



# Whispers on the Web

**A Monthly Online Newsletter for WebWhispers**

*December 2021*



# From The Editor's Desk

Greetings and Happy December!

We are anticipating the holiday season here at WebWhispers, and all that comes with it. Our December themes include "Loneliness and Laryngectomees, "Living with Uncertainty", "Coping Strategies." Yes, the physical, mental and emotional struggles of every aspect of head and neck cancer are all too real. But they do not have to be the end of the story.

This month's Whispers on the Web is about so much more than these titles would lead you to believe. It is about what results when we respond to ourselves and others in love. It is about friendship and mindfulness, and the hope that gives light in this season of the year and in our lives.

On behalf of all our WebWhispers contributing members and editors, I wish you and your families a happy holiday season. Take care and stay in touch!

*Kim, Tom, and the rest of the gang  
at Whispers on the Web*



## Whispers on the Web December 2021

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WebWhispers is an Internet based support group. Please check our home page for information about the WebWhispers group, our email lists, membership, or officers. For newsletter questions, comments or contributions, please write to [editor@webwhispers.org](mailto:editor@webwhispers.org)

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## **A REAL Pain In the Neck!**

Given what I've been writing about, prescription drugs and how easy it is to get addicted to them, I am amazed at what just happened to me. As a laryngectomee who is at a desk and on a computer almost always, I am surely accustomed to neck pain and stiffness. Before now, I could usually stand, stretch, hear and feel a release of the tension, then get back to what I was doing. (I just now did this.) I'm back now.

Within the past week or so, I started having a more serious problem with this neck and shoulder discomfort. I'll call it tension as that's what it feels like. Heat helped, but have you ever tried to walk and drive around with a heating pad strapped to yourself? Even seated at the desk using a heating pad, it eventually becomes uncomfortable. One can only fry their skin so much.

Anything else I could do would provide only minor, temporary relief. When two extra strength Tylenol wouldn't do diddly-squat with this pain, I broke down and went to the doctor. I actually had no choice as I literally could barely move my head.

So now, I am a laryngectomee with "computer neck". Tell me something I don't already know. The doctor suggested a muscle relaxer and hydrocodone for the pain until I could get some relief and set me up with a physical

therapist. I accepted the meds, saying that I would try just taking one of each so I could get to sleep at night. I felt like I could tolerate the locked up neck and shoulders temporarily if I could only get some sleep.

Regarding the PT, I've always written off thinking things like they don't how to work with a lary, they're not used to patients with zero muscle strength in the front of their neck, and what works for others would not work for me.

Had I a choice, I would opt for a physical therapist who is in close relationship with an SLP who works with laryngectomees. Now that would be good. Even better would be a physical therapist and SLP sharing the same body. What could be better than that? I was wrong and am convinced that physical therapy will help me with this.

After only the first visit, I could reach further in all directions and do any normal thing involving my neck and shoulders, and without pain. I may take up doing headstands. The DPT is amazing. The second PT session is tomorrow and I've been dreaming about it since I left the first session.

The doctor was spot on with the physical therapy referral. When I left his office I filled the two prescriptions on the way home. I took one or two of the muscle relaxer the next two evenings and again with the pain medication at bedtime for two nights only. Since starting

the PT, I don't need either medication at all. The directions were to take the muscle relaxer every four hours as needed for muscle spasms and the hydrocodone every six hours for pain. What?????

The muscle relaxer was really effective but there was no need to take it that often and the narcotic for pain would have me in total la-la land, incapable of contributing anything to my world. I just looked at the bottles to see how many he gave me. The relaxer supply is more than I would ever need but then I would have no reason to take it unless it is needed. Pretty harmless, I think. The opioid pain medication?

I've had two in the past week. He gave me forty!!! Why? Again, it is easy to see how easy an addiction is to come by.

Be careful my friends. It seems that good, compassionate doctors in their attempt to provide good care, sometimes give us more help than we need.

*Live, Laugh, and Learn,*

*Tom Whitworth  
WebWhispers President*



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## **Balance and Re-Focus**

The holiday season can be one of joy, excitement, and togetherness, but for many people, it can also be a time difficult time with added pressures, busy schedules, loneliness, and anxiety. As we prepare for the upcoming holiday season, it's important to understand how we can support ourselves, along with our family & friends during these busy, and sometimes hectic, weeks and months.

