TuSalud

For People With Severe Long COVID, Medical Care Is Out of Reach

People with long COVID who are unable to leave their beds find accessing doctors and treatments nearly impossible.

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Key points you should know:

- Research suggests that millions of adults with long COVID are unable to leave their beds and homes without severe health consequences.

- Tightening restrictions on telehealth, cross-state licensing laws, and a lack of insurance reimbursement for in-home services — coupled with a dearth of physicians skilled at treating severe long COVID — has left bedbound people unable to access quality medical care.

- Those who can access care are often left to pay out of pocket and can end up in medical debt.

- People with severe long COVID and ME/CFS are widely excluded from medical research, leading to a lack of treatments and understanding of the diseases.

For the past year and a half, Dianna Cowern has lived in almost complete darkness.

The 35-year-old MIT-educated science communicator, known for her popular Physics Girl YouTube channel, has been confined to her bed in a dark room, unable to use the bathroom on her own, read, or watch television. She can only communicate with her husband, Kyle Kitzmiller, through occasional whispers, notes, and hand signals.

Cowern has been suffering from severe long COVID since January 2023, following a COVID-19 case in July 2022. Isolated from most outside contact and typical coping mechanisms to distract from the constant pain, Cowern's quality of life, like many people with long COVID, is worse than that of

some end-stage cancers — but without an end to the suffering in sight. Kitzmiller has gone down every avenue of medical care, but, outside of a few expensive specialists, has mostly hit dead ends.

“The medical system is not set up to treat someone like Dianna,” he said. “Doctors say if she’s too sick to travel to appointments, I should take her to the hospital. But the hospital won’t admit her, because they can’t find anything wrong. It just leaves us out of the care system entirely.”

Getting medical help for any severity of long COVID is challenging. The disease can manifest as over 200 different symptoms, ranging in severity from mildly impacting quality of life to completely debilitating. For those in the most severe categories — who are barely or completely unable to leave their beds — accessing quality care is nearly impossible. Their struggles reveal yawning gaps in a medical system that chronically ill people have been falling through for decades.

The doctor’s office is a health risk

There’s no solid data on how many people with long COVID are bedbound. But scientists have studied this level of severity in myalgic encephalomyelitis (ME) — a debilitating disease for which 40% to 70% of people with long COVID could meet the diagnostic criteria. Studies estimate one in four ME cases are severe, meaning millions of the estimated 400 million people worldwide with long COVID may be unable to leave their homes.

Severe and very severe ME has been overlooked and stigmatized for decades. This can have potentially fatal consequences: dozens of people have died from ME and thousands from long COVID, though both numbers are likely undercounts.

For people with severe ong COVID, researching doctors, making appointments, and traveling even short distances to medical offices can lead to post-exertional malaise (PEM), in which even minimal effort causes a significant worsening of symptoms. People often call this period of worsening symptoms a “crash”; crashes can last days, months, or even years.

“The energy it takes to prepare for the trip, the emotional toll of the appointment, and the drive home is always immense and makes me sicker for weeks,” 27-year-old Rye Wheeler wrote to The Sick Times.

Many find that the cost of these visits is rarely worth it, as they often encounter doctors who are dismissive or uninformed about long COVID and ME. About seven months into her illness, Wheeler, formerly an avid hiker and weightlifter, could only manage a 10-minute walk. Then, a cardiologist instructed her to push through her symptoms to go for longer walks, while refusing to do further testing. She followed the cardiologist’s advice, and quickly declined. She can now only manage two minutes of walking at a time.

Natalie Schnack, 37, was advised by doctors to seek counseling for anxiety and depression and to spend 30 minutes a day on a treadmill for her severe long COVID, despite evidence that exercise

can harm people with long COVID who experience PEM. At the time, she was able to get around her home, but struggled to use the shower or stairs.

She is now mostly bedbound.

“Insurance and primary care providers have little to no information, cannot be relied upon, and can actively hurt you with their ignorance and gaslighting,” she wrote in an email.

