Ventilator Care Program
CAREGIVER EDUCATION

BREATHING INSTITUTE
www.childrenscolorado.org

Children’s Hospital Colorado
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Welcome to the Ventilator Care Program

Dear Caregiver,

Our Ventilator Care Program at Children’s Hospital Colorado designed these handouts to help you remember how to care for your child with a tracheostomy. The handouts describe your child’s anatomy and review both routine and emergent skills that are very important to keep your loved one safe. They also talk about necessary supplies. If your child requires a home ventilator, we have also included handouts to help you manage the ventilator equipment.

These handouts (and the videos that go along with them) are reminders of things you have learned and will be taught before going home from the hospital. As you know, you have learned way more than can fit into handouts. Most importantly, you are now an expert in caring for your own child!

Accidents and emergencies can (and do) happen anywhere, even here in the hospital. It is always important to stay calm, remember what you’ve learned, and call for help when you need it. Being prepared is important.

If something in a handout doesn’t make sense, please ask to have it explained. Your team is here to help and support you and your child! Also, let us know if you have ways to make any of them more helpful.

We are excited to see you make it HOME SWEET HOME!!!

Sincerely,

Dr. Christopher Baker (Medical Director)
and the entire Ventilator Care Program Team
Who is on my Inpatient Care Team?

General Information:
You will meet many different staff members during your stay at Children's Hospital Colorado. All care team members are expected to introduce themselves and explain how they will help with your child’s care. If they forget to do this, please help remind them to. You and your child are the most important part of the care team, and we will work closely with you to provide him or her with the best possible care. The list below includes team members you may meet during your hospitalization and their role in your child’s care.

**Doctors:** Children's Hospital Colorado is a teaching hospital; doctors with many different levels of knowledge will help in your child's care and you will meet many different doctors during your stay. You will mainly be working with pulmonary specialists, but it is likely that you will work with doctors from other specialties as well. The pulmonary team will include:

- **Attending Physicians (pulmonologists):** Attending physicians lead the team of your child's doctors. They have specialty education and training in treating children with breathing disorders (pulmonary medicine.)
- **Fellows:** Fellows are medical doctors with three years or more of training in pulmonary medicine. They are receiving specialty training to become pediatric specialists in pulmonary medicine.
- **Residents:** Residents are medical doctors receiving their first training in pulmonary medicine.
- **Pediatric Nurse Practitioners:** Nurse practitioners are nurses with special training and function as a mid-level provider with the doctors. There are two nurse practitioners on the pulmonary team who will provide care to your child and work with all other team members to help coordinate your child's care.

**Nurses:** Your child will be cared for by registered nurses during his or her inpatient stay. The nursing staff works as a team with doctors, other staff, and your family to provide complete patient care. We will build a primary team of nurses to care for your child. This will allow for a small team of nurses to become very familiar with your child and his or her needs. Your nurses will teach and make sure you understand everything you need to know to take care of your child before you go home. This includes caring for your child’s tracheostomy and g-tube, administering medications and feeds, and many, many more topics.

**Advanced Practice Nurse:** Advanced practice nurses are registered nurses with additional education and clinical training in a specific area of healthcare. The advanced practice nurse on the pulmonary unit (Jodi Thrasher) will help build a primary team of nurses for your child. She will work with all members of the care team to coordinate the education you will need to make sure you get home safely.

**Respiratory Therapists:** Your child's respiratory therapists will set up and monitor your child's ventilator and other respiratory equipment needed by your child during his or her inpatient stay. They will give all respiratory medications and treatments your child needs. Your respiratory therapists will teach and make sure you understand all respiratory related education to get you ready to go home. Respiratory therapy will also set up any home respiratory equipment you will need.
**Speech Therapists**: Speech therapists may work with your child on learning how to talk and learning how to eat.

**Occupational Therapists**: Occupational therapists may help your child with their daily activities, like playing, getting dressed and taking a bath. Occupational therapists may also work with speech therapists to help your child learn how to eat.

**Physical Therapists**: Physical therapists may work with your child to help them get better with movement, like rolling, sitting, crawling or walking. They may help with problems related muscle tone, strength and coordination.

**Nutritionist**: Nutritionists will work with your child's care team to make sure his or her nutritional needs are being met.

**Clinical Social Workers**: Clinical social workers give emotional support to children and their families to help them adjust to being in the hospital. Social workers can also talk to you about any financial concerns you may have about your child's hospital stay and assist you to find resources in the hospital and the community. You may ask for help from a clinical social worker at any time during your child's hospital stay.

**Child Life Specialists**: Child life specialists can help you and your child cope with the stress of being in the hospital and reach treatment goals through play and creative activities. Child life specialists can help you and your child understand medical procedures, teach your child ways to make procedures easier and less painful, give emotional support to you and your child during procedures, and provide play and fun activities for your child. Child life specialists can also give help to your child's brothers and sisters while in the hospital.

**Case Managers**: Case managers work with you and your child's healthcare team to set up homecare needs your child will have. This includes home nursing care, outpatient therapies and any non-respiratory medical equipment such as g tube supplies and feeding supplies. Your case manager will also work with your insurance company for your entire hospital stay.
The Normal Breathing System

General Information:

It is important to understand the normal breathing system to be able to understand what is normal and not normal about your child’s breathing system. The breathing system involves many parts of the body.

Parts of the breathing system

1. Nose and Mouth
2. Larynx / vocal cords (Voice box)
3. Trachea (windpipe)
4. Lungs
5. Diaphragm
6. Brain

Nose and mouth: The nose and mouth assist in bringing air into the trachea and lungs. They also allow air to exit. The nose warms, filters, and moistens the dry air when breathing.

Larynx / vocal cords (Voice box): The larynx is also known as the voice box and contains the vocal cords. It is located in the neck at the top of the trachea. The vocal cords move when air passes by them to make the sound of your voice.

Trachea: The trachea is also known as the windpipe. It is where air passes down from the nose and mouth through the larynx into the lungs.

Lungs: The trachea splits into two main branches called bronchi that deliver air into the lungs. The bronchi split into smaller and smaller branches which looks like an upside-down tree. At the end of the branches are small air-filled sacks called alveoli. In the alveoli, oxygen enters the bloodstream and carbon dioxide is removed.

Diaphragm: The diaphragm is a large muscle that sits below the lungs and assists in breathing. When breathing in, the diaphragm goes down to enlarge the chest for the lungs to expand. When breathing out, the diaphragm relaxes and goes up.

Brain: Breathing occurs as part of normal daily function. A person can control breathing to an extent by either taking a breath or holding a breath. Much of the breathing process is controlled automatically by the brain.

Please ask your healthcare provider if you have any questions regarding this information, or have other learning needs.
What is a Tracheostomy?

General Information:

A tracheotomy is a surgical procedure that creates an opening in the neck and windpipe (trachea). A tube is then placed in the opening to keep it open so air gets to your child's lungs. The terms tracheotomy (the surgery), tracheostomy (the hole), and tracheostomy tube (the actual tube) are all sometimes referred to as the “trach.”

When is it used?

Examples of when a tracheostomy may be needed include:
- Upper airway blockage by swelling, an injury, a tumor, vocal cord problems, or severe narrowing
- An illness or injury to the brain, muscles, and/or nerves that control breathing
- The need for frequent suctioning of secretions from the airway
- Long-term breathing problems that require a breathing machine (ventilator)

What happens during the procedure?

This procedure is usually done in an operating room. General anesthesia is given to prevent pain, relax muscles, and put the child to sleep. The surgeon will make a hole (stoma) in the neck and windpipe. A tube will be put into the stoma. The tube (trach) will be held in place with ties around the neck. Your surgeon will explain the benefits and risks of this procedure.

What happens after the procedure?

- The skin around the trach tube will start to heal, it is necessary to stay in the Intensive care unit during this time. Five to ten days after the surgery, the trach tube will be changed for the first time.
- Tracheostomy tubes may make it hard to make noise, talk, swallow or eat. The therapy team will work to develop goals for your child such as learning to talk and eat.
- Teaching how to care for the trach will begin in the intensive care unit and continue until your child goes home. This will include cleaning the trach site, suctioning, and changing the tube. Before going home at least two caregivers (parents) will show they can care for all of the child’s new needs.
- Anyone who is alone with your child must be fully trained to care for their tracheostomy.

