

## What Families Should Know About Tracheostomies

As the parent or guardian considering a tracheostomy for your child, we understand this is a difficult time for your family. A tracheostomy is a life-changing surgery. There are many different risks and benefits to consider. Your healthcare team at Connecticut Children's is here to answer your questions and provide support as you make this decision. This pamphlet was created for parents like you. It answers common questions about tracheostomies and ventilators. It is meant to support the conversations you will have with the healthcare team about your child's unique needs.

Your care team may include individuals from different specialties:

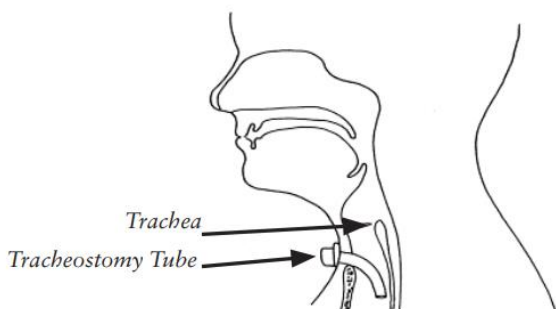
- Neonatal Intensive Care Unit (NICU)
- Pediatric Intensive Care Unit (PICU)
- Pulmonary Medicine
- Otolaryngology (Ear, Nose, and Throat)
- Pediatric Hospital Medicine
- Sunflower Kids (Pain Management & Palliative Care)
- Social work and case management



There is no “right decision” that makes sense for every child. This decision depends on your child's needs, your goals, and the community resources you can draw on for support. For many families who decide to move forward with a tracheostomy, they feel it is life-changing in a positive way.

### What is a tracheostomy?

A tracheostomy, often called a ‘trach,’ is a type of surgery where a small opening is made through the skin into the windpipe (trachea). This new opening is called a stoma. A specially trained doctor performs this procedure in the operating room. They put a small tube, called a tracheostomy tube, through the stoma into the trachea. This tube helps your child to breathe more easily. After surgery, your child will first be cared for in the Pediatric Intensive Care Unit (PICU). The number of days spent in the PICU will depend on the child's specific needs.



## Why might a child need a tracheostomy?

There are many reasons, including:

- Problems with their airways (tubes that travel to the lungs)
- Differences in the way a child's head or facial bones are formed that may affect breathing
- Weak breathing muscles or problems clearing secretions (mucous)
- Lung disease (sometimes due to premature birth) that requires a breathing machine for a long period of time
- Severe heart disease
- Differences in the brain or nerves that affect breathing. Some children have a condition that gets worse over time and needs more support

When we breathe, air moves through the nose and mouth where it is filtered, warmed, and moistened. When a child has a tracheostomy tube, the air goes **straight** into the lungs. It is very important to learn how to care for the tracheostomy tube and stoma site. This helps lower the chance of infection and keeps your child breathing comfortably. You will need special training during your hospital stay. **Two** co-caregivers must be trained before your child can go home.

## How do I care for my child's tracheostomy tube at home?

Daily tracheostomy care includes:

- Cleaning around the stoma
- Changing the tracheostomy ties
- Providing humidity and filtering the air
- Suctioning the tube as needed

Additional care includes:

- Changing the tracheostomy tube regularly
- Cleaning the used tracheostomy tube



## What problems can come up when a child has a tracheostomy?

- **Infection** – Children with tracheostomies are at a higher risk for infection in their airway or lungs. This is because the tracheostomy tube bypasses the normal filtering process of the nose and the upper airway.

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- **Mucous plug** – Sometimes, mucous can build up in the tracheostomy tube or the airway. This can cause a “plug” that stops air from reaching the lungs. If the mucous can’t be suctioned out, the tube will need to be changed right away.
- **Bleeding** – This can happen if the airways become damaged from suctioning or infection. In rare cases, children can have more serious bleeding problems.
- **Decannulation** – If the tracheostomy tube is not held in place properly, it can fall out partially or completely. This can happen if the tube is pulled on, or if a child has a strong cough. When this happens, the tube needs to be put back in right away.

### What are the benefits of a tracheostomy?

Families may report

- Improved stability of overall health in terms of breathing and nutrition
- Less time spent in the hospital, more time with family
- Better mobility and ability to work on therapy goals
- Ability to travel
- “Freeing the face” from equipment that may affect a child’s skin

### Long-term ventilation



Many children with tracheostomies, especially young infants and children with serious lung problems, need support from a ventilator (also called a ‘vent’). A ventilator is a high-tech breathing machine that pushes air through a trach tube into the lungs. Some children need to use a ventilator all the time, day and night. Other children use a vent only while they sleep, and some need it more when they are sick. Depending on the child, a ventilator may be needed for months or years. Some children require ventilator support for their entire life. We cannot predict how long your child might need a ventilator, but many times it is for years.

