

Clinical practice guide for assessment and management of adults, children and young people with symptoms of long COVID

Guidance for NSW health clinicians

NOVEMBER 2023

This clinical practice guide is intended for use by clinicians who provide care to adults, children and young people with a history of COVID-19 diagnosis, regardless of severity or COVID-19 variant of concern.

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Definition of long COVID

Long COVID is defined by the [World Health Organization](#) as:

“a condition that occurs in individuals with a history of probable or confirmed SARS CoV-2 infection, usually:

- **three** months from the onset of COVID-19; **AND**
- with symptoms that last for at least two months and cannot be explained by an alternative diagnosis” [emphasis added].^{1,2}

Note that both of these criteria are required.

A number of other terms are sometimes used to describe long COVID such as ‘post-acute COVID-19’ or ‘post COVID-19 syndrome’. These terms are not synonymous with long COVID, as they may also describe symptoms that persist immediately following acute COVID-19 illness.

The World Health Organization states “common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others and generally have an impact on everyday functioning. Symptoms may be new onset following initial illness. Symptoms may also fluctuate or relapse over time”.¹⁻³ A list of common symptoms is included in [Table 1](#).

Intended audience and application

This clinical practice guide is intended for use by clinicians who provide care to adults, young people and children with a history of COVID-19 diagnosis, regardless of severity or COVID-19 variant of concern.

People may initially present to emergency departments, specialist post-COVID-19 clinics, specialist services, e.g. rehabilitation or respiratory medicine, primary care or general practices, with ongoing symptoms that require further assessment, investigation, management and referral.

This guide is intended for use together with the [Long COVID Model of Care](#)⁴, which outlines a four-stage approach through which people with symptoms of long COVID may receive care.

Together, this guide and model of care are designed to:

- minimise the risk of fragmented delivery of care;
- avoid potential over-investigation and over-treatment; and
- identify people who would benefit from further assessment and management.

This information is not a substitute for a healthcare provider's professional judgement and is intended to provide additional guidance for the assessment and management of symptoms of long COVID, after usual clinical assessment and care. Specific information about the individual patient and consultation with other medical specialties must be considered as appropriate.

It is important to note that the evidence base on the assessment and management of long COVID continues to evolve. This document represents a living document that will be updated in line with emerging evidence.

HealthPathways

This guide is consistent with the HealthPathway Post COVID-19 Sequelae and the Royal Australian College of General Practitioners document [Caring for patients with post-COVID-19 conditions](#)⁵.

The HealthPathway was originally developed in 2020, in collaboration with the NSW COVID-19 Rehabilitation Community of Practice. It has been adopted with local adaptation in most primary health networks across NSW, for use by general practitioners (GPs), practice nurses and Aboriginal medical services. Further information on HealthPathways is available on the [NSW Health webpage](#)⁶, with access to the localised HealthPathway for the region available via the [relevant Primary Health Network webpage](#)⁷.

Background

As at 28 September 2023, there have been 4,106,116 cases of COVID-19 in NSW since the beginning of the pandemic.⁸ This number is likely to be under-reported due to the non-standardised methods of testing and reporting positive tests for acute COVID-19 infections. Recent evidence has shown that the majority of people with COVID-19 will recover completely within a few weeks.⁹⁻¹¹

A small subset of people will continue to experience ongoing symptoms for multiple weeks or months, defined as long COVID.¹² Recent data from Victoria estimates that the prevalence of long COVID among adults with symptomatic infections ranges from 0.17% to 4.4%; this prevalence is lower among vaccinated adults who were infected with the Omicron variant (0.09% for non-hospitalised adults and 1.9% for hospitalised adults).¹³ Prevalence of long COVID in children and adolescents is around 3.7% of infections (1.7% in non-hospitalised children and up to 5.2% in hospitalised children).¹⁴ International evidence suggests that COVID-19 vaccination is associated with reduced incidence and severity of long COVID.^{10,11}

A global systematic analysis identified that the median duration of long COVID in community infections was four months following acute COVID-19 diagnosis; for those people hospitalised, the median duration was nine months.⁹

The presentation of long COVID in adults, young people and children varies significantly, with more than 100 symptoms documented in the literature. People with long COVID can experience a variety of symptoms that impact quality of life, wellbeing and capacity to return to work, such as (noting that this list is not exhaustive):¹⁵

- breathlessness and cough
- chest pain and palpitations
- postural orthostatic tachycardia syndrome (POTS)
- fatigue and reduced exercise tolerance
- sleep disorders including altered sleep wake cycle, sleep maintenance disturbance and sleep disordered breathing
- cognitive impairment and poor concentration, including learning difficulties in children
- mobility impairment
- joint pain and muscle pain
- mental health conditions including anxiety and depression.

Common symptoms are listed in [Table 1](#). Significant physical, psychological and cognitive impairments may persist despite clinical resolution of the infection.¹⁶⁻¹⁸

The recommended management and model of care for people diagnosed with COVID-19 in the first 12 weeks post-diagnosis is outlined in the NSW Health document [Management of adults with COVID-19 in the post-acute phase – a model of care for NSW Health clinicians](#).¹⁹ This guide provides recommendations for assessment and management of some of the most common symptoms of long COVID for adults, young people and children.

Methodology

This guide is based on current evidence and informed by the expert clinical consensus of a team of senior clinicians from the following disciplines: multidisciplinary rehabilitation, respiratory medicine, primary care, general practice, geriatric medicine, psychiatry, cardiology, pulmonary rehabilitation and allied health disciplines including occupational therapy, physiotherapy and psychology.

The document has been informed by the work of the NSW COVID-19 Critical Intelligence Unit including:

- [Living evidence table – post acute sequelae of COVID-19 \(long COVID\)](#)²⁰
- [Exercise and long COVID](#)²¹

Factors associated with an increased risk of long COVID

There are a number of factors associated with an increased risk of long COVID:

- Hospitalisation or increased severity of symptoms during the acute phase of illness²²
- Age over 65 years²³
- Pre-existing comorbidities, particularly asthma, obesity, cardiovascular disease, diabetes and dementia²⁴
- History of cancer or immunosuppression^{22, 25}
- Frailty (assessed by use of the [clinical frailty scale](#))²⁶
- Increased stress at the time of acute COVID-19²⁷
- COVID-19 vaccination status at the time of acute illness (being unvaccinated increases risk)^{10, 11}
- Increase of inflammatory markers (from baseline) during primary infection²⁸
- Female sex²⁹

The mechanisms that lead to long COVID are not yet clearly understood and are under ongoing study – there may be a single mechanism or a number of factors involved. Possible causes include organ dysfunction as a consequence of the acute illness, a persistent hyper-inflammatory state, molecular mimicry with a dysfunctional immune response, reactivation of chronic infections or the persistence of virus in certain bodily compartments, impaired oxygen delivery due to micro-clotting and cerebral hypoxia.³⁰

Co-factors that may worsen the symptoms of long COVID include increased physical or emotional stress, adverse effects of regularly prescribed medications during severe acute illness such as sedatives, analgesia or neuromuscular blockade, physical de-conditioning and pre-existing co-morbidities.³¹ Symptoms may fluctuate and change in nature over time.³²

Comprehensive patient assessment

Regardless of the care setting in which a person presents with long COVID, a holistic, biopsychosocial person-centred approach to patient assessment is required.¹⁵ There is, at this time, no definitive single test for long COVID. Diagnosis is made by ruling out other similar conditions.³³

A comprehensive clinical history and appropriate examination should include:

- History of acute COVID-19 (suspected or confirmed)
- Nature and severity of previous and current symptoms – this should include documentation of objective markers of disease severity such as requirement for intensive care unit (ICU) admission, ICU and hospital length of stay (if applicable), the use of invasive or non-invasive ventilation or extracorporeal membrane oxygenation, arterial or venous thromboembolic complications, sepsis and any opportunistic infections in context of immunomodulators
- Timing and duration of symptoms since the onset of acute COVID-19 illness
- History of other health conditions
- Exacerbation of pre-existing conditions
- Social determinants of health assessment, e.g. interpersonal connections, work, finances and lifestyle factors
- COVID-19 vaccination status

It may help if a family member, carer or trusted friend is present to support the patient in this assessment.

Planning for surgery for patients with long COVID

Planning surgery for patients with symptoms of long COVID should include a consideration of “the effect of these symptoms on the risk of perioperative and postoperative complications in surgery”.³⁴ For further information, including suggested preoperative assessment tools, refer to the Royal Australasian College of Surgeons [Impact of Post-COVID-19 Conditions \(Long COVID\) on Surgery](#)³⁴.

Patient-reported outcome measures

An important part of the patient assessment is:

- measuring the severity and impact of the symptoms on a person’s level of function
- the degree of impairment experienced.

For example, does the person have reduced exercise tolerance? Are they needing to frequently access health services? Are they able to return to work? Is their quality of life impacted?

Long COVID-specific measures are captured in NSW via the Health Outcomes and Patient Experience (HOPE) platform.³⁵ The HOPE platform is a secure web-based platform used to house and manage the online surveys and database, enabling multidisciplinary care teams to capture, review and act on the data reported in a timely, holistic way.

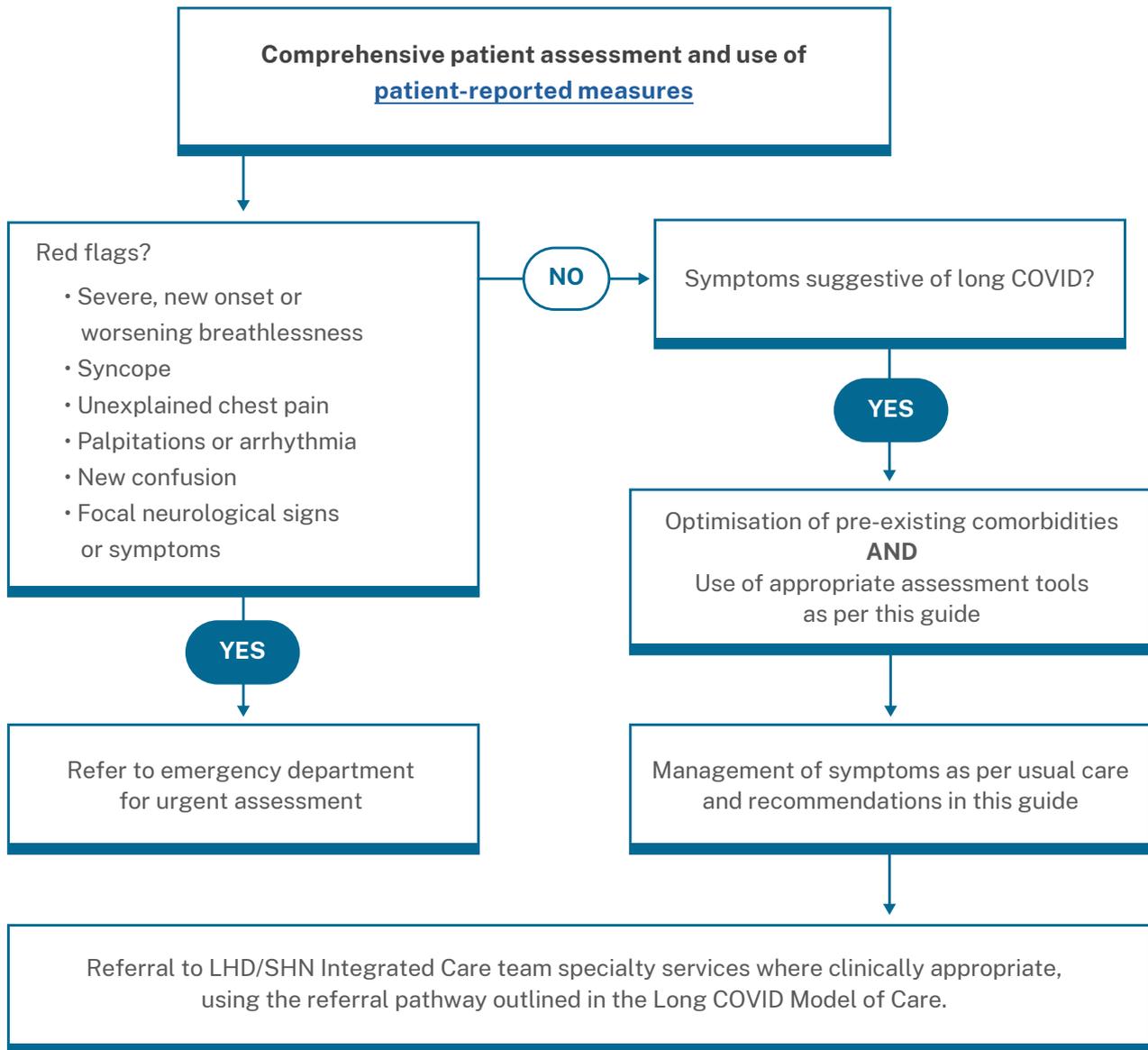
Surveys currently available in HOPE specifically for people with long COVID:

