

# WebWhispers

Sharing Support Worldwide  
Throat Cancer and Laryngectomy Rehabilitation

## Whispers on the Web

A Monthly Online Newsletter for WebWhispers

Photo CC by HMBascom

**April 2014**

Name Of Column	Author	Title	Article Type
News Views	Pat Sanders	Frances Stack, Class of '55	News & Events
VoicePoints	Tanya L Eadie, Ph.D. CCC-SLP	New Self Report Tool	Education-Med
Between Friends	Donna McGary	Joie de Vivre	Commentary
Speaking Out	Members	Did You Choose Speech Option?	Opinion
The Speechless Poet	Len A Hynds	The Song of the Sea	Prose & Poetry
Bits, Bytes & No Butts!	Frank Klett	Windows XP, Laid to Rest!	Computers

INDEX AND LINKS TO EACH ISSUE MAY BE FOUND AT: <http://webwhispers.org/news/WotWIndex.asp>

**COMMENT HERE**  
**FEEDBACK**



I am using my column to introduce Frances Stack, who had laryngectomy surgery in 1955 and her article written for HeadLines in 2000. It fits perfectly with the Speaking Out segment this month.

## Four Generations of Laryngectomees

by Frances Stack, MA,CCC ret.

Imagine, if you will, being a witness to the progress from no speech at all to ES, then AL, then TEP! This is the fourth generation of laryngectomees in my time.

The first generation was no speech at all. Before antibiotics, laryngectomees did not survive, if they did, there were all kinds of weird instruments that people used to try to talk again. I remember when I was about sixteen years old, seeing an old gentleman using a pipe with a vibrator in it. Of course, at the time, I never dreamed I would join his world.

The second generation was where I came in. Esophageal speech or no speech! The location of the tumor and skill of the surgeon determined whether the patient would produce esophageal voice. Then who knew how to teach it? There weren't many professionals who were knowledgeable about it. The artificial voice instruments at that time were cumbersome and sounded awful and both doctors and speech therapists discouraged the use of these instruments. They were convinced that every laryngectomee could develop esophageal voice, regardless of how much effort it took or how it sounded, which was certainly not true! A few, a very few, would be able to produce voice shortly after the surgery but I contend that the location of the tumor and skill of the surgeon were responsible along with the age of the patient.

The third generation, AL or instrument voice. When I was in graduate school in 1975, I was supposed to give a talk to the class about laryngectomees and voice. I brought a Western Electric instrument intending to demonstrate it. When the instructor saw the instrument, she got up and dismissed the class before I had a chance to say a word. Obviously, she was very biased against instruments. I was very angry but I couldn't challenge her because I could see my degree going out the window if I did. She taught esophageal voice and the people sounded so horrible, gulping, clunking and grimacing that they certainly would have been better off with an instrument! The good ES speakers in my club would also make me angry when they would tell AL speakers to "throw that thing away and do what I'm doing"! They never realized how lucky they were and that the AL method was not a choice but a necessity. I guess some of this still goes on today.

About five years later, I was asked to be on a program for our state group in Champaign, IL, and the biased instructor was going to be there. She retired shortly after I finished Graduate school but I had prepared my lecture with her in mind. I made a video with four instrument users who extolled the virtues of their instruments and how having them changed their recovery period from one of despair to hope for a "normal" life.

I was told she was going to be late and would miss my presentation. I threw a fit and refused to speak until she was there! I had carried this ache in my heart for all this time and wanted to "show" her! When she came in, this little old shriveled up lady held out her arms to me and whispered "Oh Frances, how little we knew back then" The ache

smiled up at me, held out her arms to me and whispered, "Oh, Frances, how nice to know each other." The anger disappeared along with any anger and I melted.

Then the fourth generation and the TEP came into being. I remember Eric Blom begging for subjects in Bloomington, where he was a guest of our state group. He needed twenty TEP laryngectomees so he and Mark Singer could present this procedure to the medical community. I sent him one fellow who was a real character but, unfortunately, this man did not do well with the procedure. We must remember that not every one is a candidate.

