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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!!!

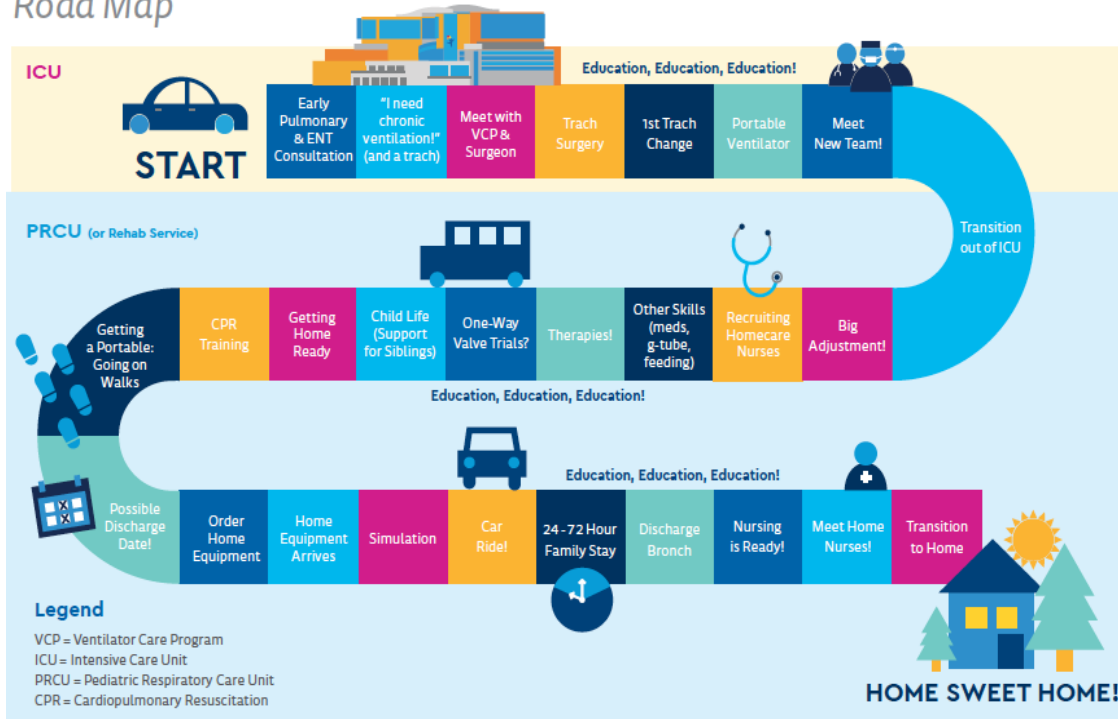
Sincerely,

Dr. Christopher Baker (Medical Director)
and the entire Ventilator Care Program Team

BREATHING INSTITUTE

Chronic Ventilation

Road Map



- Who is my team?
 - Your VCP team has many members:
 - Intensive Care Unit (ICU) medical team – the primary team who will take care of your child until the 9th Floor transfer
 - PRCU (9th Floor) medical team – prepare you and your child to go home safely
 - Nursing and Respiratory Therapy – will complete much of your training
 - Case Managers – help to arrange home care (nursing, equipment, supplies)
 - Social Workers – support you through the many challenges
 - Physical, Occupational, and Speech Therapists – will partner with you to maximize your child's strengths and address developmental goals
 - Dietitians – make sure your child receives proper nutrition to grow and thrive
 - Child Life Specialists – help patients and siblings along the way

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IN CARE OF KIDS

- What are the challenges and how will we help you?
 - This is a HUGE STRESS. – Our entire team will help support you along the way.
 - Education starts in the ICU and continues until you go home – and beyond!
 - Children with a tracheostomy/ventilator at home must have an awake/alert/fully-trained caregiver with them at all times. (For safety, they need this 24/7.)
 - We'll train at least two family caregivers to be experts (other family can also be trained).
 - This takes a LONG TIME. – One of the hardest parts is being here so long.
 - No matter the challenges, we will make a custom plan that fits your family's needs.

- When can I go home?
 - Many children will go straight home when they are discharged from the 9th Floor. This happens when all the education is complete and a safe plan is in place.
 - In some cases, children may be transferred to the hospital in their hometown after training on the 9th Floor is complete.
 - Your insurance and medical teams will have to approve the plan.
 - After going home, your child will return to VCP Clinic for follow-up.

