

LIVING WELL

Beyond COVID-19

BY RESPIPLUS™

A plan of action for life
A learning tool for patients and their families

Long COVID Rehabilitation and Management

This module will guide you through your recovery and enable you to find the physical and emotional strength to live life well beyond Long COVID.



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This guide is also available in PDF on our portal:

<https://chroniclungdiseases.com/en/resources/covid-19/>

Impact of COVID-19



COVID-19 has taken a huge toll on the population worldwide in terms of major illness and death.

According to the World Health Organization¹, as of July 13, 2022, there have been more than 554 million confirmed cases of COVID-19 and over 6 million deaths. In Canada, as of the same time period there have been almost 3.96 million cases and nearly 42,000.

Many countries including Canada have now seen multiple waves of COVID-19, each causing a range of reactions to the virus.

Some people just developed mild symptoms, like a cough and cold, and feeling more tired than usual while others experienced very severe symptoms including admission to the intensive care and being placed on a ventilator, unable to breathe on their own. It has been recognized that the elderly and those with existing medical conditions, are at increased risk of having a severe outcomes such as hospitalization and death.

1-<https://COVID19.who.int/>

What is Long-COVID

Once people are no longer contagious and have overcome the acute phase of COVID-19, their symptoms may persist or they may experience new symptoms. The Center for Disease Control (CDC) in the US has used the term post-acute sequelae of COVID-19. The World Health Organization (WHO) has used the term post COVID-19 condition to refer to these ongoing and lasting symptoms. Patients who develop Long COVID refer to themselves as "Long Haulers". A working definition issued by WHO in late 2021 described Long-COVID as: "a condition that 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 that last for at least 2 months and cannot be explained by an alternative diagnosis."²

Anyone can develop Long COVID, regardless of whether their initial COVID-19 infection was mild or severe. Long COVID can include many symptoms, and it affects people in various ways. The duration of Long COVID can also vary. Some people may have Long COVID for a couple of months while others continue to have it beyond one year. According to the CDC,³ common symptoms can include shortness of breath, tiredness or fatigue, post-exertional malaise, difficulty thinking or "brain fog", cough, chest pain, headache, fast-beating heart, joint or muscle pain, pins-and-needles feeling, diarrhea, sleep problems, fever, lightheadedness, rash, mood changes, change in smell or taste, and changes in menstrual period cycles. Because Long COVID is a new condition, information about it is still evolving.

The purpose of this module is to guide you through your recovery and to enable you to find the physical and emotional strength to live life well beyond COVID-19.

2-https://www.who.int/publications/i/item/WHO-2019-nCoV-Post_COVID-19_condition-Clinical_case_definition-2021.1.

3-https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/index.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2F2019-ncov%2Flong-term-effects.html

Welcome to "Living Well Beyond COVID-19"

You have survived the impact COVID-19 but now have Long COVID. In order to try and live well and improve your quality of life, it is important to take an overall approach to your health. You will need to, amongst other things, try and stay as physically active as possible and participate in a regular exercise program, so long as it is doable for you. You will need to try and eat healthy, sleep well and get enough rest, and try to reduce your smoking and intake of alcohol. Taking care of your mental health is just as important as your physical health.

This module will inform you on the following:

- What is Long COVID and its common symptoms?
- The importance of physical activity and how it helps people with Long COVID
- The importance of healthy habits in your recovery from Long COVID
 - dealing with breathlessness and cough
 - dealing with fatigue and using energy conservation principles
 - improving sleep
 - improving nutrition and digestive issues
- The importance of your mental health in your recovery from Long COVID
- Resources and support groups that you can connect with to help you in your recovery

Welcome to "Long-COVID Rehabilitation and Management"

This module is your guide to help you take steps to recover from Long COVID. Depending on how you feel, you may consider starting a regular physical activity routine to help you recover from Long COVID. Consider seeking the services of an exercise professional to help you develop an exercise routine personal to your specific ability and unique motivators.

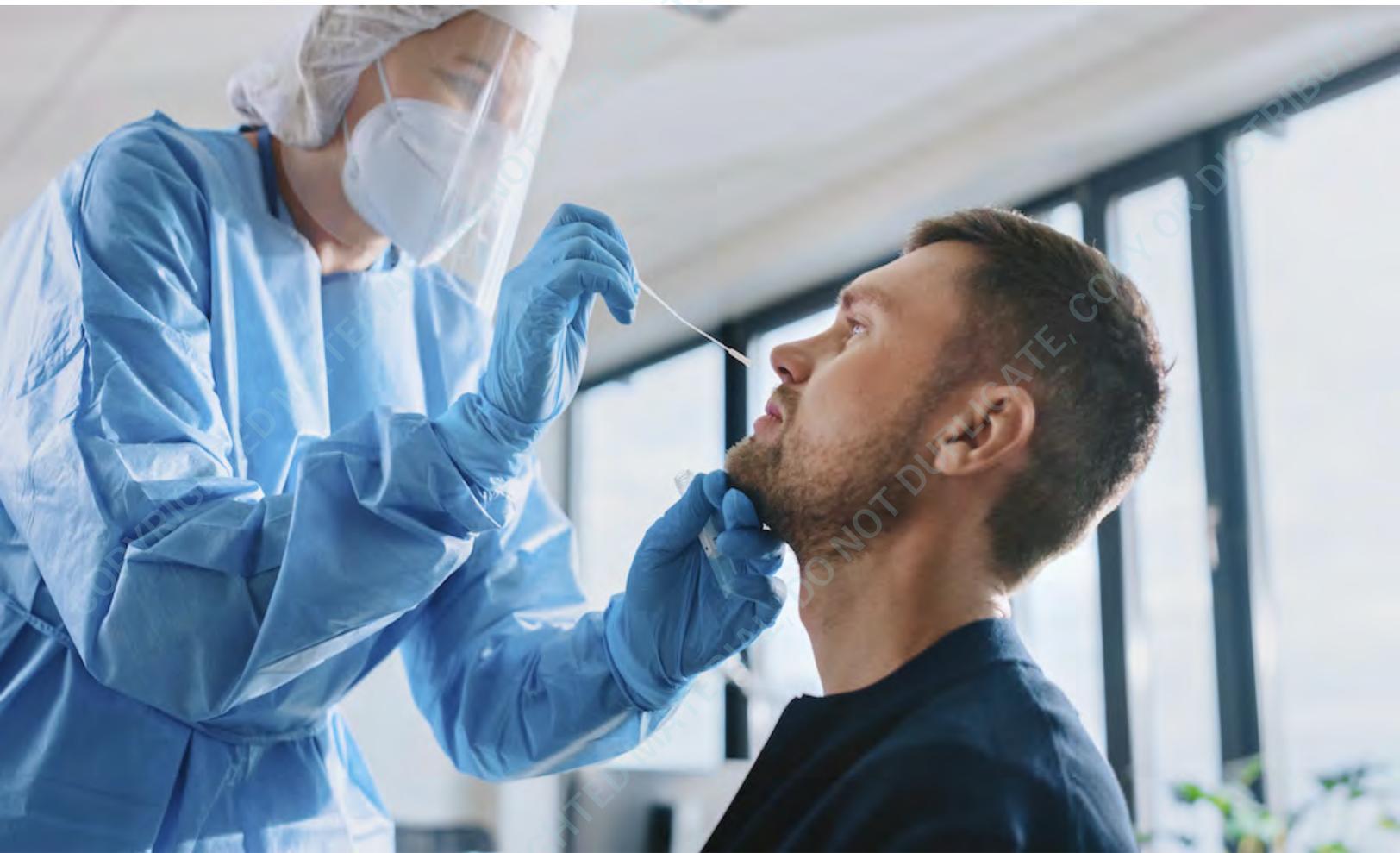
Talk to your health professional about what is right for you. Feel free to share your thoughts, feelings and concerns about your current condition with trusted family members or friends. As you forge your own road to recovery, they will form an invaluable support network, helping you put into action all the content in this module.



