

CCSN'S FIFTH LEGER SURVEY ON
COVID-19 AND CANCER CARE

“Having half the life I used to have”

CANADIAN CANCER
SURVIVOR NETWORK



RÉSEAU CANADIEN DES
SURVIVANTS DU CANCER

The impact of long-COVID on cancer
patients in Canada



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The impact of long COVID on cancer patients in Canada

Executive Summary

As the COVID-19 pandemic fades from the public eye, long-term symptoms that persist after COVID-19 – or long COVID – have become a serious public health issue. Yet long COVID is often overlooked and incompletely understood. In spring 2023, the Canadian Cancer Survivor Network conducted its fifth Leger survey to better understand the impact of long COVID on cancer patients and caregivers. The results show that the effects of long COVID on cancer patients and caregivers have varied widely and that for many, it has profoundly worsened their quality of life.

- Many cancer patients with long COVID find that fatigue, shortness of breath, depression, and other symptoms curtail their usual activities: they have trouble exercising, socializing, working, or caring for family or friends. Nearly three-quarters of respondents said they have had difficulty exercising, and more than half found their ability to work has been affected.
- These long-term symptoms have caused them stress, anxiety, and isolation. Almost two in five respondents (39 per cent) said that they were concerned about their long COVID, often because they were worried about how long their symptoms would last or whether they would get worse. They also lacked medical support and had a reduced quality of life.
- These symptoms also cause many patients difficulties in accessing cancer care. Thirty-seven per cent of patients found that long COVID made it harder for them to see the doctor managing their cancer care.
- The financial impact of long COVID is due to patients’ inability to work. Of the 20 per cent of respondents who found that long COVID impacted them financially, reduced employment income was by far the most common reason.
- Respondents felt that long COVID was not well understood by healthcare professionals and that they are not getting the support they need from the medical system. Nearly half of respondents have not received any help for long COVID; the most common reason given is that they had difficulty discussing the subject with their doctor.
- Respondents said that better access to family doctors, medication, more information about long COVID, and long COVID clinics would help them manage their long COVID better.

CCSN calls upon Canadian federal and provincial governments to provide the medical, financial, and social support that people with long COVID need. COVID-19 may no longer be a global health emergency, but that does not mean that people who have had COVID-19 can be forgotten. People with long COVID, especially those who also have or have had cancer, must not be allowed to fall through the cracks.

Background

About the survey

This was the fifth survey that the Canadian Cancer Survivor Network commissioned from Leger, beginning in the spring of 2020. The first three surveys asked cancer patients and caregivers how COVID-19 had disrupted their cancer care, and the fourth survey explored the thoughts of cancer patients and caregivers as society opened and COVID-19 restrictions were relaxed or dropped. The report of the three surveys, entitled “Thrown under the bus,” can be found at <https://bit.ly/42aeMsk>, and the report of the fourth survey, “For Cancer Patients, the Pandemic is not Over,” can be found at <https://bit.ly/4066Y9b>.

The fifth web-based survey conducted by Leger assessed the impact of long COVID on cancer patients in Canada. Responses were collected from 119 respondents between March 2 and May 3, 2023.

The topics respondents were asked include:

- How concerned they are about their long COVID and why.
- How long their symptoms have been going on, and whether they have been diagnosed with long COVID by a healthcare professional.
- What long-term symptoms they are experiencing, and whether they are getting better or worse.
- The impact of long COVID on their lifestyle and activities.
- Whether they are getting any help for long COVID symptoms.
- What, if anything, has made it difficult to get help.
- What the “new normal” is like for them.

CCSN’s five surveys on COVID-19 and cancer further its mandate to conduct research on the barriers that confront those affected by cancer in Canada, raise awareness about these barriers, and call for change where it is needed. The surveys have formed the basis of CCSN’s Cancer Can’t Wait! project about the impact of reduced access to cancer care during the pandemic, which includes webinars, articles, and pan-Canadian action campaigns.