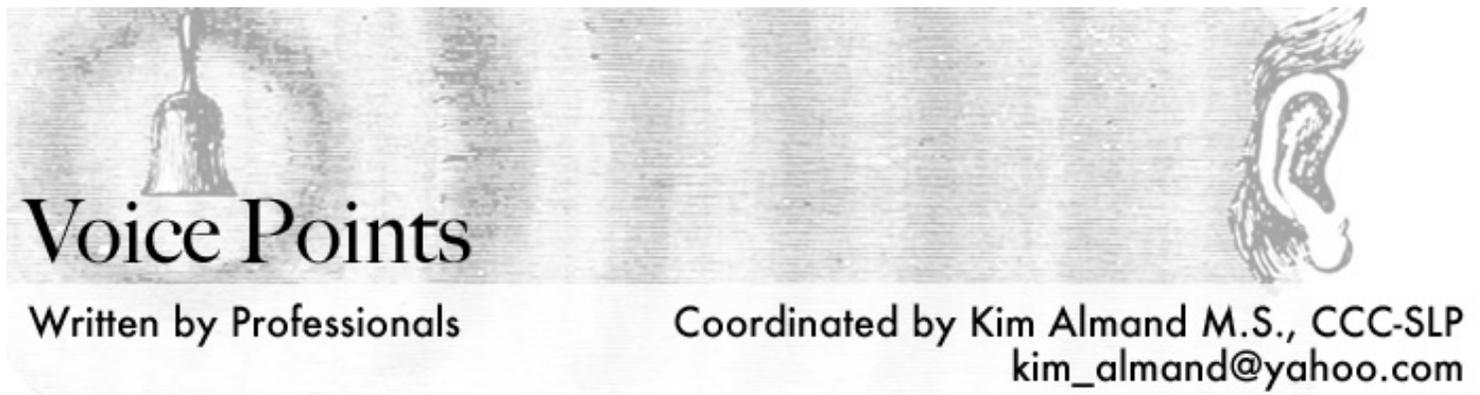
By this time, I was a guest lecturer at Mayo Clinic and Bob Keith, Clinic Director, let me insert a prosthesis in a patient. This was a first for me and I was excited and elated!

Using lung power instead of esophageal power makes a difference because it is more natural. After all, young kids can "burp" until they grow up and then our society tells us it's rude. What amazes me is that there are so few ES teachers left. TEP speech, when it works is certainly so much easier.

In reading four years of HeadLines, the concerns and pain haven't changed. The fears, anger and turmoil are still the same. I read the bound copy that I just received, then read it again. In some instances, it was déjà vu. It made me laugh and cry. Because the elation, happiness, and desire to be a better person doing for others are also still the same.

Thank you, Frances!

**Enjoy,**  
**Pat W Sanders**  
**WebWhispers President**



**Voice Points**

Written by Professionals

Coordinated by Kim Almand M.S., CCC-SLP  
kim\_almand@yahoo.com

## **New Self-Report Tool of Communicative Participation**

for Adults with Communication Disorders

Tanya L. Eadie, Ph.D., CCC-SLP

One of the greatest difficulties experienced by people who have had a total laryngectomy relates to changes in verbal communication. These changes may lead to withdrawal and social isolation, and may ultimately affect an individual's quality of life.

After total laryngectomy, voice and speech rehabilitation is achieved through various means including

electrolaryngeal speech, esophageal speech, and tracheoesophageal voice restoration. While some researchers might conclude that one alaryngeal method is superior over another (in terms of speech acoustics closest to typical speech etc.), there is a lot of variability among speakers who use alaryngeal speech modes. For example, while some individuals continue to struggle with their voice and speech, some studies have also shown that some speakers using alaryngeal speech methods may be as satisfied with voice function as some speakers with intact/healthy larynges. However, these conclusions may also be affected by how we define communication “success”. In other words, how we measure this outcome is important.

Traditional methods of assessing communication outcomes include use of speech intelligibility or voice quality measures performed by clinicians, such as speech-language pathologists. They may provide a measure of the percentage of words they can understand, “speech intelligibility”, or they might subjectively judge speech outcomes using rating scales. These outcomes may be helpful for documenting changes before and after therapy, or they might help the clinician and patient identify common goals to focus on during therapy. In addition, it is becoming increasingly common practice within all medical settings for healthcare providers to ask patients about their own perceptions of health and function. This directive is supported by the National Institutes of Health in an initiative called the Patient-Reported Outcome Measurement System, <http://www.nihpromis.org>.

Developing a self-report tool is not a simple process: we must follow careful steps to ensure that the tool is valid. If we want to measure something meaningful, we need to know that we are asking the right questions in the right way. This involves several critical phases of interviewing the people who are living with the condition. We also need to ensure that the tool is reliable and taking the survey twice, would get the same response, and that it is valid, measuring what we intend it to measure.

Self-report measures are commonly used with people who have undergone total laryngectomies both in clinical and research settings. Some of the tools may be general (i.e., investigating overall health), whereas others have been designed to measure consequences of a specific disease (i.e., investigating the influence of specific head and neck cancer symptoms on well-being). In addition, there are discipline-specific questionnaires that measure characteristics of interest within a discipline, such as how voice function affects well-being.

Results using these tools are variable. They found good overall and voice specific-quality of life levels using two questionnaires with many individuals reporting good overall quality of life one to two years post-laryngectomy but more than half of the subjects reported serious problems with communicating in noisy environments. These results suggest that we may not be asking the right questions if we want to measure how well individuals are communicating in real life situations.

While some existing self-report tools appear to measure some aspect of speech or voice function, no tools are dedicated to what we call communicative participation. This is defined as taking part in life situations where knowledge, information, ideas or feelings are exchanged, talking to strangers, ordering a meal in a restaurant, or discussing end-of-life care wishes with family members.

Due to this gap in research and clinical practice, our multidisciplinary research team at the University of Washington has begun to develop a new self-report tool called the Communicative Participation Item Bank intended to measure communicative participation in community-dwelling adults with a range of communication disorders using a 4-point scale. Items in the CPIB include interference talking to people you do not know, making a telephone call to get information, ordering a meal in a restaurant, talking to groups of people, and having a conversation in a noisy place. There are 10 items in our paper and pencil form.

