



**BRIEFING PAPER**

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# Coronavirus: Long Covid

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**Contents:**

1. Long Covid
2. Management of long Covid
3. Further reading



# Contents

<b>Summary</b>	<b>3</b>
<b>1. Long Covid</b>	<b>4</b>
Calls for greater recognition and research	5
1.1 How many people are affected by long Covid?	6
1.2 What causes some people to have ongoing symptoms of Covid-19?	7
<b>2. Management of long Covid</b>	<b>8</b>
2.1 Clinical guidelines	8
2.2 NHS services	8
<b>3. Further reading</b>	<b>11</b>
3.1 Parliamentary material	11

## Summary

[Long Covid](#) is a term used to describe symptoms of Covid-19 that persist for longer than 4 weeks. In most people, the symptoms of the virus will resolve within 12 weeks but there are some who remain ill for longer. Studies looking at the symptoms and impacts of long Covid report that people can be left with ongoing symptoms for many months which can have a significant, negative impact on their lives.

[Early figures](#) from the Office for National Statistics (based on the Covid infection survey) estimate that one in ten people testing positive for Covid-19 have symptoms that last longer than 12 weeks.

There have been calls for greater recognition and support for those affected by long Covid. Support and campaign groups report a lack of awareness and understanding amongst the general public and healthcare professionals and state that sufferers can struggle to get the care they need.

In October 2020 NHS England and NHS Improvement (NHSEI) announced plans for a network of clinics for people with long-term symptoms arising from Covid-19. NHSEI have also established a [long Covid Taskforce](#), bringing together patients, charities, researchers and clinicians to help manage the NHS approach to long Covid. In December 2020, the National Institute for Health and Care Excellence (NICE) published [COVID-19 rapid guideline: managing the long-term effects of COVID-19](#). This provides guidance on the assessment and care of individuals following an illness consistent with Covid-19 infection where symptoms have lasted for longer than 4 weeks

# 1. Long Covid

Some people who become ill with Covid-19 will go on to experience symptoms for longer periods. While there is no formally agreed definition, long Covid is the term usually used to describe symptoms that last for longer than four weeks (another term used is post-Covid-19 syndrome).

A recently published NICE guideline on [managing the long-term effects of COVID-19](#) provides some clinical definitions for Covid-19 at different stages:

- **Acute COVID-19:** signs and symptoms of COVID-19 for up to 4 weeks.
- **Ongoing symptomatic COVID-19:** signs and symptoms of COVID-19 from 4 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.<sup>1</sup>

The NHS website explains that most people with Covid-19 will have a resolution of symptoms after 12 weeks, but some people will feel ill for longer.<sup>2</sup>

Common symptoms with long Covid include:

- extreme tiredness (fatigue)
- shortness of breath
- chest pain or tightness
- problems with memory and concentration ("brain fog")
- difficulty sleeping (insomnia)
- heart palpitations
- dizziness
- pins and needles
- joint pain
- depression and anxiety
- tinnitus, earaches
- feeling sick, diarrhoea, stomach aches, loss of appetite
- a high temperature, cough, headaches, sore throat, changes to sense of smell or taste
- rashes<sup>3</sup>

For further information on the short and long term impacts Covid-19 may have on different organ systems see the September 2020 POST rapid response, [Short and long term health effects of COVID-19](#).

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<sup>1</sup> NICE, [COVID-19 rapid guideline: managing the long-term effects of COVID-19](#), 18 December 2020

<sup>2</sup> NHS, [Long-term effects of coronavirus \(long COVID\)](#), 7 January 2021

<sup>3</sup> NHS, [Long-term effects of coronavirus \(long COVID\)](#), 7 January 2021

A large international study looking at online survey results from individuals with confirmed or suspected Covid-19 infection, where the illness had persisted for longer than 28 days, described a range of reported symptoms affecting different organ systems:

In this cohort, the most likely symptoms to persist after month 6 were fatigue, post-exertional malaise, cognitive dysfunction (“brain fog”), neurologic sensations (neuralgias, weakness, coldness, electric shock sensations, facial paralysis/pressure/numbness), headaches, memory issues, insomnia, muscle aches, palpitations, shortness of breath, dizziness/balance issues, and speech and language issues.<sup>4</sup>

The study also found that a significant proportion of respondents reported reduced work capacity due to cognitive dysfunction and other symptoms which led to the “loss of hours, jobs, and ability to work relative to pre-illness levels:” It concluded that the findings “suggest that the morbidity of COVID-19 illness has been greatly underappreciated. Patients experience multisystem symptoms for over 7 months, resulting in significant impact to patients’ lives and livelihoods.”<sup>5</sup> This study has, thus far, been published as a pre-print and has therefore not been peer reviewed, the findings should be treated with a degree of caution.

