



WebWhispers

Sharing Support Worldwide
Throat Cancer and Laryngectomy Rehabilitation



June 2016

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FEEDBACK



Larydom Goldmine

Wow! I am amazed at how much I have learned through WebWhispers. I remember knowing absolutely nothing about what I needed to do to manage my “Larydom”. I first used that word in a whimsical way and may have originated it as I have not heard anyone else use it, but to me it is a very real word. Larydom is a unique realm, the new world for a Laryngectomee. In our Larydom, we strive to learn about things we never, ever, thought of. We had no reason to think of them as most if not all of us had never heard of laryngectomy. Very few of us had much awareness at all regarding cancers of the head and neck or knew of any reason to be interested in the topic. Twenty years ago, WebWhispers began meeting the needs of larys and others dealt the dastardly card, cancer of the head and neck. That has made all the difference for fighters, survivors, and caregivers around the world, including me.

The volume of information on our website is phenomenal. Analytics of our site shows me the demographics of who uses it and what they use it for. I don't see the name of the user but do see where they are, age group, gender, what part of the website is getting the most attention, and a whole lot more. Such information confirms that we are still doing well at what we do and we're going strong. We get new members every week! Those who have been around a while, the “old salts”, know their way around webwhispers.org and can probably go straight to what they want with a bag over their heads and their hands tied together. But I can assure you, to a newer Webbie, the size of our website can be mind-boggling, maybe even somewhat intimidating. That is why I want to spend some time now and then, directing our attention to what WebWhispers offers to our community.

Since the day I realized how extensive our website is, I began using it more and more and still do quite often. It is filled with answers to the most frequently asked questions and more. For instance, if you go to “Library” from our main menu, there is a list of headings on the left. Under “Possible Problems” alone, there are the following topics:

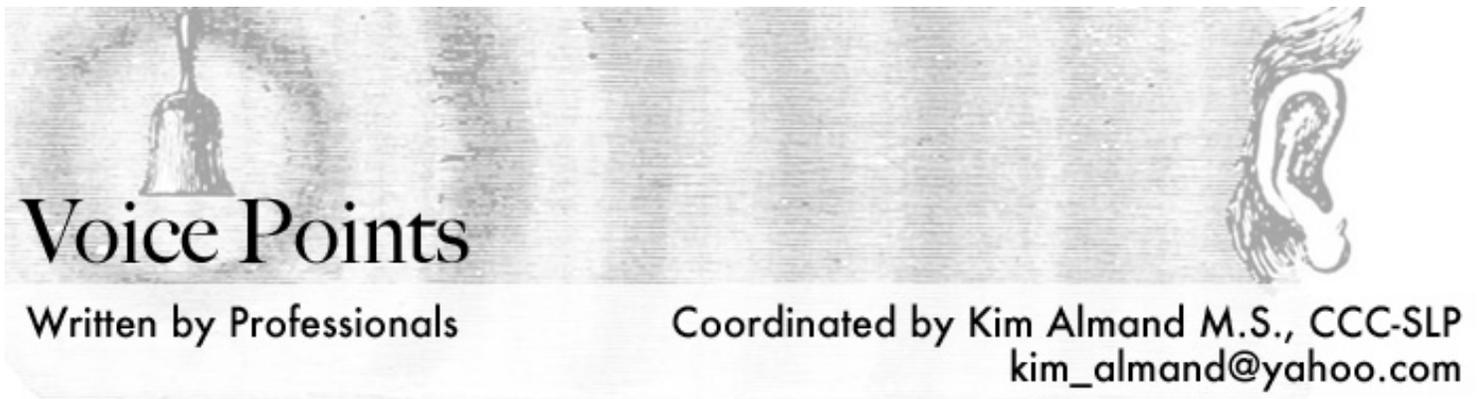
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Though most of us continue to learn along the way, some of the information on our website may seem redundant to an “old salt”, yet to a new Lary, it is like discovering a gold mine! I know, as my first days of Larydom were not that long ago. Learning from the pros can really help one not feel so overwhelmed. Keep that in mind when visiting, attending local club meetings, and anywhere else you get an opportunity to tell someone about WebWhispers. WW really can make all the difference one needs to go from sheer terror to “okay, I can do this”. As you encounter anyone who could benefit from WebWhispers, invite them to join! We’ll gladly provide brochures to help with that. Simply email a request to brochures@webwhispers.org.

Enjoy Whispers on the Web,

Tom Whitworth
WW President



Voice Points

Written by Professionals

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Long Term Effects of Radiation Therapy

The shock of the diagnosis has long since passed, and with a combination of personal strength and grit, alongside the support of family, friends and a team of compassionate nurses, you have found a way to endure

7 long weeks of radiation and chemotherapy. You rang the bell on the last day of radiation and kept the mask that secured you to the table during each treatment. Your taste may even be starting to return and the thick and rope-like saliva may be starting to thin. Your nurses, doctors and swallowing therapists greet you with

smiles and celebrate the great response to treatment.

Family and friends praise your fortitude and rejoice at your life. So why, you wonder, do you feel so far from normal? So far from cured? So far from where you imagined you might be? It is inevitable that lasting effects from cancer treatments will continue to be a part of your daily life. This is true whether the primary treatment used to treat the cancer is surgery or radiation. It seems obvious that with surgery something is removed and the loss of tissue will result in differences in speech, swallowing or breathing. But how would radiation, which avoids the invasive removal of tissue, affect one's voice, swallowing and breathing? After all, isn't radiation intended to only affect the cancer cells? In actuality the effects of radiation can be divided into short term and long term manifestations. The magnitude of these effects varies from person to person. It is easier to counsel patients about the short term side effects of radiation because they are more predictable and more likely to subside with time.

