

WebWhispers

Sharing Support Worldwide

Throat Cancer and Laryngectomy Rehabilitation

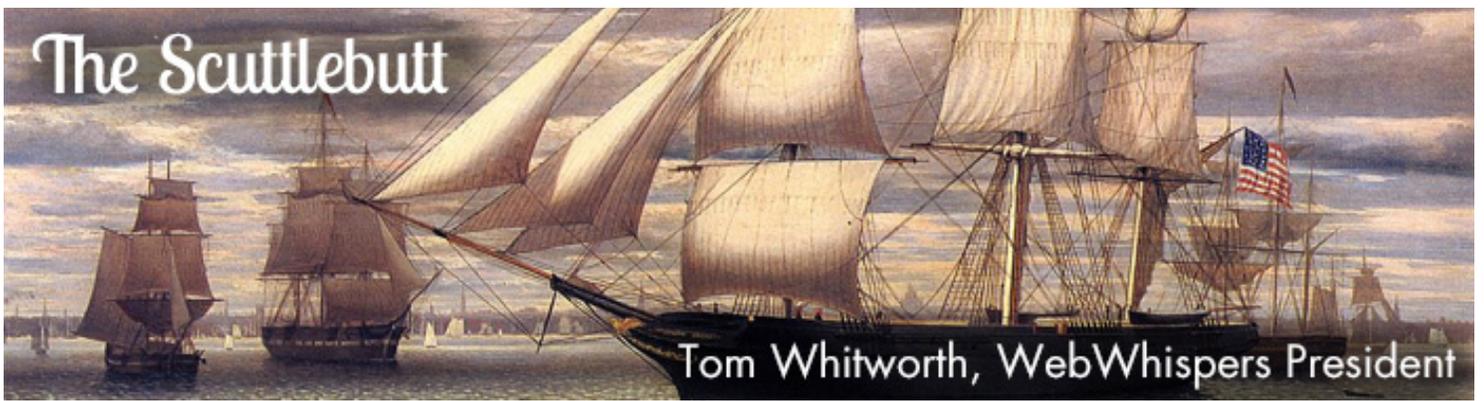


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The Vast Unknown

Four years ago, I learned my treatment had not worked and that I would need a laryngectomy. It all sounded quite devastating, as it does with most of us. I did not have time to learn very much at all before my surgery and spent less than an hour with my Speech Language Pathologist on the topic of laryngectomy and me. At least I already knew her from before. There was so much I did not know. It would be better to say I knew absolutely nothing because I was not of the frame of mind to absorb much of what she said, what the doctor said, what anyone said. Things happened so fast, there was no time for much education at all. I had no idea how much there was to learn that I would need to know. Yes, that is where the fear was. A fear of the unknown. I didn't even know what I didn't know. I remember things like seeing myself in a mirror for the first time while sitting in a hospital bed, and that wonderful PEG tube that had already been with me for 7 months. I despised that thing with every ounce of my being. I really wondered if I would be able to learn what I did not know on caring for myself and wondered if I could have life as I knew it after, all that.

Things progressed almost as fast as they did in the two or three days prior to my surgery. After I had returned home, I remember being terrified when I woke up in a chair and realized that somehow the red rubber catheter had slipped out and was lying there in my lap. The tape attaching it had given way. I remember them telling me that if it ever came out to get somewhere immediately or my TEP might close up. My wife and I both panicked. Could we get me to a facility fast enough? Then I thought, if it's that important, I'll try it myself. I found the nearest wall mirror, looked in and saw the puncture. With the confidence of an accountant performing brain surgery, I inserted the thing right where it needed to go. Then I taped the knotted end to my skin as if it needed to hold permanently. No prob, Bob. Piece of cake. I began to think then that, though I had a lot to learn, I could do this. I could take care of myself.

I also did not know that I would be speaking within two weeks using a base plate and HME or that only a few weeks after that I would be speaking hands free with my Blom-Singer ATSV II from InHealth Technologies. I certainly did not know that right after that I would be attending my first IAL Voice Institute where I would be truly astounded at how much I would learn. I had no idea that I would meet so many people who helped me feel like somebody, people I would cherish for the rest of my life.

<https://www.youtube.com/watch?v=ZtJWnLPmcx0>

Though I will always have something to learn, I have learned more than I thought I would ever need to know.

Enjoy, laugh, and learn,
Tom Whitworth
WebWhispers President



**Tell us about your outdoor activities.
Do you still do the same things as before, do them differently,
try new things? Is there anything special that you miss doing?**

Since my surgery the only outdoor activities I have forsaken are water related. I still go on long hikes and ride my bike. I loved to kayak and have all over the world. However, the chance of flipping it is very scary so I have given that up. We can all be as active as our health lets us.

