

# Caring for Someone with Long COVID

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## If someone you care about has long COVID

Recovery from long COVID can be slow. There is no “quick-fix.” Some people fully recover within months, but others continue to have symptoms years later.

If someone you care about has long COVID, you cannot take their symptoms away, but you can help to reduce the burden of their condition, help improve their quality of life, support their healing, and help them avoid relapse of symptoms.



# Educate yourself

## Symptoms and Strategies



When you are caring for someone with long COVID, it is very important to understand the symptoms they are experiencing and the strategies they need to follow so that you can be a healthy source of support in reducing and managing their symptoms.

The symptoms can affect a person not only physically, but also cognitively and emotionally. Long COVID is very different from having a “bad flu” or anything they may have experienced before. Activities that might not feel especially taxing (like spending a long time in front of a computer) or that might feel relaxing and restful (like watching TV while lying on the couch) when you have a bad flu or cold can be draining with long COVID.

In this MyGuide, you will find information on many different [symptoms](#) that a person with long COVID might experience, as well as [strategies](#) (under Road to Recovery) to help manage symptoms. We suggest you read about the symptoms experienced by the person you are caring for, and strategies that could help them, so that you are able to better support your person.

Many of the strategies involve [pacing](#) physical, cognitive, and emotional energy so that the person avoids over-exerting or overextending themselves. It is important to keep in mind that “rest” can look very different from your current understanding. You can learn more about pacing [here](#).

Long COVID symptoms often fluctuate and can be very unpredictable.

Recovery after a symptom flare up can take a long time, making commitments to activities challenging.

### **Needs and Habits**

In addition to symptoms, the person's needs and habits may also change with long COVID. For example, they may no longer enjoy or tolerate foods they used to enjoy before long COVID. They may need frequent naps.

They may prefer quiet and silence rather than having music playing in the background. They may have more difficulty multi-tasking, such as making lunch and breakfast at the same time.

When you are caring for someone with long COVID, it is important to recognize these changes as part of their post-COVID condition, along with their physical, emotional, and cognitive symptoms.

## **Listen with compassion and ask what they need**

### **Believe them**

Long COVID is an “invisible” disability. You cannot always see from the outside what the person is experiencing. Even if they look fine to you, believe them when they tell you they do not feel well or cannot do something they could normally do before COVID. It can be helpful for you to acknowledge what they are going through and validate their situation

and experiences.

### **Start a conversation**

When caring for someone with long COVID, ask how they are doing and listen to what they say in response. Instead of saying “I know how you feel” or “it will be fine,” try saying “I see how hard this is for you” and “I’m here for you.” These statements can help the person feel seen and understood for what they are going through at the moment.

### **Ask directly what they need or what you can do to help.**

For some people with long COVID, even doing everyday tasks like taking a shower or getting dressed can be exhausting. Here are some additional tasks you could take on to help. Some are small, but any pressure you can take off the person will help.

- Help with everyday chores and errands
- Help fill out forms
- Help them manage their finances, like paying bills
- Accompany them to appointments (give them a ride if possible)

The important thing is to ask. Instead of saying “Let me know if there is anything I can do for you,” try offering specific tasks to do things for them, like mowing their lawn, doing shopping or errands, or dropping off food. Ask them what is frustrating them and see if you can take that task off their plate. Be honest about what you can and cannot do... and follow through with the help that you offer.

# Support their symptom management strategies

There will be good days and bad days—symptoms can be different day to day, even from morning to afternoon to night. Be as patient and caring as possible.

It takes time for a person to learn what strategies are helpful to them and how to use them in a way that works best for them. For example, a person with brain fog might write a reminder to themselves, but then lose the paper. You can help them by writing notes for them and keeping notes together in a notebook.

The person may not be able to return to all of the activities that they could do before. Avoid comparing them to how they were before they had COVID. Instead, focus on the positive, recent changes.

