Appendix 3: Guidance documents - completed data extraction forms

Guidance document characteristics	
Endorsing Organisation/Author	Insurance & Care New South Wales (icare)
Title	Guidance on the support needs for adults with spinal cord injury (3rd Ed)
Country	Australia
Date Published	1 Dec 2017
URL	https://www.icare.nsw.gov.au/-/media/icare/unique-media/treatment-and-care/what-we-do/guidelines-and-policies/media-files/files/download-module---spinal-cord-injuries/guidance-on-the-support-needs-of-adults-with-spinal-cord-injuries.pdf
National or regional	Regional (New South Wales)
Adapted/adopted from previous guidance document? If so which guidance document was it adapted/adopted from?	This guidance is the third edition of a previous guideline. The previous editions were the *Guidelines for levels of attendant care for people who have spinal cord injury and can claim under the New South Wales Motor Accidents Scheme* released in 2002 and the *Guidelines for levels of attendant care for people with spinal cord injury* released in 2007. This revision aimed to retain what was still relevant and 'fit for purpose', update areas where information is based on research evidence, remove or add information, and use the knowledge from expert practitioners, participants and providers to inform the guidance
Based on evidence synthesis?	Yes
Based on expert consensus?	Yes
Update(s) planned (including dates)	To be reviewed in 2027
Funding	icare lifetime care (Insurance and Care) funded the development of this guidance.
Certainty of evidence grading	Like a guideline, this document provides guidance and a decision support tool. However, it is not called a guideline. Guidelines usually provide multiple statements on what course of action or actions should be taken and each statement of recommended action is graded. The recommendation and grade are usually based on a single dimension of information, which is the best available clinical research evidence. Given the complexity of this guidance topic, it was not surprising to find that the systematic literature search identified limited clinical research on which to base recommendations. There is limited research on personal assistance generally and spinal cord injury specifically. Although there is only one recommendation in this document (to consider the need to understand the person's context), the guidance includes a significant body of information to inform and guide the user
Domiciliary invasive ventilation guidance Domiciliary invasive ventilation guidance	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Pre-transition phase	**6. Use of the guidance**

Recommendation:
Decisions about the need for assistance from support workers for a person with traumatic spinal cord injury should consider knowledge and understanding of the:

- person – goals, body function and structure, activities and participation, and the stage post injury
- person's context – environmental, personal factors, attitudes, beliefs and social norms, supports (informal and formal)
- person's progress – towards their goals, their outcomes, barriers and facilitators in the person's context.

The user should refer to the decision-making framework (Figure 1) to guide their practice. Understanding the person, their context and progress will enable best-practice decision-making about their need for support workers

10. Making decisions on the need for support

There are many factors to consider when deciding on the person with spinal cord injury's need for support (bearing in mind support workers are only one type of support). The key considerations include:

- Why assistance is needed
  - understanding the person
  - understanding the person's context
  - understanding the person's progress
- Matching the need for assistance with the supports such as
  - the type of formal and informal supports that exist within the home and community
  - whether additional assistive technology is required or would assist
  - who, how and when assistance is needed
- Consideration of practical matters including
  - criteria for funding
  - 'when, how and who' will ensure that all the informal and formal supports (including support workers) are integrated and coordinated
  - each person's circumstances related to the criteria for funding.

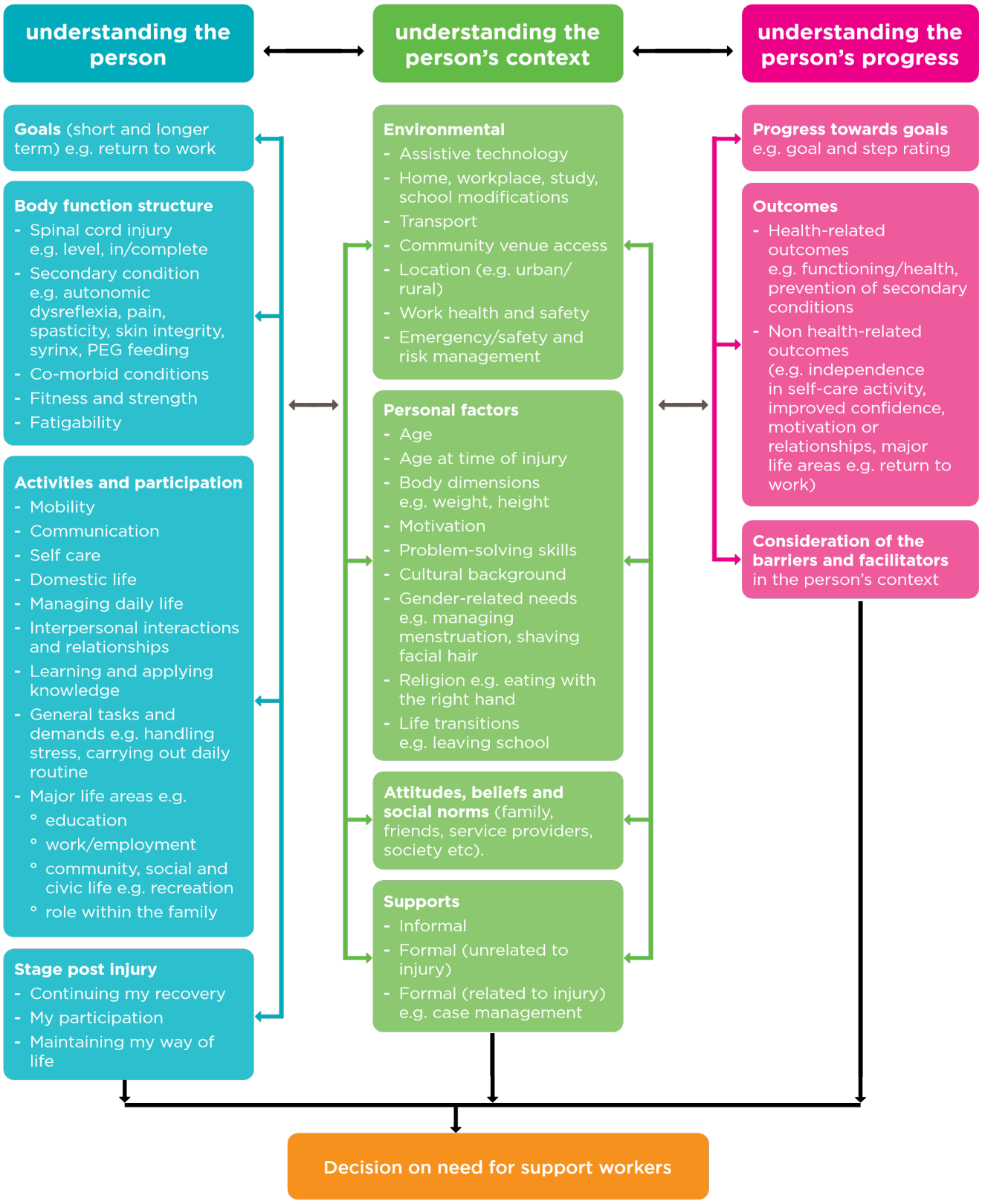
This guidance provides a decision-making framework which gives an overview of the factors to consider when deciding why assistance is needed. Following the framework ensures that the barriers and facilitators in the person's immediate context are considered before matching the need for assistance with the supports. The framework does not provide prompts for considering the practical matters. It is crucial to consider the person's performance in their own environment (or familiar environment, e.g. their workplace), rather than their capacity in a standardised test or hospital situation.

The decision-making framework is not a linear or stepwise process; it is multi-dimensional. It uses interactive scaffolding to apply best-practice reasoning, and prompts those involved in determining a person's need for support to adopt a person-centred approach and use different sources of knowledge. The sources of knowledge are categorised as:

1. Narrative: The person's own descriptions, preferences and point of view; this is so that the individual context can be understood and considered and may include knowledge from the person's family and carers
2. Evidence: Current best research evidence, scientific knowledge or established facts, including objective measures of change in individual performance

	3. General reasoning: Knowledge derived from professional experience; this may include a professional's experience of other patients/ clients/participants in similar circumstances 4. A shared view: Knowledge derived from thinking and reasoning when the person's immediate and broader circumstances are considered, including feedback from the person's family, carers and range of service providers 5. Pragmatic reasoning: Knowledge of practical issues and contextual factors, and whether these influence the ability to achieve the desired outcome. *The guidance does not recommend specific assessment tools*

Figure 1: decision-making framework for a person with spinal cord injury and their need for support workers



Transition phase	NR
General principles of home mechanical ventilation	**13.1 Benchmarks** *Those involved in providing support workers, and the support workers themselves, should aim to achieve the following best practice benchmarks.* *1. The person with the spinal cord injury is involved in the planning, delivery and monitoring of the assistance from support workers.* *2. The tasks assist and enable the person to increase and/or maintain their independence and achieve their goals.* *3. Services are integrated, aligned and communication appropriately maintained between parties, for example, personal and domestic services, case management, other providers (e.g. exercise programs).* *4. Support workers:* *• are culturally aware and sensitive* *• maintain professional boundaries with the person and the family and carer* *• work appropriately with the family and carer.* *5. Support workers and their employing organisations meet industry and professional standards and competencies.* **13.2 Coordination of supports** *The World Health Organization (WHO) defines care coordination as 'a proactive approach in bringing care professionals and providers together around the needs of service users to ensure that people receive integrated and person-focused care across various settings'. Coordination to ensure that informal and formal supports work properly and well together is critical for all those involved and particularly the person with spinal cord injury. Coordinated formal and informal supports that meet the service user's needs, so that they achieve their goals, are likely to be more cost-effective. Initial and ongoing service coordination and communication may be the responsibility of the service provider, case manager, planning facilitator, care coordinator (or one of a team of support workers), a family member or carer, the service user themselves or a combination of these. The need for coordination of formal supports may reduce over time once the routine of life and participation is established. It is important to identify and review who is coordinating supports and how.*
Technical requirements	**11. Assistive technology (equipment and products)** ▪ *Assistive technology requests should be based on comprehensive assessment and substantiation of need and shared decisions with the user. Assistive technology should be trialled in the context where it will be used (e.g. home environment) with adequate training provided to any person using the assistive technology. Additional costs may be involved in the set-up and maintenance of the assistive technology and training in its use. Assistive technology should be maintained and/or replaced according to the manufacturer's specifications and prescribing therapist's recommendations*. **11.1 Disposable items lists** <u>11.1.1 Disposable items for no motor function below C1–C3</u> ▪ Antimicrobial filters suitable for use with ventilator as ordered ▪ Heat moisture exchange (e.g. humidivent) ▪ Tracheostomy care suction catheters 12 Fr/30.5cm length ▪ Re-usable blue swivel connectors

	• 15mm x 22mm connectors • Nebuliser with T piece mouthpiece and connecting bush • Tracheostomy tubes (identical to current tube type and size prescribed as well as one size smaller as well as one size larger and one size smaller) – check exact type (i.e. LPC, cuffless, fenestrated/non-fenestrated). • Blue flex tubing lengths • Disposable Foley adaptors • 50mL syringes • Large dressing packs • 10mL ampoules normal saline • Xylocaine pre-loaded syringes • Sterile pipe cleaners • Cotton and velcro tracheostomy tapes • Normal saline sterile sachets • Sterile and non-sterile gloves • Incontinence sheets • Plastic disposable aprons • Alcohol wipes • Disinfectant handwash lotion • Disposable Yanker sucker • Sterile lubricating gel tubes • Female urinary catheters (for use during bowel care – gender is irrelevant) • Gauze squares • 10mL ampoules hydrogen peroxide • Sterile H2O nebulisers • Urinary catheters (identical to current catheter size being used as well as one size larger and one size smaller) • Quick drain catheter tube taps • Urinary drainage 750mL long tube leg bags • Catheter leg straps 45cm • Night bottle • Urinalysis dipsticks • Micropore tape (2.5cm / 1 inch) • Keyhole drain sponges <u>11.1.2 Respiratory disposables for C1–C3 ventilator dependent</u> • Antimicrobial filters suitable for use with ventilator as ordered • Heat moisture exchange (e.g. humidivent) • Closed tracheostomy care suction catheters 12FG/14FG 30.5cm length, and/or Y-suction catheters in appropriate size • Disposable ventilator circuits • Humidifier chamber • Disposable resuscitation bag (e.g. ambi-bag) • Re-usable blue swivel connectors

	• 15mm x 22mm connectors • Tracheostomy nebuliser kit with appropriate connectors • Tracheostomy tubes (identical to current tube type and size prescribed as well as one size smaller) • Spare inner tracheostomy cannula • Blue flex tubing lengths • Large dressing packs • 10mL and 50mL ampoules normal saline • 10mL syringe • Sterile lubricating gel • Hydrogen peroxide ampoules • Sterile and non-sterile gloves • Inner cannula cleaning brush • Cotton and velcro tracheostomy tapes • Suction tubing • Dressing as required for around tracheostomy, e.g. split gauze, Allevyn • Passy Muir/speaking valve • Associated consumables for Cough Assist <u>11.1.3 C4 to S5 skin, bowel and bladder management disposable items</u> (These items may be required for people with either no motor function below the level of injury OR some motor function below the level of injury.) The disposable item list is a general guide only. The person's needs should be assessed by an incontinence advisor and their personal preferences also considered. The list details all possible assistive technology that may be required for the level of motor functioning, but not all assistive technology is always required. **Bladder management equipment** Catheter – Foley type – Indwelling or suprapubic catheter • Silicone catheter – male length • Silicone catheter – female length **Catheter accessories** • Re-usable catheter thigh strap • Catheter procedure pack (sterile) containing: tray, swabs, sterile gloves, lubricating gel, sterile water ampoules, saline sachet, drape and sterile towel • 10mL syringe • Sterile xylocaine gel • Toomey syringe (catheter tip) • Sterile kidney dish • Bottle sterile saline • Split gauze/drain sponge

	• Alcohol wipes • Catheter valve (flip flow) • Specimen jar **Catheters for intermittent catheterisation*** ▪ Single use nelaton type (double or single wrapped), male or female length ▪ Single use nelaton type pre-lubricated, male or female length ▪ Single use hydrophilic catheter, male or female length ▪ Single use pre-lubricated catheter sets with collection bag, in male or female lengths ▪ Re-usable intermittent catheter sets (e.g. Cliny) *All intermittent catheter brands and types should be prescribed by a continence advisor, considering client preference for product choice. **Intermittent catheterisation accessories** ▪ Clothing hook ▪ Splint ▪ Mirror ▪ Extension tubing ▪ Sterile lubricant ▪ Glycerine ▪ Baby wipes ▪ Plastic bags ▪ Hand sanitiser **External uridome (condom) drainage** ▪ Latex one piece – self-adhesive ▪ Latex two piece ▪ Silicone one piece – self-adhesive ▪ Silicone two piece ▪ Non-lubricated condom **External drainage accessories** ▪ Double-sided tape ▪ Single-sided foam tape ▪ Condom connector ▪ Adhesive – wipes/brush on/dab on ▪ Adhesive removal wipes **Drainage bags/bottles** ▪ PVC leg bag – long tube ▪ PVC leg bag – short tube

	▪ PVC leg bag – adjustable tube ▪ Night bottle ▪ Night bag **Drainage bag accessories** ▪ Leg straps or catheter anchoring device ▪ Night bottle connector/tubing ▪ Night bag holder/stand ▪ Leg bag holder ▪ Rubber/silicone tubing ▪ Urosol detergent ▪ Milton liquid **Continence pads** ▪ Disposable pads ▪ Washable pads ▪ Washable pants ▪ Disposable bed pads (e.g. Blueys) ▪ Male continence slips ▪ Mattress protector **Sundry items** ▪ Portable urinal ▪ Xylocaine gel ▪ Uro-tainer Suby G ▪ Uro-tainer sodium chloride **Bowel management equipment** ▪ Microlax micro enema ▪ Bisalax micro enema ▪ Fleet enema ▪ Glycerine suppository ▪ Durolax suppository ▪ Lubricant gel tube (water-based) ▪ Latex or hypoallergenic non-sterile gloves ▪ Female length nelaton catheter (soft) ▪ 10mL syringe ▪ Disposable bed pads (e.g. Blueys) ▪ Trans-anal irrigation system ▪ Anal plugs ▪ Wipes/disposable towels

- Rectal tube

Skin care equipment

- Wound management (all appropriate to the size of
- wound)
- Basic dressing packs
- Variety of appropriate dressings (e.g.
- hydrocolloid, foam, hydrogel, alginate, film,
- non-adherent)
- Gauze swabs
- Combined dressing
- Saline sachets
- Retention tape
- Barrier wipes
- Crepe bandage
- Tubi-grip

Miscellaneous items

- Antibacterial handwash
- Antibacterial hand gel
- Disposable wash cloths
- Disposable apron
- Eye protection
- Air freshener spray

12.1 No motor function below the level of spinal cord injury

12.1.1 Level of support: Cervical 1-3 (C1-C3) no motor function below

- Wheel-in vehicle for transportation (full support needed)
- Intermittent suction (full support needed)
- Assistive technology for communication (moderate support needed)

Assistive technology C1-3 - no motor function below

The list for C1–C3 when the person requires ventilator support is a guide only and is not inclusive of all the assistive technology/products a person may require. Other assistive technology or products may be recommended depending on individual circumstances, personal choice and independence. All assistive technology recommendations should be developed through best-practice reasoning and person-centred assessment.

- Motorised, height-adjustable bed, with appropriate controls and equipment as prescribed including: relevant controls, bolsters, footboard, trendelenburg, head and foot raise, knee break, side/grab rails, linked to environmental control unit; partner bed to be supplied where appropriate
- High-care pressure relief mattress, full air replacement with pump
- Twenty-four hour drinking system accessible from bed and wheelchair
- Mattress overlay for emergency use/when travelling

	▪ Power tilt-in-space wheelchair with features as prescribed: head/chin/breath control, postural support devices, power recline and leg raise if required; may include attendant control system ▪ Replacement battery charger ▪ Tyre compressor/pump ▪ Pressure relief wheelchair cushions (2) and covers (2) ▪ Back-up manual or power wheelchair as prescribed ▪ Powered ceiling hoist, and portable electric hoist, hoist charger and batteries (2) ▪ Hoist slings (2 sets) ▪ Shower commode chair with prescribed features or shower trolley ▪ Portable shower hose as required ▪ Over-bed table, height adjustable ▪ Portable lightweight ramps ▪ Slide sheets ▪ Vehicle modifications for attendant-operated wheelchair accessible vehicle with safety (e.g. head and postural support, automatic tie downs) and prescribed features (e.g. air-conditioning) ▪ Independently activated environmental control systems accessible from wheelchair and bed, to include: door opener and intercom, call buzzer/intercom, monitoring system, 'back-to-base' monitored personal alarm, temperature control (reverse cycle air-conditioning at a minimum in ▪ the bedroom and living area, fan, heater, blinds), lights, bed, TV/music ▪ Communication and information assistive technology devices including hardware and software with hands-free access features such as mouth stick, speaker phone, voice activation; devices may include computer/tablet/mobile phone and telephone landline ▪ Adjustable desk ▪ Exercise equipment as prescribed ▪ Splints as prescribed ▪ Ventilators as prescribed (2) ▪ Back-up /power source for all powered devices for use when power fails ▪ Ventilator breathing circuits (3) (specific to ordered ventilator) ▪ Air Viva resuscitator (2) ▪ Mains operated suction unit for use in the home ▪ Evacuation equipment ▪ Portable suction unit, battery operated ▪ Breathing circuits as indicated for use with oxygen and air cylinder (2) ▪ Cough Assist, BiPAP and/or CPAP machine ▪ Blood pressure monitor ▪ Thermometer ▪ Medical grade sheepskin sliding mat, boots and backrest ▪ Abdominal binders as indicated ▪ Anti-embolic or compression stockings and gloves Additional assistive technology may be needed for other activities and participation in life roles depending on the person's individual preferences and lifestyle choices, for example, pre-injury activities, parenting role, work, recreation and leisure activities. This may include items such as a

	sports or recreational wheelchair, adapted sports equipment, club or other memberships, etc. Trial and possible hire of assistive technology should be considered.
Staffing	**8.2 Who is a Support Worker** ▪ *The types of assistance, support or services provided by support workers in a person's home or community include (but are not limited to) (ACIA Guideline 002 [23]):* o *personal care or support (e.g. assistance to shower)* o *housework or domestic assistance* o *transport assistance* o *community access* o *social support* o *nursing services* o *clinical supports* o *gardening and home maintenance* o *palliative care* o *respite care.* **See Technical Requirements above re: support worker requirements**
Monitoring	NR
Infection prevention and control	NR
Other guidance	**13.4 Emergency preparation** *It is important that there are plans and strategies in place to manage different emergency situations. Emergencies can range from natural disasters (e.g. storm, bushfire) to personal emergencies (e.g. fires in the home, personal safety at home or in the community). An emergency may involve anything from the support worker suddenly becoming ill and unable to work, to a breakdown of a power wheelchair when away from home, to a flood blocking access. Solutions and management strategies must be established for common emergency situations. These may include ensuring that the person and their support workers have phone numbers for after-hours support worker service providers, a support worker relief agency, and emergency mechanic or road service familiar with power wheelchairs; and emergency numbers for fire brigade, police and ambulance services. It is also important to inform the fire brigade and other emergency services of very limited mobility issues or limitations in emergency access so that if an emergency situation does arise, they are better prepared. There are resources and tools available to assist with preparing for emergencies and developing a plan. The person with spinal cord injury, their family, carer and providers (including the planning facilitator/case manager, support worker and service provider) all have responsibilities to ensure that there is an emergency plan and strategies in place. There is also a role for initiating and contributing to the development of a disability inclusive disaster plan in the local community. The 'I'm Okay' website (http://imokay.org.au/actionsteps) provides useful information and resources and outlines the following steps to prepare for an emergency:* ▪ *Know yourself and your community* ▪ *Make a plan* ▪ *Assemble an emergency kit* ▪ *Review and maintain the plan.* **13.5 Overnight assistance from a support worker**

It is important to differentiate the person's need for assistance overnight and consider the parameters of employing a support worker overnight.

<u>Overnight needs of the person with spinal cord injury.</u>
The need for assistance overnight differs with each person with spinal cord injury and their circumstances. Determining if a support worker is needed overnight should start with identifying the risks, followed by working out solutions and putting systems in place to safeguard against these (e.g. emergency call systems, pressure care equipment). Furthermore, a support worker should be provided on the basis of what does happen, not what may happen or 'in case of an emergency'. There are circumstances when there are no alternative options to overnight assistance.

There may be a need for a support worker at specific periods or in the longer term because of:

- *physical conditions such as:*
  - *autonomic dysreflexia caused by an uncontrollable irritant (e.g. irritated bowel)*
  - *treatment-resistant sleep apnoea*
  - *unstable medical conditions (e.g. a cough, need for suction, bronchitis, issues around menstruation or bowel function)*
- *requirement for re-positioning (e.g. chronic pain)*
- *personal factors or psychological condition (e.g. sleep walking, falls, anxiety)*
- *periods of exceptional circumstances (e.g. illness so that the person needs a drink, medication or PEG feed).*

<u>Employing a support worker overnight</u>
In Australia, when a support worker is employed to sleep overnight (by a service provider or the person themselves) at the premises of the person with spinal cord injury, they must be provided with a separate room with a bed and the use of facilities (e.g. bathroom). There are also other requirements under the employment award. The span for a sleepover must be a continuous period of eight hours and there must be active work immediately before and/or immediately after the sleepover period so that the support worker is paid for four hours of work for at least one of these periods. If the support worker is required to attend to the person with spinal cord injury during the sleepover period, the support worker must be paid for the period of time they have worked (with a minimum of one hour).

13.6 Support worker and service provider elements

<u>Medication administration</u>
Determining the need for support should also consider administration of medication. This should be discussed with the person, their family and carer. The risks, skill and competency required to assist the person to administer their medication should be determined and made clear to the people involved. A support worker should have completed competency training on administration of medication. A support worker should not fill a box medication compliance aid with the prescribed tablets, but may administer oral medication from the pharmacy or manufacturer-labelled medication container or a blister pack.

<u>Service provider accreditation, standards and approved providers</u>
The person with spinal cord injury needs to be involved in decisions around which service provider is engaged. For those people and families who have never needed assistance from a support worker before, identifying the appropriate service provider can be a daunting task. There are two benchmarks for selecting service providers that a user should consider when selecting a service provider:

- *Provider certification – In Australia (and other countries), there is a national quality management standard for the provision of support worker services. Service providers can undergo a quality assessment of their service and be certified under an accreditation scheme. Refer to the Attendant Care Industry Standard (ACIS) (www.acia.net.au/getting-certified).*

	▪ *Approved provider – Some (but not all) support worker funding organisations elect to screen service providers and develop a list of accredited service providers that they consider meet additional criteria such as –* ○ *the required pool of skilled support workers to meet the assistance needs of the particular group of service users that they fund (e.g. spinal cord injury, traumatic brain injury)* ○ *agreed set fees structures* ○ *geographic location and other criteria such as support worker training, worker health and safety policies, etc.* *Other factors that may be considered are rural and remote services, availability of live-in staff, or recruitment approach (e.g. service user involved with interviews and selection)* ***13.8 Work health and safety*** *Working in someone's home is a unique work environment. The responsibility to take all reasonably practicable steps to ensure the support worker's health and safety lies with the person or business or organisation undertaking (including the funder) and employing the support worker. If the service user employs the support worker directly, it is their responsibility (see Section 13.9). The steps to ensure work health and safety involve eliminating or minimising the risk of injury to the support worker (and the service user) after having considered matters such as the likelihood and severity of the risk and the means to control it. Usually the maintenance of the workplace is the responsibility of all parties involved, and this also applies when the workplace is someone's home. In practice, all parties involved (i.e. the service provider, support worker and service user) are responsible and should work in partnership to maintain safe premises. This includes the property or business owner if away from the home (e.g. hotel).* *Training and work health and safety practices not only protect the support worker, but also the safety of the person with spinal cord injury (e.g. during person-related manual lifting where there are tasks involved such as personal care, transfers). The principles of health and safety practice should be reviewed and incorporated across all environments where assistance is provided, as well as when there is a change in the environment. For example, whether the support worker is involved in providing assistance in the home, or out of the home when on holidays or in transitional accommodation, or in work or study/education environments, potential risks should be considered. Expectations around responsibilities for work health and safety training of any new support worker or for assistance in different environments need to be clarified and included in service agreements.*
Management of SCI complications	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Respiratory	NR
Bladder	NR
Bowel	NR
Skin	NR
Sexual health	NR
VTE	NR
Pain	NR
Autonomic dysreflexia	NR
Emotional wellbeing, mental	NR

health and substance abuse	
Cardiometabolic and nutrition	NR
Bone Health	NR
Palliative care	NR
Rehabilitation	NR
Wheeled mobility	NR
Other guidance	NR
Broader SCI care pathways and supports	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Governance structure	**13.3 Communication and relationships** *Mutual expectations of each of the parties involved should be discussed and agreed on. Rather than assuming this has been done, someone needs to ensure that expectations have been discussed, agreed on and some matters included in a service agreement signed by the relevant parties. Responsibilities for clarifying expectations will vary depending on who is involved. Expectations and matters that need to be clarified include:* ○ *Communication – the day-to-day practical matters of communication; what, when and how day-to-day issues are communicated* ○ *Practical issues concerning employment – for example, minimum hours per shift* ○ *Tasks for the support worker – for example, expected time frames to complete tasks; responsibilities; negotiating the support worker completing a combination of tasks (e.g. domestic and personal care)* ○ *Unfilled shifts – plans for situations where a support worker is not available, or unable to commence or complete the shift, for example, if support worker is sick, or has transport difficulties (e.g. traffic congestion)* ○ *Complaints – the procedure for making and handling of complaints to, and from, all those involved in the provision of support workers.* ▪ *There also needs to be clarity around more personal issues such as mutual respect (between the support worker and the person with spinal cord injury), consent, personal boundaries, and roles within the household.*
Funding model	*One of icare's roles is to support the long-term and lifelong needs (including support workers) of people who have sustained any of the following serious injuries: spinal cord injury, moderate to severe brain injury, multiple or specific unilateral amputations, serious burns, or blindness, whether the injury occurred through a motor vehicle crash or at work. This guidance was developed to assist with determining the support needs of participants in the schemes administered by icare.*
Care pathways	
Education across the continuum of care	**8.2 Who is a Support Worker** ▪ *The support worker should have access to training, support and advice from the service provider line manager or team leader (or arranged by the person with spinal cord injury if they are self-managing their funds).* ***13.7 Qualifications and training of support workers***

	Matching the skills and competencies of support workers to the needs of the person with spinal cord injury is critical. Different skills are needed for different tasks. For example, providing personal care requires different skills to domestic tasks. Training of support workers should also include training on safety and interpersonal relationships, not just the relevant physical skills. Beyond generic skills training, there is a need for additional orientation and (usually) onsite training related to the specific person receiving the support. At times, there may be a need for additional training when there are changes in the person's circumstances (e.g. a pressure area has developed, a fracture occurred, a suprapubic catheter was inserted) or changes in the roles within the home (e.g. carer no longer able to perform the task). The person with spinal cord injury should be involved in training the support worker. Typically the service provider is responsible for developing and providing training for the support worker. On occasions, additional support worker hours may be required to enable the training specific to the person with spinal cord injury. *The Capability Framework for Service Providers identifies the essential knowledge and skills required by the support worker to work effectively in their role. It enables the service provider to assess the induction and ongoing training of each support worker they employ. The framework consists of five sections: orientation; provide personal care; maintain a safe environment; establish and maintain appropriate interpersonal relationships; provide complex support relating to catastrophic clinical matters.* ***13.8 Work health and safety*** *Some of the topics for training in work health and safety include (but are not limited to):* ▪ *identifying risks and risk management in the home (refer to www.acia.net.au/safetymds.nsw)* ▪ *infection control and the use of personal protective equipment* ▪ *person- and assistive technology-related manual lifting* o *use of assistive technology (e.g. hoists, transfer board, slide sheet)* o *determining whether a one- or two-person lift is required (refer to the report at www.sprc.unsw.edu.au/media/SPRCFile/ Report5_13_TwoCareWorkers_Final_for_ web_June_2013.pdf)* ▪ *slips, trips and falls* ▪ *medication management* ▪ *food handling and safety* ▪ *managing difficult behaviours (where appropriate)* ▪ *prevention of workplace bullying* ▪ *first aid* ▪ *emergency plans and procedures.*
Safeguarding and ethics	**9. Choice and control for the person with spinal cord injury** ▪ *For any person, active involvement in life means having the opportunity to exercise choice, being involved in making decisions about yourself (with the support needed), and accepting the associated responsibilities. Participation and engagement in life and making choices around supports is of itself beneficial to enhance a person's self-awareness, self-identity and adjustment to changed life circumstances. While the person needs information to assist with making decisions and informed choices, they are the expert about themselves and their situation, and should be viewed as such.* ▪ *Choices might be everyday choices (like what to have for breakfast, showering in the morning rather than evening), lifestyle choices (like whether to go out and see a movie) or pervasive choices (like where to live). The person should also be able to exercise their choice around the provision of assistance from the service provider and support workers, including personal preferences (e.g. gender of carer). The right to choose also means that sometimes a person may elect not to have a support worker or assistance with a specific task. Each of us has the right to take risks and make what others may consider to be an unwise decision. Sometimes there are other factors (such*

	as living in regional or remote areas, service availability, access to services, or the service provider not being able to accommodate all of the person's preferences) which influence opportunities for choice
Other supports	**8.1 Who is the carer** ▪ *Carers should be given a choice about what care tasks they wish and do not wish to perform; this will differ according to the caring role. Some tasks are more appropriate and sustainable for carers to perform than others (e.g. assistance overnight). At other times, assistance from a support worker might make a significant difference to alleviate carer stress (e.g. by performing a household task)* ▪ *These studies, as well as expert practice and experiential knowledge, confirm the need for early screening and regular review of carer distress and strain. The circumstances of each person, their family and carers are different. If distress and strain are detected early, strategies to assist the carer should be put in place and, where necessary, treatments commenced.*
Quality assurance processes	NR
Other guidance	NR

Key: NR – Not Reported

Guidance document characteristics	
Endorsing Organisation	Praxis Spinal Cord Institute, Spinal Cord Injury Research Evidence (SCIRE) & KITE (Knowledge, Innovation, Talent and Everywhere)
Title	Canadian Spinal Cord Injury Practice Guideline (Can-SCIP)
Country	Canada
Date Published	2021
URL	https://kite-uhn.com/can-scip
International, national or regional	National
Adapted/adopted from previous guidance document? If so which guidance document was it adapted/adopted from?	Is a living guideline with 585 recommendations from 41 clinical practice guidelines that have been adopted (n=281), adapted (n=215) or newly developed (n=89) to align with the Canadian healthcare environment. *Of note recommendations outlined below refer to those that are relevant for a C1-C4 injured person with quadriplegia with ASIA A/B loss of function who is living in the community.*
Based on evidence synthesis?	Yes
Based on expert consensus?	Yes
Update(s) planned (including dates)	Update planned for 2022.
Funding	Praxis Spinal Cord Institute, Vancouver, British Columbia
Certainty of evidence grading	LEVEL A - Recommendation supported by at least 1 meta-analysis, systematic review, or randomized controlled trial of appropriate size with relevant control group. LEVEL B - Recommendation supported by cohort studies that at minimum have a comparison group, well-designed single subject experimental designs, or small sample size randomized controlled trials. LEVEL C - Recommendation supported primarily by expert opinion based on their experience, though uncontrolled case series without comparison groups that support the recommendations are also classified here.

Domiciliary invasive ventilation guidance	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Pre-transition phase	**Q.5 - HOME MECHANICAL VENTILATION** ▪ Q.5.1: Individual with cervical or thoracic SCI should be evaluated for long-term ventilation support when appropriate. Non-invasive respiratory support is the preferred mode for individuals with SCI and respiratory insufficiency. (Adapted from CTS 2011, p.13; Level C)

	▪ Q.5.2: Phrenic nerve pacing and diaphragmatic pacing in select individuals as an alternative to positive pressure ventilation (PPV) alone. (Adapted from CTS 2011; p.13; Level C)
Transition phase	NR
General principles of home mechanical ventilation	▪ Q.5.3: Individuals with cervical or thoracic SCI require regular assessment to identify the loss of lung volume, retention of respiratory secretions, development of sleep-disordered breathing, and ventilatory failure, to evaluate the need for cough assist techniques and nocturnal positive pressure support. (Adapted from CTS 2011, p.13; Level C) ▪ Q.5.4: Individuals with cervicothoracic SCI and evidence of respiratory impairment should receive regular airway clearance techniques, lung volume recruitment (i.e., manually assisted coughing and mechanical in-exsufflation) and ongoing monitoring of pulmonary function to ensure adequate airway clearance. (Adapted from CTS 2011, p.13; Level C)
Technical requirements	NR
Staffing	NR
Monitoring	NR
Infection prevention and control	NR
Other guidance	NR
Management of SCI complications	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Respiratory	**Q - RESPIRATORY** **Q.2 - ABDOMINAL BINDER AND ABDOMINAL MUSCLE STIMULATION** ▪ Q.2.1: We recommend an abdominal binder to improve pulmonary function among individuals with a neurological level of injury of C1 to T11. (CAN-SCIP 2020; Level B) ▪ Q.2.2: Electrical abdominal muscle stimulation may be offered to improve cough function only in the context of a supervised research trial. (CAN-SCIP 2020; Level C) **Q.3 - PHARMACOLOGICAL AGENTS FOR RESPIRATORY FUNCTION** ▪ Q.3.1: Inhaled Beta-2 agonists in individuals with tetraplegia and impaired respiratory function with a component of obstructive airway impairment is recommended. (CAN-SCIP 2020; Level B) **Q.4 - RESPIRATORY MUSCLE TRAINING** ▪ Q.4.1: Clinicians should introduce routine upper limb exercise and respiratory muscle training for all individuals with a T12 injury and higher to improve respiratory muscle strength and function. (CAN-SCIP 2020; Level C)
Bladder	**K - BLADDER FUNCTION** **K.1 - HISTORY** ▪ K.1.1: When referred a new patient with neurogenic bladder, a focused history and physical exam relevant to the neurogenic condition should be performed. (CUA 2019, p.161; Level C) ▪ K.1.2: Consider referral for urgent investigation if individuals with SCI have any of the following 'red flag' signs and symptoms: 1. recurrent catheter blockages (for example, catheters blocking within 6 weeks of being changed) 2. hydronephrosis or kidney stones on imaging 3. biochemical evidence of renal deterioration (i.e., estimated eGFR-write out all algorithm).

(Adapted from NICE 2012, p.51; Level C)

- K.1.3: Clinicians should be attentive to any modification of general functioning and on the appearance of any new urological symptoms and alarm signs (e.g., pain, increased spasticity, autonomic dysreflexia, infection, fever, and hematuria). (URO 2017, p.588; Level A)
- K.1.4: Clinicians should be aware that unexplained changes in neurological symptoms (for example, confusion or worsening spasticity) can be caused by urinary tract disease and consider further urinary tract investigation and treatment if this is suspected. (NICE 2012, p.51; Level C)
- K.1.5: Clinicians should assess the impact of lower urinary tract symptoms on the individual's quality of life, family members, and caregivers and consider ways of reducing any adverse impact. (NICE 2012, p.51; Level C)

K.2 - PHYSICAL

- K.2.1: Clinicians should undertake a general physical examination that includes:

1. blood pressure management
2. abdominal examination
3. external genitalia examination
4. vaginal or rectal examination (as indicated for evidence of pelvic floor prolapse, fecal loading or alterations in anal tone)
5. ISNCSCI assessment, if necessary
6. hand function
7. mobility
8. cognitive assessment

(Adapted from NICE 2012, p.50; Level C)

K.3 - VOIDING DIARY

- K.3.1: Clinicians should ask individuals with SCI and/or their family members and caregivers to complete a 'fluid input/urine output chart' to record fluid intake, frequency of catheterization, urination and volume of urine passed for a minimum of 3 days as a baseline to detect changes in bladder function. (Adapted from NICE 2012, p.50; Level C)

K.4 - URODYNAMICS

- K.4.1: All individuals with SCI and evidence of neurogenic bladders should ideally be assessed using video urodynamic as it is the gold standard to assess neurogenic lower urinary tract in individuals with SCI. (URO 2017, p.589; Level A)
- K.4.2: Attending clinicians should not stop medications that may influence lower tract function before video urodynamic; however, their administration should be considered in the interpretation of the data. (URO 2017, p.589; Level B)
- K.4.3: Clinicians should not routinely prescribe antibiotic prophylaxis before urodynamics. However, in scenarios where the individual has high-risk factors such as, evidence of vesicoureteral reflux, high voiding pressure, repeated urinary tract infection or prothesis that may be at risk of infection, antibiotic prophylaxis may be considered prior to urodynamics. (Adapted from URO 2017, p.589; Level C)
- K.4.4: Urodynamic studies should not be performed when an individual with SCI has a symptomatic UTI or pyuria to avoid worsening of the clinical condition and prevent erroneous interpretation of the urodynamic findings. (Adapted from URO 2017, p.589; Level C)

K.5 - URINARY TRACT INFECTION (UTI)

- K.5.1: Clinicians should not treat positive dipstick or culture in asymptomatic patients who catheterize except in the setting of nephrolithiasis and stone-forming bacteria as bacterial colonization will likely be present in individuals using a catheter (indwelling or intermittent), and so urine dipstick testing and bacterial culture may be unreliable for diagnosing active infection. (Adapted from NICE 2012, p.50; Level C)

	▪ K.5.2: We recommend clinicians do not screen or treat individuals with asymptomatic bacteriuria with neurogenic lower urinary tract dysfunction (except in pregnancy as it promotes antibiotic resistance and can increase the likelihood of symptomatic urinary tract infection). Treatment should be limited to individuals with positive urine culture in the presence of clinical symptoms, including leukocyturia, bacteriuria. (Adapted from CUA 2019, p.164; Level B) ▪ K.5.3: Use the presence of leukocyturia, bacteriuria, and clinical symptoms to diagnose UTI in individuals with SCI and neurogenic lower urinary tract dysfunction (except in pregnancy): treatment should be limited to individuals with positive urine culture in the presence of clinical symptoms of UTI. (Adapted from CUA 2019, p.164; Level B) ▪ K.5.4: Urinalysis and urine culture should always be obtained prior to initiating antibiotic therapy due to the increased risk of multidrug-resistant microorganisms. (Adapted from CUA 2019, p.164; Level B) ▪ K.5.5: If an individual is systemically unwell or symptoms are intolerable, collect culture, start antibiotic therapy, and modify or discontinue antibiotic therapy based on culture results. (Adapted from CUA 2019, p.164; Level B) ▪ K.5.6:Clinicians should prescribe individuals with SCI and a culture confirmed UTI with a course of antibiotics for at least 7 days and 10–14 days for those with significant infection or a delayed response. (Adapted from CUA 2019, p.164; Level B) ▪ K.5.7: Clinicians should avoid the provision of routine anti-microbial prophylaxis for individuals with SCI and neurogenic lower urinary tract dysfunction and frequent urinary tract infection. (Adapted from CUA 2019, p.165; Level A) ▪ K.5.8: Consider antibiotic prophylaxis only for individuals who have a recent history of frequent urinary tract infections once reversible causes have been ruled out (such as urolithiasis). (Adapted from NICE 2012, p.271; Level C) **K.6 - BLADDER MANAGEMENT** ▪ K.6.1: Triggering and Valsalva or Crede´ manoeuvres should be strongly discouraged due to their threat to the upper urinary tract (i.e., kidney and ureter damage) in individuals with SCI. (Adapted from CUA 2019, p.162; Level B) ▪ K.6.2: Selection of an assisted bladder drainage method (clean intermittent catheterization, urethral or suprapubic catheter) based on the individual's motor functions, anatomic limitations, bladder characteristics, prior urological complications, and quality of life. Clean intermittent catheterization is the preferred method of bladder management after SCI, where possible. (Adapted from CUA 2019, p.166; Level B) **K.7 - CATHETERS** ▪ K.7.1: Offer individuals with neurogenic urinary tract dysfunction, their family members, and caregivers specific information and training. Individuals who are starting to use or are using a bladder management system that involves the use of catheters, appliances or pads, should: 1. receive training, support and review from healthcare professionals who are trained to provide support in the relevant bladder management systems and are knowledgeable about the range of products available, 2. have access to appropriate education on managing the daily and social needs of their bladder, 3. have access to a range of products that meet their needs, and 4. have their products reviewed at a maximum of 2 yearly intervals. SCI-U Patient Education Link on Bladder: http://sci-u.ca/bladder-2 (Adapted from NICE 2012, p. 70; Level C) ▪ K.7.2: Patients with indwelling urethral catheters should be offered conversion to a suprapubic catheter in the setting of significant urethral damage (and ideally before the urethra has been irreversibly damaged and there is a risk of stress incontinence). (CUA 2019, p.163; Level B) **K.8 - NON-PHARMACOLOGICAL THERAPIES TO ENHANCE BLADDER FUNCTION**

	▪ K.8.2: The following conditions must be met before initiating a behavioural management program (e.g., timed voiding, bladder retraining or habit retraining) for those with neurogenic lower urinary tract dysfunction: 1. prior assessment by a healthcare professional trained in the assessment of individuals with neurogenic lower urinary tract dysfunction and 2. in conjunction with education about lower urinary tract function for the individual and/or their family members and caregivers. (Adapted from NICE 2012, p.84; Level C) **K.9 - PHARMACOLOGICAL THERAPY TO ENHANCE BLADDER FUNCTION** ▪ K.9.1: Oral antimuscarinics with dose-escalation are the first-line pharmacological treatment for patients with neurogenic lower urinary tract dysfunction in order to improve overactive bladder symptoms and neurogenic detrusor overactivity, decrease urgency urinary incontinence and lower detrusor pressures (CUA 2019, p.166; Level A) ▪ K.9.2: Mirabegron may be a useful alternative to antimuscarinics for individuals with symptoms of overactive bladder and neurogenic lower urinary tract dysfunction, but further evidence of urodynamic changes is needed in this population. (CUA 2019, p.167; Level B) ▪ K.9.3; Clinicians should monitor residual urine volume in individuals with SCI who are not using intermittent or indwelling catheterization after starting antimuscarinic treatment. Once therapy is initiated, clinicians should monitor for signs and symptoms of urinary retention. (Adapted from NICE 2012, p.116; Level B) **K.10 - NEUROGENIC DETRUSOR OVERACTIVITY** ▪ K.10.1: Clinicians should prescribe oral antimuscarinics with dose-escalation as the first-line pharmacological treatment for patients with neurogenic lower urinary tract dysfunction in order to improve overactive bladder symptoms and neurogenic detrusor overactivity, decrease urgency urinary incontinence and lower detrusor pressures. (CUA 2019, p.166; Level A) ▪ K.10.2: Oral antimuscarinics with dose-escalation are the first-line pharmacological treatment for patients with neurogenic lower urinary tract dysfunction in order to improve overactive bladder symptoms and neurogenic detrusor overactivity, decrease urgency urinary incontinence and lower detrusor pressures. (CUA 2019, p.166; Level A) ▪ K.10.3: Mirabegron may be a useful alternative to antimuscarinic for individuals with symptoms of overactive bladder and neurogenic lower urinary tract dysfunction, but further evidence of urodynamic changes is needed in this population. (CUA 2019, p.167; Level B) ▪ K.10.4: Alpha-blockers can be considered for the treatment of failure to empty the bladder secondary to detrusor sphincter dyssynergia; however, this is supported by weak evidence. (CAN-SCIP 2020; Level C) **K.11 - INTRAVESICAL BOTULINUM TOXIN INJECTIONS** ▪ K.11.1: Monitor residual urine volume in individuals who are not using a catheterization regimen during treatment with botulinum toxin type A. Monitor for and educate patients on urinary retention as a complication. (Adapted from NICE 2012, p.176; Level A-C) ▪ K.11.2: Before offering an intravesical botulinum toxin type A: 1. explain to the individual and/or their family members and caregivers that a catheterization regimen is needed in most individuals with neurogenic lower urinary tract dysfunction after treatment 2. ensure that they are able and willing to manage such a regimen should urinary retention develop after the treatment (Adapted from NICE 2012, p.176, Level A-C) ▪ K.11.3: Antimuscarinic drugs are the first-line treatment for detrusor overactivity. Botulinum toxin type A injections to the bladder wall should be considered when antimuscarinic drugs have proved to be ineffective or poorly tolerated. (Adapted from NICE 2012, p.175; Level A-C)

- K.11.4: Clinicians should monitor individuals with SCI, particularly those with cervical SCI, for the risk of generalized weakness (including respiratory weakness and motor weakness) after the injection of intravesical botulinum toxin type A. (CAN-SCIP 2020; Level B)
- K.11.5: For individuals receiving intravesicular botox injections should be offered prompt access to repeat injections when symptoms return. (NICE 2012, p.176; Level A-C)
- K.11.6: For individuals receiving multiple indication botox (e.g., spasticity, neurogenic bladder, aesthetic purposes), a coordinated plan amongst care providers is required to minimize the risk of adverse reactions. (CAN-SCIP 2020, Level C)

K.12 - ROUTINE URINARY TRACT SURVEILLANCE

- K.12.1: A physiatrist, urologist and/or family physician should conduct regular annual urological assessments of all individuals with SCI and neurogenic lower urinary tract dysfunction. (Adapted from CUA 2019, p.170; Level B)
- K.12.2: An annual renal and bladder ultrasound is recommended in individuals with neurogenic lower urinary tract dysfunction. (Adapted from CUA 2019, p.170; Level B)
- K.12.3: Routine surveillance cystoscopy for bladder cancer screening is not required in individuals:

1. with neurogenic lower urinary tract dysfunction;
2. with or without augmentation cystoplasty;
3. individuals who have no other signs or symptoms.

(Adapted from CUA 2019, p.170; Level B)

- K.12.4: Where feasible, video urodynamic studies or a cystogram should be performed in patients where further knowledge of the urinary tract anatomy and physiology is needed. If not feasible, urodynamic studies should be done - in the setting of worsening bladder symptoms or concerning changes in renal function (biochemical or radiologic investigations). (Adapted from CUA 2019, p.171; Level B)
- K.12.5: Isotopic creatinine clearance or 24-hour urine for creatinine clearance assessment should be conducted every one to two years to follow renal function Note: Do not rely on serum creatinine and estimated glomerular filtration rate in isolation for monitoring renal function in individuals with neurogenic lower urinary tract dysfunction. Creatinine measurement in SCI is not reflective of renal function due to low total muscle mass, causing artificially low serum creatinine. (Adapted from NICE 2012, p.292; Level C)
- K.12.6: Consider using isotopic glomerular filtration rate when an accurate measurement of glomerular filtration rate is required (e.g., if imaging of the kidneys suggests that renal function might be compromised). (NICE 2012, p.292; Level C)

K.13 - UROLOGY CONSULTATION

- K.13.1: Patients should be referred to a urologist when there is persistent and bothersome incontinence, unmitigated urodynamic parameters (such as neurogenic detrusor overactivity or poor compliance), new or worsening hydronephrosis or renal dysfunction that cannot be reversed so that the individual can consider reconstructive surgery options such as bladder augmentation, abdominal continence stoma, or urinary diversion. (CAN-SCIP 2020; Level C)

K.14 - POST-VOID-RESIDUAL

- K.14.1: Clinicians should measure the post-void residual urine volume, preferably by ultrasound with a portable scanner or clean intermittent catheterization, on different occasions to establish how bladder emptying varies at different times and in different circumstances for individuals with SCI and some ability to void. (Adapted from NICE 2012, p.51; Level C)

K.15 - STONES & HYDRONEPHROSIS

	▪ K.15.1: Clinicians should routinely discuss with individuals with SCI and their family members and caregivers that indwelling catheters (urethral and suprapubic) are associated with a higher incidence of bladder stones compared with other forms of bladder management. (Adapted from NICE 2012, p. 309; Level C) ▪ K.15.2: Clinicians should educate these individuals to look out for signs that suggest that they should consult a healthcare professional (for example, recurrent infection, recurrent catheter blockages or haematuria). (Adapted from NICE 2012, p. 309; Level C) ▪ K.15.3: Clinicians should discuss with the individual with SCI, family members and caregivers the increased risk of renal complications (e.g., kidney stones, hydronephrosis and scarring) in individuals with neurogenic urinary tract dysfunction. (Adapted from NICE 2012, p.308; Level C) **K.16 - CANCER SCREENING** ▪ K.16.1: Clinicians should discuss with the individual with SCI, family members and caregivers that there may be an increased risk of bladder cancer in individuals with neurogenic lower urinary tract dysfunction, particularly in those with a long history of neurogenic lower urinary tract dysfunction and complicating factors, such as recurrent urinary tract infections. Clinicians should educate individuals with SCI regarding the symptoms to look out for (for example, recurrent infection, recurrent catheter blockages, or hematuria), which mean they should see a healthcare professional. (Adapted from NICE 2012, p.309; Level C)
Bowel	**M - BOWEL** **M.1 - AIMS OF NEUROGENIC BOWEL MANAGEMENT** ▪ M.1.1: The aims of bowel management after SCI are to promote continence, achieve bowel emptying in a regularly scheduled timely manner, in a socially convenient way, and avoid complications. (Adapted from BOWEL 2012, p.452; Level C) **M.2 - ASSESSMENT OF NEUROGENIC BOWEL DYSFUNCTION** ▪ M.2.1: Define the level and completeness of SCI according to the current International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI) scale. (PVA-NBD 2020, p.452; Level C) ▪ M.2.2: A systematic comprehensive evaluation of bowel function, impairment, and possible problems should be completed at the onset of SCI and at least annually throughout the continuum of care. (PVA-NBD 2020, p.452; Level C) ▪ M.2.3: A comprehensive, detailed gastrointestinal history should be completed at the onset of SCI, annually, and as needed when any significant gastrointestinal changes occur. (PVA-NBD 2020, p.452; Level C) ▪ M.2.4: A physical examination should be done at the onset of SCI, annually, and upon any significant change in bowel function or health. This should include thorough abdominal and rectal examinations. (PVA-NBD 2020, p.452; Level C) ▪ M.2.5: An abdominal x-ray/computed tomography scan can be used to evaluate the extent of fecal loading, fecal incontinence due to stool overflow, and other bowel problems such as fecal impaction, bowel obstruction, megacolon, and megarectum. (PVA-NBD 2020, p.452; Level B) ▪ M.2.6: Colonic transit time testing with radiopaque markers or scintigraphy can be used to provide more information on neurogenic bowel dysfunction. (PVA-NBD 2020, p.452; Level B) ▪ M.2.7: A wireless motility capsule can be used to evaluate gastric emptying time, small intestinal transit time, and colonic transit time. (PVA-NBD 2020, p.452; Level B) **M.3 - BASIC BOWEL MANAGEMENT (BBM)** ▪ M.3.1: A BBM program should be used in individuals with both reflexic and areflexic neurogenic bowel dysfunction. (PVA-NBD 2020, p.452; Level B) ▪ M.3.2: The optimal frequency of bowel movements per week should account for an individual's lifestyle and premorbid bowel history. (PVA-NBD 2020, p.452; Level C)

	▪ M.3.3: Mechanical rectal stimulation may be used for individuals with reflexic neurogenic bowel dysfunction. (Adapted from PVA-NBD 2020, p.452; Level B) ▪ M.3.4: Manual evacuation of stool may be used for individuals with areflexic neurogenic bowel dysfunction. (Adapted from PVA-NBD 2020, p.452; Level B) ▪ M.3.5: Abdominal massage should not be used for neurogenic bowel dysfunction emptying. (PVA-NBD 2020, p.452; Level B) ▪ M.3.6: The Valsalva maneuver should not be used for neurogenic bowel dysfunction emptying. (PVA-NBD 2020, p.452; Level C) **M.4 - ADAPTIVE EQUIPMENT** ▪ M.4.1: Use of adaptive equipment, including a suppository inserter and adaptive digital stimulator, should be considered for individuals with limited hand function or difficulty with reach. (PVA-NBD 2020, p.453; Level C) ▪ M.4.2: A clinical evaluation of a pressure distributing commode/shower chair should be performed with a focus on the individual's current bowel care routine and transfer ability, goals of the individual and caregiver, and individual functionality, including postural stability, reach, and skin integrity. (Adapted from PVA-NBD 2020, p.453; Level B) **M.5 - DIET, SUPPLEMENTS, FIBER, FLUIDS, AND PROBIOTICS** ▪ M.5.1: Providers should inquire about and document diet history, including all dietary supplements that an individual with SCI is taking. (PVA-NBD 2020, p.453; Level C) ▪ M.5.2: Providers should refer to a registered dietitian if the individual has a poor appetite, poor oral intake, or significant weight changes. (PVA-NBD 2020, p.453; Level C) ▪ M.5.3: Individuals with SCI should not be uniformly placed on high-fibre diets. Increases in fibre intake from food or a supplement should be done gradually to assess tolerance. (PVA-NBD 2020, p.453; Level B) ▪ M.5.4: Foods that cause an individual with SCI to experience excessive flatulence, bloating, abdominal distension, and/or altered bowel movements should be identified and either limited or avoided. (PVA-NBD 2020, p.453; Level C) ▪ M.5.5: Providers should recommend that an individual with SCI maintain euhydration (state of optimal total body water content) and avoid dehydration to reduce the tendency to experience constipation. The amount of fluid needed to promote optimal stool consistency must be balanced with the amount needed for bladder management. (PVA-NBD 2020, p.453; Level C) ▪ M.5.6: Providers should not routinely recommend probiotics to an individual with SCI. (PVA-NBD 2020, p.453; Level C) ▪ M.5.7: Probiotics may be advantageous to an individual with SCI who is taking antibiotics by reducing antibiotic-associated diarrhea and Clostridium difficile-associated diarrhea. (PVA-NBD 2020, p.453; Level A) **M.6 - ORAL MEDICATIONS** ▪ M.6.1: Providers can use oral medications for bowel management; however, the evidence for their use is limited, and there is no data to suggest the use of one medication over another. (PVA-NBD 2020, p.453; Level C) **M.7 - USE OF SUPPOSITORIES, ENEMAS, AND IRRIGATION** ▪ M.7.1: Providers can use rectal medications for bowel management. (PVA-NBD 2020, p.453; Level B) ▪ M.7.2: A polyethylene glycol (PEG)-based bisacodyl suppository is recommended over a hydrogenated vegetable oil-based bisacodyl suppository. (PVA-NBD 2020, p.453; Level B) ▪ M.7.3: Docusate mini enemas are recommended over glycerin, mineral oil, or vegetable oil-based bisacodyl suppositories. (PVA-NBD 2020, p.453; Level B) ▪ M.7.4: The routine use of enema formulations such as sodium phosphate (Phospho-Soda), soapsuds, or milk and molasses are not recommended; however, in select individuals, intermittent use for constipation may be helpful. (PVA-NBD 2020, p.453; Level C)

	▪ M.7.5: Transanal irrigation is recommended in individuals with neurogenic bowel dysfunction who have insufficient results with BBM. (PVA-NBD 2020, p.454; Level A) ▪ M.7.6: Pulsed irrigation evacuation (PIE) in a hospital/clinic setting can be used to relieve fecal impaction. (PVA-NBD 2020, p.454; Level B) **M.8 - IMPACT OF POSTURE AND ACTIVITY ON NEUROGENIC BOWEL DYSFUNCTION** ▪ M.8.1: Regular physical activity should be encouraged as part of a healthy lifestyle. (PVA-NBD 2020, p.454; Level B) ▪ M.8.2: For some individuals, a standing program may be beneficial for bowel function but should be weighed against other means of physical activity, as well as against precautions to undertake the activity safely. (PVA-NBD 2020, p.454; Level B) **M.9 - USE OF FUNCTIONAL ELECTRICAL STIMULATION** ▪ M.9.1: Routine use of FMS for neurogenic bowel dysfunction is not recommended. (PVA-NBD 2020; Level B) **M.10 - SURGICAL INTERVENTION TO MANAGE NEUROGENIC BOWEL DYSFUNCTION** ▪ M.10.1: Malone antegrade continence enema (MACE) procedures can be used for individuals with SCI with severe neurogenic bowel dysfunction for whom other treatment modalities have failed. (PVA-NBD 2020, p.454; Level B) ▪ M.10.2: The MACE procedure can be a choice for individuals with neurogenic bowel dysfunction who prefer the option after thorough education regarding risks, benefits, and complications and after shared decision making with their providers. (PVA-NBD 2020, p.454; Level B) ▪ M.10.3: Colostomy is recommended for individuals with severe neurogenic bowel dysfunction for whom other treatment modalities have failed or who have had significant complications. (PVA-NBD 2020, p.454; Level B) ▪ M.10.4: Colostomy can be a choice for individuals with neurogenic bowel dysfunction who prefer the option after thorough education regarding risks, benefits, and complications and after shared decision making with their providers. (PVA-NBD 2020, p.454; Level B) **M.11 - MANAGING MEDICAL COMPLICATIONS OF NEUROGENIC BOWEL DYSFUNCTION** ▪ M.11.1: Providers must assess and monitor for the unique clinical presentation of gastrointestinal and intra-abdominal complications related to neurogenic bowel dysfunction in individuals with SCI. (PVA-NBD 2020, p.454; Level C) ▪ M.11.2: Providers must assess and monitor for complications that primarily affect areas outside the abdomen but that are related to neurogenic bowel dysfunction, such as AD and skin breakdown. (PVA-NBD 2020, p.454; Level C) ▪ M.11.3: Treatment for hemorrhoids is conservative; if bleeding is refractory, non-excisional techniques are warranted. Excisional hemorrhoidectomy should be avoided. (PVA-NBD 2020, p.454; Level B) **M.12 - ASSESSING INDEPENDENT USE OF TOILET FOR BOWEL CARE** ▪ M.12.1: Risk to skin integrity: all individuals with diminished/absent sensation and prolonged toileting should use a pressure-distributing seat, whether using the toilet or a shower chair. This will reduce the risk of pressure damage to the skin, but not eliminate it. Individuals with a history of skin damage and resultant scarring may not tolerate even a short sitting time safely. Minimizing the duration of bowel care through an effective and timely bowel management program is essential. (Adapted from BOWEL 2012; Level C) **M.13 - EDUCATION FOR INDIVIDUALS WITH SCI AND CAREGIVERS** ▪ M.13.1: Education for individuals with SCI, caregivers, and health care providers should be provided and comprehensive to all levels of learners. (PVA-NBD 2020, p.454; Level C) ▪ M.13.2: The components of the bowel program should be taught to individuals with an SCI as well as to caregivers. (PVA-NBD 2020, p.455; Level C) ▪ M.13.3: Education on potential complications should be completed. (PVA-NBD 2020, p. 455; Level C)

	▪ M.13.4: Education and support for the caregiver should be considered and completed when appropriate. (PVA-NBD 2020, p.455; Level C) ▪ M.13.5: Sexual intimacy and considerations related to bowel program management should be discussed. (PVA-NBD 2020, p.455; Level C) **M.14 - PSYCHOSOCIAL ASPECTS OF NEUROGENIC BOWEL DISEASE** ▪ M.14.1: Assessments of neurogenic bowel disease should include psychosocial aspects that are barriers to learning the bowel program, such as cognition (ability to learn and direct others), depression, anxiety, pain, literacy, language, and ethnic or cultural issues. (PVA-NBD 2020, p.455; Level C) ▪ M.14.2: If an individual with SCI is having multiple problems with neurogenic bowel disease or is noncompliant with the bowel program, a formal screening tool should be used to assess depression, anxiety and quality of life. (PVA-NBD 2020, p.455; Level C)
Skin	**S - SKIN INTEGRITY** **S.1 - PREVENTION - PRESSURE INJURY PREVENTION AND THE INTERPROFESSIONAL TEAM** ▪ S.1.1: Consider ultrasound imaging of the tissue to confirm and monitor with suspected deep tissue injury. (Adapted from PU-ONF 2013, p.20; Level B) ▪ S.1.2: Use pressure mapping results in conjunction with clinical findings and the individual's preference to provide education, assess support surfaces and optimize the type and duration of position changes. (CAN-SCIP 2020; Level C) ▪ S.1.3: Determine and reassess the goals of care and healability of the pressure injury with the individual with SCI and the care team. (Adapted from WOUNDCAN 2017, p.8; Level C) **S.2 - PREVENTION – EDUCATION** ▪ S.2.1: Provide individuals with SCI, their families, and caregivers with structured education about effective strategies for the prevention and treatment of pressure injuries. Be sure to deliver education at a grade 3 to 6 level using a variety of methods. Prior to providing education on pressure injury, assess the individual's health literacy, culture, and use an appropriate level of education to ensure the individual's understanding of the education through the use of teach-back. (Adapted from PU-ONF 2013, p.39; Level B) ▪ S.2.2: Provide pressure injury education using a variety of methods, including written, in-person, video, and online. (CAN-SCIP 2020; Level C) ▪ S.2.3: The education should be delivered by a trained or experienced healthcare professional and include: 1. the causes of a pressure injury 2. the early signs of a pressure injury 3. ways to prevent a pressure injury 4. the implications of having a pressure injury (for example, for general health, treatment options and the risk of developing pressure injuries in the future) 5. skin cleansing and care techniques 6. management of incontinence 7. frequency and techniques of skin inspection 8. frequency, duration, and techniques of recommended position changes 9. frequency, duration, and techniques of recommended pressure redistribution 10. nutrition as it relates to maintaining skin integrity

11. techniques and equipment used to prevent a pressure injury (i.e., support surfaces including mattresses and cushions).

