

Tracheotomy Care Handbook



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Dear Parent or Guardian:

As you have already discussed with your child's doctor, a tracheotomy will be performed on your child to help him or her breathe. This manual will help prepare you for what to expect during your child's hospital stay and discharge process. To make sure your child gets the safest care at all times, at least two caregivers must be taught how to do tracheotomy care. The education has many parts, and you and a second person will need to learn all parts of your child's tracheotomy care before he/she can go home.

Teaching will start the day of surgery for all caregivers. Over the next few weeks, you and a co-caregiver will learn all the skills you need to care for your child's tracheotomy. To make sure you and the second caregiver can safely and comfortably care for your child's tracheotomy, each of you will show how to care for him/her without coaching from the nursing staff or other family members. Both caregivers will care for the child for a 24-hour period before he/she can go home. This period is called transitional care.

The social worker and discharge coordinator will help you make plans for home equipment, supplies and nursing. Home equipment and supplies must be in place before discharge. Benefits will be explored to see if private duty nursing is available. If private duty nursing is an available benefit, it must be arranged prior to discharge.

The estimated length of stay in the hospital can vary based on your child's recovery, your learning needs, planning for home equipment and supplies, and the availability of private duty nursing. This process usually takes at least 2 weeks, but it may take longer.

This time can be very stressful for families. We are here to support you and your family during this process. To help with your learning process, we have enclosed a teaching packet that you should review before the tracheotomy surgery. If you have special learning needs, please let us know so we can make special arrangements.

If you should have any questions or concerns, please feel free to contact the airway nurses, 513-636-3448.

Sincerely,

The ENT Team

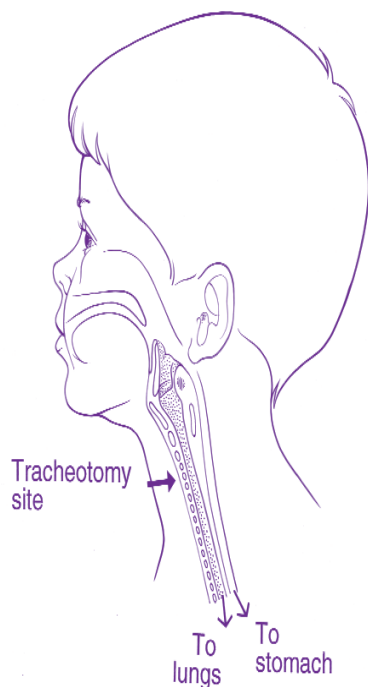
WHAT IS A TRACHEOTOMY?

A tracheotomy is a surgery where a doctor places a tube for breathing into a child's trachea (windpipe). A tracheotomy is also known as a "trach". Developed almost 500 years ago, the surgery is done for many reasons. The reasons may include:

- bypassing a blockage in the airway
- to assist patients who cannot cough out the mucus from their lungs
- to help patients who need to be on a ventilator (breathing machine) for a long time

The surgery usually is done in an operating room under a general anesthetic. The drawing below will help you see where the surgery is actually performed. The tracheotomy tube is placed below the larynx (voice box). Because of where the tube is placed, most children do not lose the ability to speak once the tracheotomy tube is put in. Some children may not be able to talk after surgery because of:

- swelling around the tracheotomy tube
- The size of the tracheotomy tube needed for the child to breathe easily
- A blockage already in the airway



The tracheotomy tube is placed in front of the esophagus (swallowing tube), so most children are able to eat normally. However, some children who have a history of choking and coughing after swallowing may still have these problems after getting a tracheotomy. Discuss your child's specific feeding needs with your doctor, nurse, dietician, or therapist.

Based on the reason your child needs the tracheotomy, it may be temporary. Most conditions that call for tracheotomies in children can be outgrown or surgically corrected. However, a tracheotomy may be needed for a long time for children who cannot cough out mucus from their lungs or need a ventilator (breathing machine). Discuss your child's condition with your doctor to understand better how long your child will require a tracheotomy.

Charles M. Myer III, M.D.

A Message From the Nursing Staff

Your child has a breathing tube called a tracheotomy and needs special care. We know this is a hard time for you and your child. You may have many questions, concerns or fears. You may be afraid you will not be able to learn how to take care of your child's tracheotomy tube.

We are here to help you learn about your child's special needs. In fact, the whole time you are here, you and the health-care team will be planning for the day your child can go home.

Based on our experience with many families who have learned to care for a child with a tracheotomy tube, we offer this advice:

- Spend time taking care of your child during the hospital stay. The more involved you are while your child is here, the better prepared you will be at home.
- Choose a co-caregiver to learn with you. You cannot provide care 24 hours a day. You will need help from someone else who knows how to take care of your child's tracheotomy tube.
- For your child's safety, any person caring for him/her will need to know all of the skills you learn while in the hospital. When your child is almost ready to go home, you and the co-caregiver should spend at least one full day and night caring for your child in the hospital. We call this "transitional" care. This time will help you prepare for the transition from hospital to home.
- Encourage your child's siblings and other family members to visit. Your child will want company and your family will begin to feel more at ease with the tracheotomy tube.
- After you have learned to care for your child's tracheotomy, be ready to help others learn to care for your child. We are glad to help with this teaching.
- Ask questions. Your health care team can do a better job taking care of your child and helping you if we know your questions and concerns.

MEET YOUR CARE TEAM

During the hospital stay, many people will be involved with your child. You will meet and work with:

- | | | |
|-----------------------|--------------------------|--------------------------|
| • doctors | • child life therapist | • respiratory therapists |
| • nurses | • dietitian | • social worker |
| • nurse practitioners | • occupational therapist | • speech therapist |
| • chaplain | • physical therapist | |

SUPPORT AT HOME

Before you are ready to take your child home, you will choose an equipment company to supply the items needed to care for your child with a tracheotomy tube. Your discharge planner and social worker will arrange for your equipment company to deliver the medical equipment to your home. You will have everything you need to care for your child when he/she comes home.

You may also qualify for home nursing. Your discharge planner and social worker will help you look at the possibility of home nursing, and can give you a list of companies that provide home care. They will talk with your doctor to decide how many hours are needed, then contact your insurance company to see if your policy will cover this service. The discharge planner and social worker will organize nursing help to begin when you go home.

LEARNING LIST FOR THE CARE OF YOUR CHILD WITH A TRACHEOTOMY

Before your child goes home, you and a co-caregiver need to learn the following care. Any person staying with your child will also need to learn all of this information.

