

Long Covid and children and young people

A guide for
occupational therapists



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Purpose

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

Occupational therapy enables children and young people to take part in activities, roles and routines that are important to them and the people who support them, at home, school and elsewhere. Occupational therapists understand the complex interaction between physical, cognitive and mental health. They can work across and within health, education and social care to support children and young people affected by Long Covid. Young people with Long Covid are best supported by a multidisciplinary team with the skills to address a wide range of needs.

This guide is for occupational therapists working with children and young people with Long Covid in all settings, including Long Covid services and other 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 parents and carers of children and young people affected by Long Covid - a companion guide for supporting adults 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 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 with lived experience. And so, we'll use this throughout the guide to describe the signs and symptoms that develop or continue after confirmed or suspected acute COVID-19 infections.

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



Key messages

- Occupational therapists are essential in enabling children and young people with Long Covid to manage and recover from its physical, cognitive, psychological and social impacts.
- Occupational therapy helps people to take part in the activities, roles and routines that are important to them – at home, in education and during their leisure time.
- 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 help support rehabilitation, where appropriate.

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

²World Health Organisation (WHO) 2021

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- Occupational therapists enable children and young people affected by Long Covid to access education. They provide information and training for teachers, recommend reasonable adjustments, and facilitate a phased return to school where appropriate.
- Occupational therapists should proactively make sure their services are available to everyone, and ensure their approaches meet the diverse needs of all children and young people and families.
- Occupational therapists should access, use and contribute to the evidence-base on Long Covid, to find and apply the intervention approaches that are 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 reoccur unpredictably, affecting people in different ways at different times.⁴ Long Covid symptoms don't seem to be related to the severity of the original infection.⁵ The evidence-base for interventions and support for children and young people who experience Long Covid is limited. Research to understand the long-term effects of COVID-19 on children and young people is ongoing. Guidance on effective self-management and rehabilitation is developing. WHO has produced a Guideline on the clinical management of COVID-19, which includes approaches to rehabilitation.⁶

We developed this guide together with:

- Children's occupational therapists across the UK who've drawn on their skills and experience in acute and community practice
- Occupational therapists caring for a family member with Long Covid
- Members of the Long Covid Kids community.

³WHO 2021, ⁴NICE 2020, ⁵NICE 2020, ⁶WHO 2022

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The role of occupational therapy

Long Covid can have a significant impact on young people's occupational performance, participation and relationships. Persistent symptoms of Long Covid that affect children's daily activities include, but are not limited to, the following:

- fatigue and energy limitation, including post-exertional malaise
- headaches and sensory disturbance affecting vision and hearing
- muscle aches, joint and nerve pain, inflammation and rashes affecting all parts of the body, including the hands and feet
- sleep difficulties/disturbance
- reduced cognitive functioning ('brain fog') affecting concentration, memory and processing speed
- neuro-psychiatric symptoms such as tics, emotional lability, restrictive eating, thoughts of self-harm – often described as Paediatric Acute Onset Neuropsychiatric Syndrome (PANS) or Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) if not better explained by a known neurological or medical disorder (see PANS/PANDAS for more information).
- abdominal pain and gastrointestinal issues
- loss of taste and smell affecting motivation to eat
- heart palpitations and shortness of breath which may re-emerge after a period of time – these may be linked to autonomic dysfunction, for example Postural Tachycardia Syndrome (pots).
- Pediatric Multisystem Inflammatory Syndrome (PIMS)
- hormonal disruptions such as early puberty or exacerbation of menstrual symptoms
- depression and anxiety.

The goal of occupational therapy is to help children and young people continue and return to the daily life activities, roles and routines that are important to them

The resource [What Is Long Covid | Long Covid Kids](#) provides a summary of signs and symptoms.

The goal of occupational therapy is to help children and young people continue and return to the daily life activities, roles and routines that are important to them. This may include remaining in or returning to school. Occupational therapists also help people adapt to changes in their abilities due to long-term conditions, including finding new ways to take part in meaningful activities. Approaches are personalised to address the needs, preferences, values and culture of each child or young person.

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Assessment, goal setting and outcome measures

Occupational therapists facilitate person-centred assessments. For the assessment the occupational therapist should:

- deliver these with respect to a person's personal, spiritual, religious and cultural needs or choices
- determine what matters to the individual, their current level of performance and their intervention 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 young 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 child or young 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 children and young people identify their therapy goals. This is important because input from specialist Long Covid teams may be time limited.
- Goals should be reviewed and adjusted regularly, through discussion between the young person 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 children and young people with Long Covid. The following occupation-focused tools may be appropriate:

- [Canadian Occupational Performance Measure \(COPM\)](#)⁷
- [Child Occupational Self Assessment \(COSA\)](#)⁸
- [The Goal-Based Outcome \(GBO\) Tool](#)⁹
- [Talking Mats – Improving communication, improving lives](#)¹⁰
- [Perceived Efficacy and Goal Setting \(PEGS\), CanChild](#)¹¹

Other multidisciplinary assessments to which an occupational therapist might contribute include:

- [EQ-5D Quality of Life](#)¹²
- [SF-36 Quality of Life](#)¹³

⁷Law et al 1990, ⁸Kramer et al 2014, ⁹Law 2019, ¹⁰Murphy et al 2007, ¹¹Missiuna et al 2004, ¹²The EuroQol Group 1990
¹³Ware et al 1992

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- [Chalder Fatigue Questionnaire](#)¹⁴
- [Revised Child Anxiety and Depression Scale](#)¹⁵
- [WEMWBS](#)¹⁶
- [Yorkshire rehabilitation screening tool](#)¹⁷
- [The depaul brief Questionnaire - post-exertional malaise](#)¹⁸

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

Occupational therapists can explore changes to bedtime routines and the environment to enable good quality sleep.



