



WebWhispers

Sharing Support Worldwide
Throat Cancer and Laryngectomy Rehabilitation

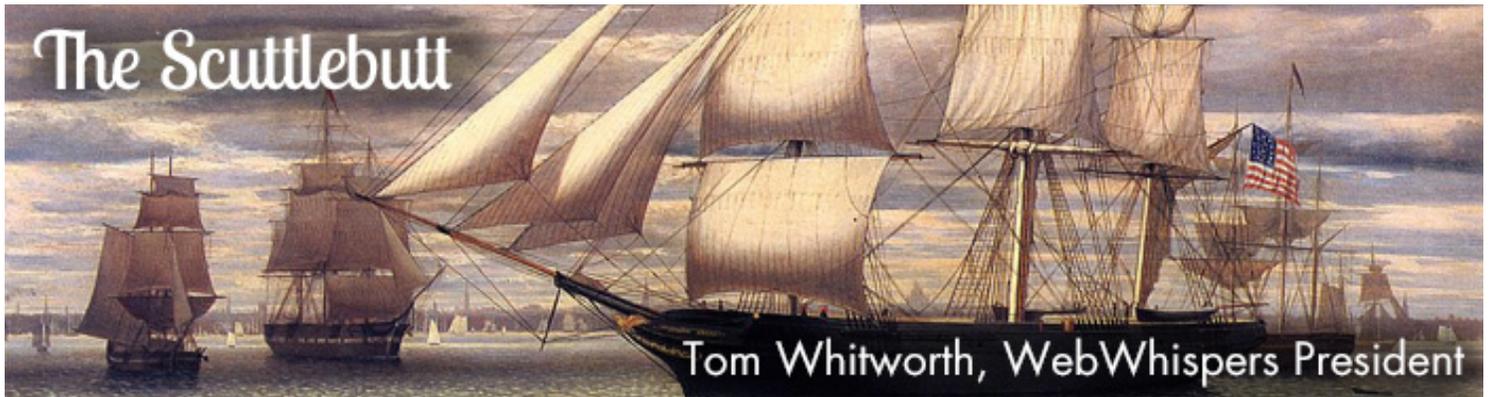


November 2016

Name Of Column	Author	Title	Article Type
The Scuttlebutt	Tom Whitworth	Attitude Really is Everything!	News & Events
VoicePoints	Laryngectomy Supplies: Part 2	Donocoff, McCarroll, and Ebersole	Education-Med
Between Friends	Donna McGary	Seasonal Beauty	Commentary
Speaking Out	Members	"Do The Season Changes Affect You?"	Opinion
Dear Lary	Noirin Sheahan	Seasonal Footsteps	Commentary
My Neck of the Woods	Mark Reichenbacher	Disabled People Working at Lowes	Member Experiences
The Speechless Poet	Len A Hynds	Halloween and a Monster	Prose & Poetry
Bits, Bytes & No Butts!	Frank Klett	Things That Confuse Me	Computers

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

COMMENT HERE
FEEDBACK



Attitude Really is Everything!

I have always been one with a grateful heart, well almost always. I'm like that most of the time but especially as Thanksgiving Day approaches in the United States. I think it was gratitude that guided me through the roughest waters of this journey. More often than not, focusing on what we have to be thankful for will lessen the burden of things we would have preferred to avoid. Among these for many of us are chemotherapy, radiation to the head and neck, and laryngectomy, those gifts that keep on giving. I think I self-coached my way through the most trying of days and most troublesome effects cancer treatment with mantras like "it beats the alternative" or "it beats being gone" when referring to the discomfort of radiation or a side effect of my chemotherapy. Yes, I can even be quoted as having often said "it beats being dead". I think my sweet wife of 38 years, Julie, likely cringed when she heard me say that, yet I think it reassured her I was dealing with my reality in a healthy way- head on.

During the first year or so of recovery and rehabilitation following my laryngectomy, and even still, I have referred to my "List of Things That Beat Having Cancer", which includes the memories of treatment plus long term things like hearing loss from chemo and the simple matter of a hole in the neck. The List has grown and covers things I would have had no frame of reference for, were it not for the journey. I really don't believe I've ever been a bad person and most people that have known me for very long at all would tell you that, yet I know I am a stronger and better person for the journey. I claim it, embrace it, and cherish it. This journey not only saved my life but made me a better man than I could ever have become without it.

Things I am thankful for:

People I would not have met otherwise: I could write a book here and just may someday. The friends, supporters, encouragers, oncology, ICU, surgical and other nurses, doctors, and others made a huge difference in how I have fared on this trip. When they say they admire me, I'm at a complete loss for words.

Speech Language Pathologists! I am privileged to have worked with at least 5 and love them all. Several others have advised about VA care, taught me a better way to use a microphone, or how to do patient visits, became my friend, and more. I treasure those in the SLP profession. Life in this world of ours would be dismal at best, without them, at least it would be for me. As a side note, when your stoma is completely uncovered, an SLP who stands directly in front of you for very long at all is probably not yet highly experienced. I recommend kindly advising so they never get coughed on. We don't want to discourage them from the profession.

Often, I am grateful for things I can laugh about that I never before had any knowledge of.

For a novice or any Lary, if we're not careful, mucus can land anywhere- on the wall, on your shoe, on your laptop screen, and possibly my favorite, which cracked my ENT up when I told him about it, on the inside of