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Understanding Long COVID



What is Long COVID?

A number of people who have developed COVID-19 continue to experience symptoms at least 12 weeks after they were first infected with the SARS-CoV-2 virus. They are no longer contagious to others but they continue to have symptoms that can affect their daily activities.

As stated earlier, according to the WHO, post-COVID-19 condition or Long COVID occurs in individuals with a confirmed or probable case of COVID-19, where symptoms persist beyond (12 weeks) from the onset of infection with SARS-CoV2, the virus that causes COVID-19 illness, lasting for at least two months, and are not explainable by another medical diagnosis.² Because COVID-19 is a relatively new condition, unlike conditions such as asthma or chronic obstructive pulmonary disease (COPD), unanswered questions remain regarding why some people develop Long COVID after having COVID-19 while others do not.

Determining the prevalence of Long COVID is challenging. A limitation to determining prevalence is that many people did not have access to COVID-19 testing.⁵ Many individuals were at higher risk of developing COVID-19 because of the nature of their work, such as healthcare professionals or frontline workers. The percentage of people who develop Long COVID has not been determined, but the estimates range⁵ between 14% to more than 50% of those who were ill with COVID-19. One study suggests that there is a higher percentage: That study found 63% of patients (1038 of 1655) who had COVID-19 said they had fatigue and muscle weakness six months after their illness.⁶

2-https://www.who.int/publications/i/item/WHO-2019-nCoV-Post_COVID-19_condition-Clinical_case_definition-2021.1.

5- <https://www.cadth.ca/overview-post-COVID-19-condition-long-COVID>

6- <https://pubmed.ncbi.nlm.nih.gov/33428867/>

What is Long COVID?

It is important to keep in mind that research and knowledge about Long COVID is *continuously evolving*. Factors such as age, sex, and overall health, amongst others, are being explored to determine how these factors influence someone's risk of developing Long COVID. One study identified increasing age, BMI and female sex as characteristic of Long COVID. Experiencing more than five symptoms during the first week of illness was associated with Long COVID.⁷

The recovery time from Long COVID will vary between patients. This is another area that is being studied and more research will provide estimates of how many people will have Long COVID and for how long.

Unfortunately, even healthcare professionals don't have all the answers when it comes to Long COVID. Your health professional can guide you to contact a COVID centre or rehabilitation program that may have more expertise in this area.



7- <https://www.medrxiv.org/content/10.1101/2020.10.19.20214494v1>

How COVID-19 affects different areas of the body

Researchers are studying the prevalence of Long COVID. One meta-analysis, which refers to a review of several studies, concluded that 80% of patients developed at least one or more symptoms associated with Long COVID.⁸

Various systems or organs of the body have been affected by COVID-19 and they include the neurologic system (the brain), the renal system (the kidneys), the hepatic system (the liver), the gastrointestinal system (stomach), the vascular system (blood flow), the cardiac system (the heart), the endocrine system (the glands), and the skin.⁹



8- <https://doi.org/10.1038/s41598-021-95565-8> (Lopez-Leon et al. 2021)

9- <https://www.nature.com/articles/s41591-020-0968-3>

How COVID-19 affects different areas of the body

The same meta-analysis also concluded there were 55 long-term effects or symptoms of COVID-19.⁸

There are studies showing the percentage of patients whose daily lives have been impacted by Long COVID. One Canadian survey of more than 1,000 respondents conducted by patient support groups found that more than half of individuals with Long COVID had to reduce their working hours and nearly three quarters (74%) had to reduce their working hours by more than 50%.¹⁰



8- <https://doi.org/10.1038/s41598-021-95565-8> (Lopez-Leon et al. 2021)

10-<https://www.newswire.ca/news-releases/pan-canadian-survey-reveals-long-term-harm-of-covid-to-brain-health-809289269.html>

Self-assessment Questions: How has COVID-19 and Long COVID affected you?

Please try to answer the following questions, in order to provide your healthcare professional with a sense of what your recovery should look like and the elements needed to consider in order to better support you to manage your symptoms of Long COVID.

Can you describe your experience and symptoms when you first had COVID-19?

Did you have a severe case of COVID-19? Were you hospitalized?

Did you receive a diagnosis of Long COVID? If so, when?

What symptoms of Long COVID are you experiencing? For example: breathlessness, loss of mobility or poor balance, muscle weakness, brain fog, pain or sensitivity, loss of feeling or sensation, any other?

Self-assessment Questions: How has COVID-19 and Long COVID affected you?

How is Long COVID affecting your daily functioning? How have your symptoms affected your daily activities or ability to work or pursue your studies?

What is your biggest concern about living with Long COVID?

- A number of health professionals may need to help you on your journey of recovery from Long COVID. For example, it may be that having Long COVID is causing you mental distress. If it is, you may consider turning to a psychologist to address the mental distress that are you are experiencing because of your Long COVID symptoms.
- Having Long COVID symptoms may be causing you stress in your home life with your family.
- You may consider turning to a social worker to help develop strategies to help decrease your stress in your home life.

The importance of Physical Activity and Rehabilitation



How exercise and physical activity will help you recover

If you have ever been in the hospital for a few days, you will have experienced a loss in muscle strength and loss in your overall fitness. You may become short of breath with activity and experience fatigue more easily. Even if you were not hospitalized and stayed home when you contracted COVID-19, you may have experienced deconditioning. This means you may have lost muscle strength and cardiovascular fitness.