- As you can see, the process takes time. The sickest babies and children sometimes have to stay in the ICU for over a year. The step that usually takes the longest is finding home nurses – families often have to wait on the 9th Floor for many months. We have worked hard to create an efficient process, but we know that your child's safety is your top priority. Safety is our top priority, too!

CONTACT US:

**[www.childrenscolorado.org/doctors-and-departments/departments/
breathing-institute/programs/ventilator-care-program/](http://www.childrenscolorado.org/doctors-and-departments/departments/breathing-institute/programs/ventilator-care-program/)**

Tel: 1 (720) 777-6181

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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.



Ventilator Care Program

Tracheostomy and Ventilator Skills Checklist

This checklist is a guide to track your progress learning the skills you'll need to take care of your child at home. You'll keep learning and practicing these skills until your child is discharged to make sure you're completely comfortable with them before going home.

Task	Caregiver initials	Caregiver initials	Nurse/RT initials	Date
1. Stoma Care/Skin Assessment				
2. Trach Tie/Chain Change				
3. Suctioning				
4. Trach Size/Backup Trach Size				
5. Routine Trach Change				
6. Emergency Trach Change				
7. Bag-Trach Ventilation				
8. CPR Anytime <ul style="list-style-type: none"> Suctioning, bag-trach ventilation and routine trach change education must be completed before taking the CPR class 				
9. Emergency Scenarios				
10. Humidification Set Up				
11. Oxygen				
12. Pulse Ox				
13. Ventilator Set up				
14. Ventilator Settings				

Task	Caregiver initials	Caregiver initials	Nurse/RT initials	Date
15. Ventilator Alarms/Troubleshooting				
16. Ventilator Circuit Change				
17. Heat Moisture Exchanger (HME)				
18. Portable Ventilator Set Up				
19. Transfer to Portable Ventilator				
20. Emergency Equipment/Go Bag				
21. Transporting Your Child <ul style="list-style-type: none"> All the above education must be finished before you can take your child off the unit without RT or nursing staff 				
22. Independent Stay <ul style="list-style-type: none"> All the above education must be finished before the independent stay 				
23. High Fidelity Simulation <ul style="list-style-type: none"> All the above education except the independent stay must be finished before the simulation 				
24. Car Ride <ul style="list-style-type: none"> All education for transporting your child off the unit must be finished before the car ride 				

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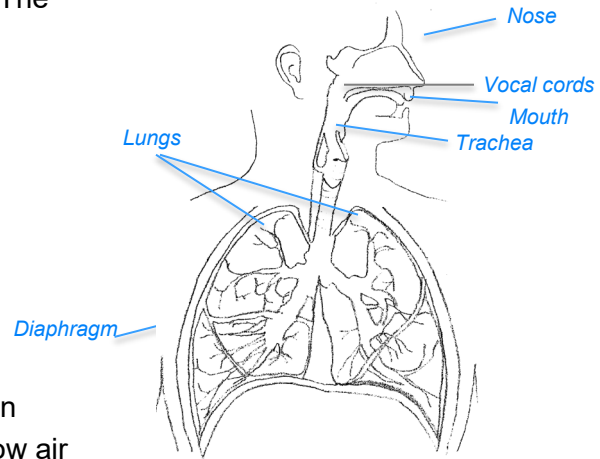
The Normal Breathing System

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 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 look 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 doctor if you have any questions regarding this information, or have other learning needs.

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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. Three to seven 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, changing the trach ties or chain, suctioning, changing the tube, and what to do in an emergency. 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.

Custom Tracheostomy

- Your child's medical team may determine that your child needs a custom tracheostomy tube. A custom tracheostomy tube is one that has a length or type of material that is different from a standard tracheostomy tube.
- These tubes need to be specially ordered and may take several days to weeks to be delivered to the hospital or home.

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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 can 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 can't breathe on their own. Sometimes a child may become dependent on a ventilator because of their 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. 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 doctor if you have any questions regarding this information, or have other learning needs.

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Understanding Mechanical Ventilation

General Information:

This handout is meant to give a basic understanding of the terms used in talking about chronic ventilation. Please ask your healthcare provider if you have questions about this information, or have other learning needs.