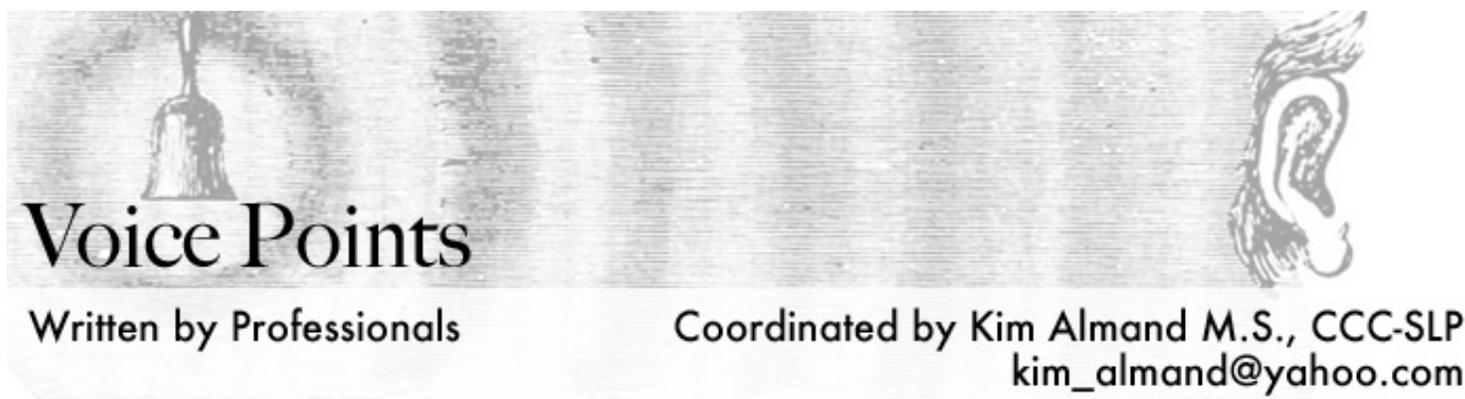
the windshield while driving. When that happened to me early on, I was grossed out for a few seconds but then the hilarity of it all set in and I had to pull over, laughing hysterically. Maybe you had to be there. Along the same line, if we're not careful to gain control of it before a sneeze or cough, an HME can end up anywhere. From two years ago, one that was fired across my two car garage is still MIA. Accidental Esophageal Speech is something I cannot explain it but it does make me laugh. I forget to occlude and words come out anyway. It seems a few of them have exactly four letters. When I try this intentionally, I'm not very good at it. I truly hope someday to get a handle on it and make use of this excellent voicing method. I happen to like the virtues of ES.

When Tom Olsavicky taught me online "Mucus is your friend" I cringed for a minute and then realized how astute he was in that advice and encouragement. It was then that I learned how patient our members are when a newbie asks the most obvious of questions and that on our website: www.webwhispers.org there is a huge volume of information on mucus and much, much more. I look forward to the development of a new medical specialty, Mucusologist. They will be the medical professionals, probably SLPs, who can determine exactly how we each can direct our humidity level at any given moment to the precise level we need, no less or no more. I now hear the Everly Brothers singing "Dream, Dream, Dream". For now, the input in "Speaking Out" will be of interest to many of us.

For almost every one of us, there is someone whose journey has been harder than our own. These are our true champions and among those I respect and admire the most, not that I don't love you all. I truly do. Yes, there are many people like this and I am thankful to know each one that I do. Our lives are better for having met them and getting to know them. Their example of resilience, positive attitude, and determination is not only impressive but inspirational to us all. They help to keep many of us going. I can assure you they have that effect on me. Mark's story under "My Neck of the Woods" and all I have read from him are among the most poignant and heartwarming stories I have experienced. He is amazingly positive. I feel sure you'll agree.

"Voice Points" has some really good information and the reflections of our entire staff combine for some excellent reading. But then, I am admittedly heavily biased. It comes with the territory.

***Enjoy, Laugh, and Learn,
Tom Whitworth
WebWhispers President***



Voice Points

Written by Professionals

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Navigating the World of Laryngectomy Supplies: Part 2 – TEP

Kathleen Moran-Donocoff, MS, CCC-SLP, Liane McCarroll, MS, CCC-SLP, and Barbara Ebersole, BFA, MA, CCC-SLP

As we discussed in our September 2016 VoicePoints article, “Navigating the World of Laryngectomy Supplies: The Basics,” the world of laryngectomy supplies is a large and confusing one. In that article, one can find information regarding what basic supplies are important, as well as where and how to purchase them. The goal of this article is to provide guidance on supplies related specifically to one type of alaryngeal voice: tracheoesophageal voice which uses a tracheoesophageal voice prosthesis (TEP). Please understand that insurance coverage and policies vary by plan and so, in turn, we will only very broadly discuss reimbursement.

BACKGROUND

Tracheoesophageal puncture is a surgical procedure to create a fistula (hole) in the wall that separates the trachea from the esophagus. This puncture allows air from the windpipe into the esophagus where it can vibrate a muscle segment (cricopharyngeus) and produce sound, which can then be shaped into speech. The puncture, however, presents two distinct problems: If we don't stent (or prop) it open, it will promptly close up by virtue of the body's natural healing process. Secondly, this hole allows food/liquid/saliva traveling through the esophagus an entry-point into the trachea. The tracheoesophageal voice prosthesis (TEP) is designed to solve these two problems, allowing for tracheoesophageal (TE) voicing and effective communication following total laryngectomy. The prosthesis serves as a mechanical stent of the puncture, keeping it open. It also has a one-way valve inside that opens toward the esophagus during speech attempts (allowing air into the esophagus) but does not open toward the windpipe during swallowing (preventing food or liquids from entering the windpipe).

SUPPLIES

Tracheoesophageal Voice Prosthesis (TEP)

There are two main types of voice prostheses:

1. Indwelling: This is initially placed by a surgeon, and removed/replaced by a speech language pathologist (SLP) or a surgeon.
2. Patient-maintained: This is initially placed by a SLP or surgeon, but after training, the patient is able to remove and replace independently at home.

It is important for patients who are interested in a TEP to discuss their options with their surgeon and/or SLP to determine what type of prosthesis is best for them. A TEP comes in varying lengths and diameters. Your SLP or surgeon will measure you to ensure your TEP is a proper fit.

Accessories (Plug, Flush, and Brush)

It should be noted that TEPs do not last forever – it is extremely important to take care of them! To prolong the life of a TEP, one must properly clean and maintain their voice prosthesis.

Brush: A brush is typically used to clean the valve of the prosthesis. Your SLP or surgeon will instruct you regarding whether you should brush, how to brush, and the appropriate frequency of brushing. All TEPs come with a brush, however you may need to order another one if your TEP lasts an extended amount of time. Your SLP or surgeon can assist you in ordering the correct size.

Flush: A flush is used to flush mucous and food through the TEP, especially after meals. Your SLP or surgeon will instruct you regarding how to flush, and the appropriate frequency of flushing. A flush does not come with every TEP; your SLP or surgeon can help you order one if needed.

