# **Considering Tracheostomy**



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# **INTRODUCTION**

# A Life-Changing Procedure

When your child has complex medical needs and a diagnosis of a serious illness, their many specialists may offer differing treatment options and opinions. It's normal to feel overwhelmed by this, especially if the procedure being recommended is life-changing. Tracheostomy is one of these.

This guide is designed to help inform conversations between families and medical providers when a tracheostomy is being considered. As with most complex decision-making, parents and providers must work together so that you can fully understand all the components of the procedure, and the projected long-term outcomes and potential effects on daily life for your child and family. It is important to get input from the entire medical team, so that you can understand how the intervention will affect your child's other systems and the family's goals of care.

Hopefully these conversations and the decision-making can occur over time, giving you the opportunity to gather information and ask questions. When there is no obvious right choice, it is all about the decision-making process.





## Understanding Why the Possibility of a Tracheostomy is Being Raised

Tracheostomy may be suggested when you and your providers are aware that your child's breathing is not optimal. There can be many explanations for this. For example, your child may have:

- Abnormal or damaged lungs due to prematurity, illness or disease
- Abnormal or damaged airways (the tubes that air travels through to the lungs)
- Abnormal heart
- Abnormal chest wall
- Abnormal or damaged brain or nerves that control breathing
- Weak breathing muscles

#### Some common causes include:

- **Prematurity:** If a child is born before developing to full term, the lungs may lack surfactant a substance that allows the lungs to expand and contract normally.
- **Structural instability:** The structure of the airway or breathing passage may not have formed properly before birth, or there may have been changes that prevent air from going to the lungs.
- **Neurological or neuromuscular conditions:** Your child has an illness or condition where the brain does not alert your child to breathe.
- **Progressive disease:** Your child's illness or condition worsens over time, and their breathing is being impaired.

# II

## Considering the Benefits, Risks and Options

A permanent tracheostomy does not correct the underlying problem; rather, it creates a stable airway. It's important to understand potential outcomes for your child with a tracheostomy and without.

Importantly families tell us they don't want the diagnosis to define the interventions their child receives —each child and family is unique and deserves full understanding of not only the medical condition but also the hopes and worries associated with the trach. When families are told their child 'needs' a tracheostomy, it takes away the opportunity to weigh the benefits and burdens and of having options.

Tracheostomy brings with it the potential for positive outcomes, and also new risks and new demands for your family. Ideally the pediatrician, specialists and the surgeons will work together with you to think about the likely short- and long-term health trajectory for your

child, with or without tracheostomy. As the surgery will change the way your child breathes and is able to participate in activities, talking about all of the treatment options, prognosis with and without a tracheostomy, and quality of life for your child and family can be helpful.

Looking together at different scenarios can be helpful. The temporary placement of tracheostomy may allow for treatment of a structural problem, or time for a premature infant's growth and strengthening of an airway. Another child may have neuromuscular disease or genetic syndrome where recovery is not anticipated, and a permanent trach would provide breathing support.

#### Maintaining adequate oxygen to the lungs with current methods:

Some children get oxygen by nasal prongs, or intermittent or continuous Non-Invasive Positive Pressure (NIPPV), or Continuous Positive Airway Pressure/Bivalve Positive Airway Pressure (CPAP/BIPAP), which involves a child wearing a mask that usually is connected to an oxygen source like a ventilator

#### Tracheostomy types – Temporary or Permanent:

- Temporary, if your child's condition is seen as temporary and with time (and growth), the trach may be removed.
- Likely permanent, if your child's condition is unlikely to improve.

#### Trach with ventilator support:

If your child's condition is progressive or at a point where the neuromuscular system and/or lungs cannot be oxygenated without mechanical assistance.

## Trach without ventilator support:

If your child has adequate muscle function and lung function to support oxygenation.

## Benefits and Risks of Tracheostomy

Here are some of the benefits and some of the risks to be considered.

#### **BENEFITS**

- Moves tubes and/or masks away from the face
- Does not always take away the ability to eat by mouth, depending the underlying illness
- Speech/vocalization may be re-learned
- May lead to their improved physical growth and cognitive development
- May allow for less medication for sedation, and allow your child to be more awake and alert
- May or may not allow your child and family's greater participation in activities outside the home

#### **RISKS**

- Potential increased risk of respiratory infection.
- May weaken the trachea
- May plug or block easily
- If mechanical ventilation is needed, the lungs become damaged over time
- May impede speaking
- Requires some restrictions on activities involving water, such as bathing or swimming,
  to prevent water from getting into the trach

## What the Surgery Looks Like

During surgery an opening is made through the neck into the trachea (windpipe). A small curved tube, usually made of plastic or silicone, is placed through this opening (stoma) to provide an airway and to remove secretions from the lungs. This tube is called a tracheostomy tube or trach tube.

