

Whispers on the Web

A Monthly Online Newsletter for WebWhispers

Photo CC by HMBazcom

October 2020



Contents

Column	Author	Title
From The Editor's Desk	Donna McGary	We Will Survive 2020
The Scuttlebutt	Tom Whitworth	Webwhispers 101
VoicePoints	Emily Iler, M.A., CCC-SLP	Pediatric Laryngectomy
My Neck of The Woods	Don Renfro	I Can't Be Indifferent to Life and Still Live
This Lary Life	WC Baker	SOUTHEAST ASIA 2006
The Agony & Ecstasy	Dr. Branton Holmberg	Chapter 13 "A Final Transformation"
Editor's Mailbox	Sharon Strohm Heck and Sgt. Pepper Heck	All You Need Is Love

From The Editor's Desk

Hello fellow survivors...deep breaths everyone...2020 is not done with us yet. I have really struggled this month to come up with something meaningful to add to this issue and I am RARELY at a loss for words. I usually run out of battery power on my EL before I run out of something to say! But nowadays, I admit to feeling disheartened and uninspired and I know I am not alone. And I think that's okay as long as I don't make it a habit.

However, the good news is our fellow WebWhispers writers, as always, have been inspiring in their resilience, optimism, good humor and shared wisdom. Please take some time to check them out. Doc Holmberg finishes up his memoirs but don't worry, he has some great escapism tales for next month and, frankly, I am totally on board with escapism right now. We may be stuck close to home these days but we can read about WC's adventures for a little armchair travel and Don Renfro always has some thoughtful insights to keep us growing. Plus some great information about how to support WebWhispers from Tom Whitworth. VoicePoints addresses pediatric laryngectomy and some of the causes. Thankfully it's quite rare, however we had a very young fellow at the last IAL and the loan closet has had several requests from SLPs for children who need to try out an EL for various problems not always related to head and neck cancer. Which only goes to prove how we are all different even if we share common problems. We are always looking for topics you want us to address so if you have some suggestions we would love to hear

from you. Editor@webwhispers.org is a direct link to us or you can post a question or comment directly on the WW daily list webwhispers@mail-list.com or even our FaceBook page.

In the meantime, as I try to distract myself traveling down the rabbit hole of the interweb I came across this fascinating article which actually has relevance to us in particular as head and neck cancer survivors: a discovery of new salivary glands!

Since my cancer, adenoid cystic carcinoma is a rare salivary gland cancer this certainly caught my eye! However, the more compelling aspect for all head and neck cancer patients is that the discovery of these previously unknown glands may help radiation oncologists in the future target treatment to avoid damaging them and help mitigate one of the worst side effects for many of us "dry mouth" and its many complications. You can read the full article here:

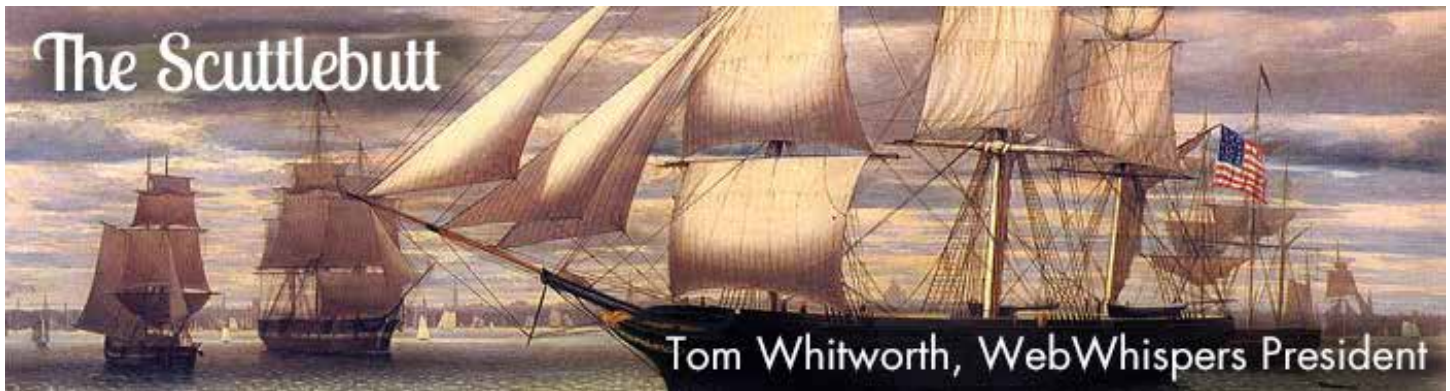
<https://www.nytimes.com/2020/10/19/health/salivary-glands-new-organs.html>

So that's lots of good reading...hope you enjoy it and then take a moment to let us know what you think!

Until we meet again, stay safe and sane and hopeful!

