

# Whispers on the Web

A Monthly Online Newsletter for WebWhispers

*February 2023*



## Whispers on the Web February 2023

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We are back! After a several month break, Whispers on the Web has returned, and we extend a hearty welcome to all our new and returning members. This month we are featuring two new contributors with uplifting stories and observations on life as a laryngectomee. What a way to catapult WebWhispers into its 27th year!

We are so grateful for the support and enthusiasm of all our members who reached out to us during the recent break. With new members joining this group each day, staying relevant and supportive can be an enormous task. We welcome comments and suggestions and urge each one of you to share your feedback and personal stories with us. Some of you may be in need of assistance from a speech-language pathologist. Please reach out to us at [editor@webwhispers.org](mailto:editor@webwhispers.org).

This month, Tom writes a special note of thanks to all our members who have invested their time and support in this organization. From our original group of 11(!) members, our organization has continued to strengthen and grow to become an international presence. And our members have remarkable stories to tell.

VoicePoints features an informative article about lymphedema, what it is and what to do for it, along with a helpful chart and image.

One does not have to be a nationally ranked skier to appreciate Len Black's "Ski More, Talk Less." A ski instructor in Stratton, Vermont, Len shares his delightful and impressive story about how it is possible to be a teacher even without a voicebox.

And finally we hear from Dick Sipp who has the kind of personal good news story that many will relate to. I first met Dick just after his laryngectomy surgery when he attended the International Association of Laryngectomees Voice Institute under the direction of Ed Stone. Dick was as optimistic and generous with his encouragement back then as he still is today.

I hope these stories will inspire each of you to also share your good news with our community. We look forward to hearing from you.

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](mailto:editor@webwhispers.org)

Kim Almand, Managing Editor  
Tom Whitworth, Editor

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## **WebWhispers 2023**

WebWhispers, the brainchild of Dutch Helms, began at a time when not all that much was online. Surely, the volume was nothing close to what is available online today. He saw a need and yes, he had a vision for it. Dutch started what became the WebWhispers we know today as a Yahoo email group with only 10 people. Things blossomed and flourished from there very quickly. We outgrew the original format and began the mail digest that is still in use today. Then came the website, electrolarynx loan closet, newsletter, Voice Institute scholarship, WebWhispers cruises, Facebook group, and more.

Dutch was not seeking fame and fortune, but simply a way we could help one another without needing to be together in-person. His idea was a brilliant one! What he started became a source of education, encouragement, and support for laryngectomees the world over, and it still is. We are still here. I doubt that Dutch even imagined that in 2023, WebWhispers would have a global presence we have today, with around 4,500 members and a vast website routinely used every month in typically 110 countries and in 140 or more languages by tens of thousands of people who need us.

Over the past three years, the pandemic brought more of us online for more reasons than before, but I think many of us somehow drifted apart. I also believe we can change that. In this community, knowing that WebWhispers exists is important, but just as important is who you know and understanding what they do.

On our homepage are links across the top that help us navigate. At the very top are links for donating to

WebWhispers, becoming a member, and a link to our members only area. Among the features just below these links are ways to contact us. One can use the "Contact Us" form to the far right. Also, using this link: <https://webwhispers.org/about-us/administration/meet-us/>, you will see photos of each of our board members and other members of the WebWhispers team, along with descriptions of what they each do. To email any one of us directly, simply click the photo. We always welcome your questions, comments, and suggestions.

In December 2022, some of our board members ran unopposed for re-election, and were therefor elected by affirmation. We operate with a nine seat board of directors, with seven of those seats currently filled as follows:

- Tom Whitworth, President- Atlanta, GA
- Sundy Mead, Vice-President, Administration & Finance- Pensacola, FL
- Jeff Vanden Hogen, Vice-President, Internet Activities- Appleton, WI
- Ron Matoon, Vice-President, Website Information (Webmaster)- Des Moines, WA
- Kim Almand, M.S., CCC-SLP, Director, Managing Editor/ Whispers on the Web- Knoxville, TN
- Michael Csapo, Director, Electrolarynx Loan Closet Custodian (along with wife, Lisa), Facebook Group Administrator, Back-up: Internet Activities & List Management-Twenty-nine Palms, CA
- Terry Duga, Director, Legal and Historical Advisor, WebWhispers Cruises

As president, I want to personally thank so many of you for your continued support of WebWhispers, Inc. As we head into our 27th year, so much has changed and yet so much stays the same. Just as we adapt and reimagine what we do, we at WebWhispers are here for you.

