

LARYNGECTOMEE



FLORIDA LARYNGECTOMEE ASSOCIATION







Updated and Expanded by the NU-VOICE CLUB OF DAYTONA BEACH

This booklet is an updated version of the booklet "Your Latest Challenge - That New Voice."

"Originally developed by the Florida Laryngectomee Association for the new Laryngectomees in our midst. With every good wish for full recovery and early speech attainment."

The original booklet was compiled by a committee of members from the Florida Laryngectomee Association. Each person having the privilege of serving as president of the association.

Committee members and original authors:

C.L. Hardwick - Cosimo Martinetto - Irvine Lyle, III - and Kenneth L. Davidson Cosimo Martinetto, served as Chairman of distribution. Nathaniel Levin, M.D., F.A.C.S., served as Medical Advisor.

Some of the original questions have been restated and/or rearranged and new questions that were not addressed in the 'original writing have been added.

We have also given it a more appropriate title

The pictures of the anatomy of the throat and the modes of speech courtesy of InHealh Technologies

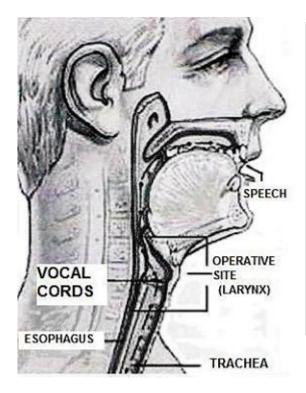
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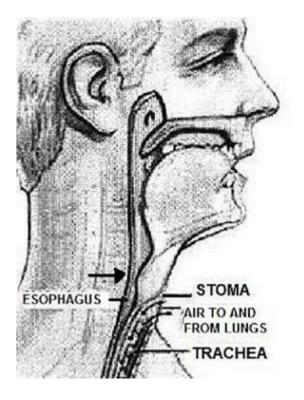
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BEFORE LARYNGECTOMY

The diagram at left shows the anatomical relationships of the larynx, esophagus, trachea, pharynx and the speech facilitators in the oral cavity (mouth).

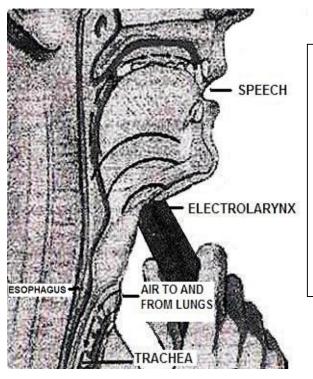
The air passes from the lungs up through the trachea, exiting the vocal cords in the larynx, creating a vibrating sound which is formed into intelligible speech in the oral cavity (mouth).



AFTER LARYNGECTOMY

The surgery removes the larynx, separating the esophagus and trachea. The trachea is turned and attached to the front of the neck creating the STOMA. This eliminates the air path from the lungs to the throat and mouth.

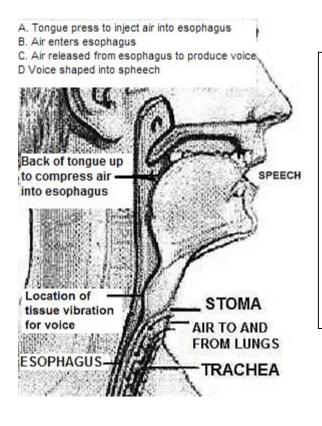
The narrow spot just above the trachea is the PE segment (arrow).



Electro Laryngeal Speech

Electro Laryngeal speech is accomplished by placing the speech aid on the appropriate spot on the neck.

The "sweet spot" is that spot that produces the most intelligible voice.

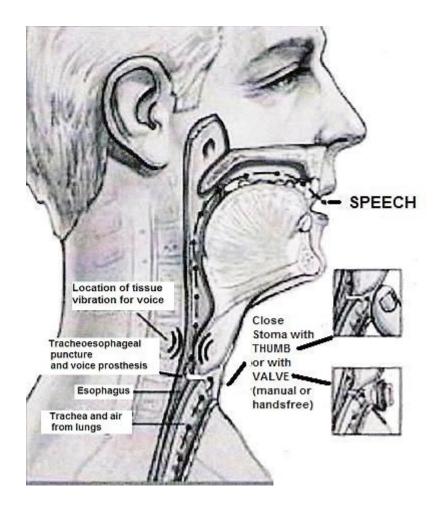


Esophageal Speech

Esophageal Speech is accomplished By injecting air to a point below the PE segment (see arrow) and as the air is allowed to return it causes the tissue at the PE segment to vibrate and voice is produced from those vibrations.

Not the A B C D procedure in upper left corner of diagram.

