



Whispers on the Web

A Monthly Online Newsletter for WebWhispers



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September 2022

From The Editor's Desk

Greetings this month to all our members and visitors!

As we usher in a new season of the year, I have been taking the time to re-explore some of the many resources available at WebWhispers online. One of my favorite sections of the website include audio clips of speech samples from various speakers with artificial larynx devices, esophageal speech, and TEP. I refer to these all the time when I want to demonstrate how the sound of the various methods of alaryngeal voice might compare. These can be found under Resources for Laryngectomees and Talking Again: <https://webwhispers.org/resource/talking-again/>. Laryngectomee Safety Kits and videos are another useful tool especially for new laryngectomee and are found in Free for the Asking: <https://webwhispers.org/resource/free-for-the-asking/>. If you want to know more about our loan closet and how to obtain an artificial larynx device, these can be found in the Services section of the website: <https://webwhispers.org/services/>. And at least a few times every month, I find myself referring back to previous Whispers on the Web newsletters for some important piece of information that I know we spoke about earlier. <https://webwhispers.org/whispers-on-the-web/past-newsletters/>

This month's Whispers on the Web is filled with more current events and perspectives on rehabilitation. You may be surprised to learn that big plans are already underway for head and neck cancer fundraising and awareness events to take place in April and May 2023 across the nation. Stacey Brill, founder of "Head and Neck Cancer: A Hard Thing to Swallow" has more details in this month's newsletter Member Contributions below. Also, hot off the presses, we have just learned that the next International Association of Laryngectomees (IAL) Annual Meeting and Voice Institute will be held on May 11-14, 2023 in St. Louis. More details to follow as soon as they are made available. Also this month, VoicePoints (VP) presents an overview of how telehealth may benefit people who have undergone total laryngectomy. Rina Abrams, speech-language pathologist, outlines why this is a common practice in many areas and which issues may qualify for a virtual visit to your SLP versus which issues are better left to an in-person visit. And What Do YOU Say provides a teaser to next month's VP column. Survivor members speak out on the topic of lymphedema, which is swelling of the soft tissues due to an accumulation of lymph fluid. It is a lot more common than you might think.

As Tom reminds us in The President's Corner, there really is something for everyone here. This organization is not just in place to serve survivors of head and neck cancer, but also our families, caregivers, and professionals. Our website, newsletter, email list, and social media sites exist to promote healing and knowledge; to provide support and encouragement to all our members. This month, whatever season you may be in, be assured that you are not alone. This is a community with a big heart to serve the needs of our members and we are glad you have come to join us.

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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

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Something for Everyone But Nothing for All

In our online conversations, there is currently an active discussion about our communication “venues.” Some use one, some use the other, and some use both, but they are different.

Some of the active members of our Facebook group do not participate in the email digest. Many of them can't because it is limited to members of the WebWhispers organization that was started by Dutch Helms in 1996. Many people don't care for Facebook and that is perfectly okay. Facebook has undergone considerable criticism of late because of what it chooses to censor. Some see political implications there and that makes them want to go elsewhere. It is surely our prerogative to make that choice. Facebook has some obvious advantages, not the least of which is, though not always, it generally provides a quicker response time.

Censorship by Facebook is something we have no control over and it is often the result of complaints from other Facebook users. If a post is offensive or in some other way viewed as inappropriate, Facebook will often remove it when it is reported to them. The moderators of WebWhispers Facebook Group will also occasionally remove a post in the group because it is considered offensive or inappropriate in some way. Rules of the road in our Facebook group are clearly posted on the site. Repeat offenders are sometimes removed from the group to help ensure a helpful, positive environment for all members of the group. Our moderators do a good job of providing a good experience by enforcing these rules.