- Invasive Ventilation:
 - **Using either an Endotracheal tube (ETT), or Tracheotomy tube for ventilation**
- Non Invasive Ventilation:
 - **Using a mask for ventilation.**
- VT or Tidal Volume:
 - **The amount 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 that 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. Gives a gentle stream of air to keep the airways open, but in addition gives another, higher pressure that will help give a bigger breath by pushing a little more air in.**
- AVAPS (Assured Volume Averaging Pressure Support):
 - **An optional setting that can be used with BiPAP**

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Is My Ventilated Child Sick?

General Information

It is important to be able to tell when your child might be getting sick and when you should call your child's doctor. You should be worried if you notice any change from your child's baseline. It is important to watch for these signs which may mean that your child is getting sick.

Change in secretions

It is important to check your child's secretions every time you suction his or her tracheostomy tube. Call your child's doctor if you notice any of the following:

- Increase in secretions: If you need to suction your child more often than you normally do or you are getting more secretions from your child's tracheostomy tube when you suction, this may be a sign that your child is sick
- Change in color of secretions: If your child is getting sick their secretions may become yellow, green, bloody, or brown. It is important to notice 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 a sign 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 starts working harder to breathe. Call 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 their ribs, under their ribs, or above their collar bone this is a sign that they are having a harder time breathing and may be sick.
- Breathing fast: If your child is breathing faster than normal this is a sign that they are working harder to breathe and may be getting sick.

Decreasing Oxygen saturations

Call your doctor if your child's oxygen saturations are going down or if they need more oxygen than usual to keep their oxygen saturations above 90%.

Wheezing

If your child is sick you may be able to hear them wheezing. Call your child's doctor if you notice this.

Fever

Call your child's doctor if they develop a fever.

Please ask your doctor if you have any questions about this information, or have other learning needs.

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Bag-Tracheostomy Ventilation: Manually ventilating your child

General information:

Sometimes, you may have to manually ventilate your child to help them 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 doctor if you have any questions regarding this information or have other learning needs.

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Routine Suctioning

General Information

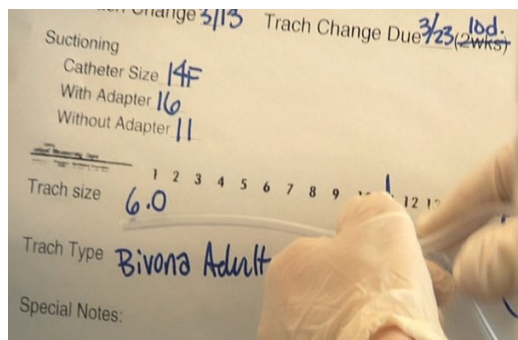
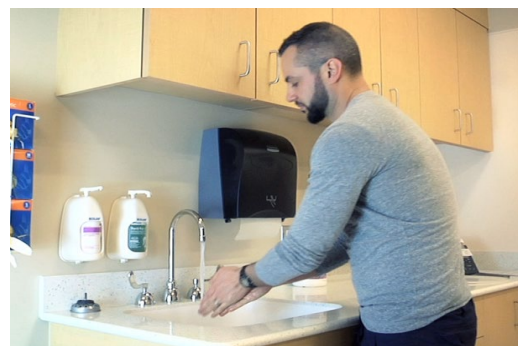
You will need to suction your child's tracheostomy to keep it open and free of secretions. To do this you will need the following supplies:

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 a clean towel or a 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 of your hands until dry.
2. If your child is on a ventilator, wipe the adaptor with an alcohol swab and let it completely dry while you prepare for the procedure.
3. Verify the measurement for suction depth.



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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 based on whether you use the adaptor or not.



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10. Insert the catheter the proper distance into 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 put a few drops of saline into your child's trach 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

Routine and Emergency trach change handouts.

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 the closed suction catheter to the suction tubing and unlock the thumb valve
4. Turn on the 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 the catheter down the tube to the length that has been told to you by your child's medical team and verify the 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 the catheter completely and make sure black tip of catheter can be seen in suction window



- Remove the top of saline bullet. Open the irrigation port and squeeze a few drops of saline into the port without activating thumb valve (the saline bullet fits directly into the port)



- Pass the 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.

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Routine Tracheostomy Change

General Information:

Changing your child's tracheostomy tube is a routine part of caring for your child's tracheostomy. When doing a routine trach change, you should have someone else that has been trained help you.

