What is Long COVID?

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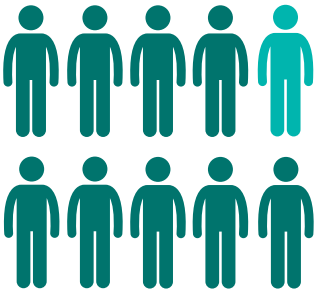
Long COVID has been preliminarily defined as the presence of signs and symptoms that develop during or following an infection consistent with COVID-19 which continue for 12 weeks or more.

Typically, it is referred to as acute COVID-19 until 4 weeks and ongoing COVID-19 from 4 to 12 weeks.



How common is Long COVID?

1 in 10 of all cases will exhibit symptoms for a period of 12 weeks or longer

Many people living with the disease were previously fit and healthy.

Children experience Long COVID symptoms similar to adults and at about the same frequency.

Long COVID affects people who have been hospitalised with acute COVID-19 and those who recovered at home. Individuals who have experienced either mild or severe COVID-19 can go on to have prolonged symptoms or develop Long COVID.

Long COVID is a multi-system disease; there are over 200 listed symptoms which occur in variable combinations and can fluctuate in both predictable and unpredictable patterns of flare-ups and remissions.

Most common symptoms after 6 months:

- extreme exhaustion (fatigue)
- post-exertional symptom exacerbation (PESE)
- problems with memory and concentration (brain fog)

Other common symptoms:

- shortness of breath
- chest pain or tightness
- difficulty sleeping (insomnia)
- heart palpitations
- dizziness
- muscle pain
- joint pain
- depression and anxiety
- tinnitus, earaches
- feeling sick, diarrhoea, stomach aches, loss of appetite
- a high temperature, cough, headaches, sore throat, changes to sense of smell or taste
- rashes

Consensus has not yet been reached on an internationally agreed Long COVID case definition. However, there is mounting evidence that Long COVID is both common and debilitating. Attempts have been made to characterise Long COVID as prolonged with multi-system involvement and significant disability.

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Rehabilitation and Long COVID

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What is rehabilitation?

Rehabilitation is defined as a set of interventions to optimise functioning in everyday activities, support individuals to recover or adjust, achieve their full potential, and enable participation in education, work, recreation and meaningful life roles.

Safe and effective rehabilitation is a fundamental part of recovery.

Rehabilitation for Long COVID must be tailored to the individual, depending on their symptoms, goals and preferences.

The World Health Organization recommends that Long COVID rehabilitation should include educating people about resuming everyday activities conservatively, at an appropriate pace that is safe and manageable for energy levels within the limits of current symptoms, and exertion should not be pushed to the point of fatigue or worsening of symptoms.

Rehabilitation for individuals recovering from COVID-19 is different for everyone. Here are some terms that may best describe your experience:

- post-intensive care syndrome
- post-viral fatigue
- permanent organ damage
- long-term COVID

Regardless of the symptoms you experience, your physiotherapist will treat you as an individual and get to know the underlying cause before starting treatment.

Effective rehabilitation interventions to support self-management of symptoms may include:

- activity pacing
- heart rate monitoring

In order to best meet your needs, a physiotherapist will work with other health professionals as part of your assessment and rehabilitation programme. Various tests may be carried out to understand and find the cause of symptoms such as:

- breathlessness
- chest pain
- heart palpitations
- fatigue
- feeling faint or fainting
- dizziness
- low oxygen saturation

Exercise prescription in Long COVID should be approached with care to minimise risk and to ensure exercise programmes are restorative and do not make the individual's symptoms worse. Rehabilitation should aim to prevent oxygen desaturation on exertion. A specialist respiratory physiotherapist may help where there are signs of hyperventilation and breathing pattern disorders. **Graded exercise therapy should not be used, particularly when post-exertional symptom exacerbation is present.**

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Fatigue and post-exertional symptom exacerbation

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FATIGUE

Fatigue is a feeling of **extreme exhaustion** and is the **most common** symptom of Long COVID. It:

- is not easily relieved by rest or sleep
- is not the result of unusually difficult activity
- can limit functioning in day-to-day activities
- negatively impacts quality of life

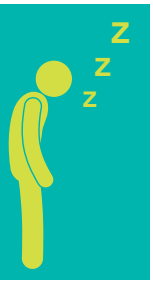
PESE

Post-exertional symptom exacerbation (PESE) is a disabling and often delayed exhaustion disproportionate to the effort made. It is sometimes described as a "crash". The activity that can trigger this worsening of symptoms can be something that was easily tolerated before, such as:

- a daily activity (eg a shower)
- a social activity
- walking (or other exercise)
- reading, writing or working at a desk
- an emotionally charged conversation
- being in a sensory environment (eg loud music or flashing lights)

Many of the symptoms experienced by those living with Long COVID are very similar to those of myalgic encephalomyelitis (ME)/chronic fatigue syndrome (CFS).

The World Health Organization recommends that Long COVID rehabilitation should include educating people about resuming everyday activities conservatively, at an appropriate pace that is safe and manageable for energy levels within the limits of current symptoms, and exertion should not be pushed to the point of fatigue or symptom exacerbation.



PESE is most often **triggered by physical activity** and exercise. Nearly **75% of people** living with Long COVID still experience PESE **after 6 months**.

The symptoms worsened by exertion can include:

- disabling fatigue/exhaustion
- cognitive dysfunction or "brain fog"
- pain
- breathlessness
- heart palpitations
- fever
- sleep-disturbance
- exercise intolerance

Symptoms typically **worsen 12 to 48 hours after** activity and can last for days, weeks or even months.

Your physiotherapist can guide you in **pacing as an activity management tool** that is also used successfully for people with ME/CFS to prevent triggering PESE.