Using a vent can help make breathing more comfortable, help kids grow, and can make it easier to handle illnesses, which means less time spent in the hospital. If your child needs a vent to breathe, family members will need extra training to learn how the device works and what to do in case of alarms or emergencies. Caring for a child on a vent is a big responsibility, as they must have a trained, awake, and alert caregiver with them **24 hours per day**. Caring for a child with a trach and a ventilator is an even bigger responsibility, as they must have a trained, awake

and alert caregiver with them **24 hours per day who can trouble shoot both trach problems as well as ventilator problems.**

Children start out using a hospital ventilator and later switch to a portable or “home” ventilator. Weaning, or decreasing ventilator support, is a process that happens when your child is doing well at home. The Pulmonary team helps patients “wean” over time, closely monitoring their progress.

Ventilators, like any other piece of technology, can have alarms or issues. You will have an equipment company to help if your vent has a problem. However, you’ll also be trained with an emergency plan if the ventilator stops working suddenly.

### **What must happen to be discharged with a tracheostomy (and sometimes, a ventilator)?**

Before you can leave the hospital or rehabilitation facility to go home, there are several key goals you must meet:

- All equipment is available.
- Caregiver training is complete and home care is in place.
- Your child must be consistently healthy enough to leave the hospital.
- If transitioning to a rehabilitation facility, a bed must be available.

There are many steps to achieve these goals. It may take weeks to months, depending on the situation.

- Caregiver education starts early and takes place throughout the hospital stay. Two caregivers must be trained in **all aspects** of tracheostomy care, including every day care and how to respond to emergencies. It is very important to spend time at the hospital where you can learn how to perform all of the care tasks your child will need. Multiple teaching sessions will be scheduled for each caregiver and it is important to attend as planned.
- A home caregiver schedule must be created and approved by the medical team, especially the teams providing outpatient care after discharge. Many times, families require a combination of home nursing and other trained family members or friends to care for their child. A child with a tracheostomy **must** be cared for by an awake, alert, trained caregiver close by **24 hours per day**. Our goal is that each family will have 24 hours per day of home nursing coverage, however this may take a long time to organize. We can only train two caregivers while admitted to Connecticut Children’s.
- The home needs to be inspected by the home care company to make sure it is safe for your child and can accommodate the required equipment, including electrical outlets.
- All equipment and supplies must be delivered to the home.

**Important note:** Children with a tracheostomy and ventilator have many medical needs and need a **team** of trained caregivers in order to live safely at home. Due to a national shortage of pediatric home care nurses, it can take months to find enough caregivers with the right training. We expect that most of our patients will need to spend time at a long-term facility after their initial hospital stay to finish training and find nursing support. Some children need to spend time



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at another facility for medical reasons, for example, decreasing ventilator support so they can switch from a hospital-style ventilator to a “home” ventilator. In some cases, there may be limited placements in Connecticut and families may need to consider out-of-state options.

### Living with a tracheostomy



Children with a tracheostomy can be a part of everyday activities and should be encouraged to follow a typical routine as much as possible. However, you may have to adapt these routines to meet your child's needs and keep them safe.

### Common questions

#### ***How will my child communicate?***

Usually, sound is produced by air from the lungs as it passes through the vocal cords, causing them to vibrate and make noise. However, a tracheostomy can affect speech. This depends on whether your child is on a ventilator, or if there are problems with their vocal cords or airway. If a child cannot speak or make sounds, they need very close monitoring. Some families use sign language, picture communication boards, or computerized communication devices. If approved by your doctor, some children can speak using a special speaking valve after a period of time.

#### ***How will my child eat?***

Some infants and children with a tracheostomy can eat and feed normally, though children with vocal cord issues may have a hard time swallowing safely. This can cause food or fluid to enter the lungs (aspiration), which can cause pneumonia and other breathing problems. These children will work closely with a speech and language pathologist. Children who use a vent most of the day may not be able to eat safely by mouth. These children may require a feeding tube that delivers food to their stomach or intestines (a G-tube or a J-tube).

#### ***Will a tracheostomy affect my child's growth and development?***

Using a tracheostomy and ventilator can impact each child differently. Some older children feel the trach/vent is a tool that improves their quality of life overall. Many families feel it makes it easier to participate in therapies. However, older children and teenagers can have social and emotional problems related to being dependent on machines. They may feel ashamed, lonely, or upset about the lack of privacy. Age appropriate activities are essential to your child's growth

and development and should be encouraged. With some precautions, your child can play just like other children.

### ***Can my child go to school?***

Most children with tracheostomies can attend school in a regular classroom, though they will require closer supervision and special care. Children with a tracheostomy require constant monitoring by a caregiver who has completed an approved tracheostomy care training program. Most states mandate that this care be provided by a nurse, such as a registered nurse (RN) or licensed practical nurse (LPN), both at school, as well as during transportation to and from school. It is important to note that daycares may not accept a child with a tracheostomy and a ventilator, so this should be considered in your planning.

