



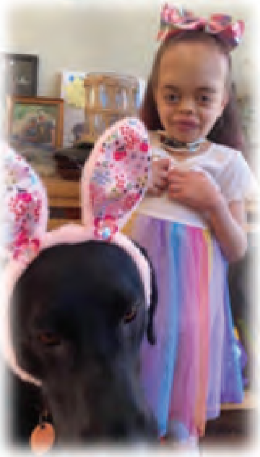
Tracheostomy Care Notebook

Children's Wisconsin











Acknowledgements

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Contents

Chapter 1—Understanding Tracheostomies

Chapter 2—Learning Daily Cares

Chapter 3—Handling Emergencies

Chapter 4—Home Care Equipment

Chapter 5—Breathing Medicines and Treatments

Chapter 6—Parent-to-Parent

Chapter 7—Once You Go Home

Glossary

Chapter 1

Understanding Tracheostomies

Objectives

This care notebook will help you prepare to go home with your child after a tracheostomy. It will help you know what to expect. The care notebook answers many of the questions you might have.

In this section you will learn:

- What is a tracheostomy?
- What does it take to go home for the first time with a tracheostomy?
- Who is your trach team?

Understanding tracheostomies

What is a tracheostomy?

- A tracheostomy, or trach for short, is an opening in the windpipe, or trachea. Your child will breathe through the trach instead of through the nose or mouth.
- The doctor made a small opening in your child's neck during surgery. It is called a stoma.
- The trach stoma lets air and oxygen pass through the windpipe into the lungs.
- Extra secretions are removed from the windpipe through the trach tube.

What is a tracheostomy tube?

- A tracheostomy tube is a short, soft, flexible plastic tube that goes into the windpipe through the stoma. It is smaller than the inside of the windpipe, so your child will not feel it.
- The trach tube keeps the windpipe open so your child can breathe easily.
- The amount of sound made is affected by the amount of air your child can breathe around the trach tube. This is because the air travels out of the stoma instead of through the vocal cords (where sound is made) and out the mouth.

Why does my child need a trach tube?

- Your doctor will talk with you about why **your** child needs a trach tube.
- Your child may need a trach to keep the airway open and help their breathing due to:
  - Birth defects that affect breathing.
  - A windpipe or breathing tube that is narrow or scarred.
  - Vocal cords that don't move like they should.
  - A problem such as softening or collapse of the windpipe or bronchial tubes.
  - A need for a ventilator to help with breathing.
  - A disease that affects the muscles or nerves that control breathing.
- Often the trach is not permanent. It may be able to be removed when your child grows or when the problem is corrected.

What extra care must I take to keep my child safe?

- Your child with a trach needs to be watched closely day and night.
- A trained adult caregiver must be with your child at all times. This person must be trained in suctioning, trach cares, trach tie changes, and changing the trach tube.
- The trained adult caregiver must also be trained in trach CPR.
- All caregivers need to practice good hand washing before and after caring for your child. This will reduce your child's risk of infection.

What happens after surgery?

After surgery, your child will go to the Intensive Care Unit (ICU).
The doctor will change the first tube after 5 to 7 days. Your child will get medicine that helps with pain and keeps your child quiet and still while healing takes place during the first week.

Sutures (stitches) are put on each side of the new trach tube. They help open the trachea so the tube can be replaced if needed. Your child's doctor will remove the sutures after 5 to 7 days. A ventilator and oxygen may also be needed to help your child's breathing.

When will my child be ready to go home?

Your child will be ready to go home when:

- They are medically stable.
- You and other caregiver(s) are fully trained in providing care.
- Home support agencies are in place.

What follow up medical care will my child need?

After discharge, your child will need follow up medical care from the:

- Pediatrician for routine child care.
- ENT doctor who performed the tracheostomy.
- Pulmonary doctor in the Tracheostomy Clinic.

The nurse on the Tracheostomy Team will coordinate your child's follow up care.

Will my child be able to talk?

The trach tube will not keep your child from learning how to speak. There are some things that will affect the amount of sound your child will make:

- The size of the trach tube.
- The amount of air your child can breathe around the trach tube.
- Air is exhaled through the trach tube instead of the vocal cords, mouth, and nose. This means your child's voice will be soft.
- Many children are able to use a "speaking valve" to help learn to communicate. Speech therapy and the trach team will work to assess your child for readiness to use this valve.

In the hospital and after discharge, your child will have speech therapy to help with talking.

Will my child need to be monitored at home?

Your child will go home on a monitor. It may be an apnea monitor or a pulse oximeter. You must use the monitor whenever your child is not in direct eye contact with you (for example, when sleeping, in another room, or in the car). The monitor will alert you to any problems with your child's breathing.

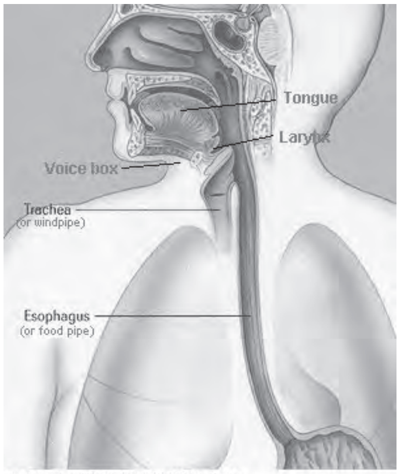
Many families also use an intercom or baby monitor to hear their child.

Will the trach change the way my child eats?

The trach tube does not affect the way your child eats food.

Some children who have trach tubes have a hard time with swallowing and gastric reflux. Because of this, some children are at risk to aspirate (inhale) food into the airway.

If your child has feeding or swallowing issues, your doctor will talk with you and decide if tube feedings will help prevent reflux or food aspiration.



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Will my child be able to do the same things a child without a trach can do?

There are only a few activities that your child cannot do. Your child cannot be under water because water would go directly into the trach tube and into the lungs.

You also need to take special care to prevent small particles like dust, sand, and fibers from getting in to the trach tube. The particles can irritate the lungs.

Your child cannot be around people who are smoking, because smoke can also irritate the lungs.

It is important for your child to have the chance to take part in activities that other children do.

Will my child be able to leave the house?

Yes, your child will be able to leave the house and travel with the family. All the equipment you need is portable or will work on battery power. You will learn which pieces of equipment you need to have with you at all times when you and your child go out of the house.

What training is needed?

Family and trained caregivers

As you are getting ready to take your child home, you will need the help of the trach team members. More importantly, you will need the support and help of family and others.

An adult caregiver who is trained to do routine and emergency trach care **must be with your child at all times**.

Many of the cares need two people to perform. You will need at least one other adult to be completely trained in your child's care. This second caregiver will learn as much about your child's care as you have. This person should be an adult who will continue to be involved in your child's life after discharge. This person will spend time with your child and be a resource and back up person for you when you cannot be with your child.

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Daily Cares and Home Equipment Training

Before your child can go home, you and the second caregiver will need to learn and demonstrate the care that your child needs.

Training includes learning about your child's:

- Physical care
- Giving medicines
- Equipment care
- Care of the tracheostomy
- Feedings

You will work closely with the nurses and respiratory therapists to learn how to:

- Suction
- Change trach ties
- Give breaths with the resuscitator bag
- Do trach care
- Change the trach tube

Once you master these skills, you will learn how to care for, set up, and clean the respiratory equipment.

You will learn trach CPR.

Simulation Training and Independent Cares

Before going home, you will use all the skills you have learned to complete simulation training. You will work together to act out emergent scenarios on a doll, using home equipment.

Lastly, before your child goes home, you will do Independent Cares. This means that while you are still in the hospital, you and the other trained caregiver(s) will provide all the care your child will need at home. You will need to do this in separate shifts from each other.

You will spend 6 to 24 hours doing all the cares for your child. You will use your child's own home equipment and supplies.

Independent Cares simulates the home environment to make sure you are ready to provide all the care and manage all the equipment your child needs at home.

ALERT: Call your child's doctor, nurse or clinic if you or your child have any concerns or if your child has special health care needs not covered by this information.

This sheet was created to help you care for your child or family member. It does not take the place of medical care. Talk with your healthcare provider for diagnosis, treatment and follow-up.

Stepping Stones to Home after Tracheostomy for ____________________

What I need to know and do to get us ready to go home.

START

☐ I can tell you why my child has a trach tube.

☐ I can tell you how my child looks if they have trouble breathing.

☐ I can do trach cares.

☐ I can change my child's trach ties.

☐ I can suction my child's trach tube by sterile and clean ways.

☐ I can show how to use the resuscitation bag.

☐ I can suction the trach tube by myself.

☐ ☐ ☐ I can do a 2 person trach change.

☐ I can do an emergency 1 person trach change.

☐ I can show how to clean my child's trach tube.

☐ I can name all the things in my child's go bag.

☐ ☐ ☐ I am learning how to use my child's equipment.

☐ I can give my child's breathing treatment

☐ I can do CPR with a trach tube.

☐ I can take my child for a walk.

☐ I can tell you about my child's meds and how to give them.

☐ I passed Independent Care.

☐ My child is ready for home.

FINISH

Sheet #2030

Stepping Stones to Home

Being in the hospital can be stressful for you and your child. Before you take your child home, we will work with you to plan for your child's discharge. We want to make sure you know what to do and how to do it. We will make sure you:

- Understand your child's condition, treatments, and medicines.
- Know what problems to look for, what to do, and who to call if you have questions or concerns.
- Feel ready to take your child home.
- Have an interpreter present if you need one.

This process will start when we first meet you. We will use this *Stepping Stones to Home* sheet. It helps us make sure you understand everything that is important to care for your child. Every circle is something you may need to know about.

We will talk about your child's care every day. We will ask you to teach-back to us these items on the storyboard. We want to make sure we explained everything you need to know in ways you understand. If we are not clear, we will explain it another way.

If you don't understand something about your child's care, please ask. It is very important that you are comfortable and feel confident to take care of your child safely at home.

Notes or Questions

Independent Care Guidelines

You and your child are almost home! The final step of your teaching is **Independent Care.** Two caregivers will provide **all** of the child's care. Each will do this over a different time. One shift will happen over a several hour period and one will be overnight. You and your Trach/Vent team will agree on the dates and times.

You will use your home equipment. Monitors in the room will be turned off, but the nurse (RN) will still respond if you need help. A respiratory therapist will check on the trach collar or ventilator during your shift. Your child's feeding and medicine schedule will be posted in the hospital room.

Before Starting Independent Care

Before you can start your shift of Independent Care, the following checklist must be complete:

- ☐ **All bedside education completed**
  - Trach cares:
    - Signs of infection or problems
    - Routine trach changes (3 times)
    - 1-person/emergency trach change (1 time)
    - Suctioning
    - Giving breaths with the ambu bag
    - GO BAG contents

  - G-Tube cares (if needed):
    - Signs of infection or problems
    - Medicine information. Show how to give, how much, and why it is needed
    - Feeding recipe and schedule
    - Button exchange (if used)

- ☐ **All home equipment teaching completed, and in your child's room, if used:**
    - Ventilator
    - Portable O_2 (oxygen)
    - Humidity systems
    - Suction machine
    - Pulse oximeter monitor (and apnea monitor if used)
    - Feeding pump
- ☐ **Trach CPR training completed**
- ☐ **Complete a walk with stroller and home equipment on the unit and off the unit.**

During Independent Care

At least 2 caregivers must complete a shift of care. One will spend 4 to 8 hours. One will spend an overnight. These are your tasks during your shift:

- ☐ Use all home equipment without help.
    - This includes fixing problems. You may need to call your DME (durable medical equipment) provider.
- ☐ Ask for all medicines when they are due.
    - Ask the nurse to bring you the medicine that is needed.
- ☐ Ask for all feeds when they are due.
    - Ask the nurse to bring you the formula/milk/food that is needed.
- ☐ Respond to alarms without nurse help.
- ☐ Suction your child when needed.
- ☐ Provide all cares for your child.
- ☐ Answer questions about your child.
- ☐ Do any emergency care as needed.

- ☐ You may take a 30 minute break.
    - You must tell the nurse if you plan to leave the room.
    - Return within the 30 minute time frame.
    - Give and get updates when you leave and come back.

- ☐ Practice taking a walk with your child.
    - You must pack up all emergency supplies and equipment.
    - The respiratory therapist will check over your set up before you leave, and when you return.

- ☐ If you are completing a night shift, please do not try to stay awake. Sleep like you would at home. You do have to wake up when your child needs anything.

After Independent Care

After **each** caregiver completes their shift, the nurse will talk about how things went. The nurse will ask how **you** felt. They will write a note in your child's chart that will look like this:

Date/Time: Caregiver arrived for independent cares. Expectations outlined and home schedule accessible in patients room. Caregiver independently set up home equipment. Independent cares started at ____. Caregiver (did/did not) provide cares to patient independently. Caregiver (did/did not) respond to all alarms appropriately. Caregiver (did/did not) ask for feeds and meds prior to time due. Caregiver interacted with patient by _____. **[RN can provide specific examples related to medical cares and personal interactions]**. Independent cares concluded at ____. **[Indicate when switch between caregivers occurs and repeat note format]**. RN reviewed report card with Caregiver A and B; Caregiver A (was/was not) successful and Caregiver B (was/was not) successful.

You need to do Independent Care again if one or more of these happened:

- ☐ RN needed to remind caregiver to give a medicine or feeding.
- ☐ RN needed to remind caregiver to suction.
- ☐ RN needed to answer an alarm.
- ☐ RN needed to help with cares. This does not include cares like trach or tie changes that do need 2 people.
- ☐ Caregiver did not know how to do cares.
- ☐ Caregiver was not able to answer questions about child.

For other health and wellness information, check out this resource:
https://kidshealth.org/ChildrensWi/en/parents

ALERT: Call your child's doctor, nurse, or clinic if you have any questions or concerns or if your child has special health care needs that were not covered by this information.

Tracheostomy team members

The most important member of your care team is you—the parent. Your trained caregivers come next. Parents know their child's needs better than anyone. Your role on the care team is to share information about your child, ask questions, and learn about the care your child needs.

You need to share information about how your child is doing and their care with the other team members.

It is important to have supportive family or friends to help. They can support you as you learn to care for your child and prepare to bring them home.

The trach team members listed below will work with you and your child's caregivers. They will do this during your hospital stay and after you go home.

Advanced practice nurse (APN)/Nurse clinician (NC)

These registered nurses specialize in managing the care of the child with a trach. They will set up care conferences to plan discharge goals. After your child goes home, they will help with home support agencies.

Registered nurse (bedside RN)

Registered nurses work with your child and family on day-to-day care. They will teach you how to care for your child's trach tube. These nurses will talk with the doctors to work toward medical stability for home.

Respiratory care practitioner (RCP)

The trach/vent RCP is the contact between you, the durable medical equipment (DME) provider (or home care company), and the hospital.

The RCP works with the homecare RCP to complete all your equipment teaching. This includes the home suction machine, pulse oximeter, oxygen setup, humidification system, and ventilator.

When you return to the clinic, the trach/vent RCP will meet with you to review your equipment and answer questions.

Social worker

A social worker helps patients and families find resources. This includes individual and family supportive counseling, resources for financial concerns, and more.

Hospital case manager

The hospital case manager works with your family to arrange:

- Home nursing care (private duty nursing or PDN), as available.
- Other equipment and supplies that are not managed by the trach/vent RCP.

Other team members

Speech/Language pathologist (SLP)

The SLP works with your child to check for safe swallowing. When your child learns to eat and vocalize with the trach tube, they will also work on speech and language skills.

Physical therapists (PT) and occupational therapists (OT)

The PTs and OTs work with your child on growth and development. They help your child learn to use muscles for rolling, sitting, standing, and walking.

Dietitian

The dietitian makes sure your child gets the nutrition and vitamins they need. They help you manage your child's nutrition and growth.

Pulmonologist

A pulmonologist is a doctor trained in the care of the lungs. They direct the medical care once your child goes home. The pulmonologist works closely with other team members and your primary care doctor or pediatrician.

The pulmonologist will see your child each time you return to Trach/Vent clinic. They will help decide the plan for your child's future care.

ENT (ear, nose, and throat) doctor

The ENT doctor specializes in care of the airway. This is the doctor who did the surgery to insert your child's tracheostomy.

As you prepare to go home, this doctor works closely with the pulmonologist and the members of the trach/vent team. They also will check on your child's stoma.

The ENT doctor will see you as you return to Trach/Vent clinic. They will check your child's airway and tracheostomy. They will also help decide the plan for your child's future care.

Primary care doctor

The primary care doctor or pediatrician will manage your child's routine medical care. This includes immunizations and regular checkups.

Your child's primary care doctor will communicate and work closely with the Pulmonologist and the ENT doctors. This will assure that your child's ongoing medical care is coordinated and meets your family needs.

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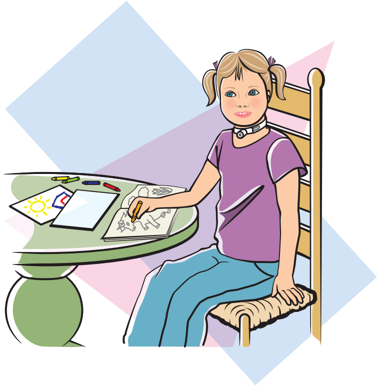
Patient Information *Series*

Use of a Tracheostomy With a Child

A tracheostomy (trake-ee-AWS-toe-mee) is the surgical cut made into the front of the neck and into the windpipe (trachea). The hole that is made is commonly referred to as a "trach" or a stoma. A special tube ("trach" tube) is placed in the hole to help a person breathe.



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Why does my child need a trach?

Your child may need a trach for many different reasons. The most common reasons are:

- *To help prevent food or saliva from going into your child's lungs (aspiration).* Children who have problems swallowing may aspirate food or saliva, which may cause a lung infection and damage the lungs. The trach can help to keep food and saliva out of the lungs.
- *To allow use of a breathing machine (mechanical ventilator) to help your child breathe* (see ATS Patient Information Series: Mechanical Ventilation). Children who have severe lung problems, or other health problems that affect breathing, may need to use a ventilator to help them breathe. The ventilator can be attached to the trach tube and allow the child to use the mouth and face.
- *To help keep your child's airway open.* Sometimes a child's windpipe is too small or blocked to allow enough air to flow in and out of the lungs. This can make it very hard for the child to breathe. The trach can help keep the child's airway open.
- *To help your child get excess mucus or secretions out of their breathing tubes (bronchial tubes).* Some children with lung problems have a lot of mucus that collects in their lungs. If your child cannot cough well enough to "bring up" mucus, the mucus may clog their airways, making it more difficult for your child to breathe. Having a trach allows the child's caregiver to suction out the mucus and keep the airway clear.

Taking care of your child's tracheostomy

Taking care of your child's trach requires certain basic skills. You will be taught how to care for your child's trach before you leave the hospital. You will need to learn:

- How to keep the skin around the trach opening as clean and dry as possible
- How often to change the tracheostomy ties
- How to position the tracheostomy tube and ties correctly
- How to suction the trach tube and prevent it from getting clogged
- How to clean/change the trach tube
- What supplies you will need at home to care for your child's trach.

If you are not sure what you should do or not do with your child's trach, ask a member of your child's healthcare team.

How often does a trach need to be changed?

A trach needs to be changed regularly. Mucus and bacteria can build up over time inside the trach. Your healthcare provider can help you decide how often the trach will need to be changed. This may be once a week or as long as once a month. Most of the time, the tubes can be cleaned and reused multiple times. You should always have a replacement tube nearby as well as a back-up trach tube one size smaller.

Can my child eat and drink with a trach?

Some children may be able to eat and drink by mouth with a trach. However, a trach can cause swallowing difficulties at times, especially when it is first put in. If your child has trouble swallowing with a trach, s/he may need to be fed in a different way, for example, a tube that goes through the nose and into the stomach (NG tube), or a tube that goes right into the stomach or intestine through the skin covering your child's belly.

You should never see food or drink coming from the trach. If this occurs, stop the feeding, and let a member of the healthcare team know at once.

Can my child talk with a trach?

Most of the time, your child will not be able to talk when she first gets a trach. This can be frustrating for families and children, especially if your child was able to talk before getting a trach. A speech therapist or other member of your child's healthcare team can work with you and your child soon after she gets a trach to help you learn ways to communicate. Some children are able to use a speaking valve that is attached to the trach to help them speak more clearly and loudly. If your child's lungs are weak, he may not be able to use a speaking valve.

Am J Respir Crit Care Med Vol. 174, P11-P12, 2006.

ATS PATIENT INFORMATION SERIES

What problems can happen with my child's trach?

Serious problems that can happen with your child's trach are:

- The trach tube becomes completely blocked (obstructed) and you are unable to unclog it. (If your child appears to have breathing problems, such as fast breathing, working hard to breathe or turning blue, the trach tube may be blocked.)
- The trach tube accidentally comes out and will not go back in.
- A large amount of bleeding (several teaspoons or more) is coming from the trach area.

If any of these problems do occur, call Emergency Medical Services (usually 911) immediately.

Other problems that are not as serious as those listed above, but need to be reported to your child's healthcare provider are:

- Your child is having a harder time breathing. (The trach tube may be partly blocked.)
- You see a small amount of bleeding in or around your child's trach.
- You think your child has an infection. Signs of an infection can be: changes in the amount, color, odor, or thickness of the mucus in or around your child's trach; your child is having more difficulty breathing than usual; fever.

Can my child's trach ever be removed?

If the reason that the trach was put in is resolved, the healthcare team may plan to remove your child's trach. Before removing the trach tube, your child's doctor may do a bronchoscopy (see ATS Patient Information Series: Bronchoscopy) to check your child's airway. Once the trach tube is out, your child will breathe through her mouth and nose again. The trach opening usually heals on its own. In some cases, surgery may be required to close it.

Tips to stay healthy with a trach

If your child has a trach, there is a higher risk for infection and other complications. Tips to help your child stay healthy with a trach include:

- Avoid infections by: washing hands often and thoroughly, making sure your child receives immunizations, and keeping your child away from others who are sick and away from crowded places like daycare centers and malls.
- Have emergency supplies with your child at all times. Ask your healthcare team for a list of supplies you should have on hand to meet your needs.
- Know how to do cardiopulmonary resuscitation (CPR). All parents and caregivers should know how to perform CPR on a child with a trach
- Have telephone service available. A land-line or cellular phone is needed at home and a cellular phone is helpful during travel.
- Avoid dust, smoke, pet hair, powders, greasy creams or ointments, and sprays that could irritate the lungs.
- Keep small toys or objects that your child could put into their trach away from your child.
- Since contact sports and water sports are not usually allowed, ask your healthcare provider what sports your child can play.
- When bathing, try not to get water in the trach. Young children may be bathed in 1-2 inches of water with the caregiver close at hand. Older children may shower.

Additional Resources:

American Thoracic Society
www.thoracic.org/sections/education/patient-education/patient-education-materials/index.html)

www.thoracic.org/sections/education/care-of-the-child-with-a-chronic-tracheostomy/index.html)

Aaron's Tracheostomy Page
www.tracheostomy.com

American Head & Neck Society
www.headandneckcancer.org

UCL Institute of Child Health
www.ich.ucl.ac.uk

Family Voices
www.familyvoices.org

℞ *What to do…*

As a parent, you are the most important person in your child's life. A medical social worker or insurance case manager can be helpful as you find the resources your child needs.

- ✔ Make sure that you are comfortable and know how to take care of your child's trach. Ask questions and practice taking care of your child's trach while your child is in the hospital.
- ✔ Work with your child's healthcare team for help with feeding and/or talking.
- ✔ Have an emergency kit and back-up trach available at all times.
- ✔ Always have a trained caregiver with your child.
- ✔ Care for your child's trach as instructed and take care to avoid infections.

Doctor's Office Telephone:

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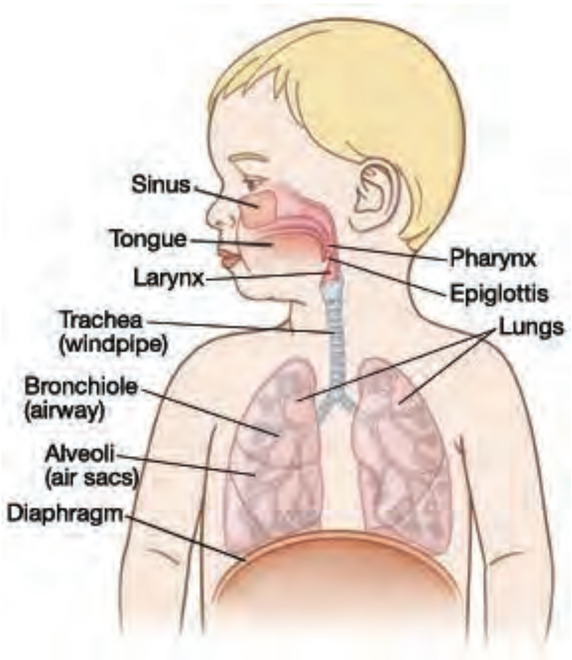
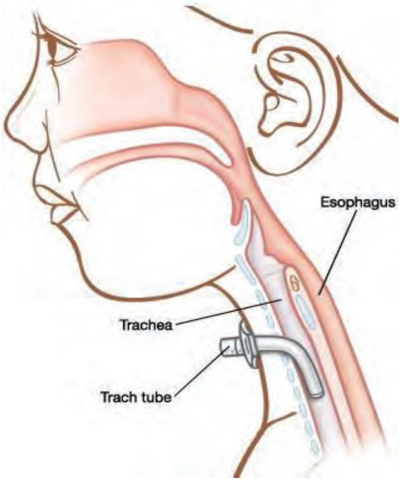
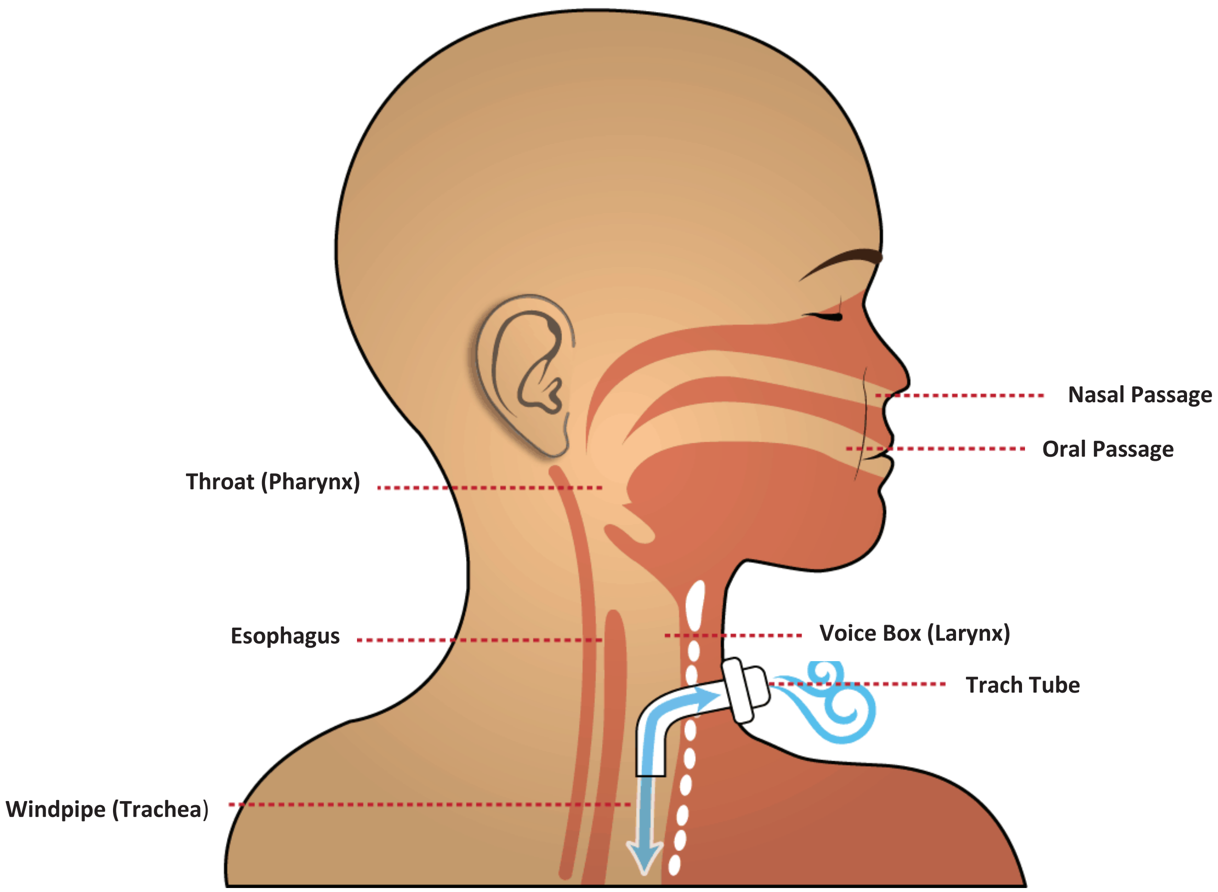

Sinus
Tongue
Larynx
Trachea (windpipe)
Bronchiole (airway)
Alveoli (air sacs)
Diaphragm
Pharynx
Epiglottis
Lungs


Esophagus
Trachea
Trach tube

Tracheostomy



Chapter

2 Learning Daily Cares

Objectives

In this section you will learn how to:

- Care for your child's tracheostomy
  - Clean the skin around the trach tube
  - Change the trach ties
  - Change the trach tube
- Suction secretions
- Give extra breaths
- Observe your child's breathing pattern
  - Note changes in breathing pattern
  - Help your child breathe easier
  - Look for signs of respiratory infection
- Treat a trach stoma granuloma

https://childrenswi.org/medical-care/tracheostomy-home-ventilator/educational-resources

Caring for your child's tracheostomy

Because the skin around the trach may become moist from secretions and humidity, it is important to routinely:

- Clean the skin around the trach tube.
- Change the trach ties that hold the trach securely in place.

