

# Pediatric Tracheostomy: Preparing for home

When your child has had a tracheostomy, you have many things to consider when preparing to bring them home.

- Knowing the medical equipment and supplies your child needs and where to get them
- Paying for equipment and supplies, and finding programs that offer funding
- Making changes to your home to support your child's care
- Creating a support system for your family and your child's care at home.

Services, equipment and caregiver availability vary across Alberta. Your tracheostomy coordinator helps you learn the skills you need to care for your child at home. Your local homecare case manager and homecare team will work with you to ensure your child's needs are met once you are home.

**Speak with your local case manager as soon as possible about what supports your child needs and where to find them.**

## Planning your child's care

As part of your child's discharge planning, a homecare case manager will learn your child's medical history and work with their hospital healthcare team to understand the supports your child will need at home. This is called a level of care assessment. The case manager works with you to create your child's care plan. The plan includes home equipment, care instructions and medical needs.

Parents or guardians are the primary caregivers for their child. As a parent or guardian, you are the primary caregiver for your child. Depending on your child's medical needs, you may need a hired caregiver to help during the day or overnight. Hired caregivers do **not** provide 24-hour care.

The number of funded hours for a hired caregiver (healthcare aide or licensed practical nurse) is based on an assessment of the child's unmet needs. This is discussed during the level of care assessment. Your homecare team determines the skill level and hours of your child needs.

Each child and their needs are unique, so there is no set number of hours for care. As with



any employee, a hired caregiver will not always be able to work, and a replacement may not be available. Parents and guardians must have an identified back-up plan for when this occurs.

## Homecare service options

Albertans have two options for home care services: self-managed care, contracted agencies and in-house caregivers. It is rare, but possible to combine these options. Your case manager will review the details of each option and help you find the best solution for you and your child.

### Self-Managed Care (SMC)

In some areas of Alberta, self-managed care is the only option. In this care model, the family is assisted to set up a business with a separate bank account, AHS will deposit funds to be used to employ caregivers that the family recruits and hires to care for their child.

- Hire caregivers of your choice (with some restrictions)
- Families will create their own business with a separate bank account where Alberta Health Services (AHS) will provide funding for you to hire caregivers of your choosing (with some restrictions).
- You will be responsible for finding, interviewing and hiring a caregiver. You will also be responsible for payroll (with guidance from AHS), accounting, filing taxes, training, scheduling and care planning.
- The cost of hiring a private caregiver varies by location across Alberta. However, the funding provided by AHS remains the same. Any additional cost will be your responsibility.

### Contracted Agencies or Vendor Services

Some areas in Alberta have nursing agencies or vendors contracted by AHS to provide your child's caregiver support. Your case manager will contact the agency for you to arrange the care based on your child's assessed level of care needs. With the help of your case manager, you and the agency supervisor will make sure the agency caregiver can meet your child's medical needs.

Nursing agency caregivers have received formal training such as health care aide certification or licensed practical nurse licensing. They will need to get additional training from their agency to care for children with a tracheostomy.

**Both caregiver options**, will require bedside training and "buddy shifts" where the hired caregiver is paired with you or a trained family caregiver to become familiar with your child and their routines. If the caregiver is from an agency the agency supervisor will support the bedside training. Caregivers cannot help with your other children as their only focus is your child with a tracheostomy.



## Funding

### **Alberta Aids to Daily Living (AADL) - supportive equipment**

AADL will fund the equipment below, which is provided by a private respiratory vendor of your choice.

- Tracheostomy tubes (13 per year)
- High humidity aerosols (such as cold nebulizer compressors)
- Heated humidity (such as Airvo)
- Suction machine and catheters
- Manual resuscitator
- Oxygen
- Speaking valves

AADL also funds ventilators, which are provided by Provincial Integrated Respiratory Services. Your discharge team will advise if your child needs the equipment.

### **Home Care Programs single-use equipment**

Home care will tell you where to get the following supplies:

- Heat moisture exchange (HME)
- Cotton-tipped applicators
- Saline
- Syringes (size 1cc, 1 per day)
- Muco lube (water-based lubricant, 2 per month)
- Drain sponges or trach dressing
- Tracheostomy ties

### **Provincial Integrated Respiratory Services (PIRS) ventilators**

PIRS is the contact for:

- Home mechanical ventilator
- Ventilator circuit

**Family or Private Insurance** - items not publicly funded. The items that families or their private insurers must pay for are:

- Disposable oxygen-related supplies (trach cradle, oxygen tubing, suction canister, corrugated tubing)
- Velcro tracheostomy tube ties}
- Oximeter (to measure oxygen saturation, optional)



- Home nebulizer for aerosolized medications
- Distilled water for humidification
- Some aerosolized medications (such as Tobramycin)

### **Non-Insured Health Benefits for First Nations and Inuit (NIHB)**

All the supplies listed above (items not currently funded) are covered for families eligible under NIHB.

## **Home Consideration**

The following are some questions to consider when getting your home ready for your child.

- Do I have a phone I can always use to receive calls, texts, voicemails and call 911 if needed?
- Where will my child sleep?
- What is the best way to set up supplies and equipment for easy access?
- Are there plug-ins for equipment near the bed?
- How will I get my child in and out of the house safely?
- Does our home need adaptations such as ramps, lifts, or additions?
- Where will I store medications and supplies out of reach of children and pets?
- Will there be space for the caregiver work at night? Is there enough light for them to work?
- How would we get out of the house (evacuate) in an emergency? What equipment/supplies do I need to grab quickly and where do we go?
- Have we talked as a family about how these changes (caregivers in the home, extra equipment) will affect all of us?
- Do my other children understand what is happening?
- Do I have people I can ask for support when I am stressed or unwell?
- What other informal supports do I have? (For example, do I have help getting other children to activities or getting groceries?)
- Who can I call for help in an emergency?
- Do I know where to access peer support and mental health support if I need it?

As you prepare to go home discuss these questions and any other concerns you may have with your case manager.