A common early side effect of head and neck surgery and radiation is lymphedema. This refers to the accumulation of fluid outside of blood and lymph vessels and it presents as swelling. In many cases this will improve to some degree with time, but it usually doesn't completely resolve. If the excess lymph fluid is present over a longer period of time it can result in hardening or fibrosis of the tissue. Soft tissue fibrosis gives the characteristic "woody" quality to the skin and soft tissues. There is a loss of the elastic qualities of the tissues and movements such as opening the mouth, turning the neck and swallowing become constrained and compromised. Lymphedema can present both in the external soft tissues of the neck with swelling, tightness and immobility of the skin and muscles as well as internally with swelling of the throat and voice box.

For many individuals the external swelling is quite prominent below the chin and occasionally it is referred to as a "turkey neck." Physical and occupational therapists with training in deep tissue massage and myofascial release offer a tremendous service to patients after radiation therapy.

In my practice I routinely recommend their services and patients almost uniformly report that they find benefit in learning these massage techniques. The swelling present internally explains, in part, why radiation can affect swallowing, speech and breathing. Longstanding swelling progressing along a continuum to fibrosis affects the fine muscles of the throat that are essential to swallowing. The old adage, "If you don't use it, you may lose it," seems to be pertinent to swallowing function with radiation. Historically, the approach to dysphagia was to address it after treatments were complete and the effects had set in.

At present there is an emphasis on engaging in swallowing exercises during therapy to keep muscles as strong and supple as possible. In addition, modern radiation techniques are better able to spare important uninvolved structures such as the constrictor muscles for swallowing and the parotid glands for saliva production. There has been improvement in the recognition of late onset swallowing difficulty. Speech and swallowing therapists will work with patients over many visits to improve oral intake and discontinue the use of feeding tubes as soon as it is safe.

Surgery and radiation for head and neck cancer can have lasting effects on several important functions of the mouth. The normal jaw range of motion can be substantially diminished resulting in a limitation in mouth opening referred to as trismus. Trismus is defined as a decrease in the opening between the front teeth (incisors) to less than 4 cm. Modern radiation techniques have decreased the incidence of trismus. Not only does trismus affect a patient's quality of life, it also can impact a patient's ability to eat, chew, speak and maintain oral hygiene. Jaw stretching and range of motion exercises are typically used to improve a patient's range of motion. In rare occasions there are surgical procedures that can be done to release scarring and improve a patient's range of motion.

Another oral ailment common after radiation therapy is xerostomia. A decrease in the production of saliva leads to unpleasant dryness in the mouth that can result in sores, difficulty speaking, swallowing and impairments of sleep. It can also lead to chronic yeast infections and dental decay. Teeth tend to decay in an acidic environment and saliva helps to neutralize this acidity.

Regular dental evaluations, judicious use of fluoride in the form of specialized toothpaste and fluoride trays, as well as aggressive oral humidification are essential to maintaining dental health. The decrease in saliva can also contribute to taste changes. While chemotherapy may often cause temporary changes in taste, radiation can have more lasting effects on taste. This depends upon the dose of radiation that is delivered to the tongue.

While taste disturbances tend to diminish with time there have been long term studies showing persistent changes at 7 years or longer. This can affect a patient's ability to maintain adequate nutrition and has an important impact on quality of life. It is important that patient with taste disturbances maintain oral hygiene and get occasional nutritional evaluations to be sure they are not deficient.

The palpable fatigue that weighs many patients down during their treatment unfortunately doesn't lift right away. The fatigue may be physical, mental and/or emotional. It can affect relationships and work productivity. Providers should be sure to discuss this with patients. Sleep is often compromised after treatment and this can be due to dryness of the mouth, pain, obstructive sleep apnea or anxiety. Patients should be informed on sleep hygiene and measures such as sleeping with the head of the bed elevated and use of a humidifier. They may need to be evaluated for obstructive sleep apnea which can be treated with continuous positive airway pressure (CPAP). Fatigue may be aggravated by anxiety and depression and this may warrant an evaluation by a trained mental health professional. In addition, the thyroid gland can be affected by radiation and regular thyroid function testing should be undertaken and supplementation given when appropriate.

While the heavy lifting may be done there are important measures patients and health care providers must keep in mind to address challenges that stem from treatment. In some ways, the radiation and chemotherapy used to treat head and neck cancers is just the beginning. A host of dedicated health care professionals in speech and swallowing therapy, occupational and physical therapy, dentistry, and internal medicine should be enlisted to maximize every patient's quality of life during and after treatment.

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Out of the Mouth of Babes

I was scrolling through back issues of our newsletter looking for something else when a column written 6 years ago, June, 2010 caught my eye. It brought me right back to the time when I navigated the new territory of **Nana's Voice**:

Several months ago I wrote about my concerns that my grand-daughter Kayleigh's language and speech development might be hampered by my "voice", a Servox, since I was the primary "day care". I was reassured by many that it would not be a problem and to just relax and enjoy being a Nanny/Granny. I am here to say, you were all right and I was just being a worry-wart. Miss Kayleigh is a veritable chatterbox and she thinks the Servox is pretty darn cool. One of her favorite games, now that she has mastered pushing buttons, is to make it "buzz" and then hold it to my neck...when I try to talk she pulls it away mischievously, so we see if I can get a word out first. As one friend noted, she probably wonders why everyone doesn't have one of those cool toys. She clearly understands me although I can't say she always listens!