### ***How would this impact the rest of the family? What are the costs?***

Caring for a child with a tracheostomy and ventilator can be difficult and stressful. It can also be very expensive, even with insurance coverage. It is important to review insurance coverage with our case managers, including coverage of home nursing and equipment. This will help you to estimate out of pocket costs. Often, one or more family members may need to stop working or work fewer hours in order to care for their child.

Travel can be challenging and children often have many appointments with different medical teams. When traveling by car, a caregiver needs to be in the back seat along with the child so they can quickly respond if they need suctioning or care. You cannot drive your child without a second trained adult.

Brothers and sisters can also feel stress related to the care their sibling needs. Despite these challenges, many families share that they are grateful to have pursued a tracheostomy for their child. Family and community support is very helpful. Our social workers are here to connect you to community resources.

### ***What supplies will I need?***



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You will have supplies at home, as well as an emergency “go bag” that goes everywhere with your child. This bag should be used for tracheostomy supplies only. It is not to be combined with a diaper bag. Some families use a wagon to make traveling easier.

Supplies include:

- Extra tracheostomy tubes
- Supplies for cleaning the skin
- Suction machine and tubing
- A self-inflating bag and mask to help you “breathe” for your child in case of emergency
- Heated humidifier
- Oxygen tank and pulse ox monitor
- Back-up ventilator, back-up battery, carrying case
- Some children may use other pieces of equipment to help clear secretions

Sometimes supply chain issues impact the availability of specific equipment.

### ***Are there resources to help our family make this decision?***

- **Courageous Parent Network** – Tracheostomy Resources (English & Spanish)  
This site includes a decision-making guide and a video library.  
<https://courageousparentsnetwork.org/topics/tracheostomy/>
- **Family Reflections** –  
This website from Johns Hopkins University was created to help families make informed decisions about tracheostomies and ventilators.  
<https://family-reflections.com/>
- **Childhood Tracheostomy Alliance**  
This group provides educational resources, caregiver grants to offset the cost, and a supply closet of donated tracheostomy supplies that can be redistributed.  
<https://www.childhoodtrach.org>
- Introductory Videos from the **Get Well Network** (available at Connecticut Children’s)
- **American Thoracic Society (ATS)** - Patient Education Resources  
<https://www.thoracic.org/patients/patient-resources/resources/tracheostomy-in-child.pdf>  
<https://www.thoracic.org/patients/patient-resources/resources/using-a-home-ventilator-with-a-child.pdf>

### ***What resources exist in our community?***

- **PATH** – Providing Hope, Support, & Information to Families – <https://pathct.org>  
This organization provides resources for Connecticut families. It can also connect families with similar circumstances through a parent support program.
- **CTFSN** – Connecticut Family Support Network – <https://ctfsn.org>

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This organization provides direct support and training for families of individuals with disabilities and special health care needs.

- **CPAC** - Connecticut Parent Advocacy Center – <https://cpacinc.org>

This nonprofit offers information (workshops, trainings) and support to families of children with any disability or chronic illness from birth to age 26.

- **The Scotty Fund** – [www.scottysfund.org](http://www.scottysfund.org)

This nonprofit offers grant funding to families of children with life-threatening or critical illness residing in the towns of Bethel, Brookfield, Danbury, Easton, New Milford, New Fairfield, Newtown, Ridgefield, Redding

- **The Tiny Miracles Foundation** – <https://ttmf.org/>

This nonprofit offers community supports to families of preemies in Fairfield and New Haven Counties.

- **My Gym Foundation** – [www.mygymfoundation.org](http://www.mygymfoundation.org)

This nonprofit awards gifts of equipment and services to children with disabilities.

If you would like to be connected with another family who has a child with a tracheostomy, you can also ask your pulmonary team.

**If you have additional questions, please reach out:**

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### Glossary:

**Airway** – The tubes connecting from the mouth to the lungs. Also referred to as breathing tubes.

**Decannulation** – Removal of a tracheostomy tube. This can happen accidentally (an emergency) or with the support of the medical team once the child can breathe on their own without the trach tube.

**Granuloma** – A tissue growth at the airway opening that can block the airway or cause bleeding.

**Mucous plug** – When mucous builds up in the tracheostomy tube and blocks air flow



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**Speaking valve** – Sometimes referred to as a “passy muir valve” – this device fits at the end of trach tube, or can be added to the tubing to allow a child to speak.

**Stoma** – The opening of the skin (on the neck) where the tracheostomy is placed.



**Trachea** – A section of the airway that connects the larynx to the lungs, often called a windpipe

**Tracheostomy tube** – A special tube that connects directly from outside the throat to the trachea – a breathing tube that connects to the lungs

**Ventilator** – A piece of machinery that supports breathing by pushing air through the tracheostomy tube to the lungs.