March 2017

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COMMENT HERE
FEEDBACK
Apologizing is Highly Overrated

Over the past several weeks, I have learned some things about being a laryngectomee that many of you will have beat me to but that others have not yet realized. During the past three years since my official entry into the Hole in the Neck Club, I can only imagine how many times I have rendered apologies or excuses for myself. Specifically, on days of poor voice, I got sick of saying “I usually do sound better than this” even when the statement was true. Undoubtedly, such behavior bruised my confidence and wasn’t even necessary.

Just last month, I was thrilled to land a consulting role, much like what I used to do B.C.. It ended abruptly after three weeks when the guy who brought in two others and me was fired, and the project I was there to lead was cancelled. Despite the NFL style sudden death, it was a wonderful experience; I enjoyed great work, lots of perks, good pay, and an incredible 27th floor view of Atlanta’s beautiful Buckhead, Downtown and Midtown areas. The office suite was an entire floor with 75-100 people. I spent much of my time going around the place, speaking to people who had not met me, and asking questions, actually interviewing them in some cases, regarding things related to my work.

By about the fourth day on this job, some things occurred to me in one of those “Wow!” moments. The office attire was quite casual, and I wore an open collar, exposing the HME, which I was obviously using in connection with my speech. It occurred to me that no one, not even one, had asked about my “button”, my condition, “what’s that”, “is that permanent”, or any of those ridiculous things I’d heard previously. I also realized that I had offered no apologies for my voice, the little doohickey on my neck, or anything else. I had interviewed in a suit and tie and voiced by sliding a finger into my shirt collar, occluding a regular HME, as some of you have seen me do. Here’s the revelation that may have made the difference in getting hired- I really think it did. I realized that during the in-person interview which followed two phone interviews, not once did I apologize for my voice, my condition, the finger slid behind my tie or anything else, for that matter. Only after realizing that the meeting had morphed into a confirmation of my abilities did I offer a very brief version of my story.

Regardless of our means of communication, none of us owes anyone an apology for the fact that we are currently fighting or have survived our battle with cancer. We owe no apology for our HME, Boogie Board, Esophageal Speech, Electrolarynx, thumb on a stoma, or for our pen and paper. On the contrary, we are a rare breed having dealt with the challenges of our experience, many of us dealing with those issues again or still. We are remarkable and have every reason in the world to be confident and never say “I’m sorry” or “pardon my…” anything! There is never a need to apologize for what we have overcome.
This issue of WotW includes a wealth of information for SLPs, caregivers, and larys, including a really active Speaking Out and a special listing of events for our community and much more.

*Enjoy, laugh, and learn,*

*Tom Whitworth*

*WebWhispers President*

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**Case Studies and Selecting a Speech Pathologist**

Do you recall the first time you had an appointment with a speech-language pathologist (SLP)? Do you remember what you thought you would be doing when seeing a SLP? Frequently when people ask me what I do for work and I tell them I am a speech pathologist, they think I work with children in schools. So when people present to their initial SLP appointment, they often do not understand why they are seeing me. I find it beneficial to explain our education and how swallowing and voice play into it. We all have the same education: bachelor’s and master’s degrees. Many go on to get a doctorate (Ph.D.) as well. After our master’s, we complete a clinical fellowship year (CFY). Ideally, the CFY provides us with additional hands-on education in the specific area of speech pathology that we would like to pursue. This is when many SLPs gain their true education with the laryngectomy population. It varies from school to school, but many SLPs receive little training on laryngectomees during their undergraduate and graduate school studies.

Because of the variations on the amount of training SLPs receive, it is important to know your SLP’s education and experience. You would ideally want to ask similar questions about any healthcare professional that you work with. As with any diagnosis, the more experience someone has, the more knowledgeable they are and the better they can help you. When it comes to the laryngectomy patient population, experience and training are key. We need to understand changes in respiration, voice, swallowing, CPR, olfaction, etc. If we do not understand these things, we may not be able to appropriately treat you. And you deserve the best care out there! Here are some key questions to ask your SLP prior to or during your first appointment:

1. What is your experience with the laryngectomy population?
2. How long have you been working with laryngectomees?
3. How many TEPs have you changed? (if applicable)
4. How many TEPs do you change per week? (if applicable)

I'm hoping that the following case studies will help you to understand how experience impacts patient
outcomes.

The first patient is Mr. J.. Mr. J. is a 59 year-old gentleman who was diagnosed with laryngeal cancer in 2014 and underwent concurrent chemoradiation. His cancer unfortunately recurred and was scheduled for a total laryngectomy. He was seen pre-operatively for laryngectomy counseling and to assess the type of voicing method for which he would be the most appropriate.

During a typical pre-operative session, it is important to assess many different areas, including cognition, vision, manual dexterity, financial situation, current voice use and anticipated ability to follow-up. Consistent transportation is an important factor especially when recommending a TEP, since patients may need to follow up somewhat frequently for prosthesis changes and management. Mr. J. was deemed to be a good candidate for any of the voicing options. He opted to defer a TEP as he wanted to become comfortable with the laryngectomy surgery alone, and wished to consider a TEP at a later date (also known as a "secondary" TEP). A "primary TEP" is one placed at the time of initial laryngectomy surgery, versus a "secondary TEP" which is placed after the initial laryngectomy surgery. Recommendations for primary versus secondary TEP placements are made based on the factors mentioned above, as well as the level of reconstruction that is anticipated with the surgery.

Mr. J. underwent his laryngectomy in 2015 and worked with speech pathology immediately post-operatively using an electrolarynx (EL). He became proficient with using the EL but after several months and meeting other laryngectomees who used TEPs, he ultimately decided he would like to pursue a TEP.

Mr. J. met with speech again for TEP counseling and an insufflation test. This is a short test wherein a catheter is attached to the stoma and fed through the nose into the newly reconstructed throat ("neopharynx"). It has a hole to close off, or occlude, the stoma. When it is occluded, air is pushed through the catheter into the throat to vibrate the muscles in the throat. The sound that is produced is a good indication of what the patient's TEP voice could sound like. It can be very helpful for people to hear their voice to help them decide if they want the TEP and can also help the SLP to determine candidacy based on ease and strength of voicing. In this patient's instance, his voice was strong and I determined him a good candidate for TEP. We discussed the pros and cons of this decision and Mr. J. understood these. He had good compliance with follow-ups and stoma care, all of which are important factors to take into account when evaluating a person for a secondary TEP. Mr. J. ultimately decided to undergo the secondary TEP.