- Post COVID-19 Functional Status (PCFS)³⁶
- COVID-19 Yorkshire Rehabilitation Screen (C19-YRS)³⁷

These surveys aim to measure the severity and impact of symptoms on a patient’s level of functioning and their degree of impairment. The tools provide the clinician with information on the most burdensome symptoms so they can focus on what matters to the patient. The surveys also provide a reference point to the patient, enabling them to focus on self-reported symptoms and demonstrate progress.

These surveys are already available for use by local health district (LHD) and specialty health network (SHN) clinicians across NSW, and are currently being implemented in general practices.

Figure 1: Guide to patient assessment for symptoms of long-COVID



Symptoms

Prevalence

Calculating the prevalence of individual symptoms is challenging due to variance in the definition of long COVID, methods and time intervals for data collection, across studies. More recent studies have confounds associated with variants, vaccines and reinfection history.^{9, 38, 39}

Accordingly, this guide lists the most commonly reported symptoms of long COVID in adults, young people and children, without reference to specific prevalence rates.

Table 1 outlines the most commonly reported symptoms of long COVID in adults, young people and children.

Table 1: Most commonly reported symptoms of long COVID by symptom type¹⁵

	Adults	Children and young people
Respiratory symptoms	<ul style="list-style-type: none"> Breathlessness Cough 	<ul style="list-style-type: none"> Runny nose Breathlessness Cough Sputum production
Generalised symptoms	<ul style="list-style-type: none"> Fatigue Fever Pain 	<ul style="list-style-type: none"> Fatigue Exercise intolerance
Cardiovascular symptoms	<ul style="list-style-type: none"> Chest tightness Chest pain Palpitations Multi-system inflammatory syndrome Myocarditis Cardiovascular dysautonomia (e.g. POTS) 	
Neurological symptoms	<ul style="list-style-type: none"> Cognitive impairment (e.g. 'brain fog', loss of concentration or memory issues) Headache Sleep disturbance Peripheral neuropathy Dizziness Delirium (in older populations) Mobility impairment Visual disturbance 	<ul style="list-style-type: none"> Sleep disorders (e.g. insomnia, hypersomnia and poor sleep quality) Headache Cognitive symptoms and behavioural challenges (e.g. less concentration, learning difficulties, confusion, memory loss)
Gastrointestinal symptoms	<ul style="list-style-type: none"> Abdominal pain Nausea and vomiting Diarrhoea Weight loss and reduced appetite 	<ul style="list-style-type: none"> Loss of appetite
Musculoskeletal symptoms	<ul style="list-style-type: none"> Joint pain Muscle pain 	

	Adults	Children and young people
Ear, nose and throat symptoms	<ul style="list-style-type: none"> • Tinnitus • Earache • Sore throat • Dizziness • Loss of taste and/or smell • Nasal congestion 	<ul style="list-style-type: none"> • Nasal congestion • Altered smell
Dermatological symptoms	<ul style="list-style-type: none"> • Skin rashes • Hair loss 	
Psychological or psychiatric symptoms	<ul style="list-style-type: none"> • Depression • Anxiety • Post-traumatic stress disorder (PTSD) 	<ul style="list-style-type: none"> • Altered mood

Commonly reported symptoms for adults versus for young people and children

For the purposes of this clinical practice guide, the most commonly reported symptoms in long COVID in adults, young people and children will be explored in further detail. This guide is divided into:

- **Section A** – Common symptoms of long COVID in adults
- **Section B** – Common symptoms of long COVID in young people and children

Table 2: Most commonly reported symptoms for adults and for young people and children included in this guide

Section A: Adults	Section B: Young people and children
1. Fatigue	1. Fatigue
2. Breathlessness	2. Sleep disorders (e.g. insomnia, poor sleep quality)
3. Cough	3. Cognitive impairment (e.g. learning difficulties)
4. Depression and anxiety (noting that these are two distinct symptoms which have been grouped for the purposes of this guide)	4. Exercise intolerance
5. PTSD	5. Breathlessness, cough and excess sputum production
6. Cognitive impairment (e.g. ‘brain fog’)	6. Altered mood
7. Joint and muscle pain or myalgia	
8. Functional mobility impairment	
9. Chest pain and tightness	
10. POTS	

Section A: Common symptoms of long COVID in adults

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Red flags

The following symptoms are red flags. Patients presenting with any of these symptoms should be referred to their local emergency department for urgent assessment and treatment.

- ▶ **Focal neurological signs or symptoms**
- ▶ **Severe, new onset or worsening breathlessness or hypoxia**
- ▶ **Syncope**
- ▶ **Unexplained chest pain, palpitations or arrhythmia**
- ▶ **Delirium or new confusion**

Fatigue

Fatigue should not be assessed in isolation. Persistent fatigue is the most common long-term issue facing people with long COVID-19.⁴⁰

Post COVID-19 fatigue can be complex and may be influenced by various, multiple factors, including central, peripheral and psychological factors.⁴¹

Post-viral fatigue is usually self-limiting, resolving within several months, but the risk of its chronicity is associated with biological, social, behavioural, cognitive and emotional factors.⁴²

For some people, post-COVID-19 fatigue can be debilitating, affecting their ability to work, look after children or study. A challenging aspect of this fatigue is post-exertional malaise (PEM), where symptoms worsen after even minor physical or mental exertion; typically worsening 12 to 48 hours after activity and lasting for days or even weeks.

PEM is a central feature of other post-viral illnesses such as myalgic encephalomyelitis (ME) or chronic fatigue syndrome (CFS).⁴³

Assessment

Post-COVID-19 fatigue is often associated with respiratory symptoms, including shortness of breath and cough. The management of shortness of breath and cough is covered in more detail below.

Assessment of the pattern and character of fatigue is required to exclude other diagnoses, such as depression, anxiety, drug or substance abuse and sleep disturbance.

The assessment should explore:³²

- other potential factors leading to fatigue and loss of motivation
- the impact of fatigue on the patient's life, function and activities, such as work, education, mobility and independence.

Investigations to rule out any secondary causes of fatigue may include:⁴⁴

- routine haematology and biochemistry, including full blood count, iron studies, urea and electrolytes, thyroid function tests, liver function tests, calcium and phosphate, erythrocyte sedimentation rate, C-reactive protein and vitamin B12 measures⁴⁵
- early morning serum cortisol and a nutritional profile, if indicated, particularly if dietary history is suggestive of issues and no other abnormalities are detected via routine pathology.

Where a secondary cause of fatigue has been excluded, a validated scale or tool may be used to assess and monitor symptoms of fatigue.

These can aid in assessing progress and response to treatment.

Suitable tools include:

- [Fatigue Severity Scale \(FSS\)](#)⁴⁶
- [PROMIS-29 \(fatigue questions 13-16\)](#)⁴⁷
- [Brief Fatigue Inventory](#)⁴⁸

In those with a history of daytime sleepiness, establish a sleep history and screen for sleep apnoea.⁴⁹ If at high risk for sleep apnoea, the person should be referred for polysomnography.

Clinicians treating patients experiencing fatigue should validate and empathise with the patient's experience and adopt a biopsychosocial model for management. A supportive and experienced team is paramount.⁴²

Management

Evidence on appropriate management of post-COVID-19 fatigue is still emerging. An illustrative example is provided below under [Case Study 1: Management of Fatigue](#).

Management of fatigue associated with similar conditions, such as ME or CFS may be useful in managing COVID-19 fatigue. This includes the following:⁴²

- **Provide patient education.** Education on the pattern and behaviour pattern and behaviour of COVID-19 (and its recovery) can help to set realistic goals and timelines for return to baseline function. Explain that it will take time to recover, particularly for those people who experienced more severe symptoms of acute COVID-19 (including those treated in ICU) who may have had some deconditioning. The concept PEM should be explained carefully to patients to prevent over-exertion.
- **Treat any underlying or comorbid conditions.** Underlying or comorbid conditions may enhance symptoms of fatigue, e.g. depression. Explore the person's individual circumstances and stressors.
- **Refer people to a local multidisciplinary rehabilitation service.** People experiencing fatigue and deconditioning after a long hospital stay will benefit from a supervised rehabilitation program. Refer to the [Long COVID Model of Care](#)⁴ for information on referral pathways.

A multidisciplinary rehabilitation team will include a rehabilitation physician, allied health clinicians (including physiotherapy, occupational therapy, social work, psychology, speech pathology, and dietetics, as required) and nurses.

Older people may benefit from review in multidisciplinary geriatric medicine clinics. People who are experiencing ongoing respiratory symptoms in addition to deconditioning should be referred to their local pulmonary rehabilitation service. Further details on pulmonary rehabilitation are provided in the Section: [Triggers for referral to pulmonary rehabilitation](#).

- **Support a phased return to work or education.**³² Assist patients with discussions with their employer or educational institutions.
- **Encourage energy conservation, relaxation training and pacing strategies.** Assist the patient to set a baseline for activities that do not make symptoms worse. A graded return to activity is recommended to prevent PEM, however, this should be self-paced rather than imposed by the clinician.⁵⁰ Referral to a clinician with expertise in pacing strategies, such as an occupational therapist, pulmonary rehabilitation physiotherapist or psychologist, may be appropriate. The US Centers for Disease Control and Prevention have published resources on the management of PEM, including a [Handout for Clinicians](#)⁵¹.
- **Improve quality of rest, sleep hygiene and nutrition to help improve energy levels.** For those also experiencing weight loss and poor appetite, referral to a dietitian may be required. Sedatives should be avoided as they rarely improve the quality of sleep.⁴² The [University of New South Wales Fatigue Clinic](#) provides evidence-based, multidisciplinary healthcare for people living with fatigue conditions, including post-infective fatigue syndrome. The clinic's website contains good advice for consumers and health professionals on the recommended management of fatigue.⁵²
- **Provide links to peer support.** Peer support and the delivery of physical and psychological support in groups has been shown to be beneficial where people can help others plan their individual management strategies in response to fatigue.⁵³

Breathlessness

▶ **Severe, new onset or worsening breathlessness or chest pain – refer patient to the emergency department.**

People recovering from an acute COVID-19 illness who were admitted to hospital and required respiratory support, such as high flow oxygen, continuous positive airway pressure, or intubation, are at high risk of persistent exertional breathlessness and reduced exercise tolerance.⁵⁴⁻⁵⁶

The severity of the acute COVID-19 infection and prior health status are the main determinants of persistent changes on chest imaging and impairment in lung function associated with long COVID.⁵⁴

For some people breathlessness continues in the weeks and months after the initial COVID-19 infection, but generally will slowly improve with time. For others, breathlessness on exertion may be noted for the first time as the person slowly increases their physical activities. The sensation of breathlessness is complex and may not directly correlate with measures of respiratory function but can still be debilitating. A person can also experience the sensation of breathlessness without any measurable drop in oxygen saturation (measured by a finger pulse oximeter).

