

Whispers on the Web

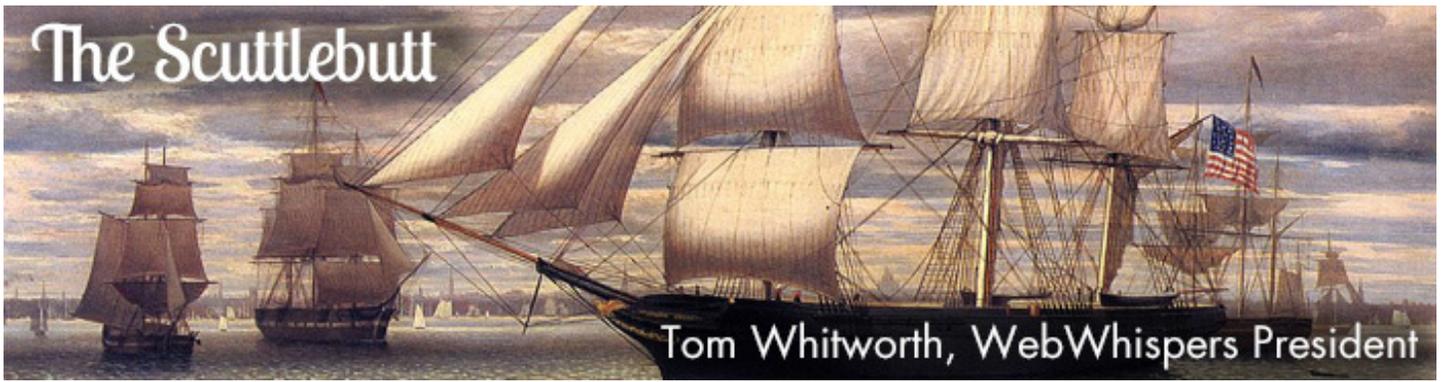
A Monthly Online Newsletter for WebWhispers

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Volunteering: Good for Your Health!

There are a number of good reasons for volunteering to help others and organizations like WebWhispers that serve them. We all know that feeling, the one we get after seeing a need and responding with “what can I do to help?”. There is a ton of information on the benefits of volunteerism for seniors, but the same concepts apply to younger people who have the time and inclination to help meet a need.

Without the effort of individuals, organizations like ours simply could not exist. Tasks don’t do themselves. Many of us are familiar with the “warm fuzzies”, that feeling we get knowing we have helped other people. Have you ever wondered what makes WebWhispers tick? It is the service of those who yearn to give back after learning first hand what it is like to receive help. That’s all well and good but did you know that volunteering is good for your health? It truly is and surely beats sitting around like a pimple on a pickle.

From createthegood.org, here are some things to consider about doing volunteer work and the benefits doing so can have on our own health:

1. Decrease your risk of depression. Volunteering with and for others increases social interaction and helps build a support system based on common commitment and interests-both of which have been shown to decrease depression.
2. Enjoy a sense of purpose and fulfillment and increase your self-confidence while you’re at it!
3. Stay physically and mentally active. A 2009 Johns Hopkins University study revealed that volunteers increased their brain functioning. Volunteer activities get you moving and thinking at the same time.

4. Reduce stress levels. By savoring your time spent in service to others, you’ll feel a sense of meaning and appreciation, which can have a calming effect.
5. Experience “The Happiness Effect”. You know that feel-good sense you get after a vigorous workout? It comes from a release of dopamine in the brain. Helping others has that exact same effect. The more you volunteer, the happier you become!

WebWhispers needs you. Whatever your talent, we can probably plug you in on something worthwhile. Some tasks are on-going and others only occasional, some require a certain skill set and yet others are easily learned. They all have something in common. They require someone like you to get them done. As we continue in our third decade of providing educational support worldwide, won’t you consider helping us?

Enjoy, laugh, and learn,



Tom Whitworth
WebWhispers President



Voice Points

Written by Professionals

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

kbalmand@gmail.com

In keeping with our recent theme of swallowing, the following is a reprint of a VoicePoints article related to dysphagia and nutrition, including some reminders about first steps to take to maintain adequate nutrition and easy swallowing. In addition, if you are looking for a little inspiration for meal preparation as we head into summer, check out this wonderful online cookbook for head and neck cancer. Published by the Head and Neck Cancer Alliance and truly full of "Healing and Easy Eats," this is another great resource whether or not you have cancer. <https://www.headandneck.org/nutrition/online-cookbook/>.