“Our medical schools do not teach this,” said Melanie Hoppers, a physician who works with the Bateman Horne Center, a treatment and research clinic for long COVID, ME, and fibromyalgia. She sought training from the clinic when she was unable to find a physician to help her teenage daughter, who has severe ME.

Hoppers said that seeking care at hospitals can be even worse than doctor’s appointments. She describes getting her daughter admitted for severe breathing and swallowing issues as “an absolute nightmare.” Doctors ignored requests for accommodations for her child’s light and noise sensitivities and suggested her health issues were all in her head.

“It felt like they were killing her,” Hoppers said, “And I’m a doctor. I can’t imagine what it would be like for a person without someone to protect them.”

Other people with long COVID and ME report hospitals refusing admission when basic tests return normal results. Victoria C., a 31-year-old who had just finished a PhD in social welfare before developing severe long COVID, was dismissed from multiple emergency rooms without treatment for severe stomach issues that left her unable to eat anything but chicken broth, causing her to lose 40 pounds. After a normal endoscopy, a gastrointestinal doctor diagnosed her with bulimia, despite her insistence that she wanted to eat, but couldn’t.

Severe long COVID patients are also often forced to forgo other critical appointments due to their inability to travel or to put themselves at risk of another COVID-19 infection, as few healthcare facilities mitigate the spread of the disease. After one in-person appointment triggered a months-long crash, Schnack could not visit the eye doctor, dentist, or get thyroid tests meant to check for cancer.

People with severe long COVID and ME are forced to make impossible decisions about their health.

The limits of telehealth

Earlier in the pandemic, telehealth and licensing restrictions were relaxed, allowing immobile patients to access care virtually from both in and out-of-state doctors. However, following the declared end to the public health emergency in 2023, many states now require initial in-person visits for new patients, do not allow out-of-state doctors to treat patients, and do not mandate that insurers reimburse telehealth at the same rate as in-office appointments.

“I lost access to all my doctors unless I saw them in person,” said Victoria. After seeing nearly two

dozen physicians and making over 20 emergency room visits, she eventually found an out-of-state ME specialist willing to see her virtually, for a fee of $300 per appointment. But the specialist could not prescribe medications due to licensing laws, and her primary care physician refused to fill the orders. (Eventually, the ME specialist got licensed in Victoria's state to provide treatment.)

Dianna Cowern found some treatment through a virtual ME specialist, but after he retired, she struggled to find another doctor willing to see her or order diagnostic tests without an initial in-person exam. "I've tried repeatedly to explain her situation and offer solutions but it's just not working," her husband, Kitzmiller, said. "I keep hitting closed doors." (Just before this story was published, Kitzmiller said they had found Cowern a new ME specialist after months of searching.)

This is an issue for doctors, too: David Systrom, a clinician and researcher at Brigham Women's Hospital in Boston who specializes in ME and long COVID, said he received directives from hospital administrators to no longer see out-of-state patients or do initial appointments remotely, or he could risk losing malpractice insurance coverage.

"I don't think any of us are truly serving our severely ill patients as we would like," said Brayden Yellman, a physician at the Bateman Horne Center. Physical exams are crucial for severely ill patients, but require doctors to go to them. However, he said, insurance often does not cover home visits, and many doctors lack the time in what he calls today's "churn and burn" medical system.

While federal programs like Medicaid and Medicare provide access to home health care, it's up to state assessors to determine if it's a "medical necessity" for a specific person. While the federal government recognized long COVID as a disability in 2021, this recognition was specific to the Americans with Disabilites Act and didn't extend to healthcare or benefit programs. For many people, the recognition has not trickled down to coverage of in-home care. Most people with severe long COVID require around-the-clock help with everything from eating to using the bathroom, but are not considered eligible for in-home services — forcing them to rely on friends or family.

Many patients report paying out-of-pocket for in-home testing and treatments, like blood draws and infusions. Victoria said that five different doctors refused to do the extensive paperwork it took to get in-home infusions approved through the disability insurance she receives from her work.

