

Whispers on the Web

A Monthly Online Newsletter for WebWhispers

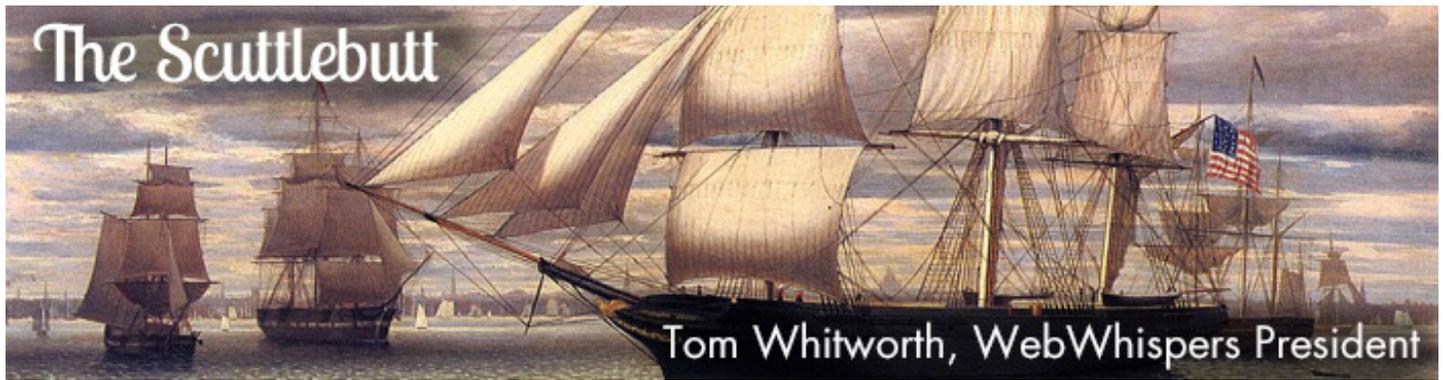
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Table of Contents

Name Of Column	Author	Title	Article Type
The Scuttlebutt	Tom Whitworth	Back It Up!	Commentary
Speaking Out	Members	Tell Us About Your Speech Therapist	Opinion
VoicePoints	Kim Webster, M.A., M.S., CCC-SLP	The (Dying?) Art of Esophageal Speech	Education-Med
Dear Lary	Noirin Sheahan	A Hot Bath – Lary-Style	Commentary
Between Friends	Donna McGary	Climbing Mount Doom	Commentary
Stand By Me	Christine Price	The One Person	Caregiver Experiences



Back It Up!

One of the most interesting things to me about our community of people is how much we vary in mode of speech. Some struggle to determine which method is going to be best for them. Many of us have a choice, but not everyone. Some who would choose speech by way of a tracheoesophageal puncture (TEP) cannot get the needed medical supplies. Others need and opt for an electrolarynx and cannot get one. Few things in life would bring me more joy than seeing this depravity ended.

Like many, I started with a dry erase board until I could use an electrolarynx. It took some effort to get the kinks out with TEP speech, but things are fine now. My voice prosthesis sticks fairly often and I'm used to that. I keep a brush on me always and one insertion of it seems to reset the device, even if it does not need to be cleaned. Unless I get completely lax, which is rare, I have a Servox or Trutone on me or at least in my vehicle, especially when driving alone. I often use an EL just so I don't forget how to use one. Personally, I like them a lot. I hope to get off my duff someday and truly learn esophageal speech. I tend to harp on having a backup to whatever method we use. That can be as simple as a battery or pen and paper. I'm sure you'll agree here that I need to practice what I preach.

Not long ago, I had an experience that truly drove home to me the importance of having a backup communication method. It also showed me how vulnerable we can be when unable to communicate. Further, I learned to not be a scatterbrained idiot. I was out running errands and stopped at the post office to check the mailbox. I can do that anytime of day or night at this location but choose to do so during the day. I happened to arrive just before the staff would be shutting down services at the counter. It was late in the day; I was tired, and I suppose, a little scattered. I pulled into a parking place, got out of my truck and closed the door. Instantly, I realized I had locked my keys in the vehicle.

This is okay, I thought. I have AAA and will just call them. As I reached in my pocket to pull out the cell phone, I

realized that it was locked inside the truck, as well. At the same time, I saw my EL sitting there in a drink holder. Somewhat embarrassed but remaining calm, I went into the post office and asked one of the clerks who recognized me if I could use his cell phone so I could call for help. I phoned AAA, gave them the address and texted my wife to let her know I would be a while. As I do fairly often, and surely at this point, I occluded with the HME to test for a voice. Nada, zilch, nuthin! Normally, that quick insert of my voice prosthesis brush fixes this in a snap. Many of you have seen me do this. The brush was in my pocket but the mirror I use with it was not. I gave up pretty quickly on trying to use the brush without being able to see into the stoma for fear of injuring myself. Standing out front, I realized that everyone had left and I was alone. The facility is not visible from the road and it began to get dark. The response time I had been told was much longer than normal and that amount of time had passed. I learned later that the driver had lots of trouble finding me with the street address. I waited well over an hour in the dark.