I saw Mr. J. a week after his TE puncture to place his first TEP and he had a strong voice quality. We discussed management and emergency care of the TEP (see Susan Bruemmer's Voice Points article December 2016 (http://webwhispers.org/news/documents/WhispersOnTheWeb-December2016.pdf) and he was instructed on its use. He required two follow-up sessions to perfect use of the TEP and did very well overall. He had several TEP changes without incident.

Nine months later, Mr. J. presented for a TEP change stating his voice had slowly become more strained and he was unable to voice at all by the time he presented to me. He also reported his swallowing had declined and he was unable to eat any solids over the past week. My initial thought was "stricture." "Stricture" is a term that is used to describe an area of narrowing of the tissues in the throat. The TEP was thoroughly cleaned (which sometimes fixes this issue) but he was still unable to voice. I removed the TEP and asked him to voice with an "open tract" (nothing in the puncture site) and no voicing was produced. I gave him a small sip of water to drink and there was liquid coming through the open tract. This was a good sign as it meant his tract was still open. This is where the "troubleshooting" starts. I placed a dilator in the tract in place of the voice prosthesis and performed flexible nasendoscopy (putting a scope through the nose to visualize the neopharynx). It was quite difficult to get the scope through as his throat was tight. The dilator was removed and Mr. J. was instructed to voice. There was no obvious airflow as viewed through the
scope. Signs again were correlating with stricture. I placed a new TEP to stent the tract but he remained unable to voice. We then proceeded to perform a modified barium swallow study (MBS), which is a moving x-ray picture of the swallow under fluoroscopy. This showed that he did indeed have a stricture at and above the level of the TEP. He was able to clear liquids and watery puree through the tightened area, albeit with much difficulty. I subsequently sent him back to his surgeon and a gastroenterologist, who performed serial esophageal dilatations. (A dilatation is when an area is stretched out.) He required serial dilatation every 4 weeks and over time his swallowing improved and his TEP voice returned to his baseline vocal quality.

Another interesting TEP troubleshooting case is Mr. R. Mr. R. is a 54 year-old gentleman who underwent total laryngectomy in 2014. His background with SLP appointments is similar to Mr. J.. One difference is that Mr. R. underwent primary TEP placement. Initially, his TEP wear time was around 3-4 months, which is a decent average. I typically troubleshoot TEPs to allow for at least a 3 month wear time. Over time, Mr. R.’s wear time became shorter and shorter. He had minimal candida overgrowth, so yeast did not appear to be an issue with his short wear time. Therefore, I recommended a MBS. This showed stricture just above the TEP site. Increased intraesophageal pressures are frequently the etiology of premature leakage. Therefore, I placed an increased resistance (IR) TEP and referred him to GI for dilatation. He underwent two serial dilatations but even with the IR, his wear time did not significantly improve. During his third dilatation, his GI doctor noted that the TEP appeared to be too short. (Of note, many GI doctors do not have much experience with TEPs. I am fortunate to work with a very knowledgeable doctor who has experience with TEPs and has gotten great information from his SLP team over the years! SLPs: remember to educate your entire team!) Because the TEP was too short, it was creating a small pocket where fluid was likely collecting. He sent pictures of the TEP from the endoscopy and I was in agreement. Given this finding, I placed a longer TEP (increased by 2 mm) with a large esophageal flange to cover the pocket that had been created. Mr. R. returned to an even longer wear time than his baseline and was satisfied with the outcome.

It is common to see a TEP that is too short pulling posteriorly and creating a pocket where the tracheal flange is, but it is obviously harder to view this when there is an esophageal flange issue. When sizing, it is important to ensure the sizer is all the way through the common party wall. It is easy to size incorrectly if the sizer “catches” in two different locations. In this patient’s case, sizing appeared correct (even when I sized him after I knew it was too short), but given the pictures we had from endoscopy, I knew he needed a longer TEP. I may have been able to see that if I had performed nasendoscopy as well, although frequently our pictures are not as clear as what the doctors can see when the patient is sedated and their secretions have been suctioned.

These case studies demonstrate the importance of always having an experienced SLP and multidisciplinary team working together. SLPs needs to know how to troubleshoot a TEP and who to consult when there are issues. Various tests are beneficial for determining what the issues are. Do your homework on all of your medical professionals to assure you are getting the best care possible. There are several continuing education courses available for SLPs with a focus on laryngectomy and troubleshooting TEPs. A list of courses is available below and frequently updated in the WebWhispers library. Contacting your local vendors and their clinical consultants is also a great way to work through issues that arise. Learning to work with laryngectomees and troubleshooting takes time and lots of brainstorming with people who have experience with these cases. Patients and SLPs should always, always ask questions!

Rina Abrams, MS, CCC-SLP
Johns Hopkins University

Meetings, Conferences and Training Workshops

For an ongoing list of upcoming events, visit the Meetings section of the WebWhispers Library: http://webwhispers.org/library/Meetings.asp
ATOS Medical
Professional training events and conferences
http://www.atosmedical.com/professional-main/professional-events/

Association for Head and Neck Cancer Rehabilitation Clinical Laryngectomy Conference (AHNCR)
June 22-24, 2017, MD Anderson Cancer Center, Houston, TX
For SLPs, students, and laryngectomees
http://www.getvoicing.org/events

InHealth Technologies
Blom TEP Course: Tracheoesophageal Puncture and Prosthesis for Post-laryngectomy Voice Restoration, Carmel, IN 2017
Course Dates: http://www.inhealth.com/course
Other upcoming events: http://www.inhealth.com/events

International Association of Laryngectomees Annual Meeting and Voice Institute
June 14-17, 2017, Newport News, VA
For SLPs, graduate students and laryngectomees.
http://theial.com/ial-voice-institute-and-annual-meeting/

The Johns Hopkins Voice Center, Greater Baltimore Medical Center
Post Laryngectomy Conference with Hands on Training of Prosthesis Management
October 6-7, 2017, Towson, Maryland
http://www.gbmc.org/UpcomingConferences

