



# TRACHEOSTOMY

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Airway obstruction is commonly seen in individuals with MPS and related diseases. The neck is typically short and the airway can be unusually narrow. In addition, the tonsils and adenoids can become enlarged and block the airway, which can also contribute to breathing difficulties. A combination of these things can prevent the individual from breathing in adequate amounts of oxygen and can lead to difficulty breathing while awake or asleep. Obstructive sleep apnea is a common airway problem in individuals with MPS. Obstructive sleep apnea is defined as temporary breathing interruption during sleep because the airway in the neck becomes blocked as muscles in the airway relax. This airflow can be improved by opening an airway using the tracheostomy procedure.

A tracheostomy (also called an artificial airway or “trach”) is a surgically created opening through the neck into the trachea, or the windpipe. A tube is usually placed through the opening into the trachea. This tube is referred to as a tracheostomy tube or a trach tube. The function of the tube is to provide an airway and to remove secretions from the lungs.

A tracheostomy is performed while the patient is under general anesthesia. After the area is cleaned, incisions are made to expose the outer wall of the trachea, which is made up of tough cartilaginous rings. A surgeon inserts the tracheostomy tube into the trachea after creating an opening through the cartilage rings. A tracheostomy tube has three parts: the outer cannula, the inner cannula, and the obturator used for inserting the tube. The outer cannula stays in the windpipe all of the time, except for cleaning. The inner cannula is a safety valve to keep the airway open. This can be removed for cleaning. How well a patient does following a tracheostomy procedure depends greatly on the well-being of the patient prior to the surgery and on the specific reason the tracheostomy was performed. Patients can expect to spend approximately 3-5 days in the hospital and usually an additional two weeks recovering.

A tracheostomy is generally a routine procedure; however, as with any other surgical procedure, there are associated risks. With the anesthesia, there is a risk of adverse reactions to medications and problems with breathing. With the surgery, there is a risk for bleeding, pneumothorax (presence of air or gas in the space between the ribs and the lungs), low blood pressure, infection, vocal cord paralysis, tracheal erosion, and the buildup of scar tissue in and around the trachea.

Having a tracheostomy may also lead to significant differences in one’s lifestyle during the adjustment to having a trach placed. It is important to discuss trach care in detail with one’s doctors. The surgical incision needs to be cleaned frequently as it heals, perhaps as many as four to five times per day. Once the skin heals, most people use soap and water to keep the skin clean and dry. Some people use a small amount of water-soluble antibiotic ointment around the skin incision. People with tracheostomies also learn to suction their trach by using a suction machine and catheter as needed.

Periodically, the tracheostomy tube will need to be changed. Changing an old tube for a new, fresh tube can be challenging, but becomes easier with time. Shortly after surgery, if the entry site has not healed properly, it may spontaneously cave in when the tube is removed and block the trachea. When the new tube is being inserted, there is also a risk for the tube to accidentally enter incorrectly. As the wound heals, the chance that either situation will occur will decrease. Many people are eventually able to change their trach tubes in their home.

One of the biggest challenges that people face following the insertion of the new airway is adjusting to new breathing patterns and the changes associated with the vocal cords. Communication is perhaps the biggest adjustment because it may be impossible for people to talk or make sounds. With proper training, some patients can learn to speak with a tracheostomy tube.

Water related activities can be hazardous to the person with a trach because there is not an easy way to hold one's breath underwater and water could enter one's lungs. Tub baths may be a reasonable solution to bath time, but some people prefer to shower. Showering can be taken with special care to shield the tracheostomy tube opening from the water. A person with a trach also may benefit from using a cotton cover or scarf as a protection from foreign particles. With proper planning, discussion with physicians, and after surgery care, a tracheostomy may significantly help individuals with MPS and related diseases who have an upper airway obstruction.