Respondent Profile

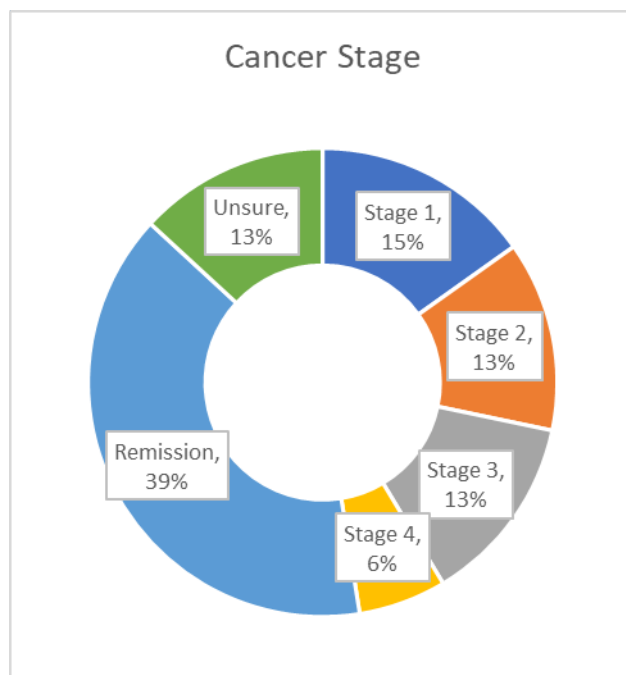
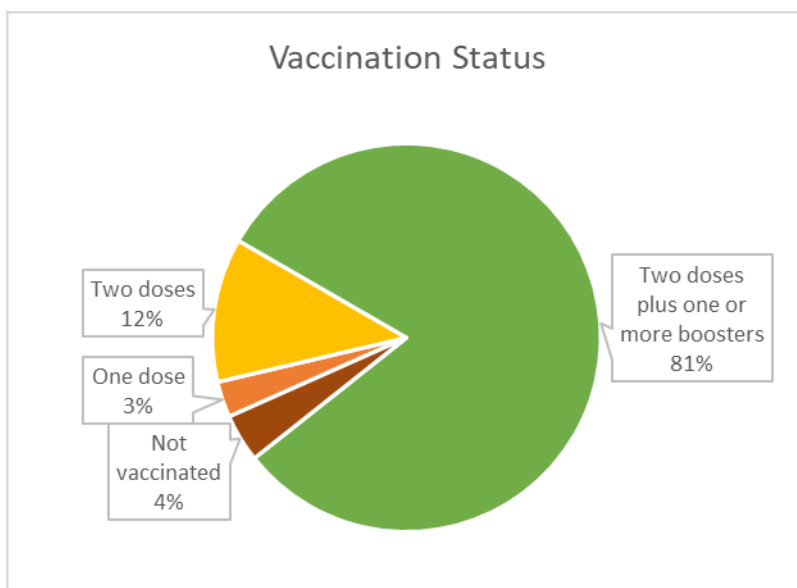
There were 119 respondents, all of whom had been diagnosed with cancer within the past ten years and had experienced long-term symptoms after having had COVID-19. Respondents lived in Canada and were at least 18 years old. Eighty-six respondents were recruited through Leger's LEO survey panel and 33 were found through web links sent to CCSN members and partner organizations.

To arrive at the final set of respondents, Leger first identified 1,505 people who had been diagnosed with cancer within the past ten years. Of these, 760 – or 50 per cent – had also contracted COVID-19, and 124 of these had long COVID. From this group, the final set of 119 respondents, all of whom had had both cancer and long COVID, completed the entire survey.

This means that about 16 per cent of the 760 cancer patients who had contracted COVID-19 have had long COVID. This is similar to the results of the Canadian COVID-19 Antibody and Health Survey, which found that 17.2 per cent of Canadian adults who had COVID-19 experienced long COVID symptoms.

About two thirds of the respondents (68 per cent) were women; the remainder (32 per cent) were men. In previous surveys, women and men were more equally represented. Research has shown that women who have had COVID are more likely to develop long COVID than men.

The average age of the respondents was 58 years. Most respondents (41 per cent) were stage 1 to 3; six per cent were stage 4 or metastatic, and 39 per cent were in remission. The remainder were unsure of their cancer stage.



Initial COVID-19 illness

Almost half of patients (46 per cent) said they were first infected with COVID-19 over a year before the survey took place; one in four said they had COVID-19 between six months and one year ago, and fewer said they were infected more recently.

Likewise, half of respondents (50 per cent) said they had moderate COVID-19, rather than mild (25 per cent) or severe (22 per cent). Most patients (87 per cent) confirmed their infection with a PCR or rapid test.