**David Kinkead – Peoria, AZ
Class of 2013**

My name is Pam Lodal. I am 61 years old and had my laryngectomy in 2017. I have always been active and love being outdoors here in Idaho. I still garden, hike, camp and ride my bike without any adaptation. Skiing has been a different story. Since I can't wear a turtleneck over my stoma, I modified a neck gaiter by cutting out a hole and covering it with mesh. That way my neck stays warm and I can still occlude my stoma to speak to my friends. Bulky ski gloves sometimes make it awkward, but it works!

I still go jet-skiing and floating or paddle-boarding on lakes or shallow rivers. I always wear a life jacket and am careful and aware of my surroundings. I do miss swimming somewhat and I've decided that white-water rafting isn't worth the risk. But I don't dwell on what I can't do, I'm just grateful for and enjoy the many things I can do!

Thank you for the wealth of information I get from "Web Whispers"!!

Pam Lodal – Boise, ID

I live in Traverse City, Michigan. I became a laryngectomee on November 22, 2016. I was an avid mountain biker prior to my laryngectomy, usually competing in about 6 races a year.

Since the surgery I discovered I can still mountain bike! I'm not as fast as I used to be, and I don't have the endurance I used to have, but I still enjoy it a great deal. I actually was able to complete a 30 mile race this past November.

The biggest problem I have while riding is mucus buildup. Because of it I can't wear HME filters while riding. I usually just wear a bib made out of an athletic shirt to cover my stoma. It works to keep debris out, but dusty days are difficult. I wish someone would make a better product.

Dan Morley – Traverse City, MI
Nov, 2016

I really haven't changed or cut back my outdoor activity since recovery from the 11/16 surgery. After radiation ended 3/17 I was anxious to get back to my normal routine. My physical recovery activity started in April. I was determined to get back in the saddle quickly. Still go camping, hiking, do gardening and yard work. I target shoot and exercise daily with 5-10K walk/runs, weather permitting. Just avoid fishing and other activities near the water however.

I do slow down a bit during winter due to weather conditions and temperature but I did that before anyway. When running I carry extra HMEs and Kleenex cuz there's a lot of additional muck generation and sometimes the HME get plugged.

I'm 69 yrs. old and have always taken care of myself, watch my diet and eat healthy food (I do all the cooking). Military training and years self-discipline have helped greatly. Never smoked although I've been inebriated on occasion as a younger man, especially while in service, but I've never lived a life of excess. Other than my lary surgery and other common 'old age' ailments (cholesterol, blood pressure, prostate) I'm in great physical shape. I encourage all lary people to get as active as possible. It's not a death sentence, it's just a life change that you'll have to adjust. Get outside and enjoy yourselves.

Dave Sherr – Lenor City, TN
Class of 2016

Swimming is the outdoor activity I miss most. Not only did I enjoy it my entire life (I'm now almost 77 and learned to swim at 3), but is arguably the best form of exercise for aging joints. When I semi-retired a decade ago, we moved as close to a usually warm, white sandy Florida beach as we could afford and still be in an urban area. Until my laryngectomy, I swam often several times a day either in the Gulf or in our large community pool. And beyond that, I really can't go boating with family and friends who don't own yachts!

The good news is that the nearby beach still provides me both exercise and a "high" of being in the great outdoors. I briskly walk 3-4 miles on the beach at least three times a week with several good friends. During these walks, we verbally try to cure the many ills of our world. Up until a year ago, I had to remain relatively silent as my then weak voice was drowned out by the surf. Now most of the time with my Provox voice prosthesis I'm able to speak loudly enough to be heard by my companions.

Tony Branch - St. Petersburg, FL
June 2016

Myself I do most anything I want just have to change HME more often. I mow, all yard work, cut n split fire wood, hunt all the time in season of course. The things I can't do is body work n paint on my cars n trucks, tractors. HME's do not stop the misty vapors. Do most anything else.

Bobby Hice – Luxora, AR

Positives-Very lucky to be able to do all of my previous non water related activities with very little or no change. Workout 5-6 days a week at gym. Road and hybrid biking essentially unchanged except that 50+ lb. weight loss makes it a little easier. Hiking essentially unchanged except breathing is a little harder. Tennis is just as mediocre as ever. Snow skiing -I have not been active for a few years but I cannot think of any reason why not with moderation. Inspired by the winter Olympics I intend to get back on the slopes.

Cautionary note: I was on Gabapentin (essentially a nerve receptor deadening drug used in lieu of opioids) for over 100 days. During that period my work with weights improved which I never credited to the drug. When I stopped the drug not only did my improvements disappear but I picked up a couple of injuries.

Challenges-water sports-swimming, surfing, stand up paddle boarding, kayaking/kayak fishing, boating etc. I was pretty active in the first two and was aiming my retirement time at all of them.

Swimming-I'm aware of the American Larysnorkel and the European Larkle and Servo- Aquathers and will be definitely taking advantage of one or two of these devices. The pool at my gym has perfect depth (4-in below stoma) at its deepest point so that if anything was to happen I could simply stand and clear.

