

Long Covid Support Information

It is important to correctly identify whether you have an acute Covid-19 infection so that you know whether to seek a test. This is important so that you know to self-isolate in order to avoid transmission to others and to seek appropriate medical support where necessary:

NHS Covid-19 Symptom List



SERIOUS COVID-19 SYMPTOMS REQUIRING IMMEDIATE MEDICAL CARE

- If you develop any of these symptoms, call your healthcare provider or health facility and seek medical care immediately.
- This is not an exhaustive list. These are the most common symptoms of serious illness, but you could get very sick with other symptoms – if you have any questions, call for help immediately.



Shortness of breath/ Difficulty breathing



Loss of speech or mobility or confusion



Chest pain

MOST COMMON SYMPTOMS



Fever



Cough



Tiredness



Loss of taste or smell

LESS COMMON SYMPTOMS



Sore throat



Headache



Aches and pains



Diarrhea



A rash on the skin or discolouration of fingers or toes



Red or irritated eyes

PLEASE NOTE:

- If you live in an area where malaria, dengue or other infections are common and you have any of above symptoms, seek immediate medical care according to the local health authorities.
- Stay in touch with your primary care provider to ensure you continue to receive the routine care you need, such as medication refills, follow-ups and other routine consultations.

Source: World Health Organization

Symptoms of Long Covid

Here are links to the [NHS](#) pages on symptoms of Long Covid. The most comprehensive survey of Long Covid symptoms amongst patients to date can be found on the [Patient Led Research study](#).

The [Long Covid Kids](#) website has further information on the long-lasting effects of Covid-19 in children, including a downloadable symptoms chart.

Symptom Management

The following links give general advice on how to support your recovery:

Lancashire NHS trust, [Covid-19 Supporting your recovery](#) - includes breathing exercises, diet, gentle exercises for mobility and core stability, fatigue and advice on mental health.

Homerton University Hospital (NHS) [Post-Covid19 Patient Information Pack](#) - helpful tips on managing breathlessness, coughing, energy conservation, relaxation and diet.

This is also an excellent site that pulls a lot of diverse information into one place [Managing Long Covid](#).

NHS Your COVID Recovery

As you find yourself recovering from COVID-19 you may still be coming to terms with the impact the virus has had on both your body and mind.

These changes should get better over time, some may take longer than others, but there are things you can do to help.

Your COVID Recovery helps you to understand what has happened and what you might expect as part of your recovery.

[Your Covid Recovery - NHS website](#)

Fatigue Management

The [Long Covid Physio](#) website contains lots of advice on pacing and has been specifically developed for people with Long Covid. Pacing is a strategy and rehabilitation technique that modifies activities in daily life, to manage symptoms such as fatigue and post-exertion malaise. Pacing has been adopted successfully by people living with a range of different health conditions, although the type of pacing used may differ.

Video series on post-COVID fatigue management

The videos below were developed by the [AWRC](#) at Sheffield Hallam University in partnership with the CRESTA clinic as Newcastle Hospitals Foundations Trust, Newcastle University, and University of Northumbria.

[Fatigue Video 1 - YouTube](#)

[Fatigue Video 2 - YouTube](#)

[Fatigue Video 3 - YouTube](#)

[Fatigue Video 4 - YouTube](#)

[Fatigue Q & A - YouTube](#)

Respiratory Recovery

The [British Lung Foundation and Asthma UK](#) have created a Post-COVID hub for people with breathing difficulties.

Dysautonomia

In the following [Dysautonomia International webinar](#) on Long COVID, researchers from Stanford University and Stony Brook University discuss dysautonomia symptoms that are occurring in some COVID-19 patients.

If you are interested in finding out more here is a [Dysautonomia International list of providers](#)

There are also location-specific [Dysautonomia International private groups](#) on Facebook tend to have much more robust lists of provider recommendations for each location.

POTS

Postural tachycardia syndrome (POTS) is an abnormality of the functioning of the autonomic (involuntary) nervous system that results in a fast heart rate. The [PotsUK](#) website provides further information on the condition.

ME/CFS

[ME Action](#) has produced a page on their website that explores the links between Long Covid and ME. Whilst there is overlap with other chronic illnesses, it is important that physicians recognize these links alongside other possible differential diagnoses, and treat COVID-19 patients accordingly. Patients' symptoms and complications vary and can result in distinct diagnoses.

Loss of Smell/Taste

A loss or change to your sense of smell or taste is listed as one of the main symptoms of Covid-19 by the NHS. The [AbScents](#) website may be of interest to those dealing with loss of smell.

[Taste & Flavour](#) is a free digital cookbook for people who are experiencing changes in taste and smell as a result of Covid-19 and was written by the co-founders of Life Kitchen, a not-for-profit cookery school for people whose taste has been affected by cancer treatment.

Tinnitus

In Dec 2020 Tinnitus was officially recognised as a symptom of Long Covid and it has been acknowledged that viruses in general can damage the ear causing tinnitus/hearing loss. [The British Tinnitus Association](#) has useful information on it's website. If you are suffering with tinnitus, it is important to reach out to your GP to discuss getting a professional assessment, as there are ways to control it. Stress and anxiety can play a big part and sound apps (ocean waves etc), meditation, yoga and social interaction (chatting to people on the phone etc) can help. The NHS recommend the [ReSound app](#) for tinnitus relief.

