

WebWhispers

Sharing Support Worldwide
Throat Cancer and Laryngectomy Rehabilitation

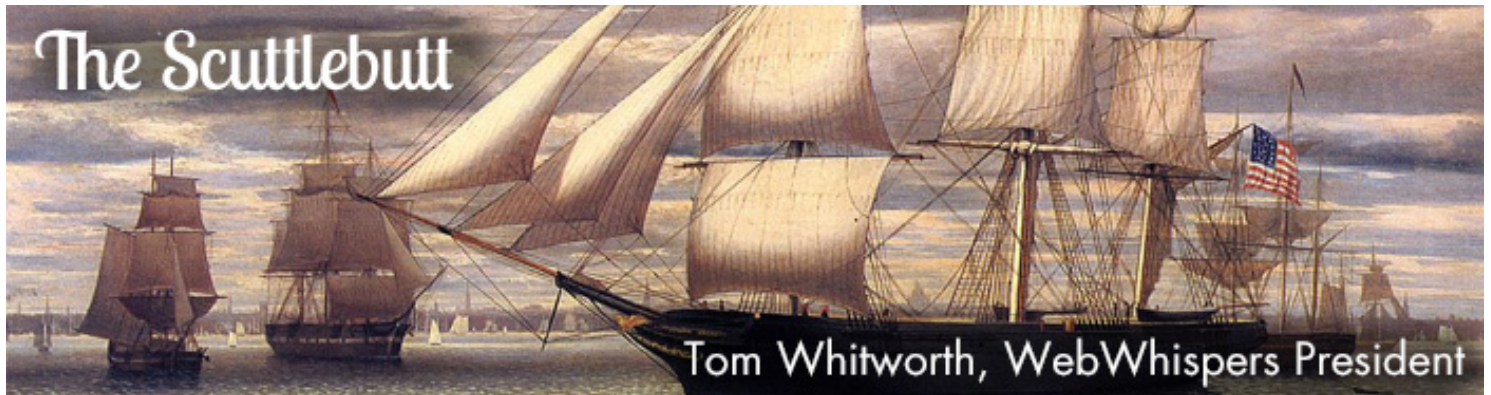


December 2017

| Name Of Column | Author | Title | Article Type |
|-------------------------|---|----------------------------------|--------------------|
| The Scuttlebutt | Tom Whitworth | Gratitude For It All | Commentary |
| Speaking Out | Members | Stoma Care | Opinion |
| VoicePoints | Brienne Ruel, M.A., CCC-SLP, Kathleen Huber, M.S., CCC-SLP | Voice Prosthesis Failure: Part 2 | Education-Med |
| Dear Lary | Noirin Sheahan | Ellie's Electrolarynx Concerto | Commentary |
| Between Friends | Donna McGary | Chronicles of A Library Robot | Commentary |
| My Neck of the Woods | Tom Whitworth | V.A.: Healthcare & A Little More | Member Experiences |
| Bits, Bytes & No Butts! | Frank Klett | Getting Around In Our World | Computers |
| From The Archives | Len A. Hynds | A Christmas Story | |

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

COMMENT HERE
FEEDBACK



Gratitude For It All

This really is my favorite time of the year and always has been, even though I admit each of the other seasons has its own significance, too. As if there were not enough Fall memories already, it seems the list of events for the last four months of the year continues to grow. If ever I need a reminder of the benefit of ups and downs, all I have to do is wait until this time of year. It really is somewhat of a roller coaster ride.

I was born November 20, 1957. My mother and I were kept in the hospital longer than normal because she had the Asian Flu. I was small but ready to go. Other than that, I don't remember a thing. Our house caught on fire around the same time in 1960 when I was not quite three years old. I still remember that so vividly that I could paint the scene, if only I had talent in that area. I have no such skill. My first surprise birthday party came in 1963 and though it is a source of fond memories, it actually scared me. The terror had something to do with all the neighbors jumping out from behind doors and other hiding places in our house and yelling 'HAPPY BIRTHDAY!' at the top of their lungs. I wasn't accustomed to that. Two days later, President John F. Kennedy was assassinated. I cannot imagine ever forgetting my feelings when that happened. I absorbed the sadness, raw grief, and fear that surrounded me during the hours and days that followed. Those emotions are just as alive today when I remember that horrific tragedy.

Fast forward a few years....My grandson Owen was born in October 2010 and his sister Lydia arrived in September 2011. My dad called them Irish twins. Of Cherokee, English and Irish decent, I guess he could use the phrase if he wanted. I finished graduate school a month later. Around the same time in 2012, my voice began to falter, originally in and out, then consistently downhill. The last time I had sung truly well had been at my daughter's wedding in June of that year. It wasn't until September 2013 that I was finally diagnosed with cancer. Why so long into things, I will never know. Radiation and chemotherapy began in October. My last radiation treatment was on Monday, November 18, followed by my final infusion on Tuesday, and my 56th birthday on Wednesday. The following year, my dad passed on the 17th as I sat alone with him. November 19 of this year, my second true surprise birthday party took place. No "gifts" had been allowed, which was awesome. The best we can give to anyone is ourselves and many dropped in that day to do so. We celebrated my fourth year of new life and that I made it to age 60 in one piece. Well, almost. That day, I pondered all these other events and what each means to me. If I ever forget the third week of November, somebody shoot me and put me out of my misery. I would have to be in sad shape.

I claim and in a sense, truly embrace each of life's events. These and many others in between make me who I am. I'm not one to brag, but I do happen to like myself at least a little. I know what I've been through and what it has done for me. I honestly believe the painful or challenging events in life are our source of empathy and compassion. Gratitude for the good and bad spurs in us volunteerism, service to and love for others.

Gratitude is not only the greatest of virtues, but the parent of all the others. – Cicero (106-43bc)

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



How Do You Care For Your Stoma?

