First Steps

A Guide for New Laryngectomees

International Association
of
Laryngectomees

Preface

This booklet is a revised and lengthened reworking of an International Association of Laryngectomees (IAL) publication, “First Steps.” “First Steps” was itself a revision of a still older IAL publication that addressed the same readers and many of the same general topics.

This publication is intended to provide basic information on living as a laryngectomee. It is designed for individuals who are facing laryngectomy surgery, those who have become laryngectomees, and their spouses/companions/caregivers/families.

The information provided in this document is not intended as a substitute for professional medical help or advice, but only as an aid in understanding problems experienced by laryngectomees and the state of current medical knowledge. A physician or other qualified health care provider should always be consulted for any health problem or medical condition.

Acknowledgements

Dozens of people, institutions, and organizations have contributed to the creation of this publication, and over many, many years. Institutions and organizations have made contributions: IAL Board of Directors and Committees, Speech-Language Pathologists (SLPs); Ear, Nose and Throat specialist medical doctors (ENTs); college professors and other knowledgeable individuals.

With the sole exception of third party graphics which are labeled, the entire document is the work of the International Association of Laryngectomees in fulfillment of the organization's mission as spelled out in the *IAL Bylaws*:

Article II - Purpose

The purpose of this organization shall be as follows:

1. To stimulate, support and improve the relations among persons who, due to the removal of the larynx because of cancer or other reasons, have lost their natural voices.

2. To encourage and maintain an exchange of ideas and methods for the learning and teaching of alaryngeal methods of communication.

3. To improve the understanding of employers about cancer in general and cancer of the larynx in particular, so that laryngectomized persons may retain or obtain employment after surgery.

4. To publish and disseminate helpful information for the better rehabilitation of those who have undergone a laryngectomy.

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Introduction

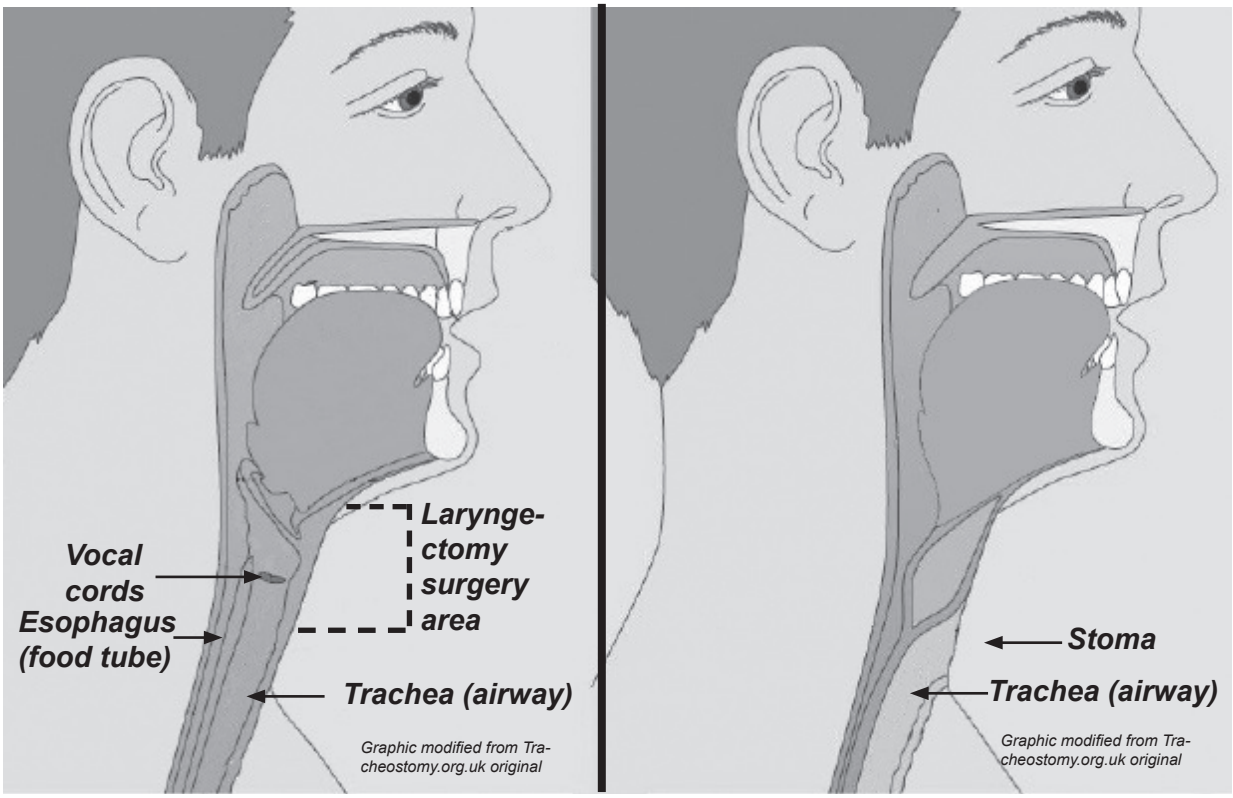
This booklet is written for individuals who are facing or have already had total laryngectomy surgery and their families/spouses/caregivers/companions.

In the total laryngectomy operation the voice box (*larynx*) is removed, and the breathing tube (*trachea*) is redirected to the outside of the neck. This new breathing opening in the neck is called a **stoma**. **After the surgery the laryngectomee breathes totally through the stoma** (*see illustration below*).

Individuals who have had this operation may be referred to as laryngectomees, individuals who have been laryngectomized, and may refer to themselves as "larys."

Although laryngectomy surgery is major surgery and it may take a long time to heal completely, **almost all laryngectomees can expect to fully recover and return to almost every activity they enjoyed before the surgery**.

Before Laryngectomy Surgery ***After Laryngectomy Surgery***



Cancer of the Larynx - Some Facts

Cancer of the larynx is one of the most curable types of cancer, especially if detected at an early stage. Almost all laryngectomees who have no other serious medical problems can expect to live long, healthy and productive lives.

There are approximately 50,000-60,000 laryngectomees in the United States. About 10,000 new cases of larynx cancer are reported each year. These numbers are decreasing because fewer people are smoking. Smoking and alcohol consumption are linked to the development of larynx cancer, along with exposure to chemicals and viruses (such as the *Human Papilloma Virus [HPV]*). Larynx cancer also can run in families (be genetic).

Men are four to five times more likely to develop larynx cancer than women because in the past men were more likely to smoke and drink alcohol. However this changed over the years and women became at increased risk. Larynx cancers are more commonly found in people over age 65 since most of these cancers take a long time to develop. Larynx cancer is also more common among Black Americans than others.

Speaking again after laryngectomy

Total laryngectomy surgery removes the larynx (vocal cords/voice box). But **almost all laryngectomees can learn a new way to speak (or communicate)**. Approximately 85-90% learn to speak using one of the three major methods of speaking described below. 10-15% do not communicate by speaking but can use computer-based or other methods to communicate.