How do we cope with anxiety or stress? What do we do when we feel overwhelmed? What do we think about when we the words "coping strategies"? Simply put, coping strategies are things we can do that make ourselves feel

better. They are positive things in our lives that bring us happiness and allow us to re-focus when we feel bad or down in any manner.

Coping strategies do not need to be large, grand scale, activities, or events. Sometimes, the most useful coping strategies are the small day-to-day things we can do that make us feel better. Some examples may include exercising, spending time outside or going for a walk, listening to our favorite song of type of music, watching a favorite television show, drawing or coloring, reading a book, or just taking 15 minutes for ourselves where we can sit in silence and allow ourselves a safe space to re-focus our thoughts & feelings.

Aside from these more personal ideas, it's also important to understand who we can talk to about our feelings and emotions, whether it be on our good day or a bad day. Having someone to confide in allows us to process our feelings by acknowledging them. Healthy coping starts with acknowledgement.

For some, support groups may be great resources. It can be impactful to hear how other people cope with their struggles and to feel the support and validation from others about our own experiences. Support groups provide a safe space for people to share, learn and support one another. It is an avenue for people to talk openly and honestly about their feelings. There is great power and shared growth from the group experience. The Head & Neck Alliance, Cancer Care and The American Cancer Society are just a few resources to review for additional information about local support groups or you can contact your physician directly to inquire about other support resources.

Another important facet of health coping during the holiday season is to remember that balance is key. As the saying goes, "all things in moderation." Overburdening ourselves with responsibilities of parties, shopping, events, etc. can lead to increased negative emotions. While we want to enjoy spending times with our loved ones, we also need to balance what time we need for ourselves. Perhaps we all need some gentle reminders during the holiday season.

**Accepting imperfection.** We all want things to be perfect, but often times we set expectations very high for ourselves and things in our lives. It's okay for things to not be perfect. It's health and normal, it just takes some practice and getting used-to!

**Focus On What You Can Control.** It's human nature and we all want to be in control of things in our lives. That being said, we have to remember that ultimately, life can be more about how we respond to things that happen in our life.

**Allow Yourself to Feel.** What does this mean exactly? It means that it's okay for you to feel

sad, happy, stressed, anxious and the list can go on and on. As we've talked about, we are only human! And we experience and deal with a lot in life, so it's only natural for us to feel different emotions as we journey through life. Allow yourself some grace, patience, and compassion as you process your emotions.

Keep yourself at the top of your priority list during this holiday season. Pay attention to your thoughts & feelings, remember your coping strategies, and take time to utilize them. Enjoy the holiday season and while you have many things to take care of, one of the most important things to take care of is yourself.

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# *Loneliness and Laryngectomees*

by Aaron Wayne

Cancer warriors face more than just the cancer itself. I see quite a few posts on our support group pages about lost friends and alienated family members, and it makes me wonder. I have had people that I considered to be good friends just leave. I know that laryngectomy changed me, but it did not change me in any substantial way. Not in any way that should turn people away from me. Yeah, I was really grouchy for a while, and I still have my moments, but I cannot imagine how that could drive people away who had previously professed to love me.

When I was first diagnosed with squamous cell carcinoma of the vocal cords, and after my tracheotomy, a friend came to visit. A longstanding friend since he had dated my daughter once, thirty years earlier. He was a friend of the family and was treated like family. There were just the two of us and we chatted. He had been there with me parachute jumping when I made a bad landing and crushed a vertebra. He was at the hospital as soon as I could have visitors. He even cut all my hair off for me to facilitate cleanliness while I was bedridden for two months. This time, he had not been to the hospital. After the operation was when he came to visit.

One of the things that we discussed was why he thought that this time, it was different. Briefly, he told me that the difference was between injury and disease. An injury, even an injury as serious as mine, was one thing but an illness as serious as cancer – he admitted that he just wasn't up for that. I didn't see him at all after our chat, until he agreed to shoot some pictures for the book I had just written. He texted me on

Father's Day and we briefly exchanged a joke or two, then: nothing.

