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Long COVID Advice and resources for healthcare professionals in primary care

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Introduction

Primary care is recognised as having a key role in supporting patients, both adults and children, with long-term symptoms of COVID-19. This includes assessing, diagnosing, referring where necessary and providing longer-term holistic support to ensure services meet the needs of our people and our communities. Figure 1 below shows this role in the adult long COVID pathway.

This document provides healthcare professionals in primary care with key information and advice to support patients who are living with long COVID along with resources to support communications with communities. It can be used by individual staff members as well as to support educational sessions in primary care.

It is being published alongside the NHS plan for improving long COVID services and the revised national commissioning guidance for post COVID services.

For any questions about this handbook or national long COVID communications, please contact: england.clinicalpolicy@nhs.net

What is long COVID?

Most people feel better within a few days or weeks of their first symptoms of COVID-19 and make a full recovery within 12 weeks. For some people, symptoms can last longer. In England 1.2 million people are estimated to have self-reported long COVID symptoms lasting longer than twelve weeks following SARs-CoV-2 infection, with 685,000 for over a year and, in the UK, 403,000 for over two years.¹ We are learning all the time about this new condition.

The long-term effects of COVID-19 are often referred to interchangeably as long COVD and post COVID syndrome. The <u>NICE/SIGN/RCGP guidance on managing long-term</u> <u>effects of COVID-19</u> (updated November 2021) gives the following clinical definitions below:

 ongoing symptomatic COVID-19: signs and symptoms of COVID-19 from four to 12 weeks

¹ Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 7 July 2022

 post COVID-19 syndrome: signs and symptoms that develop during or after COVID-19 and continue for more than 12 weeks and are not explained by an alternative diagnosis.

Anyone, even those with mild acute illness, can experience ongoing symptoms after COVID-19, and symptoms may affect people in different ways and at different times. New symptoms can also develop that people did not have during their initial illness, and symptoms may return after a period of feeling better.

Key information for general practice

Assessment and referral

Patients may present with a wide range of symptoms including but not limited to: breathlessness, fatigue, chest pains, cognitive impairment or psychological symptoms. The initial role of healthcare professionals in primary care is to exclude acute or lifethreatening complications and other unrelated diagnoses.

Assessment may include blood tests, chest X-rays or clinical tests, depending on the patient's signs and symptoms (<u>as per NICE/SIGN/RCGP guidance</u>). Advice, treatment or referral to the relevant acute or specialist services may be required.

Symptoms at four weeks from acute COVID-19 infection are common, and in most people they represent the normal tail of recovery from the acute infection. Appropriate re-assurance about the pace of recovery is likely to be helpful.

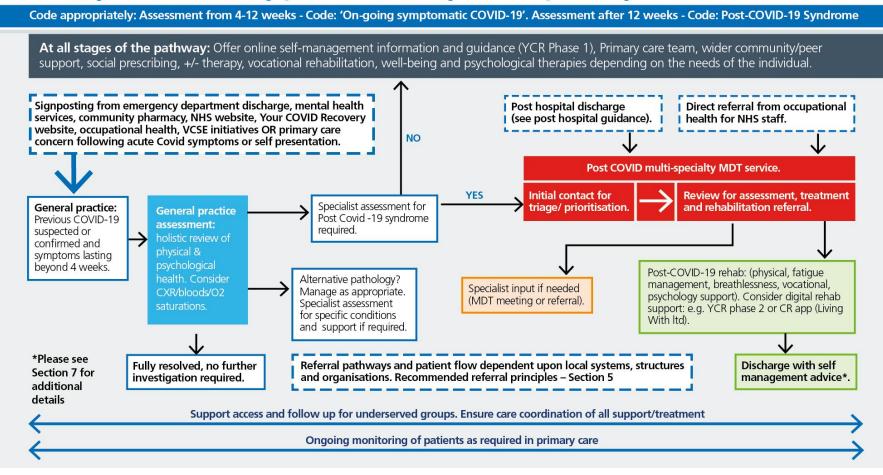
If 'ongoing symptomatic COVID-19' is diagnosed (from four weeks after infection) and other diagnoses ruled out, the following options should be discussed with the patient as appropriate to their needs:

- Signposting to self-management support including the online platform Your COVID Recovery (see below for more detail).
- Supported self-management from the practice or primary care network team; this may include input from social prescribers, health and wellbeing coaches and care co-ordinators who can also link into community groups or other existing community services as appropriate.

