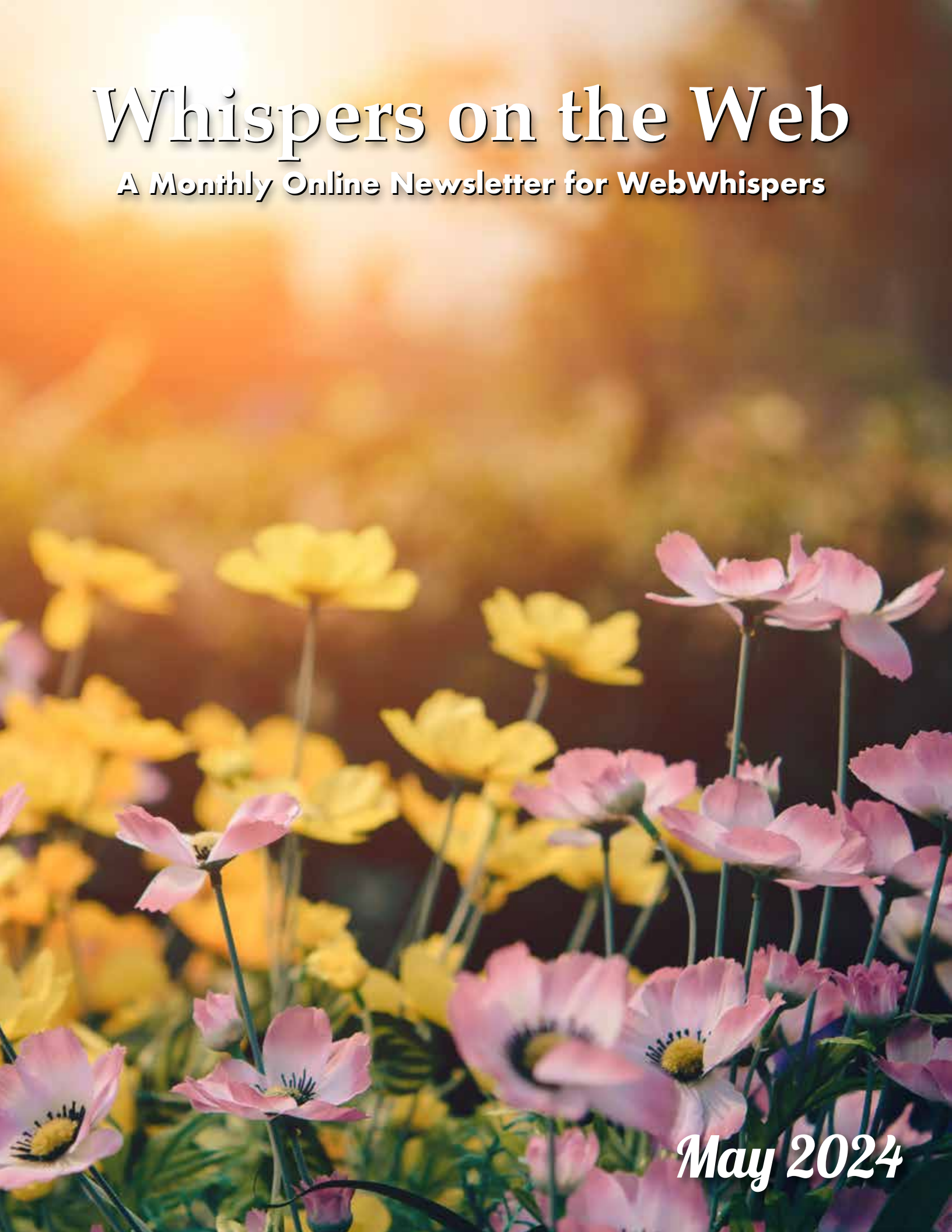


Whispers on the Web

A Monthly Online Newsletter for WebWhispers



May 2024



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Welcome Back to WebWhispers!

Hello, cherished members and friends of WebWhispers!

We are thrilled to announce the return of your favorite newsletter! After a brief hiatus, we're back with the May edition, brimming with fresh perspectives, shared wisdom, and an uplifting story.

