

Long COVID

A booklet for people who have signs and symptoms that continue
or develop after acute COVID-19

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Who is this booklet for?

This booklet is for people who have had COVID-19 (with or without a positive COVID-19 test) and have symptoms that last more than four weeks, including:

- **adults**
- **young people**
- **children.**



It may also be helpful for:

- parents of children who have had COVID-19
- other family members, partners, friends and carers.



What is this booklet about?

This booklet explains the recommendations in a guideline produced by the National Institute for Health and Care Excellence (NICE), the Royal College of General Practitioners (RCGP) and the Scottish Intercollegiate Guidelines Network (SIGN) on managing the long-term effects of COVID-19.

The booklet will cover:	The booklet will not cover:
<ul style="list-style-type: none">• Support for people who have new or ongoing symptoms after having COVID-19, including:<ul style="list-style-type: none">- assessment- common symptoms- self-management, and- rehabilitation (the process of helping you to recover). 	<ul style="list-style-type: none">• Management of acute COVID-19 (symptoms for up to four weeks)• Management of other conditions with similar features to long COVID, for example post-intensive-care syndrome and myalgic encephalomyelitis/chronic fatigue syndrome. 



Recommendations from the guideline are shown in this booklet by this symbol.

Long COVID is a new illness that healthcare professionals are still learning about. Most of the recommendations are based on the experience and expert knowledge of healthcare professionals. Research is taking place and the guidance may change when its results are known.

If you would like to see the guideline, please visit:

www.sign.ac.uk or www.nice.org.uk

What is long COVID?

After catching COVID-19, some people can feel unwell and take longer to get better than others. Long COVID can affect any part of your body with different symptoms.

Ongoing or new symptoms of COVID-19 can change and come and go over time. To describe these symptoms, healthcare professionals may use different terms. 'Long COVID' is one of them.

In this booklet we use 'long COVID' to mean signs and symptoms that last more than four weeks after you get COVID-19. When talking about long COVID, these are the definitions that healthcare professionals use:



Acute COVID-19: signs and symptoms that last up to four weeks. 'Acute' refers to first the signs of infection, rather than the severity of the illness.



Ongoing symptomatic COVID-19: signs and symptoms of COVID-19 from four weeks up to 12 weeks.



Post-COVID-19 syndrome: signs and symptoms which develop during or after an infection that is consistent with COVID-19, continue for more than 12 weeks and are not explained by another diagnosis.



Information

Information about signs and symptoms that develop during or following COVID-19 can be found on the Your COVID Recovery website here: www.yourcovidrecovery.nhs.uk/what-is-covid-19/how-can-covid-affect-you/ or NHS Inform, www.nhsinform.scot/longer-term-effects-of-covid-19-long-covid/

How can I tell if I have long COVID?

If you have had COVID-19, your healthcare professional will talk to you about what to do if your symptoms are not getting any better. Some people take longer than others to recover.

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Recommendation

Healthcare professionals think that whether you develop long COVID is not linked to how severe your COVID-19 was (including whether you were in hospital). Your healthcare professional will give you advice and information on:

- what to expect during your recovery
- symptoms to look out for that would mean you need to be seen again by a healthcare professional
- who to contact if you are worried about:
 - any new, continuing or worsening symptoms
 - difficulties with everyday activities and routines, including concerns about time off work or education
 - symptoms that go on for longer than four weeks after the start of your infection, and how to self-manage your symptoms.

If you are concerned that you still have symptoms or have new symptoms four weeks after the start of COVID-19, you should speak to your healthcare professional.

How can I tell if I have long COVID? continued

Your healthcare professional will do the following:

- Offer you a consultation appointment.
- Give you information in a format or language you can understand to help you take part in decisions about your care.



If you do not receive information in a format or language you can understand, you can ask for it.

During your recovery, you will be given a choice to have appointments by telephone, video or in person (where this is possible).

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Recommendation

Healthcare professionals do not know if vaccines have any effect on the ongoing symptoms of COVID-19. But your healthcare professional will talk to you about the importance of having them. Vaccines can help to reduce the risk of further infection. You will be given information on who can get a COVID-19 vaccine, how well vaccines work and how safe they are.

