

Whispers on the Web

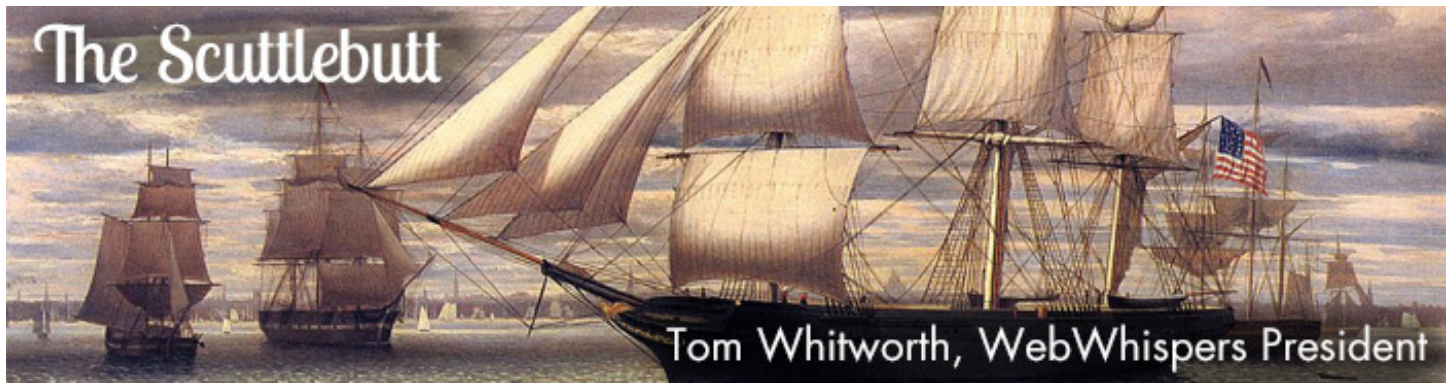
A Monthly Online Newsletter for WebWhispers

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Have a Hunky-Dory New Year!

The term meaning everything is O.K. was coined from a street named “Honki-Dori” in Yokohama, Japan. Since the inhabitants of this street catered to the pleasures of sailors, it is easy to understand why the street’s name became synonymous for anything that is considered enjoyable or at least satisfactory. And, the logical follow-on is “Okey-dokey” (navy.mil)

Here are two ways to have a great 2019:

SERVE OTHERS:

The knowledge that we have lightened the burden of others is personally rewarding. For many of us, nothing else is comparable. WebWhispers offers many opportunities to serve the Lary community and nothing about us is ever on auto-pilot. The variety of tasks includes many seemingly small things, yet things that cannot do themselves. We use MS Word, Excel, Quickbooks, Salesforce, Email, Facebook, graphics, photography, and more. Some duties can be as easy as once monthly for an hour or less. Our vast online library of information, Whispers on the Web, and each service we provide to members and followers requires the effort of volunteers. We have learned the value of having more than one person on many of these jobs and backup people are always needed. With more than 4,100 members now, we continue our effort of Sharing Support Worldwide. If you would like to help or are just curious, reach out to me at tmwhitworth@gmail.com I am sure I can find something just right for the amount of time you have to contribute.

LEARN:

Our website, email digest, and various social media groups, including ours, are often great sources of the information we need. They provide easy access to information in a flash. Local support groups are often good learning sources, if one is available in your area. If not, electronic media can fill in some of the blanks. If your area could use a lary club or head and neck support group, there lies

the opportunity to start one. Talk to SLPs and ENTs. They will be glad to help you if a need exists. For many of us, face to face learning is the most effective. That is why I am a huge fan of conferences within the head and neck community. Save the dates! For instance:

Association for Head and Neck Cancer Rehabilitation (AHNCR) hosts an annual conference, sometimes more than one. The event, affiliated with MD Andersen in Houston, is provided by leading Speech -Language Pathologists in the U.S. and Canada. WebWhispers will share the dates and details for this year as soon as we have them.

The All Chicago Laryngectomy Conference, closely associated with Lary’s Speakeasy is planned for May 23, 2019. Details will be shared as they become available. Point of contact is Lewis Trammel and the Lary’s Speakeasy Facebook Group.

The International Association of Laryngectomees (IAL) Annual Meeting and Voice Institute takes place this year in Phoenix, AZ May 16-19. Under the direction of Dr. Caryn Melvin, the Voice Institute is a marvelous learning experience for laryngectomees, caregivers, and SLPs who benefit from the extensive number of CPE credits available. The week includes the annual IAL banquet, the WebWhispers dinner (separate) and is a wonderful socialization opportunity for all who attend. For details, see the the IAL website. theial.com

Have a Hunky-Dorey New Year!

