

# Post COVID syndrome referral pathways



**Dr Vince Mak**, *Consultant Physician in Respiratory Integrated Care at Imperial College Healthcare Trust*

We are now preparing to enter a third wave of SARS-CoV-2 infections whilst we continue to deal with the backlog of patients who have had their treatments and assessments delayed by the pandemic. However, what is challenging the NHS even more are the long-term effects following SARS-CoV-2 infection – so called “long COVID”. Ongoing symptoms following an acute COVID-19 illness may encompass two scenarios: first, ongoing symptomatic COVID-19 illness with signs and symptoms persisting for between 4–12 weeks described as post-acute COVID-19; and second, post-COVID syndrome (PCS), a clinical scenario where signs and symptoms that develop during or after an infection consistent with COVID-19 illness continue for more than 12 weeks and are not explained by an alternative diagnosis. Both post-acute COVID-19 and PCS can have a significant effect on people's quality of life and are adding increased pressures to the NHS.

Almost 6% of adults in England have reported at least one lingering symptom persisting for at least 12 weeks after an acute infection with SARS-CoV-2 in research performed by Imperial College, London recently.<sup>1</sup> Extrapolating this to the whole adult population in England, this proportion equates to over 2 million people with at least one persistence COVID-19-related symptom persisting for more than 12 weeks after the acute infection and just under one million with three or more persistent symptoms.<sup>1</sup> Alarming, it is estimated that for nearly 400,000 people, their post-COVID symptoms may persist for over a year following the initial infection.<sup>1</sup>

The presence of PCS does not appear to be related to the severity of the initial acute COVID illness and affects both hospitalised and non-hospitalised patients, and even those who may have had asymptomatic infection. In

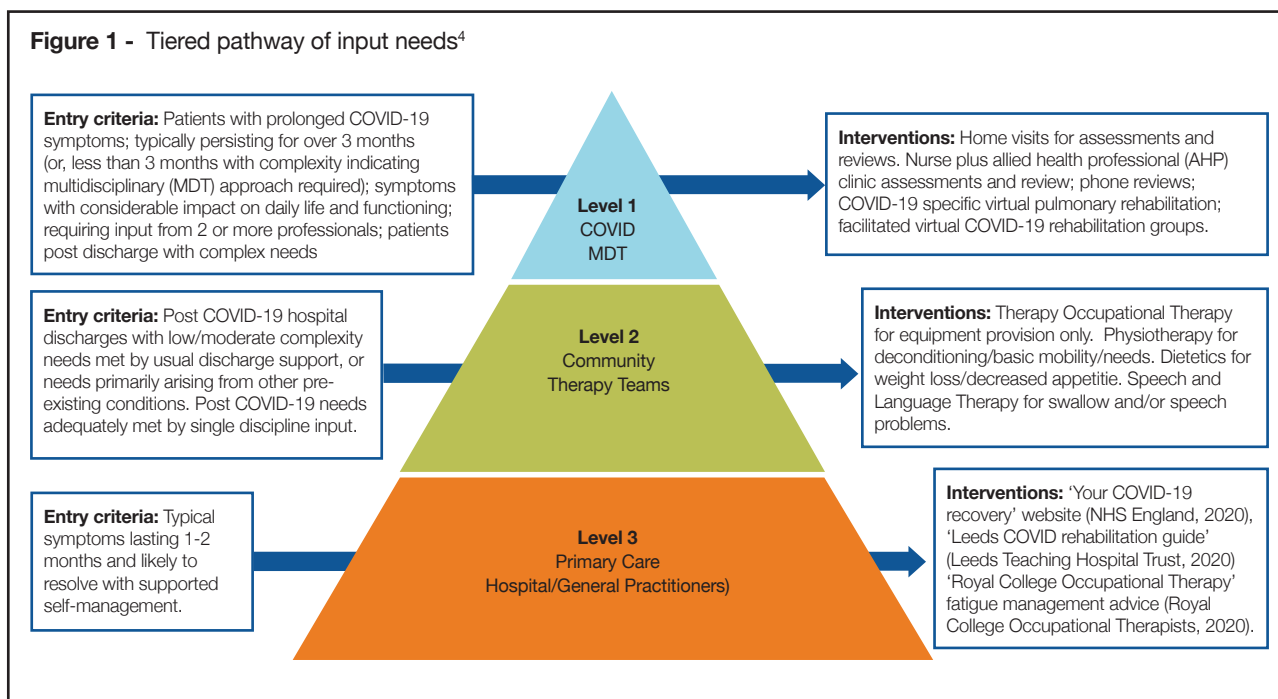
the REACT-2 cohort, PCS seemed to affect females slightly more often than males and predominantly those of middle-age. PCS may be more common among those with a pre-existing chronic health condition.