The surgery generally takes about an hour, and then the child is cared for in the Pediatric Intensive Care Unit (PICU) a week (or possibly longer, depending on the child's underlying condition). The child will receive medication for pain and medication to help minimize activity while the stoma heals. The first change of the trach tube is performed around 5-7 days after surgery. Sometime after that, the child will be transferred out of the PICU to a regular hospital unit, where caregivers will be educated and discharge planning will take place.

Some children with a trach, particularly those with progressive serious illnesses, will likely also require a ventilator to assist with oxygenation. A ventilator is a machine that pushes air into the lungs through a trach.

# III Identifying Your Hopes and Concerns for Your Child – Setting Expectations

Because tracheostomy is life-changing, the decision to proceed—or not—is a very difficult one for many parents. Tracheostomy is an option particularly when your child has a serious complex medical condition. You may decide the trach is the right intervention for your child. You may decide that the trach is not right for your child.

#### Involving Your Child

It may be that your child or young adult can express what physical and/or emotional issues they are experiencing when a tracheostomy is being considered. It will be important to address their questions and concerns. Including a primary provider, a child life specialist or someone from the palliative care team may be helpful.

## How Palliative Care Can Help

Involving the palliative care team is especially helpful when the surgery is being considered. Discussions about health trajectory, quality of life, hopes and concerns involve your values and impact your entire family. Palliative care specialists are trained to listen and to help you clarify and express your goals for your child. They understand that these discussions take time, and they will take that time with you.

If you decide that the tracheostomy is not the best option for your child, you may worry about how your child's breathing and oxygenation will be maintained. Your child's medical team will help you figure out what current methods might be changed, or what symptom management strategies can be added so that your child will not suffer. The goal is to allow your child to live and breathe in a way that helps them live the best possible life.

# IV Making the Decision

Medical providers may have strong recommendations for you, but at the end of the day, it is you (and your child, if they are able) who will live with the decision you make. However, you do not have to be alone in making the decision. The goal is that everyone involved has the space to give and receive information, ask questions, review the options, and discuss thoughts and feelings honestly and respectfully. This is what is meant by shared decision-making: the family, patient and medical team together.

Here, again, palliative care team members can be very helpful. They will make certain that the family voice leads the discussion toward the outcomes you envision for your child and family.

#### Ouestions for Your Reflection

Here are some topics to consider before you make a decision, and to discuss with members of the medical team.

- Who are your best supports to help you make this decision? Pediatrician, social worker, palliative care provider, a medical team that works with home ventilators, surgeon, other specialists, another family?
- What other information do you need to make the decision?
- Who can provide the information that you want and need?
- What worries do you have?
- What hopes do you have?



## Living With a Trach

If you have made the decision to proceed with a tracheostomy, here is what you can expect post-surgery and beyond.

## Learning Trach Care

Managing the trach involves learning new skills. During the hospitalization, caregivers will receive education and time to practice new skills. After discharge, it is best to have a medical provider who is your primary point of contact and who is available by phone or page to answer both urgent and non-urgent questions.

In the hospital, caregivers will be trained and learn how to:

- Suction the trach
- Care for the skin around the stoma (hole where the trach is inserted)
- Replace or re-insert the trach
- Manage the trach if it becomes plugged or blocked
- Recognize and address a lung infection
- Manage equipment (e.g., ventilator, monitors and suction machines and oxygen equipment, if they are needed)

## Leaving the Hospital

You will be ready to leave the hospital with your child when the following conditions are met:

- 1. At least two caregivers are trained in care of your child and trach equipment. It is ideal to also have at least one person outside the immediate family who is trained to provide care
- 2. You live in a place with access to health care workers who can provide care to the child in case of emergency
- 3. Adequate respite support for the caregivers is hopefully available
- 4. Your home environment is considered safe by the medical team that is responsible for your child's discharge

If your child needs a ventilator, additional training will be needed and may extend the hospital stay.

#### At Home with Your Child's Trach

Caring for a child will require:

- **CONSTANT** presence of a trained caregiver. The child cannot be left in the care of someone, even a very responsible person, who is not fully trained and able to give both routine and emergency care
- Equipment for both routine and emergency treatment. This includes suctioning and giving breathing support
- Having a plan for how to get emergency help at any time of day and in any type of weather conditions. This plan includes notifying, in writing, the fire department and ambulance services about your child's situation



# **CONCLUSION**

## Knowledge and Understanding are the Best Decision-Making Tools

The prospect of your child having a tracheostomy can be daunting. You will likely need time and multiple conversations with your child's care team to decide whether it makes the most sense, given your child's medical condition and your family's hopes, goals and situation. How to improve your child's respiratory function, and thus make each day be as good as it can be, is the question. The trach may be one way to do this; however, the trach also presents new challenges.

For most families, the more knowledge and understanding they have, the more equipped they feel to make this decision. Talking with clinicians and other families can be very helpful.