Before the laryngectomy surgery we spoke by using lung air to vibrate the vocal cords. These tones were then changed by using our mouth parts (tongues, lips, teeth, etc.) to form the sounds that combine to make speech. The laryngectomy surgery removes the vibrating sound source, the vocal cords (larynx). The laryngectomy surgery also cuts off the supply of air coming from the lungs and into the throat and mouth used for speaking (*see page 2*). **Laryngectomees breath only through the opening in the throat, the stoma.**

However, other forms of speech can be created by using a new pathway for air and a different body part to vibrate. Another way is putting a basic tone into the throat or mouth from outside the body and then using the mouth parts to form speech. The method or methods an individual can use to speak depend on the type and extent of surgery they needed to remove all of the cancer and rebuild the surgery site. Some individuals will have just one way to speak, while others may have one or more additional choices.

Each method of speech after the larynx is removed has different characteristics and advantages and disadvantages. The goal of obtaining a new way to speak is to meet the communications needs of the individual. And these will differ from person to person.

Electrolarynx

The *electronic artificial larynx (also called an AL, artificial larynx; EL, electronic larynx; or ALD,* [*artificial laryngeal device]*) is a battery operated device. It makes a sound and vibration that is directed into the throat and mouth of the user. The person then changes the sound using the mouth parts to create the speech sounds.

There are two basic types of ALs. One is called an *intra-oral* type since it works inside the mouth. This piece of equipment creates a buzzing sound that is transferred into the back of the mouth by a straw-like tube. You then change that sound with your mouth (lips, tongue, teeth, etc.) to form the speech sounds.

The other type of electronic artificial larynx is designed to be held under the chin or against the neck or cheek. It transmits a vibration and buzzing sound into the throat and mouth that is then used to produce speech. Some devices designed for use against the neck can also be fitted with an adapter that turns them into an intra-oral device (*see photo page 4, the intra-oral straw-like adapter is on the far left*).

A sample of electronic artificial larynges (ALs). All of them except the rectangular one on the right is used against the neck, under the chin or on the cheek.

The rectangular one is the intra-oral type where the end of the straw-like part (far right) is inserted into the mouth.

Shown on the far left is an oral adapter that can be attached to the top of ALs for use as an intra-oral device. This is often the first way laryngectomees speak after surgery.

The vibration and sound go into the mouth where the tongue, teeth and other mouth parts are used to make the speech sounds.

ALs are frequently provided to laryngectomees while they are still in the hospital recovering from the surgery. It would be painful to try and use an AL against the neck and surgical stitches or staples immediately. For this reason (and because there will be swelling in the neck and a need to keep the wound area clean) the kind of AL that can be converted by using the straw-like adapter tube, or the type designed to be used only within the mouth, may be recommended and used *(see photo above*).

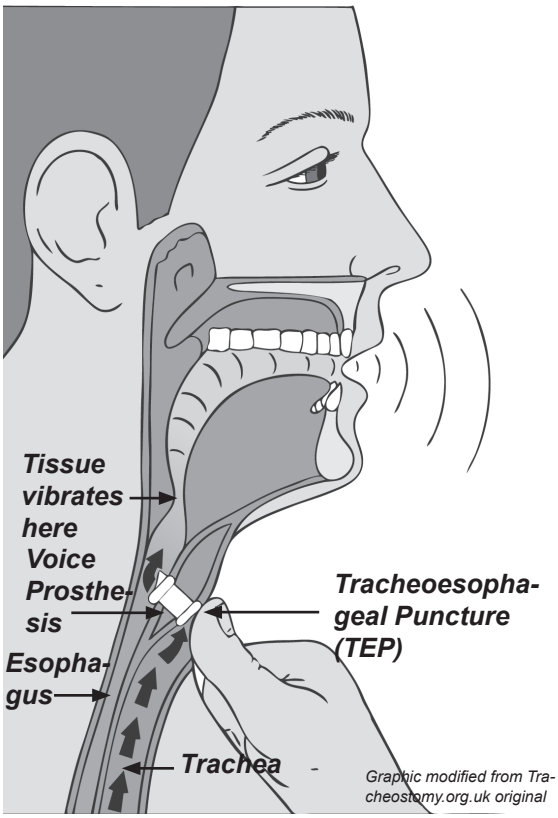
Many laryngectomees who can speak using another method of speech learn to use the AL at the beginning of their recovery and continue to own one as a back-up in case they have problems with their other speaking method.

One kind of electrolarynx (AL), on the left, is used against the neck, under the chin or against the cheek. The vibration and sound it makes are transferred to the back of the throat. This tone is then used by the mouth (tongue, lips, teeth, etc.) to make speech.

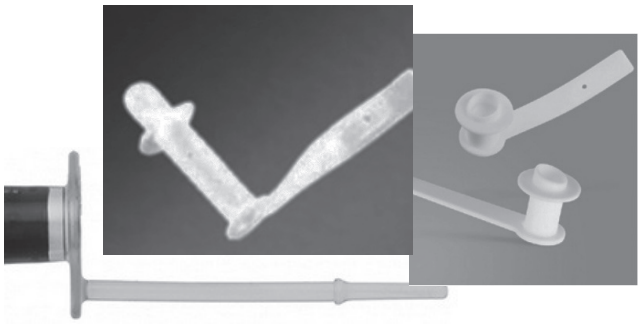
Speech/Language Pathologists (SLPs, speech therapists) can help in teaching laryngectomees the proper use of the AL to obtain the most understandable speech.

Voice Prosthesis (Tracheo-Esophageal Puncture)

Another way many laryngectomees speak is by using *tracheo-esophageal* speech with a voice *prosthesis*. A small hole (called a *puncture*) is created in the back of the *stoma* through the windpipe (trachea) and into the esophagus (feeling tube). A small tube, called a *prosthesis*, is inserted through this hole. The prosthesis keeps the puncture from healing closed. It has a one-way valve built into the end on the esophagus side. This valve lets air go through but keeps swallowed liquids from coming through the tube and dripping into the lungs.



With the TEP form of speech the stoma is blocked off and air from the lungs goes through the prosthesis and into the esophagus. The sides/top of the esophagus above the prosthesis vibrate. The tone produced is used to form the speech sounds.



Above are some examples of voice prostheses. All require a prescription. The prosthesis on the left and right are called indwelling (since they stay in place for long periods of time). They are changed by a clinician (ENT medical doctor or SLP). The top one is designed to be changed by the user or member of his or her family. After insertion the straps are cut off.

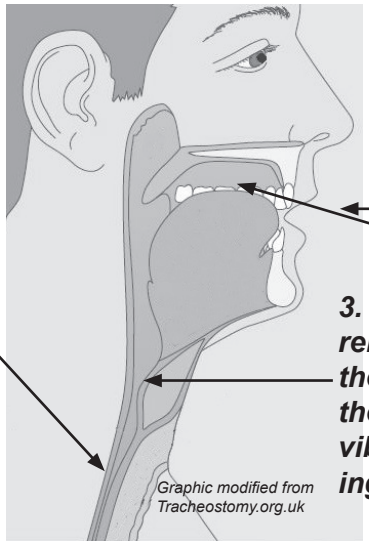
To speak the stoma is closed by use of the thumb, finger or Heat/Moisture Exchange (HME) filter, or HME that is *hands-free*. Lung air then moves through the prosthesis and into the esophagus. The air causes the walls and top of the esophagus to vibrate. This produces a tone that the mouth (tongue, lips, teeth, etc.) use to form the sounds of speech.

