

# Whispers on the Web

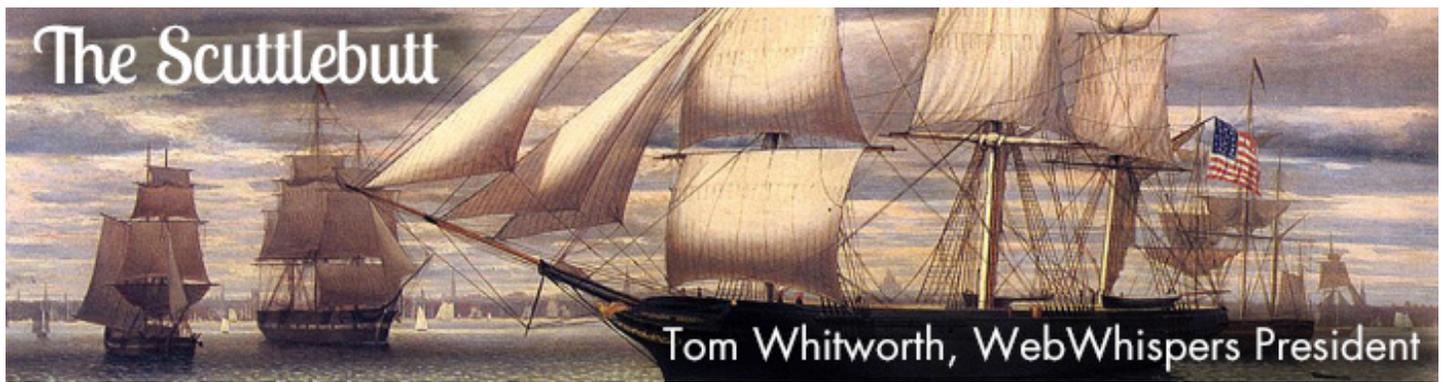
A Monthly Online Newsletter for WebWhispers

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## You Can Prevent Cancer! We ALL Can!

Web Whispers is focused on recovery and rehabilitation. We don't address the causes of our cancer much at all. In some online venues, discussing what caused our cancer is actually frowned upon. Historically, WebWhispers is one of those places. I get it. We are zeroed in on helping people with the aftermath of cancer treatment and surgery. We helped me and I am grateful to God and Pat Sanders that we did. People in 146 countries believe we do an excellent job of that-Sharing Support Worldwide. Among Pat, the IAL, all of you who helped me and still do, and those who have gone before me that were so important in my recovery, not one ever asked me how I got cancer. Why? Does that matter? No, it doesn't! We have all been through the same trauma and we are all here to help one another.

The source of our cancer is certainly more than one thing. We have cancers related to genetics, alcohol and tobacco use, GERD, Human Papillomavirus (HPV), and more. We do have some things in common, cancer being one. Another thing we have in common is that not one of us ever stood up from our chair and said "I think I'll run out and see if I can get me some cancer.". How and where we got cancer is not important. None of us can go back and change our DNA. Not one of us can put life in reverse, fix something, then come back to 2019 with this horrible disease having never happened to us. Some of us give talks at schools regarding the dangers of smoking in our attempt to help young people avoid getting cancer that way. But, what if we really could prevent others from getting cancer?

We can! In the United States alone, as many as one third to one half of adults will have HPV at some time in their lives. Most never even know as the virus sometimes goes away on its own. The virus is believed to be largely transmitted through sexual activity, but there are also other links. But when the different types of HPV, which number 100 to 200 depending on your source of information, do not go away, cancer can result. The number of cancers from the virus are many, with

cervical being the most common, but cancers of the head and neck are on this list, too. I wouldn't wish what I've been through on anyone, even Satan himself! If I can do anything to help young people avoid head and neck cancer, I should and I will. You should, too.

The Centers for Disease Control in Atlanta has done extensive research on the HPV vaccine. Their findings are that the vast benefits of the vaccine, far outweigh the uncommon risks. Generally, the vaccine can be given as early as age 9 but usually around 11 and 12, to be effective against some types of the virus. It can also be effective up to age 15, or even 26, according to some sources. From only 3 kids, my mother has 9 grandkids and 9 great-grandchildren, with one on the way, and I dearly love them all. I will be doing what I can to encourage the parents in my family to have their children vaccinated. Why? Because I CAN prevent cancer! I hope you will do the same.

For more information, take a look at these articles and websites:

[https://www.cdc.gov/hpv/parents/hpv-vaccine-for-boys-and-girls/index.html?s\\_cid=PN-NCIRD-HPV-Con-AW-HPVQs-2-Search](https://www.cdc.gov/hpv/parents/hpv-vaccine-for-boys-and-girls/index.html?s_cid=PN-NCIRD-HPV-Con-AW-HPVQs-2-Search)

<https://www.cdc.gov/hpv/parents/cancer.html>

<https://www.mayo.edu/research/forefront/mayo-clinic-cancer-center-endorses-hpv-vaccination>

Maybe a little heavy here, but this is important!

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



# Voice Points

Written by Professionals

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

[kbalmand@gmail.com](mailto:kbalmand@gmail.com)



## Strategies For a New Generation of Oral Cancer Patients

Once mostly confined to an older population, head and neck cancer is showing up in younger patients because of HPV exposure.

The face of head and neck cancer has changed since I began working as a speech-language pathologist at a university cancer center 24 years ago.