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

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.



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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. Have your helper hold your child's trach in place while you complete this step.
15. If your child has a cuffed trach; inflate the cuff using the 5cc syringe.



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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:

1. Tracheostomy tie change handout

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

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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 air dry 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 doctor if you have any questions regarding this information, or have other learning needs.

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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.
10. Trim off any excess fabric.
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:

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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:

1. Tracheostomy Stoma Care handout
2. Routine Tracheostomy Change handout

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

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Emergency Tracheostomy 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 in an emergency without the assistance of a helper.

If 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, start chest pushes or CPR. 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 are 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 a few drops of sterile saline into the trach tube; this may help to loosen the secretions
4. Suction.
5. If plug is not cleared or you are 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

If 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, start chest pushes or CPR. Call for help and call 911

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

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Independent Stay

What is an Independent Stay?

An **Independent Stay** is a chance for you to see what it will be like to take care of your child at home when they leave the hospital. The Independent Stay is part of what you need to do before your child goes home. Home care nurses may be coming to your home to help you care for your child, but they may not always be there when you need them. It is important that you know what to do. The Independent Stay is part of the education you will receive in the hospital and is NOT a pass/fail test.

During the Independent Stay

- Only one person will do an Independent Stay at a time. The person must provide all the care for the child for about 24 hours. Independent Stays may be shorter or longer than 24 hours based on the needs of the family. The length of the Independent Stay will be agreed on by the family and medical team. If there will be more than one caregiver at home, each of them must do an Independent Stay before the child can go home.
- The nurses will help you make a schedule for your child. The schedule will include medication times, feeding times, and respiratory treatments. You can keep this schedule in your child's room, and use it when you practice before the Independent Stay as well as during the actual Independent Stay.
- You need to be with your child at all times during the stay. Bring anything that you will need during the Independent Stay (clothes, phone, food, etc.).
- You will be doing all the care that your child needs during the Independent Stay, including overnight cares. This will include giving medicine, doing feedings, suctioning the tracheostomy, respiratory treatments, G-tube care, and responding to the breathing machine alarms, and pulse ox. You will ask the nurses for feeding equipment and medications when they are due.
- While you are doing all the care for your child, the nurses will still be available to help if you need them. Safety is our priority. Your child will have a bedside nurse like always, but that nurse will try to leave you alone to do the care. They will monitor your child at all times on the monitors at the nurse's station.
- If your child is not in isolation, you can take them for a walk or go to the cafeteria. You are encouraged to take your child with you if you are going to leave the bedside. You must stay at the hospital.
- We want you to be comfortable providing care for your child during your Independent Stay. We understand that you may be learning a lot of new things. If you are not comfortable doing something for your child, please ask the nurse for help. We are here to help and want you to be as comfortable as possible with all your child's cares before you go home.

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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.

Hospital Staff	What we will do:	Notes:
Case Manager	<ul style="list-style-type: none"> • Set up home care nursing and non-respiratory durable medical equipment (DME) • Set up outpatient or home based therapies • Check on insurance status and waiver status • Talk with insurance providers 	
Respiratory Therapy	<ul style="list-style-type: none"> • Set up needed respiratory equipment with respiratory companies. • Teach and make sure you understand all respiratory related education (see education checklist) 	
Registered Nurse	<ul style="list-style-type: none"> • Teach and make sure you understand all nursing related education such as g-tube, feeds, child's care, and medications. • Make a medication schedule with caregivers that is easy to understand. • Make sure you understand all respiratory related education 	
Doctors	<ul style="list-style-type: none"> • Talk with your child's primary care provider (PCP) and other community team members regarding patient's care • Make sure you understand all medical education • Make sure you understand everything you have learned about taking care of your child. 	
Social worker	<ul style="list-style-type: none"> • Ask you about other things you may need at home after discharge • Help to connect (refer) you with community programs that may help you. • Help you with division of motor vehicles (DMV) paperwork for disabled parking • Help you talk to electric companies about your child's special needs. • Help you talk to local Emergency services about your child's special needs. • Make sure you have a telephone that is a land line in your home. 	
Therapies	<ul style="list-style-type: none"> • Make therapy recommendations for home • Communicate with outside therapy agencies/therapist • Set up mobility and seating equipment if needed 	
Resident Liaison	<ul style="list-style-type: none"> • Help to schedule doctor and therapy appointments after you go home. 	