Support their need to plan ahead, to pace and prioritize their activities, to stop at the first sign of overexertion, or to change plans at the last minute. Some signs of overexertion could include [increased heart rate](#), [shortness of breath](#), pain, [headaches](#), [fatigue](#), [brain fog](#), and increased sensitivity or intolerance to noise and light.

Find activities you can do together that do not make their symptoms worse. Keep in mind that they may need to limit how long they can participate or change plans on short notice. You can help them avoid reinfection with COVID-19 by getting vaccinated and wearing a mask

when you are in public or with others.

## Advocate

### **For the person you care about**

Another way to support the person you care about who has long COVID is to advocate for them. Their symptoms could make it more difficult for them to ask for the care and support they need from health care and service providers.

First, make sure you have their permission to advocate on their behalf. Then, go with them to their health care and service appointments and help by asking questions, explaining what you have witnessed (their symptoms and challenges), and asking for what they need. The person may also need help communicating with their family and friends about their symptoms and their needs.

### **For improvements in research and services for people with long COVID**

Join an advocacy group for people with long COVID. Push for research for treatments and services for people with long COVID. See Resources for your province or territory for advocacy groups for long COVID.

## Take care of yourself

It can be difficult and stressful to support someone with long COVID. You might find that their condition has caused changes in your life, too, like different roles and responsibilities. Here are some suggestions on how to take care of yourself so that you can continue to care for them as well.

- Be kind to yourself. Acknowledge and grieve for what has been lost.
- Make sure your basic care needs are still being met. For example, eat healthy meals, exercise regularly, and get enough sleep.
- Communicate with your family and friends to manage your new roles and expectations.
- Spend quiet time together with the person you are caring for.
- Do not deprive yourself. Take care of yourself and your mental/emotional wellness. Keep up your energy and avoid stress. Keep doing what is important to you, even if the person you are caring for cannot participate right now.
- Get outside help. Access community resources for additional support. This can include joining a caregiver support group or speaking with a social worker or community health navigator. Speak to a doctor or workplace employee assistance program to explore access to additional support. There is [some research](#) showing that caregivers of people with chronic illnesses benefit from skills building, self-help, self-management, coping skills, and peer support. You can find “Resources for Caregivers” in your provincial Resources list in this MyGuide, including peer support, advocacy, educational materials, and other supports and services available for caregivers.

## **Financial support for caregivers**

There are financial supports available for people caring for someone who is ill or injured. For example, the [Canada caregiver credit](#) is a non-refundable tax credit for someone supporting a spouse or common-law partner, or a dependent with a physical or mental impairment. [EI caregiving benefits](#) provide financial assistance while you are away from work to care for or support a critically ill or injured person. Check the “Resources for Caregivers” section in your provincial/territory Resources list in this MyGuide for other financial supports that may be available in your region for caregivers.

**Supporting someone living with long COVID can be challenging, especially when there are no fast solutions. Know that your efforts are valued and necessary for the improved health of your loved one.**

## Where to next?

- Visit our [Resource Catalogue](#) and read about different symptoms that a person with long COVID might experience, as well as strategies (under Road to Recovery) to help manage symptom
- Learn more about [Pacing](#), [Heart Palpitation](#), [Breathlessness](#), [Headache](#), [Fatigue](#), [Brain Fog](#), and [Return to Work](#)
- Read the good practice statement from CAN-PCC for caregivers of individuals living with long COVID.
- Take a look at financial support options for caregivers, such as Canada Caregiver Credit and EI caregiving benefits.

- Read [a letter](#) to family and friends of someone living with long COVID. The content of this MyGuide section was adapted from this letter, which was developed by long COVID clinicians.
- Read and watch testimonials from people with long COVID on [how they experienced support](#). Texts and videos are available in English and French.
- Read this [resource sheet for caregivers](#) from the Long COVID Education and Awareness Hub (Sunnybrook St. John's Rehab). This handout is available in English.
- Read this [resource sheet about loving someone with ME/CFS](#). This handout is available in English.

