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MEDICINE

GOLISANO
CHILDREN'S HOSPITAL



A guide for parents and caregivers

Tracheostomy Care



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Dear parents and caregivers,

Having a child with a tracheostomy (trach) feels overwhelming at first. It's a big adjustment. There's so much to learn. And it's an emotional time. We'll work with you to ensure you feel ready to care for your child when it's time to leave the hospital and to go home.

We ask each family to identify **at least 2 caregivers** to learn tracheostomy care. Once home, your child will always need to be cared for by an adult who's gone through the training.

Planning your transition from hospital to home is a team effort. And you are the most important team members. The more time you spend caring for your child while in the hospital, the better prepared you'll be to provide care at home.

Nursing staff and the Care Coordinator will work with you to provide the training. Child Life staff, speech therapists, occupational therapists, and physical therapists will show you how to help meet your child's developmental and social needs.

Training sessions will take place over a number of days at convenient times for you. Usually, training lasts around 2 weeks. When both caregivers have completed the training, you each spend an extended period of time (usually 24 hours) in the supportive hospital environment providing all of the care expected at home. (We refer to this as a Comprehensive Care Demo.)

In addition, you will need to take your child on a short outing before going home. This is to practice traveling with your child. Nursing staff will be available to assist you with answering questions during this time to increase your comfort and confidence.

Social work staff will also help you determine insurance coverage for your child's care at home, as well as identifying appropriate resources. This determines what resources will be available to you at home, including equipment and nursing visits. A home care agency and equipment supplier will work with you. They'll help you set up your home to care for your child. They'll make sure you have all the supplies you need.

A community health nurse and your pediatrician will oversee home care. A nurse will visit your home to help you in the transition from hospital to home. The frequency of visits is based on your child's needs and your insurance coverage. Your child may also qualify for more extensive nursing assistance in your home. For some children this is required to ensure their safety.

We'll do our best to be clear. If we don't explain something well enough, please ask us questions. And it doesn't matter if you ask the same question more than once!

We've designed this booklet with you in mind.

There are areas throughout this booklet for you to make notes. You should feel free to write anywhere...in the margins or between the lines. This is your booklet. If there's a way we can improve it, please tell us.

In the back of this booklet is a list of words we use. We explain them. And we offer help with pronunciation, too.

What information will I find in this booklet?

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My Quick Reference Trach Guide

	Name	Phone number
Primary care doctor		
Doctor managing the trach		
Home nursing agency		
Home care supply company (vendor)		
Other contacts		

Trach brand	<input type="checkbox"/> Shiley	<input type="checkbox"/> Bivona
Trach category	<input type="checkbox"/> Neonatal	<input type="checkbox"/> Pediatric <input type="checkbox"/> Adult
Trach size:		
Trach Ties Size (Velcro™):		
Trach type	<input type="checkbox"/> Uncuffed	<input type="checkbox"/> Cuffed <input type="checkbox"/> Fenestrated
Speaking valve	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Cannula	<input type="checkbox"/> Single <input type="checkbox"/> Double	Inner Cannula <input type="checkbox"/> Disposable <input type="checkbox"/> Reusable
Weekly trach change day:		
My child <input type="checkbox"/> Can <input type="checkbox"/> Cannot be intubated through the mouth		
Ambu bag size:		
Suction Catheter size:		
Suction depth:		
Suction frequency:		
Oxygen requirements:	Day	
	Night	
Oxygen delivered by:		
How often Chest PT:		

My child’s baseline normals

Normal breathing rate: Awake _____ Sleeping_____

Normal heart rate: Awake _____ Sleeping_____

Normal oxygen level (O₂ sats): _____

Work of breathing baseline: _____

Homecare guidelines for my child



- Change the trach tube one time each week. If needed, change tube more than once a week, to keep it clear.
- Use a “little sucker” (bulb suction) to suction secretions at the trach tube opening.
- Every day, clean the neck and stoma. Use mild soap and water. Do this more frequently if needed.
- Change trach ties one time each day. It’s OK to change them more frequently, if needed.
- Monitor your child’s oxygen levels with an oximeter at all times when you are unable to see them.

Keep the Go-bag with you at all times.

My notes: _____



Part 1: Tracheostomy Basics

In this section I will learn:

1. Why my child has a trach.
2. What happens when my child has their trach removed? Can they breathe through the hole in their neck?
3. What happens when my child breathes through a trach and not their nose?
4. To describe my child's trach. What size is the trach? What kind of trach is it? What brand is it? Is it single cannula or double?

What is a Tracheostomy?

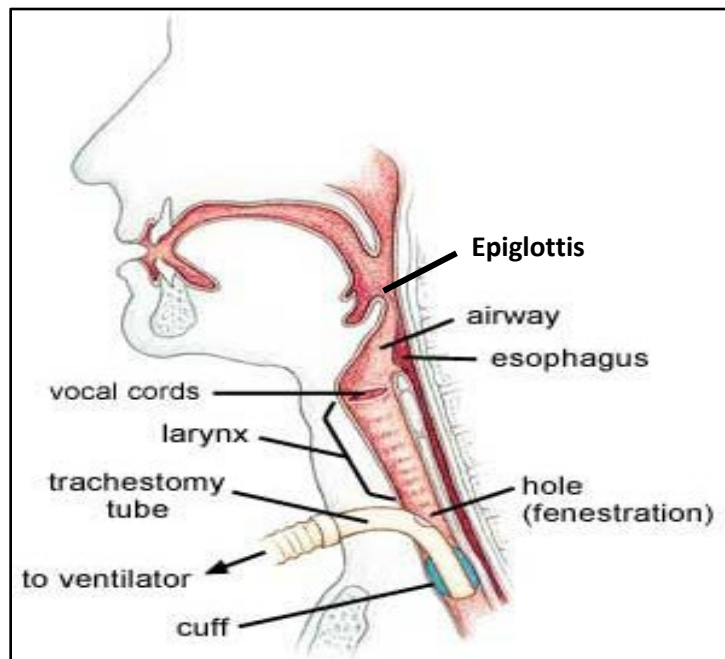
A tracheostomy is a surgical procedure. It creates an opening through the neck into the trachea (windpipe). This new opening is called a tracheostomy or stoma.

We put a tube into the stoma to keep the airway open. The tube also helps with the removal of secretions from the lungs. This tube is called a tracheostomy or "trach" tube

We place the trach tube below the larynx (voice box). And a trach is placed in front of the esophagus (swallowing tube).

Your child's ability to speak or make noises with their trach will depend on their underlying health problem. Sometimes, children find it hard to talk right after surgery.

Your child's ability to eat after the trach will depend on their underlying health problem. Some children's ability to eat will not be affected by a trach. Children will have their swallowing evaluated after surgery to determine safety in eating and swallowing.



A trach may be permanent or temporary. This will depend on the child's underlying health problem. Your child's specific needs should be discussed with your doctor or nurse prior to tracheostomy placement and ongoing.

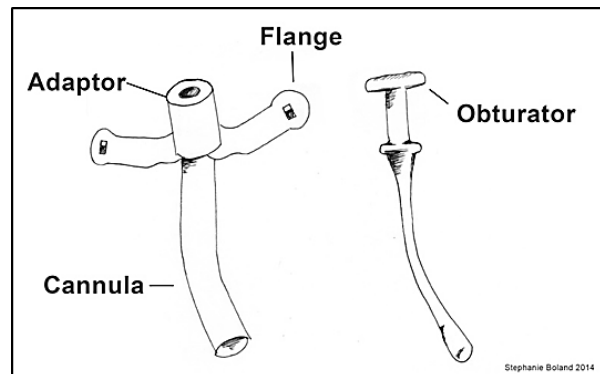
Parts of a Tracheostomy

Tracheostomy tubes come in various sizes and are made of different materials. Of the many types that exist, the most common brands at Golisano Children's Hospital are Shiley™ and Bivona®.

1. **Tracheostomy tube** is inserted and will remain in the stoma (hole)
 - Tube length and thickness are different for each child. For small children and infants, the tracheostomy tube is typically a single cannula tube.
 - Larger size tracheostomies for older children and adults may have a double cannula tracheostomy tube. With this type of tracheostomy, the outer tube acts as a permanent tube which remains in the stoma. The inner cannula acts as a removable liner. The inner cannula can be removed and cleaned, or discarded and replaced.

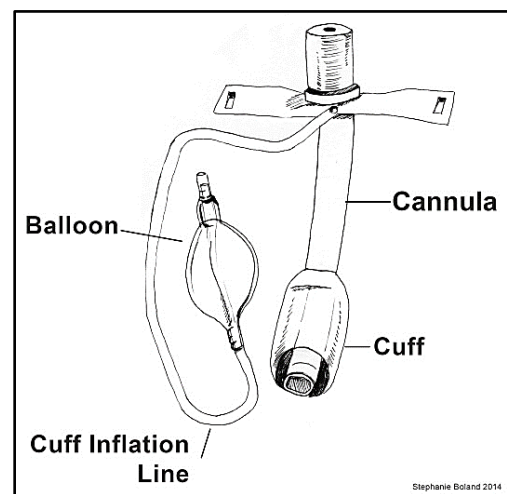
2. **Flange** (faceplate) rest on the neck. It extends from either side of tracheostomy tube. This is where ties are attached.

3. **Obturator** comes with each type of trach tube. It is used to guide the outer tube into the stoma during insertion. It is removed immediately after the trach tube is secured in place.



4. **Ties** attach to the flanges. They tie around the child's neck to keep the trach tube in place.

5. The **cuff** is a soft balloon at the end of the trach tube. Not every tube has a cuff. It's most often used for children on ventilators (breathing machines). The cuff can be inflated with water or air, depending on the type of tube your child has. When cuff is inflated, mechanical ventilation can occur. When cuff is deflated, air is allowed to pass around the tube.



6. **Bivona® Flextend Tracheostomy tubes** have an extra extension between the hub and the neck plate. There is a picture of a triangle on the trach adaptor that must be facing up towards the ceiling. When it is facing up, it ensures that the trach tube is not twisted.

Part 2: Tracheostomy Care

In this section I will learn:

1. Daily trach care.
2. To show daily trach care on my child.
3. What to do if the area around the trach becomes red, crusted, or has drainage.
4. How often to change trach ties. And what supplies I need to change the ties.
6. To show how I change the trach ties.
7. To show how I change the trach tube (and inner cannula, if present).
8. What to do if I can't get the trach back in.
9. How to clean the trach tube after it's removed.

Skin Care

It is important to keep the skin around the tracheostomy clean and dry. This will help prevent bacteria (germs) from growing. Bacteria can cause infection or skin rashes.


Clean and look at the stoma at least twice daily, and as needed. Watch for skin breakdown, redness, swelling, crusting, drainage (particularly green or yellow in color), or bad odor.

What supplies do I need?



Gather all your supplies in a clean work area.

- Hydrogen peroxide (if needed)
- Water (You can use water from your sink faucet. Do not use well water.)
- Mild soap
- 2 lint-free cloths
- Cotton-tipped swabs (You can use Q-tips® or another brand.)
- New trach ties
- Split gauze dressing
- Gloves (optional)

	<p>If trach has inner cannula, gather disposable inner cannula or trach cleaning brush, if cannula is reusable.</p>
<p>How do I do this?</p> 	<ol style="list-style-type: none"> 1. Wash your hands 2. Place child on back with small roll underneath shoulders to allow for neck extension and full view of trach. 3. Check with your child's provider to be sure it is safe for your child to lie in this position. 4. Clean neck and stoma site with mild soap and water using lint free cloth or gauze <p>Start closest to the stoma and stroke outward in a circular pattern. Cleaning from stoma outward decreases the chances of foreign material entering the airway through the stoma.</p> <p>Cleanse exposed trach and flanges to remove any drainage or crusting- DO NOT remove the trach</p> <p>May use Q-tips to clean and dry under flange.</p> <p>Be sure to avoid getting water into stoma</p> <p>If crusting is difficult to remove- clean with mixture of ½ hydrogen peroxide with ½ water</p> <p>NOTE: routine use of hydrogen peroxide may eventually increase skin irritation leading to breakdown</p> 5. Rinse with clean water 6. Dry skin and trach with dry cloth <p>Make sure no lint or debris enters trach</p> 7. The use of split gauze/dressing under the trach tube is optional <p>Use of split gauze/dressing is often determined based on volume of secretions and skin condition around the trach tube</p> 8. Avoid the use of creams, lotions or powders 9. If child has a cuffed tracheostomy, ensure cuff is inflated with prescribed amount of water 10. Check that ties are securely fastened, allowing only one finger/fingertip to fit between ties and neck

	<p>11. It is important to assess the trach stoma while cleansing for:</p> <ul style="list-style-type: none"> • Signs and symptoms of infection; redness, drainage – particularly green or yellow in color, bad odor, swelling, skin breakdown • Granulation tissue which is new tissue that forms around the trach site. It will look red/pink and “beefy”.
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Trach Care Differences While Your Child is Hospitalized

We use of a mixture of ½ hydrogen peroxide and ½ sterile water to clean around the trach site of new tracheostomies. After 2 weeks, once the trach is no longer considered new, we use sterile water with a mild soap in the hospital to clean around the trach site.


Use clean or distilled water at home with a mild soap. It's OK to use tap water but do not use well water.

