

Supporting Long Covid care

Long Covid (also known as [post-COVID-19 condition](#) and [post-COVID-19 syndrome](#)) is the experience of still being unwell in the weeks, months or even years following a COVID-19 infection.

Long Covid symptoms can have a range of effects on people, and people with Long Covid can find it hard to put symptoms into words so others know what it is really like.

This tool has been informed by the findings of the [STIMULATE-ICP active case finding](#) and [HI-COVE](#) studies which seek to understand experiences of Long Covid in order to support people's help seeking. It has also been co-developed with people living with Long Covid and professionals who work with people living with Long Covid. Our tool works to help people living with Long Covid talk about their symptoms so they can get care and support.

Topics covered within this tool:

1. [Checking if your symptoms](#) might be Long Covid (page 2).
2. [Talking about your symptoms with professionals](#) (page 4).
(this includes healthcare professionals, but also pharmacists, social prescribers, community/voluntary organisation workers and employers)
3. [Talking about your symptoms with family, friends and others](#) you might turn to for support (page 5).
(for example, faith leaders and support workers)
4. [Talking about your mental health](#) (page 6)
(emotional problems, changes in your mood and feelings of wellbeing).
5. [Advice on next steps and getting help](#) for your symptoms (page 7).
6. [Getting additional support](#) for your symptoms and the impact these might have. (page 9).

Throughout each section we have included example experiences from others with Long Covid symptoms to show that **you are not alone!**

Please navigate to the relevant section for more information.

Link addresses from this webpage:

- Post-COVID-19 condition: www.who.int/publications/i/item/WHO-2019-nCoV-Post_COVID-19_condition-Clinical_case_definition-2021.1
- Post-COVID-19 syndrome: <https://www.nice.org.uk/guidance/ng188/resources/covid19-rapid-guideline-managing-the-longterm-effects-of-covid19-pdf-51035515742>
- STIMULATE-ICP active case finding: <https://www.stimulate-icp.org/long-covid-inequalities>
- HI-COVE: <https://blog.westminster.ac.uk/hicovestudy/>

Do I have Long Covid?

Long Covid (also known as post-COVID-19 condition and post-COVID-19 syndrome) is the experience of still being unwell in the weeks, months or even years following a COVID-19 infection.

Common symptoms include:

Nervous System and Mental Health

- Headaches
- Dizziness
- Pins and needles
- Loss of taste/smell or altered taste/smell
- Visual disturbance
- Restless legs
- Head pressure
- Eye problems such as blurred vision and squinting
- Numbness including in limbs and genital areas
- Sleep disturbance
- Cognitive problems such as “brain fog”, trouble thinking, loss of concentration or memory issues
- Altered sensations in the body
- Speech problems, difficulty talking and not being able to find the words
- Anxiety
- Depression
- Weak Bladder and incontinence

Respiration System

- Cough
- Shortness of breath
- Chest tightness, pressure or pain

Cardiovascular

- Palpitations
- Chest pain

Gut

- Vomiting
- Loss of appetite
- Diarrhoea
- Feeling sick
- Abdominal pain

Musculoskeletal

- muscle and joint pains
- problems walking

Ear, Nose and Throat

- Earache
- Nasal congestion
- Sore throat
- Sneezing
- Hoarse voice
- Tinnitus

Skin and Hair

- Rashes
- Itching
- Hair loss
- Skin discolouration such as brown spots and/or marks

General

- Exhaustion or fatigue
- Fever
- Chills
- Circulation problems including going hot and cold
- Not being able to eat certain foods
- Low libido
- Pain and/or pressure in glands

These symptoms may change and come and go at different times.

Some of the symptoms you are experiencing may be associated with Long Covid. You can use the **My Long COVID Needs** assessment tool to check your symptoms and the support you need by visiting mylongcovid.org.uk.

Please note: It usually takes around **5-10 minutes** to complete My Long COVID Needs. Once you are finished, you have the option of **downloading the report** to share with professionals (if you choose to). Completing the My Long COVID Needs assessment is optional and you do not need to complete it in order to use this tool.

If you are suffering with symptoms, please seek advice from a healthcare professional.

Link addresses from this webpage:

- My Long COVID Needs assessment tool: <https://mylongcovid.org.uk/>

Difficult to talk with professionals?

Do you find it difficult to talk to professionals or seek care for the symptoms you are experiencing?

You are not alone.

We know that it can be hard telling professionals about your symptoms and the way they affect you.

We aim to make this a little easier for you, with tips on speaking to any professional. This includes healthcare professionals, but also pharmacists, social prescribers, community/voluntary organisation workers and employers. You will find this in the Next steps and additional support section.

