

# Supporting and Managing People with Long Covid in Primary Care

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### WHAT IS LONG COVID?

#### SNOMED Diagnostic Codes

The NICE/SIGN/RCGP [guidance](#) on managing long-term effects of COVID-19 provides the following clinical definitions:

**Ongoing symptomatic COVID-19** (4-12 weeks after infection)

**Post-COVID-19 syndrome** (12 weeks plus): "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**. It usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time and can affect any system in the body. Post-COVID-19 syndrome may be considered before 12 weeks while the possibility of an alternative underlying disease is also being assessed.

"In addition to the clinical case definitions, the term 'long COVID' is commonly used to describe signs and symptoms that continue or develop after acute COVID-19. It includes both ongoing symptomatic COVID-19 (from 4 to 12 weeks) and post-COVID-19 syndrome (12 weeks or more)" (NICE, Nov 21)

*As with any with any condition the diagnosis code should be resolved if the clinical course leads to recovery to usual health. If there is onset of similar symptoms after apparent recovery they should still be evaluated from first principles for safety.*

# Key points in Pathway and Diagnosis of Long Covid in Primary Care

## 1. The Patient Experience & History

- The role of the GP is crucial to the health and wellbeing of those with Long Covid. An understanding of the condition, belief in the patient experience, validation and empathy are key to building or restoring trust in health care professionals.
- Symptoms: there are [more than 200](#). The experience of Long Covid can be difficult for the patient to explain, due to both symptom fluctuation/variation and the direct effects of Long Covid: fatigue, cognitive function, and the toll of the condition on life and wellbeing.
- Although some studies are underway, there is currently no official guidance on supplements and over-the-counter medications. Patients with Long Covid often take antihistamines, aspirin, pain relief, and supplements including medication bought online, some of which may not have an evidence base and could cause harm. Specifically asking about them is important, understanding that patients may be desperate to find solutions in the absence of available treatments.

## 2. Examination and Investigation

- Symptoms are variable and can be mimicked by or mask other conditions which may occur simultaneously. Patients and clinicians must be alert to the risk of attributing all symptoms as being related to Long Covid - they could indicate for example cancer, thyroid dysfunction, pulmonary embolism, multiple sclerosis.
- Initial investigations and thorough assessments are important and should be relevant to the presenting symptoms, with the understanding that a diagnosis of Post Covid-19 syndrome is a diagnosis of exclusion, i.e. are not explained by an alternative diagnosis.

## 3. Information for Patients

As part of discussing management strategies for Long Covid, [NICE guidance suggests](#):

“Give people who have had suspected or confirmed acute COVID-19 (and their families or carers, as appropriate) advice and written information” on:

- The most common new or ongoing symptoms after acute COVID-19 (see section on common symptoms)
- What they might expect during their recovery, including that recovery time is different for everyone but for most people symptoms will resolve by 12 weeks (for those in the 4-12 week period).
- Although severe acute COVID-19 is more likely to lead to the development of ongoing symptoms, many of those with Long Covid had a relatively mild initial infection.
- “If new or ongoing symptoms occur they can fluctuate, affecting them in different ways at different times” ([NICE](#))

## 4. Referral and Management

- Primary care clinicians can help people manage many symptoms of Long Covid. “There are established treatments for managing the common symptoms often seen with ongoing symptomatic COVID-19 and post- COVID-19 syndrome, as set out in current national and local guidance, which can be followed for symptomatic relief.” ([NICE](#)).
- Referral to Long Covid clinic if available, or to an appropriate specialist, should be considered if symptoms are significant or impact on the patient’s life, or primary care management has reached its limits.

# Common Long Covid Symptom Management and Treatment Strategies

The following information contains tips and resources for Long Covid symptom management strategies in adults, once other causes have been ruled out. Pharmacological treatments have not yet been licenced but with the right multifaceted approach meaningful improvement can be seen.