Please ask your healthcare provider if you have any questions regarding this information, or have other learning needs.
What is Chronic Ventilation?

What is a ventilator?

A ventilator is a machine that helps your child to breathe. The ventilator brings oxygen into the lungs and helps get rid of carbon dioxide from the body.

Children are usually placed on a ventilator because of a medical problem that makes it hard for them to breathe well on their own. While on the ventilator, the body is able to rest so that it can grow, develop, and heal.

A ventilator is typically used for short periods, such as during a surgery or illness when your child is not able to breathe on their own. Sometimes a child may become dependent on a ventilator because of his or her medical problems. This may make it difficult to get them off the ventilator.

Some children may need to use ventilators for a very long time. However, some children can be placed on home ventilators, so that they can get out of the hospital. Taking your child home on a ventilator requires 24/7 care by you, family members, or skilled health care providers. It is important to understand the normal breathing system to be able to understand what is normal and not normal about your child’s breathing system. The breathing system involves many parts of the body.

Coming off the Ventilator

Some patients will require life-long ventilation. However, when the child’s medical problems have improved enough, “weaning” may begin. Weaning is the process of getting the patient off the ventilator. If you have questions about this, talk to your team.

A Team Effort

The ventilator care team is a group of professional and support staff who act as a team to provide personal care to children who require chronic ventilation.

These team members are:

- Parents and other primary caregivers
- Doctors: including specialists and surgeons
- Advanced practice providers (e.g., nurse practitioners)
- Registered nurses and nursing assistants
- Respiratory therapists
- Other therapists (physical, occupational, speech)
- Dietitians
- Social workers and case managers
- Other (Child Life Specialists, Spiritual Care, etc.)

Please ask your healthcare provider if you have any questions regarding this information, or have other learning needs.
Modes and Settings of Mechanical Ventilation

**General Information:**
This handout is meant to provide a basic understanding of the terms used to talk about chronic ventilation. Please ask your healthcare provider if you have questions regarding this information, or have other learning needs.

- **Invasive Ventilation:**
  Ventilation provided either by Endotracheal tube (ETT), or Tracheotomy tube.

- **Non Invasive Ventilation:**
  Ventilation by mask.

- **VT or Tidal Volume:**
  Volume of air inhaled or exhaled on each breath.

- **Frequency or Rate:**
  The number of times the ventilator is set to breathe in one minute.

- **PIP or Peak Inspiratory Pressure:**
  Highest level of pressure pushed into the lungs when breathing in.

- **PEEP or Positive End Expiratory Pressure:**
  Pressure left in the lungs at end of a breath.

- **PS or Pressure Support:**
  A set pressure above PEEP which allows for a variable sized breath volume inside that set pressure.

- **CPAP or Continuous Positive Airway Pressure:**
  A set pressure that blows a gentle stream of air into the nose to keep the airways open.

- **BiPAP (Bi-level Positive Airway Pressure):**
  Slightly different from CPAP, by adding in a higher pressure (IPAP or Inhalation Positive Airway Pressure) above the continuous pressure (EPAP or Exhalation Positive Airway Pressure) that is taken in with the breath. This pressure will help give a bigger breath by pushing a little more air in.

- **AVAPS (Assured Volume Averaging Pressure Support):**
  A Optional setting that can be used with BiPAP. This setting will let a set volume of air (VT/Tidal Volume). As with the BiPAP there are 2 other pressures and a EPAP pressure. When the lowest set IPAP is not met the machine will allow for more pressure to push in the volume of air.

Please ask your healthcare provider if you have any questions regarding this information, or have other learning needs.
Is My Ventilated Child Sick?

**General Information:**

It is important to be able to recognize when your child might be getting sick and when you should contact your child’s doctor. You should be concerned if you notice any change from your child’s baseline. It is important to watch for the following signs which may mean that your child is getting sick.

**Change in secretions:** It is important to assess your child’s secretions every time you suction your child’s tracheostomy tube. Notify your child’s doctor if you notice any of the following:

- **Increase in secretions:** If you are needing to suction your child more frequently than you normally do or you are getting more secretions from your child’s tracheostomy tube when you suction this may be an indication that your child is sick.
- **Change in color of secretions:** If your child is getting sick his or her secretions may become yellow, green, bloody, or brown, although it is important to recognize any change in color from your child’s normal secretions.
- **Increase in thickness of secretions:** If your child’s secretions are thicker than they normally are this could be an indication that your child is getting sick. It is important to recognize this change as your child is at risk for getting a plug when secretions become thicker.

**Working harder to breathe:** It is important to be aware if your child begins working harder to breathe. Notify your child’s doctor if you notice any of the following:

- **Chest muscles pulling (retractions):** If you notice that your child’s chest muscles are pulling inward between his or her ribs, under his or her ribs, or above his or her collar bone this is an indication that he or she is having a harder time breathing and may be sick.
- **Breathing fast:** If your child is breathing faster than normal this is an indication that he or she is working harder to breathe and may be getting sick.

**Decreasing Oxygen saturations:** Notify your doctor if your child’s oxygen saturations are decreasing or if he or she needs more oxygen than usual to keep their oxygen saturations above 90%.

**Wheezing:** If your child is sick you may be able to hear him or her wheezing. Notify your child’s doctor if you notice this.

**Fever:** Notify your child’s doctor if he or she develops a fever.

Please ask your healthcare provider if you have any questions regarding this information, or have other learning needs.
Bag-Tracheostomy Ventilation: Manually ventilating your child

**General information:**
Sometimes, you may have to manually ventilate your child to him or her breathe through their tracheostomy (trach). In order to do this you will need a self-inflating resuscitation bag.

**Supplies needed:**
1. Self-inflating resuscitation bag
2. Tubing to connect to oxygen supply
3. Oxygen tank

**Bag-Tracheostomy Ventilation Procedure:**

1. If your child requires oxygen; first turn on your oxygen tank or concentrator to the appropriate liter flow. Your child’s care team will determine the appropriate liter flow.
2. Connect the tubing from the ambu bag to the oxygen source. If oxygen is not available, manually bag with room air.
3. If your child is on a ventilator; you will need to disconnect the ventilator adaptor from your child’s trach. (You will skip this step if your child is not on a ventilator)
4. Once the ventilator is disconnected from the trach, attach the ambu bag directly to your child’s trach.
5. Squeeze the ambu bag with slow and steady pressure so you deliver the breath over about one second.
6. Give your child one breath every five to six seconds. (about 12-20 breaths per minute). Count out loud if you need to in order to keep this pace
7. Continue to give slow and steady breaths while watching for chest rise. This will indicate that your child is getting adequate breaths.
8. If your child is breathing, coordinate the manual breaths with your child's, so you give a breath as your child begins to inhale.

**Please ask your healthcare provider if you have any questions regarding this information, or have other learning needs.**
Routine Suctioning

General Information:
You will need to suction your child’s tracheostomy to keep it open and free of secretions. To do this you will need the following supplies:

Supplies Needed:
1. Suction machine
2. Tubing
3. Clean suction catheter kit
4. Sterile saline if directed by your child’s medical team.
5. Sterile gloves

Routine Suctioning Procedure:

1. Wash your hands. Use soap, running water, and friction for 15 seconds. Use clean towel or paper towel to dry hands. If hands are not visibly soiled, you can use a waterless alcohol based hand product. Rub it thoroughly into all areas on your hands until dry.

2. If your child is on a ventilator, wipe the adaptor with an alcohol swab and let completely dry while you prepare for the procedure.

3. Verify the measurement for suction depth.
4. Turn on Suction machine

5. Make sure pressures on suction machine are 80-120 cm of water.

6. Open the suction catheter kit making sure to keep everything inside sterile. Do not allow the package to touch anything outside of the package.

7. Put on the gloves inside the package; make sure to keep them from touching anything but the contents of the sterile suction package.

8. Connect the catheter to the suction machine. Hold the suction catheter in your dominant hand (the one you write with). Use your other hand to hold the suction machine tubing while connecting the two.

