

# SW Children and Young People Long COVID Pathway

Version 2 January 2022

Including:

- Updates to referral pathway
- Additional information on Cardiovascular and Respiratory Symptoms

This pathway was developed by the SW CYP Long COVID Pathway Group based on National Guidelines

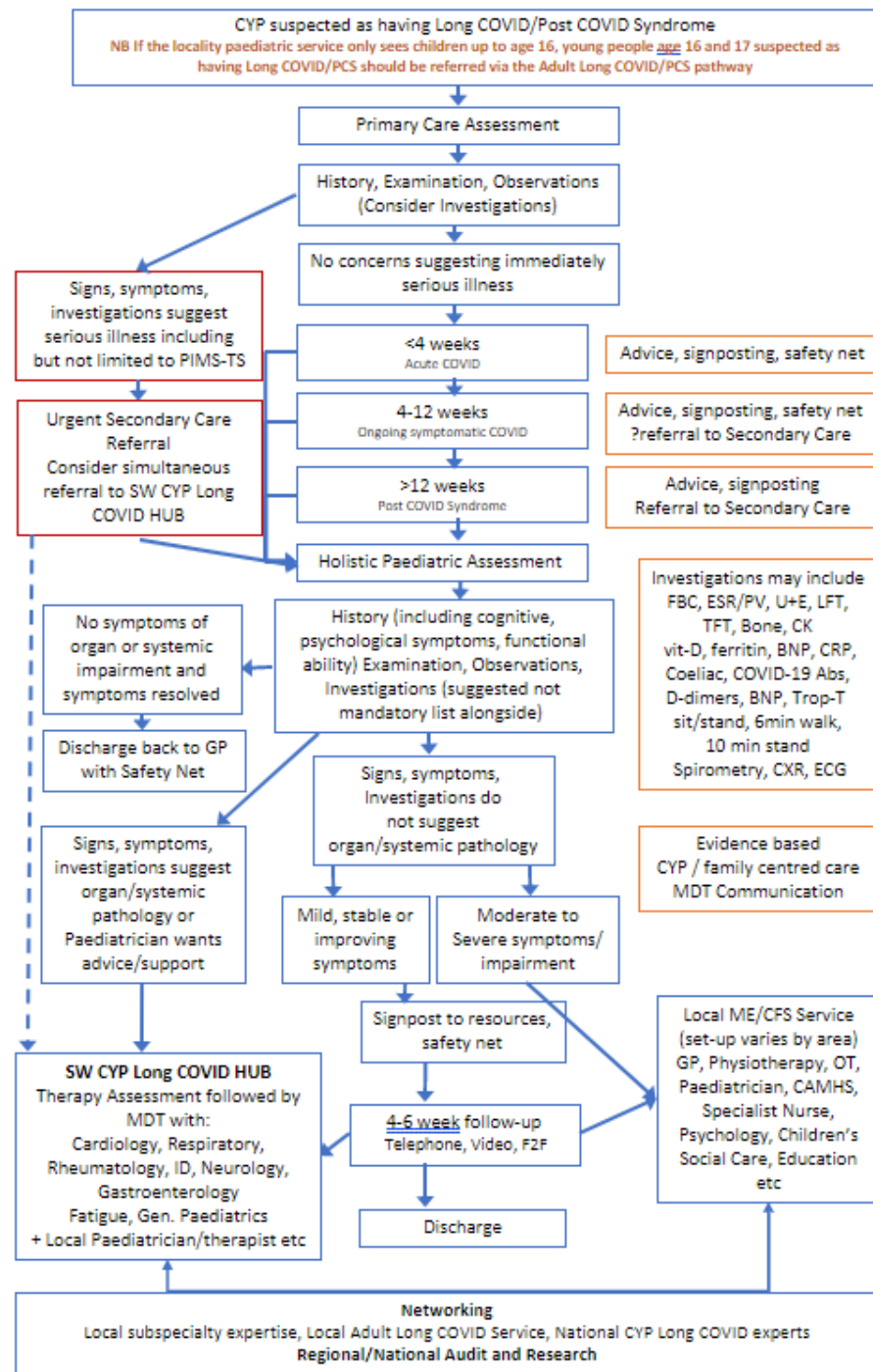
NHS England and NHS Improvement



# Post-COVID-19 (Long COVID) Definition (NICE, SIGN and RCGP)

Signs and symptoms that develop during or following an infection consistent with COVID-19 which continue for more than 12 weeks and are not explained by an alternative diagnosis

- Clusters of symptoms, often overlapping, which may change over time and can affect any system within the body
- Many people with Post-COVID-19 syndrome can also experience generalised pain, fatigue, persisting high temperature and emotional and mental health problems
- Post-COVID-19 syndrome may be considered before 12 weeks while the possibility of an alternative underlying disease is also being assessed
- Most CYP presentations are similar to Post-Viral Fatigue and ME/CFS and existing pathways can be used/adapted to support children and young people with Long COVID