I did not panic, but I did feel extremely vulnerable. I was isolated in the darkness, and with no way to communicate. When help finally arrived, I could not utter a word until he unlocked my truck. I immediately fixed my voice to tell him thank you. I learned several things that evening; make sure I have the keys before I close the door, have the cell phone, brush and mirror, and maybe even pen and paper on me. I learned that the electrolarynx comes with a lanyard for a reason. I was reminded that my life is no longer the same. Nothing is truly worse and probably some things are even better. Even so, I am different and must think differently for my own well-being.

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



“How helpful and knowledgeable was your speech therapist”

My name is Pam Lodal and I live in Boise, ID. My laryngectomy was done in Feb of 2017. My SLP is fantastic! I originally met her in 2105 for a swallow study after chemo and radiation treatment during my first bout with cancer. She was instrumental in helping me get back to a “regular” diet after having a feeding tube. I met up with her again for a pre-op appointment before the surgery. She was able to put me in touch with a few other laryngectomees before my surgery. That was a godsend and one of the best things to help prepare me for life after a laryngectomy. I saw her about one month after my surgery - that was when the doctor told me I was able to try “voicing”. She and my husband were the first people to hear my new voice with my TEP. She loaned me an electrolarynx to try out, helped me understand all the different products available and helps coordinate community events with our ATOS rep.

I don't have a set schedule for appointments, but see her whenever I need my TEP changed. Fortunately, the SLP clinic is very close and they always have someone “on call” - even holidays and weekends! She is very professional, competent, kind and caring and I don't know what I would do without her. She gives me a TEP with insertion kit to take when I travel out of state or out of the country. I never feel silly if I have a question or concern and if she doesn't have an answer, she will help me find one. She is a shining example of someone who enjoys their job, is good at it and helps more people than she will ever know! I can only wish that all the other laryngectomees out there are able to find such a wonderful therapist!

**Pam Lodal – Boise, ID
2017**

I had a pre-op visit with a speech therapist two weeks prior to surgery, at which time we discussed the various options I would have available “after” surgery. At this time, I was given demos on two different types of electrolarynxes. I was also given a form to fill out to file with the state of Wisconsin for insurance claim assistance. A month after my surgery, I again saw the therapist, and again tested the electrolarynxes to see how they sound with no vocal chords. And also attempted

esophageal speech. This did not go well for me, so my decision was to go with an electrolarynx as my ENT doctor did not think a TEP device would be suitable for me, due to my situation. I also have GERD and lots of scar tissue due to radiation due in 1996. It's been a struggle at times, and I know everyone is different. So, even though I've had tough times, I think of those that have had it a lot rougher than I, and am always thankful for the “bonus days/years” I've received.

One of the things I look forward to, is reading the stories of my fellow larynx and/or caregivers about what they have gone through or are going through. And of course, the great support that WebWhispers provides to our community.

Love to all....Live long and prosper

**Ronald P. Boudnik - Manitowoc, WI
Oct 15, 2015**

It may surprise some of our newer laryngectomees when I tell them that laryngectomy has been known since 1828. Warren Gardner, {Ph.D./SLP} wrote in his “Laryngectomee Speech and Rehabilitation Introduction,” “In 1908 Gutzman astonished the medical world by reporting he had successfully taught 25 laryngectomees to talk with esophageal speech” (ES); initially called pseudo voice by Landois in 1888. “Seeman first used the term esophageal speech in 1919.” So, you see my pre op SLP at Mayo Clinic, Rochester, MN, stood on the shoulders of a myriad of medical professionals that researched voice before him. I was in good hands now after a bumbling start at my local hospital. The “mucus retention sack” turned out to be spindle cell sarcoma, but only after weeks and two sloppy surgeries before the suggestion that I travel to “a major medical center for a possible laryngectomy”.

They already knew that radical surgery was the best way to go; neither radiation nor chemo would put an end to it. My SLP, Robert (Bob) Keith, (author of “Looking Forward” and “A Handbook for Laryngectomees”, presented most of what I needed to know those first 3 days at Mayo for consultation. Day one: I saw a video of two female teachers using ES to teach a 3rd grade, and a high school French class. I was challenged and convinced ... if they could do this, so could I ... eventually as it turned out. The next day I spent time in

the Mayo Library to get a handle on the vocabulary I was listening to, and a better understanding of what my looming decision would mean for me and my family. The 3rd day I signed the papers and started the lab work for the Monday morning surgery. I flew home to prepare my family over the weekend for another two weeks of my being away for more needed for surgery.

Yes, I was probably better prepared for what was ahead than most. As I prepared to fly back to Mayo my prayer in the morning shower was, "Well, God ... I wonder what this adventure will bring?" All that I was taught pre op was only a good beginning. The reality of the post surgical gore in the mirror undid me for a day or two. Once the shock was absorbed I learned the 3rd day to take care of my own incision and stoma. The coughing while bending at the waist was easier than using the darned suction machine so I cut that out quickly. On the 9th day I switched from N/G tube to soft diet, and my 1st ES lesson. No sound yet, but I was adamant about not needing an EL because "I was going to learn to use ES". That changed when I got home 14 days post op, and had to resume my place as wife, mother, community leader, church steward, and civic theater properties mistress. I had to talk. My first electro larynx was an Aurex that was like driving a Mack truck; very loud and very, very heavy.

