Why do some people barely get sick from COVID-19 and others seem to never get better? Canada’s long-haulers might hold some of the answers

May Warren

One day this past April, Tracey Thompson suddenly realized she couldn’t smell or taste the chicken noodle soup she was eating.

“From one spoonful to the next, it was a complete and utter absence of sensory information,” she remembers. “Like turning off a light switch.”

It was terrifying for the previously “ridiculously healthy” 52-year-old chef.

But it wasn’t her first symptom of COVID-19. And it wouldn’t be the last.

Thompson has been sick since mid-March. She was never hospitalized, advised by public health authorities fearing an overwhelmed health system at the beginning of the pandemic to deal with her “minor” symptoms at home. She’s now part of a group calling themselves COVID long-haulers — people who never got better, or had flare-ups months later.

Doctors don’t understand why they aren’t recovering, and as the first wave of people living with lingering impacts of the new virus, they could hold some of the keys for unlocking some of its mysteries. But many feel ignored by the medical establishment, uncounted in official case tallies, and falling through the cracks of care, instead turning to online communities to crowdsource their own recoveries.

Demand has been growing around the world for special post-COVID centres, which have already been set up in New York City, and the U.K. In Canada, a major research study is tracking survivors and can assist in connecting them to help. But patients like Thompson who were told not to get tested in the spring amid a backlog are not yet eligible.

For Thompson, it came on gradually. A sore throat, nausea, diarrhea, rolling fevers, and then very quickly “extreme fatigue” and shortness of breath.

She was very sick, but not dying.

Holed up in her Parkdale apartment with her Greyhound-Great Dane mix Gordie, she thought it would be a bad two weeks, and then it would be over.

But it wasn’t.

She’s still struggling with episodes of shortness of breath, a feeling of empty air, she describes as like eating cotton candy, breathing but not getting enough oxygen.

She's also had waves of new symptoms, like a fast heart rate, and the loss of taste and smell, which luckily have now come back.

The worst, she said, is unrelenting fatigue.

Thompson is still off work and daily tasks are often tough. On the bad days she can't even hold her phone.

"It's never critical but it is debilitating," she said. "I'm not good."

Before COVID, she was healthy and active. Constantly on her feet as a chef, she could "haul a 50-pound bag of potatoes up stairs."

Despite a couple of emergency room visits, Telehealth and phone appointments, a few blood tests, a lung X-ray, and an echocardiogram, she still doesn't have answers.

There are some doctors trying to figure out what's going on with people like her. A massive multi-province study, starting in Ontario, hopes to recruit 2,000 COVID survivors and follow them over time, using questionnaires and blood tests to understand their range of experiences. It will examine antibodies, how the immune system responds, genetics, and blood clotting. Interested patients can contact the team at cancov@uhn.ca.

"There are huge variabilities and the problem is we currently cannot tell which ones are going to get really really sick and which ones may just have the flu kind of symptoms," said Dr. Angela Cheung, an internal medicine specialist at University Health Network and professor of medicine at the University of Toronto.

"We don't know the whole picture right now and that's why we're doing the study."

While there are some patients who don't have symptoms and statistically most just have mild ones, "it's not only a respiratory illness, the virus can effect other systems and some people have sort of prolonged, sort of residual type symptoms," she added.

It's true that older people and those with underlying medical issues are more likely to die, or end up in intensive care.

"However, we have seen young people who have been really really sick and they don't have anything. They don't smoke, they don't vape, they don't have diabetes, they don't have high blood pressure and they're not on medications," she said.

It's an observational study. But it will also connect patients to care, lung tests for example, if they need them, and "if we find out that a certain medication or supplement or something may be helpful, we would actually offer that as well."

There are about 80 long-haulers who have reached out wanting to be in the study, but only 11 of them have positive test results, Cheung said.

So the researchers are going back to their ethics board asking for approval to do research antibody tests on these people so they can include them.

But that leaves those like Thompson still in limbo, on the waiting list for the cross-Canada study, unable to get care now and in a situation she describes as "a waking nightmare." She was tested in April, but by that point it was already negative.

There is followup care available for people who tested positive at Sunnybrook hospital, either as a patient, or at the emergency room, or assessment centre. A team has followed over 450 people, starting right after a man who had travelled to Wuhan, China arrived at the hospital as Canada's first documented case of the novel coronavirus in January.

While "well over 90 per cent never came into hospital," and the majority are fine after two weeks, everyone is offered a followup appointment at three months.

"One reassuring thing is that most people declined coming in because they're already feeling back to health," said Dr. Nick Daneman, an infectious disease physician at Sunnybrook.