**Enjoy, laugh, and learn,
Tom Whitworth
WebWhispers President**



Voice Points

Written by Professionals

Coordinated by Kim Almand M.S., CCC-SLP

kbalmand@gmail.com



Empowerment and Success in Laryngectomy Rehabilitation: Suggestions for Assisting Clients and Their Families

Caryn F. Melvin, PhD CCC-SLP
Medical Speech-Language Pathologist

Defining quality of life (QoL) is a challenge as it is multidimensional and unique to each of us. As speech-language pathologists we logically approach QoL from a speech and swallowing standpoint. Excellent tools have been developed such as the Performance Status Scales (List 1996) and the MD Anderson Dysphagia Inventory (Chen et al 2001) to assist clinicians and clients in understanding functional status and QoL as it pertains to communication and swallowing.

Certainly speech and swallowing are important for our clients and the main focus of rehabilitation as a speech-language pathologist. These are easily measured changes, quantitative in nature, and speak to efficacy of treatment. However, clinicians who work with laryngectomy clients and their families know that successful rehabilitation consists of more than success with communication and swallowing. We are witness to states of affect, poor self-esteem, issues with bodily image, marital and family discord, as well as difficulties with job and finances. There is a growing focus on understanding and measuring these more qualitative, psychological aspects associated with head and neck cancer (Vilaseca et al 2006, Gritz et al 1999, Bjordal and Kaasa, 1995). Understanding and measuring these more elusive aspects of QoL is an important step. The question then becomes, once identified, how do we assist our clients and their families with these non-speech issues?

Although most speech-language pathologists are not trained psychologists or counselors, much of the counseling with regard to these more qualitative aspects of rehabilitation falls squarely in our lap. As clinicians we are dedicated to helping our clients return to their live. Yet we are not necessarily armed with the tools to assist our clients and their families. This is not to say that

rehabilitation programs are not successful, that clients receive substandard care and do not go on to lead happy, productive lives. However, some of our clients and their families need more to assist them in achieving the best QoL. Adding techniques borrowed from the field of counseling to the speech therapy session can be beneficial not only for the client and their family but for the clinician as well. Having the tools needed to address issues beyond speech and swallowing can relieve frustration in the clinician who may have otherwise felt helpless to address issues beyond their scope of practice. This is not to say that the speech-language pathologist can replace mental health professionals. But rather we can respond to affect more appropriately, ease concerns and validate feelings in a more therapeutic and helpful way, always referring to mental health when warranted.

Counseling or counseling techniques are not a separate facet of the speech therapy session. It is not something to be done before or after working on speech and swallowing goals. Rather it is a framework for the therapy session, a way of sitting with and responding to your clients and their family. A change in the way you perceive your clients and guide them along the road to recovery and back to their lives. Beginning to incorporate counseling technique into clinical practice is easily done. The following five suggestions may prove helpful as you begin to create a different type of therapeutic atmosphere in therapy sessions.

1. Create an atmosphere of listening, valuing and acceptance
2. Enlist family members as co-workers
3. Provide information only as requested whenever possible
4. Develop a set of possible therapeutic responses
5. Validate affect appropriately.

Traditionally, speech-language pathology has followed a medical model for practice. The medical model does not necessarily view the client as a partner in the rehab process. Leuterma 1996, refers to counseling within the medical model as "counseling by persuading." "I as the professional have all of this information and experience. You as the client are ignorant of so many things that

you need to know; therefore, I can make a better decision for you than you can make for yourself.” This method of counseling is disempowering, confirming our clients feelings of confusion and inadequacy resulting in low self-esteem and poor QoL. Leuteran suggests a different approach, counseling by listening and valuing. By listening and valuing the client and their family are looked upon as a partner in the rehabilitation process, able to make good decisions. This method of counseling fosters empowerment, resulting in clients who are able to work through the many challenges associated with laryngectomy. Creating an atmosphere in which clients and their families feel valued is essential to successful rehab. Partnering with clients, understanding their needs and specific issues and concerns is key. Certainly there are topics and goals that need to be addressed in therapy. As speech-language pathologists we understand that certain topics need addressing, patients need a way to communicate, stoma care and precautions need to be addressed for safety sake and we have a protocol for moving our clients through these goals in a timely, efficient way. Our client’s goals are just as important and when addressed let them know that they have a say in their rehabilitation.

Enlisting family members as co-workers is essential in fostering empowerment. Family members struggle with understanding the aspects of communication and care as much as the client. Vocabulary, tubes, devices, stoma care, sounds and physical changes are a challenge for family members and often can leave them feeling helpless, not knowing how to care for their loved one (Salmon 1999). Spouses in particular can struggle as they learn a new way to be with and care for their loved one. Couples who have been together for years have always known how to care for and comfort each other and now the landscape has changed, abruptly, unwelcomed and permanently. Bringing family into therapy sessions allows for teaching, sharing of ideas and concerns, observation of relationships and reactions that are invaluable for both the clinician and the client and family members.

