“My Passey-Muir valve helps improve my voice.”

“My surrounding skin usually appears slightly discolored.”

“Extreme caution is necessary in water play!”
“Inquisitive, active learning and play are a must!”

“Play-acting can be very helpful!”

“Someday I’ll outgrow both my diaper and my trach!”
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Purpose of the tracheostomy:

A tracheostomy is an opening in the windpipe (trachea) that your baby breathes through instead of breathing through his nose and mouth. Often the tracheostomy is not permanent and can be removed after the problem has been corrected or the baby grows and no longer needs the tracheostomy. Babies with the following problems may get tracheostomy:

1. Birth defects that affect the baby’s breathing, such as a small jaw, vocal cord paralysis, or large tongue.
2. Tracheomalacia: noisy breathing caused by a soft or weak breathing tube.
3. Need for prolonged respiratory support (i.e., on ventilation), such as BPD.
4. Scarred or narrowed larynx: subglottic stenosis.
5. Neuromuscular diseases.
6. Aspiration.
7. Respiratory control problems, such as central hypoventilation or central apnea.

Anatomy:

1. A small opening is made from the skin to the windpipe (trachea) by a cut in the neck for a tracheostomy.
2. A tracheostomy tube is a short piece of plastic that is placed into the trachea through a surgical hole in the neck. It does not reach into the lung.
3. The baby breathes through this plastic tube instead of through his nose and mouth.
4. You will not be able to hear the baby cry or talk with the tracheostomy tube in at first. After some time, an air leak usually develops around the trach tube. Some of the air escapes through the voice box, permitting some return of voice.

Surgery:

1. Surgery takes approximately one hour. It is not the surgery, but the immediate post-op course that is frightening to most parents. Many families have not seen a mist-collar, and the monitors, the trach “stay stitches”, and even bloody secretions seem overwhelming. The child or infant is usually sedated at first and the parents or family must wait a few days even to hold their child, for reasons of safety.
2. The baby spends the first week in the ICU for recovery.
3. Hand-on teaching follows the first trach change. Many parents need everything they can to prepare for caring for a child with a trach, and there are a number of available handbooks and articles directed at the caregiver (see end of article on literature).
Complications of trachs:

1. Bleeding.
2. Infection.
3. Trach plugging.
4. Granulation (scar) tissue.
5. Skin necrosis.

Apnea monitor:

1. The baby will go home on a home apnea and cardiac monitor. The monitor counts the baby’s breathing rate and heart rate.
2. The monitor alarms to tell you if the baby is not breathing (apnea) or if the heart beat is too slow (bradycardia) or fast (tachycardia).
3. A pulse oximeter provides the oxygen saturation information and is routinely used early on.

Suctioning the trach tube:

1. Supplies
   a. Clean suction catheter
   b. Suction machine
   c. Small container of tap water (to flush catheter)
   d. Ambu bag

2. Suctioning the trach tube: Suctioning is done to clear the trach tube of mucus, so that the trach tube will not become blocked. Suctioning is done to a premeasured depth that just allows the tip of the suction catheter to come out the end of the trach tube. Suctioning more deeply may injure the lining of the windpipe. Your child’s nurse will show you how far the catheter should be inserted. You can check this depth by passing a catheter through an extra clean trach tube until the side holes close to the tip just clear the end of the tube and measuring the distance from the end of the catheter.
   a. Wash your hands.
   b. Take off the mist collar or artificial nose. If the baby is on extra oxygen, keep the collar close to the trach tube.
   c. Attach the suction catheter to the suction machine being careful not to touch the end of the catheter that will be put into the trach tube. Turn on the suction machine.
   d. Apply suction by putting your thumb over the thumbhole of the catheter. Rotate or twirl the catheter between your other thumb and first finger while inserting the catheter to the pre-measured depth and while withdrawing the catheter. Rotating the catheter allows the holes at the end of the catheter to pass over the entire inside surface of the trach tube. The complete pass of the suction catheter should take about 2-3 seconds.
   e. Repeat the suctioning procedure if you see or hear more secretions in the trach tube.
   f. If your baby is on oxygen or other supports for his/her breathing (like a ventilator), giving a few extra breaths with an Ambu bag during or after suctioning is completed may be important. Your child’s nurse or doctor will advise you about this.
   g. Rinse the catheter with tap water and wipe the outside with alcohol. After air drying, store it in a clean, dry place. Wash your hands when your equipment has been put away.
   h. Suctioning should be done at least three times each day and when needed. If your child’s secretions are increased, suctioning may need to be more frequent.
   i. Follow your home care company’s guidelines about more thorough cleaning procedures of catheters and how long to use them before replacement.
Changing tracheostomy ties:

