

The Pandemic Pandora's Box

Long COVID and Episodic Disability

May 2021



Land Acknowledgement

Realize acknowledges this land on which we work. For thousands of years, Turtle Island has been the territory of many First Nations, Inuit, and Métis Peoples.

Today, this place we call Canada, is still the home to many Indigenous peoples and we are grateful to have the opportunity to live and work and on this land.

We also acknowledge the many other peoples who have contributed to this place we now call home. We want to acknowledge the many traditions and cultural backgrounds that are represented.

You, your families, and your ancestors, all have roles to play in making this space an inclusive and welcoming one and for that, all of us at **Realize** say, Thank You!

Who is Realize?

Realize is the leading national, charitable, organization working to improve the health and well-being of people living with HIV and other episodic disabilities, across the lifespan, through integrated research, education, policy, and practice (www.realizecanada.org).

Formed in 1998, **Realize** (formerly the Canadian Working Group on HIV and Rehabilitation) promotes innovation and excellence in rehabilitation in the context of HIV and other chronic and potentially episodic conditions. To promote a comprehensive approach, **Realize** is multi-sectoral and multi-disciplinary in its membership and activities.

Realize members come from across Canada, as well as internationally, and include people living with HIV and other chronic conditions, members of community-based HIV and disability organizations, national associations of health professionals, government agencies, private businesses, universities, and the employment sector. Members elect a five – twelve-person Board of Directors to guide the organization.

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Executive Summary

The *Pandemic Pandora's Box* report analyzes the combined findings of two informal, community-driven surveys shared openly online in February 2021. The first asked adults working or seeking work in Canada about their experiences with Long COVID, while the second asked Canadian employers about their comfort level and preparedness to provide workplace accommodations to COVID-19 long-haulers. Up to 1 in 3 people who contract COVID-19 - regardless of the severity of their acute infection - risk facing Long COVID. Long COVID refers to a multitude of fluctuating, debilitating symptoms that may affect all organ systems and for many cause impairments which last for months. Of 103 long-hauler employee survey respondents, 85 met eligibility criteria. All 208 employer respondents met eligibility criteria.

Key Findings:

- Though 91% of employer respondents stated they had previously heard of Long COVID, they demonstrated a significant lack of knowledge about the condition.
- Employers demonstrated a lack of understanding about the legal requirements, meaning, and benefits of workplace accommodations.
- The most common symptoms reported by long-hauler respondents were cough, headaches or migraines, fatigue, difficulty breathing, joint pain, light headedness, muscle weakness, difficulty sleeping, chest pain, and brain fog.
- Long-haulers found the cognitive and physical aspects of work particularly challenging.
- Long-haulers faced barriers to proving their illness to access disability benefits and leave.
- Most long-haulers (86%) had disclosed their health status to their employers, but only 55% were offered accommodations in response.
- Long-haulers indicated a wide variety of accommodations would be beneficial to them, including flexible and reduced work hours, working remotely, having ergonomic furniture, re-assignment to alternative work tasks, access to a quiet space to rest at work, and attending fewer meetings.

Recommendations:

- Employers should provide long-haulers with the individualized workplace accommodations they require, including flexible work arrangements, fewer video calls, and the option to work remotely.
- Employers should focus on the functional limitations caused by Long COVID and not ask long-haulers for medical proof of their condition as a pre-requisite for accommodations.
- Employers should ensure directors, managers, and HR professionals are *all* provided with up-to-date education about episodic disabilities, workplace accommodations, and Long COVID.
- Employers and policymakers should review the research and recommendations of long-hauler patient advocacy groups.
- The Canadian government should develop national guidelines recognizing Long COVID as a medical condition that can cause impairment regardless of a patient previously receiving a positive diagnosis of COVID-19.
- The Canadian government, in a harmonized approach with its Provincial counterparts, should provide guaranteed paid sick leave.
- The Canadian government should establish a national COVID-19 and Employment Research Hub.

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Introduction

Lost among statistics of those recovered from COVID-19 is a group of people many are calling the “hidden” or “forgotten” face of the pandemic.^{1,2,3} The group call themselves “COVID-19 long-haulers.”^{4,5,6} Long COVID is a prolonged condition affecting multiple organ systems that for some follows the acute infection period of COVID-19, resulting in a wide range of unpredictable and debilitating symptoms and impairments that may persist for months¹. Common symptoms of Long COVID include extreme fatigue, malaise caused by physical or mental exertion, brain fog, joint and chest pain, heart palpitations, and difficulty breathing, which combined may lead to mood disorders and other serious complications.⁷ Scientists have not yet developed a test to confirm a diagnosis of Long COVID, although the complexity and heterogeneity of symptoms - along with their episodic and changing presentation - suffered by long-haulers are consistent worldwide.⁷

As the ranks of COVID-19 long-haulers continue to grow, so too do corresponding economic implications.⁸ The World Health Organization (WHO) suggests that up to 1 in 5 people who contract COVID-19 face ill health after the acute phase of infection² for a variety of reasons *including* Long COVID.⁷ Researchers now estimate that up to 1 in 3 people who contract COVID-19 may subsequently experience Long COVID specifically.^{9,10,11} Long COVID appears to be more common among women and those previously hospitalized for COVID-19, though its severity does not correlate with either the “the extent and nature of symptoms during the acute phase of the infection”⁷ or with the prior health status of a patient.^{12,23,14} In fact, many long-haulers never received positive antibody or diagnostic (PCR) test results for COVID-19, making it difficult for them to prove they have the condition in order to qualify for disability benefits, including costly rehabilitation.^{15,16}

The *Pandemic Pandora’s Box* report analyzes the results of two informal surveys produced by **Realize** in February of 2021 and shared openly online. The first survey was aimed at adult long-haulers living in Canada and currently working or seeking work, while the second targeted Canadian employers. The surveys assessed the lived experiences of COVID-19 long-haulers in the contexts of employment and workplace accommodations, as well as employers’ knowledge about, and experience providing, workplace accommodations. Recommendations for employers, policymakers, and the federal government follow the presentation of survey results and discussion.