***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*

**Assessment and Management of Head and Neck Lymphedema: Overview**

Lymphedema is a disorder marked by swelling of the soft tissues due to accumulation of lymph, which is a thick, viscous fluid located throughout the body. Lymph is a substance consisting mostly of water, but also containing proteins, chemicals, and white blood cells. It is very important for promotion of a healthy immune system. It is collected by lymphatic vessels, transported through lymph nodes, and eventually returned to our bloodstream. When this process is interrupted – as in the case of surgery or radiation directed at treating cancer in the lymph nodes – the fluid cannot return to the bloodstream via its normal pathways. When the fluid cannot move properly, it collects in the soft tissues and results in lymphedema.

Lymphedema is very common among patients who have undergone head and neck surgery or radiation therapy and is normally underreported. In recent years, physicians and providers have been able to diagnose more quickly and refer to certified lymphedema therapists for treatment. Up to 75% of patients will manifest some signs and symptoms of lymphedema after treatment for head and neck cancers.

Lymphedema is typically seen as doughy and diffuse swelling of the neck, face or surrounding areas. This may be more pronounced over an incision or in the area under the chin. It can also be seen along the jawline, in the cheeks, and even in the eyelids. This swelling is often worse first thing in the morning and after periods of inactivity. It tends to improve with being upright and mobile.

Lymphedema can also occur internally, involving the mucous membranes of the mouth and throat. This often occurs at the same time as external swelling, but not always. When present, internal lymphedema can cause changes in voice, difficulty swallowing, a sense of something being “stuck” in the back of the throat, and in severe cases, difficulty breathing or even with vision. Most patients with head and neck lymphedema will have both internal and external areas involved. Chronic lymphedema can lead to worsening inflammation and permanent fibrosis (scarring) of the tissues: leaving them stiff or even woody in texture.

External head and lymphedema is most commonly graded on the MD Anderson Cancer Center Head and Neck Lymphedema Scale (see below). Standardized face and neck measurements are often used to track progression of lymphedema.

**MD Anderson Cancer Center  
Head and Neck Lymphedema Rating Scale**

<i>Stage</i>	<i>Finding</i>
0	No swelling, but a sense of heaviness in the neck
1A	Visible mild swelling without pitting. Reversible
1B	Visible mild swelling with pitting. Reversible
2	Firm pitting swelling that is irreversible. No visible tissue changes
3	Irreversible tissue changes with scarring and fibrosis

The most common and most widely accepted treatment method used for lymphedema is called complete decongestive therapy, or CDT. CDT is a series of techniques including:

- (1) A form of massage known as manual lymph drainage (MLD).
- (2) Compression bandages/ clothing with special padding.
- (3) Exercises to improve the flow of lymph.
- (4) Skin care of the affected areas.

CDT has been shown to have lasting effects on the severity of lymphedema at all stages and to improve overall quality of life among lymphedema sufferers. Much of CDT may be performed at home by the patient under the guidance of a lymphedema therapist. 60% of patients with head and neck lymphedema can expect have significant improvement after CDT and an even greater percentage of improvement when coupled with improved healthy lifestyle changes.

Lymphedema can mimic other benign and cancerous conditions of the head and neck and thus it is important that you follow-up regularly with the health care professionals on your head and neck cancer team. A few examples of red flags that should prompt contact between routine visits include:

- Swelling in the face or neck that is focal rather than spread out evenly
- Swelling/masses that continue to grow or become painful
- Swelling/masses that are accompanied by fever or drainage
- Swelling/masses that are associated with breathing difficulty / voice changes

*Jocelyn Blatchley, MS, OTR/L, CLT-LANA is an occupational therapist and certified lymphedema therapist at Moffitt Cancer Center in Tampa, Florida. She specializes in oncologic rehab, including treatment of upper extremity, lower extremity, and head/neck lymphedema. She is well versed in both complete decongestive therapy treatment as well as post operative care for lymphedema following microsurgical reconstruction.*

