

Covid long-haulers face grueling fights for disability benefits

Patients and doctors say safety net is unprepared for novel claims stemming from the pandemic

By [Christopher Rowland](#)

Yesterday at 7:30 a.m. EST



Deepa Singh, 30, of Louisville, has been seriously ill for two years, racked with extreme fatigue, racing heartbeat and memory problems from long covid that she says prevent her from working. Adding to her distress, she says, has been a grueling — and so far unsuccessful — battle for disability payments.

Singh, who worked as a project manager for a Fortune 100 company, is among a cohort of long covid patients who have been denied disability benefits, either by private insurance companies, which operate benefit plans offered by employers, or by the Social Security Administration, which manages government disability benefits.

Tasked with sorting legitimate health claims from fraudulent or marginal ones, these gatekeepers now face a novel challenge as the [coronavirus](#) pandemic drags on: a flood of claims citing a post-infection syndrome that is poorly understood by the medical community and difficult to measure.

Patients cite a litany of symptoms that defy verification through basic medical tests. They become exhausted at the merest exertion. They can't remember simple words. Their hearts feel like they are fluttering. Yet neurological exams, EKGs and chest X-rays come back clean.

Doctors said in interviews they are treating long covid patients who are clearly too sick to work but who have difficulty meeting the evidence threshold insurers demand: objective medical test results showing an inability to perform work.

“I would say some denials are unjustified,” said Monica Verduzco-Gutierrez, chair of the Department of Rehabilitation Medicine at the Long School of Medicine and chief of the long covid clinic at the University of Texas Health Science Center at San Antonio. “Almost every day I’m filling out disability paperwork, writing letters of appeal and talking with people from disability companies.”

Specialized tests can measure a few long covid-related problems, such as a central nervous system disorder called dysautonomia, which affects the body’s ability to regulate itself. But there are months-long waiting lists for the tests, doctors and patients said.

The challenges are similar to those faced for years by people claiming disabilities based on chronic fatigue syndrome. But the pandemic has given rise to such claims on a far greater scale.

“We are seeing a mini epidemic of chronic fatigue syndrome,” said Benjamin Natelson, a neurologist at Mount Sinai Hospital in New York who specializes in such post-viral disorders.

In the United States, covid has infected more than 79 million people and claimed more than 950,000 lives. **Doctors have estimated there are 750,000 to 1.3 million or more Americans too sick with long covid to return to their jobs.** A recent analysis published by the Brookings Institution, based on data from various studies, suggested that long covid disabilities and workplace absences could account for 15 percent of America’s 10.6 million unfilled jobs.

Private companies and the Social Security Administration, in response to questions from The Washington Post, **declined to disclose the percentages of people with long covid whose applications for benefits have been denied.** The industry trade group, the American Council of Life Insurers (ACLI), said it did not have data that could document a rise in overall disability applications or illuminate the ratio of denied claims for long covid.

“The true impact of the virus on policyholders and people overall won’t be revealed for some time,” said Jack Dolan, a spokesman for the ACLI. “Still, companies in the [disability insurance] business are paying benefits every day on the wide variety of illnesses and injuries covered in policies.”

The Social Security Administration said it has received about 23,000 disability applications since the beginning of the pandemic that include a mention of covid in some way — less than 1 percent of all annual claims, it said.

Some covid patients are receiving disability benefits, especially those who suffered severe infections. Thousands of people spent weeks on ventilators, followed by long periods in physical and occupational therapy relearning how to walk and perform simple tasks. Many suffered strokes, brain bleeds and organ failure as the virus laid siege to their bodies.

The Post spoke to patients who, with the help of lawyers, won long-term disability benefits from the government. One, an EMT in New Jersey, suffered strokes and uses a wheelchair. Another, a New York doctor, experienced brain bleeds; his speech is frequently interrupted by sobs.

Long haulers, as patients with long covid are known, typically start with milder infections and later suffer symptoms that are not as obviously debilitating.

The Centers for Disease Control and Prevention acknowledges gaps in medical knowledge regarding long covid. It warns doctors not to rely solely on heart, lung and brain tests to diagnose the syndrome because the symptoms are so difficult to measure. "Lack of laboratory or imaging abnormalities does not invalidate the existence, severity, or importance of a patient's symptoms or conditions," the CDC cautions in its official guidance.

But whether someone qualifies for benefits hinges on their physical and mental ability to do their jobs, not on a diagnosis.

"A lot of times the insurance company is just looking at the physical requirements and saying you have a sedentary job, and nothing precludes you from sitting at a desk all day," said Mark D. DeBofsky, a Chicago lawyer who represents patients fighting for benefits. "But you have to think, you have to analyze, you have to plan, you have to use judgment. If you are not able to fully exercise those faculties, you can't work at that job."

