Answers to Frequently Asked Questions about Long COVID

April 1, 2021

Many patients report lasting effects after acute symptoms of COVID-19. **Long COVID** describes the experience of prolonged illness and an array of symptoms that evolve over time by persons who have had COVID-19 infection. The OCFP has compiled this resource to help answer common questions about long COVID and to support family physicians who may be caring for COVID “long-haulers.”

On February 19, 2021, the [COVID-19 Community of Practice for Family Physicians](https://www.cofofp.ca) hosted leading long COVID researcher and Oxford University professor, Dr. Trish Greenhalgh, to share lessons from the U.K. Here is a [recording of the Feb 19 session](https://www.cofofp.ca), which was one source of the questions here, as well as a [BMJ article](https://www.bmj.com) on management of post-acute COVID-19 in primary care, also referenced below, co-authored by Dr. Greenhalgh.

- **Is a positive COVID test required for diagnosing long COVID?**
  Testing or a positive test is not required for a diagnosis of long COVID. Long COVID can be diagnosed clinically based on history alone. A negative anti-body test does not exclude long COVID.

- **What are the symptoms of long COVID?**
  The symptoms associated with long COVID are varied and many. Most commonly, these include cough, low-grade fever and fatigue, all of which may relapse and remit, according to research published in BMJ, which includes a fuller list of symptoms. In another study in younger to mid-aged patients (median age 44), common symptoms have been identified to include: fatigue (98%), muscle ache (88%), shortness of breath (87%), and headache (83%). Functional impairment has also been noted as a common symptom of long COVID.

- **Is long COVID contagious?**
  Most people with long COVID are not contagious. It is uncertain whether long COVID is persistent infection, re-infection, an autoimmune reaction, or another condition. For some people, it may be a combination of these scenarios. Re-testing for COVID-19 should be considered if acute symptoms arise, such as loss of taste and smell, and a cough, fever or other symptoms of respiratory infection.

- **Are there any preventative measures for long COVID?**
  We do not know why some people develop long COVID and others are not affected. There is preliminary evidence of a relationship between chronic or prolonged hypoxia, and development of long COVID. Checking oxygen levels and treatment for low oxygen as needed may be helpful. Approaches to treating long COVID are described in this [BMJ article](https://www.bmj.com).

- **Is it okay for someone with long COVID to receive the COVID vaccine?**
  Having symptoms of long COVID is not a contraindication to receiving the vaccine. Certain side effects of the vaccine, including fatigue, may be similar to the symptoms of long COVID. If the patient is debilitated, has recently deteriorated or is under active investigation, it may make sense to defer vaccination so that changes in symptoms are not attributed mistakenly to the vaccine.
• **How can we tell the difference between functional impairment from long COVID or from mental health issues?**

Currently, there is no way to be certain that a patient’s functional impairment is due to long COVID rather than mental health issues. We know that some long COVID patients have expressed distressed at having their symptoms being dismissed. The relationship between patient and doctor is key to supporting the patient and accessing needed care.

• **Is long COVID another type of Chronic Fatigue Syndrome?**

There is no certainty about how or if Chronic Fatigue Syndrome (CFS) and long COVID are related. We know that CFS is not a single disease but rather a pattern of symptoms – similar to what we know about long COVID so far.

• **What follow-up care and tests are recommended for long COVID patients?**

When and what follow up tests are required will depend on the individual’s conditions and symptoms. This BMJ article includes information on management and testing based on symptoms.

This guideline released in December 2020 by the UK National Institute for Health and Care Excellence (NICE) provides advice on diagnosis and management of long COVID based both on the best available evidence and the knowledge and experience of the expert panel.

Hamilton Family Medicine has collected practical and evidence-based guidance on diagnosis and treatment for COVID, including for long-COVID.

• **What clinical services are there dedicated to long COVID?**

  o Patients who were previously hospitalized with severe COVID (i.e., ICU) are often followed post-discharge by their hospital team and may have access to support as part of follow up.

  o Advice on COVID care, including long COVID, is available through eConsult.

  o The Ontario Ministry of Health has stated that long COVID clinics may be funded by hospitals through their global budgets and that it is aware of hospital-based programs at University Health Network and Michael Garron Hospital in Toronto, London Health Sciences Centre, Windsor Regional Hospital and the Niagara Health System.

  o There are private-sector companies offering (paid) services for long COVID patients.

  o CANCOV (Canadian COVID-19 Cohort), a national observational study of COVID patients, is recruiting long COVID patients from across Canada. Study participants will receive different types of treatment, including rehabilitation, standardized assessments and referrals. Make a referral for Toronto area patients by emailing cancov@uhn.ca or send a fax to 1-866-6CANCOV (1-866-622-6268).

  o For patients, the COVID Long Haulers Support Group Canada launched on Facebook in June 2020 and currently has more than 12,000 members.