Donna McGary





Webwhispers 101

WebWhispers is constantly adding new members every week. We lose some folks due to normal attrition but the number of our membership continues to increase. At 4,251 members, I thought this would be a good time to review what WebWhispers does, how we operate, and why one would want to be a member.

Do you know the benefits of WebWhispers membership?

Our members have access to the members only part of our website, which includes contact information for each member. They can receive and participate in our members only Mail Digest, which can be sent to your inbox as messages are posted, or in our twice daily Mail Digest, or both.

The Mail Digest is published every twelve hours if there has been activity. On the digest, members can know that their question is being seen by WebWhispers members who are a patient or survivor of head and neck cancer, a caregiver, or a clinician who works with us.

Many Speech Language Pathologists are members of WebWhispers, Inc., as are all major suppliers of laryngectomy products. Membership is required to use our electrolarynx Loan Closet and also to apply for Voice Institute scholarships. (See "Save the Date" below)

Membership is free, however in order to participate in our elections and corporate matters, one must be a sustaining member. Sustaining Membership is available for an annual donation of only \$5.00. Here is the link to become a member or update your information in our system:

<https://webwhispers.org/join-us/>

Want to help WebWhispers?

With the exception of our annual dinner, where tickets are sold at our cost per person, everything we do for WebWhispers members is free. Now that we have the new website, maintenance and updating will be ongoing efforts and there are some costs associated with that. We also have expenses related to our participation in the IAL Voice Institute.

WebWhispers has various expenses throughout the year, such as the administrative costs of having and running our website, plus shipping and postage costs for our loan closet, the WW Alert kits, and getting our brochures to the people who distribute them for us worldwide.

You may be thinking "no way, nothing is free, everything with a cost is paid for by someone, somewhere", and yes, you are correct. WebWhispers operates off of voluntary gifts from members and friends. We are a 501 (c) 3, so contributions to WebWhispers, Inc. are eligible for tax deduction in the United States. We receive some donations from customers on Amazon, eBay, and PayPal when users note WebWhispers as a receiving charity. These and Facebook Birthday Fundraisers are excellent ways to help WebWhispers without costing yourself anything at all. Donations to WebWhispers can be also be made through the United Way.

Direct donations are received through PayPal (just note WebWhispers, Inc. as the payee) and also through the USPS at:

WebWhispers, Inc.
P.O. Box 1275
Powder Springs, GA 30127

SAVE THE DATE!

The 2020 IAL Annual Meeting and Voice Institute is planned for June 9-12 in Charlotte, NC. If you've attended a VI before, you know what I mean in saying to potential first timers:

Mark the date on your calendar right now and BE there.

*Enjoy, laugh, and learn,
Tom Whitworth
WebWhispers President*

Pediatric Laryngectomy

Laryngeal cancer represents between 1 to 3% of all malignant tumors and roughly 50% of ear, nose, and throat tumors. Cancers of the pediatric larynx are even rarer, accounting for less than 0.1% of all head and neck malignancies in childhood/adolescence. Less than 100 cases of childhood laryngeal cancer have been reported in the literature since the mid-1800s.

The rarity of laryngeal carcinoma within this age group may result in its underdiagnosis or delayed diagnosis. Clinical presentations in pediatric patients with confirmed laryngeal malignancy have included upper airway obstruction with noisy breathing, dysphonia (specifically hoarseness), and shortness of breath. Symptomatology may be overshadowed by other more common pediatric conditions which share similar clinical features, such as recurrent upper respiratory tract infection, upper airway obstruction, vocal abuse, or anticipated vocal changes associated with puberty.

Further complicating timely diagnosis of malignant disease is the difficulty of properly examining children due to poor tolerance of the laryngoscope. Direct visualization of the airway by laryngoscopy is a crucial part of a head/neck evaluation when there is concern for oncologic disease. A review of the literature by Gindhart et al. (1980) reported functional vocal fold mobility in 47% of cases, vocal fold fixation (unilateral or bilateral) in 37% of cases, and extra-laryngeal spread in 16% of cases. Pediatric squamous cell carcinoma shares the same physical characteristics as adult carcinoma in its irregularities, texturing, and coloring. Involvement of head/neck lymph nodes was not identified in any of the literature's previously reported cases of pediatric laryngeal cancer. Following direct examination via laryngoscopy, imaging (such as CT scan or PET scan) and biopsy are obtained to confirm a diagnosis.

Risk factors for the development of pediatric laryngeal squamous cell carcinoma (SCCa) include first- or second-hand smoke exposure, chewing tobacco use,

chemical exposure (such as asbestos), or human papilloma virus (HPV). Tobacco use is an important and significant risk factor in the development of head/neck cancers in adults, but interestingly, the primary cause for pediatric laryngeal SCCa has been identified as prior irradiation for other benign lesions of the head/neck, such as juvenile laryngeal papilloma or neurofibromatosis. Walsh and Beamer (1950) reported a case of atypical cell presence found 10 years post-irradiation for laryngeal papillomatosis, which was later confirmed to be positive for malignancy.