If breathlessness is getting worse or is so severe that it is affecting the ability of a person to perform their usual activities of daily living, then further investigation is usually appropriate. The presence of breathlessness at rest (without exertion), that is accompanied by persistent increased rate or work of breathing, requires medical assessment.

[Figure 2](#) outlines recommended assessment and management of persistent breathlessness post COVID-19. The recommended assessment and management is further illustrated in [Case Study 2: Management of breathlessness](#).

Assessment

The assessment of breathlessness should consider:⁵⁷

- the severity of the acute COVID-19 illness
- acute complications
- respiratory support that was required during the acute illness, for example the use of mechanical or non-invasive ventilation.

Review of a person's medical history should specifically include a review of co-morbid cardiac and respiratory disease.

A formal assessment of the severity of a patient's breathlessness should be made that includes the grading of its severity and the causality to recent COVID-19 infection, as well as change of this symptom over time.⁵⁷

Assessment tools

Dyspnoea-12 score

The [Dyspnoea-12 \(D12\)](#) is a global score of breathlessness severity that quantifies in terms of severity, physical and affective aspects of dyspnoea. It is validated in a variety of diseases.⁵⁸ In a recent study in the United Kingdom, self-reported D12 scores at follow-up were found to be more abnormal in those treated in the ICU during acute COVID-19 illness.⁵⁹

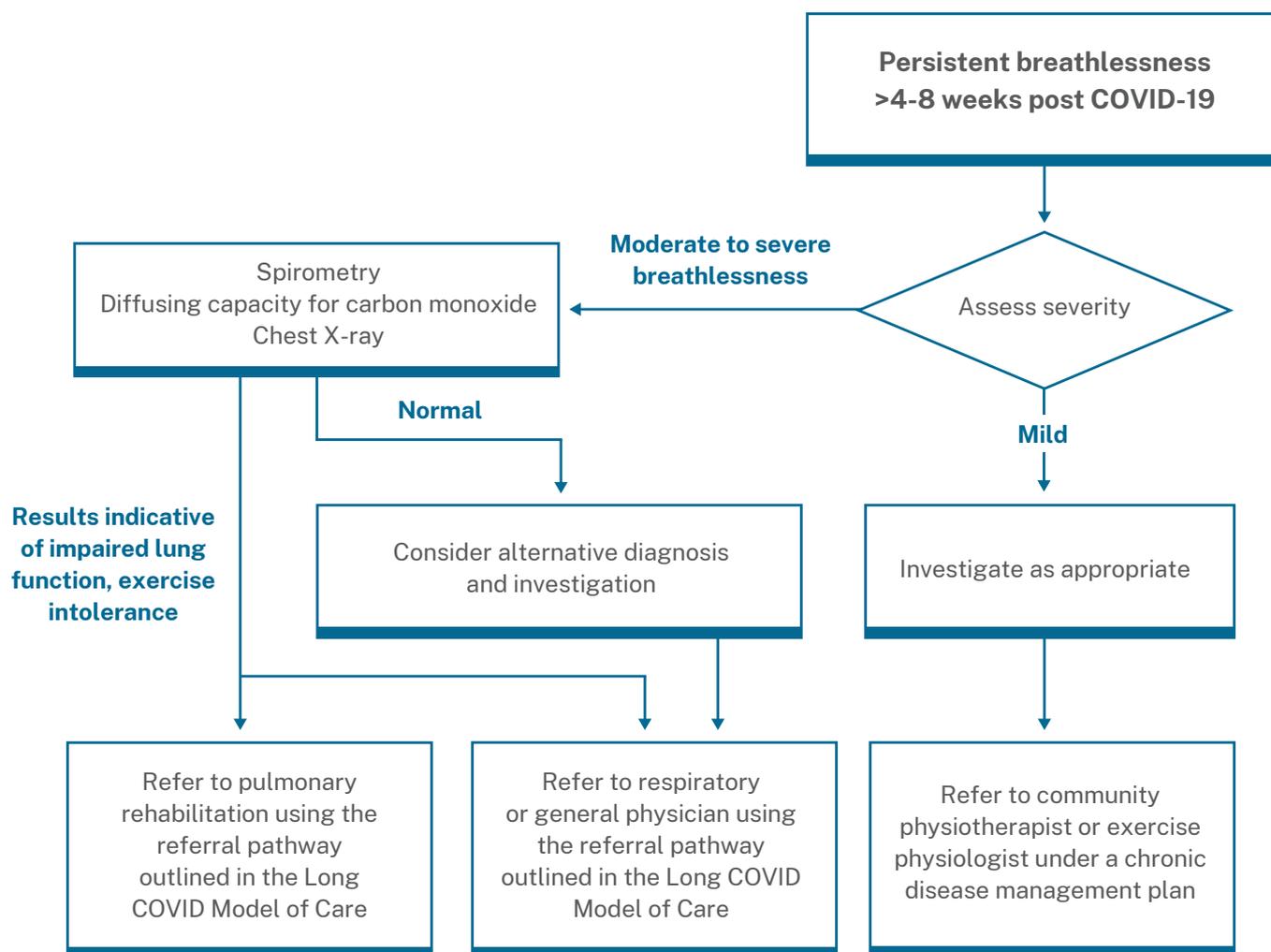
Modified Medical Research Council Dyspnoea Scale

The [Modified Medical Research Council Dyspnoea Scale](#) assesses the degree of baseline functional disability due to breathlessness, and may also be used as a comparison for future assessments.⁶⁰

Modified 0-10 Borg Dyspnoea Scale

The [Borg Dyspnoea Scale](#), while simpler to complete than the Modified Medical Research Council Dyspnoea Scale, is less responsive to assessing change as it is dependent on the activity a person is engaging in at the time of assessment. The Borg Dyspnoea Scale is usually used during or immediately after exercise as a measure of breathlessness.^{61, 62}

Figure 2: Assessment and management of persistent breathlessness post COVID-19



Persistent breathlessness

Persistent breathlessness eight weeks (or more) following COVID-19 illness should be assessed with:

- chest X-ray, which should be compared with previous chest X-rays, where available
- spirometry that is performed according to accepted European Respiratory Society and American Thoracic Society quality standards and includes pre-and post-bronchodilator (400mcg inhaled salbutamol)⁶³

- diffusing capacity of the lungs for carbon monoxide (DLCO) (a measurement of gas factor transfer).

Evidence has shown that spirometry is abnormal in only 10% of people with persistent breathlessness, and hence, all three tests should be performed.⁶⁴

Breathlessness and cardiac disease

Cardiac disease may present with worsening dyspnoea, which may be accompanied by chest pain. Consider investigations such as an electrocardiogram and echocardiogram where clinically indicated, especially in those with a history of heart disease.

Post-acute COVID-19 patients have an increased risk of myocarditis, pericarditis and coronary artery disease. The clinical assessment should consider the relative likelihood of these conditions. Further investigation and specialist referral may be appropriate.

In those with persistent breathlessness, a measure of exercise tolerance should be made with a submaximal exercise test. These tests can be performed in some lung function laboratories, by physiotherapists and in pulmonary rehabilitation programs. Clinical judgement should be exercised in recommending exercise tolerance tests in people with significant fatigue due to the risk of PEM.³²

Relevant tests include:

- Six-minute walk test with continuous monitoring of oxygen saturation and heart rate.
- Rapid exertional desaturation test, for example one minute sit-to-stand test or 40 step test.⁶⁵ This test should only be performed if oxygen saturation at rest is greater than 95%. The test should be discontinued if the patient feels unwell. If oxygen saturation decreases by 3% or more, this is indicative of significant lung disease and the patient should be referred to respiratory medicine.

Patients with persistent breathlessness, abnormal chest X-ray or lung function should be referred to the local Integrated Care team and a respiratory physician or clinic using the referral pathway outlined in the [Long COVID Model of Care](#)⁴.

In those patients with worsening of breathlessness and infiltrates on chest X-ray, consider complicating cardiac failure, or the development of interstitial lung disease.

Management

Triggers for referral to respiratory medicine

Consider referral to respiratory medicine via local Integrated Care services for all people with moderate to severe breathlessness that is limiting exercise tolerance and persistent for greater than four weeks following acute COVID-19 diagnosis.

The referring clinician should perform appropriate initial investigations **before** referral (including spirometry, DLCO and a chest X-ray). Refer to the [Long COVID Model of Care](#)⁴ for further information on referrals.

A high-resolution CT scan of the chest should not be the first screening test to assess persistent breathlessness. Aside from the cost and radiation exposure from the test, incidental abnormalities such as solitary pulmonary nodules may be found. Without the clinical need, these abnormalities may result in additional, sometimes invasive further testing.

For those people with an appropriate clinical need, the high-resolution CT scan is a valuable test to diagnose disorders such as parenchymal lung disease. Abnormalities on high resolution CT (including basal predominant interstitial infiltrates), are more commonly found in those hospitalised with acute lung disease.⁶⁶ These interstitial lung changes tend to improve with time, though may persist in a small percentage of people.⁶⁷

The clinical importance of abnormal or persistent findings on the CT should be assessed in the context of symptoms and functional impairment. In those with evidence of interstitial lung disease (persistent radiographic changes, impaired spirometry or DLCO), refer to a respiratory physician for further investigation and management.

Triggers for referral to pulmonary rehabilitation

Where there is evidence of physiological pulmonary impairment, reduced exercise tolerance and dyspnoea with exertion, especially in those that have been hospitalised for acute COVID-19, pulmonary rehabilitation may improve exercise tolerance, health-related quality of life and symptoms.⁶⁸ Evidence suggests this may lead to improved results for the six-minute walk distance.⁶⁹

The effect of pulmonary rehabilitation on breathlessness and respiratory-specific quality of life scores is not clear. Consider also the potential for traditional pulmonary rehabilitation to exacerbate symptoms of POTS or PEM.⁶⁹

Following assessment at pulmonary rehabilitation and consultation with the person, an appropriate model of rehabilitation can be offered, for example gym-based, home-based telerehabilitation, or hydrotherapy.

Pulmonary rehabilitation offers:

- individualised exercise assessment, prescription, supervised exercise training and advice on the gradual return to exercise and physical activity
- education and techniques to manage breathlessness, such as paced breathing and breathing control. Education may also include management of fatigue, including PEM, importance of exercise and physical activity, symptom management and monitoring, inhaler medication education (where applicable), smoking cessation, nutrition, psychological support, and managing cough and sputum.

The program should review people experiencing ongoing breathlessness as soon as the referral is received. Some people may only need a short program, while others, such as those who have had a long hospital or ICU stay, will need the full eight-week program.

Triggers for referral to community allied health practitioners

People with mild impairment in exercise tolerance may be suitable for treatment by a community physiotherapist or exercise physiologist, under a chronic disease management plan. Note, a second allied health practitioner or specialist must also be included in this plan under the Medicare Benefits Schedule requirements for reimbursement.⁷⁰

Alternatively, the person may be referred to a private allied health provider if financial means exist.