At that time, my patients tended to be older men with a long history of tobacco and alcohol use. Today, my patients are much younger, healthier and tobacco-free—but they have HPV, the human papilloma virus. HPV comprises more than 200 related viruses, many of which are known to cause certain types of cancer.

HPV is sexually transmitted and also known to cause cervical cancers. While other cancers are showing a decline in numbers, HPV-related cancers are on the rise. According to the U.S. Centers for Disease Control and Prevention, studies show that about 70 percent of oropharyngeal cancers in the U.S. may be linked to HPV.

### Late diagnoses

The initial symptoms of head and neck cancer are often similar to a cold or allergies: sore throat, painful swallowing, earache or voice changes. Many young, healthy people dismiss those symptoms. If they do seek help, they are often treated for allergies, infections or reflux because of their perceived low risk for cancer. Only when those symptoms persist or get worse, despite treatment with antibiotics and other medications, is the correct diagnosis made.

Other patients may not experience any symptoms at all until they notice a lump in their neck. This lump signifies the spread of cancer into the lymph nodes.

The misattributions and the lack of symptoms until a

lump appears increase the stage of the cancer to be treated. Because of this delay in diagnosis, patients with HPV-related head and neck cancer often have advanced-stage disease by the time they come to the cancer clinic for the first time.

### Better outcomes

The news isn't all bad—treatment has made remarkable progress in the past two decades. The patients with advanced oropharyngeal cancer that I saw early in my career often had poor outcomes. Their treatment required disfiguring surgeries followed by chemotherapy and radiation. The disease-free survival rate for patients in advanced stages was less than 25 percent.

However, HPV-related cancer is more responsive to radiation, chemotherapy and immunotherapy (see sources below), giving patients a prognosis for disease-free survival of 85 to 90 percent. This increased responsiveness allows physicians to de-escalate their treatment protocols, reducing the intensity and severity of the associated side effects.

Patients with HPV-related head and neck cancer often have advanced-stage disease by the time they come to the cancer clinic for the first time.

In addition, transoral robots have eased surgical approaches to these hard-to-access areas of the throat.

HPV is also the only cancer for which there is a vaccine. There are three vaccines available. They are given in two doses and are most effective if administered at puberty, prior to onset of sexual activity and exposure to the virus.

In addition to prevention, early detection is vital. The Head and Neck Cancer Alliance encourages talks during the annual oral, head and neck cancer awareness week in

April to educate middle school students about the risks, symptoms and prevention of head and neck cancer. Medical and dentistry programs are standardizing head and neck exams as a routine part of the patient visit. And media campaigns have raised awareness for the general public.

### **New population, new practices**

So how has HPV-related cancer changed my practice? Younger patients present a very different profile from older patients, and have very different needs. They are working, have spouses and young children—and have higher standards for their outcomes. They need to communicate, not just for socialization, but to perform in their jobs to meet their financial responsibilities. They want to return to an active social life that includes eating and drinking. And they want and expect to be able to do those things for a long time after their cancer treatment.

My treatment starts at the patient's diagnosis. I counsel patients about their disease and treatment and their potential effects on communication and swallowing. We start them on swallowing exercises at diagnosis, to maximize their recovery potential.

Patients undergoing transoral robotic surgery (TORS) typically have significant swallowing discomfort for about a week after surgery—not unlike the swallowing pain after a tonsillectomy—but are often sent home the day after surgery. During this time, patients are often on a liquid diet. I encourage them not to forcefully cough to allow the throat to heal.

I emphasize strategies to maximize intake while minimizing risks and discomfort. Once a patient has healed from surgery, exercises can resume. This is very different from my early-career patients, who often had a split mandible and tracheotomy, were in the hospital for one to two weeks, and on alternate nutrition for several weeks.

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Radiation therapy (RT) techniques have also changed significantly over the past decades as a result of improvements in engineering and computing: the use of photon beams, intensity-modulated RT, and adaptive RT that individually tailors the treatment and reduces the intensity of side effects.

Nonetheless, radiation toxicities can produce side effects including reduced saliva production (xerostomia), reduced

or altered taste (dysguesia), and pain with swallowing (odynophagia). These acute side effects typically show up about 10 days into radiation treatment.

I advise patients to address symptoms as they appear, modify their diet if necessary to maintain oral intake, and perform prophylactic exercises to maintain swallow function and preserve salivation, taste and mouth opening (see sources). Side effects typically resolve six to eight weeks after radiation ends, but most patients continue to experience some degree of chronic dry mouth and taste changes or sensitivities.

If patients don't address these acute effects, they may lead to chronic issues with scarring (fibrosis), reduced jaw opening (trismus), dental decay and reduced bone integrity (osteoradionecrosis), all of which can affect speech and swallowing function. To motivate patients to stick with aggressive oral care, swallow exercises and normal diet texture, I emphasize the importance of working to maintain function versus trying to regain a lost function.

Because these younger patients are surviving longer than ever before, we have no data on the long-term effects of their treatment. Reports of late radiation-acquired dysphagia (late RAD) indicate that patients are developing fibrosis years after their cancer treatment, resulting in profound swallowing deficits. I am hopeful that advances in treatment options and de-escalation of treatment will reduce the percentage of patients with late RAD, and that preventative measures through vaccination will reduce or even eliminate HPV-related cancer.