That got me thinking so I did a quick review and found this from July of 2011 titled **Listen to the Children**:

The other day I read her [Kayleigh, now 2] a book called "Don't Get Wet, Jesse Bear". We got it at the library and I had read it to her just once before. She insisted that she read it to me, this time, so she turned the pages and I read. I tried my best to do the different voices of Mama and Papa and Jesse Bear but it's not so easy with a Servox. After she got up from her nap, she was playing in the living room and I saw her pick up the book and start to "read". She said over and over again, "Don't get wet, Jesse Bear". I was amazed not just that she remembered the story so well, but she was "reading" with the exact pitch, timing and expression that I had tried to use with pitiable results, or so I thought. Apparently not since clearly she somehow understood!

She still needs a translator from time to time, but I am encouraged. Not only did she hear and understand the words, she recognized what I was trying to say in my own way. There are other interesting developments. I enunciate very clearly; one of the reasons for my success with a Servox. I have noticed that she seems to be able to read my lips. I was filling her water bottle on our way outside one time. I had my hands full, so I couldn't use the Servox. I turned to her and said, "Kay, get the cap". She stared at me for second and I repeated, "Get the cap". She walked over to the drawer, got it and proudly handed it to me, "Here, Nana, I got the cap!" That could be a handy skill, later in life. Although at this age one needs to be very careful what you

say and do around her. She is a sponge, picking up new words and phrases constantly. I swore, under my breath, so to speak, the other day and she looked at me puzzled and did an alarmingly accurate imitation. Generally when she picks up something new she will repeat it back as a question and I say it a couple more times as reinforcement. I pretended not to hear the question this time and vowed to watch my language in the future. As far as Kayleigh is concerned, I come in loud and clear.

And then I found my very first article exploring the issue in November 2009 when Kayleigh was just 6 months old, **Baby Talk**;

Perhaps some of you read my post to the WW list about my concerns as a “vocally challenged” caregiver for my baby granddaughter. The response was both reassuring and heartwarming. Not one of you snorted like my son did, when I showed him the responses. “Well of course, Mom, it’s not a problem. Everybody understands you and recognizes your voice...so does she. She’s not going to start sounding like a robot, just because she hangs out with you.” Empathy is not his strong suit, obviously. I was a bit miffed at him but, apparently, he made a good point.

I went on to share some of the responses from both speech professionals and veteran grandparents and closed that column by saying I was anxious to hear just what Kayleigh herself would have to say someday about my voice. Fast forward, the “baby” is now 7 and she has a 4 year old sister. I have been a constant in their lives; the nanny/granny next door. And I am here to say neither girl has any problem with her own speech, language or vocabulary- actually quite the contrary! So the other day I decided to ask them a few questions. Their responses were underwhelming and decidedly less eloquent than I hoped for from such normally talkative girls. Apparently there is a real art to interviewing kids and getting them to be funny or profound on demand.

What can you tell me about why Nanny talks like this?

Kayleigh, age 7: Because you had a problem with your voice. Your voice doesn’t work anymore.

Kiera, age 4: ‘Cuz she lost her voice.

What is different about Nanny?

7: They [other people] don’t have the thing you have that helps you talk.

4: Don’t know. She has to talk louder so people can hear her

Does it bother you or make you feel funny? In what ways?

7: No. I always think it doesn’t sound funny.

4: No!!!

How about when we are out somewhere and someone asks about it or stares, like Blythe on Saturday or the kids at Winslow Park? Does that embarrass you?

7: No. It doesn’t embarrass me because I know they just want to know why.

4: No. It makes me happy - that’s why I make new friends! [laughs]

Do you like having Nana read to you even though her voice sounds different?

7: Yes. [big smile]. It doesn’t bother me.

4: Uh huh....how many more questions?

Do you like Nanny's voice? Why?

7: Yes. [facial expression indicates this is a really lame question]

4: Yes. It sounds so lovely. [yes, that was her exact word and I don't think she is old enough to master either irony or sarcasm]

How is Nana's voice different from other kids' Nana's voice?

7: Because you use that thing.

4: Some people didn't lose their voice and some people lost their voice. [throws hands up and shrugs]. I want you to use two buttons when you talk to me. You can do that anytime. [the tone variable on a Servox]

What is the worst thing about the voice?

7: That you have to use it every day.

4: The quiet talk - some people can't hear you.

What is the best thing?

7: That it allows you to talk and you can make it sound funny.

4: Because it's really super-doooper funny.

What would you say to other kids who have someone in their family who sounds different like Nanny?

7: How do you like their voice? My Nana has one too. You don't need to feel scared. They probably just had an infection and they need to use it now.

4: It's okay.

Anything you want to add?

7: It's not that big a deal. You need to use it and it doesn't make any difference. I want you to keep that funny voice. I like it. Oh and also I want to add on that you are good at jokes.

4: I have a funny joke for you. [end of interview as subjects start regaling me with silly jokes]

So there you have it - the great non-issue of dealing with kids when you talk differently. I have decided that instead of "Out of the Mouth of Babes" this might be more suitably titled "The Big Meh".



What drove your decision to use the type of speech that you chose? Were the options explained to you?

**Tom Olsavicky - Newport News, VA
2008**

As suggested by my surgeon, I attended a Lost Chord Club meeting about two weeks prior to my Laryngectomy. At that meeting, one individual was using a TruTone Electro Larynx and was very well understood. After hearing others who had a TEP, a Servox and even one who used Esophageal Speech, I told my wife that if I could sound as good as the first person, then that is what I would choose to speak again. I told my doctor that I wanted to use an EL after surgery and he approved of my decision. He said if I didn't get the results that I wanted, he could always do a puncture at a later date. A week after surgery, I was loaned a TruTone and began to practice. I wasn't immediately happy because of having to use the oral adapter until my swelling subsided. Once I was able to move the EL to my neck and finding my sweet spot, I was able to have a very clear and loud voice which was every bit as good as the gentleman I first heard. It has been over eight years and I am very satisfied with my decision.

