Biggest Threat to Lary Health and Safety

"Aside from (larynx cancer) **recurrences and new primary cancers, what do you think is the biggest threat to laryngectomee health and safety?"**

This question was asked of more than 40 SLPs (Speech/Language Pathologists, speech therapists), and a half dozen medical doctors from across the United States. The group replied listing dozens of threats. However, more than half answered with some version of this threat:

"A lack of basic knowledge of laryngectomees and their changed anatomies and their breathing by medical professionals (such as confusing tracheostomy vs. laryngectomy), and subsequent inability to provide appropriate treatment. These professionals include pulmonologists, respiratory therapists, primary care physicians, nurses, anesthesiologists, SLPs, and ENT MDs." A follow-up question was sent to each person who responded to one above: **Is there *anything laryngectomees can <u>do</u>* about this problem?**

It would be impossible to list and explain all of the threats listed by those who answered within one article. So the issue of a lack of knowledge by many medical personnel about laryngectomees, their changed anatomies and the implications for appropriate medical treatments will be discussed in this article. Other threats will be covered in future issues of the *IAL News.*

There are many things laryngectomees (and/or their family members, caregivers, companions) can do to increase the odds that laryngectomees will not be injured by medical personnel who do not understand our changed anatomy and the implications for the treatments they provide us.

<u>Things you can do:</u>

1. **Identify yourself as a laryngectomee.** Many of us wear identification bracelets or necklaces. There are rubber bracelets which are bright orange or red and state: ALERT: NECK BREATHER - RESUSCITATE BY NECK, and NECK BREATHER RESUSCITATE VIA NECK STOMA. There are some bracelets which state "Laryngectomee. Total Neck Breather."

Some laryngectomees buy *Medic Alert* bracelets or necklaces which state the same information. They contain a 1-800 number that medical personnel can call and be told your medical information. This would be especially important if a laryngectomee arrived at an emergency room alone, unconscious and without a wallet or cell phone.

Always wear neck breather bracelets or necklaces 24/7. These are waterproof and don't need to be removed for any reason. We should also consider obtaining and carrying wallet cards which provide needed information for medical personnel and first responders. Some bracelets and cards are available for free (see below).

If you have a home alarm system it may have a button you can push for medical emergencies if you provide the alarm company with the information that you are a total neck breather. They would pass that along to emergency responders. Have an ICE (In Case of Emergency) phone number listed in your cell phone.

Contact your 911 administrator, local fire department, police and/or rescue squad and provide them with information that you are a total neck breather and to apply oxygen only to your neck. Tell them that a child or infant sized oxygen mask will fit over your stoma.

Get car window stickers which provide information to place on the inside of rear window glass (also available free). Obtain or make bedside signs stating that "Patient is total neck breather. Apply oxygen to stoma." When going for a medical appointment with a new doctor, to a pre-surgery visit, or if going to the emergency room bring information about being a laryngectomee including the before and after laryngectomy surgery graphics available (and discussed next).

Atosmedical.com 1 (800) 217-0025 Electrolarynx.com 1 (800) 388-8642 File of Life - folife@folife.org. 1(800) 814-1788 Inhealth.com 1-800 477-5969 Lumimaud.com. 1 (800) 255-3408

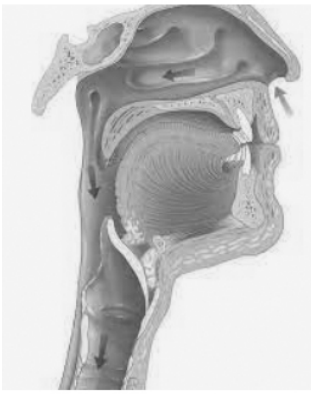
A lary recently died in an emergency room waiting area. He went because he was having a terrible time breathing. The admitting nurse classified him as a low priority <u>trach</u> patient and told him to sit (for what is typically an 8 hour wait). He died there of a mucus plug. It isn't known if they tried to revive him with an oxygen mask over his mouth and nose.

