



A quick guide for occupational therapists: **Occupational therapy and children and young people with Long Covid (Post COVID-19 Syndrome/Condition)**

Purpose

The purpose of this quick guide is to outline the unique role of occupational therapists in supporting children and young people to manage and recover from Long Covid.

The aim of occupational therapy is to enable children and young people to take part in the activities, roles and routines that are important to them and the people that support them at home, at school and in other settings. Occupational therapists' understanding of the complex interaction between physical and mental health, along with an ability to work across health, education and social care, positions the profession well to support children and young people whose participation in daily life is affected by Long Covid. Children and 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 specialist 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 specialist Long Covid services. It may also be useful to parents and carers of children and young people affected by Long Covid.

Terminology

Many people with a confirmed or suspected case of Coronavirus disease (COVID-19) feel better in a few days or weeks after infection, and most make a full recovery within 12 weeks. Some people experience longer-term symptoms however, and this condition has been described and defined using different terminology including Long Covid, Post COVID-19 Syndrome (NICE 2020) and Post COVID-19 Condition (WHO 2021).

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 confirmed or suspected acute COVID-19 infection.

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Key messages

- Occupational therapists are essential in enabling children and young people with Long Covid to manage and recover from the physical, cognitive, psychological and social impacts of the condition.
- Occupational therapy helps people whose participation in daily life is affected by Long Covid 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. They can also be used to support rehabilitation, where appropriate.
- Occupational therapy can enable people affected by Long Covid to access education by providing information and training for teachers, recommending reasonable adjustments, and facilitating a phased return to school where appropriate.
- Occupational therapists should take proactive steps to ensure that access to their services is equitable and that intervention approaches meet the diverse needs of all young people and families.
- Occupational therapists should access, use and contribute to the evidence base on Long Covid, to identify and apply the intervention approaches that are the most effective.
- Occupational therapists should collect, use and share a range of data, both to evidence the impact of occupational therapy, and as part of quality improvement activities.

Context

The World Health Organization (2021) 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.

Long Covid is complex and often presents with clusters of symptoms which can change and recur (relax and remit) unpredictably, affecting people in different ways at different times (NICE 2020). Long Covid symptoms do not seem related to the severity of the original infection and few children and young people with Long Covid have been admitted to hospital (NHS 2020). The long-term effects of COVID-19 on children and young people are unknown and are being studied.

The evidence-base for interventions and support for children and young people experiencing Long Covid is currently very limited. This quick guide has been developed in collaboration with UK children's occupational

therapists who have drawn on their skills and experience in acute and community practice, by occupational therapists who are caring for a family member with Long Covid and with members of the [Long Covid Kids](#) community.

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 e.g. tics, emotional lability, restrictive eating, thoughts of self-harm. These may be 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
- Symptoms such as heart palpitations and shortness of breath which may re-emerge after a period of time and may be linked to autonomic dysfunction e.g. Postural Tachycardia Syndrome (PoTS).
- Paediatric Multisystem Inflammatory Syndrome ([PIMS](#)) - a rare complication of COVID-19 infection
- Hormonal disruptions such as early puberty or exacerbation of symptoms in line with the menstrual cycle
- Depression and anxiety

See [What Is Long Covid | Long Covid Kids](#) for a summary of signs and symptoms.

Occupational therapy assessments and interventions focus on enabling children and young people's occupational 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 enabling young people to remain in or return to school. Occupational therapists also support people to adapt to changes in abilities arising from long-term conditions, including finding new ways to engage in meaningful activities. Approaches should be personalised to address the needs, preferences, values and culture of each child or young person.

Assessment, goal setting and outcome measures

Occupational therapists facilitate person-centred assessments and discussions, delivered in a way that respects their personal, spiritual, religious and cultural needs or choices. The aim is to determine what matters to the individual, their current level of performance and their personal intervention and support goals.

Occupational therapists should gather as much information as possible in advance of any appointment to ensure that time is used effectively and focuses on presenting needs rather than history-taking. When completing assessments, it is important to consider the physical and cognitive effort required for a young person to engage in these activities, particularly when a child or young person is affected by fatigue and brain fog. It may be appropriate to break assessments into several sessions as part of an energy conservation approach.

Collaborative goal setting is a core feature of occupational therapy and should take place when a child or young person is ready and able to identify areas that they wish to address. This may be during the initial assessment or at a later date. Specialist and community teams should decide which team is best placed to help children and young people identify their therapy goals. This is particularly important if input from specialist Long Covid teams is time limited. Goals should be reviewed and adjusted regularly, through discussion between the young person and the occupational therapist.

Long Covid is a new illness and there is currently a lack of 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 however, be appropriate:

- COPM [COPM | Canadian Occupational Performance Measure \(thecopm.ca\)](https://www.thecopm.ca)
- COSA [MOHO Web \(uic.edu\)](https://www.uic.edu/moho)
- The Goal-Based Outcome Tool [The Goal-Based Outcome \(GBO\) Tool – Goals in Therapy \(goals-in-therapy.com\)](https://www.goals-in-therapy.com)
- Other goal-setting tools which may be appropriate include [Talking Mats Talking Mats | Improving communication, improving lives](https://www.talkingmats.com) and PEGS (for children aged 5-9 years) [CanChild](https://www.canchild.ca).

