

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?

Your child will have surgery to make an opening in their 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
- Lifestyle changes such as adding more equipment
- Need for home care nursing

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

What do I need to learn to care for my child?

Go to our website to learn how to care for a child with a trach:

<https://ce.icep.wisc.edu/node/12343/ehomecare>

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

You must create a free account to access the course. You will need to enter the access code **“trachventcare”** to enroll in the course.

You can access the course on any computer (best option), tablet, or mobile device with internet access. Some older browsers and Microsoft Internet Explorer could cause an error message or not display the content correctly. Make sure you have the hardware/software listed below:

- Free, current version of Chrome (preferred), Firefox, Safari, or Edge
- Free, current version of Adobe Acrobat Reader or other pdf reader

If you have any issues with the course, please contact help@icep.wisc.edu.

When can we go home?

When you can go home depends on:

- How much time you have for training
- Your child's health
- Insurance
- Respiratory equipment available

Who would be on my child's trach team?

Your child's team will be made up of:

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

How does surgery get scheduled?

Your child will be referred to the pediatric ear, nose and throat (ENT) doctors. You will meet the doctors 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?

Decide who will be trained. At least **two** caregivers need to learn all of your child's care. Each person who cares for your child **alone** must complete the entire training process. Other family members that help you at home may also get trained. Schedule classroom training sessions with the Tracheostomy Coordinator.

Decide how many nursing hours you need in your home to help with the care of your child. It is best to set this up **before** surgery is scheduled to prevent delays in discharge. The case manager can help you set up in-home nursing. The case manager can be reached at **608-890-8045**.

Insurance may cover in-home nurses when caregivers are sleeping, working, and for a few hours each week for errands. It is also based on your child's health care needs. Please check with your insurance provider. Your in-home care options are based on where you live, and insurance coverage.

If you already have independent nurses, they need to be pediatric tracheostomy and vent certified to care for your child. This is done at the state level and can take many weeks.

We suggest that personal care workers or certified nursing assistants (CNAs) are not left alone with your child.

Meet with your home equipment provider to get any new equipment and learn how to use it.

The Day Before Surgery

This is a very busy day. Plan to go to the hospital the night before surgery. Your child will get an IV for nutrition and fluids. You will meet with many team members. They will include a child life specialist, the ENT surgeon and a team member from anesthesia.

You should bring all current and new supplies for your child. This includes:

- Vent
- Suction machine
- Cough assist machine
- Feeding pump
- Stroller or wheelchair
- 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 will be taken to the 3rd floor of AFCH. Staff will let you know where to wait during the surgery. They will also tell you when you can go be with your child. Your child will then be moved to the intensive care unit. Your child will be on a vent and will have a cuffed trach tube in place with black strings (sutures) taped to their chest.

After Surgery: Days 1-3

Your child will stay in the intensive care unit and will be watched closely. Staff will restart your child's feedings and medicines as tolerated. Staff will also restart the home vent and adjust the settings 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 will do the first trach tube change at your

child's bedside. They will also 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 includes 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 is moved from the intensive care unit to the Universal Care Unit. Here, your child will be cared for by the pulmonary team. The size and type of trach tube, vent settings and vent circuit are decided by the pulmonary team.

Your child will be given a travel humidification plan. For this, you will use 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 Tracheostomy Coordinator. There are about 8 hours of classroom training. You will learn from the manual: *Caring for Your Child's Tracheostomy*. You will practice your skills on a doll with a tracheostomy.

Topics include:

1. Caring for your child's trach tube, stoma and tie changes
2. Humidification with the trach tube
3. Suctioning your child's trach tube
4. Changing the trach tube
5. Vent terms and settings

6. Emergency care and CPR for a child with a trach
7. Using the manual resuscitation bag
8. Putting together all of the supplies needed for the "Go bag"

After classroom training each caregiver:

- Practices the skills on their child with coaching from the nurses. You can practice skills anytime you are here with your child.
- Completes three trach tube changes before going home.
- Completes CPR training for a child with a trach. Your nurse will help you schedule this class.
- Learn about any changes in your child's care and practice them before discharge.
- Learn how to use any new equipment by your equipment provider. This person will provide any new supplies needed.

Independent Care Sessions

Each caregiver will need to complete 24 hours of independent care after the training. These need to be scheduled in advance. You will use your home equipment for the independent care sessions.

Each caregiver is given time to be totally responsible for the care of your child, your child's home equipment, and to troubleshoot any issues that come up. They will be able to use AFCH staff as back up.

Each caregiver will need to show that they can care for your child on their own. It is not a test. It is a way to use what you have learned and practice doing all of your child's daily cares within the safety of AFCH.

If there are cares that need more class time or practice, you have time for that after the session.

This is not a marathon. If you prefer, you can break down the session into two twelve-hour, or three eight-hour blocks. The goal is to see what your child's care needs are during 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
- Perform CPR and any emergency procedures

Road Trip

Once you complete your independent care session, you will take your child out of the hospital on a 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 child's 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 find the available resources.

We work with you to set up home care nursing services. Your child's case manager talks with your home care nursing provider about the plan of care. It is then sent to the state Medicaid office. It may take several weeks to get approved.

Local services are found 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 area who has a tracheostomy. This gives emergency staff a chance to learn more about your child in the case of an emergency. Your utility company should be aware of your child's needs in the case of a power outage.

The discharge date is set and approved by all involved. This includes the family, pulmonary team, home equipment provider, home nursing, and community service providers.

Follow Up

Follow up is at the AFCH, neuromuscular and Trach Clinic. The Trach Clinic is held monthly on a Thursday afternoon. It is staffed by one of the pediatric pulmonary and ENT doctors. You will also meet with the advanced practice nurse, nutritionist, social worker, speech therapist, and respiratory therapist.

The clinic visit lasts at least two hours. Our goal is for you to come to the Trach Clinic at least once a year.

Who to Call

If you have questions you can reach any member of the pulmonary team by calling:

608-263-6420.

If you are a patient receiving care at UnityPoint – Meriter, Swedish American or a health system outside of UW Health, please use the phone numbers provided in your discharge instructions for any questions or concerns.

Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person's health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright © 5/2021 University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing. HF#7694