

Long COVID and Post-COVID Syndrome in Adults

This fact sheet helps you to know when and where to get help and advice and what you can do yourself to maintain and improve your health and wellbeing on the road to recovery from Long COVID.

What is Long COVID?

You may hear people referring to both 'Long COVID' and 'Post-COVID Syndrome'.

Long COVID is any signs and symptoms that last more than 4 weeks after developing COVID-19. This includes symptoms of COVID-19 that take 4-12 weeks to clear, and Post-COVID Syndrome as well.

Post-COVID Syndrome is signs and symptoms that develop during or after a COVID-19 infection that continue for more than 12 weeks and are not explained by another diagnosis

Recovery from Acute COVID-19 is unpredictable and can take 2-12 weeks or even longer after symptoms develop. Whether it is mild or needs hospital care, symptoms can continue, recur or fluctuate, and new ones may develop.

The definitions above are the ones used by The National Institute for Health and Care Excellence (NICE 2020) and in this fact sheet.

Most people get better from Long COVID and Post-COVID Syndrome. In people with diagnosed COVID-19, 3 out of 10 people will still have at least 1 symptom at 4 weeks, falling to 1 out of 10 after 12 weeks. Whether admitted to hospital or not, some people will still have symptoms at 6 months. They can range from symptoms that are mild to those that are serious and/or disabling (NIHR report, 2021). See under 'What can I do to help myself' for further numbers.

Possible Long COVID symptoms

Long COVID usually presents with clusters of symptoms, often overlapping, which can fluctuate, change over time and affect any system in the body. People with Long COVID may develop any of the symptoms below, but the commonest are fatigue, loss of sense of smell (anosmia), psychological disturbances, 'brain fog' (cognitive impairment, breathlessness, chest tightness, cough and sleep disturbance).

Generalised symptoms	Nervous System symptoms	Musculoskeletal symptoms	Gastrointestinal symptoms
Fatigue (commonest symptom)	'Brain fog', loss of concentration or memory issues ('cognitive impairment')	Joint pain	Abdominal pain
Fever	Headache	Muscle pain	Nausea
Lung symptoms	Sleep disturbance	Ear, nose and throat symptoms	Diarrhoea
Breathlessness	Peripheral neuropathy symptoms (pins & needles, numbness)	Loss of taste and/or smell	Anorexia and reduced appetite
Cough	Delirium (in older people)	Tinnitus	Psychological/psychiatric symptoms
Heart Symptoms	Dermatological	Earache	Symptoms of depression
Chest tightness	Skin rashes	Sore throat	Symptoms of anxiety
Chest pain		Dizziness	
Palpitations			

What can I do to help myself?

From the moment you think you may have Long COVID it is important to engage, ask questions and get involved in the planning and decisions that will support your recovery.

If you have internet access, the NHS site yourcovidrecovery.nhs.uk gives useful, detailed advice on how to manage a whole range of specific symptoms including breathlessness, heart symptoms, cough, anxiety and poor concentration amongst many others.

You should also be mindful of symptoms that might suggest other conditions unrelated to COVID but which still need urgent attention. A cough lasting more than 3 weeks with a negative COVID-19 test could be lung cancer, as could unexplained breathlessness. If in any doubt, speak to a GP or ring NHS 111. Other symptoms include blood in your poo, urine or spit, discomfort on swallowing, bowel changes, breast changes, new moles or abnormal vaginal

bleeding amongst many others. www.cancerresearchuk.org has a very useful diagram of the main symptoms to watch for.

You will find it useful to monitor your goals, symptom changes (a symptom tracking app might be useful for this), your progress and your personal feelings about your recovery.

Support groups have been set up and are proving useful for people to share their experiences, find common ground and offer support. Please see the section 'Where can I find out more?' for further information.

You may be able to take up the opportunity for engaging locally in activities and pastimes that you enjoy, or that you would like to try, through a scheme known as Social Prescribing. If this is something that might interest you, ask your GP practice for more information.

What can I do to help myself? (Continued)

It is important that you consider self care for your general health such as healthy eating, sleeping and getting moving again, particularly if your COVID-19 has stopped you from doing things. See the 'Managing Daily Activities' section of the [yourcovidrecovery](#) website (link below).