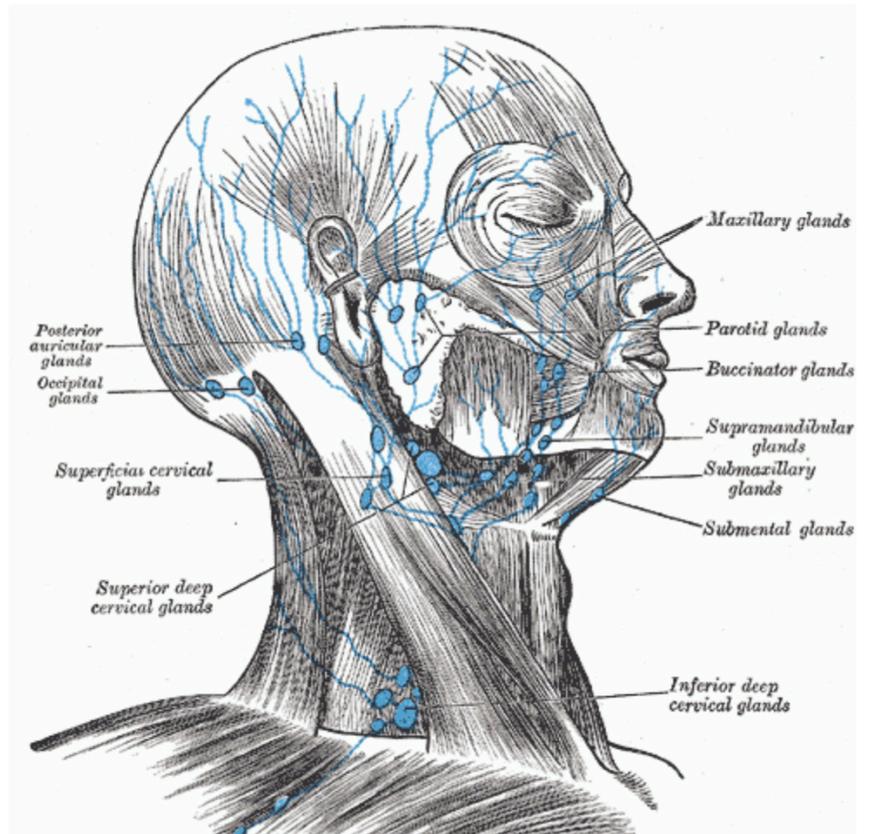
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## Member Contributions

### Ski More, Talk Less

by Len Black, PSIA Level I, CS-I, Stratton Mountain VT. by Len Black, PSIA Level I, CS-I, Stratton Mountain VT.

Sounds good. Students want less talk and more skiing. That is why they are taking a lesson. They want to ski. I understand there is value to an initial introduction and conversation to obtain the customer's goals and state of mind but after that. . . let's ski. I've heard this even from my colleagues at training sessions on the mountain. Some of the comments go like this, "That trainer talks too much. Why can't we ski? I'm getting cold standing here listening to this technical stuff I don't understand." Sound familiar?

Out of necessity, I have become more adept at talking less and skiing more. In February of 2020 I was diagnosed with Stage IV Cancer. I had two tumors on my vocal cords. Prior to the diagnosis my voice had become progressively hoarse, and my students (5 to 9-year-olds) were having a difficult time hearing me. I could not project and anyone who teaches knows how important voice projection is, especially in windy conditions.

In the middle of March of 2020 Alterra Corp closed Stratton early due to Covid 19 concerns. Two weeks later I was in the hospital undergoing a total laryngectomy. As a result, I now breathe completely and solely through my stoma (a hole in my neck). Fortunately, I did not need chemo or radiation therapy as the physicians had done a phenomenal job in removing the cancer. As a result, I healed quickly. The greatest concern I expressed to my doctors was, would I be able to

ski again. They saw no reason why I wouldn't be able to, so I set that as my goal.

In 2021, due to Covid, I decided not to teach but I did ski. I had to learn how to handle cold air entering through my stoma with my neck, mouth and nose covered with a mask.

Fast forward to the fall of 2021. The management team at Stratton have been so supportive considering my situation. I mentioned my desire to teach again, and they said, "Go for it." So, this season, as for the last 15 seasons, I taught in our Cross Cubs seasonal program.

The cold weather and wind caused a lot of problems with me being able to communicate. I needed to find a way to communicate effectively using minimal speech. I found a portable speaker with a microphone I could use to help project my voice.

