

WebWhispers

Sharing Support Worldwide
Throat Cancer and Laryngectomy Rehabilitation



September 2013

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FEEDBACK



Friends and Caregivers

Most of us are fortunate to have old friends with whom we share experiences, places, acquaintances, joys, and sorrows from years past. It is part of what allows us to not see each other for years, meet, and pick up right where we left off. We understand each other and even speak shorthand, never having to explain background information of a comment about what happened to Uncle Bob or the schoolmate who stole your favorite date, or your beloved pet, whose namesake lives with you now. Shared memories add layers to your friendship.

As we grow older we meet people who have undergone experiences that immediately lay the foundation for understanding, even if we are totally different. Having breast cancer makes sisters of us, no matter where we came from, how old we are, or any other facts of our lives, and there is a connection. I found that constantly surprising at first, having this relatedness.

And then I became a laryngectomee. I have made some of the best friends of my life, starting with the thread of having lived through this cancer or having cared for someone who did. It is a tie that binds us with the commonalities, even though we constantly have to remind ourselves, we are not the same in our experiences of surgery, radiation, chemo, and reaction. There are some experiences that we know we will all face and it will forever stay in our minds. The first time we find ourselves totally helpless to communicate over something quite small.

To many of us, this incident becomes a funny/wry story later but how many of you have come into WebWhispers angrily telling the story of how you rang for the nurse from your hospital bed and a voice came over the speaker asking, "What do you need?" Up to that point, your caregiver might have been by your side answering or taking care of whatever you needed... but here you are, all alone, tubes hanging all over, IV in place, and no way to signal, blink, nod or write a note... It is like being bound and gagged and struggling. It is perhaps the first time that we reach to take control of something and it is not there.

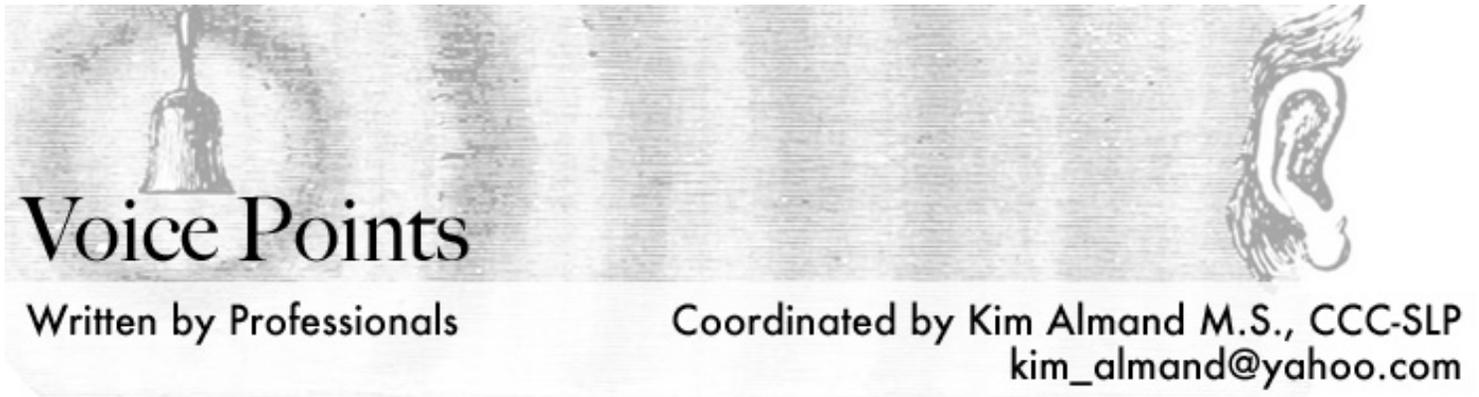
We learn from our caregivers, are shielded as much as possible from hurtful times and experiences, and they let us grow more slowly into this new situation. They go far out of their normal way to watch out for us, to be there when needed. They strain to understand what we want and can't say and they may lie awake nights worrying about what will happen next and how they can help. Their frustrations are there, as ours are, and part of their frustration is they can't do it for us. Ah, but they do... so much more than they even know.

Our families, friends, neighbors, medical professionals all contribute. If we have the chance to meet another lary cancer survivor, we learn from watching and seeing how they use the EL, or speak, or willingly show you how their hands free works. We listen and notice how the voice sounds and where you have difficulty hearing every word, yet know what they are saying. This is where we feel the thread of understanding beginning. This person has been there, done that and knows what it is like. If your caregivers are there, they look across at each other and nod. There is a thread there that goes to all of us.

I will never forget the lady that approached me... came looking for me when she heard the FI... She had tears in her

I will never forget the lady that approached me, came looking for me when she heard the LRP. She had tears in her eyes when she told me of her mother, who had died many years before without ever speaking again and how she wished she could have had one of those instruments. To her it was a beautiful sound. We had immediate recognition of each other ... the caregiver and the patient, two strangers who talked freely and comfortably together.

Enjoy,
Pat W Sanders
WebWhispers President



Voice Points

Written by Professionals

Coordinated by Kim Almand M.S., CCC-SLP
kim_almand@yahoo.com

Voice Prosthesis Reimbursement: An Advocacy Update

Meryl Kaufman, M.Ed, CCC-SLP, BRS-S
Speech Language Pathologist
Head and Neck Cancer/Dysphagia Specialist
Emory University Department of Otolaryngology,
Head and Neck Surgery

On October 1, 2010, the Medicare Change Request 6743 took effect and changed the reimbursement procedures for indwelling voice prostheses for laryngectomy patients. As a result of that change, Medicare beneficiaries can no longer order indwelling voice prostheses directly from the distributors unless they pay the full cost of the device and do not file a claim with Medicare. The ruling requires that clinics distribute and bill for indwelling voice prostheses at the time of the procedure to insert the device (CMS 2010).

This Medicare ruling poses several problems for the health care provider and for the laryngectomee receiving the prostheses. First, in order for providers to comply with this ruling, they must purchase a variety of types and sizes of prostheses to meet the potential patient need. This investment is costly and not feasible for all clinics, especially given the wide variety of types of prostheses currently on the market. Additionally, Medicare reimbursement for indwelling prostheses is less than the price that the clinic pays for the prosthesis itself. As many of you know, the average Medicare reimbursement for an indwelling voice prosthesis is approximately \$99. However, the average cost for a prosthesis is between \$200-\$350 depending on the device needed. As a result, smaller clinics have discontinued offering this service, and larger clinics are in jeopardy of having to discontinue providing this care due to the extensive losses incurred by distributing high volumes of prostheses at significant financial losses.

