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June 30, 2020

Dear Doctors,

We are a group of Canadians and permanent residents who have all experienced, or are still experiencing, symptoms of COVID-19 for months. Without any medical answers or insight into our condition, we are left living in limbo, unable to access treatment and therapies, and filled with uncertainty about our futures.

We are calling on you as the leaders of Canada's public health response to COVID-19 to establish and coordinate research into long-term illness caused by COVID-19, to ensure that medical support and care is provided to those who are experiencing COVID-19 symptoms for many weeks and months, and to implement effective standards for a presumptive diagnosis of COVID-19 for patients without a positive test.

We also call for greater public awareness of the potential for prolonged symptoms and for public health guidelines to be updated to ensure that physicians, policy makers, and employers are aware that some individuals experience long COVID-19 illnesses.

Research

Initial guidelines provided by the World Health Organization and various Centers for Disease Control around the world all stated that recovery for mild cases would take two weeks. However, many of us have had cases that did not require hospitalization and yet we are having persistent symptoms three, four, even five months after symptom onset.

We are not alone. Reports have emerged from Italy, France, the Netherlands, the United Kingdom, and the United States of patients with similar patterns of prolonged illness. Some of us have experienced periods of being asymptomatic followed by the return of symptoms. Others have had new symptoms develop over time, and still others have experienced symptoms consistently without a break since the onset of our illness.

COVID-19 is a new illness. Not only are the actual national or regional infection rates unknown, but there is no solid data on prolonged cases of COVID-19 illness. However, there is reason to believe that the number of people experiencing prolonged symptoms is not a tiny minority of COVID-19 cases. Data collected by the COVID Symptom Study app in the UK, which asked people to voluntarily enter their symptoms into an online app, suggests that 1 in 10 cases of individuals with COVID-19 symptoms experience those symptoms for three weeks or longer.¹ A Swedish phone survey conducted in early May found that nearly one-third of randomly sampled Swedes who reported experiencing at least one symptom of COVID-19 had been experiencing those symptoms for ten weeks or more.²

Public health guidance in Canada has directed people who are not critical to manage their symptoms at home to ease the burden on the medical system. As a result, many Canadians have not contacted their doctors despite experiencing ongoing symptoms. Others have tried to seek medical care and been dismissed, either for not having a positive test or because they are told COVID-19 does not last beyond two weeks. It is therefore impossible to say how many Canadians are experiencing a lingering COVID-19 illness or longer-term, possibly permanent, disability as a result of the illness.

The symptoms that we are experiencing affect every part of the body, and include:

- Fever and profuse sweating;
- A sore or scratchy throat; sneezing; runny, dry, or stuffed up nose; and sinus pain;
- Persistent cough, shortness of breath, and lung pain;
- Chest pain and pressure, including a bubbling or burning sensation in the chest, a stabbing sensation in the chest, costochondritis, and pleurisy;
- Heart issues including pericarditis, myocarditis, tachycardia, bradycardia, and arrhythmia;
- Neurological issues, including headaches, dizziness, brain fog, orthostatic intolerance, vasovagal syncope, loss of taste and smell, metallic taste, sore tongue, tinnitus, and light and sound sensitivity;
- Swollen glands and lymph nodes;
- Skin rashes and sores, random bruising, mucosal membrane sores, and esophageal burning;
- Tingling and numbness in face, hands and feet, or neuropathy;
- Muscle aches and soreness, muscle weakness, and severe muscle and joint pain;

¹ COVID Symptom Study, "How Long Does COVID-19 Last?" June 8, 2020, <https://covid.joinzoe.com/post/covid-long-term>.

² Novus, Coronastatus 0511, <https://novus.se/coronastatus-0511/>.

- Conjunctivitis, dry eyes, and vision issues;
- Extreme fatigue, and insomnia or difficulty sleeping;
- Gastrointestinal pain, nausea, diarrhea, and bloating.

Secondary infections such as thrush, strep, urinary tract infections, and skin infections are also common.