The answer to all your questions is no. Well not really. I do cover my stoma with a bandana or a "Buff". Other than that I don't humidify or irrigate. I don't use a lary tube or an HME. I have never needed a shower guard. I use regular tissues or toilet paper to deal with mucus.

I don't necessarily recommend this approach for everyone, but it has worked for me for the last 16 years. I expect that being meticulous about stoma care is probably a better choice from a health perspective, but the time and expense did not seem worth it. Since my surgery I have only had one lung infection requiring antibiotics, and that was because I was on chemotherapy for a separate cancer. I live a very active lifestyle, and my breathing is only an issue when climbing very steep hills.

While if I had been meticulous I probably would be climbing hills with ease, the flip side is I would have spent a small fortune on supplies, and more importantly spent a vast amount of time being a "cancer survivor" instead of just living.

**Kevin Berry – Barrie, Ontario
Class of 2001**

For me, stoma care is fairly easy. I use an alcohol pad to clean around my Vega and stoma. Pink bullets are great to irrigate and to moisturize the lungs. I have an inexpensive humidity gauge in my bedroom and like it to be around 60 %...never lower than 50 %. A cool mist humidifier is always handy in my bedroom. We do live on a lake in Texas so I watch for too much humidity. An Oval cover and HME from Atos works well for me during the day; however, I don't wear anything on my stoma at night to give my sensitive skin a rest from the

adhesive. A clean washcloth is by my pillow each night for rare coughing. Tissues are dangerous when drowsy as they can come apart and be sucked down lungs. Not the end of the world ...just stay calm, breathe shallow, use a pink bullet and cough a lot and be more careful the next time. My purse always carries a clean brush, fresh covers and HMEs, alcohol pads and the red tube for TEP accidents (which has never happened). Nothing extravagant, just being prepared.

Marian Cure - Cedar Creek Lake, TX

2009

I have covered my stoma with a foam filter 24/7 at home and away, awake and asleep for almost 19 years. When I go out, I wear a stoma cover over the filter. It keeps my stoma humidified and free of foreign objects. I voice with an EL.

I have never had a mucus plug and use a saline bullet as needed.

Mike Rosenkranz – Plantation, FL

1-6-99

I have a Blom Singer Advantage voice prosthesis and a Blom-Singer Hands Free Valve. I have had the hands free for nearly all of the 24 plus years since laryngectomy. So, I use the Humidifier Cap and the replaceable filters for the cap. I also wear a Romet woven stoma cover in public, not because I need the filtration, but I think it is less "in your face" for people not familiar with laryngectomees.

I use Blom-Singer PVC housings with double sided tape disks. I keep the housing on until it begins to leak and then redo the seal. I have not had a skin irritation problem to speak of over the last 24 years. I do not use an adhesive remover, they irritate my skin quickly and severely.

I sleep with a Blom-Singer Humidifier holder during the warmer months and use a large volume nebulizer with a trach mask in the winter months.

The above combinations keep mucus production in check and I do not get a lot of dried secretions around my prosthesis or stoma opening. What I do get can be removed with a long handle forceps (tweezers) in most cases. Occasionally in cold weather I do need to use a gauze pad moistened with hydrogen peroxide to loosen secretions around the stoma opening. I do not use any ointments or lubricants around my stoma.

I use a container of saline and the flushing pipette that comes with the voice prosthesis to flush my prosthesis. Since that liquid goes into my esophagus, I do not worry about maintaining sterility. Very occasionally, again in cold weather, I need to irrigate the trachea to help with clearing more viscous mucus. I use 5 ml sterile saline bullets to do this. I do not want any non-sterile substance near my lungs.

I have a cold mist humidifier in my bedroom year round. It uses distilled water that I produce myself with a distiller. It is set at 45 percent relative humidity and almost never runs during the warmer months. During cold weather I will also run a second humidifier in the living room, also set at 45 percent relative humidity.

I have not used a shower guard since one month after coming home from the hospital. If you keep the shower at or below the shoulders with your back to the shower and let it run off your head and the point of your chin when facing the shower, you will not get any water in the stoma. If a drop or two does get in, you will cough it out instantly. I do not use a laryngectomy tube and have never needed one.

I clearly remember the abundant mucus, mucus plugs and other issues right after surgery. I coped with these issues for six months until I got the hands free valve. The reduction in mucus production took a couple of weeks, but all the hassle of a hands free valve or a HME filter are definitely worth it in my opinion.

It's been an interesting, enlightening and occasionally frustrating journey over all these years. But, life is good, I do almost everything I did before laryngectomy. As I age, I do see losses in stamina and strength, but push myself as much as I can. I don't know how many years more I will be granted, but I look forward to every adventure as it comes.

Carl Strand – Mystic, Connecticut

Radiation - Summer 1991; Laryngectomy - February 10, 1993

Most of the time I cover with a foam stoma cover, when going out for dinner, visiting with friends, golf, etc. I use stoma button with HME and Hands Free Valve and it is not unusual for me to sleep with no stoma cover. I live in Florida and humidity is only a problem occasionally in winter and sometimes use a cool mist room humidifier at night. Have never used a shower guard, just bend over when washing my hair. I learned a long time ago that a little splash of water in stoma is no big deal. I understand that if hot water in face is a must that some type of guard would be necessary for the pleasure.

I keep a supply of pink bullets because I found out a year or so ago that a mucus plug can not only be troublesome but also dangerous. The wife and I both contracted bronchitis at the same time and got it cleared up fairly quickly; however, a mucus plug developed in my bronchial tube and almost cut off my breathing. I found out at the ER a few pink bullets cleared them out. I recommend that all larys secure a package and keep them on hand "just in case". \$20.00 for 100 bullets is much safer and cheaper than a trip to the ER!

Dave in Florida

Class of '05

Yes, we are all so different. I'm sure this question will bear that out. I am a TEP speaker, with EL as my main backup. I generally wear a baseplate and HME 24/7, including hands free. I also use the Luna nighttime baseplate and HME to give my skin some special treatment on an as-needed basis. I may use one every two weeks and at other times, three times or so weekly. It just depends on what I need. Occasionally, I will cover with a foam filter, for the same reason.