Plug: Inevitably, your indwelling TEP will leak. In situations like this, it's important to have a plug handy to place in the center of the TEP (same place you place the brush and flush). This will prevent food and drink from entering the airway until you are able to have your TEP changed by your SLP or surgeon.

Hands-free Accessories

Hands-free accessories allow patients to communicate without use of their hands/fingers for occlusion of the stoma. At times, patients require special adhesive housings. Your SLP will help you determine what hands-free device is best for you and provide education and training.

ORDERING SUPPLIES

Step 1: Determining what supplies you need and what brand you like best

In the United States, the two predominant companies that distribute TEPs are ATOS Medical and InHealth Technologies. Your SLP should be able to help you decide what TEP and TEP accessories are right for you.

Step 2: Obtaining a Prescription

These supplies all require a prescription from your doctor or surgeon. Typically, your SLP will assist you with getting the prescription and order form and sending it to the company. Order forms and prescription forms for ATOS, InHealth, and most Durable Medical Equipment (DME) companies are available on the companies' websites.

Step 3: Ordering Supplies

This is where things get tricky! To keep things as clear as possible, we will talk about each item separately. Things will differ between Medicare and private insurance companies.

Medicare patients are able to order directly through ATOS Medical or InHealth Technologies. Most of the time (exception is indwelling TEPs – see below), Medicare patients are required to pay upfront for their supplies. InHealth and/or ATOS will submit for reimbursement on your behalf.

Patients with **private insurance** will need to order directly through a DME company. Ordering through a DME company eliminates the need to pay upfront and then submit to your insurance company. If you have a private insurance, you should find out what your DME benefits are – some people are covered at 100% while others may have little to no DME benefits. Once you understand your coverage, you'll have to find a DME that your insurance company is contracted with. To find out what DMEs your insurance company works with, you can call your insurance company and request a list. You will need to call the DME companies on that list and ask whether they carry the specific items you need. This can be frustrating and time consuming. It's important to ask your SLP if he/she know what DMEs are in your area that cover these supplies (SLPs- Reach out to your regional ATOS and InHealth representatives!)

Indwelling TEP

Medicare: With a prescription, Medicare patients can order a TEP directly from ATOS Medical or InHealth Technologies (or any DME company!). Unfortunately, there is no reimbursement for Indwelling TEPs for Medicare patients. These TEPs generally run between \$200 and \$300 dollars. Some facilities stock

indwelling TEPs for their patients. If this is the case, you're in luck! Speak with your SLP/surgeon about whether this is an option for you.

Non-Medicare: With a prescription, private insurance patients can purchase an indwelling TEP directly from a DME. Depending on what your DME benefits are (could be anywhere from 0%-100% coverage), you will need to cover the remaining amount.

Patient-maintained TEP

Medicare: With a prescription, Medicare patients can order a patient-maintained TEP directly from ATOS or InHealth. The patient would pay upfront and ATOS or InHealth would submit for reimbursement on your behalf.

Non-Medicare: With a prescription, private insurance patients can order a patient-maintained TEP directly from a DME company (see above). Depending on what your DME benefits are (could be anywhere from 0%-100% coverage), you will need to cover the remaining amount.

Brush/Flush/Plug

Medicare: With a prescription, Medicare patients can order brushes, flushes, and plugs directly from ATOS or InHealth. The patient would pay upfront and ATOS or InHealth would submit for reimbursement on your behalf.

Non-Medicare: With a prescription, private insurance patients can order brushes, flushes, and plugs directly from a DME company (see above). Depending on what your DME benefits are (could be anywhere from 0%-100% coverage), you will need to cover the remaining amount.

Hands-Free Accessories

Medicare: With a prescription, Medicare patients can order hands-free accessories directly from ATOS or InHealth. The patient would pay upfront and ATOS or InHealth would submit for reimbursement on your behalf.

Non-Medicare: With a prescription, private insurance patients can order hands-free devices directly from a DME company (see above). Depending on what your DME benefits are (could be anywhere from 0%-100% coverage), you will need to cover the remaining amount.

Take-away Points:

Determining what supplies you need and ordering them can be a complicated and frustrating process, but it doesn't have to be.

You have resources and are not in this alone! Patients should reach out to their SLPs and SLPs should reach out to their regional representatives from ATOS Medical and InHealth Technologies. They can provide an immense amount of information, assistance, and support!

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Seasonal Beauty

Like many of us I suffered from seasonal allergies long before I became a neck-breather. So the seasonal changes have frequently precipitated some symptoms and it has just become one more aspect of this lary life. I have learned that my "breathing comfort zone" is much narrower than before and I am much more cognizant of my air/humidity/irritants now, especially since developing asthma. That said, it is quite manageable, once you get the hang of it.

Noirin Sheahan in her column this month answered the Speaking Out question a bit differently by exploring the more psychological/emotional aspects of seasonal changes. Her thoughtful and beautifully written piece, which I hope you take the time to read and ponder, got me thinking about something I read by another woman whose blog I follow called The Style Crone.

"As autumn arrives full-blown, with its stunning display of colors, I've been reflecting from an inner distance on my own life's transitions. Seasons of the year can be perceived as analogous to the stages of life.

I see myself in fall as I gaze upon the trees as they shift from green to brilliant red, orange and yellow. The stage before their leaves fall to the ground in heaps of crisp and spent beauty, they are at their most lovely. Before they appear stark and barren against the frigid winter background. Or as with humans, the end of life on the physical plane.

Why lament the lost youth of spring, when we can revel in the glorious colors and the fragrant essence of fall?"

– The Season Of Transition

Judith has eloquently captured the changing nature of beauty as we age and navigate through life's seasons. At 63 I find I am increasingly reminded of the disparity between my inner sense of myself (I really can't be much more than 40, I think) and the reality as evidenced with a glance in the mirror or a photograph. Who IS that old woman??? Then of course, there are the innocent comments from my grand-daughters, "Nanny, your skin is so wobbly. How do you do that?" or "You have funny scratchy lines all over your arm, Nan. Maybe you need some lotion." Ah, sweet child, if only it were that simple.

There is a movement among "women of a certain age" to take back the dignity and honor and, yes, even beauty, of aging. To fight back against the tyranny of "age appropriate" style and behavior; to fight back against the myth of perpetual youthfulness as desirable, even as it is unattainable. It is a struggle given the constant bombardment of products, practices and procedures "proven" to make us more youthful and thus more desirable and beautiful.