Singh was among the initial wave of long covid cases in 2020, before the medical system had even created a diagnosis code that could be entered into records. She did not qualify for a coronavirus test at the time of her initial infection in February of that year because she had not traveled to China or associated with anyone who traveled to China.

She said she tested positive for coronavirus antibodies in August 2020 (before vaccines were available), proving her infection and the root of her long-term sickness. Doctors dismissed her symptoms as psychosomatic, she said, a common complaint among long haulers.

Throughout 2020, she got sicker and struggled at work as a senior project manager. She said she couldn't keep up with the job of driving improvements in company business units, unable to multitask or communicate clearly, forgetting what had been discussed with colleagues and failing to recall simple words and phrases.

"It just got to the point where I couldn't function any more, and people were noticing more and more that I was slipping," she said.

Singh shared her story on the condition that her employer not be named in this story to avoid negative repercussions. Although the company notified her in a certified letter in November 2021 that it filled her old job, it said she can apply for a different one if her medical condition improves, Singh said.

Singh's employer contracts for employee disability benefits through a large insurance company called Unum, an international provider of workplace benefits like life and disability insurance. The company reported \$12 billion in revenue in 2021.

Singh applied for temporary disability in late 2020 from Unum but was denied, she said, describing conversations with Unum representatives that left her stressed and dispirited. She said she was told by one representative that a "young thing" like her could not be disabled by the virus.

"There were a lot of phone calls that left me in tears with that disability company," she said.

Unum eventually approved temporary disability in February 2021, after Singh appealed. She had been sick for a year.

When Singh's temporary benefits expired in June 2021, she said she was still too wiped out to work, despite regular physical therapy and speech pathology appointments. She applied for long-term disability. That bid was denied, first in September and again in November, in letters that Singh read to a Post reporter over the phone.

Unum told her she was denied because she never had a positive coronavirus test and because an antibody test in February 2021 was negative, Singh said. It did not mention her positive antibody test in August 2020, she said. In the September denial, the company noted that Singh's new primary care provider, an advanced practice registered nurse in Louisville, had just begun treating her and did not know whether Singh's ability to work was hampered.

On Oct. 20, the provider wrote an update: Singh “is being treated for post-covid long-term symptoms and continues to experience dysfunction in cognitive abilities which hinders her ability to work/complete tasks in a timely manner,” the provider wrote in case-file notes that accompanied the November denial.

Despite that assessment, the company cited medical tests that did not reveal impairment, including a neurological exam that came back normal. “Her symptoms are out of proportion to the diagnostic and exam findings and are inconsistent with functional impairment,” the denial letter said.

The company also said Singh had not proved she was disabled throughout a period that ended on Aug. 30 — an “elimination period” in disability rules, when the patient must remain disabled to qualify.

Singh said she is still awaiting a decision on her appeal of the second denial. She likened the process to getting put through a “spin cycle.”

“The process is so difficult you feel like giving up. But what then? You go back to work to a job you can’t do?” she said.

Unum says it does not comment on specific cases. It said it has approved “hundreds of thousands” of additional disability claims since the beginning of the pandemic, with an increase from pre-pandemic levels of 35 percent. The company did not provide raw numbers of benefit awards or denials resulting from long covid.

“During the pandemic, Unum has paid more disability and life claims than in our company’s history. It’s why we exist and reinforces the critical importance of employee benefits,” Unum spokeswoman Natalie Godwin said in an email. “In general, disability and leave claims connected to covid-19 have been primarily short-term events with the majority of claimants recovering before completing the normal qualification period for long term disability insurance.”

The length of time it takes to decide claims depends on individual circumstances and the “timeliness” of medical records and other submissions, Godwin said.

Responding to Singh’s statement that she was told by an Unum representative that a “young thing” like her could not be disabled by covid, Godwin added, “We have been unable to confirm the alleged statement, but we strive to make every customer interaction a learning opportunity to drive better service and support.”

The denial of temporary disability benefits by Mutual of Omaha stunned Eve Efron, 32, a long-haul covid patient from Virginia.

Since her initial illness in January 2021, Efron has struggled with physical and mental exhaustion, headaches, sleep disruption and emotional stress caused by long covid, according to medical records and correspondence she provided to The Post.

She took sick time and reduced her work schedule at Outcast, the public relations agency where she is a senior account director.

In April, as her symptoms worsened, the physician assistant treating her at MedStar National Rehabilitation Hospital discussed options with Efron and determined that she should take medical leave to rest.