	Caregiver	Co-Caregiver
1. Why your child needs a tracheotomy tube	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
2. Type, size and length of your child's tracheotomy tube	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
3. Why, when and how to suction the tracheotomy tube	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
4. Why, when and how to clean the skin around the tracheotomy tube	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
5. Why, when and how to change the tracheotomy ties	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
6. Why, when and how to change the tracheotomy tube	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
7. Humidification	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
8. Supplies to have with your child at all times	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
9. Potential emergencies and how to help your child	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
10. The signs of respiratory distress and how to help your child	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
11. How to give oxygen through the tracheotomy tube	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
12. The signs of infection	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
13. Activities your child can do and activities to avoid	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
14. How to give medications, aerosols if needed	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
15. The use of necessary equipment and monitors	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
16. Use of home equipment _____ (date of set up/education)	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
17. How to do rescue breathing and cardiopulmonary resuscitation (CPR)	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
18. 24-hour transitional care completed	<input type="checkbox"/>	<input type="checkbox"/>
19. Other _____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

When you and your co-caregiver have shown success three different times for each item above, place a check in the box and the date it was completed above the box.

We have read and understand what we must learn to give tracheotomy care. We understand these items must be learned before _____ is discharged to home under our care.

Caregiver

Co-caregiver

TYPES AND PARTS OF TRACHEOTOMY TUBES

There are many types and brands of tracheotomy tubes. The tubes also come in many sizes and lengths. Your doctor will decide the type, size and length of tube your child will need.

The type of tracheotomy tube is based on your child's:

- breathing problem
- age
- airway size
- special needs

As your child grows and his/her condition changes, these same factors will help decide the correct type, size and length of his/her tracheotomy tube.

SYNTHETIC TUBES

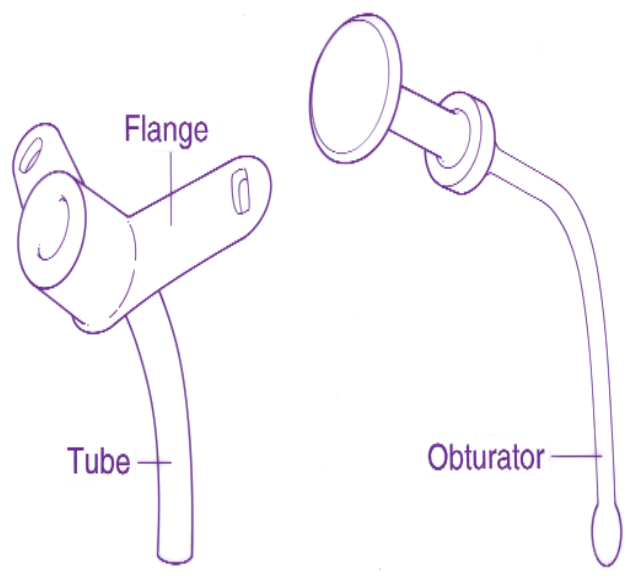
Most synthetic tubes generally have the same basic parts:

- The tracheotomy tube or cannula
- The flanges or faceplate where the ties are secured
 - Some tubes will have an extended connect neck flange
- The obturator, or guide, for inserting the tube

FLANGES:

Flanges rest on the neck. Tracheotomy ties are attached on both sides

TRACHEOTOMY TUBE:



OBTURATOR:

A guide placed inside the tube when the tube is inserted. The obturator is taken out right after the tube is put in.

Please review the package insert found with your child's trach for specific information.

SUCTIONING A TRACHEOTOMY TUBE

PURPOSE:

Suctioning a tracheotomy tube is done to:

- remove mucus from your child's tracheotomy tube and windpipe
- allow easier breathing

Mucus is the body's normal response for cleaning the airway. During the first few weeks after a tracheotomy, your child may have a large amount of mucus. This is due to the surgery itself and the tissue's normal response to the new tube. In many children, the amount of mucus should decrease over time.

WHEN TO SUCTION:

You should learn your child's normal breathing pattern so you know when he/she needs suctioning. What you see, feel and hear will tell you when to suction your child. Signs you should look for may include:

- rattling mucus not cleared with coughing
- fast rattling
- bubbles of mucus at tracheotomy opening

Advanced signs that your child needs suctioning may include:

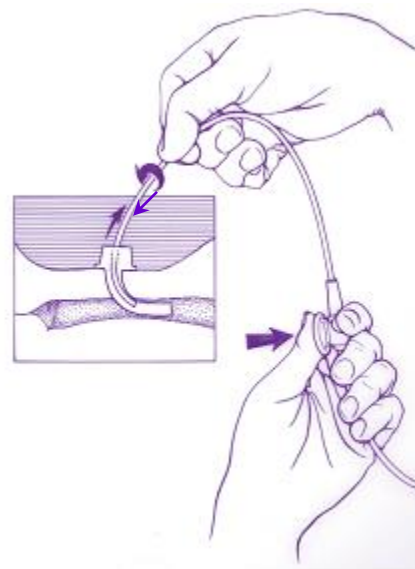
- Frightened look
- Flared nostrils (nostrils become wide)
- Restlessness
- Pale or bluish color over skin, nails, mouth
- Clammy skin
- Fast, noisy, hard breathing
- Dry, whistling sound

SUPPLIES NEEDED:

- **Disposable saline vials** (Side effects may occur with saline use, including lower oxygen levels, changes in heart rate or infection)
 - only instill saline when secretions are thick or blood tinged.
- **Suction machine** – Pressure gauges vary with suction machines; check with your equipment company about setting the pressure limit.
- **Suction catheter** – **Size** _____ (The ideal size suction catheter is 2/3 the opening of the tracheotomy tube. You may need to adjust the size if the mucus is thick)
- **Breathing bag** – With optional tracheotomy adapter for metal trach tube
- **Tissue**
- **Gloves** – (Optional) Suctioning is a clean procedure at home
- **Rinse water and paper cups** – If rinsing catheters in water instead of saline

HOW TO SUCTION

1. Wash and dry hands.
2. Set up equipment.
3. Pour rinse water into paper cup.
4. Connect suction catheter to suction machine tubing.
5. Turn on suction machine.
6. Place tip of suction catheter into water to moisten it and test to see if suction machine works.
7. Put small drops of normal saline into tracheotomy tube. (You do not have to use normal saline if mucus is thin and loose.)
8. Use a tissue to wipe away any mucus that is coughed out.
9. Using the obturator as a guide, measure how far to insert the suction catheter (many catheters have markings on them to make measuring easier).
10. Put your thumb over the opening of the suction catheter.
11. While applying suction, gently place the suction catheter into the tracheotomy tube to the premeasured mark.
12. Use a gentle rotating motion while removing the suction catheter so that the mucus is removed well from all areas. This step should take no more than 5 seconds and can be as short as 1 second.
13. Rinse the suction catheter.
14. Watch your child's color and breathing effort.
15. Let your child catch his/her breath between suctioning attempts.
16. Repeat suctioning until your child's respirations sound clear and the suction catheter returns with little or no mucus. Limit the passes of the suction catheter to three (3) times whenever possible.
17. Dispose of suctioning supplies and turn off suction machine. If you are reusing catheters at home, you may want to place used catheters in a plastic bag until you have time to wash them with soap and water. Air dry catheters and store them in an open container.
18. Wash and dry hands.