Some of the **reasons** people avoid speaking to professionals about their symptoms include:

- Fear of being accused of exaggerating illness or not being believed
- Earlier bad experiences with the NHS
- Earlier experiences of discrimination, such as ageism, racism or sexism
- Fears of rejection or dismissal
- Fear of being told symptoms are “all in the mind”
- Not wanting to have Long Covid
- Not being sure if they really have Long Covid
- Not wanting to burden the NHS or not feeling worthy of taking up NHS time
- It’s too hard to get an appointment
- Belief that no one can help with symptoms
- The changing nature of symptoms makes accessing care difficult

You can find **examples of other people’s experiences** by visiting this webpage.

Although people with Long Covid do have bad experiences, people do find ways to get support, even if they have to get support from charities and others who have Long Covid. So, it is important to reach out if you are suffering. Why not try speaking to friends or family using the advice in the [Do you need help talking about your symptoms with family or friends?](#) section, or use the resources in the [Next steps and getting support](#) section to guide a conversation with a professional.

Difficult to talk with family and friends?

Do you find it difficult talking about your symptoms with family, friends or other support networks?

We know people with Long Covid **struggle to talk** about their symptoms and feelings with family, friends and others in their social circle. This can be for a number of reasons.

Sometimes people don't want to talk to people about their symptoms **because** they:

- Are unsure that their symptoms are Long Covid
- Are worried about other people's reactions
- Believe they should have got better already
- Feeling embarrassed or shame
- Fear people will think 'it's all in their head', they are exaggerating or being
- Fear of being discrimination or stigma from within communities
- Not wanting to be seen as unwell or as someone who needs to be cared for
- Fears others will think Long Covid is not a 'real' illness

You will find **examples of other people's experiences** by visiting this webpage.

You can read more about Long Covid and stigma in this article: "Long COVID stigma may encourage people to hide the condition" at <https://theconversation.com/long-covid-stigma-may-encourage-people-to-hide-the-condition-194939>

Difficult to talk about your mental health?

Do you find it difficult talking about your mental health?

We know that **Long Covid can affect your mental health**, and that you might be suffering with your thoughts and feelings alongside your physical symptoms. For example, you may be experiencing anxiety or feeling down. This does not mean that your Long Covid symptoms are 'all in your head'. The impact of these mental health or emotional effects can be traumatic for people and many worry that they cannot talk about this and should focus on the physical symptoms.

For example, people with Long Covid have said that:

- Symptoms can be entirely mistreated as a mental health condition which is upsetting
- The language used to describe symptoms can be unhelpful
- They can be made to feel like they are exaggerating their symptoms

People living with Long Covid have suggested **different ways** to help manage their mental health and these may help you too. These include:

- Allowing themselves time to rest
- Focusing on self-care and taking time for themselves
- Speaking with others – friends, family or support groups
- Engaging with activities (both online and offline) – e.g. walking groups* or coffee mornings
- Following healthy behaviours

** for those who are able to tolerate and manage exercise*

Although people with Long Covid do have bad experiences, people do find ways to get support, even if they have to get support from charities and others who have Long Covid. So, it is important to **reach out** if you are suffering. Why not try speaking to friends or family using the advice in the [Do you need help talking about your symptoms with family or friends?](#) section, or use the resources in the [Do you need help talking about your symptoms with professionals?](#) section to guide a conversation with a professional.

Next steps and getting support for your symptoms

Finding the support, you need can be difficult, but it is important that you do seek advice and we hope this section will make it easier.

People living with Long Covid have found keeping a **diary** or making a **note** of their symptoms helpful.

Consider making a note of the **answers to these questions** before your appointment:

- When did you have the COVID-19 infection that has resulted in new symptoms?
- What new symptoms are you experiencing?
- Do these symptoms impact on your usual activities?
- What impacts do these symptoms have on your life?
- Does anything make these symptoms worse?
- What triggers your symptoms?
- When did you notice the new symptoms?
- What would you like to happen next?

Do feel free to return to ask for help from another member of the practice team if you feel the consultation did not go well.

You could discuss with your GP the possibility of a referral to a **post-COVID service** (also known as a **Long Covid service**). These are services that have been set up especially to provide care for symptoms of Long Covid.

We are aware that there are variations in service provision in different areas.

You might find it useful to connect with **social prescribing**. Social prescribing is a personalised approach to improving health and wellbeing by linking with different organisations and services that can support your needs. It is open to everyone. You can speak to your GP about accessing social prescribing.

