

# Whispers on the Web

A Monthly Online Newsletter for WebWhispers

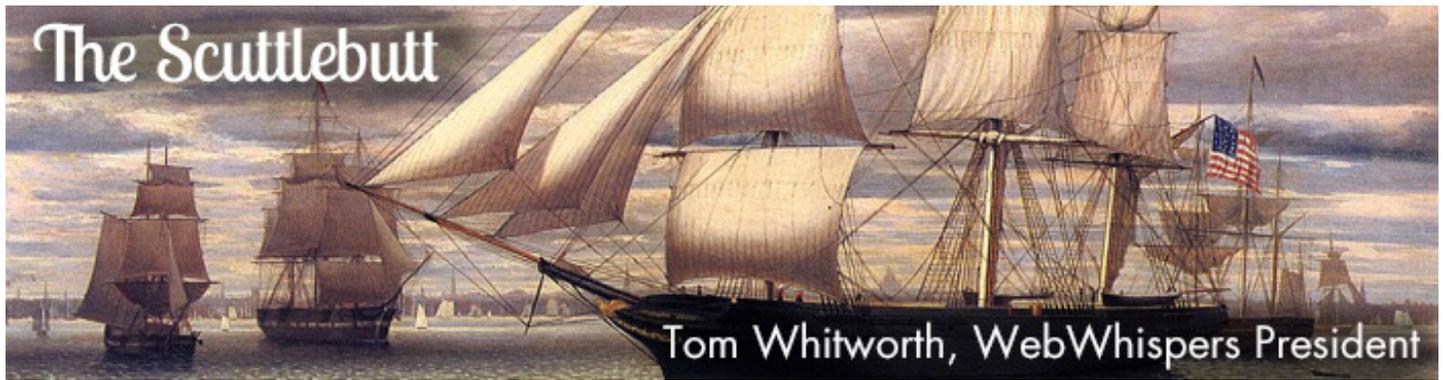
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## What Makes WebWhispers Work?

WebWhispers could not serve its purpose of “Sharing Support Worldwide” without our large network of volunteers, and others who support us. Each year, we hold our annual awards dinner as an opportunity to be together, honor those who have left us, and to express our gratitude to people who help make WebWhispers what it is. Though it has been tried several times, it is impossible to recognize everyone every year. This year, we selected from among those whose volunteer effort made a difference in WebWhispers, especially in the past year. Vivian Vanden Hogen received the first Janine Matoon Caregiver of the Year award. You can read all about it in Donna McGary’s column, “Between Friends” in the July 2018 issue of Whispers on the Web. Also, at our 19th WebWhispers Annual Awards Dinner, June 7 in Orlando, the following certificates of appreciation were presented.

**Volunteer of the Year**  
**Kim Almand M.S., CCC-SLP**  
**Editor-Voice Points**

For being a tireless advocate, compassionate educator and supporter for the head and neck cancer survivor community. For being willing to go the extra mile, put in the extra time and get the job done. For making a difference in the lives of so many grateful laryngectomees by believing in our mission at WebWhispers for complete recovery and rehabilitation for all. Thank you, Kim. We wouldn’t...we couldn’t be here without you.

**John Isler, III**

**Social Media Administrator & Laryngectomee Advocate**

There are people who endure a trying experience and recover as quickly as possible as if they are already yearning to help others on that same journey. John seems to find laryngectomees online and everywhere he goes. Patients, survivors, and caregivers seem to find him just as easily. They are greeted with a genuine smile, even online, a word of encouragement and, when possible, are directed to a source of information or help that they need. A friend to all in our community, John is the Pied Piper of laryngectomees and the ultimate advocate.

**Anne Ammenti**  
**Social Media Administrator & Advocate**  
**to the Lary Community**

Many volunteers and paid professionals do their jobs and do them well. Then there are others who take things a step further by seasoning their efforts with genuine passion for those they serve. It comes to them naturally. Authentic caring for others defines them. Anne is such a person. From her perspective as caregiver for her husband David for over twenty-five years, she is talented at helping those with a patient

in their care. Encouraging those facing surgery or recovering from it, is second nature. When people post online, Anne doesn’t just read words on a screen; she hears them from the heart of someone struggling or suffering and responds with the love of a sister or mother.

**Mike Rosenkranz, V.P.**  
**Social Media Pioneer**

A member of the WebWhispers Board of Directors since 2007, Mike managed our first entry into the world of social media. Under his direction, the WebWhispers Delphi Forum blossomed and grew into a vibrant online place to be for our community. At an age where most are not even into social media, he pioneered our arrival on Facebook, recruiting and training other administrators to address the pace at which the group grew. In both venues, his thoughts for the day, often multiple, are a source of encouragement and inspiration to all. Our senior statesman and yet a pioneer. His contribution to WebWhispers is second to none.

**Tom Olsavicky, Chief Moderator,**  
**Daily Whispers – Laryngectomy Support Digest**

For leadership, patience, and dedication in recruiting, training, and scheduling list moderators. For always being there for advice, guidance, and all those teaching moments, as any good parent would be. For keeping a watchful eye and for fixing things when they are broken. For being SUPER DAD!

**Volunteer of the Year**  
**Presented to Donna McGary,**  
**Managing Editor – Whispers on the Web,**  
**Loan Closet Custodian, Board of Directors**

Following years as Editor and writer for Whispers on the Web, Donna accepted the role of Managing Editor two years ago. When we needed a new custodian for the Loan Closet last year, she agreed to take on that responsibility, as well, though she already had plenty to do. As a board member, she is objective, honest, and always a voice of reason. Never one to settle for the status quo, in each of these roles Donna brings passion, creativity, and innovation, always making things better than they were.