Methods

On February 22, 2021, **Realize** briefly advertised two online surveys that were prepared on Survey Monkey on our Facebook, Twitter, and LinkedIn pages. The first survey was open to anyone who identified as being over 18 and had dealt with the effects of Long COVID while working or seeking employment in Canada and offered a \$50 eGift card for voluntary completion. The second was open to anyone over the age of 18 who currently employed one or more persons in Canada and offered a \$100 eGift card for voluntary completion. Self-employed persons were excluded from both surveys as research objectives focused on relational experiences between employees and employers. The long-hauler employee survey was also shared in several Canadian and international private COVID-19 long-hauler Facebook groups through one of our employee’s personal Facebook accounts. Due to a rapid and overwhelming response, both surveys were closed to new submissions by February 23, 2021.

¹ Researchers do not yet know how long symptoms of Long COVID may last, or if any may become permanent (Yelin et al., 2020).

² “Acute COVID-19 refers to the distinct period of infection during which the immune system fights off the virus; the acute phase can range from mild to severe” (O’Rourke, 2021).

Of 103 respondents to the employee survey, 85 met eligibility criteria and were included in the analysis below. Eligibility criteria required respondents to state that they were 18 or older, had previously experienced or were currently experiencing Long COVID – regardless of a previous positive diagnosis of COVID-19 – and had experience working or seeking work in Canada while dealing with the symptoms of Long COVID. All 208 respondents to the employer survey met eligibility criteria, although not all respondents provided complete data. Employers were required to state they were 18 or older and currently involved in interviewing, hiring, scheduling, and/or accommodating one or more persons in Canada. Both surveys included a mix of quantitative and qualitative questions, all of which - except the eligibility questions - were optional. Respondents were not asked about social determinants of health such as their racial identity or socio-economic status. Anyone with access to the Internet could participate in these informal surveys for the day and half they were open to accepting responses. We did not perform formal statistical analysis.

Limitations – Employer survey

Qualitative questions on the employer survey attracted a low response rate. Despite the provision of a definition of a workplace accommodation in the survey script, the answers of some employers suggested they did not understand the meaning of a workplace accommodation, most often misunderstanding that “*workplace accommodations*” were “*living accommodations*.” This reduced the reliability of subsequent responses to questions about accommodations. Not infrequently, participants’ responses contradicted their other answers. Survey design did not include all the exclusion logic required to ensure respondents did not answer questions they were unqualified to answer. Consequently, considerable numbers of responses were excluded from the following results and analysis.

Employer Survey Results

Demographics

Employer respondents were primarily located in British Columbia (31%), Ontario (29%), Alberta (20%), and Quebec (13%), with a few in Saskatchewan (5%), Manitoba (1%), and Nova Scotia (0.5%). Nearly half (43%) of employer respondents stated that they had contracted COVID-19 themselves. Most employers (89%) stated their workplaces had taken steps to enhance workplace safety during the pandemic, with most offering their employees the option to work from home (79%), and many offering reduced work hours (43%) or flexible work hours (31%), providing equipment required to work from home (35%), and updating rules and protocols for working in-person (28%).

Employers’ Employees

Approximately 40% of employers stated their employees were currently working solely remotely, 29% stated their employees worked solely on-site, and the remainder answered their employees worked in various combinations of these. At least 43% of employers indicated they knew or suspected that at least one of their employees had contracted COVID-19, among whom 78% were believed to have symptoms that lasted longer than two weeks.

Long COVID

91% of respondents stated they had previously heard of Long COVID or post COVID-19 syndrome. However, their answers to true or false statements about Long COVID demonstrated a significant lack of knowledge about its initiating factors, symptoms, and prevalence. Among the incorrect information many believed, nearly half (43%) thought Long COVID is contagious, and 40% believed everyone who contracts COVID-19 automatically experiences Long COVID afterwards. In contrast, regarding correct information, only 35% of respondents believed symptoms of Long COVID may disappear and reappear unexpectedly over time, and 21% believed that up to 1 in 3 people infected with the virus may experience symptoms lasting longer than two weeks. More respondents believed Long COVID can cause breathing difficulties (44%), changes in mobility (40%), gastrointestinal problems (35%) and changes in cognitive functioning (34%) than changes in vision (20%) or changes in hearing (15%).

Accommodations

Nearly all respondents (94%) asserted they knew what an accommodation referred to, while 86% wrote that they had heard the term used before in the context of work. However, most employers (89%) stated they had not been involved in providing an accommodation prior to the current pandemic. Among those who had, several indicated they believed accommodations referred to living accommodations (e.g., providing “an apartment for two in good condition”) despite the provision of a definition of a workplace accommodation in the survey script. Employers indicated they required access to more funds, a larger workforce, and more training to provide their employees with different types of accommodations.

Employee Survey Results

Demographics

The largest percentage of long-hauler respondents identified their primary residence as Ontario (43.3%), followed by British Columbia (26.5%), Quebec (14.4%), Alberta (10.8%), and Manitoba (2.4%) and Nova Scotia (2.4%). Of the 83 persons who responded to a question about employment status, 80.7% were currently employed full-time (in permanent, fixed-term contract, or casual contract positions), while 15.6% were employed part-time (in permanent, fixed-term contract, or casual contract positions). Only 3.6% of respondents were unemployed but seeking employment. Of those who were currently employed, about half were working remotely (including at home), while the other half were working in-person or on-site at their workplaces.

Symptoms

The most common symptoms reported by COVID long-hauler respondents were cough (44%), headaches or migraines (40%), fatigue (39%), difficulty breathing (34%), joint pain (34%), light headedness (34%), muscle weakness (31%), difficulty sleeping (28%), chest pain (25%), and brain fog (20%), though all symptoms listed on the survey were experienced by at least a few respondents. When asked which symptoms had the greatest impact on their ability to work or seek work, the commonest were fatigue, breathing difficulties or a cough, pain, mental health issues, and muscle weakness. This aligns with symptoms identified by respondents participating in an independent, international, patient-led survey on Long COVID.¹⁵ Respondents to the latter survey also reported fatigue, breathing issues, and cognitive dysfunction were the three most debilitating symptoms they experienced.¹⁵ Respondents to our survey also mentioned struggles with mental health, particularly anxiety and depression.