You can find more information here: www.nhs.uk/conditions/coronavirus-covid-19/coronavirus-vaccination/coronavirus-vaccine/

Common symptoms of long COVID

Signs and symptoms after acute COVID-19 can be highly variable and wide ranging. The most commonly reported ones include:

Respiratory symptoms

- Breathlessness
- Cough

Cardiovascular symptoms (heart and circulation)

- Chest tightness
- Chest pain
- Palpitations

General symptoms

- Fatigue
- Fever
- Pain

Neurological symptoms

- Cognitive impairment ('brain fog', loss of concentration, or memory issues)
- Headache
- Sleep disturbance
- Peripheral neuropathy symptoms (pins and needles, and numbness)
- Dizziness
- Delirium (in older people)
- Mobility impairment
- Visual disturbance

Continues on page 7 [————>](#)

Common symptoms of long COVID continued

Gastrointestinal symptoms (digestive system)

- Abdominal pain
- Nausea
- Diarrhoea
- Weight loss and reduced appetite

Musculoskeletal symptoms

- Joint pain
- Muscle pain

Psychological/psychiatric symptoms

- Symptoms of depression
- Symptoms of anxiety
- Symptoms of post-traumatic stress disorder

Ear, nose and throat symptoms

- Tinnitus (ringing in the ears)
- Earache
- Sore throat
- Dizziness
- Loss of taste, smell or both

Dermatological symptoms

- Skin rashes
- Hair loss

Children and young people may not have the most commonly reported symptoms. If you have any concerns, please discuss them with your healthcare professional.

The following symptoms are less common in children and young people than adults:

- Shortness of breath.
- Heart palpitations (heartbeats that suddenly become more noticeable).
- Chest pain.
- Persistent cough.
- Fluctuating heart rate.
- Pain when you breathe.

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Recommendation

Your healthcare professional will explore whether you may have long COVID if:

- you still have symptoms after four weeks, or
- you have new symptoms four weeks after the start of COVID-19.

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Recommendation

At your first consultation appointment, your healthcare professional will discuss and agree with you whether you need to have another appointment to assess your condition. They will also agree with you what further assessments you will need, based on your symptoms.

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Recommendation

If you need it, you will be supported through your assessment and the care you need, for example by having extra time for your appointment or having an interpreter. Your healthcare professional may ask to include your family or carers in discussions. They will agree this with you.

How will my symptoms be assessed?

Nobody understands your symptoms as well as you do. You are the best person to help your healthcare professional understand how they affect you. Your symptoms can be assessed in several ways, which will include looking at your physical and mental wellbeing.

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Recommendation

If your healthcare professional thinks you have long COVID, they will do the following.

- Take a medical history and ask about:
 - whether you have had or think you have had COVID-19, or have had a positive or negative COVID-19 test
 - your symptoms since having COVID-19
 - when the symptoms started and how long you have had them
 - any other health conditions you have.
- They may examine you to find out more about:
 - any physical symptoms you have
 - if you've noticed or are having difficulties with your memory or thinking
 - how you are managing with day-to-day activities, for example your work or education, getting about, general wellbeing, looking after yourself or feeling isolated
 - changes in your behaviour, emotions and mood.



Your healthcare professional will talk to you about the wide range of symptoms and how they may come and go over time.

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Recommendation

If you have a severe mental health condition or your healthcare professional is concerned that you are at risk of self-harm or suicide, you will be referred urgently for assessment by a mental health professional.

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Recommendation

You will be referred urgently to hospital if you have any signs that could indicate a life-threatening condition, for example:

- a low level of oxygen in your blood
- severe lung disease
- chest pain.

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Information

For information about what to do if your child seems very unwell, please visit www.nhs.uk/conditions/coronavirus-covid-19/symptoms/coronavirus-in-children/



What tests will I have?

Your healthcare professional will carry out tests to investigate your symptoms. This could help them rule out other conditions.



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Recommendation

Tests may include:

- blood tests
- if appropriate, an exercise tolerance test suited to your ability (for example a one-minute sit-to-stand test).
- measuring your lying and standing blood pressure and heart rate
- if you haven't already had one, a chest X-ray by 12 weeks if you still have breathing difficulties.