Tracheostomy Tie Changes

Tracheostomy ties help to prevent the trach tube from falling out. Ties should be changed at least daily and more frequently, when they are dirty, wet, frayed or skin breakdown is noted. Look for rash, redness, or skin breakdown on neck area. You can perform trach tie changes at the same time as cleaning the stoma of your trach.

Ties can be made of cloth (twill tape) or have Velcro™. The most frequently used ties at Golisano Children's Hospital are Velcro™ ties. Velcro trach ties may not be covered by insurance, although they are readily available for purchase from equipment suppliers. Please speak with your equipment supplier regarding obtaining the appropriate trach ties for your child.

Velcro™ trach ties may be washed with soap and water to be reused if necessary. Assure that the Velcro still holds securely after washing. **Do not wash and reuse if there is an active yeast or bacterial infection.**

<p>What supplies do I need?</p> 	<p>Gather all your supplies in a clean work area.</p> <ul style="list-style-type: none"> • Scissors (if needed to cut cloth ties) • New tracheostomy ties • Lint-free wash cloth
	<p>1. Wash your hands</p>

How do I do this?

2. Place two fingers of one hand on both sides of flange to hold trach tube in place
3. Undo tie on one side of neck and slide out of flange
4. If performing trach tie change and site care at the same time this is where you would clean/rinse/dry site on first side of the neck

Only undo one side of trach ties at a time. This allows you to quickly replace trach ties in case of an emergency during trach tie change.
5. Slip one side of the NEW tie through flange opening and securely fasten
6. Undo tie on other side of the neck and slide out of flange
7. If performing trach tie change and site care at same time this is where you would clean/rinse/dry site on other side of neck
8. Slip other side of NEW trach tie through second side flange and securely fasten
9. Check that ties are securely fastened, allowing only one finger/fingertip to fit between ties and neck. You may need to cut trach ties if they are too long.



Tracheostomy Tube Change



Tracheostomy tube changes are performed routinely in an attempt to keep the trach tube clean and prevent mucus which can plug the tube from forming.

Your doctor can help decide how often the tracheostomy tube will need to be changed. This may be once a week or as long as a month. Many brands of trach tubes can be cleaned and reused multiple times. You will receive a new trach from your equipment supplier as frequently as your insurance will allow. (This will range from monthly to every 6 months.)

Have another person help you with trach changes until you're confident doing it by yourself.



It's very important to gather all equipment in one place before starting any trach tube change. Once you remove the trach, your child needs to have the new trach inserted immediately to keep their airway open and keep breathing.

<p>What supplies do I need?</p> 	<p>Gather all your supplies in a clean work area.</p> <ul style="list-style-type: none"> • Tracheostomy tube the same size and length of the tube currently in place • Tracheostomy tube one size smaller than one in place (if available) • Obturator • Tracheostomy ties • Water-based lubricant or saline drops • Scissors • Lint-free cloth • Split gauze/dressing • Suction supplies • Self-inflating rescue bag • Oxygen (optional based on individual child) <p>For cuffed tubes will also need:</p> <ul style="list-style-type: none"> • Empty syringe • Syringe with water to prescribed amount
<p>How do I do this?</p> 	<ol style="list-style-type: none"> 1. Wash your hands 2. Prepare suctioning equipment. You need to have this ready in case your child begins to cough up secretions. 3. Place new trach ties onto one side of flange of new tracheostomy tube. 4. Assure obturator is inside of new tracheostomy tube. 5. For cuffed tracheostomy, check balloon on new tracheostomy tube by placing correct amount of water in balloon. Remove water. 6. Place small amount of lubricant or saline drops on end of new tracheostomy tube. This is not always necessary

however may be done to allow for easier, less traumatic insertion of new trach tube.

7. NEVER use petroleum or Vaseline as lubricant
8. Assure lubricant is water soluble.
9. Place tracheotomy to be inserted on a clean surface with tip facing up. (Setting it on an unclean surface can increase chances of your child getting an infection.)
10. Place child on back with small roll underneath shoulders to allow for neck extension and full view of trach.
11. Check with your child's doctor to be sure it is safe for your child to lie in this position.
12. Suction child's trach, if necessary.
13. If child has cuffed trach, remember to deflate cuff.
14. Unfasten trach ties on current trach, making sure to hold both sides of flange to assure tube stays in place.
15. When ready, quickly remove old trach.
16. Immediately insert new trach with obturator in one smooth curving motion with tip of trach directed towards back of neck. The tube should slide easily into place. Using force may cause injury, bleeding, and other problems.



Do not force the trach tube.



17. While securely holding trach in place, remove obturator immediately.

Removing the obturator allows for air to pass freely through

	<p>trach tube. Leaving an obturator in place will block a child's ability to breathe through trach.</p> <p>18. Feel for air movement.</p> <p>19. For cuffed tracheostomy, place correct amount of water into new cuff.</p> <p>20. Secure trach ties around neck, allowing only one finger to fit between ties and neck. You may need to cut trach ties if they're too long.</p> <p>21. Suction child's trach.</p> <p>22. Make sure to check your child's skin color and oxygen levels. Check to see if your child's chest is rising and falling normally.</p>
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Changing trach tube will often cause the child to cough.

Be prepared to suction or wipe secretions away. Do not let go of the tube until ties are securely fastened. Inserting a new tube can irritate the trach. You may see pink tinged secretions following a trach tube change. If you see bright red blood, report this to your doctor or nurse.



Help! I'm having a problem with tube change.

What's happening?	What should I do?
<p>The new tube won't slide into place.</p>	<p>If the new tube does not pass easily, do not force it!</p> <ol style="list-style-type: none"> 1. Keep yourself and your child calm. 2. Reposition your child so the stoma is in full view and their head is extended back. 3. If there are secretions at the stoma, wipe them away with gauze or clean towel. 4. Double-check that you have the correct size trach tube. 5. Lubricate tube. 6. Try again to insert the tube. 7. If your child's condition allows, you can use a trach tube one size smaller than the one you removed. Stomas

	<p>sometimes get smaller. This can happen because of scarring, swelling, or other issues. If this is the case, a smaller trach tube may pass and fit better than previous sized trach.</p> <p>Do this only if your child's condition permits.</p> <p>8. If you still cannot place the tube, call 911.</p> <p>9. If you are unable to replace the trach tube, and the child is having trouble breathing, you may give rescue breaths with a mask over child's nose and mouth.</p> <p>Be sure with rescue breathing to cover the stoma (hole) with gauze and tape.</p> <p>Covering the stoma makes sure that air does not escape from the stoma during breaths.</p> <p>10. Continue assisted breathing for child with bag and mask until help arrives.</p>
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Be sure to ask your doctor if your child's airway allows you to bag your child with a mask over their nose and mouth.

Cleaning the Tracheostomy Tube

Check with the manufacturer to be sure the trach tube your child has can be cleaned and reused.

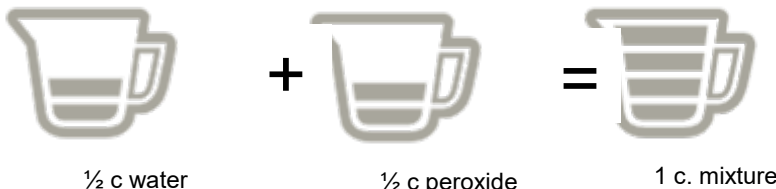
Some trach tubes are double cannulated. Some inner cannulas are disposable and should be discarded daily. If the inner cannula is reusable, they should be cleaned twice daily and as needed.

Shiley	
<p>What supplies do I need?</p> 	<p>Gather all your supplies in a clean work area.</p> <ul style="list-style-type: none"> • Peroxide • Normal saline or water • Measuring cup

How do I do this?

1. Wash your hands
2. Place cannula and obturator in a mixture of 1/2 peroxide and 1/2 water.

Example: To make 1 cup of this mixture, use 1/2 cup of peroxide and 1/2 cup of water.



3. Let tracheostomy tube soak in this solution for no longer than 30 minutes. (Longer than 30 minutes damages the tube.)

Note: Metal tubes should not be left to soak for long periods of time.

4. Clean the inside of the tracheostomy tube with a trach brush or pipe cleaner.
5. Rinse with normal saline or water.
6. Air dry on a clean surface.
7. After the trach tube and obturator are completely dry, store in a new zip lock bag. Using new, resealable plastic bag. This keeps everything clean and germ-free.




After each cleanse, inspect the tube for cracks, tears, or too much stiffness. Inflate the cuff (if present) to check for leaks. If the tube (or cuff) is damaged, don't re-use it.

Bivona

What supplies do I need?

Gather all your supplies in a clean work area.

- Soap
- Normal saline or water
- Measuring cup
- Pan with lid, for boiling water

<p>How do I do this?</p> 	<ol style="list-style-type: none"> 1. Wash your hands 2. Wash the trach tube and the obturator in warm soapy water. 3. Clean the inside of the trach tube with a pipe cleaner. 4. Rinse trach tube with normal saline or water 5. Place water in a pan and bring to a boil. 6. Place tracheostomy and obturator in boiling water and then turn water off. 7. Cover pan and let cool. 8. Once water is cool, remove the tube and obturator from the water. Hold the tube by the flanges and the obturator by its handle. <p style="padding-left: 40px;">Do not touch the tip of the tube or obturator, to keep it from getting dirty.</p> <ol style="list-style-type: none"> 9. Air dry on clean surface 10. After the trach tube and obturator are completely dry, store in a new zip lock bag. Using new, resealable plastic bag. This keeps everything clean and germ-free.
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After each cleanse, inspect the tube for cracks, tears, or too much stiffness. Inflate the cuff (if present) to check for leaks/ If the tube (or cuff) is damaged, don't re-use it.

My notes



Part 3: Suctioning

In this section I will learn:

1. How to tell when my child needs suctioning.
2. What my child's secretions normally look like.
3. What could cause changes in how my child's secretions look.
4. What are the different ways to suction my child and when to use each.
5. To show how I would suction my child with both a suction catheter and a bulb syringe.
6. To show how I would suction without electrical power.
7. What chest physiotherapy (CPT) is, and when my child may need it.
8. When I might need to do CPT more frequently than usual.
9. To show how I might do CPT on my child.

Making mucus is the body's way of keeping the airway clean. When mucus builds up, we suction. That makes breathing easier.

It's OK to do suctioning whenever it's needed. There's no fixed schedule. Some children require very little suctioning. Other children require more frequent suctioning.

During the first few weeks after a trach is placed, your child may have a large amount of mucus. This is due to the surgery itself and the body's normal response to the new tube. In many children the amount of mucus should decrease with time. We'll give you specific instructions before you go home about how often to suction your child.

Suction when:

- You notice changes in your child's breathing.
- Your child is gurgling or coughing more often.
- Your child's breathing is "noisy."
- You see bubbles or mucus coming from the trach opening.
- Your child has a lower oxygen saturation.
- If your child has a ventilator, your peak inspiratory pressure (PIP) is higher than usual.

Secretions

If your child is producing only a small amount of secretions, be sure to suction a minimum of one- two times per day in order to keep tracheostomy clear.

This is usually done first thing in the morning when your child awakens and again at nighttime. Try to avoid suctioning too frequently if not needed as this may in fact increase the amount of secretions produced.


Be sure to look at the secretions as you suction. Secretions can indicate potential irritants, infections, or complications.

What color are the secretions?	What does it mean?
White	This is the normal color.
Yellow or green	There may be an infection.
Traces of blood	There may be an irritation or swelling.
Bright red blood	There may be a serious problem.

What is the texture of the secretions?	What does it mean?
Thin	This is the normal consistency.
Thick	<p>You may want to:</p> <ul style="list-style-type: none"> • Increase the child's fluid intake (unless they have fluid restrictions or limits). • Increase humidification. • Give a nebulizer treatment (for example, normal saline nebulizers) as ordered to loosen or break up secretions. • Increase frequency of suctioning to prevent trach tube from clogging. <p>Call your child's doctor if you're worried about an infection.</p>

Chest Physiotherapy (CPT)

CPT is a way to loosen the secretions or mucus in the lungs. Some children may only need CPT now and then. Other children may need CPT every 2 to 4 hours to loosen secretions. We'll give you specific instructions before you go home about what supplies you will need for your child.

<p>How do I do this?</p> 	<ol style="list-style-type: none"> 1. Put a thin layer of clothing or blanket on your child's chest. 2. Use a cupped hand or percussor cup to percuss different areas of the chest wall. You can turn your child or sit them up to percuss areas on side and back. Do not percuss over the backbone, breastbone, or lower two ribs. 3. Perform CPT for 5 minutes on chest and 5 minutes on back, for a total of 10 minutes. 4. Make sure to always suction your child after completing CPT to remove any loosened secretions.
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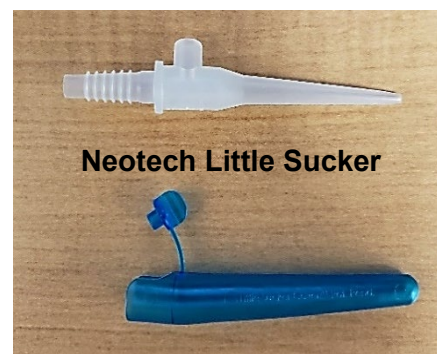
If your child has a respiratory illness or increased secretions, you may need to increase CPT time to a total of 20 minutes (10 minutes on chest and 10 minutes on back).