Nutrition in the Head & Neck Patient

Patients with cancer are at high risk for malnutrition, and those with primary tumors of the pharyngeal and hypopharyngeal structures in particular are among those most malnourished. Impaired nutritional status is associated with decreased quality of life and physical function. Commonly experienced symptoms before or after treatment include dysphagia, dry mouth, taste changes, trismus, nausea, mouth sores, and decreased appetite. These symptoms can greatly affect oral intake and ability to maintain adequate nutrition and hydration. However, early nutrition intervention in relation to these symptoms can help improve patient outcomes as well as physical function and quality of life.

Weight maintenance as well as maintenance of lean muscle mass are key goals in nutrition intervention during and after cancer treatment. In order to increase dietary intake, alterations in food and fluid temperature, changes in food texture and consistency, and increased frequency of meals and snacks may be warranted. If nausea is present, small, frequent high carbohydrate meals may be beneficial in helping to alleviate this symptom. The addition of ginger flavored lozenges as well as warm ginger tea may also be an effective strategy. Avoiding foods with strong smells and cooking in well-ventilated areas may also help with nausea.

If mouth sores are present, acidic foods or extreme food temperatures are typically not well tolerated. If there is no dysphagia, sometimes the use of a straw with beverages to help bypass the mouth sore itself can be effective. Dry mouth

can be alleviated with sugar-free candies or gum, alcohol-free mouth rinses, or sipping on water throughout the day. There are a few artificial saliva sprays and gels that may also be beneficial. It is always important to maintain good oral care even if your primary means of nutrition is not orally (ie. tube feedings).

Oftentimes, supplementation with oral nutrition shakes or high calorie, high protein foods is warranted when oral intake begins to decrease. However, oral nutrition shakes should always follow oral intake of solid foods as to not replace the meal itself. Increasing intake of high calorie foods to help maintain weight can be done in a healthy manner and does not need to consist of predominately junk or processed foods. The addition of foods such as avocado, nuts & seeds, nut butters, full-fat dairy products, eggs, lean meats, beans and legumes, and olive oil can help increase the calorie and protein content of a diet and offer the benefit of additional vitamins and minerals.

Physical activity can also play an important part in decreasing fatigue and weakness as well as maintaining lean muscle mass. Resistance training can greatly improve physical function and overall quality of life. The best strategy for encouraging exercise is to choose an exercise that is enjoyable.

Early nutrition intervention is key in preventing and minimizing nutritional deficits in patients with head and neck cancer. A multidisciplinary treatment team with early and ongoing nutrition intervention can help improve clinical outcomes and optimize quality of life.

Heather Duby Shepard MS, RD, LD, CNSC
Senior Clinical Dietitian
MD Anderson Cancer Center, Houston, TX

References: Isenring, E. Esophageal and Head and Neck Cancer. In: Marian M, Roberts, S. Clinical Nutrition for Oncology Patients. 1st ed. Sudbury, MA: Jones and Bartlett; 2010: 165-185.

Between Friends

Donna McGary

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

Photo CC by Corack5239

Two Great Reads

Following on last month's column about reading here are a couple of very different reads I found recently; both are equally fascinating and relevant.

First "The Hidden Air Pollution in Our Homes"

Outdoor air has been regulated for decades, but emissions from daily domestic activities may be more dangerous than anyone imagined.

www.newyorker.com/magazine/2019/04/08/the-hidden-air-pollution-in-our-homes

This was a real eye-opener for me plus an entertaining read about what these scientists went through as they tried to monitor indoor air. Here is just a sample as a group of them cooked a typical American Thanksgiving dinner in the test house.