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

- EQ-5D Quality of Life [EQ-5D instruments – EQ-5D \(euroqol.org\)](https://euroqol.org)
- SF-36 Quality of Life [36-Item Short Form Survey \(SF-36\) | RAND](https://www.rand.org/assessments/sf36)
- Chalder Fatigue Questionnaire [Chalder Fatigue Scale \(CFQ 11\) | Occupational Medicine | Oxford Academic \(oup.com\)](https://www.oup.com/academic/view/9780198568243/chapter-11)
- Revised Child Anxiety and Depression Scale [Revised Children's Anxiety and Depression Scale \(RCADS\) \(corc.uk.net\)](https://www.corc.uk.net)
- WEMWBS [About WEMWBS \(warwick.ac.uk\)](https://www.warwick.ac.uk/wemwbs)
- Yorkshire rehabilitation screening tool [covid-19-yorkshire-rehabilitation-scale-jan2021-apbrochure-elaros-c19-yrs-brochure.pdf \(bsrm.org.uk\)](https://www.bsrm.org.uk/covid-19-yorkshire-rehabilitation-scale-jan2021-apbrochure-elaros-c19-yrs-brochure.pdf)
- The DePaul brief Questionnaire - post-exertional malaise [A Brief Questionnaire to Assess Post-Exertional Malaise \(nih.gov\)](https://www.nih.gov/health-topics/post-exertional-malaise)

Further information about the selection and use of occupational therapy assessment tools and outcome measures can be found at: [Assessments and Outcome Measures \(RCOT\)](https://www.rcot.org.uk/assessments-and-outcome-measures)

Interventions

Occupational therapists are experts at managing complexity and identifying 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:

- **Fatigue management** – increasing awareness of the impact of physical, cognitive, emotional and social energy demands and reinforcing the key principles of pacing, planning and prioritising to avoid the 'boom and bust' cycle. This includes helping young people and caregivers break activities down into achievable parts, and planning morning / daily routines and using equipment, adaptations or support to conserve energy. Approaches also include education on the importance of quality rest, and techniques for building rest into routines. See here for more information (written for adults but many principles can be applied to children): [How to conserve your energy \(RCOT 2020\)](#)
- **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.
- **Sleep hygiene** – exploring changes to the bedtime routine and environment to enable good quality sleep. Consider adaptations such as blue light filters rather than removing phones completely as they may be a lifeline for some young people.
- **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.
- **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, 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.
- **Meaningful occupations and enjoyment** – occupational therapists understand the importance for health and wellbeing of taking part in activities that are personally valued and rewarding. Occupational therapists 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 goal ([American Academy of Pediatrics 2021](#)).

- **Role and identity** – occupational therapists 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. This includes helping young people and families navigate changes to their social environment and activities and encouraging young people to find a balance of activities that reduces their symptoms and enables recovery.
- **Pain management** – occupational therapists enable children and young people to 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.
- **Environmental assessment** – as specialists in environmental assessment, occupational therapists identify strategies and adaptations that reduce the impact of environmental obstacles on people's engagement in everyday activities at home, at school and in other settings.
- **Assistive devices** – occupational therapists 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.
- **Social support** – occupational therapists can 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 of Long Covid, providing opportunities for peer support and for young people and families to connect with each other.

Fair access

It is not necessary for children and young people to have a confirmed diagnosis of COVID-19 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 (NICE 2020).

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 equitable, 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.

Some young people and families 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.

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.

Consideration should be given to the location of in-person appointments to ensure that no families are excluded because of poor public transport or other access constraints.

Occupational therapy resources and information should be provided in different languages including easy-read versions.

Personalised approach

Occupational therapists use coaching (effective) conversations to help children, young people and caregivers understand their symptoms and identify intervention goals. However, adjustments may be necessary to account for fatigue and reduced concentration.

Occupational therapists take a self-management approach, enabling children and young people to manage their symptoms and set and work towards realistic goals. Different levels of support may be required at different times.

As well as working directly with children and young people, occupational therapists work indirectly with parents, caregivers and teachers to build their knowledge and capacity to support children with Long Covid.

Communication between occupational therapists in tertiary Long Covid services, with community colleagues and the wider multidisciplinary team is essential to ensure coordinated and timely care for children, young people and families. It also facilitates shared learning.

The timing and duration of therapeutic input should be based on the person'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

When discussing and agreeing follow-up and discharge plans, occupational therapists should consider individual preferences, goals and support needs. Young people and families should be signposted to community support networks and know how to access occupational therapy if new occupational performance issues arise after discharge. This is particularly important due to 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 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 the RCOT Data and innovation strategy (in press) for more information.

Resources:

[First findings from world's largest study on long Covid in children | UCL News - UCL – University College London](#)
[Long covid: One in seven children may still have symptoms 15 weeks after infection, data show | The BMJ](#)

References:

NHS England (2021) *National guidance for post-COVID syndrome assessment clinics*. [s.l]: NHS. Available at: <https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/11/C1248-national-guidance-post-covid-syndrome-assessment-clinics-v2.pdf>

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]: NICE. Available at: <https://www.nice.org.uk/guidance/ng188>

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

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