I recently noticed a new ad campaign for anti-wrinkle eye cream that says "Your eyes should show mischief, not your age", as if the two were mutually exclusive. It is difficult not to internalize the omnipresent message that the patina of age is valued in objects, such as fine furniture and art but not in people, especially women.

We value authenticity in our society but we applaud duplicity. It has been a compliment of the highest order to tell someone they "don't look their age" or following that, "Wow- you look terrific for your age."

We are encouraged to "own our scars" as a testament to our strength and resilience but the campaign to own our wrinkles and wobbly bits has not gained much traction. I'm not surprised – it's a tough sell even to unconventional old broads like myself HAH!! I recently had to talk to my arms and let them know how disappointed I was in them. They had been doing so well and practically overnight they just surrendered – folded. I mean, I expected as much from my butt - it was always a lazy old thing but my arms – et tu, triceps? And while I joke about it, truthfully, I am appalled at this relentless transformation.

Our responses this month to the question of seasons has sparked an interesting and insightful dialogue, ranging from the pragmatic to the sublime. Noirin's musings on the appeal of each season got me thinking I have always been a fall/winter person. Autumn is inspirational and energizing and winter, beautiful in its fierce and stark simplicity. I particularly love the quality of late afternoon winter sun as it sets down behind a snowy field at the edge of the woods.

I am thinking of my mother, nearly 90, who now does resemble an elegant old birch as it bows gracefully under age and snow, a starkly beautiful sculpture against a darkening winter sky. And I will think of myself as perhaps a maple- in early fall just as the leaves begin to turn. Yes, this is an old maple and it bears some scars, some broken limbs, a big hole where some damage was done long ago, but it is still a magnificent old tree, capable of great beauty and strength and service. And with any luck, both the birch and the maple will make it through another winter to feel the sap rise and leaves bud come spring.



“Do The Season Changes Affect You?”

**Mohan Raj – Bangalore, India
2010**

Whenever the humidity comes to 35% and below, especially in summer, I used to feel very uncomfortable due to dryness in the lungs. To compensate for such dryness, my mucous flow used to increase leading to excessive and stressful coughing. Once blood has started coming and I ended up in ICU. They used a Bronchoscope and that threw out some clotted blood as well. It was a touch and go crisis.

I learnt my lesson the hard way. I used to spray water on the bib I wore covering the Stoma {I never ever used HME cassette. I only use bibs}. That water spray solved the problem of low humidity.

I am now in to my sixth year after the surgery and over the years I find that the lungs have managed by themselves to adjust for low humidity problems. This year I did not have to indulge in water spraying.

Mercifully, Bangalore does not have any other major seasonal changes. Thanks for asking this good question. I am very interested to know how others have coped.

**Ken Alward – Laurel, DE
2012**

Yes, the change of seasons does affect my ability to speak. I use a TEP and the increased mucus build-up makes it fail with regularity. Once the change is done, there's the particulars of the season to deal with, be it dryness from the cold or sweat from heat..... Thanks for asking.

Mike Smith - North Augusta, SC

9-11-2008

Living in the Southeast, the soft wood or pine pollen each Spring can really be challenging for some laryngectomees. In this area we see the Masters play each April, but everyone living here prays for rain during that three-week span before the tournament to help knock down all the bright yellow and green pollen.

The advent of adhesive baseplates and HMEs has really helped with the pollen, but it still gets in. Some years are worse than others, especially when the rain doesn't come. When that happens, it lingers for what seems an eternity (actually 5 or 6 weeks).

In the heavier years, I would spray off both my wife's vehicle and mine, and by lunch, you couldn't drive without first using your windshield washer and wipers. People wonder why we put up with it? Well, as soon as the pollen leaves, everything is sprayed down and cleaned, the pool cover is taken off, and the pool stays open until late October or early November. Except for the pollen each Spring, this is a wonderful climate to live in, with the 4 weeks of "Winter". I mean, we have to put up the shorts at least some, right? Many people say we have Florida like weather here but without the bugs. With that, I can deal with the pollen. However, you can see me doing rain dances the first couple of weeks of March each year to offset what I know is coming....

Bruce Eastburn – Middletown, DE August 2015

August 2015 was my Laryngectomy, so this is my first fall without my nose filter! So far so good! I haven't experienced any adverse effects. Of course, here in Delaware the weather has been mild so it's probably a little early to say.

This time last year I was dealing with a lary tube and neck strap and lots of mucus. Now the mucus has subsided a lot, and I am using a Provox Xtrabase adhesive and Xtramoist HME, and getting a fairly good voice from my Provox voice prosthesis.

It remains to be seen how the cold dry air of winter will affect all this, but I am encouraged with my results so far. The last year has been very difficult, but perhaps I am beginning to see the light at the end of the tunnel.

Serge Droogmans - Newcastle under Lyme, UK 2012

I live and work in a climate that has a cool season, a very wet season, and a hot arid season. The first two do not present a problem though the hot arid period has more of an effect. Largely this is due to having to living with an air conditioner during this time and problems with dehydration. I am not too good at drinking enough fluids so I have made it a practice of drinking some oral rehydration salts in the evening. But for the most part the seasons really do not affect me much at all.

Dave Ross - Edgewater, FL

Very little effect on me. If it's very cold and dry I may sleep with a bedside humidifier for a few nights. I live in central Florida, and cold and dry means 50 degrees or less and relative humidity {in house} below 30%.

Angie Leu-Smith Lincoln, NE
'09

During the winter, when the furnace is on, I have to keep my humidifier going in my bedroom continuously so I don't get so dried out. Mucus is much easier to cough out when it is kept thin. I also use saline bullets more in the winter. I live in Nebraska and the winters are never the same.

I am also much more cautious of exposing myself to little kids that seem to carry respiratory bugs during the school year. As I'm turning 75, I find I'm not as immune as I use to be. I was a hospital nurse and I never got sick when everyone around me was having to take sick days.

Stay well this winter, that's my goal..