We have jobs that take place every day and night, others that need taking care of once a month, and everywhere in between. We also try to have a backup for many of our tasks, so having volunteers on stand by helps, too. If you would like to help, let us know. [tmwhitworth@gmail.com](mailto:tmwhitworth@gmail.com)

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



## **“Did You Have Trouble Swallowing After Your Laryngectomy?”**

When I can swallow it is strictly liquid, Jevity 1.5. Otherwise it is peg feeding.

**Peggy Balle - New York, NY**  
2013/2016

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For approximately a month after I got home I had a tube through my nose into my stomach. I drank a lot of Ensure during that time. After that month I was able to eat things like Jello and mashed potatoes and anything soft for another month. Then I graduated to big people food and could eat anything I thought I could safely swallow. To this day I still get things stuck in my throat such as bread and chicken. If I take a couple of sips of water it goes down. That's my story and I'm sticking to it.

**Chris Pieper - Fond du Lac, WI**  
2012

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I was on a feeding tube for about 25 days following my surgery, which was March 23, 2016. I had difficulty swallowing for about three weeks after I went on food again but within that time, I was pretty well back to normal. Have not had any problems since.

**Joe Rook, Salt Lake City**  
2016

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My total laryngectomy was in April 2013. On every follow up visit with my surgeon I told him I am having trouble swallowing water but not food. His answer was, to him that did not seem a major problem. Then one time I told him some pita bread and chicken got stuck in my throat and I waited 10 minutes before it went down. He recommended an esophageal dilation. He set me up for the dilation but it did not affect my difficulty swallowing water or my occasional difficulty swallowing bread or chicken or dry crackers.

I told my swallowing troubles to a doctor at an IAL meeting. He said I should ask for a modified barium swallow test. My SLP arranged for the test. As I swallowed the barium mixed with various thicknesses of liquids, my SLP and the radiologists were amazed. They said to each other, “Did you see that? That is serious.”

I asked what did they see. My SLP said there seemed to be a mass obstructing my esophagus. She said I should get PET and MRI scans. Which I did pretty quickly. I heard from my SLP that the scan did not show anything obstructing my esophagus. I should see the surgeon for his explanation.

My surgeon greeted me and then he drew a sketch of my esophagus as he saw it on the swallowing test. It had a long narrow section in the middle third of the sketch. His sketch looked sort of like an hour glass.. He said the narrowing is due to the cricopharyngeal muscle. He explained that my cricopharyngeal muscle was longer than usual. He had cut some of that muscle during my original laryngectomy but my swallowing problem was due to some length of that muscle which does not relax properly during swallowing. He can section (cut) the rest of that muscle if I need improved swallowing.

He asked what I thought of the quality of my voice and of my ability to eat and drink. I answered my voice seemed decent to me and my swallowing is only a minor bother. If my quality of life is not impacted by the current situation, he would suggest putting off the surgery. If in the future my quality of life is negatively impacted, I should call him and we can reevaluate the value of this surgery. I agreed not to have the surgery.

One of the strong reasons why I thought it was better not to have the surgery at that time is that I did not want to disturb my esophagus on which I rely to make the vibrations by which I speak.

I asked what caused the radiologist to suspect a large mass. He said the indentation during swallowing would look the same if it were due to a large mass impinging on the esophagus or if it were due to an cricopharyngeal muscle that did not relax. He showed me on his sketch of my esophagus how that would be the case.

I afterward asked where with respect to the cricopharyngeal muscle did my TE puncture lie? I was told my TEP lies just barely above the cricopharyngeal sphincter. If it was below or even at the same level I would not have a very good voice.

Since then I have taken some liquid with every bit of food. If food gets stuck, I wait for gravity to pull it down or I occlude my stoma and breath out which sometimes help push the food back into my throat.

This whole episode gave me knowledge of my swallowing problem and thus some peace of mind.

**Jay Hauben - New York, NY**  
Larry since April 19, 2013

For me it was about 4-6 wks. Before I got my first TEP put in, I was using a syringe & put my liquid nourishment in that way. It's been over

5 yrs. now & I still have to make sure I chew my foods up a lot in order to swallow because they had to make me a new throat out of a muscle from my chest but other than that I eat whatever I want."

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**Gene Maddox – Columbia, SC**

Woke up with a feeding tube stitched to my nose. Got fed up with that nonsense after the respiratory specialist banged her gorilla paws on it for the umpteenth time in the first couple of days, but doc refused to remove it until 10 days out. Same amount of days he said I could go home if I was able to eat regular food. So the next time gorilla paws banged the tube I tweaked her snooze to let her know how bad it hurt when her clumsy butt hit that tube.

No, just kidding about that. I did complain to her supervisor and got a new tech and she was more careful.

Back to swallowing.

Tenth day after surgery I sent my gorgeous Vicky Sue over to the McDee's across the street from the hospital and get me a 1/4 pounder with cheese and fries for lunch because I simply could not stand to spend another day in the hospital.

I thought that 1st bite was never going to go down and I'm no sissy when it comes to pain. How can you be after being beaten silly with a tire iron? (Whole 'nother story, that) But that attempt at eating solid food brought tears to my eyes, but . . . being the mule that I am . . . I figured all that was needed was . . . another mouthful.

Took forever to eat that lunch (or so it seemed) and I was certainly glad she had the insight to purchase two large drinks with that order cuz it took both of them to help me 'wash' that chow down.

Doc came in just as I was finishing up and he put me on soft solids for supper.

Nose tube came out and I was discharged after breakfast the next day.

Since then I've been eating and drinking anything I want. Occasionally I encounter a brief swallowing discomfort, but tis nothing that a good swig of sweet tea or coffee can't overcome and it's back to chowing down.

Will be my 12th laryversary come Halloweenie this year. Still eating and drinking anything I wish with little or no trouble at all.

Just another reason I always say: "God treats me far better than I deserve."

**Troll - Jacksonville, FL  
October 30, 2006**

Right after surgery swallowing was, and I still have some days where it still is, VERY difficult. Right after surgery, all I could do the ol' hatcherooni was thinned out oatmeal or liquids. On some days after a couple of spoonfuls, I'd be absolutely stuffed and couldn't eat anymore even if I tried.