I've surmised that US attitudes towards this activity vary significantly from those in Europe with respect to liabilities but I hope I am wrong since life affirming activities are considered to be extremely beneficial to mental health and being in the water has all kinds of benefits in addition to swimming. I did a lot of research when I was first diagnosed but the extended time I have spent on the medical hamster wheel has delayed my progress. I've been hoping to find a US hospital that runs a sizing and training program so that I don't have to go to Europe but will do so if need be. I've picked up Google hits at Johns Hopkins and Santa Barbara but no details. I've written to the IAL in the US and UK as well as the Devon and Exeter hospital in UK (who had a program) but surprisingly have not received responses. Any assistance that WW may provide is much appreciated. Once I have a relatively secure device and am confident in its use I should along with appropriate flotation devices be able to do everything on my list except small wave surfing.

Surfing- When you surf for a long time it is something you do not want to let go of. Bethany Hamilton who is relatively famous is a surfing champion who lost her left arm to a tiger shark when she was 14 said when asked why she does it stated "my passion for surfing is greater than my fear of sharks"...

Although it seems impossible I have found leads to four different TL patients who have surfed including a surfer from Oceanside CA who solved the technicalities of doing so in 1991 when he was 43 and went on to surf large waves and even compete for years. His story has appeared in IAL journals and I have tried to make contact with him relative to his device design. The photo in the IAL journal article is amazing relative to size of wave and I am nowhere that ambitious. He was a very good surfer and my expectations on this topic are very limited but if he could do it why not on a small wave quiet day in Florida? Again any help would be great.

In short depending on their personal circumstances people should at least where conceivable try things that might improve their outlook on life.

Thanks for giving us this opportunity

Tom Tully - Yardley PA and Delray Beach FL
4-19-17

Animals have always been a very special part of my life. That was especially true in 1974 when I had my laryngectomy. At the time I had a quarter horse named Cheyenne. I knew my shoulder would be

compromised when I had my radical neck dissection but I was so glad to hear that I could still ride because my back and forth arm strength would not be compromised. While I was undergoing radiation treatments for any other spots that could be in my lymph glands I couldn't even swallow, and I would spit in a cup.

At this point I didn't know how to jump a horse. The horse I had was not a jumper but there was a thoroughbred for sale for \$1,000 named Passport. I was on a leave of absence from my teaching position and my salary was reduced so I went to my Credit Union to borrow \$1000. I said I needed it to help pay my rent. I lied a bit on that one. An arrangement was worked out that if I worked one day a week in the District Office, in the course of a year my debt would be paid. After my surgery I was back riding my horse.

With Passport, my new horse, I learned how to jump fences. I also went to some horse shows and did very well. During this time I continued with my jumping lessons. There was a man at the stable named Bob and he had a beautiful horse named Different Drummer and Bob did very well showing him. After about four years, in 1978, Bob and I were engaged and we brought Passport home to the stable in Trout Valley, IL. He was very happy there especially with the two mares.

During this time we were actively looking for a horse for me. We found a beautiful chestnut mare named Paper Doll. Together she and I won many ribbons. In fact, there is a picture of us jumping that was put into the Helping Hands booklet. All of this time I was very happy, not thinking much about my own problems.

Over the course of many years I continued to own a horse. I told Bob I would always have a horse but would make the money to pay for her. Over the years I would buy two more jumping horses but I stopped showing, as it was too expensive. I moved from a show barn to a Western barn. I took Western riding lessons and was soon riding the trails with my horse Dell. Now I'm with my very last horse named Lady Amber. She is a very beautiful buckskin quarter mare. She and I will grow old together. She is twenty-one years old now and has many years ahead of her.

Over the years animals have always been very special to us. We have had five dogs and three sets of cats. Our current Black Lab is Kayla, and our two cats are Mike and Ike. We also have a very happy little cockatiel named Mr. Peepers. Animals have been our children. I can't imagine a life without them. They helped me cope with the loss of my voice and I was gifted with some very special animals.

Barbara Nitschneider – Trout Valley, IL
1974

I hope that everyone is doing well, and that this is the right place to provide my contribution regarding outdoor activities. I may be too late, but time just got away, as they say.

I am happy to say that I am still able to do almost all of the outdoor activities that I did prior to being laryngectomized. The two notable and heartbreaking exceptions are surfing, and scuba diving. I am fortunate in regard to surfing because I was finally able to figure out how to safely surf with a PEG feeding tube 5 years into my 11 year stint of having one. I had just gotten the green light, from a scuba oriented MD, to throw the tank back on and hit the reefs with my PEG tube when I got the news that I was about to become a laryngectomee. Si La Vie, I'm just happy that I had the great pleasure and privilege of having been able to engage in those sports for as long as I did.

