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'A very lonely place to be': Take COVID-19 seriously, long-haulers warn

By Caroline Catherman

Orlando Sentinel • Jul 27, 2022 at 5:30 am



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Neil Passmore and his wife, Tina, in February 2020 before Neil caught COVID-19. (Courtesy of Neil Passmore.)

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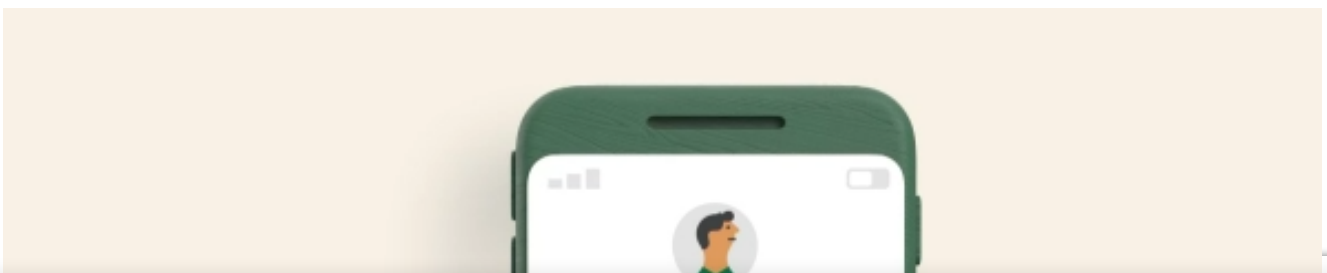


On the rare occasions when Vero Beach resident Neil Passmore goes out in public, he's often the only one in a mask.

When Passmore caught COVID-19 in June 2020, the virus hit him hard: He shook with chills, struggled to breathe, his heart raced and he had trouble regulating his body temperature. He also experienced disassociation and memory loss, among other symptoms.

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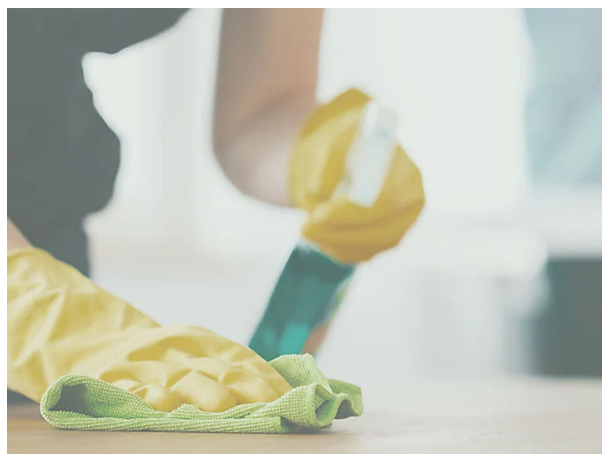


In the weeks and months after his infection, he noticed some symptoms weren't going away, and some were getting worse. After five weeks, he was often confused, stuttering and calling things by the wrong name: mailboxes became post offices, coconuts became pinecones, palm trees became pine trees.

Doctors eventually discovered optic nerve and brainstem damage.

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His second round of COVID-19 in August 2021 made all his symptoms worse, particularly his cardiac symptoms.

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More than two years later, he still struggles with regulating his body temperature, a rapid heartbeat, tinnitus, dizziness and neurological symptoms. His ongoing cognitive issues make it impossible to return to his job as a Walgreens pharmacist. He's terrified of getting COVID-19 again.

"I went from having a very good job, living like you're supposed to, working hard... for months and months, helping sick people every day," he said. "Then I get sick, and bam! That's it. You

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Passmore has long COVID-19, known also as long-haul COVID-19, or Post COVID-19 condition.

The CDC estimates [as many as one in five adults](#) who catch COVID-19 may go on to develop long COVID-19, defined by the [World Health Organization](#) as symptoms in people previously infected that last for at least two months and cannot be attributed to anything else. Common symptoms include fatigue, shortness of breath and cognitive dysfunction but the range is broad.

Now, as new, [ultra-infectious subvariants of the COVID-19 omicron variant drive up COVID-19 cases](#), advocates say it is more important than ever to speed up awareness and research the origins and treatment for the condition.

“If in the future a significant portion of the population is suffering from COVID and long-haul COVID simultaneously, this will be an extraordinary burden financially for everyone,” said Elena Cyrus, an infectious disease epidemiologist and assistant professor at the University of Central Florida.

More questions than answers

An estimated 1.5 million adults in Florida are currently experiencing symptoms of long COVID-19, based on a [summer 2022 household pulse survey](#) and [2020 population estimates](#) by the U.S. Census Bureau.

Other viruses can also cause symptoms that stick around after people recover, varying in severity or duration, Cyrus said.

“The only difference is that because of the scale of COVID, we are looking closer at it, because of the massive impact it can have,” she wrote in an email.

