



Texas Children's
Hospital®

Tracheostomy Caregiver Handbook





Welcome

Dear Caregiver,

We know that this may be a hard time for you and your child. You may have many questions and fears regarding your child's new tracheostomy tube (trach). You may be afraid to learn how to care for your child with a trach. We are here to help! We will guide you, support you and work with you every day while your child is in the hospital to prepare your family for life at home with a trach.

During your stay, you will encounter many people who are involved in your child's care. You will work with doctors, nurses, nurse practitioners, physician assistants, child life specialists, respiratory therapists, dietitians, occupational therapists, physical therapists, speech therapists, social workers, chaplains, discharge care coordinators, and many others. The primary goal of your care team will be to ensure that your child is medically ready for discharge and that you have received the proper education needed to safely care for your child at home.

Before you are ready to go home, you will need to learn how to manage your child's tracheostomy tube. You will be provided an education checklist with specific goals as well as this guidebook to use as a resource. Although learning new skills can be challenging, these tips may help make the process easier:

- Spend as much time as possible taking care of your child during their hospital stay. The more practice you get, the more comfortable you will be taking care of your child and their trach at home.
- Have a partner learn the skills with you. It is impossible for you to provide care 24 hours a day. You will need a reliable partner who knows how to care for your child and their trach, and who can provide help and support when you need it.
- Encourage siblings and other family members to visit. If possible, get them involved in the care of your child.
- Ask questions! Let your care team know if you are uncertain about anything. There is a lot to learn about caring for a child with a trach. Your health care team can do a better job of addressing your family's needs if we know your questions and concerns.

Once you are comfortable with the daily care of your child's tracheostomy, you will be scheduled for classes at the hospital. These classes will teach you how to care for a tracheostomy at home. After you finish these classes, you will complete a "rooming-in" period for 24 to 36 hours. During that time you will be independently performing all of your child's care in the hospital. This period is crucial in identifying issues that you may encounter at home. Your discharge care coordinator and social worker will help you with setting up equipment, nursing and other resources to be used at home. Your care team will ensure that you have all the necessary equipment and training that you need to care for your child.

Sincerely,

The Texas Children's Hospital Tracheostomy Team

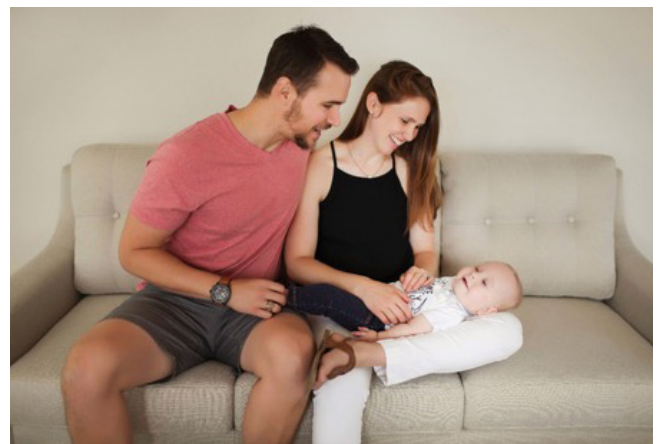
Message from a Family of a Child with a Trach

The first time we heard the word 'tracheostomy' in regard to our son was only a few minutes after he was born. Jackson came in to the world unable to breathe on his own and, after many failed extubation attempts, the neonatologist working on him asked for consent to perform a bedside tracheostomy if the next intubation failed. Thankfully, it worked, and Jackson was stabilized for the time being, but that wouldn't be the last time we talked about a tracheostomy. After months of intubation and multiple failed attempts to remove his breathing tube, it was decided that it was in Jackson's best interest to have a tracheostomy done and a stable airway created to allow him to grow and thrive.

Though we were nervous for the experience, we received some time to process what this meant for our son and our future at home. What would we need to learn to keep him safe? What type of care would he require? Will we be able to handle it? And, somewhat most timely, how will he 'look' once the procedure is complete?

I don't think I could have prepared myself for the answer to the last question. After more than four months with an endotracheal (E.T.) tube taped to Jackson's face, covering the cheeks and smile I had longed to see, I walked in to Jackson's room to see a face clear from obstruction looking back at me as if to say everything would be alright. It was one of the first times I cried at his bedside, not out of fear or worry for what was next, but out of joy and excitement for what could be.

We would spend the next few months in the hospital for procedures unrelated to his tracheostomy, but it felt like each day his tracheostomy became more and more a part of him. With the help of our amazing doctors and nurses, we became experts in 'all things Jackson', caring for his trach, participating in a tracheostomy change, and learning what to do in an emergency. We worked through the steps and goals laid out for us and, in time, it became hard to remember life with Jackson before the procedure. After six-and-a-half months at Texas Children's Hospital, Jackson was released to finally come home. Yes, it was scary, but the preparation we received in the hospital truly made the transition smooth and simple.



THANK YOU TO OUR PATIENTS & THEIR CAREGIVERS

The Trach Team would like to thank everyone, both past and present, who contributed their time to the development of this caregiver education book.

Our life is anything but normal – most infants don't have quite as much medical equipment in their rooms as our little ones do! But it is absolutely beautiful. Jackson's trach has allowed him to interact with the world, showing off his personality to everyone he meets. He is a happy, active child who loves to play and continues to amaze us everyday. He is growing and thriving, meeting milestones on his own time and learning what it means to just be a kid as opposed to a patient.

The journey you are about to go on is a hard one – no parent of a trach child will ever tell you it's not. However, it's a journey that will have you finding new courage, compassion and confidence in yourself that you never knew you had. It is a journey that will open your eyes to the strength and resilience of your child. Best of all, it's a journey many have walked before you. Connecting with and reaching out to other trach parents can only make your journey easier, so never be afraid to ask for help from those who have been there before.

Before Jackson received his tracheostomy, I would have used many negative words to explain my expectations – fear, dread and anxiety. All of these are normal feelings. It's okay to be nervous. But from one trach parent to another, let me tell you that after the procedure all of those feelings changed. Relief, joy and fun fill our lives, and we are lucky to be part of the global tracheostomy family!

The Stewart Family



Table of Contents

PART I: Basic Information & Overview

PART 2: How To...

Suction a Tracheostomy Tube	8
Care for the Stoma & Change the Velcro Tracheostomy Tie	10
Care for the Inner Cannula	12
Change the Tracheostomy Tube	14
Clean the Tracheostomy Tube	17
Prepare for Emergencies	18
Recognize Signs of Trouble	19
Use the Ambu® Bag	22
Understand the Basics of Mechanical Ventilation	23
Perform CPR	24

PART 3: Resources for Families

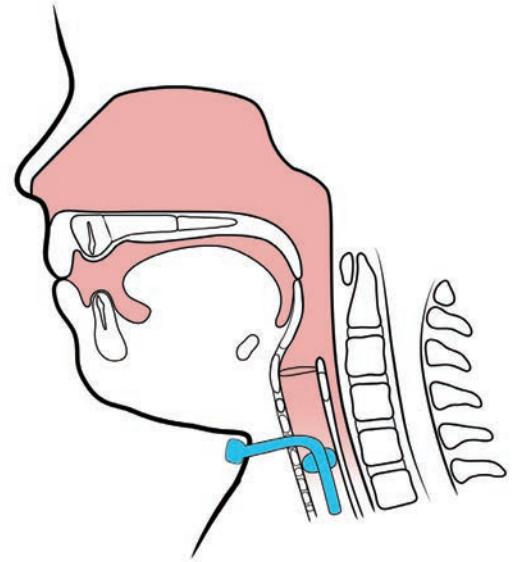
Financial Assistance	28
Help for the Caregiver	30



Basic Information & Overview

What is a tracheostomy?