Work experiences (see Appendix A)

Participants' responses to what work or job searching activities they could no longer complete due to Long COVID typically centered around work hours, mobility, meetings, and cognitive tasks. They described feeling unable to perform cognitively complex or information-processing heavy tasks; being unable to read and retain information; getting rapidly fatigued and out of breath speaking at meetings; being unable to work without frequent breaks to rest; being unable to sit or stand for long periods of time; and being limited in their mobility or ability to "get around."

While many of the symptoms described above were mentioned again when participants were asked about the most frustrating aspects of trying to work while dealing with Long COVID, several participants also discussed frustrations related to interpersonal or social aspects of employment. These included fears about being criticized by their superiors, and frustrations about colleagues' misconceptions about Long COVID which led the latter to believe their peers were "dangerous," "contagious," or over-exaggerating the severity of their symptoms. Multiple respondents also reinforced that they "can look fine and still be really sick," suggesting they were concerned about, or had directly experienced, others' skepticism about the validity of their illness.

Many respondents found it challenging to prove they had Long COVID for insurance purposes to access disability benefits and medical leave. As explained by one, "my long-term disability claim [is] being challenged as post-covid syndrome is not seen as a real diagnosis and I don't have any medical tests proving I'm sick. I would work if I could, and my employer's insurance company doesn't seem to believe that."

Accommodations

Most respondents (73%) had heard the term "accommodation" used in a workplace context before, but less than half (38%) had asked for a workplace accommodation prior to contracting COVID-19. Employees who had previously asked for a workplace accommodation were more likely to know how and where to access information about accommodations at their current workplace. They were also slightly more likely to have disclosed their health status to their current employer or union.

Most respondents (86%) had informed their employer or union that they were experiencing symptoms of Long COVID. Among those who had disclosed this, only 55% were offered an accommodation in response³. Overall, nearly half (47%) of respondents accepted an accommodation offered by their employer and/or union for their experience of Long COVID.

See Appendices B, C, D, E, F. Respondents indicated that all but one⁴ of the workplace accommodations listed as options on the survey would be helpful while dealing with Long COVID. The most popular pre-determined accommodations they felt they would find most efficacious were:

- Option to sometimes work remotely and/or from home (85%, n=55)
- Ergonomic office furniture at home⁵ (e.g., raised desk, ergonomic keyboard) (75%, n=49)
- Flextime allowing you to change or vary *when you work during the day* (67%, n=47)
- Access to a quiet place to rest at your place of work (59%, n=41)

³ It is important to note we did not ask whether *respondents* had initiated accommodation requests.

⁴ No respondents wished to change from part-time to full-time work.

⁵ A separate option for an accommodation that would provide ergonomic furniture at a person's place of work was also included on the survey.

- Time off to attend medical appointments (59%, n=41)
- Job sharing that would allow you to share certain duties or responsibilities of your job with another employee (55%, n=37)
- Job sharing that would allow you to share hours of your job with another employee (52%, n=35)
- Flextime allowing you to change or vary *which days or weeks you work* (67%, n=34)

However, when asked which accommodations would prove most helpful *if they could only choose 1-3 options*, the types of accommodations prioritized by respondents changed somewhat.⁶

- Access to a quiet place to rest at your place of work
- Flextime, allowing you to change or vary the number of hours you work per day, when you work during the day, and how many days or weeks you work
- Access to a private space to take medications at your place of work
- Relocation of a workstation closer to a washroom in the workplace
- Altered lighting at your place of work
- Cot available at your place of work
- Designated parking space at your place of work

When asked which specific work tasks and/or responsibilities they wished could be reassigned to other employees, or changed as an accommodation, respondents' answers centred on 1) fewer meetings, 2) reduced work hours, and 3) flexibility around their pace of work. They also discussed more flexible deadlines to accommodate the fluctuating and unpredictable symptoms of Long COVID.

⁶ Only 43 of the survey's total respondents answered this question, making this question's results less representative of the total sample.

Discussion

“What strikes me is that when we talk about COVID, we talk about numbers and we talk about restrictions and we talk about deaths. And now we’re talking about vaccines. We don’t spend a lot of time talking about the people that are sick.” – Dr. Ann Collins, head of the Canadian Medical Association.¹⁷

In February 2021, **Realize** posted two open surveys online; the first was directed at adults working or seeking work in Canada while dealing with Long COVID (i.e., “COVID-19 long-haulers”), while the second addressed Canadian employers. The extent, frequency, and severity of symptoms described by the COVID-19 long-hauler survey respondents paint a clear picture of the grave impact these hold for navigating employment while struggling with Long COVID. Employers demonstrated a general lack of knowledge around workplace accommodations which is particularly concerning given the legal obligation to accommodate people with disabilities.⁷ As numbers of COVID-19 infections continue to increase, so will the number of potential COVID-19 long-haulers. It is imperative to pro-actively consider how best to support long-haulers when returning to, or continuing in, the work force. This is especially important given that medical professionals and scientists do not yet know either how long symptoms of Long COVID may persist or what treatment is the most effective.

It is important to note that long-haulers included in our survey sample were almost all currently employed - only three identified as being “unemployed but seeking employment” - and were not asked to identify their incomes or the types of jobs they held. Consequently, their opinions may very well represent those of COVID-19 long-haulers with relative privilege.

Ableism

“We are real and don’t need judgement from others that think they know more than the scientists who themselves are trying to figure this out.” – Long-hauler survey respondent

The severity and level of interference resulting from symptoms experienced by long-haulers contrasted sharply with some employers’ comments regarding accommodations. When asked about their comfort providing different workplace accommodations, employers often responded with value judgements and medical assumptions. For example, when asked which accommodations they would feel least comfortable offering and why, employers called various accommodations listed in the survey - including designated accessible parking spaces - “very inconvenient,” “completely unnecessary,” “nonsense,” “not a good idea,” and “inappropriate,” and/or otherwise assumed such accommodations would not be helpful to those availing of them. Notably, after seeing “provision of a cot for an employee at your workplace” (i.e. for rest) listed as an optional workplace accommodation, several employers appeared to have mistakenly assumed the term “cot” referred to an infant’s “crib,” echoing the historic infantilization of people with disabilities.¹⁸ When asked what accommodations they offered to employees who requested them due to COVID-19 or Long COVID, one employer wrote, “He [i.e. an employee] applied [i.e. for a workplace accommodation] but I didn’t agree.” Another responded, “My employees don’t get COVID.”