Shirl McDonald

I am a new laryngectomee but have noticed that I have more coughing and thicker secretions. I am not sure if this is all weather related or that I just completed radiation 2 weeks ago. I increased my in home humidification and I'm wearing my HME (thanks John for the reminder) 24/7. Was much better today.

Tom Whitworth – Powder Springs, GA
March 2014

Wow, do they ever! My surgery, which closely followed insufficient chemotherapy and radiation, was two years, and eight months ago. Since coming home from the hospital, I have consistently had a serious dryness issue. If it has subsided much at all since then, it hasn't by much.

I always use HMEs, sleep with a humidifier, and frequently apply saline solution to promote moisture. I keep a humidity monitor nearby which usually confirms the cause of problems I may be having. Air I can't control (e.g. hotels, airplanes, airports) is often a problem for me. Even in my home, the AC is on constantly during the summer and that steals the moisture I need. Worse yet is the drop in humidity when cooler weather arrives, even here in Atlanta. When the humidity drops to 18%, I'm in for some trouble. Often, anything below 45 seems to cause problems.

The humidity I likely moaned about for decades is now my very dear friend. This fuels my dream of a Florida home someday, for the winter or maybe even year round.

Margo Ziegler – Minnetonka, MN
Permanent Trach Feb. 1996

Since getting my permanent trach back in February of 1996, I find that the cold weather here in Minnesota

bothers me much more than ever. I can't warm up the air that goes into my trachea and I have found that temps below 50 degrees can start muscle spasms in my trachea and cut my air off. It's pretty scary for me and it's happened about 6 or 7 times now since getting my tracheostomy. Thank goodness, each time this happened, I was with someone who could help drag me into a warm place ... like a car or a house or store of some kind.

So, now I don't enjoy winter like I did as I used to cross country ski, and enjoyed shoveling and being in the snow. I no longer can do that and feel quite stuck in the house during the winter months. I do drive myself to a mall now and then and walk around just to get myself out of the house, but I really miss being outside in the beautiful winter time in Minnesota. Makes me appreciate the weather we have in Spring, Summer and Fall when I can be outside as much as I want. I enjoy every minute I have with nice weather, knowing that winter is coming!

John Haedtler - New Mexico, USA
2001

For me the season change is not too bad as the change is normally slow and my neck will adjust to it with minor irritations. The hard part is when I'm with family in the cold and they are afraid of me getting sick so they go in and out of heated areas. That is what bothers me the most! Rapid change in temperatures. I have tried to tell them but they seem to know more about it then the guy that is living it! So I just stop going inside till they get the hint.

Non-laryngectomees seem to read just enough to cause problems for us. They fail to realize that we are all different, we are all going to have our own problems. Sad part is that doctors without ENT training can be the worse. I think no Laryngectomy should go in for any type of surgery without a Laryngectomy being present to stop mistakes from being made.

Bob Bauer - Hayward, CA
Class '08

Since I live in the San Francisco Bay Area, Hayward to be exact, there isn't much of a seasonal change. However, since my surgery my stamina isn't as good as it used to be especially if it gets really hot. Other than that I have no problems dealing with my stoma as the seasons change.

Joe Hilsabeck – Edelstein, IL
09

The weather in the Midwest is so varied that humidity is always a problem. When it's cold, out comes the humidifier. I have a small one in my bedroom at night, thanks for HMEs. I use a scarf around my neck also when its super cold. Rest of the year isn't as noticeable. I notice low humidity the most.

Ron Mattoon – Seattle, WA

Lary 2010

I live in Seattle so we usually have pretty mild temperatures and pretty good humidity, so weather does not affect me much. I do realize that the humidity helps a lot and when I travel to a dryer climate I notice it some. I do keep a humidity meter by my chair so I know what it is. In the summer when it is dryer and I am mowing the lawn I sometimes wear a damp scarf over my stoma to help with the humidity and it helps catch most of the stuff in the air too. After being a laryngectomy for a few years now, I take pretty much everything as normal.

Roy Donnelly - Muskoka, Ontario 2015

Good day to all,

This is my first reply so cut some slack please. Last winter was my first experience as a "lary". I live in cottage country (Muskoka, Ontario) and as a hobby clear snow from neighbors drive with a tractor. Finished radiation December 4th, 2015 and the white stuff was already on the ground. Cleared my drive and damn near froze...headed inside, warmed up and attempted a second but left it for another day. This pattern was repeated often as we had a little over twelve feet of snow. (Record is over sixteen feet in this area)

As I learned how to dress for the weather (snowmobile suit, but more important a breathable scarf) it was pleasant and I look forward to this year's dusting of the white stuff. (FYI one inch of water = ten inches of snow)

If the good lord is willing, I hope to celebrate my eightieth year.

Barb Gehring - Akron, Ohio September, 2013

The first winter in Ohio following my surgery was brutally cold and my upstairs bedroom was not reaching the humidity levels that I required to be comfortable. I frequently coughed and used a wedge pillow to elevate my upper body. Even though our furnace can be adjusted for humidity, the levels still were not sufficient for me; so I ran a humidifier downstairs during the day and one upstairs at night by the bed, checking the humidity with a hygrometer (Acurite from Target).

Last year, outdoor temps were much more mild, with very few nights or days below 20. I did not use a humidifier downstairs - only upstairs by my bed and didn't need the angled pillow. This will be my third winter and because I rarely cough at night at this point, I'll be curious to see if I still need the extra humidity by my bed. A lot depends upon the outdoor temperature.

During the warmer months, I still notice some dryness when I breathe if I have the air conditioning in my car running too long or directed at my face. If I recirculate the air in the car, it makes the humidity levels rise.

As you know, we are all different; but I firmly believe that the HME system (a round plastic disc with a sponge that is inserted into a LaryTube or Button) has made my adaptation to neck breathing much easier, as it

constantly provides warm moist air to my lungs. The pink saline bullets also help me to clear mucus, if needed.

Lucy Jepsonturner

I live in the UK, all the seasons are pretty much the same, haha

Speaking Out Question for next month is:

What person or organization has been the most help to you as a laryngectomee or caregiver?