A tracheostomy is a small opening made in the windpipe to help your child breathe more easily or to help them clear phlegm. This hole is called the stoma. A curved plastic tube (tracheostomy tube) is inserted into the hole. When a child has a tracheostomy, they will breathe primarily through the tracheostomy tube instead of through their nose or mouth. It is very important to take care of the tracheostomy site to minimize infection and promote healthy breathing.



Why does my child need a tracheostomy?

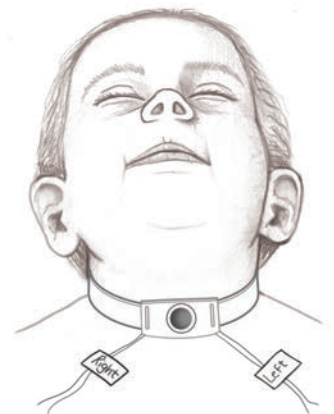
There are many reasons a child may require a tracheostomy. Reasons typically include a blockage of the airway, the need to use a ventilator to assist breathing, or an inability to properly clear the airway of secretions, such as mucus and phlegm from the lungs.

How long will be my child be in the hospital?

It is difficult to say how long each child will be in the hospital because many different conditions may be involved. Here's an example of what to expect related to the tracheostomy hospital care:

A tracheostomy is commonly referred to as a "trach." It rhymes with "rake."

Time	Expectation
Day 1	After surgery, your child will return to the intensive care unit.
Days 1-5	Your child will remain sedated to encourage healing and to prevent the tube from accidentally coming out. The ENT team will provide all tracheostomy care at this point.
Days 5-7	The ENT team will do the first tracheostomy tube change at the bedside and remove any sutures. After the first tracheostomy tube change, your child will remain in the ICU.
After the first trach tube change until the day of discharge	You will learn how to care for your child's trach. This includes how to suction the tube, clean around the tracheostomy site and change the trach tube. The Tracheostomy Team will round weekly on your child and may recommend speech/occupational and/or physical therapy to evaluate and treat your child.
Prior to discharge	You will participate in a trach simulation class, trach tube change class, trach CPR class, and a rooming-in session where you will independently care for your child while in the hospital.



Will my child be able to speak?

The ability to speak or cry may be delayed because of swelling around the tube, the size of the tube or a blockage of the airway. Soon after surgery, a speech therapist will visit to assess your child and discuss speech and language options with you. This may include the possibility of a speaking valve because having a trach will temporarily affect your child's speech and language development.

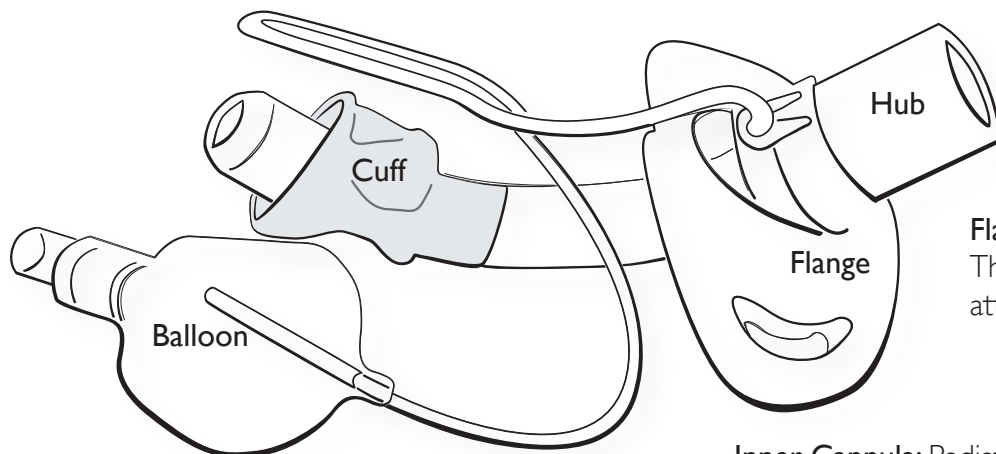
Will my child be able to eat?

A trach does not typically prevent children from eating. If your child has another underlying medical condition that affects the ability to swallow, then eating may become more difficult. A speech therapist will visit after surgery to evaluate your child's ability to eat by mouth.

What are the parts of a trach tube?

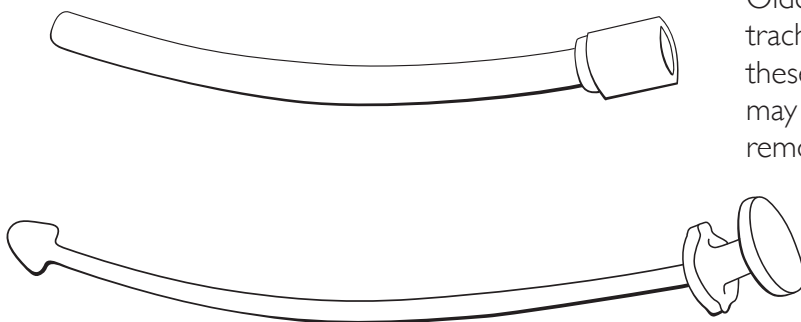
Balloon and Cuff: Not all trach tubes have a cuff. If the trach tube comes with a cuff, it will have a balloon attached to it. A cuff is on the far end of the tube and is specifically used to block air from escaping from around the tube. The cuff allows pressure to build up so that a ventilator will be effective. An expanded balloon indicates that the cuff is filled or "up" when using an air- or water-filled balloon.

Hub: The front portion of the trach tube where the ventilator or other sources of humidification connect.



Flange or Neck Plate: This is what the trach ties attach to on the sides.

Inner Cannula: Pediatric and neonatal trach tubes **do not** come with inner cannulas. Older children (adolescents) may have a trach with a removable inner cannula. In these kinds of trach tubes, the inner cannula may be removed for cleaning without removing the entire trach tube.



Obturator: A guide placed inside the trach tube upon insertion which aids in placement and is removed once the trach is in place.

What will I have to do to care for the trach tube?

You and a partner will learn to care for the trach tube and site during your stay at the hospital. A trach tube needs extra attention and care as it is an airway.

The skills you will be learning are:

- Suctioning
- Cleaning around the trach site
- Changing the trach ties
- Changing the trach tube
- Emergency care if the trach tube comes out or becomes plugged with mucus
- Recognizing signs and symptoms of distress in your child
- Resuscitation (CPR)
- Providing rescue breaths with a bag-valve mask (Ambu® bag)

How long will I have anxious feelings?