Recently, we tested the reliability and validity of the questionnaire in a large group of individuals with various communication disorders. It appears that the same items/questions may be relevant and sensitive for adults with different types of communication disorders, we found that the new tool appears to measure something that standard quality of life tools may not capture. These results suggest the value of adding this tool to complement existing outcome measures.

There are many future directions for our research with the CPiB. It will eventually allow us to administer the questionnaire using computer adaptive testing, meaning that only a subset of the items will need to be administered, which will reduce the time it takes to take the questionnaire. This is an important trait in busy health care settings, and is also critical for reducing the burden on patients. A second important line of research will soon be underway to help us measure and understand meaningful changes in communication that occur directly following a procedure such as total laryngectomy. We hope that the results may ultimately lead to the identification of better treatment methods for cancer survivors whose physical, social, and psychosocial well-being is impacted by the disease.

Author's Note: Our team would sincerely like to thank all of you who have participated in past studies that have led to the development of this new tool. We are extremely grateful for all of your time and effort. There should be a new, large scale study underway in the next few months. Stay tuned for how you may be able to participate!

#### Author

*Tanya L. Eadie, Ph.D., CCC-SLP, is an Associate Professor in the Department of Speech and Hearing Sciences, and Adjunct Associate Professor in the Department of Otolaryngology-Head and Neck Surgery, University of Washington, Seattle, WA, USA. Her research and clinical interests focus on measuring communication outcomes in a number of clinical populations, including those who have undergone total laryngectomies. Her work has past and current research support by the National Institutes of Health. She is also a past faculty member for the International Association of Laryngectomees, Voice Institute.*

#### Whispers on the Web

This article has been edited for length and clarity for more casual readers but we are placing a file containing the entire original article with all comments and references for professionals on our website.



## Joie de Vivre

There is nothing like a child's birthday to help you rediscover the meaning of joie de vivre. And it is not just the party and the presents that bring out the joy. It is the anticipation. "I am 4 now, 1-2-3-4. And in 3 days - today is Friday, tomorrow is Saturday and Sunday I will be 5." Kayleigh loves decorating all things Ariel; for the uninformed, Ariel is the mermaid princess from the Disney movie "The Little Mermaid". She loves planning her party. We have birthday

tea parties for days leading up to the event which includes making place cards for her guests, planning the menu and cleaning the house. Every aspect of this grand transition from 4 to 5 is a celebration of life in all its wonderfulness

cleaning the house. Every aspect of this grand transition from 4 to 5 is a celebration of life in all its wonderfulness.

Since my birthday falls 4 days later I am painfully aware of the difference in our attitudes and it saddens me. Actually my grand-daughter approaches everything with this enthusiasm. Kayleigh delights in each new word her baby sister learns, “Nanny, Kiera said, ‘I eat’” and is equally delighted to learn a new word of the day herself. These sparkly sandals are “appropriate for a party but they are NOT appropriate for playing in the snow”.

And it dawns on me – that is what makes her such a joy to be around. She enjoys everything around her to the fullest. Mastering a new skill is worthy of a dance around the living room. It doesn’t matter if she learned it or her sister did, it gets a dance. Lunch is a success deserving ardent hugs and peals of laughter because “these are the best carrots I have ever eaten.” This is someone who completely and totally embraces the moment, every moment, all the time. It is the sacred gift of childhood and one that adulthood usually desecrates.

We all have treasured memories as adults where we remember the best moments of this and that but they are fleeting, not every day occurrences. It’s one of the hard truths of growing up. What I have learned lately is that it is not the new skill, the best carrots, or the party presents that make the moment perfect. It is our presence in that moment that makes it perfect. Age and hard experience can make that sense of presence increasingly difficult to achieve.

Joie de Vivre celebrates the moment and I am not going to let all the tediousness of adulthood rob me of that fun anymore. If my granddaughter wants to put sparkly makeup on me and say I look beautiful because I am shiny I will embrace that moment even if I look a fright. If she scolds her sister not to put her finger on my stoma and make me cough even though they both think that is a funny trick, I will always remember this time when they both sat on my lap laughing and teasing their Nana.

Cancer takes away a lot. I will not let it take away this. Right now, right here, this moment – I will appreciate the joy of life. And maybe even do a little happy dance around the living room even if it spooks the cat. Kayleigh will totally understand.



**Your new speech option. Did you decide; were options explained to you, or were you just told what was going to happen?**

**Michael Mac Mahon, Ireland - February 2004**

I was laryngectomized at aged 66. The TEP was the only method of speech mentioned to me and I was very much unaware at the time of any other method. Quite honestly, I have no regrets about this. I had a 'voice' from the first moment of the insertion and I have maintained a good voice to the present. I use a Blom Singer dual-valve 20f 8mm TEP which I get replaced once a year in University Hospital Galway.