P.S - . Over the decades I have noticed that first impressions do seem to matter a great deal for post op results; if the patient sees and hears ES, EL or TEP first that seems to be what they are sold on over time. It seems to me a more objective presentation would be presenting all methods of speech initially because we don't know what will work best for each patient. A laryngectomy visitor that is a triple threat using EL, ES and TEP equally well has a huge advantage to offer a new patient.

Elizabeth A. Finchem - Tucson, AZ
DOS: 10/2/78

I have to say from the beginning that I had the best people working with me when I went through one of the most difficult times in my life! Thank you so very much everyone at the University of New Mexico Hospital in Albuquerque, New Mexico!

Pre-Op meeting was great. Carrol Romero-Clark sat down with me and explained all of my options. I'm glad others were there to remember all the information, Because I was still in the "Oh, My God I have Cancer" mode! I feel this is very important to remember because most don't even remember being there!

My Cancer was far enough along that Dr. Spafford told me he would rather remove the cancer then treat with Radiation. To get any smaller particles that may not be seen with the Eye during my Surgery! Great Guy! Thank You for saving my Life Dr. Spafford!

Back to my SLP! Carrol is the greatest. She is not just a SLP but a great psychotherapist. She would listen to my stupid rants and just take care of the problem. She gave me samples of all the different products to try and advised me as to what may or may not work for me. That is very important. We are not all the same so all of our needs will be different.

That is coming up on 17 years now and she is still my SLP! And more she has become a very good friend. My Other Sister you could say. She has also advised me on what to say to patients when I volunteered to speak to new cancer patients! The first time she brought me to meet the patient and left the room I was scared!

I feel the SLP can be more important than the Doctors at times! That is if you are lucky enough to find a great one! The SLP is one of the most important parts when we go through this education of our new lives! I could not have made it through all of this with my SLP and my Family! Thank you all so very much!!

John Haedtler - New Mexico, USA
2001

Prior to surgery I advised the surgeon that I would utilize TEP voice with patient changeable prosthesis unless in his judgement there was a medical problem which prevented the likely hood that It was not feasible. Accordingly, he did the puncture at time of surgery. I did not have a pre-op visit with the SLP, simply because it it was not necessary.

Two weeks post-op, immediately following a follow up with the surgeon, I visited the SLP for first time, he removed the catheter and inserted a B/S low pressure prosthesis. He then asked me to say something, I responded with "what do you want me to say"?

Long story short, two weeks later I re-visited the SLP and after giving me a short "speaking test" declared that I was at 80% "voice" capacity and gave me the advice to slow down, enunciate, and enjoy my life.

As I recall, over the next six to eight months I re-visited him (generally in conjunction with my surgeon FUs) there were a couple of visits and had my prosthesis resized as the swelling went down. It was also during this time period that Provox came out with the NID and he asked if I wanted to try it, I did and have stayed with it ever since. After the first year I don't think I saw him again for five to seven years, maybe longer.

Brent Baldwin was a great SLP at Shands Medical Center in Gainesville, FL and retired a year or so ago.

Dave Ross - Edgewater, FL

I can't remember what day it was after my surgery, but a nice man showed up at the side of my bed with what I found out later was a Servox. He said put this against you neck and press the upper button. I can't remember what day it was after my surgery because I was in a lot of pain, and kind of goofy on Morphine. At this point I was under a hundred pounds, and members of my family had been flying in from all over the country to say goodbye. Of course I didn't know that. It never entered my head that I was going to die there.

Well, He didn't tell me where to put it on my neck, so I placed it just below my right ear. When I pressed the button it almost blew my hearing aid out, and kind of scared me. I decided right then that thing was never going to work for me.

Two days later a woman showed up with another speaking device that had a long plastic nozzle on the end of it. Once again; I later discovered it was a Servox with that tube attached to the end of it. She was my SP, but I didn't know that. She said put the end of it in my mouth, and then just talk normally. I have a complete set of dentures, and that thing didn't work well either. She said that I should take it home and practice. She said that she would come back to see me in two days to see how I was doing. I have never seen her again.

When I got home I discovered that she had her name and address card taped on the Servox, so I assumed that it was hers. On my next visit to my surgeon I put the Servox in a bag, and told him go give it back to her.

My doctor was a good friend of the SP and suggested that I just give her chance. On my next visit to my surgeon I told him that I didn't want to see her because my daughter had been upset with her too after canceling some appointments with her clients so she could be in in the hospital when the SLP was supposed to be there. My surgeon have me bag with the Servox in it, and said he would recommend a new SP.

After I came home from the hospital I just used hand signs and notes to communicate with everyone. I also had a small fistula, and had to continue to use the feeding tube in my throat.

The fistula healed, so I finally I went to my new SP a 25 or 26 year old nice young lady, but I concluded that she didn't know beans when she got ready go pull out my feeding tube, and said this is probably going to smell pretty bad. She didn't seem to know that I could no longer smell.

Things went down hill from there. She said that because I am legally blind I would never be able to use an implant or something in my stoma. I had no idea what she was talking about. At that time I didn't even that the hole in my neck was called a stoma.

She was probing around in the hole where the feeding tube had been trying to measure the size of the plug to put in the hole. She kept trying to find the right size, and I could watch her ion

the next room doing something, and well over a half hour of her poking around in my stoma I had tears rolling down my cheeks. It had started to really hurt. After getting the plug in my stoma she said it was the wrong size but it should stay in. She gave me a spare plug, and told me to carry it with me at all times, and I did for two years.

