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### Acknowledgements

A special thank you to the families and professionals that generously offered their time and support in developing this handbook. With much appreciation, Raeanne Kelly, RN and Kristin Chisholm, RN

Jaimie Ferland, parent

John and Joy Corbett, parents

Wynne and Eric Lord, parents

Ashley Mirles and Scott Boucher, parents

Nadine Campbell, parent

Darlene Barnes, parent

Lisa LeBon RT

Scott Schoem, MD

Nicole Murray, MD

Katherine Kavanagh, MD

Tulio Valdez, MD

Christopher Grindle, MD

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# A Message from the Healthcare Team at Connecticut Children's

As the parent or guardian of a child with a tracheostomy, we understand that this is a difficult time for you and your child. You are likely to have many questions and concerns as you prepare to take your child home from the hospital. Your healthcare team at Connecticut Children's is here to answer your questions and provide you with the education and support you will need to care for your child at home.

This handbook is intended to serve as a reference guide to help you care for your child at home. It is our hope that this guide will help to ease some of the anxiety you might feel caring for a child with a tracheostomy tube. In addition, we offer this advice to help you as you prepare to care for your child:

- Spend time caring for your child during his or her hospital stay. The more involved you are with your child's care here, the more comfortable and confident you will feel caring for your child at home.
- Choose a co-caregiver who will be able to help you care for your child's tracheostomy tube. You cannot provide care 24 hours a day. For your child's safety, any person caring for your child must be trained in tracheostomy care.
- Ask Questions. By sharing with us your questions and concerns, your healthcare team is better able to meet your needs.
- Finally, it is important to remember to treat your child as normally as possible. Life does go on after receiving a tracheostomy. With newly learned skills and adaptations, you and your child will be able to return to everyday life and experiences.

#### Advice from former parents...

#### **EDUCATE**

- Yourself: It is your responsibility to learn everything you can about your child's condition, treatments and possible outcomes.
- Those around you: Teach the medical professionals caring for child about him or her, in particular individuals who are new to your child. You will often get asked the same questions (over and over again) by the staff regarding your child, especially when they are seeing him or her for the first time. Don't get frustrated! It is a good thing they are checking and rechecking their information and a perfect opportunity to explain things unique to your child, how they respond to certain things, why something in their medical chart may really not apply, or any number of other things.

#### **ADVOCATE**

- Be the voice of your child. You must speak up and advocate on their behalf. Never be afraid to ask questions.
- Partner with your healthcare team. While one can learn a lot through self teaching it can't replace the experiential knowledge your healthcare team has.

#### **PARTICIPATE**

• Be present as much as possible: If you are able to stay with them 24/7 do it.

#### HANDS ON

• Learn to do every aspect of care giving that you can. This will be to your benefit in the long run.

### Dear Parent or Guardian

As you have already discussed with your child's ENT doctor, a tracheostomy will be performed on your child to help him or her to breathe. This can be a frightening and stressful time for parents and families. Parents are usually apprehensive about their child having a tracheostomy, and typically have many questions and concerns about caring for their child at home. It is the goal of the ENT department at Connecticut Children's to provide our families with the support and care needed to help you through this process.

This process begins while your child is in the hospital. The length of stay in the hospital is based on your child's medical needs, your learning needs, and the plan for homecare. This process usually takes about two weeks but varies according to each individual patient. Once you are home, you are not alone. We will continue to provide support and assistance as needed to help you care for your child.

We know this is a difficult time for parents and families. We have a dedicated staff that has the experience and the knowledge to guide you on your way as you cope with the challenges before you.

Sincerely,
The ENT Team



### Learning list for the care of your child with a tracheostomy

Before your child goes home, you and co-caregiver will need to learn the following care. Use this checklist as your personal guide. It is also important to know that any person caring for your child will need to know these skills.