PCS usually presents as a cluster of symptoms, often overlapping, which can fluctuate and change over time and can affect any system in the body. The most commonly reported symptoms are fatigue, breathlessness, cognitive dysfunction (“brain fog”, including problems concentrating, disorientation and difficulty finding the right words) and persistent cough. However, there is a long list of other symptoms reported by patients including: chest pain, palpitations, fevers, generalised aches and pains, headaches, pins and needles and numbness in the limbs, dizziness, persistence of loss of smell or taste, diarrhoea, rashes and psychological problems such as anxiety and depression. These symptoms can emerge during the acute infection or after resolution of the initial symptoms during the acute phase and they can change unpredictably, affecting patients in different ways and at different times.

PCS is different from the complications of SARS-CoV-2 infection which have an identifiable pathological basis, such as lung fibrosis, myocarditis. PCS is also distinct from the side effects and complications that may arise as a consequence of the acute treatment of COVID-19 illness for hospitalised patients, such as post ICU neuropathy. Thus examination and investigations should be performed to exclude these conditions before considering a diagnosis of PCS, although it is important to recognise that these conditions can co-exist with PCS.

Patients can be considered to have PCS irrespective of whether they were hospitalised or had a positive or negative COVID test (many were infected before routine testing in the community was available). Most patients who were

**Figure 1 - Tiered pathway of input needs<sup>4</sup>**



admitted to hospital with severe COVID-19 should have had a review at 12 weeks or sooner post discharge by secondary care colleagues to assess recovery and initiate onward referral for any emergent complications or ongoing symptoms. Patients can also be assessed formally using recognised scoring systems such as the COVID-19 Yorkshire Rehabilitation Screening Tool (C-19 YRS).<sup>2</sup> In primary care, initial assessment is aimed at excluding identifiable causes that can be treated. This should include a comprehensive clinical history and appropriate examination that involves assessing physical, cognitive and psychological symptoms, as well as functional abilities. Investigations should include blood tests (including FBC, U&E, TFT, CRP, ferritin, LFTS, D-dimer and BNP) chest X-ray and ECG. Patients identified with low oxygen levels at rest or on exercise, persistent abnormalities on the chest X-ray, cardiac sounding chest pain or ECG abnormalities and suspected multisystem inflammatory syndrome in children should be referred for urgent review by the relevant secondary care service.

Once identifiable causes have been ruled out, patients with persistent symptoms can be considered to have PCS. A holistic approach to their management is important and there are several options for the ongoing management of their symptoms. Firstly, patients should be offered reassurance that most do recover with time and should be offered advice on self-management including setting realistic goals. Patients can be directed to sources of advice and support,<sup>3</sup> including support groups, social prescribing, online forums and websites including the NHS Post COVID website: [www.yourcovidrecovery.nhs.uk](http://www.yourcovidrecovery.nhs.uk), and [www.rcot.co.uk/recovering-covid-19-post-viral-fatigue-and-con-](http://www.rcot.co.uk/recovering-covid-19-post-viral-fatigue-and-con-)

serving-energy. Patients should be encouraged and supported to discuss their clinical situation with their employer, school or college and make plans for a phased return to work or education. Anxiety and depression may be an issue, especially for patients who were previously well and active. In England, patients who have anxiety or depressive symptoms can be referred to a local Improving Access to Psychological Therapies (IAPT) service or to a liaison psychiatric service if they have more complex mental health needs – (similar systems apply across other UK nations). Local rehabilitation services and community multidisciplinary teams may be available to help patients with fatigue or breathlessness issues where no underlying cause can be identified. These patients may have a form of breathing pattern disorder and may be helped by respiratory physiotherapists. Patients whose symptoms can be managed by a single discipline are suitable for community management.

Patients with more severe, persistent or unusual and complex problems severely impacting on their daily lives should be considered for referral for a specialist integrated multidisciplinary assessment in the newly set up post COVID assessment clinics where they are available. These clinics offer services to guide management including physical and psychological aspects of rehabilitation, working with the patient to develop a personalised rehabilitation and management plan and onward referral to other specialists if needed. These clinics should work in conjunction with services in primary and community care settings to provide a comprehensive programme to aid recovery. NICE has produced guidance on the management and provision of services for patients with PCS.<sup>4</sup> This three-tiered approach of self-

management, community therapy teams and specialist multidisciplinary teams is now being set up throughout the UK (Figure 1).<sup>5</sup> Referral to IAPT should occur at Level 2 if required.

In conclusion, PCS affects a significant proportion of people following acute COVID illness. The most common symptoms are fatigue, breathlessness, exertional malaise (mental and physical) and cognitive dysfunction. Patients presenting with these symptoms need a thorough assessment to exclude any treatable long-term complications following an acute COVID-19 illness. In the absence of identifiable causes, patients may be supported to self-manage with a variety of face to face and online resources. More severe and complex cases should be referred on to have a

multidisciplinary assessment in the newly formed post COVID assessment clinics.

### References

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