

Long Covid and adults

A guide for
occupational therapists



Long Covid and adults

A guide for occupational therapists



Purpose

This guide explains the unique role occupational therapists have in supporting adults to manage and recover from Long Covid.

Occupational therapy enables people to take part in the activities, roles and routines that are important to them, at home, work, in the community and elsewhere. Occupational therapists understand the complex interaction between physical, cognitive and mental health. They can work across acute, primary care, community services and social care, to support people affected by Long Covid.

This guide is for occupational therapists working with adults with Long Covid in all settings, including specialist Long Covid assessment and rehabilitation services, and acute, primary, secondary and community services.

The guide will be useful for service managers and commissioners responsible for planning and delivering Long Covid services. It may also be helpful to members of the public affected by Long Covid, and their families and carers – a companion guide for supporting children and young people is also available.

Terminology

People with confirmed or suspected cases of coronavirus disease (COVID-19) often feel better a few days or weeks after infection and most make a full recovery within 12 weeks. However, some experience much longer-term symptoms, which have been described as Long Covid, Post COVID-19 Syndrome¹ and Post COVID-19 Condition.²

The term Long Covid is preferred by many people with lived experience and will be used throughout this guide, to describe the signs and symptoms that develop or continue after a confirmed or suspected acute COVID-19 infection.

Occupational therapists understand the complex interaction between physical, cognitive and mental health.



Key messages

- Occupational therapists enable adults with Long Covid to manage and recover from its physical, cognitive, psychological and social impacts.
- Occupational therapy helps people to take part in activities, roles and routines that are important to them – at home, at work and in the community.
- Occupation-focused approaches help people to self-manage common symptoms and consequences of Long Covid, such as fatigue, cognitive issues, anxiety and depression. These approaches can also be used to support rehabilitation, where appropriate.

¹National Institute for Health and Care Excellence (NICE) 2020

²World Health Organisation (WHO) 2021

Long Covid and adults

A guide for occupational therapists



- Occupational therapists help people to remain in or return to work. They can then use self-advocacy support and advice for adjustments to address individual strengths and needs.
- Occupational therapists should proactively make sure their services are accessible to everyone and ensure their approaches meet the diverse needs of all users.
- Occupational therapists should access, use and contribute to the evidence-base on Long Covid, to find and apply intervention approaches that are the most effective.
- Occupational therapists should collect, use and share a range of data, to show the impact of occupational therapy and as part of quality improvement.

Context

The World Health Organization (WHO) defines Post COVID-19 condition (Long Covid) as:

[a condition that] occurs in individuals with a history of probable or confirmed SARS cov-2 infection, usually 3 months from the onset of COVID-19 with symptoms that last for at least 2 months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others and generally have an impact on everyday functioning. Symptoms may be new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness. Symptoms may also fluctuate or relapse over time.³

Long Covid is complex and often presents with clusters of symptoms, which can change and recur unpredictably, affecting people in different ways at different times.⁴ The evidence-base for interventions and support for people experiencing Long Covid is limited. Research to understand long-term effects of COVID-19 is ongoing and symptoms vary. Guidance on effective self-management and rehabilitation is developing. The WHO has produced a [Guideline on the clinical management of COVID-19](#), which includes approaches to rehabilitation.⁸

Estimates regarding the prevalence of Long Covid vary considerably. However, data from the Office for National Statistics (ONS) indicates that Long Covid is most prevalent in people of working age, females, people living in the most deprived areas, those working in social care and those with another activity-limiting health condition or disability.⁵

Disproportionately high numbers of people from Black, Asian and minority ethnic communities have been infected with COVID-19.⁶ The differences in prevalence of Long Covid in people of different ethnicities is not currently clear. Data being collected by the National Health Service (NHS) indicates that the majority of people accessing Long Covid assessment services are white.⁷

We developed this guide together with:

- Occupational therapists in a range of settings across the UK, who support people with Long Covid

³WHO 2021, ⁴NICE 2020, ⁵ONS 2022, ⁶Phiri et al 2021, ⁷NHS 2021, ⁸ WHO 2022

Long Covid and adults

A guide for occupational therapists



- Members of [Long Covid OT](#) – a peer support network of occupational therapy practitioners with lived experience of Long Covid.

The role of occupational therapy

Data indicates that symptoms adversely affect the day-to-day activities of roughly two thirds of people experiencing Long Covid.⁹ Occupational therapists can support people experiencing many of the common symptoms that impact on daily life, such as physical, psychological and cognitive issues, and emotional and social needs.