Ш	Why your child needs a tracheostomy tube
	Type and size of your child's tracheostomy tube
	Why, when and how to suction the tracheostomy tube
	Why, when and how to clean the skin around the tracheostomy tube
	Why, when and how to change the tracheostomy tube
	Why and how to provide humidification
	Understand the supplies needed at all times with your child
	Potential emergencies and what to do to help your child
	CPR skills specific for a child with a tracheostomy
	Understand the signs of respiratory distress and what to do to help your child
	Understand the signs of infection
	Understand the activities your child can do and those they should avoid
	How to use necessary equipment and monitors
	24 hour transition to home overnight hospital stay

# What is a tracheostomy and why does my child need one?

#### What is a tracheostomy?

A tracheostomy is a small opening through the skin into the windpipe (trachea). This opening is called a stoma. A specially trained doctor performs this procedure in the operating room. A small tube, called a tracheostomy tube, is placed through the stoma into the trachea to help your child breathe. With a tracheostomy, your child will breathe through the tracheostomy tube instead of through their mouth and nose.

Why does my child have a tracheostomy? There are many reasons a child may need a tracheostomy.

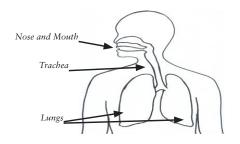
#### Reasons typically include:

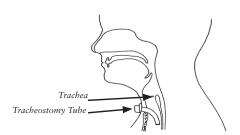
- A blockage of the airway
- An inability to clear the airway of secretions
- Your child needs a ventilator (breathing machine) for a long period of time; a tracheostomy often makes it more comfortable and easier to breathe.



#### What makes breathing with a tracheostomy different?

Normally we breathe through our nose and mouth so that air is filtered, warmed, and moistened before it goes to our lungs. When a child has a tracheostomy the air goes directly into the lungs without being filtered, warmed, or moistened. It is very important to learn how to care for the tracheostomy site in order to help decrease infection and support healthy breathing. This will require special training that you and a co-caregiver will receive before your child goes home.





## Chapter 1 - What is a tracheostomy and why does my child need one?

#### Types of Tracheostomy Tubes

There are many types of tracheostomy tubes. The type of tube your child will have depends upon your child's age, size and special needs.

- A tracheostomy tube includes the following parts:
  - 1. Tracheostomy tube or cannula
  - 2. Flanges where the ties *Swivel* are secured
  - 3. Obturator or guide for inserting the tube





A cuffed tube has a balloon on the end to allow for a tighter fit in the airway. A child that needs ventilatory or breathing support will usually need a cuffed tube.



An uncuffed tube is a tube that does not have a balloon on the end.

#### How do I care for my child's tracheostomy tube at home?

- Daily tracheostomy care includes:
  - 1. Cleaning around the tracheostomy site
  - 2. Changing the tracheostomy ties
  - 3. Providing humidity
  - 4. Suctioning the tube as needed

#### • Additional care includes:

- 1. Changing the tracheostomy tube once a week
- 2. Cleaning the used tracheostomy tube

### Suctioning a tracheostomy tube

#### Why suction?

Suctioning is done to remove mucous from your child's tracheostomy tube to allow for easier breathing.

#### When to suction?

You will learn your child's normal breathing pattern, which will help you decide when your child needs to be suctioned.

#### • Signs that your child may need suctioning include:

- 1. Rattling mucous that is not cleared with coughing
- 2. Fast breathing
- 3. Bubbles of mucous coming from tracheostomy opening

#### • Signs that your child is struggling to breathe and definitely needs suctioning:

- 1. Frightened look on his/her face
- 2. Restlessness
- 3. Flared (widened) nostrils
- 4. Pale or Bluish color of skin, nails or mouth
- 5. Decreased O2 sats
- 6. Fast and harder breathing, increased heart rate
- 7. Dry, whistling sound

#### Steps to suctioning

- 1. Hand Cleaner (if unable to wash hands)
- 2. Suction Machine
- 3. Suction Catheter, size\_\_\_\_\_
- 4. Gloves (optional for home care)
- 5. Cup with rinse water
- 6. Disposable saline vials
- 7. Blanket to secure child, if needed
- 8. Resuscitation Bag
- 9. Oxygen (if needed)









#### Chapter 2 - Suctioning a tracheostomy tube

#### How to suction

- 1. Wash and dry hands.
- 2. Pour rinse water into cup.
- 3. Connect suction catheter to suction machine tubing.
- 4. Turn on suction machine and set to prescribed suction pressure.
- 5. Place tip of suction catheter into the water and test to see if the suction machine is working.



