelius, the secretary of health and human services at the time, dozens of experts signed a letter stating that groups like the IOM “lack the needed expertise to develop ‘clinical diagnostic criteria’ for ME/CFS,” adding that “this effort is unnecessary and would waste scarce taxpayer funds that would be much better directed toward funding research on this disease.” They argued that a set of criteria known as the Canadian consensus criteria already give an accurate description of the disease.

The report’s million-dollar price tag can seem quite high if you consider that annual federal funding for CFS is about \$5 million. In 2014 the disease ranked near the bottom of a list of 244 research areas and diseases [funded](#) by the National Institutes for Health — right below hay fever, which received \$6 million.

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