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Professional Guidance for Physiotherapists working with
Children and Young People with Long COVID



Association of Paediatric
Chartered Physiotherapists

Purpose

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

The aim of physiotherapy is to enable children and young people to each reach their own unique physical potential and independence. Physiotherapists work with children and young people to join in with the activities that are important to them, at home, at school and in other settings.

Physiotherapists' work across health and education, in partnership with children, young people and their families 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 physiotherapists 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.

Key messages

- o Physiotherapists are essential in enabling children and young people with Long Covid to manage and recover from the physical impacts of the condition.
- o Physiotherapy helps children and young people whose daily life is affected by Long Covid to take part in the activities that are important to them – at home, in education and during their leisure time.
- o Physiotherapists help people to manage common symptoms and consequences of Long Covid such as fatigue, breathlessness, dizziness, joint and muscle aches.
- o Physiotherapists should work in partnership with other health professionals to deliver the most appropriate rehabilitation of children and young people living with Long Covid.
- o Physiotherapists should identify the need for onward specialist referral, for example to occupational therapy, dietetics, pain services or specialist fatigue services. This is not an exhaustive list and needs should be assessed on a case-by-case basis. There may be specialist services for Long COVID in your area.
- o Physiotherapists should work with schools or other educational settings to ensure children and young people are appropriately supported, relative to their Long COVID experience.
- o Physiotherapists 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.
- o Physiotherapists should access, use and contribute to the evidence base on Long Covid, to identify and apply the intervention approaches that are the most effective.
- o Physiotherapists should collect, use and share a range of data, both to evidence the impact of physiotherapy, and as part of quality improvement activities.

Accessing Long COVID support

- It is not necessary for children and young people to have a confirmed diagnosis of COVID-19 to access and benefit from rehabilitation.
- 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 explored and addressed (NICE 2020).
- Access to physiotherapy and / or rehabilitation should be provided fairly for everyone affected by Long Covid.
- Physiotherapists should take action to make sure that access to their services is equitable, suitable and appropriate for people with diverse needs and from diverse backgrounds.
- No person should be excluded because of poor public transport or other access constraints.
- Appointments should be offered as in-person, virtual or by telephone and a blended approach may be needed.
- People may need help to access virtual services.
- Resources and information should be provided in different languages including easy-read versions.
- Physiotherapists should consider the possibility of Long Covid for all children and young people with medically unexplained symptoms.

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.

The [CLoCk study](#), funded by the NIHR has developed new definitions of Long COVID in children. This definition was agreed using a Delphi consensus technique.

“...long COVID is a condition in which a child or young person has symptoms (at least one of which is a physical symptom) that:

- have continued or developed after a diagnosis of COVID-19 (confirmed with one or more positive COVID tests)
- impact their physical, mental or social wellbeing
- are interfering with some aspect of daily living (for example, school, work, home or relationships)
- persist for a minimum duration of 12 weeks after initial testing for COVID-19 (even if symptoms have waxed and waned over that period).”

Symptoms can vary from day to day, in severity and in number. This means that returning to education and activity in a structured way can be complex for children, families and their care teams to navigate.

Long Covid is complex and often presents with clusters of symptoms which can change and recur (relapse 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 The Association of Paediatric Chartered Physiotherapists, The Chartered Society of Physiotherapy and with members of the Long Covid Kids community.

Persistent symptoms of Long Covid which can be supported by physiotherapy include, but are not limited to:

- Fatigue including post-exertional symptom exacerbation
- Muscle weakness
- Muscle aches, joint and nerve pain
- Breathlessness and persistent cough
- Heart palpitations
- Autonomic system disturbances e.g. Postural Tachycardia Syndrome (PoTS)
- Sleep difficulties / disturbance
- Sensory issues
- Abdominal pain and gastrointestinal issues
- Loss of taste and smell affecting motivation to eat
- Brain fog affecting concentration and memory
- Depression and anxiety
- Difficulties in engaging in previous levels of physical activity

A Note on Paediatric Multisystem Inflammatory Syndrome

Paediatric Multisystem Inflammatory Syndrome (PIMS) is a rare complication of acute COVID-19 infection. PIMS is treatable and early diagnosis and treatment are helpful. Most children and young people with PIMS recover well but some may present in Long COVID services with ongoing symptoms.

