

**Leeds Children’s Hospital Long COVID Syndrome Paediatric Pathway**

Symptoms (see below) persisting in first 4 weeks after confirmed or suspected acute COVID-19 infection

**🡪 Manage in primary care**

Yes

Discharge

Symptoms resolved within 4 weeks?

No

GP to refer to local general paediatrician for further assessment and investigations to consider Long COVID Syndrome (LCS) and rule out alternative causes (see document below)

Assessment and follow up within local general paediatric clinic between 4-12 weeks after confirmed or suspected COVID-19 infection

Signpost to [NHS Your Covid Recovery](https://www.yourcovidrecovery.nhs.uk/)

Symptoms resolved within 12 weeks?

Discharge

Yes

No

Refer to Long Covid MDT clinic

Triage of referral by lead paediatrician for LTHT LCS Service to confirm if referral criteria met (as outlined in DOS) \*

**Reject referral**

**Accept referral**

Provide rationale for rejection / advice

Face to face Long COVID Service MDT

one-stop Assessment Clinic

(Further investigations as appropriate)

* General paediatrician
* Psychologist
* Physiotherapist
* Occupational Therapist

Onward referral to appropriate service(s):

* Local hospital for on-going therapy
* Specialist medical opinion
* Signpost to self-help resources

\*Criteria for referral to Leeds Children’s Hospital Long COVID Assessment Service:

Patients with symptoms involving 2 or more of the following systems:

* **Respiratory**
  + Breathlessness
  + Cough
* **Cardiovascular**
  + Chest tightness
  + Chest pain
  + Palpitations
* **Generalised**
  + Fatigue
  + Pain
* **Neurological**
  + Cognitive impairment ('brain fog', loss of concentration or memory issues)
  + Headache
  + Sleep disturbance
  + Peripheral neuropathy symptoms (pins and needles and numbness)
  + Dizziness
* **Gastrointestinal**
  + Abdominal pain
  + Nausea
  + Diarrhoea
  + Anorexia and reduced appetite
* **Musculoskeletal symptoms**
  + Joint pain
  + Muscle pain
* **Psychological/psychiatric symptoms** 
  + Symptoms of depression
  + Symptoms of anxiety
* **Ear, nose and throat symptoms**
  + Tinnitus
  + Earache
  + Sore throat
  + Dizziness
  + Loss of taste and/or smell
* **Dermatological**
  + Skin rashes

If a patient has only one persistent symptom or involvement of a single system, then manage symptomatically or refer to appropriate local/regional specialty for opinion and management. Such patients may still be referred to the Long COVID Service if it is felt symptoms are getting worse or are not being managed locally, or if patient is having multiple single system symptoms that may be felt to benefit from a MDT approach. The lead clinician for the Long COVID Service will triage referrals on a case by case basis and decide if the child is appropriate to be seen in this service.

***Note: This list is not exhaustive and is based on the NICE covid-19 rapid guideline. This list consists of common symptoms reported after covid-19 infection and children may well present with other symptoms which need to be considered as possibly being part of Long COVID.***

Referrals will be accepted from paediatricians within West Yorkshire - Leeds, Pinderfields, Bradford, Harrogate, Calderdale and Airedale. To refer a patient to the Leeds Children’s Hospital Long COVID Service patients must be 12 weeks post-COVID 19 infection or suspected infection.

Leeds Children’s Hospital will offer access to a post-COVID specialist paediatric assessment clinic, including access to a multi-disciplinary team to address the multi-system nature of the condition. The clinic will be available to all those with a likely diagnosis of Long COVID, whether hospitalised or not, and whether they had a positive test or not, as set out in NHSE recommendations.

The specialist MDT clinic will offer a physical, psychological or cognitive specialist assessment and further testing as indicated

Data regarding patients who attend this clinic will be captured within LTHT PAS system and from June 2021 Long COVID activity data on referrals, number of consultations, waiting times and the onward patient journey, will be captured.

This is a one-stop assessment clinic and following the consultation, patients will be referred on to appropriate services, where indicated, or discharged back to their local hospital/paediatrician for on-going management and support.

**Guideline**

Long COVID is a multi-system condition with a wide range of debilitating symptoms spanning fatigue, breathlessness, cough, chest pain, heart palpitations, fever, headache, muscle pain, gastrointestinal problems and loss of taste and smell. Many people with Long COVID may experience a range of psychological and cognitive symptoms such as depression, anxiety, post-traumatic stress disorder (PTSD) and ‘brain fog’ or other cognitive impairments, in addition to physical symptoms. This can also have a social impact. Symptoms can fluctuate and change over time. They are well recognised by people who are living with Long COVID and can have significant impacts on a person’s ability to carry out day-to-day activities and work.