**Jack Kehler - Ozark, AL
March 2015**

I really was not given an option. During the operation a TEP was put in. And that is what I am using. Leaking all the time and still trying to find the correct size.

Shirl MacDonald - KY

I feel I might be one of the younger (47) and newer members to the group. I live in KY. I anticipate my surgery to be scheduled this week. I think the TEP will be my choice BUT that's coming pre-surgery. I say TEP just because I have listened and watched so many YouTube videos and that's the voice sound I personally like best today.

I would be very appreciative of hearing what others choices are and why.

I look forward as I heal to spending more time on the website and in support groups getting to know everyone.

Karen Simister – Califon, NJ

I went to Penn in Philadelphia for treatment. I was offered no choice for a voice. The surgeons determined! They did the entire procedure along with insertion of prosthesis all at one time. I was told later by an intern that since I was younger (56 at time of surgery), oncologists opted for voice prosthesis. Honestly, there was so much shock with diagnosis, voicing was last on my list of questions/priorities. I don't think I even began to realize the implications of my condition. All I can really remember from early stage with ENT at University of Penn who diagnosed me saying "You'll still be able to go out to lunch." It makes me giggle today when I think about it - what a silly thing to say.

Anyway, to take the subject further, I was able to voice almost immediately after surgery. Now down the road, I am unable to speak at all (despite repeated replacements) since about a month after finishing up chemo/radiation. I've seen several SLPs along with oncologists - no one knows why. They think it may be severe neck lymphedema. I am ready to give up on the prosthesis. Thanks for the opportunity to share my opinion.

**Tom Cox – Cornwall, Ontario
2003**

I had my surgery 13 years ago and I began using a TEP prosthesis to speak with. I worked 10 more years in a very voice intensive job until I retired.

I have had no problems with the TEP and get it changed yearly just as a preventative as I have never actually had a leak. I didn't use a nebulizer or a suction machine and the humidity or lack of have not been a problem. The only TEP care that I do is to occasionally use a small brush and I have a pair of tweezers that have a scissors handle. Other than that there isn't much else I do. My voice is clear and strong so I consider myself lucky.

Dave R. – Bangor, PA

Had my surgery April 4th of this year, so I'm new here and still healing. Trying to get used to an electro-larynx for right now, have to use the straw until my neck swelling goes down.

It gets frustrating at times, seeing a speech therapist once or twice a week. Have had all my options for speech explained to me, I chose this for right now until I'm healed all the way.

Then I will see how I feel about my options. I glad I joined WebWhispers. There is a lot of good information here and I see I have a lot of adapting to do!

**David Kinkead – Peoria, AZ
7/2013**

When I first found out I needed surgery the only type of voice I knew about was EL. I asked the SLP to order one for me and we started practicing with it. My surgeon mentioned the TEP but with all the radiation he was afraid to do the puncture at that time. I used the EL exclusively for the first year then had the TEP. I am now "bi-lingual" as I am very proficient with both the EL and TEP. I use the EL more because it is easier for me but the TEP works great.

**Debra Sheridan – Franklin, TN
2014**

My anatomy drove my voice choice. I had a TEP placed at laryngectomy surgery in '14 but one year later, in conjunction with esophageal re-reconstruction, the TEP was removed. I learned how to verbalize with electro larynx tout de suite when I had no other choice. I have been practicing ES, but I am not consistent in creating audible voice, and as I don't know what I do to create sound when I do, it's a haphazard voice method for me.

I figure any voice is better than no voice.

**Lloyd Enochs - Evansville, IN
December 2009**

I voice using a tracheoesophageal puncture (TEP) and my surgeon presented that choice as the default. He said my choices were an electro larynx, a TEP or silence; esophageal speech was not mentioned. His opinion was that while the electro larynx was a more established technology, the voicing quality of the TEP was far superior. I had already had expressed my desire to get back into the workforce after surgery, so the choice of TEP made a lot of sense to me. My surgeon also arranged for me to meet with another of his laryngectomy patients prior to surgery so that I could get some first-hand, practical advice about what to expect going forward. He voiced using a TEP and was very happy with it. (He also is the person who told me about Web Whispers and the IAL.)

Previous radiation therapy had so severely scarred my neck tissues that my surgeon was concerned about post-surgical healing, He mandated a delay to ensure the laryngectomy surgery healed properly prior to creating the puncture, and then another delay to ensure the puncture healed before installing the prosthetic. My laryngectomy was in December of 2009, the puncture in May 2010 and the first TEP was installed in July 2010. I was able to speak clearly immediately after the installation and I have had no voicing problems since.

While there wasn't any real discussion concerning which voicing method I would use prior to surgery, I have no regrets about the decision to use a TEP. It has been a stable method of communicating these last 6 years and I have had no trouble with either face-to-face or telephone conversations.

As an aside, meeting with another laryngectomy patient prior to surgery was an invaluable help to both me and my wife. We were able to get the solid, real-world information that just is not available from someone who hasn't been in our position - nothing beats first-hand knowledge. He provided vital information that eased our minds considerably during that traumatic pre-surgery wait. The local ENT practice asked, and I readily agreed, to speak with new patients pre- and post-surgery. My wife and I have had one opportunity to meet a new patient and we like to think we made a positive impact on her and her caregiver. I would highly recommend each of us to contact our surgical practice and volunteer our experience. We can provide the future members of "Our Crowd" advance information, answers to concerns, practical advice, moral support

and (most important of all) proof-positive that there is a life after surgery worth having.

