

Whispers on the Web

A Monthly Online Newsletter for WebWhispers



August 2022



WebWhispers 101

WebWhispers is a laryngectomee club, and a member club of the International Association of Laryngectomees. We are constantly adding new members every week. Both online and at the recent IAL Annual Meeting and Voice Institute, we have welcomed lots of new members. At 4,345 members, I thought this would be a good time to review what WebWhispers does, how we operate, and why one would want to be a member.

Do you know the benefits of WebWhispers membership?

Our members have access to the members only part of our website, which includes contact information for each member. They can receive and participate in our members only Mail Digest, which can be sent to your inbox as messages are posted, or in our daily Mail Digest, or both.

The Mail Digest is published at least once daily, if there has been activity. On the digest, members can know that their inquiry is being seen only by WebWhispers members who are a patient or survivor of head and neck cancer, a caregiver, or a clinician who works with us. SLPs often respond to our questions and so do laryngectomees with as much as forty or more years of experience maximizing their quality of life as a laryngectomee.

Our other online venue is the popular WebWhispers Facebook Group. Though some think otherwise, participation in our Facebook Group does not constitute membership in WebWhispers. If you are on Facebook with us but not a current WebWhispers member, I invite you to use this link and apply for membership today:

<https://webwhispers.org/join-us/>

Many Speech Language Pathologists are members of WebWhispers, Inc., as are affiliates with all major suppliers of laryngectomee products, along with many laryngectomees, patients of head and neck cancer, and caregivers.

Membership is required to use our electrolarynx Loan Closet and also to apply for Voice Institute scholarships.

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WebWhispers is an Internet based support group. Please check our home page for information about the WebWhispers group, our email lists, membership, or officers. For newsletter questions, comments or contributions, please write to editor@webwhispers.org

Kim Almand, Managing Editor

Tom Whitworth, Editor

Disclaimer: The information offered via WebWhispers is not intended as a substitute for professional medical help or advice but is to be used only as an aid in understanding current medical knowledge. A physician should always be consulted for any health problem or medical condition. The statements, comments, and/or opinions expressed in the articles in Whispers on the Web are those of the authors only and are not to be construed as those of the WebWhispers management, its general membership, or this newsletter's editorial staff.

Membership in WebWhispers is free, however in order to participate in our elections and corporate matters such as voting on changes in by-laws, one must be a sustaining member. Sustaining Membership is available for an annual donation of only \$5.00. Laryngectomees donating \$15.00 or more receive a Neck Breather pin from Bruce Medical.

Want to help WebWhispers?

Use of our vast website and everything we do for WebWhispers members is free. WebWhispers has various expenses throughout the year, such as the administrative costs of having and running our website, plus shipping and postage costs for our loan closet, the WW Alert kits, and getting our brochures to the people who distribute them for us worldwide. We also have expenses related to our participation in the IAL Voice Institute and there are costs associated with the publication of "Whispers On the Web".

You may be thinking "no way, nothing is free, everything with a cost is paid for by someone, somewhere", and yes, you are correct. WebWhispers operates off of voluntary gifts from members and friends. We are a 501 (c) 3, so contributions to WebWhispers, Inc. are eligible for tax deduction in the United States. We receive some donations from customers

on Amazon, eBay, and PayPal when users note WebWhispers as a receiving charity. These and Facebook Birthday Fundraisers are excellent ways to help WebWhispers without costing yourself anything at all. Donations to WebWhispers can also be made through the United Way.

Direct donations are received through PayPal (just note WebWhispers, Inc. as the payee) and also through the USPS at:

WebWhispers, Inc.
P.O. Box 1275
Powder Springs, GA 30127

WebWhispers is constantly looking for volunteers to help us with our work. If interested, reach out to me at :

tmwhitworth@gmail.com

Contributors to our newsletter are sometimes needed, too. If you would like to provide an article for Whispers on the Web, let us know at: editor@webwhispers.org

Enjoy, Laugh, and Learn,

*Tom Whitworth
WebWhispers President*





Voice Points is written by professionals for the lary community and is coordinated by Kim Almand M.S, CCC-SLP and Erin Guidera, M.S., CCC-SLP. Please contact them with contributions or questions at Kalmand@uthsc.edu or Erin.Guidera@moffitt.org

Laryngectomy Travel Tips

Going on vacation? Here are some tips to keep in mind when preparing for your trip. It is important to be prepared (and even overprepared) to ensure you have the best trip possible and know available resources in your area in case an unexpected situation arises. Different states and counties potentially have different climates and humidity levels that could have an impact on respiration and your secretions- these changes may have a greater impact on you and your body than anticipated.

