UNDERSTANDING AND MANAGING LONG COVID – PATIENT GUIDE

(Updated October 2021)

What is long COVID?

Most people who have COVID-19 recover within a few weeks, but about one in 10 (possibly more) have symptoms that last longer. Long COVID (or post COVID-19 condition) is when people continue to experience COVID-19 symptoms for longer than usual after having COVID-19.

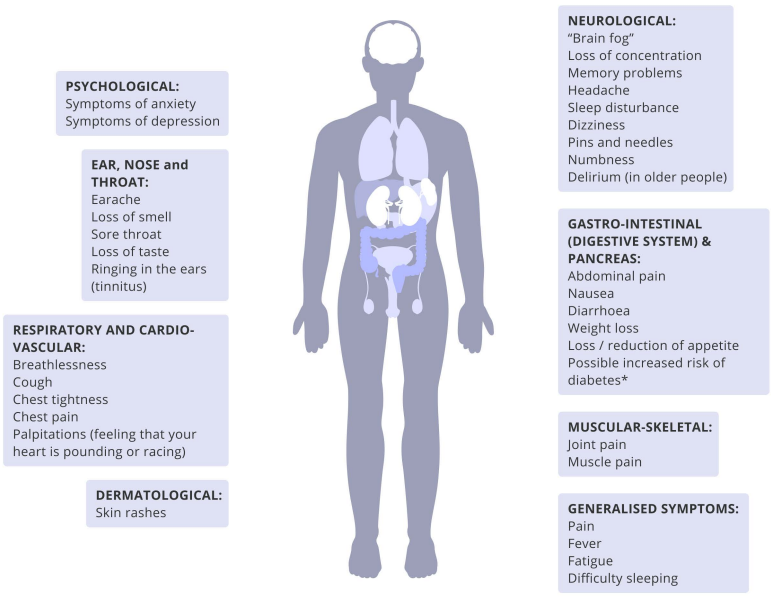
If you're still suffering from signs and symptoms more than four weeks since you got COVID-19, if your symptoms return or if you develop new symptoms, you may have long COVID. If this is the case, you're not alone. Anyone who's had COVID-19 can develop long COVID, even those who weren't very sick during the acute phase.

This guide explains what we currently (as at October 2021) know about long COVID and provides tips on how to manage some of the symptoms.

What are the symptoms of long COVID?

Long COVID can have many different symptoms – in fact, one study listed 205 different symptoms affecting 10 organs! But not everyone with long COVID gets every symptom and symptoms vary from person to person. Symptoms may also come and go, so you have good days and bad days.

According to one study, the most common symptoms people with long COVID experience six months after COVID are fatigue, post-exertion malaise (feeling unwell after exerting yourself) and cognitive dysfunction ("brain fog" and problems with memory and thinking skills).



Long COVID symptoms

How will I know if I have long COVID?

There isn't a test for long COVID yet. Doctors will need to rule out other conditions that could be causing your symptoms (such as diabetes, poor thyroid function and iron deficiency) before making a diagnosis.

What causes long COVID?

As COVID-19 is a new disease, scientists are still trying to understand what causes it. It may be due to one – or a combination – of the following factors:

- Damage to your cells from the virus.
- Tiny fragments of the virus remaining in your body; they're no longer able to infect cells but they can still disrupt your body's functioning.
- A misdirected immune response which makes your immune system attack part of your body (this is called an auto-immune reaction).

How long does it take to recover from long COVID?

Long COVID affects everyone differently – and unfortunately there's no way to predict how long recovery will take. It might be a matter of weeks or it might be several months. Factors such as how ill you were when you had COVID-19 and whether you have other health conditions may affect how long it is before you feel like yourself again. But be encouraged – most people can expect a gradual, if sometimes rather drawn-out, improvement in energy levels and breathlessness.

What treatments are available?

At the moment, there are no proven drug treatments available for long COVID, although many studies are underway to identify effective options. For now, the focus will be on managing your symptoms and gradually and safely increasing the amount of activity that you do.