• Referral into a post COVID service any time from four weeks after the start of acute COVID-19 illness. However, typically referral will not be immediate due to the need to rule out alternative diagnosis and undertake relevant investigations.

Figure 1: Primary care/community post COVID syndrome pathway for adults (Source: <u>National commissioning guidance</u> for post COVID services)

Primary care/community post-COVID-19 syndrome pathway for adults



To consider a diagnosis of post COVID syndrome patients must have a clinical history consistent with an acute COVID-19 infection, but do not need to have had a positive SARS-CoV-2 test, antibody test or a previous COVID-19 diagnosis code.

As emerging evidence suggests the severity of initial COVID-19 symptoms is not directly linked to the development of long COVID, assumptions should not be made about the longer-term impact of the virus.

Self-management: Your COVID Recovery

The <u>Your COVID Recovery</u> service provides a digital, interactive, personalised recovery programme for people recovering from COVID-19. This has two phases:

Phase 1 is a public website providing information on all aspects of recovering from COVID-19, and anyone with ongoing symptoms of COVID-19 can be signposted to the site to aid their recovery, regardless of whether they were managed in hospital or the community. The information and resources cover a range of bio/psycho/social areas of care, including physical, emotional and psychological wellbeing support offers.

Phase 2 is a tailored self-management rehabilitation plan that is remotely supported by healthcare professionals to reduce symptom burden. It enables people to set goals for their mental and physical health and receive peer-to-peer support through social community forums. It has an 'ask the expert' facility for patients to contact their local rehab service and allows patients to be monitored by their local rehab teams to ensure that they are on track with their care.

Patient access to Phase 2 is **only available after a referral** from a post COVID service once a patient is deemed fit for rehabilitation. To sign up to offer Your COVID Recovery Phase 2, please email <u>yourcovidrecovery@uhl-tr.nhs.uk</u>. Providers will be onboarded and trained in how to maximise use of the programme to support patients.

Post COVID services

The NHS has established 90 specialist post COVID services across England. Given the multisystem nature of post COVID-19 syndrome, these services bring together a wide range of healthcare professionals to offer physical, psychological and rehabilitation treatment and support. These healthcare professionals include, but not limited to: doctors, registered nurses, physiotherapists, psychologists and occupational therapists.

After ruling out acute or life-threatening complications and alternative diagnoses, primary care clinicians should consider referring people to a post COVID service any time from four weeks after the start of acute COVID-19 illness. The decision to refer should be made jointly with the person using 'shared decision-making' principles, and the support, treatment and rehabilitation needs agreed.

The referral should, where available, provide the following details:

- date of acute COVID-19 if known
- care during acute COVID-19, ie community, hospitalisation, ICU care
- duration and trajectory of ongoing symptoms following initial illness
- scope of symptoms, following full systems history
- impact of symptoms on the person's life including social impact, employment, psychological affects as well as health
- findings on clinical examination appropriate for symptoms, which may include:
 - respiratory, cardiovascular and neurological examination
 - cognitive and psychological assessment
 - lying and standing blood pressure and heart rate
 - peripheral oxygen saturation on rest and exertion
- results of appropriate investigations, which may include:
 - blood tests (if not already performed during the acute illness), such as full blood count, kidney and liver function tests, C-reactive protein, ferritin, B-type natriuretic peptide (BNP), HbA1c and thyroid function tests
 - chest X-ray, if not performed previously or still symptomatic after 12 weeks
 - 12-lead ECG.