Just eight per cent of patients were hospitalized for COVID-19. Having had a severe case of COVID-19 and having been hospitalized for COVID-19 are risk factors for experiencing long-term symptoms.

Almost all respondents have been vaccinated against COVID-19: only four per cent did not receive a vaccine.

Long COVID illness

Diagnosis

Most respondents decided they had long COVID based on their own or a family member or caregiver's observations, rather than because they received a formal diagnosis. Only 30 per cent of respondents were diagnosed with long COVID by a healthcare professional. The remaining 70 per cent self-diagnosed or had a friend or family member who suggested that they had long COVID.

Why do so few patients have a formal diagnosis? Not all of them sought one: 38 per cent did not consult a healthcare professional for long COVID. In some cases, this was because they did not have access to a family doctor. See the section "Lack of access to a doctor" below, for more on these patients' experiences.

Almost as many – 37 per cent – did see a doctor but could not get a diagnosis of long COVID. Many of these respondents found that their doctor was not receptive to the suggestion of long COVID or their doctor was not considering the pattern of their symptoms in a holistic way. For more details on respondents' difficulties getting diagnosed, see the section "Difficulty getting help from doctors" below.

A few patients said that they were not able to get a long COVID diagnosis because they did not take a test to confirm their original COVID-19 infection. These amounted to eight per cent of the respondents. Clinical practice guidelines generally do not require a test as evidence of COVID-19 infection in order to be diagnosed with long COVID or get help for it, but some clinics may require this, nonetheless.

Duration

By far, most respondents report that their long COVID symptoms are ongoing. Just 14 per cent feel they have completely recovered from long COVID, while the remaining 86 per cent say their symptoms persist. For those who say they have recovered, the average length of time it took to recover is five months.

The length of time for which respondents experienced long-term symptoms after COVID-19 varies greatly. The average duration is 11 months, but this includes a range spanning from less than three months to more than a year and a half.

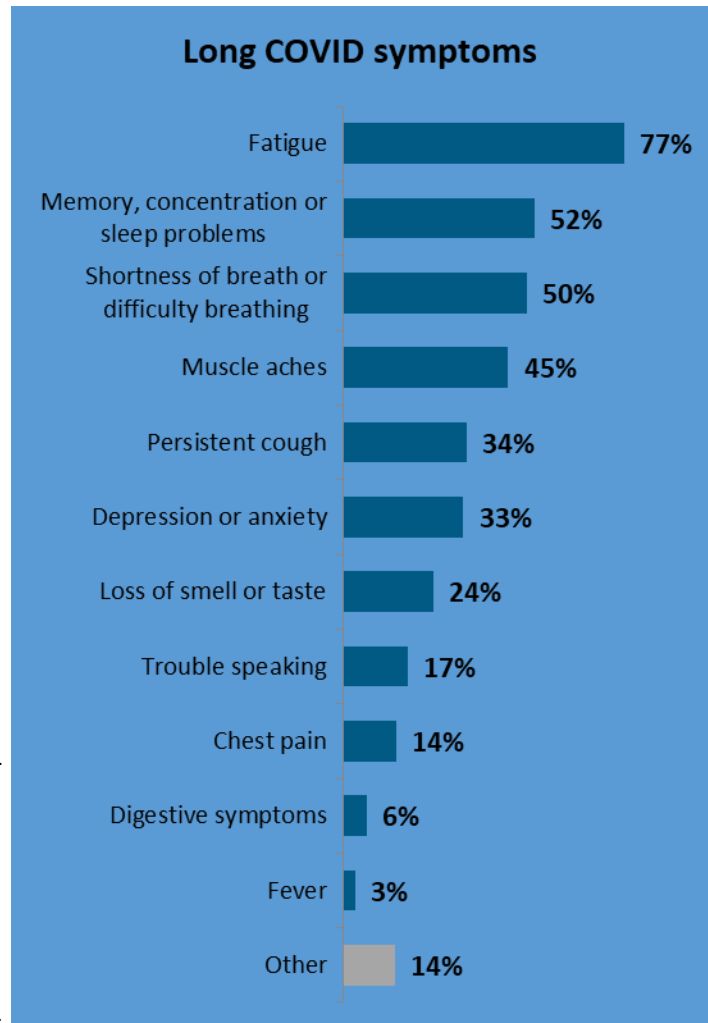
This includes both respondents who have recovered and those whose symptoms are ongoing.