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

Staff of Speaking Out



Seasonal Footsteps

Yes, the seasons affect me. When I was about 20 I first noticed that I loved springtime – the buds on the trees, the daffodils showing up, the stretching of daylight into evening – but couldn't appreciate autumn. During summer I was too busy enjoying myself to bother reflecting that I liked summer! I was always delighted to get to mid-winter's day and know the days are starting to get longer. And I still feel dismayed when midsummer's day comes along on 21st June – it seems impossible to believe that the globe is already starting on its winter journey.

My mum, on the other hand, likes winter best of all. She loves to be able to draw the curtains and light the fire and be cosy indoors. Her closest sister, my aunt, loves winter landscapes, with the trees bare. She sees this as the earth bowing to God, shedding all its glory in a prayer for renewal. And I have a good friend who really loves autumn – especially the crunch of the leaves under his feet as he walks through woodland.

I imagine our preference for the different seasons reflects our approach to life. For me, there is a real upsurge of joy in whatever is new. I thrive on hope and dreams. A bit of a Walter Mitty! So it's hardly surprising that spring is my favourite season. I do a lot of mindfulness meditation, and one of the standard exercises is to walk really slowly. So you're not walking to get anywhere, or to enjoy your surroundings, but simply to experience walking. Something most of us have been doing on autopilot since we were toddlers. Slowing it all down brings on a lot of "what's the point ...this is a waste of time" type of reactions, but if you can bear with those and persuade yourself there might actually be wisdom on offer, it can start to get interesting.

What I first noticed was how much I loved the lifting phase of the footstep. You know when your heel lifts and then the whole foot starts peeling off the ground and then lifts off? When I slowed it all down, my heart started soaring with delight at each lift-off! It was a peak experience for me – it stirred visions of heaven and angels! And because I was also grounded, just walking slowly up and down a short path, these moments of pure joy didn't lead to a crazy euphoria, but instead began to confirm my faith that there really was joy on offer from the very simple things in life – like being able to lift your feet when you want to walk.

The memory of this joy also carried me through a lot of difficulties. Even in the darkest moments, there was some part of me that could insist that somewhere in all this mess, joy would show up if only I stuck around long enough.

I'd see my natural preference for spring as part of the joy I felt on the lifting phase of the footstep. It's all about new beginnings – the start of a new year, the start of the next footstep. But it helped me to bring more balance into life when I talked to another meditator who, to my total amazement, said the part she really liked was when the foot came back down on the floor after stepping forward. For a long time, I'd been conscious of how I disliked that phase. It was so full of uncertainty. The confident swing over, the foot retreating, falling, searching for stability. And the first touch-down so light, it feels like nothing. To my mind, totally unsatisfactory! But with her insight encouraging me I searched a bit further, and began to appreciate the growing stability on offer as the weight comes down on that forward foot. How it grounds the body for the next lift-off. Something deep within me started to come down to earth.

Though I never asked her which season she preferred, my guess is that she prefers winter. Things being over. Complete. A time to recoup and stand still. No need to rush. A time of waiting. If my mum and aunt did walking meditation, maybe they would prefer that 'foot down' phase as well.

I have another friend who studies walking in the medical environment – a field known as 'Gait Analysis'. He says walking is actually a process of falling and recovering step after step. Once we got through the toddler phase most of us managed to recover without a thought. But when you slow things down, you feel the off-balance "falling" aspect of normal walking. It mostly happens when the foot is retreating from its forward swing, searching for the ground. It needs an act of faith to believe that the ground will present itself again and be trustworthy. My guess is that my friend who likes crunching the autumn leaves under his feet would also like this phase of the footstep. The letting go of momentum. Retirement. And he is a man who can enjoy the fruits of his labours. Although he had a very successful career, he seems now, in retirement, genuinely happier. So many successful people don't do well in retirement. My guess is that they are, like me, more attracted by the new, the hope, the promise of better things to come.

Summer, in my analogy, is the swing-phase of the footstep. It's a strange one! When I slow it down it draws me into mystery. What is it I'm actually experiencing? In all other phases there are obvious sensations of

touching, lifting, pressing or heaviness, but these fade into something very subtle while the foot swings forward. More than any other phase of the footstep, this one slips through all attempts at definition, refuses to be pinned down. I suppose that also reflects the fleeting happiness of long, lazy, summer days. They make us feel confident, trusting that life is good, but we can't tie down that feeling to anything concrete. It's so insubstantial; fleeting. We can't capture it. Confidently, our foot soars forward towards the inevitable stumble of autumn.

Although I still prefer spring, as the years go on, I can also appreciate what's on offer during the other seasons. Oddly, winter is now my second-favourite! Like my mum, I like the excuse to do nothing, to withdraw, take it easy, recuperate. Summer is still a challenge. Did you ever see the film "Shadowlands"? It's based on the relationship between the English writer CS Lewis and his American wife, Joy, who dies at a very young age from bone cancer. The summer before she dies, she insists that they go looking for his 'Golden Valley' – a beauty spot he loved in youth. When they find it she reflects that this memory will help him through the grief of her death. He squirms, wanting to shut out that thought on this sunny summer day. But she insists "The pain now is part of the happiness then". It's a tough lesson for all of us – to know that happiness is fleeting, and feel the pain of that knowledge. But as his wife Joy says, acknowledging that pain allows happiness to re-emerge when the summer of our joy has passed. That tough summer lesson makes autumn more bearable as I learn to appreciate the past, and look back with gratitude on all the loves that have come and gone in my life, and especially to appreciate my own efforts to add a measure of goodness to life. Autumn teaches me to love the possibility of letting go, saying 'goodbye', to appreciate the sense of a job well done.

And maybe, in a way, I've extended my life by thousands of years by studying a thousand footsteps!



Disabled People Working at Lowes

There have been a few news items recently in social media about disabled people working at Lowe's Home Improvement and I wanted to share mine. One was about a fellow that had his service dog with him at work, and the other was about a Greeter whose electric wheelchair was so worn out that his co-workers raised money to buy him a new one. I did see a discussion on Web Whispers Facebook page recently about returning to work and Lowe's was mentioned by someone who shares the same supportive environment from Lowe's management and co-workers as featured in the article.

I have been a part time cashier at Lowe's since February 2014 and in June 2015 I needed extended leave for cancer treatment and it was approved. I was out on leave for six months, and then in January I had right shoulder replacement surgery, so for a total of nine months they held my job for me. But since I had my voice box removed and could not speak, I was wondering if I could return to the same job as cashier, as communicating with customers is the most important part of that position. It is the last impression a customer has of their shopping experience, so it's important that it be positive.