I am still happily engaged in the rest of my passions. I have been a gym rat for decades, and after each trip to the surgical suite, let's see, that would be three or four times at least, I've lost count over the past umpteen years, I have always been able to get back into the gym, starting over. I don't bench press as much as I used to, since my left pectoral muscle was recruited to provide tissue and blood to the left side of my much sliced, diced and radiated neck, but I can still flex it. Apparently the other left side muscles in my shoulder, and back are pitching in and taking up the slack for the rerouted pec.

I am also an avid hiker, camper, backpacker, biker, canoer, and jog/walker (i.e., alternate jog awhile, walk awhile). I'm hoping to get up north to learn to ski and snowboard next winter, which would be a tremendous treat. So, I am very happy to still be having lots of fun outdoors as a lary.

Patrick Kerr
Class of 6/11

Next month's question is:
“Did you suffer from depression after your surgery?
If not, why do you think that was?”

Thank you for your submissions. Edits are used for length, clarity and to keep comments on subject of the month.

Staff of Speaking Out



Voice Points

Written by Professionals

Coordinated by Kim Almand M.S., CCC-SLP
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Laryngectomy Support Group? Or Group meeting?

The laryngectomy population is a truly unique one. We all have had the pleasure of working with laryngeal cancer patients, but the laryngectomy population stands out for so many reasons. All of us have worked with the patient that understands his /her situation and says, “Ok, let’s deal with this.” Or, the other type of patient that goes in a totally different direction, “I can’t do this.” We frequently have to provide emotional, physical, and mental support for patients who are grieving the loss of their voice and the anatomical/physical change in their lifestyle.

All of us remember being a young therapist working with our first laryngectomy patient in the hospital after surgery. I remember walking in the room bright eyed with a smile on my face, introducing myself and, to my surprise, the response I get was a flailing middle aged woman, throwing her tissues at me while mouthing the words “Get the “expletive” out of my room!” To say that I was a little taken aback is putting it lightly. However, I proceeded to walk into her room every day, sometimes twice a day offering my services with a smile and receiving the same or worse response. I knew it wasn’t personal. I knew what she just went through was life altering and she was dealing with it the best she could. I can honestly say that we are the best of friends

today and she still says from time to time, "I treated you so badly and you kept coming back to try to help me, I feel so awful." Sound familiar to anyone?

The role of 'support' takes on so many definitions. Yes, as therapists, we are with the patient before surgery, after surgery, and everywhere in between. That's what we do. Our support is special and different than others, but no more or less important. But we really get to know our patients, don't we? We are there when they get their diagnosis, and are usually the ones who are left in the room after the surgeon, resident and nurses leave the room. We help answer any follow up questions they or their family might have, even though we know everyone in the room is in shock and not really listening to what we have to say. We explain how their hospital stay will go, the part we play, and that we are going to be with them and their family every step of the way.

There have been many times we've heard this statement from our patients, "Support group? I don't need to go to a support group; I don't need to talk about my feelings." Or "I don't need people knowing my personal stuff." This provides insight on very unique individuals who may feel they don't need support. When we first started our support group, that's exactly what we called it...a support group. But our meaning was very different than the persona of how our patients understood it to be. Before our support group was established, we kept hearing similar things from our patients and their families. We frequently heard our patients say, "People and kids look at me funny," "I'm embarrassed to go out in public," "I don't know how to deal with this." Families usually voiced concerns such as "I don't know how to help him/her," "I've never done this before, I'm afraid to hurt him/her," and the list goes on and on and on. We thought we were doing a GREAT job talking to the patients before surgery, telling them what to expect, how things would be etc. We gave them brochures, literature, pictures, and sometimes showed videos. However, we would still get comments from our unit nurses stating, "Mr. X is upset because no one told him it was going to be like this," or "Why wouldn't anyone discuss the surgery with Mr. X?" After explaining to the nurse multiple times that we spent over an hour with the patient before surgery, we realized we were missing something. We also got the overwhelming sense that our patients felt that they were alone. We would inform them that there were other laryngectomees scattered throughout the city and state and frequently offered an "experienced" laryngectomee to speak with them.

We thought to ourselves, how can we help them? Very often a laryngectomee would come into the clinic and say, "Hey, I figured out how to deal with this!" or "I found a better way to do this." We encourage them and say, "That's great!" But it started to occur to us that many of our other patients were complaining about that very same issue. Now, as therapists, we believe we can fix all ailments for our patients, (*wink wink*), but the reality was that they were learning on their own what worked best for them despite us telling them, "The literature says to do this," or "The manufacturer/company says to do this."

The idea of a support group was not a new to us, however, as our practice and clinics grew larger, so did our patient list. It got to the point where we were fielding questions via phone and/or email or we would have patients just showing up in clinic. Now was the time. We decided that it was time to start a "Laryngectomee Support Group." The idea was a simple one, let's bring our patients and their families together to give them a place to meet, gather, talk, complain, cry and laugh together. Let's allow them to teach each other, let's allow wives to talk to wives, husbands to husbands and adult children to adult children. Let's put them all in the same room and see what happens.

