

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.



Why does my child need a trach?

Your child may need a trach for many different reasons.

The most common reasons are:

- Children who have significant difficulty using nose and mouth for breathing get trach placed to help provide direct access to breathing air in lungs.
- To allow use of a breathing machine (mechanical ventilator) to help your child breathe (For more information go to ATS Patient Information series at www.thoracic.org/patients). Children who have severe lung problems, or other health problems that affect breathing, and need to use a ventilator to help them breathe. The ventilator can be attached to the trach tube. This may be more comfortable than wearing a nasal or face mask for long periods of time.
- 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.

Though it is not usually the main reason to place a trach, having the trach makes it easier to remove mucus from the wind pipe. It 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 need to care for your child's trach at home. You will work with a durable medical equipment (DME) supply company to get these and learn how often to re-order.

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 but often is 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. You can discuss with your healthcare team if and when your child can safely eat by mouth after the trach placement. Your child would need guidance of a swallowing specialist to help in that transition. Your team can help guide and discuss with you more details regarding different way of feeding.

You should never see food or drink coming from the trach. If this occurs, stop the feeding, and let your child's 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 he or 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 (Passey-Muir® valve). If your child's lungs are weak, he or she may not be able to use a speaking valve. Your healthcare team will guide and work with your child for his/her readiness for using speaking valve.

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, your child may have lung

problems or blockage in the windpipe. You should try to suction and change the trach as you are trained to do.

- The trach tube accidentally comes out and will not go back in even when you have tried smaller size tube available as a backup.
- 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 9-1-1) 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 should try to suction and consider changing the trach tube as you are trained to do.
- 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 secretions from 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, you can ask about a plan to remove your child's trach. Your child's provider may consider use of speaking valve first. This is a one way valve that allows child to breath in through the trach and breath out from the mouth and nose. Once child tolerates a speaking valve, your provider may choose to give trials of increasing time having you "cap" the trach. This cap will completely close the trach. This is done to see if they breathe without trach through nose and mouth. Usually these are first done when the child is awake and with observation by a caregiver. Further, your healthcare team may advise doing a sleep study or other tests before they consider safe removal of trach. Often before a trach is removed, a procedure called bronchoscopy is done. This is a procedure done to evaluate child's airway in detail. Discuss the plan for removal of trach with your healthcare team.

Once the trach tube is out, your child will breathe through his or 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.
- Keep the mouth healthy with regular brushing and good oral care to avoid bad bacteria in the teeth and gums.
- 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 get in through the trach and irritate the lungs.
- Keep small toys or objects that your child could put into the trach away from your child.
- Ask your healthcare provider what sports your child can play. Contact sports and water activities are usually not allowed.
- 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.

Authors: Janet Johnston MSN, CRNP, Scott Davis MD, Marianna Sockrider MD, DrPH

Reviewer: Ann C Halbower MD, Manvi Bansal MD

Rx Action Steps

- ✓ 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.
- ✓ Get set up with a DME supply company that has all the supplies you need.
- ✓ 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.
- ✓ If you are having trouble getting resources like trach supplies or nursing help, talk to your insurance case manager and/or a medical social worker.

Healthcare Provider's Contact Number:

Resources:

American Thoracic Society
www.thoracic.org/patients

- Flexible bronchoscopy
- Home ventilation in a child
- Mechanical ventilation

Aaron's Tracheostomy Page
www.tracheostomy.com

Royal Children's Hospital Melbourne Australia
http://www.rch.org.au/kidsinfo/fact_sheets/Tracheostomy_information_for_parents/

Great Ormond Street Hospital for Children NHS UK
<http://www.gosh.nhs.uk/medical-information-o/procedures-and-treatments/living-tracheostomy>

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