New onset or significantly worsening breathlessness – consideration of deep vein thrombosis and pulmonary embolism

▶ **Severe, new onset or worsening breathlessness or chest pain – refer patient to the emergency department**

In those who present with new onset breathlessness, especially if associated with pleuritic chest or pain, calf swelling and pain, and no new changes on chest X-ray, consider deep vein thrombosis (DVT) and/or pulmonary embolism (PE). A recent study has shown that following COVID-19 illness, there was a greater than two-fold increased risk of DVT and PE.⁷¹

Investigate for DVT and PE with a serum D-dimer; and if positive when adjusted for age, consider a CT pulmonary angiogram or nuclear medicine lung perfusion and ventilation scan, as appropriate.⁷²

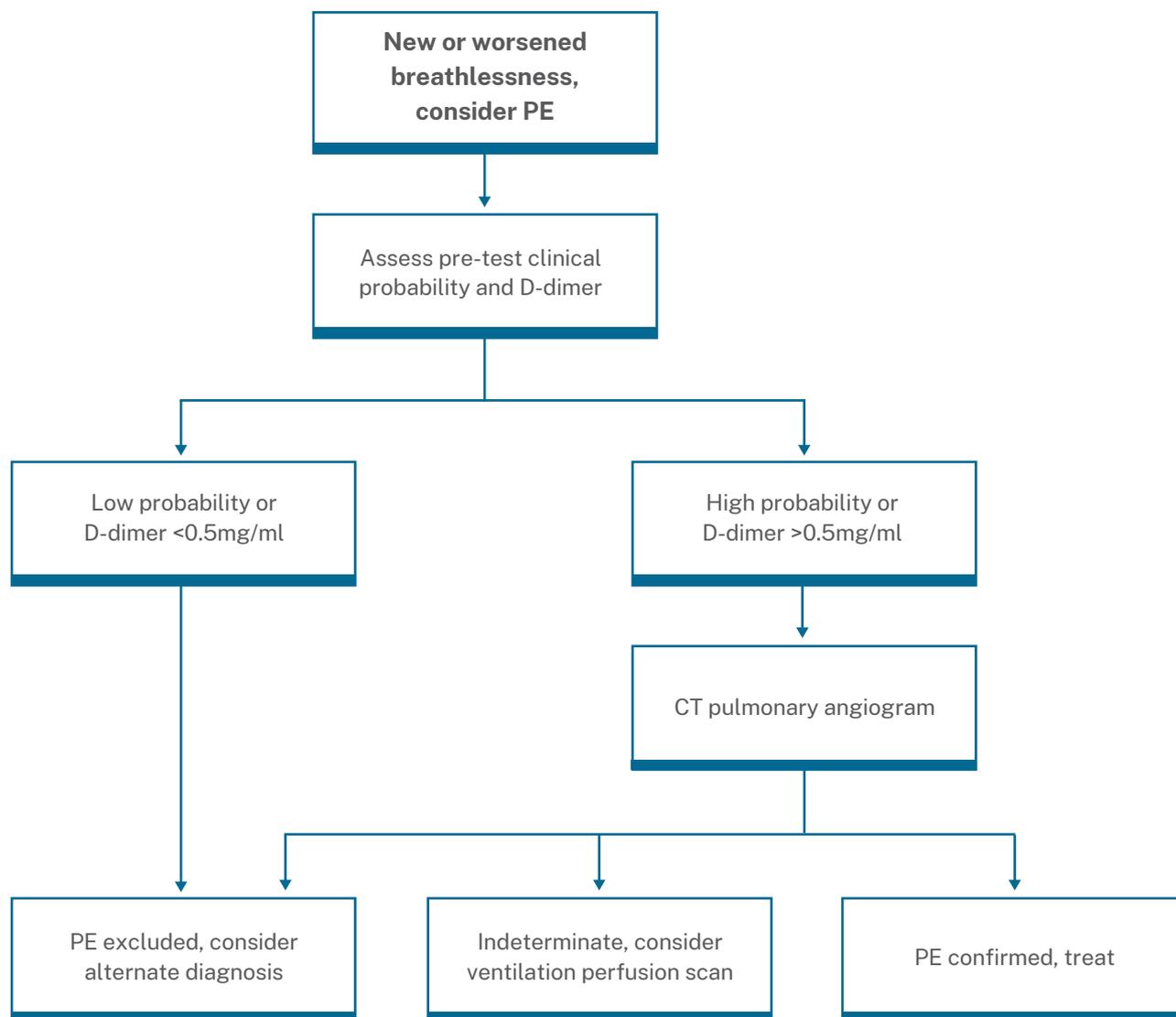
Management

In those with new onset PE or DVT, commence treatment with appropriate anticoagulation. Refer as necessary to a haematologist, respiratory physician or general physician.

In those with suspected new onset angina, atrial fibrillation or cardiac failure, initiate treatment as appropriate and consider referral to a cardiologist.

Refer all people with moderate to severe persistent breathlessness, especially those with evidence of impaired lung function and exercise tolerance, and those with pre-existing chronic lung disease, to the local pulmonary rehabilitation program using the pathway outlined in the [Long COVID Model of Care](#)⁴.

Figure 3: Suspected deep vein thrombosis (DVT) or pulmonary embolism (PE) post-COVID-19



Cough

Persistent cough is common in the first few weeks following acute COVID-19, but some people will continue to experience ongoing cough.

Assessment

- ▶ **Cough with co-existing symptoms, such as new-onset fever, dyspnoea or severe symptoms of asthma (e.g. wheeze) or severe breathlessness – refer patient to the emergency department.**

The assessment for persistent cough is similar to that described for breathlessness. The date of onset and characteristics of the cough should be confirmed.

For most people, persistent cough is dry, irritating and non-productive. If sputum is present, this should be further investigated.⁴⁴ Any co-existing symptoms should also be considered, particularly new-onset fever, dyspnoea or symptoms of asthma, e.g. wheeze, as they may indicate more urgent investigation is required.

There are several potential iatrogenic sequelae related to invasive procedures that may cause persistent cough. These include post-intubation orotracheal and post-tracheostomy irritation or sub-glottic stenosis.

The following assessments may be indicated for persistent cough:⁷³

- Spirometry (pre- and post-bronchodilator)
- Fractional exhaled nitric oxide
- DLCO
- Chest X-ray

Management

The management of persistent cough will depend on assessment findings, particularly the presence of any pulmonary abnormalities.

In the absence of any specific pulmonary findings, persistent cough is managed in a similar fashion to cough in patients with post-viral cough syndrome.

Referrals

Using the referral pathways outlined in the [Long COVID Model of Care](#)⁴, the following referrals may be indicated:

- Refer people with persistent severe cough to a respiratory physician for further assessment and management.⁷⁴ Further investigations for bronchiectasis may be indicated.

If a person is having ongoing issues with sputum production, refer to a physiotherapist with expertise in airway clearance or a pulmonary rehabilitation program. Their advice and technique may be beneficial.

Depression and anxiety

For the purposes of this guide, depression and anxiety have been grouped into a single category, noting they are two distinct symptoms which sometimes (but not always) present together.

The main risk factors associated with depression post-COVID-19 are gender (women report higher rates of depression compared to men), previous psychiatric history, psychopathology at one month follow-up, and systematic inflammation during the acute phase.^{75, 76}

One study has hypothesised the severity of depressive symptoms to be proportional to the systematic inflammation measured at baseline during acute infection.⁷⁷ Research has also shown those patients reporting depressive symptoms may also have symptoms of cognitive dysfunction post COVID-19.⁷⁸

Another key risk factor for the development of anxiety and depression post COVID-19, is uncertainty about what to expect when recovering from acute COVID-19. This highlights the need for patient reassurance, validation of symptoms, education and recommending follow-up with their GP or primary care provider.^{15, 32}

It is yet to be determined whether the high frequency of depression and anxiety post-COVID-19 is a long-term consequence of the viral infection, a consequence of the severity of other symptoms of long COVID (such as ongoing fatigue, social isolation, reduced exercise tolerance and impact on quality-of-life) or a result of the social and economic outcomes of the pandemic.⁷⁵

Assessment

The following validated scales may be used for assessment of symptoms of depression and anxiety. It is important to note that these are screening tools and should not be used on their own to make a diagnosis of clinical depression or assess severity.

- [Patient Health Questionnaire 9 \(PHQ-9\)](#)⁷⁹
- [Quality of Life in Neurological Disorders \(Neuro-QoL\)](#)⁸⁰
- [Depression, Anxiety and Stress Scale 21 \(DASS-21\)](#)⁸¹
- [Hospital Anxiety and Depression Scale \(HADS\)](#)⁸²
- [Somatic and Psychological Health Report \(SPHERE\)](#)⁸³ – this tool is particularly helpful for those suffering from persistent fatigue in addition to mental distress

Management

Treatment should be based on the severity of presenting symptoms. The NICE COVID-19 Rapid Guideline: Managing the Long-term Effects of COVID-19 recommends prompt referral to avoid delaying support for people.³² Evidence from lived experience has demonstrated that the earlier people receive help for anxiety and/or depression, the more effective the intervention.³²

Management of symptoms may include referral to specialist services as listed below under [Referrals](#), and pharmacological interventions, such as antidepressants or benzodiazepines, prescribed in accordance with HealthPathways, the [Therapeutic Guidelines](#)⁸⁴ and the [Australian Medicines Handbook](#)⁸⁵. A clinical practice guideline for mood disorders is also available from the Royal Australian and New Zealand College of Psychiatrists.⁸⁶

Evidence has found a significant reduction in anxiety following a six-week pulmonary rehabilitation program.⁸⁷ Improvements in perceived mental health, depression and anxiety have been observed following an outpatient multidisciplinary program directed at both physical and psychological reconditioning.⁸⁸

Referrals

For those with commonly reported mental health symptoms, such as symptoms of mild anxiety and/or depression, supportive counselling and close follow-up by the person's GP is indicated.

Referrals may be made to the local Integrated Care team using the pathways outlined in the [Long COVID Model of Care](#)⁴, or where financial means exist, referrals to private community-based clinicians may be available.

Psychology

A mental health treatment plan can allow a person to claim up to 10 subsidised individual and 10 group sessions per calendar year with a mental health professional, e.g. a psychologist.⁸⁹

Alternatively, online programs are available. One is [This Way Up](#), developed by St Vincent's Hospital.⁹⁰ It provides a wide range of psychological strategies to manage issues such as returning to the workplace, mindfulness and resilience tools. Other Australian online platforms include the [Black Dog Institute](#)⁹¹, [MindSpot](#)⁹², [MentalHealthOnline](#)⁹³ and [moodgym](#)⁹⁴.

Psychiatry

For those with more complex needs, referral to a consultation liaison psychiatry service or private psychiatrist may be indicated. Urgent referral to psychiatric services is available via the LHD community mental health service or via presentation to the emergency department.