(Adapted from PU-PVA 2014, p.28; Level B and PU-ONF 2013, p.39; Level B)

- S.2.4: Ensure that the individual with SCI and their primary caregiver or attendant understands and acknowledges their central role in the prevention of pressure injury. (Adapted from PU-ONF 2013, p.41; Level C)

S.3 - OPTIMIZING MOBILITY TO REDUCE PRESSURE INJURY RISK

- S.3.1: Reassess gross motor skills, abilities, and current pressure management strategies if gross motor function declines or a pressure injury develops. (PU-ONF 2013, p.136; Level C)
- S.3.2: Select and train transfer techniques for all surfaces necessary for daily activities to ensure safe repositioning and minimize skin and tissue damage during movement. (PU-ONF 2013, p.138; Level C)
- S.3.3: Teach transfers to all surfaces necessary for daily activities, as risks and abilities are context-dependent. (PU-ONF 2013, p.138; Level B)
- S.3.4: Individualize pressure-redistributing strategies using a variety of weight-shifting approaches, including automatic pressure redistribution with functional movement, active lifting or shifting, dynamic weight shifts (tilt and recline), with and without power-assist and use of gel/air cushions. Encourage leaning forward or to the side, as this produces more complete and prolonged pressure reductions than lifting vertically. (PU-ONF 2013, p.141; Level B)
- S.3.5: Use manual palpation, observation, and pressure mapping, as appropriate, to evaluate the effectiveness of weight-shifting strategies. (PU-ONF 2013, p.141; Level C)
- S.3.6: Provide information about the effective use of weight-shifting strategies, including demonstrations, into the individual's pressure management plan. Work with the individual to select a technique (lifting or leaning) and frequency that best meets the individual's needs. (Adapted from PU-ONF 2013, p.141; Level C)
- S.3.7: Ensure that an individual who does not use active or dynamic intentional weight shifts to redistribute pressure performs more frequent skin checks if activities or daily routines change. Educate the primary caregiver or attendant on conducting frequest skin checks. (Adapted from PU-ONF 2013, p.141; Level C)

S.4 - PREVENTION STRATEGIES ACROSS THE CONTINUUM OF CARE

- S.4.1: Implement pressure injury prevention strategies as part of the comprehensive management across the continuum and review all aspects of risk when determining prevention strategies. (Adapted from PU-PVA 2014, p.17; Level A)
- S.4.2: Individuals with SCI, clinicians, and caregivers should conduct comprehensive head-to-toe visual and tactile skin inspections. (Adapted from PU-PVA 2014, p.17; Level C)
- S.4.3: Directed by the individual with SCI, caregivers, clinicians, nurses, occupational therapists, assistive technologists, prosthetists, and orthotists should evaluate and monitor the individual with SCI and all of their support surfaces for optimal maintenance of skin integrity as directed by the individual with SCI. (Adapted from PU-PVA 2014, p.20; Level C)
- S.4.4: If skin irritation due to moisture develops or persists, pursue a consultation with a health care provider with continence training for evaluation, topical treatment, and review of the bowel and bladder program. (Adapted from PU-ONF 2013, p.26; Level B)
- S.4.6: Provide an individually-prescribed seating system designed to redistribute pressure and employ a power weight-shift system when manual pressure redistribution is not possible. (Adapted from PU-PVA 2014, p.21; Level A)
- S.4.7: Assess nutritional status including dietary intake and losses, anthropometric measurements, nutritional and hydration-related blood work, ability to self-feed or dependence on others for eating and drinking, and other barriers to optimal food and fluid intake, regularly across the continuum of care as nutrition is a critical aspect for prevention of pressure injury. (Adapted from PU-PVA 2014, p.23; Level B)

- S.4.8: Provide adequate nutritional intake to meet individual needs, especially for calories (or energy), protein, micronutrients (zinc, vitamin C, vitamin A, and iron), and fluids. (PU-PVA 2014, p.26; Level A)
- S.4.9: Ensure that a qualified registered dietitian or nutritionist with experience in SCI performs the nutritional assessment, determines and recommends the appropriate interventions, and assesses the outcomes across the continuum of care. (Adapted from PU-ONF 2013, p.51; Level C)

S.5 - PRESSURE REDISTRIBUTION AND SUPPORT SURFACES – SUPPORT SURFACES FOR WHEELCHAIRS AND OTHER SEATING

- S.5.1: Prescribe wheelchairs and seating systems specific to the individual with SCI that allow the individual to redistribute pressure sufficiently to prevent the development of pressure injuries. Obtain specific body measurements for optimal selection of seating system dimensions (postural alignment, weight distribution, balance, stability, and pressure redistribution capabilities). Prescribe a power weight-shifting wheelchair system for individuals who are unable to independently perform effective pressure relief. Use wheelchair tilt-in-space and/or recline devices effective enough to offload tissue pressure. Use standing wheelchairs to remobilize individuals with an existing pelvic pressure injury. Full-time wheelchair users with pressure injuries located on a sitting surface should limit sitting time and use a gel or air surface that provides pressure redistribution. (Adapted from PU-PVA 2014, p.58; Level A)
- S.5.2: Prescribe wheelchair seating systems for each individual with an SCI individualized to anthropometric fit that:

1. provide optimal ergonomics
2. provide maximal function
3. redistribute pressure
4. minimize shear
5. provide comfort and stability
6. reduce heat and moisture
7. enhance functional activity
8. inspect and maintain all wheelchair cushions at regularly scheduled intervals
9. replace wheelchair seating systems that are no longer effective.

(PU-PVA 2014, p.62; Level B)

S.6 - RECUMBENT POSITIONING

- S.6.1: Ensure proper bed positioning by using devices and techniques that are appropriate for the type of support surface and mattress and the individual's health status. Use pillows, cushions, and positioning aids to:

1. Bridge contacting tissues, including bony prominences
2. Unload bony prominences
3. Protect pressure injuries and vulnerable areas of skin. Do not use closed cut-outs in mattresses or donut-type cushions. (PU-ONF 2013, p.87; Level C)

- S.6.2: Protect the heels of all individuals with SCI while supine or reclined and while using adaptive devices (e.g., soft silicone gel sheet, soft padded anke foot orthosis (AFO)). (Adapted from PU-ONF 2013, p.89; Level C)
- S.6.3: Use a side-lying position at a 30° angle from supine that does not position the individual directly on either hip. (PU-ONF 2013, p.90; Level C)
- S.6.4: Avoid elevating the head of the bed above 30°. If raising the head of the bed is medically necessary, raise the foot of the bed before the head and limit the amount of time in this position as much as possible. (Adapted from PU-ONF 2013, p.92; Level C)

	▪ S.6.5: Avoid sitting in bed. Transfer the individual to a sitting surface that is designed to distribute pressures properly in the seated position. (PU-ONF 2013, p.93; Level C) ▪ S.6.6: Turn and reposition individuals who require assistance at least every 2 hours initially. Adjust the repositioning schedule based on the individual's skin response, determined by frequent skin checks, until an appropriate repositioning schedule is established. (Adapted from PU-ONF 2013, p.94; Level C) ▪ S.6.7: Use repositioning techniques that prevent injury to the caregiver and reduce friction and shear of soft tissues when the individual with SCI is moved. (Adapted from PU-ONF 2013, p.95; Level C) ▪ S.6.8: Avoid bed rest to treat pressure injuries in individuals with SCI. If necessary, use bed rest to offload pressure completely for a specific and limited time, such as after surgical repair of pressure injuries. (Adapted from PU-ONF 2013, p.96; Level C) **S.7 - SUPPORT SURFACES (MATTRESS)** ▪ S.7.1: Use a support surface with advanced pressure-redistributing properties, compared with a standard hospital foam mattress, to minimize peak pressure areas around bony prominences and protect soft tissue from bruising and injury. (PU-ONF 2013, p.101; Level C) ▪ S.7.2: Select a reactive support surface for individuals who can be positioned without weight-bearing on a pressure injury and without bottoming out on the support surface. (PU-ONF 2013, p.101; Level C) ▪ S.7.3: Select an active support surface if the individual cannot be positioned without pressure on a pressure injury, when a reactive support surface bottoms out, if there is no evidence of pressure injury healing or if new pressure injuries develop. (PU-ONF 2013, p.101; Level C) ▪ S.7.4: Re-evaluate the suitability of the support surface for pressure injury prevention and treatment at least every 4 years and sooner if the individual's medical condition changes. (PU-ONF 2013, p.102, Level C) ▪ S.7.5: Select smooth, low-friction, breathable fabrics for bedding and clothing to optimize microclimate control and minimize friction. (PU-ONF 2013, p.103; Level C) **S.8 - SITTING SUPPORT SURFACES INCLUDING WHEELCHAIRS (SEAT CUSHIONS AND BACKREST)** ▪ S.8.1: Use a support surface (seat cushions and backrest) with advanced pressure-redistributing properties, compared with standard seat cushions and backrests, to minimize peak pressure areas around bony prominences and protect soft tissue from bruising and injury. (Adapted from PU-ONF 2013, p.109; Level C) ▪ S.8.2: Address pelvic asymmetry, postural instability, kyphosis, and spasticity, using postural management and support surfaces. Evaluate the effects of posture, deformity, and movement on interface pressure distribution and the influence of subdermal tissue loads on sitting support surfaces. (PU-ONF 2013, p.112; Level B) ▪ S.8.3: Consider the effects of clothing, shoes, and additional layers on the surface's microclimate and pressure-redistributing properties. (PU-ONF 2013, p.112; Level C) ▪ S.8.4: Recommend support surfaces and equipment based on observations and client and caregiver feedback during the sitting simulation and trial. (PU-ONF 2013, p.113; Level C) ▪ S.8.5: Implement a trial of at least 24 hours and ideally of several days to ensure the equipment addresses pressure and microclimate issues, as well as functional and lifestyle needs. (Adapted from PU-ONF 2013, p.113; Level C) ▪ S.8.6: Provide an individually prescribed wheelchair and pressure-redistributing seating system in collaboration with the individual who will be using the equipment. Ensure wheelchair configuration, postural supports, and sitting surfaces facilitate optimal wheelchair positioning and function. (PU-ONF 2013, p.117; Level B) ▪ S.8.7: Consider a variety of factors for comprehensive pressure management when selecting a wheelchair cushion:

	1. influence of cushion characteristics, including weight, on wheelchair performance 2. pressure-redistributing or offloading characteristics at bony areas 3. positioning capabilities for postural management in resting and dynamic positions 4. maintenance of a supported and symmetrical resting posture to prevent postural deterioration over time 5. adequate stability for function and prevention of long-term postural deterioration 6. microclimate management 7. shear and friction reduction at the user-cushion interface 8. comfort (PU-ONF 2013, p.120; Level B) ▪ S.8.8: Avoid placing additional layers between a support surface and individual with unless deemed essential. If an additional layer is necessary, the layer should be thin, breathable and stretchable. (Adapted from PU-ONF 2013, p.120; Level C) ▪ S.8.9: Consider power weight-shifting technology (tilt-in-space, reclining) when other methods, such as active pressure redistribution or pressure redistribution through functional movements, are not effective or not possible. (Adapted from PU-ONF 2013, p.122; Level C) ▪ S.8.10: Encourage the use of power weight-shifting technology, such as tilt, recline, and stand, frequently throughout the day to reduce the effects of sitting pressure on bony prominences of the buttocks. Individualize these strategies for each individual using pressure mapping, palpation, and skin response. Start with a position change that can be maintained for 2 minutes, at least once every 15 minutes. (PU-ONF 2013, p.123; Level C) ▪ S.8.11: Add full tilt gradually where possible to increase blood flow over the ischial tuberosities. A minimum of 30° tilt is required to adequately redistribute pressure and increase blood flow. (PU-ONF 2013, p.123; Level B) **S.9 - OTHER SEATING** ▪ S.9.1: Assess and prescribe options for other seating needs and provide recommendations for transfers and repositioning as part of the seating assessment to ensure that these surfaces and their use do not cause pressure injuries. These needs may include: 1. bathroom surfaces, such as a commode, toilet, shower bench, or other surfaces 2. seating options for travel 3. sports wheelchairs and seating for recreational and other activities 4. any other surface the individual may use other than the wheelchair. (PU-ONF 2013, p.124; Level C) ▪ S.9.2: Use a pressure-redistributing surface on the commode or toilet to minimize pressure injury risk. (Adapted from PU-ONF 2013, p.124; Level C) ▪ S.9.3: Optimize the bowel care routine to minimize time using the commode and reassess the bowel program if more than 1 hour is required. (PU-ONF 2013, p.124; Level C) ▪ S.9.4: Consider a tilt commode if postural instability results in sliding or uneven pressure distribution on the sitting surface. (PU-ONF 2013, p.124; Level C) ▪ S.9.5: Advise and provide written information to an individual with SCI about equipment options and appropriate preventive strategies during travel. (Adapted from PU-ONF 2013, p.126; Level C) **S.10 - RISK & RISK ASSESSMENT** ▪ S.10.1: Conduct an assessment of pressure injury risk factors in individuals with SCI on admission and reassess on a routine basis, as determined by the healthcare setting, institutional guidelines, and changes in the individual's health status.

1. demographic
2. SCI-related, such as incontinence
3. comorbid medical
4. nutritional
5. psychological, cognitive, contextual, and social
6. support surface for bed, wheelchair, and all durable medical equipment surfaces, such as shower/commode chair or bathroom equipment related. Use both a validated risk-assessment tool and clinical judgment to assess risk.

(PU-PVA 2014, p.11; Level A-C)

S.11 - NUTRITIONAL OPTIMIZATION FOR THE INDIVIDUAL WITH A PRESSURE INJURY

- S.11.1: Determine energy needs through indirect calorimetry with appropriate correction to avoid overfeeding. (Can-SCIP 2020, Level B)
- S.11.2: Provide 30 to 35 kcal/kg energy daily for individuals with pressure injuries. (PU-ONF 2013, p.56; Level B)
- S.11.3: Provide 1.0 to 2.0 g/kg protein daily for individuals at risk of developing pressure injuries. (PU-ONF 2013, p.57; Level A)
- S.11.4: Provide a daily protein intake at the higher end of the range for individuals with severe pressure injuries. (PU-ONF 2013, p.57; Level A)
- S.11.5: Consult with a qualified dietician or nutritionist regarding supplementation of arginine, vitamin E, zinc and other vitamins and minerals as appropriate to improve pressure injury healing. (Adapted from PU-ONF 2013, p.58; Level B)

S.12 - ASSESSMENT OF THE INDIVIDUAL WITH A PRESSURE INJURY

- S.12.1: Upon identification of a pressure injury, perform an initial comprehensive assessment of the individual with a pressure injury, to include the following:

1. complete history and physical examination
2. complete skin assessment
3. laboratory tests (evaluate for infection and nutritional status)
4. psychological health, behaviour, cognitive status, and social and financial resources
5. availability and utilization of personal care assistance
6. positioning, posture, and equipment (e.g., wheelchair)
7. nutritional status
8. activities of daily living (ADLs), mobility, and transfer skills, as related to maintaining skin integrity
9. Home or living environment assessment

(Adapted from PU-PVA 2014, p.29; Level C)

- S.12.2: In the community, if a new pressure injury is identified, a primary care provider should be contacted immediately to initiate a care plan and make a referral to an SCI healthcare professional. (CAN-SCIP 2020, Level C)

S.13 - PATIENT ASSESSMENT - ASSESSMENT AND REASSESSMENT OF THE PRESSURE INJURY

- S.13.1: Describe and document in detail an existing pressure injury and its treatment. Include the following parameters:

1. anatomical location and general appearance
2. size of wound (length x width x depth)

3. category/stage
4. characteristics of the wound base: viable tissue (granulation, epithelialization, muscle, bone, or subcutaneous tissue), nonviable tissue (necrotic, slough, eschar)
5. infection (redness of the wound bed, temperature in the wound bed area, moisture and odour)
6. exudate amount and type
7. odour
8. wound edges (e.g., colour, raised, thickened, undermined, connected to wound bed, fistulas, pockets under the skin)
9. periwound skin (colour, temperature, dry, oily, intact, cracked, oedema).
10. wound pain
11. general condition (body temperature, autonomic dysreflexia changes, change in spasticity)
12. documentation of current treatment strategies and outcomes to date.

(Adapted from PU-PVA, p.30; Level C)

- S.13.2: Monitor, assess, document, and report any observable/visible change in wound status. Monitor the pressure injury with each dressing change or if there is no dressing, then routinely depending on the setting. Conduct a comprehensive assessment as described in S.13.1 at regular intervals. (Adapted from PU-PVA 2014, p.30; Level B)

S.14 - PATIENT ASSESSMENT - ASSESSMENT USING THE 24-HOUR APPROACH TO PRESSURE MANAGEMENT

- S.14.1: An individual with SCI and their care team, if appropriate, should perform a comprehensive assessment of posture and positioning to evaluate pressure injury risk when using new surfaces or identifying a new pressure injury. Consider all surfaces in both recumbent and sitting positions that an individual uses to participate in daily activities over the entire 24-hour period. (Adapted from PU-ONF 2013, p.70; Level C)
- S.14.2: Evaluate the progress of healing using an instrument or quantitative measure that has been shown responsive to change in wound status, such as acetate tracing, the Photographic Wound Assessment Tool (PWAT) or the Pressure Ulcer Scale for Healing (PUSH). (PU-ONF 2013, p.158; Level A)

S.15 - REASSESSMENT

- S.15.1: Establish a mechanism for a regular reassessment of the performance of sitting support surfaces specific to pressure injury prevention and treatment. Schedule reassessment at least every 2 years, or sooner if any of the following occur:

1. health status changes, including weight or medical changes
2. changes in functional status
3. equipment wear or disrepair
4. pressure injury development
5. changes in living situation.

(PU-ONF 2013, p.127; Level C)

- S.15.2: Replace seating equipment and support surfaces according to manufacturer's recommendations, or sooner if equipment demonstrates any signs of deterioration, including but not limited to wear, cracking, and allowing bottoming out. (PU-ONF 2013, p.127; Level C)

S.16 - PRINCIPLES OF TREATMENT OF A PRESSURE INJURY

- S.16.1: Consider replacing the recumbent support surface with one that provides better pressure redistribution, offloading capabilities, shear reduction, and microclimate control for individuals who:

1. cannot be positioned off the pressure injury
2. have pressure injuries on at least two turning surfaces
3. fail to heal or demonstrate pressure injury deterioration despite appropriate comprehensive care
4. have a high risk of developing additional pressure injuries
5. bottom out on the existing support surface.

(PU-ONF 2013, p.166; Level C)

- S.16.2: Assess the suitability of existing sitting support surfaces for treatment in an individual with a pressure injury. Evaluate the current sitting surface or cushion to determine if an alternative choice would better meet the individual's needs during treatment of the pressure injury. (Adapted from PU-ONF 2013, p.167; Level C)

S.17 - CREATING A PHYSIOLOGIC WOUND ENVIRONMENT

- S.17.1: Cleanse pressure injury with each dressing change without harming healthy tissue on the wound bed:

1. use normal saline, sterile water, pH-balanced wound cleansers, lukewarm potable tap water.
2. use diluted sodium hypochlorite ¼ strength to ½ strength solution for wounds with heavy bioburden for a limited time only, until clinical evidence of bioburden is resolved.
3. use the following mechanical wound cleansing techniques to remove wound debris, exudates, surface pathogens, bacteria, and residue from topical creams and ointments.
4. 4–15 pounds per square inch (psi) pressure irrigation with angiocatheter attached to a syringe, spray bottle or pulsatile lavage.
5. gentle scrubbing of the wound bed with wet gauze.
6. cleanse peri-wound skin with normal saline, sterile water, pH-balanced skin cleanser, or lukewarm potable tap water with dressing changes.

(PU-PVA 2014, p.34; Level A)

S.18 - DEBRIDEMENT

- S.18.1: Debride devitalized tissue using a method or a combination of debridement methods appropriate to the status of the pressure injury. Debride eschar and devitalized tissue with the exception of a stable heel eschar. Debride areas in which there are unstable eschar and devitalized tissue. (PU-PVA 2014, p.35; Level B)

S.19 - WOUND CARE DRESSING AND MANAGEMENT

- S.19.1: Use a dressing that achieves a physiologic local wound environment that maintains an appropriate level of moisture in the wound bed:

1. control exudate
2. eliminate dead space
3. control odour
4. eliminate or minimize pain
5. protect the wound and the periwound skin
6. remove nonviable tissue
7. prevent and manage infection

(PU-PVA 2014, p. 169 Level A)

	▪ S.19.2: Avoid using daily dressing changes if at all possible by using absorbent dressings that manage exudate and odour and remain in place for as long as possible. (PU-ONF 2013, p.169; Level A) ▪ S.19.3: Consider the use of antimicrobial dressings if signs of infection are present. (PU-ONF 2013, p.170; Level C) ▪ S.19.4: Consider adding the following adjunctive therapies to a standard wound care program to speed healing of stage II, III, or IV pressure injuries, including electromagnetic energy IB, ultraviolet-C light lb. Consider the use of pulsatile lavage hydrotherapy debridement for Stage III & IV pressure injuries secondary to SCI. (Adapted from PU-ONF 2013, p.171; Level A) **S.20 - ELECTRICAL STIMULATION** ▪ S.20.1: Use electrical stimulation combined with standard wound care interventions to promote closure of category/stage III or IV pressure injuries, unless contraindicated in the cases of untreated, underlying osteomyelitis or infection. (Adapted from PU-PVA 2014, p.43; Level A) ▪ S.20.2: Modify the treatment plan if the pressure injury shows no evidence of healing within 2 to 4 weeks. Review individual factors associated with non-healing of pressure injuries, such as the following: 1. incontinence 2. infection 3. carcinoma 4. abnormal wound healing 5. nutrition 6. medication 7. support surfaces 8. transfers 9. noncompliance (PU-PVA 2014, p.45; Level A) **S.21 - SURGICAL TREATMENT** ▪ S.21.1: Consider the use of an occlusive hydrocolloid dressing, instead of cream or dressing, for the healing of stage I and II pressure injuries. (CAN-SCIP 2020; Level A) ▪ S.21.2: Consider the use of topical phenytoin for the healing of stage I and II pressure injuries post-SCI. (CAN-SCIP 2020; Level A) ▪ S.21.3: Consider using Medihoney to improve the healing rate and residual soft, elastic scars in persistent stage III and IV pressure injuries in individuals with SCI. (CAN-SCIP 2020; Level C) ▪ S.21.4: Assemble an interprofessional team to ensure optimal management of the individual and the pressure injury before, during, and after surgery, including: 1. selecting appropriate surgical candidates 2. performing a comprehensive assessment 3. implementing appropriate preoperative management 4. selecting the best surgical option and implementing it with expertise 5. planning and implementing optimal postoperative care. (Adapted from PU-ONF 2013, p.175; Level C)

- S.21.5: Refer appropriate individuals with complex, deep, stage III pressure injury, which may include pressure injuries with undermining or sinus tracts and those with stage IV pressure injury for surgical evaluation. (Adapted from PU-ONF 2013, p.175; Level B)
- S.21.6: Involve a registered dietitian to assess nutritional status and correct preoperatively nutritional imbalances that are anticipated to have a significant effect on the success of surgical repair. (PU-ONF 2013, p.177; Level B)
- S.21.7: Know and implement appropriate postoperative care after all pressure injury surgical repair:

1. assess and manage pain
2. evaluate support surfaces
3. position the individual to keep pressure off the surgical site
4. consider using an active bed surface when pressure on the surgical flap is unavoidable
5. consider using a Clinitron® air fluidized therapy bed after surgery
6. arrange a seating and postural assessment at the appropriate time during the postoperative mobilization period
7. progressively and gradually mobilize the individual to a sitting position over at least 4 to 8 weeks to prevent re-injury of the pressure injury or surgical site
8. provide education on pressure management and skin inspection.

(Adapted from PU-ONF 2013, p.184; Level C)

S.22 - OPTIMIZATION OF HEMATOLOGIC AND BIOCHEMICAL PARAMETERS FOR PRESSURE INJURY HEALING

- S.22.1: Screen for common conditions, such as anemia, inflammation, diabetes, and hypothyroidism, which are known to delay healing, to ensure appropriate treatment. Perform the following tests:

    1. complete blood count, including hemoglobin, hematocrit, white blood cell count, absolute lymphocyte count, serum albumin and description of red blood cell morphology
    2. iron profile, including ferritin, serum iron, percentage saturation, and total iron-binding capacity
    3. inflammatory markers: C-reactive protein, prealbumin and erythrocyte sedimentation rate
    4. endocrine factors, including fasting or random blood glucose, hemoglobin A1C, and thyroid function tests.

  (Adapted from PU-ONF 2013, p.61; Level B)
- S.22.2: If an individual with SCI is at risk of pressure injury development as indicated by biochemical, anthropometric and lifestyle factors, the registered dietitian should implement aggressive nutrition support measures. The range of options may include medical food supplements and enteral and parenteral nutrition. Research suggests that improved nutrition intake, body weight and biochemical parameters may be associated with reduced risk of pressure injury development. (NUTR 2009, p.36; Level A)

S.23 - TRAINING AND EDUCATION OF HEALTHCARE PROFESSIONALS

- S.23.1: Provide training to healthcare professionals on preventing a pressure injury, including:

1. who is most likely to be at risk of developing a pressure injury
2. how to identify pressure damage
3. what steps to take to prevent new or further pressure damage
4. who to contact for further information and for further action.

(NICE PU 2014, p.385; Level B)

	▪ S.23.2: Provide further training to healthcare professionals who have contact with anyone who has been assessed as being at high risk of developing a pressure injury. Training should include: 1. how to carry out a risk and skin assessment 2. how to reposition 3. information on pressure redistributing devices 4. discussion of pressure injury prevention with patients and their caregivers 5. details of sources of advice and support. (NICE PU 2014, p.385; Level B)
Sexual health	**R - SEXUAL HEALTH & RELATIONSHIPS** **R.1 - INTRODUCTORY RECOMMENDATIONS** ▪ R.1.1: Clinicians should ensure that discussions regarding sexuality and reproductive health occur with individuals with SCI in acute, rehabilitation, and community settings as sexuality and reproductive health is one of the highest priorities for individuals with SCI. (Adapted from CSCM 2010, p.304; Level C) ▪ R.1.2: Clinicians should use the Permission, Limited Information, Specific Suggestions, and Intensive Therapy (PLISSIT) as a model for framing sexual health discussions. (Adapted from CSCM 2010, p.305; Level C) ▪ R.1.3: Clinicians should engage in open, non-judgmental conversations about sexuality based on an individual's readiness/interest early on in care and throughout their lifespan. Maintaining privacy, respect and professional boundaries while taking into consideration the individual's life context and sexual expression regardless of gender preference and orientation is recommended. (Adapted from CSCM 2010, p.305; Level C) ▪ R.1.4: All health professionals interacting with individuals with SCI should have access to resources/education, a basic knowledge of sexual health issues after SCI, and specialists knowledgeable on sexual health. (Adapted from CSCM 2010, p.305; Level C) ▪ R.1.5: SCI rehabilitation centres should support the education and training for a local sexual health mentor who can support their colleagues to allow for the development of a sexual health support network throughout the country. (Adapted from CSCM 2010, p.305; Level C) **R.2 - EDUCATION** ▪ R.2.1: Clinicians should develop a sexual health education and treatment plan with the individual based on their sexual history, physical exam findings and preferences. (Adapted from CSCM 2010, p.309; Level C) ▪ R.2.2: Clinicians should educate individuals with SCI about the effects of prescription medication (over-the-counter and herbal remedies) on sexual response and fertility. (Adapted from CSCM 2010, p.309; Level C) ▪ R.2.3: Clinicians should educate individuals with SCI about the effects of alcohol, tobacco, and other drugs, as well as unhealthy eating habits and obesity, on sexual response and fertility. (Adapted from CSCM 2010, p.309; Level C) ▪ R.2.4: When counselling on the sexual health of an individual, clinicians should consider socio-cultural and religious influences and do not make assumptions about sexuality based on age. (Adapted from CSCM 2010, p.313; Level C) ▪ R.2.5: Use professionally approved educational videos and vetted websites when providing sexual health education using media. Institutions should provide sexual health educators institutional access to these resources. (Adapted from CSCM 2010, p.313; Level C) ▪ R.2.6: Clinicians should ensure premenopausal women with SCI have proper information regarding the effect of injury on menstruation and discuss contraception options. If menses have not resumed one year after injury, an endocrinology referral should be sought by the primary care provider. (CAN-SCIP 2020; Level C)

	▪ R.2.7: Education should be provided to men with SCI that reflex erections could occur with either sexual stimulation or nonsexual stimuli. (Adapted from CSCM 2010, p.320; Level B) **R.3 - RELATIONSHIPS** ▪ R.3.1: Individuals with SCI and their partners should be provided opportunities to discuss and ask questions regarding intimacy, sexuality, and fertility during all phases of care (acute, rehab and community). Providers must protect the confidentiality of both partners. (Adapted from CSCM 2010, p.329; Level C) ▪ R.3.2: Discuss and offer guidance on maintaining or developing interpersonal and sexual relationships. Discuss the added cautions of using the Internet to meet new partners, particularly relating to how to discuss or present disability online. (CSCM 2010, p.330; Level C) ▪ R.3.3: Encourage romantic partners to seek caregiving services in order to provide care for activities of daily living that may affect the sexual relationship. (Adapted from CSCM 2010, p.331; Level C) **R.4 - SEXUAL HISTORY & ASSESSMENT** ▪ R.4.1: Clinicians should ensure that a comprehensive medical assessment of the genital and reproductive systems is conducted after SCI. This assessment should include screening for cancers and sexually transmitted diseases per non-SCI guidelines. Additional considerations exist for prostate screening in men with SCI, as many factors may affect PSA levels. (Adapted from CSCM 2010, p.308; Level A) ▪ R.4.2: The primary care provider should refer the individual with SCI to an accessible office or specialist to ensure screening is completed. If the primary care provider's office is not accessible, or they are not personally able to perform comprehensive sexual reproductive care. (CAN-SCIP 2020; Level C) ▪ R.4.3: Perform a physical examination using the International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI), with special attention to the preservation of sensation from T11–L2 and S2–5, along with a determination of the presence of voluntary anal contraction and reflexes to assess sexual function. Assess the impact of the individual's injury on sexual responses (i.e., genital responses, based on a neurologic examination). Full physical examinations and neurological assessments should be conducted regularly in order to detect changes over time that may affect sexual function. (Adapted from CSCM 2010, p.308; Level B) ▪ R.4.4: Clinicians should routinely assess sexual and medical history (pre- and post-injury), desire, erection, ejaculation, lubrication, and pain with sexual acts. (CAN-SCIP 2020; Level C) ▪ R.4.5: Clinicians should consider evaluating men with SCI for testosterone deficiency, particularly in those with a concomitant head injury, untreated sleep apnea, or in cases of chronic opioid use. (Adapted from CSCM 2010, p.311; Level C) ▪ R.4.6: Clinicians should consider conducting a urethral trauma assessment in individuals with SCI who use intermittent or an indwelling catheter to empty the bladder as this may affect sexual activity. (CAN-SCIP 2020; Level C) **R.5 - OPTIMIZING SEXUAL WELL-BEING/POSITIVE BODY IMAGE AND SENSUALITY** ▪ R.5.1: SCI clinicians should discuss and consider the following principles to ensure sexual well-being: 1. Maximize inherent sexual potential prior to using medical interventions 2. Adapt to limitations with the use of medical therapies or sexual aids and 3. Remain open-minded during sexual adaptation. (CAN-SCIP 2020; Level C)

	▪ R.5.2: Clinicians should routinely provide information on methods to enhance sensuality by using all available senses. Encourage individuals with SCI to consider expanding their sexual repertoire to enhance sexual pleasure following injury. The emphasis of the discussion should be pleasure and not just function. (Adapted from CSCM 2010, p.313; Level C) ▪ R.5.3: Ensure that individuals with SCI receive counselling that promotes a positive body image and encourages respect for one's body after SCI. (CSCM 2010, p.331; Level C) ▪ R.5.4: Discuss fluctuations and potential changes that may occur with sexual desire, interest, arousal and orgasm following SCI. (Adapted from CSCM 2010, p.319/320; Level B) ▪ R.5.5: Self and/or partner exploration is encouraged. Strategies and aids can be recommended based on their limitations, interests, and needs (i.e., hand function, difficulty holding on to devices, leg floppiness, finding straps). (Adapted from CSCM 2010, p.320,321; Level A) **R.6 - PHYSICAL AND PRACTICAL CONSIDERATIONS – BLADDER** ▪ R.6.1: Performing bladder emptying prior to sexual activity is strongly recommended, and individuals with SCI should be encouraged to explore contingency plans if incontinence is to occur. (Adapted from CSCM 2010, p.315; Level B) ▪ R.6.2: Discuss any bladder dysfunction with their partner, as optimization of bladder management will improve socialization and relationships. (Adapted from CSCM 2010, p.315; Level B) ▪ R.6.3: Proper securing of catheters during sexual activity to maintain urethral integrity should be discussed. (Adapted from CSCM 2010, p.315; Level B) ▪ R.6.4: Indwelling urinary catheters should be secured for sexual activity to limit friction in both men and women. We recommend that condoms are placed over the penile shaft and catheter in men. (Adapted from CSCM 2010, p.315; Level B) **R.7 - PHYSICAL AND PRACTICAL CONSIDERATIONS – BOWEL** ▪ R.7.1: Optimize bowel routine as part of participating in sexual activity to avoid incontinence. (Adapted from CSCM 2010, p.315; Level C) ▪ R.7.2: Educate individuals with SCI that penetrative anal sexual activity may have increased risk of complications such as issues with skin integrity due to decreased sensation in this area, provocation of anal contraction or relaxation and unwanted incontinence. (Adapted from CSCM 2010, p.315; Level C) **R.8 - PHYSICAL AND PRACTICAL CONSIDERATIONS – SENSATION** ▪ R.8.1: Educate individuals with SCI on changes to sensitivity following SCI, including potential hypersensitivity, hyposensitivity, allodyna or lack of sensation. Individuals with SCI may find it most beneficial to focus on pleasurable areas and work on desensitizing areas of hypersensitivity. (CAN-SCIP 2020; Level C) ▪ R.8.2: Discuss the potential for discovering and developing new areas of the body that may stimulate sexual arousal (i.e., erogenous zones, areas with intact sensation) and lead to enhanced sexual pleasure. (CAN-SCIP 2020; Level C) **R.9 - PHYSICAL AND PRACTICAL CONSIDERATIONS – MOBILITY, SPASTICITY AND CONTRACTURES** ▪ R.9.1: Inform individuals with SCI that it is common for the degree of spasticity to change as a result of sexual activity. (Adapted from CSCM 2010, p.316; Level C). ▪ R.9.2: Discuss safety issues with individuals with SCI and their partners when engaging in sexual activity. Positioning options should be discussed as related to their level of mobility, and positioning aids can be recommended as needed. Sexual activities involving the use of a wheelchair, hot water shower or shower equipment should be discussed, and factors relating to balance and trunk stability should also be considered on an individual basis. (Adapted from CSCM 2010, p.318; Level C)

R.10 - PHYSICAL AND PRACTICAL CONSIDERATIONS – SKIN INTEGRITY

- R.10.1: Individuals with SCI should be encouraged to perform skin checks regularly after sexual activity. Positioning aids (such as support pillows) to limit pressure points and friction can be recommended if issues with skin breakdown occur. (Adapted from CSCM 2010, p.315; Level C)

R.11 - PHYSICAL AND PRACTICAL CONSIDERATIONS – AUTONOMIC DYSREFLEXIA

- R.11.1: Autonomic dysreflexia can be triggered with sexual stimulation in individuals with injury levels T6 and above. Individuals with SCI are encouraged to have a blood pressure cuff at home and following autonomic dysreflexia protocols. If autonomic dysreflexia becomes problematic in sexual activity, individuals with SCI are encouraged to speak to their health care providers to look at ways to modify stimulation or medications. (Adapted from CSCM 2010, p.316; Level A)

R.12 - TREATMENT OF SEXUAL DYSFUNCTION

- R.12.1: Ensure that individuals with SCI are aware of the risks related to sexual services or products available without a prescription. (Adapted from CSCM 2010, p.322; Level C)
- R.12.2: Assess the current level of erectile function in men with SCI and suggest interventions taking into consideration the level of invasiveness, cost, and side effects. (Adapted from CSCM 2010, p.322; Level C)
- R.12.3: In men, if testosterone deficiency is determined to be a contributing factor in his lack of libido or sexual dysfunction (including lack of PDE5i response for erections), consider testosterone replacement therapy. For men wishing to be biological fathers, alternative medications can be prescribed to raise serum testosterone without interfering with sperm production. (Adapted from CSCM 2010, p.322; Level C)
- R.12.4: Inform men with SCI about the full range of options for treating erectile dysfunction and develop an individualized treatment plan as needed. Educate men with SCI about:

1. oral medications, such as PDE5i, to treat erectile dysfunction
2. risks and benefits of vacuum devices for the treatment of erectile dysfunction
3. intracavernosal injections for the treatment of erectile dysfunction
4. Permanent penile prosthesis (also known as implantable penile protheses) for the treatment of erectile dysfunction when nonsurgical treatments are ineffective or unsatisfactory.

(Adapted from CSCM 2010, p.323; Level C)

- R.12.5: Clinicians should provide individuals with SCI with education and training on vibrators that are available to enhance genital arousal orgasmic potential. (Adapted from CSCM 2010, p.325; Level C)
- R.12.6: Clinicians should discuss the benefits and risks of the use of medications such as sildenafil and flibanserin for sexual arousal disorder in women with SCI. (CAN-SCIP 2020; Level C)
- R.12.7: Educate women with SCI about the effects of perimenopausal and menopausal changes on sexual function, bone health, accelerated metabolic aging, and metabolic syndrome after SCI. (Adapted from CSCM 2010, p.328; Level C)

R.13 - FERTILITY

- R.13.1: Perform semen analysis for men interested in biological fatherhood in order to provide information and make recommendations for achieving pregnancy. (CSCM 2010, p.328; Level A)
- R.13.2: Provide women with SCI information about fertility, birth control and pregnancy. (Adapted from CSCM 2010, p.326; Level B)
- R.13.3: Inform women that fertility is often preserved following an SCI and encourage pre-conception counselling on the effects of SCI on pregnancy labour and delivery. (Adapted from CSCM 2010, p.326; Level B)

	▪ R.13.4: Men and women with SCI should be individually informed of the possibility of biological parenthood, adoption and donor insemination. (Adapted from CSCM 2010, p.328; Level B) **R.14 - CONTRACEPTION** ▪ R.14.1: Inform women on the safest birth control options available on an individualized basis. If there are concerns related to contraindications, referral to a specialist to determine an appropriate method is necessary. (Adapted from CSCM 2010, p.326; Level C) **R.15 - PREGNANCY** ▪ R.15.1: Outline the steps that can be taken to ensure the best medical outcomes for the pregnant woman with SCI. Recommend that a multi-disciplinary team (including general practioner, physiatrist, OB-GYN, physiotherapist, occupational therapist, nurse) with SCI expertise be involved throughout the pregnancy. (Adapted from CSCM, p.326; Level B) ▪ R.15.2: Provide advance training (i.e., shoulder exercise program to support transfers during pregnancy), frequent monitoring of wheelchair seating, transfer technique and status of daily activities to ensure safety during pregnancy. (Adapted from CSCM 2010, p.326; Level C) ▪ R.15.3: Closely monitor autonomic dysreflexia and its complications during pregnancy, labour, delivery, and breastfeeding. (Adapted from CSCM 2010, p.327; Level C)
VTE	**T - VTE PROPHYLAXIS** **T.1 - PROPHYLAXIS OF DEEP-VEIN THROMBOSIS (DVT)** ▪ T.1.3: Combined mechanical methods of thromboprophylaxis (intermittent pneumatic compression devices with or without graduated compression stockings) and anticoagulant methods of thromboprophylaxis should be used particularly in the acute care phase, as soon as possible after injury, unless either option is contraindicated. (CSCM 2016, p.223; Level C) ▪ T.1.4: Oral vitamin K antagonists (such as warfarin) should not be used as thromboprophylaxis in the early acute care phase following SCI. (Adapted from CSCM 2016, p.223; Level C) ▪ T.1.6: We recommend against the use of low-dose or adjusted-dose unfractionated heparin in the prevention of VTE in SCI (unless low-molecular-weight heparin is not available or contraindicated). (CSCM 2016, p.222; Level B) **T.2 - ANTICOAGULANT METHODS OF THROMBOPROPHYLAXIS - SCREENING PATIENTS FOR ASYMPTOMATIC DEEP-VEIN THROMBOSIS** ▪ T.2.1: Individuals with SCI should not routinely be screened with doppler ultrasound for clinically inapparent DVT during their acute-care admission. (Adapted from CSCM 2016, p.227; Level B) **T.3 - DIAGNOSIS** ▪ T.3.1: Duplex doppler ultrasound, impedance plethysmography, venous occlusion plethysmography, venography, and clinical examination are recommended as potential diagnostic tests for DVT in individuals with SCI. (Adapted from CNS-DVT 2013, p.244; Level C) **T.4 - ANTICOAGULANT METHODS OF THROMBOPROPHYLAXIS - DURING THE REHABILITATION PHASE** ▪ T.4.1: Anticoagulant thromboprophylaxis should continue for at least eight weeks after injury in individuals with limited mobility. (Adapted from CSCM 2016, p.224; Level C) ▪ T.4.3: One of the following options may be used as thromboprophylaxis in the post-acute rehabilitation phase: low-molecular-weight heparin, oral vitamin K antagonists (INR 2.0-3.0), or a direct oral anticoagulant. (CSCM 2016, p.224; Level C) **T.5 - THROMBOPROPHYLAXIS IN CHRONIC SCI PATIENTS WHO ARE REHOSPITALIZED**

	▪ T.5.1: Individuals with chronic SCI who are hospitalized for medical illnesses or surgical procedures should receive thromboprophylaxis during the period of increased risk. (CSCM 2016, p.231; Level C)
Pain	**P- NEUROPATHIC PAIN** **P.1 - PAIN ASSOCIATED WITH SCI** ▪ P.1.1: The International Spinal Cord Injury Basic Pain Data Set is recommended as the preferred means to assess pain, including pain severity, physical functioning, and emotional functioning, among SCI patients. (CNS-ASSESS 2013, p.40; Level A) **P.2 - SCREENING FOR NEUROPATHIC PAIN** ▪ P.2.1: All patients with SCI must be screened by any member of the healthcare team for pain using a simple yes/no question. If pain is present at screening, an assessment to determine the type of pain, its intensity and interference should be conducted. Screening for pain should occur at admission to acute and prior to discharge. (Adapted from CANPAIN DIAG 2016, p.S8; Level C) **P.3 - DIAGNOSIS OF NEUROPATHIC PAIN** ▪ P.3.1: Diagnosis of neuropathic pain, including its causes, should be informed by: 1. a complete patient history 2. a physical examination 3. the International Spinal Cord Injury Pain (ISCIP) Classification system 4. investigations. (CANPAIN DIAG 2016, p.S9; Level C) *Clinical considerations:* A complete patient history should focus on determining the nature of pain symptoms that could indicate potentially reversible causes, aggravators and/or mimics of neuropathic pain, and the consequences of pain on function and quality of life. Essential elements of a complete patient history are the following: 1. Nature of pain: onset or triggering event, position or location, quality (for example, burning, electric shock-like), radiation, severity, timing (for example, constant or intermittent, spontaneous, or evoked) and aggravating or alleviating factors 2. Changes in neurologic status: changes in strength, sensation, or spasticity 3. Associated symptoms: ask about red flag signs and symptoms such as vasomotor instability (Red flags are serious underlying conditions that may cause, aggravate or mimic NP. Red flag indicators are symptoms and signs that suggest that a particular condition may be present. It is essential to identify red flags, as effective treatment could significantly improve or eliminate NP if managed appropriately and if left untreated may have serious adverse consequences for the patient). 4. Screening for interference: interference with sleep, physical function and mood or emotional function 5. Recent changes in health: new medical diagnoses such as diabetes and other conditions predisposing to polyneuropathy 6. Additional historical components: based on presentation and suspected etiology. The physical examination should include, at a minimum, neurologic, skin, and musculoskeletal examinations. Additional systems should be examined based on symptoms. Essential elements of the physical examination are the following: 1. Vital signs 2. International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI)

3. Reflexes, tone
4. Range of motion assessment of extremities, joint swelling or redness
5. Visual inspection of the skin for integrity
6. Calf measurement to assess for deep vein thrombosis
7. ISNCSCI autonomic standards.

Additional physical examination components may be included based on presentation, for example:

1. Primary abdominal region pain: abdominal screening examination
2. Respiratory involvement: chest assessment
3. Autonomic symptoms: assessment for etiology of autonomic dysreflexia (noxious stimuli).

Determining a specific etiology can be difficult and may require additional investigations. The selection of these investigations is geared towards the diagnoses of greatest clinical likelihood, and diagnostic tests are based on the presentation. It is essential to image the appropriate area of the spinal cord for all patients with any change in neurologic status, such as changes in neurologic level, tone, and reflexes. If any suspicion of urinary tract infection exists, it is important to perform a urinalysis and culture and sensitivity. Patients with primary abdominal region pain should have an abdominal ultrasound, radiography, or computed tomography as necessary to determine the source of the pain; blood work may include lipase, amylase, liver enzymes and kidney function tests. Signs and symptoms suggesting respiratory involvement could lead to further investigations such as chest assessment or radiography. In patients in whom pulmonary embolism is suspected, a computed tomography angiogram or ventilation/perfusion lung scan should be performed. Other investigations should be performed based on the differential diagnosis, as appropriate.

- P.3.2: Assess for serious underlying conditions (red flags) that may cause, aggravate, or mimic neuropathic pain and that require further investigation and prompt medical review. (CANPAIN DIAG 2016, p.S10; Level C)

Red flags:
Red flags are serious underlying conditions that may cause, aggravate, or mimic neuropathic pain. Red flag indicators are symptoms and signs that suggest that a particular condition may be present. It is essential to identify red flags, as effective treatment could significantly improve or eliminate neuropathic pain if managed appropriately and, if left untreated, may have serious adverse consequences for the patient.

Red flag table: https://www.nature.com/articles/sc201689/tables/1

- P.3.3: Assess and manage psychosocial factors (yellow flags) that may contribute to pain-related distress and disability. (CANPAIN DIAG 2016, p.S10; Level C)

Yellow flags:
Addressing psychosocial factors (yellow flag conditions) is essential for treatment success in an individual who has pain after SCI. Yellow flags can complicate and exacerbate the presentation of neuropathic pain and may contribute to pain-related distress and disability. Examples of yellow flag conditions or factors include the following:

1. Depressive symptoms

2. Altered appetite
3. Poor motivation to complete daily activities or work because of pain
4. Decreased participation in valued activities
5. Pre-existing pain problems with evidence of poor adjustment
6. Avoidance of activities associated with pain
7. Extensive periods of rest or bed rest
8. Evidence of catastrophic thinking, preoccupation with pain prognosis, significant anxiety, and panic symptoms
9. Use and dependence on alcohol or illicit substances
10. Increasing opioid dependence or misuse
11. Disruption of sleep quality and/or duration
12. Lack of support from family members towards pain and activity.

- P.3.4: Address patient concerns, expectations and needs as part of the neuropathic pain assessment. (CANPAIN DIAG 2016, p.S11; Level C)

Clinical considerations:
It is vital to remember that pain is subjective, and individuals differ in their expectations of treatment and needs with regards to pain. As a result, it is important to develop rehabilitation goals and the treatment plan in partnership with the patient. Goals of treatment, such as improvement in function, reduction in pain severity and improvement in mood, should be reviewed before initiating a particular treatment. Consider using SMART (Specific, Measurable, Agreed upon, Realistic and Time-based) goal methodology when setting treatment goals. Establishing specific treatment targets also allows evaluation of treatment benefits.

- P.3.5: Standardized evaluation of treatment response should be carried out by the healthcare team at regular intervals. (CANPAIN DIAG 2016, p.S11; Level C)

Clinical considerations:
Monitoring a patient's response to treatment, including efficacy, tolerance, dose-escalation, and side effects, is vital to modifying any suboptimal treatments. Such modification should be performed as rapidly as feasible. Adverse events need to be balanced against treatment benefits when determining whether to continue treatment, and discussion with the patient should inform decision-making.

Comparing treatment targets with achieved outcomes helps determine whether continued use of a treatment is worthwhile. It is also important to assess domains of intensity, mood, and function when determining treatment success. In addition to the International Spinal Cord Injury Pain Basic Data Set (ISCIPBDS v2.0), supplementary standardized measures such as the opioid risk tool may be used to evaluate outcomes not contained in the data set. As some medications to treat neuropathic pain, such as opioids, are subject to misuse, it is important to monitor for aberrant behaviour, as this may indicate either misuse or inadequate pain control. The National Opioid Use Guideline Group provides additional recommendations for opioid use.