When she was through she gave me a box with a new Servox in it. That's when I discovered that my insurance company had paid for the first one also.

I got used to it right away, but heard about a TruTone that I could vary the sound, so I bought that too. For some reason one of my two Servox Els works a lot louder and better than the other Servox or TruTone. I have asked the Servox company about this, but they have never responded. There seems to be something they might not even know. Now I have a bunch of 9 volt batteries, and eight rechargeable ones.

As it stands now I don't have an SLP, and rely on Whispers for all my advice along with Troll and several others on WW. That's my story an I'm sticking to it.

Johnnie Dontos – Woodway, WA
11/30/2015

My only preoperative visit was with the doctor, but he did not explain much other than I would have no vocal cords and would breathe through a stoma. I had already gone through a partial laryngectomy so I knew some of that to expect. My SLP was new in the position but she was great to try to help. WebWhispers was my main sources of information. Every time my SLP would schedule a visit to help me I had already learned most of what she was going to talk about before the visit from WebWhispers. I was not able to meet another laryngectomy for almost 10 months after my surgery. Meeting another laryngectomy would have saved me a lot of worry and anxiety. My first chance to meet another laryngectomy was on one of the WebWhispers cruises. I was lucky that year, the cruise was up to Alaska and left from Seattle close to where I live. It was wonderful and I learned more in that week than I had in the previous 10 months. I cannot thank those that helped me enough because they a huge difference in my life.

WebWhispers was my lifeline and my source of information for a long time. The need for a local support group became very obvious. A couple of us discussed it and started our group. Again, WebWhispers members and IAL was my source of information to learn what I needed to know for this too. Pat Sanders and Ed Chapman were tremendous help. I will always be so grateful to them and will miss them.

Ron Mattoon - Seattle, WA
2010

I first met my SLP when I was going through radiation and follow up. I confess I did not want to meet her as I never wanted to imagine myself needing one. She was by my side as I prepared for surgery, explaining my options and going so far as loaning me an EL to try while I still had my vocal chords. She tried to prepare me, and my family, for what to expect post surgery from a non-medical perspective. She came by every day to provide support and encouragement.

I had my surgery November 30, 2012. I have seen her regularly every three months since that date and sometimes in between when I have had an "emergency". She is always there for me. Yes, she has provided me with options, some of which I have tried, others not (hands free for example). In summary, she has encouraged me, educated me, and supported me throughout my journey. She is my friend, my guardian angel and her name is Colette Nault, Ottawa Hospital..

**Susan Burgess - Ottawa, Canada
2012**

I have experienced a rather unique experience with speech pathologists. Nearly 28 years ago my ENT thought I was a voice abuser, singing in four choir/choruses and chairing a number of organizations. She sent me to a speech pathologist, Susan Cullen, for vocal exercises and training in avoiding vocal abuse. Three months later, the ENT did a biopsy of the lesion on my right vocal cord and was shocked to find it was cancerous. She removed the cancerous tissue and I spent seven weeks undergoing radiation therapy. During this entire time I continued with speech therapy, restoring a semblance of normal speech and even something of a singing voice.

When the cancer recurred eighteen months later and it was determined that laryngectomy was the only option, the speech pathologist went to the hospital loaner closet and presented me with a variety of electrolarynxes, stating that although there would be other alaryngeas speech options, esophageal speech or tracheoesophageal speech, the electrolarynx was probably my first method of speaking and would be a backup device if I was able to use other methods of speech. I decided on the Romet as my choice of electrolarynx.

She also stated that she was not an expert in laryngectomy rehabilitation and put me in contact a speech pathologist, Dr. Mary Bellandese, who was both able to train in esophageal speech and was experienced in fitting voice prostheses. I had a primary puncture with my laryngectomy and was fitted with a Blom-Singer duckbill voice prosthesis four weeks later. My first speech pathologist, Susan, continued to work with me on my new tracheoesophageal speech and my second speech pathologist, Mary, was my go to person for issues with the voice prosthesis.

Both Susan Cullen and I attended a workshop, four months

after my surgery, at the University of Connecticut for laryngectomees, speech pathologists and ENT's. My second speech pathologist, Dr. Bellandese was one of the individuals presenting the workshop. It was here that I first met Dr. Jim Shanks, Dr. Shirley Salmon and Dr. Zilpha Bosone. The two of us learned a great deal. She and I continued speech therapy for another three months at which point my insurance ended.

I continued my relationship with Dr. Bellandese for another ten years, being filled with a Blom-Singer Hands Free Valve and switching to Blom-Singer low pressure voice prostheses. When I decided to switch to an indwelling voice prosthesis because I was getting leakage around the prosthesis due to compromised tissue, Dr. Bellandese recommended that I leave her and switch to a speech pathologist at Yale New Haven Hospital who was able to fit and install indwelling prostheses. I then became a patient of Lynn Acton and have continued to have that relationship until this day.

As I said at the beginning, I experienced a rather unique relationship with speech pathologists. Not only did I have long term relationships with them, but they were open and honest about their strengths and weaknesses. I had the opportunity early on to meet three of the best in laryngectomy rehabilitation, Drs. Shanks, Salmon and Bosone. I continued my relationship with them over a number of IAL Voice Institutes. I am eternally grateful to all of them.

