



Government of **Western Australia**
Department of **Health**

WA care pathway for adult home-ventilated patients

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Foreword

The *WA care pathway for adult home-ventilated patients* (the Pathway) for patients undergoing treatment and ongoing management is complex. It involves multiple healthcare providers and covers a range of institutions, both public and private. The Pathway maps this journey for people with the specific medical conditions requiring home ventilation, aiming to foster an understanding of the whole pathway and its distinct components to promote quality care and patient experiences. This Pathway acts as a reminder that the patient is the constant in this journey and that the health system has a responsibility to deliver the care experience in an appropriate manner.

The Pathway was developed to improve service delivery and care across Western Australia (WA). This need arose from the lack of uniformity of services provided by the various Health Service Providers (HSP). The aim is to improve patient outcomes by facilitating optimal care across WA using evidence-based, best practice pathways of care. Patient treatment regimens will vary, but the principles and expectations of optimal care are constant.

The *WA care pathway for adult home-ventilated patients* will guide strategies to:

- improve quality of life
- enhance the quality of care across the continuum by improving risk adjusted patient outcomes, promoting patient safety, increasing patient satisfaction and optimising the use of resources
- improve coordination and service outcomes providing a statewide, consistent approach to service delivery that facilitates the auditing of pathways and service planning.

A wide range of clinicians were consulted and/or participated in the development of this pathway.

Summary

Please note that not all patients will follow every step of this pathway.

Support: Assess supportive care needs at every step of the pathway and refer to appropriate health professionals organisations

Step 1 Presentation, assessment (investigations) and referral

Consultation with the patient will depend on the diagnosis or reason for admission.

Home-ventilation patients will:

- be referred to a sleep medicine/respiratory medicine department for review, initiation on long-term ventilator and ongoing management
- be required to be seen in the respiratory outpatient department clinic and referred for sleep study or other tests and then reviewed
- explore and apply for potential support programs such as private insurance, compensation for injury related to motor vehicles or work, and the National Disability Insurance Scheme (NDIS).

Assessment will depend on the condition and presentation. **Assessment** may include:

- clinical evaluation
- lung function testing
- arterial blood gases and other pathology tests
- sleep studies
- trial of non-invasive ventilation.

Timeframes for **referral** should be informed by evidence guidelines and be dependent on the referrer, urgency and speciality. From the date of receiving the referral the patient should be seen within two weeks on average. If the condition requires, the patient should be able to be seen on the same day.

Step 2 Treatment planning

Treatment planning: Ideally, all newly diagnosed/referred patients should have their treatment discussed in a multidisciplinary team (MDT) meeting.

The level of discussion will be dependent on both clinical and psychosocial factors. There may also be a need to review existing treatment plans for patients who have been discussed previously.

Support Program responsibilities

Agreement regarding Health and Support Program responsibilities must be clearly articulated for each individual patient to ensure there are no gaps in care. Potential programs include:

- Private-Private Health Insurance or personal out-of-pocket
- Compensable – Insurance Commission of WA (ICWA) and the Catastrophic Injury Support Scheme (CISS), or Workers Compensation
- National Disability Insurance Scheme (NDIS)
- Department of Veteran's Affairs (DVA)
- State Government Equipment Programs.

Responsibility of individual team members:

- Review and support the patient as clinically appropriate throughout their presentation.

The MDT should determine the treatment plan for home needs and the appropriateness of discharge to the patient's home.

Step 3 Treatment

Treatment: The advantages and disadvantages of each treatment and associated potential side-effects should be discussed with the patient. Treatment options may include:

- full invasive ventilation with or without oxygen therapy; tracheostomy
- non-invasive ventilation (NIV)
- supportive management.

Treatment intent

- Improve quality of life without expectation of cure.
- Increase survival.
- Reduce hospital admissions.

The lead clinician should discuss treatment intent and prognosis with the patient and their family/carer prior to beginning treatment.

Initiation of home ventilation can be in three settings:

- Outpatient
- Inpatient
- Patient's home

Training

Patients, family and carers should be routinely trained in use of ventilation. The primary care giver/s must demonstrate the necessary skills in equipment set up, use and understanding of the patient's physical condition.

Step 4 Ongoing management

Management: After completing initial treatment, patients should be provided with a treatment summary and follow-up care plan including roles and responsibilities of the MDT.

Follow-up care: Dependent on the service provider and the patient's needs. Patients can be reviewed at 6-8 weeks following the commencement of ventilation. After initiation of ventilation, clinical review should occur within the first two to three months to assess symptoms, technical problems, ventilator settings, compliance and success.

Palliative and end-of-life care follow-up: Timely and appropriate referral to palliative care services. Referral should be based on need and not prognosis.

Further clinical reviews should occur every six to 12 months by the sleep/respiratory physician.

Step 5 End-of-Life

Multidisciplinary palliative care: Consider referral to palliative care if not already underway at this stage including:

- nursing, pastoral care, palliative medicine specialist back-up, inpatient palliative bed access as required, community home palliative care, social work and bereavement counselling
- discussion with general practitioner (GP).

Withdrawing ventilation

Senior clinicians should validate the patient's decision and lead the withdrawal of assisted ventilation.

Assessment of capacity to make the decision to stop ventilation is mandatory.

