

Panel asks: What defines chronic fatigue syndrome?

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Disorder that causes overwhelming exhaustion will receive a long-awaited clinical definition.

(HealthDay)—Chronic fatigue syndrome is about to get a new clinical definition, with the hope that it will help physicians better diagnose people afflicted with the mysterious and complex disorder.

On Tuesday, the Institute of Medicine will release a long-awaited report that will define diagnostic criteria for [chronic fatigue syndrome](#) and examine whether a new name for the disease is warranted.

The report could prove a landmark moment following years of struggle for people with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), who often have had to fight to convince their own doctors that something was truly wrong with them, said Suzanne Vernon,

scientific director of the Solve ME/CFS Initiative.

"I believe we are at a tipping point for people suffering from ME/CFS, where we are going to be able to get people diagnosed, and with that diagnosis comes the ability for us to really lay the groundwork for much more effective treatment for ME/CFS," Vernon said.

Chronic fatigue syndrome is marked by prolonged and overwhelming fatigue that is not improved by sleep or bed rest, according to the U.S. Centers for Disease Control and Prevention. People with CFS also might suffer muscle and joint pain, headaches, recurring sore throat and tender lymph nodes.

"If you have severe exhaustion combined with inability to sleep and 'brain fog,' and there's no other obvious cause, then you likely have chronic fatigue syndrome," said Dr. Jacob Teitelbaum, director of the Fatigue & Fibromyalgia Practitioners Network.

More than 1 million Americans have chronic fatigue syndrome, the CDC says, making it more prevalent than multiple sclerosis, lupus and many forms of cancer. CFS occurs most often in people in their 40s and 50s, and occurs four times more often in women than men.

Chronic fatigue syndrome is extremely difficult to diagnose. There are no tests for it, and other illnesses can cause similar symptoms, the U.S. National Institutes of Health says. Diagnosis often is a process of elimination, with a person's doctor ruling out a number of other possible illnesses before suspecting CFS.

Up to now, doctors have had to rely on a case definition of chronic fatigue syndrome created in 1994 that was intended mainly to help researchers get a better handle on what at the time had not been conclusively determined to be an actual illness, Vernon said.

"Case definitions are great tools for epidemiologists, for disease hunters to get to the bottom of what's causing a malady, but they have to evolve in order to keep up with what you're finding," Vernon said.

Since that time, a lot of light has been shed on chronic fatigue syndrome. Doctors in 2014 linked CFS to inflammation of the nerve cells of the brain, and some now believe people with the syndrome are fatigued because something has gone wrong with their immune response.

"When you get the flu, when you get acutely sick, your body mounts a response against whatever is making you sick. That requires a significant amount of energy, and that energy is directed toward the immune response working directly and effectively," Vernon said. "Now imagine if the inflammatory response doesn't go away, and it continually requires the input of energy to maintain that response."

Some researchers believe the problem might lie in the hypothalamus, the part of the brain that regulates a wide range of different functions in the body.

"The illness represents an energy crisis on the cellular level. If you put too much demand on your body, the circuit breaker called the hypothalamus goes into a hibernation mode," Teitelbaum contends. "It takes people out of the game before they can do themselves harm."

Chris Fraker developed chronic fatigue syndrome in 2009. He also has type 1 diabetes, a disease caused by a faulty immune system, according to the U.S. National Institute of Diabetes and Digestive and Kidney Diseases.

Fraker currently is on vitamin therapy and taking antiviral drugs, but said he still feels the effects of CFS.

"When you're having a crash, it's like the worst type of fatigue you could ever feel. If you're holding up a cellphone, your arm feels like you've been using weights for hours even though you've only been holding it for five minutes," said Fraker, 44, of Miami.

Before chronic fatigue syndrome, he noted, "I could run up a flight of stairs and be a little winded but otherwise fine. Now when I do it I feel like I'm on the edge of collapse. You feel like you've been hit by a train."

While there is a need for an updated definition that reflects advances in the understanding of chronic fatigue syndrome, a number of leading researchers and physicians initially opposed the Institute of Medicine stepping in to help craft that definition.

In a letter sent to then-U.S. Secretary of Health and Human Services Kathleen Sebelius in late 2013, dozens of CFS specialists asked that the federal government cancel the contract under which the IOM would craft its report. They instead urged that the government outright adopt a definition published in 2003, known as the Canadian Consensus Criteria. They noted that this definition was created by researchers and doctors directly involved in ME/CFS.

However, the U.S government chose to let the IOM proceed with its work, which means that a number of researchers are looking to Tuesday's release with what would best be described as cautious optimism.

Vernon and Teitelbaum both said they hope that the IOM chooses to adopt most of the tenets of the Canadian Consensus Criteria.

One absolute positive of the IOM report will be its effect on the medical community, which still struggles to see chronic fatigue syndrome as a real disorder, Vernon said.

"The IOM is such a prestigious body. It's the medical arm of the National Academy of Sciences. When the IOM talks, the medical community listens," she said.

With the broad acceptance of a standard clinical definition, chronic fatigue syndrome patients could expect to see more support from physicians and, importantly, more coverage by insurance companies, Teitelbaum said.

People with chronic fatigue syndrome often have to convince their doctors that they aren't suffering from depression, even though their exhaustion has not left them depressed and they continue to enjoy many pleasurable interests—just no energy to pursue them, he explained.

"You have no idea how frustrating it is to have a real devastating illness and have no name for it, to have people thinking you're a crazy person," Teitelbaum said. "Having a definition that really defines what a person has will help them get the care and support they need."

More information: For more information on chronic fatigue syndrome, visit the [U.S. Centers for Disease Control and Prevention](https://www.cdc.gov/).

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