

Choosing a Tracheostomy for a Child with a Neuromuscular Disorder

This handout explains what a tracheostomy is and can help you decide if this is right for your child.

What is a tracheostomy?

Surgery is done to make an opening in your child's neck called a stoma. The stoma goes to the windpipe (trachea). A tracheostomy (trach) tube is put in the stoma to help your child breathe. Your child breathes through the trach instead of their nose or mouth.

How do I decide?

You meet with members of the pulmonary and palliative care teams to talk about the pros and cons of a tracheostomy. These include:

- Changes to your child's health
- Life style changes such as adding more equipment
- Need for home care nursing

This is your choice. Take time to think about the quality of life and the things your child likes to do. Ask yourself how a tracheostomy may change these things. We support your choice.

If you would like to know what you need to learn to care for a child with a tracheostomy go to our website www.uwppc.org

- Click on Educational Resources.
- Click on Self Study Modules.
- Click on Pediatric Tracheostomy and Ventilator Care.

This website is used to train caregivers about tracheostomy and ventilator (vent) care.

The amount of time it takes to prepare families to go home varies. It depends on:

- How much time you have for training
- Your child's health
- Insurance issues
- If respiratory equipment is available

If you choose a tracheostomy for your child, our team helps you get ready. Our team is made up of:

- Pulmonary doctor
- Advanced practice nurse (APN)
- Respiratory therapist (RT)
- Nurses and your child's primary nurse
- Child life specialist
- Social worker
- Case manager
- RT Discharge planner

How does surgery get scheduled?

The pediatric pulmonary doctor refers your child to the pediatric ear, nose and throat (ENT) doctors. You meet them in clinic or the day before surgery. Surgery is set based on your schedule, and the doctor's schedule.

What do I need to do before surgery?

1. Decide who will be trained

- **At least two caregivers** need to learn all of your child's care.
- Anyone who cares for your child **alone** must complete the whole training process. Other family members that help you at home may also get trained.
- Schedule classroom training sessions with the Pediatric Pulmonary Clinical Nurse Specialist.

2. Decide how many nursing hours are needed in your home to help with the care of your child

- It is best to set up nursing coverage **before** surgery is scheduled to prevent delays in discharge.
- Insurance may cover in home nurses when caregivers are sleeping, working, and a few hours each week for errands. It is also based on your child's medical needs. Please check with your insurance provider.
- Your options of using a nursing agency or independent home nurses are based on where you live, and insurance coverage.
- The clinic case manager can help you set up in home nursing. The case manager can be reached at 608-890-8045.
- If you already have independent nurses, they need to be pediatric tracheostomy and vent certified to care for your child with a tracheostomy. This is done at the state level and can take many weeks.
- We recommend that personal care workers or certified nursing assistants (CNAs) are not left alone with your child with a tracheostomy.

3. Meet with your home equipment provider to get any new equipment and learn how to use it. Equipment and supplies will be ordered from your home equipment provider.

The Day Before Surgery

The day before surgery is very busy. Plan to go to the AFCH universal care unit the night before surgery. An IV is placed in your child for nutrition and to stay hydrated. You meet with many team members, such as a child life specialist, the ENT surgeon and a team member from anesthesia. It is important that

you bring all current and new supplies. This includes your child's:

- Vent
- Suction machine
- Cough assist machine
- Feeding pump
- Stroller or wheel chair
- New equipment or supplies that have been ordered before surgery
- Communication device
- List of medicines
- Information about and supplies for your child's feeding routine

The Day of Surgery

Your child is taken to the 3rd floor of AFCH for surgery on the home vent. The AFCH staff lets you know where to wait during surgery and when you can be with your child. After surgery, your child is moved to the Pediatric Intensive Care Unit (PICU). Your child is on a vent after surgery and has a cuffed trach tube in place with black strings (sutures) taped to their chest.

After Surgery - Days 1-3

Your child stays in the PICU and is watched closely. Feedings and medicines are restarted as tolerated. The home vent is also restarted with settings adjusted as needed. The sutures stay taped to your child's chest and the trach ties are not changed. Staff suction your child's trach tube often to keep it clear of mucus. Airway clearance therapies are given as needed. On Day 3, the ENT doctors do the first trach tube change at your child's bedside and take out the sutures taped to your child's chest. After this, we would like you to be part of your child's cares. This included suctioning routine stoma care, trach tie changes and trach tube changes.

After Surgery – Day 4 Until Discharge

After the first trach tube change, your child moves from the PICU to the Universal Care Unit and is cared for by the pulmonary team. The size and type of trach tube, vent settings

and vent circuit is decided by the pulmonary team.