Can I take vitamin and mineral supplements to help?

Within the long COVID community a high-dose vitamin stack of niacin (vitamin B3), vitamin C, vitamin D, quercetin and zinc is popular. Some people feel these work for them, but we don't yet have robust scientific studies to show whether these supplements really help.

Should I have the vaccine if I have had long COVID?

While there hasn't yet been much research done in this field, small surveys done amongst long COVID patients should reassure people with long COVID that their chance of experiencing an overall worsening of their symptoms after vaccination is small. More than half saw at least some improvement to their symptom status. As you can get reinfected with COVID, and emerging evidence suggests that the more times you have COVID the worse your overall health gets, it makes sense to be vaccinated.

Diet, exercise and sleep – important building blocks for recovery

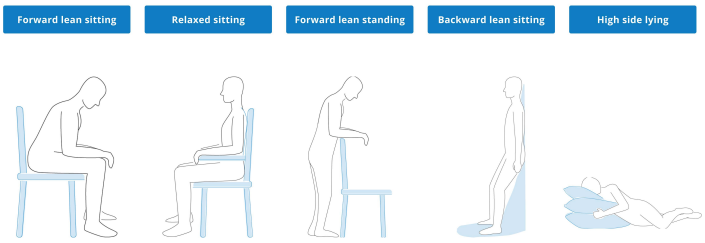
When you have long COVID, getting plenty of sleep, eating a healthy diet and gradually and safely increasing your activity levels can help you manage some of the symptoms and improve your health and wellbeing.

Establishing a good sleep pattern	Eating a healthy diet	Doing regular physical activity
Why it matters One of the symptoms of long COVID can be sleep disturbances – which is unfortunate as a lack of sleep or poor sleep quality can make long COVID fatigue worse. Try to establish good sleep hygiene to boost your chances of getting a good night's sleep.	**Why it matters** When you're recovering, it's important to give your body the right nutrients to repair itself. The impact of diet on long COVID has not yet been fully researched but there are some general pointers to be aware of.	**Why it matters** Regular physical activity can improve strength, give you more energy and help reduce breathlessness, fatigue and joint and muscle pain. It can also help you sleep better and combat anxiety and low mood.
What you can do • Make your bedroom a restful environment, with few flashing lights, effective curtains and no phone or other digital distractions. • Keep regular sleep hours. • Try to help your body's internal clock optimise your sleep by going to bed and waking up at the same time each day (even at the weekend). • Avoid stimulants like caffeine and alcohol close to bedtime. • Relax before bed – have a warm bath, read under soft light, listen to soothing music or use a relaxation technique (there are some suggestions at the end of the article). • If you often lie awake worrying about tomorrow, set aside time before bed to make a list for the next day. This can help put your mind at rest.	**Why it matters** • Try to incorporate elements of the Mediterranean diet into your eating habits (see below). It has long been known that the Mediterranean diet promotes good health – it has antioxidant, anti- inflammatory and anti-thrombotic (clotting) properties which are all very important when recovering from COVID-19. • Stay well hydrated.	**Why it matters** *Remember, you shouldn't push yourself too hard or try to exercise in the way you did before you were ill. Instead, work up slowly, exercising regularly for short periods rather than trying to do long bouts.* • Start with just walking for five minutes without stopping (or less if you feel breathless and tired). • Gradually build this up, by one or two minutes each day. • Once you can do 10 minutes without stopping aim to do two 10-minute walks a day. • Once you can achieve three 10-minute walks aim for two 15-minute walks. • Gradually progress to a 30-minute walk. • Once you can walk for 30 minutes without stopping, you can begin to build up your speed. *It's normal to feel out of breath, warm and sweaty during and after exercise, but if you feel uncomfortable take a break to recover. Aches in your muscles after exercising are also normal but shouldn't last for longer than a couple of days.* **If you experience any extreme pain, shortness of breath or dizziness, stop and seek advice.**

Managing specific long COVID symptoms

Managing breathlessness: One of the main symptoms people with long COVID report is breathlessness. Breathlessness can be frightening and make you anxious, but remember that breathlessness itself can't harm you and you will recover your breathing.