**Sally North – Dallas, TX
1990**

Instead of my choosing my method of speak, it choose me. It started when I got my laryngectomy in Florida in 1990. In those years, not much was known about doing a TEP. I was never given a choice about which method of speech I would use. I had a TEP done about three months after my original operation. When I went to see a Speech Language Pathologist, she put in the biggest duck bill prosthesis that there was. I believe it was a 3.6. Obviously she had never worked with any prosthesis. I was not able to speak for over a year.

Then I found a great Speech Language Pathologist in San Antonio TX, who sized me down and gave me a 2.6 prosthesis and from there I have been well taken care of by some of the greatest Speech Language Pathologist there are.

Brenda Patterson – Mooresville, IN

I am 58 and a purchasing professional. Being able to continue to work was critical to me since it will be several years before I am eligible for Medicare and I need health insurance. I live near Indianapolis and am fortunate in that respect with access to many health care professionals.

I am a two time cancer survivor – Hodgkin's Lymphoma in my neck and chest 30 plus years ago, with chemo and 8 weeks of radiation. Then diagnosed 4 years ago with stage 4 throat and thyroid cancer treated with a full laryngectomy and radiation. Needless to say, so much radiation has left me with very severe scarring in the throat and neck region. It was 5 months before I was able to find any method of speech at all.

I tried the electro larynx, but was unsuccessful with it due to the swelling and scarring – just as well, I was a bit put off by the tone of it for me personally. I finally was able to speak with an indwelling TEP and began to speak. I have struggled with speech and the effort it requires making me red faced and woozy if I have to speak for a long period. It seems there is very little space between my TEP and back of my throat. I have had a couple of dilations with slight improvement but I feel that I am probably at my optimum.

I recently required another surgery to enlarge my Stoma as it had shrunk to about 3/8". I thought this surgery would be a walk in park, given what I had been through previously but the tissue in my neck was very, very slow to heal, leaving me with a period of 2 months with no speech at all. I guess the lesson in this is that it would have been good to have a "back up" method of speech – something to think about for the future.

Good luck to everyone in your "challenge" to find the best method for yourself. This whole thing seems to be an evolution for many of us, requiring that we are willing to try new things and make changes as we go along on this journey.

**Barb Gehring - Akron, Ohio
September, 2013**

A week prior to my surgery, my ENT surgeon urged me to speak with one of his patients who used a TEP, to

see if I were interested. I found that this man's new voice was easily understood in person, as well as on the phone, and he answered a multitude of questions the day we met. He also highly recommended the WebWhispers site on the internet. I also met with an SLP on my team who gave me a general overview of the 3 possible voicing choices, as well as booklets, pamphlets, illustrations - all of which I was too overwhelmed to read those 2 days before surgery.

My daughter gave me a Boogie Board for communication in the hospital, and because at the time it was brand new on the market, my doctors and nurses were very interested in the device for use by their future patients. For me, it became my only method of communication for 9 months. I also downloaded an app for my phone called Speak It which allows you to type a word or phrase and a male or female voice will speak exactly what you've typed. I found the Boogie Board to be much faster for me.

Before my release, my SLP introduced me to a woman who used esophageal speech and also guided me in the use of an electro larynx. The EL was given to me to take home.

Later, chemo and radiation treatments so impaired my ability to swallow, that my peg tube wasn't removed until 8 months following surgery. An esophageal dilation was tried and 2 weeks later, a TEP puncture was performed. I could speak immediately, although my voice was an octave lower, and I soon noticed that it was more difficult to swallow pills or food unless it was pureed. Last year, after 2 more unsuccessful dilations and worsening speech, my voice and swallowing doctor removed the prosthesis, with the intention of placing the puncture in a new area that was not so strictured. I began using the electro larynx, rarely writing on the Boogie Board, and have not yet returned for a new puncture because I'm loving my ability to eat a wider variety of food.

Belinda Roddy - Martinsville, IL
Oct, 2015

I use a TEP to speak. My surgeon recommended using this. Esophageal speech wasn't mentioned until after surgery when the puncture had been made and the feeding tube inserted. The SLP said I bet you would have been good at esophageal speech, and I can get a few words out through ES when I don't think about it! I personally didn't want to use an electro-larynx. (I was traumatized as a child by an uncle who had one and it scared me to death!) I had one brought to my room after surgery but, told the SLP I didn't want it. She took it back the next day.

Carl Strand - Mystic, CT
Radiation Therapy summer of 1991
Laryngectomy February 10, 1993

When my laryngeal cancer returned, my ENT and I went to the Yale Head and Neck Cancer Conference to explore options. The universal consensus of the Conference was that a total laryngectomy was the only viable choice. It was mentioned that I was a promising candidate for a voice prosthesis, but I did not know what that was and at that point all I heard was that my voice was going away.

I had been working with a speech pathologist and she produced an assortment of electro larynxes from the loaner closet. She said she would order which ever one I preferred and have it for me right after surgery. I decided on the Romet and simply assumed that would be my method of communication.

My ENT had other ideas. She determined that she would do a primary puncture at the time of laryngectomy. I was not consulted or informed of this decision, which today I find unthinkable.

As my shock and dismay lessened a little, I remembered the option of a voice prosthesis. There was only one speech pathologist in my area who was familiar with them and could fit them. She and I established contact and she explained what the normal procedure would be to establish my candidacy for a prosthesis and to proceed with a puncture and a fitting.