- A travel humidification plan is developed using an in-line heat moisture exchanger (HME) also called an artificial nose.
- **Caregivers complete training sessions in a classroom setting outside your child's room.**
- If you do not want to leave your child in the care of the AFCH staff during these classroom sessions, arrange for someone who you trust to care for your child. This needs to be someone who is not part of the training process because all caregivers are trained at the same time.
- Training sessions are scheduled with the Pediatric Pulmonary Tracheostomy Coordinator. There are about 8 hours of classroom training.
- The classroom training includes learning from the manual: Caring for Your Child's Tracheostomy and demonstration and practice of skills on a doll with a tracheostomy.
Topics include:
 - Caring for your child's trach tube, stoma and tie changes
 - Humidification with the trach tube
 - How to suction your child's trach tube
 - How to change the trach tube
 - Vent terms and settings
 - Emergency care and CPR for a child with a tracheostomy
 - How to use the manual resuscitation bag
 - How to put together all of the supplies needed for the "Go bag" for the tracheostomy
- After classroom training each caregiver:
 - Practices the skills on your child with coaching from the

nurses. You can practice skills anytime you are here with your child.

- Completes three trach tube changes before discharge
- Completes CPR training for a child with a tracheostomy with AFCH staff. Your nurse will help you schedule this class.
- Is taught any changes in your child's care and has a chance to practice them before discharge.
- Is taught how to use any new equipment by provider. This person will provide any new supplies needed,

Independent Care Sessions

- **Each caregiver successfully completes 24 hours of independent care after all the training is complete.**
 - These need to be scheduled in advance
 - Your home equipment is used for the independent care sessions.
 - It gives each caregiver time to be totally responsible for the care of your child, your child's home equipment, and trouble- shooting any issues that come up, using AFCH staff as back up.
 - It allows each caregiver to demonstrate caring for your child independently. It is not a test. It is a way to pull together all you have learned and practice doing all of your child's daily cares within the safety of AFCH.
 - If there are areas that need more class time or practice, you have time for that after the session.

- This is not a marathon. If you like, you can break down the session into two twelve hour, or three eight hour blocks. The goal is to experience your child's care needs across a 24- hour day.
- **A trained care provider must be with your child at all times.**
 - During the session you may take your child out of the room. You need to stay on the unit to be close to a trained care provider until you are fully trained.
- **After you complete your independent care session you can take your child off the unit within AFCH. You must have your child's "Go bag" with your child at all times and you need to be able to:**
 - Use the home equipment
 - Do trach care
 - Suction and change a trach tube,
 - Do CPR and the emergency procedures

Road trip

Once you complete your independent care session you take your child out of the hospital on pass before discharge. This includes getting your child ready to ride in your car. If needed, we have a car seat specialist to help you make sure your child can safely ride in your car.

What else needs to happen?

- **We let your primary care doctor know that your child now has a tracheostomy.**
- **Financial resources are arranged in your community.** Home care equipment and home nursing often need to be approved before your child can go home. Your child's case manager and social worker work

together with you to coordinate the available resources.

- **We work with you to set up home care nursing services.** Your child's case manager talks with the home care nursing provider you chose to give information for the plan of care. It is then sent to the state Medicaid office. It may take several weeks to get approval for financial coverage for the needed nursing services.
- **Local services are identified and contacted before discharge** to provide home or community based care after your child goes home. Services may include speech, physical, and occupational therapy, community social services, or contacts with local school staff. These services often include Birth to Three, or Early Childhood.
- **We would like you to let your local emergency staff and utility company know that there is a child in the community who has a tracheostomy.** This gives emergency staff a chance to learn more about your child in the case of an emergency, and for your utility company to be aware of your child's needs in the case of a power outage.
- **The discharge date is set and approved by all involved;** family, pulmonary team, home equipment provider, home nursing, and community service providers.

Follow up is at the AFCH, neuromuscular and trach clinic

- You have been to the pulmonary and the neuromuscular clinics.
- The Trach Clinic is held monthly on a Thursday afternoon. It is

staffed by one of the pediatric pulmonary and ear, nose and throat doctors. You will also meet with the advanced practice nurse, nutritionist, social worker, speech therapist, and respiratory therapist.

- The trach clinic lasts at least two hours because of the number of people to see your child..
- Our goal is for you to come to trach clinic at least once a year.

If you have questions you can reach any member of the pulmonary team by calling **608-263-6420**.