TIPS on suctioning: If there are bloody streaks in the mucus, check suctioning depth and try using saline drops with suctioning. More time on the mist machine may also help decrease blood in the mucus. If the blood in the mucus does not get better within 24-28 hours, notify your doctor. **If you see bright red blood, your child needs to be seen right away by your doctor.**

TRACHEOTOMY SKIN CARE

PURPOSE:

Skin at the tracheotomy site needs to remain clean and dry. If drainage collects around the tracheotomy tube, germs can grow and cause infection or skin rashes.

WHEN:

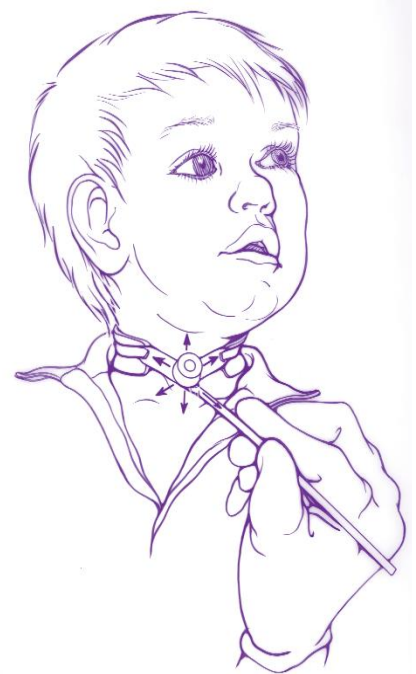
Look at this area and clean it 2-3 times a day, or more often if there is redness, irritation, drainage or cuts.

SUPPLIES NEEDED:

- Mild soap and water when skin is healed
- ½ strength hydrogen peroxide (mix equal parts hydrogen peroxide and water) when skin is not healed
- Cotton swabs
- Paper cups
- Mepilex Lite product (optional)

HOW TO CLEAN:

1. Wash and dry hands.
2. Set up supplies.
3. Look at the neck, noting cuts or signs of infection.
4. Prepare soap and water or ½ strength hydrogen peroxide in a clean cup.
5. Dip cotton swab in solution.
6. Starting at the stoma, stroke away from the tracheotomy opening, using one stroke per swab. Discard swab.
7. Clean the flanges of the tracheotomy tube.
8. Using dry cotton swabs, dry the skin the same way you cleaned it.
9. Again, look at the neck.
10. Apply a dressing for excess drainage or if tracheotomy tube is rubbing the skin.
11. If using gauze, do not cut it since frayed fibers may be breathed in the tube.



SIGNS OF INFECTION:

- Redness
- Swelling
- Drainage
- Cuts
- Foul odor

HOW TO TREAT SKIN PROBLEMS:

The use of creams and lotions on the neck and the tracheotomy site is not routine. Call your doctor or nurse practitioner if there is:

- any signs of infection or irritation of the skin surrounding the tracheotomy tube
- skin care problem at the tracheotomy site

TRACHEOTOMY TIE CHANGE

PURPOSE:

Tie changes are done to prevent the tracheotomy tube from falling out, and to prevent skin breakdown and rashes on the neck.

WHEN:

Ties are changed at least daily or when ties are wet or dirty.

SUPPLIES:

- Scissors
- Hemostats
- Extra twill tracheotomy ties or self-fastening ties



HOW TO CHANGE TWILL TIES:

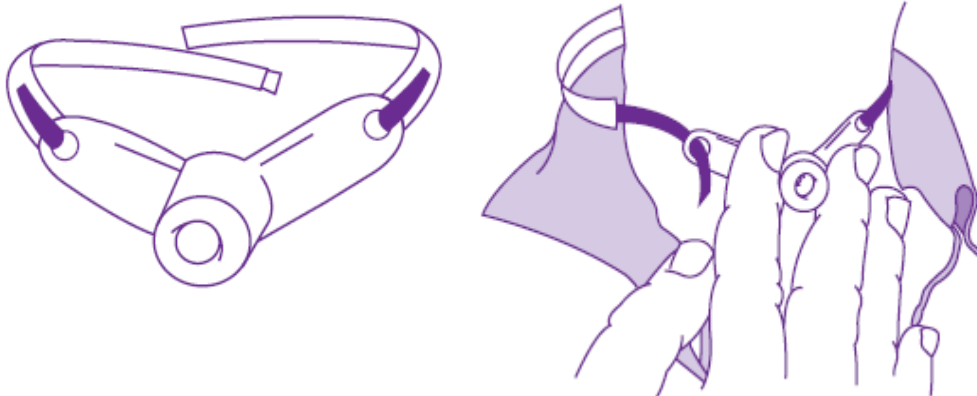
- Ask a second person to help with tie change. The second person will hold the tracheotomy tube in place while the first person is changing the ties.
- If possible, do not cut the old ties until the new ties are secured. Slide the soiled ties up or down to allow you to put the new ties on the flange at the same time.
- Cut one piece of cotton twill tape long enough to fit around the neck, double back and be tied.
 - Cut at an angle to prevent fraying.
- Thread the tape through the hole of the tracheotomy tube flange from back to front. Pull the end of the tie through the hole using the hemostats or tweezers for about 8-10 inches. Pull tightly while holding the tube.
- Using the other end of the twill tie, repeat the process for the other side of the tube. Bring both pieces of tie together into the first part of a square knot.
- Check the new ties and see that only one finger/fingertip can slide under the ties. Be certain the tie lies flat against the neck and there is no slack in the tie. Complete the square knot. Recheck the new tie and see that only one finger/fingertip can slide under the ties. The location of the knot should be moved each time it is tied to prevent skin breakdown. The best location for the knot is between the shoulder and back of the neck.
- Flex the child's head slightly while tying to make sure the ties are secure in all positions. If irritation is noted on the neck, protection can be applied. This involves either placing a gauze pad at the point of rubbing or using different ties.
- Cut the old ties and remove them. Recheck the new ties to be sure that only one finger/fingertip can slide between the ties and the neck. The second person must hold the tracheotomy in place as the first person secures the new ties. Secure the ties by tying three square knots.