Cleaning the skin around the trach tube

Introduction

Cleaning around the trach is called "stoma care." You will do stoma care once a day, or more often if secretions are present.

Supplies

- Clean cotton swabs (4–6) or clean washcloths
- Tap water in a clean container
- Mild soap (non-perfume soap such as Ivory® or Johnson's®) and water in a clean container

Note: Do **not** use powders or ointments around the stoma that your child could breathe in or inhale.

Steps

1. Wash your hands.
2. Place the cotton swabs or a clean washcloth in the soap and water.
3. Clean the skin around the stoma using each cotton swab only once. You may use a clean washcloth.
4. Wipe the swab or cloth away from the edge of the stoma.
5. Repeat with each new swab around all the edges of the stoma.
6. Repeat with tap water to rinse off soap. If using cloths, use a new washcloth.
7. Note if there is redness, swelling, tenderness, or a change in the color, thickness, or odor of the drainage.

8. Let the skin air-dry or wipe it gently with a dry washcloth.
9. Wash your hands.

Special instructions

If there are dried or crusty secretions, clean with equal parts hydrogen peroxide and tap water.

Changing the trach ties

Introduction

- You will change the trach ties once a day and as needed.
- Changing the trach ties requires two people:
    - One person holds the tube in place and positions your child.
    - The second person changes the ties.

Supplies

- Clean trach ties
- Blanket roll for under your child's shoulders
- Suction equipment and catheter
- Scissors to cut new ties to size (or remove old ties)
- Stoma dressing as needed

Steps

1. Wash your hands.
2. Suction before changing the ties.
3. Place the blanket roll under your child's shoulders. This lets you see the tracheostomy better.
4. You may need to swaddle your child to avoid too much movement.
5. While your helper holds the tube securely in place, remove the trach ties.

6. While your helper holds the trach in place, clean the neck with soap and water.
7. Dry skin thoroughly.
8. Examine your child's neck for rash, redness, or skin breakdown.
9. Apply skin cream or other skin protectants, as recommended by your child's care team.
10. Thread the clean ties into each side of the trach flange and attach.
11. If needed, apply stoma dressing.
12. Check the tightness of the new ties by gently pulling on the trach to make sure it is snug.
13. Wash your hands.

Alternate trach tube holders: Twill tape

Introduction

Tracheostomy tube ties are used to hold the tracheostomy tube in place. Twill tape ties are used for very active infants and children who may pull or play with their tube holder. Twill tape ties are tied in triple knots, so they are safer than Velcro® ties for these children.

It takes two people to change tracheostomy tube ties.

Call the doctor if there are any open areas, swelling, or redness under the ties.

Supplies

- Scissors
- Tweezers or hemostat
- Twill tape: Length: ______
- Stoma dressing, if used

Steps

1. Wash your hands.
2. Cut the correct length of twill tape.
3. Cut the ends of the twill tape to form a point.
4. Have one person hold the tube in place. This person cannot let go of the tube until the new ties are in place and secure.
5. The other person should cut and remove the old ties.
6. Pull the new tie through the trach tube flange. (You may use tweezers or hemostats to help with this.)
7. Bring the ends together and straighten the ties.
8. Bring both ties around the neck. Pull the bottom tie through the other hole in the neck plate.
9. Tie ends together in a bow.
10. Replace the stoma dressing, if used.
11. Check the tightness of the ties. Only one of your fingers should fit between the ties and the neck.
12. Pull loops of bow to form a knot. Then triple knot the ties. The person who has been holding the tracheostomy tube may now let go of it.
13. Cut off any extra twill tape. Leave one inch at the end so you can get to the knot easily.

Special instructions

If you are in an emergency and need to change the ties by yourself, follow the steps above, but do **not** cut off the old ties until you have secured the new ties.

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Changing the trach tube

Introduction

- The trach tube change does not hurt your child.
- Changing the trach ties requires two people:
  - One person holds the tube in place and positions your child.
  - The second person changes the ties and inserts the new tube.

Do not change the trach tube by yourself unless absolutely necessary or in an emergency.

- You will change the trach tube once a week and as needed.
- You may also change the trach tube more frequently if:
  - Your child has a hard time breathing, but suctioning or calming do not help.
  - Your child has bleeding from the trach tube.
  - You have a hard time inserting the suction catheter.
- Unless it is an emergency, change the trach tube before your child eats or at least 2 hours after eating. This will reduce the chance that your child will vomit.

Supplies

- Clean trach tube in the same size your child wears
- Next size smaller trach tube (downsize)
- Water-soluble lubricant (such as Surgilube® or K-Y®)

  Note: Do **not** use Vaseline® to lubricate. It is not water-soluble.
- Resuscitator bag and mask with oxygen attached if your child is on oxygen
- Clean trach ties
- Blanket roll for under your child’s shoulders
- Empty syringe (for cuffed trach tube)
- Suction equipment and catheter

Steps

1. Wash your hands.
2. Suction your child's trach tube as needed before changing it.
3. Open the clean trach, keeping the tube clean. Check the tube carefully for tears, cracks, or other problems.
    - If your child has a cuffed trach tube, check the balloon on the cuff before inserting the clean trach to be sure it inflates completely. Check for any leaks from the cuff.
4. Attach trach ties to the clean trach.
5. If needed, lubricate the outside of the clean trach (as well as the insertion guide/obturator) with a *small* amount of water-soluble lubricant for ease of insertion.
6. Place prepared trach tube on a clean surface (with tube pointing up).
7. Place the blanket roll under your child's shoulders so that you can see the trach stoma better.
    - For routine trach changes, you may need to swaddle your child with a blanket to avoid too much movement.
8. If your child has a cuffed trach tube, deflate the cuff completely by removing all the water or air from the cuff with a syringe.
9. Remove the trach ties from the old tube.
10. Person 1 removes the old trach tube using an up-and-out motion. If the child is on a ventilator, keep the ventilator tubing connected to the trach as you remove the old trach.
11. Person 2 gently inserts the new tube with the obturator in place. Direct the tube in a back-and-down motion (pointing toward the toes) as your child breathes in.

12. Immediately remove the obturator after the new tube is in place. **Your child cannot breathe unless the obturator is removed.**
13. While person 2 is holding the trach tube, person 1 gives 2 to 3 breaths with the manual resuscitation bag. If your child is on a ventilator, return the child to the ventilator. Watch for the chest to rise.
14. Secure trach ties. Person 2 does **not** let go of the trach tube until the trach ties are secure.
15. Check the tightness of the new ties by gently pulling on the trach to make sure it is snug.
16. If using a cuffed trach tube, re-inflate the cuff to the recommended volume.
17. Check your child's breathing.
18. Wash your hands.

Special instructions

- Examine your child's neck for rash, redness, or skin breakdown.
- The trach should be snug when pulled on gently.
- Examine the old trach tube for secretions, color, and plugs.
- Clean and store the old trach tube as instructed.

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Cleaning a Shiley® tracheostomy tube

Purpose

Clean the tube every time you change it. A clean tube must always be ready and available for a routine or emergency change.

Supplies needed

- ☐ Basin for cleaning
- ☐ Sterile water
- ☐ Peroxide
- ☐ Guide (Obturator)
- ☐ Basin for sterile water
- ☐ Container and lid
- ☐ **Zip lock bag**

Procedure

1. Mix equal parts of sterile water and peroxide. This is half-strength peroxide.
2. Wash trach tube with warm tap water and a mild soap such as Ivory® Liquid to clear the secretions, rinse the trach tube with warm tap water. Push the guide through the trach tube to remove secretions in the tube.
3. Soak the tube and guide for one minute in the half-strength peroxide.
4. Rinse the tube and guide with sterile water. Check for any secretions. Re-clean if needed.
5. Soak the tube and guide in sterile water for one hour to remove the peroxide.
6. Put the tube and guide on a clean surface to air dry. **Dry completely** before storing.
7. Store in a container with a lid or zip lock bag. If there are water droplets in the container or bag, the tube is not completely dry. Bacteria will grow if the tube is not completely dry. Re-clean the tube.

Special directions

- Check the tube for cracks. Throw away if it is cracked.
- Do **not** store the trach tube with the guide in the tube.
- Order new trach tubes monthly.
- If your child uses a Shiley cuffed trach tube, throw away after each use.

ALERT: Call your child's doctor, nurse, or clinic if you have any questions or concerns or if your child has special health care needs that were not covered by this information.

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Cleaning a Bivona® tracheostomy tube

Children's Wisconsin

Purpose

Clean the tube every time you change it. A clean trach must always be ready and available for a routine or emergency change.

Supplies needed

- ☐ Basin for cleaning
- ☐ Sterile water
- ☐ Peroxide
- ☐ Guide (Obturator)
- ☐ Pan for boiling water
- ☐ Plastic wedge
- ☐ Container and lid
- ☐ Zip lock bag

Procedure

1. Mix equal parts of sterile water and peroxide. This is called half-strength peroxide.
2. Wash trach tube with warm tap water and a mild soap such as Ivory® Liquid to clear the secretions, rinse the trach tube with warm tap water. Push the guide through the trach tube to remove secretions in the tube.
3. Push the guide through the trach tube to remove secretions in the tube.
4. Soak the tube and guide in the basin of half-strength peroxide for one minute.
5. Fill the pan with tap water and bring to a boil on the stove.
6. Remove pan from heat.
7. Place the trach tube and the guide in the water.
8. Cover the pan and let the parts soak for 20 minutes.
9. Drain the water. Put the tube and guide on a clean surface to air dry completely.
10. Store all parts in a clean container with a lid or zip lock bag. If you see water droplets, the tube is not completely dry. Take it out and re-clean it. Bacteria will grow if the tube is not completely dry.

Special directions

- Check the tube for cracks. Throw it away if it is cracked
- If your child has a cuffed tube, check the cuff for holes or discoloration by gently inflating cuff prior to storing. If holes or discoloration are present, or if the cuff does not re-inflate, throw it away. Deflate cuff completely prior to storing clean trach.
- Do not store the trach tube with the guide in the tube.
- Order new trach tubes monthly.

- If your child's Bivona trach tube has a swivel cap on it, when cleaning:
  - Use the plastic wedge to take the swivel cap off of the adapter.
  - Replace the swivel cap. If you do not replace the swivel connector, the manual resuscitator bag and/or ventilator will not fit on the trach tube like it should.

ALERT: Call your child's doctor, nurse, or clinic if you have any questions or concerns or if your child has special health care needs that were not covered by this information.

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Suctioning secretions

Introduction

You will need to suction the trach tube so that mucous does not block airflow through the tube. Suctioning is needed to keep the breathing passages open and let your child breathe easily.

- Suction your child's trach tube at least 3 to 4 times daily.
- If secretions are increased or thick, you may need to suction more frequently.

- If secretions are thick and sticky, you may insert normal saline drops into the tube before suctioning.
- Suction before your child eats to reduce the risk of vomiting.
- Suctioning may cause coughing, but it does not hurt your child.
- Suctioning is done only to a pre-measured depth. Always know your child's suction depth.

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Supplies

- Suction machine with connecting tubing attached
- Clean suction catheter
- Normal saline
- Clean cup of water to flush catheter
- Clean cup of equal parts hydrogen peroxide and tap water
- Resuscitator bag with oxygen if your child is on oxygen or a ventilator
- Clean gloves

Steps

1. Wash your hands.
2. Put on clean gloves (unless otherwise ordered).
3. Prepare your child for suctioning by explaining the need to suction.

   For infants: Place infant on their back or in a position where their neck and stoma are easy to see. If needed, you can swaddle your infant in a blanket to prevent too much movement.
4. Remove your child's trach collar, artificial nose, or ventilator.
5. Attach the suction catheter to the connecting tubing. Keep the tip of the catheter clean.

If your child needs:	**Then:**
Frequent suctioning	Change the suction catheter three times a day.
Less frequent suctioning	Change the suction catheter once or twice a day.

6. Turn on the suction machine.
7. Check the suction pressure by placing your thumb over the thumbhole on the catheter.

8. Apply suction pressure by placing your thumb over the thumbhole.
9. Insert the suction catheter into your child's trach tube only to the pre-measured depth.
10. As you insert and withdraw the catheter from your child's trach tube, gently roll the catheter between your thumb and index finger to suction the entire inside surface of the trach tube.
11. Apply suction for no more than 5 to 7 seconds.
12. Give 3 to 5 extra breaths with the resuscitator bag after removing the suction catheter. Assess the need for extra breaths.
13. Clear the suction catheter by dipping it in the clean water and applying suction.
14. Check your child's breathing.
15. Repeat the suctioning procedure if you see or hear more secretions in the tube.
16. Clean the suction catheter with equal parts hydrogen peroxide and tap water, then rinse with water.
17. Store in a clean dry place, such as a paper towel or a plastic storage bag.
18. Wash your hands.

Special instructions

- Suctioning is done only to a pre-measured depth. This allows only the tip of the suction catheter to come out the end of the trach tube.
- Suctioning too deep may injure your child's airway.
- Your nurse will show you exactly how far to insert the suction catheter.
- Watch your child for changes in the amount, thickness, and color of secretions.

ALERT: Change the trach if:

- You can't get the suction catheter to go in to the measured length.
- Your child doesn't look right even after suctioning.

Tracheostomy reference sheet

Child's name: ____

Trach type/Size: ____

Custom made trach: ☐ Yes Size/Length: _____________

☐ No

If cuffed trach: _________ mL of water OR _________ mL of air

When cuffed: _________________________

Type of trach ties: ☐ Cotton

☐ Velcro

Suction catheter size: ____________ FR

Length of insertion: ______________ cm

Trach changed on: _______________

Next change date: _______________

Giving extra breaths

Introduction

If your child cannot breath on their own, they will need extra breaths with the resuscitator bag to inflate the lungs. Your child may need extra breaths during the suctioning procedure.

1. Squeeze and release the bag with your hand to deliver a breath to your child's lungs.
2. Watch your child's chest rise as you squeeze the bag and air goes into your child's lungs.

If you see:	**Then:**
Chest rise	Continue to step 3.
No chest rise	Suction the trach tube. Continue to step 3.

3. Repeat the squeeze-and-release motion 3 to 5 times. Try to use a rhythm that matches your child's breathing pattern.
4. Check your child's breathing.
5. Remove the resuscitator bag from your child's trach tube.
6. Reattach the artificial nose (HME), humidity system, or ventilator tubing.
7. Wash your hands.

ALERT: Change the trach if:

- You can’t give a breath with the resuscitation bag.
- Your child just doesn’t look right.

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Observing your child’s breathing pattern

Breathing is usually very comfortable and easy when your child has a trach tube. Your child may have trouble breathing if they:

- Have changed how fast or slow they breathe.
- Work harder to breathe.
- Sound different.

If you are concerned about your child’s breathing at any time, call your child’s doctor or call for emergency help.

Noting changes in breathing patterns

Normal changes

A change in your child’s breathing pattern happens normally when your child is:

- Asleep.
- Awake and very active.
- Very tired.

Abnormal changes

A change in breathing pattern may **NOT** be normal when your child:

- Has a fever.
- Has an infection.
- Has secretions collecting in the trach tube.
- Has a low oxygen level in the blood.
- Is working hard to breathe.

Signs of breathing problems

- Nostril flaring in and out with breaths
- Lips or skin are blue, gray, or pale color
- Whistling from the trach tube
- Restlessness
- Retractions or rib muscles are sucking in with breathing
- Increased crankiness
- Slow or fast heartbeat
- Frequent coughing
- Noisy breathing
- Can't catch their breath
- Increased breathing rate
- Heavy or hard breathing
- Sweating

Helping your child breathe easier

Try some of these suggestions to help your child breathe easier:

- Change your child's position and check the trach tube.
- Suction the trach tube.
- Give your child breaths with the resuscitator bag.
- Change the trach tube.
- Check the ventilator system.

- Check the humidification system and temperature setting.
- Give your child a breathing treatment (nebulizer or inhaler). (See Chapter 5, *Breathing medicines and treatments* for more information.)
- Call your child's doctor.
- Call 9-1-1 for immediate medical help.
- Begin CPR if needed.

Signs of a respiratory infection

Call your doctor if your child has:

- A fever higher than 101 °F (38.3 °C).
- Colored tracheal secretions (yellow, green, tan, pink, or blood-tinged).
- An increased amount and thickness of secretions.
- The need for suctioning more often.
- A change in their normal breathing pattern.
- Heavy breathing.
- Retractions.
- Frequent coughing.
- Inactivity or sleepiness.

Special instructions

- Suction your child's trach tube before giving nebulizer medicines.
- Watch your child's breathing and reaction to the medicine given during the nebulizer treatment.
- Do not allow your child to eat while taking a nebulizer treatment.

How to apply silver nitrate

Silver nitrate can be used to treat granulation tissue at G-tube, J-tube, GJ-tube and trach sites.

What is silver nitrate?

It is a medicine on a wooden stick.

Why is silver nitrate used?

It is used to shrink and get rid of extra skin tissue called granulation tissue. The medicine can be used on the granulation tissue around feeding tubes on the belly and tracheostomy tubes.

What is granulation tissue?

It is extra skin tissue that grows on wounds as they are healing.

How do I use the silver nitrate?

Only use the medicine after talking with your child's doctor or nurse. Do not use the medicine if you were not shown how to use it. Do not use around trach tubes if the granulation tissue is all the way around the trach stoma.

Follow these steps to use the medicine. Have someone help you hold your child so they do not move a lot.

Feeding tubes 	**Trach tubes** 
1. Get your supplies - Gloves - Gauze - Silver nitrate - Vaseline or barrier cream	1. Get your supplies - Gloves - Gauze or Mepilex - Silver nitrate
2. Wash your hands.	2. Wash your hands.
3. Put gloves on to protect your hands.	3. Put gloves on to protect your hands.
4. Use your finger to spread Vaseline or barrier cream on the skin around the granulation tissue. **Do not use Vaseline on trach sites**. This can be harmful.	4. Use gauze to remove any moisture at the stoma before you use the silver nitrate. **Do not use Vaseline on trach sites**. This can be harmful.
5. Take one stick and dab or roll on the granulation tissue. It will turn a gray or white color when treated. The medicine on the stick will turn from brown to white. This is normal. Keep putting the medicine on the granulation tissue until it is all treated.	5. Take one stick and dab or roll on the granulation tissue. It will turn a gray or white color when treated. The medicine on the stick will turn from brown to white. This is normal. Keep putting the medicine on the granulation tissue until it is all treated.
6. Blot the skin with gauze every couple times you dab the skin. This helps soak up extra medicine instead of staying on the skin.	6. Blot the skin with gauze every couple times you dab the skin. This helps soak up extra medicine instead of staying on the skin.

7. After all the granulation tissue is treated, put a split gauze on the skin for one hour. This will help soak up any drainage.	7. After all the granulation tissue is treated, leave the area open to air for at least 4 to 5 hours.
8. Put the used stick in a plastic bag and seal it. Throw the bag in the garbage.	8. Put the used stick in a plastic bag and seal it. Throw the bag in the garbage.
10. Remove or change the split gauze after one hour.	10. If your child uses a trach dressing, may place it on after 4 to 5 hours.

What happens to the tissue after the medicine is used?

The treated granulation tissue will dry up and fall off. This may take 1 to 2 days.

How do I know if I should use more medicine on the tissue?

Follow your child's doctor or nurse's directions. Wait 24 hours before using the medicine again. Do not use more than 5 days in a row.

How do I store the silver nitrate?

Keep the medicine sticks in the package. Store the package in a safe place. Keep out of reach of children and pets. Throw away any expired medicine in a sealed plastic bag. Do not flush down a toilet.

What do I do with the medicine after my child's granulation tissue is gone?

You can keep the medicine if it is in a safe place and not expired. Your child's doctor or nurse may tell you to use the medicine again.

Special information

The site may be sore after this medicine is applied. The medicine can cause some stinging. This goes away after a few minutes.

Sometimes silver nitrate may cause a mild skin injury. This is rare. The skin can be burned and red. It will heal. Do not let the medicine touch any other skin or surfaces.

Stop using the medicine if skin around the tube is stained, open, blistered or peeling. The dark color will go away, but it may take up to one week.

Check the size of the granulation tissue every day with cares.

Other teaching sheets that may be helpful

- 3005 Feeding tube granulation tissue

ALERT: Call your child's nurse if you or your child have any concerns or:

- The granulation tissue does not get smaller in size.
- The granulation tissue is not gone in 5 days.
- The skin around the tube is open, blistering or peeling.
- Your child's special health care needs were not covered by this information.

Other safety tips

Feeding

- Your baby or child may not eat by mouth.
- Your child may need tube feedings if there are problems with swallowing or reflux. Your child's doctor and speech therapist will teach you how to safely feed your child.
- All children with tracheostomy tubes are referred to speech therapy—both in the hospital and once they go home.
- Never prop a bottle for your baby.
- Always hold your baby during feedings.

Bathing

- Never leave your child alone in the tub.
- Use caution with bathing. Your child may be bathed in the tub, but do not let any water get into the trach tube.
- Use the HME (artificial nose) to prevent water splashes while bathing.
- If your child is on a ventilator:
  - Make sure the ventilator is not plugged into an electrical outlet during bathing.
  - Use battery power.
  - Protect the ventilator from water splashing.
- Turn your child's head to the side when washing hair so water does not get into the trach tube.
- Do **not** let your child swim or submerge under water.

Clothing

- Special clothing is not needed.
- Clothing that covers the trach should not be worn. The trach tube should be visible.
- Keep fuzzy clothing, blankets, and stuffed animals away from the trach.
- Do not use clothing and items with tiny beads, sparkles, or fibers that may get into the trach tube.
- If your child is on a ventilator:
  - The ventilator tubing should be above all clothing and blankets.

Chapter

3 Handling Emergencies

Keeping your child safe

All adult caregivers must be checked off as independent by a member of your child's health care team (RN, RT). You may use your Stepping Stones to help train more caregivers.

- Your child needs to be watched and monitored closely day and night.
- Use your home pulse oximeter monitor whenever you are not directly interacting with your child and when your child is asleep.
- Your emergency Go Bag and emergency equipment should be with your child at all times.

Safety tips

- Many families use a portable intercom or baby monitor to hear their child from another room.
- Do not allow smoking or vaping around your child or in your home.
- Do not use powders, chlorine bleach, ammonia, or aerosol sprays in the same room as your child.
- Avoid lint, dirt, and anything small that the child could place in their trach tube.
- Notify the electric, gas, and telephone companies that you have a child with a tracheostomy. In the event of a power outage, getting your power back on would be a priority.
- Contact your local fire department or emergency first responder *before* your child comes home from the hospital. Let them know that your child now has a trach tube and ventilator in your home.
- If you have additional children, create an emergency plan in case you have to call 911 or ride in an ambulance.

Knowing when to call your child’s doctor

Call your child’s doctor if your child has:

- A fever greater than 101 °F (38.3 °C).
- Secretions that are green or foul smelling.
- Bleeding from the trach tube.
- Difficulty breathing that is not relieved by suctioning or changing the trach.
- A rash or unusual drainage around the trach tube.

- Food or liquid coming through the trach.
- Frequent plugging of the trach.

You should also call if you have trouble changing your child's trach tube. Alarms from the monitor or the ventilator are another reason to call your child's doctor.

This can be your child's pediatrician, pulmonary, or ENT doctor.

Changing the trach tube in an emergency

Supplies

- Two spare trach tubes from the Go Bag or near your child's bed. The two trach tubes in your Go Bag should always have the trach ties on and ready.
    - One spare trach is the same size as your child's trach.
    - One is the next-smaller size, or down size, trach tube.
- Blanket roll
- Resuscitator bag
- Lubricant (water-soluble)

Steps

1. Stay calm.
2. Call for a second trained caregiver to help you.
3. Try to replace the trach tube with the same size trach your child normally wears.
4. If you are not able to place the same size trach tube, reposition your child with a blanket roll under the shoulders to help you see the stoma better.
    - Insert the tube when your child breathes in.
    - Make sure the tube is lubricated.

5. Try to place the same size trach tube again.
6. If this still doesn't work, place the down size trach tube into your child's stoma, and call your child's doctor.
7. If you are not able to place the down size trach tube, check your child's breathing pattern.
8. If your child is not breathing or needs help with breathing, cover the stoma with a piece of tape and give your child breaths with the resuscitator bag and mask over the nose and mouth.
9. Call 911 to get emergency assistance and tell the operator that your child has a trach and is having trouble breathing.

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Giving extra breaths with the resuscitator bag

Introduction

- If unable to breathe on their own, your child will need extra breaths with the resuscitator bag to inflate their lungs.
- Your child may need extra breaths with the resuscitator bag during the suctioning procedure.

Supplies

- Resuscitator bag

Steps

1. Wash your hands.
2. Remove the HME (artificial nose), humidity system, or ventilator tubing from the trach tube.
3. Attach the resuscitator bag to the trach tube.
4. Squeeze and release the bag with your hand to deliver a breath to your child's lungs.
5. Try to use a rhythm that matches your child's breathing pattern.
6. Watch your child's chest rise as you squeeze the bag and air goes into your child's lungs.

If the air:	**Then:**
Goes into your child's lungs	Continue to step 7.
Does not go into your child's lungs	Suction the trach tube. Continue with step 7.

7. Repeat the squeeze-and-release motion 3 to 5 times.
8. Check your child's breathing.
9. Remove the resuscitator bag from the trach tube
10. Reattach the HME (artificial nose), humidity system, or ventilator tubing.

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Stocking your “GO BAG”

Trach tube supplies

Purpose

A GO BAG has all the supplies needed to manage your child’s airway if you need to do an emergency trach change. The GO BAG must be with your child at all times. Restock your GO BAG often as you use supplies.

Supplies needed

☐ **Same-size trach tube**

Same-size trach tube with trach ties attached in a Ziploc bag or other clean storage container

☐ **Smaller-size trach tube**

Used if you cannot get the same-size trach tube back into your child.

☐ **Water-soluble lubricant**

Goes on the trach tube prior to inserting in stoma.

☐ **Normal saline**

Used with suctioning if the secretions are thick. It is also used to instill drops into the trach tube if the artificial nose is used longer than ordered.

☐ **Trach ties**

Used to secure the new trach.

☐ **Suction kits**

Used to remove secretions from the trach tube.

☐ **Scissors**

Used to cut the old ties if you are not able to remove them.

☐ **Manual Resuscitator Bag**

Used to give breaths and should have the appropriate sized mask. .

☐ **Tape**

If you can’t get a trach back in and your child needs breaths you would put tape over the stoma and provide mouth to mouth or bag mask ventilation.

☐ **Suction machine**

Keep fully charged and carry the power cord with you at all times.

☐ **Heat Moisture Exchanger (HME)**

Special directions

- Any type of bag can be used for the GO BAG. Make sure:
  - It is easy to carry.
  - It is big enough to hold supplies.
  - The supplies can be easily found.
- Do not put extra supplies in this bag.
- Always check the GO BAG when you are taking over for another caregiver. You don't know if they took something out and did not replace it.
- Keep a supply list in your GO BAG. This will help guide caregivers if they do not remember what is needed.

ALERT: Call your child's doctor, nurse, or clinic if you have any questions or concerns or if your child has special health care needs that were not covered by this information.

For more health and wellness information check out this resource:
https://kidshealth.org/ChildrensWi/en/parents

Performing CPR with the trach tube

Your child's fully stocked Go Bag holds all needed items for an emergency.

Steps

1. If your child has trouble breathing or is not acting right, examine the tracheostomy tube first to determine if the:
    - Trach tube is out.
    - Trach tube is plugged.
    - Correct size trach tube is in place.
    - Oxygen (if in use) is off the trach.
    - Ventilator (if in use) is off the trach.
2. Check your child's breathing, chest rise and skin color.
3. Follow the steps for *Lifesaver CPR for infants and children with a trach* on page 3-11.

Remember:

Suction ⇨ Bag ⇨ Change the trach

4. When in doubt, change the trach tube out and then call 911. Tell the operator that your child has a trach and is having trouble breathing.

Key points

- If you have someone to help you, have them call 911.
- If you are home alone, unlock the door after calling 911.
- Post a copy of the *Lifesaver CPR for infants and children with a trach* guide at your child's bedside.

- Program emergency telephone numbers in each caregiver's phone or post emergency telephone numbers near each landline.
- In your child's home care binder or care plan, have a copy of your address, location, and directions to your home. This helps if another caregiver needs them.
- Keep the Home Resource Telephone List in your child's Go Bag.
- Keep the fully stocked Go Bag with your child at all times.

