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## VII  APPENDIX
Dear Parent or Guardian:

As you have already discussed with your ENT (Ear, Nose and Throat) doctor, a tracheotomy will be performed on your child to help him or her breathe. This letter is written to help prepare you for what to expect during your child’s hospital stay and discharge process. To ensure the safest care for your child at all times, at least two caregivers must be educated in the care of the tracheotomy. The education has many parts, and you and a second person will be required to learn all parts of your child’s tracheotomy care before discharge to home.

There are learning requirements that must be met before discharge can occur. Teaching will start the day of surgery for all caregivers. First, all parts of the teaching plan must be met by you and your co-caregiver. Then, to ensure that you and the second caregiver can safely and comfortably care for your child’s tracheotomy, you each will be expected to show that you can care for your child, without coaching from the nursing staff or other family members for a 24 hour period. 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 according to 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 a 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, 513-636-4610.

Sincerely,

The ENT Team
WHAT IS A TRACHEOTOMY?

A tracheotomy is a surgery in which a doctor places a tube for breathing into a child’s trachea (windpipe). 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, and to aid 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. Drawings are included below to help you see where the surgery is actually performed. As you can see, 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 inserted. However, speech may not be possible in some children after surgery due to swelling around the tracheotomy tube; the size of tracheotomy tube needed for the child to breathe easily, or if there is already a blockage in the airway.

Although the tracheotomy tube is placed in front of the esophagus (swallowing tube), most children are able to eat normally. However, some children, because of their other medical conditions or feeding history, may have problems eating, choking or coughing after swallowing. Discuss your child’s specific feeding needs with your doctor, nurse, dietician, or therapist.

Depending on the reason your child needs the tracheotomy, it may be is temporary. Most conditions which require tracheotomies in children can be outgrown or surgically corrected. However, a tracheotomy may be needed for a long time for those 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

Welcome to our nursing unit. Your child has a breathing tube called a tracheotomy and needs special care. We know that this is a hard time for you and your child. You may have many questions, concerns or fears. You may be afraid you won’t 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, throughout your stay, you and the health-care team will be planning for the day your child can return 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. Remember, any person caring for your child with a tracheotomy tube will need to know all of the skills that you learned while in the hospital.
• When your child is almost ready to go home, you and your co-giver should spend at least one full day and night with your child in the hospital. We call this ‘round the clock time “transitional” care. This time will help you prepare for transition from hospital to home.
• Encourage your child’s brothers, sisters and other family members to visit. Your child will want company, and your family will begin to feel more comfortable about the tracheotomy tube.
• 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
• nurses
• nurse practitioners
• Chaplain
• child life therapist
• dietitian
• occupational therapist
• physical therapist
• respiratory therapists
• social worker
• speech therapist

SUPPORT AT HOME

Before you are ready to take your child home, you will choose an equipment company to supply the items you need to care for your child with a tracheotomy tube. Your discharge planner and social worker will make arrangements with your equipment company to deliver medical equipment to your home so that you have everything needed to care for your child upon discharge.

You may also qualify for home nursing. Your discharge planner and social worker will help you explore the possibility of home nursing and can give you a list of companies that provide home care. They will consult with your doctor to determine the number of hours recommended, then contact your insurance company to determine policy limitations. Additionally the discharge planner and social worker will co-ordinate nursing to begin upon discharge.
LEARNING LIST FOR THE CARE OF YOUR CHILD WITH A TRACHEOTOMY

Before your child goes home, you and a co-caregiver will need to learn the following care. Also, it is important to know that any person your child will be staying with needs to learn all of this care.

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<td>Co-Caregiver</td>
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<td>2. Type and size of tracheotomy tube your child has</td>
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<td>3. Why, when and how to suction the tracheotomy tube</td>
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<td>8. Supplies to have with your child at all times</td>
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<td>9. Potential emergencies and how to help your child</td>
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<td>16. How to give oxygen through the tracheotomy tube</td>
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<td>17. 24 hour transitional care completed</td>
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<td>19. Other _________________________________</td>
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When you and your co-caregiver have demonstrated competence with each of three trials of a skill or learning area on the above list, place the date it was completed in the box.

