HOME INSTRUCTIONS FOR THE CAREGIVERS OF A CHILD WITH A TRACHEOSTOMY

A Guide For Caring For Your Child



Date: 02/17 Author: TRACh Team

Dear Caregiver,

This tracheostomy book was made to serve as a resource for you. The layout of this book is the order in which you will learn the skills needed to care for your child. We encourage you to review this book and write down any questions you may have in the note sections. Please keep this book with you at all times so you are ready for each teaching opportunity. The medical team will be happy to answer any questions you may have.

We understand that this is a stressful and difficult time for you and your child. The medical team will support you through this process by giving you education and keeping you updated on your child's medical condition. We will help you learn to care for your child's needs in preparing to go home. It is important that you have at least two caregivers who will learn how to care for your child. We will ask that all caregivers be at the hospital throughout this learning process to make sure all caregivers are comfortable caring for your child.

All caregivers will learn the skills listed in the book that are needed to care for your child. Once you have learned each skill, you will begin to practice that skill with your child. The nurses and respiratory therapists will work with you on these skills until you become comfortable.

After you have learned all of the required skills and are able to perform them independently, all caregivers will be expected to complete a room in. During the room in, each caregiver will independently give all cares for your child to include suctioning, trach care, medications, respiratory treatments, feedings, management of all home medical equipment, and routine care of your child. These tasks will be done with no help from the medical staff. Each caregiver will complete the room in individually before discharge.

If you have any questions, please contact:

Children's Health Tracheostomy Team: Tracheostomy RRT at 214-456-9764 or Tracheostomy RN at 214-456-9001. A message for either the Tracheostomy RRT or RN may be left at 214-456-2532.

Our Children's House Tracheostomy Team: 214-531-9388

Sincerely,

The Medical Team

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Basic Airway Anatomy

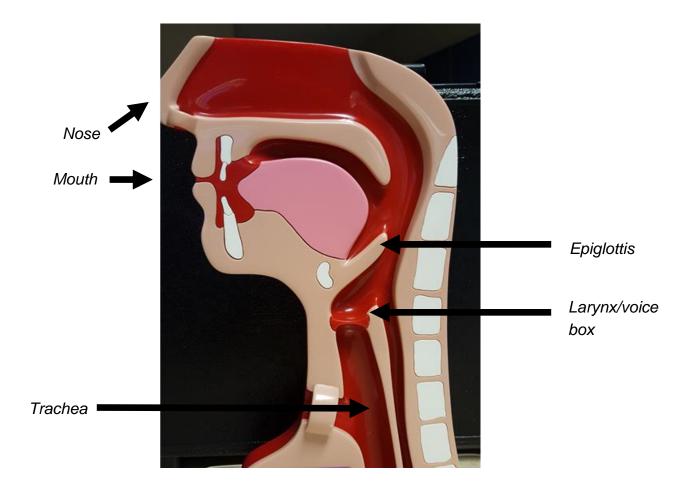
The Respiratory System is made of structures that help your child breathe. Breathing consists of the exchange of oxygen and carbon dioxide and is controlled by the brain. Adequate oxygen intake is needed for the vital organs, such as the heart, brain, liver, kidneys, intestines, and lungs to function and the body to grow. The following are the some of the structures located within the respiratory system.

<u>Nose and Mouth</u>-- Air comes in through the nose and mouth, where it is warmed and humidified before going to the lungs. The nose also filters the air as it enters the body. Warm humidified air keeps the tissue in the respiratory system from drying out.

<u>Larynx or voice box</u>—The area above the trachea that holds the vocal cords. Air moves over the vocal cords and that is how the voice is able to be heard.

<u>Epiglottis</u>—The area above the larynx that covers the entrance to the trachea to prevent food and liquid from entering the lungs when eating.

<u>Trachea</u>-- The large tube that branches off and connects to the lungs. This is often called the wind pipe.

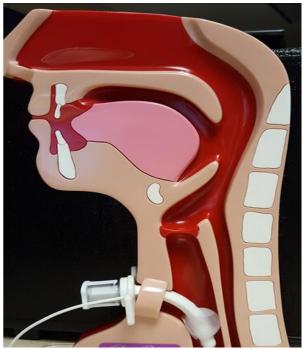


What Is A Tracheostomy?

Your child had a tracheostomy tube placed in the trachea, or windpipe, during surgery. We call this tube a "trach." The trach sits in a small opening made through the neck, called a **stoma**. This will now be the place where your child will breathe. Air will now enter and leave through the trach.

Several medical conditions can require children to get a trach. The length of time your child needs their trach varies from child to child, depending on their condition. Some trachs are only needed short term, while others are more long term. Your child's plan of care with the trach will be discussed with you by your child's doctor.

While your child is recovering from the surgery and the stoma is healing, your child will need to stay in bed. The ENT surgeon will decide when to change the trach tube for the first time. This will be five to ten days after the trach tube is placed. After the first trach tube is changed, we will begin practicing with your child the skills you have learned in the classes.



Since the trach is below the larynx (voice box), no air goes through the vocal cords. It is important to know that it will be some time before your child will be able to make any voice sounds. Your child will work with the speech therapist to practice making these sounds with their voice, if possible, and/or they will learn new ways to communicate.

The esophagus (feeding tube) and the trachea are two separate tubes. After the trach surgery, the area in the neck will be swollen. It will take some time before your child can swallow food safely. The sense of smell and taste may be different after your child has a trach placed. Your child will work with a speech therapist to learn and develop the skills needed to swallow solids and liquids safely with a trach.

Family Education and Expectations

Education begins before trach placement, once your physicians have talked to you about trach as an option for your child.

- The pre-trach evaluation will be done with the Tracheostomy Team to discuss your educational needs, figure out caregivers, and find out if any changes in lifestyle and living are needed.
 Children with a trach will need a car seat, stroller/wheelchair (if applicable), and his or her own bed for sleeping.
- 2. The first trach class, if possible, will be scheduled within 48 hours of your child having surgery.
- 3. You will be given a mannequin (if available) to practice trach skills until skills may be performed with your child.
- 4. The second trach class will be scheduled once you have completed trach class #1 and understand the skill set.
- 5. Is it important for you to be at the hospital each day to learn to care for your child.
- 6. CPR class will be completed before rooming in.
- 7. Ventilator classes #1 and #2 will be done after the doctors have chosen the type of ventilator your child will go home with.
- 8. Completion and understanding of all skills related to caring for a child with a trach will be determined by the Tracheostomy Team Educators.
- 9. Caregivers must be at the hospital for home medical equipment delivery and education from the medical equipment company.
- 10. Rooming in will be scheduled after completion of all education by all caregivers. Rooming in must begin at the time scheduled and all care must be given on schedule for successful completion of rooming in process.

TRACh Family Education Skills

All caregivers must show how to do each skill and not need prompting to finish the TRACh teaching. Once each skill is reached, caregivers will Room-In and get ready to go home.