For a full summary of signs & symptoms, visit [What Is PIMS?](#) for a summary of signs and symptoms.

Screening for Serious Pathology

Patients should be discussed with doctors and considered for cardiac or respiratory screening when appropriate.

The 1-minute sit to stand or 6-minute walk test can be useful for screening tool for desaturation and response to exercise, but will not be appropriate for all patients, particularly those struggling with mobility or severe fatigue.

Consideration of Post Exertional Symptom Exacerbation (PESE) should be applied in all assessment and treatment sessions and form part of the education package. PESE is a disproportionate response triggered by any kind of exertion, for example: physical, cognitive, emotional, or social. The response is variable. Significant and disabling symptom exacerbation can occur up to 72 hours after exertion, making it difficult to predict or manage. Recovery from an episode of PESE can take days or even months. Assessment itself may be a trigger for PESE, hence it is important to take time and care to avoid flare up.

Assessment, goal setting and outcome measures

Physiotherapy should focus on enabling children and young people to reach their individual potential and personalised care is key. Throughout the physiotherapy pathway, children and young people should be offered reassurance and validation of their symptoms, and given the opportunity to tell their story, in their own words, in their own time.

Approaches must be personalised to address the needs, preferences, values and culture of each child or young person. Physiotherapists should adopt a self-management approach, enabling children and young people to manage their symptoms and set and work towards realistic goals. Discussions around personal expectations of children, young people and their families should form part of any subjective assessment.

The aim of any subjective assessment is to determine what matters to the individual, their current level of performance and their personal intervention and support goals.

When completing assessments, it is important to consider the physical and cognitive effort required for a young person to engage in these activities, particularly if they are impacted by fatigue and brain fog. It may be appropriate to break assessments into several sessions or to offer pacing breaks within sessions if needed. Rehabilitation goals must be reviewed regularly, in collaboration with the young person and form the basis of the rehabilitation plan.

Physiotherapists must ensure that communication between tertiary Long Covid services, with community colleagues and the wider multidisciplinary team is coordinated to deliver timely care and support for children, young people, and families. This also facilitates shared learning.

Long Covid is a new illness and there is currently a lack of evidence regarding the specific use of outcome measures with children and young people with Long Covid. The following may be appropriate, but physiotherapists should be guided by local decisions and most importantly, the child or young person and their presenting features. All symptoms can be exacerbated by anxiety, and it is important to offer reassurance and validation of the experience of the child / young person. Clinical reasoning must be applied to any assessment or outcome tools measure selection. The following may be helpful *:

- C19-YRS
- PEDSQL
- EQ-5D-5L
- SF-36
- Chalder Fatigue Questionnaire
- The DePaul brief Questionnaire
- Revised Children's Anxiety and Depression Scale (RCADS)
- Strengths and Difficulties Questionnaire (SDQ)

**Some tools may require licensing*

Care should be taken to select outcome measures appropriately, particularly where there is a risk of PESE. Children, young people, and their families should always be given contact details of the service in case they need to report or discuss any latent symptoms or escalation of symptoms that occur following assessment.

Interventions

Physiotherapists are experts at managing complexity and developing personalised interventions that consider an individual's rehabilitation goals. Physiotherapists should support multidisciplinary and multiprofessional rehabilitation goals using a family focused approach. All treatment offered should be tailored to the individual child or young person and be delivered in the context of their wider holistic health. Physiotherapy interventions for children and young people experiencing Long Covid may include:

Managing the impact of pain

Pain may be experienced by children and young people with long covid for a variety of reasons. It may be that it is part of their long covid, or it may be a secondary effect caused by the change to their day-to-day activity that long covid has caused. Whilst physiotherapists are unable to treat pain itself as a symptom, they are skilled at helping to address the underlying causes and helping to reduce the impact of symptoms on a young person's life. It is important that any joint or muscle pain is fully assessed to rule out any other potential underlying causes. Physiotherapists should have training in the management of musculoskeletal issues specific to children and young people. Escalation to specialist paediatric pain services may be appropriate and this should be expedited using locally agreed pathways.

