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COMMENT HERE

FEEDBACK
Yep, It’s Me Again

While considering other suitable topics I could write about here, another continued to stick its head in the door and holler “what about me?”. It is called the International Association of Laryngectomees Annual Meeting and Voice Institute and it just won’t stop calling my name. Seriously, this is a topic I’ve written and spoken plenty of to the point that some may be sick of hearing from me about it. Sorry, I can’t help you with that and there are good reasons why.

I will never forget the effect my first Voice Institute had on me as a new lary, because the benefits were truly that profound. The short story? Without what I learned there and the overall experience, I know that my life as a laryngectomee would not have turned out as well as it has. Things now would be sadly different and I can’t even let my mind go there. I learned about the event only a month or so in advance and thought I didn’t have enough time to pull it off. To say that I arrived on a shoestring would be less than truthful. My shoe string had three repair knots and was reinforced with duct tape. With knowledge of a little financial assistance and hard-core determination, I did make it to Buffalo for the event. I have not missed one since and the upcoming VI will be my fifth. I hope to see and/or meet you there, especially those of you who think you can’t make it happen! If you haven’t already planned to attend, do so now. See the links below.

http://theial.com/ial-voice-institute-and-annual-meeting/

Need help getting there?

WebWhispers has scholarship funds available for WW members who are recent laryngectomees and other members who have not previously attended a Voice Institute. Additional applicants are considered based on other criteria, but only after newbies and Voice Institute first-timers have been assisted with attending the event.

Note: Applicants must first register for the Voice Institute before applying and all awards are distributed at the
WebWhispers Dinner on Thursday night, June 7, in Orlando. Click here to complete and submit the WebWhispers Scholarship Application:

https://webwhispersinc.formstack.com/forms/webwhispers_scholarship

For scholarship questions, email us at scholarship@webwhispers.org

The WebWhispers Annual Awards Dinner is not included in your VI registration and reservations are required. For more information on the dinner and how to make reservations, use the link below. This is our only face-to-face event of the year.

Please join us!


Florida or bust!

Enjoy, laugh, and learn,
Tom Whitworth
WebWhispers President

"What method of speech do you use and why did you choose it?"

I knew absolutely zilch about picking a way to voice before or after losing my vocal chords to cancer, and the Face-breathers of my doctor's office and the hospital were of little help. Sooo . . . my only method the first six months was pen and paper.

My SLP was a tad more helpful and I went back to my doctor to inquire about the TEP. Don't know if he was against them or not, but he told me I wasn't a good candidate for one and he informed me of all that could go wrong with them. Cost was also a factor. My stoma is only about the size of a dime. Don't know if that was THE reason I wasn't a good TEP candidate, but it mattered little by that point. My doctor was a crusty ol' coot that believed one could have a good life without buying into all the "contraptions" being sold to Lary's and one must be able to purchase them regularly if one chose to begin using them… We were not.

Next on the list was the EL and esophagus speech. Loved the EL, but couldn't afford one and I suffer a profound hearing lose in both ears. But couldn't afford hearing aids at that time. Had no insurance and, while
we were able to find help here in the county to cover all the med bills thus far . . . they weren't fond of buying an EL or helping with my hearing problem.

About a year or so into this amazing neck-breathing journey I met (via WebWhispers) Debi Austin and she sent me one of her old EL's. Wasn't quite able to get it to sound as deep as I'd have liked, but it was a blessing for sure. So what if I sounded a little girlish. I'm comfortable in my manhood.

Only problem was . . . continued usage in lengthy conversations caused me to have severe muscle spasms in my neck. Talking middle of the night charley horse painful. Whee doggie them is fun, eh?! No one could explain WHY that happened, naturally. Kept on using it, of course, but had to limit myself so I didn't have these spasms and yes . . . I have an EL as backup and I still have muscle spasm if I use it for long conversation.

Long about 2008 I heard from Ultra Voice.

Yes, yes . . . I know . . . many dissatisfied customers out there, but I am not among them.

From the very beginning I was happy as the cat that ate the canary. Man I loved this way to voice and still do. The folk at Ultra Voice have from day one always been willing to work with me to get (and keep) my voice working. Through phone calls, emails, and video chats so they could hear what I was talking about when problems arose.

Wouldn't dream of not having my Ultra Voice.

Troll - Florida
Class of 2006

My name is Thomas F. Mosser and I had my laryngectomy 8/13/2014, and I use esophageal speech to communicate.

So let me relate my story and how I got to esophageal speech. The doctor was going to do a puncture for a TEP, however for some reason at the time of the operation he was unable to do the puncture. When he met with me after the surgery he said he could do the puncture at a later date. So that was fine with me and in the meantime I learned about WebWhispers. So home I went with an Electrolarynx with no idea what I was to do with it. I had a visiting nurse come visit me and helped me with the Electrolarynx. At this time I was checking out the TEP and found that there were a lot of negatives to go with it. As you know we are all different. I thought to myself that it might be a good idea to try esophageal speech. So the VN hooked me up with a SLP and we went from there. I started out going every day and then 3 days and then 2 days and finally to 1 day a week. When I was going to my SLP and before I met with her I was practicing using Edmund Lauders audio on esophageal speech. That was very helpful and I would listen and work with it 2 - 3 times a day. It took me about a year to become good at esophageal speech and I'm so glad that I did.

I believe that there could be a better system expanding all the examples that are available and just not go with a TEP. The TEP is quick and you are able to speak relatively quick however a person should be able to converse with a person with a TEP, electrolarynx, and esophageal speech and be able to make a decision based on what is best for the individual.

I hope this was not too long and you are able to follow my story. Thank you for allowing me the chance to share it.

Thomas F. Mosser – Bethlehem, PA
8/2014
I can't remember what day it was after my surgery. I was in a lot of pain, and kind of goofy on Morphine. At this point I was under a hundred pounds, and members of my family had been flying in from all over the country to say goodbye. Of course I didn't know that. It never entered my head that I was going to die there.