   - **Note:** Your non dominant hand is NO LONGER sterile and you should not touch any part of the suction catheter that will enter the trach with this hand.

9. If your child is on a ventilator; you may insert the suction catheter directly into the ventilator adaptor. You can also disconnect the adaptor from the child’s trach using your non sterile hand and suction directly into the trach. Remember the suction depth will change if you use the adaptor or not.
10. Insert the catheter the proper distance in to the trach without applying suction

11. Once the desired distance has been reached, apply suction by putting your thumb over the hole in the catheter while you gently pull the catheter out of the trach. Roll the catheter between your thumb and forefinger as you pull the catheter out.

12. Apply suction for no longer than 5 seconds at a time.

13. If the secretions are thick, you may use saline on the next suction pass if your child’s medical team has told you to do this.
14. You may use the same suction catheter multiple times in a row as long as it stays sterile. and does not touch anything but the trach.

15. Suction as many times as you need to until you are no longer getting secretions when you suction. Make sure to give your child time to take a few breaths between each suction pass.

Please ask your healthcare provider if you have any questions regarding this information, or have other learning needs.

Additional Resources:
1. Routine and Emergent trach change handout
Inline Suctioning

General Information:
You will need to suction your child’s tracheostomy tube to keep it open and free of secretions. Inline suction catheters should be changed every seven days or as needed if the catheter gets clogged or sterility is not maintained.

Supplies Needed:
1. Inline suction catheter
2. Suction machine
3. Suction tubing
4. Sterile saline if directed by your child’s medical team

Procedure:
1. Gather needed supplies
2. Wash hands with soap and water or use waterless hand sanitizer.
3. Connect closed suction catheter to suction tubing and unlock thumb valve.
4. Turn on suction machine.
5. Push the catheter down your child’s tracheostomy tube to the length told to you by your child’s medical team. You will know you are at the right depth when you see this number in the suction window as shown below.
6. Pass catheter down tube to the length that has been told to you by your child’s medical team and verify suction depth in the suction window. Suction depth should appear in the middle of the window as shown below.
7. Press the thumb valve down with one hand (the one you write with) and pull back the catheter while securing the tracheostomy tube in place with the other hand.
8. If the secretions are thick, you may use saline on the next suction pass if your child’s medical team has told you to do this.
   - Withdraw catheter completely and make sure black tip of catheter can be seen in suction window.
   - Remove top of saline bullet. Open irrigation port and squeeze a few drops of saline into port without activating thumb valve (saline bullet fits directly into port.)
   - Pass catheter down tube to the length that has been told to you by your child’s medical team.
   - Press the thumb valve down and pull back catheter while securing the tracheostomy tube.

9. Suction as many times as you need to until you are no longer getting secretions when you suction. Make sure to give your child time to take a few breaths between each suction pass.
10. Rinse suction catheter with saline after you finish suctioning. To do this:
   o  Make sure the catheter is pulled back all the way and that the black tip of the catheter can be seen in the suction window.
   o  Remove top of saline bullet. Open irrigation port and squeeze saline into port while activating the thumb valve at the same time.
   o  Rinse until catheter is cleared of all secretions.

11. Make sure that the black tip of the catheter can be seen in the suction window when you are done suctioning your child and that the saline port is closed. Make sure to disconnect the inline suction catheter from the suction tubing and lock the thumb valve.

Additional Resources:
   Routine and Emergency Tracheostomy Change handouts
   Routine Suctioning handout

Please ask your healthcare provider if you have any questions regarding this information, or have other learning needs.
General Information:
Changing your child’s tracheostomy tube is a routine part of caring for your child’s tracheostomy.

Supplies Needed:
1. Same size trach with obturator
2. Sterile Lubricant
3. Small Towel
4. New trach ties or chain
5. 5 ml syringe if your child has a cuffed trach.

Procedure:

1. Wash your hands. Use soap, running water, and friction for 15 seconds. Use clean towel or paper towel to dry hands. If hands are not visibly soiled, you can use a waterless alcohol based hand product. Rub it thoroughly into all areas on your hands until dry.

2. Place child on his/her back on a flat surface. Roll the small towel or blanket and place it under your child’s shoulders to extend his/her neck. This will enable you to visualize their trach and stoma.

3. Open the new trach package.

4. Place a small amount of lubrication on the end of the trach.
5. If your child has a cuffed trach; inflate and deflate the cuff on the new trach to make sure it is intact.

6. Return back to the package until you are ready to use it to ensure that it stays clean.

7. Prepare to remove your child’s trach. If your child has a cuffed trach; deflate the cuff using the empty 5 mL syringe.

8. While holding your child’s trach in place, undo your child’s trach ties or chain. You may need a second person to help complete this step.

9. If your child is on a ventilator; disconnect the ventilator adaptor from your child’s trach while continuing to hold the trach in place.

10. Remove the new trach from the package with your dominant hand taking care not to touch the trach to anything.

11. Remove your child’s trach with your non-dominant hand and immediately place the new trach into your child’s stoma with your dominant hand.

12. If you are unable to easily insert the new trach; remain calm. Pull the trach back out, slightly reposition your child and try again.

13. Once the new trach is in place, immediately remove the obturator. If your child is on a ventilator reconnect the ventilator adaptor to the trach.

14. Replace trach ties or chain to secure trach.

15. If your child has a cuffed trach; inflate the cuff using the 5cc syringe.

Please ask your healthcare provider if you have any questions regarding this information, or have other learning needs.
Tracheostomy Stoma Care

General Information:
You will need to keep your child’s skin at the tracheostomy site clean and dry. If drainage is allowed to sit on the skin around the tracheostomy tube, germs can grow and cause infection or skin rashes. You should clean your child’s tracheostomy site at least once a day and as often as needed to keep the site clean and dry.

Supplies Needed:
1. Saline Wipes
2. Any ointments prescribed by your child’s doctor
3. Cotton swab applicators (if ointment has been prescribed by your doctor)
4. Dressing if recommended by your child’s healthcare team

Procedure:
1. Gather needed supplies
2. Wash hands with soap and water or use waterless hand sanitizer.
3. Using a sterile saline wipe, clean around your child’s tracheostomy site, starting at the stoma and working your way out. Discard the saline wipe when it becomes dirty. Use as many saline wipes as needed to get the skin around your child’s tracheostomy site completely clean.
4. Clean the wings of the tracheostomy tube using saline wipes.
5. Allow the skin to dry completely before applying any ointments or dressings.
6. If your child's doctor has prescribed an ointment apply it using a cotton swab applicator, taking care not to get any ointment into the stoma.
7. Apply a dressing if it has been recommended by your child’s healthcare team. If using a gauze dressing, make sure to use one that already has a slit in it. Never use gauze that you have cut yourself as frayed fibers can be breathed into the tracheostomy tube.
8. Be sure to notify your child’s doctor if you notice any of the following things around your child’s tracheostomy site: redness, drainage, foul odor, swelling, or any places where the skin is broken.
9. If your child uses Velcro trach ties you can change these after cleaning your child’s trach site. If doing this, make sure to use a saline wipe or wash cloth with mild soap and water to clean all the way around your child's neck where the old trach ties were. Allow your child’s neck to dry completely before applying new trach ties. See tracheostomy tie change handout for more information on how to change your child's trach ties.

Additional Resources:
Tracheostomy tie change handout

Please ask your healthcare provider if you have any questions regarding this information, or have other learning needs.
Cleaning a Tracheostomy Tube at Home

General Information:

Your child’s tracheostomy tube will need to be cleaned and disinfected before you reuse it. This is especially important when your child has a custom-made tracheostomy tube.

Supplies Needed:

1. Distilled water
2. Hydrogen Peroxide
3. Small clean and dry bowl
4. Cotton swabs
5. Obturator
6. Gloves
7. Mild dish soap

Procedure:

- Put on gloves. Wash the used tracheostomy tube under running water using mild dish soap to remove secretions. The mild dish soap will remove secretions and skin oils.
- Put a cotton swab through the hole in the trach tube if it will fit, or you can use the obturator. This will help clean secretions from the inside of the tube.
- Pour even amounts of hydrogen peroxide and distilled water into the small bowl to make a half and half mixture. Soak the tracheostomy tube in the mixture for 30 minutes.
- Thoroughly rinse the cleaned tube with distilled water. Throw away the hydrogen peroxide mixture.
- Shake off any water and air1dry the tracheostomy tube completely.
- Place the tracheostomy tube in small sealable dry container. Place the clean tracheostomy tube at your child’s bedside to use again.
- If using a stainless steel bead chain, wash, rinse, disinfect and dry the same way as the tracheostomy tube. When dry, the chain may also be stored with the clean tracheostomy tube.