There is ongoing research looking at the effects of long Covid on different organ systems. Early findings in a study (also a pre-print, not yet peer reviewed) looking at organ impairment in young, low risk patients showed that almost 70% had impairment to at least one organ four months after first symptoms.<sup>6</sup> The Oxford Biomedical Research Centre report on another study looking at lung function in patients with long term symptoms. In an initial small group of previously hospitalised patients, a specialised MRI technique found that all participants have weakened lung function.<sup>7</sup>

The [PHOSP COVID study](#) will follow large numbers of previously hospitalised patients with long Covid, to look at the short, medium and long term impacts of Covid-19.<sup>8</sup>

## Calls for greater recognition and research

A number of long Covid support groups have been established to provide information and support for those affected by long Covid. These groups highlight the ongoing ill health suffered by those affected by long Covid, and report that people have felt unsupported.

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<sup>4</sup> [Characterizing Long COVID in an International Cohort: 7 Months of Symptoms and Their Impact](#), Hannah E. Davis, Gina S. Assaf, Lisa McCorkell, Hannah Wei, Ryan J. Low, Yochai Re’em, Signe Redfield, Jared P. Austin, Athena Akrami, medRxiv 2020.12.24.20248802; doi: <https://doi.org/10.1101/2020.12.24.20248802>

<sup>5</sup> Ibid.

<sup>6</sup> [Multi-organ impairment in low-risk individuals with long COVID](#), Andrea Dennis, Malgorzata Wamil, Sandeep Kapur, Johann Alberts, Andrew D. Badley, Gustav Anton Decker, Stacey A Rizza, Rajarshi Banerjee, Amitava Banerjee, medRxiv 2020.10.14.20212555; doi: <https://doi.org/10.1101/2020.10.14.20212555>

<sup>7</sup> NIHR Oxford Biomedical Research Centre, [Hidden lung damage from COVID-19 revealed in new study](#), 1December 2020

<sup>8</sup> [PHOSP- COVID study website](#)

The [Long Covid SOS campaign group](#) reports a lack of awareness for long Covid amongst the general public and healthcare professionals, and states that people struggle to get the care and recognition they need. It is aiming to put pressure on the Government to recognise the needs of those with long Covid and raise awareness of the condition:

The aims can be summarised as 'Recognition Research Rehab':

1. Set up a working group to address the needs of long-term Covid-19 sufferers
2. Commission urgent research into this condition
3. Ensure that all practitioners are empowered to treat these patients appropriately
4. Establish multi-disciplinary clinics to properly assess, test, diagnosis and care for them
5. Focus on the economic implications: provide long-term sick leave, financial support and take steps to ensure employers are made fully aware<sup>9</sup>

In its December 2020 interim report, the [APPG on Coronavirus](#) calls on the Government to formally recognise long Covid and to expand the ongoing research on long term symptoms to those who were not hospitalised with the condition. It states that the Government should establish a national registry for people living with long Covid and should publish regular figures on how many people are affected.<sup>10</sup>

### 1.1 How many people are affected by long Covid?

The Office for National Statistics plans to produce analysis of the prevalence of long Covid and risk factors for long Covid symptoms. In December they released [some early experimental results](#) using the Covid-19 infection survey, as well as linked healthcare and census datasets.<sup>11</sup>

Of respondents to the [Covid-19 infection survey](#):

- **1 in 5** of those testing positive for COVID-19 have symptoms for **five weeks** or longer
- **1 in 10** of those testing positive for COVID-19 have symptoms for **twelve weeks** or longer

Based on this, they estimate that in late November, between 153,000 and 221,000 people in private households in England were living with symptoms that had lasted for between five and twelve weeks.

