ORGANISATIONAL MODEL OF CARE

# Long COVID model of care

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NSW GOVERNMENT

AGENCY FOR CLINICAL INNOVATION

The ACI Respiratory and Rehabilitation networks

**The information in this resource should not replace a clinician's professional judgement.**

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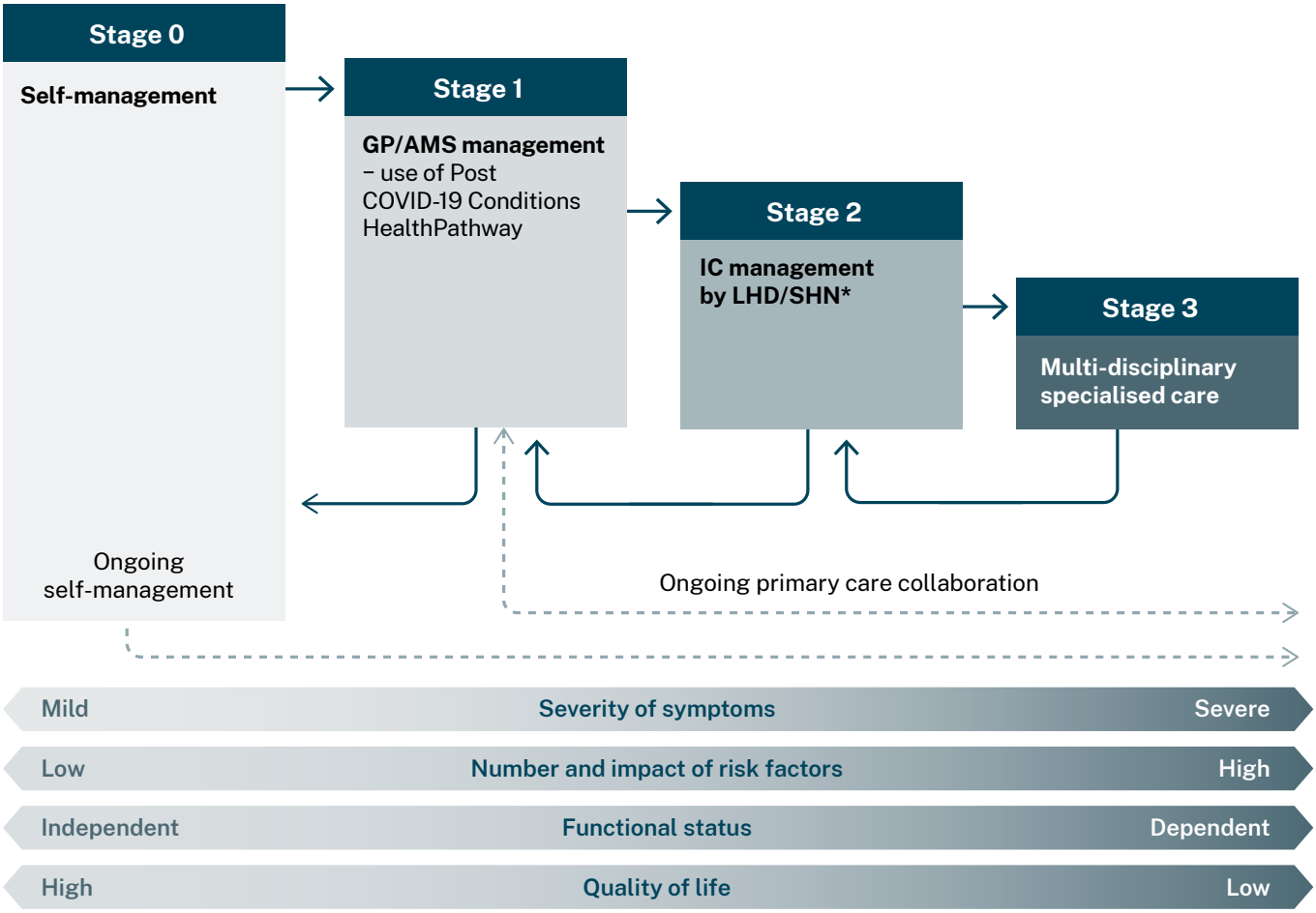
# At a glance

## This organisational model of care outlines a four-stage approach through which people with symptoms of long COVID may receive care.

0. **Self-management:** A person manages their symptoms with episodic support from a general practitioner (GP), Aboriginal Medical Service (AMS) or community-based allied health practitioner (such as physiotherapist, psychologist and/or exercise physiologist).
1. **GP or AMS management:** A person receives ongoing care through their GP (with an allied health team, where available) or AMS.
2. **Integrated care (IC) management:** A person receives navigation and coordination of care, including referral to specialist services, where required by a dedicated local health district (LHD) or specialty health network (SHN) team.
3. **Multidisciplinary specialised care:** A person receives review and management via a multidisciplinary specialist service, such as respiratory, cardiology or rehabilitation, based in a LHD or SHN.