- 6. Use premeasured technique to determine suctioning depth. (Insert the suction catheter through a spare tracheostomy tube so that the tip just protrudes beyond the end of the tube. Mark this length.)
- 7. Position your child on his/her back; older children may choose a sitting position. Small children may require help from another person to hold the child still and often do better if they are wrapped snuggly in a blanket.
- 8. Instill two or three drops of normal saline if needed for thick secretions. Regular use of saline is not recommended. Use saline only if the mucus is very thick, hard to cough up or difficult to suction.
- 9. Put your thumb over the opening of the suction catheter.
- 10. While applying suction, gently place the suction catheter into the tracheostomy tube to the premeasured mark.
- 11. Gently remove the catheter as you twirl or rotate the catheter between your forefinger and thumb. This step should take no more than 5 seconds.
- 12. Rinse the suction catheter.
- 13. Allow your child to rest between each suctioning. Look at your child's color and breathing. Provide oxygen if needed.
- 14. Repeat suctioning as needed to clear mucus.
- 15. Look at the mucus.
  - Normal: Clear with no odor.
  - Infection: Yellow, green with foulsmelling odor.
  - Blood: Pink tinged or a few streaks of blood are OK. Note: If there are bloody streaks in the mucus, check suctioning
    - depth. More time on the humidity mask may help decrease blood in the mucus. If the blood in the mucus does not get better after following these instructions call your doctor.

\*If you see bright red blood, you should call your doctor right away.

- 16. Disposable suction catheters should be discarded. In home care, catheters may be used more than once before disposal.
- 17. Turn suction machine off.
- 18. Wash and dry hands.



### Tracheostomy skin care

#### Why we need to do skin care?

Secretions from the tracheostomy tube build up around the tracheostomy site and provide a nice environment for bacteria to grow. This can lead to infection, skin irritation and breakdown

#### When do we need to do skin care?

The skin around the tracheostomy needs to be clean and dry. Clean and look at this area at least 2 times a day, or more often if there is redness, irritation or drainage.

#### Steps to cleaning

- Gathering supplies
  - 1. Mild soap and water
- How to Clean
  - 1. Wash and dry hands.
  - 2. Place your child in a comfortable position where you are able to see and access the stoma and the surrounding skin. Small children may need to lie on their back with a small roll under their shoulders.
  - 3. Mix the soap and water in the bowl.
  - Dip the cotton swab or washcloth into the soapy water. Clean around the tracheostomy stoma in a circular motion. Start at the inside and work toward the outside.

- 2. Cotton swabs
- 3. Gauze or wash cloth
- 4. Small clean bowl



- 5. Clean the flanges of the tracheostomy tube.
- Assess the skin area for any signs of skin breakdown, irritation or infection.
- 7. Wipe area clean removing any soapy residue.
- 8. Pat the tracheostomy area dry with a clean washcloth or gauze.
- 9. Check the skin under the tracheostomy ties.
- 10. Wash and dry hands after trach care.

Note: If you are having difficulty removing secretions with soap and water, you may use ½ strength hydrogen peroxide (mix equal parts hydrogen peroxide and water) to clean the skin followed by water.



#### How to treat skin problems

- Call your doctor if there are any of the following skin problems around the stoma or underneath the tracheostomy ties.
  - Redness, Drainage, Foul odor, Swelling, Skin breakdown
- Check with your doctor before applying any powders or ointments near or around the trach. If the doctor wants your child to have a special powder applied to his/her neck put a little on a gauze pad and then carefully pat the neck with the powder being careful not to create a dust cloud that could enter your child's airway.

### Changing tracheostomy tube ties

#### Why should the trach ties be changed?

Your child's tracheostomy tube is held in place with trach ties. Tie changes are done to ensure the tube is secured properly and to prevent irritation and skin breakdown on the neck.

#### When to change the trach ties?

Trach ties should be changed once daily or when the ties are wet or dirty.

#### Steps to changing the trach ties:

This procedure should not be done alone. Another person must be present to hold the tracheostomy tube in place while you change the ties.

