

Long Covid: definition, diagnosis and management

Thuvia Flannery*, Hannah Brady Sawant*, Tracy Lee, Gerda Bayliss, Rachel Tarrant, Jenna Shardha, Denise Ross

This article, the first in a three-part series on Long Covid, provides a definition of post-Covid-19 syndrome and Long Covid. It highlights the considerations for diagnosis and an overview of the management of commonly reported symptoms through the experience of one of the 90 NHS England commissioned post Covid (Long Covid) assessment clinics, in addition to lived experiences of persons with Long Covid (PwLC). The next two articles in this series will look at the use of digital technology in Long Covid self-management and virtual group assessments.

KEYWORDS:

■ Long Covid ■ Common symptoms ■ Diagnosis
■ Patient pathways ■ Service development

The Covid-19 pandemic led to rapid changes in how health care could be accessed and delivered in the UK. This was aimed at protecting acute NHS services and limiting face-to-face contacts, which were likely to increase the spread of the novel virus (NHS England, 2020). The early emergence of post Covid-19 syndrome (PCS), synonymous with and more frequently referred to as Long Covid (LC), presented an unanticipated and unique set of health needs at a time of considerable disruption to existing NHS services (Health Foundation, 2022).

Compounding factors included:

- ▶ Limited understanding of the aetiology of the condition
- ▶ Its apparent multisystem involvement

Hannah Brady Sawant, district nurse and Thuvia Flannery*, physiotherapist, clinical research fellows, Leeds Long Covid Rehabilitation Service, Leeds Community Healthcare NHS Trust; Jenna Shardha and Rachel Tarrant, clinical pathway co-ordinators, Leeds Long Covid Rehabilitation Service, Leeds Community Healthcare NHS Trust; Denise Ross, head of healthcare professional academic development, Leeds Teaching Hospitals NHS Trust; Tracy Lee and Gerda Bayliss, patient members of the patient, carer and public involvement (PCPI) group*

*Hannah Brady Sawant and Thuvia Flannery are joint authors of this article

‘Long Covid is globally described by persons with LC (PwLC) as a complex, multifaceted condition with physical, mental and social implications.’

- ▶ Absence of a diagnostic test
- ▶ Lack of knowledge on safe and effective management approaches that could address commonly reported symptoms

(Halpin et al, 2021; Health Foundation, 2022).

As Covid-19 infection rates increased exponentially in the UK, the incidence of LC has followed a similar trajectory. The Office for National Statistics (ONS) data from November 2022 estimates that approximately 2.2 million people in the UK are self-reporting LC symptoms, the equivalent of 3.4% of the population (ONS, 2022).

WHAT IS POST-COVID-19 SYNDROME/LONG COVID?

The National Institute for Health and

Care Excellence (NICE, 2022) defines post-Covid-19 syndrome as:

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. It usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time and can affect any system in the body.

(NICE, 2022: 5).

Long Covid is commonly used to describe signs and symptoms that continue or develop after acute Covid-19. It includes both ongoing symptomatic Covid-19 (from four to 12 weeks) and post-Covid-19 syndrome (12 weeks or more) (NICE, 2022). For this reason, the umbrella term Long Covid (LC) will be used throughout the following text.

COMMON SYMPTOMS OF LONG COVID AND DIAGNOSIS

Long Covid is globally described by persons with LC (PwLC) as a complex, multifaceted condition with physical, mental and social implications (Carson, 2021). Long Covid symptoms may include fatigue, breathing issues (shortness of breath), ‘brain fog’ (cognitive impairment), depression and anxiety, palpitations, dizziness, dietary issues, and joint pain (NICE, 2022) (Table 1). For these reasons, LC is considered a multisystem condition with symptoms that may improve and then be exacerbated over time conducive with a non-linear path to recovery (Centers for Disease Control and Prevention [CDC], 2022; Greenlagh et al, 2022).