Score	Energy levels	Thinking	Breathing	Mobility / Activity	Mood
NORMAL	I am able to manage all usual activities <input type="checkbox"/>	I can think clearly and my mental ability is basically ok <input type="checkbox"/>	I am back to normal <input type="checkbox"/>	I am back to normal <input type="checkbox"/>	My mood is basically ok <input type="checkbox"/>
MILD	I am feeling tired but managing normal activities <input type="checkbox"/>	I am OK apart from brief thinking lapses <input type="checkbox"/>	I am not quite back to normal, but I can do everything I need to <input type="checkbox"/>	I am nearly back to normal <input type="checkbox"/>	I am OK apart from moments of low mood or anxiety <input type="checkbox"/>
MODERATE	I am feeling tired, needing to rest frequently, restricting normal activities <input type="checkbox"/>	Most days I have some difficulty with memory, concentration or work finding <input type="checkbox"/>	I am breathless on hills/stairs/walking fast <input type="checkbox"/>	I have to move more slowly, but doing everything <input type="checkbox"/>	Most days I feel low in mood <u>or</u> anxious <input type="checkbox"/>
SEVERE	I have significant tiredness, occasionally unable to participate in normal activities <input type="checkbox"/>	My memory or concentration is now poor and I struggle to think <input type="checkbox"/>	Difficulty breathing stops me doing some things <input type="checkbox"/>	I struggle with some activities <input type="checkbox"/>	My mood or anxiety is having a significant effect on my usual activities <input type="checkbox"/>
	I have significant tiredness, and am unable to participate in normal daily activities <input type="checkbox"/>	I just cannot think or remember, and this is having a significant effect on my usual activities <input type="checkbox"/>	I am breathless on minimal activity <input type="checkbox"/>	I can barely get around <input type="checkbox"/>	I feel hopeless <input type="checkbox"/>
	Fatigue is debilitating and persistent. I am dependent on others for all tasks <input type="checkbox"/>	I am forgetting or unable to do important tasks that put me or others at risk of harm <input type="checkbox"/>	I am breathless at rest <input type="checkbox"/>	I am bed-bound <input type="checkbox"/>	I feel that life is not worth living <input type="checkbox"/>

Image by 'Joined Up Care Derbyshire' fauzia.begum2@nhs.net

This grid has been produced by "Joined Up Care Derbyshire" fauzia.begum2@nhs.net. It has been developed to help people with Long Covid describe the severity of their symptoms to professionals. This can be taken to your primary care consultation.

Please note: This grid only contains the **most common symptoms** associated with Long Covid. Please feel free to add in the symptoms that are bothering you the most if this is more helpful to you. 'I am back to normal' means that this symptom is the same as it was prior to your COVID-19 infection.

Do you need additional support?

Below you will find a list of **services and resources** that you may find useful.

NHS Resources

- Long Covid NHS website: <https://www.nhs.uk/conditions/coronavirus-covid-19/long-term-effects-of-coronavirus-long-covid/>
- Your Covid Recovery: <https://www.yourcovidrecovery.nhs.uk/>

Long Covid Charities

- Long Covid Support: <https://www.longcovid.org>
- Long Covid SOS: <https://www.longcvidsos.org>
- Long Covid Kids: <https://www.longcovidkids.org>

Mental Health and Wellbeing

- **Samaritans:** <https://www.samaritans.org> or 116 123
Samaritans provide 24 hour support, every day of the year to anyone who is struggling.
- **Mind:** <https://www.mind.org.uk> or 0300 123 3393
Mind provide advice and support to empower anyone experiencing a mental health problem.
- **Hub of Hope:** <https://hubofhope.co.uk>
The Hub of Hope is the UK's leading mental health support database. It is provided by national mental health charity, Chasing the Stigma, and brings local, national, peer, community, charity, private and NHS mental health support and services together in one place for the first time.

Additional Support

- **Citizen's Advice:** <https://www.citizensadvice.org.uk> or 0800 144 8848
The Citizens Advice service provides free, independent, confidential and impartial advice on a range of topics including debt, benefits, health, employment and law.
- **National Debtline:** <https://www.nationaldebtline.org> or 0808 808 4000
Free debt advice
- **Shelter:** <https://www.shelter.org.uk> or 0808 800 4444
Housing and homeless charity
- **Age UK:** <https://www.ageuk.org.uk> or 0800 678 1602
Charity supporting older adults
- **ACAS:** <https://www.acas.org.uk> or 0300 123 1100
ACAS provide free and impartial advice to employers, employees and their representatives on: employment rights, best practice and policies resolving workplace conflict.
- **The Trussel Trust:** <https://www.trusselltrust.org> or 0808 2082138
A nationwide network of food banks providing emergency food and support to people facing hardship.
- **Carers UK:** <https://www.carersuk.org> or 0808 808 7777
Advice and support for unpaid carers.
- **Mind advice** on how to find peer support : <https://www.mind.org.uk/information-support/drugs-and-treatments/peer-support/finding-peer-support>

- **Long COVID Physio:** <https://longcovid.physio>
Long COVID Physio is an international peer support, education and advocacy, patient-led association of Physiotherapists living with Long Covid and allies.
- **Long Covid guidance for employers:** https://www.fom.ac.uk/wp-content/uploads/longCOVID_guidance_managers_04_small.pdf
A useful resource for employers with practical advice on facilitating return to work of employees with Long Covid.
- **Long Covid guidance for healthcare professionals:** https://www.fom.ac.uk/wp-content/uploads/longCOVID_guidance_04_small.pdf
A useful resource for healthcare professionals on return to work for patients with Long Covid.
- **Local leisure and community centres** in your area may have information regarding localised support.
- For **social prescribing** referrals please contact your GP.