Despite being almost completely bedbound, she's only been able to get home healthcare once after being hospitalized with a COVID-19 reinfection. Victoria was left with open bedsores when the agency abruptly stopped coming. "If someone is elderly or has cancer they get all kinds of resources for this," Yellman said. "But trying to prove to others that someone needs this [care] when they're 30 years old is really, really difficult."

Even when patients navigate these hurdles, the cost of treatment can be prohibitive. Many people with severe long COVID require medications from specialized compounding pharmacies, which are exponentially more expensive and often not covered by insurance.

Few physicians specializing in long COVID or ME accept insurance, and their fees can quickly add up. For example, long COVID-focused telehealth startup RTHM costs $1,000 per month, plus a $1,500 onboarding fee — and that doesn't include testing expenses not covered by insurance. In an email, a RTHM representative said they recently began offering online asynchronous assessments and medication check-ins for between $49 to $59 dollars for 90 days, but that option was not yet suited for the severe population.

The Bateman Horne Center, which currently operates with a combination of insurance and patient fees, plans to transition to an all-fee model due to limitations with insurance reimbursements. Executive director Rob Ence said they will still offer free and reduced-cost services for patients in need. However, they can only accept around 50 new patients a year.

This leaves many severe long COVID patients in debt just to get care. Victoria estimates she has about $30,000 in past-due medical bills.

Left out of research

Underpinning the lack of care for severe long COVID is a shortage of research. Only two of the current 13 clinical trials under the NIH's $1.5 billion RECOVER study for long COVID claim to focus on more severe patients. Only one directly addresses PEM and emphasizes pacing, an already established lifestyle modification for ME. Both trials require in-person visits to a medical facility, which excludes many severe patients from participating.

Leora Horwitz, a researcher at New York University who leads RECOVER's adult observational study, said that in almost every state, there are mobile vans that can travel closer to participants' homes for observational testing. One site can conduct all visits in patients' homes, but it's only available to people in the initiative's pregnancy study. The initiative does not currently have plans to further expand for people with severe symptoms to participate.

"People who are truly bedbound can participate but are likely only able to contribute to survey data, limiting our ability to capture their physiologic data," Horwitz said in an email. There are no plans to expand in-home visits to severe participants.

The current dearth of research on severe long COVID mirrors the situation with severe ME over the decades. "We've seen NIH funding for 30 years fail to move the needle on what we can offer folks who are bedbound, and it's an unacceptable situation," said David Putrino, director of the Cohen Center for Complex Chronic Illness at Mount Sinai. "[Government agencies] tell you priority will be given to those who recruit a diverse cohort, but they do not include diversity in disability."

Putrino believes the failure to study more severe patients stems from a lack of creativity rather than an inability to do so. He points to an ongoing study he's co-authoring with Yale researchers examining the effects of a 15-day Paxlovid course on long COVID symptoms.

This study was completely decentralized, with medication shipped to participants and blood draws done in-home conducted in 48 U.S. states. In another ongoing study, he received a grant from

Uber to transport researchers to patients' homes. Wearable devices could also help researchers collect data from people with more severe symptoms, he said.

"Obtaining a more representative sample of the population and studying a group that has not been researched for decades is more important than a little inconvenience on the part of the investigators," Putrino said. Study designs that exclude severe patients will not only skew data, but also risk missing individuals exhibiting the most prominent biological signs of the illness, he added.

Even studies that examine patients with milder symptoms but require travel to participate could affect results: the trip to the study site might exacerbate their symptoms, masking any potential positive effects of the intervention being studied.

"When we fail to prioritize the disability community, it's not just detrimental to them, it's detrimental to all of us," Putrino said.

Until better research yields better treatments, patients like Victoria are left in a state of agonizing limbo. "Right now I'm not sure where to go, what to do, or who to talk to," she said. "It feels like I'm slowly dying alone."

Kaelyn Lynch is a freelance multimedia journalist and filmmaker living with Long COVID whose work has appeared in outlets such as National Geographic and Outside. She is currently in post-production on a short film about severe long COVID.

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