SELF-FASTENING (Velcro®) TIES:

Some children are switched from twill ties to self-fastening ties in the hospital because they are easier to use and less irritating to most necks. However, they are not for every child. Style and fit is very important for safe use. Some children are sensitive to the material in the self-fastening ties. If your doctor permits your child to use them, a prescription will be sent to your equipment company. There are several brands, so you may choose the one that meets your child's needs.

HOW TO CHANGE SELF-FASTENING TIES:

- Remove the old ties, while the second person holds the flange of the tracheotomy tube.
- Slip the self-fastening tab through the opening of the tracheotomy flange, folding it back onto the cloth material to fasten it securely.
- Repeat this step on the other side.
- With the child's head flexed forward slightly, bring the two ends together, fastening the third self-fastening tab to the material.
- Check that self-fastening ties are secure, only allowing one finger/fingertip to fit between the tie and the neck.



Tips:

- If using self-fastening ties, you must check the ties often throughout the day to make sure the Velcro® is secure.
- If cleaning and reusing Velcro® ties, check the ties to make sure the Velcro® hold is still strong. Wash them in mild soap and water only, and line dry.

TRACHEOTOMY TUBE CHANGE

PURPOSE:

To prevent mucus plugs in the tracheotomy tube and to keep the tracheotomy tube clean.

WHEN:

Change the tracheotomy tube every 1-2 weeks. Two trained people are preferred for routine trach changes. In an emergency, you must be prepared to change the tube by yourself.

SUPPLIES:

- Current size and length tracheotomy tube
- Size smaller and correct length tracheotomy tube
- Tracheotomy ties
- Water-based lubricant
- Scissor
- Hemostats (or blunt tipped tweezers)
- Supplies for suctioning
- Tissues
- Self-inflating bag

HOW TO CHANGE:

1. Wash and dry hands.
2. Prepare ties. Secure the Velcro® ties to the flanges, or insert twill ties into one of the flanges. Place tracheotomy tube on clean surface. Avoid touching the cannula on any unclean surface.
3. Prepare suctioning equipment.
4. Suction your child's tracheotomy tube.
5. Place the child on his/her back with a small roll under his/her shoulders. If your child cannot tolerate lying on his/her back, we will teach you the side lying or sitting position technique.
6. Have one person loosen the ties, holding the tracheotomy tube in place and calming the child.
7. The second person moistens the tip of the tracheotomy tube with lubricant.
8. The first person removes the old tracheotomy tube when the second person is ready.
9. The second person inserts the tracheotomy tube in one smooth curving motion, directing the tip of the tracheotomy tube toward the back of the neck. ***Do not force the tube!***
10. Remove the obturator, holding the tracheotomy tube securely. Feel for air movement with your fingers, or check for coughed or suctioned secretions.
11. Changing the tracheotomy tube will cause the child to cough. Have tissues ready to wipe secretions or prepare to suction. ***Do not let go of the tube!***
12. Secure the tracheotomy ties, only allowing room for one finger/fingertip between the neck and the ties.



- Check with your doctor or nurse before placing your child in this position. Some children should **not** be placed in this position.

IF THE TUBE DOES NOT PASS EASILY:

- Remain calm and act quickly.
- ***Do not force the trach tube!***
- Let your child relax and breathe.
- Reposition the child so the head is back and the stoma can be seen.
- Remove the tube. Relubricate the tube, checking to make sure you are not trying to insert the tube upside down. Try inserting the tube again.
- If you still cannot place the trach tube, **call 911**. Start rescue breathing and/or CPR if trach tube change is not effective.
- Try to insert the size smaller trach tube. Remember that you can give your child breaths with a mask over the nose and mouth if you can not get the trach in place.
- When your child is pink, continue mask bagging and try to insert the size smaller trach tube.
- Insert a suction catheter through the size smaller trach tube. Guide the suction catheter into the stoma. Then slide the trach tube over the suction catheter and into the stoma.
- Remove the suction catheter. Connect the trach ties. Take the mask off the breathing bag and place the breathing bag on the new trach.
- Breathe for your child until he/she is breathing on his/her own or until help arrives.
- After the emergency is over, call your child's doctor for advice if the size smaller trach tube could only be placed.

Note: Most children with trachs can be mask bagged over the nose and mouth when you can not get the trach tube into the stoma. Ask your doctor if your child's airway allows mask bagging in this emergency.

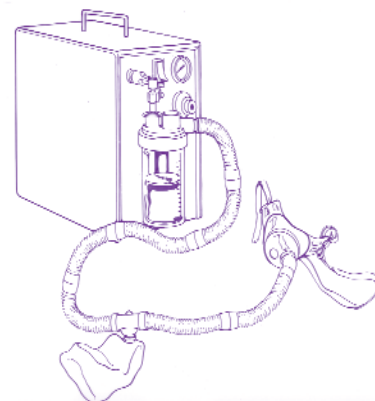
Tips: It is helpful to keep an emergency tube and a set up with ties in a small plastic bag in your emergency trach bag. Use this trach tube with ties for your routine trach tube change every one to two weeks. Then place a new trach tube and ties in a small plastic bag in your emergency trach bag. You never want to keep the emergency tube and ties in your emergency trach bag for more than two weeks.

HUMIDIFICATION

PURPOSE:

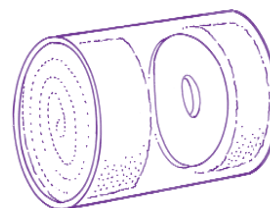
Your nose warms, moistens and filters air that you breathe. With a trach, air your child breathes goes directly into the lungs through the trach tube. Extra humidity is needed to:

- Prevent your child's trach tube from clogging off with mucus
- Keep the mucus loose by preventing dry air from getting in your child's lung. Dry air may cause more coughing and blood-tinged mucus.



You can supply extra humidity by:

- A mist collar
- An "artificial nose"
- A room humidifier



MIST COLLAR

A mist collar should be worn when:

- Your child is asleep
- Oxygen is being used through the trach tube
- Your child has thick or blood-tinged mucus

Always be sure your mist is working and there is enough water supply to make the mist.



ARTIFICIAL NOSE

An "artificial nose":

- Holds your child's own warmth and moisture in the airway
- Filters small objects from the airway

An "artificial nose" can be worn:

- During the day when off the mist setup
- Outside on cold or windy days

The "noses" are changed daily or as needed when damp or soiled.