The agenda for the first meeting was simple. Let's bring them together in solidarity and allow patients and families, to realize, "I'm not the only one going through this." We will sit, meet, talk, and get to know each other. We, as therapists, would be there to coordinate and help the conversations move forward. We also wanted to know what they want out of this sort of group meeting. Turns out, they had wonderful ideas. We mixed therapist, patient, and family ideas to develop a meeting that would happen twice a year, once in the Spring and once in the Fall. They were adamant that they didn't want to meet every month. Our state is a large, rural state and a lot of our patients have to travel a fair distance to be able to attend.

We tried our best to explain what we were doing; however, many patients and families didn't show up for our

first meeting. We followed up with those patients and asked “why” they didn’t attend. Many simply said that they didn’t need a support group which made us realize that we needed to do a better job in explaining to patients and families what ‘type’ of a meeting we had in mind. We eventually changed it to a Laryngectomy Group Meeting. We changed the format and organized the meeting to include topics of conversation that were specific and interesting to them. Yes, the title changed but the purpose was the same; and little did they know that they were all there in support of one another and their families.

Today, our Laryngectomy Group Meeting still meets twice a year. We have organized it into something very special for this unique population of patients and their families. We have guest speakers from both ATOS, In-Health, and Lauder Enterprises who come and give mini presentations on laryngectomy topics. We introduce new products or new ways to address certain issues. We, the therapists, have begun mini presentations of our own on subjects relating to Speech Pathology and laryngectomy. Topics include radiation effects, anatomy changes, breathing/speaking techniques, swallowing, lymphedema, and quality of life. These are subjects that we address in clinic or during an outpatient visit. What makes these meetings special is that our audience is unique. They participate and add their thoughts and opinions which can be varied and lively at times. It has become a safe place to express frustrations, concerns and gratitude.

Our favorite part of the entire meeting is watching the interaction of the patients and their families. The exchange of knowledge from an old laryngectomy of 17 years to a new one of 3 months is invaluable. We love the hugging of one wife to another and watching their eyes meet with that acknowledgement of ‘I know what you’re going through’. And yes, we love the solemnness of the realization from patients and families as they find out that Mr. or Mrs. X is no longer attending because they have passed on or their cancer has returned. The laughs, the jokes, the seriousness, we love it all. And it is evident that they get out of it what they need as well.

So whether you decide to call yours a “support group” or not, let us not forget the reason we are all here: to support, to meet, to help, to educate, to be a good therapists and good listeners, and to be a friend when required. Remember, they are not only our patients, they become our friends.

We would encourage those laryngectomees and families who have not attended their support/group meetings to reconsider. You have a ‘voice’ and it may be your comment or statement that has a profound effect on another laryngectomy or their family member. It may be the one thing they have been waiting to hear!

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The New Mexico Laryngectomy Association (NMLA) meets twice a year, Spring /Fall

Information can be obtained from the University of New Mexico Hospital Speech Pathology Department, 3 Middle, 2211 Lomas Blvd N.E., Albuquerque, New Mexico 87106.

Contact Carol Romero-Clark M.S., CCC-SLP, Manager of Speech Pathology , 505-272-2455 or caromero@salud.unm.edu



Dear Lary

Noirin Sheahan

Speaking Up

Last month I was telling of my friend Catherine's temporary disability because of a fracture in her leg and how our chat about managing disabilities made me realise that I haven't taken active steps to minimise communication problems to the extent that she is now planning details of her day so as to minimise the number of journeys. I realised I'd let myself slip into becoming a quieter person as my way of adapting to laryngectomy, and that it was time I started thinking about what I need to communicate and how best to manage this.

Asking myself "What do I need to communicate today?" has been a bit of a challenge. I don't find a list of things tripping out that I could jot down and then tick off. Most of my pre-laryngectomy chatter happened without any planning. I was just thinking aloud. At times this was a kind of running commentary on whatever I was doing. "I'll get the butter out of the fridge." "I must remember to buy potatoes". "Now, where did I put my glasses?"

None of these are earth shattering pronouncements, and it can become irritating if someone overdoes it. But this kind of chatter also keeps us in contact with one another. It's a reminder that I'm here and that I want to be in touch with whoever's nearby. And a lot of harmony flows from knowing about small stuff: if someone else is going to buy potatoes at least I don't have to do that, and because someone is getting the butter out of the fridge I might as well put on the toast.

But Ellie (my EL) wouldn't be up to this level of communication. A person says "Where did I put my glasses?" as they're picking up newspapers and cushions to find the hidden spectacles. Ellie however, demands attention and careful handling to keep her on the sweet spot. She splutters and farts in protest if I let my hands stray towards other tasks.

The result is that I (and I'm sure most laryngectomees) do things silently. We don't stream our thoughts to others. If one of them knew where our glasses were, they wouldn't say so as they don't know we're missing them. No one puts on the toast because they're hunting in the fridge for the butter that we've just put on the table.