TRACHEO ESOPHAGEAL SPEECH (TEP)



Tracheo Esophageal Speech is accomplished by the presence of a Tracheo Esophageal Prosthesis which is inserted through the TracheoEsophageal Puncture (TEP).

The prosthesis diverts air from the lungs into the esophagus below the PE segment which causes the tissue of the PE segment to vibrate (as in esophageal speech). Intelligible voice is produced from these vibrations.

Note the inserts showing how to occlude the stoma with the thumb (or finger) or with a tracheostoma valve. The tracheostoma valve can be manual or automatic (handsfree).

The Whats and Whys of Laryngectorny.

Q. What is a laryngectomy?

A. A laryngectomy is the surgical removal of the larynx.

Q What is the difference between laryngectomy and laryngectomee?

A. Laryngectomy With a "y" is the surgery.

Laryngectomee with two "Es" is the person.

Q. What is the larynx and what is its function?

A. The larynx is the Adam's apple - the voice box. It is the organ of speech, located at the top of the trachea. As we breathe air in and out of the lungs it passes through the voice box. If we stimulate the vocal cords while exhaling it will cause them to vibrate and using our lips, tongue, etc. we are able to produce understandable speech from those vibrations.

Q. Why is a laryngectomy performed?

A. The most common reason the larynx is removed is because of damage caused by cancer. Depending on the amount of damage to the larynx, different amounts of the larynx may be removed. Because of the spread of the cancer, a laryngectomy sometimes necessitates the removal of surrounding tissues, organs, and/or lymph nodes. There are a few cases of laryngectomy being done for reasons other than cancer. But they are very rare.

Q. Does cancer of the larynx always mean the larynx will be removed?

A. At one time it did. But in recent years, new innovative procedures have been developed that allow parts of the larynx to be left.

Q. What are these procedures?

A. Supra-glottic, Hemi, and near total are descriptive names for recent developments of laryngeal surgery. These procedures remove only the diseased portions of the larynx. No stoma is created and the voice is left intact although it does have' the raspy esophageal voice sound. A very recent technique, developed in Germany, is Laser surgery, used for most head and neck cancers. This procedure is non invasive preserves the natural voice.

Q. Why is there a hole in my throat after laryngectomy? And what is it called?

A. The epiglottis, located above the larynx, acts as a gateway to direct the air to the lungs through the larynx, or the food to the stomach via the esophagus. With removal of the larynx, the epiglottis can no longer perform this function because there is a loss of connection to the trachea (breathing tube). Thus, as a part of the surgery, the trachea is directed outward, and secured to the neck to direct air directly to the lungs for respiration. This creates the hole in the neck. called a *stoma*. This is a permanent opening in the throat, by which you will breathe fur the rest of your life (see drawing "after laryngectomy"). The esophagus is left intact to direct foods to the stomach as before.

Q. How long must I wear the tube in my stoma?

A. Early on, the tube is worn to maintain the size and openness of the stoma. How long it is worn varies greatly with the individual. Some wear it permanently, some at night only, most do not wear it at all after leaving the hospital. Your doctor will make this decision based on the extent or type of surgery and other factors of your healing.

Q. How do I care for my tube?

A. It is very important to keep the tube clean and clear of any obstructions. The frequency of cleaning will depend on the amount of mucous generated by the individual which will collect in the tube, restricting breathing. To clean the tube simply remove it, and using a cylindrical bottle brush or a pipe cleaner push a piece of dampened gauze through the tube several times until there is no evidence of mucous. Soaking in warm water will loosen any hardened mucous that may be present. It is advisable to have two tubes. One in the stoma while the other soaks. Common peroxide may be used to soak the tube, with a thorough rinsing afterwards. Periodically the tube should be boiled or otherwise sterilized.

Q. What about dust or dirt getting in the stoma?

A. It is imperative that you keep the stoma covered. You must remember the stoma is now a direct connection to the lungs. Before your laryngectomy you breathed through your nose, which provided a goodly amount of filtering of the air you breathed. Not so anymore. The only filter you have now is any form of cover or filter you wear over the stoma. Dust particles - pollens - toxic fumes - etc. will no longer be 'filtered out when you breathe it in. Dust, while simply sweeping the floor, is now a bad guy. Without a stoma cover or filter, everything in the air now has an unimpeded path to your lungs. There are cases where flies and gnats have been breathed into an uncovered stoma.

