



## POST COVID-19 CONDITION

### OCSO BIWEEKLY SCAN OF EVIDENCE #26

June 18-July 1, 2022

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#### SCOPE

This biweekly update presents an analysis of new evidence, guidance and issues related to post COVID-19 condition and synthesizes the current state of knowledge. Comprehensive lists of details and resources on this issue are available at the Office of the Chief Science Officer (OCSO).

#### CURRENT STATE OF KNOWLEDGE

According to the World Health Organization (WHO), post COVID-19 condition (PCC) refers to persistent symptoms occurring 12 weeks or more after an acute COVID-19 infection, which persist or reoccur for a minimum of 8 weeks. The most common [symptoms](#) that we know of in adults include: fatigue, memory problems, sleep disturbances, shortness of breath, anxiety and depression, general pain and discomfort, difficulty thinking or concentrating and post-traumatic stress disorder (PTSD). There is still a lot that we don't know about post COVID-19 condition in children.

PCC is also referred to as long COVID, post-acute sequelae, post COVID-19 symptoms, and post-acute COVID-19 syndrome. Prior to the WHO definition, a number of studies reported on post-acute sequelae (PAS) from 4 to 12 weeks post diagnosis. The Public Health Agency of Canada (PHAC) released [a review of the current international evidence \(November 2021\)](#). Over 100 symptoms or difficulties conducting usual activities of daily living were reported.

There is limited data suggesting that the condition may be more likely to develop in those:

- who were hospitalized during acute infection;
- had more than 5 COVID symptoms during the acute phase;
- have pre-existing respiratory disease;
- are older;
- are women; and
- have other co-morbidities or have higher BMI.

There's currently no universally agreed-upon approach to diagnose and treat post COVID-19 condition. Early evidence suggests that vaccination with 2 or more doses may help reduce the risk of developing post COVID-19 condition if infected. Emerging evidence points to the importance of multidisciplinary care given the heterogeneity of symptoms associated with PCC. Multidisciplinary teams in "long COVID" clinics have been set up to include professionals from the following fields: rehabilitation, respiratory and cardiac consultants, physiotherapists, occupational therapists, psychologists, etc.

People who have been hospitalized or who needed intensive care during recovery appear to be at greater risk of experiencing longer-term effects. However, recent research shows about [30% to 40%](#) of people who weren't hospitalized for their initial COVID-19 infection still report symptoms beyond 12 weeks. Canadians suffering from PCC and who are unable to work because of their symptoms may be eligible for support through: [Employment and Skills Development Canada's Employment Insurance \(EI\) Program](#) and [Canada Pension Plan Disability Benefits](#).

This week's scan includes an [article](#) published in the *Lancet* examining long COVID symptoms in children aged 0–14 years in Denmark, as well as [research](#) published in *Radiology* revealing the causes of long COVID via lung-imaging research at Western University.

## GUIDELINES OR STANDARDS

- **WHO** developed a [clinical case definition](#) of PCC in October 2021. This first version was developed by patients, researchers and others with the understanding that the definition may change as new evidence emerges.
  - *“Post COVID-19 condition occurs in individuals with a history of probable or confirmed SARS CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms and that last for at least 2 months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others and generally have an impact on everyday functioning. Symptoms may be new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness. Symptoms may also fluctuate or relapse over time.”*
  - **WHO**: Q&A [page](#) on Post-COVID-19 Condition (February 2022).
- **US CDC** describes [Post-COVID conditions](#) as a wide range of new, returning, or ongoing health problems that people experience after first being infected with the virus that causes COVID-19. The CDC posted [Interim Guidance](#) (Updated June 2021) for healthcare providers on Evaluating and Caring for Patients with Post-COVID Conditions. Post-COVID conditions can be considered a disability under the [Americans with Disabilities Act \(ADA\)](#). The CDC also released information on [Caring for People with Post-COVID Conditions](#) (Updated March 2022). CDC is using [science](#) to learn more about post-COVID conditions.
- **UK NICE**: Rapid [guidelines](#) for managing the long-term effects of COVID-19 (Updated March 2022).
- **Chartered Society of Physiotherapy** in UK published its COVID-19 [rehabilitation standards](#) (July 2021).
- [Guidelines](#) to help doctors manage long COVID patients published in *British Journal of General Practice* (August 2021).
- **UK NHS** [guidance](#) for Post-COVID syndrome assessment clinics (April 2021).
- [Guidance](#) for **Canadian Rehabilitation and Exercise Professionals** on Post COVID-19 condition and rehabilitation management strategies (August 2021).
- **Government of Canada**: [COVID-19 for health professionals - Post COVID-19 condition](#) (continuously updated)
- **Center for Effective Practice** – [COVID-19: Clinical Guidance for Primary Care Providers - Long-term symptoms / Post-acute sequelae of COVID-19 \(PASC\)](#) (last updated April 2022)
- *Wiener klinische Wochenschrift*: [Guideline S1: Long COVID: Diagnostics and treatment strategies](#) (December 2021)
- American Academy of Physical Medicine and Rehabilitation (**AAPM&R**): [Cognitive Symptoms Guidance](#) & [Breathing Discomfort Guidance](#) (December 2021).
- Royal Australian College of General Practitioners (**RACGP**) [guidance](#) for GPs caring for patients with post–COVID-19 conditions (December 2021).
- European Society of Clinical Microbiology and Infectious Diseases (**ESCMID**): [Rapid guidelines for assessment and management of long COVID](#) (February 2022)
- **ACAS** (UK-based Advisory, Conciliation and Arbitration Service): [Long COVID – advice for employers and employees](#) (last reviewed April 2022)
- **Ontario Health** [Post COVID-19 Condition - Guidance for Primary Care \(PDF\)](#)
- **Scottish Government Guidelines**: [Managing the long-term effects of COVID-19](#)