Local fire departments may give out File of Life kits (or buy for .89 cents). The File of Life is a magnetized medical record holder that goes on your refrigerator. Emergency responders are trained to look for them. (see previous page)

2. Learn how your breathing (respiratory) system has changed, and what you can do to improve the quality of the air you breathe.

It is helpful to know how your breathing system worked before you became a laryngectomee. What follows is an explanation of the breathing system of non-laryngectomees and how it worked before laryngectomy surgery:

Upper breathing system



Air enters the nostrils of the downward facing nose. Large particles in the air may catch on nose hairs. The area above the nostrils is called the *nasal cavity*. The surface is typically coated with mucus and it catches contaminants such as dust, fibers, pollen, viruses, bacteria, etc.

The curved ridges in the nasal cavity cause the air to tumble, and more of the contaminants are trapped in mucus. Our noses may run and the mucus may need to be blown into a tissue, or a tickle sensation can cause a sneeze. This also helps remove the contaminants.

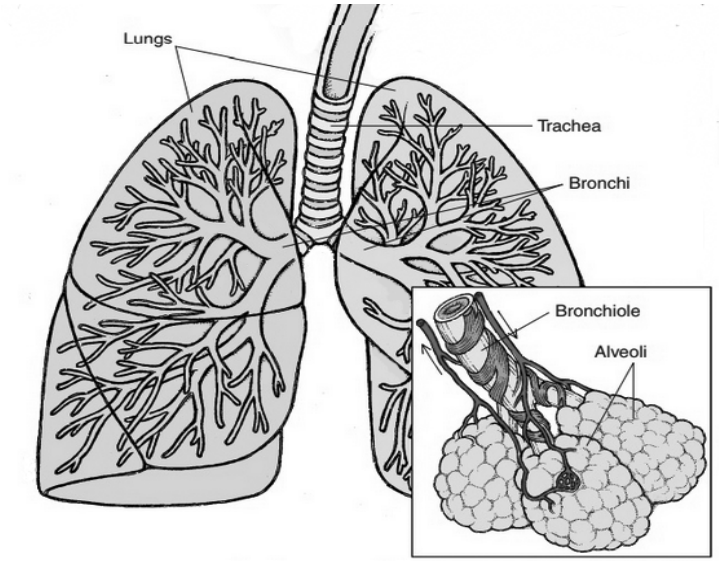
There are many causes of a runny nose. Pollen may still get in your nose, or your nose can react by producing more mucus because the air is cold, dirty, or dry. Saline spray helps.

The air then travels down the back of the throat (*pharynx*), which is also mucus coated, through the larynx (voice box), and down the wind pipe (called the *trachea*).

It continues down the trachea and into the lungs and then into the branches of the lungs called *Bronchi.* These are like the large branches of a tree.

These further divide into smaller branches, and even smaller ones (see *Bronchiol*i in the insert in the graphic to the upper right.)

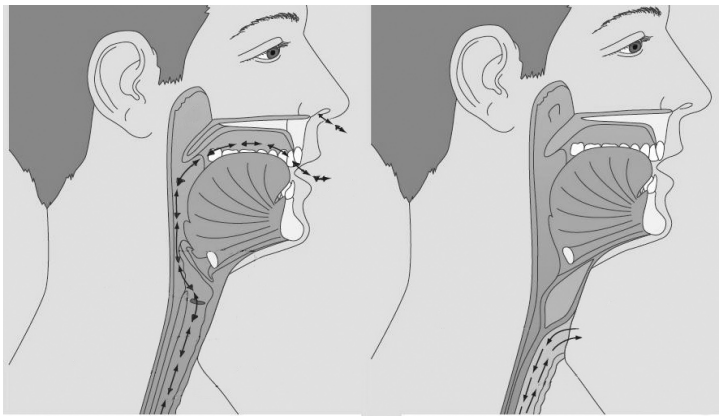
At the end of each of these small branches are sacks (called *alveoli*). This is where waste gas, carbon dioxide, is exchanged for oxygen which is then carried throughout the body by the blood stream. By the time the air gets to the *alveoli* sacks in the lungs it is body temperature (98.6 degrees F), 100% humidity (like fog), and usually very clean.