Q. What would indicate that I have breathed unwanted particles in and what should I do?

A. Normally you will have a coughing spell, or a sensation of burning, depending on what the substance is. A toxic fume will elicit a sensation of burning or drying of the mucous. On the stoma cover you can see a round dark spot where the air passes through the cover and into the stoma. As this spot thickens breathing becomes noticeably more difficult. Normally the darkening of the' stoma cover is no problem, provided it is changed frequently. With a noticeable inhalation of unnatural particles the cover or filter should be replaced immediately. The stoma should be cleaned and flushing the trachea with a saline solution should be considered if there is a significant amount of foreign material in the trachea. If pain or bleeding occurs and cannot be stopped, you should seek medical attention.

Q. What kind of covering should I wear over the stoma?

A. There are many types and styles of covers. It should be of a material that permits free breathing, yet will prevent unwanted matter from entering the stoma. Many people wear a foam stoma protector of some type. They range from a 6" or 8" piece of material with straps around the neck to a small 2" or 3" square piece of foam that sticks directly to the skin with double sided tape. Others wear a "HME" (Heat Moisture Exchange) Filter which is much more effective at removing small air borne particles and helps retain heat and moisture in one's breath. HME filters require the use of a housing, tube or button to retain the filter. Also many wear fashionable covers on top of the covers or filters. Many of the larger covers can be washed and used repeatedly; the small stick on foam protectors and HME filters are one time use. All are readily available from several laryngectomy supply companies.

For looks, women wear high lace collars, necklaces, cameos, chokers or decorative scarves. Some Wear "pop beads". Men wear ties and or ascots. Both men and women wear turtle necks. The possibilities are endless.

Q. What can I do to avoid drying and crusting?

A. The first step to always wear a cover or filter. This will help keep the stoma / trachea moist and warm. Second, when you have a problem of drying, periodically spray directly into the stoma with a saline solution. Commercial solutions are available under several names such as Nu-Mist, Ayr and others. Wal-Mart has the Equate brand that is quite a bit cheaper than the others. However you can make up your own saline solution by adding 1/8 teaspoon of Kosher salt to one cup of boiled water. Do NOT use table salt. Adding 1/8 teaspoon of baking soda will adjust the PH balance.

In extreme situations you can relieve the condition by sitting in your bathroom with the shower running full blast with only hot water. The resulting steam filled air will quickly loosen the crusted mucous and permit a good cleaning.

Q. Can I smoke? Drink?

A. Smoke only if you want to continue to increase the chance of the cancer returning. If alcohol is consumed, moderation is always advisable.

Q. Will I be able to swim with the hole in my throat?

A. Most doctors do not approve or recommend that laryngectomees swim. Many laryngectomees, however, have found they can, with great caution, still enjoy a "dip in the pool" (shallow end only, for obvious reasons). Also, there is a swimming aid know as a "Larkel" which is much like a snorkel attached to the stoma.

Q. Can I return to work?

A. Yes. Most all laryngectomees who had the surgery while they were still working returned and were very productive workers, in fields ranging from Carpenters and Painters to Doctors and Lawyers. How soon you will be able to return to work will depend on such things as the speed of your healing and your ability to learn a new means of communication.

Q. Are there any special precautions to take when I return to work?

A. Yes. If you work in an industrial environment, with dust - fumes - or anything of that sort, extra care must be taken to filter the air you breathe. If you wore special breathing equipment before your surgery it must now be adapted to fit over the stoma. In a non industrial environment care should still be taken to keep the stoma covered and the cover kept clean.

Q. Should I avoid heavy lifting?

A. No, not really. In most cases your laryngectomy will not be the main factor in any restrictions on lifting. After you are completely healed you will usually be able to lift the same amount of weight as before your surgery.

Q. What is meant by the terms "Radical Surgery" and "Lymph Node Dissection"?

A. The terms radical surgery and lymph node dissection are usually combined into the one term "Radical Neck Dissection". This can be unilateral or bilateral (on one side or both). This means that lymph nodes, muscles, nerves and tissues have been removed from the neck. This is done to insure that no cancerous cells were left to spread through the lymphatic system. This causes a drastic change in the appearance of the neck. The shoulder on the side affected droops markedly and sensitivity is lessened. Upward movement of the arm is reduced. There are rehabilitation procedures designed to increase the use of the shoulder and neck muscles.

Q. Is there a simple exercise that is beneficial in the case of radical surgery?

A. Yes. A simple procedure that requires no equipment is to simply stand sideways against a flat wall or door jamb. Raise the affected arm as high as comfortably possible, the use the fingers of the extended hand to "walk" up the wall or door jamb, until the arm is extended to full length. If the surgery was bilateral do this with each arm. This should be done several times a day. Regular practice will restore good use of the arm and shoulder. Your SLP or Doctor will give you more instruction for rehabilitation.