Please ask your healthcare provider if you have any questions regarding this information, or have other learning needs.
Tracheostomy Tie Change

General Information:
Velcro ties or a tracheostomy chain are the recommended ways to secure your child's tracheostomy tube. Immediately after surgery, a twill tie will be used.

- Velcro ties should be changed at least once a day or if they become wet or soiled, soiled ties can lead to skin breakdown.
- The skin should be looked at for redness, openings, or rashes. If any of these things are noted, notify your child's doctor.
- Ties should always be changed with 2 people, except in an emergency.

Changing Velcro Tracheostomy Ties:

Supplies Needed:
1. Velcro ties
2. Small towel or blanket if your child is an infant
3. Supplies needed for cleaning of tracheostomy stoma (see Tracheostomy Stoma Care handout)

Procedure:
1. Gather needed supplies
2. Wash hands with soap and water or use waterless hand sanitizer.
3. If your child is an infant place a small towel or blanket rolled up under his or her shoulders in order to more easily visualize your child's neck and tracheostomy tube.
4. Clean your child's tracheostomy stoma before changing the Velcro ties (see Tracheostomy Stoma Care handout for instructions on how to do this.)
5. While a second person holds your child's tracheostomy tube in place, remove the old Velcro ties.
6. Use a saline wipe or wash cloth with mild soap and water to clean all the way around your child's neck where the old tracheostomy ties were.
7. Thread the self-fastening tab through the flange of the tracheostomy tube, folding it back onto the cloth material and fastening it securely.
8. Repeat on the other side of the tracheostomy tube.
9. With your child sitting up (while a second person continues to hold the tracheostomy tube in place) bring the two ends of the Velcro ties together at the back of your child's neck. Fasten the third self-fastening tab to the material.
11. Check that the Velcro ties are secure, allowing for one finger to fit between the tie and your child's neck.
Changing a trach chain:

If your child is using a chain to secure the tracheostomy tube it can be left in place for two weeks. You will need to clean the chain daily when doing stoma care. It is recommended that the chain be either changed, or taken off and cleaned every two weeks when the tracheostomy tube is changed.

**Supplies Needed:**
1. Stainless steel bead chain
2. Small towel or blanket if your child is an infant
3. Supplies needed for changing tracheostomy tube (see Routine Tracheostomy change handout)

**Procedure:**
1. Gather needed supplies
2. Wash hands with soap and water or use waterless hand sanitizer.
3. If your child is an infant place a small towel or blanket rolled up under his or her shoulders in order to more easily visualize your child's neck and tracheostomy tube.
4. It is easiest to place the chain on a clean tracheostomy tube and change the tube with the chain in place; however, the chain may be changed with the tracheostomy tube in place if needed.
5. For either method, place the chain through the wings of the tracheostomy tube by bringing the chain up through one side, across the front and above the hub and down through the other side. Trim the chain and fasten with the clasp.
6. Check that the chain is secure, allowing for one finger to fit between the chain and your child's neck.

**Additional Resources:**
- Tracheostomy Stoma Care handout
- Routine Tracheostomy Change handout

Please ask your healthcare provider if you have any questions regarding this information, or have other learning needs.
Emergency Trach Changes

There are many situations when a tracheostomy will need to be changed very quickly. Some of these examples include: trach falling out (decannulation) and plugged tracheostomy.

- It is very important that tracheostomy emergency supplies are with your child at all times in your child’s go-bag.
- An emergency tracheostomy change should be performed as rapidly as possible. It is important to remain calm.
- All caregivers should know how to change a tracheostomy emergently without the assistance of a helper.

At any point you are concerned about your child’s airway or breathing and your child is not getting better, call for help and call 911. If at any point your child stops responding and becomes unconscious chest pushes or CPR should be started. Call for help and call 911.

Decannulation/Falls out:

- One complication with a tracheostomy tube is the potential for a partial or complete decannulation. A decannulation is when the trach becomes partially or completely dislodged.
- This could happen as a child becomes more active, while changing trach ties or turning your child. Sometimes it happens because the trach ties or chain is too loose.
- Signs a tracheostomy tube is out or partially out include:
  - Your child is breathing fast or working harder to breathe
  - Your child’s chest muscles are pulling
  - Your child’s color changes
  - Oxygen saturations decrease.
  - If your child is on a ventilator when decannulation occurs you may see and hear a low pressure alarm.
- If your child has frequent decannulations it is important to notify your primary care provider, pulmonologist or ear, nose, throat (ENT) provider.

Plugged Tracheostomy:

- Another complication with a tracheostomy tube is a partially or completely plugged tracheostomy.
- The trach tube may become plugged for several reasons, including thick secretions, lack of humidification, dehydration, the child is unable to cough, or not suctioning enough.
If secretions are thick or have a change of color notify your primary care provider or pulmonologist.

Signs you might see if your child’s tracheostomy is plugged or partially plugged include:

- Your child is breathing fast or working harder to breathe
- Your child’s chest muscles are pulling
- Your child’s color changes
- Oxygen saturations decrease.
- If your child is on a ventilator, high-pressure alarm may sound.

Decannulated Tracheostomy: emergency procedure

1. Grab the nearest trach tube to insert into your child’s stoma. In some cases this may be the trach that fell out.
2. Use an obturator to help place the trach back into the stoma.
3. If unable to get trach back in place, get the size smaller trach with the obturator to guide into the stoma.
4. Secure the tracheostomy with ties or chain.
5. If tracheostomy tube is cuffed inflate the cuff.

   **A routine trach change can be performed after the child recovers if the trach that fell out was used for this emergency.**

Partially or completely Plugged Tracheostomy: emergency procedure

1. In an emergency situation like a plugged tracheostomy or very thick secretions, it may be necessary to suction further than you do with routine suctioning.
2. Insert suction catheter until coughing occurs. This will help movement of secretions in the event of an emergency.
3. Instill few drops of sterile saline into the trach tube, this may help to loosen the secretions.
5. If plug is not cleared or unable to pass the suction catheter, stay calm.
6. Perform a trach change
7. Replace a new trach into the stoma using the obturator.
8. If unable to get trach back in place, get the size smaller trach with the obturator to guide into the stoma.
9. Secure the tracheostomy with ties or chain.
10. If the tracheostomy tube is cuffed inflate cuff.

At any point you are concerned about your child’s airway or breathing and your child is not getting better, call for help and call 911. If at any point your child stops responding and becomes unconscious chest pushes or CPR should be started. Call for help and call 911

Please ask your healthcare provider if you have any questions regarding this information, or have other learning needs.
Getting Ready to Go Home: Hospital Care team “To Do List”

General Information:
- There are lots of things to do when getting ready to take your child home to make sure your return home is as smooth as possible.
- Many of these things the family/caregivers need to do, however Children’s Hospital Colorado has responsibility for some of these things also.
- Below is a list of things **your care team will do** to prepare your child for discharge.