A nice man showed up at the side of my bed with what I found out later was a Servox. He said put this against you neck and press the upper button

Well, He didn’t tell me where to put it on my neck, so I placed it just below my right ear. When I pressed the button it almost blew my hearing aid out, and kind of scared me. I decided right there that damn thing was never going to work for me.

Two days later the woman showed up with another speaking device that had a long plastic nozzle like on the end of it. Once again I later discovered it was a Servox with that tube attached to the end of it. She was my SP, but I didn't know that. She said put the end of it in my mouth, and then just talk normally. I have a complete set of dentures, and that thing didn’t work well either. She said that I should take it home and practice. She said that she would come back to see me in a couple of days to see how I was doing. I have never seen her again.

When I got home I discovered that she had her name and address card taped on the Servox, so I assumed that it was hers. On my next visit to my surgeon I put the Servox in a bag, and told him go give it back to her.

He was a good friend of the SP and suggested that I just give her a chance. On my next visit to my surgeon I told him that I didn't want to see her, and my daughter had been upset with her too. Then he gave me bag with the Servox in it, and said he would recommend a new SP. After I came home from the hospital I just use hand signs and notes to communicate with everyone. I also had a small fistula, and had to continue to use the feeding tube in my throat.

The fistula healed, so I finally I went to my new SLP, a 26 year old nice young lady, but I concluded that she didn’t know beans when she got ready to pull out my feeding tube, and said this is probably going to smell pretty bad. She didn’t seem to know that I could no longer smell. Things went down hill from there once again. She concluded that just because I am legally blind I would never be able to use an implant or something in my neck. I had no idea what she was talking about. She was probing around in the hole where the feeding tube had been trying to measure the size of the plug to put in the hole. She kept trying to find the right size, and I could watch her in the next room doing something, and well over a half hour of her poking around in my stoma I had tears rolling down my cheeks. It had started to really hurt. She apologize and said that she didn’t have the right size so she had to put one a size larger than I needed, but it would work just fine. She gave me a package with a replacement plug, and said to carry this with me at all times just in case the plug popped out. I carried it around in my pocket for two years, and when I discovered that I could never put in anyway I quit carrying it.

Then she gave me a box with a new Servox in it. That’s when I discovered that my insurance company had paid for the first one also.

I got used to it right away after I sound the sweet spot. In the meantime, I had heard about a TruTone that I could vary the sound with, so I bought that too. For some reason one of my two Servox Els works a lot louder and better than the other Servox or TruTone. I have asked the Servox company about this, but they have never responded. There seems to be something they might not even know. I have had other suppliers tell me that I have a very good Servox, and I should stick with it.

Now I have a bunch of 9 volt batteries, and eight rechargeable ones. Replaceable batteries for my Servox are over $40 at Amazon. I have one spare, and I hope that it will last a long time. As it stands now I don’t have an SP, and rely entirely on Ron Matton and Rita Burfitt all my advice along with Troll and several others at WW.

That’s my story an I’m sticking to it.
My Husband Dave West had surgery May 2015. The TEP hole closed over Sept 2015. Waited two years and got a new TEP May 2017. Couldn’t talk till Feb 2018 when they changed the size to 12mm. Then it leaked so we just got a 12mm duckbill. Not leaking and can talk. Sometimes he just talks without covering stoma hole. But it’s a whisper. Still nice to hear both ways.

Cathy West - Garden Bay, BC

I had my laryngectomy in August 2017. At the time I didn’t know anything about availability of different methods of speech. I didn’t even know that TEP can be done later on after the surgery. So, I had TEP with installed prosthesis at the time of laryngectomy surgery. When I was in the hospital (M D Anderson, Houston) recuperating, sales people approached me about the electronic larynx but I really didn’t quite understand the message. Thus with TEP and the prosthesis in place, I had no choice but to stick with TEP method of speech. After about 8 months from the surgery, the adhesives I tried still leak and my stoma is not quite ready to accept a lary button. I can speak only with the bare stoma closed with my thumb. Even then, the mucus tends to cover the opening of the prosthesis which stops me from talking unless I clear the opening with a brush. I am working on it.

That’s my story. If anybody has any comments on any of my problems, I would love to hear from them.

Raj Phansalkar - Ponca City, OK

I chose the EL. Because the TEP I read has lots of problem with it and not for everyone, but a lot of people use it. And it’s more work daily. And you have to pay for a new one out of pocket every time they change it. My medical only covers the procedure. Not the part.

Susan Belz – Philadelphia, PA

I had a total laryngectomy on Aug.21/17. Right from the beginning the surgeon only talked TEP and so that is what I ended up with. Additionally, prior to the operation I communicated with two laryngectomees and they both had TEPs and so I learned from them what life would be like post operation. They are both very effective and competent TEP speakers. I managed to speak quite well with the TEP and was content to believe this is the way it will be for me going forward. However, I’ve had a recent experience that’s changing my outlook. I won’t go into the details but about 1 month ago my fistula closed so obviously I couldn’t talk anymore.

Surgery to reopen the fistula can’t happen until May. So an ENT friend of mine suggested I get an electrolarynx in the interim so I can talk. I did so and have been using it for about 1 month now. I’ve become quite proficient speaking with it and I’m communicating very well. A side effect I continued to have after the operation while using the TEP was a lot of gas and almost constant pain in my stomach. Since the fistula closed I have no gas and no pains in my stomach (I understand that those side effects are supposed to disappear (with time). Also cleaning is a snap compared to cleaning when the prosthesis is in.
So I'm at a cross roads because with the fistula closed I'm feeling great and I like that feeling :) I'm seriously thinking about leaving the fistula closed and continuing to use the TruTone Electrolarynx. Can anyone relate to my experience?

Gerry Stanton – Kanata, ON
2017

I have decided on using TEP (inserted during laryngectomy surgery) mostly guided by advices from speech pathologists and listening and watching others at laryngectomees’ support group here at the University Hospital. I am still struggling with selecting the best (for me) housing for HMEs.

Jan Czarnecki – Alberta, Canada
10/2017

My name is Christine Pieper and I live in Fond du Lac, Wisconsin. I use a Tobii Dynavox Churchill Litewriter as my form of speech. The radiation I had did too much damage to my neck, and they had to use so much muscle and whatever to rebuild it, that I was told I couldn't use a voice prosthesis. That's fine by me, I am doing just fine. My surgery was April 11, 2012.