Symptoms

The long-term symptoms that respondents have experienced are highly varied. Fatigue is by far the most common; 72 per cent of respondents said fatigue was one of their symptoms. It is followed by shortness of breath or difficulty breathing (57 per cent), problems with memory, concentrating, or sleeping (53 per cent), and muscle aches (47 per cent). This pattern of symptoms is similar to what has been observed in the general population.

Fatigue, the most common long COVID symptom, is also the one that respondents mention the most often as affecting their everyday life. *“The relentless fatigue does interfere with everyday activities; it is difficult to keep up with routine exercise”* wrote an Ontario bladder cancer patient. Many have been unable to work full-time because of the severity of their fatigue (see “Reduced income,” below, for more on patients’ difficulty working).

Trouble breathing is one of the symptoms that respondents found most distressing. Some found it concerning because they felt it could also be a cancer symptom: *“I wish doctors would take long covid more seriously. I really want my wheeze diagnosed,”* wrote an Ontario stage 3 breast cancer patient. *“There is that lingering fear of recurrence of breast cancer in the lungs*



with a wheeze.” Fifty per cent of respondents reported that difficulty breathing, or shortness of breath, were among their symptoms.

Mental health symptoms: One in three respondents said that depression or anxiety was one of their long COVID symptoms. For some, low mood is part of a larger pattern of symptoms and is related to the sense of isolation and difficulty with ordinary activities caused by fatigue and other symptoms. A British Columbia uterine cancer patient described her symptoms as: *“chronic fatigue and weakness; mentally, physically, emotionally. Continued low energy and unable to*

exercise for more than 20 minutes, and longer recovery period from that exercise, which leads to low mood.”

Moreover, close to half of the 32 patients experiencing depression or anxiety said their symptoms were getting worse – a much higher proportion than with other symptoms. For all other common symptoms, most patients said that they were not getting any better or worse.

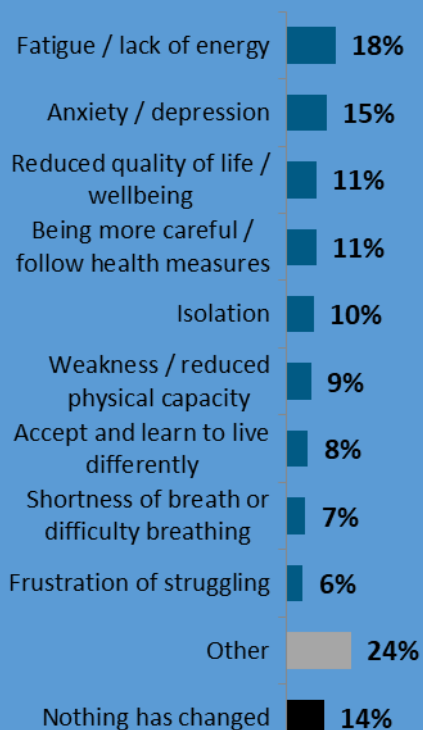
Cognitive symptoms, such as memory problems and brain fog, were also common; respondents found these some of the most unsettling and stressful symptoms. *“At various points I thought I had irreversible brain damage,”* wrote an Ontario neuroendocrine cancer patient. *“I couldn’t even make out simple words like ‘the,’ it was that bad. There was nothing available to help, even though it was becoming recognized that this is an issue.”* A stage 3 breast cancer patient in British Columbia, when asked about what the ‘new normal’ is like for her, responded: *“No more ‘normal!’ Too much stress now.*

Memory loss and speaking difficulty alone is scary

and is making ‘normal’ a thing of the past.”

Changes to the sense of **smell or taste** were reported by almost one in four respondents (24 per cent). These alterations to normal sensation have a serious effect on patients’ quality of life, as for the Ontario stage 3 breast cancer patient (also quoted above) who wrote: *“[I] eat very bland foods as nothing tastes right. Everything smells bad so would like to know if normalcy will come back.”* A Quebec skin cancer patient mentioned similar symptoms: *“Smell of smoke quite constant, I choke and sensation also in the eyes. Do not feel anymore or sense anything else. Fear of staying like that always.”*

Characteristics of "New normal"



A wide variety of **other symptoms** were reported, including trouble speaking, digestive symptoms, and headaches.