For patients, the clinical problems resulting from this ruling may include limited access to adequate TEP care,

delayed placement of prostheses if clinics do not stock their size prosthesis regularly, and increased expenses for purchasing prostheses. Additionally, patients can no longer be reimbursed if they purchase a “back up” prosthesis for use in the event of an emergency when traveling. As a result, safety issues such as aspiration pneumonia due to delays in changing leaking prostheses, temporary loss of speech if plugs or catheters must be utilized to resolve the leakage until care can be rendered, and/or permanent loss of the TEP puncture may occur as a result of the changes.

Because of this ruling and resulting consequences, several advocacy initiatives were instigated to help correct the problem. Immediately following the ruling, the American Speech-Language and Hearing Association appealed to the Centers for Medicare and Medicaid through several communications explaining the potential risks to patients that this change poses. Additionally, in the November 2011 International Association of Laryngectomees Newsletter, IAL lobbied its members to write to congress to express their concerns that the change request poses for their TEP management and safety. Although these efforts were timely and appropriate, CMS did not change the policy.

Subsequently, laryngectomy advocacy initiatives were then re-ignited at a meeting during the 2012 ASHA convention last year in Atlanta. This meeting consisted of ASHA members, TEP manufacturers, and ASHA health care economics committee leaders. The focus was on developing an action plan to improve reimbursement for tracheoesophageal voice prostheses and create a coalition of interested parties to achieve our mutual goals of improving overall care and access to care for the laryngectomy patient. However, those efforts and communications revealed that ultimately CMS will be most likely to consider changing the rule if this is a patient/consumer led initiative, not one led by healthcare providers.

So where does that lead us? What should we do? Well, we need your help to get a broad perspective on what, if any, impacts have occurred in the laryngectomee community as a result of the Medicare change request of 2010. Jeff Searl, speech-language pathologist and a professor at the University of Kansas Medical Center, and I are surveying laryngectomees and speech pathologist to gain a better understanding of both the patient and the provider perspectives on the issue. Andrew Palmer, of the Oregon Health Sciences Center, originally developed this survey linked below and has graciously given permission to re-use it here. If you completed the survey when it was released some months ago, we are asking you to complete it again. Please do not duplicate if you recently completed the survey in August through the WebWhispers list. Jeff and I will then summarize the data in an effort to gain a better understanding of how to attempt to address the issues moving forward. All of the information provided in the survey will be kept confidential. No names will be used in analyzing or reporting the data.

The following link will take you to the patient survey:

<https://www.surveymonkey.com/s/TEPRuleChange>

And this link will take you to the SLP/provider survey:

<http://www.surveymonkey.com/s/9WZJVMK>

Thank you in advance for completing the survey by September 20, 2013. Once we have the responses analyzed, Jeff and I can provide a summary back to the list. We will also be presenting the information to our professional peers at the upcoming American Speech Language and Hearing Association annual convention in Chicago this November. We hope that together, we can work to make changes that benefit us all and allow us to continue receiving and providing the care that is needed to be safe and successful tracheoesophageal speakers.



Very Special People

This month the Speaking Out question deals with caregivers and the responses were, naturally enough, from the lary point of view. That got me thinking about a very special person in the WW family. Sunny Bakken (and her name certainly suits her personality) has written about her experiences caring for her husband, Ron, who passed away in November of 2007. She found solace in telling their story, continuing to work as a volunteer with WebWhispers and staying in touch with the friends they made here. I only met Sunny in person at the IAL in Spokane this past June and we had an instant connection. I remember reading her moving story "Dancing With Ron" when it first appeared in this newsletter back in March and May of 2008 and I think it appropriate to re-print excerpts here as a tribute to the special people who not only care for us but take care of us when necessary. Someone asked Sunny why she continued to be involved with WW even after her husband died and she replied simply, "Because it is important." Here is one special caregiver's story. I must say this is powerful and graphic but it is also important. Thank you, Sunny and all the other caregivers who face this challenge with us hand in hand every day.

Dancing with Ron

MEETING – June, 2000

Ron was a pretty independent guy, single 20 years, retired Navy Chief. We had both been married before. Both of us said, "Been there, not sure if I want to do it again." Ron was country all the way. Knew all the "old" country music and was a great dancer. I was into line dancing and newer songs but I loved dancing with him and he taught me to two-step. He would ask, "Who's singing that old song?" I would answer, "I'm from Hawaii; not a whole lot of 'old time' country on the radio." And we would laugh and dance.

He had been battling a sore throat for some time and another doctor confirmed he had Squamous Cell Carcinoma on his false vocal cord. Options were surgery, maybe not preserving the vocal cords or radiation and he opted for radiation, a massive amount of 70 treatments. Not being his wife, being unable to talk to the radiologist about problems was difficult. He was a small guy to begin with and I could see he was losing a lot of weight but he fought this until he realized that he could no longer swallow and was living on pain meds. The doc decided he had to have a stomach tube and it was placed as an out-patient procedure. He was so sick that night and the home nurse never showed us about the tube. It was a house of horrors and the next day Ron was in the hospital, where they found his system was shutting down and every level was below normal. He was in for a week and the first evening he was home he had a formula pack on a pole (like you see IVs hang from); it had a machine that was automatically "feeding" slowly. A home nurse came in and showed us, his son who lived with him, and me how to prepare his meds for his tubes, change the formula bag, set the machine. He was on his way to finish radiation and then recovery. But the after effects of the radiation were terrible. No one told us the problems that would crop up. The burns, inside and out, the loss of his saliva glands, dry mouth, the change in taste and eating.

May 2001 we got married. Things were good, even great. Still dealing with the radiation effects, but scans were

May 2001, we got married. Things were good, even great. Still dealing with the radiation effects, but some were good, nothing showing up and we had a good year and a half. He loved road trips. We took one across country to his home state of North Dakota and, from there, went to Minnesota to visit his mom and sis.