This is likely the case if you become hospitalized with COVID-19. You may be short of breath when you need to exert yourself and find that you tire easily. Generally speaking, the longer your stay in hospital, the bigger the setback in your daily functioning. Which means, if patients have a severe case of COVID-19 and end up in the intensive care unit, they will likely have a longer road to recovery than patients who did not have to go to the intensive care unit or patients who did not have to be hospitalized at all.

Whatever your experience was when you were acutely ill with COVID-19, and whatever your current experience is with Long COVID, exercise and physical activity will help you.



How exercise and physical activity will help you recover

There are many benefits to exercise. These include physical benefits such as:

- improving your endurance and overall energy,
- decreasing your breathlessness,
- increasing your muscle strength and
- improving your balance.

Exercise and physical activity also have psychological benefits such as:

- decreasing your stress,
- improving your mood and overall mental health, and
- improving sleep.



The importance of Physical Activity and Rehabilitation

Even a long time after having suffered from COVID-19, some people will be experiencing symptoms such as breathlessness and have different difficulties in carrying out their day-to-day lives. The medical community in Canada, in particular the Canadian Thoracic Society, recognizes that people living with Long COVID may be in need of rehabilitation. **The goal of rehabilitation, in whatever form it takes, is to help you recover and live your life to the fullest.**¹²

Who will benefit from rehabilitation

Any patient that is physically deconditioned, which means you have to put more effort than normal, to perform daily living activities, will likely benefit from participating in a rehabilitation program. Some exercise programs may need to be more structured. It will depend on you as an individual with Long COVID and what symptoms you are having and how severe the symptoms are.

12-<https://cts-sct.ca/wp-content/uploads/2021/11/Published-Article-COVID-19-Implications-Pulm-Rehab.pdf>

The importance of Physical Activity and Rehabilitation

Eligibility

Several distinct groups of patients will likely benefit from a rehabilitation program after having COVID-19.

- Patients who were in the intensive care unit and may or may not have been on a ventilator to help them breathe.
- Some patients who had an extended stay in hospital and who may have received additional oxygen to help them breathe, as well as some patients who experienced respiratory symptoms when they were in hospital.
- Some patients who did not need to stay in hospital but who continued to have symptoms after they were no longer infectious, with those symptoms likely being due to COVID-19.

Your healthcare professional will evaluate your health status, and together with you, they will define what your recovery needs are, as well as what kind of exercise type and intensity is right for you.

If you have a condition like postural tachycardia syndrome (PoTS)* you may be concerned about starting an exercise program.

*Postural orthostatic tachycardia syndrome (PoTS) is a condition that affects blood flow. It can cause the development of symptoms, such as lightheadedness, fainting, increase in heart rate, when you stand up from a lying down position.⁴

4-<https://my.clevelandclinic.org/health/diseases/16560-postural-orthostatic-tachycardia-syndrome-pots>

Access to a formal rehabilitation program

A good starting point is to check with your healthcare professional as to what supportive services are available in your community to help you in your recovery from Long COVID. You may also want to contact support groups like the [COVID Long Haulers Support Group Canada](https://www.covidlonghaulcanada.com/)¹⁵ to find out about healthcare resources in your neighbourhood.

Access to rehabilitation programs will vary across Canada, but there are efforts to make sure that you get the rehabilitation that you need. The names of the different rehabilitation programs for patients with Long COVID may be different depending on where you live in Canada:

- In Alberta, for example, a rehabilitation program designed for people with Long COVID is referred to as Long COVID respiratory support.
- Pulmonary rehabilitation has been shown to be an effective way to improving health status in people with chronic respiratory conditions by decreasing shortness of breath and fatigue and improving exercise tolerance and has become a standard of care for many patients.¹³

Your healthcare team will work with you to address your Rehabilitation access needs:

- If you can't get to your rehabilitation appointment, there may be transportation options that are available to you.
- If language is a barrier, there may be translation services for patients so they can understand the content of the rehabilitation program.
- Another option may be that you can access the rehabilitation program virtually through your mobile phone, tablet, laptop or your desktop computer so you do not have to worry about travelling to participate in your rehabilitation program.

13- Am J Respir Crit Care Med. 2013 Feb 15;187(4):347-65(<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3869834/#b3-copd-9-027>)

15 - <https://www.covidlonghaulcanada.com/>

Assessment

Your healthcare professional will first conduct an assessment to see what your rehabilitation needs are depending on your symptoms, how severe your symptoms are, and what your goals are in terms of what you want to be able to do in your daily life.

What your assessment will likely involve:

- Your level of dyspnea will be assessed, which is the medical term for shortness of breath.
- Your capacity to exercise will be measured: you will be asked to perform tests such as the 6-minute walk test and the 1-minute sit-to-stand test.
- You may be asked to do balance tests.
- You may be asked to walk three or four meters so that a health professional can assess how well you walk on your own.
- You will likely be asked to perform a chair stand test.
- You may be assessed for PoTS because having this condition might restrict your ability to exercise.



General recommendations

An exercise professional like a kinesiologist or physiotherapist or qualified trainer can help you to develop an exercise program that will suit your needs. You will want to determine when and where you exercise, for how long and for how often, and what type of exercise you will perform. It may be that you exercise in your home, or at a rehabilitation centre, or at a gym. You may want to exercise outdoors if the weather is good and climate is comfortable.

Here are some general tips when you start off exercising:

- **Start with a warm-up.** This prepares your body for exercise. It should take about 5 minutes and you should be a little out of breath after five minutes.
- **Dress comfortably.** That may mean wearing loose clothing. Dress so that you can move your body easily.
- **Drink plenty of water when you exercise.** Even if you are doing exercise like swimming or aqua fitness where you would not sweat, you need to drink plenty of water.

There are also guidelines for exercise, like the Canadian 24-Hour Movement Guidelines for Adults, that have been developed by the Canadian Society for Exercise Physiology. The guidelines suggest that you should try to add movement throughout your day. Ideally, you should aim to do at least 150 minutes (five times per week for 30 minutes each time) per week of moderate-to-vigorous physical activity. As a patient with Long COVID, do not put pressure on yourself to achieve 150 minutes of activity per week. Think of it as a goal that you can work towards.

For more information about getting active, you can visit [ParticipACTION.com](https://www.ParticipACTION.com).

Health and Safety while exercising

Depending on how severe your symptoms of Long COVID are and depending on whether you were hospitalized when you had COVID-19 and needed extra oxygen, a kinesiologist or exercise physiologist may want you to wear an oximeter.