Quality of Life

Long COVID has had an impact upon every aspect of respondents' lives. Four in five respondents (82 per cent) say that long COVID has affected their overall well-being, and most say that it has hindered them from exercising (74 per cent), participating in social engagements (70 per cent), and engaging in hobbies, sports, volunteering, and other activities (67 per cent).

Ability to engage in activities

Fatigue, difficulty breathing, and muscle pain – some of the most common symptoms – combine to restrict patients' ability to carry out their ordinary activities. For a liver cancer patient in Ontario, long COVID severely limits what she can do – the 'new normal' for her is *"not able to be more active (walking, gardening, sitting at a restaurant too long)."* This loss of ability can be very demoralizing, as one stage 1 prostate cancer patient in Quebec found: *"I am diminished to about 30% of my abilities; I feel devalued,"* he wrote. Difficulty exercising is a common complaint that also falls under this category: a Quebec metastatic breast cancer patient finds that she has *"reduced motor skills, reduced bodybuilding, less endurance, sudden fatigue and shortness of breath at the slightest effort."*

Ability to work

More than half of respondents (52 per cent) found that their symptoms made it difficult to work. *"I am self employed, and due to the fact [that] I have been too sick and/or suffer from extreme fatigue I was unable to work,"* wrote a skin cancer patient in Ontario. Some find that their symptoms vary from day to day, making it impossible to work on a predictable schedule. *"Some days are worse than others,"* wrote an ovarian cancer patient in Quebec, *"and I can not predict whether or not I will be able to go to work."*

See below under "Reduced income" for more on the impact of fatigue on long COVID patients' ability to work.

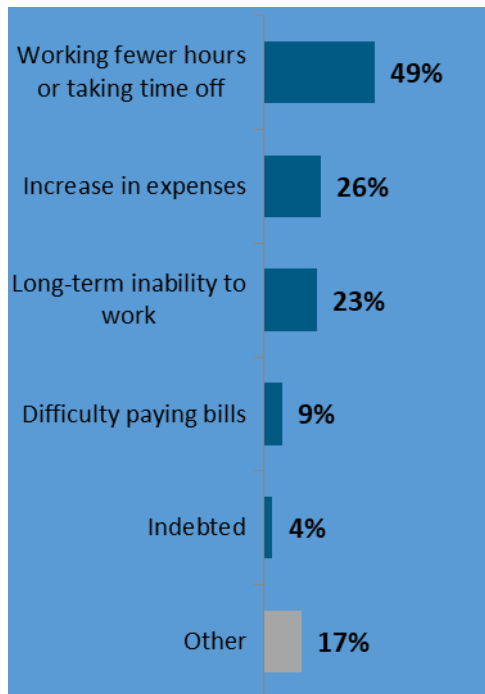
Ability to care for others

When someone with long COVID has caregiving responsibilities, their long-term symptoms can also have an indirect impact on the quality of the lives of others. A majority of respondents – 59 per cent – said that their symptoms had reduced their ability to care for others in their family. *"My husband gets personal support workers, but I couldn't get help from anyone to heat up soup or something for him ... when I couldn't get out of bed,"* wrote a breast cancer patient in Ontario. *"I don't know if he ate much of anything during that time."* Another Ontario patient with

metastatic breast cancer wrote that she “*had to have my long-term roommate go into [long-term care] because I couldn’t support his life needs anymore.*”

Sense of isolation

I don't have cancer anymore, but I still have long COVID. I still feel quarantined, in isolation.



– A breast cancer patient in remission in Quebec

A number of respondents expressed a sense of isolation or feeling left on their own. For many cancer patients and survivors, this feeling comes from a dissonance between their own experience and the assumptions made by society around them: long COVID has, for many, devastated their lives and made it necessary to take extra precautions to avoid getting COVID again or another illness; but much of society now presumes that COVID-19 is just no longer a concern and should no longer affect anyone’s life.

The ‘new normal’ with long COVID for one leukemia patient in Ontario is “*social isolation and reduced mental and physical health. Massive psychological repercussions.*” For her, part of the psychological impact comes from the way others do not recognize the effects of long COVID: “*I don't trust most people*

anymore because the sheer amount of people who are comfortable or complacent about how this virus impacts my life is disheartening and impossible to reconcile,” she continued.