Late 2002, his throat was bothering him and he was not eating much, mostly oatmeal, cream of wheat, soup - what he could tolerate. Finally, after much bugging from me he went for a scan in March and the cancer was back in the same place. We saw a ENT and the prognosis was not good. A total laryngectomy was recommended and the surgery was explained. When we left the doctor's office we were both in shock that he was going to have major surgery and no voice.

We headed for a local casino's coffee shop there in Las Vegas to have something to eat, to talk, and to contemplate. While walking toward the coffee shop we saw a gentleman walking toward us with what looked like a speaking device - the same thing the doc had just shown us a picture of. We looked at each other and Ron said, "I'm going to talk to him." This gentleman had been a laryngectomee for 20+ years. He told us not to worry, you may not have a voice, but you can still make yourself heard! Once we got used to the sound of his EL it was easy to understand. Talking to this man must have been a gift, because some of our fears eased.

April 12, 2003, Ron went in for surgery with a voice and 4 hours later he had none. He recovered well and came home 4 days later. Home Care showed me how to care for him. Ron again had a stomach tube but not for as long this time. Soon he could drink the formula. That kept his weight normal and the nutrition in balance. He would still try to eat once in a while - eggs, soup, things like that.

We had a SLP who made visits to the house to teach Ron how to use the EL. She was another gift for us as she started meetings with other laryngectomees in the area, ones she had treated. Soon a laryngectomy club was started and it is still going strong. The club members would go to nursing schools to explain exactly what a laryngectomy was, how the breathing system has changed and what it means to live a life as a "lary". Not all of this was easy for Ron. He was very embarrassed at first to talk in public. People have a tendency to do a head swivel when they hear this strange sound but he got better and more confident. Things were different but we were very happy.

Before his laryngectomy I did some searching for information. I found a wonderful web site, WebWhispers, a nonprofit group, which was founded by a laryngectomee. We both became members; it had an email list and a website for information. A wealth of help and shared experiences from others who have been larys for years was available and this email list had people from all over the world.

August 2004, scans done, as routine. A spot was on his right upper lung and on his tongue. To our horror, the biopsy showed cancer - the same type. Chemo started. Six weeks, once a week. He did well, no sickness and they monitored him closely.

Ron was not a vain man except about his hair. He had dark, thick hair. Before chemo, he got a buzz cut. One day when I came home from work he had a fresh razor and said, you have to shave my head. This was spookier than taking care of his surgery site!

Scans were done again and the spot on the tongue was gone, but the cancer in the lung, while it had shrunk, was still there. Another round of chemo was done. This time he lost every hair on his body. They say the hair comes back differently and I've seen the effects on others. Ron's did, thinner and straight as a stick. He said, "Oh, well, guess I can't be vain about my hair anymore." He always had such a good outlook on everything.

February 2005, scans. Wow, everything looks clear! With cancer, they progressively move the scans out - 3 months, 6 months, a year. Next scan in June, the spot was back on the lung, bigger. It was too close to the area radiated before and the chemo hadn't worked, so surgery was scheduled. Ron was worried more about this surgery than the laryngectomy but the surgery went well, no cracked ribs to get to the site. Hospital stay was not a good thing. He picked up an infection, which kept him hospitalized 3 extra days. He came home, somewhat sore but glad to have it over and, again, started healing.

One of our road trips had been to Southern Oregon. I loved it and so did Ron so we talked of moving there. As long as the snow didn't stick, he could deal with the occasional snowfall. He put his mobile home up for sale in September, not thinking it would sell fast. Within three weeks he had an offer. We weren't ready to move yet, so a short term apartment that would take the dog was found. I continued to work and Ron and his son took a trip to Oregon in October to check out places. The second day he called me at work, found a mobile park, out in the country. Would I like that? It was a small community way out in the country with deer and rabbits. That night talking to him, he had also found a mobile home, a model. I looked it up on the Internet and it looked perfect. Arrangements were made and notices were given. People at work couldn't believe I let my husband pick out a house without my seeing it. That's the thing - we thought so much alike and he was right - I loved the house.

December 2005, we made our big move to Oregon. We got here in the middle of one of the wettest winters they've had in years and were starting to get settled in, when a neighbor stopped by to introduce herself. I will forever be grateful that she did as Sue and Gary (her husband) became my rock later. During the spring and summer, Ron and Gary built a small deck off the carport. We would go out in the morning and enjoy the morning sun and in the late afternoon we watched the sun set over the mountains.

Ron was very lucky getting the doctors he did here in Oregon. The care here is tremendous, a smaller city type of mentality I think. Scans were once again set up as routine. His ENT, Oncologist, Primary - all of them caring. All good.

Nov 2006 - There is a different problem, not to do with cancer. Ron has a blocked femoral artery in his left leg. A bypass is done in December but he didn't get the full use of the leg back. The doctor said, "The bypass could be sitting on a nerve, or a nerve was nicked." This is the only doctor who disappointed us. Ron is walking with a cane and he does ok with it, but it upsets him.

Jan 2007 - Ron can't lift his left arm higher than chest height, some weakness, numbness, in his fingers and the back of his neck is bothering him. CT scan, MRI done to confirm. The cancer is back, now on C2-C3, back of his neck. Chemo will not work on this type of cancer - the same type as before. In the end, the chemo didn't clear up the lung, just vanished for a bit to return. We understand what's next. A Neurosurgeon is recommended, authorizations rushed, and surgery is scheduled for February 8th. Ron never hesitated.

Feb 2007 - Surgery is done and Sue is waiting with me. The surgeon says the tumor looked like someone had poured plastic and created a dome. No way to get it all without possible paralysis. I can't and won't fall apart. I'm seeing Ron in his room soon. He learns of the surgery and the damn stuff still stuck to his spine. He says, "Well, just gotta fight again."

Radiation can be done in this area, so it's set up, 32 treatments. His oncologist says, "You should have a good summer, we'll see what we have in the Fall. Take a vacation, have some fun."

End of May 2007 - Ron's hips are bothering him. He goes from using the cane to the walker. Daily it seems worse. The oncologist sets up an MRI, two hours, twilight sleep, full spine. Next day, we are told the cancer has now spread down his spine, into the nerve endings at the end of the spine called the Horse Tail.

Meetings are set, the oncologist, the radiologist. The best way to attack this is to radiate the whole spine. Ron never wavers, he says "Let's do it" but when we get home, all of this hits us like a semi-truck. If the radiation didn't work on the neck and it spread - will this round work? We have no answers, but to not try is to quit. Quitting is not in Ron's vocabulary. Radiation is started in mid- June.