I actually do still have a suction machine and use it when I'm in the house. Though I have a strong cough, the machine is simply better at getting more mucus out at one time, usually around twice daily. From what I hear, I do produce more than most people and this just saves me some time.

I measure the humidity level and use a humidifier in the bedroom at night. In the shower, I use a snap on shower guard almost always, occasionally still using the white rubber collar, but only when needed for a specific reason. In a pinch, I can shower occluding with an HME but always have to cover with something. It has more to do with my height and the location of the shower head than anything else.

This next point may shock some. I do not use the pink bullets, except for when traveling, and only then if I remember to take them. Almost always, I clean and moisturize with the prosthesis brush and flusher, using a saline formula from the "Stoma Care" section of our website. It has served me well and my highly experienced SLP has no problem with doing that. At her advice, I sterilize the container and the water quite easily and also sterilize all utensils (brush, flush, tweezers, etc.) with peroxide at least weekly.

Tom Whitworth - Marietta, GA
Sep 2013-March 2014

I have used HME's and Stabilibase adhesive since I had my surgery. I did have a lary tube for a few weeks then went to the adhesive. I also use a suction machine to aid in the cleanup. I don't suction deep with it but use it only for cleaning after using a saline bullet or first thing in the morning when I am first coughing. I have never used a humidifier even in the dry weather of Arizona. I however do use the little blue shower guard. I wear my adhesive and HME all day and night every day.

David Kinkead - Peoria, AZ
2013

Interesting question this month and lots to cover, (so to speak.) I am retired and spend most of my time around the home. Inside, I just use a foam pad. When I go out in public, I use a dickie or bandana over the pad to keep dirt out and moisture in. In a social situation, I use a baseplate and an HME. I still use a dickie or bandana over that most of the time. I found that when I was working that folks may be curious about my voice, but if they couldn't see what was going on, I could do my job easier than I could if I had to answer questions all day.

I have a whole house humidifier and that usually covers the winter dryness. I do have a small portable one if I need it. I don't use a Lary tube anymore, but I do use a shower guard. I've tried other ways, but like that I can just stand under the shower and not worry, so, that works for me.

When I sleep, I just have the foam pad on and haven't had any problems. I use my home made (on the WW site) saline to irrigate and loosen phlegm to keep me breathing clearly. I clean my TEP 2X a day, or more if need be. I've been doing this for 7 years. So far, so good.

Michael Cohn - Wheeling, IL.
10/10

I have a TEP and I use a Stabilibase baseplate and extra moist HME during the day and for sleeping at night, all though a lot of mornings the HME is lying next to me instead. I have the pink saline bullets that I use only rarely, when my throat feels dry or itchy and I'm coughing a lot. I do use the Atos shower guard. I tried using a humidifier but I live in Georgia where it's pretty humid most of the year and it was a pain to clean. I clean my stoma after removing the baseplate with the adhesive remover with tweezers and an alcohol pad, then a

gauze pad with soap and water. The Stabilibase often lasts 2 days unless I am using the hands-free.

Karyn March
2012 lary

I wear a Provox NID TEP valve which I rotate every 5/6 weeks. Initially I had a lot of problems with candida but this is now under control so a valve will last me about 1.5 years. I use the Provox Optiderm base plate as I like the thicker texture. If I am going to speak a lot then I will apply a little glue in the morning to make sure that the base plate stays fixed.

I use the HME Xtramoist filter most of the time though recently I have used the Xtraflow as I was recovering from a chest infection. I was operated in Oct 2012 and completed radiation in Jan 2013. Initially I used a nebulizer twice a day but found that I really did not need it. However, this year I have had two chest infections and have started using the nebulizer again. I will probably continue with this as it keeps everything nice and moist and I can cough up all the gunk in the morning and have done with it for the rest of the day.

I also use quite a bit of anti-acid medication. I can eat anything but a lot does not agree with me these days but in recent months I have found my stomach to be settling down a lot more. The one thing I have learned is that the "new breathing system" is not static, it changes. What was not a problem initially can become a problem 3 years later. For the rest I use a buff head scarf to cover my stoma when going out.

Serge Droogmans – Newcastle, UK

I was in the hospital for a long time, had 3 surgeries back to back, and at home was left weak. My brilliant surgeon sent a physical therapist and an occupational therapist to my home, and a nurse. Truly was a great help. the occupational therapist showed me how to shower safely so, I have never had to use a shower guard, etc. It is freeing, and also, what water does get in my stoma, keeps thing cleared and I have little trouble with thick mucus. My SLP insisted that I use HMEs to make sure my stoma was protected, almost 9 years later, I am still showering free, and using HMEs. My stoma has never gotten smaller grateful for this, my stoma is good, perfectly shaped, and no issues at all related to stoma care..... Cancer has come back time and again and lost an eye. But.... we have to be grateful for the good things and I am.

Lynn Foti - Akron, OH
May 2009

I graduated into the world of Lary October 30, 2006.

Eighteen months after that I broke free of all machines (suction, humidifier) and have not bothered with any of them since. Did continue to "check" the fit of my Lary tube every few months after that until several years ago when I stopped doing even that.

I use a foam cover regularly, but other than that . . . nothing. No HME's. No saline. Nothing.

Do use a steamy washcloth to break up mucus when it gets cold here in the Sunshine State because it does thicken, and I do use said steamy cloth to loosen the 'crusties' that collect from time to time around the inner edges of my stoma.

Other than that . . . God has been far better to me than I deserve concerning this new life cancer sent me on.