#### • Gathering supplies

- 1. Scissors
- 2. Trach ties
- 3. Rolled towel or small blanket if needed

#### • How to change trach ties

- 1. Wash and dry hands.
- 2. Measure tie to the desired length by holding the tie around your child's neck. Cut away any extra length.
- 3. Place your child in a comfortable position. Older children may choose a sitting position. Small children should lie on their back with a small roll under their shoulders. Small children will require help from another person to hold the child still and often do better if they are wrapped snuggly in a blanket.
- 4. Have your helper hold the trach tube in the stoma while you remove the old trach ties.
- 5. With your helper holding the trach tube securely thread the fastener tabs through the openings on each side of the trach tube flange.
- 6. Fold each tab back onto the cloth material to fasten securely.
- 7. Bring both ends of the tie around the neck and secure with the Velcro closure.
- 8. Check the neckband to be sure that it is flat against the skin and is not too tight or too loose. You should be able to get one (1) finger under the Trach tie.
- 9. Discard old trach tie.
- 10. Wash and dry hands.







## Tracheostomy tube change

#### Why?

To prevent mucus build-up in the tube and to keep the tracheostomy tube clean.

#### When?

Typically the tracheostomy tube is changed once per week or in the event of an emergency situation such as mucous plugging.

Check with your doctor for your child's specific recommendations. It is best to change the trach tube before eating or at least two hours after eating.

#### Steps to changing the tracheostomy tube:

Routine tracheostomy tube changes should not be done alone. Another person must be present to hold the tracheostomy tube in place while you change the tube. In an emergency, you must be prepared to change the tube by yourself.

#### • Gathering supplies

- 1. Emergency equipment ready for use
  - Same size trach tube\_\_\_\_\_
  - 1/2 size smaller trach tube \_\_\_\_\_
  - Resuscitation bag with oxygen
- 2. Suction equipment ready for use
  - Suction catheter size\_\_\_\_\_
- 3. Same size trach
- 4. Trach ties
- 5. Water soluble lubricant
- 6. Scissors
- 7. Gloves (optional)
- 8. Rolled towel or small blanket



#### Chapter 5 - Tracheostomy tube change

#### • How to change trach tube

- 1. Wash and dry hands.
- 2. Remove new trach from its packaging and examine it for any damage or flaws.
- 3. If it is a cuffed tube, check cuff inflation.
- 4. Prepare the new trach by placing the obturator in the trach tube and attaching the trach ties. Place the trach on clean work surface.
- 5. Moisten the tip of the trach tube with lubricant.
- 6. Position your child on his/her back with a small blanket under their shoulders. Older children may choose a sitting position. Small children will require help from another person to hold the child still and often do better if they are wrapped snuggly in a blanket.
- 7. Suction tracheostomy tube.
- 8. Have your helper hold the trach tube in the stoma while you remove the old trach ties.
- Wipe/clean the area around the trach as needed while your helper continues to hold the tube securely.
- 10. Place the new trach tube in your hand.
- 11. When ready, your helper will pull the old trach tube out with an upward, outward motion.
- 12. You will then, quickly insert the new tube gently with an inward, downward motion.
- 13. Remove the obturator, holding the tracheostomy tube securely. Listen and feel for air movement.
- 14. Secure the trach ties. Adjust the trach ties so (1) finger fits comfortably between the neck and tie.
- 15. Changing the trach tube will cause the child to cough. You may suction if needed.









Do not force the tube!

#### If unable to insert tracheotomy tube:

- Remain calm
- Let child relax, reposition head and neck.
  - Try to reinsert tube again.
- If still unable, try to insert ½ size smaller tube.
  - If cannot get smaller trach in, Call 911.
  - Check to make sure child is breathing.
    - Begin CPR if needed.

Note: Notify your doctor if you have any difficulty inserting the tracheostomy tube or if a smaller sized tube was placed.

#### Chapter 5 - Tracheostomy tube change

#### Cleaning the tracheostomy tube:

Bivona tracheostomy tubes can be cleaned at home and reused. For all other tracheostomy tubes, follow the instructions listed on the "instructions for use" provided with your child's tracheostomy tube.

#### For Bivona Trach's

#### • Gather supplies

- 1. Dirty tracheostomy tube
- 2. Obturator
- 3. Distilled water
- 4. Clean plastic bag
- 5. Cleaning kit
- 6. Mild soap





#### • How to clean trach: Step 1

- 1. Inspect tube for any damage or excessive wear.
- 2. Do not use tube that is damaged.
- Gently clean trach and obturator with mild soap and water, removing debris with soft brush and pipe cleaners.
- 4. Rinse tube and set aside to dry.
- 5. When the tube and obturator are completely dry, store in a clean plastic bag until the next use.