⁷ All Canadian employers and service providers have a legal duty to accommodate people with disabilities until the point of undue hardship (Canadian Human Rights Commission).

Researchers have found people with episodic disabilities may be suspected of “malinger.”¹⁹ Understandably, long-haulers expressed related fears about social discrimination, worrying that they would be seen as “dangerous” or “contagious,” or would be criticized for an “unprofessional” appearance as they compensated for symptoms they were experiencing. In this vein, long-haulers also repeatedly implored employers to demonstrate compassion and understanding. While they asked for employers to trust that they “are not ‘faking’ symptoms, even if [they] ‘look fine,’” they also recognized that “it is hard to have them [i.e., employers] understand what is going on when the doctors don’t even know what is going on.”

Cognitive limitations in a knowledge economy

“I feel cognitively slower and as such it takes much longer to accomplish work tasks.” – Long-hauler survey respondent

The functional limitations caused by cognitive symptoms of Long COVID are particularly significant in a knowledge or information-based economy. COVID-19 long-hauler respondents, both in an international survey¹⁵ as well as our own, reported symptoms of brain fog, cognitive dysfunction, and memory impairment, including poor attention or concentration, difficulty thinking, difficulty with executive functioning skills, difficulty problem-solving or decision-making, and slowed thoughts.^{15,20} They reported these cognitive symptoms had the greatest impact on their ability to work. Respondents reported trouble making decisions, focusing, concentrating, “finding words,” negotiating, multi-tasking, reading, and analyzing information, and/or found their information processing was slowed or strained when processing complex or multiple sources of information. This is particularly important given that remote work will likely remain the norm throughout the pandemic, and because long-haulers may need to continue to work remotely even after the pandemic is resolved to accommodate their needs for frequent breaks and rest.

Accommodations – Long COVID and episodic disability

“[My] employer and colleagues don’t understand how cyclical it is, and how just because I was feeling better last week doesn’t mean I’m not feeling worse this week.” – Long-hauler survey respondent

The wide array of unpredictable and fluctuating symptoms caused by Long COVID mean that no single accommodation will prove effective for all long-haulers, and accommodation plans for individual employees will likely vary over time as well. Long-hauler respondents’ desire for flexibility, reduced hours, opportunity for frequent rest, and more awareness among employers about the unpredictable nature of their symptoms align with those of other long-haulers²¹ as well as employees working with different types of episodic disabilities.²² Multiple studies confirm flexible work arrangements are the accommodation type most commonly required by people with episodic disabilities and intermittent work capacities.²³ It is interesting to note that more long-hauler survey respondents (67%) indicated they would benefit from flextime allowing them to change or vary *when they worked during the day*, as opposed to flextime allowing them to change or vary *which days or weeks they worked* (59%), or flextime allowing them to change or vary *the number of hours they worked per day* (39%). Many respondents also noted they could not work over-time.

The ability to take frequent breaks and rest as needed is particularly essential for COVID long-haulers due to the overwhelming fatigue they experience along with post-exertional malaise (PEM). PEM can be triggered by both physical exertion and mental exertion, and may last for several days at a time.¹⁵ Reduced hours alongside the opportunity to vary when work hours are completed during the day would provide long-haulers with the flexibility required to work without further exacerbating symptoms or potentially triggering a full relapse – a real

risk of over-exertion.¹⁵ Expressions of fear and anxiety surrounding the uncertainty of Long COVID and its illness trajectory, or when patients can expect to return to their previous baseline levels of health, also surfaced repeatedly. “We are scared because this is a big unknown,” wrote one respondent.

Though graduated return to work plans are often recommended as accommodations for people with episodic disabilities who require extended periods away from work, these plans may not meet the needs or match the symptomology of long-haulers. As explained by Malli, “For COVID patients who are out of the initial acute and contagious stage, recovery can be slow, complicated and nonlinear, with the majority reporting lingering symptoms that fluctuate in intensity and frequency, relapsing or intensifying after physical or mental exertion, *requiring them to stagger their return to work*” (emphasis added).²⁴ In an international patient-led study, 86% of respondents reported experiencing a relapse in symptoms, and among them, half stated their relapses had occurred irregularly, without clear triggers.¹⁵ A **Realize** long-hauler survey respondent explained: “Long COVID is cyclical, so a return to work plan with longer hours each week may not work, compared to the ability to set hours based on capacity to work each week.”

Remote work

“Good god, give me ergonomic tools so that my poor exhausted body isn’t also struggling from working at the kitchen table. I can’t afford an office chair or more furniture.” – Long-hauler survey respondent

Some employers may falsely believe they are not obligated to provide workplace accommodations to employees working remotely, wrongly assuming work from home nullifies the need for workplace accommodations at all. For example, when asked about their preparedness to offer accommodations to employees dealing with Long COVID, one employer respondent wrote, “No, we’re a tech company. We don’t have many people. They all work from home.” Nearly twice as many long-hauler survey respondents felt they would benefit from the provision of ergonomic office furniture in their homes as opposed to their places of work. Many highlighted the fatigue, pain, and breathlessness that can result from sitting through, and speaking at, long online meetings - particularly when these are held on-camera. Notably, 85% percent of long-hauler survey respondents indicated they would benefit from the option to *sometimes* work remotely, as opposed to 28% who preferred the option to work *solely* remotely. This suggests that employees with episodic disabilities do not necessarily want to work remotely when they have the capacity to work on-site.

A new kind of disability

“I’m telling you; I am not the same” – Long-hauler survey respondent

In many ways, the plight of long-haulers is one shared by others with episodic disabilities “whose disabilities do not conform to corporeal templates of government classification.”²⁵ In the case of COVID-19 long-haulers, this is further exacerbated by the dearth of knowledge about Long COVID *and* its lack of singular clinical definition, although an ICD-11 code for “Post COVID-19 condition” exists.²⁶ With so little known about Long COVID, and no definitive test for it, many doctors mistakenly misdiagnose or dismiss long-haulers, which may make it difficult for them to get the notes required for accommodations.²⁷ In a nation-wide survey conducted by CBC News with over 1000 respondents, 50% of them stated that “physicians did not believe them when they presented with [Long COVID] symptoms.”²⁸ To this end, multiple **Realize** survey respondents noted the challenge of proving they have Long COVID for insurance purposes in order to access disability benefits and medical leave. As explained by one, “my long-term disability claim [is] being challenged as post-covid syndrome is not seen as a real diagnosis and I don’t have any medical tests proving I’m sick.” Those who are unemployed due to Long COVID cannot access the Canada Recovery Benefit either.²⁹

Long-haulers also face the challenge of being a group of disabled people with a “new” disability. This means they cannot turn for mentorship to those who have lived experience with their disability, who might be able to provide guidance about how to adapt to living with it. Several long-hauler survey respondents also spoke to the disorientation they felt learning how to live with disability.

