



Caring for your child with a tracheostomy


**Intermountain
Primary Children's Hospital**
The Child First and Always®





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What is a trach?

A tracheostomy [tray-kee-AH-stoh-mee], or trach [trayk], is a surgically created hole (stoma) [STOH-muh] in the windpipe (trachea) [TRAY-kee-uh]. It provides another airway for breathing when your child can't breathe normally through their nose and mouth. A tracheostomy tube is inserted through the stoma and held in place with a strap around the neck.

This book explains how trachs work, how to care for your child's trach, and what you can expect when your child has a trach.

Your child can live a normal life

"People always ask us how we do it, and I just let them know that this has just become our new normal. You just have to have the mindset and the perception that your child can do anything. Decide what kind of life you want your child and your family to live, and figure out a way to make that happen."

Presley's mom

How does my child breathe with a trach?

When your child has a trach, they will breathe through the tube and not through their nose and mouth.

Normal breathing

Air goes through the nose and mouth through the upper airway, down the windpipe and into the lungs. The hairs in the nose filter out dust, pollen, and dirt. The upper airway warms and humidifies the air before it reaches your child's lungs.

The upper airway also contains the epiglottis [eh-pee-GLAH-tiss] and vocal cords. The epiglottis is a small flap of tissue that acts like a trap door. It opens to allow air into the lungs and closes to direct food and liquid into the esophagus [eh-SAH-fuh-gus] (tube going to the stomach). Air going through the vocal cords (voice box) makes sound and voice.

Breathing with a trach

When your child breathes through a trach tube, air no longer goes to the upper airway. It now goes through the trach tube directly into the lungs. Air is not warmed, humidified, or filtered, and there is little to no air going through the vocal cords.

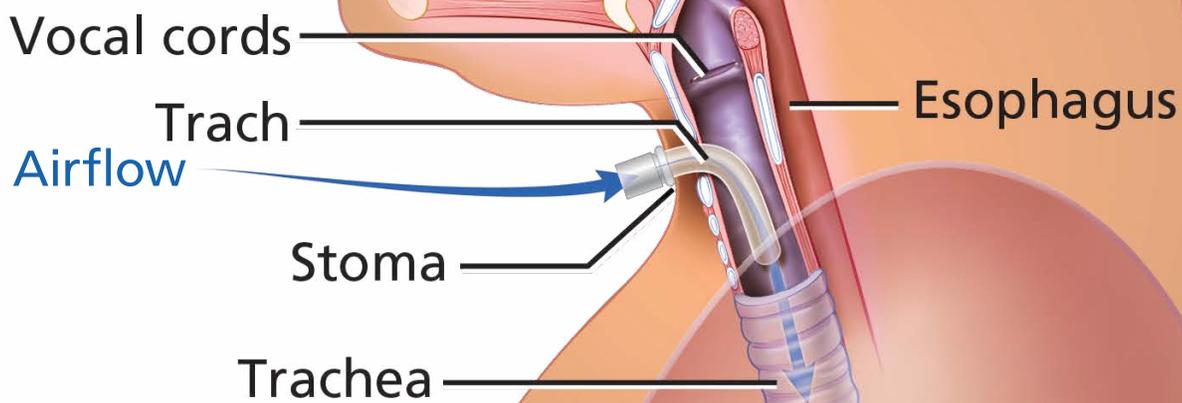
There are many reasons why children need a trach. What is the reason your child has a trach? Write your answer in the box below.

My child has a trach because:

Tracheostomy checklist

Before you take your child home, the trach team will ensure you are ready to care for your child with confidence. At least 2 caregivers must be trained, but multiple caregivers can attend the hospital trach training sessions. You can also train other caregivers yourself once your child is at home. This is what you will need to learn:

- The trach team will assess your learning needs:**
 - Meet with your family and explain the trach teaching process and timeline
 - Schedule interpretation services as needed
 - Tell your medical team if caregivers need special learning techniques or help
- Go to all training sessions:**
 - Begin training as soon as possible so that you will have enough time to learn before your child comes home
 - Review the written information, including Primary Children's Hospital's Trach Training booklet
 - Attend ALL scheduled 2-hour trach classes (only one session per day)
 - Demonstrate trach cares on a doll (simulation)
 - Demonstrate trach cares on your child (bedside pass-off)
- Understand and plan for your child's trach training schedule:**
 - Class 1: Introduction to tracheostomy tubes and patient assessment
 - Class 2: Suctioning and breathing treatments
 - Class 3: Trach site care, tube tie change, and tube change 1
 - Class 4: Trach tube change 2, tracheostomy CPR, and emergency preparedness
 - Class 5: Rooming-in (minimum of 12 hours; follows PCH tracheostomy ventilator rooming-in guidelines)
- Assemble the tracheostomy to-go bag using the tracheostomy travel bag list**



Where is the trach placed?

A trach is a surgical cut made in the neck into the windpipe (trachea). A tube is placed through this opening (stoma) directly into the windpipe.





Types and parts of a trach

There are many parts of a tracheostomy tube, but you'll soon learn to put it together correctly. Read on to learn about the different trach types and parts, and how they all work together.

Your child's progress may surprise you

"Laynie has the best attitude on the whole planet. Her trach has given her life, and she wouldn't be here without it. Doctors can't believe the progress she's made. You make what you want for your child. It's pretty amazing what they can accomplish."

Laynie's dad

Types and sizes of trach tubes

The size of a trach tube is defined by the internal tube diameter (how wide the tube is), length (neonatal, pediatric, or adult), and manufacturer. For example, your child might have a 3.5 pediatric Shiley tube.

The trach team will determine your child's trach tube type and size.

My child's trach tube type and size is:



Shiley™ trach



Bivona® trach



Infant, pediatric, and adult trachs

Parts of a trach tube

There are a few parts that you will learn once your child's trach type and size has been chosen. The pictures below will help you identify the individual parts of a trach.

Body/cannula: Tube that goes through the stoma into the airway.

Flanges or neck plates: Hold the trach tube in place with trach ties.

Connector: Standard 15-mm piece that sticks out of the neck and connects to all trach equipment.

Obturator: Guides the tube into the stoma when you insert it.

Cuff: Inflated with air to create a seal that stops or reduces air flow through the mouth and nose. Most children do not have cuffed trach tubes, but they may be used to stop air leaks if your child uses a mechanical ventilator. Cuffs can also protect your child from aspirating if they don't have a strong cough. Most teens and adults have cuffed trach tubes.

Balloon: Small, soft plastic piece at the end of the inflation line. An inflated balloon (full) indicates the cuff is inflated. A deflated balloon (empty) indicates the cuff is deflated.

Inner cannula: Tube within a tube that can be removed for cleaning mucus. Pediatric and neonatal trach tubes do not have inner cannulas.







Speaking valve

Speaking valve: One-way valve put on the trach to help your child use the upper airway and speak. Your child breathes in through the valve, and it closes when they exhale. This forces air around the tube through the vocal cords and upper airway.



HME or Artificial nose

Heat moisture exchanger (HME) or artificial nose: Provides portable moisture to the trach tube. The HME collects heat and moisture in the air your child breathes out. When they inhale, the HME adds heat and moisture to the inhaled air.



Trach guard

Trach guard: Protects the trach tube opening from small objects that could plug it (like beads or buttons).



Caps and plugs

Caps and plugs: Block the air entering the trach tube. Your child will breathe in and out through their nose and mouth when the trach tube is capped.



Disconnect wedge

◀ **Disconnect wedge:** Disconnects tight-fitted connections on the trach tube (such as ventilator tubing, HMEs, or speaking valves).