Step 6 Transition from paediatric to adult care

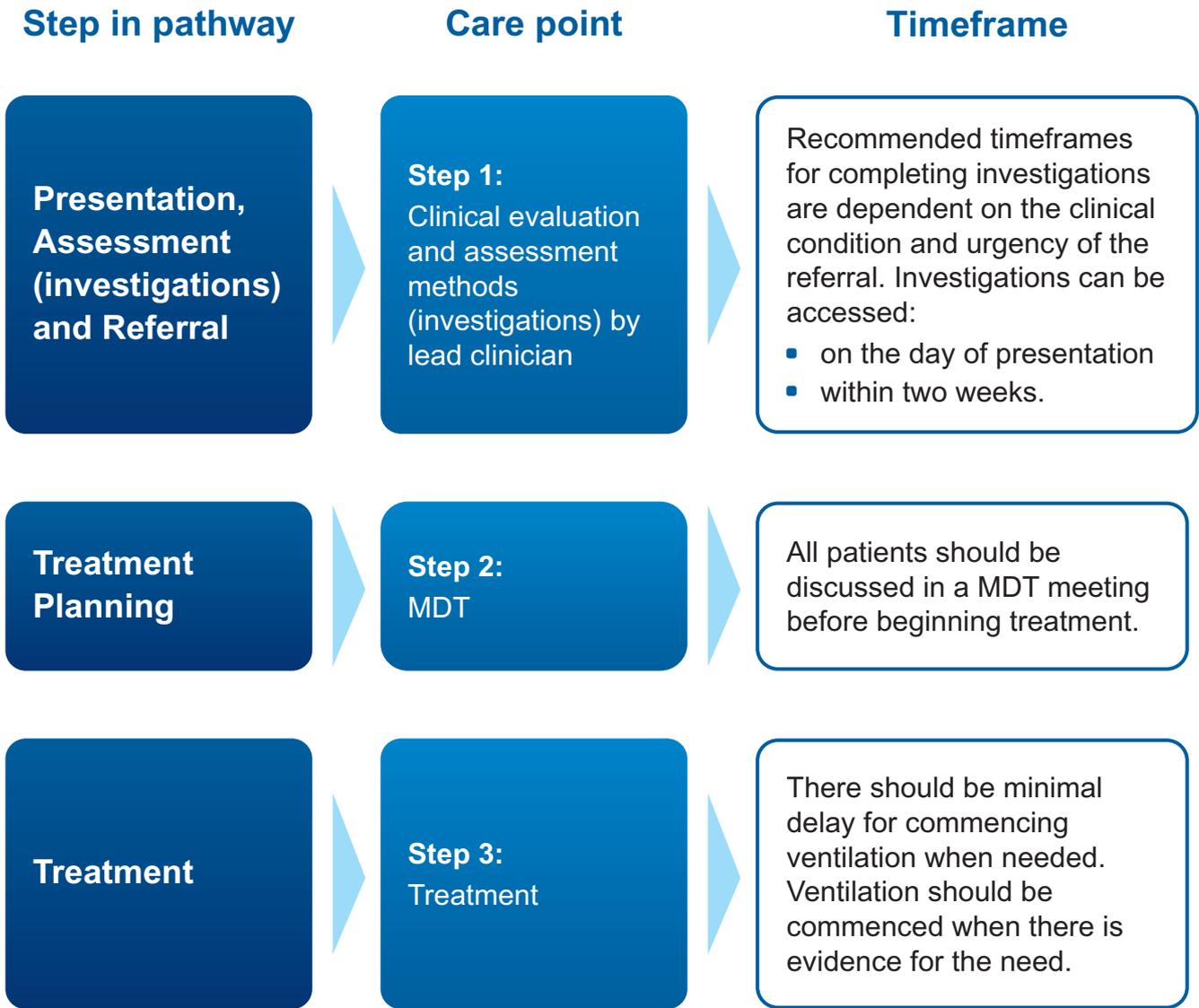
The transition for young adults on ventilation is a staged process requiring close collaboration between paediatric and adult specialist teams.

Discussions about potential differences in ventilator equipment provision between paediatric and adult services should commence 24 months prior to transition (16 years).

Refer to WA care pathway for paediatric home-ventilated patients.

Optimal timeframes

Timeframes for assessment and referral: Timeframes should be informed by evidence-based guidelines where they exist, while recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress. The following recommended timeframes are based on expert advice from the contributors to the Pathway.



Intent of the WA care pathway for adult home-ventilated patients

The Pathway is planned to guide the delivery of consistent, safe, high-quality and evidence-based care for home-ventilated patients 16 years and older.

The intent of a home-ventilation service is to:

- deliver care in the community and not in a hospital setting with the least burden of care on primary carers
- promote the patient's independence and freedom of movement (e.g. wheel chair-mounted ventilator)
- improve access to services in the community from the time of respiratory failure diagnosis, resulting in reduced hospitalisation
- manage disease progression in the community with the right team
- prolong life expectancy.

The Pathway aligns with key service improvement priorities, including access to coordinated multidisciplinary care and supportive care and reducing unwanted variation in practice.

The Pathway provides clinicians with a resource to guide care across the continuum of care and progression of disease with a focus on patient-centred care and quality and safety improvements.

Out of scope

- Home-ventilated children under 16 years of age.

Refer to the WA care pathway for paediatric home-ventilated patients.

Support and communication

Supportive care

An individualised clinical assessment is required to meet the identified needs of an individual, their carer and family. While all patients require general information, many will require specialised intervention. Assessment and referral to appropriate health professionals or organisations is required to meet the identified supportive needs of an individual, their carer and family. Full open discussion should occur with the patient, carer and family at each visit. Advice should be given to access those services that are not provided by the hospital (OCP 2014).

Supportive care needs to be assessed and referred to appropriate health and/or organisations as required to meet the needs of individual patients, their families and carers. Supportive care may include multiple agencies. Referral should be as required.

Specific issues that may arise include:

- physical symptoms such as pain
- difficulty in breathing or swallowing, persistent new or changed cough, chest and or shoulder pain, weight loss or loss of appetite, unresolved chest infection and management of oral secretions and aspiration risk

- assistance in managing complex medication regimens, multiple medications, assessment of side effects and assistance with difficulties swallowing medications – referral to a pharmacist may be required
- decline in mobility and/or functional status as a result of treatment
- management of communication disability
- emotional and psychological issues including, but not limited to, body image concerns, fatigue, existential anxiety, treatment phobias, anxiety/depression, interpersonal problems and sexuality concerns
- isolation from normal support networks, particularly for rural patients who are staying away from home for treatment
- guidance for financial and employment issues such as loss of income and having to deal with travel and accommodation requirements for rural patients and caring arrangements for other family members
- legal issues (including advance care planning, appointing power of attorney, and completing a will).
- the need for appropriate information for people from culturally and linguistically diverse backgrounds.
- management of end-of-life care (OCP 2014).

Disclaimer

Whilst WA Health may facilitate access to ventilator and related equipment and consumables through the provision of prescriptions and/or advocacy with relevant agencies and organisations, WA Health is not a provider of ventilator and related equipment and consumables.

Background – Adult home-ventilated patients

Ventilation is a feasible and effective method of managing hypercapnic respiratory failure and is now considered first line therapy in the management of chronic respiratory failure. Home ventilation can assist those patients whose breathing is inadequate to maintain life during wakefulness and/or sleep. It can be provided in the patient's home and or/on their wheelchair and allows the patients to live at home rather than being cared for fulltime in a hospital setting (ACI 2012).

The main purpose for providing ongoing therapy is to reduce symptoms (e.g. breathlessness, sleep disruption), maintain or improve quality of life and, where possible, enhance survival.

Definitions and modes of ventilation

Invasive ventilation refers to the application of ventilator assistance with the use of an invasive airway, usually tracheostomy.

Non Invasive Ventilation (NIV) refers to the application of ventilator assistance without the use of invasive airway. In the vast majority of cases therapy will be delivered with positive pressure devices. Positive pressure therapy may be delivered with either volume or pressure ventilators. Volume present ventilation delivers a fixed volume irrespective of the patient's respiratory mechanics and requires a circuit with low leak. In contrast, pressure present ventilation delivers fixed pressures during inspiration and expiration. These devices are less susceptible to leak but the delivered volume can vary with changes in the patient's respiratory pulmonary mechanics (ACI 2012).