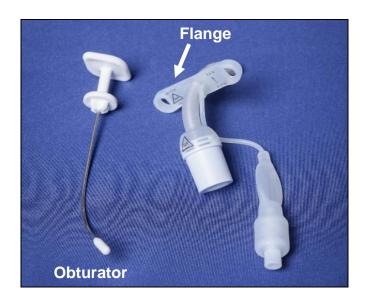
Skill	Without prompting, caregiver:	Date Reached
TRACh Care	Gathers all supplies and performs the steps of trach care.	
TRACh	Shows the right way to suction and knows	
Suctioning	when to suction at the right time.	
TRACh	Gathers all supplies and performs the steps	
Change	of trach change.	
TRACh		
Breathing	Gives breathing medicines and treatments.	
Treatments		
Feedings	Sets up and gives feedings on schedule.	
Medicines	Gives proper dose of all medicines.	
Ventilator Care	Shows how to handle and care for home ventilator.	
Cale	verillalor.	
TRACh	Verbalizes types of trach emergencies and	
Emergencies	how to care for child during each	
	emergency.	

Types And Parts Of Tracheostomy Tubes

Trach tubes come in many types, sizes and lengths to meet your child's needs. Your doctor will decide the best trach for your child. It is important to know that the type and size of your child's trach will change as they grow or have different medical needs.

Most trachs have the same basic parts, which are: the trach tube or cannula, the flange, and the obturator.





<u>Cannula</u>-- this is the piece that will be put into the stoma and rest in the child's airway.

<u>Flange--</u> the "wings" on the part of the trach that sits outside the neck where the trach ties will attach.

<u>Obturator</u>-- a strong piece of plastic placed inside the trach to allow easier insertion of the tube during trach change. It is immediately removed after the trach change.

CUFFED TRACHEOSTOMY TUBES



Sometimes, for many different reasons, children need a trach with a small balloon on the outside that is either filled with air or water. We call this a cuff. A cuff can help your child with ventilation if they need a ventilator. Your doctor will decide if your child will need a cuffed trach.

Suctioning The Tracheostomy Tube

WHY DO I SUCTION?

You will need to suction your child's trach to remove mucus from the airway. Suctioning may be uncomfortable, but will not cause your child any pain. Suctioning will help your child breathe easier.

After the trach is placed, you may notice your child has more mucus and needs more frequent suctioning. This extra mucus is normal after surgery and should improve over time.

WHAT WILL I SUCTION?

- You will normally suction mucus that is thin and clear to white in color.
- Yellow or green mucus may mean your child has an infection.
- Thick mucus may mean that your child needs more humidification.

WHEN DO I SUCTION?

You should suction as needed, based on the needs of your child. We will help you in learning the baseline for your child's breathing. This will allow you to know when your child needs suctioning.

Other signs to look for are:

- Your child may be restless and is not able to be calmed.
- Your child may breathe faster or harder.
- You may hear a rattling or gurgling noise from the trach.
- You may hear a rattling noise from the chest.
- You may see bubbles of mucus at the trach.
- Your child may have a frightened look.
- Your child's nostrils will flare out.
- The color around the mouth may be pale or blue.
- The skin around the rib cage may "pull-in" or retract.

HOW TO MEASURE SUCTION LENGTH?

To measure your child's suction catheter depth place the suction catheter in a clean trach until the catheter extends 1mm beyond the tip of the trach. Observe the measurement at the insertion point; this will be the number and/or color you will suction to.



HOW DO I SUCTION?

Suctioning is done as a clean technique. A clean technique means that tasks are performed in a way to make sure the equipment does not become contaminated or dirty. It is important to wash your hands, use a clean suction catheter, and wear gloves (single use catheter kits have gloves) each time you suction. Be sure not to allow the tip of the catheter to touch any surfaces. This will contaminate the suction catheter and put your child at risk for infection.

TYPES OF SUCTION CATHETERS

. Below you will see the 3 main types of suction catheters that can be used in the home:



Ballard In-Line-- most commonly used in ventilator dependent children, but can also be used in trach-only children. With this catheter, you will suction to a specific color that is associated with a number. Your Durable Medical Equipment (DME) company will help you with the frequency of changing these catheters.



<u>Single-Use</u>—the kit contains a suction catheter and sterile gloves. With this catheter, you will put on the gloves in the package and suction to the premeasured number. These catheters are to be thrown away after each use.



Sleeved Suction Catheter-- these catheters are covered by a clear plastic sleeve. With this catheter, you will suction to a premeasured number. These catheters are to be changed daily or if the catheter touches any surface.

SUCTION SUPPLIES

- Suction machine
- Suction catheters
- Self-inflating bag WITH face mask
- Normal saline or sterile water in disposable cup
- Disposable gloves
- Disposable saline vials or "bullets", if needed

STEPS FOR SUCTIONING

- 1. Wash hands with soap and water for 15 seconds and dry hands with a clean towel.
- 2. Have all of your child's equipment set-up and ready on a clean bedside table.
- 3. Connect suction catheter to suction machine tubing.
- 4. Turn on machine and check to make sure suction pressure is correct.
- 5. Two or three drops of saline may be squirted down the trach. If mucus is thin, saline may not be needed.
- 6. Gently put the catheter into the trach to the premeasured length.
- 7. Place your finger/thumb over the suction valve to make a vacuum and pull out the catheter.
- 8. The suction process should take 3-5 seconds.
- 9. Check the amount, color, and consistency of the mucus and rinse the catheter if needed with saline or sterile water.
- 10. You may need to repeat these steps until the mucus is cleared.
- 11. Clean and/or place suctioning supplies in proper location and turn off suction machine.
- 12. Wash and dry hands.

HELPFUL HINTS FOR SUCTIONING

- If you are suctioning blood tinged mucus, this may mean your child needs more humidification.
- You may use more saline when suctioning if mucus is too thick.
- Check suction depth to make sure you are not suctioning past your premeasured number/color
- Notify your doctor if blood tinged mucus does not improve.
- You should never suction bright red blood. This is a medical emergency and your child should be seen immediately.
- Never re-insert a suction catheter into the trach that has been in your child's mouth or nose.

Tracheostomy Skin Care And Trach Ties

Regular care to the skin of the neck underneath the trach ties is needed to keep the area clean and to prevent infection and skin breakdown. Trach care needs to be done at least once every day, or more frequently if the ties become wet or soiled. Trach care should be performed with two caregivers.

SUPPLIES NEEDED

- 3 wash cloths
- Mild soap
- Cotton applicators
- Spare trachs
 (same size & smaller size)
- Sterile water or saline
- Clean trach ties cut to appropriate length
- Shoulder roll

- Gauze dressing (optional)
- Foam dressing (optional)
- Scissors

STEPS FOR CLEANING

- 1. Wash hands with soap and water for 15 seconds and dry hands with a clean towel.
- 2. Set up supplies on a clean bedside table.
 - a. Wet cotton applicators with sterile water or saline.
 - b. Prepare a soapy wash cloth, wet wash cloth, and dry wash cloth.
 - c. Cut the correct length for trach ties to fit your child's neck.
 - d. Connect back Velcro on new ties. Do not cut Velcro tabs.