Assessing your child

Knowing what your child looks and acts like normally will help you realize when something has changed. You are the expert on your child, and their care team will rely on you to know if there is a problem. Here's how to assess your child each day.

Connecting with other trach parents

"One of the NICU moms I met also became one of our best friends. She has a trach baby, and we text or call each other every single day. It's been really nice to have a friend to lean on who's going through the same thing we are."

Finley's mom



Assessing your child

Respiratory rate (RR)

Know your child's normal resting respiratory rate (RR), which is _____ breaths per minute.

A higher RR may be caused by an increase in activity, temperature, secretions, or pain. Infection or lack of oxygen in the blood may also cause a higher RR. A lower RR may also happen with sedation or sleep.

Heart rate (HR)

Know your child's normal heart rate, which is _____ beats per minute.

A higher HR can occur with increased activity, temperature, secretions, infection, or pain. A lower HR can occur with sedation, sleep, or lack of oxygen. You should know how to find your child's pulse in several different places. If you don't, ask your child's healthcare provider for help.

Cough

Be aware of your child's cough. Notice when they cough, how much they cough and how long they cough. Most children don't cough very often, but coughing depends on your child's lung disease or secretions.

Positioning

Normally, your child will not need to be in a special position to breathe easier. However, children with lung diseases like bronchopulmonary dysplasia (BPD) [bron-co-PULL-moh-neh-ree dis-PLAY-zee-uh] may prefer a special position, like sitting upright, lying on their stomach, or lying on their side.

The lungs are like branches on a tree. Putting your child in different positions will help drain the different areas of the lungs.

Tactile [TAK-til] fremitus [FREM-eh-tiss]

You may feel bubbling or rattling when you put your hand on your child's chest. This is called fremitus and is a good sign that secretions in the airway may need to be cleared. You can clear your child's airway by suctioning it or having them cough.

Lung secretions

Be aware of your child's secretions. Watch for changes in the amount, color, odor, and thickness of your child's secretions. Though secretions can be produced in the lungs, nose, and mouth, the following tips refer to lung secretions.

Amount

- The amount of secretions your child produces can vary through the day.
- Some children have a lot of secretions in the morning; others have more secretions in the afternoon.
- You will learn your child's normal amount of secretions over time.

Color

- The lungs normally produce clear or cloudy white secretions.
- If your child has bronchitis, an infection, or lung disease, you may see green or yellow secretions.
- Many types of pneumonia cause brown secretions.
- When your child's airway is bleeding, you may see pink secretions.

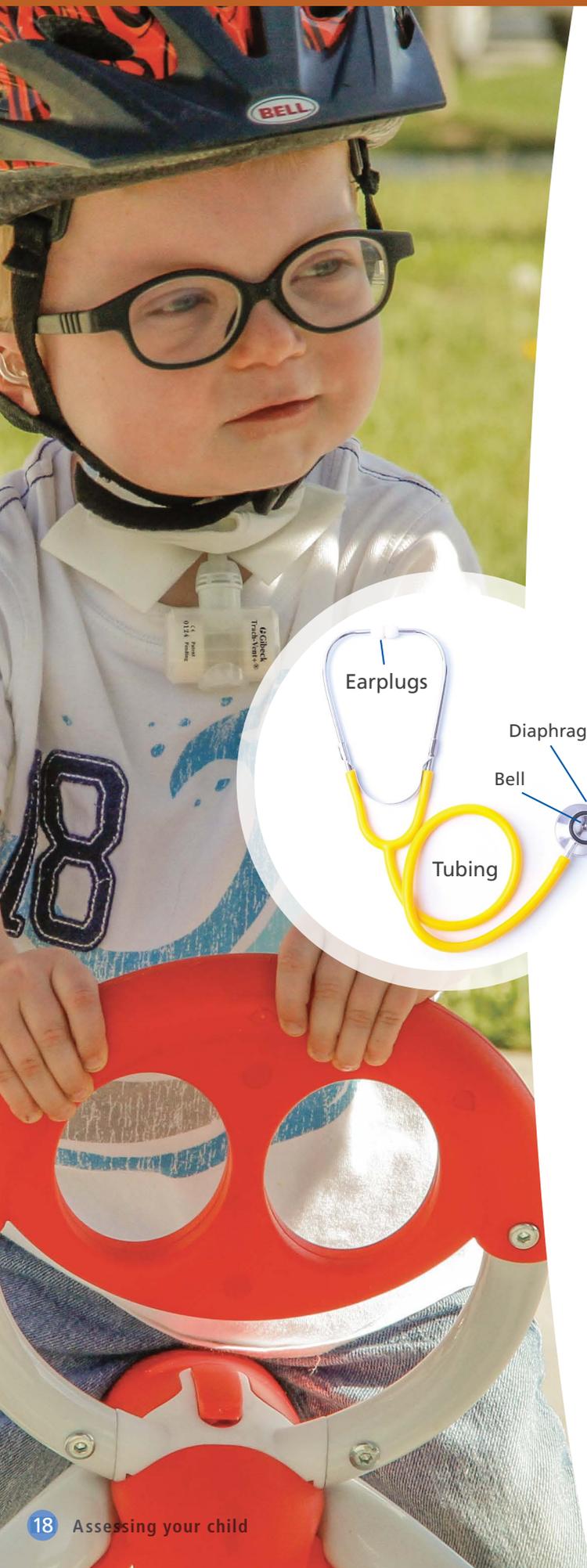
Odor

Changes in your child's secretions' odor may indicate an infection.

Thickness

- The thickness of your child's secretions may increase or decrease depending on their hydration, activity, and the time of day.
- Some medicines can affect the thickness of your child's secretions.
- Changes in the weather can affect the thickness of your child's secretions.
- Thick secretions may mean your child is dehydrated or needs more moisture in the air they breathe.





Retractions

Your child may have to work to move air in and out of their trach tube and lungs. Retractions occur when the muscles between and below the rib cage pull inward. You may also see:

- The skin pulling downward just above the breastbone and collarbones
- Restlessness
- Nasal flaring or nostrils widening
- Neck, arm, and shoulder muscles moving

Breath sounds

You can listen to your child's lungs through a stethoscope. The stethoscope is made up of earplugs, tubing, a bell (for listening to the heart) and a diaphragm (for listening to the lungs).

Press the stethoscope diaphragm firmly against your child's bare chest to avoid false breath sounds. Listen to all areas of the lungs. They fill the chest cavity on both sides, from top to bottom.

- **Normal breath sounds:** Clear, breezy, or the sound of wind
- **Crackles:** Wet, fine, or Velcro-like. You will usually hear crackles when your child breathes in.
- **Rhonchi (RON-ky):** Gurgling or bubbling in the larger airways. These sounds often clear with coughing or suction.
- **Wheezing:** Musical. They are often associated with asthma or narrowing airways and heard most often when your child breathes out.
- **Stridor:** Low-pitched, musical sound when your child breathes in. Stridor can often be heard without a stethoscope.
- **Diminished breath sounds:** Lack of air movement or sounds. This may occur with shallow breathing or be a result of infection, pneumonia, or a mucus plug.

It may take some practice for you to become comfortable listening through a stethoscope (also called auscultation). These tips can help:

- Focus on noticing changes in your child's breath sounds rather than trying to remember the names for the sounds
- Remember that sounds can transmit from one part of the lung to the other
- The sound originates from the area where you hear it loudest

Skin color

Skin color can show whether your child's blood has enough oxygen. A bluish color, known as cyanosis [sy-uh-NO-sis], may indicate a low oxygen level. You may see cyanosis best in the lips, gums, and nail beds.

