

What is Post-COVID or Long COVID?

Category: 1. Introduction

What is Long COVID or post COVID-19 condition (PCC)?

The name 'long COVID' was created early in the pandemic by people experiencing persistent symptoms after a SARS-CoV-2 (the virus that causes COVID-19) infection. It has several other names. For example, the World Health Organization (WHO), also calls Long COVID 'post COVID-19 condition', or PCC. In *MyGuide*, we use 'Long COVID'.

Long COVID also has many definitions developed by organizations worldwide, including the World Health Organization, the US Centers for Disease Control and Prevention and the National Academies of Sciences, Engineering, and Medicine. There is agreement that Long COVID is an infection-associated chronic condition that occurs after SARS-CoV-2 infection. Symptoms continue or develop three months after initial infection and impact day-to-day function. Common symptoms include fatigue, shortness of breath and cognitive dysfunction, but more than 200 symptoms have been identified.

Who is at higher risk of Long COVID?

Long COVID can affect people of all ages, ethnicities, socioeconomic backgrounds, and levels of health. However, research shows that the following are risk factors for developing Long COVID after having COVID-19 illness:

- Being unvaccinated for COVID-19
- Being female sex assigned at birth
- Having more pre-existing medical conditions
- Having more severe initial COVID-19 illness
- Having a history of depression
- Having a history of lung disease
- Having a history of smoking
- Having an unhealthy body weight

Symptoms of Long COVID

There are many symptoms of Long COVID, and some of the most common symptoms include fatigue, shortness of breath (or breathlessness), brain fog, pain, sleep problems, and post-exertional malaise (PEM).

These and many other common symptoms of Long COVID are covered in *MyGuide*. Symptoms can show up immediately after the acute COVID illness or they may arise weeks or months afterwards.

Different people experience different groups of symptoms from Long COVID. In fact, Long COVID may be an illness with multiple different 'subtypes.'

As part of their Long COVID, some people may also experience a worsening of a symptom that they had before, such as headaches. Some people may develop a new condition such as postural orthostatic tachycardia syndrome (POTS), or diabetes.

What causes Long COVID?

Scientists around the world have been working to determine what causes some people to develop Long COVID after their COVID-19 illness.

There are several possible mechanisms.

- COVID-19 virus or viral particles remain in the body after the initial illness (also known as residual virus).
- The body creates antibodies that attack the body by mistake (also known as immune system dysregulation).
- There is inflammation of the cells that line the blood vessels (also known as endothelial cell dysregulation).
- There are problems in the parts of our cells that generate energy for cells in our body (also known as mitochondrial dysfunction).
- There is an increase in blood clotting in small vessels of the body (also known as micro blood clots).
- There are problems in the part of our nervous system that controls our 'fight or flight' and 'rest and digest' responses (also known as autonomic nervous system dysregulation).

How long does Long COVID last?

The duration of Long COVID symptoms varies from person to person.

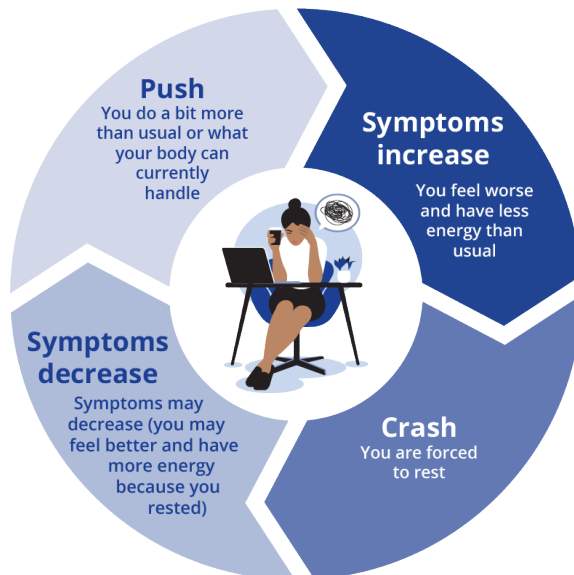
Studies have shown that for many people, symptoms recover by the one-year mark following the initial illness. However, some people have symptoms that last longer than this, with symptoms still present after 2 years.