The treatment approach for laryngeal cancer is multimodal, meaning a combination of surgical intervention, radiation therapy, and sometimes chemotherapy is used to control disease progression. The goal, when possible, is "organ-preservation" by addressing the disease with chemoradiation therapy and avoiding surgical resection; however, sometimes tumor growth is so extensive that surgery is recommended. Treatment for pediatric laryngeal cancer is especially complicated. Radiation therapy can result in a multitude of devastating long-term effects including misshapen bone and tissue growth, dental abnormalities, visual impairments, disrupted hormone function, brain bleeds, tissue death (including tissues of the larynx), esophageal narrowing, and dysphagia (difficulty swallowing).

Most reported cases of pediatric laryngeal cancer were treated with simultaneous radiation and chemotherapies, with infrequent pursuit of total laryngectomy; however, a handful of cases of total laryngectomy have been reported. The youngest reported case of pediatric total laryngectomy was that of a 20-month-old male for malignant tumor of the larynx by Peterson (1950). Special consideration should be made for pediatric patients when implementing speech-language therapy, especially within a child's formative years of language acquisition when the focus is on habilitation (skill learning) rather than rehabilitation (skill re-learning). Milestones of typical speech/language

development (such as age-appropriate speech sound distortions), receptive language function, and cognitive communication should all be considered by the speech-language pathologist (SLP) when working with a laryngectomized child. Furthermore, multiple methods of alaryngeal communication should be offered and trialed with the child. The use of an electrolarynx and esophageal speech have been documented as viable approaches to alaryngeal speech restoration in children.

There are currently no documented cases of tracheoesophageal prosthesis (TEP) use in pediatrics; however, one could consider similar candidacy factors to that of an adult when evaluating a child's appropriateness for TEP use: tissue integrity and wound healing abilities, prognosis for functional alaryngeal voice (may be simulated by a special examination called air insufflation testing), contraindications for surgical procedure, accessibility to a skilled SLP, financial means, and patient motivation for TEP. Additional speculative factors specific to the pediatric population could potentially include: continued tissue growth and development (and resulting potential for tract migration or distortion), guardian ability to assist in caring for the prosthesis, risk for prosthesis dislodgment and obstructing of the smaller pediatric trachea with subsequent asphyxiation, and more.

Although pediatric laryngeal carcinoma may be rare, thorough work-up for malignancy remains indicated when the cause for the child's symptoms remain unclear or inconsistent with other more common illnesses of childhood. The speech-language pathologist and head/neck physician play integral roles in the recognition of concerning clinical features and timely diagnosis of pediatric laryngeal cancer. When working with a child who has undergone total laryngectomy, the speech-language pathologist should be equipped with the knowledge and skillset to address the speech/language developmental needs of the child as well as the complexities of alaryngeal voice restoration following total laryngectomy.

Alternative Etiologies Warranting Pediatric Total Laryngectomy

Beyond laryngeal carcinoma, other causative factors have been reported to result in total laryngectomy in children:

Synovial Sarcoma: Synovial sarcoma is a rare but aggressive tumor that typically arises in the lower

extremities of adults but has, in extraordinary cases, arisen in the head and neck. Alhatem et al (2019) described the cases of 3 children ages 10 to 16 years old who underwent total laryngectomy for synovial sarcoma involving the larynx.

Chemical Ingestion: Jacobs and Abramson (1979) detailed the case of a 20-month-old male who underwent total laryngectomy following ingestion of lye, which resulted in life-threatening scarring of the airway for which tracheostomy was insufficient.

Neurofibromatosis: Neurofibromatosis is a rare genetic condition characterized by the growth of tumors along nerves within the skin, brain, spinal cord, and other parts of the body. Chinn et al (2013) summarized multiple pediatric cases warranting partial or total laryngectomy for neurofibromas resulting in upper airway obstruction.

Traumatic injury: Gardner et al. (1962) reported a case of laryngectomy in a 12-year-old male following an accidental shotgun blast.

Emily Iler, M.A., CCC-SLP
Speech-Language Pathologist
Emily.iler@shands.ufl.edu
UF Health Shands Hospital & UF Health Shands Children's Hospital

Hi everyone! My name is Emily and I have been a practicing Speech-Language Pathologist and member of the IAL for 2 years. I am a proud two-time graduate from the University of Florida (Go Gators!) and work within the university's affiliated hospital system. I began my career working with patients undergoing treatment for various head and neck cancers but have since transitioned to work with pediatrics. Despite this transition, I still have a soft spot within my heart for my wonderful laryngectomees with whom I have worked.