Pain medication and medical steroids are given but I can still see the pain. By the second week, he became totally disoriented, sleeping too much, talking about strange things, ended up in the hospital again, this time in a diabetic coma. He is not a diabetic and this spike in BS to 800 was caused by the steroids.

This episode also caused his weaker left leg to become unusable. PT came to show me how to transfer him from a

bed to a wheelchair. Four days later, I can take him home. During these days, I was informing Sue and Gary what was going on. They rigged a ramp to get him into the house, had gone to a loan closet to get a wheelchair. Sue told the owner of the park, "We don't have time to draw up pictures but they need a ramp. Gary is buying material as we speak and he is starting this afternoon when it's cooler."

July 5, 2007 - I pull up in front of the house, there is lumber piled and a rigged ramp that got him into the house. Gary tells Ron he'll be back when it's cooler and start on the ramp. Later, I go out and see not only Gary but the owner of the park and three other neighbors working to get this ramp done. A 40' ramp was done in three days! Unbelievable! We are given a gift once again.

Ron's health insurance (Retired Navy) assigned a case worker, a great help, and we got wheels going on various things we needed. Then, she mentioned Hospice and we had decisions to make together. Finally, toward the end of July we met with a Hospice In-Take Nurse. She explained that Hospice is not just for the final stages, but anytime when a prognosis is bad. We decided that having a nurse coming by to be sure things were going good would be a help. We were told that if Ron's condition turned around, we could drop the Hospice program - always be able to go back. We were thinking, things will turn. Ron went on Hospice the end of July. At first as they introduce the "team" we had a lot of visits- chaplain, social worker, the nurse, phone calls etc. When things finally settled down, Ron had a great and wonderful nurse named Lorraine.

The transferring from the bed to the chair got easier. Bed baths became routine as Ron could still sit up, still use his left and right arms/hands and his right leg was still strong. We spent days sitting in the sun, taking walks around the community. At one point, we got an appointment at the VA facility. Because of Ron's wonderful health insurance, TriCare, he never used the VA in the past. The doc he saw had already had the information from Hospice and doctors. This visit was basically to move along with getting a power chair. This would give Ron independence, plus he would get a kick out of it. He loved this chair.

Sep 2007 - transferring Ron is getting harder, we can see some weakness. A Hoyle lift was delivered, it actually looked like something you would hoist a car engine with. Ron felt as if his lungs were being crushed when being pulled up. Lorraine had mentioned a hospital bed a couple of times in the past and it was time. Ron was hesitant but he trusted Lorraine, who always said to me, "He's such a fighter". A bed was brought in, set it up in the living room. Ron's point was why in a bedroom? I totally agreed so he is out here all the time.

Gradually the strength in Ron's left hand was going and then gone. Almost daily, I could see things going. No longer able to control the TV remote, having a hard time holding his EL up to his neck to speak, his right leg was getting spastic. When I could no longer transfer him from the bed to the chair, Sue and Gary were there every morning and night to help with this and during the evening Sue would sit on one side of Ron, Gary on the other while I fixed sheets or even managed to change them. This couple gave up so much to help us, standing dinner dates, meetings and lots of daughter and grandkids visits. Ron always said he had an angel sitting on his shoulder. I believe he was given two more angels for his shoulders in Sue and Gary.

Every time Lorraine came, she would tell me later, "I don't know how Ron is doing this." Transfers were getting dangerous for both Ron and us, Lorraine was checking into a different kind of lift that would work with a hospital bed. She also worried about pneumonia.

- Ron was very agitated. He was seeing people waiting for him, he's never met my mom, but she was waiting. I asked if she had a drink and cigarette and if his mom had her glass of brandy - he smiled. He asked for a picture of Christ, gospel music. A call to Sue, she hustles again - and brings down what he's asked for. He says "Where is the Christmas tree?". He finally went to sleep and when he woke up he said " I don't know what that was about". I asked him if he wanted the tree set up, he smiled and said there was no need. I was outside with the dog, Ron told Sue he was going to die but he wasn't scared anymore. He asked her to pray for him.

Mid-week, Ron is calm, pain patches are working and doses of morphine are keeping him pain free. He's sleeping a lot. Lorraine visits, takes his vitals, oxygen is going down, BP is holding its own. Every time she thinks Ron is not going to make it another day, he proves her wrong. She tells me that because he is a lungectomy, he probably

going to make it another day, he proves her wrong. She tells me that because he is a laryngectomy, he probably won't have the fluid buildup that can cause a "death rattle". Since he breathes straight into his lungs, his body won't have to deal with the moisture from the nose and mouth.

He has some secretions in his stoma and I use the suction. He has been able to cough and move the secretions but now I have to irrigate the area to get a reflex to I can clear the secretions with the machine. He sleeps.

Lorraine comes by, talks to Ron, takes vitals, the heart is working harder to provide oxygen. She'll be by on Friday with another patch. He sleeps. Friday, a new patch is put on, vitals are lower, Ron's breathing has changed again. More time between deep breaths, then several short breaths.

I'm not sleeping much. Since the hospital bed was brought in, I had been sleeping on a roll away bed. Now I grab a blanket and curl up on the couch, listening. The dog has taken to hanging out under the bed during the day. They say animals know. Sue and Gary keep a vigil with me, every morning and evening. Sunday, Lorraine on her day off, stops by to put another patch on, she is making sure he has no pain. Vitals are at bottom. Ron is moving his eyebrows and I see his lips twitch. Is he talking to people waiting? Are they telling him it's ok?

I talk to him constantly, "Bandit and I will do fine, I'm staying in the house you picked out and one we made a home." I tell him I'm going to miss him like hell and back, he is my love and will always be with me.

Monday 11/26/07- I've not slept much during the night. I listen to Ron's breathing and it has changed once again. Much more shallow, a longer time between breaths. I'm working on a blanket, listening, listening. Ron takes a deep breath, exhales. I wait, wait, wait. 7:45 am and my friend, my love, my husband, my world, is now out of pain.