**Carl Strand, Mystic CT
Radiation Summer of 1991;
Laryngectomy February 10, 1993**

I had had experience with professional speech & language pathologists (SLPs) long before my laryngectomy. It was a 3-year journey to find the cancer that eventually took my voice. During that time, I came to appreciate the knowledge, professionalism, and dedication of these health care professionals. Three rounds of speech therapy to try to correct the "problems" with my voice--that turned out to be laryngeal cancer--gave me a good insight into the profession and into how the voice and voice apparatus works. I am a biologist and educator, so the entire anatomy/physiology aspect was fascinating as well.

With regard to my actual laryngectomy due to cancer, I did NOT get a great deal of pre-operative information--at least not to the degree that I would now expect and certainly not as much as I desired (being a bio-geek and all). I learned the most pre-operatively through my own efforts and research. I know now that I was a somewhat (maybe a lot) more informed than most people before heading into surgery, because I asked lots of questions and my Doc appreciated my interest and enthusiasm for the anatomy/physiology aspects of what I was going through. [My Doc is a wonderful person and an excellent physician! ...But that's for another Speaking Out question.]

But all that is NOT to say that I was “well-informed.” I simply did not know enough to understand what the important questions really were. I had never met a laryngectomee before, so I had no conception of what this new future might mean for various aspects of my life. Like most laryngectomees, I had hundreds of questions within a week or so of starting this journey. I felt ill-informed, but I was informed “enough” to satisfy the administrators and all their paperwork.

I was first introduced to my SLPs the day after my laryngectomy, while in initial recovery in the hospital. I *might* have met one of them the day before surgery, but I was hazy all that day from the day’s gastric tube surgery and all the hustle & bustle in my room while I was being prepped for the laryngectomy. So many people were in and out of my room that day that is it all a blur. (Another related side issue here is me wondering how all those people expected me to absorb much less remember everything that was said to me and done to me that day?)

I have two SLPs, Lauren R. & Kacy G., who work as a team--and they are simply excellent! I met one and then the other as they came up to my room from their practice on the ground floor of the hospital; taking time to introduce themselves, asking how I was doing, patiently allowing me to reply via writing, hand motions, and a new app I had on my iPad (they really liked that app!). There, they helped me begin the long process of education about my laryngectomy and all the changes that I would now be experiencing.

During my week-long stay in the hospital, I saw one or the other of my SLPs every day or two and they always took plenty of time with me--never acting like they were in any kind of hurry. They inspected the surgical site and the process of the healing around my TEP, answered every question, provided me with tips that might make the current situation easier, and gave me instructions and tips about handling things once I left the hospital.

I am coming up on my second anniversary of the laryngectomy (Nov 1) and EVERY experience I have had with Lauren and Kacy has been positive and encouraging. They swap out my TEPs, address my questions, offer helpful tips, help to smooth the various frustrations I constantly experience with insurance issues (that, right there, is a huge deal!), and treat me not as “another patient,” but as the individual that I am. We get along wonderfully and I could not ask for more in regards to professional knowledge, expertise, and compassionate care.

When I am bopping around on various fora, FaceBook pages, and other Internet sites frequented by other Larys, I quickly realize how fortunate I am to have Lauren and Kacy at my back--or even by my side. So many other people have a difficult time even *finding* a “Lary knowledgeable” SLP, much less one (or, in my case, two!!) that understand the issues and step up to provide education, lend aid & support, and generally serve as another “voice” for us as we navigate our way through our new world.

Kirk A. Janowiak - West Lafayette, IN
“Class of 2016”

I’ve already written about my first SLP, Robert Keith, at Mayo who retired in 1991, and “Uncle” Jim Shanks, Ph.D./SLP. This time I’d like to tell you about my 2nd SLP, Sherry Gant Johnston, that worked with me back in Kalamazoo, MI. She had attended the Mayo Seminar 4 months before I met her. I was her first laryngectomee following that Seminar. We both had a copy of Warren H. Gardner’s book, Laryngectomee Speech and Rehabilitation. We learned together chapter by chapter.

She was able to get me to accept the EL I had refused while we worked up to 3 syllables using ES. She was wise enough to refer me to a family counselor, and allowed me to pause as needed for radiation, and family stress. While I was “pausing” she took it upon herself to learn to use the EL, and used it for a week at work and at home. Then she tried to use the ES she was developing along with me at work and at home. Her husband forbade her to use it at home because he found it disgusting. Interesting. (Yes, they divorced eventually.) My hat is off to her for all the extra effort she put into developing her skill and understanding of what it is like for a new laryngectomee day in and day out.

I am honored to have had her as a friend, therapist, and guide for as long as we worked together. She was the spark that helped me start a local group at the clinic 3 months post op; it is still functioning thank to Tom Cleveland picking up the reins after I moved to CA in 1985. She also helped me organize my first statewide conference in Kalamazoo in 1983. We were an active team.

Elizabeth A. Finchem
DOS: 10/2/78
Tucson, AZ

Next Month’s Question:

What were your larynx cancer symptoms. How long before you were diagnosed?