**The GP/AMS remains a core member of the healthcare team at all stages of treatment. Person-centred self-management and education is at the core of each stage of this model.**

### The long COVID organisational model of care




* For children and young people, upon receipt of the referral, the IC care coordinator is to directly escalate the care to the LHD paediatric service.

# Summary

Long COVID is defined by the World Health Organization (WHO) as:[1, 2]

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.

Note that both criteria are required.

A number of other terms are sometimes used to describe long COVID such as 'post acute COVID-19 condition' 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.

This document outlines a principles-based model of care for adults and children with symptoms of long COVID. It provides stages of guideline-based care[3] across general practitioners (GPs) and Aboriginal Medical Services (AMSs), primary health networks (PHNs), local health districts (LHDs) and specialty health networks (SHNs) within NSW. The model of care can be adapted by PHNs, LHDs and SHNs to ensure it meets the local needs.

Implementation of this model of care at the LHD/SHN level will require executive sponsorship and a formalised governance process. This process should include a localised framework for operationalisation of the model, including pathways for escalation to specialist services.

## Principles of the long COVID model of care

There are five principles of the long COVID model of care:

1. **Evidence-based care**
2. **Collaborative care**
3. **Person-centred care**
4. **Equity of access to care**
5. **Value-based care**

These principles are fundamental to the successful management of people with long COVID who have functional impairment along with correctable clinical symptomatology. The application of these principles will demonstrate an improvement in outcomes that matter to people with long COVID, the clinicians who care for them and the system that supports this care.

# Long COVID model of care

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# Introduction

As at 26 January 2023, there have been 3,875,249 cases of COVID-19 in NSW since the beginning of the pandemic[4] (although this number is likely to be underreported due to the non-standardised methods of testing and reporting positive tests for acute COVID-19 infections). Recent evidence[5] has demonstrated that the majority of people with COVID-19 will recover completely within a few weeks. 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.[5]

A small subset of people will continue to experience symptoms for weeks or months, defined as 'long COVID'.[5] Recent data from Victoria estimates 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).[6] Prevalence of long COVID in children and adolescents is around 3.7% generally (1.7% in non-hospitalised children and up to 5.2% in hospitalised children).[7]

Evidence for the prevalence and management of people with unresolved symptoms following acute infection with COVID-19 remains limited due to a lack of standardised diagnostics for long COVID and evolving evidence.[8]

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):[9]

- breathlessness and cough
- chest pain and palpitations
- postural tachycardia syndrome (POTS)
- fatigue and exercise intolerance
- sleep disorders
- cognitive impairment and poor concentration, including learning difficulties in children
- mobility impairment
- joint pain and muscle pain
- mental health.

In the current clinical environment, across NSW there is large variability in the type and location of care available for people with symptoms of long COVID. These people are currently managed via one or a combination of the following:

- self-management
- GP/AMS management
- other primary care and allied health providers (e.g. community-based physiotherapist, psychologist, exercise physiologist)
- single specialist care for single system symptoms (e.g. respiratory)
- multiple specialist care for multi-system symptoms (e.g. multidisciplinary rehabilitation)
- dedicated long COVID clinics. These clinics are currently available in several LHDs/SHNs – other LHDs/SHNs use existing multidisciplinary rehabilitation and other specialised services to treat people with long COVID.

Access to services also varies, which can lead to under or over referral to the right level of care and poor patient experience and outcomes.

The long COVID model of care aims to support a standardised approach to delivering guideline-based care[3] for people with long COVID that is person-centred and evidence-based. The model outlines the different settings in which care may be delivered and different stages of care depending on a person's needs. For care of adults with ongoing symptoms in the first 12 weeks post acute COVID-19 illness, please refer to Management of adults with COVID-19 in the post-acute phase: A model of care for NSW health clinicians.[10]

Use of the long COVID model of care will align to, and be supported by:

- utilisation of Community HealthPathways, including clinical guidance and referral mechanisms to support GPs/AMSs, to identify and treat symptoms for the majority of people who can be well managed by GPs/AMSs, as well as triggers for escalation to specialist care (where required)
- a referral process to LHD/SHN Integrated Care Planned Care for Better Health (PCBH)[11] teams to support assessment of and coordination for people who may require access to acute or sub-acute services to manage particular symptoms associated with long COVID. Within this model of care document, this team will be referred to as the 'Integrated Care team' or 'IC team'.
- use of patient-reported measures (PRMs) in HOPE to assess and track adult patient outcomes.

## Methodology

The long COVID model of care is informed by an evidence review[12] and has been developed in consultation with the Long COVID Clinical Expert Reference Taskforce (LC-CERT). This group consists of clinical experts, experienced service managers from the NSW Agency for Clinical Innovation (ACI) and representatives from the NSW Ministry of Health. See the Acknowledgements section for the membership list of the LC-CERT.