I live in a small West of Ireland town and I have met only one or two other laryngectomees in the ten years as we are few and far between in this neck of the woods. Consequently, I suppose I get greater value than most from Webwhispers as I eavesdrop on all you people on the other side of the Atlantic. When strangers sometimes ask me (as they will) why I put a finger to my throat, I explain it thus: On my first day in school my teacher told me that if I wished to say something I should put up my hand. I have never lost the habit!!

---

**Richard Crum, IN - July 1988**

I was 45 years old, a professional Auctioneer and real estate broker. I had a total laryngectomy at Barns Hospital in St. Louis MO. I had stage 3 cancer of the Larynx. After the surgery I used an electro larynx for about a month. In that month with the help of Ed Lauders Book and Tapes from "Self Help for the Laryngectomy" I learned enough esophageal speech to get by. I did not feel that my esophageal speech was good enough to enable me to make a living for my family.

In Oct 1988, I had the TEP procedure done and I have used it ever since. It has enabled me to continue in my profession. I do not call bids but am still involved in the auction business. I make my living as an appraiser of both real estate and personal property. The TEP was a good choice for me. I still use esophageal speech at times and I am glad I have not lost it over the years.

---

**John Hendrix - August 3, 2011**

When it was confirmed that I would definitely need the Lary surgery, I was told of three options. The first two were the EL and ES. The surgeon did not take much time with the first two but really went in depth with the third, a TEP. Looking back, I truly believe they wanted to do it this way as it is more lucrative for them. More extensive work and it requires you in most cases to periodically come back for maintenance. Just more \$\$\$ for all involved. Don't get me wrong, I think the TEP is a wonderful creation, and for some folks, the absolute best option. My only gripe is the surgeon did not really go into the potential problems with a TEP, a few of which I either went through or continue to fight, nor did they push the benefits of the other two options. Hindsight being 20/20, I would have liked to have tried ES before going with the TEP. In my case, my TEP did not heal correctly or very quickly, and while it is manageable, and I have a decent voice with it, I wonder "what if" sometimes. I had my surgery done where they prefer to do the TEP at the time of the surgery, if this is the option you chose. Even if a person believes they want the TEP, I think there should be a healing period first before initiating the puncture. Just my humble opinion.

All that said, I thank God for being alive, able to breathe, and to be able to talk. I am forever grateful for what I have. By the way, I had my surgery at MD Anderson in Houston. I wish MD A approached things a little differently, now that I am more knowledgeable on the subject, but I have to also add that the folks at MD are very good at what they do and extremely good people inside and out. I think it is huge benefit for anyone who is able to connect with this site before their surgery to get a look at the big picture of what they will be facing. Even better to also meet a Lary before surgery as discussed in last month's Speaking Out question. I sure wish I could have done both.

---

**Jim Fohey, Oscoda MI - class of 94**

Prior to my surgery in 94 the doctor said I would be started out with a servox while in the hospital as he was of the belief that a lary should start out right away with some sort of communication device for their wellbeing and then progress to the TEP. So I was given a Servox to use while in the hospital, granted due to the swelling it took a few days to be understood but by discharge I was doing pretty good on it. Due to some healing issues and having to stay on a feeding tube for a while the TEP was not done until about a year and a half later.

Once done after a few days I was told to occlude my stoma a talk which I could without any device being put in, how happy I was and so were the doctors. So they put in the device and off I went home to demonstrate at my business that I would no long sound like a R2D2 and CP3O combination. All worked well for as long as I had it. One night I started to cough really hard in the middle of the night and coughed it out, I put it back in or so I thought but I guess I didn't get it all the way secure or coughed it out again later in the night because come the morning I had no voice. So out came my servox and off to work to open and let my manager know I was off to the doctors some 3 and half hours away by the time I was there the opening had healed over and we could not break through. My doctor called Dr. Blom for a suggestion and was told let it heal over completely and then redo the operation.

As time went on I just never went back to have the operation now after all these years there is no reason to do it. I do wish I still had the TEP as I had a good strong voice, but as someone once told me you build a bridge and get over it and move on. I have, and have my trusty Servox and its two standbys at hand. I also use some ES speech but for long discussions, it is the Servox.

---

### **Rita Kinney, Aptos, CA - March 1993**

When I had my surgery in 1993, I was introduced to the Servox and sent to a speech therapist to learn esophageal speech. I attended a California conference and met Dr. Jim Shanks, who was wonderful and tried to get me to relax, but I guess I didn't have the patience to master this type of speech.

After a year and a half I met Dr. Mark Singer who had his staff administer the insufflation test and I couldn't believe the quality of my voice. I immediately had my surgeon perform the puncture so I could speak with the TEP. There was another CAL Conference in San Francisco and with the help of Carla Gress, I was fitted with the right size and also introduced to the hands free equipment.

Needless to say, I have had a wonderful quality of life and I am very grateful for the dedication and help I received from Dr. SInger and Carla Gress.