- P.3.6: The evaluation of treatment response should include assessment of changes in pain intensity, mood and function using the International Spinal Cord Injury Pain Basic Data Set (ISCIPBDS) v2.0. Evaluation also includes an assessment of adverse events, aberrant behaviour, and compliance. (CANPAIN DIAG 2016, p.S11; Level C)

Clinical considerations:
Monitoring a patient's response to treatment, including efficacy, tolerance, dose-escalation, and side effects, is vital to modifying any suboptimal treatments. Such modification should be performed as rapidly as feasible. Adverse events need to be balanced against treatment benefits when determining whether to continue treatment, and discussion with the patient should inform decision-making.

Comparing treatment targets with achieved outcomes helps determine whether continued use of a treatment is worthwhile. It is also important to assess domains of intensity, mood and function when determining treatment success. In addition to the ISCIPBDS v2.0, supplementary standardized measures, such as the opioid risk tool, may be used to evaluate outcomes not contained in the data set. As some medications to treat neuropathic pain are subject to misuse, such as opioids, it is important to monitor for aberrant behaviour, as this may indicate either misuse or inadequate pain control. The National Opioid Use Guideline Group provides additional recommendations for opioid use.

International Spinal Cord Injury Pain Basic Data Set (ISCIPBDS) v2.0:
https://www.iscos.org.uk/uploads/sitefiles/Data%20Sets/Papers%20from%20Spinal%20Cord%20-Data%20Sets/ISCIBDS_Pain_2.pdf

- P.3.7: All patients with new-onset or worsening pain need to be reassessed. (CANPAIN DIAG 2016, p.S11; Level C)

Clinical considerations:
It is critical to pay particular attention to late-onset pain or sudden worsening of chronic pain. New-onset or worsening chronic neuropathic pain may require exclusion of treatable causes of the pain, assessment for new-onset red flag or yellow flag conditions and a full neuropathic pain assessment.

P.4 - DELIVERY OF CARE FOR NEUROPATHIC PAIN

- P.4.1: Delivery of care for neuropathic pain in individuals with SCI should be:

1. coordinated
2. interprofessional
3. timely
4. patient-centred
5. using a biopsychosocial framework
6. evidence-based.

(SYS CARE 2016, p.S25; Level C)

Clinical considerations:
Numerous factors affect the presentation of chronic pain, including psychosocial and environmental factors. Conversely, chronic pain can significantly affect function, mood, and social relationships. Therefore, management of chronic pain after SCI in patients with complex presentations requires an interprofessional or interdisciplinary team approach that incorporates medical, physical, educational and cognitive-behavioural components. Communication between healthcare providers, between healthcare providers and administrators, and between healthcare providers and the patient is a central tenet of coordination of care services.

	A biopsychosocial framework should guide the structure of a program and individual care plans. This model considers the interplay between physiology, psychology and social factors on the pain experience that affects neuropathic pain outcomes for individuals with SCI. As proposed by Strauss et al., evidence-based decisions are essential to advancing practice, with priority given to SCI-specific guidelines and studies. ▪ P.4.2: An individual with SCI and either: 1. new-onset or worsening spinal cord injury-related neuropathic pain, and/or, 2. ongoing pain that is difficult to manage and/or, 3. dissatisfaction with their current pain management protocol, should be screened and assessed by a clinician with experience in managing individuals with SCI. (SYS CARE 2016, p.S25; Level C) *Clinical considerations:* It is essential to involve clinicians with SCI experience when working with patients who have SCI-related neuropathic pain, who present with any of the conditions outlined in Recommendation V.4.2. A clinician with SCI experience can recommend relevant referrals, assessments, investigations, and treatment steps as appropriate. If necessary, on the basis of the results of the assessment, then this individual can act as a gatekeeper to team-based care for SCI-related neuropathic pain. If a diagnostic workup is required to determine the etiology or triggers of neuropathic pain after SCI, it is essential to involve the rehabilitation medicine specialist to ensure that relevant conditions are considered, and that appropriate investigations are implemented. ▪ P.4.3: Multidisciplinary care coordinated through an SCI rehabilitation team is recommended when significant functional impacts and/or significant psychological comorbidity factors resulting from neuropathic pain need to be addressed. Further, a detailed plan of care shared among healthcare providers needs to be implemented across primary, secondary, and tertiary services. (SYS CARE 2016, p.S25; Level C) *Clinical considerations:* It is important to recognize that pain management strategies should also address the functional and psychological impacts of pain, as current treatments may not eliminate pain or even reduce it effectively. As patients should expect to live with some degree of pain and discomfort, it is essential that they learn to minimize the impact of these symptoms on their daily lives. Generally, delivery of comprehensive care through an SCI rehabilitation team has been shown to be central to improving SCI outcomes. Access to such a team is therefore essential to managing complex functional impacts and/or psychological comorbidity more effectively. Currently, the implementation of specialized treatments may require access to a specialized pain clinic. Open communication and coordination between pain specialists and the SCI specialist team is required. Moving forward, we recommend that, given the unique needs of the SCI population, these treatment options be available at SCI-specific rehabilitation facilities. As patient needs evolve, team members may change over time. The team approach to patient care can improve access to care, quality of care, and cost-effectiveness. The team approach is effective in increasing diagnostic accuracy and timeliness of treatment, which can improve health outcomes and patient satisfaction while increasing resource utilization efficiency and job satisfaction for clinicians. In addition, the team approach can streamline communication with patients and families. It is also important to consider the role of telemedicine, e-consults, and

	other forms of distance communication to allow staff from specialized rehabilitation centers to continue to provide oversight when travel is a barrier to optimal care delivery, such as may occur for patients in rural areas. The multidisciplinary team should develop a detailed and integrated rehabilitation care plan that includes a focus on neuropathic pain in alignment with Accreditation Canada 2014 standards (https://accreditation.ca/spinal-cord-injury-rehabilitation-services). Multidisciplinary care should take a patient-centred, goal-directed, holistic, and functional approach to pain management that incorporates the caregiver and/or significant other in the care plan. Members of the multidisciplinary team should include the various rehabilitation disciplines such as physiatry, physiotherapy, occupational therapy, psychology, social work, nursing, and other professionals as needed. ▪ P.4.4: An individual with neuropathic pain as a result of SCI should be discharged from specialized care when three conditions are met: 1. a stable plateau has been reached in pain severity and/or pain-related functional status 2. an ongoing plan linked to resources and provider follow-up is in place 3. self-management techniques have been taught. (SYS CARE 2016, p.S26; Level C) *Clinical considerations:* The goal at discharge from specialized care should be stable pain severity and optimized function relative to an individual's ongoing pain severity. Complete alleviation of pain is not usually a realistic outcome. A stable plateau may be considered to have been reached when the care providers and the patient feel maximal gains have been reached, given the available time and resources, in managing pain and its impact on everyday functioning. Periodic reassessments by specialized care providers may be appropriate after discharge to ensure the stability of pain management. The goal of self-management education is to equip the patient to manage pain as independently as possible. The SCI rehabilitation team should engage in continuous quality improvement, including evaluation and feedback efforts regarding their pain management practices based on patient outcomes. The plan, which is part of the ongoing care for neuropathic pain management, must be available to the patient before discharge from rehabilitation, and the patient must be educated about its elements. The plan must also be provided to any post-discharge care providers at discharge and especially to the provider assuming primary management of the patient. Useful items to include in the discharge plan, depending on the complexity of the case and the team members involved in care, are current medication, a medication titration plan, a plan for future pain management, nonpharmacologic treatment modalities, scheduled ongoing rehabilitation visits, and suggestions for the timing of follow-up and re-referral to rehabilitation. As much as possible, a discharge plan should also remove barriers to accessing services and identify appropriate community resources for each patient. It is often possible to identify suitable resources by working with partner organizations and allied services. It is essential to integrate the principles of self-management into the discharge plan and patient education, to support the maintenance of a patient's function and stability of pain management after discharge. Self-management interventions commonly involve psychoeducation to develop or improve self-efficacy skills in goal setting, problem-solving, management of psychological consequences, medication management, symptom management, social support, and communication. ▪ P.4.5: Techniques should be:

1. demonstrable or actionable by the individual,
2. matched to the individual's abilities,
3. linked to further community support.
   The goal of self-management education is to equip the patient to manage pain as independently as possible. (Adapted from SYS CARE 2016, p.S27; Level C)

Clinical considerations:
Evaluation of practice supports accountability and improvement. The subjective nature of pain and the challenging nature of successful pain management make continuous quality improvement critical to ensuring that the individual's needs continue to be met and that resources are used appropriately. Essential elements of a quality improvement program are process and outcome indicators to demonstrate the status of practice change. Process indicators, such as monitoring measure implementation, should include intent and by target. Outcome indicators, such as a reduction in the intensity of an individual's pain over time, should be measured using the International Spinal Cord Injury Pain Basic Data Set element on pain intensity to accurately assess change produced by practice activities.

P.5 - RECOMMENDATIONS FOR NEUROPATHIC PAIN TREATMENT – FIRST-LINE THERAPY

- P.5.1: Gabapentin should be used for the reduction of neuropathic pain intensity among individuals with SCI. (CANPAIN TREAT, p.S16; Level A)
- P.5.2: Pregabalin should be used for the reduction of neuropathic pain intensity among individuals with SCI. (CANPAIN TREAT, p.S15; Level A)

P.6 - RECOMMENDATIONS FOR NEUROPATHIC PAIN TREATMENT – SECOND-LINE THERAPY

- P.6.1: Tramadol may be used for the reduction of neuropathic pain intensity among individuals with SCI. (Adapted from CANPAIN TREAT, p.S16; Level B)

Clinical considerations:
Tramadol is recommended as second-line therapy for SCI-related neuropathic pain. A single randomized, placebo-controlled trial found a significant reduction in pain intensity with tramadol compared with placebo, but the evidence quality was downgraded because of wide confidence intervals. The Canadian Guideline for Safe and Effective Use of Opioids for Chronic Non-Cancer Pain is a useful resource for general information on opioid management and prescription considerations. Although tramadol is not a scheduled drug in Canada, in the United States, it is a Schedule IV drug.

The maximum daily dosage of tramadol is 400mg, divided into up to four daily doses. Treatment is usually initiated at 50mg QD or BID and titrated, based on efficacy and tolerability. Common adverse effects are sedation, nausea, and constipation. A slight increase in the risk of serotonin syndrome can be seen when tramadol is combined with other monoaminergic drugs such as tricyclic antidepressants.

- P.6.2: Lamotrigine may be considered in those with incomplete SCI (AIS B, C, or D) for the reduction of neuropathic pain intensity. (CANPAIN TREAT, p.S16; Level B)

Clinical considerations:

	Evidence for the efficacy of lamotrigine has been demonstrated only in patients with incomplete SCI. As a result, lamotrigine is recommended as second-line therapy only in this population. One randomized placebo-controlled trial showed that lamotrigine significantly reduced the intensity of neuropathic pain for patients with incomplete SCI, but the evidence quality was downgraded because of wide confidence intervals. Lamotrigine dosage was titrated to a maximum of 400mg per day. Common adverse effects were dizziness, somnolence, headache, and rash. It should be noted that lamotrigine has a black box warning issued by the United States Food and Drug Administration (FDA) for serious skin rashes, including Stevens-Johnson Syndrome. **P.7 - RECOMMENDATIONS FOR NEUROPATHIC PAIN TREATMENT – THIRD-LINE THERAPY** ▪ P.7.1: Transcranial direct current stimulation (tDCS) may be considered for reducing neuropathic pain intensity among individuals with SCI. (CANPAIN TREAT, p.S16; Level A) *Clinical considerations:* tDCS is recommended as third-line therapy for patients with SCI-related neuropathic pain on the basis of four RCTs focused on neuropathic pain in patients with SCI. Minor side effects of tDCS include skin irritation, which can be minimized by preparing electrodes with saline and the skin with electrode cream and by increasing current gradually, and phosphene, the visual perception of a brief flash of light, which is not actually present, if an electrode is placed near the eye. ▪ P.7.2: Combined visual illusion and transcranial direct current stimulation may be considered for reducing neuropathic pain intensity among individuals with SCI. (CANPAIN TREAT, p.S17; Level A) *Clinical considerations:* The combination of visual illusion and tDCS is recommended as third-line therapy. The main side effects of this combined therapy included mild headache and fatigue. **P.8 - RECOMMENDATIONS FOR NEUROPATHIC PAIN TREATMENT – FOURTH-LINE THERAPY** ▪ P.8.1: Transcutaneous electrical nerve stimulation (TENS) may be considered for the reduction of neuropathic pain intensity among individuals with SCI. (CANPAIN TREAT 2016, p.S17; Level C) ▪ P.8.2: The dorsal root entry zone (DREZ) procedure may be considered in exceptional circumstances and as a last resort for reducing neuropathic pain intensity among individuals with SCI. (CANPAIN TREAT 2016, p.S17; Level C) *Clinical considerations:* Evidence of benefit for the DREZ procedure exists, but the risk of the procedure does not justify its use beyond exceptional circumstances. Risks associated with the DREZ procedure include paresis, neuropathy or radiculopathy, ataxia and a variety of surgical complications such as persistent incisional site pain, cerebrospinal fluid leak, wound infection, subcutaneous hematoma, and bacteremia. ▪ P.8.3: Levetiracetam should not be used for reducing neuropathic pain intensity among individuals with SCI. (CANPAIN TREAT 2016, p.S18; Level A) ▪ P.8.4: Mexiletine should not be used for reducing neuropathic pain intensity among individuals with SCI. (CANPAIN TREAT 2016, p.S18; Level A) **P.9 - NON-PHARMACOLOGICAL THERAPIES**

	▪ P.9.1: Individuals may try several different pharmacological and non-pharmacological methods if deemed safe after consultation with a clinician (e.g., massage, cannabis, osteopathy). We recognize the existence of a number of complementary health strategies that pose a limited risk and can be used in isolation or in combination. Some may find these therapies beneficial to reducing neuropathic pain intensity. (CAN-SCIP 2020; Level C)
Autonomic dysreflexia	**J - AUTONOMIC DYSREFLEXIA (AD)** **J.1 - BLOOD PRESSURE FOLLOWING SPINAL CORD INJURY** ▪ J.1.1: Be aware that, compared with the general population, individuals with SCI are likely to have the following systolic blood pressure differences: 1. In the supine resting position, adults with injuries at or above T1 will likely have low blood pressure (on average systolic blood pressure ~110 mmHg) 2. In the seated resting position, adults with injuries at or above T6 will likely have low blood pressure (on average systolic blood pressure ~100 mmHg) 3. Age-related changes in blood pressure (i.e., pediatric age group and older individuals) may be different. (PVA-AD 2020, p.640; Level C) **J.2 - MANAGEMENT OF AUTONOMIC DYSREFLEXIA** ▪ J.2.1: Individuals with an SCI at or above T6 may present with the signs and symptoms of autonomic dysreflexia, including: 1. Elevated systolic blood pressure greater than 20 mmHg above their usual baseline in adults 2. Sudden-onset headache 3. Possible bradycardia or tachycardia 4. Cardiac arrhythmias, atrial fibrillation, premature ventricular contractions, and atrioventricular conduction abnormalities 5. Profuse sweating and/or flushing of the skin, typically (face, neck, and shoulders) or possibly below the level of the lesion 6. Piloerection (goosebumps) above or possibly below the level of the lesion 7. Blurred vision and/or spots in the individual's visual fields 8. Nasal congestion 9. Feelings of apprehension or anxiety 10. Few or no symptoms other than elevated blood pressure (Adapted from PVA-AD 2020, p.640; Level C) ▪ J.2.2: Be aware that autonomic dysreflexia may appear with minimal or no symptoms (silent autonomic dysreflexia or those with cognitive/verbal communication limitations) despite a significantly elevated blood pressure. (PVA-AD 2020, p.640; Level C) ▪ J.2.3: Check the individual's blood pressure. (PVA-AD 2020, p.640; Level C) ▪ J.2.4: If signs or symptoms of autonomic dysreflexia are present, but blood pressure is not elevated, and the cause has not been identified, refer the individual to an appropriate consultant, depending on symptoms. (PVA-AD 2020, p.640; Level C) ▪ J.2.5: If autonomic dysreflexia is diagnosed, identify the trigger(s) in order to manage blood pressure. (PVA-AD 2020, p.640; Level B) ▪ J.2.6: If blood pressure is elevated, immediately sit the individual up and lower the legs, if possible. (PVA-AD 2020, p.640; Level B) ▪ J.2.7: Monitor blood pressure and pulse frequently (every 1 – 2 minutes) until the individual is stabilized. (PVA-AD 2020, p.640; Level B) ▪ J.2.8: Loosen any clothing or constrictive devices. (PVA-AD 2020, p.640; Level B) ▪ J.2.9: Determine whether the individual has recently taken a vasopressor or an antihypotensive agent. (PVA-AD 2020, p.640; Level C)

	▪ J.2.10: Quickly survey the individual for other triggers, beginning with the urinary system. (PVA-AD 2020, p.640; Level B) ▪ J.2.11: If an indwelling urinary catheter is not in place, catheterize the individual. (PVA-AD 2020, p.640; Level C) ▪ J.2.12: If the elevated blood pressure is at or above 150 mmHg systolic prior to catheterization, consider rapid-onset and short-duration pharmacological management to reduce the systolic blood pressure without causing hypotension. (PVA-AD 2020, p.640; Level C) ▪ J.2.13: Consider the use of an antihypertensive agent (such as nitropaste, nifedipine, hydralazine, or sublingual clonidine) with rapid onset and short duration. (PVA-AD 2020, p.640; Level C) ▪ J.2.14: Prior to the use of nitropaste or any other agent containing nitrate, first, inquire about whether the individual has recently taken a phosphodiesterase type 5 inhibitor (PDE5i). (PVA-AD 2020, p.640; Level B) ▪ J.2.15: Prior to inserting the catheter, instill lidocaine jelly 2% (if immediately available in the room where the individual is being treated) into the urethra and wait approximately 5 minutes, if possible. (PVA-AD 2020, p.641; Level C) ▪ J.2.16: Avoid applying pressure over the bladder (Credé maneuver) or suprapubic tapping, as this may exacerbate autonomic dysreflexia. (PVA-AD 2020, p.641; Level C) ▪ J.2.17: If the individual has an indwelling or suprapublic urinary catheter, check the system along its entire length for kinks, folds, constrictions, or an overfilled drainage bag and for correct catheter placement. If a problem is found, correct it immediately. (Adapted from PVA-AD 2020, p.641; Level C) ▪ J.2.18: If there are no problems with the tubing, drainage bag, or catheter placement and the blood pressure is still elevated, gently irrigate the bladder with a small amount (10-15 cc) of fluid, such as normal saline at body temperature, to determine whether the catheter is blocked. Irrigation should be limited to 5-10 cc for children under two years of age. Do not continue to irrigate or attempt to flush the bladder if the fluid is not draining from the catheter, as this will only cause increased bladder distention and increase blood pressure. (PVA-AD 2020, p.641; Level C) ▪ J.2.19: If the catheter is blocked, remove and replace it. (PVA-AD 2020, p.641; Level C) ▪ J.2.20: If there is a history of difficulty passing a catheter in a male, consider using a coude´ catheter or consult urology. (PVA-AD 2020, p.641; Level C) ▪ J.2.21: Prior to replacing the catheter, consider instilling lidocaine jelly 2% (if immediately available) into the urethra or suprapubic tract and wait 3-5 minutes, if possible. (PVA-AD 2020, p.641; Level C) ▪ J.2.22: If difficulties arise in removing or replacing the catheter, in addition to instilling lidocaine jelly, consider initiating new or increasing previous pharmacological treatment and an emergency urology consultation. (PVA-AD 2020, p.641; Level C) ▪ J.2.23: Monitor the individual's blood pressure during bladder drainage. (PVA-AD 2020, p.641; Level C) ▪ J.2.24: If acute symptoms of autonomic dysreflexia persist, including sustained elevated blood pressure, suspect fecal impaction. (PVA-AD 2020, p.641; Level B) ▪ J.2.25: If the elevated blood pressure persists at or above 150 mmHg systolic, strongly consider pharmacological management prior to laying the individual down to check for fecal impaction. (PVA-AD 2020, p.641; Level C) ▪ J.2.26: If fecal impaction is suspected, check the rectum for stool, using the following procedure: 1. Premedicate with a pharmacological agent. 2. With a gloved hand, generously instill a topical anesthetic agent, such as lidocaine jelly 2%, into the rectum. 3. Wait 3-5 minutes, if possible, for sensation in the area to decrease. 4. Then, with a gloved hand, insert a lubricated finger into the rectum and check for the presence of stool. 5. If present, gently remove, if possible. (PVA-AD 2020, p.641; Level B)

	▪ J.2.27: If autonomic dysreflexia becomes worse, or stool cannot be removed, stop the manual evacuation, and administer pharmacological or additional pharmacological intervention and additional topical anesthetic. When blood pressure is stable below 150 mmHg, proceed with an aggressive bowel evacuation regimen. (PVA-AD 2020, p.641; Level B) ▪ J.2.28: If there is no fecal impaction or blood pressure elevation persists despite disimpaction, check for other less frequent causes of autonomic dysreflexia. If there are no obvious triggers or if the blood pressure cannot be managed locally, the individual must be referred to the hospital emergency department for evaluation, management and possible hospital admission. (PVA-AD 2020, p.642; Level C) *Triggers* Autonomic dysreflexia has many potential causes. It is essential that the specific cause be identified and treated in order to resolve an episode of autonomic dysreflexia and to prevent recurrence. Any painful or irritating stimuli below the level of injury may cause autonomic dysreflexia. Bladder and bowel problems are the most common causes of autonomic dysreflexia. The following are some of the more common potential autonomic dysreflexia triggers: Urinary System – Bladder distention – Bladder or kidney stones – Blocked catheter – Catheterization – Detrusor sphincter dyssynergia – Shock wave lithotripsy – Urinary tract infection – Urological instrumentation, such as cystoscopy or testing requiring catheterization GI System – Appendicitis – Bowel distention – Bowel impaction – Gallstones – Gastric ulcers or gastritis – GI instrumentation – Hemorrhoids Integumentary System – Constrictive clothing, shoes, or appliances – Contact with hard or sharp objects – Blisters – Burns, sunburn, or frostbite – Ingrown toenail – Insect bites – Pressure injuries Reproductive System – Sexual activity, including sexual intercourse

	– Sexually transmitted diseases – High sexual arousal and/or orgasmic release – A second orgasmic release or ejaculation soon after the first orgasm will likely provoke more severe autonomic dysreflexia Male – Ejaculation – Epididymitis – High-intensity vibrators used to induce ejaculation – Priapism (especially from intracavernosal injection) – Prostatitis – Scrotal compression (sitting on scrotum) – Sperm retrieval (EEJ and vibratory stimulation) Female – Lactation, breastfeeding, mastitis – Menstruation – Painful intercourse and/or friction – Pregnancy, especially labour and delivery, including ectopic pregnancy – Vaginitis Other Causes – Boosting (an episode of autonomic dysreflexia intentionally caused by an athlete with SCI in an attempt to enhance physical performance) – Deep vein thrombosis – Excessive alcohol intake – Excessive caffeine or other diuretic intake – Fractures or other trauma below the level of injury – Functional electrical stimulation – Heterotopic bone – Over-the-counter or prescribed stimulants – Pulmonary emboli – Substance abuse – Sunburn – Syringomyelia – Surgical or invasive diagnostic procedures – Unguis incarnatus ▪ J.2.29: While the individual is being evaluated in the emergency department, continue to closely monitor blood pressure to guide pharmacological management of autonomic dysreflexia and investigate other causes. Consider hospital admission if: 1. There is poor response to the treatment specified above. 2. The cause has not been identified. (PVA-AD 2020, p.642; Level C)

	▪ J.2.30: After successful identification of the trigger and treatment of the elevated blood pressure, monitor the individual for symptomatic hypotension every 2-5 minutes until the blood pressure is stable. (PVA-AD 2020, p.642; Level C) ▪ J.2.31: Following an episode of autonomic dysreflexia, a health care provider should consider the following: 1. If the individual is an inpatient or in the clinic, monitor closely for at least 2 hours for recurrent autonomic dysreflexia or hypotension. 2. If at home, instruct the individual to seek immediate medical attention if autonomic dysreflexia symptoms reoccur. 3. Prescribe a blood pressure monitoring device to the individual for home monitoring. (PVA-AD 2020, p.642; Level C) ▪ J.2.32: Document the episode of autonomic dysreflexia and record the effectiveness of the treatment in the individual's medical record, including the following: 1. Presenting signs and symptoms and their course 2. Recordings of blood pressure and pulse 3. Treatment instituted and response to treatment 4. Restoration of blood pressure and heart rate to normal levels for the individual 5. Diagnosis of a history of autonomic dysreflexia in order to inform future clinicians of the risk in the individual and prior response to treatments initiated 6. Identification of the cause (trigger) of the autonomic dysreflexia episode 7. Whether the individual is comfortable, with no signs or symptoms of autonomic dysreflexia or secondary complications, such as neurological changes, increased intracranial pressure, or heart failure (PVA-AD 2020, p.642; Level C) ▪ J.2.33: After the individual with SCI has been stabilized, review the precipitating cause of the autonomic dysreflexia episode with the individual, family members, significant others, and caregivers to educate them regarding instigating factors, recognition, management, and prevention of future autonomic dysreflexia episodes. 1. Adjust the treatment plan to ensure that future episodes are recognized and treated to prevent a medical crisis or, ideally, are avoided altogether. 2. Discuss autonomic dysreflexia during the individual's education program so that he or she will be able to minimize the risks known to precipitate autonomic dysreflexia, solve problems, recognize early onset, and obtain help as quickly as possible. 3. Have an ongoing conversation and continue education at annual evaluations or clinic appointments. 4. Give a written wallet card/guide or instruction sheet or consider a medical alert bracelet. (PVA-AD 2020, p.642; Level C) **J.3 - AUTONOMIC DYSREFLEXIA: SEXUALITY (RECOMMENDATIONS FOR SEXUAL ACTIVITY IN THE HOME SETTING)** ▪ J.3.1: Be aware of and educate individuals with SCI at or above T6 that sexual activity may provoke autonomic dysreflexia. (PVA-AD 2020, p.642; Level C) ▪ J.3.2: Be aware that for men and women with SCI at or above T6 who use intense sexual stimulation (including vibratory stimulation), the likelihood of autonomic dysreflexia is increased. (PVA-AD 2020, p.642; Level C) ▪ J.3.3: Encourage individuals with SCI at T6 and above to periodically monitor their blood pressure during sexual activities. (PVA-AD 2020, p.642; Level C)

	▪ J.3.4: Individuals prone to autonomic dysreflexia during sexual activity should be encouraged to use a home blood pressure monitor. (PVA-AD 2020, p.642; Level C) ▪ J.3.5: If sexual activity causes symptomatic autonomic dysreflexia, individuals should be encouraged to immediately cease sexual stimulation and follow autonomic dysreflexia protocol. (PVA-AD 2020, p.642; Level C) ▪ J.3.6: Consider instructing and prescribing pharmacological prophylaxis prior to sexual activity in selected individuals who: 1. Have no history of symptomatic orthostatic hypotension (OH) 2. Are not taking medication that may potentiate hypotension 3. Developed autonomic dysreflexia with systolic blood pressure at or above 150 mmHg (i.e., during vibratory stimulation, ejaculation, orgasm, sperm retrieval, or urological procedures) 4. Have symptomatic autonomic dysreflexia and/or systolic blood pressure greater than 150 mmHg prior to sexual activity or during sperm retrieval (PVA-AD 2020, p.643; Level C) ▪ J.3.7: If pharmacological treatment for autonomic dysreflexia is used in a home setting, instruct individuals on how to recognize, monitor, and treat pharmacologically induced hypotension. (PVA-AD 2020, p.643; Level C) ▪ J.3.8: Instruct individuals at risk of autonomic dysreflexia to recheck blood pressure within 5 minutes of cessation of sexual activity, regardless of symptoms. If the individual's high blood pressure does not resolve after 5 minutes, refer to steps for treatment of autonomic dysreflexia. (PVA-AD 2020, p.643; Level C) ▪ J.3.9: Instruct individuals that if all conservative home measures to treat autonomic dysreflexia or pharmacologically induced hypotension following sexual activity are unsuccessful, an urgent visit to the emergency department is warranted. (PVA-AD 2020, p.643; Level C) **J.5 - AUTONOMIC DYSREFLEXIA IN PREGNANCY, LABOR AND DELIVERY, AND THE POSTPARTUM PERIOD** ▪ J.5.1: Instruct health care professionals that women with SCI who have the potential of developing autonomic dysreflexia are at increased risk of severe autonomic dysreflexia during pregnancy, labour, delivery, and breastfeeding and should be followed by a multidisciplinary team. (PVA-AD 2020, p.644; Level C) ▪ J.5.2: An antepartum consultation with an anesthesiologist and the establishment of a plan for induction of epidural or spinal anesthesia at the onset of labour is recommended to assess the risk of autonomic dysreflexia and to prevent it, in accordance with recommendations of the American College of Obstetricians and Gynecologists. (PVA-AD 2020, p.644; Level C) ▪ J.5.3: In pregnant women prone to autonomic dysreflexia, careful and frequent monitoring of the fetus is recommended, especially during labour and delivery. (PVA-AD 2020, p.644; Level C) ▪ J.5.4: Autonomic dysreflexia must be differentiated from preeclampsia during pregnancy and labour to ensure appropriate treatment. (PVA-AD 2020, p.644; Level C) ▪ J.5.5: Although individuals with SCI may not perceive pain during labour, anesthesia should be used to prevent autonomic dysreflexia in women with SCI at T6 and above. Spinal or epidural anesthesia is the most reliable method of preventing autonomic dysreflexia by blocking stimuli that arise from pelvic organs. (PVA-AD 2020, p.644; Level C) ▪ J.5.6: Educate women who have the potential to develop autonomic dysreflexia that postpartum breastfeeding, breast engorgement, or mastitis may trigger autonomic dysreflexia. (PVA-AD 2020, p.644; Level C) **J.6 - INDUCED AUTONOMIC DYSREFLEXIA ("BOOSTING")**

	▪ J.6.1: Inform individuals with SCI that self-induced autonomic dysreflexia (e.g., boosting) to benefit daily activities and/or sports performance is a dangerous practice that can result in uncontrollable, life-threatening increases in blood pressure. (PVA-AD 2020, p.644; Level C) **J.7 - ORTHOSTATIC HYPOTENSION** ▪ J.7.1: Be aware that orthostatic hypotension, defined as a decrease in systolic blood pressure of = 20 mmHg, may occur in individuals with lesions at T6 and above on the assumption of an upright posture from a supine position, regardless of whether symptoms occur. (PVA-AD 2020, p.644; Level C) ▪ J.7.2: To accurately diagnose orthostatic hypotension in individuals with SCI, perform an orthostatic challenge evaluation (e.g., sit-up test or head-up tilt test). (PVA-AD 2020, p.644; Level C) ▪ J.7.3: To prevent or manage orthostatic hypotension in individuals with SCI, first, consider treating to maintain baseline blood pressure by using nonpharmacological interventions. (PVA-AD 2020, p.644; Level C) ▪ J.7.4: Consider pharmacological interventions to treat both symptomatic and asymptomatic orthostatic hypotension in individuals with established SCI when nonpharmacological interventions prove to be ineffective. (PVA-AD 2020, p.644; Level C) **J.8 - THERMODYSREGULATION - HYPOTHERMIA (CORE TEMPERATURE LESS THAN 35.0°C/95OF)** ▪ J.8.1: Monitor for signs and symptoms in individuals with SCI at T6 or above who are at risk for developing hypothermia when exposed to a cold environment. (PVA-AD 2020, p.644; Level C) ▪ J.8.2: If possible, obtain a rectal temperature when evaluating an individual for hypothermia because skin temperate is not accurate for monitoring core body temperature. Oral and tympanic are also acceptable methods of temperature monitoring. (PVA-AD 2020, p.644; Level C) ▪ J.8.3: Use ambient temperature regulation, insulated clothing, blankets, warm humidified air, and intake of warm fluid into the gastrointestinal tract to help prevent and manage hypothermia. Heating devices should be used with extreme caution in insensate areas. (PVA-AD 2020, p.645; Level C) ▪ J.8.4: In cold ambient environments, instruct individuals to consider avoiding alcohol intake, as it causes vasodilation and heat loss. (PVA-AD 2020, p.645; Level C) ▪ J.8.5: Be aware of and discuss with individuals with SCI that certain medications or substances may disrupt temperature regulation (hypo- or hyperthermia), including alpha-agonists (e.g., tizanidine, clonidine), narcotics, oxybutynin, gabapentin, and antidepressants that are norepinephrine and serotonin reuptake inhibitors. (PVA-AD 2020, p.645; Level C) **J.9 - THERMODYSREGULATION - HYPERTHERMIA (CORE TEMPERATURE MORE THAN 37.8°C/100OF)** ▪ J.9.1: Monitor for signs and symptoms of hyperthermia in individuals with SCI at or above T6 who are at risk for developing hyperthermia when exposed to a hot environment. (PVA-AD 2020, p.645; Level C) ▪ J.9.2: Treat hyperthermia by decreasing the individual's core temperature. This includes moving to a cooler environment (preferably an air-conditioned setting), drinking cool liquids, washing with tepid water, and resting. (PVA-AD 2020, p.645; Level C) ▪ J.9.3: Provide education regarding measures to help prevent neurogenic hyperthermia. Preventative measures include wearing appropriate lightweight and light-coloured clothing, maintaining a proper temperature-controlled room (e.g., use of air-conditioning), frequently drinking cold fluids, maintaining appropriate hydration, and having a water spray and/or fan for exposed skin. This is especially important when in a hot environment. (PVA-AD 2020, p.645; Level C) ▪ J.9.4: Be aware of and discuss with individuals with SCI that certain medications or substances may disrupt temperature regulation (hypo- or hyperthermia), including alpha-agonists (e.g., tizanidine, clonidine), narcotics, oxybutynin, gabapentin, and antidepressants that are norepinephrine and serotonin reuptake inhibitors. (PVA-AD 2020, p.659; Level C)

	▪ J.9.5: During exercise, individuals with SCI at T6 or above should be monitored for neurogenic hyperthermia. (PVA-AD 2020, Level C) **J.10 - HYPERHIDROSIS** ▪ J.10.1: Evaluation of hyperhidrosis in individuals with SCI at T6, or above T6, should rule out more extensive autonomic dysfunction such as autonomic dysreflexia. (PVA-AD 2020, p.670; Level C) ▪ J.10.2: In the absence of a rise in blood pressure, prevention and management of hyperhidrosis should include identifying other possible triggers. (PVA-AD 2020, p.670; Level C) ▪ J.10.3: In those individuals in whom isolated hyperhidrosis is not associated with an identifiable and modifiable cause, consider empirical treatment with anticholinergic medications unless contraindicated. (PVA-AD 2020, p.670; Level C) ▪ J.10.4: If anticholinergic medications do not relieve hyperhidrosis or are not well tolerated, secondary medications could be considered. (PVA-AD 2020, p.670; Level C)
Emotional wellbeing, mental health and substance abuse	**O.1 - SCREENING, ASSESSMENT AND TREATMENT** ▪ O.1.1: Integrate mental health professionals with education, training, and experience in SCI, as well as in general mental health and substance use disorders (SUDs) within comprehensive inpatient and outpatient SCI rehabilitation programs. (PVA-EWB 2020, p.160; Level C) ▪ O.1.2: Routinely screen all individuals with SCI for mental health disorders, SUDs, and suicide risk as part of inpatient and outpatient rehabilitation. (PVA-EWB 2020, p.160; Level C) ▪ O.1.3: Include current symptoms and lifetime history in screening and assessment of mental health disorders and SUDs. (PVA-EWB 2020, p.160; Level C) ▪ O.1.4: Refer individuals who screen positive for a mental health disorder or SUD to a mental health professional for a diagnostic assessment and initiation of treatment, if indicated. (PVA-EWB 2020, p.160; Level C) ▪ O.1.5: Engage individuals with a mental health disorder or SUD in shared decision-making for their treatment. (PVA-EWB 2020, p.160; Level C) ▪ O.1.6: Systematically evaluate valid and standardized measures of progress to inform care and adjust treatment (measurement-based care) for mental health disorders or SUDs. (PVA-EWB 2020, p.160; Level C) ▪ O.1.7: Refer to follow-up treatment and coordinate care upon discharge or transition to the next phase of care, if indicated. (PVA-EWB 2020, p.160; Level C) ▪ O.1.8: Clinicians should consider referring individuals with SCI to peer support networks or to outpatient psychological consultations prior to discharge. Small group cognitive behavioural therapy-based treatment programs should be used to decrease depressive symptoms following SCI. (CAN-SCIP 2020, p.160; Level C) **O.2 - DIAGNOSIS-SPECIFIC DISORDERS: ANXIETY DISORDERS** ▪ O.2.1: Use a brief, valid measure that has good sensitivity to screen all patients for general anxiety and panic disorders: 1. early during the initial inpatient hospital or rehabilitation stay 2. as a repeat screen if indicated to assess persistence of symptoms or change in status 3. at the first post-discharge follow-up point 4. at future time points, depending on risk stratification factors such as prior positive anxiety screening results or preinjury history of psychological disorder. (PVA-EWB 2020, p.160; Level C)

	▪ O.2.2: Refer patients with positive screen results or those suspected of having an anxiety disorder to a mental health provider for a diagnostic assessment to assess for conditions such as generalized anxiety disorder or panic disorder. Rule out the possibility that the symptoms are better explained by the effects of the medical condition, medications, drugs, the environment, or other factors. (PVA-EWB 2020, p.160; Level C) ▪ O.2.3: To minimize anxiety, support anxious patients with specific and nonspecific therapeutic strategies provided by all health care professionals (physicians, nurses, therapists, psychologists, social workers, and others) who work with them. (PVA-EWB 2020, p.160; Level C) ▪ O.2.4: Treat generalized anxiety disorder, panic disorder, or other clinically significant anxiety by using pharmacological and/or nonpharmacological interventions on the basis of salient clinical considerations and patient preferences. (PVA-EWB 2020, p.160; Level C) ▪ O.2.5: Consider pharmacological treatment for anxiety, if indicated. (PVA-EWB 2020, p.161; Level C) ▪ O.2.6: Consider nonpharmacological treatment for anxiety. (PVA-EWB 2020, p.161; Level C) **O.3 - DIAGNOSIS-SPECIFIC DISORDERS: MAJOR DEPRESSIVE DISORDER (MDD)** ▪ O.3.1: Screen all individuals with SCI for major depression by using a brief, valid measure that has good sensitivity and specificity: 1. early during the initial inpatient hospital or rehabilitation stay 2. as a repeat screen if indicated to assess persistence of symptoms or change in status 3. at the first discharge follow-up point 4. at least annually or more frequently, depending on risk stratification factors such as prior positive screening results and chronic pain. (PVA-EWB 2020, p.161; Level C) ▪ O.3.2: Refer patients with positive screen results or those suspected of having a depressive disorder to a mental health provider for diagnostic assessment and treatment. (Adapted from PVA-EWB 2020, p.161; Level C) ▪ O.3.3: Follow up on positive screening test results by using a valid diagnostic assessment to confirm conditions such as major depressive disorder or adjustment disorder (including sufficient persistence of symptoms and interference with rehabilitation or role functioning) and rule out the possibility that the symptoms are better explained by the effects of the medical condition, medications, drugs, the environment, or other factors. (PVA-EWB 2020, p.161; Level C) ▪ O.3.4: Follow up on positive screening test results by using a valid diagnostic assessment to confirm conditions such as major depressive disorder or adjustment disorder (including sufficient persistence of symptoms and interference with rehabilitation or role functioning) and rule out the possibility that the symptoms are better explained by the effects of the medical condition, medications, drugs, the environment, or other factors. (PVA-EWB 2020, p.161; Level C) ▪ O.3.5: Treat major depression by using pharmacological and/or nonpharmacological approaches on the basis of clinical presentation (e.g., comorbid conditions), treatment efficacy, and patient preferences. (PVA-EWB 2020, p.161; Level A) ▪ O.3.6: Consider pharmacological treatments for major depression. (PVA-EWB 2020, p.161; Level A) ▪ O.3.7: Consider nonpharmacological treatments for major depression. (PVA-EWB 2020, p.161; Level A) ▪ O.3.8: Clinicians should consider prescribing cognitive behavioural therapy as a treatment option for individuals with SCI and caregivers to reduce depressive symptoms. (CAN-SCIP 2020; Level A) **O.4 - DIAGNOSIS-SPECIFIC DISORDERS: SUBSTANCE USE DISORDERS** ▪ O.4.1: Screen all patients for common substance use disorders:

	1. Before discharge into the community, use a brief, valid measure that has good sensitivity to screen for lifetime use of and problems with alcohol, other (illicit) drugs, tobacco, marijuana, and nonmedical use of prescription medications 2. depending on initial screening results and other risk factors, rescreen patients for recent substance use in outpatient rehabilitation or primary care. (PVA-EWB 2020, p.161; Level C) ▪ O.4.2: Refer patients with positive screen results or those suspected of having a substance use disorder to a mental health provider for a diagnostic assessment and treatment of substance use disorder criteria. (Adapted from PVA-EWB 2020, p.161; Level C) ▪ O.4.3: Support patients with substance use disorder with nonspecific and substance use disorder -specific relationship skills, used by all health care professionals (physicians, nurses, therapists, psychologists, social workers, and others) who work with them. (PVA-EWB 2020, p.161; Level C) ▪ O.4.4: Treat substance use disorders within rehabilitation to the extent possible by using pharmacological, nonpharmacological, and community-based approaches on the basis of clinical presentation (e.g., comorbid conditions), length of stay, treatment efficacy, and patient preferences. (PVA-EWB 2020, p.161; Level C) ▪ O.4.5: Use medication-assisted treatment for substance use disorders, including opioid use disorders and alcohol use disorders, when indicated. (PVA-EWB 2020, p.162; Level C) ▪ O.4.6: Consider nonpharmacological treatments for substance use disorders. (PVA-EWB 2020, p.162; Level C) ▪ O.4.7: Consider referral to community-based substance use disorder treatment programs and self-help resources. (PVA-EWB 2020, p.162; Level C) **O.5 - POSTTRAUMATIC STRESS DISORDER (PTSD) AND ACUTE STRESS DISORDER (ASD)** ▪ O.5.1: Screen all patients for ASD within 1 month of SCI and for PTSD after the first month. Screening should occur: 1. early during an initial inpatient hospital or rehabilitation stay 2. as a repeat screen if indicated to assess persistence of symptoms or change in status 3. at the first post-discharge follow-up point 4. at future time points beyond 6 months, depending on risk stratification factors, such as being a veteran or other trauma-exposed professional or having subthreshold symptom severity on prior screening examinations. (PVA-EWB 2020, p.162; Level C) ▪ O.5.2: Refer patients with positive screen results or those suspected of having ASD or PTSD to a mental health provider for a diagnostic assessment of ASD or PTSD criteria. (PVA-EWB 2020, p.162; Level C) ▪ O.5.3: Support patients with PTSD with nonspecific and PTSD-specific relationship skills used by all health care professionals (physicians, nurses, therapists, psychologists, social workers, and others) who work with them. (PVA-EWB 2020, p.162; Level C) ▪ O.5.4: Treat ASD and PTSD within rehabilitation to the extent possible by using pharmacological and nonpharmacological approaches on the basis of treatment efficacy, clinical presentation (e.g., comorbid conditions), length of stay, and patient preferences. (PVA-EWB 2020, p.162; Level C) ▪ O.5.5: Offer patients with brief, evidence-based psychological interventions to treat ASD and prevent PTSD within the first month after injury. (PVA-EWB 2020, p.162; Level C) ▪ O.5.6: Offer patients with PTSD evidence-based, trauma-focused psychological treatment. (PVA-EWB 2020, p.162; Level C) ▪ O.5.7: Offer patients with ASD pharmacological treatment if trauma-focused psychotherapies are not available or not preferred. (PVA-EWB 2020, p.162; Level C)

	▪ O.5.8: Offer patients with PTSD pharmacological treatment if trauma-focused psychotherapies are not available or not preferred. (PVA-EWB 2020, p.162; Level C) **O.6 - SUICIDE** ▪ O.6.1: Formally screen individuals with SCI for suicidal ideation by using a brief, standardized, evidence-based screening tool. Screen for suicidal intent and behaviour in individuals who report suicidal ideation. Screen: 1. early during the initial inpatient hospital or rehabilitation stay 2. as a repeat screen if indicated to assess persistence of symptoms or change in status 3. at an early discharge follow-up point, and 4. at least annually or more frequently depending on risk stratification factors. (PVA-EWB 2020, p.162; Level C) ▪ O.6.2: Recognize warning signs for suicide and expedite the evaluation of such signs by a trained professional. Take immediate follow-up action for anyone who displays direct warning signs for suicide (e.g., suicidal communication, preparation for suicide, and/or seeking access to or recent use of lethal means). (PVA-EWB 2020, p.162; Level C) ▪ O.6.3: Stratify suicide risk on the basis of severity and temporality (acute or chronic) to determine appropriate therapeutic interventions and care setting. (PVA-EWB 2020, p.163; Level C) ▪ O.6.4: Facilitate comprehensive assessment by a trained professional to integrate information about suicidal intent and behaviour, warning signs, ability to maintain safety, and factors that impact the risk of suicidal acts. (PVA-EWB 2020, p.163; Level C) ▪ O.6.5: Hospitalize individuals with high acute risk for suicide to maintain their safety and aggressively target modifiable factors. Directly observe them in a secure environment with limited access to lethal means (e.g., kept away from items with sharp points or edges, cords/tubing, toxic substances). (PVA-EWB 2020, p.163; Level C) ▪ O.6.6: Address chronic increased risk for suicide in the context of long-term outpatient therapy with established providers, adjusting the frequency of contact on the basis of risk level. (PVA-EWB 2020, p.163; Level C) ▪ O.6.7: Establish a treatment plan for high-risk individuals that fosters therapeutic alliance with mental health professionals and includes evidence-based suicide-focused psychotherapies. (PVA-EWB 2020, p.163; Level C) ▪ O.6.8: Optimize treatment for coexisting mental health and medical conditions that may impact the risk of suicide. (PVA-EWB 2020, p.163; Level C) ▪ O.6.9: Educate the at-risk individual, family, and caregivers about suicide risk and treatment options. Provide information on suicide prevention resources, including crisis lines and services (e.g., the Canada Suicide Prevention Service number 1-833-456-4566). (Adapted from PVA-EWB 2020, p.163; Level C) ▪ O.6.10: Establish a safety plan for individuals considered to be at high risk for suicide. Limit access to lethal means (e.g., restricting access to firearms, making use of gun locks, limiting medication supply). (PVA-EWB 2020, p.163; Level C) ▪ O.6.11: Augment personal and environmental protective factors that may mitigate suicide risk. Enhance coping skills. (PVA-EWB 2020, p.163; Level C)
Cardiometabolic and nutrition	**N.1 - MANAGEMENT OF CARDIOMETABOLIC DISEASE RISK COMPONENTS AFTER SCI - LIFESTYLE INTERVENTION (NUTRITION AND PHYSICAL ACTIVITY)** ▪ N.1.1: Clinicians should evaluate all adults with SCI for cardiometabolic disease at the time of rehabilitation discharge. For those already discharged from rehabilitation, evaluate for cardiometabolic disease at the earliest opportunity and at three-year intervals. (Adapted from NASH 2018, p.402; Level C)

- N.1.2: Clinicians are recommended to use the American Heart Association (AHA) definition and the five constituent hazards of obesity, insulin resistance, dyslipidemia (including individual risks of low high-density lipoprotein cholesterol (HDL-C) and elevated triglycerides (TG), and hypertension)), as cardiometabolic disease risk components for individuals with SCI. (Adapted from NASH 2018, p.402; Level C)

N.2 - EXERCISE TO IMPROVE FITNESS AND CARDIOMETABOLIC HEALTH

- N.2.1: Clinicians should introduce all individuals with SCI to adapted physical activity throughout their lifespan, regardless of prior participation in physical activity. Behaviour change interventions may facilitate physical activity participation. (CAN-SCIP 2020; Level B)
- N.2.2: Individuals with SCI should exercise regularly according to their ability and follow the exercise recommendations provided in the Canadian SCI Physical Activity Guidelines (version 2). Consider arm ergometry and upper extremity resistance training as a way to improve cardiometabolic health. Canadian SCI Physical Activity Guidelines: https://doi.org/10.1038/s41393-017-0017-3 (Adapted from Nash 2018, p.408; Level C)
- N.2.3: Individuals living with SCI should engage in at least: 20 minutes of moderate to vigorous-intensity aerobic exercise 2 times per week AND 3 sets of strength exercises for each major functioning muscle group, at a moderate to vigorous intensity, 2 times per week to improve cardiorespiratory fitness and muscle strength. (GINIS 2017, p.16; Level A)
  Resources
  1. SCI Action Canada Resources: https://sciactioncanada.ok.ubc.ca/resources/
  2. Strength Training Exercises for Individuals with Paraplegia: http://fhsd-sciactioncanada-2019.sites.olt.ubc.ca/files/2019/11/home-strength-training-guide-paraplegia.pdf
  3. Strength Training Exercises for Individuals with Tetraplegia: http://fhsd-sciactioncanada-2019.sites.olt.ubc.ca/files/2019/11/home-strength-training-guide-tetraplegia.pdf
  4. Strength Training Videos for Individuals with Paraplegia or Tetraplegia: https://sciactioncanada.ok.ubc.ca/resources/active-homes/
  5. Activities for Power Wheelchair Users: https://sciguidelines.ubc.ca/tools-for- success/activity-examples/activities-for-power-wheelchair-users/

N.3 - NUTRITION ASSESSMENT AND MANAGEMENT

- N.3.1: A registered dietitian should assess individuals with SCI for age, ethnicity, gender, time since injury, level of injury, activity level, dietary habits, smoking behaviour, alcohol intake, and weight status as these factors are associated with abnormal blood lipids, particularly decreased HDL cholesterol. (Adapted from NUTR 2009, p.10; Level A)
- N.3.2: Consider establishing caloric targets and consider indirect calorimetry, if available, to estimate energy expenditure and assess energy needs. If not available, clinicians should consult a dietician and use caloric diaries. (CAN-SCIP 2020; Level C)
- N.3.3: Clinicians may consider instituting the following nutritional measures in the post-acute period:

1. For all individuals with SCI, adopt a heart-healthy nutrition plan focusing on fruits, vegetables, whole grains, low-fat dairy, poultry, fish, legumes, non-tropical vegetable oils and nuts while limiting sweets and sugar-sweetened beverages, and red meats
2. Adopt the Dietary Approach to Stopping Hypertension (DASH) nutritional plan or Mediterranean nutritional plan if hypertension or additional cardiometabolic risk factors are present. DASH Nutritional Plan: https://www.heartandstroke.ca/get-healthy/healthy-eating/dash-diet

(Adapted from NASH 2018, p.407; Level C)

- N.3.4: A registered dietician treating individuals with SCI living in a community setting should have SCI-specific nutrition and energy needs expertise and knowledge to conduct a nutrition assessment as part of the annual medical exam to develop and implement an individualized therapeutic nutrition plan. The nutrition assessment should include but is not limited to:

1. Food and nutrition-related history (specifically knowledge deficits, beliefs and attitudes, body image, mealtime behaviours, physical ability to self-feed, access to food- and nutrition-related supplies, meal preparation and food avoidances)
2. Anthropometric measurements (specifically body composition and weight)
3. Biochemical data, medical tests and procedures (specifically serum lipid and glucose levels)
4. Social history (specifically isolation)
5. Nutrition-focused physical findings (specifically bowel and bladder function).

(NUTR 2009, p.6; Level B)

- N.3.5: An annual nutrition assessment by a registered dietitian should be conducted to identify nutrition-related concerns that may affect the health and quality of life of individuals living with SCI. (NUTR 2009, p.6; Level B)

N.4 - NUTRITION ASSESSMENT FOR PREVENTION AND TREATMENT OF OVERWEIGHT AND OBESITY

- N.4.1: The registered dietitian should assess the weight and body composition of the individual with SCI and adjust energy levels or implement weight management strategies as appropriate. See Nutrition Assessment recommendations for methods to determine weight and energy needs, and American Dietetic Association Adult Weight Management Evidence-based Nutrition Practice Guideline (https://www.andeal.org/vault/pqnew132.pdf) for methods to manage weight and obesity. (NUTR 2009, p.25; Level A)

N.5 - OBESITY

- N.5.1: Clinicians may consider assessing individuals with SCI for obesity beginning at discharge from rehabilitation:

1. Where possible, measure body composition using 3- or 4-compartment models to report obesity in adults with SCI until validated, clinically appropriate equations become available. Classify adult men with >22% body fat and adult women with >35% body fat as obese and at high risk for cardiometabolic disease.
2. A body mass index (BMI) ≥22 kg/m2 is the cut-off point when used as a surrogate marker for obesity in individuals with SCI. Adult men and women with BMI ≥22 kg/m2 are at high risk for cardiometabolic disease. Test at least every three years following initial assessment when tests are normal in asymptomatic adults with SCI.