We've missed this connection with you all and are eager to dive back into discussions that matter most to our community. This newsletter isn't just a collection of articles; it is built from your own unique experiences.

We return with an invitation for each of you to contribute AND also to express our heartfelt gratitude. A big thank you goes out to everyone who has shared their stories with us in the past—you've made a real difference. And to those considering sharing for the first time, know that your future contributions are just as valuable. Your insights and experiences can offer support and strength to others. Your voice has power, and your story could be exactly what another member needs to hear!

In this edition, we are pleased to feature an article celebrating the continued relevance of esophageal speech. Kim Webster describes how she has taught this method of alaryngeal voice in the past and why and how it remains a strong voice option. We also discuss a common post-radiation treatment condition called trismus, which can significantly impact quality of life. We delve into what it is and what symptoms to watch for. And you will not want to miss Dr. Steven Foster's inspiring true story "The Song Remains the Same." It is a story that speaks to the strength and spirit of hope at the heart of our community.

We are delighted to be back in action with this May edition—a symbol of perseverance and community strength. Thank you for standing by us during our pause and we look forward to hearing more from you.

Warm regards,

The WebWhispers Team

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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We're Back!

Welcome! We're glad you're back and we're glad we are back, too!

You might say that the rumors of our demise have been greatly exaggerated. Whispers on the Web is still here and so is WebWhispers. Now in our 28th year, we are not going anywhere and are still right here with you.

However, there have been some challenges with Whispers on the Web and we are addressing them. Scarcity of contributors has been the biggest issue.

In past years, we had a nice compliment of contributors who wrote for our publication every month or almost every month. This group was no less than six people in addition to our Voice Points contributors. These people were, well....., you!

Yes, Whispers on the Web is a newsletter by laryngectomees, for laryngectomees, and about laryngectomees, and others in our community. Of course, caregivers and others have written for us as well, and for the same audience- larys, caregivers, and SLPs. Some of our best reads have come from caregivers and professionals who care for us and about us.

Each and every person in this community has a story to share and that is what WotW is about. As an SLP, you might tell us about that nameless patient who impressed you with their determination during recovery and rehabilitation, the one that inspired you to continue working

with us, and absolutely the one that made you laugh. Laryland is not without its comedy, that's for sure.

As caregiver, you might tell us about maintaining the bear in your house, or the crusty old buzzard in your care. Your perspective on living with a laryngectomee cannot be matched by anyone. It is your experience and we want to hear about it; all of us do, especially those in the same boat with you, other carers.

We laryngectomees often feel that our story is the same as that of any other lary. We mistakenly think that this journey is only about chemotherapy, radiation, laryngectomy, supplies, medication, conditions, and yep- mucus. Yes, there are commonalities in all of our stories. I assure you however, that no two stories are exactly the same; each of our stories is unique. Only your story is about YOU.

Whoever you are in this community, you have something to share and our audience needs what you have to offer. For questions about writing for us or simply to submit a proposed article for Whispers on the Web, email us at Editor@webwhisper.org We'll be waiting for you.

Love to you all,

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

Current Thoughts on the State of Esophageal Speech: It's Not as Grim as I Once Thought

The tracheoesophageal puncture and prosthesis (TEP) was developed in 1979 and revised in 1989 by Eric Blom and Mark Singer (Singer, et al., 1989). It became popular in the decade following its revision and has been a favorite for patients, otolaryngologists and speech-language pathologists with declining use of electrolaryngeal (EL) speech and esophageal speech (ES) over the past 40 years. Still, all 3 modes of communication remain options for individuals undergoing total laryngectomy (TL). Yet, it is increasingly rare to see esophageal speakers and even more rare to find a speech-language pathologist who can teach esophageal speech to patients undergoing TL.

When I took a course taught by Jeri Logemann and Cathy Lazarus in speech rehabilitation after TL at Northwestern University in 1990, we learned about both EL and ES as options. We also learned about a new method of speech with a TEP. We had clients to work with each afternoon and were training them in the use of both EL and ES. Many with an EL wanted to have another option in case their EL battery ran out or if they wanted to speak hands-free. Some wanted to develop the ability to produce at least single words or short phrases with ES in cases where they could not easily use the EL.