Providing information and education only as requested whenever possible is a challenge. As professionals we have a wealth of information we are eager to share. Shared inappropriately or at the wrong time can have a negative impact on the rehab process. Clients will typically ask the questions they need to at the moment they need the information. If we offer information they did not ask for we are not listening to their needs at that moment. Not listening sends the message that they are not valued. The well-intended information may be overwhelming and confusing at that moment and fuel the feeling of loss of control.

If clients are not asking questions throughout the therapy process it may be they do not know where to begin. Giving

your clients information they can take home and look through or watch on DVD can be a springboard to those conversations you need to have with your client, topics you need to cover. Asking your client and any family members in attendance, “What do you need to know?” at the start of each session will provide the opportunity for them to ask questions that make sense at the time for them. If family members are in attendance they too should have an opportunity to be asked this same question. Explain that each of them may need something different and that is very normal. We are all different, all progress at different paces and our needs at any given time are unique. Asking the very simple question, “What do you need to know?” and addressing only that need, assures clients and families they are listened to and have some control over their rehab. Control is empowerment and points our clients and their families toward a better QoL.

Encouraging participation of family members in their loved ones therapy allows for them to part of decision making. When they are part of the decision making they feel valued, empowered and will typically support the decision. For example, as artificial larynx devices (ALD) are being considered, family members present can indicate which device is easier to understand, giving feedback to the client in order to arrive at a decision that is best for all. As a method of speech is being learned and mastered, talk about communication breakdowns and how they would like to approach communication repair. How many times should the client try to communicate with their ALD before they resort to writing their message? When everyone is part of the decision making process frustration is minimized and feelings of empowerment and control continue to grow. Clients and their families begin to see that although not always easy, they can work together to make good decisions and they are in control of their healing and recovery.

Addressing affect in session is often uncomfortable for clinicians, clients and family members. Much of this discomfort stems from our belief that there are ‘good emotions’ and ‘bad emotions’. When all emotions are viewed as necessary tools in the healing process we no longer see them as good or bad. Clients and family members often communicate that they equate displays of emotion with weakness. Assuring them that an emotional response to catastrophic events such as laryngectomy is normal can give them to permission to express what they are feeling. Reminding all family present that everyone’s healing journey is different is essential. One family member may be angry, while another is confused and the client may be experiencing guilt. This is normal. We don’t all experience the same emotions at the same time.

Encourage understanding of the differences and remind clients and their family members that healing is not a hierarchical process. We don't experience one emotion, graduate to the next and leave the previous ones behind. Feelings of guilt may seem to be worked through when months later they resurface. That is the nature of healing and the emotions we experience while we heal.

Developing a set of therapeutic responses is helpful when addressing effect of clients and their families in the therapy session. How we respond to emotional expression can either hinder healing or move it along. For example consider this statement from a client, "I'll never be any good at esophageal speech. And I hate that buzz box!" How would you respond to that statement? There are several options depending on the client and where they are in the rehab process. Certainly a typical way of responding is the content response where we would schedule additional therapy to continue working on esophageal speech and perhaps give them written information on learning esophageal speech. However, people will often say one thing and mean another. Maybe a content response is not the most therapeutic, helpful response. There are alternative ways to respond to our clients. Choosing the most appropriate response can facilitate healing and result in better rehab outcomes. Consider the following alternative responses to that same statement.

Counter question: "What happened that makes you think you'll never learn?"

This is a facilitative response that places the ball in the client's court, inviting them to share what the problem really is. It is a safe response that facilitates resolution and therapeutic movement.

Commenting: "You sound so frustrated. And you've put so much work into learning esophageal speech. I hate to see you give up."

This response supports their beliefs without challenge. It is validating and caring and provides a nonjudgmental atmosphere where they can feel safe in expressing the real issue.

Reframing: "You know it really does take time to perfect esophageal speech. I wonder if you would be willing to share your story/frustrations at the next meeting. I know others have had a similar struggle and you may all benefit from hearing each other's stories."

Timing of this response is essential. It is best used with those clients who have been in therapy for some time and a more seasoned. It encourages responsibility and also sends a message that they can solve this for themselves.

Sharing self: "Learning something new is always hard. I remember when I was learning (fill in the blank) it was very difficult. I felt like giving up sometimes."

Sharing responses remind clients that they you are human, that as humans we all face struggles. Sharing can strengthen the client – clinician relationship but should only be used if you are comfortable revealing personal information. If you do share a personal story it should be brief and take care not to let the session become about you.