"The morning of the second simulated Thanksgiving began simply enough, with the researchers making themselves breakfast. Vance and three helpers arrived at the house at half past eight. The kitchen was open plan and modest, with peeling laminate surfaces and flimsy cabinets, but its countertops were crammed with instruments for monitoring airborne particles: a condensation-nucleus counter, a differential-mobility analyzer, and so on. Wires threaded all around the room, and stainless-steel hoses led to four trailers outside, which contained equipment too big to fit in the kitchen..."

...The conversation turned into a kind of play-by-play pollution commentary. When Vance peeled an orange for the cranberry sauce, Arata noted that its fragrance—that is, its monoterpene VOCs—had made the readings on his instrument soar. Abeleira, checking levels of nitric oxide and carbon dioxide during a brief lull before the turkey went in, observed, "They're orders of magnitude higher than outdoors." It was the same for fine particulate matter—particles small enough to reach deep inside our lungs. By around eleven o'clock, the fine-particulate concentration had risen to such a level that, if the house were a city, it would have been officially labelled polluted. Concentrations peaked when the stuffing,

and, later, the pies, came out of the oven. And, for nearly an hour, fine particulate matter was within the range that the Environmental Protection Agency's Air Quality Index defines as "very unhealthy." If outdoor air reaches these levels, a public alert is triggered, warning that even healthy individuals are at risk of serious damage to the heart and lungs."

They even had folks living in the test houses for weeks at a time going through routine housekeeping tasks/activities of daily living and monitoring things such as emissions from cleaning, cooking and yes even flatulence!!!

I am not sure what the implications of all this is for us since if these particulates potentially pose a problem for healthy folks with intact filtering systems, we must be more susceptible. Even with the best HME 24/7 it isn't as good as what nature intended. But I do know it explains why cooking sometimes seems to trigger coughing/breathing issues for me and just for the record toasters and stir fry are two of the biggest offenders!!

The second read is closer to home. I am very pleased to introduce a new contributor to Whispers on the Web. Dr. Branton Holmberg has written a memoir called *Agony and Ecstasy of Finding My Voice*. He was born with a cleft palate and at age 74 developed throat cancer. He has led an extraordinary life and he writes with simple eloquence, a wry sense of humor, and no self-pity about his struggles and triumphs. We are starting in this May issue to run his book under the "My Neck of the Woods" header and will run excerpts each month. This first entry is a bit long but it is just so good and there was no earlier stopping place. I dare you to not want to get mean old Miss Light fired and be eager to read next month's installment!!

I look forward to your reviews and comments on either or both of these recommended reads for May and welcome your suggestions for more "good reads"!

Dear Lary

Noirin Sheahan

Awkward Encounters

Yesterday I took the ferry from Wales to Ireland. I found a window seat that would let me catch the first glimpse of the coast. The window seats are arranged in groups of six around a table. I was sipping tea and reading when a man with an American accent asked if the surrounding seats were taken. With the book in one hand and the tea mug in the other I couldn't answer, and was torn between shaking my head to indicate 'No, they're not taken' and nodding 'Yes' to indicate he was welcome to sit in any of them. As a compromise I waved the book towards the group of seats and smiled which I hoped he would take as meaning 'you're welcome to any of these'. He looked puzzled but I kept nodding and smiling as he edged towards a seat and sat down while his partner sat down beside him. I smiled again at their blank, uncertain faces and then withdrew into my book to give them time to get used to this strangely silent woman – probably not fitting their picture of 'the friendly Irish'!

They started chatting and I picked up that she preferred to sit with her back to the direction of travel while he wanted to see where they were going. "After all" he said "I want to catch my first glimpse of the Emerald Isle". The thought that I should offer him my seat flitted through my mind without settling long enough for me to act on it. But it got me to look towards the horizon and sure enough I could see Lambay Island coming into view. Still silent, I leant forward to get his attention and then pointed out the window. He looked askance, but eventually turned around to look in the direction I was pointing. "Ah..." he exclaimed "my first glimpse of Ireland is it?" I nodded yes and then fished out Ellie (my electrolarynx) to tell him it was Lambay Island.

I would have liked to tell them that it's a wildlife sanctuary and about the morning when, on a sailing holiday with a group of friends, we anchored beside its cliffs to eat breakfast. We had stopped the previous night in Malahide where the estuary is so shallow you can only enter and leave at high tide. The sun had been setting behind the church spire as we zig-zagged along the narrow channel towards the village. Then, with the morning sun peering over the horizon we had cast off again to follow a line of boats navigating the slender estuary on their way out to sea. It's always been a magical memory for me.