Identification: bring documentation stating that you are a neck breather (i.e., medical ID bracelet, wallet card)

Should you require medical attention it is important that providers and medical personnel be aware that your upper and lower airway are disconnected. This is crucial so that you are properly taken care of in a safe and effective manner.

Necessary Supplies:

Heat and Moisture Exchange: Pack 1 HME per 24 hours + extras. Consider bringing extras in case you have an increase in secretions caused by different climates in the various locations you are visiting, or in case of flight delays that may extend your trip.

Different types of HMEs may be important depending on what you will be doing during your trip. Consider higher humidification and resistance versus less humidification/resistance depending on the climate and your activity level.

All supplies necessary for HME housing: baseplates, skin glue, adhesive remover.

Intraluminal devices

Should you feel like your stoma is starting to close or shrink, it is good to have something handy that can be worn if needed.

Do not forget cleaning supplies such as brushes for the intraluminal devices.

Shower guard

Portable suction

Current list of prescription medications and dosages

Electrolarynx (EL) with extra batteries

Even if you have a tracheoesophageal voice prosthesis (TEP), consider a backup method of voice. If your TEP starts leaking or falls out, you may need another way to communicate.

Red rubber catheter

If you have a TEP and it becomes dislodged, you will need to prevent closure of the tract with the catheter. In the event of leakage, a small catheter may be inserted through the prosthesis to eliminate leaking.

Be familiar with facilities in the area that provide laryngectomy care

Should any unfortunate or unforeseen situations arise, know where to go. Some hospitals or facilities are better equipped with staff who are familiar with laryngectomy care. Especially with TEP problems: not all speech pathologists know how to replace prostheses and troubleshoot TEP issues. Your SLP should be able to advise you ahead of time.

Be sure to either bring an extra TEP with you or at least be familiar with your type and size if you need to tell a provider.

Flying to your destination? Here are some tips for plane travel:

The air on planes contains less moisture and there is a change in pressure compared to being on ground level. This air may be an irritant and lead to an increase in mucus production with potential for thicker secretions. It is very important to make sure you are wearing your HME while on board.

Hydration is key! It is very easy to get dehydrated while flying. Drink plenty of water and avoid alcohol and/or caffeine as much as possible.

Pack all necessary laryngectomy supplies in your carry-on bag. This way, should you need anything during the duration of your flight it is accessible. Also, should your luggage not make it to your final destination, you will not be without the essentials.

Preparation is the key to having a successful trip. Why worry about having to locate necessary supplies or search for a clinician's help in an

unfamiliar environment during a potentially stressful situation? Having all your 'ducks in a row' before you depart for your vacation will result in the best possible outcomes even if a sticky situation arises.

Tara Segalewitz, M.A., CF-SLP, is the current medical speech-language pathology clinical fellow at Tampa General Hospital. She is a proud double gator completing her undergraduate and graduate education at the University of Florida. Tara has a passion for the acute care medical setting focusing on dysphagia diagnostics with special interest in transplant patients and head and neck cancer care. tsegalewitz@gmail.com





What Do YOU Say?

How did you go about choosing your current method of speech?

Many of you will remember our "Speaking Out" column by Jack Henslee. It was among our most popular columns in Whispers on the Web. In that same vein, this new column is designed to share member comments each month. If you are a laryngectomee, caregiver, friend, SLP, MD or other professional we want to hear from you!

I'm from up north in the James Bay area. At the time I became a lary, the only way of communicating was with an EL. Many years later the TEP was offered but I declined as I was accustomed now with the other.

-Emile D.

I was going to a speech therapist who showed me how to use an EL and tried to teach me esophageal speech. After going to a CAL Conference in 1994 I was introduced to the TEP. Another Lary friend and I went to UCSF and Dr. Mark Singer had us both do an insufflation test to see if we were good candidates. I sounded good and have been a TEP speaker ever since.

-Rita Kinney

After surgery, I had a TEP installed but my stoma is a little too deep and I do not get a good seal. I tried numerous times to install the adhesive baseplates but it just didn't help, but I am still trying with using a trach foam. I have been using an electrolarynx for the past 6 years which works just fine.

-Gerard Viverito

I was working with a speech pathologist before my surgery and she gave me a lineup of electroarynges to try. I chose the Romet, thinking that was going to be my voice to come.