#### • How to clean trach: Step 2

- Right before the next use, bring a pan of distilled water to a boil. Take the pan from the heat, remove the trach and obturator from the plastic bag and place into the pan of water. Let cool.
- 7. Once cool, remove the tube and obturator from the water, holding the tube by the neck flange and the obturator by its handle.
- 8. Allow to dry on a clean towel
- 9. It's ready for your next trach change.



### Preventative and emergency care

#### Why?

Air is normally warmed and moistened by our nose before it enters our lungs. When a child has a tracheostomy tube the air bypasses the nose and goes directly into the lungs. Humidity, or the amount of moisture in the air, protects the lining of the lungs and keeps our secretions from drying out.

- Humidification must be provided to:
  - 1. Keep secretions loose to prevent mucus from plugging the tube
  - 2. Preventing dry air from entering the lungs causing irritation and bleeding

#### How can I provide humidity when my child has a trach?

- You can provide humidity to your child the following ways:
  - 1. **Mist Collar (trach mask)** The mist collar is worn over the tracheostomy tube. The mist collar is attached to a machine called an air compressor that has a nebulizer filled with water. This produces a "mist" that the child is able to breathe in through the tube.





- 2. Heat Moisture Exchange (HME) Sometimes called an "artificial nose". This is a humidifying device that fits onto the end of the trach tube. HMEs hold your child's own moisture and warmth in the airway. HMEs must be changed daily and when it becomes wet or soiled with secretions. Your doctor will tell you if your child can use an HME.
- 3. Room Humidifiers Room humidifiers add extra moisture to the air in the room. They are sometimes used by older children who do not like mist collars and seasonally

#### When should humidity be provided?

- Humidity should be provided through the mist collar when:
  - 1. Your child is asleep during naps and at night
  - 2. Secretions are thicker than normal or blood-tinged
  - 3. If your child is receiving oxygen
- An HME may be used:
  - 1. During the day when your child is off the mist collar
  - 2. Outside on cold or windy days

Note: If your child is on a home ventilator, you will receive special instructions regarding the use of this equipment.





#### Chapter 6 - Preventive emergency care

#### Emergency bag equipment:

Having a child with a tracheostomy does not mean that you need to stay at home. You can go to the park, shopping or visiting with friends and family, but you must always be prepared for an unexpected breathing problem.

Wherever you go, you must take with you an emergency equipment bag.





#### • The following items should be included:

- Portable suction with suction catheters (always carry more than you think you might need)
- 2. Same size tracheostomy tube with ties in place
- 3. ½ size smaller trach tube
- 4. Resuscitation bag

- 5. Normal saline
- 6. Water soluble lubricant
- 7. Scissors
- 8. Extra trach ties
- 9. Syringe if your child has a cuffed tube
- 10. Tap water to flush suction catheter
- 11. Hand sanitizer
- 12. Emergency phone list

#### What problems should I be looking for?

When you leave the hospital you will have learned all the skills necessary to take care of your child's tracheostomy at home. Even with the best care, problems may arise that can cause difficulty breathing.

#### Signs of Respiratory Distress

One of the most important things you will need to recognize are signs that your child is having difficulty breathing.

#### • Early signs of breathing trouble may include:

- 1. Noisy breathing
- 2. Fast breathing
- 3. Restlessness
- 4. Infants may have trouble sucking
- 5. Difficulty eating or refusing to eat

#### • Later signs of breathing trouble may include:

- 1. Difficulty breathing (pulling in of the skin between the ribs, below the breast bone or above collar bones)
- 2. Flared nostrils
- 3. Anxiety, frightened look
- 4. Pale, gray or blue color around lips, skin or nail beds
- 5. Low O2 saturations for children on pulse oximetry

#### Chapter 6 - Preventive emergency care

#### **Emergency Scenarios:**

#### Mucus Plugging

Mucus can collect in the tracheostomy tube or the airway and cause a "plug".