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Recommendation

Symptoms of postural tachycardia syndrome (PoTS) have been reported in people with long COVID. PoTS is an abnormal increase in heart rate that happens after standing up. It is associated with symptoms that include lightheadedness, palpitations and fatigue. These can sometimes be misdiagnosed as anxiety or panic attacks, and should be investigated.

What tests will I have? continued

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Recommendation

If you have mental health symptoms such as mild anxiety or mild depression, you may be referred:

- for psychological therapies, or
- to a liaison psychiatry service if you have more complex physical and mental health needs.

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Information

For more information about liaison psychiatry services, please visit www.rcpsych.ac.uk/mental-health/treatments-and-wellbeing/liaison-psychiatry-services



What I found really useful is having some investigations.



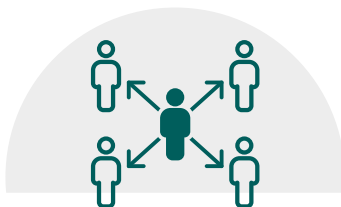
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Recommendation

If your healthcare professional thinks your symptoms are not related to COVID-19 and may be due to another condition, you may be offered other tests. You may also be referred to a specialist in that condition.

How will my care be planned?

When planning your care, it is important that you are involved in discussions and decisions.



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Recommendation

After an assessment, your healthcare professional will discuss and agree with you what further assessment, support and rehabilitation you need and how to provide it. This will include:

- advice on self-help (see pages 14 and 15), and
- depending on your need and services available in your area:
 - support from integrated primary care, community and mental health services
 - referral to an integrated multidisciplinary assessment service (involving various professionals from health and social care)
 - referral to specialist care if you have complications. Specialist care is given by healthcare professionals who have been trained in treating specific health problems. For example, if your kidneys were affected by your COVID infection, you may need to see a specialist kidney doctor (nephrologist).

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Recommendation

To work out what support you need, your healthcare professional will talk to you about:

- the overall impact of your symptoms on your life
- how your symptoms may change or come and go, and how you might need different levels of support at different times.

What can help?

Various things may help your recovery including self-management and rehabilitation.

What can I do to help myself?

At your first appointment to assess your condition, you will be given advice and information on how you can manage your symptoms.

Things you can do for yourself

Set realistic goals with the help of your healthcare professional



Keep a record of:

- your goals and what you would like to achieve
- new symptoms or any changes in your symptoms
- the progress you are making towards your goals
- how you feel your recovery is going



Keep a symptom diary - a symptom-tracking app can help you do this



Know who to contact if you are worried about your symptoms or you need more support



Continues on page 15 —————>

Things you can do for yourself continued

Look at further sources of advice and support your healthcare professional has mentioned to you. These include:

- support groups
- online forums and apps, for example [NHS inform](#) or the open-access part of the [NHS website Your COVID recovery](#)
- how to get support from other services, including social care, housing, and employment, and advice about financial support.

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Make sure you have information about new or continuing symptoms of COVID-19 that you can share with your family, carers and friends. Your healthcare professional will give you it.

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Making sense of, and managing, chronic illness may become easier in peer-support communities (often though not always online), where new members learn practical approaches from more experienced ones...

Information

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Healthcare professionals do not know if taking over-the-counter vitamins and supplements helps with long COVID symptoms, makes symptoms worse, or has no effect at all.

Information

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Healthcare professionals do not know what medication can help treat long COVID. If you have symptoms, you can use the normal treatments for them – such as using a cream for a skin rash.

What will happen if I am referred for rehabilitation?



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Recommendation

If you are referred for rehabilitation, you will be assessed by one or more people from the rehabilitation team who will work out what help you need from different services. This could include physical and mental aspects of rehabilitation.

The team will make sure that all your symptoms have been investigated and it is safe for you to start rehabilitation.

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Recommendation

The team will work with you to develop and agree a personalised rehabilitation and management plan. This discussion will include:

- areas of rehabilitation and interventions based on the assessment
- deciding and setting goals and how to work towards them
- how to manage all your symptoms and what to do if they return or change
- advice on managing your return to work or education.