The voice prosthesis comes in two different basic types. One kind is the *patient-changed* and it is designed to be changed by the laryngectomee or a family member. The other, called an *indwelling*, is designed to be changed by a medical professional, such as an ENT MD (Ear, Nose and Throat Medical Doctor) or SLP [Speech/Language Pathologist, speech therapist]). Both types require a prescription.

The creation of the *puncture*, or hole between the trachea and esophagus, can be done at the same time as the laryngectomy surgery (called a *primary puncture)*, or done after you have healed from the surgery (*secondary puncture*).

Traditional Esophageal Speech

In traditional esophageal speech air is injected, “inhaled” or otherwise moved into the esophagus, trapped by the muscle around the esophagus, and then brought back up. The movement of this air vibrates the walls of the esophagus and produces a sound. The mouth (tongue, teeth, lips, etc.) uses the tone to form the sounds of speech.



Of the three major types of speech following laryngectomee, traditional esophageal speech generally takes longer to learn than the other two. However, it has advantages that many laryngectomees think makes it worth the effort. There are some Speech/Language Pathologists (SLPs) who can assist laryngectomees in learning traditional esophageal speech. Additionally, some laryngectomee support groups can provide instruction or refer you to a teacher. There are also self-help books and tapes that can help teach this method of speech. Recently instruction has been offered on the Internet through Zoom.

Other Methods of Speech.

Those who are unable to use any of the three methods mentioned above can use computer generated speech using either a standard laptop computer or single purpose speech aid. Other products are being developed. If the individual who have larynx cancer can still speak they might want to record their voice. The sample may possibly be used by Artificial Intelligence to produce a voice similar to your original one.

With the computer generated type-to-speech method the user types what they want to say on the keyboard and the computer will say out loud what has been typed. Some cell phones can also be used to speak out loud what you type. Other technologies are being developed which can come closer to sounding like traditional speech.

An example of an electronic speech aid. You type what you want to communicate and the computer speaks it out loud. A laptop computer or some cell phones can also be used.

(Graphic from Lightwriter).

After Surgery Care at Home

Keeping your stoma clean

It is important to keep the area around the stoma clean.

Supplies:
(1) Q-Tips or cotton swabs (the long handled Q-Tips are the safest since they are less likely to be dropped down the stoma)
(2) Hydrogen peroxide
(3) Tweezers (long handled ones that cannot drop down your stoma), or surgical clamp (hemostat) which is available at many hobby, medical supply, tool stores, and on line.

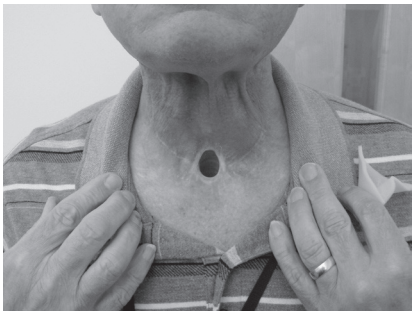
Mix a half and half solution of hydrogen peroxide and water in a small container. Dip the Q-Tip or cotton swab in the peroxide solution and carefully clean the ***outside*** edges of your stoma for a month following surgery. Do this in the morning and evening.

Once the outside edges of your stoma have healed you may only need to use the peroxide solution if dried mucus accumulates on the edges. You can also clean the general area around your stoma with soap and water and a washcloth, being careful to keep the soapy water from getting into your stoma.

You may also need to use the tweezers or surgical clamp (dip them in the peroxide solution to clean them and shake off any remaining solution) to remove bits of clumped or dried mucus or other material that may accumulate in and around the stoma. Soften dried mucus before pulling it off to avoid bleeding.

A surgical clamp (hemostat) is a good substitute for tweezers to remove clumps of dried mucus. You may need to soften the hardened mucus first with saline spray to avoid any bleeding.

On the right is a stoma after the healing process has completed. The stoma is permanent and the new way laryngectomees breathe. Stomas should be covered at all times with an HME (Heat/Moisture Exchange filter), foam filter or good lined cloth stoma cover. *(See pages 8-9.)*



Some laryngectomees also spray or squirt a little sterile saline (salt water) solution (0.9%) into their stomas and then cough it up. They may do this one or more times a day, or as needed.

You may be supplied by the hospital with what are called “saline bullets,” or little plastic tubes of sterile salt water, or you can use a product such as “Simply Saline” or “NeilMed Nasal Mist” available in drug stores and stores like Walmart. One or both of these products should also be kept on hand, particularly for the new laryngectomee, in case a *mucus plug* develops (*see “Suction Machine” section on page 11*).

Keeping the stoma from shrinking

Two kinds of laryngectomee tubes (also called vents or buttons). They fit into the stoma to keep it open. The two on the bottom can be used with an HME (Heat/ Moisture Exchange) filter.

The surgically created opening in your neck is called a *stoma*. As the stoma heals and forms scar tissue there may be some shrinkage in its size. Shrinking of the stoma is called *stoma stenosis (*or *microstoma)*. If your doctor provided you with a soft silicon or other type of laryngectomee tube (also called a *vent* or *button*), **w**ear it as directed. If your doctor did not provide you with a tube and you notice a significant shrinkage in the size of the stoma as it heals notify your doctor or SLP (speech therapist).

It is also very important to keep to your schedule of follow-up appointments with your doctor and speech therapist.

Covering the stoma

It is *very* important that you **keep your stoma covered at all times** in order to keep out dirt, smoke, dust, bugs, etc., from getting into your windpipe and lungs. This is essential and critically important. **Stomas must be covered 24 hours a day.**

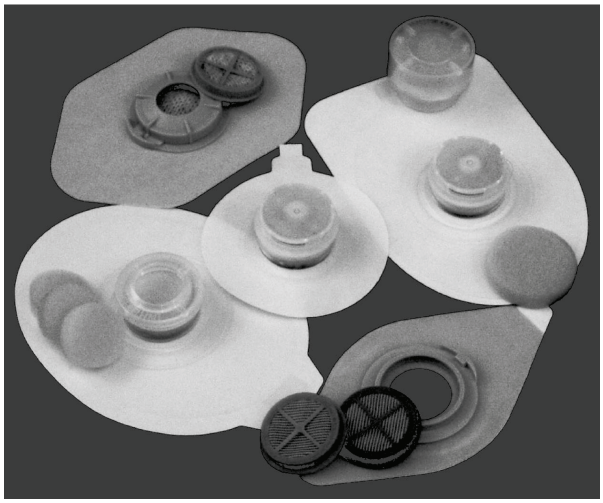
Stoma covers come in a countless variety of types, styles and colors. Pictured to the right are small foam squares that are glued over the stoma, larger foam ones covered by mesh fabric, crocheted covers, home sewn ones, one made of lace (which should be used over a foam cover), and many covers that look like ordinary shirts, dickies or other clothing. The important thing is that the cover be an effective filter.