I Can't Be Indifferent to Life and Still Live

By Don Renfro

"The opposite of love is not hate, it's indifference. The opposite of art is not ugliness, it's indifference. The opposite of faith is not heresy, it's indifference. And the opposite of life is not death, it's indifference."

Elie Wiesel

For me, it is the responsibility of every living being to believe in something. Not because it is the "right thing to believe" or the "popular thing to believe" but because it is what I believe.

Several years ago I got in contact with a friend of mine I had grown up next door to when I was in elementary and junior high school. I brought her down to stay with me a couple of times and during one of our visits we were talking.

She stated that she had never voted in her life. We were both in our late 50's and I was baffled to find out that I knew someone that had never voted. I stated that I always vote because too many people have died or put their life on the line for me to get the right to vote and so I do it to not allow their efforts to have been in vain.

She went on to state that the reason she does not vote is because what if she voted for the wrong person? For me this was true indifference.

I always believed that the opposite of love was not hate but indifference but was not always clear what that meant to me even though I believed it. Today it is much clearer to me, the difference between hate and indifference. When I hate someone or something I am totally invested in that what I hate. What it is I hate occupies my mind and my spirit. When I am indifferent about someone or something there is no space in my mind occupied by that that I am indifferent to.

When I was a child I hated liver. Having liver for dinner, although it was not very often, was still a very traumatic experience for me. When I grew up my wife used to like to order liver and onions when we went out for dinner. I no longer hated liver but was quite indifferent about it. It was not my choice or preference but it was no longer a source of hate for me.

Today indifference is somewhat of a benchmark for me to know I have moved past a hurt or trauma. Back in 2005 my wife and I were separated and I was staying with a friend I had known since high school. He was dating a girl that he had known from work. In all the years I had known him he was never one to fall in "love" with a girl. This girl he was in love with and had all went well he would have probably married her. Later he found out that she was not in love with him and was still going out with other men. This absolutely destroyed him. He went into a depressive state and began to hate this girl with a passion I had never seen in him. To this day I do not believe he ever moved into a state of indifference towards her. I had stopped even mentioning her name because of the hatred it would bring out in him. For him, in regards to her, he was never able to move from hatred to indifference.

For me I cannot allow something or somebody to have that much control over me and my thinking. While I am engrossed in hating them I am missing out on what there is to offer in my life. I lose. It is to my best interest to move past the infraction to my soul to a place where I can truly be indifferent to the situation and thus gain my freedom to live my life without the pain associated with the infraction.

I remember when I had my laryngectomy and waking up to a world that was nothing like I ever imagined and having feelings of some hatred towards my plight even though I was alive. It was not an overly burdening plight of my thinking but the thought was still there. It took a while after leaving the hospital and living my new life that my thinking moved from life is a burden, maybe to indifference, to live is great. I truly do not know if I was ever indifferent to having a laryngectomy but I know today I am truly grateful to be alive because of having had a laryngectomy.

You old timers already know this, for the others, one thing I always heard from my peers was it gets better. For me getting better was when my mindset shifted from "now what" to this is great! There have actually been times I have felt privileged to have had a laryngectomy. When I woke up in the hospital after surgery I could not have in my wildest dreams ever believed that I would feel privileged by what I had experienced.



SOUTHEAST ASIA 2006

W. C. Baker

One of the problems common to those of us in our so-called golden years, is the occasional inability to recall things from our memory as quickly as we once did. One of the most common frustrations associated with this phenomenon is, if I remember right, being unable to find the name of someone we might have known for decades. I caught a glimpse of myself in the mirror the other day, something I prefer to avoid doing, and said to myself, who's that old guy, he looks familiar. Then I noticed that the guy in the reflection had a runny nose, just like me. Well, I might not be the quickest deer in the headlights, but I figured that one out right away.

Back in the early 20 aughts, when I was chair of the Equipment Program for California's Deaf and Disabled Telecommunications Program, we were approached by a non-eponymous Larry. That is to say that Larry, as I recall, was not a Lary. I think I remember him having a fully functional larynx. But we've already established that my recollections cannot necessarily be trusted. My apologies, Larry, if you should happen to read this and find that I have been remiss in the telling of it. Where was I? Oh Yes, Larry was seeking electrolarynxes (is that the plural, or would it be electro larynges?) to take to laryngectomees in Viet Nam. I don't know quite what Larry's motives might have been, but they seemed good and true and noble, and maybe a bit compensatory for our unfortunate involvement in having been a contributor to the incidence of cancers in their country. So, I agreed to furnish him with any and all ALDs which we might be able to find.