## Scope

The scope of the long COVID model of care aligns with the Clinical practice guide for assessment and management of adults with post-acute sequelae of COVID-19,[3] which outlines assessment and management of the top 10 symptoms of long COVID. It is acknowledged there may be other symptoms requiring assessment and management.

| In scope | Out of scope |
|---|---|
| • Adults, young people and children with symptoms of long COVID<br>• Ways of organising care delivery for people with long COVID | • Complications arising from acute infection with COVID-19 (less than 12 weeks post initially testing positive for COVID-19 – the care of patients in the post-acute phase is outlined in the Management of adults with COVID-19 in the post-acute phase: A model of care for NSW health clinicians.[10] This includes post-infectious inflammatory conditions in children known as paediatric inflammatory multisystem syndrome or multi-inflammatory syndrome in children.<br>• Management of pre-existing, comorbid conditions unrelated to previous COVID-19 infection<br>• Guidelines for the clinical management of long COVID<br>• Additional funding for the provision of care for people with long COVID<br>• Development of specific education resources for clinicians and self-management resources for patients, acknowledging clinicians may adopt or adapt existing educational resources for local use |

## Priority and vulnerable populations

For people who are vulnerable and have specific needs, their experience and engagement will be enhanced by their healthcare providers involving local support services. Some of the groups who may need to access these services may include (but are not limited to):

- Aboriginal people
- people from culturally and linguistically diverse backgrounds
- people who are significantly socially disadvantaged (e.g. people with no fixed address, those who have low/no income and children living in out-of-home care)
- older people who live in residential aged care facilities
- people with physical and intellectual disabilities
- people living with a mental illness
- people who are refugees or who are seeking asylum
- people who are currently or have recently been incarcerated.

## Intended audience and application

This model of care is intended for use by:

- GPs (and their teams, where available) and AMSs
- LHD/SHN executives and managers
- IC clinicians who are coordinating care for people with long COVID
- NSW Health clinicians who provide assessment and management for people presenting with complex symptoms of long COVID.

# Care principles

The care principles are the foundation for delivering guideline-based care. There are five principles that should be applied across the entire patient journey, irrespective of the stage at which the care is being provided.

1. **Evidence-based care** – care is provided according to current scientific and clinical evidence and in concordance with Long COVID Guideline-based Care[3, 9] (noting that the evidence base for long COVID is emerging rapidly, with current evidence currently captured in Living Evidence - Post Acute Sequelae of COVID-19 (Long COVID)[8]).
2. **Collaborative care** – a coordinated, concerted approach utilising multiple teams, including IC and clinical teams, may be required for people with more complex presentations of long COVID. Care is provided with the understanding that most symptoms can be managed by individual members of various clinical teams.
3. **Person-centred care** – each person's long COVID sequelae will have their own unique presentation, and individualised assessment, referrals and care planning will be required. Care is then provided in accordance with presenting symptoms, risk factors and individual circumstances, with the understanding that many other conditions may explain these symptoms. People should receive the right care, in the right place, at the right time and by the right clinician on the basis of their symptoms.
4. **Equity of access to care** – standardisation of processes to ensure all people in NSW can access appropriate care for long COVID as required. Care is accessible via the escalation pathways described in this model of care, ensuring that resources are appropriately prioritised for those people with the greatest need for specialised care.
5. **Value-based care** – care that improves health outcomes that matter to people, experiences of receiving care, experiences of providing care, and the effectiveness and efficiency of care. Care is provided in a way that prioritises existing clinics and services over specialised long COVID services, avoids over-investigation, over-diagnosis and over-treatment of people, ensuring that highly specialised care is available for people with significant symptom burden and severity of functional impact.

# A staged approach to care

There are four stages that describe where care can be stepped up or down, depending on the patient need:

0. Self-management
1. Primary care by GPs/AMSs and the use of Post COVID Conditions Community HealthPathway
2. Integrated Care management by LHD/SHN
3. Multidisciplinary specialised care by LHD/SHN teams, clinics and services.

Each stage of care will be underpinned by patient self-management and support.

## A note on red flags

A person presenting with any of the following symptoms, regardless of location, should be referred to the local emergency department (ED) for urgent assessment:[3, 9]

- Severe, new-onset or worsening breathlessness or hypoxia
- Syncope
- Unexplained chest pain, palpitations or arrythmias
- Severe psychiatric symptoms including risk of self-harm or suicide
- Delirium
- Focal neurological signs or symptoms.

## Stage 0: Self-management

Most people with symptoms of long COVID will self-manage with episodic support by primary care providers, including GPs and their teams, AMSs and community-based allied health practitioners, such as physiotherapists, psychologists and exercise physiologists, until symptoms resolve.

The provision of patient education and support for self-management is fundamental to care delivery across all stages of the care continuum. Symptoms of long COVID may change and fluctuate over time. It is important for people to monitor their symptoms on an ongoing basis and seek additional support if required.

For further details, refer to the Patient education, health coaching and self-management section.