Mucus production

Mucus, also known as sputum, phlegm, or secretions, protects the tissue lining of the lungs, throat, and airways and keeps them from drying out. It also traps any dust, bacteria, or pollen you breathe in.

Your body will produce more mucus in response to the surgery and the trach tube.

The body makes mucus to try to wash the irritation, like tears when you are poked in the eye, out of the trach tube. Things that can affect your child's mucus:

- Cold or dry air, windy days, and rain
- Dust both inside and outside
- Respiratory infections
- Not bathing regularly
- Pollution, smog, and inversions
- Aerosol sprays, perfume, cleaning products, or things with strong smells

Pay attention to the air your child breathes. If you can see or smell the air, your child can breathe these particles through the trach into their lungs.





Good handwashing

Good handwashing is one of the most important ways to prevent spreading sicknesses and germs. Wash your hands with soap and water before doing trach care. If soap and water are not available, you may also use hand sanitizer.

You should wash your hands:

- Before and after cooking
- Before eating meals and snacks
- Before and after taking care of wounds, changing bandages, giving medicines or caring for someone who is sick
- After using the toilet or helping a child use the toilet
- After changing a diaper
- After blowing your nose, coughing or sneezing in your hands
- After playing with animals
- After touching garbage and shopping carts, gardening, or handling any chemicals or cleaning products
- After shaking hands with someone

It's especially important to always have clean hands when working with a trach, whether cleaning or changing it.

Never touch the part of the trach that goes inside the stoma.

Hand washing with soap and water



Wet hands with warm, running water.



Apply soap.
Lather well.



Rub hands together for at least 15–20 seconds.
Scrub all surfaces of your hands and fingers.



Rinse well.
Dry with a clean or paper towel.
Use the towel to turn off the faucet.

Hand washing with sanitizer (hand rub product)



Apply hand rub product to hands.



Cover all surfaces of hands and fingers.
Rub together until your hands are dry.





Suctioning

Suctioning helps remove the mucus your child can't cough or clear out on their own. To suction, you need a suction machine with tubing, a suction catheter, and saline (sterile salt water). You should use the saline only when you need it.

Your child doesn't need to be limited by their trach

"Laynie has performed on a cheerleading team for 3 years and loves to be involved in family activities, including swimming. Her grandparents have a pool, and we all go swimming as a family probably 3-4 times a week during the summer. We just have to keep our hands on Laynie at all times, and we don't let her go above her stomach in the water. She has a little mermaid tail she likes to splash around in."

Laynie's mom

How to suction

The 8 steps below will guide you through the suctioning process. Each numbered step coordinates with an image on the following page.

To begin suctioning:

- 1 Wash your hands well with soap and water.
- 2 Connect the suction catheter to the suction machine tubing.
- 3 Turn on the suction machine.
- 4 Check suction pressure (it should be between 80-100 mmHg).
- 5 Insert the catheter to the pre-measured mark.

To determine the distance of your premeasured mark

– Insert catheter into a spare trach tube until the catheter tip reaches the end of the trach tube. Allow space for the HME or artificial nose. This is how you determine how far to insert the suction catheter.



- 6 Place your thumb over the suction port and slowly pull out the suction catheter from the trach tube.
- 7 Suctioning should normally last about 5-10 seconds.
- 8 If needed, let your child breathe before passing the catheter again.

If the mucus is thick and sticky, you may put 2-3 saline drops into the trach tube to help your child cough and loosen the mucus. Stop suctioning when the airway is clear.

Cleaning up

- Rinse the catheter after using it to keep it clear of secretions.
- Turn off the suction machine and store the catheter.
- Pay attention to the color, smell, thickness, and amount of the secretions.
- Follow the equipment company's instructions to clean the suction canister and tubing.

Keep the following tips in mind when you suction:

- Suctioning too deep may cause irritation and bleeding (occasional small streaks of blood may be normal).
- Do not suction the nose and the mouth with the same catheter you used for the trach tube.
- Encourage your child to cough up secretions on their own.
- Do not use saline drops every time you suction.
- Suctioning too often can cause your child to produce more secretions.

You should suction when you notice your child:

- Is coughing more often
- Is working hard to breathe
- Looks blue or pale
- Is restless and/or agitated
 - Or, if you notice:
 - Your child's oxygen levels are dropping
 - Secretions are bubbling at the trach tube opening
 - Mucus is rattling inside your child's chest
 - Your child can't cough out secretions on their own



Humidification

Humidity is the amount of moisture in the air. When your child breathes through their trach tube, the air does not go through the nose, which is the body's natural humidifier. Your child will need artificial humidification through a trach mask or artificial nose.

Proper humidification will decrease the risk of thick secretions plugging the trach tube. You don't need another home humidifier or humidifier system.

Secretions can become dry and sticky when:

- Your child is sick
- Your child is taking certain medicine
- Your child is not drinking enough
- It's hot, windy, raining, or polluted



My child's pre-measured mark is: _____

My child's catheter size is: _____

Notes about my child: _____







Trach site care

Caring for the trach site helps prevent infection. It also helps you know if the trach is working right and whether any parts are broken.

Trachs can give your child a better quality of life

“When it became clear that Finley would need to start using the CPAP machine again or have the trach surgery and potentially go home, that was music to our ears. Finley has never been happier. She breathes easier, she doesn’t get ‘air-hungry’ anymore. She just doesn’t struggle.”

Finley’s mom

Cleaning the trach site

You should clean around the trach tube at least twice a day. This area (the hole in the neck) is known as the stoma.

These 5 steps will guide you through the trach site cleaning process. Each numbered step coordinates with an image on the following page.

To clean the stoma:

- Wash your hands well with soap and water.

Supplies you will need:

- Mild soap and water or normal saline **(a)**
- Cotton-tip applicators **(b)**
- Clean pre-cut dressing if used **(c)**
(Do not cut your own gauze dressing, as loose strings could be breathed into the trach tube.)
- Washcloth and towel **(d)**



- 1 Put a rolled towel or blanket under your child's shoulders so you can easily reach the stoma. Smaller children may need to be swaddled.
- 2 Take off the old gauze dressing if used and discard it.
- 3 Clean the skin around the tube using cotton swabs dipped in soap and water or saline. Always move the swab outward from the stoma. Use as many swabs as needed to remove dried secretions.
 - Clean your child's chin and neck area with the washcloth, soap, and water or normal saline.
 - Watch the stoma site, and tell your child's doctor if you notice:
 - Redness and irritation
 - Swelling
 - Bleeding
 - Foul smell
- 4 Dry the area around the stoma site, chin, and neck well.
 - Apply ointments as needed or ordered by your child's healthcare provider.
- 5 Place a new, clean dressing (if used).

Changing the inner cannula

Some larger trach tubes have an inner sheath called an inner cannula. This fits inside the trach tube and can be easily removed for cleaning without removing the entire trach tube.

Disposable inner cannulas should be thrown away after use. Non-disposable inner cannulas may be cleaned and reused. Wash inner cannulas according to manufacturer guidelines.