Modes of ventilation:

- Non-invasive positive pressure ventilation – ventilator assistance via a mask.
- Invasive ventilation – ventilator assistance via a tracheostomy.
- Negative pressure ventilation – ventilator assistance using a chest cuirass or iron lung.
- Diaphragm pacing – ventilator assistance by electrical stimulation of the phrenic nerves to the diaphragm muscles.

Home ventilation service

Home ventilation service is ventilation self-administered by the patient or the patient's carer.

Refer to Appendix 1 Current service provision – ventilation recording, reporting and funding

Goals of non-invasive ventilation

The goals of providing long-term ventilation will vary depending on the patient's primary disease process. For those patients with stable or slowly progressive disorders, the purpose of providing ongoing therapy is to increase survival while maintaining or improving the quality-of-life. In rapidly progressive disorders, the primary goal is to palliate symptoms.

In all cases, ventilation provides the opportunity to stabilise or improve respiratory insufficiency, allowing the patients to return to the community. The non-invasive approach also permits earlier intervention in the course of the disease than is possible with invasive techniques, reduces acute care costs by decreasing hospital length of stay and readmissions, and simplifies the burden of care related to managing chronic respiratory failure in the home (ACI 2012).

Medical conditions managed by ventilation

Home ventilation has been shown to improve survival, reduce hospital admissions, improve symptoms and quality-of-life in patients with conditions that cause chronic hypercapnic respiratory failure.

The main diagnostic groups that develop respiratory insufficiency and are subsequently treated with ventilation are patients with:

1. neuromuscular disorders that result in respiratory failure – both rapid and acute progression (e.g. Duchenne muscular dystrophy, motor neuron disease, spinal muscular atrophy, cerebral palsy)
2. spinal cord injury
3. chest wall disorders (e.g. kyphoscoliosis, scoliosis, thoracoplasty)
4. obesity hypoventilation syndrome
5. pulmonary disease (e.g. chronic obstructive pulmonary disease)
6. cystic fibrosis
7. hypercapnic/non hypercapnic central sleep apnoea.

Complex home-ventilation patients

These include:

- children on home ventilators transitioning to adult service
- patients with tracheostomies
- patients with rapidly progressive diseases (motor neuron disease)
- patients requiring ventilation more than 18 hours a day
- those starting home ventilation for the first-time excluding motor neuron disease, country patients requiring telehealth and telemonitoring.

WA care pathway for adult home-ventilated patients

The Pathway outlines **five critical steps** in the patient journey. While the five steps appear in a linear model, in practice, patient care does not always occur in this way but depends on the particular situation (such as type of medical condition, when and how the condition is diagnosed, prognosis, management and patient decisions, and psychological response to treatment).

The Pathway describes the care that should be provided at each step.

Step 1: Presentation, assessment (investigations) and referral

This step outlines the process for presentation and appropriate referral to the HSP. The types of assessments undertaken by the general or primary practitioner depend on many factors, including access to diagnostic tests, and medical specialists and patient preferences.

The support and liaison role of the General Practitioner (GP) and practice team in this process is critical.

Generally, patients may present to the HSP by any of the following:

1. Outpatient clinic.
2. Unplanned admission to hospital through Emergency Department.
3. In hospital – recognition of respiratory failure during an inpatient stay.
4. Intra hospital referral – referral from a consultant (such as neurology, respiratory).
5. Planned transition from Perth Children's Hospital (refer to Step 6: Transition from paediatric to adult care).

Consultation with the patient will depend on the diagnosis or reason for admission. The patient requiring ventilation will either be:

- referred to a respiratory/sleep medicine department for review, initiation on long term ventilation and ongoing management; or
- seen in the respiratory/sleep outpatient department (OPD) clinic and referred for sleep study and then reviewed. Ventilation can be initiated in OPD, in the sleep unit or as an inpatient.

Generally, ventilation should be commenced when there is evidence of (but not limited to):

- daytime hypercapnia
- nocturnal hypoventilation. Symptoms of nocturnal hypoventilation may include sleep fragmentation, morning headaches, hypersomnolence and cognitive dysfunction
- progressive respiratory muscle weakness where future respiratory failure is expected.

Assessment methods

The assessment will depend on the condition and presentation. Methods usually include:

- clinical evaluation

- lung function testing
- blood gases and other pathology tests
- sleep studies
- trial of non-invasive ventilation.

Apart from clinical evaluation, investigations prior to referral are not expected.

- Hypoxemia, hypercapnia, or an elevation in serum bicarbonate indicate the need for additional respiratory assessments and interventions.
- Patients with progressive respiratory muscle weakness and other restrictive thoracic disorders should be observed regularly with lung function and oximetry testing. Blood gas testing should be performed if sleep hypoventilation is suspected.
- Polysomnography should take into account the underlying aetiology of respiratory failure and the functional capacity of the patient and should be performed where there is a history suggestive of sleep-disordered breathing. Measurement of transcutaneous carbon dioxide during polysomnography is recommended if sleep hypoventilation is suspected.
- Consideration for polysomnography also includes symptoms of impaired sleep quality (such as daytime somnolence, waking headache or grogginess, fatigue, impaired cognition, impaired short-term memory, irritability, anxiety and depression) or symptoms of sleep-disordered breathing (such as frequent awakening, snoring, choking, gasping, waking dry mouth, waking dyspnoea or witnessed apnoeas).
- Where there is no overt sign of respiratory compromise, serial vital capacity testing, respiratory muscle testing, capillary blood gas testing and oximetry should be performed for surveillance.

Timeframe to be seen by the sleep and/or respiratory physician for assessment procedures following referral

The below provides a guide for completing investigations. Depending on the clinical condition and urgency the below is recommended.

Clinical condition	Timeframe
Acute respiratory failure	Within 24 hours – immediate
Chronic respiratory failure	Within 4 weeks
Evolving respiratory failure	Within 2 weeks

These investigations are organised by the sleep and/or respiratory physician, or lead clinician who assesses the patient.

Referral pathway

The HSP should provide clear routes of rapid access to specialist evaluation.

Timeframes for referral should be informed by evidence-based guidelines (where they exist), clinical urgency and speciality/medical condition. It is recommended from the date of receiving a referral the patient should be seen within two weeks on average. If the condition requires, the patient should be able to be seen on the same or next day.

Step 2: Treatment planning – clinical governance

Step 2 outlines the process for planning subsequent treatment. The guiding principle is that interaction between appropriate MDT members and the patient is central to treatment planning to support/enable patient centred care.

The aspects below should be considered when planning treatment for an adult home-ventilated patient.