Two years in, there are still more questions than answers as to the disease’s origins: Could tiny blood clots be cutting off blood flow to some parts of the body? Does the coronavirus sometimes stick around in certain areas? Could COVID-19 make some people’s immune systems go haywire, causing chronic inflammation? Those are three leading theories, researchers told Science Magazine [in a June article](#). In all likelihood, there is no single cause, but rather multiple factors working together.

There are no go-to proven treatments either, said Dr. Irene Estores, who opened the UF Health COVID RESTORE (rehabilitation, support, training, outreach and research) Treatment Program in Gainesville in July 2021. This is one of just five [post-COVID](#) care centers listed by the Survivors Corp, a grassroots patient advocacy effort.

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She points out long COVID research is moving forward, albeit slowly.

“We know more about long COVID — both mechanisms and treatments — now than we did two years ago. So, we just keep on working,” Estores said.

She has a long waitlist. Seeing patients is time-consuming, as is helping them apply for disability insurance benefits.

“Patients need to recognize that we do want to help, but physicians need resources to be able to help,” Estores said. “It will take more than just commitment from physicians ... This requires a concerted effort from health systems and from the government.”

The National Institutes of Health in February 2021 announced a \$1.15 billion initiative, RECOVER, to fund investigations into the condition, though since then the initiative has faced criticism for its slow speed and lack of transparency, a [June Science Magazine article reports](#).

Many of Estores’ patients have made progress, and she emphasizes this. But she acknowledges that it can be easy to give up.

“I can understand why... they feel this way. My patients tell me how hard it is. And I can see it,” Estores said. “... I can tell you that my patients who continue to work with me on this, we go somewhere.”

Terrified of reinfection

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Danielle Jordan, 21, first caught COVID-19 in August 2020 and suffered with long COVID-19 for months after. (Matthew Rossi Jordan)

Faced with chronic, often unexplainable symptoms and no proven treatments, having long COVID-19 can feel hopeless, said Danielle Jordan, 21, from Coral Gables.

Jordan caught COVID-19 as a healthy 19-year-old. She couldn't walk without pain, accurately taste or smell, or regulate her rapid heartbeat in the three months that followed. Though many symptoms faded, she still suffers from parosmia and dysgeusia: distorted smell and taste.

Jordan's mental state is in recovery, too.

"What I wish people knew about long covid was the effects it can have on one's mental health. It is a very lonely place to be in if no one around you is going through what you are going through," Jordan wrote in an email. "... It's been horrible."

When the University of Miami student was exposed to the virus again in September 2021, she had panic attacks multiple times a day out of fear she'd test positive again.

Brian Hartin, who spoke to [the Orlando Sentinel in October](#) about his lack of energy, brain fog and depression, is about 80% recovered from long COVID-19 after about two years. He's working again, though in a lower position than he was before because his health is still unpredictable.

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The 37-year-old Lakeland resident, like Jordan, is desperate to get better and scared of catching COVID-19 again.

Their fears aren't unfounded.

Saint Louis Health Care System researchers found that each time a person catches COVID-19, their risk of new health problems may increase, a [draft study of over 5.6 million people](#) said. It is currently awaiting peer review.

Others have moved on

Hartin doesn't sense the same concern he has about COVID-19 in others, however.

A couple of weeks ago, he heard his coworkers joking that they were so burnt out, they wanted to catch COVID-19 just as an excuse to take time off.