ROOM HUMIDIFIERS

Room humidifiers add extra moisture to the room. They are sometimes used:

- By older children who do not like mist collars
- Seasonally when the air is drier

Clean humidifiers carefully to prevent mold and spore growth.

TIPS: What to use if your child is refusing to wear a mist collar or "artificial nose".

Try:

- Loose fitting cloth bib without plastic backing
- Saline drops with or without suctioning
- A play or quiet area close to the mist machine
- A room humidifier – is sometimes approved for older children

CAREGIVER NOTE PAGE

EMERGENCY BAG EQUIPMENT

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

YOUR CHILD SHOULD HAVE HIS EMERGENCY EQUIPMENT WITH HIM AT ALL TIMES!

The emergency equipment should include:

1. Same size and length tracheotomy tube with ties already in place
2. One size smaller tracheotomy tube with the ties already in place
3. Suction machine (unit should be fully charged)
4. Suction catheters
5. Self-inflating bag with face mask and adaptors, if indicated
6. Normal saline
7. Extra tracheotomy ties
8. Scissors
9. Hemostats
11. Water based lubricant
12. DeLee suction
13. Phone list
14. Syringe, if the trach tube has a cuff
15. Other

Tip: The emergency trach bag should be sturdy. It should close completely and allow the contents to be easily found.

SIGNS OF RESPIRATORY DISTRESS

Before you leave the hospital, you will be able to take care of your child with a tracheotomy tube and prevent most breathing problems. One of the most important things you will learn are the signs that your child is having breathing trouble.

Early signs of breathing trouble may include:

- Noisy breathing
- Fast breathing
- Sweaty, clammy skin
- Restlessness
- Change in breathing pattern

Later signs of breathing trouble may include:

- Hard breathing seen as sinking in of the chest, neck, or ribs or head bobbing
- Flared nostrils
- Blue or pale gray color around the lips, nails and skin
- Your child does not wake to your touch or when calling his/her name

If your child is having trouble breathing and your child does not get help, he/she could stop breathing. You either need to call 911 or your doctor, depending on how bad his breathing is. You also need to take steps to check and clear his airway until help arrives, using the care that you have been taught.

MUCUS PLUGGING

WHAT IS A MUCUS PLUG:

Mucus can collect in the tracheotomy tube or airway and cause a “plug,” making it difficult for your child to breathe easily.

WAYS TO PREVENT A MUCUS PLUG:

- Make sure your child drinks, or gets plenty of fluids through his feeding tube.
- Use a mist collar with the tracheotomy tube while your child is sleeping or if mucus is thick or blood tinged.
- Use an artificial nose when mist is not in use.
- Encourage your child to cough out secretions.
- Suction twice a day unless your child can clear his/her own secretions by coughing or as needed.
- Use saline drops to help loosen mucus with or without suctioning.
- Perform routine tracheotomy tube changes.

SIGNS THAT A TRACH MAY BE PLUGGED:

- Fast, noisy, hard breathing
- Dry whistling sound from the tracheotomy tube
- Restlessness
- Clammy skin, sweating
- Complaints from your child that he/she cannot breathe
- Trouble passing a suction catheter through the tracheotomy tube
- Blue color around lips, nails and skin
- No breathing and your child does not wake to your touch or when calling his/her name

HOW TO REMOVE A MUCUS PLUG:

- Try to suction the tracheotomy tube.
- Place saline drops into the tracheotomy tube, and try to suction again.
- Repeat saline drops into the tracheotomy tube and push the drops down to the plug with puffs of air from your breathing bag attached to the tracheotomy tube. Try to suction again.
- Change the tracheotomy tube if you cannot pass a suction catheter.
- Call 911, start rescue breathing and/or CPR if trach tube change is not effective.

ACCIDENTAL DECANNULATION

WHAT IS ACCIDENTAL DECANNULATION:

When the tracheotomy ties are too loose, the tube can be coughed out, tugged out, or can fall out of the airway, and your child cannot breathe easily.

WAYS TO PREVENT ACCIDENTAL DECANNULATION:

- Check to make sure the tracheotomy ties are secure, dry and intact throughout the day and whenever you suction.
- If the ties are loose, tighten them. If they are tearing, replace them.
- Do not allow your child or any other person to pull at the tracheotomy tube ties.
- Keep the right humidity level and suction as needed to control the amount of secretions. Too many secretions can cause coughing.

SIGNS THAT A TRACH MAY HAVE COME OUT:

- Fast, noisy hard breathing
- Restlessness
- Clammy skin, sweating
- Complaints from your child that he/she cannot breathe
- Blue color around lips, nails and skin
- Some children can make sounds louder than they could before it came out
- No breathing and your child does not wake to your touch or when calling his/her name

HOW TO REPLACE A TRACH TUBE:

- Remain clam, but act quickly.
- If someone is with you, call out to them that the tracheotomy tube is out.
- Insert trach tube, as instructed in section, “TRACHEOTOMY TUBE CHANGE”.
- Call 911, start rescue breathing and/or CPR. Always get help and call your doctor if your child is having trouble breathing or if you are unable to place the same size tracheotomy tube.

* It is ok to slide the old tube that has just come out back in if it is the only tube in the area, and your child is having trouble breathing. After your child is safe and calm, you should replace clean tube.

** Discuss with your doctor, nurse practitioner, nurses, or respiratory therapists specific things you can do for your child if you cannot replace the tracheotomy tube.

TIPS: If your child is likely to pull the tracheotomy ties or tube, self-fastening ties is not a good option. Speak with your nurse or nurse practitioner about other tracheotomy tie options. If you are washing and reusing self-fastening ties, be sure to check the tie for a secure hold. Refer to the section called “TRACHEOTOMY TUBE CHANGE”.

BLEEDING FROM THE TRACHEOTOMY TUBE

WHAT CAUSES BLEEDING FROM THE TRACH:

- Bright red blood coming from the tracheotomy tube is serious, and may be a sign of serious irritation or ulceration of the airway. Your child needs to be seen by a doctor right away.
- Bloody streaks in the mucus is also concerning, and may be from:
 - a dry airway
 - frequent, deep, vigorous suctioning
 - infection
 - coughing too much, especially with loose ties
 - irritation from the fit of the trach tube
 - trauma of the tube
 - foreign body in the airway

HOW TO PREVENT BLEEDING:

- Keep regular check-ups with the doctor to make sure the trach tube is the right fit.
- Use the suctioning technique outlined in the section, “SUCTIONING”.
- Use humidification. See section on “HUMIDIFICATION”.
- Get early treatment for your child, if he/she shows signs of infection or increased coughing.