As clinicians working with laryngectomy clients and their families we want the best possible outcomes for all concerned. We strive to provide the best possible environment for healing while helping our clients and their families learn the ins and outs of laryngectomy. By adding a few different tools to our therapeutic tool box, partnering with and empowering our clients we can begin to address not only the quantitative aspects of care but also address, within our scope of practice, the qualitative aspects that result in a truly improved QoL.

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Between Friends

Donna McGary

"That which does not kill us makes us strong."

Photo CC by Corack5239

You Never Know

Recently there have been some heart-warming comments on our WebWhispers daily list about talking with strangers. You can follow the thread if you go to the Members Only section in the upper right hand of our website and click on daily list. From there you can access all our list mail by date and/or subject. The daily list/digest is our moderated and confidential space for questions/answers and comments about this lary life. It is password protected but if you are a member you already have that on file (hopefully) or can get it from the weekly updates from us. I am not publishing that info here because this newsletter like much of our website is free and open to anyone seeking information and resources.

However, I will tell you the gist of that wonderfully heart-warming thread was you might be surprised at the number of folks who LOVE our voices...for they are the voices of loved ones from their past. This is part of the post that started it off...

I was standing alone while my friend went to get the title papers. the man began to talk again to me directly, I replied using my servox, I noticed his eyes grew wide, I thought may he was surprised or startled, but my gut said NO there is some thing more, a soft stare from looking back at me he said, His father spoke with his finger to his throat, I could see a slight tear coming from his soft stare, I smile.

He reached out and shook my had firmly, I did not dare ask him any questions about his father, Before he left he shook my hand again firmly as before, He said he was very happy to meet me! I was likewise, perhaps his father had passed; I hope not. But I was so glad to meet this stranger, it made my day somehow, felt we both went away better off, crossing our paths of life.

That was quickly followed by similar tales...

I have had three or 4 similar experiences. Recently, a woman sitting next to me on a number 1 subway train in NYC, heard me speaking with my wife and asked if she could talk with me. She said her uncle was one of the early TEP speakers maybe in the 1960s. She only knew his TEP voice. She was happy to hear my voice which brought back sweet memories of him. When she got home she was going to call her brother to remind him of their uncle. She thanked me for talking with her and bringing back those memories. She told me her uncle went many places meeting laryngectomees, demonstrating TEP speech and helping them as much as he could.

There were others including my own experience a few years ago when a young waitress became teary-eyed upon hearing me speak. Her own grandmother had used an EL and she had kept her "voice" just to listen to it from time to time. When I told her that it was the only voice my own granddaughters had ever known she nodded, "I love hearing you talk. It's like hearing my grandma again!"

Noirin Sheahan writes in her column this month about the difficulty of "small talk" with our new voices. I understand completely and often just don't bother...not wanting to call attention to myself. But what if any of us in these situations had just chosen to stay silent or ask someone else to speak for us. What an extraordinary moment we would have all missed!

One of my favorite Dr Seuss stories is "Horton Hears a Who" where one small "Yap" makes a difference.... Suddenly all the naysayers hear "We are here...We are Here...We are Here!" And Horton is absolutely right "A person's a person no matter how small."

So get out there and yip or yap...you just never know who's listening!!

Stand By Me

The Caregivers Journey



Spouse / Caregivers Rap Sessions

Every year when my husband and I come to the IAL Annual Meeting and Voice Institute one of the highlights of my week is to attend the Spouse/Caregiver rap session. Dr. Caryn Melvin is our coordinator. She makes us all feel at home and with her tender heart listens to our problems and concerns. The rap sessions are very laid back and informal. Caryn reiterates in the beginning that what is discussed in this rap session stays in the room. I love the fact that it is all confidential.

We all sit around the room in a big circle. We begin with introducing ourselves and mention where we live. Caryn will bring up a subject and we all get a chance to share our thoughts and opinions on being a caregiver and the journey that we are on with our loved ones! No one seems to feel intimidated by what is said or by advice that they are given by the group. We are all there to give our love and support to the new caregivers who are starting their journey.

This past year we had 20 people attend the rap session which was awesome. For me it is meeting up with old friends and making new friends. Over the years we all have laughed and cried and shed many tears over some of the compassionate caregiver stories that are generated from the heart. If you are a new caregiver who is traveling down this road alone please consider one of these sessions. You will not be disappointed, and you will find it well worth your time.

In closing I would like to say please consider keeping this Whispers on the Web's column "Stand by Me" going by writing a few brief paragraphs on your care-giving journey. We all can learn so much if the information is shared.

Thank You!! I hope everyone had a Merry Christmas and Happy New Year.

Too often we underestimate the power of touch, a smile, a kind word, a listening ear, a honest compliment, or the smallest act of caring and all of which have the potential to turn a life around."