There are many different kinds of stoma covers. The most effective ones are called *HME* (Heat/Moisture Exchange) filters since they form an airtight seal around the stoma. All air breathed in passes through the HME filter. Your *clinician* (ENT medical doctor or Speech/Language Pathologist) can fit you for one of these filter systems.

In addition to filtering out dirt HMEs (Heat/Moisture Exchange) filters also store some of the moisture and heat from the air you breathe out. When you inhale, the heat and moisture stored in the filter returns to your lungs. These filters help in bringing the air you breathe very close to what it was in temperature, moisture and cleanliness before your surgery and will help reduce mucus.

HME (Heat/Moisture Exchange) filters are attached by means of a glued on housing, or a tube/button or vent such as those shown on page 8. Using these filters have been shown to reduce the amount of mucus and coughing.

Some examples of Heat/Moisture Exchange filters (HMEs). The base is glued around the stoma and a housing containing a filter is inserted. In addition to filtering and cleaning the incoming air they can also store some of the moisture and heat from exhaled air. The warmth and moisture is returned when you inhale. They reduce the production of mucus since the air is cleaner, warmer and more moist. Some laryngectomees are able to use them without the glued on housing. Instead they use a laryngectomy tube (vent, button) *(See example on page 8).*



Other available filters include a foam patch that is glued above your stoma by a tear off strip. Cloth stoma covers are also available. The most effective are those which are lined to help with both filtering and storing some heat and moisture to reuse when you inhale.

Coughing and Mucus

Becoming a laryngectomee means that any mucus (also called *phlegm*) produced by your lungs and windpipe has to come out your stoma since you can no longer cough it up into your mouth area and then swallow it, spitting it or, or by blowing your nose. Since the air reaching your windpipe and lungs is often less clean, moist and warm, the lungs and windpipe become irritated and often produce more mucus. This may gradually decrease over time. Wearing a heat/moisture exchange filter (HME) can reduce coughing and excess mucus.

If you feel a cough coming on, quickly remove your HME and use a tissue or handkerchief to form a cup over your stoma to catch the mucus. Then wipe the area around your stoma.

Many laryngectomees dislike coughing and having to deal with the mucus that it produces. They may also misread it as a sign of a respiratory infection. But it is important to understand that coughing up mucus is the new way laryngectomees keep their windpipes and lungs moist and clear of dirt, dust, smoke particles and other contaminants that still manage to get into them. Producing mucus is the body's way of protecting itself and laryngectomees should **not** try to eliminate mucus and coughing.

The ideal consistency for mucus is clear, or nearly clear, and runny or stringy. But this consistency is not easy to maintain since our environments change as the weather does and as we move around to different places. As previously mentioned, a flow of mucus is a good thing since it is the mucus that coats and protects the trachea (windpipe) and helps clean out any dirt, dust, etc. which gets into the lungs. In addition to keeping your home humidity up, you may need to increase your liquids intake. Plain water is best.

Increasing your Humidity

Before becoming a laryngectomee the upper part of your respiratory system conditioned the air that reached the lungs by warming it to body temperature (98.6 degrees F.), filtering it clean, and causing it to have a relative humidity of 100%. Increasing the humidity in your home to between **45-55% relative humidity** (no higher) can help reduce mucus production and keep the stoma and trachea (windpipe) from drying out, cracking and bleeding. In addition to being painful, these cracks can also become pathways for infections.

Some homes have furnaces that also humidify the air, and you can set the humidity level just as you set the thermostat for heating and cooling. If not, you may be more comfortable if you purchase one or more portable humidifiers.

The most maintenance free types of portable humidifiers are the steam or evaporative ones. The cool mist types work as well, but typically require daily cleaning and may expel a mineral dust that can be breathed in and/or deposited on home surfaces. Some of the more expensive portable humidifiers come with a dial where you can set the humidity level you want. Otherwise, you might want to purchase a digital humidity gauge (called a *hygrometer*) from a store such as Walmart in the part of the store where indoor/outdoor temperature gauges are sold; or on line.

A portable humidifier can help keep the air in a room at 45-55% relative humidity. This is the ideal range for laryngectomees to help keep their tracheas (windpipes) from drying out.

An inexpensive digital humidity gauge

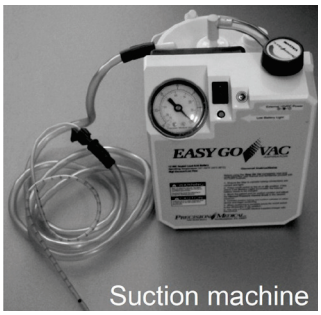
You can also help to humidify the air reaching your lungs by dampening the foam filter or cloth stoma cover with clean plain water. As mentioned above, wearing an Heat/Moisture Exchange (HME) filter system is very helpful. Taking a steamy shower or breathing in water vapor from a tea kettle (not too close since steam can burn) can also provide relief from dryness. **Do not use any creams or lotions containing oils of any kind *inside* the stoma**. Your doctor, however, may recommend the use of *water soluble* lubricants such as “Surgi-lube” or “KY Jelly.”

The ideal level in the indoor air laryngectomees breathe is from 45-55% relative humidity. This will help keep the stoma from drying out and cracking, and help reduce excessive mucus production caused by breathing air that is too dry, cool or dirty.

If the humidity level is too low your trachea can dry out, crack, and produce a little bleeding. If it is more than a little or does not quickly respond to increasing the humidity call your doctor. If the increasing amount or color of the mucus is concerning, talk with your doctor. Changes in color may indicate a lung infection.

Suction Machine - Mucus Plug

A suction machine may be ordered for you before you leave the hospital to take home. Use it as directed, and also if you are unable to cough up your mucus or if you develop a *mucus plug*. Mucus can become thick, stick to itself and form a plug that blocks part or, rarely, even all of your airway.



Suction machine

A suction machine is used to remove mucus from the stoma and breathing tube.

If you suddenly develop an unexplainable shortness of breath use the suction machine to remove the plug. Mucus plugs may also be successfully removed by using a saline "bullet" (0.9% sterile salt water in a plastic tube) or a product such as "Simply Saline" (*see page 7*). Squirting some into your stoma may loosen the plug so you can cough it out. If you are unable to remove the plug after several attempts you need to call 911 and get immediate medical attention. If your oxygen level is low make sure an oxygen mask is put on your stoma (NOT your mouth and nose)

Emergency Information

Laryngectomees are "neck breathers." Instead of breathing through our mouths and noses, **we now breathe only through the opening in our necks,** the stoma. It is important that it is obvious that we are neck breathers, and the best way is to wear a bright red or orange bracelet available from Atosmedical.com and Luminaud.com.

Brightly colored rubber alert bracelets can be obtained free from the vendors listed above.

Medic Alert jewelry can alert emergency medical personnel that you are a laryngectomee and that if oxygen needs to be used that the mask should only be applied to the stoma. *(Graphics from Medic Alert).*

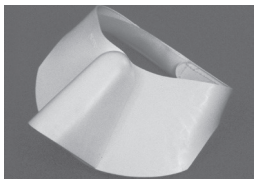
You might also want to consider wearing a bracelet that contains your medical history on a USB computer flash drive. (See Carememoryband.com). You can obtain these from many drugstores or stores such as Walmart. If you have a smart phone there may be an application on it labeled "Health" or something similar where you can store your medical information.