Sunny Bakken



Caregiving

From the list:

Harry Wintemberg, FL - 1982

We all know what a large mountain we have to climb as the patient, but too few understand the adjustment and recovery process a spouse and family goes through. To be suddenly, without training, to be living 24/7 with a person who cannot talk is a challenge no one can properly prepare for. Over my 31 years as a lary, I have not encountered any effective programs that are designed to prepare the spouse or family members

properly for this new experience.

From my personal email:

Max from Delaware - Class of 1993

This e-mail struck me as something we have not read much about recently. Maybe a short inclusion in the next newsletter might be a good reminder for us older Larys to not forget the other half of this equation. The current newsletter really is above the best. Lots of good reading.

Marian Cure, Cedar Creek Lake, TX - 2009

From the beginning of this journey, I was surprised to wake up from an emergency trachea surgery to see all my precious adult working children by my side. How did they get there so quickly. My sweet neighbor had rushed me to the ER with her wig on crooked and fluffy pink house shoes. I could also see my fellow church members and pastor outside the ICU.

As time went by, food began to come in that sustained my caretakers and myself. Adult children took off work to make sure I was never left alone in the hospital and then to stay at my house until I got on my feet a couple of weeks later. One granddaughter slept on the floor by my side in the hospital. A daughter in love took my two dogs into her home and kept them safe. My son, whose voice was calling me to wake up in the midst of such pain. I didn't want to wake up.

A church friend, Fran, started showing up unannounced to force me to use the EL even though I really didn't want to talk. A neighbor, Susan, would call and say, let's practice with your "Charlie," and she would sit on the swing with me forcing me to talk. Another daughter slept by my side when I was in the hospital getting the TEP. I appreciate the friends who call out "She's o.k." when I start coughing at bridge and various clubs. Last but not least, my husband, who never left my side and beat the ambulance driving to another city hospital. He had told the ambulance driver to "catch me if you can". Eighty mph didn't catch him.

People's generous help has given me many a smile and realization that I'm not alone. Thank you all!

Mike Rosenkranz, FL - Jan 1999

Caregiving is a two-way street. From the time of my diagnosis, my caregiver was my daughter, Sue, as all my energy and spare time had for years been devoted to my being a caregiver for my wife, Sylvia. It was an adjustment to change from the giving to receiving of care. It became my incentive to become self-sufficient in what may have been record time. In intensive care, the second time my cannula was cleaned and about to be reinserted, I informed the nurse, in writing, it was not as clean as the first time it had been cleaned, and insisted it be done again. At home, the home care nurse watched me take care of my stoma the first time, and said goodbye, that I didn't need her. Incentive works wonders.

For over 14 years, Sue would care for me following two hip replacements, a bad fall, severe cellulitis and numerous trips to the ER, while caring for her mother when I was unable to. On occasion, I would care for Sue following a few incidents brought about by her having her father's genes. Sylvia is gone now. But I believe she went peacefully, knowing that Sue and I would continue to be caregivers for each other. The incentive is still there.

John Haedtler, New Mexico - 2001

Mine was 11 and a half years ago, I was not able to speak to a Laryngectomee prior to my surgery. But I must say that now I realize just how much my ENT and my SLP did for me to make me aware of my new way of life and what

and now I realize just how much my ENT and my SLP did for me to make me aware of my new way of me and what to expect. They both were very open and blunt at times! Looking back now I would not have it any other way! I can not express how important it is for the hospital staff to work with the patient and their families.

I was very fortunate to have a caring ENT staff and SLP staff to work with me and understand that we all have problems coping with all of this. Maybe this is why I volunteer to speak to new patients and SLP students. We are not just a body having surgery, We are a person! And we are all different so the hospital staff needs to adjust to our needs, not just their's!

Now a days I have been reading of problems mostly caused by Hospital staff not wanting to work with us and try to force us to do things their way, I would love to see them on the other side of the examination! Or tell all ENT's and SLP's to spend one week without speaking? How do you think they will act after a week? I doubt if any will take a try at it? If you're willing I am willing to make a movie of it!

Anita Lewis, Colorado - 2010

My situation was a little different than some of the other people who have gone through this surgery due to cancer. I had throat cancer back in 1999 and was doing well until 2006 when I started developing pneumonia. I had pneumonia 11 times in 4 years and my doctor finally realized that I was aspirating every thing I ate or drank due to the affects of the radiation I went through.

My choices were to either die in less than 10 years, have a feeding tube inserted or have my esophagus separated from my trachea and end up without vocal chords. I discussed my options with my husband, children and grand kids and made my decision to do without vocal chords. I had no idea what I would go through and was not well prepared.

My doctor did have a couple of ladies that were larys come and talk to me after my surgery while I was still in the hospital. We have become good friends and it helped me quite a bit. I do think that pre-surgery info would be helpful but a lot of the medical people have no idea, therefore are unable to help much.

Len A.Hynds, of Ashford, Kent England - 2004 The Speechless Poet.

I have been a Laryngectomee for nine years, and there is no doubt that the first two years were the worst, as I slowly learned to live this new way of life. A new way of breathing, always worried if I was getting enough air into the lungs. Being on Warfarin because of metallic heart valves ten years previously, caused swollen haemeroids to bleed for no apparent reason, which was so embarrassing. The numerous problems with leakage, stoma shrinkage, granulation and all the other minor things. My poor wife, Tilly, must have been driven mad by my seemingly always rushing off to hospital in some sort of panic.

Then at the end of two years, Tilly went down with a serious illness, and after a period in hospital she came home but now went everywhere in a wheel-chair, which folded and went into the car. I became her registered carer, looking after her day and night, and suddenly all my own problems ceased, and I no longer rushed off to the hospital at the drop of a hat. I cared for her for five happy years, and even though immobile, she was always laughing with her mind as sharp as a button, and we travelled far and wide. She loved me doing her silver hair in a perm every Friday night, and I became quite expert at it. She also loved my cooking. I think that those last five years of her life of our 63 years wed were her happiest.

She's been gone now for two years, and having no one to worry about and care for, those silly worries about myself started to come back. But I no longer rush off to the hospital, as she taught me a real lesson in this life during those five years. I had no time to think of petty foolish things, which had appeared so large in my mind. I was the official carer, but she did more caring for me than she will ever realize.

caregiver, but she did more caring for me than she will ever realize.

Jack Craig - class of 1997

After I had my hemi-laryngectomy in 1995, I was feeling lower than whale droppings. My wife brought me to Sedona, Arizona where the vortex system around the area is known for its healing properties. I did not buy into any of that until our last day here.