Laryngectomy surgery removes the voice box (l*arynx*), brings the windpipe (*trache*a) forward to the front of the neck/upper chest, creates a hole there (the *stoma*), and stitches the *stoma* to the t*rachea*. *Now, when the laryngectomee inhales the air bypasses the <u>entire</u> upper respiratory system.* It now only goes down a short length of the trachea and directly into the branches of the lungs. <u>The air is cooler, drier and dirtier.</u>

Breathing Before Laryngectomy Surgery

Breathing After Laryngectomy Surgery



The cooler, drier and dirtier air can cause many problems, including serious ones. But there are things laryngectomees can and should do to improve the quality of air they breathe:

First, ***cover the stoma at all times...24/7.***

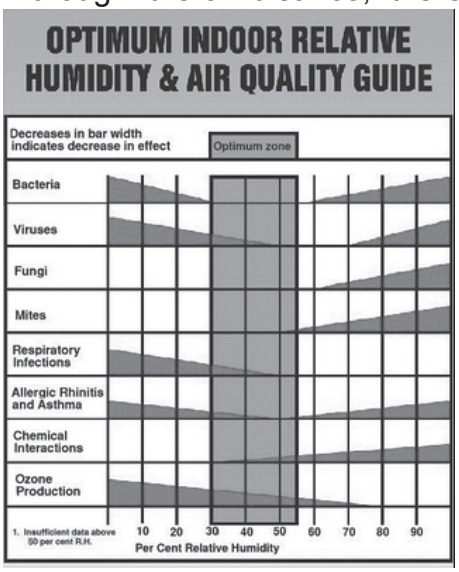
Stoma covers vary in how effective they are in screening out dirt, dust, smoke particles, viruses, bacteria, etc. The most effective are those where all air entering the stoma is filtered. These are the HME (Heat/Moisture Exchange) filters which attach to the stoma with a glued-on housing, or inserted into a lary tube or button.


Lary Button with HME

Other types of covers include the foam patch, combination mesh fabric with foam insert, cloth types including lined ones, and others. The most effective at cleaning the incoming air are those which filter out the smallest particles.

Second, ***maintain a free flow of mucus.*** Mucus is <u>essential</u> for the health of our lungs! It is the natural way the lungs bring contaminants up and out. It also keeps the lungs and trachea (windpipe) coated and protected. Without the free flow of mucus upwards the trachea can dry, crack, bleed, and become an entry way for germs. It can cause respiratory disease including pneumonia, which is a major killer. Mucus is 95% water.

Without mucus moving upwards, mucus plugs can form (including fatal ones) which partially or completely block breathing. The color of mucus can tell us if we have a prosthesis leak (if you wear one), or if we have a respiratory infection. Healthy mucus is clear or whitish, and we need to cough it out a number of times a day. Although it is a nuisance, it is essential to our health.



The major threat to free flowing mucus in larys is dryness. Keeping well hydrated with water helps; so drink plenty. Tea and coffee actually dry you out. It is recommended that laryngectomees keep their indoor humidity at between *40-55%*. This is the zone for maintaining the healthiest indoor air (see chart bottom left)


$13 Humidity Gauge

If you have a whole house humidifier you can set it like you do the thermostat. If not, you can get a humidity gauge and one or more portable electric humidifiers. Many prefer the steam type humidifier since it uses tap water and does not disperse the minerals dissolved in tap/well water as dust.

$15 Portable Humidifier

In order to loosen mucus many laryngectomees use “pink bullets” (salt dissolved in sterile water) which come in sealed plastic containers, or use salt nasal sprays like *NeilMed Nasal Mist* or *Simply Saline*. Check the spray bottles to confirm that they only contain purified water and sodium chloride (salt), with sodium bicarbonate. A brand without sodium bicarbonate is *Little Remedies Nasal Mist*.