Posting on the email digest, though not as active as it used to be, is still there for those of us who choose to use it. The list still exists and, as in the past few days, still has activity. What generates activity on the list? You! For those not in the Facebook group wanting more information on a topic or wanting to ask a questions of our 4500 or so members, share or ask to the email list. Non-members wanting access to the email



digest need only to join WebWhispers here: <https://webwhispers.org/join-us/>

In the recent discussions, someone asked why the information on the Facebook group is not shared on the list. I'm sure there are a number of good reasons but the first that come to mind for me are: (1) It does not belong there as it was not offered by the writer on the list but on Facebook. WebWhispers members who are also in the Facebook group can post in both places if they want their information or question to be in both. (2) WebWhispers members, not in the Facebook group and wanting access to what is there, should join it! It's easy to do. Answer a few simple question and that's it.

The policies for our email list and the FB group are very similar in terms of what is appropriate behavior. Though something may slip by once in a while, we generally do not tolerate posts in either place that are rude, vulgar, profane, bullying or intentionally insulting in nature. We also do not allow soliciting or posts that are deemed to be medically inaccurate. As with everything WebWhispers, we do not condone the offering of medical advice. We share with one another what has worked for ourselves and suggest that readers check with their professional care team before making any changes in care for themselves or a laryngectomee in their care. Personally, my go to for that is my speech language pathologist or another SLP I know and trust. They know a thing or two because they've seen a thing or two.

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

Telehealth for People who have Undergone Total Laryngectomy

Telehealth has been around for many years, but grew dramatically when the COVID-19 pandemic occurred. You may hear it referred to as telehealth, virtual medicine, telemedicine, telemed (abbreviated version), or something else of that variety. Many clinicians around the country and the world learned a whole new platform for seeing patients and were required to learn it quickly. There were a lot of bumps in the road as we clinicians and patients learned the technology, but we have made it work! There are certainly still some glitches, but it has proven to be an effective model for delivering speech language pathology (SLP) services in some situations. It has also allowed for greater collaboration among providers and patients, including support groups.

There are a variety of platforms for performing telemedicine and the platform may vary depending on where the speech pathologist (SLP) or other disciplines are working. At my hospital we use an application called WebEx, which is accessed through the patient portal. This is a secure HIPAA compliant portal. There are additional options if that doesn't work as unfortunately it isn't 100% reliable. At times we use Zoom, or an application called Doximity. There are additional platforms available as well. The facility you are working with can direct you as to which portals they

use and how to attend a virtual session. Not all facilities offer teletherapy as an option. This may be for a variety of reasons.

Some visits are certainly not possible to complete via telemedicine. Some examples of when it would be possible to be seen for telemedicine include electrolarynx therapy, possibly some stoma care, possibly mastering a tracheoesophageal voice prosthesis (TEP) speech. Some examples of when telemedicine may not be a possibility include some stoma care, secondary TEP evaluation requiring an insufflation test, swallowing evaluation, or changing a TEP. These are not possible as they require hands-on activities.

Stoma care can vary as at times the SLP can explain virtually how to place an adhesive baseplate for example; however, if the person placing it is still having difficulty then they may need to be seen in person in their clinic. It is also important to note that SLPs have a large variety of samples in their clinics so if one thing isn't working we can easily try another thing if the patient is physically present. At home you are more limited to the only supplies you have. There are times when I see someone virtually and we determine that I then need to see them in person for an additional visit at a later date. The chart below can be used as a quick reference

to help guide decision making on whether or not to be seen in person or virtually.

Possible* virtual visit:

- Electrolarynx therapy
- TEP therapy focusing on voicing
- Some stoma therapy
- Pre-operative total laryngectomy counseling

In person visit

- TEP change
- TEP troubleshooting
- Some stoma therapy
- Swallowing evaluation
- Secondary TEP evaluation including insufflation test

**Possibly virtual depending on what specifically is required during the visit. Please check with your SLP to determine if virtual is possible.*

The speech pathologist providing the service needs to be licensed in the state you are physically in at the time of your visit. For example: if you live in North Carolina and are at home at the time of your visit then they will need to be licensed in North Carolina; however, if you are on vacation in Maine at the time of your visit and your SLP is not licensed there then you cannot see them while you are on your vacation. Evaluation and treatment sessions are billed through your insurance just as they are

with in person visits. You can check with your insurance to find out your specific coverage.