Resources

- *Lifesaver CPR for infants and children with a trach* teaching sheet (#1293) on page 3-11
- Home Resource Telephone List (see Chapter 7).
- Lifesaver CPR for Infants and Children with a Trach

  https://chw.wistia.com/medias/vqqetdqq7i

Lifesaver CPR for infants and children with a trach

Follow these steps if your child is having trouble breathing or is not breathing.

Airway

If your child is gasping or having trouble breathing, mucous may be plugging the trach tube.

① Suction the trach.

② If you can't get the suction catheter down or clear the trach, or if your child still isn't breathing, change the trach and fasten the new trach ties.

If in doubt, change the trach out!

Breathing

After changing the trach:

① Give 2 breaths with the manual resuscitator bag. You should see a gentle chest rise with each breath.

② If your child is still having trouble breathing, is gasping, or is not responding, shout, "Help! Call 911!"

Compressions

If your baby does not start breathing on their own or is not responding, start compressions.

① Draw an imaginary line between your child's nipples.

② Press down on your child's chest so it compresses ⅓ to ½ the depth of the chest. Do 30 quick compressions at a rate of at least 100 per minute. Push hard and fast.

For infants: Use two fingers.

For children over 1 year: Use the heel of one hand.

③ Give 2 breaths to the trach with the manual resuscitator bag. Steps 2 and 3 (30 compressions and 2 breaths) are one cycle.

④ After doing cycles of CPR for 2 minutes, call 911.

⑤ If your baby still does not respond, keep doing cycles of breaths and chest compressions until emergency help comes.

If you have a second person to help:

① One person first calls 911, then gives compressions continuously at a rate of at least 100 per minute.

② The other person gives 1 breath with the manual resuscitator bag every 2 to 3 seconds.

Chapter

4

Home Care Equipment

Introduction

This chapter teaches you about the equipment used at home for children with tracheostomies and ventilators.

- ☐ Care schedule for home respiratory equipment (#1600)
- ☐ Manual resuscitator bag (#1119)
- ☐ Home monitor: Pulse oximeter (#1559)
- ☐ Apnea monitor use (#1213)
- ☐ The humidification system (#3052)
- ☐ The humidification system—DreamStation (#3050)
- ☐ The humidification system—Trilogy 100 EVO (#3051)
- ☐ The humidification system—myAIRVO 2 (#3053)
- ☐ Heat and moisture exchanger (#3034)
- ☐ Passy Muir speaking valve (#1265)
- ☐ Trilogy/EVO ventilator (#1836)
- ☐ Astral ventilator (#1835)
- ☐ Ventilator information guide (#1215)
- ☐ Vent alarm explanations
- ☐ Home oxygen with a tracheostomy tube (#3054)
- ☐ What you need for your teaching session (#1163)
- ☐ What you need for your teaching session—trach only (#1128)

Care schedule for home respiratory equipment

Children's Wisconsin

Care schedule and battery life

Clean

Clean with warm soapy water				
	Daily	**Weekly**	**Monthly**	**As needed**
Suction canister and lid	✓			
Nebulizer kit	✓			
Trach ties	✓			✓
Manual resuscitator		✓		
Apnea monitor belt		✓		✓
Suction tubing				✓
Clean with rubbing alcohol				
	Daily	**Weekly**	**Monthly**	**As needed**
Temp probe			✓	

Deep Clean

Deep Clean with Control III or vinegar and water				
	Daily	**Weekly**	**Monthly**	**As needed**
Manual resuscitator		✓		
Suction canister and lid		✓		
Nebulizer kit		✓		

Changing equipment

Changing equipment, per insurance allotment of supplies					
	2x Daily	**Daily**	**Weekly**	**Monthly**	**As needed**
Suction canister and lid				✓	
Suction tubing			✓		
Suction filter				✓	
Nebulizer kit			✓		
Water bag					✓
Heated wire tubing				✓	
Disposable bag				✓	
Water canister			✓		
Trach mask (alternate with clean mask)		✓			
Trach ties		✓			✓
Trach tube			✓		✓
Oxygen Tubing				✓	
MDI Chamber				✓	

Equipment battery life

Equipment	Battery life
Suction Machine	45 min. (continuous run time)
Apnea monitor	15 hours
Pulse Oximeter	4-6 hours
LTV – Internal/Portable	1 hour/3 hours
Trilogy 100 – Internal/Portable	3 hours/3 hours
Trilogy Evo – Internal/Portable	7 ½ hours/ 7 ½ hours
Astral – Internal/Portable	8 hours/ hours

ALERT: Call your child's doctor, nurse, or clinic if you have any questions or concerns or if your child has special health care needs that were not covered by this information.

Manual resuscitator bag

Children's Wisconsin

Purpose

The manual resuscitator bag is used to give your child extra breaths.

Use the bag between suction passes, after suctioning, or whenever your child needs help to breathe.

The resuscitator bag also includes a mask. The mask has to cover both the mouth and nose. The mask size needs to be changed as your child grows. A smaller size mask can be considered for the stoma.

Using the bag

1. Connect the bag to the tracheostomy tube.

If your child	Then
breathes on their own	Squeeze the resuscitator bag as soon as your child begins to breath in.
does **not** breathe on their own	Squeeze the bag at the same rate as the ventilator.

2. As you squeeze the bag, watch your child's chest rise.
3. As soon as your child's chest rises, release the bag.
4. Repeat this cycle of squeezing and releasing until your child is back to their baseline.

Using oxygen with the bag

If your child	Then
has oxygen ordered	Use it when hand ventilating your child at the flow determined by your medical team, and to maintain oxygen saturation between 90%-92%.
does not have oxygen ordered	Keep your child on room air.

Testing the bag

1. Cover the patient outlet port with your hand and squeeze the bag. The pop off valve should rise, allowing air to escape.
2. Cover the patient outlet port and press down on the pop off valve at the same time. The bag should not be able to be squeezed.
3. If you are able to hear or feel air during the tests above, check all connections making certain they are tight.

If the bag	Then
deflates	Check that all connections are tight. Be sure the yellow washers are laying flat and do not have holes.
does not deflate	The bag has been put back together correctly.

Note: Your home care company may give you a permanent or disposable resuscitator bag. Follow their recommendations for cleaning your type of bag.

Special directions

- Always have the bag in the same room as your child.
- Always keep a back-up resuscitator bag in your GO BAG.
- Be sure one resuscitator bag is with your child when the other bag is being cleaned.
- If any of the washers have holes or are torn, call your home care provider.

ALERT: Call your child's doctor, nurse, or clinic if you have any questions or concerns or if your child has special health care needs that were not covered by this information.

Home Monitor: Pulse Oximeter

What is a pulse oximeter?

It is a monitor that checks oxygen levels in the blood. It should be used throughout the day. Your child's doctor may have you use it continuously if needed.

How do I hook it up?

1. Connect the probe to the monitor cable.
2. Turn the machine on.
3. Put the probe on the hand, foot, finger, or toe. Be sure that the light sensors line up.

Note: If the oximeter is used for more than spot checks, the probe must be moved every 8 hours to prevent burns.

Special directions

- Bright lights may give a false reading. Use a sock, mitten, or blanket to cover the probe.
- Measure your child's pulse oximeter reading when they are calm. Lots of movement will give a false reading.
- If the machine alarms, check your child:
  - Is your child breathing faster or slower than normal?
  - Does your child's skin color look different than normal?
  - Is your child sweating or does the skin feel cold to the touch?
- Do not place probe over nail polish.
- Always use the monitor:
  - While your child is sleeping.
  - When you cannot see your child.
  - As instructed by your child's physician.
  - If you are in the car alone with your child or on a long car ride.

Do not change the amount of oxygen your child is getting unless told to do so by your child's doctor.

Problem-solving

- Is the probe on your child's hand or foot?
- Are the connections at the cable and probe tight?
- Is your child moving or upset?
- Is there a good signal on the monitor? You should see a wave form or a signal bar.

Problem-solving continued

- Is the probe in direct light?
- Is the probe too loose or too tight?
  - Check your child's pulse and compare it with the heart rate reading on the monitor:
    - If your child's heart rate matches the O_2 Sat (oxygen saturation), the reading is correct.
    - If your child's heart rate does not match the O_2 Sat, the reading is a false reading.

Note: If the old probe still isn't working after trying all of the steps above, try a new probe.

How do I clean it?

- Unplug the machine.
- Wipe the monitor off with a damp cloth.
- Wipe non-disposable probes off with alcohol.
- Change disposable probes as instructed by your home care provider.

ALERT: Call your child's doctor, nurse, or clinic if you have any questions or concerns or if your child has special health care needs that were not covered by this information.

For other health and wellness information, check out this resource:
https://kidshealth.org/ChildrensWi/en/parents

Apnea monitor use

Children's Wisconsin

For patients with a Trach or Vent

What does the apnea monitor do?

The apnea monitor will alert you if your child's heart rate goes too high or too low. It will also alert you if there are pauses in your child's breathing.

What supplies do I need?

- ☐ Apnea monitor
- ☐ Leads – Black lead patches **or** Sticky leads
- ☐ Belt
- ☐ Lead wires
- ☐ Patient cable
- ☐ AC cable

How do I hook up the monitor?

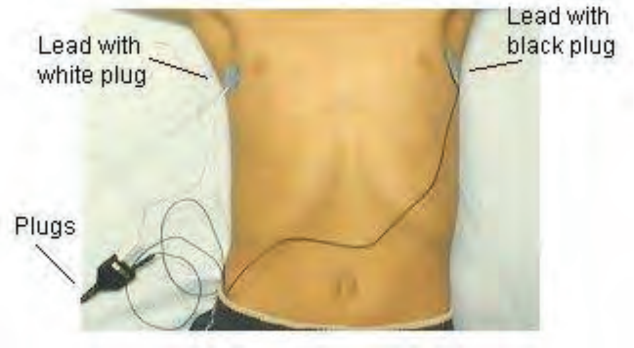
Belt leads

1. Plug the AC cable into a wall outlet.
2. Plug the patient cable into the monitor.
3. Plug the lead wires into the patient cable.
4. Slide the metal ends of the wires into the black lead patches.
5. Put the patches on the belt so they sit under the arms (white plug on the right, on the left).
6. Use the Velcro to attach the belt to your child so the belt fits snug around the chest at the nipple line.

Note: The black lead patches are **not latex-free**. Please tell your child's doctor if your child has a latex allergy or sensitivity.

Sticky leads

1. Plug the AC cable into the wall outlet.
2. Plug the patient cable into the monitor.
3. Plug the lead wires into the patient cable.
4. Attach the sticky leads to the chest under the arms at the nipple line (white plug on the right, black plug on the left).



Special directions

Always use the monitor:

- While your child is sleeping.
- When you cannot see your child.
- As instructed by your child's physician.
- If you are in the car alone with your child or on a long car ride.

Note: Do not stop using the monitor without talking with your child's doctor.

- At home, make sure you can easily see and hear the monitor.
- Put the monitor on a sturdy table or shelf.
- The monitor has a battery that will run for 15 hours.
- The monitor is used as an additional alarm for children on a ventilator, and the only alarm for children with a trach.

Alarm cause	Possible reason
High heart rate	Your child may be crying, restless, have a fever, or need to be suctioned.
Slow heart rate	Your child may be in a deep sleep or not breathing. An oxygen or ventilator tube may be disconnected. The trach tube may be plugged or out of your child.
Slow breath or apnea	Your child may not be breathing or may not have taken a breath within the set alarm limit. The trach tube may be plugged or out of your child.

How do I clean the monitor?

1. Once a week, hand wash the belt with warm, soapy water.
2. Wipe the black lead patches off with warm, soapy water.
3. Wipe the monitor off with a damp cloth to remove dust.
4. Change the sticky leads as needed or as you were told by your child's home care company.

ALERT: Call your child's doctor, nurse, or clinic if you have any questions or concerns or if your child has special health care needs that were not covered by this information.

The humidification system

What is a humidification system?

The humidification system has many parts. Together, the parts deliver warm, moist air and oxygen to your child's trach tube. This air helps keep the secretions thin. Secretions in the lungs can block the trach tube if they are too thick.

1. Compressor

Purpose

This machine is where air flow comes from. The air travels to the heater, and delivers the warm, moist air to your child. This machine is not where oxygen comes from.

Guidelines

- Keep the compressor free from dirt and dust.
- Keep curtains and bedding away from the compressor.
- Do not put the compressor against the wall. Do not block the filter.
- Do not smoke near this device.
- Keep the compressor on the floor or other smooth, flat surface.

Procedure

- Your compressor may be set using pressure or flow. This will be determined by your home healthcare provider.
- To check the **pressure**, turn the compressor on.
- Block the air outlet with your finger. The needle on the pressure gauge should read the pressure taught to you by your home healthcare provider. Make sure you are eye level with the gauge. If it does not, adjust the dial.
- To adjust the dial, it should be pulled out. Push the dial in to lock it in place.
- To check the **flow**, turn the compressor on.
- Adjust the flowmeter to the set liter per minute taught to you by your home healthcare provider. Make sure you are eye level with the flowmeter. If it does not, adjust the flowmeter.

Troubleshooting

- Is the compressor plugged into the outlet?
- Is the electrical outlet working?
- Is the compressor on?
- Is the filter clear and clean?
- Is the pressure set?
- If the compressor still does not work, call your home healthcare provider.

2. Heater

Purpose

To heat up the air from your compressor, which will deliver warm, moist air to your child's trach tube. It will alert you to temperatures too hot, or too cool.

Guidelines

- Make sure the temperature probe, and heater wire adapter are in good working order.
- To see the temperature, your machine may display this on the front panel (as shown above). For some machines, you will need to push and hold the Alarm Silence button.
- Make sure you have the right amount of water in the heater canister.
- You can use sterile or distilled water in the canister, not tap water.
- If possible, do not place the heater set up near a window or vent.

Note: The compressor and the heater work together. One cannot be on without the other.

Troubleshooting

- Is the heater plugged into the outlet?
- Is the electrical outlet working?
- Is the heater on?
- Is the temperature probe connected?
- Is the temperature probe broken?
- Is the heater wire adapter connected?
- Is the heater wire adapter broken?
- Is there water in the canister?
- Is there air flow coming from the compressor?
- If all else fails, change the circuit.
- If the heater still does not work, call your home healthcare provider.

3. Circuit set up

Supplies

- ☐ Trach collar mask
- ☐ 1-six inch length of corrugated tubing
- ☐ Package of corrugated tubing with wire
- ☐ Temperature probe
- ☐ Heater wire adapter
- ☐ Water chamber
- ☐ Bag of sterile water (if provided by your home healthcare provider)
- ☐ Oxygen tubing (if your child is on oxygen you will need 2)
- ☐ Reducing adapter
- ☐ Multi-access adapter, if using oxygen

Special directions

- If any water collects in the corrugated tubing, drain it away from your child.
- The corrugated tubing should always be kept below the level of your child's chest (not draped over a crib railing or pack 'n play).
- Always have a supply of inhalation water for the humidifier.

NOTE: Refer to Oxygen teaching sheet #3054 if your child requires the use of supplementary oxygen.

Refer to HME teaching sheet #3034 for information on portable humidity setups.

ALERT: Call your child's doctor, nurse, or clinic if you have any questions or concerns or if your child has special health care needs that were not covered by this information.

The humidification system

What is a humidification system?

The humidification system has many parts. Together, the parts deliver warm, moist air and oxygen to your child's trach tube. This air helps keep the secretions thin. Secretions in the lungs can block the trach tube if they are too thick.

1. DreamStation CPAP Device

Purpose

This machine is where air flow comes from. The air travels to the heater, and delivers the warm, moist air to your child. This machine is not where oxygen comes from.

Guidelines

- Keep the device free from dirt and dust.
- Keep curtains and bedding away from the device.
- Do not put the device against the wall. Do not block the filter.
- Do not smoke near the device.
- Keep the device on a smooth, flat surface.

Procedure

- To check the pressure, turn on the CPAP device.
- Be sure that the device is set to a pressure of 4.
- Disconnect your tubing from the back of the device to listen for, and to feel air flow if you are not sure.

Troubleshooting

- Is the device plugged into the outlet?
- Is the electrical outlet working?
- Is the CPAP device on?
- Is the filter clear and clean?
- Is the pressure set to 4?
- If the device still does not work, call your home healthcare provider.

2. Heater

Purpose

To heat up the air from your CPAP device, which will deliver warm, moist air to your child's trach tube. It will alert you to temperatures too hot, or too cool.

Guidelines

- Make sure the temperature probe, and heater wire adapter are in good working order.
- To see the temperature, your machine may display this on the front panel (as shown above). For some machines, you will need to push and hold the Alarm Silence button.
- Make sure you have the right amount of water in the heater canister.
- You can use sterile or distilled water in the canister, not tap water.
- If possible, do not place the heater set up near a window or vent.

Note: The CPAP device and the heater work together. One cannot be on without the other.

Troubleshooting

- Is the heater plugged into the outlet?
- Is the electrical outlet working?
- Is the heater on?
- Is the temperature probe connected?
- Is the temperature probe broken?
- Is the heater wire adapter connected?
- Is the heater wire adapter broken?
- Is there water in the canister?
- Is there air flow coming from the CPAP device?
- If all else fails, change the circuit.
- If the heater still does not work, call your home healthcare provider.

3. Circuit (tubing) set up

Supplies

- ☐ Trach collar mask
- ☐ 1-six inch length of corrugated tubing
- ☐ Package of corrugated tubing with heater wire
- ☐ Temperature probe
- ☐ Heater wire adapter
- ☐ Water chamber
- ☐ Bag of sterile water (if provided by your home healthcare provider)
- ☐ Oxygen tubing (if your child is on oxygen, you will need 2)
- ☐ Reducing adapter
- ☐ One way valve
- ☐ Bacteria Filter
- ☐ Multi-access adapter, if using oxygen

Special directions

- If any water collects in the corrugated tubing, drain it away from your child.
- The corrugated tubing should always be kept below the level of your child's chest (not draped over a crib railing or pack 'n play).
- Always have a supply of inhalation water for the humidifier.

NOTE: Refer to Oxygen teaching sheet #3054 if your child requires the use of supplementary oxygen.

Refer to HME teaching sheet #3034 for information on portable humidity setups.

ALERT: Call your child's doctor, nurse, or clinic if you have any questions or concerns or if your child has special health care needs that were not covered by this information.

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The humidification system

What is a humidification system?

The humidification system has many parts. Together, the parts deliver warm, moist air and oxygen to your child's trach tube. This air helps keep the secretions thin. Secretions in the lungs can block the trach tube if they are too thick.

1. Trilogy 100/EVO

Purpose

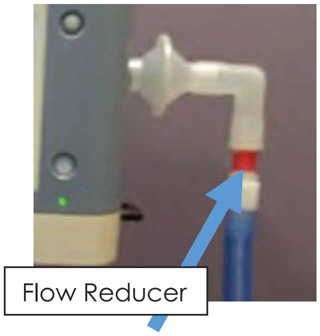
This machine is where air flow comes from. The air travels to the heater, and delivers the warm, moist air to your child. This machine is not where oxygen comes from.

Guidelines

- Keep the device free from dirt and dust.
- Keep curtains and bedding away from the device.
- Do not put the device against the wall. Do not block the filter.
- Do not smoke near the device.
- Keep the device on a smooth, flat surface.

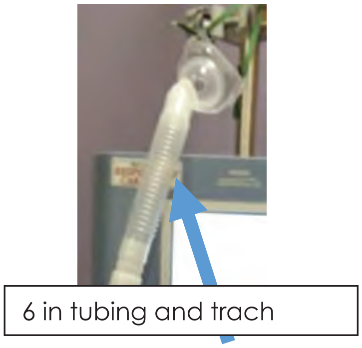
Procedure

- Switch the ventilator to the correct program which will be set by your home care provider. This is even more important if you use the Trilogy as a ventilator **and** for your humidity set up.
- Place the flow reducer adapter into the tubing.
- Remove any exhalation valve, and replace it with the 6 inches of tubing and trach mask.



Flow Reducer

Exhalation Valve



6 in tubing and trach

Troubleshooting

- Is the device plugged into the outlet?
- Is the ventilator device on?
- Is the correct program selected?
- Is the flow reducer adapter in the tubing?
- Is the electrical outlet working?
- Is the filter clear and clean?
- Is the CPAP pressure set to 4?
- Has the exhalation valve been removed from the tubing?

If the ventilator still does not work, call your home healthcare provider.

2. Heater

Purpose

To heat up the air from your ventilator, which will deliver warm, moist air to your child's trach tube. It will alert you to temperatures too hot, or too cool.

Guidelines

- Make sure the temperature probe, and heater wire adapter are in good working order.
- To see the temperature, your machine may display this on the front panel (as shown above). For some machines, you will need to push and hold the Alarm Silence button.
- Make sure you have the right amount of water in the heater canister.
- You can use sterile or distilled water in the canister, not tap water.
- If possible, do not place the heater set up near a window or vent.

Note: The ventilator device and the heater work together. One cannot be on without the other.

Troubleshooting

- Is the heater plugged into the outlet?
- Is the electrical outlet working?
- Is the heater on?
- Is the temperature probe connected?
- Is the temperature probe broken?
- Is the heater wire adapter connected?
- Is the heater wire adapter broken?
- Is there water in the canister?
- Is there air flow coming from the ventilator device?
- If all else fails, change the circuit.
- If the heater still does not work, call your home healthcare provider.

3. Circuit (tubing) set up

Supplies

- ☐ Trach collar mask
- ☐ 1-six inch length of corrugated tubing
- ☐ Package of corrugated tubing with wire
- ☐ Temperature probe
- ☐ Heater wire adapter
- ☐ Water chamber
- ☐ Bag of sterile water (if provided by your home healthcare provider)
- ☐ Oxygen tubing (if your child is on oxygen you will need 2)
- ☐ Reducing adapter
- ☐ Multi-access adapter, if using oxygen

Special directions

- If any water collects in the corrugated tubing, drain it away from your child.
- The corrugated tubing should always be kept below the level of your child's chest (not draped over a crib railing or pack 'n play).
- Always have a supply of inhalation water for the humidifier.

NOTE: Refer to Oxygen teaching sheet #3054 if your child requires the use of supplementary oxygen.

Refer to HME teaching sheet #3034 for information on portable humidity setups.

ALERT: Call your child's doctor, nurse, or clinic if you have any questions or concerns or if your child has special health care needs that were not covered by this information.

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The humidification system

What is a humidification system?

The humidification system includes a flow generator, heater, and oxygen adapter. Together, the parts deliver warm, moist air and oxygen to your child's trach tube. This air helps keep the secretions thin. Secretions in the lungs can block the trach tube if they are too thick.

1. MyAirvo2

Purpose

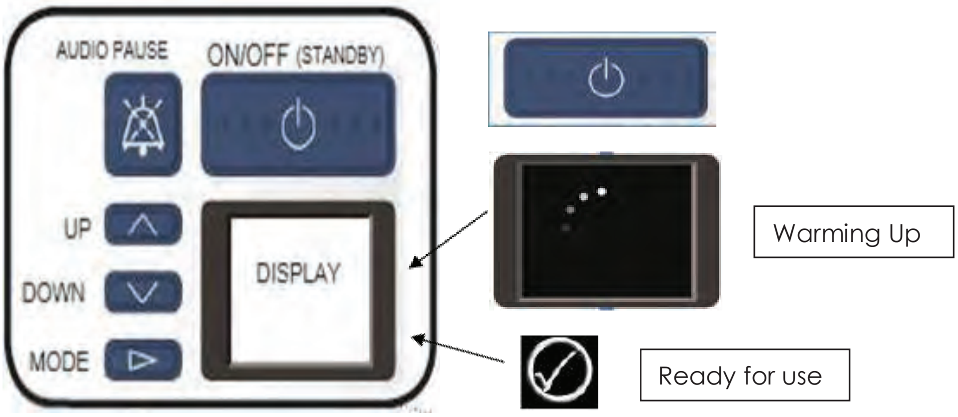
This machine is where air flow comes from. The air travels through the heater, and delivers the warm, moist air to your child. This machine can also deliver oxygen.

Guidelines

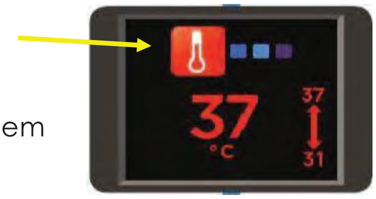
- Keep the device free from dirt and dust.
- Keep curtains and bedding away from the device.
- Do not put the device against the wall. Do not block the filter.
- Do not smoke near this device
- Keep the device on a smooth, flat surface.

Procedure

- Attach breathing circuit and filled water chamber before powering on.
- Turn on your device. It will begin to warm up.
- Wait until the "ready for use" symbol appears on the screen.



Heater



3 target temperatures:
  a. 37 degrees C- Ideal
  b. 34 degrees C- if compliance at 37 degrees is a problem
  c. 31 degrees C- for face mask only

Flow

10-25LPM- increments of 1LPM

25-60- increments of 5LPM

Note: trach collar use- 10-20LPM

Drying Cycle

- Press and hold the ON/OFF button for 3 seconds, a melody sounds, this will start the drying cycle.
- The cycle runs for 99 minutes.
- Make sure the child is not wearing the device while the cycle is running.
- The device will automatically turns off once the drying cycle is complete.
- To turn off the MyAirvo2 without running the drying cycle, press and hold the ON/OFF button for 5 seconds.
- This cycle will help to keep your tubing clean, and help to keep the circuit working its best.

Troubleshooting

1. Is the device plugged into the outlet?
2. Is the electrical outlet working?
3. Is the filter clear and clean?
4. Is the correct flow set?
5. Is the correct pressure set?
6. Are you in the correct mode?
6. If the MyAirvo2 still does not work, call your home healthcare provider.

3. Circuit (tubing) set up

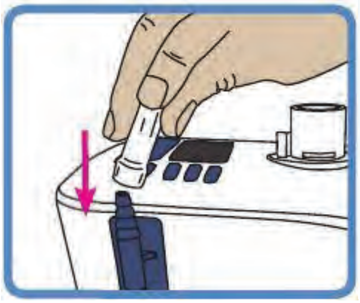
Supplies

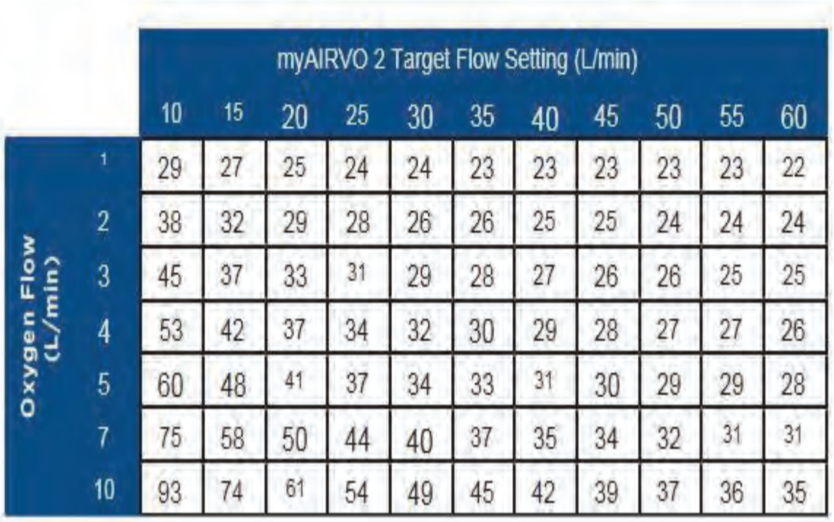
- ☐ Trach collar (mask) OR Direct connect adapter
- ☐ Package of corrugated tubing with wire
- ☐ Water chamber
- ☐ Bag of sterile water
- ☐ Oxygen tubing, if your child is on oxygen

Changing the circuit

1. Run Drying Cycle between uses, 99 minutes.
2. Change the circuit as instructed by your home care provider.

Oxygen Chart





Oxygen Flow (L/min)	myAIRVO 2 Target Flow Setting (L/min)										
	10	15	20	25	30	35	40	45	50	55	60
1	29	27	25	24	24	23	23	23	23	23	22
2	38	32	29	28	26	26	25	25	24	24	24
3	45	37	33	31	29	28	27	26	26	25	25
4	53	42	37	34	32	30	29	28	27	27	26
5	60	48	41	37	34	33	31	30	29	29	28
7	75	58	50	44	40	37	35	34	32	31	31
10	93	74	61	54	49	45	42	39	37	36	35

Special directions

- If any water collects in the corrugated tubing, drain it away from your child.
- The corrugated tubing should always be kept below the level of your child's chest (not draped over a crib railing or pack 'n play).
- Always have a supply of inhalation water for the humidifier.

NOTE:

- Refer to Oxygen teaching sheet #3054 if your child requires the use of supplementary oxygen.
- Refer to HME teaching sheet #3034 for information on portable humidity setups.

ALERT: Call your child's doctor, nurse, or clinic if you have any questions or concerns or if your child has special health care needs that were not covered by this information.