There are many theories as to what might be causing our ongoing symptoms, including persistent viral infection, an immune overreaction to dead viral RNA, molecular mimicry, dysautonomia, post-viral fatigue, the reactivation of dormant viruses within the body by COVID-19, and the onset of new illnesses such as diabetes. However, these are all very different conditions that require differing therapeutic approaches. Patients and doctors can't know what the best treatment to pursue is without an adequate understanding of the cause.

We also don't know when it is safe for us to be around others. Medical advice in some provinces has been to self-isolate for either fourteen days or until 24 hours or 72 hours after symptoms have resolved. Some of us have been having symptoms without a break for months, afraid to be around our own family members for fear of transmitting the virus to them. Others have had symptoms go away for days or even weeks only to have them reappear again. When this happens, we don't know whether we need to self-isolate again to protect people around us. It is difficult mentally, emotionally, and physically to self-isolate for months with no end in sight. We are also deeply worried about transmitting the illness to our loved ones or our communities.

There also needs to be research into the average duration of COVID-19 symptoms in order to better understand what recovery looks like and provide appropriate guidance to physicians, employers, and public officials. In addition to understanding what therapeutic needs COVID-19 survivors have, policymakers and employers need to understand how much sick time might be required to fully recover or what kinds of accommodations and supports might need to accompany a return-to-work. Public screening guidelines need to account for the fact that an individual might have symptoms for months, which creates challenges for accessing medical care and other essential services.

Medical support

To ask someone to self-isolate at home and manage their own symptoms without medical support for two weeks and for five months are two very different prospects. It is not reasonable to ask people with such extensive physical symptoms and such a prolonged illness to go without medical support. We need family doctors and emergency room physicians alike to have a greater awareness of the havoc this virus is causing throughout our bodies. We need access to medical tests, in addition to symptom management and care.

We have been trying, for months, to deal with symptoms that are often severe and scary, and that significantly affect quality of life. Some of us continue to visit the Emergency Department with heart issues, neurological issues, or shortness of breath months after the onset of symptoms. Some of us are formerly fit athletes who are still unable to walk around the block or up stairs due to stabbing chest pain, shortness of breath, and postural tachycardia months after initial illness.

Seeking medical care from personal care physicians has been challenging as many are only offering telephone consultations. Some of us have received supportive care, but many of us have had the experience of being told by our family doctor or a specialist that there's nothing they can do for us despite persistent coughing, shortness of breath, chest pain, or chronic gastrointestinal issues. As a

result, some of us have spent hundreds of dollars on supplements and alternative care practitioners such as naturopaths to try to gain some symptom relief.

Often doctors and specialists are compassionate but admit that they simply don't know why COVID-19 affects the body the way it does and are unable to offer any assistance.

However, many of us have also had the experience of being dismissed as having anxiety rather than having our symptoms taken seriously. We have been told that our symptoms can't possibly be related to COVID-19 because:

- We didn't meet the restrictive criteria for testing that was in place in March and April;
- We haven't traveled internationally or been exposed to a known case;
- Some doctors don't believe that COVID-19 illnesses persist beyond 2-6 weeks; or
- We had a negative COVID-19 test (despite the fact that the rate of false negatives is known to be high and the risk of having a false negative increases with the amount of time that has passed after symptom onset).

This lack of support from the medical community causes great psychological harm and stress, which can exacerbate our physical symptoms.

Furthermore, many of us fall into a gray area of not having a positive test or a recent exposure but still having COVID-19 symptoms. This means that many medical services and other health and wellness appointments are not available to us. We can't go to the dentist or get a massage. We can't have in-person appointments with our primary care physicians. We are in limbo, unsure if we are infectious but unable to pass a screening questionnaire. Physicians and health care facilities, meanwhile, are struggling to decide on a case-by-case basis whether to allow individuals with symptoms to access their services.

Presumptive diagnosis

For many reasons, access to testing was extremely limited across Canada during the early phase of the pandemic. Many of us did not qualify for early testing. Some of us had doctors confirm that we likely had COVID-19 but were told to stay home and manage our symptoms rather than seeking testing. Some had to fight for several weeks to access a test, arguing that our symptoms merited a diagnosis. As a result, many of us have never been tested.