3. Place shoulder roll under child's shoulder blades.



- 4. Ask a second caregiver to help with trach care; this person will hold the trach tube in place while you clean the skin. This person **cannot** let go of the trach tube until the new ties are in place and secure. The person holding helps make sure the trach tube stays in the stoma.
- 5. Remove the trach ties from the left and right flange.
- 6. Remove soiled dressing (if dressing used).
- 7. Working in sections, use wet cotton applicators to clean skin around stoma and under the flange of the trach tube. Using a rolling motion, work from the center and move outwards. Never wipe in a back and forth motion. Assess the stoma for signs of infection such as redness, swelling or drainage. Use only one cotton applicator per swipe.
- 8. Working in sections, use dry cotton applicators to dry the skin around the trach stoma and under the flange of the trach tube. Using a rolling motion, work from the center and move outwards. Never wipe in a back and forth motion. Use only one cotton applicator per swipe.



Stoma Care should be done once daily or as frequently as you feel necessary, simply by repeating step 7 & 8.

- 9. Clean from front to back all areas of your child's neck with the soapy wash cloth. Then rinse with a wet wash cloth. Pat dry with dry wash cloth.
- 10. Assess skin of the neck for signs of infection, redness, swelling, open areas or drainage.
- 11. Slip the thin Velcro® flap through the opening on the flange and fold it back onto the trach tie.
- 12. Repeat this step on the opposite side.





13. After this is completed, check to make sure the trach ties are not too tight or too loose by fitting one finger in between the neck and the tie. If the tightness of the ties is correct, the person holding the trach tube can let go.



Changing The Tracheostomy Tube

Every week you will change your child's trach to stop mucus from collecting in the trach and plugging it off. You will also change your child's trach sooner if it accidentally comes out or becomes "plugged" with mucus before your routine trach change.

Trach changes should always be performed with **two people**, unless in an emergency scenario.

SUPPLIES NEEDED

- Clean trach with obturator (same size)
- Clean trach with obturator (one size smaller)
- Velcro ties cut to fit your child's neck
- Syringe (for cuffed trachs)
- Oxygen if necessary

- Lubricating jelly
- Shoulder roll
- Suctioning supplies
- Self inflating bag WITH face mask
- Sterile water for inflating the cuff if needed

STEPS FOR CHANGING THE TRACH

- Wash your hands with soap and water for 15 seconds and dry your hands with a clean towel.
- 2. Get the same size trach tube ready.
- 3. Inspect the trach tube for cracks, tears, or stiffness. If the trach tube is cuffed, inflate and deflate the cuff before changing to make sure it is working and no leaks are found.
- 4. Place trach tube in lubricating jelly.
- 5. Place shoulder roll under your child's shoulder blades.
- 6. Suction the trach tube if needed as outlined in Steps for Suctioning.
- 7. Remove trach ties; perform trach care as outlined in *Tracheostomy Skin Care and Trach Ties*.
- 8. If your child has a cuffed trach, be sure to deflate it now with a syringe.
- On the count of three, have the second caregiver remove the old trach tube and lay it to the side. Your child will be able to breathe for a few seconds while you put in the clean trach tube.

10. Put in the new trach tube and immediately remove the obturator with your free hand while holding the trach tube in place.



- 11. Next, secure the trach ties around your child's neck; you should only be able to place one finger in between the neck and the ties. . If the tightness of the ties is correct, the person holding the trach tube can let go.
- 12. If your child has a cuffed trach tube, fill the cuff as directed.
- 13. Lastly, clean the old trach tube. Examine the old trach tube. See the section on *Cleaning Your Trach Tube* for further instruction.

FALSE TRACK

False tracking can occur when replacing the trach tube. This happens when the trach tube goes into the stoma but not into the airway. Air will not go into the lungs with false tracking. Your child will have breathing problems and may turn blue if this happens. Immediately remove the trach tube and put it back in to get it in the correct place.

HELPFUL HINTS FOR CHANGING THE TRACH TUBE

- You will NOT be hurting your child when you change the trach tube.
- It can be difficult to change the trach tube if your child is crying and upset. Your child may also cough during trach tube changes.
- Try to keep them calm during the trach tube change.
- You should NEVER force the trach tube into the stoma—this will put your child at risk of placing the trach tube into the wrong area, also known as a "false track."
- We recommend you change your child's trach tube before they eat or a few hours after eating to try to stop your child from vomiting.

IF UNSUCCESSFUL REPLACING THE TRACH TUBE:

- Try to reposition your child so their head is flexed back and you can see the stoma more easily.
- If your child is crying and upset try to wait until calm and then put in the trach tube.
- If you cannot get the same trach tube into the stoma, try to put in the one size smaller trach tube. If you place the smaller size trach tube in your child, call your child's ENT doctor.
- If your child continues having trouble breathing or if you are unable to place a trach tube in your child, provide bag/mask breathing over the mouth/nose while covering the stoma, call 911 and begin CPR, if needed.
- Continue to give your child bag/mask breathing until:
 - o they are breathing on their own,
 - the trach tube is re-established, or
 - emergency personnel arrives

Cleaning The Tracheostomy Tube

CLEANING YOUR TRACH TUBE WHILE IN THE HOSPITAL

While your child is in the hospital, clean your child's trach tube with mild soap and sterile water.

CLEANING YOUR BIVONA TRACH TUBE AT HOME

Once you are discharged home to clean the trach tube you will:

- 1. Soak the trach tube and the obturator in a container with hot soapy water for 60 minutes. Use a mild soap for this.
- 2. Make sure the water reaches all parts of the trach tube to be cleaned. This includes flushing the water through the trach tube.
- 3. Rinse the trach tube and obturator thoroughly with clean water.
- 4. Allow the trach tube and obturator to dry completely before placing in a clean plastic bag. Remember to replace the trach ties and lubricating jelly in the emergency bag.
- 5. While cleaning, inspect the trach for cracks, tears, or stiffness. If you find any of these, notify your DME so a replacement can be ordered. **Do not reinsert a damaged trach tube back into your child.**

At home you can also sanitize the **Bivona** trach tube:

- 1. Before the next use of the trach tube, remove the trach tube and obturator from the plastic bag and place them side by side in a pan of boiling clean water.
- 2. Cover the pan and REMOVE IT FROM THE HEAT.
- 3. Allow the water to cool to "hand hot" before removing the trach tube and obturator. The water should still be hot but cooled enough to touch without getting burned. Handle the trach tube by the flange and the obturator by the handle.
- 4. Allow the trach tube to cool and dry completely then get ready for the trach tube change.
- 5. Always refer to your product guide for instructions on cleaning and care.

CLEANING YOUR SHILEY TRACH TUBE AT HOME

Once you are discharged home, to clean the trach tube you will:

- 1. Clean with water and mild soap.
- 2. After cleaning, thoroughly rinse with sterile saline to remove any soapy residue.
- 3. While cleaning, inspect the trach for cracks, tears, or stiffness. . If you find any of these, notify your DME so a replacement can be ordered. Do not reinsert the damaged trach tube back into your child.
- 4. Allow the trach tube and obturator to dry thoroughly before placing in a clean plastic bag. Remember to replace the trach ties and lubricating jelly in the emergency bag.
- **5.** Always refer to your product guide for instructions on cleaning and care.