- Obtain consent to share information with other organisations to assess eligibility for the relevant Support Programs (see below list).
- Designated lead clinician (the lead clinician may change over time depending on the stage of the care pathway and where care is being provided).
- MDT member to coordinate patient care.
- Develop and document an agreed treatment plan at the MDT meeting with the goal to engage and consult with the family/carer and other health professionals; to make holistic, continuity of care plans for the prescription and provision of equipment, consumables, all care attendant requirements, clinical support and management and social supports to enable discharge from hospital to live in the community; and exacerbation action plans for self-management and contact details for clinical support following discharge.
- Ensure the agreed treatment plan is accessible to relevant team members, including the GP, and recorded.

There is evidence that MDTs can improve outcomes in a range of patients. In both acute and primary care settings multidisciplinary-care is associated with improved clinical outcomes and other indicators such as hospital admissions. The design of the care team and the contribution of disciplines are the primary determinants of quality of care for people with chronic illnesses (Australian Government, DOH, 2012).

Support Programs

The following are some of the programs that can be considered for supporting home ventilation.

1. Private

Includes both Private Health Insurance or personal out-of-pocket.

2. Compensable

Insurance Commission of WA (ICWA) (<https://www.icwa.wa.gov.au>) can provide compensation for care and support (including medical treatment and rehabilitation) for individuals who are injured and able to establish the fault of another driver or unable to establish the fault of another driver (see CISS below). ICWA injury insurance claims can be made online or by calling the Insurance Commission on +61 (8) 9264 3333.

Catastrophic Injury Support Scheme (CISS) (<https://www.icwa.wa.gov.au/motor-injury-insurance/product-information/catastrophic-injuries-support>). CISS provides lifetime treatment, care and support for people catastrophically injured in motor vehicle crashes in Western Australia who are unable to establish fault of another driver. Catastrophic injuries are spinal cord injuries, traumatic brain injuries, multiple amputations, severe burns and permanent traumatic blindness. CISS is funded through motor vehicle injury insurance in WA. For further information about CISS call ICWA on +61 (8) 9264 3333.

Worker's Compensation. Individuals who are injured at work may be able to claim on their employer's insurance for the cost of treatment, care and support depending on the severity of their injury. Worker's Compensation is a legislative requirement for businesses in WA. It can protect injured workers by providing weekly payments to cover loss of earning capacity, payment of reasonable medical and rehabilitation expenses, and other entitlements.

- Workers' Compensation insurance is available through many insurance companies.
- Further information is available at <https://www.workcover.wa.gov.au>.

3. National Disability Insurance Scheme (NDIS) (<https://www.ndis.gov.au>)

NDIS is a national insurance scheme whereby people with moderate to severe disability who are aged under 65 when they first access NDIS can access reasonable and necessary support services, including education, employment, social participation, independence, living arrangements and health and wellbeing. The National Disability Insurance Agency (NDIA) is an agency of the Commonwealth Government that administers the NDIS.

Ongoing home ventilation supports (as opposed to diagnosis and clinical treatment) **may** be regarded as disability-related health supports which can be planned and funded through NDIS. The need for disability-related health supports must directly relate to an NDIS participant's functional impairment, where the support need is ongoing and is most appropriately funded or provided by the NDIS.

New potential NDIS participants need to apply for access to the scheme by calling the National Disability Insurance Agency on 1800 800 110 to make an Access Request or applying online at <https://www.ndis.gov.au>.

4. Department of Veterans' Affairs (DVA)

DVA funds health, aged care and disability care services for eligible veterans. This may involve ongoing support services or occasional care and treatment. Home ventilation supports **may** be able to be funded by DVA through its Rehabilitation Appliances Program (RAP). Potential users should call 1800 555 254 or go to www.dva.gov.au/rap.

5. State Government Equipment Programs

State Government programs include public hospital services, and community services for individuals who cannot meet their own needs or have them met through the above Programs. In 2020–21, home ventilation support **may** be available for eligible individuals through Community Aids and Equipment Program (CAEP). New potential CAEP users can apply via the WA Sleep Disorders Research Institute (WASDRI).

Responsibilities of individual team members

It is recommended that all patients have a GP. The GP as the primary care provider has a number of roles in all stages of the Pathway including referral, coordination and continuity of care as well as providing information and support for a particular phase.

The care coordinator may change over the course of the Pathway.

The lead clinician is responsible for overseeing the activity of the team.

Members of the multidisciplinary team for ventilation patients

The MDT should comprise the core disciplines integral to providing good care. Team membership will vary according to the medical condition/diagnosis but should reflect both

clinical and psychosocial aspects of care. Additional expertise or specialist services may be required for some patients (Department of Health 2007c).

Patients should have access to at least the following:

- Physiotherapist
- Occupational therapist
- Dietician
- Social worker
- Clinical psychologist
- Nurse.

Other MDT members include:

- Medical specialists e.g. sleep physician, neurologist
- Sleep scientist
- Clinical nurse consultant/specialist
- CNS complex transition program, nurse manager of the ward
- Speech pathologist
- Palliative care specialist
- Pharmacist
- Scientific officer.

In certain cases, patients will be reviewed by the specialist at a dedicated clinic (such as neurology clinic) to enable the patient to be discussed as needed with relevant staff at the time of presentation.

The optimal timing for multidisciplinary team planning

Newly diagnosed/referred patients should be discussed in a MDT meeting to discuss treatment. The level of discussion may vary depending on clinical and psychosocial factors.

There may also be a need to review existing treatment plans for patients who have been discussed previously.

Results of all relevant tests and imaging should be available for the MDT discussion. The care coordinator or lead clinician should also present information about the patient's concerns, preferences and social circumstances at the meeting (Department of Health 2007c).

Multidisciplinary team roles

Credentialed sleep physician duties

- Clinical governance of the patients and service.
- Triage referral.
- Diagnosis and overseas management.
- Educates patient on home ventilation.
- Prescribes home ventilation and settings.
- Orders and interprets lung function and sleep studies.
- Supervision, teaching and training of sleep trainees.
- Follow-up and fine tuning home ventilation.
- Provides inpatient consultation service.

- Home visits.
- Attends MDT meetings and transition clinics.
- Provides strategic direction to the home-ventilation service including audit, adverse event review, mortality and morbidity meetings and service development.
- Supports applications.

Critical care physician duties

- In consultation with credentialed sleep physician (above).

Sleep scientist duties

- Equipment ordering, stocking and assisting with servicing.
- Setting up, supervising and scoring complex sleep studies.
- Downloading equipment data for patient surveillance.
- Setting up home-ventilation equipment in the outpatients clinic.
- Trouble-shooting problems with fitting masks and ventilator-synchrony.
- Telemonitoring rural and remote patients.
- Phone calls from patients.

