



Alberta Health
Services

Alberta Children's Hospital

Complex Airway Services

A REFERENCE GUIDE FOR FAMILIES
LIVING IN THE CITY OF CALGARY

CHILDREN WITH COMPLEX AIRWAY NEEDS

NOVEMBER 2016

Alberta Children's Hospital Complex Airway Services Reference Guide

Table of Contents

	Page
Welcome! _____	2
Team Members _____	2
Complex Airway Clinic _____	4
Combined Clinic _____	6
Telephone Support _____	7
Inpatient Support _____	7
In the Home _____	8
Family and Caregiver Education _____	8
Partnerships _____	8
Care Transitions _____	10
Important Documents _____	11
Glossary _____	12

**** Terms in *italic, bold* are defined in the glossary at the end of the document ****

Welcome to Alberta Children's Hospital Complex Airway Services

Welcome!

The Complex Airway Services (CAS) team welcomes you! When your child leaves the hospital our team will work with you to manage the care and support required because of your child's **tracheostomy**, as well as their **ventilator**, if your child has one. While your child is in hospital we will work with your inpatient team to make sure everything you will need is in place before your child goes home. Our team includes physicians and other healthcare providers from the Alberta Children's Hospital (ACH) Complex Airway Clinic, Ear-Nose-Throat (ENT) Clinic, and Calgary Pediatric Home Care Services. When you leave the hospital we will support you and your family through regular outpatient clinic appointments and home visits. Telephone support is also available if issues arise between visits. If your child is readmitted to the hospital we will work with the inpatient team to support your child's care as needed. Our goal is to provide you and your child with **coordinated care** throughout your journey.

Team Members

Pediatric Respiriologists and Pediatric Ear-Nose-Throat (ENT) Specialists are the physicians responsible for managing and coordinating your child's care related to your child's tracheostomy, as well as the ventilator, if your child has one.

- **Pediatric Respirologists** are pediatricians with specialized training and experience in the diagnosis and treatment of disorders of the respiratory (breathing) system. There are three Respirologists on the team – Drs. Marielena DiBartolo, Karen Kam, and Ian Mitchell. These Respirologists will share responsibility for your child's overall care plan and will focus on management of your child's breathing status.
- **Pediatric Ear-Nose-Throat Specialists**, also known as Otolaryngologists, are medical doctors that specialize in the management of conditions of the ear, nose, throat, and related structures of the head and neck. There are three Ear-Nose-Throat Specialists on the team – Drs. James Brookes, Derek Drummond, and Warren Yunker. The Specialist who placed your child's tracheostomy will be your primary Specialist. Your primary Ear-Nose-Throat Specialist will work closely with the Respirologists to plan your child's long-term care.

A Calgary Pediatric Home Care primary Registered Nurse (RN) and Registered Respiratory Therapist (RRT) will help coordinate your child's care. Please note that during telephone consults and clinic visits, the nurse and respiratory therapist may or may not be your primary RN or RRT.

Be assured that all team members work closely together to provide the care and support your child requires.

The Complex Airway Services (CAS) allied health team consists of health care providers from both the Alberta Children's Hospital and Calgary Pediatric Home Care. The allied health team members you may see will depend on the needs of your child.

- **Allied health team members you may see during a clinic appointment:**
 - An occupational therapist (OT), also known as a feeding therapist, will be involved if your child is having concerns with feeding and/or swallowing difficulties or if your child requires support to develop normal feeding patterns (i.e. sucking, swallowing, chewing or moving on to solids);
 - A registered dietitian (RD) will monitor your child's growth and feeding and provide advice/intervention as needed;
 - The speech-language pathologist (SLP) evaluates and intervenes to support your child's ability to communicate and swallow. A speech-language pathologist usually becomes involved when your child is ready to be assessed for a speaking valve; and,
 - A social worker (SW) supports you and your child through education and counseling, advocacy for resources, and access to information and supports.

- **Allied health team members you may see at home:**
 - An occupational therapist supports your child to participate in regular activities of daily living by assessing and managing any developmental issues or equipment needs;
 - The physiotherapist (PT) offers assessment and intervention to help your child's ability to move, interact, and play in the home and community;
 - A speech-language-pathologist evaluates and intervenes to support your child's ability to communicate and swallow; and,
 - A social worker supports you and your child through education and counseling, advocacy for resources, and access to information and supports.

