

# WebWhispers

Sharing Support Worldwide

Throat Cancer and Laryngectomy Rehabilitation

## Whispers on the Web

A Monthly Online Newsletter for WebWhispers

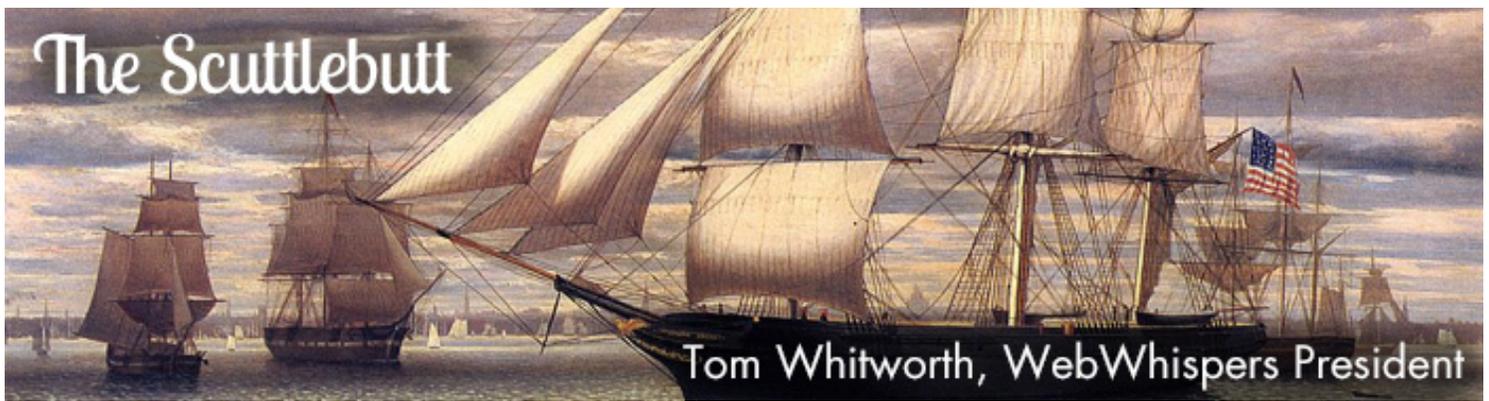
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## A Voice of Reassurance

The IAL Annual Meeting and Voice Institute in Dallas, June 2016 offered a Laryngectomy Visitation Training seminar by Ann McKennis and Candy Moltz which I attended. Although it was all valuable, Ann, in particular, made some points that really hit home with me. She talked a lot about what not to do and what not to say to a laryngectomy candidate. I really don't believe I could have been so insensitive as to have done those things, but it was an important reminder. We often are eager to share our own story. Mine is a very positive story of survival. I can give you the five minute or the thirty minute version. However, if I were to detail the potholes (**more than bumps in the road**), the setbacks, the struggle and pain I endured, I would likely scare both patients and caregivers half to death. Had I heard all that from a laryngectomy before my surgery, I likely would have been more focused on my life insurance and safe deposit box than the suddenly impending laryngectomy. I had only a weekend to process everything and knew almost nothing. Maybe I knew so little that it kept the fear at bay. I know that I would not have received any benefit from a litany of someone else's challenges.

I surely am not the authority on pre-surgery visits, but my approach seems to be working well. My method is a mixture of common sense, consideration for someone headed down Lary Lane and their caregivers, and yes- my teaching from Ann McKennis.

First, there is the friendly introduction. It is as simple as "Hi, I am Tom". The patient sees and hears me speak. That alone is a good start and an excellent icebreaker, if one is needed. The sooner I move the focus from me to the patient, the better the visit will be. The value of our time together begins when my new friends start talking. Sometimes I need to prod with a few questions. Which ones depends on a number of things but rarely are they all needed for anyone.

How ARE you? How are you feeling? What are you thinking? What are your concerns? What questions do you have? What fears do you have? Some people don't want to talk about that last one. We tend to perceive it as a sign of weakness but let's face it, each of us had fears prior to surgery, at least until we were sedated. No one should ever head into a surgery in fear. The best source of relaxation and peace is that which comes from having our deepest fears allayed. Fears are often subconscious. I know mine were. We can't verbalize something we know nothing about. Answers are great, but we often don't know which questions to ask. It truly is helpful to get both the patient and caregiver(s), if available, to ask every question they have. Once they have posed all of their questions, then, and ONLY then, I offer some advice about things they did not address that I truly feel my new friends need to know. This is when I share a bit about recovery and rehabilitation as I do want to be honest and helpful. I present potential issues post-surgery but just enough to help the patient and caregiver(s) to avoid fear if and when they encounter these.

My goal is always to alleviate fear and have them know that communication, good health, and life continue on.

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



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## "Have You Ever Tried Esophageal Speech?"

I had my laryngectomy in July of 1988. My doctor did not do placement of a prosthesis at the time of surgery. I learned to use my Servox right away and started to learn esophageal speech about 3 weeks post op. I had a good SLP and found that I could do esophageal pretty well after about a month. I used esophageal speech until I had a prosthesis put in in late October of 1988. I currently use a Blom-Singer valve most of the time but I have found that esophageal speech is like learning to ride a bike. Once you learn it stays with you.

