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A. General information

What is long COVID?

- Some people have lingering physical, cognitive and/or mental health problems for weeks or months after having COVID-19.
- Long COVID symptoms have been reported in people who have tested negative for COVID-19.
- Long COVID was originally named by patients who had ongoing problems. It may also be called "long haul 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 not hospitalized.



How many people experience long COVID?

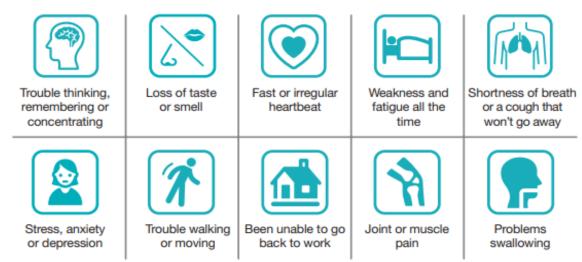
 We are gathering information in Alberta, from other provinces, and from around the world about long COVID. Many research studies indicate that about 20% of people who had COVID-19 continue to have lingering or ongoing symptoms. Other research studies indicate a higher prevalence.

How long will people have long COVID symptoms?

 Because it is a new condition, it is very difficult to predict how long COVID will affect each person. Many people improve after several weeks of managing their own symptoms. For others, the symptoms are more severe and last much longer, up to many months. Symptoms can show initial improvement and then worsen.

What are the most common symptoms of Long COVID?

- Research suggests there are up to 200 symptoms of long COVID.
- Patients and their families are the best source of information about their symptoms and the effects on their daily lives. A full history and interview is recommended.



- Some people with long COVID appear to meet the diagnostic criteria for Myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome (CFS). ME/CFS is not fully understood but it is known to affect multiple systems of the body and could explain some of the long term effects of COVID-19 (Public Health Agency of Canada and CDC).
- Information is continually changing to reflect new knowledge and understanding of the condition. For example, one common symptom is extreme fatigue or debilitating fatigue, not just tiredness. Activity and exercise may be harmful for patients with fatigue from long COVID and may even cause worsening of symptoms.



B. When and where to find help

When should people call 911 or visit the nearest Emergency Department?

Patients are being advised to call 911 or visit the Emergency Department if they are:

- having trouble breathing (struggling for each breath, only able to say 1 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 find information and advice about long COVID symptom management and available services for adult patients?

- Resources for health professionals can be found on AHS' <u>Recovery & Rehabilitation</u>
 After COVID-19 and Information for Community Physicians sites.
- A 5 part, Long COVID Resources Video Series has been developed and can be found on the AHS YouTube channel.
- AHS' Allied Health Professional Practice and Education team developed the "Rehabilitation after COVID-19-Allied Health Provider Education Series". Recordings and slides are 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 their own symptoms but some will need more specialized care. Others may need an assessment of their symptoms to best meet their needs.



- The new Post COVID-19 Functional Status Scale (PCFS) and Symptom Checklist 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.
- A complete list of self-management resources and advice for patients is on the AHS website called Getting Healthy after COVID-19.
- 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.
- For more information view <u>Post-Acute and Continuing Care specific Frequently Asked</u> Questions for Healthcare <u>Providers</u>.

How are patients with long COVID tracked?

 AHS and partners are collecting information and reporting on long COVID, based on emerging Canadian and international standards. A long COVID dashboard will be available in early 2022.

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. Other large international Facebook groups include Survivor Corps and Body Politic.
- On the <u>AHS Together4Health site</u>, members of the public can ask questions and participate in an on-line forum.

C. Vaccination

Should people with long COVID get vaccinated?

- Yes. AHS strongly recommends that people get fully vaccinated as soon as they are eligible according to <u>Alberta's COVID-19 vaccine program</u>, 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.