You can also obtain cards to carry in wallets or purses and stickers that go on the inside of your rear car windows that contain information about caring for a laryngectomee in an emergency such as a car accident. You can obtain these from the International Association of Laryngectomees, www.TheIALvoice.org., or vendors. You may also want to notify your local emergency medical service (EMS or fire department) that you breathe exclusively through your neck and that if oxygen is needed to apply it only to your neck, and also that you may not be able to speak.

Showering and Bathing After Laryngectomy

With the use of precautions to keep water out of your stoma, laryngectomees should be able to shower or take a bath in a bathtub. When showering direct the water below your stoma or onto your back. A detachable shower head can be helpful.

A shower guard can be purchased that fits around the neck and keeps water out of the stoma.



You can purchase a shower guard from a vendor that can be located through the The-IALvoice.org., WebWhispers.org. and Larysspeakeasy.org. web sites. It is designed to fit tightly around your neck and has a shield over your stoma to permit breathing as you shower, but prevents water from getting in. Some laryngectomees just cover their stomas briefly with a wash cloth while directly under the shower.

Those who prefer to take a bath in a tub can do so as long as the water level does not reach the stoma. Wash the areas above the stoma with a soapy washcloth. The important thing to remember is to keep water out of the stoma.

Radiation and Chemotherapy

People with head and neck cancers including cancer of the larynx (voice box, vocal cords) may receive radiation alone, or in combination with chemotherapy and/or surgery. Radiation and chemotherapy may be used to destroy the cancer so that surgery is not required. It may also be used before surgery to shrink the tumor, or after surgery to make sure that any cancer cells left are destroyed that might have spread beyond the location of the original cancer.

Radiation

Radiation therapy (also known as *irradiation, radiation, radiotherapy*) is used to destroy cancer cells. Cancer cells are easier to destroy while they are dividing and growing. Since cancer cells divide and grow faster than normal cells they are more likely to be destroyed by radiation while the healthy cells may be damaged, but recover.

If your *oncologist* (cancer specialist doctor) recommends radiation treatments a plan will be set up that includes the number of treatments, the schedule, and the total dose, or amount, of radiation. This will be based on the kind and location of the tumor, your general health, and other treatments you are receiving at the same time or have previously received.

Possible Side Effects of Radiation

The side effects of radiation vary for different individuals. They will depend on the area being treated, the amount of radiation given, equipment used, and your general health. During the beginning of radiation treatments you may experience some swelling, dry mouth, changed taste, and fatigue (tiredness). As time goes on you may develop thickened saliva, mouth and throat sores, redness in the treated area and loss of taste. Your doctor will recommend ways to deal with these side effects. As eating and drinking become more difficult it may be necessary to place a feeding tube into the stomach in order to keep your weight up and your body supplied with the calories it needs to heal. Usually within a month or so after radiation is complete the mouth and throat sores will heal, the tube removed, and you can eat more comfortably.

Although methods are continually being developed to deal with it, dry mouth can still be a permanent side effect and require the frequent drinking of liquids throughout the day, especially during mealtimes, and the possible use of artificial saliva.

Some long term side effects for some people include swallowing problems (*see separate section on page 14*). Scar tissue can develop in the mouth and throat and muscles that control swallowing can be damaged. Evaluation and treatment by a speech/language pathologist (SLP) who specializes in swallowing problems may be required.

Other long term effects can include dental problems because of dry mouth since one purpose of saliva is to protect teeth from decay, and radiation may damage the blood vessels to the teeth. Special fluoride treatments may help with dental problems along with brushing, flossing, and having your teeth cleaned regularly. However, in some cases it is necessary to remove teeth before radiation if they will be in the area receiving radiation and are too decayed to preserve by filling or root canal. This is because an unhealthy tooth can serve as a source of infection to the jawbone, which can be particularly difficult to treat after radiation.

If the *thyroid gland* in your throat is in the radiated area it may no longer produce enough of the thyroid hormone. If the thyroid gland is no longer functioning completely or at all, thyroid hormone replacement is simple and involves the taking of an inexpensive pill daily (*see pages 17-18*).

If your surgery also included the removal of lymph nodes in your neck and shoulder area you may need physical rehabilitation for the neck and shoulders (*see pages 17-18*).

Some laryngectomees experience wound healing problems following surgery, particularly in areas that have received radiation. Wounds that are slow to heal are called *fistulas*. If the wound does not heal using standard medical procedures such as antibiotics and dressing changes you may be referred to a wound specialist M.D. These medical doctors have a number of specialized methods they can use to help hard-to-heal wounds.

Chemotherapy

Chemotherapy is usually used with more advanced cancers. It is used to kill the tumor, to help keep cancer cells from spreading, or to give relief from symptoms. Chemotherapy may be used in combination with radiation to increase the effectiveness of radiation treatments. Chemotherapy can weaken cancer cells and make them easier to kill.

In some cases chemotherapy is given as part of *palliative care* (medical treatments designed to prolong and improve the quality of life rather than destroy the cancer). This may be done when the cancer cannot be treated by radiation or surgery, or because cancers have spread to other parts of the body such as the lungs, brain, or bones. Chemotherapy can help with pain control, appetite, breathing and swallowing difficulty, and other problems.

Possible Side Effects of Chemotherapy

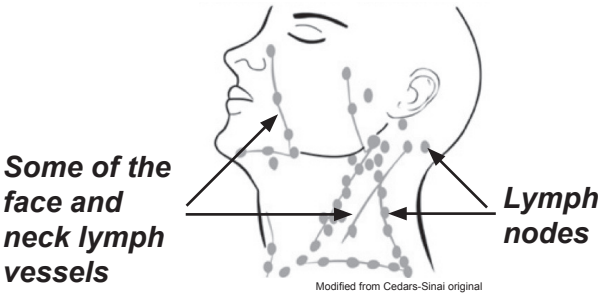
The kind and type of possible side effects of chemotherapy depend on the individual. Some people have few side effects, while others have more. And many people do not experience side effects until they are near the end of their treatments. For many individuals these side effects do not last long. The side effects of chemotherapy also depend on the type of drugs used, and the amount and frequency of the treatments.

Some possible side effects include nausea, vomiting, hair loss, sores and sensitivity in the mouth and throat, problems with swallowing, general fatigue (tiredness), numbness in the hands and feet, hearing loss, infections, kidney damage, bleeding problems, and others. Your oncologist (cancer specialist doctor) will watch for and treat these side effects.

Swelling of the Face and Neck (Edema)

As part of the total laryngectomy surgery lymph vessels are cut. These vessels are similar to blood vessels except instead of carrying blood they are pathways for a liquid that carries white blood cells throughout the body to fight infection. The vessels are connected to lymph nodes that act like filters and trap infected material. There are about 200 lymph nodes in just the head and neck area.