Troll – Jacksonville, FL
Class of 2006

Bruce has a TEP and uses the Atos oval Flexiderm baseplates. Since they do not stick very well to his skin, he also has a lary button and alternates them using an Extraflow HME filter. He does irrigate his stoma twice a day by squirting saline into it and coughing it out. We buy the saline in the small plastic tubes. It also loosens the "crunchies". I then use a long pair of tweezers to pull out the mucus. I have found that the long q-tips (the ones with the wooden stick) are good to use also for the sticky stuff. You can wrap the mucus around them. Works really well on the TEP. Just make sure before you use it to be sure the cotton tip is on securely. If the outside of his stoma gets red and irritated, I put some Desitin ointment around the outside edge and the irritation is gone by morning.

When not using a baseplate or the button, Bruce uses the foam squares to cover his stoma. He sleeps with one on. He uses the blue Atos shower guard, the one that attaches to the baseplate and has no problem in the shower. He also puts it on before shaving. As for a humidifier, we live in Florida so we only need to use one when the humidity drops below 55%. His surgery was at the end of February this year, so we haven't gone through a winter yet, but we normally don't need to turn the heat on too often.

Janice Leger - Barefoot Bay, FL

Had laryngectomy with radical neck dissection Oct 2012 with removal of lymph nodes and use only my own esophagus to talk. Have since had three ESO dilations. I use foam filter cover which I cannot seat to cover stoma completely so use neck bib plus always a scarf.

Do not use shower bib account showers too difficult to do alone. For moisturization I have a Vicks humidifier plus also dampen foam filters. Occasionally I moisturize with steam and towel overhead. Used both cotton tips and vaseline to paint area around stoma but quit that about six months ago after reading not to and started using KY jelly plus gauze but it is a mess. A piece of gauze is very awkward trying to paint jelly on and also trying to dampen and clean with peroxide so searching for right material or object for that as I use two-three filter covers daily. I always sleep always with both filter and scarf and on a recliner as it eliminates the head movement which causes too much pain. I live alone and I'm almost 87 plus, 115 miles from a medical facility. No other major med problems except vertigo and walking problems. Your website has been a god send to me. Lots of times in just relieving my worry's some. Want to get on your FaceBook once I can ever figure out how to. Thank you for listening.

Virginia Johnson – Beatty, NV
2012

I don't know if anyone has mentioned that there is another very good use for KY Jelly. It's not petroleum based and helps to keep the rim around your stoma from drying and crusting. I use the Laryngofoam pad to cover my stoma. Saline solution to help cough up mucus. I don't use a shower guard. I wash my hair under the sink faucet and take baths instead of showers.

**Betty from the Land of 10,000 Lakes
2000**

As a TEP user, I used to use various products prior to baseplate application. But, gradually stopped all the removers, preps, swabs, etc. and now just use the baseplate adhesive. I have found getting the skin around the plate area clean and warm gives me the best results; averaging 3-4 days on a baseplate. I do use a saline 'pink bullet' each time I change a baseplate. And, not using an alcohol swab has sure reduced skin irritation. The shower guard that fits into the baseplate helps in the shower. At night, it is either the regular HME or, if it is time to change baseplate, I will take it off and just use a foam patch overnight. Experimentation over the years has worked well for me. I do have a humidifier, and use it sometimes in the winter when humidity gets below 30%.

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

I buy sterile saline in bulk and transfer it to a mister and 10 ml syringes. I use the mister to clean around the stoma each morning and evening before bed. Also, each morning and evening I irrigate my stoma with the syringes to clean out the mucus. I use a lary tube 24/7 due to stenosis.

During the day I cover my stoma with foam patches from InHealth and at night cover my stoma with cloth stoma protectors also from InHealth. I use a nylon shower guard and I use a bedroom humidifier nightly when I sleep. I also buy 3ml saline bullets to put in my pocket in case I need to moisturize while out and about. At no time is my stoma uncovered. I have a TEP and use a Provox NID for speech.

**Jim Olcott - Bakersfield, Ca.
2010**

I always use Base plate with Provox HME. I irrigate 5 times a day with saline solution. I do one breathing treatment a day with a nebulizer and I sleep in a room with a humidifier. At the present time, I am doing well. Had the laryngectomy two years ago.

**Preston Kilpatrick – Houston, TX
2015**

I may have mentioned this somewhere before, but for Speaking Out I will repeat some of it. When I first came home from the hospital I was terrified of the shower, and just took sponge baths. There was a heavy

humidifier that I could hardly lift with about 25 feet of hose for the mask, and I kept spilling the water when reattaching it to the bowl. I felt that I was a prisoner in my bedroom. It didn't take me too long to get rid of that monster along with the big suction machine that I wasn't using. I bought a small pair of curved pliers to pull the dried mucus out of the stoma. That was another mistake. Then I read a post from another lary that said he just digs it out with his fingers. That also works for me now after the first couple of explorations down that hole. A piece of cake.

Then I bought a \$40 stoma guard, and took a shower. It leaked because to make it water proof it had to be really tight around my neck, and because of the after effects of my surgery that is impossible, so I put it away. Because I had lost so much weight, all the way down to 99 pounds, my daughter thought I might fall in the shower, so she bought me a small stool to sit on. I wish I would have had that stool fifty years ago.

It really didn't take me very long to figure out that a little water down my stoma wasn't going to kill me. Today I sit on the stool and use my hand held shower head. I wash my hair, and shave in the shower. A shower to me is just like it always has been. Using the stool to dry off my legs and feet works so I don't have to bend over.. I don't have too many bend overs left anyway.

I know everyone will tell me I am crazy, but I only cover my stoma when I leave home just to hide the hole. I am at my computer right now without a cover. I also sleep without a stoma cover. I have a bunch of collar bans that I don't really know what they are for, but they were left over from my tracheotomy days. I also use dried out baby wipes that I staple to those nice soft collars.