There is some variability in resolution or self-management of symptoms (Greenlough et al, 2022). A LC diagnosis can therefore be difficult to obtain and without this a referral to a LC clinic to access treatment may take many weeks or months and, in some circumstances from the initial wave of patients, years. This is due in part to the complexity and fluctuating nature of reported symptoms, i.e. fatigue might improve so an individual could get back to some normal activities but then would have a sudden relapse (Greenlough et al, 2022), difficulty accessing health services as a direct effect of the pandemic on healthcare systems, and finally, lack of knowledge and awareness of the condition. Possible explanations for the symptoms outlined in *Table 1* can include organ damage by the Covid-19 virus, dysregulated inflammatory state, ongoing viral activity, and immune system responses (CDC, 2022), or several of these interacting simultaneously (Greenlough et al, 2022).

Diagnosis is currently based on persisting symptoms that cannot be explained by any other cause (NICE, 2022). Persons suspected of having LC may require screening for common cardiac, respiratory, neurological, musculoskeletal, and digestive conditions before a diagnosis of LC can be formally made. However previously, tests and scans may have been conducted in a disjointed manner which might contribute to the uncertainty of

Table 1: Commonly reported symptoms of Long Covid

System	Common symptoms
Cardiac	Chest tightness, palpitations, chest pain
Respiratory	Breathlessness
Neurological	Cognitive impairment ('brain fog'), insomnia, headache, dysautonomia (including postural tachycardia syndrome [PoTS] with erratic heart rate with labile blood pressure [BP])
Digestive	Abdominal pain, nausea, loss of appetite, heartburn
Musculoskeletal	Diffuse joint and muscle pain, costochondritis
Psychological	Anxiety, depression, intrusive memories and/or thoughts
General	Post exertional malaise, fatigue, fever, difficulty communicating

not knowing what is happening that PwLC report as being a major issue with the condition (Fancourt et al, 2022). It is therefore still possible that some people with LC symptoms, from early 2020 Covid-19 infections, remain undiagnosed and so unable to access existing LC health interventions.

The list of symptoms described in *Table 1* are those most commonly experienced within clinical practice, however this is not exhaustive as each person's experience of LC can vary greatly. In addition to these symptoms, PwLC can experience profound lifestyle changes. These can include reduction in full-time employment and financial instability. The Institute of Fiscal Studies (IFS) estimates that UK workers with LC represent £1.5 billion per month in lost earnings (Financial Times, 2022). A recent University of Portsmouth study highlighted a startling reduction in workforce availability due to LC (Reuschke and Houston, 2022). This inevitably negatively impacts on social interaction,

personal relationships, and for some, a sense of loss of their former self (Fancourt et al, 2022).

In terms of demographics, the Leeds Long Covid Rehabilitation Service (LLCRS) sees PwLC with an age range from 16–91 years, and a mix of both males and females. However, it has been identified that the caseload within the LLCRS are predominantly female (68%), have an average age of 48 (Parkin et al, 2021; Flannery, Brady-Sawant et al, 2022), and have not been admitted to hospital for Covid-19 infection (74%) (Parkin et al, 2021). The risk of LC can be increased in (Crook et al, 2021):

- ▶ Those with pre-existing asthma
- ▶ Women who are aged between 50 and 60 years
- ▶ Those who had poor mental or physical health before the pandemic
- ▶ Those with obesity (Thompson et al, 2022).

Few other clinical risks have been identified (Cook et al, 2021) and more investigation as to the reasons behind these risk factors is required (Thompson et al, 2022).

LLCRS SET UP AND PATIENT PATHWAYS

The LLCRS was officially launched in September 2020 following a rapid process of collaborative development (*Figure 1*) and has a current caseload of 1,166 PwLC as of December 2022, having discharged 1,200 of its 2,366 total cohort.