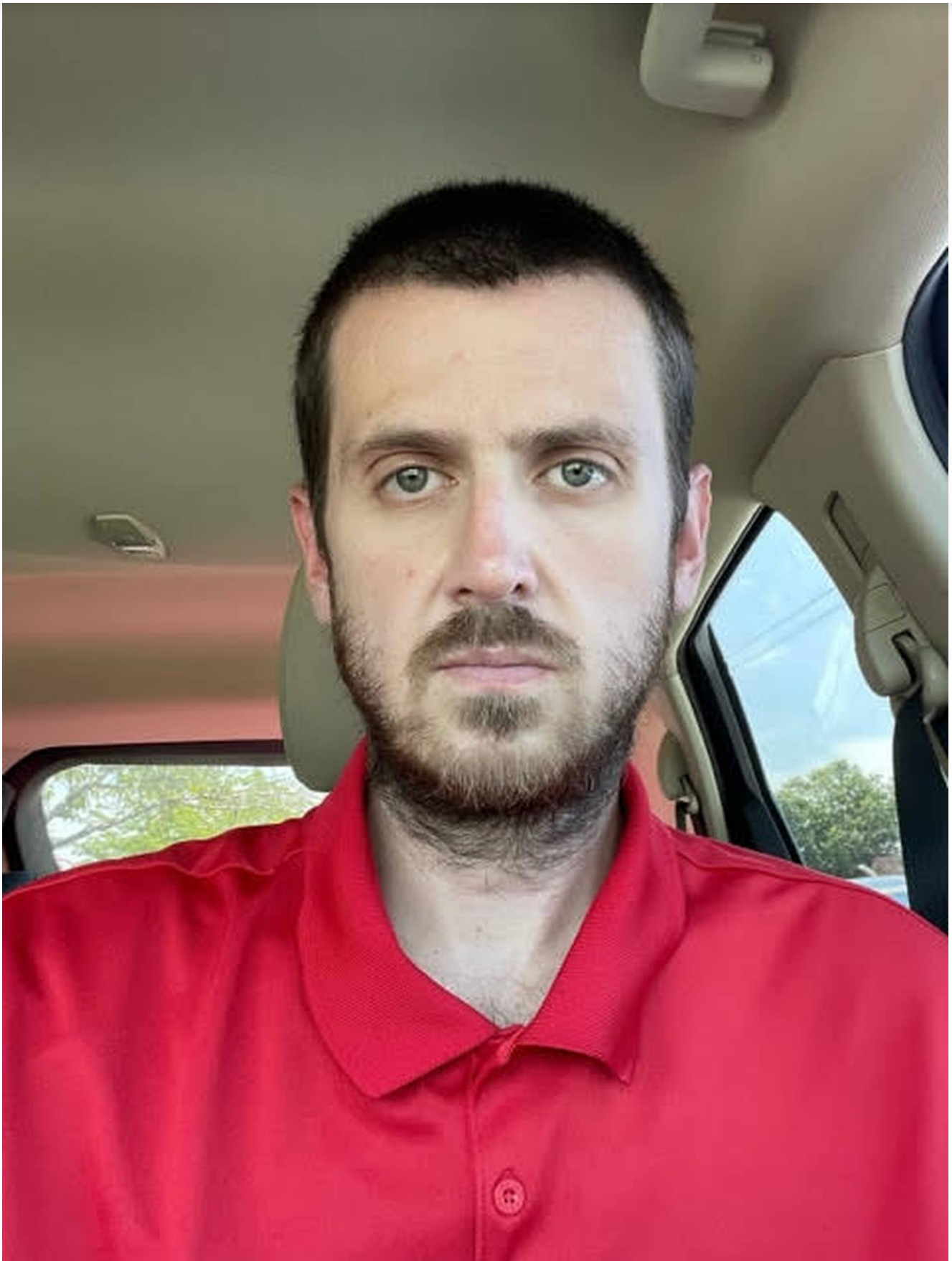
"I was like, really? You don't want to have what happened to me happen to you, and you're talking about it just so casually," Hartin said.

Doctors, too, have dismissed Hartin because there's no clear cause for his symptoms.

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Brian Hartin, from Lakeland, has struggled with long COVID-19 symptoms for about two years. (Courtesy of Hartin)

“There’s only so many times that you can go to the doctor or go to the ER and they tell you that

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true, because I wouldn't feel the way that I feel if there wasn't something wrong," he said.

Some doubt long COVID's existence. Jeremy Devine, a resident psychiatrist at McMaster University in Hamilton, Ontario, wrote [a Wall Street Journal op-ed suggesting](#) long COVID-19 can be explained in most cases by underlying mental health issues.

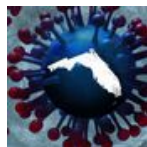
Florida Department of Health spokesperson Jeremy Redfern tweeted, "[long COVID = anxiety](#)" from his personal account to the House Select Subcommittee on the Coronavirus Crisis in June.

Both faced swift backlash from physicians, psychiatrists, other mental health professionals and activists.

Passmore says for their sakes and his, he hopes the general public takes long COVID-19 and the current wave seriously.

"Maybe the new variants aren't killing as many people, but there's still a lot of risks with them," he said.

Resources are growing



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In the meantime, for those already struggling, there are resources, many of them established by long COVID-19 patients themselves.

Estores' program is accepting new patients at <https://ufhealth.org/integrative-medicine/contact>; patients can call 352-265-9355 and specify they're looking for long COVID-19 treatment.

She said patients should expect a waitlist at her clinic and others.

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Other [post-COVID-19](#) care centers and contact information can be found on the website of the Survivors Corp, a grassroots patient advocacy effort.

Support groups have also sprung up, such as [COVID-19 Long Haulers Support](#) on Facebook.

The Patient-Led Research Collaborative, a group of researchers with long COVID-19 born out of another support group, has resources as well.

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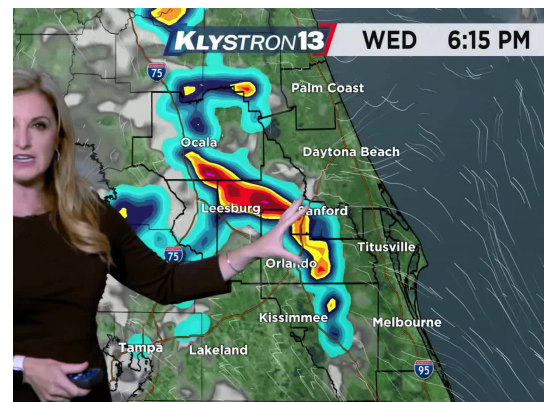
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