So it was that Rachel and I selected Southeast Asia for the only booked tour in all our travels. (I consider The Galapagos islands to have been a local tour when we were visiting Ecuador, etc.). Larry, whose surname I can't remember, I'm not even sure of the Larry part, Larry gave me an entrée into the Hanoi laryngectomee group. The Doctor who lead the Hanoi laryngectomees, gathered them at the Hanoi hospital for a visit. I was the only esophageal speaker. As I remember it, there might have been a couple of TEP users in the group, but the



preferred speech mode was the ALD. None of them spoke very much, and many spoke not at all. I may have been projecting, but I felt a certain level of resentment, maybe even malevolence. Certainly understandable. Although I had been discharged from the Marine Corps four years before Tonkin, I appeared to be of an age that I could have been one of the American troops that had invaded their country. It was an uncomfortable feeling.

Hanoi was pretty much the middle of the trip which had started in Bangkok Thailand. Bangkok and Chiang Mai were very touristy, with the temples at Chiang Mai being of more interest than the bustle of Bangkok. Laos felt to me to be one of the most laid-back places I've been. When we woke in a Lao village on the Mekong, we found

a quiet bustle as the day started. Motor scooters were the main mode of transportation, some carrying as many as four people. The main street was lined with women filling the bowls of Buddhist monks for their morning meal. In the afternoon, we took fast boats with their long propeller shafts sticking out some 5 feet to travel in shallow water. After a few nights in magical Luong Prabang with its Monastery, the tour group boarded a slow boat to Vientiane. Our last night in Laos featured a street fair and a farmer's market. The atmosphere throughout Laos had been relaxed, the people warm and engaging.

The sense that we were entering a different place was palpable as the bus crossed the border between Laos and Viet Nam. The rice paddies were pools of activity stepping down the mountainside. The contrast with the more laconic Laos was not only at the border, but permeated the length of the country. After a couple of days in the ancient city of Hué, we took the train to Vinh and on to Hanoi. Large craters were visible from the train possibly scars of the American war. Visiting the laryngectomees in Hanoi was not only the geographic pinnacle, it also represented the most direct and most intense involvement with the people, always my favorite part of any trip. Trees, rivers, sky structures, all the physical aspects of a country are ubiquitous, or, as they say in Laos, "same, same, but different". It is the people who live there that give a country its unique character. As different as Viet Nam was from Laos, so was the perception of difference between north and south Viet Nam. Saigon was a non-stop high energy bustle.

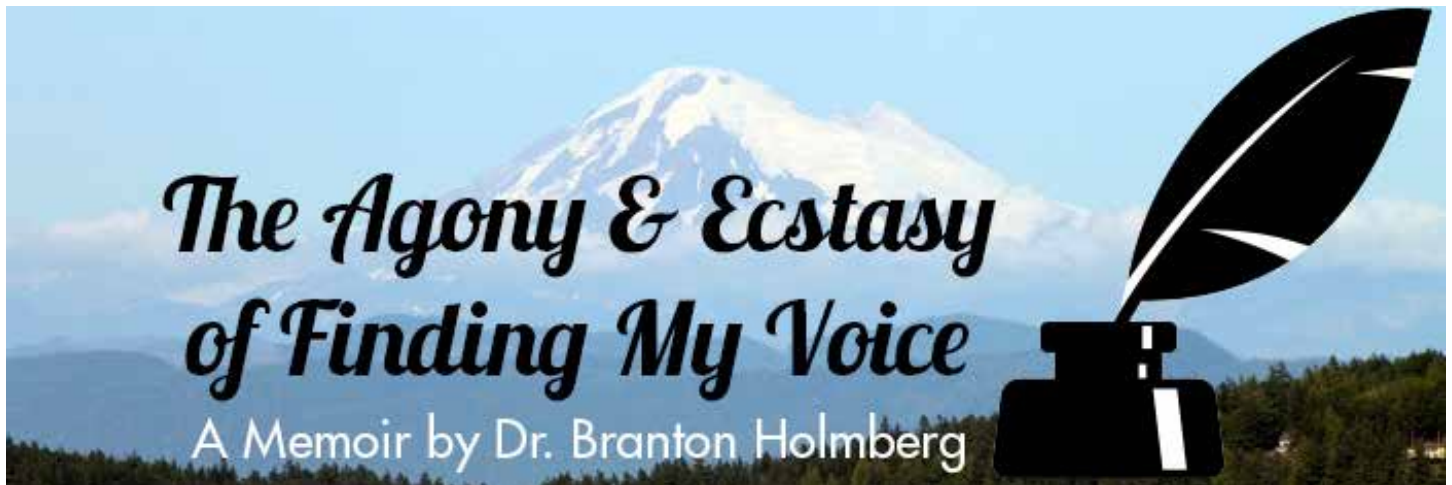
Yet another transition from one energy level to another, was strongly felt on entering Cambodia. Again, I may have been projecting, but it seemed that Cambodia was under a pall, dimmed now by time. Not too far into the smiling friendly eyes there is a remembrance of the terrors inflicted by the Khmer Rouge. Walking on the Killing Fields of Cheung

we found bones, hard white little pieces of people's bodies protruding in the dirt. A commemorative stupa filled with bones, overlooks the field. A tour of a school that was converted to a prison displays photos of absolute terror. As much as one quarter of Cambodia's population fell victim to the Pol Pot. Regime. the serenity of Angkor Wat stands in marked contrast to the Killing Fields. Arriving early in the morning, as the jungle awakens, Angkor Wat lies in a mist of serenity. Then the other tourists arrive and the worlds largest temple complex transforms from a place for transcendence to a hive of tourists clambering over every bit of it.