~Leo Buscaglia

[Editor's Note - contributions can be sent to editors@webwhispers.org Thank you!!]

Dear Lary

Noirin Sheahan

New Year Resolution

My New Year resolution is to make more small-talk. I'm not too bad at speaking up when I have something I really want to say, but chatting for the sake of chatting was never my forte, and laryngectomy has given me an extra excuse to be 'the quiet one' in company.

It's not the worst of crimes – one friend tells me he would appreciate if all the babblers in the world could become as succinct as a laryngectomee! He likes the way I say what I need to say using the minimum number of words. And before Ellie (my electrolarynx) came along another friend said he always breathed a sigh of relief when he saw me enter a room. With my whiteboard and marker he knew there would be a few quiet spells while people waited for me to write. Otherwise, he said, constant chatter would exhaust him. What I sensed as a loss, he sensed as a treasure.

But I know I could make a bit more of an effort to speak up. Especially at home – it's easy to get lazy, withdraw into a newspaper, computer screen or book rather than get Ellie into gear and have her say a few words on my behalf. It would be more respectful of my mother and the carers who come every day to help her with meals and dressing and exercise. And it would be a way of saying 'I won't let laryngectomy define who I am'.

This thought has been reinforced by a National Geographic film series called 'Genius' which I've recently been watching. It depicts the life of Albert Einstein. As well his genius for physics he had high moral standards which often got him into conflict with the establishment. Unlike most theorists he found it hard to isolate himself and needed open-hearted debate in order to develop his ideas. He was also exceptionally patient and generous in his encouragement of younger students. But his personal life was often messy – and the break-up of his first marriage to Mileva Malek was tragic. He and Mileva met at university and fell in love. It was really unusual for a woman to attend university at that time (late 1890s) and especially to be studying physics. But Mileva was brilliant. She worked together with Einstein on all his early papers, though he never credited her by name. When she challenged him on this he argued that she was so much part of him there was no need to make any public statement on the matter. The title 'Frau Einstein' said it all, in his view.

Mileva did not agree and with good reason. Whatever difficulty modern women have in juggling career and family, Mileva had it a hundred times worse. Gradually she became side-lined into her role as mother of his children rather than equal partner in

scientific research. As he grew in fame, her stature diminished. Depression followed and their relationship became more and more acrimonious. During their final row, he asked her "Do you really hate me so much?" She replied "No, I hate myself. I hate the person I have become because of you."

As portrayed in the film, we're left in little doubt that Einstein treated her abominably. But Mileva's tragedy was also of her own making. She let his appalling behaviour define who she was, the terms of their divorce, the stories her children learned about their father. Einstein treated her abominably. Bitterness was her choice in response. It was her own bitterness that hurt her most deeply in the long run, not Einstein's behaviour.

I feel sad when I think of Mileva. I also see how, in a minor way, I make my own 'Mileva-mistakes' every day. Five years ago, I would have said a few words to my mother as a matter of course while we looked out into the garden. But I often hold back nowadays, thinking It's not worth the effort when all I have to say is something like "Oh look at the birds feeding on the peanut holder".

For 2019 I vow to remember that whenever I do this, I'm letting laryngectomy define who I am. And OK, laryngectomy is part of who I am. It would be unrealistic to expect no change in communication when speech now takes such an effort. But I can't afford to let it silence me. I know very well that the thought 'it's not worth the bother of saying that' isn't purely rational. There is a seed of bitterness there too. Life has given me laryngectomy. Like Mileva Malek, I'm scowling inwardly in response.

How could Mileva have responded differently? She could hardly be blamed for scowling when she was forced to change nappies rather than attend her lectures. On point of principle Einstein had refused her father's offer of a dowry which would have enabled them to employ someone to look after the children – what woman wouldn't scowl! But since a woman had no say in such matters in the early 1900s, she needed to work extra hard to prevent the scowl on her face from settling into her heart. Easier said than done, I know. But for our own long term happiness, we have no choice in this matter either.

Unlike Mileva, there is something practical I can do - I can refuse to be silenced by this unwanted state of laryngectomy. My 2019 New Year Resolution is to make at least one irrelevant comment every day!



Tell Us About Your Journey

In mid-January 2009, I went to my local urgent care to get something for the continued hoarseness of my voice. A quick exam led to a look at my vocal chords and within 30 minutes, I had been admitted to Mt Auburn Hospital in Cambridge MA. I had a laser surgery procedure on January 20, 2009 to remove a tumor on one of my vocal chords.

While waiting to start radiation and chemo, the tumor grew back to a size that blocked my airway. I remember speaking to the 911 operators on March 1 from my back porch; but I don't remember falling down the back stairs into the driveway. Fortunately, the emergency responders found me and took me to an emergency room, where a tracheotomy was performed.