A review of available evidence and acute NHS trusts' follow-up of discharged patients to check on their Covid-19 recovery, identified

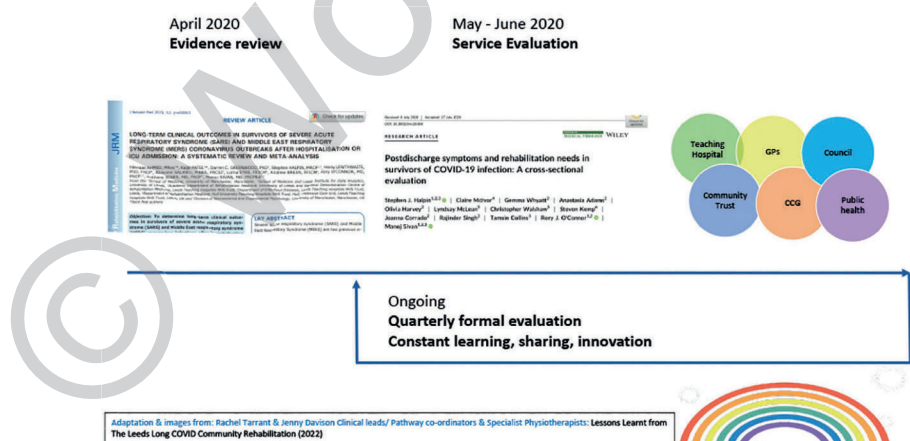


Figure 1.
Leeds Long Covid Rehabilitation Service innovation: rapid, dynamic and intersectoral.

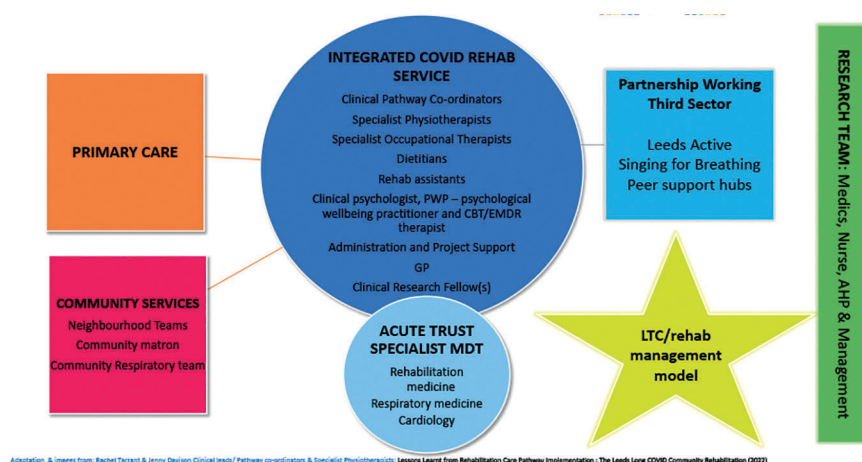


Figure 2.

Leeds Long Covid Rehabilitation Service Model.

the unmet needs of PwLC in the community (Halpin et al, 2021). Many PwLC presented with a cluster of the debilitating symptoms described in *Table 1* and means of addressing these were sought by adopting a co-design approach to intersectoral service development involving a local acute NHS trust, NHS community services and third-sector organisations — thus embracing an integrated care system (ICS) model (NHS England, 2022).

This involved a close relationship with local commissioners and public health services at a challenging time in the Covid-19 pandemic. NHS England's commissioning of post Covid-19 syndrome clinics followed, and there are now 90 nationally, with established guidelines which are regularly updated (NHS England, 2022).

Leeds Long Covid Rehabilitation Service accepts referrals from general practitioners (GPs) or community-based teams, such as district nursing, therapy or specialist services via the single point of referral. This means that PwLC rely on being identified by these health professionals. It is recognised that PwLC are often not diagnosed within a beneficial timeframe, or in some cases, not at all (Greenhalgh et al, 2022). Referrals are accepted for PwLC who are 16 years old and over. The service receives between 80 and 140 referrals per month (Flannery et al, 2022), with a waiting time for initial assessment of over 18 weeks during December 2022. Delays in treatment are recognised as common, and that

a supportive role in primary care services is essential to assist with the management of this (Greenhalgh et al, 2022). Patients with LC are sent an 'opt in' letter and once they have confirmed they wish to receive care from the service they are asked to complete a set of outcome measures, i.e. Covid-19 Yorkshire Rehabilitation Scale (C19YRS), Modified Fatigue Impact Scale (MFIS), Medical Research Council Dyspnoea Scale (MRC) and EuroQol 5 Dimension scale (EQ5D). These outcome measures are itemised in the C19YRS app, although those unable to complete via the app or website can complete a paper version.

