



Meet the Long Haulers Developing ME/CFS

Long COVID and ME/CFS: Understanding the Connection

The outcome for COVID-19 long haulers will not be uniform. Some long haulers are recovering, some will suffer long-term organ damage, and a subset are developing distinct, post-viral diseases that are neither new nor mysterious.

Myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS) is one of these post-viral diseases. We expect that 10-12% of all people with COVID-19 will go on to develop ME/CFS, based on scientific evidence from past viral outbreaks.

“The coronavirus pandemic is very likely over time to create almost a pandemic of ME [myalgic encephalomyelitis],” said Dr. Ron Tompkins, a surgeon from Massachusetts General Hospital who also researches ME/CFS, [quoted in an article](#) in Time magazine.

Long Haulers Reporting ME/CFS Symptoms

Kelly Towart, 35, from Connecticut, is seven months out from getting COVID-19 and even light exertion can cause an onset of post-exertional malaise (PEM), leaving her on the couch for days. Kelly is the mother of two little girls, a 23-month-old and 5-year-old, and for the first four-and-a-half months of having COVID-19, she was completely unable to care for them.

[Post-exertional malaise \(PEM\)](#) is the cardinal symptom of ME/CFS, unique to the disease, where cognitive or physical overexertion can lead to a flare of symptoms and/or the appearance of new symptoms, often presenting 24 hours after the triggering event. *Post-exertional malaise is not the same as fatigue*, although profound fatigue can also be present in people with ME/CFS, as well.

Long hauler Jake Elsas, 53, from Atlanta, GA says his symptoms align perfectly with ME/CFS but he is still waiting to receive an official diagnosis from his doctor. Previously healthy with no

underlying conditions, Jake has been sick since March 18th. His most troubling symptoms are PEM and brain fog.

Distinguishing between Long COVID Subsets

Long haulers are also reporting symptoms of postural orthostatic tachycardia syndrome (POTS).

It is essential that the media and medical community **distinguish between ME/CFS and POTS** when communicating about long haulers. Even though ME/CFS and POTS are often comorbid, they are different diseases, and treatments beneficial for POTS may actually harm someone with ME/CFS.

There are several long COVID clinics offering gradual exercise and reconditioning programs for long haulers. While recumbent exercise has been shown to be helpful for some people with POTS, **long haulers showing symptoms of ME/CFS should NOT undertake graded exercise**, which can have serious, long-term consequences for their health.

The CDC does not recommend graded exercise for ME/CFS and has stated that [graded exercise may cause harm](#).

People with ME/CFS have a significantly impaired cardiovascular response to exercise, explains Mark VanNess, associate professor of health, exercise and sport sciences at the University of the Pacific.

“It seems like exercise is a preventative medicine for just about every disease,” VanNess said. “We have to remember that does *not* apply to ME/CFS. Aerobic exercise can make people with ME/CFS very, very ill.”

People with ME/CFS have long reported a deterioration in their health after undertaking graded exercise, even at low levels and for short periods of time. A recent, [large-scale survey](#) found that 80% of people with ME found no benefit or *significantly worsened* on graded exercise regimens.

People with ME/CFS who were given a period of enforced rest from onset had the best prognosis, according to [this study](#).

Long haulers showing symptoms of ME/CFS should be **encouraged to pace** their activity. Pacing means being active when able, resting when tired, and planning extra rest ahead of strenuous activities. The goal is to avoid a push-crash cycle.

Jennifer, 53, is a registered nurse living in San Diego who had moderate COVID-19 in early March but was not severe enough to be hospitalized. After six months of ongoing symptoms,

Jennifer began to feel strong enough to attempt cardio and strength training exercises at a reduced capacity. Jennifer's experience of attempting to gradually exercise and subsequently worsening her health, possibly irreparably, is common among people with ME/CFS.

After one 15 minute workout on the treadmill, Jennifer began to crash, experiencing chest pain, extreme fatigue and trouble concentrating. She had to spend several days on the couch recovering - at one point, too weak to even lift herself off the couch. Her activity level never reached the pre-treadmill level again, and even walking around the house causes increased chest pain and fatigue. Jennifer is still unable to go back to work as a nurse. Complete rest and pacing only provide mild relief.

#MEAction has just launched a [Stop. Rest. Pace campaign](#) to encourage long haulers to rest as needed, and not to push themselves to exercise.