---

### **Tom Olsavicky, Pres., Newport News, VA - 2008**

After I was told that I would be losing my voice box, I began researching the alternatives on the internet and through a local lost chord club. I talked to the surgeon who said that he would do a primary puncture if I wanted but he advised me to wait a few months since I had radiation prior to surgery. I agreed to wait six months and then I would know exactly what I wanted. I talked with my SLP, she did an insufflation test and I sounded very good so a TEP was a possibility. However, I was concerned that a TEP would be more maintenance and more recurring changes than I would like. I also didn't want the worry of finding an SLP while traveling. Esophageal speech was something that I tried but was not having any luck. Then I heard a fellow at the Tidewater Lost Chord Club who was using a TruTone EL and I liked his sound and volume. That convinced me that if I could sound nearly as good, then that is the way I would go.

I attended an IAL Conference just four months after surgery and met Tony Talmich and listened to his demo of the TruTone. I was convinced that a TruTone EL was for me. I was lucky to be able to find my sweet spot, I sound every bit as good as the other club member, I can be understood even of the phone and I have not looked back. Even my grandkids love it. Tom Olsavicky, Pres., Peninsula Lost Chord Club

---

**Maureen Mark, Pittsburgh, PA - July 9, 2013**

I was really never told much about how I would speak. I was given an EL about day 3, post op, showed how to use, and left to learn on my own. I saw the doctor 2 weeks after my surgery, and at that time he said, "Let's get you talking", and I was sent next door to the SLP dept., where they proceeded to put a tep in, and I have been talking with that ever since....

I must say, they were really bad on the communication part of this whole ordeal, and I did not know enough about it to ask what was coming next. Every step of it has pretty much been a surprise, other than what I learned myself from WebWhispers. And I thank God every day to have had that resource.

---

**Debbie Deaton**

I wasn't really given any information, I was just told I would get a TEP. Even with the TEP though, 1.5 years was wasted NOT talking because I was made to use the stickies and they would never stick longer than 10 minutes because the mucus would always bust the seal. So after 1.5 years of not working, the ST finally put holes in my lary tube which eliminated the need for the stickies and I've been talking ever since. I don't know why they waited so long to do something as simple as put holes in the lary tube. I wasted a lot of money on stickies that didn't work and I spent a loooooong time being depressed over not being able to talk.

May God bless you today and everyday!

---

**Dave Aitchison, Canada & S. TX - April 2012**

I had a bit of advance notice before my laryngectomy so used the time to research voice choices. My SLP was supportive although she only had worked with TEPs. We are Canadians that have a winter home in South Texas. Our insurance would not pay to have a TEP changed in the USA. I watched several You Tube videos on esophageal speech and also was fortunate enough to have Jim Lauder write me after one of my posts. He sent me Self Help for the Laryngectomy . After my surgery I met Elizabeth Finchem through WW.

After one session I was able to call my wife. I chose to call her Scotch Tape as it was either that or Cup Cake, and Cup Cake sounded too gushy. Those were the first words I had been able to utter for three months. I was so proud of myself. I continued to chat with Elizabeth over the next couple of months and became reasonably proficient. I am now two years post surgery.

I continue to be an advocate of esophageal speech. I am addressing a group of SLP students in late March in Edinburg, TX. I warned their instructor that I use ES and he was quite pleased. The point of my recent postings on Daily Whispers was to educate the medical community and I can assure you there will be twenty new SLP students that will be very familiar with ES when my discussions with them are finished.

Good luck all and stay positive.

---

**Len Hynds of Ashford, Kent, England - 2004.**

I am always amazed when the new members are announced in the digest, and of those in America, it is said that they had not yet decided as to what type of speaking to have. I can only speak for the main hospitals in my own county of Kent in England, and I believe it to be general throughout trhe country, but at the time of the operation, even though

the three types of speaking were mentioned briefly, it was assumed by all that a TEP prosthetic valve would be installed, but if that was not possible for whatever reason, it is only then that an alternative is spoken about fully. You are not given the remarkable choice in the beginning, that you have in America, but those who use the electro-larynx, normally have no other means, and those who use air from the stomach, keep their valves in position whilst learning to speak hands free.

---

### **Lynn Foti, Akron, Ohio - May 2009**

My decision to use a TEP prosthesis was made because I had no idea that esophageal speech was an option. I tried using an EL, but because of the extensive scarring on my neck and the large amount of swelling, I was unable to find a sweet spot. I also tried using the straw that goes in your mouth, but that didn't work either, for the same reasons. My mouth was swollen inside, my tongue, and for a long time, I couldn't even get my tongue to stay put in my mouth and had to push it in with my fingers.

I had had 3 surgeries within less than a month, and it took over a year for most of the swelling to go down, as of now, after nearly 5 years, I still have swelling in the neck area, and spots that are hard too. The scars are very deep. The TEP was easy for me, and I was able to speak with it immediately, it was over 7 months after my last surgery, so I had time to heal from the esophageal reconstruction. I have been mostly happy with it, have had a few issues with leaking and having to drive a good distance to get it changed, but it is closest to my old voice, and works out pretty well. I am glad we have that option.

