Health Facts for You

Preparing for your child's tracheostomy

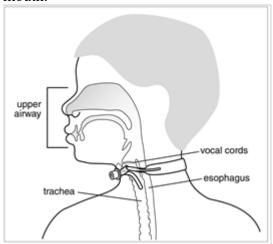




This guidebook will help you learn more about your child's medical condition including the need for a tracheostomy.

What is a tracheostomy?

A tracheostomy is an opening in your child's neck that goes to the windpipe (trachea). Surgery is done to make an opening called a stoma. A tracheostomy ("trach") tube is put in the stoma to help your child breathe. Your child will breathe through the trach instead of the nose or mouth.



Why do children need a trach tube?

Children need a trach tube for many reasons. Some children need a trach to keep their airway open, while others need help to breathe.

Children who have trouble keeping their airway open to breathe might have a narrowing of their airway, called stenosis. Causes may include:

- Growths or tumors.
- Birth defects.
- Vocal cords problems.

Children needing extra help to breath may need a machine called a "ventilator." Conditions that may cause this include longterm lung disease, complex heart disease, or problems with their nervous systems, which affect breathing. Children with general muscle weakness, such as neuromuscular disease, may need to be ventilated too.

Why does my child need a trach?

It is important to know why your child needs a trach. You and your child's doctor will talk about this. Please ask questions if you do not understand these reasons.

My child has a trach because:			

Learning About My Child's Trach

Once the decision is made to have a trach, you will learn how to care for the trach. The pulmonary nurse will meet with you to talk about training and scheduling classes. Training includes 4 classes. These classes are taught by a nurse and respiratory therapist. You will also have independent practice with guidance and assistance from your child's nurse. Two care givers need to complete the training. This ensures that your child has someone available at all times to take care of their trach.

When training is done and you have equipment for home, independent 24-hour care sessions must be done by both care givers. If needed, a car seat test will be done to ensure your child is safe in your car seat. You will practice packing everything and taking a "road trip" in the car before discharge.

My Child's Hospital Trach Team

There are many people on your child's trach team. It may be hard to know who does what and their roles. These are some of the people that will help make your child's plan.

Child's Caregivers

You! Yes, you are a vital member of your child's trach team. You will learn how to do all the cares your child needs.

Primary Nurse

A primary nurse is assigned when your child comes to the hospital. This nurse may change as needed. They will coordinate your child's care. This nurse is your "go to" person for questions about treatment and discharge plans.

Otolaryngology (ENT) Attending Doctor

This is a doctor trained to care for diseases and disorders of the ear, nose and throat (ENT). This doctor cares for your child's trach during the surgery and for at least the first 3 days after surgery. They do the first change of your child's trach tube after surgery.

Pulmonary Attending Doctor

This doctor is trained to care for diseases and disorders of the lungs. They care for your child's trach after the first trach change and will be charge of your child's medical care once the trach has been placed. They supervise resident doctors and medical students, and make decisions about your child's tests, treatments and discharge plans. This doctor changes 1-2 times a week.

Resident Doctors

A doctor who has finished medical school and is now learning more about caring for sick children. They are supervised by attending doctors.

Tracheostomy Coordinator

A nurse who helps you learn how to care for your child's trach and will teach the training classes. This nurse will help coordinate the care and planning to go home.

Respiratory Therapist

They regularly check your child's breathing and their trach equipment, do breathing treatments and give medicines to help your child breathe more easily. They also help with education about your child's medicines and treatments needed at home.

Respiratory Therapist Discharge Planner

They help organize and coordinate your child's respiratory equipment and supply needs for home. They will teach you about equipment and therapies for your child.

Social Worker

They help you to find resources in your child's community, help expand and strengthen your child's social support network and support you and your child with emotional, physical, and financial concerns.

Case Manager

They work with the team to create a discharge plan, help organize home care, nursing, and therapies for home. They coordinate equipment and supplies for your home.

Speech Therapist

They work closely with you and your child on speech, language, communication, and swallowing. They help to create a plan for eating and drinking.

Physical and Occupational Therapists

They work closely with you and your child to promote movement and function. They help to create a plan to support your child's important learning and development skills.

Registered Dietitian Nutritionist

They work with your child's team to create a feeding plan that meets your child's nutritional needs.

Health Psychologist

A doctor who assesses mood and behavior in children with health issues. They help you find helpful ways to cope with the stress of having a child with complex health issues.

Child Life Specialist

They teach your child and their siblings about chronic conditions in easy to understand ways. They work with your child to make plans to cope with painful procedures.

