

WebWhispers

Sharing Support Worldwide
Throat Cancer and Laryngectomy Rehabilitation

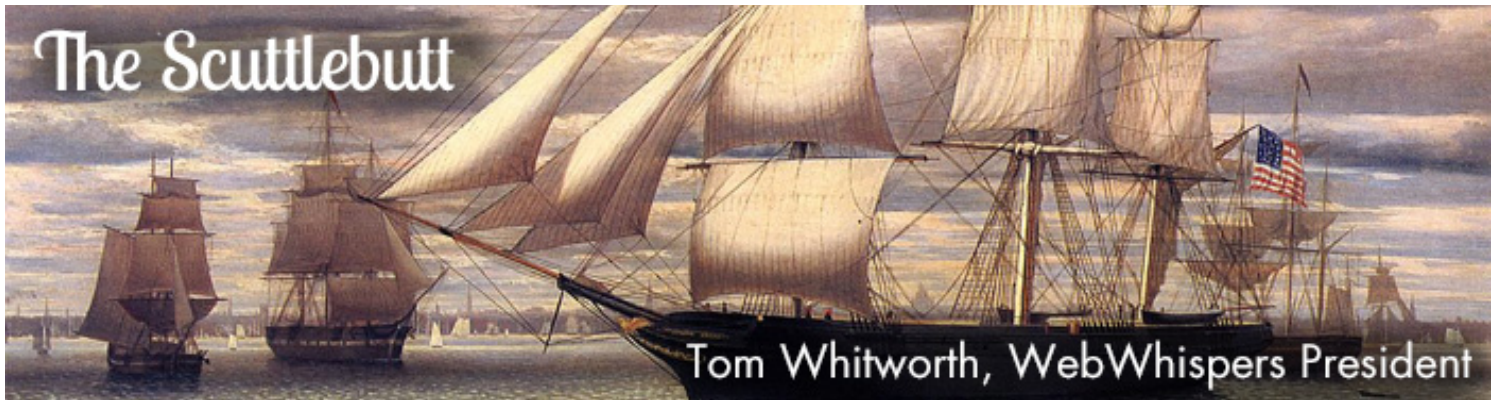


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A Lary State of Mind

Who Knew?

Laughter really is the best medicine and has no adverse side effects that I am aware of. I have found that adversity is easier to handle when I can laugh about it or at least smile in the midst of it.

The following is a collection of things that I either didn't know pre-laryngectomy, I know them better now, or they have taken on an entirely new meaning. Only Larys would get any of this. One of the reasons our larger gatherings and local groups are so important is that there we are understood.

Spellcheck doesn't recognize "Laryngectomee" as a word. The same applies to most people.

Mucus can make you laugh. My ENT cracked up the day I told him about me unexpectedly coughing while driving only to look up and see the expelled culprit sliding down the inside of my windshield. At first, all I could think of was "how gross". Then I began to laugh so hard, I started looking for a place to pull over to avoid wrecking my truck and taking out a McDonald's.

My wife's grandfather retired from Kimberly-Clark, makers of Kleenex. Damn, I should have bought stock in that company!

In junior high, I thought cooties were fictional. They really do exist! They sometimes hang out in my stoma and must be removed with tweezers.

Cleanliness is.....well, cleanliness!

Removing my larynx did not change who I am, though it may have made me a better person.

I can sing without a voice box, only fewer notes. You might call it my joyful noise.

Silence really can be golden, like when my comments would add fire to a heated discussion and my voice prosthesis gets stuck. By the time I get it fixed, the subject has changed. This sometimes keeps me out of trouble. Some things really are better left unsaid, anyway.

"Can't get a word in edgewise" has a totally different meaning.

So does “it’s not what you say; it’s how you say it”.

It is now a little easier to keep a secret.

More often now, I say something “under my breath”.

People who never cared what I had to say, still don’t and never will.

Sometimes I choose to remain silent. The difference now is that it doesn’t bother anybody. By now, they’re used to it.

Even the most highly experienced hospital personnel can be clueless about where to put my oxygen mask. All those years in the Navy and I never had the slightest interest in getting a tattoo. Now I want one that includes an arrow in the center of my chest pointing to my stoma with these words underneath: “OXYGEN GOES HERE!”.

Laryngectomees can make the best of friends. We appreciate one another more.

Navy Boot Camp was NOT challenging.

We can laugh without making a sound. Laughter is laughter. It doesn’t have to be audible; it is involuntary and comes from the soul.


When I “spoke” with a marker and dry erase board, a picture really was worth a thousand words.

I may call someone a pain in the butt but I will never again call anyone a pain in the neck.

Never feed the cat right after your dinner. When Pat Sanders asked me on the phone if I’d ever done that, I laughed because yes, I had! Poor little cat.

Choose your words wisely, you may have trouble swallowing them.