**Richard Crum – Jeffersonville, IN**

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I learned esophageal speech right after my surgery in 1988, when the only alternative was EL. I spoke fluently and worked in public schools until I retired. After 20 years my speech began to lose quality and eventually I lost it altogether from late-term radiation fibrosis. A year and a half ago I got a TEP which serves me well in close quarters but isn't loud enough to use the phone.

**Carolyn Anderson, Whiting, New Jersey**

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I live in Papillion, NE. My surgery was in September of 2002. I could no longer use prosthetic speech because of leaks around the prosthesis. I was re-punctured about 4 years ago but continued to experience leakage around the prosthesis. It was at this point that I began to use esophageal speech and now it is my only form of speech.

**Steve Wiemeyer - Papillion, NE**

*"You may know about God, but do you know God?"*

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My name is Fred Armani. Lary since 03/04. List our home address as Pleasant Garden, NC, but we live in our Motor Home. Just turned 74 last month. Tried ES back in 04-05 and was unsuccessful. Much of the problem was a Provox speech prosthetic was installed during my surgery and trying to learn ES with it in just did not work. I have above average speech with my prosthetic and I wasn't willing to have it removed. Also I am a Vet so my supplies are provided at no cost.

## **Fred Armani – Pleasant Garden, NC**

*PS: I used to attend the WW Conventions and have had my voice recorded many times. Always mistaken for a Female when I answer the phone.*

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I wasn't going to respond this month, because my answer to Jack's questions are "none of the above". But, as a 25 year tracheoesophageal speaker, I have also become a somewhat functional esophageal speaker, not by deliberate effort, but almost as a "by the way" process.

I also have my 25 year old Romet and am pretty fluent with the electrolarynx if needed. It was very good to have several years ago after some surgery and complications.

When the phone rings and I just put adhesive around the stoma for my housing, I can usually answer and speak esophageally. I'm not fluent, but can usually be understood. So, that's something other TE speakers might try over time.

## **Carl Strand – Mystic, CT Laryngectomy February 1993**

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I am working on it. Have gotten instruction. Takes a lot of work and patience.

## **Jim Duggan – Sioux City, IA**

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I was definitely aware of esophageal speech and hopeful that it would work for me. I had a half dozen lessons with a great teacher. I practiced and gave it my best shot but did not have what it takes to make it work. Too much scar tissue? Now I have a TEP which I feel has given me my life back.

## **Sarah Alessandro – Quincy, MA 2013**

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I was never told about esophageal speech before my surgery. I first learned about it at my first IAL meeting. It sounded interesting and I have heard some people use it very well. I don't think I have the interest or motivation to learn, however when used properly it is a good alternative.

## **David Kinkead - Peoria, AZ Class of 2013**

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Yes. I was made aware of esophageal speech (ES) by watching a video of two teachers using it very well. That was 6 days before my total laryngectomy. I was sold, and set ES as my goal.

Yes, I was one of those who didn't need an electro larynx (EL) at first because I was going to learn ES. That changed when I got home to manage my family, home, church, schools, and community theatre responsibilities. I contacted my local SLP and began the learning process. What a celebration we had when I reach 3 syllables, but then I started post op radiation therapy.

I had no idea I had fallen through the cracks of “the team approach”. The OR notes transcriber omitted the hand written note that the right lobe of the thyroid was taken with the larynx.

Then the radiation fried the left lobe and I could no longer manage ES voice. It’s true, the endocrinologist told me why this mattered. He started me on Synthroid, and in 6 weeks I was using ES instead of the EL

Day by day I was so comfortable using ES I forgot to take my EL with me for several errands. People understood me well enough that I had a new level of confidence in my ES ability. I continued to do what I could to improve my ES voice, and before long I was teaching it at conferences and the IAL VI after passing the test the SLPs took at the end of the 1982 IAL meeting. I was a little surprised when my supervising SLP in a nearby town had me teaching ES to small classes of his laryngectomee patients 3 days a week, and grad students who watched me through a two way mirror behind me. I was unaware I was teaching double classes for months. That was my “internship” under a supervisor that had to sign for me at the end of the year. By 1984 I was listed in the IAL Directory of Alaryngeal Speech Instructors. There’s more to tell, but for now I’ll close with an invitation for you to visit my “Esophageal Speech Support” group on FaceBook.

**Elizabeth A. Finchem – Tucson, AZ**

**DOS: 10-2-1978**

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I use the speech prosthesis developed by Dr. Blom to speak. Dr. Haymaker, my surgeon performed the puncture as part of the total. I have successfully used the prosthesis ever since. While I may ruffle some feathers saying this, I consider TEP speech to be a form of Esophageal Speech.

It. Is certainly based on the same principle to produce sound. The major difference is how air is. delivered to the esophagus. It is a sort of "cheating ES, so to speak. While it’s not perfect, it has been a great boon, allowing me to practice law and argue in court.