(Adapted from Nash 2018, p.402; Level C)

N.6 - HYPERTENSION

- N.6.1: Clinicians should consider adopting the Canadian Heart and Stroke Guideline as the primary method of assessment for blood pressure measurement in individuals with SCI. Measure blood pressure at every routine visit and at least annually. (Adapted from NASH 2018, p.403; Level C)

N.7 - PHARMACOTHERAPY FOR HYPERTENSION

- N.7.1: Clinicians should use the Canadian Heart and Stroke Guideline for treating hypertension in the general population for treating individuals living with SCI. (Adapted from NASH 2018, p.412; Level C)
- N.7.2: Clinicians should consider SCI-related factors when selecting an antihypertensive agent, such as the effect of thiazide diuretics on bladder management. Orthostatic hypotension is a known side effect of anti-hypertensive treatments. (NASH 2018, p.413; Level C)

N.8 - IMPAIRED FASTING GLUCOSE, PRE-DIABETES, AND DIABETES

	▪ N.8.1: Clinicians may consider screening adults with SCI for diabetes and pre-diabetes and repeat testing yearly if tests are normal. (Adapted from NASH 2018, p.402; Level C) ▪ N.8.2: Adopt the Diabetes Canada clinical practice guideline to diagnose diabetes and pre-diabetes based on either fasting plasma glucose (FPG), the 2-hour plasma glucose (2hPG) value after a 75-g oral glucose tolerance test (OGTT), or A1C criteria. (Adapted from NASH 2018, p.403; Level C) **N.9 - DYSLIPIDEMIA** ▪ N.9.1:Primary care physicians and/or physiatrists should routinely conduct screening for lipid abnormalities for all individuals with SCI living in the community to reduce morbidity and mortality. Individuals with SCI have a higher incidence and a higher prevalence of earlier onset of cardiovascular disease. (Adapted from NUTR 2009, p.4; Level B) ▪ N.9.2: Perform annual screening of individuals with SCI in the presence of multiple risk factors or when evidence of dyslipidemia is confirmed, or treatment is initiated. (NASH 2018, p.404; Level C) **N.10 - PHARMACOTHERAPY FOR DYSLIPIDEMIA** ▪ N.10.1: Guide patient selection for pharmacotherapy by other factors commonly seen in SCI, such as low levels of HDL-C. Initiate statin monotherapy using at least a moderate-intensity statin (e.g., rosuvastatin 10–20 mg/day). Refer to the Canadian Heart and Stroke Guideline when initiating statins. (Adapted from NASH 2018, p.411; Level C) **N.11 - DIABETES- PHARMACOTHERAPY FOR DYSGLYCEMIA, TYPE-2 PRE-DIABETES & TYPE-2 DIABETES** ▪ N.11.1: Clinicians should use a threshold of risk for HbA1c levels greater than 7% as a criterion to emphasize lifestyle intervention. (Adapted from NASH 2018; p.410; Level C). Diabetes Canada Clinical Practice Guideline: http://guidelines.diabetes.ca/docs/CPG-2018-full-EN.pdf **N.12 - BARIATRIC SURGERY FOR CARDIOMETABOLIC DISEASE RISK** ▪ N.12.1: Consider bariatric surgery as a last resort for individuals with morbid obesity and SCI due to the significant peri- and postoperative risks. If bariatric surgery is considered, an SCI clinician should provide preoperative, perioperative, and postoperative consultative services to the surgical and anesthesia teams to alert them to unique risks associated with SCI. In individuals with morbid obesity in SCI who have failed available options for weight loss, refer to a bariatric program to assess alternate treatments and appropriateness for surgery. (Adapted from NASH 2018, p.414; Level C)
Bone Health	**L.1 - ASSESSMENT OF FRACTURE RISK** ▪ L.1.1: All adults with SCI resulting in permanent motor or sensory dysfunction should have a dual-energy X-ray absorptiometry (DXA) scan of the total hip, proximal tibia, and distal femur as soon as medically stable. (Adapted from BMD 2019, p.2; Level B) **L.2 - DXA TESTING** ▪ L.2.1: In adults with SCI, total hip, distal femur, and proximal tibia bone density should be used to diagnose osteoporosis, predict lower extremity fracture risk, and monitor response to therapy where normative data are available. (Knee DXA Protocol: https://www.kite-uhn.com/clinical/tools/knee-dxa-protocol) (BMD 2019, p.4; Level B) ▪ L.2.2: Serial DXA assessment of treatment effectiveness among individuals with SCI should include evaluation at the total hip, distal femur, and proximal tibia, following a minimum of 12 months of therapy at 1- to 2- year intervals. Segmental analysis of total hip, distal femur, and proximal tibia subregions from a whole-body scan should not be used for monitoring treatment. (BMD 2019 p.6; Level B) **L.3 - PREVENTION OF OSTEOPOROSIS**

	▪ L.3.1: There is no established threshold BMD value below which weight-bearing activities are absolutely contraindicated. BMD and clinical risk factors should be used to assess fracture risk prior to engaging in weight-bearing activities. (BMD 2019; p.7; Level C) **L.4 - TREATMENT OF OSTEOPOROSIS** ▪ L.4.2: Individuals with motor complete SCI should be offered Alendronate (70 mg weekly), Zoledronate (5 mg IV) or Denosumab (60 mcg via subcutaneous injection) to maintain proximal and distal femur and proximal tibia BMD, following a discussion of evidence-based benefits and risks. (CAN-SCIP 2020; Level A) ▪ L.4.3: Zoledronate should not be offered to individuals with renal impairment. (CAN-SCIP 2020; Level A) ▪ L.4.4: Individuals with low bone mass should be offered vitamin D supplements to maintain lower extremity BMD. (CAN-SCIP 2020; Level A) ▪ L.4.5: In individuals with SCI with low knee region BMD, FES cycling at least 3 times per week and 5 hours per week should be offered to maintain or improve knee region BMD in the areas stimulated, following a discussion of evidence-based benefits and risks. (CAN-SCIP 2020; Level C)
Palliative care	NR
Rehabilitation	**F.1 - GENERAL RECOMMENDATIONS (SPECIALISED REHAB)** ▪ F.1.5: SCI-specific rehabilitation should be offered to individuals living with chronic SCI when new achievable rehabilitation goals are identified. (CAN-SCIP 2020; Level C) ▪ F.1.6: Timely access to the full continuum of intensity-appropriate specialized care at transition points (i.e., acute to inpatient post-acute, inpatient to outpatient) is recommeded. If insufficient time has been allowed in specialized rehabilitation care, the impact on the family/caregivers and health care costs are significant. (CAN-SCIP 2020; Level C) **G.1 - GENERAL RECOMMENDATIONS (COMMUNITY-BASED REHAB)** ▪ G.1.1: Clinicians should conduct regular and accessible interdisciplinary follow-up to determine progress towards functional goals. (CAN-SCIP 2020; Level C) ▪ G.1.2: Clinicians should assist individuals with SCI to establish a mechanism for regular performance of sitting support surfaces assessment specific to pressure injury prevention and treatment. Schedule reassessment at least every two years, or sooner if any of the following occur: 1. health status changes, including weight or medical changes 2. changes in functional status 3. equipment wear or disrepair 4. pressure injury development 5. changes in living situation. (Adapted from PU-ONF 2013, p.127; Level C) ▪ G.1.3: Replace seating equipment and support surfaces according to manufacturer's recommendations, or assessment by an assistive technology specialist or occupational therapy, if equipment demonstrates any signs of deterioration, including but not limited to wear, cracking, and allowing bottoming out. (PU-ONF 2013, p.127; Level C)
Wheeled mobility	**U - WHEELED MOBILITY** ▪ U.1.1: The assessment for wheeled mobility should be completed by a clinician with training in wheelchair prescription and experience working with individuals with SCI, physical therapist and/or occupational therapist. (Adapted from OTA 2013, p.13; Level C)

	▪ U.1.2: The clinician should assess the prospective wheelchair user's functioning, consider the individual's goals and environment, involve the individual with SCI and relevant others, apply clinical reasoning, use research evidence to guide decisions, keep appropriate records of the intervention, and consult with other specialists where appropriate. (Adapted from OTA 2013, p.13; Level C) ▪ U.1.3: Assessment for the prescription of a wheelchair, power assist device, or scooter should include trials for an adequate period while performing activities in environments that are usual and relevant to the individual with SCI and their caregiver (including the home environment or similar and surroundings, and anticipated modes of transport). (Adapted from OTA 2013, p.23; Level C) ▪ U.1.4: Assessment for the prescription of a wheelchair or scooter should include consideration of the seating system and its integration with the wheelchair and consideration of referral to a seating specialist for individuals with complex postural and control needs. (Adapted from OTA 2013, p.24; Level B) ▪ U.1.5: Wheelchair satisfaction and safety should be reassessed by a clinician with experience in SCI at 3-months post-procurement of a wheelchair, and at each follow-up visit, as needed. (Adapted from OTA 2013, p.24; Level C) ▪ U.1.6: The clinician with SCI expertise should consider an individual's behaviour, psychological status, cognitive status, and perceptual skills when considering the risk of causing harm to themselves or others prior to and during the trial of a wheelchair or scooter and refer to a suitable health professional, as needed. (Adapted from OTA 2013, p.28; Level C) ▪ U.1.7: In instances where an individual with SCI does not have the cognitive or perceptual capacity to independently operate a powered wheelchair over different environments or an extended period of time, controls for the support individual as well as the client should be considered. (Adapted from OTA 2013, p.29; Level C) ▪ U.1.8: Refer individuals with SCI to other specialist services (e.g., optometrist, ophthalmologist, audiologist, mobility trainers) when a vision or hearing impairment is identified. (Adapted from OTA 2013, p.31; Level C) ▪ U.1.9: The individual with SCI should be trained to use compensatory techniques when a visual deficit exists, and their safety to use the device should be reviewed in the environment the device will be used, including the road. (Adapted from OTA 2013, p.31; Level C) ▪ U.1.10: A clinician with SCI experience should educate the wheelchair user and their caregiver about the risks of upper limb pain and injury, the means of prevention and risk minimization treatment, and the need to maintain fitness. (Adapted from OTA 2013, p.38; Level C) ▪ U.1.11: The individual with SCI and caregiver should be informed that alcohol, cannabis, prescribed medications (where relevant), and illicit drugs may impact their capacity to safely operate a wheelchair or scooter. (Adapted from OTA 2013, p.40; Level C) ▪ U.1.12: SCI clinicians should prescribe seating systems based on individual considerations and assessment. (Adapted from OTA 2013, p.46; Level C) ▪ U.1.13: SCI clinicians should consider personal factors, activities and wheelchair features when considering and evaluating a wheelchair for an individual's sitting and ride comfort: personal factors, activities, and wheelchair features. (Adapted from OTA 2013, p.47; Level B) ▪ U.1.14: The factors that should be considered with respect to foot propulsion include pelvic stability and posture, and the ability to recover a better posture. In order to achieve foot propulsion, symmetry of posture may be compromised, which has potential long-term musculoskeletal implications. (OTA 2013, p.54; Level C) ▪ U.1.15: Power-assisted wheelchair wheels should be considered as they may improve functional mobility and performance for wheelchair users with reduced upper limb function. (OTA 2013, p.54; Level B) ▪ U.1.16: SCI clinicians should assess stroke propulsion pattern, positioning used, energy expenditure and efficiency, and determine the optimal wheelchair and propulsion pattern for the individual with SCI to minimize the risk of injury to their upper extremities for all manual wheelchair users. (CAN-SCIP 2020; Level C) ▪ U.1.17: Prior to rehabilitation discharge, the clinician with experience with SCI should facilitate the provision of client/support individual training on the wheelchair or scooter to improve skill and performance. (Adapted from OTA 2013, p.60; Level A)

	▪ U.1.18: We recommend that wheelchair training for individuals with SCI includes: elements of instruction, practice sessions, and experience in the community/potential environments delivered by an experienced SCI clinician. (Adapted from OTA 2013, p.60; Level A) ▪ U.1.19: At a minimum, the novice wheelchair or scooter user should receive training delivered by a clinician with experience with SCI on wheelchair use for an average of three to four hours over a number of weeks in approximately 30-minute sessions. The practice sessions are in addition to individual training time. (Adapted from OTA 2013, p.61; Level A) ▪ U.1.20: Face-to-face wheelchair skills training should primarily be conducted on an individual basis, although practice sessions can involve buddy/paired or peer methods. (Adapted from OTA 2013, p.62; Level B) ▪ U.1.21: The therapist should ensure that the individual with SCI is provided with information regarding the options for and availability of maintenance and repair service, plus who to contact. (OTA 2013, p.72; Level C) ▪ U.1.22: The therapist should inform the individual with SCI and caregiver that the wheelchair or scooter should undergo at least one maintenance service prior to the expiry of the manufacturer's warranty period. (Adapted from OTA 2013, p.72; Level C)
Other guidance	**V - ACTIVITY-BASED THERAPY** ▪ V.1.1: All individuals with SCI should be considered for individual assessment for the potential benefits of standing as physiologically stable, and it is practically possible following SCI. (Adapted from CGFS 2013, p.11; Level A) ▪ V.1.2: Specific goals should be identified for the individual with SCI based on the initial assessment and on-going evaluation. Suitable outcome measures should be used. (CGFS 2013, p.12; Level C) ▪ V.1.3: Individuals with an acute or subacute cervical SCI be offered functional electrical stimulation as an option to improve hand and wrist function. (Adapted from TIME 2017, p.235S; Level C) **W - MOBILITY AND WALKING** ▪ W.1.5: Functional electrical stimulation, if available and there are no contraindications, can be a positive adjunct to this in individuals with incomplete SCI with upper motor neuron pattern in their lower extremities. (CAN-SCIP 2020; Level B) **X - UPPER LIMB** ▪ X.1.1: It is recommended that individuals with SCI be referred to community-based exercise programs with periodic reassessment by an SCI clinician to maintain their fitness and wellness and optimize and monitor their function. (PRAXIS 2020; Level B) ▪ X.1.2: We recommend that neuromuscular-assisted arm cycle ergometry be offered as a means to increase muscle strength in individuals with tetraplegia. (PRAXIS 2020; Level B) ▪ X.1.3: Consider offering individuals with chronic incomplete tetraplegia (more than one-year post-injury) massed practice (repetitive activity) of task-oriented skills. Somatosensory stimulation is an important adjuvant to massed practice to augment hand function. (PRAXIS 2020; Level A) ▪ X.1.4: Transmagnetic brain stimulation for augmenting function in SCI is under investigation and requires further evidence. (PRAXIS 2020; Level C) ▪ X.1.5: Auricular and electrical acupuncture therapy for augmenting function in SCI is under investigation and requires further evidence. (PRAXIS 2020; Level B) ▪ X.1.7: For individuals with thumb web space contractures, stretching is likely not effective in reducing the contracture and therefore not recommended as an independent modality. (PRAXIS 2020; Level A) ▪ X.1.8: A shoulder exercise and stretching protocol including protractor stretches and shoulder retractor strengthening can be used reduce the intensity of shoulder pain. (PRAXIS 2020; Level A)

	▪ X.1.9: Consider referring patients with tetraplegia to a quarternary trans-professional upper extremity clinic for assessment of candidacy of peripheral nerve transfer or tendon transfer for restoration of upper extremity function. Referral with specific functional goals is recommended. (PRAXIS 2020; Level A) ▪ X.1.10: For assessment of the natural history of SCI disease, we recommend International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI), Graded Redefined Assessment of Strength, Sensibility and Prehension (GRASSP), and self-care subscore of Spinal Cord Independence Measure (SCIM). For interventions, if a reconstructive surgery, the ISHT and grasp and release test\TRI-HFT should be used at baseline and discharge. If stimulation therapies are being used to restore hand function, then use the TRI\HFT. (PRAXIS 2020; Level C) ▪ X.1.11: Functional electrical stimulation therapy (FEST) should be prescribed at least 3 times per week for a total of 40 hours for individuals with an AIS A complete injury and incomplete injury. (PRAXIS 2020; Level C)
Broader SCI care pathways and supports	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Governance structure	NR
Funding model	NR
Care pathways	**I - COMPREHENSIVE HEALTH & WELLNESS** ▪ I.1.1: It is recommended that individuals with SCI living in the community have a team of health care professionals with delineated roles who coordinate care (e.g., primary care, physiatrists, urology, respirology, occupational therapy, physical therapy, psychology, social work, recreational therapy, etc.). (CAN-SCIP 2020; Level C) ▪ I.1.2: All health care professionals should use telehealth/telecounselling, eHealth technologies (e.g., electronic consult, virtual visits), and outreach clinics wherever possible to provide timely and equitable access to care, and avoid potential long transportations to the outpatient clinic, for all individuals with SCI as allowed by the nature of the clinical problem. (CAN-SCIP 2020; Level C) ▪ I.1.3: Primary care providers and/or physiatrists should perform an annual comprehensive preventative health evaluation for all individuals with chronic SCI. (CAN-SCIP 2020; Level C)
Education across the continuum of care	**B.2 - INFORMATION AND SUPPORT FOR PATIENTS, FAMILY MEMBERS AND CAREGIVERS** ▪ B.2.1: Individuals with SCI should have timely access to local peer support services and community-based programs to increase the quality of life and community participation after injury across their lifespan. (CAN-SCIP 2020; Level C) ▪ B.2.2: Education for individuals with SCI, caregivers, and health care providers should be provided and comprehensive to all levels of learners. (PVA-NBD 2020, p.454; Level C) **B.3 - EDUCATION FOR INDIVIDUALS WITH SCI AND CAREGIVERS – AUTONOMIC DYSREFLEXIA** ▪ B.3.1: After the individual with SCI has been stabilized, review the precipitating cause of the autonomic dysreflexia episode with the individual, family members, significant others, and caregivers to educate them regarding instigating factors, recognition, management, and prevention of future autonomic dysreflexia episodes. o Adjust the treatment plan to ensure that future episodes are recognized and treated to prevent a medical crisis or, ideally, are avoided altogether. o Discuss autonomic dysreflexia during the individual's education program so that he or she will be able to minimize the risks known to precipitate autonomic dysreflexia, solve problems, recognize early onset, and obtain help as quickly as possible. o Have an ongoing conversation and continue education at annual evaluations or clinic appointments. o Give a written wallet card/guide or instruction sheet or consider a medical alert bracelet. (PVA-AD 2020, Level C)

B.4 - EDUCATION FOR INDIVIDUALS WITH SCI AND CAREGIVERS – BOWEL

- B.4.1: The components of the bowel program should be taught to individuals with an SCI as well as to caregivers. (PVA-NBD 2020, p.455; Level C)
- B.4.2: Education on potential complications should be completed. (PVA-NBD 2020, p. 455; Level C)
- B.4.3: Education and support for the caregiver should be considered and completed when appropriate. (PVA-NBD 2020, p.455; Level C)
- B.4.4: Sexual intimacy and considerations related to bowel program management should be discussed. (PVA-NBD 2020, p.455; Level C)

C.1 - TRAINING AND EDUCATION OF HEALTHCARE PROFESSIONALS – PRESSURE INJURY

- C.1.1: We recommend healthcare professionals with expertise in wound care provide training to healthcare professionals on preventing a pressure injury, including:

1. who is most likely to be at risk of developing a pressure injury
2. how to identify pressure damage
3. what steps to take to prevent new or further pressure damage
4. who to contact for further information and for further action.
   (Adapted from NICE PU 2014, p.385; Level B)

- C.1.2: Provide further training to healthcare professionals who have contact with anyone who has been assessed as being at high risk of developing a pressure injury. Training should include:

1. how to carry out a risk and skin assessment
2. how to reposition
3. information on pressure redistributing devices
4. discussion of pressure injury prevention and management with patients and their caregivers
5. details of sources of advice and support
6. information regarding the importance of nutrition related to pressure injury prevention.
   (Adapted from NICE PU 2014, p.385; Level B)

C.2 - TRAINING AND EDUCATION OF HEALTHCARE PROFESSIONALS – SEXUAL HEALTH

- C.2.1: Clinicians should develop a sexual health education and treatment plan with the individual based on their sexual history, physical exam findings and preferences. (Adapted from CSCM 2010, p.309; Level C)
- C.2.2: Clinicians should educate individuals with SCI about the effects of prescription medication (over-the-counter and herbal remedies) on sexual response and fertility. (Adapted from CSCM 2010, p.309; Level C)
- C.2.3: Clinicians should educate individuals with SCI about the effects of alcohol, tobacco, and other drugs, as well as unhealthy eating habits and obesity, on sexual response and fertility. (Adapted from CSCM 2010, p.309; Level C)
- C.2.4: When counselling on the sexual health of an individual, clinicians should consider socio-cultural and religious influences and do not make assumptions about sexuality based on age. (Adapted from CSCM 2010, p.313; Level C)
- C.2.5: Use professionally approved educational videos and vetted websites when providing sexual health education using media. Institutions should provide sexual health educators institutional access to these resources. (Adapted from CSCM 2010, p.313; Level C)

	▪ C.2.6: Clinicians should ensure premenopausal women with SCI have proper information regarding the effect of injury on menstruation and discuss contraception options. If menses have not resumed one year after injury, an endocrinology referral should be sought by the primary care provider. (CAN-SCIP 2020; Level C) ▪ C.2.7: Education should be provided to men with SCI that reflex erections could occur with either sexual stimulation or nonsexual stimuli. (Adapted from CSCM 2010, p.320; Level B) **C.3 - TRAINING AND EDUCATION OF HEALTHCARE PROFESSIONALS – EMOTIONAL WELL-BEING** ▪ C.3.1: Psychology services should be available in acute, inpatient and outpatient rehabilitation care settings as part of the multi-disciplinary interprofessional team. (CAN-SCIP 2020; Level C) **C.4 - TRAINING AND EDUCATION OF HEALTHCARE PROFESSIONALS – TELEREHABILITATION** ▪ C.4.1: Use telerehabilitation for the prevention and management of pressure injuries in individuals with SCI. (Adapted from PU-ONF 2013, p.192; Level A)
Safeguarding and ethics	**B.5 - SUPPORT FOR VULNERABLE ADULTS** ▪ B.5.1: An interprofessional team, consisting of members with professional knowledge and competency should provide support for vulnerable adults (physical, economic, social, or emotional vulnerability), particularly those who are socioeconomic disadvantaged, homeless, lacking social support, have pre-existing severe mental health issues or are victims of assault or violence. (Adapted from NICE 2016, p.16; Level C) ▪ B.5.2: Clinicians should work with family members and caregivers of these vulnerable adults (physical, economic, social, or emotional vulnerability) to provide information and support while considering the individual's age, developmental stage, and cognitive function. (Adapted from NICE 2016, p.16, Level C) ▪
Other supports	**F.3 - COMMUNITY CARE (SPECIALIZED REHAB)** ▪ F.3.1: Individuals with SCI should have timely access to local peer support services and community-based programs to increase the quality of life and community participation after injury across their lifespan. (CAN-SCIP 2020; Level C) ▪ F.3.2: Family and caregivers should be screened at follow-up for evidence of excess stress and burnout and provided with support as needed. (CAN-SCIP 2020; Level C) **G.2 - COMMUNITY CARE (COMMUNITY-BASED REHAB)** ▪ G.2.1: Personal support workers providing care to individuals with SCI should receive education about SCI with online or in-person training on best practices at a minimum. Individuals with SCI should be provided with education on how to direct their own care. (CAN-SCIP 2020; Level C) ▪ G.2.2: Individuals with SCI should have timely access to local peer support services and community-based programs to increase the quality of life and community participation after injury across their lifespan. (CAN-SCIP 2020; Level C) ▪ G.2.3: Family and caregivers should be screened at follow-up for evidence of excess stress and burnout and provided with support as needed. (CAN-SCIP 2020; Level C) **H - VOCATIONAL REHABILITATION** ▪ H.1.1: Individuals with SCI should be offered information on job placement services during rehabilitation. (CAN-SCIP 2020; Level C) ▪ H.1.2: Individuals more than two years post-SCI who have severe walking limitations, are full-time wheelchair users or live alone should consider applying for a service dog to improve school and employment integration and participation. (CAN-SCIP 2020; Level B)

Quality assurance processes	NR
Infection prevention and control	NR
Other guidance	NR

Key: NR – Not Reported

<table>
<tr><th colspan="2">Guidance document characteristics</th></tr>
<tr><td>Endorsing Organisation</td><td>Canadian Thoracic Society</td></tr>
<tr><td>Title</td><td>Home mechanical ventilation: A Canadian Thoracic Society clinical practice guideline</td></tr>
<tr><td>Country</td><td>Canada</td></tr>
<tr><td>Date Published</td><td>2011</td></tr>
<tr><td>URL</td><td>https://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.686.7360&rep=rep1&type=pdf (full guidance document) & https://cts-sct.ca/wp-content/uploads/2018/01/CTS-HMV-Executive-Summary-2011_Final.pdf (main guidance document)</td></tr>
<tr><td>International, national or regional</td><td>National</td></tr>
<tr><td>Adapted/adopted from previous guidance document? If so which guidance document was it adapted/adopted from?</td><td>No</td></tr>
<tr><td>Based on evidence synthesis?</td><td>Yes</td></tr>
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<tr><td>Funding</td><td>The CTS receives unrestricted grants, which are combined into a central operating account to facilitate knowledge translation activities of all CTS Guideline Committees. Sources include the Canadian Institutes of Health Research, AstraZeneca Canada, GlaxoSmithKline Inc, Pfizer, Talecris and Boehringer Ingelheim Canada. Funds were specifically donated for the HMV Committee by the ALS Society of Canada, Muscular Dystrophy Canada, Respironics, Rick Hansen Foundation/Laval University, VIASYS Healthcare, VitalAire Canada Inc and West Care Medical. No sponsors played a role in the collection, review, analysis or interpretation of the scientific literature or in any decisions regarding the key messages presented in this document. As such, the CTS Home Mechanical Ventilation Committee is functionally and editorially independent from any funding sources of the CTS, and is accountable to the CTS Respiratory Guidelines Committee and the CTS Board of Directors.</td></tr>
<tr><td>Certainty of evidence grading</td><td>
<table>
<tr><th>Grade of recommendation/ description</th><th>benefit versus risk and burdens</th><th>Methodological quality of supporting evidence</th><th>Implications</th></tr>
<tr><td>1A/strong recommendation, high-quality evidence</td><td>Benefits clearly outweigh risk and burdens, or vice versa</td><td>RCTs without important limitations or overwhelming evidence from observational studies</td><td>Strong recommendation, can apply to most patients in most circumstances without reservation</td></tr>
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1B/strong recommendation, moderate quality evidence	Benefits clearly outweigh risk and burdens or vice versa	RCTs with important limitations (inconsistent results, methodological flaws, indirect or imprecise) or exceptionally strong evidence from observational studies	Strong recommendation, can apply to most patients in most circumstances without reservation
1C/strong recommendation, low-quality or very low-quality evidence	Benefits clearly outweigh risk and burdens, or vice versa	Observational studies or case series	Strong recommendation but may change when higher quality evidence becomes available
2A/weak recommendation, high-quality evidence	Benefits closely balanced with risks and burden	RCTs without important limitations or overwhelming evidence from observational studies	Weak recommendation, best action may differ depending on circumstances, patients' or social values
2B/weak recommendation, moderate-quality evidence	Benefits closely balanced with risks and burden	RCTs with important limitations (inconsistent results, methodological flaws, indirect or imprecise) or exceptionally strong evidence from observational studies	Weak recommendation, best action may differ depending on circumstances, patients' or social values
2C/weak recommendation, low-quality or very low-quality evidence	Uncertainty in the estimates of benefits, risks and burden; benefits, risk and burden may be closely balanced	Observational studies or case series	Very weak recommendations; other alternatives may be equally reasonable

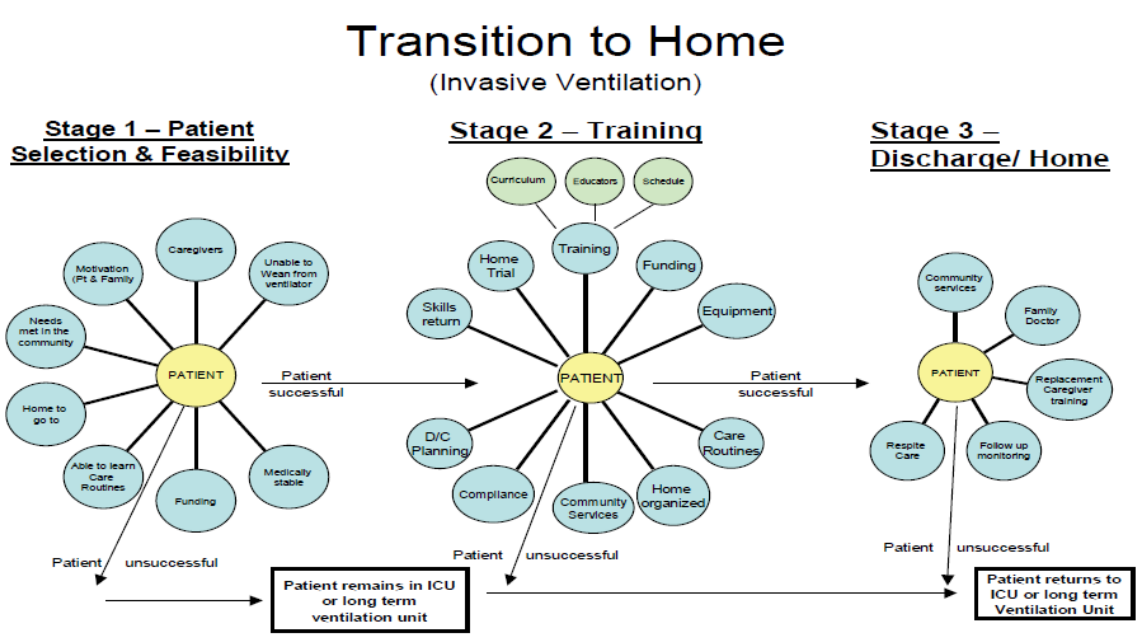
Domiciliary invasive ventilation guidance

Topic	Recommendation/criteria (Source, Certainty of evidence (if applicable))
Pre-transition phase	▪ The candidate should be medically stable without constant or frequent monitoring, tests or treatment changes. (Consensus) ▪ The candidate and family must be motivated (Consensus): • VAIs must express interest in transitioning/living in the community. • The family should express commitment to having the VAI live in the community. • The family is willing to provide support (physical, emotional and financial). ▪ The candidate must have an adequate home setting (Consensus): • Identifiable home to live in, suitable to the needs of the VAI. • Home is adaptable as necessary. ▪ The candidate must have sufficient caregiver support (Consensus): • Caregivers identified and committed to provide sufficient hours of care to meet the needs of the VAI. • Available government-funded care hours identified. ▪ The candidate must have access to adequate financial resources (Consensus): • Sources of financial assistance identified and accessed. • Sufficient financial resources available to meet projected costs. ▪ The candidate must have access to equipment appropriate for the needs (Consensus): • Appropriate equipment selected and ordered. • Sources for ongoing supplies identified ▪ *Patient, family, caregivers and an interdisciplinary team of health care professionals must work together to create a comprehensive care plan for discharge to a safe, effective, and sustainable home environment. Once a VAI is discharged to the community, it is important that they maintain an open line of communication with the health care providers. This should include the primary care physician (family*

	doctor) and the respiratory medicine specialist caring for the patient in the community, to promote and facilitate safety and medical stability. To this end, a well-structured follow-up program must also be established from the beginning (supplementary guidance) ▪ *A comprehensive assessment of the patient must be carried out by an interdisciplinary health care team who will ultimately provide the necessary training - ideally with a rehabilitative approach. Often overlooked, individuals discharged to the community on a ventilator have a particular set of psychosocial issues that must be addressed. (supplementary guidance)* ▪ *The VAIs and their families must be informed about the advantages and disadvantages of leaving the hospital. Although at home the VAIs could be close to family members in a familiar environment, on leaving the hospital, they may feel isolated from professional help and might feel insecure and overwhelmed by the tasks involved in the care (supplementary guidance).* ▪ *Once a ventilated patient has been identified as suitable for HMV, the in-hospital care routines should be reviewed and changes implemented as quickly as possible. This review is to be considered from the perspective of limited professional caregiver supervision and intervention in the community (supplementary guidance).* ▪ *Simplification of care is particularly important when VAIs are to be transferred out of the Intensive Care Unit (ICU) to a less intense level of care where the HMV will be organized. Transferring to a 'stepdown' unit can be considered "weaning the patient from the ICU" and the beginning of rehabilitation… It is important that the ICU team, include the family in the daily routine, once the patient has been identified as requiring long-term ventilation. This approach will improve competency and confidence (supplementary guidance).* ▪ *Equipment and supplies must be ordered as early as possible in the transition process to avoid delays in the discharge to the community (supplementary guidance).* ▪ *The ventilator model, mode of ventilation, the interface and the parameters need to be established early in the transition process. The benefit of doing this work at the beginning of the program will be to maximize the patient's compliance, confidence and comfort. The success of the long-term ventilation depends on adapting the mechanical ventilation to the patient's needs (supplementary guidance).* ▪ *It is strongly suggested that a publicly funded system to support VAIs in the community includes timely access to equipment and a structured, ongoing educational program (supplementary guidance).* ▪ *In certain cases, an assessment of the home setting is recommended for safety and accessibility. This is particularly useful when renovations are to be made. The home environment needs to be able to support the technological needs of the patient. The renovations necessary to accommodate the VAIs and the additional caregivers must start as soon as the decision of home ventilation has been made (supplementary guidance).* ▪ *Links to community services and resources should be established well in advance of the discharge date. Home care, government nursing agencies and equipment supply companies must be contacted early in the transition process. Community services might be organized with the local discharge planner. Home care, including home visits from nurses, and other professional services such as physiotherapy, respiratory therapy, occupational therapy, social work or psychology, take time to arrange. Links to local transportation services should be investigated, to allow patients to leave the home either for leisure activities or for medical appointments (supplementary guidance).* ▪ *Where it is available, links to Respite Care facilities/organizations should be provided to that patient and family as part of the transition process (supplementary guidance).* ▪ *At the time of discharge it is recommended that a checklist is used in order to cover all aspects of the necessary care that will be provided at the home (supplementary guidance).* ▪ *The communication and coordination among numerous agencies involved in the care of the VAIs at home, needs to be organized prior to the discharge to avoid gaps and misunderstandings that could jeopardize a safe and sustainable HMV. When the patient is discharged, it is important to establish a plan for regular medical follow-ups (supplementary guidance).*

	▪ *The primary care physician should be informed of the medical condition and needs of the patient. Ideally a schedule of reassessments should be given to the patient. If the transition occurs from the acute care hospital, a link to a community physician experienced in ventilatory care needs to be made, so the ventilatory parameters can be assessed and adjusted as necessary (supplementary guidance).*
Transition phase	▪ *Trial discharge: Progressive discharge with patients going home for one or two nights will allow the patient, caregivers and health providers to get information about gaps in the preparation for discharge to the community. The patient and the caregivers are then able to apply and test their knowledge of managing at home. Once they return to the training centre, patients and families should be encouraged to share concerns and difficulties encountered in the home trial. Solutions are discussed with the transdisciplinary team to make the transition as smooth as possible (supplementary guidance).*
General principles of home mechanical ventilation	▪ Protocols for weaning with PVFB should be considered for appropriate patients with tetraplegia who are dependent on ventilation. (Grade of recommendation 1C) ▪ In the long term, individuals with SCI require regular monitoring to identify the development of sleep disordered breathing or respiratory failure and evaluate the need for NIV. (Consensus) ▪ *At follow-up, the tolerance and the effectiveness of the ventilatory support, the day-time ABGs and the gas exchange overnight need to be assessed. The choice of the frequency of follow-ups will depend on the natural course or the seriousness of the disease process and the availability of follow-up facilities (supplementary guidance).* ▪ *Assessment of the VAIs during sleep is important to provide maximal nocturnal management. An assessment one to three months into HMV is recommended after elective initiation of nocturnal ventilatory support or, after discharging invasively ventilated patients (supplementary guidance).* ▪ *For VAIs that require continuous ventilation, the assessment should be both during the day time and at night. Subsequently, annual reassessments are recommended. This can be done in a hospital setting, in a respiratory sleep laboratory or at home (supplementary guidance).* ▪ *In certain cases, patients require increasing assistance from the ventilator, and in those VAIs that require more than 14 hours/day of ventilatory support, a second ventilator needs to be provided in case of mechanical failure. An emergency plan must be in place for such inevitable events as a power failure (supplementary guidance).*
Technical requirements	For invasive ventilation: ▪ As long as adequate, sustained ventilation is ensured, long-term tracheostomies should be cuffless or cuff deflated if possible. (Grade of recommendation 2C) ▪ Heated humidity is recommended over heat-humidity exchangers. (Grade of recommendation 1A) ▪ Minimally invasive rather than deep suctioning is recommended when possible. (Grade of recommendation 2B) ▪ MI-E and MAC for tracheostomy airway clearance should be strongly considered through tracheostomy to complement or replace deep suctioning. (Grade of recommendation 1C) ▪ Clean, as opposed to sterile, conditions are adequate for home secretion clearance and suctioning. (Consensus)
Staffing	▪ *Depending upon the setting in which the patient is being prepared for HMV, the composition of the interdisciplinary team will vary and accommodations must be considered. For instance, if no occupational therapist is available, a physiotherapist or a nurse must address*

	the activities of daily living. Although it is a limiting factor, the absence of a respiratory therapist on the team might be filled by a physician experienced in HMV and a respiratory nurse. The ability of team members to cross professional boundaries to fully prepare the patient is essential (supplementary guidance) ▪ *Sufficient caregiver support is a crucial element in assessing the suitability of a VAI to go home although not everyone will require the same level of support. For a fully dependent patient, a routine care plan with coverage for 168 hours of care a week (24 h/day) must be produced. Sufficient caregiver support must be arranged to allow for sick time, vacations and unscheduled personal commitments (supplementary guidance)*
Monitoring	NR
Infection prevention and control	NR
Other guidance	NR
Management of SCI complications	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Respiratory	▪ Phrenic nerve pacing is recommended in selected individuals as an alternative to PPV alone. (Grade of recommendation 2C) Regular airway clearance techniques (LVR, MAC and MI-E), clinical assessment and ongoing monitoring of pulmonary function is recommended to ensure adequate airway clearance. (Grade of recommendation 1C)
Bladder	NR
Bowel	NR
Skin	NR
Sexual health	NR
VTE	NR
Pain	NR
Autonomic dysreflexia	NR
Emotional wellbeing, mental health and substance abuse	NR
Cardiometabolic and nutrition	NR
Bone Health	NR
Palliative care	NR
Rehabilitation	NR
Wheeled mobility	NR
Other guidance	NR
Broader SCI care pathways and supports	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Governance structure	NR
Funding model	The candidate must have access to health care support in the community (Consensus):

	• A government-funded ventilatory service is necessary to provide appropriate access to equipment and respiratory care.
Care pathways	
Education across the continuum of care	There must be comprehensive initial training, plus ongoing education and training for patient and caregivers once they are in the home setting (Consensus): • Initial education organized to accommodate learning, practice and inclusion of caregivers in the care routine as early as possible. ▪ *The education of patients and caregivers should be holistic and individualized as the degree of dependency differs among the VAIs (supplementary guidance).* ▪ *Training caregivers under 18 years of age or full time students should be avoided or considered carefully. Parents of young children may also be unsuitable care caregivers because of the time commitments to the children, especially if the VAI is not part of the household (supplementary guidance).* ▪ *Ideally, the VAI should be treated as the primary caregiver and taught to direct and/or perform his or her own care. Occasionally, the patient may find himself in situations where they have to guide an untrained bystander to perform care. In addition, when the VAIs are trained as primary caregivers, they have a sense of confidence, independence and dignity. As part of the training of families and caregivers, it is important that they be prepared to provide an increasing level of care related to the progression of disease/disability (supplementary guidance).*

- *The education and training sessions must include the following key issues: respiratory care, nursing care including feedings, dressing and toileting, activities of daily living, safe transfers and mobility aids, leisure activities, psychosocial issues, medications management and management of emergency situations. The respiratory care training and education for all VAIs and caregivers need to include:*
    1. *Basic respiratory anatomy and physiology*
    2. *Airway management*
        a. *Ventilator management and trouble shooting*
        b. *Breath stacking, volume recruitment maneuvers and MAC*
        c. *Use of the MI-E when available*
- *For invasively ventilated individuals, additional respiratory education must include:*

    1. *Tracheostomy and tracheostomy tube care*
    2. *Suctioning (and MI-E, when available)*
    3. *Manual Ventilation (bagging)*
    4. *Tracheostomy changes*

- *Training sessions should accommodate the different learning capabilities and needs of patients and caregivers. The use of oral, written and audiovisual material is recommended (supplementary guidance).*
- *Knowledge and Skills that VAIs and caregivers need to know prior to discharge to the community*
    1. *Ventilator functioning and trouble shooting*
    2. *Maintenance of ventilatory support with manual ventilation (bagging)*
    3. *Maintenance and care of circuits and accessories (connections and cleaning)*
    4. *Airway maintenance for tracheostomized patients (suctioning)*
    5. *Care needs for totally or partially dependent VAIs*
        a. *Full range of motion to avoid contractures*
        b. *Positional changes to avoid tissue trauma*
        c. *Bladder and bowel routines*
        d. *Management of medications*
        e. *Feedings (oral or enteral)*
        f. *Communication techniques*
    6. *Management of emergency situations (what to do, who to call, where to go)*

Education check lists for Invasive ventilation (supplementary guidance)
Learning Objectives: At completion of training, the participant will be able to:
A. Patient Care

1. Describe the parts of the respiratory system and how they function (in very general terms only).
2. Describe how changing body position or eating a meal can affect breathing.
3. Explain why a patient with a tracheostomy tube might not be able to speak.
4. Explain the importance of drinking water and/or using a humidifier to manage secretions.

	5.Describe why heart rate (pulse) or breathing rate may change with activity or illness. *6. Describe possible signs and symptoms of a chest infection and the caregiver's responsibilities in the care of the patient.* *7. Explain the importance of proper hand hygiene and gloves in preventing the spread of infection.* *8. Explain when to call 911* ***B. Funding, Equipment Supply and Emergency Management*** *1. Explain the role of the Provincial Government in funding the equipment.* *2. List the supplies not covered by government funding that the client is responsible for.* *3. Explain where the ventilator came from and how to contact them.* *4. List the equipment provided by government funding.* *5. Explain the name, phone number and role of the home care company.* *6. List the supplies that come from the home care company, how to place an order and funding.* *7. Describe the role of the home care company in an emergency.* *8. Describe the role of the Health care Centre that prepared and trained the patient in the future care* *9. Describe the role of the Health care Centre that prepared and trained the patient in an emergency.* *10. Explain the role of the family physician in the care of the client.* *11.Describe the role of the acute care hospital in an emergency or power failure situation.* ***C. Tracheostomy Care/ Speaking Valves*** *1. Explain why a patient might need a tracheostomy.* *2. Name the parts of the tube.* *3. Explain how to properly clean around the tracheostomy stoma and describe what equipment is needed.* *4. Demonstrate correct inflation and deflation of a cuffed tracheostomy tube.* *5. Explain the purpose of an inner cannula.* *6. Demonstrate the proper technique for inserting or removing an inner cannula.* *7. Describe how to clean and take care of a speaking valve.* *8. Demonstrate how to properly connect and disconnect the patient from a ventilator.* ***D. Suctioning/ Manual Ventilation*** *1. Explain why a patient might need suctioning.* *2. Demonstrate how to correctly set up the suction equipment.* *3. Explain why it is important to use two gloves when suctioning.* *4. Demonstrate clean suctioning technique including asking the patient for direction before and during suctioning.*

	5. Explain why suctioning should be done only when needed, trying to avoid over suctioning or frequent suctioning. *6. Explain what to do if blood is suctioned from the trachea.* *7. Explain what difference it might make if the patient takes blood thinners.* *8. Explain how to troubleshoot the suction unit.* *9. Describe correct disposal of dirty suction equipment including suction catheters and gloves.* *10. Demonstrate how to stock the portable suction bag for use outside the home.* *11. Explain where supplies such as suction catheters come from.* *12. Explain the importance of the manual resuscitation bag.* *13. Demonstrate how to test and use the manual resuscitation bag.* *14. Demonstrate proper use of the mechanical in/exsufflator if available (Tracheostomy adapter, pressure settings, tubing changes for secretions, cuff inflated/deflated).* *E. Ventilator Care* *1. Describe the purpose of a ventilator and when a patient might need one.* *2. Demonstrate what needs to be turned on and checked when starting the ventilator at the bedside.* *3. Demonstrate what needs to be turned on and checked when starting the ventilator on the wheelchair.* *4. Demonstrate how to change the water in the humidifier.* *5. Explain what kind of water is used in the humidifier.* *6. Explain what needs to be plugged in when the wheelchair is not in use.* *7. Demonstrate how and when to make ventilator setting changes.* *8. Demonstrate how to check the ventilator high and low pressure alarms.* *9. Describe the kind of situations that make the low-pressure alarm ring and what to do for the patient.* *10. Describe the kind of situations that make the high-pressure alarm ring and what to do for the patient.* *11. Describe any other alarms on the ventilator.* *12. Explain how to give an MDI/ puffer with the ventilator.* *13. Demonstrate how to assemble and disassemble the ventilator circuit.* *14. Demonstrate changing the ventilator circuit and checking the ventilator after changing the circuit.* *15. Describe how and when to clean the ventilator circuit and change the filters.*
Safeguarding and ethics	▪ Physicians must actively work collaboratively with the patient, family members and other health professionals involved in the health care decision-making process while at all times maintaining respect for patient autonomy, dignity and confidentiality. (Consensus) ▪ It is important to proactively counsel capable patients and establish clear advanced directives (regarding issues such as crisis management and end-of-life care) in a timely manner, ensuring that patients fully understand and appreciate the reasonably foreseeable outcomes of their decisions. Physicians must work with patients to help prioritize their values, interests and preferences.(Consensus) ▪ When considering the most appropriate location for ongoing ventilation issues relating to safety and the patient's values, beliefs and preferences must be the primary considerations for making such decisions providing optimal independence, respect for patient autonomy and increased quality of life. (Consensus)

	▪ In the event that the patient lacks decisional capacity regarding specific treatments, substitute decision-makers and clinicians must incorporate the patient's advance care directives in the decision-making process or, where there are no known advance care directives, to act in the patient's 'best interests'. (Consensus) ▪ One must recognize one's own biases and endeavor to participate in a collaborative and fair decision-making process that primarily addresses, reflects and respects the values and wishes of the patient. (Consensus) ▪ A plan of care should involve full-disclosure of pertinent information and a clear and coherent strategy, which would enable the patient to make fully informed decisions. This will allow any members participating in the patient's care to be held accountable for their duties and obligations. (Consensus) ▪ Given the reality of scarce resources, any process of allocating limited care resources must be in accordance with distributive justice and due process. (Consensus) ▪ The well-being of caregivers and the exhausting responsibilities of care must be considered. Caregivers should be supported, educated with regard to healthy coping strategies, and provided with some form of respite care whenever possible and desirable. (Consensus).
Other supports	The candidate must have access to health care support in the community (Consensus): • Follow-up care available as appropriate (tracheotomy tube changes, ventilator reassessments and assessment of the ongoing effectiveness of the ventilatory support). • Medical follow-up to allow for appropriate changes to the mode of ventilation (ie, from invasive to noninvasive and vice versa, from continuous to nocturnal and vice versa). • Professional services available postdischarge.
Quality assurance processes	NR
Other guidance	NR

Key: CTS – Canadian Thoracic Society; LVR - lung volume recruitment; MAC - Manually assisted coughing; MI-E - mechanical in-exsufflation; PPV - e positive pressure ventilation; PVFB - progressive ventilator-free breathing; VAI - ventilator-assisted individuals. NR – Not Reported

Guidance document characteristics	
Endorsing Organisation/Author	German Society for Pneumology and Respiratory Medicine (DGP) as the lead society, supported by other organisations under the umbrella group of the Association of the Scientific Medical Societies in Germany (AWMF)/ Windisch et al.
Title	German National Guideline for Treating Chronic Respiratory Failure with Invasive and Non-Invasive Ventilation: Revised Edition 2017 – Part 1 & Part 2
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Date Published	26 June 2018
URL	https://www.karger.com/Article/FullText/488001 (Part 1) https://www.karger.com/Article/FullText/488667 (Part 2) https://www.awmf.org/leitlinien/detail/ll/020-008.html (Original guideline, in German)
National or regional	National
Adapted/adopted from previous guidance document? If so which guidance document was it adapted/adopted from?	This is an update of the 2010 guideline published by the German Respiratory Society. However it has also undergone extensive revision.
Based on evidence synthesis?	Yes
Based on expert consensus?	Yes
Update(s) planned (including dates)	NR
Funding	DGP
Certainty of evidence grading	Not conducted
Domiciliary invasive ventilation guidance	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Pre-transition phase	**5.2.2 How Is Ventilation Therapy Implemented?** ▪ Establishment of home mechanical ventilation must take place in a home mechanical ventilation centre **6.1 Which Forms of Care Are Available for Home Mechanical Ventilation Patients and How Do They Differ from One Another?** ▪ With respect to quality of life and perspectives, the appropriate living arrangements (own home, shared living, or inpatient nursing facility) as well as the proper type of care (independent living vs. assisted or specialised nursing care) should be

	determined in consultation with the patient and, next to his/her medical requirements, be oriented towards the patient's wishes and needs. ▪ *The leading clinician is responsible for the organisation of outpatient medical and nursing care up to the point where the care of the patient is taken over by the treating physician (general practitioner and/or other specialists) in an outpatient sector. The patient is allowed to leave the hospital after the establishment of HMV only if the provision and funding of subsequent care can be fully guaranteed. The more dependent the patient is on the ventilator and the reduction in autonomy that results, the more extensive the transition into the outpatient care sector is, meaning the whole process can potentially take weeks. (supplementary guidance)* ***6.2 Which Tasks Are Undertaken by the Home Mechanical Ventilation Centre before and after Discharging the Patient?*** ▪ Home mechanical ventilation should be initiated at a home mechanical ventilation centre with relevant expertise and should be organised by such a centre following discharge from hospital ▪ *Following patient discharge, the HMV centre remains available on a consultation basis for patients and relatives, as well as for the treating physician, nursing staff, participating therapists, and the ventilation equipment provider. Furthermore, the ventilation centre also carries out regular patient check-ups. For emergency care services, regional hospitals that are close to the patient's living quarters should be integrated into the care program. (supplementary guidance)* **6.3 What Needs to Be Observed before a Ventilated Patient Is Discharged into the Home Mechanical Ventilation Sector?** ▪ Prior to discharge from hospital, the patient has been transferred to the ventilation machine that corresponds to the one intended for home mechanical ventilation, with appropriate and validated adjustment of the ventilation parameters. (Quality indicator) ▪ The appointment for the first check-up examination at the home mechanical ventilation centre has been arranged prior to discharge and noted in the patient's medical report. (Quality indicator) ▪ The patient must be in a stable state prior to hospital discharge. ▪ The cost transfer for nursing care and supply of medical aids must be guaranteed by the clinic prior to discharge. ▪ Post-hospital care in a home mechanical ventilation centre must be organised prior to discharging the patient. **8.4 How Is the Indication for Invasive Mechanical Ventilation Established in the Event of Definitive Weaning Failure?** ▪ Invasive home mechanical ventilation is only established after consent is given by the extensively informed patient and/or his/her legal guardian. The content of the information is documented and signed by the informing doctor and patient/legal guardian. In this context, determining the patient's wishes is documented in a comprehensible fashion. (Quality Indicator) ▪ The indication for invasive home mechanical ventilation after definitive weaning failure must not only be based on medical facts (the need for continuing invasive ventilation) but also on ethical aspects. ▪ The individual wishes of the thoroughly informed patient must be taken into account for the therapy decision-making process. ▪ To determine the indication for invasive home mechanical ventilation in cases where the patient is not able to provide consent, an inquiry into the patient's wishes – if possible through the undertaking of an ethical case conference – must be comprehensively documented.

	▪ *Before discharging a patient with invasive HMV into the home sector, the curative or palliative medical therapy goals of the outpatient care need to be defined. They should be documented along with the content of an advanced health care directive (if available) in the letter of discharge (supplementary guidance)* ***8.5 Where Should Invasive Home Mechanical Ventilation Be Initiated following Weaning Failure?*** ▪ The initiation of invasive home mechanical ventilation for patients with definitive weaning failure takes place in – or at least in collaboration with – a specialised weaning centre or in a home mechanical ventilation centre with expertise in invasive home mechanical ventilation. The discharging centre, or the centre participating in the discharging process, is available to the home therapy team for consultation. (Quality Indicator) ▪ Invasive home mechanical ventilation should be initiated in a specialised weaning centre or a home mechanical ventilation centre with expertise in invasive home mechanical ventilation (Ch. 5.1); at the very least, this process must take place via consultation with such a centre. ▪ If a patient with invasive ventilation is released from a clinic that is not a ventilation centre, a ventilation expert from such a specialised centre must be enlisted within the shortest time period (maximum 3 months). Alternatively, an assessment of weaning potential and the home care situation should be undertaken in consultation with a specialised ventilation centre by an authorised/privately registered physician with expertise in mechanical ventilation. Absorption of costs by the cost bearer for domestic health care must be limited up until this time point. ▪ *Beyond the valid, expert-based diagnosis of definitive weaning failure, the medical prerequisites for safe release of the patient into the outpatient sector are:* o *Haemodynamic stability without the use of vasoactive medication.* o *Absence of acute hyper- or hypoactive delirium* o *Stable renal function or the securing of outpatient renal dialysis therapy, including the availability of a dialysis unit* o *Existence of a nutrition plan, including the potentially necessary application devices (PEG, Port, Boroviac catheter)* o *A safe medication plan that can be used and prescribed within the outpatient sector* o *A lack of demand for regular immobilisation, blood sampling, imaging, or invasive interventions/therapy measures (supplementary guidance)* ▪ *Before discharging the patient into the outpatient sector, a screening test for MRP must be carried out and the result immediately reported to the intended care facility. Appropriate hygiene measures based on legal specifications and institutional recommendations are to be arranged between the discharging hospital and the outpatient care team. (supplementary guidance)*
Transition phase	**6.4 Managing the Transfer of a Patient to a Home Mechanical Ventilation Setting Can Present as a Challenge: How Is This Organised?** ▪ Upon discharge from hospital, the patient receives a medical report with the below-specified information. (Quality Indicator) ▪ Outpatient care of the ventilated patient must be completely organised before discharge from hospital. ▪ The discharge process must be organised under the responsibility of the treating clinic by a transition management team, with the assistance of a checklist. ▪ The patient or the legal guardian of the patient must be comprehensively informed (e.g., through the use of relevant information sheets) about the potential care options available) ▪ *The transfer management team should collaborate closely with the patient or legal guardian, as well as the caregivers and/or relatives, and consist of the following professionals:*

	○ *Coordination transfer manager (e.g., physician, respiratory therapist or case manager with extensive experience in HMV)* ○ *Treating physicians (in- and outpatient)* ○ *Nursing team (in- and outpatient)* ○ *Equipment provider* ○ *Social workers, social education specialists (if needed)* ○ *Therapists (if needed)* ○ *Funding bodies* *(supplementary guidance)* ▪ *During the transfer process, which usually takes 2–3 weeks – or potentially longer under certain circumstances – early arrangement of the definitive date of discharge is particularly important for further coordination of the various personnel required, and for guaranteeing the outpatient care service. Hereby, the patient is entitled to an independent and a comprehensive, neutral consultation, combined with the provision of information about relevant self-help organisations, since discussions with patients can help them to accept their situation and structure their daily routine. The consultation should not be directly related to the transfer management process, but should instead in advance provide an overview of the various types of living and care arrangements available. The use of checklists is recommended for the highly complex transfer process. (supplementary guidance)* ▪ *Listed below are the minimum requirements for a proper transfer operation, which should be processed before discharge from hospital, specified in the medical report, and given to the patient as a copy before he/she leaves the clinic. Checklists for assisting the transfer process should be oriented towards these minimum requirements:* ○ *Diagnoses and therapy goals* ○ *Post-hospital medication including pro re nata (PRN) medication* ○ *Information about the medication administered before discharge from hospital, particularly sedatives, analgesics, and antibiotics* ○ *Screening test results for multidrug-resistant pathogens (MRP)* ○ *Recommendations and time intervals for clinical follow-up examinations, including arrangement of the first check-up appointment at the HMV centre* ○ *Proposed living and care arrangements* ○ *Extent of care (nursing staff attendance times)* ○ *Time frame and content of nursing provisions* ○ *Technical set-up of ventilation and monitoring, including accessories* ○ *Type of ventilation interface; cleaning and change over intervals* ○ *Ventilation mode, with specification of all parameters* ○ *Duration of mechanical ventilation and potential spontaneous breathing phases* ○ *Oxygen flow rate during mechanical ventilation and spontaneous breathing phases* ○ *Measures for secretion management* ○ *Application of inhalable medication* ○ *Planning of dietary requirements* ○ *Information about the social environment that will contribute to the patient's care* ○ *Psychosocial support for the patient and relatives (if necessary)* ○ *Arrangement of training sessions for patient and relatives*

	○ *Additional resources (e.g., wheeled walker, toilet seat raiser, nursing bed, communication aids, consumables, continence items, wound management, etc.)* *(supplementary guidance)* **14 Spinal Cord Transection** **14.7 What Sort of Technical Aids Are Required for Disease Monitoring in Patients with Spinal Cord Transection?** ▪ Permanent pulse oximetry monitoring is necessary in partly and fully dependent mechanically ventilated patients with spinal cord transection. ▪ Capnographic monitoring of patients with spinal cord transection injuries is indicated in many situations in the home mechanical ventilation setting ▪ Capnometric monitoring of spinal cord transection patients should therefore be supplied in the following cases: ○ Patients undergoing invasive HMV via a single circuit system, in accordance with DIN EN ISO 80601-2-72: 2015 ○ Patients with an unstable ventilation situation due to clinically relevant vegetative dysregulation. ○ Patients with additional central respiratory dysfunction. ○ *When an implanted phrenic or diaphragm stimulator is applied (due to the absence of volumetry).* ○ *For patients in whom a general change in ventilation parameters and/or modes are intended in the home setting.* ○ *When spontaneous breathing performance is unpredictable and depends on the day-to-day form of the patient.* ○ *For permanently or partly ventilated children, in consultation with the treating paediatrician (supplementary guidance)* ▪ *Breathing volume during spontaneous and stimulating activities can be measured by a spirometer. This measurement can take place either via a mouthpiece or a tracheal cannula adapter. A prescription for spirometry is indicated when ventilation takes place through phrenic nerve/diaphragm stimulation (due to the absence of volumetry) or for monitoring spontaneous breathing during intermittent ventilation (assessment of breathing performance). (supplementary guidance)* ▪ *The indication for a second ventilation device and an external battery is always made independently of the daily ventilation times, since unforeseeable complete dependency on a respirator can occur due to the specific complications and characteristics associated with spinal cord transections. Furthermore, daily mobilisation of the patient into the wheelchair is the goal of therapy, hence the need for an external battery. (supplementary guidance)* ▪ *In spinal cord transection lesions from C0 to C3, and in congenital or acquired central respiratory disorders, the subsequent systems can be implanted. Currently, there are 2 different systems for diaphragm stimulation.* ○ *Phrenic Nerve Stimulation (indirect stimulation)* ○ *Diaphragm pacing (direct stimulation)* *(supplementary guidance)*
General principles of home mechanical ventilation	**8.6 What Should Be Noted for the Outpatient Medical Care of Patients with Weaning Failure?** ▪ The provision of medical care in the outpatient sector is secured through home doctor visits. (Quality Indicator) ▪ The ventilation centre responsible for the long-term supervision of the patient is available for consultation with the treating physician. (Quality Indicator) ▪ After first implementing invasive home mechanical ventilation due to definitive weaning failure, check-up examinations must take place at least once a year in a specialised ventilation centre. ▪ The therapy goals of patients with invasive home mechanical ventilation due to definitive weaning failure must be regularly reviewed by a physician.