Respiratory scientist duties

- Performing lung function tests and arterial/capillary blood gas tests for home-ventilation patient diagnosis and monitoring.

Respiratory nurse duties

- Home visits.
- Remote and rural home visits.
- Clinics – inpatient/outpatient.
- In-reach-visiting, point of contact for patients and carers.
- Re-stocking equipment and administration.
- Training patients, carers and nursing homes on the home-ventilation equipment.
- Tracheostomy care.

Physiotherapist duties

- Airway clearance training for both patient and carer (e.g. use of cough assist machines).
- Clinical governance, teaching and training on airway clearance equipment.
- Home visits for airway clearance and cough assist carer training.
- Pulmonary rehabilitation in home or at local centre.
- Prevention of contractures.

Speech pathologist duties

- Assessment of swallowing and speech difficulties.
- Providing communication tools.
- Recommendations on videofluoroscopy.
- Advice on PEG tube.

Occupational therapist duties

- Home equipment for self-care (home modifications).
- Mobility equipment (wheelchair and wheelchair mounting).
- Call alarms.
- Electrical power failure plans (alarms, synergy notification).

Social work duties

- Advocacy and navigation of the Support Programs such as NDIS and interaction with health department and hospitals.
- Case management to coordinate services including non-government organisations (e.g. MSWA and Motor Neurone Disease Association of WA)
- Help with carer and patient respite and carer burnout.
- Electrical power failure plans (alarms, synergy notification).

Dietitian duties

- Gastrostomy feeding initiation and carer education.
- Managing malnutrition (e.g. Duchene muscular dystrophy).

Scientific officer duties

- Creating a database.
- Managing database – maintain for recall of faulty ventilators.

General practitioner duties

- Vaccination including flu and pneumococcal and other prevention screening.
- General medical care for patients/family.
- Facilitates team access to advice and rapid access to the home-ventilation lead and other team members.
- Assists with home care co-ordination (ACAT assessment/NDIS).
- Mental health plan for psychological needs of patients and carers.

Assessment/planning of patient/carer/family/home needs

The guiding principle is that interaction between appropriate MDT members should determine the holistic continuity of care plans to meet all home needs. A thorough assessment at admission and during hospital stay will determine the appropriateness of discharge to the patient's home. These needs should be clearly prescribed and documented for any external organisation/program responsible for the planning and approval of funding and contracting service providers to deliver care in the home.

MDT members involved in assessment of home needs/for discharge should be performed (at least) by:

- credentialled sleep/respiratory physician
- nursing staff
- occupational therapist
- social worker
- physiotherapist.

Equipment required/organised for home discharge include but are not limited to:

- clinical equipment (dependent on type of medical condition) – ventilators, nebulisers, monitors, suction devices, batteries, servicing equipment
- home equipment and modifications to wheelchairs, mask fitting and ventilator synchrony, alarms etc.
- electrical power failure plans (alarms, Synergy notifications) and energy subsidy
- ambulance cover
- airway clearance and cough assisted carer training
- coordination of services including non-government organisations (e.g. MSWA, and Motor Neuron disease association WA)

Life support registration

The registration of patients requiring life support equipment to their energy retailer is critical to ensuring patients are provided the required protections. When life support equipment is registered at a patient's supply address the energy retailer must:

- not disconnect the supply of energy for failure to pay a bill while the patient continues to reside at that address and requires the use of life support equipment
- prior to any planned interruption, provide at least three business days written notice (or electronic means) to the patient's supply address.

Registration forms can be obtained from:

- Synergy's form for life support registration https://www.synergy.net.au/Your-home/Manage-account/Register-for-life-support?tid=Registerforlifesupport:help_advice:Registerforlifesupport
- Horizon Power's form for life support registration https://horizonpower.com.au/media/1072/hp_3_17963-life-support-application-form-270418.pdf

Medical confirmation must be provided by the patient's specialist for registration. An MDT member should be responsible for organising application forms for patients.

Life Support Equipment Electrical Subsidy Scheme

The Life Support Equipment Electrical Subsidy Scheme is provided to assist financially disadvantaged persons, or their dependants, to meet the electricity costs of operating life support equipment at home. The subsidy is aimed at persons who hold a means tested concession card, (or dependants of people who hold means tested concession cards), who use specified life-support equipment in their home under specialist medical advice.

Application forms can be obtained from:

- www.wa.gov.au/organisation/departments-of-finance/subsidies-rebates (forms and factsheets).
- Forms for Life Support Equipment Electricity Subsidy Scheme (Health care card or concession card holders only) <https://concessions.communities.wa.gov.au/Concessions/Pages/Life-Support-Equipment-Electricity-Subsidy-Scheme.aspx>.
- Energy Subsidies Enquiry Line (08) 9262 1373.

Medical authorisation must be provided by the patient's specialist. An MDT member should be responsible for organising application forms for patients.

Local power supplier

The patient's local power supplier must be contacted for priority service in the event of a blackout.

Waste management

The patient will need to request an extra bin from their local council at their cost.

Local hospital emergency department

The local hospital emergency department must be contacted regarding the patient residing in their catchment area in case of an emergency.

Health Service Provider

The Health Service Provider technical services department to confirm the safety and sufficiency of the patient's home power supply.

Communication with the patient/family/carer

Full, open discussion must occur with the patient, carers and family at each clinical visit.

The lead clinician or members of the MDT should:

- establish if the patient has a regular or preferred GP
- discuss a timeframe for treatment with the patient and carer
- discuss benefits of multidisciplinary care and obtain patient consent to their health information being available to the team for discussion at the MDT meeting
- offer individualised information which meets the needs of the patient and carer (this may involve advice from health professionals as well as written and visual resources)
- offer advice on how to access information from websites, community and support groups
- use a professionally trained interpreter as required to communicate with people from culturally and linguistically diverse backgrounds.

All appointments should be followed by written communication to all clinicians involved, and if applicable to the patient/carer. The GP should be informed at all points to try to ensure shared care.

Communication with the general practitioner

Members of the MDT or lead clinician should:

- ensure regular and timely communication with the GP regarding the treatment plan and recommendations from MDT meetings
- contribute to the development of a chronic disease and mental healthcare plan as required
- discuss management of shared care
- invite the GP to participate in MDT meetings if applicable (consider using video or teleconferencing) (OCP 2014).

Step 3: Treatment

Step 3 outlines treatment options for home-ventilated patients. For detailed information on treatment options refer to the treating hospitals clinical practice guidelines for the management of ventilation in adult patients.

Treatment intent

The treatment intent can be defined as one of the following:

- Improve quality-of-life without expectation of cure.
- Increase survival.
- Reduce hospital admissions.

