

Chest  
Heart &  
Stroke  
Scotland



# LIFE WITH LONG COVID



ESSENTIAL GUIDE

# This Essential Guide is about adjusting to life after COVID.

It provides:

- Advice on adjusting to long-term symptoms and explaining your condition to others.
- Advice on getting back to work safely with ongoing symptoms.
- Information on financial support and benefits that may be available to you or someone who cares for you.



This document may not contain the latest information. For regular updates, visit [www.nhsinform.scot](http://www.nhsinform.scot)

# What is Long Covid?

Many people recover quickly from COVID-19, but some may take longer to get better. When the symptoms are ongoing for 12 or more weeks, this is referred to as Long Covid.

Whether or not you develop Long Covid does not seem to be linked to how ill you were when you first get coronavirus or if you were hospitalised because of it. People who had mild symptoms of coronavirus at first can still develop Long Covid.

Long Covid overlaps significantly with Chronic Fatigue Syndrome (ME/CFS). In one 2022 study, over half of people with Long Covid met the criteria for an ME/CFS diagnosis.



# Long Covid symptoms

Long Covid is still not well understood, but some common symptoms seem to be:

- Fatigue and muscle weakness.
- Breathlessness.
- Aches, pains, and headaches.
- Palpitations or other heart issues.
- Ongoing cough or breathing problems
- Difficulty standing – heart racing, dizziness, or blurred vision. This can include a condition called PoTS.
- Cognitive or mental changes, including 'brain fog'.
- Post-Exertional Malaise (PEM).



CHSS has more detailed information on many of these symptoms:

**[www.chss.org.uk/resources-hub](http://www.chss.org.uk/resources-hub)**

# Explaining Long Covid

Because of how new Long Covid is, you may face extra difficulties in explaining your condition to others – even doctors. You may, at times, face disbelief or scepticism from people about your condition.

Remember that you are the expert on your own health. If you are concerned about a doctor or health professional not understanding your condition, there are resources available to support you in standing up for yourself at medical appointments. It may also be helpful to take someone with you to appointments, for support.

For tips on talking to your doctor, see our factsheet on Making The Most of an Appointment with your Doctor.

Find more information on your rights as a patient at [www.citizensadvice.org.uk/scotland/health/nhs-healthcare-s/](https://www.citizensadvice.org.uk/scotland/health/nhs-healthcare-s/)



# Dealing with uncertainty

It's normal to have some uncertainty in your life. Being ill raises all kinds of questions about what comes next, from your symptoms to your day-to-day activities to what treatments you might need. Because Long Covid is a new diagnosis and the evidence is still being collected on how it works, this uncertainty is much greater.

You may find this stresses you out, makes you depressed or frustrated, or prevents you from feeling able to commit to anything. It can also be frustrating when people ask questions about your condition which you may not be able to answer.

Some level of uncertainty is unavoidable, but there are ways to manage your uncertainty while supporting your mental wellbeing and helping you to relax a little.

Make short-term plans and goals to give yourself some immediate structure. Planning just a day or week in advance can help give you a sense of a future to look forward to.

Instead of trying to follow every piece of news or information that comes out about Long Covid, set aside one day every month or two when you will look into new developments.

Keep a diary or journal, which you can look back on to gauge your progress. You will often find you've made more progress than you realised.

Speak to friends, family, or a licensed therapist about your feelings. Joining a support group can also help.

Try to remind yourself that not every changed plan is a disaster. It can help to hear this from someone else, so if you find yourself spiralling, call a friend or family member for reassurance.

# Adapting to new symptoms

Part of the journey of Long Covid is getting your head around what your symptoms mean for you. The answer will be different for every person, but there is help available to support you with your symptoms, and with making lifestyle changes to accommodate them.

You don't have to get it right first try. It may take a while to find what works for you, and to get used to the changes in habits and routines that may be needed.

Chest Heart and Stroke Scotland offer a range of resources to help you manage specific symptoms like fatigue, breathlessness, and pain. You can find these booklets and others at **[chss.org.uk/resources-hub](https://chss.org.uk/resources-hub)**.



Talking to other people with Long Covid can help you to feel better, and also to pick up ways to handle symptoms. You might want to join a group like Long Covid Support (**longcovid.scot**) or a local network.

It's important to be gentle with yourself. Remember that there will be setbacks and difficulties in any recovery – a bad day doesn't mean you've failed. Forgiving yourself and being kind to yourself are the most important things in finding a healthy way forward with your condition.

Try to set yourself small, reasonable goals. Having something to work towards, even if it's small, is a great motivator for recovery.

Remember that there's no schedule for getting better, and no deadline. Every step towards coping is a step in the right direction, no matter when it happens.