However, until then, we have to educate the public and our colleagues on head and neck cancer and advocate for the rehabilitation services our patients need in the years following treatment.

*Julie Blair, MA, CCC-SLP, is a clinician and instructor at the Medical University of South Carolina. She is an affiliate of ASHA Special Interest Groups 3, Voice and Voice Disorders; and 13, Swallowing and Swallowing Disorders (Dysphagia). blairju@musc.edu*

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# Between Friends

Donna McGary

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

Photo CC by Cu-art15239

## Impressed and Inspired

After reading all the articles in this issue I am feeling more than a little humbled and more than a lot grateful. WebWhispers is an amazing community and I really just want you all to read what folks have written this month. Start off with Speaking Out and the remarkable accounts of folks' recovery and rehabilitation. My new favorite expression from David Smith in Tennessee is "laryness happiness". He also notes that both "confidence and awkwardness are contagious" and if we are confident folks around us tend to view us that way. What a great observation. I never thought of it that way but it is so true.

Then read what our two newest contributors, Don Renfro & WC Baker have to say about lary life. I am fascinated by the different ways we all "keep on keeping on". I had no idea my favorite "Monkee", Davy Jones was so philosophical. Read My Neck of the Woods to better understand "altitude and attitude".

And of course Doc Brandon Holmberg continues his delightful memoir. You can get the whole shebang free online just for the asking if you just can't wait to find out what he's up to next!

There's more this month to ponder but to say I'm impressed and inspired would be an understatement. Please, stop reading me, go read them!!!

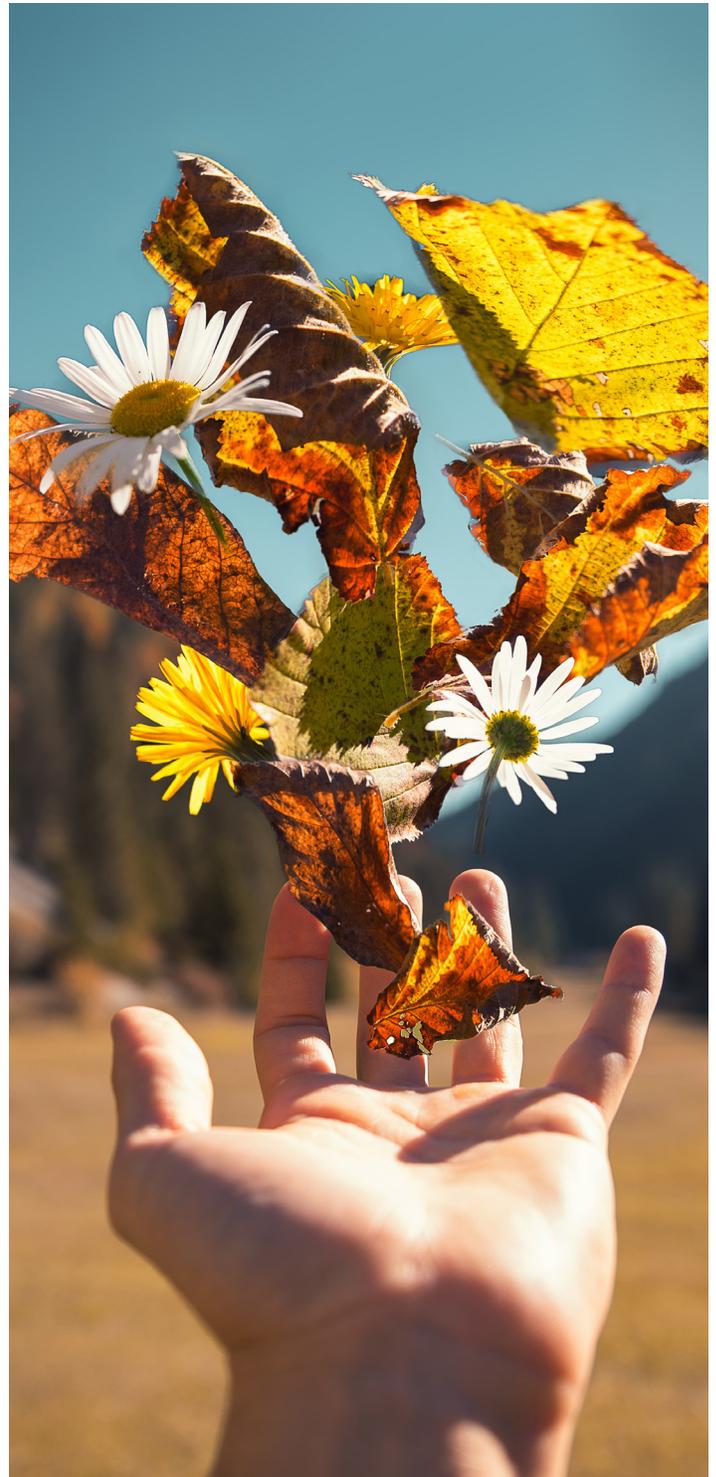
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*Donna McGary Managing Editor*

*Kim Almand VoicePoints Editor*

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*This is mostly for all of us who are more than 3 years out but we welcome any and all responses. We often talk about laryngectomy recovery and rehabilitation in terms of months and years rather than days and weeks. 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?*

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I am going on 20 years and recall that around 2-3 years, if I recall correctly, things had stabilized physiologically and I was doing everything I wanted to do and that I had been doing prior to the surgery. The few things I could no longer do (be heard in a noisy restaurant etc.) were relatively easy to deal with. We moved a couple of times so in the new environment there were new people to meet who for the most part seemed to accept my condition quickly and we moved on.