Lowe's has accommodated my situation well. Management, co-workers, and customers all have been great that way. Lowe's is mindful of my condition and avoids having me work totally alone. I am usually "in the middle" at main checkout in case there is a situation like getting a price for an item I can't find on the web site, then the head cashier can go check the shelf tag or call someone in the department for me.

Text-to-talk is my method of choice for voice communications. I use my own tablet and speaker and an electronic slate for short messages, such as when a customer asks where an item is located in the store, I can write "Aisle 15." I have found E-Triloquist software program (www.etriloquist.com) to provide the most accurate pronunciation and voice inflection of all the voice apps and software that I have tried so far. E-Triloquist also allows me to have a menu of pre-recorded statements such as, "Would you like loading assistance?" and I can type in as the situation requires, like "Customer assistance needed with keys at the hardware desk," which I can play and page overhead.

I try to make it fun and comfortable for everyone because many people have not come into contact with a person that has had their voice box removed. I let children use my electronic slate and draw pictures on it. I often show how my computer set up works and they are intrigued with what technology can do. Customers frequently have questions about my condition, and I don't mind sharing so that they have a better understanding.

There are many regular customers that look for me and will wait in my line rather than go to an open register. In one case, another cashier and I were both standing out in front of the registers where we greet customers when we are not checking someone out, and she said to a passing customer, "Are you ready to check out?" and the customer said, "Yes, thank you, but I'm going to HIM!" Several customers have given compliments to management for my customer service as well, which is shared in an email distribution to all store employees.

It's not uncommon for Lowe's to have 50+ applicants for one position. They do hire all types of people of all ages for all positions. Like any other situation, the person has to be able to do the essential parts of the job for which they are hired with reasonable accommodation. One way for someone to see if it's a good match is to hire on in a seasonal position in February or March. In many cases, if you are reliable and want to stay, they will try to fit you in somewhere when openings occur.

There are several in-store jobs that don't involve a lot of customer interaction for people that may be self-conscious about speech such as "assembler," someone who puts together things that come in a box like wheel barrows, grills, picnic tables, etc. or to set up seasonal displays such as outdoor furniture for the summertime or Halloween displays. Also, there are folks that re-set display space when items are discontinued or not selling so fast, or to make more room for in demand items. There is one job dedicated to changing price tags when sales come and go. People late in the day or overnight unload trucks and bring merchandise out to the floor. There are also jobs in supply centers loading trucks that deliver to stores. Most jobs require speaking and all jobs potentially involve some lifting or other physical effort, but as cashier that is limited.

Many people having voice box removal do qualify for disability, but for those that either do not qualify or like me find a situation like this good for physical recovery and mental and social activity, I certainly would recommend that they consider pursuing their interests.

~Mark Reichenbacher , West Virginia 2015 ~



Halloween and a Monster

It was Halloween. The front door bell rang and expecting a friend, I did not affix the Buchanan bib around my neck nor did I put the hall light on. So I opened the door in semi-darkness, only to find six rather small, seven year olds all scarily dressed with their faces painted in a skeletal design. Each was holding a torch to their face upon which shone a green eerie light.

The obvious ringleader I recognised as my neighbour's grandson, a lad I had spoken with on many occasions. He had obviously said to them, before ringing the bell, that in this bungalow lived a man, who spoke words out of his neck, and on shining his green torch at my neck, exposing my stoma for all to see, he said triumphantly, "There, what did I tell you."

Five little mouths and eyes opened wide, as they all shone their green torches on my neck and face, at the sheer horror of being so close to a real Halloween monster. Because they were so low, not all my face was illuminated in that eerie light, with my eye sockets being like the hollow darkness of death. There were moans and sighs all around, and they completely forgot to say, "Trick or treat." as I fumbled for coins to give them, the young ringleader said, "Could you show them. Could you make words come out of your neck?"

I duly put thumb to throat, and wished them all a happy Halloween. They looked astonished, and all took a step backward. The young ringleader's chest swelled with pride. There is no doubt I had done the young man a power of good that evening. I wished them all goodnight, and as I closed the door, I heard him boasting as they walked down the path, "Of course, he's a friend of mine. He's very good really. Does Christmas presents."



Bits, Bytes and No Butts!



Frank Klett

Things That Confuse Me...and Things That Don't

With the Advent of Windows 8 we were introduced to many new "techie" things and phrases. Most are genuinely new while others are creative acronyms for the same old stuff. One of the newest and perplexing to me is UEFI which is going to replace our BIOS ...Yuck! Sounds like a bad day at the office.

UEFI is an acronym for Unified Extensible Firmware Interface. It is occasionally, albeit technically incorrectly, referred to as "UEFI BIOS". It must have taken me 2-3 years to finally get BIOS and just enough to know the minimum I needed to live with it. Now they have this UEFI to supercede my BIOS and only God and Microsoft know why. But in case you are interested here's the brief version. I want to give credit to Leo of Ask Leo fame for his words of knowledge. "The UEFI, like the BIOS it is designed to replace, is software built into PCs, and performs functions such as:

- Power On Self Test (POST)
- Loading of the operating system from bootable media, such as the installed hard drive, an inserted bootable CD or DVD, or a bootable USB device
- Acting as a standard interface layer between operating systems and the installed hardware

A UEFI typically has a user interface of some sort that is accessible (only) at power-on, before any operating system is loaded. This UI, which is typically more extensive than previous BIOS UIs, allows many of the configuration options, diagnostics, and other manufacturer-specific functions to be accessed before any operating system is loaded.

One of the more notable, and occasionally frustrating, features of UEFI is "secure boot". Secure boot allows the boot process to be "locked down" according to the PC manufacturer's specifications, preventing unauthorized operating systems or boot sources from loading. Like the BIOS, the UEFI is typically stored in re-programmable ROM, allowing it to be updated using special reprogramming software. Unlike the BIOS, additional portions of the UEFI may be stored on reserved areas of a computer's hard disk."

Glossary Terms are featured selections from *The Ask Leo! Glossary*. Have a term you'd like defined? [Submit it here](#).