Heat and Moisture Exchanger (HME)

Humid-Vent®

Purpose

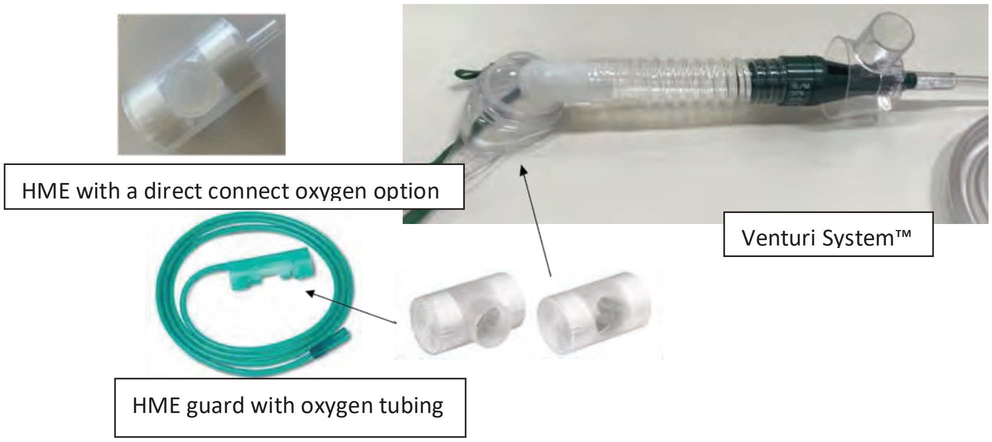
The HME/Humid-Vent, also called the artificial nose, is used when your child is not able to use the home humidification system that provides heat and moisture to your child's tracheostomy tube and airway.

Types of artificial noses

1. This type is used with a **ventilator**. 	 2. This type is used only for a child with a **trach**.

Guidelines

- Use it only with a doctor's order.
- Use it to provide heat and moisture to your child's trach when the home humidification system is not used.
- **If your child uses oxygen, always use oxygen when using the artificial nose**.



- Your home healthcare provider may offer you different options to add in oxygen.
- Use the percentage of oxygen closest to or above the percentage ordered, never below.

Caring for the artificial nose

- Do not wash the nose. The filter paper will become harder to breathe through, and this may cause respiratory distress.
- If your child coughs or throws the nose on to the floor, wipe it with rubbing alcohol. Let it dry and put it back on your child.

Special directions

- If your child has more secretions than normal, do not use the nose. The secretions can make breathing hard for your child.
- Replace the nose every 24 hours.
- Have your child wear the nose when traveling and for portability at home.
- Increase length of time as your child tolerates. Watch for increased secretions. This may take up to 24 hours.
- Use only while awake.

ALERT: Call your child's doctor, nurse, or clinic if you have any questions or concerns or if your child has special health care needs that were not covered by this information.

Passy-Muir® speaking valve

Purpose

The Passy-Muir speaking valve has many benefits:

- Increases vocalization
- Improves sense of taste and smell
- Optimizes secretion control/management/organization
- Restores air flow to the natural upper airway
- Supports optimal feeding and language development
- Restores physiologic PEEP
- Improves core stability
- Decreases tracheal suctioning

Your child breathes in through the speaking valve and tracheostomy tube. They then breathe out through their nose and mouth.

Types of valves

1. This type of valve is used for a child with a **tracheostomy**.			2. This type of valve is used by a child with a **ventilator**.

Guidelines

- **Always deflate** the cuff if your child uses a cuffed tracheostomy tube.
- The trach-only speaking valve fits on the trach tube with a gentle twist. Remove it with a gentle twist the other way.
- The ventilator speaking valve is put in the breathing circuit using an adapter.
- If your child uses oxygen, oxygen **must be used** when wearing the speaking valve.

Special directions

- If your child has problems breathing while using the valve, remove it. If the problem continues while using the valve, call your doctor.
- Your child may use humidity while wearing the valve.
- Remove secretions by rinsing under warm water.
- **Remove the valve when giving breathing treatments.**
- **Do not use this valve when your child is sleeping or ill.**
- **Someone needs to be with your child while they are using the valve.**

Daily Cleaning instructions

1. Swish the valve around in warm, soapy water. **(Not Palmolive)**
2. Rinse with warm water.
3. Put on a clean surface to air dry.

Note:

- You **do not need** to disinfect the valve unless your home healthcare provider tells you to.

Warning. Do not use hot water, peroxide, bleach, vinegar, alcohol, brushes, or Q-tips on the valve. This may cause damage.

- There are many speaking valve manufacturers. They each may have valves that come in different colors or shapes. Talk with your child's doctor or speech therapist if you have questions about your child's speaking valve.


LTV Ventilator


Trilogy Ventilator


Astral Ventilator
single limb


Astral Ventilator
dual limb

ALERT: Call your child's doctor, nurse, or clinic if you have any questions or concerns or if your child has special health care needs that were not covered by this information.

For other health and wellness information, check out this resource:
https://kidshealth.org/ChildrensWi/en/parents

Trilogy™/EVO ventilator

Children's Wisconsin

Set up and maintenance

What does the Trilogy do?

It gives extra breaths or pressure to help your child breathe easier.

What supplies do I need?

- ☐ Trilogy ventilator
- ☐ Bacteria filter
- ☐ Swivel or omniflex adapter
- ☐ Oxygen tubing (if needed)
- ☐ Heater
- ☐ Water chamber
- ☐ Inhalation water
- ☐ Temp probe & heater- wire adapter
- ☐ Circuit (heated wire)
  - Short & long tubing
  - Exhalation valve
  - Deadspace adapter

How do I set up the equipment?

1. Wash your hands.
2. If your child uses oxygen, put the oxygen tubing on the back of the machine.
3. Add the bacteria filter.
4. Add the water chamber to the heater.
5. Put the circuit together.
   - Connect the short tube from the bacteria filter to the water chamber.
   - Connect the long heated wire tube to the water chamber and then add the exhalation valve and the deadspace adapter to the end.
6. Put the temperature probe into the circuit. One is close to the exhalation valve and one is close to the water chamber. Plug the blue end into the right side of the heater.
7. Put the heater-wire adapter into the prongs at the end of the circuit. Plug the yellow end into the right side of the heater.
8. Plug the ventilator into a wall outlet.

How do I change the circuit?

1. Change the circuit, adapters, and heater chamber as you were instructed by your home care company.
2. Be sure that you are setting up the new circuit the same way as the one you are switching out.

Note: Keep using oxygen tubing unless it is cloudy, dirty, or wet inside.

Why is it important to keep the ventilator clean?

1. This will lower the risk of your child becoming sick
2. This will keep the ventilator in its best condition.

Note: Follow your home care company's recommendations for cleaning schedule and solutions.

What should I know about keeping the Trilogy charged?

1. Always keep the ventilator plugged into a wall outlet when not traveling.
2. When traveling in the car, use the **car's adapter** for power, if needed.

Warning: Use the **internal battery** only in a true emergency, such as an extended power outage.

Other teaching sheets that may be helpful

- 1215 – Ventilator Controls and Alarms

ALERT: Call your child's doctor, nurse, or clinic if you have any questions or concerns or if your child has special health care needs that were not covered by this information.

For other health and wellness information, check out this resource:
https://kidshealth.org/ChildrensWi/en/parents

Astral™ ventilator

Set up and maintenance

What does the Astral do?

It gives your child extra breaths or pressure to help your child breathe easier.

What supplies do I need?

- ☐ Astral Ventilator
- ☐ Bacteria filter
- ☐ Swivel or omniflex adapter
- ☐ Oxygen tubing (if needed)
- ☐ Water Trap
- ☐ Heater
- ☐ Water chamber
- ☐ Inhalation water
- ☐ Temp probe and heater-wire adapter
- ☐ Circuit (heated wire)
  - Dual Limb **Or**
  - Single Limb with exhalation valve and pressure lines

How do I set up the equipment?

1. Wash your hands.
2. If your child uses oxygen, put the oxygen tubing on the back of the machine.
3. Add the water chamber to the heater.
4. Add the bacteria filter to the right side labeled "to the patient." This is the inspiratory side.
5. Put the tubing together:
   - Connect the short tube from the bacteria filter to the water chamber.
   - **If using a dual limb circuit**
     - Connect the water trap to the front of the ventilator on the side labeled "from the patient."
     - Connect the inspiratory limb (blue) tubing to the other side of the heater chamber.
     - Connect the expiratory limb (white) tubing to the water trap.
   - **If using a single limb circuit**
     - Connect the exhalation valve to the patient end of the inspiratory tubing.
     - Connect the other end of the inspiratory (blue) tubing to the water chamber.
     - Connect the pressure lines to the front of the ventilator labeled "from the patient."

Set up continued

6. Put the temperature probe into the circuit. One is close to the exhalation valve **or** Y-connector. One is close to the water chamber. Plug the blue end into the right side of the heater.
7. Put the heater-wire adapter into the prongs at the end of the circuit. Plug the yellow end into the right side of the heater.
8. Plug the ventilator into the wall outlet.

How do I change the circuit?

1. Change the circuit, adapters, and heater chamber as you were instructed by your home care company.
2. Be sure that you are setting up the new circuit the same way as the one you are switching out.

Note: Keep using oxygen tubing it is cloudy, dirty, or wet inside.

Why is it important to keep the ventilator clean?

1. This will lower the risk of your child getting sick.
2. This will keep the ventilator in its best condition.

Note: Follow your home care company's recommendations for cleaning schedule and solutions.

What should I know about keeping the Astral charged?

- Always keep the ventilator plugged into a wall outlet when not traveling.
- When the **external battery** is not in use at home, plug it into the charger. You should have this from the home care company. Follow the instructions from the home care company.
- When traveling in the car, use the **car's adapter** for power, if needed.

Warning: Use the **internal battery** only in a true emergency, such as an extended power outage.

Other teaching sheets that may be helpful

- 1215 – Ventilator Controls and Alarms

ALERT: Call your child's doctor, nurse, or clinic if you have any questions or concerns or if your child has special health care needs that were not covered by this information.

For more health and wellness information check out this resource:
https://kidshealth.org/ChildrensWi/en/parents

This sheet was created to help you care for your child or family member. It does not take the place of medical care. Talk with your healthcare provider for diagnosis, treatment and follow-up.

Ventilator information guide

Children's Wisconsin

What does the ventilator do?

The ventilator gives extra breaths or pressure to help your child breathe easier.

What do the displays mean?

Airway pressure

- Green lights estimate the amount of pressure it takes to deliver the breath. It should match the number displayed as PIP.

Display window/screen/menu

- Here, alarms are seen as they happen. The alarms display, or flash, until you press the Reset button.
- Spontaneous measurements also display here.

Display window readings

VTE (exhaled tidal volume)	This is the size of the breath that the ventilator recognizes is coming back to the machine through the tubing. This number may change from breath to breath.
VTI (inhaled tidal volume)	This is the size of the breath that the ventilator is delivering.
PIP (Peak Inspiratory Pressure)	This is the actual amount of pressure it takes to deliver the breath (airway pressure).
PEEP (Positive End Expiratory Pressure)	This is how much air, or pressure, is left in the lungs before taking in a breath.
Ve/MVe (exhaled minute volume) **and/or Vi/MVi** (inhaled minute volume)	This is a measurement of the volume of air that moves in and out of the lungs in one minute.
f (frequency) **or RR** (respiratory rate)	This is the total number of breaths the machine is giving plus what your child is taking.
MAP (Mean Airway Pressure) **or Avg. P**	This is a number representing the average pressure in the lungs while on the ventilator.
I:E	This is a ratio of how long the child is breathing in, and breathing out.
Vcalc or PIF	This is the highest flow it takes to deliver the ventilator breath.
Leak	This is a calculation of how much air is not returning to the ventilator through the tubing from the amount that was originally delivered.
FiO2	This is the percentage of oxygen going through the ventilator.

What do the lights mean?

Patient effort	Lights up briefly when your child triggers a breath.
External power	**Green**: The external battery is fully charged. **Yellow**: The external battery is low. Plug ventilator in a wall socket. Put the battery on the charger. **Battery Symbol**: Green color represents the percent of the battery charged.
Charge status Charge status (continued)	**Green**: The internal battery is fully charged. **Yellow**: – If solid, the internal battery is being charged. – If flashing, the battery Is being checked. **Red**: – The internal battery cannot be charged. – Contact DME supplier. **Battery Symbol**: A lightning bolt shows the battery is actively charging. The battery will be all green when fully charged.
Battery level (internal battery only)	**Green**: Full charge **Yellow**: Half charged **Red**: Will be empty in about 7 minutes. **Battery Symbol**: Green color represents the percent of battery charged.

Note: When the ventilator is unplugged from a wall outlet, the external battery source (if in place) will be used first, and then the internal battery. When plugged back into a wall outlet, the internal battery will charge first, then the external battery (if in place).

How are the settings done?

All prescription settings and alarms are doctor-ordered. They will be set by your child's respiratory healthcare provider. If the doctor changes the orders, the settings are to be changed only by the respiratory healthcare provider.

Ventilator settings ordered for your child

- Ventilation Type
- Mode
- Breath Rate
- Tidal Volume/Pressure Control
- Inspiratory Time
- Sensitivity
- Pressure Support
- PEEP
- High Pressure Alarm
- Low Pressure Alarm
- Low Minute Volume Alarm
- Circuit Disconnect Alarm
- Oxygen Percentage

Settings definition

Ventilation type	Either pressure or volume ventilation will be ordered.
Mode	AC (Assist/control) – Your child can take more breaths than the ventilator gives, each breath delivered has the same volume/pressure. SIMV – Your child can take more breaths than the ventilator gives, each volume breath delivered has a different pressure. CPAP – Your child takes breaths on own with a set end pressure.
Breath rate	The number of ventilator breaths given in 1 minute. This will be the minimum amount of breaths delivered by the ventilator.
Tidal volume	The set volume that determines the size of breath the ventilator gives.
Pressure control	The set pressure that determines the size of the breath the ventilator gives.
Inspiratory time	How fast a breath goes in.
Sensitivity	How hard or easy it is to trigger the ventilator.
Pressure support	An amount of pressure used only with spontaneous breaths. This decreases the work it takes to breath with the ventilator tubing connected.
PEEP	Pressure left in the lungs at the end of the breath, before starting the next breath. It holds the lungs open all of the time.
Alarms	High pressure – Something is blocking the breath being given. You child may be coughing, crying or hiccupping. The tubing could have water in it, or be kinked. Low pressure – Leak in the system, either around the trach tube or in the ventilator tubing. Low minute volume – The ventilator is not getting enough air flow back, over the course of one minute, letting you know there is a big leak or decannulation. Circuit Disconnect – Uses resistance in the tubing and trach tube to measure and indicate a large leak and/or decannulation.
Silence/Reset	Silences the ventilator for one minute. Resets alarm messages.
On/Standby	Turns the ventilator on and off.

Using the Control Lock

The Control Lock is a safety feature. The setting cannot be accidentally changed if the ventilator is bumped or touched by others who have not been trained. The home care company will teach you how to lock and unlock your ventilator.

Using Manual Breath

- This lets you give extra breaths to your child.
- The extra breath is the same size as the one ordered by the tidal volume or pressure control setting in the prescription.
- The extra breath is **not** to be used in place of giving a breath with the Resuscitator Bag.

What do the alarms mean?

An audible alarm sounds and a message shows in the display window. The Trilogy and Astral Ventilators have 3 types of alarms.

- High Priority (Red) - Require immediate response
- Medium Priority (Yellow) - Require prompt response
- Low Priority (Grey) - Require awareness. These alarms alert you to a change in ventilator status.

Message	Meaning	Action
Vent Inop	The machine shuts down if it can't safely operate, or operates at a limited level.	**If this alarm goes off while on your child, take your child off the ventilator and give breaths with the resuscitator bag until another vent is set up.**
Any Alarm Alert		**If the alarm continues:** 1. Take your child off the ventilator and hand ventilate with the resuscitator bag. 2. Contact the home care company. 3. Put your child on a back-up ventilator.
Silence/Reset		Once the problem is corrected, press the **Silence/Reset** button twice to clear the message in the display window.

Message	Meaning	Action
Disc/Sense/ Circuit Disconnect	Is the circuit disconnected? Is the airway pressure line occluded, pinched, wet, or disconnected?	Check all connections. Contact the home care company and/or your health care provider if this continues.
Low Min Vol (Low minute volume)	Does your child have a leak around the trach? Is your child disconnected from the ventilator? Is the trach tube in your child's neck?	Check all connections. Try repositioning your child, by turning the head or rolling to other side to decrease leak at the trach tube. Inflate cuff if available. Check if there is water in one of the small clear tubes.
High Pres (High pressure alarm)	Something is in the way of the breath being delivered. Is your child coughing, crying, hiccupping, or upset? Is there water in the tubing? Does your child have a large amount of secretions? Is it hard to get the catheter in? Do you think the trach tube is plugged?	Empty water from the tubing. If there is a large amount of secretions, suction your child. If it is hard to get the catheter in or you think the trach tube is plugged, change the trach tube.
Low Pres (Low pressure alarm)	There is a leak. Can you hear air leak around your child's trach? Are all the connections tight? Did you disconnect and reconnect the tubing?	If you can hear air leak around your child's trach, reposition your child. Do a leak test if alarm continues. (LTV)

Message	Meaning	Action
Check Circuit/ Circuit Fault	Is there water in the circuit? Is the circuit kinked? Are there leaks in the circuit?	Check circuit for water or leaks. Perform a Learn Circuit (Astral) If alarm continues, replace the circuit.

Other teaching sheets that may be helpful

- 1253 – LTV™ Ventilator Set Up and Maintenance

ALERT: Call your child's doctor, nurse, or clinic if you have any questions or concerns or if your child has special health care needs that were not covered by this information.

Low Priority Alarm

SLOWER Consecutive Chirps

High Priority Alarm

FASTER Consecutive Chirps

ALWAYS start at your child's airway, then work your way back to the vent.

SUCTION → **BAG** → **CHANGE THE TRACH**

HIGH PRESSURE: ***"Something is in the way"***

- Secretions/Plug
- Coughing
- Crying
- Laughing
- Kinked Tubing
- Water in Tubing
- Hiccupping
- Bearing down

LOW PRESSURE: ***"Something is missing"***

- Disconnection
- Leak around trach tube
- Decannulation
- Hole in tubing

LOW MINUTE VENTILATION: ***"Decannulation Alert"***

- Flow is not getting back to the vent through the circuit
- Leak around trach tube
- Decannulation

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Home Oxygen with a Tracheostomy Tube

What is an oxygen system?

Oxygen (O2)

Purpose

The oxygen system allows your child to get the prescribed amount of oxygen, by using a set number called a liter flow.

Guidelines

Your oxygen system will consist of both a stationary system, and a portable one. Your home care provider will instruct you on how to use these.

- Use the oxygen system at all times, as ordered by your child's physician.
- Check the amount of oxygen in the portable tank before using it.
- Your home healthcare provider will help you figure out how much flow to use as ordered by your child's physician.

Special directions

- Keep the oxygen supply at least 5 feet from any heat source like a radiator or fireplace.
- Do not smoke with oxygen in use.
- Do not use electrical devices, including electric toys, blankets, etc. near the oxygen because they may cause sparks.
- Do not use petroleum or acetone based products on your child such as Vaseline™ or nail polish remover, as these items are flammable.
- Follow all directions provided by the home care provider.

Stationary oxygen systems

- An oxygen concentrator is the machine that will deliver oxygen while you are in your home.
- This machine is not portable, it has to be plugged into a wall outlet.
- This machine pulls in air from the room it is in, and concentrates the oxygen from that air to deliver to the child.
- An oxygen tubing will be used to connect this machine to the ventilator at the oxygen adapter on the ventilator. Do not add into the ventilator tubing.
- An oxygen tubing will be used to connect this machine to your stationary humidification system, and will be added into the tubing.

Portable oxygen systems

- Oxygen tanks are used for portability. They come in two forms: Liquid and Compressed.
- Your home healthcare provider will work with you to decide which size tanks will work best for you.
- Portable liquid oxygen tanks should always be kept upright and should not transported in the trunk of a car.
- If liquid oxygen is in very hot or cold temperatures, this could cause oxygen to leave the tank fast.
- The portable compressed oxygen tanks may be transported in the trunk of a car and may lay flat.


Liquid Oxygen Tank


Compressed Oxygen Tank

- When your child is using the HME (Heat & Moisture Exchanger, or artificial nose) continue to use oxygen.
- Your home healthcare provider may offer you different options to add in oxygen.


HME with a direct connect oxygen option


Venturi System™


HME guard with oxygen tubing

- Use the percentage of oxygen closest to or above the percentage ordered, never below.

Note: Refer to HME teaching sheet #3034 for more information on HME use.
Refer to your specific Humidification System teaching sheet for more information on tubing set up.

ALERT: Call your child's doctor, nurse, or clinic if you have any questions or concerns or if your child has special health care needs that were not covered by this information.

What you need for your teaching session

This sheet will help you know what equipment to have ready for your teaching sessions. These sessions help you get ready to care for your child. Both caregivers must attend each session together.

The company that supplies your child's equipment is called your DME. "DME" is short for Durable Medical Equipment.

☐ **Session #1- with DME Respiratory Therapist (RT) in your home.** The DME RT will bring equipment to your home and teach you how to use it.

☐ **Session #2- with DME Respiratory Therapist (RT)** May be at Children's or in your home.
Equipment needed:
- ☐ Pulse ox machine with probes and power cord
- ☐ Portable suction machine with power cord
- ☐ Nebulizer machine
- ☐ One Ventilator with power cord
- ☐ Oxygen Tank (if your child uses oxygen)

☐ **Session #3- With Trach/Vent RT at Children's**
Equipment needed to be at the hospital:
- ☐ Pulse ox machine with probes and power cord
- ☐ Portable suction machine with power cord
- ☐ Nebulizer machine
- ☐ One Ventilator with power cord
- ☐ Oxygen Tank (if your child uses oxygen)
- ☐ Resuscitation bag or you can use the one in your child's room

☐ **Session #4- Simulation, Teach Back and walk Trach/Vent RT at Children's**
Equipment needed at the hospital:
- ☐ Pulse ox machine with probes and power cord
- ☐ Portable suction machine with power cord
- ☐ One Ventilator with power cord
- ☐ Oxygen Tank (if your child uses oxygen)
- ☐ Resuscitation bag (can use the one in child's room)
- ☐ Go-Bag (in child's room)
- ☐ Stroller

***Bedside cares and CPR must be completed and checked off with RN before the next session.**

☐ **Independent Care:**
Equipment needed at the hospital for independent care and discharge:
- ☐ Pulse ox machine with probes and power cord
- ☐ Portable suction machine with power cord
- ☐ One Ventilator with power cord
- ☐ Oxygen Tank (if your child uses oxygen)
- ☐ Resuscitation bag from room
- ☐ Fully stocked Go-bag
- ☐ Stroller

Equipment photos on next page

Equipment reference photos

Trach and Vent

Portable suction machine:

Pulse ox machine:

Resuscitator Bag:

Ventilator:

Portable Oxygen:

Go-Bag:

ALERT: Call your child's health care provider if you or your child have any concerns related to this teaching sheet or if your child has and special care needs not covered by this information.

This sheet was created to help you care for your child or family member. It does not take the place of medical care. Talk with your healthcare provider for diagnosis, treatment, and follow-up

What you need for your teaching session

Trach-only

This sheet will help you know what equipment to have ready for your teaching sessions. These sessions help you get ready to care for your child. Both caregivers must attend each session together.

The company that supplies your child's equipment is called your DME. "DME" is short for Durable Medical Equipment.

☐ **Session #1- With DME Respiratory Therapist (RT) in your home.** The DME RT will bring equipment to your home and teach you how to use it.

☐ **Session #2- With DME Respiratory Therapist (RT) teaching.** May be at Children's or in your home.

Equipment needed:

- ☐ Pulse ox machine with probes and power cord
- ☐ Portable suction machine with power cord
- ☐ Nebulizer machine
- ☐ Oxygen Tank (if your child uses oxygen)

☐ **Session #3- Teaching with Trach/Vent RT at Children's**

Bring this equipment to the hospital:

- ☐ Pulse ox machine with probes and power cord
- ☐ Portable suction machine with power cord
- ☐ Nebulizer machine
- ☐ Oxygen Tank (if your child uses oxygen)
- ☐ Resuscitation bag or you can use the one in your child's room

☐ **Session #4- Simulation, Teach Back and Walk with Trach/Vent RT at Children's**

Equipment needed at the hospital:

- ☐ Pulse ox machine with probes and power cord
- ☐ Portable suction machine with power cord
- ☐ Oxygen Tank (if applicable)
- ☐ Resuscitation bag (can use the one in child's room)
- ☐ Go-Bag (in child's room)
- ☐ Stroller

***Bedside cares and CPR must be completed and checked off with RN before the next session.**

☐ **Independent Care:**

Equipment needed at the hospital for independent care and discharge:

- ☐ Pulse ox machine with probes and power cord
- ☐ Portable suction machine with power cord
- ☐ Oxygen Tank (if your child uses oxygen)
- ☐ Resuscitation bag from room
- ☐ Fully stocked Go-bag
- ☐ Dreamstation or Air Compressor
- ☐ Stroller

Equipment photos on next page

What you need for your teaching session

Trach-only

Equipment reference photos

Portable suction machine:

Dreamstation:

Air compressor:

Pulse ox machine:

Portable Oxygen:

Resuscitator Bag:

Go-Bag:

ALERT: Call your child's health care provider if you or your child have any concerns related to this teaching sheet or if your child has and special care needs not covered by this information.

Chapter

5

Breathing Medicines and Treatments

Introduction

If your child goes home from the hospital with medicine, your team will teach you about the medicine your child needs. You will get a list of the medicines for your child. This section would be a good place to keep the sheets for those medicines.

Your child may also go home with respiratory treatments that help move secretions to make suctioning them out easier. These treatments are called bronchial hygiene treatments. You do these treatments with your medicine treatments.

Your doctor will give you a "Well Plan" so that you know how many times per day to do these breathing treatments. You may also get a "Sick Plan" so you know what to do when your child becomes sick."

There are some common medicines your doctor may prescribe to help your child's breathing with a tracheostomy.

- Albuterol is a medicine that is most commonly taken by nebulizer treatment and inhaled, or breathed, into the lungs. It relaxes the muscles of the airway and opens up the breathing tubes. This makes breathing easier.

- Pulmicort is a steroid medicine. It is inhaled into the lungs. This helps to decrease and prevent swelling in the airway. It may not make your child feel better right away. Steroid medicines often take a few days to a few weeks for effects to be noticed. There are other steroid medicines to reduce swelling of the airway tissue that your child's doctor could prescribe.
- Pulmozyme (or Dnase) is also taken by nebulizer. It breaks up secretions in the lungs.
- Tobramycin is a nebulized antibiotic used to treat infections in the lungs. Your child may also need other antibiotics taken by mouth to treat infections.
- Diuretics are medicines that work to help balance the amount of water and sodium in the body. Too much extra fluid sometimes causes swelling and interferes with proper lung function. This can increase how hard your child has to work to breathe. Diuretics can reduce the amount of extra fluid or swelling in the lung tissue. Two common diuretics are Chlorothiazide and Spironolactone.

Key points

- Suction your child's trach tube before giving inhaled medicines.
- Watch your child's breathing and how they react to the medicine given during the treatment.
- Do not let your child eat while getting a nebulizer treatment.

Giving an MDI and manual breaths:

https://chw.wistia.com/medias/6epjn1fyyb

Teaching sheets in this chapter

☐ Nebulizer treatments for patients with a tracheostomy tube (#1276)

☐ Metered dose inhalers (MDI) for children with trach tubes (#1029)

☐ Order of inhaled respiratory medicines (#1037)

☐ Albuterol HFA (#1509)

☐ High dose Tobramycin for inhalation (#1873)

☐ Pari LC nebulizer (#1864)

☐ Vest therapy (#2145)

☐ Cough assist machine (#2146)

☐ Interpulmonary percussive ventilation (IPV) (#2147)

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Nebulizer treatments

For patients with a Tracheostomy Tube

Purpose

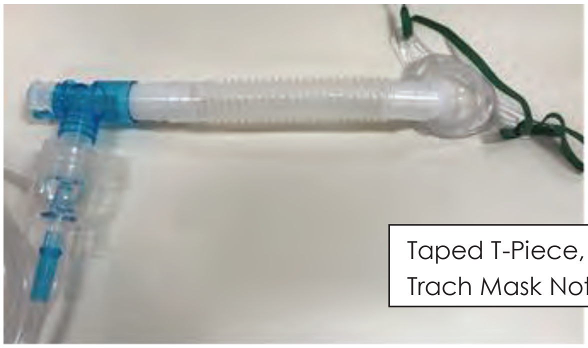
- To deliver medicines that treat wheezing or move secretions.
- To give inhaled corticosteroids and antibiotics.
- To use a saline vial as another source for humidity.

Supplies needed

- ☐ Nebulizer machine
- ☐ Medicines
- ☐ Nebulizer Kit
  - — Nebulizer cup
  - — T-piece
  - — 6 inch corrugated tubing (if not on a ventilator)
  - — Trach Mask (if not on a ventilator)
  - — Clear oxygen tubing

Giving the treatment

1. Wash your hands.
2. Make sure the plastic piece inside the nebulizer cup is clicked in place. Connect the top of the nebulizer cup with a firm twist.
3. Medicine can be added from the top.
4. Saline may be needed, and added to your nebulizer cup with the medication to fill to a volume of 3-5mLs.
5. Connect the nebulizer cup to the machine by using the clear oxygen tubing.
6. Insert the nebulizer cup into the T-piece.
7. Insert the T-piece into the tubing.
8. You may also place tape over one end of the T-piece and connect to the 6in of corrugated tubing and trach mask (if you are not using a ventilator).
9. Turn the machine on.



