

More awareness and investment needed to support people with long COVID, says report

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More long COVID awareness and education is needed among doctors, nurses, care providers and the public in Canada to reduce stigma around the condition and legitimize the disability, according to a new report

from Simon Fraser University.

The recommendation is one of a series identified in a [report](#) released by the SFU-based Pacific Institute on Pathogens, Pandemics and Society (PIPPS). The report summarizes the findings of two focus groups of unpaid caregivers, professional [care providers](#), long COVID researchers and people with long COVID (longhaulers) to understand and identify barriers to support, delivery of care and information, and determine future research priorities.

"It's an invisible and new condition," says Kayli Jamieson, a longhailer who co-led the focus groups as part of a larger study with Kaylee Byers, an assistant professor in SFU's Faculty of Health Sciences. "Many people don't believe that long COVID is real or exists. And unfortunately, that permeates through the health care system. Even outside of the medical system, there is a broader societal awareness that is lacking."

Long COVID is a multi-systemic condition that may begin weeks after a COVID-19 infection and can last for years, often requiring leave from employment to rest and manage symptoms. Statistics Canada found that more than 3.5 million Canadian adults (about one in nine) have experienced long COVID symptoms, with 40 percent reporting difficulties accessing health care. Despite hundreds of studies into the condition, no standard cures or treatments have been approved.

"These studies legitimize what is happening and help destigmatize the impact this is having on every aspect of our society right now," says Jamieson. "We want to be visible, but we're increasingly being made invisible. As one unpaid caregiver in our study said, "I think there needs to be a cultural shift in terms of people believing that long COVID exists.'"

Jamieson caught COVID-19 in 2021 and has been dealing with long COVID symptoms ever since. She was a new master's student at the time and went from having a lot of energy and working two jobs to being unable to work and going on [medical leave](#).

"It's a drastic change," she said. "The cognitive difficulties—I wasn't even able to understand my own previous work when I was reading it. And the fatigue is disabling. There are so many triggers, like even reading an email, or socializing. And that could just about be enough to leave you bedbound due to post-exertional malaise."

In addition to the [brain fog](#) and exhaustion, Jamieson's symptoms included rashes, tinnitus, chest pains, shortness of breath and tremors.

Ultimately, Jamieson says she hopes the report will help inform policy and improve the health care for people impacted by the condition. She also hopes that it will lead to destigmatization around long COVID and increased funding for awareness and research.

"Through conversations with patients, caregivers, clinicians, and researchers, we've come to recognize that long COVID doesn't just impact individuals, it impacts communities," says Byers, the study's principal investigator.

"Long COVID is challenging our health care systems and revealing the urgent need for stronger supports for all aspects of this illness including increased awareness, centralized sources of information, funding for long COVID-care inclusive of [mental health](#) and greater investments in patient-centered research."

More information: Report: [pipps.cdn.prismic.io/pipps/Zg2 ...](https://pipps.cdn.prismic.io/pipps/Zg2...)

[yreportApril2024.pdf](#)

Provided by Simon Fraser University

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