

LONG COVID



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

It explains:

- What we know about Long Covid, and how you can find out more as the situation develops
- What symptoms to expect, advice and tips to help you manage your symptoms
- Reaching out: talking about Long Covid and where to find ongoing support

This document may not contain the latest information. For regular updates, visit

www.nhsinform.scot



Most people recover from COVID within 3 months, but around 10% of people still show symptoms after 12 weeks.

Long Covid can affect people of any age and background, including children, regardless of how bad the original COVID symptoms were – some people experience Long Covid symptoms without ever having been aware that they were ill to begin with!

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

- Women
- People over the age of 60
- People of Afro-Caribbean background
- People with asthma, diabetes, or other long-term health problems

Long Covid Symptoms

There is a lot of variation in symptoms, but some common ones include:

- Fatigue
- Breathlessness, cough, chest heaviness or pressure
- Postural tachycardia syndrome (POTS)
- Aches, pains, and headaches
- Palpitations or heart murmur
- Rashes, itching, or pins and needles
- Fever
- Mental health problems like depression, anxiety, and stress

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 **Long Covid & Fatigue**.

Find it on our website: chss.org.uk



Breathlessness

Many people with Long Covid experience breathlessness, especially after exercise. You may feel chest pain, struggle to catch your breath, or find yourself getting dizzy or lightheaded

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 by a therapist or physio.

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

Find it on our website: chss.org.uk

PoTS

Postural tachycardia syndrome, or PoTS for short, is a neurological problem common in people who have had COVID.

PoTS is a condition where standing up makes your heart rate increase ("tachycardia") and may cause you to experience symptoms like:

- Lightheadedness or dizziness
- Heart palpitations
- Weak or shaking movements
- Blurred vision
- Fatigue or difficulty with exercise

It may also cause gut problems like constipation or pain in your lower abdomen.

POTS can be treated either with medication or with small changes to your lifestyle. If you have the symptoms above, talk to your doctor about the possibility that you have POTS.

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 constant(**chronic pain**).

These pains may respond to over-thecounter 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.

Types of pain include:

Physical pain

This pain is in response to an injury – for example, a bruise, strain, or cut. If it's internal (e.g. a stomach ache) it can be hard to know whether there is a physical problem or not. If your pain is consistently in the same place, you might want to go to a doctor to see whether there is a physical injury.

Hypersensitivity

This is a kind of pain where your nervous system is oversensitive to stimuli. In other words, something that wouldn't ordinarily hurt (like a light touch or tickle) hurts you. The best way to deal with it is to avoid stimuli, and if possible, take some painkillers.

Neurogenic pain

This pain is due to the misfiring of neurones, and isn't necessarily responding to an actual physical problem. Paracetamol may help, but often the best solution is to simply wait it out.

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 not dangerous and will usually pass on their own.

Some people also have chest pain, especially after exercise

Around 1/4 of people who have 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.

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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

Chest Heart & Stroke Scotland publish a 'Mental Wellbeing' guide, which has more information on managing your mental health, and is available online.



To be diagnosed with Long Covid, you have to have had COVID 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)

Keep a symptoms diary if possible

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:

- NHS Inform nhsinform.scot
- o CHSS website chss.org.uk
- longcovid.org
- Your Covid Recovery yourcovidrecovery.nhs.uk



Finding support and help

CHSS provides a range of services, such as:

- the Hospital to Home service
- o AdviceLine (call **0808 801 0899**)
- In-depth information about specific symptoms, which you can find on chss.org.uk

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

Friends and family can offer key 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, physiotherapy, 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: adviceline@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.

Chest Heart & Stroke Scotland

NO LIFE HALF LIVED

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Published Apr 2022 Next planned review Oct 2023