Taped T-Piece, 6 in Corrugated Tubing, Trach Mask Not for Ventilator use

Note: If your child uses oxygen, you may need to increase the liter flow while you are running your nebulizer treatment.

10. When the medicine begins to sputter, tap the side of the nebulizer cup. When the medicine is gone, turn off your nebulizer machine.
11. Remove the T-piece and nebulizer cup from the ventilator circuit and reattach the ventilator circuit as used before.
12. If oxygen liter flow was increased during the treatment, return it to its original liter flow.


LTV Ventilator


Trilogy


Astral Ventilator
Single Limb


Astral Ventilator
Dual Limb

Cleaning the equipment

After each treatment

1. Rinse the nebulizer cup and T-piece with warm water.
2. Air dry on a clean cloth.

Every night

1. Wash the nebulizer cup and T-piece with warm soapy water.
2. Rinse well.
3. Air dry on a clean cloth.

Weekly

Replace the nebulizer kit.

Special directions

Follow the instructions from your child's home care provider if using more than one nebulizer kit per week.

ALERT: Call your child's doctor, nurse, respiratory therapist, or clinic if you have any questions or concerns or if your child has special health care needs that were not covered by this information.

Metered Dose Inhalers (MDI)

For patients with a tracheostomy tube

What is a Metered Dose Inhaler (MDI) used for?

An MDI is used to treat wheezing or to give corticosteroids. It can be used while traveling or when the nebulizer machine cannot be used. You may also hear this referred to as an inhaler.

What supplies are needed?

- Manual Resuscitator bag
- AeroChamber mini™
- Meter dose inhaler
- Oxygen (if it is ordered)

What are the steps for using a MDI?

1. Connect the manual resuscitator bag to the end with the canister. If your child uses oxygen, you may hook up oxygen to your bag as you would when you give breaths.
2. Shake the MDI canister before using.
3. If new, or not used in a while, prime the MDI by spraying 4 times into the air.
4. Put the MDI canister into canister Port.
5. Put the other end of the chamber on your child's trach tube.
6. After your child exhales, press the MDI canister down to give **one** puff.
7. While your child breathes in, squeeze the manual resuscitator bag. Give your child 2 to 5 deep breaths with the bag.
8. Take the Chamber off your child's trach tube.

If your child…	Then…
Uses oxygen	1. Put your child back on the trach collar between puffs. 2. Shake the MDI again before giving the next puff.
Does not use oxygen	Continue to step 9.

9. Repeat steps 4 through 7 for each puff ordered.

Special directions

- Suction your child before giving the MDI.
- The chamber is ordered through your durable medical equipment (DME) provider, not the pharmacy.
- If using more than one respiratory medication (nebulizer or MDI), refer to the order of medications teaching sheet. Adjust if additional medications are temporarily added such as antibiotics.
- **Replace the equipment as directed by your home healthcare company.**

For other health and wellness information, check out this resource:
https://kidshealth.org/ChildrensWi/en/parents

ALERT: Call your child's doctor, nurse, or clinic if you have any questions or concerns or if your child has special health care needs that were not covered by this information.

Order of inhaled home respiratory medicines

Breathing treatments keep your lungs healthy. It is good to know what your medicines do so you understand why you take them. They work best if you take them in the right order. **If there is a medicine on this list that you do not take, skip that step.** If you take an inhaled medicine that is not on the list, ask your healthcare provider where it goes in the order.

Take medicine in this order:

1. **Fast acting Bronchodilators (such as Albuterol, Xopenex®, Combivent®, or Atrovent®)**

   These medicines relax the airways. **Always** take this before the hypertonic saline.

2. **Hypertonic saline**

   Saline is salty. It will bring more water into the airways. This helps to thin the mucus so it is easier to cough out. Do not mix 7% hypertonic saline with other medicines in your nebulizer cup.

3. **Pulmozyme® (DNase) or Mucomyst®**

   These medicines also help to thin the mucus in the lungs. **Always use a separate nebulizer kit for this medicine.**

4. **Airway clearance and huff cough**

   Now it is time to clear the airway. This is called bronchial hygiene. You may use the vest, Acapella, PEP, CPT, breathing exercises or other devices. These treatments will help move the mucus out of the airways. It is good to **huff cough** during and after your airway clearance therapy to get the mucus out of your lungs. The mucus in the lungs may be full of germs. Getting as much of it out as soon as possible is very important.

Note: You can do Steps 1, 2, or 3 at the same time you are on the vest.

5. **Inhaled antibiotics (such as TOBI®, Colistin®, or Cayston®)**

   Now that the lungs are clear **after** airway clearance, it is time for the inhaled antibiotic. This helps kill the germs left in the lungs after airway clearance.

6. **Inhaled steroids (such as Flovent®, Advair®, QVAR®, Pulmicort®, Symbicort®, Dulera®, Asmanex® or Alvesco®)**

   Airways can get swollen from infection, irritation or allergy. An inhaled steroid will help reduce this swelling. Take this medicine last so it gets to the lungs when they are the most clear.

ALERT: Call your child's doctor, nurse, or respiratory therapist if you have any questions or concerns or if your child has special health care needs that were not covered by this information.

For other health and wellness information check out this resource:
https://kidshealth.org/ChildrensWi/en/parents

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Albuterol

(Albuterol, Accuneb®, Proventil HFA®, Ventolin HFA®, ProAir HFA®, ProAir RespiClick®, Xopnex HFA®)

Reason for prescribing

Albuterol is a rescue or quick relief medication used to relax the muscles around the airways. It helps them stay open so air can move freely in and out of the lungs. This medicine makes it easier for your child to breathe.

This medicine comes in two forms:

- Inhaler pump or puffer. This is sometimes called a MDI (metered dose inhaler).
- Liquid to use in a nebulizer.

How and when to give the medicine

Always use a spacer or holding **chamber** with the inhaler or puffer. Your nurse, doctor or therapist can help you learn how to use a spacer.

Shake the inhaler or puffer before each use.

Use this medicine right away when asthma symptoms start:

- Cough.
- Wheezing.
- Tight or heavy chest.
- Cough at night.
- Playing less

This medicine begins to work very quickly. Asthma symptoms should be better in 5-10 minutes after taking the medicine.

The medicine will work in the body for up to four hours.

Quick relief medicine should be taken for asthma symptoms or before activities. If the medicine is used too often it can be dangerous.

Your child's doctor, nurse or respiratory therapist will give you a plan to help explain how and when to give this medicine. Ask the doctor, nurse, respiratory therapist or pharmacist any questions you have.

Possible side effects

Some people have restlessness, nervousness, shaking hands, fast or pounding heart beat when they take quick relief medicines.

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Special information

- Ask your provider for an Asthma Management Plan.
- Avoid your asthma triggers.
- Quick relief medicine should not be needed more than two times a week during the day or more than two times a month during the night. Quick relief medicines should not be refilled more than two times a year. Call your provider if you are needing more quick relief medicines. You may need a stronger type of medicine to control your asthma.
    - Keep this and all medicines out of reach of children.

ALERT: Call your child's doctor, nurse or clinic or go to urgent care or emergency room right away if emergency signs start.

- Emergency signs:
    - Rescue medicine is not working.
    - Breathing getting harder and faster.
    - Coughing and coughing without stopping.
    - Difficulty talking, walking or sleeping.
    - Nose opening wider.
    - Ribs sticking out.
    - Lips or fingernails turning blue.

This sheet was created to help you care for your child or family member. It does not take the place of medical care. Talk with your healthcare provider for diagnosis, treatment and follow-up.

Tobramycin: High dose for inhalation

(TOBI® and other approved generics)

Tobramycin (TOBI) is a medicine used to treat chronic lung infections. It comes as a liquid that is made into a mist. This is called nebulized. Your child breathes in (inhales) the mist during a treatment.
Your child's doctor or nurse will explain how and when to give this medicine to your child.

Possible side effects

Tell the doctor, nurse, or pharmacist if your child has these or any other side effects:

- Ringing in the ears
- A sore throat
- A hoarse voice
- Changes in hearing
- Dizziness
- Wheezing

Supplies needed

- Home Nebulizer machine, called a compressor.
- Only use the Pari LC® Plus nebulizer to give TOBI and other approved generics.
- Tobramycin inhalation solution 300 mg.

Steps to follow

1. Wash your hands.
2. Take the cover off the nebulizer cup.
3. Twist and remove the smaller end of the ampule.
4. Squirt all of the medicine into the nebulizer cup. Do **not** dilute with saline solution. Put the cover on the nebulizer cup.
5. Start the treatment. It should last 10 to 15 minutes.
6. If the treatment takes longer than 10 to 15 minutes, you may need to replace:
   - Your Pari LC Plus nebulizer
   - The compressor
   - The compressor filter

If your child is taking more than one medicine

Take them in this order:

_____ Short-acting Bronchodilator (Albuterol or Xopenex®)
+Pulmicort Respules® or Intal® may be mixed with Albuterol and be given together
_____ Anticholinergic (Atrovent®, Combivent ® or Duoneb®)
_____ Hypertonic Saline
_____ DNase (Pulmozyme®)
_____ Bronchial hygiene / Airway Clearance
_____ Long-acting Bronchodilator
_____ Antibiotic
_____ Inhaled Steroid

Special information

Do not let anyone else take this medicine.

General information about TOBI or generic medicine:

- Never use a nebulizer with a clogged nozzle. If the nozzle is clogged, no mist will come out. It will need to be replaced. Clean the Pari LC right away after nebulizer treatment. This will help keep it from getting clogged.
- To replace the compressor, call your Durable Medical Equipment supplier or the CF Center at (414) 266-6730.
- Do not mix this medicine with other medicines. You may use the same Pari LC nebulizer as you use for the bronchodilator medicine. Rinse the nebulizer well with sterile water before adding the medicine. If you do not rinse the nebulizer, this medicine may foam.

Storage, refills and when to throw away the TOBI or generic medicine:

- **Keep this medicine out of the reach of children.**
- Store this medicine in the refrigerator. If a refrigerator is not available, store the foil pouches at room temperature for up to 28 days. Un-refrigerated medicine may darken in color. It is normally slightly yellow. The color change does not change the quality.

You should not use TOBI or generic:

- If there are particles in the solution.
- If it has been stored at room temperature for more than 28 days.
- If it looks cloudy.
- After the expiration date.

ALERT: Call your child's doctor, nurse, or clinic if you have any questions or concerns or if your child has:

- Any side effects.
- Special health care needs that were not covered by this information.

For other health and wellness information check out this resource:
https://kidshealth.org/ChildrensWi/en/parents

PARI LC PLUS® Nebulizer

Purpose

The PARI LC PLUS® is a nebulizer kit. It is used to turn medicine into a mist so that it can be breathed in. When your child breathes there are valves that open and close. This helps decrease medicine waste. Each PARI LC PLUS® kit should last for 6 months.

Supplies needed

- PARI LC PLUS® nebulizer. See Figure 1.
    1. Inspiratory valve cap
    2. Top of medicine cup
    3. Nebulizer cup
    4. Connecting tubing
- Nebulizer machine (any brand name compressor will work)

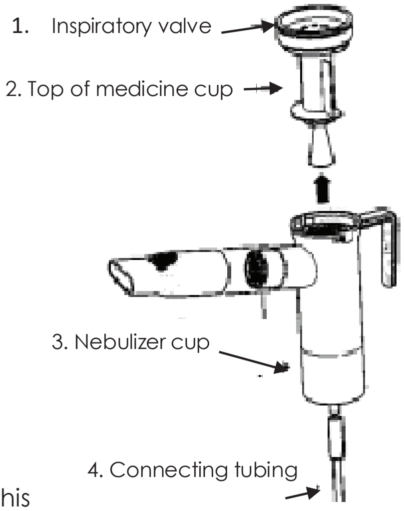

Figure 1

How and when to use the PARI LC PLUS®

Your child's doctor or nurse will tell you how and when to use this device. If you have questions, ask the doctor, nurse or pharmacist. Follow these steps.

1. Clean your hands with soap and water or hand sanitizer.
2. Place the **valve cap** on the **top** of the **medicine cup**. Press firmly.
3. Place the **mouthpiece,** with the valve facing up, or the **mask** on the outlet. See Figure 2.
4. Place the medicine in the **nebulizer cup**.
5. Place the **top of medicine cup** onto the **nebulizer cup**.
   Twist into place.
6. Connect the tubing to the bottom of the cup. Connect the other end to the machine.
7. Turn the machine on.
8. Hold the nebulizer level during the treatment. Close your lips around the mouthpiece, or place the mask over the face. Breathe slowly and slightly deeper. Breathe through your mouth if you are using the mouthpiece.
9. Turn the machine off when the medicine is all gone. The treatment should last about ten minutes.

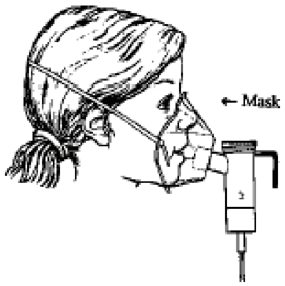

Figure 2

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Clean the PARI LC PLUS® right after each treatment

1. Take the Pari LC□ PLUS® apart.
2. Wash all parts with warm, soapy water. Do not immerse the tubing.
3. Rinse with warm water.
4. Let the parts air dry.
5. Disinfect before you use your nebulizer again.

Disinfect and sterilize the PARI LC PLUS®

1. Clean the equipment first, then disinfect.
2. Disinfect your Pari LC PLUS® as directed by your healthcare provider.
3. Disinfect with one of these methods:
    - Boil in water for 5 to 10 minutes.
    - Top shelf dishwasher safe. Your dishwasher must reach at least 158 degrees for 30 minutes to disinfect. Do not leave the nebulizer parts in the dishwasher for the dry cycle.
    - **Electric steam** baby bottle sterilizer. Follow the maker's instructions. Do not use a microwave sterilizer. All of the pieces of the nebulizer handset can be disinfected in the electric steam sterilizer. Do not leave the nebulizer parts in the sterilizer during the dry cycle. Be sure to allow enough time for the sterilizer to cool before opening the unit to remove the nebulizer pieces.
    - Soak all parts (except tubing) in a solution of 1 part white vinegar and 3 parts water. Soak for one hour. Rinse with water. Throw the vinegar solution away after using. **If your child has Cystic Fibrosis, do not use vinegar for disinfecting.**
4. Let all parts air dry. First drain the parts on a clean towel. Replace the wet towel with a dry one and let air dry.
5. Store in a clean plastic bag.

ALERT: Call your child's doctor, nurse, or clinic if you have any questions or concerns or if your child has special health care needs that were not covered by this information.

For other health and wellness information check out this resource:
https://kidshealth.org/ChildrensWi/en/parents

Vest therapy

What is a vest machine?

A vest machine is used to loosen mucus from the airways by vibrating the chest. This helps move the mucus so you can cough or suction it out easier.

The machine connects to the vest with a hose. The vest is worn over the chest. The machine makes air pulses that wiggle the chest.

Why do I need a vest machine?

The vest machine helps make it easier to get mucus out of your lungs.

- There is mucus that is hard to move in the lungs.
- There may be areas of lung collapse because of your mucus.
- It can be hard to cough up mucus in the lungs. You may also need to suction the mucus.

How is the vest machine different from chest physiotherapy (CPT)?

With the vest machine:

- You do not need to change your position during your treatment. All lobes of the lungs are treated at the same time.
- Treatments takes less time.
- Treatments are consistent.

How is a vest machine used?

- Your machine has some settings.
    - The pressure setting is how tight the vest feels on the chest.
    - The frequency setting is how fast the machine wiggles the chest.
    - The time setting is how long your treatment is set for.
- Your provider will decide the right settings for your machine.
- Your vest equipment company will program the machine settings.
- Your provider will tell you how long and how often to do treatments.
- There are some nebulizer medicines that can be given during the vest treatment. Your provider will tell you which ones to give during your vest treatment.
- During the vest treatment, you may stop the machine to cough or clear mucus at any time.
- After the vest treatment, always huff cough. If you have a suction machine, use that to clear the mucus.
- You may have a sick plan for when your mucus is not controlled.

ALERT:

- Call the equipment provider f you have questions or concerns that your equipment is not working properly.
- Call your child's doctor, nurse, or clinic if you have any questions or concerns or if your child has special health care needs that were not covered by this information.

This sheet was created to help you care for your child or family member. It does not take the place of medical care. Talk with your healthcare provider for diagnosis, treatment and follow-up.

#2145 September 2021

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Cough assist machine

What is a cough assist machine?

A cough assist machine helps to push and pull air in the lungs like a cough.

The machine has several settings:

- **Inspiratory Pressure**: this pushes air into your lungs like a big breath.
- **Expiratory Pressure**: this pulls mucus out of your lungs like a big cough.
- **Pause:** The time in seconds between each cycle of in and out.

Why do I need a cough assist machine?

- You may have weak muscles. Your cough may not move mucus easily.
- You may get sick often.

How does a cough assist machine work?

- Your provider will decide the settings, length of treatment, and how many times a day to do this treatment.
- Your equipment company will set up the machine.

How is a treatment done?

Do this treatment after all your other breathing treatments. This treatment can also be done anytime you need help coughing.

If you use a mask put the mask on tight so the machine can push and pull out the cough easier.

It you use tracheostomy tube your equipment company will give you an adapter to place right on your trach tube.

Repeat these steps 3 times:

1. Use the machine to do 5 coughs in a row.
2. Suction any mucus that you have coughed up.
3. Rest if needed.

ALERT:

- Call the equipment provider if you have questions or concerns that your equipment is not working properly.
- Call your child's doctor, nurse, or clinic if you have any questions or concerns or if your child has special health care needs that were not covered by this information.

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#2146 September 2021

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Intrapulmonary percussive ventilation (IPV)

What is IPV?

IPV helps open your airways and move mucus in your airways. It does it with small, fast bursts of air. You will notice a mist. This helps to loosen the mucus. This makes it easier to cough or suction the mucus out of your airways.

When might IPV be needed?

If you have:

- Cystic Fibrosis
- Bronchiectasis, this is when there are issues with the large airways
- Smoke Inhalation
- Atelectasis, this is when a small area of the lung collapses.
- Aspiration, this is when fluid or food is inhaled in to the lungs

How does an IPV work?

- An IPV treatment can be done with just saline. You can also give some nebulizer medicines with it.
- The speed of busts of air helps to loosen mucus and move it.
    - Faster bursts loosens mucus.
    - Slower bursts move mucus up and out of the lungs.
- When your machine is delivered, the home care company will set it up. They will teach you how to use it.
- Your doctor will tell you to give nebulizer medicines, just saline, or both. They will tell you:
    - how and when to do the treatments.
    - length of treatment.

Special Notes:

- If you have a tracheostomy tube, you will get an adapter to use with you trach.
    - **Make sure the air or water in your trach tube cuff is removed before starting the treatment.**
    - **After the treatment replace the air or water in the trach tube cuff.**
- Place the mask over the face and nose. Hold the mask firmly. Keep the cheeks tight.
- Huff cough or suction after your treatment to get the mucus out.
- If you have a sick plan, your doctor will tell you how to change your treatments.

ALERT:

- Call the equipment provider if you have questions or concerns that your equipment is not working properly.
- Call your child's doctor, nurse, or clinic if you have any questions or concerns or if your child has special health care needs that were not covered by this information.

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Chapter

6

Parent-to-Parent

Messages from other parents

Parents of children with tracheostomies share their thoughts, feelings and ideas. This can be very helpful to parents who are new to tracheostomies.

This chapter also gives you information to use when you have or are looking for home nursing.

Parent videos

Watch these helpful videos of parents who have a child with a tracheostomy.

Parents of children in the hospital

https://chw.wistia.com/medias/0up6uaaylw

Foster parent interviews

https://chw.wistia.com/medias/qnwgb6kxzu

https://chw.wistia.com/medias/oo1d781rfg

Trach/Vent Clinic interview

https://chw.wistia.com/medias/9xlcppn6zk

Tips and tricks from our parents

In the hospital after trach placement

- As a parent, you have the right to speak for your child and advocate for their care.
- Being at the hospital as much as possible for extended periods of time, including overnight.
- Doing ALL of my child's care.
- Packing up our stroller, leaving the unit, and walking with our child:
    - I wish I would have spent even more time at the bedside.
    - Leaving the house takes a lot of time and preparation.

Getting ready to go home after trach placement

- We had a touch lamp in our child's room that was always on did, but was very easy to turn up in case of a nighttime emergency.
- I am glad I worked with my DME company to organize my house before my child came home.
- Invest in a 3-drawer plastic shelf unit and plastic containers with lids for all the supplies.
- We installed a wireless doorbell in our child's room that the nurses can push to quickly notify us in case of an emergency

Working with your DME provider

- Make a list of supplies you order using the order numbers to help keep track of trends of your supply needs.
- Always check your order when you first receive it to ensure that your supplies are all there. Don't wait until needed.

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How to plan for traveling

If your child has complex needs

Dates of Travel: ________________________________

Where you are going: ____________________________________

Flying: ☐ Driving: ☐

Person has: Trach ☐ Vent ☐ Oxygen ☐

If using oxygen: Medical Team has said they are "safe to travel" ☐

Oxygen %/LPM ________________

Caregiver:

Give your Medical Team and DME provider at least 1 month to help you with your travel needs. The more time they have to help you, the better.

Make an emergency contact list, have phone numbers and addresses for the following:

- DME companies, your current company and the one at your destination.
- Local (children's) hospitals where you are going, and along your route.
- Doctors.
- Children's Wisconsin Pulmonary Line/ Complex Care Program.

Remember to have these numbers written down on paper. During travel you may not have WIFI or a phone or tablet may run out of battery and you will need to call.

Know the battery life of your equipment, and charging options.

Order extra disposable supplies and medicines in the months before your trip. This will include anything that is "as needed". This will help so you do not run low while packing. You will also be fully stocked when you get back.

Talk with your DME company

Be sure to tell your DME the details of your trip. This includes dates and where you are going.

DME can:

- Make sure you have the right amount of disposable supplies.
- Help with oxygen needs:
  - Offer a portable oxygen concentrator (POC). This is needed for flying. If not, could help with a rental agreement with another DME company. You might have to pay for your rental time.
  - Explain the position your Oxygen should be in while driving.
  - Explain how to secure your tank.
- Review which equipment will need to travel with the patient, and which could be shipped. This might mean a GO bag or an extra feeding tube. It will depend on your child's needs.

- Find a DME provider where you will be staying, in case of problems with equipment or supplies.
- Discuss battery life and charging options.
- **Discuss the options for shipping supplies** (respiratory, feeding, incontinence, and/or hygiene) about 7 to10 days before the trip. This can:
    - save room in the car.
    - reduce items carried through the airport.
    - give you time to call to make sure the items were received (in good condition).
    - find out where you can pick them up when you arrive.

If anything was damaged during shipping, you still have the chance to pack those items.

- May be able to help with packing in the home. Ask them.

Talk with your Medical team about:

- Updated DME orders for medical supplies (both trach/vent and feeding) in case you need to replace supplies or equipment.
- Updated orders for your Trach/Vent/Oxygen/Feeds in case you have an ER or hospital admission.
- Updated prescriptions with refills available, even PRN (as needed) medicines.
- How to travel with medicines and tube feedings that need to be refrigerated.
- Humidity plan (Heat and moisture exchanger (HME), saline drops, saline nebulizer treatments).
- If you are going to a Theme Park, or other park, be sure that oxygen (tanks or portable oxygen concentrator) is allowed.
- **If driving**: Your travel route, where you will stop and local (children's) hospitals along the way.
- **If flying**: Print any **forms needed** from the airline's website. Some forms will be:
    - Medical clearance form.
    - Letter including medical equipment, supplies, and medicines that are medically necessary to fly onboard with the patient.
    - Oxygen needs.

Check with Airport to learn about any accessible options. For example, see if an accessible bathroom requires an appointment.

- Make sure your seat has enough space to store all of your equipment safely.

How Children's Wisconsin Team can help:

- Make sure that the patient's DME provider knows of the travel plans, and can assist with the above topics.
- Help to find the closest (children's) hospital to the place you are going, and on your route. If driving, discuss the route to help with places and times to stop. These are to offer humidity, charge batteries, spend the night, and safely transport oxygen.
- Update DME orders so they can be given to another DME provider where you are going. You may need this if your child needs more supplies or equipment.
- Place a "Home Supply Needed" order for a Portable Oxygen Concentrator (POC) if your child is on oxygen.
- Help with airline forms as needed.
    - Write a letter for the airline listing what equipment and supplies are medically necessary to be with the patient.
    - Medical clearance form.
- Review battery life, and charging options for home equipment.
- Review options for portable humidity.
- Review your medicine and feeding plan.
- Create an Emergency Plan for your child.

ALERT: Call your child's doctor, nurse, or clinic if you have any questions or concerns or if your child has special health care needs that were not covered by this information.

Home care nursing

Private duty nurse (PDN)

A child with a trach often needs round-the-clock care by caregivers. They must be trained in routine and emergency trach care. There are other resources and people to help you at home.

One home resource is your PDN. Children with trach tubes can often get private duty nursing care in the home. This is done through state funding or a private insurance plan.

PDNs are RNs or LPNs who may be independent nurse providers. They do this work through the state or may work for a home care-nursing agency.

Home nursing can be difficult to find in Wisconsin. Our team will work with you to try to find and get it set up. Home nursing might not be in place before your child goes home.

The PDN provides care to your child in your home for an approved amount of hours per week. This can help you to return to work, care for your other children and keep up with events and every day activities.

The PDN helps you care for your child safely at home and works closely with your child's doctors and the trach/vent team.

Your child's nurse clinician and the discharge planner will work with you to decide the schedule of a PDN that will be most beneficial for you.

Durable medical equipment (DME) provider

You will work with a DME provider to get the equipment your child needs at home. This includes:

- a humidification system and/or a ventilator.
- a suction equipment.
- a pulse ox machine.
- resuscitation bags.
- trach supplies.
- oxygen.

The trach/vent team will work with you and your insurance company to help choose a DME provider that will best meet your needs.

Before your child goes home, all of their equipment and supplies will be delivered to your home or to the hospital. You will use the equipment for your teaching sessions, independent cares, and at home.

Your DME respiratory therapist will help you with equipment issues at home. They can be reached at any hour.

Your DME provider will work with our trach/vent RTs and your child's doctor. They stay in contact as changes in your child's respiratory equipment and supplies are needed.

Clinic visits

After your child goes home, they will need to come back to the Tracheostomy Home Ventilator Clinic (Trach/Vent clinic) within one month. After that, your child will come back for routine clinic visits every three to six months.

The visits usually take 2 to 3 hours. All the trach/vent team members meet with you and your child and review your child's care. During each clinic visit the team will:

- Review your child's condition and plan of care.
- Make changes to ventilator settings and oxygen.
- Change medicines and dosages.
- Order lab tests or x-rays.
- Continue your teaching and go over any new information.

Items to bring to clinic

- A list of your child's medicines
- Supplies your child will need while you are in clinic
- Fully stocked go bag, pulse oximeter, suction machine, oxygen, chargers, and ventilator (even if your child doesn't use it all the time)
- Questions and concerns to discuss with team members

Trach/Vent team members you will see

Medical assistant

- Measures your child’s height and weight.
- Checks your child’s blood pressure, heart rate, breathing rate, and temperature.
- Collects a tracheal culture, if needed.
- Reviews and updates your child’s medical history since the last visit.
- Reviews your child’s medicines.

Nurse clinician

- Discusses private duty nursing (PDN).
- Reviews your child’s daily schedule.
- Discusses activity and therapy.
- Answers questions and discusses concerns.

Respiratory therapist

- Measures your child’s oxygen saturation.
- Reviews current oxygen and ventilator settings.
- Makes ventilator or oxygen adjustments, if needed.
- Initiates new trials—off the ventilator, speaking valce, or capping.

Note: If your child needs a humidification set up for clinic appointments, call the Respiratory Therapy Department to make arrangements before you come.

Dietitian

- Reviews your child’s growth and feeding intake.
- Makes suggestions for changes, if needed.

Social worker

- Assesses personal, family, school, or other problems.
- Provides resource options for your child or yourself.
- Reviews current family issues that affect your child's trach or ventilator needs.

ENT doctor

- Checks your child's ears, nose, and throat.
- Checks your child's airway, stoma, and tracheostomy.
- Reviews and makes changes in the plan of care, if necessary.
- Helps with any trach tube changes.

Pulmonary doctor

- Reviews your child's history.
- Reviews medicines and tolerance.
- Performs a physical examination.
- Discusses tracheal secretions.
- Orders lab tests or x-rays.
- Orders a sleep study, bronchoscopy, or pulmonary tests, if needed.
- Coordinates the recommendations of all team members.
- Reviews the plan of care and sets goals with team members.
- Discusses your questions and concerns.
- Communicates with your child's other doctors.