***Enjoy, laugh, and learn,
Tom Whitworth
WebWhispers President***



Voice Points

Written by Professionals

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Three Causes of Tracheoesophageal Voice Prosthesis Leakage

Like all valves, a tracheoesophageal voice prosthesis (TEP) breaks down with time, requiring replacement. But what causes that breakdown? And why do certain individuals require TEP changes more frequently than others? Below, you'll find information about 3 main causes of TEP breakdown leading to leakage. Always remember—if you are experiencing early TEP leakage, it is important to talk to your doctor and SLP in order to determine the cause of leakage and to help with management.

Reflux

A large percentage of laryngectomees have been found to have reflux. In fact, recent studies indicate that percentage to be as high as 80% (Smit et al., 1998). Gastroesophageal reflux disease, or 'GERD' for short, occurs when stomach acid comes back up into the esophagus. Laryngopharyngeal reflux, 'LPR' or gastropharyngeal reflux, 'GPR' are names for refluxed contents that come up through the esophagus and into the throat. Reflux often contributes to early valve breakdown which may result in leakage through the TEP. It may also lead to tracheoesophageal puncture tissue changes, such as enlargement of the tract or granulation tissue, possibly leading to leakage around the prosthesis. There are various proposed reasons for the higher incidence of reflux in laryngectomees. One cause may be post-surgical changes related to cutting of the upper esophageal sphincter, which is often a routine part of the laryngectomy surgery. A second possible cause is xerostomia, or dry mouth, which interferes with the reflux barrier resulting in prolonged acid exposure to the esophagus (Smit et al., 1998). Signs and symptoms of reflux may include: regurgitation of acid or food; bad breath, changes in swallowing such as food sticking or pain, and frequent belching. There may or may not be a burning sensation in the chest or throat. Behavioral techniques to reduce reflux include the following: eat smaller more frequent meals; elevate the head of the bed 6-8 inches; stay upright during and at least an hour after meals; avoid eating three hours before bed; and avoid tight clothing and bending at the waist. Cutting back on foods such as coffee, tea, peppermint, chocolate, citrus fruits and juices, spicy and acidic foods, fried and fatty foods, and alcohol may also be beneficial. Talk to your doctor if you feel you have reflux to discuss medical management options.

Biofilm

Tracheoesophageal voice prostheses are typically made of medical grade silicone due to its flexibility as well as its mechanical properties. Unfortunately, silicone has a tendency to become colonized quickly by micro-organisms (Talpaert et al., 2015). This, in conjunction with the humidity and temperature of the esophagus, results in an ideal environment for biofilm to grow. A common site for biofilm growth is on the valve of the voice prosthesis. This may result in early breakdown of the valve causing leakage through the prosthesis and the need for more frequent prosthesis changes. Formulation of biofilm on the valve may also lead to increased air flow resistance making it harder to speak. Controlling the growth of biofilm is critical in extending the life of the prosthesis and thus in maintaining a healthy tracheoesophageal puncture and healthy lung tissue. Yeast most identified within the biofilm include species of candida; however, studies have shown that there are many types of micro-organisms found growing on voice prostheses, including various types of bacteria. Therefore, we use the term 'biofilm' rather than 'yeast'. In most prostheses cultured, a mixture of yeast and bacteria are found. The types of biofilm that colonize on the prosthesis are often due to lifestyle and diet. Research has been and continues to be conducted on ways to prevent or reduce biofilm including modifying the surface of the prosthesis, using probiotics or antifungals prophylactically, and trials of synthetic saliva (Talpaert et al., 2015). Maintaining good oral care along with the use of proper prosthesis cleaning techniques, including brush and flush, may also reduce the risk of biofilm.

Dysphagia--Difficulty Swallowing

It is difficult to pinpoint the incidence of dysphagia, or swallowing difficulty, in the laryngectomy population. According to research, dysphagia impacts somewhere between 17% (Balfe et al., 1982) and 70% (Maclean, Cotton, & Perry, 2008) of all laryngectomees. Per Maclean et al., this discrepancy in incidence may be due to varying definitions in the severity of dysphagia.

A total laryngectomy surgery drastically changes the overall physiology of the swallow. During the surgery, the larynx and hyoid bone, which previously contributed to upper esophageal sphincter opening, are removed. The trachea and esophagus are separated from one another. The pharynx and esophagus, which were previously attached to the trachea, must be surgically closed and reconstructed. Depending on the extent of the surgery, other structures—including the tongue, base of tongue, pharynx, or esophagus—may also be surgically altered or removed. Tissue from other parts of the body may even be required for reconstruction. Furthermore, radiation therapy can cause additional tissue damage and lead to radiation fibrosis.

While there are many causes for dysphagia, dysphagia can impact tracheoesophageal voice in two primary scenarios: when there is reduced swallow pressure and when there is elevated swallow pressure.

