

Summary of joint guideline on the management of long COVID

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NICE, SIGN and the Royal College of General Practitioners have published a joint guideline on identifying and managing the long-term effects of COVID-19 ('long COVID') in adults, young people and children. This article summarises the main points of the guidance.

Observational studies show that a large proportion of people who survive COVID-19 develop long-lasting symptoms including breathlessness, fatigue and cognitive impairment in the weeks following the acute phase of infection – a syndrome known as 'long COVID'.¹⁻⁴ Given the prevalence of COVID-19, managing this high burden of symptoms presents a significant challenge to health services. NICE, the Scottish Intercollegiate Guidelines Network (SIGN) and the Royal College of General Practitioners (RCGP) have published a joint guideline covering diagnosis, management and monitoring of long COVID (NG188/SIGN 161).^{5,6}

The guideline describes the care that should be offered to "people who have signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 4 weeks and are not explained by an alternative diagnosis". The guideline clinically defines three phases following COVID-19 infection, as follows:

- **Acute COVID-19:** Signs and symptoms of COVID-19 for up to 4 weeks
- **Ongoing symptomatic COVID-19:** Signs and symptoms occurring from 4 weeks up to 12 weeks

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

Table 1. Common signs and symptoms of long COVID (ongoing symptomatic COVID-19 and post-COVID-19 syndrome)^{5,6}

- **Post-COVID-19 syndrome:** Signs and symptoms that develop during or after infection, continue for more than 12 weeks and are not explained by an alternative diagnosis. It may also be considered before 12 weeks while an alternative underlying disease is being assessed.

The term 'long COVID' can be used as a general term to describe the signs and

symptoms that continue or develop after acute COVID-19, and includes both ongoing symptomatic COVID-19 and post-COVID-19 syndrome. Symptoms are highly variable and wide ranging; some of those most commonly reported are listed in Table 1.

Identifying and assessing people with symptoms of long COVID

The emergence of new symptoms 4–12 weeks after onset of acute illness suggests ongoing symptomatic COVID-19; persistence beyond 12 weeks suggests post-COVID-19 syndrome. People with confirmed or suspected COVID-19 should be given information about what they might expect during their recovery, including possible new symptoms and how to self-manage them. Whether to investigate or refer is left to the clinician's discretion, bearing in mind that some people don't report the common symptoms and some vulnerable groups are at increased risk.

The symptoms of long COVID are non-specific and patients may feel they are not taken seriously. The symptoms can fluctuate and vary between individuals; their impact can be far-reaching and independent of the severity of acute COVID-19, the type of symptoms experienced, and a positive or negative test. A holistic approach to assessment is therefore essential.

Investigation and referral

There is no unique approach to investigating possible long COVID. Rather, the guidance lists routine investigations – such as X-rays, blood tests, exercise tolerance tests – that help to exclude other diagnoses. Patients who may have a life-threatening complication should be referred immediately. Examples cited are severe hypoxaemia or oxygen desaturation on exercise, signs of severe lung disease, cardiac chest pain, multisystem inflammatory syndrome in children, and severe psychiatric symptoms or risk of self-harm or suicide. If other diagnoses are ruled out, a patient with suspected long COVID should be referred to an integrated multidisciplinary assessment service – if one is available – at any time from four weeks after the onset of acute COVID-19.

Planning care and management

The nature of long COVID symptoms means that the focus of management is on supporting self-management and rehabilitation. Breathlessness, fatigue and 'brain fog' are among the most commonly reported long-term symptoms and the rehabilitation plan should address these. The level of support and rehabilitation should be agreed with the patient and their families/carers and should include advice on self-management (supported if necessary), and appropriate referral for specialist care. This should take into account the likelihood that needs will vary over time and that, although individual symptoms may not warrant intervention, the combined impact of multiple symptoms may be significant.

Support should include ways to self-manage symptoms, such as setting realistic goals, who to contact for help, and sources such as support groups, social prescribing, online forums and apps (though none are specifically recommended). Patients should know how to access social care, housing and employment services and how to get advice about financial support. They should be supported in their discussions with employers and schools – for example, by negotiating a phased return.

Rehabilitation should be individualised and patient-led, with assessment by health professionals and self-monitoring – for example, with a tracking app to record progress towards personal goals and recovery. Older people may need extra support, such as a short-term care package, advance care planning and help to tackle social isolation, loneliness and bereavement. Children may need specialist referral.

Follow-up, continuity of care and service organisation

There is little evidence to guide practice, and the guideline tries not to limit future options as the individual's circumstances change. How and to what extent follow-up and monitoring is necessary should therefore be agreed with the patient. It may be carried out in person or remotely, in the clinic or, with sufficient help, at home.

The range of services and disciplines

involved in the management of long COVID spans health and social care, and the primary and secondary care sectors. It is therefore important to ensure that information and planning is shared and integrated. People need to know what is happening: they should be given copies of their care plans, their discharge letters, clinical records, rehabilitation plans and prescriptions. Wherever possible, they should see the same healthcare professional or team and have a care coordinator or a single point of contact. This may be challenging at a time when staff are sorely overstretched because the NHS does not have a strong record on personal continuity of care.

The multidisciplinary service should be led by an appropriately experienced doctor, though there is no evidence for this choice. It should be capable of assessing the full range of physical and mental health problems and conducting investigations, and have access to specialist support. Rehabilitation services should, according to local needs and resources, be integrated and multidisciplinary. The wide range of skills provided by health professionals should include expertise in treating fatigue and respiratory symptoms. The core team should at least include occupational therapy, physiotherapy, clinical psychology, and psychiatry and rehabilitation medicine. Local integrated referral pathways should be established between primary and community care, multidisciplinary rehabilitation services and specialist services, and multidisciplinary assessment clinics and specialist mental health services.

Recommendations for research

It is only a year since long COVID was recognised and there is still much to learn about it. What is the natural history of post-COVID-19 syndrome and how does its presentation vary by age and in children and pregnant women? What is its prevalence among groups such as black, Asian and minority ethnic group communities? More research is needed to establish which interventions are best, what the needs of different groups are, whether clusters of symptoms are predictive of a treatment response, and whether exercise inter-

ventions are useful. There are currently no validated screening tools and it is not known whether they would assist management.

Summary

If current estimates of the prevalence of long COVID are accurate, the NHS faces a potentially large increase in demand for support and rehabilitation. NHS England has allocated funding to develop services and has already established 69 assessment centres.⁷ This guideline shows how existing resources should be deployed to deliver supportive, patient-focused care and access to specialist expertise while retaining openness and flexibility.

NICE, SIGN and the RCGP state the guideline was developed using a 'living' approach, meaning it will be continuously reviewed and updated as new evidence emerges.

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Declaration of interests

None to declare.

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