**Terry Duga – Indianapolis, IN**

**Class of 1997**

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I have been using ES for 14 years. My local support group ( 2nd Voice Speakers Group) meets weekly to help our members develop ES. Anyone in the Toms River NJ area is welcome to join in.

**George Cocking – Toms River, NJ**

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Yes, I speak it somewhat. I can use it if I have my hands full or in a sink full of dishes and cannot use my finger on left hand to cover stoma. It’s not as clear, fast, or as loud, as my TEP speech, and I do not want to use it a lot, but I can say a few sentences.

**Linda Palucci – Kissimmee, FL**

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I use TEP for voicing. I tried Esophageal speech. I had a very good teacher. The little success I had, was due to the TEP puncture. You can’t practice Esophageal speech if you have a puncture through the parting wall. Air through the puncture will interfere with the swallowing air needed for esophageal voicing.

**Rex Schardein – Louisville, KY**

Got a TEP, tried ES Speech and failed to get a word out, Laryngectomy was June 10th 2015. Like the TEP system but would be nice to have an alternative.

**Fred Simpson – Boston Links -England**

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As a Lary, no - never considered it. When I was younger I could drink beer (quick gulps with air) and used the esophageal speech method to recite (belch) the alphabet. Does that count? My favorite letter to say was "W". So I'm capable of doing it, but no...if I gulp enough air, I tend to flatulent (fart). So I have NOT considered using that as a daily speaking option.

**Lisa OFarrell – Chicago, IL  
August 28, 2017**

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After my surgery in 1993 I was introduced to this form of speech. I took lessons for 6 months and did get some words out. I was really determined to try this method as I didn't want more surgery. I went to a CAL Conference and Jim Shanks worked with me. He showed me how to relax. He was the master, but I was introduced to the TEP and after an insufflation test at Dr. Singer's office, there was no turning back. My voice quality was excellent.

There were problems with fitting the prosthesis in the beginning, but I have to say it was the best choice for me for the last 23 years.

**Rita Kinney – Aptos, CA  
March 1993**

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Yes, thanks to my being advised of Web Whispers several months prior to my surgery I was aware of ES as well as TEP and EL. I researched all three, choose TEP, advised the surgeon that was my preference and he agreed to do the puncture at time of surgery unless he found a medical reason not to do so. Three basic reasons I choose TEP were 1) ease of acquiring voice, 2) volume and 3) clarity which, fortunately, came easily for me.

I later became acquainted with Elizabeth Finchem and was very impressed with her voice. I considered learning how to voice with ES but never made the effort because I had/have a very good TEP voice and never experienced problems that were of negative consequence plus I acquired an EL immediately post-op, easily attained a reasonably voice with very little effort and have maintained the unit for back-up if ever required.

I think it is important to note that I had several months' time pre-op to research all aspects of becoming a Lary and never depended on my medical team for voicing information, but only concurrence concerning the decisions I made.

**Dave Ross in Florida  
Class of '05**

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Hi, my name is Phyllis and I voice using Esophageal Speech. Also for back up I have my EL device. I had a hard time after my surgery and it took me 5 months before I went home. So. Didn't speak at all, now you barely can shut me up. I spoke via Skype with Elizabeth A Finchem and then I taught myself. None of the SLP in NY could help me with Esophageal Speech!! I have been a member on about 4-5 sites for us Laryngectomees.

**Phyllis Mc Queen – Brooklyn, NY**

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I tried E S very sincerely and seriously. It just did not work out.

It is like singing. Not everyone can become a good singer however hard it is tried. So is ES I think. Success in ES has got something to do with structure of esophagus, maybe. Most people may not be structured favorably and you can do nothing about it apart from accepting defeat. No wonder it is becoming a lost art.

TEP worked fine for me from the time of TL surgery. But even that failed for the last two years. I found it is getting more and more difficult to speak with TEP, leading to excessive cough and mucous flow. Over time, there has been a lot of structural changes. Stoma has been moving downwards and getting misaligned with TEP puncture. Hard blowing led me to Hernia surgery.

I have taken a step back. I am now with good old Electrolarynx. Old is gold!

**Mohan Raj – Bangalore, INDIA**

**Lary Mar 2010**

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After my laryngectomy I first was given an electrolarynx - a Western Electric - which you don't see anymore. It was given to me by a nurse who worked in a veteran's hospital. She taught me how to use it. At the same time I was working with a speech pathologist. I was getting nowhere with her. So my doctor put me in touch with Dr. Jeri Logemann, a well known speech pathologist. At the time of my surgery there were only two options for speech — esophageal speech and if all else fails, an electrolarynx. They were frowned upon at the time. There was no such thing as a TEP or an HME.

After my first session with Dr. Logeman, she drew a picture for me of what esophageal speech looked like. That was an eye-opener for me. That very first session I was able to produce sound. I continued working with her for five years. My insurance didn't cover the speech lessons, so after a year she didn't charge me, but I would visit with all of her future patients. I learned to vary the pitch of the sound, how to be able to handle a long sentence, and how to produce the "H" sound. I went back to teaching the following year and taught with my new voice for 16 years. All I need was a microphone. My voice did not hinder my job as a teacher at all.