Q. Will radical surgery make leaning to speak more difficult?

A. No! It will have no effect on learning to speak.

Q.-What is a fistula?

A. A fistula is an abnormal duct or passage resulting from injury; disease, or a congenital disorder that 'connects an abscess, a cavity, or a hollow organ to the body surface or to another hollow. For us there is a good and a bad fistula. A good fistula is one surgically created (TEP) for insertion of a voice prosthesis. A bad fistula is one that forms as a result of improper healing.

Q. What is the PE segment?

A. The PE segment is the newly formed connection of the Pharynx and the Esophagus. This is where the Pharynx and the Esophagus were connected after the larynx was removed. This is the new source of sound for esophageal and TEP voice.

Q. What is an insufflation test?

A. The insufflation test is a procedure to determine the ability of the PE segment to function properly. A 16 French catheter is inserted about 25 centimeters down the throat, via the nasal passage to a point below the PE segment. Usually; the speech pathologist, or the doctor, will blow air into the tube while the patient tries to relax and let the air return up through the mouth. This return of air will cause the PE segment to vibrate and a sound will be heard. The quality and tone of this sound will be used to decide several things.

If the sound is constant and of constant volume, "ahhhhbhhhhhh", it may be concluded that the PE segment is functional, and a prosthesis should produce good sound. If the sound is strained and sporadic "ah--ah--ahhh-ah-abhh-ah" it means the PE segment is either too tight or the muscles around the throat are too tight, thus not letting the air return. When there is good sound the decision may be made to go with the prosthesis. If there is not good sound there is certainly no reason to try the prosthesis, and it may be determined to perform a myotomy.

Q. What is a myotomy?

A. Myotomy is a minor surgery, done after laryngectomy, to cut some of the neck muscles to relieve constriction of the esophagus. This is done to enhance the ability to attain esophageal, or permit more efficient TEP speech.

Q. After laryngectomy, will I regain my sense of taste?

A. Yes, in time your taste will likely return to near normal, if not even better than before surgery if you smoked because years of smoking "numbed" your taste buds to the point that your taste wasn't nearly what you thought it was. As the taste buds recover, your taste will become a pleasure again. However, only bitter, sweet, sour and salt tastes are sensed with the tongue; all other "tastes" are actually sensed by the olfactory buds in one's nasal passages and these are not as "productive" as pre-surgery (as explained in the following answer) and hence your taste may be "different" than before.

Q. Will I be able to smell?

A. Yes, but not quite as well as before. Because have to breathe through our nose to smell we wrongly think we have lost our sense of smell. Again, there are procedures and techniques that can be taught to greatly enhance your sense of smell. Your SLP, or another laryngectomee, can explain techniques to enhance your ability to smell.

Q. How can I blow my nose?

A. You can be taught to expel the air that is in your mouth out through your nose and effectively blow it. If you voice with TEP, you can force air through your nose by occluding, closing your mouth and expelling air from the lungs. Again, your SLP or a laryngectomee can explain these techniques.

Q. Will I have difficulty swallowing?

A. You might or might not. As indicated by the diagram on the following page, certain muscles are affected by the surgery. Also, after surgery the anatomy of your throat and esophagus changes with the healing process and the final condition of your swallowing "mechanism" can not be pre-determined. If you do have difficulty swallowing, cut your food into small pieces, chew thoroughly and drink lots of liquid. However, if you still have problems swallowing, or if there is any pain associated with swallowing contact your Doctor. On a positive note, be aware that if a piece of food sticks in your throat it will NOT cut off your breathing as before. All you will have to concern yourself with is either getting it down or back up and you will be able to breath normally through your stoma during the process.

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These muscles are in the operative area and are affected by the surgery. As a result, swallowing can be compromised and food or liquid in the esophagus is likely to be "regurgitated" back into the mouth when bending over or lying down prior to the food/liquid being completely in the stomach.

Q. Will cold weather affect my stoma?

A. Yes., in cold weather there is less humidity in the air and it will tend to dry the stoma, causing the mucous to harden. As a result, it is even more important to wear stoma covers and filters in cold weather. Also, drink lots of water to keep the body hydrated which will aid in minimizing mucous.

Q. What humidity level is best for a laryngectomee?

A. 40% to 60% humidity is pretty well accepted as the best level for the laryngectomee. Cold, dry or dusty air is to be avoided. In general, laryngectomees fare better in the summer months, and warmer climates. Digital hygrometers can be purchased very inexpensively and are a good bet for laryngectomees to be certain their humidity level is where it needs to be.