My longest friendship is with a man I met as a boy in Casper, Wyoming. We went through school together until high school, when I left to join the Navy in 1965. After the Navy, Shelley and I moved back to Wyoming, and we renewed our friendship. When I moved back to California we stayed in touch by telephone over the decades and saw each other every few years or so. The last time we were together was the 50th high school reunion in Casper. After I sent him a copy of my book, I stopped hearing from him. I have sent e-mails and Facebook messages, but he does not respond.

Then my neighbor. He was always at my place, sitting in the man cave out back, smoking cigarettes, listening to the radio, and bumming beers. I do not see very much of him these days. We just wave when we see each other, or chat briefly when we are both on the same part of the sidewalk. I know why he's like that, mostly, and it really doesn't bother me because I do know his reasons.

The man that I thought was my best friend moved to England with his wife, shortly after I had the total laryngectomy. The last time that we had together was a walk in the woods, in the hills above Malibu. We stayed in touch with emails until last December, when my book had just been made available. He said that he had ordered a copy, so I waited for him to get back to me with his review, as we usually did review each other's work. I waited in vain. I finally broke down and sent him an email asking him what was afoot. He said that he was really glad



to hear from me and that he had 'tried to push me out of his life' but still often thought of me and would explain his reasons when his life had calmed down a little.

I am lucky that I have only lost a handful of friends. And I hope that they miss me as much as I miss them. I am also lucky that not one member of my family has abandoned me like some fellow warriors have told me about their family members. In fact, most, if not all my family members respect me even more because of the fight that I am putting up.

But I hear others who have had family desert or even spurn them, and I simply cannot understand that. Are those individuals merely weak? Do they find it easier to run away? Could it be fear? Is it because they are reminded of their own mortality? Or is it because they fear MY inevitable death, that they think all cancer is fatal? That they need to say "goodbye"

NOW, instead of watching and waiting for my expected demise?

Obviously, there is ample evidence that it is not fatal: there are hordes of individuals that HAVE survived, that ARE cancer free and are living their best life. But could it be a subliminal fear, fear that they themselves are not even aware of? Why do marriages break up? I read stories of spouses leaving their larys, saying that they are NOT caregivers. Did they forget what they vowed at the wedding? Some single larys have asked "Who will want me with my disfigurement?" My answer: You will find someone, someone who is NOT shallower than a mud puddle in a pothole. I know because it has happened to other lary friends.

I don't have any answers. I have theories and I have my suspicions, but I don't know why some people turn away. What I DO know is that the ones who do stick around are precious!

## Living with Uncertainty

By Noirin Sheahan

This Christmas I am hoping to get home to Ireland for a few weeks. When the pandemic found its way to the UK last year, I had been making a retreat at a meditation centre in Wales. Then the lockdown happened, and one thing led to another and I've now relocated to live here. This had been my long-term aspiration for my golden years and I have to thank the pandemic for making it happen sooner than I expected!

Because of Covid restrictions I haven't been able to get home since and have missed my annual check-ups with the ENT and other clinics. I'm hoping to catch up with these as well as with family and friends over the Christmas break.

But there's still a lot of uncertainty. Will I need to quarantine? Where can I do this? Friends have offered their house as they will be away, but that's a hundred miles away from the hospital for clinic visits and from my friends and family. Would it even be worth going at all if I have to spend two weeks in quarantine? And if no quarantine, is it fair to visit friends when I could be bringing the virus into their home?

My mind keeps repeating these questions, searching for some solid ground to build my plans upon. But there are no definite answers. The question is how to rest within the uncertainty, not let myself get stressed by it all.

Luckily, I have a meditation practice to help me through. Mindfulness trains us to observe ourselves, see when we're getting caught into habits that lead to stress. Basically, it is our reactions to feelings that catch us out. Obviously, we like it when we feel good, confident, happy. Instinctively we then try to amplify and prolong those states, suppress little irritations that get in the way. But human life just won't deliver permanent happiness. What we learn through repeated observation is that it's easier on our system to relax, let those lovely states fade when we're no longer feeling good, perhaps we're irritated, angry, impatient.

To our surprise we learn that it is also possible to relax with unpleasant states like irritation,



anger and impatience. Once we're observing them mindfully, they don't lead on to cascades of negative thoughts about how rotten the world is, or how useless I am. They are simply experienced as physical sensations, unpleasant ones like tension and burning. Once we get the hang of observing negativity, we can even enjoy their raw energy. In this embrace, the anger burns out.