**Barbara Nitschneider – Cary, IL**

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It was never explained or discussed with me. The two options introduced to me were either/ both electro larynx or TEP voice prosthesis. I opted for the latter because it was generally simpler to learn with what seemed a more natural sound.

**Tony Branch - St. Petersburg, FL**

**June 2016**

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## Next Month's Question: "Did You Have Swallowing Problems After Laryngectomy?"

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

Staff of Speaking Out



Voice Points

Written by Professionals



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### Esophageal Speech: Getting First Sounds

Standard esophageal speech (SES or ES) is one of the three primary methods of oral speech restoration following total laryngectomy. A benefit of this method of speech is that it requires no additional devices or batteries to produce voice. It is hands-free and, once established, entails minimal visits to the ENT and speech-language pathologist (SLP). SES does, however, require a significant amount of training and practice just to get initial sounds. Up to 6-12 months of guided practice and beyond is not uncommon for adequate use of SES, and even longer time may be necessary to develop speech excellence. SES is not appropriate for every person with a laryngectomy, not every SLP will know how to instruct in the method. However, with appropriate instruction and the proper candidate, SES may be an excellent method. From the beginning stages of sound acquisition, it is important to understand the anatomy and physiology responsible for sound production as well as the various methods of air intake used to facilitate sound. This article is an introductory explanation of some of the basics of esophageal speech and the terminology used when teaching and learning to get those first sounds.

Esophageal speech is a method of voicing produced by vibration of the pharyngoesophageal (PE) segment. This PE segment, located between C4-C7, is a narrowed segment of striated muscle where the hypopharynx joins the esophagus. It becomes the new vibrating source for voice during esophageal speech. This vibration occurs when air is moved into the upper esophagus and back up over the PE segment, creating sound. This sound then moves through the oropharynx and nasal cavities for resonance and articulation to produce speech.

Two chief methods of air intake into the esophagus for SES include air injection and inhalation. At some point, most experienced esophageal speakers learn to use a combination of both types of air intake. In the injection method, positive air pressure is increased in the oral cavity through the movement of the lips and tongue during specific sound production (obstruents, sonorants, and vowels), forcing air from the mouth into the esophagus. In general, the tongue should help push air from the mouth back to the pharynx; then the back of the tongue and pharynx force the air down into the esophagus. A speaker may be instructed to: “Capture a ball of air in the middle of the mouth, and hold it against the roof of your mouth with your tongue (or hold the tip and sides of the tongue firmly against the roof of the mouth).” From this position, there are four possible combinations of steps and respective instructions to assist in moving air posteriorly and into the PE segment. These postures include: use of a lip seal with a tongue pump; a lip seal and tongue sweep; no lip seal and tongue pump; and no lip seal with a tongue sweep. To return air to the oral cavity, the speaker is then instructed: “As you feel the ball of air ‘go down’ into your neck, quickly but gently push the air back up. Open your mouth and say ‘aaa.’” [1]

In the inhalation method, air in the oral cavity is sucked, rather than forced, into the upper esophagus. Negative pressure is increased below the level of the PE segment through the use of rapid intake of air through the stoma and through a relaxed PE segment. An example of some simple instructions: “Open your mouth with your tongue resting gently on the floor of your mouth. Take a quick breath and you will hear a clicking sound when you have filled the esophagus with a little bit of air. Say ‘aaa’ as the sound rolls out your mouth.” It may be helpful to encourage facilitators such as sniffing and raising the head and chin while inhaling.

#### **A few additional points to consider in the beginning stages of SES training:**

- Include relaxation techniques for oral, facial and shoulder muscles prior to initiating SES and throughout therapy sessions.
- Practice lip and tongue strengthening exercises in conjunction with speech training.
- Notice any sounds that are made spontaneously or with little effort in the days and weeks postoperatively and in the beginning stages of practice. Identifying the method of air intake and reinforcing repetition of those sounds is a great place to start shaping esophageal speech.
- Take in small amounts of air: a little less than one tablespoon per syllable is required for sound production.
- Frequent, short periods of practice each day!
- Do not eat immediately prior to practice.
- Esophageal speech is not “swallowing” the air.
- “Slow and soft.” “Easy in, easy out.” “Do not push!”
- It is easier to avoid distractors (e.g., stoma blasts, klunking, head turning and contorted facial expressions) at the beginning of training rather than to eliminate these habits later.

Perhaps most importantly, no two people are exactly alike and no two therapy methods are/should be exactly alike. Be patient with yourself, whether you are a person with a laryngectomy, a caregiver, spouse, or SLP!

There are several valuable resources on SES, both in person, print and digital media. Sample words and checklists are often helpful for the repetition and drilling involved in achieving consistency as sound production is initiated. The following are a few suggestions. Need additional support or references? Feel free to reach out

([kbalmand@gmail.com](mailto:kbalmand@gmail.com)) and we can help link you to more excellent people or resources.

[Esophageal Speech Support](#) public group on Facebook.

[The Clinician's Guide to Alaryngeal Speech Therapy](#) by Minnie S. Graham.