You may find the following positions ease your breathlessness – use them when resting or moving around.



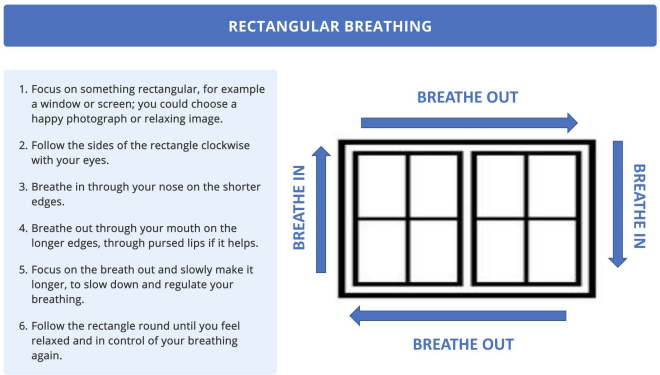
To manage your breathlessness and reduce its impact on your activities, try the following breathing control:

- Take a slow breath in through your nose.
- Try to relax your shoulders and neck.
- Allow the air to fill up from the bottom of your lungs to the top of your chest.
- Breathe gently out through pursed lips (as if you are blowing out a candle) to create space for the next breath.

When you're moving – walking on the flat, climbing stairs or negotiating slopes – try to keep your shoulders and upper chest relaxed and use your breathing control. Time your breathing with your stepping:

- Breathe in – one step.
- Breathe out – one or two steps.

If you're feeling particularly breathless, "rectangular breathing" may help you recover and may also help you feel less anxious.



Managing cough: If you're troubled by a cough, the following tips may help:

- Make sure you stay well hydrated.
- Try steam inhalation: pour hot (not boiling) into a bowl and put your head over the bowl, covering your head and bowl with a towel and inhaling the steam.
- If your cough is dry and irritable, drink warm water with honey and lemon to soothe the throat.
- Try drinking small sips of a soft drink or swallowing repeatedly.
- If your cough is productive, try lying on one side – as flat as you can to drain the phlegm – or moving around to help you cough the phlegm out.
- A technique called the active cycle of breathing may help you to clear your chest. This video shows you how to do it.

Managing fatigue: With long COVID you may find that you are frequently tired and that your energy levels fluctuate from day to day, which can be difficult and upsetting.

With this in mind, note how tiring different activities are for you. It will help you understand the pattern of your fatigue and enable you to manage and adapt better.

- Recognise that the fatigue is real. Be gentle on yourself and explain to family, friends and colleagues the impact that fatigue is having on your life.

- Try relaxation techniques. Mindful meditation, aromatherapy, yoga, tai chi and other techniques can help improve your sleep pattern and release stress.
- Keep an activity diary. For a week or two, keep a record of your daily activities (physical, social, cognitive (thinking) or emotional) and how you feel at the time and afterwards. Also note if you had a good day. A diary can help you spot unhelpful activity patterns, such as irregular sleep patterns or "boom-and-bust" behaviours.
- Remember the building blocks – try to sleep well, eat well and exercise gently.

The **"Three Ps"** – planning, pacing and prioritising – may also help you with your fatigue:

1. **Planning:** Organise your daily routines to allow you to complete essential activities when you have the most energy
2. **Pacing:** When you've planned an activity, pace yourself to sustain your energy level until it is complete
3. **Prioritising:** Look carefully at your work, family and social roles and, for now, keep only those roles that are necessary and pleasurable

Managing memory and thinking problems: People with long COVID sometimes report problems with memory, attention, concentration and executive function (mental processes that allow us to problem solve, make decisions, plan ahead and see tasks through). If you're worried that you are experiencing these problems, it might help to acknowledge that you're having issues. Chatting your worries over with family and friends may help you all feel that you can talk about the problems and look for ways of coping together.