Christine Pieper - Fond du Lac, WI
4/2012

I'm just starting to use esophageal speech. I bought your book ‘Look Who's Talking’ about a month ago and am currently working through the exercises. On #10 right now.

I use esophageal speech all the time and everywhere I go but take my EL ‘crutch’ along for backup. Hopefully I’ll be able to leave it at home soon. I’m feeling very confident with my new voice.

Didn’t really know much about the esophageal method until I encountered a fellow at an Atos meeting that was using it and that inspired me to try. Best decision I’ve made lately.

Your book is very helpful as well so thanks for that. Hopefully someday when I’ve mastered the technique I too will be able to inspire others, that’s my goal anyway.

Dave Sherr – Lenor City, TN
11/16

Before my laryngectomy in 2002, I was very keen to use a voice prosthesis and had a primary puncture. Soon after the operation I was able to produce valve speech at a decent volume. I was keen to return to my work as a teacher but a problem became apparent at an early stage. Using the valve the pressure I produced meant the baseplate seal failed too easily and speaking through the day was unrealistic. As a result, an electrolarynx became my first choice and I successfully went back to teaching using one.

I now spend much time helping others get the best out of an electrolarynx, or trying to persuade them to use one rather than remain voiceless. For some patients valve speech will never be possible, and for many others, if only on a temporary basis, an electrolarynx will be a vital piece of equipment.
Puncture at time of surgery. Given EL in hospital and used for the first few weeks post op. Prosthesis installed, unable to speak at first due to constricted PE segment. Botox corrected it and now a TEP speaker, hands free with valve mounted in Barton Mayo button.

Working fine for 18 years.

Dick Sipp – Midland, MI
2000

Four days before my total laryngectomee my SLP introduced me to the idea of Esophageal Speech (ES) by having me watch a pretty good video made by two ladies who used ES very well. Both were teachers who had returned to their teaching jobs; one taught 3rd grade, and the other taught high school French. Lovely, feminine, intelligible speech that sounded normal enough to assume they had a laryngitis. I was convinced I could do this, too. My post op speech goal was set in my mind, and I told my family that I would return home “with a working vocabulary using ES”. Little did I know how many hurdles I’d need to get over before I realized my ambitious goal. After surgical healing there was the radiation, and more healing. It took a while to find out the biggest hurdle was NO thyroid function. Chances are good that I was somewhat hypothyroid before the laryngectomy; which included the removal of the right lobe of the thyroid, then radiation fried the left lobe. Nobody told me about any of this until a neighbor who was a long time surgical nurse recognized my symptoms.

I did go to speech therapy and managed 3 syllables of ES before, and shortly after my radiation, but soon there was nothing reliable happening ES wise. I used my electro larynx to get on with my life for almost 2 years before I met a new endocrinologist who had studied at Mayo Medical School and knew that my surgical protocol had entailed removal of the right thyroid lobe as well. He started me on a low dose of Synthroid, and gradually increased the dosage. With 6 weeks I was speaking with ES, as well as the teachers I had seen on the video. You may ask how does thyroid function have anything to do with ES? The symptoms include: water weight gain, depression, confusion, loss of memory, libido, hairline & bottom 1/3 of eyebrows, body temperature control, and more. I asked this very question, and was told that when the body swells with water weight the brain and tissue also swell like a cooked sausage, so for ES the body needs the agility and flexibility for the required coordination needed to produce ES. I bless that doctor to this day.

I chose ES in the fall of 1978 for the simplicity of it, and the very natural sounding voice. I stand by my choice. It was worth the wait and struggle to get over the manmade hurdles to reach my goal. I take pleasure in sharing my gift, and “pay it forward” by teaching ES.

Elizabeth Finchem –Tucson, AZ
1978

I have used an Electrolarynx of one type or other almost exclusively for the past 17 years. By choice? Not really. Initially, I did not have much of a choice as far as method goes. At a 4 week post surgery appointment, my surgeon expressed great disappointment in me that I had not already developed and mastered Esophageal Speech. I suspect he was old schooled and after trying very hard to develop Esophageal Speech and failing, I gave up on it. Surgeon said I was lazy, had I been able to speak at the time I may have
uttered some choice words of my own to him myself. :-)

Like many others, at first, I resented the robotic inhuman sounding device. Three months later, an entire forest eradicated from my use of pen and paper, I was persuaded to reconsider the Electrolarynx as a viable option. In time I became better at producing fairly intelligible speech with these devices.

A couple years out, at an IAL Annual Meeting and Voice Institute, I became fascinated with the Tracheoesophageal method of speech and volunteered for an insufflation test to determine if the method would work for me. I passed the test with flying colors, however, I learned that prosthesis maintenance and replacement was not covered by my insurance and therefore that method would prove cost prohibitive for me.

I have adapted quite well to the Electrolarynx devices and can produce intelligible speech with many brands. As is often asked and subsequently answered:

Q:) What Voice method is BEST?
A;) The one that works for YOU!

Michael Csapo – Twentynine Palms, CA
Class of 2000

Next Month’s Question:
“How is your health insurance when it comes to lary supplies?”

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

Staff of Speaking Out
Heat-moisture exchange (HME) systems help restore some functions of the nose to neck breathers: warming, humidifying, and filtering the air they breathe. This reduces coughing and mucus production substantially. A heat-moisture exchange system usually consists of a cassette (a circular device filled with material that retains heat and moisture), and a housing for the cassette, which may be a laryngectomy tube, laryngectomy button, or adhesive baseplate. As speech-language pathologists, we know how important heat-moisture exchange is for the pulmonary health of our laryngectomy patients. We try to ensure that everyone involved with the patient’s care understands this importance, and we go out of our way to make sure the patient is compliant with using the HME system. But sometimes we face stumbling blocks—inconsistent education of staff and caregivers, poor access to supplies, non-compliance….we’ve all experienced them. So how do we solve this multifaceted problem?