It is recommended that these are completed monthly following the initial completion to facilitate tracking of symptoms. Once the initial outcome measures are completed, PwLC are currently offered a 'first assessment' telephone appointment. This is followed by the virtual rehabilitation programme (VRP), which provides education on LC and self-management approaches in a group setting on Microsoft Teams digital platform (Flannery et al, 2022). This is complemented, where needed, with face-to-face and virtual clinician input.

The LLCRS clinical team includes physiotherapists, occupational therapists, dietitians, psychological therapies, GPs and rehabilitation assistants, working alongside a dedicated LC research team and hospital-based services. Therapies use a health coaching approach in

partnership with each individual to self-manage the main LC symptoms being experienced, namely:

- ▶ Physiotherapists provide techniques to assist with breathlessness
- ▶ Occupational therapists offer pacing techniques to help with fatigue
- ▶ Dietitians support nutritional aspects
- ▶ Psychology practitioners address emotional issues associated with LC, such as anxiety, depression, intrusive memories and/or thoughts (post-traumatic stress disorder [PTSD]).

This multidisciplinary team (MDT) approach is required by NHS England (NHS England, 2021) and is recognised as essential for the management of LC symptoms globally (Carson, 2021).

Often PwLC are asked to keep diaries of symptoms and activities to assist with identifying triggers of exacerbations of symptoms and insight into lived experience (CDC, 2022). Other interventions focus on breathing exercises or gradual increases of activity (CDC, 2022), which overall should support self-management (Greenlagh et al, 2022).

Team members are also able to refer between one another based on the specific needs of the PwLC as they change. In the case of patients with complex needs, there is the ability to discuss their care at a weekly MDT meeting. This consists of LLCRS team members and respiratory, rehabilitation and cardiology consultants. They are able to discuss PwLC at an individual level and raise any concerns. This alleviates the need for the lengthy process of new referrals to individual specialities and avoids unnecessary duplication of tests and subsequent delays. This ICS model has encouraged close liaisons between GPs, community services and the local acute NHS services to best meet the needs of PwLC in a timely manner. There are also links to third-sector organisations, which provide peer support and assistance with access to technology and financial management support.

ONGOING SERVICE DEVELOPMENT

It is recognised within the LLCRS that there is a developing evidence base of knowledge surrounding LC, and therefore ongoing service evaluation and development is essential. The need for building this knowledge base is recognised by the National Institute of Health Research (NIHR), which states that £50 million of funding from the government is currently in circulation to provide guidance for healthcare professionals and PwLC (NIHR, 2022).

Within the Leeds services, this is supported by a dedicated research team consisting of two clinical research fellows (one district nurse and one physiotherapist), clinical academic supervisors, operational leads of the LLCRS clinical team, and ongoing benchmarking, reviews of guidance and communication with other LC services. Much of the research team's work is focused on amplifying the needs and voices of PwLC so that the service can meet these. To assist this, a patient, carer and public involvement (PCPI) group has been developed, with members contributing towards identifying current service and research needs. Alongside this, research is being carried out collaboratively with the team and academics, for example, the LOCOMOTION study (Sivan et al, 2022).

Some of the additional challenges faced by the LLCRS include encouraging those less well represented communities (including Black and minority ethnic groups, those with learning disabilities and Gypsy and Traveller communities) to access services, and addressing digital literacy and availability of technology. There are ongoing service development projects to understand and deal with these challenges.