All this I would have loved to share but alas he looked puzzled and embarrassed as he tried to follow Ellie's efforts to croak 'Lambay Island'. After several attempts, I simplified it to 'Island' and once he grasped that it was an island rather than the mainland, I left it at that and went back to my book.

Perhaps thirty or forty minutes later he took out his phone and was looking at a map of the Irish Sea, mistaking Lambay Island for the Isle of Mann and saying how strange that this was so near Dublin. I hesitated but then decided it would be worth making one more attempt at a friendly connection. I decided to let my phone do the talking this time and searched for a description and photo of Lambay Island and offered this to them. Again it felt very awkward and they both looked nonplussed, and of course the link failed and I had to re-search for the information but eventually they took my phone and worked out what I was trying to say. By now they were smiling cautiously at me though obviously still taken aback. Their expectation of 'the friendly Irish' had not included a laryngectomy!

A few minutes later, it was time for them to go to the car deck and we said goodbye. Just before leaving, the man turned and said apologetically "I wish we had asked you to join us earlier. I wanted to, but didn't know ..." he tailed off, looking sad. I presumed he was trying to find a way to acknowledge my speech handicap without offending me so I attempted something between a smile and a grimace in the hope this would say 'that's OK, I understand, Ellie's a bit of a bummer isn't she?' as I waved goodbye.

It was ironic – he could speak but couldn't put his thoughts into words. I'd wanted to share all my thoughts aloud, but couldn't make myself understood. We both failed to communicate as we had wished. But it didn't really matter. Even though it was an awkward encounter, it felt meaningful. I'd managed to convey a friendly attitude, he'd managed to tell me he appreciated this and was sorry that laryngectomy had got in the way. Even a thousand words would not have added anything more important than that felt connection of friendliness and sympathy. I'll remember them fondly and I'm sure it's the same for them. Between Ellie's awkward croaking and his awkward apology, we'd managed to say it all.



Agony and Ecstasy of Finding My Voice *A Memoir by Dr. Branton Holmberg*

INTRODUCTION

I learned late in life my mother thought when I was born with a cleft lip and palate God was punishing her. This was shared with me by her older sister when I was in my early fifties. As I reflect on the agonizing battles I had with mom, I'm sure my rebellion against her domination of me only reinforced that belief.

This memoir will take you from the agony of my childhood as a kid with a harelip, cleft palate and speech impediment to the marvelous ecstasy of finding a dental device when I was 26 years old that would change my voice, and my life forever. Then you will plunge with me once again into the agony of completely losing the voice I'd so lovingly found when I was starting my master's degree in School Psychology. I became a laryngectomee at the age of 74.

The journey takes you through many transformations in my life each leading to dimensions of self-awareness and personal capabilities far beyond the disfigured and below average kid I thought others saw me as throughout the childhood years I spent with my mother, father and brother. It lays the foundation for the creation of this book and many others I began writing two years after I lost my voice to thyroid cancer in 2010. My writing is the ecstasy of the voice I've found again.

Until the time I became a graduate student I harbored the belief people heard me with the speech impediment of a cleft palate. Then one of the most amazing transformations of my life happened and my professional career expanded exponentially.

You'll see my life as a child, teenager, Air Force medical corpsman and college student, Graduate Teaching Assistant (when I got my new voice), Associate Professor of psychology, college/university administrator, Adjunct Professor, business and organization development consultant, entrepreneur and author. It's been an amazing journey and one I never expected to take because of my physical disfigurement and speech impediment.

The last part of my journey deals with my present experience which in my wildest dreams I never imagined would haunt me again. My voice was taken from me and once more I've had to deal with trying to get people to understand me when I'm trying to talk to them, this time with an artificial voice.

It's a story not only of moments of dark despair, but of wondrous transformations through which I was able transition into rewarding personal triumphs. You'll see how significant the beliefs I've held

about myself have been in creating the world I've lived in. In the end it's a story about using my love for writing fiction as the voice I've lost to cancer. I'll show you glimpses of things I've written.