#### • Signs of mucus plugging:

1. If the plug is making it difficult for the child to breathe then he/she may have symptoms of respiratory distress.

#### • Ways to prevent mucus plugging:

- 1. Use mist collar when your child is sleeping or when secretions are thicker than normal
- 2. Use HME when off the mist collar
- 3. Make sure your child is adequately hydrated
- 4. Encourage your child to cough out secretions
- 5. Suction as needed to clear secretions from the tracheostomy tube
- 6. Perform routine tracheostomy tube changes

#### • How to remove a mucus plug:

- 1. Try suctioning the tracheostomy tube.
- 2. Place one or two saline drops into to the tracheostomy tube to loosen secretions, then suction again.
- 3. If the child is showing signs of respiratory distress, change the tracheostomy tube.

#### Bleeding from the tracheostomy tube

Bright red bleeding from the tracheostomy tube may be a sign of serious damage to the airway. Your child should be seen by a doctor right away.

It is not unusual to have occasional blood-tinged or pink colored secretions.

#### • Causes of this type of bleeding may include:

- 1. Dry airway
- 2. Frequent, deep suctioning
- 3. Infection
- 4. Irritation from the tracheostomy tube (granuloma)
- 5. Excessive coughing
- 6. Trauma from the tracheostomy tube
- 7. Foreign object in the airway

#### How to prevent bleeding:

- 1. Use humidification
- 2. Use appropriate suctioning technique

#### Chapter 6 - Preventive emergency care

- 3. Keep regular appointments with the doctor to make sure the trach tube is fitting properly
- 4. Use water based lubricant when changing trach tube to prevent trauma

#### • How to treat blood-tinged mucus:

- 1. Gently suctioning to the appropriate depth
- 2. Increase use of humidity
- 3. Provide saline as directed by the doctor

#### Accidental Decannulation

If the tracheostomy tube is not secured properly it can easily be pulled out, coughed out or fall out. If the tracheostomy tube comes out partially or completely, your child may have difficulty breathing.

#### • How to replace the tracheostomy tube if it comes out accidentally:

- 1. Stay calm, but act quickly
- 2. Keeping the airway open is always the first priority
- 3. Reinsert the tube immediately. If the spare trach is not handy, replace the one that came out. Later, when the situation is calmer, you can replace with a clean trach tube.
- 4. If the regular size tube does not fit, try the ½ size smaller tube
- 5. If you are unable to reinsert the tube, call 911, start CPR as needed
- 6. Always call your doctor if you have had difficulty reinserting the trach tube or needed to insert a smaller size
- \*\* Two spare trachs should be with your child at all times. One should be the same size and the other should be a ½ size smaller for emergency replacement. Keep these 2 trachs taped to the head of your child's bed as well as in your travel bag. \*\*\*

#### • Ways to prevent an accidental decannulation:

- 1. Make sure the tracheostomy ties are secure, dry and intact.
- 2. If the ties show any sign of wear, such as tears or thinning, they should be replaced.
- 3. Discourage your child from touching or pulling on the trach. Try not to focus too much attention on the act, because this will only reinforce the unwanted behavior.

#### Infection

Children with tracheostomies are at a higher risk for respiratory infections, because the tracheostomy tube bypasses the normal filtering process of the nose and the upper airway.

#### Chapter 6 - Preventive emergency care

#### • Symptoms of infection:

- 1. Yellow or green secretions
- 2. Increased or thickened secretions
- 3. Fever
- 4. Foul odor
- 5. Fast breathing or change in breathing pattern
- 6. Congested lung sounds
- 7. Lethargy

#### • Treatment for infection:

1. Call your doctor with any signs or symptoms of infection

#### • Prevention:

- 1. Wash hands routinely. Hand washing is the single most important way to stop the spread of infection.
- 2. Use antibacterial hand sanitizer when you can't wash your hands.
- 3. Avoid exposure to persons who are sick or have a cough.
- 4. Provide humidity.
- 5. Wear HME as indicated by your doctor.
- 6. Ensure your child maintains a healthy diet and regular exercise.
- 7. Be sure all of your child's immunizations are up to date. Flu vaccine may be recommended.
- 8. Second hand smoke is a risk factor for respiratory infections. A child with a tracheostomy should not be exposed to smoke.
- 9. Regular disinfection of toys, doorknobs, remote controls, especially during cold and flu season.

# Living with a tracheostomy: Tips for daily living

The most important thing to realize when leaving the hospital is that life can return to normal. Children with a tracheostomy can participate in everyday activities and should be encouraged to have as normal a routine as possible.

#### Communicating with a Tracheostomy

Normally, sound is produced by air from the lungs passing through the vocal cords causing them to vibrate and make noise.