“<u>Never</u> assume that medical staff understand how you breathe” ***Brian Shute, Ph.D., CCC-SLP***

Never let medical personnel put an oxygen or anesthesia mask on your mouth and nose without questioning them on whether they understand that you are a laryngectomee and total neck breather.

Compiled by David Blevins

Part Two on threats to laryngectomy health and safety will appear in the July issue of the *IAL News*.

Biggest Threat to Lary Health and Safety

Part 2. Part 1 appeared in the May edition of the IAL News

Part 1 can be read at TheIAL.com under Publications-*The IAL News*. If you have not read it, please do. Part 1 reported on a survey of over 45 speech therapists and a half dozen MDs. The threat to laryngectomee health mentioned by the majority was: **"A lack of basic knowledge of laryngectomees and their changed anatomies and their breathing by medical professionals (such as confusing tracheostomy vs. laryngectomy), and subsequent inability to provide appropriate treatment. These professionals include pulmonologists, respiratory therapists, primary care physicians, nurses, anesthesiologists, SLPs, and ENT MDs."**

Part 1 stated that laryngectomees can minimize the chances that medical professionals will injure them and even cause their deaths. Several things were recommended:

1. Identify yourself through bracelets and necklaces, cards carried in wallets or purses, notifying first responders ahead of time, use car window stickers, and others.
2. Learn how your breathing worked before you became a laryngectomee and how it now works. Know that you are a *total neck breather*.

The article also stated that the air reaching our lungs is now dirtier, drier, and cooler.

Never let an oxygen mask be placed over your nose /mouth, or a tube down your throat.

It described ways to improve our breathing by urging us to wear a stoma cover 24/7, maintain an indoor humidity level of between 40-55%, and listed ways to maintain a good flow of mucus (which is essential for healthy lungs and windpipe.) It concluded with a quote and the advice to never allow medical personnel to put an oxygen or anesthesia mask over your mouth and nose, or a tube down your throat, without questioning them on whether they understand you are a laryngectomee and total neck breather.

It is a sad fact, but **laryngectomees (and their loved ones/caregivers) must stand guard and advocate for themselves until they are certain that medical personnel who will provide treatment understand our changed breathing systems.**

Like anyone else, we would like to fully trust a doctor, nurse or other medical provider we have gone to for treatment. It really seems an unfair burden on us to possibly have to educate these professionals about how we breathe. Unfortunately, the facts tell us that we should ask questions and make sure they understand what a total neck breather is.

"Never assume that medical staff understand how you breathe." ***Brian Shute, Ph.D., CCC-SLP***

A Laryngectomee's Nightmare

A lary was scheduled for spinal surgery. Hospital records clearly stated: "total neck breather." The surgeon, nurse anesthetist and anesthesiologist either hadn't read the record, or had not understood it. They tried to give her oxygen and anesthesia down her throat. Things went south and they called an emergency code with doctors racing to the operating room. Some doctor removed her TEP prosthesis, and then another thought the TEP puncture was a tear in the trachea and tried to repair it. She could have suffered brain damage or died. She survived when she was transferred to a hospital that knew how to treat larys. It is not known if she sued the first hospital. (Reported by a medical doctor.)

On His Deathbed

A Speech Therapist (SLP) stopped to visit a hospitalized laryngectomee friend who was dying. When she came into the room she saw that an oxygen mask had been placed over his nose and mouth. She asked a nurse why, and she replied, "To make him comfortable." She explained that he was a laryngectomee and total neck breather and that oxygen going into his stomach was not "making him comfortable." She refused to leave until the oxygen was provided through his stoma. (Reported by an SLP [speech therapist.])

Why?

How is it possible that a doctor, nurse, anesthesiologist, respiratory therapist, speech therapist, or nurse anesthetist does not know how we breathe? How can so many make terrible mistakes that injure us or worse?