Even though I love to write, I find it difficult to describe how meaningful it's been to me to be loved and supported by my wife Margaret, my children James, Ann, and John, my grandchildren and great grandchildren and all others who've touched my life with love.

I regret not telling those who are now gone how much their support during my struggles to save myself from my own despair meant to me. The love and support of all of them has been my salvation and given me more happiness than I thought could exist for me in this lifetime. That happiness has gained depth as I've acquired the wisdom to see how family, relatives and friends have made my life what it is. I love each and every one of them far more than I can find ways to express with the written word.

As my journey continues I hope you'll follow me in my writings as I share what I call the second voice of my life. It too has lifted me from great despair and given me the opportunity to communicate worlds of imagination that've brought me far more pleasure than I thought I would ever find again.

Perhaps you will find my fiction stories as enjoyable to read as I've found them enjoyable to write. If that's true I'll feel endlessly blessed.

Chapter 1 "God's Punishment"

My brother Warren, my only sibling was three years and four months older than me when I was born. The celebration of my birth was marred when it was discovered I had a cleft lip and palate which caused great anxiety for my mother not only because she was not able to breast feed me, but the belief God was punishing her with my disfigurement. Aunt Gladys, mom's next older sister, told me when I was in my mid-fifties my mother had confided in her when I was born that she felt God had punished her for things she'd done and that's why I was born with a cleft lip and palate. I have no idea what the sins were she felt she was being punished for. I never asked after I discovered she was carrying that burden because I was sure she'd never tell me.

Mom described to me on many occasions over the years how I lost a lot of weight as they were trying to get enough nourishment in me at the hospital and she thought I was starving to death. She was afraid she was going to lose me and took me home against the orders of the doctor. The details are vague to me now but from what I recall about her telling about how she saved me was that she pumped milk from her breasts and fed me with a cooking baster.

However she did it I'm forever grateful. That was the beginning of the agonies of living with a facial deformity as well as a speech impediment that eventually led me to ecstatic self-revelations of abilities I never thought myself capable and a life I never thought it would be my good fortune to live.

Once I was healthy enough the surgeon operated on my cleft lip. My left nostril was only half the size of my right one and the physical cleft in my face was on the left side of my upper lip and ran through the smaller nostril, my upper gum line and the hard palate in the roof of my mouth. It left me without the normal amount of soft palate which helps you speak normally. Although the surgeon did a fine job sewing up the cleft in my lip, there was nothing he could do about correcting the shape of my nose. There was nothing that could be done either about my soft palate and I was left with an abnormally small one.

I was a year old when we moved from Puyallup to Tacoma, Washington where dad got a job as a conductor on the cities trolley cars. He worked all his life in that line of business and retired as a bus driver trainer for the Tacoma Transit Company.

I became aware of my disfigured nose, the ugly scar running up into my left nostril and my misshapen lip line very early in life. It was there every time I looked in the mirror, and I knew it was there every time someone looked at me.

My mother assured me it was nothing I should be concerned about because the surgeon had done a wonderful job and I looked as good as any other kid. It didn't work.

To me my harelip was an obvious physical disfigurement everyone saw immediately. The lip line of my upper lip was pyramid shaped under my left nostril due to my physical growth after my surgery as an infant. That nostril being half the size of my right one made my upper lip and the left side of my face horribly obvious to me, and even more horribly obvious to others. I was sure of it.

From a very early age my mother, the completely dominant force in our family, had a different way of treating my older brother Warren than she did me. Throughout our childhood years she held him up as the standard I should meet when I was going through the grade school classes he'd gone through. That was never to be because we were never on equal footing, I was born with a physically visible cleft lip and an abnormally small soft palate resulting in a speech impediment that made me the target of mimicking and teasing by my peers and had me doing everything I could to be as invisible as I could make myself. Warren on the other hand was born without any physical blemishes and was clearly understood when he spoke. On top of that he was admired by his peers.

My disfigurement coupled with sounding like I was talking through my nose when I spoke, which I was because I didn't have enough soft palate to keep my voice from sounding like it was coming out through my nose, became teasing fodder for my peers and they were relentless.

