Whispers on the Web
A Monthly Online Newsletter for WebWhispers

August 2019

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My, How I’ve Grown

As a child, I remember encountering friends of the family and relatives who had not seen me in a while. It seems like every single one of them exclaimed “My, how you’ve grown”. It happened like clockwork, so my brother and I came to expect it and chuckled when it did. The look from Mama that followed our muted giggling, would alter our behavior for the remainder of the day. I was often tempted to respond with “did you think I would shrink?”. Of course, I didn’t dare say that and didn’t even think about it for very long for fear of what would surely happen to me. With Mom nearby, I could hear the sound of her backhand swishing through the air on its way to take off my head. She is a Korean War era army veteran and never had to remind us of that. With Daddy, my life would just be suddenly shortened.

One day, in first grade, the tag to my Healthtex shirt was sticking out so that the kid behind me could see it was size 3X, not the typical size 6. Obe was my next door neighbor and friend so I was quite bothered with him announcing my itty bitty shirt size to the class, spurring laughter from what seemed like the entire world. I had locked myself in the bathroom one day while wearing that shirt, red with horizontal white stripes. The teacher claimed she liked it so much that she was going to take it off of me and keep it. It had been my favorite shirt and I believed her so I high-tailed it to the potty where I remained until my mom arrived to take me home, as moms did in those days. But eventually I did grow, leaving boot camp a strapping young lad of five feet seven and a half inches. That was way before age and gravity shrunk me nearly a whole inch. But this is not the kind of growth I really have in mind.

B.C. (Before Cancer), I did not think of myself as arrogant, insensitive, or judgmental with regard to other people, though I was. Most people thought of me as a really nice guy but they had no idea what ran through my mind at times. I could see a beggar on the side of the road, you know the kind with a nasty cardboard sign saying “Need money for food”. Yes, I would feel sorry for him but would likely ponder why he didn't just go get a job and buy his own damned food. Now I would be far more inclined to immediately wonder how he became homeless and hungry and what we should be doing about it. Something began his misfortune and there is the root of the problem.

An obese person would be in my way in the store, scooting along in one of those jazzy power chairs, blocking the entire aisle and I couldn't get my toothpaste. Somewhat in disdain, I would wonder if the power wheelchair was needed because of the obesity or was actually the cause of it. Yes, I could be that bad. Now, in the same scenario, I would be far more likely to consider her plight. It’s bad enough to be in this God-forsaken Walmart. Being in that thing has to make it worse. I’ve been there, waiting in the car, until I finally got up the guts to drive my own way through the store, chasing my wife and caregiver as onlookers undoubtedly considered how I got myself that way.

Yes, I have definitely grown. What is more important is how I have evolved. You have, too. A few decades ago, we were encouraged to be tolerant of one another. Was tolerating other people actually a good thing? Then we graduated to acceptance. Okay that’s a little better, but what a lovely thought- I accept you? We have come a long way. I surely have! We can do better. Let’s grow beyond tolerance and acceptance, learning to honor and embrace our differences, pimples, powered wheelchairs, roadside hunger signs, warts, different voices, stomas and all.

https://www.youtube.com/watch?v=ofhw0IWPVZc

Enjoy, laugh, and learn,
Tom Whitworth
WebWhispers President
It bears keeping in mind that effects from radiation therapy may occur days, weeks, months and even many years after the treatments have completed. The WebWhispers library and prior VoicePoints columns are good places to refer to for additional information on specific issues such as xerostomia, lymphedema, eating and menu planning. Useful links are provided below.

We want to hear from you, our readers! What are some of the other long-term effects you (or your patients, loved ones) have experienced from radiation therapy, and what has helped along the way?

Long Term Effects of Radiation Therapy

The shock of the diagnosis has long since passed, and with a combination of personal strength and grit, alongside the support of family, friends and a team of compassionate nurses, you have found a way to endure 7 long weeks of radiation and chemotherapy. You rang the bell on the last day of radiation and kept the mask that secured you to the table during each treatment. Your taste may even be starting to return and the thick and rope-like saliva may be starting to thin. Your nurses, doctors and swallowing therapists greet you with smiles and celebrate the great response to treatment.