[Look Who's Talking: A Guide to Esophageal Speech](#) by Jack Henslee

[Self Help for the Laryngectomee](#) by Edmund Lauder; ed. by James Lauder

[WebWhispers library](#): Excellent audio examples of esophageal speech and an additional online resources including an article entitled "Speaking Esophageally" by Jim Shanks under the webpage heading [Talking Again and Esophageal Speech](#).

[International Association of Laryngectomees Voice Institute](#): Hands-on guided practice with experienced faculty and laryngectomees. Next year's meeting is in June, 2019 in San Diego. Stay tuned for more details.

1. Graham, MS, *The Clinician's Guide to Alaryngeal Speech Therapy*. Newton, MA: Butterworth-Heinemann, 1997; 99-133.

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## Saying 'Hello'

For me, saying 'hello' is possibly the most challenging aspect of laryngectomy. It's the clash of contradictory emotions. On the one hand there's the joy of seeing the person. On the other there's the grief of not being able to express that joy in the way I'd done for over sixty years.

Luckily I can get Ellie (my electrolarynx) to say hello for me. But it's not at all the same thing. If you listen to people (especially women) saying 'hello' it's quite different to ordinary talk. Both pitch and volume rises. It can sound like they are crying out or even a squeal of pleasure. The same sound they might make if their team

scored a goal. It's a physical release of emotional energy.

When I meet a friend, I feel a stream of joy bubbling up from my chest. It gets as far as my throat and then gets jammed. There's nowhere for the bubbles to go. My throat feels constricted. Many of us feel this constriction – I heard another lary say it was as if the surgeon had fastened a strip of Velcro around his throat during laryngectomy. It feels very uncomfortable and often my tongue, jaw and face tense up as well. At this stage I can identify at least two emotional threads – a joyful centre in my heart and a sense of confusion and concern in my throat and face. This complex mixture can easily lead on to frustration, sadness and anger.

Sometimes Ellie croaks 'hello' and this lessens the tension. Other times I can't even get that much out. My tongue and lips aren't obeying orders – they're too tense to move. This happens especially if I'm out walking and meet a friend unexpectedly. Even smiling can be difficult and sometimes all I can do is to wave a 'hello' then point to my throat and shake my head, hoping they get a message of friendliness along with the inability to express this.

The challenge is also heightened if I'm meeting someone after a long absence. The first time I noticed this was on one of my early post-op outings when I went to stay with friends. I hadn't seen them for months and had wonderful memories of previous visits to their home. As the car came to a halt, I felt myself jamming up with tension. It was really quite painful. I remember gasping for breath. Because there were so many bits of machinery that had to get out of the car with me, my difficulty went unnoticed. I couldn't have explained anyhow as it was all so confusing and unexpected.

But when the same thing happened the next time I visited my friends, I was able to explain my difficulty to my friend Catherine. Luckily she understood intuitively what it would be like not to be able to say hello. It was a great relief just to have told someone and have been understood. After that, although the 'hello' tensions developed as before, I didn't mind it so much.

But a couple of weeks ago, the pattern re-surfaced – this time in an even more challenging way. I went to Galway to stay with my friend Finola. She met me at the station and I got through the initial 'hello' without difficulty. We were driving to her house when the trouble started. I had been aware of some background sadness since getting into the car, but didn't feel inclined to mention this, being more interested in chatting and catching up. Then she mentioned a mutual friend who had been bereaved and now going through a lot of grief. Instantly my background sadness amplified itself out of all proportion. I felt physically weak and absolutely dispirited. My inner world went black. It was all so sudden and so confusing that I couldn't articulate anything. Even the effort of getting Ellie to my throat and organising for her to say something felt overwhelming. I just wanted to shut out the world.

Finola asked if I was OK and I managed a thumbs up and a sign that I was tired. I sat back and let the misery reign supreme for a while, hoping that acknowledging it mindfully would help it pass. Currents of energy crisscrossed my body, driven forward by bursts of hope, crushed by counter-currents of negativity – anger, despair and cynicism were the most prevalent themes. The only solace was to bring some compassion into the picture. Compassion watched as the streams of negativity surged forward and ebbed away. Then another burst of hope and the cycle would repeat, but each time, compassion for my unhappy state grew stronger. After a while I was able to get Ellie into gear and tell Finola that the mention of our mutual friend's troubles had kicked off something within me. Again she understood immediately which was a great relief.

Although I was able to function and chat normally after that, I was at some level struggling with negativity much of that first evening. During an almost sleepless night I let the emotions run their course mindfully. Eventually I saw that my sudden plunge into negativity was to do with the grief of having lost my voice. The mention of our friend's bereavement had let the lid off – it gave my emotions an external focus. But deep down it was all about me – not wanting the new post-laryngectomy 'me', wanting the old me. The old me would have greatly enjoyed the drive home. And would have given joy expression – not only in the way I said 'hello' but in all kinds of inconsequential remarks about this and that - whatever came into my head. Gabbling happily, I would have felt renewed, affirmed by the encounter. Now there was no gabbling. Ellie's harsh

robotic squawks told me that phase of life was over.