Post-traumatic stress disorder

Reported rates of PTSD post-COVID-19 illness vary, but tends to be higher in those who were hospitalised during the acute phase of illness.⁹⁵ The diagnosis of PTSD, as defined in the Diagnostic and Statistical Manual for Mental Disorders, 5th Edition (DSM-V) requires exposure to a traumatic event, which is defined as "actual or threatened death, serious injury or sexual violence".⁹⁶

Some people may develop exacerbation or perpetuation of pre-existing PTSD from unrelated trauma, whereas others may have new onset PTSD following COVID-19 illness.⁹⁷ Similar incidences of PTSD have been noted in other epidemics such as severe acute respiratory syndrome (SARS), Middle Eastern respiratory syndrome (MERS) and ebola.⁹⁸

Characteristics that are associated with the development of PTSD following COVID-19 illness include female gender, history of psychiatric disorders, and delirium or agitation during acute illness.^{95,99} A greater number of persistent ongoing symptoms is also positively correlated with post-COVID-19 illness-related PTSD.⁹³

PTSD is known to be a common feature of post-intensive care syndrome, exacerbated by the use of sedation and analgesia in the ICU.¹⁰⁰

Assessment

There are two distinct diagnostic systems with differing criteria for PTSD:

- **DSM-V** includes 20 different symptoms across the domains of re-experiencing, avoidance, negative cognitions and moods, and hyperarousal⁹⁶
- **International Classification of Diseases, 11th revision (ICD-11)** includes six symptoms across three domains: re-experiencing, avoidance and hyperarousal¹⁰¹

Management and referral to psychology or psychiatric services

A comprehensive account of evidence-based treatment of new and established cases of PTSD can be found in the National Health and Medical Research Council (NHMRC) [Australian Guidelines for the Prevention and Treatment of Acute Stress Disorder, Post Traumatic Stress Disorder and Complex PTSD](#).¹⁰² A medication prescribing algorithm is included in these guidelines.

Some people experiencing PTSD may be adequately managed by their GP using some of the treatment modalities listed in these guidelines.

Other people may benefit from referral to a clinical psychologist for specific trauma-related therapy such as trauma-focused cognitive behaviour therapy, eye movement desensitisation and reprocessing, imagery rehearsal therapy or equine therapy.⁹⁷

Referral to a psychiatrist may be indicated in cases of severe, persisting symptoms impacting on functioning or where more complex pharmacotherapy advice is required. Refer to the [Long COVID Model of Care](#)⁴ for referral pathways.

Cognitive impairment ('brain fog')

- ▶ **Refer patients with new delirium, or focal neurological signs or symptoms to the emergency department or community acute mental health team for urgent review.**

A commonly reported symptom of long COVID is ongoing cognitive symptoms such as 'brain fog', confusion and loss of memory post COVID-19 illness.⁴⁰ The most affected cognitive domains were the executive functions, memory and speed of processing.¹⁰³

Risk factors associated with cognitive impairment include female gender, pre-existing cognitive impairment, frailty, increased age, hospitalisation (particularly those treated in ICU with sedatives or analgesia), acute respiratory distress syndrome during hospitalisation and delirium during acute illness.¹⁰³

Ongoing cognitive impairment may affect occupational, psychological and functional outcomes and lead to substantial detriments to quality of life.

Delirium in the context of acute-COVID-19 illness may reveal underlying dementia.

Assessment

There are a number of validated screening tools to assess for cognitive impairment, including those listed below. Each of these tools, as well as supplementary information, is available on the ACI website, [Screening and Assessment Tools for Older People](#):

- Mini-Mental State Examination (MMSE)¹⁰⁴
- Montreal Cognitive Assessment (MoCA)¹⁰⁵
- Rowland Universal Dementia Assessment Scale (RUDAS) – for people from culturally and linguistically diverse backgrounds¹⁰⁶
- Kimberley Indigenous Cognitive Assessment (KICA-Cog) – for Aboriginal and Torres Strait Islander people, particularly those living in rural and remote areas of Australia¹⁰⁷
- General Practitioner Assessment of Cognition¹⁰⁸.

One of the limitations of these tools is that they are designed for use with older people, particularly those with symptoms of dementia, and may have limited sensitivity for cognitive decline in younger populations.¹⁰⁹

Tools that may be more suitable for younger people with cognitive symptoms include:¹¹⁰

- [Digit Span Forward and Backway](#) – attention and working memory¹¹¹
- [Trail Making Test Part A and B](#) – processing speed and executive functioning¹¹²
- Hopkins Verbal Learning Test Revised¹¹³.

When using these tools, it may be useful to also consider a standard measure of intelligence quotient and a person's level of education, to help inform interpretation of the results.

It is helpful to also have the person subjectively describe their symptoms. The following terms may also be used to describe persistent cognitive impairment post-COVID-19 illness: brain fog, mental slowness, difficulty in maintaining attention and focus, executive processing problems, memory problems and learning, articulation or psychomotor coordination difficulties.

It is important to note that cognitive impairment may be secondary to other long COVID symptoms such as depression and fatigue, and a holistic health assessment is required.¹¹⁴ Assessment of cognitive impairment should be followed up by assessment of functional outcomes and quality of life, to ascertain the impact on a person's activities of daily living.

Suitable tools include:

- [EuroQol-5 Dimension \(EQ-5D-5L\)](#)¹¹⁵
- [Barthel Index](#)¹¹⁶
- [12 Item Short Form Survey \(SF-12\)](#)¹¹⁷
- [PROMIS-29](#)⁴⁷.

Management

The treatment of cognitive impairment will depend on the types of symptoms described by the person. Referral to a multidisciplinary rehabilitation program, geriatrician and/or neuropsychologist may be indicated, via the pathways outlined in the [Long COVID Model of Care](#)⁴.

The following interventions have been shown to demonstrate improvement in symptoms of cognitive impairment:

- Physiotherapist-designed or supervised individualised activity and movement program.

Cautious clinical judgment should be used in recommending exercise to people with significant fatigue, due to the risk of PEM³²

- Rehabilitation programs based on endurance and balance training have demonstrated improvements in cognition¹¹⁸
- A full medication review by a GP or rehabilitation physician, as some medications may exacerbate symptoms. For a person aged over 65, a geriatrician should be consulted
- Improved sleep hygiene
- Improved nutrition
- Neuropsychological rehabilitation strategies, usually performed by a neuropsychologist or multidisciplinary rehabilitation service. The strategies may include neuroplasticity-based therapies such as cognitive mapping, errorless learning and repetition of information^{119, 120}

Joint and muscle pain

Joint (arthralgia) and muscle pain (myalgia) and stiffness is commonly reported post-COVID-19 illness. The causes for this include, but are not limited to:

- immobility, particularly for those hospitalised and treated in ICU (including the use of neuromuscular blockage and/or sedation)
- loss of muscle mass and muscle dysfunction as a consequence of acute illness¹²¹
- proning, a common intervention for hospitalised patients, can also increase the risk of ongoing joint and muscle pain, peripheral neuropathy and compressive neuropathy
- worsening of osteoarthritis or rheumatoid arthritis due to inflammatory molecules damaging cartilage during acute COVID-19 illness
- use of steroid medications as a treatment for acute COVID-19
- new onset autoimmune polyarthropathy
- reduced levels of activity or exercise secondary to ongoing fatigue
- critical care neuropathy and peripheral neuropathy.¹²²

Pain may be localised to a particular region or be generalised and widespread.¹²³

Assessment

A full patient history should be undertaken, each involved joint inspected and palpated, and range of motion estimated. The presence of tenderness, warmth or swelling should be investigated.

Movements, time of day or activities that exacerbate symptoms should be noted.

A medication history should be obtained. The clinician should explore if the person gains relief from over-the-counter medication such as anti-inflammatory agents, topical treatments, heat or ice.

Blood tests and imaging may be required based on history and examination findings. For those with a history of rheumatoid arthritis or new onset polyarthropathy, testing of antibodies and rheumatoid factors may be warranted, with referral to a rheumatologist where indicated.

Management

In most instances joint and muscle pain experienced following COVID-19 illness will self-resolve.

Conservative management is usually adequate. Analgesia such as paracetamol or anti-inflammatories, such as ibuprofen, may be recommended. The use of heat packs may also provide relief. A physiotherapy assessment should be sought for individualised activity or movement prescription, particularly in the event of restricted range of motion or weakness.

Cautious clinical judgment should be used in recommending exercise to people with significant fatigue due to the risk of PEM.³²

If pain continues, referral to a rehabilitation medicine specialist, rheumatologist or pain specialist may be indicated, using the pathways outlined in the [Long COVID Model of Care](#)⁴.

Functional mobility impairment

Reduced mobility and functional outcomes are a commonly reported symptom of long COVID, particularly in people aged 65 years and over or those living with frailty. Examples include the reduced ability to engage in household activity, physical activity and stand up after sitting in a chair.¹²⁴

Emerging evidence suggests that even people diagnosed with mild to moderate COVID-19 can have ongoing functional challenges.¹²⁴ In older adults, without intervention, reduced mobility can result in fatigue, deconditioning and muscle atrophy which may lead to frailty.

Assessment

Consistent with the International Classification of Functioning, Disability and Health (ICF) definition, people should be asked to report changes in their mobility in three domains:¹⁰¹

- Ability to move around their home, for example standing up after sitting in a chair
- Ability to engage in housework
- Ability to engage in physical activity, for example walking up a flight of stairs without assistance

For people aged 65 years or older, the [Physical Activity Scale for the Elderly](#) may be used to assess information on leisure, household and occupational activity.¹²⁵

Triggers for referral to physiotherapy and/or occupational therapy for further assessment

Referral to a physiotherapist may be indicated for further assessments including:

- [six-minute walk test](#)¹²⁶
- [five time sit to stand test](#)¹²⁷ or [thirty second sit to stand test](#)¹²⁸
- [Berg balance scale](#)¹²⁹
- [timed up and go test](#)¹³⁰
- [Barthel index](#)¹³¹
- [functional independence measure](#)¹³².

Cautious clinical judgment should be used in recommending exercise to people with significant fatigue due to the risk of PEM.³²

Assessment by an occupational therapist will include assessment of both physical activity, function, and home environment. This is particularly important if concerns for safety of the person in their own home are present.

Management

Triggers for referral to multidisciplinary rehabilitation

For those people with significant mobility impairment, particularly associated with deconditioning, referral to a rehabilitation physician for a comprehensive multidisciplinary rehabilitation assessment and intervention is recommended.¹³³

Multidisciplinary rehabilitation may be delivered in an inpatient, day program or outpatient modality depending on symptom burden. An individualised program is provided across the continuum of care by an interdisciplinary team.¹³⁴ This rehabilitation program may involve interventions including falls prevention, muscle strengthening, balance training, training for activities of daily living (for example cooking), home assessment and cognitive mapping.

Referrals may be made using the pathways outlined in the [Long COVID Model of Care](#)⁴.

Triggers for referral to outpatient or community allied health services

In mild to moderate cases of reduced mobility, referral to an outpatient or community physiotherapist and/or occupational therapist is appropriate. Exercise prescription and education can be provided to improve functional abilities, pacing and energy conservation.

Adding in a social element via a group program, such as a falls prevention or exercise group, may improve adherence and motivation.

Cautious clinical judgment should be used in recommending exercise to people with significant fatigue due to the risk of PEM.¹⁰

Technology may be used to support self-directed exercise programs. Assessment of the safety of the home environment by an occupational therapist may include recommendations for home modifications or assistive technology, where required.

Referrals may be made to private, community-based practitioners (where financial means exist) or via the referral pathways outlined in the [Long COVID Model of Care](#)⁴.

Chest pain and tightness

▶ **Syncope, unexplained chest pain, palpitations or arrhythmias – refer patient to the emergency department for urgent assessment**

Evolving evidence has shown that persistent chest pain is one of the most common long-term symptoms in patients who have had a confirmed COVID-19 infection.¹³⁵ Persistent cardiac symptoms including chest pain, palpitations, and tachycardia for up to six months indicate underlying cardiovascular complications.¹³⁶ However, the clinical priority is to thoroughly investigate patients who present with chest pain and differentiate non-specific chest pain from life-threatening complications.¹³⁷

Post-acute sequelae of COVID-19 (PASC)-cardiovascular syndrome is defined as a heterogeneous disorder that includes widely ranging cardiovascular symptoms, without objective evidence of cardiovascular disease using standard diagnostic testing.¹³⁸ Common symptoms include chest pain, dyspnoea, palpitations, exercise intolerance, orthostatic intolerance and PEM.