For many people with Long COVID, the symptoms fluctuate from day to day. Long COVID is a dynamic medical condition, meaning that it has ups and downs. There may be days where it's difficult to manage activities of daily living and days where it is easier. There also may be periods where you might feel like you have recovered, but then experience a recurrence or 'relapse' of symptoms. To help reduce the frequency of 'relapses' many people with chronic conditions find it helpful to use a strategy called pacing.

People with Long COVID may also experience worsening of their symptoms after they become sick, such as when they catch a virus. Knowing this, many people with Long COVID are careful to avoid reinfection with SARS-CoV-2 and other viruses. If you have Long COVID and get COVID-19 again, there are medications that you can take to limit the severity of your illness, Please see the [CAN-PCC recommendation comparing Paxlovid, remdesivir, and molnupiravir](#), as well as [the recommendation comparing metformin and Paxlovid](#) for more information about these medications for people with Long COVID who get a new COVID-19 infection.

What you may notice

Some people living with Long COVID experience a **push/crash cycle**.



For example, they may have a 'good day' (less symptoms) and end up doing too much (push) then 'pay for it later' (increased symptoms) and be forced to rest to recover (crash).

This 'crash' is called **post-exertional malaise (PEM)**. The worsening of symptoms during this crash is sometimes called 'post-exertional symptom exacerbation (PESE).' PEM and PESE are often used interchangeably. We will mostly use 'PEM' in *MyGuide*.

The level of activity or cognitive effort may not seem like much and the 'crash' may not occur until 1 to 3 days afterwards.

This can make it very challenging to find out what activities are increasing symptoms. This connection between symptoms and activities can change over time. Activities can be physical, cognitive/mental, or social/emotional.

The worsening of symptoms in response to activity level is what is experienced by people with myalgic encephalomyelitis/ chronic fatigue syndrome (ME/CFS), a chronic condition that can occur after an infection. Much of the content in *MyGuide* will focus on managing the Long COVID symptoms that worsen in response to activity.

What you can do about it

There are many strategies that people with Long COVID have found helpful to manage their symptoms and improve their overall functioning and quality of life.

One of these strategies is pacing, which many people with Long COVID and PEM find helpful for decreasing their symptoms and improving their overall functioning over time, along with medications and other treatments where they are available.

My Guide Long COVID is organized into different sections to help you with your Long COVID symptoms and help you improve your daily living.

- Symptoms section contains topics that offer information to help identify, explain, and understand common symptoms of Long COVID, such as post-exertional malaise (PEM), fatigue, and brain fog.
- Road to Recovery section contains topics that offer information on treatments and strategies to help manage common symptoms, such as energy conservation and pacing, prescription medications, heart rate monitoring, and breath work. This section also contains information on returning to activity and returning to work.
- Next Steps section contains topics such as becoming a self-manager and how to participate in Long COVID research.
- Provincial and Territorial Resources section offers some helpful resources that are available in your province or territory.

Please note that if you are experiencing acute symptoms, we recommend seeking medical attention.

Where to next?

- *MyGuide: Long COVID* is organized into different sections to help you with your Long COVID symptoms and help you improve your daily living.
 - **Symptoms section** contains topics that offer information to help identify, explain, and understand common symptoms of Long COVID.
 - **Road to Recovery section** contains topics that offer information on treatments and strategies to help manage common symptoms. This section also contains information on returning to activity and returning to work.
 - **Next Steps section** contains topics that further assist you with your journey with Long COVID.
 - **Provincial and Territorial Resources section** offers some helpful resources that are available in your province or territory.
- Review the recommendations by CAN-PCC on:
 - [Using metformin or Paxlovid](#)
 - [Using Paxlovid, remdesivir and molnupiravir](#)
- Watch [this video](#) to listen to advice from other people with Long COVID.
- [Healthexperiences.ca](#) compiled videos where individuals with Long COVID describe [when they first realized they had Long COVID](#), and [which symptoms of Long COVID they experience](#).