It's the middle ground of 'no particular feeling' that's often harder to bear. There isn't any draw towards these, they seem irrelevant, not worth bothering about. It's hard work persuading ourselves that there is something worth attending to in simple experiences like sitting still or walking.

Thinking about Christmas brings me through the full range of feeling. Thoughts of home and meeting friends makes me happy, while the Covid uncertainties bring me down. Between the extremes I'm in that middle ground where all my plans subside into 'don't know if that will work'.

When I can admit that I don't know how Christmas will work out, another form of knowing takes centre stage. Body awareness tells me that I am alive and breathing right now. Can I let that knowledge be enough? The fleeting sensations of the breath coming and going, those sensations I usually ignore, think irrelevant by comparison to all my plans and worries – could they actually be my source of stability and strength?

I hope I'll get home, get to meet family and friends, get to my clinics. And I trust that if none of these work out, I'll still have my good friend, body awareness, to wish me a happy Christmas wherever I am!

# THE SILENT PARTNER

My First Year as a Laryngotomee

## Chapter 9: GAG ME WITH A...

### GAG ME WITH A...

My first TEP lasted two weeks before it developed a leak due to a yeast buildup on the valve. This is fairly common and I was given a replacement. When the replacement also sprung a slight leak and I went to have it replaced with an upgraded version coated with silver oxide to help minimize the yeast buildup, the pathologist gave me some green colored water to drink while she watched to evaluate the extent of the leak. When I chugged the last of the water, about half a tablespoonful of it backwashed up through my nose and came out into my face mask. (I have had a slight difficulty swallowing since the surgery.) So she sent a message to the doctor who did the initial puncture for the TEP and I followed up with a message of my own a few days later. After the doctors and the speech pathologist conferred, it was decided that I should get another type of swallow evaluation called an Esophageal Manometry Test, where a motility nurse sticks a long, thin catheter up through your nose and down your throat while you are swallowing to help it down. The tube contains up to 36 pressure sensors spaced along its length at 1 cm intervals to measure your esophageal function.

In high school, I had been entered in science fairs during both ninth and eleventh grade. (I still have the ribbons: second place in my division at local in ninth grade and fourth at regional in eleventh.) I was starting to feel less like a professional patient and more like a science project.

As usual, my vitals were taken before I was shown to a small room, slightly smaller than a walk-in closet, where the procedure was to take place. It was your basic single purpose room, painted a color too neutral to give a

definite name to. It had an exam table, a chair, the equipment, and a sink. Above the sink was a cabinet, and beneath the cabinet, a sign: "WASH CLEAN HANDS ONLY"

My nose was anesthetized with a squirt of Lidocaine first and then a liberal application of the same by means of a long wooden swab. It had to be left sticking out of my nostril for twenty seconds or so while it took effect. Looking down at it I immediately thought of Pinocchio. When I was quite numb, I laid back and he lubed the tube and began gently feeding it up my nose and down into my stomach, with me swallowing continuously to assist its passage.

Then, using a syringe identical to the ones I had used to feed myself through my g-tube, he gave me small mouthfuls of saline water to swallow at short intervals. That was followed by doses of a thicker liquid, then by small bits of cracker that I chewed and swallowed. Then he sat me up and we started again in that position. Finally he pulled the tube slowly and gently out and I was done.

No matter how unpleasant all of this may sound – it isn't. While it wasn't very pleasant, I was genuinely surprised at how not unpleasant the procedure was. And now with this new sword swallowing ability and the miming skills I had acquired when I was mute I'm ready to join the circus!

9-5-20: It looks like this section is going to be longer than I had thought. It has been 364 days since the 'awake trach' and yesterday I got the swallow test results. I also received an e-mail notification from Atos regarding a seminar on this very problem. Apparently tracheostomees often have swallowing problems after surgery. Just one more of the 'Things They Should Have Told Me'.

Last night I found out that I can scream. I wasn't very loud, but just trying was cathartic. I couldn't pull out my hair (too short) so I grabbed my ears and busted loose. Even with my HME in place, I still could be heard at a short distance and there was no mistaking what I was doing.

Another milestone, if you can call it that: Alexa answered to my new 'voice' for the first time, and asked for my name! I've always been suspicious of Alexa, always listening. Perhaps 'she' has been eavesdropping all this time and finally reasoned that she was hearing a human speaking. Maybe it's not as far as a milestone, but certainly a step in the right direction.