By the end of March, I was undergoing radiation and chemo treatments and progressing well.

In September, I packed up my home in the Boston suburbs and moved to Indiana with my fiancée. We purchased a house and I started renovations.

In October, I had my first appointment with my new Indiana ENT, who immediately recognized that the tumor had grown back once again. And on December 11, 2009, I had a complete laryngectomy.

Since then, my wife and I have done a lot of travelling, both in the US and abroad, and I returned to work as a software developer in early 2012 which also involves lots of travel. I have been cancer-free just over 9 years.

Lloyd Enochs - Evansville, IN December 2009

I started with my first throat cancer in 2005 when my voice was hoarse. I had two laser surgeries to remove tumors and then had a partial laryngectomy to remove and reconstruct one of my vocal cords. I spent 5 months setting in a chair breathing through a 4 mm trach because they had to use a pediatric one. They could not get an adult one in my airway. I had to suction it every 30 minutes to keep it clear day and night for the 5 months.

In 2009 my cancer was back when I found a lump in my throat. We found it just before Christmas so I waited until my doctor was back in town to have surgery in Jan 2010. I ended up with a total Laryngectomy. That was a mistake to wait as the cancer spread

to all my lymph node in my throat and to the base of my tongue so they were involved in the surgery. I had 2 complete rounds of radiation treatments and Chemo in the process. I ended up with a stoma reconstruction, 7 throat dilations, and 5 surgeries to install TEP valves, that still do not work (but I still have it). It will probably take another surgery to get the TEP working properly.

I guess you could say that I do not give up easily. About 4 years ago I found out that I had prostate cancer and had surgery for that too. All my surgeries have been in Seattle, WA where I live.

I was so lucky that my wife was a Registered Nurse so I had wonderful support from her and my family. WebWhispers was also a lifeline for me to learn what I needed, plus the support of friends that I have met through IAL and WebWhispers. Thank you all!

Ron Mattoon - Seattle, WA 2010

My journey has been a long one that started in 1962 when I was misdiagnosed with a cancer over my upper lip. It was finally found to be cancerous in 1967, requiring several operations involving plastic surgery to rebuild my face.

In October 1976 once again misdiagnosed. I was talking on the telephone when all of a sudden, I lost my voice. My doctor was sure that I had cancer of the vocal chords, but the biopsy came back negative. The following June I lost my voice again. This time the biopsy was positive.

Dr. Al Novak thought he could get rid of it with laser surgery at the Fred Hutchinson Cancer Research Center. However, it didn't work so his staff wheeled me over to the Swedish Hospital where Dr. Novak operated to not only remove the cancer, but somehow was able to rebuild my vocal chords. It took two or three months of speech therapy to learn breath control, and slowly I developed a godfather-like voice.

In 2013 I had a constant sore throat, and my doctor sent me to the lab for a swallow test. And the radiologist assured my daughter that there wasn't any cancer. WRONG AGAIN. At that time I weighed 165 pounds, and then I started losing weight. When I got down to 130 pounds and still had a good appetite, my doctor sent me to Dr. Chu. He immediately sent me across the floor from his office at the Poly Clinic for a catscan. At the same time, he called the Swedish Cancer center in Edmonds, WA telling them they were sending a patient out there.

After the 35 days of radiation and six weeks of chemo that most of us go through my radiologist said I was cancer free, and the staff had me ring a bell, and I was applauded by everyone. After looking at the results of my catscan, my oncologist wasn't so sure, and he was right. So I had a tracheotomy, and what a miserable few months I spent with that. During a routine checkup in late October or early November my cancer had returned, and on November 30, 2015 I became another Lary.

Johnnie Don't - Woodway, WA
11/30/15

Forty years ago, October 2, 1978, I finally had a total laryngectomy at Mayo Clinic/Rochester, MN following months of misdiagnoses.

The family suffered flu symptoms from January to April so that's what the doctor thought I was messing around with so he did cultures that were always negative for staph and strep. It took until June to convince him that "something was growing in my throat", and I needed a referral to an ENT. I had lost 20# without dieting, food was getting stuck in my throat, and swallowing saliva took a long time. I was living on Chloroseptic for sore throat. It was July when the old ENT declared I had a "mucus retention sack" in my throat and the ENT would drain it at the local hospital. Instead he discovered with a sloppy biopsy that something else was indeed growing between my vocal cords. That session ended up with ten days in hospital on steroids because my throat swelled shut. Later surgery by his younger office mate removed this odd looking tumor they labeled pseudo malignant. Two weeks after that surgery, complete with trach, and ear to ear incision, I was told that I would need to go to a major center, like Mayo, for a total laryngectomy to find out what sort of tumor they had already removed. He sent tissue samples ahead of me while we drove the 500 miles to Mayo. It was stage 4 spindle cell sarcoma, and only radical surgery was the recommended treatment; chemo and radiation wouldn't touch this variety of cancer. Mayo had discovered this strain, and named it, so they knew what to do for the best outcome. From Tuesday through Thursday I learned a lot about what was going to happen, made my decision, did the pre surgery lab work, and flew home on Friday to prepare the family for the upcoming changes.