We stopped off at the last vortex on our way back to Phoenix and as soon as I stepped onto the formation all I could see was lime colored stripes and I was told I was going to live. Two years later when I had my full laryngectomy and long afterwards, that day in Sedona got me through some rough times. Our house now looks out onto that vortex formation that kept me going. I know that sounds like a very large stretch but that is what happened to me and I can only thank my wife everyday for bringing me out here.

Libby Fitzgerald, Sherman, CT - 1998

When I had my lary surgery, I had wonderful support from family and friends and that undoubtedly helped in my recovery and generally positive outlook. I was able to go back to work and also got involved with lary rehabilitation programs. Since that time, I've had several surgeries and treatments related to my rare type cancer and the family support continues to this day. The one person I'd like to recognize above all is my husband, John. About 2 years ago, I went into acute respiratory failure and spent a lot of time in the ICU. After recuperating in the hospital, the thing I wanted most was to go home. However, with needing a ventilator overnight and various other treatments and medical equipment, that would be difficult to accomplish unless someone trained in using that equipment was with me all the time. My amazing husband decided he could be trained if they would allow that. Because he taught biology for many years, he had a basic interest in scientific topics. He ended up spending 2 days and 2 nights with me at the hospital learning all the procedures I would need, practicing them and finally getting the go ahead as my medical caregiver, which was above and beyond his usual support. Coming home had been my goal only made possible by his dedicated love and support.

This man continues to truly amaze me and because my stamina is limited, he does most of the food shopping, a lot of the cooking and all the heavy housework. For a man who really detests shopping, he's come a long way and for someone who just cooked now and then, he's made some very delicious meals. At the end of the day, when he's all tired out, he needs to know how much everything he does has mattered. I can't say enough about what this has meant and continues to mean. I am truly blessed and wish his type dedication for our fellow larys. While most of us won't need this level of caregiving. it is possible and I wanted to share my gratitude.

Dave Aitchison - April 2012

When I was initially diagnosed with thyroid cancer, it didn't sound like I'd need a whole lot of care as the doctors did not give me much hope. With a wonderful medical team, my determination and my wife beside me all the way, caregiving has been a huge part of my life. I was initially discharged on a feeding tube. My wife very quickly got the hang of cleaning the bags, filling etc. as I was still quite groggy. I had a couple of additional surgeries through the winter, including a tracheotomy then, in April I was told I'd need a laryngectomy. The surgery was performed late at night and when I left the operating room, it was discovered that there was no room in ICU so I was put in a room and my wife became my ICU nurse. I slept OK that night but I know Dianne was awake all night wiping mucus, helping me to cough and all the other nasties that go on. In the morning Dianne was complaining of blurred vision. When the regular nurse came in to do her rounds, I wanted my glasses to see what was going on. I tried them on and realized that Dianne had put mine on through the night. Well I thought the young nurse was going to crack up. These old

people even share glasses!!!

One thing Dianne did right from the beginning of my journey was keep a journal of events, When a doctor would talk to us, she'd take notes. Appointments, treatments etc all there. There are even a few notes from my granddaughter written when I was in ICU. We still keep it up as my fight is a long ways from over. Every now and again we read back. Some laughs, a few tears, but a wonderful record of our journey.

Of course, my life has changed but Dianne's life has been turned completely upside down. I would take care of everything - banking, investments, maintenance etc. Now she has taken the reins and is getting to know what is needed and when. My need for a care giver has decreased significantly but her moral support makes the trip much easier.

I commented in a Webwhispers post a while back about the way the local cancer society recognizes caregivers. I don't know how else it could be done. I know I have to drag Dianne out from the crowd when that part of the program starts as she says she just did what is needed - no big deal. I have not mentioned that she was also helping her mother fight esophageal cancer at the same time. Talk about multi tasking!!

My heart goes out to any of you that are going through this alone. Even if you are managing with all the physical things that you need to do, the mental stuff is just as important and with no one to talk to,..... well I can't imagine.

Lynn Foti, Akron, OH - May 2009

My son, James was only 26 years old in April 2008, when I was diagnosed with stage 4 Squamous Cell throat cancer. I talked with him about it, and told him that I was considering NOT doing any treatment, and just letting nature take it's course. He was adamant that I had to go through whatever was necessary, and he would be there to help me along the way. I explained to him that I had been through this with my son Pete in the early 80s, and it is not an easy road. Also, let him know that in spite of treatment, I may not be able to beat this. He would not let that happen.

He moved in with me, and he took me to EVERY single radiation, and chemo appointment, it was a hard battle, I had 36 radiation treatments, and was mostly wiped out by them. He took care of everything. I had a radiation burn on my neck that was quite severe, but he helped me through it all. In April 2009, the cancer had returned, and the only option was a laryngectomy. He was there the entire time, I ended up crashing at the doctor's office and stopped breathing, an emergency tracheotomy was done and I woke in the hospital intensive care unit 3 days later. Two weeks after, the laryngectomy was done, and it was discovered that my esophagus was badly damaged from the treatments, so 3 weeks later my esophagus was rebuilt from my inner forearm. I wanted to give up, was so depressed and tired of being sick, tired of hospital stays, and not being myself any longer. James held me up, he never let me quit, he took great care of me when I couldn't take care of myself, and kept his cool through it all. Without him, I doubt if I would have done any of it, he was a rock, my rock.

He is now 31 and the father of a baby girl, and is showing the same perseverance that he had when I was so sick. I have a good life now, very happy that I am still here to enjoy what is left of it all. I can only credit James. He was the reason I am still on this side of the grass. Thanking God, and James daily.

Bob Kanjian, Clearwater, FL - Lary Class of 2002

Had my surgery in May, 2002, and my wife Carol has been my care giver since day one. Without Caro,I I am sure I would not have accomplished being the person I am today. We have been married 48 years since May, 1965.

Jim Fohey, Oscoda MI - class of 1994

I had my Laryngectomy October 1994, I was and still am single thus I was in a quandary about my care after the operation. My daughter was able to help for a week or two but she had her own life to live with school and a job and lived in Florida. My son lived some 200 miles from me and he also had his life and a full time job to take care of. The doctor had a visiting nurse come in for a while to check to be sure I was thriving as she knew less about the laryngectomy than I did at the time. To help me a lady that worked for me, a friend, pitched in and helped with the inevitable ups and downs we go through. She would allow me to ramble on at times and other times tell me, "Enough. Build a bridge and get over it."