Initially, it will be difficult to see your child sedated with a trach tube. We understand that there will be overwhelming moments and some increased anxiety, but your child will be closely monitored in the intensive care setting. Your child will have the chance for the surgical area to heal with close care provided by the ENT team and the ICU staff. Approximately 5 or 6 days after the surgery, the bedside nursing team will begin to incorporate you into the daily care of your child and as well as educate you about caring for your child and their trach tube.

IT'S NORMAL TO FEEL OVERWHELMED

This process may feel overwhelming, but our Trach Team will ensure you are comfortable caring for your child before your child is discharged home. You will learn to develop a routine that works for you and your child. After you complete your skills training, you will participate in a 24-36 hour “Rooming-In” period, in which you will independently care for your child in the hospital. This will be an opportunity where you will demonstrate the ability to care for your child when you are home.



Overview of Terms

Detailed Instructions are Provided in this Book

SUCTIONING A TRACH TUBE

Suctioning a trach tube removes mucus from your child's trach tube to make breathing easier and to prevent infection.

Mucus production is the body's way to clean the airway. During the first few weeks after surgery, your child may have a large amount of mucus. This is due to the surgery itself and the airway's normal response to the new tube. In many children, the amount of mucus will decrease over time. Suctioning is required to remove secretions on a regular basis. This may be the first skill you learn during your course of trach education. It is important that you learn the proper suctioning technique in order to protect your child's lower airway. [See page 8.](#)

STOMA CARE & CHANGING THE VELCRO TRACH TIE

Skin at the trach site needs to remain clean and dry. If drainage collects around the trach tube, germs can grow and cause an infection or a skin rash. This area should be cleaned at least twice a day.

[See page 10.](#)

TRACH TUBE CHANGE

Trach tubes are changed monthly to prevent mucus plugs from occurring in the tube and to keep the trach tube clean. You will learn to change the trach tube on a simulation doll, and then you will perform a trach tube change on your child prior to discharge. [See page 14.](#)

VENTILATION

A ventilator is a machine that helps a child to breathe when they are unable to breathe well enough on their own. It can be used on a full- or part-time basis. If your child will need a ventilator at home, ventilator teaching will be scheduled with your home care company and will take place at the hospital prior to discharge. They will provide information on the specific ventilator that you will have at home. The ventilator settings will have been chosen specifically for your child. These settings should not be changed unless advised by your doctor.

HUMIDIFICATION

Your nose warms, moistens and filters the air that you breathe. With a trach, the air your child breathes goes directly into the lungs through the trach tube. Extra humidity is needed to prevent your child's trach tube from clogging with mucus and to prevent the lining of the airway from becoming dry and irritated. Humidification can be provided through the heated humidifier attached to the ventilator as well as through the following:

- Humidified Tracheostomy Collar (HTC) – This is tubing that is connected to a water heater at one end. The other end provides humidification through an opening at the trach tube. This is usually worn at night and during nap times for patients that do not use a ventilator.

- Humidified Moisture Exchange (HME) – This is commonly referred to as an “artificial nose.” It is a humidified filter that attaches to the end of the trach tube. This device is worn usually during the daytime when your child is active as long as your child is not having thick secretions.

DECANNULATION

As your child progresses, they may get to a point where they are ready to have their trach tube removed. This process is called “decannulation.” After an airway evaluation by the ENT surgeon, your child will begin capping the trach tube during the day. Your child’s trach should never be capped unless they are awake and under direct supervision. Once your child is tolerating capping all day, they will be admitted to the hospital for capping overnight while they sleep. If they do well, the following morning the trach tube will be removed, the stoma will be covered with a dressing, and your child will be monitored for another night in the hospital. The trach stoma will close up on its own over the next few weeks. We recommend keeping the area covered with a gauze and an adhesive bandage. You will bring your child in for a follow-up visit with the ENT surgeon to make sure the stoma is closing correctly.



BEFORE GOING HOME

We want to make sure that you and at least one more caregiver are comfortable taking care of your child and the trach once you are at home. These are the skills you will need:

- ☐ Suctioning and Stoma Care
- ☐ Trach Tube Change
- ☐ Ventilator Management (if required)
- ☐ Trach CPR
- ☐ Trach Simulation Lab
- ☐ Rooming-In with Your Child



Caring for Your Child at Home

BATHING

Hygiene is important for all children, especially those that are chronically ill. When bathing your child with a trach tube, it is important not to submerge your child in water. They can sit in a tub or basin with a few inches of water. While washing their hair you should make sure to tilt their head back and use a handheld shower head or cup for rinsing so that the direct water spray does not enter the trach tube.

Tip: Many times trach care after bath time becomes a routine during your child's hospitalization. It may be a good idea to continue that at home if your schedule allows.



CLOTHING

Many patients prefer to wear scarves or bandanas over their trach tube for comfort. It is recommended to avoid tight clothing and/or bibs over the trach tube as well as fabrics or accessories that can shed or have stray fibers. It is important that nothing blocks or enters the airway.

Tip: Turtlenecks are not recommended for patients with trach tubes as they can block access to the trach tube.

PLAYING

Your child should continue to play and be active, but remember to keep harmful or small objects that can block a trach tube away from young children. We do not recommend swimming, diving or submerging in any body of water as this can cause water to enter your child's trach tube. Also, it is important to avoid all contact sports. They can increase the risk of the trach tube coming out.





SLEEPING

It will take time to get adjusted to your routine once you return home. Your child will have a pulse oximeter on overnight to monitor oxygen levels. It is important to have the emergency equipment in the same room with your child at all times.

SCHOOL

A trach does not limit your child's ability to attend school. During school hours there should be a caregiver at the school who is able to suction your child's trach tube and know how to change out the trach tube in case of an emergency. Call your school district and discuss with them what type of caregivers they are able to provide. If you have any questions about this, please talk to your social worker prior to discharge so they can assist you.

Tip: Remember to send your child's emergency trach bag to school.



TRAVELING

Traveling with a trach and/or ventilator requires special planning. It is possible to go out and travel with your child once they have a trach and/or portable ventilator, but it is important to take all essential medications and emergency equipment, including all of your child's trach supplies and the power cords for the ventilator. Prior to discharge, you will undergo training on what to keep in your emergency bag as well as ventilator training should your child go home with one.

Tip: Contact the airline before booking your trip for any specific requirements involving durable medical equipment (DME) and nursing. Your physicians as well as DME and nursing companies can also be good resources.

ENVIRONMENT

Do not smoke around your child. Smoke is very irritating to your child's airway, lungs and ears.