My position with my current organization was created as an addition to the head and neck multidisciplinary team, so I had the opportunity to help develop our laryngectomy HME care program from the ground up. Prior to this, our patients were poorly compliant with HME’s, and education was sparse. Now, our program provides education and support for heat-moisture exchange use at every level, starting with preoperative counseling, continuing during the inpatient stay, and expanding at the outpatient level.

Our patients are more compliant with their HME systems as a result.

**The Preoperative Phase**

I typically introduce heat-moisture exchange systems during the preoperative phase. I explain to the patient and caregivers that a laryngectomy tube will be placed after surgery to house the HME system. I show them what the laryngectomy tube and HME cassettes look like and explain the purpose of the HME system. I provide educational materials for review at home as well.

**The Acute Hospital Phase**

The best way to facilitate HME compliance is to introduce the system early and educate the patients consistently, and this starts in the immediate post-operative period. Our facility provides a kit for new laryngectomies that includes a laryngectomy tube, 30 high flow HME cassettes, neck straps, cleaning brushes for the tube, and a shower guard. We also provide written information about the use and care for all the items. When we first introduced our laryngectomy kits, we provided extensive training to nurses and respiratory therapists as part of their ongoing competencies.

Laryngectomy tubes are placed as early as possible, oftentimes in the operating room. The patients and their caregivers learn to place and remove the HME cassette and laryngectomy tube early during the hospital stay. Surgeons and nurses provide the initial education, and SLPs and respiratory therapists reinforce this whenever possible.

Starting this process in the hospital and providing patients with sufficient supplies for the transition home has led to much better compliance with the HME system upon discharge.

**The Outpatient Phase**

During the outpatient care phase, further support for HME use is provided. I see all laryngectomy patients in conjunction with the head and neck surgeon at the first postoperative visit. Most of them arrive wearing the HME system and report consistent 24 hour daily compliance. At this point, we help them with troubleshooting and continue to encourage compliance. Once the patient heals, we introduce alternative HME housings to the laryngectomy tube, including various adhesive baseplates and laryngectomy buttons. If appropriate, we may recommend a regular flow HME cassette to maximize humidification.
It is often difficult for patients to acquire heat-moisture exchange supplies initially as there are not many durable medical equipment companies who stock these specialized items. Many patients become overwhelmed with this process and require assistance with finding a DME provider. It is helpful to keep a list of approved providers for different insurance plans. In some cases, an insurance company will approve a contract with one of the manufacturers of HME supplies. The insurance company pays the in-network rate for supplies for a defined time period.

Heat-moisture exchange systems are key in improving the pulmonary function of laryngectomy patients. The use of these systems positively impacts quality of life and comfort in social situations for them. Ensuring proper education and patient compliance involves a multidisciplinary team committed to these goals at all levels of care.

**Dear Lary**

With A Little Help From My Friends …

How come I’m so much more accepting of laryngectomy when visitors are around? I smile, I’m happy to listen, I willingly forego my share of cake and bikkies (taking a bite would keep my tongue fully occupied and prevent me from talking). I’m often tempted to override my body’s plea for silence to let acid reflux drain back into the stomach where it belongs. I’m not put off when I notice my visitor frowning as they attempt to concentrate, to decipher speech from noise as I talk. I’m just grateful to them for making the effort. Basically I become more outgoing, more sociable, more agreeable, less defined by the limitations of laryngectomy. But sometime after the door closes behind them I slip back into ‘the old me’. Irritated by the harsh sound of my voice (“Why bother making small-talk with a voice like this?”), annoyed if I’m asked a question as I munch the leftovers (“Do they not know I can’t eat and talk?”), depressed by requests for help (“Do they not know how hard it is living with laryngectomy?”), looking askance if someone offers a compliment (“They obviously don’t know the real me!”).

Then again that ‘old me’ evaporates with the next ring of the doorbell! Some joyful part of me gets reborn. It’s all quite unconscious. I don’t set out to be nice to visitors. It just happens. The visitor wakes up ‘nice Noirin’ and tucks her up again as they close the door, leaving ‘the old Noirin’ to brood by her bedside.

The pattern predates laryngectomy. I remember – perhaps it was 20 years ago – driving to a conference to do with work. I was in foul humour, hating my job, finding it stupid and hopeless, hating everyone related to work, hating the obligation to waste an evening with all this pretence and folly. Then I got to the function and met a colleague. My troubles evaporated in an instant! I got genuinely interested in whatever we chatted
about, glad to be part of the team, inspired, and quite hopeful that it would all work out.

On my way home afterwards I was amazed to reflect on such a transformation. Especially as I wouldn’t really think of myself as a ‘people person’. I’m more cerebral. I studied science and engineering and had always been happy to spend long hours tinkering away at an electrical circuit or a computer program or any technical project. Though I enjoyed working with others, it never bothered me to work alone.

What was I to make of myself? Was the ‘real me’ the foul-thinking one who had driven to the function? Or was it the smiling happy one who attended the function? Or the reflective one who drove home? Did I need friends more than I thought? Was I not actually the independent, scientifically minded, self-motivated person I had believed myself to be? And even nowadays – is the ‘real me’ the good-natured one who welcomes visitors and loves to chat despite the limitations of laryngectomy? Or is it the grumpy one who hates these limitations, is bored by small talk, groans inwardly at requests for help?

My best hypothesis to date is that there’s no ‘real me’. Who or whatever I detect inside is as variable as the Irish weather, bright and breezy in the morning, rain spreading from the west in the afternoon, icy cold at night.

But the wonderful thing is the detector. It’s not defined by the weather. Mindfulness has been my detector for the inner world of moods, thoughts and feelings, seeing how these are affected by the outer world of doorbells ringing, people chatting and laryngectomy. Slowly, imperceptibly, the detector takes the turbulence out of ferocious weather, nurtures a sunnier climate.

But the weather can get worse before it gets better! It’s easier to forget about ‘bad-tempered Noirin’ as soon as a sunnier mood comes along. To remember her in the full light of day is a challenge. The habit of self-judgement locks in hard. Bad-tempered Noirin is very bad indeed. She has to be quelled, defeated, squashed out of existence.