Conclusion

This report analyzed the combined results of two online, community-driven surveys shared by our non-profit in February 2021. The surveys sought to better understand the experiences of employees and employers in Canada in relation to Long COVID - a condition that can result in numerous prolonged and debilitating physical, cognitive, and psychological symptoms. Participants shared how their symptoms impacted their ability to work and described workplace accommodations they felt would be helpful in response. The experiences they shared highlighted the need for accommodations even while working remotely, including at home. Flexible work arrangements allowing for frequent breaks and rest, reduced work hours, fewer meetings, and a greater understanding from employers about the unpredictable and fluctuating nature of Long COVID were also requested. It is imperative that employers hear these messages and requests by long-haulers if they are to prepare for the 200 000+ Canadians who may be returning to the workforce while recovering from, or adjusting to, the array of impairments caused by Long COVID.²⁸ If up to 1 in 3 people with COVID-19 may become long-haulers, the number of workers who may require accommodations to rejoin or continue to work in the formal economy is immense. There are also significant social justice implications given the disproportionate rates and impacts of COVID-19 on marginalized groups, and the subsequent likelihood that the same groups are over-represented among long-haulers as well.^{10,24} As long-haulers continue to publicly share their lived experiences, and research about this difficult-to-diagnose emerging condition continue to reveal more about its prognosis, employers should be actively preparing themselves to accommodate this “new” group of people with episodic disabilities.

Recommendations

For employers:

A) Accommodations for COVID-19 long-haulers

- 1. Provide individualized workplace accommodations to ensure they meet different employees’ needs.**
Both symptoms and the impact of these on a long-hauler’s capacity to work will vary greatly depending on individual circumstances (e.g., one’s employment status, employment industry, income security, etc.). Further, given the substantial range in symptoms caused by Long COVID, it is imperative that employers focus on employees’ individual functional limitations as opposed to their statuses as long-haulers. Freelancers performing contract work should also be afforded the same right to accommodations as their peers.²¹
- 2. Consider providing flexible work arrangements, fewer meetings (especially when these require video/screen time), and the option to work remotely.**
These accommodations can help address long-haulers’ needs for frequent breaks and time to rest, as well as account for the unpredictable and episodic nature of Long COVID. Re-assignment to alternative types of work may also help mitigate cognitive impairments caused by Long COVID.

3. Prepare contingency plans for long-hauler employees in case they experience sudden and unexpected relapses that change their capacity for work.

Long-haulers are prone to extreme exhaustion and post-exertional malaise, and many are unaware of relapse triggers. Smaller organizations should have plans in place to ensure work deliverables are not compromised if an employee must take an unexpected leave.

4. Consider setting aside centralized funds for accommodations during the pandemic.

While it is already considered good practice to set aside part of a yearly budget for accommodations, long-haulers may require more accommodations than previously anticipated. Accommodations are also still required for remote work.

5. Refrain from asking for medical notes where possible, and if necessary, ask doctors to affirm an employee's functional limitations as opposed to their official diagnosis.²⁸

Since many long-haulers cannot prove they previously contracted COVID-19, and there are no confirmatory diagnostic tests for Long COVID, it is important that employers trust long-haulers are requesting accommodations in good faith.

B) Education and Awareness

1. Ensure directors, managers, HR professionals, and supervisors are *all* provided with education about episodic disabilities, workplace accommodations, and Long COVID.

Employers in all industries would benefit from regular training on the legal obligation to accommodate people with disabilities; the efficacy, reasoning behind, and benefits of providing workplace accommodations; and how to effectively implement them. Greater awareness about episodic disabilities is essential if employers are to feel invested in hiring and accommodating those who have them.¹⁹

Providing resources and training to the personnel listed above on best practices in providing accommodations to people working remotely is also recommended.

2. Given the unprecedented nature of Long COVID, directors, managers, HR professionals, supervisors, and others involved with workplace policy and/or accommodations should be *continuously* provided with up-to-date resources on Long COVID as they emerge.

Personnel should be encouraged to self-educate about the subject as well.

C) COVID-19 Long-hauler Advocacy

1. Review the research and recommendations of long-hauler patient advocacy groups.

COVID-19 long-haulers have proven formidable self-advocates who have pushed countries worldwide to instigate research as well as recognize the legitimacy of, and provide care for, their condition. As the experts on their own lives and experiences, it is important to follow their lead. An [online petition by Covid Long-Haulers Support Group Canada](#) as well as an [open letter addressed to Canada's chief medical officers](#)²⁷ include detailed lists of recommendations, including those listed in this report. People interested in keeping up to date with the latest developments in long-hauler research, advocacy efforts, and care in Canadian settings should consider following Long Covid Canada (@LongCovidCanada) on Twitter and through their forthcoming [website](#), as well as following the Covid Long-Haulers Support Group Canada (@susiegoulding9) on Twitter and through their [website](#) respectively. Many other international patient-led groups can also be found online.

For Government

C) Policy

1. **The Canadian government should develop national guidelines that explicitly recognize Long COVID as a medical condition that can cause impairment and disability - whether a patient previously received a positive diagnosis for COVID-19 or not.**^{28,29}

Without official recognition of the legitimacy of “a medical condition...in its infancy”³¹ many long-haulers cannot access:

- Specialized post-COVID medical care³
- Long-term disability benefits through work³² (e.g., insurance coverage for the costs of physical therapy and vocational rehabilitation)
- Federal COVID-19 support benefits and programs for people with disabilities
- Other federal benefits and supports for people with disabilities

2. **The Canadian government, in a harmonized approach with its Provincial counterparts, should provide guaranteed paid sick leave.**^{33,34}

Long-haulers who do not qualify for disability benefits may be forced to continue working when they would greatly benefit from time off to focus on rest and rehabilitation instead. The longer COVID-19 long-haulers spend attempting to self-manage their condition while working, the longer it will take for them to recover.