Some days, if I bent over, I could swallow and the next day THAT wouldn't even work. It finally got so annoying that I said something to the doc. He put me on a liquid diet until another doc said "dilation you silly goose neck". AHA, a whole new world. First dilation was a HUGE swallowing improvement for about a week. So I had dilations once a week, which got moved to every other week, and then every three weeks. Right now, I am a dilation a month and I'm a happy swallower. I can tell when I'm up for another dilation because the swallowing becomes a bit difficult. Expectations down the road...yearly dilations and then maybe a dilation here and a dilation there.

But it certainly made a WORLD of difference immediately -- for which I was/and still am thankful and grateful.

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**Lisa O'Farrell – Chicago, IL  
August, 2017**

No swallowing issues at all. Worked from day one. Can eat anything.

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**Ron Fonte – McMurray,  
2012**

Fed by tube after lary surgery ! I woke up with a feeding tube in my nose after my laryngectomy surgery. As I recall, I had to eat with that tube for about two weeks after my surgery. Then, they had me do a swallowing test (to check for swallowing ability, leakage, aspiration, etc) and I passed it, so they removed the tube, and let me start eating and drinking by mouth. Over the next year, I had 3 recurrences, and 3 more major neck surgeries, and 3 more times woke with a feeding tube in my nose, and it stayed there for anywhere from 5 days to 10 days after each of those surgeries. I had radiation to my neck in 2013, my laryngectomy in 2014, two recurrences surgeries in 2014, thyroid removal surgery in 2015, radiation again to my neck in 2015 (and chemo). I never got a feeding tube during my two courses of neck radiation (but should have during the first one - very painful swallowing).

So, I'm now 5 years out from my 1st neck radiation, and 3 yrs. out from my 2nd neck radiation, and I've always been able to swallow both liquid and food somewhere between great and decent. My esophagus was stretched one time - about 2015. If I try to swallow pills the size of a full size aspirin, that have sharp / square edges, they will get stuck in my throat and I have to just patiently and calmly wait for them to "melt" (5--15 minutes) before they will go down. (I can't die from this throat blockage, b/c I of course breathe through my neck, not my mouth/nose). --- Soooo, my swallowing is still pretty good, as long as I chew my food very thoroughly. I've thought about going ahead and having my esophagus stretched again, but will probably wait until my swallowing gets harder than it is now.

NOTE: A year ago, I had my GI Dr. try to do a balloon stretch, while he was doing a routine upper GI scope. My swallowing was "ok" at the time, but I thought he might as well try to stretch it a little while he's in there doing the scope. After I woke up, he told me he tried the balloon stretch, but was afraid of tearing my esophagus, so he aborted the attempt. I later told my ENT laryngectomy surgeon about this, and he said, "David, if you ever need your esophagus stretched, you come to me. I do these all the time on irradiated laryngectomies and I understand the tissue and I am NOT afraid of tearing your esophagus".

He convinced me that an ENT surgeon is probably a better choice than a GI doc for doing esophagus stretched on irradiated throats. (Perhaps it depends on which doc has the most experience with which type of throat procedures, throat surgeries, which has done throat reconstructions, which sees more irradiated patients, etc, etc).

I quickly got tired of the time and mess of using the big manually operated syringes to feed myself formula through my nose tubes. It was boring, messy, sticky, and your arm and hand gets tired pressing constantly on the syringe. I tried doing it really fast, to get it over with quicker, but that upset my stomach. So, I slowed down to a much slower feeding rate and felt better afterwards. So, b/c of the boring, tiresome mess of using the manual syringes, I got on eBay and bought me a (Kangaroo brand) feeding pump and some feeding bags - \$350.00, and a rolling stand (\$75.00) to hold the pump and bag of formula.

It was FABULOUS ! I just poured my feed in the bag, hung it on the rolling stand, attached the battery operated pump on the rolling stand, and pressed the start button. Then, I could sit down and watch TV, or walk around and push the rolling stand around with me, just like at the hospital. --- I made a 15 minute phone attempt to get my insurance company (Blue Cross) to buy the pump and stand for me, but of course they made it such a huge bunch of BS to go through that hung up and decided to just buy one myself.

**David Smith - Strawberry Plains, TN**  
**Class of 2014.**

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I had my Lary in February this year and at first I had a lot of difficulty swallowing. Six months on I can eat Shepard's pie jacket potato with cheese and mayo so things are improving. I don't think anyone eats normally do they?

**Elaine Payne - Blackbush Lane, UK**  
**2018**

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I was treated for pharyngeal cancer in early 2002 with 15 days of chemo and 31 days of two sessions of radiation each day. Over time the scar tissue from the radiation, the gift that keeps on giving, compromised my ability to swallow. I spent nearly two years with a feeding tube and several bouts of pneumonia. Breathing became more difficult and I had an emergency tracheotomy in late June, 2015. In late August, 2015 I had a total laryngectomy. Two months later I had an ultra valve inserted. I began eating and speaking

again and in January of 2016 I had the feeding tube removed. I have gained back the 30 pounds that I lost and am always hungry and ready to eat. I now use an Activalve and speak pretty well although it can be difficult to understand my speech during a telephone conversation. I can eat pretty much everything, although I find it difficult to swallow steak and lobster so I don't bother. It took time, experimenting and patience but life is good.

**Dick Spiers - Mashpee, MA**  
**2017**

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In introduction even though I have had more than my share of issues in the past months and still have cancer, I am divided in providing anything resembling positive experiences in consideration of those that have so many more challenges than I do. I have a 68-year-old neighbor who did not have a TL but who, because of radiation, has not had any food by mouth for over eight years and I know that there are many others out there with the same or worse issues. It is such a personal journey.

The choice is whether to provide positive encouragement or potentially inadvertently make someone feel worse about their own situation. My conclusion is that there is no definitive answer except to be sensitive in not being overly enthusiastic in representing your own story.