# Stage 1: Primary care by GPs/ AMSs and use of the Post COVID-19 Conditions Community HealthPathway

## Key components of primary care

Most adults, young people and children with symptoms of long COVID can be managed well within primary care.[9] The timeframes for recovery from acute COVID-19 illness can vary widely. It is important to monitor and manage an individual's recovery while allowing adequate time for symptom resolution. Reassurance, support and validation of the person's experience is paramount. The provision of self-management strategies and resources to people to support rest and pacing of activity, eating well, wellbeing and management of comorbid conditions is crucial.[9]

It is acknowledged that people may present with symptoms of long COVID to a variety of primary care providers, including, but not limited to, GPs, AMSs and community-based allied health practitioners, such as physiotherapists, psychologists and exercise physiologists. For the purposes of this model of care and the staged approach to management, referrals to LHD/SHN services can be made by GPs and AMSs.

A statewide consistent Community HealthPathway for 'Post COVID-19 Conditions' assists GPs/AMSs with care of this patient cohort. It can be accessed through the local Community HealthPathway portal. Referral guidance provided in the portal is based on eligibility criteria for local services. Early phase management of ongoing symptoms should include ruling out secondary diagnoses[9] or other related conditions, and is further outlined in the Post COVID-19 Conditions Community HealthPathway.

**The Community HealthPathway:**

- Supports GP and AMS teams to manage people with long COVID within the community setting
- Facilitates the screening of people with long COVID whose care can no longer be managed by GP/AMS teams alone and who require referral to local IC teams.

> Each LHD/SHN should provide access to an on-call physician or clinical nurse consultant during business hours. The GP/AMS can contact the on-call clinician at any time to seek advice on individuals with more complex needs who are being managed within Stage 1.

Access to the on-call clinician will support effective management for these individuals, as well as minimise the risk of over-investigation, overtreatment and inappropriate referrals. This access may be managed through the IC team or via a specialist service with experience in long COVID symptomology, such as multidisciplinary rehabilitation medicine, respiratory medicine or geriatric medicine services. Access to an on-call paediatrician or paediatric clinical nurse consultant should also be made available to provide guidance to GPs/AMSs for children and young people.

There are some people who will require specialised review, intervention and/or management for some of their symptoms via the Stage 2 pathway. Suggested indicators for escalation are outlined in Box 1.

### Box 1: Indicators for escalation for people requiring specialist review or management via Stage 2

Presence of any of the following may indicate a person requires their care to be escalated from the GP/AMS to the local IC team for further investigation and referral where clinically appropriate:

- Multiple, intractable, ongoing symptoms that are resistant to usual care by the person's GP/AMS, resulting in significant functional impairment, inability to work or attend school, inability to resume life roles (e.g. caring for children) and impact on quality of life or mental health
- Where further investigations are required and unable to be performed or ordered within primary care (e.g. access to lung function testing by primary care may be limited in some areas)
- Complex psychosocial concerns requiring intervention and/or intensive care coordination in collaboration with the GP/AMS (e.g. mental health, drug and alcohol, homelessness, or risk of homelessness).

## Mechanisms of escalation to the IC team

Escalation to the IC team can occur one of two ways:

1. **Referral by GP/AMS via central intake**

   Each LHD/SHN IC team has a centralised intake e-mail address. Details of how to make a referral and the relevant e-mail address are available via the Post COVID-19 Conditions Community HealthPathway.

2. **The Risk of Hospitalisation (ROH) algorithm, noting that this algorithm is currently only applicable to adults**

   A person presenting to ED may be flagged based on their ROH. ROH is a meaningful prediction of a person's unplanned hospitalisation in the next 12 months. It is based on an extensive list of demographic and socioeconomic factors as well as hospitalisation and medical history.[11]

## Timing of escalation

The timing of escalation from the GP/AMS to the IC team will vary among patients and their overall symptom burden, and will be based on the clinical judgement of the treating GP/AMS.

It is acknowledged that the timing of escalation may be sooner than the defined long COVID time period of three months, particularly for those who experienced more severe acute COVID-19 infection (including hospitalisation). The GP/AMS should use the LHD/SHN on-call service and/or the IC team to seek additional clinical advice and guide the timing of the escalation if uncertainty exists.

## Escalation for children and young people

Children and young people with symptoms of long COVID may be escalated to Stage 2 by their treating GP/AMS via centralised intake, as outlined above.

# Stage 2: Integrated Care management by LHD/SHN

Local IC teams will facilitate the support and coordination of care for people who can no longer be managed by GP or AMS teams alone (refer to Box 1: Indicators for escalation for patients requiring specialist review or management via Stage 2).

Local IC care coordinators will work across multidisciplinary and multi-specialty areas. These care coordinators will work together with a person's GP/AMS to ensure people with long COVID can access specialist services across NSW Health, as well as other community providers for management of their long COVID symptoms. Collaboration between the care coordinator, the GP/AMS, the person and their carer(s) will ensure continuity of care.

As with Stage 1, patient education and guided self-management remain crucial. Health coaching is a key enabler to improve health literacy and empower people to better understand and manage their symptoms.