When the lymph vessels are cut lymph fluid accumulates in the face and neck and produces swelling called *edema* (or *lymphedema).* This swelling often begins in the hospital following surgery and can continue for some time afterwards. The swelling often goes down by itself over time as the lymph fluid finds other pathways to drain. Sleeping with the upper part of the body in an elevated position can use gravity to speed the process of lymph fluid drainage.



A specially trained cancer massage therapist may be able to help the condition. Massage from other sources including self-massage may be dangerous and is not recommended.

Swallowing Problems

Many laryngectomees experience problems with swallowing (the problem is called *dysphagia*). Swallowing involves the coordination of more than 20 muscles and several nerves. And any damage done to any part of the system by surgery or other treatments such as radiation can produce problems with swallowing.

Almost all laryngectomees experience swallowing problems immediately following surgery. However, the overwhelming majority of them quickly relearn how to swallow and experience no further problems. Still others may only need to make minor adjustments in eating such as taking smaller bites, chewing more thoroughly, drinking more liquids while eating, etc.

Because of the type of surgery they required a very few laryngectomees are unable to swallow at all and must be fed indefinitely through a tube (called a *G-Tube*, or *Gastrostomy Tube*). It is inserted into the stomach and liquid nourishment supplied through the tube.

Still others experience serious swallowing problems but can be helped to learn to improve their ability to swallow by working with an SLP (Speech/Language Pathologist) who specializes in swallowing disorders. You may need to ask your doctor of speech therapist for the name of an SLP who specializes in this area.

Returning to Work

Many people who become laryngectomees are able to return to their jobs after they have healed. And this includes jobs that require speaking such as teachers, salesmen, police

officers, ministers and many others. If you can do so try and keep your rights to return to your job. Many employers are unaware about cancer survival and may assume you will not be able to continue doing what your job requires. You may feel pressured to resign or retire early. If possible, avoid making any option-ending decisions when you are stressed and vulnerable. You may have to educate yourself and your employer about what laryngectomees can do. (U.S. residents might want to check the Americans With Disabilities Act, particularly if they believe they are victims of discrimination).

Connecting with other laryngectomees (in person and on line)

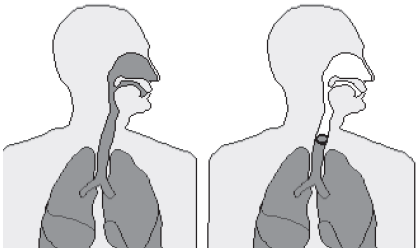
It is extremely important and valuable to connect with other laryngectomees. Being visited by a fully recovered laryngectomee before the surgery while in the hospital, after the surgery, and connecting with other laryngectomees after you return home helps to break down isolation and speed recovery. It is helpful to know that you are not alone and that others have faced what you are facing and can help you through it. Connecting with other laryngectomees can also provide you with living examples of how you can successfully recover and return to a full life.

You may live in a community that has a laryngectomee support group. You can find out by asking your ENT MD, SLP (speech therapist), local chapter of the American Cancer Society, or via the Internet at Larysspeakeasy. org., webwhispers.org., or TheIALvoice.org. Some laryngectomee support groups meet via the internet using Zoom, or combined with in-person meetings.

The major Internet-based laryngectomee support club is WebWhispers. Membership is free. You can join at webwhispers.org. You can get answers to most questions you may have from the group. It maintains a loaner closet for temporary loan of an electronic larynx (AL/EL). Another source of laryngectomees for a free loaner AL/EL and free laryngectomee supplies is Larysspeakeasy.org.

Respiratory Rehabilitation

Respiratory System



Before laryngectomy | After laryngectomy

The laryngectomy surgery bypasses the upper part of the respiratory system. Before the surgery air came into your nose or mouth and traveled to the back of your throat and then down the windpipe (trachea) and into the lungs. Following the laryngectomy surgery air now goes directly into the stoma and down the trachea into the lungs. Laryngectomees lose the top part of the respiratory system that filtered, warmed and humidified the air we breathed.

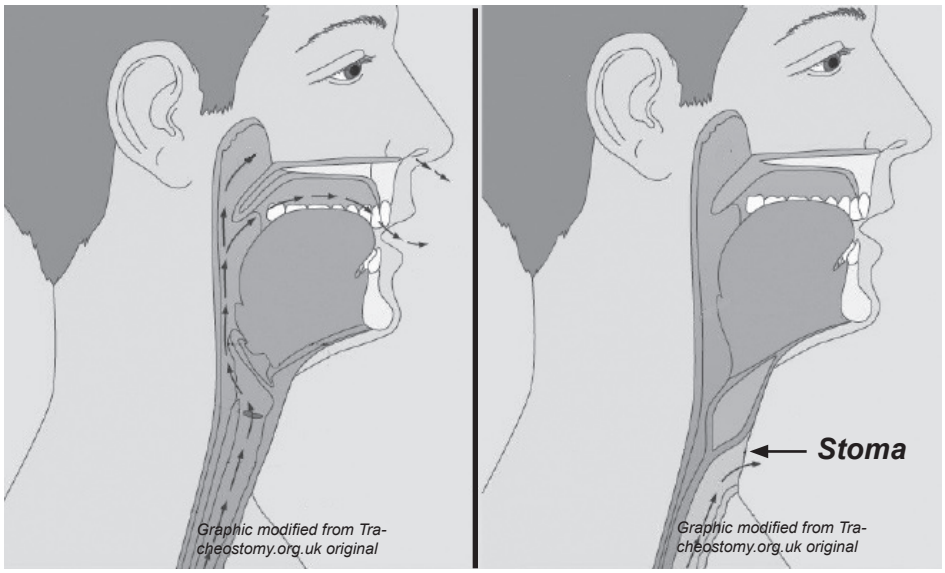
It is actually easier for laryngectomees to breathe since there is less air flow resistance provided by the upper part of the respiratory system. But because it is easier to get enough air the lungs do not need to inflate and deflate as completely as before. It is therefore not unusual for laryngectomees to develop reduced lung capacity and breathing efficiency.

However, there are several things laryngectomees can do to keep lung capacity up. One is to put back some resistance to breathing so that you have to more fully inflate the lungs. The use of an HME (Heat/Moisture Exchange) filter that has resistance can help. (*See pages 9 and 10*). Exercise can also be helpful. If you are not already active see your doctor to make certain that it is safe for you to begin an exercise program that gets your heart and breathing rates up. Deep breathing exercises also help,. Depending on your doctor's recommendation, something as simple as walking for a half hour every other day can contribute to keeping your body, including your heart and lungs, in good shape.

Emergency CPR

Cardiopulmonary Resuscitation (CPR) are emergency methods used to restore heart and breathing functions. Performing CPR is more difficult when the person needing or giving CPR is a laryngectomee. This is because of the way laryngectomees breathe. If the person needing CPR is a laryngectomee then restoring his or her breathing no longer involves moving oxygen through their nose or mouth into the lungs. The only pathway open to the lungs for laryngectomee is through the stoma. And if the person giving CPR is a laryngectomee they cannot perform mouth-to-mouth breathing, although chest-compression only CPR has been approved for use.