Getting Help

Medical Appointments

It is a good idea to take with you notes of key points you wish to convey and questions to ask, and also to take notes during appointments.

UK: The [NICE clinical guideline](#) states that patients may be referred by their GP 4+ weeks from known or suspected Covid-19, and that you don't need to have a positive test result or to have been hospitalised. People should be offered tests and investigations tailored to their signs and symptoms to rule out acute or life-threatening complications and find out if symptoms are likely to be caused by Long COVID or a new, unrelated diagnosis.

US: The [CDC clinical guideline](#) states that post-COVID conditions are a wide range of new, returning, or ongoing health problems people can experience four or more weeks after first being infected with the virus that causes COVID-19. Even people who did not have COVID-19 symptoms in the days or weeks after they were infected can have post-COVID conditions.

[Top tips for doctors to recognise and manage Long Covid, written by two UK GPs](#)

[The locations of Long Covid Clinics in England announced on the 18th December 2020](#)

The Clinics listed are now being referred to as Assessment Services and may not yet be fully operational. It is best to ask your GP to clarify what is available at local level. Please complete our [Long Covid Clinics](#) survey to feedback on your experience.

What you can do if you are still struggling to get help:

If you live in England, you can write to:

Your GP or GP Practice Manager. Also, your GP practice should have a Patient Participation Group, consisting of patients and carers, the practice manager and one or more GPs.

Your local Healthwatch, (there is one in every area of England). They aim to serve as a champion for the public in all matters relating to healthcare.

Your Clinical Commissioning Group. CCGs commission much of the NHS care including most hospital care. In some (but not all) areas, this includes GP services. Here is a handy tool if you are unsure of your CCG.

The following link provides more information as to how patients can have a say in their local healthcare services.

You can also write to your local MP and request that they advocate on your behalf.

1. Getting help from your GP: UK (England) template letter

This template letter you can share with your GP highlights how to request that:

- your illness is assigned the correct Long Covid diagnostic code;
- you are referred to a Long Covid clinic/assessment service;
- while awaiting a clinic referral you are referred for further investigations/treatment/support services as appropriate.

Please select the sections relevant to your own circumstances. There is a list of suggested references at the bottom of the template that you can also include where relevant.

[GP Letter Template](#)

2. Getting help from your GP: UK handout

Long Covid ScotlandThe Scottish campaign group have produced a printable/email-able leaflet for people to take to their GP.

[Click here to download the PDF](#)

3. Getting help from your GP: codes

SNOMED CT is a structured clinical vocabulary for use in electronic health records. The use of SNOMED CT as a consistent vocabulary for recording patient clinical information across the NHS helps ensure data is recorded consistently and accurately.

[Click here to download the PDF](#)

4. Long Covid in Children: Symptom Chart

A clear and informative chart of Long Covid symptoms in children based on information gathered from the [Long Covid Kids study](#). Long Covid Kids have teamed up with the PeopleWith to provide an App that enables parents to log their children's symptoms, generating a health report that can be shared with their GP. The information gathered will also help to develop a better understanding of Long Covid in children.

[Click here to download the PDF](#)

5. Return to work guide: For recovering UK workers

This leaflet offers guidance for workers from Occupational Health Professionals on how to manage getting back to work after COVID-19 infection and Long Covid. This leaflet is relevant to people already in employment or looking for work.

[Click here to download the PDF](#)

6. Advice on safe rehabilitation

These [leaflets](#) offer advice from Physiotherapists on how to resume activities at a pace that is safe and manageable. As it is currently unknown when and by what amount physical activity (including exercise or sport) is safe or beneficial, people should not be encouraged to push to the point of fatigue.

Mental Health and Bereavement

- **Vivup Phone 0330 380 0658**
- [Samaritans](#) Phone 116 123
- [Mind](#) - the mental health charity
- [Every Mind Matters](#) - practical tips/activities on looking after your mental health for all ages
- [The Help Hub](#) - Free confidential telephone/video consultation with trained therapist/counsellor
- [Childline](#) - support for under 18's Phone 0800 1111
- [Practitioner Health](#) - free therapy sessions for NHS workers
- [National Bereavement Alliance](#) - directory of bereavement support organisations, that offer specialist advice and support to adults and children that have lost someone close to them.
- [Cruse Bereavement Care](#) - Experienced volunteers provide free and confidential advice, information and support for anyone who has been

bereaved, by telephone, email or face-to-face. They also offer support to young people on their website. Phone: 0808 808 1677

Work, Benefits and Finance

- [Citizens Advice](#)
- [GOV.UK](#) advice on work and financial support
- [Personal Independence Payment \(PIP\)](#) - advice on claiming
- [Gov.uk PIP](#) - how to claim
- [Citizensadvice.org.uk](#) PIP points table
- [Citizensadvice.org.uk](#) PIP how decisions are made
- [Disabilityrightsuk.org](#) PIP a guide to making a claim
- [Turn2us.org.uk](#) - PIP: What is the PIP test
- [Money Saving Expert](#) - Financial advice including coronavirus specific guides
- [Step Change](#) - free confidential advice on debt/money management
- [Debt Advice Foundation](#) - free confidential debt advice
- [Support information for NHS employees](#)
- [SOM Return to Work Guide for Recovering Workers](#) - The Society of Occupational Medicine
- [Returning to work with ongoing COVID-19 symptoms](#) - Four videos of guidance for employees and managers