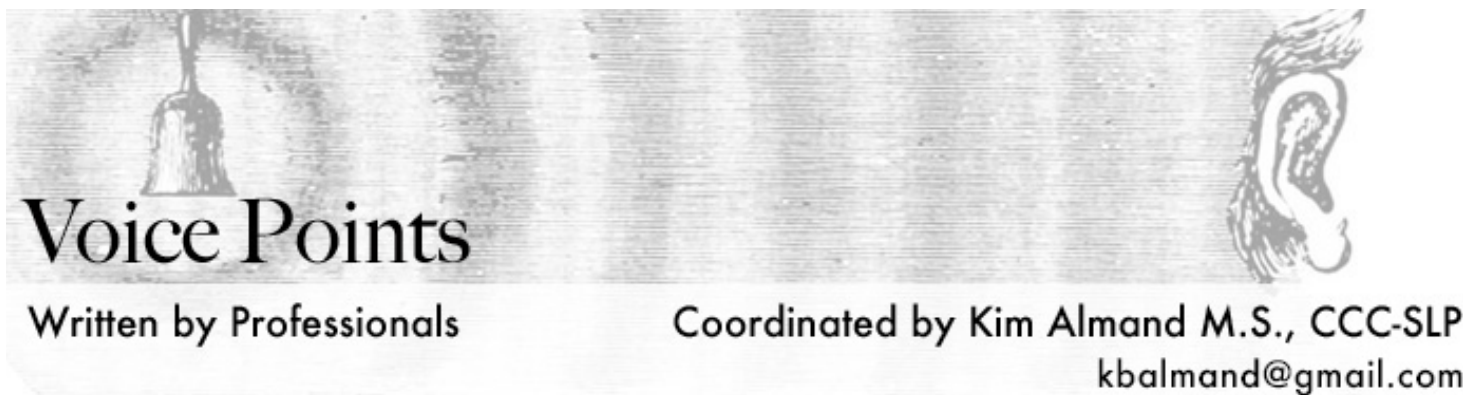
Years ago I read somewhere we will swallow an average of 14 spiders and bugs in our life time. I think if something is crawling around in my stoma I will wake up and cough it out

Johnnie Dontos - Woodway, WA
11/30/2015

Next Month's Question:
“Tell us about your pet or pets
and how they affect your life or you theirs.
Photos are welcome.”

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

Staff of Speaking Out



Editor's Note: the following is the conclusion of last month's article, Voice Prosthesis Failure: The Impact of Reflux and Biofilm by Brienne Ruel and Kathleen Huber. Please refer to the November 2017 Whispers on the Web newsletter for Part 1 of 2: <http://webwhispers.org/news/nov2017.asp>.

Even if you do not have a tracheoesophageal puncture (TEP), the education about reflux and biofilm, along with the reflux management strategies noted below are valuable resources for just about all of us.

Wishing all our readers a happy holiday season and best wishes in the new year!

Voice Prosthesis Failure: The Impact of Reflux and Biofilm Part 2 of 2

Reflux and biofilm impact tracheoesophageal puncture sites and voice prostheses. The degree and severity to which it contributes to failure is still open for debate. Anecdotally, introduction of a proton-pump inhibitor (PPI) for reflux management, patients often report improved voicing abilities. Most studies indicate that with the introduction of a proton-pump inhibitor medication, voicing improved. No study suggests any evidence as to what degree, if any, pharyngeal reflux disrupts the actual prosthesis or one-way valve. One primary reason for this seems to be that it is difficult to discern whether reflux or biofilm is the culprit concerning voice prosthesis failure.

A recurring theme in the literature related to the lifespan of the tracheoesophageal voice prosthesis is the presence or absence of a history of radiation treatment. Radiation to the salivary glands can result in lower oral pH levels, altered salivary flow rate and oral microflora changes (Elving et al., 2002), all of which likely contribute to biofilm and eventual prosthesis failure.

Reflux management is a physician-directed piece of a comprehensive assessment to determine what may be leading to prosthesis failure. We encourage our patients to consult with their Otolaryngologist, or a Gastroenterologist for assessment and treatment. Medical treatment is most often conservative, pharmaceutical, and empirical use of a proton pump inhibitor or other acid suppression such as an H2 blocker, for a minimum of 2-3 months. More recalcitrant or severe cases of pharyngeal reflux or GERD sometimes require surgery. In those instances, you would also likely be experiencing more frequent and notable symptoms than just device failure, especially given there is no evidence to suggest that acid reflux in isolation deteriorates the voice prosthesis. Providers may assess and treat symptoms early, such as using a scope to visualize the esophagus and tracheoesophageal puncture site for any granulation tissue to rule out other potential anatomic reasons for prosthesis failure.

What can you do? We often suggest that our patients implement the following behavioral strategies in an effort to reduce or eliminate reflux symptoms:

- Eliminate tobacco products and reduce or eliminate alcohol (correlated with increased reflux)
- If applicable, manage diabetes effectively
- Elevate head of bed when sleeping
- Remain upright at least 60-90 minutes after meals
- Avoid eating large meals, especially in the evening. Try for smaller, more frequent meals throughout the day.
- Avoid trigger foods such as spicy foods, foods with high fat content or foods with high sugar content
- Take your reflux medication as directed. It is important to be consistent with your dosage and DO NOT stop the medication even if you feel asymptomatic, unless directed by your physician.
- If you require frequent replacement of your voice prosthesis, consider your radiation history, as this may be contributing to altered salivary flow rate and oral microflora changes. Talk with your doctor about trialing N-acetylcysteine or probiotic supplement in an effort to reduce the rate of biofilm formation along the esophageal aspect of the silicone voice prosthesis.

While there are some differences among types of prostheses, there are certainly proactive steps that one can take to increase the lifespan and function of the voice prosthesis. Talk with your Speech-Language Pathologist about your concerns and remember: managing a voice prosthesis is a process that requires patience and thoughtful trouble-shooting. It is important for your tracheoesophageal voice restoration care to be managed as part of a comprehensive multidisciplinary approach in an effort to minimize the discomfort and/or frequency of prosthesis changes, while maximizing communication restoration.