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.

Learn about my child's care	Date DONE	General Information:	Notes:
		Receive Ventilator Care Program Handbook and handouts	
		Schedule appointments to learn about my child's care <ul style="list-style-type: none"> • The care team will work with you to find times that work with your schedule 	
		Learn about and participate in my child's care: become Independent!	
		Go to scheduled care conferences with the hospital care team.	
	Date DONE	Watch videos regarding my child's care	Notes:
		"Manually ventilating your child"	
		"Emergency Airway Care: Ventilator Malfunction"	
		"Emergency Airway Care: Decannulation"	
		"Emergency Airway Care: Plugged Tracheostomy"	
	Date DONE	Attend a CPR Anytime Tracheostomy CPR class	Notes:
		<ul style="list-style-type: none"> • This class is provided by Children's Colorado here in the hospital. • Your care team will tell you when you are ready to take the class and help you to schedule it. 	
	Date DONE	24-72 hour stay	Notes:
		Each caregiver needs to complete a 24-72 hour stay in the hospital with your child. <ul style="list-style-type: none"> • This will help prepare you to be home with your child without help from the hospital staff. • 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. 	
		Caregiver #1 (who) _____ When _____	
	Caregiver #2 (who) _____ When _____		
	Caregiver #3 (who) _____ When _____		

Get my home and car ready	Date DONE	Make a special space for your child at home	Notes:
		See “Helpful hints for home” and “Equipment” sections to help you do this.	
	Date DONE	Get your car ready:	Notes:
		Car Seat: <ul style="list-style-type: none"> Get a car seat and bring to hospital for child’s fitting Go on Car Ride: <ul style="list-style-type: none"> The care team will help you to go on car rides with your child before you go home. This will help to make sure the car seat and all needed supplies will fit and work well while you are driving. 	
Get my child’s medications ready	Date DONE	Learn about my child’s medication	Notes:
		Obtain medication handouts / information	
		Learn about what each medication does and how it helps your child.	
	Date DONE	Create a schedule of my child’s home medications	Notes:
		The care team will work with you to develop a schedule that works for you and your family’s needs.	
	Date DONE	Fill Prescriptions:	Notes:
		Obtain child’s medication prescriptions from for doctors.	
		Fill at the pharmacy 3-7 days before you go home.	
	Learn how to give your child’s medications with your home supply. Practice with the nurses.		
Meet with my community care partners	Date DONE	Meet with home care companies	Notes:
		Complete a home visit with the home nursing agency <ul style="list-style-type: none"> You will probably meet with the Nursing director and your child’s new home nurses. 	
		Complete a home visit with the respiratory company <ul style="list-style-type: none"> The respiratory company will make sure your home is ready for the ventilator equipment. 	
		Meet with other medical equipment companies if needed	
	Date DONE	School and Day Care:	
		<ul style="list-style-type: none"> Create an Individual Education Plan (IEP) with your school district. (age 3 and up when applicable). You will need to meet with your child’s teachers to do this. The Learning Services team can help you to do this. 	
		<ul style="list-style-type: none"> If your child is less than 3 years old: Create an “Individualized Family Service Plan” with Colorado Early Interventions team member or with your home state. 	

Important People to talk to:	Date DONE	Pediatrician and Pulmonologist	Notes:
		<ul style="list-style-type: none"> Find a pediatrician. Your doctors can help you with this. Identify phone numbers and other ways to communicate with your primary pulmonologist. 	
	Date DONE	Make follow-up appointments with care providers.	Notes:
		<ul style="list-style-type: none"> Hospital staff and resident Liaisons will help with this. 	
	Date DONE	Local power company:	
		<ul style="list-style-type: none"> Contact your power company to let them know the importance of keeping power in your home. 	
		<ul style="list-style-type: none"> Get the completed required form for Children's Colorado to give to the power company Social work can assist you in this process. 	
	Date DONE	Local Telephone Company:	
		<ul style="list-style-type: none"> Get a landline telephone in your home. 	
	Date DONE	Division of Motor Vehicles (DMV):	
	<ul style="list-style-type: none"> Get a handicap parking permit. Social Work will assist in getting forms completed. 		
Date DONE	Local Fire Department:		
	<ul style="list-style-type: none"> 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 be 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.