Update in Tracheoesophageal Voice Restoration and Laryngectomy Care,
Mass Eye and Ear and Stanford
March 17-18, 2017, Boston, Massachusetts

SpeechPathology.com
Laryngectomy: Basic Training
Course #6344

ASHA.org
Alaryngeal Speech Options for Laryngectomy Patients
Item #(s): WEB15253F
Down the Rabbit Hole (and back in time)

My first column for Whispers on the Web was in March of 2005. Over the years I have had some outstanding company. Writers from all over the world, with extraordinary experience, skill, talent, education and background have shared their expertise and perspective. I have worked closely with many of them as we put together this newsletter, by and for the lary community. One of my favorites was Scottish writer, Rosalie MaCrae, who wrote for us from September 2006 to February 2009 when she passed away suddenly. I was disappointed I never met her in person especially since we had planned a get-together when she came “over the pond”. She was a wonderful writer and story-teller with an eccentric and colorful style. I edited her column and was often reminded of that quote attributed to either George Bernard Shaw or Oscar Wilde, depending on your source that “America and Great Britain are two countries divided by a common language”.

Recently I went looking for an old article from WotW and in scrolling through the index I went back in time and down the rabbit hole. What a treasure trove of great columns we have. Our WotW index list tables of contents for every issue from September, 2003. Available to read in either HTML or PDF, they are also easy to print should you wish. It is interesting to notice the way we have evolved over the years and fascinating reading. Here is the link- check it out but be prepared to stay awhile!

http://www.webwhispers.org/library/whispers-on-the-web.asp

While I was looking for an old article I came across this from Rosalie, so typical of her wit and style. From time to time I will be using this space to highlight some of my personal favorites from over the years. This particular column is from March, 2007. Delightful whether you are meeting her for the first time or re-visiting an old friend.

LARY CHARIVARI
by Rosalie Macrae

I had decided to call my column 'Lary Charivari' this month, as it rhymed, looked quite distinguished, and 'charivari' meant gossip. I thought. Then I looked it up. A Freudian error. Apparently it was a noisy mock serenade in rural France to force cohabiting, unmarried couples to wed, sharpish, before they shamed the community. And in godly parts of North America they still call it a 'shivaree'. People in masks who probably think they are pillars of the community, bang metal implements outside the windows of the shameless pair in the middle of the night. And if you are a widow contemplating marriage before you have done enough mourning you get the same treatment. I'd be interested to hear from any shivaree-ers and I promise my lips are sealed.

However in parts of Europe it means 'shiny'. Much more pleasant. In the Alps they even have a radio station called 'Charivari' which makes lots of noise on top of an alp I suppose if you are lost. The happenings I write about are as pleasant as possible although it would be presuming on your intelligence and living in cloud cuckoo land to pretend that the contradictory upsy-downsy life of the laryngectomee is always agreeable.

Anyway this is a great place to be, as Jessica Lange said to me last week at the Selfridges Valentine chocolate counter. Good throw-away line that. I had just bought a little box of chocolates, very chic with brown silk bands on it, for AMIK (A Man I Know) when this melodious female voice said to me that she just loved that stripey little number and was going to get one in a larger size.

No, she was not referring to the pretty rainbow scarf I purchased from WW moderator a couple of Christmases ago, Sorry, Barb. And it looked so boho with my grey flannel coat. I expect she admired that too, though. Anyway, I recognised this luminous beauty immediately. Ms. Lange is appearing in The Glass Menagerie at the Apollo Theatre in London for a few weeks. We'd passed the theatre on the way to pick up our tickets for the Sound of Music and I'd wished silently that I were going there instead. But didn't want to spoil things for my three granddaughters, all dressed up for their delayed Christmas treat.

Tennessee Williams who wrote it as you know, died, poor man, of choking on the stopper of his eye drop bottle. And someone I read about used superglue drops in his eyes by mistake, the tubes being virtually identical, especially when you need eyedrops.

I said to Jessica that she could hand the Swiss chocolates round to the cast. She understood my EL immediately, admired my use of it, and said she was going to keep the box afterwards to put, well, things in, didn't I know. I agreed and said you couldn't get into my house for boxes for things.

That was pleasant. In fact it was that kind of day. I turned round to tell the girls who Jessica Lange was but they were in a trance. The leader of Franz Ferdinand was at the counter, buying a red sugar rose on a long green marzipan stem--uh huh. I'd just about heard of them--and told 17-year-old Georgia, the biggest granddaughter who looks like a young Bree in Des Hou that she was a pretty girl. They were all clutching their throats in ecstasy and I wanted to change my HME discreetly, so off we went in a howling gale to the New World Chinese place in Soho, which is renowned for its wonderful dim sums, reasonable prices, and exceptionally unfriendly waitresses.
Thank goodness I had posted a booking, snail mail. No website, a good sign of authenticity for starters. A large black-haired dolly in a grey Mao tunic spread her arms across the entrance, all gilt curlicues and dragons, and said no no no no, fullupfullopfullup. The girls, country bumpkinesses more used to being leered at by lads with straw hanging out of their hats than being victims of aggression, shrank back into the Force 10.

Granny was not having it though. I waved my Servox in the air with mugwumpian authority and said a table for four was booked for Macrae And Party. She stopped, stared, listened, said “Aaaaaah”. I had explained in the letter about The Voice and the really special noodles it needed, and we were ushered through to the gaudiest, greatest dim sum place in the world we decided later.

The head waitress told me her uncle was like me. She trilled to the other waitresses that it was too many cigarettes and they all laughed and clapped their hands. Telling them that dodgy throats were in my genes would have been too complicated so I allowed them to treat me delightedly as a Fag-Ash-Lil whose past had caught up.

Never were dumplings so light, beans greener or monosodium more glutamated. The head waitress never left my side. One sip of green tea and the cup was replenished from on high, in a delicate steaming spray above my butterfly hairpinned head. When I spoke they all hushed at the nearby tables, crammed in early celebrations of the Chinese New Year and when we left were each presented with a pair of ivory chopsticks. Long life to honourable uncle who had made it so special. Oh yes. The Sound of Music was pretty special too.