Vocational rehabilitation

It is recognised that long COVID can have a detrimental effect on a person's ability to work, care for others and carry out their usual activities.

Most people experiencing long-term symptoms of COVID-19 are of working age. Return to work personalised advice and support should be offered as a core component of rehabilitation, and made recommendations for the person's employer where appropriate. Where possible, consider referring to the person to occupational health for advice on returning to work.

Data management and coding

Data is critical if we are to learn more about this new condition, including its prevalence and natural history, to inform clinical management, and service planning and design.

Data on long COVID needs to be consistently and accurately coded and captured in primary care.

The core SNOMED codes for general practice are:

- post COVID-19 syndrome (132516100000102): 12 weeks plus after infection
- ongoing symptomatic COVID-19 (1325181000000106): 4–12 weeks after infection
- referral to post COVID assessment clinic (132503100000108)
- **signposting to Your COVID Recovery** (1325021000000106): when signposting patients to the public Your COVID Recovery website (phase 1)
- **post COVID-19 syndrome resolved** (1326351000000108): to be used at the patient's and clinician's discretion when all symptoms have fully resolved and there is no evidence of persisting organ impairment, or if an alternative diagnosis has been made that accounts for all symptoms.

Please note that healthcare professionals need to enter '**Post-COVID**' (with the dash) when searching for the codes. Further guidance on coding, including recommended code sets, is available in the <u>national commissioning guidance for post COVID services</u>.

A number of templates are available within the major EPR systems to support general practice assessment and coding of long COVID. These have been co-designed with and align with NHS England guidance, eg:

- TPP SystmOne Long Covid Management Primary Care 1.0
 - access using 'Search Features' function \rightarrow type 'long' to bring up
- EMIS Long COVID Management v1.0
 - access using Template Runner \rightarrow type 'long' to bring up
- Ardens Long COVID Template

- see website for details on how to access and use.

To improve detection of possible cases of long COVID, practices are encouraged to routinely code COVID-19 diagnosis (or add COVID-19 as a 'Problem') for those who test positive for COVID-19.

Tackling inequalities

COVID-19 has had a disproportionate impact on disadvantaged groups including people from deprived and ethnic minority groups. These are the groups that face inequality in access to healthcare and support, leading to poorer health outcomes.

Systems and practices should consider how they can reduce potential inequity of access to services including post COVID services. This could include using existing infrastructure, such as by working with the practice patient participation group (PPG) and system partners to help raise awareness of support (such as the <u>Your COVID</u> <u>Recovery</u>) and to understand any potential barriers to accessing support and treatment.

As with any new condition, patient awareness of post COVID-19 syndrome may vary. While many people may link their ongoing symptoms to previous COVID-19 infection, others may not have experienced a severe acute infection, or may be unaware they contracted the virus.

Once other causes of symptoms have been excluded, healthcare professionals should 'think long COVID' when patients present with symptoms that could be indicative of post COVID-19 syndrome. They should ask the patient to determine if they have previously had COVID-19 (confirmed or suspected) and when. As noted above, absence of a positive COVID-19 test or antibodies does not preclude a diagnosis of long COVID.

Supporting children and young people with long COVID

Current evidence is that most children and young people experience only mild symptoms following COVID-19 infection or are asymptomatic. However, a small number do experience long COVID.

The NHS has established 14 long COVID paediatric hubs across England to co-ordinate post COVID care for children and young people across a range of services. These specialist hubs consist of multidisciplinary teams who can provide assessment services and remote support to other clinicians to ensure ongoing holistic support.

Healthcare professionals who are concerned a child has long COVID should refer them either to the local paediatric service or local post COVID service (if it accepts paediatric referrals), which will then decide whether to refer onto a paediatric hub as appropriate.

Patient-facing resources

Long COVID patient information leaflet

This <u>printable patient leaflet</u> contains key messages on recovering from COVID-19 and the support available to patients, their families and unpaid carers.