Interventions and support

Occupational therapists expertly manage complexity and identify personalised interventions that consider an individual's needs and symptoms in relation to their occupational goals. Occupational therapy interventions and support for children and young people experiencing Long Covid include:

- **assistive devices** – occupational therapists can recommend equipment such as seating and bathing aids to enable children and young people to take part in self-care and other activities as safely and as independently as possible.
- **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, prompts and apps.
- **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 school 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 young people and caregivers break activities down into achievable parts, plan morning/daily routines and consider the use of equipment, adaptations or support to conserve energy. Fatigue management includes education on the importance of quality rest and techniques for building rest into daily routines – our publication [How to conserve your energy](#)¹⁹ provides additional information on this; it's written for adults but some principles can be applied to children and young people.

¹⁴Chalder et al 1993, ¹⁵Chorpita et al 2005, ¹⁶Tennant et al 2007, ¹⁷O'Connor 2022, ¹⁸Cotler et al 2018, ¹⁹RCOT 2020

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- **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 young people to identify the activities that are important to them and recommend strategies to enable their participation.
 - Referral for screening for cardiac involvement and post-exertional malaise may be required if returning to sports and physical activity is identified as a therapy goal.²⁰
- **mental health** – occupational therapists use their knowledge of physical and mental health to help children and families understand the relationship between Long Covid and feelings of depression and anxiety.
 - They help children and young people 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, schoolwork/learning and social/leisure activities. Validating people's experience and recognising young people's resilience is key to building trust and promoting recovery, especially for young people whose symptoms have been doubted and who have struggled to access healthcare support previously.
- **pain management** – occupational therapists help children and young people use a variety of pain management strategies including relaxation, activity-scheduling and cognitive approaches so they can take part in self-care, school and leisure activities. These strategies should be personally meaningful.
- **return to education** - a key focus for occupational therapy is providing individually tailored support to enable access to education.
 - Facilitating an extended, phased return to school (when appropriate) is more likely to sustain recovery than returning too quickly. The occupational therapy role includes liaising with and educating school staff, parents and caregivers about Long Covid and adapting school occupations such as handwriting and PE.
- **role and identity** – part of the occupational therapy role is to support young people to come to terms with changes to their life and activities as a result of Long Covid, helping them to accept a new (temporary or fluctuating) sense of identity. They help young people and families navigate changes to their social environment and activities and encourage young people to find a balance of activities that reduces their symptoms and enables recovery.
- **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 rather than removing them completely as they may be a lifeline for some young people.

²⁰American Academy of Pediatrics 2022

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- **social support** – occupational therapists will signpost children, young people and families to organisations and services that offer support and information.
 - Online groups such as [Long Covid Kids](#) have been developed and are managed by people with lived experience. They provide opportunities for young people and families 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 indicate a possible serious illness (such as sepsis, meningitis or febrile neutropenia) have been eradicated.²¹

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

Occupational therapists should consider the possibility of Long Covid for children and young people with medically unexplained symptoms, who are seen in other occupational therapy services. The high incidence of asymptomatic cases in children means that Long Covid may be missed in children and young people with pre-existing diagnoses such as autism.

Services should consider where in-person appointments are held, to ensure that families aren't excluded because of poor public transport or other access constraints.

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

Occupational therapists must ensure their support is accessible and consider ways to engage with people who may not seek help themselves.

²¹NICE 2020

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Personalised approach

Occupational therapists:

- use coaching (effective) conversations to help children and young people and caregivers 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 children and young people to manage their symptoms and work towards realistic goals. Different levels of support may be required at different times.
- work indirectly with parents, caregivers and teachers to build their knowledge and capacity to support children and young 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 for children and young people and families.

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

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 young people and families to community support networks so they know how to 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.

Occupational therapists should evaluate the value and benefit of interventions by measuring changes in occupational performance, participation and well-being. Outcome data should be reviewed and used to improve the quality, value and effectiveness of the services provided.

Evidence

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

Occupational therapists should continue to access, evaluate and contribute to the evidence-base to build evidence of the effectiveness of occupational therapy for children and young people with Long Covid. All services can evaluate the value and benefit of interventions by measuring changes in

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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](#)²² for more information.

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[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 children, young people and families and with members of the Long Covid Kids community. We'd like to thank all contributors and members of the RCOT Publications Group for their valued input.