The approach for Stage 2 will vary between facilities and LHDs/SHNs depending on local resources, the patient cohort and the number of people who require care by these teams at any one time. Where possible, LHDs should aim to use existing IC roles, provided these clinicians have knowledge in the assessment and care of people with long COVID. Virtual care may be appropriate for the purposes of providing IC interventions, particularly in LHDs with small numbers of people over a large geographic area or in districts with large numbers of people requiring care.

Before ending enrolment in the IC post-COVID initiative, the care coordinator will work with the patient's GP/AMS to ensure adequate services are in place in the community to support the ongoing health and social needs of the person, allowing the person to achieve their goals and manage the physical, social and psychological aspects of recovery.

## Special considerations for children and young people

Children and young people may be escalated to the IC PCBH care coordinator via centralised intake, as outlined above; however, unlike adults, they are not enrolled in the IC post-COVID initiative.

Upon receipt of the referral, the role of the IC care coordinator is to directly escalate the care to the LHD paediatric service. Each LHD/SHN should have an established local process to support this referral, including assessment of the urgency of referral.

## Care coordination and navigation

Given the complex and multidisciplinary nature of long COVID management, care coordination, health coaching and navigation are key to successful management of people with symptoms of long COVID, as is referral to specialist LHD/SHN clinicians and teams, where required. These specialist teams may include multidisciplinary rehabilitation, respiratory services and cardiopulmonary rehabilitation, among others. A list of suggested services is provided in Appendix 1: List of suggested specialist services.

Once care of an individual is escalated to an IC team, the team will coordinate the person's needs and may facilitate referrals to specialist clinicians and teams as required. Refer to Box 2 for indicators for escalation for people requiring specialist review or management via Stage 3.

The IC state-wide streamlined patient flow is outlined in the Planned Care for Better Health Post-COVID Transformation Plan. For more information, please contact moh-integratedcare@health.nsw.gov.au

**Care coordination and navigation may:**

- link clinical and support teams through facilitated case conferencing for the purposes of shared care planning and shared decision making.[9] Where clinically relevant, this may include the person's GP/AMS and multiple specialist groups (e.g. dual management of a person by rehabilitation and respiratory teams). Where clinically appropriate, the person and their carer(s) should also be included in case conferencing.
- establish a clear flow of information between multiple clinicians and services. This should include documentation of all assessments, outcomes and prescribed management plans.
- provide health coaching and strengthen the health literacy of people with long COVID and those who support them to facilitate self-management, including information on how to escalate appropriately. Paper and/or electronic evidence-based resources to enable self-management should be provided.
- enable access to the most appropriate care in a timely way, including home monitoring where required
- provide documentation and liaison with appropriate GP/AMS and specialist services
- facilitate referrals for people with more complex presentations to appropriate specialty, multi-disciplinary rehabilitation services or long COVID clinics (where required).

## Patient flow within LHD/SHN IC teams

Each local IC team will establish how people with symptoms of long COVID who are referred to them will flow in and out of their care.

Consideration must also be given to how communication to and from specialist clinicians and teams will flow to all clinicians involved in a patient's care in a patient-centred way, particularly clinically relevant information about patient education and self-management strategies.

### Box 2: Indicators for escalation for people requiring specialist review or management via Stage 3

As outlined above, the key role of the IC team is to facilitate care coordination and navigation, including health coaching, remote monitoring and liaison between different clinical teams as required. For some people with long COVID, the support provided by the IC team is adequate to meet their physical and psychosocial needs. For others, escalation to specialist services or clinics is required.

Severe symptoms affecting a person's functional capacity, such as inability to work and/or perform life roles like caring for children, may indicate the need for escalation to Stage 3. Some of these symptoms are listed below (note this list is non-exhaustive):

- Significant fatigue associated with post-exertional malaise
- Significant cognitive impairment
- Ongoing unresolved breathlessness
- Ongoing symptoms of orthostatic intolerance
- Mental health and wellbeing issues not responding to Stage 1/2 management strategies or inability to access support in the community
- Complex psychosocial issues requiring input from multiple clinical and social services
- Requirement for complex care to be delivered under a person-centred goal-directed rehabilitation plan.

## Stage 3: Multidisciplinary specialised care by LHD/SHN teams, clinics and services

Specialised LHD/SHN teams, clinics and services may be required for people with ongoing severe or debilitating symptoms. People may be referred to specialist services either by IC teams or there may be circumstance where this occurs directly through GP/AMS teams using existing referral pathways.

It is important to note that specialist services should be used for the purposes of further investigation, coordination of care and management that cannot be successfully achieved as part of stages 1 and 2.

This may be the result of intractable symptoms and/or complex comorbid disease following assessment and appropriate investigation and management in primary care prior to referral to specialist services.

Local specialist service referral criteria should be consulted for a list of required diagnostic investigations.

### Components of multidisciplinary specialist LHD/SHN clinician and service pathways

There are multiple pathways that may be used if an individual requires management via a multidisciplinary specialist pathway. Each PHN, LHD and SHN across NSW represents a unique healthcare delivery environment, with a range of enablers and challenges to the delivery of high-quality long COVID care that will meet the patient's needs. The components of this pathway should therefore be locally adapted for implementation of this model of care to support the delivery of clinical care in consideration of local services available.