Following surgery, after I began to absorb all that had happened and was lucid enough to hear what was being explained, I found that I had a feeding tube coming out of my new stoma. The ENT explained what she had done. My speech pathologist was horrified that there had been no evaluation of my ability to speak with a voice prosthesis. None the less, four weeks after I left the hospital, the ENT, speech pathologist, my wife and I met together and I was fitted with a Blom-Singer Duckbill prosthesis. I said AAAH and my wife cried. That was 23 years ago and a Blom-Singer - now Indwelling prosthesis has been my primary method of communications ever since.

I'm not sure that you can find much choice in the above story. Yet, the outcome was certainly good. I'm very vocally active, chairing meetings, leading classes and what have you. It certainly returned me too much of the life before laryngectomy.

Noirin Sheahan – Killester, Ireland

I use an electro-larynx, but didn't really chose this. At first I was assured I'd get a puncture a few months after the laryngectomy and then a TEP. So the electro larynx was expected only as a temporary stop-gap. But my neck never loosened enough to let the surgeon make the puncture.

I did choose the type of electro larynx. I started with a Servox which was provided by the Health Service. But then I heard [Tony Talmich demonstrating the TruTone](#) and was so impressed I got one myself immediately. Unfortunately I never mastered it as well as Tony - maybe because I have a lot of nerve damage to my tongue. But I get some degree of tone control - much more so than with the Servox.

My main gripe is the unpleasant and very unfeminine tone. But it lets me communicate with friends and live independently and contribute usefully to society so that is a lot to be grateful for.

Sundy Mead - Cary, IL Lary 0712

I voice with a TEP and had an excellent surgeon. Everything happened very quickly after diagnosis as the tumor was large. I was not given a choice or did anyone explain much of anything. TEP was done during surgery.

I was however, told that I would be able to speak again and sound like myself. Didn't know or find out about the TEP or what it was until 1st visit to SLP after discharge. I was just getting staples out of my neck later that day so she only had me try an EL to get me by until I could put an adhesive on my neck. EL didn't work at all but the next week was good for an adhesive so TEP had been my only means of voicing since. (Deep stoma and can't occlude with thumb or even 2 fingers).

Next month's question:**Do you or did you have any eating problems as a result of your treatment?**

Please tell us about it pro or con by sending your response to: speakingout@webwhispers.org along with your name, where you live, and the date of your surgery.

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

Staff of Speaking Out

**Our “Human” Voice?**

The Speaking Out question this month got me thinking about my own perceptions of the electro-larynx and how these have changed over the years. My working life had all been spent in hospitals. So naturally enough I saw quite a lot of very sick and disabled patients over the years. For some reason – was it some weird foresight? – my only “I never want that for myself” reaction was when I heard a man using an electrolarynx. My thoughts were along the lines of “How awful to lose your humanity like that”. Obviously I was over-reacting and way off the mark, but that was the impression I took from his robotic voice. If I had spoken directly to him, rather than just hearing his voice in the distance, I hope I would have made a better judgement. As it was however, the strong impression I took away from that brief encounter was “Thank God that’s not me”.

I also remember one time in the waiting area of ENT, hearing the man beside me chatting with his wife using his EL. Again the mechanical drone struck me as de-humanising, but I was also taken aback by the fact that I couldn’t understand a word he was saying. It amazed me that his wife could answer without any problem and that they were carrying on a conversation. I remember being doubly-amazed when hearing her chuckle! That someone could tell jokes using that weird instrument? That they could have a ‘normal’, friendly relationship? That they could feel good enough about being alive to tell a joke? I was astounded. To me his situation was completely tragic. But obviously he and his wife didn’t agree.

When the doctors first started talking about a recurrence of cancer (I’d had my first bout in 2005 –

successfully treated with radiotherapy) I remember saying to friends “So long as I don’t end up with one of those awful machine voices”. And I remember them quickly reassuring me “Oh no, no, no ... that won’t happen to you”.

Fast-forward and you find me with my own electrolarynx strapped around my neck every day for the past three years. And what, from the outside, struck me as an appalling tragedy for any human being, doesn’t feel at all so bad from the inside. Of course, of course, of course, I would love to have my old voice back. But I don’t think about that too often. It’s a loss, but a bearable one. What can still amaze me is how easily others accept my squawky voice and treat me with complete respect. Somewhere deep down, I expect them to have my initial, horrified reaction. If so they are hiding it well, bless them!

When, after trying three times to make a puncture, my surgeon told me he was giving up on that possibility and that I would be permanently using the electrolarynx, I first felt devastated. But now I’m not so sure. I think the main thing is clarity. I have met two or three TEP users who were very difficult to understand. I was not too pleased to see how impatient I became with them – I had expected myself to be more understanding. But sadly, I have to admit, impatience won out. For that reason, I now think that clarity is more important than the sound of the voice – people get used to that within a few sentences. For example, one of the first people I met who used a TEP was a very pretty woman. But when she spoke, what I heard was the growl of a dog! The voice and the appearance were so incongruous – my mind couldn’t put them together. I almost jumped back, wondering where the dog was and was he going to bite. After a few sentences though, I had forgotten about my fright, and as I could understand her easily, I found her very pleasant to be with. By contrast, I find that trying to guess what a person is saying makes for a very tiresome conversation.

One possible advantage of the electrolarynx is that it immediately signals there is a physical basis for our poor speech. I know many larys don’t like to think of themselves as disabled or handicapped but I think that people are more patient when they know you have a physical handicap. The sight and sound of the electrolarynx puts me in a ‘disability’ box for them – and luckily our society has developed positive attitudes towards disability. So this means I go into a “This is someone you should be nice to” box. Whereas, when someone speaks very indistinctly with a TEP, the listener doesn’t know they’ve had throat surgery and can be putting them in lots of other boxes e.g. drugged, uneducated, too shy and awkward to speak up, mentally retarded, weird. And while of course, we should all treat every human being with respect, no matter what their circumstances, the plain fact is that we don’t! We have all kinds of prejudices against mental handicap and the many other labels you might place on someone who speaks in a peculiar, indistinct manner.