Q. What can I do to increase humidity?

A. Use a room humidifier; just be sure not to use one that leaves a white powdery deposit -- that will also be taken into your lungs and is very hard on electronic equipment as well. Boil water and breathe the steam into the stoma. Routine use of a saline solution or in extreme cases turn the shower on hot and sit and breathe the steam.- A good stoma cover will trap the humidity in normal breathing -- wet the stoma cover and as you breathe through it the moisture will be taken in.

Q. How does air conditioning affect the laryngectomee?

A. In the process of cooling the air, air conditioners extract moisture from the air, so the humidity needs to monitored continually. Even so, air conditioning is recommended, because the laryngectomee seems to need a movement of the air. Many times a ceiling fan will serve the purpose. Most of the time humidity is not a major problem. If it becomes a continuing problem consult your physician.

Q. Are there things I should avoid?

A. Yes. Avoid areas where toxic or agitating fumes, dust or any thing that will irritate the stoma or trachea are present. Be particularly careful when showering. If you go out on a boat be sure of it's seaworthiness. One technique is to wear two life preservers, one in the normal manner and the other backwards on top of the first. This will help keep the neck above the water line if for some reason you have to go in the water. There is also a "High Lift" inflatable life vest available which is much better than the standard vests, BUT don't depend on 'this too much. Remember, if your stoma goes below the water line for longer than you can keep it occluded you will almost certainly drown.

If you do not cover your stoma,' do not eat small or crumbly foods while lying down.

Q. Can I shower with the hole in my throat?

A. Yes, there are devices to prevent water from entering the stoma. Some laryngectomees wear a baby's bib with the plastic side out while showering. Wearing your stoma cover/filter might provide sufficient protection, especially if you direct the flow of water away from the stoma. When washing the hair, if you make sure the chin is lower than the stoma (by bending over) the water will not get in the stoma. Any water that may get in the stoma will cause a lot of coughing, but no real damage unless it is a direct flow of water into the stoma.

AN EXTREMELY VALUABLE SOURCE OF INFORMATION, HELP AND SUPPORT CAN BE FOUND AT: <u>WWW.WEBWHISPERS.ORG</u>

ALL LARYNGECTOMEES AND THEIR CAREGIVERS SHOULD ACCESS THIS WEB SITE AND GO TO THEIR LIBRARY FOR ALMOST UNLIMETED INFORMATION ON LIVING AS A LARYNGECTOMEE AND POST ANY AND ALL QUESTIONS YOU MAY HAVE -- YOU WILL RECEIVE ANSWERS FROM FELLOW LARYNGECTOMEES WHO HAVE WALKED IN YOUR SHOES.

SOCIAL ACTIVITIES

Q. Should I attempt to mingle socially?

A. Absolutely. The quicker you get out among people the better. Go out to eat – place your own order, take every opportunity to discuss issues within a group, use the phone often, etc.

Q. Are there special problems for the married to a laryngectomee?

A. Yes, two things are happening. One person has to learn to live as a laryngectomee and the other has to learn to live WITH the laryngectomee and these two are very different things. Early on the laryngectomee must learn to be patient while healing and learning how to communicate with his/her new voice.

SPOUSAL QUESTIONS

Q. Whether it is asked or not, the foremost question on the mind of a spouse is "Am I going to lose my partner?".

A. Laryngeal cancer is second only to skin cancer in curability. There are laryngectomees that had their surgery 30, 40, 50 years ago and are living happy fulfilling lives. There is very good reason to believe you and your spouse will have many good years together.

Q. What about the cancer? Will the surgery cure the cancer?

A. No, laryngectomy does not "cure" cancer, it removes the cancer that was there.

Q. After the cancer is removed will we then be cancer free?

A. This is where the term "one day at a time" comes in. Statistically, if we survive $2\frac{1}{2}$ years we will have a good chance of surviving 5 years at which time we have a good chance the cancer will not return.

Q. How will the laryngectomy affect our sex life? (This is another question not always asked.)

A. In general it will have no real affect on your sex life. Many laryngectomees, in fact, find their sex life improves after surgery, particularly if the laryngectomee has been a heavy smoker.

Q. After the laryngectomy, will we be able to do all the things we need to do?

A. The fear of the unknown is the worst kind of fear. Yes, you both will be able to do everything needed to live a happy, normal life.

Q. What about normal activities such as yard work, motor trips, attend sporting events, etc.?

A. Yes – Yes – Yes. The only real change will be the sound of your spouse's voice unless, of course, he/she likes to YELL at sporting events or go scuba diving.

Q. Why does my spouse talk to other people but "mouth" his words to me?

A. Your spouse is being lazy -- don't allow it! It is in the laryngectomee's best interest to always talk at the best of their ability. Practice is key to a good voice for a laryngectomee and the best practice is to DO!