I think having a business I owned, a busy restaurant where I was the head chef, got me back sooner than I would have otherwise as I needed to be there. My manager was great, but in this type of business the customers like to see the owner. My biggest problem was how will my employees, let alone the customers, understand me, but I had become very good with a Servox so it worked out.

The loss of my taste was a problem and at times once back in the kitchen, I had to have someone taste things to make sure they were right as so many things tasted different now. Between my manager, the help, and customers being supportive, I got back to work quickly and adjusted to the new normal. That is not to say there weren't moments where I wondered why, but then I would be told to build that bridge and get over it, as it is what it is. I was very lucky to have a great cast of characters around me. It is hard to realize it has been 19 years since that fateful day when I said my last words before sleep overtook me, never to speak with a full voice again.

Maggie Scott - October 2012

I have been very fortunate to have 'many' people in my life to help me through it:

My two children, who make me laugh by teasing me and not letting me get away with feeling sorry for myself.
My old friends from grade school, who all got together and made sure I had everything I needed for my hospital stay.
My current friends and colleagues who gave me support and continue to do so.
My mom and brothers, who would take my place if they could.

The people at Cancer care, who continue to help with their knowledge, care and compassion which includes everyone there (surgical team, SLP, the radiology department, counsellor, reception, volunteers, etc).
The hospital staff that helped me through the first 10 days.

The people at Webwhispers that can relate, help with problems, give suggestions, let me benefit from their experiences, and give me much needed support.

Strangers that I run into and ask questions and entertain me with their reactions. Haha. I have many stories on that, but I will share one recent one. My daughter and I went to the grocery store and I had my hands full with a few things. The cashier asked me a question, so I put down the items so I was able to press my HME to talk. She looked at me with horror and said 'oh...wow!' I said 'its ok, I can talk. I just have to press this button.' She said 'oh...wow!' again and at this point I couldn't look over at my daughter because I knew she would start laughing. So I paid for my few items and she said it one more time 'oh...wow!...technology!' My daughter and I just about peed our pants laughing when we got out of the store but she was right...wow...technology! I often think how amazing it is to be able to talk without vocal cords!!

The person that has helped me most though is my husband. Without him, I'm not sure how I would have made it through the last year. He has been by my side throughout. From diagnosis to present. He is at every doctor appointment. Was able to work from my bedside at the hospital and insisted being there from morning until night. He has been my nurse, my support, my advocate, my translator, my cheerleader, the person who runs interference for me, the guy i argue with, and my closest friend. He looks at me with the same love in his eyes that he always did.

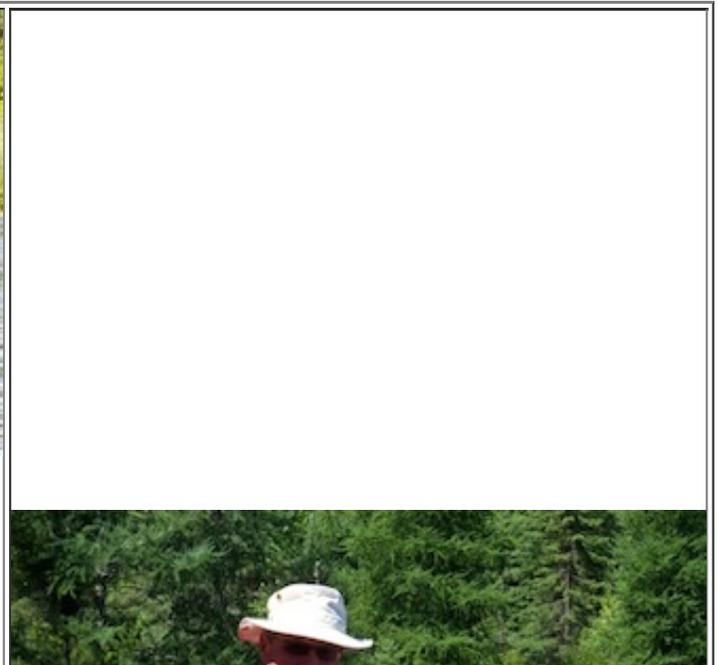
One more story on that subject. The resident took my Trach Tube out the day after surgery early in the morning before my husband arrived. It was kind of a scary experience and I of course wondered what 'the hole' looked like. When he arrived he said 'oh they took the tube out' in a sort of matter-of-fact way with no look of surprise on his face. I asked him to get me a mirror which he did, and I had a look of surprise myself and mouthed the words 'it's huge!'. At that moment the nurse walked in. She looked at him and said, 'Why did you give her that mirror?' To which he responded, 'Because she asked me to'.

So when I think about 'caregivers' I think of him first.

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



Investments in Living





I realize that everyone is different. What is important to one person is of little concern to another. For many of us, the activities we do are central to who we think we are. Runners run, swimmers swim, and hunters hunt. These are often more than just idle pastimes, they often define the participants. To give up on what makes them happy is paramount to giving up on life.

For me water is one of the things that has been central to my being. As a kid when I wasn't swimming I was fishing. When they told me that swimming and canoeing were out of the question, I was as devastated by that as by losing my voice.

I was forty when they rearranged my anatomy. There was a reasonable possibility that I might spend more of my life as a Lary than I spent with a larynx. I decided fairly quickly that I was not going to let the cancer take everything away from me.

It has been almost 12 years now. For those of you who have met me, you know that I do swim still. And when I am at the pool I dive in head first. You also know that I still ride motorcycles, and that I rode to the IAL conventions in both Kansas City, and Durham. I also still canoe and fish, but I forked out the money for the Mustang Survival vest to help mitigate the risks. I have not been sky diving since the operation, but I when my son gets up the nerve to jump, I will go up with him.



I do not consider these foolhardy risks. I consider these investments in living.

I respect the choices of those who decide to become risk adverse post cancer. Everyone makes their own choices but I found the choice to be fairly clear. Cancer almost killed me. If I stop doing all the things that defined me because of fear, then it doesn't really matter that I am technically still breathing, the cancer has already killed me.

I would say that it's just my two cents, but up here we got rid of pennies so I guess it is a whole nickel.