<table>
<thead>
<tr>
<th>Hospital Staff</th>
<th>What we will do:</th>
<th>Notes:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case Manager</td>
<td>• Set up home care nursing and non-respiratory durable medical equipment (DME)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Set up outpatient or home based therapies</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Check on insurance status and waiver status</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Talk with insurance providers</td>
<td></td>
</tr>
<tr>
<td>Respiratory Therapy</td>
<td>• Set up needed respiratory equipment with respiratory companies.</td>
<td>• Teach and make sure you understand all respiratory related education (see education checklist)</td>
</tr>
<tr>
<td>Registered Nurse</td>
<td>• Teach and make sure you understand all nursing related education such as g-tube, feeds, child’s care, and medications.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Make a medication schedule with caregivers that is easy to understand.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Make sure you understand all respiratory related education</td>
<td></td>
</tr>
<tr>
<td>Doctors</td>
<td>• Talk with your child’s primary care provider (PCP) and other community team members regarding patient’s care</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Make sure you understand all medical education</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Make sure you understand everything you have learned about taking care of your child.</td>
<td></td>
</tr>
<tr>
<td>Social worker</td>
<td>• Ask you about other things you may need at home after discharge</td>
<td>• Help to connect (refer) you with community programs that may help you.</td>
</tr>
<tr>
<td></td>
<td>• Help you with division of motor vehicles (DMV) paperwork for disabled parking</td>
<td>• Help you talk to electric companies about your child’s special needs.</td>
</tr>
<tr>
<td></td>
<td>• Help you talk to local Emergency services about your child’s special needs.</td>
<td>• Help you talk to local Emergency services about your child’s special needs.</td>
</tr>
<tr>
<td></td>
<td>• Make sure you have a telephone that is a land line in your home.</td>
<td>• Make sure you have a telephone that is a land line in your home.</td>
</tr>
<tr>
<td>Therapies</td>
<td>• Make therapy recommendations for home</td>
<td>• Help to schedule doctor and therapy appointments after you go home.</td>
</tr>
<tr>
<td>Resident Liaison</td>
<td>• Communicate with outside therapy agencies/therapist</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Set up mobility and seating equipment if needed</td>
<td></td>
</tr>
</tbody>
</table>

12-11-2013 SEM
Getting Ready to Go Home: Caregiver To Do List

General Information:
- There are lots of things to do when getting ready to take your child home to make sure your return home is as smooth as possible.
- Many of these things are the family/caregivers need to do, however Children's Hospital Colorado will help you to do these things.
- Below is a list of things you will need to do before your child can go home. You can write the date to help you keep track of when you get things done.

<table>
<thead>
<tr>
<th>Learn about my child’s care</th>
<th>Date</th>
<th>General Information:</th>
<th>Notes:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Receive Ventilator Care Program Handbook and handouts</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Schedule appointments to learn about my child’s care</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- The care team will work with you to find times that work with your schedule</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Learn about and participate in my child’s care: become Independent!</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Go to scheduled care conferences with the hospital care team.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Date</th>
<th>Watch videos regarding my child’s care</th>
<th>Notes:</th>
</tr>
</thead>
<tbody>
<tr>
<td>DONE</td>
<td>“Manually ventilating your child”</td>
<td></td>
</tr>
<tr>
<td></td>
<td>“Emergency Airway Care: Ventilator Malfunction”</td>
<td></td>
</tr>
<tr>
<td></td>
<td>“Emergency Airway Care: Decannulation”</td>
<td></td>
</tr>
<tr>
<td></td>
<td>“Emergency Airway Care: Plugged Tracheostomy”</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Date</th>
<th>Attend a CPR Anytime Tracheostomy CPR class</th>
<th>Notes:</th>
</tr>
</thead>
<tbody>
<tr>
<td>DONE</td>
<td>• This class is provided by Children’s Colorado here in the hospital.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Your care team will tell you when you are ready to take the class and help you to schedule it.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Date</th>
<th>24-72 hour stay</th>
<th>Notes:</th>
</tr>
</thead>
<tbody>
<tr>
<td>DONE</td>
<td>Each caregiver needs to complete a 24-72 hour stay in the hospital with your child.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• This will help prepare you to be home with your child without help from the hospital staff.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Your healthcare team will work with your family to decide who should complete a stay and how long that stay needs to be for each caregiver.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Caregiver #1 (who)</th>
<th>Date</th>
<th>When</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Caregiver #2 (who)</th>
<th>Date</th>
<th>When</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Caregiver #3 (who)</th>
<th>Date</th>
<th>When</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Get my home and car ready</td>
<td>Date</td>
<td>Make a special space for your child at home</td>
</tr>
<tr>
<td>--------------------------</td>
<td>------</td>
<td>------------------------------------------</td>
</tr>
<tr>
<td></td>
<td></td>
<td>See “Helpful hints for home” and “Equipment” sections to help you do this.</td>
</tr>
<tr>
<td>Date</td>
<td>DONE</td>
<td>Get your car ready:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Car Seat:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Get a car seat and bring to hospital for child’s fitting</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Go on Car Ride:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• The care team will help you to go on car rides with your child before you go home.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• This will help to make sure the car seat and all needed supplies will fit and work well while you are driving.</td>
</tr>
<tr>
<td>Get my child’s medications ready</td>
<td>Date</td>
<td>Learn about my child’s medication</td>
</tr>
<tr>
<td></td>
<td>DONE</td>
<td>Obtain medication handouts / information</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Learn about what each medication does and how it helps your child.</td>
</tr>
<tr>
<td></td>
<td>Date</td>
<td>Create a schedule of my child’s home medications</td>
</tr>
<tr>
<td></td>
<td>DONE</td>
<td>The care team will work with you to develop a schedule that works for you and your family’s needs.</td>
</tr>
<tr>
<td></td>
<td>Date</td>
<td>Fill Prescriptions:</td>
</tr>
<tr>
<td></td>
<td>DONE</td>
<td>Obtain child’s medication prescriptions from for doctors.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Fill at the pharmacy 3-7 days before you go home.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Learn how to give your child’s medications with your home supply. Practice with the nurses.</td>
</tr>
<tr>
<td>Meet with my community care partners</td>
<td>Date</td>
<td>Meet with home care companies</td>
</tr>
<tr>
<td></td>
<td>DONE</td>
<td>Complete a home visit with the home nursing agency</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• You will probably meet with the Nursing director and your child’s new home nurses.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Complete a home visit with the respiratory company</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• The respiratory company will make sure your home is ready for the ventilator equipment.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Meet with other medical equipment companies if needed</td>
</tr>
<tr>
<td></td>
<td>Date</td>
<td>School and Day Care:</td>
</tr>
<tr>
<td></td>
<td>DONE</td>
<td>• Create an Individual Education Plan (IEP) with your school district. (age 3 and up when applicable).</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• You will need to meet with your child’s teachers to do this.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• The Learning Services team can help you to do this.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• If your child is less than 3 years old:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Create an “Individualized Family Service Plan” with Colorado Early Interventions team member or with your home state.</td>
</tr>
<tr>
<td>Important People to talk to:</td>
<td>Date</td>
<td>Pediatrician and Pulmonologist</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
</tbody>
</table>
| | | • Find a pediatrician.  
• Your doctors can help you with this.  
• Identify phone numbers and other ways to communicate with your primary pulmonologist. | |
| Date | Make follow-up appointments with care providers. | Notes: |
| D.O.N.E. | | • Hospital staff and resident Liaisons will help with this. | |
| Date | Local power company: | Notes: |
| D.O.N.E. | | • Contact your power company to let them know the importance of keeping power in your home.  
• Get the completed required form for Children’s Colorado to give to the power company  
• Social work can assist you in this process. | |
| Date | Local Telephone Company: | Notes: |
| D.O.N.E. | | • Get a landline telephone in your home. | |
| Date | Division of Motor Vehicles (DMV): | Notes: |
| D.O.N.E. | | • Get a handicap parking permit.  
• Social Work will assist in getting forms completed. | |
| Date | Local Fire Department: | Notes: |
| D.O.N.E. | | • Talk to local fire department to let them know about your child’s medical needs | |
| Other: | | | |
Helpful Hints:
Equipment & Storage, Home Nurses and More
Tips from Families Who Have Been There!

General Information:
- There are a lot of supplies needed to care for your child with a tracheostomy and/or ventilator. Spending time organizing your home and supplies will helpful when you transition home.

- It is helpful to use clear plastic tubs and drawers to store supplies. These can also be labeled on the outside, so that you don’t have to rummage around trying to find what you need (especially important in an emergency situation).

- It is easiest to keep like supplies together, as well as grouping supplies needed for the same area (i.e. group diapering supplies together, group trach supplies together, etc.).

- Create a “Trach Cares” bin. You probably had one of these at your child’s bedside in the hospital, and know how useful it is to have needed items handy and within arm’s reach.

- You could also create a “G-Tube Cares” bin.