How to Suction a Tracheostomy Tube

WHEN TO SUCTION

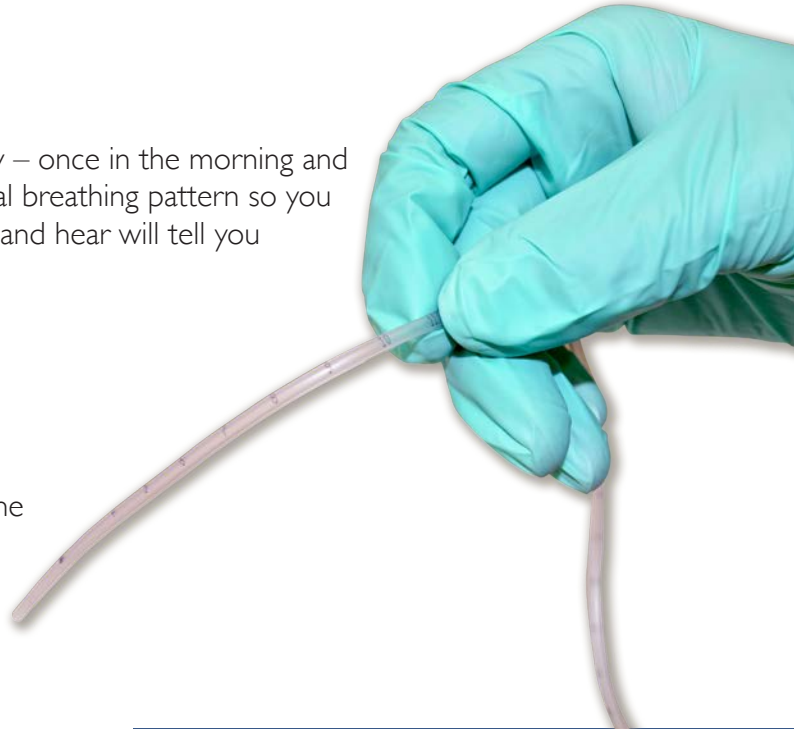
Your child will need to be suctioned at least twice a day – once in the morning and once in the evening. You should learn your child's normal breathing pattern so you know when they require suctioning. What you see, feel and hear will tell you when to suction your child.

Signs you should look for may include:

- Noisy breathing
- Rattling
- Bubbles of mucous at the trach opening
- Increase in respirations and/or working hard to breathe

SUPPLIES NEEDED

- ☐ **Suction machine** – Pressure gauges vary with suction machines; check with your equipment company about setting the pressure limit.
- ☐ **Suction catheter** – Catheter size may vary depending on your child's trach size (The ideal size suction catheter is 2/3 the opening of the trach tube).
You may need to adjust the catheter size if the mucus is thick.
- ☐ **Ambu® bag/resuscitation bag**
- ☐ **Gloves** – (Optional) Suctioning is a clean procedure at home.
- ☐ **Suction depth** – You should have a pre-measured suction depth chart; if you misplace the chart, then contact your ENT doctor.



Signs that your child needs suctioning urgently may include:

- **Frightened look**
- **Flared nostrils**
- **Restlessness**
- **Pale or bluish color to skin, mouth or nails**
- **Clammy skin**
- **Dry whistling sound and fast, noisy, hard breathing**

HOW TO SUCTION WITH A STANDARD CATHETER

1. Wash your hands.
2. Set up suction catheter and suction machine.
3. Put on gloves if needed.
4. Attach suction catheter to suction tubing.
5. Turn on suction machine.
6. Insert suction catheter into trach tube to pre-measured length.
7. Apply suction by placing your thumb over the thumb-control valve. Twirl the catheter between your thumb and forefinger as you pull the catheter out of the trach tube. Do not suction the airway for longer than 4 seconds at a time in order to allow your child to recover.
8. Assess your child's breathing.
9. Provide oxygen should your child need it.
10. Repeat the steps if your child requires more suctioning.
11. Suction your child's nose and mouth if needed.
12. Rinse the suction catheter with water if you plan on reusing the catheter.
13. Clear the tubing by suctioning a small amount of water through it.
14. Turn off the suction machine.
15. Wash your hands.



HOW TO SUCTION WITH AN IN-LINE SUCTION CATHETER

1. Wash your hands.
2. Put on gloves if needed.
3. Attach suction catheter to suction tubing.
4. Turn on suction machine.
5. Insert suction catheter into trach tube to pre-measured length.
6. Apply suction by placing your thumb over the thumb-control valve. Pull the suction catheter out of the trach tube. Of note, one hand should always be on the trach tube to ensure the ventilator tubing is not disconnected.
7. Do not suction the airway for longer than 4 seconds at a time in order to allow your child to recover.
8. Assess your child's breathing.
9. Provide oxygen should your child need it.
10. Repeat the steps if your child requires more suctioning.
11. Suction your child's nose and mouth if needed.
12. Rinse the suction catheter with water if you plan on reusing the catheter.
13. Clear the tubing by suctioning a small amount of water through it.
14. Turn off the suction machine.
15. Wash your hands.

If there are bloody streaks in the mucus, re-check suctioning depth and make sure you are not suctioning too deeply. If the blood in the mucus does not lessen within 24-48 hours, notify your doctor. If you see bright red blood, your child needs to be taken to an Emergency Room right away.



How to Care for the Stoma & Change the Velcro Tracheostomy Tie

STOMA CARE

Skin at the trach site needs to remain clean and dry. If drainage collects around the trach tube, germs can grow and cause infection or skin rashes. Look at this area and clean it at least twice daily or more often if needed. The trach ties should be changed at least once a day or whenever soiled or damp to maintain skin integrity. Do not cut gauze since frayed fibers may be breathed into the tube.

SUPPLIES NEEDED

- ☐ 8 cotton swabs
- ☐ 4 gauze pads
- ☐ Velcro® trach tie
- ☐ Dressing
- ☐ Shoulder roll
- ☐ Water

HOW TO CLEAN

1. Wash and dry hands.
2. Set up supplies.
3. Wet 4 cotton swabs and 2 gauze pads with water.
4. Cut a new trach tie to the appropriate size.
5. Place a shoulder roll under your child or have them tilt their head back to expose their neck if possible.



6. Remove soiled dressing.
7. Look at the neck, noting any areas of skin redness, irritation, breakdown or extra skin tissue (as seen in photo).



8. While the collar is in place, cleanse the upper, lower, left and right part of the stoma by separating it into 4 quadrants using the 4 wet cotton swabs. Wipe from the stoma outward one area at a time with a clean cotton swab in each area.
9. Use 4 dry swabs to dry the trach site moving from the stoma outward one area at a time in the same manner.





10. Hold the trach in place with one hand and remove one Velcro® strap at a time with the other hand and place to the side.



11. Cleanse each side of the neck with a wet gauze pad from stoma outward then dry the neck with dry gauze pad from stoma outward.



12. Attach a new trach tie by looping in one Velcro® tie into the flange of the trach, pass the remaining tie behind the neck and loop the second Velcro® tie into place.



13. Place an absorbent dressing (split gauze or specialty dressing) under the trach tube.



14. Ensure there is only a one-finger width between the trach tie and the back of the neck.

HOW TO TREAT SKIN PROBLEMS

The use of creams, lotions, and powders (example: Nystatin) on the neck and the trach site is not routine. Call your provider if there is any sign of infection or irritation of the skin surrounding the trach tube.

Signs of infection:

- Redness
- Swelling
- Drainage
- Cuts
- Foul odor
- Yellow or green secretions

How to Care for the Inner Cannula

CHANGING THE INNER CANNULA

If your child has an adult-sized trach tube (most teenagers do), then chances are their trach tube has an inner cannula. The inner cannula can be **disposable** or **reusable**. If the inner cannula is reusable, then it should be cleaned twice daily, or more frequently should your child require it. The disposable inner cannula should be changed at least once every day and as needed. The entire trach tube should be changed monthly regardless of the type of inner cannula.