After you check out the index and get lost in the rabbit hole ☺ let me know if you have any favorites you’d like to see here. I’ll do my best to get them re-published.

editor@webwhispers.org

http://www.webwhispers.org/library/whispers-on-the-web.asp
Are You Concerned About Your Healthcare and Supplies?

I think you need to ask those that are not from the US to explain their healthcare. For instance, many believe everything is paid for by social medicine. That isn't always the case. Some have insurance above and beyond the basic "healthcare" because with the basic care they may not have the choice of doctor, hospital, etc. or they may have to wait, etc.

I'm trying to avoid having people get upset. There truly isn't something for nothing. Social medicine is paid for by higher taxes. Again, I'm not advocating for either type of insurance....just saying the whole story needs to be told.

I don't know of anyone going to another country for cancer treatment. We are lucky to have such great cancer doctors and treatment here.

Rita Burfitt – Morristown, NJ

I am always concerned about my health care. I have mine through my job, and have carried the full cost a few times when layed off. The choice of plans is made by people outside my sphere of influence. With the rising cost of supplies and the lower reimbursements I wonder how many providers will leave the market. I know people in the medical industry and they don't like it either. But, it's the golden rule - those with the gold make the rules.

Ray Riess – Brook Park, OH

Several years ago, I wrote of the free medical treatment in the UK, and supplies and equipment being immediately available. Including Suction Machines, Nebulizers, Invalid beds if required, armchairs, hand rails and bath seats, and everything that a patient at home would need, including wheelchairs, but I received a rebuke from a laryngectomee in the States, that insurance was the correct way of dealing with those needs,
and offered to send me a copy of the Declaration of Independence. Oh dear!

I never write of the politics of another country, so I have avoided saying anything about the subject. But I am thinking of those poor souls who have no insurance. Everything is free in the UK for those who are sick, and we do know that we are taken advantage of by the tourists, but what the heck, emergencies must be dealt with instantly.

Let’s hope that the States soon find out which way they are going.

Len Hynds – Newtown, UK

I am a member and live in Manchester UK where football is football.

Seriously I order my supplies every month on the Internet through a company who specializes in supplying base plates and HMO. The company faxes my order to my G.P who signs the prescription and I get my supplies five working days from me ordering. There are never any questions asked. I just order what I need.

I know in the states you have really different systems but when you take out your private medical insurance you should always read the small print. Cheapest is not always best.

I had a problem with travel insurance but in the end I got a company, who as I have had my Lary over three years totally ignored it, and I get it at normal price.

I am of to Brisbane in six weeks time to see my son and two grandchildren. We have been twice before and I have never had any problems either on the plane or at Brisbane with my Tracki.

Ian Coates – Manchester, UK

For several years now my primary insurance has been Medicare with Medi-Cal (California's version of Medicaid) as a secondary. I am on a limited income with a strict budget. Medicare will reimburse me about 35% on foam filters but I have to pay full price up front. Medi-Cal has never paid any part of the foam filters. I charge them to my credit card with hopes that I get the 35% reimbursement check back from Medicare before I have to pay my credit card bill. There is also the small benefit of the rewards from using the credit card.

I also use those pink bullets to irrigate at least twice daily, using several ampules daily. These used to be covered by insurance but not anymore. With a prescription I was paying out of pocket over $30 for 100 ampules. I found a place online where I can order 1000 ampules for around $100 and they will last me about a year. Even without insurance help I am saving about $250 on the saline bullets a year from this supplier. I could probably make my own saline and save even more doubloons but I prefer the convenience and sterility of the ampules and need not worry about what's lurking in the water.

Things seem to get worse with each passing year on my insurance plans. I know many others are in the
same boat with ever increasing deductibles and copays. Seems our Social Security benefits increase by 0.3% this year while the actual cost of living seems more like 10%. I feel truly sorry for those who are even less fortunate than myself because I understand how difficult it is to make ends meet with the rising costs of everything. So, if you too are financially challenged, use a rewards credit card when you can, shop for bargains online and when the rare opportunities avail themselves get those free samples from some of our Vendors, who I have come to know as some of the most compassionate people on this earth.

Blessings to all,

Michael Csapo - Twentynine Palms, CA
Class of 2000

I recently lost my retirement health insurance that I was supposed to have for the rest of my life. This also included my wife, which has lung cancer, so it came at a very bad time. I was able to get other insurance at a significantly increased price, but we are covered. So far our coverage has been good. We used to order all my supplies, then pay for them up front. We would then get the small amount, that would get reimbursed. Thanks to ATOS I have been able to get some of the supplies I need and they handled the insurance, which has been a big help. I hope the companies keep working to get our supplies covered so we do not have as much out of pocket expense. I use one of the cheapest TEP valves but I still get only about 30% reimbursement on it. I do not know what will happen in the future, but I hope it continues to improve as we are on a fixed income, like many of us.

Ron Mattoon - Seattle, WA
2010

I suppose anything can happen in the current political climate in the United States, but I cannot conceive of the congress eliminating Medicare. My current healthcare is Medicare Parts A and B, plus AARP Medicare Supplement Plan N. My medications are covered by AARP Medicare RX Plans. Both the Supplement and the RX Plan have premiums which total about $170 per month.

I commented in last month's Speaking Out about my experience with laryngectomy supplies, so I will not repeat that. As far as general medical and prescription coverage are concerned, my current healthcare is very good with a modest premium and small copay. As of today, I am not concerned about a continuation of these plans, but I remain vigilant and engaged with the political scene.

As a soon to be 80 year old male I have some significant health issues. The most pressing is wet macular degeneration in my left eye. The treatment for that, which I have been getting for seven years, is injections every 5 or 6 weeks. The usual billing for this is about $3,000.00. It does not take a degree in mathematics to calculate how devastating that would be without insurance. The alternative is blindness, loss of personal freedom, ability to drive and ability to read. The other alternative is bankruptcy and a nursing facility. My other health issues pale in significance to that and probably would be manageable.

Again, I cannot conceive of our elected representatives committing the political suicide of messing with
Medicare. And, I doubt that AARP and its insurer United Health Care are not making a profit on the plans which they offer.