- Try getting one set of clear plastic drawers and labeling them for G-Tube use. Fill one drawer with feeding bags, one with catheter tip syringes and extensions, and one with G-tube equipment cleaning supplies. Keep this set near the kitchen area where feedings will be prepared (i.e. designate a shelf in the pantry, a specific cabinet that little hands can’t get into, etc.).
• If you are using a changing table, it is a good idea to use one with open shelving. Try using open bins on the shelving to store commonly used items near your child, and then refill as needed. You could also store the suction machine here.

• Use a canvas shoe bag that can hang over a door or off the end of the crib for supplies. Label the front and all the basic supplies you use can be kept in here. (ie: trach ties, saline bullets, suction catheters, GT supplies, etc...)

• Use a microwave cart with wheels to hold your mist collar set up. Use baskets on the top for supplies and the compressor and heater can be on the bottom shelf. Use an extension cord and this can roll to wherever you need it, even outside.

• Create a space with a shelf for storing items needed when you transport your child. This area will need an electrical outlet so batteries can be charged. If all items you need for going out are together it is easier to remember everything.
Other Helpful Storage hints:

- Create a small tub or basket for daily G-tube and feeding supplies. You can keep the daily bag, pump, mug for heating milk/formula, bottle, syringes for meds, etc. all in one easy to find, non-cluttered area.
- Use sets of plastic drawers to organize trach and suction equipment and keep it near the child’s area.
- Create a “bathing space” if you won’t be using the bathroom for bathing. This could be a basket with towels, washcloths, soap and lotion next to the baby tub (which fits nicely in the kitchen sink, if that is accessible).
- Post child’s schedule so that all caregivers can easily find it. That way when the parents are gone caregivers can maintain consistency with the child’s schedule. (i.e. On the fridge, next to child’s bed or play space, etc.) Also make a copy to give to the nurses to keep in their information binder.

Be prepared for emergencies:

- Keep a clean trach attached to ties or chain in a baggie and tape it to the ventilator for emergencies.
- Post a sign of emergency airway care near vent for all caregivers

Hints for Home Nursing: Having extra people in your home

- Create a “nurse area.” This will give them space to chart, store paperwork, and keep their coats and other belongings during their shift.
- Don’t be afraid to ask for more nursing hours or to cut back your nursing hours based on your comfort with caring for your child. This is your child and they are here to support you in caring for your child.
- Don’t be afraid to ask your nurses for more assistance or to ask them to step back. Many of the nurses are used to doing total care for their patients. Let them know that you are able to care for your child and want to provide care. Likewise, don’t be afraid to ask them to help more if you are feeling overwhelmed.

Include your child in your family’s life!

- Have them sit with you while having dinner, bring them into the room you are in to play, take them outside with you, if they are an infant, carry them with you in a baby carrier. It is more difficult to organize moves due to the ventilator, but not impossible. Be creative!
- Ask for help from other parents who have been through this. The hospital has a contact list of parents willing to discuss what home life is like. Parents WANT to share their knowledge and experiences to make your transition home easier. You are not alone – use your resources!
- HAVE FUN! It has been a long journey and you finally made it home. ENJOY EVERY MINUTE!
**Transporting Your Child**

*Stroller Hints from Families Who Have Been There*

**General Information:**
- Transporting your child with a tracheostomy and ventilator can be difficult. The large amount of equipment and your child’s unique needs means finding a stroller or wheelchair can be hard to do.
- The lists below are products used by families who have found them helpful. It is important to talk with your child’s physical therapist before you decide on a stroller so you can choose the best one for your child’s unique needs.

<table>
<thead>
<tr>
<th>Stroller Type</th>
<th>Positives</th>
<th>Negatives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maxi-Cosi Foray Stroller</td>
<td>- Provides good support for children with poor muscle tone</td>
<td>- Expensive</td>
</tr>
<tr>
<td></td>
<td>- Holds kids up to about 4 years old</td>
<td>- There is enough room to carry ventilator and trach supplies, but not much else.</td>
</tr>
<tr>
<td></td>
<td>- Moves around well.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Folds and goes in a car easily.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Joovy Caboose Stroller or Baby Trend Sit n Stand Stroller</td>
<td>- Holds an infant car seat</td>
<td>- Does not provide good support for children with poor muscle tone once they are too big for an infant car seat.</td>
</tr>
<tr>
<td></td>
<td>- Moves around well.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Folds and goes in a car easily.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Storage is great for vent and trach supplies</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bob Jog Stroller</td>
<td>- Holds an infant car seat</td>
<td>- Expensive</td>
</tr>
<tr>
<td></td>
<td>- Provides good support for children with poor muscle tone</td>
<td>- Bulky, takes up a lot of space in car, not easy for narrow isles in stores</td>
</tr>
<tr>
<td></td>
<td>- Holds kids up to about 5 years old</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Moves around well.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Storage is adequate for vent and trach supplies</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kid Cart</td>
<td>- Provides excellent support for children with poor muscle tone</td>
<td>- Expensive</td>
</tr>
<tr>
<td></td>
<td>- Storage is designed for vent and trach supplies</td>
<td>- Bulky, can be hard to transport in a regular car</td>
</tr>
<tr>
<td></td>
<td>- Specially designed for your child</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Insurance will often cover the cost</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wheelchair</td>
<td>- Provides excellent support for children with poor muscle tone</td>
<td>- Not designed for infants and toddlers</td>
</tr>
<tr>
<td></td>
<td>- Perfect for older children who need support getting around</td>
<td>- Bulky, can be hard to transport in a regular car</td>
</tr>
<tr>
<td></td>
<td>- Specially designed for your child</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Storage is designed for vent and trach supplies</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Insurance will often cover the cost</td>
<td></td>
</tr>
</tbody>
</table>
Tracheostomy Equipment needs: 
What you will need every month

General Information:
- There are a lot of supplies needed to care for your child with a tracheostomy and/or ventilator. Spending time organizing your home and supplies is helpful.
- The supplies should arrive 3-5 days before your child comes home. Double check that all supplies have arrived and you have everything you need before taking your child home.
- The number of supplies you can receive will be different depending on your insurance company. If you are running low on supplies contact the company that sends your Durable Medical Equipment (DME) supplies. Sometimes a letter of medical necessity from your doctor can help increase the number of supplies.

<table>
<thead>
<tr>
<th>Topic</th>
<th>Supplies</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Trach</strong></td>
<td>□ Same size trach (this is the size in use) (4)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Size smaller trach for emergencies (1)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Velcro ties (30)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Ties to secure swivel adaptor to trach – Either white ribbed twill ties (1 roll) or Sureties (2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Scissors (for cutting ties) (2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ IV sponges (2 boxes) (if using a trach dressing)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Cotton tip applicators (Q-tips) (2 boxes)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Trach chain (2 chains) – obtain from CHCO RT</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Chain Cutter (1) – obtain from CHCO RT</td>
<td></td>
</tr>
<tr>
<td><strong>Suctioning</strong></td>
<td>□ Suction catheters (1 case)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Suction machine (2 machines with power cords)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Suction canister with tubing (2 full set ups)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Saline Bullets (2 boxes)</td>
<td></td>
</tr>
<tr>
<td><strong>Ventilator</strong></td>
<td>□ 2 Ventilators set to child’s individual settings</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Heated vent tubing for bedside vent (4 sets)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Vent tubing for portable vent (4 sets)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Humidifier for bedside vent (1)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Humidity chamber (4)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Swivel adaptors (4)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Flexible adaptors (4)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Artificial nose for use with portable vent, also called an HME. (30)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Vent air filters (2 for each ventilator)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Power cords for each vent</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ External battery for portable vent</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Car power adapter for portable vent</td>
<td></td>
</tr>
</tbody>
</table>
| Mist Collar Supplies | ☐ Corrugated tubing (1 box)  
☐ Drain Bags (4)  
☐ Tracheostomy Masks (4)  
☐ Nebulizer chamber (4)  
☐ Humidity Chamber (4)  
☐ O2 port (1)  
☐ Compressor |  |
|---|---|---|
| Other Related Supplies | ☐ Ambu-bag – (Self inflating resuscitation bag) (2)  
☐ Go Bag (2) (see handout, “Transporting my child who is ventilated” for contents)  
☐ Oxygen tubing (length based on need)  
☐ Nebulizer set up (1)  
☐ MDI set up- both for inline use and for use directly with the trach (1 each)  
☐ Pulse Ox machine (1 with power cord)  
☐ Pulse Ox Probes (2)  
☐ Oxygen –(either liquid or a concentrator in addition to smaller portable tanks)  
☐ Gloves (4 boxes)- Gloves are needed for the home care providers |  |
| Water Supplies  
(NOT supplied by DME) | ☐ Distilled water in bottles (1 case)  
(To fill the humidity chamber on the humidifier) |  |
| Other | | |
**Gastrostomy (G-Tube) Equipment needs:**
**What you will need every month**