HOW TO HANDLE BRIGHT RED BLEEDING:

- Call 911.
- Stay calm.
- Gently suction the length of the trach tube.
- Use saline to help soothe the airway and prevent plugging.
- If the bleeding has subsided, use humidity until help arrives.

HOW TO HANDLE BLOOD STREAKED MUCUS:

- Gently suction the length of the trach tube.
- Increase use of saline, if indicated.
- Wet the end of the tracheotomy tube with saline or water based lubricant when changing the tracheotomy tube.
- Increase use of humidity.
- Call your doctor for a check-up.

ASPIRATION

WHAT IS ASPIRATION:

The passage of solids, liquids, or saliva into the airway instead of into the esophagus.

WHAT CHILDREN ASPIRATE:

Some children with tracheotomies eat normally. Others have medical issues that may make it hard to chew and swallow, either before or after a tracheotomy tube is placed, or both. Another small group of children, especially older children, may have a tendency to aspirate. Special therapists and treatments can help children who have trouble with chewing and swallowing.

SIGNS THAT YOUR CHILD MAY BE ASPIRATING:

- Choking or coughing with swallowing
- Watery trach secretions, especially after swallowing
- Drooling or holding saliva and fluids in the mouth
- The color of the food or liquid that your child is swallowing is coughed from the tracheotomy tube
- Your child may have frequent lung infections

HOW TO PREVENT ASPIRATION:

- Thicken liquids with artificial thickeners.
- Eat foods like pudding, baby foods, cereals, jello and yogurt (thicker liquids are usually easier to swallow than thin liquids).
- Chew and swallow slowly.
- Sit upright while eating or drinking.
- Follow doctors orders on eating/feeding.
- Give medications as ordered since many medications help with secretions or improve stomach emptying.

HOW TO HANDLE ASPIRATION:

- Watch your child eat and drink.
- Suction the tracheotomy tube using saline until the tube is clear of the fluid or food your child was eating.
- Change the tracheotomy tube if it is plugged with fluid or food.
- Call your doctor if your child is showing signs of aspiration – your doctor can arrange tests to check for aspiration.
- Work with swallowing therapists, if indicated.

Tip: Remember, your child can aspirate when vomiting, too. If your child does vomit, try to keep it out of the tracheotomy tube by turning the child's head to the side and suctioning the trach. Place babies on their side to sleep.

BRONCHOSPASM

WHAT IS BRONCHOSPASM:

Bronchospasm is a rare event. Usually, it is a reversible tightening of the muscles in the airway, causing narrowing and blockage of the airway. If untreated, it can threaten the life of your child.

WHAT CAUSES BRONCHOSPASMS:

- An allergic reaction
- Cold/infection
- Exposure to smoke or fumes
- Dust
- Cold air
- Small objects that can enter the airway and cause irritation or swelling of the airway

WHAT ARE THE SIGNS OF BRONCHOSPASM:

- Coughing
- Wheezing
- Sweaty, clammy skin
- Restlessness
- Feeling of tightness in the chest
- Unable to catch his/her breath
- Fast, hard breathing where you see sinking of chest, neck or ribs and/or head bobbing
- Flared nostrils
- Blue or pale gray color around the lips, nails and skin
- Your child does not wake to your touch or when calling his/her name

HOW TO PREVENT BRONCHOSPASM:

- Avoid those items listed that can cause bronchospasm.
- Talk with your doctor about your child's risk for bronchospasm, and if your child needs medications and treatments to prevent bronchospasm at home.
- If your child is showing signs of early bronchospasm, call for help. Your doctor or life squad can get needed medications to help stop bronchospasm, or get your child to a hospital.

HOW TO MANAGE A BRONCHOSPASM:

- Call 911.
- Remain calm.
- Help your child stay calm.
- If you have an oxygen supply at home, give your child oxygen as directed.
- Give medications as prescribed by your doctor.
- Gently suction the tracheotomy tube – if the tube is open, and suctioning seems to aggravate your child's breathing, stop.
- If the tracheotomy tube is plugged, and suctioning does not clear the plug, gently change the tracheotomy tube.
- Begin rescue breathing or CPR if needed.

CAREGIVER NOTE PAGE

PHYSICIAN'S ORDER FORM

<p>Suction machine:</p> <input type="checkbox"/> Portable <input type="checkbox"/> Electric <input type="checkbox"/> Transformer/ Rectifier/ Recharger	<p>Suction catheters:</p> Size: _____ <input type="checkbox"/> Kits <input type="checkbox"/> Single <input type="checkbox"/> Suction connecting tubing	<input type="checkbox"/> Durable air compressor <input type="checkbox"/> All-purpose nebulizer <input type="checkbox"/> Tracheal cool mist <input type="checkbox"/> Room humidifier
<input type="checkbox"/> HME/ artificial noses <input type="checkbox"/> Speaking valves <input type="checkbox"/> Saline disposable vials <input type="checkbox"/> Distilled water	<input type="checkbox"/> Resuscitation bag: Size _____ <input type="checkbox"/> Face mask: Size: _____ <input type="checkbox"/> Emergency trach bag	Tracheotomy tubes Brand: _____ Size: _____ Length: _____ One size smaller: _____ <hr/> <input type="checkbox"/> Tracheotomy adapter
<input type="checkbox"/> Self-fastening ties <input type="checkbox"/> Twill ties <input type="checkbox"/> Sof-wiks <input type="checkbox"/> Mepelix: _____ <input type="checkbox"/> Telfa	<input type="checkbox"/> DeLee Suction <input type="checkbox"/> Surgilube <input type="checkbox"/> Control III Solution <input type="checkbox"/> LuerLock Syringe Size: _____	
1. Oxygen flow rate: _____ liters per minute (lpm) <input type="checkbox"/> Titration range: _____ 2. Mode of delivery: <input type="checkbox"/> Trach <input type="checkbox"/> Other: _____ 3. Duration: <input type="checkbox"/> Continuous <input type="checkbox"/> While sleeping <input type="checkbox"/> _____ hours per day		
Determination of Oxygen Needs: Test results: SpO2 % Room air FIO2/lpm _____ OR ABG of mmHg Room air FIO2/lpm _____ Tested During: <input type="checkbox"/> Rest <input type="checkbox"/> Sleep <input type="checkbox"/> Exertion Test Date: _____ Performed by: _____		
<input type="checkbox"/> Oximeter for continuous monitoring of compromised airway. <input type="checkbox"/> Oximeter to monitor SpO2 to be maintained at or above %. <input type="checkbox"/> Check every _____ hours or as necessary. <input type="checkbox"/> Other, specify: _____ Alarm Settings for oximeter Saturation: Low _____ % High _____ % OR <input type="checkbox"/> OFF (no high limit setting) Heart Rate: Low _____ High _____ OR <input type="checkbox"/> OFF (NO HR alarms)		

Managing Physician: _____ Pager #: _____

Physician Signature/Credentials Date/Time Pager #

EQUIPMENT MAINTENANCE

Equipment maintenance is very important in your child's care. Cleaning the equipment as directed helps prevent infection. Maintaining the equipment as directed keeps it safe and functioning properly for your child.