We have read the list of tracheotomy care to learn, and we understand what is required 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. Your doctor will decide the type and size of tube your child will need. The type of tracheotomy tube your child can be based on:

• Your child’s breathing problem
• Your child’s age
• The size of your child’s airway
• Special needs your child might have

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
• The obturator or guide for inserting the tube

![Diagram of SHILEY and BIVONA tracheotomy tubes]

**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 being inserted. The obturator is removed immediately after the tube is placed.
SUCTIONING A TRACHEOTOMY TUBE

PURPOSE:
To remove mucus from your child’s tracheotomy tube and windpipe, and to allow easier breathing. Mucus is the body’s normal method of cleaning the airway. During the first few weeks after a tracheotomy, your child may form a large amount of mucus because of the surgery on the airway, 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 that you know what you see, feel, and hear when he or she needs suctioning. Signs which may indicate the need to suction may include:

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

Advanced signs that your child need to suction may include:
• Frightened look
• Flared nostrils
• Restlessness
• Pale or bluish color (over skin, nails, mouth)
• Clammy skin
• Fast, noisy, hard breathing
• Dry, whistling sound

SUPPLIES NEEDED:
• Saline bottles or disposable vials. (Side effects may occur with saline use, only instill saline when secretions are thick or blood tinged. These side effects include lower oxygen levels, changes in heart rate, or infection.)
• Suction machine – Pressure gauges vary with suction machines; check with your equipment company about setting the pressure limit.
• Suction catheter – Size _____ (The idea size suction catheter is ½ the opening of the tracheotomy tube. You may need to adjust the size if the mucus is thick.)
• Eye dropper/syringe – If using bottles of saline
• Paper cups
• Breathing bag – With optional tracheotomy adapter for metal trach tube
• Tissue
• Gloves – (Optional) Suctioning is a clean procedure at home
• Rinse water – If rinsing catheters in water instead of saline.
HOW TO SUCTION

- Wash and dry hands
- Set up equipment
- Pour rinse water into paper cup
- Connect suction catheter to suction machine tubing
- Turn on suction machine
- Place tip of suction catheter into water to moisten it and test to see if suction machine works
- Put small drops of normal saline into tracheotomy tube. (You do not have to use normal saline if mucus is thin and loose.)
- Using a tissue, wipe away any mucus which is coughed out
- Ask your child to take three deep breaths (or with breathing bag, give child 3-5 breaths)
- Using the obturator as a guide, measure how far to insert the suction catheter (Many catheters have markings on them to make measuring easier.)
- Without applying suction pressure, gently insert the suction catheter into the tracheotomy tube just past the end of the tracheotomy tube. (Deeper suctioning may be needed and can be done safely if your child has a poor cough or is not clearing the mucus from the airway. Your nurse will review when and how to use deeper suctioning)
- Put your thumb over the opening of the suction catheter to create a vacuum
- Use a gentle circular motion while removing the suction catheter so that the mucus is removed well from all areas. This step should take 5-10 seconds
- Rinse the suction catheter
- Watch your child’s color and breathing effort.
- Let the child catch his breath (or repeat bag breathing) between suctioning attempts
- Repeat suctioning until your child’s respiration’s sound clear and the suction catheter returns with little or no mucus. (Limit the passes of the suction catheter to 3 times whenever possible to prevent tissue trauma)
- Dispose of suctioning supplies and turn off suction machine (If you are going to reuse catheters after home, you may want to place used catheter in a plastic bag until you have time to clean them.)
- Wash and dry hands.

TIPS on suctioning: If there are bloody streaks in the mucus, 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:
Clean and look at this area 2-3 times a day, or more often if there is a redness, irritation, drainage or cuts.

SUPPLIES NEEDED:
- ½ strength hydrogen peroxide – mix equal parts hydrogen peroxide and water (OR)
- Mild soap and water once skin is healed
- Cotton swabs
- Paper cups
- Gauze 2x2x or telfa (optional)

HOW TO CLEAN:
- Wash and dry hands
- Set up supplies
- Look at the neck, noting cuts or signs of infection
- Prepare ½ strength hydrogen peroxide in a clean cup
- Dip cotton swab in hydrogen peroxide solution
- Starting at the stoma, stroke away from the tracheotomy opening, using one stroke per swab. Discard swab
- Clean the flanges of the tracheotomy tube
- Using dry cotton swabs, dry the skin the same way you cleaned it
- Again look at the neck
- Apply a dressing, if needed for excess drainage or if tracheotomy tube is rubbing the skin.
- Do not cut the gauze, to prevent frayed fibers being breathed in the tube.