Family and friends praise your fortitude and rejoice at your life. So why, you wonder, do you feel so far from normal? So far from cured? So far from where you imagined you might be? It is inevitable that lasting effects from cancer treatments will continue to be a part of your daily life. This is true whether the primary treatment used to treat the cancer is surgery or radiation. It seems obvious that with surgery something is removed and the loss of tissue will result in differences in speech, swallowing or breathing. But how would radiation, which avoids the invasive removal of tissue, affect one’s voice, swallowing and breathing? After all, isn’t radiation intended to only affect the cancer cells? In actuality the effects of radiation can be divided into short term and long term manifestations. The magnitude of these effects varies from person to person. It is easier to counsel patients about the short term side effects of radiation because they are more predictable and more likely to subside with time.

A common early side effect of head and neck surgery and radiation is lymphedema. This refers to the accumulation of fluid outside of blood and lymph vessels and it presents as swelling. In many cases this will improve to some degree with time, but it usually doesn’t completely resolve. If the excess lymph fluid is present over a longer period of time it can result in hardening or fibrosis of the tissue. Soft tissue fibrosis gives the characteristic “woody” quality to the skin and soft tissues. There is a loss of the elastic qualities of the tissues and movements such as opening the mouth, turning the neck and swallowing become constrained and compromised. Lymphedema can present both in the external soft tissues of the neck with swelling, tightness and immobility of the skin and muscles as well as internally with swelling of the throat and voice box.

For many individuals the external swelling is quite prominent below the chin and occasionally it is referred to as a “turkey neck.” Physical and occupational therapists with training in deep tissue massage and myofascial release offer a tremendous service to patients after radiation therapy.

In my practice I routinely recommend their services and patients almost uniformly report that they find benefit in learning these massage techniques. The swelling present internally explains, in part, why radiation can affect swallowing, speech and breathing. Longstanding swelling progressing along a continuum to fibrosis affects the fine muscles of the throat that are essential to swallowing. The old adage, “If you don’t use it, you may lose it,” seems to be pertinent to swallowing function with radiation. Historically, the approach to dysphagia was to address it after treatments were complete and the effects had set in.

At present there is an emphasis on engaging in swallowing exercises during therapy to keep muscles as strong and supple as possible. In addition, modern radiation techniques are better able to spare important uninvolved structures such as the constrictor muscles for swallowing and the parotid glands for saliva production. There has been improvement in the recognition of late onset
swallowing difficulty. Speech and swallowing therapists will work with patients over many visits to improve oral intake and discontinue the use of feeding tubes as soon as it is safe.

Surgery and radiation for head and neck cancer can have lasting effects on several important functions of the mouth. The normal jaw range of motion can be substantially diminished resulting in a limitation in mouth opening referred to as trismus. Trismus is defined as a decrease in the opening between the front teeth (incisors) to less than 4 cm. Modern radiation techniques have decreased the incidence of trismus. Not only does trismus affect a patient’s quality of life, it also can impact a patient’s ability to eat, chew, speak and maintain oral hygiene. Jaw stretching and range of motion exercises are typically used to improve a patient’s range of motion. In rare occasions there are surgical procedures that can be done to release scarring and improve a patient’s range of motion.

Another oral ailment common after radiation therapy is xerostomia. A decrease in the production of saliva leads to unpleasant dryness in the mouth that can result in sores, difficulty speaking, swallowing and impairments of sleep. It can also lead to chronic yeast infections and dental decay. Teeth tend to decay in an acidic environment and saliva helps to neutralize this acidity.

Regular dental evaluations, judicious use of fluoride in the form of specialized toothpaste and fluoride trays, as well as aggressive oral humidification are essential to maintaining dental health. The decrease in saliva can also contribute to taste changes. While chemotherapy may often cause temporary changes in taste, radiation can have more lasting effects on taste. This depends upon the dose of radiation that is delivered to the tongue.

While taste disturbances tend to diminish with time there have been long term studies showing persistent changes at 7 years or longer. This can affect a patient’s ability to maintain adequate nutrition and has an important impact on quality of life. It is important that patient with taste disturbances maintain oral hygiene and get occasional nutritional evaluations to be sure they are not deficient.