The health insurance industry is not running a charity. They make significant profits from the policies they write and attract any number of investors. I don't see why this will change.

**Carl Strand, Mystic CT**
**February 10, 1993**

Fortunately, I am well covered through my Senior Advantage policy with Kaiser Permanente and through the VA. Kaiser covers 100% of the Atos indwelling speech prosthesis; and the SLP prosthesis insertion with a small co-pay. The VA supplies me with all of my other lary supplies (HMEs, base plates, FreeHands devices, etc.) for free. I am so grateful for the VA because the Kaiser co-pay on the supplies is almost equivalent to the retail price charged from Atos.

**Greg Smith - Windsor, CA**
**2004**

It is difficult to obtain the supplies we need for FreeHands HMEs. The suppliers will tell you one thing, and then it doesn't work that way either. So, this may only pertain to me.

I have used ExtraBase as my valve holder for years. I was told by Atos that they were changing their system to make it easier to receive reimbursements from our Insurance companies, so I felt easier about the situation.

However, my insurance company told me that they don't reimburse for anything. They only work with suppliers that accept their payments directly.

So the one company that has always accepted my insurance company's direct payment is Edgypark. The problem is that Edgypark no longer carries anything made by ATOS. They do however carry everything made by InHealth, Blom-Singer.

Blom-Singer makes a valve holder very similar to ExtraBase, and Edgypark carries it, and my insurance company will pay Edgypark directly for it.

Whew!

An unnamed generous person gave me 7 months of Atos FreeHands Cassettes, and I have 2 new FreeHands HMEs. So I'm in business for at least the next 7 months on cassettes, and 5 or 6 years on the FreeHands HMEs. If I am unable to find a FreeHands cassette source in the next 7 months, then I will be moving on to the regular HME as they will also fit into the new valve holders I'm receiving.

My voice prostheses have actually become less expensive for me, I receive those from Edgypark as well, and they are made by Blom-Singer.
I would suggest to everyone to look at every supplier that has a catalog online to find the supplies you need. They may not be the same ones you're used to, but may be adaptable.

Sorry about the length of the letter.

Steve Staton  
Feb. 15th 2007

My bad experience ....... I have been using Humana Gold Advantage insurance for several years and have been very happy until January 3rd when I discovered that having assumed that I had automatically signed up for 2017 I wasn't, and have been fined several hundred dollars

Johnnie Dontos  
1/30/2015

I have nothing but good things to say about the VA. All I have to do is email my provider and in about 3 days my supplies are in the mail with no charge. The only thing I pay for is meds at $9.00 for 30 days. All my hardware, HME, BASEPLATE gauze stoma cleaning items, and voice prosthesis Free. God bless the USA

Jack Keane – Charlotte, NC

"All possible" changes and effects? Frankly the topic sentence is far too broad and ill defined. List a specific proposal and we may be able to intelligently discuss the impact of that proposal but, all possible "?

One possible Medicare proposal, with significant political support, sometimes called premium support and other times called vouchering, would essentially shift Medicare away from an open-ended commitment to pay for medical services and toward a fixed government payment or subsidy for each beneficiary who would then buy their own insurance either from the traditional government plan or from private insurers.

What specific changes that impact laryngectomy specific needs has actually been proposed at this time?

It seems that what I have seen online is issues about Medicare rules on who can install and/or provide certain items, low reimbursement to providers from Medicare, and a reluctance by providers to participate in Medicare.

Nick Fuhs – Wilmington, DE  
Class of 94

Am I worried about my health coverage? Not really. What I am worried about is the coverage for my supplies. As you all know Atos stopped taking the Medicare allotment for the Stabilibase at the end of October last year. I didn't like that they didn't warn us of that change. Then they said to try the new hands free assist
device! It will work really well they said! It doesn't! I don't think they tested this device on women! I feel like I wasted my co-pay money on that. Then I find out that Atos is out of network for me this year. I have been trying to find a company that will take the Medicare allotment for over a month. I haven't sent in any order this year yet. I'm glad I had extra supplies! It looks like I will have to go with my least favorite DMG company this year, as they are "in network" this year. They now have my script for the supplies, although they haven't called me yet, as of 2/18. This is the same company that has canceled my order on occasion, or I had to wait for the order to be approved though corporate! That's 8 to 12 weeks! Being on disability doesn't give me the freedom to pay for my supplies up front then waiting for reimbursement. If I go with one of these "mom and pop" DMG suppliers that's what I would have to do. I just keep praying that it will get better.

Belinda Roddy – Martinsville, IL

Hi Webbies,

My insurance experience convinced me that finding consistent coverage for an indwelling TEP (provided and inserted in a Hospital or Clinic by a professional) from Medicare is an impossible maze of contradictions. It varies by state and provider. Some Larys have had Medicare provide TEP coverage by asking for help from their legislators and some have changed their provider to a teaching or university Hospital in their state and got coverage. However, I understand that the VA provides coverage for everything, as they should.

Bear in mind that obtaining coverage for one submitted claim does not guarantee that the next claim filed will be covered even if it is exactly the same. I went through the appeal process and included a letter from my Mayo ENT refuting the finding that my TEP was not necessary! The billing department sent them pages of my health care documents regarding my laryngectomy and radiation treatment. My next TEP was inserted several months later and Medicare refused coverage.

I reached the conclusion that Medicare is in the business of not covering claims, and changes its reasons for refusal in order to pay as little as possible. Further, the paper work involved in forcing them to honor my claim each time for my TEP was not worth the frustration.

It matters not whether the Lary thought he had solved the problem through legislative, regulatory or bureaucratic means. The outcome is transitory at best. The rule governing coverage may change the next day. As of now in Florida, Medicare pays nothing for my TEP.

I will continue to pay the full cost because I prefer to use a TEP and I justify the expense by adding it to my never ending medical and dental tax deductions.