My child's inner cannula type is:

1



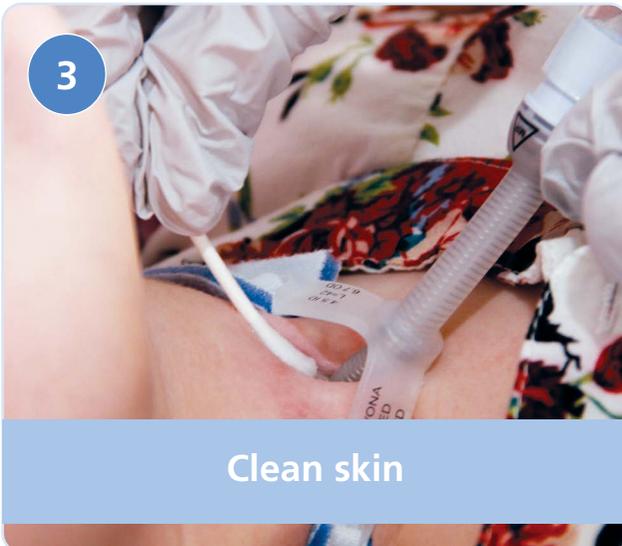
Rolled towel under shoulders

2



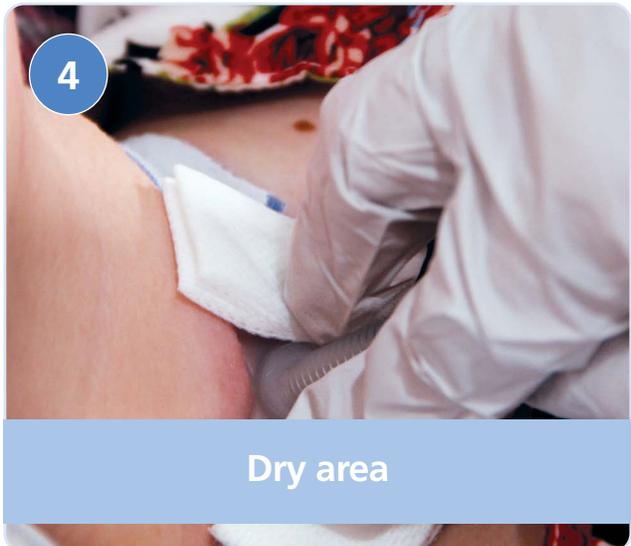
Remove old gauze dressing

3



Clean skin

4



Dry area

5



Place new, clean dressing

Changing trach ties

Disposable trach ties should be changed at least daily. They may also need to be changed if they are wet, loose, soiled, or causing pressure on your child's skin. There are several types of ties, such as hook-and-loop (Velcro®), shoelace, or medical-grade chains. Chain ties may not need to be changed daily.

These 6 steps will guide you through changing the trach ties process. Each numbered step coordinates with an image on the following page.

To change trach ties:

- Wash your hands well with soap and water.

Supplies you will need:

- New trach ties (a)
- Towel (b)
- Wash cloth, mild soap and water (c)



- 1 Find another person to help you change the trach tie. Decide who will hold the trach tube and who will change the trach ties.
- 2 Position your child so you can easily reach the trach ties. Smaller children may need to be swaddled.
- 3 Hold the trach tube in place as you remove the old trach ties.
- 4 Clean the neck area where trach ties have been, checking the skin for any rashes, redness, or irritation.
 - If you see irritation, call your child's healthcare team.
 - Apply any ointments or powders* the healthcare provider prescribes.
Helpful hint: Use only a small amount of powder and apply it with your fingertips or cotton balls.
***Never sprinkle powder directly onto your child's neck or near the stoma site.**
- 5 Place the new trach ties. To make sure you get the correct fit:
 - Make sure you place one finger between your child's neck and the tie. If you have large fingers, use the tip of your little finger to determine the correct fit.
 - Sit your child upright to make sure the tie is still properly fitted across the back of their neck.
 - If you are using Velcro ties, make sure the tabs are lying flat and not rubbing the neck. Trim the tabs as needed.
- 6 If reusing, wash trach ties by hand.



1

Teamwork



2

Position child and supplies



3

Remove trach ties



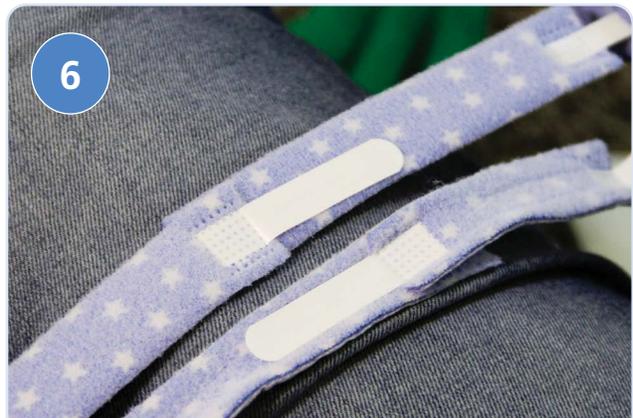
4

Clean and check the neck area



5

Place new trach ties



6

Wash and reuse old trach ties



Changing a trach tube

You should change your child's trach tube regularly as your child's healthcare provider recommends. You may change the tube once a week or even monthly.

Planned and unplanned trach tube changes both use the same equipment and techniques. You need to be ready to change the trach tube at any time. Always have trach change equipment available.

If you have a planned tube change:

- Change the trach tube before your child has eaten or at least 2 hours after they have eaten
- Ask a second person to help when changing the trach tube

You may need to do an unplanned tube change if:

- A mucus plug clogs the tube
- The trach tube comes out accidentally
- Your child is having trouble breathing and suctioning is not helping

Trachs are not as scary as they seem

"As soon as Laynie got a trach, it was like my child came alive again. It's amazing what your child can do when they can breathe easily and they're not fighting for every breath."

Laynie's dad

Changing the trach tube

These 12 steps will guide you through changing the trach tube process. Each numbered step coordinates with an image on the following page.

To change the trach tube:

- Wash your hands well with soap and water.

Supplies you will need:

- Clean trach tube (a)
- Clean trach ties (b)
- Resuscitation bag and mask with stand-by oxygen (c)
- Normal saline or water-soluble lubricant (d)
- Suction catheter and suction set-up (e)
- Luer-tip syringe if the trach tube has a cuff (f)

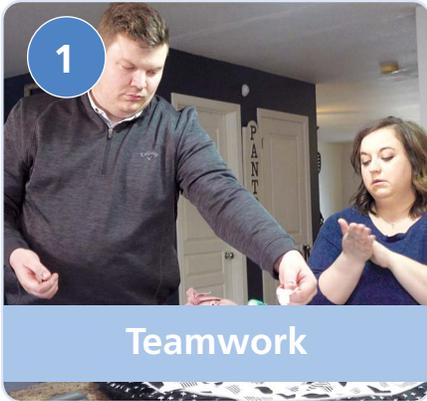


- 1 Decide who will remove the old trach and who will place the new one.
- 2 If the trach tube is cuffed, pre-check the new trach tube cuff with a syringe for leaks by injecting a small amount of air into the cuff. Then deflate the cuff completely.
- 3 Insert the obturator [OB-tur-ay-tur] into the new trach tube.
- 4 If needed, lubricate the tube with water-soluble gel or saline.
- 5 Put a rolled towel or blanket under your child's shoulders so you can easily reach the stoma. Smaller children may need to be swaddled.
- 6 Deflate the cuff if your child has one.
- 7 Remove the trach ties from around your child's neck while holding the trach tube to prevent accidental removal.
- 8 Remove the old trach tube by gently pulling it out and downward.
- 9 Insert the new trach tube by following the natural curve of the trach tube, using a gentle arcing motion.
 - If you have trouble inserting the tube, pull it away from the stoma, readjust the insertion angle, and attempt to insert the trach again.
 - If you continue having trouble inserting the tube, wait for your child to take a breath and insert the trach when they inhale.
- 10 Immediately remove the obturator.
- 11 Inflate the cuff (if your child has one).
- 12 Secure the trach tube with clean trach ties and check the ties for a correct fit.