I should add that I consider myself to be very lucky to have had a very good outcome with the surgery, did not require any reconstruction that involved flaps, and have had few after effects beyond the standard that most of us have from radiation and surgery. Attending several IAL conventions and participating in the support groups did a great deal to make me realize that I was fortunate to have good results from the treatment I received and continue to receive from a talented medical team.

Dick Sipp  
2000

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I am now 4 years done. I do not think about it now. Just part of my normal life. Luckily at 83 I am retired so an extra hour in the morning and night in the bathroom is not important. In the supermarket talking to my wife with my Solatone if someone looks round I give them a smile and carry on. No Problem.

Colin Lovering  
UK

I am a lary since 2014. And I am satisfied with my lary life. I'm happy. I started feeling pretty "normal" within a few mos of my laryngectomy. I did have several recurrences and additional surgeries, pec flap, throat reconstruction, but always recovered well. I also had thyroid and lung cancer. Lost half a lung. Recovered well. I just have to hike slower.

The fact that I have a good voice (electrolarynx) helps in my laryness happiness, I'm sure. I rarely feel handicapped. I do "feel" my disability somewhat when my grandchildren come to swim at our house. I can't do everything they can do in the water, but I put an inner tube type float tube around my waist, up under my arms (very secure) and play in the pool with them. Just no roughhousing. And I wear an HME with baseplate and dunk my head under while pressing the HME button (not recommended my my Drs). Also, I feel slightly handicapped when I go out to loud restaurants to meet friends. I often have to lean over real close to them to talk, or type on my "BIG" text phone app and show them the words I want to say. But my friends and I are totally used to that.

I pretty much have zero self consciousness about being a laryngectomee or about my EL voice, because it's a good and easy to understand voice, and because I'm so used to talking to people I don't know, almost daily. And I've seen evidence that the several recent lary TV commercials have helped raise "lary awareness" and increase the public's understanding of us. I go to and socialize at restaurants, church, funerals, parties, etc, and have stood up spoken in large rooms full of people I don't know. I've noticed that both confidence and awkwardness are contagious; if I appear confident with my voice, others usually feel comfortable with it. If I appear awkward with it, others will be. Even when used with confidence, my buzzy voice does occasionally raise a few eyebrows, but it doesn't bother ME. It bothers THEM. It used to bother me and not them. Interestingly, this slowly transitioned to it bothering them, but not me.

I'm very confident talking in public places. In fact, after 6 years of my new normal, I often forget I am even using an EL. It does occasionally, but rarely, seem to make a waitress or clerk

a little nervous. But I can usually turn their awkwardness into entertainment, by making a silly comment, and then we both get a laugh out of my voice. I often say, "I don't really have to use this thing to talk. I just do it for fun." That gets them every time. I've noticed and have come to appreciate that people give me a little more consideration and respect than before I was a laryngectomee.

People are a little kinder to me than before. People want to hug me more often than before. This is all a win-win. Helps me, helps them. And often when talking to a stranger, I can sense that I have touched them in a good way. I've made a few people emotional, simply by regular chit chat. Apparently, I've either made them appreciate their lack of handicaps, or made them appreciate me for prevailing over my handicap, or both. It's hard to describe. A young male clerk at an office supply store once said, "Hey buddy, you made my day!" Not knowing what to say, I just smiled and shook his hand. I'm a happy lary.

David Smith, Tennessee

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I'll say that two years and three months after surgery, I find myself as I was before. This having a hole on my neck is just the way things are now. I take care of my stoma mornings after rising and nights before showering. Just like I did before with my nose. Wearing the HME is routine and talking, either pushing on my HME or using the electrolarynx are also routine. I live comfortably with my "new" way of breathing and talking.

Marco Mercado-Torres

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Although I am not yet 3 years out from my surgery, it was about this time 3 years ago that I realized something wasn't right and I needed to see a Dr. I was getting out of breath walking 20 feet, I was tired all the time and I just didn't look like myself. Fast forward to diagnosis, Nov 2017 and all I wanted was to have the cancer out of my body and I didn't give any thought to the aftermath. I'm glad, because it may have changed my mind about my treatment choices. My scars don't bother me, my hole doesn't even really bother me (except when I have to cough and there's not a tissue in sight) but, my voice is still a hard hit for me to take. I feel like I lost so much of my personality when I lost my voice. I'm not 100% sure I'll ever feel differently. I struggle every day with making phone calls or knowing I'll have to speak to someone new. Without a doubt the worst part of this for me are social events, trying to speak in a large group of friends, keeping up with the conversation, joking and laughing. Singing in my car, I still do it, more like lip syncing, but I'm the only one that knows that. No I wasn't a good singer, in fact I was terrible, but in my car that didn't matter. Crying... even crying isn't the same anymore. Just the little things I took for granted before. I appreciate life more now, I take time to feel a moment, I smile more and I love that I've been forced to appreciate the things that I once may have taken for granted. So in some ways yes, it has altered my life tremendously but they are not all bad.

