

## Long COVID

### What is long COVID?<sup>[1]</sup>

Coronavirus disease is an infectious disease caused by a novel betacoronavirus (an RNA virus) known as severe acute respiratory syndrome-coronavirus 2 (SARS-CoV-2 infection). The disease associated with it is now referred to as 'COVID-19'.

Long COVID (sometimes called post COVID-19 syndrome or post COVID-19 condition) is a multi-system condition with a range of debilitating symptoms:

- The signs and symptoms continue or develop after acute COVID-19 infection, with ongoing symptoms for more than 4 weeks, and are not explained by any alternative diagnosis.
- Long COVID includes both ongoing symptomatic COVID-19 (from 4-12 weeks) and post-COVID-19 syndrome (12 weeks or more).
- Long COVID may consist of a number of distinct syndromes, which can include post-ICU syndrome, post-viral fatigue syndrome, long-term COVID syndrome, and permanent organ damage.

12 weeks after infection there is a steady reduction in the number of people who have persistent symptoms of COVID-19. However, in people who have symptoms which persist for over 12 weeks many report that these problems are severely debilitating. Around 70% of people report their ability to undertake daily activities is adversely affected, while 20% report that this has been 'limited a lot'.

People who have had COVID-19 may also be more likely to develop new health conditions such as diabetes mellitus, heart conditions, or neurological conditions compared with people who have not had COVID-19.

Post-COVID conditions are very variable and may be attributable to a number of underlying causes, which may include:

- Organ damage resulting from acute phase infection.
- Complications from a dysregulated inflammatory state.
- Ongoing viral activity associated with an intra-host viral reservoir.
- Autoimmunity.
- Inadequate antibody response.

The prognosis for people with long COVID is also very variable. It is not possible to predict whether a person is likely to develop post-COVID-19 syndrome based on their symptoms (or clusters of symptoms) or were admitted to hospital during an acute COVID-19 infection.

## How common is long COVID?<sup>[1]</sup>

Studies show that around 10–20% of people infected by SARS-CoV-2 may go on to develop symptoms that can be diagnosed as long COVID. However, exact numbers of those living with the condition are uncertain.<sup>[2]</sup>

An estimated 2 million people in the UK were experiencing self-reported long COVID in July 2022. The prevalence of self-reported long COVID was highest in:<sup>[3]</sup>

- People aged 35 to 69 years.
- Females.
- People living in more deprived areas.
- People working in social care.
- People aged 16 years and over not working and not looking for work.
- People with another activity-limiting health condition or disability.

A study of long COVID in children and young people found that up to 1 in 7 children and young people may have symptoms linked to the virus 15 weeks later.

A meta-analysis identified the following risk factors for developing long-term effects of COVID-19:

- Female sex.
- Poorer pre-pandemic mental health.
- Poor general health.
- Asthma.
- People who are overweight or obese.

Other studies identified the following additional risk factors:

- Smoking or vaping.
- Previous hospitalisation for acute COVID-19.
- Severe COVID-19: greatest risk of neurological or psychiatric diagnoses.
- Aged 70 years or more, white ethnicity: greater absolute risk of death, readmission, and multiorgan dysfunction after discharge.

However, younger patients and ethnic minority individuals had greater relative risks compared to people aged 70 or more and those in the white ethnic group, respectively, and a recent large retrospective matched cohort study found that black, mixed ethnicity and other minority ethnic backgrounds were at increased risk of persistent symptoms.

People who are not vaccinated against COVID-19 and become infected may be at higher risk of developing post-COVID conditions compared to people who were vaccinated and had breakthrough infections. A UKHSA rapid review found that:

- People who received two doses of a COVID-19 vaccine were less likely to develop long COVID symptoms, or they had symptoms for a shorter duration, compared to people who were unvaccinated. This is supported by a number of studies.

- People who were vaccinated after being infected with COVID-19 also reported a shorter duration of post-COVID symptoms compared to those who were unvaccinated.
- Two doses of the COVID-19 vaccine provided a high level of protection against long COVID compared to one dose or no doses.

People who have experienced multisystem inflammatory syndrome (MIS) during or after COVID-19 illness may be at higher risk for ongoing multiorgan system effects and post-COVID conditions. MIS in children is rare and occurs 2 to 6 weeks after infection. It develops in less than 0.1% of children with COVID-19 (median age 8.6 years) and requires intensive care support in 68% of cases.

