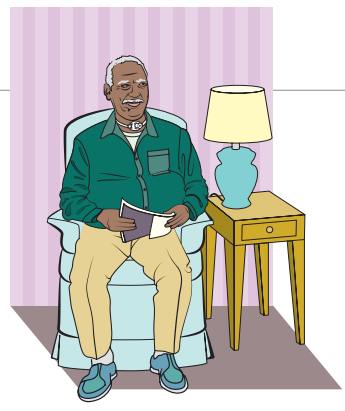


# Living with a Tracheostomy

Part 2 of 2

If you or a loved one has recently had a tracheostomy while in the hospital, you may have a lot of questions about the future. Many people live for a long time with a tracheostomy (often simply called a “trach”). Everyone’s experience as to why they needed a trach and what will be needed in the future will differ (see ATS Patient Information Series on Tracheostomy, Part 1 to review reasons for trach placement). However, having one most often requires some adjustments to your lifestyle and careful planning to ensure adequate care.



## Can I go home with a tracheostomy?

Some patients with a tracheostomy are able to go home. One major factor in moving back home is whether you still need a breathing machine (ventilator) to help you breathe. Other factors include whether you or your caregiver(s) are able to take care of your needs and how healthy you are.

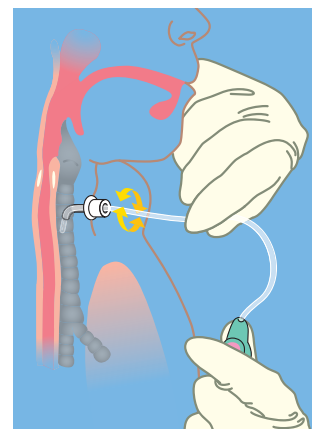
- If you required a trach for an injury or blockage of your windpipe and your health is otherwise good enough, you may be able to go home directly from the hospital.
- If your trach was placed because you could not breathe well enough on your own without a ventilator, you may need to go to a long-term acute care facility for some period of time. Staff at a long-term acute care facility can work on weaning you off the breathing machine as you are able to breathe on your own. If you cannot wean, a plan will be made with you for your care needs. If you are able to wean, you may be able to go home even if you still have a tracheostomy tube.
- In some cases, people who still require a breathing machine can go home with careful planning and education.

## How do I care for my tracheostomy at home?

You and your caregivers will need to be trained and have your skills checked so you can safely take care of your trach at home. Some of the activities discussed are:

- **Cleaning:** A major part of tracheostomy care is cleaning every day. In the hospital, the staff will clean your tracheostomy site and tube. At home, you will be responsible for most of the day-to-day cleaning. A visiting nurse may be available to answer questions. How you need to clean your trach tube and the stoma (the hole in your neck) depends on the type of tube you have and if you are still connected to a breathing machine. In general, the trach tubes with an inner cannula must be cleaned regularly to prevent the buildup of dried mucus. The skin around your stoma and your neck must also be cleaned 2-3 times a day to remove dried mucus and to avoid excess moisture on your neck that can cause a rash.

- **Suctioning:** You and your caregivers will be taught to suction to remove mucus plugs that you cannot cough up. Suctioning may bring on a coughing spell and give you a temporary feeling of shortness of breath. Over time, you will become more familiar with this feeling and be able to manage it. If the color of your mucus changes, you should inform your healthcare provider.
- **Showering:** You will need to be very careful when you shower with a trach. You will need to cover the opening in your neck and the trach tube with a waterproof covering to prevent water from getting into your lungs. You will need to get these supplies before you go home.
- **Tube Changes:** Depending on the type of trach tube and the advice of your medical team, your tube will need to be exchanged for a new one every 1-3 months. A healthcare provider (such as the ear nose and throat doctor, lung doctor, or respiratory therapist) usually does the first exchange in the hospital. Depending on the support you have, later changes can be done at home. In many cases, caregivers can be trained to safely change tracheostomy tubes. They should always be trained to do an emergency replacement if the tube gets plugged or comes out.
- **Equipment:** Going home with a trach will require you to have several pieces of equipment. You may need oxygen and/or a ventilator. You may have a special mask that can push air into your lungs (called a bag-valve mask or ambu-bag). Most people need a portable suction machine to help suck out mucus. This also requires disposable suction catheters (such as the “whistle tip” catheter), and saline solution. You and your caregivers will be trained on how to use all your special equipment before you go home.