SUPPLIES NEEDED FOR **REUSABLE** INNER CANNULA CARE

- ☐ Tracheostomy Clean and Care Tray
- ☐ Gloves
- ☐ Sterile water
- ☐ Hydrogen peroxide 3%
- ☐ Dry storage container for reusable inner cannulas
- ☐ Extra inner cannula or temporary inner cannula depending on the type of trach tube



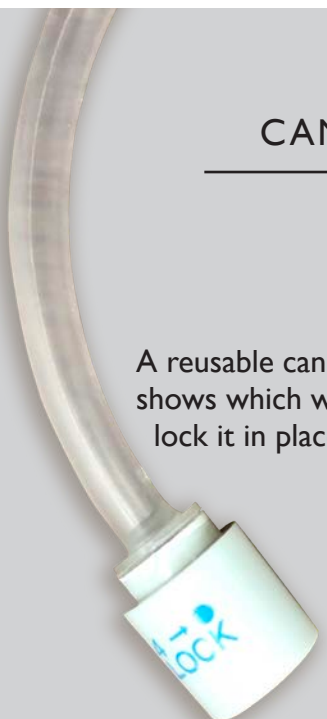
STEPS TO FOLLOW

1. Gather your supplies, open the Tracheostomy Clean and Care Tray, remove the supplies and place on a clean surface.
2. Fill the large space in the tray with 4 ounces of sterile water and 4 ounces of hydrogen peroxide.
3. Place the extra inner cannula or temporary inner cannula where it is accessible.
4. Assist patient to a comfortable position.
5. Put on gloves.
6. Holding the trach tube securely, unlock inner cannula.
7. Remove the dirty inner cannula and place in the tray containing water and hydrogen peroxide.
8. Insert a clean inner cannula or temporary inner cannula into trach tube and lock into place.
9. Change into new gloves.
10. Grasp the dirty inner cannula by the hub with one hand. Cleanse the inside of cannula by pulling pipe cleaners through the cannula using the other hand. Pull in one direction only.




11. Cleanse the outside of inner cannula with a gauze pad.
12. Rinse the inner cannula in sterile water and gently shake dry.
13. Inspect inner cannula for cleanliness and repeat cleaning process if secretions or crusting are present.
14. If a temporary inner cannula is in place, then remove and replace with a clean inner cannula.
15. Place the cleaned inner cannula in a dry, storage container and label container with date and time.

HOW TO TELL IF THE INNER CANNULA IS REUSABLE OR DISPOSABLE



A reusable cannula shows which way to lock it in place.



A disposable cannula reads "do not clean or reuse."

SUPPLIES NEEDED FOR **DISPOSABLE** INNER CANNULA CARE

- ☐ Gloves
- ☐ New disposable inner cannula of the same size

STEPS TO FOLLOW

1. Gather your supplies, open the new disposable inner cannula and place on a clean surface.
2. Assist patient to comfortable position.
3. Put on gloves.
4. Holding the trach tube securely, unlock the dirty disposable inner cannula and remove it.
5. Insert the new disposable inner cannula into the trach tube and lock or click into place.

How to Change the Tracheostomy Tube

CHANGE TUBES MONTHLY

Trach tubes are changed monthly to prevent mucus plugs from occurring in the tube and to keep the trach tube clean. You will learn to change the trach tube on a simulation doll, and then you will perform a trach tube change on your child prior to discharge.

Two trained people are preferred for routine trach changes. In an emergency, you must be prepared to change the tube by yourself.

SUPPLIES

- ☐ Trach tube – current size and length
- ☐ Second trach tube – one size smaller
- ☐ Trach ties
- ☐ Supplies for suctioning
- ☐ Water-based lubricant
- ☐ Resuscitation Ambu® bag
- ☐ Shoulder roll
- ☐ If your child has a cuffed trach, you will need a syringe and sterile water (if it is a water cuff trach)



STEPS TO FOLLOW

1. Wash and dry hands. Gather supplies.
2. Prepare the trach tie.
3. If your child's trach tube is cuffed, then test the new trach tube cuff by inserting the recommended amount of sterile water or air depending on the type of cuff, and then deflating the cuff.
4. Place the new trach tube with the obturator inserted on a clean surface.
5. Prepare suctioning equipment.
6. Suction your child's trach tube.
7. Place the child on their back with a small roll under the shoulders. If your child cannot tolerate lying on their back, then have your child in a sitting position. Consider swaddling your child if they are active. It is recommended to change the trach tube before feeding time to prevent vomiting as a result of the tube change.
8. Have one person hold the trach tube in place with one hand and loosen the ties with the other hand.





9. The second person moistens the tip of the trach tube with lubricant.
10. The first person deflates the cuff of the old trach tube if there is a cuff and removes the tube while the second person prepares for the next step.



11. The second person inserts the trach tube in one smooth curving motion, directing the tip of the trach tube toward the back of the neck and down. *Do not force the tube!*
12. Remove the obturator, holding the trach tube securely. Attach the ventilator tubing if your child is ventilated and re-inflate the cuff if needed. Changing the trach tube will cause the child to cough. Have tissues ready to wipe secretions or prepare to suction. *Do not let go of the tube!*



13. Secure the trach ties and place trach dressing. Only allow room for one finger/fingertip between the back of the neck and the ties.
14. Pass the suction catheter through the new trach tube.

Note:

Please refer to page 16 if you are unable to replace the trach tube.

IF THE TUBE DOES NOT INSERT EASILY

- Act quickly and remain calm.
- Do not force the trach tube!
- Reposition the child so the head is back and the stoma can be seen. If your child has a large chin and small neck, ensure that the chin is pulled back and the stoma/neck is exposed.
- Remove the tube. Re-lubricate the tube, checking to make sure you are not trying to insert the tube upside down. Try inserting the tube again.
- If that does not work, try to insert the smaller size trach tube.
- **If you still cannot place the trach tube, call 911. Start rescue breathing and/or CPR.**
- Remember that you can give your child breaths with a mask over the nose and mouth while covering the trach stoma site if you cannot get the trach tube in place.
- After the emergency is over, call your child's doctor for advice if the size smaller trach tube was the only tube that could be placed.



Tip: Always keep the same size trach tube and one size smaller in your emergency equipment bag.

How to Clean the Tracheostomy Tube

BIVONA BRAND TRACHEOSTOMY TUBE CLEANING INSTRUCTIONS

SUPPLIES

- ☐ Container
- ☐ Warm water
- ☐ Mild soap
- ☐ Lint-free swab
- ☐ Storing container

STEPS TO FOLLOW

1. Soak the trach tube and obturator separately in a container of warm water and mild soap for 60 minutes. Ensure that the wash reaches all parts of the product to be cleaned.
2. Remove any contamination with a lint-free swab.
3. Inspect the trach tube for any residual contamination and repeat the process if necessary.
4. Rinse the tube inside and out with clean, warm water.
5. Let trach tube air dry then store in dry, clean container.

Tip: If your child is hospitalized and is having their trach tube sterilized, then remember to include the obturator.

The trach tube and obturator can be sterilized up to 5 times before the product should be discarded. Make a note of every time the tube is sterilized. If the tube becomes damaged or has been sterilized more than 5 times, it should be discarded. Please refer to manufacturer's instructions for further clarification.