Long Covid symptoms are wide ranging and may affect multiple body systems.¹⁰ The most common symptoms occupational therapists address when supporting people with Long Covid are:

- fatigue
- pain
- anxiety and depression
- sleep disturbances
- breathlessness
- cognitive difficulties, such as brain fog and problems with memory and concentration
- autonomic dysfunction

Occupational therapists can support people experiencing many of the common symptoms that impact on daily life, such as physical, psychological and cognitive issues, and emotional and social needs.

Occupational therapy assessments and interventions focus on enabling performance and engagement. Occupational therapists can support people to maintain and return to the roles and activities that are important to them – this may include helping people remain in or return to employment. They can also help people adapt to changes in abilities arising from long-term conditions, such as finding new ways to engage in meaningful activities. Approaches are personalised to address the needs, preferences, values and culture of each person.

Occupational therapists are key members of multidisciplinary teams in dedicated Long Covid assessment clinics and rehabilitation services. They also support people with Long Covid in a range of existing settings, including:

- primary care
- community rehabilitation teams
- occupational health and vocational rehabilitation services
- specialist fatigue management and pain management services
- pulmonary and cardiac rehabilitation teams
- post-ICU clinics
- mental health services
- social care and housing services
- third sector organisations and leisure services

⁹ONS 2021, ¹⁰NICE2020

Long Covid and adults

A guide for occupational therapists



Assessment, goal setting and outcome measures

Occupational therapists facilitate person-centred assessments and discussions. They should:

- deliver these with respect to a person's personal, spiritual, religious and cultural needs and choices
- determine what matters to the individual, their current level of performance and their goals
- collect as much information before appointments to make the best use of time available to focus on current needs
- consider the physical and cognitive effort required for a person to engage when completing assessments, particularly when they are affected by fatigue and brain fog – break assessments into several sessions to conserve energy if needed.



Collaborative goal setting is a core feature of occupational therapy.

- It should take place when the person is ready and able to identify areas they want to address – this may be during the initial assessment or at a later date.
- Specialist and community teams should decide who is best placed to help people identify their therapy goals. This is particularly important because input from specialist Long Covid teams may be time limited.
- Goals should be reviewed and adjusted regularly, through discussion between the individual and the occupational therapist.

Long Covid is a relatively new illness and there's limited evidence regarding the specific use of occupational therapy assessment tools and outcome measures with people with Long Covid. The following occupation-focused tools may be appropriate:

- [Canadian Occupational Performance Measure \(COPM\)](#)¹¹
- [Model of Human Occupation Screening Tool \(MOHOST\)](#)¹²
- [Occupational Self-Assessment \(OSA\)](#)¹³

Occupational therapists also use a range of generic assessment and outcome tools, which cover areas including:

- anxiety [Generalised Anxiety Disorder Assessment \(GAD-7\)](#)¹⁴
- cognition – [Montreal Cognitive Assessment](#),¹⁵ [Addenbrooke's Cognitive Examination](#)¹⁶

¹¹Law et al 1990, ¹²Parkinson et al 2006

Long Covid and adults

A guide for occupational therapists



- fatigue – [Fatigue Assessment Scale](#),¹⁷ [Fatigue Severity Scale](#)¹⁸
- function – [Work and Social Adjustment Scale](#),¹⁹ [Patient Health Questionnaire-9](#)²⁰
- self-management – [Patient Activation Measure](#).²¹

Additionally,

- the [National commissioning guidance for post COVID services](#)²² recommend the use of the [EQ-5D-5L](#) Health Related Quality of Life (HRQOL) measure and the [EQ Visual Analogue Scale \(EQ VAS\)](#)²³
- the [COVID-19 Yorkshire Rehabilitation Scale](#)²⁴ was developed with occupational therapy input and is commonly used in Long Covid assessment clinics
- the [Symptom Burden Questionnaire for Long COVID \(SBQ-LC\)](#)²⁵ captures symptoms from 16 categories to measure their impact on daily life, and is designed for use by clinicians and researchers.a

occupational therapists support people to increase activities incrementally in a planned and flexible way by using occupational performance and analysis skills.

Our webpage on [assessments and outcome measures](#) provides more information about the selection and use of occupational therapy assessment tools and outcome measures.