Pharmacist

They review your child's medicines on admission, during your stay and before discharge. They check medicine safety and teach about how to use medicines and their side effects.

Students

Students are in school to be doctors, nurses or other members of the medical team. They are supervised by a fully trained team member.

What You Can Expect with Surgery

Here at American Family Children's Hospital (AFCH) we want you to know what to expect in the first few days after surgery. In general, this is what you and your family can expect, but it may vary based on your child's needs.

Day of Surgery

Your child is taken to the third floor of AFCH for surgery. Staff let you know when you can be with your child. They also take your phone number and tell you where to wait during surgery. Your child will stay in or be moved to the Pediatric Intensive Care Unit (PICU) or Neonatal Intensive Care Unit (NICU).

Your child will have the trach tube in place. This tube will have black strings called sutures taped to the left and right side of your child's chest. The sutures are connected to your child's trachea and help keep their stoma open. They prevent the stoma from closing before it is healed if the trach tube accidentally comes out.

Days 1-3 After Surgery

The staff in the Intensive Care Units (ICU) do careful assessments on your child. They monitor your child's breathing and vital signs closely. The sutures remain taped to your child's chest.

Your child's trach tube ties will not be changed. Your child's ENT doctors will check your child's trach daily and change the gauze, if needed. Hospital staff will suction your child's trach tube often to keep it clear from secretions. Your child will restart their regular medicines and diet slowly and as tolerated.

During this time only the ICU staff and doctors will care for your child's trach. This allows time for it to heal. Even though you cannot care for your child's trach right away, there are steps you can take to begin to learn. The ICU staff can teach you how to suction your child. You can begin to read materials you are given.

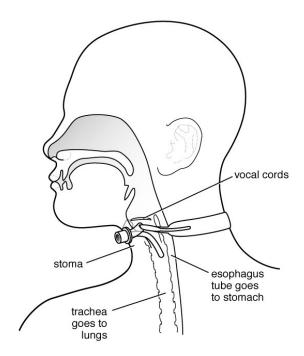
Days 3-5 After Surgery

ENT doctors will change your child's trach tube for the first time. They will remove the sutures that have been taped to your child's chest. Your child's trach ties will also be changed. After the ENT doctors have done the first trach tube change, the ICU staff will begin doing routine cares.

When medically stable, your child will move out of the PICU or NICU to a general care unit. The pulmonary team will manage your child's trach care. Once you are on a general care unit, more in-depth home training begins.

Swallow Concerns After a Tracheostomy

Swallowing is very complex. Swallowing needs perfect timing and coordination to make sure food and fluid safely go into the esophagus (the tube that goes from your mouth to your stomach). When your child has a tracheostomy, the anatomy, airflow and sensation of airway and throat structures change. This may affect the timing and coordination of swallowing. This may result in food or fluids going into the airway.



Swallowing Problems

A tracheostomy makes it harder to sense that something is in the airway. Sometimes, food or fluids sneak down the airway without knowing it or without causing a cough to clear it. This is called **silent aspiration**. When aspiration happens, there is a greater risk of choking and/or pneumonia. Your child may seem to do well eating and drinking but may still be at high risk for silent aspiration. Silent aspiration can lead to illnesses that may increase your child's hospital stay.

Swallow Study

Your child will have tests to check for swallowing problems. A Speech-Language Pathologist (SLP) will start with a clinical swallowing assessment. The SLP looks for feeding readiness skills such as alertness, and communication. They will also do small trials of foods or fluids with different consistencies. This depends on your child's age. The SLP closely watches and feels for signs of trouble swallowing and decides if your child is ready for more tests.

Videofluoroscopic Swallow Study (VFSS)

The risk of silent aspiration with a tracheostomy is very high. Your child will not be able to eat by mouth until having a Videofluoroscopic Swallow Study (VFSS). This study uses moving x-rays to clearly see where food or liquid is going when swallowing. Your child is fed different consistencies of barium. Barium is a substance that shows up well on x-rays.

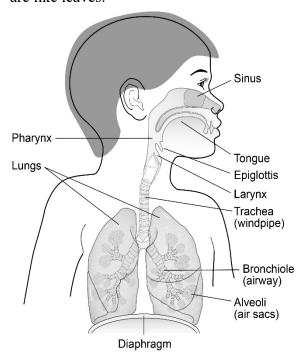
The SLP may feed your child, or we may ask a parent or caregiver to help if this will make it easier for your child to do the study. The SLP and Radiologist watch closely to see how and where the barium travels. We may try different thicknesses of foods, different positions, or different cups, utensils or bottles to figure out the safest options. After the study, the SLP reviews the video, and talks with you and your child's doctors about the safest way to feed your child based on the results of the VFSS.