Before Laryngectomy Surgery **After Laryngectomy Surgery**



The graphic omn the left shows that before laryngectomee surgery we breathed in and out through our mouths and noses. After the surgery laryngectomees can ONLY breathe through the hole in our necks (the stoma). The nose and mouth are permanently detached from the breathing system.
The arrows show the direction of airflow during exhalation (breathing out).

Training is recommended before performing CPR. Laryngectomees and their loved ones need to find out where training is available in their areas. Check the materials available from the IAL. Your American Red Cross Chapter, American Lung Association or American Heart Association can tell you about training available locally. However, when saving a life is the issue everyone should be able and willing to perform CPR to the best of their ability.

A CPR method that can be used by a laryngectomee to perform resuscitation on a non-laryngectomee, and by a non-laryngectomee on a laryngectomee, is called the “Hands-Only” or “Chest Compression Only” method.

Directions for performing “Hands-Only” or “Chest Compression-Only” CPR are:

If an adult suddenly collapses who is not responsive...

“Hey, are you OK?” (Shaking or poking them). If no response:
1. Send someone to **call 911**, or call yourself.
2. Get directly over the victim with the person laying on a hard surface such as the floor or ground. **Put the heel of your hand in the middle of the person’s chest between the nipples, put your other hand on top of the first, and lock your elbows.**

3. **Press down hard and fast 100 times per minute (the tempo of the disco song "Staying Alive") until help arrives. Do not stop.**

You can view videotapes of Hands-Only CPR here:
crp.heart.org.

Getting Oxygen During Medical Treatments or Emergencies

There are very few laryngectomees in the general population. Unfortunately, this means that it is not at all unusual for medical personnel to not know how laryngectomees breathe. They frequently mistake us for "trache" patients, or individuals who continue to breath through their mouths and noses even though they also have a hole in their necks (a tracheostomy) to help them breathe.

If oxygen needs to be used on a laryngectomee it should be provided ONLY TO THE NECK, since the nose and mouth are no longer connected to the lungs (*see page 2*). If the laryngectomee needs oxygen and an oxygen mask is put over the nose and mouth they may suffer brain damage or even death.

There is NEVER a medical reason for a total laryngectomee to have an oxygen mask put on their nose and mouth. Anyone who puts one on a laryngectomee is making a potentially fatal mistake. If we need oxygen it MUST be delivered through our stomas only. (*See page 11 for ways to clearly identify yourself as a total neck breather.*)

It may take several months for the surgical scars to heal. After they have healed many laryngectomees can benefit from therapy they obtain from a physical therapist, exercises they can do on their own, or a combination. Depending on the kind of surgery the laryngectomee has, he or she may benefit from stretching exercises for the neck and shoulders. You doctor or physical therapist can tell you when it is safe for you to put stress on the surgical scars.

Thyroid Problems

More than half of all laryngectomees develop problems with their thyroid glands. This gland is located in the neck area and it produces a hormone that regulates every cell and organ in the body. Radiation and/or the laryngectomy surgery can injure the thyroid and cause it to not produce enough of the hormone. This condition is called *hypothyroidism*.

Since the hormone affects every organ in the body the symptoms can vary widely. Some of them are depression, sleepiness and fatigue, weight gain, apathy, constipation, sweatiness, hot flashes, dry itchy skin, intolerance to cold, forgetfulness, premature gray/coarse/dry hair, swollen eyelids/puffy face, thinning eyebrows and other hair loss, inability to concentrate, muscle weakness or cramps, constipation, numb and tingling hands, anxiety, headache/dizziness, hearing loss, slowed heart rate, aches, pains, arthritis, decreased sexual interest, and many others.

The diagnosis is made with a simple blood test. Laryngectomees and their loved ones may have to remind their family physicians to test for hypothyroidism since the symptoms are shared with many other medical conditions. Many family doctors are not aware that low thyroid levels is a common problem for laryngectomees.

Treatment almost always requires lifelong therapy. But the treatment only involves taking a small and inexpensive pill daily, and your doctor periodically rechecking your blood to make sure the dose is correct.

Dealing with Emotions

Almost all laryngectomy surgeries are performed in order to remove cancer. And according to the American Cancer Society, depression, along with anxiety, are common in all cancer patients. However, depression is fairly easily treated in 3/4s of all who have it. In many cases just the passage of time can get the individual and their loved ones over the anxiety and depression that can follow the diagnosis of cancer and dealing with the treatments and side-effects.

We all differ to the extent that emotions have a serious effect on our lives, for how long, and whether we require professional medical help to get through them. Both the laryngectomee patient and loved ones may become depressed and/or anxious. Not all laryngectomees become seriously depressed or anxious, but enough do that it is important to monitor ourselves and loved ones/caregivers for symptoms.

The treatment of serious depression requires a diagnosis by a psychologist or psychiatrist, although your family doctor may treat milder cases. But before referring the laryngectomee to a specialist your family doctor may first want to check for *hypothyroidism,* or decreased output from the laryngectomee's thyroid gland. Depression is one of a large number of symptoms for low thyroid and many laryngectomees develop this problem. Fortunately, hypothyroidism is easily treated with an inexpensive pill taken daily.

Whether depression requires professional assistance to treat depends on whether the emotional problems are severe, long lasting and/or they interfere with normal life activities. Although very rare, any suicidal thoughts, preparations or other actions should be treated as an emergency situation.

Glossary of Terms

Alaryngeal –Without a larynx.

Cancer - A general term for a large group of diseases, all characterized by uncontrolled growth and spread of abnormal cells. Cancer cells are abnormal and eventually form tumors that invade and destroy surrounding tissue; they may even spread via the lymph system or blood stream to distant areas of the body. (*See Metastasis and Malignant Tumor*).

Ear, Nose and Throat MD -- ENT. Medical specialization that treats laryngectomees and others.

Esophageal Speech – A method of producing sound from air trapped in and then released from the esophagus.

Esophagus – The food passage from the throat to the stomach.

Hands-Free Valve -- A valve that goes over the stoma. It uses the pressure of exhaled breath to close a valve and direct air through the prosthesis without using a finger or thumb .

Heat/Moisture Exchange Filter (HME) -- Filter placed over the tracheostoma which stores some heat and moisture when a laryngectomee exhales and is returned when they inhale.

Laryngectomy – The surgical removal of the larynx or voice box, resulting in the loss of normal speech. A *laryngectomee* is someone who has undergone this operation.

Laryngectomy Tube -- A silicon tube that goes in the stoma to reduce *stenosis*, and/or hold a filter or a hands-free valve.

Larynx – The organ of sound, sometimes called the "voice box." The larynx is made of cartilage and muscle and is lined by a mucous membrane similar to that lining the mouth and nasal passages.

Lymph – A clear fluid circulating throughout the body (via the lymphatic system) that contains white blood cells and antibodies and fights bacteria.

Lymphedema -- Swelling (*edema*) caused by the accumulation of lymph fluid in a part of the body. It is common for laryngectomees to have lymphedema in the face and neck following surgery.

Lymph Glands – Also called lymph *nodes*. These glands produce lymph fluid. They normally act to filter impurities in the body.