The communication block can affect us at broader levels too. Before Catherine's prompt, the only way I'd registered this block was when I saw that, a few years ago, I'd made a couple of important life-decisions without first talking them over with friends. I hadn't consciously chosen to hold back from discussing these matters. But the things I was thinking about inside my head never found a way of slipping into the conversation.

I suppose I always found listening easier than speaking of my own activities or inner dilemmas. The world 'out there' seems easier to understand than the world of conflicting emotions and half-formed stories that I occupy 'in here'. Words don't form readily to describe my inner world. Amongst friends, some pre-

laryngectomy magic allowed that pent-up inner story to find its way, in little spurts and trickles into the conversation. With each trickle I'd start to feel more confident and 'at home'. In that warmth my inner dilemmas didn't seem so jarring and could condense themselves into thoughts and words. Chatting to friends helped me understand myself.

It was only when I saw that I'd made these important decisions without discussing them with friends that I realised that the pre-laryngectomy magic wasn't happening anymore. Unconsciously and unintentionally I was withdrawing - even from my best friends. I realised I was going to have to be more proactive in conversations so as to get some air-time for my inner world.

The first thing to do was to tell them of the changes and decisions I'd made. I emailed some people and met with some others. With one group the news slipped out easily and we were able to chat about the ins and outs of the matter. With the other group, I completely failed to steer the conversation towards my way. We were meeting over lunch and almost from the start I felt uneasy and self-conscious, thinking 'How do I introduce this topic?' while they were chatting enthusiastically about other things. Once or twice I glimpsed an opening, but the topic changed before I could get Ellie into gear. As lunch was drawing to a close I finally blurted out something about having problems telling people my news post-laryngectomy and that I needed to let them know of a couple of changes to my life. I sensed an awkward silence as I was saying this and following on from my news. It was more like a monolog than a conversation. At least my news was 'out there' but it all felt clunky and a bit embarrassing.

Now that Catherine's email has prompted me to look at my communication patterns again, I'm wondering whether I need to start small, and get used to 'interrupting' people if that's the only way I can keep myself within the conversation. I've often thought of asking people to listen out for Ellie's wordless buzzes as a sign I want to say something and that they need to wait a few seconds so I can get her connected up.

So far I've been too embarrassed to ask for special treatment like this. I'm not normally up-front about my needs. But maybe that's one of the life-lessons laryngectomy is asking me to learn.

The great thing about having to write a column for Webwhispers every month is that it makes me face up to aspects of Lary life that I'd prefer to ignore. And I'd certainly prefer to ignore this one! The easy option for me is to keep silence and be content as a good listener- a role I enjoy . But having registered the isolating effects of this, I vow to make a greater effort to get Ellie to speak up more often on my behalf.



With a Little Help From Our Friends

So I was walking through the Target parking lot the other day and noticed a woman rather slowly getting out of her car as a man waited and tenderly attended to her. I was struck by her distinctive long platinum braid and cool lace up boots and by the fact that she needed a footed cane to maneuver. I thought she looked familiar but until she smiled and called out, "Hello!" I didn't realize it was Sharon, a woman who works at the town office and has been on medical leave for some time. I asked how she was doing and she replied, "Mending" as she picked her way across the parking lot. I don't know the nature of her illness but it clearly took a terrible toll. I realized then that the long braid was a wig and she was really struggling to walk. BUT she had made such an effort to get out for this bit of shopping at Target. She had on makeup and a cute outfit- like she always had when I would see her at the Town Hall. I commented on how adorable her outfit was and well it suited her and she responded in kind. It was the easy kind of interaction women do every day... but I realized as I walked into Target some days it is neither easy nor simple for us to put our best foot forward, so to speak.

Recently I have come across a number of articles which seem to be contradictory. Most of these were in the context of aging, visibility and women, in particular. One school of thought is "fake it until you make it" and the other addresses the issue of feeling one age while clearly being and looking another and that somehow being demoralizing. We are constantly bombarded with aspirational (and unrealistic) images and messages that glorify youthfulness, health, fitness, a particular type of vibrancy and success few of us actually resemble or achieve at any age.

So how can we be authentic, match our outside to our inside, be comfortable in our skin when, in fact, we are not "feeling the love"? If we want to look 20 years younger than we are, we can't fake it 'til we make it. Just trying to makes us look foolish and only postpones the inevitable. Then the other day I had an epiphany of sorts as I struggled with that very question. That spate of articles, my chance encounter with Sharon and my upcoming 65th birthday all collided and I had an "aha moment". Truth be told, I don't feel 45 nor am I shocked that I look 65. 45 was great – it actually was a pretty good time in my life but other than having the skin and joints and fully functional larynx I had at that age, I don't want to BE that woman again. I am truly more comfortable in this saggy skin than I was in that smoother one. I am more self-aware and confident than I was then. I certainly am wiser and more thoughtful. I have been through a lot in the last 20 years; some of it was pretty rough stuff and it shows but I made it through and am a better person as a result.