Of course we have prejudices against physical disability too. But I think that particular box is a little less challenging than the other possibilities mentioned above. And at least people know what box to put us in! If there’s one thing we like as human beings, it is to know what we are dealing with. The EL helps with that, so at least the person can concentrate on understanding what we might be saying, rather than working out which box to put us in.

Maybe things have come full circle and when I’m in a supermarket, there are some people hearing me from a distance and saying to themselves “How awful to lose your humanity like that”. Maybe others are saying “Thank God that’s not me”. Fair enough. So long as they treat me respectfully it doesn’t trouble me what they are saying to themselves. And that is one thing I have to be very grateful for – that hardly anyone in the three years since my surgery, has treated me with anything but kindness and respect. That says a lot for our society. And of course I’ve had to outgrow my own anti-electrolarynx prejudices, which has rendered me a wiser and kinder person. Ironic that something that seems ‘dehumanising’ can actually bring out the best in our humanity.



A Story that Needed Telling

I guess in a way this story is about unconditional love, hope, faith and even death. It begins in 1978 when I was 27 years old. My father, whom I loved with all my heart, was told he had cancer. Yes, the nasty word that can stop you right in your tracks. Now I loved my mother as well and would do just about anything for her. But my father was special to me. We were not what I would call close as he worked almost all the time. He loved his work and after dinner, he often went back to the office to finish what he needed. Still, I had what I felt was a great childhood because of him.

The doctor told him he had cancer of the lungs and it was very bad. He was terminal and was given six months if we were lucky. He was a smoker and a heavy one at that. I never knew how many packs he smoked, but I would guess at least two a day. He had a chest x-ray just six months before and there was nothing; he was clean. Now it was so advanced it was in the main artery to his heart. It would take a heart and double lung transplant to save him and that was never going to happen. He went to some of the best doctors back then and was sent to a radiologist who treated him with such a very high dose cobalt that it almost burned a hole in his lung.

I took this quite hard, as you can imagine. I was taught you never embarrass the family and the importance of having manners. Well, one night while lying in bed and unable to sleep, I sort of said a prayer. It was more like trying to make a deal with God than a prayer, but what did I have to lose, right? My dad was dying! I remember saying that I would trade places with my father if you will just give him five or ten more years. So just take me instead. I guess I did understand the phrase, I would die for you. I always felt I could never be the man that he was.

After his treatment, we went to the coast for a week for him to recover. I remember asking what I could do for him. He answered he would like to see me surf one more time. Wow, that was not what I expected, but since that was what he asked I went to town and rented a surfboard. He always said, "Son, the older you get the colder the water is." In my teens, I thought that was stupid. That water is always the same temperature. I grabbed the surfboard and headed to the water. It was at that moment when my foot hit the ocean I realized my father was right. The older you get the colder the water is! I surfed; we both enjoyed the day together and I was able to give him something.

My father lived six years, not six months. The last year was not real good; his main thought was his next

breath. I didn't live in the same town, but my wife made sure I could always go to see him. She never wanted me to say I wished I were there. We had long talks and many, many times in the last two years he would say something that just made no sense. Well, until an hour or more, then I would just start laughing. It did make sense and on a much higher plain than I was. I was lucky to have known him and I hope I'm a better person for it.

The last year was the worst as he had to go to the hospital, and I was told I could not come up to see him. He would know how bad it was if I showed up in the middle of the week. That was very hard on me, but I did understand the why of it. He said his goodbyes to my brother and mother and passed away without me. We had said our good bye already.

It is 29 years later and I have throat cancer. I always felt I would get lung cancer, and who knows I still might. I went to the hospital of my choice, and to save me I had to have a laryngectomy to remove the tumor. Most thought I would not make it, but somehow I just knew I would. I was at peace and had a good life if I didn't make it. I made my will and even wrote my own obituary including everything I wanted down to the songs. Just to cover the bases.

I did very well. Yes, I was as scared as I have ever been. I prayed just give me the strength to handle what is going to happen. I knew I was losing my vocal cords. When I woke up from an eight-hour surgery, which I slept through just fine, I asked, (well - wrote) the nurse, am I in ICU? I expected to be there as it is very common for the first 24 to 48 hours. She just smiled and said, no, you are in your room. Right then I knew my prayers were answered.

Today I was thinking about my father, and then it hit me. He was given six months, I prayed to give him five more years and take me instead. My father got six years and maybe God made that deal with me after all. All I know is he answered my prayers, and despite the odds I knew I would be fine, too. Makes me wonder was it divine intervention that gave my father the six more years, or my deal. I guess someday I will find out for sure, but for now, I am grateful.

William Cross



A Dreadful Thought

I have told the story many times how, after my laryngectomy, I felt trapped inside my own head with the silence, unable to speak. Whilst wired and tubed and recovering, with my free hand I started composing, feeling very sorry for myself until the joy of living struck me. This was one of those first poems, when I related my body to a large house that I was trapped in.

THE HOUSE THAT COULDN'T SMILE

By Len A.Hynds

It's dull in the huge place where I live,
dull and dismal, so quiet and grey.
No smiles, just echoes of dead laughter,
the ghosts of yesterday, passing through.

Oh for sunlight, warmth and love,
childrens toys and running puppies.
Shrieks of joy, candle-lit tree.
To live, just not reside.

