Return to Activity

Category: 3. Road to Recovery

Long COVID and physical activity

Many people believe that the fatigue and disability experienced by those with Long COVID is simply a result of deconditioning or inactivity. This statement is not true, and is a common misconception about fatigue in Long COVID.

The fatigue that comes with Long COVID is a result of physiological changes to the body. One of the symptoms of Long COVID is post-exertional malaise (PEM) or post-exertional symptom exacerbation (PESE) which are conditions where even very minimal exertion (including physical, cognitive, or social/emotional) can lead to a disproportionate worsening of fatigue and symptoms, and the worsening of symptoms can last a Long time.

Each person has a different goal when it comes to returning to physical activity. Your goal might be to return to doing daily activities, like preparing food. If you were quite active before Long COVID, your goal may be to return to certain physical activities or exercise. Whatever your goal, you will use the same strategies, regardless of the type or the intensity of activities you want to return to.

This topic focuses on returning to physical activity. The same principles can be applied to returning to all types of activities, including cognitive activity.

Physical exercise programs can be a valuable strategy for some people who have Long COVID **but do not experience PEM**. Based on current research evidence, the Canadian Guideline for Post COVID-19 Condition suggests activity, movement, or exercise based interventions for people with Long COVID who do not experience post-exertional malaise (PEM) or post-exertional symptom exacerbation (PESE).

For people who experience PEM or PESE as part of their long COVID, traditional graded exercise programs should be avoided. A graded exercise program is where a person gradually increases exercise duration or difficulty, pushing the limits of their endurance, week after week. These programs are typically prescribed to help people recover from deconditioning or inactivity. **However, graded exercise programs will typically trigger PEM and make Long COVID symptoms worse rather than better over time.** For people with PEM, it is important to stop and rest before they feel tired. **Therefore, the graded approach should be avoided for people experiencing PEM or PESE.**

Instead, for people who experience PEM or PESE an approach called **symptom titrated activity progression** is typically recommended. A symptom titrated approach involves gradually increasing or decreasing activity based on symptoms to find the best level for each person. This will be reviewed in more detail later in this section.

The first step to getting back to the physical activities you enjoy: Finding your energy envelope

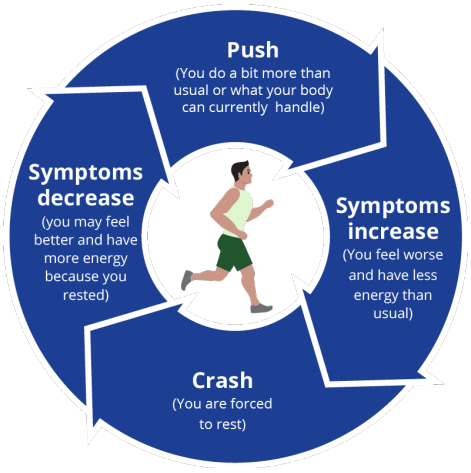
The first step towards increasing your physical activities without worsening PEM symptoms, is to find and live within your energy envelope. If you are currently struggling with a pattern of some good days and some bad days, or feel you are often 'crashing', you are not yet ready for activity progression. Keep in mind that this crash can be delayed by 1 to 3 days after the time of the activity.

Finding your energy envelope involves **significantly** reducing physical, cognitive, environmental, and social/emotional activities or triggers to a point where your symptoms become less severe and more stable. For example, it may look like having low to no Long COVID symptoms over a period of at least 1 to 2 weeks.

This process often involves major changes to your daily life so that you can find true symptom stability, and this can feel very difficult. However, it is incredibly important to break the push-crash (or PEM) cycle to be able to improve. It is also something that tends to take a lot of time and effort to find.

Many people are surprised by how much they need to pace themselves and work to reduce their triggers.

Trying to increase your activity levels before you have found this stability (also known as your energy envelope) will most likely cause post-exertional malaise, which can make your condition worse for longer and prevent your symptoms from improving.