If they got reprimanded by adults when they heard them mimicking me it increased the intensity of their mimicry when the adults weren't around. I learned to make myself as unnoticeable as I could in school. I always tried to sit at the back of the room as far from the teacher and my peers as I could get.

More often than not my grade school teachers, believing they were helping me with my speech impediment, would have me sit in the front of the room where they could make sure I was called upon as often as the other kids. They called on me all the time, at least if felt that way to me.

I'm sure my birth defect wasn't the only way my mother thought God was punishing her. I'm convinced she thought I was slightly mentally retarded because I was just getting passing grades where Warren had gotten superior grades.

This created a paradox that perplexed me for years. Whenever I was around other kids parents with my mother she'd tell them how well I was getting along in school and how well liked I was, but I heard and felt a very different story from her when we weren't around others.

My favorite hideout in grade school was the library. Everyone had to be quiet there so I found it was a safe haven from the mockery that surrounded me everywhere else in school. That's where I fell in love with reading and spent as much time there as I possibly could. I was fascinated with deep sea divers and read everything I could find about them.

Other ways I found to lock out the world was to lay in front of the old Silvertone floor model radio in our living room and listen to all the old radio shows my parents would let me. Warren and I went to the Saturday matinee movies at the local theater as often as our folks would let us. I think I spent the greatest amount of my time as a kid reading comic books and trading them to other kids around the neighborhood to get ones I hadn't read.

When I was a fifth grader my teacher, an old spinster named Miss Light, had us write an original story as an English assignment. I wrote what I thought was a terrific story about a deep sea diver and all the dangers he faced. When I turned it in and she read it she made me get up in front of the class and read it. The snickering and whispering among the kids in the class while I was forced to read my story was obvious and intensified my awareness of talking through my nose. I was absolutely miserable.

Miss Light, fully aware of what was going on, said nothing. She knew what would happen and deliberately allowed it to happen.

When I finished reading my story she told the class I'd copied it out of a book and had cheated on the assignment. She said I'd plagiarized the story and told the class what plagiarizing meant. She put a big red F on my paper and had me hold it up for everyone to see. She wanted that to be a lesson to every kid in class.

I was not only humiliated having to suffer the obvious embarrassment and terrified feelings I went through reading my story to the class, my teacher was calling me a cheater and gave me an F for all the hard work I'd put into that assignment and I hadn't copied a word of it from any books I'd ever read.

To be continued...



This column originally ran in October 2016.

“How has your cancer(s) changed your life?”

Mike Rosenkranz - Plantation, FL
1/6/99

My first cancer (prostate) turned me into a gentleman of leisure. I had planned to retire at 70, but retired on my 68th birthday. My second cancer (larynx) was a true learning experience. This was readily seen by others and I found myself putting folks at ease because they were unsure how to react to my loss of voice. I joined WW in '99, became a volunteer in 2000 and that was the start of my second career, full-time volunteer. My third cancer (kidney) is monitored quarterly. No change since diagnosis last fall. My cancers have made me appreciate the extended life I have been given. I try to live that life to the fullest extent possible, and encourage others to do the same. Life is too precious to waste time on the negatives. Enjoy the extended lives you were given by your lary surgery. I am always making plans for my next adventure. This year it was an Alaska cruise. Next year, Scotland.

Carl Strand - Mystic Connecticut
February 10, 1993

Of course I had the change in voice, taste, sense of smell that all laryngectomees face, some more than others. The most important change for me, though, was my relationship with others. I am a Coast Guard officer by training and an engineer by profession. I have always been an introvert and very confident of my ability to figure out things for myself. My laryngectomy brought (or maybe forced) me out of my comfort zone. In the first place, the major outpouring of support I received made me realize that my introversion was not a barrier to the people I knew and worked with. In the second place it made me (I think) a kinder, gentler person who is more tolerant of others and their failings. Finally, it made me realize I needed to reach out to others both inside the laryngectomy community and outside in the community at large, which really put me outside my comfort zone. It has been a rewarding, if not always comfortable, 23 years.