Keep a spare clean trach tube in the same container and place at all times. Make sure all caregivers know where the spare trach is.

If you can't replace the trach tube

- Reposition your child and attempt to place the trach tube again.
- Try to place a smaller trach tube if you have one.
- If your child is not breathing, provide rescue breaths. You can give breaths mouth to mouth, or by mouth to trach. If your child still isn't breathing, call 911.



1 Teamwork



2 Pre-check cuff



3 Insert obturator



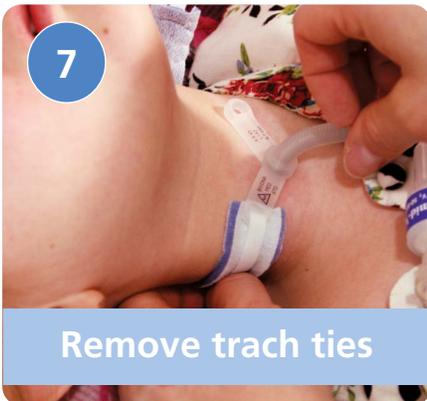
4 Lubricate



5 Rolled towel



6 Deflate



7 Remove trach ties



8 Remove old tube



9 Insert new tube



10 Remove obturator



11 Inflate cuff



12 Secure new trach ties





Cleaning a dirty trach tube

You should clean your child's trach tube every time you change a trach. Depending on your child's trach schedule, you will need to clean a dirty trach tube once a week or once a month. You'll also need to clean the trach tube if your child has an emergency trach tube change.

Family members can become caregivers

"My sister, who lives about 20 minutes away, attended all 5 of the trach classes. She was learning right as we were learning. Then she came back and would practice on Finley with us. I knew that she was going to be the closest family member, and that was a huge lifesaver."

Finley's mom

Cleaning a dirty trach tube

These 5 steps will guide you through cleaning a trach tube. Each numbered step coordinates with an image on the following page.

To clean a tube:

Wash your hands well with soap and water.

Supplies you will need:

- Dirty trach and obturator (a)
- Fragrance-free mild dish soap and water (b)
- Distilled or sterile water (c)
- Small soft-bristle scrub brush or pipe cleaners (d)
 - For Bivona trach: pan or container of boiling water
- Clean lint-free cloth or paper towel (e)
- Clean container or new plastic zip bag to store clean trach (f)



- 1 Wash the dirty trach tube with the mild soap and water until visibly clean.
Gently scrub all areas inside and outside the trach tube using the soft-bristle brush or pipe cleaner.
- 2 Rinse the entire trach tube inside and outside with distilled or sterile water. Make sure to wash all soap residue off. Soap can be very irritating to the airway.
- 3 Inspect all parts of the trach tube and obturator-tube, flange, cuff, and obturator, for any cracks, discoloration, or smell.
Do not use any tube that is cracked, discolored or smells bad.
- 4 **For the Bivona trach only: Place the clean Bivona trach tube in boiling water.**
 - Make sure the boiling water has been removed from the heat source.
 - Allow the water (with the Bivona trach tube and obturator) to cool to room temperature. **Do not boil the Shiley trach tube. This is for the Bivona trach tube only.**
Place the clean trach tube and obturator on the lint-free cloth or paper towel.
- 5 Allow it to completely air dry in your child's room so it doesn't get contaminated from germs in the bathroom or kitchen. Once the trach tube is dry, put it in a clean, dry container or plastic bag.

1



Wash tube with soap, water and brush

2



Rinse tube inside and out

3



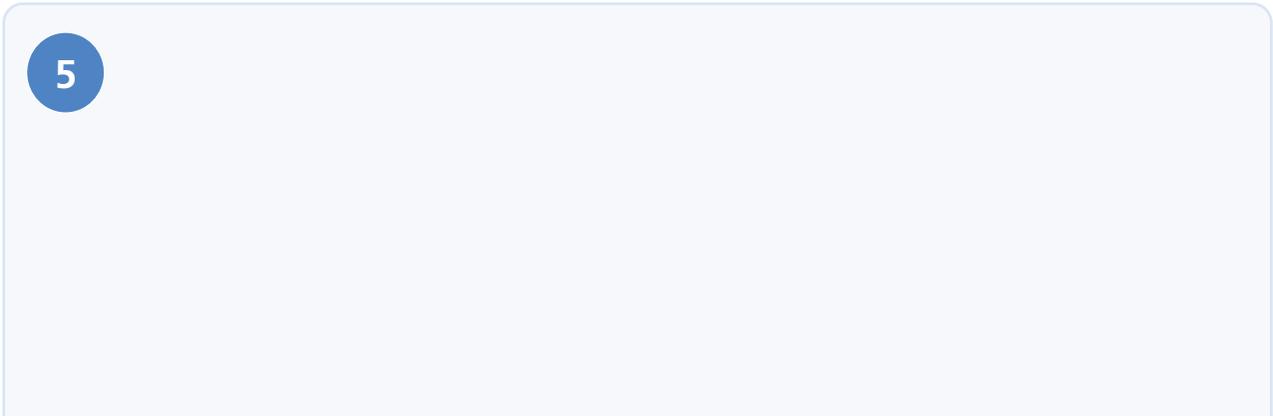
Inspect parts

4



Boil trach – Bivona only

5



Air dry trach and place it into a clean dry container





Trach emergencies, home equipment, and supplies

Emergencies come in many forms, from broken equipment, to power outages, to the need for rescue breathing and CPR. Create an action plan and know where to find help so you are prepared.

You have support all around you

"Talk with your family and allow them to help. In the beginning, I really wanted full control. Allowing them to help and do things is actually going to save you a lot of stress, and it's helpful for the child to know that there are other people that can help them, too. If you let your kids be a part of trach care and explain things to them, it's not scary."

Presley's mom

Preparing for emergencies

To keep your child safe in an emergency, follow the instructions below.

Always have your trach to-go bag accessible and fully stocked with supplies (see appendix).

- Review the American Heart Association's CPR Anytime kit.
- Have an emergency power source plan for extended power outages.
- Tell electric and gas companies you have a child at home using life-saving devices.
- Tell your local fire station you have a child at home using life-saving devices.
- Have back-up plans for broken equipment, including pulse oximeters, suction machines, and oxygen concentrators.
- Have a back-up plan for trach-trained caregivers who may be sick or unexpectedly unavailable.