I have not had any problem with liquids since the initial surgery but have had difficulties with everything else. My opening dimensions are less than what is considered a stricture I'm told, but I have an area of stenosis that does not allow a scope to pass. In the beginning I got by with Boost plus, soup (usually without any solids), smoothies, scrambled eggs etc. If something got stuck it would take a lot of time to clear I've had to go the bed a couple of times without being able to clear the blockage.

A few months after initial surgery I had two base of tongue surgeries which set me back further. All in all I've lost over 50 pounds but that's OK. In fact everything is ok and I am so very grateful to be able to do what I can do. Despite previous radiation and surgeries, I still have a sense of taste and smell that varies from day to day but I have it. Leek and potato soup has been a godsend!

I started a dilation program about 4-5 months ago. Under a mild general anesthetic they insert balloons of increasing sizes and pump them up. Takes less than half an hour but from what I've read some people have issues like tearing etc. some serious.

I've had three without those issues. First one no real help, second maybe a little, third-definite improvement. If memory serves I was up to 13mm. Separately I had a TEP installed last September. By January it had rotated allowing the puncture on the back side to heal on its own and prevent replacement valve insertion. The third dilation opened the puncture up causing leakage. That combined with the fact that I was put on chemo for 18 weeks has delayed anymore dilations but only for now God willing. One of the collateral benefits of the third dilation is that I find it easier to clear blockages rather easily using a finger.

Even with dilation if I were to try and swallow a single kernel of

corn it would cause blockage. Eating is hit or miss and takes a great deal of time and tons of water but I can eat.

Amazingly by nibbling and chewing a lot I can eat a burger with roll and thinly sliced tomato as well as tuna and meatball hoagies. To eat half a burger or half of a six inch hoagie/sub takes 20 -30 minutes.

I hollow out the roll and toast. Hard is better than soft for me for items that are absorbent and can swell with liquids. My philosophy right or wrong is that for bread products of any kind if they get stuck I just keep flooding them with liquid until they breakdown and then use my throat to force them down. If it is something that will not eventually react with liquid, I use the finger and the gag reflex. I've gotten pretty good at the latter and remember I'm technically a rookie.

Restaurants cause a great deal of concern and planning and I mainly avoid them. Even with planning they are hit and miss. Before dilations I went out three times with only a couple of trips to the bathroom total. I had lentil salad, soup and flaky fish but also had potatoes.

After dilation I went out in Orlando at the IAL/WW event and ordered clam chowder (giving all larger pieces of clam to my wife) and tuna poke appetizer. I had to make five trips to the bathroom but luckily the private bathroom was next to our table. A week later I had eggplant spaghetti which was absolutely fine. Alcohol use increases the frequency of blockage greatly. I'd like to believe it's because it encourages me to try and swallow more than I should but it probably makes the new throat muscles less effective.

To that point my SLP originally told me that the flap taken from my forearm did not have the same muscles as the throat it replaced and that would affect my vocalizations and swallowing. However, subsequently my surgeon stated that the forearm certainly has muscles and that both should improve over time. Hopefully encouraging to those to whom it applies or may apply.

I will keep trying to get better at swallowing and as I learn more will be happy to report more if deemed to be helpful.

### **Tom Tully – Yardley, PA**

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Ten days after my laryngectomy I was still not doing a good job of swallowing, but was released from the hospital anyway. I had a primary puncture for a voice prosthesis so my feeding tube was through the puncture and my wife and I did the feeding through that while I gradually relearned how to swallow. That did not take more than a few added days.

Following that, I had no swallowing difficulties for over twenty years. In the fall of 2015 I began to have difficulties swallowing pills. Following some back and forth with my ENT, I consented to have an esophageal dilation done in January 2016.

The procedure seemed to go well, but about five days later I began to have problems and was found to have a tear in the esophagus that developed into an abscess and a fistula into the area beside my stoma. I went through a week in ICU, several procedures to clean out the abscess,

several more weeks in the hospital and a month in rehabilitation. It was three months before I got rid of a laryngectomy tube and had my TE voice back and was able to eat solid food. I have not had any further swallowing problems, but certainly caution anyone to be aware of all factors when considering esophageal dilation.

### **Carl Strand, - Mystic CT Laryngectomy 1993**

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As an adult I have always had a difficult time swallowing large pills, however swallowing food was never on issue. I do tend however to eat slowly, take small bites & chew thoroughly. After my surgery in 9/2016, I had several occasions where things like unbuttered bread, French fries, rice, chicken breast & raw veggies would get stuck. Since we breathe out of our neck, we won't choke to death.

I once had a piece of uncooked celery caught in my throat overnight. Swallowing progressively got worse & I had to crush even the smallest of pills & totally avoid any of the above mentioned foods. On 4/06/2018 I had esophageal dilation performed by the ENT doctor/surgeon who had performed my total laryngectomy. Based on other Lary experiences, I recommend an ENT surgeon as opposed to a GI surgeon. Normal opening for swallowing is 42, mine was 28, surgery increased to 36. I still eat slowly, take small bites & chew thoroughly, however I can eat anything I want.

### **Cyril Due eke – New Baltimore, MI A very blessed Lary, Class of 2016**

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Thank God have never had any swallowing issues since my surgery. I can eat anything I did before and consider myself very lucky. My only regret is I can't smell it but my wife always makes a point of saying how good my cooking smells!

### **Mark Stoughton – Sanford, NC 2016**

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Yes my Laryngectomy affected my swallowing. It seems like when I swallow I get a lot of air along with whatever it is I am swallowing. I then sometimes get the hiccups from I am guessing all the air. I also seem to have more trouble moving the food to the back of my throat in order to swallow. I sometimes feel like I cannot get my mouth to open as wide post surgery. I just try to cope with these difficulties and hope they will improve with time.