A very common Long COVID symptom is loss of sense of smell. There is evidence that this can be improved through 'smell training' by sniffing four different fragrances several times a day. A popular choice is rose, eucalyptus,

lemon and clove. The www.fifthsense.org.uk and www.AbScent.org websites include good advice.

If your symptoms are not improving or are concerning, then you should contact your GP practice. Work with your healthcare professionals to set goals that are realistic, meaningful and at a pace that is right for you, both before and after you have had any investigations or a Post-COVID clinic appointment.

Remember you are not alone

In April 2021, the ONS reported that in the four week period to 6 March 2021: **1.1 million people** have had symptoms for more than 4 weeks (Long COVID); **697,000** had symptoms for more than 12 weeks (Post-COVID Syndrome); **70,000** still had symptoms after a year of suspected COVID-19; **674,000** had symptoms that adversely affected their lives and **196,000** had symptoms that limited their daily activities 'a lot'.

What can I expect to happen?

Most people will get better from Long COVID within a few weeks. If your symptoms are not severe, you may be able to manage them yourself – see the previous section.

If you have visited your GP and Long COVID is suspected, your healthcare professionals will gather further information (a medical history) from you. This will include whether you have had, or think you have had, COVID-19, your physical symptoms, how long you have had them and whether you have any other conditions such as diabetes, heart disease, lung conditions such as COPD, and mobility problems.

They will also ask you whether you are experiencing problems with your memory or thinking (some people describe this as a 'brain fog'), how you are coping on a day to day basis and any changes to your mood and behaviour. They may check your oxygen levels during test such as getting you to sit and stand over one minute or ask you to monitor your oxygen

levels at home. This is done via a small device gently clipped onto the end of a finger.

To make sure you get support from a range of health care professionals, if your symptoms are prolonged or severe, you may be referred to an NHS Post-COVID clinic or to local services for specific conditions.

Further examination and appropriate investigations will be arranged to see if your symptoms are being caused by something else and to find out how your COVID-19 infection is affecting you. These might include blood tests, appropriate exercise tolerance testing, blood pressure and heart rate monitoring, a chest X-ray if there are ongoing breathing problems, and appropriate referrals for any mental health concerns.

Follow up is essential. As symptoms of Long COVID can fluctuate and new ones appear, you may feel well when you are first seen, but still need follow up.

When to seek medical help

If you think you may have Long COVID

If you are worried about suspected Long COVID symptoms that last longer than 4 weeks, are worsening, are not improving or are concerning you, contact your GP practice. It will be important for them to establish whether this is a part of Long COVID, or due to an unrelated health issue which might need immediate attention.

Acute COVID-19

If you think you are developing COVID-19 for the first time, go to NHS Online to help with the diagnosis or ring the Coronavirus helpline on: 0800 028 2816 (open 8am to 10pm every day) if your questions can't be answered online.

If you experience any worsening, changing or new symptoms during the acute stage it is important to let your healthcare professional know.

Phone 111 if your symptoms worsen during isolation, especially if you are in a risk group, breathlessness develops or worsens or your symptoms haven't improved in 10 days. Once you have been professionally assessed it is important to follow up with your healthcare professional as arranged between you.

To find out about using the NHS during the COVID-19 pandemic:

- ◆ Visit the website of your general practice
- ◆ Use the NHS App
- ◆ Call the surgery
- ◆ Visit NHS.co.uk

Where can I find out more?

Please see the complementary leaflet to this one on the Long COVID (Post-COVID Syndrome) section of the [NHSEI](#) website.

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

<https://www.sign.ac.uk/media/1825/sign-long-covid-patient-booklet-v2.pdf>

COVID-19 rapid guideline: managing the long-term effects of COVID-19

NICE guideline [NG188] – Information For Public

<https://www.nice.org.uk/guidance/ng188/informationforpublic>

Your COVID Recovery

<https://www.yourcovidrecovery.nhs.uk>

Covid-19 Survivors Group UK:

https://www.selfhelp.org.uk/COVID-19_Survivors_Group_UK

Long COVID Support:

<https://www.longcovid.org>