### What happens to the tracheostomy once I can breathe on my own?

- If your airway is good and you no longer need a ventilator to breathe, your trach tube may be removed. This process (called 'decannulation') involves switching the tracheostomy tube to smaller and smaller tubes over time to allow the opening in your neck to slowly close.
- Before the tube is removed, your medical team will have you cover the trach tube with a 'red cap' to ensure that you are able to breathe on your own without any problems.
- Once your medical team is confident that you can breathe without the tube, it will be taken out. The opening in your neck will usually close on its own, leaving a small scar.

### Can I talk with a tracheostomy?

- If the voice box (vocal cords) is not injured, many people can learn to talk with a tracheostomy. To do this, most people must be able to spend some time breathing without the support of a ventilator.
- If your trach has a balloon (cuff), the air must be let out of the balloon before trying to talk. A 'speaking valve' is then attached to the trach tube. This allows you to breathe in through the tube but also forces you to breathe up and out through your vocal cords so that you are able to speak.
- Speech therapists often help people learn how to talk with a trach. Not everyone can talk with a trach and you should discuss this with your medical team.

### Can I eat with a tracheostomy?

- Some people with a tracheostomy who are fully awake and alert are able to eat. There can be a fine balance between getting enough nutrition and having good strength to swallow, and reducing the risk of food or fluid unintentionally going down into your lungs (known as "aspiration"). The specific food you are able to eat depends on the strength and coordination of your swallowing muscles. Some people may enjoy tastes but still get most of their needed nutrition from a feeding tube.
- Right after having a tracheostomy surgery, you likely will have a feeding tube in your nose or through the belly directly into the stomach (a gastrostomy tube) for nutrition until you are able to eat by mouth.
- You will need careful re-training of chewing, swallowing, and coordination of breathing to eat with a trach in place. This can take weeks to months to learn. Speech therapists and nutritionists can often help this process.

### What are long-term risks associated with a tracheostomy?

- With a trach, you will be at higher risk for lung infections like pneumonia. Careful cleaning of the trach and stoma can help reduce the risk of infection.
- There is always a risk of bleeding with a trach. There is a very small risk of bleeding during tracheostomy surgery itself. A person can also bleed if the trach tube breaks through the wall of the windpipe and into a blood vessel in the neck. This is extremely rare but dangerous.
- Many people who have a trach have some trouble coughing out mucus from their lungs. This may be due to reduced

muscle strength and/or airway or lung problems. The trach tube may also get blocked by a large piece of mucus (called a mucus plug), so it is important to know how to suction it out.

- There is a chance the trach tube could fall out of the opening in the neck by accident. In the first few days after surgery, only a trained healthcare provider should put the tube back in. The longer the tube has been in place, the easier it is to simply put one back in (and the one that comes out should be cleaned). However, for people who have trouble breathing, this can be difficult and your medical team will teach you and your caregivers what to do in such a situation. You should always have a back-up trach tube with you. Sometimes a size smaller is used in case of emergency.

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## Rx Action Steps

Action steps before going home with a tracheostomy:

- ✓ Talk with your medical team about why you need a tracheostomy and your personal goals.
- ✓ Discuss how likely it is that you may need to stay attached to the breathing machine (ventilator) if you still need one.
- ✓ Discuss all the equipment that you will need at home and make sure you and your caregivers are trained on how to use them.
- ✓ Make sure you have a team of caregivers that can help you transition home and continue to provide you emotional and physical support.
- ✓ Always have emergency contact information for your health-care providers as well as a back-up tracheostomy tube.
- ✓ Make sure you know how to keep your tracheostomy site and tube clean and dry.

Healthcare Provider's Contact Number:

## Recommended Reading:

### ATS Patient Education Series

[www.thoracic.org/patients](http://www.thoracic.org/patients)

- Mechanical Ventilation
- Palliative Care
- Tracheostomy in Child

### MedLine Plus—Tracheostomy Care

<https://www.nlm.nih.gov/medlineplus/ency/patientinstructions/000076.htm>

### Breath of Life

<http://www.bolhme.com/education/tracheostomy&suctioning.pdf>

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