**FATIGUE in Long Covid is extremely common.**

**Fatigue management should be tailored to the individual patient's experience.**

<b>Key steps</b>	<ul style="list-style-type: none"><li>o Usual investigations for underlying causes should be undertaken, e.g. anaemia, hypothyroidism, raised HbA1c</li><li>o Prepare the patient: tests may well be normal.<ul style="list-style-type: none"><li>o Normal results do not change the symptoms - they are real</li><li>o Explain that there are ways to manage fatigue/symptoms.</li><li>o Encourage symptom/activity diary: example <a href="#">here</a></li></ul></li></ul> <p><b>Important to note that fatigue may get worse at the time of the activity or over the following hours/days, which can make pacing difficult.</b></p>
<b>PESE</b>	<p>Post Exertional Symptom Exacerbation (defined as: <b>disabling and often delayed exhaustion disproportionate to the effort made</b>) is experienced by a significant proportion of those with Long Covid and can make it more difficult to learn to pace activity.</p> <p>Activity that triggers this worsening of symptoms may be something that was easily tolerated before, such as:</p> <ul style="list-style-type: none"><li>o Physical activity: getting out of bed, taking a shower, sitting up, walking</li><li>o Cognitive activity: talking, sensory environment, loud noise, flashing lights</li><li>o Emotional activity: engaging socially</li></ul> <p>Overdoing one activity can affect all elements, e.g. cognitive over-exertion can cause worsening cognitive and physical fatigue.</p>
<b>Management</b>	<ul style="list-style-type: none"><li>o Treat contributing factors e.g. PoTS, anaemia, asthma etc</li><li>o <b>Pacing</b>: Balancing energy availability to prevent symptom deterioration. A period of several weeks or months stability without crashes is often needed before activity can safely be increased.</li></ul> <p>Pacing enables the patient to maintain a stable baseline, and the ability to plan and function within their available energy envelope.</p> <ol style="list-style-type: none"><li>a. <b>3 P's: Pacing, Prioritise, Plan.</b></li><li>b. The Royal College of Occupational Therapists has a useful <a href="#">resource</a></li><li>c. Keeping an activity diary can help with pacing. Try to identify the cause of crashes.</li><li>d. <a href="#">Spoon theory</a> can help people understand their energy levels and plan accordingly.</li></ol>
<b>Useful Links</b>	<p><a href="#">PESE booklet</a> <a href="#">Pacing videos</a> <a href="#">Spoon Theory of Pacing</a> <a href="#">Conserving Energy video series</a> <a href="#">CFS Health</a> <a href="#">Long Covid Physio: Exercise</a></p> <p><b>Note: PESE can also impact other Long Covid symptoms, however the treatment principles above apply</b></p>

## BREATHLESSNESS / DISORDERED BREATHING

Shortness of breath is an important symptom after COVID-19 infection and can have several causes, some potentially serious requiring different treatment approaches. It is an important symptom which should always be comprehensively investigated to exclude red flags. Causes to consider include anaemia, heart failure, ischemic heart disease, [respiratory disease](#), disordered breathing pattern, allergy/asthma, PE, cancer.

**Investigations** might include CXR, FBC and any others relevant to potential causes.

**Breathing pattern disorder (BPD): usually a diagnosis of exclusion.**

Common in Long Covid, the cause is not clear. It may be multifactorial or linked to dysautonomia. Steps to consider when checking breathing pattern:

- Nose - is the patient breathing through the nose or the mouth?
- Diaphragm - is breathing when relaxed deep and abdominal or using chest muscles?
- Breathing rate - is it fast, slow or irregular?
- Improving breathing patterns can have a positive impact on other symptoms e.g. PoTS

A useful screening tool can be found [here](#), a score of >4 is indicative of a **BPD**

### Treatment

Follow local pathways and give simple breathing exercise advice e.g. square breathing through nose. If not improving consider referral to respiratory physio if available, or via Long Covid clinic, who can also refer to [ENO Breathe](#)

**For patients:** self-help via [Asthma+Lung UK](#) [UCLH Breathing Retraining Videos/Part 2](#) NHS Hampshire and Isle of Wight [Breathing Pattern Workshop](#)

**For GPs and patients:** [Physio for BPD](#) [Chest Heart & Stroke Scotland](#)

## COGNITIVE DYSFUNCTION/'BRAIN FOG'

This is often found in Long Covid and may present as loss of executive function, impaired memory (particularly short-term), processing difficulties, sensory overload, word finding issues, symptoms similar to concussion (confusion, feeling dazed or disconnected, poor concentration, 'irritability'). Symptoms typically fluctuate with periods of clear cognition.

Constant or progressively worsening cognitive symptoms should prompt consideration of other causes. Mental health problems including anxiety and/or depression may also co-exist, as with other long term conditions.

**Investigations** Impaired memory should be investigated in line with existing guidelines. Reversible causes can be excluded by tests such as bloods for FBC, ESR, CRP, U&Es, calcium, HbA1c, LFT, TFT, B12, folate; other investigations that may be clinically indicated in some people include CXR, urine microscopy and culture, syphilis serology and HIV testing.

GP assessment of memory using standard scoring systems, symptom and activity diaries. Many patients perform normally on simple assessment but still struggle to perform work or carer roles.

### Treatment

Consider referral to Long Covid clinics (if available) or to neurology for in-depth assessments, including requesting imaging where appropriate. More research is needed to understand Covid's full effect on the brain. No specific treatment has been identified but self-management techniques such as good hydration, good sleep, regular breaks, pacing, using a calendar, reminders on phones, notes to help memory, can be helpful.

Consider referral to neuro rehab service if available.

**Resource for GPs** [BMJ](#) [Lancet review](#)

[RCSLT advice](#) for patients on communication, thinking/cognitive changes [NHS Inform](#)

## PAIN

Pain is frequently reported in Long Covid: common presentations include muscle and joint pain, headaches, chest pain and neuropathic pain.

Pain can vary with activity, can be excruciating and debilitating, mild or variable, as well as moving location or staying in one place. Pain can also be a symptom of PESE and therefore pacing plays an important role in management. Presentation can be similar to fibromyalgia in some patients.