1. Supplies
   a. Twill tape or bias seam tape or shoe laces or Velcro holder
   b. Blanket roll for shoulders
   c. Scissors
   d. Blanket for mummy restraint—it may be necessary to wrap baby snugly to prevent wiggling.
   e. Chains (like those used for military dog tags)

2. Changing the ties: Do not change the tracheostomy ties by yourself unless absolutely necessary.
   a. Change ties daily or when:
      - Ties become loose (should fit snugly when neck is bent forward)
      - Ties become wet or dirty.
      - Square knot causes pressure on your baby’s skin.
      - The trach is changed.
   b. Suction before changing ties. Suctioning decreases chances of the baby’s coughing while ties are off. Movement of the tube often causes the baby to cough and bring up mucus.
   c. Changing ties requires two people—one person to hold tube in place and position baby, and the other person to change the ties.
   d. Place blanket roll under shoulders to expose the tracheostomy area.
   e. Slide old ties from center of hole to top on both sides of the tracheostomy tube.
   f. Insert new ties under old ones.
   g. Secure new ties with a square knot. Ties should be tight enough to easily slip one finger underneath the tape.
   h. Cut off old ties and remove. Guard tips of scissors with your fingers.
   i. Examine neck daily for redness, skin breakdown, or rashes.

   If using trach holder or Velcro trach tie:
   - remove one side of Velcro holder while holding the trach in place. Thread the clean holder in this side, then go to the other side and repeat the process.
   - clean the dirty trach holder with warm soapy water and hang or lay flat to dry. It may be used for as long as it is clean and functional.

Cleaning the tracheostomy opening (stoma):

1. Supplies:
   a. Tap water
   b. Q-tips or cotton swabs
   c. Basin
   d. Gauze trach dressing

2. Cleaning:
   a. Clean area around tracheostomy opening in neck (stoma) daily and when the area is soiled.
   b. Support tracheostomy tube with a finger while cleaning.
   c. Roll Q-tip dipped in water over skin under tracheostomy to remove crusted secretions.
   d. Rinse with Q-tip dipped in clear water. Pat dry with gauze or clean cloth.
   e. Wash skin around neck with clear water and a mild soap such as Basis or Neutrogena.
3. Place gauze trach dressing around trach tube. Change dressing as often as necessary to keep skin dry.
   a. May use pre-cut trach dressings (more expensive)
   b. May use 4x4 gauze without fiber filling. Fold to fit under trach tube. Do not cut gauze because small fibers can get into the trach and windpipe.

4. Clean stoma 2-3 times a day if an odor is present (or more often, if there is drainage present).

5. Powders and lotions must not be used around the trach stoma.

6. If ordered by the baby’s doctor to treat irritations or rashes, apply ointments in a thin layer. (Ointments under the trach collar can make the skin irritations worse. Sometimes clean and dry is best.)