---

### **David Kinkead - July, 29, 2013**

When I was told I needed to have the operation, everything was a blur. While I went to one of the finest cancer hospitals in my area, I was the first laryngectomy at this hospital. I did much research on line for speech options and I told them what EL to order. No other option was explained by the SLP. She showed me a TEP in box but her or I didn't really know what it was.

My ENT has mentioned that since I had radiation two years before my surgery he wanted to wait until I healed to see about a TEP. I never heard anything about ES. I had issues with the healing and now almost eight months later have started on a liquid diet. I am very good with the EL. I go to a support group at a different hospital and most of the people there speak with the TEP. No one uses ES although a few do use a no hands TEP and sound real good. I would put my ability to be understood against any of the TEP people. I hope to eventually get a TEP and go hands free but with the radiation damage, I may not be able to.

---

### **Harry Wintemberg, FL - 1982**

In the late 70's and early 80's the TEP option was very much in its infancy in the United States and from what I was told and/or read the failure rate gave one cause to think twice before going that route. EL's were very popular due to their providing the patient with a quick and relatively easy way to start communicating audibly, BUT inexperience of the patient and the quality of voice reproduction sounded the like synthesized voice of "ET" (the movie).

Esophageal (ES) manner of speaking then, as it is now, was a more difficult and time-consuming option. Also most speech pathologists did not have the training or skills to qualify as an ES instructor. So floundering in this sea of confusion, I was introduced to one who had her PHD with her thesis in ES. Like winning the lottery, I immediately registered with her and spent 4-5 months of total devotion to my obsession for learning ES. It is now 32 years later and there isn't a shred of doubt they were the best and most rewarding months of my life. Can everyone develop this skill? Absolutely not! The scope of the surgical procedure, radiation damage to healthy tissue and other factors like motivation, dedication, etc. all determine the probability of success.

---

### **Terry Duga, Indianapolis, IN - 1995 Total**

When I had my total laryngectomy, Eric Blom was the SLP working with my surgeon, Dr. Ronald Hamaker. That practice had pioneered the Blom-Singer prosthesis and operation. I had been lucky enough earlier to witness a patient receive his first prosthesis and say his first words. There was no question that I wanted to have that type of speech.

Dr. Hamaker performed the puncture as part of the main operation. This worked two benefits,

1. I did not have to have a second procedure.
2. The feeding tube was put down the puncture rather than my nose. Having had a feeding tube down my nose when I had a partial laryngectomy, I was thankful for the puncture placement of the tube.

When I had healed sufficiently the feeding tube was removed and the prosthesis placed. I was able to speak, though I admit it took me a little while to become a good speaker, and I have continued with the prosthesis ever since.

I am a huge fan of the prosthesis. Yes, it is not perfect, but it is a great way to get good speech that can be heard.

---

### **Jack Davidson - Sep 2012**

My surgery was done at the VA hospital in Dallas. Speaking options were not mentioned beforehand. When I came out of surgery I had a TEP (puncture) with a rubber tube going through it to keep the puncture from closing. The tube was attached to my chest by a few sutures. While in intensive care after surgery, one of the SLP's came by to explain what the tube was and showed me pictures of (Drawings) of the inserted prosthesis (sideview).

Two months later I was fitted with a prosthesis and was taught how to speak. It worked almost immediately. Eight months later it began leaking. They replaced it, and will continue to do so as needed. I requested an EL to use as backup. They gave me a Servox- free of charge.

I cannot say enough good things about the VA in Dallas. The care is wonderful and I have never paid anything for services, durable goods, equipment or supplies.

---

### **Linda Palucci, Florida - 11 1/2 year lary**

I sort of just "go with the flow" when Doctors told me I needed surgery, to stay alive, I immediately said Okay. They asked me if I wanted to live or talk. I choose the former. Anyhow, dr said he could put something in my throat that would allow me to talk. I guess my cancer was pretty serious, 'cause they got me in for the operation real fast. My GP told me years later, she didn't think I was going to "make it". Good thing I didn't know that then, I might have given up.

After surgery, they gave me an EL, which allowed me to communicate. But I could not speak softly with it and everyone within 25 feet could hear what I said. I was tested and fitted with a TEP, which I eventually mastered. And I also learned ES enough to use, but can not speak as loud and fast as I do with TEP. I like the TEP, I sound pretty natural, rarely have a problem and can speak pretty decent, on the phone, plus, yell across a room, or football field. My singing voice needs help, but then, I never could sing. The thing I miss most with this whole situation is I can't swim any more. But I guess it's a small price to pay to be able to continue to stay here and enjoy my family and friends.

---

### **Bishop Duncan M. Wanjig**

My best option is use of electrolarynx (Servox # one). A friend in USA introduced me to it. I am a preacher, Teacher and a counselor. No other is better than this for me. I also fairly well with ES. My laryngectomy was done in 1994 ie Twenty years of happy life with my wife Sarah and our Three children Mercy, Tabitha (married to Daniel) and John. I am a grandfather of 2 kids. I am a Kenyan and live in Thika (Kenya) a City of Pineapples.