We used methods described by Shirley Salmon and Jeri Logemann (Salmon, SJ, 1986; Logemann JA, 1999) to explore different methods of air injection: consonant injection, inhalation method and glossopharyngeal press. We first had to learn

to use these methods ourselves. We practiced after class at night and were encouraged to use carbonated beverages to help feel where the air expulsion should occur. We were taught not to rely on carbonation but to learn to bring air up or in to the pharyngo-esophageal (PE) area to produce sound. Then we tried to increase the consistency of sound production with each method to 80% or more. Once we were successful, we then tried to extend the duration of the sound.

With each trial, we were not to allow ourselves (or our trainees) to grimace or make any distracting sounds during the air injection or sound expulsion. This was very difficult. We used mirrors and each other to give feedback until we reached a level of success where we could produce a word or short phrase with good intelligibility. We then tried to help patients learn to produce or improve esophageal speech in our afternoon lab sessions after classes. Some of the volunteers were very successful and enrolled as clinic patients the following semester. I worked with a lovely woman ("Ms. Jean") who was a long-time EL user who wanted to be equally skilled at esophageal speech. We worked together for the semester after the class ended, and she was able to communicate in short sentences with good intelligibility, and no audible or visible distractors. It was one of my first motivations for continuing to work with patients with head and neck cancer.

Over the years, I have always advocated for patients to develop skill with as many alaryngeal

speech modalities as possible. I have never viewed alaryngeal speech rehabilitation as a choice among methods, nor do I favor one over another. I think all have pros and cons. I think some are better for certain people than others. I also have seen that one method may work well for a while and then due to anatomic, physiologic or cognitive changes, another method may be preferable. Being skilled with at least 2 methods gives people options. Background noise, hearing acuity of the listener, setting and situation are all factors which may affect the best method of communication to use.

Some years ago, Robin Samlan, PhD and I taught a course to SLPs on the different methods of speech for patients with TL. I jokingly dressed as the grim reaper, and we played ominous music as we introduced the topic of ES. We suggested that it may be a “dying art,” and advocated for all the positives of learning to use and teach ES. It is the only intrinsic method of alaryngeal speech. It requires no plugs, batteries, brushes or tubes. It is always hands-free. You cannot forget it at home or drop it in the toilet! It does take some time to develop (for many), and it is sometimes less audible than EL or TEP speech. For some, the length or duration of an utterance may be shorter than with EL or TEP. It is difficult to speak during or even right after a meal, although this can be true of TEP speech as well. There are clear advantages to learning ES.

In the last 40 years, TEP for speech has become common. It is not without issues, however. In the time since chemoradiation has developed as a definitive cure for some laryngeal cancers, we have seen more issues with TEP use. There are more TEP failures and a lot of troubleshooting for leaks through and around the prostheses. My colleagues and I investigated this some years ago and discovered that salvage TL was more highly associated with TEP leakage and other problems than primary TL (Starmer, et al, 2009). More recently, there seem to be problems with PE segment spasm, requiring Botox injection and other interventions to facilitate TEP speech. The spasm affects esophageal speakers similarly (Doyle, PC & Damrose, EJ, 2022). As clinicians and physicians are becoming more skilled at

troubleshooting PE segment spasm, we can help patients achieve TEP speech. The authors suggest that “The elimination of PES spasm provides evidence that justifies the reconsideration of ES. Consequently, ES may return as an increasingly viable post-laryngectomy voice and speech rehabilitation option.”

Perhaps the grim reaper’s appearance was a bit premature. Will ES have a resurgence in popularity? I would like to think so. I will certainly continue to include it in my courses and encourage SLPs to learn how to instruct patients with TL on how to use it. I still discuss it as an option with all my patients pre-operatively and for those with TL that use EL or TEP.

Now, if only the Tokyo pneumatic device could make a comeback...