# Getting back to work

Getting back to work while dealing with Long Covid is something many people will face. It can feel great to get back to work, but it can also be scary, stressful, or exhausting.

Do not force yourself to go back to work before you're ready. Do not let your manager or workplace pressure you into it, either. If finances are pushing you back to work before your symptoms stabilise, you may need to find alternative sources of income. Find out more in our booklet on **Financial Support**.

When you do feel ready to go back to work, know your rights. Your employer is legally required to support you to work with a disability or long-term illness. Support is available for both you and your employer.

Find out more in our booklet on **Returning to Work** and our factsheet on **Employment Rights**.



# Work adjustments

Adjustments to your work could include:

- Changing your schedule/hours to manage symptoms and health appointments.
- Negotiating additional sick leave.
- Changing your responsibilities to avoid tasks which exacerbate your symptoms.
- Working from home full-time or part-time.
- Accessible work spaces or equipment.

A healthy working environment will look different for everybody, so discuss options with your line manager. Remember that your employer is legally required to make reasonable adjustments or provide solid reasons for why they are unable to do so.

You and your employer may be eligible for support from the Access to Work programme. Go to **[www.gov.uk/access-to-work](https://www.gov.uk/access-to-work)** for more information.

# Advice and support

It is important not to try and face Long Covid alone.

There are many people in your life who may be able to support you with practical, emotional, and health issues.

These could include:

- Friends and family.
- Work colleagues.
- Your GP practice or other primary healthcare providers.
- Long Covid support groups or networks.
- Local care services.
- Physiotherapists and occupational therapists.

You can also find advice and support through:

## **Chest Heart and Stroke Scotland**

Call **0808 801 0899** to speak to one of our trained Advice Line practitioners.

**[www.chss.org.uk](http://www.chss.org.uk)**

**Email: [adviceline@chss.org.uk](mailto:adviceline@chss.org.uk)**

You can also find a wide range of information, including easy-read and non-English language versions, on our Resources Hub:

**[www.chss.org.uk/resources-hub](http://www.chss.org.uk/resources-hub)**

This includes information on:

- **Long Covid**
- **Tiredness and Fatigue**
- **Breathlessness**
- **Chronic Pain**
- **Financial Support**
- **Return to Work**
- **Educational Support**
- **Mental Wellbeing**

# Further reading

## **Benefits Calculator**

An online tool to find out what benefits you are entitled to and how to claim them.

**[www.gov.uk/browse/benefits/entitlement](http://www.gov.uk/browse/benefits/entitlement)**

## **Carers Scotland (part of Carers UK)**

Advice and support for carers and the people they care for.

**[www.carersuk.org/scotland](http://www.carersuk.org/scotland)**

**Tel: 0808 808 7777** (Mon-Fri 10am-4pm)

## **Citizens Advice Scotland (CAS)**

Offers free, confidential, impartial advice on finance, employment, housing and many other issues.

Find your local CAS office at

**[www.cas.org.uk/bureaux](http://www.cas.org.uk/bureaux)**

For online advice and information go to:

**[www.citizensadvice.org.uk/scotland](http://www.citizensadvice.org.uk/scotland)**

Call our Advice Line FREE on 0808 801 0899

## **Home Energy Scotland**

Scottish Government-funded free energy advice, support and grants to help heat your home and reduce your energy bills.

**[www.energysavingtrust.org.uk/scotland](http://www.energysavingtrust.org.uk/scotland)**

**Tel: 0808 808 2282**

## **NHS Scotland Healthy Working Lives**

Advice and information for employers on health, safety and wellbeing in the workplace. Provides a range of free services including workplace visits and training.

**[www.healthyworkinglives.scot](http://www.healthyworkinglives.scot)**

**Tel: 0800 019 2211**

## **National Debtline**

Provides free, confidential and independent advice on how to deal with debt problems.

**[www.nationaldebtline.org](http://www.nationaldebtline.org)**

**Tel: 0808 808 4000**

(Mon-Fri 9am-8pm, Sat 9.30am-1pm)

Our publications are free to everyone in Scotland, in PDF and in print. See them all at [www.chss.org.uk/resources-hub](http://www.chss.org.uk/resources-hub)

For free, confidential advice and support from our Advice Line Team, contact:

**0808 801 0899 (Mon-Fri 9am-4pm)**

**text ADVICE to 66777**

**[advice@chss.org.uk](mailto:advice@chss.org.uk)**

One in five people in Scotland are affected by chest, heart and stroke conditions or Long Covid. Go to [www.chss.org.uk/supportus](http://www.chss.org.uk/supportus) to find out how you can help us support more people in Scotland.

To give feedback or request alternative formats, email: [health.information@chss.org.uk](mailto:health.information@chss.org.uk)

**Chest  
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**Scan here to see  
all our resources!**

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