Note:

Shiley Tracheostomy Tubes are single-use only and should not be cleaned and reused.

How to Prepare for Emergencies

YOU WILL NEED EMERGENCY TRACH EQUIPMENT

Regular trach care for your child can prevent most breathing problems. Yet accidents can happen and breathing problems can occur. You must be prepared.

Your child's emergency equipment must be with them at all times!

THE EMERGENCY TRACH EQUIPMENT SHOULD INCLUDE

1. Trach tube – current size and length
2. Trach tube – one size smaller
3. Pre-cut trach ties to fit your child
4. Suction machine (unit should be fully charged)
5. Suction catheters
6. Self-inflating bag/Resuscitation bag with face mask and adapters
7. Extra trach ties
8. Scissors
9. Water-based lubricant
10. Syringe, if the trach tube has a cuff
11. Sterile water for water-cuff tubes
12. 2x2, 4x4 split gauze pads
13. Cotton swab applicators
14. Airway information card
15. Other items you have found useful

The emergency trach bag should be sturdy. It should close completely and allow the contents to be easily found. Pre-cut trach ties will need to be modified as your child grows.

TRAVEL BAG CHECKLIST

Be prepared! Emergencies and breathing problems will happen. You have the training to manage the situation.

- ☐ Emergency trach equipment (listed above)
- ☐ Medications
- ☐ Portable suction machine
- ☐ Ventilator, power cords and batteries
- ☐ Monitoring devices
- ☐ Portable oxygen with regulator and key
- ☐ Emergency contact numbers



Check your emergency travel bag before every outing to ensure that all items are restocked.

How to Recognize Signs of Trouble

What should I look for if I think my child is in trouble?

1. SIGNS OF RESPIRATORY DISTRESS

- Flared nostrils
- Rapid breathing or change in breathing pattern
- Noisy breathing
- Clammy and sweaty skin
- Restlessness

What to do: Suction the trach tube. Provide breaths using the Ambu® Bag. (See page 22.) Call 911 if in severe distress.

2. MUCUS PLUG

A mucus plug is a collection of mucus that has clogged the airway.

- May have symptoms of respiratory distress if unable to breathe easily.
- Can be prevented through adequate fluid intake, proper suctioning, and coughing.
- A mucus plug may be removed by suctioning the airway.
- If the plug cannot be removed by suctioning, change the trach tube.

What to do: When in doubt, change out the trach tube.

3. BLEEDING

It is not unusual to have occasional blood-tinged or pink colored mucus. However, bright red blood may be a sign of serious damage to the airway.

Causes of bleeding may include:

- Dry airway
- Frequent suctioning beyond the recommended depth
- Infection
- Excessive coughing
- Irritation from the trach tube
- Foreign body aspiration

How to prevent bleeding:

- Suction when necessary and avoid frequent deep suctioning.
- Use appropriate methods of humidification.

What to do:

- Notify your ENT provider if you notice mild, blood-tinged secretions.
- **If you see bright red bleeding from your child's trach, call 911.**

4. ACCIDENTAL DECANNULATION

If the trach tube is not secured properly, it is easy for your child to cough, pull, or have the trach fall out. If the trach comes out partially or completely, your child may have difficulty breathing.

Prevention

- Make sure the trach ties are secure, dry and intact.
- There should only be one-finger width between the trach collar and your child's neck.
- If the ties are showing signs of wear such as thinning of the tie or tears, it is time to replace the ties.
- Do not allow anyone to pull at the trach, particularly your child.

What to do:

- If the trach comes out, replace the tube as you would when performing a trach tube change



5. ASPIRATION

This occurs when secretions or food particles from the mouth, esophagus or stomach enter the airway.

Signs of aspiration

- Drooling
- Coughing or choking with swallowing
- Food contents in the secretions from the trach
- Frequent lung infections

Prevention

- Have your child sit upright during feedings and afterward for 30 minutes.
- Encourage slow eating and small bites.

What to do if aspiration occurs:

- Carefully watch your child's eating and drinking.
- Suction the tube until the secretions are clear of the liquid or food particles.
- Change the tube if it is clogged.
- Notify your provider if your child is showing signs of breathing difficulties.
- Work with a speech therapist as recommended.

Remember that your child can also aspirate if they vomit. It is best to turn your child's head to the side and suction.

6. INFECTION

Since air inhaled through a trach is not filtered by the body, your child is at an increased risk for infections.

Signs of infection

- Fever
- Foul odor
- Yellow or green secretions
- Redness or bleeding at the stoma site
- Fast breathing or change in breathing pattern
- Lethargy

If you feel that your child's trach may be infected, please call your provider.



How to Use the Ambu[®] Bag

DIRECTIONS

You should use the self-inflating bag when your child is showing signs of difficulty breathing, including having a blue or pale color around the lips and face, struggling for breath, or if they have stopped breathing.

1. If you have oxygen available, attach the tubing of the self-inflating Ambu[®] bag to the oxygen tank. Turn on the oxygen tank.
2. Place the adapter end of the bag on your child's trach tube making sure it fits securely on the trach tube.
3. Squeeze in the sides of the bag with one hand until you see chest rise. As you squeeze the bag, the air in the bag flows into your child's lungs. Release the bag, and it will reinflate with more air. You will be taught how fast to give these "breaths."
4. As you squeeze the bag, look at your child's chest to make sure that it rises with each breath. If you do not see the chest rise, check to see that the bag is securely attached to the trach tube. If you still do not see the chest rise, then the trach tube may be obstructed or out of place. **You need to change or reinsert the trach tube right away.** After replacing the trach tube, put the bag back on the trach tube and start squeezing the bag as before.
5. Continue to squeeze breaths into your child's lungs until you can tell that your child is better, with pinker color and less labored breathing. You should suction the trach tube as needed as you continue to give breaths.
6. If you are using the self-inflating bag because your child stopped breathing, call 911 and follow instructions for CPR.



Ambu[®] is a registered trademark name for a manufacturer of these devices. The actual device is called a bag valve mask resuscitator or BVM resuscitator. Image courtesy of Ambu Inc.



How to Understand the Basics of Mechanical Ventilation

MECHANICAL VENTILATION

A ventilator is a machine that assists with breathing and may be used on a full- or part-time basis.

Prior to hospital discharge, ventilator teaching will be scheduled with your home care company to take place at the hospital. They will provide information on the specific ventilator that you will have at home. The ventilator settings will have been chosen specifically for your child. These settings should not be changed unless advised by your doctor. Ventilator settings are reevaluated as your child grows. You should become familiar with your child's ventilator settings.

Note:
Room air is 21% oxygen

BASIC VENTILATOR SETTINGS MAY INCLUDE

- Oxygen (if needed).
- Rate – the number of ventilator breaths delivered per minute.
- Tidal volume – the volume of air the ventilator will deliver with each breath.
- Peak inspiratory pressure – the total pressure needed to push a volume of air into the lungs. It is routinely displayed by mechanical ventilators.
- PEEP (positive end-expiratory pressure) – a small positive pressure that is set at the end of expiration and keeps the airway from collapsing.
- Pressure support – helps the child's own inspiration effort and decreases the work of breathing.