Lack of support from the medical system has also made patients feel unmoored. The Ontario leukemia patient continued: “*My GP doesn't seem to be concerned so there was no offer or suggestion to seek support. I feel like I'm just on my own, so I continue to isolate as much as possible to protect myself.*” Similarly, a stage 2 brain cancer patient in Ontario said she was very concerned about her long-term symptoms “*because long COVID might make the other health issues worse, and doctors are not ready to give someone like me (with cancer) the diagnosis of long COVID. Which leaves me isolated with no support.*”

Other patients mentioned feeling isolated because of the precautions they take to protect themselves from catching COVID-19 again. “*I was hospitalized for five days because of my intestines; I can have seizures at any time and it's out of control,*” wrote a metastatic breast cancer patient in Quebec. “*I'm afraid to eat, to go out. I have new medications that reassure me, but it remains a stress. I still wear the mask everywhere, I don't see many people, for fear of catching it again.*”

Anxiety and uncertainty

Uncertainty about whether their illness will ever get better – or whether it will get worse – was an oft-mentioned source of stress. *“I fear it starts to worsen – any other thing and then one thing after the other and ... You can guess what happen after that going down the ladder!!!”* wrote a caregiver for a brain cancer patient in New Brunswick. Likewise, a leukemia patient in Alberta shared that he was concerned *“because I hope everyday these symptoms would go away, but they mostly still are there, and it is frustrating feeling like I will never get better again.”*

For some, it is the unpredictability of long COVID that is a source of stress – the possibility that the most debilitating symptoms could recur and wreak havoc on their lives again. An Ontario neuroendocrine cancer patient (also quoted above) recounts their fears that their worst long COVID symptoms may return:

When I got COVID and long COVID, it was horrible. ... I NEVER want to go through anything like that again. It was terrifying. To this day, there are times where I feel there are glimmers of long COVID in my brain. I [am] worried that if I get COVID again, the impact on my brain will be even worse and leave me with deficits.

Financial well-being

Long COVID has had a serious impact on many cancer patients’ financial health. Of the 119 respondents, 47 cancer patients – or 40 per cent of respondents – said that long COVID had some financial impact on their lives; 20 of these said that the financial impact was significant.

Reduced income

I don’t have the energy to put full days together and it’s terrible. I find I can work for an hour or two before I need to rest. It’s frustrating.

-- Alberta melanoma and thyroid cancer patient

The most common reason for financial adversity was reduced employment income. Some respondents said they could not work as many hours as usual, had to take unpaid sick days, or had to move from a full-time to part-time position. These account for almost half of the respondents impacted financially by long COVID. Others lost all of their income, either because they had to take extended unpaid time off, or because they lost their job entirely.

Fatigue is the main symptom that is responsible for respondents’ difficulty working. *“I don’t have the energy to work the hours I had worked prior to getting Covid,”* wrote a B.C. uterine cancer patient. *“I find myself both mentally & physically overwhelmed and have trouble working.”*

For a tongue cancer patient in Alberta, loss of income exacerbated her existing financial insecurity: *“I’m already on a disability fixed income and long COVID has taken away my energy to supplement my fixed income with allowable part time earnings. My energy is inconsistent which makes it difficult to commit to even part time work.”*

Increased cost of living

Many respondents found that their costs had increased because their symptoms – mainly fatigue – made it necessary to pay for services that they would otherwise perform themselves. This includes the cost of food delivery and transportation (e.g., taxis). Increased expenses were a cause of financial strain for 26 per cent of the respondents impacted financially by long COVID.

A stage 2 cancer patient in Alberta explains how long COVID has added to the cost of everyday life: *“I have had to purchase all the products to care for myself – it is costly; I also then lose opportunity to shop for myself and then have to spend money for food delivery, which is huge burden as I have a child, and then pay taxi; there is a rolling ball that keeps going financially because of not being well. Rather than taking care of daily things, having to have them done for you, for example, is costly.”* A liver cancer patient in Ontario concurred, writing that long COVID caused financial difficulties for her because of *“not being able to shop in person, having to pay someone to shop for me.”*

For patients who are themselves caregivers for others, long COVID also presents costly challenges. *“I’m the caregiver for my mother and had to cover the cost for someone else to drive her to her appointments,”* the Ontario liver cancer patient continued. A metastatic breast cancer patient in Ontario wrote that her *“inability to support a long-term housemate has doubled my expenses. Rent takes up my entire pension and I have been living on credit cards, but I have exhausted my savings now, so I don’t know.”*

Cancer care

We must stop suspending our immunotherapy treatments at the slightest symptom. To never again be able to have a simple runny nose for fear of having our treatments cancelled is inhumane.