Just in case you need a link for the latest Windows10 downloads this one will get you there and yes it is free. <https://www.microsoft.com/en-us/software-download/windows10>

Now in case you're wondering why this could be important ...well it seems the newest versions of Windows (since Windows 8 was introduced) are intended to run on PC's with UEFI instead of BIOS. This is intended to be an additional security feature to protect us from bad things and from ourselves. Microsoft's theory is that if they are able to control what we can run on our PC's then not only are we safer, but so are our online friends (who are now more protected from other infections). Consequently you need to be sure you know if your version of Windows will run on a BIOS system or if it needs the UEFI to meet standards.

Amazon Echo Revisited

Amazon has started shipping its newest Dot and at \$49 each they are going pretty quickly. In fact should you care to you can have one for each room of the house or your office. If you own an Echo you probably love it or hate it, depending on your expectations versus your usage.

I have owned one for about 2 years now and I am somewhere in the middle. I use it daily but if it died I could live without it since many of the things I use it for I can use my PC for.

One question came up regarding speaking to Echo as a Lary...damn fine question! I use a Tru-Tone and I have found the Echo does not like it unless I use the hand held remote. This is a case of what voice you have chosen and just how well you have mastered your clarity and enunciation. I have found it seems to be a matter of voice volume than clarity though I am sure it is a matter of both to some degree.

If you are considering a voice activated device of any kind I would base my decision on your experience with Siri or Cortana, which you already have available on your PC or Mac.

Just a brief review:

What's New With Echo Dot 2?

First came the tall, speaker-rich original Echo (\$179); then the hockey puck-sized Echo Dot, priced at just \$99; and now a second-generation Dot that does everything the original Echo did, and more, for only \$50. The Echo Dot 2 is slightly smaller than the first Dot. Its speakers are equivalent to a smartphone's - not high-fidelity, but adequate for close-range communication. But you can also connect the Dot 2 to your own speaker system via a 3.5 mm plug or Bluetooth for surround-sound weather reports.

TV and Media

We already have many alternatives to broadcast television. For the new generation the cable companies have been hard pressed to give a compelling reason for them to "pay" for their entertainment. The reasons are various but for most it's a matter of expense and lack of choice.

Once upon a time the cable companies convinced the government entities that in order to build an infrastructure to support providing cable service to their communities they would need the right to be the sole provider of those services in order to recoup their costs and to continue a viable long term service. And there you have it "Hook Line and Sinker". We were had! Contrary to cable the satellite providers did not have the same protection required, hence we can select their service instead of cable.

The new service market includes many ways to select your entertainment provider or providers. We have **Netflix (\$8 per month)**, **Hulu (\$8 per month)**, **Amazon Prime (included in Prime Membership)**, **Sling TV (\$20 per month)**, **Snag Films (Free)**, and soon to be **You Tube Pentium (No Pricing announced)** and **Apple TV (no pricing announced)**.

Depending on one's tastes and budget it is now possible to selectively purchase media services as you desire or none at all by using the old standby antenna for over the air broadcasts. The links below will provide more info and reviews on the various products:

Sling TV

http://www.cnet.com/news/sling-tv-comes-to-xbox-one-adds-history-lifetime-to-base-20-package/?tag=nl.e404&s_cid=e404&ttag=e404&ftag=CAD1acfa04

Apple TV

http://www.cnet.com/news/apple-said-to-plan-launch-of-subscription-tv-service-to-in-the-fall/?tag=nl.e404&s_cid=e404&ttag=e404&ftag=CAD1acfa04

This is a Security Reminder for All Yahoo Users

If you are a Yahoo user for email or news or any of the Yahoo services that require you to sign into your account then you need to know that your password and info may have been compromised. Yahoo finally release the news that they had been the target of a humongous hack which resulted in over 500 million passwords being captured. Change your passwords now if you have not done so in the last 2-3 weeks. The folks at CNET have been following this since it was announced by Yahoo and recommend you change your password now even if you weren't a regular Yahoo user. Better safe than sorry. Follow the link below for more specifics:

<https://www.cnet.com/news/yahoo-500-million-accounts-hacked-data-breach/?ftag=CAD1acfa04&bhid=22689509801318612450239913742762>

Stay secure by updating insecure programs on your computer with the Secunia PSI

“The **Secunia Personal Software Inspector (PSI)** is a free computer security solution that identifies vulnerabilities in non-Microsoft (third-party) programs which can leave your PC open to attacks. Simply put, it scans software on your system and identifies programs in need of security updates to safeguard your PC against cybercriminals. It then supplies your computer with the necessary software security updates to keep it safe. The Secunia PSI even automates the updates for your insecure programs, making it a lot easier for you to maintain a secure PC.”

Using a scanner like **Secunia PSI 3.0** is complementary to antivirus software, and as a free computer security program, is essential for every home computer. One of my favorite free for home users' security programs is Secunia's PSI, which ensures your critical programs are up to date. This is critical to a safe system since most program updates are released to plug holes in the software that have been found to be a way for hackers to gain access to your system.

You can download and install PSI by going to: http://secunia.com/vulnerability_scanning/personal/

Press the download button and once it is downloaded “run” the installation package. The program is self installing and will scan your system for your programs. Once the scan is complete it will give you a report of your programs and of any that need to be updated. By simply clicking on the programs that need updating PSI will download them for you and begin the installation process. Once the initial scan and updates are complete PSI will run in the background for you to ensure your system stays current and secure.

Additional security Thoughts Using a VPN

Online security and personal information theft have been increasing issues for all users and it seems we all need to relook at our online habits. One of the very best online security tools has been getting a lot of press lately. The world of VPN (Virtual Private Network) has nearly all the answers for us in today's online world. A VPN is software you can download and install, which will then allow you to mask you online identity or even appear off-line or from another part of the world, masking your true location.

I know much of this is beyond what most people think they are capable of, however a little reading and you can be up and running in no time.

Dave's Computer Tips has a very well put together article on VPN's and just why they are so effective; https://davescomputertips.com/5-best-reasons-for-using-a-vpn/?utm_source=wysija&utm_medium=email&utm_campaign=Weekly+Recap+Newsletter

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. You can read over the questions and insights of other Larys as well as ask questions and get answers from our knowledgeable members.

And for our newest members remember to visit the **WebWhispers 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.

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