The answer has a number of parts:

1. There are very few laryngectomees. Most sources estimate that there are 50,000 to 60,000 total in the U.S. It is a tiny percentage of the total adult population; a tiny fraction of one percent. The number of laryngectomy surgeries is estimated at about 10,000 per year. But the number of laryngectomees who died in that year is not known. Death certificates list the cause of death such as heart or respiratory failure and not that the person was a laryngectomee.
2. A medical professional, even one who has had some explanation of our breathing at some point in their training, can go through an entire career and never treat one of us. "Use it or lose it." Like everyone else, medical people can forget.
3. Medical personnel may not know that they do not know that our anatomy is different, and therefore how to treat us.

So they may fall back on patients they have seen before who have holes in their necks, "trachs." But the mouths and noses of trach patients are still connected to their lungs. Their neck hole typically helps them get a little more oxygen when something in the upper respiratory tract is partly blocked. But if they are having surgery, a tube can be put down their throats (intubated) and oxygen and anesthesia provided. If they try to intubate a lary that way no oxygen or anesthesia can reach the lungs.

4. It would not be unusual for a description of a laryngectomee's changed anatomies to never be discussed in the initial programs of SLPs, MDs (until they specialize in ENT), anesthesiologists, respiratory therapists, etc. The educational programs are simply full of information which applies to the other 99.999% of the population.

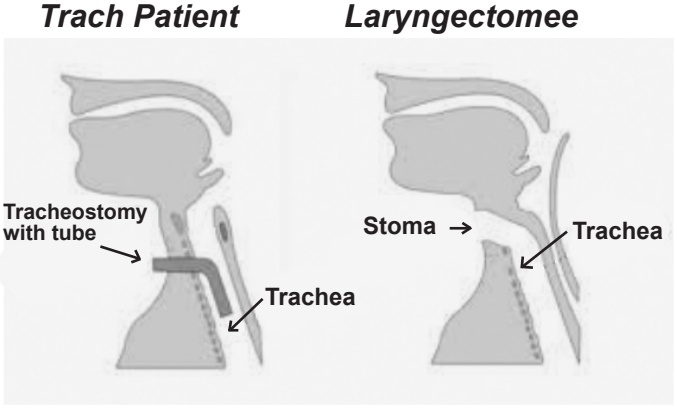
But as the first article which appeared in the May issue of the *IAL News* explained, there are things we can do to minimize the chances that medical personnel make mistakes in our treatment.

In the survey of 45 SLPs and several MDs. the second most mentioned threat to laryngectomee health and safety was depression.

Dealing with Depression

"Sir, I'm sorry to tell you that it IS cancer and at an advanced stage, and the only option is to surgically remove your larynx, your voice box."

That statement is terrifying and overwhelming to many. It rattles their world and raises questions about survival, jobs and income, loss of a sense of who they are, impact on loved ones, loss of friends and hobbies, and many other fears. It is so world shaking that a few people refuse to have the surgery. If they were afraid of losing their voices and having a hole in their necks, they often end up with both as the cancer grows. A few take their own lives.



The trach patient continues to breath through the mouth and nose. In surgery a tube for oxygen and anesthetic can be put down their throats. The laryngectomee can only have a tube put down their stomas.

But if they agree to the surgery, they face an extremely long physical recovery along with what can be severe and long lasting communications and other problems. It's said that recovery from laryngectomy is not a matter of days and weeks, but months and even years.

There is a great deal of information laryngectomees need to learn, and the cancer may come at a time in their lives when dealing with many changes and learning a lot of new things is far from easy. For those without a support system of spouse, other family, caregiver or friend it can be especially overwhelming.

There is a growing reluctance of many medical personnel to ask a fully recovered laryngectomee to visit with the patient before and after surgery. There is a decrease in the number of laryngectomee support groups, and an inability of some larys to have the tools and knowledge to find support

groups on-line.