Interventions and support

Occupational therapists expertly manage complexity and identify personalised interventions that consider people's needs and symptoms in relation to their occupational goals. They recognise that each person's experience of Long Covid is unique and authentic, and that symptoms and support needs may change and fluctuate over time. Occupational therapy interventions and support for people experiencing Long Covid include:

- **assistive devices** – occupational therapists can recommend equipment such as bathing, seating and mobility aids to enable people to take part in self-care and other activities as safely and independently as possible.
- **building activity tolerance** – occupational therapists support people to increase activities incrementally in a planned and flexible way by using occupational performance and analysis skills.
 - They consider all aspects of life such as self-care, domestic activities, parenting and caregiving - as the individual desires. They must consider appropriate approaches to activity and post-exertional symptom exacerbation (PESE). This is to make sure that cognitive, sensory/ environmental and emotional load are recognised when assessing the situation, as well as physical increases in activity.
- **cognitive functioning** – occupational therapists are trained to address cognitive issues and can identify strategies and tools to help with memory, concentration and planning, including use of visual cues and prompts, and apps.

¹³Baron et al 2006 ,¹⁴Chalder et al 1993, ¹⁵Chorpita et al 2005, ¹⁶Tennant et al 2007, ¹⁷O'Connor 2022, ¹⁸Cotler et al 2018, ¹⁹RCOT 2020, ²⁰Kroenke et al 2001, ²¹Hibbard et al 2004, ²²NHS England and Improvement 2022, ²³TheEuroQol Group 1990, ²⁴O'Connor et al 2022, ²⁵Hughes et al 2022

Long Covid and adults

A guide for occupational therapists



- **environmental assessment** – occupational therapists are specialists in environmental assessment and can identify strategies and adaptations to reduce the impact of environmental obstacles on people's engagement in everyday activities at home, at work and in other settings.
- **fatigue management** – occupational therapists can increase awareness of the impact of physical, cognitive, emotional and social energy demands and reinforce the key principles of pacing, planning and prioritising to avoid the 'boom and bust' cycle.
 - They can help people break activities down into achievable parts, planning daily routines, and using equipment, adaptations or support to conserve energy. This should include education on the importance of quality rest, and techniques for building rest into routines – our publication [How to conserve your energy](#)²⁶ provides additional information on this.
- **meaningful occupations and enjoyment** – occupational therapists understand the importance for health and wellbeing of taking part in activities that are personally valued and rewarding. They work with people to identify the activities that are important to them and recommend strategies to enable their participation.
 - They must consider the safety of approaches to activity before making recommendations, and they must regularly monitor and review the individuals' responses to interventions to identify any PESE. World Physiotherapy has produced specific guidance on [safe rehabilitation approaches for physical activity and exercise](#).²⁷
- **mental health** – occupational therapists use their knowledge of physical and mental health to help people understand the relationship between Long Covid and feelings of depression and anxiety.
 - They help people to use anxiety management techniques and activity scheduling to enable them to take part in the activities that matter to them, while ensuring a balance of self-care, work and social/leisure activities. Validating people's experience and recognising their resilience is key to building trust and promoting recovery, especially for those whose symptoms have been doubted and who have struggled to access healthcare support previously.
- **pain management** – occupational therapists help people use a variety of pain management strategies including relaxation, activity-scheduling and cognitive approaches so they can take part in self-care, work and leisure activities. These strategies should be personally meaningful.
- **return to work and education** – a key focus for occupational therapy is providing individually tailored support to enable access to employment and education.
 - The occupational therapy role includes liaising with and educating employers about Long Covid and may involve a personalised plan to help with a phased return to work or education, such as using the RCOT [Allied Health Professions Health and Work Report](#).
- **role and identity** – part of the occupational therapy role is to support people to come to terms with changes to their life and activities arising from Long Covid, helping them to accept a new (temporary or fluctuating) sense of identity. They help people to find a balance of activities that reduces their symptoms and enables recovery.

²⁶RCOT 2020, ²⁷World Physiotherapy 2021

Long Covid and adults

A guide for occupational therapists



- **sleep hygiene** – occupational therapists can explore changes to bedtime routines and the environment to enable good quality sleep.
 - Adaptations such as blue light filters should be considered for phones and other digital devices as these may be essential tools for work and personal life.
- **social support** – occupational therapists will signpost people to organisations and services that offer support and information. These may offer social prescribing for support with social needs, such as benefits advice, financial assistance and individual rights.
 - Online groups such as [Long Covid Support](#), developed and managed by people with lived experience, provide opportunities for people to connect and provide peer support.

Fair access

A confirmed diagnosis of COVID-19 isn't needed to access and benefit from occupational therapy. Interventions should be offered at the earliest opportunity once any symptoms that may affect the person's ability to participate in rehabilitation safely have been investigated.²⁸

Access to occupational therapy should be provided fairly for everyone affected by Long Covid. Occupational therapists should take proactive steps to ensure that access to their services is fair, and that intervention approaches are suitable and appropriate for people with diverse needs and from diverse backgrounds.

