

Patient Submitted Questions from FAQ June 26, 2023

“I have noticed that if I am doing something I love and busy and very focused with activity... that I can easily push through without my typical fatigue...when that happens, I feel like I am faking Long COVID for all the other days when I feel exhausted... which is so much of my life. So therefore, if I have long COVID would I never be able to push thru and have energy for a fun day of activity.”

As discussed in the session is it important to avoid PEM where possible, as it leads to the days of exhaustion and there is evidence to suggest onset of new symptoms with more PEM. For activities that you want to participate in, using energy conservation strategies like pacing and prioritizing can help you do activities within your energy limit. There is additional information in the various sessions posted on the portal.

“A recent MRI showed that I have frontoparietal parenchyma volume loss, presumably due to Covid infection (as prior MRIs did not show this, and timing corresponds with significant cognitive challenges I’ve experience instantly and continuously since first days of infection). I’m banking on neuroplasticity and my determination to recover most of my lost skills eventually. Is that realistic?”

Neuroplasticity is a process that can help people regain function after other events/illnesses. We do not currently have research that says that it is a certainty with Long COVID.

“Re: the pre/post MRI. Is it happening that those of us with Long COVID continue to show decline in the brain... or do we have the covid assault and then we have a post Covid new baseline... or could I continue to decline due to the same medical impacts that caused the initial decline in my brain?”

There continues to be research into the mechanisms of Long COVID and at present, we do not have a clear answer to this question.

“Dr. Cheng mentioned helpful to have thorough blood screen including hormones. Is there a template for what is thorough so I can ask for such from my doctor?”

“Is there a doctor in the Toronto area to be referred to? Are there a host of tests that doctors recommend?”

There are no specific long COVID doctors in Toronto. Referrals to specialists are based on presentation of symptoms. The types of tests/investigations are determined by the doctor that is responsible for your care. These two articles offer some information on assessment of Post COVID Condition for primary care:

<https://www.cmaj.ca/content/195/2/E76>

<https://www.bmj.com/content/bmj/378/bmj-2022-072117.full.pdf>

“What are your thoughts on gabapentin as medication for long COVID?”

Any medications for the management of long COVID are determined by the types of symptoms you have and in consultation with your health care provider.

“Is there any relation between a strong reaction to the shots and long COVID?”

The research highlights that 10-15% of people with long COVID experience a flare up of symptoms with vaccination/boosters.

“Given the potential mechanisms for Long COVID, are there treatments that may not be appropriate for some symptoms. E.g. does catheter ablation make sense for tachycardia when the tachycardia may be a result of Long COVID?”

Correct, given the potential mechanisms, not all treatment options will be appropriate for every long COVID patient. We are not able to comment on specific treatments for tachycardia, as the reasons can vary. Any cardiac treatment would need to be consultation with your health care provider.

“What does literature say about recovery rate and times?”

The research available is not able to provide a timeline for recovery. From our experience in the clinic, how much someone recovers or how long it takes varies individual to individual.

“Are people with underlying conditions more susceptible to long COVID?”

The article on by Davis et al (*Long COVID: major findings, mechanisms and recommendations*) suggests that the potential risk factors for Long COVID include: female sex, type 2 diabetes, EBV reactivation, presence of specific antibodies, connective tissue disorders, ADHS, chronic urticaria and allergic rhinitis but a third of people with Long COVID do not have pre-existing conditions. Other research has listed high blood pressure, chronic lung disease, obesity and depression as risk factors.

“Can stem cell treatment help?”

At this point in research, there are no definitive treatments for Long COVID.

“What are you seeing/doing about visual complaints/fatigue? Are visual deficits/blurriness a potential cause of cognitive crashes?”

A lot of patients have hypersensitivity to light, blurry vision, screen sensitivity that can trigger fatigue/PEM/PESE. Patients need to adapt their workspace, use glasses/sunglasses, pacing to manage their visual challenges. Some patients consult an optometrist, neuro-optometrist, neurologist or ophthalmologist.

“Could it be possible that diaphragm constriction/stiffness of ribs restricting oxygen flow/distribution and causing long COVID symptoms such as brain fog, dizziness, fatigue, orthostatic intolerance, etc. in some of us?”

The possible mechanisms for Long COVID were reviewed during the session. Difficulty with breathing can worsen symptoms. If you are having difficulty with breathing, it is helpful to rule out organic causes with your doctor. If there are no underlying causes for your shortness of breath, you are likely experiencing a dysfunctional breathing pattern, and may benefit from practicing breathing exercises. If you having trouble with practicing breathing, it may be helpful to consult a physiotherapist who can provide further assessment and treatment of your breathing patterns.

“Could tight / restricted diaphragm and disordered breathing be a root cause of both dysautonomia and fatigue and crashes/PEM?”

Dysautonomia is caused by a dysregulation of your autonomic nervous system, which can in turn can affect your breathing patterns.

“Could it be possible that the type of dysautonomia that long COVID patients have is different from POTS or only seeing POTS? Causing HR variability? Significant swings in blood pressure with minimal effort like standing up, etc. Is it helpful to see a neuro specialist for those of experiencing symptoms of dysautonomia?”

“Are other small exercises with dysautonomia?”

There will be a handout available on the portal that addresses dysautonomia and POTS. POTS is one specific type of dysautonomia but you can also have symptoms of dysautonomia that do not meet the criteria for POTS. The handout has some information on management strategies. A cardiologist might be involved in diagnosing dysautonomia or POTS.

“Impact of depression and anxiety from long COVID?”

Depression and anxiety might be a new diagnosis or might worsen after COVID. They are both conditions that have known treatments and management strategies. It would be helpful to address those with your health care provider to help with managing Long COVID.

“I was recovering from a heart issue and was walking a block or 2 after covid I have trouble making it 20 yards, standing any amount of time. Over time, I have not been able to improve. I need to push through this SOB for my cardio issue. Will look on site for info.”

It may be helpful for you to consult a physiotherapist who has experience with Long COVID to provide you with a treatment plan given your cardiac history.

“What is the best way to see if antivirals will be needed if I do become positive? I needed antivirals/paxlovid last time on day 1 with Covid in US last May 2022 and was still hit hard?”

“Do I need to go to hospital if I test positive and start to get any symptoms? Or can walk-on clinic make prescription or assess if needed if I do get Covid again now that back home here in ON? Or best to go straight to hospital quickly if symptoms develop? Not sure if a second case of Covid with long Covid will mean worse symptoms??/ or less symptoms compared to before but want to be ready just in case.”

It is helpful to speak with your doctor about what to do in the event you do become re-infected. They could help you decide what treatments are appropriate. You would only present to the hospital in the event of an emergency. Pharmacists in Ontario are also able to prescribe antivirals, but they would still need to complete an assessment to determine if it is appropriate.

<https://www.ontariohealth.ca/sites/ontariohealth/files/2022-04/Guidance%20for%20health%20care%20providers%20-%20Access%20to%20Paxlovid%20-%20EN.pdf>