



Alberta Health
Services

Alberta **Children's** Hospital

Tracheostomy and Ventilator Education Program Module 15: Transitions

Disclaimer

This material is intended for use by trained family members and caregivers of children with tracheostomies who are patients at the Alberta Children's Hospital. Although reasonable efforts were made to confirm the accuracy of the information, Alberta Health Services does not make any representation or warranty, express, implied or statutory, as to the accuracy, reliability, completeness, applicability or fitness for a particular purpose of such information. This material is not a substitute for the advice of a qualified health professional, so please seek medical advice from an appropriate health professional for questions regarding the care and treatment of any patient. Alberta Health Services expressly disclaims all liability for the use of these materials, and for any claims, actions, demands or suits arising from such use.

Transitions

- Transition means moving from one state to another
- In terms of a child with a tracheostomy, transitions occur when your child moves from one area or level of care to another
- This may occur because your child's needs have changed or because your child has reached a milestone such as being ready for school

Transition from PICU to U2

- When your child is medically stable and can be moved safely to another unit because they no longer require intensive care, they will be moved to U2 for care of their tracheostomy/ventilator supports and any other supports they may require
- A multidisciplinary meeting with all staff involved in your child's care will occur to prepare for your child moving to U2
- You will be given an opportunity to tour U2 prior to your child's move

Transition from U2 to Home

- Once your child is medically stable, your medical team will help you start preparing to go home
- You will complete your training and skills to make sure you are ready to care for your child at home
- You will work with your Home Care staff to organize your home and your child's home equipment, and arrange for your home caregivers
- You will be supported by staff who will help you prepare for your child's safe discharge home – sometimes a child may be transferred from Alberta Children's' Hospital to another Hospital first prior to going home if you live outside of Calgary

Readmissions to Hospital

- Your child may be readmitted to hospital for a procedure or an illness
- This readmission to hospital may be to ER, PICU, U2, or for a day procedure in the OR
- Because your child has a tracheostomy, you will be bringing your emergency kit and suction unit with you
- Based on your child's needs, you may need to bring other home equipment with you
- Depending on how long your child's stay is, your home caregivers may be impacted

Rotary Flames House (RFH)

- RFH is a free standing pediatric hospice that provides planned and emergency respite, transition, symptom management and end of life care to children who are living with a serious illness
- Your child has access to RFH because they have a tracheostomy
- An introductory tour is arranged for families who are eligible to access Rotary Flames House

Rotary Flames House (RFH)

- RFH provides pre-booked respite to the family to support children with trachs:
 - Each family can book up to 30 nights/year (based on the April 1st to March 31st booking calendar year)
 - It is recommended that no visit is longer than 14 nights at a time
- Family members are welcome to stay with their child during these respite admissions if they wish
- Meals and accommodation are provided at no charge to the family
- RFH runs a number of outpatient programs that your family may be invited to access

School – Pre-School

- At the age of 2 ½ (by September 1st) your child may be eligible for PUF (Program Unit Funding)
- This means Alberta Education will provide funding for rehabilitation and learning needs to prepare your child for Grade 1
- This service is available as a home based or centre based program
- Home Care Staff like your Physiotherapist, Occupational Therapist, Speech and Language Pathologist, and Social Worker will assess your child for eligibility and help transition you over to the PUF program
- PUF is available for 3 years

School – Elementary, Junior, Senior High

- Your child can start Elementary school in Kindergarten (age 4 before March 1 of the calendar year to start school in the following September)
- You will register your child in school through your chosen school board, then meet with the school to determine your child's nursing care needs during school hours
- Your child will have a Case Manager from Home Care coordinating the nursing care in school
- The school board will then contract Alberta Health Services to provide that nursing care (tracheostomy care, g-tube feeds etc.) – this could be LPN (Licensed Practical Nurse) or HCA (Health Care Aide) level of care, 1:1 care, or in a group setting

School – Elementary, Junior, Senior High

- You will be responsible for sending your child's medications, home equipment, supplies, and formula to school with them every day including their trach emergency kit and suction supplies
- As your child ages and progresses in the school system, their level of care/expectations will be adapted in accordance with their age, ability, and cognition
- When your child starts attending school regularly, your respite hours will decrease

Care Transitions – Peds to Adult

- A child with a tracheostomy will transition from a single cannula tracheostomy tube to a double cannula tube as their airway gets bigger
- A child with a tracheostomy tube is managed in the community through Pediatric Home Care with home caregivers in place and the Complex Airway Clinic (CAC)
- At age 18, medical supports in the community change to Adult Home Care without caregivers (which may be combined with other programs like AISH (Assured Income for the Severely Handicapped) and PDD (Persons with Developmental Disabilities) and the Trach Clinic at the Peter Lougheed Hospital
- Adult services equipment funding is the same in terms of tracheostomy tubes and suction supplies but other supplies are not covered

Decannulation

- In Combined Clinic; CAC and ENT (Ear Nose & Throat Team), your child's long term tracheostomy plan will be reviewed annually and a decision may be made at some point that your child may no longer need his/her tracheostomy tube (decannulated)
- If your child is successfully decannulated, you will no longer need caregivers or receive funding for equipment and supplies
- You may continue to be followed temporarily by a Respiriologist, but will eventually be discharged from CAC and Home Care
- Your Community Pediatrician will continue to support you and your child with any subsequent health needs

Care Transitions – LPN/HCA

- Your child will be assessed at a certain level of care before leaving the hospital – LPN or HCA – based on his/her care needs
- This level of care will be re-assessed annually and on an as-needed basis as your child's care needs change
- This means your child's needs may increase or decrease, and Home Care will adjust the level of care accordingly
- Your Case Manager from Home Care will assess and discuss these changes with you as they occur, and make the adjustments as needed

Respite Hours

- Respite care is relief care that is above your night time caregiver support
- Your child has been approved for either 10 (tracheostomy) or 20 (tracheostomy with ventilator support) hours of respite care
- These hours, LPN level of care, can be scheduled during the day, evenings or on weekends
- You are not required to stay home with your caregivers during your respite hours
- Once your child begins school, his/her respite hours will be decreased