Tracheostomy Basics

How Your Child Breathes

We want you to understand how your child breathes. The respiratory system is split into the upper and lower airways. Think of the respiratory system like an upside-down tree. The upper airway is the trunk and the lower airway are like branches and leaves.

Air enters the upper airway through the nose and mouth. The nose and mouth filter, warm, and moisten the air. Then, the air moves down (the trunk) through the throat (pharynx), past the voice box (larynx), and into the windpipe (trachea). The trunk then begins to split into the branches. This split begins at the end of the trachea (carina) and moves to the lower airway. The lower airway is formed as the branches divide out and become smaller and smaller. These branches are the bronchi. At the ends of the bronchi there are small air sacs (alveoli) that are like leaves.



As we breathe, we inhale and exhale. We breathe in air with oxygen. It travels through the mouth down the upper airway, to the alveoli and passes into the blood stream. In the blood stream, oxygen moves into the cells. The carbon dioxide moves from the blood stream into the alveoli, through the upper airway and back out the mouth. We then breathe out the carbon dioxide.

The **diaphragm** is the main muscle that helps us breath. It is a large dome shaped muscle below the lungs. We also use **intercostal muscles** to help us breath. They are located between the ribs.

Normal Breathing Patterns and Signs of Distress

It is very important to keep track of your child's breathing pattern. This helps you notice any concerning changes. You need to know what your child's normal or baseline breathing pattern is. Many different factors help to decide if your child is in any distress. These include:

- Skin color
- Skin characteristics
- Respiratory rate
- Heart rate
- Breathing effort
- Breathing sounds

Normal Breathing

- Easy breathing effort
- No nasal flaring

Abnormal Breathing

- Abdominal breathing or severe abdominal breathing
- Slight to severe retractions
- Some to severe nasal flaring

What to Expect for Your Child **Breathing Sounds** You will get to know what is normal for • Normal: Quiet your child. This is considered your child's • Abnormal: Coughing, stridor (high "baseline." Make notes about your child's pitch throat sounds), grunting, baseline. Learn what is not normal for your wheezing (musical sounds) • My child's baseline: child. **Skin Color** • Normal: Pink, warm Notes • Abnormal: Pale, white, blue gray • My child's baseline: _____ **Skin Characteristics** • Normal: Dry • Abnormal: Sweaty, cool, clammy • My child's baseline: _____ **Respiratory Rate** • Normal: • Abnormal: Faster or slower rate My child's baseline: **Heart Rate** • Normal: • Abnormal: Faster or slower rate My child's baseline: ______ **Breathing Effort** • Normal: Awake, alert, content, easy breathing effort • Abnormal: Less active, restless, irritable, lethargic, nasal flaring, retractions, head bobbing My child's baseline: _____

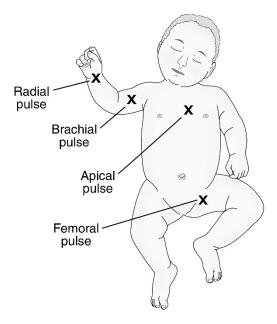
Counting Your Child's Heart Rate

The **heart rate** is the number of heart beats in one minute.

- 1. Use a watch with a second hand or a stopwatch.
- 2. Place your index and middle finger over the heart or major artery. See below for options.
- 3. You will feel a beating sensation.
- 4. Count how many beats in one minute.

Options for Finding the Pulse

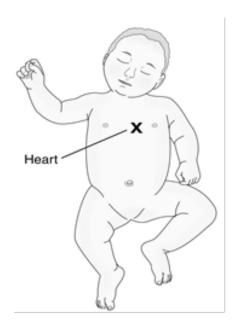
- **Apical pulse:** put your fingers over your child's left chest over the heart to feel the heart beating
- **Brachial pulse:** put your fingers above the elbow on the inside of the arm
- **Radial pulse:** put your fingers on the wrist just past the thumb
- **Femoral pulse:** put your fingers on either side of the groin and press down



Using a Stethoscope to Count Heart Rate

These are the steps for listening to your child's heart rate.