Dr. Chhetri couldn't see me until October 13 and my TEP is leaking again, so it's time for another replacement. This time Ms. Lanciault thinks we should try yet another type of TEP.

9-17-20: This visit to replace my TEP was with Ms. Christie Hall. I'm not too sure that I like this one. The 'handle' has to remain attached in this model, and the valve is stiffer. The reason for not removing the attached strap wasn't made clear, but the stiffer valve is supposed to be less susceptible to leaks. Unfortunately it also makes it a little more difficult to use for conversation and I hadn't gotten real proficient with the old model yet.

9-18-20: I went to Nvision today for an assessment prior to another procedure on my eyes, called YAG, to clear up some fuzziness in my vision. It's a good thing, writing has been very difficult lately. While there, the doctor asked when I had quit smoking. That got me to thinking, and I came up with a new design for an HME decoration. Years ago I had some 'No-no Stickers' made up, the red circle and bar design everyone is familiar with on a clear plastic adhesive sheet that could be applied over any picture to make a sign banning whatever the image was. One's mother-in-law for instance. So I came home and made a NO SMOKING pictograph and stuck it on a fresh HME. And just for the record – I quit smoking on August first of last year, cold turkey. But I STILL crave a cigarette once in a while.

9-22-20: I'm really not liking this newest TEP. Not only does the strap collect more gunk, it also makes it a little harder to clean. On top of that, the valve doesn't always work due to clogging or whatever, and I can't always use it

for its intended purpose – to talk!

9-26-20: The TEP strap will not stay taped up. It pulls loose and gets in the way. Today, I showered before I cleaned my stoma and the strap got stuck in my shower snorkel, thereby diminishing the flow of air. Not really dangerous, just irritating as all get out!

10-2-20: This TEP is now leaking. It would appear that two weeks is about it for me wearing one of these things. In some patients they can last six months or more. Maybe when we get this swallowing problem licked, they will last longer, but who knows?

Now I have a choice of plugging the TEP with a number 10 catheter tip and going without my voice when I want a glass of water or put up with the status quo until I see Dr. Chhetri and drink thicker liquids for the time being. I think I still have some thickening powder around here from some months back that I can use for water or OJ, but I reckon come Saturday night I might have to switch from Coors to Guinness Stout.

Communication with Shelley is becoming more and more difficult. Shelley had a few small strokes this spring and that has affected her ability to read. So when I can't use my TEP, I have to write things down. Unfortunately, this only works if I print very large, short words. Even that won't work if what I am trying to tell her is even a little bit complicated. She has also somehow acquired the habit of mumbling or talking quietly enough that I can't hear her. This is exacerbated by my diminished ability to hear. Furthermore, she asks questions I could answer with a nod, a shake of my head, or a shrug if she was looking at me. (She also tries to talk me when I am in another room at the other end of the house, but she has always done that.) And then when I get frustrated and a little short-tempered, she thinks that I am mad at her.

10-6-20: I went to the endocrinologist yesterday for a follow up. She is prescribing thyroid medication and vitamin D therapy. My blood pressure was up a little and she asked if I checked at home – yes, but not as often as I

should. Right after I was released from the hospital I took a reading every day, as well as noting my weight and sometimes my pulse rate and/or temperature. As of yesterday, my blood pressure and my weight had both gone up. 'White Coat Syndrome' only accounts for some of the blood pressure elevation, it has gone up a little at home also. As for the weight increase, twenty pounds in two or three months is mostly due to the sequestration. Of course all those cookies I gobble during prime time aren't helping any. I much prefer weighing less than I do right now, but I am told that the weight gain is making me look healthier. But I know being overweight is not healthy. My ideal weight was twenty pounds ago.

