



Stanford University Cancer Center Department of Otolaryngology – Head and Neck Surgery

A Patient's Guide to Total Laryngectomy



Introduction

Your Stanford Cancer Center Team has created this informational packet for you and your caregivers. We hope that you will find this information helpful as you get ready for surgery and recovery.

Information has been divided into the following sections:

- Section 1: What is a “total laryngectomy”?
- Section 2: Getting ready for surgery
- Section 3: Recovering after surgery
- Section 4: Changes after surgery
- Section 5: Learning to care for your airway
- Section 6: Getting ready to go home
- Section 7: Helpful resources

Section 1:

What is a laryngectomy?

A total laryngectomy is a surgery to remove the voice box (larynx). It is most commonly done to treat cancer. A person who has had this surgery is sometimes referred to as a laryngectomee.

After surgery, breathing is done through a permanent opening in the neck called a stoma. A removable breathing tube (laryngectomy tube) may be placed temporarily or permanently in the stoma to help keep it open for easy breathing. The stoma is necessary to separate the breathing and swallowing passages in order to minimize the potential for food or liquid going into the lungs (aspiration).

One of the biggest challenges after laryngectomy is learning a new way to talk since the voice box has been removed. Your team will discuss the options described in this packet with you to help you decide which option is best for you.

Please feel free to discuss any questions or concerns you may have with someone from your healthcare team.

Section 2:

Important numbers and information

My surgeon: _____

My nurse coordinator: _____

Nursing station: _____

ENT resident on call: _____

Stanford emergency department: _____

My speech pathologist: _____

My family doctor: _____

Home care company: _____

Equipment:

Laryngectomy tube and size: _____

Humidifier and oxygen: _____

Speaking method: _____

Prosthesis type and size: _____

Home/environment safety checklist

Please be sure that you have the following at home where you will be staying after surgery:

- Electric service and outlets for equipment
- Working phone service
- No throw rugs
- Working refrigerator
- Adequate heat/ventilation
- Running water available
- Working smoke detector
- Main bathroom/bedroom on same floor
- Easy access to home entrance
- Notify your local fire station that someone at your home will be a “neck breather” for their records

Other: _____

Before admission

“To do” list

- Review this packet and make a list of questions for your doctor, nurse, and speech pathologist
- Review the home safety checklist and make necessary changes/repairs to your home
- Decide where in your home you will keep needed equipment like a suction machine or a feeding pump
- Gather pen and paper, white board, or “Boogie Board”) to help with communication in the hospital. There are also “text to speech” apps that you can download to a smartphone.
- Decide who will help care for you after you leave the hospital and try to have them at your pre-operative appointments
- Purchase a humidifier to use in your bedroom and/or main living area after surgery
- Look into local support groups (see page 25)
- Purchase a medic alert bracelet (<http://medicalert.org>)
- Please keep all appointments with your care team

Before you arrive at the hospital

We are pleased that you have chosen Stanford Healthcare for your treatment. We are fully committed to your recovery and a quick return home.

Tests: Before surgery you will need some routine tests such as xrays, blood tests, EKG, and an updated physical exam. Your team will ensure all needed tests are performed before surgery.

Pre-operative examination and consent for surgery: In most cases, your pre-operative examination and consent for surgery will occur 1-2 weeks before surgery. This will be your opportunity to ask questions about surgery and recovery with the team. You will then be asked to sign a permission slip (consent form) for surgery.

Smoking: If you are a smoker, we strongly encourage you to stop smoking before surgery. Smoking increasing the rate of wound complications after surgery. Also, Stanford Hospital enforces a “No Smoking” policy.

Diet: You must not eat or drink anything after midnight the day before your surgery. This reduces the risk of vomiting and getting stomach contents in your lungs during surgery.

When you arrive at the hospital

All of your personal items must be removed before going to the operating room. This includes jewelry (leave at home), clothing other than your hospital gown, dentures, glasses, contact lenses, hearing aids, and hairpins. Leave valuables at home or give them to family. Your personal items will be secured by staff in the pre-operative area.

You will meet with members of the surgical and anesthesia teams before surgery to review any last minute information.

You may be given medications by mouth, needle, or IV in preparation for surgery. The side rails of your bed will be raised to remind you to stay in bed after receiving these medications.