Dual Cannula Tracheostomy Tube w/Inner Cannula

WHAT IS AN INNER CANNULA?

Older children may have a trach tube with an outer and an inner cannula. If your child requires this type of trach tube, the entire trach tube will be changed once a month. The outer cannula holds the airway open. The inner cannula fits inside the outer cannula and is changed daily. The re-usable inner cannulas are cleaned with warm water and mild soap and can be reused. The disposable inner cannulas are thrown away after each use. This is usually done with trach care.

There are two kinds of cannulas:

<u>Disposable</u>— thrown away after each use.



Re-usable-- cleaned and reused.



Note Page				

Humidification

WHAT IS HUMIDIFICATION?

Children <u>without</u> tracheostomies take a breath in through their nose or mouth. The air is filtered and warmed before it goes into the lungs. Now that your child has a trach, a device must be used to filter and warm the air. Your child will need to use the heated trach collar system or Heat Moisture Exchanger (HME), also known as the "artificial nose."

TRACH MASK OR TRACH DIRECT CONNECT

A trach mask is a device that is placed around the neck. The trach direct connect attaches to the trach tube. This allows warm, moist air to be blown directly into the trach tube. This system is most often worn when your child is sleeping. Oxygen can also be given through this device if needed







HEAT MOISTURE EXCHANGER (HME)

The HME is also known as the "artificial nose." It is a small, disposable device placed onto the tip of the trach tube that uses the warmth and moisture from your child's airway. The HME has filter paper on the ends. It also stops small things from getting into the airway through the trach tube. This device can also be used to give oxygen. If mucus clogs the HME, you can try to remove the mucus.

Emergency Preparedness

When you are traveling or at home with your child, an emergency bag of equipment should always be ready and available to you. Accidents can happen. We want you to be ready. Your emergency bag should be large enough to have all the supplies in 1 bag.

TRAVEL SUPPLIES/EQUIPMENT

- Same size trach tube and obturator.
- Smaller size trach tube and obturator
- Suction catheters
- Self-inflating bag WITH face mask
- Normal saline
- Extra trach ties
- Lubricating jelly
- Scissors
- Syringe if your child has a cuffed trach tube
- HME'S
- Phone list of emergency contacts and physicians
- Ventilator
- Feeding Pump
- Portable Suction Machine
- Pulse Oximeter Machine
- Oxygen Tank
- Nebulizer (if necessary)
- Fully charged back-up battery
- Car adapter for your battery
- Medical Record with ventilator settings, medications and treatments.

Be sure to take all electrical cords for equipment in case you need to plug equipment into an electrical outlet when you reach your destination.

NOTIFYING COMMUNITY RESOURCES

It is important to notify community resources before your child's discharge. This will let them be better prepared in case of an emergency or should there be an interruption of services. These community resources include:

- Ambulance/ Emergency Medical Service (EMS)/ Fire department
- Electric/ Phone/ Gas Company

Be sure that your home address can be seen from the street. This will make it easier for EMS to locate your home in case of an emergency.

Submit an application with the Public Utility Commission of Texas for children with chronic conditions or critical residential customers.

- The application can be accessed at http://www.puc.texas.gov, search for "Application for Chronic Condition or Critical Care Residential Customer Status".
- For questions about the application, call the customer's transmission and distribution utility (TDU) during normal business hours at the phone number below:

TDU:	Phone:	Fax:	Email Address:
AEP Texas Central	877-547-5513	361-880-6027	billing-dereg_texas@aep.com
AEP Texas North	877-547-5513	361-880-6027	billing-dereg_texas@aep.com
CenterPoint Energy	713-945-6353	713-945-6357	criticalcare-res@centerpointenergy.com
Nueces Electric	800-632-9288	361-387-4139	criticalcarereg@nueceselectric.org
Oncor	888-313-6862	800-666-3406	contactcenter@oncor.com
Sharyland Utilities	800-442-8688	432-756-2866	suhelp@sharyland.com
Sharyland Utilities-McAllen			
Texas-New Mexico Power	800-738-5579	972-420-7628	criticalcare@tnmp.com

Contact List

Name of Child
Address
Birthday
Home Phone number
Parents/caregivers
Parent/Caregiver Phone number
School and phone number
Insurance Company and phone number
Local Fire Department and phone number
Electric Company and phone number
Telephone Company and phone number
<u>Providers</u>
Primary Care doctor and phone number:
ENT doctor and phone number
Pulmonary doctor and phone number
Specialist and phone number
Specialist and phone number
Pharmacy and phone number
DME Company and phone number
Nursing Agency and phone number

Caregiver Safety Checklist

Each time you are with your child, check the things below:

- 1. Your child is correctly connected to pulse oximeter machine when needed.
- 2. Pulse oximeter alarm settings are correct and sound when child is disconnected.
- 3. Trach tube is in place.
- 4. Trach ties are one finger tight.
- 5. Trach tube is connected to ventilator/humidity source.
- 6. Ventilator is set as ordered.
- 7. Trach emergency bag is within reach and has all supplies.
- 8. Self-inflating bag is connected to oxygen.
- 9. Suction is working and suction catheters are within reach.
- 10. Blank nursing order sheets are in travel bag.
- 11. Check medications and supplies for amounts. Call for refills if needed.
- 12. Back-up batteries are charging.
- 13. Emergency contact list is available.

Vital Signs

Vital signs are an important piece of assessing your child for problems and can be a clue that your child is not feeling well. It is important that you begin to learn what the normal heart rate, respiratory rate and oxygen saturation are while your child is well.

HEART RATE/PULSE

Heart rate is the number of beats per minute the heart beats. At home, you should count your child's pulse for 1 minute (you will be taught how to find your child's radial and/or brachial pulses); this will give you the child's heart rate. You can also use the pulse oximeter machine for your child's heart rate.

YOUR CHILD'S NORMAL HEART RATE:

RESPIRATORY RATE

Respiratory rate is the number of breaths per minute your child takes. This number will let you know if your child is breathing faster than normal or too slow. You will be taught how to count your child's respiratory rate.

YOUR CHILD'S NORMAL RESPIRATORY RATE: _____

OXYGEN SATURATION

Oxygen Saturation is the amount of oxygen in your child's blood. We get this number by placing a probe on your child's finger, toe or the outside part of their foot. This probe is called a "pulse ox". If your child is moving or kicking, you will not be able to get a correct reading. Wait until your child is calm and still before getting the oxygen saturation number. If you are unsure of your child's oxygen saturation, remember it is more important to look at your child's color and the way they are breathing to see if there is a problem.

KEEP YOUR CHILD'S OXYGEN SATURATION ABOVE: ____

Your doctor will tell your child's oxygen saturation range to you. Do not change these limits unless told by your physician.

Respiratory Distress

WHAT IS RESPIRATORY DISTRESS?