The palpable fatigue that weighs many patients down during their treatment unfortunately doesn’t lift right away. The fatigue may be physical, mental and/or emotional. If can affect relationships and work productivity. Providers should be sure to discuss this with patients. Sleep is often compromised after treatment and this can be due to dryness of the mouth, pain, obstructive sleep apnea or anxiety. Patients should be informed on sleep hygiene and measures such as sleeping with the head of the bed elevated and use of a humidifier. They may need to be evaluated for obstructive sleep apnea which can be treated with continuous positive airway pressure (CPAP). Fatigue may be aggravated by anxiety and depression and this may warrant an evaluation by a trained mental health professional. In addition, the thyroid gland can be affected by radiation and regular thyroid function testing should be undertaken and supplementation given when appropriate.

While the heavy lifting may be done there are important measures patients and health care providers must keep in mind to address challenges that stem from treatment. In some ways, the radiation and chemotherapy used to treat head and neck cancers is just the beginning. A host of dedicated health care professionals in speech and swallowing therapy, occupational and physical therapy, dentistry, and internal medicine should be enlisted to maximize every patient’s quality of life during and after treatment.

Aaron M. Weiland, MD, Assistant Professor Section Head and Neck Surgical Oncology Division of Otolaryngology – Head and Neck Surgery; University of Wisconsin School of Medicine and Public Health, Madison, Wisconsin

Xerostomia http://webwhispers.org/library/DryMouth-Xerostomia.asp

The Importance of Dental Health https://www.cancercare.org/publications/269-the_importance_of_dental_health
Let’s Talk

When WebWhispers started the Speaking Out column back in May 2011 we had no idea it would become so popular. To be honest, back in those days we struggled to get folks to even let us know they were reading the newsletter, let alone respond to it. Speaking Out changed all that. Folks who never wrote in to the WW daily list sent us great comments and forwarded valuable information. Earlier this year when Jack said he had no more questions for SO he passed the torch to Tom Whitworth and me. The old warrior knew his time was coming…may he rest in peace.

For a time we have maintained SO by recycling some of the best over the last 8 years. And much of your responses are still relevant but we need new insights and experiences.

The very first SO question was “How Many IAL meetings have you attended? What was your favorite memory?” We had lots of wonderful responses and to bring things full circle, a new writer/contributor for us and a new laryngectomee has written about his first IAL in this issue. Check out Don Renfro’s column under “My Neck of the Woods”.

As we move forward we would like to try something new. When you read the latest VoicePoints column edited by Kim Almand, our expert SLP, she addresses the issue[s] of long-term radiation damage. And she asks this question…..

We want to hear from you, our readers! What are some of the other long-term effects you (or your patients, loved ones) have experienced from radiation therapy, and what has helped along the way?

Let’s pool our resources….ask some good questions and get some good answers from the experts….and that would be all of us!!

You can respond to her question by emailing: speakingout@webwhispers.net

That’s the first VoicePoints/Speaking Out collaboration and we plan to publish those responses along with some responses from various professionals addressing our issues with both short and long-term radiation effects. But first we want to hear from you, our regular WW readers.

Second, I also have a new Speaking Out question for next month.

This is for all my friends who are more than 3 years out. We often talk about laryngectomy recovery and rehabilitation in terms of years rather than months. Do you feel differently now about your self/your new identity than you did earlier? Do you think the years have made you more comfortable with your voice and neck breathing? Or have you found it to be more challenging? Are you self-conscious or do you wear the scars and neck hole as a badge of courage. In other words, can you tell us when you realized you had transitioned from recovery mode to full rehabilitation?

Again the address for responses is: speakingout@webwhispers.net

I look forward to hearing from you. Thanks!!