Curative treatment is rare for certain conditions. In this case supportive treatment for most patients will provide symptom relief, improve quality-of-life and may even prolong life. For other progressive conditions, ventilation provides quality-of-life, symptom control and is part of palliative management as the disease progresses.

The lead clinician should discuss treatment intent and prognosis with the patient and their family/carer prior to beginning treatment.

The treating medical team to discuss advanced care planning and Goals of Patient Care with the patient as there can be multiple benefits such as ensuring a person's preferences are known prior to and respected after loss of decision-making capacity (AHMAC 2011).

Treatment options

The advantages and disadvantages of each treatment and associated potential side-effects should be discussed with the patient.

Treatment options depend on diagnosis/prognosis and patient/family perception of quality of life.

Treatment options may include:

- full-invasive ventilation with or without oxygen therapy; tracheostomy
- non-invasive ventilation
- supportive management.

Timeframe for commencing treatment

Timeframes for beginning treatment should be informed by evidence-based guidelines (where they exist) while recognising that shorter timelines for appropriate consultation and treatment can reduce patient and family distress.

Clinical waitlist times can impact commencement of treatment; however there should be **No Delay** for commencing ventilation when needed.

Requirements for care of home-ventilation patients in WA

Staff and hospital centre characteristics

The following are the requirements for optimal care of home-ventilation in WA to provide initial assessment of patients, equipment and support home and regional services.

Initiation of home ventilation can be in three settings

- **Inpatient.**
- **Outpatient.**
- **Patient's home** (discussed under Training for assisted ventilation).

Inpatient

- Inpatient capabilities for acute and chronic non-invasive ventilation for the set-up of home ventilation and care of home-ventilation patients admitted to hospital.
- A clearly defined pathway to emergency care and advice after hours.
- High dependency and intensive care unit.
- Access to basic haematology and biochemistry testing.
- Appropriately trained allied health staff: physician, nurses, physiotherapist, occupational therapist, dietician, social worker.
- Access to speciality opinions (neurology, palliative care, cardiology, ENT surgery).
- Sleep study to titrate.
- Bariatric care and equipment, PEG feeding (appropriate staffing), pressure mattresses, appropriate toileting facilities.
- NDIS planner, support coordinator or service providers (as appropriate).

Outpatient

- Accredited sleep or respiratory physicians.
- Trainee respiratory sleep physicians.
- Sleep and respiratory scientists.
- Access to inpatient sleep study tests with transcutaneous CO₂ for both diagnosis and ventilation titration monitoring, blood gas testing and complex lung tests.
- Telehealth capabilities.
- Cloud access for monitoring home ventilators remotely (rural and remote patients).
- Speech services.
- Physiotherapy services for airway clearances, contractures, rehabilitation.
- Dietician.
- Nursing expertise (such as PEG gastrostomy and continence nursing expertise).
- Access to other speciality opinions (neurology, palliative care, cardiology, gastroenterology, interventional radiology, ENT surgery).
- Nurses (where available).
- CoNeCT or similar home-based program for high needs vulnerable patients e.g. children transitioning to adult services using home ventilation.
- Social work.
- Engineering for Assistive Technologies (wheelchair, communication, etc)
- NDIS planner, support coordinator or service providers (as appropriate).

Regional centres

- Hospitals may provide monitoring and continued care to patients in regional centres.
- Provide regional outpatient and home services.
- Respiratory, sleep or general physician.
- Registered nurse – ability to train existing nursing (NCCCP regional nurses).
- Investigations – blood gases and basic lung function tests.
- Telehealth capabilities.
- Ability for remote monitoring of home ventilators (rural and remote patients).
- Formal linkages to a metropolitan sleep centre.

Remote areas

In remote areas, local support is provided by:

- GPs.
- Remote Area Nurses.
- Aboriginal Liaison Officers.

Telehealth, telemonitoring and visiting by home ventilation nurse or team to remote areas may be used to minimise journeys to Perth.

Respite and residential care

Any need for respite or residential care should be undertaken by the patients MDT, GP, palliative care team or by the residential My Aged Care ACAP assessment.

Initial training for assisted ventilation

Specific skills and knowledge need to be acquired by patients and or their carers during the process of acclimatisation to assisted ventilation. Patients, family and carers should be routinely trained in the use of ventilation and any extras, in particular warning signs of deterioration. Acclimatisation and education for home-ventilated patients should occur at hospitals where there is a sufficient through-put of patients requiring long-term assisted ventilation. Appropriate contact details (phone, email etc) must be given to the patient/family/carer to address any urgent changes; and the patient and/or carer must be aware of who to contact for medical and technical difficulties

In order for a patient to be successful with assisted ventilation in their home environment they and their carers must feel comfortable with the concept of assisted ventilation, their equipment and ventilator settings and have enough knowledge to be able to problem solve or know who to contact when required. As patients will have different levels of cognition, physical abilities, treatment tolerance and treatment acceptance, the time course of acclimatisation can vary significantly between individuals.

Training and experience in ventilation is very important and adequate numbers of skilled people should be available throughout the 24 hour period. Inexperienced people in the area of ventilation, can inadvertently cause distressing episodes of dyspnoea, pain from mask application or inappropriate continuation or discontinuation of ventilation. If carers and family are appropriately trained in ventilation, an inpatient or supported home setting can be appropriate for the end-of-life in chronic respiratory failure patients.

The primary care giver(s) must demonstrate the necessary skills in equipment set-up and use and should demonstrate understanding of the patient's physical condition (ACI 2012).

Minimal requirements for training

Changes in patient's physical condition

The patient/family/carer must be aware of how to monitor:

- Respiratory rate.
- Chest excursion (amplitude and synchrony with machine delivered breaths).
- Colour changes.
- Diaphoresis and lethargy.
- Body temperature.
- Heart rate.

Ventilator

The patient/family/carer must demonstrate:

- familiarity with the most important parts of the ventilator and how to operate it
- familiarity with the main alarms on the ventilator
- ability to react to problems related to ventilation
- knowledge of the ventilator settings if possible or know where a copy of their most recent ventilator settings can be obtained
- they know how the ventilator acts in the event of a loss of mains power and how to respond during power failure
- they know how to change or clean the filter
- they know the level of urgency to seek a response for medical attention or equipment replacement
- understanding that if the ventilator is locked they will not accidentally alter the settings.

Patient-Ventilator Interfaces

The patient/family/carer must demonstrate knowledge of:

Tracheostomy

- competency with placing and adjusting the tracheostomy tubing
- the different parts of the tracheostomy – how to dismantle and put back together, and the implications of a broken or missing piece
- how to adequately clean the parts
- the implications of excessive leakage or aspiration on patient-ventilator synchrony, patient tolerance and patient comfort
- their understanding of the need to check the equipment regularly for wear and tear (especially tracheostomy and tubing)
- how to manage tracheostomy emergencies
- how to safely entrain oxygen into the system if supplemental oxygen is required.