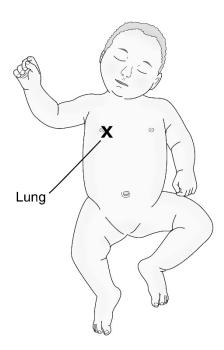
- 1. Put the earpieces in your ears, tips facing forward.
- 2. Gently rub the flat round piece at the end of the stethoscope. You should be able to hear through it.
- 3. Use a watch with a second hand or stopwatch.
- 4. Listen to the heart by placing the stethoscope on the left side of the chest between the child's nipples.
- 5. Count each time your child's heart beats. The heart rate has two sounds (lub-dub) that is counted as one heartbeat.
- 6. If you can't count for 60 seconds, count for at least 30 seconds and double the number.



Counting Your Child's Respiratory Rate

The **respiratory rate** is the number of breaths your child takes in 1 minute.

- Use a watch with a second hand or a stopwatch.
- Watch your child's chest go up and down. This is one breath. Or you can put your hand on your child's chest to feel the breath if this is easier.
- Count how many breaths your child takes in 1 minute.



Using a Stethoscope to Count Respiratory Rate

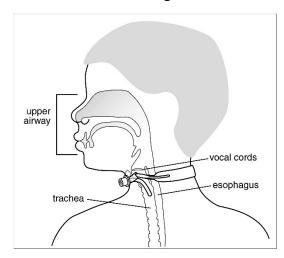
You may need to use a stethoscope to listen to your child's breathing. Here are the steps.

- 1. Put the earpieces in your ears, tips facing forward.
- 2. Gently rub the flat round piece at the end of the stethoscope. You should be able to hear through it.
- 3. Use a watch with a second hand or stopwatch.
- 4. Listen to the lungs by placing the stethoscope on the right side of the chest.
- 5. You will hear an inhale and exhale; this is one breath. Count each time your child takes a breath for 60 seconds.
- 6. If you can't count for 60 seconds, count for at least 30 seconds and double the number.

Types of Trach Tubes

Uncuffed Trach Tubes

A trach tube is a flexible soft plastic tube. It is smaller around than the inside of your child's airway. There are many brands and sizes of trach tubes. They come in different sizes and lengths. Your doctor will decide which type of trach tube and size is best for your child. As your child grows, the trach tube is switched to a larger size.



You need to know all of the parts of the trach tube.

- **Adaptor** is the outside opening of the trach tube. It is the same size on all trach tubes.
- Flange is the wings on both sides of the connector. The trach ties attach to the trach tube through the small holes on the flange. You can find the brand and size of the trach tube on the flange.
- Cannula is the curved part of the tube. It goes through your child's stoma into their airway.
- **Obturator** is a stiff rounded-tip guide that fits inside the trach tube. It is only kept in place when the trach tube is changed. It makes the trach tube stiffer and easier to insert. You take it out of the trach tube once the tube is in place.

Length and Size of Trach Tubes

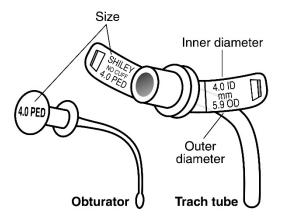
The tracheostomy tubes are measured by its length and size of diameters. Both vary from tracheostomy to tracheostomy. The diameters of the tracheostomy tube are measured by inner and outer diameters.

- Inner diameter (ID) of the tracheostomy tube is the size of the opening.
- Outer diameter (OD) is the thickness of the tube.

Trach tubes are measured in millimeters. There are three lengths of tracheostomy tubes commonly used with children.

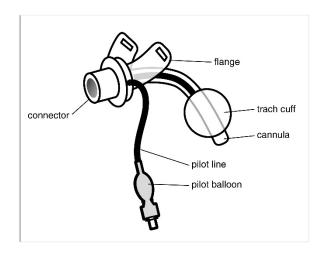
- 1. **Neonatal** or **NEO** tracheostomy tube is the shortest. It is commonly used for infants.
- 2. **Pediatric** or **PED** is used for older babies and children. It is slightly longer than a neonatal tube.
- 3. **Pediatric long** or **PDL** is the longest type of pediatric tracheostomy tubes. It is used for older children.

Your pulmonary team will decide the best size and length for your child.



Cuffed Trach Tubes

A cuffed trach tube has a small balloon at the lower part of the tube. The cuff is filled or inflated with air or sterile water to give it a snug fit in your child's airway. This kind of tube helps some children breathe more easily. When inflated, it seals the airway outside of the trach tube and allows the ventilator to give better breaths. The breaths given by the ventilator go straight to the lungs and do not leak out of your child's mouth or nose. Your pulmonary doctor will work with you to decide if this is the best type of trach tube for your child.