Reduced swallow pressure: Esophageal dysmotility is the primary culprit for reduced swallow pressure. Normally when a person swallows, the muscles of the pharynx and esophagus contract and “squeeze” the food or liquid down the food tube. These contractions must have adequate force and must be synchronized moving from high to low in order to be effective. Esophageal dysmotility occurs if the contractions are not strong enough, are absent, or are not synchronized properly. This can leave food or liquid residue in the pharynx or esophagus, often leading to a wet or “gurgly” TEP voice during or after meals. Per Soolsma et. al., low esophageal pressure can even cause the valve of the prosthesis to “open inadvertently or close insufficiently...during deep inhalation or swallowing,” leading to prosthesis leakage.

Elevated swallow pressure: Elevated swallow pressure can occur if something impedes the flow of food or liquid moving through the neopharynx or esophagus. Think of a garden hose: If you put your finger in front of the spout to impede the flow, pressure in the hose increases. An increase in esophageal pressure can cause the TEP valve to leak more quickly, as the valve has to withstand higher pressure during the swallow. Causes of elevated swallow pressure include: stricture, pharyngoesophageal spasm, or external compression on the esophagus (e.g., osteophytes).

It is always important to pay attention to your swallow function and report any changes to your MD and SLP. Changes may include: food or liquid feeling “stuck” in the throat; having to swallow multiple times per bite of food or sip of liquid; wet or “gurgly” TEP voice during or after meals; having to chew foods thoroughly or wash food down with a sip of liquid; and/or having to avoid hard/dry/sticky foods.

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Is WW Enough?

I have been a member of the hole in the neck gang and using a Servox EL for over 15 years now. First, living not too far from Boston, Massachusetts and now just north of Portland, Maine. I can count on one hand the number of times I have “run into” someone like me and two them were because of a mutual acquaintance! The first time I ever met anyone who talked and breathed like me was when I was invited to a get-together for folks with adenoid cystic carcinoma organized by my dear friend, Libby Fitzgerald, who I “met” online. Subsequently through WebWhispers and the IAL I have met many more but out and about during my daily life I have met a few folks here and there who would comment upon hearing me talk that they had a relative or knew someone like me but actual “sightings” were rare. And just for the record, I am not a recluse nor am I shy about using my voice - except on the phone – still have to work on that.

I have a little side-line doing house/pet sitting for some folks in the area and imagine my surprise when I got a text from one of them saying she had recently met a woman who “was just like you” and who would love to meet me after my friend mentioned she knew someone locally who also used an EL. I called her and we chatted and connected on social media. I wrote that I was involved with WW and suggested that she might want to check us out since I didn’t recognize her name. Turns out she was a member 10 years ago when she first had her laryngectomy. But what she said next really gave me pause for thought:

The first year of my new life I was on Web Whisperers all the time but found in my case I felt I was hiding from real life and avoiding going out in the world. The first year I hardly left the house and was embarrassed to be in public. I've come a long way since then, realized I had the right to live as much as anyone else. Now you can't slow me down. I've never really known anyone else that is like me or talks with an EL, when I would go to the hospital I would occasionally see someone but they were usually in a wheelchair and hard to understand. I was delighted that you are easy to understand! I use a TruTone and it is my favorite. I started with Servox though, actually have one in a box but have lost the battery somehow but have the standing charger, if you're ever in need you can have it as I won't use and I have 2 TruTones.

We have yet to meet IRL but I suspect we’ll have much to chat about. In the meantime, we are both busy with real life and, that, I think, was exactly her point.

It can be very tempting to satisfy all our social needs online. We can access news/information/gossip/art/whatever ... name your pleasure ... it’s all at the touch of your fingertips. The internet is a wonderful resource as is WebWhispers but it can be a trap. I am proud to be a part of an online organization that offers hope, education and support to folks who so often can’t find it elsewhere but, let’s be honest, real life happens off the net.

The proof is right here in the fabulous articles every month in our newsletter. We are out and about, making a difference, talking our talk, walking our walk. Get out there IRL – you never know who you may meet or the places you can go!



Other than the loss of your voice, what is the biggest change in your life as a result of becoming a laryngectomee?

My answer to your Question: My most upsetting loss to me is I can't laugh out loud. I totally miss that. I am Blessed to be alive and well and am so very thankful for all my Blessings.

I also found out that people want to know how I got all my cancers and why I talk like this. Well it's a great time to tell the folks that I am a Jesus follower and he allowed it but didn't give it to me. He gave me this time to witness to folks that ask, that I am a miracle and this conversation came out of this Godly new voice I have. I have been blessed so much.

Have a wonderful healthy year to all our Brothers and Sisters in Lary Land.
Gods Blessings upon everyone.

Carol McCaskill – Bend, OR
Lary Class 2000

Being a laryngectomee has given me three advantages that I did not previously have:

- I am never anonymous; the people I meet always remember me. They may not remember my name, but they always remember who I am.
- When I telephone someone the second and subsequent times, I do not have to introduce myself, they always know who it is.
- Lastly, and most importantly, the people I am speaking to always listen to me, When I had a "normal" voice, I was not always listened to. This was a substantial advantage when I was an in-school mentor for the Boys and Girls club. I was a mentor to one child each year for 10 years, a different child each year. They were in grades 4 to 6, 10 to 12 years old.

For your further information, I use esophageal speech.

David Cowan – Edmonton, Alberta Canada
Class of 1988

As I sit this morning at my computer, I am pondering the question of the day

One annoyance has been maneuvering the medical suppliers complicated system to order my supplies and finding a company that will directly bill insurance. This seems to change without notice and suppliers suddenly decide to stop carrying supplies that I had been ordering for years. More than an annoyance, absolutely frustrating ...

I hope the IAL meeting will be a success. I wish I could attend this year; unfortunately, it conflicts with another obligation.

Sending you all best wishes and travel blessings

Fay Flanary – Belchertown, MA
Laryngectomy since 2001

The pure prejudiced handling of my company not allowing me to return to work a year ago as they say they cannot guarantee my safety... to whom I don't know. I was cleared by docs to work but they seem to think I turned into a handicapped invalid. The anger I have is stressful. Maybe suing them is an option, but that would require funding for a lawyer of which I don't have. The operation and radiation was hard but the thing that's really hard is surviving!!!!

Dave Johnson – Edmonton, AB

I was very focused on my job and family before my laryngectomy. I traveled a lot so I tried to spend all the time I could with my kids when I was home. After becoming a laryngectomee I realized that there was so many other things that I was missing too.

After my surgery, I quit thinking or planning about the future and was just taking it a day at a time. A speaking out question for the WebWhispers newsletter made me realize that I needed to still plan ahead, but my focus was much different. I still spend as much time as I can with my kids and grandkids but I never thought how precious and fragile life was. I now enjoy life more than I ever did before. I take the time to enjoy the little things that I would have missed before because I was too busy. Spending time playing with the grandkids and enjoying the little things has become a much bigger priority to me. I think most of us experience a similar awakening as we realize that you have to enjoy life now and at every opportunity because missed chances do not come again.

Ron Mattoon - Seattle, WA

2010

I think the biggest change in my life is how people perceive me. As much as I try to convince them I lost my voice not my mind, I sometimes feel like the special kid in school. I find people talk over me more. I was a training manager for a large retail organization and I was used to being listened to. Now not so much. I am a very quiet person now and even when I want to join in the conversation I sometimes cannot. Whatever, enough of my pity stuff, my life is pretty good. A loving wife, a great group at Web Whispers, and I am very involved in cancer support groups. Looking forward to Virginia.

David Kinkead – Peoria, AZ

- I can't laugh without sounding like Deputy Dawg.
- Some people are indeed prejudiced towards me.
- I stand out in a crowd when I speak as heads turn, obviously.
- The ability for me to be spontaneous has been greatly diminished.
- People easily drown me out or talk over me.
- Arguing is almost futile.
- I can't shout if necessary.
- Not to mention, changes in the bedroom atmosphere.

Gerald Hughes – Houston, TX

My biggest challenge is trying to speak in a complete sentence. When I stop to catch my breath, the person I am talking to thinks I am finished and they begin to talk. That is very frustrating. Hanging in there. I use my hands to indicate I am not finished talking. That usually works. You all take care.

Jack Kehler - Ozark, AI

3/03/15

I became a member in 97' at the age of 44. It was pretty devastating at the time. For a while I felt pretty sorry for myself and thought life as I knew it and my goals for what I wanted to accomplish was pretty much over. Having two teenage boys 16, 14 of age at the time of my surgery I couldn't dwell on myself for long. I knew I had to pull myself up and finish the job of raising them with my awesome husband.

Any one that has had teenage boys knows that it can be a big hard job at times. I think that them watching me overcome some really tough medical issues made them proud of their Mom and better persons themselves. It made us stronger as family. They watched their father being the best husband. Now almost 20 years later they are both great husbands, providers for their family and the best fathers. I think the whole experience made us all a lot stronger.

I went on to fulfill my dreams and goals. My big plan was to get my real estate license after my sons were on their way. Well I did get my license and have been selling real estate in metro Atlanta for 15 years. I am with Berkshire Hathaway HomeServices Georgia Properties and was in top13% Company wide in 2016. I am a life time member of the Million Dollar club. I got the courage to reach that because soon after my surgery (about a year) I started going to schools doing public speaking on Tobacco Ed. Funny how helping others starts helping yourself. It really got my confidence back.

I also visit patients in the hospital before and after surgery. I am the president of our local support group Greater Atlanta Voice Masters. I work part time for InHealth Technologies as a Patient Consultant for the last 4 years. I love the Company and the people at InHealth Technologies! I love getting to travel and talk to different clubs around the country. I have seen so much of our great country that I might have missed if not for being a member of our "club". And a real bonus is meeting my BFF Tina Long that had her surgery 6 months after mine. We have the best time and travel all around Georgia doing Tobacco Ed.

The best joy is watching my 5 grandchildren 6 and under grow. 4 girls one boy in the middle. I am truly blessed. I am also an 8 year breast cancer survivor. I am caretaker of my 94-year-old mother that lives with us in her own apartment in our terrace level. My husband also received his real estate license and helps me with my business. Life is busy, messy and wonderful! I wouldn't change a thing!

**Janice Hayes – Marietta, GA
1997**

Well so far it's been people's reactions to my not being able to speak yet. They either think I'm deaf which is understandable, or treat me like I'm mentally challenged which is not understandable. I have noticed though that people (and I'm hoping I didn't do this during my 'normal' time) tend to treat the disabled like little children. This whole thing has also made me aware how people just don't read very well or quickly :).

Thanks for everything.

Deb Shukert - Chesapeake Beach, MD

We have obviously all seen changes with the loss of our primary voice being at the top of the list. When looking past that, I was surprised at the response to this question from my wife of 40 years. She indicated since my surgery (on September 11, 2008), I have become a much nicer person being much more thoughtful and caring to her as well as to others including family and others I have met as a result of the surgery.

I have to admit for about a year after my laryngectomy I was angry, at no one in particular, but once I settled in I accepted the way things had changed, I received my first real break when a dear friend asked if I would take over the management of the local support group, and I found the wonderful feeling you get when you help others, not for gain, but just for helping. Being almost 9 years post-surgery now, without a doubt I think the participation in the support group model is what really helped me. This included hospital visits, home visits, talking with countless families who had such a high level of anxiety, and the positive feeling you get when doctors and SLPs put their faith in you to do those things. This became so rewarding to me personally, and made all that work very worthwhile.

It is not easy being a laryngectomee, but I have found there are still many rewarding things I can accomplish, for myself, my marriage and family, and for those I have yet to meet.

Mike Smith - North Augusta, SC
9-11-2008

*"Life is mostly froth and bubble
Two things stand in stone
Kindness in another's trouble
Courage in your own."*

Joseph Fahlbusch Heitzler - Rolling Hills, CA

The loss of your voice is devastating, especially if you have been used to giving lectures, training and managing, and speaking frequently from the witness box from the "Old Bailey" the central criminal court, or other such establishments, where every word is carefully noted by very clever people of both the law and the media. I had gone six months without uttering a sound, before a valve was fitted, and not to be able to join in conversations during those six months was so terribly frustrating.

It was during that time, that I realized that I was becoming withdrawn, and not having contact with people, was seriously affecting me. My only method of communication was by writing, but being a naturally slow writer, I went to a College for a short course to speed up that writing, and was told I had a natural ability in telling stories and writing poetry. I applied to Kent University in my speechless state to start a three-year course, hoping in that way, my new method of expression would be in stories or poetic form. They accepted me at the great age of 75, speechless and a person who had left school at the age of twelve. They were very brave.

Whoever heard of an old copper, who had no time for such things as poetry, an ex-smoker since an early age, a drinker, but not to excess, but also speechless. However, everybody was very kind, and other students, mostly youngsters would read out my work, which of course I had never heard spoken, but suddenly realized that in sad poems, I could see some were affected by crying, and in fun writing they were laughing out loud.

I had found my new way of expressing myself. When I did stand and read my first poem myself, they were delighted and clapped. My new career had started.

You are never too old.

Len Hynds – Newtown, UK

Post-laryngectomy, I became far more aware of the power of community, of friendships and of the need to be

flexible, to be more accepting and to be a kinder, gentler human. I did not acquire this awareness without some prodding and without some kicking and screaming, voice or no voice.

To quote a small section of Max Ehrmann's Desiderata,

*"Take kindly the counsel of the years,
gracefully surrendering the things of youth.
Nurture strength of spirit to shield you in sudden misfortune.
But do not distress yourself with dark imaginings.
Many fears are born of fatigue and loneliness.
Beyond a wholesome discipline,
be gentle with yourself."*

**Carl Strand, Mystic Connecticut
Laryngectomy February 10, 1993**

So, first let me tell you what I didn't lose. I didn't lose the love of my wife, and family. In August we will have been married for 46 years, and still have a wonderful marriage. Other than being a bit short winded, we still hike into wilderness areas, to enjoy the surroundings. I haven't lost my ability to enjoy, and sometimes hold, a great barbecue. I haven't lost the appreciation for the good friends that I still have. I've kept my home, and never lost the material possessions that were dear to me.

In the beginning I was told that your voice is who you are, in the sense of that's how people perceive you, or your personality, by how you sound. I believed that for a while, but no longer. People treat me the same as they always have. I'm still me. I'm proud that I was able to move thru this, and keep a semblance of the life I had before. I think that I am a better person than I was, and I try to be empathetic to others that I see going thru a medical problem that has taken over their lives. So maybe I've gained more than I've lost ...not really! Sure, I really wish that it had never happened.

Steve Staton – Sun City, CA

There are two major differences in us.

We breathe through STOMA. Copious amount of oxygen gets inhaled unrestricted which is a lot of health ingested throughout the day. We can feel the benefits.

The second benefit is we talk to the point. We do not waste words. People listen to us attentively and are happy to do what we want. Things get done easier and with much less effort.

Two real blessings in disguise.

**Mohan Raj - Bangalore, India
Lary Mar 2010**

Class of 2016 but the first go around with Cancer of the throat was 1998. So the first treatment, radiation, most likely resulted in the necessity of the loss of my voice box. However, I did come away with a real positive and that is I now listen and hear much better than before the "loss" and I do not engage in idle conversation's. I focus now on giving more to others and being a Happy, Humble person.

Best wishes on your Journey and remember you are the only source for determining who you shall be.

Jim Sibert – Beaverton, OR
Class of 2016

Other than the loss of my voice, the biggest change to my life has been the gratitude I have for life itself. It has been 7 years since my laryngectomy and my scans and bloodwork have been clean to date. Cancer is such an insidious disease and I have seen firsthand how it has taken the lives of my mother and brother in addition to many friends.

I am so grateful to be able to function at a fairly high level. I play tennis, work out in the gym, go fishing and hunting in Wyoming each fall and lead an active life. I speak with a TEP and am told that my voice is very clear and strong. I do not consider my laryngectomy to be a handicap or a liability. I am reminded of an old saying: "Nothing is good or bad only as the mind perceives it so." I am grateful to be alive.

Jim Olcott - Bakersfield, CA
2010

My biggest problem is having to eat with a feeding tube. I'm 5 months out and have a fistula in my neck that causes food or drink to come out or worse go into lungs, waiting on the surgeon to see if it can be repaired. I don't really care about not talking but not eating is killing me.

Thanks for my vent

John Miller

Just coming up to my 2nd anniversary. I find I am more positive and enthusiastic about life now than before the op. It definitely makes one focus on the good things in life, rather than the down sides.

Yes, I do get frustrated when people do not understand me sometimes, but hey that's their fault not mine. Children and a few adults love it when I do my Darlick voice. When I look around at others who have problems I realize how lucky I am... 81 and enjoying life.

Colin Lovering - Northam, Bideford, UK

**Next month's question is:
How long have you been a laryngectomee and how did you discover WebWhispers?**

Thank you for your submissions. Edits are used for length, clarity and to keep comments on subject of the month.

Staff of Speaking Out



Brave New World

What has changed since laryngectomy? Becoming different. That's a big change. The odd one out. The weirdo. Thank goodness it's not PC nowadays to call us weirdos or to laugh and point. But children break the rules and stare, trying to work out how we fit in. Deep down we're all children, trying to work out how things fit. At the safest, easiest level we fit by simply that – fitting in. We're herd animals. Anyone who stands out is at risk.

Quite a few friends, family and even strangers have commented on my courage. Though they don't spell-out what it is I have to be courageous about, I guess they are thinking of how difficult it is to be marked as different, disadvantaged, to stand out from the crowd in an unpleasant way. Standing out from the crowd is fine if it's to shine more brightly than others. But to be outstanding because of a difficulty, physical, mental or social, that's not what anyone dreams of. When we lost our natural voices we entered a new world where we need to be brave.

Of course there are advantages to being different: 99% of people go that extra mile to help, which they might not do if I were 'normal'. And it gives something meaningful to talk about with strangers. If they ask about my voice and laryngectomy we find a level of connection that's much deeper than the usual "How are you doing? Where do you come from?" chit-chat that 'normal' strangers have to start with.

Another advantage is that I have lower expectations for myself in conversation. Pre-laryngectomy my most common habit was to play the 'eager listener' role – suggesting a word if someone seemed stuck, finding a

question or comment to keep a line of chat going. I'm easily drawn into the world of others – they always seem far more interesting than my own! But this also brings a downside – anxiety about keeping the channel of communication open. The more I get drawn into the world of the speaker the more my own world shrinks. So it's actually disrespectful – both to myself and to the other, who I'm placing on an unnecessary and precarious pedestal.

So speaks the voice of wisdom! But the allure of the world of others traps me again and again. Laryngectomy has helped me combat the habit. I can no longer slip in quiet suggestions, egging the other along the path their story is forming in my mind. I have to let them be, to tell their story in their own way, at their own pace. It's a letting go.

Letting go, I find, is a challenge. What once seemed easy, almost part of me, is now beyond my reach, out of my control. It takes a lot of wisdom to reassure myself that this is a perfectly normal and necessary part of life. The body and heart grieve as wisdom prises open their tight grip on joy.

I'm exaggerating a bit as it's the only way I can express what's going on inside while I'm not-saying "Oh yes I see what you mean..." or whatever other way I would have kept an enthralling line of conversation going pre-laryngectomy. I don't end up bursting into tears, but the not-saying of quiet conversation fillers is a challenge for me. A mini-death even. But somehow the world continues, and I move blithely along myself, each breath pushing through my abdomen insisting that this is the way the world is, not the way I want it to be, but somehow OK, navigable.

So laryngectomy is helping me combat my 'eager listener' habit. One consequence is that I expect less of myself in conversation. I'm not so attached to people's stories, better able to maintain some objectivity on their allure and delight. I can feel more respect for the person and a degree of awe for how they managed the challenges and joys sketched by their words. 'Rather you than me!' I say to myself, glad of the quiet flow of my breath, registering, with relief, that we are separate people with our own paths through life, and that all we can really offer one another is a good wish.

So there are advantages to being different. But it's not a life for the faint-hearted! My psyche, with its strong herd-instinct, prefers to disappear into the crowd. Not to challenge, not to stand out.

Nowadays, almost 4 years post-laryngectomy, it's usually no problem on the surface. I can breeze my way through daily life, knowing the electrolarynx won't get in the way of anything too important. It's only now, as I think about this in answer to Jack's "Speaking Out" question for the month, I'm forced to dig below my bright-and-breezy surface layer, into the murkiness that lies below.

Embarrassment is the first emotion I excavate, with its tinge of shame that says: "Sorry I'm such a burden... I'd much prefer to be like you ...". But in fact I know very well that having intact vocal chords doesn't make life perfect for people, and that a lot of them could be going through crippling anxieties beneath their own bright-and-breezy surface layer. My difficulties are broadcast by the electrolarynx, theirs are hidden. Deep down we're not that different.

Deep down, the challenge for us all is to respond to the troubles of this imperfect world with kindness. Although I'd prefer to be on the giving end of kindness, my public role nowadays, in this brave new world of laryngectomy, is to receive. It flows in abundance – through the patience of receptionists and shop-assistants who work out what I want, the respect of friends and family who treat me the same as ever, the nod of a

stranger who acknowledges my predicament and signals their sympathy.

I'm glad of all these, I need them all. The only problem is that hard kernel inside that insists that I'm perfectly OK, completely independent, needing nothing from no-one, an everlasting source of bright-and -breeziness. That perfect person would of course, not need to use an electrolarynx! So I'm an embarrassment to myself – or that image of myself generated by the hard kernel of delusion.

So Lary dear, I have to admit that you're doing another great service for me – chipping away at that hard kernel of delusion, showing me that I'm part of this imperfect world, vulnerable, patched together, in need of kindness.



The Boy With Blue Eyes

Camel caravans still crossed enormous distances of desert in 1948, as they had done for thousands of years, there still being very few roads as such. Although we were very near the Red Sea, we were on the fringes of the great Sahara which swept south around Cairo towards us.

We used to carry out two man patrols, with a jeep and trailer, between the Suez Canal Zone and Egypt proper, and occasionally came across nomadic Arabs in that desolate desert. These desert Arabs were entirely different from their town or mud village cousins, as they moved from oasis to oasis, and were terribly old fashioned in so many ways. They were honest to a fault, and in their theatrical sincere greeting of touching their forehead, their lips and then their heart, I would match them and show them every courtesy, which delighted them.

We were on such a three day patrol, when many miles away I spotted tiny black figures, so we decided to stop and see who they were. Within half an hour, I could see three camels with riders approaching. They were desert Arabs, and I waved in friendship. We started the kettle going for tea, our fire being an old biscuit tin, half filled with sand with petrol poured on it and lit. As they got closer, I could see an elderly grey bearded Arab, with his nine year old grandson sitting behind him and the old man's two sons each riding a camel. I

held my mug of tea aloft, and pointed to the blanket I had spread on the sand, inviting them to join us in tea with a flourish of my arm.

They got the camels to kneel, and then sit, and they alighted. After much salaaming and greetings so loved by them, they joined us, the grandfather having the privilege of the blanket seat, sitting with crossed legs. He was the only one who could speak English, but my Arabic was good enough for all. They told me they were going to buy camels from another tribe. Frank, my colleague, did the honours with tea, and passed round cigarettes, whilst I cut slices of bread, spreading tinned British butter and strawberry jam which they had never tasted before. The little boy never said anything, but I could tell that he wanted more, so I cut up the whole loaf for them.

I suddenly realised that the little lad was staring at my blue eyes and realised that he also had blue eyes. I said to the grandfather in English that the boy had the same colour eyes as myself and appeared never to have seen another person with blue eyes. The old man thought for a moment and then said in English, " His father was an English soldier, who wanted to marry my daughter He approached me properly, and I agreed. But he was sent away, saying that he would return but he may have been killed. He didn't know about his son. Then Mohammed sent Abdullah to us." He pulled the young boy towards him and kissed him tenderly. The two brothers smiled at their father's affection for the young lad.

When farewells were said with much salaaming, the lad kept turning round looking at us as they rode away into the distance. It didn't matter that he didn't know his English father, he was surrounded by so much love in that family.

Bits, Bytes and No Butts!



Frank Klett

Lions and Tigers and Bears, Oh My!! It's an Dangerous World out there!

In the past year we have been clobbered on all sides with security warnings and End of the World predictions on a regular basis; so much so that we become numb to it and tend to disregard the message(s). It is now a question of SOBER UP! Take one day and do nothing more than update your systems and just get it over with...but who's battle plan do we follow?

I have found that the vast majority of technically knowledgeable tend to agree on the basics of cyber-security: use solid and unique passwords, keep your software up to date, use common sense when you respond to unsolicited emails and finally be very very cautious with your social media accounts.

So I am offering you a chance to give some thought to your security as you read over the suggestions of some of the best minds in the business (no, not mine). First start with a Google Security check up. Simply click and let the software do its thing. This is a Google software project designed to review and help you verify your public information. Please don't let the Google label scare you, but if it does you may never know. Here is a run down from Bob Rankin:

http://askbobrankin.com/doiit_free_google_security_checkup.html

Another security checkup is specifically for your Facebook account. Ask Dave Taylor has a very instructive article for you Facebook users as a way to maintain the highest degree of privacy and security. Running the app and answering a few questions can save you grief and heartache later (hopefully not) so consider it time well spent. And keep in mind this is not a one and done thing. You want to plan on doing security audits on a monthly or bi-monthly basis to keep your system privacy tight and not a vulnerable target. Click the link below and see how your Facebook account measures up:

<https://www.askdavetaylor.com/run-facebook-privacy-checkup/>

One of the suggestions from all the experts is to use a 2 point verification. What this means is to combine your password login with a second means of verifying your identity. Most call for your phone as a means of confirming your identity, so you login as usual and after your password is entered and confirmed you will get a text message with a code you can enter which will complete you verification. This may sound like a lot and it is, but you are making it much more difficult for a potential threat to access your account information. And that is worth a bit more effort on your part.

Keep in mind your camera and microphone can also be a source of exploitation so be sure you limit any access to them for other apps and check them to be sure they are off when they are supposed to be.

Keeping your software up to date has gotten easier over the past couple of years with the addition of security apps published by several software houses. I have long used PSI (Personal Security Inspector) which scans my system constantly looking for out dated software. When it finds one out of date it will notify you and link you up with the site to download the current version. The Personal Software Inspector (PSI) is a free utility tool from Flexera (formerly Secunia). It scans your hard drive for executable files, reads the meta-data in each file to determine the program's version number, transmits that info to PSI, compares the versions on your computer to PSI's database of programs and their current versions, and reports back to PSI what needs updating. PSI automatically installs updates when it can; if user action is required it provides helpful instructions such as the URL where updates can be found.

Bob Rankin has an article on the subject of maintaining an up to date system and the various options available to you:

http://askbobrankin.com/keeping_software_updated_simply.html

Bob also as an excellent article on doing a 5 point tuneup for hackers to protect your system. Some of the information will seem to be overlapping which gives you an idea o their importance:

http://askbobrankin.com/5point_tuneup_for_hacker_defenses.html

If this is somewhat overwhelming to you just do what you can at the moment and save this information for when your time is more open. Just don't blow it off!

Bob Rankin also gives us a heads up on a relatively new scam that is being seen and that people are getting suckered into. Read Bob's article and use caution when downloading unrequested software, regardless of the source. Keep in mind on the internet a user can say he is anybody and uses that to his advantage.
http://askbobrankin.com/beware_of_this_clever_new_scam.html

On the money saving side of this month's tech info is the various VOIP phone options: VOIP=Voice Over Internet Protocol. Just so you know they all use the same technology, so whether you subscribe to Magic Jack or Ooma or your local ISP's phone service its all the same ...using the internet rather than the physical use of landlines to carry your voice messages. And no more "long distance" charges...remember those.

So now that you know that you can shop based upon price and compatibility with your hardware/software suite. Bob Rankin goes into greater detail with an emphasis on the Magic Jack product (I have used Magic Jack since 2008 and have been very happy with the service and even happier with the cost.) In fact I was so pleased with the service I bought 2 additional units for my kids who were in college and needed the phone service but not the monthly costs. I bought the units and one year's service for \$39. Today's service plans include service for your cell phones, which saves a ton in charges since there is no per minute charges. Today I use the 5 year plan which costs \$99 for 5 years, plus sales tax.

But on to Bob's article and his thoughts:

http://askbobrankin.com/replace_your_landline_with_magicjack.html

And just the usual reminder to make it a point to visit our forum and Facebook page for more helpful ideas and information on our new lifestyle.

And finally a bit of Jazz from the KOHAR's Symphony Orchestra for our Armenian friends out there from Yerevan, the capital of Armenia, and one of the world's oldest continuously inhabited cities:

<http://www.flixxy.com/amazing-big-band-jazz-orchestra-performance-in-armenia.htm>

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