By Kim Webster, MA, MS, CCC-SLP

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The Song Remains the Same

Steven Foster

This is a song story of hope. As a young lad I played trombone and dabbled with various saxophones. I started with the trombone in 3rd grade and played through the 10th when other things got in the way. I have always loved music, all genres, except rap. I am fortunate that my dad has always been quite hip and loves music too. At an early age he introduced me to Jefferson Airplane, Elton John and the Don Shirley Trio. He has always had eclectic taste and is still very much into finding new and exciting music. My mom is a fan of vocalists, especially Barbara Streisand and Mario Lanza, while one of my grandfathers and two uncles were big into old Country music. I enjoyed all of that, but gravitated to Pink Floyd, Led Zeppelin & The Who. In my early years I would often spend evenings in a circle of friends singing and playing music. In the '70s and '80s, I was dancing the night away in clubs, with music pounding through my body. For a brief moment, I even did security at rock & roll concerts. Most definitely, music is in my heart and in my soul.

One of my best friends asked me several months ago what I miss the most: being able to smell or being able to sing. This is a tough question to answer for us laryngectomees. As a former chef, the loss of smell while cooking and eating is dramatic, and there are many other things I miss being able to smell. Of course, there are some ways to improve our olfactory handicap, but they are at best a mediocre substitute. Singing...well that is a problem. I can do it, but I must hold my baseplate and HME secure to get any reasonable volume, and it is quite monotone. While my first thoughts to the question were uncertain, after careful consideration I would definitely say singing. Now, many would say that I couldn't sing that well before, but I beg to differ and one's singing ability is often quite lovely in the ear of the producer.

With this background in mind, here is what



happened 2 months ago. My wife, Linda and I go to estate sales a lot. We were recently at a fabulous sale of a former University of Oklahoma English professor and his wife, Dr. David and Betty French. It was full of many things of interest to me but especially attractive were hundreds of Classical music vinyl records (another story) and several beautiful recorders. Recorders are precursors to the flute. They were huge in the baroque period and often have a focal role in chamber music, especially some composed by Haydn and Bach. They are still used to this day, albeit limited. On the second day (½ price day) I went back alone and as I was appeasing my vinyl addiction; I had the brilliant idea to buy a couple of recorders. I selected one and while contemplating another, our reality suddenly

dawned on me... "What are you doing you silly boy? You can't play the recorder. You've had a laryngectomy. The days of wind instruments are over for you." It was startling that it took me at least 5 minutes to remember this. Of course, I put the recorders down, paid for my vinyl and headed home; a bit melancholy, but more transfixed on how my mind had temporarily forgotten my (our) present condition. On the way home I called Linda to tell her the interesting story about me almost buying the recorders. She said: "Well why don't you go back and get them; they are quite beautiful. We could display them in the house." Linda had been there the day before and seen them. So, I went back. By this time there were only two left and I snatched them up at ½ price.

The following week, I saw Tracy Grammer, our wonderful speech-language pathologist. I told her the story of the recorders. She said: "I had a person who had a laryngectomy who played the Native American flute. I made her an adapter so that she was able to play through her stoma!" I was so excited. The thought hadn't really entered my mind that I could actually play one of these instruments.

Over the next few weeks, we worked on several prototypes and eventually developed a couple of adapters that allow me to play. It is truly AMAZING! I ran around the chemistry department like a little boy demonstrating to everyone that I could, my newfound ability. We made a video of me playing an abbreviated scale on the recorder for Tracy's trip to ATOS in Sweden. I promptly sent this to all my family members and friends. Linda even posted it on her Facebook page.

Here's the rub though, I don't know how to play the recorder. Nevertheless, with my musical background, instruction from the Internet and hunger to generate some music out of my body, I will prevail. So far, I haven't been a very good student, but perhaps by the time of my scheduled recorder demonstration at the November meeting I will be able to play a simple ditty; we will see.

When I started this piece with "This is a song story of hope" not only is it a take on a line used by Robert Plant before a live version of the Led Zeppelin song "A Stairway to Heaven," but it is also a statement for me and all of us laryngectomees.