SIGNS OF INFECTION:
- Redness
- Drainage
- Foul odor
- Swelling
- Cuts

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 for advice
- if there is any signs of infection or irritation of the skin surrounding the tracheotomy tube
- and to be seen for a 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 tracheotomy ties
• Optional 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 during the tie change, 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 two pieces of cotton twill tape long enough to fit around the neck and be tied.
• Cut at an angle to prevent fraying. Fold the angled end over about ½ inch and poke a small hole into the doubled end about ¼ inch from the fold.
• Thread the tape through the hole of the tracheotomy tube flange from back to front. Pull the other end of the tie through the hole using the hemostats’ or tweezers. Pull tightly while holding the tube. (This secures the tie to the tube without using knots and does not tug the tracheotomy tube from the child’s neck.)
• Repeat the process for the other side of the tube. Bring both pieces of tie together and tie a square knot.
• Check the new ties and see that only one finger can slide under the ties. The location of the knot should be moved each time it is tied to prevent skin breakdown. Flex the child’s head slightly while tying to ensure 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. Re-check the new ties to be sure that only one finger 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 to self fastening ties following their tracheotomy tube change on the 5th POD, 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’s skin is sensitive to the material in the neck tape. They are expensive, and some insurances limit the number used. If your doctor permits you child to use them, a prescription will be sent to your equipment company. There are several brands from which to chose that may help fit 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 to fit between the tie and the neck.

Tips:

- If using self-fastening ties you must check the self-fastening ties often throughout the day to make sure the Velcro is secure.
- If cleaning and reusing Velcro ties, the ties must be checked to see that the Velcro hold is still strong. They can only be washed in mild soap and water, and line dried.
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. It is helpful to have 2 people present to change the tracheotomy tube. In an emergency, you must be prepared to change the tube by yourself.

SUPPLIES:
- Two trained people are preferred for routine changes
- Current size tracheotomy tube
- Size smaller tracheotomy tube
- Tracheotomy ties
- Water based lubricant
- Scissors
- Hemostats (or blunt tipped tweezers)
- Supplies for suctioning
- Tissues
- Breathing Bag

HOW TO CHANGE:
- Wash and dry hands
- Prepare ties and tie to flanges, place tracheotomy tube on clean surface. Avoid touching the cannula on any unclean surface.
- Prepare suctioning equipment
- Suction your child’s tracheotomy tube
- Place the child on his/her back with a small roll under his/her shoulders
- One person cuts or loosens the ties, holding the tracheotomy tube in place and calms the child.
- The second person moistens the tip of the tracheotomy tube with lubricant.
- The first person removes the old tracheotomy tube when the 2nd person is ready.
- The 2nd 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!!
- Remove the obturator, holding the tracheotomy tube securely. Feel for air movement with your fingers, or check for coughed or suctioned secretions.

*Check with your doctor or nurse before placing your child in this position. Some children should not be placed in this position.
• Changing the tracheotomy tube will cause the child to cough. Have tissues ready to wipe secretions or prepare to suction and DO NOT LET GO OF THE TUBE!!!
• Tie the tracheotomy ties only allowing room for one finger between the neck and the ties.

IF THE TUBE DOES NOT PASS EASILY:
• DO NOT FORCE THE TRACH TUBE!
• Hold the tube in place, remove the obturator, and let the child relax and breathe
• Try to insert the tube again.
• Reposition the child so the head is back and the stoma can be seen.
• Remove the tube, relubricate, and try again.
• 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.
• Ask someone to call for emergency help if not able to replace the trach tube
• Call you doctor for advice if only the size smaller trach tube can be placed.

Tips: It is helpful to have emergency tubes set up with ties and in a small plastic bag, ready to go should an emergency occur.
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. There are a few ways to add extra humidity to:
• Prevent your child’s trach tube from clogging off with mucus.
• Prevent dry air that may cause more coughing and blood-tinged mucus.

A mist collar keeps:
• The airway warm and moist.
• Keeps mucus loose.

An “artificial nose” helps:
• Hold your child’s own warmth and moisture in the airway.
• Filter small objects from the airway.

A room humifier helps:
• Add extra moisture to the room

WHEN:
Adding humidity to the airway should be part of your child’s daily routine.

MIST COLLAR
A mist collar should be worn when
• Your child is asleep
• Oxygen is being used through the trach tube
• It is needed for thick or blood-tinged mucus.

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

ARTIFICIAL NOSE
An “artificial nose” can be worn
• During the day when off the mist setup.
• Especially when outside on cold or windy days.
• The “noses” are changed daily or as needed when damp or soiled.

ROOM HUMIDIFIERS
Room humidifiers are sometimes used
• By older children who do not like mist collars.
• Seasonally when the air is drier.

Humidifiers should be cleaned thoroughly to prevent mold and spore growth.

