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We know too little about Covid-19 'long-haulers.' We need a comprehensive study

Covid patients are reporting persistent, long-term symptoms of chronic fatigue. Let's get to the bottom of this.

By Oved Amitay and Anthony L Komaroff
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'A recent CDC report found that 35% of respondents who tested positive for Covid-19 and had symptoms didn't feel like they were back to normal 2–3 weeks after testing.' Photograph: Marco Di Lauro/Getty Images

“Long-haulers” is no longer just a job description for truckers.

This term now refers to the growing number of people who contracted Covid-19 and have continued to have symptoms for more than 100 days – even though tests reveal no virus left in the body. Covid-19 “long-haulers” continue to struggle with debilitating symptoms, often alone, in the shadows of this devastating disease. Having escaped the worst, they nevertheless continue to struggle. It feels like a betrayal.

Symptoms reported include headaches, difficulty concentrating and extreme fatigue. In one survey of 1,500 people with confirmed or suspected Covid-19, conducted by a [Facebook community](#) of long-haulers more than half continued to have debilitating symptoms for more than three months. A [recent CDC report](#) found that 35% of respondents who tested positive for Covid-19 and had symptoms didn’t feel like they were back to normal 2–3 weeks after testing. Although Covid-19 is considered most dangerous to the elderly or immunocompromised, the study noted that one in five respondents aged 18-34, without prior chronic medical conditions, said they hadn’t completely recovered. This is particularly concerning since much of the current spread of new cases in the US is in younger people.

In fact, it’s not unusual for patients to develop chronic, debilitating symptoms after infection by a wide variety of viruses, bacteria and other microorganisms. The phenomenon is called “post-infectious fatigue syndrome”. It can follow common infections, like mono or Lyme disease, or emerging and more severe diseases caused by Ebola, SARS and West Nile Virus.

The symptoms of post-Covid long haulers can be indistinguishable from those typical of the illness called myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). Indeed, in many people with ME/CFS the illness started after an infectious-like illness or well-documented infection. The US National Academies of Sciences, Engineering and Medicine and the Centers for Disease Control and Prevention estimate that as many as 2.5m Americans were suffering from ME/CFS before the Covid-19 pandemic, generating direct and indirect costs of \$17-24b annually. The pandemic may drive these numbers higher.

Dr Anthony Fauci, the head of the federal government’s infectious diseases institute, has acknowledged a possible connection between Covid-19 and ME/CFS: “Even after you clear the virus, there are postviral symptoms,” he said in [an interview](#) with Medscape. “And it’s extraordinary how many people have a postviral syndrome that’s very strikingly similar to myalgic encephalomyelitis/chronic fatigue syndrome. They just don’t get back to normal energy or normal feeling of good health.”

We agree with Dr Fauci: Getting the pandemic under control is obviously the top priority, but we also should not ignore the long-term impact of Covid-19. The threat of severe illness and death may be behind them, and the virus may no longer be detectable in their bodies, but some people with Covid-19 remain seriously incapacitated. We need to figure out why, and try to fix it.

A study of Covid-19 long haulers may well also shed light on ME/CFS and post-infectious fatigue syndromes following infections other than COVID-19. One major obstacle to

understanding the long-term effects of Covid-19 is the lack of available data. The scientific community – public and private – needs to gather as much data as possible while we are still in the early phases of this Covid-19 era.

Solve M.E., a national organization dedicated to ME/CFS, recently launched the You + M.E. Registry and Biobank, and a companion app, to allow people to report their symptoms, medical information (like treatments), activity and life events, and to provide blood samples that can help researchers understand the connection between Covid-19 and ME/CFS. This database can be one source of the data needed to understand the long-haulers, and others with ME/CFS.

There are currently bills in both houses of Congress to increase funding for the study of ME/CFS. We need the federal government and the life sciences industry to support increased research on ME/CFS, including the likely connection to COVID-19. We need to understand why some people are simply not recovering. The only way we can arrive at answers is to make a concerted and collective effort that unites patients, caregivers, physicians, researchers in both academia and industry, policymakers, and philanthropies.

Let's study the long-haulers now. This research could improve care for the millions who have been infected by the Covid-19 coronavirus – and those who already have ME/CFS, as well.

- Oved Amitay is President and CEO of Solve M.E., a private charitable foundation dedicated to improving the care of people with the disease ME/CFS
- Anthony L Komaroff is Professor of Medicine at Harvard Medical School and Senior Physician at Brigham & Women's Hospital in Boston

Contact

Phone: 704-364-0016 | **Website:** www.solveme.org | **Email:** solvecfs@solvecfs.org

Facebook: [SolveMECFSInitiative](https://www.facebook.com/SolveMECFSInitiative) | **Twitter:** [@PlzSolveCFS](https://twitter.com/PlzSolveCFS) | **Instagram:** [solve_cfs](https://www.instagram.com/solve_cfs)