WebWhispers is an Internet based support group. Please check our website for information about the WebWhispers group, our email lists, membership, or officers. For newsletter questions, comments or contributions, please write to editor@webwhispers.org

Donna McGary Managing Editor
Kim Almand VoicePoints Editor

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On national radio here in Ireland at the moment there is a regular message from a woman (at least I think it's a woman) with a speech handicap. She says that she wants to be able to express her opinions and how she feels without being ridiculed or told to shut up. She can only say this very slowly and has little or no intonation; it sounds as though every word is a huge effort. The clip has been prepared by a human rights agency and gives a concluding statement (delivered by a fluent speaker): “because we’re all human, we’re all equal”.

I find it quite a challenging message – really has made me think. I have to admit that what struck me most is how much I dislike the sound of her voice. And how much dislike gets in the way of clear thought, compassion or empathy. I am shocked to think that people might tell her to shut up, but can see that temptation within myself as well. I never realised how deeply attached I am to hearing ‘normal’ speech.

It would be different if I was talking to her. Then I’d see her face, her eyes, her body. I’d relate to her as a person just like me. But because it’s radio, and all I have is this disembodied voice that labours every word, it’s not so easy.

It’s not that the tone of her voice is jarring, the way laryngectomy speech can be. The sound itself is OK, it’s the struggle she seems to be making to get out each word. That’s what’s really disturbing for me. As if I’m witnessing distress.

Naturally we want to prevent distress. That’s why I want her to stop talking. When I think about it however, it’s MY distress I want to relieve. She wants to talk - that’s exactly what she’s saying! So my job is to manage my distress, minimise it as best I can so as to give her my full attention as she speaks.

Part of my discomfort is also coming from a vague, half-thought along the lines “maybe people hear ME like that”. Not a pretty thought. I’d prefer to think others get a good feeling when they meet me. Sobering to think it could be distressing for them - quite a blow to my self-esteem.

Life keeps dishing me new blows to my self-esteem. But nobody gets off Scot free. Bereavement, illness, climate change, poverty … we put on a happy face but there is lots of sorrow in life too. How can we be content within a world that abounds in unpleasant, distressing stuff? I count myself enormously lucky to have started learning mindfulness when I was about thirty. That gave me thirty years practice at making sense of the world before laryngectomy came along to dig deep into my remaining illusions.

How does mindfulness help? It grounds the distress in the simple, reality of a breathing body. And within that reality we start to recover. As I remember the radio message now, my face and neck tense up, pins-and-needles jab in my throat and jaw, my breath feels constrained. Thoughts seem to lock themselves into the body, clenching on to their favourite bits of flesh and bone. The question is whether I can trust that all this is welcome; it’s just life teaching me whatever lesson this radio-message is asking of me. Squirming unhappily at finding myself in the dunce’s corner, I start to decipher the message: I’ve been expecting too much of the world. Expecting beautiful things like fluent speech to be a given, something I can take for granted in myself and in others. But of course it’s not. My voice, along with the rest of my body, is mortal; it’s not designed to last forever. I feel resentful, aggrieved. It’s as if I’ve been swindled, clutching at fool’s gold.

As I squirm in discontent, something else starts to attract attention: a quietness, a willingness to listen. It’s so subtle, so unremarkable and yet it’s the pivot on which my whole being can turn. I take a deep breath. Life becomes bearable again. I can sense good will trickling through the bitter sensations of distress. After a few painful breaths I can admit I’ve been an idiot, not recognizing what a treasure I had for sixty years as a fluent speaker, what treasures I still enjoy in a body that can walk and talk (thanks to my trusty EL) and breathe. I feel especially relieved and grateful that my being has found its way through this latest challenge – this radio-message from hell that brought out the best within me. Gratitude lets me bear the bitter sensations willingly.

After a while gratitude also extends to the woman behind the voice on the radio. I’m glad she found the courage to speak up on behalf of all with speech impairment. Hopefully many others are processing her message at deep levels within themselves. Perhaps, like me, they’re seeing hidden prejudice, finding the thread of kindness that simply listens to the harsh voice of condemnation, learning their own way to accept the downsides of life. Perhaps this seeing, finding, listening, learning is what makes us all human, all equal?
My Neck Of The Woods
A Member’s Experience

A Week In The Desert
Don Renfro

This is about my experience at the IAL Annual Meeting and Voice Institute 2019 this May.