TIPS: What to use if your child is refusing to wear a mist collar or “artificial nose”:
• A loose fitting cloth bib without plastic backing
• Saline drops with or without suctioning
• Set up a play or quiet area close to the mist machine.
• A room humidifier is some time approved for older children.
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. **YOU CHILD SHOULD HAVE HIS EMERGENCY EQUIPMENT WITH HIM AT ALL TIMES!**

The emergency equipment should include:

1. Same size 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. Breathing bag, with adaptors if indicated.
7. Extra tracheotomy ties.
8. Scissors.
10. Water based lubricant.
12. Phone list.
13. Other

Tip: The bag should be sturdy and close completely, so items do not fall out. Some parents used diaper bags, large purses, or backpacks.
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 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 calling his or her name

If your child is having trouble breathing, and your child does not get help, he or 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.
MUCOUS PLUGGING

WHAT IS A MUCOUS 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 MUCOUS PLUG:
- Make sure your child drinks, or gets plenty of fluids through his feeding tube
- Use a mist collar with the tracheotomy tube with sleep, or if mucus is thick or blood tinged
- Use an artificial nose when mist is not in use
- Encourage coughing out secretions
- Periodic suctioning
- Use saline drops to help loosen mucus with or without suctioning
- Performing 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 or she cannot breathe
- Difficulty 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 calling his/her name

HOW TO REMOVE A MUCOUS 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.
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. Yet others have other medical issues that may add to their trouble chewing and swallowing, either before and 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:
• Thickening liquids with artificial thickeners or foods like pudding, baby foods, cereals, jello and yogurt (thicker liquids are usually easier to swallow than thin liquids).
• Chewing and swallowing slowly.
• Sitting upright while eating or drinking.
• Following doctors orders on eating/feeding.

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.
ACCIDENTAL DECANNUULATION

WHAT IS ACCIDENTAL DECANNUULATION:
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 DECANNUULATION:
• Check that the tracheotomy ties are secure, dry and intact whenever you suction and throughout the day.
• If the ties are loose, tighten them. If they are tearing, replace them.
• Do not allow your child or any other person pull at the tracheotomy tube.

SIGNS THAT A TRACH MAY HAVE COME OUT:
• Fast, noisy, hard breathing
• Restlessness
• Clammy skin, sweating
• Complaints from your child that he or 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 calling his/her name

HOW TO REPLACE A TRACH TUBE:
• Remain calm, 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 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 not breathing. Yet, after your child is safe and calm, you should place a 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 prone to pulling the tracheotomy ties or tube, self-fastening ties are not a good option for your child. 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. Also 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
  – excessive coughing, 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 ensure the correct fit of the trach tube.
• Use the suctioning technique outline in the section, “Suctioning”
• Use humidification, as previously outline.
• Seek early treatment of 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 of 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.
BRONCHOSPASM

WHAT IS BRONCHOSPASM:
Bronchospasm is a rare event. Generally it is a reversible tightening of the muscles in the airway, causing narrowing and blockage of the airway. If gone 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, or small objects that can enter the airway and cause irritation or swelling of the airway.

WHAT ARE THE SIGNS A BRONCHOSPASM:
• Coughing
• Wheezing.
• Sweaty, clammy skin
• Restlessness
• Feeling of tightness in the chest
• Inability to catch their breath
• Fast, 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 calling his or 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 medicines 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 C.P.R. if needed.
CPR WITH A TRACHEOTOMY TUBE
SUGGESTED EQUIPMENT LIST

MEDICAL NECESSITY IS DETERMINED FOR THE INDIVIDUAL CHILD

- Suction machine
  - Portable
  - Electric
- Suction catheters Size __________
- Suction connecting tubing
- Saline disposable bottles
- Durable air compressor, all purpose nebulizer, tracheal mist collar
  - Heated Temp __________
  - Cool
- Size of Mask __________
- Room humidifier
- Heat and moisture exchangers OR artificial noses, quantity per month __________
- Resuscitation bag Size __________
- Tracheotomy adaptors, if needed for metal trach tube or T-tube, Size __________
- Face mask Size __________
- Monitors
  - Heart Rate (HR) / Apnea Limits:
    - High HR __________
    - Low HR __________
    - Apnea delay
  - Pulse oximeter Cont
    - Spot check
    - Settings: Low Sats __________
    - Low HR __________
- Oxygen Conc/liter flow __________ Mode of delivery __________
  - Carrier
  - Oxygen analyzer
  - Portable System
  - Type of adaptor for portable
  - Documentation of O2 sats for provider, insurance
- Air compressor, hand held nebulizer, updrafts
- Ventilator (Double check with MD/RT) Type __________
  Ventilator equipment: i.e. cascades, circuits, etc. __________
  __________
  __________
- Tracheotomy tubes Brand __________ Size __________ Length __________
  One size smaller __________
- Self-fastening ties
- Twill ties
- Hydrogen peroxide
- Cotton-tipped applicators
- Distilled water
- Tap water
- Pipe cleaners
- Commercial disinfectant
- Small paper cups
- Tissues
- Gauze
- Telfa
- Sof-Wik
- Mucous traps - Size __________
- Intercom
- Speaking valve – Type __________

NOTES:
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 also insures the safety and proper functioning of the equipment.