VENTILATOR PROBLEMS

If problems occur with your child's ventilator, be sure to call your DME or ventilator equipment agency. If alarms are sounding, however, it may be something you can fix at home.

Low Pressure Alarm – Check:

- Is the tubing secure on the trach tube and the ventilator?
- Is the trach tube in place underneath the dressing?
- Is there a crack or hole in the ventilation tubing?
- Is the trach tube cuff properly inflated with air or water (if applicable)?

High Pressure Alarm – Check:

- Is the trach tube blocked?
- Does child need suctioning?
- Is there water in tubing or is it pinched or kinked?
- Is your child crying or coughing?

Low Power Alarm – Check:

- Is the ventilator plugged into an electrical outlet? Is the battery charged? Does the battery need to be changed?

How to Perform CPR

NEWBORN TO 1 YEAR **CPR AND RESCUE BREATHING FOR INFANTS**

You arrive on the scene: Check the scene for safety.

Check the infant for consciousness.

Gently tap the shoulder or flick the bottom of the heel and shout.

If no response: **Call 911 immediately.**

If the infant is lying on their stomach, turn over onto their back. The infant should be lying on a hard, flat surface.

Check for Breathing and Signs of Life

Watch the infant's chest for any normal movement.

Look for signs of life and breathing. Using no more than 10 seconds, check for pulse and ensure the trach tube is in place.

If No Breathing or Signs of Life

Begin CPR

1. Position 2 or 3 fingers on the center of the infant's breastbone just below the nipple line.
2. Compress the chest 1 ½ inches in depth 30 times.
3. After the compressions, give 2 breaths using the resuscitation bag attached to the trach.
(See page 22.) Gently squeeze the bag and give 2 breaths – just enough to make the infant's chest rise.
4. Continue with 30 compressions and 2 breaths (1 cycle); 30 compressions and 2 breaths, etc.

If the Breaths Do Not Make the Chest Rise:

1. Suction the trach tube.
2. Change the trach if it is plugged or dislodged.
3. Give 2 breaths to the newly placed trach using a resuscitation bag.
4. Continue CPR until another rescuer takes over, you see signs of life, or help arrives.

**If you are alone, perform 5 cycles
of CPR before calling 911**

AGES 1 TO 8 YEARS

CPR AND RESCUE BREATHING

You arrive on the scene: Check the scene for safety.

Check the child for consciousness.

Gently tap the shoulder and shout.

If no response: **Call 911 immediately.**

If the child is lying on their stomach, turn them over onto their back. The child should be lying on a hard flat surface.

Check for Breathing and Signs of Life

Watch their chest for any normal movement. Look for signs of life and breathing. Using no more than 10 seconds, check for pulse and ensure the trach tube is in place.

If No Breathing or Signs of Life

Begin CPR

1. Position the heel of one hand on the center of the child's chest
2. With your elbow locked and straight, lean over the child's chest and compress the chest 2 inches in depth 30 times.
3. After the compressions, give breaths using a resuscitation bag attached to the trach. (See [page 22.](#)) Gently squeeze the bag and give 2 breaths – just enough to make the chest rise.
4. Continue with 30 compressions and 2 breaths; 30 compressions and 2 breaths, etc.

If Breaths Do Not Make Chest Rise

1. Change the trach if it is plugged or dislodged.
2. Give 2 breaths to the newly placed trach using a resuscitation bag.
3. Continue CPR until you see signs of life, another rescuer takes over, or help arrives.

**If you are alone, perform 5 cycles
of CPR before calling 911**

AGES 8 AND OLDER

CPR AND RESCUE BREATHING FOR OLDER CHILDREN AND ADULTS

You arrive on the scene: Check the scene for safety.

Check the child for consciousness.

Gently tap the shoulder and shout.

If no response: **Call 911 immediately.**

If the child is lying on their stomach, turn them over onto their back. The child should be lying on a hard flat surface.

Check for Breathing and Signs of Life

Watch their chest for any normal movement. Look for signs of life and breathing. Using no more than 10 seconds, check for pulse and ensure the trach tube is in place.

If No Breathing or Signs of Life

Begin CPR

1. Position the heel of one hand on the center of the child's chest. Place your other hand on top.
2. With your elbows locked and arms straight, lean over the child and compress the chest at least 2 inches in depth 30 times.
3. After the compressions, give breaths using a resuscitation bag attached to the trach. (See page 22.)
Gently squeeze the bag and give 2 breaths – just enough to make their chest rise.
4. Continue with 30 compressions and 2 breaths; 30 compressions and 2 breaths, etc.

If Breaths Do Not Make Chest Rise

1. Change the trach if it is plugged or dislodged.
2. Give 2 breaths to the newly placed trach, using a resuscitation bag.
3. Continue CPR until you see signs of life, another rescuer takes over for you, or help arrives.

**If you are alone, perform 5 cycles
of CPR before calling 911**

Resources for Families of a Child with a Trach

This section of the trach handbook is provided to help you access resources that may assist you in caring for your child now that they have a trach. We want to make sure you have the support you need to care for your child once discharged.



Financial Assistance

SUPPLEMENTAL SECURITY INCOME (SSI)

1-800-772-1213

SSI is a program of the Social Security Administration that provides a monthly check and Medicaid to patients who are disabled and whose household income is below a certain level. Your child may qualify for SSI because of their diagnosis and/or complex medical needs.

The Social Worker will provide you with a brochure entitled “What You Should Know before You Apply for SSI Disability Benefits for a Child.” This brochure explains the process, but is not the application. To file for SSI for a child, you have to call the number above and tell them that you want to file for disability for your child. They will schedule an appointment where you provide the necessary information to file. This appointment can be a telephone appointment if you request, as your child is in the hospital. If you prefer to go to the SSA office, they can schedule a face-to-face appointment. The brochure describes the information you will need such as the names and addresses of all the doctors that have seen your child. The Social Security Administration will request the medical records as they want them to come directly from the provider; therefore it is not necessary for you to obtain the records on your own. Texas Children’s Hospital will not release any records while your child is currently hospitalized. If you need documentation of your child’s diagnosis, medications, and such, ask the social worker to obtain a letter with the needed information signed by the physician. This is usually sufficient to initiate the process. Once your child is discharged, your medical records will be released to SSA if you have signed the release.

If your application for SSI is denied, please follow through with the appeal process. During the appeal, your child’s records are reviewed by a physician. Many children with complex medical needs who were initially denied are approved once appealed. Please note that although your child may qualify medically for SSI, if the household income is above a certain limit, you will be denied.

Obtaining a status of medically qualified for SSI will be helpful when applying for other programs. You should still apply, even if your income is above the limit.



MEDICALLY DEPENDENT CHILDREN'S PROGRAM (MDCP)

1-877-438-5658

MDCP is a Medicaid Waiver Program. Medicaid Waiver Programs are a group of programs for children with disabilities. These programs provide your child with Medicaid even if your income is too high to qualify for regular Medicaid. They can also provide you and your child with a wide variety of extra services such as extra home nursing care (above and beyond what Medicaid provides), respite care, equipment (such as a wheelchair lift) not covered by Medicaid, and home modifications (such as a wheelchair ramp).