The maintenance of your equipment will vary based on your child's needs. Equipment will also vary from different equipment companies. That is why you will need to follow your equipment company's maintenance schedule. Your equipment company will meet with you in your home before your child leaves the hospital. They will teach you how to use and maintain the equipment. The equipment company will also have a person on call 24-hours a day to help you with any questions or problems.

MY EQUIPMENT COMPANY IS: _____

PHONE NUMBER: _____

MY CONTACT PERSON FOR
SUPPLIES OR QUESTIONS IS: _____

EQUIPMENT MAINTENANCE

You can use the following chart to remind you what type of care your equipment needs and how often the care should be done. It may be helpful when talking with your equipment company.

EQUIPMENT	TYPE OF CARE (disinfect, replace, check function)	HOW OFTEN
suction machine		
suction catheters		
suction connecting tubing		
durable air compressor		
all-purpose nebulizer		
mist collar/wide bore tubing		
twill ties		
room humidifier		
heat-moisture exchanger		
resuscitation bag		
tracheotomy adaptors		
face mask		
monitor _____		
oxygen		
oxygen tubing		
oxygen humidity		
small air compressor updrafts		
hand-held nebulizer		
tracheotomy tubes		
ventilator equipment		
saline		
self-fastening ties		
hydrogen peroxide		
distilled water		
commercial disinfectant		
DeLee suction		
speaking valve		
Artificial nose		

Remember, your child's emergency trach bag must be with him/her at all times.

HOME CARE TIPS

Here are some tips for you to consider in your child's care. Feel free to write your own tips and share them with your nursing staff and health care team.

1. If you have to suction your child during a meal, do so gently to decrease the chance of vomiting.
2. Your child should not go under water!
 - a) Watch your child closely at bath time to prevent water from entering the tracheotomy tube. Wear an artificial nose on the tracheotomy tube to prevent splashed water from entering the tube.
 - b) Children with tracheotomies should not swim.
3. When washing your child's hair, carefully pour water over the hair with a cup as your child is laying back with his/her head and neck supported (see drawing below).



4. Do not use powders or aerosol sprays around your child.
5. Avoid contact sports.
6. Avoid hairy or fuzzy clothing around the tracheotomy tube. Do not use clothing that blocks the tracheotomy tube (for example, turtleneck shirts).
7. When choosing a pet, consider one that can live outside or that will not shed.
8. Do not smoke around your child. Smoke is very irritating to your child's airway, lungs, and ears.

ADD YOUR TIPS HERE:

NORMAL SPEECH AND LANGUAGE DEVELOPMENT

Newborn – 12 months: The child is listening to you and understanding the words you say. He/she is practicing speaking by cooing and babbling.

12 months: The child may say a word or a few words.

12 – 18 months: The child is increasing the number of words he/she can say. He/she may have two word phrases like “more juice”.

18 months – 2 years: The child is more verbal and speaks with three to five word sentences.

3 years – 4 years: The child is perfecting his or her language. He/she should be understood by a stranger and able to tell a story that happened to him or her in the recent past.

THE EFFECTS OF A TRACHEOTOMY ON COMMUNICATION

Having a tracheotomy may have an impact on your child’s ability to talk. Some of those reasons might be:

1. If the laryngotracheal space is very small or scarred, your child will not be able to pass enough air up through the vocal cords to make sounds.
2. If the vocal cords are scarred, the sound from the cords may be hoarse or raspy. If one or both of the vocal cords cannot move, your child’s sounds will vary based on the position of the vocal cords.
3. Often, children with tracheotomies have other problems. If your child was born early, he/she may have problems with language. If your child has a history of head trauma or injury to the spine, there may be a neurologically based reason for your child’s trouble with communication.
4. The size of the tracheotomy tube needed to keep your child’s airway safe may decrease the amount of air that can pass up through the vocal cords to make speech.

It is important to remember that the removal of your child’s tracheotomy tube may not be the answer for your child’s problem with talking.

A qualified speech therapist may test your child in these areas:

ELEMENTS OF COMMUNICATION

1. Receptive Language: This is the understanding of the spoken, written or signed word.
2. Expressive Language: This is the telling of thoughts through speech, writing, or signing. It is the thinking process of putting words together and knowing words.
3. Speech or articulation: This is the sound used to make language.
4. Voice: This is the quality of the sound made by the vocal cords
5. Fluency: This is the rhythm of speech, how it flows.

WHAT IF MY CHILD CAN'T TALK?

Having mild to severe problems with talking does not mean being unable to communicate. Giving your child a solid language base is very important. There are many options that can help your child to communicate:

1. Sign Language: Sign language is not only for children who cannot hear. If your child does not have the voice to communicate his/her needs well, then he/she can sign his/her needs and thoughts.
2. Artificial Larynx: This device is usually for older children who have some experience with verbal communication. The device helps the sound made by the child get up into the mouth as the child mouths out the words.
3. Augmentative Communication Device: This device is more like a computer. The child selects the word on the board, and the computerized voice says the word selected by the child.
4. Picture Communication Device: This can be made for the child with different pictures or personal objects. By pointing to the object, the child relays his/her needs or thoughts. The child can help in the making of his/her personal picture board.
5. Speaking Valve: This valve is placed on the tracheotomy tube. It lets the child inhale through the valve and upon exhaling, the valve closes allowing air to pass through the vocal cords. **IT IS NOT FOR ALL CHILDREN WITH TRACHEOTOMIES**, and does not work well for children who continue to have stenosis above the tracheotomy. It is only used with your ENT doctor's permission. Check with your ENT doctor to see if this valve is an option for your child.

GOING TO SCHOOL

Public Law 94-142 states that all children have the right to free, suitable public education. This law is very important for children with disabilities. Children with tracheotomies can receive special education services through this law. This law provides for the education of your child in the "least restrictive environment". This means your child should attend regular classes whenever possible. It also means that your child has the right to any services he/she needs to attend regular classes.