My emergency plan is:

My emergency power source is:

My emergency phone numbers are:

My equipment company is:

My back-up plan for trained caregivers is:

Trach CPR

If your child is unresponsive, call or have someone else call 911, then do the following:

1 Assess the airway

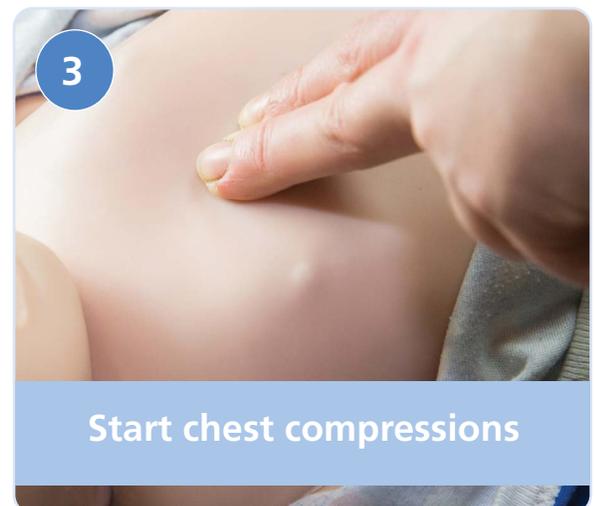
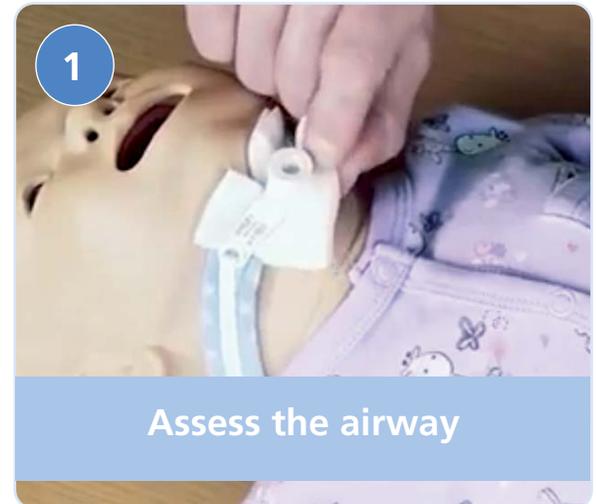
- Is the trach tube kinked? If so, replace it with a new trach tube.
- Is the trach tube plugged? If so, attempt to clear tube with suctioning. If you can't clear the tube, replace it with a new trach tube.

2 Assess breathing

- Is your child breathing? Look at the chest for movement and listen for air moving in and out of the trach tube.
- If the child is not breathing, give 2 breaths. The three different ways to give a breath are:
 - Attach the resuscitation bag to the trach tube and give breaths.
 - Put your mouth to the trach tube.
 - Give your child mouth-to-mouth breaths with your finger gently plugging the trach tube or stoma.
- If you can't get air through the trach tube, replace it with a new trach tube.
- Give 2 rescue breaths.

3 Start chest compressions

- For infants (younger than a year old):
 - Put 2 fingers just below the nipple line in the middle of the chest.
 - Push down hard and fast, at least half the depth of the chest.
 - Give 2 breaths to 30 chest compressions at a rate of 100 compressions per minute.
- For children (1-8 years old):
 - Put the heel of one hand in the middle of the chest.
 - Push down hard and fast, at least half the depth of the chest.
 - Give 2 breaths to 30 chest compressions at a rate of 100 compressions per minute.
- For adolescents and adults (8 years old or older):
 - Put one hand in the middle of the chest. Put your other hand over the first and lock fingers.
 - Push down hard and fast, at least half the depth of the chest.
 - Give 2 breaths to 30 chest compressions at a rate of 100 compressions per minute.



Home equipment and supplies

Case management will help you get the equipment and supplies you need to take your child home. A durable medical equipment (DME) provider will supply all the machines and disposable supplies you need for your child.

The DME provider will bring the equipment to the hospital before you go home so you can practice with the machines. They will teach you how to use and clean the equipment. Most DME providers will deliver disposable supplies in bulk once a month.



Home support

Case management will also arrange people to help you when you go home, including volunteers and paid professionals.

Volunteers are people you recruit, such as family, friends, babysitters, or neighbors.

Paid professionals may provide services for visits, such as speech therapy or a doctor appointment. They also come to your home and care for your child so you can do other things. Anyone who takes care of your child needs to be completely trained in trach cares and trach CPR.

Your insurance may not cover home nursing, so think about other people who could help care for your child. They must be completely trach-trained and comfortable responding to any problem that might come up.

Several federal and state programs can help you pay for resources once you get home. Your case manager or social workers can explain the programs available and help you fill out the needed forms.

Notes about my DME provider:

Professional services for my child:

Volunteers who will help me:

**Questions for my case manager
and social worker:**







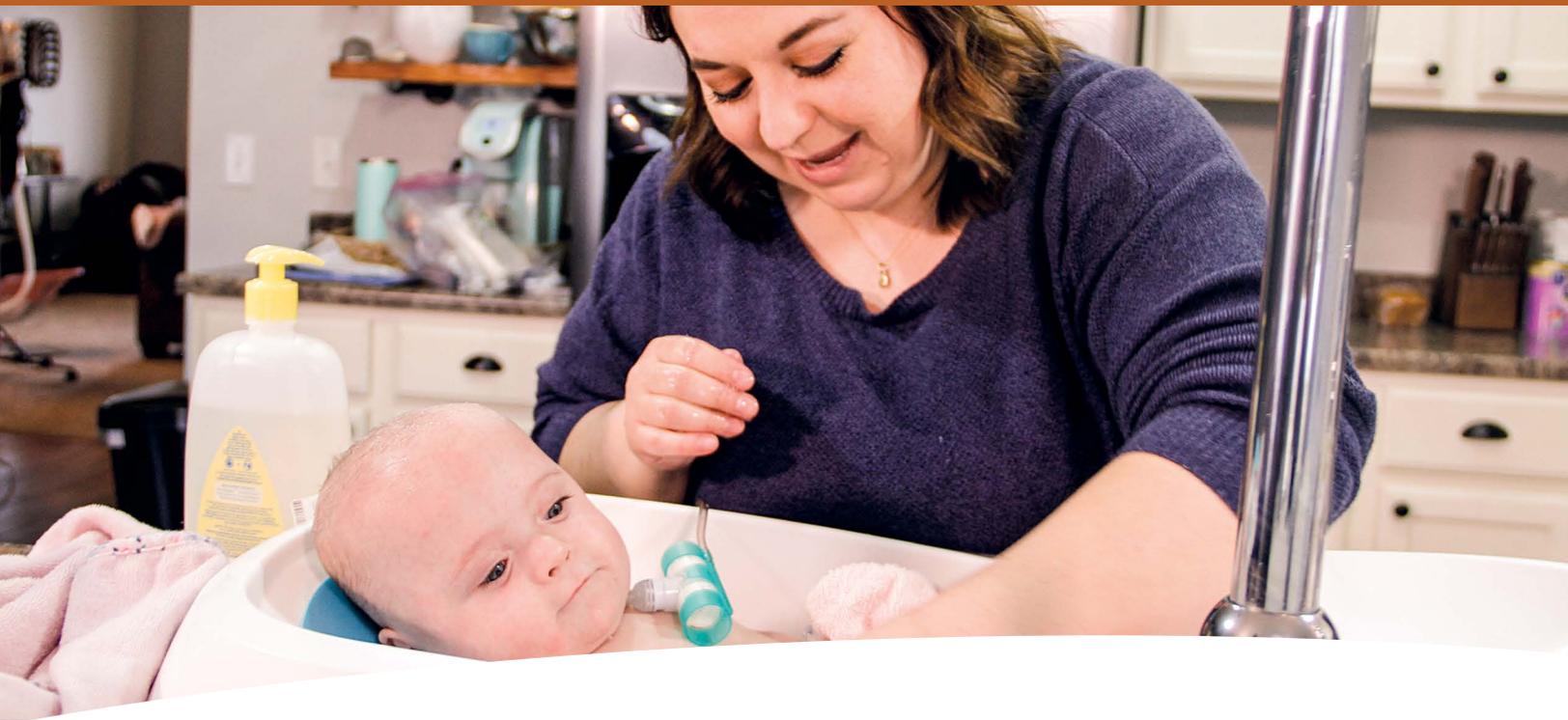
Daily life

While your child does have to be more careful when they have a trach tube, they can still do many of the same things other children can do.