---

**Dave Ross, Edgewater, FL**

I have TEP voice as a result of:

- 1) having been made aware of the Web Whispers site a year or two before my surgery,
- 2) my investigation of all matters concerning total laryngectomy surgery including voicing options and the pro and cons of each,
- 3) having the immediate need for good intelligible voice for public speaking,
- 4) ordering my surgeon to provide me with TEP unless there were medical reasons for not doing so.

That was nine years ago and I am very happy I made the choice.

---

**Manny Castillo, Valley Village, CA - Class of 2004**

I am very happy to be alive!

My doctor and friend Dr. Larian made several attempts to save my vocal cords after I was diagnosed with cancer of the left vocal cord. First, was the radiation treatment which was very successful for about 7 months. The cancer returned and Dr. Larian did a partial Laryngectomy and I was able to speak, not as good as I would have wanted but At least I was understood. About 11 months later the cancer returned. At this time there was no other option available but a complete Laryngectomy.

Before the surgery Dr. Larian, my wife and I had a meeting and he described in details what was going to happen and the possibility of a very long recovery time. But, I never forget his final words: "Manny, no matter how long it will take, I promise, you will be able to speak again." And by Golly, I now can speak!!!

My puncture was done during the surgery and one month later the "TEP" prosthesis was inserted and believe it or not I was able to speak right away. My first word was ahhh, ahhh, OK!

The rest is history that was in 2004.

---

**Robert Legros, Québec, Canada - 2011**

I had my total laryngectomy on April 5, 2011 at the Gatineau Hospital, in Gatineau, Québec, Canada.

It was my surgeon's intention to give me at TEP. No other option was discussed at that time. I met with a volunteer who was using a TEP, and I assumed that was it.

Because of complications, a TEP procedure could not be performed. Complications lasted for about three months, when he informed me that it would be several months before he would even consider a TEP. I was loaned an EL, which I did not like. And I did not want to wait.

I did some research and found out about esophageal speech and discussed it with my SLP. I started learning ES in early October 2011. I picked it up very quickly, and soon was able to carry on a conversation.

---

**Pete Meuleveld, Salem, OR - June 2010**

When I had my consultation and decided on the laryngectomy surgery, I made it clear I wanted the best voice that would be closest to my original voice. The TEP procedure was the obvious selection, and the cost and maintenance factors were explained. Other options were also explained. In the few days before the surgery, I looked at and listened to examples on websites of esophageal and artificial larynx speakers. I then decided to go ahead with the

TEP and am glad I did.

### **Lorna Larson, St. Louis, MO - January 16, 2014**

I saw the SLP a couple of days before my surgery. I was inpatient at the hospital at the time, so the nurse had to go with me. She had never sat in one of these appointments, so she learned a lot too.

During the visit, the SLP went over how life will change for me with the laryngectomy. I didn't have anytime to do research, so this was very helpful.

She also explained the 3 ways I would be able to talk, EL, TEP, and ES. I ruled out TEP quickly, as I had prior radiation and there were risks involved. Plus, I didn't think I could handle the additional maintenance.

After the surgery, at my second visit with the SLP, I was practicing some of the vowel sounds that tend to be troublesome when using the EL (D, T, K, etc.) As I practiced - out came ES - I thought it was just annoying burping. I don't speak ES yet, but have my exercises, so I practice when I can.

One night, I was reading a book, and my son was washing dishes in the kitchen. I said something to him using ES. He turned around, shocked - and said "Mom, you just talked!".

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



*During a recent holiday on our way to the summit of Mount Snowden in North Wales, on a single track mountain railway, we paused to allow a train descending to pass. As I gazed at the towering mountains, deep valleys, and watched a tiny stream on its way to the sea, I marvelled that all this landscape had been formed by tiny streams like that one millions of years ago, carving this majestic scene. By the time we had reached the summit an hour later, I had formed this poem in my mind, and had made myself as that young stream racing excitedly to the sea, with all the exuberance of a new young life.*

## THE SONG OF THE SEA

My song was born in a crystal pool  
as my glacier mother wept.  
My snow and ice, no longer cool,  
melted and I was swept.

My song at first was a pebble sound  
as I carried those friends with me.  
They danced along, upon the ground,  
as we played towards the sea.

Across high meadows, still with snow,  
being kissed by drinking hares.  
Leaping salmon, then diving low,  
avoiding hungry bears.

Through dead woods, so white and still,  
carving snowdrifts from the banks.  
My song now sounds, oh! quite shrill,  
as snowdrops nod their thanks.

I'm bringing life to all I pass,  
the stately elk who plods.  
I hear a vixen say to cubs,  
"It's the nectar of the gods."

I swerve round boulders, green and swift,  
strength gaining all the time.  
Broken branches above me drift,  
in my currents foaming rime.

My gentle song is now a roar,  
down rapids leaping high.  
Such excitement as my wave tops soar,  
as if to reach the sky.

And soon I'm joined by others,  
all racing to the sea,  
and we streaming band of brothers,  
all joyous to be free.

Careless hurtling over waterfalls,  
laughing through the mist.  
Shouting at the canyon walls,  
with all those rainbows kissed.