### Changing the tracheostomy tube:

1. Equipment
   a. Tracheostomy tube with obturator (guide)
   b. Shoestring ties or twill tape.
   c. Scissors.
   d. Blanket roll to support shoulders.
   e. Blanket for mummy restraint—it may be necessary to wrap baby to prevent wiggling.
   f. Oxygen tank with Ambu bag attached.
   g. Smaller size trach tube (in case of need)

2. Changing the tracheostomy tube
   a. Do not change the tracheostomy tube by yourself unless absolutely necessary.
   b. **WASH YOUR HANDS.**
   c. Suction baby before changing trach tube.
   d. Attach ties to new or clean trach tube with obturator in place. The obturator serves as a guide to provide easy insertion of the trach tube, although it is not usually necessary and occludes the trach when in place.
   e. Lubricate new trach with a small amount of water-soluble lubricant or saline
   f. Place tube in the sterile tray until ready to insert new or cleaned tube. Keep tube portion clean.
   g. Place blanket roll under shoulders to expose neck area.
   h. A mummy restraint may be necessary to prevent the baby from wiggling.
   i. Cut old ties
   j. Remove old trach tube with one hand using an up-and-out motion (follow angle of tube). Don’t be alarmed if secretions are coming out of the stoma when the trach is out.
   k. Insert new or cleaned tube gently. Direct tube back and down.
   l. If you use the obturator, remove it as soon as tube is in place. Your baby cannot breathe unless the guide (obturator) is removed.
   m. Tie snugly in place, allowing a finger-width slack.
   n. Allow baby to breathe until calm (a few seconds), supporting trach tube with your finger.

3. Your baby may cough, cry, turn red, or sweat. He is OK. This does not hurt the baby. Calm him by talking and holding. Give him a few breaths with the Ambu bag or a little extra blow-by oxygen to calm him. A pacifier may help.

4. Change the trach tube every 1-2 weeks (as directed by your baby’s doctor) or for:
   a. Distressed infant who does not respond to suctioning or usual calming methods.
   b. Bleeding from tracheostomy tube.
c. Difficulty inserting suction catheter.
d. Whistling through trach which is not relieved by suctioning.

5. Change tube before feeding or at least 2 hours after feeding. Avoid changing just before feeding if your baby is upset because of hunger.

6. Inspect the removed tube for color change, mucus plugs, or odor.

**Cleaning the tracheostomy tube:**

The medical equipment supply company will teach you how to clean the tracheostomy tubes and what to use for cleaning.

**Humidification / Moisture requirements:**

A humidifier and tracheostomy collar (trach collar) are used to filter and moisten air entering the windpipe (trachea) because the baby does not breathe through his nose or mouth.

1. Supplies:
   a. Air compressor machine
   b. Cascade humidifier with mounting bracket, nebulizer jar
   c. Corrugated tubing and drip bag
   d. Trach collar
   e. Sterile, distilled water (boil distilled water for 10 minutes and let cool to room temperature)
   f. Cleaning solution (recommended by home equipment company), large container with lid for cleaning solution
   g. Spare valve for air compressor

2. How to use:
   a. Fill nebulizer jar with sterile water to line on jar
   b. Attach nebulizer jar to air compressor.
   c. Connect trach collar to tubing with bag in place (corrugated tubing to bag to corrugated tubing) and attach nebulizer.
   d. Turn on machine and look for mist from trach collar.

**Cleaning equipment:**

**Daily:**
1. Change nebulizer jar and trach collar.

2. Fill clean nebulizer jar with sterile distilled water.

3. Check to make sure suction machine is working.

4. Check suction tubing as well.

**Every other day:**
1. Rinse tubing and drip bag with tap water

2. Clean using solution recommended by the home equipment supply company.

**After use or weekly:**
Clean ambu bag and face mask in solution recommended by the home equipment supply company.
More information:

1. Your baby may have trach collar and humidity off during the day if allowed by your baby’s doctor. An “artificial nose” type humidification device may be adequate.

2. Use trach collar and humidity during naps and at night to keep trach moist and prevent mucus plugs.

3. If humidifier is not available (during long trips or power failure), place one drop of saline every hour or two into the trach tube to moisten trach tube and windpipe.

4. The windpipe (trachea) of your baby is small and easily plugged with mucus, so the humidifier with trach collar provides a direct source of moisture that a vaporizer cannot.

5. If mucus becomes thick, move the numbered ring on the humidifier to a lower number. The usual setting is 50%. Increasing the baby’s fluid intake may help thin the mucus.