I flew back to Mayo on Sunday and surgery on Monday. 14 days in hospital with great care from all. The pre op counseling had helped prepare me as much as possible, but those early days of learning to take care of my own incision and stoma were not easy steps, but doable. By the 9th day the NG tube was removed, started on liquids, soft foods and speech therapy for ES. At first I refused to try the EL because that was not my goal, but 3 weeks later I did accept a loaner EL from my local SLP. I took it home to figure out how to make it work so I could communicate with my 6 children, (3 sons were away at college), also needed a way to keep all my church and community commitments. 35 Radiation post op was given to cover any seed cells that may have escaped the safety margins while 3 doctors and 4 hospitalizations messed around in the throat area. I made it this long so I guess we, our entire team, did a good job of saving my life and preserving the quality of my life.

Elizabeth A. Finchem - Tucson, AZ
DOS: 10/2//78

I found out I had squamous cell cancer the beginning of March, the only symptom I had was a lump on my neck, no laryngitis, sore throat and not a smoker. I was 51 and very healthy so I was shocked and got many second opinions plus we went to the tumor board at Stanford. I ended up having my surgery at Kaiser in Santa Clara, CA. I had a laryngectomy, pectoral flap, radical neck dissection, and radiation treatments. That was over 25 years ago.

Rita Kinney
March 1993

This journey started for me with a swollen lymph node in my neck at 52 years old on 4/1/2004. Chemo and Radiation didn't get rid of the tumor so on 8/12/2005 I had the Laryngectomy Surgery. After the wound not healing due to radiation damage I had a pec flap surgery and 20 hyperbaric dives. 14 years later I'm doing very well. Thank God, a Great Surgeon and a Family that fought for me.

Dennis Holte - Boise Idaho
2005

One Sunday in October of 2008, I was singing in choir a simple response, missed a note badly, and knew something was wrong. Monday my ENT told me no more singing because you have a paralyzed vocal chord. Shortly thereafter came the news: throat cancer and a laryngectomy needed, a procedure beyond his capacity. Because of its awkward placement, it would need a skilled team to remove all the cancer, so off I went to Emory University Hospital, and two month there with complications, a move to a hospital in my Rome home, fistula complications, my ENT calling for advice country-wide, and my wife being told I probably would never leave the hospital alive. At the end of the third month and with amazing speed, those fistulas closed, completely, within 10 days and I was sent home 2 days later.

I lost my voice but I can use a Cooper-Rand since I have no sweet-spot, nor can I tolerate a TEP due to extensive radiation treatments which failed, but I do speak clearly if I am slow and deliberate. I have also re-found my composing voice: the Berry College Singers performed my arrangement of Oh Come, Oh Come Emmanuel at the 2017 Lessons and Carols, and I have written a few more pieces since and hope for their performances to.

For me, then, this is a Merry Christmas, and I trust it is so for all of the WebWhispers Family and Beyond. I am 82, 83 on 1/3/19

Brad Gooch - Rome, GA
2008

Next Month's Question:
Would You Do A Larynx
Transplant If Possible?



From the Archives

This first ran in July 2007 and seems just as relevant today ~ Donna

Is That a Lary I Hear?

I guess not too many civilians can say that they could recognize a lary at 100 paces. I have made it my life's work to be of service to others in whatever way possible. Funny how, when you are open to the universe, it brings gifts. Some may call them coincidences but not me.

I was in line in the landscaping department at a home improvement store (behind the guy none of whose items had a sticker), patiently waiting to check out my four items (all of which did have stickers) and noticed a slender woman, just behind me in line, exchanging plants from her tray; first it was marigolds, she looked up as if in thought, then switched to begonias, then repeated and came back with two marigolds and some... periwinkles, was it?

When it was my turn to check out, I assisted the cashier: two of these, three of these and four of these, as I held up the UPC codes for him to scan. As I was signing the receipt, the cashier began to scan this lady's plants. She whispered, "Two of these, two of these and two of these." "Excuse me?," exclaimed the cashier. The lady repeated her whispers. I went off to the car thinking...is that a lary?

In the parking lot, as I was putting down paper in the trunk to protect the carpet, the same lady wheeled her cart up to the car parked next to mine. I now realized there WAS something different at the notch in her blouse collar. I said, "Excuse me," and she turned around. "Are you a laryngectomee?" I asked. Am I not bold? She looked and whispered, "Yes," and came closer to speak further. "But I have not had

my larynx removed. It was damaged in treatment."