Jennifer Karkenny (Malkiewicz)  
January 2017

I'm twenty six years out and a lot of my recovery has not changed in that time. I was very fortunate to have support from my family, my church, local civic organizations and my employer. I received my voice prosthesis four weeks after surgery and returned to my job as a senior utilities engineer six weeks after surgery. There were early issues with eating and swallowing, physical strength and endurance, and some self-image.

I went through the normal post surgery issues with mucus until getting a hands-free valve six months after surgery. I fought with yeast issues for about a year until an infectious disease specialist got me a prescription for Nystatin which other doctors kept ignoring. Several years out, surgery and radiation finally caught up with my thyroid and I became a Synthroid user. About six years out, radiation, the gift that keeps on giving, caught up with my lower front teeth. Root canals and stainless posts handled that for another ten years, but finally I had three implants and a permanent plate to resolve the issue. All of these issues were relatively minor in my mind and did nothing to affect my long term recovery or self-image.

I continued working for four years after surgery, finally retiring in 1997 with a Golden Handshake. I continued my involvement with civic organizations, still chairing two today. I remained active in my church, having been treasurer now for 22 years. My family lives nearby and I see them no less than weekly. My wife did pass away 14 years ago, but again with family and church support, I have been able to cope quite well - I think. I live alone in a 600 sq ft accessory cottage to my original home. I'm a decent cook, reasonable housekeeper and manage quite well.

There are obvious issues of aging now 26 years later. I'm 82 years old. Everything takes longer, upper body strength is diminished, eyesight is affected. memory is not always what it used to be. But I consider this to be a normal part of growing old and all things considered am in reasonably good health. My TE voice is still among the best with the upside being I'm always recognized and the downside being I can't be understood in crowds.

Back to the basic question - I was fortunate to be rehabilitated early and am still fortunate that my rehabilitation continues to be stable. We're all different. I consider myself to be one of the lucky ones.

Carl Strand - Mystic Connecticut

Laser surgery and radiation - 1991 Laryngectomy - February 10, 1993

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My perception of my "new identity" has not changed. I think this is because I have always felt my total laryngectomy only changed the sound of my voice, not how I or others "identify" me. I was fortunate in having an excellent TEP voice two weeks post op when I received my first prosthesis and was quite comfortable with my voice and "neck breathing". More challenging? Certainly, in some ways but when I learned that I should not expect to be understood in a noisy, loud situation and it was necessary to be careful with enunciation it was less of a challenge and more of a conditional handling of my communication techniques.

I don't consider myself to be "self-conscious" of my scars. I am aware, however, that a "big ol' hole" in a person's throat can be quite a shocker to others and, as a matter of common courtesy, keep my stoma covered (not hid) when in public. This seems to only stir the curiosity of others without offending them. As far as transition from recovery mode to full rehabilitation, I was fortunate in discovering WebWhispers well in advance of my surgery and had the time to do a lot of research. This, in addition to my immediate good voice left me with practically no mental/psychological, only physical rehabilitation. Even though I found the surgery physically traumatic I was in good physical condition going in and worked through the six months or so with little interruption to my life.

One last thought: I continue to experience new situations as a Laryngectomy and adjust accordingly. A lesson learned is that "nothing is forever". Thank you Dutch Helms for opening this wonderful portal to the World of Laryngectomees.

Dave Ross in Florida  
Lary Class of '05

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Life after laryngectomy can be quite normal if you work at making it that way. I am a professional saxophone player who reluctantly had the surgery in 2015. I thought that my playing days would be all in the past and I began looking for alternatives to satisfy my artistic needs. I do also play guitar and keyboards, but those did not provide the same satisfaction as saxophone playing did. So, also being good with fixing things, I came up with a way to use some tubing to reroute my breath from my stoma into my mouth. I then made some tweaks to my electronic saxophone and I am now able to play again. I play with several bands at night clubs, Legion Posts, VFW's, etc. and I am really a better player than than before surgery. My biggest complaint is that it is hard for people to hear my voice when I speak using my EL in the usually loud bar settings. And of course there is the constant airway maintenance that we have to deal with. But those aside, I feel that I again live a totally normal life.

I urge those who have had the surgery or are about to have it, to keep a positive attitude and not look for issues. Rather, look for accommodations and modifications to lifestyle and the physical world around yourself, which will allow you to be "normal." I realize how lucky I am to have had a successful and routine surgery and thank all of my providers for what they have done for me. But when it comes to your mental health, it is so important to remain positive and to focus on what you can control in your life rather than what you cannot. I have made some adjustments, and my experience tells me that this is what it takes to have a good life post surgery. Give yourself time for these adjustments, and try to think outside of the box when confronted with obstacles. We can do amazing things if we set our minds to it.

If there are other former sax players out there who want to learn

from my experience, please send an email and I will respond.

Donald Thiel AKA Hurricane Donnie

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In the beginning...

I saw no light at the end of a very dark tunnel as I had refused chemo so my doctors saw fit to inform me my chances of surviving went from a dismal 35% down to an even more dismaying 10-15%. All during radiation treatment (36) those suppose to know kept telling me: Won't be able to ride. Sell your bike. Won't be able to do this, that, and the other. Won't, won't, won't.

Had lots of mucus so I had a suction machine. Had another machine that provided 'misted air' to help break it up so I could breathe better. Couldn't be away from them for very long, but the buggers were so BIG there was no way to carry them every where I had to go.

Six months post op I decided enough was enough and tried to drown myself.