And so at last I reach the sea,  
trying to join those adults grand.  
But those massive waves keep ignoring me,  
as they crash against the land.

I see beams of the goddess moon

I soon learn of the goddess moon,  
as we swim towards her light,  
but come the dawn, oh so soon,  
the sun pulls us from her sight.

This sun I'm told, this life will end,  
and I'll rise as a ghostly mist,  
midst thunder, and the lightning's rend,  
compressed like a darkened fist.

I pray that on some mountain I'll fall,  
as snow or new born rain,  
to be wrapped in mother glacier's shawl,  
and then be born again.

## Bits, Bytes and No Butts!



Frank Klett

### The End of an Era - Windows XP will be Laid to Rest

#### The King is Dead, Long Live the King Are you still living in 2001?

Every Windows user will remember (maybe) the day in Fall of 2001 when Bill Gates introduced Windows XP to an audience in New York City. The memorable moment is that this announcement came on the heels of 9/11 and came to be used to tell the World that NYC and the USA had resilience.

Windows XP has proved to be very very resilient...even more than Microsoft would have ever predicted. After 13 years XP still commands 29% of the World market (depending on whose numbers you use) and many of the daily functions for ATM's and other CPU dependent machines.

Microsoft will officially cease supporting XP on 8 April 2014...just a few days away. What does this mean? Lots of experts have their own ideas...Bill Pytlovany developer of WinPatrol says:  
<http://billpstudios.blogspot.com/2014/03/tell-microsoft-to-rethink-windows-xp.html>

Never to be shy in sharing his thoughts Leo Notenboom chimes in with this video:  
<http://askleo.com/what-to-do-about-windows-xp/>

---

The always vigilant Windows Club adds their concerns for user security and suggests possible workarounds:  
<http://www.thewindowsclub.com/windows-xp-end-of-life>

Should all of this concern you? If you are a Mac user the answer is no...if you have purchased a new computer in the last 6 years the answer is no. But if you are using a hand-me-down computer or simply have no idea then just go to your Control Panel and select "System" for all you need to know about the operating system on your computer and other information you probably not care about right now.

If by some slim chance you are using XP then you need to decide if you will keep using after having been informed of the risks or you can upgrade your PC to Windows 7 or 8.1.

### **Tips and Tricks!**

We have had a number of posts lately in our Daily Whispers on Esophageal Speech (ES) and I find each post valuable in my own search for info on "how to" learn ES. No one has yet mentioned the use of Skype for teaching ES...Elizabeth Finchern has used it for just that purpose over the years. For those of you who have mastered the ES technique you may be able to share you knowledge face-to-face with a member who is trying to learn.

### **Not a Forum member yet?**

Then just follow the link below for the trail to sign up for this terrific site and the very best lary info available!  
Webwhispers Forum: <http://forums.delphiforums.com/webwhispers/start>

Do you find yourself wanting to have a cup of coffee with a group of your closest friends? Be sure to check into the Webwhispers Forum during the week and join the rest of us in sharing information in a 'coffee in the morning' sort of way. All sorts of "hot" news and tips that make our lives richer and just plain fun. You'll find everything from Lary issues, life lessons, Marlene's greatest tips ever, and just plain fun with Maureen's updates on Bean. If you're not using this great little bit of high tech you are missing one of the best things in our Lary life. Hope to see you there. Mike's thoughts on the world through his eyes of anti-myopic wisdom will certainly engross you.

Our Vendors are offering discounts and having contests just for signing up...but you have to visit the Forum to be eligible...so "Come on down!"

Did you know our forum has a Chat Room available for those who have a common interest and would like to discuss it in real time. You can use it for group discussions, general BS or for any other use you can think of. Just set a time to meet ...log on and click on Chat Room at the bottom of the start menu and voila you are ready to chat away.

And then there is our new editor in our Delphi Forum which Mike has activated for us. This is a welcomed improvement in how we send and reply to messages and offers much friendlier options. You can post you thoughts, questions, best wishes, and photos to share with the Webwhispers community.

**WebWhispers is an Internet based support group. Please check our [home page](#) for information about the WebWhispers group, our email lists, membership, or officers.**

**For newsletter questions, comments or contributions, please write to [editor@webwhispers.org](mailto:editor@webwhispers.org)**

**Managing Editor - Pat Wertz Sanders**

**Editor - Donna McGary**

**Disclaimer:**

The information offered via WebWhispers is not intended as a substitute for professional medical help or advice but is to be used only as an aid in understanding current medical knowledge. A physician should always be consulted for any health problem or medical condition. The statements, comments, and/or opinions expressed in the articles in Whispers on the Web are those of the authors only and are not to be construed as those of the WebWhispers management, its general membership, or this newsletter's editorial staff.

**As a charitable organization, as described in IRS § 501(c)(3), WebWhispers, Inc is eligible to receive tax-deductible contributions in accordance with IRS § 170.**

**© 2014 WebWhispers**

**Reprinting/Copying Instructions can be found on our [WotW/Journal Index](#).**

Copyright © 2014 WebWhispers.org