But this strategy has its limits. If Noirin is all bad, who is squashing her? Although the question can’t be answered in words, I can explore it mindfully, dropping it into my psyche like a stone drops into a pool of water. The stone disappears, but you can feel the ripples. So too my body might tense and shudder as my mind contemplates the mystery of this human nature, with its impulses to anger and selfishness and its contrary impulses to friendliness and generosity.

More and more often, nowadays, I can detect a middle ground, the potential for both extremes. If mindfulness switches off I go about my daily business without noticing that every moment has this incredible potential for ‘good Noirin who accepts laryngectomy and still finds the world beautiful’, ‘bad Noirin who hates laryngectomy and can’t cope with life like this’ and all the many shades in between.

Just noticing the potential gives me courage. ‘Bad Noirin’ loses her ‘bad’ label and becomes more like an ache. A quiet kindness tiptoes towards the ache, suggesting forgiveness and care. It’s scary to trust my aching bits to human kindness which can so easily turn to anger or selfishness. But what choice have I? As the body relaxes, thoughts register the underlying problem: the fear of moving on. Who will I be without my heartache, my loyal attachment to the fluent-talking Noirin of five years ago? How can I say goodbye to this beloved version of myself?

I don’t have the answer yet, but am confident that mindfulness will help me carve a path through the aches and grumbles of a not-fully-accepting-laryngectomee, help me smile again when the doorbell rings. In the meantime, I’ll get by with a little help from my friends!
Vivaldi the Browser, Huawei Matebook?, Windows Gotcha!

I recently had an email question from one of our members regarding the ability to update his Windows 10 operating system to the latest build. A build is the software developer's way of identifying the various versions of a specific software suite...since a software suite is constantly under some stage of refinement, bug fixing, and in some cases simple adding or deleting features. With all this going on the developer must have a reference point to ensure that the software remains stable during these processes...this is called "Configuration Control" in the software development community. So why am I rambling on about this? Just to provide those of you who need it a very brief idea of the parts and pieces of what it takes to develop and maintain that Facebook icon you take for granted each day.

So here is where the question I received led me. Microsoft has actually taken a money-making trick first started by Apple Inc. Back in the early days of software and hardware development, Apple realized that the quality of their products was the edge they needed to remain competitive with the "other" operating systems and hardware developers. The problem now was not the quality of the product but how to drive future sales for a product that doesn't die? Solution: "Engineered Obsolescence".

Apple began developing new features and apps with dependency upon new or modified hardware components. The result was for the user to upgrade his/her hardware in order to realize the benefits of the new features.

Today's Windows 10 has the similar requirement and folks are finding out that their computer is no longer satisfactory for upgrading to certain versions since they do not meet the hardware requirements. Why you ask? Very simple...in order for Microsoft to gain the support of the hardware entities they had to provide a reason for the consumer to upgrade their hardware thus driving up PC sales. If this was not done the PC market would be non-existent today.

Our options:

1 - Switch to a Linux operating system...too scary for most people.
2 - Continue using the version of Windows 10 you are currently on and forsake some of the newer features.
3 - Install Windows 7 and have an operating system that will be supported until 2020 and probably longer.
4 - Give in and buy a new Computer system that meets all the new perquisites of Windows 10. This should be a safe option for the next 5-6 years.

I recently read a review on a laptop/tablet similar to the Microsoft Surface made by a Chinese company, Huawei,(pronounced: Wah Way ) called a Matebook. For comparisons, the Surface sells for $1,200 to $2,400 depending on selected options.

The Matebook lists for $699 to $999 depending on options. I was fortunate to find the Matebook on sale for $599 and decided to finally make the change. I have been using it for about 3 months now and have been
more than happy with the performance and feel of this neat little PC. I am certain we will be seeing more Huawei products on sale here in the USA since Huawei is the largest Electronics manufacturer in Asia. The quality of the product and the pricing level makes it a very attractive alternative to our legacy product lines.

Last month I wrote about the Vivaldi Browser and its threat to the reign of the Chrome browser the current number One browser of choice. I decided to load it on my systems and give it a full out and out run for the money (Which is free of course).

https://news.filehippo.com/2018/02/vivaldi-browser-better-than-chrome-is-it-the-next-big-thing/

I can see now why the critics were excited about it. It has the same basic engines that drive Chrome, but the interface has been built around the most requested features of the user community. It is still under going some changes even today to meet customer demands. If you haven't tried it do yourself a favor and give it a test run, maybe this weekend.

Take a swing over to this link and you will have this new browser up and running in no time...while there you can read another serious review for this super-duper terrific browser:

https://news.filehippo.com/2018/02/vivaldi-browser-better-than-chrome-is-it-the-next-big-thing/

While the program downloads and installs enjoy a few moments with the Celtic Woman:

https://www.youtube.com/watch?v=DquA6KyHTos

For those of you who enjoy the games and surveys on Facebook you might consider curbing your activity in light of recently disclosed facts. It seems all those surveys and games were a very simple way of gathering information about you and you habits and preferences. Read on for more information:

https://askbobrankin.com/alert_facebook_surveys_and_quizzes.html

As you may know by now we have a new volunteer driving the ship in our Forum...Mike Csapo is an old hand at getting things rolling and making it enjoyable for all. Be sure and stop in and let Mike know just how you feel about him and his creative ideas.

So far his plan for June is to have a multi- team attempt to castrate a bull at 20,000 feet using only a "John Wayne" can opener and 4 toothpicks! Go Team!!
childhood. I joked that although we didn’t sing “Kumbaya”, incredulously, we did have a sing-a-long! Those few days in Boston, when I was only a few years into this journey were a revelation. This year in Orlando, Florida from June 6-9 will be my 10th Annual Meeting.

Click here for more information and to register: https://theial.com/ial-voice-institute-and-annual-meeting/

To be honest, I go now more for the social aspects of connecting with new friends and WW members who I only know online and to re-kindle old friendships. Because I have no local face to face to support group, meetings like this are a real treasure and I learn something new every time I go. It really is our very own summer camp!

I thought it would be interesting to re-read what some of our members have written about their experiences at these meetings over the years so we have re-printed two different Speaking Out Questions from 2013 and 2015 in the following column, “From The Archives”.