The 3 Ps above may also be useful for helping you cope with memory and concentration issues and the following suggestions may help with particular aspects of memory and thinking skills.

Managing attention and concentration problems: When you're trying to carry out a task and struggling to concentrate it may help to:

- Reduce distractions.
- Listen to gentle instrumental music.
- Plan regular breaks.
- Add interesting tasks between others that are a bit more dull.
- Reward yourself for getting through the tasks you are less interested in.

Managing memory problems: External aids can be really helpful if you're struggling to remember things:

- Use a calendar app on your phone to remind you when you have to do things, even small tasks like putting out the bin.
- If you don't want to use a cell phone, use a paper calendar with plenty of space for each day.
- Get into the habit of checking it at regular times of the day, say first thing in the morning and last thing at night.
- Use your phone or a notebook to remind yourself of things that you have done.

Managing executive problems:

- Set up a regular routine that works well for you as this will reduce the demands on your brain. Think through all the things you want to do regularly every day, or every week, put them into a schedule and practice this routine until it becomes second nature.
- Make a clear plan before approaching any new or complicated problem or situation, break the problem down into all the steps you need to take, write each one down and what you need for it and then follow your plan. Keep checking back to check you haven't gone off course and also to check if you need to make any changes.
- Try and establish a habit of pausing during any complicated activity and taking a moment to think. Ask yourself, 'What did I set out to do?', 'How am I getting on?', 'Do I need to change my approach?' or 'Do I need to take a break?'.

Managing the emotional impact: Not recovering from acute COVID-19 within an expected time frame can lead to frustration, confusion and fear. Being very unwell or hospitalised with COVID-19 can have a profound emotional impact too. You may feel anxious, worried or low or you may struggle to sleep.
The following tips might help:

- Don't watch or read too much news or social media if it makes you feel anxious.
- Speak to family and friends.
- Try to do activities that you find enjoyable and relaxing.
- Don't be too hard on yourself if there are some things that you're finding more difficult to do. Remind yourself that recovery takes time.
- Focus on the things you can control, such as eating well, exercising and having a good sleep routine.
- Try relaxation techniques like those mentioned above.

When should I seek medical help?

Contact your doctor if you have:

- Worsening shortness of breath.
- Chest pain.
- A new or returning fever.
- Worsening ability to concentrate.

Moving forward

Having long COVID can be painful, upsetting and worrying. It's not uncommon to feel frustrated both with the course of the condition and the fact that people may dismiss your complaints as being psychological rather than physical. Remember: you are not alone.

As your condition gradually improves, remember to keep a balance of quality rest, routine and fun activities. Stress and worry use energy so give yourself time and be kind to yourself.

Helpful resources

- Royal College of Occupational Therapists. How to conserve your energy: practical advice for people during and after having COVID-19. https://www.rcot.co.uk/conserving-energy

- Chartered Society of Physiotherapy. Covid-19: the road to recovery activity planner. https://www.csp.org.uk/system/files/documents/2020-06/001751_covid19-the_road_to_recovery_activity_planner_v3.pdf

- Mental Health Foundation. How to look after your mental health during the coronavirus outbreak. https://www.mentalhealth.org.uk/coronavirus

- Mind. Coronavirus and your mental health. https://www.mind.org.uk/information-support/coronavirus/

- Asthma UK and British Lung Foundation. Post-COVID HUB. https://www.post-covid.org.uk/

- Facebook. Long Covid Support Group. https://www.facebook.com/groups/longcovid

- Purely Pacing. https://www.jenniejacques.com/post/purely-pacing

- Advanced Wellbeing Research Centre (AWRC). An introduction to fatigue and how to manage it for people recovering from COVID-19. https://www.youtube.com/watch?v=nIcOVUqQMfI