Some of us were tested but only weeks after symptom onset. Research has shown that the timing of the test can significantly affect the results, with the likelihood of receiving a false negative dramatically increasing nine days after symptom onset. By Day 21, the likelihood of a false negative is 66%.³ A throat or nasal swab also cannot determine whether the virus might be present elsewhere in the body. Despite these limitations, doctors continue to be influenced by negative tests results in spite of the swabs having been done weeks after symptom onset to either tell us that we never had COVID-19 or that our ongoing symptoms can't possibly be COVID-19 related any longer.

Similar questions are being raised about the accuracy of COVID-19 antibody tests. There is also early research emerging which suggests that not everyone who had a COVID-19 infection develops

³ Lauren M. Kucirka, Stephen A. Lauer, Oliver Laeyendecker, Denali Boon, and Justin Lessler, Variation in False-Negative Rate of Reverse Transcriptase Polymerase Chain Reaction–Based SARS-CoV-2 Tests by Time Since Exposure. *Annals of Internal Medicine* (2020). <https://doi.org/10.7326/M20-1495>.

antibodies.⁴ We are very concerned about reports from France, the UK, and the US that COVID-19 antibody tests are also being used to deny diagnosis and medical treatment to COVID-19 patients.

The accuracy of tests and the newness of the virus both argue in favour of also using a presumptive diagnosis, rather than just testing, to identify COVID-19 patients. However, the extreme limitations that were placed on testing in the early months of the pandemic demand that a presumptive diagnosis be adopted. Otherwise, too many Canadians in need of medical care will be and are being excluded.

Although there is limited data so far, evidence from a comprehensive survey of long-term COVID-19 illnesses conducted by patients themselves suggests that there is no difference in the pattern of symptoms between those who tested positive and those who tested negative or were not able to access a test.⁵ Adopting a standard but comprehensive list of symptoms, in combination with factors such as a pattern of relapse/recovery, exposure to known cases, and timing of illness onset, could result in a presumptive diagnosis that will allow individuals to participate in research and access medical care.

In addition to access to medical care, we are concerned about the implications of not using a presumptive diagnosis for access to sick leave and income security programs such as the Canada Emergency Response Benefit. When employers don't understand that COVID-19 can be a very lengthy illness and demand a medical note; when public programs such as the CERB and Employment Insurance require a medical note for sick leave; and when penalties are being implemented for fraud and misrepresentation, we are very concerned that some of us can't access a diagnosis and appropriate medical care. This will force people back to work before they are ready, putting their long-term health at risk and potentially putting the health and safety of others at risk.

There also needs to be acknowledgement of how many people became ill in the early weeks of the pandemic when access to testing was extremely limited and the struggle we have waged since to obtain a diagnosis and official recognition that our illness and ongoing symptoms are COVID-19.

Our experience

We are different ages and ethnicities, coming from different regions across the country, with different career fields. Some of us were extremely healthy before getting sick; others had chronic health conditions. Our symptoms have varied; some of us have been and still are seriously ill, while others are dealing with lingering or occasional symptoms. Some of us have children and family members with similar symptoms and ongoing health issues; others have experienced this journey alone. What we all share in common is an extremely prolonged experience of COVID-19 symptoms and a need for answers and medical support.

⁴ Payne DC, Smith-Jeffcoat SE, Nowak G, et al. SARS-CoV-2 Infections and Serologic Responses from a Sample of U.S. Navy Service Members — USS Theodore Roosevelt, April 2020. *MMWR Morb Mortal Wkly Rep* 2020;69:714–721. DOI: <http://dx.doi.org/10.15585/mmwr.mm6923e4>

⁵ Patient-Led Research for COVID-19, *Report: What Does COVID-19 Recovery Actually Look Like?*, May 11, 2020, <https://patientresearchcovid19.com/research/report-1/>.

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We ask you to urgently address these concerns: to commence research into long-term COVID-19 illnesses, to ensure that medical support and care are provided to those who are experiencing COVID-19 symptoms for many weeks, and to implement standards for a presumptive diagnosis of COVID-19 for patients without a positive test.

Thank you for your attention and support, as well as all of the hard work you are doing to guide Canada through this unprecedented public health situation. If we can assist you in any way, please know that we are ready and willing to do so. You can contact us at LongHaulCovidCanada@gmail.com.

Sincerely,

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