There are 2 main types of suctioning

1

Fine tip suctioning (shallow)

Secretions are suctioned at the opening of the trach after the child has coughed them up. This type of suctioning is only used to suction the outside of the trach tube. **These should never be placed inside the trach itself because it will block your child's airway.**



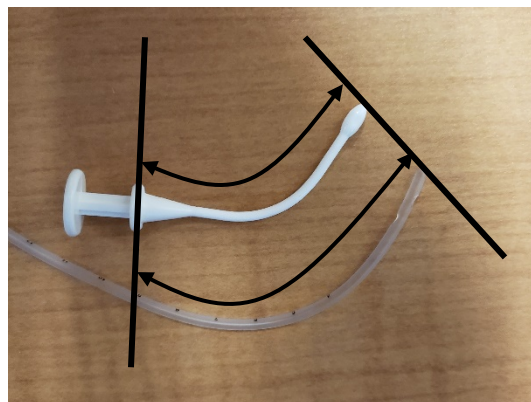
2 Pre-measured catheter suctioning (deep)

Suction that is measured according to the length of the trach tube. This allows for suctioning the complete length of trach tube. The suction depth will differ according to your child's trach size.



We can show you how to measure the correct suction depth using the obturator or the backup trach tube of the same size. You do not want the tip of the suction tube to extend past the end of the tracheostomy tube.

Never suction beyond the trach length or you'll hurt your child!



How to suction

While your child is in the hospital, we'll suction your child using a sterile (germ-free) method. We'll use a new catheter each time. And we'll wear sterile gloves each time, too.




When you go home, you'll want everything to be clean. You won't be using the same sterile method as we used in the hospital. You'll use a clean catheter. You'll have just-washed hands or non-sterile gloves. The suction catheter must not touch any unclean surface while suctioning.

Don't suction your child with too much pressure. This can hurt the child's airway.

- For children under 1 year old, safe suction pressure is usually 60 to 80 mm/Hg.
- For children over 1 year old, safe suction pressure is usually 80 to 100 mm/Hg.

Check with your healthcare team to determine safe suctioning pressure for your child.

Your home care vendor will teach you how to change the suction pressure on the home suction machine.

<p>What supplies do I need?</p> 	<p>Gather all your supplies in a clean work area.</p> <ul style="list-style-type: none"> • Suction catheter of correct size • Suction system • Water • Saline (optional) • Non-sterile gloves (optional)
<p>How do I do this?</p> 	<ol style="list-style-type: none"> 1. Wash your hands 2. Attach suction catheter to suction system. Make sure that suction is functioning properly. 3. Insert suction catheter into trach up to pre-determined length. 4. Cover suction port with thumb and twirl catheter as you remove it from trach.  <ul style="list-style-type: none"> • Insert catheter without thumb over port.



- Place your thumb over the port to suction.

5. Don't suction for more than 10 seconds.

Your child gets less air when you suction. The suction catheter also blocks the trach tube, making it difficult for the child to breathe.

6. Allow at least 30 seconds between each time you suction. This allows the child enough time to rest and breathe.

7. If secretions are thick, suction saline or water up into the catheter by placing tip of catheter into saline or water while applying suction. This will help clean and clear the catheter of secretions.

Keep your suction machine plugged in when you're not traveling.



If there's a power outage, you should have several hours of battery power for suctioning.

If you lose electricity for a long time or your suction machine isn't working, you can attach a syringe to a suction catheter to suction your child.





Help! I'm having a problem with suctioning.

What's happening?	What should I do?
The suction catheter won't go in.	<ul style="list-style-type: none"> • Tracheostomy is plugged. • The suction catheter might be too big. Be sure you have the right size suction catheter for child's tracheostomy. <p>If you have the correct size catheter, and it still doesn't go in, change the tracheostomy.</p>
Suction machine is not working or suctioning properly.	<ul style="list-style-type: none"> • Be sure that the suction machine is plugged in and turned on. • The suction pressure might not be set properly. Test suction pressure by turning machine on and blocking end of the suction tubing. With end blocked, you will be able to read the pressure on the pressure gauge. Use control knob to adjust to desired safe suction pressure • The suction canister might be too full. Be sure that the canister has been emptied, suction tubing has been changed, and filter has been changed. <p>Use bulb suction or suction catheter attached to 60 mL syringe, if needed.</p>

Using Saline Drops to Loosen Secretions

If your child has very thick secretions, you may need to place a small amount (a couple drops) of saline into the tracheostomy.

This small amount of saline loosens the secretions. This allows you to suction them out better. You do not want to place too much saline into the tracheostomy. It can cause harm.

You must immediately suction the child after placing saline in the trach. This removes both the saline and any secretions.



Do not put saline into a trach regularly. This can push bacteria (germs) further down into the lungs and increase chances of infection.



Cleaning and Reusing Suction Catheters

You can reuse suction catheters, if you need to. If a catheter has not come into contact with an unclean surface, you can clean it and reuse it. Store the catheter in a clean container, original package, or clean plastic bag after cleaning. Throw away suction catheters after using them for 24 hours.

Do not reuse suction catheters when your child has a cold or respiratory infection. You don't want to give germs back to your child.

Based on the frequency of suctioning your child needs and the number of catheters provided or approved by your insurance company, you may not need to reuse suction catheters.

Cleaning and Reusing Suction Catheters

<p>What supplies do I need?</p> 	<p>Gather all your supplies in a clean work area.</p> <ul style="list-style-type: none"> • Dish soap • Hot water • Clean, dry container
<p>How do I do this?</p> 	<ol style="list-style-type: none"> 1. Wash your hands 2. Wash catheter and suction canister inside and out with hot soapy water. Dish soap is ideal. Do not use soaps that contain lotions. 3. Rinse well with warm water. It is important that there is no soapy residue left on catheters. You can use the suction machine to suction warm water through the suction catheter to ensure it is well rinsed. 4. Air dry. Do not place any heat on catheter to dry as this can cause damage to the catheter. 5. Store in a clean, dry container

Part 4: Humidification

In this section I will learn:

1. Why my child needs humidification.
2. Different ways to humidify my child's trach, and when to use each.
3. Why I might need to increase humidification.
4. When my child might need a nebulizer.
5. How to give my child a nebulizer.

Why is humidification important?

The nose functions to warm, moisten, and filter the air we breathe. In a child with a tracheostomy, air goes directly into the lungs through the trach tube. Extra humidity may be needed to:

- Keep mucus loose
- Prevent the tracheostomy tube from getting plugged up with hard, dried mucus
- Prevent coughing from dry air

Ways to provide extra humidification

Mist collar (also referred to as trach collar)

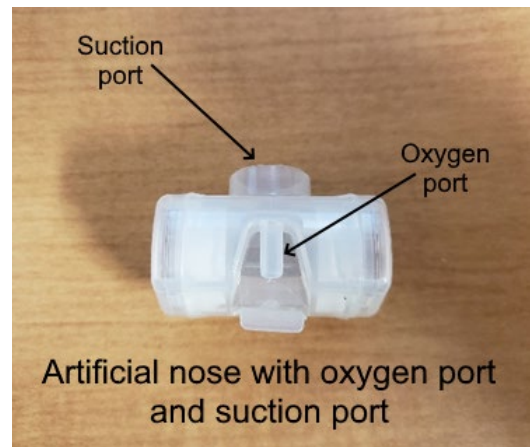
- Collar that is placed over tracheostomy tube.
- Can deliver oxygen if needed
- Recommended at nighttime and naptime for infants and smaller children
- Recommended for all children if secretions are thick and during times of respiratory illness

Note: An adequate amount of water is needed to supply a sufficient mist



Artificial nose (may also be called a humid-vent or HME)

- Acts to capture the child's own warmth and moisture in their airway
- Filters small particles from entering airway
- Used when off the mist collar when child is awake
- May help protect the airway on cold and windy days when outdoors
- Need to watch closely to make sure it does not become plugged with secretions.
 - Change at least daily and when full of secretions. If HME becomes wet with secretions or plugged, throw it away and replace it with a new one. You cannot clean the HME.
- Your child's HME can only be used for 24 hours and must be thrown out after this time.
- Remove HME if child becomes agitated (may be a sign it is plugged with secretions)
- Some HME's have additional ports on them as seen here. The oxygen port allows you to deliver oxygen if needed and the suction port opens and allows you to suction your child without removing the HME.



Room humidifier

- Machine which adds extra moisture to a room
- Sometimes used by older children who do not like mist collars
- Good to use when the air is very dry
- Need to make sure the humidifier is clean at all times. Filters may get moldy. Follow manufacturer's guidelines for cleaning.

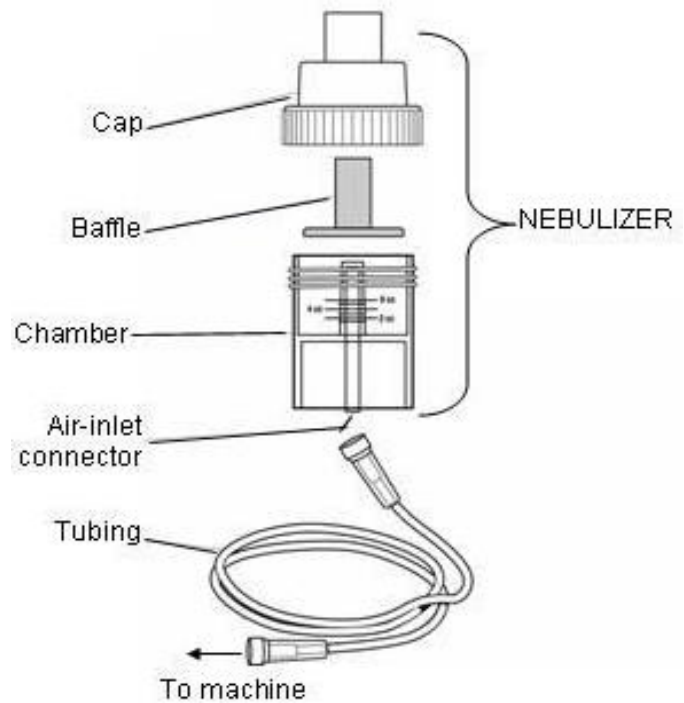
During winter home heating season, the air in your house may be dryer. Humidification needs may increase to prevent irritation and tracheal plugging.

Nebulizers

Your child may require nebulizer treatments at home. If so, you'll have a nebulizer machine at home.

The nebulizer machine delivers medicine as a mist. Your child breathes it into their airway. Then the lungs absorb it.

It's important to give nebulizers correctly.



CORRECT

Attach the nebulizer to the elbow of the trach collar.

Air moves freely in and out around the trach

Never attach the nebulizer directly to your child's tracheostomy.

When the nebulizer is attached directly to the tracheostomy, air is flowing into your child at a high rate.



This prevents your child from breathing out.

This can cause many problems.

INCORRECT



Giving a nebulizer

<p>What supplies do I need?</p> 	<p>Gather all your supplies in a clean work area.</p> <ul style="list-style-type: none"> • Nebulizer kit with medication cup • Medicine • Nebulizer (aerosol) machine <p>✓ Does your child wiggle around a lot? You may need a second adult to help keep your child in a safe position.</p> <p>✓ If your child wears an artificial nose, remove it before starting. Replace it afterward.</p>
<p>How do I do this?</p> 	<ol style="list-style-type: none"> 1. Wash your hands 2. Place baffle into nebulizer chamber. 3. Place medicine into the nebulizer chamber. Screw the cap onto the chamber. 4. Connect the trach mask or collar to the top of the nebulizer cap.

	<p>The nebulizer should always be given with a trach mask/collar to prevent problems.</p> <ol style="list-style-type: none"> 5. Connect one end of the tubing to the bottom of the nebulizer. Connect the other end to the aerosol/nebulizer machine. 6. Place trach mask or collar over trachestomy. 7. Plug in the aerosol machine. 8. Turn the machine on. 9. Once nebulizer is done, suction your child's trach to remove secretions.
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Cleaning the Humidification Equipment

What's the equipment?	How do I clean it?
Clean aerosol tubing 2-3 times a week.	<ol style="list-style-type: none"> 1. Clean with hot soapy water 2. Rinse completely 3. Allow to fully air dry
Clean nebulizer kits daily	<ol style="list-style-type: none"> 1. Clean with hot soapy water 2. Rinse completely 3. Allow to fully air dry
Assure room humidifiers are completely cleaned daily	<p>Rinse and refill daily to prevent bacterial growth.</p> <p>Be sure to check machine air filters regularly. Bacteria, mold, and dust can collect quickly. Follow manufacturer guidelines for cleaning.</p>

My notes



Part 5: Go-bag & emergency equipment

In this section I will learn:

1. What trach-related equipment to include in a Go-bag.
2. What are the differences in supplies I would take for a short trip (1-2 hours) and a longer trip (several days).
3. The things that I need to have with us whenever we go anywhere.
4. How to provide humidification to my child's trach while we're out.
5. How to monitor my child while we're out.

Problems may happen at any time. Whether planning for a short trip out of the house or a long vacation, it's important to be prepared. Your child should have emergency equipment and supplies with them at all times.

You will be taught how to pack your emergency bag before going home. Have this packed and ready to go at all times.

When you return home, immediately replace any items used.