It is bittersweet reading since some of these folks were special friends who I won’t be seeing again but I look forward to meeting new friends and making new memories.

ATTENDING THE IAL?
(Originally appeared January 2013)

Ed Chapman, President - Southeastern Washington Laryngectomee Club
(Ed’s club is one of the host clubs for the IAL in 2013)
The Southeastern Washington Laryngectomee Club was started in 1969 by Romaine Olsen and Alice Shaw, two speech-language pathologists who worked in the school system. However, Romaine’s husband, whom had recently fought cancer, and Dr. Pyke, an ENT, asked Romaine if she could help a recent laryngectomee. That was the beginning of the club. Membership has varied throughout the years with a maximum attendance of 25 and as low as 3 members.

We have been fortunate enough to have Susan Bruemmer, a speech-language pathologist, as an advocate for the club from 1978 to present. Even in the leanest of years, when the membership was down to three, Susan held the club together with the attitude that we needed to be there for the that one laryngectomee that may come along at any time.

Over the years members have come from as far away as Goldendale, Walla Walla, Milton-Free-Water, Seattle (when there wasn’t a support group there) or in other words as much as 5 hours of travel time all
because we have always been there for support.

The club has met at various facilities throughout the years including the rec room of the Pasco Housing Authority, the Pasco Senior Center, and currently we meet at the Tri-City Cancer Center/Wellness Center in Kennewick, WA.

Focus of the club has been educational but mostly social...a place where laryngectomees can feel comfortable asking questions, talking, and finding out helpful hints from other laryngectomees/caregivers. We always have a luncheon provided by a member and have potlucks in June and December. We meet the first Sunday of every month except January, July, and August. We have a Loan Closet with assorted laryngectomee supplies. Pre-op and post-op visits are provided as needed by an SLP and laryngectomee. Members have encouraged and been active in the revitalization of The Spokane support group that now meets the first Monday of the month.

The Southeastern Washington laryngectomee club and the Spokane Laryngectomee Club are working together (with the support of the Portland, OR, and Seattle WA, clubs) to host the 2013 IAL meeting and Voice Institute in Spokane. We are planning some new activities (that will be announced by the IAL at a later date) and with the meeting hotel, The Red Lion Hotel by The Park, being within walking distance of a major park and downtown, including a mall and 40 some restaurants, we hope to have a venue for all to enjoy.

Come visit us anytime.

Marlene E. Haynes, Webb City, MO - 1996
Oh yes, I have attended many IAL conferences and each year come from there with such a feeling of belonging and I always make my friendship list longer, wonderful people always attend and I enjoy talking to them and getting to learn and hear how others live.

The IAL conference is a wonderful place to learn, I highly recommend anyone that has never been before to attend take the Voice Institute, if you can. Looking forward to Spokane, 2013.

DeWayne Boesen, Kenesaw, Nebraska - 2010
I have been one of the luckier ones. I did not have to have any Chemo or Radiation and my recovery has been fairly uneventful. My Physician is in Omaha, which is about 180 miles one way for me and I have virtually no local support to fall back on.

My wife and I first attended the IAL conference in Kansas City in 2011 and went again in Durham last year. The conference is “OUTSTANDING” and we can’t began to tell you how much we enjoyed attending. I would recommend it highly for any Lary or caregiver. You find out that there are others like you, many of which have much greater obstacles to overcome. We would like to attend again in 2013 but don’t know if we will be able to afford the trip to the west coast.

Pat Sanders, WebWhispers and all the others that are on the board are very friendly and helpful and add to the success of the conference. I only wish I could be more involved.

Neil & Naomi Arnold, Mendota Heights, MN - Aug 2011
Neil and I attended the IAL meeting last June in Durham, NC. It was ten months after his laryngectomy in August of 2011. We feel fortunate we were able to participate. It was a learning opportunity for both of us, but mostly it was so encouraging to be with others who had experienced the same things we had. The positive attitudes of everyone attending was contagious. Learning how to deal with the issues facing laryngectomees, seeing all the vendors and their products, working with SLPs (and having our SLP in attendance with us),
sharing the concerns caregivers face are just a few of the benefits from attending.

Meeting the dedicated leaders of the IAL and Webwhispers was a privilege. We hope to attend other meetings in the future to see our new friends and continue to learn, share, and have fun together.

Jim Fohey, Oscoda, MI - Oct, 1994
I was able to attend the meeting in Nashville TN in 2000. It was a real eye opener, I met many people who had much greater challenges then I and handled them better then I know I would have. Met some who had the same challenges or less then I and handled them poorly, in my estimation. But it was a great learning experience and a lot of fun.
I enjoyed the Web Whispers dinner and had a chance to meet Dutch and many folks from all over the world. It is something I would wish everyone had a chance to do at least once, as you gain a lot of insight in to what it is to be a laryngectomee.

Elizabeth Finchem, Tucson, AZ - Oct, 1978
Yes I have attended many IAL meetings since my first in 1981; missing only four AM/VI over the decades due to health reasons or family emergencies. I've also been a regular attendee at CAL meetings and been an invited speaker at a few other Regional meetings over the years. Why so many? My first IAL meeting was important to me as the founder of my local club.

Five years into monthly local meetings I attended my first IAL meeting so I could get some program ideas and learn as much as I could to share with my local club members. I was very surprised to find out about the work the Voice Institute does for new laryngectomees and SLPs that wish to have a hands on learning experience working with new and rehabilitated laryngectomees. Two years later I was invited to run for a seat on the IAL Board of Directors so I could be a part of the planning and operation of the IAL. I'm still there helping to pave the way for the newest laryngectomees. Whether it is local, state, regional or national there comes a time when our issues are resolved and we find we are in a position to help our neighbors.

Ron Mattoon, Seattle, WA - 2010
I attended my first IAL in Kansas City, just over a year after my Laryngectomy. It was one of the best experiences of my life. I learned SO much, but the best part was the people. I found them all more positive and helpful than I could have imagined. I met so many new friends and will consider them friends for life. There was no support group in my area and the things I learned, along with the help I got, enabled me to start a support group and help others. Thanks to IAL and WebWhispers I can live a much fuller life, instead of trying to figure out how to deal with the changes in my life. I encourage everyone to attend IAL, if you have the opportunity. Thank all of you!!!