# Primary Care

- Family based approach considering family functioning and parental anxiety
- Many patients and their families may be able to self-manage with support and information on symptom and energy management
- Advice to education providers may be required
- Some children and young people will require referral to secondary care. The duration and type of symptoms is a guide but is flexible
  - <4 weeks – concerns about significant acute illness
  - 4-12 weeks – concerns about organ impairment, worsening general symptoms
  - >12 weeks – ongoing symptoms
- Primary care professionals should refer to secondary care using existing local pathways (i.e. District General Hospital Paediatrics or Bath Fatigue Service if that is the usual route of referral)
- If there are concerns about organic Cardiovascular or Respiratory conditions refer to South West Long COVID Hub AND District General Hospital Paediatrics

# Supporting and enabling self-care

- [yourcovidrecovery.nhs.uk](https://yourcovidrecovery.nhs.uk) online rehabilitation platform was developed for adults with Long COVID to enable ongoing support and enhance self-care
- There is ongoing work to develop additional resources for Children and Young People and adapt the resources on Your COVID Recovery. When available these resources will be made available on NHS Futures and cascaded to secondary care links and primary care by the working group

# Secondary Care Assessment

- Thorough holistic assessment similar to other complex, multiple symptom presentations
  - Physical
  - Emotional/Mental Health
  - Social/Family
  - Education
- Purpose
  - to identify those who need specialist input and management for organ impairment
  - to tailor appropriate support for other wide-ranging symptoms that may significantly affect quality of life
  - assess family attitudes to illness and experience of pandemic period
  - assess impact of the illness on the child and family including day-to-day functioning and access to education

# Investigations

## This is not a definitive list

Investigations at discretion of Paediatrician may include:

- FBC, ESR/PV, CRP, Thyroid, Liver, Renal, Bone, CK, Ferritin/Iron, Coeliac, ANA, vit D, vit B12
- SARS-CoV-2 serology, EBV and CMV
- Troponin, D-Dimers and VWF/ADAMTS
- Faecal calprotectin
- Urine albumin/creatinine ratio
- Tests for exercise tolerance and postural symptoms (see [www.nice.org.uk/guidance/ng188](http://www.nice.org.uk/guidance/ng188))
  - Sit-to-stand test
  - Six-minute walk test
  - Lying/standing BP and HR, 3 minute or 10 minute active stand
- ECG, Echocardiogram
- Spirometry
- Imaging

# Secondary Care Management



- Advice
- Information using same resources listed in Primary Care section
- Children and young people may need further therapeutic input, rehabilitation, psychological support, specialist investigation or treatment using an MDT approach. Consider:
  - Referral/Communication with local therapy services and Education
  - Referral to South West Long COVID HubInvolvement of local therapists and the South West Long COVID Hub may be appropriate
- Follow-up



# Common cardiovascular symptoms in Long COVID

If palpitations or chest tightness are present:

- Ask about severity of initial COVID infection. Was patient admitted? Was oxygen required?
- Ask about high fevers for > 5 days, whether fevers have continued (and how high)
- Enquire out about timing of palpitations and/or chest tightness and investigations so far
- Consider anxiety (check RCADS)

For palpitations:

- Are they an irregular one or two beats, or are they very fast over a longer period of time?
- Do they come on suddenly or go away suddenly? Or do they come on gradually?
- What were they doing just before the palpitations?
- How long did the palpitations last?
- Are there associated symptoms (loss of consciousness, altered consciousness, chest pain, dizziness or shortness of breath during the palpitations or chest pain)?
- Why did they stop? (did they do Valsalva?).

# Common cardiovascular symptoms in Long COVID

## Assessment:

- Consider Postural Orthostatic Tachycardia Syndrome (10-minute active stand or tilt table). Use caution in CYP with severe fatigue as this can increase symptoms
- Provide advice on increased fluid, increased salt, muscle exercises, increasing movement (see [www.potsuk.org](http://www.potsuk.org) for guidance)
- Consider an ECG
- Consider Valsalva manoeuvre, if this is helpful then palpitations are due to arrhythmia - refer
- Consider timed breathing, if this is helpful, then palpitations are due to panic - reassure

## Refer to the South West Long COVID MDT if CYP with the following symptoms:

- Sudden onset & termination of fast HR suggests pathway mediated tachycardia. This is not COVID related so check for symptoms before COVID infection.
- Associated with: faints; loss of consciousness; change in conscious level; chest pain; dizziness or SOB at the time of the palpitations.
- Chest pain which is prolonged or like a heavy weight.