Stroller Type	Positives	Negatives
Maxi-Cosi Foray Stroller	<ul style="list-style-type: none"> ▪ Provides good support for children with poor muscle tone ▪ Holds kids up to about 4 years old ▪ Moves around well. ▪ Folds and goes in a car easily. 	<ul style="list-style-type: none"> ▪ Expensive ▪ There is enough room to carry ventilator and trach supplies, but not much else.
Joovy Caboose Stroller or Baby Trend Sit n Stand Stroller	<ul style="list-style-type: none"> ▪ Holds an infant car seat ▪ Moves around well. ▪ Folds and goes in a car easily. ▪ Storage is great for vent and trach supplies 	<ul style="list-style-type: none"> ▪ Does not provide good support for children with poor muscle tone once they are too big for an infant car seat.
Bob Jog Stroller	<ul style="list-style-type: none"> ▪ Holds an infant car seat ▪ Provides good support for children with poor muscle tone ▪ Holds kids up to about 5 years old ▪ Moves around well. ▪ Storage is adequate for vent and trach supplies 	<ul style="list-style-type: none"> ▪ Expensive ▪ Bulky, takes up a lot of space in car, not easy for narrow isles in stores
Kid Cart	<ul style="list-style-type: none"> ▪ Provides excellent support for children with poor muscle tone ▪ Storage is designed for vent and trach supplies ▪ Specially designed for your child ▪ Insurance will often cover the cost 	<ul style="list-style-type: none"> ▪ Expensive ▪ Bulky, can be hard to transport in a regular car
Wheelchair	<ul style="list-style-type: none"> ▪ Provides excellent support for children with poor muscle tone ▪ Perfect for older children who need support getting around ▪ Specially designed for your child ▪ Storage is designed for vent and trach supplies ▪ Insurance will often cover the cost 	<ul style="list-style-type: none"> ▪ Not designed for infants and toddlers ▪ Bulky, can be hard to transport in a regular car

Welcome to The One-Way Tracheostomy Valve Clinic

What to expect at your visit:

Before Your Visit:

- Coordinate your visits
- Get pre-authorization of your insurance

During Your Visit:

- Find the One-Way Valve Clinic on the 2nd floor of the outpatient pavilion in the Multidisciplinary Clinic
- Check in for your visit at the Multidisciplinary Clinic check-in desk.
- Meet with the speech-language pathologist and respiratory therapist in a consult room. This room is set up in a playful way to put your child at ease.
- You will answer some brief medical and developmental questions about your child.
- Your child will have some manometry testing. This is a very simple and non-invasive way to measure how much space there is between the trachea and the tracheostomy tube.
- If appropriate, your child will complete a trial with a one-way tracheostomy valve.
- You may be asked to fill out a short questionnaire about your child's voice and communication.
- We will come up with 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 send the results of your visit to your primary care or referring doctor.
- Feel free to contact us via phone, email, or MyChart with any questions or concerns.
- We may recommend follow-up consultations as long as your child has a tracheostomy.

Helpful Hints:

- To complete the evaluation, you must bring your child's suctioning equipment, pulse oximeter and spare

IN CARE OF KIDS

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 favorites of 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 get here 30 minutes before your scheduled appointment so that you have time to park and get checked in.

One-Way Valve Clinic Notes

You can use this area to list questions you would like to discuss at your visit:

3.

4.

5.

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

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Author: Ventilator Care Program Team | Approved by Patient Education Committee | Valid through 2021

The information presented is intended for educational purposes only. It is not intended to take the place of your personal doctor's advice and is not intended to diagnose, treat, cure or prevent any disease. The information should not be used in place of a visit, call or consultation or advice of your doctor or other health care provider.

Children's Hospital Colorado complies with applicable Federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability, or sex. • ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-720-777-1234. • CHÚ Ý: Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi số 1-720-777-1234.



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 discharge. Double check that all supplies have arrived before taking your child home.
- The number of supplies you can receive varies by insurance provider. If you find that supplies are running low contact your DME providers. In some cases a letter of medical necessity obtained from your provider can help increase the number of supplies.