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<sup>9</sup> [Long Covid SOS website](#) [accessed 14 January 2021]

<sup>10</sup> APPG on Coronavirus, [Interim Report](#), December 2020

<sup>11</sup> ONS, [The prevalence of long COVID symptoms and COVID-19 complications](#), 16 December 2020

## 1.2 What causes some people to have ongoing symptoms of Covid-19?

Covid-19 is a new disease and it is not yet known why some people continue to have symptoms for longer than others. The ongoing symptoms do not appear to be linked to the severity of the initial infection.<sup>12</sup>

The British Society of Immunology published a briefing note on the Long-term immunological health consequences of COVID-19 in August 2020. This calls for urgent research into the long-term immunological impacts of the disease. The report states that it appears that the virus SARS CoV-2 could cause long term damage to different organ systems of the body, in a number of ways:

- Direct effect of infection and tissue damage;
- Excessive inflammation causing tissue damage;
- Post-viral autoimmunity; and
- Blood clots causing damage.<sup>13</sup>

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<sup>12</sup> BBC News, ['Long Covid': Why are some people not recovering?](#), 5 October 2020

<sup>13</sup> British Society of Immunology, [Long-term immunological health consequences of COVID-19](#), 13 August 2020

## 2. Management of long Covid

### 2.1 Clinical guidelines

In December 2020, the National Institute for Health and Care Excellence (NICE), the Royal College of GPs (RCGP) and the Scottish Intercollegiate Guidelines Network (SIGN) published [COVID-19 rapid guideline: managing the long-term effects of COVID-19](#).

This provides guidance on the assessment and care of individuals following an illness consistent with Covid-19 infection where symptoms have persisted for longer than 4 weeks. This includes investigations and referrals, management and follow up. The guideline also makes recommendations about research on long Covid.

The Director of the Centre for Guidelines at NICE, Paul Chrisp, said that the guideline would give people information on what to expect and when to ask for medical support. He noted that there was still a number of unknowns with regards to long Covid and that the guidelines will adapt as knowledge of the condition and how to manage it grows.<sup>14</sup>

There have been some concerns expressed about the new guidelines. In a comment piece for the medical journal *The Lancet*, healthcare workers affected by long Covid said that the guideline:

- did not provide an adequate description of the clinical picture of long Covid;
- did not provide enough information about what is known about what causes long Covid;
- introduces new definitions of the condition without a clear rationale, and
- is “overly focused on self-management, psychological support, and rehabilitation, resulting in the potential for “watered-down” versions of NHS long COVID clinics that do not provide thorough physical assessment of patients.”<sup>15</sup>

### 2.2 NHS services

In October 2020 NHS England and NHS Improvement (NHSEI) announced plans for a network of clinics for people with long-term symptoms arising from Covid-19. NHSEI have also established a [long Covid Taskforce](#), bringing together patients, charities, researchers and clinicians to help manage the NHS approach to long Covid.

On 7 October NHS chief executive Sir Simon Stevens announced £10 million of additional funding to help kick start and designate ‘long covid clinics’ in every area across England, to complement existing primary, community and rehabilitation care.<sup>16</sup> While some of these clinics were already in operation

<sup>14</sup> NICE, [NICE, RCGP and SIGN publish guideline on managing the long-term effects of COVID-19](#), 18 December 2020

<sup>15</sup> [Long COVID guidelines need to reflect lived experience](#), *The Lancet*, 20 December 2020

<sup>16</sup> NHS England and NHS Improvement, [NHS to offer long Covid help](#), 7 October 2020



in November 2020, NHSEI published plans for 40 clinics which would be available from early December 2020. NHSEI also published [commissioning guidance](#) on 6 November, with each integrated care system working towards the provision of at least one such service.<sup>17</sup> Ten sites have been earmarked for the Midlands, seven in the North East, six in the East of England, South West and South East respectively, five in London and three in the North West.<sup>18</sup>

Patients will be able to access services through a GP referral or referral from other healthcare professional, allowing doctors an opportunity to rule out any other possible underlying causes for symptoms, such as suspected stroke, lung cancers or respiratory conditions. These specialist clinics will support patients suffering from various symptoms of long Covid. The Government has said that every patient experiencing symptoms will undergo a physical and psychological assessment to help address the problems being faced.<sup>19</sup>

The NHS has also developed an online programme called '[Your COVID Recovery](#)', which is designed to help individuals recover from the long term physical and mental effects of coronavirus. This online tool was announced by NHS England and NHS Improvement on 5 July 2020 ('[NHS to launch ground breaking online COVID-19 rehab service](#)') as part of wider NHS plans to expand access to Covid-19 rehabilitation treatments. This platform is being developed in two phases: phase 1 enables patients and their families or carers to access further information around recovering post Covid-19. It includes information on areas including mental health and wellbeing, to physical strength and returning to work. Phase 2 of the platform will provide a virtual rehabilitation programme for individuals who have ongoing complications.