There are three different Medicaid Waiver Programs and each one is directed toward a particular group of children. MDCP is for children with many medical needs and equipment. This is the waiver program for most children with trachs.

All of the waiver programs have long waiting lists, ranging from 4 to 10 years, but the MDCP has a way for some children to obtain MDCP within a few months. If your child has at least two medical needs such as a trach and a g-tube, they may be able to bypass the long waiting list by utilizing the Rider 28/Money Follows the Person process. The Social Worker will provide you with additional information on MDCP and the Rider 28/Money Follows the Person (MFP) Process.

If you have private insurance, it is extremely important that you obtain MDCP. MDCP provides more nursing hours and other services than most private insurance companies allow, therefore, it will be very beneficial for your family. MDCP gives your child Medicaid which can be used in addition to your private insurance. Once your child has MDCP, they can remain on the waiver until they turn 21. Although they no longer allow families to apply for the Rider 28/MFP process while their child is hospitalized, the process takes a few months, so you should start the process now.



Help for the Caregiver

PRIVATE DUTY NURSING (PDN)

Your child will most likely qualify for PDN. Your Care Manager will assist you in determining if your insurance company covers this service and, if so, for how many hours. They will provide you with a list of companies that offer PDN and assist you in setting up appointments so that you can choose a company that best meets your needs. The Care Manager will also set up all your home health care services which includes durable medical equipment and supplies.

PHYSICAL THERAPY/ OCCUPATIONAL THERAPY/ SPEECH THERAPY

The Care Manager will help you set up PT/OT/Speech Therapy if this is something your doctor feels will benefit your child. There are many companies that provide these services, so the Care Manager will assist you in locating the provider that best meets your needs based on the area where you live, the type of medical insurance you have and which services your doctor orders. If your child is under 3 years old, the Social Worker will also make a referral to Early Childhood Intervention (ECI) if you are not already receiving ECI services.





EARLY CHILDHOOD INTERVENTION

ECI is a statewide program for families with children, birth to age three, with disabilities and developmental delays. ECI supports families to help their children reach their potential through developmental services. The goal is to teach you activities and strategies you can use every day with your child. Services are provided by a variety of local agencies and organizations across Texas and are provided in the home and in community settings such as child care facilities, play groups and Mothers' Day Out programs.

ECI provides evaluations and assessments at no cost to families to determine eligibility and need for services. Families and professionals work as a team to plan appropriate services based on the unique needs of the child and family. ECI asks families who can afford to do so to share in the cost of services, but no child and family will be turned away because of an inability to pay. Families with children enrolled in Medicaid do not pay for any ECI services. The social worker can provide you with more information.

HANDICAP PLACARD

Since your child has a trach, you may qualify for ambulance transport to attend medical appointments. But if you don't need an ambulance transport, it may be helpful for you to have a handicap placard so that if and when you use your own car, you can park close to entrances. The social worker will assist you in obtaining the handicap placard application and getting it signed by a physician. Once you have the signed and notarized application, you take it to your county tax office to obtain the placard. The social worker will usually check that the disability is permanent just so that you do not have to go renew the placard as often. This terminology makes for less paperwork. It is not a medical determination. You qualify for two placards, so you should get both of them if you have more than one family car, or if you just want an extra.



ELECTRICITY CRITICAL CARE FORM

If you are a Texas resident and have a medical condition that could become life threatening if your home were to lose power, you may qualify for critical care or chronic condition status with your electric service provider. If your child has a trach and is vent dependent, your household will qualify. The social worker will assist you by obtaining the form and getting the physician to complete the medical status. Once completed, the form must be faxed from the doctor's office or the hospital in order to be accepted. Then, your electric provider accepts the form and gives you critical care status, your household will be flagged so that in the event of a power outage, restoring your power will be a priority. The electric company cannot guarantee that you will not have interruptions in service, but they will make every effort to restore your service as soon as possible. It is still your responsibility as a caregiver to ensure you have a backup source of power so that your child's life is not in danger. If you are having financial difficulties, it is imperative that you call your provider and set up a payment plan. They will work with you because they do not want to be responsible for your child being without life-sustaining equipment.

EVACUATION ASSISTANCE

If you live in Texas, you know that we are prone to hurricanes; but wherever you live or travel, natural disasters are always possible. Because your child has special needs, it is important for you to plan ahead in the event of a disaster. If you register with Health and Human Services by calling 211, they will place you on a roster that allows the agency to make arrangements for your child should a disaster occur. Whether you need to be evacuated from your home or need a place to go that has electricity, they can help, if you are registered. If they do not know about your child, they may not be able to send help when you need it. It only takes a few minutes to register. Please make sure you do.



SUPPORT GROUPS

Participating in a support group with other parents that understand what you are going through may be helpful. While there may not be a support group specifically for parents of a child with a trach, there are support groups for many diagnoses. Whatever condition has necessitated your child getting a trach, there is probably a support group for that. Your social worker can help you locate a support group that meets face-to-face, or via social media sites such as Facebook. We do not have support groups that meet here at the hospital because when your child is here at the hospital, most caregivers want to be at the bedside to care for their child and be available to meet with the medical team. It is very common, however, for parents to create their own support network of caregivers that are here at the same time. We encourage you to talk with other parents in the lounge or that you see in the unit. If you all are here together, you already understand what the other is going through, so don't be afraid to reach out.

Websites:

- The Global Tracheostomy Collaborative: globaltrach.org
- Aaron's Tracheostomy Page: www.tracheostomy.com
- TrachCare: www.trachcare.org
- Facebook Page – Moms of Trach Babies



RELATIVES AND FRIENDS

Your relatives and friends want to be there to support you, but they may not know how to help. Let them know that your child will need special care because of the trach, but they will need the same love and attention that any child needs. Your child has a trach, but they are still a child.

Caring for a child with a trach involves additional time and energy, so let your relatives and friends help you. Although they will need to be trained on trach care in order to assist you with the actual care of your child, they can do other things. For example, going to the grocery store with a child with a trach can be a challenge, so let them shop for you. Your relatives and friends want to help, so tell them what they can do that will be helpful.



TEXAS CHILDREN'S HOSPITAL TRACH TEAM

We are all here to assist you and your family as you adjust to life with a trach. Please feel free to ask questions and make suggestions. You are the expert on your child. If you need something that we have not mentioned, we can definitely help you research for what you need. Your comfort with caring for your child is of utmost importance to us.



Common Steps for Any Tracheostomy Emergency

- 1**
Suction
to the
correct depth.
- 2**
Bag
through the
tracheostomy.
- 3**
Change
the trach tube.
If the regular size
does not work try the
smaller sized tracheostomy.
If the smaller size doesn't
work, bag the mouth with
the mask (and call 911).
- 4**
Start CPR
and call 911
if the child
becomes
unresponsive.

Always check to see if each step works and if not go on to another step.
It is ok to start on 2, 3, or 4.

Texas Children's Hospital
in the Texas Medical Center
6701 Fannin St, Level 5
Houston, TX 77030
832-822-3250

West Campus
18200 Katy Fwy, Level 4
Houston, TX 77094
832-227-1420

The Woodlands
17580 Interstate 45 South, Level 3
The Woodlands, TX 77384
936-267-7400