Signs of breathing problems:

1. Restlessness or increased irritability.

2. Increased breathing (respiratory) rate.

3. Heavy, hard breathing.

4. Grunting, noisy breathing.

5. Nasal flaring (sides of nostrils move in and out with breathing).

6. Retraction (sinking in of breastbone and skin between the ribs with each breath).

7. Blue or pale color.

8. Whistling from the trach tube.


10. Change in pattern of heart rate (less than 80 or more than 210 beats/minute).

11. Bleeding from trach tube.
   a. Report to doctor immediately.
   b. Irrigate tube with saline and suction.
   c. If bleeding continues, replace trach tube with a clean one.

CPR (cardiopulmonary resuscitation):

You will take a basic CPR class. We will teach you how to do CPR with the trach and how to use an ambu bag to breathe for the baby.

If the baby stops breathing:

1. **SUCTION TRACH TUBE AT ONCE.**

2. Replace trach tube if it has come out, is blocked with mucus, or your baby does not improve with suctioning. Tie trach ties!!!

3. Begin CPR if baby does not breathe when trach tube is clear.
**CPR with a tracheostomy:**

Call for help!!

1. Stimulate baby by gently shaking.

2. Position baby on a hard flat surface with his nose pointed straight up.


4. Listen and feel for breath by placing ear over tracheostomy. Look at chest to see if baby is breathing.

5. Place mouth or attach ambu bag over trach tube to form a seal.

6. Give 2 quick puffs. Observe to see if chest moves like an easy breath.

7. Feel for brachial heart rate (pulse) in the bend of the arm for 5 seconds and check to see if baby is breathing on his own (look, feel, and listen for air movement).

8. If you feel a pulse, breathe with mouth or ambu bag on tube. Count 1-2 breathe, 1-2 breathe.

9. If air is leaking from the nose and mouth, close them with your hand.

10. If you do not feel a heart rate in 5 seconds or if the heart rate is less than 60 bpm, do chest compressions and breathe for baby with mouth or ambu bag on trach tube. Press ½ to 1 inch with each compression. It is a little tricky to use the ambu bag and do chest compression, but you will learn how. Count:

    |   |   |   |   |   |
    |---|---|---|---|---|
    | 1 | 2 | 3 | 4 | 5 |
    | Breathe |

    This rate is about 100 times a minute. The breath is about 1 to 1 ½ seconds long.

11. Check heart rate and breathing about every minute. Do what the baby is not doing.

12. Call your local Emergency number or ambulance team for help if your baby does not respond.

13. Have baby taken to the nearest hospital.

**Call doctor if...**

1. Food or liquid comes though the trach.

2. There is a rash, drainage, or unusual odor around the trach opening.

3. Mucus becomes green or foul smelling (normal color is clear or whitish).

4. Bleeding occurs from the trach tube.

5. Difficult breathing not relieved by suctioning or changing trach.

6. Unable to replace trach tube.

7. Baby stops breathing.
Emergencies and treatments:

1. Plugged trach:
   a. Suction and use ambu bag.
   b. Change trach if baby does not improve.

2. Coughing out trach tube:
   a. Insert new clean trach tube as soon as possible.
   b. Reinsert old trach tube until clean trach tube is available.

3. Vomiting:
   a. Suction if you think vomit has gone down tube.
   b. Observe for coughing, respiratory distress, fever.
   c. Call doctor.

4. Unable to replace trach tube:
   a. Try to insert smaller trach tube.
   b. Call Emergency Team – 911.
   c. Trach opening (stoma) will not close up suddenly.
   d. Give mouth-to-trach opening CPR if not breathing OR block trach opening and use mouth-to-mouth CPR.

General care:

Feeding:
1. Your baby can be fed as a normal baby.
2. Burp well and place on right side or in infant seat after feeding.
3. DO NOT PROP THE BOTTLE.
4. Do not let your baby have a bottle unless you are present (in case choking occurs).

Bathing:
1. Your baby can be bathed in tub, but do not let water get into the trach.
2. NEVER LEAVE YOUR BABY ALONE IN THE TUB.
3. Baby’s head must be held during hair washing so that water does not enter the trach.
4. Change the trach ties after the bath if they get wet.