D) Budget

1. **The Canadian government should fund and organize specialized clinics and medical support for COVID-19 long-haulers in all provinces and territories.**

Currently long-haulers face geographic barriers to accessing the specialized care and rehabilitation they need.³⁵

E) Further Research

1. **The Canadian government should establish a national COVID-19 and Employment Research Hub to study evidence-based work supports for this population.**^{27,28}

Further research on the employment experiences of COVID-19 long-haulers is needed on many fronts, including to better understand how best to accommodate them at work.

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Hyperlinks:

Support for Covid Long Haulers - Change.Org Petition by Covid Long-Haulers Support Group Canada

<https://www.change.org/p/canadian-government-needing-recognition-of-research-and-offer-rehabilitation-for-covid-19-long-haulers>

Open letter to Canadian health officials by Canadian long-haulers

https://drive.google.com/file/d/1Es3HoRIldVZ9H2_2Xrcz5gqTKElylhyY/view

Long COVID Canada website

<https://longcovidcanada.ca>

Covid Long-Haulers Support Group Canada website

<https://covidlonghaulcanada.com>

Appendix A

Long COVID symptoms and how they interfered with work – survey respondents’ direct quotes

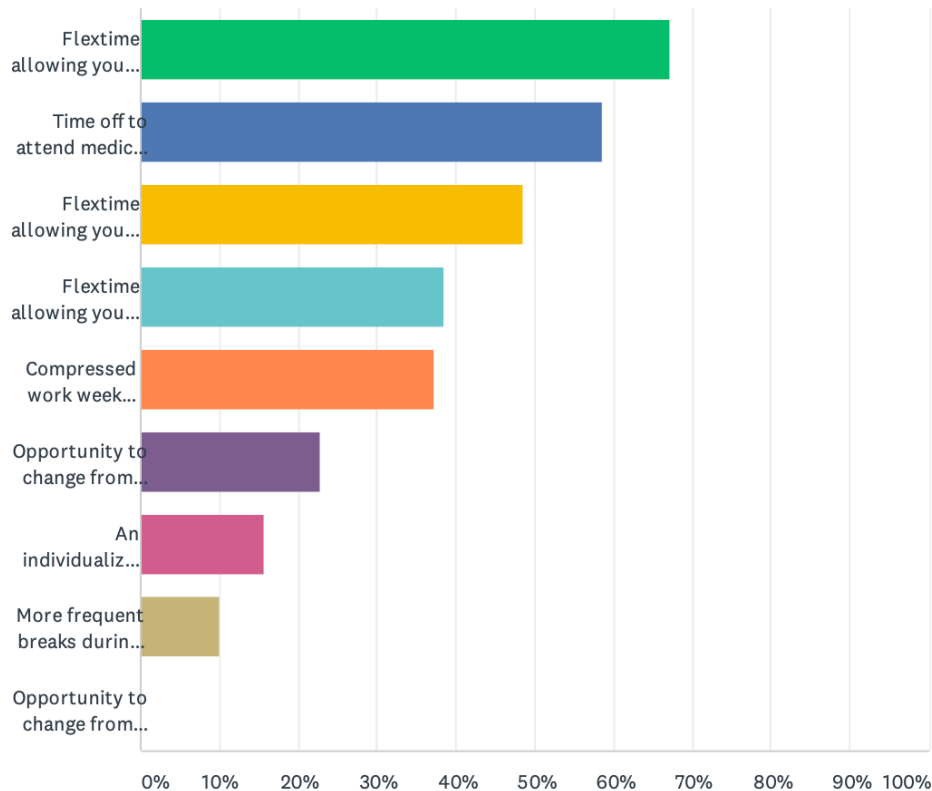
Cognitive	Fatigue	Breathing	Pain	Image	Mental Health
“I cannot make decisions, process complex information, focus on multiple sources of input, or event sit for long periods of time.”	“Working from the office I have to rest every hour or two.”	“I get short of breath if I sit for a long time (I had to change my seating arrangements and get a stool because [a] a chair backrest gives me soreness in [my] chest and upper back which makes breathing more complex).”	“Working at a computer for long periods of time is impossible due to fatigue, muscle pain.”	“Hair loss, because of bad appearance.”	“I get depressed easily.”
“Have difficulty reading and retaining anything that I do.”	“Working 8 hours a day without breaks/naps/ stretches is impossible.”	“Speaking for a long time during meetings is now not possible as I get breathless and fatigued.”	“Blisters and skin infections as they made sitting up difficult at times.”	“Cough, affect[s] the image.”	“My job requires multi tasking which is hard to do with anxiety and brain fog.”
“Accounting and financials. Taking a step back as the math and analytical aspect causes headaches and confusion.”	“I am working remotely, but it would be hard for me to have the energy to walk around my office should I need to return.”	“Long meeting[s] which requires lots of talking. I’m out of breath after 5-10 min talking.”	“Fatigue and muscle pain make it nearly impossible to sit up for long periods of time.”	“Slouching in the office.”	“Have no energy and am depressed because my heart is not the same.”
“I feel cognitively slower and as such it takes much longer to accomplish work tasks.”	“It’s impossible to wake up in the morning even with ADHD medication.”	“Shortness of breath while seat[ed] for a long time.”	“My left hand is constantly tingling which makes typing very frustrating.”	“Sluggish when it comes to spending time with clients.”	

Cognitive (cont.)	Fatigue (cont.)	Breathing (cont.)	Pain (cont.)	Image (cont.)	Mental Health (cont.)
"Negotiate, because my reflexes are getting slower."	"I don't have the energy to make it through the workday."	"The cough is so unpleasant that my throat is on fire."	"I also have sensitivity to sound and light making screen time challenging."	"Losing my hair has made me look less good."	
"I cannot remember left from right most days and cannot process information quickly."	"The fatigue is unrelenting."	"Difficulties in breathing were the worst. It made me feel like I was going to faint all the time."			
"Fatigue and cognitive issues, problems concentrating, memory problems, difficulty finding words. I need to think for my job."	"Muscle weakness resulting in overall lethargy"				
"It is difficult for me to concentrate and remember."	"I can't travel for long because I'm tired."				
"I also tend to look for words I usually know."					
"My attention span has decreased a lot."					

