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

The aim of occupational therapy is to enable people to take part in the activities, roles and routines that are important to them, at home, at work and in community and leisure settings. Occupational therapists’ understanding of the complex interaction between physical, cognitive and mental health, along with an ability to work across acute, primary care, community services and social care, positions the profession well to support people whose participation in daily life is 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 useful to members of the public affected by Long Covid, and their families and carers.

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 much longer-term symptoms, 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 a confirmed or suspected acute COVID-19 infection.
Key messages

• Occupational therapists are essential in enabling adults affected by 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, 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. They can also be used to support rehabilitation, where appropriate.

• Occupational therapy can enable people affected by Long Covid to remain in or return to work, using self-advocacy support and advice regarding adjustments to address individual strengths and needs.

• 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 users.

• 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). The long-term impacts of COVID-19 are still being studied, and symptoms vary from person to person.

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 health and social care, and those with another activity-limiting health condition or disability (ONS 2021).

The differences in prevalence of Long Covid in people of different ethnicities is not currently clear, but it is known that disproportionately high numbers of people from Black, Asian and minority ethnic communities
have been infected with COVID-19 (Phiri et al 2021). Data being collected by the NHS indicates that the majority of people accessing Long Covid assessment services are white (NHS 2021).

The evidence base for interventions and support for people experiencing Long Covid is currently very limited. This quick guide has been developed in collaboration with UK occupational therapists supporting people with Long Covid across a range of settings, and members of Long Covid OT – a peer support network run by and for occupational therapy practitioners with personal lived experience of Long Covid.

## The role of occupational therapy

Data from the ONS indicates that symptoms adversely affect the day-to-day activities of about two thirds of people experiencing Long Covid (ONS 2021). Occupational therapists can support people experiencing many of the common symptoms that impact on daily life, including physical, psychological and cognitive issues, as well as emotional and social needs.

The symptoms of Long Covid are wide ranging and may affect multiple body systems (NICE 2020). Occupational therapists supporting people with Long Covid report that the most common symptoms they address include:

- Fatigue
- Pain
- Anxiety and depression
- Sleep disturbances
- Breathlessness
- Cognitive difficulties, e.g. brain fog and problems with memory and concentration
- Autonomic dysfunction

Occupational therapy assessments and interventions focus on enabling 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 people to remain in or return to employment. 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 person.

Occupational therapists are key members of multidisciplinary teams located 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

Assessment, goal setting and outcome measures

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

Occupational therapists should gather as much information as possible in advance of appointments to ensure that time is used effectively and focuses on presenting needs rather than history-taking. When completing assessments and outcome measures with individuals, it is important to consider the physical and cognitive effort required to engage in these activities, particularly for people 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 the person feels ready and able to identify areas that they wish to address. This may be during an initial assessment but may be better undertaken at a later date. Specialist and community teams should decide which team is best placed to help 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 individual 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 people with Long Covid. Occupation-focused tools currently being used by occupational therapists in Long Covid settings include:

• **Canadian Occupational Performance Measure** (COPM) (Law et al 1990)
• **Model of Human Occupation Screening Tool** (MOHOST) (Parkinson et al 2006)
• **Occupational Self-Assessment** (OSA) (Baron et al 2006).

Occupational therapists are also using a range of generic assessment and outcome tools, covering areas including:

• Function (e.g. **Work and Social Adjustment Scale**, Mundt et al 2002; **Patient Health Questionnaire-9**, Kroenke et al 2001)
• Fatigue (e.g. **Fatigue Assessment Scale**, Michielsen 2003; **Fatigue Severity Scale**, Krupp et al 1989)
• Cognition (e.g. **Montreal Cognitive Assessment**, Nasreddine et al 2005; **Addenbrooke’s Cognitive Examination**, Mathuranath et al 2000)
• Self-management (e.g. **Patient Activation Measure**, Hibbard et al 2004)
• Anxiety (e.g. Generalised Anxiety Disorder Assessment (GAD-7), Spitzer et al 2006).
NHS England and Improvement recommend the use of the following tools within the National guidance for post-COVID syndrome assessment clinics (2021a).

