

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



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 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 heart murmur
- Ongoing cough or breathing problems
- Difficulty standing – heart racing, dizziness, or blurred vision
- Cognitive or mental changes, sometimes called ‘brain fog’



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.

Find more information on your rights as a patient at www.citizensadvice.org.uk/scotland/health/nhs-healthcare-s/nhs-patients-rights-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 difficult not to be frustrated 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 in a way that supports your mental wellbeing and helps 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 later. 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](https://www.chss.org.uk).

Talking to other people with Long Covid can not only make you feel better, but also help you to pick up ways to handle symptoms. You might want to join a group like Long Covid Support ([longcovid.scot](https://www.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 after COVID is something many people will have to deal with. It can feel great to get back to work and back to normal, but it can also be scary, stressful, and exhausting.

Don't force yourself to go back to work before you're ready, and don't let your manager or workplace pressure you into it, either. If finances are a problem which are forcing you back to work before you're in a stable place with your symptoms, there are alternatives and benefits which may be available to you; some of these are covered at the end of this booklet.

When you do feel ready to go back to work, make sure you know your rights. Your employer is legally required to support you in working with a disability or long-term health condition, and there is support available for both you and your employer.

Your rights at work

Legally, your employer must make any reasonable adjustments to accommodate your health. If your employer refuses accommodations, you can ask for an explanation and/or appeal the decision.

You cannot legally be fired on the basis of disability. Your employer is responsible for making sure you are not treated badly at work as a result of your illness or symptoms.

You have the right to privacy. You don't have to answer any questions about your health, and your employer is not allowed to punish you for not answering.

If you are being discriminated against or your employer is not meeting their responsibilities to you, help is available through ACAS ([acas.org.uk](https://www.acas.org.uk)), the Citizens Advice Bureau ([cas.org.uk](https://www.cas.org.uk)), or your trade union.

Work adjustments

Adjustments to your work could include:

- Changing your schedule or hours to accommodate fatigue, periods of bad health, and extra health appointments
- Negotiating additional sick leave
- Changing your responsibilities to avoid tasks which exacerbate your symptoms
- Working from home full-time or part-time, even if others return to the office
- Providing extra equipment or accessible spaces in the workplace
- Reducing your hours

A healthy working environment will look different for everybody, so it's important that you discuss options with your line manager. Remember that it's your right to have any reasonable accommodations which allow you to do your job.

Help with returning to work

You may be eligible for support from the Access to Work (AtW) programme. This is a government programme that offers a range of support to you if you are disabled or have a long-term health condition. Examples of support include specialist equipment, help towards additional transport costs and mental health support. Go to www.gov.uk/access-to-work for more information.

If you or your employer is struggling to arrange accommodations at work, there is guidance and advice available through NHS Scotland Healthy Working Lives.

If you are unemployed or unable to return to your old job, but are looking for something new, the Disability Employment Advisor at your local job centre can advise you on different career options or retraining.

It is always worth discussing a return to work with your doctor or other health professional.

Financial support and benefits

If you are living with Long Covid, or caring for someone who is, you may be entitled to financial support or benefits.

It can be helpful to speak to a social worker, a welfare rights officer, Citizens Advice Scotland, or your local carers centre or money advice centre about what financial support or benefits may be available to you.

Some benefits are 'means tested' – based on you and your partner's savings and income. This affects how much money you receive.

You, or someone who cares for you, may be entitled to the following:

Attendance Allowance – helps with extra costs if you are 65 or over and have a disability that means you need someone to help look after you.

Carer's Allowance – money you may be entitled to if you care for someone who gets certain benefits for at least 35 hours a week.

Council Tax Reduction – help for people to pay their council tax bill if they are on a low income or claiming certain benefits.

Personal Independence Payment (PIP) – help with some of the extra costs you may have if you have long-term ill-health or a disability. PIP is replacing Disability Living Allowance

Universal Credit – a payment to help with your living costs if you are on a low income or out of work. Universal Credit has replaced Housing Benefit, Income Support, income-based Jobseeker's Allowance, Employment and Support Allowance (ESA), Child Tax Credit and Working Tax Credit. The Citizens Advice Bureaux in Scotland can provide you with more information about Universal Credit (their contact details are at the end of this guide).

Further information and advice

Benefits Calculator

An online calculator to help you find out what benefits you may be entitled to and how to claim them.

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

Tel: 0808 808 7777

(Mon-Fri 10am-4pm)

Citizens Advice Scotland (CAS)

Citizens Advice Scotland (CAS) is the Citizens Advice Bureaux in Scotland. CAS offers free, confidential and impartial advice on finances, benefits, employment, housing and many other issues.

To find your local CAS office, go to www.cas.org.uk/bureaux

For online advice and information go to: www.citizensadvice.org.uk/scotland

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

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
Tel: 0800 019 2211

National Debtline

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

www.nationaldebtline.org (webchat is also available on the website)
Tel: 0808 808 4000
(Mon-Fri 9am-8pm, Sat 9.30am-1pm)

Pension Credit

The quickest way to apply for Pension Credit is over the phone (paper applications are also available).

www.gov.uk/pension-credit/how-to-claim
Tel: 0800 99 1234
Textphone: 0800 169 0133
NGT text relay (if you cannot hear or speak on the phone): 18001 then 0800 99 1234
(Mon-Fri 8am-7.30pm)

Tax Credits

Information on different tax credits that may be available to you.

www.hmrc.gov.uk/taxcredits
Tel: 0345 300 3900
(Mon-Fri 8am-8pm, Sat 8am-4pm)

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.

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