## How long does long COVID last?

Long COVID is a very variable condition and it is not currently possible to provide any general information about COVID recovery, both in terms of duration and long term outcome.

There is a great deal we don't currently know about long COVID, including the long term effects of COVID-19) and it will take some time to understand the underlying causes and symptoms associated with long COVID as well as knowing how long it can last.

## Long COVID symptoms <sup>[4]</sup>

In July 2022, the most commonly reported symptoms were fatigue (62%), shortness of breath (37%), difficulty concentrating (33%), and muscle ache (31%).

However, the signs and symptoms after acute COVID-19 are very variable and wide-ranging, and may fluctuate, with exacerbations triggered by physical or mental stress. Symptoms may evolve, may become permanent, and new symptoms or conditions may develop.

Common symptoms of long COVID include:

- Generalised symptoms: fatigue, fever, pain.
- Cardiovascular symptoms: chest pain, chest tightness, palpitations.

- Dermatological symptoms: hair loss, skin rashes (eg, urticaria).
- Ear, nose and throat symptoms: dizziness, vertigo, earache, loss of taste and/or smell (with loss of enjoyment of food and mealtimes), nasal congestion, sore throat, tinnitus.
- Gastrointestinal: abdominal pain, diarrhoea, nausea and vomiting, weight loss and reduced appetite.
- Musculoskeletal symptoms: joint pain and/or muscle pain.
- Neurological symptoms: autonomic dysfunction, cognitive impairment, delirium (older populations), headache, impaired mobility, peripheral neuropathy, sleep disturbance, visual disturbance.
- 'Brain fog' is described by many patients, with variable effects on the nervous system: poor concentration, feeling confused, thinking more slowly than usual, fuzzy thoughts, forgetfulness, mental fatigue.
- Mental health symptoms: anxiety, depression, post-traumatic stress disorder (PTSD), post-intensive care syndrome (PICS).
- Respiratory symptoms: shortness of breath, cough.

Gradual decline, deconditioning, worsening frailty or dementia, or loss of interest in eating and drinking can be signs of ongoing symptomatic COVID-19 or suspected post-COVID-19 syndrome in older people.

Multisystem inflammatory syndrome in children (MIS-C) may cause variable and multisystem presentations, most often involving the gastrointestinal tract, skin, mucous membranes and the cardiovascular system. In some cases the clinical picture may resemble [Kawasaki disease](#), especially in cases with shock, toxic shock syndrome and macrophage activation syndrome.

## Diagnosing long COVID<sup>[1]</sup>

Symptoms following an acute COVID-19 infection may be wide-ranging and fluctuating, and vary in nature over time. Tests and investigations should be tailored to the signs and symptoms to exclude an acute, life-threatening complications, or symptomatic COVID-19, post-COVID-19 syndrome new diagnoses.

No laboratory test can definitely distinguish post-COVID presentations from other conditions. If clinically indicated, offer blood tests, which may include: full blood count, renal function and liver function tests, C-reactive protein, ferritin, B-type natriuretic peptide (BNP), HbA1c, thyroid function tests, lipid profile and vitamin D levels.

Other investigations which may be useful to determine disease severity and exclude other conditions include:

- Exercise tolerance test suited to the person's ability (for example, the 1-minute sit-to-stand test). During the exercise test, record the level of breathlessness, heart rate and oxygen saturation.
- Chest X-ray: offer a chest X-ray 12 weeks after acute COVID-19 if continuing respiratory symptoms and clinically indicated. Chest X-ray appearances alone should not determine the need for referral for further care.
- Electrocardiography.

For people with long COVID, clinical evaluation, blood tests, chest X-rays, and electrocardiography may all be normal. Investigations and referral will otherwise depend on the nature of the presenting symptoms and differential diagnoses considered.

## Long COVID treatment<sup>[4]</sup>

Arrange emergency admission for people with life-threatening signs and symptoms. Arrange referral for other people with urgency depending on clinical judgement.

If emergency admission or referral is not necessary, options include:

- Supported self-management, plus support from integrated and coordinated primary care, community, rehabilitation, and mental health services.
- Referral to an integrated multidisciplinary assessment service.
- Referral to specialist care for specific complications.