What should I carry?	Why?
Extra trach tube with obturator, the same size and length of what is currently in place	In case the current tracheostomy tube gets clogged or falls out, you'll have a new, replacement trach tube ready.
Trach and obturator one size smaller than the current tube	In the case the stoma becomes narrowed or trach tube of current size cannot be replaced, you'll have a tube one size smaller ready to use.
Extra tracheostomy ties	In case current ties become loose, frayed or broken
Syringes for cuff inflation and deflation (if cuffed tube)	Will allow you to deflate cuff, if necessary (for trachs with a cuff)
Water-based lubricant or saline drops	To lubricate tube in case you need to reinsert tube
Split gauze	To keep secretions and moisture away from skin

Continued on next page...

What should I carry?	Why?
Suction catheters (fine tip, bulb syringe, deep suction catheters)	
60 mL syringe	Can be used for suctioning with a catheter if no power source.
Measuring tape	For measuring proper length for deep suctioning
Self-inflating bag with mask Tracheostomy adapter, if needed, for bag to fit over trach	Assure appropriate size is taken with child. To be used in case of emergency to assist with rescue breathing in the event the child is unable to breathe for themselves
Gauze	To be used to cover stoma site in the event rescue breathing is needed
Tape	To tape gauze over stoma site
Scissors if cloth ties used (not necessary if using Velcro ties)	
Water bottle	For cuff inflation/deflation, if you have a cuffed tube
Normal saline pink squirts	Could be used for nebulizers, instilling small amount into trach to loosen secretions, or to clean out suction catheters. This will depend on your child's needs.
Extra humid vents ("noses" if you're using them)	To warm and humidify air and prevent fine particles from entering trach
Suction machine (fully charged and with power cord)	Assure it is fully charged and operating correctly
Oximeter/Monitor (fully charged and with power cord)	Assure it is fully charged and operating correctly
Oxygen (if needed for your child) Be sure to include tubing, adaptors, and key if needed to turn the tank on.	Check to make sure there is enough oxygen to last for several hours.
Ventilator, if needed (fully charged and with power cord)	Assure it is fully charged and operating correctly
Charging cords for all equipment (suction machine, oximeter, ventilator, feeding pump)	In case you are out of the home for longer than expected and equipment needs to be charged
List of emergency phone numbers	

Go-bag & emergency equipment list



Go-bag contents

- | | |
|---|---|
| <input type="checkbox"/> Trach tube with obturator (same size) | <input type="checkbox"/> Suction catheters (for deep suctioning) |
| <input type="checkbox"/> Trach tube with obturator (1 size smaller) | <input type="checkbox"/> Little sucker suction |
| <input type="checkbox"/> Trach ties | <input type="checkbox"/> Syringe to use with catheter for suctioning if no power to suction machine |
| <input type="checkbox"/> Syringe for trach cuff inflation/deflation if indicated | <input type="checkbox"/> Measuring tape |
| <input type="checkbox"/> Water-based lubricant | <input type="checkbox"/> Normal saline pink squirts |
| <input type="checkbox"/> Split gauze | <input type="checkbox"/> Bulb syringe |
| <input type="checkbox"/> Gauze (to place over stoma site in event rescue breathing is needed) | <input type="checkbox"/> Scissors |
| <input type="checkbox"/> Tape (to tape gauze over stoma site) | <input type="checkbox"/> Humid-vents ("Noses" if applicable) |
| <input type="checkbox"/> Resuscitation bag and mask | <input type="checkbox"/> Water bottle |
| <input type="checkbox"/> Trach adapter if needed for resuscitation bag | <input type="checkbox"/> List of emergency phone numbers |
| | <input type="checkbox"/> |

Other equipment

- | | |
|--|---|
| <input type="checkbox"/> Suction machine with battery charged | <input type="checkbox"/> Ventilator with battery charged |
| <input type="checkbox"/> Oxygen, if indicated (tubing, adaptors and key) | <input type="checkbox"/> Feeding pump with battery charged |
| <input type="checkbox"/> Oxygen saturation monitor with battery charged | <input type="checkbox"/> Charging cords for all equipment (suction machine, oximeter, ventilator, feeding pump) |
| <input type="checkbox"/> | <input type="checkbox"/> |

Part 6: Changes in breathing and CPR

In this section I will learn:

1. To assess my child's breathing
 - a. Determine my child's usual sleeping and awake breathing rates.
 - b. Describe my child's usual breathing.
 - c. Notice when my child is having trouble breathing.
 - d. Know when my child may need oxygen or need more oxygen.
 - e. To set up and provide oxygen to my child.

2. CPR, home monitors, and hand ventilation
 - a. When to begin CPR.
 - b. Show you I can do CPR.
 - c. When to bag mask ventilate my child.
 - d. What to watch for while bag mask ventilating.
 - e. What to do if I'm having problems bagging.
 - f. Show you I can bag ventilate my child through tracheostomy.
 - g. Where to keep the resuscitation bag.
 - h. What to do if I can't find the resuscitation bag in an emergency.
 - i. Show you I know how to use a home monitoring device.

Respiratory distress is when your child is having trouble breathing or can't take in the amount of oxygen their body needs. It's important to know your child's signs of breathing trouble.

It's important for you to know your child's baseline breathing effort, oxygen levels, and breathing rate.

You will be monitoring your child's oxygen saturation at home using an oxygen saturation monitor (oximeter). We'll tell you what a normal oxygen saturation is for your child. When the oxygen level drops below your child's normal, that's called "desaturation."

Breathing rate is the number of breaths your child takes in one minute. In order to count the respiratory (breathing) rate, place your hand on your child's chest and count the number of times the chest rises in one minute.

How will I know if my child is having trouble breathing?

Movement

- Retractions (sharp pulling in of the chest below and between the ribs with each breath)
- Shallow breathing
- Increase in breathing rate or effort
- Nostril flaring
- Restlessness
- Increased sleepiness
- Use of abdominal (belly) muscles to breathe

Sounds

- Rattling mucus not cleared with cough
- Stridor (an abnormal, high-pitched, musical breathing sound caused by a blockage in the airway. It is usually heard when taking in a breath.)
- Bubbles of mucus at trach tube opening
- Fast, noisy, hard breathing
- Grunting noise
- Periods of time where breathing completely stops (apnea)
- Wheezing (breathing with a whistling or rattling sound in the chest)

Skin

- Pale, bluish color over skin, lips, and nails
- Damp and sweaty

Will my child need extra oxygen?

Some children with tracheostomies need extra oxygen. They may need it all the time or only when they are sleeping, sick, eating, or playing more actively. When your child is receiving oxygen, it's important to use humidity with the oxygen to decrease the drying out of your child's airway.

It's important to know how much oxygen your child usually needs. Depending on your child's need, they may receive oxygen in different ways. Types of oxygen support include:

- Trach Collar/Mask (see humidification section for more information)
- Artificial "nose" with oxygen port
- Ventilator
- Resuscitation/ambu bag (see Below)

Types of home oxygen therapy systems include:

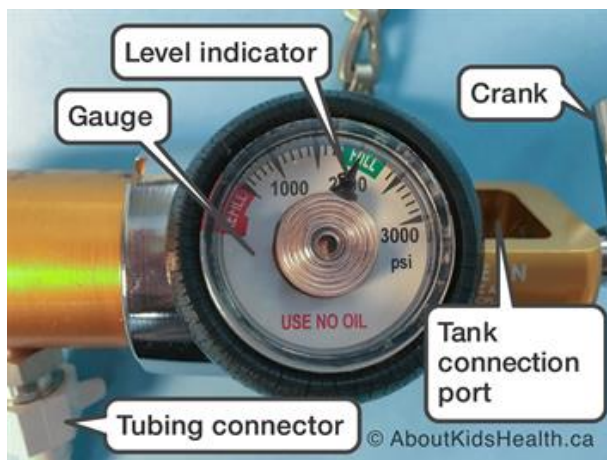
- **Oxygen concentrator:** A concentrator is a machine that makes oxygen by taking in air from the room and separating the oxygen. You will have a stationary (not movable) oxygen concentrator at home.
 - Your home oxygen concentrator may be louder than what you are used to hearing in the hospital.
 - Your child may be on different oxygen flow on your home equipment than they were in the hospital.
- **Oxygen cylinder or tank:** Your child will use portable oxygen tanks for travel outside of the home or as a backup during a power failure. Your oxygen tank will have a gauge that will tell you how much oxygen is left in the tank. How long the oxygen tank will last depends on your child's oxygen flow rate and the size of the oxygen tank.

Always check your portable tanks before leaving home to be sure that you will have enough oxygen while traveling. Plan to bring extra in case of unexpected delays.

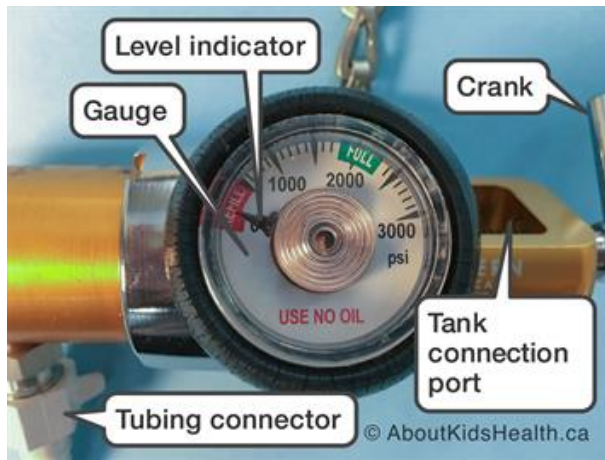
A portable oxygen tank with gauge attached to top



A portable oxygen tank gauge showing the tank is full



A portable oxygen tank gauge showing the tank is empty



When going to a doctor's appointment, tell the clinic staff that your child is on home oxygen therapy. You can use their supply of oxygen during the appointment so that your supply from home does not run out.



Smoking is a fire hazard with oxygen use. Do not smoke or allow anyone else to smoke in the area where your child is using oxygen.

What should I do if my child has trouble breathing?

1. Check that the trach tube is clear of secretions. Suction if needed
2. If you are not sure the tube is clear, remove the inner cannula, if present. If there is not an inner cannula, take out the trach tube and replace immediately with a new trach tube.
3. If your child is on oxygen, check that tubing is not kinked and the tank is not empty.
4. If applicable give your child prescribed nebulized saline, albuterol, or saline drops.
5. After nebulizer treatments, perform CPT. Then suction your child.
6. Contact 911 following guidelines provided in the AHA CPR course.
7. You, and anyone that will be caring for your child at home, should complete an American Heart Association (AHA) CPR course. You will receive basic information about CPR before going home, but this does not replace an AHA CPR course. Your Care Coordinator will discuss how to find a local AHA CPR course.

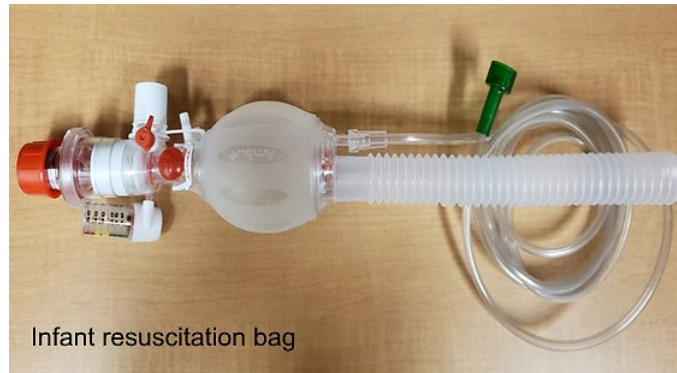
Please refer to separate CPR training sheets for more information.

Bag-Mask Ventilation

Bag-Mask ventilation is a way to deliver breaths and oxygen to your child when they are unable to adequately breathe on their own.

You will use a resuscitation bag/ambu bag in order to squeeze air into your child's lungs.

There are three different sizes of ambu bags. Your child will be sent home with the correct size. Be aware that as your child grows, they will need a bigger size ambu bag. Your vendor can supply you with this bigger size.




Infant resuscitation bag

Use the resuscitation bag when:

- Your child stops breathing.
- Your child has signs of breathing problems.
 - Poor or no chest rise
 - Poor skin color or a drop in oxygen levels (O₂ sats)
 - Inadequate breath sounds
 - Abnormally low breathing rate
- There is a problem with your child's ventilator.

Steps for Bag-Mask Ventilation

<p>How do I do this?</p> 	<ol style="list-style-type: none"> 1. Turn on oxygen to resuscitation bag. Flow should be 6-10 liters. 2. Attach the resuscitation bag to the tracheostomy. 3. Gently squeeze breaths into your child. Do not give too big a breath. This could hurt your child's lungs. 4. Release the bag so your child can breathe out and the bag can fill up with air. Bag at a rate of 1 breath every 3 seconds. Watch for good chest rise.
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	<ol style="list-style-type: none">5. If you are not getting good chest rise, your child is not getting enough air.6. If child does not respond or breathing does not get better, call 911.7. Continue bagging until your child begins to breathe on their own or the ambulance arrives.
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If your trach has a hub, the resuscitation bag fits directly onto the trach hub.

If your trach does not have a hub, you'll need an adapter that fits in the trach tube opening. You'll attach the resuscitation bag to the adapter. We'll let you know which one you have.