Occupational therapists should offer a range of options, including in-person appointments, printed resources, and virtual and telephone consultations to enable people to access support in ways that suit them. A mixture of approaches may be needed, and people may need help to access virtual services.

Interventions may be delivered one to one or in groups to best meet the needs of individuals and the demands on the service. Group interventions can help to develop a sense of shared experience, validation and peer support.

Some people may not seek help to manage symptoms of Long Covid. Occupational therapists should ensure their support is accessible and consider ways to engage with people who may not seek help themselves.

Services should consider where in-person appointments are held, to ensure that no one is excluded because of poor public transport or other access constraints.

Occupational therapists should offer resources and information in different languages, including easy-read versions.

Access to occupational therapy should be provided fairly for everyone affected by Long Covid.

²⁸NICE 2020

Long Covid and adults

A guide for occupational therapists



Personalised approach

Occupational therapists:

- use coaching (effective) conversations to help people understand their symptoms and identify intervention goals. Adjustments may be necessary to account for fatigue and reduced concentration.
- take a self-management approach, to enable people to manage their symptoms and work towards realistic goals. Different levels of support may be required at different times. This may also include support to use appropriate self-management apps.
- work directly with individuals, and indirectly with family members, caregivers and employers, to build their knowledge and capacity to support people with Long Covid.

Communication between occupational therapists in tertiary Long Covid services, community colleagues and the wider multidisciplinary team is essential for coordinated and timely care of individuals – and facilitates shared learning.

The timing and duration of therapeutic input should be based on the person's individual needs and their progress towards their occupational goals. Slow-stream approaches are likely to be most appropriate for many people given the fluctuating and episodic nature of Long Covid, and the prevalence of fatigue and PESE.

Discharge and follow-up

Occupational therapists should consider the preferences, goals and support needs of individuals when discussing and agreeing follow-up and discharge plans. They should signpost people to community support networks and make sure they know how to re-access occupational therapy if new occupational performance issues arise after discharge. This is particularly important because of the relapsing and remitting nature of the condition.

Evidence

Occupational therapists should be open and honest with people whilst the evidence-base for occupational therapy and Long Covid is still emerging. People should be reassured however, that the recommendations and support provided are based on current thinking about best practice.

Occupational therapists should consider how the existing evidence-base for related symptoms, conditions and rehabilitation approaches may be applied with adults affected by Long Covid. Evidence may be taken from other chronic and post-viral conditions, such as ME/chronic fatigue syndrome, as well as episodic illnesses and disabilities.²⁹

²⁹Brown and O'Brien 2021

Long Covid and adults

A guide for occupational therapists



Regularly updated sources of evidence about Long Covid and rehabilitation approaches include:

- [Cochrane REH-COVER Rapid Living Systematic Reviews](#)
- [National Institute of Health Research \(NIHR\)](#)

Occupational therapists should continue to access, evaluate and contribute to the evidence-base to build evidence of the effectiveness of occupational therapy for people with Long Covid. All services can evaluate the value and benefit of interventions by measuring changes in occupational performance, participation and wellbeing. Outcome data should be reviewed and used to improve the quality, value and effectiveness of the services provided.

Visualising individual and service outcome data for key stakeholders, for example staff, commissioners, public and patient groups can demonstrate the impact of occupational therapy and encourage an appetite for data and innovation. See our [Data and Innovation Strategy](#)³⁰ for more information.

References:

Baron K, Kielhofner G, Iyenger A, Goldhammer V, Wolenski J (2006) *The Occupational Self Assessment* (version 2.2). Chicago: Model of Human Occupation Clearinghouse.

Brown DA, O'Brien KK (2021) Conceptualising Long Covid as an episodic health condition. *BMJ Global Health*, 2021;6:e007004. Available at: <https://gh.bmj.com/content/6/9/e007004>

Hibbard JH, Stockard J, Mahoney ER, Tusler M. (2004) Development of the Patient Activation Measure (PAM): conceptualising and measuring activation in patients and consumers. *Health Services Research*. 39(4p1): 1005-1026.

Hughes SE, Haroon S, Subramanian A, McMullan C, Aiyegbusi OL, Turner GM et al. (2022) Development and validation of the symptom burden questionnaire for long covid (SBQ-LC): Rasch analysis *BMJ*. 377 :e070230 @

Kroenke, K, Spitzer, RL, Williams, JBW. (2001) The PHQ-9. *Journal of General Internal Medicine* 16, 606–613.