NATIONAL AND INTERNATIONAL DEVELOPMENTS (JUNE 18 - JULY 1)

CANADA

- (NEW) Cause of long-COVID symptoms revealed by lung-imaging [research](#) at Western University. Using a functional MRI where patients inhale xenon gas, researchers can see in real-time what is happening inside the lungs. Preliminary results show symptoms are related to microscopic abnormalities that affect how oxygen is exchanged from the lungs to red blood cells. The research was published Tuesday in [Radiology](#). Having participants inhale the gas while being scanned by the MRI allowed researchers to see how the 500 million air sacs in the lungs deliver oxygen to the blood. In the case of long-COVID patients, the transition of the oxygen was depressed compared to healthy volunteers.
- (NEW) The Government of [Yukon](#) has formed a working group to learn more about post COVID-19 condition and those who are experiencing its effects. The working group will rely on emerging research and personal experiences to develop information and resources for Yukoners, or those caring for Yukoners, with post COVID-19 condition.

UK

- (NEW) Symptoms of long COVID are more frequently reported by women, those with poor overall health before the pandemic, and those aged 50 to 60, according to a new UK-based [study](#) in *Nature Communications*. The study was based on results gathered from 6,907 people with self-reported COVID-19 from 10 population-based longitudinal health surveys in the United Kingdom that had been in place prior to the pandemic.

US

- (NEW) A statewide May 2022 [survey](#) of Oregon residents (n=695) indicated unvaccinated Oregonians were about 2.5 times more likely to suffer from long COVID than vaccinated. While the sample of Native Americans is relatively small, the survey found that over 30% of them report suffering from long COVID, compared to state average of 8%. Every single Native American in the survey who reported having had COVID also indicated suffering from long COVID. The effects of long COVID also appear to have an outsized impact on people with ‘some college’ (38% of individuals in this group that had COVID) and those with bachelor’s degrees (27% of this group’s COVID+ individuals). It is unclear why this is the case, but the differences are statistically significant.

EMERGING SCIENTIFIC EVIDENCE (JUNE 18 - JULY 1)\*

EVIDENCE PRODUCTS

TITLE AND AUTHOR	EVIDENCE TYPE	SUMMARY
<a href="#">Cardiopulmonary exercise testing to evaluate post-acute sequelae of COVID-19 (“Long COVID”): a systematic review and meta-analysis</a> (Durstefeld et al)	Systematic Review (Available in <i>medRxiv</i> )	Objective was to estimate effect of COVID-19 infection on exercise capacity including those with and without LC symptoms and to characterize physiologic patterns of limitations to elucidate possible mechanisms of LC. Included studies of adults with SARS-CoV-2 infection at least three months prior that included CPET measured peak VO2. By meta-analysis of 9 studies including 404 infected individuals, peak VO2 was lower among infected versus uninfected individuals. Meta-analysis of 9 studies with 464 individuals with LC, peak VO2 was lower compared to those without symptoms. Deconditioning was common, but