This device is a way of measuring the oxygen level in your blood (referred to medically as oxygen saturation) and how well oxygen is being sent to various parts of your body such as your arms and legs.

A clip-like device called a probe is placed on a body part, such as a finger or ear lobe. The probe uses light to measure how much oxygen is in the blood. This information helps your healthcare professional decide if oxygen is required. The oximeter should be placed so the healthcare professional can see it.



Health and Safety while exercising

Staying safe when you exercise

- Avoid exercising outdoors when the weather is very hot and humid. If you can access an air-conditioned location when it is very hot and humid, you can exercise in that location.
- Drink a lot of water if you exercise on very warm days.
- Wear comfortable shoes and clothing.
- Make sure you have enough space and a clear area when you exercise.
- Exercise in an area that is well-ventilated and has good air exchange.
- If you have poor balance or challenges moving around on your own and need assistance, it would be a good idea to have someone else with you while you are exercising.
- Walk as fast and far as you can while respecting your own limits.
- Do not hold your breath and stop as often as you need to.
- If you feel light-headed or have chest pain, sit down right away and practice pursed-lip breathing (you will learn about this in the module).
- You need to tell your health professional about any side effects you may be having from exercise like unusual sweating or light-headedness or chest pain.

Contraindications to exercise

Your health professional will help you determine if you have any specific contraindications to exercising. Your health professional who is working with you will realize that you need to progress slowly and are in a period of recovery with an aim to get back to normal.

Strategies to better manage the impact of Long COVID



Dealing with breathlessness: The Pursed-lip Breathing technique

Pursed-lip breathing is one technique that you can use to help you feel less short of breath on a regular basis.

Have you heard about the pursed-lip breathing technique? If yes, are you using it? How and when?

Goal:

With this technique, you breathe out slowly, which allows you to exhale more air.

Benefits of this technique:

- Reduces breathing frequency and shortness of breath.
- Helps you return to your normal breathing pattern after exercise or effort.
- Improves your ability to perform different activities.
- Increases your sense of control over your own breathing.

Points to remember:

- The focus should be on expiration.
- Expiration should be longer than inspiration, but not forced.
- First master this breathing technique while at rest. Then you will be able to use it when you are performing activities that require effort.

Dealing with breathlessness: The Pursed-lip Breathing technique

Technique used at rest

- Inhale slowly through your nose until you feel that your lungs are filled with air, without forcing.
- Purse your lips as you would if you were whistling or about to kiss someone.
- Exhale slowly while keeping your lips pursed. Make sure to take longer to breathe out than you would to breathe in. Remember to keep your lips pursed.
- Do not force your lungs to empty.

Technique used while walking

- Inhale 1...2...
- Exhale 1...2...3...4...

Technique used while carrying parcels

- Before lifting a heavy object, inhale through the nose.
- Bend down and pick up the object while exhaling through pursed lips.
- Use pursed-lip breathing while carrying the object. Repeat the process when putting the object down.
- Always bend at the knees, keeping your back straight.

Consult with your doctor and healthcare professional if you have difficulties in dealing with your breathing. They can properly assess the situation and build a treatment plan that works for you.

Dealing with cough

Cough is a symptom of Long COVID that many people experience. Depending on the severity of symptoms, you may have a sense of mucous in your throat and feel the need to clear your throat frequently.

If you had been hospitalized with COVID-19 and had a breathing tube inserted to help you breathe, you may find that your voice is hoarse. You may also find that your throat and upper airway are more sensitive to the environment than before you had COVID-19.

You may find that you are sensitive to various scents in the air as well, such as perfumes or fragranced products. Being exposed to these scents can trigger a cough, sensation of throat tightness, or restriction of breathing.

Having a persistent hacking cough can be exhausting and get in the way of your daily functioning. There is a proper way of coughing, just as there is a proper way of breathing.

Tips for dealing with persistent cough:

- Do not smoke.
- Try breathing through your nose instead of through your mouth.
- Try sucking on low-sugar boiled sweets.
- If you are coughing at night while in bed, try lying on your side or use pillows to prop yourself up.

- If you are experiencing a persistent cough, you can try the "stop cough technique". In this technique, if you feel the urge to cough, close your mouth and cover it with your hand.
- At the same time, make yourself swallow, stop breathing, and pause.
- When you start to breathe again, breathe in and out softly through your nose.

Dealing with Fatigue: Energy Conservation

Staying active and keeping up your routine is important when you have Long COVID. Learning how to manage your fatigue whilst performing your day-to-day activities will help you save energy and delay the onset of fatigue.

Goal:

You should make a goal of performing your daily activities more efficiently to try and avoid or limit fatigue and shortness of breath.

Benefits of energy conservation and fatigue management:

- Minimize your fatigue and shortness of breath.
- Better perform daily activities according to your level of energy.
- Decrease frustration and irritability.

Points to remember:

- Try to get a sense of the times of the day when you have the least and most amount of energy.
- Do not forget to do activities that help you relax and recharge.
- Avoid rushing, even if you are the type of person who finds it hard to slow down. Do not try to do everything at once or too many things at once.
- Be aware of your body position and your breathing when performing an activity.
- Think about standing straight and putting your shoulders back and pushing your chest out. This type of posture will help you to breathe more easily.



Energy conservation principles

For each energy conservation principle, provide some examples of how you would apply some of these principles when doing some of your daily activities.

- **Prioritizing your activities**

- Evaluate what you have to do in a given day versus what you would like or love to do.
- Do not perform activities that are not essential.

- **Planning your schedule**

- Stay active within your limits.
- Plan a realistic schedule for the day, week or month.
- Try to schedule the activities that require more energy (e.g., grocery shopping, medical appointments, vacuuming), at the time of day you have the most energy.



Energy conservation principles

- **Pacing yourself**

- Understand your limits and respect them.
- Slow down your rhythm: a slower and regular rhythm uses up less energy.
- Slow down when you speak, laugh, eat or cough, since these actions can interrupt your regular breathing rhythm and cause you shortness of breath.
- Alternate heavy and light tasks, e.g., don't go grocery shopping the same day you're vacuuming.
- Include relaxation breaks in your schedule.

- **Positioning your body**

- Be aware of what movements (e.g., bending or reaching) cause you more shortness of breath or fatigue.
- See how you can organize the storage spaces in your home to reduce the need for reaching and bending.
- Avoid carrying heavy objects. As an alternative, try pushing, pulling or sliding objects. You may find that less demanding.
- When you must carry something heavy, hold it as close to your body as possible.
- If you feel tired, perform most of your activities while sitting (you will use less energy sitting than standing).