Technical requirements	**4.2 Invasive Ventilation** ▪ A second ventilation machine and an external battery are essential for ventilation times ≥16 h/24 h. ▪ A pulse oximeter is necessary for selective measurements and possibly for continuous measurements in certain disease groups (i.e., spinal cord transection, paediatrics). ▪ A small-diameter spare cannula must be made available. ▪ For application of speaking valves, a cuffless cannula, a completely unblocked cannula, or a fenestrated cannula must be used. ▪ Conditioning (humidification and moistening) of the ventilation air is mandatory. ▪ Two aspirator devices are necessary ▪ *A ventilation machine with an internal battery is necessary both for its use in patients with life-sustaining mechanical ventilation and for patients who are unable to remove the mask by themselves. When spontaneous breathing ability is strongly reduced (daily ventilation time ≥16 h), an external battery with sufficient capacity is necessary. (supplementary guidance)* ▪ *In contrast to NIV, the use of an alarm system for invasive ventilation is mandatory. Disconnection and hypoventilation alarms should be present. (supplementary guidance)* ▪ *A ventilation bag with an oxygen connection port for use in tracheal cannulae and masks is required (supplementary guidance)* ▪ *The ventilation machine should be chosen so that a lasting or even temporary decline in the patient's ventilatory function can be sufficiently dealt with (supplementary guidance)* ▪ *Exchanging a ventilation machine for another type or switching the ventilation mode should therefore take place during surveillance in hospital. Alteration of the ventilation parameters is only permitted under the responsibility of a physician with sufficient ventilation expertise* ▪ *The addition of oxygen should follow the individual technical guidelines for each ventilator. (supplementary guidance)* ▪ *Usage statistics and pressure/flow records stored within the machine are useful for assessing therapy quality and adherence (supplementary guidance)* ▪ *Machine-adjacent particle filters in the air inlet vicinity are necessary. Filters in the outlet vicinity of the machine are mandatory for hospital use. A definitive statement regarding particle filter use in HMV is not possible due to a lack of relevant studies (supplementary guidance)* ▪ *Before reinstating a ventilation machine previously used by another patient, hygienic preparation of the device according to the manufacturer's instructions is mandatory. (supplementary guidance)*
Staffing	**6.5 Who Is Involved in the Provision of Home-Based Care?** ▪ *The following professionals should contribute to the outpatient care of a ventilated patient:* o *Physicians (general practitioners and/or other specialists)* o *If applicable, an outpatient nursing team (specialised/ assisted)* o *Equipment provider for the configuration of the prescribed medical devices and their technical maintenance* o *If applicable, an outpatient therapeutic team (speech therapists, occupational therapists, physiotherapists, social therapists, educators, psychologists)* o *Funding providers* *(supplementary guidance)* **6.12 In Which Cases Can the Extent of Nursing Care Be Reduced (So-Called "Reduction of Care")?**

- The indication for reduction of care must be made by the entire multidisciplinary team in conjunction with the patient concerned.

- *The definitive implementation of reduction of care may only occur in consensus with the patient/legal guardian, the relatives, the multidisciplinary care team of nurses and therapists, and the registered physician responsible. The following factors should be ensured for the reduction of care:*
  - *The patient and his/her caregivers should demonstrate a pre-existing willingness for the reduction of care.*
  - *Stable mechanical ventilation status.*
  - *The securing of outpatient medical supervision and accessibility to a HMV centre.*
  - *The securing of specialised, patient-appropriate treatment with consumables and aids; relatives and caregivers who are not officially qualified should be trained in their use.*
  - *A stable family situation with the guarantee of safe implementation of the necessary treatment measures.*

  Care of the patient should also be ensured during the absence of qualified nursing staff. If necessary, individual, target-oriented training measures can be organised on site (supplementary guidance)

7 Nursing Qualifications for Home Mechanical Ventilation Care

- Nursing specialists must complete the qualifying process with precise content and scope: at least one basic course with the qualification of "Nursing specialist for outpatient home mechanical ventilation."
- Nursing staff assigned to the care of ventilated patients must have (at least for every 12 patients) a division manager with additional qualifications in "respiratory therapy," "anaesthetics/intensive care nursing," or "Nursing expert in outpatient mechanical ventilation."
- Nursing aids, physician assistants, and remedial therapists may not work independently whilst caring for ventilated patients. Before potential undertaking of basic nursing duties within the nursing team, all persons from these occupational groups should receive introductory training and specific instruction.

7.6 Can Nursing Aids, Medical Assistants, Remedial Therapists, and Similar Professionals Participate in the Care of Ventilated Individuals?

- *Nursing aids, physician assistants, and remedial therapists may only work in the ventilation care branch as a part of a nursing team with nursing specialists (shared living communities or inpatient nursing facilities). Independent specialised nursing care of ventilated individuals is only possible with the qualifications described in Chapters 7.4. and 7.5. Following the relevant introductory training, these occupational groups can undertake basic nursing care work with ventilated patients (patient positioning, personal hygiene and grooming, patient transfer, nourishment, communication). Advanced training courses for this purpose should be developed in the future. (supplementary guidance)*

14 Spinal cord transection
14.6 What Needs to Be Observed for Nursing Care in the Home Setting?

- *Permanent clinical monitoring by qualified nursing staff and the securing of all selectively required, disease-specific care measures is ensured through a nursing care service that meets the legally required quality standards for structure, processing, and outcome. (supplementary guidance)*

	▪ *The possibility of incorporating a patient's relatives into the care program should be considered on a case-to-case basis, since they can often be emotionally affected (especially in emergency situations) and hence not always be relied upon to securely carry out the necessary therapy measures. It should also be ensured that a second person is available for carrying out basic care duties (extensive body care, transfers, etc.) when the patient has a ventilation dependency and mobility-limiting factors exist (e.g., obesity, contractures, spasticity, dysregulation) (supplementary guidance)*
Monitoring	**5 Initiation, Adaptation, and Control of Home Mechanical Ventilation** ▪ Ventilation therapy must improve the symptoms of hypoventilation by way of PCO2 reduction. ▪ The criteria for supplementary long-term oxygen therapy should be reviewed once the best possible ventilation set-up has been achieved. ▪ The first ventilation check-up must occur soon after ventilation establishment and evaluate treatment success on the basis of subjective, clinical, and technically measureable parameters. ▪ Modification of ventilation (ventilation set-up, ventilation interface) must only be carried out under the instruction of a physician. ▪ Structurally equivalent devices can be exchanged with identical settings. Structurally different devices must be exchanged under controlled conditions. ▪ Endoscopic identification of the correct tracheal cannula location must take place when switching to a different tracheal cannula model ▪ *There are no scientific data to indicate how often a home-ventilated patient should undergo check-ups. According to opinions published in the literature, the suggested check-up intervals range from a few weeks to up to 1 year. Given that it often takes time to adapt to HMV in the initial phase, this Guideline recommends that the first check-up with nocturnal diagnostics occurs within the first 4–8 weeks of implementing NIV. Repeated check-ups can be useful in the event of poor therapy adherence; if therapy efficacy is still lacking despite optimal therapy set-up, mechanical ventilation should be ceased. This decision is solely the responsibility of the treating physician in the mechanical ventilation centre. In principle, check-ups are recommended at least 1–2 times per year, depending on the type, degree of stability, and progression of the underlying disease, as well as the quality of the settings thus far. Shorter check-up intervals may be necessary in cases where there is rapid progression of the underlying disease. (supplementary guidance)* ▪ *The initial basic clinical diagnosis consists of general and respiratory failure-specific history-taking as well as a physical examination. The following (technical) tests are also essential:* o *Electrocardiogram (ECG)* o *Diurnal and nocturnal BGA under room-air conditions, or in the case of long-term oxygen therapy, with the prescribed oxygen flow rate* o *Lung function tests (spirometry, whole-body plethysmography, respiratory muscle function tests, if applicable [e.g., P0.1, PImax])* o *Basic laboratory tests* o *X-ray of the thorax, with consultation of earlier X-ray images if necessary* o *Polygraphy, polysomnography (if necessary)* o *Exercise testing (e.g., 6-min walking test) (supplementary guidance)* ▪ *Further tests are quite often necessary for special or unclear disease profiles and should therefore be made available:* o *Continuous nocturnal CO2 measurements (e.g., transcutaneous [PtcCO2])* o *Assessment of effective coughing* o *Vital capacity (VC) measurements in sitting and supine positions*

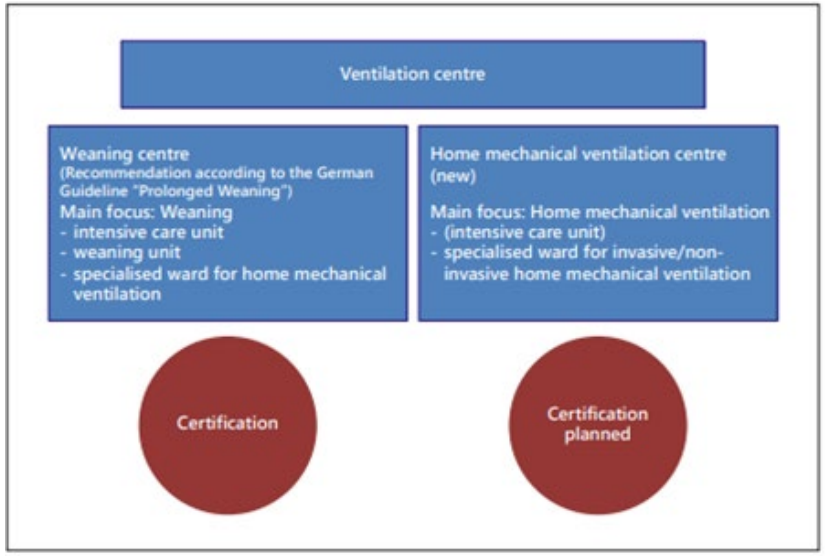
	○ *ECG, in cases where there is historical or clinical evidence for left or right heart insufficiency, coronary disease, or heart defects* ○ *Ultrasound of the diaphragm* ○ *Endoscopic procedures (laryngoscopy/bronchoscopy)* ○ *Fibreoptic endoscopic evaluation of swallowing (supplementary guidance)* ▪ *Non-volitional tests for respiratory muscle strength are desirable but are not always available]. Similarly, neurophysiological examination of the diaphragm and phrenic nerve should be aimed for in special cases as an alternative to ultrasound. For such cases, the enlistment of neurological/neurophysiological expertise should take place early on, and collaboration with a neuromuscular clinic should be sought (supplementary guidance)* ▪ *In addition to the tests outlined above, the check-up examination should be supplemented by the following:* ○ *Adherence to therapy* ○ *Assessment of the clinical success of ventilation* ○ *Side effects of the ventilation (e.g., mask issues, nasal mucosa problems)* ○ *Inspection of the ventilation system (e.g., ventilation set-up, humidification unit, ventilation interface, accessories)* ○ *Screening of nocturnal ventilation efficacy Notwithstanding are the technical check-ups in the context of medical product legislation, which should essentially be carried out by the manufacturer (supplementary guidance)* ▪ *Measures that should be undertaken in the event of acute deterioration of the patient's health status should be discussed with all those involved in the ongoing care process. This plan of action should contain the necessary steps for approaching emergency situations (positions for facilitating respiration, oxygen administration, cannula exchange, secretion management, medication [e.g., antibiotics], emergency calls, etc.), but should also be oriented towards the patient's wishes and stipulations. Ideally, all other measures that are either desired or not wished for by the patient should be laid down in an advanced health care directive (supplementary guidance)* **6.10 What Especially Needs to Be Observed for the Surveillance and Documentation of Home Mechanical Ventilation?** ▪ *Ventilation parameters and alarm limits are set according to the physician's instructions; in this respect, the establishment of individual, needs-based alarm limits should receive special attention. The replacement ventilation device (if available) should also be checked once per shift for function and accuracy of the current ventilation parameters. The replacement device should be within reach of the patient, properly functioning, preset, and on standby for connection to a power source, thus allowing it to be put into use when necessary without endangering the patient (supplementary guidance)* **6.11 What Is the Procedure when a Ventilation Patient Undergoes Clinical Deterioration in the Home Setting?** ▪ *Clinical deterioration of a patient requires medical consultation. In life-threatening situations, the appropriate emergency services should be alerted and adequate emergency measures should be implemented in the meantime; in all other situations, the treating outpatient physician (or his/her cover) should be called in. In such situations, both the advanced health care directive and the fundamental therapy goals have to be taken into account. The supervising HMV centre should be available to provide advice to physicians in the outpatient sector, to emergency physicians, or to admitting physicians in the hospital (supplementary guidance)* **8.6 What Should Be Noted for the Outpatient Medical Care of Patients with Weaning Failure?** ▪ After first implementing invasive home mechanical ventilation due to definitive weaning failure, check-up examinations must take place at least once a year in a specialised ventilation centre.

	▪ The therapy goals of patients with invasive home mechanical ventilation due to definitive weaning failure must be regularly reviewed by a physician. ▪ *For invasively ventilated patients with complex multiple morbidities, home doctor visits are imperative to minimise logistically complex and hazardous transports by vehicle. The ventilation centre responsible for the long-term supervision of the patient should therefore be available for consultation with the private treating physician. In the future, the telemedicine branch might be able to support these consulting sessions through offers such as teleconsultation (supplementary guidance)*
Infection prevention and control	NR
Other guidance	NR
Management of SCI complications	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Respiratory	NR
Bladder	NR
Bowel	NR
Skin	NR
Sexual health	NR
VTE	NR
Pain	NR
Autonomic dysreflexia	NR
Emotional wellbeing, mental health and substance abuse	NR
Cardiometabolic and nutrition	NR
Bone Health	NR
Palliative care	**16 Ethical Considerations and Palliative Medicine** ▪ In very advanced or rapidly progressing chronic respiratory failure, patients and their relatives must be informed as early as possible about the potential imminent respiratory emergencies and the therapeutic options for the end stage of the disease. ▪ A partner-like relationship must take place between patient, physician, and nurse, even in the final phase of life, whereby medical competence but also clear statements about the prognosis, particularly in relation to questions about the end of life, and the duty of medical care remains indispensable. ▪ The rejection of a particular treatment as expressed in an advanced health care directive is binding for the treating physician, as long as the situation at hand corresponds to the one described in the advanced health care directive and there are no indications for a subsequent change of will. The content of the advanced health care directive should be regularly updated. ▪ As an alternative to the hitherto used terms "withholding" and "withdrawing" of ventilation, the term "change of therapeutic goal" should be used; hereby, the principles of palliative medicine should be applied using pre-emptive pharmacological therapy for dyspnoea, agitation, and pain, in combination with non-pharmacological therapy options. ▪ A private area should be available where patients are enabled a dignified dying process in the presence of their relatives.

	16.7 What Is the Nature of the Dying Process during or after Mechanical Ventilation? ▪ *If the decision has been made to end mechanical ventilation in a patient, all available options as well as the principles of palliative care medicine as mentioned below should be applied. For the nursing component, reference can be made to the nursing guidelines for pain management, which optimise the interdisciplinary collaboration in pain therapy. (supplementary guidance)* ▪ *Principles of palliative medicine* o *Freedom from pain and agitation* o *No acceleration, but also no prolongation of the dying process* o *Acknowledgment of life and death as physiological processes* o *Integration of psychological and spiritual aspects* o *Life support until the end, and support for relatives (supplementary guidance)*
Rehabilitation	NR
Wheeled mobility	NR
Other guidance	NR
Broader SCI care pathways and supports	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Governance structure	**6.6 What Kind of Demands Are Placed on the Treating Physician in the Home Mechanical Ventilation Sector?** ▪ The outpatient treating physician must undertake the responsibility of outpatient treatment of a patient receiving home mechanical ventilation therapy. ▪ The supervising home mechanical ventilation centre must become involved where necessary and be available for advice ▪ *Knowledge about the expected course of the disease, the prognosis, and the nursing and therapeutic measures required is necessary for the physician to be able to professionally advise the patient and clearly formulate the goals of the mechanical ventilation therapy. The physician should therefore be able to demonstrate experience in out-of-hospital ventilation and should carry out home visits. With the relevant qualifications, this task can be taken on, for example, by a general practitioner, similarly by a respiratory specialist, an anaesthetist, a paediatrician, a neurologist, an internal medicine specialist, or a specialist with extra training in intensive care medicine and hence mechanical ventilation. If the required medical expertise is not available, the supervising HMV centre should become involved on an advisory basis. Medical care can also be generally undertaken by a team of physicians from different disciplines that correspond to the disease profile of the patient. In the future, the multisector medical care network should be supported by intersectoral telemedicine procedures such as teleconsultations. (supplementary guidance)* **6.8 What Sort of Requirements Exist for Equipment Providers in Relation to the Supply of Ventilation Aids?** ▪ The equipment provider must carry out an initial briefing on the ventilation device in accordance with medical product laws and guarantee permanent availability with a prompt, needs-based service. ▪ *The equipment provider is responsible for the initial briefing on the ventilation machine and its entire set of accessories (e.g., oxygen supply, respiratory gas humidifiers) as well as the monitoring devices. Furthermore, the equipment provider serves as the primary contact for technical problems. An authorised equipment provider must be appropriately qualified. The initial*

	briefing should take into account the current versions of the guidelines outlined in the Medical Products Law (German: Medizinproduktegesetz, MPG) and the Medical Products Operator Ordinance (German: Medizinprodukte-Betreiberverordnung, MPBetreibV). Functional checks, maintenance intervals, and safety-related inspections should be carried out in accordance with the manufacturer's suggestions. The commissioned equipment provider should guarantee round-the-clock availability and provide a prompt, needs-based service. It should be possible to resolve technical problems with the ventilation device within 24 h. Notifiable matters must be reported both to the safety representative of the company supplying the device and the Federal Institute of Pharmaceuticals and Medical Products (German: Bundesinstitut für Arzneimittel und Medizinprodukte, BfArM). Such matters include functional defects, breakdowns, changes in device features or performance, and any incorrect labelling or description on the product or its operating manual that could directly or indirectly lead to the death or serious deterioration in the health status of the patient, the device operator, or any other person. (supplementary guidance) **6.9 What Sort of Need Exists for Therapeutic Services and What Sort of Demands Are Placed on the Therapists?** ▪ Physiotherapy, speech therapy, and occupational therapy should, depending on the relevant indications, form an inherent part of the outpatient treatment program for home-ventilated patients, and be prescribed by the treating physician at a suitable intensity level ▪ *The therapist is obliged to demonstrate familiarity with each ventilation device if he/she is working independently with the ventilated patients, without the presence of a qualified nurse. In addition, skills in the areas of endotracheal suctioning, tracheal cannula management, oxygen application, and emergency response are required in order to be able to react accordingly in specific cases of need. These special features require evidence for the completion of a relevant advanced training course in compliance with the medical delegation responsibility. (supplementary guidance)* **7.3 What Are the Special Requirements of the Nursing Services and Facilities That Care for Ventilated Patients?** ▪ *In the ventilation sector, the facility must appoint specialised nurses as division managers. The number of appointed division managers in a facility should be oriented towards the number of patients requiring care. The division manager should be responsible for no more than 12 patients. Within the nursing sector, the division manager serves as a disseminator of knowledge; the division manager and nursing manager should not be one and the same person. Each ventilated patient and his/her relatives are informed of their appointed division manager.* ▪ *In terms of its organisational responsibilities, the nursing service ensures that the specialised nurses designated to care for the ventilated patients receive proper introductory training and are installed according to their skills and knowledge. The nursing service should be reachable 24 h a day, 7 days a week (supplementary guidance)* **7.7 What Are the Special Features of Assisted Care in the Context of a Care Support Model or an Employer Model?** **7.7.1 Care Support Service** ▪ Aid personnel working as part of a nursing/assistant service should receive qualified training before commencing work with home mechanically ventilated patients, e.g., in the form of a basic course that abides with the minimum requirements of the DIGAB, or a similar alternative offer ▪ *The responsibility for the decision-making process associated with HMV care lies with the leading physician at the hospital, together with the patient and his/her caregivers. If the decision falls in favour of the care support model, the physician should*

	inform the patient of the risks associated with receiving care from nursing staff who do not carry any formal qualifications. The patient should then be ready and able to take on this responsibility. (supplementary guidance) ▪ *When outpatient ventilation care occurs through aids who are employed by a nursing/assistant service, the responsibility for teaching and training lies with the nursing/assistant service (organisational responsibility of the employer) in close consultation with the patient concerned. In this respect, the personal capabilities of the patient are of great importance. It should be properly assessed which directions/instructions can be undertaken by the patient on an independent basis, and which should be organised by the nursing/assistant staff. Aids can also be in the form of registered carers without formal qualifications. The patient should provide documented approval for the selection of aid personnel. (supplementary guidance)* **7.7.2 Employer Model/Personal Budget** ▪ For the care of mechanically ventilated patients carried out by aid personnel either from a commercial enterprise or within the realm of an employer model/personal budget model, formally and informally qualified aids should complete the appropriate training courses that fulfil the minimum requirements of the basic course (Ch. 7.5). ▪ *HMV patients who wish to organise their own assisted care, independently of a commercial nursing/assistant service, can opt for the personal budget/employer model. Hereby, the patients take on the role of "employer" and knowingly accept the associated potential risks, in order to be able to determine their own lifestyle. The selection of personal aids ("employees") and their introductory training and organisation of tasks should occur independently and under the authority of the patient. Organisational competency is therefore an important prerequisite for this form of care (supplementary guidance)* ▪ *The extent of training and qualification required by aid personnel should correspond both to the patient's individual needs and the necessary level of support and care. This should be ascertained through discussion between the leading physician and the patient. The employer model places special demands on the patient itself, on one side as employer, on the other as instructor. Here, extra organisational support from the patient's family is particularly helpful. The skills required to attain instructional competency are often acquired through the patient's own initiative, but can also be supported through patient associations, self-help groups, and/or budget consultants. Based on the general experiences of this Guideline's expert panel, a mixed team comprising formally trained (registered) caregivers and informally trained aid personnel has proven to be a successful approach to the complex care program associated with HMV. The enlistment of external experts with experience in the respective disease profile and the necessary therapeutic and nursing measures is recommended at least for the introductory training of aid personnel, but can also be useful in the further course of care. Measures for quality control are regulated within the personal budget objective agreements between the patient and the health insurance provider. To this end, uniform, content-related criteria for such quality control would be desirable. (supplementary guidance)*
Funding model	NR
Care pathways	**5.***1 What Are Ventilation Centres?* ▪ *There is currently no clear definition of a ventilation centre. This Guideline distinguishes between a weaning centre and an HMV centre (expertise in NIV or invasive HMV). "Ventilation centre" is used as an umbrella term (with different lines of focus). The following definitions deliberately refrain from naming professional groups. The most significant specialist disciplines are quoted as examples. The following section semantically distinguishes between three different types of ventilation centres:* o *I. Weaning centre* o *II. HMV centre with expertise in invasive HMV* o *III. HMV centre (with special focus on NIV) (supplementary guidance)*



- *Patients who are either undergoing or have undergone prolonged weaning are primarily cared for at the weaning centre; this can also include patients undergoing invasive HMV. The primary purpose of HMV centres (Group III) is the initiation of mechanical ventilation, mainly non-invasive, and in some cases, invasive (mainly elective, but also under emergency conditions); Group II centres have an additional focus on the initiation and monitoring of patients receiving invasive HMV. In the future, the certification of centres for HMV should be implemented on an occupational policy level. (supplementary guidance)*

5.1.1 What Are the Tasks of a Home Mechanical Ventilation Centre?

- HMV should be organised by a HMV centre. The home-ventilated patient requires this centre for the setup, monitoring, and optimisation of the ventilation therapy, for emergency admission in cases of deterioration, and as a contact partner for the home nursing team and treating general practitioner. Failed weaning that requires continuous/intermittent invasive HMV should be attested by the weaning centre, where HMV should also be initiated. If relocation of the patient for this purpose is not feasible, initiation of HMV should take place in close coordination with the weaning centre

5.1.2 What Sort of Expertise Is Required in a Home Mechanical Ventilation Centre?

- *Given the complexity of the patient's multiple morbidities, it should be possible at any time to integrate the therapeutic expertise from other relevant specialty disciplines (e.g., palliative medicine, neurology, or paediatrics) with that of a specialized respiratory physician for mechanical ventilation. Close consultation across the various disciplines needs to take place. Expertise in HMV is indispensable. The machine-specific requirements arise from the diagnostic necessities for initiation or monitoring of ventilation, as follows. (supplementary guidance)*

Education across the continuum of care	**7.2 What Sort of Special Knowledge and Skills Are Relevant to Home Mechanical Ventilation Care?** ▪ *The following knowledge and professional skills are specifically required for working in the outpatient intensive nursing care sector:* o *Physiology of breathing and ventilation* o *Diseases with respiratory failure* o *Ventilation machine technology* o *Monitoring/clinical observation* o *Oxygen therapy* o *Masks and tracheal cannulae, and their use* o *Tracheostoma management* o *Methods for mobilisation and elimination of secretions* o *Inhalation techniques* o *Management of airway humidification* o *Crisis management/emergency management* o *Psychosocial support/promotion of social participation* o *Hygiene management in the outpatient sector* *(Supplementary guidance)* ▪ *Due to the specific profile of demands placed on nursing staff, this Guideline recommends the following measures for quality control:* o *Structured introductory training for new employees* o *Enablement of an additional qualification for staff (basic course, Ch. 7.5; expert course, Ch. 7.4; nursing specialist for outpatient paediatric ventilation, Ch. 7.9)* o *Refresher courses* o *Professional support for nursing staff by employees with special expertise (division manager; Ch. 7.4)* o *Networking with each of the regional ventilation centres (Ch. 5.1) as well as with the privately registered physicians who specialise in the care of home-ventilated patients* *(Supplementary guidance)* **7.4 Who Is Eligible to Take on the Role of Division Manager in a Nursing Service/Facility That Cares for Ventilated Patients?** ▪ *For eligibility to work in an outpatient ventilation care facility for adult patients, a division manager should, in addition to the completion of a state-accredited qualification in a specialised nursing discipline (registered public health nurse, paediatric nurse, or geriatric nurse), be qualified in one of the following areas* o *Respiratory therapist with nursing training* o *Anaesthetics/intensive care nursing specialist* o *Nursing specialist with at least 3 years' professional experience in the ventilation sector (intensive care unit, weaning unit, specialised ventilation unit, or HMV) within the last 5 years and successful completion of a certified expert course (a structured, extra-occupational training course with around 200 contact hours) for "Nursing care expert in outpatient ventilation" (Supplementary guidance)*

Expert courses should be quality-assured through certification from professional societies and correspond at the very least to the requirements set down by the DIGAB. (www.digab.de/weiterbildung). The option to install nursing specialists with training in geriatric care is based on positive experiences indicating that – independent of the 3-year basic training course – the necessary competency for this purpose can be achieved through personal engagement and advanced training; this, however, needs to be confirmed through additional quality-controlled measures. (Supplementary guidance)

7.5 What Are the Requirements of Nursing Specialists Who Work as Part of a Nursing Service or in a Nursing Facility?

- *All nursing specialists amongst the nursing staff who work independently with ventilated patients (specialised nursing care) should, in addition to the completion of a state-accredited nursing specialisation (registered public health nurse, paediatric nurse, or geriatric nurse), be qualified in one of the following areas:*
  - *Respiratory therapist*
  - *Anaesthetics/Intensive care nursing specialist*
  - *Nursing specialist with at least 1 year of specific professional experience in the ventilation sector (intensive care unit, weaning unit, specialised ventilation unit, or HMV) within the last 5 years*
  - *Nursing specialist with an additional qualification in the form of a successfully completed, certified expert training course (a structured, extra-occupational training course with around 200 contact hours) for "Nursing care expert in outpatient ventilation" These basic courses should be quality-assured through certification by specialist societies and at the least correspond to the requirements set down by the DIGAB (www. digab.de/weiterbildung) (Supplementary guidance)*

7.8 How Can Relatives Be Prepared for the Nursing Care of Ventilated Patients?

- For the care of mechanically ventilated patients carried out by relatives, a needs-based, individually tailored introductory training program should be performed and documented early on in the discharging clinic (preferably a home mechanical ventilation centre).
- *In cases where relatives are integrated into the care program, structured introductory training sessions occurring around, as well as directly with, the patient should take place early on, namely while the patient is still residing in the HMV centre. Accordingly, a training program should be established that is repeatedly performed until each activity is mastered by the relatives. Ideally, this training should take place within short sessions of around 30 min duration. The aim of these training measures is to acquire a definitive, individually tailored occupational competence so that proper care of the patient can be carried out. For the implementation of relatives into the outpatient care of ventilated patients, enlistment of experts with experience and skill in the actual disease profile, and the application of necessary therapeutic measures, should be considered, at least for broadening the introductory training process, and for providing further support, if needed. The content of Chapter 7.2 is thematically relevant and can be adapted to the individual circumstances and needs of the patient. Relatives should be informed in a timely manner about the options available for easing the burden associated with this type of care (self-help groups, forums). (Supplementary guidance)*

	7.10 What Are the Special Qualification Requirements for Therapists Working in the Home Mechanical Ventilation Sector? ▪ *Physiotherapists, occupational therapists, and speech therapists working independently with ventilation-dependent patients should either have experience in the diseases at hand and their particular therapeutic implications or be trained accordingly (supplementary guidance)* **7.11 What Are the Special Qualification Requirements for Physicians Working in the Home Mechanical Ventilation Sector?** ▪ *The special requirements for physicians involved in outpatient care of ventilation patients are described in Chapter 6.6 (supplementary guidance)* **7.12 Which Particular Topics Should Be Theoretically and Practically Taught in the Advanced Qualification Course?** ▪ *Diseases with respiratory failure* ▪ *Gas exchange; differentiation between hypercapnic and hypoxic respiratory failure, and their development and therapy* ▪ *Different forms of mechanical ventilation including machine parameters; ventilator alarm functioning* ▪ *Invasive ventilation and NIV interfaces; functional check-ups; maintenance, care, and cleaning of cannulae and masks* ▪ *Cannula management; handling of cannula attachments; tracheal cannula exchange* ▪ *Tracheostomal management* ▪ *Operation, effectiveness, and handling of humidification systems* ▪ *Oxygen application, especially in combination with a ventilator; potential dangers of dealing with oxygen; risk of reduced respiratory drive during spontaneous breathing* ▪ *Indication for and implementation of the surveillance systems and interpretation of the results* ▪ *Secretion management, especially with respect to the particularities of the individual underlying diseases* ▪ *Criteria for monitoring spontaneous breathing periods prescribed by the physician* ▪ *Recognition of emergency situations and undertaking of emergency measures for mechanically ventilated patients* ▪ *Procedures for artificial feeding, including application systems and risks* ▪ *Recognition of swallowing disorders and aspiration* ▪ *Legally relevant stipulations (advanced health care directive, medical product law)* ▪ *Special requirements for the psychosocial support of long-term ventilated patients* ▪ *Hygiene in the home ventilation sector* *(supplementary guidance)*
Safeguarding and ethics	**16.4 What Needs to Be Considered when Drafting an Advanced Health Care Directive?** ▪ *It should be conveyed as early as possible to the patient, relatives, and caregivers that in the case of a respiratory emergency, the most secure way of preventing an undesired intubation with the potential for subsequent long-term ventilation is through a precise declaration of intent with concrete stipulations on how to act (advanced health care directive, AHCD). The AHCD should be formulated under expert (especially medical) advice. Finally, the AHCD should be documented. (supplementary guidance)* **16.5 What Is the Procedure when Patients Are Incapable of Communicating/Expressing Their Wishes?** ▪ *When the patient is incapable of communicating or expressing his/her will, he/she is represented by a health attorney or a legally appointed guardian, who is normally a medically lay person. A health care proxy allows one person to authorize another to perform in an emergency situation some or all tasks on behalf of the appointer. The guardian or health attorney is required to express the actual or presumed wishes of a patient who is incapable of making decisions. In well-founded cases, and in consensus with the guardian of the incapacitated patient, gradual or abrupt withdrawal of treatment can take place even without the patient's permission, if this corresponds to his/her presumed wishes. (supplementary guidance)*

	▪ *Next to the presumed wishes of the incapacitated patient (that are conveyed by the authorised person), the AHCD in particular sets the precedent for the actions of the persons involved. The rejection of a particular treatment (as expressed in an AHCD) is binding for the treating physician, as long as the situation at hand corresponds to the one that is described in the AHCD and there are no indications for a subsequent change of will. The AHCD becomes more binding for the treating doctor as the formulations of the patient's wishes become more detailed; this particularly holds true when a professional consultation is documented. The AHCD should state, however, that under certain circumstances and with respect to the individual situation, the patient does not categorically reject a temporary intervention (e.g., tracheotomy for invasive ventilation) in the event of a potentially reversible crisis (e.g., in the form of treatable pneumonia) (supplementary guidance)* **16.6 When Should Mechanical Ventilation Therapy Be Minimised or Withdrawn Completely?** ▪ *If there is no hope even for the stabilisation of quality of life that corresponds to the expectation of a home-ventilated end-of-life patient, it is ethically justified to discuss and (if necessary) undertake a change in therapy goals in the form of therapy limitation or withdrawal. However, the transfer of a patient to a hospice does not necessarily represent the indication for withdrawal of mechanical ventilation therapy; it can also be continued for the treatment of dyspnoea in a palliative context. To this end, coordination between the resources and facilities of the hospice and the treating palliative care physicians is useful. (supplementary guidance)* ▪ *Once mechanical ventilation has been started it should neither be forcefully or automatically continued nor must it be potentially "terminated" or "withdrawn." Instead, mechanical ventilation therapy should, like other treatments (medication, nutrition, infusion therapy, etc.), be checked regularly (e.g., daily), with strict consideration of the patient's will for its ongoing justification/indication (supplementary guidance)* ▪ *Termination of mechanical ventilation in such a situation is designated as passive euthanasia in Germany. This is legally allowed and ethically justified, but should also be clearly distinguished from culpable "killing on request". In accordance with the guidelines of the National Ethics Committee, the following notions are defined:* o *Killing on request is defined in accordance with §216 StGB as the situation in which somebody is assigned to the killing by the explicit and serious demands of the person to be killed and induces death in a directed and active manner. Killing on request is forbidden in Germany.* o *The situation of letting somebody die is present when life-sustaining measures are refrained from, limited, or terminated/withdrawn – as long as this corresponds to the wishes of the patient or, in incapacitated patients, the originally expressed or presumed wishes. Letting somebody die is not a criminal act in Germany.* o *End-of-life therapies carry the primary aim of relieving the patient's suffering. Through the use of strongly effective medication for the control of symptoms, a potentially unavoidable shortening of life can be legally tolerated. This type of end-of-life therapy is not a criminal act in Germany. (supplementary guidance)* ▪ *According to §217 StGB (the intention of supporting another person's suicide or allowing, providing, or mediating in a business-like fashion the opportunity to commit suicide), the business-related assistance of suicide has to be distinguished from the above-described notions. People who do not act in a business-related setting and are either the relatives or close associates of the person mentioned in §217 StGB section 1 are exempt from punishment. (supplementary guidance)*
Other supports	NR
Quality assurance processes	NR
Other guidance	NR

Key: NR – Not Reported

Guidance document characteristics	
Endorsing Organisation/Author	Piedmont Region/ Regional Commission for the coordination of the Pneumological Clinical Network of the Piedmont Region
Title	Recommendations – Guidelines for long term home mechanical ventilation
Country	Italy
Date Published	2021
URL	https://www.regione.piemonte.it/web/sites/default/files/media/documenti/2021-10/linea_guida_per_la_ventilazione_meccanica_domiciliare_a_lungo_termine_regione_piemonte_2021.pdf
National or regional	Regional (Piedmont)
Adapted/adopted from previous guidance document? If so which guidance document was it adapted/adopted from?	NR
Based on evidence synthesis?	NR
Based on expert consensus?	YES
Update(s) planned (including dates)	NR
Funding	NR
Certainty of evidence grading	Not conducted

Domiciliary invasive ventilation guidance	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Pre-transition phase	Prescription for long term HMV can only be made by: ▪ Pulmonologist with expertise in treatment of acute and chronic respiratory failure and mechanical ventilation also working in Hospital or in University Hospital. These experts must correctly verify the prescribing process, the choice of the appropriate ventilator based on the patient's needs, the interface, the hours of use and the monitorning frequency ▪ Anesthesia and Resuscitation Specialists limited to cases of ventilator-dependent patients discharged directly from Intensive Care Unit or in absence of qualified Pneumological center. In case of a prescription by an intensivist the follow-up of the patient must be agreed before discharge with a pulmonological prescribing center that will guarantee the patient's care The patient can be discharged once it is ascertained that home care will be efficient. Active humidification, if indicated The patient must be given a list that includes all data necessary for a safe discharge. **Checklist**

	▪ Type and characteristics of the ventilator and instruction for its settings. Detailed description of the circuit used, the expiratory valves (if present), the entire interface and methods for interface sanitizing ▪ Second ventilator (in selected cases) ▪ Resuscitator Balloon (AMBU) in the selented case ▪ Aspirator ▪ Alternative power source (battery and UPS) for selected cases ▪ Active humidifier, if indicated ▪ Pulse oximeter ▪ cough assistant ▪ Consumable list ▪ Description of the correct assembly of the patient-ventilator circuit and of the humidifier ▪ Instructions for alarm managing ▪ Instructions on the correct positioning of the interface and its hygiene ▪ Tracheal aspiration procedure ▪ tracheal cannula management procedure ▪ emergency procedure ▪ device malfunction management and possible solutions instruction If the patient, due to his or her disability, is obliged to be confined to his own home, checkup must be guaranteed by the outpatient pulmonary service There must be Informed consent for home mechanical ventilation
Transition phase	The patient's return home must include collaboration between the hospital pulmonary team and the GP.

General principles of home mechanical ventilation	The pulmonary prescribing center must guarantee an adequate pathway during hospitalization,post-discharge and follow-up Post-discharge: ▪ Patient follow-up ▪ fibrobronchoscopic check (if requested) ▪ Guarantee urgent visits
Technical requirements	**Consumable** ▪ 24 tube-circuit kits complete with expiratory valve (if single-tube circuit) and collection condensation tray ▪ 24 humidifier chambers + demineralized sterile water (change twice / week) or 365 HME ▪ 2 internal spongy air filters ▪ 150 catethers mount (2-3 / week) equipped with swivel connector and possible tube for aspiration ▪ 365 suction tubes ▪ 365 artificial nose with oxygen attachment ▪ 12 speaking valves ▪ 1 tracheostomy tube per months ▪ ambidextrous sterile gloves for cannula change (1 for each cannula change required) ▪ sterile lubricant in single-dose sachets (1 each cannula change required) ▪ 30 packs / months of sterile gauze 10 x 10 cm ▪ 30 vials / months of 10 ml physiological solution ▪ 30 / months specific tracheostomy dressings ▪ surgical aspirator set: change every 15 days Commercial disinfectant

	Interfaces for invasive VMDLT The choice of a correct tracheal cannula is essential not only to ensure correct ventilation, but also to prevent some complications related both to the natural airway bypass and to the interface itself. It is recommended to use cannulas made of soft material, with low pressure cuffs. Cannula positioning should be checked endoscopically to ensure that the distal portion of the cannula is concentric and co-linear with the trachea. Endoscopic control must always be performed before discharge (ensure correct positioning of the cannula in trachea, cannula aligned with the trachea in the various postures of the neck, with cuffed and capped cannula, absence of granulations or other alterations of the tracheal lumen).
Staffing	NR
Monitoring	Regarding the follow-up plan for patients in long term HMV, it is essential to schedule a first evaluation visit no later than two months after discharge and subsequently at least once every 4-6 months. Goals of the follow up visit are: ▪ The Effectiveness of the therapy assessment ▪ Assessment of the clinical conditions ▪ Assessment of patient compliance to ventilatory treatment ▪ Ventilator setting check ▪ Ventilator interface check and of any pressure lesions ▪ control of lung function by performing functional tests Regardless of the accuracy with which the tracheal cannula is managed, the prescribing center must guarantee an endoscopic check at least every six months to check for the possible onset of complications related to the presence of an artificial airway
Infection prevention and control	The risk of infection at home is considered to be lower than in the hospital. Therefore, the circuits can be changed at weekly or even longer intervals, except when the circuit is dirty with secretions. The clean tracheal aspiration technique is the usual method for aspiration in domestic situations, with a significant reduction in the need for aspiration toilets
Other guidance	None
Management of SCI complications	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Respiratory	NR
Bladder	NR
Bowel	NR
Skin	NR
Sexual health	NR
VTE	NR
Pain	NR
Autonomic dysreflexia	NR
Emotional wellbeing, mental health and substance abuse	NR

Cardiometabolic and nutrition	NR
Bone Health	NR
Palliative care	NR
Rehabilitation	NR
Wheeled mobility	NR
Other guidance	NR
Broader SCI care pathways and supports	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Governance structure	**Respiratory Home Care system (called Integrated Care)** The care relay on the collaboration and coordination between the reference pneumological center and the territorial team, in which medical, nursing, rehabilitation, social, psychological, nutritional, technical and care giver (family members, volunteers) functions can be insured. The integrated care requires: ▪ that domiciliary plan must be shared between the Pulmonology center, caregivers and GPs ▪ the evaluation of the feasibility of the domiciliation project by the GP and the local services that will take care of the patient; ▪ adequate training on the use of equipment not only for care-givers, but also for GPs if deemed necessary Domiciliary plan must be clearly agreed during the discharge phase between all the actors involved: prescribing center, GP, local and specialist services, patient and family
Funding model	NR
Care pathways	NR
Education across the continuum of care	**<u>Training of care-givers</u>** It is necessary to provide external help either by professional nurses or by assistance staff adequately trained to the management of ventlated patient. It is also necessary to evaluate the need for psychological support to the family to counteract the stress to which it is subjected. **Care-giver education plan** ▪ Stoma dressing ▪ Recognition of aspiration need and the effectiveness of aspiration ▪ Tracheal aspiration technique ▪ Decannulation and possible cannula change ▪ Recognize warning signs in the variation of the characteristics of bronchial secretions ▪ surgical aspirator management **Ventilator management** ▪ Turning the ventilator on and off; ▪ Correct assembly of the ventilation line ▪ Correct connection of the patient to the ventilator ▪ Humidifier Assembly and setting ▪ procedure and timing for replacing consumables ▪ Change circuit, humidification chamber and dust filter ▪ Rotation and activation of the spare ventlator;

	▪ Interpretation and eventual resolution of the ventilator alarms ▪ Management of electricity interruptions (use of the battery, activation of the generator) ▪ Breakdown management (telephone number of the technical assistance center with a technician available 24 hours a day) **Clinical-instrumental patient monitoring** ▪ Ability to read the expired tidal volume and respiratory rate ▪ blood pressure and SpO2 measurements **Recognition of signs of airway infection** ▪ Fever ▪ Increased secretions ▪ Change in the characteristics of the secretions (color, quantity, odor, density) ▪ Worsening of breathlessness or respiratory rate **Non-invasive management of bronchial secretions** ▪ Manual cough assistance, ▪ Cough assistance with mechanical insufflator-exsufflator ▪ Postural drainage **Urgency management** ▪ Call to the prescriber center ▪ Evaluation of oxygen saturation ▪ Dyspnea management ▪ Assisted cough **Emergency management** ▪ Territory emergency service alert ▪ Ambu ventilation ▪ Emergency removal of the tracheal cannula (spontaneous decannulation, obstruction of the cannula) and possible replacement ▪ First aids for cardiopulmonary resuscitation **Nutrition** ▪ Mouth nutrition: correct patient posture and assessment of swallowing ability ▪ Enteral nutrition: correct posture to avoid the risk of ab-ingestis; use of the nutritional pump; preparation, administration (time and method) of the mixture for nutrition; management of PEG (or jejunostomy) ▪ Parenteral nutrition: washes; dressing, recognition of signs of infection **Nursing** ▪ skin integrity (daily hygiene and hydration; prevention of pressure sores with postural passages and use of anti-decubitus devices) ▪ mobilization (use of aids: wheelchairs, comfortable chairs, lifters, sliding sheets); nursing of the oral cavit ▪ management of the bladder catheter and the diuresis bag (change of aids, recognition of signs of infection) ▪ alvo control (registration of the number of defecations, first measures to be taken in case of diarrhea and constipation)
Safeguarding and ethics	NR

Other supports	**Technical assistance service** ▪ Since patients are partially or completely dependent on the operation of a device, the technical assistance service is strictly required to ensure the supply, control and maintenance 24 hours a day of the equipment used to provide the VMDLT ▪ Mechanical equipment, must be periodically checked and recalibrated and replaced promptly if malfunctioning ▪ technical assistance service must be active 24 hours a day, 7 days a week, all year round, including holidays for emergency interventions ▪ Technical assistance service must ensure by contract: o periodic home visits for preventive maintenance of the ventilator o consumables supply; o rapid emergency interventions in case of ventilator malfunctioning and immediate replace in case of failure that cannot be repaired quickly. In the event of a technical failure, the ventilator must be repaired or replaced in times that do not endanger the patient's life (the intervention time must not exceed the patient's autonomy time from the respirator); o During home visits, the ventilator operation must be evaluated in its entirety. In particular, the status of the filters must be checked in order to replace them and the tidal volume, respiratory rate, airway pressure values during the entire respiratory cycle, FiO2 and the alarm system must be checked . During the technical check, the flow and pressure sensors will have to be recalibrated if necessary ▪ Technical service examination must also constitute an opportunity to review, together with the care-giver, the procedures for good use of the ventilator and the ventilator patient circuit**.**
Quality assurance processes	NR
Other guidance	NR

Key: NR – Not Reported

Guidance document characteristics	
Endorsing Organisation/ Author	Apulia Regional Health Agency (A.Re.S.)
Title	Regional guidelines Home Mechanical Ventilation. Description and acquisition of pulmonary ventilators for hospital and home treatment for chronic respiratory insufficiency and sleep breathing disorders.
Country	Italy
Date Published	30 Jul 2013
URL	https://test.sanita.puglia.it/documents/36106/272857/Proposta+di+Linee+guida+sulla+ventilazione+meccanica+domiciliare+%28LINEE_GUIDA__VENTILAZIONE_MECCANICA_DOMICILIARE.pdf%29/7be38029-8561-47a3-b8aa-10737bf7801b
National or regional	Regional (Puglia)
Adapted/adopted from previous guidance document? If so which guidance document was it adapted/adopted from?	Not stated
Based on evidence synthesis?	Not clearly specified.
Based on expert consensus?	Yes
Update(s) planned (including dates)	NR
Funding	NR
Certainty of evidence grading	NR

Domiciliary invasive ventilation guidance	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**

Pre-transition phase	▪ Appropriate patient selection
	  ○ Consolidated tracheal stoma in case of tracheostomy ventilation.
	  ○ Stability of oxygenation also in case of tracheal aspiration or cannula change
	  ○ pCO2 monitoring (normocapnia) using home ventilator
	  ○ Before discharge, the patient must be ventilated with the ventilator that will be used at home and its settings must be unvaried for at least 4 days in the presence of stable respiratory compensation
	  ○ Stable medical therapy
	  ○ Adequate nutritional intake
	  ○ Overall clinical stability (for at least one week)
	  ○ Adequate level of home care support.
	▪ Assessment of swallowing ability, phonation and nutritional intake
	▪ Informed consent acquisition
	▪ Choice of the appropriate, ventilator, interface, ventilation type and prescribed respiratory humidification
	▪ Compilation form for electricity supplier and emergency call
	▪ Prescription of appropriate home-care equipment (Insufflator-Exsufflator, Mechanic, oximeter, surgical aspirator, possibly 2nd ventilator and alternative energy source [internal battery and uninterruptible power supply] for patients who have respiratory autonomy of less than 4 hours or who are resident far from hospitals or from the service technical assistance centre)
	▪ Prescription of the consumables
	▪ Adequate training of caregivers before discharge
	▪ Follow-up plan
	▪ Identification of any need for nursing home care

Transition phase	NR
General principles of home mechanical ventilation	▪ Ventilator delivery within 2 working days of the request ▪ Ordinary manintanance at least twice a year with release of the "intervention report" certifying the suitability of the equipment ▪ Extraordinary maintenance to be carried out within 24 hours for non-urgent reasons within 6 hours for urgent reasons
Technical requirements	**INVASIVE MECHANICAL VENTILATION WITH VOLUMETRIC FAN OR BILEVEL FAN ST (>16 HOURS/DAY)** **Consumables** ▪ Tube circuit kit complete with expiratory valve set ▪ Condensation collector: 12/year ▪ Humidifiers: 12 chamber /year or 180 passive humidifiers/year ▪ Internal spongy air filters: 2/year ▪ Catheters Mount: 100/year ▪ Tracheal cannulas (according to medical prescription): minimum 4 / year ▪ Possible speaking valve according to medical prescription: up to 1 / year ▪ Disposable tubes (according to medical prescription): max 60-240 / month

	▪ Metalline (trachea dressing): 1 / day ▪ Antibacterial filters: 12 / year ▪ Cannula tape: 36/year Worned/damaged consumables must be replaced within 12 hours **Accessory equipment** Essential ▪ second ventilator ▪ Ambu (resuscitator) ▪ Aspirator with the following minimum characteristics: o 220 V electric power and battery o suction power control with effective vacuum increase between value range (≈0 - ≈ 0.80 Bar) o vacuum gauge o air flow measured at the inlet of the suction nozzle ≈15 liters per minute o capacity of the secretion collection vessel ≈ 1000 ml o suction power adjustment between - 40 and - 70 kPa o overflow valve o reduced size and weight o carrying handle o built according to UNI EN ISO 10079-1 standards ▪ Uninterruptible power supply (if requested by the prescriber) - 12 antibacterial filters for aspirator - 4 connections between aspirator and tube - 1 oximeter with alarms for continuous monitoring
Staffing	**Personnel provided by the ventilator provider must:** ▪ Work in coordination with the prescribing center and with the specialist who treats the patients at home ▪ be trained to properly relate to patients ▪ be familiar with the home equipment and technologies ▪ be able to train the patient and/or care-giver in the correct use of the equipment provided (based on operating and safety standard) ▪ set the parameters ventilator only with the authorization of the prescribeing center and the specialist ▪ guarantee phone answering 24 hours ▪ respect the confidentiality of clinical data and patient privacy
Monitoring	NR
Infection prevention and control	NR
Other guidance	None
Management of SCI complications	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Respiratory	NR
Bladder	NR
Bowel	NR

Skin	NR
Sexual health	NR
VTE	NR
Pain	NR
Autonomic dysreflexia	NR
Emotional wellbeing, mental health and substance abuse	NR
Cardiometabolic and nutrition	NR
Bone Health	NR
Palliative care	NR
Rehabilitation	NR
Wheeled mobility	NR
Other guidance	NR
Broader SCI care pathways and supports	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Governance structure	. **Ventilator provider must guarantee:** ▪ Home delivery of the prescribed equipments ▪ Instruction for use (in Italian) for all the equipments provided ▪ Ordninary and extraordinary maintenance (if the time required for repair exceeds 12 consecutive hours, the patient must be given an identical device) ▪ Preliminarly and recurring device checks at patient home ▪ Provide both the prescribing center and specialist with the activity data of the device (aggregate and disaggregate) ▪ Technical assistance of the electro-medical equipments also outside the patient domicile Prescribers are **pulmonologists,** with in-depth knowledge of respiratory intensive care and respiratory physiopathology, able to perform the instrumental tests necessary to establish the indications of VMD and to define the optimal choice of the most appropriate ventilatory prosthesis, or **intensivists** As for the The conformity of the devices covered by the contract is verified by the Contracting Authority (SA), with the collaboration of the prescriber or other specialist operating in the prescribing facility and in compliance with art. 312 and following of Presidential Decree 207/2010. The operation is intended to verify, for the goods supplied, the conformity to the type or models described in the tender documentation, in the offer and in the relative annexes.