Ginny Huffman – Atlantic Beach, FL
2005

I am new to Medicare and Medigap plan F provided by Anthem BCBS. I am not new to being a lary, surgery in 2001. Medicare coverage started in Dec of 2016 as did the plan F Medigap. An order was place in January of 2017 with InHealth Technologies. Medicare paid their part to InHealth and applied what they would to my
deductible. At this point Anthem should have received the claim and covered the deductible amount and then some. This is not the case as of yet. For Anthem to know a claim exists there has to be established by Anthem, a "crossover connection". My problem is this crossover connection is still not in place. Many calls to all parties involved have not resolved the problem. InHealth has been paid. Medicare did what little they do. Anthem has done nothing as of yet. I, as per my deal with InHealth, am left holding the bag as I paid them for the order with expectation of being reimbursed by either Medicare or Anthem.

Rex Schardein – Louisville, KY
2001

In short, NO.. not at all. I have been a Lary for 12 years and all of my medical services, equipment, supplies and drugs have been covered under Medicare Advantage HMO policies. My out of pocket expenses for premiums/co-pays have been next to nothing. During the 12 years I have had policies with 2 different companies and my experience with both has been quite satisfactory. I currently pay no monthly premium and the co-pays have gone down the past 2 years. I only changed companies because I moved and the first company does not cover the area where I now live. The only minor problems I have experienced have been due to sometimes less than quality customer service of the DME suppliers, but I found that a little intervention on the part of the insurance company straightened out the situation. No big deal, just free enterprise at work.

Dave Ross, Inverness, FL

YES YES YES! Problems getting supplies ALWAYS for 4 years now! I am on MEDICAID in Connecticut. Some of you have seen my posts and comments about this issue.

I was handed an Rx on day 16 postoperative from my SLP for a backup TEP, and foam filters (my puncture was done during surgery). They knew I was on Medicaid and the Rx was a form for INHEALTH. I could not speak so I ordered foam filter from Amazon and paid. Then I get an Rx from SLP 10 days later for HME supplies. I used EL and called InHealth only to be informed I need a 3rd party to order. I lucked out with small DME place who somehow was able to order for me and bill insurance. After a year they decided not to order for me. (I was their only customer for these). Needless to say I tried to call every supplier I could find . NO LUCK TO THIS DAY! At this very moment in time I am still looking.

I am lucky to have had donations and a grant for a year of supplies. Just do not know where or how to get my next prosthesis or HME's!! This gets harder all the time and I am on a fixed income supporting a grandchild. I contacted a Congresswoman and am hoping one of the suppliers will begin to bill Medicaid so I can get supplies. Medicaid will not reimburse if I were able to pay. EL just does not work for me to be understood no matter how much I try and as far as covering stoma I have tried just covers but it's not feasible for me to be choking up mucus every few minutes. If no HME or TEP I QUIT!

Sharon Severini – Waterbury, CT
11/2012
Hello, I am from the UK and can say that I certainly have never had any problems. People think we get our supplies for nothing but in fact we have to pay into “the system” since starting work which in my case I was 15. As I am now 67 and I think I have contributed a few bob by now!

I am able to order from a number of suppliers but tend to use a company called Countrywide as they give excellent service and are available for advice and guidance more or less all of the normal business hours either by phone or by email.

I order direct by email and it is ready for collection usually within 5/6 days. The system used to be that I ordered on line and then Countrywide sent the script to the doctors who signed it and returned it to them, and then they delivered to my door which was amazing service but somehow the system has changed to as I stated previously. But it is still very good and no hassle for me to go and collect.

Sorry to read about the problems some of you have overseas and I hope it gets better for you all as to have to put up with the medical problem is bad enough without having the hassle of getting supplies, God bless.

Trevor Hutson - Stony Stratford, UK

I am fortunate to have medical coverage thru the VA, being a former member of the Armed Forces. That said, when Medicare cut the coverage on DME, durable medical equipment, it really affected us in the Lary community. I wrote to my Senator, Congressman, AARP, and anyone I could think of. Most answered with a standard form letter, but I never saw or heard about any action on it. Being we are in the minority, Medicare doesn't act very quickly in making any changes. The only way I can envision any action, is we need to act as one large group in pressuring Medicare to extend the coverage for our supplies.

I hope one day this will happen and restore the coverage for our TEP and other needed equipment.

Aaron Futterman - Buffalo Grove, Illinois
Class of 12/2010

Next month’s question is:
Will you be attending this year’s IAL Meeting and the Annual WebWhispers Dinner in Newport News, VA this June. Have you ever attended one?

Thank you for your submissions. Edits are used for length, clarity and to keep comments on subject of the month.
Staff of Speaking Out
Extending the Limits of Good-will

People who push my buttons show me the limits of my good-will and I find this very humiliating…

A recent example - good-will suggested that I visit an elderly relative. It was a lovely day, and I just knew she would appreciate being taken for a drive and walk, maybe lunch in a café. (In retrospect I saw that I didn’t know this at all – I just assumed so because that was what I wanted to do!) Instead I found her morose, not particularly welcoming, and was quickly saddled with sheets that needed ironing and folding. Into the heart of good-will, disappointment and irritation insinuated themselves quietly.

Oh that I could simply have been aware of these unwelcome intruders, or that my heart would have gone a step further and chose compassion instead! Compassion for myself, in my disappointment and resentment. Compassion for my neighbour trapped in bad humour. From that a gracious willingness to help might have emerged, and in all likelihood we would both have cheered up naturally.

But negativity crept into my heart and set itself up as master without my noticing. We got into a tussle folding a sheet, me turning it one way, she the other. “Don’t do it that way” she said crossly. Instead of following her lead, anger drove me to let go of one corner of the sheet so as to get my electrolarynx onto the sweet spot to retort “Take it easy, we’ll get there”. But of course the corner of the sheet fell onto the dusty garage floor. “Now look at what you’ve done” she grumbled, “I’d be better off doing them by myself!” We both tightened into our respective knots of irritation and resentment, glowering at one another.

A storm of anger blew up in my head bringing a stream of self-righteous thoughts: “She has no right to make me do this work… she hasn’t a clue how to treat a visitor…” But somewhere in the midst of the storm I felt a sinking shame for having let the visit deteriorate into a dog-fight and a recognition that I had let myself be caught in the powerful bind of self-centring. Once caught, how much effort it takes to stop tightening the chains of my way, my opinions versus her ridiculousness, her hopelessness. By comparison, shame’s suggestion felt humiliating: that she was simply someone who I was rejecting in anger. No more to it than that.