#### • The Effects of A Tracheostomy On Communication:

- 1. Speech production may be affected when a child has a tracheostomy, because all or some of the air from the lungs goes out the trach tube and bypasses the vocal cords.
- 2. Your child's ability to make sound will depend on how open the airway is and if the vocal cords are functioning normally.
- 3. If the airway is narrowed or scarred, air from the lungs is blocked from passing through the vocal cords to make sounds.
- 4. If the vocal cords are scarred or paralyzed, they do not vibrate normally to produce sound.
- 5. The size of the tracheostomy 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.

#### What If My Child Can't Make Sounds or Talk?

Any non-speaking child, especially if they are less than a year old, should be closely monitored.

#### • Important Points for the child that cannot make sounds:

- 1. Use your apnea monitor or pulse oximeter during naptime and at night, or when not in visual contact.
- 2. Direct supervision of young children is recommended.
- 3. You will learn your child's behaviors and expressions that will indicate their needs.
- 4. Even though your child cannot cry or speak it's important that you speak to them in a normal manner, read books and name objects to encourage speech and language development.

#### Chapter 7 - Living with a tracheostomy: Tips for daily living

#### • Alternative methods of communication:

- 1. **Sign language:** Sign language is not only for children who cannot hear but also for children who cannot speak. Sign language can be learned as early as 9 months of age.
- 2. **Picture Communication Board:** Can be made for the child with different pictures or personal objects. The child is able to communicate their thoughts or needs by pointing to the pictures or objects.



- 3. Computerized Communication Device: The child selects the word on the board and the computerized voice says the word.
- 4. Passy Muir Valve (PMV): It is a one way valve that attaches to the outside of the trach tube. The PMV opens when the child breathes in, and closes as the child breaths out. This forces air around the trach tube and up through the vocal cords, allowing for the child to make sounds.
- \*Requires Doctors permission: A PMV is often used to help a child with a tracheostomy speak, but does not work well for children who have stenosis (narrowing) above the tracheostomy.

#### Eating/Feeding with a Tracheostomy

In general, infants and children with a tracheostomy can eat and feed normally. Some children who have problems with their vocal cords may have difficulty swallowing. This can cause food or fluid to enter the lungs leading to pneumonia and chronic respiratory problems. These children will work closely with a speech and language pathologist (SLP) to develop a safe feeding plan that allows for normal growth and development.

#### **Guidelines for Feeding**

#### Infants

- 1. It's a good idea to suction before feeding. This often prevents the need for suctioning during or after meals, which may stimulate coughing that could result in vomiting.
- 2. While breastfeeding or bottle feeding it's important to have a cloth bib on your infant to prevent formula or breast milk from entering the trach.
- 3. Avoid plastic bibs which may block trach tube.
- 4. Never prop a bottle to feed an infant.
- 5. Hold infant in upright position while feeding and burp frequently.

#### Chapter 7 - Living with a tracheostomy: Tips for daily living

#### Children

- 1. Young children should always be supervised during eating to make sure they do not put food into their trach.
- 2. You can use a loose fitting cotton bib to cover the trach to prevent food from entering.
- 3. Avoid plastic bibs which may block the trach tube.
- 4. Encourage adequate fluid intake.

**NOTE**: If food or fluid is seen in the trach, suction the trach and mouth immediately. Then, call your Doctor.

#### **Bathing**

Children love to take baths. With extreme caution your child will too. Never leave a child unattended in the bathtub. Water poses a serious threat for all children, but particularly for children with tracheostomies. Water that enters the trach tube goes directly to the lungs and can cause drowning.

#### Children

- 1. Always prepare a shallow bath.
- 2. Prevent water from splashing into the trach. For extra safety, your child may wear a trach mask or an HME.
- 3. If water should enter the trach, suction immediately.
- 4. Small children should not be allowed to shower.
- 5. With added precautions an older child may be allowed to shower. Cover trach area with trach mask or HME and adjust the showerhead to hit your child's body well below the neck area.
- 6. When washing your child's hair lay the child back while supporting the head and neck. Pour water to the back of the head while keeping the trach area dry. For extra safety, your child may wear a trach mask or an HME.

Caution: Avoid using powders and aerosols. Particles and fumes from powders and aerosols can enter into the lungs through the trach and cause breathing problems.

