

LONG COVID



ESSENTIAL GUIDE

This Essential Guide is about what to do if you have Long Covid.

It explains:

- What Long Covid is.
- What symptoms to expect and how to manage some of them.
- How Long Covid is diagnosed.
- Where to find information, help, and support.

What is Long Covid?

Most people recover from COVID within a few months, but around one in ten people still have symptoms six months after they were infected.

Long Covid can affect people of any age and background, including children. Long Covid can happen regardless of how bad the original infection was – some people have Long Covid without ever having been aware that they were infected to begin with!

Some groups of people do seem to be at higher risk of developing long-term symptoms, including:

- Women.
- People with asthma, diabetes, or other long-term health problems.

What causes Long Covid?

It is still unclear why some people develop Long Covid after a COVID infection.

However, the theory most supported by the evidence is that your immune system stays activated after you recover from the original infection, and this starts to affect the rest of your body.

Blood tests on people with Long Covid show higher amounts of the chemicals that are released when your immune system is fighting a virus, even long after the virus itself has been cleared out of your system.

This makes your immune system over-sensitive, which can mean that your immune system attacks your own body. It can also mean that, when you get any other infection, you react more strongly, get more ill, and stay ill for longer.

There are other aspects of COVID that can contribute to Long Covid, like:

- Severe COVID, as well as treatment like intubation or being on a ventilator, can physically damage your organs.
- The COVID virus can stay in your body for a long time.
- Trauma and anxiety around your experiences with COVID can affect your physical health, leaving you more vulnerable to illness.
- COVID can starve parts of your body of oxygen, leading to cell damage. Your body working harder to move limited oxygen around your body may also put strain on your cardiovascular (blood) system.

Your blood flow may be affected by Long Covid.



Symptoms of Long Covid

There is a lot of variation in symptoms, but the most commonly recognised ones are:

- Fatigue.
- Post-exertional malaise.
- Cognitive changes.
- Breathlessness.
- Aches, pains, and headaches.
- Sleep difficulties.



The most common pattern is for Long Covid symptoms to vary over time. Sometimes you may feel better, and then the symptoms may return or worsen later.

Some people also experience other symptoms, including:

- Dizziness, vertigo, or other balance issues.
- Palpitations or other heart issues.
- Muscle weakness.
- Persistent coughs or chest pains.
- Rashes, itching, or pins and needles.
- Fever or chills.
- Damaged sense of taste and/or smell.
- Mental health problems like depression, anxiety, and stress
- Neurological issues like PoTS

Changes to your nervous system can also affect your gut, causing digestive issues.

Long Covid symptoms can lead to difficulties with mobility, social and mental wellbeing, and activities of daily life.

Fatigue

Fatigue is the most common symptom of Long Covid.

Fatigue is not just being tired, sleeping a lot, or lacking motivation. It is a condition which affects every part of your body. It means that you have less energy and may struggle to do things that used to be easy.

The most important thing you can do for your fatigue is to avoid **triggers**. Try to notice what causes your symptoms to get worse, and try to balance your activity to avoid exhausting yourself.

There are some techniques you can use to reduce the effect of fatigue. Many people with fatigue are still able to enjoy life.



For more information about fatigue, check out our booklet on **Tiredness and Fatigue** and our factsheet on **Long Covid Fatigue**.

Long Covid is also characterised by something called **post-exertional malaise**, experienced by up to nine out of every ten people with Long Covid.

Post-exertional malaise (PEM) means that after exercising or otherwise overstretching yourself, your symptoms become dramatically worse. This can make it difficult to function for days or even weeks after you exert yourself.

Because Long Covid so often includes post-exertional malaise, it is important **not** to try to push through your symptoms or will yourself to do everything you feel you should do. The best way to manage Long Covid symptoms is through carefully pacing and managing your activity to avoid overworking yourself.



Breathlessness

Many people with Long Covid get breathless, especially after exercise. You may feel chest pain, struggle to catch your breath, or find yourself getting dizzy or light-headed.

This may get better over time, especially if you are supported with pulmonary rehabilitation or other recovery programmes.

You can also learn management and positioning techniques which may help you to reduce the impact of breathlessness.

Because Long Covid often comes with fatigue, you should be careful in any exercises given to you, and make sure you let your physiotherapist or practitioners know about your condition.

For more information about breathlessness, check out our booklet on **Breathlessness** and our factsheet on **Long Covid Breathlessness**.



Cognitive changes

Long Covid can affect your:

- Thinking.
- Focus and concentration.
- Memory.
- Communication skills.

This is mostly due to the impact of fatigue and post-exertional malaise.

These effects usually come and go depending on your level of fatigue and general health.

You can prepare for these difficult periods by building support networks, keeping a to-do list, and writing yourself notes. It is also important to be honest with the people around you if you are struggling.