There have been a number of PQs on support for people with long Covid, including the following response on research being carried out in this area:

**Asked by:** Baroness Sheehan | **Party:** Liberal Democrats

To ask Her Majesty's Government what plans they have to set up a working group to address the needs of people experiencing long-term health effects of COVID-19.

**Answering member:** Lord Bethell | **Department:** Department of Health and Social Care

We have held discussions with interested stakeholders, including clinicians, academics and researchers, to better understand and mitigate the long-term impacts of COVID-19. Further discussions have been held between senior clinicians to review the different options to provide longer-term support of people who have had COVID-19.

To ensure the best use of National Health Service resources for clinical research during the acute phase of the pandemic, the National Institute for Health Research (NIHR) established a single United Kingdom-wide process to prioritise COVID-19 research as

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<sup>17</sup> See also the NHS Confederation [Member briefing: Understanding long Covid](#), 2 December 2020

<sup>18</sup> NHS England and NHS improvement, [NHS launches 40 'long COVID' clinics to tackle persistent symptoms](#), 15 November 2020

<sup>19</sup> PQ122748, [Coronavirus: Health Services](#), 8 December 2020

Urgent Public Health Research. Through this process, the NIHR Clinical Research Network is providing support to expedite delivery of Urgent Public Health Research, by fast tracking the local set-up, management and delivery of studies to help understand, prevent and manage COVID-19. This includes the Post-HOSPitalisation COVID-19 study, led by the University of Leicester, to understand and improve long-term outcomes for survivors following hospitalisation with COVID-19. The research currently underway will continue to inform future NHS service design and provision.

In July, we launched the new 'Your COVID Recovery' service, which forms part of NHS plans to expand access to COVID-19 rehabilitation treatments for those who have survived the virus but still have problems with breathing, mental health problems or other complications. Alongside bringing back non-urgent services in a safe way and maintaining a high state of readiness for any future increase in COVID-19 cases, local health leaders are currently working with councils and voluntary groups to plan how they will meet the additional ongoing demand for rehabilitation services post-COVID-19.<sup>20</sup>

Separate information is available on the response to longer-term effects of Covid-19 infection in [Scotland](#), [Wales](#) and [Northern Ireland](#).

## 3. Further reading

NICE, SIGN and RCGP, [COVID-19 rapid guideline: managing the long-term effects of COVID-19](#), 18 December 2020

The Lancet, [Long COVID guidelines need to reflect lived experience](#), 21 December 2020

ONS, [The prevalence of long COVID symptoms and COVID-19 complications](#), 16 December 2020

NHS, [Long-term effects of coronavirus \(long COVID\)](#)

[The risk of long covid must be a primary consideration in policy decisions](#), BMJ, 12 Jan 2020

[Long Covid Support Group](#)

[Long Covid SOS](#)

NHS England, [Long COVID patients to get help at more than 60 clinics](#), 18 December 2020

Department of Health and Social Care, [Health Secretary warns of long-term effects of COVID-19 as new film released](#), 21 October 2020

### 3.1 Parliamentary material

#### [Coronavirus: Clinics](#)

##### **Asked by: Russell, Dean**

To ask the Secretary of State for Health and Social Care, what progress has been made on the roll out of long covid clinics.

##### **Answering member: Ms Nadine Dorries | Department of Health and Social Care**

NHS England and NHS Improvement have provided £10 million to fund over 40 pioneering specialist clinics for people suffering from the long-term effects of COVID-19. The plans for these clinics were published on 15 November and guidance was made available on 6 November.

NHS England and NHS Improvement committed to ensuring post COVID-19 assessment clinics will be available from early December 2020. In response, each integrated care system is working towards the provision of at least one such service.

A number of these clinics are already established and have started to accept patients. More information about the clinic locations and how to access them will be released in the near future.

**24 Dec 2020 | Written questions | House of Commons | PQ 129128**

#### [Coronavirus: Health Services](#)

##### **Asked by: Furniss, Gill**

To ask the Secretary of State for Health and Social Care, what advice he has given to primary care services on (a) handling and (b) treating people suffering from the long term effects of covid-19.

**Answering member: Ms Nadine Dorries | Department of Health and Social Care**

In July 2020, the National Health Service launched the 'Your COVID Recovery' service to support the recovery of people who have been in hospital or suffered at home with the virus. This is a two-phase endeavour with phase one being available as an open, publicly available site containing general information on all aspects of recovering from COVID-19, including physical, emotional and psychological wellbeing. Over 100,000 people have used the online service since it was launched in July.