There should also be networked processes in place to seek required advice from specialist services in other LHDs/SHNs if not available locally. For children and young people, local paediatric services may need to liaise with the Sydney Children's Hospitals Network specialist services for additional advice and support.

Examples of multidisciplinary specialist pathways that may be required for management of a patient with symptoms of long COVID are listed below. **Ongoing partnership with the person and their GP/AMS remains paramount, regardless of the specialist pathway used.**

#### a) Multidisciplinary rehabilitation services

The multidisciplinary and collaborative care nature of rehabilitation medicine services provides opportunities for integration across the healthcare journey for people with long COVID. This is supported by the Rehabilitation Medicine Society of Australia and New Zealand's position statement on the Role of Rehabilitation Medicine Physicians in the management of COVID-19 patients.[13]

Rehabilitation medicine physicians and rehabilitation services play a role in offering ambulatory goal-oriented rehabilitation for a variety of symptoms, such as immobility, cognitive impairment, pain, pervasive fatigue and inability to return to work. Multidisciplinary rehabilitation services can deliver tailored rehabilitation programs for persisting and fluctuating symptoms and disabilities in those with long COVID. Referral to this service may be indicated where there are multi-system problems that result in interrelated activity and participation limitations requiring a cooperative, biopsychosocial approach to assessment and treatment.

**b) Respiratory and pulmonary rehabilitation services**

Respiratory teams and pulmonary rehabilitation services can address the respiratory symptomatology of long COVID to advise and enable appropriate investigations and interventions, and work towards improved outcomes for these individuals. Respiratory services should develop an appropriate approach to triage, assess and investigate people with persistent respiratory symptoms related to long COVID, especially in the assessment of persistent breathlessness.

Pulmonary rehabilitation services can provide multidisciplinary support for outpatients in whom breathlessness due to cardiorespiratory compromise is present. This is particularly the case for those individuals who had significant respiratory compromise during their acute illness and/or comorbid cardiorespiratory disease.

Respiratory teams and pulmonary rehabilitation services should work collaboratively with local multidisciplinary rehabilitation services so that patients are referred to the most appropriate type of rehabilitation. The prescription of exercise to those people with symptoms of post-exertional malaise (PEM) should be approached with caution – further guidance on PEM is provided in the Clinical Practice Guide for Assessment and Management of Adults with Post-acute Sequelae of COVID-19.[3]

**c) Partnership with other clinical services that may support people living with long COVID (may include, but not limited to):**

- Cardiac teams and cardiac rehabilitation services
- Neurology teams
- Gastroenterology teams
- Endocrine teams
- Mental health teams
- Drug and alcohol services
- Homeless health services
- Geriatric teams
- Community health services
- Haematology teams
- Immunology teams
- Infectious diseases teams
- Aboriginal Health Services

**d) Support services**

The development and maintenance of strong partnerships with various stakeholders involved in supporting the care of people with symptoms of long COVID is key to successful clinical outcomes. Some of these services include, but are not limited to, partnerships with local family and community services, and partnerships with local priority population services.

# Key elements to support care delivery across the three stages

## Person-centred care that can be adjusted in real time

People with long COVID should be provided access to specialist LHD/SHN clinicians and teams to receive person-centred care when they are acutely unwell. This will allow for real-time adjustments to be made to their care to alleviate symptoms or prevent deterioration that could result in presentation to local EDs and/or admission to hospital. This person-centred care delivery should include:

- Presentation to GP or primary care provider for new-onset symptoms
- Escalation to local IC teams for care coordination, navigation and support
- Escalation to specialist services for people with exacerbation of symptoms currently being managed by those local services (e.g. worsening fatigue for patients currently being managed for fatigue by a multidisciplinary rehabilitation team).

Local operational processes and escalation pathways should be established, and patients provided with details of who to contact in the event of exacerbation of symptoms, including outside of operational hours.

## Virtual care

Virtual care is any interaction between patients receiving healthcare and their care team occurring remotely, using any form of communication or information technologies with the aim of facilitating or maximising the quality and effectiveness of clinical care.[14] For patients with symptoms of long COVID, access to virtual care can support assessment and management via primary care, referral to specialist LHD/SHN clinicians and teams, as well as the communication of information between clinicians and providers involved in the care.

For direct clinical care, it is most useful when the specialist clinician and the patient already have an established relationship for continuity of care. Virtual care can complement care delivery but should not replace interventions that are best carried out face-to-face.