Richard Crum, Jeffersonville, IN - 1988
I have been to 22 IAL meetings since my laryngectomy surgery. I must say that I have learned something at every one of them. When I started going the meetings were one week for the Voice Institute and one week for the IAL. Because of money and time restraints they have been combined since 1995.
I am looking forward to the Spokane, WA meeting in June of 2013.

The Voice Institute & IAL AM
What to change?
What would you like to see and learn?
[originally appeared August 2015]
Tom Whitworth - March 2014
The Voice Institute in Buffalo was within three months of my surgery and I had only been speaking consistently for about six weeks, so few things could have been of more value to me than the VI. I knew early on that I wanted to be in Baltimore in 2015 and I wasn't disappointed there either. The volume of information has been incredible, especially for a new Lary. Jodi Knott as director and each of the faculty presentations have been excellent. Delicate topics, like intimacy and self-image have been skillfully presented and are particularly helpful. I also think vendor support and anything hands on are critically important. The banquet is always a blast! It seemed like a lighter crowd this year and I don't know what that can be attributed to. Having only the two events to compare, I'm not aware of negatives to mention.

I like everything about the WW dinner and it is really a highlight of the AM/VI, at least for me. The WW table is good and is a great way for us to meet people. Depending on attendance at the VI, maybe a drawing or contest would increase the number of visitors to our table.

David Kinkead - 2013
Peoria, AZ
I was fortunate to be able to attend the recent IAL meeting and Voice Institute in Baltimore. I think the most useful (and fun) part of the VI was the interaction between the Larys, the students and SLPs. I enjoyed learning about the students and answering all their questions.

While the lectures were good for the students who do not get laryngectomy training in their studies, most of the issues covered were covered by my surgeon or my SLP. I also learned a lot about care and speaking from the experts. It was enjoyable to talk to the doctors who really know the subject of laryngectomees.

When I asked Pat Sanders if it was worth it to go to the IAL meeting she told me that it was something where I would learn a lot and meet some very nice people. She was right on both accounts. I urge everyone that has the means to plan on attending the conference next year in Dallas.

Loyd Enochs - Dec 2009
Evansville, IN (home), Mechanicsburg, PA (work)
I have only attended one Annual Meeting/Voice Institute, in Kansas City, and the most important/useful part of the program for me was the visit to the KU Medical Center, and the clinical evaluation. That was by far the most significant as the advice and assistance imparted was invaluable in my being able to use HME/baseplates for more than 10 minutes at a time. Between the physical evaluation of my stoma, advice on what my stoma anatomy translated to in terms of what to look for in a baseplate, and recommendation of how to tweak the installation of the baseplate to best fit my neck, I left that one session with breakthrough knowledge. I used it to get me back to work less than 9 months later (having doubted that I would ever be able to work again).

If only one event from the VI program was to remain, the clinical evaluation would be my choice of event.

Carl Strand - Radiation Therapy 1991, Laryngectomy 1993
Mystic CT
I had attended six Voice Institutes as a Laryngectomee Trainee before this year's Voice Institute in Towson. There was an eight year gap from Burlington to Towson.

At all previous Voice Institutes, I was paired with a Speech Pathologist plus several Graduate Students and we worked hands on with a small group of VIP's. At Towson, the Laryngectomee Trainees were working in a much larger group of VIP's and Speech Pathologists and the Graduate Students were not a part of our
I much preferred the earlier model where we formed something of a bond with the Students and the VIP’s. I felt that there was little opportunity for the Students to interact with the Laryngectomee Trainees and as a result, their total experience was somewhat limited. I recall discussions with the Student Speech Pathologist in the past where they felt they had learned so much during the breakout sessions.

Elizabeth Finchem - DOS/ Nov. 2, 1978
Tucson, AZ
The question has become: “How the Voice Institute will be structured/conducted in the future”?  

Having attended countless week long seminars as well as the Voice Institute since 1979 for my own rehab and then training as an alaryngeal speech instructor I have witnessed what works and what has fallen short with changes that seemed like little adjustments to save money and time. 

The best results for both laryngectomee (VIP - Very Important Pupil) and (LT - Laryngectomee in Training) happened during the years when teams of one or two VIPs and LTs were created for the week. The team had a Supervisor PhD/SLP, SLP students and a couple of observers that moved from one hotel room to the next. The team set realistic goals for EL, ES and TEP improvement. Something obtainable and maybe beyond if possible.

Some returned annually to continue improving their speech, and some learned how to help others back at their local club. Some started a local club to help the newest laryngectomees face to face. In recent years the speech breakouts have had too many in the group and too few instructors for this sort of personal attention. However, the TEP clinic does offer this sort of personal attention that hasn't been available to EL and ES users as in the past. This is a need that deserves attention.

Lynn Foti - May 2009
Akron, Ohio
I was extremely fortunate to have a chance to go to the IAL this June. It has been a dream of mine for the 6 years I have been a lary, and thanks to some generous people I finally was able to get there.

I attended the VI, and thought it was great. I mostly loved working with the SLPs and the graduate student SLPs. I was very happy with how everything was coordinated, and got to know some of the people who worked so hard to make this fabulous. One of the nicest parts was when we all split into small groups and spoke one on one with the graduate students.

The entire conference was astounding to attend, the WW dinner, the IAL dinner, and the connections made with other larys. What a good thing, for any lary to experience. The VI gave me a lot of insights into issues I was not aware of regarding my own speech, and the way I deal with it. The absolute whole of the IAL annual meeting was the culmination of several years of trying to better my own life as a laryngectomee. I was able to go in the pool with the help of Bob Herbst, Tony Talmich, and John Isler... it was wonderful to go under water for the first time since my surgery.

On the whole, I was pleased with the Voice Institute and how it was conducted, learned some things I didn't know, even after all this time. I would recommend it to anyone. Thanks to the IAL, and WW, and The Lauder group.