Suctioning

Lungs produce mucus to help the lining of the airway stay moist and helps to remove particles and germs from the lungs.

Normally, the mucus moves up the trachea until it can be swallowed or coughed out.

Children with trach tubes often cannot cough the mucus out of the trach tube. This can become dangerous if your child is not able to clear the secretions from the tube.

Suctioning removes the mucus or secretions from your child's airway and trach tube.

This helps your child breathe more easily.

When to Suction

You need to suction your child's trach tube at least 2 times a day. This helps to prevent mucus from building up and plugging the trach tube. Some children have certain times during the day that they need suctioning more often. Common times are when they first wake up or before they eat. Some children need it after they are active or crying. You will learn what your child's suctioning needs are as you learn more about care of a trach.

Signs That Suctioning Is Needed

- Mucus in the trach
- Gurgling or rattling in the chest
- Coughing
- Restlessness
- Breathing hard
- Color changes
- Sweating
- Retractions
- Nasal flaring
- Coarse breath sounds
- Faster heart rate
- Faster breathing rate
- Low oxygen levels
- Ventilator alarms

What signs does your child show when they need to be suctioned? (Circle or write in the blank lines below.)

How Deeply to Suction Your Child

You need to make sure you do not suction your child too deeply. This may cause damage and granulation tissue in the trachea. Suction only to the length of your child's trach tube.

Each brand and size of trach tubes has a different length. You will need to adjust the depth anytime your child's trach tube size or brand changes.

- Measure the depth on a used trach tube using a suction catheter.
- If you measure on a clean trach tube, you will need to reclean the tube.
- You will also want to know this depth any time you add any extra devices to your child's trach tube.
- For example, if you add a trach guard or a swivel attachment, you will need to know the depth from the opening of that device to the end of the trach tube.

Size of the Suction Catheter

Each brand and size of trach tubes' diameter is a little different. If the diameter of the suction catheter is too large it will not insert smoothly into your child's trach tube. It may even fully block the tube, making it hard for your child to breath. If the diameter of the suction catheter is too small, it will not suction your child's secretions as it should.

Check the diameter of the trach tube with a suction catheter anytime your child's trach tube changes size or brand. The diameter of the suction catheter is measured in French (fr).

To figure out the correct French (fr) size, you can double the trach size. For example, a 3.0 trach will fit a 6fr suction catheter. A 3.5 trach will fit an 8fr catheter.

Mv	Chil	ld's	Track	ı Tube

Brand:		
Suctioned	d with a	fr suction catheter to
the	_ cm mark.	

Example:

My child's trach tube is a 4.5 pediatric uncuffed Shiley. My child is suctioned with a 10fr suction catheter to the 5.5 cm mark.

How to Suction: Sterile Versus Clean Technique

We will teach you how to use a sterile and clean suction technique. When your child is in the hospital, you will use the sterile technique. This helps decrease the risk of your child getting an infection from germs that are in the hospital.

Equipment Needed

- Suction machine with canister and suction tubing
- Suction catheter kit
- Trach card showing how deep to suction
- Saline or sterile water

Steps for Sterile Technique

- 1. Wash your hands or use hand sanitizer gel.
- 2. Make sure all your equipment is within reach.
- 3. Turn the suction machine on.
- 4. Check suction pressure. You can do this by putting your thumb over the end of the suction tubing. The pressure gauge will rise.
- 5. The suction pressure depends on the age of your child. Too much suction pressure can damage your child's airway.

- 6. Adjust suction as needed.
- 7. Open the suction catheter kit.
- 8. Find the small cardboard box with plastic inside from the suction catheter kit. Open the box and pour saline or sterile water into the plastic lined box.
- 9. Put on sterile gloves.
- 10. Use your dominant hand as your "clean" hand.
- 11. Do not touch anything else with this hand except the suction catheter. Be careful not to let the end of the suction catheter touch anything else.
- 12. Use your non-dominant hand as your "dirty" hand. Use it to hold the suction tubing.
- 13. Insert the suction catheter into the suction tubing with your "dirty" hand.
- 14. Hold the suction catheter with your "clean hand" at the pre-measured depth of the catheter.
- 15. Remove anything covering the trach, such as trach collar, HME or ventilator circuit, with your "dirty hand."
- 16. Place thumb of your "dirty hand" over the suction catheter valve to create suction.
- 17. Slide the suction catheter tip into your child's trach tube. Roll the catheter in between your index finger and thumb. Suction as you enter and as you exit.
- 18. Insert the suction catheter until you reach the suction depth on the trach card. Do not suction for more than 5 seconds.
- 19. With thumb still on suction valve and suction catheter in trach tube, continue to roll suction catheter between the index finger and thumb as you are pulling out the catheter.