Anxiety and depression are common in laryngectomees as it is in other cancer patients. But depression frequently goes undiagnosed and untreated (studies have shown that primary care physicians fail to diagnose at least half of their depressed patients, particularly the elderly). A diagnosis of "clinical depression" is made based on how long the symptoms are lasting and how much they interfere with normal life activities.

Written questionnaires are often used to screen for depression. An example is one which asks for a yes or no answer to ten questions: "Over the past two weeks have you experienced:

- feelings of sadness and/or irritability?
- loss of interest or pleasure in activities once enjoyed?
- changes in weight or appetite?
- changes in sleeping patterns (not enough or too much)?
- feeling guilty?
- inability to concentrate, remember things, or make decisions?
- fatigue or loss of energy?
- noticeable restlessness or decreased activity?
- feeling hopeless or worthless?
- thoughts of suicide or death?"

With this questionnaire from the National Mental Health Association answering "yes" to five or more questions, or "yes" to the last one (for which you need to seek immediate professional help) are strongly suggestive of "clinical depression." However, this diagnosis must be made by a psychiatric professional. Since depression is a symptom of thyroid gland problems, thyroid function needs to be ruled out.

Clinical depression is readily treatable with medications, counseling, or a combination of both. A number of very effective and non-habit forming medications are available. There are a number of approaches used in counseling. Self-help groups are beneficial. "Talking" therapies, such as cognitive-behavioral therapy provided by psychologist, psychiatrists or others, has been proven effective. See your primary care physician, psychologist or psychiatrist for diagnosis, referral, and/or treatment.

But the isolation and depression most laryngectomees experience is not "clinical depression" requiring professional help. Instead, there are many things laryngectomees can do to improve their isolation, anxiety and feelings of loneliness.

Communicate

Communicating is very important, especially for laryngectomees, and by whatever method or methods they have. Communication has been described as the most important of all life skills. It is what enables us to pass information to other people and to understand what is said to us.

But communication is also the means of establishing and maintaining relationships with others. Communication is essential to mental health. By expressing ourselves we can free the thoughts and feelings bottled up inside. It is a release.

Connecting with people including other laryngectomees is very helpful. Attend local support club meetings in person or via Zoom. For those without a computer or smart phone, public libraries have computers and people who can help with connecting them with support groups including the Internet's WebWhispers, the largest laryngectomee support group. It is a great source of information and people who care.

Stay Healthy

Exercise: a minimum of 30 minutes most days. Even just walking can be very beneficial. Get outside, just that can be uplifting. Maintain a healthy diet and weight. Take multivitamin supplements. Get enough, but not too much, sleep. Keep to the schedule for follow-up and standard medical visits. Keep well hydrated. Coffee and tea do not count. Drink water and reduce drinking sugared beverages. Reduce sitting and screen time. Avoid using alcohol or drugs to self treat your feeling down.

Etc.

Volunteer. Visit a local, state or national park; botanical garden or zoo. Treat yourself. Join a church or become more involved in yours. Listen to music you like. Meditate. Do gardening. Help someone. Give to charity. Try and fill your hours and days with anything which makes you feel good about yourself.

Part Three, and the last in the series, will appear in the November issue of the *IAL News*.

Compiled by David Blevins

Biggest Threat to Lary Health and Safety

Part 3. Part 1 appeared in the May edition, and Part 2 appeared in the July issue of the IAL News.

Parts 1 andf 2 can be read at TheIAL.com under Publications-*The IAL News*. Especially if you have not read Part 1, please do. It is important. Parts 1, 2 (and 3) report(ed) on a survey of over 45 speech therapists and a half dozen MDs.

The threat to laryngectomee health mentioned by the majority was: **"A lack of basic knowledge of laryngectomees and their changed anatomies and their breathing by medical professionals (such as confusing tracheostomy vs. laryngectomy), and subsequent inability to provide appropriate treatment. These professionals include pulmonologists, respiratory therapists, primary care physicians, nurses, anesthesiologists, SLPs, and ENT MDs."** In one study of 12 hospitals, 26 laryngectomees died as a result.