An increased risk of myocarditis and pericarditis has been found in patients who were diagnosed with a COVID-19 infection.⁷¹ In the 12 months following acute COVID-19 illness, a large veteran cohort in the United States demonstrated an increased risk of ischemic heart disease, including acute coronary disease, myocardial infarction, ischaemic cardiomyopathy and angina.⁷¹ An increased incidence of arrhythmias including atrial fibrillation is also reported post COVID-19 diagnosis.⁷¹

There is a potential overlap between cardiopulmonary symptoms of long COVID and deconditioning attributable to acute COVID-19 illness.¹³⁹

Assessment

Most cases of chest pain following COVID-19 infection are self-limiting, however it is important to ensure a thorough emergency assessment for any patient presenting with acute cardiac chest pain. Consider other diagnoses in patients presenting with acute chest pain, including acute coronary syndrome, pulmonary embolism and arrhythmias; and further investigate and treat as appropriate.

New-onset chest pain should be evaluated in the emergency department using the [New South Wales \(NSW\) Health Guideline Pathway for Acute Coronary Syndrome](#).¹⁴⁰

This pathway recommends the use of:

- serial electrocardiograms and troponin testing to risk stratify patients into groups requiring invasive angiography or suitable for non-invasive testing with exercise stress testing
- CT coronary angiography or stress echocardiography, depending on local availability and patient factors.

Further evaluation of chest pain should include echocardiography to investigate left ventricular function, exclude regional wall motion abnormalities and exclude the presence of pericardial effusions.¹⁴¹

Refer to the [Australian Clinical Guidelines for the Management of Acute Coronary Syndromes](#) for further guidance as required.¹⁴²

Management

Management of chest pain post COVID-19 is dependent on the cause identified using the [Pathway for Acute Coronary Syndrome](#)¹⁴⁰ evaluation. Clinicians should follow the Heart Foundation of Australia and Cardiac Society of Australia and New Zealand's [Australian Clinical Guidelines for the Management of Acute Coronary Syndromes](#)¹⁴².

In the majority of cases, no concerning cause is identified, and the management is supportive. For patients without evidence of ischaemia, management may include a 1-2 week trial of non-steroidal anti-inflammatory drugs (NSAIDs) with addition of low-dose colchicine, as required. Notably, if the symptoms worsen with NSAIDs, oesophagitis and oesophageal spasm should be considered.¹³⁸

For competitive athletes, return to sport following long COVID should be guided by whether cardiopulmonary symptoms are still present. If symptoms are still persisting and PASC-cardiovascular syndrome is excluded, structured and individualised graded exercise is recommended during the recovery process.¹³⁸

The use of specific therapeutic agents for management of cardiovascular symptoms, including angiotensin-converting enzyme (ACE) inhibitors, remains investigational with no supporting evidence from clinical trials currently available.¹⁴³

Postural orthostatic tachycardia syndrome (POTS)

POTS, or tachycardia on standing, is a form of dysautonomia (autonomic nervous system dysfunction), which is commonly reported by patients with long COVID.

Patients will generally report symptoms of dizziness, light headedness or palpitations. It is common for palpitations to occur as a result of deconditioning after prolonged inactivity during the acute COVID-19 illness. Psychological distress may also lead to heart palpitations in people who have recovered from COVID-19.¹⁴⁴

The diagnostic criteria for POTS are:¹⁴⁵

- upright or standing heart rate change sustained for 10 minutes in the absence of hypotension, evidenced by:
 - an increase in heart rate (greater than or equal to 40bpm in person 12-19 years of age **OR** 30bpm in adults aged 20 or older)
 - **OR** an increase in heart rate to more than 120bpm (any age).

Assessment

In the assessment of POTS it is important to screen for alternative causes for tachycardia, including pulmonary embolism, sepsis, thyroid disease, dysrhythmias and anxiety. Investigations should be tailored to history and clinical findings.¹⁴⁵

Where appropriate, consider:¹⁴⁵

- ECG
- 24-hour ECG
- 24-hour ambulatory blood pressure or heart rate
- chest X-ray
- echocardiogram
- blood tests.¹⁴⁵

In primary care, the following tests may also be indicated:¹⁴⁵

- Active stand test
- NASA lean test

Referral to a specialist service for a head up tilt test may be indicated.¹⁴⁵

Management

The evidence-base in the management of POTS, in the context of long COVID, is limited. There is a lack of robust evidence about the effectiveness of some therapies.¹⁴⁶

Management of post-COVID-19 POTS is complex. Referral to a cardiologist with experience in managing POTS is recommended. Referral may be made using the pathways outlined in the [Long COVID Model of Care](#)⁴.

Current suggested management guidelines include a variety of non-pharmacological and pharmacological interventions.¹⁴⁷

Table 3: Suggested treatments for postural orthostatic tachycardia syndrome (POTS)

Pharmacological	Non-pharmacological
<ul style="list-style-type: none"> • Alpha and beta blockers • Anticholinesterase inhibitors • Ivabradine • Peripheral vasoconstrictors • Central adrenergic blockers • Volume expanders 	<ul style="list-style-type: none"> • Compression hosiery • Replace fluid: 2-3L/day • Sleep optimisation • Salt: 10g/day unless contraindicated • Relaxation techniques such as yoga • Sleep optimisation

Source: BMJ Infographic Orthostatic tachycardia after COVID-19¹⁴⁵

Patients should try to identify and avoid triggers.

A graduated return to activity is recommended:

- starting with recumbent or semi-recumbent exercise, such as cycling, swimming or rowing
- with patients moving on to exercise in an upright position once the ability to stand improves.¹⁴⁷

Cautious clinical judgement is required when recommending exercise to patients with PEM.³²

Case study 1: Management of fatigue

Demographics	54 years old, male, non-Aboriginal (Sam)
Social	Works full time as a financial analyst with a major bank. Lives with his wife and 14-year-old son in Newcastle.
Medical history	Non-smoker, occasional consumption of alcohol (beer). BMI 40.

Sam was diagnosed with COVID-19 in April 2022 after visiting family in Hawaii. Sam experienced a sore throat and runny nose.

Sam returned to work seven days later. He observed his thinking was slowed and he was unable to calculate financial information as easily as before. He was unable to interpret a report he had written prior to his trip to Hawaii, and he felt exhausted at the end of each day. Sam discussed the challenges he was experiencing with his supervisor, however due to his workload, Sam persevered with working full time for the next two weeks. Sam's fatigue worsened and he decided to take one week off work.

Sam started his own exercise program, believing that if his fitness improved, his fatigue would improve. Sam experienced sleep disturbance, often waking in the middle of the night and being unable to get back to sleep. He also reported several episodes of dizziness to his GP. Sam expressed frustration and distress at his inability to resume his usual activities and the impact this was having on his family and colleagues.

Assessment and management

Sam's GP undertook routine blood haematology and chemistry – all of these results were normal. The GP asked Sam to keep a diary, recording sleep patterns and activity, to try to identify triggers for fatigue. The GP also provided reassurance and support to Sam, validating his experience.

Sam continued to experience symptoms for 12 weeks after his COVID diagnosis. He returned to his GP who conducted the COVID-19 Yorkshire Rehabilitation Screen tool to identify the most troublesome of symptoms. Based on the results of this screen, the GP undertook the following interventions:

- Referral for polysomnography, given Sam's sleep disturbance and high BMI as a risk factor for sleep apnoea
- Prescription for antidepressant medication and referral to a community-based clinical psychologist under a mental health care plan to manage symptoms of low mood and low motivation

Using the referral pathways outlined in the [Long COVID Model of Care](#)⁴, Sam was referred to the local Integrated Care team.

The Integrated Care team started health coaching and referred Sam to a local occupational therapist to assist with pacing and energy conservation strategies. Sam also saw a physiotherapist who prescribed an individualised exercise program designed to minimise the risk of PEM.

Together, Sam's treating team, along with his GP, developed a phased return to work plan which was negotiated with his employer. Sam returned to work five months after his acute COVID-19 infection.

Case study 2: Management of breathlessness

Demographics	42 years old, female, non-Aboriginal (Jenny)
Social	Works full time as a high school teacher. Divorced, living with her three young children in Wollongong, NSW.
Medical history	Non-smoker, occasional consumption of alcohol. History of back pain due to car accident 10 years ago managed with regular physiotherapy and massage. Attends gym regularly.

Jenny was diagnosed with COVID-19 in June 2022. Her three children also contracted COVID-19 at the same time. During the acute phase of the illness, Jenny experienced fevers, chills, muscle aches and a cough. Jenny returned to work two weeks later once all her children returned to school.

Jenny continued to experience breathlessness which was particularly noticeable when required to speak for prolonged periods while teaching. She found it challenging to climb the stairs at school. Jenny also began to experience intermittent palpitations which she described as a feeling of 'flutter' in her chest. She reported a sense of tightness across the chest at times.

Assessment and management

Jenny saw her GP six weeks after acute COVID-19 illness. Her GP undertook baseline biochemistry and haematology, which was all normal. Her ECG showed sinus rhythm and tachycardia, and her blood pressure was within normal limits. Her GP provided validation and reassurance to Jenny, recommending she pace her activities and avoid strenuous physical activity where possible.

Jenny continued to experience ongoing symptoms and returned to her GP six weeks later. At this time, the GP referred Jenny for the following tests, using the referral pathways outlined in the [Long COVID Model of Care](#)⁴:

- Chest X-ray
- Holter monitor
- ECG
- Spirometry
- DLCO

No abnormalities were detected, however Jenny continued to experience ongoing symptoms. Her GP referred her to a respiratory physician who ordered a ventilation/perfusion (VQ) scan. The VQ scan showed bilateral mismatched perfusion defects consistent with a pulmonary embolus.

Jenny started anti-coagulant medication (Apixaban). Her symptoms gradually resolved over the next four weeks.

Section B: Common symptoms of long COVID in children and young people

As with adults, there is no specific diagnostic test or biomarkers to diagnose long COVID in children and young people under the age of 16 years. Diagnosis is made by excluding other potential comorbid or contributing factors.

Symptoms of long COVID in young people and children should not be assessed in isolation and often co-exist with other symptoms or pre-existing concerns, unrelated to acute COVID-19 illness. Assessment and management strategies for symptoms are interrelated.

For Section B, management of symptoms has been collated into a single section for ease of use and to avoid duplication.

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Children and young people are more likely to be asymptomatic or develop mild illness with an acute COVID-19 infection, compared to adults. Symptoms of long COVID and their impact may differ to adults. Symptoms described in children and young people are non-specific and can occur with other childhood infections and illnesses.^{3,148}

The impact of symptoms of long COVID on the functional status of children and young people can be wide-ranging. Children and young people and carers report changes in eating habits, physical activity, participation in sport and other activities, behaviour, school attendance and performance, maintenance of social roles and learning difficulties.

The cause of symptoms can be multifactorial and may be related to the COVID-19 pandemic and lockdowns such as social isolation, anxiety and depression and home-based schooling, rather than the COVID-19 illness itself.¹⁴⁹ Pre-existing conditions (both diagnosed and undiagnosed) may be exacerbated by the new symptoms, particularly in the areas of cognitive and functional capacity and abilities.