Your child can travel with a trach

“When we first took a trip, it was to Park City, which is just 45 minutes from our house. Once we realized we could do that, we started going to California and lots of places around Utah. We’ve flown to Hawaii, we’ve gone on hot air balloon rides, and Presley plans on going to Mexico. We just live a really normal life. You have to give it more thought when you do go places, but it’s doable. You can still live the life you want to live and carry on as you were doing before the trach.”

Presley’s mom



Daily life

Playtime: It is important that your child has normal, age-appropriate playtime. This will help them reach developmental milestones. A child with a trach can use swings and bouncy chairs, play on the floor, and even do tummy time. Look at the toys your child plays with. Be aware that any small object that can be put in the nose or ear could easily go into their trach tube.

Communication: Your child's speech may be affected by a trach tube. Many parents worry they won't be able to hear their child cry. Speech therapy can help with this. Some children may be able to use a speaking valve to help them talk.

Discipline: Many parents are afraid to discipline a child with a trach tube. However, if you allow your child to do things other children aren't allowed to do, your child will soon recognize the power they have. Do not change the training, discipline, and love you give your child after they have a trach. Treat your child the same way you treat other children. Use rewards and consequences appropriate to their age and the situation.

Eating: Many children can eat normally with a trach. A swallow study can be done to see how well your child can eat and swallow.

Bathing: Children with tracheostomies can bathe and shower. However, you must protect the trach tube from water at all times. It is best to do trach cares after bath time and then put on clean, dry trach ties.

Clothing: Your child can wear their normal clothes with their trach. However, avoid turtlenecks, plastic-backed bibs, necklaces, or any clothing that could block the trach tube opening. Do not give your child blankets, pillows, stuffed animals or linens that could produce lint.

Pets: Your child should not have a pet bird and should avoid touching birds or going to places where birds live. Bird feathers have dust and mites that can enter your child's trach tube and make it hard to breathe. Your child can have other pets. Be sure to always wash your hands and your child's hands after touching, playing with, or caring for any animal.

Respiratory infections

A child with a trach is more likely to get respiratory infections. This is because the air they breathe is not filtered. Prevent respiratory infections by:

- Washing your hands and your child's hands well at all times
- Avoiding those who are sick with colds or flu
- Not smoking or allowing your child to be around secondhand smoke
- Keeping all equipment clean and well-maintained

School: Make arrangements with your local school district for your child to attend school. Have a safety plan in place and make sure your child's school and teachers know the plan.

Travel: Your child can take both short trips (grocery store, field trips, school bus rides) and long trips (vacations, air travel, camping). You just need to plan ahead.

- Call your DME provider to help with battery life, back-up equipment, and resources in the area where you're traveling.
- Contact airlines, cruise lines, and hotels about medical help, special accommodations, and travel requirements.
- Make sure your child can breathe easily in their car seat. Nothing should block the trach tube when they are properly strapped in.
- Pay attention to changes in weather, altitude, and environment. These can affect your child's breathing and secretions.
- When you are traveling alone in the car with your child, stop the car when you need to provide care. Do not drive and give your child care at the same time.

Challenges

You may encounter many different kinds of challenges, including:

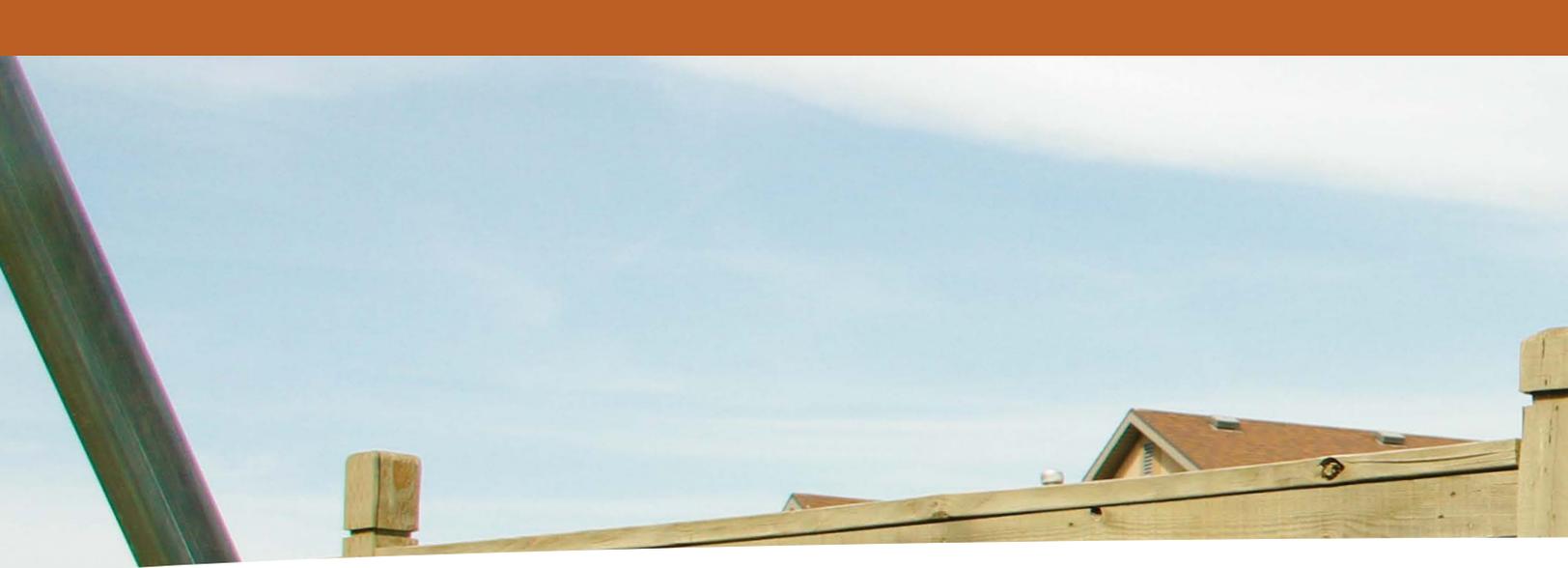
- Feeling overwhelmed
- Increased stress
- Marital problems
- Sibling jealousy, anger, or resentment
- Loss of privacy
- Loss of sleep
- Social isolation
- Financial burdens
- Physical demands
- Blurring parenting and caregiving roles
- Grieving the loss of a normal life

To manage these challenges:

- Take time for yourself, spouse or partner, and other children.
- Train other family and friends to help.
- Talk with other parents or caregivers in similar situations.
- Encourage your child's siblings to express their feelings.
- Use all the equipment and supplies, funding options, and government programs and assistance available.

The information in this booklet will help you feel more comfortable taking care of your child.

Remember: You are the expert on your child and a valued member of the healthcare team. You are your child's best advocate.



Glossary

Artificial nose: A device that provides moisture to the air breathed in through the trach tube. Also called an HME.

Auscultation (oss-cull-TAY-shun): Listening to the lungs with a stethoscope.

Bacteria (back-TEE-ree-uh): Germs that can cause infection.

Balloon: A small, plastic inflatable sac at the end of the trach tube cuff.

Bronchopulmonary dysplasia (bron-coh-PULL-mun-air-ee diss-PLAY-zee-uh), or BPD: Form of chronic lung disease that affects newborns.

Cannula (CAN-you-lah): The tube part of the tracheostomy tube.

Catheter (CATH-uh-turr): A thin, flexible tube used for suctioning.

Crackles: Wet, fine, or Velcro®-like sounds made in the lungs by secretions or fluid.