For more information, see our factsheet on **Brain fog**.



Aches and pains

People with Long Covid often report pain in their joints and muscles. This pain may happen in response to overuse or overwork, but it may also be consistent (**chronic pain**)

These pains may respond to over-the-counter pain medications such as ibuprofen, aspirin, or paracetamol. You should always be careful not to exceed the recommended dose of these medications.

Chronic pain is often triggered by specific factors, like heat, cold, tiredness, or certain forms of exercise. If you keep an eye on your responses to different environments, you can start to avoid these triggers.

It is important to know whether your pain is **neuropathic** (i.e. caused directly by the nervous system) or is actually a response to a physical injury or stimulus. If you're not sure, it's always safer to assume there's a real injury.

Long Covid also causes headaches for around three out of every ten people. These may respond to painkillers like paracetamol or ibuprofen, or you could try lying down in a darkened room.

Along with pain, around half of people with Long Covid find that they have muscle weakness. This can lead to mobility problems or difficulty with managing day-to-day activities.

If you are finding that you cannot manage daily activities, you may be able to get support through a physiotherapy or Occupational Therapy service.



For more information about pain, check out our booklet on **Chronic Pain**.



Heart conditions

Some people with Long Covid, especially those who were hospitalised when they first got ill, develop heart problems.

The most common heart problem is **palpitations**. This is when your heart beats very fast and irregularly, which can cause you to feel dizzy or panicked. It may also hurt. Palpitations are usually harmless and tend to pass on their own. Seek help if you have other symptoms in addition to palpitations or they happen repeatedly.

Some people also have chest pain, especially after exercise.

A small number of people with chest pain may turn out to have a condition called **myocarditis**. This is an inflammation (swelling) of your heart muscle. It can cause pain and discomfort, but it is usually not dangerous.



Fever

People with Long Covid seem to be more likely to get feverish when stressed or ill, even when they do not have other COVID symptoms.

If you experience regular bouts of fever, discuss with your doctor or health professional how you can manage these. Many people find that they can bring a fever down by taking paracetamol.



IMPORTANT: You should never take more paracetamol than is suggested on the label. If you are taking other medication, talk to your doctor to make sure that none of them will interact with paracetamol.



Mental health

Almost half of hospitalised COVID patients, and many COVID patients who were never hospitalised, say they have mental health issues as a result of their experiences.

As Long Covid is still poorly understood and the situation continues to develop, you may also have to deal with uncertainty and doubt about the future, which can be very stressful.

Many people who have had COVID report:

- Depression.
- Anxiety.
- PTSD.
- Stress or stigma around their experiences.

For more information, check out our booklet on **Mental Wellbeing**.



Getting a Diagnosis

To be diagnosed with Long Covid, you have to have had COVID-19 at some point, and other possible causes of your symptoms have to be ruled out.

Not all doctors are familiar with Long Covid. To help your doctor diagnose you:

If you know you have had COVID, mention this to the doctor when discussing any possible Long Covid symptoms.

If you are unsure whether you have had COVID, ask for an antibody test (this may not provide accurate results if you have been vaccinated, however).

If possible, keep a symptoms diary.

Be upfront about any other illnesses, injuries, or stresses you may recently have experienced.

Keeping up to date

We have done our best to provide the most up-to-date information in this guide. However, because this is a published document, updates are limited.

For ongoing, regularly updated information on Long Covid and symptom management, visit these websites:

- o NHS Inform - **nhsinform.scot**
- o CHSS website - **chss.org.uk**
- o **longcovid.org**

There may be Long Covid support networks in your area. It's also worth taking a look on Facebook and other social media.



Finding support

CHSS provides a range of services, such as:

- Community Healthcare Support service
- Advice Line (call **0808 801 0899**)
- In-depth information about specific symptoms and how to manage them, available on **[chss.org.uk/resources-hub](https://www.chss.org.uk/resources-hub)**

CHSS also has support groups for Long Covid, and Long Covid exercise classes. To find out more, call our Advice Line.

Friends and family can offer support with managing your symptoms and can also provide a listening ear

Your doctor, with your agreement, may refer you to other health professionals and support services e.g.: occupational therapy, counselling, physiotherapists, or pain clinics.

Our publications are available for free to anyone in Scotland who needs them. Go to www.chss.org.uk/publications for all our resources, including other Essential Guides in this series.

For free, confidential advice and support from our **Advice Line nurses**, call: 0808 801 0899 (Mon-Fri 9.30am-4pm), text: NURSE to 66777 or email: advice@chss.org.uk.

Across Scotland, over one million people – that's one in five of us – are living with the effects of a chest, heart or stroke condition. We are here to help everyone who needs us. But we need your support to do this. Go to www.chss.org.uk/supportus to find out how you can help more people in Scotland.

If you would like this resource in an alternative format, please contact our Advice Line nurses.

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