Respiratory distress happens when your child shows different signs that may mean they are having trouble breathing. These are warning signs that let you know that your child may need medical attention to help them breathe. We want you to understand what your child looks like when they are well or at their "baseline". This will help you to notice if something is wrong with your child or if your child is having is in an emergency. We want you to be able to act quickly in case of an emergency.

POTENTIAL SIGNS OF RESPIRATORY DISTRESS

RESPIRATORY RATE— the respiratory rate is the number of times your child breathes in one minute. If your child is breathing too fast or too slow, it may mean your child is having trouble breathing and/or cannot get enough oxygen to the body.

<u>Wheezing--</u> a continuous, whistling sound made when your child is breathing. It may mean your child's airway is narrowed or occluded.

COLOR CHANGES— a pale, blue or grayish color noted around your child's mouth. This may mean your child is not getting enough oxygen to their body.

NASAL FLARING-- this happens when the openings of the nose flare out during breathing. This may mean your child is having difficulty breathing.

RETRACTION-- this happens when the skin around the rib cage pulls-in when your child breathes in. This may mean your child is having difficulty breathing.

HOW DO I RESPOND?

- Check to make sure your child's trach tube has not come out.
- Suction your child's trach tube and/or nose or mouth.
- Change the trach tube if it is plugged or occluded.
- Provide oxygen to maintain their oxygen saturation at the level ordered by your doctor.
- Reposition your child; try to sit them more upright.
- If your child continues having trouble breathing, help them with breathing by either bagging the trach or give bag/mask breathing over mouth/nose while covering the stoma, call 911 and begin CPR, if needed.

Manual Ventilation

WHEN SHOULD I USE MANUAL VENTILATION ("BAGGING")?

- 1. Airway emergencies.
- 2. Ventilator circuit changes.
- 3. Troubleshooting a ventilator problem.
- 4. When your child's ventilator is not working.

HELPFUL HINTS FOR MANUAL VENTILATION

- Give the same number of breaths as the rate set on the ventilator.
- If the self-inflating bag has a PEEP valve adjust to the PEEP set on the ventilator.
- Watch for chest rise when squeezing the bag to give a breath.
- Do not leave the bag attached to your child without squeezing it to give breaths. Your child will not be able to breath.



Potential Emergencies

WHAT IS A MUCUS PLUG?

Mucus can become dry and thick and collect in the trach tube. Mucus can build up and block the trach tube. This means the trach tube is "plugged" off and your child needs immediate attention.

WAYS TO STOP A MUCUS PLUG FROM HAPPENING

- Make sure they are getting the proper amount to drink by mouth or by gastric tube to stay well hydrated.
- A heated trach collar system is to be used while your child is sleeping.
- Use a heated trach collar system if you notice your child's mucus is too thick or blood tinged.
- Use an "artificial nose" or HME when the trach collar is not being used; usually during the daytime.
- Use saline drops to help make the mucus thinner.
- Change the trach tube weekly.

SIGNS THAT A TRACH TUBE MAY BE PLUGGED.

- Your child may be restless and is not able to be calmed.
- Your child may breathe faster or harder.
- You may hear a whistling noise from the trach.
- Your child may have a frightened look.
- Your child's nostrils may flare out.
- The color around the mouth may be pale or blue.
- Your child's pulse oximeter reading may be lower than normal.
- The skin around the rib cage may "pull-in" or retracts.
- You may be unable to pass the suction catheter through the trach.

HOW TO REMOVE A MUCUS PLUG

- 1. Put saline drops into the trach tube and try to suction your child's trach tube.
- 2. If not able to suction the mucus plug from trach, change the trach tube.
- 3. If your child is having trouble breathing or if you are not able to place a new trach tube, give bag/mask breathing over mouth/nose, call 911 and begin CPR, if needed.

WHAT IS AN ACCIDENTAL DECANNULATION?

Accidental decannulation is when the trach tube comes out of the stoma by mistake. This sometimes happens when trach ties are too loose, during trach care, or if it was accidentally pulled it out.

WAYS TO STOP ACCIDENTAL DECANNULATION FROM HAPPENING

- Check to make sure the trach ties are fastened securely frequently throughout the day.
- If you notice the ties are loose, tighten them immediately.

SIGNS THAT A TRACH MAY HAVE COME OUT

- You may hear your child's voice if you were not able to hear their voice before.
- Your child may be restless and is not able to be calmed.
- Your child may breathe faster or harder.
- Your child may have a frightened look.
- Your child's nostrils may flare out.
- The color around the mouth may be pale or blue.

HOW TO REPLACE A DECANNULATED TRACH

- 1. Stay calm to think clearly.
- 2. Notify someone near you that "the trach has come out!"
- 3. Reinsert trach tube as you would if you were routinely changing the trach.
 - During this time, it is okay to replace the old trach tube that has just come out if a clean trach is unavailable. Once your child is back to baseline, replace this trach tube with a clean one.
- 4. If not able to replace the decannulated trach tube, reposition your child's head and try to put in the trach tube again. You may need to re-lubricate the trach tube.
- 5. If you cannot get the same trach tube into the stoma, try to put in the smaller size trach tube.
- 6. If your child continues having trouble breathing or if you are not able to place a new trach tube, give bag/mask breathing over mouth/nose while covering the stoma, call 911 and begin CPR, if needed.
- 7. Continue to give bag/mask breaths to your child until: they are breathing on their own, the trach tube is put back in, or until emergency personnel arrives.

WHAT CAUSES BLEEDING FROM MY CHILD'S TRACH?

Bleeding from the trach is concerning and may indicate an emergency. If you are seeing bright, red blood from the trach, this is a serious emergency and you need to call 911. Other times, you may notice blood-streaked mucus, this may be from:

- Suctioning the trach too deep.
- · Your child may have an infection.
- Your child is coughing more than normal.
- Your child may have irritation from the trach in the airway.

HOW TO STOP BLEEDING FROM HAPPENING

- Always go to scheduled doctor's appointments to make sure the trach size is still right for your child.
- Suction the way you were taught, be sure to not go too deep.
- Use proper humidification.

WHAT TO DO IF YOU NOTICE BLOOD STREAKED MUCUS

- 1. Re-measure your trach tube with a suction catheter to make sure you are not going too far.
- 2. Increase humidification.
- 3. Notify your doctor.

WHAT IS ASPIRATION?

Saliva, foods and liquids are normally swallowed and go to the stomach through the esophagus, or feeding tube. Some children have difficulty swallowing and sometimes these substances get into the lung. This is called aspiration.

SIGNS THAT YOUR CHILD MAY BE ASPIRATING

- Your child may cough or choke shortly after swallowing.
- You may notice when suctioning, the mucus is the same color as the food or liquid your child is eating or drinking.
- Your child is getting sick a lot and in the hospital for lung infections.
- You child may have symptoms of respiratory distress after eating or drinking.