What can help? continued

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Recommendation

To make sure you know what's happening, you will be given a copy of your care plans or records to keep.

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Recommendation

Your healthcare professional will be able to support you when you talk to your employer about returning to work, or to your school or college about continuing your education. An example of this would be to suggest a phased return.

What happens if I need extra support?

Some people may need more care than others, for example if you are older or have disabilities. Your healthcare professional will look out for this and will work with you.

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Recommendation

If you are older or have a disability, you will be offered more support. This could include a short-term care package, advance care planning, and support with looking after yourself if you are living alone or have had a bereavement.

How will I be followed up?

Attending follow-up appointments with your healthcare professionals is an important step in your recovery.



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Recommendation

Your healthcare professional will do the following:

- Discuss and agree with you how often you will need follow-up appointments to check your progress and recovery.
- Discuss and agree which healthcare professionals should be involved.
- Ask what is the best way to check up on your progress, for example face-to-face or on-line.
- Check your current symptoms and discuss changes, for example any worsening symptoms and how these affect your life and wellbeing.

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Recommendation

You may be given the option to monitor yourself at home, for example to check your own heart rate, blood pressure and oxygen level. If this is agreed as part of your assessment, your healthcare professional will support you to do this.

They will discuss with you what the measurements mean and make sure you know when to ask for more help.



Information

Your healthcare professional will look out for symptoms that change, which could mean you need to be referred to a specialist or have more tests.



Recommendation

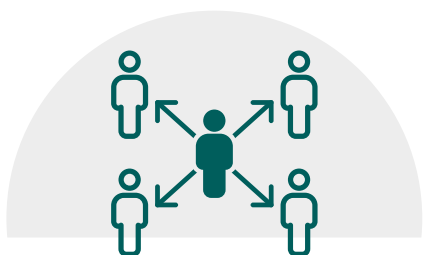
Depending on how you are getting on, healthcare professionals will jointly discuss and agree with you a discharge plan. They will talk with you about the best way to do this, by understanding your preferences, goals and other support available to you from friends, groups and family. Healthcare professionals will explain to you who to contact if your symptoms get worse.

My contacts

You can use this space to write down contact details for people involved in your care.

Who will be involved in my care?

You may see a range of professionals with various specialist skills who will help with different aspects of your recovery.



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Recommendation

The team caring for you may include experts in treating fatigue and respiratory symptoms, including shortness of breath. For example, a team could include specialists in:

- occupational therapy
- physiotherapy
- clinical psychology and psychiatry
- rehabilitation medicine.

Other specialists may be brought in, depending on your specific symptoms, for example:

- dietitian
- orthoptist (eye specialist)
- speech and language therapist.

Where can I find out more?

If you haven't found what you're looking for, here are some further sources of information. The organisations we have listed may be able to answer your questions and offer support.

National organisations

NHS inform: Longer-term effects of COVID-19 (long COVID)

www.nhsinform.scot/longer-term-effects-of-covid-19-long-covid

NHS inform is a national health information service for Scotland. The website provides a range of information and advice about COVID-19, for example self-care guides.

NHS 24

www.nhs24.scot

Phone: 111

NHS 24 is an online and out-of-hours phone service providing the Scottish people with access to health advice and information 24 hours a day, 365 days a year.

NHS 111

111.nhs.uk

Phone: 111

NHS 111 is an online and out-of-hours phone service providing people in England and Wales with access to health advice and information 24 hours a day, 365 days a year.

NHS Your Covid Recovery

www.yourcovidrecovery.nhs.uk

NHS Your COVID Recovery can help you understand what has happened and what you might expect as part of your recovery. The website also provides information for family, friends and carers.

Chest Heart & Stroke Scotland

www.chss.org.uk/coronavirus/coronavirus-information-and-support/long-covid

Helpline: 0808 801 0899

advice@chss.org.uk

or text NURSE to 66777

Chest, Heart and Stroke Scotland's 'Long COVID Support Service' allows people with long COVID to speak to nurses who are trained in managing some of the most common symptoms, such as breathlessness and fatigue.

We would like to thank the public partner (a volunteer who works with us), the carer and the people with experience of long COVID who contributed to the development of this booklet.



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