Recovering after surgery

After surgery you will either go to the Post-anesthesia Care Unit (PACU) or the Intensive Care Unit (ICU)

PACU: The PACU or recovery room is an area where you may be taken immediately after surgery to recover from anesthesia. In the PACU you are closely watched until you are ready to go to your room. You can expect to stay in the PACU for a minimum of one hour. Your vital signs (pulse, temperature, and blood pressure) will be checked often. Pain medication will be given as needed. Every effort will be made to control any discomfort you are having. You will be given oxygen to breathe. Your stoma will be suctioned regularly. You might have nausea or vomiting as side effects of surgery and anesthesia. Medication will be given if this occurs to relieve your symptoms. After you have recovered you will be taken to your hospital room.

ICU: If you go to the ICU your vital signs (pulse, temperature, blood pressure) will be checked often. A nurse will always be close by to help you.

Relief of pain and discomfort: The area of your surgery may hurt or burn. You might feel generally sore and stiff. As your body heals you will feel more comfortable. You will need to communicate with your care team about your pain. Be sure to let the nurse know when you start having pain before it becomes severe. Pain medication may not completely end the pain but will help you feel more comfortable in order to take part in your care.

Respiratory care: After anesthesia it is important to prevent buildup of fluid and mucus in your lungs. After laryngectomy you may experience a weak cough and difficulty managing mucus. Your mucus may be thick and bloody at first, but this is normal. Suctioning will be an important part of your care after surgery. You will be suctioned every hour for the first 1-2 days and as needed. You will need to continue suctioning when you return home and your care team will teach you all you need to know before you leave the hospital. As you get stronger you will require less frequent suctioning.

Blood clots: A blood clot can occur after surgery due to decreased physical activity. This decreased activity causes the blood in your veins to move slowly and possibly to clot. Special stockings and compression devices will be placed before surgery to improve circulation. You will wear these until your team notifies you to stop. You will also be asked to do simple leg exercises. You may require a blood thinning medication.

What can I expect as a laryngectomee?

Activity: Eventually you should be able to perform most usual activities that you enjoyed before surgery. One activity that will not be possible is swimming. This is because water entering the stoma will lead directly to the lungs and may lead to drowning.

Feeding tube: You will be fed through a feeding tube immediately after surgery to allow your surgical area to heal fully. The amount of time you will need a feeding tube varies from 10 days to longer if there are issues with healing. The feeding tube may go in through your nose (NGT) or your stomach (PEG). Proper nutrition is very important for healing after surgery. Your weight will be closely monitored. Once you are allowed to start eating, your speech pathologist and nutritionist will help you to determine what kinds of foods to start with.

Breathing: You will breathe through the stoma in your neck, not your nose and mouth. The stoma is permanent.

Coughing: When you cough, you will cough through your stoma, not your mouth. Be sure to cover your stoma when you cough.

Nose blowing: It is very difficult to blow your nose after a laryngectomy since you don't have air coming from your lungs to your nose. Ask your speech pathologist for tips on nose blowing.

Taste and smell: You may notice reduction in your sense of taste and smell after surgery. This is due to the reduction of airflow through your nose and mouth. Your speech pathologist can teach you tricks to help improve your sense of taste/smell.

Eating: Once you are finished with the feeding tube you will start with softer foods that will go down easily. Though swallowing may require more effort than before surgery or you may need to wash solid foods down with liquids, most people are able to get back to their normal diet.

Speaking: After surgery, you will not be able to communicate like you did before surgery due to removal of the voice box. Your speech pathologist will help you to regain communication.

Bearing down: It might be more difficult to hold your breath and bear down (like for lifting something heavy or having a bowel movement). You may require a stool softener to help with bowel movements.

How will I deal with changes after surgery?

It is very common for patients to be concerned regarding changes in their appearance and voice after laryngectomy. You may worry about how friends and family may react, and whether you will return to your normal life. It is not uncommon to feel anxious or depressed. These are normal reactions and there are many options to help you with your recovery.

Discuss your concerns with your nurses and doctors. Your care team is experienced in helping people through difficult recoveries and is your best source of accurate information. Don't feel embarrassed by any questions or concerns you may have.

Share your concerns with family and friends. Your family will also be struggling with issues about returning to your normal life. Keep your communication open as you embark on this journey together.