### **Tom Bohrer – Pleasant Plains, IL May, 2018**

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Following my initial surgery and my doctor's ok to begin a soft diet, I had minimal swallowing difficulty with most moist food. Later, though, radiation treatments so impaired my ability to swallow that my peg tube wasn't able to be removed for 8 months. Finally, an esophageal dilation was tried, followed 2 weeks later by a TEP puncture. I could speak in a very low voice immediately, but

I noticed that it was more difficult to swallow pills or food unless it was pureed. The food and pills would get caught in my narrowed esophagus, so I would use the button on my HME to help dislodge either the food or a pill by forcing air through that space. Or at times, a mashed banana and water would help the food slide down.

Different sized prostheses were tried, as well as 2 additional unsuccessful dilations performed, and as my speech worsened, my Voice and Swallowing doctor decided to remove the prosthesis with the intention of placing a new puncture in an area that was not so strictured. I began using an electrolarynx as the puncture healed and have not returned for a new puncture because I'm able to eat anything and am understood easily by most people.

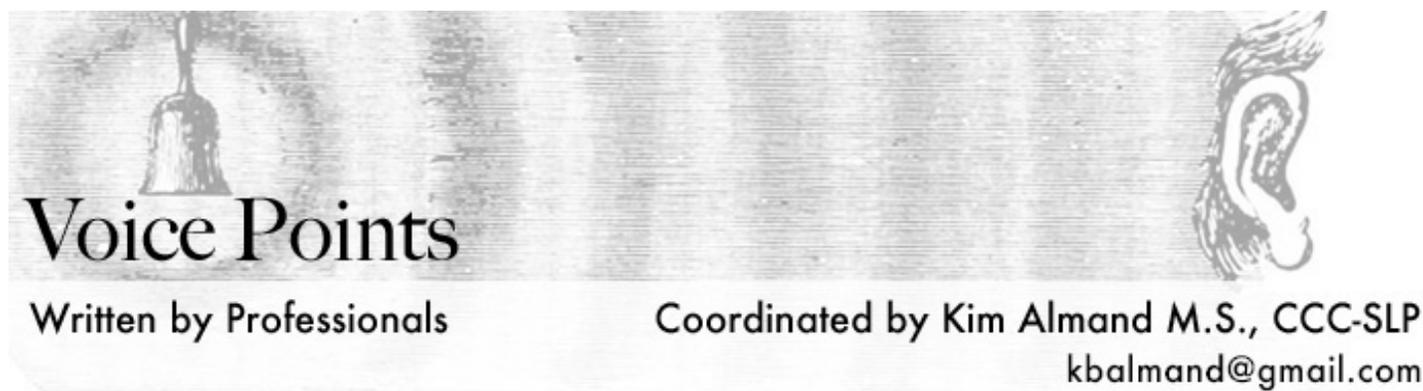
It is 3 years later and I'm still relying on my electrolarynx to speak.

I have decided that I am able to eat most food if I take small bites, chew forever and chase it down with lots of water. If I'm with a

group of people at a dinner, I finish eating when they do and take the rest of my food home with me. Just remember that your food is now moving from your mouth to your stomach mostly by gravity; so remember to sit up straight and stretch your neck upwards to aid in the flow of food. For many, this is not possible and you must rely on a peg tube to receive nutrients, so I consider myself a most fortunate lary.

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

## **Next Month's Question: Did you have a caregiver during your recovery and if so how important was she/he?**



### **Maximizing Swallowing After Total Laryngectomys**

Swallowing problems (dysphagia) after total laryngectomy may be temporary or long term. Risks of dysphagia include malnutrition, limitations in social situations and reduced quality of life.

The laryngectomy procedure involves complete surgical separation of the respiratory and gastrointestinal tracts. For this reason, the laryngectomized individual does not risk aspiration of swallowed material. Instead, dysphagia following total laryngectomy is mostly characterized by problems with propulsion of material through the "new" post-surgical swallow passage referred to as the neopharynx.

Videofluoroscopic evaluation of swallowing conducted by an experienced speech pathologist is a critical component of post-laryngectomy

rehabilitation. Not only does this dynamic radiographic procedure provide objective evidence regarding swallow function in this unique patient population, it affords the speech pathologist an opportunity to introduce compensatory strategies and consider specific interventions while the patient is being evaluated. Some strategies are considered indirect interventions (not actual "exercises"), while other interventions consist of direct exercises "customized" to a patient's specific swallowing disorder.

### **Strategies and Exercises to Maximize Bolus Propulsion**

*\*Note: these types of interventions are evaluated for usefulness by the SLP during the swallow x-ray*

- Tongue base retraction exercises
- Head rotation
- Effortful swallow

## **General Strategies to Maximize Swallowing Efficiency**

- Sit fully upright while eating/drinking
- Remain upright for at least 30-45 minutes after mealtime
- Alternate food and liquid consistencies to help “wash” foods through the neopharynx
- Alternate food and liquid consistencies to help clear residue from neopharynx
- Swallow multiple times for each bite of food

## **Diet Modifications**

- Avoid tough/hard solids
- Avoid “sticky” foods
- Moisten dry/crumblly foods with sauces, gravies

For patients undergoing radiation treatment after total laryngectomy, a potential problem is lack of saliva (xerostomia) which can greatly impact oral manipulation and propulsion of food. Diminished sense of smell is very common after total laryngectomy since transnasal airflow has been removed as a result of the surgery. Diminished sense of taste may also arise as a result of chemotherapy, radiation or surgical resection. All of these factors can impact appetite and result in reduced food intake and poor nutritional status during a time when optimal nutrition is critical.