What happened next many will say PSHAW that's bull snot, and that be okay because ye be free to make that decision. Other's will say: "How do you know it wasn't your own voice telling your conscience that." Again...it be your choice to make, but know this truth. I was in the master bath. Doors locked. Wife working and I'd taking some muscles relaxers before getting in the big tub of hot water.

I did not push myself up once I slipped under the water because I was asleep. Believe, don't, your choice. Just know I 'FELT' someone lift me out of the water and, as I sat coughing out water I HEARD (did not imagine) that presence very clearly asking: " What's the matter? Don't you trust me?" My life changed after that.

As a biker life has always been one great big adventure. Modern day pirates we were. Riding our iron steeds into any town USA doing what we wanted, taking what we desired, and to hell with anyone that didn't like it. Those days (at least for me) began to change after I got saved. Yeah, yeah, I know what you're thinking...Just another knucklehead Christian spewing bible speak to those that do not wish to hear it." And you are wrong. Your soul, your choice.

Two months after that night I put those machines in the closet and they still reside there to this day. Bike went into the shop to be checked out and made road worthy four months after that night.

Did put a windshield on it like all the naysayers said I should oughta . . . but three weeks later that puppy came off. I'm old school biker. Don't care what others prefer, but I don't like windshields or fairings. No cup holders, nor stereos., and I ride in the ran and cold just as well as when the sun be shining. And granted living in Florida certainly helps me live that

dream, but even when I resided along the shores of Lake Erie so many years ago -- we rode -- even in the snow.

Naysayers said I needed the windshield to protect me if I got caught in the rain. Same day I took it off I got caught in a Florida afternoon deluge. Saw it coming from a mile away. Wall of water. Whiteout they be called. No place to hide. No bridges, nor gas stations/convenience stores about, and no trees. Certainly not going to stand beside the road in a downpour like and idiot. So I rode right into it because that was the only other choice I had. And I didn't drown.

Be 13-years post op come 10/30/2019. Life's back to normal as much as it can be. I'm 67 this year. Getting gray, but still riding as bike is our only means of transportation. Blood/ox always checks out at high percentage or better than most face breathers. I have a blast with kids because they are always fascinated by the biker guy in line behind them. Then I speak: "you're right kid. I am an alien from the planet Trollite. (Because I'm called Troll by everybody)" I've got a whole spiel developed just for the kiddies.

Badge of Honor? I'm glad to be a survivor of 13-years. No denying that, but I'm even more proud of the fact that late one night . . . in my darkest hour . . . the Savior I had excepted in 1976 actually came to ME . . . and asked me to trust Him. And because I did He gave me what so many were telling me I could not have. My life back.

Oh, sure . . . been a few adjustments, but for the greater portion . . . I have been thoroughly blessed. Far greater than I deserve. I eat what I want. Ride . . . and haven't had any problems health-wise since my treatment ended. Suffered no hair loss, nor nausea, or any of the numerous maladies they say you'll experience during treatment. Actually gained weight. Which I'm finally shedding. Breathing's good. No machines. Able to eat what I want.

Like I said -- blessed far more than I deserve.  
Thank you Jesus.

Troll  
Class of 2006

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My surgery was June 2010. For almost a year, whenever I was out 'in the world', I figured I was the always center of everyone's attention. So, if I had to cough and clear my stoma, I would always have to find a restroom, secluded corner or any place where no one would see me. But, then I finally realized that it was not all about me! People all around have their own troubles; and are coughing, hacking and sneezing themselves. Nobody cares what I do. That was the breakthrough for me to get comfortable with my new normal. Sure, if I'm in a social situation, I'll be a bit discrete; but totally at ease now.

Peter Meuleveld, Salem, Oregon  
June 2010

My surgery was April 1, 2008 and like so many others, I was feeling down, mad, and wondering why me. However, within one year, my SLP kept encouraging me to start a Lost Chord Club to help others. I didn't think I was the right person for doing this but she saw something in me that I didn't. She was so adamant that I would do well, that at 14 months post surgery, I decided that I would give it a shot, mainly just to show her what I was talking about. She found us a meeting spot and I started the Peninsula Lost Chord Club with just me, my wife and one other Laryngectomee. It took three months for us to start getting more attendees and I got hooked. When the attendance kept growing it did something that I was not expecting, it actually made me feel that I had a purpose in life and it made me grow as a human being. By helping others, I began to feel more secure and confident in what I was doing and I think it actually helped me heal and grow. It has now been 10 years and I still see the club growing. As with any club, we have lost some folks along the way but there always seems to be new members looking for help, camaraderie and just a place where they can feel comfortable with folks who sound different. I think I am a better person, inside and out, for listening to that SLP and I will always be grateful for her insight.