Sitting in meditation, painful memories like these often come up. Letting go of thoughts, the body finds it easier to relax into shame than to tighten into self-righteousness. Perhaps that’s what we mean by “body wisdom” — our body can lead us to truth which our logic can deny. In time shame eases into forgiveness and a deeper commitment to good-will. Remembering the many painful lessons I’ve had on my meditation cushion, I couldn’t
pretend there was no option but to stew in self-righteous anger. After a minute of silently folding sheets (meekly following her every folding decision!) I summoned the energy for an apology for having made a fuss and dropping the sheet. Luckily this was rewarded by “That’s OK, you are very kind to call and help me. Sorry I snapped at you. I’m having a bad day and you got the brunt of it.” I smiled at her in relief. It felt like such a gift to find ourselves back in the happier, easier realm of friendliness and we soon took a break for a cup of tea and chat, and eventually got out for that drive.

Three ways I can extend the limits of good-will and avoid those humiliating lessons which demonstrate the impossibility of living happily without it: Spot the untested assumptions which so easily creep into the heart of good-will, skewing thoughts towards my happiness rather than whoever I am supposedly bestowing my good-will. Strengthen mindfulness so that I spot irritation before it creates a tight familiar world of my way, my opinions etc and from which all intruders must be repelled. Turn away from that familiar world whenever I find myself defending it, groping my way towards an unfamiliar freedom where there are no intruders and nothing to defend.

How to Use a Nebulizer – And Other Pulmonary Solutions

Jack Henslee

One of the challenges of being a laryngectomee is how to do things like use a nebulizer, and inhaler, to promote better pulmonary health, and we often get questions about how to take a pulmonary function test (PFT). I recently had a PFT and in the process (with a little experimentation) learned a few things that might be helpful to some of you.

My primary concern was how to effectively use the nebulizer so let’s start with that.

At first I was given a pediatric mask to go over my stoma, which was hooked up to the nebulizer. While this worked there was also quite a bit of leakage around the edges so it was replaced with a trach mask. That was big improvement with less leakage but for the best results you need a direct, sealed shot into your stoma. Something like a face breather taking the medication directly into the mouth, but actually better since in our case the medication doesn’t have to travel through the mouth and throat before it reaches the trachea.

There are basically 3 ways to get a direct shot into the trachea although other variations may be possible.

1. A nebulizer can be connected directly to a lary button/tube like the Barton Mayo or the Atos Lary Button if
you have a Hudson RCI, Multi-Adapter (H1422) as pictured in the illustration. You can purchase these at numerous places for about $2.50 with an internet search. I got mine at www.DirectHomeMedical.com. One end of the connector goes into the flex hose of the nebulizer kit, and the other plugs into the lary button/tube. (See Pictures below)

2. If you use an HME base plate then you can also plug the adapter into them just like above. In my case the base plate works a lot better because the connector sits deeper into it than with the lary button/tube. The base plate holds it more firmly whereas with the button or tube you have to hold it perfectly in place or it will slip out.

3. The third option, which I haven’t tried, is a special HME that has an oxygen port built into the side of it. In this case you don’t need the flex hose or the adapter. You use a trach mask set-up and plug the oxygen tube directly into the HME port. These special HMEs can be found at www.trachs.com.

Trach Mask Configuration

Base Plate/Stoma Button-Tube Configuration
The last picture above is a Symbicort inhaler that is plugged into an extender, then the Hudson adapter is plugged into the extender, and then a baby bottle nipple with the tip cut off, is attached to the end. The nipple is then inserted into the stoma and you spray whatever medication you use into the extender. Some medications work best when the spray has a chance to “mist” before it reaches the trachea, so the extender allows space for it to mist. The above set-up does a great job of this but it had to be modified a bit, and there are many types of extenders out there that this may not work with. So this is just something to help you visualize what may work in your case.

Finally, we get back to the elusive Pulmonary Function Test that many of you have been told can’t be done on a laryngectomee, or that the respiratory specialist doesn’t know how to do it. But rather than me trying to explain it all I will refer you a great video made by our own Bill Cross that shows you how to do it. So watch the video at https://www.youtube.com/watch?v=5KzuMLB6WrA, then order yourself a Hudson Adapter, get a base plate or stoma button, and educate your respiratory specialist if you ever need to do the test.

In 1965 I heard about a commercial fishing boat that was just sitting in a shipyard in Guayaquil, Ecuador, so I flew down to look at it. The boat was originally built by the American government and given to Cuba as a research vessel. I purchased the boat for $15,000. I had the boat hauled out to survey it myself.
I hired about 30 Ecuadorians to ship off the bottom paint, and I was paying them an equivalent of US 15 cents an hour, and it took them three weeks to finish the job. I could have had the entire job done in a Seattle shipyard in about two hours with a sand blaster. I could spend hours telling this story. Some of them are just hilarious. There wasn’t any refrigeration, so I bought a bunch of live chickens for the trip to Seattle. Those chickens provided fresh meat and believe it or not laid colored eggs. One rooster to keep them happy.

I have been almost everywhere in the world that I wanted to go, and a couple of places I didn’t. Of all places in the world that I have been I’ve never seen such abject poverty…. I flew six Seattle fishermen down to bring the boat back to Seattle. It broke down in Punta Arenas, Costa Rica … another great story, and I went back to visit three or four times.

Then it broke down in Acapulco during Mardi Gras. An even better story was after I had fixed a brokendown bus full of tourist from Mexico City. I became the local hero, and was invited to stay with the Harbor Master and his wife. She had a sister that lived in Seattle, and had me take some gifts home for her. Then a short stop in San Diego, and on to Seattle.

There's a very sad ending to this story. My three partners and I renamed the Reina del Caribe to just Reina, and converted her to a king crab fishing boat (like the "Deaddleist Catch". It was caught in a 140 MPH storm off the Aleutian Islands and lost with all hands on the maiden voyage.
Note: We really love it when we get feedback on an article or when one of you submits your own story to us about your travels, or for that matter anything that may be of interest to our group. Johnnie, one of our fellow Larys, sent the above in response to the Retirement in Ecuador article last month. While it may not relate to being a laryngectomee or other cancer survivor, we thought it an interesting adventure experienced by one of us so we printed it.