Topic:	Supplies:	Notes:
<u>Trach</u>	<input type="checkbox"/> Same size trach (this is the size in use) (4) <input type="checkbox"/> Size smaller trach for emergencies (1) <input type="checkbox"/> Velcro ties (30) <input type="checkbox"/> Ties to secure swivel adaptor to trach – Either white ribbed twill ties (1 roll) or Sureties (2) <input type="checkbox"/> Scissors (for cutting ties) (2) <input type="checkbox"/> IV sponges (2 boxes) (if using a trach dressing) <input type="checkbox"/> Cotton tip applicators (Q-tips) (2 boxes) <input type="checkbox"/> Trach chain (2 chains) –obtain from CHCO RT <input type="checkbox"/> Chain Cutter (1)- obtain from CHCO RT	
<u>Suctioning</u>	<input type="checkbox"/> Suction catheters (1 case) <input type="checkbox"/> Suction machine (2 machines with power cords) <input type="checkbox"/> Suction canister with tubing (2 full set ups) <input type="checkbox"/> Saline Bullets (2 boxes)	
<u>Ventilator</u>	<input type="checkbox"/> 2 Ventilators set to child's individual settings <input type="checkbox"/> Heated vent tubing for bedside vent (4 sets) <input type="checkbox"/> Vent tubing for portable vent (4 sets) <input type="checkbox"/> Humidifier for bedside vent (1) <input type="checkbox"/> Humidity chamber (4) <input type="checkbox"/> Swivel adaptors (4) <input type="checkbox"/> Flexible adaptors (4) <input type="checkbox"/> Artificial nose for use with portable vent, also called an HME. (30) <input type="checkbox"/> Vent air filters (2 for each ventilator) <input type="checkbox"/> Power cords for each vent <input type="checkbox"/> External battery for portable vent <input type="checkbox"/> Car power adapter for portable vent	

<u>Mist Collar Supplies</u>	<input type="checkbox"/> Corrugated tubing (1 box) <input type="checkbox"/> Drain Bags (4) <input type="checkbox"/> Tracheostomy Masks (4) <input type="checkbox"/> Nebulizer chamber (4) <input type="checkbox"/> Humidity Chamber (4) <input type="checkbox"/> O2 port (1) <input type="checkbox"/> Compressor	
<u>Other Related Supplies</u>	<input type="checkbox"/> Ambu-bag – (Self inflating resuscitation bag) (2) <input type="checkbox"/> Go Bag (2) (see handout, “Transporting my child who is ventilated” for contents’ <input type="checkbox"/> Oxygen tubing (length based on need) <input type="checkbox"/> Nebulizer set up (1) <input type="checkbox"/> MDI set up- both for inline use and for use directly with the trach (1 each) <input type="checkbox"/> Pulse Ox machine (1 with power cord) <input type="checkbox"/> Pulse Ox Probes (2) <input type="checkbox"/> Oxygen –(either liquid or a concentrator in addition to smaller portable tanks) <input type="checkbox"/> Gloves (4 boxes)- Gloves are needed for the home care providers	
<u>Water Supplies</u> (NOT supplied by DME)	<input type="checkbox"/> Distilled water in bottles (1 case) (To fill the humidity chamber on the humidifier)	
<u>Other</u>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	





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.

Topic:	Supplies:	Notes:
<u>G-Tube supplies</u>	<input type="checkbox"/> G-button set (2)- if applicable <input type="checkbox"/> Mic-key/Mini One extensions (4)- if applicable <input type="checkbox"/> Straight entry extension tubing for venting G-Tube (1)- if applicable <input type="checkbox"/> Feeding bag (30) <input type="checkbox"/> Cath tip 60ml syringes (8) <input type="checkbox"/> IV sponges (2 boxes)- if needed <input type="checkbox"/> Feeding pump with power cord (1) <input type="checkbox"/> Feeding pump carrying bag (1) <input type="checkbox"/> IV pole (1) <input type="checkbox"/> Formula (one month supply)	
<u>Supplies NOT provided by your enteral feeding company:</u>	<input type="checkbox"/> Maalox-Aquaphor ointment : you can mix your own at home. Your care team can show you how to do this. <input type="checkbox"/> Special tape for sensitive skin: (examples include Molnlycke Health Care Products, like mepitec tape and mepilex . You can purchase these at Walgreens as special order, but they can be expensive. <ul style="list-style-type: none"> ○ You can work with your nurses to change to products that are easier to get at home. ○ Sometimes Medicaid will cover these products with a letter of medical necessity. The case manager can help you with this 	
<u>Other:</u>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	



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 your supply companies will not send you.
- 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.