	Verification of operation in the clinical use of the devices will be carried out in contradiction with the awarded company (DA) and with the technicians of the manufacturer of the devices no later than twenty days from the completion of the installation. Invasive ventilation by tracheostomy for >16 hours per day will be managed by the pneumologist of the territorial unit or by intensivist?
Funding model	Regional health care system
Care pathways	NR
Education across the continuum of care	NR
Safeguarding and ethics	NR
Other supports	**Responsibilities of emergency call (118)** ▪ 118 is responsible for managing the home health emergency and transport to the hospital in unstable conditions 118 intervene in: ▪ Case of emergency ▪ whenever a transfer to hospital is necessary, as the patient's condition is not considered stable by the treating physician ▪ At the time of discharge, the necessary elements for management must be provided to 118 **Electricity supplier** ▪ The electricity supplier must be informed that a person is at home ventilation. A form is to be sent by registered mail to the electricity supplier. It is necessary to indicate the number of the user and the holder of the contract rather than the name of the patient. ▪ The patient should be provided with the toll-free number of the provider.
Quality assurance processes	NR
Other guidance	None

Key: NR – Not Reported

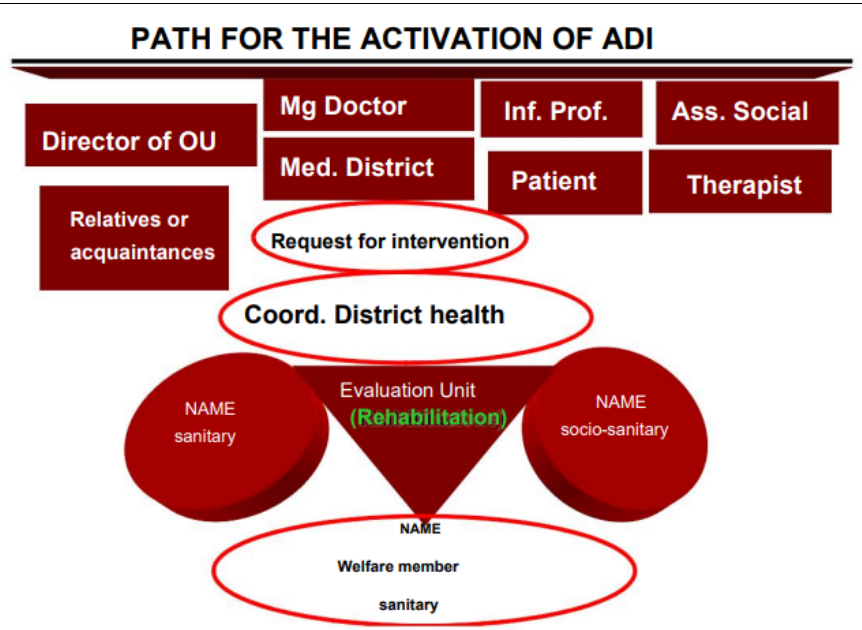
Guidance document characteristics	
Endorsing Organisation/Author	Regional Health care council (Campania)
Title	Regional guidelines: home mechanical ventilation. Adults and pediatrics
Country	Italy
Date Published	NR
URL	https://www.bing.com/ck/a?!&&p=36013a94f78765a8JmltdHM9MTY2Mzg5MTIwMCZpZ3VpZD0yZjI4ZmZiZS1kNmIzLTZiMDYtMWVhMS1lZWYzZDdmZTZhNzMmaW5zaWQ9NTE1OQ&ptn=3&hsh=3&fclid=2f28ffbe-d6b3-6b06-1ea1-eef3d7fe6a73&u=a1aHR0cHM6Ly9pbmZlcm1pZXJpYXR0aXZpLml0L2luZGV4LnBocC9jb21wb25lbnQvcGhvY2Fkb3dubG9hZC9jYXRlZ29yeS8xNC1hcmVhLWNyaXRpY2E_ZG93bmxvYWQ9MTY2OmxnLXZlbnRpbGF6aW9uZS1hc3Npc3RpdGEtcmVnaW9uZS1jYW1wYW5pYQ&ntb=1
National or regional	Regional (Campania)
Adapted/adopted from previous guidance document? If so which guidance document was it adapted/adopted from?	NR
Based on evidence synthesis?	NR
Based on expert consensus?	Yes
Update(s) planned (including dates)	No
Funding	NR

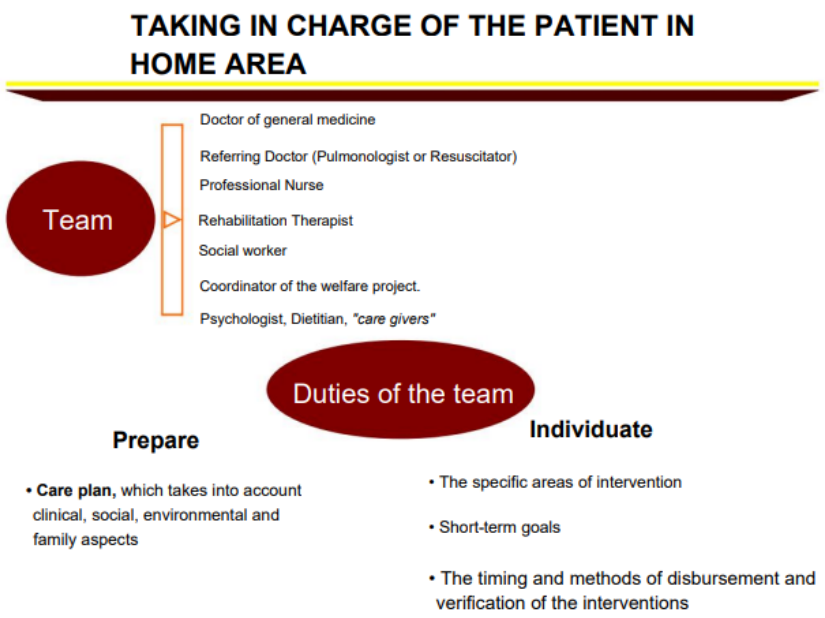
Certainty of evidence grading	NR
Domiciliary invasive ventilation guidance	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Pre-transition phase	**General clinical stability** ▪ absence of sepsis ▪ haemodynamic stability with no need for invasive haemodynamic monitoring ▪ absence of arrhythmias and heart failure ▪ absence of haemorrhages ▪ renal function and acid-base balance or on dialysis treatment **Respiratory stability** ▪ ability to clear secretions both spontaneously or with assistance ▪ absence of severe dyspneic episodes ▪ Airway resistance and pulmonary compliance stability, with change in pressure peak less than 5 cmH_2O (except for coughing fits) ▪ adequate oxygenation (SaO2 $\geq$ 90%) with stable FiO_2 (less than 60%) and PEEP less than 5 cmH_2O (it is allowed a higher PEEP value in case of sleep apnea) ▪ stable oxygenation during aspiration ▪ stable setting of the ventilator **Psychosocial factors** ▪ patient capable and motivated to participate at their own care ▪ presence of caregivers able to adequately respond to the goals of the personal medical care ▪ motivated and capable care giver, identified and trained before the discharge ▪ stable family situation or adequate assistance for 24 hours ▪ family environment prepared to adapt to the patient's situation **The prescribing center must ensure:** ▪ The "follow-up" either directly or by prior agreement with another reference center in charge of the patient care ▪ the availability of several ventilator with different technical characteristics ▪ the possibility of carrying out the tests necessary for the adequate setting and evaluation of the correct use of the ventilator ▪ the compilation of a "checklist", which verifies the essential clinical and technical requirements to start the patient discharge at home ▪ the prescription of the equipment provided by the NHS, using a unified model which also includes the therapeutic plan, assisting the patient in submitting the application for civil disability. This formalso acts as a statistical and data transmission sheet to the Campania Region ▪ the patient and/or caregiver training to complete the therapeutic plan, certifying point by point the implementation of the teaching with relative verification of effectiveness ▪ the request for informed consent to the long term HMV ▪ the possibility of guaranteeing fibrobronchoscopic control in the reference center or ASL (Health Local Autorithy) **Recommendations for prescribing long term HMV**

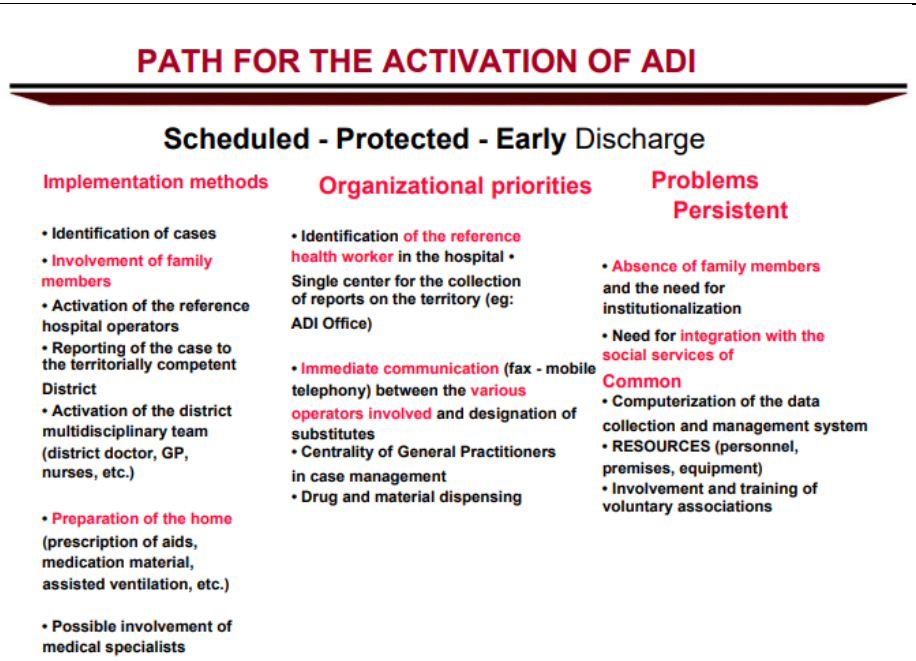
	▪ The patient must be discharged with the same type of ventilator used in the hospital. The ventilator must be chosen taking into account, if possible, any exclusivity contracts stipulated between the supplier companies and the Health Local Authority (ASL). The choice of ventilator, in the case of invasive ventilation, must be agreed with the home care unit, taking into account the availability and purchase programs of the ventilator ▪ Discharge must take place after a sufficient period necessary to have the optimal ventilator settings for patient's needs and to complete the patient and/or caregiver training to the prescribed ventilator. Patient discharge must take place in agreement with the home care team to quickly take charge of the patient care ▪ The prescription of the ventilator must be associated with annual consumable and any other equipment prescriptions,that are necessary for the patient's home management It is advisable to use systems to verify the patient's ventilator compliance
Transition phase	NR
General principles of home mechanical ventilation	**Respiratory treatment plan: "CHECKLIST"** ▪ Ventilator prescription with description of its essential characteristics ▪ Patient follow-up planning ▪ Prescription, in selected cases, of a second mechanical ventilator. Patient requiring> 20 hours / day of IMV or who cannot sustain spontaneous ventilation for more than 4 hours, if survival is dependent on mechanical ventilation, should be provided with a second ventilator and an alternative source of energy (battery and uninterruptible power supply). The battery, in particular, allows for outside the house activity ▪ Prescription, in selected cases, (neuromuscular in Non-Invasive Mechanical Ventilation (NIMV) with severe cough deficiency, patients in Invasive Mechanical Ventilation) of the resuscitator balloon (AMBU) ▪ Prescription of mesh and battery surgical aspirator in patients with swallowing deficiency or hypersalivation, bronchial hypersecretions with partial cough deficiency, and in patients undergoing Invasive Mechanical Ventilation with the possibility of prescribing 2 mesh and battery aspirators ▪ Prescription, in selected cases, of an alternative source of energy (battery and UPS) for the ventilator ▪ Prescription, in selected cases, of an active humidifier ▪ Prescription, in selected cases, of oximeter and mechanical insufflator exsufflator. The possibility of the pulse oximeter prescription is under an operating protocol, which provides for accurate methods for intervention when threshold values are exceeded ▪ Prescription of suitable annual consumables ▪ Pattient and caregiver training documents ▪ Detailed description of o correct assembly of the ventilation set (circuit, passive or active humidifier, valves and exhalation systems) o connection of the patient to the ventilator (mask and anchoring cuff positioning or procedures for insufflation/desufflation of the tracheal cannula o use of ventilator (on/off) o alarm management high / low pressure, low tidal volume, ventilator malfunctioning o disinfection o aspiration and humidification of secretions plan o management of urgency and emergency o any additional techniques
Technical requirements	▪ 24 tube-circuit kits complete with expiratory valve (if single-tube circuit) and collection condensation tray ▪ 24 humidifier chambers + demineralized sterile water (change twice / week) or 365 HME filters ▪ 2 internal spongy air filters

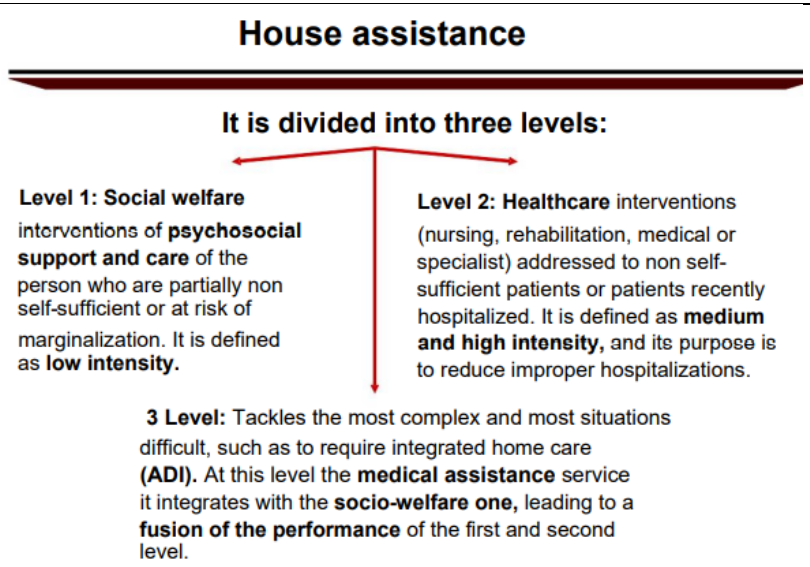
	▪ 104-156 catether mount (2-3 / week) equipped with swivel connector and possible tube for aspiration ▪ 3-10 suction tubes per day unless otherwise specified ▪ 1-3 artificial nose with oxygen attachment per day ▪ 12 speaking valves ▪ 1 tracheostomy tube 15-45 days (in special cases every 7 days) ▪ ambidextrous sterile gloves for cannula change (1 for each cannula change required) ▪ sterile lubricant in single-dose sachets (1 each cannula change required) ▪ 1-3 packs / day of sterile gauze 10 x 10 cm ▪ 1-3 vials / day of 10 ml physiological solution ▪ 1-3 / day specific tracheostomy dressings ▪ surgical aspirator set: change every 15 days ▪ Commercial disinfectant
Staffing	NR
Monitoring	**Evaluation of the effectiveness of ventilation** ▪ day and night symptoms ▪ daytime gas exchanges ▪ night monitoring during ventilation ▪ patient-ventilator interaction: leaks, out of synchrony, volumes **Disease progression assessment** ▪ Spirometry ▪ Mechanics: MIP, MEP, Peak cough ▪ Chest X-ray: in selected cases ▪ Echocardiodoppler: in selected cases **Adherence to the treatment** ▪ Number of ventilation hours per day ▪ Side effects related to the non-invasive and invasive interface **Ventilator operation check** ▪ Ventilator setting ▪ Interface for non-invasive ventilation and tracheostomy tube ▪ Circuits **Assessment of the persistence of adequate socio-economic conditions to continue home ventilation**
Infection prevention and control	NR
Other guidance	NR
Management of SCI complications	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Respiratory	NR
Bladder	NR
Bowel	NR

Skin	NR
Sexual health	NR
VTE	NR
Pain	NR
Autonomic dysreflexia	NR
Emotional wellbeing, mental health and substance abuse	NR
Cardiometabolic and nutrition	NR
Bone Health	NR
Palliative care	NR
Rehabilitation	NR
Wheeled mobility	NR
Other guidance	NR
Broader SCI care pathways and supports	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**

Governance structure	

	
Funding model	Regional Healthcare Service

Care pathways	

	
Education across the continuum of care	NR
Safeguarding and ethics	NR
Other supports	NR
Quality assurance processes	NR
Other guidance	NR

Key: PEEP: Positive End-Expiratory Pressure; IMV Invasive Mechanical Ventilation; MIP: Maximal inspiratory pressure; MEP: Maximal expiratory pressure

<table>
<tr><th colspan="2">Guidance document characteristics</th></tr>
<tr><td>Endorsing Organisation/Author</td><td>Established at the initiative of the Dutch Association of Physicians for Pulmonary Diseases and Tuberculosis, and the Association for Respiratory Support. Authorised by a range of Dutch associations and societies</td></tr>
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<tr><th>GRADE</th><th>Definition</th></tr>
<tr><td>High</td><td>▪ there is high certainty that the true effect of treatment is close to the estimated effect of treatment as stated in the literature conclusion;
▪ it is very unlikely that the literature conclusion will change when results from new large-scale research are added to the literature analysis.</td></tr>
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▪ it is possible that the conclusion changes when results of new large-scale research are added to the literature analysis.</td></tr>
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	▪ there is a real chance that the conclusion will change when results from new large-scale research are added to the literature analysis.
Very low	▪ there is very low certainty that the true effect of treatment is close to the estimated effect of treatment as stated in the literature conclusion; ▪ the literature conclusion is very uncertain.

Domiciliary invasive ventilation guidance

Topic	Recommendation/criteria (Source, Certainty of evidence (if applicable))
Pre-transition phase	**2.4 What does the intake (to the CTB) consist of?** ▪ During the intake (to the CTB), conduct investigations that on the one hand inform the practitioners about the patient's respiratory situation and, on the other hand, provide a good picture of the safety of chronic ventilation for the patient in his/her living situation ▪ Carry out (if necessary) a pre-assessment in the home situation if information about the safety of ventilation in the home situation is insufficiently clear from conversations ▪ Contact relevant specialisms, such as a rehabilitation team, and coordinate actions and policies **2.4 Which diagnostics are performed in the context of an indication for chronic ventilation?** ▪ Perform the following diagnostic activities o anamnesis and social anamnesis o physical examination, lung function examination, blood gas analysis, any additional examination. o If nocturnal hypoventilation is suspected, consider a transcutaneous nocturnal PtcCO2 in the residence **2.4 How can the patient be optimally informed?** ▪ Inform the patient and his relatives well and completely about the consequences of living with chronic ventilation, the advantages and disadvantages of the different types of ventilation and of forgoing treatment ▪ Where possible, coordinate with the (rehabilitation) doctor about the care and (ACP) advanced care planning. **4.1 When can a patient on chronic ventilation be discharged safely?** ▪ Do not discharge the patient with ventilation from the hospital until the ventilation is effective and comfortable. ▪ Make sure that the ventilation can be continued safely, effectively and comfortably in the living situation. . **4.6 What information should the main practitioner receive when placed in the home situation?** The CTB:

	▪ Informs the lead practitioner in complex ventilated patients prior to discharge. ▪ Informs as soon as a patient has been to the CTB for intake and the indication for chronic ventilation has been made, inform the general practitioner or the doctor of the institution where the patient is staying via a letter of discharge. ▪ If necessary, telephone contact can be made in advance of this letter, if it is expected that ventilation will have to be started in the very short term. **4.7 What information and materials should the patient receive when placed in the residence situation?** The CTB: ▪ Provides each ventilated patient with a CTB folder with all relevant information about the ventilation. ▪ Creates a webshop for every patient for ordering disposables. ▪ Ensures the presence of spare material on the day of discharge in the patient's residence situation.
Transition phase	**4.1 When can a patient on chronic ventilation be discharged safely?** ▪ Ensure that complex patients are visited at home on the day of discharge by a nurse from the CTB. In less complex patients, this can also take place in the following days or weeks. *The patient is preferably visited by a CTB nurse on the day of discharge to check whether the ventilator has been properly constructed, to answer further questions and, if necessary, to provide additional training to informal caregivers and/or professional care providers. In less complex patients, this visit may take place in the following days or weeks. The first contact after dismissal can then take place by telephone, for example.* *If the patient has to be transported by ambulance upon discharge, the department where the patient is admitted will request this. It is explained that this is a ventilated patient*
General principles of home mechanical ventilation	NR
Technical requirements	***3.5 Invasive ventilation*** ▪ Preferably choose a cannula with inner cannula. ▪ Preferably choose an uncuffed cannula. ▪ Preferably choose an unvensterdled cannula. ▪ Every invasively ventilated patient has at least one spare cannula and one emergency cannula. ▪ A suffocated ventilated patient always has an emergency cannula in his immediate vicinity.

	▪ Every invasively ventilated patient without or with limited ventilation-free time is given access to a hand breathing balloon for his safety. ▪ He always has this hand breathing balloon in his immediate vicinity. ***Choice of equipment*** ▪ The CTB determines the choice of ventilator and the interface based on the patient's personal profile. ▪ The safety of a patient is leading for the provision of a second ventilator. ▪ The CTB provides a second ventilator at least with a ventilation duration of more than 16 hours per day. ▪ In invasively ventilated patients, always use an electric humidifier for night ventilation and for non-invasively ventilated patients on indication. ▪ Use an HME filter (a so-called artificial nose) in invasively ventilated patients during the day on the wheelchair during the day. *Choice of cannulas in patients with a tracheostomy* ▪ *Preferably, a cannula with an inner cannula is chosen, if possible an uncuffed cannula or a cannula with inner cannula is preferably chosen. Should crusting and obstruction occur in the cannula, the inner cannula can be removed and cleaned while the outer cannula remains in place. An uncuffed cannula is preferred because the patient can still speak and thus also alarm. In case of aspiration or air leakage, a cuffed cannula can be chosen (with an inflated balloon around the cannula).* ▪ *The use of fenestrated cannulae is not recommended due to the risk of granulation tissue ingrowth into the cannula, which can lead to obstruction in the cannula and lead to bleeding upon insertion of an inner cannula* ▪ *For safe ventilation, every invasively ventilated patient has at least one spare cannula and an emergency cannula. The emergency cannula should be one size smaller than the own cannula* ▪ *The frequency of cannula changes depends on the safety situation, hygiene and the type of cannula. The patient-related agreements about changing the cannula are recorded in the information provision for the patient.* ▪ *An emergency cannula should be in close proximity at all times with the patient being cuffed. In the unlikely event that a cannula change does not succeed, the smaller emergency cannula can be placed. The CTB provides the emergency cannula. The patient is responsible for always having this cannula within reach* *Hand resuscitator* ▪ *For safety reasons, every patient with invasive ventilation without or with limited ventilation-free time is provided with a manual resuscitation balloon with a harmonica tube. In practice, this is the airstack balloon that he must always carry with him* *Choice of equipment*

	▪ *The most important arguments in the choice of ventilation equipment and ventilation mode are the estimation of the feasibility of the best possible combination of effectiveness and comfort* ▪ *The choice takes into account safety and, where possible, the wishes of the patient. For example, adequate alarm options must be available if the patient is unable to act on his own* ▪ *Also, the ventilator's audible alarms should be strong enough to be noticed by the patient and/or caregiver.* ▪ *If a patient needs many hours of ventilation per 24 hours, an unsafe situation can arise if the ventilator fails. Then it is important that the patient has a second device as a back-up. This is in any case done with a ventilation time of sixteen hours or more, but in the case of a potentially rapidly progressive condition (including ALS) also with less than sixteen hours. Other circumstances also make it possible for the CTB doctor to indicate an additional ventilator or spare device* ▪ *In addition, the patient's lifestyle plays an important role. If he is mobile, a compact model respirator will be chosen* ▪ *The individual situation of the patient necessitates customization and good consultation at the ventilator institution. The choice of ventilator is determined by the CTB on the basis of the patient's personal profile* *Humidification* ▪ *Adequate, ie active, humidification of the inhaled air is important for comfortable ventilation. For night ventilation, an electrical humidifier is always placed in the breathing circuit for invasively ventilated patients. During the day, in principle, an HME filter (the so-called artificial nose) is used for ventilation on the wheelchair, because there are no really good options for active ventilation on the wheelchair* **4.5 What is needed for adequate alerting of ventilated patients and what are the responsibilities?** The CTB: ▪ Sets the alarm limits on the ventilator. ▪ Together with the healthcare institution and/or the supplier of the call system, ensures the link between the ventilator and a central call system. ▪ Adjusts alert requirements when the patient's ventilator care profile changes. ▪ Checks an adapted alarm together with the healthcare institution. The setting: ▪ Has an adequately functioning central call system. ▪ Is responsible for the follow-up of the alarm within a time appropriate to the ventilation care profile. ▪ Is responsible for correct interpretation of the alarms, timely follow-up of the alarms and to act accordingly. In the home situation, the patient (or his representative) with a PGB (personal budget) (not in kind) or PAB is responsible for: ▪ Adequate alerting. ▪ The deployment of sufficient and competent care providers, who are able to follow up the alarm within a time appropriate to the ventilation care profile.

With ventilation care profile 1 or higher, the patient has another option to call for help, such as an extra pressure bell.

Always check whether disconnection and obstruction cause an alarm to come through when the patient is left unsupervised.

The CTB nurse makes periodic home visits, performs standard checks and tests safety and alarms.

Reliable transmission of alarms and adequate response are important conditions to provide ventilated patients with sufficient safety in their living situation. The degree of dependence on ventilation and the need for care differs per patient. Also, the situation of a patient can change over time due to, for example, progression of the disease.

In general, the less self-reliant someone is, the higher the demands on the alarm. See table below.

Ventilation care profile	*Alarm option 1*	*Option 2*
Ventilation care profile 0	*No alarm necessary, remote assistance is sufficient*	
Ventilation care profile 1 *Patient must be able to be helped within 30 minutes*	*Healthcare provider within earshot of the alarm signal and always patient-initiated alarm option*	*Voc-connected device AND patient-initiated alarm capability* *Remote Assistance*
Ventilation care profile 2 *Patient must be able to be helped within 15 minutes*	*Healthcare provider within earshot of the alarm signal and always patient-initiated alarm option*	*Voc-connected device AND patient-initiated alarm capability* *Short-range assistance*
Ventilation care profile 3 *Patient should be able to be helped within 5 minutes.*	*Healthcare provider within earshot of the alarm signal and always patient-initiated alarm option*	*Voc-connected device AND patient-initiated alarm capability* *Help in the vicinity*
Ventilation care profile 4 *Patient must be able to be helped immediately*	*Under the direct supervision of healthcare provider*	*Device linked to VOC/MOS AND patient-initiated alerting capability*

VOS= Nurse Call System
MOS= Medical Call System. A MOS is only useful if the lead time < is 1 min.

If a patient with ventilation care profile 1 or higher does not want his ventilator to be connected to the call system or prefers a residential environment where a link is not possible, this will be recorded in the patient file

Reliable alerting and adequate response are important prerequisites for providing adequate safety for ventilated patients in their living environment. The tasks and responsibilities with regard to the adequate organisation of the alerting and response in the residence situation are defined as follows.

The CTB is responsible for:

- *issuing an advice on the alert, depending on the ventilation care profile of the patient concerned;*
- *the ventilator and setting the alarms of this ventilator;*
- *ensure, together with the institution or supplier, a functioning link between the ventilator and, where appropriate, other monitoring equipment to the central call system so that alarms are reported perceptibly;*
- *supplying the cable that transmits the alarm from the ventilator to the institution's central call system;*
- *checking the alarm on the basis of a checklist of alerting in case of patient transfer;*
- *periodic home visit by the CTB nurse in which standard checks are made to test the alarm situation.*

In the event of a change in the ventilation care profile, the alarm requirements are adjusted by the CTB. The CTB and the institution ensure adjustment and control of the adjusted alarm.

Home situation:

- *In the home situation, the CTB gives the patient and caregivers individual advice about the alarm. There must be a secure personal call system. The condition is that alarm signals from the ventilator are perceptible by caregivers and that the patient has his own possibility of alarming to call caregivers at all times.*
- *The patient or his representative is responsible for following or ignoring advice.*
- *The patient or his representative who acts as the client from a PGB budget or PAB is responsible for the deployment of competent and sufficient care providers (see the module 'Training for chronic ventilation').*

Patients should also be trained where they are able to do so, so that they are experts in the handling, medical equipment, risks and actions in emergency situations:

- *Some of the patients act as a client from a PGB and purchase their own care and must be aware of the requirements to be set.*
- *In practice, the patient is a carrier of information for his specific situation.*
- *An explicit condition of performing reserved actions by non-professionals is that the recipient agrees to this, for this the patient must be aware himself.*

7.1 What equipment and related technical equipment is used in the living situation with patients of the Center for Home Ventilation (CTB)?

Technical equipment, equipment and disposables

We use the term technical equipment for all technology related to ventilation (non-exhaustive!):

- *ventilators including batteries*
- *hoses/filters/artificial noses/valves/(speech)valves/swivles/caps*
- *interface (mask, mouthpiece, pillows, cannula, spare and emergency cannula)*
- *humidifier*
- *suction equipment*

	▪ *airstack and hand breathing balloon* ▪ *cough machine* ▪ *monitoring (O_2 and CO_2)* ▪ *trolley* *Nebulizer, the alarm system of the residence situation, wheelchair and oxygen administration are covered by the technical equipment, but not by the responsibility of the CTB. The task of the CTB is to ensure that the technical equipment can be used safely, even if combinations are made with technical equipment that is not the responsibility of the CTB.* *The consumables needed in respiratory care; gauzes, gloves and syringes do NOT fall under the term technical equipment, as well as fixation of cannulas and chin straps.* *For a subgroup of the technical equipment, we use the term ventilator for ease of reading. This is equipment with plug, which requires maintenance and registration; ventilator, active humidification, suction equipment, coughing machine and monitoring.* ***7*.2 How long can the different parts of the ventilation circuit be used safely and efficiently?** **What minimum requirements must be set for the water used in the active humidifier in order to be able to use it safely?** **What does it take to safely redeploy ventilators to another patient**? ▪ Use fresh tap water in the active humidifier which works via heating / evaporation. ▪ Replace the parts of the ventilation circuit in case of damage, clean in case of visible contamination and periodically replace CBTOs according to common prescription. ▪ Disinfect the ventilator externally before using it on another patient. *The following rules of thumb apply to cleaning and replacing disposables:* ▪ *Defective or non-functioning (parts of) the ventilation circuit are immediately replaced. The patient or healthcare provider monitors that sufficient stock is immediately available.* ▪ *It is advised to wipe the inside of the masks once a day with a damp cloth. If visibly contaminated, clean household (with a pH-neutral cleaning agent).* ▪ *The pot of the humidifier is emptied daily and supplied with clean water and should be cleaned domestically at least once a week.* ▪ *Clean hoses that are visibly contaminated.* *Cannulas:* ▪ *Silicone cannulas (without inner cannula): change by appointment and clean household with a cotton swab or gauze and let dry. The frequency of change is agreed individually.*

- *Cannulas with inner cannula: change inner cannula at least twice a day, clean household and put away dry. Change outside cannula by appointment.*
- *Usually two cannulas are used at the same time, which are replaced by 2 new ones after 2 times 28 days.*

Airstack accessories and hand breathing balloon:

- *Airstack or hand breathing balloon:*
  - *Cleaning: if necessary externally*
  - *Replaced: if defective, max. 1x per year*
  - *Airstack mask/ airstack hose+ accessories:*
    - *Cleaning: daily cleaning*
    - *Replaced: if defective*

When leaving the hospital, after a respiratory infection or after a course of antibiotics, the entire ventilation circuit is replaced.

These cleaning instructions are derived from the regulations of the national Working Group on Infection Prevention, the revision date of which has now expired (WIP guideline pneumonia in ventilated patients; non-drug prevention).

7.3 Who determines whether a wheelchair structure is necessary?
What criteria are there for wheelchair construction?
Who is responsible for construction and final inspection?

- The CTB doctor or nurse (UK) sets the indication for building equipment on the wheelchair.
- When choosing an electric wheelchair for patients with a progressive disease, the possibility of possibly building a ventilator later is taken into account.
- The company that carries out the superstructure is ultimately responsible for a safe combination of (electric) wheelchair and the ventilator plus any accessories and documents this.
- The company that carries out the construction has an appropriate quality system.
- The owner of the wheelchair is responsible for the maintenance of the wheelchair.
- The CTB is responsible for the maintenance of the assembled equipment.

Staffing	**4.4 What requirements may be imposed on the occupancy rate of competent personnel?** ▪ The healthcare provider: o Ensures deployment and planning of sufficient and competent personnel. o Regularly assesses the commitment and continuity of the staffing in relation to the needs of the patient(s). *The care/assistance to patients with chronic ventilation is care in acute, potentially life-threatening situations with short response times. This care requires the deployment of sufficient competent and competent personnel (see the module 'Training for chronic ventilation'). Due to the high risks, the occupation with competent personnel must be well arranged at all times.* *There is no literature available on standards for staffing in ventilators. Determining the minimum occupancy is justified on the basis of patient- and organizational factors. In this context, it is relevant to define the responsibilities of the patient, the provider and the CTB in the cooperation agreements regarding the quality and continuity of the necessary care/assistance. These agreements are recorded in an agreement. This can be a framework agreement, service agreement or cooperation agreement. (see the module 'Appropriate support and care provision")* *The healthcare provider determines the occupancy of skilled staff for chronic ventilation based on the weighting of the following factors.* ▪ *Patient-related factors* o *the ventilation care profile;* o *ventilation-free time;* o *hand function;* o *ability to speak/communicate;* o *swallowing function, danger of aspiration* o *cuffed cannula* o *care needs based on physical condition;* o *cognitive abilities;* o *social self-reliance and/or insight into illness (ability to take control, to ask clear questions and to wait for the arrival of the care provider);* o *duration of the care operations;* o *frequency of care operations;* o *presence of informal care/family;* o *possibilities to be able to alarm (both motor and cognitive).*

	▪ *Organisational factors* o *care demand from other patients in the organizational unit;* o *distance that staff must bridge to patient(s) must be such that the required response time is achieved;* o *technical devices to transmit the alarm signal of ventilators to the healthcare provider.* *The wishes of the patient with regard to his care are taken into account in the weighting of these factors. The deployment of sufficient skilled personnel is the responsibility of the healthcare provider.* *This should check regularly, especially when there are changes of patients, whether there are still sufficient competent staff present.*
Monitoring	**2.4 How does the follow-up process go?** ▪ At each outpatient clinic visit, consider the patient's initial wish with regard to ventilation ▪ After the intake, make clear agreements with the patient about the follow-up process, terms and education in cough-supporting techniques. **2.4 How often will the patient with an indication for chronic ventilation be seen in the outpatient clinic in the long term?** ▪ In the event of an indication for chronic ventilation, agree the number of contact moments per year with the patient in the long term, in connection with the progression of the disease. ▪ In practice, 1 to 4 times per year check-ups have been shown to be a good frequency, with 4 times per year in the case of rapidly progressive diseases and once a year in slowly progressive diseases. Depending on the progression of the disease, the CTB doctor or nurse can make other agreements with the patient. **5.1 What does it take to determine that ventilation is effective, comfortable and safe?** ▪ During periodic check-ups, evaluate the effectiveness, comfort and safety of chronic ventilation. ▪ Make periodic home visits to patients with chronic respiratory failure and chronic ventilation. ▪ The CTB doctor or CTB nurse indicates home visits and their frequency on the basis of disease progression, ventilation complexity, complications and co-morbidity ▪ Holds at least annual outpatient checkups. ▪ If desired and possible, consider the option of (video) calling instead of physical check-up at the outpatient clinic. ▪ Perform annual transcutaneous blood gas measurements (CO2 and SpO2) and/or blood gas checks to evaluate/measure the effectiveness of chronic ventilation.
Infection prevention and control	NR
Other guidance	**5.2 What is the policy for acute and intercurrent medical problems?**

- Make sure that every patient has access to an emergency step-by-step plan.
- Consult with the CTB doctor if treatment is to take place in a chronic ventilated patient that may affect ventilation and/or breathing.
- In case of respiratory or respiratory problems, contact the CTB. Every CTB has a 24/7 on-call service.
- In case of technical problems and malfunctions, please contact the technical equipment maintenance company. This has a 24/7 availability service.

5.7 What should happen in the event of a power failure?

- Make sure that all patients with chronic ventilation have a protocol 'what to do in case of short and long-term power failures'.
- The patient must share the content of this protocol with other data subjects.

5.8 What are the options for respite care for ventilated patients?

- Develop a plan to improve respite care options for chronically reassigned patients.

- *Respite care is funded from a variety of sources depending on the funding of the patient's care. Respite care can be financed from a PGB (WMO, ZvW or WLZ). Respite care can take place in an institution, such as overnight care, but also at home, by calling in extra professional help.*
- *In situations where care can be arranged within a nursing home or other residential institution, additional professional help is often needed that is competent and competent for providing care to respiratory patients. If this is not present within the own organization, cooperation with other organizations or the involvement of freelancers can be a possibility.*
- *When respite care has to be used, consultation with the financier is necessary, such as health insurer or care office.*
- *Patients and their loved ones would like respite care close to home. However, the number of options for safe care for respiratory patients is very limited, especially for the more complex patients. Via www.vsca.nl it is visible which WLZ institutions have experience with ventilated patients. Unfortunately, this does not mean that they automatically have the opportunity to provide respite care. Very occasionally, individual agreements can be made with institutions for temporary admission.*
- *Respite care can also be a bridge to introduce a patient and an institution to each other, with a view to full admission in the future.*
- *There are insufficient options for respite care for patients on ventilation.*

9.3 What should a patient with chronic ventilation take into account when going on holiday?

- The CTB gives the patient a standard medical letter and a customs declaration in the CTB folder.

- The patient takes the CTB folder with ventilation settings with him when travelling.

9.4 Should all patients with (potential) ventilatory failure with or without chronic ventilation undergo a High Altitude Simulation Test (HAST) for a flight?

- Advise patients with chronic ventilation to use the ventilation during a flight, especially if they are sleeping. A HAST is then superfluous.

- Refer patients at risk of respiratory failure, who are not yet on ventilation, for a HAST

Management of SCI complications	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Respiratory	**3.6 Which cough support techniques should be used, in which patients and when?** ▪ For a timely start with the right cough support technique, regularly (at least 1 time a year) assess peak cough flow (PCF), vital capacity (VC) and cough phase. ▪ Start airstacking if: ▪ cough flow < 270 L/min and/or ▪ FVC of ≤ 50% of the predicted value or < 1.5 l and/or ▪ mouth pressures (MEP) of < 60 cm H_2Oh; and/or ▪ clinical signs of insufficient coughing strength. ▪ Consult with CTB doctor about using cough machine if air stacking is insufficiently effective. ▪ Start MI-E only after consultation with the CTB doctor at: o recurrent respiratory infections despite maximum conservative measures such as air stacking, manual compression and spraying. o a PCF < 160 l/min as a bronchial secretion cannot be coughed up sufficiently with other recruitment techniques or cannot be sufficiently removed with bronchial toilet in the invasively ventilated patient. ▪ Set up the MI-E as follows: o Assess the correct settings for each patient in terms of pressure and length of inspiration time. o The best PCF is achieved with a suboptimal MIC. o Avoid high pressures and short inspiration times in patients with bulbar complaints.
Bladder	NR
Bowel	NR
Skin	NR
Sexual health	NR
VTE	NR
Pain	NR
Autonomic dysreflexia	NR
Emotional wellbeing, mental health and substance abuse	NR
Cardiometabolic and nutrition	NR
Bone Health	NR
Palliative care	**5.9 What are the options for hospice care for ventilators?**

- Develop a plan to improve hospice care options for chronically reassigned patients

- *For respiratory care, competent and competent care is necessary. In general, this is only possible within a high care hospice. Characteristic of a high care hospice is that there is a multidisciplinary team present and specialized nurses are present 24 hours a day. In an 'almost at home' hospice these are missing. The number of high care hospices in the Netherlands is small. Hospices are often willing to discuss in individual cases whether the conditions for safe care can be met. In hospice care, too, patients like to be admitted near their loved ones.*
- *Nursing homes with specialized ventilation care do have the ability to provide palliative care in the last phase of life.*
- *At the moment there is a lack of hospices in the Netherlands that offer the possibility of palliative care for ventilator patients. Making an improvement plan must become part of the implementation plan of the directive.*

11.1 When can a patient's ventilation be terminated?

- In case of undisturbed cognition, end the ventilation if the patient wants to.

- Preferably discuss with the patient at the start of the treatment his wishes regarding chronic ventilation as a life-prolonging treatment, including any wishes for ending it. This applies to all practitioners of patients with chronic ventilation.

- Coordinate the actual termination of chronic ventilation with the patient and with all practitioners among themselves from the patient with chronic ventilation.

- Preferably, as the main practitioner for the end of the chronic ventilation, always contact the CTB doctor, and vice versa, and if necessary a palliative consultant.

In accordance with the WGBO (Medical Treatment Agreement Act), the termination of chronic ventilation at the request of the patient falls under normal medical practice and does not concern the assessment or granting of a euthanasia request.[1]
The doctor who is confronted with such a request needs a guideline on how to act unambiguously, because it is a process that is far-reaching and complex from a medical-technical, psychosocial and ethical point of view (Edwards & Tolle, 1992).
With progression of respiratory failure, the effectiveness of ventilation may decrease. Most patients on chronic ventilation eventually die from progression of their respiratory failure or as a result of complications such as respiratory infections. However, it is also possible that the patient asks the attending physician to end the ventilation. The reason may be that the benefits no longer outweigh the disadvantages because the pillars of chronic ventilation, being effectiveness and comfort, can no longer be achieved.

Until now, there was no Dutch guideline or guideline with practical advice on medical, ethical, organizational and guidance aspects in ending chronic ventilation.
This module deals with the coordination with the patient and between practitioners themselves and on the organization and implementation of the termination of chronic ventilation at the patient's home, in a hospital, nursing home or in a hospice.

Tuning

In the context of advance care planning (ACP) and joint decision-making, the main practitioner, the CTB doctor and other practitioners must regularly make agreements with the patient about his wishes regarding chronic ventilation as a life-saving and therefore life-prolonging treatment, including any wishes for its termination (see Annex I). , organization). It is important to discuss this at the first consultation with the CTB and, if necessary, to repeat it regularly on the basis of the progression of the disease, whereby appointments can be made again (see the module 'Chronic ventilation in the residence situation'). Living with a progressive disease is often an emotional process, in which boundaries can gradually shift the course of the disease over time.
When chronic ventilation is actually terminated, coordination must take place with the patient and between the practitioners themselves. The desire to eventually stop the ventilation is often motivated by lack of effectiveness and because the patient no longer finds life with the ventilation meaningful, for example because the benefits no longer outweigh the disadvantages. It is also possible that there is so much co-morbidity in addition to the ventilation that this seriously affects the quality of life. Quality of life is subjective but extremely important. This can be motivated by a person's views on life, of his ethical, religious and social vision. Lack of quality of life can therefore only be indicated by the patient himself.

In accordance with the WGBO, a chronically ventilated patient should be informed early and repeatedly about his right to stop the ventilation. This responsibility rests primarily with the CTB doctor. The desire to discontinue ventilation is usually expressed by the patient longer in advance. However, this desire can also arise acutely during a complication. It is important for both the patient and the practitioners to be aware of this. For that reason, it is recommended that the patient writes down his wishes in a declaration of will (Van Malenstein ea, 2018).

Discontinuation of life-prolonging treatment such as chronic ventilation is part of normal medical practice and is not euthanasia (Van Malenstein ea, 2018, VSCA, 2012). The patient dies a natural death from progressive, irreversible respiratory failure. The medical assistance provided in that phase is aimed at avoiding or combating respiratory distress and discomfort, not at ending life (Truog & Burns, 1992).
It is recommended that the main practitioner contact the CTB doctor, and vice versa, and if necessary, a palliative consultant. As a result, he not only supports the patient and his relatives in an accurate way, but also himself: the procedure can form a heavy practical and emotional burden (Faull et al., 2014).

11.2 Who takes the lead in organizing the termination of ventilation?

- The main practitioner takes the lead in the organization and starts the procedure of terminating the ventilation.

11.3 How is the execution of the termination of ventilation?

- Administer opioids and benzodiazepines in anticipation if discomfort and respiratory distress are provided upon termination of ventilation.
- Prefer the intravenous route over the subcutaneous one for continuous titration of medication on the effect and for a rapid effect in acute respiratory distress.
- Sedate only in anticipation at a ventilation-free time of no more than a few minutes. Sedate so deeply that the patient is not awake before the ventilation is stopped.
- Turn off the alarms and turn off any saturation meter that may be present when the ventilation ends.

	▪ Preferably, the main practitioner or a loved one chosen by the patient takes off the breathing mask or loosens the ventilation circuit of the trachea cannula and then turns off the ventilator. ▪ Continue oxygen if this gives effect and has already started. Do not start oxygen routinely given very limited evidence. ▪ Stop the ventilation completely or gradually reduce the ventilation. Make this choice depending on the wishes of the **patient** in combination with the experience of the CTB team. **11.4 How to deal with patients with cognitive impairment and end ventilation?** ▪ When ending chronic ventilation in patients with acquired cognitive impairment, fall back on the initial will of the patient. ▪ If it is not known what the initial will of the patient is, then the decision of terminating the chronic ventilation lies with the legal representative, the partner, family, general practitioner, rehabilitation doctor, doctor for the mentally handicapped or specialist in geriatric medicine.
Rehabilitation	NR
Wheeled mobility	**9.1 How can a patient with chronic ventilation be safely transported by private transport or wheelchair taxi?** ▪ Keep the emergency kit in close proximity to the patient during transport, even if he is not currently being ventilated. ▪ Alternative to a hand breathing balloon is a working spare ventilator. ▪ Determine the guidance needs of a patient with ventilation on the basis of Table below. ▪ In addition, keep the following things in mind at the time of transport: o patient's condition, o frequency of suction, o duration of operations, o traffic situation. ▪ Adjust the number of supervisors when transporting several chronically ventilated patients at the same time. ▪ In busy traffic conditions, take an extra companion with you in addition to the driver. ▪ Take into account the available space in the vehicle to be able to trade. ▪ The person who performs the actions must be competent. ▪ Fix the wheelchair well. In all forms of transport, the safety of the patient is paramount. Problems around ventilation can also arise during transport, such as the loosening of a hose, a mucus plug that clogs a cannula or a problem with the ventilator. This means that there must be sufficient qualified (see the module 'Training for chronic ventilation') support available during transport which can intervene adequately and with appropriate urgency when necessary. To determine the minimum support, the ventilation care profile is used (see Annex I ventilation care profiles). The indicated response time is the time within which to respond to problems and ensure that the patient can breathe freely again or be ventilated. The response time is related to the ventilation-free time. The patient's ventilation care profile indicates the response time.

Assistance with transport can be provided by various persons such as the driver of the wheelchair taxi, PGB-ers, informal caregivers, volunteers or possibly an employee of the care institution where the patient is staying.
A supervisor of a ventilated patient must be competent to perform necessary actions, such as suction. To make this possible, the breathing balloon, transport suction equipment, suction hoses and the emergency package containing, among other things, the spare and emergency cannula must also be present in the vicinity of the patient during transport. These appointments can be found in the CTB folder.

The most important factors in determining the need for guidance during transport are:

- the use of the ventilators during transport,
- the necessary response time in the event of ventilation problems,
- the patient's own ability to act and alarm,
- the patient's condition at the time of transport,
- the traffic situation.

A driver may, if competent, be the person performing the operations when there is sufficient response time and ventilation-free time, otherwise a second person must be present during transport. This person must be competent in performing the necessary actions.

For each patient, it must be determined whether, and if so which guidance is necessary. The table below (Table 1) is a guide in determining the need for assistance in transport. In addition, factors such as the frequency of suction and the duration of the actions influence the need for guidance.
In case of illness, cold, or other peculiarities, the ventilation-free time and response time may be shortened and a new consideration must be made.
An estimate of the traffic volume must always be made in advance. In busy traffic situations, it may be impossible for the driver to stop and provide assistance in time. Then an extra supervisor is necessary.
The table assumes one patient per vehicle. If several chronically ventilated patients are transported at the same time, the number of supervisors must be adjusted accordingly. In this situation, the available space in the vehicle must also be taken into account. The person who performs the actions must have sufficient space for this.

Table 1 determination of assistance with transport of 1 patient in normal condition per vehicle and quiet traffic

Definition	*Accompaniment*
Patient acts himself (ventilation care profile 0) or does not use ventilation during transport	*No assistance needed with transportation*
Ventilation care profile 1	*One competent care provider needed, this could be the driver)*
Ventilation care profile 2, 3 and 4	*One competent care provider needed, this cannot be the driver*

In summary: when transporting a patient with a response time of more than 15 minutes on a quiet traffic route with sufficient opportunity to stop, the driver can also be the accompanying person, who can intervene in acute situations with regard to ventilation. Of course, he must be capable of doing so. In patients with ventilation care profile 2 and higher (ventilation-free time is 15 minutes or less, so the patient must be helped within 15 minutes or less) and in other traffic situations, a competent supervisor almost always has to be involved.

The Code for Safe Transport for Wheelchair Users (VVR).
The Code VVR concerns the safe transport of wheelchair users in a wheelchair taxi. The code is not specifically aimed at wheelchair users with chronic ventilation. For safe transport in a wheelchair taxi of wheelchair users, new agreements have been laid down in the renewed VVR Code in the sector. We are working on a sector covenant so that the patient can be transported and the taxi operator has certainty about the transportability of the wheelchair.
In addition to numerous test requirements, the NEN-ISO 7176-19 standard also indicates that 'not meeting those test requirements' may not lead to the refusal of the transport of otherwise easily secured wheelchairs. If a 'secure' wheelchair can be replaced by a 'safely transportable' wheelchair, then that is preferable. A transitional period has been set until 31 December 2021, during which wheelchairs that do not meet the requirements may be transported on condition that they can be safely secured.

9.2 How can a patient with chronic ventilation be safely transported by ambulance?

- Make sure that every patient who also needs to be ventilated during transport has an ambulance card with instructions regarding equipment and who to reach in emergency situations.

- Consult with the CTB doctor or nurse on duty in case of unplanned and planned ambulance transport.

- When requesting the planned transport, clearly indicate:
  - how the patient can be transported safely
  - whether and how ventilation in the ambulance should be continued
  - whether the trolley should be taken with you.

The current National Protocol ambulance care states:
'Most ventilators used in ambulance care do not have the quality or setting capabilities of the patient's own ventilators. Switching to equipment other than what the patient is used to can cause dysregulation; for that reason, preference is given to the use of one's own ventilators. This applies to both an unstable and a stable patient. This can only be deviated from if the patient is not sufficiently stable with his own equipment, or if the transport is urgent and it is not feasible to transfer the patient with his own equipment.'
(https://www.ambulancezorg.nl/themas/kwaliteit-van-zorg/protocollen-en-richtlijnen/landelijk-protocol-ambulancezorg).
The ambulance nurse makes the decision whether ventilation on their own equipment is feasible and safe.

It must be possible to continue ventilation during ambulance transport. During transport, these patients may need to be given oxygen in addition to ventilation.
When transporting ambulances to the hospital, it must be taken into account that the ventilation must also be able to continue in the hospital. The patient's ventilator must therefore be taken in the ambulance including a power cord, because during hospitalization the 'normal' electricity supply is used. When the ventilator is mounted on the wheelchair, the energy supply from the wheelchair battery is controlled. This must also be able to be charged. Also take these necessary cords with you.
The equipment must be secured in the ambulance, in accordance with the ambulance protocol.
Preferably, a caregiver of the patient is present in the ambulance, because he knows the patient and can operate the equipment.
When requesting the planned transport, the applicant for the transport clearly indicates how the patient can be transported safely and whether and in what way ventilation in the ambulance should be continued.

	The submitting specialist is responsible for deciding that the patient can be transferred safely and who is competent to guide the patient. In the case of unplanned transport, the doctor or ambulance nurse concerned may contact the CTB doctor or CTB nurse for consultation. *The MICU is only intended for interclinical transport of ICU patients. As a starting point for an interclinical transfer, the level of care of the referring hospital is maintained along the way. For the patient who is not in need of ICU, regular ambulance care will usually suffice.* *The ambulance nurse determines whether a MICU should be used. This applies to both planned and unplanned transport. Deployment of a MICU for scheduled transport is rare.* *In order to make the ambulance services better prepared, it has been agreed that invasively ventilated patients will be reported by the CTB nurses upon discharge from the hospital*
Other guidance	NR
Broader SCI care pathways and supports	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Governance structure	**1 Home – Chronic Ventilation** ▪ *The CTBs are all affiliated with a teaching hospital, they are the pivot in the care of patients with (imminent) chronic total respiratory insufficiency, regardless of the underlying disease.* **4.2 What about appropriate support and care?** ▪ Responsibilities of the CTB: o Provides timely advice to the patient on appropriate support and care provision based on the patient's risk profile and coordinates this with the potential healthcare provider. o Informs the patient and his caregivers or care institution about changes in the patient situation that are relevant to the quality and continuity of required care / assistance. o Determines whether a patient can be discharged to the residence location, taking into account the facilities and care/assistance necessary to ensure the safety of the ventilated patient. o Transfers the relevant data for aftercare of the patient in the residence situation to the transfer nurse or medical social worker. ▪ Responsibilities of the care provider o Informs the patient and the CTB about the care/assistance offer and the associated response times for unplanned non-emergency questions and in emergency situations. o Assesses whether the patient can be accepted on the basis of the care/assistance that the CTB believes is necessary to ensure the safety of the ventilated patient. o Discusses with the patient and/or his relatives the quality of the offer in relation to the risks of the individual situation in relation to the quality of life and wishes of the patient. o Discusses the risks of a patient's choice that deviates from the CTB advice and records the interview and its results in the medical file. ▪ Agreement o Conclude an agreement between CTB and institutions in which patients with chronic ventilation reside in which mutual rights, obligations and responsibilities are named.

	○ *The patient has the right to choose. The healthcare provider assesses whether the patient can be accepted on the basis of the care/assistance that, according to the CTB, is necessary to guarantee the safety of the ventilated patient. In consultation, the patient and the provider can deviate from the advice of the CTB if certain circumstances give reason to do so. Both healthcare provider and patient thus take responsibility for the agreements made. If this entails additional health risks, the healthcare provider must be able to demonstrate that the patient is well informed about these risks and accepts them well. For example, by making a note in the patient's file.* ▪ Division of tasks ○ The hospital to which the CTB is affiliated has a clearly described division of tasks between the CTB and the transfer nurse. This transfer nurse is not about patients who start with chronic ventilation in another hospital. ○ The CTB informs the main practitioner of a patient who starts chronic ventilation in another hospital regarding the expected actions of the local transfer nurse. *Organizing care after discharge from hospital is often a complex matter. The organization of this differs per hospital. The transfer nurse (TFVK) plays an important role in a number of hospitals. In other hospitals this is done by the medical social worker (MMW) of the CTB. A care coach deployed by the patient can also play an important role or perform a number of tasks* *The hospital to which the CTB is affiliated has a clearly described division of tasks between the CTB and the TFVK* *Clear agreements are made at patient level in advance who will monitor progress, who will do what and how communication will take place. These agreements are recorded in the electronic patient file* ○ *The TFVK/MMW consults with the care recipient or his representative and coordinates the aftercare within the possibilities offered by the wishes of the patient, the medical condition, the support system, the law and the social card.* ○ *The above activities of the TFVK/MMW apply to patients who are admitted to the ward in the hospital where the CTB is housed. If a patient has been admitted to another hospital and the chronic ventilation has started there, the CTB gives advice on what should be arranged by the local TFVK. These tasks are therefore not done by the TFVK/MMW of the hospital to which the CTB is affiliated.* ○ *After a (temporary) admission to a rehabilitation centre and discharge to a new home situation (e.g. nursing home), admission and aids are arranged from the rehabilitation team.* *Tasks of the TFVK/MMW* ○ *Makes an inventory of the demand for care that meets the specific needs of the patient.* ○ *Consults with the rehabilitation team, if this is also involved.* ○ *Makes an inventory of what care can be offered by informal carers.* ○ *Makes an inventory of what other care is needed in addition to ventilation-related care.* ○ *Takes stock of whether there are any limiting factors in the patient's home and refers to relevant others such as occupational therapy and WMO.* ○ *Advises in consultation with the disciplines involved temporary aids for bridging and orders these, such as a high-low bed, a standard model wheelchair, end. from the ZvW in anticipation of resources from the WMO.* ○ *In consultation with the CTB, arranges the alarming within the patient's alarming possibilities.*

	○ *If necessary, find a suitable provider for home care and mediate in the necessary training of the home care team.* ○ *Handles the application for home care administratively and draws up execution requests.* ○ *Asks already deployed (contracted) home care organizations for form of financing (PGB or care in kind from ZvW / WLZ).* ○ *Supports if necessary when applying for an extension of the self-employed package, Meerzorg and extending zvw indication if that is the case.* ○ *If the patient is dependent on non-plannable care, in which care and proximity must be offered, the TFVK/MMW submits an application to the CIZ (Centrum Indicatiestelling Zorg) for the award of a WLZ indication with a care gravity package (ZZP). The patient must be informed in advance about the possibilities and consequences of a WLZ indication application. This information can be provided by the TFVK/MMW.* ○ *The advice of a rehabilitation doctor, specialist in geriatric medicine or CTB doctor (depending on the residence situation) is added as a medical basis. After receiving the indication, the TFVK/MMW arranges an admission to a nursing home or expansion of care at home.* **4.7 Who is responsible for the cannula care of patients with a cannula without ventilation?** ▪ Consider transferring patients with a tracheal cannula who are no longer ventilated to an ENT doctor for cannula care. ▪ The CTB accompanies patients with a trachea cannula who are no longer ventilated and still use a coughing machine. ▪ If possible, teach patients with a tracheal cannula who are no longer ventilated airstack as a replacement for using the cough machine. **5.3 What is the policy for complaints if the patient stays at home or in a healthcare institution to which no doctor is attached?** The general practitioner: ▪ can contact the CTB in case of medical problems that may (even if in doubt) be respiratory or respiratory related. ▪ treats himself or refers to a specialist for acute and non-respiratory or non-respiratory complaints. The patient contacts: ▪ the maintenance company in the event of purely technical problems of the technical equipment related to ventilation. ▪ the general practitioner in case of non-respiratory or non-respiratory-related medical problems. ▪ the CTB for non-acute respiratory and/or non-acute ventilation-related medical problems (also in case of doubt). ▪ *When patients stay at home or in a healthcare institution to which no doctor is associated, the GP is always the first point of contact for all acute medical matters. If the problem is not acute, but respiratory and/or ventilation related, the CTB is the first point of contact.* **5.5 In which hospital and in which department should a patient with chronic ventilation be admitted to the hospital?** ▪ In emergency care, the patient preferably admits to the nearest (regional) hospital, unless otherwise agreed due to complexity of the patient's illness.

- In the event of a respiratory or ventilatory problem, admit the patient to a department that specializes in monitoring and treating patients with a respiratory or ventilatory problem.
- Where possible, make use of your own healthcare providers during hospitalization. This applies not only to the nursing department, but also to medium care and intensive care.
- Responsibilities:
    - The doctor with whom the patient presents in the hospital as well as the doctor who takes over a chronically ventilated patient coordinates the specific aspects of the care for the chronically ventilated patient with the CTB doctor on duty and the patient
    - The treating medical specialist is the patient's main practitioner, unless the patient is admitted to a CTB department.

5.6 Who is responsible for adjusting the chronic ventilation?

- Adjust chronic ventilation only on the advice of or under the responsibility of the CTB doctor. This applies to all adjustments concerning the duration of the ventilation, equipment, interface or setting.
- Change the non-invasive ventilation to invasive ventilation or vice versa only during an admission.

6 Coordination in the care chain for chronic ventilation (organization of care)
Within the chronic ventilation chain, it is essential for the safety of the patient that there are clear and good agreements about responsibilities, coordination and information transfer. Patients with chronic ventilation have this ventilation on the basis of an underlying suffering, so that there are almost always several practitioners involved with the patient.
In order to prevent ambiguity and therefore dangerous situations for the patient, clear agreements must be made about main and co-practitionership, consultancy and about which information is essential to transfer. It must also be clear to the patient and his carers who, in each situation, is the contact person to be addressed.