Q. Where can I get the information I need to know in order to properly care for my spouse?

A. You will be instructed by a doctor, nurse or SLP as to what is required of you. If not, INSIST on being informed -- it is their professional responsibility. But, the laryngectomee should soon be caring for him/herself so do not over extend your care when this time comes. You should both participate in a local support group to learn all the ins and outs of being a laryngectomee and caregiver.

Most rehabilitation material is directed to the laryngectomee; the spouse, however, has to face almost as many new things as the laryngectomee. The best thing you can do is, along with the laryngectomee, join and participate in a local support group where you will be able to interact with other spouses.

Q. What are the benefits to attending laryngectomee club meetings?

A. They are immeasurable. Contact with other laryngectomees will give you a feeling of. Confidence and you win see others in your same predicament. You will see many who have gotten through your present stage of recovery and are coping with everyday life You will see and hear laryngectomees at every stage of speech development.

A support group is the caregiver's handbook. One can talk to and relate to others who have "been there, done that". Contact other laryngectomees and their caregivers as often as you can; you will be amazed at their desire to offer help and support!

Q. How can we communicate when I'm in the other end of the house?

A. There is no one easy answer to this question. Much depends on the nature of the couple's existing relationship as well as the mobility and voicing capabilities of the laryngectomee. If the laryngectomee is ambulatory a signaling system such as a bell or clap of the hands might be considered. In any case, mutual consideration of and for each is crucial.

Q. Sometimes I feel guilty because I want to continue to do some of the things I did before the surgery, like going to the beauty shop, but I'm afraid to leave him.

A. You should not! Life must go on. The sooner you both go back to your lives the better. Daily things such as shopping must continue. Look back at the last question. When you go out for whatever reason, call the house and when he answers ask yes and no questions. Again, determine ahead of time what taps on the phone mean. One tap could mean yes - two = no - three = I don't know - a series of taps could mean come home immediately I need you.

Q. I get very lonely because of the silence and that makes me feel guilty.

A. Don't feel guilty. It is a normal reaction. Plan activities with friends and family to bring activities back into your life.

Q. Why do people you have known for years drift away from you now?

A. This is a hard question to answer. Perhaps it is because they are not sure of how to respond. If they just slowly move a way, they don't have to respond.

Q. Why does the laryngectomee whisper to the spouse and talk to others?

A. A question restated. Speaking with esophageal or TEP speech can be a tiring procedure. Using the electro larynx is somewhat time consuming (having to pick it up, place it properly, then talk. Many times with the spouse the statements are short and the speaker is simply trying to make the comment quicker and with the least effort. The spouse should discourage this type of response.

Speech After Laryngectomy

Q. How will I be able to speak if the surgery removes my vocal cords?

A. There are three common ways for a laryngectomee to speak after surgery:

1) Electro Larynx

2) Esophageal Speech

3) TracheoEsophageal Speech (TEP)

Also, there are new electronic devices being developed, referred to as "Artificial Larynx", that are being used by some.

Q. What are the differences?

A. 1) The electro larynx is a battery driven device that produces an audible vibrating sound. When the "head" of the EL is pressed against the lower chin or neck area the sound is transferred into the throat which is, in turn, transmitted into the throat. The sound is then formed into intelligible speech by the mouth, tongue and lips.

2) Esophageal speech is produced by taking air down the throat to a point in the esophagus below the PE segment (the junction between the pharynx and the esophagus), then allowing the air to return causing the PE segment to vibrate and voice is formed from these vibrating sounds.

3) TracheoEsophageal Speech (TEP). The prosthesis connects the trachea and the esophagus, directing the lung air into the esophagus when the stoma is occluded causing the PE segment to vibrate and speech is produced from these vibrations.

Q. When will I be able to start learning?

A. It depends on several factors -- how fast you heal- what type of voice you choose -- availability of a competent instructor. You can begin EL (Electro Larynx) training with an oral adapter prior to your surgery. As soon as the throat tissue is pliable enough to effectively transmit the sound into the throat/oral cavity you can start learning normal use of the EL with the "head" pressed directly against the lower chin/upper throat and finding your "sweet spot".

Esophageal voice training is usually not started until after any radiation treatments you may be required to take. If none, then as soon as the throat is sufficiently healed to stand the strain of the muscular activity needed to make sound.

TEP voice instruction can only take place after the prosthesis has been inserted. This can be within one week of the surgery or months, depending on your healing process and the protocol practiced by your medical team.

Q Where will I find a speech instructor?