Malignant Tumor – A mass of cancer cells. A malignant tumor may invade surrounding tissues or spread to distant areas of the body. (See Metastasis).

Metastasis – The spread of cancer cells to distant areas of the body by way of the lymph system or bloodstream. The term "metastases" refers to these new cancer sites.

Neck Dissection – The surgical removal of lymph glands and some surrounding structures within the neck and shoulder area.

Oncologist -- Medical doctor who specializes in the diagnosis and treatment of cancer.

Partial Laryngectomy – The surgical removal of part of the larynx. The extent of the surgery depends on the nature of the disease in each case.

Pharynx – The pharynx or throat is composed of three parts. The part above the back part of the throat of the mouth is called the *nasopharynx* because it is in the area of the nose. The part between the of the mouth and the base of the tongue is called the *oropharynx* because it is part of the oral or mouth cavity. The part from the base of the tongue to the entrance into the esophagus is called the *hypopharynx.*

Physical Therapist – Physical therapists plan, organize, and administer treatment in order to restore functional mobility, relieve pain, and prevent or limit permanent disability for those suffering from a disabling injury or disease.

Prosthesis -- A small silicon tube with a one-way valve in the end. It permits air to enter the esophagus where it can be used to vibrate tissues creating a tone that can be used for speech. One type, the patient-changed, is replaced by the laryngectomee or caregiver, and another, the indwelling, is changed by a clinician such as an SLP or ENT MD.

Radiotherapy – Treatment of cancer with high-energy radiation. Radiation therapy may be used to treat the cancer, reduce the size of a tumor before surgery, or to destroy any remaining cancer cells after surgery. Radiotherapy can also be helpful in shrinking recurrent cancers to relieve symptoms.

Rehabilitation – Programs that help patients adjust and return to a full productive life. Rehabilitation may involve physical restoration, such as the use of prostheses, counseling and emotional support.

Social Worker – Social workers offer supportive counseling to individuals, families, and groups to cope with their problems and referral to service resources within the community.

Speech-Language Pathologist (SLP) – A specialist in the evaluation and treatment of persons with disorders of verbal communication and swallowing disorders..

Stenosis -- Shrinkage of the tracheostoma (stoma).

Stoma – A surgically-created opening or orifice on the surface of the body. For laryngectomees it is the hole in the neck used for breathing.

TEP – Tracheo-Esophageal Puncture. This is a surgical procedure to create an opening between the back of the stoma (the *trachea*) into the food tube (the *esophagus*). A second meaning is that the term is often used to describe the prosthesis that goes into the puncture.

Trachea – The windpipe. The air passageway between the larynx and the lungs.

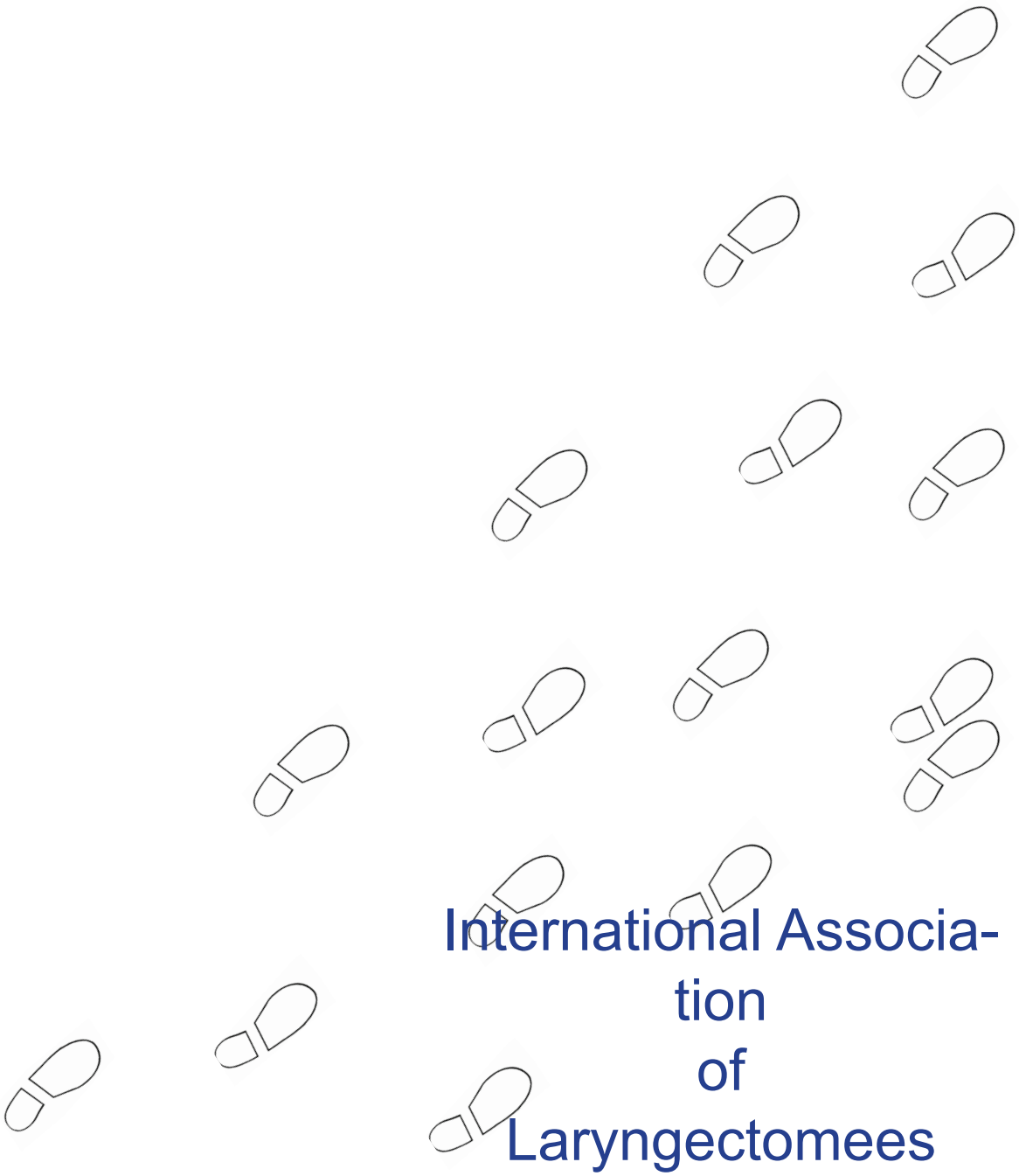
Tumor – An abnormal tissue swelling or mass; may be either benign or malignant (cancerous).

Vocal Cords (true cords) – Two small shelves of muscular tissue within the *larynx*. When air passes between them, they vibrate and produce sound.

X-ray – Radiant energy used to diagnose and treat disease, such as cancer. High doses of X-rays can kill cancer cells.

Directory of Laryngectomee Product Businesses

There are a number of companies that sell products laryngectomees need and want. Contact information changes. For a complete current list of vendors who sell products of interest to laryngectomees go to this IAL web site address: TheIALvoice.org,, Webwhispers.org, , Larysspeakeasy.org.



International Association of Laryngectomees