Kevin Berry - Ontario, Canada
Class of 2001

It was a beautiful sunny fall morning the day after the twin towers came down. It was the morning I kissed my then 15 month old daughter and walked the 20 minutes from my home to the hospital to get my larynx removed.

By 3:00 pm that afternoon, I was wondering if was worth going on. I was horribly disfigured, stripped of my voice, and emotionally decimated.

15 years later I see things a little differently. I was given 15 years to watch my daughter grow. I was given 15 to fall in love again and spend 12 fabulous years with my new partner. I was given 15 years to learn a little humility and I was forced to listen as well as speak.

15 years later I am not as pretty, well spoken, or as wealthy as I was, but 15 years later I feel I have had a chance to become a better man. What else could a man wish for.

For those just starting the journey, try not to despair over what you have lost, try to rejoice in the new opportunities you have been given. It may often not seem like much of a gift, but every day on this side of the daisies, is gift far too valuable to be squandered.

Len Hynds - Newtown, UK

Your whole life starts to change from the moment you are told that you have a cancer, not only in life style, but also in the emotional aspect.

In lifestyle, I ran my own business selling car parts, for the car repair industry, employing a few people, but with about 200 customers throughout the two counties of Sussex and Kent. I was 74 at the time, with no intention of retiring, but the news was rather shattering as I had so many people who were dependent upon me, especially my dear wife, who could not run the business, so I decided to give it to the two most senior people, as a gift.

In settling the paperwork, for a tidy handover with no debts for them, I tried to send in my tax returns six months in advance, only to be sent a cheque a few days later, by the Head of the local tax department saying that I had money owing to me. This could not be possible, as I was always most careful. To leap ahead to close this particular incident, some four years later whilst I was at University, we were all listening to a tutor who was complaining bitterly about a Tax Inspector, and I told the story of my experience. A lady present in the refectory, interrupted, saying, "I know of this. I am a friend of the wife of your inspector, who was the head of department. I was there when he told us of your letter, and showed it to us."

She went on, "He never told either of us, that on that very day he had been told he had a lung cancer himself. He told his wife after I had left. He died a few months afterwards." I am convinced that the cheque he sent me, was written in a moments compassion, and as he was in what he thought was a similar position.

The consultant Surgeon to do my operation, was most interested to perform on somebody who had metallic heart valves, a pacemaker and various other bits and pieces, but he performed perfectly. That was nearly thirteen years ago, and you slowly learn to live this new life, and thank your lucky stars that you are a survivor.

John Haedtler - New Mexico, USA
Laryngectomy 2001

This may sound crazy, but getting cancer was one of the best things to happen to me! Please don't shoot me! Just listen! I learned more about medicine and doctors than any one of us want to know! I learned more about myself than most of us do! I found strengths that I never knew that I had. So bottom line getting Cancer has helped me!

Before getting cancer I never would have thought of speaking to groups of people. I'm just a big chicken! But I have spoken to SLP students in their class on voice restoration! And I have let Students change my prosthesis. The classes are so great. You can watch the students as they realize what the books and videos were talking about. To be able for them to see and touch a real Laryngectomy is Amazing! I'm not sure who gets more out of it???

Getting Cancer has taught me to be and stay Positive! I really feel that the Positive attitude does more for us then any Radiation and Chemo! I also was taught by the best! Every single employee at the University of New Mexico Hospital! They all saved my life! I'm sure some people that know me are mad at UNMH, but that is their problem not mine!

I wish all of us an enjoyable ride through all of this.

Remember ... This is just one more stage of life! It can only be positive if we make it positive!

Colin Lovering - Northam, Bidefor - UK
June 2015

Having a laryngectomy has given me a new lease of life. I am 80 years of age and am fitter now than for the 3-4 years previous to the Op. O.K. I have lost my voice, but I have a TEP, and an electric SolaTone

I have lost the sense of smell, but sometimes that can be a good thing. For some reason, I know not why, I no longer like 3 or 4 foods that I used to enjoy, but I still enjoy plenty of other foods, just have to remember to eat smaller bite sizes and chew slower, not to wolf it down like I used to. I still forget sometimes not to bend over after eating. My wonderful specialist nurse said at the beginning "Your stoma will heal up, persevere." After 6-7 months I did not believe her. Then just under the year it suddenly healed up. now it is firm and does not shrink up.