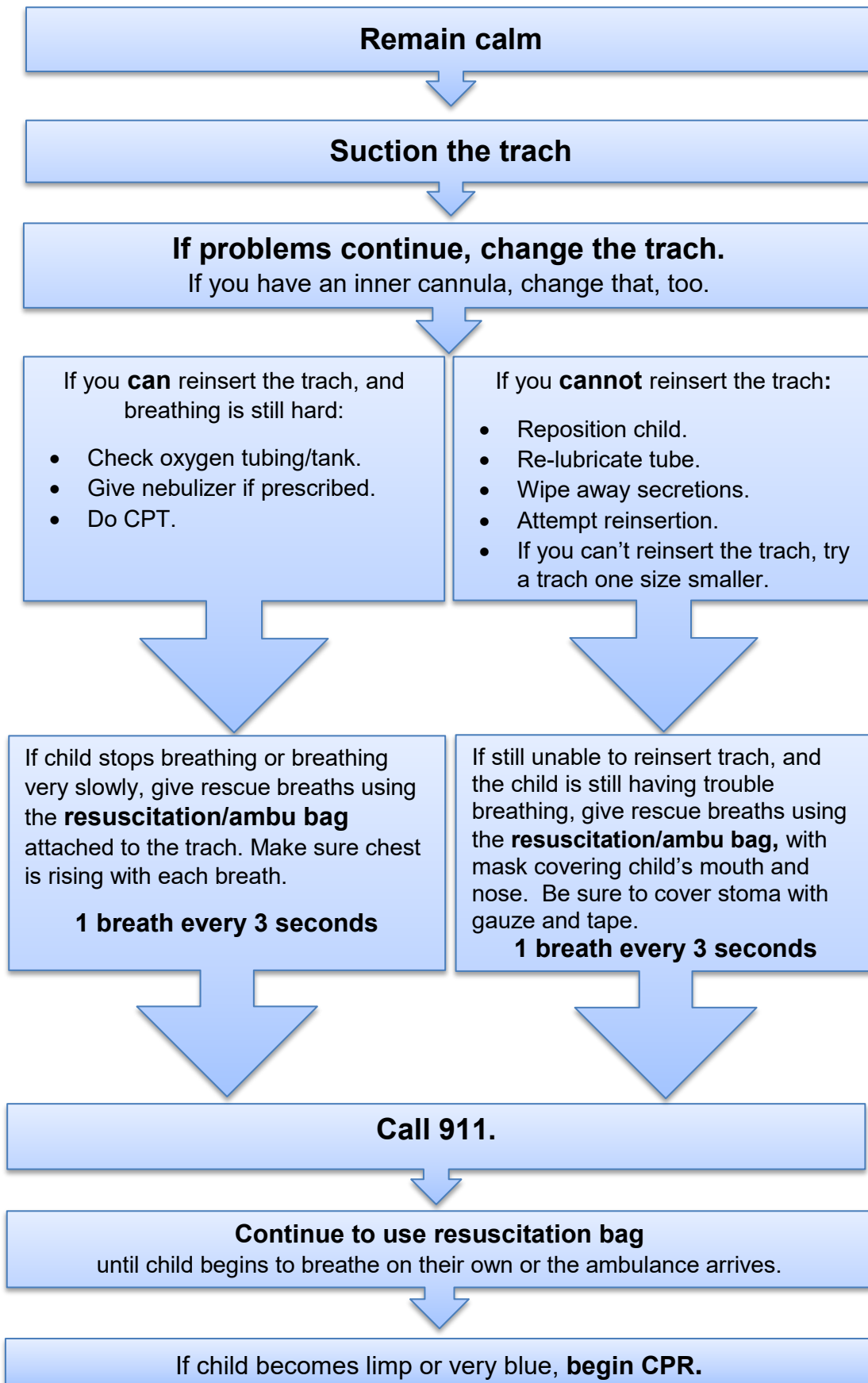


If your child has trouble breathing, desaturations, or any other breathing problems, follow the steps outlined in the “Respiratory Distress Pathway” (next page) before starting CPR.

My notes



Respiratory Distress Pathway



Part 7: Symptom Management & Problem Solving

In this section I will learn:

1. What to do if my child is having trouble breathing.
2. What to do if my child is breathing faster, color looks pale or blue, is struggling to breathe, is not breathing, or breathing very slowly.
3. What to do if the trach is plugged or partially plugged.
4. How to figure out if the trach is in the wrong place. And what to do about it.
5. What other things could be making my child agitated and seem not to be getting enough air and oxygen. And what signs to look for.
6. What to do depending on what was causing the irritation/agitation.
7. What could cause blood tinged secretions? What would you do about this?
8. What to do right away if I see food or formula in my child's trach. And what I should be concerned about if this happens.
9. What to be concerned about if my child vomits.
10. How to protect the trach. What to do if vomited food gets into the trach.
11. Signs of trach site (opening) infection. What to do if the trach site is infected.
12. To recognize my child's normal secretions. What to do if my child's secretions increase, decrease, become thick, change color, or start smelling bad.
13. How to tell if my child has a fever or a cold and what to do about it.
14. What to do if my child is sick and not drinking as much as normal. What will happen to secretions and what to do about it.
15. What happens if my child is sick and not drinking as much as usual. And what to do about it.
16. What might happen to the trach if weather is very cold, windy, wet, or dry. How to protect the trach from these weather changes.
17. About the danger of small objects in the trach. How to prevent small objects from getting into the trach. What to do if a small object got into the trach.
18. When to call the doctor. When to call 911.
19. Which hospital emergency department to use.

If your child is having trouble breathing, the trach tube falls out or becomes blocked, and you cannot immediately solve the problem, call 911.

What's the problem?	Why is this happening?	What should I do?
Yellow, green or colored secretions; OR bad odor to secretions	Infection	<ul style="list-style-type: none"> • Contact your doctor's office and report symptoms • If your child has a fever or an increase in difficulty breathing, contact your doctor immediately • If breathing becomes severe, call 911
Blood-tinged secretions	<p>Not enough humidification</p> <p>Irritation to respiratory tract from suctioning too vigorously</p>	<ul style="list-style-type: none"> • Increase humidification • Stay well hydrated • Assure you are gently suctioning to the appropriate depth • If it persists or becomes worse, contact your doctor's office
Frank bleeding/bright red blood	<p>Irritation and injury to airway</p> <p>Active bleeding from a blood vessel</p>	<ul style="list-style-type: none"> • At times, there may be some oozing around trach after a trach tube change. If oozing does not decrease, contact doctor's office • For unexplained bright red or frank bleeding, contact doctor or call 911
Thick secretions	<p>Dehydration</p> <p>Not enough humidification</p>	<ul style="list-style-type: none"> • If not fluid restricted, increase fluids • Increase humidification • If prescribed, give nebulizer to help loosen secretions • Suction trach

Blocked or plugged trach	Thickened or dried secretions Obstruction by foreign body	<ul style="list-style-type: none"> • Attempt to suction. • If little or no improvement, change trach or inner cannula. • If still little or no improvement, call 911. • May repeat suctioning. • If child stops breathing, begin CPR.
Trach tube falls out and another is available		<ul style="list-style-type: none"> • Replace trach tube. • If unable to replace, immediately call 911.
Trach tube falls out and another is NOT available		<ul style="list-style-type: none"> • Call 911. • If child is having trouble breathing, give rescue breaths with resuscitation bag with mask covering mouth and nose. (Cover stoma with gauze and tape.)
Food coming out of trach	Possible aspiration fistula	<ul style="list-style-type: none"> • Stop child from eating and drinking, or turn off tube feed immediately. • Suction trach. • Contact doctor immediately for instructions. • If child is having trouble breathing, call 911.
Trouble breathing or change in breathing	Many possible reasons	<ul style="list-style-type: none"> • If there is a change in breathing and it is not causing immediate distress to the child, call the doctor. • For severe trouble breathing, high-pitched wheezing, or shortness of breath with or without sweating, fever, agitation, anxiety and/or drowsiness, call 911.

		<ul style="list-style-type: none"> • Be prepared to give rescue breaths or start CPR if child's condition gets worse.
Skin around stoma is red	<p>Irritation</p> <p>Possible infection</p>	<ul style="list-style-type: none"> • Increase frequency of skin care, making sure to keep area clean and dry. • If stoma remains red and is associated with colored drainage or fever, contact the doctor.
Granulation tissue at stoma	Too much movement of the trach tube	<ul style="list-style-type: none"> • Alternate position of ventilator tubing. • Make sure trach ties are tight enough. • Call ENT to make them aware. Your child may need a cream for the site.
Ventilator (for ventilated children) is not maintaining pressure	<p>Leak within system</p> <p>Deflated cuff on trach</p>	<ul style="list-style-type: none"> • Check balloon on trach for inflation. • If leaking or cannot inflate, replace trach. • Check ventilator tubing. • If there's trouble breathing, call 911. • Be prepared to give rescue breaths or start CPR if child's condition gets worse.

My notes



Part 8: Ventilator dependent children

In this section I will learn:

1. How to suction my child with Ballard while on ventilator.
2. What a disconnect wedge is and when to use it.
3. My child's ventilator settings and what they mean.
4. How to give my child humidification while on the ventilator.
5. How to give humidification while traveling with the ventilator.
6. How to change my child's ventilator circuit.

Some children need to go home with mechanical ventilation. This means using a ventilator (breathing machine) that can move air in and out of your child's lungs. This is used when your child cannot breathe well enough on their own. Your child may need continuous ventilation (24 hours per day) or ventilation for only part of the day (for example, only at night).

You will need some extra training to learn how to manage the ventilator. You will get training on the ventilator from your home care vendor before you go home.



Here are some extra resources for those patients who have a ventilator.

Suctioning

When using a closed suctioning technique (**Ballard**), you do not need to disconnect your child from the ventilator to be suctioned.




This closed system allows the suction catheter to remain clean.



<p>What supplies do I need?</p> 	<p>Gather all your supplies in a clean work area.</p> <ul style="list-style-type: none"> • Closed Suction Catheter (Ballard) of correct size. This will be attached to child's trach/ventilator. • Suction machine • Pink "Saline Squirts." <p>At home you may use bottled water and syringe from your home care company.</p>
<p>How do I do this?</p> 	<ol style="list-style-type: none"> 1. Wash your hands. 2. Attach suction catheter to suction system. <ul style="list-style-type: none"> • Make sure that suction is on and functioning properly. • Make sure that thumb valve is "unlocked." 3. With one hand, hold the trach tube so it doesn't move. Use the other hand to insert the catheter to the premeasured depth. <ul style="list-style-type: none"> • This length will be different than the length with "open suctioning." 4. Do not apply suction while inserting the catheter into the trach tube. 5. Apply suction by pushing down thumb valve while you slowly remove the catheter. Be sure to hold on to the trach while removing the catheter. <ul style="list-style-type: none"> • It's important to hold on to the trach so it doesn't accidentally get pulled out of place. 6. Don't suction for more than 10 seconds. <ul style="list-style-type: none"> • Suctioning decreases the amount of oxygen (air) that your child is receiving. The suction catheter also blocks the trach tube, making it difficult for the child to take a breath. 7. Wait at least 30 seconds between each time you suction. This allows your child time to rest and breathe.

	<p>8. Be sure to clean out the Ballard to remove secretions. To do this, attach a saline pink squirt to the saline port. Then apply suction while squirting in the saline.</p> <ul style="list-style-type: none"> • Be sure to suction while instilling saline to prevent it from going down the trach. • Some vendors will only provide saline bottles and syringes to clean out Ballards. Ask your vendor how to clean the Ballard this way at home.
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Nebulizer treatments using a ventilator

<p>What supplies do I need?</p> 	<p>Gather all your supplies in a clean work area.</p> <ul style="list-style-type: none"> • Nebulizer kit with medication cup • Blue T-Piece connector • Medicine • Nebulizer (aerosol) machine
<p>How do I do this?</p> 	<ol style="list-style-type: none"> 1. Wash your hands. 2. Place baffle into the nebulizer chamber. 3. Place the medicine in the nebulizer chamber. 4. Screw the cap onto the chamber. 5. Unhook the ventilator tubing and insert the T-piece into the ventilator tubing on the inhalation side. 6. Insert the nebulizer cup into the T-piece that is now in line with the ventilator circuit. 7. Connect one end of the tubing to the bottom of the nebulizer and the other end to the aerosol/nebulizer machine. 8. Plug in the aerosol machine. 9. Turn the machine on.  <p>T-piece and nebulizer cup</p>

	10. Once nebulizer is done, suction your child's trach to remove secretions.
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Nebulizer attached to T-piece which is in line with the ventilator circuit

Disconnect Wedge

All Bivona® trach tubes come with a disconnect wedge. This wedge is designed to make it easier to disconnect attachments, such as the ventilator, without pulling on the trach tube itself. This disconnect wedge should be with your child at all times.



Ventilator Settings and Alarms

It's important to know your child's ventilator (vent) settings.

You'll go home with a paper telling you what the vent settings are for your child. Leave this sheet posted on your ventilator. Every day, check that the vent is set correctly.

Your child's doctor will decide when to change the ventilator settings. Do not ever change the ventilator settings by yourself!