Long COVID in children and young people tends to be more common in older children and adolescents, females, those with allergies or other chronic underlying conditions, and in those with more severe symptoms during the acute phase of COVID-19 illness.¹⁵⁰

Long COVID in children and young people is distinct from paediatric inflammatory multisystem syndrome (PIMS-TS) or multisystem inflammatory syndrome in children (MIS-C), a paediatric hyperinflammatory disease phenotype with features of Kawasaki disease and toxic shock syndrome which typically occurs two to four weeks after acute COVID-19 infection.¹⁵¹⁻¹⁵⁶

Assessment and screening tools

The assessment and management of symptoms of long COVID in children and young people can be more challenging than in adults, due to the need to consider the developmental trajectory of skills during childhood and adolescence. Age-based, norm-referenced, standardised screening and assessment tools should be used.

Comprehensive patient assessment

Regardless of the care setting in which a young person or child presents with symptoms of long COVID, a holistic, person-centred approach to assessment is required. Where possible, assessment should also be family-centred and involve a parent or carer.

A comprehensive clinical history and examination should include:

- history of acute COVID-19 illness, including any reinfections (suspected or confirmed)
- the nature and severity of previous and current symptoms (this should include documentation of objective markers of disease severity such as requirement for hospital admission and the use of oxygen therapy)
- timing and duration of symptoms since the onset of acute COVID-19 illness
- history of any other health conditions
- exacerbation of pre-existing conditions
- assessment of any relevant family history, social circumstances and current stressors
- COVID-19 vaccination status

For young people aged 12-24, the [NSW Health Youth Health and Wellbeing Assessment Guideline](#)¹⁵⁷ (GL_2018_003) and corresponding flow diagram presents current best practice for conducting a youth health and wellbeing assessment. This assessment is a holistic, flexible approach designed to build rapport and engage with a young person in a clinical setting.

The most commonly used assessment tool is a HEEADSSS assessment (**H**ome; **E**ducation and **E**mployment; **E**ating and **E**xercise, **A**ctivities, **H**obbies and **P**eer Relationships; **D**rug Use, **S**exual activity and sexuality, **S**uicide, self-harm, depression, mood and sleeping patterns, **S**afety and spirituality).¹⁵⁷

A resource for GPs providing this assessment is also available.¹⁵⁸

There are a number of validated tools that can also be used to assess the impact on symptoms on multiple domains of wellbeing – further detail is given in [Appendix 2](#). However, the mainstay of assessment, particularly for non-paediatric specialist clinicians, remains comprehensive patient assessment.

Engagement with schools

For school-aged children, a review of cognition and learning difficulties should be done in the first instance, in partnership with the child or young person's school. Consent of a parent or carer is required.

It is important for the primary care provider to engage early with the school. The school should provide information on the impact of the child's symptoms. The primary care provider should be available for the school to contact for advice, and for case conferencing with the school, child or young person and parents and carers, as required.

Support by the school may include a phased return to full-time school attendance, special consideration for assessments or use of a learning support officer or teacher's aide.

Fatigue

As with adults, fatigue in children and young people should not be assessed in isolation and may overlap with other symptoms such as sleep disturbance, anxiety and depression. Fatigue in children and young people may present in many ways such as drowsiness, inability to concentrate, school avoidance and a reluctance to participate in previously enjoyed activities.

Assessment

Underlying causes for fatigue should be explored by the primary care provider.

Assessment of the pattern and character of fatigue is required to exclude other diagnoses, such as depression, anxiety, and sleep disturbance. The assessment should consider other potential factors contributing or leading to fatigue and loss of motivation.¹⁴⁹

The impact of fatigue on the child or young person's life, function and activities, such as school and sport and other activity participation, should be explored. A symptom diary may be used to track fatigue, to try to identify any precipitating or triggering factors.

Investigations for fatigue to rule out any secondary causes may include routine haematology and biochemistry, including full blood count, iron studies, urea, calcium and electrolytes, thyroid function tests and vitamin B12 and folate measures.⁴⁵ A nutritional profile may also be indicated, particularly if dietary history is suggestive of issues and/or no other abnormalities are detected via routine pathology.⁴⁴

Where the presence of any secondary cause of fatigue has been excluded, a validated scale or tool may be used to assess and monitor symptoms of fatigue. Refer to [Appendix 2](#) for suggested tools.

Sleep disorders

Sleep disorders, including insomnia, excessive daytime sleepiness (hypersomnia) and poor sleep quality, are commonly reported by children or young people with long COVID.^{159, 160} The impact of sleep disorders on energy levels, ability to concentrate, behaviour and quality of life can be significant.

Sleep disorders have significant overlap with fatigue and cognitive impairment and are often difficult to differentiate.

Assessment

As with fatigue, underlying causes of poor sleep should be explored – these may include excessive use of electronic devices, caffeine and sugar intake, and anxiety. The corresponding use of medication which may promote sleepiness, e.g. anti-seizure medication, should also be explored.

A symptom diary may assist in determining underlying causes and triggers. The child or young person and their parent or carer should also be asked about sleep patterns and quality prior to acute COVID-19 diagnosis, to determine any pre-existing issues with sleep.¹⁶¹ Suggested screening tools that may assist are listed in [Appendix 2](#).

Cognitive impairment and learning difficulties

Poor concentration, challenges with executive functioning, processing speed and working memory are some of the symptoms described by children and young people with long COVID.¹⁶² Behavioural challenges such as hyperactivity, inattention and impulsivity may also be present.

These symptoms may be made worse by fatigue and sleep disturbance. The impact of these symptoms on behavior and mood, motivation to participate in school, academic performance and overall quality of life can be significant.

Assessment

Underlying causes of apparent cognitive impairment should be explored. These may include poor sleep quality, mental health issues such as anxiety or depression, substance use, changes in social or family circumstances, among others. Some cognitive issues such as poor concentration and learning difficulties may be pre-existing and worsen following an acute COVID-19 diagnosis.

Assessment of cognition and behaviour in children and young people, without engaging a specialist in these areas, can be particularly challenging given the different age and developmental norms.

Chosen screening tools should consider the validated age range.

Consultation with a paediatric clinical neuropsychologist may be indicated to determine:

1. The most appropriate screening tool to be used;
- OR**
2. Whether more comprehensive assessment is required.

Suggested screening tools are included in [Appendix 2](#).

Exercise intolerance

Exercise intolerance in children and young people may overlap with other similar symptoms such as fatigue, sleep disturbance and breathlessness. Exercise intolerance may present as a limited ability to perform activities of daily living, play with peers or participate in sports programs. Symptoms may be increased by triggers such as prolonged physical exertion, stress, hunger and dehydration.¹⁶³

Assessment

Assessment tools will vary depending on the symptoms associated with the exercise intolerance. The clinician should discuss the nature of the exercise intolerance with the child or young person and their parent or carer to identify the nature and character of the exercise intolerance.

For exercise intolerance related to fatigue and sleep disturbance, refer to relevant sections above. Assessment of breathlessness is detailed below. Other assessment tools that may assist are listed in [Appendix 2](#).

Breathlessness, cough and excess sputum production

▶ Severe, new onset or worsening breathlessness or chest pain – refer patient to the emergency department.

Children and young people may report ongoing respiratory symptoms such as breathlessness, cough and excess sputum production (with or without nasal congestion). Symptoms may be episodic, occur on exertion only or continuous.

Assessment

The assessment of respiratory symptoms in children and young people is similar to that of adults. As is the case with adults, it is important to note that symptoms may persist in the absence of abnormal findings.¹⁶⁴

The assessment of breathlessness should consider the severity of the child or young person's acute illness, acute complications and the respiratory support that was required during the acute illness,

where relevant. Pre-existing respiratory conditions such as asthma should also be considered.

Suitable assessment tools to ascertain the severity of symptoms include:

- [Paediatric Dyspnoea Scale](#)¹⁶⁵
- [Dalousie Dyspnoea and Perceived Exertion Scales](#) (pictorial version available)^{166, 167}
- [6-minute walk test](#) (with reference to age-based norms)¹⁶⁸⁻¹⁷¹

Investigations may include:

- Chest X-ray, which should be compared with previous chest X-rays, where available
- Spirometry (which can be reliably performed for children aged six or older)¹⁷²
- DLCO (a measurement of gas factor transfer)

Management

Persistent breathlessness eight weeks (or more) following COVID-19 illness should be investigated by a paediatric respiratory physician. Referrals may be initiated via a private provider or via the pathway outlined in the [Long COVID Model of Care](#)⁴.

Altered mood

Children and young people may experience long COVID symptoms of altered mood, such as depression, anxiety and challenging behaviours.¹⁵⁹ As with other symptoms in children and young people, these symptoms may overlap with others.¹⁵⁹ For example, a child or young person may exhibit signs of depression due to fatigue, or anxiety due to disturbed sleep patterns.

Behavioural challenges such as irritability, impulsivity, school refusal and aggression may be worsened by or contribute to other symptoms such as fatigue and sleep disturbance. It is also challenging to determine if symptoms of altered mood are a consequence of a previous acute COVID-19 infection or a consequence of the tremendous stress associated with the pandemic itself (including social isolation, home-schooling and family pressures).^{149, 159}

Children and young people with pre-existing diagnoses of depression, anxiety and neurodevelopmental disability may experience a deterioration of symptoms or behavior as they recover from acute COVID-19.

Assessment

The clinician should comprehensively assess the child or young person for symptoms of altered mood, with both the patient (for those old enough to be able to self-report) and parent or carer, to obtain a complete picture of the clinical situation.

Clinicians completing a psychological evaluation of a child or young person should evaluate psychosocial function using validated assessment tools. It is important for the following domains to be assessed: functioning across school, social and family settings, with attention to prior learning, developmental and mental health diagnoses (where relevant).¹⁶⁴

Suitable assessment tools are outlined in [Appendix 2](#).

Management

For children and young people with long COVID, the role of parents and carers is important. They should continue to provide a nurturing environment and maintain the child or young person's daily routine as much as possible.

The focus of management of long COVID for a child or young person should be on planning an individualised, goal-directed return to baseline physical, cognitive, academic and social activity.¹⁶⁴ This should be family-centred, supportive and include validation for the child or young person's experience.

Management strategies should include:

- **Development of pacing and energy conservation strategies** for common activities such as school, social and sporting events. Considerations include:
 - using cautious clinical judgement when prescribing exercise for patients with PEM¹⁶⁴
 - developing a reconditioning program including aerobic exercise (for those without PEM)
 - consulting an exercise physiologist or physiotherapist
 - using an exertion scale to assist with estimating the level of exertion^{167, 173}
 - using an activity diary to assist with identifying triggers to fatigue.

- **Optimisation of nutrition status** (including use of supplements if required) and correction of any underlying nutritional deficiencies.
- **Giving advice on achieving adequate sleep**, including:
 - promoting regular sleep and wake times
 - minimising the use of electronic devices and other sources of blue light before bed
 - reducing sugar and caffeine intake, where applicable
 - age-appropriate bedtime rituals
 - minimising exciting or strenuous activities prior to bed
 - for older children and adolescents, restriction of naps to 20 minutes and not after 3pm
 - sufficient physical activity before bed
 - considering pharmacotherapy such as melatonin, for those with severe sleep disorders. Advice from a paediatrician or paediatric sleep physician may be required to ascertain safety and dosage.
- **A gradual return to cognitive activity**, such as:
 - a phased return to full-school hours, as negotiated with school
 - additional support by the school, e.g. the provision of a learning support officer, special considerations for assessments and exams, scheduled rest periods.
- **Planning emotional and wellbeing support**, such as:
 - cognitive behavioural therapy to treat anxiety and mood disorders through the development of skills to “reduce physiological arousal, redirect attention, challenge automatic thoughts, and activate problem solving skills”¹⁶⁴
 - behavioural activation focusing on intentional engagement in enjoyable activities
 - acceptance and commitment therapy
 - activities with peers to reduce social isolation.