As your child grows, the various allied health providers may be less involved with your child's care, particularly if your child accesses these supports through pre-school or school-based services.

Complex Airway Clinic

The Complex Airway Clinic (CAC) is available to all children with tracheostomies. The focus of the clinic is to address respiratory, feeding, and growth matters. Your child will be seen by the Respiriologist, nurse, respiratory therapist, and, if necessary, allied health providers.

Frequently Asked Questions (FAQ's):

Q: Where is the clinic?

A: The clinic is one of the many Respiratory Clinics. The clinic can be found on the third floor:

- Take the main elevators to the 3rd floor;
- Turn left off the elevator and then turn left to walk down the long hallway;
- Check in with the receptionist at the first waiting room on the left.

Q: How often do clinics occur?

A: Complex Airway Clinic is scheduled every Wednesday, alternating mornings (8:30 am – 12:00 pm) and afternoons (12:30 – 4:00 pm).

- Your first appointment at the clinic is usually scheduled for 7 to 10 days after discharge. Visits are usually more frequent after you first leave the hospital. Further clinic visits are scheduled every one to four months depending on your child's needs, age, and clinical status.

Q: What will happen at a clinic appointment?

A: You and your child will be greeted by the clerical staff, then your child's weight and height will be measured, and you will be shown to a clinic room.

- The Respiologist, nurse, respiratory therapist, and allied health providers will come to your room for assessment, treatment, or procedures, if required. These procedures may include:
 - Collection of a tracheostomy secretion sample;
 - A **tracheostomy tube change/exchange** ;
 - **Oximetry**;
 - **Ventilator weaning**; and/or,
 - A scope through the tracheostomy tube.
- Home care supplies (if you are supported through the Children with Complex Airway Needs Program) may be provided at clinic appointments if arranged in advance.

Complex Airway Clinic continued...

Q: How long will you be at a clinic appointment?

A: Clinic appointments vary in length depending on the focus of the visit but are typically 60-90 minutes. Longer appointments may occasionally be required to perform more lengthy procedures.

- Please arrive 10 minutes early for your appointment as late arrivals disrupt clinic time for other families and may result in rescheduling your appointment.
- The clinic values your time and tries to keep on schedule. The team will inform you of your anticipated appointment length, if clinic is running late and/or if we need to change the length of your appointment.
- You will be phoned the week prior to an appointment to confirm:
 - The purpose of your clinic visit;
 - Team members you are scheduled to see;
 - Anticipated length of appointment;
 - Procedures that need to be completed before the appointment; and,
 - Any additional equipment or supplies you will need to bring with you to the appointment.

Q: What do I need to bring to clinic appointments?

A: Alberta Health Care card;

- ***Emergency tracheostomy supplies;***
- Tracheostomy Passport;
- Tracheostomy Change Log;
- Spare tracheostomy if tube change is occurring;
- Medication list and prescription refill requests;
- Food, if feeding assessment is to occur;
- Back-up ventilator if ventilator changes are to be made; and,
- Oximeter, if overnight oximetry was completed prior to appointment.

Combined Clinic

Combined ENT-Complex Airway Long Term Planning Clinic is a clinic appointment where your child is seen by the Ear-Nose-Throat Specialist, Respiriologist, registered nurse from the Complex Airway Clinic and Ear-Nose-Throat Clinic, and respiratory therapist. The purpose of the clinic visit is to evaluate the status of your child's airway, discuss long term plans for surgeries and/or potential removal of the tracheostomy.

Frequently Asked Questions (FAQ's):

Q: Where is the Combined Clinic?

A: Combined Clinic is one of the Sensory Clinics. The clinic can be found on the second floor:

- Take the main elevators to the second floor;
- Turn left off the elevator and then turn left again to walk down the long hallway;
- Check in with the receptionist at the first waiting room on the left.

Q: How often do clinics occur?

A: Combined Clinic is scheduled Tuesday afternoons (1:00 – 3:30 pm)

- Children are usually seen once per year. Some children will only be seen every couple of years.
- We try to schedule this appointment for the same time each year. Notification of your appointment time is mailed to you at the beginning of the year.

Q: What will happen at a clinic appointment?

A: You and your child will be greeted by the clerical staff and you will be shown to a clinic room;

- The Ear-Nose-Throat Specialist, Respiriologist, nurses, and Respiratory Therapist will come to your room for assessment, treatment, and procedures, if required. These procedures may include:
 - Scope through the tracheostomy and/or nose;
 - Collection of a tracheostomy secretion sample;
 - Change/exchange of tracheostomy tube; and/or,
 - Stoma treatment.