Energy conservation principles

- **Pursed-lip breathing technique**

- Use pursed-lip breathing when doing physical activities.
- Exhale when an effort is required (e.g., when opening a heavy door: inhale, then exhale as you pull the door open).

- **Positive attitude**

- Try to be patient and tolerant towards yourself and your family and friends.
- Keep your sense of humour.
- Visualize yourself as a person who makes the most of what they have and the things that they can do, rather than focusing on what you don't have and the things that you can't do.
- You will feel more empowered by putting yourself in control of the demands you place on yourself and making sure that those demands are in keeping with your capabilities.

Remember: Talk to your doctor and healthcare professional if you feel additional help is needed to deal with fatigue. An occupational therapist may also be able to help you.

Coping with Post-Exertional Malaise

Whilst there is a common saying, that if there is no pain, then there is no gain, this saying does not apply when it comes to recovering from Long COVID. You may perform what you think is not a strenuous activity, like household chores, and then feel exhausted, or even go out for an evening to socialize and find your energy is depleted. This is referred to as post-exertional malaise. You want to avoid getting into a vicious cycle of "pushing and crashing". This refers to doing too much at once "pushing" and then finding that you have symptoms that may last for days or even weeks, what is referred to as "crashing".

Here are some techniques you can employ to avoid the "**push and crash**" cycle of **Post-Exertional Malaise**:

- **Pace your activities:** If you push yourself too much, it might be more than your body can endure. As a consequence, you may have more severe symptoms later.
- **Think of your energy as contained in an envelope.** There is only so much energy in that envelope to expend. By paying attention to how much energy you are taking out of the envelope, you can place limits on physical activities as well as mental activities and socializing. As a result, you can gain better control of your symptoms and have more consistency and stability on a day-to-day basis.
- You may want to consider **tracking your activities** with forms, logs, worksheets, or wearable technology. Tracking your activities will help you to see adapt your daily life so you can better control your symptoms of Long COVID.

If you are working with a kinesiologist or exercise physiologist on a tailored exercise program for you, they will likely ask you questions to see if you have experienced post-exertional malaise. You may be asked if you experienced a worsening of your fatigue/energy levels after your last exercise session and how long the worsening of your symptoms lasted.

Coping with brain fog

Brain fog is one of the common symptoms that individuals with Long COVID have. It is not a clinical or medical term. When people complain of brain fog, they describe their thinking as unclear and fuzzy, not sharp. You may experience this from time to time when you have had an illness like the flu or are jet-lagged perhaps did not get enough sleep or took a medication like an anti-histamine which made you drowsy. In those cases, you would wait to get over the flu, or your jetlag, or for the effect of the medication to wear off. You would be able to think clearly again.

If you have brain fog all the time, you may not be able to think clearly again and get back to normal. You may not be able to hold your attention or focus for very long. If you are experiencing brain fog that will not go away, you should see a healthcare professional, such as your family physician if you have one, and tell them about your symptoms. You may have other neurologic symptoms such as weakness, numbness, tingling, loss of smell or taste.

Here are some strategies to help you cope with brain fog:¹¹

Try doing aerobic exercise. The general guideline is to exercise 30 minutes per day for five times per week. If you are just starting, it is better to start slowly and try several minutes a day of aerobic exercise a few times per week. Follow the indications of your healthcare team.

Focus on eating a healthy diet that is rich in fruits and vegetables.



11-<https://www.health.harvard.edu/blog/what-is-covid-19-brain-fog-and-how-can-you-clear-it-2021030822076>

Coping with brain fog

Sleeping well. Sleep is a time when your brain and body are healing from the day. Sleep restores your brain and body so they can function well during the day.

Participate in social activities. Many of us like to socialize and spend time with other people. We like doing this because it makes us smile and laugh and improve our mood. Participating in social activities and interacting in person with others helps our thinking and memory as well. You might consider doing things like taking a class to try to learn a new language or participate in a social club such as card playing or joining a book club.

Engage in cognitive pursuits. You might want to consider practicing activities that help stimulate your brain, your thinking, and your memory, such as doing crossword puzzles or playing chess or doing jigsaw puzzles. You might want to try relaxing activities like meditation and mindfulness to quiet your mind. Listening to relaxing music may also be helpful.

Keeping a positive attitude. Being optimistic and keeping a positive attitude is also helpful in coping with your brain fog. Some research has suggested that an individual's reaction time, memory, and executive functioning are negatively affected if they have a condition like depression. Trying to have a positive outlook on life and see things in a positive light will help you to cope with your brain fog. Being in a negative mindset may only make your brain fog worse.

Talk with your doctor to see if there are any potential treatments that can be prescribed to help you with your symptoms.

You might also want to see a mental health professional to assist in you trying to reframe your thinking to view things in a more positive light.

Getting a good night's sleep

Getting a good night's sleep is very important if you have developed Long COVID. Some people may find that symptoms they experience, such as coughing, breathing difficulties, or digestive issues, interrupt their sleep. One of the keys to good sleep hygiene is consistency in your sleep. As a result of not getting enough sleep, people with Long COVID, many of whom already have fatigue as a symptom of their condition, may feel they have even more fatigue during the day without a good night's rest and are not able to function at their best.

How many hours of sleep do you get a night, on average?

Is there anything you do to help make sure you get a good night's sleep?

Do you feel rested after sleeping?

Do you find your Long COVID symptoms are worse when you don't get a good night's sleep?

Putting sleep problems to rest

Goal:

To get a good, restful sleep

Benefits of sleep:

- Restores daytime energy
- Improves the ability to think clearly
- Reduces anxiety
- Reduces depression
- Improves mood

Points to remember:

- Everyone has trouble sleeping at one time or another.
- There is no "correct" amount of sleep per night.
- Every person sleeps for a period of time that is healthy for them. The question of whether or not you are getting enough sleep depends on if you feel rested and can function effectively during the day.
- Some people have chronic challenges with sleeping, such as people who are shift workers who have work schedules that change week to week.
- Since the pandemic started, many people have complained about having trouble falling asleep because the pandemic has taken them out of their normal, daily routines. Remember that you are not alone in your difficulty to fall asleep.



Do not force yourself to sleep

This will only make you more frustrated. It is better to get up than stay in bed and toss and turn and not fall asleep. Try reading in bed. Avoid using electronic devices like your phone or a tablet when you are in bed. Many sleep experts caution that the light given off from these devices can stimulate your brain, making it harder for you to fall asleep. Remember also to keep the room where you sleep cool and dark. You can also use one of the relaxation techniques listed later on this module.