I realized I wanted my outside to reflect my true inside. I wanted the way I dress and act – the way I present myself to the world to convey my spirit, my love of life, my humor and intelligence, my experience, my bad ass self and my kind self. Our scars and wrinkles, our stomas and unusual voices are our badges of courage. Remember that funny scene in Jaws where the two guys compete by showing off their scars? We made it thus far – we are survivors!

Some days it is easier to be a warrior, put on our armor and go out into the fray. Other days it takes a lot of effort to put ourselves out there but like Sharon, we put on that wig and some makeup and bravely go to the store and call out hello to an acquaintance. And lo and behold, someone notices us, notices we made that effort, kind words are exchanged and things are a bit better.

Noirin writes of a similar dilemma in her column, The Mindful Lary, both this month and last about having withdrawn from conversations sometimes because of the effort required to talk now and her efforts to change that behavior. Somedays we need some encouragement. Some days we offer it. Either way, we need our friends and they need us. Web Whispers offers a unique source of encouragement and opportunity for a unique community. I may be the only Library Robot Nanny in these parts but I know I am not alone. When I am weary of fumbling for my EL to try to speak I know she is struggling with the same thing over across the pond. On those days when it is a struggle to pull myself together and go into the school and then I come home and write to tell her about the child who told me shyly how cool he thinks my voice is she will smile and be as encouraged as I am to keep on keeping on. That's what friends are for.

Check this out for all of us here at WebWhispers:

Bits, Bytes and No Butts!



Frank Klett

Can We Trust Information on The Internet?

Since the recent Presidential election many questions have been raised concerning the impact of technologies on the end results. Pres. Trump has termed much of the Internet information and that of the media itself as being "fake news". There are those that agree with him to the point of digging deeper into the sources and credibility of many various news reports. It has also brought to the front the fact that our media news sources are paid for services and thereby prone to report what sells. Of course this should not surprise anyone since we the consumers seek information from sources who tend to report on our areas of interest.

I have heard more than one person quote a news item as gospel since they saw it on Facebook. Oh my, seems we have a true issue of credibility here...not with Facebook itself but with the control over the information reported there; other than paid advertisers we have little to rely on for truth worthiness. The following paragraph was submitted to Leo Notenboom who is a respected source of technology information and his reply follows it. His reply points to many things to be considered before taking the news as valid.

"I'm a computer science student, and I'm confused about the extent to which I should rely on the internet for the information about computers. For example, if we take the term "IP address," then a lot of information has been provided on (for example, Wikipedia), which is a lot more than what is written in the recognized books. My question is how much should I rely on the web for such technical aspects?"

<https://askleo.com/how-much-can-i-trust-information-on-the-internet/>
[Medieval Tech Support had its advantages...](#)

Have our systems of password rules made us less secure?

If you consider that certain (many) websites require that our passwords be structured according to certain criteria then you have already given anyone with the desire to "crack the code" the ground rules for what to look for in both length and content. Bob Rankin has written an excellent article on password rules and how most tend to weaken rather than strengthen our online security. [Read on to consider your own password](#)

structures...

Improve your online security by using an alternate DNS

Improving your system speed (actually INTERNET searching) is through the use of an Alternate DNS (domain name service) ...your INTERNET provider already provides you with a DNS, however, there are other DNS's available which have streamlined the search functions and are more efficient in finding your information. Most are free and install with little effort. While this may all sound very technical and not for the mere human computer user it is actually quite easy to set up and once it is set up you never have to think about it again.

Again, [Bob Rankin has an article to steer you through the process if you feel the change is what you would like to try...](#)

Are you using Facebook Messenger? If so you need to pay close attention to what Bob Rankin has to tell us in the following article...https://askbobrankin.com/just_say_no_to_facebook_messenger_malware.html

The **WebWhispers Facebook Group** is our meeting area along with the Webwhispers Forum. Many of our members are on Facebook, so we knew it was time to have a Facebook home. We invite all our members to join us in our Facebook Group and the Forum.

Happy Birthday to Mike R. for the 94th time on March 4th!! Well Done Sonny!!

If you are not a Facebook user then you might enjoy a visit to our **Forum**...hosted on Delphi the Forum is a Members only group which limits the access to only those of our hole in the neck group...you can read over the questions and insights of other Larys...as well as ask questions and get answers from our knowledgeable members.

The **Forum** is our open area to ask questions and exchange thoughts...there are many categories of interest and you'll find the answers to many of your questions. FORUM: <http://forums.delphiforums.com/webwhispers/start> **If you have any question contact the Forum manager Mike Csapo.**

And for our newest members remember to visit our library for answers to many of your questions. Our Library <http://www.webwhispers.org/library/library.asp> is one of the most complete collections of information aimed specifically at the Laryngectomy Community...in fact, it may be the only one. Taking the time to browse the library and become familiar with the contents will make it even more useful for when you do need to find out a piece of information.