Voice Points

Written by Professionals

Coordinated by Kim Almand M.S., CCC-SLP

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The (Dying?) Art of Esophageal Speech

Some years ago, my colleague Robin Samlan, PhD, and I co-taught an evening class on speech rehabilitation after total laryngectomy (TL) to SLP graduate students. We struggled with how to present information on esophageal speech (ES) in a salient and meaningful way. We had both come of age as SLPs when ES was a main communication modality, albeit one that was ever quickly being replaced by electrolaryngeal (EL) and tracheo-esophageal (TEP) speech modalities. We lamented it as a “dying art,” both for teachers and learners. “That’s it!” we thought. One of us will come out dressed as the grim reaper, maybe even play eerie music in the background while the other proceeds to explain to the students the many advantages of this speech method for laryngectomees. Once we have their attention, we can then impart our knowledge of how to actually teach this to patients: the principles, air injection/inhalation methods, how to decrease audible and visible distractors, fine-tuning the speech, etc. Well, WE certainly thought it was a great idea. If memory serves me, it went over a bit like a led balloon. Thankfully, we don’t depend on our comedic skills to make a living. We did cover the necessary material as I do in all of my courses to graduate SLPs and for continuing education for professional SLPs on TL speech rehabilitation. I sometimes wonder how many of the hundreds of students I have taught over the years, have actually tried to teach ES to a patient. I am guessing the number would be a single digit.

In the archives of this publication, there are excellent articles on the principles and mechanisms of ES as well as advice from the trenches on troubleshooting, best practice methods and pros and cons of using ES over other methods (see *Speaking Esophageally* by Jim Shanks, PhD; 2005). In this article, I chose to discuss my personal experiences with ES and continue to argue for it as a worthwhile option that should continue to be taught to graduate students hoping to work with patients with total laryngectomy.

I was first introduced to ES in a graduate school summer elective on head and neck cancer. The three methods of

speech were given equal time and focus in the classroom. I recall being mesmerized by our guest lecturer, Frances Stack, SLP and esophageal speaker. She was a dynamic speaker that commanded your full attention. The course director, the late, great Jeri Logemann, insisted that we leave this course with knowledge, experience and confidence in presenting all methods to our future patients and with confidence in our abilities to teach all three methods. My first patient in clinic the following semester was a lovely woman, Jean, who was a skilled speaker with the electrolarynx (EL) but wanted the flexibility of being able to use a hands-free, battery-free, intrinsic speech modality as well. We worked from sound production through about 9 seconds duration and 15 syllables per air charge by the end of the semester. She was a well-motivated patient that worked hard on home practice. She was one of my more rewarding and confidence-building patients in my graduate student career and part of my inspiration for focusing my career on the head and neck cancer population.

Fast forward about 20 years, and while years sometimes pass where I do not teach a single eructation to a patient, I still offer it as a viable option when the opportunity arises. Interestingly, despite my strong training and above-average skills in this modality, I have very few patients that I can take credit for training through the adept conversational level. That being said, I do have a handful of patients that are excellent esophageal speakers. Most took my beginner lessons and either learned to fly of their own accord or had supplemental training from other patients, the ever-rarer speech classes that are adjuncts to TL support groups or by other self-teaching methods using video and written material, much of which is accessible via this forum.

In 2018, and in my two decades of experience, two common scenarios come to mind warranting ES as a modality that is still worth its weight in gold. With the ever-increasing problem of TEPs in salvage TL, frequent leaks, spongy tissue, irregular stomas and punctures, many patients decide that the risk/benefit ratio of having a TEP is not worthwhile. Although some decide to use an EL and a few explore options like pneumatic devices, ES is sometimes

an ideal choice. For those that experienced excellent sound vibration and adapted the sound as their own, reproducing it intrinsically, without the hassle of prosthesis changing and leaking, ES comes quite naturally. After learning the basics, two of my patients, such as Mark and JP, took off on their own. The freedom they experienced from being able to speak of their own accord was rewarding in unspeakable ways. I remember Mark saying he would sit in his car in the driveway upon returning home from work each evening and practice longer and longer utterances, experimenting with the nuances and finer points of suprasegmentals and such. Then there are those like Larry and Sam who wanted the skill as a supplement to their primary method (EL for one; TEP for the other) in order to be able to produce short responses, hands and devic-free. Larry is a regular church-goer and finds it easier to speak quietly during services and less distracting to converse after services using ES rather than his EL. Sam, a painter by trade, has never liked using a hands-free valve with his TEP and finds it safer and more convenient to utter yes/no or a short phrase while up on a ladder, paintbrush in hand.

Whatever the reason, whether by forced choice or alternative option, there are a myriad of indications and advantages to using ES either as a main or supplemental communication option for patients with TL. Thankfully, the Voice Institute of the IAL still continues to include ES training for SLP students in its hands-on annual course. I will certainly continue to include teaching ES in my graduate elective courses for SLPs hoping to work with patients with head and neck cancer, and I will continue to advocate this method for my patients undergoing TL. Let's hope I can keep the grim reaper costume in the trunk!

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Kim is a speech-language pathologist with over 25 years' experience working with children and adults with a variety of communication and swallowing disorders. Her clinical focus has been on dysphagia and head and neck cancer patients. She is an assistant professor in the departments of otolaryngology, head and neck surgery and in neurology. She works part-time in research with PPA patients using tDCS and language therapy. She is also an adjunct faculty member at University of Maryland and Towson University. She lectures locally and nationally and publishes on head and neck cancer rehabilitation.