**General Information:**
- There are a lot of supplies needed to care for your child with a gastrostomy (G-Tube). Spending time organizing your home and supplies is helpful.
- Feeding supplies should be delivered to the hospital by your feeding supply company 3-7 days before your child goes home.
- Make sure you take a few days to try out the new supplies to make sure they work and that you are comfortable using them.
- The number of supplies you can receive will be different depending on your insurance company. If you are running low on supplies contact the company that sends your Durable Medical Equipment (DME) supplies. Sometimes a letter of medical necessity from your doctor can help increase the number of supplies.

<table>
<thead>
<tr>
<th>Topic:</th>
<th>Supplies:</th>
<th>Notes:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>G-Tube supplies</strong></td>
<td>□ G-button set (2)- if applicable</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Mic-key/Mini One extensions (4)- if applicable</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Straight entry extension tubing for venting G-Tube (1)- if applicable</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Feeding bag (30)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Cath tip 60ml syringes (8)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ IV sponges (2 boxes)- if needed</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Feeding pump with power cord (1)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Feeding pump carrying bag (1)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ IV pole (1)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Formula (one month supply)</td>
<td></td>
</tr>
</tbody>
</table>

| Supplies NOT provided by your enteral feeding company: | □ Maalox-Aquaphor ointment: you can mix your own at home. Your care team can show you how to do this. |
|                                                       | □ Special tape for sensitive skin: (examples include Molnlycke Health Care Products, like mepitec tape and meplex. You can purchase these at Walgreens as special order, but they can be expensive. |
|                                                       | o You can work with your nurses to change to products that are easier to get at home. |
|                                                       | o Sometimes Medicaid will cover these products with a letter of medical necessity. The case manager can help you with this |

| Other: | □ | □ | □ |
Supplies NOT Provided by DME

General Information:
- There are a lot of supplies you will need to care for your child with ventilator and G-Tube that are NOT provided by your DME companies.
- You will need to buy or get the below items to support your child’s care, the equipment delivered by the durable medical equipment (DME) company, and your home nurses.

<table>
<thead>
<tr>
<th>Topic</th>
<th>Supplies</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Supplies</strong></td>
<td>Medicine and vitamins&lt;br&gt;Medicine syringes&lt;br&gt;Syringe caps&lt;br&gt;Medicine cups&lt;br&gt;Baby food/Oral food&lt;br&gt;Diapers / Baby wipes&lt;br&gt;Diaper creams and other ointments&lt;br&gt;Thermometer&lt;br&gt;Blue med clamps&lt;br&gt;OB pads&lt;br&gt;Distilled Water&lt;br&gt;All other basic baby supplies your child would need if they did not have a trach.</td>
<td></td>
</tr>
<tr>
<td><strong>Equipment</strong></td>
<td>Extension cords with three prong capability&lt;br&gt;2 power strips with three prong capability&lt;br&gt;Shelf to hold batteries and extra equipment that is charging&lt;br&gt;Flashlight/night light (disc ones that you can just push work best)</td>
<td></td>
</tr>
<tr>
<td><strong>Cleaning</strong></td>
<td>White Vinegar for cleaning trach supplies&lt;br&gt;Bottle of rubbing alcohol for cleaning&lt;br&gt;Bottle of hydrogen peroxide for cleaning supplies (not for use on skin- it actually damages skin)&lt;br&gt;Baby bottle brush&lt;br&gt;Plastic tubs for soaking equipment</td>
<td></td>
</tr>
<tr>
<td><strong>Storage and Organizing</strong></td>
<td>Baggies for storing equipment (Freezer quality gallon and quart, Regular plastic snack size)&lt;br&gt;Permanent markers for labeling&lt;br&gt;Larger plastic bins for storing supplies&lt;br&gt;Clear plastic drawers for supplies&lt;br&gt;Baskets for organizing supplies</td>
<td></td>
</tr>
<tr>
<td><strong>Supplies for your home Nurses:</strong></td>
<td>Paper towels or inexpensive washcloths (This is for them to use after washing their hands. They are not allowed to use a hand towel that is used by the whole family.)&lt;br&gt;Hand sanitizer&lt;br&gt;Hand Soap in the bathroom they use most&lt;br&gt;Toilet Paper</td>
<td></td>
</tr>
</tbody>
</table>
**General Information:**
- It is very important that the equipment used to help your child is clean and working correctly.
- This is important to prevent infections in your child and to make sure the equipment will continue to work correctly.
- This list will help you remember all the important things you will need to do to make sure your equipment is clean, working well and is safe for your child.

<table>
<thead>
<tr>
<th>How Often</th>
<th>What to Do</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Every Day:</strong></td>
<td>□ Fill humidity chamber (Change out sterile water bag as needed)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Charge all batteries, portable ventilator, suction machine and feeding pump</td>
<td></td>
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<tr>
<td></td>
<td>□ Maintain full oxygen tank near child’s space (Keep connected to ambu bag)</td>
<td></td>
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<tr>
<td></td>
<td>□ Rinse out suction canisters with soap and water (Leaving a little soapy water in the canister helps secretions not get dried out easier to clean.)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Change HME if used that day</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Check/refill contents in Go Bag</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Change out feeding bag</td>
<td></td>
</tr>
<tr>
<td><strong>Every Week:</strong></td>
<td>Choose the same day of the week to do these things, like every Monday.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Change vent tubing and swivel adaptor on both ventilators</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Change humidity chamber</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Clean filter on oxygen concentrator</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Clean filters on ventilators (this can be done multiple times during the week, depending on environment, situation, etc.)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Change tracheostomy tube</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Change mist collar tubing and mask</td>
<td></td>
</tr>
<tr>
<td><strong>Every Month:</strong></td>
<td>Choose the same day of every month to do these things, like the first Monday of the month. This makes it easier to remember.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Change in-circuit air filters on both ventilators</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Change out suction canisters</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Change out all empty oxygen tanks and call for replacements</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Inventory supplies and order new month’s supplies</td>
<td></td>
</tr>
</tbody>
</table>
Transporting My Child who is Ventilator Dependent

General Information:
It is very important to have emergency supplies with your child at ALL TIMES. You will need a “go bag” with all needed emergency supplies that always stays with your child. This emergency bag should be sturdy, close completely with a zipper, and allow the contents to be easily found within the bag.

Supplies needed:
- Go Bag
  - Extra trach (size in use) – with obturator
  - Extra trach - Size smaller for emergencies
  - Trach ties/chain
  - Trach cleaning supplies
  - Artificial noses – HME
  - Chain cutter (for those who have a chain)
  - Suction Catheters
  - Saline Bullets
  - Alcohol wipes
  - Extra G-tube button
  - G-tube extension
  - G-tube care supplies
  - Sterile water
  - Wet wipes
  - Lubricant packets
  - 5ml syringe
  - Ambu bag
  - Rescue Vac and supplies

- Charged Transport ventilator (back up ventilator) on current settings.
- Spare battery and AC power cord: charged.
- Oxygen tank and spare O2 tank with “O” ring for seal.
- Power cords for external battery and ventilator.
- Car charger power cord for ventilator
- Portable Suction Machine
- Hand sanitizer or antibacterial wipes
- Regular baby needs
- Other feeding supplies not in “go bag”
- Stroller or wheelchair

Transportation procedure:
1. Ensure ventilator battery is well charged as well as the back-up battery.
2. Place child in stroller or wheelchair.
3. Make sure all equipment (including the obturator) is ready and or attached to chair when appropriate.
4. Place child on transport ventilator
5. Make sure your child is stable, has good chest rise and HME (“nose”) is in line.
6. Turn off bedside ventilator when you are sure the child is ready to go and breathing well.
7. Attach circuit to stroller or wheelchair to ensure no hoses get run over or kinked.