Most of us have been around for a long time and have experienced many things, and we would love to hear about your adventures and other experiences. You can submit them to editor@webwhispers.org. Don’t worry…We will edit for you. LOL
Springtime Whimsy

Reprinted from March 2014

My Robin Redbreast Friend

A dear little robin, with a breast of the brightest red,
flew into my garden, just waiting to be fed.

And the very next morning, he brought his wife to see,
and now I had two robins, singing just for me.

They then hopped around my garden looking everywhere,
for a hidden nest for them, and their babes to share.
They found a very old flower pot, hidden quite away,
and built their nest inside it, nearly all the very next day.

The lady robin sat in the nest, and the first egg she did lay,
until at last, five of the best, just laying one every day.
She kept them warm, both day and night,
the babes inside safe from the foxes sight,

With their little heads a-bobbing, the parents did await,
whilst that little cock robin with love looked after his mate.

Soon the eggs hatched, and there in the nest,
those chicks, perfectly matched with the pinkest of breasts.

Soon they had feathers, just like their mum,
whilst there, in the nest, and catching the sun.

But then came that day, when it was real sad,
the little chicks flew far away, leaving mum and dad.
So if a Robin Redbreast, your garden he does choose,
smile and you’ll be blessed, and in life, you'll never lose,

THE SPRING FANFARE

The rising sun, smiles on all today,
my daffodils turn and begin to play,
blowing their trumpets so silent and clear,
so that all the fairy folk can hear.

Tossing their heads in the gentle breeze,
spreading their arms with carefree ease.
Wriggling their toes, beneath the ground,
avoiding those stones which always are found.

Telling the flowers, ’It’s not so bad,
now spring is here, you should be glad.”
Their flash of yellow covers the earth,
giving crocus, narcissus, such joy and mirth.

Trumpeting to all, “You must today,
happily feel, glad and gay,
look up, look up, to greet the sun,

If you build it... they may buy it?

Now we have virtual reality...hmmm... okay now what?
I have long questioned just what new tech ideas and products do we really need. We have "phones" that are sold for their camera quality and social media features; what ever happened to making phone calls? Now we have Samsung introducing their Galaxy 7 with virtual reality features and they need an extensive ad
campaign to tell us all about this wonderful new tech solution in search of problem. Personally I have a problem of strapping my cell phone on my head in some Flash Gordon looking head piece and walking down the road.

Just what is this new tech we need so badly? Remember 3D and 3D glasses? Well that’s sort of it except V/R surrounds you while 3D was simply in front of you. What uses can be found for such an idea? One is the innovations to the medical world (and it won't be cheap), another is entertainment, of course. Don’t just watch a movie but climb right in there and get dirty with your favorite cowboy or girl. One entertainment author has gone so far as to create a game of the Trayvon Martin tragedy (I say that because a life was lost) with all its bloody content. Understandably the families of those involved have issues with this "game", however I can see this being the use of V/R in a training environment for the military and law enforcement, if it isn’t already.

Of course we need more social media outlets so the advertising companies can follow us around and attempt to meet our every need based upon sites visited. Just when you think you have found a new exciting feature in our tech universe it turns out to be as old as mankind itself. The art of gossip, information sharing or just plain BS has taken on a new face today. It’s called Social Media AKA: Facebook, Twitter, Pintarest, MySpace, Delphi, Google +, Email ... the list goes on and on. Please keep in mind that you don’t really know many of the people or those who say they are people on the World Wide Web. Among the marvels of today’s tech innovations it seems that our ancient need to share information and to learn of the plights of others has created a vast new business for our entrepreneurs. Part of the beauty of this technology is that there is no right or wrong ... simply what you as an individual prefer. The interfaces that have been created to appeal to us are seeking 90% acceptance and seem in constant flux to achieve that goal.

Dave Taylor's newsletter had an article that perfectly summarizes my feelings on waiting to buy the newest technologies. http://www.davescomputertips.com/when-you-buy-a-new-pc-its-already-superrseded/

The really big news for this time of year was the decline for orders of the Apple Watch. Another article from Dave's newsletter and written by Judy Novotny (whom I think is an excellent tech journalist) will tell you all about her experience buying her Apple Sport Watch and her decision to forestall upgrading the watchband for another $249 ... my, my... http://www.davescomputertips.com/my-apple-watch-buying-experience/

Spring is coming...Spring cleaning time! Your computer is just like any other machine requiring some routine maintenance to keep it running smooth and out of the shop. One of the biggest things that can trash your computer is heat....caused by the passing of electricity through your computer's components. The heat that is generated can be dramatically increased as dust and pet hair builds up inside the PC cabinet and even blocking the fans used to exhaust the heat. There are signs of overheating you can watch including you computer unexpectedly shutting down AKA: The Blue Screen of Death. Your PC is reacting to the rising heat by shutting itself down to protect its components. Maintenance on your computer is relatively simple, as long as you keep it simple. To clean the exhaust fans start by powering down the PC, unplug it from the electrical outlet...next place it in an area with good lighting and room to work...remove the side cover (which is what most cases have to access the interior) and locate the exhaust fans. With a can of compressed air blow the dust from the fan and fan blades. There should be no reason to remove any components, just be sure to clean the fan and the vent covers to allow for as much free air flow as possible. Once you have completed these steps simply reverse the order and replace the side panel and return your newly cleaned PC to its usual place. Plug it in and power it up. You should notice a difference in the PC's heat and even the speed may be improved.
An excellent way to be safe and alerted to the changes in heat is to install a free and simple to install utility such as SpeedFan, Open Hardware Monitor or Core Temp. The download links for these utilities and more information on them can be found by following this Bob Rankin link...
http://askbobrankin.com/your_computers_worst_enemy.html

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 and is our open area to ask questions and exchange thoughts. There are many categories of interest and you'll find the answers to many of your questions. If you haven't already joined the forum you can simply contact forum managers Bill Cross or Mike Rosencrantz for any questions you may have.

FORUM: http://forums.delphiforums.com/webwhispers/start

And for our newest members remember to visit our library for answers to many of your questions. Our Library 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.
http://www.webwhispers.org/library/library.asp

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For newsletter questions, comments or contributions, please write to editor@webwhispers.org

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