Consider attending support group meetings or participating in online support groups. Other patients have walked the path you are walking and may have helpful tips on how to cope and recover. Many patients like to "give back" to new patients and will be happy to meet with you and your family. Your speech pathologist can help to connect you with someone who has been through the same surgery.

How will the speech pathologist help me?

The speech pathologist will help you with your swallowing and communication. Learning to speak again is a process that may take several months of practice. The speech pathologist will serve as your coach and teacher. Although your voice box is gone, you can communicate using different options, including:

Non-verbal communication: In the early days after surgery you will use non-verbal communication like writing, gesturing, and using text to speech apps. These methods are slower than speaking and can be frustrating. Try to be patient during this early stage of recovery.

Electrolarynx: The electrolarynx, or artificial larynx, is a battery-powered device that is held to your neck or used with a straw that goes in your mouth. It vibrates to create sound which you can shape into speech. This can be started using the oral straw early after surgery. It is important to remember that not only are you learning to use this device, but your family is also learning to listen to it. Again, patience is important as you learn to use this device. California will provide this device free of charge and your speech pathologist will help you to order this.

Tracheoesophageal voice prosthesis (TEP): A voice prosthesis is a device that allows you to speak using the muscles and tissues

in your swallowing passage. At the time of your surgery, your surgeon may create a small opening (puncture) in the wall between your windpipe (trachea) and your swallowing tube (esophagus). A one-way valve (prosthesis) is then placed in this opening. Once you have healed enough, your speech pathologist will teach you how to cover the stoma to send the air through the prosthesis and into your esophagus. This will allow you to speak.

Swallowing: Swallowing after laryngectomy can be effortful or slow to progress. Sometimes there are structural changes after surgery that require further intervention. Your speech pathologist can evaluate your swallowing concerns and may complete an x-ray swallow test called a Modified Barium Swallow (MBS) to determine what treatments will be of greatest benefit.

How will I care for my airway?

You will need equipment and supplies to care for your airway. Your case manager and nurses will work together to determine what supplies you need and will help you learn how to order these items from your home care company.

Supplies needed:

- Suction machine with connective tubing, electrical power, and battery back up
- Suction catheters
- Tweezers
- Room humidifier
- Hydrogen peroxide
- Gauze pads and Q-tips
- Syringe or plastic eye dropper with small bottle for saline
- Clean quart container for saline
- Sterile saline

Making saline at home:

If you make your own saline instead of purchasing it, it is very important that you work with very clean pans and containers. Wash your hands well before making or using saline.

1. Start with clean hands, pans, and containers.
2. Put saline storage jar and lid in one pan and cover with tap water
3. Put 4 ¼ cups tap water in a second pan.
4. Boil both pans for 10 minutes.
5. Add 2 teaspoons of table salt to one quart plain boiled tap water and stir to dissolve. Cool to room temperature.
6. Poor cooled water into the clean, boiled storage jar. Place the lid on tightly and store in the refrigerator.
7. Pour the small amount you need for each cleaning or suctioning session into a smaller container (Don't dip anything into the larger supply jar of saline).
8. Make a new batch every day.

How do I handle mucus in my airway?

Mucus is made in the airway. It is normal and expected. Before your surgery, you cleared mucus through your nose and mouth. After surgery you will clear mucus through your stoma. Most patients do not need to use a suction machine long term.

Any time you hear or feel mucus rattling in the airway you must do something to clear it to keep your airway open. To clear the mucus, follow these steps until you are able to breathe easily.

1. Bend forward and cough. Catch the mucus from your stoma, not your mouth.
2. If this does not work, squirt a small amount of saline into the stoma and cough again.
3. If this does not work, suction.
4. If you are still unable to clear your airway despite these measures, call for help. Continue trying to cough and suction while you wait for help to arrive.

The key is to prevent mucus from building up by keeping your airway warm and moist using these strategies.

- Wear a heat and moisture exchange filter (HME)
- Squirt saline into your stoma several times each day
- Use a humidifier close to the head of your bed and wherever you spend large amounts of time
- Consider a home humidifier

How do I suction my stoma and airway?

Supplies:

- Suction machine
- Suction catheter
- Saline
- Gloves

Follow these steps:

1. Wash your hands well.
2. Open the suction catheter and attach it to the suction machine.
3. Turn on the suction machine.
4. Put on your gloves.
5. Take a deep breath in.
6. Insert the suction catheter into the stoma about 3-4 inches or until you start to cough.
7. Breathe out and try to cough.
8. Suction the mucus out of the airway by covering and uncovering the suction port with your thumb, rotating the catheter in a circle-like motion, and slowly pulling the catheter out.
9. Catch your breath.
10. Repeat suction as needed.