An example of these management strategies is provided in [Case Study 3](#).

Referrals to specialist services

For a child or young person with ongoing, difficult to control symptoms that are not responsive to the management strategies outlined above, referral to a paediatrician or adolescent medicine service may be indicated. Referral can be made to a private provider or via the pathway outlined in the [Long COVID Model of Care](#)⁴.

Where symptoms of altered mood interfere with daily functioning and quality of life, additional support and psychological intervention may be required, e.g. school counsellors, youth mental health organisations such as Headspace, family counselling services and peer support youth groups.

Case study 3: Management of a young person with symptoms of long COVID

Demographics	14 years old, female, non-Aboriginal (Sasha)
Social	In Year 8 at school. Lives with her parents and younger sister in suburban Sydney.
Medical history	No underlying medical conditions. Has met all developmental milestones.

Sasha contracted COVID-19 in November 2022, most likely from her school friends. During the acute phase of the illness, Sasha experienced a mild fever for two days and a runny nose and cough for three days. She returned to school 10 days post-infection, as she missed her friends, but stated she did “not feel quite right”.

Over the coming weeks, Sasha’s parents noticed that Sasha seemed excessively tired. She would need to go to bed most afternoons after school and started missing one to two days of school a week.

Sasha’s teacher contacted her parents to advise she had fallen asleep in class on one occasion. Sasha reported she was having difficulty concentrating at school and she stopped attending her weekly dance class which she had previously enjoyed.

Despite her fatigue, Sasha’s sleep quality was poor, and she would often wake multiple times per night. Sasha’s parents observed that her mood was low, she was becoming increasingly withdrawn and became anxious about seeing people and going to crowded places. Sasha also reported frequent headaches and occasionally complained of feeling dizzy.

On one occasion, Sasha needed to sit down in the middle of the aisle in a grocery store due to dizziness. Sasha told her parents she felt like her heart was racing.

Assessment and management

Despite rest, Sasha’s symptoms did not improve, so her parents took her to the family GP for assessment and advice.

The GP took a thorough patient history to exclude any concerning other symptoms, e.g. chest pain, syncope and abnormal movements. The GP explained to Sasha and her parents that some people developed persistent symptoms post-COVID-19, but that these could improve with time and support.

The GP performed a thorough examination, including cardiovascular, respiratory, neurological and gastrointestinal. In particular, the GP assessed blood pressure and heart rate both lying and then standing (at 1 and 10 minutes), noting any changes. A urinalysis and finger prick blood glucose level were performed.

The GP spoke with Sasha separate from her parents to perform a psychosocial history and no further concerns or stressors were identified.

The GP arranged for routine blood tests to exclude anaemia and iron deficiency, check thyroid function, and ensure normal blood electrolyte levels including calcium. A 12-lead ECG was performed and was normal.

The GP provided verbal and written advice about symptoms of long COVID and self-management, including advice on sleep hygiene, pacing and energy conservation and nutrition.

With the family’s permission, the GP contacted the school’s assistant principal to provide feedback on a diagnosis of probable long COVID and the need for potential assistance with flexible school attendance. The GP discussed the likelihood of recovery over the coming months and booked a follow-up appointment with Sasha and her parents in one month’s time.

The GP emphasised ‘[red-flags](#)’ for re-assessment sooner, and the possibility of a paediatrician referral if the situation was not improving over time.

Sasha returned to the GP one month later and reported an improvement in symptoms and mood. Over the coming three months, she gradually returned to full-time school attendance and resumed her dance classes and social activities.

Appendix 1: Self-management resources and support for wellbeing and sleep

The following is a non-exhaustive list of online resources and apps for use by children and young people with mild to moderate symptoms, and their parents and carers, for the purpose of self-management.

Service	About	Age group
Head to Health	Australian Government Department of Health and Aged Care website with free or low-cost digital mental health resources from trusted service providers. Includes online forums, phone, chat and email services, and apps	<ul style="list-style-type: none"> All ages of children and young people Parents and carers Health professionals
KidsHelpline Phone: 1800 55 1800	Free and confidential 24/7 online and phone counselling service	<ul style="list-style-type: none"> Ages 5-25 Parents and carers Schools and teachers
Niggle	A free app developed by KidsHelpline and Queensland University of Technology to support mental and physical health, relationships and school	<ul style="list-style-type: none"> Ages 5-25 Parents and carers
headspace	Australia-wide organisation with online information about emotional wellbeing of people aged 12-25 years. Also provides support in person, phone or online for mild-moderate mental health issues	<ul style="list-style-type: none"> Ages 12-25
Brave	A free interactive online program for the prevention and management of anxiety	<ul style="list-style-type: none"> Ages 3-17
iBobbly	A social and emotional wellbeing self-help app for young Aboriginal and Torres Strait Islander peoples aged 15 years and over, developed by the BlackDog Institute	<ul style="list-style-type: none"> Ages 15+
Sleep Health Foundation	A not-for-profit charity that aims to raise community awareness about the value of sleep and its common disorders. Includes a series of resources for adults, children, young people and school teachers	<ul style="list-style-type: none"> All ages Parents and carers School teachers Health professionals
Sleep Ninja	A free, evidence-based app developed by the BlackDog Institute to assist young people with sleep problems, based on Cognitive Behavioural Therapy for Insomnia (CBT-I)	<ul style="list-style-type: none"> Ages 12-16
WHO: self-management of long COVID for adolescents	A comprehensive leaflet that provides advice to help adolescents understand and manage their long COVID, e.g. managing activities of daily life and education	<ul style="list-style-type: none"> Ages 12 years and over Parents and carers

Appendix 2: Validated assessment tools for children and young people

Tool	Description	Applicable long COVID symptoms	Suitable age groups	Further information
PROMIS 25+ Translated versions	Assesses six domains over the past seven days: <ul style="list-style-type: none"> • Depressive symptoms • Anxiety • Physical function-mobility • Pain interference and intensity • Fatigue • Peer relationships 	<ul style="list-style-type: none"> • Fatigue – Items 17-20 • Sleep disorders – Items 21-24 • Altered mood – Items 13-16 	<ul style="list-style-type: none"> • Self-report: ages 8-17 • Parents and carers of child ages 5-17 	<ul style="list-style-type: none"> • Available for use without license • Available in multiple languages
Functional disability inventory (FDI)	15 items to assess difficulties in participating in activities due to physical health over past three months	<ul style="list-style-type: none"> • All (to assess overall symptom burden) 	<ul style="list-style-type: none"> • School-aged children and adolescents • Parent proxy form available 	<ul style="list-style-type: none"> • Available for use without license • Available in multiple languages • Provides an overall total score – requires clinicians to assess specific areas to determine symptom burden • Tool is sensitive to changes in patient status due to medical treatment
Paediatric quality of life scale (Peds QL)	Multiple versions available to assess impact of symptoms on quality of life: <ul style="list-style-type: none"> • Generic core version (21-23 items) • Brief version (15 items) • General well-being version • Cognitive functioning version • Multidimensional fatigue-scale • Other medical issues version Measures function across 4 subscales <ol style="list-style-type: none"> 1. Physical functioning (8 items – generic version) 2. Emotional functioning (5 items) 3. Social functioning (5 items) 4. School functioning (5 items) 	<ul style="list-style-type: none"> • Fatigue (use fatigue-specific scale) • Sleep disturbance • Cognitive impairment • Altered mood • Exercise intolerance 	<ul style="list-style-type: none"> • Multiple versions available: • 2-4 years old (completed by parent or carer) • 5-7 years (completed by non-carer) • 8-12 years • 13-18 years • Parent or carer proxy form 	<ul style="list-style-type: none"> • License fees may apply. See https://eprovide.mapi-trust.org/instruments/pediatric-quality-of-life-inventory for further details • Available in multiple languages • Used in a Danish study of long COVID symptoms in children: Berg SK, Palm P, Nygaard U, et al. 2022¹⁷⁴

Appendix 2 (cont.)

Tool	Description	Applicable long COVID symptoms	Suitable age groups	Further information
Strengths and difficulties questionnaire (SDQ)	<p>A 25-item screening questionnaire across 5 subscales:</p> <ol style="list-style-type: none"> 1. Emotional symptoms 2. Conduct problems 3. Hyperactivity and inattention 4. Peer relationship problems 5. Prosocial behaviour 	<ul style="list-style-type: none"> • Altered mood • Cognitive impairment 	<ul style="list-style-type: none"> • 2-17 years • Multiple versions available • 2-4 years (completed by parent or carer) • 4-17 years (parent or carer version) • 11-17 years (self-report version) • Follow-up versions also available to determine success of interventions 	<ul style="list-style-type: none"> • Paper versions may be downloaded and photocopied without charge for non-commercial purposes • Used by paediatric mental health services • Used in the UK CLoCK study of long-COVID in children and young people
Pediatric symptom checklist (PCS)	<p>A 17-item or 35-item questionnaire that helps identify and assess changes in emotional and behavioural problems in children</p> <p>There are three subscales:</p> <ol style="list-style-type: none"> 1. Internalising 2. Attention 3. Externalising 	<ul style="list-style-type: none"> • Cognitive impairment • Altered mood • Fatigue (35-item questionnaire only) • Sleep disturbance (35-item questionnaire only) 	<ul style="list-style-type: none"> • 17 item and 35 item questionnaires for both child and parent or carer available • 4-15 years (17 item) • 4-18 years (35-item questionnaire) 	<ul style="list-style-type: none"> • Available for use without license online • Available in multiple languages

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Glossary

CFS	Chronic fatigue syndrome
CT	Computed tomography
DLCO	Diffusing capacity of the lungs for carbon monoxide
DVT	Deep vein thrombosis
ECG	Electrocardiogram
GP	General practitioner
LHD	Local health district
ME	Myalgic encephalomyelitis
NSAIDs	Non-steroidal anti-inflammatory drugs
PASC	Post-acute sequelae of COVID-19
PE	Pulmonary embolism
PEM	Post-exertional malaise
POTS	Postural orthostatic tachycardia syndrome
PTSD	Post traumatic stress disorder

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A/Professor Philip Britton	Staff Specialist, Paediatric Infectious Diseases, The Sydney Children's Hospitals Network
A/Professor Anthony Byrne	Thoracic Physician, St Vincent's Public and Private Hospitals; President – Thoracic Society of Australia and NZ (NSW/ACT Branch); Global Health Researcher, Partners in Health, Socios En Salud Peru
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Professor Steven Faux	Senior Staff Specialist, Rehabilitation and Director, St Vincent's Hospital Department of Pain Medicine; Conjoint Professor, St Vincent's Clinical School, University of New South Wales; Adjunct Professor, School of Medicine, University of Notre Dame, Sydney
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Dr Brendan McMullan	Paediatric Infectious Diseases Physician and Microbiologist, Sydney Children's Hospitals Network
Renee Sandells	Clinical Psychologist, Department of Pain Medicine, The Children's Hospital at Westmead, Sydney Children's Hospital Network
Louise Sellars	Rehabilitation Network Manager, Agency for Clinical Innovation
A/Professor Lissa Spencer	Clinical Specialist Physiotherapist (Pulmonary, Cardiac and Chronic Disease Rehabilitation), Royal Prince Alfred Hospital, Sydney Local Health District; Clinical Associate Professor, University of Sydney
Dr Aravinda Thiagalingam	Senior Staff Specialist, Cardiology, Western Sydney Local Health District; Senior Lecturer, Westmead Clinical School, University of Sydney
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