

# COVID-19 'Long-Haul' Symptoms Overlap With ME/CFS

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*Editor's note: Find the latest COVID-19 news and guidance in Medscape's [Coronavirus Resource Center](#).*

People experiencing long-term symptoms following acute COVID-19 infection are increasingly meeting criteria for [myalgic encephalomyelitis/chronic fatigue syndrome \(ME/CFS\)](#), a phenomenon that highlights the need for unified research and clinical approaches, speakers said at a press briefing Thursday held by the advocacy group [MEAction](#).

"Post-COVID lingering illness was predictable. Similar lingering fatigue syndromes have been reported in the scientific literature for nearly 100 years, following a variety of well-documented infections with viruses, bacteria, fungi, and even protozoa," said Anthony Komaroff, MD, professor of medicine at Harvard Medical School, Boston, Massachusetts.

[Core criteria](#) for ME/CFS established by the Institute of Medicine in 2015 include substantial decrement in functioning for at least 6 months, [postexertional malaise \(PEM\)](#), or a worsening of symptoms following even minor exertion (often described as "crashes"), unrefreshing sleep, and cognitive impairment and/or [orthostatic intolerance](#).

Patients with ME/CFS also commonly experience painful headaches, muscle or joint aches, and allergies/other sensitivities. Although many patients can trace their symptoms to an initiating infection, "the cause is often unclear because the diagnosis is often delayed for months or years after symptom onset," said Lucinda Bateman, MD, founder of the Bateman Horne Center, Salt Lake City, Utah, who leads [a clinician coalition](#) that aims to improve [ME/CFS management](#).

In an international survey of 3762 COVID-19 "long-haulers" [published](#) in a preprint last December, the most frequent symptoms reported at least 6 months after illness onset were fatigue in 78%, PEM in 72%, and cognitive dysfunction ("brain fog") in 55%. At the time of the survey, 45% reported requiring reduced work schedules due to their illness, and 22% reported being unable to work at all.

Bateman said those findings align with her experience so far with 12 COVID-19 "long haulers" who self-referred to her ME/CFS and [fibromyalgia](#) specialty clinic. Nine of the 12 [met criteria](#) for postural orthostatic tachycardia syndrome (POTS) based on the 10-minute NASA Lean Test, she said, and [half also met the 2016 American College of Rheumatology criteria for fibromyalgia](#).

"Some were severely impaired. [We suspect a small fiber polyneuropathy in about half, and mast cell activation syndrome in more than half](#). We look forward to doing more testing," Bateman said.

To be sure, Komaroff noted, there are some differences. "Long COVID" patients will often experience breathlessness and ongoing anosmia (loss of taste and smell), which aren't typical of ME/CFS.

But, he said, "many of the symptoms are quite similar...My guess is that ME/CFS is an illness with a final common pathway that can be triggered by different things," said Komaroff, who's also a senior physician at Brigham and Women's Hospital in Boston, and editor in chief of the Harvard Health Letter.

Based on [previous data](#) about CFS suggesting a 10% rate of symptoms persisting at least a year following a variety of infectious agents and the predicted 200 million COVID-19 cases globally by the end of 2021, Komaroff estimated that about 20 million cases of "long COVID" would be expected in the next year.

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## "A Huge Investment"

On the research side, the National Institutes of Health recently appropriated \$1.15 billion dollars over the next 4 years to investigate "the heterogeneity in the recovery process after COVID and to develop treatments for those suffering from [post-acute COVID syndrome]" according to [a February 5, 2021 blog](#) from the National Institute of Neurological Disorders and Stroke (NINDS).

That same day, [another NINDS blog](#) announced "new resources for large-scale ME/CFS research" and emphasized the tie-

in with long-COVID syndrome.

"That's a huge investment. In my opinion, there will be several lingering illnesses following COVID," Komaroff commented, adding "It's my bet that long COVID will prove to be caused by certain kinds of abnormalities in the brain, some of the same abnormalities already identified in ME/CFS. Research will determine whether that's right or wrong."

In 2017, NINDS [had announced](#) a large increase in funding for ME/CFS research, including the creation of four dedicated research centers. In April 2019, NINDS held a 2-day conference highlighting that ongoing work, [as reported by Medscape Medical News](#).

During the briefing, NINDS clinical director Avindra Nath, MD, described a comprehensive ongoing ME/CFS [intramural study](#) he's been leading since 2016.

He's now also overseeing two long-COVID studies, one of which has a similar protocol to the ME/CFS study and will include individuals who are still experiencing long-term symptoms following confirmed cases of COVID-19. The aim is to screen about 1300 patients. Several task forces are now examining all of these data together.

"Each aspect is now being analyzed...What we learn from one applies to the other," Nath said.

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## Advice for Clinicians

In response to questions from *Medscape Medical News*, Bateman and Nath offered clinical advice for managing patients who [meet ME/CFS criteria](#), whether they had confirmed or suspected COVID-19, a different infection, or unknown trigger(s).

Bateman advised that clinicians assess patients for each of the symptoms individually. "Besides exercise intolerance and PEM, the most commonly missed is orthostatic intolerance. It really doesn't matter what the cause is, it's amenable to supportive treatment. It's one aspect of the illness that contributes to severely impaired function. My plea to all physicians would be for sure to assess for [orthostatic intolerance], and gain an understanding about activity management and avoiding PEM symptoms."

Nath noted that an often-challenging situation is when tests for the infectious agent and other blood work come back negative, yet the patient still reports multiple debilitating symptoms. This has been a particular issue with long COVID, since many patients became ill early in the pandemic before the polymerase chain reaction (PCR) tests for SARS-CoV-2 were widely available.

"The physician can only order tests that are available at their labs. I think what the physician should do is handle symptoms symptomatically but also refer [patients to specialists](#) who are taking care of these patients or to research studies," he said.

Bateman added, "Whether they had a documented COVID infection — we just have to let go of that in 2020. Way too many people didn't have access to a test or the timing wasn't amenable. If people meet criteria for ME/CFS, it's irrelevant...It's mainly a clinical diagnosis. It's not reliant on identifying the infectious trigger."

Komaroff, who began caring for then-termed "chronic fatigue syndrome" patients and [researching](#) the condition more than 30 years ago, commented that "every cloud has its silver lining. The increased focus on post-infectious fatigue syndrome is a silver lining in my mind around the terrible dark cloud that is the pandemic of COVID."

*Komaroff has received personal fees from Serimmune Inc, Ono Pharma, and Deallus, and grants from the NIH. Bateman is employed by the Bateman Horne Center which receives grants from NIH, and fees from Exagen, Inc, and Teva Pharmaceutical. Nath is an NIH employee.*

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