## **For Patients With Xerostomia**

- Maximize hydration with decaffeinated liquids
- Consider using artificial saliva and oral lubricants (confer with otolaryngologist for recommendations)
- Decreased Sense of Smell & Taste
- Add spices to food
- Use condiments with food
- Experiment with a wide variety of familiar and unfamiliar foods to determine likes/dislikes

## **Dysphagia Requiring Medical or Surgical Intervention**

Scar tissue can create a stricture or significant narrowing in the swallow passage after total laryngectomy. The problem might be temporarily relieved with stretching procedures (dilatation). This is only done under the care of a physician. A surgical procedure might eventually be necessary to release the stricture. Some patients may have a

fold of tissue (pseudoepiglottis) at the base of the tongue related to the surgical closure at the time of total laryngectomy. The pseudoepiglottis may form a pouch that collects food or liquid, resulting in effortful swallowing when the patient attempts to clear the material. If the pouch is large enough, a surgical procedure might eventually be needed to fix the problem.

## **Conclusion**

It is essential for speech pathologists to discuss potential for dysphagia during the pre-operative counseling session ahead of total laryngectomy. Speech pathologists must also advocate for the videofluoroscopic evaluation of swallowing during the post-operative rehabilitation period. Dietitians should be viewed as valuable members of the post-operative team, not just immediately after surgery but over the long term. Patients are strongly encouraged to pay close attention to their swallowing so they can alert health care professionals to any new or persistent problems related to ingestion of food and liquid (including weight loss) so that appropriate evaluation and treatment interventions can be initiated as soon as possible.

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**Carol Blossom Stach, MA, CCC-SLP, BRS-S**

**Michael E. DeBakey VA Medical Center  
Houston, Texas**

# Dear Lary

Noirin Sheahan

## **From Outcast To Hero: Changing Social Attitudes Towards Disability**

Most of us are aware of how much we needed our friends and family to help us recover after laryngectomy. Especially in those early days when we were suddenly learning to live without our natural voices. My nerves would be jangling with some unnameable fear before visiting hour, but one smile from my visitor lifted the cloud. Suddenly I would be confident that I could live well with laryngectomy. I had never dreamt how much reassurance I would need to cope with life without a voice.

My operation was at the end of July and I was still in hospital when it came to the all-Ireland football final on 22nd August. Dublin were playing Mayo and there was great excitement throughout the ward. One woman had hired a TV for the occasion which had been placed at the foot of her bed and in the early afternoon a group began to gather round to watch the match. I hadn't attempted to socialise with other patients since the operation but decided to bite the bullet and join in. I gave a little wave of salute as I approached but no one made any response. In fact the group seemed to go quiet when I joined them. I felt horribly self-conscious. The thought "No one wants a mute around when they're trying to enjoy themselves" ran through my mind. I only waited a few moments before quietly slipping back to my own bed.

Perhaps it was my unacknowledged fear of rejection that somehow dampened the group energy. Unacknowledged fears tend to bring out the worst in situations. The one good thing about that first attempt to socialise was that it showed me my fear of social isolation, of being an outcast.

Luckily I had a mindfulness practice to help me acknowledge that fear rather than become totally stymied by it. During my next outings I could then follow Susan Jeffers' advice to "Feel The Fear But Do It Anyway". Although I often felt afraid, I was always pleasantly surprised at how friendly people were. Usually they went

out of their way to help me get whatever I needed. I had never really reflected on it before laryngectomy, but now I started to acknowledge the kindness behind society's positive attitude towards disability.

This wasn't always the case. Even in my own family there is the story of my grandmother's brother Tim who had a lame leg. He once tried to visit her after she married, but she wouldn't let him in. She didn't want him 'showing her up' in front of her new neighbours. Sounds appalling to us nowadays, but a hundred years ago there was widespread superstition that disability was a sign of God's wrath. So the person, and their whole family were stigmatised, thought to be cursed for their evil deeds. Naturally my grandmother didn't want to pass that burden on to her own children.

Luckily my grandmother's sister was not so overwhelmed by that superstition, and Tim was welcome in her home and managed to make a living for himself as a tailor.

Over the years since laryngectomy I've often reflected on this story and realised how much of my present quality of life is due to our present-day belief in the rights of disabled people to dignity and respect. As a salute to all who have smoothed our post-laryngectomy path, I thought it would be useful to record some of that development here. I'm no historian but a few hours with Google yielded the following information.

Early history isn't encouraging. I learned that the ancient Greeks considered sick people as inferior, and Plato recommended that the deformed be put away in "mysterious unknown places". During the 16th century, Luther and John Calvin indicated that persons with disabilities were possessed by evil spirits – this is the kind of thinking that led to my grand-uncle Tim being rejected by my grandmother. Even up to the middle of the 20th century we had the practice of eugenics, where the disabled were subject to marriage prohibitions and forced sterilization.

We have to thank Louis XIV of France (the Sun King) for leading society in a more compassionate direction during the latter half of the 17th century when he commanded the construction of hospitals and homes for disabled soldiers. Prior to that injured soldiers returning from war were often rejected by their families and reduced to begging for their needs. Perhaps Louis was worried that this would deter younger men from joining his army, or perhaps his motives were nobler. One way or the other he built “Les Invalides” in Paris to provide care and shelter for disabled soldiers. This caught the imagination of other royals and soon afterwards Charles II of England followed suit and Chelsea Hospital opened in London in 1691. A more benign, caring attitude towards disability began to take root.

During the 20th century, the numbers of disabled people increased dramatically following the first and second world wars. Alongside this, medical advances were allowing people to live longer despite illness and disability. But disabled people were still marginalised – disability was seen as shameful; the disabled person was taught to accept meekly whatever care they were given and not to rock any boats.

The change in attitude in recent years is in large part due to Ed Roberts, born in California in 1939. He contracted polio when he was just 14, and returned home from hospital paralyzed from the neck down except for two fingers on one hand and several toes. According to Wikipedia: “He attended school by telephone communication until his mother, Zona, insisted that he attend school once a week for a few hours. At school, he faced his deep fear of being stared at and transformed his sense of personal identity. He gave up thinking of himself as a “helpless cripple,” and decided to think of himself as a “star.” He credited his mother with teaching him by example how to fight for what he needed.”