The bipartisan war that was to prevent the spread of Communism in Viet Nam, Laos and Cambodia saw hundreds of thousands killed. The three countries still bear the scars and disfigurement of its people and its countryside, yet they are nonetheless Communist today. It accomplished nothing but death and destruction. Not to denigrate the service of the Americans who fought. I had friends who died there. Rather, I add my voice to those who would chastise the Government that sent them.







Chapter 13 “A Final Transformation”

As a writer I feel I've found my voice again. It's opened up new dimensions for me that've brought me pleasures I never imagined possible, much like my experiences when I found I loved my voice once it stopped coming through my nose.

Having to deal with my ability to try to effectively communicate verbally twice in my life has taught me many things. What I saw initially as cruel afflictions, have both turned out to be blessings that have defined much of my life. During the years I was growing up, I would have given anything to be someone who didn't have a harelip. It was only after I matured I came to realize it had forged in me a determination to prove I wasn't the misfit I thought everyone was seeing me as, including my mother, father and brother.

All through my grade school years my mother relentlessly compared me to Warren and constantly pointed out to me I should be doing better in school because he had. He'd always gotten better grades from the same teachers I had, when he'd had them three years earlier. There was no question in my young mind my mother thought I was not only her physically deformed child, I was also her mentally slow child. Did she see that too as another of God's punishments?

Those early traumas set me on the path of proving to the world I was more than what I thought others believed I was. I think our perception of what we think others think of us is enormously powerful in the determination of what our life will be like. It has been for me.

I discovered, through my experience with my dental device, I'd created mental images of myself that weren't how others saw me at all. That became crystal clear when Margaret, and then my parents, told me they either

noticed very little difference, or no difference at all in the clarity of speech.

Then by a stroke of good fortune, I had the opportunity to spend several years as a sensitivity trainer. That helped me find ways to share who I was and talk about things that had shaped my life. Every one of the workshops I ran gave me more and more insight into myself, and those around me. Those experiences helped me realize the only way I would find out whether I had the capability to do things I dreamed about doing was to challenge myself to take risks in new fields of endeavor.

As I look back over the years, I see I've gone through a wonderful progression starting from the time I began living with my Uncle Jim and his family. My life up to that point had been a constant, and disheartening struggle of coping with my family, especially my mother, my peers, and myself regarding my harelip and the inner turmoil of feeling I was damaged goods.

Moving in with my uncle and his family I've always considered one of the best things that ever happened to me. My life made a 180 degree turn and set me on a path more rewarding than I would have ever thought possible.

What he did, and Aunt Gladys too the summer I worked for her, had far more meaning to me than either of them ever realized I'm sure. It's a sad commentary on myself to look back and realize how little I told them about how much I loved them and what a huge difference they made to me when I needed it most.

Next were the years I spent as a medical corpsman and the totally unique experience's I had during that time. I look back in amazement at how those experiences were even made possible to me. I was certainly in the right place at the right time, there is no question in my mind about that.

It was during that time I should have been more aware I was speaking without many noticeable problems but I was still so conscious of the air going into my nose when I spoke, I was dogged with the feeling I sounded like a kid with a harelip and I still had the visible evidence of it.

Then I became Dr. Crawford's graduate teaching assistant, going on for my master's degree. It amazes me as I return in my mind to those years, the titanic struggle I was going through inside myself and how little of that was apparent to anyone around me. I'm certain that if the opportunity to be fitted with my dental device hadn't occurred, my life would have remained in a world of private self-pity never having the self-confidence to be successful in a world I felt I didn't fit into.

I truly thank God for the transformation I went through then because it's helped me touch the lives of so many others that I would never have come in contact with otherwise. I'm thankful to have been told by others I've made a difference in their lives too. I've never felt richer than when those moments occur.

Stepping into the world of becoming a businessman was a direct result of the self-confidence I'd built in myself as a professor. That coupled with the many opportunities I had to work with Dr. Pettit as a consultant gave me a lot of opportunity to see inside the world of business.

I was confident that if I continued to teach at various universities part-time as an adjunct professor, and developed my own consulting business, I could make it on my own as an independent businessman. I stepped out into a brave new world as an entrepreneur.

Buying a nursing home in 1978 was a huge step for us. With 61 beds and the responsibility of keeping it operational 24/7 was a big commitment on both of our parts. I give Margaret, as administrator of it, the credit for turning it into a nursing home that had a waiting list of those wanting to come into it.