I had a wonderful surgeon, a caring consultant, a super specialist nurse to follow up with me.

Finally, a lovely understanding wife who pops in my button or tube for me because of my arthritic hands.

Apart from not being able to whistle as I used to all day, ----- I am blessed

Branton Holmberg - Wauna, WA
2010

I've been a lary since August 2010. They first removed 1/2 of my thyroid in 2000 and with a radioactive iodine treatment and it looked like I was cancer free until early 2010 when there was a sudden spike in my thyroglobulin blood count and the cancer became very aggressive again. The decision was made to remove the rest of my thyroid gland, believing that would be all that was necessary. When they operated in August they found the cancer had spread to my larynx and trachea and they removed the larynx and 4" of my trachea. The result was that I have a deeply recessed stoma and the only communication device I can use is an AL.

I was retired when I had the 2010 operation so I did not have to face the issues of earning my living with my voice which I found fortunate because I was a university professor, business owner and business consultant during my career. What I found deeply troubling though was once again having to deal with issues of clearly communicating with my voice. I was born

with a cleft lip and palate and my childhood was plagued with many of my peers mocking my nasal speech. When I entered graduate school in psychology I was fitted with an obturator which cleared up all aspects of my nasal speech and made all the difference in the world to me. I went on to have a career I would have never dreamed possible before I got that fantastic speech aid. I've written of those experiences in a memoir.

Then in 2010 I found I was thrown once again into the world of trying to clearly communicate verbally. All the early years of my life returned with a vengeance and I retreated from interacting with others and kept my social interactions to a minimum. My biggest concern was communicating with my grandchildren and great grandchildren whom I dearly love. They were all in their early childhood years. My wife and children had no problem understanding me but my grandchildren and great grandchildren did. Although they loved the Mr. Robot sound of my voice, prolonged communication with them was difficult.

From this frustration I found a whole new dimension to my life. I became an author and began writing adventure, and science fiction/ fantasy, stories using myself as one of the main characters and family members, grandchildren and great grandchildren as characters as well. I've written a series of 57 adventure books in what I call my Saturday matinee book format. The books run between 65 and 110 pages or so on a 6" X 9" printed page, and can easily be read in an hour or two which is about the amount of time I sat through a Saturday matinee movie when I was a kid. I loved those matinees and they've been a big influence on the stories I've written

Many of the books are written to a young adult audience which is the audience the Harry Potter books were written to. A lot of the stories have elements of the Indiana Jones type of adventures to them.

I continue to write and I must tell you I'm having more fun than I ever thought possible. My grandchildren, and great grandchildren, are enjoying an aspect of their grandfather, and great grandfather, I'm very proud of.

Bless each and every one you my fellow larys. I hope each of you find your way to have fun too.

Trevor Hutson -UK
September 2015

It all came as a sudden shock, from first going to the docs to having to have an emergency trachy, then a huge 6 week wait in hospital while they decided the best course of action for me, eventually followed by a laryngectomy and another 3 weeks recovery but thank God I did not have to have chemo or radio therapy.

They fitted a TEP same time as the operation.

How has it changed my life is a huge question. My background was catering and I was also a lecturer and a performer so a very hands on people person.

Food was an important part of my life and not just from eating. Now I have a very limited sense of smell, I really miss the smell of the morning, of rain, mostly the smell of my wife's hair.

Taste is slightly better. I can sometimes taste all major groups but only if strongly flavoured like loaded with garlic etc. but other times it's just going through the motions to fuel the body. Very difficult to talk and eat so mealtimes can be difficult especially if out with friends as joining a conversation is difficult as by the time I have swallowed and forced whatever down the conversation has moved on to totally other things which can be frustrating.

Lots of other problems which I know you all face so enough said by me.

Overall I am lucky to still be here to experience it all and for that, I thank God every day for giving me another one. I will stay strong and positive and I realise that I just do things differently now.

Stay positive and yes, sometimes it is hard but the good bits outweigh the bad.

Good luck to you all and good health to enjoy it.

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*Donna McGary Managing Editor
Jack Henslee Speaking Out Editor
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