

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 Scottish Intercollegiate Guidelines Network (SIGN), the National Institute for Health and Care Excellence (NICE) and the Royal College of General Practitioners (RCGP) on managing the long-term effects of COVID-19.

The booklet will cover:	The booklet will not cover:
<ul style="list-style-type: none">• Management of 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. 	<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 chronic fatigue syndrome 



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

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 people usually start to feel better in a few weeks. Unfortunately, some people take a lot longer to get better. Long COVID can affect your whole body.

Ongoing or new symptoms of COVID-19 can change and come and go over a period of 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, definitions that healthcare professionals use, are:



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



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

Healthcare professionals also talk about the signs and symptoms of COVID-19 that last up to four weeks. This is called '**acute COVID-19**'.



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/



Signs and symptoms in **children and young people** are different from those in adults. Information can be found here www.nhs.uk/conditions/coronavirus-covid-19/symptoms/coronavirus-in-children/

How can I tell if I have long COVID?

If you have had COVID-19, the healthcare professional you speak with will talk to you about what to do if your symptoms are not getting any better. Unfortunately, there is no way to predict how long recovery will take.

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Recommendation

Whether you develop long COVID is not thought to be linked to how severe your COVID-19 was (including whether you were in hospital). The healthcare professional you speak to will give you advice and written 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
 - 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.

Your healthcare professional will do the following:

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



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

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

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)

Continues on page 6 —————>

Common symptoms of long COVID continued

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

Gastrointestinal symptoms (digestive system)

- Abdominal pain
- Nausea
- Diarrhoea
- Anorexia and reduced appetite (in older people)

Musculoskeletal symptoms

- Joint pain
- Muscle pain

Psychological/psychiatric symptoms

- Symptoms of depression
- Symptoms of anxiety

Ear, nose and throat symptoms

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

Dermatological symptoms

- Skin rashes

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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 whether you need to have another appointment to assess your condition. They will also agree with you what further assessments will be needed, based on your symptoms.



...actually just the experience of being heard and feeling like somebody got it and was being kind about it... I just kind of needed to know that I wasn't losing it really and it was real what I was experiencing...

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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 else understands your symptoms as well as you and 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.

‘ The symptoms were like a game of whack-a-mole. Different ones would surge at different times and in different places in my body.

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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 be a life-threatening complication, for example:

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

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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 some tests to investigate your signs and symptoms. This will also 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

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



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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 will be offered other appropriate tests. You may also be referred to a specialist in that condition.



What I found really useful is having some investigations.

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 your assessment your healthcare professional will discuss with you and agree what further assessment, support and rehabilitation you need and how this will be provided. This will include:

- advice on self-management, with the option of supported self-management (see pages 13 and 14), and
- depending on your need:
 - support from primary care, community and mental health services
 - referral to a multidisciplinary assessment service (involving various professionals from health and social care)
 - referral to specialist care if you have complications.

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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, even if each individual symptom by itself may not feel that bad
- 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 approaches can help your recovery including self-management and rehabilitation. There is specific information about older people and children on page 17.

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
- 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 14 —————>

Things you can do for yourself continued

Look at further sources of advice and support your healthcare professional has made you aware of. 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 this.

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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...

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Recommendation

You may be put in touch with a link worker or support worker who will work with you to find ways to improve your health and wellbeing.



It is not known if taking over-the-counter vitamins and supplements will help you manage long COVID symptoms. It is also not known if they are harmful or do not affect the treatment of COVID-19.

What will happen if I am referred for rehabilitation?

Rehabilitation is the process of helping you recover from your condition and getting you as close as possible to how you were before.



Recommendation

If you are referred for rehabilitation, you will be assessed by a team who will work out what help you need from different services. This could include physical, psychological and psychiatric aspects of rehabilitation.

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



What would be most helpful is... a COVID clinic that had experts from respiratory, cardiology, rheumatology, neurology, physiotherapy etc, so you could go along for half a day and see people from these different departments, they can refer you for tests and you can get a plan in place...

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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 your assessment
- deciding and setting goals and how to work towards them
- how to manage all your symptoms, for example advice and education on managing breathlessness, fatigue and brain fog.

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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, for example by suggesting a phased return.

How will I be supported if I'm older?

If you are older, you may not have the most common ongoing or new symptoms so your healthcare professional will look out for this.

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Recommendation

If you are older, you will be offered extra support if you need it. This could include a short-term care package, advance care planning and support with looking after yourself if you have no-one at home, or if you have had a bereavement.

What support can be expected for children?

Children may not have the most common symptoms. Your healthcare professional will look out for this.

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Recommendation

Your healthcare professional may wish to make an early referral for your child.

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 remotely.
- 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 that you know when to ask for more help.

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

Who will be involved in my care?

You will 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 will 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.

Where can I find out more?

If you haven't found what you're looking for, we think it would be helpful for you to visit the following websites.

Websites



NHS inform

www.nhsinform.scot/illnesses-and-conditions/infections-and-poisoning/coronavirus-covid-19/

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 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.

We would like to thank the public partner, the carer and the people with lived experience of long COVID who contributed to the development of this booklet.



Healthcare Improvement Scotland

Edinburgh Office

Gyle Square
1 South Gyle Crescent
Edinburgh
EH12 9EB

0131 623 4300

Glasgow Office

Delta House
50 West Nile Street
Glasgow
G1 2NP

0141 225 6999