Mask Ventilation

- competency with placing and adjusting the mask and headgear, without significant leakage
- the different parts of the mask – how to dismantle and put back together, and the implications of a broken mask or a mask with a missing piece
- adequate handling, placement and understanding of the importance of the expiratory valve
- how to adequately clean the parts such as the mask's tubings
- the implications of excessive face-mask leakage or mouth leakage on patient-ventilator synchrony, patient tolerance and patient comfort
- their understanding of the need to check the equipment regularly for wear and tear (especially mask and tubing)
- how to rapidly remove the mask in the case of nausea or vomiting
- how to safely entrain oxygen into the system if supplemental oxygen is required.

Humidifiers and Nebulisers

The patient/family/carer must know:

- how to attach, clean and fill the heated humidifiers
- how to empty humidifiers for transport, especially if they are integrated units
- that if nebulisers are to be frequently entrained through mouth pieces or oro-nasal masks, extra attention should be paid to cleaning the expiratory ports and anti-asphyxial valves (where present)
- why nebulisers are utilised.

Support and contact information

The patient/family/carer must:

- have the name and telephone number of the service to contact during work hours for standard problem solving advice
- know that during an emergency situation, the patient should be transported to an emergency department, via emergency services
- have an itemised list of the names, phone numbers and addresses of the retailers which are supplying their masks, tubing, filters and other ancillary equipment
- know who is responsible for the maintenance of their ventilator and that they should speak with their ventilator supplier and understand the process in the event of an issue with their ventilator.
- have the relevant and up-to-date phone numbers for clinical and technical support available 24 hours a day.
- have a written plan of action for predictable problems such as power cuts, chest infection, and equipment failure
- have access to clinical support for service providers.

Equipment

Success with ventilation is reliant on appropriate selection of equipment and settings.

Ventilator

- For patients who require ventilation overnight a single ventilator without a built-in battery could be used. Most non-invasive ventilators are not approved for life support, these would be appropriate for these patients
- For patients dependent on life support for greater than 16 hours or require a non-invasive ventilator for day use on wheel chair, two ventilators that are approved for life support with a built in battery and exterior battery should be used. The second is a backup if one ventilator is faulty or there is a power failure
- In the instance of wakeful hypoventilation which does not require invasive ventilation, NIV should be supplied by a ventilator that has been approved for life support
- Those needing invasive ventilation should only be supplied a ventilator that has been approved for life support
- One or two ventilators maybe required depending on need, safety and location of patient. Patients who live remotely, or need a wheel chair mounted ventilator or have rapidly progressive disease will often need two ventilators. If the final ventilator is likely to be a life support ventilator then this should be used earlier, to avoid the need to frequently change ventilators
- Ventilator and batteries needs to be serviced regularly (ACI 2012).

Masks and consumables

The choice of interface or mask is a major determination of NIV success or failure.

Overall, long-term mask choice should be based primarily on patient comfort and acceptance, whilst ensuring that it is both safe and effective. Every effort should be made to ensure that air leaks are minimised, patient comfort is maximised and that the mask can be easily applied and removed.

Patients may need to trial up to four masks in the initial introduction of NIV. They may require up to two (2) masks per year not including parts such as seals. Filters on ventilators usually need to be changed frequently (e.g. every six months). Patients often require specialised tubing such as a heated tube. Oxygen may need to be entrained via adapters (ACI-AVI 2012).

Adjuncts to home ventilation

- Cough assist machines.
- Oxygen.
- Suction machines in some patients.

Step 4: Ongoing management

Management by the health system

After completing initial treatment, patients should be provided with a treatment summary and follow-up care plan including a comprehensive list of issues identified by all members of the MDT (where applicable). Transition from inpatient to outpatient or home care will vary depending on the patient's medical condition. The treatment plan provided to the patient and GP will also vary according to the service provider.

Communication

After initial treatment, the patient, carer, family and GP should receive a treatment summary. The patient should also be provided with a manual/information that includes written instructions on the ventilator, servicing, trouble shooting and cleaning and power subsides.

Follow-up care

Follow-up phase is driven by individual clinical and supportive care needs. It is important that follow-up care is evidence based and consistent with guidelines. Responsibility for follow-up care should be agreed between the lead clinician, the GP and relevant members of the MDT with an agreed plan to outline what medical/non-medical follow-up is required. The plan must be discussed with the patient.

Follow-up is dependent on the service provider and the patient needs. In particular circumstances, follow-up care can safely and effectively be provided:

- In the primary care setting (hospital, routine clinics, ad hoc clinics etc.).
- By suitably trained staff (nurse led follow-up, Sleep Physician, PT/OT etc.).
- In a non-face-to-face setting (telehealth).

Access to a range of health professionals may be required including sleep physician, physiotherapist, occupational therapist, nurse, social worker, dietitian, clinical psychologist and palliative care provider. Follow-up care may be required for issues such as:

- airway clearance
- rehabilitation
- sleep studies if tolerating home ventilation poorly
- lung function tests
- palliative and end-of-life care.

Follow-up timeframe will depend on the patient's condition. Patients can be reviewed at six to eight weeks following the commencement of ventilation to determine the clinical response to therapy. After initiation of ventilation, clinical review should occur within the first two to three months to assess symptoms, technical problems, ventilator settings, compliance and success.

Further clinical reviews should be performed by a sleep Physician/Respiratory Physician or Respiratory clinic every six to twelve months, again assessing symptoms, compliance, technical problems, lung function, oximetry and further investigations (including ABGs and overnight oximetry or Polysomnography) as required.

Home visits are co-ordinated by specialist centres and can be conducted by:

- home visiting nurse consultant, or nurse
- health professionals competent in airway clearance and in training patients and carers on cough assist machines
- home visiting occupational therapists.

Items required by visiting staff include car, mobile phone, duress alarm and laptop (for ventilation downloads).

Sleep physician and nurse to train patient/family/carers in use of ventilation – particularly warning signs of deterioration with contacts to a sleep physician to address any urgent changes. Home visiting nurses to conduct tracheostomy training.

Step 5: Palliative and end-of-life care

Palliative care seeks to prevent, relieve, reduce or soothe the symptoms of disease or disorder without effecting cure (ACI-AVI 2012). Using this description, palliative care is not restricted to patients who are dying or in hospice programs, and suits the description of the use of ventilation in certain disorders, such as rapidly progressive neuromuscular disorders and during advanced stages of other diseases where the focus has shifted from improving survival to quality of life which aims to enhance physical, emotional or social comfort for the patient (ACI 2012).