Part 1 stated that laryngectomees can minimize the chances that medical professionals will injure them and even cause their deaths. Recommendations included:

1. Identify yourself through bracelets and necklaces, cards carried in wallets or purses, notifying first responders ahead of time, using car window stickers, and others.
2. Learn how your breathing worked before you became a laryngectomee and how it now works. Know that you are a *total neck breather*.

The article also stated that the air reaching our lungs is now dirtier, drier, and cooler.

It described ways to improve our breathing by urging us to wear a stoma cover 24/7, maintain an indoor humidity level of between 40-55%, and listed ways to maintain a good flow of mucus (which is essential for healthy lungs and windpipe.) It concluded with a quote and the advice to never allow medical personnel to put an oxygen or anesthesia mask over your mouth and nose, or a tube down your throat, without questioning them on whether they understand you are a laryngectomee and total neck breather and not a trach patient.

Never let an oxygen mask be placed over your nose /mouth, or a breathing tube down your throat.

It is a sad fact, but **laryngectomees (and their loved ones/caregivers) must stand guard and advocate for themselves and loved ones until they are certain that medical personnel who will provide treatment understand our changed breathing systems.**

Part 2 discussed the second most frequent answer to the question about laryngectomee health and safety - depression. Clinical depression and less serious forms were discussed and recommendations made.

Part 3, the final one in the series, deals with other important threats to laryngectomee health and safety. The original question asked in the survey was:

"Aside from (larynx cancer) **recurrences and new primary cancers, what do you think is the biggest threat to laryngectomee health and safety?"**

Recurrences of larynx cancer and the development of *new cancers* are a major threat to laryngectomees. The chance of larynx cancer returning after treatment depends on the type of cancer, location, stage, and the effectiveness of treatment. Recurrence is most likely to occur in the first two to three years. Being five years free from a recurrence is taken as an indication that a return of the original larynx cancer is highly unlikely.

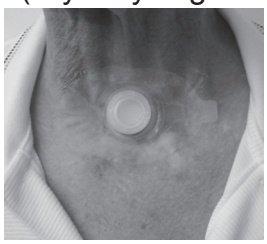
The recommended schedule for follow-up visits to your ENT doctor following laryngectomy is once per month the first year. Every 2-4 months the second year, every 4-8 months the third year, and once per year thereafter. Keep those appointments, and report any changes. This is your first defense against a recurrence or new cancer.

The chances of developing a new primary cancer depends, in part, on the cause of the larynx cancer. If the lary was a smoker other parts of the anatomy were also exposed to the chemicals in tobacco. The development of lung

cancer is not unusual in laryngectomees who smoked and/or were heavy drinkers. The combination of the two increases the risk significantly. Many larys who were smokers will be scheduled for an annual chest x-ray.

However, if you smoked a least one pack a day for 30 years, or 2 packs for 15 years, are age 55-80, and if you stopped smoking less that 15 years ago there is a different recommendation. The Centers for Disease Control recommend that you have a LOW DOSE CT scan <u>every year</u> until you are more than 15 years since you stopped smoking or you turn 80. CT scans are much more accurate in detecting lung cancer than x-rays in early stages when they are more successfully treated. If you meet the requirements stated above, ask your doctor if you should receive an annual LOW DOSE CT-scan (a yearly regular CT-scan would expose you to too much radiation.)

CT Scan



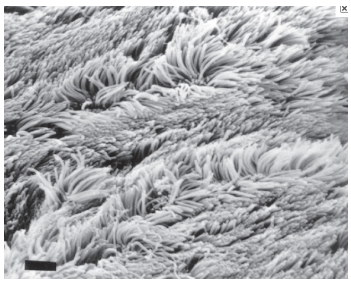
A Heat/Moisture Exchange filter in a glued-on housing

<u>*Lung infections*</u> can be very dangerous for laryngectomees. Untreated *pneumonia* can be life threatening. Wearing the most effective stoma covers 24/7 helps prevent lung infections. The more effective stoma covers are those which cause all of the incoming air to be filtered, such as the Heat/Moisture Exchange filter (HME). Other types of covers have varying degrees of protection. Some larys increase the effectiveness of their square foam stoma covers by doubling them.