Krupp LB, LaRocca NG, Muir-Nash J, Steinberg AD. (1989) The fatigue severity scale. Application to patients with multiple sclerosis and systemic lupus erythematosus. *Archives of Neurology*. 46(10):1121-1123.

Law M, Baptiste S, McColl M, Opzoomer A, Polatajko H, Pollock N. (1990) The Canadian occupational performance measure: an outcome measure for occupational therapy. *Canadian Journal of Occupational Therapy*. 57(2):82-87.

³⁰RCOT 2021

Long Covid and adults

A guide for occupational therapists



Mathuranath PS, Nestor PJ, Berrios GE, Rakowicz W, Hodges JR. (2000) A brief cognitive test battery to differentiate Alzheimer's disease and frontotemporal dementia. *Neurology*. 55(11):1613-1620.

Michielsen HJ, De Vries J, Van Heck GL. (2003) Psychometric qualities of a brief self-rated fatigue measure: The Fatigue Assessment Scale. *Journal of Psychosomatic Research*. 54(4):345-352.

Mundt JC, Marks IM, Shear MK, Greist JH. (2002) The Work and Social Adjustment Scale: a simple measure of impairment in functioning. *British Journal of Psychiatry*. 180:461-464.

Nasreddine ZS, Phillips NA, Bédirian V, Charbonneau S, Whitehead V, Collin I, Cummings JL, Chertkow H. (2005) The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. *Journal of the American Geriatric Society*. 53(4):695-699.

NHS England (2021) COVID-19 post-covid assessment service. [s.l]: NHS. Available at: <https://www.england.nhs.uk/statistics/statistical-work-areas/covid-19-post-covid-assessment-service/>

NHS England (2022) National commissioning guidance for post COVID services. [s.l]: NHS. Available at: <https://www.england.nhs.uk/publication/national-commissioning-guidance-for-post-covid-services/>

National Institute for Health and Care Excellence (2020, updated 2021) COVID-19 rapid guideline: managing the long-term effects of COVID-19. [NG 188]. [s.l]. London: NICE. Available at: <https://www.nice.org.uk/guidance/ng188>

O'Connor RJ, Preston N, Parkin A, Makower S, Ross D, Gee J, Halpin SJ, Horton M, Sivan M. (2022) The COVID-19 Yorkshire Rehabilitation Scale (C19-YRS): Application and psychometric analysis in a post-COVID-19 syndrome cohort. *Journal of Medical Virology*. 94(3):1027-1034.

Office for National Statistics (2022) Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 1 December 2022. [s.l]: ONS. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/latest>

Parkinson, S., Forsyth, K., & Kielhofner, G. (2006). *The Model of Human Occupation Screening Tool (Version 2.0)*. Chicago, IL: Model of Human Occupation Clearinghouse.

Phiri P, Delanerolle G, Al-Sudani A, Rathod S (2021) COVID-19 and Black, Asian, and Minority Ethnic Communities: a complex relationship without just cause. *JMIR Public Health and Surveillance*;7(2):e22581.

Spitzer RL, Kroenke K, Williams JB, Löwe B. (2006) A brief measure for assessing generalized anxiety disorder: the GAD-7. *Archives of Internal Medicine*. 166(10):1092-1097.

The EuroQol Group (1990) EuroQol-a new facility for the measurement of health-related quality of life. *Health Policy*. 16(3):199-208.

Long Covid and adults

A guide for occupational therapists



World Health Organization (2021) A clinical case definition of post COVID-19 condition by a Delphi consensus. [s.l.]: WHO. Available at: https://www.who.int/publications/i/item/WHO-2019-nCoV-Post_COVID-19_condition-Clinical_case_definition-2021.1

World Health Organization (2022) Clinical management of COVID-19 patients: living guideline. [s.l.]: WHO. Available at: <https://apps.who.int/iris/bitstream/handle/10665/362783/WHO-2019-nCoV-Clinical-2022.2-eng.pdf>

World Physiotherapy (2021) World Physiotherapy response to COVID-19 Briefing Paper 9: safe rehabilitation approaches for people living with Long Covid – physical activity and exercise. London: World Physiotherapy.

Other resources:

[RCOT Long Covid webpage](#)

[Health Education England e-learning modules: long COVID programme](#)

Acknowledgements:

This RCOT guide has been developed with occupational therapists working with adults with Long Covid and with members of Long Covid OT. We'd like to thank all contributors and members of the RCOT Publications Group for their valued input.