Dear Lary

Noirin Sheahan

A Hot Bath – Lary-Style

Pre-laryngectomy, a hot bath was one of my favourite treats. I tried a couple of times after the operation, but found that keeping my neck out of water was way more challenging than keeping my nose out of harm's way. But just recently I (literally) toppled across a solution.

It's all down to climate change. For any of you who have visited Ireland, you'll know that the weather is always a topic for conversation. There might be a light drizzle in the morning (a grand soft day!), lashing rain by lunchtime and just when you've given up hope, the sun appears to give a glorious evening.

But the past year has taken us all by surprise. We're used to it being unpredictable. But we're not used to extremes. If we get a day or two of sunshine, we reckon we've had a good summer. If we get a few inches of snow, that's the winter over and done for another year. And although we get lots of wind and rain, we never get hurricanes ...

...Until, last October, hurricane Ophelia became the most easterly Atlantic hurricane on record and brought the highest wind speeds ever recorded in Ireland. The met office had issued 'status red' warnings and almost every business, school and crèche was closed down. People were asked to look out for any elderly or ill neighbours, and my 91-year-old mother was served the most delicious dinners of her life from her neighbours!

Then in February came 'The Beast from the East' – a polar vortex from Siberia bringing freezing temperatures. It clashed with Storm Emma coming in from the Atlantic and the result was a week where everything ground to a halt amidst snowdrifts of several meters. There were some great stories too – people pushing ambulances through the snow, staff at Dublin 'Hareport' rescuing baby hares stuck in the snow, the boys who pulled a drowning German Shepard from the River Shannon.

Then, in June, the sun came out. We had the hottest summer anyone can remember – six weeks with hardly a drop of

rain. There were downsides – wildfires in the hills and a severe drought. As a response there was a hosepipe ban, and it was this that eventually toppled me into my bath.

To keep the garden going I set up a 'grey water' system, diverting pipes carrying the run-off water from the bathroom sink and shower, and from the washing machine so that they filled buckets I could later use in the garden. I soon discovered just how much water goes down the drain every day. My standard bucket just couldn't contain the run off from a shower or a clothes wash. So I purchased two giant 8-gallon soft-rubber buckets, and the garden survived the longest drought in 20 years.

The rains are back now and I was tidying away my array of giant buckets when it occurred to me that, hunkered down, I might fit into one of these myself. I brought it into the bathroom, turned on the shower and filled the bucket about half-way, stepped in, hunkered down and discovered I had badly underestimated my body size. With my feet and lower legs underwater, there was no way of squeezing my bottom in beside them. Well then, I thought, how about a bottom-up approach? Let's see how much of me it can haul into the tub with it. So I stepped outside again, aimed my bottom towards the centre of the bucket and toppled in backwards.

There was a mini-tsunami as my nether regions displaced most of the water in the tub, but it settled down to give me my most comfortable bath in years. The water came short of stoma level but high enough for warmth. The rubber was soft enough to contour to my back and support a sleepy slouch and also soft under my knees so my lower legs could dangle lazily outside. I'll add a standard bucket of hot water to the recipe next time so my feet aren't left out in the cold.

This is the life, I thought to myself. All I need is a cool drink and a good book and I'd have half an hour of heaven!

Stand By Me

The Caregivers Journey



The One Person

This first appeared under the header of WebWhisper Columnist in January 2010. I thought it worth sharing again because it honestly addresses the complex emotions some caregivers face every day, particularly those whose loved one faces multiple issues and has not made a full recovery and rehabilitation.
~Donna McGary, Editor~

A little while ago Donna asked me if I would like to write an article about care-givers. Because I am one of said people it has taken me far longer than I anticipated in getting around to actually doing it - time is a precious commodity for carers and must be taken where and when as possible. For many this article will not be appropriate - because "your" larys have gone on to lead independent lives - this is for others, like myself, who are carers 24/7 - in my case, approaching year 11 now. The title may have thrown you slightly - but please read on and it will hopefully become somewhat clearer.

Being "a carer" is not a term I like very much. There are other words for what I and many others do every hour of every day for those we love who have, however reluctantly, become a part of this unusual world we inhabit - I call it Laryworld. There are many alternatives to the word carer: care-giver, helpmate, spouse who loves a person and helps them, a child (of any age) giving love and help to a parent, a friend helping another friend - the list goes on.

I decided that before writing about my true feelings here, I had better check that I was not the only person to feel - in some way - so cheated. I asked, on our British website Laryngectomy Life, for the thoughts of other caregivers and the answers were a revelation! I knew that deep inside me, to my absolute shame, I felt resentful and cheated. Cheated of all the things that my husband and I had planned to do now that the family was grown. Our dreams, worked towards together for so many years, lay in ashes around us. Now, alas, they are all out of the question. After the horror that is the lary journey, my husband contracted various other problems which, to my sorrow, limit his life very severely

both physically and in length of time left. This means, of course, that my life is also restricted; our days are governed by 6 hours on a nebuliser and trips are out of the question for him/us, because where he is, I am too.

Some of the words which came from the other caregivers about their own personal feelings are most certainly NOT what I expected. I thought it was just me who felt this way. It turns out others feel the same and as I list the words we all have used to describe our feelings, I would ask you to please not judge, not until you have walked in our shoes for any length of time.