In an ordinary day I am often caught up in this grief. It's the sudden surge of joy that bring it up e.g. when I meet a good friend – especially if I haven't seen them for a while and am visiting them rather than on my own turf. Can also happen when I come home after being away for a time. Just when I want to be happy! If it could only wait till I'm alone or sitting in meditation, then I'd be happy to let it rip. But emotions have no manners! Grief shows up exactly when I want to be friendly and outgoing.

To end on a positive note: I have every faith that my psyche will learn from this episode. That's the magic of mindfulness. It hurts to be mindful while we're going through a bout of negativity, but the payoff is wisdom. This body-mind complex that we inhabit is intelligent. It doesn't want to go through the same pain all over again. So it finds some new way of coping. I can't say what will happen when I next meet an old friend after a long absence. But I've no doubt I'll have moved on a bit. I'll be more accepting of 'the new me' and more grateful for Ellie's help in maintaining friendship. In the long run I'll probably even get to like Ellie's unusual way of croaking 'Hello'!



## Salute to the Caregivers

WebWhispers honored many folks this year at our Awards Banquet at the IAL in Orlando but there is one particular group who deserves special recognition. Caregivers don't get enough credit and to be honest, we don't always give them a voice. We harp on and on about "our voice" but what about theirs? This year we honored a special caregiver but, really, her tribute was for many. Viv Vanden Hogen, 2017 Mary Jane Renner IAL Caregiver of the Year, gave a moving testimonial to her friend and fellow caregiver Janine Mattoon. We were all pretty teary-eyed. Janine was a nurse by profession and a dedicated caregiver who needed to be cared for herself in the end by her devoted husband, Ron. They made a monumental effort last year to come to the IAL in Newport News, knowing it would be her last. Ron, who was WebWhispers 2017 Volunteer of the Year and Janine took care of each other and their devotion touched us all. We never know what road we may have to travel until it stretches before us.

I tried to acknowledge those challenges with these remarks:

"A lot of caregivers out there tonight, right? It's a thankless task sometimes, isn't it? We can be a cranky bunch, I know. You put up with a lot. Spouses bear a heavy burden and when you took your vows for better or worse, through sickness and health no one anticipated this.

*For all the times you hid your own fears to help us be brave  
For all the times you bit your tongue when we were difficult  
For all the times you cheered and cajoled and encouraged  
For all the times you held our hand when you wanted to kick our butts  
For all the times you did kick our butts because it was what we needed  
For all the times you believed in us more than we believed in ourselves  
For all this and more....  
Thank you all and we are so grateful you stood by us.  
Today we stand by you!*

We want to start a new column for Whispers on the Web tentatively called “Stand by Me” written by and for caregivers. We welcome all contributors, caregivers, folks who want to pay a tribute to their caregivers and anyone else with something to say on the subject to send their thoughts to me at [editors@webwhispers.org](mailto:editors@webwhispers.org)

I think it's high time caregivers had a voice/place at our table!

For your listening pleasure:

<https://www.youtube.com/watch?v=AyFILjdNqk8>

<https://www.youtube.com/watch?v=hwZNL7QVJjE>



## **Where Do I Put the Ladder?**

Marcos Antonio Salazar

That bunch of mangoes was tempting up there at the end of a branch of the giant tree. From my height I saw her too high and very hard to get to them. My brother and I planned a way to reach them. Difficult but possible task. While my brother was watching for the owner of the estate, I started the promotion: first I held myself to the trunk and dragged myself up to the first pitchfork, then followed by a branch, stood up and then to another. I used my bare feet, nails, fingers, knees, elbows... little by little I went away from the ground and close to the place where those delicious fruits were.

After many minutes I had reached the finish line. But, surprise! All the mangoes were stung by bees and birds: Damaged, rotten. The disappointment was huge to see that there was no trophy for so much effort and risk. I had done well, but it had been useless.

Similar experiences would be repeated throughout my life, albeit on another stage, in another dimension. In

The course of my years I have risen, I have fought, I have arrived... but above the void continues. Over the years I have encountered many recipes that promise to be the formula to be successful, I have been offered multiple stairs that could lead me to another type of: success. Some of these stairs have on their steps honesty, perseverance, hard work; others with phrases like: wanting is power, everything is in the mind, if I say I can, I can...; recipes with various ingredients: Mapping goals, goals, strategies, plans, actions, tasks. If you don't know where you go, any road is good; there appeared the ladder called the law of attraction, the positivity, in every crisis you have to see an opportunity, etc... most excellent stairs, all with steps They take him up, overweight with wise advice.

The problem is, they don't tell me where to lay that ladder. Consequence? I usually put her on a wrong wall and when we get to the last step: surprise! The Mangoes were rotten. When I got to see this, I got the explanation why so many "successful" people became drug addicts, and commit suicide. People who came to the summit of power, with Fame, Money...

I think this is a good way to tell you dear reader that I found the right wall, I'm totally sure of it. It is called the kingdom of heaven and for more than two thousand years we were told that it was close, that you and I can be part of it. You have a ladder with the best of these steps and her in the kingdom of heaven and begin to ascend for it... then you will come to the prize, to success, to victory, to the ripe and healthy bunch of mangoes. There, no disease is able to deprive you of happiness. I assure you.

