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Health

With long-haul covid-19, important advice for patients, doctors and researchers

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Perspective by Julie Rehmeyer, Jennifer Brea and [Brian Vastag](#)

Back in February, as the United States was bracing itself for the first onslaught of the novel coronavirus, we and other chronically ill patients braced ourselves for a different threat: Many more people, we were sure, would soon be joining our ranks. So we've been saddened but unsurprised at news of patients with "long-haul covid-19" who have struggled for months with ongoing and devastating symptoms after getting covid-19, including shortness of breath, fatigue, chills, pain, fever, cognitive problems, difficulty regulating blood pressure and heart rate, and many more.

We wish you newcomers to the land of poorly-understood chronic illness didn't have to join us, but now that you're here, we'd like to offer practical advice to help you (and your doctors and researchers) find your way around.

First, here's how we knew you were coming: We've watched patients develop our illness, myalgic encephalomyelitis (sometimes called chronic fatigue syndrome, ME or ME/CFS), after getting sick from a wide variety of viruses and other pathogens. While most people recover from viral infections, some unlucky percentage of people experience symptoms that last long after their immune systems have apparently wrestled the virus into submission.

We see this in patients with an array of unrelated pathogens: 90 percent of [those with Ebola](#); 11 percent of those with [Ross River virus, Q fever or Epstein-Barr virus](#); and 40 percent of those with [severe acute respiratory syndrome](#) (which, like covid-19, is caused by a coronavirus). Why, then, would covid-19 not be the same?

Even the unlucky patients with post-viral symptoms don't always develop [full-blown ME](#). But for those who do, rather than recovering and getting back to ordinary life, they linger in a half-life, hobbled by pain, exhaustion, sensory sensitivity, cognitive impairment or crashing blood pressure especially after exertion, even for something as simple as taking

a too-brisk walk or just brushing teeth. We get slammed back into bed, the intensity of our symptoms redoubled.

The symptoms many [long-haul covid-19 patients are reporting](#) are eerily familiar to us, especially the descriptions of getting worse every time they exert themselves. And it's not just us noting the similarity. Scientists including [Anthony S. Fauci, director of the National Institute of Allergy and Infectious Diseases](#), have too.

Regardless of whether your persistent symptoms turn out to be due to ME or organ damage or something else, you're going to need to hone your navigational skills in the shadowlands of poorly understood, chronic illness.

Here are a few tips, based on our experiences and those of many others:

- Above all, trust your body. When your body tells you to rest, rest. Ignore advice to gradually build up your activity regardless of how you feel. That advice has been pushed hard on ME patients over the years, with influential studies claiming to show its efficacy. But many of us who have tried it have gotten worse and stayed worse as a result. The science claiming to back this approach has [shocking flaws that ME patients exposed with decades of effort](#). Yet, some doctors are advising it again for long-haul covid-19. The reality is that you're going to have to learn to pace yourself. That advice may sound trivial, but pacing is a true skill. A good start is to wear a heart monitor all the time and stop whatever activity you're doing as soon as your heart rate begins climbing. But watch out: Mental exertion counts, too.
- Reject any suggestion that your symptoms are all in your head, another notion that has for decades been inflicted on ME patients. Psychotherapy can help you cope with the enormous stress of being sick, but it's unlikely to directly heal your body. Look for a therapist who has experience with chronic illness and who will believe and support you, and protect yourself from anyone who doubts the reality of your illness.
- Don't expect doctors to have all the answers. Instead, view them as one resource among many. They don't have the answers for long-haul covid-19 because it is a new illness, but they also don't have them for ME, because the illness has been neglected by both researchers and medical schools. You are going to have to find — no, bushwhack — your own path. [Fellow](#) patients, found on such websites as [Body Politic \(WeareBodyPolitic.com\)](#), will be one of your richest sources of help for this.

[Online patient groups](#) are invaluable for finding patients to learn from and for companionship on the journey, but use groups with caution, since they can devolve at their worst into pseudoscientific echo chambers.

Even though science has yet to answer most questions about long-haul covid-19 (or ME, or most chronic illnesses), don't abandon scientific inquiry as a tool. The BodyPolitic is conducting a valuable survey of patient symptoms, and some long-haul patients are creating their own research at [Patientresearchcovid19.com](#). Push for smarter research and increased research funding, following in the steps of some ME groups, such

as [MEAction.net](#) and [SolveCFS.org](#). Reason scientifically about your experiences to guide your treatment. If you have the skills, read scientific studies related to your illness. [Participate in studies](#) and cooperate with researchers to help guide their work.

- If you're too sick to work, get savvy about [how to survive financially with long-haul symptoms](#). As much as you may hope and expect to recover soon, don't just spend down your savings, gambling on improving before you hit zero. The statistics on ME are sobering: [Studies show](#) that ME patients on average report being [significantly more disabled](#) than those with heart failure, multiple sclerosis, diabetes, [cancer](#), [rheumatoid arthritis](#) or lung disease.

If you have short-term or long-term disability insurance through your job, take paid leave. Some states, such as California, afford up to a year of short-term disability benefits to all workers. The federal Family and Medical Leave Act also provides 12 weeks of unpaid leave while protecting your job. If you are self-employed, buy an individual long-term disability policy. If you have been unable to work for five months or longer, you can and should apply for Social Security Disability Insurance, as well. (Most long-term disability policies require claimants to apply for SSDI to receive additional private benefits.)

- If you're a doctor treating long-haul covid-19 patients, get comfortable not having the answers. Above all, don't conclude that patients' symptoms must not be that severe because the tests appear normal or patients look well. Reassure them that you believe them and are in this with them, even though we don't yet know the best way to help. [A 2013 study](#) showed that less than one-third of medical schools include ME/CFS in their curriculum, so you'll need to educate yourself. The [U.S. ME/CFS Clinician Coalition](#) is a good place to start and it can help you direct your patients to relevant specialists. Because Black, Latinos and Native Americans are more likely to get covid-19 and have complications from it, it's important to watch for implicit biases that could lead you to discount their symptoms. Since we don't have proven treatments, be open-minded about low-risk, unproven treatments, and help your patients think scientifically about such experiments.

And if you're a researcher, please study long-haul covid-19. Don't let it end up ignored as ME has been. Last year, the National Institutes of Health spent only \$15 million on ME research (by comparison, it spent \$109 million on multiple sclerosis, which has a similar prevalence and can be similarly debilitating).

Long-haul covid-19 is from a new virus, but it's part of an old pattern. We need a radical transformation in how we treat chronic illness; in the relationships between patients, doctors and researchers; in the support we offer patients who aren't likely to get better next week. So unfortunately, you long-haul covid-19 patients haven't just contracted a prolonged illness — you've inherited a battle.

The good news is that you're not alone. We've been fighting for you since before any of us had ever heard of covid-19.

Julie Rehmeyer, a mathematics and science writer, is author of ["Through the Shadowlands: A Science Writer's Odyssey Into an Illness Science Doesn't Understand."](#) She first developed ME symptoms in 1999. Filmmaker Jennifer Brea, co-founder of #MEAction, directed the documentary "Unrest" (2017), about the chronic illness she has experienced following a high fever in 2011. Brian Vastag is a former Washington Post science writer who has had ME since 2012.