From the Archives

Should I Plant Annuals Or Perennials?

Editor's Note: Paul Daniels wrote a number of columns for us and had a wonderful blog about his life in gardening and so much more before he passed away. We first learned of his wonderful perspective when he wrote about his wife fashioning a shower guard for him from a baby's plastic diaper pant shortly after his surgery...complete with pictures. He was a treasure and yet another WotW writer who I would have loved to meet in person.... and spend some time wandering (and no doubt laughing) with him through his gardens. I wish his blog was still available – he remains a hoot!

I talk funny, well different, that is I communicate with an electronic device called a Servox, as I lost my vocal chords to throat cancer back in 2000. I've gone 3 rounds with throat cancer, first time I was scared to death, second time I lost my vocal chords and hence my natural voice and the third time it nearly killed me. After I lost my voice I took early retirement. I was a salesman; I decided that the market for salesman that couldn't talk was small to say the least and would only get smaller... So what else could I do? I started gardening!!!!.....And boy my life ain't been the same since, I thought losing my ability to talk was a life changer, hey gardening is even more so but in a good way.



When you've had cancer you're always worried it's coming back or has it already come back and I don't know it, all natural responses to having had the disease. Will I still be alive this time next year? I had thoughts like that a good bit of the time, tried not to let on to my loved ones but hey I was scared. And then it happened, not all at once but slowly slowly. I kinda got involved with gardening through the back door so to speak. I had a friend who fed birds on their back patio and raccoons came there too and one evening the birds and the raccoons really put on a show and I was hooked, hooked line and sinker. I was going to feed me some wild birds and have wildlife come to my yard to visit me (as I interpreted it. Why I'd have company all the time, birds, squirrels, coons, hey who or whatever wanted some food and water....And I'd watch them every day and evening as I sat out there while reading or listening to the radio. And then I started reading books about feeding birds and read about this other foreign thing I'd never heard of before, 'gardening for birds'.....Gardening for birds?.....What the heck is that?.....Well 3 or 4 hundred or so perennials, annuals, shrubs, roses, vines later, I know what gardening for birds is all about.

Oh back to that other thing, cancer and my doctor....Well I'm tooling along again in life going to every nursery

I can find without a GPS in the car, bought every plant that would even remotely provide food for birds and critters, bought so many kinds of bird feeders my wife threatened to leave me if I bought another one, and bird seed, good lord I went through 200 lbs. a month in bird seed like it wasn't nothing. And not regular black oilers like I feed them now but hulled sunflower seeds, the kind they don't even have to crack to eat, the filet mignon of bird seed.....and then low and behold on one of the checkups come to find out I'd had a reoccurrence of cancer, in my case about as close a thing to a death sentence as you'd get with the kind of cancer I had and the stage etc.

Well I might be getting ahead of myself here, you see I'd been immersed in the world of plants by now for several years and all I looked forward to was seeing them little perennials poke their little heads outta the ground about February, March or so.....I got to thinking about them plants coming back instead of me dying this week or next month or next year, I just about forgot about me and mostly thought about the plants, the flowers, the fragrance of the flowers, the bird's songs, the flittering movement of birds among the flower beds of our yard.....Heck I'd about plumb forgot about cancer....I wasn't going to die, heck I needed to be here to mulch them coneflowers next year, I mean who's going to weed?....Hey I'm going to be here, I got a reason to be here.....One that's not so much about me but about something else.....No doubt about it boys and girls, gardening gives you a reason to look forward to next year and the next and the next without just the fact that "hey I wanna be here and don't wanna die", which is a reasonable expectation I guess but not completely satisfying in certain respects.....

Oh back to that other thing, cancer and my doctor.....So I'm sitting in his office and he comes in with his surgical nurse and she grabs my hand tenderly and squeezed it like I might die while I'm sitting there in the chair, right away I know the news ain't good and it ain't....most folks in my situation now have a year maybe, probably less but before he has time to tell me anything substantively about what's going on with me I just ask him one question, "Hey doc, give it to me straight, should I plant annuals this year or perennials?" Well I kinda had a goofy grin on my face that I have when I said it and I looked at him and he looked at me and the surgical nurse looked at me and they both looked at each other and then we all burst out laughing at the same time.....That was 8 years ago, I've been growing perennials all these years and I'm still here, you see I gotta be.....I mean who's gonna mulch the coneflowers....Who's going to weed? And everytime I go for my yearly checkup I ask the Doc the same old question after he checks me out, "Do I plant perennials or annuals this year Doc?" and then we all burst out laughing.....

One caveat, some folks aren't as lucky as I've been so far, they're situation is grave and the humor I implied in my own situation in no way should belittle the fight these folks have on their hands even as we speak. I wish them all well.

Paul from Alabama

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For newsletter questions, comments or contributions, please write to editor@webwhispers.org

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