A. In most cases your ENT will refer you to a speech pathologist connected to the medical facility he/she is connected with. The local American Cancer Society is another source. The IAL (International Association of Laryngectomees) has a website <u>www.theial.com</u> where they list Qualified Instructors around the world. The FLA (Florida Laryngectomee Association) <u>www.flavoice.org</u> also has a list of instructors in Florida. And there are state organizations in several other states who also maintain a list of instructors. The IAL also has a listing of local laryngectomee support groups who will often have a speech pathologist they work with who can provide the training required. Additionally, the internet based laryngectomee support group <u>www.webwhispers.org</u> is an invaluable source of information. Q How long will it take to learn to talk?

A. The most famous laryngectomee statement is "all laryngectomees are different". This means there is no answer to this question. If you ask how long will it take to be a good speaker - the answer is "from now on". The laryngectomee learns something new and different every day to enhance his/her voice. The more you practice the better you will be.

Q. Will I be able to talk on the telephone?

A. Yes. You will be able to talk on the telephone using any of the three forms of speech; it is, however important that you be aware your new voice requires EXTRA effort on your part to be easily intelligible, especially on the phone. Early on when learning, call a friend on the phone to test your voice. The more you communicate with people, whether on the phone or not, the better you will get. Concentrate on enunciation and speaking slowly. Special amplifying telephones are available in many states. See your SLP or go online for details.

Q. Is it difficult to learn to speak using these techniques?

A. Yes and no. The electro-larynx takes very little training and is immediate. TEP speech is almost as immediate, but it does have other considerations such as another minor surgery to insert the prosthesis (the surgeon may opt to perform the puncture at the time of the laryngectomy which would eliminate the need for the secondary minor surgery). Some training for speech and maintenance of the prosthesis is required. Esophageal speech generally requires extensive training and practice to accomplish

Q. Which is the best way for me to speak?

A. To say one way is better than the other is hard to say. It depends so much on the individual. Some laryngectomees are restricted because of the results of the surgery as to what type of voice they can best handle. In the end, the best for you is the one that works for you.

Q. Will I be able to learn to use one of these methods?

A Yes! The more effort you expend the better you will be able to speak, whichever method you choose.

Q. How will I communicate until I can talk?

A. Early on, in the hospital you will communicate by writing. Be sure and take an "erasable marker board" and LOTS of marker pens (figure one per day). If you purchased on got on loan from a laryngectomee support club an electro larynx you <u>might</u> be able to utilize the oral adapter "straw" for communication. You won't know unless you try it! From there it will depend on what method of voicing you have chosen, your doctor's criteria and your individual recovery situation -- remember, EACH laryngectomee is different.

Q. Is it true that a laryngectomees cannot talk while under emotional stress?

A. Yes, this is true in general terms. However, the laryngectomee will learn to somewhat control this reaction. This emotion can be a bad or good emotion, either way the laryngectomees is momentarily unable to speak well. The secret is to relax and speak slow and soft. Do not be afraid to let people know you have trouble voicing when "choked up". Sometimes the laryngectomee becomes frustrated and upset when someone cannot understand him. This is like a snowball rolling downhill. The more frustrated the speaker gets, the less he is understood. Again, stop - relax - slow down – gather yourself - then speak soft and slow.

Q. Why do people shout at me when they talk to me?

A. That question is as old as the first laryngectomee. If they have difficulty hearing or understanding you, it is probably the same as many hard of hearing people talking loudly -- because they can't hear well they feel you can't either.

Q. What about an emergency, when the laryngectomee may be unconscious?

A. An organization called "Medic Alert" maintains a medical history of persons who might face just such a situation. They provide the individual with a bracelet or a pin that has a phone number to call to get the medical information needed to treat the person. You must apply for this yourself. Your Doctor, SLP or the ACS has the information for registration. Also, there are decals, necklaces and bracelets available which identify us as "neck breathers" and contains other important information about our care and contacts.

Q. Does the surgery sometimes prevent one form speaking?

A. Yes, it is possible, but such cases are extremely rare. I would not anticipate such a condition unless the surgeon advised, pre-op, that it was a likely outcome.

TEP Questions & Answers

Q. What is TEP speech?

A. It is a form of alaryngeal speech produced by using a prosthesis.

Q. What does TEP stand for?

A. There are two commonly used terms. While both are used to describe one form of alaryngeal speech, one is more correct than the other when discussing speech. Tracheo Esophageal Puncture is the term that correctly describes the surgery that creates a designed fistula (hole) between the esophagus and the trachea. This is done to permit use of the Tracheo Esophageal Prosthesis.