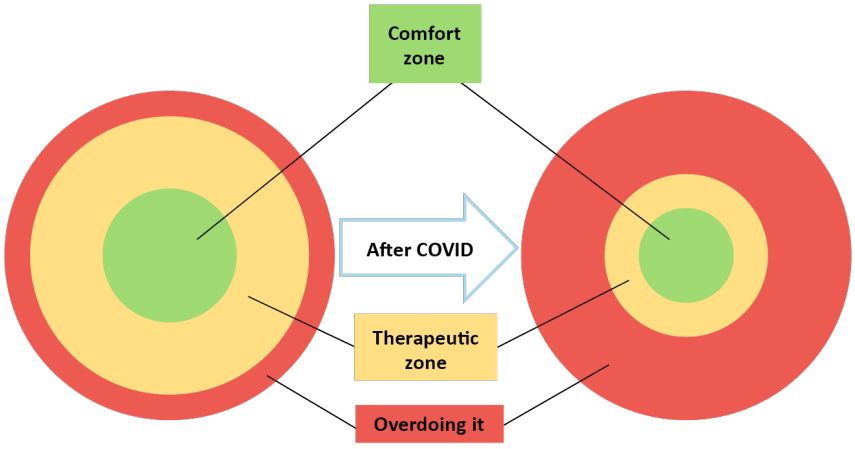


However, your emotional and mental wellbeing is important too, and being able to participate in some form of physical activity can be helpful. If this is the case for you, think about what you value about the activity and try to adapt it to fit your current energy level.

For example, if you love hiking, perhaps it is important for you to connect with nature. If so, make sure you get a little fresh air when you can and consider whether a short, slow walk on a level surface (if this is within your safe limits), or sitting or lying down outside may be something you enjoy that fits within your energy envelope.

Activity zones

With Long COVID, you can think of activity progression as expanding your energy envelope. To visualize this, you can use this picture of activity zones.



The left side of the figure shows what your activity zones typically looked like before you developed Long COVID. The right side shows after.

- activities you can do very easily are in the **comfort zone** (green colour).
- activities that are a bit more challenging but do not cause PEM fit in the **therapeutic zone** (yellow colour).
- Activities that lead to worsened symptoms or post-exertional malaise fit in the **overdoing it** zone (red colour). For some people, even normal daily activities may fall within this zone. If that is the case for you, consider exploring community supports or services to help with these.

With Long COVID, you have likely noticed that activities that used to fit within your comfort and therapeutic zones have decreased significantly, while activities in your overdoing it zone have increased.

To gradually expand your energy envelope, you must live within it for a prolonged period of time (within the green and yellow zones). Spending time within the red zone (overdoing it) for too long and/or too often will shrink your energy envelope over time, meaning it will take less and less activity to trigger your symptoms.

Physical activity within your therapeutic zone

Once symptoms are relatively stable, it is recommended that you practice activities that fall within your 'therapeutic zone'. How do you know if a physical activity is in your therapeutic zone? Here are two helpful tools you can use to help determine if a physical activity is at an appropriate intensity for you.

1. Heart rate monitoring is a useful tool to help you engage in a physical activity without overdoing it. The idea is that you can keep your heart rate low enough to avoid overexertion.
2. Rate of perceived exertion (RPE).
   With Long COVID, it is not recommended to push yourself. Instead, physical activities in your therapeutic zone should feel like no more than a moderate effort (RPE 3). In other words, a little more than what would be completely easy and comfortable, but it should not feel at all hard to do (RPE 4 or more).

Rating	Descriptor
0	Rest
1	Very, Very Easy
2	Easy
3	Moderate
4	Somewhat Hard
5	Hard
6	.
7	Very Hard
8	.
9	.
10	Maximal

These tools give an idea of the intensity of a physical activity, but they do not take into account the volume of your activities in a day or week. These tools also do not account for the cognitive or emotional energy that you use during the day, which can also reduce your body's capacity for physical activities.

It is very important to also monitor your symptoms for at least 3 days following an activity. This is because sometimes your heart rate will be below the heart rate threshold, and it will feel like the rate of perceived exertion (RPE) is 3 or less, but may still fall outside your energy envelope. Heart rate and RPE can be helpful

tools in addition to symptom monitoring, but symptom monitoring is the only way to be 100% sure whether or not an activity triggers worsening of symptoms, also known as PEM.

Symptom titrated activity progression

This is an approach to progressing activity that is recommended for people experiencing post-exertional malaise (PEM) or post-exertional symptom exacerbation (PESE). This is usually a much gentler and slower approach to activity, which involves very carefully increasing or decreasing activity in response to symptom severity.

You only increase activity if your symptoms have remained stable and low. You do not attempt to keep doing an activity if your fatigue or overall symptoms have increased or are high.