When we bought it, there was a high rate of turnover in personnel. Many of the positions were low paying due to state funding of many aspects of the operation of nursing homes. Within the first year she had the staff turnover rate down to nearly zero and a group of employees that truly enjoyed working for her.

After we sold it, the next few years of my life were involved with taking care of family members. The first in that succession was my father who'd developed kidney disease and had to be on dialysis. Then he lost his eyesight and became totally dependent on my mother.

I give her a world of credit for being absolutely devoted to dad during his final years. She refused to put him in a care facility and I'm thankful we lived close enough I could give her a substantial amount of help in caring for him. It was shortly after he died that my brother's wife had a terrible stroke that took her as near to death's door as I've ever seen anyone, and I'd seen a lot of people go through the process of dying, including my father.

In what seemed an instant of time, my brother was diagnosed with lung failure in his left lung and his progression toward death happened quickly.

Not long after that my mother developed Alzheimer's disease and I went through putting her into a nursing home and other types of care facilities until she too succumbed to the fate we all face.

The final chapter in my years as a caregiver and guardian of the care of family members ended when my brother's wife passed away sixteen years after she suffered her nearly fatal stroke.

It was just prior to Velta's death I lost my voice to thyroid cancer. I was without the ability to speak normally for the second time in my life. When that happened I fell into the dark labyrinth of speech difficulties I went through as a kid.

The first two years after losing my voice, I found myself again dealing with all the old fears and shame I'd felt as a kid when others couldn't clearly understand what I was trying to say to them. Thankfully I'd long been retired and could limit my contact with others as much as I wished. I did just that.

It took me several months to learn to use my artificial larynx to a level I was comfortable with. During that time any encounters I had with others that left them asking questions about what I was trying to communicate, threw me back into the frustration of why others were failing to understand me. In my mind, and to my own ear, I was saying it clearly yet it wasn't being understood. It brought back those long ago feelings of being a misfit.

It was out of that labyrinth of frustration, self-recrimination and despair Dr. Jack Crawford's book "Time Shadows and Tall Tales", led me to think about my own writing skills and whether I could create a new dimension in my life.

I found as I sat down to write the first pages of my Sam 'n Me adventure series my imagination came alive with the characters I was creating and the settings I put them

in. The excitement of what I was creating grew rapidly and more and more adventures came to mind each time I finished the one I was working on. It opened a world of satisfaction I never dreamed possible.

The world of my writing may be limited to my loved ones and friends who've found I've written my fictional adventures. If that's the extent of those who read my stories it will satisfy my purpose in writing them. I've included in this memoir examples of the books I've written since becoming a laryngectomee. I fear that some who see that inclusion will conclude I'm blatantly trying to get them to buy the fiction books I've written

and nothing could be farther from the truth. Including examples of what I've written is the only way I know of showing you the new voice I've found that has saved me from the agonies of despair from losing the voice I so lovingly found when I was starting my master's degree program.

My writing lets me soar into fascinating realms of my imagination and take me away from the mundane struggles of verbal communications with others. By showing you these examples I hope you will see glimpses of how rich those imaginary worlds are to me and how they let me speak without the agonies of an artificial voice.



I had a full laryngectomy on March 5, 2015. I wanted to share part of my story to offer hope to other survivors.

Sharon Strohm Heck and Sgt. Pepper Heck

On June 25, 1967, the Beatles broadcasted the world's first global television link. They performed live via satellite "All You Need Is Love" to an audience of over 400 million people spread across the globe in 25 countries.

In 1967, many of my generation fervently hoped at least TRYING to follow the beautiful maxim found in all the great prophets teachings to "love your neighbor as yourself" and to "treat others as you wish to be treated" just might save the world. John Lennon's words even in those idealistic times did seem, however, a bit naive. Easy for a millionaire singer/songwriter to preach "All You Need Is Love" while some of us were struggling just to meet the most fundamental of Maslow's Hierarchy of Needs: food, water, and shelter. Now, when humanity seems to be ripping the flesh off itself layer by layer, the words "All You Need Is Love" might seem hopelessly blind to the hate that sometimes seems to rule our species.

I hope you will forgive my indulgence. I am going to write a story of an incident where I am convinced Love gave me the will to survive and Love saved my life:

I have been blessed with the true love of family and friends

throughout my life, starting with my Mom and Dad, Sister and Brother. Late in my life, however, the love of my wife, Sharon, saved me to live a few more years.

In the summer of 1975, after my undergraduate work at UF and before I started teaching, I treated myself to a solo camping/bicycling tour of sweet New England. On that tour, I fell in love with New England. I also dreamed of someday working at a small, residential New England college and soaking up the four seasons. In 1985 after completing my PhD, however, I went down a career path that led me to serve as a higher education administrator primarily at large, southern colleges and universities.