6.1 How is the division of responsibility if the patient is in the hospital?

The main practitioner:
- is the specialist to whom the patient was referred and/or with whom the centre of gravity of the treatment lies or has been placed.
- is the responsible specialist for medical policy in general.
- is the primary point of contact with regard to the patient and the general practitioner.
- has a coordinating function towards fellow practitioners and consultants.

The CTB doctor is a co-practitioner for the problems surrounding chronic respiratory failure, including ventilation if the chronically ventilated patient is admitted by another medical specialist.

The co-practitioner is responsible for his part in the diagnosis, treatment, guidance and provision of information.

The main or co-practitioner can engage a consultant such as the CTB doctor for the purpose of the policy of a particular patient.

A consultant is a doctor of another specialty, engaged to obtain an opinion or advice on a certain aspect of the diagnostics, the therapy to be instituted, guidance and information provision.

6.2 How is the division of responsibility if the patient is staying at home or in a healthcare institution?
Responsibilities:

- The general practitioner is the main practitioner when a patient with chronic ventilation stays at home or in a healthcare institution to which no doctor is attached.
- When a patient with chronic ventilation stays in a healthcare institution to which a doctor is attached, this doctor is the main practitioner.
- In both situations, the CTB doctor is a co-practitioner in the field of the problems surrounding chronic respiratory failure, including ventilation.

6.3 How is the coordination and information transfer arranged?
Main practitioner:

- When referring, convey the information that there are specific circumstances due to chronic respiratory failure and chronic ventilation and that the CTB is a co-practitioner in this area.

- The general practitioner or the doctor associated with the care institution arranges that information is also available in the evenings and weekends so that the patient with chronic respiratory failure and chronic ventilation is adequately advised and treated.

6.4 What information should the lead practitioner receive from the CTB physician when treating a patient with chronic respiratory failure and chronic ventilation?

- The CTB provides the patient's main chronic ventilator with relevant information regarding risky and reserved actions, hospitalization policies and perioperative concerns.

Reserved and risky actions
In patients with chronic respiratory failure and chronic ventilation, healthcare providers sometimes need to perform reserved and risky actions. These acts fall under the BIG Act, art. 35 and 38. This concerns, among other things, the following actions:

Reserved acts:

- *changing the entire trachea cannula*
- *suction of the airways through a trache cannula*

Risky actions:

- *on and off the ventilation*
- *changing the inner cannula*
- *care of the tracheostomy*
- *setting up a speaking valve*
- *drip of physiological salt 0.9%*
- *inflating and emptying the cuff of the trachea cannula*
- *changing cannula strap*
- *touching on game meat around the trachestomy*
- *ballooning*

- *airstacking*
- *mechanical in-/exsufflation (treatment with the 'cough machine', the coughlator)*

The main practitioner is responsible for the expert and competent execution of the above actions. As a doctor, the main practitioner is authorised to perform these actions, but that does not automatically make him competent to do so. If these actions are delegated, the lead practitioner must ensure that the executive care provider, nurse or caregiver is competent and authorized to perform the actions expertly and safely. If necessary, the lead practitioner should ensure that supervision and interventions are possible.

The lead practitioner of a patient with chronic respiratory failure and chronic ventilation may be asked to sign an execution request for the reserved and risky actions that apply to the patient. This can also be done by the CTB doctor.
From a legal point of view, an execution request for risky actions is not necessary, but many healthcare providers /healthcare institutions find the clarity in the application process of an execution request for both reserved and risky actions outweigh the administrative burden.

Hospitalisation and discharge
When admitted to the hospital, the patient must always bring his own ventilator with accessories and the CTB folder. After all, chronic ventilation usually cannot be stopped for a few days or nights. In the unlikely event that the ventilation cannot be continued in the normal way for the patient due to the clinical condition of the patient, the patient must be monitored and ventilated respiratory in an Intensive Care (ICU) department or sometimes in another department with expertise in this area and the possibility of respiratory monitoring, for example Medium Care (MC) or pulmonary department, a.o. depending on underlying disease. See the module 'Chronic ventilation in the living situation'. In case of doubt about the need for this, telephone consultation with the CTB is recommended. Given its specific expertise, it is important that the CTB is involved in the assessment of whether staying in a department other than an ICU is safe and responsible. In principle, the latter is only possible if the clinical condition of the patient is stable. Conditions are that the patient is able to:

1. *carry out his ventilation as at home independently,*
2. *communicate and alert effectively and*
3. *simple ventilation-related problems to solve yourself.*

Another possibility is that the patient has his own healthcare provider who can operate the ventilation during the admission.

Every healthcare provider who takes care of the patient must have access to the telephone numbers through which the CTB can be reached. These numbers are listed in the CTB folder that the patient has with him.
More information about emergency care for muscle diseases can be found via https://spoed.spierziekten.nl/

For the continuity of adequate ventilation care at home, the CTB must be informed in good time of the intention to discharge the patient home. If the patient is discharged home, it is formally transferred back to the general practitioner or doctor attached to the healthcare institution, who in turn becomes the main practitioner. The CTB remains a co-practitioner and must also be informed about the course of the admission and dismissal with a written transfer and/or a letter of resignation.

Perioperative points of attention
The patient must have access to his own ventilators with accessories, if necessary, in advance, per- and postoperatively. It is important to realize that the patient with chronic respiratory failure and ventilation usually has no or limited respiratory reserve. In order for an operation to proceed safely with as little chance of respiratory complications as possible, a number of conditions must therefore be met:

1. *Normoventilation prior to the procedure, both during ventilation and during spontaneous respiration: PCO_2 4.7-6.0 kPa or 35-45 mmHg, unless the patient has not been normocapnic on a ventilator or breathing spontaneously. Think of patients with COPD. Verification is desired by means of a capillary or arterial blood gas analysis. The situation of optimal ventilation concerns both patients who are only ventilated at night and patients who are also ventilated during the day. If there is a suspicion of retention of bronchial secretion or incipient respiratory infection, elective procedures should be dispensed with, especially if invasive ventilation techniques are indicated.*
2. *The patient's location of the procedure may require a different interface (mask or cannula), ventilation setting or duration of ventilation. For example, an operation on the face can mean that the (mouth) nose mask temporarily no longer fits due to swelling. In the case of an operation on the nose, the patient can temporarily not be ventilated through the nose and should be adjusted to mouth ventilation a few weeks before the procedure. This should be done in consultation with the CTB.*
3. *The patient's posture during the procedure is important. In case of diaphragm weakness, flat supine position during spontaneous respiration is usually poorly tolerated. During regional anaesthesia in a flat supine position, the use of patients' own ventilators is therefore essential, whereby a different interface must be chosen depending on the procedure if necessary. During general anaesthesia, more pronounced gas exchange disorders should be taken into account than in non-respiratory threatened or non-respiratory insufficiency patients.*
4. *Postoperatively, (respiratory) monitoring of the ventilation and possible treatment in an ICU department is usually indicated. If chronically non-invasively ventilated (NPPV) and perioperatively endotracheally intubated patients can be extubated postoperatively, they should have clear awareness so that postoperative NPPV can be resumed in the PACU (Post Anaesthesia Care Unit) or in the ICU if necessary.*

Treatment
Because of the potentially breath-depressive effect of morphineomimetics, sedatives, anxiolytics and oxygen, this should be handled very cautiously. If this medication is still necessary, the ventilation should be monitored (pulse oximetry supplemented with blood gas analysis and observational breathing).

6.5 What can the main practitioner expect from the CTB of a chronically ventilated patient?

- The CTB is available 24 hours a day, 7 days a week.
- The main practitioner can easily fall back on the expertise of the nurses and doctors of the CTB or on-duty pulmonologist 24/7

7.1 What equipment and related technical equipment is used in the living situation with patients of the Home Ventilation Center?

What are the responsibilities with regard to purchase, use, replacement, updates, upgrades and preventive and corrective maintenance?

The hospital to which the CTB falls owns the ventilators and is responsible for their adequate functioning.

There is an agreement between the CTB and a certified supplier/certified maintenance company in which agreements are made about:
- instruction
- preventive maintenance - including (mandatory) safety updates,

	▪ the policy for resolving malfunctions. The maintenance company: ▪ performs periodic preventive maintenance in accordance with the factory specifications, ▪ performs any (mandatory) updates in coordination with the CTB within the time limits set by the manufacturer, ▪ records activities in the context of maintenance. The CTB can view these at any time. ▪ reports immediately (= same day) unsafe situations to the CTB. The CTB checks the maintenance company for the maintenance carried out. The mutual responsibilities between the CTB and the user are laid down in the CTB folder.
Funding model	**4.3 Who makes the application for placement in a nursing home or form of housing?** ▪ The patient or his legal representative applies for a WLZ indication for placement in a nursing home or form of housing. ▪ When staying in a hospital, the main practitioner provides the medical data to substantiate the WLZ indication application for nursing home admission or housing during hospitalization. ▪ In the home situation, the general practitioner provides the medical data to substantiate the application for the WLZ for nursing home admission or admission in a residential form. ▪ The CTB doctor reports the patient to the nursing home or form of housing with an adequate transfer of the ventilation-related care. *In general, a WLZ indication is necessary for placement in a nursing home or residential care centre. The patient or his legal representative makes this application for placement in a form of housing or nursing home. For this, supporting medical data are necessary. If during hospitalization it appears that the patient will have to move to a nursing home or form of housing, the main practitioner provides this medical data. In the hospital, it is customary for the placement support to be done by transfer nurses (TFVK) or a medical social worker (MMW). In consultation with the patient and the CTB, the TFVK/ MMW looks for a nursing home or form of housing with adequate ventilation care for the patient. If necessary, this is a bridging place until a place in the preferred institution becomes available or the 24-hour care at home is guaranteed.* *The CTB doctor is responsible for the registration with the nursing home or form of housing and ensures an adequate transfer of the ventilation-related care. It is customary for the nursing home to do an intake at the hospital or the patient's place of residence to get acquainted with the patient and to take note of the care intensity. In this visit, it is also assessed whether the patient's demand for care does not exceed the possibilities of the institution.*

	If at a later stage, if the patient lives at home with the ventilation, it is decided that the patient will have to move to a nursing home or form of housing, then the general practitioner and / or the rehabilitation doctor is responsible for providing the supporting medical data for the application for the indication.
Care pathways	**2.1 Which patient groups can be referred to a CTB for chronic ventilation and cough support techniques?** *There are four designated centres for chronic ventilation in the Netherlands. They are experts in the field of chronic respiratory failure, chronic ventilation and cough support techniques for certain patient groups. These CTBs use unambiguous criteria with regard to referral and indications for initiating chronic ventilation.* **1. Home –Chronic Ventilation** *Home ventilation centres (CTBs) have a central role in the chronic ventilation chain. The CTBs are all affiliated with a teaching hospital, they are the pivot in the care of patients with (imminent) chronic total respiratory insufficiency, regardless of the underlying disease.* *2.2 At what point can patients be referred to a CTB?* *Referrals to the CTB can be made electively from the outpatient setting or from the inpatient setting following an acute event. In the latter case, the CTB doctor visits the ICU for a consultation* *2.3 How can a patient be referred to a CTB?* *In most cases, the referral to a CTB is made via a referring pulmonologist, neurologist, intensivist or rehabilitation specialist or, where appropriate, a US (nurse specialist) or PA (physician assistant).* *The CTBs in the Netherlands are located in Groningen, Utrecht, Rotterdam and Maastricht. The four CTBs each serve a region. The postal code of the patient's residential address determines which CTB the patient is referred to* **2.4 When does the intake take place and which issues must be addressed during the intake so that the care recipient and care provider can make a joint decision about the follow-up process?** *The CTB sees the patient for an intake after referral* ▪ *within 2 weeks in patients with rapidly progressive disease* ▪ *within 2 weeks when the patient is admitted to a hospital and cannot be discharged, unless the patient does not yet meet the criteria for initiation on chronic ventilation.* ▪ *within 6 weeks in patients with a less rapidly progressive disease*
Education across the continuum of care	**8.1 What are the conditions for performing reserved and risky actions in patients with chronic ventilation?** ▪ Follow training on reserved and risky actions and the operation of the medical equipment. ▪ The CTB provides tailor-made advice on the patient's risk and the resulting recommendation for the content of the training. ▪ The CTB that treats the patient provides the execution requests regarding reserved and risky actions.

	▪ Consult the joint online education platform of the CPOs for up-to-date action schedules (www.ctbscholing.nl). ▪ In case of respiratory or respiratory problems, contact the CTB. Every CTB has a 24/7 on-call service. ▪ In case of technical problems and malfunctions, please contact the technical equipment maintenance company. This has a 24/7 availability service. *Patients with chronic ventilation are a relatively small group with very diverse conditions. In the case of chronic ventilation, care also includes reserved and risky actions, knowledge of equipment and emergencies.* *The basic training courses for professional caregivers (including nurses, doctors, caregivers) generally do not provide sufficient knowledge and skills for performing the necessary actions on a patient with chronic ventilation. Knowledge and skill in handling the specifically used equipment and acting in specific emergency situations is also not provided.* *Professional caregivers are those who work professionally in healthcare and are entitled to payment of wages. Non-professional care is support and care provided by informal carers (family members, neighbours, friends) and volunteers. The term 'non-professional care providers' does NOT give a value judgment, only the indication that the care is provided non-professionally. Informal carers who are paid from the PGB are seen as professional caregivers.* *<u>The BIG Act, reserved and risky actions</u>* *The BIG Act states that anyone may perform medical acts except the so-called reserved acts. These reserved acts may only be carried out by professions that have been declared competent. There are two groups of professionals. Independently authorized persons who may perform a reserved act on their own authority include doctors, dentists, physician assistants (PA) and nurse specialists (USA). In addition, there are people working in professions that are not independently qualified (for example, nurses). They do not set the indication but carry out these actions on behalf of an independently authorized person. They will receive an implementation request for this. In principle, all professionals may perform reserved actions provided that the legal conditions are met. These rules are laid down in Articles 35 and 38 of the BIG Act:* ▪ *the client (doctor/PA/VS) is expert and competent to make the indication;* ▪ *the client (doctor/PA/VS) gives instructions and ensures that supervision and intervention are possible, insofar as this is reasonably necessary;* ▪ *the client (doctor/PA/VS) determines that the contractor is competent to properly perform the reserved actions;* ▪ *the contractor (care provider) acts on behalf of the independently authorized;* ▪ *the contractor (healthcare provider) acts according to the instructions given;* ▪ *the contractor (healthcare provider) determines that he is competent to perform the reserved actions properly.* *For implementation in practice, this means that healthcare professionals can perform reserved actions if they:* *a. have a request from an independent competent, a doctor, PA or USA. This is called an execution request. This describes which reserved and/or risky actions must be performed on the patient in question;* *b. have an action schedule to carry out the actions;* *c. be competent;* *d. be able to reach the CTB nurse on duty in case of problems in the execution of the reserved and risky actions.*

For non-professional care providers, it applies that they do not fall under the BIG Act and may perform the actions at home provided that they are trained. However, it is important that both the care recipient and the care provider act carefully and that the care recipient agrees that the care provider performs the action. If a healthcare provider is going to perform a reserved action such as changing a tracheal cannula, careful preparation and execution are also necessary. That is why we apply ***the same*** *standards of care here as for professional care provision and incompetence is also unauthorized.*
In addition to reserved actions, there are also so-called risky actions.
These risky actions must be handled very carefully because of the risk to the patient in case of careless execution.

The table below provides an overview of reserved and risky actions with regard to ventilation and cough support techniques.

Type of ventilation		
Invasive	*Reserve*	*Risky*
	Sucking out the upper respiratory tract	*On and off ventilation*
	Changing the entire trachea cannula	*Ballooning*
		Dripping of physiological salt (0.9%)
		Inflating or emptying the cuff of the trachea cannula
		Care of the tracheostomy
		Changing the cannula strap
		Changing an inner cannula
		Treatment with the cough machine (= coughlator)
		Touching on wild meat around the tracheostomy
		Airstacking
		Setting up a speaking valve
		Cough machine treatment invasive
Non-invasive	*Reserve*	*Risky*
		On and off ventilation
		Airstacking
		Cough machine treatment non-invasive

<u>Handling of medical equipment</u>
Training of healthcare providers in the handling of medical equipment is a prerequisite for the expert and responsible use of medical technology. The covenant 'Safe application of medical technology in medical specialist care' (2016) sets conditions for the operation of medical equipment. As of 1 January 2016, all users must be demonstrably competent in accordance with the Assessment Framework of the Health and Youth Care Inspectorate, which is in line with this covenant.

<u>a. Execution requests</u>
According to the BIG Act, an execution request is only mandatory for reserved acts and not for risky acts. Execution requests are written out by the practitioner who delegates this action to a competent healthcare provider.
From the professional field, a clear process is valued and the CPOs also provide an execution request on request for risky actions.

b. Being competent

The CPOs have developed a joint training programme to enable healthcare providers and patients to become competent. See the module 'Setting up for chronic ventilation'.

Patients are different in terms of the risks they run and therefore also their care needs. Important here is the risk assessment of incidents, the severity of care and the response time. The CTB assesses this on the basis of the ventilation care profiles for chronic ventilation (VSCA, 2009) (see Annex II ventilation profiles). Based on the assessment of the risks, the CPOs give individual advice with regard to the training of care providers and the patient himself.

The CPIs provide information to patients and advice on the importance of adequately trained staff. Patients also need to know what risks they run and what good care must meet in order to make well-considered choices. In addition, they act as information carriers and sometimes as clients.

Although the CTB advice is very urgent, every person has the right to his own choices and the life of his life. Sometimes the right to one's own choices results in conflicting interests. Patients who knowingly want to take certain risks should not expect healthcare providers to go along with this if this exceeds their own limits or poses a risk to themselves.

It is of great importance for the safety of the patient with chronic ventilation that all those involved are aware of their responsibilities with regard to their competence, acquiring and maintaining their knowledge and skills:

- *The healthcare provider, whether or not BIG registered, is responsible for his own competence.*
- *The patient is responsible for the deployment of competent employees in the case of care providers paid from a PGB, PAB and / or volunteers / informal caregivers.*
- *The professional healthcare provider is responsible for the deployment of competent personnel.*

c. Action schedules

Action schedules are derived from the protocols of the CPOs and made suitable for healthcare providers outside the hospital. All reserved and risky actions must be carried out according to an action schedule. The four CPBs have developed a joint knowledge system on ventilation care, in which the jointly developed action schedules for reserved and risky actions can be found. See: www.ctbscholing.nl.

d. The CTB nurse on duty is available 24/7

A CTB nurse on duty is available 24 hours a day, seven days a week, and is available to patients, informal carers, caregivers, nurses and medics. A CTB or pulmonologist can always be reached as a rear guard.

Outside office hours, the CTB nurse is primarily the approachable person, in consultation with the CTB/pulmonologist.

The technical equipment maintenance company must be available 24 hours a day, seven days a week to resolve technical problems and malfunctions. The phone number of the maintenance company is located in the patient's CTB folder. The time within which the technical problem must be solved by repair or replacement is a maximum of four hours for life-supporting equipment. In case of doubt whether the problem is only technical, you can consult with the CTB.

8.2 What does the training consist of and who should be trained and tested?

- The training consists of the following components:
  - E-learning modules with theory, followed by a digital knowledge test.
  - Skills center or bedside teaching for non-professional caregivers.
  - Practical learning period (PLP).

- Assessment (practical test with the patient) only with professional healthcare providers.

- Caregivers who perform reserved and risky actions must be trained.
- Patients who are able to do so, in whom reserved and risky actions are performed must be trained.
- Test healthcare providers who perform reserved actions on patients with ventilator care. Incompetence is unauthorized.
- Test healthcare providers who perform risky actions on patients with invasive ventilator care.
- Test healthcare providers who use the cough machine on patients with respiratory care.

Chronic ventilation is very specialized and requires special training from the caregivers. This is not guaranteed in regular training courses. Ramsey ea (2018) and Kun ea (2015) describe the importance of proper training of caregivers with regard to incidents and calamities surrounding complex care.
The CPBs are centres of expertise for chronic ventilation. Based on this expertise, they provide the training so that the care providers receive expert and up-to-date training. The four CPBs are jointly responsible for the training programme for content, programme structure and functionality. This programme has been jointly developed. The e-learning results in fewer (scarce) personnel having to be deployed. The training programme and the implementation of actions are more unambiguous at national level. The collaboration is laid down in a cooperation agreement of the four University Medical Centers (May 2017), see www.ctbscholing.nl.

What does the training consist of?
A program has been developed with different learning lines for professionals and non-professionals. The theory that is offered is the same, but the way in which skills are acquired and tested is different. According to the legislation, there is no mandatory assessment for informal carers (non-professionals). In order to guarantee the quality of care, informal carers are urgently advised to follow the e-modules and the teaching material offered in the media library. On the basis of a checklist, the informal caregivers learn the actions so that they are carried out in the right way. After this, the informal carer may carry out these independently.
The education is modular and is offered with a combination of e-learning modules, classroom skills education and a practical learning period. In a module, the theoretical underpinnings and the skills training in the practical learning period are brought together into a learning unit. The content of the modules is linked to various ventilation-related themes, which in turn are derived from the training competency profile.
The handling of the equipment provided by the CTB is incorporated into the learning routes 'non-invasive ventilation', 'invasive ventilation' and 'cough machine' on the online platform.

The training consists of the following components:
1. *E-learning modules with theory, followed by a digital knowledge test.*
2. *Skills center or bedside teaching for non-professional caregivers.*
3. *Practical learning period (PLP).*
4. *Assessment (practical test with the patient) only with professional healthcare providers.*

Training and testing

To ensure that the actions are carried out properly by the care providers, training and testing is carried out.

- *In connection with the difference in risk, a distinction is made in testing between actions related to invasive and non-invasive ventilation: In the case of invasive ventilation, all actions are tested.*
- *The use of the cough machine is defined as high-risk and is therefore tested in both invasive and non-invasive ventilation patients.*
- *Operations on non-invasive ventilation and air stacking do not need to be tested.*
- *Care gravity plays an important role. A higher ventilation care profile increases the risk of the actions, more expertise is needed.*

<u>Who should be trained and tested?</u>
All caregivers who are not qualified and competent must be trained before performing reserved and risky actions. In addition, training must take place on the medical equipment to be used and how to act in emergency situations specifically aimed at chronic ventilation.

Patients should also be trained where they are able to do so, so that they are experts in the handling, medical equipment, risks and actions in emergency situations:

- *Some of the patients act as a client from a PGB/PAB and purchase their own care and must be aware of the requirements to be set.*
- *In practice, the patient is a carrier of information for his specific situation.*
- *An explicit condition of performing reserved actions by non-professionals is that the recipient agrees to this, for this the patient must be aware himself.*

8.3 By whom should be trained and tested?

Schooling:

- invasive procedures are performed by CTB nurses.
- non-invasive procedures are performed by CTB nurses or instructors of non-invasive ventilation.

Review:

- invasive procedures are performed by CTB nurses or delegated assessors.
- non-invasive cough support techniques are performed by CTB nurses or delegated testers.

In addition to being teachers, CTB nurses are also testers and assessors. CTB nurses themselves train caregivers in invasive ventilation care.
The CTB has trained and mandated skilled caregivers within a healthcare facility or with patients with their own care team as delegated assessors (GT) and instructors non-invasive procedures. Both also monitor the quality and continuity of ventilation care, supervise the learning process and are addressable persons for the CTB.
Delegated assessors may also test on behalf of the CTB and have been trained for this purpose by the CTB. They guide healthcare providers in the implementation of the care for chronically invasive and non-invasive ventilation and cough techniques. They test and assess these trajectories.
The instructors non-invasive procedures provide guidance on non-invasive ventilation, air stacking (AS) and treatment with the cough machine non-invasive (HMNI). They have successfully followed the non-invasive learning routes.

In the case of invasive ventilation, all actions are tested.
The use of the cough machine is defined as high-risk and is therefore tested in both invasive and non-invasive ventilation patients.
The CTB nurse agrees who the tester is when using the cough machine non-invasively.
The other care providers are tested by the delegated assessor or the CTB nurse if there is no delegated assessor (yet).

See www.ctbscholing.nl for a detailed description of the requirements for delegated testers and instructors non-invasive actions

	8.4 When and with what frequency is training needed? ▪ Repeat training and testing after three years.
Safeguarding and ethics	**2.4 When does the intake take place and which issues must be addressed during the intake so that the care recipient and care provider can make a joint decision about the follow-up process?** ▪ *Advance Care Planning (ACP) can be a good support aimed at supporting patients and their families by continuously re-evaluating the patient's perceptions and what are meaningful and achievable goals with regard to care and treatment.* ▪ *ACP anticipates the situation in which a decision must be made hastily or the patient is no longer able to indicate his wishes. This focuses not only on the physical domain, but also on the cognitive, emotional and existential problems*
Other supports	NR
Quality assurance processes	NR
Other guidance	**10. What does it take to transfer a child on chronic ventilation to a CTB adult?** ▪ Follow the recommendations of the Transition Care Quality Standard. ▪ Start transition as early as possible after the 12th year of life and with a plan. ▪ Start transition with the parents. ▪ Make an overview of all healthcare providers involved before and after the transfer. ▪ Invest in a warm transfer to the new main practitioner (usually general practitioner). ▪ School peers in ventilation care, so that they can go out with the young people as buddies. ▪ Make and communicate clear agreements about who to call for what in case of medical problems. ▪ Name who will direct the transition. ▪ Make and communicate clear agreements about the direction of young people who are not able to take control themselves.

Key: NR – Not Reported

Guidance document characteristics	
Endorsing Organisation/Author	Accident Compensation Corporation (ACC)
Title	Spinal cord injury guidelines
Country	New Zealand
Date Published	July 2017
URL	https://www.acc.co.nz/assets/provider/spinal-cord-injury-guidelines.pdf
National or regional	National
Adapted/adopted from previous guidance document? If so which guidance document was it adapted/adopted from?	In 2002 the New South Wales Motor Accidents Authority (MAA) released Guidelines for levels of attendant care for people who have a spinal cord injury. The MAA Guidelines have been used within the New South Wales Motor Accidents Scheme to determine care levels for people with a spinal cord injury living in the community. Since then, the 2002 version has been revised and superseded by the 2007 version. ACC obtained permission to use the MAA 2007 Guidelines on a temporary basis, while an expert informant group adapted the contents for New Zealand conditions.
Based on evidence synthesis?	Yes
Based on expert consensus?	Yes
Update(s) planned (including dates)	Not stated
Funding	Not stated
Certainty of evidence grading	N/A

Domiciliary invasive ventilation guidance	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Pre-transition phase	**Assessor instructions for using these guidelines** ▪ *Assessors must use the Serious Injury Support Needs Assessment form (ACC4202), which contains the FIM/FAM tools for determining the support needs of people with a spinal cord injury. Assessors should use the findings of their assessment to back up their professional advice about the amount (total number of hours) of attendant care likely to be needed by the injured person.* ▪ *Assessors should use the findings of their assessment to back up their professional advice about the amount (total number of hours) of attendant care likely to be needed by the injured person. Assessors should pay particular attention to the definitions in these Guidelines for:* o *Level 1 and Level 2 attendant care* o *Supervision* o *Active nights* o *Sleepover care* ▪ *If Level 2 attendant care is advised, then this will need to be corroborated by the information provided in the Functional independence measure (FIM) or Functional Assessment Measure (FAM) Score of 5 or Less section and the Medical Support Needs section on the Support Needs Assessment form ACC4202.*

- *Assessors' advice about the total number of hours of attendant care should be cross-referenced against the recommendations in these Guidelines ('Section 2: Client Circumstances' of the Support Needs Assessment form provides the relevant level of lesion and ASIA score information). The calculation of FIM/FAM scores should be double-checked for errors if the assessor's view of the amount of attendant care needed falls outside those recommended by these Guidelines.*
- *Assessors who propose attendant care hours above or below the levels recommended in these Guidelines must provide information in the Individual Home Support & Like Services section of their Support Needs Assessment that provide the reasons why an exceptional response is required. The information must include:*
  - *evidence about the person's individual circumstances that makes their needs for attendant hours different to a typical person with the same level of injury*
  - *evidence of what other alternatives to attendant care have been considered, and for what reasons those alternatives have been discounted.*

ACC staff instructions for using these guidelines

- *Before their first meeting with the client, Support and Service Coordinators need to access the client's medical notes for the level of lesion and ASIA score information, and then review the relevant section of the Guidelines to familiarise themselves with the nature of their client's injury.*
- *The client's first Support Needs Assessment needs to be completed as part of planning for discharge from the spinal unit or rehabilitation facility. Support and Service Coordinators need to carefully review the advice given in the assessment against the recommended number of hours of support given in these Guidelines. Support and Service Coordinators should pay particular attention to the definitions in these Guidelines for:*
  - *Supervision*
  - *Active nights*
  - *Sleepover care.*
- *These Guidelines do not have recommendations for hours of supervision as these are incorporated into the recommended hours for attendant care. The recommendations for the total number of hours of attendant care are given without specific reference to whether this care is at Level 1 or Level 2. A high proportion of Level 2 attendant care is to be expected for clients with spinal cord injuries at C1-C3, but would be exceptional for clients with an injury at C4 and below.*
- *Any advice that Level 2 attendant care is needed should be cross-checked with the evidence that the assessor has provided in the FIM or FAM Score of 5 or Less section and the Medical Support Needs section on the Support Needs Assessment form (ACC4202).*
- *When reviewing provider options for Level 2 attendant care, bear in mind that if family members are being considered they will need extensive additional training before they start providing attendant care, and they will require on-going supervision to ensure Level 2 standards of care are being provided consistently and reliably.*

Assessor advice for hours within guidelines

If the proposed hours of attendant care are within the parameters set out in the Guidelines, then move directly onto researching provider options for discussion with the client and their partner/family supporters.

Assessor advice for hours outside guidelines

If the proposed hours of attendant care are outside the parameters set out in these Guidelines, check the reasons why an exceptional response is required (refer to the 'Individual Home Support & Like Services' section on the Support Needs Assessment form). If the

	reasons are absent or insufficient, phone the assessor to obtain it. No additional fees will be paid to the assessor for this. Make sure the reasons justifying an exceptional response are properly documented and attached to the assessment for future reference. ***Factors that affect attendant care*** *Factors that may reduce the amount of attendant care* *Factors that may reduce the amount of attendant care below the recommendations in these Guidelines include:* ▪ ***Increased functional independence*** *from the rehabilitation process, and adjustment over time to the injury, can decrease the amount of attendant care.* ▪ ***Individual choice****. Allowance must be made to enable an individual to exercise choice. For example an individual may choose to carry out a task with less assistance, although assistance is available, and the task takes a longer time to complete; or, an individual may choose to restrict the number of agencies involved in providing their support.* ▪ ***Being a young adult*** *is a time of increased independence away from the family and social activity where the person would be expected to start accessing some levels of natural support from their peers and the wider community.* ▪ ***Living situation****. A highly modified environment or moving into a shared household where the other residents share some domestic tasks can reduce the requirement for support. Unsuitable accommodation can increase the need for support.* ▪ ***Assistive technology and modified equipment*** *for communications and transport can increase a person's independence and reduce their reliance on an attendant carer to perform these tasks for them.* *Factors that may increase the amount of attendant care* *Factors that may increase the amount of attendant care above the recommendations in these Guidelines include:* ▪ *The period* ***following initial discharge*** *from hospital until a home routine is established.* ▪ ***Age at time of injury.*** *An older individual may have different support requirements than a younger person with the same level of injury. For example, an older person may not have the same level of upper body strength as a young person with the same level of injury and thus may require human assistance with wheelchair transfers.* ▪ ***Body weight, strength and body shape*** *e.g. extra personnel may be required to safely assist with transfers.* ▪ ***Sleepover care*** *may be required if the person has autonomic dysreflexia and lives alone. A person who experiences autonomic dysreflexia should have a medical assessment by a spinal cord injury specialist to determine if sleepover care or registered nursing care and supervision are necessary.* ▪ ***Medication****, including the administration and side effects of medication.* ▪ ***Co-existing conditions****, such as arthritis, obesity, depression, spasms, contractures, pressure sores, spinal syndromes, or poorly controlled neuropathic bowel dysfunction.* ▪ *The period following* ***hospitalisation, surgery, or acute treatments****.* ▪ ***Major life transitions*** *such as the loss of employment, moving from school to work, relationship difficulties, illness, loss of informal support system, death/separation/divorce or retirement. However, attendant care should only be considered as a last resort after more appropriate responses such as referral to a psychologist or counsellor have been tried and have proved to be not viable* ▪ ***Ageing*** *– general and specific factors related to the disability. For example, a person who has been independent in transfers and has used a manual wheelchair may over time develop early onset of arthritis or over-use syndrome because of the additional strain on their arms.*

	▪ ***Pregnancy*** ▪ ***Responsibility for children****. There may be a need for greater flexibility in hours and the provision of services.* ▪ *Access to* ***all appropriate support****, eg housing modifications* ▪ ***Geographical location of the individual*** *e.g. increased travel time to specialist appointments and access to community facilities.* ▪ ***At work, school or study****, if the appropriate level of support cannot be provided by the facility.* ▪ *The person's potential function should be considered against their life factors and the need to* ***conserve energy*** *for more intensive functional tasks and / or the prevention of overuse injuries. For example, a person may choose to use their energy to participate in work and therefore requires attendant care on work days, despite being capable of independence in that area.* ▪ ***Potential for harm*** *– some people can actually harm themselves by doing things independently that other people with the same level of injury would have an attendant carer support them with. For example, a person transferring independently can inadvertently damage their skin through a shearing motion, which they don't notice because of lack of sensation. If this person also has very little attendant care, the damage may go unnoticed for some time, thereby risking infection and major skin breakdown.* ▪ *Extreme independence leading to possible* ***self-harm*** *should be considered before approving any request for amounts of attendant care significantly below the recommendations in these Guidelines.* ▪ *Conversely, some people may ask for an attendant carer to help them with tasks that others with the same level of injury carry out independently. In such cases, options for building up the person's confidence and belief in their abilities, and some social contact with others with a similar level of injury would be a more appropriate response than increasing the amount of attendant care.* ***Recommendations for attendant care*** *The recommendations are based on:* ▪ *the level of injury to the person's spinal cord* ▪ *an assessment of the person's upper extremity motor function and related motor scores using the American Spinal Injury Association (ASIA) Standard Neurological Classification of Spinal Cord Injury* ▪ *an assessment of the person's ability to walk.* *The recommended hours of human support are for a 'typical' person with a spinal cord injury who lives independently (alone or with others) in the community in an appropriately modified environment. When assessing a person's support needs, individual circumstances will always need to be taken into account. There are a range of factors that can put a person outside the range typically required by people with the same level of injury.*
Transition phase	NR
General principles of home mechanical ventilation	NR
Technical requirements	NR
Staffing	**Active nights** This refers to the continuous or regular attention by an attendant care worker to perform such tasks as ventilator management or tracheal suctioning throughout the night. The attendant care worker must be awake throughout the night. Active night care is

definitely required on a permanent basis by people with a lesion at C1-C3 and an ASIA score of A. This requirement has been built into the guideline's recommended total hours for attendant care.

Attendant care

Attendant care is a technical term that describes the support that a person with a spinal cord injury needs, in order to do tasks they would have been doing for themselves prior to their accident. The legislation that ACC operates under (the Accident Compensation Act 2001) defines attendant care as

- personal care (physical assistance to move around and to take care of basic personal needs such as bathing, dressing, feeding, and toileting)
- assistance with cognitive tasks of daily living such as communication, orientation, planning, and task completion
- protection of the person from further injury in his or her ordinary environment
- attendant care does *not* include child care, domestic activities, or home maintenance.

ACC distinguishes between two types of attendant care, according to the client's level of medical and behavioural needs. Level 1 attendant care is what people with a spinal cord injury will typically require in most circumstances. Level 1 attendant care includes:

- assistance with undressing and dressing, transferring into and out of the bath or shower, washing and drying, hair washing and monitoring the condition of skin/scalp
- assistance with personal grooming activities, hair maintenance, teeth cleaning, cleaning & trimming finger/toe nails
- assistance with eating and drinking, observing and monitoring food intake, helping with sticking to special diets, preparing food, ensuring the person is positioned correctly and has access to any specialist utensils needed
- assistance with transfers to and from the toilet/commode and hygiene activities, assistance with the use of appliances and aids such as day/night urinary collection bags and associated hygiene
- transferring from bed to wheelchair and vice versa, ensuring safe mobility around the home including making sure aids such as walking sticks, frames and wheelchairs are maintained and safe
- physically assisting the person's mobility inside and outside their home
- coaching in activities of daily living, in conveying and receiving information and interacting with other people
- developing personal skills such as planning, communication, task completion, and maintaining emotional control
- giving support to protect the person from further injury in their normal home environment.

Level 2 attendant care includes all of the above activities, but due to the injured person's high medical or behavioural needs, the complexity of all of these tasks is greatly increased. The consequences of performing these tasks incorrectly are usually severe and prolonged for the injured person. Therefore, providing Level 2 attendant care requires a level of knowledge and skill that is equivalent to that possessed by a *registered nurse.*

C1-C3 ASIA A or B recommendations

<u>Levels of human support</u>

Home nursing: 2 to 5 hours per week

- For a medically stable person who is receiving attendant care services, routine monitoring visits and clinical interventions by an appropriately skilled registered nurse are required. This would include catheter changes, skin integrity checks, medication review, trachea tube changes and identifying and addressing training needs.

Attendant care: Minimum 190 hours per week/28 hours per day

	▪ Total required support is 28 hours daily. This level of support for adults is based on 24-hour active care, plus additional: o two hours (morning care for bowel management, showering, grooming, transfers) o one hour (afternoon care for transfers and skin integrity) o one hour (night-time care for transfers, skin integrity, and settling). ▪ If the person is medically stable, attendant care is generally provided under the supervision of a registered nurse, by people who have successfully completed competency-based training. The competency-based training needs to cover: o administration of medication o autonomic dysreflexia o bagging o bladder management – female/male catheterisation and supra-pubic catheterisation o bowel management o emergency tracheostomy change o equipment use and maintenance o oxygen therapy o percutaneous endoscopic gastrostomies (PEG) feeding o respiratory function o skin integrity o spinal cord injuries o suctioning o tracheostomy care ventilator management and failure. ▪ If the treating team identifies that the person is significantly medically unstable (eg with severe dysreflexia) this situation may best be managed with appropriately skilled registered nurses providing all attendant care. However, there may be some circumstances where this level of care is not available (eg in remote geographic areas). In all cases, access to a registered nurse for support and advice is required at all times with all programs routinely and regularly reviewed by an appropriately skilled registered nurse. Each situation requires individual assessment of needs and circumstances. Support arrangements should always be negotiated with the family as they may wish to have some family time with minimal staff disturbance. Home help: 5 to 12 hours per week ▪ These duties may include meal preparation, personal laundry, shopping (with the person) and specific household tasks. If the person is medically stable, these routine daily domestic duties can be performed by a home helper without any additional training. It is recommended that the home helper be provided with a contact system such as a. transportable intercom or monitor that they carry with them. Community access: 0 to 7 hours per week ▪ A second person is required as a driver for all community access for people who require ventilator support. The other hours are highly variable depending on the individual's age, lifestyle, and the amount of support the activity requires (eg playing cards, fishing, going to the movies, socialising with friends). Child-care services, educational support and vocational support

	▪ The categories of child-care services, educational support, and vocational support have not been allocated a range of support hours. The support requirements in these categories are very specific to the individual's circumstances and should be based on a specialist assessment of the individual's needs. For example, if eight hours of educational/vocational support is required at an education facility or workplace, there is likely to be a reduced need for domestic meal preparation in the home.
Monitoring	NR
Infection prevention and control	NR
Other guidance	NR
Management of SCI complications	
Topic	Recommendation/criteria (Source, Certainty of evidence (if applicable))
Respiratory	NR
Bladder	NR
Bowel	NR
Skin	NR
Sexual health	NR
VTE	NR
Pain	NR
Autonomic dysreflexia	NR
Emotional wellbeing, mental health and substance abuse	NR
Cardiometabolic and nutrition	NR
Bone Health	NR
Palliative care	NR
Rehabilitation	NR
Wheeled mobility	Mobility ▪ Full assistance required for all transfers – including use of a hoist with 1-2 assistants – due to a range of factors such as the weight of the person and spasms ▪ Possible ability to manoeuvre power chair with head, chin, or sip control or other adaptive device Full assistance required with transport.
Other guidance	Personal care activities ▪ Full assistance required for bowel/bladder management, bathing/showering, lower body dressing and upper body dressing. Daily living activities ▪ Full assistance required with all domestic duties ▪ Range of abilities varies from limited to good use of head mouse for computers, keyboards, telephones, turning pages and environmental controls ▪ Range of assistance required varies from full assistance to independence when using communication technology, depending on workstation set-up and equipment availability

	▪ Likely to require housing modifications to resolve barriers to getting into, out of and around the home (for example, more space to accommodate the turning radius of a power wheelchair), space to accommodate equipment (for example, electric bed), and appropriate facilities to maintain personal hygiene and address issues around body temperature regulation and personal safety ▪ Transport via motor vehicle will require either a mobility taxi or travel as a passenger in a vehicle that provides accessibility, safety during transportation, and adequate room for equipment.
Broader SCI care pathways and supports	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Governance structure	NR
Funding model	NR
Care pathways	NR
Education across the continuum of care	NR
Safeguarding and ethics	NR
Other supports	NR
Quality assurance processes	NR
Other guidance	NR

Key: NR – Not Reported

Guidance document characteristics	
Endorsing Organisation/Author	Butna et al & Minister of Health (Poland)
Title	Practical aspects of nursing care provided to patients diagnosed with amyotrophic lateral sclerosis receiving home mechanical ventilation & Amendment of the Regulation on guaranteed benefits in the field of nursing and care services as part of long-term care†
Country	Poland
Date Published	10 Jul 2014
URL	Review article (https://journals.viamedica.pl/palliative_medicine_in_practice/article/view/69905) & Regulations (https://www.prawo.pl/akty/dz-u-2014-960,18112991.html)
National or regional	National
Adapted/adopted from previous guidance document? If so which guidance document was it adapted/adopted from?	Review article refers to Amended 2014 Regulations
Based on evidence synthesis?	N/A
Based on expert consensus?	N/A
Update(s) planned (including dates)	N/A
Funding	N/A
Certainty of evidence grading	N/A

Domiciliary invasive ventilation guidance	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Pre-transition phase	▪ The qualification should be carried out at a hospital department due to the possibility of fully monitoring the implementation of mechanical ventilation which ultimately is to be carried out in the home environment. The physician conducts a physical examination involving the assessment of the patient's general health and assesses arterial blood gas results, pulse oximetry, capnometry and polysomnography results enabling the assessment of the patient's respiratory function which informs the decision whether or not to qualify the patient for home ventilation. ▪ Before the patient leaves the hospital department, it is vital that initial training is provided to the patient's future caregivers on the most important issues related to the care of a ventilated individual. It is also necessary that the patient's place of stay is prepared in advance in terms of logistics and organisation, for example, that disposable equipment is provided such as suction catheters for clearing bronchial secretion and tracheotomy tubes. The family and caregivers declaring the willingness to provide care are required to sign a questionnaire of informed consent to provide care for a home-ventilated patient (NIV or IV) in

	accordance with the principles outlined by a particular home ventilation centre and submit a written certification of their skills acquired in the field of providing care for a mechanically ventilated individual.
Transition phase	NR
General principles of home mechanical ventilation	NR
Technical requirements	▪ The nurse's role is to provide the appropriate amount of equipment necessary to care for a patient subject to invasive ventilation in the home setting. The family and caregivers should be aware of the location of equipment necessary for patient care in the house, be properly trained in the use of such equipment and recognise that, in certain situations, the patient's life may depend on it, which is also the nurse's responsibility. ▪ It is recommended to have a set of equipment for tracheotomy tube replacement (tube, syringes, gel, sterile gloves) prepared and in sight at all times. The family should be prepared for the necessity to perform immediate tracheotomy tube replacement in the event of its obstruction. The patient's house should also be equipped with a bag valve mask and a manual aspirator in case the electric one fails ▪ The 2014 Regulations as amended specify that in order for home benefits for home mechanically ventilated adults to be guaranteed, there were certain requirements regarding medical and auxiliary equipment, housing conditions and other conditions: o At the place of stay of the recipient: ▪ a) a respirator equipped with: – ▪ battery allowing: free use of a wheelchair, maintaining the operation of the respirator for up to 4 hours, ▪ air filters in the system, ▪ a set of adjustable parameters, ▪ 2 alarms: disconnection of the system and excessive pressure in the respiratory tract, ▪ b) aspirators – depending on the patient's needs, ▪ c) tracheostomy care kit – depending on the patient's needs, ▪ d) equipment necessary for the operation of the respirator, including single use, ▪ (e) pulse oximeter, ▪ (f) a self-expanding breathing bag with a one-way valve and a face mask; o At the place of service provision ▪ a) portable ECG apparatus, ▪ (b) a medical first aid kit, ▪ (c) a nurse's bag for each nurse equipped with: ▪ basic disposable equipment and materials, including a set for injection, transfusion fluid transfusions, dressing kit, set of basic surgical instruments, protective package, ▪ a set for inserting and removing the tube and for feeding through a tube, stoma, ▪ a set for feeding through the fistula and fistula care, ▪ a set for inserting, rinsing and removing the catheter, ▪ disinfection package, ▪ anti-shock kit, ▪ glucometer,

	▪ thermometer ▪ apparatus for measuring blood pressure, ▪ a set for performing hygienic and care treatments and activities, ▪ personal protective equipment: aprons, masks, gloves. o In terms of housing there must be: ▪ 1. a room adapted for office purposes and for the storage of medicines, dressing materials and medical equipment ▪ 2. be able to provide telephone contact
Staffing	▪ In the case of non-invasive ventilation, one healthy caregiver is required, while at least two are required to care for an invasively ventilated patient. ▪ Application of IV indicates that at least two trained caregivers are needed. It is often the case that one family member has to quit their job, which can decrease the family's financial resources. ▪ The 2014 Regulations as amended specify that in order for home benefits for home mechanically ventilated adults to be guaranteed, staff with a certain qualification were required to be involved in the care of the patient: o Doctor with: ▪ 1) specialist in the field of: anaesthesiology or anaesthesiology and resuscitation, or anaesthesiology and intensive care, ▪ or 2) a specialist in the field of: anaesthesiology or anaesthesiology and resuscitation, or anaesthesiology and intensive care and neurology or lung diseases, ▪ or 3) a specialist in the field of: anaesthesiology or anaesthesiology and resuscitation, or anaesthesiology and intensive care and a doctor with a first degree specialization in the field of: anaesthesiology, or anaesthesiology and resuscitation, or anaesthesiology and intensive care or neurology or lung diseases, ▪ or 4) a specialist in the field of: anaesthesiology or anaesthesiology and resuscitation, or anaesthesiology and intensive care and a doctor in the course of specialization in the field of: anaesthesiology and intensive care or neurology or lung diseases. o Nurse with: ▪ one year's work experience and completed a specialization or qualification course, or during these specializations or courses: • 1. in the field of anaesthetic and intensive care nursing, • or (2) in the field of palliative care, • or (3) in the field of long-term care, • or 4. in the field of nursing for the chronically ill and disabled, • or 5) specialized in palliative care or caring for a mechanically ventilated adult patient, or caring for a mechanically ventilated child o Other staff: ▪ A person conducting physiotherapy. ▪ In relation to the care of those requiring home invasive mechanical ventilation, the Regulations stipulate a minimum of; ▪ a) medical advice at the recipient's home not less than 1 time per week – for each recipient and constant availability in shift or on-call system

	▪ b) nursing visits not less than 2 times a week – for each recipient and constant availability in shifts or on call telephone system ▪ c) visits of the person conducting physiotherapy, not less than 2 times a week – for each recipient ▪ (the maximum frequency and overall number of home visits referred to in points (b) and (c) shall be determined individually by the doctor providing the guaranteed benefits to the recipient).
Monitoring	NR
Infection prevention and control	NR
Other guidance	NR
Management of SCI complications	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Respiratory	NR
Bladder	NR
Bowel	NR
Skin	NR
Sexual health	NR
VTE	NR
Pain	NR
Autonomic dysreflexia	NR
Emotional wellbeing, mental health and substance abuse	NR
Cardiometabolic and nutrition	NR
Bone Health	NR
Palliative care	NR
Rehabilitation	NR
Wheeled mobility	NR
Other guidance	NR
Broader SCI care pathways and supports	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Governance structure	NR
Funding model	▪ The home care of a mechanically ventilated patient is a service contracted by the Polish National Health Fund carried out by specialised long-term care centres providing professional medical care and necessary equipment ▪ The 2014 Regulations as amended outline the conditions required for the provision of guaranteed services in the field of nursing and care services as part of long term care.
Care pathways	NR
Education across the continuum of care	▪ It is also the nurse's responsibility to provide the caregivers with all necessary theoretical and practical information. The nurse educates the caregivers in the scope of monitoring the patient condition using a pulse oximeter and interpreting the measurement results, performing tracheobronchial toilet preserving the safety precautions, ventilating the patient with a bag

		valve mask, recognising symptoms of tracheostomy tube obstruction or leaking balloon/cuff, replacing the tracheostomy tube in the event of its obstruction, interpreting ventilator alarms and implementing actions to eliminate causes of such alarms. Proper education of caregivers ensures safety of the patient. It should be noted that, in the event of a sudden deterioration of the patient's health, the caregivers are obliged to call an ambulance. Due to significant motor deficits, patient care also includes provision for full-body hygiene and toileting, as well as pressure ulcer prevention
Safeguarding and ethics	NR	
Other supports	NR	
Quality assurance processes	NR	
Other guidance	NR	

Key: † This document which focused on ALS was included as it had criteria that were relevant for invasive mechanical ventilation regardless of diagnosis. NR – Not Reported

Guidance document characteristics	
Endorsing Organisation/Author	Swiss Society of Pulmonology/ Janssens
Title	Long-Term Mechanical Ventilation: Recommendations of the Swiss Society of Pulmonology
Country	Switzerland
Date Published	10 Dec 2020
URL	https://www.karger.com/Article/FullText/510086
National or regional	National
Adapted/adopted from previous guidance document? If so which guidance document was it adapted/adopted from?	Update of previous recommendations published in 1996, 2006 and 2010 by theThe Swiss Society of Pulmonology (SSP) and the Swiss Society of Pediatric Pulmonology
Based on evidence synthesis?	Yes
Based on expert consensus?	Yes
Update(s) planned (including dates)	NR
Funding	NR
Certainty of evidence grading	NR
Domiciliary invasive ventilation guidance	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Pre-transition phase	**8. Transition between Acute Care and Home (or Long-Term Institution)** Success of long-term home [NIV (or NIV in a heath care institution)] depends on appropriate preparation and timing of the transition, anticipation of present and future requirements in terms of environment and training of caregivers, and anticipation of disease progression. Providing appropriate psychological, social, and financial support for the family and caregivers is also of major importance. A multidisciplinary assessment and preparation of the transition to home care is necessary to include all the possible aspects of patient management in his/her new environment. Practical teaching should be started early and performed throughout the hospital stay for caregivers and level of competence and understanding should be regularly assessed by the hospital team. A checklist may be useful to ensure coverage of all necessary tasks to be performed at home. Evaluating the adequacy and ergonomics of the home environment, and, if necessary, performing the required changes, must be organized with the social workers, ergotherapists and physical therapists/physiotherapists **Table 6: Goals for transition from hospital to home care (or institution)** ▪ Ventilator settings must provide the best possible control of alveolar hypoventilation (monitored by PtcCO2 and/or ABG) ▪ Patient is stabilized, and comfortable with his/her home ventilator

	▪ The patient or his/her caregivers are autonomous in putting on and taking off the mask and in maintenance of the equipment (cleaning, use of the humidifier, etc.) ▪ Necessary home care is organized (intervention of nurses, other healthcare workers [HCWs], chest therapists, physical therapists, technical control of ventilator and other devices) ▪ Home caregivers have been trained for all technical tasks, and written support is provided ▪ Professional support can be reached 24 h/day and 7 days/week to provide appropriate guidance ▪ When required, backup equipment is immediately available on site ▪ Financial aspects are covered, and patient and/or his/her family are not exposed to a burden they cannot face Home healthcare providers must ensure that: ▪ they have been extensively informed of all relevant items regarding patient and treatment before he/she is transferred ▪ all caregivers (GP, pulmonologist, chest therapist, etc..) are identified, and that all necessary contact information is in their possession ▪ they have enough qualified/trained HCWs to provide a high level of care with substitutes in case of leave absences, sickness leaves, etc. ▪ they offer a hotline for technical support 24/24 h 7/7 day ▪ they will provide regular feedback to the pulmonologist in charge, as well as results of tests agreed upon with the treating pulmonologist (i.e., pulse oximetry, data from ventilator software, transcutaneous capnography, etc.) ▪ HCWs within the Health Care Provider organization receive regular and structured training in the field of management of chronic respiratory failure
Transition phase	NR
General principles of home mechanical ventilation	NR
Technical requirements	**7.4.3. Consequences of TPPV (Long-term positive pressure ventilation via tracheostomy)** To improve quality of life, mobility is an important aspect for patients on TPPV. Therefore, 2 ventilators, of which one is portable or attached to an electrowheelchair should be available. These ventilators must have built-in batteries that allow a safe mobility for several hours. **7.4.4. Practical Aspects** *Cannula and cuff.* Different cannula types are available (length, angle, diameter, flexible vs. rigid, with and without cuff, fenestrated vs. closed). The choice of the right tracheal cannula size and length is important to avoid leakage and damage to the trachea. Regular change of the outer tracheal cannula should be performed, at least initially, by an experienced team. Typical intervals are 6–8 weeks but depend on the amount of secretions and other aspects (e.g., local pain). A replacement tracheal cannula of the same size and of a smaller size should always be available. Inner cannulas are often changed several times a day. An inflated cuff reduces the risk of aspiration but cannot reliably protect from this complication. Conversely, an inflated cuff can cause pressure ulcers and compromise swallowing. It is recommended to apply a low cuff pressure that is periodically monitored, and to avoid permanent cuff inflation. A tracheotomy affects swallowing and speech. In the initiation phase of TPPV, intensive training of laryngeal function and speech training while the cuff is deflated are important. Some patients with preserved bulbar function may not need a cuffed tracheal cannula or require TPPV with an inflated cuff only during sleep. When a cuff is inflated and seals the trachea properly, secretions cannot enter the lower airways. However, if patients cannot swallow secretions, they may accumulate above the cuff balloon. This results in

	desensitization of the cough reflex in the upper airway and larynx. A deflated cuff allows airflow towards the upper airway for speaking and coughing. It is important that the tracheal cannula chosen is thin enough to allow air passage to the upper airway while the cuff is deflated, especially during use of a one-way speech valve (Passy Muir® or similar valve). Application of a speech valve while the cuff is inflated can be life-threatening since only an inward flow is possible. If a fenestrated cannula is used, both a closed and a fenestrated inner cannula must be available. When using the fenestrated inner cannula and a deflated cuff together with a speech valve, phonation is facilitated due to air flowing around the cannula and through the fenestration towards the larynx. *Circuits.* Different circuits (single- vs. double-limb) are available for TPPV. Both a single-limb non-vented circuit with an exhalation valve (active circuit) or, less commonly, an intentional leak connector (passive circuit) and a double-limb circuit with separate inspiratory and expiratory limbs are available for TPPV. Separate in- and expiratory limbs allow a reliable quantitative monitoring of VT, minute ventilation, and leaks. However, a single-limb circuit is easier to handle. *Ventilators.* Different life-support ventilators are available for invasive HMV. 2 ventilators are mandatory for security reasons in highly dependent patients. Different settings for day- and night-time may be used. Pressure-controlled ventilation (PCV) or volume controlled ventilation are more commonly used than PSV in TPPV. A target-volume might be set in addition to pressure modes, but advantages of this have not been demonstrated so far. Specific alarms are available for invasive ventilation with life-support ventilators. Noteworthy is the fact that VT and VE cannot be accurately measured when cuff is deflated (unintentional leak through upper airway): this impairs alarm functions. *Humidification.* Heated humidification is standard in invasive HMV during the night to avoid desiccation of the airways and thus bleeding and obstruction with mucus plugs. However, humidification is seldom feasible in patients who are mobile in a wheel-chair: in this situation heat- and moisture-exchanging filters are sufficient in most cases. *Suctioning and mechanical in-/exsufflation.* Suctioning of the upper and lower airways is routinely performed in TPPV. Deep suctioning should be limited because of the risk of mucosal lesions. Chest physiotherapy (assisted cough techniques) and mechanical in-/exsufflation with a Cough assist are important adjunctive measures to mobilize peripheral secretions towards the central airways. **7.4.5. Special Considerations in Spinal Cord Injuries** As in all ventilator-dependent patients, a second device is always necessary if daily requirement for ventilatory support is ≥16 h. This is also the case if the patient needs a ventilatory support during daytime while using an electric wheelchair, to enhance mobility and autonomy. Indeed, ventilator settings in a sitting position may differ from those used supine, and repeated dismantling and reinstalling of ventilators on a wheelchair may cause a safety problem. In this case, a built-in battery with a sufficient autonomy is necessary ("life support device") and a supplementary battery may be required
Staffing	NR
Monitoring	**7.4.5. Special Considerations in Spinal Cord Injuries** In all patients with spinal cord injury and ventilatory support, a regular follow-up is required, initially at 3- to 6-month intervals, and subsequently once or twice a year
Infection prevention and control	NR
Other guidance	NR

Management of SCI complications	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Respiratory	**5.5. Mechanical Insufflation/Exsufflation in NMD** The SIG suggests the following recommendations for implementing the use of MIE: ▪ In all cases, clinical assessment is mandatory, and MIE devices may be considered as necessary irrespective of cough peak flow values. ▪ The indication for MIE is based on the inability to clear secretions in an effective manner (clinical assessment) and measurements of the cough peak flow: ○ 270 L/min: cough is probably efficient. ○ 160–270 L/min: cough may be inefficient; it is mandatory to instruct the patient and caregivers on appropriate assisted cough techniques and, if they fail, to evaluate MIE devices. ○ <160 L/min: spontaneous cough is most probably inefficient to clear secretions from the airways, and the use of assisted cough techniques is mandatory. If they fail or are not feasible, MIE devices are necessary
Bladder	NR
Bowel	NR
Skin	NR
Sexual health	NR
VTE	NR
Pain	NR
Autonomic dysreflexia	NR
Emotional wellbeing, mental health and substance abuse	NR
Cardiometabolic and nutrition	NR
Bone Health	NR
Palliative care	NR
Rehabilitation	NR
Wheeled mobility	NR
Other guidance	NR
Broader SCI care pathways and supports	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Governance structure	**1.9. Where, How and by Whom Should Home NIV Be Implemented and Followed?** In Switzerland, long-term HMV, irrespective of the diagnosis or setting, must be prescribed by a certified pulmonologist who can initiate the treatment and provide appropriate instruction to the patient and caregivers. The indication for HMV is usually reviewed by the medical advisor of the medical insurance **7.4.4. Practical Aspects** In general, TPPV patients and patients with an anticipated ventilator dependency should be managed in a specialized tertiary center by a multidisciplinary team. A specific knowledge of circuits, cannulas, humidifiers, ventilators, speech functions, and TPPV-associated complications is mandatory.
Funding model	NR

Care pathways	NR
Education across the continuum of care	**7.4.3. Consequences of TPPV (Long-term positive pressure ventilation via tracheostomy)** Specific, formal lay person training programs exist for instance in France and Germany but not in Switzerland
Safeguarding and ethics	NR
Other supports	NR
Quality assurance processes	NR
Other guidance	NR

Key: NR – Not Reported

Guidance document characteristics	
Endorsing Organisation/Author	British Association of Spinal Cord Injury Specialists
Title	Service Specification: Spinal Cord Injury Clinical Network – Standards of Care 2022
Country	UK
Date Published	2022
URL	http://www.bascis.org.uk/?page_id=10
National or regional	National
Adapted/adopted from previous guidance document? If so which guidance document was it adapted/adopted from?	N/A
Based on evidence synthesis?	No
Based on expert consensus?	Yes
Update(s) planned (including dates)	N/A
Funding	N/A
Certainty of evidence grading	N/A

Domiciliary invasive ventilation guidance	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Pre-transition phase	**3. Discharge planning** The initial rehabilitation admission phase is only the beginning of long-term care. It is essential that the patient, family and carers are prepared for discharge and that the patient and carers are discharged in a collaborative manner. This will involve ensuring that the patient is physically and psychologically ready for discharge, with appropriate support from local services, appropriate wheelchair and seating, as well as points of contact and support as required. This person-centred integrated approach must ensure that spinal cord injured patients are discharged from the centre with the optimum seating arrangement for their needs, and can then face the future with the confidence that comes from having a good wheelchair and cushion that supports their functional independence, reduces secondary care issues and enables them to lead the life they want to lead. The discharge process and planning should start from the time of diagnosis, throughout their initial rehabilitation. This must be done in a collaborative manner with the patient involvement, family and friends (as desired), local services as well as specialist advice. 3.1 There are many parts to this process and the list below are only some areas that need to have a clear plan, to ensure that the patient is fit for discharge: ▪ Medically stable ▪ VTE prophylaxis management regime established

	▪ Medication administration method established ▪ Autonomic Dysreflexia awareness and management regime ▪ Tracheostomy care plan and management regime in place ▪ Ventilation care plan and management regime in place ▪ Inspiratory Muscle Training programme established ▪ Assisted cough method identified and management regime in place ▪ Swallow management plan established. ▪ Speech management plan established. ▪ Bladder continence management regime established: o Patients should have base line imaging for the renal tract o Baseline urodynamics. o Long-term bladder management established and agreed by the patient. o Plan should be in line with NICE guidance for neurogenic bladder ▪ Bowel continence management regime established o Long-term routine of the bowel has been established and agreed by the patient. o Bowel routine and method established and local support agreed if required. o Plan should be in line with NICE guidance for neurogenic bowel. ▪ Pain pharmacological management regime established ▪ Pain therapeutic management regime established ▪ Validated pressure area score on discharge ▪ Nutritional assessment and long-term plan established. ▪ Skin management regime established for bed ▪ Skin management regime established for wheelchair ▪ Nutritional plan for weight management established ▪ Sensory restoration and normalisation management regime established ▪ Spasticity medical management regime established ▪ Spasticity therapeutic management regime established ▪ Oedema management regime established 3.2 Referrals to the local relevant medical specialities must be completed prior to discharge. This may include specialists such as: ▪ Respiratory physician for ventilated patients and most tetraplegics. ▪ ENT referral for patients with tracheostomy. ▪ Psychiatry referral for patients with mental health problems 3.3 Wheelchair provision is an essential part of rehabilitation. It is essential that an appropriate wheelchair is provided or hired by their Wheelchair Service. 3.4 At the point of discharge all patients must be seen by the liaison spinal cord injury nurse and a follow-up visit agreed within 2 weeks of discharge.