Kevin Berry
Barrie, Ontario
Lary since Sept 12, 2001



GOD WORKS IN A MYSTERIOUS WAY

Whilst preparing to drive off today from a supermarket car park, I saw another car arrive, and a young couple get out, with their small daughter. I thought I recognised the young lady first and looking at the husband, who was dressed in a smart suit, with shock realised that the last time I had seen him, he had been a seventeen year old delinquent, and part of his court punishment was that he was to perform work on behalf of the community.

This had been in 2005, and I had been asked just previously if I could handle a group of juvenile delinquents to build and transform a park in the centre of a square, containing bungalows, one of which was mine. I agreed, and the organiser brought me ten male teenagers and six females, none of whom were exactly happy with the prospect of working for nothing, especially with a supervisor who was a laryngectomee. The first thing I did was to have them all in my rear garden, having tea, and going over the very detailed plans that had been prepared by a team of architects and design artists.

I will not go into detail how I won them over, but we became friends. Part of our job was to make mosaics into the pathways and I showed them pictures of Roman and other mosaics and how they had lasted for nearly two thousand years. I got them to make mosaics to their own design. They were so proud of their mosaics, and even brought their parents to see them and to be introduced to me. We set them into the pathways at set intervals. My own mosaic, was a viking sailing ship under full sail.

We had almost completed our garden which took up the whole of the centre of the square, with seats, trees and flowers, when we had a visit one day from the team of architects and artists who had planned what we had accomplished. I could see many a chest raised in pride as they were complimented on what they had achieved. As the bosses moved away, one of the young artists, an Irish girl who had been introduced as Shavawn, offered to go and bring us all refreshment. She was a beautiful young lady probably about 18 or 19, and all my young men were

absolutely tongue tied.

As she left, one of them said, " Len, please, oh please write me a poem for her."

The girls all laughed, and all the boys grinned, some no doubt wishing that they had asked me first. I quickly wrote a poem and wrote his name on the top, and passed it to him. When she returned he told her that he had written a poem, and she read this:

WHAT'S IN A NAME

*Just one word, but it tells us all,
of pictures painted in Tara's Hall.
A land of heroes, and harps that call,
with Celtic music that does enthral.*

*Just one word, spoken softly so,
with Erin's lilt, so sweet and low.
A thousand years of song does show,
in that one word, said softly slow.*

*Just one word, sounds like Shavawn,
the Emerald Isle saw it born,
spoken with love since Celtic dawn,
said so lovely this September morn.*

Her name of course was spelt Siobhan. He asked for a date and got one. Since then she has transformed his life, a smart young man now in a good job. Looking at them as they went into that supermarket there is no doubt that they are very much in love.

Doesn't God work in mysterious ways.

Bits, Bytes and No Butts!



Frank Klett

Baby it's Hot in Here!

How hot is it?

Many do not realize that the PC or laptop they are using is actually a very sophisticated engineering marvel of

electricity at its finest. Because it is electrical it generates heat, which is its greatest enemy. The components of our modern marvels are weakened and even destroyed by excess heat, so to resolve this, our PC's come with built-in safety switches. Most CPU (Central Processing Units), which are the brains of the PC are set to shutdown the system when the heat reaches a critical point, in most configurations this 70 deg Celsius. The critical temp can vary by manufacturer.

Curing the heat blues - Bob Rankin has a bit of advice for us in this article...<http://tinyurl.com/nyfa8ey>

Heat builds up when the air inside the PC is not venting correctly. The system fans and vents are designed to keep the interior heat from rising to the point of causing damage. Many of us have pets or live in dusty areas that have no respect for the heat in our PC's. I recommend that at least once a year the average user open their PC case and clear all vents and fans of any accumulated hair and dust.

Before opening your case, be certain you have turned off the power and unplugged your PC! The interior of the PC may seem scary, but you won't hurt anything if you simply follow the safety tips in your owners manual and keep your hands off anything you are not certain of. Cleaning the vents and fans can usually be done easily with a can of compressed air available online or at your local PC shop. You can also clean the interior with a small brush using a flashlight, if needed. Depending on just how dirty the interior is will give you a good idea of how often you will need to clean it. I use the beginning of each new season as my reminder since I have two cats.

A word of caution, do NOT use compressed air on any of the CD-ROM or DVD drives insides. You can damage the laser in the units. Only 'dust' the outsides.

Finally, if you have a desktop never put the tower in an enclosed area such as a closet or up against a wall under your desk. Keep it in an open area with about 3-4" all around for best ventilation. If you have a laptop consider getting a cooling pad for it (if you haven't already) and save your lap from the heat, as well as your laptop. Cooling pads are relatively inexpensive and can be had for \$10 to \$30 depending on features. You only need one that has cooling fans and these will plug directly in to your laptop's USB port.

How do you know it's too hot?

There are several options you can use, which are free and very easy to install on just about any Windows based system (I am not familiar enough with Apple products to provide options for their products). I use Core Temp which can be found with a google search and installs in a matter of 2-3 minutes. Most of the options offer an additional layer of heat protection by allowing you to set your own alerts before your system's heat approach the critical level.

Bob Rankin again offers some of his preferred ideas...<http://tinyurl.com/lkd7b5r>

So How do I Know What's Going On?

There are several free programs available to tell you everything and more than you may want to know about your PC and its internals. Some will even develop a catalog for you of all your installed programs and their license numbers (which can be a life saver) so you can have a total listing of everything you have invested in your electronic life.

Bob Rankin again gets the nod to give us his thoughts and product recommendations: <http://tinyurl.com/ku25t7b>

Frank's Hot Tip

Do you find yourself wanting to have a cup of coffee with a favorite friend? Be sure to check into the Webwhispers Forum during the week and join the rest of us in sharing information in a coffee in the morning sort of way. All sorts of "hot" news and tips that make our lives richer and just plain fun. You'll find everything from Lary issues, life lessons, Marlene's greatest tips ever, Mike's wonderful words of wisdom and just plain fun. If you're not using this great little bit of high tech you are missing one of the best things in our Lary life. And be sure to enter our next drawing for a brand new EL 1000 from InHealth Technologies.

FORUM: <http://forums.delphiforums.com/webwhispers/start>

See you in the forum!

Frank

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

Managing Editor - Pat Wertz Sanders

Editor - Donna McGary

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