WHAT TO DO IF YOUR CHILD ASPIRATES

- 1. Suction your child immediately until the trach tube is clear of the food or fluid your child aspirated.
- 2. If you feel like the trach tube is plugged with food, change the trach tube.
- 3. If you think your child is showing signs of aspirating, notify your doctor immediately.
- 4. You doctor may refer you to a speech therapist for evaluation and therapy.

HOW TO STOP ASPIRATION FROM HAPPENING

- Thicken liquids as taught by your doctor or speech therapist.
- Place your child in a sitting position when eating or drinking.
- If your child is an infant, keep them upright after feedings for at least 30 minutes.
- Your doctor may decide that your child needs a medication(s) to help stop aspiration by decreasing stomach acid and/or help the food empty from the stomach.

Remember, your child is at risk for aspiration if they vomit. Turn your child on their side to stop the vomit from getting into the airway.

Suction the trach tube immediately.

Note Page				

Nursing And Equipment For Home

The care coordinator will help you choose your nursing and equipment companies for home. Once you have chosen a Durable Medical Equipment (DME) Company, the equipment will be ordered and delivered to the hospital to allow you to practice with your equipment during your room in before discharge. This also helps us to see if the equipment is working before discharge.

The DME Company will teach you how to use and maintain your equipment. The DME Company will also have a person on call 24-hours a day to help you with any questions or problems you may have with your equipment once you are home.

Check the amount of your supplies and equipment. When you start to run low, notify your DME Company of what is needed.

Home Portable
Suction Machine



Oxygen Concentrator



Compressor for heated trach collar



Home Pulse
Oximeter Machine



Living With A Tracheostomy

Having a child with a trach can be stressful and constant care is needed. This is why we require a second caregiver to learn how to care for the trach. You may also decide to train other family members to care for your child once you are home. This will allow you to take breaks or do things on your own. We want you to feel comfortable leaving your child to do these things.

While in the hospital, we will help you to make a daily schedule for your child. Daily schedules help to keep you organized. A schedule also helps all members involved to know the plan for your child and allows consistency in your child's care. It is important to know that this schedule may change depending on your child's needs; feel free to change your child's schedule to meet their needs.

It is important to know that your child needs daily trach care <u>in addition</u> to normal care for a child their same age. This includes oral care, bathing, and feeding. Be sure to play and interact with your child, just as you would with any other child. You child still wants to be loved, comforted, and played with.

SIBLINGS

The child life specialist will actively be involved with helping your other children become comfortable with the trach. They will help the sibling to answer questions about the trach, understand safety regarding the trach, etc.

GENERAL HOME SAFETY

- Your child should <u>never</u> be submerged in water. During bath time, take extra caution in protecting your child's airway. Be sure that your child wears the HME to prevent splashed water from getting in the trach tube.
- Your child should not swim. If your child plays in a wading pool, be sure to protect the trach tube by having your child wear the HME.
- If you wash your child's hair, use a cup and carefully pour water over the hair while your child is lying with their head back.
- The use of powders, hairsprays, bleach and/or ammonia around your child can be very dangerous. These chemicals can make a vapor that can get into your child's trach and harm the airway.
- Be sure that clothing does not block the trach tube.
- Do not smoke around your child.
- Be sure to always have a working flashlight in your child's room.

STOPPING INFECTION FROM HAPPENING

Hand washing before, after, and between cares for your child is the <u>best</u> way to stop infection from happening and supports keeping your child healthy.

- Check with all visitors before they come to your home for symptoms of illness. Family and friends who are ill should not visit your child.
- Sick siblings should stay away from your child as much as possible.
- Caregivers with cold symptoms, fever, or respiratory symptoms should wear a mask whenever caring for a child with a tracheostomy. If possible, another caregiver should care for the child.

ORAL/MOUTHCARE

Having a trach, involves special thought when it comes to oral hygiene. Because your child now has a trach, the air your child breathes now enters and leaves through the trachea, causing the mouth to dry out. This can increase odors and bacteria in the mouth, putting your child at risk for infection or pneumonia. Frequent and thorough oral hygiene is necessary in stopping infection from happening.

CAR SEAT SAFETY

Children with trachs still need to follow state laws regarding child safety seats and seat belts. You should continue to use car seats or seat belts on your child as you would for their age, weight and height. You medical team will help you with making sure your child is properly seated in the car.

CHALLENGES

Having a child with a trach will be stressful, but it will also be rewarding. Your child will bring you much joy and happiness. You may also have helplessness, sadness, guilt, anger, depression, and grief at times. This is normal. You may face some challenges such as:

- Difficulty in learning your child's care.
- Adjusting to having nurses in your home.
- Addition of doctor appointments and therapies to daily life.
- · Financial and employment issues.
- Obstacles in getting special education and adjustments for your child at school.
- Sibling jealousy and resentment.
- Lack of support.

The Social Worker can give you information about resources in the community to help you cope with these challenges and problems as they come up. The Social Worker will also give information about governmental programs to meet your child's special needs.

Communication And Speaking Valve

It is important to remember that it will be some time before your child will be able to make any voice sounds. When your child is ready, a speech therapist will work with your child to help with re-learning this skill. Some children can use a speaking valve called Passy-Muir that fits on the trach or connects in-line with the ventilator circuit. Other children learn sign language and some learn to cover the trach tube with their finger long enough to make sound and talk.



After surgery, your child will breathe through the trach instead of through the nose and mouth. The air they breathe in and out will not go through the upper airway/vocal cords (mouth, nose). As a result, your child will have changes with swallowing and speaking.

WHAT IS A SPEAKING VALVE?

A speaking valve is a medical device used with a trach that creates a "closed respiratory system" that allows your child to breathe out through the mouth and nose instead of the trach. A speech language pathologist will decide if your child can use a speaking valve.

HOW DOES A SPEAKING VALVE WORK?

The speaking valve is a one-way valve that fits on the trach tube or in-line with the ventilator circuit. The speaking valve closes after air is breathed in causing air breathed out to flow through the vocal folds, mouth and nose. This allows the voice to be made, improves communication, and gets the patient back to a more normal upper respiratory system. As your child works with a Speech Language Pathologist and is able to wear the speaking valve for longer periods, long-term benefits can include: speeding up ventilator weaning, possible trach removal and stoma closure when no longer needed, and improved quality of life.

WHAT ARE SWALLOWING BENEFITS USING A SPEAKING VALVE?

The speaking valve:

- Helps cough up mucus in your child's mouth.
- Helps swallowing by increasing the pharyngeal pressures needed to move food down the pharynx and into the esophagus.
- Brings back sense of smell and taste; increasing appetite and improving nutritional intake.
- Returns subglottic air pressures to generate a stronger cough, which will improve swallowing and may decrease aspiration.
- Decreases mucus and the need frequent suctioning.

WHAT ARE VOICE AND COMMUNICATION BENEFITS USING A SPEAKING VALVE?

- For infants and toddlers, the speaking valve increases language development in the early stages
 of life (i.e. babbling and cooing) leading to optimal outcomes for developmentally appropriate
 communication.
- For pediatric/adolescents who have previously been able to talk and have had trach surgery, the speaking valve can help in making a clearer voice with more normal phrasing, better vocal quality, and increased volume.
- If the patient is not able to vocalize, there are other methods of communication. Other methods include sign language, picture cards, and communication boards.