		dysfunctional breathing, chronotropic incompetence, and abnormal oxygen extraction were also described.
<a href="#">Sex differences in sequelae from COVID-19 infection and in long COVID syndrome: a review</a> (Sylvester et al)	<i>Review</i> (Available in <i>Curr Med Res Opin</i> )	We conducted literature reviews to uncover differential effects of sex on sequelae from COVID-19 and on long COVID syndrome. COVID-19 sequelae in the categories of psychiatric/mood, ENT, musculoskeletal, and respiratory were significantly more likely among females (vs. males), whereas renal sequelae were significantly more likely among males. The likelihood of having long COVID syndrome was significantly greater among females, with the odds of ENT, GI, psychiatric/mood, neurological, dermatological, and other disorders significantly higher among females and the odds of endocrine and renal disorders significantly higher among males. Sex-disaggregated differences for COVID-19 sequelae and long COVID syndrome were observed.
<a href="#">Impact of COVID-19 vaccination on long COVID: a systematic review and meta-analysis</a> (Byambasuren et al)	Systematic Review (Available in <i>medRxiv</i> )	We aim to assess impact of COVID vaccinations administered (i) before and (ii) after acute COVID-19, including vaccination after long COVID diagnosis, on the rates or symptoms of long COVID. The most common long COVID symptoms studied include fatigue, cough, loss of smell, shortness of breath, loss of taste, headache, muscle ache, trouble sleeping, difficulty concentrating, worry or anxiety, and memory loss or confusion.. Current studies suggest COVID-19 vaccinations may have protective and therapeutic effects on long COVID. More robust comparative observational studies and trials are urgently needed to clearly determine effectiveness of vaccines in prevention and treatment of long COVID.
<a href="#">A health and lifestyle framework for management of post covid-19 syndrome based on evidence-informed management of post-polio syndrome: a narrative review</a> (Dean et al)	Review (Available in <i>Eur J Pyshiother</i> )	We conducted a narrative review to establish the basis for an evidence-informed health and lifestyle framework that underlies the management of post-polio syndrome, as a prototype for managing post covid-19 syndrome. Multi-morbidity, the non-communicable diseases (NCDs) and their risk factors, is strongly associated with SARS-CoV-2 susceptibility and poor outcomes including death. Poliomyelitis survivors may exhibit debilitating sequelae decades after infection, thus their presentations are often confounded by limitations associated with NCDs and their risk factors. An evidence-informed health and lifestyle framework is described. Its 3 levels of analysis and intervention include: (1) health status; (2) lifestyle practices (smoking; nutrition; weight; sedentariness, activity/exercise; sleep; stress); and (3) the 3 levels of WHO's International Classification of Functioning, Disability and Health.
<a href="#">The role of physical activity for post-covid-19 syndrome</a> (Cherneva et al)	Review (Available in <i>General Medicine</i> )	This review aims to summarize data, regarding post-COVID-19 syndrome, as well as, to explain that regular physical activity could reduce many of the symptoms and long-term effects of COVID-19 infection.

## SELECTED LITERATURE

TITLE AND AUTHOR	SOURCE	SUMMARY
<a href="#">Long COVID symptoms in SARS-CoV-2-positive children aged 0–14 years and matched controls in Denmark</a>	<i>Lancet Child Adolesc Health</i>	After the acute phase of SARS-CoV-2 infection, children can develop long COVID symptoms. We aimed to investigate the prevalence of long-lasting symptoms, the duration and intensity of symptoms, quality of life, number of sick days and absences from daycare or school, and