Tom Olsavicky, President  
Peninsula Lost Chord Club  
Newport News, VA  
2008 Laryngectomee

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My treatment for pharyngeal cancer began in January of 2002 and consisted of 3 weeks of 24 hrs per day chemo broken into a week in the hospital and two weeks off. The chemo treatment was followed by 31 days of twice a day radiation. Over time the scar tissue from the radiation, the gift that keeps on giving, continued to grow and compromised my voice box. After several bouts of pneumonia and considerable weight loss I had a tube inserted in my stomach so that I could be on a liquid diet. My voice was weakening all the while. In June, 2015 I had an emergency tracheotomy and in August a total laryngectomy. I began eating light foods shortly after and in October, 2015 had an ultravalve installed and after 1.5 years of using the tube I began eating regular food. I had the tube removed January, 2016 and use a TEP to speak. I spent 5 days in the hospital for the trach and then the lary and those were the only days that I missed golf and other activities. After the trach I carried my suction machine with me while playing golf etc for two months and rarely used it after that. I have not used it in several years. Until I could speak I carried a note book and pencil with me to communicate. An interesting and humorous result was I would present my note to someone in a store, bank, etc and often they would respond in writing on my pad even though I could hear fine. With one exception everyone treated me respectfully and were very helpful. After the total lary I had difficulty finding the right valve and experienced a lot of leaking and blocking of the various valves resulting in frequent visits to the clinic at Massachusetts Eye and Ear. I now use an Activalve and the current one has been in a year. I also use lary clips that last

anywhere from a few hours to a few days. I occasionally use the straps to secure the lary tube but find that they begin to fray at the edges after a few days. I am not impressed with the quality of the products supplied by Atos. I am 79 and I lead a normal active life and am not restricted in anyway. I have a strong voice that draws attention when in a restaurant, store or other places of business. Usually just a glance and an occasional stare. From day one I have been determined to lead a normal and enjoyable life and continue to do so. I pay attention to what nurses and clinicians show and tell me and I am constantly experimenting in an effort to learn and develop. I believe that a positive attitude is the key to our survival as laryngectomees.

Dick, Class of 2015

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I am very fortunate. With my TEP I have a low voice like Barry White and a high voice also. Gives me great voice inflection. After 8 years I've had no problems. Replace my TEP every 6 months. My routine is get up in the morning and twist my brush in the tep. Then I can voice. Other than that... Thru the day if I cough and stoma gets blocked I use a flashlight and stainless tweezers to clear the blockage. Oh and a mirror.

I still go into my swimming pool. And shoot billiards every Wednesday. No problems with any food. French fries get stuck on my TEP but not always. Need to chew better. But life is good.

I visit probable larys and give them hope that there is life after the surgery. Let them know it not a cake walk. But to hang in there. Too much life to live.

Robert Megrey  
Brunswick, Ohio

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I am about three and a half years out so I may not yet have the "seniority" to answer your question.

I don't see my stoma or my voice as a "badge of honor" but simply as the only available means to have saved my life. The attendant outcomes such as breathing differently and sounding differently and not being able to modulate my speech are simply facts and nothing I do can change them. It is what it is. Accept it as the price of still being able to hug your grandchildren.

The one thing being a Lary has taught me is patience or if not that, the acceptance of frustration. Everything takes longer than you want it to and the healing process takes forever. You cannot will your body to heal faster than it can and you had better adjust to that reality or you are in for a miserable couple of first years.

My coworkers and to a large degree my customers have come to accept my new reality and they look upon it as just the way things are for me. Sometimes my speech degrades and they just have to listen harder. But to them, and to me, it is just the way it is for me.

Perhaps as I spend more years at this, my attitude will change. It has since the surgery and I would not be surprised if it continues as I progress in this journey.

Joe Rook, 2016

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I guess that I am borderline. I had a tracheotomy in January of 20015, but the cancer was still there, so I became a Lary 11/3/15. I honestly say that I haven't really noticed any real difference in my personal life.

I was 85 years old when I became a Lary, and have been a shut-in pretty much since I became legally blind in 2004. Beside that most of the people that I grew up and worked with are dead.

I will be 90 September 24th Birthday cake

Johnnie Dontos 11/30/15  
Woodway, WA

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On September 11th, it will be 11 years since my surgery. I started with a TEP. During that time, I have lost my puncture twice by accident and once on purpose. I have talked all three primary ways. I have worn literally every prosthesis that Blom Singer and Provox has offered, and just within the last five years or so, settled in on the Provox NID patient changeable prosthesis, primarily because my body seems to like it a bit more than its counterpart on the Blom Singer side, and because my prostheses always seemed to fail during a time when my SLP was not available. So doing it myself has taken away a lot of the grief that goes with device failure. I've watched Congress make some bonehead decisions where laryngectomees are concerned, and then like frosting on a cake, watched both InHealth and Atos Medical each revise their contracts with the third party medical supplier (Edgepark Medical), where overnight my prosthesis cost went up 400%, and I found out quickly that my Blue Cross Blue Shield for Federal Employees which had worked so well for the first half of my time as a laryngectomee, was not working at all the second half, to the extent that Edgepark Medical does not even accept my insurance at all, after the contract revisions with InHealth and Atos Medical. I elected to take BCBS into retirement in 2005, and while it was a great payer for all the pre-surgery issues, the second opinion, and finally the surgery, for the past three years or so the \$610.00 monthly premium hasn't helped with the day to day laryngectomee needs.

But if you read this as a rant, it is far from that. One of the things I learned early on in this new laryngectomy life, is we all have to learn to roll with the punches, find out what works best for us, and then find normalcy in our lives. It's not the easiest thing to do at times, but it is there if we look for it. For me personally, I was given the opportunity to run a support group for a number of years, and visited with a large number of both pre-surgery and post-surgery laryngectomees and their

families. During that time, I met several who had had or were about to have more extensive surgery than me, and those who were not able to produce sound and speech as well as I could, which humbled me greatly. And one of the most important things to happen to me was that I had my surgery on 9-11, and that first three or four years when I would start the “woe is me” feeling, I could snap out of it right away when thinking of the real 9-11 and all of those families who lost love ones forever.