That was my way in. I told her my name and shook her hand. She whispered hers. I held her hand and gently squeezed it. I asked if she had had a bout with cancer and she said that yes, she had. I asked if she was aware of the WebWhispers website, newsletter, and the international support available to her on the internet. She was not. I told her about my friend, Pat Sanders, the meetings and cruises, the myriad support available and after writing the web site address on back, gave her my card.

She then told me, "My name is also spelled with an 'i' and I have to tell you something. I have never shopped at this store before. This isn't even my neighborhood. I haven't been much of anywhere for the past year, but something told me to come here today."

I cannot tell you how that meeting touched something deep down inside me. The knowingness that I have purpose. That if each one of us were to reach out to one person and touch them, the world might be an even better place.

Pat told me recently that my "flower" lady had contacted and joined WW. That makes me feel good about life.

Shari Aizenman, Massage Therapist



Thank You and Farewell

It is the nature of the beast that we lose members of our WebWhispers family every month. We always recognize those members at our awards banquet at the IAL/VI annual meeting. Sometimes, though, we lose members who have made extraordinary contributions to the lary community and their tireless advocacy and unflagging support warrant some special notice. In the last two months we have lost two such warriors. We have all been enriched by their lives.

Mike Rosenkranz (aka Shmuel Mitchell on Facebook) died December 22nd at the age of 94. Mike became a laryngectomee in 1999 and never let that diminish who he was in any way. He volunteered with WebWhispers for decades, becoming a member of our board of directors in 2007. He served as Vice President of Website Activities since 2009. Mike was dedicated to the Lary community and a servant to all around him. With his positive outlook on life and sense of humor, he was a source of encouragement and joy to us all. He will be truly missed but leaves us with his unforgettable legacy.

Tom Whitworth made that sad announcement to the WebWhispers family but as he noted it only begins to describe the many ways Mike influenced our community. In 2017 he was awarded the WW Distinguished Service Award (only one of many awards over the years recognizing his dedication to the lary community) at our annual banquet in Newport News and it acknowledged both his adventurous curiosity (he was still traveling the world in his 90s) and his relentless optimism, good humor and dedication to posting inspirational sayings.

He maintained that zeal for life and robust humour until the very end. He was fun and feisty, a truly memorable character who will be dearly missed by all who loved him and appreciated his zest for life.

Mike Rosencranz...
Our Very Own Creative Explorer.....

*I slept and dreamt that life was joy.
I awoke and saw that life was service.
I acted and, behold, service was joy.*

~Rabindranath Tagore

~Donna McGary

Barbara Nitschneider was diagnosed with larynx cancer at the age of 28. She was teaching 2nd grade children at the time and continued to do so for over 30 years. At first she used an electro larynx and then esophageal speech with an amplifier.

I first met her in Winnipeg Canada at my first IAL Conference in 1991. That was probably her 15th conference but I never really got to know her until 1997 when we both served together on the IAL Board of Directors. Of course by then she had a lot of experience and was very helpful in educating me and others as to procedures, responsibilities, and the many functions of the IAL.

She was encouraged by many to run for IAL President someday but her only ambition was to be the best IAL Secretary possible, and she accomplished that for many years... right up to the end.

In all she attended over 40 IAL meetings which I'm sure is a record that may never be broken. But, in addition she also attended several California Association of Laryngectomee conferences where she was a guest speaker and supporter. While not an active voice on WebWhispers she has attended most of the WW dinners for the past 15 years.

She also traveled to Croatia to attend a Confederation of European Laryngectomees Conference, representing and promoting the IAL in order to share best practices in laryngectomee rehabilitation. She once described that as her best trip ever. This was done at no cost to the IAL.

Something that few know is that she attended 2 Telecommunications Equipment Program conferences to advocate that all states provide a free electrolarynx to all laryngectomees, something that only about 15 states did at that time. Thanks in part to her efforts 5 more states started to provide that support, and while it was some years later, Illinois her home state, came on board recently.

But her generosity and compassion didn't end there. In her "spare" time she volunteered at Main Stay stables to help autistic kids by riding horses, and she went back to school to be licensed as a substitute teacher for severely disabled children.

They say life is short, and hers ended too soon at her home in Trout Valley, IL on Oct 22, 2018 at age 71. But she lived it to the fullest dedicated to helping others. I am honored to have been her friend and to have represented both the California Association of Laryngectomees and the WebWhispers organization at her memorial in recognition her amazing years of service to others.

She was caring, compassionate and dedicated to helping others. But most of all she was my friend!

~Jack Henslee

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*Donna McGary Managing Editor
Jack Henslee Speaking Out Editor
Kim Almand VoicePoints Editor*

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