Disclosures: We have no financial relationship with any company that manufactures voice prosthesis or related devices and furthermore the references cited herein were chosen without bias toward any company product mentioned in the included literature.

Brienne Ruel, M.A., CCC-SLP and Kathleen Huber, M.S., CCC-SLP
Speech Language Pathology
University of Wisconsin-Madison Voice & Swallow Clinics
Department of Surgery-Division of Otolaryngology

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Ellie's Electrolarynx Concerto

My mum is in hospital recovering from a bad chest infection. I'm away in the UK, teaching a meditation course. I'm phoning her regularly, and the other day she said: "It's lovely just to hear the sound of your voice". I was gobsmacked. The sound of my voice ... lovely??? I said something like "I'm surprised anyone could think of my voice as lovely!" and she said "Well it's you. And it's the only voice you have. I'm so grateful for it, that you learned to use the electrolarynx. Where would we be without it?"

Hmmm I have to admit she is ten steps ahead of me in the gratitude and equanimity department on this one. A bit embarrassing considering I'm the one supposed to be teaching meditation!

Could I start thinking of my new voice as lovely? Could I be grateful for the electrolarynx? I was grateful for it when I first learned to use it – such a step up from scribbling notes on a whiteboard. But familiarity breeds contempt and nowadays I easily find fault – with the harsh, unfeminine sound, the robotic tone, the need to talk at a quarter normal speed, and repeat myself again and again to strangers or the hard of hearing, the way it can swing around and bump into things if I lean over, the way it gets caught underneath my cardigan and I have to fumble around with buttons and straps before replying, 20 seconds too late, that I only want milk and not sugar in my tea ... I could go on and on, but you get my drift. Gratitude is not high on the list of thoughts that the electrolarynx brings to mind!

But they do say that grateful thoughts rewire the brain for happiness. So I'll try to make a habit of saying "Thank you" to my new electrolarynx voice. I'll call her Ellie! Here goes: "Thank you Ellie. You give me a voice and I'm grateful for it. My mum even thinks it's a lovely voice. May I learn to appreciate you."

By chance, a colleague needed to use the telephone (which is beside the computer in our tiny little office) just after I wrote that last sentence, and I went off to make a cup of tea and chatted for a while before sitting down at the keyboard again. When I looked back at computer screen and saw the word "appreciate" I suddenly realised that I'd just had a pleasant conversation without any of the limitations I'd been bellyaching about previously. Maybe Ellie is a good friend just waiting to be discovered! A little wave of gratitude welled up giving me a really good start for my new resolution.

That easy conversation hadn't registered as anything to appreciate until I read the word 'appreciate'. We're hard-wired to notice difficulty, psychologists tell us, and to take for granted, even ignore, whatever is easy and doesn't challenge us. Part of the fight or flight neuronal mechanism we had to develop to survive. So we see our lives as a series of problems to overcome, barely registering everyday blessings like being safe and warm and well-fed. And being able to communicate – however poorly, however slowly. We have to train

ourselves to start noticing these blessings. Some people keep gratitude diaries. I tried that, but was never good at keeping any kind of a diary and that didn't work for me. Maybe if I just focus on the electrolarynx (Ellie dearest!) my negative perceptions might shift a bit.

And perceptions can change. Sometimes dramatically. A few years ago I was doing walking meditation in what had once been a ballroom. Walking meditation is a standard mindfulness exercise. You walk slowly along the same line over and over again. This really drums it in that you're not walking to get anywhere. You're just walking for the sake of walking- feeling your feet lifting and falling. It's all part of learning to live in the present moment and discovering the "Power of Now" as Eckhard Tolle calls it. I was on my own in the ballroom for about half an hour with the sun streaming in through its big windows, tracking my feet through their steps, tracking my mind through its thoughts and hopes and fears. Then someone came in. Although there were oceans of space all around, they decided to walk only a few feet away from me. Instantly my mood blackened. I felt invaded, angry, dismayed. But the weird thing was that I also saw the room go black! It was only because I was being mindful that I could see the link between the outer darkening and my sudden change of mood. The perception was so real - I looked out the window expecting to see that a huge cloud had covered the sun. But no, the sun was shining as bright as before. I had to admit that my mind was projecting it's black humour out on the world. And yet, if I was giving evidence under oath, I would have sworn the room went dark.

I was astounded to discover that I'm actually painting a picture of the world based on my mood. Whatever is going on 'out there', my perception of it depends on what's going on 'in here'. So much for detached objectivity!

But there's good news in that too. The world "out there" can brighten up when my attitude softens and my mood lightens. If I develop gratitude for the electrolarynx, would my brain re-wire itself to hear music rather than noise when I speak? Go on brain, nudge a few neurons around. Tune into Ellie's Electrolarynx Concerto!



Chronicles of A Library Robot

If you have been reading my column for any length of time you know I am pretty much stupid in love with my grand-daughters and my life has changed radically because of them. I was really worried early on that my

“new voice” was going to be an issue for them. I am here to tell you that it not an issue but an asset (almost-but read on to hear the full story).

After the girls (ages 5 and 8) started back to school, now full-time for both, I was at loose ends. I had been the Nanny Granny since they were babies and I had a bad case of the Empty Nest Syndrome.

So being the grand-mother hen missing her chicks I decided to see if I could volunteer at their school. Well, yes I could and guess what happened... I am a celebrity!! The following are actual true stories of Nanny, The Library Robot.....

Chapter 1:

I am at the school library today, behind the desk, quietly sorting/checking in books while the librarian (an absolute gem who I have known for several years) is doing her instructional segment. Then the group (3rd graders- 8-9 yr olds- same age as my older grand-daughter, Kayleigh but in different class) is disbursed and given “free quiet reading/research time” and one boy wants a particular book and he asks me where to find it. I apologize and say I don’t know where it is since I am new perhaps Mrs D can point me in the right direction. WELL... a few seconds later it is pretty clear this boy and his friends are no longer interested in finding the book but VERY interested in me.