10-8-20: Today we each had a meltdown. I was cooking breakfast and Shelley was on the telephone trying to sort out my medical appointments when I got frustrated with trying to cook and communicate at the same time. Shelley mistook this for anger at her and ran into the bathroom sobbing and crying that I hated her. This triggered more frustration and anger on my part. Not being able to talk magnified everything completely out of any reasonable proportion. I broke down and sobbed. I tried to talk but ended up tearing out my HME and hurling it across the room. This has got to be the hardest thing we have had to face since the surgery. I know we will be able to get past this but I don't know how. In order to try to explain, I wrote a note to Shelley and a copy of that note follows. I only wanted to cook a nice breakfast, but that's ruined now. The bacon is overcooked and cold and I just don't feel like eating at the moment, much less cooking. I am starting to feel a sense of defeat or of helplessness. I haven't mentioned the pandemic much because this is just supposed to be about the laryngectomy and I just wanted to tell that story. A laryngectomee reading this after the pandemic has been brought under control would be having a much different experience than I am.

I have contacted Dr. St. John's office and requested a referral to Dr. Dafter\*. Dr. Dafter is

the psychologist on her team, whom I mentioned earlier. I am not really prone to depression and never have been, but this year has been...

Well you know, 2020. And I need to have someone I can talk to, even if I have to do it in writing. My male best friend moved to England with his wife, so once or twice a year while they are here on holiday, I have his ear for a few brief hours. Shelley is my other best friend, but I really can't talk to her as well as I would like.

I confess to being a cynic, but I certainly do not consider myself a pessimist. I do get to feeling pretty dismal at times, but after I have been able to go off by myself and give it some thought and indulge myself in a little introspection, I start feeling better. I woke up this morning craving bacon, with eggs fried over medium in a little of the bacon grease. So at three o'clock I started cooking breakfast again. As usual, Shelley and I played backgammon. While we ate the kitten grabbed my toe under the table and I was laughing again, the first time since nine o'clock.

10-17-20: Monday I had my left eye done and can now drive again. I was waiting for this so that I could go to the DMV and renew my license, but when I went on the website, I found out that everybody got a one year extension, so I'm good until next July! Tuesday turned out to be a little disappointing. I thought I was going to be seeing Dr. Chhetri about my swallowing problem but it was just another swallow test that he ordered to compliment the manometry I had. I did get my TEP replaced though. Ms. Lanciault decided to try a different size this time and I didn't like it that much at first, but it seems to be working better than the last one now that I've gotten it broken in. This swallow test involved an x-ray machine (or something like an x-ray machine) and barium. While the machine took pictures, I swallowed. First was a thin barium liquid, then barium nectar (slightly thicker), followed by barium pudding, and finally barium pate on crackers.

10-21-20: Today it has been one year since the

laryngectomy. I thought that this narrative would be finished today, but I still have a sonogram, a biopsy, and an MRI coming up in the next two weeks. I will see Dr. St. John on November 3, and she will let me know how this story will end.

10-26-20: The new TEP is still working and seems easier to use than the previous ones. I am talking a little better with it and even managed a weak squeak of a whistle yesterday!

10-30-20: Yesterday I went in for a sonogram and biopsy of the lump under my chin. I had the sonogram first and the result told the doctor that I didn't need the biopsy! I have to have blood work done and one more MRI on Monday. On Tuesday, I have an appointment with Dr. St. John. However, I still have not had a reply from Dr. Chhetri's office, so I can't be sure that this story is finished yet.

While assisting with the cooking this evening for the two of us and six guests, the shortcomings of using a TEP really came home: we have a very small kitchen and someone is always in someone else's way, and I have to elbow people out of the way because I can't talk with my hands full. Seven o'clock: Dr. Blood, a Fellow from Dr. Chhetri's office called to advise me that they are referring me to Dr. Conklin, an esophageal specialist.

HALLOWEEN 2020: I made yakisoba for our weekly pinochle game with Jim & Barbara. We had a bowl of candy by the front door just in case, but had no trick-or-treaters come to the door. Bones was ready to ride, wearing his black mask with the dancing glow in the dark skeletons on it, but there wasn't anywhere to go. My 'costume' this year consisted of a very nice black dress shirt that I may have worn maybe two or three times since I bought it and a realistic looking fake eyeball glued onto my HME. My cloth mask was also black, with silver cobwebs on it.