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Making Home Care Work for You

To prepare this booklet, information was gathered from written materials as well as interviews and focus groups providing input from families who are currently using home care for their children with special needs. Agency providers and state administrators also gave generously of their time and expertise. From this research, critical findings surface around four central themes: information, recruitment, training, and retention. This section reviews the findings and examines the challenges of these central themes as well as strategies to address the challenges.

Information

Increasingly, families are gaining information about home care and accessing it. The proven benefits of respite care, which is a more familiar program to families in Wisconsin, have paved the way for families' comfort with leaving their children in another person's care. However, there is a need for clear and accurate information to be made more readily available to families.

Families report that they have limited amounts of information about home care. Many do not know that the Wisconsin Administrative Code outlines covered and non-covered services for Medicaid recipients. Many say that they have never seen a copy of the administrative code. Many commented on a general feeling of confusion about which federal, state or local program funds their child's home care. Additionally, across the state there appears to be a wide range of "interpretations" of exactly what families are eligible for in terms of home care for their children. Clearly, information is variable across the state and parents are often told different things depending on whom they talk to. The age of the child seems to be an important criterion in some counties. For example, if an infant or toddler cannot typically dress him or herself, an agency may decide that the child does not qualify, citing "parenting" as a non-covered service. While it is true that all very young children require assistance with activities of daily living, a very young child with a disability may require care that far exceeds "normal" parenting. Parents are encouraged to seek the services, one of which may be home care, that will enable them to better meet the needs of all members of their family.

Still other families report that home care was available because both parents or a single parent work outside the home. The number of hours of service seemed to be connected to the parents' employment, though it is interesting to point out that the regulations for home care do not indicate this variable as part of the eligibility criteria. This question stems from the definition of medical necessity HFS 101.03(96m), which states that Medicaid provides services that identify, prevent or treat a condition and that the service meets a set of standards for appropriate care. The Division of Health Care Financing states that parent availability and ability is considered in the approval process! For example, if a parent has a disability, this may allow for more home care for her child with a disability since she is restricted in her ability to provide care.

For families, it is crucial that a lot of detailed information is given to the home health agency so that those reviewing the prior authorization process have a clear picture of the actual situation.

Recruitment

Finding quality workers to work in home care for a child with a disability is a common struggle for families. Several challenges and strategies are addressed below.

> *"I want people to see my child for who she is, not her disability."*

Challenges:

Families report that finding high quality, trustworthy people to work in home care is an overwhelming challenge. Many times, families are eligible for home care and yet may have either chronic or intermittent problems in finding care workers.

The Barriers to Finding Care Workers

- Lack of transportation or a bus route for workers in rural areas.
- Lack of choice from agencies with the burden falling on the family to find a care worker.
- Lack of pediatric experience and family-centered interest in the worker pool.
- Low wages and employee benefits.
- Competition from other employment opportunities including retail, food service, and residential centers.

Strategies:

While it can be a challenge to find home care workers whom you can trust and value, there are some successful strategies that families have shared. Families should consider how they find care workers. Is it out of your control or do you have a significant role to play? By taking an active role in choosing a home care worker, by investing time and energy up front, you are more likely to have a successful outcome.

Parents across the state have discovered a creative assortment of recruitment strategies. One mother always selects a home care worker through word-of-mouth by someone she trusts who has recommended the individual. One family sends a personal letter to friends, asking if they know of anyone who might be interested in working with their child. Other parents ask the home health agency for a few names and then initiate telephone screening and direct-contact interviews. Some parents have tapped into the availability of a close relative who would rather do meaningful work with a nephew than a shift job. Families living near colleges and universities have posted their personalized job announcements on bulletin boards in targeted departments (e.g., nursing, physical therapy, special education).

Recruitment may be out of a parent's control depending on the home health agency's policy. Yet even if there is no parental control over the recruitment process, it is important for each family to take some time considering what qualities they would like to see in a home care worker. Parents may benefit from asking themselves the following questions before they seek a worker:

Know What You Want

- Do I want the worker to be a relative or someone I already know in so (e.g., cousin, aunt, church member, neighbor)?
- How long do I hope this person will, work with my child (e.g., at least a year, for the summer)?
- What are the human resources in my local community (e.g., college students, W2 recipients, second income/part-time)?
- What are the qualities most important to me (e.g., honesty, trustworthiness, safety, good communicator)?
- How independent can the caregiver be (e.g., can I leave my child alone with the worker and not worry)?

For families who are in a position to search for their own home health workers, the following methods may be helpful: newspaper ads, student job center, church/community bulletin boards, and word-of-mouth. Families should ask the providing agency if there are restrictions on hiring (e.g., age, skill-level, citizenship).

What to Include in a Job Description?

- Wage
- Hours/days
- Characteristics of applicant
- Expectations of job
- Location, transportation
- Specific contact information
- An indication of your family values uniqueness, interests, and what will be fun/rewarding about the job

Sample Job Description:

Home care worker, $8/hr, 3-7 pm daily. Provide care in our home for our 8-year-oid daughter with a physical disability. Looking for an energetic, thoughtful, sensitive individual to assist with activities of daily living (dressing, feeding, bathing). A great opportunity for those preparing for the "helping" professions. On bus line. Call Helen at 333-0409, evenings.

Once you have completed and posted the job description, phone calls will come. Or if an agency is pre-selecting care workers, you may still receive calls from a pool of potential care workers. (Note: some families may not be provided with input into this process through agency policy.) Being prepared for the calls with a telephone screening approach will make this process easier.

What to Ask During a Telephone Screening

- *Experience with individuals with disabilities:*
  Could you tell| me what experience you have had working with adults or children with disabilities?
- *Hours/days available:*
  How many hours are you hoping to work?
  What days are you available?
- *Purpose in seeking position:*
  Can I ask why you are interested in this position?
- *Other commitments/responsibilities:*
  Do you have another job or are you in school?
  How long do you plan on being in this area?
- *Children:*
  What experience do you have with children?
  Do you enjoy interacting with children?
- *Transportation:*
  Do you have a car or another way of getting here?
- *Physical strength:*
  This job requires lifting my child who weighs ______ pounds.
  Would you be able to perform this function?
- *Allergies:*
  We have a cat, are you allergic to animals?
- *Ask them to problem solve:*
  How would you handle the following situation _________________?
- *Ask if they have questions:*
  Do you have any questions?

Following the telephone screening, you may choose to interview potential home care workers. Invite applicants to your home to meet your family. Be sure you ask for the applicant's phone number and name in case you need to reschedule the visit. While some parents have very specific questions for applicants, others gain information through an informal discussion/conversation. Whichever technique you feel comfortable with, the following suggestions for the interview may help you begin to think about what information is helpful to you in this process.

What to Ask During an Interview

(Can be mixed into conversation or asked as discrete questions)

- Determine length of commitment:
  When you think about this position, how long do you anticipate working here?
- Examples of personality traits:
  Can you tell me about a time when you had to have incredible patience in order to do something? Can you tell me about a time when you had to be exceptionally energetic, playful, or creative? Have you ever encountered a conflict in the workplace and if so, how did you handle it?
- Knowledge about people with disabilities:
  Have you ever known a person with special needs; a neighbor, classmate, cousin?
- Experience with children:
  Have you ever worked with children: baby-sitting camp?
- Hobbies, special interests
  What do you like to do in your spare time: art, sports, garage sales?
- General work experiences:
  What have your previous work experiences been?
  What types of experiences have, been the most difficult for you?
- Qualifications:
  What sort of training, certification or licensure do you have?

During the interview, the parent should make sure that the applicant has complete information, so there is an understanding of what is involved in caring for his/her child on good and bad days. Families repeatedly emphasize the importance of being up-front with potential care workers, believing that if the worker chooses to stay knowing the full range of the child's situation, then the worker will be prepared and do a better job. If a child has episodic bouts with illness, self-abusive behavior, pain or other health conditions that come and go, it benefits all involved if these episodes are clearly addressed early on in the process. A parent may say to an applicant: *There will be days when my son cries almost all day and try as I may I can't help him feel better. These days will be very frustrating and sad. There will also be days when he is feeling great, laughs out loud and wants to get involved in the world around him.*

Knowing your own values and how those relate to household practices is something to share as part of the interview process. For example, if television is restricted in hours or days this should be clear up-front. The parents to discipline should be stated and an applicant needs to be comfortable in following through on the parents' approach, not their own. Religious beliefs are highly personal and parents may choose to ask the applicant about whether or not his/her religious beliefs will potentially be in conflict with the family’s approach to daily life.

For example, in one family a child participates in yoga, and the personal care worker has refused to be involved in this due to her personal religious beliefs. The level of cleanliness in a home can at times conflict with an applicant's personal standards. Again, addressing these issues in the very beginning and using the information gathered as part of the selection process can alleviate conflicts down the road.

Things to Look for During an Interview

- Individuals who show up on time as scheduled for an interview may indicate future punctuality, responsibility and reliability.
- An individual's ability to communicate his/her ideas and respond to your questions may indicate listening and speaking skills, and breadth of knowledge which may indicate an ability to respond to instructions/feedback, initiate communication, and articulate difficulties in an emergency.
- An individual's ability to interact with the children may indicate a genuine enjoyment of children, if children like the applicant, it may indicate a knowledge of age-appropriate behavior and language. Look for the way your child is addressed arid/or included, by the applicant through greeting, eye contact, and voice. Does the applicant talk directly to your child? Does the applicant speak more simply, slowly and loudly when addressing your child? Does the applicant say good-bye to your child upon departure?
- Individuals who have previous experience with children and/or at least one person (cousin, neighbor) with a disability are more likely to be comfortable and prepared to work in home care with children.
- Individuals who have career goals involving the helping professions and look at this experience as a steppingstone to their careers are more likely to be stable workers.
- An individual's body language and type of eye contact may lead you to think he/she is judgmental.
- Individuals who are athletes, lifeguards or have experience in manual labor may be more likely to have the necessary physical strength for the job.
- Individuals whose values are rooted in helping those in need may be strong candidates.

In the example provided earlier, where the parent shares that there are days when she cannot console her child, the parent understands that patience, an easy-going style and understanding are crucial characteristics for working with children who are medically complicated.

What to Think About During an Interview

- Do you have a gut feeling that this person would work out well?
- Are the applicant's interests similar to yours?
- What are his or her values and how well do those match yours?
- What is your hoped-for outcome from the match and how does that blend with the applicant's hoped for outcome?
- Is this likely to be a mutually beneficial relationship; is there potential for reciprocity?
- Is there something about this person that makes you want to get to know her better?
- Is there something about this person that really annoys you, but you cannot figure out what it is?

After you have interviewed the available workers, think about each one and try to envision him or her in your home and with your child. Ask your children what they thought of the applicants. While you ideally want the best qualified worker, parents report that there may be times when they have to "settle for less," because the need for home care is so great that for a short-term solution, something is better than nothing. This is important because lack of home care may result in a parent's need to stay home, creating a loss of employment. In the attendant guide Working Together (1998), the authors caution: "Beware of Being Too Choosy," pointing out that part of the process of obtaining and securing home care is dependent on some compromises. It is crucial for families to identify those pieces of the puzzle they are willing to relinquish (e.g., exact hours preferred), and those that cannot be compromised (e.g., safety). A long-term lack of home care may also result in harm to the child, either through unavoidable neglect or general inability to provide quality care because of other competing commitments. A lack of long-term home care may also result in harm to the caregiver, whether through physical or emotional strain.

Follow-Up

Typically, the home health agency will obtain references, yet you may also wish to ask the applicant for two references. You may want to say *I really feel positive about the experience you bring to this position. I always ask applicants for two to three references just as part of this process. Could you provide me with references, perhaps including one person who has known you for a long time?* Some applicants will need to call you back with phone numbers and names. When you contact the reference, below are some sample questions to consider. Be sure to begin by clearly identifying yourself, your reason for calling, and ask if this is a good time to talk. Be sure to close by thanking the reference for his/ her time and information.

What Questions to Ask a Reference

- How long have you known________?
- In what capacity have you known_________?
- Can you speak to his/her strengths?
- Can you speak to his/her weaknesses?
- What do you think will be the most challenging to him/her about this job?
- Would you recommend ___________ to work with a child?
- Is there anything else you'd like to tell me?

Orienting and Training the New Care Worker

Once a new home care worker is ready to take care of your child in your home, you need to consider how best to orient the worker. While home health agencies take some responsibility for this activity, many parents opt to be actively involved. The training may include highly individualized information not only about your child's condition, but also about where equipment, medications, and other supplies are kept within the home.

The home care notebook (in Appendix A), which many parents develop as a way to share information about their children, is a useful tool when explaining your child's needs. Often there is a large amount of information for the worker to learn at first and many people have trouble retaining volumes of information when it is given in a short period of time. Therefore, the book provides a written statement of need and can be referred to over time. The book is also a place to record ongoing changes and information.

Parents report they often engage the previous or existing home care worker in training the new worker. This strategy serves two purposes: it frees the parents' time to do other activities, and it offers the worker perspective to the new employee. For a new home care worker to hear the same information from two different perspectives will enhance his/her understanding and better prepare him/her for the job. This strategy may not be supported by the home care agency, in terms of paying two workers at the same time. A family could ask if they are allowed to use other funds, (e.g., COP, CIP, Respite), to pay one of the workers during the training period.

Parents emphasize the importance of being up-front with the new worker and sharing information openly. Working side-by-side with the new worker offers you a chance to create a conversational approach to training. You may demonstrate a procedure and then say, "Would you like to try now?" Ask how they think it went and then provide your feedback. After the new worker has demonstrated the ability to provide care, staying close by and available for the first few weeks will increase the quality of the training. Listening to the new worker and the child while at work in another room is a useful way to monitor the situation and also allows you to intervene when necessary. For example, many children will test a new worker, and the parent's role is to inform the care worker about what is acceptable behavior and what is not. Parents need to look for the quality of the worker's performance.

Ways to Evaluate Performance

- Is the child's safety a top priority?
- Is the follow-through on your training goals being carried out as instructed?
- Is the use of language age-appropriate and positive?
- Is the care worker demonstrating an effort to learn and do a good job in a conscientious manner?

Frequent and clear feedback during the orientation phase will likely improve the overall success of the match. It is a good idea to "check-in" at the end of each day during the initial orientation phase. Ask if the worker has any questions or concerns. It is harder to give critical feedback after the training phase. Below are several suggestions for developing your own role as a trainer of new home care workers.

How You Can Teach the New Worker the Job

- Recognize that you do have an influence on how the new worker perceives your child and his/her disability.
- Accept that the hew worker is a new learner in this situation (your home) and will not know everything right away. Remember back to. when you first learned caregiving skills and demonstrate respect for that experience in others.
- Provide support to the new worker in a warm, instructional way Acknowledge the new learner's abilities as. they surface. Emphasize the positive.
- Model conscientious behaviors and thinking out loud to encourage the new worker to approach the work as you do. Model age-appropriate language and interactions.
- Practice and develop interpersonal skills as you create a learning environment that is interesting, clear and supportive.
- Nurture an approach of high expectations, coupled with forgiveness and understanding. Remember that this work can be very difficult emotionally and physically; home care workers need support.

Retention

Challenges:

Parents can play an active role in retention- the process of keeping a home care worker, working with your child. Retention is dependent on many variables, some of which are beyond the family's control. Being aware of retention issues can help you understand home care more clearly and give you a sense of what is within your control and what is not.

Situations may occur that have nothing to do with the family. For example, many parents report that an ongoing struggle with home care is that the direct care worker may be suddenly switched by the agency, resulting in a brand-new worker showing up at the family's door. In this situation, families report feeling unwilling to leave their children with a stranger and feel frustrated by the poor communication flow between agency and family.

Retaining a home care worker also depends on what you as a family do to actively nurture the relationship and match. Once you have secured a worker, the need for close attention to the situation is critical to the success of the home care.

As a parent, you may want to monitor the care worker's satisfaction with the job. The following indicators may be signs that your worker is dissatisfied or otherwise questioning his/her job.

Some Common Signs of Job Dissatisfaction

- Is the care worker chronically late, does not show up, or cancels frequently?
- Does the care worker seemed bored, overwhelmed or disinterested in the work?
- Has the care worker shown an interest in this sort of work, but now that he/she Is actually doing it sees that it is not what he/she wants to do?
- Does the Worker spend more lime following you around the house or sharing personal stories than spending time providing care for your child? Does the care worker spend more time cleaning dishes than interacting with your child?
- Does the worker need to earn a living, or is this a work-experience while pursuing another priority (e.g., education)?
- Does the worker need to earn a living and has another source of income with a higher wage?
- Is the care worker having personal difficulties preventing him/her from following through on life commitments in general?

If you feel that the match is not working out well, communication with the home care worker is crucial. When a family would like to let a care worker go after realizing that it is not a good match and/or the child's welfare is at stake, this can be done with the support of the home care agency.

When you lose a care worker, understanding why you lost him or her can help you to move past the feelings of disappointment and sadness you may experience.

Some of the greatest challenges faced by parents are found when workers suddenly, and often unexpectedly, leave the job. Sometimes they will provide notice, sometimes not. Sometimes a worker may simply not show up and that is the way you are informed of the resignation. This is often hard for families since parents may question themselves and perceive this as a personal failure. Children also may feel hurt when a care worker calls to resign, instead of coming to the home to say good-bye. Finding ways to talk about this with your children is also important so they understand that it was nothing that they did and reassuring them that family will always love them and be there for them.

There is no way around the hurt feelings that naturally surface for many families when they suddenly lose a worker. Healing emerges from a careful review of what occurred and an objective understanding of why the worker left. Periodic self-evaluation of your own behaviors is important to the ongoing process of improving your own communication and management skills. And there are times when we all make regrettable mistakes. For many parents, there is comfort in understanding why a match did not work out. Many times, it just was not a good match, and no one is to blame.

Families may again refer to the Wisconsin Medicaid Administrative Code, which delineates rules about discharge. Agencies discharging clients have their own rules, yet also need to follow the code regarding giving notice, HFS 105.16(10)(f), 105.19(9) and 107.112(3)(b). In general, licensed Medicaid certified home health agencies must inform the parents if a service is discontinued and assist parents to find another agency for that same service. These guidelines are outlined in section HSS 133 of the Administrative Code and the Bureau of Quality Control governs this area. Families can file complaints if necessary and may begin by calling the Medicaid Recipient Hotline.

Strategies:

To ensure the success of the match, parents report that communication is the key. Some families keep a communication notebook, where all information is shared between home, school and community. This allows the home care workers to see the child as a complete person across environments. One family asks all workers to initial the notes after reading them to ensure that everyone stays in the information loop. Other parents develop "goals for the day," or checklists that are updated daily to confirm that key activities are accomplished.

When families do encounter challenges to home care, the following approaches may help them address the problem before it results in an irreconcilable difference.

Ways to Address Concerns:

- Be direct, with a smile and friendly tone.
- Acknowledge that something is difficult to do and that it took you a while to learn how to do it, then demonstrate the correct way to do it.
- Mode! behaviors you want to see in them.
- Ask the worker how he/she is doing with a particular procedure and acknowledge the parts of the procedure that are going well and what needs attention.
- Determine if the difference is detrimental or just different and okay.
- Talk with a trusted friend and brainstorm about solutions.

While communication around issues of the child's care is critical, parents have also found that personalized communication with the worker is needed. Developing a relationship between a parent and worker increases the prospects of a mutually beneficial outcome. First, you as the parent are in a better position to foresee difficulties if you have frequent conversations with the worker. Asking questions about the worker's life allows you to gain a sense of future plans, interests and strengths. You can then capitalize on any hobbies or special talents.

> "Some of them fall in love with my son."

This conversation also gives the worker the message that you care about him/her, that he/she is not just a person coming into your home to do a job. This mutual sharing and communicating is an essential component of an effective partnership.

Parents report that successful matches between parent and worker ultimately result in long-term relationships, a stronger bond between child and worker and increased trust and caring on both ends. Many families about a special worker who has stayed connected to their family for years. In these situations, the level of care sprouts from deep roots; parents use the word "love" to describe the relationship. Families say that some workers feel like members of the family, acting as role models to their typically developing children and as trusted advocates.

Acknowledging and demonstrating respect for workers is a key retention strategy according to families.

Ways to Acknowledge Workers

- Remember a card or gift on birthdays/holidays.
- Comment on specific actions you noticed and appreciate.
- Tell them of your child's fondness for them.
- Let them know that their own family should be their priority.
- Keep the refrigerator stocked with their favorite beverage.
- Listen to their personal stories.
- Share personal stories with them.
- Show flexibility.

Ways to Show Respect for Workers

- Thank them as they leave each day.
- Provide specific and timely feedback when they do something well.
- Build a relationship; show interest in them as people.
- Be realistic about the energy it takes to care for your child and make sure your expectations are fair.

In addition, periodically self-evaluate your own behaviors. Are you showing the home care workers respect, flexibility and support? Are your expectations realistic? Remembering that possibly no one will ever do things as well as you, the parent, and letting go of expectations that the worker can read your child's every movement and cry is necessary for home care to work. If your home care experience is marred by frustration, tension and a chronic feeling of dissatisfaction, then it is time to step back and talk with a trusted friend or professional about the situation. Overall, home care should be an enhancement to your life; and if it is not, you should carefully review the issues.

Challenges and Benefits to Home Health Care

Challenges

Having another person to provide care for your child at home is unquestionably a benefit for many families. The benefit is countered by the challenge of the invasion of a very private zone, your home. Your home is probably the one place where you can totally be yourself and do things however you choose. Once you have home care in place, your home becomes more public.

> *"Be careful what you ask for; you may get it."*

In a sense families are used to this, since from early on we have frequently exchanged highly personal information for services. Home care is an extension of the many times we have opened up our lives to others in order to receive services. This opening is difficult for many families and consumes a lot of energy in terms of planning, monitoring and continuously improving the process. Parents say: "It takes a lot of energy having others in your house;" "It needs a lot of attention;" and it is "draining, exhausting, takes lots of emotional energy."

Holidays can be difficult times for families, since it is common for workers to take personal vacations at this time. However, parents report this inconvenience as part of the "give and take" of the family-worker relationship.

Many families have experienced frustration with the home care agencies, especially around the issue of communication. Families have had concerns about the poor return on phone calls and responses to requests. One family member commented that she felt her family was not a high priority for the agency, which accounted for the poor communication. Another parent was devastated by an agency's attempt to take her to court for alleged child negligence.

> *"In my life, I don't have anything that is confidential anymore. We have no privacy."*

Another challenge is the availability or lack of home care workers and whether the parents are permitted to be involved in the selection of the workers. On the other hand, many parents have excellent experiences with their provider agencies, indicating that the quality of business etiquette and philosophical framework varies widely from one agency to the next.

Several families report that they stay with the same home care agency, despite dissatisfaction, because the thought of "start-up" with a new agency is overwhelming. The issue of start-up exists not only with switching agencies, but also with switching home care workers. Initiating the process of start-up consumes huge amounts of energy. Parents need to once again tell all the details of their child's condition, explaining, requesting. And ultimately, many parents feel the burden falls on them to initiate, follow-up and ensure completion of the process. Building new relationships also takes energy and time.

In families where there are siblings, issues may arise that require further thought and action. Clearly, the covered service of home care is limited to individuals who are eligible. However, while in a family's home it is often impossible to ignore the presence of siblings. Parents need to honor the fact that the home care worker is there for the child with special needs, yet there are ways to support sibling relationships. One example is seen at mealtime when the whole family and the worker are at the kitchen table. The worker may feed your child with a disability, yet your other children are there as well, and this may be a time to model sibling interaction. Siblings may gravitate to a worker and compete for his/her attention. Parents can offer support by their presence and by intervening when appropriate.

Benefits

If securing home care for your child is difficult, why is there increasing interest and use of this service? Because in the overall balance of the equation there are net benefits. Parents report that the experience of receiving home care is highly positive because of the relationships that are built and the actual care that is provided. Families describe the incredible people who come into their lives, the role models for typically developing children and the feeling of satisfaction in the power of one-person (your child) to create meaningful change in another person's (care worker's) life. Parents clearly see that home care allows them to go to work, get things done (e.g., errands, advocate, school meetings, other services), and spend time with their other children.

In interviews with parents of children in a Madison Medical Assistance personal care program, a study found: "Repeatedly when I asked parents what personal care meant to them, they stated 'my sanity.'" (Van De Graaff, 1999). Further, parents report that home care allows them to maintain an "age-appropriate" relationship with their child, since typical development usually involves a gradual increase in independence, especially in personal care! Parents also stated that the care needs of their children are so extensive that it would be physically impossible to meet the child's needs without help from another person.

With time, parents gain experience in how best to secure home care for their children. The process of obtaining home care is one that generally improves overtime as you, a parent, become increasingly savvy and figure out how to meet the needs of your family. And there is a sense of satisfaction in this skill as it develops. This booklet is intended to share some of those strategies with families so that the wheel does not need to be continuously recreated. However, you alone will discover the nuances of home care and the details that work for you.

This booklet provides parents with the appropriate information and supports for their care giving roles, in the hope that they can exert more control over their choices and direction, thereby ensuring meaningful and fulfilling lives. Appendix B offers a few reflection pieces which may help parents think about their roles as caregivers. Home care for children with significant disabilities is one approach to supporting families so that parents maintain their health and success.

Parents' Perspectives: Areas of Concern

Parents who are receiving services expressed gratitude for the help they have received; they also recognized areas where the current system could be improved. A few of these key areas of concern and corresponding questions are summarized below:

> **Worker Categories of Care:** While each home health agency or personal care agency follows the same Medicaid regulations for covered services, they have some latitude in deciding which level of care to request for a child with a long-term disability. This latitude is in part to allow the nurses to decide what tasks can be delegated to a worker, and consequently what the nurse can assume responsibility for. As a result, families with very similar children may be receiving different services (e.g., nursing, home health aide, personal care) depending on the agency they access. With many children surviving premature or traumatic birth experiences and living longer lives, there are more children with long-term needs who require skilled care for gastrostomy-tube (g-tube) feedings and medications, for example. These are the children who seem to receive greatest variability in the category of care.
>
> ***Question:*** *Is this variability acceptable or does it cause families to feel like the quality and extent of the services they receive have to do less with their child's disability and more with where they live?*

Parenting versus Extraordinary Caregiving: A parent's care for a child with a disability is different from that of a worker in that typically it is fueled by an overwhelming sense of unconditional love. Yet the care that most children with significant disabilities require is extraordinary and can be distinguished from "normal" parenting by the amount of time and physical and mental energy it consumes. Medicaid regulations state that parenting is a non-covered service as part of the interpretation of the medical necessity regulation. Yet medical services are sometimes denied based on an interpretation of these services as "parenting."

Question: *Is there a need to establish the differences between "normal" parenting and the parenting of a child with a significant disability to ensure that the two are not perceived as the same?*

Care within the Home: Children with long-term disabilities have become increasingly involved in their local communities, participating in a wide variety of activities outside of the home, (e.g., parks, libraries, malls, business establishments, swimming pools, day cares). When these children leave the house to enter into community settings, their need for assistance (e.g., mobility, feeding, toileting, medications, suctioning) continues. The growing acceptance and push for community integration is inconsistent with the Medicaid regulations that largely limit personal care services to care within the home (with some exception).

Question: *Do the societal trends toward community integration require personal care guidelines to be updated to allow for flexibility of where the service is received or do families need to be encouraged to creatively patch together various funding resources to meet their needs?*

Allotment and Usage of Hours: Most families live highly dynamic lives that change with the time of year and the health of their children. While the home is the constant for families and the parents are the constant for their children, routines change with school schedules, hospitalizations and vacations. A child may be allotted eight hours of personal care a day. During the school year, an average of two hours a day is used. In the summer, however, the family needs ten hours a day if the parents work outside of the home and there is no summer school program.

Question: *Are families adequately informed of their right to request a new prior authorization process every time their needs change (e.g., change in recipient's or family's situation) or have the current prior authorization amended to provide greater flexibility as needs change?*

These questions indicate a need for future discussion between parents, workers and administrators on policy issues, especially around home care regulation. This booklet concludes with a call for future study, advocacy and quality assurance.

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Phone: (608) 266-7826
FAX: (608) 267-3906
E-Mail: wiswcdd@dhfs.state.wi.us
Web Site: http://www.wcdd.org/

Questions for hiring private duty nurses

How long have you been a nurse?

Do you have pediatric nursing experience? Have you ever worked with infants or children?

Do you have experience with home care?

Are you certified in the care of a child with a tracheostomy and home ventilator?

What do you like about being a home care nurse? Why are you interested in home care?

What is your biggest challenge with being a home care nurse?

Do you have other job or school obligations?

What hours are you able to work with my child? Which days of the week?

How much flexibility do you have? Could you possibly be available on short notice if I have another nurse cancel a shift?

When could you start?

Do you have reliable transportation?

If your own child is sick, do you have back-up child care options?

Can you provide me with references from other parents whose children you have cared for?

____

____

____

If you have never done home care, do you have other work references?

____

____

____

Will you be able to go with my child to doctor appointments? To school?

____

____

____

Are you willing to case manage?

____

____

____

What is the best way to contact you?

____

____

____

What questions do you have for me?