Interventions offered may include:

- exercise programmes to address biomechanical imbalances including hydrotherapy where indicated and it is safe to do so
- advice around activity management to manage the impact of pain
- advice around the use of non-pharmaceutical pain management e.g. the use of ice and heat packs
- advice around relaxation and mindfulness
- restorative movement- encourage movement where appropriate

Autonomic issues

Children and young people with Long Covid sometimes experience dizziness, increased heart rate, palpitations and other signs of autonomic dysfunction and Postural Orthostatic Tachycardia Syndrome (POTS).

POTS is due to an abnormal response by the autonomic nervous system (ANS) and is characterised by Orthostatic Intolerance (OI) i.e. symptoms in the upright position mostly relieved by lying down.

When a child or young person without POTS stands up, there is a physiological response mediated by the ANS. Blood vessels narrow (vasoconstriction) and heart rate increases slightly to maintain blood supply to heart and brain.

In POTS, this automatic adjustment to upright posture is not working correctly, blood vessels widen (vasodilation), resulting in an excessive rise in heart rate, increased epinephrine and norepinephrine in the blood and altered blood flow to the brain.

Other symptoms include; fainting, nausea, bloating, abdominal pain, cognitive dysfunction - 'brain fog', poor sleep, exercise intolerance, shakiness, sweating, postural headaches and migraines.

There are some simple measures that may help for example: ensuring good hydration, adding additional salt to the diet, strategies to minimise triggers such as standing and hot baths, use of compression, learning counter manoeuvres (such as lowering to the floor, feet up), and gentle exercise starting in lying if necessary.

Exercise can be helpful although physiotherapists need to be aware of PESE. Increasing leg strength and core muscles helps to pump blood back to the heart. Physical exertion can initially worsen POTS so factor in recovery time afterwards. If appropriate exercise should be gradually increased in duration and intensity and this can take 6 weeks - 3 months to have an effect.

Suitable exercise might include: Swimming, rowing, recumbent biking (progressing on to upright biking), pilates (beginning with mostly horizontal exercise), lower limb resistance training, with a gradual progress to more upright activities such as walking.

For more information on POTS visit: <https://www.potsuk.org>

Breathing/ Breathlessness

Breathlessness may be experienced by children and young people with long covid for a variety of reasons. It may be that it is part of their long covid, or it may be a secondary effect associated with other factors.

Breathlessness can be due to a breathing pattern disorder and this may provide a basis for the assessment and treatment of breathlessness in children and young people with long COVID.

Physiotherapists should always consider the multidisciplinary perspective and consider whether the wider healthcare team can offer support for example. Would the child or young person benefit from a Lung Function test? Has a chest X-ray been completed? Is review from another discipline warranted e.g. respiratory, occupational therapy, psychology?

During a physiotherapy assessment for breathlessness, observe the child or young person's breathing pattern and rate, and for indicators such as frequent sighing / yawning, difficulty co-ordinating breathing and talking. Ask about whether the child or young person is experiencing pins and needles in hands/arms or around their mouth. Are they experiencing heart palpitations or light-headedness? Sensations of breathlessness can be worsened by anxiety and stress, so it is important to address the stress response to triggers with all children and young people.

As part of an assessment for breathlessness, it may be appropriate to use specific outcome measures or screening tests such as the Nijmegen questionnaire, Original or modified Borg score of the 1-minute sit to stand test. Exercise tests must be applied judiciously and safely, considering the personal preferences of the child or young person and the likelihood of any adverse effect. Think PESE first.

