

Frequently Asked Questions - Providers

Long COVID Symptoms or Health Concerns for Healthcare Providers

A. General information

What is Long COVID?

- Some people experience ongoing physical and mental health symptoms for weeks or months after testing positive for COVID-19.
- Long COVID symptoms have been reported in people who have tested negative for COVID-19.
- This is commonly referred to as “Long COVID”, “Post COVID”, “Post COVID-19 Syndrome” or “Post COVID-19 Condition”.

Why do some people get Long COVID?

- We don't yet know why some people have ongoing symptoms after initial recovery from COVID-19 and some do not. Research is ongoing.
- Long COVID can affect anyone – old or young, people who are healthy, and people with or without other health conditions. It can happen whether people were hospitalized for COVID-19 or only had mild symptoms.

How many people experience Long COVID?

- We are gathering information in Alberta, from other provinces, and from around the world about Long COVID. Some research studies indicate that about 20% of people who had COVID-19 have lingering symptoms for 12 weeks or longer, but the occurrence may be 25% or higher.
- Although research is limited and is still ongoing, a recent review by the U.S. National Institute of Health Research (March 2021) states that for those not admitted to hospital, at least 20-30% experience at least one enduring symptom one month later and 10% three months later. For those admitted to hospital, between 50% and 89% have at least one enduring symptom after two months and more recent studies suggest there is still a high prevalence after six months.
- Long COVID appears to be more prevalent among women and young people/children.

How long will people have Long COVID symptoms?

- Because it is such a new condition, it is very difficult to predict how Long COVID will affect each person. Many people recover after several weeks of managing their own symptoms. For a smaller proportion of people, the symptoms are more severe and last much longer. Symptoms can show improvement and then worsen.

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Are people with Long COVID still contagious?

- Since most people with ongoing symptoms test negative for the virus, it is very unlikely that they are contagious. However, ongoing public health preventive measures should be followed.
- Generally, patients are considered clear of their active COVID-19 infection after 14 days from symptom onset. However, depending on testing results, illness severity, and/or if their symptoms have improved or stabilized to a new or pre-existing baseline, this could vary.
- Isolation and testing are recommended if a person develops new symptoms that could be COVID-19, even if they have been vaccinated.

What are the most common symptoms of Long COVID?

- People may experience one or more symptoms in the following areas:

Breathing / Respiratory:

- Feeling short of breath
- Cough that won't go away
- Stuffy nose (congestion)

Weakness / fatigue:

- Feeling very weak and/or tired
- Feeling worse after activity
- Sleeping difficulties

Pain:

- Joint and/or muscle pain
- [Sore throat](#)
- [Headaches](#)

Eyes / Ears

- [Changes to vision](#)
- [Changes to hearing](#)
- [Ringing in your ears](#) (tinnitus)

Mental health symptoms:

- Brain fog / cognitive changes
- Trouble with memory and/or concentration
- Depression
- Anxiety
- Stress

Eating / Digestion:

- Difficulty eating, drinking, swallowing
- Loss of taste and/or smell
- Diarrhea, constipation, nausea and vomiting

Other physical symptoms:

- Fast or irregular heart beat
- Fever (recurrent or persisting)
- Feeling dizzy
- Skin rash

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B. When and where to find help

When should people call 9-1-1 or visit the nearest Emergency Department (ED)?

- Patients are being advised to call 9-1-1 or visit the ED if they are:
 - having trouble breathing (struggling for each breath, only able to say one word at a time)
 - having a hard time waking up
 - feeling very confused
 - passing out or fainting
 - having chest pain

When should patients call their primary health care provider?

- Patients are being advised to contact their healthcare provider if they:
 - are worried about recovery
 - have persistent shortness of breath
 - are short of breath doing tasks that are normally easy
 - have persistent issues with attention, memory, thinking, and/or low energy levels
 - have symptoms that prevent regular daily activities or make them difficult - for example, caring for oneself or going back to work or school
 - feel depressed, anxious, or stressed

Where can I and my patients find information and advice about Long COVID symptom management and available services?

- Resources for health professionals can be found on AHS' "[Recovery & Rehabilitation After COVID-19](#)" and "[Information for Community Physicians](#)" sites.
- AHS' Allied Health Professional Practice and Education team is providing the "[Rehabilitation after COVID-19-Allied Health Provider Education Series](#)" via Zoom. No registration is required. Recordings from the webinars will be posted on the "Recovery & Rehabilitation" site mentioned above.
- A comprehensive resource for providers called the "Rehabilitation & Allied Health Practice Considerations Post COVID-19" has been developed and can be found [here](#).
- Most people can manage symptoms on their own but some will need care that is more specialized. Others may also need an individual assessment of their symptoms to best meet their needs.
- Self-management information and advice options include:
 - A **self-management resource** has been developed for people living in Alberta. It can be found on the [MyHealth.Alberta.ca](https://myhealth.alberta.ca) website in 11 languages and is searchable by symptom.
 - **Resources for patients** are posted on the AHS COVID-19 website called "[Getting Healthy after COVID-19](#)". This site is updated as new information becomes available.
 - The [Rehabilitation Advice Line](#) (RAL) (1-833-379-0563) provides free rehabilitation advice and general health information for people living in Alberta who are over 18 years of age, including wayfinding for access to services for people with Long COVID symptoms. Occupational