____

____

____

Questions for interviewing a nursing agency

Does your company guarantee shift coverage?

Will I be able to have the nurses that I want? May I interview individual nurses before assigning them to my child's case?

Who is available during and after business hours should I have questions or concerns?

What happens if I do not want a nurse to return to my home because of personality conflict or problems with the nursing care?

Will I be expected to train nurses in the care of my child?

Questions for a nurse's references

How long have you known ____________?

What is your relationship to this nurse?

What do you see as their strengths?

What are some of their weaknesses or limitations?

Would you recommend this nurse?

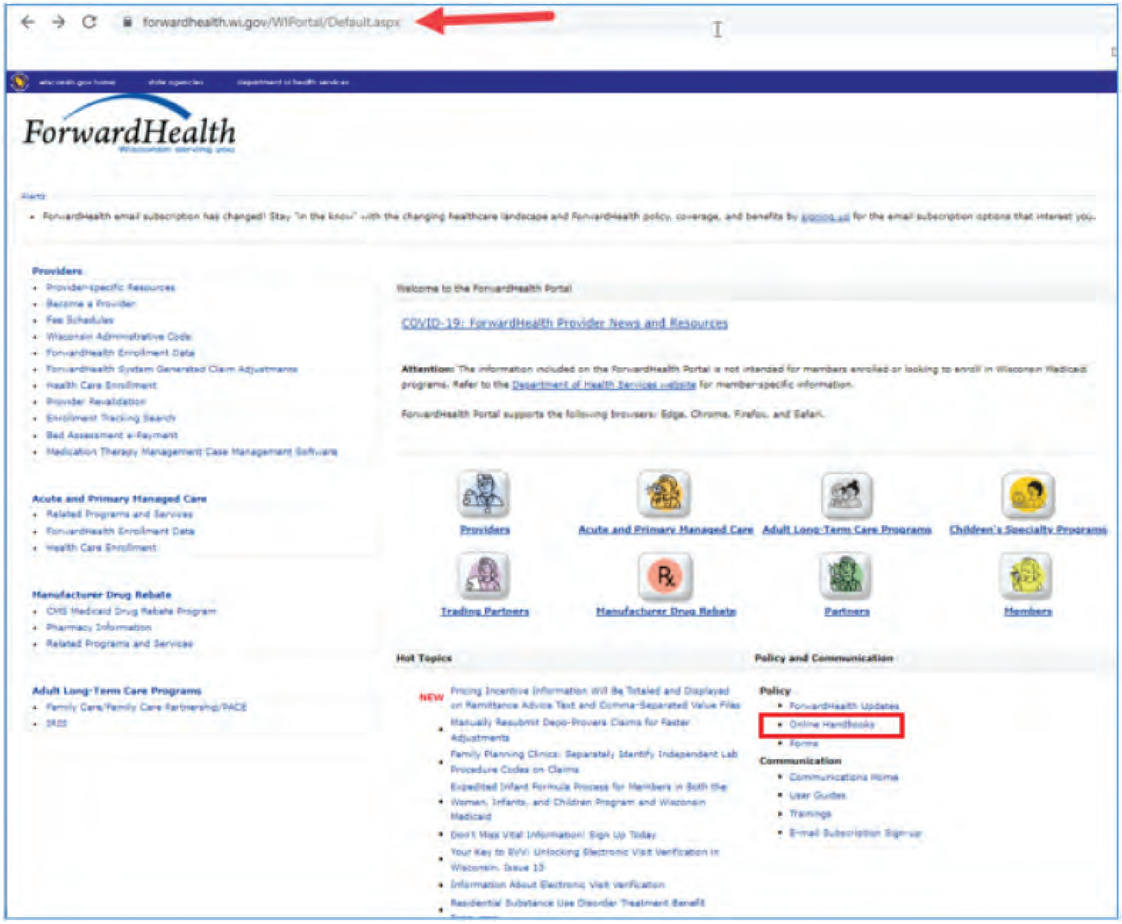
Are you certified to care for a child with a tracheostomy and home ventilator?

Would you like to add anything?

Finding the Nurses in Independent Practice online handbook

To find the handbook:

1. Go to the State of Wisconsin ForwardHealth website: https://www.forwardhealth.wi.gov/WIPortal/Default.aspx



Welcome to the ForwardHealth Portal

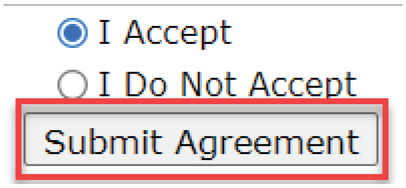
COVID-19: ForwardHealth Provider News and Resources

Attention: The information included on the ForwardHealth Portal is not intended for members enrolled or looking to enroll in Wisconsin Medicaid programs. Refer to the Department of Health Services website for member-specific information.

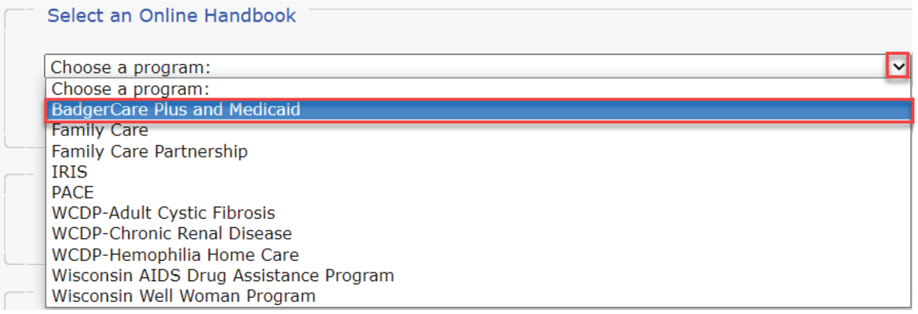
ForwardHealth Portal supports the following browsers: Edge, Chrome, Firefox, and Safari.

2. Under **Policy**, click **Online Handbooks**.

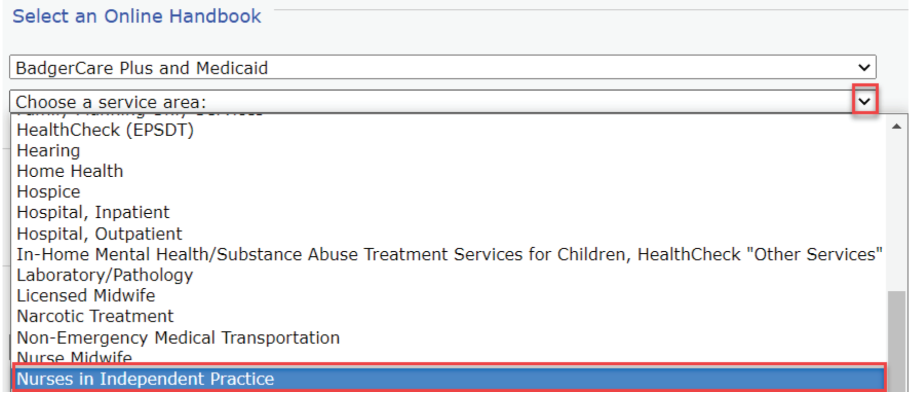
3. Scroll to the bottom of the page, click **I Accept**, and then click **Submit Agreement** to accept the terms and conditions for the site.


● I Accept
○ I Do Not Accept

4. In the Select an Online Handbook section, click the down arrow and select BadgerCare Plus and Medicaid.



5. Click the down arrow next to **Choose a service area** and select **Nurses in Independent Practice**.



6. in the **View Section and Chapters** area, fill out the sections outlined in red below. You can print out the pages needed or order them from the State of Wisconsin.

View Sections and Chapters

- ⊞ Provider Enrollment and Ongoing Responsibilities
- ⊞ Covered and Noncovered Services
- ⊞ Prior Authorization
  - ⊟ Forms and Attachments
    - All Topics
    - An Overview
    - Attachments
    - Documentation Requirements - Private Duty Nursing
    - Obtaining Forms and Attachments
    - Plan of Care
    - Prior Authorization Request Form
    - Prior Authorization Request Form Completion Instructions for Private Duty Nursing
    - Private Duty Nursing Prior Authorization Acknowledgment
    - Required Documentation for Private Duty Nursing Prior Authorization Requests
    - Supporting Clinical Documentation
    - When a Home Health Agency is the Prior Authorization Liaison

eHomecare

FREE COURSE
on Caring for Children with a Tracheostomy with/without a Ventilator

Create an account and enroll for FREE until December 31, 2022 at https://ce.icep.wisc.edu/ehomecare

Who Should Complete the Course?

- Nurses
- Physicians
- Respiratory Therapists
- Homecare Providers
- Family Caregivers
- Students
- Anyone interested in learning more about caring for this population

SCAN ME

Course Description

eHomecare is an online training program designed to provide comprehensive information on caring for children with a tracheostomy with/without a ventilator. **eHomecare** includes five modules:

- Pediatric Airway and Tracheostomy
- Oxygenation and Ventilation
- Suctioning and Bronchial Hygiene
- Tracheostomy Care and Tube Changes
- Emergency Preparedness

FREE CEUs

Upon successful completion of all course components, you will have the option to receive **4.75 hours of FREE continuing education credits (CEUs).** It will take approximately 4-5 hours to complete the course. You do not have to complete the course in one sitting. Upon completion of the course, you will also be able to access it as a reference at any time.

Questions? Please contact whitmore.research@son.wisc.edu

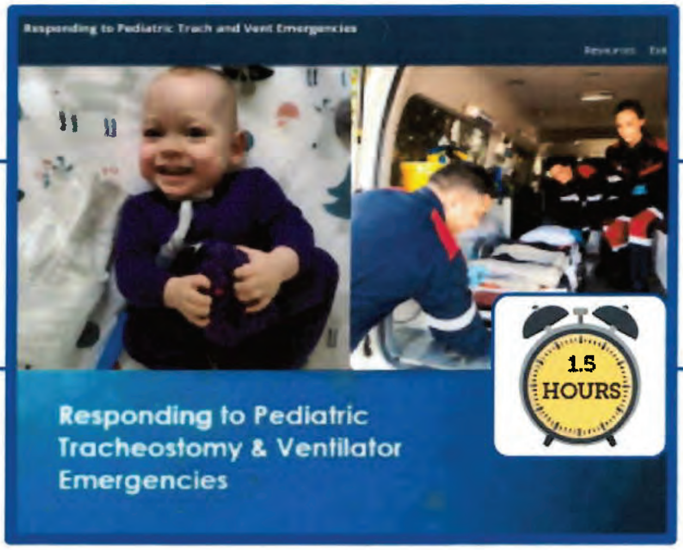
School of Nursing
UNIVERSITY OF WISCONSIN–MADISON

Children's Wisconsin

PEDIATRIC EMERGENCY MEDICINE TRAINING

RESPONDING TO PEDIATRIC TRACHEOSTOMY & VENTILATOR EMERGENCIES

WISCONSIN
Emergency Medical Services for Children
Children's Health Alliance of Wisconsin


Responding to Pediatric Trach and Vent Emergencies

Responding to Pediatric Tracheostomy & Ventilator Emergencies

SIGNUP TODAY

☑ **Upon completion of this training, you should be able to:**

- Describe pediatric patients first responders may encounter who have a tracheostomy and/or a ventilator.
- Explain the importance of working with caregivers and the extent of their knowledge. Describe parts of the pediatric tracheostomy tube.
- Identify the "Go Bag" and emergency equipment that must travel with the patient to the local emergency room.
- Review the procedures for hands-on suctioning, tracheostomy tube changes, and manual ventilation.
- Explain the treatment for the most common pediatric emergencies for children with a trach tube.
- Review the procedure for CPR for a child with a trach tube.
- Review the types of home ventilators and their features.
- Explain troubleshooting techniques for ventilators.

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Filing a PDN complaint with the state

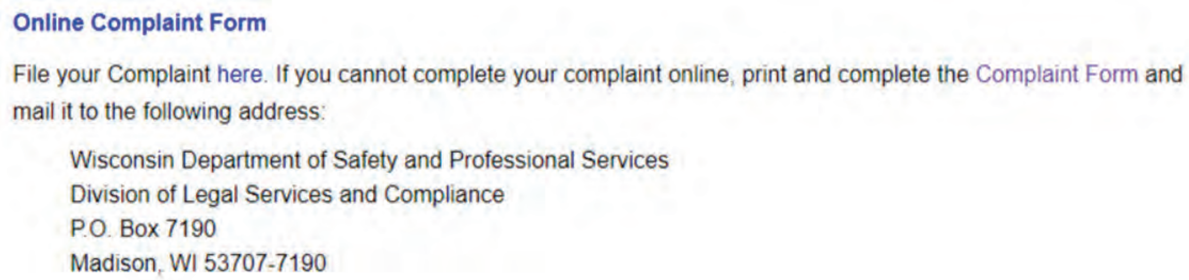
https://dsps.wi.gov/Pages/SelfService/FileAComplaint.aspx

https://dsps.wi.gov/Documents/102DLSC.pdf

The above links take you to the **File A Complaint** page on the website, where you can fill out a form online or print one to mail to the state.

You get there through the Department of Safety and Professional Services website as follows:

1. Go to https://dsps.wi.gov/.
2. Click **File a Complaint** in the **Frequently Visited** section (about halfway down the page on the right side).
3. Click **Online Complaint Form** at the top of the page **OR** click the **Complaint Form** link on the page to print a copy you can fill out and mail in.



Online Complaint Form

File your Complaint here. If you cannot complete your complaint online, print and complete the Complaint Form and mail it to the following address:

Wisconsin Department of Safety and Professional Services
Division of Legal Services and Compliance
P.O. Box 7190
Madison, WI 53707-7190

On the File a Complaint page, you can also go to the **Additional Resources** section on the right side of the page.

Click **Authorization for Release of Records Form** to download the 2004DLSC.pdf file. It has useful instructions to help you complete the forms for filing complaints.

The phone number is listed on the form: 608-266-7482

Wisconsin Department of Safety and Professional Services

DIVISION OF LEGAL SERVICES AND COMPLIANCE

Mail To: P.O. Box 7190
Madison, WI 53707-7190
FAX #: (608) 266-2264
Phone #: (608) 266-2112

Ship To: 4822 Madison Yards Way
Madison, WI 53705
Email: dsps@wisconsin.gov
Website: http://dsps.wi.gov

COMPLAINT FORM

Complaint filed by: Mr./Ms./Mrs. (First, Middle, Last)	
Address:	
City: State: Zip:	
County:	Phone # with area code: ( )
Email address:	
Patient name (if applicable): Mr./Ms./Mrs. (First, Middle, Last)	Patient date of birth:
Patient contact information (if applicable):	Is patient deceased? ____ No ____ Yes Date of Death: _______________

People and/or Entities the complaint is against:	
Address:	
City: State: Zip:	
County:	Phone # with area code: ( )
Email address	
If your complaint involves a trade has this project been submitted for review/approval? ______ No ______ Yes ___________________ Transaction ID	
If your complaint involves a building, when was the building constructed?	

1. When did the incident occur (If you do not know the exact date, make as close an estimate as possible)?

2. Where did the incident occur (include town/city/village/county)?

3. Have you tried to resolve this matter? If so, please provide details.

4. If your complaint is, or has been, under consideration by another agency or court please provide that information.

5. Who else has information related to this incident? Provide names, addresses, email addresses and phone numbers for those persons.

6. Describe the incident. Include as much specific information as possible. Attach additional pages if needed. Attach copies of any relevant documents or evidence such as contracts, photographs, medical records, billing statements, personal notes, pill bottles, etc. It is very important that you do not dispose of any information or evidence even after you have filed a complaint.

SIGNATURE **DATE**

Wisconsin Department of Safety and Professional Services

DIVISION OF LEGAL SERVICES AND COMPLIANCE

INSTRUCTIONS FOR COMPLETING AUTHORIZATION FORM(S) FOR HEALTH CARE COMPLAINTS

Complete and return Authorization Form only if your complaint involves a health care professional.

Authorization Forms give your permission for our agency to obtain copies of treatment records, discuss that treatment with the persons who provided the treatment, and use the records as part of our inquiry and/or investigation of the complaint and, if necessary, during any hearing that may follow.

You may make additional copies of this blank form to cover additional facilities and/or offices where treatment was provided.

The patient, or other person, if this is legally allowed, will need to fill in the blanks on the form before signing the form and returning it to us.

- **Patient's Name:** Insert the name of the patient whose records we will be requesting.
- **Patient's Date of Birth:** This will be necessary to identify the patient.
- **I, ___________________________ hereby authorize ______________________________________**

  Insert the name of the individual authorizing the release of records after the word "I" and insert the name of the individual or facility which treated the patient after the words "hereby authorize".

  Examples: " Metropolitan Hospital "
  " Dr. Jane Doe "
  " Southside Dental Clinic "

- **Signature:** Sign the form legibly.
- **Date:** Put the date the form is signed.
- **Authority for signing:** If the patient is a minor, is deceased, or is not competent to sign, the parent, legal guardian, next of kin, or estate representative should sign:

  Examples: " James Smith, parent of Michael Smith, a minor child "
  " Mary Jones, surviving wife of Henry Jones, deceased "
  " Steve Green, personal representative for Sandy Blue "

MAIL TO:

Wisconsin Department of Safety and Professional Services
Division of Legal Services and Compliance
P.O. Box 7190
Madison, WI 53707-7190

If you do not include the completed Authorization Form(s), we may not be able to investigate your complaint.

If you have any questions about completing the Authorization Form(s), please contact Department staff at (608) 266-2112.

Thank you for taking the time to complete this document.

Wisconsin Department of Safety and Professional Services

DIVISION OF LEGAL SERVICES AND COMPLIANCE

Mail To: P.O. Box 7190
Madison, WI 53707-7190
FAX #: (608) 266-2264
Phone #: (608) 266-2112

Ship To: 4822 Madison Yards Way
Madison, WI 53705
Email: dsps@wisconsin.gov
Website: http://dsps.wi.gov

AUTHORIZATION FOR RELEASE OF INFORMATION

Completion of this form is voluntary

Patient's Name: ____ **Patient's Date of Birth:** __________________

I, ______________________________ **hereby authorize** ____

and all staff or employees of that facility or office to provide the Wisconsin Department of Safety and Professional Services (Department) and its attached Boards, or any attorney, investigator, employee, or agent thereof, with copies of all health care records relating to the above named patient in your possession or under your control, regardless of origin, including, but not limited to, the following: admission records, physical examinations and histories, nurses notes, progress notes, diagnostic test records, physician notes and orders, medication orders and records, operative reports, laboratory work, prescription and dispensing records, x-ray films, radiology reports, anesthesia records, physical therapy records, occupational therapy records, fetal monitoring strips, respiratory therapy records, consultation reports, pathology reports, emergency room records, discharge summaries, drug and alcohol treatment records, and mental health/psychiatric treatment records. This is to include records relating to HIV treatment, if such treatment has been given. I further authorize you to allow these persons to examine and copy any records or information relating to the above named patient. A reproduced copy of this Authorization Form shall be as valid as the original.

This disclosure is being made for the purposes of a legal inquiry and any subsequent proceedings by the Department and its attached Boards. Unless revoked earlier, this consent regarding records is effective until two (2) years from the date of signature. I understand that: (a) I may revoke this authorization at any time by sending a written notice of revocation to the Department at the above address; or by sending a written notice of revocation to the above health care provider; (b) information obtained as a result of this consent may be used after the above expiration date or revocation; (c) the information that the Department receives under this request will not be re-disclosed except in the case of a Department or board proceeding, or a valid open records request and then only under the circumstances permitted by law and re-disclosed information is no longer protected by privacy laws; and (d) the completion or non-completion of this consent has no effect on any treatment, payment, enrollment or eligibility for benefits by any health care provider.

I have been informed, pursuant to Wis. Admin. Code § DHS 92.03(3)(d), that I have the right to inspect and receive a copy of any mental health treatment record materials which are disclosed as a result of this authorization, as required under Wis. Admin. Code §§DHS 92.05 and 92.06.

I further authorize you to discuss with these persons, any matters relating to the treatment of the above named patient.

____

Signature

____

Date

____

Authority for Signing (i.e., Parent of Minor; Guardian of Ward or Incompetent; Personal Representative or Spouse of Deceased)

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Chapter

7

Once You Go Home

Your trach journey continues once you go home. You can reach out to the trach/vent team at any time with questions.

This chapter offers additional resources for you to use at home.

Contacting your care providers

Home resource telephone list

The trach/vent nurse who is working with you and your child will help you complete the Home Resource Telephone List before you go home.

Keep this list available and post a copy near each of your telephones. It is a complete listing of emergency, hospital, team and community phone numbers of those involved with and knowledgeable about your child's care.

Hours

Your child's pulmonary doctor or the pulmonary doctor "on call" is always available to assist you and answer questions about your child's care.

If you have an emergency situation, call 9-1-1.

NOTE: This telephone list is just an example.

HOME RESOURCE TELPHONE LIST

Child's Name: Parent:
Address:
Telephone:

HOSPITAL:	Children's Wisconsin:	414-266-2000
	9000 W. Wisconsin Ave., PO Box 1997, Milwaukee, WI 53201-1997 OR:	800-556-8090
Children's Hospital Emergency Department:		414-266-2626
Pulmonary Department Nurses' Call Line:		414-266-6730
Physicians/Clinics (Central Scheduling for ALL Clinics):		877-607-5280

Pulmonary:	Dr. Julie Noe	414-266-6730
	Weekends & Evenings: Call 414-266-2000 and ask for Pulmonary Doctor on call)	
Pediatrician:	Dr. Samir Mullick	414-873-3440
ENT:	Dr. Tim Martin	414-266-6461
Other Doctors:	GI Clinic	414-266-2851
	Dr. Karen Zorek	414-266-3695
HOPE	Neonatal Development Clinic	414-266-6898
	Eye Clinic	414-266-2020
	Audiology Clinic	414-266-2934

Trach Team Members:

Trach/Vent Nurse Clinician:	Cindy Griffith RN, NC	414-266-3733
Social Worker:	Amada Schlosser, MSW	414-266-2866
Respiratory Care:	Lisa Molkentine, Holly Jacobson, & Grace Flanagan, RRT's	414-266-6698
Dietician:	Jenna Ladwig RD	414-266-6638
Discharge Planner/HCM	Penny Spaeth RN (PICU)	414-337-7261
CHW Speech Therapist	Christine Bueckers, SLP	414-266-2925
CHW Speech Therapist	Lane Hepp, SLP	414-266-8921

Community Resources:

Home Nursing:	Pediatric Skilled Nursing (PSN) @ MCFI	414-937-2089 414-937-2020
Equipment Company:	Pediatric Home Services (PHS)	414-323-8747
Therapies/School:	MCFI	414-937-2089
	Milwaukee County Birth to Three Program	414-289-6799
Pharmacy:	Skywalk Pharmacy - CHW	414-266-1893
Transportation:	Own Car	
Veyo Ride View (Medicaid sponsored medical transportation)	https://veyo.com/rideview.	866-907-1493
Trained Caregivers/Phone:		
Other Resources:		

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Southeast Regional Center
Children and Youth with
Special Health Care Needs

Children's
Wisconsin

Top 10 Reasons to Call or Visit

The Southeast Regional Center for Children and Youth with Special Health Care Needs

Located in the Daniel M. Soref Family Resource Center, Children's Hospital of WI

1. **Hope and encouragement:** We can support you through the ups and downs of caring for a child or young adult with special health care needs. We serve children and youth 0-21 years old with special needs or disabilities.

2. **Information:** We can connect parents and professionals to local and state resources to help make life easier. We can help you problem solve issues related to education, funding, transition and more.

3. **Parent-to-parent support:** As ***parents of children with special needs*** we can offer one-on-one support to your family. We have information about support groups, parent to parent matches with Parent to Parent Wisconsin and connections through Caring Bridge™

4. **Managing care:** Learn how to be a positive advocate for your child. Pick up your free care notebook to help you organize the needs of your child.

5. **Family library:** Our lending library has more than 2,000 books, DVDs and brochures. Some of these resources are in Spanish. Materials are also written for patients, siblings and young adults. You can find the full library list here

6. **Education and training:** Visit the "Calendar of Events" on our website for an on-line list of workshops, family activities and trainings. Check it out!

7. **Health benefits counseling:** We also have information on health benefits and financial supports. We can give you ideas on what to do when your insurance or other health care coverage won't pay.

8. **Help with education issues:** Many parents have questions about Birth to 3, Individual Family Service Plans (IFSPs), Individualized Education Plans (IEPs), extended school year and other school concerns. We can help answer these questions.

9. **Transportation resources:** We also have information about a program (Title 19 also known as Medicaid) that can pay for mileage for your child's medical appointments.

10. **Transition to adulthood:** As your youth with special needs moves into adulthood other resources will be needed. We can share ideas related to health care, guardianship, SSI, education and employment.

Like us on Facebook

Contact us:

(414) 266-6333 or (800) 234-5437

serc@chw.org
www.southeastregionalcenter.org

Hours:
Monday – Friday 9:00am-5:00pm

All services are free.

The Southeast Regional Center for Children and Youth With Special Health Care Needs is funded by Children's Hospital of Wisconsin, a MCH Title V Services Block Grant, through the Maternal Child Health Bureau of the Health Resources and Services Administration, Department of Health and Human Services and The Daniel M. Soref Charitable Trust.

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Your Social Worker can help you decide what resources may benefit your family. Some of the resources that may be available include:

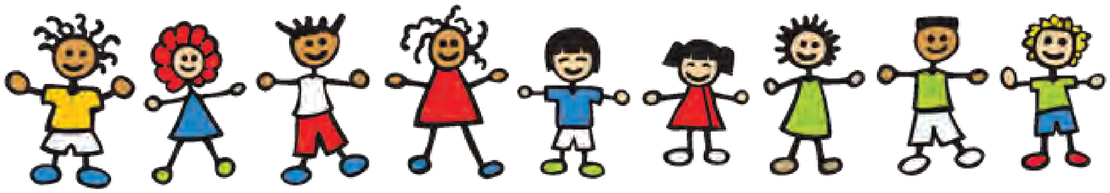
Financial and insurance

- **Supplemental Security Income (SSI)** is a federal program that provides additional income for children with disabilities. Children can receive SSI if they meet SSI's definition of disabled and you and your child have a low income and limited resources. Apply at your local Social Security Office, by calling 1-800-772-1213 or on-line at www.ssa.gov.
- **Medicaid** is a health care program for people with a low income and limited resources. In WI children who get SSI benefits can also get Medicaid. Apply by contacting your local county agency or on-line at www.access.wisconsin.gov.
- The **Katie Beckett Program** is for children under 19 years old with long-term disabilities or complex medical needs and living at home. Children who are not eligible for other Medicaid programs because their parents' income or assets are too high may be eligible for Medicaid through the Katie Beckett Program.
- **Wisconsin Works (W-2) Services** is a program that provides employment preparation services, case management and cash assistance to eligible families. If you do not have enough money to pay your bills and you need help finding and keeping a job you may be eligible. Apply at your local W-2 agency.
  - If you are not ready to look for work because you or an immediate family member is disabled, you may be eligible to participate in W-2 Transitions (W-2 T) and receive a monthly payment.

- **Children's Hospital Financial Counseling Office**—If you are worried about paying medical bills, Financial Counselors are available to talk about insurance coverage and payment programs. Contact Financial Counseling at (414) 266-5700.

Nutrition

- **FoodShare WI** (formerly FoodStamps) was created to help stop hunger and to improve nutrition and health. FoodShare helps people with limited money buy the food they need for good health. Apply at your local agency or visit www.access.wisconsin.gov.
- **WIC Program**—The purpose of the Special Supplemental Nutrition Program for Women, Infants and Children (WIC) is to promote and maintain the health and wellbeing of nutritionally at-risk pregnant, breastfeeding and postpartum women, infants and children. To apply contact a local WIC office near you.



Early intervention and education

- The **Birth to Three Program** is an early intervention program for children ages birth to 36 months who have developmental delays or disabilities. The program provides support in understanding a child's unique development. Contact the Birth to 3 Program in the county where you live if you are concerned about your child's development.
- An **Individualized Education Plan (IEP)** is a written education plan for students who are eligible for special education services. The IEP details classroom help and changes that are needed to meet the student's individual goals. Anyone can make a written referral and some schools have a specific form.

- **Section 504 Plans** are used in public schools to make sure that students with disabilities can fully participate in all activities to the same level of students without disabilities. If a student is eligible, a plan is written up for that student to access programs and after-school activities.

Transportation

- **Transportation or mileage reimbursement**—Eligible families can use a transportation company for bus tickets, rides or request mileage reimbursement for a child's medical appointments. MTM, Inc. arranges transportation for eligible Medicaid and BadgerCare Plus members throughout WI. Contact MTM at 866-907-1493.
- **Disability Parking Permits**—Parking placards and license plates for people with disabilities are issued by the Wisconsin Department of Transportation (WisDOT) Division of Motor Vehicles (DMV). The DMV offers parking permits for both temporary and permanent disabilities. All placards or plates require medical authorization. A child with a tracheostomy and/or ventilator is eligible and your team can assist with completion.