For more information on Breathlessness / Breathing pattern Disorders, visit:

<https://www.physiotherapyforbpd.org.uk/>

<https://www.blf.org.uk/support-for-you/long-covid/breathlessness-support/managing-breathlessness/introduction-to-breathlessness>

Energy Management

Fatigue is a very common symptom for children and young people with long covid, and energy management techniques can be useful to help them manage the impact of this on their lives, whilst still doing some of the things that are important to them. A child or young person may find they have insufficient energy to attend school or take part in their hobbies or just manage the day to day. Doing too much can lead to a “boom or bust” cycle. Energy types can be divided into Physical, Cognitive, Emotional and Social. These types can be listed in an activity diary using a traffic light system.

Using activity diaries to track energy expenditure and fatigue levels may be a useful part of energy management. All energy management strategies should take into account the personal interest and goals of the young person. Where a young person has struggled to engage with education activity management strategies can be used to support phased returns to school. In these instances, physiotherapists should work alongside young people families and schools or colleges to offer expert guidance on appropriate timetables and timescales for a gradual return to education.

By teaching a young person or child to code their daily activities, ensuring that not all high energy (red) activities are grouped together, but interspersed within moderate energy (Amber) and low energy (green) then more of a balance is met.

A child/young persons’ school and any extra-curricular clubs should be made aware of the need to pace activities through their time in that facility, and to this end made aware of the need for regular rest breaks, to help that child/young person self-manage.

Return to physical activity

Many children and young people will wish to return to previously enjoyed physical activities as they recover from long covid. If the young person has been less active for a period of time due to their long covid symptoms they may need support and guidance to return safely to previous activity levels. Physiotherapists should advise and educate young people and their families about a return to activity and offer advice on how to safely increase activity levels and avoid PESE. This advice should be tailored to the young person, taking into account their physical ability and personal goals.

It is important for parents and caregivers to monitor children/young people’s fatigue levels and ensure that they do not enter the realm of the boom or bust cycle.

If a child/young person has previously enjoyed sports, they should not be made to feel that they need to make a quick return to competing and may require further testing before returning, especially if they have had long covid with inflammatory or cardiovascular complications.

Discharge and follow-up

When planning for discharge, physiotherapists should work in partnership to consider individual preferences, goals and support needs. Children and young people should be supported to join support networks, have a knowledge of how to self-manage their symptoms and know how to access the service again in the future if new

physiotherapy issues emerge. This is particularly important due to the relapsing and remitting nature of the condition.

Evidence

Physiotherapists should be aware that the evidence-base for rehabilitation 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.

It is the professional responsibility of all physiotherapists to continue to access, evaluate and contribute to the evidence-base to build evidence of the effectiveness of rehabilitation and physiotherapy for children and young people with Long Covid.

All services should evaluate the value and benefit of interventions by using and interrogating outcome measure data. The data should drive improvements in the quality, value and effectiveness of the services provided.

References:

Bath Specialist Paediatric ME/CFS services resources for clinicians. Available at:

https://www.ruh.nhs.uk/patients/services/clinical_depts/paediatric_cfs_me/index.asp

CSP Long Covid guidance

<https://www.csp.org.uk/news/coronavirus/long-covid-resources/long-covid-clinical-guidance/what-long-covid>

Long Covid Kids Support Guide

<https://www.longcovidkids.org/support-guide>

NHS England (updated 2022) National guidance for post-COVID syndrome assessment clinics. Available at:

<https://www.england.nhs.uk/publication/national-commissioning-guidance-for-post-covid-services/>

National Institute for Health and Care Excellence (updated 2021) COVID-19 rapid guideline: managing the long-term effects of COVID-19. Available at: <https://www.nice.org.uk/guidance/ng188>

Royal College of Paediatrics and Child Health. PIMS: the COVID-19 linked syndrome affecting children-information for families. Available at <https://www.rcpch.ac.uk/resources/pims-covid-19-linked-syndrome-affecting-children-information-families>

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

World Physiotherapy Long Covid guidance
<https://world.physio/covid-19-information-hub/long-covid>

Your COVID Recovery resources for children and young people
<https://www.yourcovidrecovery.nhs.uk/children-and-young-people-with-covid/>

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