People With Long COVID Face Barriers to Government Disability Benefits

Many people with long COVID are falling through the cracks of a system that was difficult to navigate even before the pandemic.

November 10, 2022 By Betsy Ladyzhets and Kaiser Health News

When Josephine Cabrera Taveras was infected with COVID-19 in spring 2020, she didn't anticipate that the virus would knock her out of work for two years and put her family at risk for eviction.

Taveras, a mother of two in Brooklyn, New York, said her bout with long COVID has meant dealing with debilitating symptoms, ranging from breathing difficulties to arthritis, that have prevented her from returning to her job as a nanny. Unable to work — and without access to Social Security Disability Insurance or other government help — Taveras and her family face a looming pile of bills.

"We are in the midst of possibly losing our apartment because we're behind on rent," said Taveras, 32. Her application for Social Security disability assistance, submitted last fall, was rejected, but she is appealing.

Like many others with long COVID, Taveras has fallen through the cracks of a system that was time-consuming and difficult to navigate even before the COVID pandemic. People are facing years-long wait times, insufficient legal support, and a lack of clear guidance on how to prove they are disabled — compounded by the challenges of a medical system that does not have a uniform process for diagnosing long COVID, according to health experts and disability attorneys.

The Biden administration promised support to people with long COVID, but patient advocates say many are struggling to get government help.

The Centers for Disease Control and Prevention defines long COVID broadly, as a "range of ongoing health problems" that can last "weeks, months, or longer." This description includes people, like Taveras, who cannot work, as well as people with less severe symptoms, such as a long-term loss of smell.

The Social Security Administration has identified about 40,000 disability claims that "include indication of a COVID infection at some point," spokesperson Nicole Tiggemann said. How many people with long COVID are among the more than 1 million disability claims awaiting processing by Social Security is unknown.

In recent months, about 5% of new disability claims filed by Allsup, an Illinois-based firm that helps people apply for Social Security, involved people dealing with COVID, said T.J. Geist, a director at the firm. Other firms report similar figures.

The long waits for disability assistance often end in denial, in part because long COVID patients don't have the substantial medical evidence that federal officials require, Geist said. There is no standard process for diagnosing long COVID. Similarly, Social Security "has yet to give specific guidance on how to evaluate COVID claims" for the government officials who review applications, he said.

A recent report from the Brookings Institution estimates that 2 million to 4 million people are out of work because of long COVID. A study published in September by the National Bureau of Economic Research puts the number at 500,000.

Advocates suggest that many people with long COVID have yet to recognize their need for government benefits and could start applying soon.

"I did not understand that I was disabled for four years because my ability would fluctuate so much," said Alison Sbrana, a patient-advocate with the long covid support group Body Politic. She has a chronic disease whose symptoms are similar to long COVID's in many cases and has received Social Security disability payments for several years.

"If you apply my timeline to people with long COVID, even people who got sick in early 2020, we're not going to know the full extent of their ability to work or not until 2024," she said.

In July 2021, the Department of Health and Human Services formally recognized long COVID as a disability. Expanding on the recognition, the department and the White House published a report in August 2022 that summarizes the "services and supports" available for people with long COVID and others who have experienced long-term impacts from the pandemic.

But accessing support is not as simple as White House announcements may suggest. First, the July 2021 guidance recognized long COVID under the Americans with Disabilities Act (ADA) but didn't extend to the Social Security Administration, which runs benefit programs.

Under the ADA, long COVID patients who can still work may ask their employers for accommodations, such as a space to rest or a more flexible schedule, said Juliana Reno, a New York lawyer who specializes in employee benefits. Social Security, however, has more stringent standards: To receive disability insurance, people must prove their long COVID symptoms are so debilitating that they cannot work.

"The application process is very demanding, very confusing for patients," Sbrana said. "It also entirely depends on you having this substantial breadcrumb trail of medical evidence."

Most applications are denied in the first round, according to Sbrana and other advocates. Patients typically appeal the decision, often leading to a second denial. At that point, they can request a court hearing. The entire process can take a year or more and usually requires legal assistance.

The pandemic extended these wait times, as Social Security offices closed and did not quickly shift to remote operations. Moreover, common symptoms such as brain fog can make filling out online applications or spending hours on the phone with officials difficult.

Long COVID patients who were hospitalized with severe symptoms can submit paperwork from those hospital stays and are more likely to receive benefits, Geist said. But for the people who had mild cases initially, or who have “invisible-type symptoms” like brain fog and fatigue, Geist said, documentation is more difficult. Finding a doctor who understands the condition and can sign off on symptoms may take months.

Amanda Martin, a long COVID patient and advocate, is one of those lost workers. Martin got COVID in April 2020 while working as a subcontractor for the U.S. Navy and lost that job when they were unable to recover quickly.

At first, unemployment benefits provided support, but Martin’s symptoms — including intense fatigue and brain fog — continued. More than two years after the initial infection, Martin is still “on bed rest 90% of the time,” they said. Martin receives food stamps and Medicaid but doesn’t have help paying for other essentials, such as gas. Their application for federal disability benefits has been denied twice.

“I am currently a year into the [application] process; I have eight to 11 months remaining,” Martin said. “I have $50 in my savings account.”

Many people with long COVID don’t have the financial resources to hire a lawyer — or access to a doctor who can help with their documentation, which makes the situation even tougher.

Patient advocacy organizations are pushing for a more efficient application process, specific guidance for officials who evaluate long COVID cases, and faster eligibility for Medicare coverage after a disability application is approved. (The typical wait is two years.)

The organizations also serve as support groups for people with long COVID, sharing resources and providing reassurance that they aren’t alone. Some organizations, such as the nonprofit Blooming Magnolia, even collect funds for direct distribution to people with long COVID. But patients say these efforts don’t come close to the scale of funding needed.

Taveras, the Brooklyn mom, said she knows many other people who are grappling with similar issues. “We’re trying to get support from the government, and we’re not getting it,” she said. Taveras set up a GoFundMe page to request support for her family.

This story was published by Kaiser Health News on November 9, 2022. It is republished with permission.