Virtual care has been used successfully in multiple settings relevant to the management of people with long COVID, including cardiopulmonary rehabilitation and general multidisciplinary rehabilitation.[15-17]

Virtual care interventions are best used for patients with symptoms of long COVID in accordance with these principles:

- Patient preference
- Undertaking an initial risk screening to ensure clinical safety
- Patient's ability to effectively operate and interact with virtual care must be considered
- The patient and the clinician must have access to digital technology to facilitate the use of virtual care
- Support for the patient and the clinician to use the technology effectively must be available
- If using videoconferencing platforms, the patient must have a stable internet connection
- When undertaking care via videoconferencing within NSW Health, only endorsed and supported NSW Health platforms should be used
- Decisions about the extent to which virtual care is used should be made according to the local context of the clinical service
- All virtual care interventions should be documented in the patient's medical record.

## Patient education, health coaching and self-management

The provision of patient education, health coaching and guided self-management for symptoms of long COVID is paramount and an integral component of person-centred care delivery, regardless of the stage of and setting where care is being provided.[18]

All clinicians, irrespective of the setting, who are providing care to people with symptoms of long COVID need to tailor education on disease and system navigation to meet the health literacy needs and ability of patients and their carers to understand, receive and act on the information.

Providing education and self-management about the symptoms of long COVID requires all clinicians to have two important skills:

1. A basic understanding of long COVID, its presentation and associated treatments
2. An understanding of how to navigate the healthcare system in a timely and appropriate way (particularly in the context of multimorbidity).

Several resources are available to clinicians to help them ensure people are partners in their own care. These include:

- RACGP patient resource: Managing post-COVID-19 symptoms: what to expect during recovery[19]
- NHS Your COVID Recovery[20]
- WHO: Support for rehabilitation: self-management after COVID-19 illness.[21]

## Routine data reporting and review (including PRMs)

LHDs/SHNs, GPs/AMSs and statewide systems should provide clinicians involved in the care of patients with long COVID timely access to relevant data. Further detail on data capture and use is outlined in the Planned Care for Better Health Post-COVID Transformation Plan. For more information, please contact moh-integratedcare@health.nsw.gov.au.

### Health Outcomes and Patient Experience platform

Long COVID–specific measures are captured in NSW via the Health Outcomes and Patient Experience (HOPE) IT platform.[22] 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 are:

- The Post COVID-19 Functional Status (PCFS)[23, 24] scale
- The COVID-19 Yorkshire Rehabilitation Screen (C19-YRS).[25, 26]

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 information on the most burdensome symptoms so they can focus on what matters to patients. 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 LHD/SHN clinicians across NSW and are currently being implemented in general practice.

# Organisational roles and responsibilities

There are several key organisational elements that support the success of the long COVID model of care. Each has differing responsibilities, which are outlined in Table 1 below.

**Table 1: Organisational roles and responsibilities**

| Organisation | Roles and responsibilities |
|---|---|
| PHNs | Support GPs and general practice teams |
| Aboriginal system focused healthcare bodies | Support AMSs |
| NSW Ministry of Health Integrated Care team | Support local IC teams |
| NSW Agency for Clinical Innovation | Specialist clinician support through relevant clinical networks, including the Respiratory and Rehabilitation Networks<br><br>Support LHD/SHN patient-reported measures leads for local implementation of long COVID–related surveys into HOPE |
| LHDs and SHNs | Provision of specialty care clinicians and teams |

## Implementation of the model of care

Implementation of this model of care at the LHD/SHN level will require executive sponsorship and the establishment of a formal governance process. This process should include:

- A localised framework for operationalisation of the model, including pathways for escalation to specialist services
- On-call arrangements for clinicians to provide advice and guidance to GPs/AMSs as outlined in Stage 1: Primary care by GPs/AMSs and Post COVID-19 Conditions Community HealthPathways on page 11.

# Case study: Management of a person with long COVID

The following de-identified case study has been provided by the IC team in regional NSW.

| | |
|---|---|
| Demographics | 48 years old, female, non-Aboriginal (Sally) |
| Social | Married with two step-children. Full-time employment |
| Medical history | Recurrent urinary tract infections<br>Diagnosed with COVID-19 in April 2022 and managed in community |

## Stage 1: Management by GP

Sally, a previously healthy 48-year-old woman, who had been fully vaccinated, acquired COVID-19 in April 2022. She experienced fever, sore throat, generalised myalgias and fatigue. She self-isolated at home and did not require medical assistance during her acute illness.

Four weeks later she was still experiencing ongoing palpitations, extreme fatigue and some breathlessness. The breathlessness was not sufficient to prevent her from her usual activities, but she felt it slowed her down. She found household chores or carrying the shopping would leave her feeling exhausted. Before getting COVID-19 she would regularly walk; she found that while she could still do this but even walking short distances would leave her feeling exhausted. When she attempted to return to work part-time, she had worsening symptoms of severe fatigue and was unable to return to full-time duties.

Baseline blood tests were normal. Her GP arranged investigation with an ECG followed by a 24-hour Holter monitor. They also organised a chest X-ray and performed spirometry before and after bronchodilator. No issues were detected. Her GP arranged for direct referral to a visiting cardiologist for review, using the Stage 3 specialist pathway.

Her GP also provided supportive management and recommended self-management strategies for these symptoms.