– A metastatic breast cancer patient in Quebec

CCSN’s first three surveys on COVID-19 and cancer focused on the hindrances patients faced in accessing cancer care during the pandemic. Although most of the public health restrictions that caused those hindrances no longer exist, many cancer patients still find that long COVID limits their access to cancer care. For example, 37 per cent of respondents said that long COVID has had some impact on their ability to see the doctor managing their cancer care in person. The same number said that it has made it harder for them to get help for new cancer symptoms or

side effects of treatment. More than three in ten (34 per cent) said it has hindered their ability to get tests for their cancer.

Explaining how her long COVID symptoms interfere with her cancer treatment, a colorectal cancer patient in Quebec wrote that she was concerned about her long COVID *“because I can not always do my chemo and radiotherapy treatments – they always test me before having a treatment, and if I have a fever and my blood tests are not good, either it is my red or white blood cells that have been affected.”* A metastatic breast cancer patient in Quebec expressed a similar frustration *“We must stop suspending our immunotherapy treatments at the slightest symptom. To never again be able to have a simple runny nose for fear of having our treatments cancelled is inhumane. I am afraid to get on with my life, my children still wear masks at school and are the only ones. ... we too must be allowed to be like others and to be able to receive our treatments. When we have cancer, we should also be prioritized for follow-ups.”*

Younger patients may have experienced greater difficulties getting cancer care than older patients. More than half of respondents younger than 55 years (51 per cent) said that long COVID made it harder for them to get rehabilitative care after their cancer treatment; and almost as many – 49 per cent – said it hindered their ability to get help for new symptoms or side effects. By comparison, 26 per cent and 30 per cent of respondents aged 55 years or older, respectively, said they experienced these impacts.

Barriers to getting help

Almost half of respondents – 47 per cent – said that they had sought help for their long COVID but could not get it, and an additional nine per cent said that they did not know where to seek help. The most common reasons that respondents were unable to seek help for long COVID were difficulty discussing their illness with their doctor, difficulty obtaining a diagnosis, and difficulty accessing a doctor.

Difficulty getting help from doctors

Challenging to get others to understand, let alone accept the severity of the impact Long COVID has had on me. The denial in the medical field and public is frustrating and it is isolating. I work hard mentally to not let it negatively affect me but it's a constant frustration.

A tongue cancer patient in Alberta

Of those who tried but could not get help for long COVID, one in five (or 11 of the 119 respondents) said that one of the barriers they faced was a lack of receptivity or knowledge on the part

of their doctor. These patients found that their doctor was dismissive of them, did not recognize that they had long COVID, or did not know how to help them.

Some patients have found that doctors do not listen to them when they bring up long COVID.

“No one believes in long COVID, or health care providers don't have enough information about long COVID – when [it is] mentioned, you get ignored,” said a lung cancer patient in Manitoba.

“It would be helpful if I had a family doctor that I could rely for treatment and assistance, not to mention [one] who actually listens and believes what I tell him,” said an Ontario skin cancer patient in remission.

Others said that their doctors only considered their symptoms individually, rather than holistically. *“Family doctors don't know that individual symptoms are long COVID so treat each separately. All tests come back negative – three hospitals have told me I'm so healthy,”* said a metastatic breast cancer patient in Ontario.

“As you get older, your symptoms are dismissed as getting older, must be arthritis, must be diabetes, etc., etc., instead of listening to the patient who has carried their body around and intimately knows it – or they dislike you asking too many questions and see you as difficult,” said a stage 2 breast cancer patient in British Columbia. Another patient, with stage 2 brain cancer in Ontario, said: *“Having different medical issues, including cancer, tends to get doctors to concentrate on those issues. And when they find that all is normal with those health issues, they disregard the rest, and it seems they don't want to say it is long COVID.”*

Lack of access to a doctor

Generally, to get into a long COVID clinic or program, a patient must be diagnosed with long COVID and referred by a doctor. For people who do not have a family doctor, this makes it harder to find someone who can diagnose them and refer them to specialized programs. *“Having a GP ... to get a referral for some sort of physio or to a respiratory treatment would help greatly,”* wrote a stage 1 uterine cancer patient in British Columbia when asked about barriers to getting help for long COVID. This was the third most common reason respondents gave for difficulty accessing long COVID care, corresponding to five per cent of respondents. In 2019, 14.5 per cent of Canadians aged 12 and older did not have a family doctor or other regular health care provider.