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#### Chapter 7 - Living with a tracheostomy: Tips for daily living

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#### Chapter 7 - Living with a tracheostomy: Tips for daily living

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#### **Getting Dressed**

You do not need to buy special clothes for your child; just be careful the clothing does not block the tracheostomy tube. New clothing items should be washed prior to wearing to ensure lint particles are removed.

Avoid: crewnecks, turtlenecks, and buttons in the back, necklaces, shoulder straps and clothes that shed lint or fibers.

Use: v-neck tops and clothing that buttons in the front. A cotton bib or handkerchief can be worn over the trach tube when it is cold outside to help warm the air.

#### Playtime

Play is essential to your child's growth and development and should be encouraged. With some precautions, your child can play just like other children.



#### • Precautions:

- 1. Water safety is extremely important. A child with a tracheostomy cannot protect his/her lungs from drowning if an accidental fall into the water should occur.
  - a. No swimming.
  - b. Avoid water sports
- 2. Avoid sandboxes and beaches. Sand can easily get into your child's trach and lungs.
- 3. Avoid toys that shed fur or fuzz.
- 4. Avoid toys that have small pieces that could be placed into the trach.
- 5. If you choose to have a personal pet, it is best to choose one that can either live outside or one that does not shed.
- 6. Supervise young children at play.

#### Chapter 7 - Living with a tracheostomy: Tips for daily living

- 7. Watch play with other children so that toys, food or fingers are not put into the trach tube.
- 8. Monitor other children at play to be sure they do not pull on the trach tube.
- 9. No contact sports.
- 10. Avoid activities with chalk, glitter, aerosols that could be inhaled into the lungs through the trach. Other irritants include: facial and bath tissue, perfumes, aerosolized sprays, hairspray, deodorizers, cold air, powders.

#### Going to School

Under IDEA (Individuals with Disabilities Education Act) all children with disabilities have the right to a free appropriate public education (FAPE). This law ensures that children with tracheostomies can receive educational and supportive services in the "least restrictive environment". This means your child should attend regular classes whenever possible. It also means your child has the right to additional services, such as speech and language therapy, special education, nursing, as needed to attend regular classes.

Both state and federal law require each child that qualifies for these services, receive an individualized educational plan (IEP) or a 504 Plan. Educators and parents, in collaboration with health personnel, meet yearly to develop the educational goals and medical plan of care.

Most children with tracheostomies can attend a regular classroom. However, the child with a tracheostomy will require closer supervision and special care. Children with a tracheostomy require continuous monitoring by a caregiver who has completed an approved tracheostomy care training program. Most state regulations mandate that this care be provided by an RN or LPN at school, as well as transportation to and from school. Working with your child's school and health personnel will ensure your child can attend school in a safe and secure environment.

### Glossary of Commonly Used Medical Terms

#### Airway

The term used to describe air passages

#### Bronchoscopy

Exam to look at the inside of the trachea and air passages that lead to the lung

#### Decannulation

Removal of tracheostomy tube

#### **Epiglottis**

A flap that during swallowing covers the opening to the larynx (voice box) to keep food or fluid from entering the lungs

#### Granulation

A term used to describe excess tissue or scar tissue. It sometimes appears around the stoma.

#### Larynx

The voice box located at the top of the trachea. It produces sounds and protects the airway by preventing food or fluid from entering it.

#### **Normal Saline**

A solution made from water and salt. It can be used to help break up thick mucus.

#### Obturator

When inserting the tracheostomy tube the obturator helps provide strength and direct the tube. After use always store the obturator by the bedside in case an emergency insertion is needed.

#### Stoma

The opening through the skin where the tracheostomy is place.

#### Glossary of Commonly Used Medical Terms

#### Trachea

The passage between the larynx and the lungs often called the windpipe.

#### Tracheotomy

The surgical procedure that creates a tracheostomy

#### Tracheostomy

The opening into the windpipe creating an artificial airway

### References

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Bissell, Cynthia M (2008). Pediatric Tracheostomy Home Care Guide.Sudbury, Massachusetts: Jones and Bartlett Publishers.

Cinncinnati Children's Hospital Tracheostomy Care Handbook: http/www.cinncinatichildrens.org/health/info/ent/trach-manual.htm.

## NOTES


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