Topic:	Supplies:	Notes:
<u>Supplies</u>	<input type="checkbox"/> Medicines and vitamins <input type="checkbox"/> Medicine syringes <input type="checkbox"/> Syringe caps <input type="checkbox"/> Medicine cups <input type="checkbox"/> Baby food/Oral food <input type="checkbox"/> Diapers / Baby wipes <input type="checkbox"/> Diaper creams and other ointments <input type="checkbox"/> Thermometer <input type="checkbox"/> Blue med clamps <input type="checkbox"/> OB pads <input type="checkbox"/> Distilled Water <input type="checkbox"/> All other basic baby supplies your child would need if they did not have a trach.	
<u>Equipment</u>	<input type="checkbox"/> Extension cords with three prong capability <input type="checkbox"/> 2 power strips with three prong capability <input type="checkbox"/> Shelf to hold batteries and extra equipment that is charging <input type="checkbox"/> Flashlight/night light (disc ones that you can just push work best)	
<u>Cleaning:</u>	<input type="checkbox"/> White Vinegar for cleaning trach supplies <input type="checkbox"/> Bottle of rubbing alcohol for cleaning <input type="checkbox"/> Bottle of hydrogen peroxide for cleaning supplies (not for use on skin- it actually damages skin) <input type="checkbox"/> Baby bottle brush <input type="checkbox"/> Plastic tubs for soaking equipment	
<u>Storage and Organizing</u>	<input type="checkbox"/> Baggies for storing equipment (Freezer quality gallon and quart, Regular plastic snack size) <input type="checkbox"/> Permanent markers for labeling <input type="checkbox"/> Larger plastic bins for storing supplies <input type="checkbox"/> Clear plastic drawers for supplies <input type="checkbox"/> Baskets for organizing supplies	
<u>Supplies for your home Nurses:</u>	<input type="checkbox"/> 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.) <input type="checkbox"/> Hand sanitizer <input type="checkbox"/> Hand Soap in the bathroom they use most <input type="checkbox"/> Toilet Paper	



Equipment Maintenance

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.

How Often:	What to Do:	Notes:
<u>Every Day:</u>	<ul style="list-style-type: none"> <input type="checkbox"/> Fill humidity chamber (Change out sterile water bag as needed) <input type="checkbox"/> Charge all batteries, portable ventilator, suction machine and feeding pump <input type="checkbox"/> Maintain full oxygen tank near child's space (Keep connected to ambu bag) <input type="checkbox"/> 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.) <input type="checkbox"/> Change HME if used that day <input type="checkbox"/> Check/refill contents in Go Bag <input type="checkbox"/> Change out feeding bag 	
<u>Every Week:</u>	<p>Choose the same day of the week to do these things, like every Monday.</p> <ul style="list-style-type: none"> <input type="checkbox"/> Change vent tubing and swivel adaptor on both ventilators <input type="checkbox"/> Change humidity chamber <input type="checkbox"/> Clean filter on oxygen concentrator <input type="checkbox"/> Clean filters on ventilators (this can be done multiple times during the week, depending on environment, situation, etc.) <input type="checkbox"/> Change tracheostomy tube <input type="checkbox"/> Change mist collar tubing and mask 	
<u>Every Month:</u>	<p>Choose the same day of every month to do these things, like the first Monday of the month. This makes it easier to remember.</p> <ul style="list-style-type: none"> <input type="checkbox"/> Change in-circuit air filters on both ventilators <input type="checkbox"/> Change out suction canisters <input type="checkbox"/> Change out all empty oxygen tanks and call for replacements <input type="checkbox"/> Inventory supplies and order new month's supplies 	

Transporting My Ventilator Dependent Child

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 let 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
- 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. Make sure the ventilator battery is well charged as well as the back-up battery.
2. Put your child in a stroller or wheelchair.
3. Make sure all equipment (including the ventilator) is ready and attached to the chair when appropriate.
4. Put your child on the transport ventilator
5. Make sure your child is stable, has good chest rise and HME (“nose”) is in line.
6. Turn off the bedside ventilator when you are sure the child is ready to go and breathing well.
7. Attach the circuit to the stroller or wheelchair to make sure 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.

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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 inflatable 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