The alternatives to a family doctor, for many, are walk-in clinics and hospital emergency departments, but in many cases, these are also difficult to access, because of long wait times or because they don't exist nearby. *“It's next to impossible to even get a phone appointment with the urgent care place and we no longer have any walk-in clinics in our city,”* the same British Columbia patient continued. *“I ... have avoided the emergency department as it's not the place to go to and they are overwhelmed there as well.”*

Without a family doctor, a patient cannot talk to someone who knows their medical history and can take other conditions they have into account when diagnosing and treating them. This is especially an issue with long COVID, since it is not straightforward to diagnose. “[Long COVID’s] impact on my life has been devastating in all aspects,” wrote a stage 3 breast cancer patient in Ontario. “And in three years I’ve had two new family doctors, and both have now closed their practices.” Soon, she wrote, “I’ll have no family doctor and no understanding of how to access ongoing care for complex comorbidities.”

Lack of long COVID clinics

Post-COVID clinic services need to be expanded, not closed, as the piecemeal and delayed help to address the various symptoms is not adequate and probably exacerbates the problem and is likely much more costly than having the specialized clinics.

— A British Columbia vulvar cancer patient in remission

When asked about what support they needed to manage their long COVID, 80 per cent of respondents said they needed specialized clinics and programs that treat or help manage long COVID. Not all patients live in areas where such clinics or programs exist. For example, an ovarian cancer patient in Quebec finds it hard to access support because these clinics “are limited and are often situated far from where I live.” Similarly, an Ontario stage 2 lung cancer patient said that her main barrier to accessing help was that there were “no treatment programs in my area.” Long COVID clinics are currently only present in four provinces – Ontario, British Columbia, Alberta, and Quebec.

Other respondents find that wait times to access clinics are untenably long. “First long COVID clinic was underwhelming. On waiting list for Toronto Western – a year’s waiting list,” wrote a stage 3 breast cancer patient in Ontario. That metastatic breast cancer patient also said she “was referred to a [long COVID] clinic at Toronto Western 6 months ago – haven’t heard a thing. No social services support. Or psychiatric [help] available. Feel very overwhelmed trying to manage it myself.”

Some people find that specialists are looking just at a single condition and not holistically at a person’s health. The same stage 3 breast cancer patient continued: “I desperately need nutritional counselling because of competing dietary needs for different conditions – not available under OHIP, and a dietician only focuses on one condition, not competitors. None of the specialists or the family doctor will deal with or manage long COVID.”

Conclusion: Cancer Can't Wait!

When CCSN first surveyed cancer patients in 2020 at the beginning of the COVID-19 pandemic, the results showed that cancer patients were left behind. Now, it is again clear that cancer patients are not being taken care of when it comes to the long-term symptoms after COVID-19. Cancer patients with long COVID are not the only ones whose lives have been turned upside-down by their long-term symptoms and who are feeling worried and isolated because of a lack of support. Yet their situation is nonetheless unique because of their need for continual access to cancer care, their often-compromised immune systems, and the other ways in which the pandemic has already worn cancer patients down and left them behind.

When an emergency disrupts people's lives and threatens their access to essential healthcare, governments must ensure that cancer patients' care continues – not only in the short term, and not only their cancer care. As an increasing number of long COVID cases emerge and the impact of this condition on people's lives becomes clearer, as new COVID-19 variants develop, and as other emergencies such as record-breaking wildfires across Canada, flooding, and storms cause mandatory evacuations, power failures, and disruption of day-to-day lives of so many Canadians, governments in Canada must ensure that cancer patients' healthcare, whether for cancer or for long COVID, is not jeopardized. Continuing cancer care must be included in emergency preparedness plans in every municipality, province and territory.

Cancer can't wait!

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CANADIAN CANCER SURVIVOR NETWORK
1750 COURTWOOD CRESCENT, SUITE 210
OTTAWA, ONTARIO K2C 2B5
CANADA

PHONE: 613-898-1871

EMAIL: INFO@SURVIVORNET.CA

WEBSITE: WWW.SURVIVORNET.CA

CHARITABLE REGISTRATION NUMBER:
83454 0882 RR0001

TWITTER/X: @SURVIVORNETCA