In 2013, the dream of returning to New England to close out my career became a reality. My wife Sharon and I loaded up my trusty Dodge Dakota pickup and a U-Haul trailer and in late January off we went. Along the way, my persistent soar throat got worse. Two Florida doctors had diagnosed my sore throat as allergies, but Sharon convinced me to seek out a new Ear, Nose, and Throat surgeon as soon as possible. Through sheer luck and Sharon's loving nudging, I picked the right surgeon, Dr. Karen Miller. On my first day of work, Sharon and I started a journey that would include horror, seemingly endless pain, and yet at times incredible love.

By Friday of my first week on the job and with Sharon by my side as I was admitted to the hospital, I went into exploratory surgery.

Soon after the surgery I got the news: I had 4th stage throat cancer. I had a 97% chance of dying in 6 weeks without treatment. With treatment, I had a 40% to 60% chance of staying on the planet a few more years. Treatment would be 36 sessions of maximum radiation and 4 cycles of maximum chemo.

Here's were the love really kicks in. When I told Sharon, of course, she was stunned. Then she smiled into my eyes, took my hand, and said "hell Dr. Heck, 36 days is nothing." In essence, Sharon gave me the will to survive.

I'll try not to bore you with too many horrifying and yet sometimes beautiful details. Sharon and I got up at 4 am for 36 straight days to make the hundred mile journey for radiation. She helped me into bed as the radiation sickness took hold. She helped me clean myself when I had radiation sickness. During the third cycle of chemo, she was there for me when I went into seizures.

Sharon brought soup to me as I recovered. She rejoiced with me when Dr. Miller announced that the tumor was gone. As I struggled back to work, far too fatigued to do much of anything after work, Sharon helped me to bed.

When my permanently suppressed immune system could not fight off Lyme disease, Sharon cared for me as I struggled with that horrible nightmare. She lifted my head up so I could drink water when Lyme disease robbed me of any strength.

In 2015, the real battle began. The throat cancer returned. My only option was a full laryngectomy. Essentially, that means during 13 hours of surgery, surgeons slit your throat open from ear to ear. Then they slice out your vocal cords, construct a permanent pipe leading directly to your lungs, and leave you with a one inch hole in your neck that you breath through until your death. They also insert a voice prosthesis into your throat so that most of the time you can speak. Your vocal sounds are distorted. Frequently, you need special care to replace the prosthesis. But again, Sharon was by my side through all of this.

As I was on a gurney waiting to go into surgery for the laryngectomy, Sharon held my hand as one surgeon told me "don't go through with the surgery since the cancer has spread to your lungs." Another surgeon told me I must go through with the surgery since they were not certain the cancer had spread. Sharon looked me in the eye, smiled and said she loved me, and told me she would be there for me in the ICU recovery room.

Sharon sat alone in the Dana Farber Hospital, Boston, waiting room during my 13 hours of surgery. In the recovery room, as I drifted in and out of consciousness truly not understanding if I was alive or dead, Sharon's smiling face remained etched in my soul.

Throughout my 14 days of recovery in ICU, Sharon walked from the hotel to the hospital to greet me each morning with a smile. Sharon walked through the worse Boston snow storm in living memory. The sidewalks were tunnels with walls packed 15 feet high with snow. The wind howled. The sun remained hidden behind grey clouds. Yet Sharon came each morning with good cheer, with a beautiful smile, and with love that eventually erased my wish that I had died on the surgeon's table.

After my release from Dana Farber, I faced six weeks in bed trying not to choke to death on my own secretions. Without the music of the Beatles and other favorite musicians, without books, and especially without Sharon, I honestly don't know how I would have survived.

Frequently, Sharon had to come rushing into our bedroom, turn on the emergency suctioning system, place the suction tube into my lungs, and save me from choking. When I struggled to return to work, I caught numerous "chest attacking viruses" through my open breathing hole. During several ICU emergencies for life threatening pneumonia, Sharon called the ambulance, followed it to the hospital, and again saved my life.

Now with the surge of the pandemic, Sharon lives with a man that has all the major risk factors. She lives with a man who has a hole in his neck that he breathes through and many other permanent disabilities. Sharon tells me that all we have faced together has only brought us closer. I tell her that her love and caring saved my life. I tell her I am a lucky man. I tell her that I love her. I tell her that on some deep level "All You Need Is Love."

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

Donna McGary Managing Editor • Kim Almand VoicePoints Editor

Disclaimer: The information offered via WebWhispers is not intended as a substitute for professional medical help or advice but is to be used only as an aid in understanding current medical knowledge. A physician should always be consulted for any health problem or medical condition. The statements, comments, and/or opinions expressed in the articles in Whispers on the Web are those of the authors only and are not to be construed as those of the WebWhispers management, its general membership, or this newsletter's editorial staff.