"People should know that the majority of people recover with no lingering symptoms."

He notes there's not a lot of data on long-term patients, and those who were never hospitalized. The team hopes to eventually share data on this and other trends.

A July survey published in the U.S. Morbidity and Mortality Weekly Report of 292 people who had tested positive for COVID-19 but were never hospitalized, found 35 per cent were still feeling lingering symptoms weeks later. Among 18-34-year-olds with no chronic medical conditions, one in five did not feel back to their normal selves.

And a research letter from a group of Italian scientists found that out of 179 patients who had recovered from COVID, 87 per cent reported at least one persistent symptom, particularly fatigue and shortness of breath, weeks later.

But it's not clear how many are suffering in Canada, which has seen almost 127,000 COVID-19 cases nationwide, as they are not tracked in daily case counts either provincially or federally.

That's something Chandra Pasma, a 40-year-old whose entire family of five considers themselves long-haulers, would like to see Canada start doing.

"How do you know it's not an issue when people were told to stay home and not seek medical care and then there's no attempt to be systematic or survey?" she said over the phone from Ottawa.

"You literally have no idea. You're flying blind."

She wants an "official acknowledgment" from a chief medical officer of health or health minister of the people like herself and an update to the public health guidelines to include long-haulers.

"We're still being told it's an illness where a tiny minority of people get sick and die and the rest recover in two weeks," she said.

"I think it might change people's risk analysis if they understand that previously healthy young people are still sick five months out."

This would also help validate their experiences so that they're not left to "argue" with their doctors over symptoms.

She'd also like to see the establishment of something like the Mount Sinai Hospital post-COVID clinic in New York. "Centralized care where multiple specialists are working together," where there's "not only that communication and co-ordination but then developing a rehab plan together."

Like Thompson, who turned to Canadian and British COVID long-hauler support groups, Pasma has found some solace in a Slack group called Patient-Led Research for COVID-19, which published its first report on symptoms in May.

In the vacuum of knowledge around recoveries, these groups have become beacons for long-haulers like Thompson and Pasma, and a source of real-time research involving survivors.

The Survivor Corps Facebook group, started by 46-year-old Long Island photographer Diana Berrent from her bedroom in isolation, is another source of information and support.

It now has over 96,000 members from around the world.

Along with the website, the group is a "one-stop shop" for support and emerging science.

"We become the canary in the COVID coal mine, because we were seeing the real-life experiences of people in real time," said Berrent on the phone from just outside New York City.

The group has noticed that there seems to be two groups of people, those like Thompson who have had chronic symptoms since they were first infected, and others, like Berrent, who experience "flare-ups" of new symptoms after periods of feeling recovered. It's mostly women, although it's not clear if that's maybe just because women are more involved in the social media groups.

Berrent has given blood to countless vaccine research trials, "and we encourage everyone to do the same because so many of the answers to this virus lie in the bodies of survivors."

The group's administrators also partnered with Indiana University on a report surveying their members on symptoms, and are working with other institutions on other studies.

But Berrent says long-haulers also need comprehensive care, now. As cases continue to grow worldwide, the need will only grow.

"You can really look at it as a blueprint to the next decade or more of public health," she said. Many, like herself, are previously healthy and active people.

There are "30-year-olds who were running marathons up until this who now can't climb a flight of stairs and they're writing their living will. It's tragic," she added.

"There are going to need to be COVID-care centres in the same way there exists urgent-care centres. It has to be part of our public health-care conversation going forward."

Patients coming together to fill in gaps in knowledge and advocate for care, reminds epidemic historian Mitchell Hammond, an assistant professor at the University of

Victoria, a little of the early days of the HIV/AIDS crisis in the ‘80s and ‘90s.

That very different disease became a “kind of paradigm for patient advocacy” as communities of gay men in urban centres reached out to networks with a “burning urgency” for support, and to fight for research and treatments.

But it hit a “group of people that were already stigmatized,” who didn’t have the bird’s eye view of the crisis, or the global attention COVID does.

All of the focus on finding a COVID vaccine makes Hammond think of another moment in history: the polio epidemic.

That virus was “conquered” after the discovery of a successful vaccine in the 1950s and the mass immunization programs that followed.

But “then the people who were left with chronic illness or chronic disability experienced feelings of frustration,” he said, “because they were the people who were kind of left behind.”

It’s something Thompson, back in her Parkdale apartment, worries about, as conversations centre on lockdowns, daily case counts, and how those who haven’t been infected yet can get back to normal life.

“I’m just in a holding pattern,” she said. “Any kind of help would be a gift.”

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