Clothing and bedding:
1. You do not need to buy special clothing for your baby.
2. Clothing that covers the trach should not be worn. Also avoid plastic bibs.
3. Necklaces, strings, fuzzy clothing, fuzzy blankets, and stuffed animals should be avoided. Tiny beads or fibers from these articles can get into the trach.
4. Purchasing a portable intercom system so you can hear the baby when you are in another room is helpful.
Making sounds and talking:
1. At first you will not be able to hear the baby cry or make sounds. This is because the air from the lungs does not pass through the vocal cords.
2. He will learn to talk around the trach tube.
3. It is important that you talk to him as you would any other baby.
4. Speaking valves such as the Passé-Muir valve can aid in talking when it is medically appropriate.

Nursing care/Baby-sitters:
1. A baby with a trach needs to be watched closely all day. Plans must be made to teach another caregiver how to care for the baby.
2. It is important that parents be able to rest and go out without the baby!
3. Some parents use a TV monitor, which they find helpful in watching the child.

Safety tips:
1. Use extra caution during baths or showers to avoid any water getting into the trach.
2. Animals with fine hair should not be in the house.
3. Keep home as free from lint and dirt as possible.
4. Do not use powders, chlorine bleach, ammonia, or aerosol sprays in the same room as the baby. Particles and fumes get into the lungs through the trach. This will cause a “burning feeling” and breathing problems.
5. Do not smoke or allow others to smoke around your baby. It's irritating to the baby's airways.
6. Watch play with other children so that toys, fingers, and food are not put into the trach tube.
7. Do not buy toys with small parts that can easily be removed.
8. Always carry your GO BAG supplies when you leave home.
9. No swimming.

Weather:
1. During freezing temperature, avoid allowing baby to breathe cold air directly into the trach. This can cause tracheal spasm and form small ice particles in the mucus if exposed for long periods of time. Keep the baby’s head and neck loosely covered with a blanket. Tie a scarf loosely around the neck of an older child.
2. Protect the tracheostomy on dusty windy days when dust particles may enter the trachea and cause drying or crusting mucus.

Brothers and sisters:
1. It is important to help older brothers/sisters to understand why and how the baby breathes through a trach.
2. This is usually a frightening situation for older brothers/sisters and requires parents’ support and teaching to ease their initial discomfort and fear.
3. It may be helpful to involve brother and sister’s help in small tasks such as holding the baby still, helping clean equipment, etc.
4. Watch young brothers and sisters around the baby!
Counting baby’s breathing:

1. You may want to count the baby’s breathing rate twice a day when the baby is quiet or asleep. You can write the number in a record book you bring to the doctor.

2. One count is a breath in and out. Sometimes the baby holds his breath briefly, breathes fast then slow, stretches or moves. Count the breathing as best you can.

3. Call the doctor if the breathing rate is 15-20 counts higher than usual or your baby is working hard to breathe. Make sure the baby is not too warm or does not have mucus in his trach.

24-hour schedule:

1. You will be very busy at home.

2. It helps to have a calendar with your day’s activities clearly marked.

3. Some things you will do several times a day and some things you do several times a week. Organization and a schedule are important. So is help from family members.

4. It is important to teach several people to care for the baby so you can have a break and get out by yourself.

Baby’s weekly schedule:

Daily:

1. Stoma care:
   a. 1-2 times a day, or more if necessary.
   b. Do more often if skin breaks down, there is a large amount of secretions, or odor noticed.
   c. Replace trach ties when wet (may use Velcro trach holder, bias tape purchased at any sewing store, twill tape, or shoelaces).