Sally also engaged a community-based physiotherapist who recommended pacing and a graded activity program supported by use of an activity diary; however, Sally did not find the advice of the physiotherapist or self-management strategies provided by her GP helped with the resolution of her symptoms.

## Stage 2: Management by local IC team

Sally was referred to the WNSWLHD IC team four months after acute COVID-19 illness by her GP. The assigned care coordinator performed the COVID-19 Yorkshire Rehabilitation Screen over the phone, with multiple symptoms identified as listed above. Sally also expressed symptoms of low mood and anxiety. Sally was enrolled in the PCBH post COVID program. The outcome of the assessment was discussed, a person-centred care plan was developed and Sally commenced receiving health coaching.

Due to significant symptom burden and functional impact, the care coordinator escalated Sally's care to a Stage 3 pathway.

## Stage 3: Management via specialist services

In partnership with Sally's GP, the care coordinator escalated Sally's care to the local multidisciplinary rehabilitation medicine service and respiratory clinic.

Under the leadership of a rehabilitation physician, Sally received a coordinated, goal-directed rehabilitation plan, which included:

- Occupational therapy – to support energy conservation, pacing and return-to-work strategies/plan
- Social work – to support Sally's mental health and provide guidance for financial support and complete application for Centrelink.

The respiratory clinic also assessed Sally. They repeated spirometry pre and post bronchodilator as well as performing gas transfer measures, and found that these were within the predicted range. They reviewed her chest X-ray and agreed it was normal. A six-minute walk test was measured and found not to be impaired. Given the normal results of these investigations and the fact that Sally did not have severe acute COVID-19 nor previous cardiorespiratory disease, she was reassured that she did not have significant pulmonary impairment. Sally was encouraged to follow the strategies advised by occupational therapy and to continue to engage in a long-term strategy of gradual improvement in exercise tolerance with a community physiotherapist.

Virtual care was utilised for all assessments and interventions. The IC care coordinator was able to support Sally through this process.

To ensure shared care planning and collaboration between teams, case conferencing was undertaken on a weekly basis, including all involved clinicians and Sally's GP (when available). The respiratory clinic team worked closely with the rehabilitation team to guide progression of Sally's functional activities, linked to her return-to-work program.

## Transition of care to GP

Sally experienced a gradual reduction in the severity of her symptoms. Four months after enrolment in PCBH, her care was transitioned back to her GP, and she returned to the workplace. Sally continues to receive supportive counselling via the LHD social work team.

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# Appendix 1: List of suggested specialist services

The following is a non-exhaustive list of suggested specialist LHD/SHN services that may be used for the management of people with long COVID. It is acknowledged that there is a variation in the type and name of services available between LHDs/SHNs.

- Multidisciplinary rehabilitation services
- Respiratory outpatient clinics
- Pulmonary rehabilitation
- Cardiac rehabilitation (or joint cardiopulmonary clinics)
- Geriatric medicine services
- Chronic and complex disease services or programs
- Forensic Mental Health Drug & Alcohol
- Community-based short-term restorative packages, e.g. COMPACKs, Safe and Supported at Home

# Glossary

| | |
|---|---|
| Aboriginal Medical Service (AMS) | Community controlled health services available across NSW for Aboriginal and Torres Strait Islander people. Includes access to GPs, mental health clinicians, dental and eye care, visiting specialists, GP specialty clinics (e.g. diabetes and chronic care), Aboriginal health workers and nurses. |
| COVID-19 Yorkshire Rehabilitation Scale (C19-YRS)[26] | A validated 22-item condition-specific measure for post COVID-19 syndrome. |
| Health Outcomes and Patient Experience (HOPE) | HOPE is the NSW Health purpose-built IT platform for the capture and management of patient-reported measures. Further information is available on the ACI website. |
| Integrated Care | Integrated Care involves the provision of seamless, effective and efficient care that reflects the whole of a person's health needs.<br><br>In NSW, this includes state-wide strategies that coordinate and encourage better communication and connectivity between health services in primary, community and hospital settings, and provide better access to community-based services closer to home. |
| Planned Care for Better Health (PCBH) | PCBH is one of NSW Health's priorities in improving outpatient and community-based care and a key enabler in identifying people at risk of hospitalisation in the next 12 months. PCBH builds on the existing connecting care model to better coordinate care for patients with chronic complex health and social needs by assessing their holistic care needs and linking them with support services to reduce the risk of unnecessary hospital presentations, provide a better experience of care and improve patient outcomes. PCBH delivers a broader, more preventative focus shifting from acute episodic care to concentrate on support that is integrated and centred on the patient's goals and care needs.<br><br>The PCBH initiative is one of eight NSW Health Integrated Care initiatives.<br><br>Further information is available on the NSW Health webpage. |
| Primary care | The first point of contact for the health system. Includes general practitioners and community-based allied health clinicians (e.g. physiotherapists). A person may self-refer to these services – no referral is required. |
| Post-COVID functional status (PCFS) scale[23] | A validated, ordinal scale to assess a person's post–COVID-19 functional limitations. |

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