11-2-20: I'm going in for more blood work today, then an MRI of my neck. In honor of the MRI, I will be wearing my HME decorated with

the black and yellow radiation warning sign. Whether or not anyone will notice remains to be seen. (Yes, I'm aware that an MRI doesn't involve radiation.) UCLA is a wonderful medical center with great people and parking that is totally screwed. You need to show up fifteen or twenty minutes early just to be sure that you have enough time to find a space. Then allow an extra fifteen to twenty when you leave. First you have to find a working walk up kiosk to pay for parking. When all of the walk up pay kiosks are down you have to pay at the exit, which causes a traffic jam in the rest of the lot. Then there is always some turkey that can't do the drive-up payment and a line of waiting cars starts to block the intersections. They just increased the minimum parking fee to fourteen dollars (apparently just as unlucky as thirteen was).

The MRI was not what I expected. I had to wear another contraption similar to my 'fencing mask' to immobilize my head and neck, this time with headphones (but no music) and a mirror so I could see my toes. I was in the machinery longer than I thought I would be compared to previous scans I have had, so I slowly counted to myself again. This time I got to four hundred eighty for the first part and only two hundred something for the second part.

The machinery made a lot more noise than a CT or the radiation chamber. At different times it hummed, it whirred, it whined, it made a sound like a jackhammer, and once in a while I heard what sounded like someone walking around inside the machine. I was required to strip down to my skivvies and socks then given pajamas to wear even though they were only scanning my neck.

11-3-20: Boy, did I ever !!!! that up! My appointment with Dr. St. John was at 1015 and I thought it was at 1430. My new appointment is on 11-10 and maybe after that visit I can finish this story.

11-7-20: Another Saturday pinochle night and while I was cooking the spaghetti sauce,

I noticed the faint smell of garlic. There are some things that I can smell from time to time, the first one I noticed was a few months ago: ripe bananas. Strangely, I can't smell the rather pungent odor of menthol and camphor in the pain relieving gel that Shelley lovingly slathers on my right shoulder, but I can feel it in my airway. Smelling the garlic, however faintly tonight, reminded me of something I had read about that I thought was called 'reverse smelling'.

After looking that up on my tablet I found that something similar was also called 'backwards smelling' in an article in Bon Appetit magazine (May 17, 2017) and in a PBS story that aired back in May of 2017, but both were about smelly cheese and involving people who could already smell. For us larys however, it is called reverse smelling.

According to the Journal of the Royal Society of Medicine Volume 78, June 1985 this is described as follows: "Manipulation of cheeks and jaw with the mouth closed causes rapid volume changes in the buccopharynx such that increases in volume cause inflow of air through the nose and decreases of volume result in the reverse. This 'artificial sniff', although less powerful than a conventional sniff, presents the vapour stimulus to the olfactory mucosa." They refer to this as 'buccopharygeal sniffing'(BS) and the effectiveness is measured by 'maximal inspiratory sniff rate' (MISR). If I did the BS correctly then it doesn't work very well for me.

Then there is the 'polite yawning' technique formally called a Nasal Airflow-Inducing Maneuver (NAIM) which consists of an extended yawning movement with simultaneous lowering of the jaw while keeping one's mouth tightly closed, repeating several times if necessary. This comes from JAMA and sounds to me like the American version of explaining reverse smelling and sounds easier to do.

In any case, my experience would indicate

that using my TEP to talk will sometimes result in detecting an aroma or odor if I am close to the source, like bending over the stove. In any case, I could just open my mouth and use a small battery powered fan to blow the olfactory stimuli into my nose.

Two other places I've found to look this sort of thing (and many other things for us larys) are: [practicalslpinfo.com](http://practicalslpinfo.com) and The Laryngectomee Guide from the America Academy of Otolaryngology and authored by Itzhak Brook, MD, MSc who also is a laryngectomee. It is available through Amazon in book form or Kindle edition. I just ordered the book\*\*. It looks like it is a serious and scholarly version of what I've been trying to write.

11-10-20: Dr. St. John was very pleased with my progress (and pretty happy to get a draft copy of this booklet). She wants one last PET-CT scan, but I'm going to send this manuscript to the printers, so the story continues but the book must end.

\*Dr. Dafter: I mentioned Dr. Dafter earlier while explaining how I became a 'Professional Patient' and I'm afraid that I may have taken his importance to the expert team assembled by Dr. St. John a little too lightly at the time. Dr. Roger Dafter, PhD is a licensed psychologist who is on Dr. St. John's team to help cancer and other medical patients. His specialty is the role emotions play in mind/body healing.