Family support

- The **Children's Long Term Support Waiver Program** provides services for children and young adults under the age of 22 with significant developmental, physical, or emotional disabilities. Supports and services are available to help waiver participants and their families remain in their home or community.
- **WI Regional Centers—Children and Youth with Special Health Care Needs**—Wisconsin has five Regional Centers dedicated to supporting families with children and youth with special health care needs. They help families get answers, find services and connect to community resources.

- **Aging and Disability Resource Centers (ADRCs)** are friendly, welcoming places where you can go for information about transitioning to adult services or living with a disability as an adult. The ADRC provides information on a broad range of programs and services, helps people understand the various long-term care options available to them, helps people apply for programs and benefits and serves as the access point for publicly funded long term care. Contact your local ADRC if you have questions or for help.
- Join the **Global Tracheostomy Collaborative** to CONNECT-SHARE-PARTNER. Visit www.globaltrach.org.

Transition to Adulthood: Adult Guardianship

General Information:

- Parents are legal guardians of their child until they turn 18. Every person is a legal adult at the age of 18. An adult can make their own choices about important issues. Learn more.
- Some adults with a cognitive disability may not understand information well. This could keep them from making choices that are in their best interests.
- If an adult is not able to make choices about medical, legal or money issues, a guardian may be needed.
- During the teen years, you should start thinking about whether your child will need a guardian. Many adults with disabilities can make choices with support. There is a process called Supported Decision-making. https://wi-bpdd.org/index.php/supporteddecision-making/
- Use the resources below. You can also talk with your child's teacher, health care provider and other parents about your options.

If an adult needs a guardian:

- Contact your doctor, social worker or county human services department. Ask about the guardianship process.
- Most people hire a lawyer to help them but it can be done on your own, known as Pro Se.
- The adult will need to have a competency evaluation. This is done by a doctor, psychiatrist, or psychologist. This report tells the court about how well the adult makes choices. It is only good for 6 months before the court hearing.
- A court hearing is done to complete the process.

Resources for adult guardianship:

- Aging and Disability Resource Center (ADRC). dhs.wisconsin.gov/adrc/index.htm. This site will let you know if you can get help from your county.
- Children's Wisconsin (CW) Guardianship Clinic. Call (414) 266-3465 to see if your adult child, age 17½ years old, qualifies for this clinic.
- Wisconsin Regional Centers for Children & Youth with Special Health Care Needs. Gives other referrals, ideas of lawyers who know about guardianship and information about the process. dhs.wisconsin.gov/cyshcn/ regionalcenters.htm
- Wisconsin Court System. You will be able to get adult guardianship paperwork at this site. http://wicourts.gov/forms1/circuit.htm#guard.
- Competency Evaluation form. You can see and print the form at this site. http://wicourts.gov/formdisplay/GN-3130.doc?formNumber=GN-3130&formType=Form&formatId=1&language=en.
- Wisconsin Guardianship Support Center. A statewide resource center staffed by lawyers. Call Toll-Free Helpline (855) 409-9410; e-mail: guardian@gwaar.org . https://gwaar.org/guardianship-resources
- Wisconsin State Bar. www.wisbar.org/forpublic/INeedaLawyer/pages/i-need-a-lawyer.aspx. (800) 362-9082

This sheet was created to help you care for your child or family member. It does not take the place of medical care. Talk with your healthcare provider for diagnosis, treatment and follow-up.

#1372 February 2020 Page 1 of 1

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Becoming an adult

When teens become adults, they have new health care needs. Finding and using adult health care will take a few steps.

Where to go for health care

- You will need to find a doctor who sees adults. Talk to your current doctor or your insurance company about doctors you can see.
- If you are seeing any specialists they can help you find adult specialists.
- Make sure any new doctors are in your insurance plan.

Paying for health care

It is important to always have health insurance to help pay for your healthcare needs. Make sure you understand your insurance.

- **Healthcare insurance through your job:** Your job may offer this. Ask your employer.
- **Healthcare insurance through your parents:** You may be able to stay on your parents' insurance for a time.
  - If your parents' insurance plan covers children, you may be able to stay on their plan until you turn 26 years old.
- **Marketplace coverage (also known as Obamacare):** Almost everyone can get a Marketplace plan. Financial help is based on how much you earn. For more details call 1-800-318-2596.

- **Medicaid (may be called BadgerCare):** In Wisconsin, if your insurance is under your parents' BadgerCare plan it will change when you turn 19 years old. You will need to apply for your own plan. The BadgerCare plan is based on how much money you earn. To apply for Medicaid (BadgerCare) go to https://access.wisconsin.gov/

More resources for people with disabilities

- **Katie Beckett Waiver:** If you have insurance through the Katie Beckett Waiver it will end when you turn 19 years old. Apply for insurance through one of the Medicaid programs. You will get a letter about what to do next.
- **Health benefits for workers with disabilities:** Medical Assistance Purchase Plan (MAPP) allows people with disabilities who are working, or want to work, to get insurance through the Wisconsin Medicaid Program. You may have to pay for it. It will depend on how much money you make. Search 'MAPP WI' online for more information.
- **Supplemental Security Income (SSI):** Persons with disabilities may be able to get SSI. Apply or reapply in the month you turn 18 years old. Do not do it any earlier or your parents' income will be counted. To start the process call Social Security Administration (SSA) at 1-800-772-1213. You can also visit your local SSA office. Ask your social worker if you need help.
- **Aging and Disability Resource Center (ADRC):** Your local ADRC is the best place to find helpful resources. They can help with adult services you might need like:
  - Housing
  - Transportation
  - Medicare, Medicaid and Social Security

For information about your county's ADRC, go to www.dhs.wisconsin.gov/adrc.

Children's Wisconsin

Education, Training and Employment

- If you have an **Individualized Education Plan (IEP) or a 504 plan** you can stay in school until you:
  - earn enough credits to graduate or
  - turn 21 years old.
- Before you leave high school, talk to your vocation or transition coordinator at your school. They can help you make a plan for your future. Your local **Department of Workforce Development (DWD)** can also help. For information go to https://dwd.wisconsin.gov/dvr/

- If you are getting Medicaid and also start to work, it is very important to find out how much you can earn and still keep your benefits. Talk with your assigned caseworker.

- **Ticket to Work (Work Incentive Improvement Act)** is a program for people with disabilities who work. It may let you keep your Medicaid benefits if you cannot get health insurance from your job. You may have to pay for Medicaid. For more information call 1-608-261-0050.

Decision-making

- **Advanced Directives** (Also called a living will or Power of Attorney): These are legal documents that you can use to say what should be done for your health if you are no longer able to make your own decisions. Talk to your doctor or a social worker for more information.

- **Supported Decision Making**: Sometimes you may need extra help to make important decisions. Family and friends can help you make decisions. For more information call the Children's Hospital Family Resource Center at 414-266-3169.

- **Guardianship:** For persons who are not able to make medical decisions for themselves, a parent or another adult will need to apply for guardianship. This is a legal process done in court. It is best if Guardianship is done by the age of 18 years old. It should be started at 17 years and 6 months old. To get help with this contact your local Aging and Disability Resource Center.

For other health and wellness information, check out this resource:
https://kidshealth.org/ChildrensWi/en/parents

#1869 June 2022

Healthcare Transition

STAY A STEP AHEAD

Healthcare Transition is the change from a PEDIATRIC model of care (parents and caregivers make most decisions) to an ADULT model of care (most adults make their own healthcare decisions).

Step 1: Start talking transition

Age 12-14

- Know the names of doctors and reasons for seeing them.
- Allow time for the youth patient to meet with the physician alone.
- Fill out a checklist to prepare for adult healthcare.

Step 2: Be in the know

Age 15-17

- Youth, families, and doctor need to know youth's
  - unique medical needs
  - communication style
  - disability
  - diagnosis
- Youth and family need to learn about privacy and consent before age 18.

Decisions Need To Be Made Before 18th Birthday

Step 3: Transition to adult care

Age 18 & up

- Ask current doctor to recommend doctors who care for adults.
- Check on insurance coverage.
- Be sure medical records are sent to adult doctor(s).

Health Transition Wisconsin: healthtransitionwi.org
Wisconsin Regional Centers for Children and Youth with Special Healthcare Needs: dhs.wisconsin.gov/cyshcn/regionalcenters.htm

Healthcare Transition RESOURCES

Wisconsin Resources

- **Build Your Bridge** - Training for families available through Wisconsin Regional Centers for Children and Youth with Special Healthcare Needs dhs.wisconsin.gov/cyshcn/regionalcenters.htm
- **Bridging the Gap** - Presentation at conferences and for community groups Email: healthtransitionwi@waisman.wisc.edu
- **Closing the Gap** - Training and technical assistance for medical practices to develop & implement healthcare transition strategies Email: healthtransitionwi@waisman.wisc.edu

Got Transition & National Resources

- **For Families** – 5 steps to prepare for Health Care Transition gottransition.org/resource/?five-steps-prepare-for-hct
- **For Youth and Young Adults** – Navigate the transition journey and get answers to your questions about moving to adult healthcare. gottransition.org/youth-and-young-adults/

  Sample Transition Readiness Assessment for Youth gottransition.org/6ce/?leaving-readiness-assessment-youth

  Take a quiz: Are You Ready to Transition? gottransition.org/youth-and-young-adults/hct-quiz.cfm
- **For Parents and Caregivers** – Find out how you can help your child move to the adult healthcare system. gottransition.org/parents-caregivers/

  Take a quiz: Is Your Youth Ready to Transition to Adult Health Care? gottransition.org/parents-caregivers/hct-quiz.cfm

  Sample Transition Readiness Assessment for Parents/Caregivers gottransition.org/6ce/?leaving-readiness-assessment-parent
- **For Healthcare Providers**

  Learn about the Six Core Elements™ that introduce a structured process to implementing youth to adult health transition for youth and young adults with and without special health care needs. gottransition.org/six-core-elements/

  American College of Physicians Condition-Specific Tools: https://www.acponline.org/clinical-information/high-value-care/resources-for-clinicians/pediatric-to-adult-care-transitions-initiative

Healthcare Transition is a process that takes time and involves youth & families, pediatric & adult providers and coordination with other transition activities.

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Emergency care information

If this is a medical emergency, call 9-1-1 right away!

Date last updated:______________

Child's name: ____________________________ Birth date: _______________________

Language spoken at home:____

Weight:__________ Height:__________ Date checked: _______________

Legal guardian: ____

Address: ____

Daytime phone: ____________________________________

Allergies: ____

Brief medical history (Diagnosis, medical and surgical treatments)

Current medicines

Name	Dose	Times given

Past emergencies (what was the emergency and what worked best to treat it?)

Insurance or other funding

Primary insurer: ____
Policy number: ___________________
Contact name: ___________________
Daytime phone: __________________ FAX:_____________________
Address: ____

Secondary insurer: ___________________________________
Policy number: ___________________
Contact name: ___________________
Daytime phone: __________________ FAX:______________________
Address: ____

Emergency Contacts

Primary healthcare provider: _______________________________________

Daytime phone: ______________________ Evening phone: _________________

Primary hospital: ____

Address: ____

Phone: ______________________________

Other: ____________________________ Relationship: _____________________
Daytime phone: __________________ Evening phone:________________

Other: ____________________________ Relationship: _____________________
Daytime phone: __________________ Evening phone: ________________

Family information

Child's name: ________________________________ **Nickname:**_______________

Birth date: ____________________ Social Security Number ________________

Diagnosis: ____

Blood type: ________

Legal guardian: ____

Address: ____

Family members

Mother's name: ______________________________________

Address: ____

Daytime phone:________________________Evening phone: ________________

Father's name: _______________________________________

Address: ____

Daytime phone:_________________________ Evening phone: _______________

Siblings

Name _________________________________ Age _________

Name _________________________________ Age _________

Name _________________________________ Age _________

Important family information

Language spoken: _________________________________

Other language: _____________________________________

Interpreter's name: ____________________________________

Daytime phone: __________________ Evening phone: _________________

Emergency contact

Daytime phone: _______________________ Evening phone: ____________________

School

School name: ____

Contact name: ______________________________________

Address: ____

Daytime phone: ____________________ Evening phone: _____________________

Days and hours: ____

Child care provider

Name of daycare: ____

Contact name: ______________________________________

Address: ____

Daytime phone: ___________________ Evening phone: ____________________

Days and hours: ____

Immunizations

Make sure your child is up to date on all immunizations. This record will also be helpful at your child's school.

Date	DTP	Polio	Measles, Mumps, Rubella	Hib	Tetanus (Adult)	Hepatitis B	Varicella (chicken

Date	Flu vaccine	Pneumoccal vaccine	Meningococcal vaccine		

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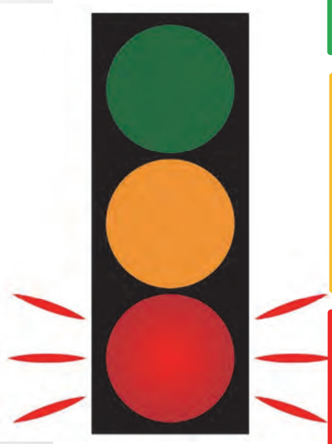
My Oxygen Information

My Baseline oxygen is

_____%

To maintain oxygen saturation above

_____%



At baseline oxygen %/LPM, and have a stable oxygen saturation.

Increased oxygen %/LPM, **within prescription**, to maintain oxygen saturation.
Call the Pulmonary Nurse

Increased oxygen %/LPM needed is **above prescription** to maintain oxygen saturation.
Go to the local E.R.

When I use my _______________

I use _______ LPM

When I use my _______________

I use _______ LPM

Type of Oxygen I use:


☐


☐

Compressor Pressure

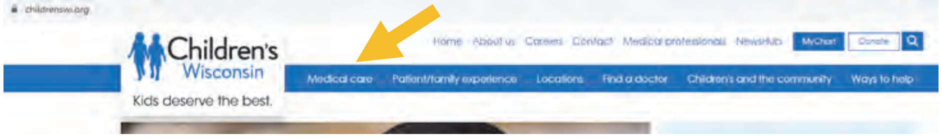
LPM	FiO2	Ventilator	Trach Collar	HME
.5				
1				
1.5				
2				
2.5				
3				
3.5				
4				
4.5				
5				

Children's
Wisconsin
Kids deserve the best.

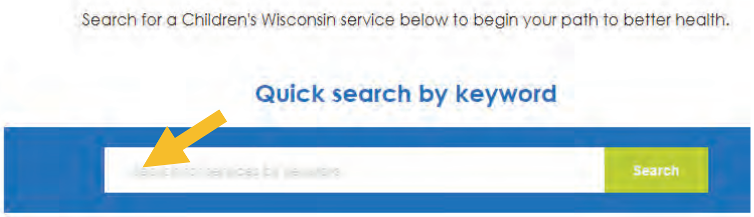
Navigating the Tracheostomy/Home Ventilator Program Web Page

https://childrenswi.org/

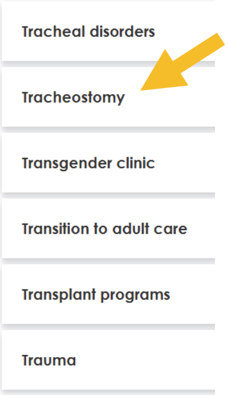
- Across the top of the page, in the blue banner, click on "Medical Care"



- This will bring up 2 options to search. You may either type in "trach" to the search bar,


Search for a Children's Wisconsin service below to begin your path to better health.

- OR, click on the letter "T" and click on "Tracheostomy"



- The Search bar in the middle our page contains a “drop down” list – found using the arrows at the far right side of the search bar.

  - Click on “Community Resources” in that drop down list
  - On the left hand side of the Community Resources page, click on “Educational Resources”
  - There are several videos on that page. Each is one “chapter” in our “New Normal: Your Child’s Tracheostomy and You” DVD

- Click on the QR Code below. This will take you right to our Web Page!

Children's
Wisconsin
Kids deserve the best.

Navigating to the Children's Wisconsin Trach/Home Vent Webpage

Google search the main, Children's Wisconsin webpage:

https://childrenswi.org/

Across the top of the page, after the following headings, there is a "search" icon, 🔍 right next to the "donate" tab.

Home About us Careers Contact Medical professionals NewsHub

- When you click on the "search" icon, a box will open up. Type the word "Trach" in the search box.

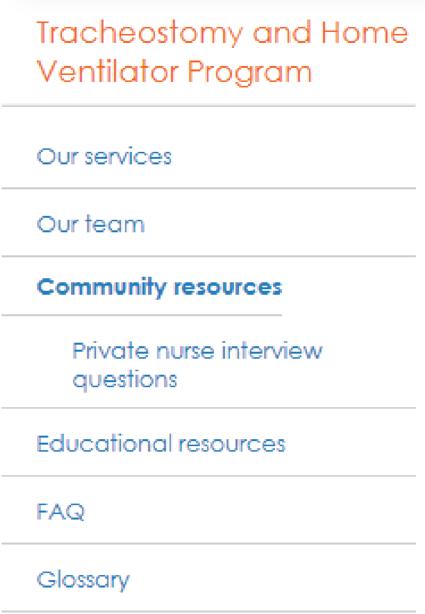
- Scroll to "Medical Care" in the results, and the link to the **Tracheostomy and Home Ventilator Program** is listed first. Open that link.

- The Search bar at the top of our page contains a "drop down" list – found using the arrows at the far right side of the search bar.

- Choose "Community Resources" in that drop down list.

Community resources

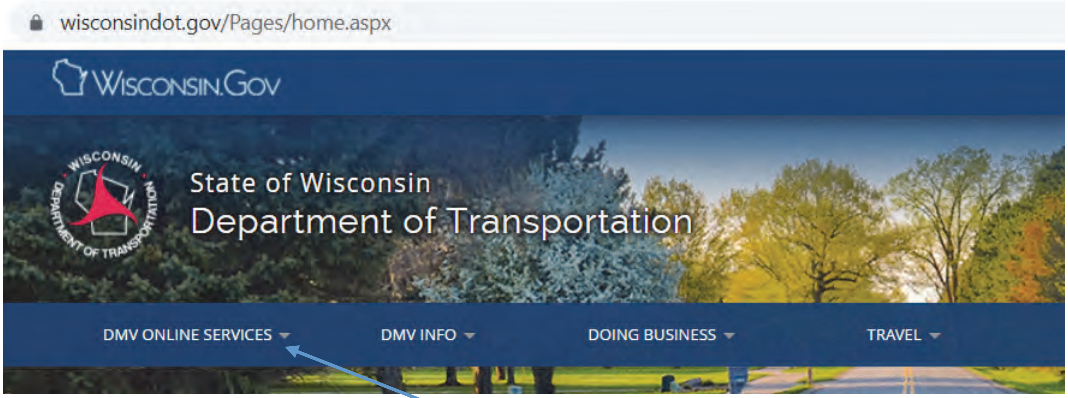
- On the left hand side of the Community Resources page, choose: "Educational Resources" in the list of options.



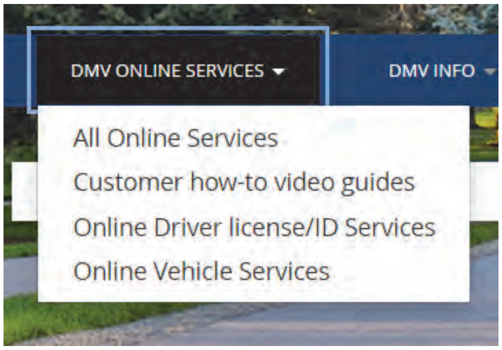
- There are several videos you can access regarding tracheostomies on that page. Each is one "chapter" in our "New Normal: Your Child's Tracheostomy and You" DVD.
- There are several additional educational videos you can reference.

Disabled Parking Application

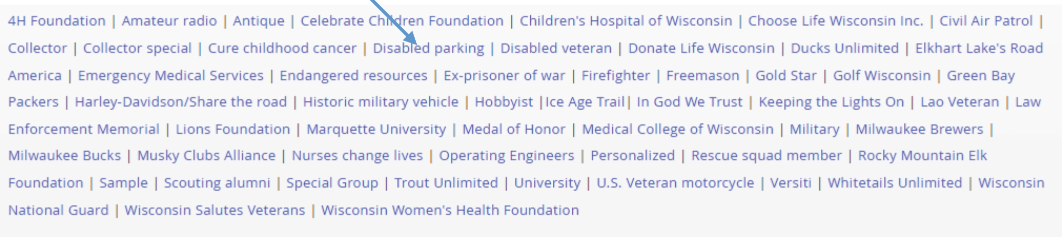
1. Online search- Wisconsin Department of Transportation



2. Click on DMV Online Services

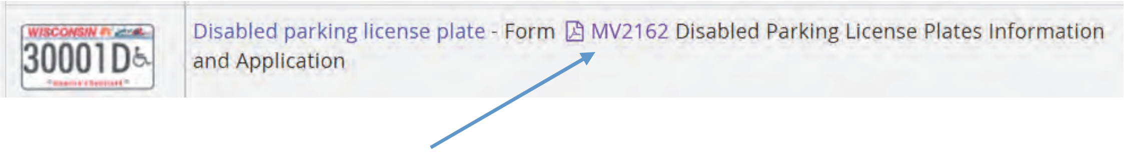


3. Choose Online Vehicle Services
   a. Title and Plate Services
   b. Special Plates
   c. Disabled Parking



4H Foundation | Amateur radio | Antique | Celebrate Children Foundation | Children's Hospital of Wisconsin | Choose Life Wisconsin Inc. | Civil Air Patrol | Collector | Collector special | Cure childhood cancer | Disabled parking | Disabled veteran | Donate Life Wisconsin | Ducks Unlimited | Elkhart Lake's Road America | Emergency Medical Services | Endangered resources | Ex-prisoner of war | Firefighter | Freemason | Gold Star | Golf Wisconsin | Green Bay Packers | Harley-Davidson/Share the road | Historic military vehicle | Hobbyist |Ice Age Trail| In God We Trust | Keeping the Lights On | Lao Veteran | Law Enforcement Memorial | Lions Foundation | Marquette University | Medal of Honor | Medical College of Wisconsin | Military | Milwaukee Brewers | Milwaukee Bucks | Musky Clubs Alliance | Nurses change lives | Operating Engineers | Personalized | Rescue squad member | Rocky Mountain Elk Foundation | Sample | Scouting alumni | Special Group | Trout Unlimited | University | U.S. Veteran motorcycle | Versiti | Whitetails Unlimited | Wisconsin National Guard | Wisconsin Salutes Veterans | Wisconsin Women's Health Foundation

Or, scroll down to the Disabled Parking Plate



Disabled parking license plate - Form MV2162 Disabled Parking License Plates Information and Application

4. Click on the link for the form

https://wisconsindot.gov/Documents/formdocs/mv2162.pdf

Notes

Notes

Glossary

A

Aerosol—Breathing treatment to deliver medication in a mist that is absorbed in the lungs. Also called Nebulizer treatment.

APN—Advanced Practice Nurse.

Apnea—Abnormal pauses in breathing lasting longer than 15 to 20 seconds. This can cause the breathing monitor to alarm and alert you to check your child's breathing.

Apnea monitor—A machine that sounds an alarm when an infant stops breathing.

Artificial airway—Another word for tracheostomy tube.

Artificial nose—See HME.

B

Bacteria—Germs.

bpm—Breaths per minute.

Bradycardia—A slow heartbeat.

Bronchoscopy—An examination performed by a doctor using a small tube inserted into the nose or mouth to view the inside of the trachea, bronchi and air passages.

C

Cartilage—Tough tissue rings that the windpipe is made of.

Catheter—Tube used to remove or inject fluids into the body.

CBC—Complete blood count.

CO_2 (carbon dioxide)—Gas that the body eliminates through the lungs.

CPAP—A device that provides Continuous Positive Airway Pressure while your child is breathing to prevent airway collapse.

CPR (Cardio Pulmonary Resuscitation)—A method for getting someone to breathe again once they have stopped.

Cyanosis—A bluish color to the lips or skin that happens when the oxygen level in the blood is low.

D

Decannulate—Removal of the tracheostomy tube when your child no longer needs the tracheostomy.

DME—Durable medical equipment.

Dysphagia—Difficulty swallowing.

Dyspnea—Difficulty breathing or shortness of breath.

E

ENT doctor—Ear, nose, and throat doctor.

Epiglottis—A flap of tissue covering the opening of the larynx (voice box) during swallowing to prevent food or fluid from entering the lungs.

Exhale—Breathe out.

Expiration—Breathe out.

F

Fistula—An abnormal tube-like passage from one body cavity to another.

G

Go Bag—Portable emergency equipment that must always be carried with your child as long as your child has a tracheostomy.

Granuloma (granulation tissue)—Growth of new tissue in or around the tracheostomy stoma. A granuloma may bleed if irritated or cause obstruction to the trach tube if it grows too big. May be treated by your child's ENT doctor, to help shrink excessive growth.

H

HME (Heat and Moisture Exchanger)—Also called an artificial nose, this small plastic device fits on your child's trach tube to provide portable humidification.

Hydrogen peroxide (H_2O_2)—A mild antiseptic and cleansing agent.

Hypoventilation—Reduced rate and depth of breathing.

Hypoxia—Low oxygen level in the body.

I

IEP—Individual Education Plan.

Inhale—Breathe in.

Inspiration—Breathe in.

L

Laryngectomy—Removal of the larynx.

Laryngomalacia—A condition that occurs when the structures of the larynx are abnormally soft or floppy and collapse inward during breathing causing obstruction of air flow.

Laryngoscopy—Examination of the interior of the larynx with a scope.

Laryngotracheoplasty (LTP)—Laryngeal and tracheal reconstructive surgery.

LTR—Laryngotracheal Reconstruction.

Larynx—Area located above the trachea containing the vocal cords. The function of the larynx is to protect the airway when the vocal cords are closed and to produce voice when air passes through the vocal cords. Also called the voice box.

LPN—Licensed Practical Nurse. The LPN works with the case manager to provide private duty nursing.

M

Malacia—Abnormal softness or floppiness of a part of the airway that collapses inward during breathing.

MAP—Mean airway pressure.

MDI—Metered dose inhaler.

ml—Milliliter.

MSW—Medical Social Worker.

Mucous (mucus)—Slippery fluid produced in the lungs and windpipe.

N

NC—Nurse Clinician.

Nebulizer machine—A machine that delivers medicine in a mist that is absorbed in the lungs. The medicine is then inhaled into the airways.

NICU—Neonatal Intensive Care Unit.

NIP—Nurse in Independent Practice.

O

O_2—Oxygen.

Obturator—Part of the tracheostomy tube to help guide it into the opening in the neck.

OT—Occupational Therapist.

Otolaryngologist—Ear, nose, and throat doctor.

P

PDN—Private duty nurse or Private duty nursing.

PEC—Pediatric Extended Care.

PEEP—Positive End Expiratory Pressure.

PICU—Pediatric Intensive Care Unit.

PIP—Peak inspiratory pressure.

Pneumonia—A disease of the lungs characterized by inflammation and consolidation followed by resolution and caused by infection or irritants.

PT—Physical Therapist.

Pulmonologist—Lung doctor.

R

Resuscitator bag—Plastic device used to inflate the lungs of someone not breathing on their own. Used to give extra breaths between suctioning or ventilator tubing changes.

Retractions—Pulling in at the chest during breathing.

RN—Registered Nurse.

RT (RCP)—Respiratory Therapist or Respiratory Care Practitioner

S

Saline—Normal saline or 0.9% sodium chloride solution similar to water found in the body.

Secretions—Another word for mucous.

Sinusitis—An inflammation of the sinus.

SLP (Speech and Language Pathologist)—A person trained to help with speaking and swallowing problems.

Speaking valve—A one-way valve that lets air come in through the tracheostomy tube, but then sends it out past the vocal cords and mouth to make talking possible.

Stenosis—Narrowing or constriction of a segment of the airway that causes obstruction of airflow. Most commonly stenosis is in the area below the epiglottis or trachea causing noisy breathing (stridor) or shortness of breath.

Sterile—Free from germs.

Stoma—The opening made at the front of the neck into which the tracheostomy tube is placed.

Stridor—Noisy breathing usually caused by obstruction of air through the airway.

Subglottic stenosis—Narrowing or constriction of the airway below the epiglottis.

Suctioning—A catheter tubing is inserted into the tracheostomy tube and mucous or secretions is removed from the tracheostomy using a suction machine.

Suction machine—A machine used to suction the trach tube so that mucous in the trach tube will not block air flow through the tube.

T

Tachycardia—A rapid heartbeat.

Trach—Short for tracheostomy tube.

Trachea—The part of the airway between the voice box and the lungs. Also called the windpipe.

Tracheomalacia—Abnormal softening or floppiness of the tissue in the windpipe causing collapse and obstruction to airflow.

Tracheostomy—An opening in the windpipe or trachea for breathing through instead of breathing through the nose or mouth.

Tracheostomy ties—Velcro ties that go around the neck to hold the tracheostomy tube securely in the windpipe.

U

URI—Upper respiratory infection.

V

VE—Exhaled minute volume.

Ventilator—A mechanical device to assist breathing that moves air and oxygen in and out of the lungs. Also called a respirator or breathing machine.

Vocal cords—Two strips of tissue in the voice box in the neck.

VTE—Exhaled tidal volume.

W

WIC—Women, Infants and Children. WIC is a Special Supplemental Nutrition Program.

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