IS THE SPEAKING VALVE FOR EVERYONE?

The speech language pathologist can assess your child for use of a speaking valve. Your child's pulmonary and neurological status, their ability to tolerate a deflated cuff, and their ability to manage secretions will determine if a speaking valve can be used. It is important to talk to your medical team and physicians early in your child's care, in order to give the best opportunities for development and maintenance of swallowing and voicing for communication. The speech language pathologist plays a role in making sure that patients and caregivers know how to get the best quality of life when living with a trach.

It is important to continue reading and communicating with your child. This is how they will learn how to speak.

Please refer to the product guide that comes with the speaking valve for cleaning instructions.

Emergency Disaster Planning

This information can be used to help you maintain the best safety and care of your child during an emergency or natural disaster (tornado, flood, ice storm or environment accident) while at home.

If you have a medical emergency always call 911 or follow instructions from community disaster broadcasts.

PREPARE AN EMERGENCY KIT BEFORE A DISASTER

An emergency supply kit is a simple way to help you and your family after a disaster. Keep a portable emergency supply kit ready to help in case you need to leave home during the emergency. Always keep your kit in the same place, and make sure everyone in your family knows where it is. Refresh your kit every now and then to make sure it has what you may need (list shown in table below).

EMERGENCY KIT SUPPLY LIST		
Bottled water (three-day supply of four quarts per person per day)	Food (three-day supply of non-perishable foods such as canned meats, fruits, and vegetables)	
Can opener, pocket knife, eating utensils, cups, plates, and bowls	First aid kit and at least a 30 day supply of prescription medications	
Whistle to signal for help	Dust mask	
Plastic sheeting and duct tape to shelter-in-place	Battery-operated radio and extra batteries	
Flashlight and extra batteries	Tools, signal flares, and matches	
Fire extinguisher	Sanitation products such as moist towelettes, toilet paper, paper towels, soap, detergent, bleach, and disinfectant	
Clothing to include a change of clothing (long sleeved shirt, long pants and sturdy shoes)	Bedding (sleeping bag or warm blanket) for each family member	
Special items for babies, the elderly, disabled persons or others with special needs	Cash or traveler's checks	
Important documents (kept in waterproof containers) such as insurance policies, deeds, titles, stocks, birth certificates, passports, wills, immunization records, etc.	If you have a pet, include pet food, a carrier or cage, and a leash	
Garbage bags and plastic ties	Local maps	
Prescription medications and glasses	Emergency reference material such as first aid book	
Mess kits, paper cups, plates and plastic utensils, paper towels	Paper and pencil	

IN CASE YOU ARE ORDERED TO LEAVE YOUR HOME

• Sometimes in a natural disaster, you will hear a message ordering you to leave your home for your safety. You should decide now where you will go if this happens. This means you will have to evacuate your home. Some places include local hotel, Red Cross shelters in the area. You may also decide to leave the area to stay with friends or family who live in a safe area. You can register with your local police station if you need help if you need to evacuate. It is best to register now, before a disaster happens. You may register by calling 211 and asking for your area's "special needs transportation registry". After giving your zip code, the operator will give you the number of your local police station. Check that you have an emergency contact on record with your child's doctor, and any home care agency you may use.

www.211texas.org

- In case you may need to evacuate, please let your child's doctor and your home care agency i know where you plan on going. Remember, let friends and family know where you will be.
- Take important papers with you, i.e. identification that includes your local address (driver's license, insurance or Medicaid card, home insurance policies, insurance claim forms).

FOR POSSIBLE DANGEROUS WEATHER

It is often hard for weather forecasters to know where floods, tornados, and ice storms will happen or how long. Listen to local TV or radio for weather updates.

- Have your car ready. Make sure you have plenty of gas. Check the pressure of your tires, as well as your oil, Make sure you have water in case you need it for the radiator.
- Refill your child's medicines (prescriptions). Try to have at least a two-week supply of all needed medicines.
- Make a plan for your pets. Some shelters do not allow you to bring your pets. Call your
 veterinarian (pet's doctor), the local SPCA or the Humane Society to see where you can take your
 pet in case of emergencies.
- Clear your yard of loose objects. Have a neighbor, friend or family member help you with securing your lawn furniture, trashcans, etc., if high winds are expected.

COMMUNICATION AFTER A DISASTER

- After a disaster, regular methods of communication such as landlines and cellular networks may not be working.
- Text messages are the best way to communication after a disaster. A text message will go through easier than a call and does not tie up cellular lines needed by emergency responders.
- As soon as possible, let your family, friends and your Home Care agency and medical provider(s) know of your status and where you will be staying.

INJURIES AFTER A DISASTER

 If your child or a family member are injured and need emergency assistance, call 911 if phones are working and you are able.

LEAVING YOUR HOME AFTER A DISASTER

- If leaving the inside of your home after a disaster, look around you carefully.
- Look for fallen electrical lines, fallen utility poles and trees, uncovered sewer drains and manholes, broken water mains and gas lines.
- It is better not to leave your home unless it is a danger to you.
 Wait for approval from the appropriate authorities before leaving your home.

Important Resources

The following tables includes a list of resources and contact information for each:

Resource:	How to contact:
SPECIAL NEEDS TRANSPORTATION REGISTRY	The best planning includes calling now for pre-registration if you will need evacuation assistance during a disaster <u>www.211texas.org/211/</u>
RED CROSS	Disaster relief • 877-505-4800 (toll-free) • http://www.redcross.org/services/prepare
	Find a shelter, loved ones and recovery assistance • https://www.redcross.org/get-help
RED CROSS ANIMAL SAFETY	For animals and pets • http://tinyurl.com/RedCrossPetSafety
CENTERS FOR DISEASE CONTROL AND PREVENTION	Resources on how to prepare for an emergency • http://emergency.cdc.gov
TEXAS DEPARTMENT OF PUBLIC SAFETY	Texas evacuation routes • www.txdps.state.tx.us/dem/hurricane.htm
FEDERAL EMERGENCY MANAGEMENT AGENCY	Disaster mitigation, preparedness, response, recovery, education, and references. • 1-800-621-FEMA (3362) • http://www.fema.gov
READY	How to prepare before, during, and after disasters, build emergency kits, financial aid information, etc. • http://www.ready.gov
READY	Emergency Preparedness for Kids https://www.ready.gov/kids/build-a-kit
Free Red Cross Mobile Apps	 Emergency Tornado Hurricane Earthquake Wildfire Flood Shelter First Aid Pet First Aid Hero Care

Emergency Readiness Checklist

The table below is a checklist to help make sure you are ready for an emergency. Read each item on the checklist to be sure you are ready for any emergency.