Appendix B

Q26 Which of the following accommodations would you find most helpful in allowing you to return to work, continue to work, find work, and/or perform your work duties while dealing with long COVID, if you could access any you desired? Please select all that apply. Work schedule:

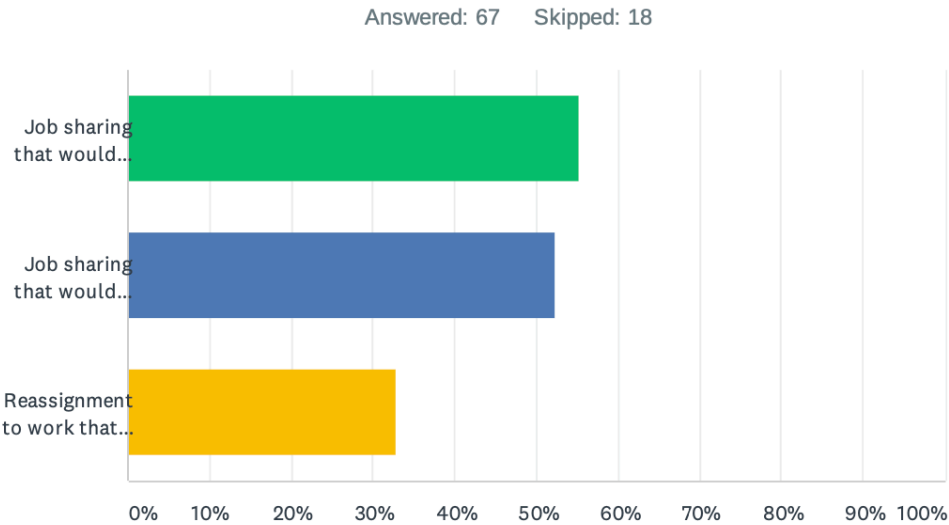
Answered: 70 Skipped: 15



ANSWER CHOICES	RESPONSES	
Flextime allowing you to change or vary when you work during the day	67.14%	47
Time off to attend medical appointments	58.57%	41
Flextime allowing you to change or vary which days or weeks you work	48.57%	34
Flextime allowing you to change or vary the number of hours you work per day	38.57%	27
Compressed work week allowing you to work longer hours for fewer days each week	37.14%	26
Opportunity to change from full-time to part-time work	22.86%	16
An individualized "Return to Work Plan" allowing you to gradually return to work and increase your hours and responsibilities over time	15.71%	11
More frequent breaks during the workday	10.00%	7
Opportunity to change from part-time to full-time work	0.00%	0
Total Respondents: 70		

Appendix C

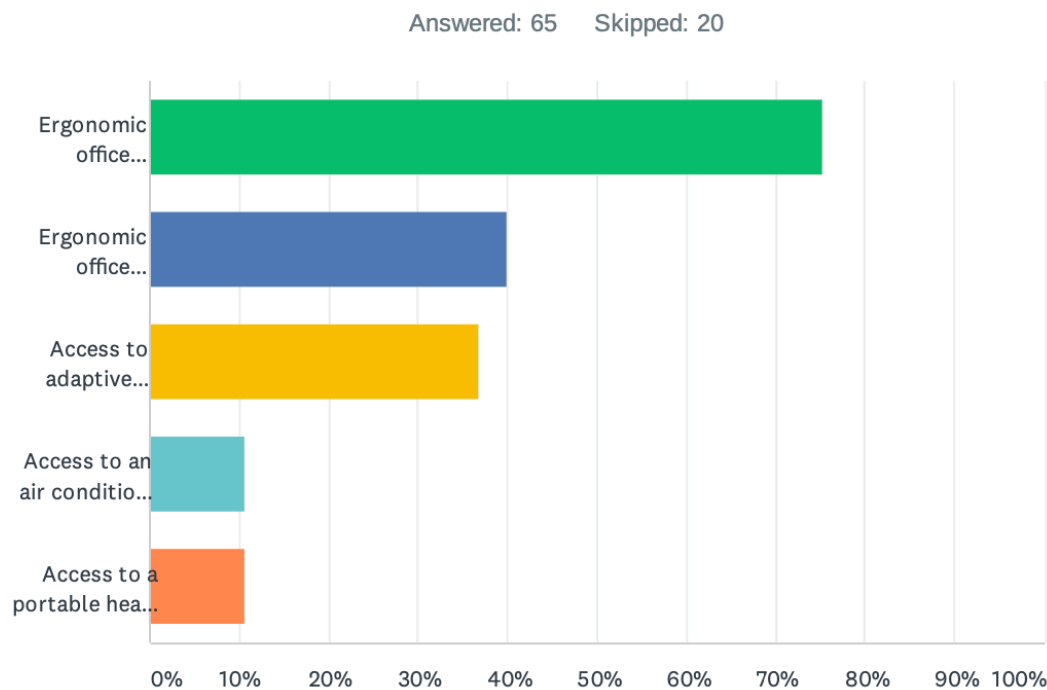
Q27 Which of the following accommodations would you find most helpful in allowing you to return to work, continue to work, find work, and/or perform your work duties while dealing with long COVID, if you could access any you desired? Please select all that apply. Work tasks and responsibilities:



ANSWER CHOICES	RESPONSES	
Job sharing that would allow you to share certain duties or responsibilities of your job with another employee	55.22%	37
Job sharing that would allow you to share hours of your job with another employee	52.24%	35
Reassignment to work that is more aligned with your current abilities (e.g. work that is less physically or mentally demanding)	32.84%	22
Total Respondents: 67		