What is the ventilator setting?	What does it mean?
Breath Rate (F)	The number of breaths delivered to your child in one minute
Inspiratory Pressure (IP)	The preset pressure to be delivered during your child's in breath
Positive End Expiratory Pressure (PEEP)	The amount of pressure that is left in the lungs at the end of the out breath. This allows the air sacs in the lungs to remain partially open.

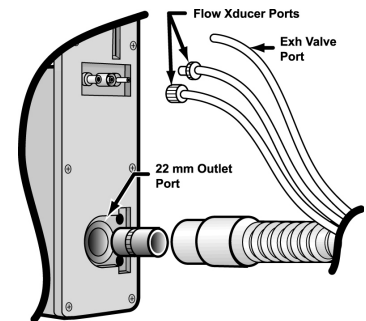
Peak Inspiratory Pressure (PIP)	The highest level of pressure that is in the lungs during the in breath
Pressure Support (PS)	The amount of pressure that is given to assist your child when they are taking their own breaths.
Tidal Volume (TV)	The amount of air that is delivered to your child's lungs during one breath
Inspiratory Time (IT)	The amount of time it takes for one breath to be delivered on the in breath

What is the alarm?	What should I do?
High Pressure	<p>Occurs when the Peak Inspiratory Pressure (PIP) is more than the High Pressure alarm that is set on the ventilator. This means there is increased pressure in the lungs.</p> <ul style="list-style-type: none"> • Is your child coughing or crying? • Does your child need to be suctioned? • Is your child's trach plugged? • Is there water in the tubing? • Is the tubing kinked or pinched? • Does your child need a nebulizer treatment?
Low Pressure	<p>Occurs when the Peak Inspiratory Pressure (PIP) is less than the low pressure alarm set on the ventilator.</p> <ul style="list-style-type: none"> • Did the trach come out? • Has your child become disconnected from the ventilator? (Follow the tubing from your child all the way back to the ventilator to make sure everything is connected and that tubing is tight.) • Is the trach cuff inflated and is there enough water in the cuff? • Is there water in the tubing?
Low Minute Ventilation	Occurs when the low minute volume alarm that is set on the ventilator is lower than what the child is doing.

	<p>Minute ventilation is your child's respiratory rate (how fast they are breathing) x the Tidal volume (how much air is going into the lung during each breath).</p> <ul style="list-style-type: none"> • Did the trach come out? • Has your child become disconnected from the ventilator? (Follow the tubing from your child all the way back to the ventilator to make sure everything is connected and that tubing is tight.) • Is the trach cuff inflated and is there enough water in the cuff? • Is there water in the tubing? • Is your child's respiratory rate or tidal volume low?
High PEEP	<ul style="list-style-type: none"> • Is your child coughing or crying? • Does your child need to be suctioned? • Is there water in the tubing?
Power Lost	<p>Occurs when your child's ventilator switches from external battery (plugged into the wall) to internal battery (the battery pack).</p> <ul style="list-style-type: none"> • Is there power in the home? • Did the ventilator become unplugged from the wall? <p>It's important that you start to think of a solution to get external power whether that is a generator or going to a family/friends home. It's important to always have your battery pack charged.</p>
Disc/Sense	<p>This occurs when the ventilator senses a circuit issue</p> <ul style="list-style-type: none"> • Has your child become disconnected from the ventilator? (Follow the tubing from your child all the way back to the ventilator to make sure everything is connected and that tubing is tight.) • Are the sensor lines attached to ventilator and not pinched or blocked? • Is there water that has accumulated in the sensor line?

Other Information

- It is important that you change the position of your child's ventilator tubing to prevent injury to the trach stoma. You can change which direction it is laying across the chest. The trach tubing is heavy so be sure it is not pulling on the trach. You can clip the tubing in place to prevent pulling.
- Your ventilator will have a **heated humidifier system** that is part of the ventilator circuit. This provides warmth and humidification to the airway. Be sure to check the level of sterile water in the humidifier chamber to be sure it does not run out of water. Lack of humidification can cause thick mucus and increase the chance of the trach plugging.
- When you travel with your ventilator you will use a "**dry circuit.**" This means you use a humid vent placed into the circuit rather than using the inline humidification with water. This ensures that your child still gets humidification while traveling.
- You will change your ventilator circuit and Ballard suction catheter once weekly. When **changing ventilator circuit**, you should have another trained person bag ventilate your child while you change the circuit. This ensures that your child does not have too long of a pause in their breathing. The picture shows how to attach the ventilator circuit. Your child's vendor will teach you more on this.



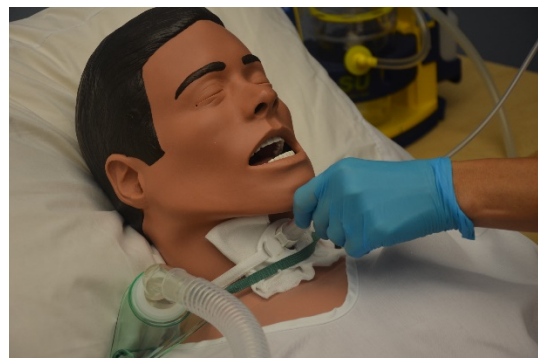
My notes




Part 9: Emergency scenarios

We want you to be as comfortable as possible when going home with your child. There may be times at home when you need to act quickly to help your child. Below are different scenarios that could happen at home or while you are out with your child.

You will practice these scenarios with the Care Coordinator so you can feel more comfortable. You will be using your emergency Go-bag to obtain all necessary supplies/equipment that you need. You will then perform all care on the trach doll.



<p>What supplies do I need?</p> 	<p>Gather all your supplies</p> <ul style="list-style-type: none"> • Emergency bag fully packed • Oxygen • Suction • Oximeter
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Scenario 1: Your Child's monitor is alarming.

Caregiver assessments and interventions	Response
<p>Assess Equipment:</p> <ul style="list-style-type: none"> • Is the oximeter probe correctly on child and is it reading correctly? • Is the oxygen attached if applicable? Is the oxygen tubing kinked? • If applicable, is the ventilator still attached and not kinked? 	<ul style="list-style-type: none"> • Oxygen probe is attached and working correctly • Oxygen is attached, turned on, and the tubing is not kinked • The ventilator is still attached and not kinked

<p>Assess Child:</p> <ul style="list-style-type: none"> • What is child's oxygen saturation level? • What is the child's color? • Is child having any increased work of breathing (retractions, nasal flaring, increased breathing rate, restlessness, etc.)? <p>Interventions:</p> <ul style="list-style-type: none"> • Suction trach • Increase oxygen (Or place on oxygen if not normally on it) 	<ul style="list-style-type: none"> • Oxygen saturation is currently 87% • Lips have a bluish tinge • Your child is having retractions and nasal flaring. They are also breathing faster than normal and appear very restless
<p>Reassess Child:</p> <ul style="list-style-type: none"> • What is child's oxygen saturation level? • What is the child's color? • Is child having any increased work of breathing (retractions, nasal flaring, increased breathing rate, restlessness, etc.)? <p>Interventions:</p> <ul style="list-style-type: none"> • If ordered give nebulizer such as Normal saline or Albuterol • Perform CPT after nebulizer • Suction child after CPT 	<ul style="list-style-type: none"> • Oxygen saturation is 90% • Lips look slightly more pink • Child is still having mild retractions and nasal flaring
<p>Reassess child:</p> <ul style="list-style-type: none"> • What is child's oxygen saturation level? 	<ul style="list-style-type: none"> • Oxygen saturation is 98%

<ul style="list-style-type: none"> • What is the child's color? • Is child having any increased work of breathing (retractions, nasal flaring, increased breathing rate, restlessness, etc.)? 	<ul style="list-style-type: none"> • Pink • Child is breathing comfortably and is smiling at you <p>What other steps would you take if oxygen saturation level remains low?</p>
<p>Interventions:</p> <ul style="list-style-type: none"> • Increase oxygen flow • Call your child's doctor • If oxygen saturation continues to drop and breathing gets worse, Call 911 • If child becomes limp or very blue start CPR 	

Scenario 2: Your child's monitor is alarming and oxygen saturations are decreasing from their normal baseline.

Caregiver assessments and interventions	Response
<p>Assess Equipment:</p> <ul style="list-style-type: none"> • Is the oximeter probe on child correctly? Is the oximeter reading correctly? • Is the oxygen attached if applicable? Is the oxygen tubing kinked? • If applicable, is the ventilator still attached and not kinked? 	<ul style="list-style-type: none"> • Oxygen probe is attached and working correctly • Oxygen is attached, turned on, and the tubing is not kinked • The ventilator is still attached and not kinked

<p>Assess Child:</p> <ul style="list-style-type: none"> • What is child's oxygen saturation level? • What is the child's color? • Is child having any increased work of breathing (retractions, nasal flaring, increased breathing rate, restlessness, etc.)? <p>Interventions:</p> <ul style="list-style-type: none"> • Suction trach • Increase oxygen (Or place on oxygen if not normally on it) 	<ul style="list-style-type: none"> • Oxygen saturation is currently 79 % • Lips have a bluish tinge • Your child is looking panicked and appears as if they are unable to get any air in. They do not have chest rise. • You are unable to suction your child or don't get many secretions, what will you do now?
<p>Interventions:</p> <ul style="list-style-type: none"> • Get your emergency equipment and prepare for trach change. • Remove the old tracheostomy and place the new tracheostomy of same size into stoma on neck <p>(Follow instructions for tracheostomy replacement as given previously in training).</p>	<ul style="list-style-type: none"> • Your child's tracheostomy goes in easily, now what should you do?
<p>Interventions:</p> <ul style="list-style-type: none"> • Secure tracheostomy tube in place • Suction your child's tracheostomy <p>Assess Child</p> <ul style="list-style-type: none"> • What are your child's current oxygen saturations? 	<ul style="list-style-type: none"> • You are now able to suction your child and get clear/white secretions from tracheostomy • Oxygen saturations are 98%

<ul style="list-style-type: none"> Assess your child. Are they having increased work of breathing (retractions, nasal flaring, increased breathing rate, restlessness, etc?) 	<ul style="list-style-type: none"> Your child is looking at you smiling and they do not appear to have any increased work of breathing <p>What other steps would you take if oxygen level remains low?</p>
<p>Interventions:</p> <ul style="list-style-type: none"> Increase oxygen flow Call 911 If child becomes limp or very blue start CPR 	

Scenario 3: Your child's monitor is alarming. You walk into your child's room and the trach is lying next to them in the bed.

Caregiver assessments and interventions	Response
<p>Interventions:</p> <ul style="list-style-type: none"> Get your emergency equipment and prepare for trach change. Place the new tracheostomy of same size into stoma <p>(Follow instructions for tracheostomy replacement as given previously in training).</p>	<ul style="list-style-type: none"> The tracheostomy will not go in. What are you going to do?
<p>Interventions:</p> <ul style="list-style-type: none"> Reposition head to make neck more visible Place more lubricant on trach tube of same size 	

<ul style="list-style-type: none"> Place the new tracheostomy of same size into stoma on neck 	<ul style="list-style-type: none"> The tracheostomy will still not go in. What are you going to do?
<p>Interventions:</p> <ul style="list-style-type: none"> Attempt to place tracheostomy one size smaller into stoma on neck. 	<ul style="list-style-type: none"> The trach tube one size smaller goes in easily. What are you going to do now?
<p>Interventions:</p> <ul style="list-style-type: none"> Secure tracheostomy tube in place Suction your child's tracheostomy <p>Assess Child</p> <ul style="list-style-type: none"> What are your child's current oxygen saturations? Assess your child. Are they having increased work of breathing (retractions, nasal flaring, increased breathing rate, restlessness, etc?) 	<ul style="list-style-type: none"> You are now able to suction your child and get clear/white secretions from tracheostomy Oxygen saturations are 98% Your child is looking at you smiling and they do not appear to have any increased work of breathing <p>What will you do next?</p>
<p>Interventions:</p> <ul style="list-style-type: none"> Call your child's provider to make them aware you had to place the one size smaller tracheostomy. The doctor will instruct you on what to do next. 	

Part 10: Adapting to a tracheostomy

In this section I will learn:

1. What's different about feeding a child with a tracheostomy?
2. What to be concerned about when bathing my child so the trach is protected.
3. What's the danger of using powders or aerosols around my child?
4. Some things I need to be especially careful about to protect the trach during play time.
5. How my child's trach will change:
 - Feeding and swallowing
 - Positioning
 - Speech and ability to make noise
 - Play
 - Mind and body development

Positioning (infants less than 1 year old)

Place infants less than 1 year old on their backs for naps and night time sleeping. Positioning tips below are important for an infant's development and should be supervised by an adult caregiver.



Lying on back

- Allows child to work on reaching for hands and feet. Use crib gyms or dangle toys to strengthen muscles.
- Your child may require a slight incline with the mattress while sleeping. You can do this in several ways:
 - Raise the head of a hospital bed.
 - Place books, blocks or bed risers under the feet of the crib on one side. You will need to make the one side of crib 3-5 inches taller.
 - Place a wedge under the mattress

Tummy Time

- This is an important position in a child's development that helps neck and mid-section strength.
- Use a rolled blanket, towel, or Boppy® under your child's upper chest as they lie with belly to the ground.
- Place toys or a person in their view to encourage interest.
- Only do tummy time when your child is awake and being watched. If your child falls asleep during tummy time, move them to their back.