Why Some Long Haulers are Struggling to get a Diagnosis

Even when long haulers clearly exhibit the symptoms of ME/CFS, receiving a diagnosis for the disease is arduous since the majority of medical providers are not educated about ME/CFS, or treat it as a diagnosis of exclusion, meaning they want to rule out other diagnoses first. Like all diseases, ME/CFS requires differential diagnosis, and diagnosis is based on positive signs and symptoms. The time it takes for long haulers to receive a diagnosis can hamper their chances of recovery in the long run.

There has long been a crisis of clinical care for ME/CFS. Currently, there are only 15 practicing ME/CFS specialists in the country - many of them nearing retirement age. At the same time, less than one third of medical schools teach about the disease.

The current rate of new COVID-19 infections in the U.S. means that the number of people with ME [could more than double](#) in the next two years, exacerbating the clinical crisis already at hand. Before the pandemic began, [1 million Americans](#) already struggled with ME/CFS.

Scientific Evidence of Viral Outbreaks Leading to ME/CFS

This is not the first time a coronavirus has resulted in documented ME/CFS. There is a long, well-documented history of viral outbreaks triggering the disease. An infection is the most common trigger of ME/CFS: up to 80% of patients develop ME following an infection.

"It came to us as no surprise that ME/CFS symptoms would arise in the post-Covid population," said Dr. Avi Nath, a clinical director at NINDS, during an [NIH Interagency ME/CFS meeting](#) on Aug. 11.

- A [study](#) on SARS showed that 27% of survivors still met CFS criteria several years after developing SARS.
- A [study](#) on Epstein-Barr virus, Q Fever, and Ross River virus showed that ~12% of subjects across the board met ME/CFS criteria at 6 months after clearing the infection.
- A [study](#) of people with mononucleosis (Epstein-Barr virus) produced identical numbers: ~12% of subjects across the board met ME/CFS criteria at 6 months after clearing the infection.

There are also a handful of [highly-publicized outbreaks](#) leading to ME/CFS: some of the biggest ones include the Epstein-Barr Viral outbreaks in New York; the Lake Tahoe outbreak in Nevada; and the Royal Free Outbreak in London.

Dr. Anthony Fauci has [emphasized in several interviews](#) that people who are not recovering after contracting COVID-19 are showing symptoms “that are highly suggestive of myalgic encephalomyelitis and chronic fatigue syndrome,” including severe fatigue, cognitive problems, chills and sweats and sleep problems.

Why Different Viruses can Trigger ME/CFS

That a wide variety of different infectious organisms can lead to the same disease-state may seem surprising – but ME/CFS may be caused by the body’s unexpectedly uniform reaction to any number of assaults.

“I wouldn’t suggest that coronavirus is the cause of ME; rather, innate immune mechanisms in response to a virus may cause it, meaning that many viruses can probably [initiate ME/CFS],” said [Dr. Ian Lipkin](#), the Director of the Center for Infection and Immunity and a coronavirus and ME/CFS expert.

It is not yet clear what causes the symptoms of ME/CFS, and research is exploring various theories.

“People with ME/CFS, and possibly the post-COVID long haulers, may have an ongoing low level of inflammation in the brain, or decreased blood flow to the brain, or an autoimmune condition in which the body makes antibodies that attack the brain, or several of these abnormalities,” [wrote Dr. Anthony Komaroff](#), Professor of Medicine at Harvard Medical School.

The pandemic has created a unique opportunity to understand how a viral infection can lead to ME/CFS in real time. ME/CFS researchers at Stanford, Columbia and the NIH are launching studies on COVID-19 patients to understand how the virus may lead to ME/CFS.

“The COVID-19 pandemic is an unprecedented opportunity to study the biological factors that may determine or predict the development of ME/CFS,” said Ron Davis, PhD, director of the Stanford Genome Technology Center. Davis is overseeing a team of researchers investigating COVID-19 patients to understand if and how their infection leads to ME/CFS.

The Future for Long Haulers

#MEAction has issued a report about the NIH’s plan for addressing long COVID and ME/CFS research. **The bottom line is that the NIH lacks a strategic plan to address long COVID.** [Read the report.](#) (The NIH has neglected ME/CFS research for the past 40 years, allocating [few](#) research dollars [relative to disease burden.](#))

Resources on Long COVID & ME/CFS

[#MEAction](#) is an international organization of patients, caregivers and allies fighting for recognition and research for ME/CFS.

- Review our [Journalist Guide for Reporting on ME/CFS](#) to learn the facts and history about the disease and ensure your reporting is accurate and informed.
- Watch our [seminar for long haulers](#) about a potential diagnosis of ME/CFS.
- Read our [Research Summary](#) for the past 10 years of research into ME/CFS.

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