End-of-life care considerations may be appropriate when the patient's symptoms are increasing, and functional status is declining. It is concerned with maintaining the patient's quality of life and addressing their health and supportive care needs as they approach end of life, as well as the needs of their family and carer. Consideration of appropriate venues of care is essential. The principles of a palliative care approach to care need to be shared by the team when making decisions with the patient and their family.

The WA End-of-Life and Palliative Care Strategy 2018–2028 (the Strategy) outlines the values and priorities for end-of-life and palliative care in WA. It describes how services can work collaboratively to provide integrated high-quality care at end of life. The Strategy is applicable to all services in WA with a focus on supporting people and their family/carer at end of life. *The Goals of Patient Care* should be utilised and discussed in collaboration with the MDTs, patient and family to set and outline realistic and agreed goals for the care of the patient in the event of clinical deterioration.

Multidisciplinary palliative care

If not already underway, referral to palliative care should be considered at this stage for planned respite (including nursing, pastoral care, palliative medicine specialist back-up, inpatient palliative bed access as required, social work and bereavement counselling) with GP engagement.

If not already in place, the patient and carer should be encouraged to develop an Advance Care Plan (AHMAC 2011). It is important that an Advanced Care Plan is reviewed on a frequent basis as the underlying disease may change rapidly in the end stage of disease and patient views about the benefits of treatment may change accordingly.

The palliative care team may consider seeking additional expertise from a:

- pain specialist
- respiratory physician
- pastoral care or spiritual advisor
- bereavement counsellor
- therapist.

The team might also recommend accessing:

- home and community-based care
- specialist community palliative care workers
- community nursing
- Silver Chain hospice care.

Consideration of an appropriate place of care and preferred place of death is essential.

Ensure carers and families receive information, support and guidance regarding their role according to their needs and wishes (Palliative Care Australia 2005).

Withdrawing ventilation

When patient on ventilation requests its withdrawal, the reasons for the request should be explored and all options considered.

The decision to withdraw ventilation must be discussed with the patient (or enduring guardian), specialist and MDT.

Step 6: Transition from paediatric to adult care

The transition for young adults on ventilation is a staged process which requires close collaboration between paediatric and adult specialist care teams. The choice of primary adult specialist and respiratory support will depend on the underlying diagnosis of the young person, the locality of services and clinical decision. The timing of transition can be especially difficult in adolescents with a progressive disorder who are nearing the terminal stage of their disease.

Decisions regarding transition should be individualised taking into account:

- disease stability
- developmental maturity
- educational and social situation.

Paediatric and adult specialist teams should:

- develop a joint transition plan to ensure smooth transition of care and equipment
- meet to discuss individuals in transition prior to transfer to adult health services.

Adult health services should:

- provide youth friendly resources
- ensure staff members are educated in the management of young people with chronic health problems
- provide family focused care.

Discussions about potential differences in the provision of ventilator equipment between paediatric and adult services should commence 24 months prior to the transition (16 years).

Depending on the young person's abilities, they should be encouraged to learn how to maintain their ventilator equipment and mask, know how their equipment is put together and how it works, and become independent with ventilator application prior to transition to adult services. This should be prompted from an early age.

Refer to the WA care pathway for paediatric home-ventilated patients

Appendix 1

Current service provision – ventilation recording, reporting and funding

There is a wide variation in the provision of hospital and home ventilation services across HSPs and there are significant limitations in current service capacity. The patients on home ventilation have become increasingly complex with multiple co-morbidities and often severe disability. They may have intellectual, communication, sensory, swallowing, and mobility problems in addition to other health problems. This is particularly highlighted by patients who have survived childhood due to non-invasive ventilation (Duchenne, muscular dystrophy spinal muscular atrophy, nemaline (rod), etc) and now are transitioning to adult services.

Classification of Tier 2: 10.19 Ventilation – home delivered service

Ventilatory support is a process by which gases are moved into the lungs by a device that assists respiration by augmenting or replacing the patient's own respiratory effort.

Home delivered service is ventilation self-administered by the patient or the patient's carer.

At present, only service events for ventilator-dependent patients are classified as in scope under the National Health Reform Agreement (NHRA). Ventilator-dependent patients are defined as having met at least one of the criteria below:

- Patients who cannot maintain spontaneous ventilation for four or more consecutive hours.
- Patients who require non-invasive ventilation for a minimum of 18 hours per day.
- Patients who require more than 16 hours ventilator support and live where a replacement ventilator cannot be provided within four (4) hours.
- Patients who require ventilation during mobility as prescribed in their care plan.
- Patients ventilated via tracheostomy for a minimum of eight (8) hours per day.
- Patients with central hypoventilation syndrome.
- Patients who require long-term overnight non-invasive ventilation every night for chest wall deformity-related or neuromuscular-related chronic respiratory failure.

Procedures for patients who meet the above criteria

- Bi-level positive airway pressure (BiPAP)
- Continuous positive airway pressure (CPAP)
- Diaphragm pacing
- Negative pressure ventilation (iron lung)
- Ventilation via tracheostomy.

Exclusions

- Consultation or education in medical respiratory clinic where no ventilation was undertaken (20:19).
- Consultation or education in allied health/clinical nurse specialist respiratory clinic where no ventilation was undertaken (40:40).

Clinic Registration

HSPs that provide home-delivered ventilation to ventilator dependent patients are NOT required to register home ventilation clinics on the Non-Admitted Clinic Management System.

Counting

Generally, for a non-admitted service event to be counted, each of the criteria in the definition of a service event should be met. Home delivered ventilation is an exception to this rule, as there is no interaction between a patient and a healthcare provider. However, all other criteria in the definition of a service event must be met:

- Non-admitted patient.
- Therapeutic/clinic content.
- Dated entry in the patient's medical record (e.g. Care Plan outlining treatment). Whilst a daily written entry in the patient's medical record each day is not necessary, there must be sufficient documentation in the patient's medical record to support their care plan.

For each patient, all non-admitted patient sessions performed per month are to be bundled and counted as one non-admitted patient service event per patient per calendar month regardless of the number of sessions. If a patient is admitted to hospital for the entire month, exclude that month's recording.

Activity recording and reporting

All activity undertaken in a non-admitted patient setting is in-scope and is to be recorded in an approved electronic patient information system; either a core or a satellite system.

The information system must be capable of supporting the reporting requirements for Activity Based Funding.

For further details on the recording and reporting requirement see the Non-Admitted Activity Recording and Reporting Mandatory Policy, <https://ww2.health.wa.gov.au/about-us/policy-frameworks/information-management/mandatory-requirements/collection/non-admitted-activity-recording-and-reporting-policy>

(Independent Hospital Pricing Authority Tier 2 Non-Admitted Services Definitions Manual 2018-2019. Version 5.0)

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