Combined Clinic continued ...

Q: How long will you be at a clinic appointment?

A: Appointments are scheduled for 30 minutes.

- Please arrive 10 minutes before your appointment.
- You will be phoned the week prior to an appointment to confirm:
 - The purpose of your clinic visit;
 - Team members you are scheduled to see;
 - Approximate length of appointment;
 - Procedures that need to be completed before the appointment; and,
 - Any additional equipment or supplies you will need to bring.

Q: What do I Bring to our Combined Clinic appointments?

A: Alberta Health Care card;

- Emergency tracheostomy supplies;
- Tracheostomy Passport;
- Tracheostomy Change Log;
- Medication list and prescription refill requests; and,
- Oximeter if overnight oximetry was completed prior to appointment.

Telephone Support

- Telephone support is **always** available! Team members are only a phone call away
24 hours per day, 7 days per week
 - (403) 943-1790 Monday to Friday 0800-1600
 - (403) 955-7211, ask for the Respiriologist on call
- The Complex Airway Services Family Contact List will be given to you by your primary nurse or respiratory therapist before you are discharged from the hospital. This list details who to call when you have questions or concerns.

Inpatient Support

There are times when your child may be admitted to the hospital for management of an illness, an elective surgery, or to make ventilator changes. The Pediatricians (also known as Hospitalists) or Pediatric Intensive Care Doctors will consult the Respiriologist on your admission. The Respiriologist will then communicate with the Complex Airway Services team to best support and coordinate care of your child.

In the Home

Preparing to take your child home with a tracheostomy and providing safe care in the home is the Complex Airway Services team's priority. There are many steps and decisions to be made before you and your child will go home for the first time. Options and support service delivery will be discussed with you. We are here to help and support you through this time.

If you are already at home with your child, the team will support you to maintain a safe and successful home environment. Our team members are available by phone at any time to answer questions, address concerns, and to support you and your child.

Family and Caregiver Education

We will teach you and your family how to care for your child. Your learning will start early in your child's hospital stay to help you build the knowledge and skills you need to care safely and confidently for your child.

Your education will focus on tracheostomy and ventilator care (if applicable) and includes hands on practice, resource materials, online learning, as well as simulation based training. This education will help prepare you for the transition from the hospital to home.

Partnerships

- **Alberta Aids to Daily Living (AADL)**
 - A program funded by Alberta Health that assists with long-term funding for basic medical equipment and supplies. Visit
 - <http://www.health.alberta.ca/services/aids-to-daily-living.html> for more information.
 - The Respiratory Benefit Program is one part of Alberta Aids to Daily Living that is operated through Alberta Health Services to fund some of the respiratory equipment and supplies you will need in the home.
 - The Respiratory Outreach Program is another part of Alberta Aids to Daily Living that provides ventilator equipment, supplies, and support to you, home care professionals and in-home caregivers.

- **Alberta Children's Hospital Outpatient Clinics**
 - Outpatient clinics work collaboratively with each other to deliver the best healthcare to you and your child. This may include **multi-disciplinary meetings** or trying to arrange appointments on the same day/time.

Partnerships continued ...

- **Calgary Lab Services**
 - Offers a full range of diagnostic tests to help the team in managing your child's health. There are many locations throughout the city, including an outpatient lab at Alberta Children's Hospital, so no matter which lab you choose, our team will have access to your child's reports.
 - Visit <http://www.calgarylabservices.com/> for details.

- **Calgary Pediatric Home Care Program**
 - The Calgary Pediatric Home Care Program is a multi-disciplinary team of pediatric specialists that assesses your child's needs at home and school, when applicable, reinforces education to you and your family, and provides in-home professional and support services. The level of support and services depends on the assessed need and will be in collaboration with services recommended through the provincial Children with Complex Airway Needs Program.

- **Community Pediatricians**
 - Several community pediatricians in Calgary partner closely with our team to care for children with complex airway needs. We can refer you to one of these pediatricians or you may choose one of the many pediatricians or family physicians in your community.