Cardiopulmonary resuscitation (car-dee-oh-PULL-mun-air-ee ree-suss-ih-TAY-shun), or CPR: Emergency life-saving procedures done when someone's heart or breathing stops.

Cuff: A balloon at the end of the trach tube that can be inflated to stop air flow through the mouth and nose.

Cyanosis (sigh-uh-NO-siss): A dusky or bluish discoloration of the skin or nailbeds caused by low oxygen levels in the blood.

Decannulate (dee-CAN-you-lait): To remove the trach tube from the stoma.

Dehydration (dee-high-DRAY-shun): The body's reaction when it doesn't have the amount of water that it needs.

Durable medical equipment, or DME: Machines and disposable supplies used to provide care at home.

Epiglottis (epp-ih-GLOTT-iss): A flap of tissue that opens and closes to seal off the windpipe during eating so food or liquid cannot be breathed into the lungs.

Esophagus (ee-SOFF-uh-gus): The tube that connects the mouth to the stomach.

Exhale: To breathe out.

Fremitus (FREM-ih-tus): Bubbling or rattling you can feel by putting your hands on a child's chest.

Heat and moisture exchanger, or HME: A device that provides moisture to the air breathed in through the trach tube. Also called an artificial nose.

Humidification (hue-MID-iff-ih-CAY-shun): To make the air damp with moisture.

Hydration (high-DRAY-shun): The supply of water to keep the body moist or fluid balanced.



Flange (FLAN-jee): The part of the trach tube where the trach ties attach to hold the tracheostomy tube in place.

Inhale: To breathe in.

Inner cannula: Removable inner tube on adult tracheostomy tubes.

Mucus: A sticky or slimy liquid produced by the lungs and windpipe. Also called secretions, sputum, or phlegm.

Mucus plug: A thick, sticky accumulation of mucus that can block the tracheostomy tube, windpipe, or other lung passages.

Nasal flaring: Widening the nostrils while breathing in.

Obturator (ob-too-RATE-orr): A plastic or metal stick you put inside the tracheostomy tube to make the trach tube stiff when you change it.

Oxivent: Connector with oxygen tubing that clips onto the artificial nose to deliver oxygen.

Retractions (ree-TRACK-shuns): Pulling or sucking in the skin and muscles around the bones of the neck, chest, and stomach when breathing in.

Rhonchi (RON-ky): Coarse bubbling or gurgling sounds made in the lungs by secretions.

Saline (SAY-leen): Salt water similar to fluid found inside the body.

Secretions (suh-CREE-shuns): Sticky or slimy liquid produced by the lungs and windpipe. Also called mucus, sputum, or phlegm.

Speaking valve: One-way valve that attaches to the tracheostomy tube and helps make talking possible.

Sputum (SPEW-tum): Sticky or slimy liquid produced by the lungs and windpipe. Also called mucus, secretions, or phlegm.

Sterile: Free from all germs.

Stoma (STOW-muh): Surgical hole in the neck where the tracheostomy tube is placed.

Stridor (STRY-door): Harsh, vibrating sound made when breathing in.

Suction: To suck out the mucus or secretions.

Swab: A bit of sponge, cloth, or cotton, sometimes fixed to a stick, for cleaning the stoma (cotton swab).

Swaddle: To wrap a child in a blanket with their arms tucked at their sides.

Trachea (TRAY-kee-uh): The windpipe.

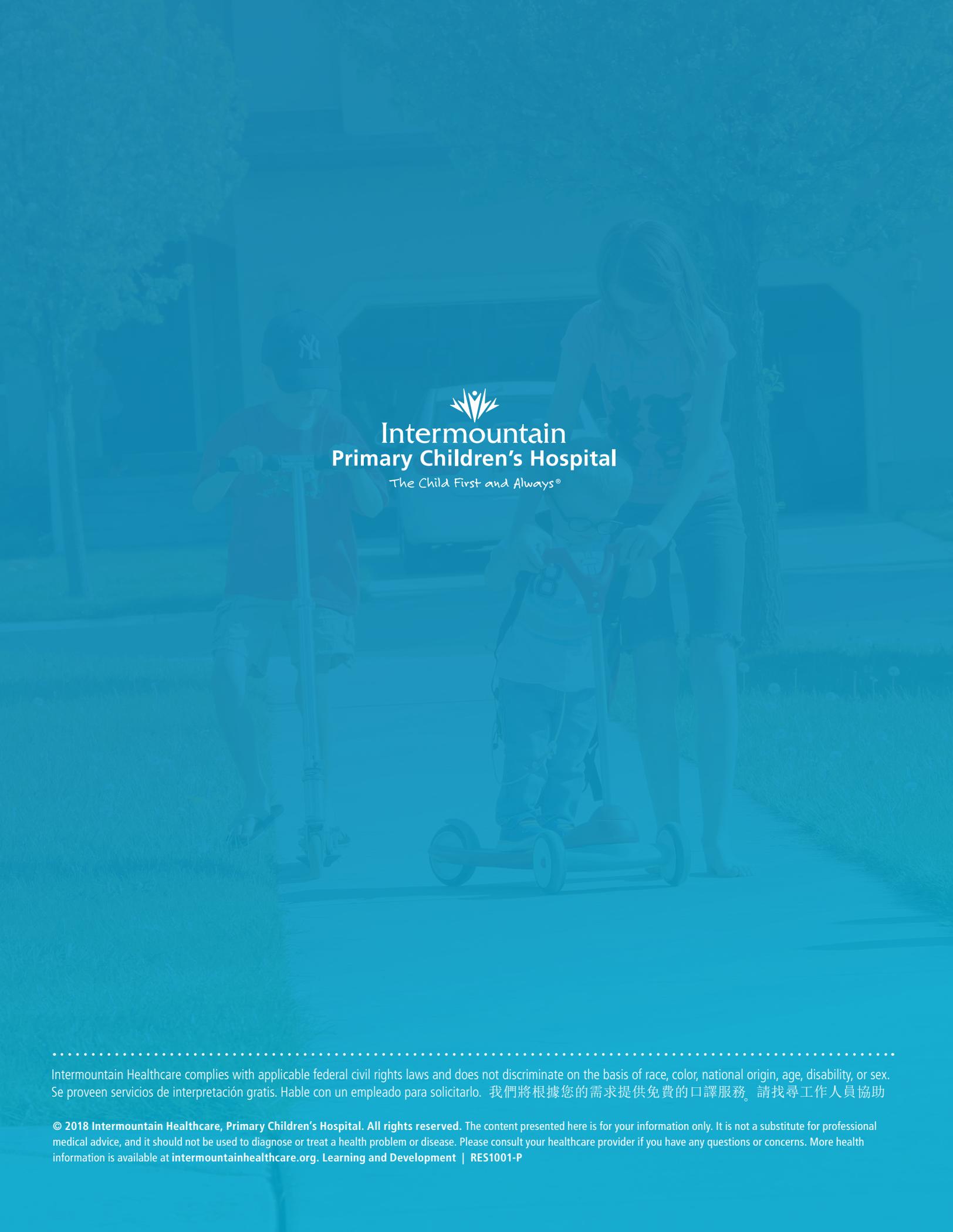
Tracheostomy (tray-kee-OSS-toh-mee) **tube:** Plastic tube put into the stoma that holds the airway open. Also called a trach tube.

Vocal cord: Two strips of tissue in the voice box that vibrate to make sounds when you talk.

Water-soluble gel: Gel that dissolves in water.

Wedge: Piece of plastic used to disconnect tight-fitted connections on the trach tube.

Wheezing: Musical sound made by narrowed airways in the lungs.




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