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- therapists and physiotherapists provide information on activities and exercises that help with physical concerns.
- **Health Link** (8-1-1) provides free advice from registered nurses, pharmacists, and dietitians along with general health information. This service is available 24-hours daily, including holidays.
 - **Mental Health Help Line** (1-877-303-2642) provides free confidential and anonymous advice about mental health programs and services. This service is available 24-hours daily, including holidays. More mental health resources can be found on the webpage: [COVID-19 Mental Health Resources | Alberta Health Services](#).
 - **“Supporting Your Recovery after COVID-19” education classes** are available through the Alberta Healthy Living Program. Register online here: <https://app.booking.ca/ahlp Calgarypub/index.asp> or call 403-943-2584.
- People requiring more personalized or targeted supports are being advised to contact their **family physician or healthcare team** for assessment and possible referral to a specialty clinic or rehabilitation services. Specialty clinic locations/links are listed below and currently have limited capacity:
 - [Respiratory Clinic / Pulmonary Medicine Peter Lougheed Centre Calgary](#)
 - [Respiratory Clinic / Pulmonary Medicine, Rockyview General Hospital, Calgary](#)
 - [Pulmonary Care Clinic, Kaye Clinic, Edmonton](#)
 - [COVID-19 Recovery Clinic, Edmonton North Primary Care Network](#)

Will rural communities have the same access to Long COVID services as large centers?

- Physicians and staff throughout the province (including family doctors and community care providers) are receiving education and resources to care for patients with Long COVID as part of their practice. Virtual care is also an option in some situations.

We already have a waitlist for rehabilitation services in my zone. How will AHS, Covenant Health and private rehabilitation providers cope with the increased demand?

- Referrals, assessment and reassessment of patients with Long COVID-19 symptoms should be prioritized in accordance with routine referral and treatment processes.
- Prioritization should include consideration of risk for acute care admission (or re-admission), risk for presenting to an ED, risk for higher level of care needs, patient struggling to manage in current care environment, risk of social isolation, and length of illness or severity of symptoms.
- All patients waiting for services should be provided with information regarding self-management.

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I am a family physician with patients who need rehabilitation for Long COVID. What are my options?

- Most patients experiencing Long COVID can self-manage their symptoms, with assistance from their primary health care provider (see list of resources above).
- The new Post COVID Functional Status Scale (PCFS), Symptom Checklist and Care Pathways (developed at a provincial level) can be accessed [here](#). Zone-specific pathways are in development and will help guide the care of patients with Long COVID and identify local/available resources.
- This information will be on Specialist Link, Connect MD and AHS Zone websites once completed.

Therapists (including physiotherapists, occupational therapists and psychologists) are developing treatment regimens for Long COVID but many have out-of-pocket fees that are unaffordable for some patients. What options are available to these patients?

- Most people experiencing Long COVID can manage their own symptoms as they recover. All of the resources and supports listed above in the “How can I get information and help if I have symptoms of Long COVID” section are available to people living in Alberta, free of charge.
- Because services vary across the province, people are being advised to consult with their local health care providers about services that are available in their area at no cost or reduced cost or call the Rehabilitation Advice Line.
- People who are struggling at home (functionally and/or financially) are encouraged to call the RAL and/or the Mental Health Help Line for information about available supports.

Are there any evidence-based rehabilitation treatment guidelines for clinicians?

- The Neurosciences, Rehabilitation and Vision Strategic Clinical Network (NRV SCN) has formed a panel of experts and is leading a consensus process to develop practice recommendations. The first step is asking for feedback from clinicians on their questions and challenges.

How are patients with Long COVID tracked?

- A data group is in the process of defining the scope and parameters for collecting information and reporting on Long COVID, based on emerging Canadian and international standards. Reports will start to become available in late summer 2021.

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Are there any on-line support groups for patients with Long COVID?

- Several on-line support groups are emerging and some patients find them valuable. For example, the COVID Long Haulers Support Group Canada launched on Facebook as a private group in June 2020 and now has more than 13,000 members. Other large international Facebook groups include Survivor Corps and Body Politic.

C. Vaccination

Should people with Long COVID get vaccinated?

- AHS recommends that people get vaccinated as soon as they are eligible according to [Alberta's COVID-19 vaccine program](#), regardless of whether they have already had COVID-19. People are being advised to speak with their family physician or healthcare team if they have questions about vaccination or their health.
- Some people may experience changes to their Long COVID symptoms after vaccination, however, more research is ongoing to study this.

D. Other

The UK has opened up more than 80 clinics to address Long COVID. What is happening in Alberta?

- We are continually learning from other jurisdictions, especially those who have been dealing with Long COVID for a longer period of time.
- England has a population of ~68 million people, while Alberta's population is ~4.4 million. Per capita, those 80 clinics would translate to 5 in Alberta. Although we have only just started our response to Long COVID, a number of clinics are already available. Links can be found [here](#).

How do staff and physicians keep up-to-date on new information about Long COVID?

- AHS has panels of experts who are continually monitoring reliable information and research from around the world. Their role is to recommend new or revised protocols and/or practices based on the best available evidence and distribute the information to staff and physicians, including community practitioners.

How can providers tell the difference between functional impairment(s) from Long COVID or from mental health issues?

- Currently there is no way to be certain that a patient's functional impairment is due to Long COVID or mental health issues. We know that some patients with Long COVID have expressed

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distress at having their symptoms dismissed. The relationship with the patient and understanding their medical history is key to providing the most appropriate support and care.

- The [PCFS and Symptom Checklist](#) (mentioned above) is an effective tool to support providers in identifying a patient's functional status, which will inform the level of support and/or rehabilitation patients require for their recovery.

Is Long COVID related to Chronic Fatigue Syndrome?

- There is currently no certainty about how or if Chronic Fatigue Syndrome (CFS) and Long COVID are related. We know that CFS is not a single disease but a pattern of symptoms – similar to the situation with Long COVID.