• EQ-5D-5L Health Related Quality of Life (HRQOL) measure, including the EQ Visual Analogue Scale (EQ VAS).

Another commonly used tool in Long Covid assessment clinics, which was developed with occupational therapist input, is the COVID-19 Yorkshire Rehabilitation Scale.

Advice and further information on the selection and use of assessment tools and outcome measures can be found at: Assessments and Outcome Measures (RCOT)

Interventions
Occupational therapists are experts at managing complexity. 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. They understand that a person's pre-existing health and support needs and personal circumstances must be considered when setting goals and planning interventions.

Occupational therapists work with people to identify personalised intervention approaches that consider all of an individual's needs and symptoms in relation to their occupational goals. They help people to identify self-management strategies that enable them to maintain or regain their independence.

Some of the specific areas of intervention that occupational therapists are skilled in applying with adults affected by 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 individuals break activities down into achievable parts, planning 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 effectively. More information is available from: 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 brain fog, 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.

• **Pain management** – enabling people to 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. This includes liaising with and educating employers about Long Covid and may involve a personalised plan to enable a phased return to work or education, for example using the *Allied Health Professions Health and Work Report* (AHPF).

• **Mental health** – occupational therapists use their knowledge of physical and mental health to help individuals 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, 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.

• **Role and identity** – occupational therapists 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. This includes helping people to navigate changes to their social environment and activities and encouraging people to find a balance of activities that reduces their symptoms and enables recovery.

• **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 people to identify the activities that are important to them and recommend strategies to enable their participation. The safety of approaches to activity must be considered before making recommendations, and individuals' responses to interventions should be regularly monitored and reviewed to identify any post-exertional symptom exacerbation (PESE). Helpful guidance on safe rehabilitation approaches for physical activity and exercise has been produced by *World Physiotherapy* (2021).

• **Building activity tolerance** – using occupational performance and analysis skills, occupational therapists support individuals to increase activities incrementally, as appropriate, in a planned and flexible way, considering all aspects of life such as self-care, domestic activities, parenting and caregiving - as the individual desires. Consideration of appropriate approaches to activity and PESE must be provided, ensuring that not only physical increases in activity but also cognitive, sensory/environmental and emotional load are recognised when assessing the situation.

• **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 work and in other settings.

• **Assistive devices** – occupational therapists recommend equipment such as bathing, seating and mobility aids to enable people to take part in self-care and other activities as safely and as independently as possible.

• **Social support** – signposting to local organisations and services such as social prescribing, for support with social needs including benefits advice, financial assistance and individual rights. There are a number of online groups such as *Long Covid Support*, developed and managed by people with lived experience of Long Covid, which enable those with Long Covid to connect and provide peer support.
**Fair access**

It is not necessary for people to have a confirmed diagnosis of COVID-19 to access and benefit from occupational therapy. Interventions should be offered at the earliest opportunity, in agreement with the individual, once any symptoms that may affect the person's ability to participate in rehabilitation safely have been investigated (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.

Interventions may be delivered one to one or in groups, in order 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 amongst participants.

Some individuals 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.

Consideration should be given to the location of in-person appointments to ensure that no individuals are excluded because of poor public transport, for example.

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

**Personalised approach**

Occupational therapists use coaching (effective) conversations to help people 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 people to manage their symptoms and set 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.

As well as working directly with individuals, occupational therapists work 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, with community colleagues and the wider multidisciplinary team is essential to ensure coordinated and timely care for individuals. It also 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

When discussing and agreeing follow-up and discharge plans, occupational therapists should consider individual preferences, goals and support needs. Individuals 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.

### Evidence

Occupational therapists should be open and honest with people whilst the evidence-base for occupational therapy and Long Covid is still emerging. Reassurance should be given 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 might be applied with adults affected by Long Covid. As well as evidence for other chronic and post-viral conditions, such as ME/chronic fatigue syndrome, this may also include episodic illnesses and disabilities (Brown and O'Brien 2021).

Regularly updated sources of evidence regarding 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 then 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.
References


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