If shortness of breath is keeping you awake, take your medications as prescribed and sleep in a semi-sitting position, using pillows to position your upper body at a thirty-degree angle. This will help you with your breathing so shortness of breath will not be something that will keep you awake.

If coughing is keeping you awake, use your controlled cough technique.

- If you are still having trouble sleeping and feel tired during the day, talk to a health professional like your family doctor. Your family doctor or another health professional can help you find out what may be keeping you from sleeping and treat the problem.
- It may be that things like your worries and anxiety or even low-level depression are keeping you awake at night. Your family doctor may refer you to a psychologist or a therapist to learn skills to help you fall asleep at night.



Nutrition and digestive issues

The link between Long COVID and your diet.

Long COVID can have consequences on your everyday life. It has come to be associated with symptoms such as:

- Fatigue
- Loss of appetite
- Loss of sense of taste
- Loss of sense of smell
- Digestive problems (for example, abdominal bloating or constipation or stomach pain)
- Cough
- Shortness of breath

Symptoms such as these may cause you difficulties in sticking to a healthy diet.

In your case, are there symptoms that are causing you difficulties with maintaining a good nutrition?

Various symptoms and situations may adversely affect you when it comes time to eat, to prepare meals or to shop for groceries. Your symptoms of Long COVID can contribute to bad eating habits and eventually to poor nutrition.

In the following pages you will find information and tips to better deal with challenges of maintaining good nutrition.

What keeps you from eating well?

Has having Long COVID affected your weight? Have you lost or gained weight without wanting to?

Do you have any difficulties to shop for food or prepare your meals? Please explain.

Are you having difficulties that keep you from eating well (loss of sense of smell, loss of taste, fatigue and lack of energy, digestive issues like abdominal bloating, and others such as brain fog)? Please explain.



Strategies to deal with food preparation and digestive issues

Within the following examples, identify the challenges that correspond to your current situation. Try to apply the proposed recommendations to address the challenges in your life that may be obstacles to good nutrition.

Check if this problem corresponds to your situation	Select recommendations that may be useful
<p>Difficulties in preparing meals</p> <p><input type="checkbox"/></p>	<ul style="list-style-type: none"> • Plan for meal preparation in large quantities and freeze leftovers • Buy prepared or frozen meals as an option • Enquire if you could gain access to services such as [Meals on Wheels] • Consider using grocery delivery services that deliver all the ingredients and recipes to make specific meals • Rest before preparing your meals if you find it takes a lot of energy to prepare your meals <hr/> <hr/>
<p>Difficulties in grocery shopping</p> <p><input type="checkbox"/></p>	<ul style="list-style-type: none"> • See if your grocery store offers delivery services • If you are having financial issues, do not hesitate to reach out for help. A healthcare provider or community leader may help you find solutions to your financial issues such as using coupons or using services of community kitchens • Try to be well rested before going to grocery shop so you have energy and can think clearly <hr/> <hr/>

What keeps you from eating well?

Check if this problem corresponds to your situation	Select recommendations that may be useful
<p>Breathlessness</p> <p><input type="checkbox"/></p>	<ul style="list-style-type: none"> • Try to be rested before you start to make your meals • Eat slowly • Rest before preparing your meals if you find it takes a lot of energy to prepare your meals <hr/> <hr/>
<p>Early satiety (feeling full after a few bites) and anorexia (loss or important decline in appetite)</p> <p><input type="checkbox"/></p>	<ul style="list-style-type: none"> • Eat foods that are energy rich (examples such as whole milk, cream soups, nuts, nutritional supplements) • Reduce the amount of liquid ingested with meals. Drink 30 to 60 minutes before or after your meal to leave room for high energy foods. • Eat five to six small meals instead of three large ones. • Eat food that you like • Remember to eat for your health, even though you may enjoy it less if you have had a loss of taste and smell, something that patients with Long COVID may experience • If you find that your food has an after taste, try to eat it cold. In this way, the after taste will be less pronounced. <hr/> <hr/>

What keeps you from eating well?

Check if this problem corresponds to your situation	Select recommendations that may be useful
<p>Bloating (sensation of distention due to gas)</p> <p><input type="checkbox"/></p>	<ul style="list-style-type: none"> • Eat slowly so you avoid swallowing air • Avoid using a straw to drink • Avoiding chewing gum and drinking carbonated drinks • Avoid eating large quantities of foods that cause a lot of gas like cabbage, cauliflower, broccoli, onions, and melons • Ask your doctor to verify the presence of any food intolerance you may have (lactose, gluten) <hr/> <hr/>
<p>Constipation</p> <p><input type="checkbox"/></p>	<ul style="list-style-type: none"> • Gradually increase your intake of fiber, such as whole grains, legumes, fruits such as prunes, vegetables, etc. • If you are eating a small quantity of food, you may consider taking fiber supplements. You can talk to a health professional like your family physician or a pharmacist about fiber supplements • Drink enough water. Target to drink 6 to 8 glasses of water per day if you do not have any medical restrictions • Eat meals at regular hours each day to improve your intestinal regularity • Stay active to improve your intestinal regularity. <hr/> <hr/>

If any of these problems persist or if you are experiencing unwanted weight loss, it is important to be referred to a nutritionist for a complete nutritional evaluation. A nutritionist will be your best ally to finding solution for you. If you are having problems swallowing, let your health professional know this.

Dealing with stress, anxiety and depression

Patients with Long COVID may experience post-traumatic stress because of the ordeal they had when they were acutely ill with COVID-19, such as being hospitalized or in the intensive care unit.

If you are having mental health issues as a survivor of COVID-19, you are not alone. A very recent McMaster University survey of 827 respondents who had had acute infection with COVID-19 found that anxiety attacks and mood swings were common in respondents.

If you experience post-traumatic stress, some techniques that are outlined in this section of this module may be helpful to you. You also may consider seeking the help of a psychologist or therapist, in addition to trying these techniques, to help you cope with anxiety and/or post-traumatic stress.

The federal government has produced an app called **PTSD Coach Canada**¹⁶, which provides self-help tools to deal with post-traumatic stress and can be downloaded to a mobile phone.

Depression is another mental health condition that patients with Long COVID may experience. Some of the techniques described in this module, such as visualization, positive thinking, and negative thought stop thinking, may help you to feel better and less depressed. A federal government resource is a website called **Wellness Together Canada**¹⁷, that provides information on how to access mental health support as well as a way to text or phone to reach out if you find you are in crisis.

You can also visit the website of the **Canadian Mental Health Association**¹⁸ and find a local chapter of the association. They will direct you to resources. There are options for counselling that are in-person or online that are available at no cost. If you have private insurance or can afford to pay out-of-pocket for a psychologist or therapist, you can explore those options.