Digital innovations

The LLCRS use of digital technology to deliver self-management allows earlier intervention to greater numbers of PwLC while accelerating the uptake of e-health as per the *NHS Long Term Plan* (NHS England, 2019). Within the LLCRS, the

Before my illness I was extremely fit and active, with no medical issues, and had three vaccinations in 2021. My illness started with flu-like symptoms in December 2021, confirmed by a Covid PCR test. After a month, I tried a phased return to my physically active job, but my symptoms worsened, and I have been on sick leave ever since. My main post-Covid infection symptoms are fatigue, post-exertional malaise, tachycardia and myalgia. I have had to reduce my physical activity to only 10–15 minutes of light housework and gentle exercise each day, and my illness is stable, but not improving with rest.

Tracy's story, 59 years

I was referred to the Long Covid service in May, and had a telephone appointment in October. I received assurance that I was self-managing my illness well, i.e. following the advice in the Long Covid rehabilitation booklet, but that I should reduce my mental activity as this impacts fatigue. I have my physical assessment and rehabilitation therapy appointments booked in January, with returning to work being my primary goal, but I am expecting to have to change my job to a sedentary role to achieve this. I have participated in Long Covid research studies involving fatigue and vocational rehabilitation.

I caught Covid in the first wave, and then what we now know as Long Covid. It was a frightening and traumatic experience. I struggled to breathe, I suddenly couldn't walk, among a whole host of other scary symptoms. During this time the support I had was minimal. I found it very confusing and scary that I couldn't get help when I was obviously so ill. The best doctors and nurses I spoke to during this time were the ones that empathised, listened, admitted that they didn't know. These small words of support were beacons in among a sea of denial. The amount of work that went into trying to get myself any support and help was incredibly frustrating.

Gerda's story, 43 years

My restorative yoga practice has been a lifeline, as it has given me a focus and way to help myself. With my own experience and other teachers' support, I have been able to ease my symptoms, support and rehabilitate myself. It helped me at the start when I was struggling to breathe as I could get myself into positions to ease my breath and also my panic (they prone patients in the intensive care units [ICUs] when breathing is bad as it helps to bring the breath more into the back lungs). I believe that my yoga has eased my symptoms, headaches, palpitations, panic, anxiety, dizziness, nausea to name just a few. It's also helped me deal with the relentlessness of having a chronic illness.

As I am coming out of the other side after two years, the physical symptoms are less but the emotional impact of Long Covid is still ongoing. My yoga practice gives me a focus and support still.

10-week virtual rehabilitation programme (VRP) provides education and peer support, while the C19YRS app supports self-management through validated outcome measures, telephone clinician input and assessment. The former two are the focus of the second LC article in this series of three.

In addition, virtual courses for relaxation, stress and anxiety in LC and low mood are facilitated by the team. A new digital health addition planned for 2023 will be virtual group assessments (VGA), where PwLC are assessed in groups of six to eight followed by attendance on the VRP. The aim of this new intervention is to reduce waiting times, allowing for earlier interventions and peer support. The implementation and evaluation of this will be included in the third and final article of this three-part series about LC.

LONG COVID LIVED EXPERIENCE

The LLCRS continues to engage with PwLC to shape and influence service developments from direct individual feedback, taking part in formal evaluations and through the Leeds LC PCPI group. Two PCPI partners are co-authors of this article and describe their lived experience in the patient stories here.

CONCLUSION

Long Covid is a complex, multi-system condition with fluctuating symptoms, that have a great impact on the individual and for which no other cause can be found. Primary and community services are most likely to encounter PwLC requiring a diagnosis of LC, an exclusion of other pathologies, and referral to LC clinical services. The evidence base that underpins interventions for LC is still being developed and at this time no specific cause has been identified. Community-based health coaching utilising an MDT with direct links to acute care services allows for an ICS management approach for this community. People with LC should be supported to be active participants in their health care and benefit from peer support and signposting to third-sector organisations. **JCN**