<p><a href="#">(LongCOVIDKidsDK): a national, cross-sectional study</a> (Kikkenborg et al)</p>		<p>psychological and social outcomes in children aged 0-14 years who had been infected relative to controls with no history of infection.</p>
<p><a href="#">The presence of symptoms within 6 months after COVID-19: a single-center longitudinal study</a> (Emecen et al)</p>	<p><i>Ir J Med Sci</i></p>	<p>Aim was to describe presence of symptoms in COVID-19 patients within 6 months after diagnosis and to investigate the associated factors in terms of reporting symptoms. Total of 5610 patients agreed to participate in study. Symptom frequency was 37.2%, 21.8%, and 18.2% for first, third, and sixth months. Tiredness/fatigue, muscle or body aches, and dyspnea/difficulty breathing were most common symptoms. Older age, female gender, bad economic status, current smoking, being fully vaccinated before COVID-19, having more health conditions (<math>\geq 3</math> conditions), having more symptoms (<math>&gt; 5</math> symptoms), and hospitalization (intensive care unit) were associated with reporting of symptoms.</p>
<p><a href="#">Long COVID: care and support needs from the perspective of "long-haul" patients and primary care practitioners - a mixed-methods study from Baden-Wuerttemberg</a> (Stengel et al)</p>	<p><i>Z Evid Fortbild Qual Gesundheitswes</i></p>	<p>Aim of study was to explore experiences and ideas for continued development of medical care of long COVID from the patients' (PAT) and primary care practitioners' (PCP) perspective. Between third and fourth COVID-19 wave in Germany, a mixed methods study was conducted by patients and PCPs in districts in Baden-Wuerttemberg to a paper-based questionnaire. Responses of <math>n = 72</math> PCPs and <math>n = 126</math> PAT showed heterogeneous assessment regarding satisfaction with medical care of long COVID as well as perception of attitude towards patients and their disease in both groups. Results support an interdisciplinary, intersectoral and interprofessional stepped-care concept for long COVID in Germany with PCPs as first contact persons, integration of specialized contact points and knowledge transfer.</p>
<p><a href="#">Prevalence of COVID-19 and Long COVID in Collegiate Student Athletes from Spring 2020 to Fall 2021: A Retrospective Survey</a> (Massey et al)</p>	<p><i>medRxiv</i></p>	<p>We surveyed a convenience sample of 18 collegiate school administrators, representing about 7,000 student athletes. According to survey responses, 9.8% of student athletes tested positive for COVID-19 in spring 2020 and 25.4% tested positive in the academic year of fall 2020 to spring 2021. About 4% of student athletes who tested positive from spring 2020 to spring 2021 developed Long COVID, defined as new, recurring, or ongoing physical or mental health consequences occurring 4 or more weeks after SARS-CoV-2 infection.</p>
<p><a href="#">Long Coronavirus Infection is Associated with Significant Sleep Disturbances as Detected by Wearable Health Devices</a> (Mekhael et al)</p>	<p><i>J Med Internet Res</i></p>	<p>We assess long-term effects of COVID-19 through sleep patterns from continuous signals collected via wearable wristbands. Patients with a history of COVID-19 were compared to a control arm of individuals who never had COVID-19. Study includes 122 COVID-19 patients and 588 controls. Total sleep time was positively correlated with respiratory rate (RR) and oxygen saturation (SpO<sub>2</sub>). Increased awake sleep phase was correlated with increased heart rate (HR), decreased RR, heart rate variability (HRV), and SpO<sub>2</sub>. Increased light sleep time was correlated with increased RR and SpO<sub>2</sub> in COVID-19 group. Deep sleep duration was correlated with decreased HR, and increased RR and SpO<sub>2</sub>. When comparing different sleep phases, long COVID-19 patients had decreased light sleep time and decreased deep sleep.</p>
<p><a href="#">Characterising patterns of COVID-19 and long COVID symptoms: Evidence from nine UK longitudinal studies</a> (Bowyer et al)</p>	<p><i>medRxiv</i></p>	<p>We analysed individual symptom prevalences and characterised patterns of COVID-19 and long COVID symptoms across nine UK longitudinal studies, totalling over 42,000 participants. Conducting latent class analyses separately in three groups ('no COVID-19', 'COVID-19 in last 12 weeks', 'COVID-19 &gt; 12 weeks ago'), data did not support presence of more than two distinct symptom patterns, representing high and low</p>