This was the first conference I attended since having my laryngectomy and I was encouraged to attend by a fellow member whom also has a laryngectomy, from my support group.

It began with a gorgeous five-hour drive through the desert. Arriving at the hotel we encountered accommodations that were nothing less than luxurious. From the lobby, to the rooms, it was very impressive.

The next day we attended workshops. We attended Bodily Changes Following Total Laryngectomy, Introduction to Esophageal Speech, Introduction to the Artificial Larynx Device and participated in the Speech Evaluations. That evening we attended the Meet and Greet. All in all the day was full and informative. It was so nice to meet others dealing with the same situation I am dealing with and experiencing success. When things are not going good it is easy to feel bad about my situation. Seeing people that have the same things to deal with as I do and they are happy gives me hope and allows me to keep my “bad” moments in perspective and remember they are just moments and they will get better.

One of my most memorable experiences was being in a place where I was the “norm”. If during a workshop somebody began coughing, you know like we do, people did not all turn around and stare at them like what happens when out in public. It felt so nice to be “normal”. If I had to get up and excuse myself to go out and for lack of a better word, hack something up, it was no big deal. I guess what I am saying is that I felt overwhelmingly accepted and it felt good.

After the Meet and Greet my friend and I went to the lobby and played chess. It turned out to be a very social activity as people came and joined us. It was quite the social activity. Provided me with the opportunity to meet other attendees and fellowship with people on my same path in life, it was truly rewarding.

Thursday we went in and out of workshops all day. Visited the vendor’s room where I was assisted with my Electrolarynx. I have recently lost the ability to use my TEP due to a fistula and never really was able to use my Electrolarynx due to still experiencing excessive swelling from radiation. I was assisted by different individuals that even provided me with attachments to help get a better voice from my Electrolarynx. It was better but I will need for the swelling to continue to go down to effectively use my Electrolarynx. In the evening we attended the reception hosted by Bruce Medical and the Web Whispers Banquet. It was very rewarding to see the people acknowledged for their contributions all year to the organization as well as their contributions to organizing conference we were attending. I saw one gentleman, a person with a laryngectomy, which appeared so happy he glowed. I watch him the rest of the evening and the next day and he just always appeared to be so happy. It was very inspiring. I saw another lady that spoke with Esophageal Speech so well I was not sure if she had a laryngectomy. Up to now I had never met anyone that used Esophageal Speech. None of the members in my support group did. The only thing I knew about Esophageal Speech was what I had read and it was hard for me to imagine it was possible to achieve an audible voice with this method of communication. She was the first person I had ever seen that used this method of speech and with such efficiency. I felt as if Esophageal Speech could be an alternative for me when my TEP was unavailable like it is now. After the banquet we again returned to the lobby for our nightly games of chess. We were again joined by other attendees who socialized with us and helped to make or visit to the conference a memorable experience.

Friday, we attended HME hands-on Clinic with In Health, The Making of the Documentary “Segue” and the Laryngectomy Communication Challenges In the Community, which was a trip to the Heard Museum to observe people with a laryngectomy communication in public. The museum trip was truly a high point for me. I love learning about and being exposed to people of a different culture than my own. The museum trip provided me with insight into Native Americans from the region that I had not been exposed to before.

Saturday, we attended Options for Voice Amplification and What it’s Really Like! Both were enjoyable and informative. And again hearing other’s experiences gives some validation and reality that what I am going through is real and not just the result of an overactive imagination or a need to feel sorry for myself. We then met at the pool for a Swim Demonstration. This was truly the high point for me. When I had my surgery the one thing I never stopped grieving was the loss of my ability to swim. I have always loved the water and swimming, the solitude and quite experienced when underwater is very soothing. This demonstration let me know that swimming is still a possibility in my life.