I have a motto and that is, I refuse to be kept down. My life has been a series of challenges and I continue to overcome adversity; having a laryngectomy is simply another. Several have suggested that I upload a recorder video to YouTube. I haven't done so yet, but plan to when I get a song in the repertoire. Who knows, YouTube today, Jimmy Falin tomorrow!

There are probably others of you who are musically inclined and talented. Maybe we could put together some kind of support group band. Wouldn't that be groovy? So I present this challenge to us all: Be not afraid to think outside the box; know no boundaries; don't look at our limitations, look instead for the things we can do to fill our lives and the lives of others with joy, music and merriment.

This article was originally printed in 2015 in the Sooner NuVoice News, OU Med & Stephenson Cancer Center, Oklahoma City and re-printed here with permission

Steven Foster was unable to speak for several months after his surgery (160 days to be precise) but once he was able there were no limits to his ambition or his achievements. He did indeed play a few ditties on his recorder at a 2015 NuVoice meeting in Oklahoma City. With more practice he was ready for a full performance to a packed house at their Christmas party the following month.

Steven Foster, Ph.D. is also Director of the University of Oklahoma Mass Spectrometry, Proteomics & Metabolomics (MSPM) Core Facility, located in the Department of Chemistry and Biochemistry in the Stephenson Life Sciences Research Center on the Research Campus in South Norman.

Trismus After Head and Neck Cancer Treatment

According to a recent study, nearly 25% of patients who underwent radiation and/or chemotherapy for their cancer required a salvage total laryngectomy for recurrent or persistent disease, or because of chronic aspiration or necrosis of the larynx. Previous history of radiation may increase a person's risk of something called trismus.

Trismus is a condition in which the mouth does not fully open. It can cause painful spasms in the muscles and joints that surround the jaw. It is more likely to occur in patients who have had surgery or radiation to the head and neck area, specifically the palate, maxilla, mandible, tongue, retromolar trigone, cheek, or lips. It can also occur in patients who have had treatment to the base of tongue.

Trismus can occur at any time during, immediately after, or years after cancer treatment. It is less likely to occur if treatment was focused only on the lower part of the throat; however, surgery and radiation to the head and neck regions are known risk factors for trismus.

There are various signs and symptoms of trismus. These include:

- Not being able to open the mouth as wide as usual.
- A typical mouth opening should be about 3-4 fingers stacked together between the upper and lower teeth or gums.
- Jaw muscles feel tight, like muscle cramps.
- Jaw pain when not talking or at rest/without movement.
- Jaw pain or discomfort with chewing or yawning.

It is very important to manage trismus. If trismus becomes severe, it can have a negative impact on daily life.

Some potential issues include inability to perform oral care or place dentures. Trismus may also result in reduced movement or discomfort with talking, chewing, or opening the mouth.

If you suspect you may have trismus, please reach out to your head and neck physician. They can refer you to see a speech-language pathologist. Many speech-language pathologists are trained in managing trismus and may assess your mouth opening and treat the trismus through different methods.

They may provide you with jaw stretches, manual therapy, or even prescribe directed use of a device to help the trismus (e.g., OraStretch, TheraBite, or Dynasplint devices).

Robin Neary, MS, CCC-SLP

Robin Neary, MS, CCC-SLP has been a licensed speech-language pathologist for the last 10 years. She currently works at H. Lee Moffitt Cancer Center, where she helps patients with their swallowing and communication concerns. She works closely with the head and neck cancer patient population, including patients who have undergone a total laryngectomy. Her contact information is robin.neary@moffitt.org



OraStretch press jaw motion rehab system for trismus, head and neck cancer radiation therapy, and trauma. (craniorehab.com)



<https://dynamplint.com/product/jaw/>



<https://www.craniorehab.com/therabite>



Request for Contributions

Do you like to write? Have a gift for encouragement? Want to offer wisdom or support?

The editors of Whispers on the Web are currently looking for member contributors for our newsletter

Who: Persons with a laryngectomy, spouses, or caregivers

What: One or more articles, 1-2 pages in length

How: Please email editor@webwhispers.org if interested.

Questions? Please contact the editors at editor@webwhispers.org

We look forward to hearing from you!