Appendix D

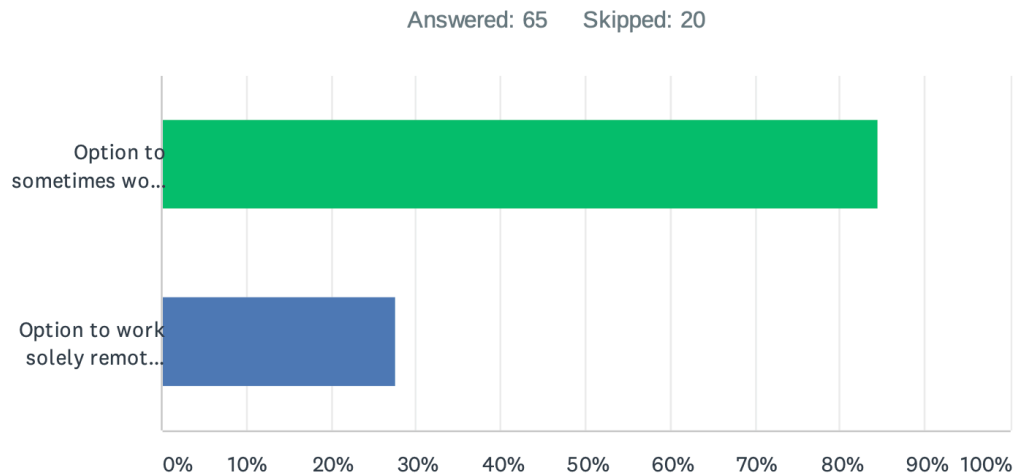
Q28 Which of the following accommodations would you find most helpful in allowing you to return to work, continue to work, find work, and/or perform your work duties while dealing with long COVID, if you could access any you desired? Please select all that apply. Work equipment:



ANSWER CHOICES	RESPONSES	
Ergonomic office furniture at home (e.g. raised desk, ergonomic keyboard)	75.38%	49
Ergonomic office furniture at your place of work (e.g. raised desk, ergonomic keyboard)	40.00%	26
Access to adaptive technologies or devices (e.g. a headset for your phone, software that reads digital documents aloud)	36.92%	24
Access to an air conditioner and/or fan	10.77%	7
Access to a portable heater	10.77%	7
Total Respondents: 65		

Appendix E

Q29 Which of the following accommodations would you find most helpful in allowing you to return to work, continue to work, find work, and/or perform your work duties while dealing with long COVID, if you could access any you desired? Please select all that apply. Work location:

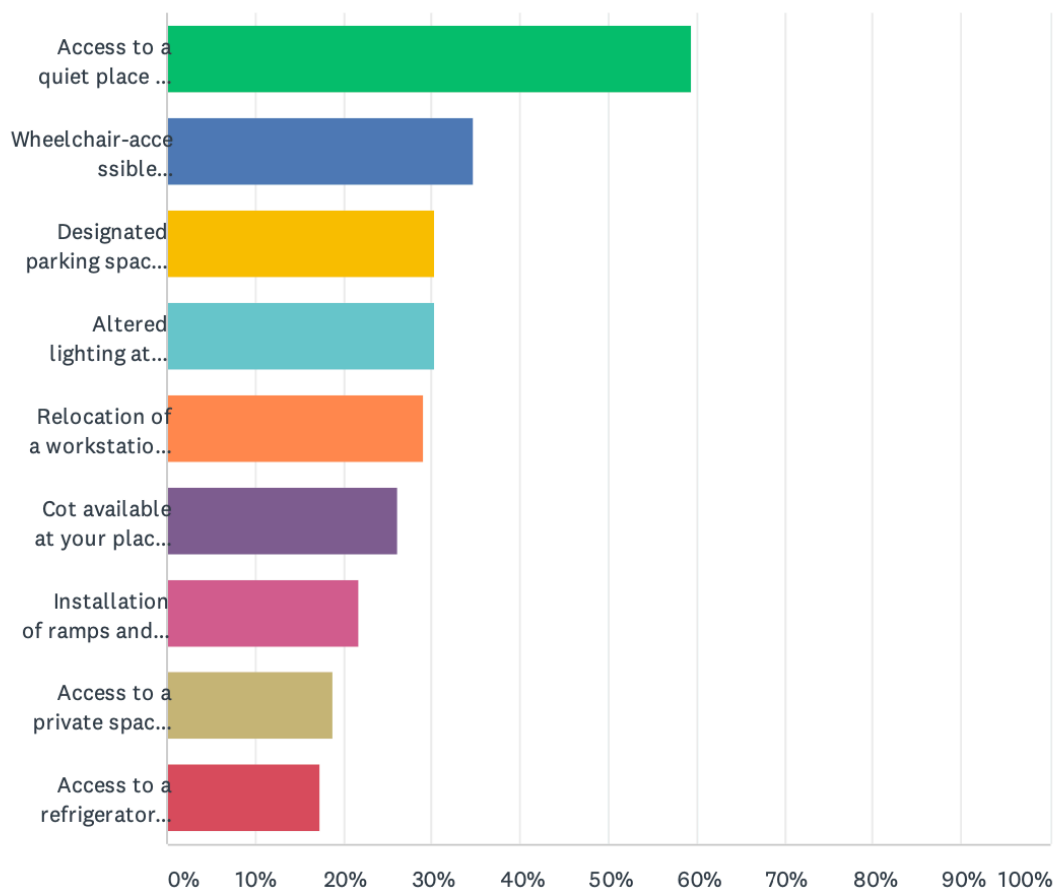


ANSWER CHOICES	RESPONSES	
Option to sometimes work remotely and/or from home	84.62%	55
Option to work solely remotely and/or from home	27.69%	18
Total Respondents: 65		

Appendix F

Q30 Which of the following accommodations would you find most helpful in allowing you to return to work, continue to work, find work, and/or perform your work duties while dealing with long COVID, if you could access any you desired? Please select all that apply. Place of employment:

Answered: 69 Skipped: 16



ANSWER CHOICES	RESPONSES	
Access to a quiet place to rest at your place of work	59.42%	41
Wheelchair-accessible washrooms at your place of work	34.78%	24
Designated parking space at your place of work	30.43%	21
Altered lighting at your place of work	30.43%	21
Relocation of a workstation closer to a washroom in the workplace	28.99%	20
Cot available at your place of work	26.09%	18
Installation of ramps and/or handrails at your place of work	21.74%	15
Access to a private space to take medications at your place of work	18.84%	13
Access to a refrigerator to store medications	17.39%	12
Total Respondents: 69		