\*\*11-12-20 The Laryngectomee Guide just arrived from Amazon and I could not be more pleased. There is no topic of concern or interest to me that it doesn't cover.



*~This column first appeared here in 2010. We've reprinted it in previous years and a number of you wrote in saying how much you enjoyed Len's holiday story, so it is now a Web Whispers tradition- maybe our own "It's A Wonderful Life". ~*

## **A Christmas Story**

The onset of these darker evenings, and the thoughts of Christmas which is now only a few weeks away, remind me of those halcyon days of childhood which are so strong in my memory. I was seven and could only dream of wonderful presents. I knew that mum and dad could not afford what I so dearly wanted, that wooden fort in the toyshop window. For two years I had stood outside, just gazing at it, and those marvellous Scots soldiers in their kilts, red coats and white helmets lining the ramparts. The youngest of seven children, with very little money coming into the household, you soon realise that your own personal wants are not even mentioned, so I never told anyone of my heart's desire.

Let me convey you to our darkened bedroom on the evening of that Christmas Day. My two brothers were asleep. I lay between them in our large bed, and being the youngest, I had to sleep at the opposite end between their feet. Charlie was always on my left, and with him being shorter than Alf, I could get a clear vision over the top of his covered feet, so I always slept on my left side. What a day it had been. I loved Christmas; it was always so exciting. And this had been one

of the most thrilling days of my life, and as it was drawing to a close, we had been sent to bed.

I lay there, looking over Charlie's covered feet, at the faint glow at the window which was coming from the gas lamp outside. Even Jack Frost knew it was Christmas. He had made his own decorations on the inside of the glass window panes, as our breath froze into the most wonderful shapes. They were like sparkling diamonds, and I wondered what part of that pattern was my own frozen breath, and if it was forming those intricate close knit patterns because we were brothers.

Before falling asleep, Charlie had blown out our candle, but I could still see my present in the faint glow from the window. It was the wooden fort, with its ramparts lined with those Scottish soldiers. I could not believe it when I had been given it earlier that day. I used to stand outside that toyshop for such long periods just gazing in, that nearby stall holders, wearing mistletoe in their woollen hats, and faces glowing from their acetylene lamps, would nudge each other, and say to me, " You'll get it if you're a good boy".

Well I was good, or so I thought, but would miserably say to myself, ' I can't even tell them what I want.' The man from the toy shop came out and spoke to me on a few occasions, and I asked him what regiment it was, and after peering in, he said, " Why, they're the Camerons, a Scottish Regiment and they're fighting in a country called Afghanistan right now."

My sister Kit had read us several stories written by a man called Kipling, and one story was about those Afghans sweeping down the Khyber Pass to ravage and ransack India, and they had been doing this for hundreds of years. As he spoke, I was with that regiment marching up the pass, kilts swirling, bagpipes playing, returning the fire from the mountainsides.

When Dad had carried that fort into the parlour with the soldiers lining the walls, I could not believe my eyes. They were the Camerons. I was so filled with emotion that I felt tears coming into my eyes, but brushed them away, knowing that boys don't cry like girls, but wondered how on earth did they know what I had wanted. Mum said, " The shopkeeper told us what you wanted, and how you had been so good for business just gazing in. He sent you these as a present." She produced another box with a further 12 Camerons inside.

Dad said, " There was this one who had a leg broken in the shop, and was going to be thrown away. I told the shopkeeper that you might like him." As I took this one, the one with the leg missing, I realised that here was a hero. He had lost his leg fighting those Afghans. I looked at

my fort in the faint light and there he was, in a position of honour standing to attention in the uppermost tower.

British troops are still fighting those Afghans all these years later, and now they have their American colleagues with greater fire power to stand beside them.

It was the following summer, the exact circumstances elude me, but during a visit to our home by some relation, I was given a whole sixpence to spend, and I went to the market to buy something I had long coveted. As I crossed the road to enter the market, I saw a man sitting on the pavement with his back resting against the wall. A crutch leant against the wall beside him.

The poor man only had one leg, which was stretched out in front of him, and beside it a soldier's Glengarry cap which had a few coins in it. The poor man was begging.

As I was passing, he picked up the cap to take out the few coins, and I saw the most beautiful silver badge on it. I read the word Camerons. I put my sixpence in his cap.



*We'll see you in the New Year!*