	3.5 Where needed a package of care must be in place with funding agreed. All essential equipment for activities of daily living such as transfers, bathing and access must be in place for a safe discharge. Where needed additional training will be provided to local health care teams to ensure appropriate manual handling, repositioning and therapy. 3.6 Appropriate step down facilities may be required for discharge prior to final discharge home. This may be for several reasons, but any facilities must ensure that patient care is not affected and that this is for a defined period. 3.7 On discharge, a multi-disciplinary summary which includes the long-term plan, must be completed before discharge. The summary should include the outcome measures on admission and discharge: ISNCSCI (ASIA). This should also include future follow-up and diagnostic tests required. 3.8 The discharge report should be completed and forwarded to the referring consultant, general practitioner, local allied health staff and psychological services as required. 3.9 Patients should be referred, as desired, for support from SCI charities including SIA, Back-up & Aspire. 3.10 A medical follow up after discharge should be carried out between 6-12 weeks according to the patient's condition. The date should be given to the patient before discharge. 3.11 Discharge information must be made available to the primary carer, General Practitioner, local Nursing team, Physiotherapy/Occupational therapy teams and psychological aspect.
Transition phase	**2.12 Reintegration** Reintegration is an essential part of the long-term management and plan of a spinal cord injured patient. 2.12.1 Visits should be considered to community environments including leisure and retail venues as prioritised by patient. Further visits to local area to familiarise patient access with their GP surgery, dentist, faith facilities, local shops, exercise venues or other places identified by patient will be beneficial and help problem solve initial access issues on discharge 2.12.2 Facilitation of overnight stay out of the SCI centre, at home or in an independent living assessment unit (local funding of care where required), is recommended during the end stages of the initial in-patient rehabilitation period.
General principles of home mechanical ventilation	NR
Technical requirements	NR
Staffing	**2.1 Spinal Cord Injury MDT (Based out of SCI centre)** ▪ The MDT must include specialist and identified Case Manager/Keyworker, Consultant in Spinal Cord Injury, Dietitian, Nurses, Orthotist, Occupation Therapist, Pharmacist,, HCPC registered Clinical/Counselling Psychologist and Liaison Psychiatrist, Physiotherapist, Speech and Language Therapist and Urologist ▪ 2.1.4 Patients will have a keyworker to facilitate communication, involvement of family and friends (as requested by the patient) and to act as an advocate, coordinating the rehabilitation process.

	▪ 2.1.5 patients will have a designated team member for discharge planning. These individuals will deliver or be able to sign post to support in regards to discharge planning (housing, equipment, care), benefits advice, co-ordinating DST, community liaison and referrals and co-ordination of case conferences and goal plantings. ▪ 2.1.5 Patients will have a mid-stay case conference with their MDT, community professionals, family and/or friends as specified by the patient to outline discharge expectations and estimated discharge date ▪ Case Manager / Key Worker / Social Worker / Discharge Co-ordinator o Discharge planning (housing, equipment, care) o Benefits advice o Co-ordinating funding applications o Community liaison and referrals o Co-ordination of case conferences and goal planning 2.6 Occupational therapy and physiotherapy ▪ 2.6.23 Home and/or discharge environment assessed and recommendations made including equipment provision or referral ▪ 2.6.24 Assessment for and recommendations made for therapy follow-up ▪ 2.6.25 Patient education programme in support of problem solving and self-management 4.4 Clinical Nurse Specialists (can be MDT approach when deemed appropriate) ▪ 4.4.1 Patients should be able to access clinical nurse specialists for SCIC advice, urology, continence, fertility, sexual function, Intra thecal baclofen and tissue viability. ▪ 4.4.2 Specialist clinics should be available for urology and continence procedures, as well as tissue viability follow up and pressure sore management ▪ 4.4.3 All ventilated and SCIC patients with respiratory needs should have access to reviews by the SCIC respiratory team. ▪ 4.4.4 Patients with baclofen pumps should be regularly reviewed and have access to baclofen refill clinics.
Monitoring	<u>.2 Medical Follow up (Consultant led to include MDT members as appropriate)</u> 4.2.1 Once a patient is discharged from their first episode of care/rehabilitation, they should be reviewed in an outpatient setting at the following intervals. These appointments can be face to face, virtual or telephone clinics. It is recommended that a standardised proforma be used ▪ 6 – 12 weeks post discharge ▪ 6 months ▪ Then annually for 5 years ▪ Then every 2 years or as required 4.2.2 However if any patient presents or contacts the centre with issues related to SCI they should be reviewed on an ad hoc basis.

	4.2.3 MRI or radiological procedures should only be performed when there is a clinical need. i.e. neurological changes or new increased pain. 4.2.4 The following assessments should be completed ▪ Expedited INSCSCI 6 months, 1 year, 2 year post injury ▪ Psychological health screen 4.2.5 Access to restoration clinics should be available e.g. nerve and tendon transfers, shoulder clinics, spinal cord implants
Infection prevention and control	NR
Other guidance	NR
Management of SCI complications	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Respiratory	NR
Bladder	NR
Bowel	NR
Skin	NR
Sexual health	NR
VTE	NR
Pain	NR
Autonomic dysreflexia	NR
Emotional wellbeing, mental health and substance abuse	NR
Cardiometabolic and nutrition	NR
Bone Health	NR
Palliative care	NR
Rehabilitation	NR
Wheeled mobility	NR
Other guidance	NR
Broader SCI care pathways and supports	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Governance structure	NR
Funding model	NR
Care pathways	**4. Lifelong follow up and re-admission** 4.1 Standardised timings for follow up care In accordance with national service specification, all centres are to have an agreed pathway for follow up care.

	The ongoing health needs of those with SCI should be subject to surveillance by the SCIC MDT. Intervention and treatment should be undertaken locally where possible and by the specialist SCIC team when not. Potential health needs include, but are not limited to: ▪ Autonomic dysreflexia, autonomic dysfunction of cardiovascular system, neurology, pain, tissue viability, bone density, weight management, tissue viability ▪ Bowel, bladder, sexual function & fertility, respiratory function, mental health and coping, function, mobility (wheelchair and ambulation), upper limb overuse complications, posture and seating, spasticity 4.1.1 Professionals providing outpatient assessment and treatment services should include Medics, nurses, PT, OT, orthotics, SALT, dietetics, psychologists and psychiatrists <u>4.2 Medical Follow up (Consultant led to include MDT members as appropriate)</u> 4.2.1 Once a patient is discharged from their first episode of care/rehabilitation, they should be reviewed in an outpatient setting at the following intervals. These appointments can be face to face, virtual or telephone clinics. It is recommended that a standardised proforma be used ▪ 6 – 12 weeks post discharge ▪ 6 months ▪ Then annually for 5 years ▪ Then every 2 years or as required 4.2.2 However if any patient presents or contacts the centre with issues related to SCI they should be reviewed on an ad hoc basis. 4.2.3 MRI or radiological procedures should only be performed when there is a clinical need. i.e. neurological changes or new increased pain. 4.2.4 The following assessments should be completed ▪ Expedited INSCSCI 6 months, 1 year, 2 year post injury ▪ Psychological health screen 4.2.5 Access to restoration clinics should be available e.g. nerve and tendon transfers, shoulder clinics, spinal cord implants <u>4.3 Urology Follow-up</u> This should take place at the same time as the agreed medical follow-up. Patients should have ultrasounds and urological reviews as per the NICE guidance; *Urinary incontinence in neurological disease: management of lower urinary tract dysfunction in neurological disease. 2012*. Where possible ultrasounds should be done in the patients local hospital. This should be arranged through link nurses and staff employed to support SCI centres in the acute trusts. <u>4.4 Clinical Nurse Specialists (can be MDT approach when deemed appropriate)</u>

	4.4.1 Patients should be able to access clinical nurse specialists for SCIC advice, urology, continence, fertility, sexual function, Intra thecal baclofen and tissue viability. 4.4.2 Specialist clinics should be available for urology and continence procedures, as well as tissue viability follow up and pressure sore management 4.4.3 All ventilated and SCIC patients with respiratory needs should have access to reviews by the SCIC respiratory team. 4.4.4 Patients with baclofen pumps should be regularly reviewed and have access to baclofen refill clinics. <u>4.5 Patients admitted to general hospitals.</u> 4.5.1 Spinal cord injury centres need to support patients who are admitted to general hospitals by providing a robust outreach/in-reach service, which can support education and training for general ward staff. All SCI individuals should be encouraged to contact their SCIC when they have a planned/unplanned hospital admission. 4.5.1 All SCIC are to offer a patient passport/care plan. <u>4.6 Spinal Cord Injury Centre Re-admission Criteria</u> In accordance with national service specification, all centres will have an agreed local pathway for re-admission in the following domains: ▪ 4.6.1 Planned admissions SCI Centre o Elective surgical admissions: Ring fenced beds for surgical admissions if SCIC does not have designated additional surgical ward. Surgical interventions including urology, colorectal, plastic surgery, intrathecal devices, hand/limb surgery. o Investigative purposes, scans/procedures to investigate deterioration in neurology/functional loss o Specific admission for a SCI component of care and management e.g. Bowel/Bladder/Skin/AD/Spasticity ▪ 4.6.2 Two stage rehabilitation – top-up rehabilitation Referrals can come from: 1. 2nd phase of rehabilitation following first admission to SCIC where rehabilitation was suspended or could not be completed at that stage 2. Need can be established following 3-6-12 month follow up/global review clinic 3. Referral via GP, other specialities, community OT/Physiotherapy teams 4. Concern raised by Spinal outreach/liaison nurses Centres to maintain a waiting list for these patients and identify goals and agree length of stay prior to admission. ▪ 4.6.3 Emergency Admissions SCI centres are not an emergency service, but can accept transfer after discussion with spinal outreach/SCI consultants. Emergency transfers should be explored and expedited if a patient experiences

	1. Failure of intrathecal device, if device implanted/managed by SCI centre. 2. Uncontrolled Autonomic dysfunction 3. Multiple SCI complex issues that cannot be managed in acute hospital despite specialist outreach input. ▪ 4.6.4 Maternity care – SCI patient to remain under primary care of maternity and obstetrics with supplementary outreach support from link spinal cord injury centre.
Education across the continuum of care	**2.11 Education for Patients** 2.11.1 All patients must have personal discussion(s) with or without family and friends (as patient desires) to explain their diagnosis and prognosis of spinal cord injury. All SCICs to provide a relative or support day as part of the education process. The education required will change over time and will need to be available for life long support. The learning needs for the patient as well as friends and family should be considered. Different techniques will be required to ensure appropriate education for the patient and their support network. 2.11.2 A relative's day should be provided at least once per year. 2.11.3 A personal multi-disciplinary patient education programme provided to include 1:1, peer support, group education and self-directed techniques with varied resources to meet patient's preferred learning styles, including: ▪ tissue viability ▪ autonomic dysreflexia ▪ bladder management ▪ bowel management ▪ sexual function ▪ respiratory function and management strategies ▪ cardiovascular consequences of SCI and long term fitness planning ▪ shoulder protection ▪ posture and deformity ▪ wheelchair maintenance ▪ the spinal cord and spinal column and what happens when it is damaged, ▪ neuroprotection and recovery, spasms and spasticity ▪ accessing benefits ▪ returning to work and vocation ▪ living with personal carers ▪ mental health and coping, access to SCI support organisations ▪ nutrition and weight management ▪ pain ▪ infection prevention and sepsis ▪ medication ▪ living with spinal cord injury ▪ SCI specific nutrition including healthy eating and the role of diet in ▪ prevention of chronic nutrition related complications ▪ sleep hygiene

	▪ swallowing and communication difficulties
Safeguarding and ethics	NR
Other supports	NR
Quality assurance processes	NR
Other guidance	NR

Key: NR – Not Reported

Guidance document characteristics	
Endorsing Organisation/Author	Respiratory Information in Spinal Cord Injury
Title	Carer training – Standards expected in terms of knowledge and skills Consensus statement on behalf of RISCI (GBI)
Country	UK
Date Published	Apr 2013
URL	N/A (unpublished)
National or regional	National
Adapted/adopted from previous guidance document? If so which guidance document was it adapted/adopted from?	N/A
Based on evidence synthesis?	NR
Based on expert consensus?	NR
Update(s) planned (including dates)	N/A
Funding	NR
Certainty of evidence grading	N/A
Domiciliary invasive ventilation guidance	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Pre-transition phase	NR
Transition phase	NR
General principles of home mechanical ventilation	NR
Technical requirements	NR
Staffing	NR
Monitoring	NR
Infection prevention and control	NR
Other guidance	NR
Management of SCI complications	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Respiratory	NR
Bladder	NR
Bowel	NR
Skin	NR
Sexual health	NR
VTE	NR

Pain	NR
Autonomic dysreflexia	NR
Emotional wellbeing, mental health and substance abuse	NR
Cardiometabolic and nutrition	NR
Bone Health	NR
Palliative care	NR
Rehabilitation	NR
Wheeled mobility	NR
Other guidance	NR
Broader SCI care pathways and supports	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Governance structure	NR
Funding model	NR
Care pathways	NR
Education across the continuum of care	It is becoming increasingly common for patients with a tracheostomy or ventilator to be cared for outside the acute hospital environment. Individuals with more complex care needs are being looked after in their own homes, or in long term care facilities. As a result there is an expectation that care, nursing, medical and other staff will have the necessary skills and knowledge to care for these patients safely and competently. An intra-disciplinary team has worked together to formulate evidence based guidelines. These guidelines form a framework to which home care providers and nursing homes can formulate their own competency or training statements. **Staff knowledge needed to look after ventilator users:** 1. A clear understanding of the global concepts of ventilation 2. Able to interpret observations relating to the efficiency of the individuals breathing. 3. Understand tracheostomy tubes in relation to the anatomy in which they are placed. 4. Understand features of the tracheostomy tube specific to the individual. **Staff skills needed to look after ventilator users:** 1. Basic understanding of the particular ventilator used. 2. Ability to manage the tracheostomy tube. 3. Ability to perform chest clearance techniques including suction. 4. Ability to perform manual ventilation The home care provider should evidence that their staff have been trained or have access to training for all of the following standards, and that this training is updated regularly. **Care Aspects are divided into five categories** 1. Ventilation

	▪ Set up vent and circuitry ready for use, check and document against prescription and configuration ▪ Perform ventilator safety checks ▪ Respond appropriately to alarms ▪ Attach the machine to the patient and start and stop treatment ▪ Perform routine cleaning and maintenance, to include battery and power management ▪ Provide manual hand ventilation when needed ▪ Troubleshoot clinical and technical problems and escalate in a timely manner to an appropriate source of assistance 2. Interface ▪ Understand specific features of chosen interface ▪ Apply to patient ensuring correct fit / seal ▪ Perform routine cleaning and maintenance and ensure replacement when necessary ▪ Troubleshoot problems 3. Tracheostomy ▪ Provide routine care of the stoma and tracheostomy tube ▪ Perform routine and emergency tracheostomy tube changes ▪ Perform sterile suction procedure beyond the length of the tracheostomy tube ▪ Troubleshoot clinical and technical problems and escalate in timely manner to appropriate source of assistance 4. Management of Associated equipment ▪ Correct set up of all associated devices ▪ Operate and apply equipment appropriately to the patient ▪ Perform routine cleaning and maintenance including power and battery management ▪ Troubleshoot clinical and technical problems and escalate in timely manner to appropriate source of assistance 5. Emergency and urgent care needs ▪ Understand need, and have access to 24 hour support ▪ Appropriate decision making and procedure for emergency / urgent / routine contact for clinical and technical issues.
Safeguarding and ethics	NR
Other supports	NR
Quality assurance processes	NR
Other guidance	NR

Key: NR – Not Reported

Guidance document characteristics	
Endorsing Organisation	American Association for Respiratory Care (AARC)
Title	AARC clinical practice guideline. Long-term invasive mechanical ventilation in the home--2007 revision & update
Country	USA
Date Published	Aug 2007
URL	https://www.aarc.org/wp-content/uploads/2014/08/08.07.1056.pdf
National or regional	National
Adapted/adopted from previous guidance document? If so which guidance document was it adapted/adopted from?	An update of a 1995 guideline by AARC
Based on evidence synthesis?	NR
Based on expert consensus?	NR
Update(s) planned (including dates)	NR
Funding	NR
Certainty of evidence grading	NR
Domiciliary invasive ventilation guidance	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Pre-transition phase	**HIMV 8.0 ASSESSMENT OF NEED** ▪ 8.1 Determination that indications are present and contraindications are absent (see below) ▪ 8.2 Determination that the goals listed in 2.1 (see below) can be met in the home ▪ 8.3 Determination that no continued need exists for higher level of services ▪ 8.4 Determination that frequent changes in the plan of care will not be needed **HIMV 4.0 INDICATIONS** ▪ 4.1 Patients requiring invasive long-term ventilatory support have demonstrated: ○ 4.1.1 An inability to be completely weaned from invasive ventilatory supportor ○ 4.1.2 A progression of disease etiology that requires increasing ventilatory support. ▪ 4.2 Conditions that met these criteria may include but are not limited to ventilatory muscle disorders, alveolar hypoventilation syndrome, primary respiratory disorders, obstructive lung diseases, restrictive lung diseases, and cardiac disorders, including congenital anomalies. **HIMV 5.0 CONTRAINDICATIONS** Contraindications to HIMV include:

	▪ 5.1 The presence of a physiologically unstable medical condition requiring higher level of care or resources than available in the home. Examples of indicators of a medical condition too unstable for the home and long-term care setting are: o 5.1.1 FIO2 requirement > 0.40 o 5.1.2 PEEP > 10 cm H2O o 5.1.3 Need for continuous invasive monitoring in adult patients o 5.1.4 Lack of mature tracheostomy ▪ 5.2 Patient's choice not to receive home mechanical ventilation ▪ 5.3 Lack of an appropriate discharge plan ▪ 5.4 Unsafe physical environment as determined by the patient's discharge planning team o 5.4.1 Presence of fire, health or safety hazards including unsanitary conditions o 5.4.2 Inadequate basic utilities (such as heat, air conditioning, electricity including adequate amperage and grounded outlets) ▪ 5.5 Inadequate resources for care in the home o 5.5.1 Financial o 5.5.2 Personnel ▪ 5.5.2.1 Inadequate medical follow-up ▪ 5.5.2.2 Inability of VAI to care for self, if no caregiver is available ▪ 5.5.2.3 Inadequate respite care for caregivers ▪ 5.5.2.4 Inadequate numbers of competent caregivers. A minimum of two competent caregivers are required. 10.3 Finances: HIMV can only be instituted and maintained with adequate financial resources to provide the necessary equipment and personnel to manage the patient's care
Transition phase	NR
General principles of home mechanical ventilation	**2.1 The goals of HIMV are** ▪ 2.1.1 To sustain and extend life ▪ 2.1.2 To enhance the quality of life ▪ 2.1.3 To reduce morbidity ▪ 2.1.4 To improve or sustain physical and psychological function of all VAIs and to enhance growth and development in pediatric VAIs ▪ 2.1.5 To provide cost-effective care **HIMV 6.0 HAZARDS AND COMPLICATIONS** ▪ 6.1 Deterioration or acute change in clinical status of VAI. Although ventilator-associated complications in the home are poorly documented, experience in other sites can be extrapolated. The following may cause death or require rehospitalization for acute treatment. o 6.1.1 Medical: Hypocapnia, respiratory alkalosis hypercapnia, respiratory acidosis, hypoxemia, barotraumas, seizures, hemodynamic instability, airway complications (stomal or tracheal infection, mucus plugging, tracheal erosion, or stenosis), respiratory infection (tracheobronchitis, pneumonia, bronchospasm, exacerbation of underlying disease, or natural course of the disease

	○ 6.1.2 Equipment-related: Failure of the ventilator, malfunction of equipment, inadequate warming, and humidification of the inspired gases, inadvertent changes in ventilator settings, accidental disconnection from ventilator, accidental decannulation ○ 6.1.3 Psychosocial: Depression, anxiety, loss of resources (caregiver or financial), detrimental change in family structure or coping capacity **HIMV 7.0 LIMITATIONS** In the home care setting, making and implementing changes in the plan of care may take longer than in a health care facility.
Technical requirements	**HIMV 10.0 RESOURCES** 10.1 Equipment ▪ 10.1.1 Ventilator(s)—Choice should be based on patient's clinical need. Patient's medical needs may dictate that more than one ventilator be provided. ○ 10.1.1.1 Ventilators chosen for home care must be dependable and easy for the intended caregivers to operate; small size and lightweight are desirable. ○ 10.1.1.2 Mobility is frequently an essential element of the plan of care of the patient. The mechanical ventilator system chosen for such a patient should allow mobility. ▪ 10.1.2 With portable, volume-cycled ventilators, use of the SIMV mode increases work of breathing ▪ 10.1.3 Complex and non-portable components are not recommended for HIMV but may be used to meet the needs of certain patients ○ 10.1.3.1 Ventilators powered by external compressed gas sources are less desirable ○ 10.1.3.2 A second ventilator should be provided for ▪ 10.1.3.2.1 Patients who cannot maintain spontaneous ventilation for 4 or more consecutive hours ▪ 10.1.3.2.2 Patients who live in an area where a replacement ventilator cannot be provided within 2 hours ▪ 10.1.3.2.3 Patients who require mechanical ventilation during mobility as prescribed in their plan of care ▪ 10.1.4 Preventive maintenance should be provided at the frequency recommended under manufacturer guidelines ▪ 10.1.5 An adequate power source must be available to operate the ventilator consistent with patient needs. This may be supplied by one or more of the following methods ○ 10.1.5.1 Alternating current (AC) is the primary power source for most long term care ventilators. Emergency AC power should be available in the long term care facility. ○ 10.1.5.2 Direct current (DC) by external battery may be used to allow mobility and as an emergency power source. The internal battery of the ventilator should be used only for short-term use. It should not be used as a primary source of power. ○ 10.1.5.3 A portable generator may be recommended for the VAI if frequent power outages occur or if the home is in a remote location ▪ 10.1.6 Alarms ○ 10.1.6.1 A patient-disconnect (eg, low pressure or low-exhaled-volume) and a high-pressure alarm are essential. ○ 10.1.6.2 If patient disconnection is likely to produce a serious adverse effect, a remote alarm and a secondary alarm may be indicated. A secondary alarm may be based on chest-wall impedance and cardiac activity, exhaled volume, end-tidal CO2, or pulse oximetry with alarm capabilities ○ 10.1.6.3 Audible alarms must be loud enough to be heard by caregivers in all areas of the home.

	▪ 10.1.7 Humidification systems are essential for invasive mechanical ventilation. The type of system used is determined by the patient's medical needs and the patient's need for mobility. It may be appropriate for the patient to use more than one type of system, based on those needs. o 10.1.7.1 Heated humidifier (temperature probes should be provided) o 10.1.7.2 Heat - moisture exchanger (HME) can be used during transport and to enhance mobility and may be used in lieu of a heated humidifier if the HME is determined to meet the patient's medical needs ▪ 10.1.8 Ventilator circuit and accessories as medically indicated ▪ 10.1.9 Self-inflating resuscitation bag with tracheostomy attachments, oxygen port if oxygen is prescribed, and mask of appropriate size ▪ 10.1.10 Replacement tracheostomy tube of appropriate size, plus a tube one size smaller should be available at all times ▪ 10.1.11 Suction equipment including a battery-powered aspirator for patients who leave the home or when indicated as an alternate source in the event of a power failure ▪ 10.1.12 Supplemental oxygen as medically indicated ▪ 10.1.13 VAI must have an adequate means of communicating their needs/desires and have the means to summon help from their caregivers in the case of emergency ▪ 10.1.14 VAI and caregivers must have functioning phone lines so that they can contact and be contacted by medical personnel in the case of emergency **HIMV 12.0 FREQUENCY:** ▪ 12.1 The frequency of ventilation (and the patient's ventilator-free time) is dictated by the patient's physiologic needs and is determined in consultation with the patient's physician. ▪ 12.2 The frequency of assessment of the VAI and the patient-ventilator system must be noted in the evolving total care plan as determined by the health care team, in conjunction with the VAI and their caregivers.
Staffing	10.2 Personnel ▪ 10.2.1 Health care professionals capable of providing direct patient care and possessing demonstrated competencies to monitor and assess both the patient and equipment are essential. Health care professionals should be credentialed (RRT, CRT, RN) and/or licensed practitioners with documented knowledge and demonstrated competencies so as to: o 10.2.1.1 Understand the patient's disease, plan of care, goals, and the limitations of invasive mechanical ventilation o 10.2.1.2 Assess patient's response to invasive mechanical ventilation o 10.2.1.3 Make recommendations for changes in respiratory management of patient, including weaning as necessary o 10.2.1.4 Train and monitor lay caregivers o 10.2.1.5 Monitor patient's ongoing ventilatory status o 10.2.1.6 Communicate results of assessment to the health care team ▪ 10.2.2 Lay caregivers (family members, personal care attendants, non-credentialed health care personnel such as nurse's aides) can be taught tasks and techniques of care for a specific VAI. Appropriately trained lay caregivers must demonstrate competency in: o 10.2.2.1 Proper set up, use, troubleshooting, and routine maintenance of the equipment and supplies o 10.2.2.2 Identification of adverse patient response to invasive mechanical ventilation o 10.2.2.3 Response to the hazards of invasive mechanical ventilation o 10.2.2.4 Response to emergencies such as ▪ 10.2.2.4.1 Power failure

	▪ 10.2.2.4.2 Acute life threatening events such as accidental decannulation or medical deterioration of the patient ▪ 10.2.2.4.3 Failure of the equipment or supplies ▪ 10.2.2.5 Appropriate infection control procedures ▪ 10.2.2.6 Use and application of any additional techniques required for ongoing care of the VAI, such as suctioning and the use of ancillary equipment
Monitoring	**HIMV 9.0 ASSESSMENT OF OUTCOME** At least the following aspects of patient management and condition should be evaluated periodically as long as the patient receives HIMV ▪ 9.1 Implementation and adherence to the plan of care ▪ 9.2 Quality of life ▪ 9.3 Patient satisfaction ▪ 9.4 Resource utilization ▪ 9.5 Growth and development in the pediatric patient ▪ 9.6 Change in prognosis ▪ 9.7 Unanticipated morbidity, including need for higher level site of care ▪ 9.8 Unanticipated mortality **HIMV 11.0 MONITORING** The frequency of monitoring should be determined by the ongoing individualized care plan and be based upon the patient's current medical condition. The ventilator settings, proper function of equipment, and the patient's physical condition should be monitored and verified: with each initiation of invasive ventilation to the patient, including altering the source of ventilation, as from one ventilator or resuscitation bag to another ventilator; with each ventilator setting change; after moving the patient (eg, from the bed to a chair); on a regular basis as specified by individualized plan of care. All caregivers, both professional and appropriately trained lay caregivers, should follow the care plan and implement the monitoring that has been prescribed. After being trained and evaluated on their level of knowledge and ability to respond to the VAI clinical response to each intervention, lay caregivers with documented competency may operate, perform routine maintenance tasks, monitor equipment, and perform personal care required by the VAI. ▪ 11.1 After completing training, demonstrating competency and if directed in the VAI's plan of care, the lay caregivers should monitor the following o 11.1.1 Patient's physical condition (may include the following: respiratory rate, heart rate, color changes, chest excursion, diaphoresis and lethargy, blood pressure, body temperature) o 11.1.2 Ventilator settings. The frequency at which alarms and settings are to be checked should be specified in the plan of care. ▪ 11.1.2.1 Peak pressures ▪ 11.1.2.2 Preset tidal volume or preset pressure control ▪ 11.1.2.3 Frequency of ventilator breaths ▪ 11.1.2.4 Verification of oxygen concentration setting or flow rate of oxygen bled into the ventilator system ▪ 11.1.2.5 PEEP level (if applicable) ▪ 11.1.2.6 Appropriate humidification of inspired gases ▪ 11.1.2.7 Temperature of inspired gases (if applicable) ▪ 11.1.2.8 Heat-moisture exchanger (HME) function (if applicable) 1

	○ 1.1.3 Equipment function ▪ 11.1.3.1 Appropriate configuration of ventilator circuit ▪ 11.1.3.2 Alarm function ▪ 11.1.3.3 Cleanliness of filter(s)—according to manufacturer's recommendation ▪ 11.1.3.4 Battery power level(s)—both internal and external ▪ 11.1.3.5 Overall condition of all equipment ▪ 11.1.3.6 Self-inflating manual resuscitator—cleanliness and function ▪ 11.2 Health care professionals should perform a thorough, comprehensive assessment of the patient and the patient-ventilator system on a regular basis as prescribed by the plan of care. In addition to the variables listed in 11.1.1- 11.1.3.6, the health care professional should implement, monitor, and assess results of other interventions as indicated by the clinical situation and anticipated in the care plan. ○ 11.2.1 Pulse oximetry—should be used to assess patients requiring a change in prescribed oxygen levels or in patients with a suspected change in condition ▪ 11.2.1.1 A physician's order for pulse oximetry must be obtained before oximetry testing is performed ○ 11.2.2 End-tidal CO_2—may be useful for establishing trends in CO_2 levels ▪ 11.2.2.1 A physician's order for end tidal CO_2 monitoring must be obtained before end tidal CO_2 monitoring is performed ○ 11.2.3 Ventilator settings ▪ 11.2.4 Exhaled tidal volume ▪ 11.2.5 Analysis of fraction of inspired oxygen ▪ 11.3 Health care professionals are also responsible for maintaining interdisciplinary communication concerning the plan of care ▪ 11.4 Health care professionals should integrate respiratory plan of care into the patient's total care plan. Plan of care should include ○ 11.4.1 All aspects of patient's respiratory care ○ 11.4.2 Ongoing assessment and education of the caregivers involved
Infection prevention and control	**HIMV 13.0 INFECTION CONTROL** ▪ 13.1 Both professional and lay caregivers should be aware of the potential for transmission of both chronic and acute infection from patient to caregiver and from caregiver to patient and should take the steps necessary to avoid that transmission. Aspects of avoidance include ○ 13.1.1 Careful hand cleansing and barrier protection when appropriate ○ 13.1.2 Careful disposal of medical waste ○ 13.1.3 Maximizing protection of patient, family, and caregivers (eg, influenza immunization) and minimizing exposure to persons with acute infections (eg, limiting visitors with upper respiratory infections) 13.2 Evidence is lacking to support an optimal plan for changing and processing ventilator circuits and ancillary equipment in the home. The standard of care in the home is that ventilator circuits need not be changed more often than once each week. However, CDC guidelines and studies from institutional settings suggest that ventilator circuits need only be changed when visibly soiled.
Other guidance	NR
Management of SCI complications	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Respiratory	NR
Bladder	NR

Bowel	NR
Skin	NR
Sexual health	NR
VTE	NR
Pain	NR
Autonomic dysreflexia	NR
Emotional wellbeing, mental health and substance abuse	NR
Cardiometabolic and nutrition	NR
Bone Health	NR
Palliative care	NR
Rehabilitation	NR
Wheeled mobility	NR
Other guidance	NR
Broader SCI care pathways and supports	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Governance structure	NR
Funding model	NR
Care pathways	NR
Education across the continuum of care	NR
Safeguarding and ethics	NR
Other supports	NR
Quality assurance processes	NR
Other guidance	NR

Key: NR – Not Reported

Guidance document characteristics	
Endorsing Organisation	Consortium for Spinal Cord Medicine
Title	Respiratory Management Following Spinal Cord Injury: A Clinical Practice Guideline for Health-Care Professionals
Country	USA
Date Published	Jan 2005
URL	https://pubmed.ncbi.nlm.nih.gov/16048145/
International, national or regional	National
Adapted/adopted from previous guidance document? If so which guidance document was it adapted/adopted from?	No
Based on evidence synthesis?	Yes
Based on expert consensus?	Yes
Update(s) planned (including dates)	Not planned
Funding	Administrative and financial support provided by Paralyzed Veterans of America
Certainty of evidence grading	**Hierarchy of the Levels of Scientific Evidence** **Level** — **Description** I — Large randomized trials with clear-cut results (and low risk of error) II — Small randomized trials with uncertain results (and moderate to high risk of error) III — Nonrandomized trials with concurrent or con-temporaneous controls IV — Nonrandomized trials with historical controls V — Case series with no controls **Categories of the Strength of Evidence Associated with the Recommendations** **Category** — **Description** A — The guideline recommendation is supported by one or more level I studies. B — The guideline recommendation is supported by one or more level II studies. C — The guideline recommendation is supported only by one or more level III, IV, or V studies

	Levels of Panel Agreement with the Recommendations **Level** — **Mean Agreement Score (out of 5 point scale)** Low — 1.0 to less than 2.33 Moderate — 2.33 to less than 3.67 Strong — 3.67 to 5.0
Domiciliary invasive ventilation guidance	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Pre-transition phase	**Electrophrenic Respiration** 19. For apnoeic patients, consider evaluation for electrophrenic respiration. (Scientific evidence–V; Grade of recommendation–C; Strength of panel opinion–Strong) **Discharge Planning** 38. Working with the multidisciplinary rehabilitation team, the patient, and his or her family, develop a discharge plan to assist the individual with ventilator-dependent spinal cord injury in transitioning from the health-care facility to a less restrictive environment, preferably a home setting. (Scientific evidence–NA; Grade of recommendation–NA; Strength of panel opinion–Strong) The discharge plan should include the following elements: ▪ An environment modified to accommodate wheelchair accessibility and respiratory needs. ▪ Trained 24-hour assistance. ▪ Medical resources. ▪ Appropriate durable medical equipment, including respiratory equipment. ▪ Transportation. ▪ Financial resources assessment. ▪ Leisure interests. ▪ Vocational pursuits. The discharge planning process begins in the health-care setting with a thorough evaluation of the patient, family, and social support systems; the patient's educational and vocational background; cultural influences; and financial and living resources. Careful coordination of the patient's resources and support systems is essential to a safe and efficacious discharge. **Home Modifications** 39. Evaluate and then modify the home environment to accommodate the demands of wheelchair access and respiratory equipment. (Scientific evidence–NA; Grade of recommendation–NA; Strength of panel opinion–Strong) The discharge setting should include adequate access and egress. It should have space for the patient to move about in his or her wheelchair; facilities for bathing or showering; and mechanisms for heating, cooling, and ventilation. The environment should be free of fire, health, and safety hazards, and it should have adequate electrical service to support the added demands of medical equipment.
Transition phase	NR
General principles of home mechanical ventilation	NR
Technical requirements	**Durable Medical Equipment**

	41. Prescribe the appropriate durable medical equipment for home use based on the evaluations of therapy staff and the patient. Consider emergency provisions (e.g., backup generator and alarms) and assistive technology as part of a safe and effective environment. (Scientific evidence–V; Grade of recommendation–C; Strength of panel opinion–Strong) A carefully prescribed power wheelchair allows for patient mobility, independent weight shifts, and portable ventilation. Respiratory equipment includes two portable ventilators and all ancillary supplies and equipment (e.g., suction, oxygen, IV therapy, nutritional therapy). An electric hospital bed with adjustments and appropriate overlay or mattress, a reclining padded commode chair for toileting and showering, a mechanical power lift for safe transfers, and a backup manual wheelchair are all necessary equipment. Emergency call systems and technology (e.g., environmental control system, voice-activated computer and telephone) will enhance the independence of the patient with ventilator dependent spinal cord injury.
Staffing	**Caregivers** 40. Home health-care workers, family members, privately hired assistants, and others trained in personal care and respiratory management of the individual with spinal cord injury should provide care or be available to assist the patient 24 hours a day. Efficient care of the patient depends on careful charting by home caregivers and proper management of the home medical supply inventory. (Scientific evidence–NA; Grade of recommendation–NA; Strength of panel opinion–Strong) Persons with spinal cord injury who use a ventilator should be trained to be able to give explicit instructions on their personal care to assistants and caregivers
Monitoring	NR
Infection prevention and control	NR
Other guidance	NR
Management of SCI complications	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Respiratory	**Prevention and Treatment of Atelectasis and Pneumonia** 5. Monitor indicators for development of atelectasis or infection, including: ▪ Rising temperature. ▪ Change in respiratory rate. ▪ Shortness of breath. ▪ Increasing pulse rate. ▪ Increasing anxiety. ▪ Increased volume of secretions, frequency of suctioning, and tenacity of secretions. ▪ Declining vital capacity. ▪ Declining peak expiratory flow rate, especially during cough. (Scientific evidence–V; Grade of recommendation–C; Strength of panel opinion–Strong) 7. If the vital capacity shows a measurable decline, investigate pulmonary mechanics and ventilation with more specific tests. (Scientific evidence–NA; Grade of recommendation–NA; Strength of panel opinion–Strong) 8. Implement the following steps to clear the airway of secretions:

	▪ Assisted coughing. ▪ Use of an in-exsufflator/exsufflator. ▪ IPPB "stretch." ▪ Glossopharyngeal breathing. ▪ Deep breathing and coughing. ▪ Incentive spirometry. ▪ Chest physiotherapy. ▪ Intrapulmonary percussive ventilation. ▪ Bronchoscopy. ▪ Positioning (Trendelenburg or supine). (Scientific evidence–NA; Grade of recommendation–NA; Strength of panel opinion–Strong) 10. Successful treatment of atelectasis or pneumonia requires reexpansion of the affected lung tissue. Various methods include: ▪ Deep breathing and voluntary coughing. ▪ Assisted coughing techniques. ▪ Insufflation—exsufflation treatment. ▪ IPPB "stretch." ▪ Glossopharyngeal breathing. ▪ Incentive spirometry. ▪ Chest physiotherapy ▪ Intrapulmonary percussive ventilation (IPV). ▪ Continuous positive airway pressure (CPAP) and bi-level positive airway pressure (BiPAP). ▪ Bronchoscopy with bronchial lavage. ▪ Positioning the patient in the supine or Trendelenburg position. ▪ Abdominal binder. ▪ Medications. (Scientific evidence–III/IV; Grade of recommendation–C; Strength of panel opinion–Strong **Intractable Atelectasis** 11. If the patient needs mechanical ventilation, use a protocol that includes increasing ventilator tidal volumes to resolve or prevent atelectasis. (Scientific evidence–V; Grade of recommendation–C; Strength of panel opinion–Strong) 12. Set the ventilator so that the patient does not override the ventilator settings (Scientific evidence–III/V; Grade of recommendation–C; Strength of panel opinion–Strong) **Surfactant, Positive-End Expiratory Pressure (PEEP), and Atelectasis** 13. Recognize the role of surfactant in atelectasis, especially when the patient is on the ventilator. (Scientific evidence–None; Grade of recommendation–NA; Strength of panel opinion–Strong) **Atelectasis**

	14. Use a protocol for ventilation that guards against high ventilator peak inspiratory pressures. Consider the possibility of a "trapped" or deformed lung in individuals who have trouble weaning and have had a chest tube or chest surgery. (Scientific evidence–V; Grade of recommendation–C; Strength of panel opinion–Strong) **Pneumonia** 15. Employ active efforts to prevent pneumonia, atelectasis, and aspiration. Scientific evidence–IV/V; Grade of recommendation–C; Strength of panel opinion–Strong) **Sleep-Disordered Breathing** 21. Perform a polysomnographic evaluation for those patients with excessive daytime sleepiness or other symptoms of sleep-disordered breathing. Scientific evidence–V; Grade of recommendation–C; Strength of panel opinion–Strong) 22. Prescribe positive airway pressure therapy if sleep disordered breathing is diagnosed. (Scientific evidence–V; Grade of recommendation–C; Strength of panel opinion–Strong) **Dysphagia and Aspiration** 23. Evaluate the patient for the following risk factors: ▪ Supine position. ▪ Spinal shock. ▪ Slowing of gastrointestinal tract. ▪ Gastric reflux. ▪ Inability to turn the head to spit out regurgitated material. ▪ Medications that slow gastrointestinal activity or cause nausea and vomiting. ▪ Recent anterior cervical spine surgery. ▪ Presence of a tracheostomy. ▪ Advanced age. (Scientific evidence–V; Grade of recommendation–C; Strength of panel opinion–Strong) 24. Prevent aspiration by involving all caregivers, including respiratory therapists, speech therapists, physical therapists, pharmacists, nurses, and physicians, in the care of the patient. Institute an alert system for patients with a high risk for aspiration. Position the patient properly. Ensure easy access to a nurse call light and alarm system. Have the patient sit when eating, if possible. Screen patients without a tracheostomy who have risk factors or signs and symptoms of dysphagia. If the patient is found to be aspirating and is on large ventilator tidal volumes, monitor the peak inspiratory pressure closely. (Scientific evidence–NA; Grade of recommendation–NA; Strength of panel opinion–Moderate) 25. Consider a tracheostomy for patients who are aspirating. If the patient has a tracheostomy and is aspirating, the tracheostomy cuff should only be deflated when the speech therapist—and possibly a nurse or respiratory therapist as well—is present. (All involved personnel should be expert in suctioning.) Monitor SPO2 as an early indicator of an aspiration impact. (Scientific evidence–NA; Grade of recommendation–NA; Strength of panel opinion–Strong)
Bladder	NR
Bowel	NR
Skin	NR

Sexual health	**Intimacy and Sexuality** 35. Explore issues of intimacy and sexuality with the patient and other appropriate parties. (Scientific evidence–NA; Grade of recommendation–NA; Strength of panel opinion–Strong)
VTE	**Pulmonary Embolism and Pleural Effusion** 16. Monitor ventilated patients closely for pulmonary embolism and pleural effusion. Scientific evidence–V; Grade of recommendation–C; Strength of panel opinion–Strong)
Pain	**Pain** 30. Assess the patient's level of pain, if any, and establish the type of pain to determine the most appropriate physical and psychological treatment modalities. (Scientific evidence–NA; Grade of recommendation–NA; Strength of panel opinion–Strong)
Autonomic dysreflexia	NR
Emotional wellbeing, mental health and substance abuse	**<u>Psychosocial Assessment and Treatment</u>** **Adjustment to Ventilator-Dependent Tetraplegia** 26. Consider the manner in which the individual is accommodating to the spinal cord injury, including the individual's post-injury psychological state. (Scientific evidence–NA; Grade of recommendation–NA; Strength of panel opinion–Strong) **Enhancement of Coping Skills and Wellness** 27. Assist the patient and family in the development, enhancement, and use of coping skills and health promotion behaviors. Scientific evidence–NA; Grade of recommendation–NA; Strength of panel opinion–Strong) **Affective Status** 28. Monitor the patient's post-injury feeling states, specifically for the emergence of depression and anxiety. (Scientific evidence–V; Grade of recommendation–C; Strength of panel opinion–Strong) **Substance Abuse** 29. Assess the patient for the presence of comorbid substance abuse beginning in the acute rehabilitation setting (Scientific evidence–V; Grade of recommendation–C; Strength of panel opinion–Strong)
Cardiometabolic and nutrition	NR
Bone Health	NR
Palliative care	NR
Rehabilitation	NR
Wheeled mobility	NR
Other guidance	**Secondary Mild Brain Injury** 31. Assess for possible comorbid brain trauma as indicated by the clinical situation. (Scientific evidence–NA; Grade of recommendation–NA; Strength of panel opinion–Strong)
Broader SCI care pathways and supports	
Topic	**Recommendation/criteria (Source, Certainty of evidence (if applicable))**
Governance structure	NR

Funding model	**Finances** 43. Evaluate thoroughly the patient's personal and financial resources and provide expert guidance in applying for benefits and coordinating assets to maximize all available resources. (Scientific evidence–NA; Grade of recommendation–NA; Strength of panel opinion–Strong) A financial evaluation should take place at the onset of the discharge planning process. It is essential to identify all available resources and to encourage the patient and family to apply for them. Examples include income assistance; medical insurance; and disability specific, community, and public benefits. Financial resources are fundamental to determining where and which patient needs are met. Basic needs to be met include medications, supplies, equipment, home modifications, transportation, and caregiver services.
Care pathways	NR
Education across the continuum of care	**Education Program Development** 37. Plan, design, implement, and evaluate an educational program to help individuals with SCI and their families and caregivers gain the knowledge and skills that will enable the individual to maintain respiratory health, prevent pulmonary complications, return home, and resume life in the community as fully as possible. (Scientific evidence–V; Grade of recommendation–C; Strength of panel opinion–Strong) Patients, family members, and caregivers of individuals with SCI experiencing respiratory care issues need a comprehensive educational program to help them achieve the best possible outcome. To be effective, the program plan should follow these guidelines: ▪ Rely on established functional outcomes of the individual's respiratory function, which includes the ability to breathe with or without mechanical assistance and to adequately clear secretions. The program should take into consideration contextual factors such as the patient's physiological and psychosocial status, level of injury, medical stability, treatment protocols and therapies, method and place of care delivery, readiness to learn, and available resources. ▪ Integrate patient, family, and caregiver education and support during all phases of care, from acute rehabilitation to community reintegration. The use of a clinical care pathway for spinal cord injuries, of which patient education is a critical component, has resulted in improved patient care and fewer complications. ▪ Provide support, reduce anxiety, clear up any misconceptions, and foster a sense of control among family members during the acute phase. Establish the readiness of the patient, family members, and caregiver to learn, and engage the hands-on cooperation of family and peers in the training as soon as possible. ▪ Individualize the approach to meet the specific social, emotional, educational, and cultural needs of the patient, family, and caregiver. Pay particular attention to learning styles, educational level, literacy, and fluency with English. ▪ Provide information in a supportive and sensitive manner, recognizing that the stress of SCI and ventilator dependency may disrupt the usual learning process. An information-only approach will not reduce anxiety among ventilator-dependent paediatric patients unless additional active relaxation components are implemented. ▪ Prepare the patient for respiratory interventions before they occur to minimize feelings of anxiety and loss of control. Warzak et al. (1991) suggest a relaxation package, including muscle relaxation and imagery techniques, to reduce anxiety during daily ventilator and tracheostomy care. ▪ Encourage the patient, family, and caregiver to actively participate in activities that foster learning about and commitment to respiratory care in real-world settings. Possibilities include trips and outings away from the health-care facility. ▪ Make use of a wide variety of teaching methods, including written materials, interactive educational devices, games, SCI multimedia tools, videos, Web-based resources, individual and group sessions, and patient and family workshops.

	▪ Specify outcomes that are demonstrable, measurable, and observable. Evaluation and documentation of the outcomes should cover three areas: knowledge, performance of requisite skills, and feelings of confidence. Evaluation should occur throughout the process to measure the extent to which learning has occurred. In addition, a broad range of topics should be covered: ▪ Anatomical structures and functions, including the effects of SCI on respiratory functions. ▪ Client-specific SCI issues, such as degree of independent breathing; goals and limitations of respiratory management; and respiratory health maintenance needs and requirements, including smoking cessation. ▪ Health-care procedures and treatments: o Cardiopulmonary resuscitation. o Tracheostomy care and replacement of trach tube. o Bronchial hygiene protocols, chest percussion, and postural drainage. o Strength and endurance exercises for respiratory muscles. o Assisted coughing. o Medications, inhalation therapy. o Safe swallowing, voice/speech production and specimen collection. o Potential problems and complications, infection control, and safety practices, including knowledge of health-care and other community resources. ▪ Commonly used respiratory supplies and equipment: o Mechanical ventilators; equipment malfunction or failure; hazards, alarms, and emergencies in the case of power failure. o Humidifiers, oximeters, end-tidal CO2. o Resuscitation bags. o Suction equipment; response to acute threatening events, such as accidental decannulation or medical deterioration of the patient.
Safeguarding and ethics	**Decision-Making Capacity** 32. Determine the individual's capacity to make decisions and give informed consent on medical related issues by examining the following: ▪ Organicity. ▪ Medications. ▪ Psychological reactions. ▪ Pre-morbid substance abuse. ▪ Pain. (Scientific evidence–NA; Grade of recommendation–NA; Strength of panel opinion–Strong) **Advance Directives** 33. Discuss advance directives, specifically the living will and durable power for medical health care, with the competent patient or the patient's proxy to determine the validity of the documents post trauma. (Scientific evidence–NA; Grade of recommendation–NA; Strength of panel opinion–Strong) **Establishment of an Effective Communication System**

	36. Assess the patient's ability to communicate, and ensure that all staff can effectively interact with the patient to determine his or her needs and concerns. (Scientific evidence–NA; Grade of recommendation–NA; Strength of panel opinion–Strong)
Other supports	**Family Caregiving** 34. As appropriate, assess and support family functioning (Scientific evidence–NA; Grade of recommendation–NA; Strength of panel opinion–Strong) **Transportation** 42. Use a van equipped with a lift and tie downs or accessible public transportation to transport the person with ventilator-dependent spinal cord injury. The patient should be accompanied by an attendant trained in personal and respiratory care. (Scientific evidence–NA; Grade of recommendation–NA; Strength of panel opinion–Strong) **Leisure** 44. Explore and provide information on diversionary pursuits, leisure interests, local community resources, and adaptive recreational equipment. (Scientific evidence–NA; Grade of recommendation–NA; Strength of panel opinion–Strong) **Vocational Pursuits** 45. Arrange a vocational evaluation to determine special aptitudes, interests, and physical abilities; factor in the need for transportation and attendant services. (Scientific evidence–NA; Grade of recommendation–NA; Strength of panel opinion–Strong) **Transition Resources** 46. Identify medical and other transition resources in the home community, including: ▪ Local specialists. ▪ Respiratory services. ▪ Home supply and durable medical equipment vendors. ▪ Pharmacies. ▪ Home health-care services. ▪ Advocacy groups. (Scientific evidence–NA; Grade of recommendation–NA; Strength of panel opinion–Strong)
Quality assurance processes	NR
Other guidance	NR

Key: NR – Not Reported

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