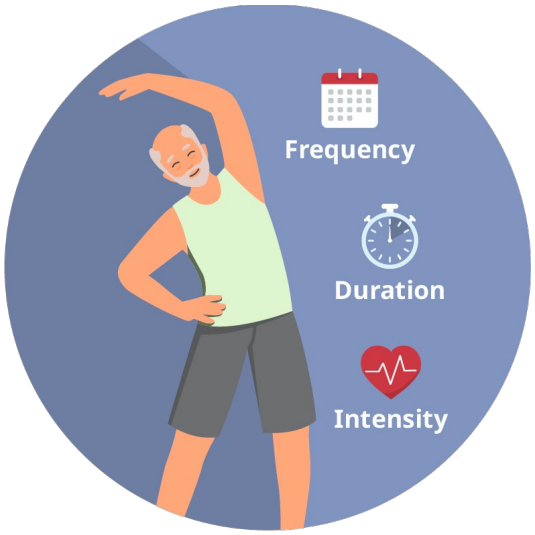
Principles of symptom titrated activity

1. Find your energy envelope. This is by far the hardest step, and can take months to years to find, but it is so important. Ideally you should be experiencing low to no symptoms for at least 1 to 2 weeks consistently before building up activities.
2. Choose just one activity to focus on. What are your goals? What brings you joy? What activities could add quality to your life as it is right now? Is there a modified way you can do the activity to start out? The activity does not need to be formal exercise. Think about functional or leisure activities you want to do. Examples include cooking, playing with your pet, going for walks, or seeing friends.
3. Figure out your safe baseline for the activity you choose. How much of this activity do you think you can do right now without causing a flare in your symptoms? Can you modify the activity to bring it within your safe limits? This will take some trial and error, and it is best to start with something very small and conservative. You may even start with just 30 seconds or a minute of a very gentle activity to test the waters.
4. Monitor your heart rate. For any physical activity, you can monitor your heart rate throughout to make sure you do not go over your safe threshold. If you do, you can apply pacing strategies so that your heart rate remains lower. You can try going slower, taking some breaks, or doing some breath work to see if you can bring your heart rate down. You can also add breaks before and after, or try the activity at a better time of day for you. If your heart rate is still over that number, your body may not be ready for that particular activity yet.
5. Go back to your energy envelope baseline. After you have tried the activity, go back to your energy envelope baseline (your usual safe routine) for a couple of days and monitor your symptoms. If your symptoms increase, then the activity was likely in the 'overdoing it' zone. If this happens, first let your symptoms return to baseline, and then start with a smaller level of activity. However, if you have low

to no symptoms over the next 3 days of going back to your usual baseline, you can try that exact same activity again. Stay at this activity level for 7 to 10 days, making sure your symptoms remain stable.

6. Slowly build up the activity if your symptoms remain stable. It is recommended to increase the frequency of the activity before the duration, before the intensity.
    a. **Increase frequency.** For example, if your activity is walking slowly for 5 minutes once per week, you could start by increasing the frequency to twice per week, then 3 times per week, and so on.
    b. **Increase duration.** If your symptoms are stable with the increase in frequency, you can then try increasing the duration–try taking a longer walk. Use the 10% rule, which means adding a maximum 10% to an activity at a time. This means the slow 5-minute walk could be increased to a slow 5 and a half minute walk.
    c. **Increase intensity**. Once you have increased the frequency and duration of your activity without symptoms, then you can start thinking about increasing the intensity. In our example, this means walking a little faster or starting to try walking up small hills. Please note that in practice, intensity is something that should be added much later on when a person's activity tolerance has significantly improved.

As a reminder, the body's response to exercise and physical activity with Long COVID is much different than in most other illnesses or conditions and requires a different approach. If you are currently trying to continue to exercise through this, and you have PEM/PESE **and** you have high or unpredictable symptom levels, please consider temporarily scaling back or stopping your exercise or physical activity routine to find symptom stability first.



Other strategies to help you return to physical activity

- **Try incorporating rest breaks into your physical activity and use breath work to keep your heart rate lower to allow your body to recover.**
    - Interspersing breathing exercises, especially those that slow down your breathing, can help pace your activities to a level your body can handle.
    - Use your breath with strengthening exercises – exhale to lift, inhale to lower. This will help you calm your nervous system, keeping your heart rate and breathing rate lower.
- **For physical exercise, starting in a lying down or reclined position is often better tolerated – this will use less energy and you can more fully rest between intervals of activity.**
    - You may start with just a couple of gentle stretches or mobility exercises to see how your body and symptoms respond. Remember to use a symptom titrated approach and start small.
    - You may want to avoid upper body strengthening at first, especially movements with your arms overhead or your weight supported on your arms.
        - These types of exercise can demand much more energy, increase your heart rate too much or trigger feelings of breathlessness. These considerations are particularly important if you have the symptoms of postural orthostatic tachycardia syndrome (POTS).

Please note that the approach to physical activity and exercise with Long COVID and PEM/PESE is incredibly nuanced and should be individualized. Working with a clinician who is aware of PEM is strongly recommended.

Where to next

- Read the recommendation by CAN-PCC on activity, movement and exercise-based interventions for people with Long COVID who do not experience post-exertional malaise (PEM) or post-exertional symptom exacerbation (PESE).