Each day was a challenge, but teaching children is so rewarding, I did not want to give up. The kids were the best. On the chair lift, they would ask, "Why do you talk with a speaker? And why does your voice sound funny?" I would explain that I no longer had a voice box due to cancer and this is how I must sound from now on. "Oh" they would reply and accept my explanation. After all, they wanted to ski and have fun! So did I.

Frankly, I think it was important for the kids to

experience an individual with an impairment and to realize that although I may not sound the same as them, I am really no different from others they may encounter. For many, it may have been the first time in their young life they have been introduced to an impaired individual. Hopefully this will lead to greater acceptance, empathy and understanding of people who may appear to be different than themselves.

My greatest concern was keeping the kids safe while on the mountain as I couldn't speak loudly or yell. So, my supervisor provided an apprentice who would assist me in managing the group and ensuring the kids knew what to do in case they got separated from the group. Since I teach the same group of kids every weekend, they and their parents became accustomed to my expressions and the sound of my garbled voice.

Teaching was not much different than before except I did a lot more demonstrating and less speaking. Hand signals and gestures became more important and concise demonstrations of skills were paramount. I found myself using signals with my ski poles and hand gestures which the group learned and became accustomed to. I relied on my assistant to demo certain skills and to communicate my desires. When appropriate, I would take a student, one on one, to work on a specific skill.

The beginning of the season was spent on moving from wedge skiing to parallel, learning how to slide slip, hockey stop, skiing backwards, doing whirlybirds, skiing basic terrain park features and of course, lots and lots of turning on lower mountain terrain and use of edges. Building confidence and skills in the basics was my early season goal. As the season progressed, we tackled



more difficult and steeper terrain and again, demonstrating how to side slip down steeper terrain eased many nerves. I used hand signals when I wanted the group to stop or to park and often had students lead the group to a desired destination. Overall, my supervisor and I found this to be a very effective way of teaching and having fun, less talking!

Would this style translate when teaching adults? I had to find out, so I taught some private lessons and began working with a senior group, who meet twice a week to ski with the guidance of an instructor for two hours. Although these were intermediate skiers, many started later in life and had not learned some of the basic skills we teach beginners. So, instead of speaking a lot, I demonstrated skills I wanted them to experience. Skiing backwards was a huge step for these adults. I could see the fear in their eyes when I demonstrated but we used beginner terrain and once several of them got the hang of it, the rest followed. The excitement of learning something they saw their grandkids doing was evident. They had fun and looked forward to mastering that skill and moving onto to 180's and 360's. I can't wait till next season to get them into the terrain park!

So yes, you can talk less and ski more. You can even teach without a voice box. It seems less talk translates to more fun, resulting in a more effective lesson. There are, however, some limitations. I realized early on that class management would be an issue. There are times when I would have over 10 students in a session. The addition of an apprentice to assist with the class was a necessity but I could manage a class size of five or less by myself especially towards the later third of the season when the kids were accustomed to my teaching and where we would go on the mountain.

So challenge yourself. See if you can incorporate less talk and more action and fun into your teaching!

I would like to know if there are other individuals with a total laryngectomy who are certified ski instructors. So please feel free to reach out to me at [lenblack@yahoo.com](mailto:lenblack@yahoo.com) as I'm sure we are a unique group. Finally, I would like to express my thanks and gratitude to the staff and management team at Stratton Mountain who always encouraged me when I felt down and uncertain about my ability to provide the quality instruction we love to deliver.

Len is a PSIA Certified Level I and CS-I at Stratton Mountain, Stratton VT.





# Member Contributions

## A Good News Story

Richard Sipp

This is a good news personal story! It is offered not to claim any special knowledge or to recommend some magic formula that eliminates the challenges of life with a laryngectomy. It is about my good fortune to have been treated by a talented team of medical providers that gave me the opportunity for a nearly normal post laryngectomy life for the past 22 years and counting. The observations will come at the end, so stay tuned.

In 2000, I was enjoying the last few years of a commercial and USAF pilot career. We were looking forward to an upcoming retirement and move to an air park home on the coast of Georgia.