*Footnote: Marcos is a good friend of mine from Costa Rica. In 2009 I had the privilege of working with him and other Costa Rican's in establishing the Costa Rica Association of Laryngectomees, of which he became President. He does not speak English and I do not speak Spanish so all of our contact has been through interpreters over these past 9 years. I recently discovered that he now has terminal lung cancer and that his family is promoting a book he wrote titled "Wisdom of the Road" which chronicles his life's journey, and I wanted to share the above passage with you since most of us can relate to it in some degree.. I just knew him as someone that greatly cared about others... never dreamed that he is also a great writer.*

~ Jack Henslee



## **To Saline or Not**

Jack Henslee

There are many things in life that make you want to just take pause and say, "Really?" Others make your eyes roll, clench your teeth, shudder in disbelief, or even embrace things as absolute fact even though there is little or no supporting evidence of truth or accuracy. Then there are those that just want to make you scream!

As laryngectomees we have our fair share of unique problems and we are fortunate to have numerous sources of information to address some of these issues. For example, the WebWhispers List Server, WW FaceBook page, IAL Facebook page, Independent Association of Laryngectomees Facebook page, several other web pages such as WebWhispers and its great library, and of course "Whispers on the Web", the best laryngectomee newsletter in the world!

So the question becomes just how accurate is all that information? Do you really believe everything you read, can you be sued for giving bad info that harms someone, can we or the websites be sued because we allowed someone to post bad information and don't you have some responsibility for verifying what you read via a second opinion or other source? Can't you make your own decisions? Do you want to tell people that your way is absolutely the best way?

All the sources above are nonprofit and administered by volunteers, and the people that post are people that have experienced the same thing, along with a few professionals that volunteer information, and for the most part they only relate their own experiences...good and bad, and a common comment we see after a post is, "Remember, we are all different and what works for me may not work for you!"

I have seen a lot of things posted on the internet that make me cringe a little and sometimes laugh. A few years ago we had someone that wrote a lot about wearing an HME 24/7 because of the danger that dust mites might crawl into your stoma when you sleep. I was never clear as to why he was never concerned about the other seven or so orifices in the body unless he thought stomas were some kind of magnet. Then we have the ones that say they can't use an EL because of scar tissue, when the biggest orifice in the body (your mouth) works very well with an EL. Or, I can't learn esophageal speech because my TEP allows air into my throat. While I may think these are "inaccurate" statements, they don't hurt anyone and of course we are all different!

But the main purpose of this little rant is to talk about saline. There is no question that the stoma needs to stay moist and that moisture can come in many forms. Some people may think they don't need it but none the less they still receive it in various forms every day; hydration, simple stoma cover, HME, live in a high humidity climate, use a humidifier, steam from a shower, saline bullets that they buy, and saline that they make themselves. For full disclosure... all of the above apply to me except I don't live in a high humidity climate.

Now in my case the shower is my go to option. I'm in there every day, all I have to do is breathe but if I really feel clogged up I'll get my wash cloth really hot and breathe through it. But alas there are those that think that's terrible because the shower water isn't sterile. When I travel I carry saline bullets with me just in case I need them which is seldom, but if I'm at home and feel the need I make my own saline and squirt it down with a syringe. But then some think that's wrong because I used table salt and boiled tap water instead of distilled water, or some salt I've never heard of. Plus, they say I have to throw it out after a day because it's no longer sterile! Really??

Now some of these people may think I'm reckless or a slob; maybe I think they are germaphobic and I can live with that. In fact, I have lived for 30 years as a lary doing what I do and you should also do what you think is safe or at least an acceptable risk in your case.

It's Enough To Make You Scream!

*(Note: Do you have a subject that wants to make you scream? Please send them to editor@webwhispers.org)*



*Given all the responses to this month's Speaking Out question about esophageal speech it seemed appropriate to re-visit an article on the subject from an SLP, first published in VoicePoints in August 2009.*

## **Esophageal Speech – A Dying Art?**

Esophageal speech is a “non surgical” means of voice restoration for laryngectomees which involves producing sound by injecting air into the esophagus (using three possible methods) and creating sound by vibrating the neoglottis or pharyngoesophageal (PE) segment. Esophageal speech is one of three possibilities for the return of voice/sound for a new total laryngectomy. In the past, esophageal speech was treated as the “gold standard” and/or most preferred method of speaking for laryngectomized individuals. However, in the early eighties it fell from favor with the advent of a functional tracheoesophageal voice prosthesis (TEP) which became more popular as it was “easier to learn” and created more fluent voice because lung air was available for voicing (see chart). Esophageal Speech was no longer presented as the best option because of the time it took to learn (average 6 months). And, possibly, because health care professionals developed potential bias for the “easier/faster” methods. There had been reimbursement issues for the “longer to train”, esophageal speech, method. The release from pen and paper was largely influenced by the bias of the health care delivery system.