The Tracheo Esophageal Prosthesis is the device inserted into the puncture that directs the lung air through the puncture into the esophagus generating the vibrating sounds' necessary for voicing.

Q. What is done in the Tracheo Esophageal Puncture procedure?

A. A fistula (hole) is created through-the common wall between the esophagus

Q. How much does it cost?

A. The cost will vary with the Medical Facility and the amount of testing or pre surgery treatment necessary. When it is done at the time of the laryngectomy the cost is included in the cost of the laryngectomy When it is done later, it is a separate outpatient surgery and has its own cost.

Q. How does the prosthesis work?

A. The prosthesis is a small tube made of silicone with a one way valve in the esophagus end with flanges to hold it in place. The device is inserted into the fistula with the valve end resting in the esophagus. When the stoma is occluded, (covered to prevent air from escaping while exhaling), it forces the air through the one way valve into the esophagus. As the air passes through the esophagus into the mouth it causes a vibration to take place in the esophagus. This vibrating sound is converted into intelligible speech by the mouth, tongue and lips.

Q. How long do the prostheses last?

A. This is a hard question to answer. The life of a prosthesis depends a lot on the maintenance schedule of the user. Depending on the maintenance provided and the type of prosthesis it may last a few weeks up to several months. Many prosthesis failures are due to yeast infections.

Q. What is yeast infection and what causes it?

A. Yeast infection is a growth in the mouth and throat of the fungus Candidas Albicans which may develop and grow on the prosthesis. This will generally cause the prosthesis to leak which will require a new prosthesis. Once the yeast has grown on the prosthesis it can not be removed. Yeast can generally be controlled by the drug Nystatin and/or a regimen of Acidolphilus, a bacteria naturally occurring in milk products. It can also be purchased OTC in tablet or capsule form. Your ENT or SLP can determine if you are experiencing a yeast problem.

Q. Is there more than one kind of prosthesis?

A. Yes. While there are several manufacturers, there are two basic types of prostheses. The "standard" type is inserted and removed by the laryngectomee. The expected life span of this type is three to four months. The "Indwelling", which must be inserted and removed by a physician or a speech pathologist, is expected to last four to six months.

Q. What are the advantages of one over the other?

A. Each type has advantages and disadvantages. The "standard" TEP may be removed and inserted by the laryngectomee thus eliminating their dependence on medical personnel for such procedure. Also, the standard does not last as long; however, it is less expensive. It can, and must be, cleaned (in place) daily with a pipette or syringe and/or prosthesis brush; some also use tweezers. The number of times daily cleaning will be required depends on the laryngectomee's mucous situation. Some users find it will last longer if it is removed and soaked Hydrogen Peroxide every few days.

The "Indwelling" lasts longer. Even though it is expected to remain in place for four to six months, many laryngectomees wear theirs much longer. The indwelling will also require daily in place cleaning. It can only be removed or inserted by a physician or a speech pathologist.

Each type of prosthesis is equal in its ability to produce voice.

Q. Are there problems associated with the TEP?

A. There are several things that can happen. Yeast infection or the body's reaction to a foreign body can cause a leakage around the prosthesis. Irritation from removal and replacing of the prosthesis can also cause problems. But these can generally be very well controlled by medication and proper stoma care In worst case conditions the prosthesis may need to be resized and replaced.

Q. What is the Hands Free valve?

A. Normally the thumb or finger is used to occlude the stoma to permit TEP speech. The Tracheostoma hands free valve is a device that fits in a housing over, or a "button in, the stoma. It is a normally open valve, which permits normal breathing. When you exert more air pressure, by inhaling a little deeper and then exhaling with more force, the valve will close diverting the air into the esophagus and out the mouth, creating speech.

Q. Is TEP speech better than the other forms of speech?

A. Like so many other questions about laryngectomees, there is no yes or no answer. Each method has advantages and disadvantages and each laryngectomee must find that method which suits him/her the best.

Electro-Larynx speech:

Advantages: It is immediate -- requires the least amount of instruction and less maintenance than TEP. Disadvantages: Unnatural sound, dependent on batteries, harder to attain enunciation and harder for some to understand. Requires the use of one hand to operate.

Esophageal speech:

Advantages: Requires no maintenance, leaves both hands free and appears to be natural speech. Disadvantages: Hardest to learn, little volume control and momentarily affected by food/liquid intake.

TEP speech:

Advantages: Most efficient form of alaryngeal speech, requires minimal amount of training, produces more volume and length of utterance and with use of Handsfree valve both hands are free.

Disadvantages: Requires most amount of maintenance, requires one hand to occlude if Handsfree valve not used, may increase out of pocket expenses to laryngectomee depending on insurance coverage.