

# Primary Care Assessment and Treatment of the Patient with Long Covid

## CONTENTS:

### Key Points in Pathway and Diagnosis of Long Covid in Primary Care:

1. [The Patient Experience and History](#)
2. [Examination and Investigation](#)
3. [Information for Patients](#)
4. [Referral and Management](#)

### Common Long Covid Symptom Management and Treatment Strategies

[Fatigue](#)

[Pain](#)

[Allergies and Rashes](#)

[Palpitations / Tachycardia](#)

[Breathlessness / Disordered Breathing](#)

[Sleep](#)

[Other Long Covid Symptoms](#)

### Help and Resources

## SNOMED Diagnostic Codes

**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)

# 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. Validation, and belief in the patient experience is key to building or restoring trust in health care professionals.
- Symptoms and 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.

## 2. Examination and Investigation

- Symptoms are variable and broad and can be mimicked by or mask other conditions which may occur simultaneously. Patients and clinicians must be alert to the risk of dismissing all symptoms as being related to Long Covid e.g. cancer, thyroid dysfunction, PE, MS.
- Initial investigations and thorough assessments are important and should be relevant to the presenting symptoms, with the understanding a diagnosis of Post Covid-19 syndrome is a diagnoses 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).
- The likelihood of developing ongoing symptomatic COVID-19 or post-COVID-19 syndrome is not considered to be linked to the severity of their acute COVID-19 (including whether they were in hospital)
- If new or ongoing symptoms occur they can fluctuate, affecting them in different ways at different times” ([NICE](#))

## 4. Referral and Management

- Primary Care can manage many symptoms of Long Covid. Symptomatic relief of common symptoms are possible within primary care. “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

**FATIGUE in Long Covid may be split into two main types:**

|                           | Fatigue with Post-Exertional Symptom Exacerbation (PESE)   | Fatigue without PESE  |
|---------------------------|--|---|
| <b>Definition</b>         | Disabling and often delayed exhaustion disproportionate to the effort made. Activity that triggers this worsening of symptoms may be something that was easily tolerated before, such as: a daily activity (e.g. a shower), a social activity, walking (or other exercise), cognitive, emotionally charged conversation, being in a sensory environment (e.g. loud music or flashing lights) | Constant tiredness, unrelated to activity, without “crashes”, Can be approached via the more traditional “deconditioning” pathway, often with good response to physiotherapy and light and gradually increased exercise, e.g. gentle walking, swimming.                   |
| <b>Treatment Aims</b>     | Pacing can be important when balancing energy levels with activity and avoiding crashes. It enables the patient to maintain a stable baseline, and the ability to plan and function within their available energy envelope.<br>Treat contributing factors e.g. PoTS, anaemia, asthma etc   | To gradually improve activity levels through gradual increase, correlated to symptoms.<br><br>Treat contributing factors e.g. PoTS, anaemia, asthma.  |
| <b>Helpful Strategies</b> | 3 P’s: Pacing, Prioritise, Plan.<br>The RCOT has a useful <a href="#">resource</a><br>Keeping an activity diary can help with pacing. Try to identify cause of crashes.<br><a href="#">Spoon theory</a> can help people understand their energy levels and plan accordingly.   | 3 P’s: Pacing, Prioritise, Plan.<br>The RCOT has a useful <a href="#">resource</a><br>Since activity does not produce significant or disproportionate worsening of symptoms, programmes such as pulmonary rehab, social prescribing, gym referral, can be useful options. |
| <b>Useful Links</b>       | <a href="#">PESE booklet</a> <a href="#">Pacing videos</a> <a href="#">Spoon Theory of Pacing</a><br>Note: PESE can also impact other Long Covid symptoms, however the treatment principles above apply  | <a href="#">NHS Your Covid Recovery</a>   |

## PAIN

There are many causes of pain in Long Covid: muscle, inflammation, cardiac, neuropathic etc.

Pain can vary with activity, can be excruciating and debilitating, mild or variable, as well as moving location or staying in one place.

### 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.
- 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.

## 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 in GI disturbance is currently being studied to determine if it is beneficial to prescribe.

## 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:

This 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.

Resources for patients: [PoTS UK](#)

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

## SLEEP

Long Covid can disturb sleep for many reasons. It is helpful to understand if the patient has trouble:

- Falling asleep
- Staying asleep
- Both

Is something keeping the person awake that can be treated? E.g. pain, palpitations, sweats or worries. Can these be treated?

Is the patient resting enough during the day? Many 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. Clean sleep should be offered and CBT if available.

## BREATHLESSNESS / DISORDERED BREATHING

Shortness of breath is common after COVID-19 infection and can have several causes.

**Investigations:** Other causes e.g. anaemia, heart failure, scarring, lung damage, allergy/asthma, PE

**Disordered breathing syndrome: usually a diagnosis of exclusion.**

Can be triggered by physical effects of Covid-19 infection resulting in an abnormal breathing pattern. There is no one diagnostic tool. 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? A [study](#) found that in younger people hyperventilation may not be present in disordered breathing syndrome.

### 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](#)

**For GPs and patients:** [Physio for BPD](#)

## OTHER LONG COVID SYMPTOMS

[Studies](#) have identified up to 200 different Long Covid symptoms, including cognitive dysfunction, 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](#).



# 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

## Finances

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

## Resources

- [Long Covid SOS Resources](#) page for health professionals and pages for patients [www.longcovidsos.org/resources](http://www.longcovidsos.org/resources)
- Management of LC: [e-learning Module](#): UK Royal College of General Practitioners.
- [BMJ Long Covid update](#) Sept 2022
- [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

Long Covid SOS

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