11. Clear the suction catheter of mucus by pulling saline through it until it is clear.
12. Remove your gloves and wash your hands.

How do I clean my stoma?

The stoma needs to be cleaned often to prevent infection and to keep the airway open. Do this at least twice each day or more if you have a lot of mucus, redness of the skin, or foul odor from this area.

Supplies:

- Hydrogen peroxide and sterile saline (50/50 mix)
- Gauze pads
- Q-tips
- Tweezers

Follow these steps:

1. Wash your hands
2. From the time of surgery until the stoma is healed, you will clean the stoma using sterile gauze and 50/50 mixture of hydrogen peroxide and sterile saline.
3. Start at the stoma and wipe away from it. Use Q-tips or gauze for one wipe only.

4. Make sure the peroxide solution is wiped/rinsed off with saline.
5. Use tweezers if needed to pick any dry or crusty mucus from the stoma. Use peroxide-saline solution first to loosen up.
6. Gently pat your skin dry with a dry cloth

How do I take a shower?

Order a commercially available shower guard if you did not receive one during your hospital stay. You will be able to wash your hair and all parts of your body as long as you have your shower guard on. This will keep water from going into your lungs. You will not want to submerge your neck in a bath as this will lead to water filling your lungs and possible drowning.

When should I call my doctor?

Please call the Otolaryngology – Head and Neck Surgery doctor on call if any of the following occur:

- Trouble breathing
- Foul smelling, thick airway mucus
- Fever of 101 or greater for more than 24 hours
- Increased bleeding, redness, swelling, or soreness around the stoma
- Narrowing of the stoma
- Severe coughing
- Suture line opens

What if there is an emergency at home?

Until you learn to speak, you might want to keep a recorded message near your phone that says, “ Please send an ambulance immediately to (your address). I am a neck breather who cannot speak. This is a recorded message.” By doing this you will have a way to ask for help when calling 911. You will also want to alert your local fire station that there is a neck breather at your address in case of emergency.

How can I be safe with my new airway at home?

- No smoking!
- No swimming or otherwise submerging in water up to your neck.
- Cover your stoma in the shower
- Cover your stoma during shaving and haircuts as well as when around dust, sawdust, soot, smoke, insects, or other small particles that can be inhaled.
- Wear your heat and moisture exchange filter as much as possible.
- Make sure your smoke alarm is working as you may not be able to smell smoke well.

Companies that sell laryngectomy products

Atos Medical
(800) 217-0025
www.atosmedical.us

Boston Medical
(800) 433-2674
www.trachs.com

Bruce Medical Supply
(800) 225-8446
www.brucemedical.com

Dean Rosecrans
(800) 522-4425
www.deanrosecrans.com

Griffin Laboratories
(800) 330-5969
www.griffinlab.com

In Health Technologies
(800) 477-5969
www.inhealth.com

Lauder Enterprises
(800) 388-8642
www.electrolarynx.com

Luminaud, Inc
(800) 255-3408
www.luminaud.com

Other resources

Webwhispers is an online support forum. www.webwhispers.org

The American Cancer Society (ACS) is a very good source for information and resources. Some financial and housing support is provided through the ACS.

www.cancer.org

Supporting Patients with Oral, Head, and Neck Cancer (SPOHNC) is a patient-directed organization with online and print resources as well as live support groups. The Stanford chapter of SPOHNC meets the first Tuesday of each month from 4-530 pm in the Stanford Cancer Center. Other regional chapters can be located on the website.

www.spohnc.org

The Head and Neck Cancer Alliance provides resources and information online as well as sponsors head and neck cancer screening events.

www.headandneck.org

National Cancer Institute (NCI) Provides information on treatments, dealing with side effects, and clinical trials. www.cancer.gov

International Association of Laryngectomees: Provides information on annual events for patients after laryngectomy. www.theial.com

Foundation for Voice Restoration: Information and local support for laryngectomy patients. www.getvoicing.org

Stanford Smoking Cessation Program: <https://stanfordhealthcare.org/for-patients-visitors/smoking-cessation.html>