- 20. Once out of the trach tube, take your thumb off the valve to clear mucus from the suction catheter.
- 21. If secretions are thick, insert the catheter tip into the sterile water in the lined cardboard box and place thumb over valve. Suction water through the catheter to clear it. Repeat if needed.
- 22. When done suctioning, remove suction catheter from tubing.
- 23. Throw away the catheter and gloves.
- 24. Turn off suction machine.

Clean Suctioning Method

When your child is not in the hospital, use a clean suctioning method. This is because there is less of a chance that your child will get an infection from the germs in your home. You and any caregiver living in the house do not need to use gloves. Your child's home care nurses should wear gloves.

To suction using the clean method, follow the instructions above. (Family members do not put on sterile gloves.) When done suctioning your child, suction sterile water from the cardboard container to clean catheter of mucous. The suction catheter can be reused for up to 8 hours and stored in the original package or clean storage device such as a Ziplock® bag. Keep the suction catheter clean by not touching anything but the inside of the storage package or the inside of the trach. If the catheter touches anything unclean or is unable to be flushed free of mucous then it should be thrown away.

Suctioning Tips

- Suction as you enter and exit your child's trach.
- Roll the catheter as you suction. This allows all surfaces of the trach tube to be suctioned.
- Do not suction for longer than 5 seconds because it can block the trach tube and prevent air from reaching the lungs.
- If your child's secretions are thick, you may need to use sterile water or saline to clear the suction catheter.
- Often you will need to suction more than once to make sure the mucus is out. If you need to suction a third time, wait for several seconds to give your child a chance to take some breaths. If your child is on a ventilator, you can reconnect and allow the ventilator to give your child a couple of breaths.
- If mucous is thick and you're having trouble removing secretions from the trach, try dropping 2-3 drops of sterile saline, just enough to reach the mucous, into the inside of the trach. Then suction with the suction catheter. If the mucous still does not clear the trach after suctioning the saline drops out, you may attempt another 2-3 drops. Do not put too much saline inside the trach because too much will go into the lungs and increase risk for irritation, infection and prevent ventilation.

What to Look for When Suctioning

You need to look at your child's mucus when suctioning. It can tell you if your child is getting ill or dehydrated. Look at the thickness, amount, and color of the mucus.

Thickness

Mucus should be thin. It should be easy for you to suction it out of the trach tube. If it gets too thick it can plug the trach tube. **This is an emergency** and needs to be addressed right away. Change the trach tube if you are not able to clear the plug with suctioning.

Thick mucus may be caused by a lack of humidification, dehydration, or a respiratory infection. Be sure that your child is getting enough time on the heated humidification.

If you think your child is dehydrated from a lack of fluids, try giving extra fluids if you can. Watch for any other signs of a respiratory infection when your child has thicker mucus. Call your doctor and seek treatment if your child has a respiratory infection.

Amount

Each child makes a different amount of mucus. You will get to know what is normal for your child. Asking yourself these questions can help you figure out if your child has had any changes in the amount of mucus they produce:

- How much mucus is in the catheter when I suction?
- How many times have I had to suction to clear my child's airway?
- How often do I need to suction?

More mucus may be a sign that your child has a lung infection. You will want to watch for any other signs of an infection. Call the doctor (pulmonologist) if you think there is an infection. Less amounts of mucus mean that your child needs more humidification or is dehydrated. Make sure that your child is getting enough time on their heated humidification. If you think they are dehydrated, you can try giving them extra fluids.

Mucus Color			
What color is it?	What could it be from?	What should you do?	
Clear	Normal	Nothing	
White			
Cream colored			
Slightly yellow in			
the morning and			
clears during the day			
Yellow	Infection	Look for other signs of infection	
Tan			
Green			
Pink	Pink: irritation from	Pink: watch for more redness	
Red	increased suctioning,	Red : watch closely, call your doctor if it	
Brown	coughing, trach tube	doesn't improve within an hour or it is	
	change or scar tissue	enough blood to fill a suction catheter	
	Red: active bleeding	Brown: Watch for it to become more red	
	Brown: old bleeding		