After the swim demonstration we departed for home. It had truly been a rewarding event. If you have been around for a while I do not have to tell you the benefits of attending conferences. If you are new to this community I cannot urge you enough to attend as soon as possible. Seeing all the people there at the event, people with laryngectomees is like being able to look into a crystal ball and see my own future and how wonderful life can be with a laryngectomy. Also, nowhere else on earth, can I find so much information and resources that I can benefit from in one place. I was transformed from “going to a conference sounds like an Ok idea” to “I can’t wait to get to my next conference”. I now look forward to attending many more in the future as well as this one again next year. I look at attending these conferences as one of my privileges for having a laryngectomy.
Agony and Ecstasy of Finding My Voice
A Memoir by Dr. Branton Holmberg

The summer between my junior and senior year, I went back to Springfield, Missouri to work for my Aunt Gladys in the 2 nursing homes she owned there. In my mother’s family of eight children, Gladys was the fifth born and my mother was the sixth, with James and Leora born after her. Among my aunts in mom's family, Gladys was my favorite and I felt she shared the same affinity for me my Uncle Jim did. She’d stayed with us in Tacoma on several occasions when she was working to get her nursing degree in public health at the University of Washington. She had firsthand experience with the relationship between me and my mother.

I worked my fanny off the summer of 1953 and the reward Aunt Gladys gave me for all that hard work was something I never dreamed in a million years would happen. She bought me my first car. When the end of summer rolled around and it was getting near the time for me to head back to Uncle Jim’s she asked me what I thought about having a car of my own. It had the effect she knew it would, I was dumbfounded but it didn’t take long for me to tell her it was the best thing that could ever happen to me.

She knew what it would mean to me to be one of the very few kids in school to own my own car. It was her way of giving me a huge boost to my self-esteem. Her husband, Roy Davis, owned a small cattle ranch outside Springfield and an old farmer friend of his had a ’41 Chevy coupe that was in great running condition and was willing to sell it. That’s the car Aunt Gladys bought for me.

When Uncle Roy drove it into the driveway of their home in town where I was staying, it was the dirtiest car I think I’ve ever seen, but it looked like a million bucks to me. It’d been used by the farmer to haul everything under the sun around his farm and barnyard. He hadn’t washed it in years and there were remnants of every kind of barnyard element you can think of on it, and in it.

The only intelligent thing he’d done when he’d turned the car into a carryall around the farm was to throw canvas coverings over the seats so they at least came through the Armageddon of farm life in pretty good shape.

I spent a week cleaning the car up. When I finally got the animal droppings washed off of it, and cleaned out of it and had it the way I wanted it, I put six coats of wax on it. When I was done everyone was amazed at how much better it looked. No one could tell it’d once been the ugly mess it was when I first got my hands on it, it was a black beauty.

Aunt Gladys put a new set of tires on it, gave me $150.00 and the car as payment for the work I’d done for her that summer, and I headed back to Washington. Mom and Dad only found out how I was coming back after I left Missouri. Gladys called them to tell them what she’d done.

Mom always used to say she was “Madder than a wet hen” about things that irritated her and that’s exactly how she felt toward her sister. I think that only made Gladys happier.

I can never bless Aunt Gladys enough. She gave my self-esteem a bigger shot in the arm than I’d ever had before and it did me a world of good. It was my second transformation.

I was on top of the world when I got back for my senior year of high school. It was amazing how quickly classmates started popping out of the woodwork wanting me to pick them up and take them to school, and mess around after school riding around in “my car”. It was even more amazing how quickly they lost interest when they lost interest when they discovered I needed them to chip in gas money to get us around.

That car was the greatest treasure I could ever dream of having and Aunt Gladys knew it. I was one of the few seniors who had a car of their own and my self-esteem grew
by leaps and bounds. I felt my sensitivity about my cleft lip scar and speech impediment were getting less noticeable to others and it became easier for me to interact with them. Uncle Jim and Aunt Joyce had a special place in their hearts for me and it was the happiest two years of my life I’d ever known. Although I got pretty good grades my last two years of high school, I only made it to a 1.99 GPA and the school board wasn’t going to award me my high school certificate. The grades from my sophomore year were so lousy they kept me from getting a 2.0 GPA which was the level required for graduation.

My mom stepped up to the plate when I was preparing to graduate and did something I’ll always be grateful for, she got me the opportunity to be in the graduation ceremonies to get my high school diploma. I never doubted she could be a force when she was determined and she was about my getting that diploma.