Please ask your healthcare provider if you have any questions regarding this information, or have other learning needs.
Community Resources

Parent to Parent of Colorado: http://www.p2p-co.org/
Parent to Parent of Colorado (P2P-CO) is a parent-led and run organization that assists other parents of children with special health care needs. The organization offers support groups, Colorado-specific resources, and opportunities to be involved in public policy.

Community Centered Boards:
https://www.colorado.gov/pacific/hcpf/community-centered-boards
Case Management Services offers county-based resources available to residents. The Boards can assist families in arranging services for their children (like Early Intervention, or Family Support Services). The Boards are also able to help problem solve issues with services.

Pulmonary Hypertension: http://www.phassociation.org/patients
A site about pulmonary hypertension (PH) with opportunities to connect to other families diagnosed with PH, education materials, and links to other websites with PH information.

Rocky Mountain Down Syndrome Association: http://www.rmdsa.org/
This organization has information about Down syndrome and opportunities to connect to other families with children who have Down syndrome. The organization has events through the year to meet others and raise funds for Down syndrome research. They have information on community resources available.

Breathe Easy Facebook Group
A closed Facebook group for families with children who have (or had) a tracheostomy. A request must be sent to the group administrator in order to join. This site is in no way monitored, controlled or viewed by members of the Ventilator Care Program at Children’s Hospital Colorado.

These resources are to provide support for families who have children with complex respiratory conditions. Medical advice from these resources is no replacement for that given by your medical team at CHCO. For respiratory questions or concerns, contact the Pulmonary Clinic at (720) 777-6181. For emergencies, call 911. Children’s Hospital Colorado is not affiliated with any of these organizations and does not endorse any of the information that they may give you.
WELCOME TO THE ONE-WAY TRACHEOSTOMY VALVE CLINIC

What to expect at your visit:

Before Your Visit:
- Coordination of scheduling
- Pre-authorization of insurance

During Your Visit:
- Find the One-Way Valve Clinic within the Multidisciplinary Clinic on the 2nd floor of the outpatient pavilion.
- Check in for your visit at the Multidisciplinary Clinic check-in desk.
- Meet the speech-language pathologist and respiratory therapist in a consultation room. This room is set up in a playful environment in order to achieve higher tolerance and success.
- You will answer some brief medical and developmental questions about your child.
- Your child will participate in manometry testing. This is a very simple and non-invasive way to measure the air space between the walls of the trachea and the tracheostomy tube, with an adaptor placed on the tracheostomy hub.
- If appropriate, your child will complete a trial with a one-way tracheostomy valve while engaged in fun and motivating activities.
- You may be asked to complete a short questionnaire about your child’s voice and communication.
- We will create and give you a plan for the one-way valve at the end of the visit. This plan will include our contact information.

After Your Visit:
- We will coordinate care with home therapists.
- We will also communicate the results of your visit to your primary care or referring provider.
- Feel free to contact the speech-language pathologist or respiratory therapist via phone, email, or MyChart with any questions or concerns.
- We may recommend additional follow-up consultations in this clinic as needed, as long as your child has a tracheostomy.

Contact Us

For more information, or to schedule an appointment, please call 720-777-6181.

Arwen Jackson, MA CCC-SLP:
720-777-4460
arwen.jackson@childrenscolorado.org

Roberta Cox, RRT: 720-777-5140
roberta.cox@childrenscolorado.org

For information about our Tracheostomy Clinic, call 720-478-0281, and for our Ventilator Care Program, call 720-777-6181.
Helpful Hints:
- To complete the evaluation, you must bring your child’s suctioning equipment, pulse oximeter and spare tracheostomy tubes.
- If your child uses a ventilator during the day, please bring it to the visit (even if you are in the process of weaning).
- It is a good idea to bring toys or activities that are especially motivating for your child.
- Bring a current Individualized Education Plan (IEP) or therapy-related paperwork to the visit. Your home therapist is also welcome to attend.
- Plan to arrive 30 minutes before your scheduled appointment time to allow for ease of parking and check-in.

One-Way Valve Clinic Notes
You can use this area to list questions you would like to discuss at your visit:

1. 
2. 
3. 
4. 
5. 

Thank you for allowing us to take care of you and your child!
**Glossary**

**Airway** – the nose, mouth, and trachea, including the tracheostomy tube

**Artificial Nose** – a filter that fits on the tracheostomy (trach) tube to trap humidity when a child is not connected to a humidifier (see below). Also known as: HME- Heat Moisture Exchanger

**Ambu Bag** - self inflatble resuscitation bag for “bagging” (providing positive pressure ventilation) for your child

**Aspiration** - when solids, liquids, or saliva goes into the airway (trachea) instead of the esophagus

**Cap** - covers the trach when it is not needed; helps to prepare your child to have the trach removed

**Catheter** – A small, soft tube that connects to suction. Used to remove secretions from the trach tube, mouth, and nose

**Durable Medical Equipment (DME)** - this medical equipment is not disposable. This is also often used to refer to the companies that provide medical equipment for your child

**Decannulation** - removal of the tracheostomy tube from the trachea. May be accidental and need to be reinserted emergently; or on purpose by the doctor when a trach tube is no longer needed

**Esophagus** – the tube food goes down from the mouth to the stomach

**Face Mask** – a mask used in an emergency; to be placed over your child’s nose and mouth to assist in breathing

**Humidifier** – A machine that adds extra moisture to the air or ventilator circuit

**Lumen** - the inside of a tube (such as a tracheostomy tube)

**Modes of Ventilation** - different ways the ventilator can provide breathing support

- **Continuous Positive Airway Pressure (CPAP)** - Provides a constant increased pressure to the lungs to make it easier for a patient to breathe in
- **Pressure Support (PSV)** - Allows the patient to initiate all breaths but continues to provide pressure support and PEEP
- **Synchronized Intermittent Mechanical Ventilation (SIMV)** - Provides pressure support, PEEP and a rate to support your child above their own initiated breaths
- **Average Volume Assured Pressure Support (AVAPS)** - Provides pressure support to achieve a set tidal volume with each breathe

**Obturator** – a guide “stick” that fits inside the trach tube to add some stiffness to the tube when reinserting it into the stoma. It is removed as soon as the tracheostomy tube is in place.
Oxygen Compressor - a machine that concentrates oxygen from the air to give to a patient.

Retractions – pulling in and out between ribs, below ribs, or under the neck when a child is breathing

Saline - sterile saline (salt water) that can be used for suctioning

Secretions - the fluid created in the lungs and trachea that is expelled during coughing and suctioning (also known as: mucus or boogers)

Self-Inflating Bag – a breathing bag that helps to ventilate your child during suctioning or in an emergency. Also called an Ambu Bag.

One-way valve – a valve that is placed on the tracheostomy tube to help your child work on swallowing and speaking

Stoma - the hole that was surgically created for the tracheostomy tube to enter into the trachea

Trach Collar - a device used to create heat and humidity around the open tracheostomy when not attached to the ventilator (this is very important)

Tracheotomy - a surgical procedure to create a stoma for placement of a tracheostomy tube

Tracheostomy tube - the tube that is inserted into the trachea via the stoma to provide an artificial airway either to bypass the upper airway or to provide long term ventilation

Ventilator- the machine that assists a patient in breathing by mechanically delivering breaths via the tracheostomy tube

Ventilator Settings - the levels on the mechanical ventilator machine

- Tidal Volume - the volume of air delivered with each ventilator breath
- Rate - the least amount of times the ventilator will deliver a breath each minute
- PEEP - Positive end expiratory pressure - the amount of pressure left in the lungs at the end of a breath
- Pressure Support - the pressure supplied to the vent circuit for supporting extra breaths (when a child breathes faster than the “rate” – see above)
- Inspiratory Time - the time, in seconds, that they ventilator takes to deliver a breath