Pat Sanders in AL, 1995
When I attended my first IAL in 1999 in Reno, the high points were meeting the people that I knew from
correspondence and the greatest amount of time was spent as an LT at the Voice Institute. I worked hard, was exhausted from keeping up with all but came back so excited, knowing I would be back the next year when it was to be held in Nashville.. near enough for me to drive to.

I was back at the Conference in Nashville..2000 but this time unwillingly as the new WebWhispers Vice President. We at WW had a big edge of sadness from losing our beloved Joe Casey at the end of 1999 and then losing his replacement Carter Cooper about a month before the TN IAL. We were still stunned. Again, seeing the people I had met the previous year was wonderful and I met many more from the Eastern side of the country.

At this stage, 20 years into being a lary, I have to say that visiting with the folks, old and new, is wonderful. I learn so much from you and am able to share it with others through WebWhispers. Speaking of learning, all the vendors are great fun to see again and the new products are exciting. We have our standard Dinner for a get together.

I did ask about next year's VI if we might go back to have something like 10 minutes to tell the VI attendees what WW is and what we do. We are the perfect place for them to do follow up online about everything they learn there from the great programs and teachers we have. I want them to know about the Educational Library and the Email Distribution list where we ask question and get answers not available anywhere else...I want them to know about the Whispers on the Web newsletters with a professional column every month and the Speaking Out opinions along with stories about us and our interests. We have an account at Delphi Forums with message Boards, and FaceBook Groups growing by leaps and bounds. What we all learn there at the convention, we share here at WebWhispers.

Pat Sanders, President of WW since 2006


First let me say that I have always recommended the conference and Voice Institute to laryngectomees, especially those that are new and/or having problems. I have always thought that the Voice Institute was such a good learning experience for both the laryngectomee and other speech pathologists. Having the "top" speech pathologists in this field teach the classes and help those with problems has always been one of the reasons that I have encouraged people to do the Voice Institute. I truly hope that never changes!

How are we going to have speech pathologists know how to deal with the many issues that laryngectomees have, if they aren't taught by the best? I have always been impressed with the speech pathologists, including those at this years conference. If this changes I don't think that new speech pathologists will attend. For them, there is a cost and being away from their patients. With the way things are going the medical institutions are not going to pay for the speech pathologist to attend the Voice Institute as continuing education. As far as I am concerned the speech pathologist is the laryngectomees' best friend.

I've been to the IAL conference three times and the Voice Institute twice. The first was Vancouver (2002), there was so much going on that sometimes I didn't go to the Voice Institute class because I wanted to go to the other session that was at the same time. I was new to being a laryngectomee and there was so much to take in...wonderful!

The second time I went was in Burlington, VT (2007). I did the Voice Institute again and this time I went to all the sessions. The only thing I did not do was the clinic since I did not have a TEP at the time. When others went to the clinic there were sessions for those that weren't going. Again, a wonderful learning experience.

At each of these conferences there were more vendors than this time. I am glad that those that came this year were the ones that seem to always be supportive of laryngectomees. They always take the time to explain the products, let you try them. They are well versed and knowledgable with all their products. What would we do without them? They are another reason that I always tell people to go to the conference. This is
the one place where you can try different products, like the electro-larynxes. Most hospitals, speech pathologists don't have all of them to try out. The speech pathologists have to use the products "their facility" says to use. That isn't always the best one for the patient. With things changing in the medical world this is going to become a very important issue for the laryngectomee. Where else can we try out and see all the products? My thanks to our vendors!

I noticed that there were changes the way the conference was run this year. There was definitely something missing when I went to register. It wasn't the same welcoming feeling I got when I've been to the conference before. What's going on with the IAL?

I do have to say that the facility was great. The people at the hotel couldn't be more helpful. They were so accommodating. In fact, they brought a meal to Pat and I when we were sitting at the WW table, even when they were finished serving and wouldn't accept a tip. I can't say enough about them.

Needless to say, the Webwhispers table and all the people involved with Webwhispers should be applauded for all they do. I don't think Pat ever left that table. I was able to sit with her and truly enjoyed being able to speak with all the people we email with. What would we do without Webwhispers?

Honestly, when I got home from the conference I told my husband that I didn't think I'd be going again. It was great to see the people that I met before. It was wonderful to meet new people. That might be a reason to go again but there was definitely something missing this year. I can't put my finger on it but....

Rita in NJ

Jack Henslee - Class of 79, 88, & 95
Stockton, CA

I attended my first Voice Institute in Winnipeg, Canada back in 1991 and have been personally involved in the planning and management of 8 others. There have been several (some may say many) changes over the years and of course everyone doesn't agree if they were good or bad.

In 1991 we reported on Sunday evening then began an arduous 5 day training marathon that started at 8:00 AM, and some days ran until 9:00 PM. Most of the lectures were divided into 2 groups; SLPs and Laryngectomee Trainees, then VIPs. A few sessions were attended jointly and several times a day teams would get together for hands on training (See Elizabeth's response above). This was called a dual track and later evolved into a single track to save some money.

In 1999 or 2000 we decided to reduce the VI to 4 days instead of 5, and Dr. Ed Stone introduced the Hands On Clinics enjoyed today where SLPs could actually see or perform TEP changes for the first time, and laryngectomees received a free prosthesis for volunteering. This became the "new standard" for the VI and has continued through this year. It is currently unclear if they will do that next year.

A strictly personal opinion of mine is that the changes and cost reductions were necessary to survive financially and as long as they are well managed the impact is minimal to the overall mission. The clinics serve as a great learning experience but in return some great possible locations for the IAL Annual Meetings have been rejected because there was no clinic available in that city, and as a result IAL could not move around enough to make attendance affordable to more people, and some locations were just hard to sell. A final thought is that in recent years some Voice Institutes have had more staff that SLPs in attendance. Of course the SLP students swell the numbers which helps reduce hotel costs and generates some extra revenue, but in reality probably less than 10% of them will ever see another laryngectomee. They are most sincerely welcome and we need to train them since almost no one else does, but I think the priority should always be the laryngectomee and the SLPs that serve us, and any change should take that into
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