2. Wash suction bottle in hot soapy water.

3. Chest Physiotherapy (or CPT):
   a. 2-3 times a day (if recommended by the baby’s doctor)
   b. Before feeding or at least 2 hours after feeding

4. Change trach collar and tubing.

5. Change water bottle for humidifier.

6. Check to make sure suction machine is working.

Every other day:

1. Clean humidifier in solution recommended by home equipment supply company.

2. Clean suction bottle and tubing in solution recommended by home equipment supply company.

3. Clean trach collar and tubing in solution recommended by home equipment supply company.

Weekly (or as needed):

Change trach
   a. Always suction before changing trach.
   b. Change before feeding or at least 2 hours after feeding.
“GO BAG” for traveling:

1. De Lee suction catheter.
2. Bulb syringe.
4. Trach tube with tie (same size and size smaller).
5. Scissors.
7. Saline (two or three 5 cc vials).
8. 4 x 4's or trach sponges.
10. Emergency phone numbers.
11. HME devices (heat moisture exchanger)
13. Portable oxygen.
14. Hospital, insurance, and pharmacy cards available in baby’s own “wallet”

Recipes:

1. Saline
   a. ½ teaspoon of table salt added to 8 ounces of boiled water
   b. Add salt when water is warm.
   c. Cool before using.
   d. Store in sterile bottle (bottle boiled in pan of water 10 minutes after water begins to roll).
   e. Make new every day.

2. Sterile distilled water
   a. Boil tap or bottled water 10 minutes after water begins to roll.
   b. Store in sterile bottle.

3. Hydrogen peroxide
   a. Must buy.
   b. Keep out of sunlight.
   c. Do not use if cloudy or does not bubble when applied.
Supplies:

1. All of the home supplies you need will be provided through a home equipment and supply company. The hospital makes these arrangements with a company near where you live.

2. The supply company will contact you at home or while you room-in with your baby.

3. The supply company will tell you when and how to order supplies. They will give you a phone number to call if you have equipment problems. Call them if your equipment breaks or to reorder supplies.

Help:

1. Several programs are available to help provide medical and financial care of your baby. The Child Services Coordinator in your community or a social worker can help find out if you are eligible for the programs. Babies are eligible for different reasons and some may not be eligible or approved. Information can be obtained from your baby's social worker during the hospital stay.

   a. Medicaid (and Cap-C)
   b. Children’s Special Health Services
   c. SSI (Supplemental Security Income)
   d. Medically Needy Program
   e. AFDC (Aid to Families with Dependent Children)

2. It is a lot of hard work to care for a baby with a trach. Yet most parents still prefer to have the baby at home.

3. We ask several family members to learn the care so everyone can get some rest.

4. Some insurance companies approve home-nursing care for a baby with a trach. We contact your insurance company to find out if they provide this service.

5. Home health agencies or public health services are used for short visits. These visits are an hour or less. The nurses answer questions, help with special treatments and help with medications. They may weigh the baby or watch a feeding. They work with your doctor to follow the baby’s condition and progress.

6. Even though it is difficult to find people to babysit, it is important to teach other people to care for the baby so you can go out.

7. Respite services which provide relief for parents may not be available in all communities or for babies with trachs.

8. If you get too tired or frustrated, call the doctor or social worker. We will try to help.

Doctor visits:

1. Your baby returns to the hospital clinic to follow his breathing problems and trach.

2. If you see more than one doctor (eye, surgery, breathing, x-ray, lab, development), check to see if the appointment can be made for the same day.

3. At first it seems you spend most of your time going to the doctor.

4. As the baby’s health gets better, the visits become less frequent and some doctors will not need to see him.

5. You will take the baby to a local baby doctor for routine baby care and shots. Make an appointment to see him the first week the baby is home.

6. We mail your doctor a report of your visits to the hospital clinics.
Emergency notification:

1. The home equipment company will call and write the following agencies to inform them that your baby has a serious medical problem:
   a. Rescue squad.
   b. Telephone company.
   c. Electric/gas company.

2. The letter asks that you be placed on the priority list for notification of anticipated interruptions of service.

3. The letter asks that you be placed on the priority list for service reinstatement in the event of unexpected interruption of service.

My equipment supply company is:

Name: ___________________________________________________

Address: ___________________________________________________

Telephone: ________________________________________________

Trach literature:


“Life with a trach can be full and active!”

With special thanks to Parker’s mother, Cory, for her significant contribution to this manual and for sharing these photographs of her son.