### General principles of pain management:

- Identify the main underlying type of pain.
- Investigation: have any specific causes been ruled out? E.g. stress fracture, DVT, herpes zoster.
- Standard guidelines on pain management should be followed. Treat migraine as per usual practice.
- Consider referral to chronic pain services if appropriate.
- Help the patient manage their pain and its impact on their life; what does it stop them doing?

### Realistic expectations:

- Be honest about the causes of pain in Long Covid not being fully understood.
- Where appropriate explain that the treatment aim is to reduce pain and enable the best possible quality of life, but it may not completely eliminate the pain.
- Avoid the overuse of analgesics (danger of 'analgesic headache').

## PALPITATIONS / TACHYCARDIA

### PoTS (Postural Tachycardia Syndrome), Dysautonomia and Inappropriate Sinus Tachycardia (IST)

- Can have a significant impact on ability to function and perform activities of daily living.
- Can contribute to fatigue and produce symptoms which mimic anxiety: chest pain, fast heartbeat.
- Can be triggered by posture, eating, heat, exertion and relieved by rest/laying down.

### Treatment options:

PoTS can be diagnosed in primary care, see [PoTS UK](#). Treatment includes simple measures such as avoidance of triggers, adequate fluid intake and if BP allows, adding salt to food/water. Activity/exercise should be supine/recumbent. Consider [NASA Lean Test](#), holter monitor

Resources for patients: [PoTS UK](#) [Autonomic Profile home-based test](#)

For GPs: [GP Guide: PoTS UK](#), [RCGP Info](#)

## ALLERGIES AND RASHES

Urticaria and allergic reactions can occur in some people with Long Covid.

### Treatment:

Avoid triggers and consider using antihistamines as per standard protocols. NB: The use of H2 blockers (such as famotidine) in GI disturbance is currently being studied.

## SLEEP

Long Covid can disturb sleep - it is helpful to understand if the patient has trouble:

- Falling asleep
- Staying asleep
- Both

Ask whether particular symptoms are keeping the person awake such as pain, palpitations, sweats or worries. Can these be treated?

Is the patient resting enough during the day? Many people with Long Covid find that pushing through and not taking breaks results in a "tired but wired" state. Frequent rests throughout the day, or short naps at midday can help.

Consider sleep apnoea if the patient has daytime sleepiness. Consider the [Epworth Sleepiness Scale](#), taking a collateral history where feasible, and referral for sleep studies if appropriate. Sleep hygiene training should be offered and cognitive behavioural therapy for insomnia (CBTi) if available.

## OTHER LONG COVID SYMPTOMS

[Studies](#) have identified up to 200 different Long Covid symptoms, including sore throat, voice problems and many others. [NICE](#) guidelines advise that existing treatments for similar symptoms in other conditions can be used for corresponding symptoms presenting in Long Covid patients. ***"However, there is a lack of evidence for pharmacological interventions to treat the condition itself."*** Studies are ongoing.

**Smell/Taste:** Loss of smell and taste may impact upon appetite, health and mental health. Information and resources for patients, there are guides to making kits themselves. e.g. [NHS Scot Loss of smell and taste LC](#). [RCSLT](#) has resources on smell/taste problems, throat difficulties and swallowing



# Help and Resources

## Mental health, social and wellbeing

Wellbeing and mental health should be asked about carefully and sensitively. As with other chronic conditions, the experience of living with Long Covid can impact mental health through social isolation, fear for survival, physical discomfort, loss of previous function (both mental and physical) and financial difficulties related to long term sick leave. Appropriate support and treatment, where needed, should be arranged.

## Work

Support people in discussions with their school, college or employer about returning to education or work, for example by having a phased return. For advice on returning to work, follow national guidance, e.g. NICE's guideline on workplace health: [Long-term Sickness Absence and Capability to Work](#).

A useful leaflet is available from SOM. The Government's [Access to Work Scheme](#) offers financial support to enable people with a disability or chronic condition to get back to work. FOM has a [guide](#) for patients with Long Covid on return to work. Useful resources from [ACAS](#) and [Citizens Advice](#)

## Finances, benefits and wider community support

Consider signposting, e.g. to [Citizens Advice](#), support groups, and advising about prescriptions and [prepayment certificates](#) if appropriate.

[Social prescribing](#) [Link workers](#) [Benefits advice](#)

## Resources

- [Long Covid SOS Resources](#) pages for health professionals and patients
- Royal College of General Practitioners [e-learning Module](#)
- [BMJ Long Covid update](#) Sept 2022
- [Long Covid Care](#) – supporting patients with help-seeking
- [CFS Health video series](#)
- [Long Covid Physio video series](#)
- [Long Covid Kids - support pack](#) for parents, children with Long Covid and GPs
- [When to return to activity](#) after Covid-19 infection for sports/athletes
- [SIGN](#) Long Covid Patient Information Leaflet
- WHO self-management [leaflet](#) for adolescents

Long Covid SOS

Charity registered in England and Wales no 1199120

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