To smile again, to open the doors,
the windows, my heart.

And now for a couple of satirical ones, as I promised.....

(Imagine that I had not survived the operation, and as my spirit hovered over a lifeless body. I would probably have composed this piece of nonsense.)

A DREADFUL THOUGHT

By Len A.Hynds

Here lies a head, that often ached,
here lie two hands, that oft did shake.
Here lies a brain of odd conceit.
Here lies a heart, that often beat.

Here lie two eyes, that often wept,
but in the night, but seldom slept.
Here lies a tongue, that whining talked.
Here lie two feet that feebly walked.

Here lies the stomach and the breast,
where loads of indigestion pressed.
Here lies the liver, full of bile.
Here lies that nauseating smile.

Here lie the bowels, human tripe,
tortured with wind, and twisting gripe.

Here lie the nerves, so often twitched,
with painful cramp, and poignant stitch.

Here lies the back, oft racked with pain,
corroding kidneys, damned chilblains.
Here lies the skin, with scurvey fed,
with pimples and eruptions red.

Its got alas, a cancer death,
compressed the lungs, and stopped the breath.
These poor organs could no longer go,
because the bellows had ceased to blow.

My spirits, Oh! so sadly sag,
I couldn't resist that final fag.

*I have suddenly realised that the word 'fag ' means something entirely different
in American. In England a fag is the end of a cigarette, or another term is "dog end".
I put it in of course, as it was cigarettes over a long period that gave me cancer.*

*On one occasion, I coughed, dislodged a newly fitted valve, and swallowed it.
Luckily it made its way down into the stomach and not the lungs. With the dilator in place and driving with
one hand, I made my way into the hospital, and in the car park, wrote this note for Sister Barbara Wagstaff.*

NATIONAL HEALTH SERVICE PROPERTY LOST

By Len A.Hynds

Dear Babs, you must please forgive me,
I lost your Blom-Singer valve.
When I coughed it became free,
so I write, my conscience to salve.

I coughed and then I swallowed it,
to a darker recess it went.
Speechless, but anger made me spit,
such surroundings, it never was meant.

But please, instead of charging me,
can we wait until it's passed through.
To use as a spare, and quite happy,
if you want it for stock, as new.

Maybe you should warn Speech Therapy,
as a new branch of medicine is here.
So they can deal with ' Words Free '
that are now coming out of the rear.

~ Editor's Note: This was Len's very first Speechless Poet column for us back in November 2009. Worth re-reading certainly and a wonderful example of his talents for our many new members who are reading it for the first time. He's a real treasure! ~

Bits, Bytes and No Butts!



Frank Klett

Avoiding "Text Neck", Cheap PC's and Other Tech Bytes

Text Neck is a somewhat new and just recently diagnosed condition...caused by...you guessed it, holding one's head in a downward position for a long period of time...no, not caused by smoking! There are actual studies being conducted to help identify and hopefully resolve the issues that are arising from our new technologies.

The following article from CNET provides more info:

http://www.cnet.com/how-to/how-to-avoid-text-neck/?ftag=CAD3c77551&bhid=226895098013186124502399137427_62

You can even find apps to help you through this pain in the neck!

Amazon is adding even more convenience to our shopping needs...enter **Amazon Prime Fresh!** Newly launched **Amazon Prime Fresh** is a grocery/food ordering system that provides Amazon's Prime members with total grocery and food shopping services including same day delivery service. This service is being offered in limited markets for now, but will soon be expanded to the entire Amazon marketplace. **Amazon Fresh** is being offered with a 30 day free trial. After which there is an annual fee added on to your **Prime** membership fee for a total of \$299. This covers all delivery charges, except tips. The service offers food and other meal offerings from local markets and prepared meals from many of your local favorites.

To get more info and to see if you are in an area that is currently being offered this service go to:

https://fresh.amazon.com/MembershipBenefits?pf_rd_s=slide-4&pf_rd_p=2506664842&pf_rd_t=101&pf_rd_i=1&pf_rd_r=14JZST9Q6JJ2J98HATX7

Windows 10 has been out for almost a full year now and we are still finding new commands and uses for its many features. There is app for "**Contact Support**", **Quick Access for File Explorer**, and once again the **God Mode** option. **Bob Rankin** has rounded up the newest insights for Windows 10 and the ways we can make it work better for us. If you have never used the **God Mode** before Bob tells you how to set it up and make your

life with Windows 10 much easier:

http://askbobrankin.com/ten_windows_10_features_you_didnt_know_about.html?awt_l=CasIU&awt_m=lqL4EY_LweP6SL

In general, the current pricing for PC's and laptops has remained at a fairly affordable level. The manufacturers have taken the old ideas for marketing hot new features and cooled them down considerably. It seems they found out that the vast majority of buyers were no longer interested in the speed and flashing lights; rather the buying public simply wanted better value for the money they laid out. Add to that the vast improvements made in operating systems by both Microsoft and Apple have created a much more knowledgeable buyer. Today you can purchase a very capable laptop for less than \$300 and less than \$200 if you consider a Chromebook. All in all it is a buyer's market and this trend seems to be the tech marketplace for the next decade.

For all you Apple users, Google has finally broken the window to allow users to install Google products such as the Gboard for the iPhone and iPad; it is Google's newest keyboard for the Apple Community. As usual, the 3rd party add-ons for any product go a bit further to satisfy the needs of the users. Head over to the link below and check out the latest Google offerings for the Apple World:

<https://itunes.apple.com/us/app/gboard-search.-gifs.-emojis/id1091700242?mt=8&ign-mpt=uo%3D8#>

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