- Support and rehabilitation options include:
  - Fatigue management.
  - Psychological and psychologically informed interventions.
  - Breathing pattern retraining.
  - Occupational health support and vocational rehabilitation.

Manage people with specific symptoms appropriately, eg, anxiety, breathlessness, chest pain, cough, delirium, depression, diarrhoea, dizziness and vertigo, fatigue, headache, joint and muscle pain, palpitations, post-traumatic stress disorder, sleep disturbance, tinnitus.

Optimise management of pre-existing comorbidities and offer lifestyle advice (eg, diet and exercise, sleep, stress reduction, alcohol, smoking).

Encourage people to follow current government guidance on vaccination. COVID vaccines may help long COVID symptoms, but improvement may be modest, not everyone will benefit, and some people may experience worsening of symptoms.

Use a multidisciplinary approach to guide rehabilitation, including physical, psychological and psychiatric aspects of management.

Encourage people to keep a record of, or use a tracking app to monitor their symptoms, goals, recovery and any changes in their symptoms (especially in response to potential triggers, such as exertion, foods, menstruation, and treatment or medications).

Ensure effective information sharing and integrated working by sharing clinical records and care and rehabilitation plans promptly between services and through multidisciplinary meetings, either virtual or in person. Give people a copy of their care plans or records, including discharge letters, clinical records and rehabilitation plans.

## **Referral**

Urgently refer people with ongoing symptomatic COVID-19 or suspected post-COVID-19 syndrome to the relevant acute services if they have signs or symptoms that could be caused by an acute or life-threatening complication, including:

- Hypoxaemia or oxygen desaturation on exercise.
- Signs of severe lung disease.
- Cardiac chest pain.
- Paediatric inflammatory multisystem syndrome.
- For psychiatric assessment, if they have severe psychiatric symptoms or are displaying a high risk of self-harm or suicide.

Consider referring to an appropriate service, such as an integrated multidisciplinary assessment service, any time from 4 weeks after the start of acute COVID-19, after ruling out acute or life-threatening complications and alternative diagnoses. For example, if:

- Multiple severe symptoms (especially if both physical and mental health are affected), or profound functional impairment.
- Symptoms having a significant impact on normal activities of daily living, including attendance at work or, for children and young people, access to education or attendance at school.
- Persistent symptoms following a severe acute illness (for example, a period in intensive care).
- The diagnosis is in doubt, or atypical symptoms.
- Further assessment is needed to confirm safety and appropriateness of either self-management or supported rehabilitation.

Consider referring for psychological therapies if they have mental health symptoms, such as symptoms of mild anxiety and mild depression, or to a liaison psychiatry service if they have more complex needs (especially if they have a complex physical and mental health presentation).

Consider referring children with ongoing symptomatic COVID-19 or post-COVID-19 syndrome from 4 weeks for specialist advice, depending on clinical judgement. Refer to general paediatrics, or a specialist post-COVID hub as appropriate.



Do not exclude people from referral to an integrated multidisciplinary assessment service or for further investigations or specialist input based on the absence of a positive SARS-CoV-2 test (PCR, antigen or antibody) as long as the case definition criteria are met.

## Follow up

Use shared decision-making to decide how often follow-up and monitoring are needed, which healthcare professionals should be involved and whether appointments should be in person or remote. Take into account the person's needs, services involved, and the person's symptoms.

Consider supported self-monitoring at home which can include heart rate, blood pressure, pulse oximetry, or symptom diaries.

Consider additional support for people with ongoing symptomatic COVID-19 or post-COVID-19 syndrome who may be vulnerable, for example, older people and people with complex needs. Additional support may include short-term care packages, advance care planning and support with social isolation, loneliness and bereavement, if relevant.

Encourage to follow current government guidance on vaccination.

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## Further reading

- [Long COVID: Advice and resources for healthcare professionals in primary care.](#) Royal College of General Practitioners, July 2022.
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- [Gupta M, Gupta N, Esang M;](#) Long COVID in Children and Adolescents. *Prim Care Companion CNS Disord.* 2022 Apr 26;24(2):21r03218. doi: 10.4088/PCC.21r03218.

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