It needs to be said here that my mother was a strikingly attractive woman which makes me think that giving birth to a deformed child was even more traumatic to her. Anyway I’m sure she was dressed to the nines and ready to fight demons when she met with the principal to demand to know why I wasn’t going to be allowed to be a part of the graduation ceremony.

He pointed out the discrepancy between the grade point I had and the one required for graduation. It’s my understanding that after a rather heated argument he told her she’d have to take the matter up with the School Board and that would require a special meeting which he wasn’t sure they’d agree to. She told him to call a meeting or she’d have her attorney see they met with her.

My imagination tells me it must have been quite a meeting in which she pointed out the progress I’d made in my grades during my junior and senior years and denying me a diploma based on what she was sure was less than the 1/10th of a grade point they were concerned about could be corrected if they were to check my grades with all the teachers I’d had. I have no doubt she made clear she’d pursue things legally if I wasn’t allowed to graduate with a diploma.

I went through the graduation ceremonies and received my diploma along with the rest of my classmates thanks to my very strong willed mother.

To be continued...
Becoming a Laryngectomee

by W.C. Baker

There may be no clearer evidence of Karma than my becoming a Laryngectomee. This is not to say that all laryngectomees are autogenerated, but this one was. I was a smoker, only a pack-a-day smoker, but I also consumed the more heavily tar-laden marijuana, at different times in my life on a daily basis. In fact, I found that, for me, tobacco and marijuana enhanced each other, especially when smoked while drinking. It was not at all unusual to find me with a drink in one hand, a joint in the other and a cigarette on standby in the ashtray. I eschewed cocaine and opiates, but did dabble with hallucinogens on occasion. I knew that I was not living the healthiest life style, and finally succeeded in quitting cigarettes after many more or less serious attempts. I never did quit marijuana use, but switched from smoking to edibles when I became a neck breather. At this stage of life, because of concerns about the effect it might have on my brain I use it only rarely.

Community theater and choral singing were a big part of my life, but I always had a day job. I had the pleasure of doing a number of great roles on stage, and 6 months before my surgery I took my excellent bass voice to Carnegie hall with a university chorus.

There was no small amount of panic when the company I was working for went out of business, ending a 25-year career in corporate management. But silver linings do happen. Though the vicissitudes of fate were considered to have been tragic at the time, I came to appreciate the course my life had taken. Being at an age that made it impossible to continue in corporate management, I embarked on a new career.

In my 50s, I returned to school in pursuit of teaching credentials. I had spent a few months in Mexico after the job loss and thought of going for a Bilingual/Cross Cultural certificate. In the first Semester of doing a practicum for a Special Education course, I worked with a kindergarten that included children with cerebral palsy and was grabbed by the heart. I switched on the spot to Special Ed Physically Handicapped. This was the silver lining to the cloud that loomed when I lost my job. Teacher training included a section on Speech that exposed me to the issue of alaryngeal speech. I also worked extensively with young adults with cerebral palsy in programs outside of school. When I got my certificate and started teaching my Special Ed class, I discovered a lump under the right side of my jaw. It turned out to be a metastasis that had traveled from a primary in the piriform sinus at the top of the trachea.

A speech pathologist friend of mine whose husband had been a laryngectomee, loaned me a book that she had used in her practice, and told me about her husband’s experience. So, these elements prepared me for my surgery: The Speech Section in my teacher training; working with people with cerebral palsy; a speech pathologist friend whose husband had been a laryngectomee; Calvin, a laryngectomee who mentored me through the surgery and after. Most important among these factors was knowing the students and young adults with physical disabilities. Most of them had never known any life other than the one that distorted their limbs, distorted their speech and put them in wheel chairs. That is their life. They never wanted sympathy, but welcomed empathy. For someone with cerebral palsy an expression of sympathy, no matter how sincere or well-meaning, is likely to be heard as demeaning. Any good teacher or therapist, or care giver learns from their students, clients, or patients. What I learned from mine is that to make the most of your life, first know yourself as honestly and completely as possible, then do the best can with what you’ve got. Thus armed I went into surgery fully confident that all would be well. I was turning a new leaf and embarking on another new life. What an adventure it has been.