		<p>symptom burden, in each group. Comparing high symptom burden classes between 'COVID-19 in last 12 week,' and 'no COVID-19' groups we identified symptoms characteristic of acute COVID-19, including loss of taste and smell, fatigue, cough, shortness of breath and muscle pains or aches. The identified symptom patterns among individuals with COVID-19 &gt; 12 weeks ago were strongly associated with self-reported length of time unable to function as normal due to COVID-19 symptoms, suggesting that the symptom pattern identified corresponds to long COVID.</p>
<p><a href="#">Evidence of recent Epstein-Barr virus reactivation in individuals experiencing Long COVID</a> (Peluso et al)</p>	<p><i>medRxiv</i></p>	<p>Epstein-Barr virus (EBV) reactivation has been proposed as a driver of Long COVID (LC). In cohort of 294 hundred adults with history of COVID-19, we observed that LC symptoms such as fatigue and neurocognitive dysfunction at median 4 months following initial diagnosis were associated with serological evidence of recent EBV reactivation, but not with ongoing EBV viremia. Long COVID was also observed in the small proportion without evidence of prior or recent EBV infection, suggesting EBV reactivation is not a prerequisite for this condition.</p>
<p><a href="#">Natural course of post COVID-19 condition and implications for trial design and outcome selection: A population-based longitudinal cohort study</a> (Ballouz et al)</p>	<p><i>medRxiv</i></p>	<p>Objective was to evaluate longer-term symptoms and health outcomes within a cohort of SARS-CoV-2 infected individuals in Switzerland (1543 adults with confirmed SARS-CoV-2 infection and 628 adults without infection). 25% of infected individuals did not recover by 6 months. Of those, 67% and 58% also did not recover at 12 and 18 months after infection, respectively. Hospitalization for acute COVID-19, pre-existing fatigue and pain or discomfort, and presence of specific systemic, cardiovascular, or musculoskeletal symptoms at 6 months were associated with persistent non-recovery. Symptom prevalence was higher among infected individuals compared to non-infected individuals at 6 months and 12 months.</p>
<p><a href="#">Prevalence of long COVID in a national cohort: longitudinal measures from disease onset until 8 months follow up</a> (Petersen et al)</p>	<p><i>Int J Infect Dis</i></p>	<p>In this longitudinal study from the Faroe Islands, we present prevalence of long COVID in mainly non-hospitalised patients who were followed for up to 8 months. 226 individuals participated at baseline of which 170 participants had more than 3 months follow-up. Of these, 39% reported persistent symptoms median 168 days after the acute phase and 8% reported severe persistent symptoms. Most prevalent symptoms were fatigue (16%) and smell (17%) and taste (14%) dysfunction. Long COVID was more common in people reporting daily medication use.</p>
<p><a href="#">Long COVID burden and risk factors in 10 UK longitudinal studies and electronic health records</a> (Thompson et al)</p>	<p><i>Nat Commun</i></p>	<p>The frequency of, and risk factors for, long COVID are unclear among community-based individuals with a history of COVID-19. To elucidate the burden and possible causes of long COVID in community, we coordinated analyses of survey data from 6907 individuals with self-reported COVID-19 from 10 UK longitudinal study (LS) samples and 1.1 million individuals with COVID-19 diagnostic codes in electronic healthcare records (EHR). Proportions of presumed COVID-19 cases in LS reporting any symptoms for 12+ weeks ranged from 7.8% and 17%. Increasing age, female sex, white ethnicity, poor pre-pandemic general and mental health, overweight/obesity, and asthma were associated with prolonged symptoms in both LS and EHR data, but findings for other factors, such as cardio-metabolic parameters, were inconclusive.</p>

\*Note: Content may have been published prior to this scan period but was only available through applying our search strategies during this period.

## COMMENTARIES, LETTERS AND OPINION PIECES (JUNE 18-JULY 1)

- [Difficult questions about long COVID in children \(Lancet Child & Adolescent Health\)](#): A small proportion of children have had serious sequelae of SARS-CoV-2 infection itself, with the most dramatic being multisystem inflammatory syndrome in children (MIS-C). A less well-defined entity, termed long COVID or post-COVID-19 condition, has been suggested, referring to children with long-lasting symptoms after SARS-CoV-2 infection that are not explained by another disease. In contrast to MIS-C, the symptoms attributed to long COVID are non-specific and occur frequently in otherwise healthy children; headache, mood swings, abdominal pain, and fatigue are all common, and, although they can be symptoms of a disease, they often are not. The occurrence of these symptoms after infection with SARS-CoV-2 does not necessarily mean that they are caused by the infection.
- [Glacial pace for U.S. Long Covid grants \(Science\)](#): NIH RECOVER’s flagship, [an observational study](#) of up to 40,000 people, has come under fire from patient advocates and some scientists who say it lacks transparency and is moving far too slowly. As of 6 June, the study had signed up [3712 adults](#), or 21% of its adult enrollment target of 17,680. Among children, numbers are even lower: Ninety-eight children are participants in a study aiming to enroll 19,500 of them. Critics note that other countries have been more nimble. By July 2021, the UK had funded 15 Long Covid research projects aimed at diagnosis and treatment. An independent review published by the Rockefeller Foundation found that, as of February, NIH had funded just eight of 200 Long Covid trials listed in the US ClinicalTrials.gov database. NIH acknowledges the critiques and says it has already “obligated or committed” the \$1.15 billion, slated to be spent over 4 years. NIH added in a statement that it expects to announce winners of the long-awaited January funding within 2 weeks. And the agency says it has dedicated multiple staff to RECOVER, reinforced by other NIH experts and the outside firm Deloitte. But given the growing concern about the condition—recent estimates are that one in five U.S. COVID-19 survivors is afflicted—U.S. researchers say more urgency is needed.