16-<https://www.veterans.gc.ca/eng/resources/stay-connected/mobile-app/ptsd-coach-canada>

17-<https://www.wellnesstogether.ca/en-CA>

18- <https://cmha.ca>

Identifying stressors in your life

Living Well with Long COVID means knowing what kind of things trigger your anxiety, and determine how you respond to those triggers. Figuring out how to better respond to them will help to reduce your anxiety and better cope with stress. If you have shortness of breath as a symptom of Long COVID, by learning to relax and reduce your anxiety, you will likely be able to breathe more easily and not become short of breath as quickly.

Here are some examples of common stressors for people, and some are specific to individuals with Long COVID.

Personal:

- Personal illness/handicap
- Change in self-esteem
- Change in financial status
- Change in habits (sleep, nutrition, exercise, smoking)
- Change in ability to function on a daily basis
- Lack of acceptance by others about their medical condition

Work, daily activities and environment:

- Loss of job, disability leave, retirement
- Moving to a new home or apartment

Identifying stressors in your life

Family and social network:

- Separation/divorce
- Sexual difficulties
- Illness or death of spouse, family member or close friend
- Conflicts with family members or friends

What about you? Are you experiencing stress, anxiety or depression feelings as result of Long COVID?

What is your biggest concern about living with Long COVID?



Relaxation Techniques

What do you do to relax?

What do you think relaxation can do for you?

Goal:

To relax your body and quiet your mind

Benefits

- Help you feel more in control of your emotions
- Slow down your breathing
- Decrease muscle tension
- Reduce stress and anxiety

Deep breathing "diaphragmatic breathing" technique:

You will be more relaxed if you close your eyes and think about a quiet place or the word "calm" or another word that makes you feel calm and brings you stillness.

1. Put one hand on your abdomen.
2. Breathe in deeply.
3. Feel your abdomen inflate. Push your abdomen out as much as possible when you are inhaling. This will help your lungs fill up with air.
4. Exhale through your mouth while keeping your lips pursed (as if you were about to whistle).
5. Feel your abdomen returning to its normal position.
6. Wait after each exhalation until you are ready to take another deep breath.
7. After a few times, you will find your own rhythm. For example: one deep breath for 5 normal breaths.

If you start feeling dizzy, take a few normal breaths before starting again.

Mental Images (Visualization)

People can picture different images. One way to think of them is as "mental movies" running through your mind. These images can be of persons, places, things or accomplishments and they can be positive or negative. For example, it is common for people who suffer from chronic illnesses to be preoccupied with thoughts of how they used to be, how things used to be in their lives, and focus on everything that they have lost. It is easy for them to view things negatively and not focus on the things in their lives that are positive.

Visualization Techniques

Now create your own positive image using a visualization technique called positive thinking. In this technique, you focus your attention on a positive mental image.

Think of what you already have, what you have the power to improve in your life, and what would make you happier.

Describe your image.

Mental Images (Visualization)

Positive Thinking

1. Concentrate on a positive image.
2. Begin to relax.
3. Use all your senses (i.e., sight, sound, touch, taste and smell) as best as possible to make your image seem more real. For some patients with Long COVID, this may be challenging if they don't have all their senses working well. If are you using sight, if you are visualizing yourself on a cruise, see the clear blue sky, the sparkling water and the wonderful scenery.
4. End this visualization exercise by retaining your image.
5. Do these visualization exercises once daily.



Dealing with negative thoughts

It is sometimes easier to focus on the negative things in your life, on what is wrong in your life. You will need to develop more awareness, so you can rapidly recognize when you are dwelling on something negative (this is also called ruminating). Here is a technique to help you deal with these thoughts:

Negative Thought Stopping Technique

1. Imagine a big stop sign is in front of you and tell yourself to "Stop!"
2. Switch the negative image to something pleasant and relaxing.
3. Repeat the steps as needed until the negative thoughts go away.

Other suggestions:

Try not to compare your life to the lives of others. The lives of others may look happy and fulfilling but they may also be experiencing difficulties. You may want to consider limiting your use of social media if you find you are comparing your life to the lives of others and it is negatively affecting your view of your own life. If you find that your use of social media is helping you feel connected to others and is positively affecting your outlook, then you can consider continuing to use it.

As you can expect, it is best to focus on being appreciative for the good things in your life. It can take some effort at the beginning, but when done on a regular basis, it can become a new way to look at your life.

Remember: talk with your doctor and healthcare professional if you feel additional help is needed to deal with your stress, anxiety or any negative thoughts.

What about alcohol, smoking, vaping and using cannabis?

Although the use of stimulants is common, they need to be considered carefully by someone living with Long COVID as they can have serious effects on physical and mental well-being.

Alcohol

It may feel that things like consuming alcohol may help you relax, but alcohol can have the opposite effect if you consume too much. If you are going to consume alcohol, it is best to practice moderation. Try not to overly depend on alcohol to help you relax or reduce your anxiety or depression.

Smoking

If you are a smoker, it is best to avoid, or quit smoking if you have Long COVID. Smoking can negatively affect your recovery. If you are experiencing symptoms like shortness of breath or fatigue, smoking can worsen those symptoms.

Cannabis

As cannabis has been legal in Canada for more than three years, Canadians are free to use cannabis recreationally. However, smoking cannabis may have similar deleterious consequences as smoking cigarettes, as it contains toxic and carcinogenic substances. Cannabis smoking is related to a greater incidence of chronic cough and production of phlegm.¹⁴

Vaping

Vaping has been associated with severe lung and pulmonary illnesses, particularly when using products purchased on the illegal market.

You may want to discuss with your healthcare team how to safely consume cannabis, alcohol or tobacco products, if this is your decision. Remember that some of these products may interact with other medications. You may also want to learn more about the use of cannabis for medical purposes and if this is appropriate for you.

14-https://www.ccsa.ca/sites/default/files/2020-04/CCSA-COVID-19-Cannabis-Smoking-and-Vaping-Report-2020-en_1.pdf

Improving your outlook and dealing with acceptance

It is unknown which patients will have to manage with Long COVID and for how long. If you have been suffering with Long COVID for a prolonged period, you have seen the need to recognize and acknowledge the limits of what you can currently do. For example, if you used to be a very active person, you may have had to scale back your plans.

You may have feelings of grief and frustration, and you may mourn the loss of your life as it used to be prior to having COVID-19 and Long COVID. However, you will still be able to enjoy life. You are now finding ways to adapt to a new normal and give yourself permission to have bad days as well as good days.