Checklist	Yes
Emergency bag (self-inflating bag, etc.) is set up.	
Oxygen ready for emergency use.	
Know how to hook up your child's oxygen to the ventilator and self-inflating bag.	
Suction machine works and is ready for use at all times.	
Know how long the ventilator battery should last before recharging.	
Telephone number for your child's main doctor is easy to find.	
Extra supplies and connectors ready in case of tubing breaks or leaks.	
Health plan insurance card is with you.	
Know your child's medicines, when they take them, and any allergies.	
All daily medicines for your child are with you.	
Have information from your child's doctor about their medical condition and treatment plan.	
Know your child's emergency transportation plan.	
Have a transportation plan to get your child to their doctor's office.	
Back-up caregiver known and named.	
Letters of Medical Necessity given to the electric and telephone companies.	
Know your Emergency Evacuation Plan.	

Resources for Families

<u>http://www.tracheostomy.com/-</u> provides information about trachs and facilitates parent-to-parent networking.

http://www.trachkids.org/- in association with Tracheostomy.com, this website is all about real-life kids with Trachs.

<u>http://globaltrach.org/-</u> partners with hospitals and providers to improve the care, safety and quality of life of every individual with a tracheostomy or laryngectomy.

https://www.facebook.com/MomsOfTrachBabies- group of mothers of children who have trachs, for networking and support.

https://www.facebook.com/Kids-with-Vents-157729187587825/- Kids with Vents is a place to share your experiences, seek information, ask questions, offer help, and find encouragement.

<u>http://www.passy-muir.com-</u> recognizes the importance of communication for the human spirit and provides information about passy-muir valves.

<u>http://complexchild.org-</u> a monthly online magazine written by parents of children with special healthcare needs and disabilities.

http://txp2p.org- Texas Parent to Parent (TxP2P) provides parent-to-parent support, resource referral, and education.

GLOSSARY

Airway: the stoma, trach, and the trachea

<u>Artificial Nose</u>: a small filter that fits over the trach; otherwise known as a Heat Moisture Exchanger or "HME"

Aspiration: when saliva, solids or liquids enter the lung

Bag/Mask Breathing: providing breaths with the self-inflating bag and face mask

Baseline: how your child looks/acts when they are well

<u>Cardio-Pulmonary Resuscitation (CPR)</u>: done in an emergency for a person who is not breathing and/or does not have a heart rate. This consists of bag-mask breathing and compressions

<u>Carina</u>: area at the end of the trachea where the trachea branches to the left and right lungs. The end of the tracheostomy tube needs to be above this.

<u>Catheter</u>: a plastic tube used to remove mucus from the trach

<u>Clean Technique</u>: a technique used to perform a procedure while making sure the equipment does not become contaminated or dirty

Compressions: pressing downward on the chest in a firm and rhythmic fashion

<u>Cuff</u>: a small balloon on the outside of the trach that is either filled with air or water

Decannulation: when the trach comes out of the stoma

<u>Diaphragm</u>: large muscle below the lungs that controls breathing

Dysphagia: difficulty swallowing

Epiglottis: a thin flap of tissue that covers the entrance to the airway during swallowing to prevent food and fluid from entering the lungs

Exhale: breathe out

Esophagus: the feeding tube connecting the mouth to the stomach

<u>Face mask</u>: a mask that attaches to the self-inflating bag, which covers the nose and mouth **Glottis:** the area inside the voice box or larynx where the vocal cords

Inhale: breathe in

Intercostal: space between the ribs

Larynx: the voice box

Mucus Plug: a collection of mucus in the trach making it difficult for your child to breathe

Normal saline: sterile solution made up of salt and water. This helps to thin secretions

Phonation: talking or making sounds with the vocal cords

Pulse oximeter: machine that monitors the oxygen saturation of the blood

Retractions: pulling in of the chest muscles during breathing

Secretions: another word for mucus

<u>Self-inflating bag</u>: a breathing bag used to breathe for your child that does not need oxygen to work

Subglottis: the part of the airway below the vocal cords in the voice box

Suctioning: clearing the mucus from the tracheostomy tube, nose or mouth with a catheter

Supraglottis: the part of the airway above the vocal cords in the larynx

Stoma: a small opening in the neck for patients with a trach

Trach: another word for tracheostomy

<u>Trachea</u>: the windpipe or airway, which connects to the lung

Tracheotomy: a surgery where the doctor places a tube in the neck for breathing

Ventilator: a machine that provides breaths and/or oxygen

Vocal cords: 2 strips of tissue within the larynx that open and close to the allow noise or speech

References

- 1. American Thoracic Society. (2000). Care of the Child with a Chronic Tracheostomy. American Journal of Respiratory Critical Care Medicine, 161.
- 2. Bryant, K., Davis, C., Lagrone, C. (1997, June). Streamlining Discharge Planning for the Child With a New Tracheostomy. *Journal of Pediatric Nursing*, *12*(3), 191-192.
- 3. Children's Hospital of Philadelphia. (2012). *Breathe Easy: Caring for Your Child with a Tracheostomy at Home.*
- 4. Cincinnati Children's Hospital. (2010). *Tracheostomy Care Handbook*. Retrieved on March 28, 2011 from http://www.cincinnatichildrens.org/assets/0/78/847/877/db29d0e9-5b1f-4af3-ae9c-7b1088a04f0c.pdf
- 5. Covidien. (2011). Shiley tracheostomy tube product guide.
- 6. Cranio-Maxillofacial Surgery Institute. (n.d.). Sleep apnea treatment: Tracheostomy. Retrieved on June 27, 2011 from http://www.cmfsinstitute.com/sleep-apnea-treatment/tracheostomy.php
- 7. Hartigan, E.M. & Campisciano, S.M. (2008). Tracheostomy tube: Change. J Verger & R. Lebet (Eds.), *AACN Procedure Manual for Pediatric Acute & Critical Care* (71-74). St. Louis Missouri: Saunders, an imprint of Elsevier, Inc.
- 8. Hartigan, E.M. & Campisciano, S.M. (2008). Tracheostomy tube: Stoma care & tie change. J Verger & R. Lebet (Eds.), *AACN Procedure Manual for Pediatric Acute & Critical Care* (60-67). St. Louis Missouri: Saunders, an imprint of Elsevier, Inc.
- 9. Hartigan, E.M. & Campisciano, S.M. (2008). Tracheostomy tube: Suctioning. J Verger & R. Lebet (Eds.), *AACN Procedure Manual for Pediatric Acute & Critical Care* (78-82). St. Louis Missouri: Saunders, an imprint of Elsevier, Inc.
- 10. McGrath, B.A. (ed) (2014). Comprehensive tracheostomy care: The national tracheostomy safety project manual. West Sussex, UK: John Wiley & Sons, Ltd.
- 11. Mitchell, R. B., Hussey, H. M., Setzen, G., Jacobs, I. N., Nussenbaum, B., Dawson, C., ... & Merati, A. (2012). Clinical consensus statement tracheostomy care. Otolaryngology--Head and Neck Surgery, 0194599812460376
- 12. http://www.passy-muir.com/what_is
- 13. http://www.practicalslpinfo.com/swallowing-with-a-tracheostomy.html
- 14. Smiths Medical International, Ltd. (2013). Bivona flextend tracheostomy tube produce guide.