- **Family Support for Children with Disabilities Program (FSCD)**
 - Offers supports and services to encourage healthy development and participation in activities at home and in the community for children with chronic disabilities.
 - It is a parent-driven program that your social worker can help you access.
 - More information about the program can be found at <http://www.humanservices.alberta.ca/disability-services/14855.html>

- **Pharmacy**
 - It is important for your child to have the right medication at the right time for the right reason. It is essential for you to understand your child's medication needs and keep an up-to-date list of all medications, vitamins, and supplements. Your community pharmacist is an important member of your child's healthcare team so we recommend you choose one pharmacy that shares prescription information with **Alberta Netcare**. Visit <http://www.albertanetcare.ca> for more information.
 - Some useful medication tracking lists and tools can be found at <http://www.albertahealthservices.ca/medlist>

Partnerships continued ...

- **Rotary Flames House (RFH)**
 - Rotary Flames House is a facility based respite care option available to you. Services offered include day programming, overnight stays, and family support. Please visit <http://rotaryflameshouse.ca/index.php> for more details.

- **Schools**
 - The Calgary Board of Education and the Calgary Catholic School Division contracts in-school nursing care to the Calgary Pediatric Home Care Program to ensure a safe learning environment for your child. Once consulted, a Calgary Pediatric Home Care nurse will determine the health care supports needed for your child at school. More information will be provided when it is time for your child to enter the school system.

- **Vendors**
 - There are many companies selling medical equipment and supplies to Albertans. You will be provided with an Alberta Aids to Daily Living approved list of vendors prior to discharge home. You may choose one vendor from the list.

Care Transitions

- **Decannulation** is the process of removing the tracheostomy tube and allowing the stoma to close. There is a significant amount of planning involved in decannulation that is usually discussed and considered at your Combined Clinic appointments. We assess your child's need for a tracheostomy at each visit and appointment. If your child is decannulated, the team will work with you to transition medical care to the appropriate physician(s). Depending on your child's needs, the Calgary Pediatric Home Care team may continue to provide support to your child and family in your home.

- **Transition to Adult Care:** If it is anticipated that your child will have a tracheostomy after the age of 18, plans to transition care to adult services will begin at approximately 16 years of age. The team will help prepare you and your child for the changes in care, support, and funding that occur with this transition.

Important Documents

- Community Emergency Tracheostomy Algorithms
- Complex Airway Clinic Family Contact List: a complete list of important contacts. Your primary nurse or Respiratory Therapist will give this to you prior to discharge home.
- Medication List: a complete, accurate, up-to-date list of all medications, vitamins, and supplements your child is taking.
 - Tools to help you to create and maintain the list:
 - <http://www.albertahealthservices.ca/medlist>
 - <http://www.albertahealthservices.ca/mobile.asp>
- Tracheostomy Change Log: a tool that allows accurate record keeping about the tracheostomy, and tracheostomy changes and exchanges that may occur at home or in the clinic.
 - If your child has a Bivona tracheostomy tube, this is also where you can record the number of times the tracheostomy has been cleaned.
- Tracheostomy Passport: a tool that summarizes important information about your child's tracheostomy, medical history, and current care. This tool can be shared with Emergency Departments, hospital staff, or your community pediatrician to help support continuity of care.
 - These should be reviewed and updated regularly at your Complex Airway Clinic appointments
 - Please feel free to write important information or changes between appointment visits

We look forward to partnering with you and your family to provide the best care possible for your child.

Glossary

Coordinated care means bringing resources, needs, and services together to best care for your child's health. It promotes collaboration and cooperation.

Decannulation means the process of removing the tracheostomy tube and allowing the stoma to close.

Emergency tracheostomy supplies are materials you will need to have close at hand in case of an urgent situation.

Multi-disciplinary involves bringing together health care providers across disciplines to address the health care needs of your child.

Oximetry is a noninvasive method of monitoring the oxygen levels in the blood.

Pediatric Ear-Nose-Throat Specialist means a medical doctor that specialize in the management of conditions of the ear, nose, throat, and related structures of the head and neck. Also known as Otolaryngologists.

Pediatric Respiriologist means a medical doctor of children with specialized training and experience in the diagnosis and treatment of disorders of the respiratory (breathing) system.

Tracheostomy is a small surgical opening through the skin and into the windpipe – the stoma

Tracheostomy Tube Change is replacing a tracheostomy tube for a tube that is a different size, type, or brand.

Tracheostomy Tube Exchange is replacing the tracheostomy tube with the same size, type, and brand of tube.

Ventilator means a machine that helps a person breathe

Ventilator weaning is decreasing the level of support the child receives from the breathing machine. This will result in the child having to do more of work of breathing.