Ed later developed the Independent Living Movement. Rather than feeling ashamed of disability, he argued the need to celebrate the courage required to live with physical / mental limitations. His movement coincided with the new wave of veterans returning injured from the Vietnam War. Their energy galvanised into the disability rights movements and a number of U.S. disability groups emerged in the 1960s. These groups were able to tap into the growing consciousness of human and civil rights championed by people like Martin Luther King

and Betty Friedan. The disability rights movement broadened the civil rights agenda to demand that society provide the supports needed for disabled people to live independently and with dignity. There is a video of the landmark disability rights protests of 1967 in Washington and California which captures the spirit of the times: <https://www.meriahnichols.com/the-disability-rights-movement/>

As a result of the pioneering work of US disability groups, most societies nowadays are respectful towards disability. It's standard for taxis, public transport and buildings to have wheelchair access. While these changes don't directly impact on those of us with speech problems, we benefit from society's more positive attitude. Apart from my first unhappy social outing, I can only count three or four times I've felt unwelcome out of hundreds or even thousands where I've been treated with respect – often getting a good dollop of extra help when people realise my difficulty in speaking.

I'm always grateful to all who support my mindfulness practice for helping me accept laryngectomy. But I also need to thank Ed Roberts, his mother Zona, the injured Vietnam war vets and all who changed social attitudes towards disability. They have played a huge part in restoring my confidence. It's humbling to learn how much of our sense of self depends on how others view us. If my laryngectomy operation had happened a hundred years ago, and even if there was an electrolarynx for me to use, no doubt I'd have learned by now to stay quiet and use it only to answer questions not to ask them. But thanks to the 1960's rights' movements I now go about my business much as before.



## Our Caregiving Journey

Hi, my name is Viv Vanden Hogen and my husband is Jeff. We live in Darboy WI.

In 2005, Jeff had a total laryngectomy due to a history of thyroid cancer, I would like to share a little bit about our caregiving journey. I'm going to begin by saying that caregiving is not an easy job. It is very demanding, and your emotions get high, but you have to hang in there together! Jeff made it easy with his positive and upbeat attitude. He was very proactive with his own care and needs. We did have our ups and downs on some issues but once we realized that we were a team going through this life crisis together and having peace of mind that there was light at the end of the tunnel made it a whole lot easier on the both of us. On one of my depressing days I thought about our marriage vows "for better or worse until death do us part" and I thought you know I did not sign up for this but then again neither did Jeff. So, we worked toward our goal of getting Jeff back on track by finding a happy medium in the process which turned out to be a win situation for the both of us.

Too often when you are a caregiver you neglect your own health and well-being and put your needs on the back burner. When you take care of yourself both of you benefit.

You have to be very careful that you do not run the risk of caregiver burnout, so you have to learn how to deal with different emotions, especially feelings of anger, guilt and depression.

I had to have patience and compassion in understanding what Jeff was going through along with providing emotional support as needed. Lots of times I had to bite my tongue with his negative comments when I was doing my best at the time. Walking out of the room really helped!

When going through this journey you lose some of yourself

and your well-being along with your independence and freedom. You just can't jump in your car and go shopping or out to lunch with the girls knowing that Jeff was home and you were worried. I learned to step back and smell the roses and did some of the things I loved to do like reading a good book and have coffee with my sister and go out for walks. Being that Jeff was so independent we did not need a family member to come over.

Caregiving is a stressful job and many of us are not cut out for it but we manage and do the best we can. It includes assisting with personal care, preparing meals, shopping, housework, laundry, running errands, going to doctor appointments, overseeing medications and coordinating visiting nurse visits.

For me caregiving for Jeff gave me a sense of accomplishment that we could work through this life crisis together. We did attend a caregiving support group. They are very beneficial because you feel less lonely or isolated when you know someone else is going through the same thing and they can feel your pain. You will be able to open up and share your concerns along with having your questions answered. It reduces stress, anxiety and depression. It is a place to meet new friends and be able to socialize.

In closing I would like to give a few words to ponder:

Life is not the way it is supposed to be. It is the way it is now during this most difficult time. The way you cope with it is what makes a difference.

Your patient may not remember much of what you said to them or told them to do but they will always remember how you made them feel.

Caregiving is being there when you want to be someplace else.

And finally: Not all of us can do great things but we can do small things with love.

# Between Friends

Donna McGary

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

Photo CC by Cusack5239

## Being Your Own Caregiver

We have been giving some well-deserved attention to the caregivers here lately. They are often the unsung heroes of our journey. But as we continue to recognize the unique issues they face as they stand by us (see our new column Stand By Me for firsthand accounts) I want to start another discussion.

What about those of us who are our own caregivers? Not all of us have family or close friends willing and/or able to step in and help us out when we are struggling. Maybe we are unwilling to ask for or accept help but regardless some of us may really have to fend for ourselves....or think we do anyway. That can be a tough and lonely place to find yourself in.

But for some of us being alone is how we best cope with challenges. A while back I learned of a new way to distinguish between an introvert and an extrovert. I had always assumed the bubbly, outgoing, talkative types were extroverts and the quiet, shy, unassuming types were introverts. But that's too simplistic it turns out. You are an extrovert if you need people, energy, excitement, stimulation to recharge your batteries. Introverts need quiet, alone, "down" time to recharge.

And that made a LOT of sense to me. I love people, love the energy of crowds, am a talker (even w/ an EL, as my Dad famously said, "That didn't even slow her down") and obviously have no problem being a public spectacle as anyone who witnessed my neck-hold on "Lil Bro Tom" at the recent WW Awards Dinner could attest.

But....when I'm struggling, either physically or mentally, I "go to ground". Actually in my circle we call it "going under the garage" like what an animal does when it is hurt or sick. Turns out I am an introvert, which means traditional methods of caregiving just don't work for me. I have to be alone and sort things out myself. If I need your help I'll ask for it but fussing over me will make me crazy.