On 7 October the NHS announced £10 million is to be invested this year to help kick start and designate 'long COVID-19' clinics that will be available to all patients in England. Alongside this, new guidance has been commissioned by NHS England from the National Institute for Health and Care Excellence (NICE) on the clinical case definition of 'long COVID-19'. This will include patients who have had COVID-19 who may not have had a hospital admission or a previous positive test. It will be followed by evidence-based NICE clinical guidelines that will outline the support that 'long COVID-19' patients should receive, enabling NHS doctors, therapists and staff to provide a clear and personalised treatment plan. This will include education materials for general practitioners and other health professionals to help them refer and signpost patients to the right support.

**4 Nov 2020 | Written questions | House of Commons | PQ 102893**

**[Coronavirus: Vaccination](#)**

**Asked by: Moran, Layla**

To ask the Secretary of State for Health and Social Care, what plans the Government has for eligibility for potential covid-19 vaccines for people with long covid symptoms.

**Answering member: Jo Churchill | Department of Health and Social Care**

The Joint Committee on Vaccination and Immunisation (JCVI) are the independent experts who advise Government on prioritisation at a population level. Based on scientific analysis and modelling data, the JCVI will advise on which cohorts of the United Kingdom's population will be eligible for vaccination, should a safe and effective vaccine be found. This will depend on factors such as the properties of the vaccine, those most at need (including frontline health and social care workers) and the unique medical circumstances of individuals.

The committee's interim advice is that the vaccine should first be given to care home residents and staff, followed by people over 80 and health and social workers, then to the rest of the population in order of age and risk. Further work is being undertaken to understand more about the groups most at risk of serious disease and death from COVID-19 infection. Any advice will need to be modified depending on the characteristics of the vaccines, when these become available.

We will consider the Committee's advice carefully as we continue to plan for a vaccination campaign.

**22 Oct 2020 | Written questions | House of Commons | PQ 100534**

### [Long Covid](#)

**Asked by: Carmichael, Mr Alistair**

What steps he is taking to support people with long covid.

**Answered by: Jo Churchill | Department of Health and Social Care**

I am sure that the right hon. Gentleman would welcome yesterday's announcement that the National Institute for Health and Care Excellence and the Scottish Intercollegiate Guidelines Network will work with the Royal College of General Practitioners to develop guidelines to support patients and practitioners in the treatment of and recovery from the disease. This follows on from the NHS launch in July of the Your COVID Recovery service, which provides personalised support for individuals. In addition, we are funding research into covid-19, including a study of 10,000 patients who were admitted to hospital with covid, building our understanding of the long-term effects and helping direct those improved treatments that are needed.

**HC Deb 6 Oct 2020 | PQ 907116**

### [Coronavirus](#)

**Asked by: Thompson, Owen**

To ask the Secretary of State of Health and Social Care, if he will make it his policy to recognise long covid as a medical condition.

**Answering member: Ms Nadine Dorries | Department of Health and Social Care**

The National Health Service and the wider scientific community are currently working to better understand the disease course of COVID-19 infection, including the prevalence, severity and duration of symptoms, and how best to support recovery. The National Institute for Health Research and UK Research and Innovation have invested £8.4 million in the Post-HOSPitalisation COVID-19 study, to understand and improve long-term outcomes for survivors following hospitalisation with COVID-19. The research will inform future NHS service design and provision and the Government is currently considering options for future work in this area.

**6 Oct 2020 | Written questions | House of Commons | PQ 92836**

### [Employment: Coronavirus](#)

**Asked by: Gwynne, Andrew**

To ask the Secretary of State for Work and Pensions, what guidance her Department has published for employers to support employees suffering from the long-term effects of covid-19.

**Answering member: Justin Tomlinson | Department for Work and Pensions**

Research into the long-term health symptoms and impacts of COVID-19 is ongoing. However, it is clear that for some of those who have survived, the virus and the treatment they have received to combat it will have a lasting impact on their health.

Employers have particular responsibilities towards disabled workers including making reasonable adjustments to avoid disabled workers being put at a disadvantage. DWP's new Employer Help site provides advice on employment of disabled people, explaining how Access to Work and Disability Confident can help businesses to ensure their practices are fair and inclusive.

The law is clear: to discriminate directly, or indirectly, against anyone because of a protected characteristic such as age, sex or disability, race or ethnicity is unlawful. All equality and discrimination laws and obligations continue to apply during the coronavirus pandemic.

**10 Sep 2020 | Written questions | House of Commons | PQ 85966**

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