Recognising the importance of defining this emerging condition to enable diagnosis, NHS England commissioned the National Institute for Health and Care Excellence (NICE), which worked with the Scottish Intercollegiate Guidelines Network (SIGN) and Royal College of General Practitioners (RCGP), to produce a rapid guideline on managing the long-term effects of COVID-191 . This was first published in December 2020 and set out the following clinical definitions:

• Acute COVID-19: signs and symptoms of COVID-19 for up to 4 weeks.

• Ongoing symptomatic COVID-19: signs and symptoms of COVID-19 from 4 to 12 weeks.

• Post-COVID-19 syndrome: signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis.

The majority of children and young people (CYP) experience only mild symptoms following COVID-19 infection or are asymptomatic. However, there is evidence that some will experience Long COVID, and a minority of children may develop a delayed onset systemic inflammatory response known as Paediatric Inflammatory Multisystem Syndrome (PIMS-TS or PIMS) following COVID-19 infection. Symptoms of Long COVID are believed to be similar to those experienced by adults, although this needs to be understood more clearly. According to April 2021’s ONS estimates, around 7.4% of children 2-11 years and 8.2% of those aged 12-16 years report continued symptoms at 12 weeks after infection.

There is a minimal, though evolving, evidence-base in Long Covid. The most common symptom reported is fatigue, but symptoms across multiple systems are reported (as detailed above) and in some adults there is evidence of organ damage. There are reports of children having similar prolonged symptom clusters to adults, following suspected or confirmed Covid-19 infection, but further research is needed to establish whether children may also suffer organ impairment.

*Differential diagnosis:*

The spectrum of symptoms for children and adults with Long Covid is broad and therefore the differential diagnosis for children presenting with the features of Long Covid is wide-ranging.

It is important to consider a differential diagnosis and investigate appropriately for other causes for the presenting symptoms.

Dependent on symptom presentation the differential might include:

• Rheumatological conditions e.g. JIA, SLE, Dermatomyositis

• Inflammatory conditions e.g. IBD

• Chronic infections, including reactivation (eg TB, HSV, EBV)

• Malignancy – for example leukaemia, lymphoma

• Autoimmune – Coeliac disease, Thyroid disorders

• Adrenal insufficiency

• Organ impairment – renal, liver, pancreatic, cardiac, respiratory

• Neurological conditions – Venous sinus thrombosis, malignancy, stroke

*Assessment and investigations to be done in secondary care paediatric clinic prior to referral:*

*Assessment:*

* Height and weight
* Observations - HR, RR, BP and O2 saturations
* For children with postural symptoms - Lying and standing BP and HR
* Full systemic examination

*Laboratory investigations:*

* FBC, blood film, ESR
* U&E, LFT, TFT, CRP, Bone profile, Vitamin D, Ferritin, Random glucose
* Creatine kinase
* Immunoglobulins, Coeliac screen
* Covid-19 antibodies
* Consider CXR, 12 lead ECG, D-dimers and Troponin-T for children with chest pain/breathlessness or tachycardia

**Outcomes from secondary care review**

**A: No concerning symptoms or signs of possible specific organ impairment/systemic disease and symptoms resolved**

* Offer reassurance and safety net
* Discharge to GP and ensure patient and family aware of possibility of fluctuating course and new symptom onset and to seek further review if concerns

**B:** **No concerning symptoms or signs of possible specific organ impairment/systemic disease and symptoms stable/improving:**

* Offer reassurance and safety net
* Offer pacing advice [CFS Self Help pacing tutorial](http://www.cfsselfhelp.org/pacing-tutorial)
* Sign-post to [NHS Your Covid Recovery](https://www.yourcovidrecovery.nhs.uk/) website
* Consider overall trajectory of their symptoms, taking into account that symptoms often fluctuate and recur so they might need different levels of support at different times.

Offer telephone follow-up consultation in 4-6 weeks

**C: Children with symptoms or signs limited to one system or with persistent single symptom (e.g. just breathlessness or just palpitations, etc):**

* Refer directly to the relevant specialty

**D: Children with multiple symptoms as detailed above, persisting for longer than 12 weeks, and assessment and investigations above do not find alternative cause:**

* Refer to the Long covid clinic
* Sign-post to [NHS Your Covid Recovery](https://www.yourcovidrecovery.nhs.uk/) website while awaiting assessment in the MDT clinic

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*Date: 02/07/21*

*Review date: 01/07/22*