Side lying

- This is a great position to work on reaching for toys with both hands and gaining coordination of mid-section muscles

Sitting





- May need to support trach tube while sitting.
- Can use Boppy for positioning.
- For child whose head may fall forward when placed in an upright position, a semi-reclined back may be helpful.
- For transportation, you can place a child with a trach in a regular car seat. For larger children, adaptive car seats are available, if needed

Activities of Daily Living



Shirts with buttons down the front or with larger openings for the head are easier to put on.

Be sure the shirt neckline is not too close to trach. Be careful that it doesn't cover the trach and block your child's airway.

	<p>No swimming.</p> <p>Children with a trach cannot submerge in water. Water will get into their airway and they will drown.</p>
	<p>A child with a trach is still able to bathe while sitting in a tub.</p> <p>You must avoid getting water into the trach.</p> <p>Your child must never go under water.</p> <p>Never leave a child alone in the tub.</p> <p>Older children may shower using a shower guard.</p>
	<p>It is important to clean your child's mouth twice a day.</p> <p>If your child is older they can brush their teeth like normal. For a younger child you can swab your child's mouth with gauze or use a finger tooth brush. You may need to suction out the mouth after brushing and rinsing teeth.</p> <p>Cleaning mouth/teeth helps to prevent your child from getting sick.</p>
	<p>For children who are allowed to eat, softer foods are easier to swallow than crunchy, hard foods.</p> <p>Follow the direction of your doctor and speech and swallow therapist.</p>

Aspiration

Aspiration is when solids, liquids, or saliva get into the airway. Normally, all food goes into the esophagus, not into the airway.

Some children with a trachs are able to eat normally. Others have medical issues that may make it hard to chew and swallow. Trouble chewing and swallowing is called dysphagia.

What are the signs that my child may be aspirating?

- Choking or coughing with swallowing. (Not all people cough when they aspirate.)
- Watery trach secretions, especially after swallowing.
- Drooling or holding saliva and fluids in the mouth.
- Coughing up or suctioning food, liquid, or colored secretions from the trach.
- Frequent lung infections.
- Poor chewing ability, trouble moving food around in the mouth.

How do I manage aspiration?

- Stop feeding the child by mouth.
- Suction the trach tube until the tube is clear of the fluid or food your child was eating.
- Change the trach tube if it's plugged with fluid or food.
- Call your doctor if your child is showing signs of aspiration.



Your child can aspirate when vomiting, too. If your child does vomit, try to keep it out of the tracheostomy tube by turning the child's head to the side and suctioning the trach.

How do I prevent aspiration?

- With your doctor's permission, consult a Speech Language Pathologist (SLP) for a swallowing evaluation. Your SLP can help to determine what foods and liquids are least likely to be aspirated.
- If your SLP recommends, thicken liquids to the recommended consistency using an approved thickening agent.
- Chew and swallow slowly.
- Sit upright while eating and drinking.
- Follow doctors' orders on eating and feeding.

- Give medicines as ordered, since many medications help with secretions and improve stomach emptying.
- Always supervise your child when they're eating and drinking.

Communication

Having a trach may have an impact on your child's ability to talk. Some possible reasons for this include:

- Your child may not be able to pass enough air up through the vocal cords to make sounds due to scarring, swelling, or a large-sized tracheotomy tube.
- A hoarse or raspy vocal quality may occur due to reduced movement of one or both vocal cords.
- Your child may have a delay in their language development.

Having trouble talking does not mean being unable to communicate. We communicate in many different ways throughout the day.

A speech-language pathologist (SLP) can assess your child and make recommendations. This may include speech therapy and referrals to special early childhood programs. There are many options that can help your child communicate.

- Sometimes a **speaking valve** is placed on the end of the trach tube. The valve allows the child to inhale (breathe in) through the valve. When they exhale (breathe out) the valve closes. This allows air to pass through the vocal cords. The speaking valve doesn't work for everyone. It's only used with your doctor's permission. You must remove the speaking valve when your child is napping or sleeping.
- You can make your own **picture communication tool**. Make this using different pictures of things, including your child's personal objects. By pointing to the picture, the child communicates their needs or thoughts.
- **Sign language** is not just for children who cannot hear. If your child does not have the voice to communicate their needs well, they may be able to sign their needs and thoughts.
- An **Augmentative and Alternative Communication (AAC) Device** is similar to a computer. The child selects the word or phrase on the board. Then a computerized voice says the word or phrase out loud. A speech-language pathologist (SLP) can help.

Child Development






How your child learns and grows continues to be an important part of their life. Keeping things as normal as possible will help your child to learn and grow. Focus on the things that your child can do to learn. This focus will give your child a healthy normal development.

You may need to make special arrangements for your child's formal education. Your child's school district will need to assess your child for educational and therapy needs. Attending school is possible with a supportive plan in place. The school district will work with you to determine how to meet your child's safety needs. They'll work with you to determine what support your child will need to attend school.

Special programs (called, "early intervention") are available for some infants and preschoolers based on their individual needs. You can discuss this with your doctor.

Environment

Here are some things to remember about providing a safe environment for your child.

	<p>While playing outside, sand or dirt should not be allowed anywhere near the trach.</p>
	<p>Warm weather humidity may make breathing difficult or change the consistency of their secretions.</p>
	<p>Breathing cold air may cause the airway to spasm or tighten.</p>
	<p>Even though your child is not breathing through their nose, they still can be affected by allergens, such as pollens or perfumes.</p>
	<p>Smoking should never be allowed near a child with a tracheostomy. It's best to reduce or eliminate environmental irritants such as smoke from a woodstove or fireplace, pet dander, and household dust.</p>

Part 11: Going home (discharge planning)

In this section I will learn:

1. What community agencies will be involved with my child?
2. Is the "Important Phone Numbers List" completed?
3. Are all follow-up appointments made?
4. When is our comprehensive care demonstration scheduled?
5. When is our outing scheduled?

Before your child goes home, there are many services we need to set up.

Your child will have a home nursing agency that will come out to the house once or twice a week. They will also have a vendor who will supply all the equipment and supplies you need for home.

Comprehensive Care Demonstration

After you have successfully completed all training, you're ready to do your comprehensive care demonstration,

This gives you the chance to practice everything you've learned. By doing this in the hospital, you're able to ask questions which may not have come up in previous training sessions.

A care demonstration provides your child's care team with the information they need to be sure you and your child are safe to go home. It can also provide information to assist us in providing additional education or resources before you leave.

We must document completion of all training before starting a care demonstration.

Two trained caregivers must perform the comprehensive care demonstration for the designated amount of time, usually 24 hours, with the child before going home. We'll review requirements for the demonstration with you ahead of time.

Outing

Once two trained caregivers have completed the comprehensive care demonstration, you'll be required to go on an "outing" out of the hospital with the child. This allows you

to show that you're comfortable packing up all the necessary supplies and equipment and traveling in a car with your child.

Steps for the outing include:

- Get your child packed up into stroller/wheelchair with all necessary supplies and equipment. This equipment will include suction machine, oximeter, feeding pump, oxygen, emergency bag, and ventilator if needed. You will use your Go-bag/emergency equipment checklist to ensure that you have everything.
- Transfer your child and all their supplies and equipment into the car.
- Go to desired location previously agreed upon with Care Coordinator.
- Transfer child back into car with all their supplies and equipment.
- Bring child back to child's room at the hospital.

Other important information

You will need a home inspection prior to discharge. This is done by your supply vendor to ensure that the house can accommodate a child with a trach. Your Care Coordinator will discuss this further with you.





Contact your local ambulance and fire services to make them aware that your child will be home with a tracheostomy.

It is a good idea to bring your child to the ambulance and fire services in person so that they can meet your child. If your child has any special needs, please make them aware.



Contact your local power company to make them aware that they need to place your child on a high priority list.

Being on this list makes your child a high priority if there were to be a power outage. There are sample letters below to be given to the fire department, ambulance service, and the power company.

	<p>It is important that you have a phone at home in case of an emergency.</p> <p>Be sure that this phone is near you and your child at all times. It is OK to only have a cell phone as long as you have good cell service in the home and your cell phone is charged.</p>
	<p>You will need a stroller or wheelchair that fits your child as well as all of their equipment.</p> <p>We recommend a double stroller or a large single stroller with a large storage space underneath. Equipment that will be required to fit on the stroller includes suction machine, oximeter, feeding pump, oxygen, emergency bag, and ventilator (if needed).</p> <p>Please speak to your Care Coordinator about the best stroller or wheelchair options. They will work with you to make sure all necessary supplies and equipment will fit.</p>

Tips for Going Home with a Medically Fragile Child

Going home is a milestone to celebrate. But it can be overwhelming for most parents.

Even though your child may have significant needs, they can now be a part of your daily family life. The home environment will support their learning, growth, and health. All of the things you want most for your child will be at your fingertips without the need to travel to and from the hospital.

Here are some suggestions shared from other parents to give you a greater sense of confidence. And hopefully, prevent you from feeling alone as you ease back into life at home.

Medical Information

The Care Coordinator will start a 3-ring notebook called a “Care Binder” with all of your child’s important medical information, emergency numbers, and instructions organized in one location.

Some parents have found it helpful to maintain this binder. It can be used by other trained caregivers to

**“Organization
is key in
helping to
reduce stress.”**

answer questions regarding your child's care while you rest. It can also help communicate changes in care so that everyone is on the same page.

Items you may want to include in your binder:

- Your child's Daily Care Schedule (for example, feeding routine, treatments, and a current medicine list including their purpose and how to give them)
- Important phone numbers including doctors, visiting nursing agencies, vendors, etc.
- Supportive services information (such as Early Intervention)
- Specialized education resources such as gastrostomy tube care, tracheostomy care, colostomy care, etc., including a list of all supplies needed
- Troubleshooting guides for various potential issues (such as respiratory plan, inability to flush a PICC line, G-tube dislodgement, etc.)
- All discharge papers and follow-up appointment papers
- Nursing sign-in sheet for at home nursing staff
- Communication notes for caregivers (including parents) to write notes about your child's behaviors, medical needs, etc. during their scheduled shift with your child

MyChart (<https://mychart.urmc.rochester.edu>) is an online way to securely access your child's medical information including upcoming appointments and current medicines. You can use MyChart to communicate with your child's healthcare providers. Your Care Coordinator can help you get this set up before you go home.

Daily Care Schedule

Having a schedule of medicines, feedings, treatments (such as pulmonary interventions), dressing changes, etc. as well as nap and play times will help you stay on schedule. It will also help you see what time of the day you might need extra help.

Equipment and Supplies

Storage

Purchase a plastic chest of drawers and stock it with all the supplies delivered to your home.

Label the drawers. Place a note on the outside of the drawer with the product name, reference number, number needed each month, and the vendor who supplies the

product with their contact information. This will help in reordering supplies from the correct supply company. It will be easier for you and your caregivers to tell the supply/vendor companies what exactly you need. (See below.)

It can also be helpful to have a smaller set of your child's supplies in the bedroom. Most often the nurses will do the dressing changes, blood draws, wound assessments on the first floor, which means that is the main location for supplies. It can be helpful, however, to have some additional supplies upstairs (or in other highly visited areas of your home). So, if you need to address an issue, you do not have to carry your child and all their gear back downstairs to take care of it.

Ordering

Keep a clearly printed list with the names of supplies and ID number, manufacturers, vendors with their phone numbers, amounts that come in a package, and how many are needed each month. This helps with ordering supplies, troubleshooting, and organizing any changes in your child's care.

Sometimes providers, supply vendors, and manufacturers will make mistakes, provide the wrong order, or stop making a product. Many parents have found it helpful to keep copies of delivery and order forms handy.

Home Life

Find time when you can be alone as a family without medical interventions and other caregivers such as nurses.

Try to schedule time for yourself, especially if you are the primary caregiver. Caring for a special-needs child is tiring. You may feel overwhelmed. This is normal.

Caring for your own mind and body is important to prevent burnout. Even 10-15 minutes in the shower, or with a book, or going for a walk outside the house can help you feel better.

Your child needs you at your best. Giving yourself time and caring for yourself gives them a happier and healthier parent.

Going Out

Keep a supply bag fully stocked with appropriate medical supplies. You will need and want to get out of your house. This stocked bag (enough for a 4-hour trip or more as you travel longer distances) will help you go when you are ready.

Remember to check and resupply the Go-bag immediately upon returning home so it will not delay or prevent your next outing.

Keep a small tote with non-perishable supplies in the trunk of your car including a change of clothes (appropriate for child's growing size and change of seasons), diapers, wipes, blankets, gloves, syringes, etc.

Other Helpful Tips

Use a dry erase board for quick notes and reminders. As parents, you will have ideas and thoughts you want to remember. With a medically fragile child, these thoughts may occur when the child's other parent is not around. A dry erase board can be a great tool for remembering an idea, phone calls, supplies that are needed right away, or even to leave a note for one another.

Have a large calendar highly visible so that you can keep track of all appointments. It can also be useful to put reminders in your phone and set an alarm.

Keep a document that includes your child's name, date of birth, medical conditions, medicines, and doctors' names and phone numbers in your child's diaper bag or pump bag when you travel. As a precaution for roadside emergencies, fold and place a second copy in a zip lock bag and tape it to the back of the car seat.