- Fear
- Resentment
- Sorrow
- Guilt
- Loneliness
- Constant Anxiety
- Tired
- Afraid
- Anger
- Loss of "me" time
- Overwhelmed
- Isolated

However, the one word that always appeared amongst all these very real and heartbreaking feelings - was LOVE for the patient. I think if we are honest, we all will admit to having felt every single one of these feelings at one time or another. It may be difficult to understand unless you too have walked the rocky road that is caring. Like me, we all love our charges/patients, call them what you will, but it does not stop these negative feelings creeping in unannounced and uninvited to fill us with doubts, fear and, for me, overwhelming tiredness.

The most wonderful response I received was from Phyllis in Georgia, U.S.A., whose husband has just had his laryngectomy. I print it here in its entirety. It will also explain my somewhat obscure title for this piece !

Christine,

I don't know another good title, but I know how I feel.

I feel like I am the one person in the world who settles him when he feels bad or is anxious.

I am the one person in the world who he can snap at and get frustrated with without having to later try to explain that he was tired or felt bad or was simply blue.

I am the one person in the world that he saved his sweet potato pie for today because he knows how much I love sweet potato pie.

I am the one person in the world who he scoots over in the hospital bed for and pats the bed for me to get in with him.

I am the one person in the world who has been married to him for 35 years--and we both admit some of those years were longer than others.

I am the one person in the world who leaves the hospital every evening with the prayer that he is stronger tomorrow and I can take him home soon.

I am the one person in the world who is scared to death to take him home because I am afraid I will not be able to care for him properly.

That is how I feel.

Phyllis Conn

Georgia

How wonderful is that piece? Thank you for allowing me to reproduce it here, Phyllis.

Christine Price (Wales)



Between Friends

Donna McGary

"That which does not kill us makes us strong."

Photo CC by Corack5239

Climbing Mount Doom

It is 4AM and I can't sleep. Partly because I have a cold which is messing with my asthma and the duo-nebs I used make me jittery and partly because, like most of my country, I am heartsick over the spectacle we have become and the bitter divisiveness and rancor we are acting out. There is no escaping it, except maybe in a novel, and even then some reference will be made and I am reminded once again that we human beings are a quarrelsome and vindictive tribe, not easily given to generosity of spirit or goods.

This is not the time nor the place for me to make a case for my particular views. But it is appropriate to say that I am sick to death of the phrase "no matter which side of the aisle you sit on...". The fact that we are using that now practically meaningless distinction to define us and divide us should give every one of us pause. I say practically meaningless because I think it is obvious to most of us that political parties these days are less about policies, programs and people than they are about power.

As I mused on that discouraging thought it occurred to me that we need Frodo. It's no wonder the Lord of the Rings has resonated so long for so many of us both in the novel and more recent excellent film adaptation. For the uninitiated here is a Wikipedia introduction.

The Lord of the Rings is an epic high fantasy novel written by English author and scholar J. R. R. Tolkien. The story began as a sequel to Tolkien's 1937 fantasy novel The Hobbit, but eventually developed into a much larger work. Written in stages between 1937 and 1949, The Lord of the Rings is one of the best-selling novels ever written, with over 150 million copies sold.[1]

The title of the novel refers to the story's main antagonist, the Dark Lord Sauron,[a] who had in an earlier age created the One Ring to rule the other Rings of Power as the ultimate weapon in his campaign to conquer and rule all of Middle-earth. From quiet beginnings in the Shire, a hobbit land not unlike the English countryside, the story ranges across Middle-earth, following the course of the War of the Ring through the eyes of its characters,

not only the hobbits Frodo Baggins, Samwise "Sam" Gamgee, Meriadoc "Merry" Brandybuck and Peregrin "Pippin" Took, but also the hobbits' chief allies and travelling companions: the Men, Aragorn son of Arathorn, a Ranger of the North, and Boromir, a Captain of Gondor; Gimli son of Glóin, a Dwarf warrior; Legolas Greenleaf, an Elven prince; and Gandalf, a wizard.

There is a wonderful scene in the first movie (The Fellowship of the Ring, 2001) where the Council is meeting to discuss the threat and as it dissolves into partisan acrimony Frodo (and ultimately his fellow Hobbits & everyone else present) step up to the seemingly impossible task of destroying the evil power threatening their lands.

www.youtube.com/watch?v=TrJJ6ncp1fc

The key word here is power and this, unfortunately seems to be hardwired in our human DNA.

Power tends to corrupt; absolute power corrupts absolutely. ~Lord Acton, British historian 1834-1902

As I researched that well-known quote, which, full disclosure, I actually heard the first time from Linc of The Mod Squad back in the 60's, I read the full letter from Lord Acton and discovered that he had more to say on the matter. It seems that some things never change.

Great men are almost always bad men, even when they exercise influence and not authority, still more when you superadd the tendency or the certainty of corruption by authority. There is no worse heresy than that the office sanctifies the holder of it.

I have become more cynical lately about our ability to rise above this human tendency. I have seen support groups like WebWhispers and the IAL suffer fissures due to power struggles...well-meaning people can be intractable and power hungry too. From the PTA to the US Congress we humans seem to be fractious and flawed even when it comes to working together for the common good. Does that mean we simply give up and stop trying to make a difference? No, of course not, but some days it seems as impossible a task as having Frodo cast the ring into the fires of Mount Doom.