

To the family and friends of someone living with post COVID,

Post COVID is a very complex and poorly understood condition. There isn't even one name that people agree upon for it yet. You will hear it called post COVID, long COVID, long-hauler COVID, post-acute sequelae of COVID-19, and post-acute COVID-19 syndrome. Whatever the name, post COVID can be serious and debilitating. There is a wide variety of symptoms associated with post COVID; how it affects each individual is unique. Also, we have learned that these symptoms can fluctuate and be unpredictable day to day. To make the situation even more challenging, many of the symptoms are "invisible," meaning it isn't obvious that the person is ill. Dealing with an invisible illness can bring additional burdens of managing stigma, judgment, and disbelief.

The ongoing support of family and friends is essential for people living with post COVID as they face daily challenges.

People living with post COVID are not able to participate in their regular activities. The activities a person living with post COVID can safely manage may be drastically less than what they could before they got COVID. Some are not yet able to return to work and may be more dependent on others than before. This can lead to the loss of self-confidence. The limited knowledge and understanding about post COVID can be scary and people may feel that they are alone or that they need to constantly "prove" their illness. Often, people cannot turn to activities they used to enjoy to relieve stress because it will lead to fatigue and worsening of symptoms. Recovery from post COVID does not follow a straight line; sometimes there are setbacks or relapses. The unpredictability of the symptoms also means they cannot commit or often have to change plans at the last minute, which can strain relationships. All of this can cause significant stress, anxiety, depression and other mental health challenges.

How can you help someone living with post COVID?

Recovery from post COVID can be slow. There is no "quick-fix." Some people fully recover within months, but others continue to have symptoms years later and are unable to return to all parts of their former lives. You cannot take the symptoms away, but you can help to reduce the burden and improve the quality of life for someone living with post COVID.

- **Educate yourself.**

Understanding the symptoms your loved one is experiencing and the strategies they need to follow to manage these symptoms is vital. Symptoms can affect a person physically, cognitively, and emotionally, making it very different from having a “bad flu” or anything they may have experienced before. Many of the strategies involve pacing to avoid over-exerting or overextending themselves. Information on many of the post-COVID symptoms and management strategies can be found here: phsa.ca/postcovid

- **Start a conversation. Listen with compassion.**

The isolation and uncertainty associated with post COVID is challenging. Acknowledge and validate the situation your loved one is going through. Ask how they are doing and listen to their response. Instead of saying, “I know how you feel” or “it will be fine” try saying, “I see how hard this is” and “I’m here for you.”

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

For some people, even completing basic tasks like taking a shower or getting dressed can be exhausting. Your help with chores and errands can help your loved one pace themselves and manage their symptoms. Managing finances, filling out forms, and attending appointments with them can help too. Or maybe they just need to talk to someone about their challenges. Speak to your loved one about the help you can offer. Be honest about what you can and can’t do.

- **Support their symptom-management strategies.**

Be as patient and caring as possible. The onset and intensity of the symptoms fluctuate; there will be good days and bad days. It takes time for a person to learn what strategies are helpful and how to use them. For example, a person with brain fog might say, “I need to say this now before I forget,” unintentionally interrupting you or randomly changing the subject. You might remind them to write things down to help them remember.

- **Support the “new normal”.**

Your loved one may not be able to return to all of the activities that they could do before. Avoid comparing the person 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, and brain fog.

- **Enjoy each other.**

Seek activities you can do with your loved ones that do not worsen their symptoms. Understanding that they may need to limit how long they can participate or to change plans on short notice.

Take care of yourself!

It can be difficult and stressful to support someone with post COVID. Often, their limitations have caused changes to your roles and responsibilities too. As time goes on, this can take a significant toll on everyone involved.

- 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.
- Don't deprive yourself. Keep doing what is important to you, even if your loved one can't participate right now.
- Get outside help. Speak to your family doctor or workplace employee assistance program to explore access to additional supports.

Supporting someone living with post COVID is challenging, especially when there aren't fast solutions. Know that your efforts are valued and necessary for the improved health of your loved one. Thank you.¹

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