My notes



Equipment & supply list for home

Your vendor will provide you with the supplies you'll need at home. Below is a list of possible supplies that you will get at home. Your child's insurance will determine the quantity and types of supplies you get.

A few items that are no longer covered by insurance but you will need at home include:

- Hydrogen peroxide
- Cotton-tip swabs (non-sterile) like Q-tips®
- Water-based lubricant
- Unsterile procedure gloves.

You can buy these supplies from medical supply companies, drug stores, or most large grocery stores.

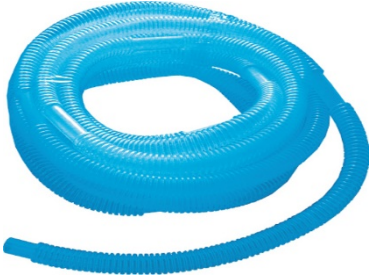

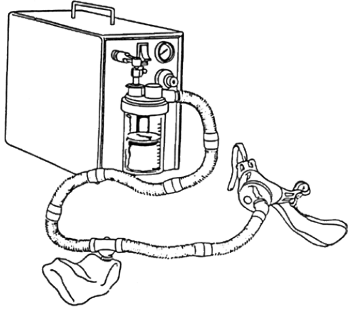
The Care Coordinator can help you fill out the number of items you will get each month at home. This will be done with the help of your child's equipment vendor.

Item and size	How many?
Trach tube supplies	
Trach Tube size _____	
Back up trach tube size _____ (one size smaller)	
Disposable inner cannula (if applicable)	
Scissors (if using twill tape ties)	
Velcro trach ties	
Twill tape	
Trach split gauze	
Trach care kits	
Water-based lubricant (This may not be covered by insurance.)	
Hydrogen peroxide (This may not be covered by insurance.)	
Plain or distilled water	
Cotton-tipped swabs (This may not be covered by insurance.)	
Pipe cleaners (take all and store from trach cleaning kits)	
Speaking valve (if applicable)	

60 cc Luer lock syringe	
Manual resuscitation bag: size _____	
Mask for resuscitation bag: size _____	
Humidification supplies	
Corrugated tubing	
Trach collar	
Artificial noses (humid vents)	
Large volume air compressor aerosol bottles	
Suctioning supplies	
Suction machine (portable)	
Long/short suction machine tubing	
Suction canisters with lids	
Suction catheters (for deep suctioning) size _____	
Respiratory saline: 3 cc and 10 cc	
Yankauer	
Little sucker suction catheter	
Unsterile procedure gloves: size _____ (This may not be covered by insurance.)	
Medicine supplies	
Nebulizer machine	
Nebulizer kit with trach collar	
Medicine syringe	
Trach adapters for MDIs (if needed)	
Monitoring equipment	
Pulse oximeter and monitoring supplies	
Cardiorespiratory monitor and monitoring supplies	
Oxygen equipment	
Oxygen source	
Oxygen tubing	
Aerosol machine	
Feeding supplies	
Gastrostomy tube: size _____ Type _____	
Feeding pump	
Feeding pump bags	

Formula Type: _____	
Catheter tipped syringes Size: _____ cc	
Clamp or plug for end of tubing	
Tubing adaptor for mickey button	
Other items	

What might my child's supplies look like at home?

Aerosol supplies		
 <p>Aerosol jar/Nebulizer</p>	 <p>100 Feet corrugated tubing</p>	 <p>1000 mL Sterile Water</p>
 <p>50 PSI Humidifier</p>	 <p>Trach Collar Set-up</p>	 <p>Trach collar Set-up example</p>

Suction supplies



Suction canisters



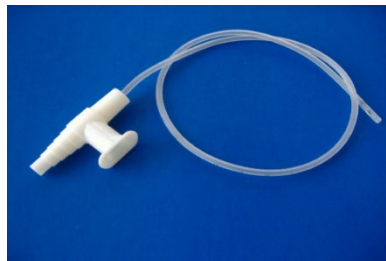
Suction connective tubing



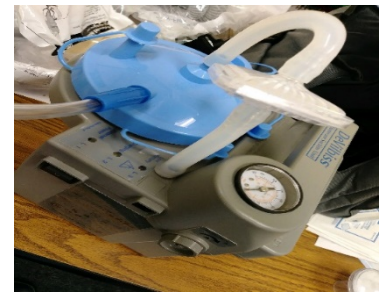
Yankauer suction



Little sucker suction



Suction catheter



Suction machine

Oxygen supplies



Oxygen concentrator







Oxygen Litter flow knob on concentrator


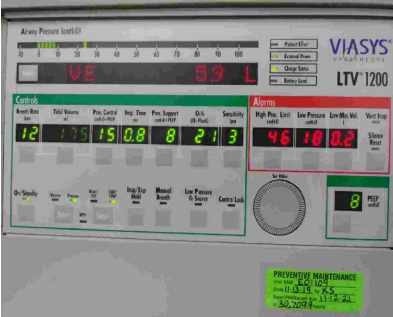





Ambu Mask

Pulse oximeter supplies

 <p>Pulse oximeter</p>	 <p>Patient cable</p>	 <p>Disposable pulse oximeter probes</p>
 <p>Coban tape</p>		

Ventilator supplies

 <p>LTV Ventilator</p>	 <p>LTV Ventilator screen</p>	 <p>LTV Battery Sprint Pack</p>
 <p>Ventilator tubing connections</p>	 <p>Bacteria filter</p>	

Where can I find more information?

- **Golisano Children's Hospital Family Resource Library** (libraries.urmc.edu/gch)

Located on the first floor of Golisano Children's Hospital (GCH) (room 1.1177), the Family Resource Library is staffed by a professional librarian who can help you:

- Find reliable and helpful medical information
- Set up and use MyChart
- Use an iPad or personal computer

You can visit the library during normal business hours. Or you can email, call, or send us a question through our **Ask-A-Librarian** service. (www.urmc.edu/miner/ask_librarian)



Phone: (585) 275-7710

Email: GCH_Library@URMC.Rochester.edu

- Aaron's Tracheostomy Page
www.tracheostomy.com
- St. Louis Children's Hospital Interactive Trach Learning
http://sitelinks.bjc.org/tracheostomy/a001_introduction_welcome.html
- American Speech-Language-Hearing Association
"Making effective communication, a human right, accessible and achievable for all."
www.asha.org/public/speech/disorders/aac/
- American Thoracic Society Patient Information Series: Use of a Tracheostomy with a Child
www.thoracic.org/patients/patient-resources/resources/tracheostomy-in-child.pdf
- Bissell, C. (2008). Pediatric Tracheostomy Home Care Guide
Publisher: Jones & Bartlett Publishers
ISBN-10: 0763753866
ISBN-13: 978-0763753863
- "Breath of Life" A Caregiver's Guide to Pediatric Tracheostomy Care
www.patienteducation.tv/trach_video.php

Let's define some of the words we're using.

Apnea (APP-nee-uh)	A condition that occurs while you're sleeping. You either stop breathing for a short period of time or you have slow breathing.
Artificial nose	Also called Humid-vent, Heat Moisture Exchanger, or HME. A small filter device that fits over the trach tube and provides warmth and humidification. HMEs are vital to maintain thin secretions and prevent mucus plugs.
Aspiration (a-spuhr-A-shun)	A condition where you breathe in something like food or liquid that is not air into your airway.
Bacteria	Germs that grow and can cause infection.
Ballard Suction	Closed suction system in which the suction catheter is protected inside a sterile sleeve. This is used when a patient is on the ventilator.
Bronchospasm (BRON-koh-spazm)	Sudden, strong muscle tightening and opening of the airways in the lungs, which makes you cough.
Burnout.....	A state of emotional, physical, and mental exhaustion caused by a lot of stress. It occurs when you feel overwhelmed, emotionally drained, and unable to meet constant demands.
Cardiopulmonary Resuscitation (CPR)	An emergency lifesaving procedure that is performed when the heart stops beating. It consists of breathing as well as chest compressions in order to move blood and oxygen to vital organs within the body.
Catheter	A small, soft tube that connects to suction to remove mucus from the trach tube.
Chest physiotherapy.....	A way for clearing mucus out of the lungs. Keeping the lungs clear helps your child breathe easier.
Clammy skin.....	Sweaty skin

Cuff.....	The inflatable balloon on some tracheostomy tubes.
Cyanosis (sai-yuh-NO-suhs).....	A bluish discoloration of the skin, lips, and nails due to decreased oxygen levels in the blood.
Decannulation (dee-can-you-LAY-shun).....	Occurs when the trach tube is removed from the stoma. This can occur accidentally or can be planned when your child no longer needs the trach tube to breath.
Desaturation (dee-sat-yuhr-A-shun)	When the oxygen level goes below your child's normal levels.
Diaphragm (DAI-uh-fram)	The big muscle below the lungs that controls breathing.
DME	Durable Medical Equipment
Dysphagia (dis-FAY-jee-ah).....	Trouble swallowing
Epiglottis (eh-puh-GLAA-tuhs).....	A flap or tissue covering the opening of the larynx (voice box) during swallowing to prevent food or fluid from entering the lungs.
Esophagus (eh-SAA-fuh-guhs).....	The tube that connects the mouth to the stomach.
Exhale/Expiration.....	Breathing out
Face mask.....	A soft piece that fits over the nose and mouth and attaches to the self-inflating bag.
Flange (flanjj).....	The part of the trach tube that rests against the neck and holds the ties. It contains information on the type and size of tube your child has.
HME	Heat and Moisture Exchanger, also called the artificial nose. A small filter device that fits over the trach tube and provides warmth and humidification by trapping it from exhaled air.
Humidifier	A machine that puts extra moisture into the air.
Hypoxia (hai-PAAK-see-uh).....	Low oxygen levels in the body
Inhale/Inspiration	Breathing in

Inner cannula.....	A smaller tube that fits into the outer cannula of the tracheostomy tube. The Inner Cannula is changed more frequently to prevent buildup of secretions.
Instillation.....	A way of giving medicine in the form of a liquid or by drops, directly into the trach.
Larynx (LEH-ringks).....	The voice box. Function is to protect the airway when the vocal cords are closed and to produce voice when air passes through the vocal cords.
Mucous (Mucus).....	Slippery fluid produced in the lungs and windpipe.
Mucous plugs.....	A collection of thick secretions that can get stuck in or at the end of the tracheostomy tube preventing airflow from properly moving through the trach.
Nebulize (NEH-byoo-lized) medicine.....	A medicine that comes as a liquid but is turned into a mist by a machine. This allows the child to inhale the medicine as a mist.
Normal saline.....	Sterile salt water
O ₂ (oh-2).....	Oxygen
Oxygen concentrator.....	A home oxygen machine that makes oxygen.
Obturator.....	The piece that fits into the trach tube to make it easier to slide the trach tube into the stoma.
Oxygen Saturation Level.....	Sometimes referred to as "O ₂ sats" or simply "sats." It is the percent of oxygen that is in your child's blood. This level is based on your child's condition. Your health care team will let you know what is normal for your child.
Oximetry (Pulse Oximeter).....	The device that measures your child's oxygen saturations. A probe will be attached to your child which allows their oxygen saturations and heart rate to appear on the monitor.
PDN.....	Private Duty Nurse

Pulmonologist (puhl-mahn-AHL-o-jist)	A medical doctor with advanced specialty training in pulmonary (lung) disease.
Rescue breathing	Breathing for a person who is not breathing.
Resuscitator bag.....	A bag used to provide manual breaths through the trach or with a mask.
Retractions	A sign of respiratory distress in which there is pulling or sucking in of the chest muscles, neck muscles and diaphragm during breathing.
Room Air.....	The air around us contains 21% oxygen. When your child is not receiving any oxygen we say that they are on “room air.”
RT.....	Respiratory Therapist
Saliva.....	Natural fluid in the mouth that helps you chew and swallow. It also keeps the mouth moist and teeth healthy. Spit.
Secretions.....	A substance, such as saliva, mucus, and tears that the body produces and releases.
Self-inflating bag	A breathing bag that fills with room air and does not need oxygen to fill, used to provide breaths to the child either directly into the trach or through a mask covering the mouth and nose with the stoma covered
Speaking valve	A one-way valve that allows air to come in the tracheostomy tube, but then sends it out past the vocal cords and mouth to make talking possible.
Stenosis.....	Narrowing or constriction of a part of the airway. This can cause obstruction of airflow.
Stoma	Surgical opening in neck in which the tracheostomy tube is placed
Suctioning.....	A catheter tubing is inserted into the tracheostomy tube and mucous or sections are removed from the tracheostomy using a suction machine.

Trachea (TRAY-kee-uh)	Windpipe
Tracheitis (tray-kee-EYE-tiss).....	An infection of the trachea (windpipe)
Tracheotomy (tray-kee-AA-tuh-mee)	A surgical procedure where a doctor creates a stoma and places a tube for breathing into a child's trachea
Tracheostomy (tray-kee-AA-stuh-mee).....	The name of the opening that is created during the tracheotomy procedure
URI	Upper Respiratory Infection
Ventilator	A mechanical device to assist breathing that moves air and oxygen in and out of the lungs. Can also be called a respirator or breathing machine.
Wheeze	A whistling sound resulting from a narrowing in the respiratory tract.
Yankauer (YANG-kow-er).....	A rigid plastic or metal suction device to help you remove secretions (like saliva) from your child's mouth

Other words I want to remember: