



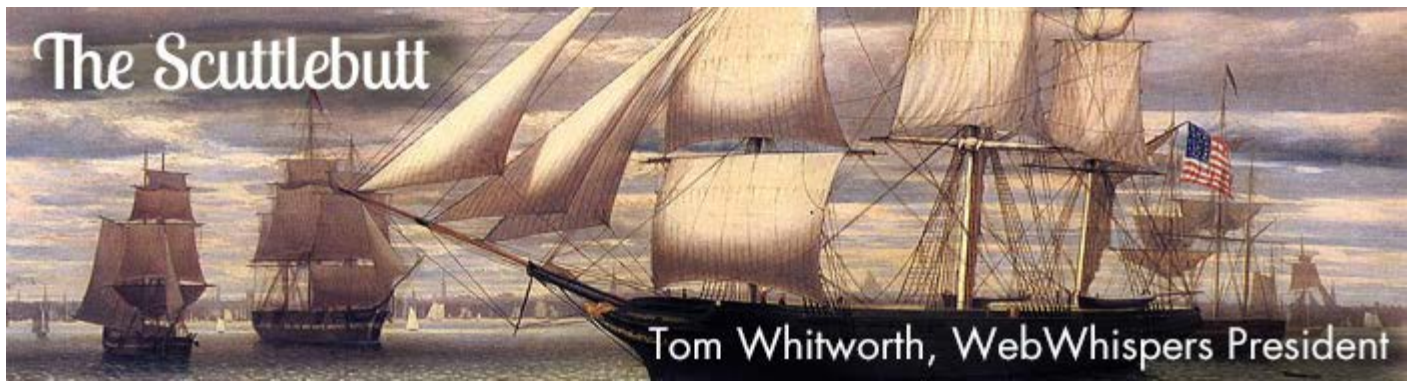
March 2019

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Ringin The Bell

Though this time of year certainly brings its beauty, the cusp between late Winter and Spring have never been at the top of my list, at least not until now. Pollen in the South always bothered me more than it did most people and I would be miserable for a few weeks. Apparently, that is still the case. Until a few years ago, I thought that was a really bad thing. Little did I know.

Five years ago, was about three months following my chemotherapy and radiation treatments. I was still reeling from it all but each of my three doctors felt like everything was good. I had hardly ever even heard of surgery for throat cancer, much less knew what it involved. Toward the end of that treatment plan, my doctors, all three, were convinced I was good to go. My medical oncologist even gave me the option to forego my final chemotherapy infusion. Having endured what I already had, I did not want to take a chance and skimp at the end of the process. Since everything had worked so well, I saw that last dose as icing on my cake and chose to have it. We forgot to have me ring the bell because I was so sick. It totally slipped my mind. About three months later, I had what I call the confirmation PET scan. "All clear" was about as far from the truth as you can get. I not only had cancer but it was far more advanced than ever and far more aggressive than we had thought. A laryngectomy would be needed and was immediately arranged for as quickly as the O.R. could get me on the schedule-three business days. My surgery, planned for around four hours, took eight. I'll spare you the details but it was less of a bump in the road and more like a Florida sinkhole with me driving Herbie. In the aftermath, I held on to my ultra-positive attitude. I reminded myself that sweating bullets over anything challenging does not make it better.

So how did this become my favorite time of year? On March 12, Dr. Michael Vick saved my life. There is no doubt about that. Within the next few weeks, things started falling into place. I was speaking hands free in about seven weeks. I remember how overjoyed my wife Julie was when I called her from my truck voicing with my Blom-Singer ATSV II from InHealth Technologies. I had so much to be grateful for. I was still here. Grandchildren Owen and Lydia, 3 and 2 at the time, joined me in the recliner on every visit. Poppy had a bad boo-boo and it was their job to make me better. That they surely did. My new life was truly grand in so many ways but there was something missing other than my larynx.

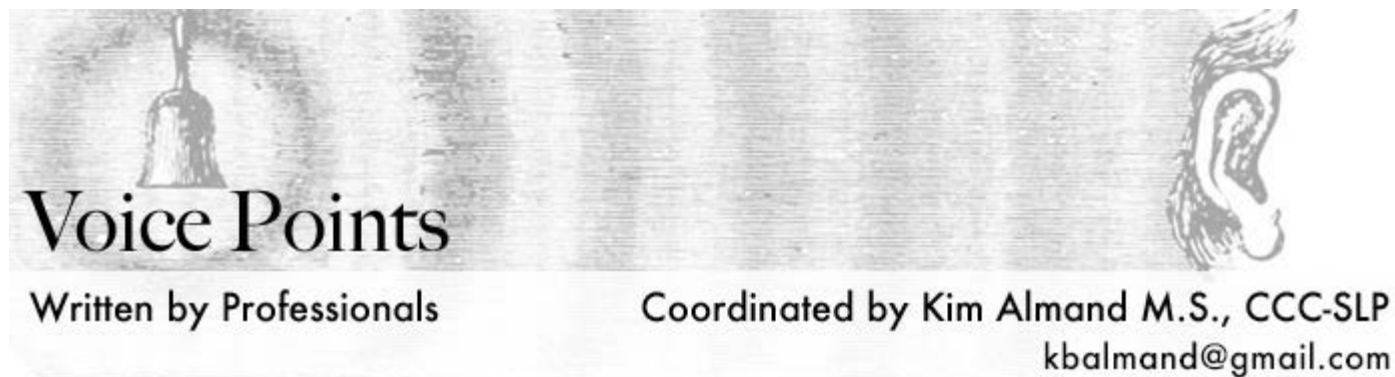
Deep within me was that feeling that there was something I was forgetting, something I needed to do. I had no idea. About that same time, I remembered and found WebWhispers and nothing could have been more precisely what I needed. I knew no other laryngectomees and had never even seen one. I had only had the electrolarynx demonstrated by an SLP, though she was and is very good. Esophageal Speech was something I had heard about but I didn't know anyone who truly understood it. When I joined WebWhispers, that all changed. Within a week, I was signed up for my first IAL Voice Institute, which was made possible by scholarships from Lauder, InHealth Technologies, and Atos Medical. My new life was electrified and nothing would ever be the same. I cannot imagine life without the people I have met through WebWhispers and the Voice Institute. Nothing compares.

On March 12, 2019, I will be five years cancer free. I have an appointment with my medical oncologist just so she can be with me to ring that glorious bell. It will ring louder than ever before!

Enjoy, laugh, and learn,

Tom Whitworth

WebWhispers President



Head and Neck Cancer: Resource Roundup

We have not updated our resource list in some time! Many excellent websites for information, community support and patient education in head and neck cancer are online and can be found as posted back in a previous VoicePoints Roundup: <http://www.webwhispers.org/news/apr2017.asp>. It is still worth a look! In addition, see below for a refresher on some swallowing terms that you may or may not have not heard of before. To be continued next month.

If you have not attended a professional education/training course recently, now is the time to consider your options for the upcoming year. Many new and ongoing training courses in head and neck cancer are available around the US at varied levels of instruction and participation for clinicians, laryngectomees and caregivers. These are excellent courses to take advantage of. Please contact me at: kbalmand@gmail.com if you are aware of additional opportunities out there in the US (and beyond) that are not listed. We will spread the word. Hope to see you at some of these events!

March 8-9, 2019: 2019: Multidisciplinary Head and Neck Cancer Update: 7th Annual Symposium
<http://www.clevelandclinicmeded.com/live/courses/multi-head-neck/>

March 15-16, 2019: Stanford/Harvard TEP Course
<https://med.stanford.edu/ohns/education/courses.html>

TBA: Contemporary Methods for Functional Success After Head and Neck Cancer: The MD Anderson Method
<https://www.mdanderson.org/education-training/professional-education/cme-conference-management/conferences/speech-pathology-and-audiology-conference-.html>

May 12-19, 2019: International Association of Laryngectomees
<https://www.theial.com/2019-voice-institute-annual-meeting>

February 27-29, 2020: Multidisciplinary Head and Neck Cancers Symposium
<http://headandnecksymposium.org/2020-Multidisciplinary-Head-and-Neck-Cancers-Sympo>

Sponsored by Atos Medical and InHealth Technologies:

Atos Medical Professional and Community Events (Check their website for events close to your home)
<https://www.atosmedical.com/professional-main/professional-events/>
<https://www.atosmedical.com/community/community-events/>

Blom TEP Course: Tracheoesophageal Puncture and Prosthesis for Post-Laryngectomy Voice Restoration (Monthly courses available)
http://www.inhealth.com/product_p/tep_course.htm

Glossary Terms: Check your knowledge on definitions related to common (and not so common) swallowing terminology involved in the anatomy and physiology of swallowing, swallow studies, and procedures involving the pharynx and stomach.

amotility: unable to move spontaneously.

anastomosis: connection made surgically; surgical seam.

anastomotic stricture: a narrowing, usually by scarring, of a surgical seam (anastomosis).

aphagia: the inability or refusal to swallow.

aspiration: breathing foreign objects such as food, saliva, or stomach contents into the airway.

barium: chalky solution used as a contrast agent used to coat the inside of organs, such as the esophagus, stomach or intestines so that they will show up on an x-ray.

Barrett's Esophagus: condition in which tissue in the tube connecting the mouth and stomach (esophagus) is replaced by tissue similar to the intestinal lining; often diagnosed in people who have long-term gastroesophageal reflux disease.

base of tongue: the back third portion of the tongue.

biofilm: a very thin, slim layer of microorganisms that sticks and covers the surface of an object.

BOT: base of tongue.

candida: most common type of fungal infection in humans; if healthy bacteria levels are disrupted or the immune system is compromised, candida can begin to overproduce. When the mouth is affected, it is commonly called thrush.

cervical esophagus: the top part of the esophagus that extends from the bottom of the throat (hypopharynx) to the thoracic esophagus, which travels through the chest and ends in the stomach.

cGy: a unit of absorbed radiation dose equal to one hundredth (10^{-2}) of a gray, or 1 rad.

circumferential: going around the [outside edge](#) of a round or [curved area](#), [object](#), [organ](#), or [body part](#).

dilation: the action of stretching or enlarging an organ or part of the body.

dysphagia: difficulty swallowing.

endoscopy: a procedure involving insertion of a long, flexible tube (endoscope) down the throat and into the esophagus. A tiny camera is attached to the the end of the endoscope to allow examination of the esophagus, stomach and the beginning of the small intestine.

esophageal: pertaining to the esophagus, the muscular tube that conveys food from the pharynx at the back of the mouth to the stomach.

esophageal manometry: a test used to measure the function of the lower esophageal sphincter (the valve that prevents reflux of gastric acid into the esophagus) and the muscles of the esophagus.

esophageal spasm: abnormal muscle contractions in the esophagus.

esophageal speech (ES or SES): This contrasts with traditional laryngeal speech which involves vibration of the vocal folds. Instead, air is injected into the upper esophagus and then released in a controlled manner to create sound used to produce speech. Esophageal speech is a learned skill that requires speech training and much practice.

esophageal stricture: a narrowing of the esophagus.

esophagectomy: the surgical removal of all or part of the esophagus.

esophagitis: inflammation that may damage tissues of the esophagus. Esophagitis can cause painful, difficult swallowing and chest pain; causes include stomach acids backing up into the esophagus, infection, oral medications and allergies.

esophagram: a study to determine how well the esophagus is working.

esophagus (oesophagus): “food tube,” connecting the throat (pharynx) with the stomach. The esophagus runs behind the trachea and heart, in front of the spine; it is approximately 8 inches long and lined with moist pink tissue (mucosa).

eosinophilic esophagitis: a type of white blood cell (eosinophil) builds up in the lining of the esophagus. This buildup, which is a reaction to foods, allergens or acid reflux, can inflame or injure the esophageal tissue.

esophageal dilation: procedure that allows your doctor to dilate, or stretch, a narrowed area of the esophagus [food tube].

esophageal lumen restoration (ELR): technique developed to reopen the esophageal lumen thereby restoring a patient's ability to swallow.

esophagology: study of the structure, physiology, and diseases of the esophagus.

esophagoscopy: procedure in which a flexible endoscope is inserted through the mouth or nares and into the esophagus, to treat conditions of the esophagus.

fluoroscopy: imaging technique to obtain real-time moving x-ray images of internal structures



Our New Tribe

If you hang around WebWhispers long enough you realize that there are some issues that predominate. Mucus is probably number 1, closely followed by prosthesis leakage, swallowing issues, voice options and failures. However, most everyone also says something like this, “We are all different”, meaning your experience and mine might not mesh and what I say worked for me might not be useful for you. While that is true, we are all the same in one way. Our anatomies have changed quite radically and we now breathe and talk very differently from the general population.

So, welcome to our new Tribe and if you haven’t already met us, it’s time you did. The International Association of Laryngectomees (I admit I laughed out loud when I first heard that name- surely you are joking, I thought!!) has a meeting every year, historically in the United States. The AM also includes the Voice Institute which is a training program for both new laryngectomees to better understand their situation and improve voicing and also to train and educate student SLPs (speech/language pathologists(AKA therapists) who want to work with “Our Tribe” how to help us on our path to full rehabilitation. It is an extraordinary collaboration between patients, caregivers and medical professionals that has served thousands of us since its inception in 1960.

We at WebWhispers believe so strongly in the value of attending both the Annual Meeting and the Voice Institute that we have several programs available for financial aid. Some are sponsored by vendors, others by bequests from late members. These stipends have grown over the years and can make a substantial dent in the cost of attending. We are proud and happy to be able to continue support for the Voice Institute.

WebWhispers members can apply for scholarships to help them attend the IAL Voice Institute in Phoenix May 15-18. First time Voice Institute attendees get top priority, other newer laryngectomees are next. Other factors are also considered but these two groups are considered first.

Register to attend the IAL Voice Institute first, then complete our application form using the link below.
https://webwhispersinc.formstack.com/.../webwhispers_scholars

What is SO important about attending an IAL/VI is not just the basic information...how does this part work now, how do I talk, swallow, cough, eat, live a normal life again; it's meeting your Tribe. Here at the IAL we are the majority and those in the minority, professionals and vendors are here to help us on this journey and we ARE the heroes. No need to be embarrassed about coughing, honking, belching, squawking, suddenly silent or troublesome swallowing. We have all been there. Take your time. It's all good.

You will forge lifetime friendships with folks you never would have met otherwise. This year the IAL/AM/VI is in Phoenix, Arizona. Here is the IAL link to register and get all the info on programs and accommodations.
<https://www.theial.com/2019-voice-institute-annual-meeting>

My first was in 2005 and I likened it to Lary Summer Camp. Make new friends, but keep the old. I hope to see you there!!



Editor's Note: Back in October, 2014 the Speaking Out question was about any special caregivers or others that may have assisted you in your recovery. The obvious family members are ok but what about others that may have been unexpected such as church members, someone that drove you around, a person you worked with, or maybe just a kind moment from someone that accepted you and didn't ignore you. Maybe an SLP that went the extra distance or a vendor that truly cared. What a nice ti-in to this month's question on what to tell newbies!

Dr. Susan Rosenkranz - daughter of our WW VP, Mike Rosenkranz

I've always been a little leery of the word caregiver—conjuring up images as it does

of an altruistic angel, selflessly ministering to the injured and ailing. As anyone who knows me will quickly attest, that is decidedly not a role for which I am suited. Perhaps, in those first uncertain days after Dad's laryngectomy in 1999, I filled what has come to be accepted as the care-giving role. However, once we left the frightening confines of the hospital, Dad and I slowly relaxed into what is now our own unique relationship: partners.

To me, "caregiver" implies that one person is doing all the work, seeing to the needs of the other. Dad and I are more like cohorts. We talk to each other constantly – not always in the most dulcet tones—but openly and honestly. Dad lets me know what he needs, and I let him know, sometimes rather grumpily, whether it's something I can do, or whether I think it's something he should be doing for himself. I'm not so sure I'm a caregiver to my father as much as a constant goad. I push and prod.

Mind you, I don't have to do that much, as Dad is amazingly self-sufficient. Yet, there are times when that independence can be a double-edged sword. Over the course of the past ten years, as my father's needs have changed, I know there have been times when he has been frustrated or discouraged, but has not wanted to ask for help. In times such as these, I cannot underestimate the vital necessity of listening, and keeping open lines of communication.

But, I have also learned something very important. Human nature being what it is, we do not always tell each other in words what we feel or want to express. I keep my ears open, but I have found it even more important to listen with my heart. It is the heart that tells you when a loved one needs you. It is the heart that knows instinctively when the burden is too heavy and must be shared. It is the heart that tells you to ignore all the words and listen instead to the silences. Your ears may hear, "No problem. I can do this." But watch closely and observe.

Your heart will let you know when to reach out a hand.

Maureen Mark - 7/2013

When I had my 3rd go round with cancer, I decided not to return to work.....There was a lady there who always offered me encouragement in the way of emails and cards.....she made a point of sending me a card almost every week without fail and they always perked me up and made me realize others were thinking of me as I was going through the lonely treatments.....she always found the perfect card, sometimes they had cats on them, sometimes just offering kind thoughts, but I really appreciated receiving them.....so, Kathy Heyer, want to let you know how grateful I am to have you there for me, and that you really helped me during the many months of treatment.....Thank you from the bottom of my heart.....

Richard Crum

I had my surgery in St. Louis MO. I had a very good SLP named Dennis Fuller. I live in Southern Indiana and right after my TEP I was having problems. Dennis called Dr. Eric Blom since I was only 100 miles south of Indianapolis. Eric and I got to be good friends as well as helping me with my minor problems. Because of our friendship I was able to contact Inhealth and work with them as a consultant. I have met quite a few very nice people over the years. I have traveled the US & Canada as well as a trip to Italy with Inhealth. I have seen things and met people that I would never have met if it had not been for my work with Inhealth.

Len Hynds, the Speechless Poet

There is no doubt that when first diagnosed as having throat cancer your whole world changes, as you are convinced that you will not survive, and it will only be a question of months before you no longer exist. All your family and friends are stunned, all thinking the same, and you are surrounded with sympathy, and with many, a form of embarrassment as they just don't know how to handle it, or even be in your presence.

With the medical profession it is pure efficiency they are interested in, and really they have no time for your emotional turmoil, but it is not forgotten, and the Ward sister takes it on herself, to introduce an existing Laryngectomee, normally on the evening before the operation, when all the family are gathered. Under our 'Buddie' scheme, and as you speak and tell them of your life, you can see their faces change and smiles appear.

You give them confidence. More importantly the patient, that there most certainly, is life after cancer. In my case. the regular 'Buddies' were away on holiday etc, and I got a Laryngectomee, a rather old gent, who had a chip on his shoulder, and angry at the cards dealt him. He spoke of people staring at him as he spoke, and how he angrily spoke to them, He was not a good 'Buddie' but I learned from him. Over the last ten years, I have been 'Buddie' to about ten who are now close friends and any potential 'Buddies, I take with me on those very important first visits when you calm all those frightening emotions amongst family and the patient. So I can sit back now and know they are doing a great job.

Marilyn(Mickey) Schlossberg - 2009

There are so many folks who have been so wonderful to me since becoming a lary in 2009. Although my son and his family live in California and I live in R.I. they are always there for me- E mails, visits, cards etc. Then my wonderful friends. Many live in my building (condos). We get together daily offering support and encouragement. When home I see Gregg Bunting M.A.,CCC-SLP my speech therapist at Mass Eye and Ear--none better! Then when in California Ann Kearney M.A.,CCC-SLP speech therapist at Stanford Hospital --- what a wonderful person. Without these two therapists I know I would not have progressed as I have.

I am 91 years young and although I have had bumps in the road I push on and enjoy every day because of the support I have had.

Carl Strand, Mystic Connecticut - February 1993

One of the most influential mentors in my journey as a laryngectomee was Charlie. My wife dragged me kicking and screaming to a laryngectomee support group meeting about three months after surgery. There I met Charlie.

Charlie was the person who told me that I could take a shower without a collar - keep the spray on your shoulders or below when your back was to the spray - let it hit the top of your head when facing the spray. Charlie was the person who showed me how to smell again and to blow out candles - took a while to learn to pump my tongue to move air through my nose, but I succeeded.

Charlie was the guy who never missed a meeting and always made the coffee. He was an excellent esophageal speaker, always ready to help and never said a word about my decision to go with a voice prosthesis.

Charlie had a recurrence of cancer about ten years ago. It was inoperable, wrapped around his carotid artery and not responsive to radiation. He did not die gently. I tried to speak at his memorial service and like all emotional situations, my esophagus spasmed. Then my electrolarynx died.

I'll always miss Charlie and think of him when we have our monthly new voice meeting.

Marilou Percival, Ontario, CA - 8/2/2013

Thanks for the opportunity to thank so many people who helped me with my recovery. My SLP James did a wonderful job getting me to speak. He worked with me and did not show frustration with me when I would repeat the same mistake over

and over. He taught me great exercises to loosen up those stiff neck and shoulder muscles. I would get in such a rush to talk, I would drop the first word more times than not, he taught me to breathe in, occlude, hold for two seconds and then speak. By golly, that worked then and still does. I will see him for a few more sessions when I am ready for Hands Free.

Another group that I received support from is the Bible Study group I joined spring. At that time, I still was not proficient in speaking, but when I was able to use one, two, or however many they would cheer me on. They are a very accepting group and an honor to be a part of the group.

Lastly, my third support comes from our local Baristas. I go to the Starbucks that is one-half mile from our house. They knew my order for a long time, but when a new Barista is on the the register and I would tell them my order, rather than have Ron speak for me like he had for the previous months, they say yea, Marilou!!! I have found overall the support from the general public is terrific.

Noirin Sheahan, Dublin, Ireland - July 2013

Just yesterday I went into a shop in a main railway station to buy a travel card for a friend. I took out a wallet with my own card to show to the shopkeeper so as to be sure to get the right card. I spoke using my electrolarynx and after I paid and said goodbye I went outside to wait for my bus. There were lots of people standing in front of me. Then suddenly there was the shopkeeper saying, 'Sorry, but you forgot this' and handing me back my wallet with my own travel card. I hadn't even missed it and probably wouldn't have until I got on the bus. The wallet had not only my cards but a cheque for 1,000 euro! She saved me so much hassle and stress by that act of kindness. I don't know how she found me as the station has a big waiting area for trains and I was outside in a bus-shelter behind a big crowd of people. This was at rush hour when she would do the most of her business for the day.

I thought that was incredibly kind of her. I don't know if my electrolarynx speech had touched her somehow or whether she would have done that for anybody. Or maybe another had spotted me with my electrolarynx and microphone and loudspeaker and were able to tell her which way I had gone. If so, it shows that it can sometimes pay to be different.

One way or they other I feel very fortunate to have met her.



The Leaky Bucket

I liked Tom's 'Leaky Bucket' story from the December issue which he had remembered when another laryngectomee said he now thought of himself as 'damaged goods'. The poor old leaky bucket also felt like 'damaged goods' until the man carrying the bucket pointed out all the flowers that had grown along their path because of its trail of water drops. So we don't have to think of ourselves as 'damaged goods'. We just work in a different way now - not in such an obvious and straightforward way as before; perhaps so subtly it takes someone else to point out how we benefit others.

When I took up meditation teaching again, about a year after laryngectomy, I found it hard to believe that anyone would choose a meditation teacher with a robotic voice. For meditation guidance, you normally want soothing tones, and the quiet atmosphere of a meditation room contrasts so sharply with the squawk of an electrolarynx. Whether it was out of loyalty or compassion I don't know, but quite a few people came on my first retreat, and I asked them afterwards if they would be willing to write something for the centre's website which might help others to think about the pros and cons of coming on a retreat led by a laryngectomee. They all gave positive feedback and these excerpts in particular relate to Tom's 'Leaky Bucket' story:

"I do miss Noirin's voice but I want to embrace this new voice and its technology and feel glad that she is still up for encouraging us on this path. How can we be anything but inspired?"

"It is a reminder of the impermanence of the faculties. Speech, sight, hearing, moving about - we take them for granted, and perhaps don't use them as we should. A teacher who is unperturbed and continues to work as usual impresses one with the sustaining nature of the path, which does not change with circumstances. I hope the example will teach me to use the gift of speech wisely and not too often."

"There was that wonderful testimony that when something tragic happens we can all rally and something quite wonderful fills the loss."

I had really needed to hear this positive feedback, being one of those people who easily fall prey to self-doubt. I find it much easier to feel proud of my abilities than to trust that my limitations might inspire or

touch others. But obviously they do.

Despite all this feedback and wise reflection I have to admit that a large part of me would still prefer to be the well-sealed bucket rather than the leaky one! I suppose it's only natural – which of us doesn't want to feel able, independent, successful? We were all brought up on fairy stories. Tell me one of these where the princess ends up breathing through her neck, unable to speak?

It takes humility to appreciate the kindness and compassion our slow awkward speech might draw from others. But these are the flowers that the 'leaky bucket' of laryngectomy is watering as we go about our daily lives. Kindness, patience, compassion, humility. Not showy flowers – they don't call attention. That's probably why we don't value them as deeply as we should.

I'm glad to have a meditation practice to sustain me through the challenge of laryngectomy. When I relax and let attention dwell on present experience, stories of success and ability quickly fall away. In fact all the stories of 'me, a laryngectomee' and 'you, who speak so fluently' and 'what I achieved' and 'what I need' all lose their footing. They start up but finding no nourishment, fall silent again. What's left in the silence are those unobtrusive flowers of kindness, patience, compassion. The next moment my habitual acquisitiveness starts composing stores about 'my kindness' or 'your compassion'. It's like grabbing the flowers, trying to bunch them up into a bouquet for the world to admire. It doesn't work! The flowers quickly fade.

Very humbling! But it's good to be developing an aspect of life which is not affected by stories of laryngectomy, fluency, success or failure. An aspect of life which does not differentiate between leaky buckets and well-sealed ones. And, in the end, won't all buckets start leaking?



~Editor's Note: John sent this in as a response to the Speaking Out question. It is longer than our usual replies and we thought it should be read in its entirety here~

A week before my surgery, I was visited by Bill Porter, President of the New Voice Club of Minneapolis, Minnesota.

If at all possible, I would recommend a visit like this for everyone before their surgery.

For me, it was more valuable than all of the advice I got from all of the doctors, nurses and SLPs.

Bill didn't say much and I didn't say much. Finally he said "Do you want to see it?" He reached up, pulled aside his patch and showed me his stoma.

This gracious act of kindness was a turning point in my life. Here was a guy with a hole in his neck and he still played golf a couple times per week.

Bill's visit gave me the courage to let go of my anger, my denial, my reluctance and get on with what I had to do.

I will be forever in his debt. I hope some day I can play it forward.

This is a letter I wrote to my friends just after my surgery 4 years ago. Maybe it will be helpful to some of the new Larys.

I had my Total Laryngectomy Surgery at Mayo on Friday, September 19, 2014. Checked in at 10:00 am - all done and back in my hospital room by 8:00 pm that evening. Woke up in a total panic because I was breathing thru my nose and I knew that wasn't supposed to be possible with total laryngectomy – wanted to shout out to someone "you made a mistake", but of course that wasn't possible because I no longer had a voice.

Of course my body was just playing tricks on me – I was in fact breathing thru my stoma, not my nose, but my nose didn't know that and had convinced my pea brain that it was still in charge of breathing and doing just fine, thank you. Wish someone would have warned me about the "sympathy pains" my nose would be having when I woke up.

Spent the next 4 days recovering at St Mary's/Mayo hospital in Rochester, Minnesota. Made the two hour drive back to my home in Minneapolis, Minnesota noon Tuesday September 23rd. Did three days on the feeding tube at home, then returned to Mayo on Friday September 26th for the swallowing tests. Passed with flying colors and had the feeding tube removed from my nose. Stopped for a DQ chocolate malt (extra thin) on the way back – a day that will live in infamy!

My surgery was done by Dr. Moore, a world class surgeon at a world class hospital. I never really had any concerns about the surgery – I knew I had the best of the best with Dr. Moore and his team. I was, however, very concerned about my recovery and care after the surgery and asked questions incessantly until I reached the point where everyone I talked to gave me the same answer "trust us, we know what we're doing". At that point I knew I had to let go and just get it done.

I woke up in the hospital with a tube behind each ear to drain the excess fluids that build up when they cut out a bunch of lymph nodes from your neck. Apparently this is standard protocol at Mayo, even if your tests show no cancer in the lymph nodes: slit your throat from ear-to-ear, remove some lymph nodes and test them for cancer. In my case, 20 on the left, 22 on the right, cancer: 0 out of 42. So... the good news: cancer free; the bad news, a larger wound to heal than I had planned.

I also woke up with four other tubes running to my body: catheter, O2-Mister, IV-drip, and pulse/O2 measurement device. Those six tubes made me feel like I was wrapped in a strait jacket. I think the medical profession should seek advice from some industrial engineers on ways to make hospital stays more user friendly. I made up my mind right then that getting those tubes removed was going to be my top priority.

I learned early that if I told the Nurses I wanted to walk, they would temporarily disconnect me from most of those tubes – they think walking is so important that they'll bend over backwards to accommodate you if you say you want to walk. One hour after arriving in the room, I told the male nurse I wanted to stand up. "OK" he said, disconnected several tubes and helping me to a standing position. "Now what", he said. I just shook my head to indicate I just wanted to stand there. "Why", he said. I told him in a short note

scribbled on a white board that even if I had a catheter, I still wanted to pee standing up! He just smiled; I got that catheter out the next day.

After that, I walked all the time, and the more I walked, the less conscientious they got about re-hooking me up to those darn tubes. Word even got back to the doctors – they figured I must be in good shape if I did all that walking and they released me after 4 days.

In fact, my stay in the hospital had not been as uneventful as it appeared. My surgery had been delayed one week to give me a chance to meet with a Pulmonologist about COPD maintenance strategies after Total laryngectomy. Turns out that was a wasted delay because it did not improve my breathing or sleep for the four nights I spent in the hospital. The Pulmonologist recommended that my ADVAIR/SPIRIVA COPD inhalers be replaced by PULMICORT/DUONEB delivered in nebulizer form.

The inhalers take about 1 ½ minutes per day – the nebulizers about 1 ½ hours per day. In spite of that, I agreed the nebulizers were a good choice while in the hospital and for a limited time at home afterwards. Unfortunately, the recommendations never made it all the way to the Nurses and I was never offered or given the DUONEB. Once I got home, I started up on the “optional” DUONEB and found that if I used it right before Lavage, it would free up a good size phlegm plug and immediately open up my airway and make my breathing feel wonderful.

In addition to my impaired lungs, I also had to deal with the change from sleeping on my side to sleeping on my back. All my life I have slept on my side – changing to sleeping on my back was a major re-do.

If I turned even 2 degrees left or right I would wake up coughing – I think the stoma tube would move slightly and rub where it shouldn't.

I slept in a recliner all four nights in the Hospital, never in my bed. Even though I was dog tired, I would get up several times each night and walk the corridors of the hospital all by myself, just to get a few minutes of respite from the coughing and the crushing weights in my chest.

Since arriving home, I have experimented with beds, couches, chairs, and flat on the floor. I've tried multiple combinations of pillows and multiple angles of elevation: If too steep, I can't fall asleep; if too shallow, I wake up in 15-20 minutes gasping for air. (Can't Lavage every 15-20 minutes, doesn't do any good.) I guess this is one where you just have to be patient and let time heal. Each day I am home I sleep a little better and a little longer.

We have set a target of leaving by car to drive back to Florida on Friday, October 10th. Exactly 3 weeks from the date of the surgery and 2 weeks from the date I had the feeding tube removed.

I have 4 goals that I hope to accomplish in the next 2 weeks - before I leave for Florida.

DIET

Move from a thin liquid diet today to the point where I can eat a full serving of Mom's favorite tuna hot-dish with no problems.

LYMPHEDEMA

Find a local therapist knowledgeable in lymphedema facial massage to start me headed in the right direction on reducing the swelling in my face. Right now, my body doesn't know what to do with all the extra lymph fluids building up so it just shoots them down to a pool below my chin and along my jaw line. I look like I just went 3 rounds with a heavyweight half my age, and I'm a welterweight.

SPEECH

Get my own Electrolarynx and give back the used one lent to me by Bill Porter, President of the New Voice Club of Hennepin County. Then get at least one training session with an SLP on how to use it. This is the vibrating wand that you press up to your neck and lets you talk like Darth Vader. There are other ways to

regain speech but I made a choice to delay the added surgery for those methods so I could focus on the best possible breathing and swallowing out comes first. This is what I will be using for somewhere from 2 to 8 months.

COPD Maintenance

Find alternatives to nebulizer delivery. Either switch to Metered Dose Inhalers (with spacer) or get off maintenance entirely. The current marginal improvement in breathing does not justify the 1 1/2 hours per day investment of time.

.....
TOTAL LARYNGECTOMY FOUR YEARS LATER 2/26/2019

I am blessed in so many ways.

I eat and drink whatever I want whenever I want – no problem.

I got rid of that darn Lary-tube and replaced it with base-plates so now I'm back to sleeping anywhere and anyway I want – no problem.

Over time, my body has figured out what to do with that extra lymph fluid so I am back to being the handsome devil my wife married 35 years ago – no problem.

I found out I could attach an Infant Child Mask to an MDI spacer and it provides a perfect connection between my COPD inhaler and my stoma (google BreatheRite - MDI Spacer). I also switched from 2 inhalers twice per day to a single inhaler once per day so my breathing is now great – no problem.

Finally, I learned to be quite good at speaking with the Electrolarynx, then, after six months, I had the TEP surgery and learned to be quite good at speaking with the speech prosthesis.

I've had the usual amount of setbacks with sizing problems, leaking problems, etc. which can be quite annoying in the heat of the battle but I just keep telling myself "don't turn into that angry, ornery old man you used to make fun of back when you were a kid."

Keep searching for solutions, keep moving forward, and keep doing what you can to get a little better each day.

I am now living on a golf course in Florida and playing golf a couple times per week. God bless you Bill Porter where ever you are!

~John Zimdars



"What is the most important thing you would tell a new or soon-to-be lary and his or her family/friends/support system?"

I think the main thing that a new patient should know is that you are not alone. There are many of us that will help you and you will make it. I thought I would not be able to do any of the things I enjoyed when I had my surgery. I found from meeting others that I could do anything I wanted. I might have to take some other precautions when doing things like woodworking due to the fine dust but I can still do it. I often tell patients that there are only two thing I cannot do. One is be a good singer, which I never was before, but I think Tony Talmich proved me wrong. The other is I was a certified diver. If I really wanted I could find a way to do that too but I think the risk is too great and it was time to give that up.

Do not give up hope!!! A good life is still there for you as long as you keep up a good attitude and never give up.

**Ron Mattoon
Seattle 2010**

Be patient and stay positive are the most important words you can give a new Laryngectomee.

**Tom Olsavicky
Yorktown, Va. 2008 Lary**

Our life will be different, but it is definitely not the end of the world. Be sure to try all options for speaking and stoma care available, and review WebWhispers often.

After a period of time - weeks, or months - your daily care time is similar to those wearing contact lenses.

**John Greider,
St Louis, Class of 2000**

The single most important thing that is common for the patient, caregiver(s), family and friends is to maintain a positive attitude about the patient's condition and future.

Dave Ross
Inverness. FL - Surgery March, 2005

Other than the standards of "Things Get Better Over Time" and "We're All Different", I would tell new Larys to get out into the local community as soon as possible. I have found that there is a lot of support out there in just doing normal activities. People seem to respond to us as we make our way into our 'New Normal'. Store checkers, restaurant servers, bartenders, and such usually remember us and provide encouragement and support.

Peter Meuleveld
Salem, Oregon - June 2010

A new lary or soon to be lary... it's going to be a lifestyle change/ adjustment which will seem too difficult to bear. BUT once you accept this as an exploratory life learning adjustment process and go with the adjustments that make your new venture a more familiar daily experience – it gets so much easier. Have faith that things get better... they do and you will grow in ways you've never thought to make you stronger.

Lisa OFarrell,
Chicago, 8/2017

I believe that learning to take care of yourself is critical. You learn by trial and error. I have seen several folks who rely on a care giver to do everything and I think to myself, what happens if they become unavailable? Plus they cannot know how your body is feeling or reacting. I was 76 when I had my total, I live alone so I had to learn everything and I have done very well. Be independent, open-minded and willing to experiment and learn. Be positive and determined!

Dick, Class of 2015

Even though for some people it could scarcely be described as a life-changing operation it is always an anatomy-changing operation but,thankfully, it doesn't take long to become accustomed to it . Be prepared for the first weeks after surgery, they will be difficult and painful. You will be breathing through a hole in the neck and you may even have some concerns for your safety when you sleep in case a sheet covers the stoma. You need have no worry on that score; should any interference occur with your breathing Mother Nature will awaken you to correct the situation.

Though the journey after surgery differs from person to person there are certain common problems. Among the first of these is the disposal of mucus brought up by coughing. In my own case I remember feeling that

what I considered the large amount of mucus was an indication of some serious abnormality. But of course it was simply the body reacting to the altered breathing mechanism. As time goes on that will decrease and become more manageable. Learning to speak again is another but this depends on too many variables for a ready answer and each person must choose the method that best suits.

Be patient with your progress. I have heard it said that it takes about four months for a laryngectomee to again feel reasonably comfortable in his/her own skin and this is something that accords well with my own personal experience. There are so many things to be resolved- new ways of speaking and communicating and of course certain types of occupations may require some necessary changes. Bear in mind, however, that a substantial number of laryngectomees return to an active and productive life. There are doctors and teachers and lawyers who have resumed their former professions as well as mechanics, barbers taxi-drivers and hundreds of others who have gone back to their jobs.

Believe me, there is life for the laryngectomee. And the time will come when you will, for all intents and purpose, almost have forgotten your condition. That has been my own experience. I am a lary now for fifteen (15) years. Fifteen years that I can honestly say have been as eventful and enjoyable as the sixty-six that went before.

Though now eighty-one (in met office lingo '81 millibars and falling slowly') I'm active and enjoying excellent health.

Things turn out best for those who make the best of how things turn out. Be not afraid.

Michael Mac Mahon
Class of 2004

The most important thing I could tell a future laryngectomee is the importance of learning patience, as recovery time is slow. As a child we learned the recovery time of a knee scrape, and as we got older we applied the same principles to other sicknesses and injuries. One of the toughest transitions we'll ever have to overcome is laryngectomy surgery, due to its effect on our communication with others, the way in which we consume food and liquids, the way it changes our physical appearance, and even the way we cough and expel mucus from our bodies.

Even with all this doom and gloom, a post-surgery laryngectomee can overcome all of the things listed above, with the help of medical specialists, subject matter experts, which includes other laryngectomees, family and/or other loved ones, and most importantly, keeping a positive outlook. This not only will assist the laryngectomee but will also help the loved ones/caregivers who are trying to assist.

Keeping your head up with a positive outlook will help greatly in the recovery phase of surgery.

Mike Smith
9-11-2008

I would tell a new Lary that there are much more debilitating diseases than what we have & that there are always things to be grateful for. Make a gratitude list whenever you feel down & remember that God always has a plan that is for our greater good & for His Kingdom.

Love & Blessings,

Cyril Dueweke
Lary 9/2016

Recently, some old friends asked me would I get in touch with their friend Linda (not her real name) who was expecting to have a laryngectomy. I decided not to overload Linda with too much info and let her ask questions at her own pace as we got to know one another. Here's a copy of my first email:

Hello Linda,

I'm Pete and Cath's friend from Dublin who had a laryngectomy in 2013 because of cancer in the throat. I now speak with an electrolarynx.

Pete told me you have oesophageal cancer so that's different to me but I think you are also facing a laryngectomy now. I'm sorry to hear that - it is very tough to lose your natural voice. Some people are able to have a voice-valve inserted and their new voice can sound hoarse but otherwise very good. I hope this works for you.

But also to say that life doesn't end with losing your voice. I was very anxious at first but somehow came through that. Like most people who go through some horror, I discovered joys in many things I had previously taken for granted – e.g. I spent hours and hours looking out the window at a tree or at the clouds in the sky. It seemed the tree and the sky could absorb all my anxieties, let them fizzle away to nothing.

I'll sign off here but do feel free to ask me about anything you like, or just keep in touch.

I will be thinking of you - do you have a date yet for the operation?

*With love and good wishes,
Noirin*

She got back and 6 months later we're still in contact and our friendship has been inspiring for both of us. Pete and Cath were friends of Linda, so for them I concentrated on what I needed from friends at the time of laryngectomy. Here's what I said to them:

"The kinds of visitors that helped me were one's who didn't need to talk too much, as every word others say remind you that you can't reply. So meditators are ideal.

Not that people have to be completely silent, but just not needing to chat all the time.

But some sort of 'communication' is needed, and what worked for me was people who would be happy to hold hands or run their fingers along my hands as a gesture of support. One or two friends were able to give me massage and that was wonderful - just hand or foot massage - nothing too challenging. I also asked one friend (Margaret) to manage my visitors as it can be overwhelming if too many people arrive and there's that normal expectation of smiling and saying hello, and in fact you can't do either. So I made out a list of people who I thought would smooth my way back into social life and Margaret then contacted them to arrange for one or other to call each day, and told others to stay away for the moment. No one took offense - they all understood.

Another suggestion would be to see could you get a whiteboard and non-permanent markers for Linda. Hands are too shaky to manage biro and notebook for a while but I was able to scrawl a few words on a

whiteboard. The hospital had one for me but it was all dirty and marked from people using permanent markers by mistake, so probably no harm having a spare".

Noirin Sheahan
Dublin, Ireland - 2013

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

Staff of Speaking Out



2019 Voice Institute/International Association of Laryngectomees Annual Meeting

Hello WebWhispers,

The 2019 VI/AM (Voice Institute/International Association of Laryngectomees Annual Meeting) in Phoenix, Arizona is quickly approaching. May 15 will be here before we know it!!!

If you have not made your reservation yet, please go to our website at: www.theial.com and register.

There is a link to the hotel on our site as well which offers a very affordable rate of \$89.00 and is good for two days before and two days after our conference. You can come early or stay late and plan a day trip to the Grand Canyon. Phoenix is a beautiful city and there is much to do and see. We have arranged a tour of the Heard Museum of Native American Art for Friday afternoon with bus service to and from the museum. To learn more about the museum you can go to <https://heard.org/>

Our Voice Institute Director, Caryn Melvin, has engaged some excellent speakers. From Bill Brummel, an award winning documentary producer, director and writer to Dr. David Lott from the Mayo Clinic in Phoenix. In addition to being Director of the Laryngeal Surgery Program at the Mayo Clinic he is also the Director of the Center for Regenerative Medicine at the Mayo Clinic. These speakers promise to be very interesting and Informative.

We are urging all laryngectomees to sit in on the Voice Institute classes. There is a lot to be learned, even for a seasoned laryngectomee. You can ask questions and in so doing help SLP's better understand some of our problems. We surely can help each other.

The most important part of our conference is the great feeling you get just sharing with other folks like yourself. Many lasting friendships are made and we look forward to seeing each other every year. To take a more active role you can always offer to be a member of the Board of Directors. We also need a treasurer so please consider this as well.

Looking forward to seeing you in Phoenix.

Helen Grathwohl, IAL President

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