- Ask your healthcare team to help you finding dedicated Long COVID resources in your area, or patients communities that can support you in your journey.
- You can also discuss with them the need to have additional services such as psychologist, social worker or counselling help.



In summary: Keeping a healthy lifestyle in the long term

Living a healthy lifestyle, including having a healthy diet, exercising regularly, keeping a smoke-free environment and moving to action are habits that will help you regain your energy and have a positive outlook in life. However, you must take steps to make positive changes and make sure you have the self-discipline to maintain them.

Feel free to go back and review any areas in this workbook that you want to spend more time on. Continue to work toward a healthy lifestyle. This will further benefit your quality of life.

Remember: You have a lot of power in your hands to improve your life. Invite your friends and family to join you and implement new healthy habits. Your healthcare team may help you find the needed inspiration by putting you in contact with the right organizations and/or with other people that have succeeded in this journey.



Let us hear the story of "Louise", 34 years old

As an orderly, I had to take care of several patients with COVID. During my first contact with an infected patient, I unfortunately contracted it.

I was very sick. For 12 days I could barely take care of my children and myself. Fortunately, we were well taken care of.

Once the infection passed, I was extremely weak and tired. My doctor had to postpone my return to work. Little by little, I was getting stronger, but unfortunately, some things didn't seem to be getting better. I was in a constant mental fog. I was having trouble doing the hobbies I used to do (puzzles, knitting). I also had trouble doing mental calculations and expressing myself. I would forget words and mix up words.

The slightest effort would make my heart race just folding the laundry or emptying my dishwasher. Walking up the stairs became a real exercise. I had to rest between each chore. Even though I wanted to get back to work, I couldn't.

After four months off work, my doctor recommended a gradual return to work. At first, I worked two days a week. After each shift, I felt sick. I was suffering from post-exertional malaise. My glands were swollen, my throat was sore, my heart was pounding, and I was exhausted.

To get through it, I had to learn to listen to my body and give myself more rest periods. For example, after each day of work, I tried to get as much rest as possible by cooking simple, quick meals and leaving the household chores that could wait. The next day, when the kids were at school, I would take a nap before picking them up and again, only the essential household chores were done. When my energy returned, I did a little more, taking several rest periods between each task. Gradually, I managed to increase my work days until I was back to full time. It was a long process but by listening to my body and following a slower but constant pace, I got there.

Without really knowing why or how, my condition has slowly improved and now I can say that I am better. At times, I still have shortness of breath, palpitations, and mental fog, but it's not as bad as it was at the beginning. Learning to listen to yourself and respect your limits is the key to success!

Without really knowing why or how, my condition has slowly improved and now I can say that I am better. At times, I still have shortness of breath, palpitations, and mental fog, but it's not as bad as it was at the beginning. Learning to listen to yourself and respect your limits is the key to success!



Now, let's test your confidence level

On a scale of 1 to 10, circle the number that best represents the confidence that you have in your ability to apply the strategies and techniques taught in this module.

1. To control your reactions when facing stressful situations and use the relaxation techniques taught in this module?

1 2 3 4 5 6 7 8 9 10
not at all confident very confident

2. To use the breathing techniques taught in this module?

1 2 3 4 5 6 7 8 9 10
not at all confident very confident

3. To use the energy conservation principles to help with fatigue, cope with brain fog and prevent post-exertional malaise?

1 2 3 4 5 6 7 8 9 10
not at all confident very confident

4. To help you deal with digestive issues and improve your nutrition?

1 2 3 4 5 6 7 8 9 10
not at all confident very confident

5. To help you cope with sleeping issues you might be experiencing?

1 2 3 4 5 6 7 8 9 10
not at all confident very confident

Now, let's test your confidence level

6. Do you think the relaxation techniques taught in this module can help you to better manage your stress and anxiety?

1 2 3 4 5 6 7 8 9 10
not at all confident very confident

7. Do you think the breathing techniques taught in this module can help you to better manage your shortness of breath ?

1 2 3 4 5 6 7 8 9 10
not at all confident very confident

8. Do you think the energy conservation principles taught in this module can help you to better manage your fatigue?

1 2 3 4 5 6 7 8 9 10
not at all confident very confident

Check your confidence level

If you feel confident in managing your condition, continue to apply during your daily activities the techniques and strategies taught in this module.

If you do not feel confident managing your condition, what are the reasons?

What could you do to feel more comfortable using the techniques and strategies taught in this module?

Setting goals and planning ahead!

You have learned new skills to better understand and manage your Long COVID symptoms. It is important to establish a plan by writing down your objectives (the small steps are as important as the big ones!) and the time to achieve them.

My objectives to better cope with Long COVID for the next month:

1. _____
2. _____
3. _____

Are you confident that you can attain your objectives for the next month?

1	2	3	4	5	6	7	8	9	10
not at all confident								very confident	

My objectives to better cope with Long COVID for the next__months:

1. _____
2. _____
3. _____

Are you confident that you can attain your objectives for the next__months?

1	2	3	4	5	6	7	8	9	10
not at all confident								very confident	

Notes:

Patient's Signature

Date: _____

Healthcare Professional's Signature

Date: _____

The integration and maintenance of your program

Take the time to review your objectives and your plan...

Which objectives have you been able to attain? How did you manage to attain these objectives?

Are there any objectives you have not yet attained? Which ones?

What could help you attain your objectives?

Notes:

Helpful Resources

The COVID Long Haulers Support Group Canada (www.COVIDlonghaulcanada.com) is working on recognition from government officials and the public and want it to be understood that long-haulers are not recovered. This is an umbrella group for provincial support organizations including Alberta, British Columbia, Ontario, Quebec and the Atlantic Provinces. Through their efforts of sharing lived experiences with media and creating momentum, they hope to create change. They have a Facebook page that is a closed private group for members of the group to communicate with each other. There is also a Long COVID Kids Canada group as children can also develop Long COVID.

Neurological Health Charities Canada (NHCC) (www.mybrainmatters.ca) is a coalition of organizations that represent people with brain diseases, disorders and injuries in Canada. NHCC provides leadership in evaluating and advancing new opportunities for collaboration specific to advocacy, education and research to improve the quality of life for people affected by brain conditions. NHCC is open to charities and non-profit organizations with a specific interest in brain conditions.

Canadian Mental Health Association (CMHA) (www.cmha.ca) CMHA is a Canada-wide organization that promotes mental health and supports people recovering from mental illness.

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"Living with Long-COVID is a daily challenge, one that I am hoping will get better over time. In the meantime, it makes me happy to know that there are some management options for me to try so that I can carry on living my life to the best of my abilities. It's been a journey, but I think this module will help me get through each day."

Amelia, 34, living with Long-COVID