REFERENCES

- Carson G (2021) Long Covid Forum Group. Research priorities for Long Covid: refined through an international multi-stakeholder forum. *BMC Med* 19(1): 84
- Centers for Disease Control and Prevention (2022) *Post-Covid conditions: information for healthcare providers*. Available online: www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care/post-Covid-conditions.html
- Crook H, Raza S, Nowell J, Young M, Edison P (2021) Long Covid — mechanisms, risk factors, and management. *BMJ* 374: n1648
- Fancourt D, Steptoe A, Bradbury A (2022) *Tracking the Psychological and Social Consequences of the Covid-19 Pandemic across the UK Population: Findings, Impact, and Recommendations from the Covid-19 Social Study (March 2020 – April 2022)*. UCL, London. Available online: www.covidsocialstudy.org/_files/ugd/064c8b_fa25a87fd1ba4e99b7d069e7af76c64a.pdf (accessed 12 December, 2022)
- Financial Times (2022) *Long Covid to leave lasting mark on UK economy, says IFS*. Available online: www.ft.com/content/a48db365-ee15-440a-8028-0905f71194b1 (accessed 12 December, 2022)
- Flannery T, Brady-Sawant H, Tarrant R, Davison J, Shardha J, Halpin S, et al (2022) A mixed-methods evaluation of a virtual rehabilitation program for self-management in post-Covid-19 syndrome (Long Covid). *Int J Environ Res Public Health* 19: 12680
- Greenhalgh T, Sivan M, Delaney B, Evans R, Milne R (2022) Long Covid — an update for primary care. *BMJ* 378: e072117
- Halpin SJ, McIvor C, Whyatt G, Adams A, Harvey O, McLean L, et al (2021) Post discharge symptoms and rehabilitation needs in survivors of Covid-19 infection: A cross-sectional evaluation. *J Med Virol* 3(2): 1013–22
- Health Foundation (2022) *Covid-19 impact inquiry exploring the pandemic's implications for health and health inequalities*. Available online: www.health.org.uk/what-we-do/a-healthier-uk-population/mobilising-action-for-healthy-lives/covid-19-impact-inquiry
- NHS England (2019) *The NHS Long Term Plan*. Available online: www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf
- NHS England (2020) *Second Phase of NHS response to Covid-19*. Available online: www.england.nhs.uk/coronavirus/documents/second-phase-of-nhs-response-to-covid-19/#primary_care
- NHS England (2021) *Long Covid: the NHS plan for 2021/22*. Available online: www.england.nhs.uk/coronavirus/documents/long-covid-the-nhs-plan-for-2021-22/
- NHS England (2022) *What are integrated care systems?* Available online: www.england.nhs.uk/integratedcare/what-is-integrated-care/ (accessed 12 December, 2022)
- National Institute for Health and Care Excellence (2022) *Covid-19 rapid guideline: managing long-term effects of Covid-19*. NICE, London. Available online: www.nice.org.uk/guidance/ng188 (accessed 11 December, 2022)
- National Institute for Health and Care Research (2022) *Researching long Covid*. Available online: www.nihr.ac.uk/covid-19/researching-the-long-term-impact.htm
- Office for National Statistics (2022) *Coronavirus (Covid-19) latest insights: infections*. Available online: www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/coronaviruscovid19latestinsights/infections#long-covid (accessed 12 December, 2022)
- Parkin A, Davison J, Sivan M, et al (2021) A multidisciplinary NHS Covid-19 service to manage post-Covid-19 syndrome in the community. *J Primary Care Community Health* 12
- Reuschke D, Houston D (2022) The impact of Long Covid on the UK workforce. *Applied Economics Letters*, DOI: 10.1080/13504851.2022.2098239. Available online: www.tandfonline.com/doi/full/10.1080/13504851.2022.2098239
- Sivan M, Greenhalgh T, Darbyshire JL, Mir G, O'Connor RJ, Dawes H, Greenwood D, et al (2022) Locomotion consortium. Long Covid Multidisciplinary consortium Optimising Treatments and services across the NHS (LOCOMOTION): protocol for a mixed-methods study in the UK. *BMJ Open* 12(5): e063505
- Thompson EJ, Williams DM, Walker AJ, et al (2022) Long Covid burden and risk factors in 10 UK longitudinal studies and electronic health records. *Nat Commun* 13(1): 3528

Copyright of Journal of Community Nursing is the property of Wound Care People Limited and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.