Your COVID Recovery

The information and advice on <u>Your Covid Recovery</u>, including the guidance on managing common symptoms, is available as downloadable PDFs and can be printed for patients who prefer paper copies.

Information on long COVID research

The National Institute of Health Research (NIHR) is funding new research studies to help improve understanding of long COVID. Information outlining this research is available on their <u>website</u>.

The NIHR have also shared a new themed review that rounds up NIHR long COVID research and summarises the findings to date. This information is available here.

If you are interested in taking part in long COVID research see <u>Be part of research</u> where you will be able to search for long COVID studies.

Patient-facing channels

Key messages for patients and the public, e.g. on practice websites or social media channels, include:

- Most people infected with COVID-19 feel better within a few days or weeks of their first symptoms and make a full recovery within 12 weeks. For some people symptoms can last longer.
- If you are concerned about any of your symptoms, contact your GP surgery they can offer you an initial consultation and provide access to any further assessments or care they determine you need.

- You should contact your GP surgery if you are experiencing:
 - new or worsening symptoms following COVID-19 infection, especially if you are concerned about symptoms that have been present for four weeks or longer, as you would for any other health issue
 - any symptoms that are affecting your ability to carry out normal daily activities.
- You do not need to have had a positive COVID-19 test result to get help. A member of the general practice team will assess you and provide the support you need in the first instance.
- After your assessment, your general practice team will talk to you about what they think is happening and discuss the support they think you need to help you get better. For example, you may be signposted to the Your COVID Recovery website for online advice on self-management, or referred to a specialist post COVID clinic, a specialist with expertise in your specific problem or a rehabilitation service.

Additional resources

Supporting health and care staff with long COVID

<u>Office of National Statistics</u> data suggests healthcare staff may be disproportionately affected by post COVID-19 syndrome: higher prevalence rates among them are reported compared to those working in other sectors.

It is important that the NHS role models its approach as a responsible and supportive employer and takes care of colleagues who have worked so hard throughout the COVID-19 pandemic. NHS England has developed <u>guidance</u> for NHS organisations detailing the support available for staff.

While the support available in primary care may depend on the employing organisation, the universal offer for NHS staff in England is as follows:

- All NHS colleagues have direct access to a suite of national services to support wellbeing such as apps, helplines, e-learning resources -in addition to local health and wellbeing support services. You can find more information on our <u>website</u>.
- All doctors across the country can self-refer for psychological assessment and support to the free <u>Practitioner Health Programme</u>.

- As part of the national health and wellbeing offer, training is available for line managers and teams in having safe and effective health and wellbeing conversations with colleagues.
- A number of enhanced health and wellbeing pilots are in place in systems covering 700,000 staff. These include the 14 pilots launched in 2021/22 to focused on supporting the wellbeing of primary care colleagues (including general practice, dentistry, optometry and pharmacy colleagues).

Educational materials for primary care teams

These resources have been developed to help teams adapt their services to the needs of those with long COVID:

- Health Education England (HEE) e-learning modules: Long COVID programme
- Your COVID Recovery
- RCGP: <u>Management of the long term effects of COVID-19</u>
- Patient safety learning and RCGP resource: <u>Post COVID-19 syndrome: What</u> <u>support can patients expect from their GP?</u>
- Queen's Nursing Institute: <u>Living with COVID19 community and primary care</u> <u>nursing resource</u>
- Kam A, Dowdall M (2021) <u>Managing the long-term effects of COVID-19</u>. (Pharmacists in community and primary care should be able to provide patients with appropriate advice and support to manage their symptoms.)
- NIHR resources
- <u>The Faculty of Occupational Medicine: Guidance for return to work for patients</u> with post-COVID syndrome
- NICE/SIGN/RCGP <u>https://www.nice.org.uk/guidance/ng188/chapter/Update-information</u>
- Long COVID network on the <u>FutureNHS platform</u>

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This publication can be made available in a number of other formats on request.