They are in a circle around the librarian asking lots of questions. I stand up from behind the desk as she smiles and says, “Why don’t you ask her? She can explain.” I gave a brief show and tell to one of her summer library reading groups so she knows I am cool with this. She introduces me by way of saying I am Kayleigh and Kiera’s Nana and several of them know Kayleigh.

They were fascinated with how it worked, why I needed it and when I offered to demonstrate how it worked with my spare so they could try it, I had a line of kids wanting to try! Even the ones who didn’t try watched and commented. I had kids taking 4 or 5 turns to practice- some were pretty good once they got the hang of not trying to whisper or talk and just mouth the words.

Then they had some excellent questions. One little boy in particular wanted to know if I missed my old voice and I answered honestly that I missed reading with expression & singing to my granddaughters. He then wanted to know what was the part I liked the best about my new voice! This from an 8 year old!! The librarian had to tear them apart from me as I promised to bring in even more ELs next week so we could practice together.

As they were lining up to leave, the original most curious boy called out, “Goodbye Mrs. Robot, see you next week!” It being Halloween and the day of the costume parade for the younger kids I had told them I didn’t need a costume I could just go as myself “Nanny the Robot”. I’m pretty sure I’m one library volunteer those kids won’t forget!

Chapter 2:

No, they haven’t forgotten. I went in today and started checking/sorting books behind the desk while 2nd graders were on the reading stairs. Once their program was over one little boy jumped up announcing, at the top of his lungs, “Look, the Library Robot Lady is here!” I was deluged with hugs and shy kisses and jostling in line to have the library robot check out their book.

Later that day as parents began to filter into the lobby to pick up their kids one Mom came into the library with her pre-schooler. I was talking to the librarian and heard some animated conversation. “Well, yes, I think you are right. That IS the Nanny Robot.” And a little 3 year old marched up to me, pointing to the EL and

demanded to try it out. Turns out her older sister was in one of the classes and “Nanny, The Robot Librarian” had been a subject at the dinner table. The little one was very proud of the fact that she had actually used the robot voice; something her big sister hadn’t.

The school librarian is totally cool. She is young and new school- she wants the library to be a place where kids are comfortable and discover the joy of reading and learn that the world is wide and exciting. And somehow, I and my strange voice play into that perfectly.

Some of them want to know why my voice doesn’t work, some want to know how my new voice does, but all are surprisingly accepting that I have a robot voice and not only accepting but really think it’s great.

Stay tuned for further Chronicles and be sure to check out Noirin’s column this month – The Mindful Lary and meet Ellie- my Irish counterpart. I wish I’d thought to name my voice Ellie. Wait til I tell my library friends about that!



V.A. Healthcare & A Little More

Though I have heard it said that VA care is socialized medicine, I beg to differ on that. I don’t expect to ever hear that from anyone who is in the VA Healthcare System either. VA healthcare is not automatic for any class of people though it is backed by government funds. It is not even available to all U.S. veterans but only to those who also meet other qualifications. In my opinion, there is no question about it, VA care is earned. I have shared previously about how to apply for VA care and some of the features that have been really helpful for me. In particular, my SLP has addressed my laryngectomy/TEP care magnificently. Christina has been diligent and completely dedicated to determining what will work best for me. My wife and I both consider her to be among our greatest blessings. She is a treasure even if she did graduate from the University of Florida. No way would I have my very expensive hearing aids without the VA. The folks in audiology are great, too. You can imagine how I felt when someone tried to tell me that I would no longer be able to use the VA with the new healthcare options on my horizon. I am so glad I followed up on that! Never assume that what you are told is true. Verify.

I retired as a reservist, so Tricare kicked in for me on my birthday in November. We’re taking the option of Tricare Prime for what I consider to be a meager enrollment fee. Also, Medicare kicked in as primary on November 1. I started this journey insured by an employer backed health care policy and ended up keeping that policy under

the COBRA laws when the employment came to an end. A few months later, I had a policy in force under the ACA, and then transferred to VA care. After the fact, I was told by the ACA people that one can't get healthcare from two government agencies. Though that has turned out to be untrue, VA Healthcare and Obamacare cannot be used simultaneously. What a convoluted mess my wife and I were in. We had to drop the policy to keep VA care for me. I have learned so much on all of this over the past couple of months. I had to! My situation now is that have excellent coverage for my wife of nearly 40 years. That's a darn good thing. Medicare will be my primary, Tricare my secondary coverage. I can continue my VA care but the VA does not bill Medicare. They will bill Tricare though. So, either way, I can now get the help I need on a consistent basis, inside or outside of the Veteran's Administration.

To hopefully dispel some myths:

- Not every veteran is necessarily eligible for VA health services.
- Care is not necessarily free.
- Some VA patients do have co-pays, and other costs.
- Service-related factors come into play as do income levels and available insurance coverage.
- The only way to be sure is to apply and wait for your determination. Mine came within two weeks.

Many veterans deal with mental health issues, as do cancer patients and survivors, in general. Depression is certainly not uncommon among veterans dealing with cancers of the head and neck. Free support is available.

Here is the link to the VA Mental Health Crisis website: https://www.mentalhealth.va.gov/suicide_prevention/

Veterans, Service Members or their loved ones can also call this number:

Dial 1-800-273-8255 and Press 1 to talk to someone

My personal thank you for serving!

Tom Whitworth

WebWhispers President

Bits, Bytes and No Butts!



Frank Klett

Getting around in our World, and Who's Philo?

As a head and neck cancer support group WebWhispers has earned the respect of our members: patients, caregivers and the medical community by years of providing factual and accurate information. We have done this through the ongoing dedication of our super volunteers ... without whom we would not exist. Everything that gets done gets done by our volunteers: no one gets a dime for their efforts.

We have several areas we maintain to maximize our information flow including the WebWhispers Forum, the WebWhispers Facebook Group, the WebWhispers Library, and our on line email list for direct questions and answers from members. You can access any of these areas with your PC, laptop, tablet or phone...though I personally prefer a PC or laptop since I have a keyboard readily available.