So, the question presents, “Is esophageal speech a dying art?” And/or, “Is there a place for esophageal speech in contemporary voice restoration therapy?” Are health care professionals remiss to not encourage this viable form of communication? Resoundingly, “Yes,” is the answer to all questions. Whether one is using an artificial larynx (AL) or TEP speech, esophageal speech may compliment and potentially, over time, become the preferred method of voice restoration for a motivated laryngectomee who recognizes its value.

As most total laryngectomy surgical procedures currently encompass a myotomy, surgical cutting of the cricopharyngeus muscle, esophageal speech does appear easier to learn than in the past. This may be one of the reasons that many Laryngectomees have reported producing “accidental sound” which is understood by their spouse without occluding their stoma for TEP use and/or without their artificial larynx. When this occurs, the speech pathologist should help the individual understand how and why this occurs. Providing the laryngectomee with Edmund Lauder’s classic book, *Self Help for the Laryngectomee* may be of assistance.

In addition, one should encourage active practice of mastering the basic elements of esophageal speech production, namely:

- 1) Consistency of sound,
- 2) Immediacy of sound,
- 3) Duration of sound.

Training should also occur to assist the laryngectomee to understand how they are able to produce sound via

the three primary methods:

- 1) Inhalation of environmental air (negative air pressure in esophagus sucks air in from pharynx),
- 2) Consonant injection and/or
- 3) Tongue pump injection or ideally a combination of all three.

Consonant injection and tongue pump, or glossopharyngeal press involve increasing air pressure in the mouth and the pharynx to push air through the PE segment which is “trapped” and vibrated back through the PE segment as sound.

Eventually, with practice, the laryngectomee should learn to combine all three methods for greatest fluency and normalcy of voicing. Paul Scriffignano, who was the Executive Secretary (?????) of the International Association of Laryngectomees (IAL) in 1985, demonstrated this highest level of achievement. Often wearing a coat and tie, with no evidence of a visible stoma the average listener just thought he was a “normal speaker” with a low, breathy voice. There was no evidence of stoma noise and/or tongue pump “clunk” in his speech. He was an excellent example of combining the three methods of air injection.

In addition, two recent examples come to mind. One patient, who was using an artificial larynx, prior to her TEP surgery, demonstrated how she was able to speak “short phrases.” “They just come out”, she said, “And my husband understands.” Even after her TEP she said it was easier to speak esophageally for short communication. She continues to develop and perfect her technique. She is “a natural esophageal user.”

The second example is of a gentleman who was successfully using an indwelling TEP for 6+ years with an average of 6 months plus wearing time. He caught a cold and with violent coughing, he kept dislodging his prosthesis. He then realized that he could produce short phrases that his wife understood even when he had his obturator in place when he was waiting to have his “dislodged prosthesis” reinserted. With minimal speech pathology assistance in training the patient to relax while producing voice vs. pushing while producing sound, he is now able to produce 5-7 word sentences esophageally.

In conclusion, the art of esophageal speech is alive and well and/or should be a part of voice restoration after laryngectomy, as a complimentary/back-up voicing method and/or as a primary means of communication. Once one has mastered consistent sound production via one of the three injection methods with reasonable immediacy and duration, they should work with a knowledgeable SLP to develop expertise for greater articulation intelligibility, loudness and pitch variation. Speech Pathologists working with laryngectomees always educate the patient to all three restorative voice restoration methods, have knowledge and experience in training all three methods of alaryngeal speech, and offer the choices without significant bias. It may be prudent to remind patients of their options throughout their lives and not just at the beginning of treatment. Do not allow Esophageal Speech or it’s training to become a dying art.

METHOD	ADVANTAGE	DISADVANTAGE
<b>Artificial larynx (AL)</b>	<ul style="list-style-type: none"><li>▪ Easy/quick to learn</li><li>▪ Reasonable cost</li></ul>	<ul style="list-style-type: none"><li>▪ Sounds “robotic”</li><li>▪ External reliance (you have to remember to take it with you)</li><li>▪ Should have two if it’s your “primary communication mode”. i.e. if one breaks you have a backup</li></ul>

<p><b>Tracheoesophageal Voice Prosthesis (TEP)</b></p>	<ul style="list-style-type: none"> <li>▪ Sounds more natural, i.e.</li> <li>▪ Increased fluency as lung air is utilized</li> <li>Hands free option</li> </ul>	<ul style="list-style-type: none"> <li>▪ Involves surgical procedure</li> <li>▪ Increases attachment to health care professional (especially with indwelling)</li> <li>▪ Increases impact on party wall tissue</li> <li>▪ Consumable supply, "on-going" cost</li> <li>▪ Requires "up keep," care that some may be uncomfortable with, and/or lack eyesight or manual dexterity to use</li> </ul>
<p><b>Esophageal Speech (ES)</b></p>	<ul style="list-style-type: none"> <li>▪ Non surgical</li> <li>▪ Decreases reliance on health care worker</li> <li>▪ Self-contained – don't have to remember anything external to self-users one's "own body," as is</li> <li>▪ No additional cost once learned</li> </ul>	<ul style="list-style-type: none"> <li>▪ Time to learn proficient speech (approximately 6 months)</li> <li>▪ Lacks fluency of TEP</li> </ul>

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