Educators, health personnel, parents and, when appropriate, the child, meet yearly to develop the educational goals and a medical plan of care. These plans should meet the individual needs of your child's health and education.

Someone at the school must be trained in the care of your child's tracheotomy. Most state's Board of Nursing recommend that an R.N. or L.P.N. be involved in your child's care, either directly at the school site or through education and delegation of that care to a health aide, as well as special transportation to and from school. Working with your child's school and health personnel can assure he/she will be safe at school. Remember, the emergency trach bag must be with your child at all times.

If you need help enrolling your child in school, contact your school system, your nurse, doctor, or child advocacy group.

SOCIAL SERVICES

A social worker is available to speak with patients and family members about a wide variety of concerns and needs. Social workers often work with families to arrange for a well-planned admission to the hospital. They may help arrange transportation, lodging and meals. A social worker may also help prepare your child for the admission and treatment.

Coping with a child's illness, hospital stays, or managing home care may be very stressful for families. The social worker can provide supportive counseling to the patient and family throughout the admission.

Airway patients often require special arrangements for a safe and timely discharge. The social worker works with the family and health care team to develop a discharge plan that meets the individual needs of the patient and family. The social worker may help families get resources, like nursing care, equipment, insurance coverage, extended care facility placement and counseling.

Please ask to meet with the social worker if you have financial concerns or need community resource information. If you feel it would be helpful to have a support person for counseling or need help dealing with the hospital staff, ask to see the social worker. Social workers may also assist families with parenting, custody, visitation, behavioral problems, substance abuse, or other concerns.

SUPPORTIVE RESOURCES FOR FAMILIES

The following is a summary of resources other families have found useful. See your social worker if you would like any additional information.

Carepages and Family Resource Center - Carepages is a free resource that lets you set up your own web page to update friends and family on your child's hospitalization. They can read your updates and send you responses. You can also post photos on the site if you choose. If you need help with Carepages, go to the Family Resource Center. The Family Resource Center helps connect families with available resources in the community, region and nation.

Special Needs Resource Directory - Cincinnati Children's has created a one-step resource directory to assist caregivers of children with special health care needs.
www.cincinnatichildrens.org/special-needs .

Pastoral Care - A chaplain is always on-call in the hospital, 24 hours a day, 7 days a week. The chaplain can provide support to every family, regardless of religious affiliation or participation. Whatever your specific need, please feel free to ask your nurse to contact the chaplain for you. Clergy from your own congregation are welcome and encouraged to visit you and your child.

FINANCIAL RESOURCES/MEDICAL COVERAGE

See your social worker if you are interested in applying for any of the following:

Financial Services - Financial counselors are available to *help* families with: financial and billing questions, insurance verification and benefits, and online billing services. They will also help if you are applying for additional resources.

MEDICAID - This program may provide insurance coverage for your child. Even if you have private insurance, you may be eligible for Medicaid as secondary coverage. You must usually meet financial eligibility requirements to qualify, though there are exceptions to this rule.

BCMh - Bureau for Children with Medical Handicaps

Ohio Residents: This is a state run program designed to help with medical expenses for families whose child has a qualifying medical condition

Indiana Residents: Also called “Special Healthcare.” Families can contact their county Department of Public Welfare to apply.

Kentucky Residents: Also called “Commission for Children with Special Healthcare Needs”. Call (502) 429-4430 to start the application process.

West Virginia residents: For Children with Special Health Care Needs (CSHCN) call (304) 558-5388 to apply.

SSI – Supplemental Security Income - This is a federal program run by the Social Security Administration. It pays monthly checks to disabled individuals who meet income guidelines. A disabling condition is one that is serious in nature, is expected to last more than 12 months, or could result in death. If you believe that your child may be eligible, you can begin the application process by calling: 1-800-772-1213.

Early Intervention - This program provides developmental follow-up for babies, including services like occupational therapy, physical therapy, speech, nurse visits, etc. until your baby reaches age 3. Research shows that the first three years of a baby’s life are the most important for brain development, so intervention during this time period is very effective.

LODGING AND MEAL SERVICES

The CCHMC **Guest Services Department** is an information and referral service that can assist out of town families in making travel and lodging arrangements. You can reach them at (888) 894-1374 or (513) 636-5009.

Ronald McDonald House (513) 636-7642. Provides overnight lodging for families that live outside of the 40-mile radius of Cincinnati and have a child at Children's. You may make reservations 24-hours in advance of arriving. Space is limited, and there is usually a waiting list for a room. The fee is \$25 a day and is negotiable based on the family's ability to pay. Ask to speak to the Ronald McDonald House Manager if you have questions about payment.

Guest Dining Program - Parents and guests may purchase a guest dining card to order from Children's Hospital's dining menu. Each guest dining program card is good for one meal, including: one entrée or soup and sandwich, two side orders, one fruit or dessert, and one beverage. Purchase cards at any cash register in the Food Court.

GLOSSARY

Air compressor: A machine that you will have at home that changes room air into oxygen

Airway: The nose, mouth, and trachea, including the tracheostomy stoma and tube

Artificial nose: A small filter that fits over the trach tube

Aspiration: The passage of solids, liquids, or saliva into the airway instead of into the esophagus

Bronchospasm: A tightening of the muscles in the airway making it hard to breath

Cardiopulmonary resuscitation: Breathing and pumping the heart for a person who is not breathing

Catheter: A small, soft hose that connects to suction to remove mucus from the trach tube

Clammy skin: Sweaty skin

Decannulation: When the trach tube comes out of the stoma

DeLee suction: A piece of emergency equipment that helps remove mucous

Esophagus: Swallowing tube

Face mask: A soft piece that fits over the nose and the mouth and attaches to the self-inflating bag

Flange: The part of the trach tube that holds the ties

Hemostat: An instrument that clips on to the ties to help you put them into the flange

Humidifier: A machine that puts extra moisture into the air

Hydrogen peroxide: A clear liquid that is a gentle skin disinfectant

Larynx: Voice box

Normal saline: Sterile salt water

Obturator: The piece that fits into the trach tube to make it easier to slide the trach tube into the stoma

Rescue breathing: Breathing for a person who is not breathing

Self-inflating bag: A breathing bag that fills with room air and does not need oxygen to fill.

Stoma: The surgical opening in the neck

Trachea: Windpipe

Tracheotomy: A surgery where a doctor places a tube for breathing into a child's trachea, also known as a "trach"

Ventilator: Breathing machine