STOP trying to push your limits. Overexertion may harm your recovery.

REST is your most important management strategy. Do not wait until you feel symptoms to rest.

PACE your daily activities and cognitive activities. This is a safe approach to navigate triggers to symptoms.

Physical activity and exercise interventions warrant caution as rehabilitation strategies among people with Long COVID and persistent symptoms of disproportionate breathlessness on exertion, inappropriately high heartbeat (tachycardia), and/or chest pain.

Graded exercise therapy should not be used, particularly when post-exertional symptom exacerbation is present.

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How to use pacing with your physiotherapist

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Pacing is a self-management strategy during activity to avoid post-exertional symptom exacerbation (PESE). When pacing you do less activity than you have energy for, keeping activities short, and resting often.

1 Learn about your energy reserve/reservoir

- Your energy reserve is how much energy you have each day – this will vary so it is best to find your baseline by using an activity and symptom diary. Your "baseline" is what you can do fairly easily on a good day and only just do on a bad day.
- You should always aim to leave some energy at the end of the exercise – don't keep going until you feel tired.

2 Learn how much energy you have

Your activity and symptom diary should start to show some patterns. You can now reduce or modify your activity levels so that you don't trigger PESE or "crash". This will help you find a level of activity you can maintain on both good and bad days, unless you have a relapse. Learn to recognise early signs of PESE and immediately initiate stop, rest, pace to avoid a crash.

3 Learn how to use the 4 Ps to help you plan your activities

- **Prioritise** what you really need to do in a day or week. Question whether all activities are necessary. Can someone else do it? Can I change the activity so it is easier for me?
- **Plan** in your main prioritised tasks for the day. Plan in your rest time so the day is paced.
- **Pacing** – break up your activity into smaller, more manageable tasks with rest breaks.
- **Pleasure** – spend some energy on things you enjoy to help improve your quality of life.

4 Learn how to save energy

- Learn to say no.
- Avoid the temptation to "do just a little more".
- Modify your activities to use less energy.
- Take short cuts and ask for help.

5 Learn to rest between activities

- Rest means absolutely minimal activity and little or no mental stimulation.
- During rests avoid activities that can be stimulating, such as TV and social media.
- Try some meditation and/or breathing exercises instead.

Can I ever do more?

- When your symptoms improve you will experience less weakness and fatigue. Work with your physiotherapist to find out how to increase your activity levels very gradually, such as carrying out some core strengthening exercise or increasing the amount you can walk by 10%.
- Be realistic and stay flexible – try to create a weekly routine, but accept that some days you will need more rest than others and avoid your triggers.
- Focus on your accomplishments instead of symptoms or what you have not achieved.

Heart rate monitoring

Your physiotherapist can teach you how to take your heart rate. Then, take your heart rate every morning before getting out of bed. Keeping your heart rate within 15 beats per minute of your weekly average should reduce the risk of PESE.

Activity management or pacing is likely to be a safe and effective intervention for managing fatigue and post-exertional symptom exacerbation (PESE). Heart rate monitoring is likely to be a safe and effective intervention for managing fatigue and PESE.

Graded exercise therapy should not be used, particularly when post-exertional symptom exacerbation is present.

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Breathing exercises

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Breathing exercises can help your lungs recover after COVID-19. As well as helping you deal with feelings of anxiety and stress, breathing exercises can help restore diaphragm function and increase lung capacity. Breathing should be effortless and quiet - if you can hear your breathing you may be working too hard.

A physiotherapist can guide you through the following exercises.

1 Breathing exercise while on your back

Lie on your back and bend your knees so that the bottom of your feet are resting on the bed.

- Place your hands on top of or around the sides of your stomach.
- Keep your mouth closed throughout.
- Breathe in gently through your nose and feel your stomach rise/expand.
- You don't have to breathe all the way in - save big breathing for activity.
- As you exhale, just let the air leave your lungs gently; you don't have to push or force the air out. Feel tension release as you breathe out.
- Repeat for one minute.

2 Breathing exercise while on your stomach

Lie on your stomach and rest your head on your hands to allow room to breathe.

3 Breathing exercise while sitting

Sit upright on the edge of a bed or in a sturdy chair.

4 Breathing exercise while standing

Stand upright and place your hands around the sides of your stomach.

5 Yawn to a smile breathing exercise

- Sit upright on the edge of your bed or in a sturdy chair.
- Reach arms overhead and create a big stretching yawn.
- Bring your arms down and finish by smiling for three seconds.
- Repeat for one minute.

This exercise incorporates motion with deep breathing, which helps increase coordination and build strength in the arms and shoulders. It also opens up the muscles in your chest to give the diaphragm space to expand.

6 Humming breathing exercise

- Sit upright on the edge of your bed or in a sturdy chair.
- Place your hands around the sides of your stomach.
- With your lips closed, breathe in gently through your nose and feel your stomach rise/expand.
- Once your lungs are full, keep your lips closed and exhale while humming, making the "hmmmmmm" sound. Notice how your hands lower back down.
- Again, inhale through your nose, then exhale through your nose while humming.
- Repeat for one minute.

This information has been adapted from the following sources:
www.hopkinsmedicine.org/health/conditions-and-diseases/coronavirus/coronavirus-recovery-breathing-exercises;
www.physiotherapyforbpd.org.uk/wp-content/uploads/2017/06/YOUR-Guide-to-Good-Breathing.pdf

Do not begin exercises, and contact your doctor, if you have: a fever; shortness of breath or difficulty breathing while resting; chest pain or palpitations; new swelling in your legs.

STOP exercise immediately if you develop any of the following symptoms: dizziness; shortness of breath more than normal; chest pain; cool, clammy skin; excessive fatigue; irregular heartbeat; any symptoms you consider an emergency.

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