## MEDIA HIGHLIGHTS (JUNE 18 – JULY 1)

### CANADA

- [The evolving picture of long COVID \(CMAJ\)](#): People exposed to SARS-CoV-2 in the spring of 2020 — before vaccines, variants, and new therapeutics — may not experience the same long-haul symptoms as those exposed during the later Delta and Omicron waves. There also needs to be more understanding of the mechanism of the disease, which could open a door to potential treatment, says Alain Piché, a microbiologist, infectious disease physician, and director of a post-COVID clinic in Sherbrooke. “At this point, we really need new drugs or known drugs that will be effective against long COVID, because I’m seeing so many patients that have a huge impairment on their daily lives,” he says.
- [Experts explore long COVID-19 treatments as thousands of Albertans seek relief \(Globe & Mail\)](#): Neeja Bakshi, medical director of Park Integrative Health in Edmonton, described long COVID as a very debilitating condition, impacting work and home lives. Dr. Bakshi launched a long COVID treatment program in January. So far, they have seen about 100 patients and are receiving nearly 20 referrals a week from people across Alberta and from neighbouring provinces that either have long wait times or different programs. James Wood, a spokesperson with Alberta Health Services, said about 2,250 Albertans have been “referred to specialty medicine” as of May due to post-COVID symptoms lasting longer than three months. Mr. Wood said the agency’s Rehabilitation Advice Line, which provides free advice to people with persistent COVID-19 symptoms, has also connected with more than 8,700 people.

### GLOBAL

- [How common is long COVID? Why studies give different answers \(Nature\)](#): Enormous databases do not necessarily allow scientists to solve long COVID mysteries, such as how well vaccination protects against the condition. Another issue is how symptoms are recorded in the claims and electronic medical records. Doctors often record codes for several symptoms and conditions, but they rarely list a code for every symptom a patient is experiencing, and the choice of codes for a given condition might vary from one doctor to the next. This could lead to differences in whether and how long COVID is reported.

## POST COVID-19 CONDITION RESOURCES

- [Long COVID Physio](#): Long COVID Physio is an international peer support, education and advocacy, patient-led association of Physiotherapists living with Long COVID and allies. They post various educational [videos](#) on long COVID.

- [John Hopkins Medicine - Long-Term Effects of COVID-19](#)
- [C19 Recovery Awareness \(US\)](#): The mission of the Long Haul COVID Fighters is to provide support for those whose health has been affected by COVID-19, promote public awareness and education regarding lengthy COVID recovery, and advocate for the medical, mental health, and social interests of long haul COVID survivors.
- [COVID-19 Virtual Library of Health Data and Evidence \(Canada\)](#): Resources to knowledge products, data and evidence on the impacts of COVID-19, which includes post COVID-19 condition. This is a searchable collection of products funded and published by the Government of Canada.
- [Lullabies for long COVID \(UK\)](#): An online program developed in collaboration with the English National Opera could help with rehabilitation, by improving mental health and symptoms of breathlessness.
- [Solve Long Covid Initiative \(US\)](#): The Solve ME/CFS Initiative is a non-profit organization that serves as a catalyst for critical research into diagnostics, treatments, and cures for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), Long Covid and other post-infection diseases.
- [PASC Guide \(University of Michigan\)](#): A resource for people with PASC/long COVID.
- [Health Education England \(HEE\) e-learning modules: long COVID programme](#)
- [Voices of Long COVID \(US\)](#): Voices of Long Covid campaign features testimonials from a diverse group of people ages 18-29 who are suffering from long-term complications of COVID-19 infection.
- [Dignity Health \(US\)](#): COVID-19 and Chronic Illness Recovery Program based in the U.S. has helped over 2,000 people struggling with COVID long-term effects ("COVID long haulers"). Treatment is exercise-based for lingering or long-term conditions (sequelae) from having the virus.
- [Altea \(Switzerland\)](#): A network for sharing evidence-based information on the long-term effects of COVID-19.
- [Pandemic-Aid Networks](#): Long COVID research library.
- [Post-COVID-19 Functional Status Scale](#): An overview of a patient self-reported scale that helps to support assessment of functional status and recovery after the SARS-CoV-2 infection.
- Ontario College of Family Physicians: [Resources on Post-COVID Condition](#).
- [Agency for Clinical Innovation \(Australia\)](#): Living Evidence - post acute sequelae of COVID-19.
- Pre-populated literature searches: [Long COVID search](#) (LitCovid) and [Long COVID search](#) (NIH)
- [PAHO](#) Webinar Series on Post COVID-19 Condition launched 17 February, 2022, from 10:30 am to 12:30 pm (EST).
- [Body Politic COVID-19 Support Group \(Global\)](#): Housed on the Slack app, group members have access to dozens of different channels, which give space for more personal discussion. Some of the channels include those specifically for medical professionals, parents of children with Covid-19, LGBTQ+ individuals, BIPOC+, and different regions around the world.
- [Patient-Led Research Collaborative \(Global\)](#): Self-organized group of Long COVID patients working on patient-led research around the Long COVID experience.
- [British Heart Foundation \(UK\)](#): UK-based foundation with resources on long COVID.
- [COVID Long Haul \(Canada\)](#): Canada's largest online platform for COVID survivors, their family members and anyone searching for the most up-to-date information about the pandemic. There is a COVID long-haulers [support group](#) and a [Report on Pan-Canadian Long COVID Impact Survey \(PDF\) \(June 2021\)](#)