If you are interested in completing visits virtually you will need to check with your SLP to see if this is an option depending on the type of visit it is and if their facility offers telemedicine. If they do not you can ask your SLP for a recommendation on who may offer it, or you may choose to continue with in-person visits.

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Have you ever had lymphedema, and if so, what helped?

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

I had lymphedema post-laryngectomy but not nearly as pronounced as some of us have to deal with. Still, I hated the big lump on one side and was sure glad when it began to subside. I learned so much on the topic at my first IAL Voice Institute only weeks following my surgery.

As I was getting my things into the hotel room and walked past a mirror, I was terrified by the size of the lymphedema. It was bigger than ever and yes, I was concerned. I wasn't even sure of what it was I was seeing. By morning, it had subsided a bit. Boy, had I come to the right place.

I learned that flying can cause it to enlarge. That morning or the next, Brad Smith CCC-SLP and Certified Lymphedemas Therapist presented on the topic and demonstrated a massage method that helped me immensely.

It even worked on me some as I followed the instructions and tried it right there during the presentation.

Brad was scheduled for a hands-on class I think the next day, and needed a volunteer. I was happy to help and eager to learn more so my hand went up as fast as lightning. For the class, he demonstrated the method on my lymphedema and taught me how to do it for myself. The students were amazed at watching the technique work right before their eyes and at how easy it was to learn. It takes 30 minutes to do. Again, I had come to the right place!

-Tom Whitworth





Head and Neck Cancer: A Hard Thing to Swallow Race Schedule

In the spring of 2023, individuals battling head and neck cancer will be getting the wider attention they deserve. In April and May, races will be held across seven states to bring recognition to this increasingly common cancer. The events raise funds to support patients and caregivers in the local area; increase community awareness; and provide a fun opportunity for patients, caregivers, physicians, healthcare providers and supporters to interact in a positive and life affirming activity.

2023 will be the 11th year the “Head and Neck Cancer: A Hard Thing To Swallow” 5k run and 2 mile walk has been hosted by Partners in Care, a not-for-profit oncology foundation. Funds raised from each event stay in that local community and provide financial assistance to those diagnosed with head/neck cancer regardless of when they were diagnosed. This financial assistance includes services and products related to the diagnosis that patients would otherwise go without due to costs.

The 2023 races have a superhero theme...come dressed as your favorite superhero to add to the fun!

The 2023 race schedule is as follows:

- 4/15 9am Tri-Cities WA:
Columbia Point Marina
- 4/16 9am Redding CA: Lake Redding Park
- 4/22 7am Key West FL: Higgs Memorial Park
- 4/22 6pm Miami, FL:
Larry & Penny Thompson Park
- 4/23 7am Broward County, FL:
Tradewinds Park
- 4/29 8am Cape Coral, FL: Jaycee Park
- 4/30 8am Sarasota, FL: Payne Park
- 5/4 6pm Charleston, WV:
(Venue To Be announced)
- 5/6 8am Winston-Salem, NC:
Jamison Park-Muddy Creek Greenway
- 5/7 8am Asheville, NC: Carrier Park
- 5/7 4pm Greenville, SC:
Conestee Park Nature Preserve
- 5/13 9am Denver, CO: Carpenter Park
- 5/14 9am Colorado Springs, CO:
America The Beautiful Park

Everyone is encouraged to get involved whether it be volunteering prior to or the day of events, walking/running in person or virtually, helping to distribute race information in your community, or many other volunteer opportunities. More information will be coming at www.yourpartnersincare.org or contact race founder and chairperson at Sbrill@aol.com.

The races are guaranteed to be a fun time for a great cause. If you are interested in hosting a free oral/head/neck cancer screening at one of the races, please email event founder and chairperson Sbrill@aol.com for more information.

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*Look for the next issue of
Whispers on the Web in October*