But Mutual of Omaha, her employer's disability insurance carrier, in August rejected Efron's claim for temporary disability insurance totaling \$7,500 for the five weeks she was away from work. It said after reviewing the medical records that her illness was not severe enough to interfere with work, according to correspondence Efron shared with The Post. It dismissed her final appeal last month.

Efron's claim and appeals included emails and notes from the MedStar physician assistant emphasizing the importance of the medical leave.

"Eve's medical conditions ... were inconsistent with the demands of her job and, in my judgment, would improve only if she stepped away from work for a period of time," wrote Kathryn Pellegrino, the physician assistant. MedStar declined to make Pellegrino available for comment.

During the appeal, Mutual of Omaha reviewed her social media accounts, noting that she had recorded a promotion in September 2021 on LinkedIn. It cited the promotion as evidence that she was able to perform her job satisfactorily. It also cited her clearly written correspondence to the company as an indication that she did not suffer cognitive problems. And it said her medical record lacked any objective test that showed a lack of function that prevented her from doing her job.

"It seems clear that Mutual of Omaha doesn't trust my doctors ... to be able to make a diagnosis. It feels really wild to me to undercut their medical judgment in that way," Efron said. She said her promotion in September had no bearing on her illness in May and early June, when she took medical leave. She said an uncle who is a lawyer helped craft her appeal letters.

With the final denial of her appeal last month, Efron said she is resigned to not receiving any compensation for the time she missed work. She continues to work now, still plagued by headaches and fatigue, worried that she will never return to normal.

Mutual of Omaha would not comment on Efron's case.

"Each claim, whether arising from covid or any other condition, is evaluated based on the specific facts of that case," as well as terms of the insurance policy and state and federal law, Mutual of Omaha said in a statement. The company reported \$11 billion in revenue in 2020.

In Los Angeles, lawyers for Wendy Haut, a sales representative for an educational software company, Cengage Learning, have filed suit against insurance carrier Reliance Standard. The suit claims the company improperly denied her long-term disability claim despite symptoms including asthma and chronic cough that she did not have before **her** coronavirus infection. Several doctors attested to Haut's disabling symptoms, according to the lawsuit, including her primary care doctor who submitted an assessment in November 2021, the month before Reliance denied Haut's application for benefits.

"To date she experiences constant mental fog and forgetfulness, especially short term memory, and thought processing," the doctor, Eric Mizrahi, said, according to the suit. "She is literally incapable of assuming her responsibilities of daily living without assistance." Mizrahi did not respond to request for comment. Haut's lawyers also did not respond.

Reliance Standard — a division of a Japanese insurance giant, Tokio Marine Holdings, with more than \$45 billion sales in its last fiscal year — declined to comment. Cengage said in an email it plays no role in determining the outcome of disability claims.

Outside of Pittsburgh, Laurie Bedell received word from the Social Security Administration late last month that her application for long-term disability had been rejected. She caught covid along with the rest of her family at Thanksgiving in 2020. Her father died after a hospitalization. Bedell has remained in a state of physical exhaustion with myriad symptoms. She had to leave her job making more than \$100,000 as a nursing supervisor at a home care agency.

She applied for state unemployment benefits but was denied. Because she was too sick to work, she did not meet the unemployment criteria of actively looking for a new job.

Bedell submitted what she said was thousands of pages of medical records from the Cleveland Clinic and doctors in Pennsylvania to the Social Security Administration for her application for disability benefits, including pulmonary function and cognitive tests that she said showed impairment. She continued to submit additional test results after her initial application, with what she said was medical proof of 12 different diagnoses, including post-exertion malaise, chronic fatigue syndrome, dysautonomia, small fiber neuropathy, irritable bowel syndrome, and anxiety and depression.

The Social Security Administration sent her for an independent physical examination before issuing the denial. Bedell said she thought the independent evaluator recognized the severity of her condition.

But according to the written denial she received, sections of which she shared with The Post, SSA determined that “you experience pain, but the evidence shows that you are still able to stand, walk, lift, carry and bend. At times you are depressed. However, this would not prevent you from performing routine work in a low stress environment. You have some limitations on your activities. However, the severity of your condition does not totally disable you.”

Agency spokeswoman Nicole Tiggemann declined to comment on Bedell's case, citing privacy laws. Social Security requires a finding that a disabling condition will last at least one year or result in death before awarding benefits, she said. In 2016, the agency was criticized by a government watchdog for not conducting timely reviews to make sure people receiving benefits are still disabled.

"Disability evaluations are based on function," Tiggemann said, "not diagnosis."

Meanwhile, Bedell said she has cashed out her 401(k) to pay the bills. She said she and her husband may soon be forced to move because they can't afford their \$1,800 monthly rent without ongoing financial help from her mother.

The couple had been hoping to buy the house they are renting. For now, that plan has been scrapped.