- [BC ECHO for Post-COVID-19 Recovery \(Canada\)](#): BC ECHO for Post-COVID-19 Recovery is a learning community of specialists and community health-care providers who use case-based learning to improve care for those recovering from [symptoms post-COVID-19](#).
- [Long Covid Support \(UK\)](#): Peer support and advocacy group aiming to facilitate international peer support and campaigning in the UK for recognition, rehabilitation and research into treatments.
- [Long COVID SOS \(UK\)](#): Long-term sufferers formed the LongCovidSOS campaign to put pressure on the UK government to recognise the needs of those with Long Covid, and to raise awareness among the general public and employers.
- [Survivor Corps \(US\)](#): One of the largest and fastest growing grassroots movements connecting, supporting, and mobilizing COVID-19 Survivors to support research. They have a [list](#) of Post-COVID Care Centers (PCC) and a PCCC Best Practices [Guide](#).
- [The Center for Chronic Illness \(US\)](#): Aims to promote well-being and decrease isolation for those impacted by chronic illness through support and education. Their online support groups are professionally-facilitated and offer psychoeducational tools for coping.
- [Blooming Magnolia \(US\)](#): Mission is to empower others by providing a platform to strengthen & protect mental health and support those afflicted with Long-Covid through education and funding of therapeutic research. They have a list of support groups and resources on their website.
- [Long COVID Alliance \(US\)](#): US-based network of patient-advocates, scientists, disease experts, and drug developers who have joined together to leverage their collective knowledge and resources to educate policy makers and accelerate research to transform our understanding of post-viral illness.
- [Long COVID Kids \(UK/US/Canada\)](#): Parent & patient led advocacy & support group based in the UK.
- [Long COVID Physio \(US & UK\)](#): International peer support, education and advocacy group of Physiotherapists living with Long COVID, founded in November 2020 by Physiotherapists living with Long COVID from the UK and US.
- [Patient-Led Research Collaborative \(Global\)](#): Group of Long COVID patients working on patient-led research around the Long COVID experience.
- [CANCOV- Patient resources \(Canada\)](#): CANCOV is a research platform grounded in a prospective longitudinal 1-year cohort study of patients infected with COVID-19.
- [COVID Patient Recovery Alliance \(CPRA\) \(US\)](#): CPRA aims to bring together leaders in business, health care, research, academia, data and analytics, and patient advocacy to develop solutions that coordinate diverse data sources, inform models of care, and ensure adequate payment for long-COVID patients. Their [report](#) outlines recommendations for federal policymakers to promote recovery.
- [British Lung Foundation \(UK\)](#): UK-based charity sharing resources on navigating the NHS, breathlessness support, movement and energy support for long COVID patients.
- [Living with Long COVID \(US\)](#): COVID-19 Long-Haulers and Post-COVID Support Community.

**Note:** Previous OCSO Post COVID-19 Condition Scans can be found [here](#).