That is the beauty of WebWhispers. We actually can be all things to all people. You need to ask a specific question, we can help. You want to express your shock and disbelief.... we will listen and understand. You want to cry, we will give you a shoulder. You want to brag, we will give you a fist pump. All from the quiet anonymity of your living room.

You need to say nothing at all but read and know there is a community out there who has your back when, and if, you should need us. You can "lurk" as I do, meaning I read each and every post both in WW and several other blogs I follow but I feel no compunction to respond. I am fine being just where I am. I am taking care of myself my way... and hopefully WebWhispers helps you take care of yourself your way.



# From the Archives

*I first met Dennis and his wife as we traveled together in the hotel shuttle to the airport after the 2006 IAL annual meeting in Schaumburg, IL. I was struck by his terrific TEP voice and surprised to learn he was a newbie. As we chatted I mentioned I was always looking for writers for the newsletter and I received this a few months later. It is still one of my favorites. His sense of humor and “can-do” attitude still make me smile. I hope you enjoy it as well!*  
~Donna McGary~

## **Just Your Basic Plumbing Job**

*Dennis in Idaho*

When I was told I had cancer in my neck, I didn't realize how easy it would be for me to understand what was needed to save my life.

When the doctors said “laryngectomy”, I said, “What? What is that?” We were told the primary tumor was on my voice box. So they would remove my voice box and I would have a hole in my neck to breath through. They said if everything went well, I could have a TEP installed in my throat that would allow me to talk.

We were given a book called Self Help For The Laryngectomee and sent home to think about it. After crying, getting mad, asking “why me?” and trying to deal with all the other thoughts that shot through our minds, I remembered the book.

After the initial shock wore off and I looked through it, I realized this was my only chance of living past 52 years old. My father died of cancer at 59 years old and I thought he was young. Now I was 7 years younger facing the same thing.

A year before I had gone through three rounds of chemo and 37 IMRT radiation treatments. I understood the theory of how these treatments might work and I also was told all the damage they might do to my body. But, there was a lot of maybe it will damage this and maybe it will kill this and maybe, maybe, maybe. As disappointing as it was to be told about needing a laryngectomy, this surgery made perfect sense to me.

You see, after being in the plumbing and pipefitting industry for 35 years, I could see they were going to remodel the plumbing in my throat, to cut the cancer out!

I had installed oxygen and vacuum lines in hospitals. So I understood how the suction and oxygen lines worked. When I got back home, I bought a portable suction machine. (\$250.00) I felt if this is how I'm going to live out my life then I wanted the luxury of having one to help keep my stoma clean.

When the TEP was explained to me, I said, “It's a check valve. I have installed 100's of them on water lines”. A check valve is like a piece of pipe with a disc in it that will open when pressure runs through it in one direction and will close when pressure tries to go the other direction. So when the disc in our TEP gets dirty with anything, it will not seal and leaks.

Now the joke at home and at work is I have a check valve in my neck. When it leaks, I can say my check valve is leaking and everyone understands. If it gets stuck and I can't talk, I just say my check valve is clogged up.

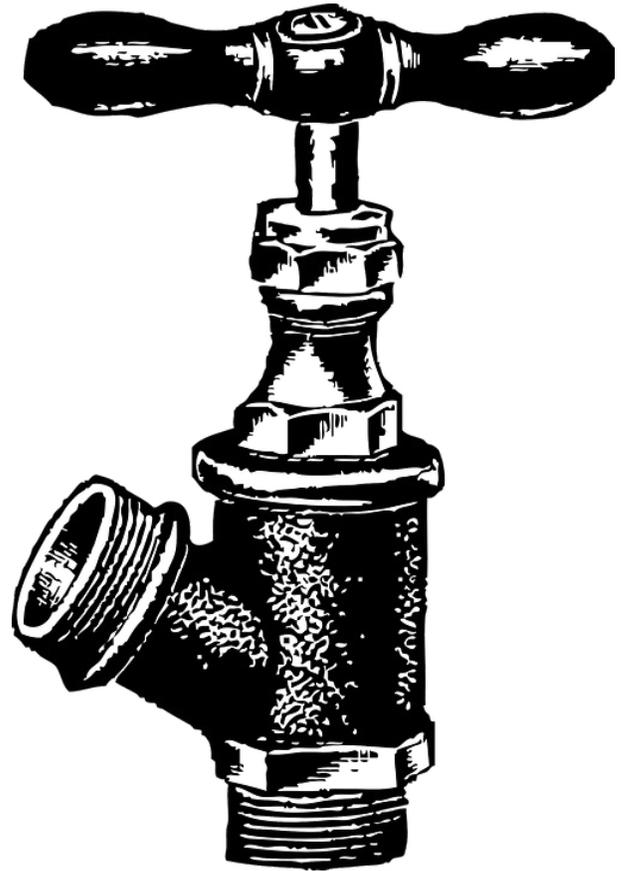
Have you heard of the old saying when someone is choking, “it went down the wrong pipe?” That doesn't happen to Larys anymore unless they have a

TEP. I also learned that after I eat, if I bend over or lay down the food tries to flow out of my stomach. Back to basic plumbing.

Before they cut out our voice box, the vocal cords, in addition to giving us our voicing mechanism, also worked like a flapper type valve to direct the air into our lungs and our food into our stomach. As we all know, now we have one pipe that goes straight to our lungs and one pipe that goes straight to our stomach.

Just like we have to be careful not to let anything fall into our stoma, because it goes straight to our lungs, we also need to understand that when we put something into our stomach, there is no valve in that pipe to hold the food down in our stomach.

When they do a laryngectomy on some one, they cut out the complex piping system in our throat and leave us with a simple two-pipe system. So when I became a Lary, it was easier for me to understand what this surgery did to my body by just thinking of it as remodeling the plumbing in my neck.



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