# Common cardiovascular symptoms in Long COVID

Many CYP will experience the following symptoms (and therefore reassure):

- Raised heart rate which doesn't come on suddenly and go away suddenly and is there quite a lot of the time. This is called Inappropriate sinus tachycardia. This is seen when CYP are less fit (because they have been unwell), anxious, and can be seen during recovery from an illness.
- Occasional skipped beats
- Brief stabbing chest pain

# Common respiratory symptoms in Long COVID

- If Shortness of Breath (SOB) is present: Ask about severity of initial COVID infection. Were they admitted? Did they ever require oxygen? Find out about timing of SOB, associated symptoms such as cough and investigations done so far.
- SOB on exertion is normal given the level of disability (+/- normal SaO<sub>2</sub>) then reassure (6 minute walk test might be helpful to quantify deconditioning)
- SOB is more than would be expected, if there is respiratory distress or SOB at rest:
  - Check FBC, CRP
  - Check CXR, SpO<sub>2</sub> and Spirometry
  - Consider Dysfunctional Breathing. (see below)
  - Refer to South West Long COVID Hub
- Cough: Obtain a clear history: triggers, timing, sputum.
  - Check FBC, CRP
  - Check CXR, SpO<sub>2</sub> and Spirometry
  - Refer to South West Long COVID Hub

# Dysfunctional breathing

Signs	Symptoms
Mouth breathing Short, shallow breaths Quick and erratic Noisy Raised shoulders Movement at the top of the chest	Breathlessness Persistent coughing Excessive yawning or sighing A feeling of not being able to take a deep breath ...also dizziness, poor concentration, pins and needles, bloating, fatigue, and lethargy.

- In addition to above questioning consider use of Nijmegen Questionnaire – <https://www.physiotherapyforbpd.org.uk/test-your-breathing/>
- Be reassuring that this is normal and treatable
- Signpost to - My recovery - [Coronavirus Recovery: Breathing Exercises | Johns Hopkins Medicine](#)  
Physiotherapy for Breathing Pattern Disorder – <https://www.physiotherapyforbpd.org.uk/self-help/>
- Offer follow-up or Refer to local respiratory physiotherapy if available

# South West Long COVID Hub Virtual MDT



- Referrals from Consultant Paediatricians and Specialist Therapists detailing comprehensive assessment and investigation results by letter emailed to [ubh-tr.swpaedlongcovidhub@nhs.net](mailto:ubh-tr.swpaedlongcovidhub@nhs.net)
- GPs can refer directly but must refer also to local secondary care paediatrics
- All referred patients have a telephone assessment with a specialist therapist
- Referral, investigation results and therapist assessment will be shared with members of the MDT at least 72 hours before the Virtual MDT
- The composition of the MDT includes general and specialist paediatricians, therapists, the local referring paediatrician and any therapists involved
- A summary of the MDT discussion and recommendations will be sent to the referrer detailing specialist investigations and treatment

# SW CYP Long COVID Network



## Regional Team

Clinical Lead for SW CYP Long COVID Service	Richard Tozer	<a href="mailto:r.tozer@nhs.net">r.tozer@nhs.net</a>
Regional Lead for SW CYP Long COVID	Rachel Byford	<a href="mailto:rachel.byford@nhs.net">rachel.byford@nhs.net</a>
Network Support Officer	Stacey Burch	<a href="mailto:stacey.burch@nhs.net">stacey.burch@nhs.net</a>

## DGH Leads

Royal Cornwall Hospitals	Sarah Rattigan	<a href="mailto:sarah.rattigan@nhs.net">sarah.rattigan@nhs.net</a>
University Hospitals Plymouth	Sam Broad	<a href="mailto:samuel.broad@nhs.net">samuel.broad@nhs.net</a>
North Devon District Hospital	Dermot Dalton	<a href="mailto:sermot.dalton@nhs.net">sermot.dalton@nhs.net</a>
Torbay and South Devon	Richard Tozer	<a href="mailto:r.tozer@nhs.net">r.tozer@nhs.net</a>
Taunton and Somerset	Alexandra Powell	<a href="mailto:alexandra.powell@somersetft.nhs.uk">alexandra.powell@somersetft.nhs.uk</a>
Dorset	Janet Kelsall	<a href="mailto:janet.kelsall@uhd.nhs.uk">janet.kelsall@uhd.nhs.uk</a>
	Ruth Newman	<a href="mailto:ruth.newman@dchft@nhs.net">ruth.newman@dchft@nhs.net</a>
	Emma Haynes	<a href="mailto:emma.haynes@dchft@nhs.net">emma.haynes@dchft@nhs.net</a>
Salisbury	Chris Anderson	<a href="mailto:chris.anderson1@nhs.net">chris.anderson1@nhs.net</a>
Gloucestershire	Marie Wheeler	<a href="mailto:marie.wheeler1@nhs.net">marie.wheeler1@nhs.net</a>

## SW CYP Long COVID Hub

Service Manager	Laura Borg	<a href="mailto:laura.borg@uhbw.nhs.uk">laura.borg@uhbw.nhs.uk</a>
Clinical Lead	Esther Crawley	<a href="mailto:esther.crawley@bristol.ac.uk">esther.crawley@bristol.ac.uk</a>
Administrator	Alice Trevarthen	<a href="mailto:alice.trevarthen@uhbw.nhs.uk">alice.trevarthen@uhbw.nhs.uk</a>