The WebWhispers Facebook Group is our meeting area along with the Webwhispers Forum. Many of our members are on Facebook, so we knew it was time to have a Facebook home. We invite all our members to join us in our Facebook Group and the Forum.

If you are not a Facebook user then you might enjoy a visit to our Forum; hosted on Delphi the Forum is a Members only group which limits the access to only those of our hole in the neck group. It is our open area to ask questions and exchange thoughts. There are many categories of interest and you'll find the answers to many of your questions. If you haven't already joined the forum you can simply contact one of the forum managers for any questions you may have. FORUM: <http://forums.delphiforums.com/webwhispers/start> you will be asked to join the Forum if it is your first visit and before you know it you'll be in the Forum...if you have any question contact the Forum managers Bill Cross or Mike Rosenkrantz.

And for our newest members remember to visit our library for answers to many of your questions. <http://www.webwhispers.org/library/library.asp> is one of the most complete collections of information aimed specifically at the Laryngectomy Community...in fact it may be the only one. Taking the time to browse the library and become familiar with the contents will make it even more useful for when you do need to find out a piece of information.

Aside from the online groups we maintain this newsletter and our Electro Larynx loaner closet plus so much more!

And for us techies there is a new choice for the cable-cutters. Philo is a non-cable subscription service that delivers cable programming to your device of choice. What makes it hot is the price starting at \$16 per month up to \$20 per month. Philo offers a free trial and does not require a credit card for the initial setup

The details are spelled out for us by Bob Rankin so read his article at the link below:
https://askbobrankin.com/will_philo_replace_your_cable_tv_subscription.html



From the Archives



The Speechless Poet - Len A. Hynds

~ This column first appeared here in 2010. We've re-printed it in previous years and a number of you wrote in saying how much you enjoyed Len's holiday story, so it is now a tradition- maybe our own "It's A Wonderful Life".

~

A Christmas Story

The onset of these darker evenings, and the thoughts of Christmas which is now only a few weeks away, remind me of those halcyon days of childhood which are so strong in my memory. I was seven and could only dream of wonderful presents. I knew that mum and dad could not afford what I so dearly wanted, that wooden fort in the toyshop window. For two years I had stood outside, just gazing at it, and those marvellous Scots soldiers in their kilts, red coats and white helmets lining the ramparts. The youngest of seven children, with very little money coming into the household, you soon realise that your own personal wants are not even mentioned, so I never told anyone of my heart's desire.

Let me convey you to our darkened bedroom on the evening of that Christmas Day. My two brothers were asleep. I lay between them in our large bed, and being the youngest, I had to sleep at the opposite end between their feet. Charlie was always on my left, and with him being shorter than Alf, I could get a clear vision over the top of his covered feet, so I always slept on my left side. What a day it had been. I loved Christmas; it was always so exciting. And this had been one of the most thrilling days of my life, and as it was drawing to a close, we had been sent to bed.

I lay there, looking over Charlie's covered feet, at the faint glow at the window which was coming from the gas lamp outside. Even Jack Frost knew it was Christmas. He had made his own decorations on the inside of the

glass window panes, as our breath froze into the most wonderful shapes. They were like sparkling diamonds, and I wondered what part of that pattern was my own frozen breath, and if it was forming those intricate close knit patterns because we were brothers.

Before falling asleep, Charlie had blown out our candle, but I could still see my present in the faint glow from the window. It was the wooden fort, with its ramparts lined with those Scottish soldiers. I could not believe it when I had been given it earlier that day. I used to stand outside that toyshop for such long periods just gazing in, that nearby stall holders, wearing mistletoe in their woollen hats, and faces glowing from their acetylene lamps, would nudge each other, and say to me, " You'll get it if you're a good boy".

Well I was good, or so I thought, but would miserably say to myself, ' I can't even tell them what I want.' The man from the toy shop came out and spoke to me on a few occasions, and I asked him what regiment it was, and after peering in, he said, " Why, they're the Camerons, a Scottish Regiment and they're fighting in a country called Afghanistan right now."

My sister Kit had read us several stories written by a man called Kipling, and one story was about those Afghans sweeping down the Khyber Pass to ravage and ransack India, and they had been doing this for hundreds of years. As he spoke, I was with that regiment marching up the pass, kilts swirling, bagpipes playing, returning the fire from the mountainsides.

When Dad had carried that fort into the parlour with the soldiers lining the walls, I could not believe my eyes. They were the Camerons. I was so filled with emotion that I felt tears coming into my eyes, but brushed them away, knowing that boys don't cry like girls, but wondered how on earth did they know what I had wanted. Mum said, " The shopkeeper told us what you wanted, and how you had been so good for business just gazing in. He sent you these as a present." She produced another box with a further 12 Camerons inside.

Dad said, " There was this one who had a leg broken in the shop, and was going to be thrown away. I told the shopkeeper that you might like him." As I took this one, the one with the leg missing, I realised that here was a hero. He had lost his leg fighting those Afghans. I looked at my fort in the faint light and there he was, in a position of honour standing to attention in the uppermost tower.

British troops are still fighting those Afghans all these years later, and now they have their American colleagues with greater fire power to stand beside them.

It was the following summer, the exact circumstances elude me, but during a visit to our home by some relation, I was given a whole sixpence to spend, and I went to the market to buy something I had long coveted. As I crossed the road to enter the market, I saw a man sitting on the pavement with his back resting against the wall. A crutch leant against the wall beside him.

The poor man only had one leg, which was stretched out in front of him, and beside it a soldier's Glengarry cap which had a few coins in it. The poor man was begging.

As I was passing, he picked up the cap to take out the few coins, and I saw the most beautiful silver badge on it. I read the word Camerons. I put my sixpence in his cap.

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Editor - Donna McGary

Editor - Jack Henslee

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