However, my ENT surgeon had other ideas and when I came out of my total laryngectomy surgery I had a primary puncture and a feeding tube in the puncture. Four weeks after surgery, the speech pathologist that was qualified to fit voice prostheses was somewhat skeptical about my ability to voice without any insufflation test but fitted me with a Blom-Singer duckbill prosthesis. Voicing came a bit slowly, but gradually improved. I have used a Blom-Singer voice prosthesis now for 29 years and am acknowledged to be one of the more proficient TE speakers in our community.

-Carl Strand, Mystic Connecticut

Did not have a choice. Surgery was too radical. 8-year survivor using the electrolarynx and doing great.

-David

I decided on TEP after a pre-op meeting with an experienced lary, John Ready. TEP was put in during surgery.

-Robert Bauer

I tried the TEP and did not work well for me. So I went with the EL and have been very successful for several years. I did not have a lot of advice early in my journey and the EL works great for me.

-David Kinkead

I went to the Tidewater Lost Chord Club Meeting prior to my surgery, listened to the different types of voices and heard a gentleman using a TruTone EL. On the way home from the meeting, I told my wife that if I could sound half as good as that guy, that is the unit I would like to use after surgery. I ordered the device, found my sweet spot and haven't shut up since.

-Tom Olsavicky





Member Contributions

Don't Leave Home Without It!

Lary Car Kit Everyone has one – right? Maybe not. I am kind of a provision nerd. I like to have at least one of everything I could possibly need when I go somewhere.

Because of vocal cord cancer, I had a total laryngectomy in 2014. It was frustrating for a little while, trying to figure out what exactly I needed to carry with me, what items in my shirt pocket, and what items in my car. Suddenly, at 59 years old, I had to make a major change in my daily pocket carry items, and my car supplies. I found there were some new things that I needed to keep with me when I am out of the house.

Back to the Lary Car Kit in a minute. First: IN MY POCKETS always: A stainless steel pocket mirror (unbreakable), an extra HME “filter”, some Q-tips for whirling away mucus near the opening of my stoma, and a couple of napkins to put the used Q-tips in. I always keep a cloth stoma “bib” in a pocket; a nylon or cloth one that can be wadded up or sat on without issue.

I eventually started only wearing collared outdoor type shirts with two Velcro (preferred) or button pockets on the front. The collar keeps my electrolarynx tether from rubbing my neck, and the two pockets give me plenty of room for the lary supplies.

My stoma bibs have velcro straps to hold them around my neck. You can see them online. Many colors and styles. You tuck them into your shirt, so they look fine. Actually, with a fancy silk bib and a suit on, you look like a movie star! Some have strings that tie behind your neck, and others a “clasp” of some type.

Why carry a bib? Well, occasionally most of us have the unexpected sneeze, or coughing fit. This sometimes clogs our HME (filter) with mucus and we can no longer breathe, or at least not breathe without restriction. If we have an extra HME in our pocket we can remove the soiled one and pop in a fresh one. But what if we don't have an extra HME, or what if we have a hard Motherload sneeze and blow out our baseplate? With the stoma bib in pocket, you can either put it on and cover the whole mess

until you get to a restroom, OR immediately go to a private area (bathroom, behind a tree, in your car) and remove the baseplate, clean your neck up, and just wear the stoma bib the rest of the day, or until you get to your “Lary Car Kit.”

I actually wear a stoma bib INSTEAD of a baseplate and HME to places I don’t want to have to worry about an HME or baseplate sneeze “blowout t”:church, funeral home, grandkid’s school performances, etc. Because no matter whether you cough or sneeze hard, the bib will still cover everything, and no one will even know if you’ve “had an accident.”

Lary Car Kit??? What’s that? Well, I found that when I would be out driving somewhere, I’d sometimes wish I had something I didn’t have in my pocket: tweezers, extra Q-tips, extra bib, an extra mirror in case I’d forgotten my pocket mirror, a flash light if your phone doesn’t have one, several extra baseplates, several HMEs, baseplate removal pads, baseplate “glue” pads, Roloids, etc.

So, I made up a Lary Car Kit, and put all these items in it. I found a zippered nylon container on Amazon around 10” x 8” by 4” high online. Search “zippered nylon pouch”, or hair dressing or hair clippers bags: they are about the right size and some have multi-compartments, which is handy.

I added a phone charger to the kit. It is very handy when traveling, but I leave it in my car all the time. I eventually made THREE of these Lary Kits: one for my car, one for wife’s, and one for my truck – to save the hassle of moving it all the time. I am never without one

--David Smith