For nearly a year I was experiencing periodic episodes of laryngitis-like loss of voice, chronic coughing, and other minor symptoms. My GP could not identify a cause for these symptoms. About that time someone suggested that I see an ENT specialist which I did. In a short time, he had inserted a laryngeal scope and said "You have something growing on your vocal cords." And so, the journey that we all are familiar with began.

The initial recommendation was a course of 35 radiation treatments. A cure rate of 95% was offered. The course of 35 treatments began and was completed. I was fortunate to tolerate the treatments as well as can be expected. Unfortunately, over the next few months, there was no improvement in the symptoms. I suspected

I was in trouble when the same ENT again scoped my throat and sort of threw the scope back on his counter and said, "the growth is still there". A change in medical institutions to one more experienced with laryngeal surgery was recommended. This was the first of many recommendations which were made and nearly always followed and led, in the end, to positive results.

I was told I needed a laryngectomy and that the surgeon would attempt to remove the cancer with a hemi-laryngectomy to preserve half of the larynx. As we have all experienced, I was very anxious about the prospects of what life would be like after the surgery. I was introduced to the team of practitioners who would be treating me. I told everyone that my goal was to fly again and that I would do whatever it took to meet that goal. One of those was a speech pathologist who suggested I attend one of their regular monthly support group meetings where I could meet others who had similar cases. My initial reaction to this experience was neutral at best. A couple of the attendees were having a difficult time with various complications and were having difficulty communicating. Fortunately, this was the first of many instances of what I will call good luck. A woman was there who displayed a positive attitude, a good TEP voice, and she related several new things she had begun doing again since her relatively recent surgery. I thought, if she is OK, maybe I can be too.

The surgery was scheduled for October of 2000. As I awoke from the surgery, the first thing I heard was my wife saying, "it did not go as we hoped, you had a total laryngectomy." Fortunately, again, the hospital had a small unit dedicated to head and neck surgery recovery and so the care was excellent with all of the staff very familiar with the recovery. One of the best days was around day 5 or so when a nurse said, "what you need is a shave." She climbed up on the bed and gave me a wet blade razor shave, I felt like a new man.

The tracheoesophageal puncture was completed at the time of surgery and used as a feeding tube for the first few weeks. There was also a return trip to the hospital for a few days to treat a fistula. This was a little more difficult as it was a general treatment ward where the staff was not as familiar with a laryngectomy.

The initial few weeks of recovery went well. The first attempt at voicing with the prosthesis did not work. The SLP determined the reconstructed throat area was "tight." A Botox injection treatment cured that minor difficulty.

After another month or so I flew with an instructor pilot and demonstrated the ability to communicate with air traffic control. I was again a fully qualified pilot. We continued with our plans to move to Georgia. A few years later the 1st of two wonderful granddaughters arrived and we returned to Michigan. For the last 22 years I've been blessed with a full and healthy life including hundreds of hours of volunteer and personal flying. We've also worked several part time volunteer jobs.

## OBSERVATIONS

One of my most significant positive influences early on was the Web Whispers email list and attending an International Association of Laryngectomees (IAL) Annual Meeting and Voice Institute. I was inspired by Pat Sanders, Dutch Helms, Jim Shanks and many others. Fair warning, here comes the sermon: Over the years the WW email list has morphed into several

online groups dedicated to helping fellow head and neck cancer patients. Naturally, the majority of exchanges include some sort of problem or a new individual who is overwhelmed with what they are facing. Thank goodness for these prolific groups and the mostly caring and thoughtful responses. I fear, however, that a new patient first experiencing this exposure might walk away with the impression that most people who have had the surgery have nothing but ongoing problems. This mistaken impression is probably because a large population of laryngectomy survivors who are doing fine and have gone on with active lives do not participate in support groups. For the same reason, I believe attending an IAL conference can be a positive life changing event. Being with a large group of otherwise normal people will provide a whole new perspective. At the last conference I asked three SLP speakers what percentage of their laryngectomy patients they considered to be normal, routine maintenance, TEP speakers. All three agreed that 80% of their patients were in that category and one also said that number is supported by other data as well. The remaining 20% would also include new patients who are in the early stages of recovery and acclimation.

In closing, when contributing advice on social media, always preface advice as something that worked for you but refrain from categorical direction. We seldom know the full circumstances of someone's condition and an unqualified "Do or don't do one thing or another" may be very harmful. Finally, share your good news and encouragement!