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 recommendations for maintenance. 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 should you have any questions or problems.

MY EQUIPMENT COMPANY IS: ________________________________________________

________________________________________________

________________________________________________

MY CONTACT PERSON FOR SUPPLIES OR QUESTIONS IS: __________________________
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              | Replace                                        | Plastic:  |
| Metal:                         |                                                |            |
| ventilator equipment           |                                                |            |
| sodium cloride                 |                                                |            |
| self-fastening ties            |                                                |            |
| hydrogen peroxide              |                                                |            |
| distilled water                |                                                |            |
| commercial disinfectant        |                                                |            |
| mucus taps (DeLee suction)     |                                                |            |
| speaking valve                 |                                                |            |
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. Bath time should be closely watched to prevent water from entering the tracheotomy tube. An artificial nose should be worn 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 or her head and neck supported (see drawing below).

4. Do not use powders or aerosol sprays around your child.

5. Contact sports should be avoided.

6. Avoid hairy or fuzzy clothing around the tracheotomy tube. Also do not use clothing that blocks the tracheotomy tube (for example, turtle neck 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 or she is practicing speaking by cooing and babbling.

12 months: The child may have even said a word or a few words.

12–18 months: The child is increasing the number of words he/she can say. He or she may have two word utterances such as “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 or she should be able to be understood by a stranger and be 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, the need for a tracheotomy is seen in children with other problems. If your child was born early, he or 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 difficulty 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.
Your child may be tested by a qualified speech therapist 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.

**BUT 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 has 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 Board:** This can be made for the child with different pictures or personal objects. By pointing to the object, he/she communicates his/her needs or thoughts. The child can help in the making of his/her personal picture board.

5. **Speaking Valve:** This is a valve that is placed on the tracheotomy tube. It allows the child to 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 after a recent Micro L&B, and after the child has been monitored by the nurse to be sure he/she can tolerate wearing the valve.
GOING TO SCHOOL

Public Law 94-142 states that all children are entitled to free appropriate public education. This law is very important in the education of children with disabilities. Children with tracheotomies are entitled to 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 is entitled to any services that are necessary for such attendance in regular classes.

Educators, health personnel, parents and, when appropriate, the child, must meet yearly to develop the educational goals and 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 our school and health personnel can assure your child will be safe at school.

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 frequently work with families to arrange for a well-planned admission to the hospital. Assistance may be provided with arranging transportation, lodging and meals. Guidance may be provided to help with preparing the child for the admission and treatment.

Coping with a child’s illness and hospitalization, or managing home care, may be very stressful for families. The social worker may be consulted to 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. Resources which the social worker may facilitate include nursing care, equipment, insurance coverage, extended care facility placement and counseling.

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

THE CARING NETWORK

The Children’s Caring Network is an information and referral service that assists families from outside the Greater Cincinnati area in making travel and lodging plans when they bring a child to Cincinnati Children’s Hospital Medical Center. Many motels, hotels, car rental agencies, and restaurants have joined Children’s Caring Network to offer discounts to out-of-town families during their medical visits to Cincinnati Children’s Hospital Medical Center. Other services a family may find helpful are discounted banking services, a variety of recreational activities, and airline discounts. Local families are referred to our social services department for assistance.
FINANCIAL HELP

Contact your Social Service Worker for details and requirements for these programs.

State programs and federally funded programs which may reimburse you for certain services your child may require:

- BCMH – Bureau of Children with Medical Handicaps (Ohio only)
- Commission for Children with Special Health Care Needs (Kentucky only)
- SSI – Social Security Income
- Family Resource Services Program
- WIC – Women, Infants, and Children – State funded program that helps provide formula and food to needy families.
- WAIVER – State funded program for children with tracheotomies which may help provide home nursing care. May vary from state to state.
- EPSDT – Early Periodic Screening, Diagnosis and Treatment Services (Kentucky only)

EMOTIONAL SUPPORT

There are many support groups in the community and the U.S. where you may meet other people who are going through similar experiences. The following are ways to connect with some of the groups available:

- Family Professional Resource Center – This CCHMC organization helps to connect families with available resources in the community, region, and nation.
- Tracheotomy.Com is a website that is not only a resource to families with children with conditions that require tracheotomies, but also connect families with other families with children of similar diagnoses and care issues.