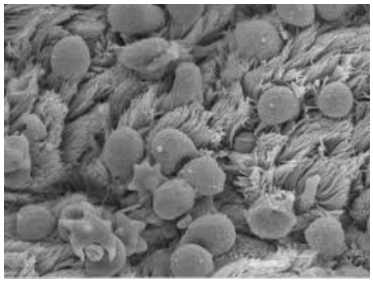
A Heat/Moisture Exchange filter in a "Lary Button" which fits into the stoma.

The color of mucus can indicate a lung infection. If mucus is no longer transparent or white but has a green or yellow coloring it probably means an infection. See your doctor immediately. These infections are usually effectively treated with antibiotics.

Although they *are fairly rare, a <u>mucus plug</u> is capable of being deadly.* Under normal circumstances, mucus moves upwards from the lungs and through the windpipe (trachea) by microscopic waves of hair-like cilia to our throats where we can cough the mucus out. But especially if our mucus becomes dried out and thickens the cilia may no longer be able move mucus upwards. If enough accumulates mucus can form a plug which blocks the movement of air. It can cause the collapse of a lung.

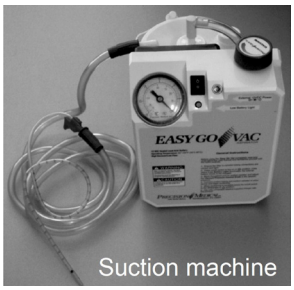


Respiratory Cilia



Respiratory Cilia carrying tiny blobs of mucus

Some new laryngectomees are sent home from the hospital with a suction machine to be used to vacuum out mucus and prevent plugging. Laryngectomees can also reduce the chance of the formation of a mucus plug by keeping their flow of mucus thin and watery. This can be done by staying well hydrated, maintaining an indoor humidity of 45-55%, wearing a Heat/Moisture Exchange filter, squirting sterile saline water into their stomas and then coughing it out. Some use saline "pink bullets" to squirt down into the stoma, others may use a saline spray.

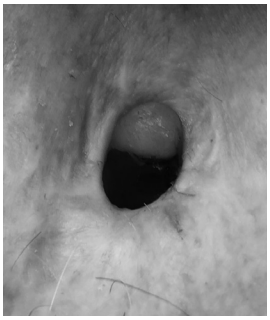


Suction machine

Sterile Saline Spray and "Pink Bullets"

Some laryngectomees experience <u>*shrinking of their stomas*</u> (stoma stenosis, micro-stoma). If the stoma is too small it can effect the movement of air into the lungs making it harder to breathe. The solution for many is to wear a lary tube or button at least part of the day to stretch out the stoma..

Another problem for some laryngectomees is the <u>*formation of granulation tissue*</u>, especially around the TEP prosthesis. The tissue growth is the body's attempt to heal an unnatural opening.



A shrunken stoma. The part hanging down is granulation tissue.

Granulation tissue can be removed in the ENT MD's office. An extreme case of stoma stenosis may require surgical revision (stoma plasty) to enlarge it.

Another problem for some laryngectomees is the *shrinking (stenosis) of the esophagus (feeding tube)* making it difficult to swallow. The solution for many is to have their esophagus stretched (dilated) by their ENT MD. A few laryngectomees can self-dilate using what is called a "bougie"

For those laryngectomees who were treated with *radiation* there can be long term complications including the formation of "fistulas" (holes that may not heal on their own). Carotid arteries can be damaged, and, in extreme cases, radiation can contribute to the development of another cancer.

We laryngectomees need to educate ourselves. There are relatively few of us so we may encounter medical professionals who have never treated a lary and who mistake us for trach patients. There are many things we can learn and do to protect ourselves. (Compiled by David Blevins)