I still struggle going to places to eat that are a bit noisy with my wife and friends, because it is hard to communicate, but I still go because my wife deserves some normalcy as well, and I just deal with it. And speaking of my wife, we celebrated our 42nd anniversary yesterday, and she plays such a large role in standing beside me and being my advocate when I couldn't do some things. So much so I will forever be indebted to her for the first couple of years post-surgery.

The biggest physical difference between year 1 and year 11 is I cough much less now than then. I've worn baseplates and HMEs around the clock for 10 years, and I credit the use of the HME as the biggest reason for my cough reduction. It also took me a while to learn what my triggers were, or some things that were making me cough. In the first 4 or 5 years, I just couldn't handle the plug-in air fresheners and they would trigger an immediate cough. I had the same reaction to perfumes or hairspray. I tolerate those things much better now, and I think it is just my body making the necessary adjustments over time. From year 1 to year 11, there has been one thing that has not changed, and that is to conceal the stoma, by wearing the baseplate and HME and covering those with a shirt with a high neckline or wearing a high neck tee-shirt under another shirt. Every laryngectomee should cover their stoma for health reasons, as there is nothing preventing insects or dust or other debris to enter the stoma if left uncovered. Also, it is not pleasant or appealing to look at. It really isn't.

I see the first couple of years post-surgery as a time of transition. I wanted to blend in with the crowd, both mentally and physically, and it took me a couple of years to get to that. I can now eat pretty much anything, as long as I remember I am a laryngectomee, which means smaller bites. The only thing I don't eat is the dinner roll that comes with the steak...I can eat the steak OK but I leave the roll on the plate. When with a group, I also order the smaller steak where I can finish reasonably close to everyone else. It took me a little time to learn that one.

My youngest grandson (age 6) comes over for a visit and says “Pop-Pop, is your sore throat feeling better?” I answer him with a truthful answer by saying “Yes son, it is feeling better.” And it is.

Mike Smith  
9-11-2008

In September, it will be 6 years since my laryngectomy surgery. I've settled into a daily routine just as all of us have and am not self-conscious about my voice, although I used to dread using my electrolarynx. Too many startled looks! Now, I feel very comfortable leaving my house by myself to shop, buy groceries, go to a movie with a friend or to doctors' appointments, and even to fly by myself to visit grandchildren. Interaction with everyone I've encountered has been most positive. My one hangup, though, is being in large groups of people where I can't even hear myself speak. My frustration is at a very high level when I can't be heard or understood. Therefore, if I'm able to, I request a table in a restaurant which is against a wall or in a booth and this seems to make conversations easier. At a baseball game, I often resort to using a Boogie Board to converse.

I do remember that from the very first month following surgery, I was conscious of how my appearance could affect others, including my family. I felt that no one should feel uncomfortable being exposed to the hole in my neck; therefore scarves and turtlenecks are my show of respect for anyone I interact with and a Lary Button with an HME is my protection for my stoma and lungs. Life is good!

Barb Gehring 2013  
Akron, Ohio



# This Lary Life

## It's Showtime

by W.C. Baker

It's been long enough now, that the memory has dimmed somewhat. Like most November Monday nights before and since, I watched Monday Night Football. No beer with this one though. I was in a hospital room waiting for my laryngectomy surgery to be performed early Tuesday morning. I had concerns that anyone who is facing major surgery might have, but the prospect of losing my voice was not really that much on my mind.

Most things that we do are simply "done". We mere mortals "do" dishes; We "do" the ironing We "sweep", and "clean", and "make" and etc. Gods and Doctors, however, "Perform". Miracles are "performed" by Gods, surgeries are "performed" by Doctors. I won't go so far as to deify my surgeons, nor do I consider my surgery to have been a miracle. It is more as if the surgery they performed can be viewed as an art form. At least I liked the thought that I was in the hands of a Doctor who was going to create a work of art using me as the medium for a masterpiece. As it turned out, I was totally satisfied with the excellent job done, I mean, "performed".

The surgery began early in the morning and continued late into the afternoon or early evening. My only memory was looking up at bright lights as I was put on the table and saying "I'll talk to you later". Yeah, wise guy, we'll see about that. My last laryngeal words were counting backward by 7s from 100. I have no Idea how far I got. I woke up without a voice. Well, "woke up" is kind of an exaggeration. I came to semi-consciousness, feeling the massagers keeping the blood going in my lower legs. I did a quick inventory tentatively feeling the upper pecs to determine if they had done a flap to reconstruct my pharynx. Ah, still there, all is well. My first attempt to make a voice was a silent chuckle when a nurse asked me, "Do you know the difference between a tire and 400 condoms? Of course, I could not answer verbally, but I made it clear that I understood the question and was waiting for the answer in wild anticipation. Well, once

again, not too wild. "The tire is a Goodyear", responded the nurse, "400 condoms, that's a Great Year." My laugh was silent but sincere. My return to consciousness was established.

Upon being taken to the room that was to be my home for the next 10 days, I became aware of the tube attached to a bag hanging from a stand, stuck in my nose and going to my stomach. As soon as I was able to stand, I put on something to cover my southern exposure, grabbed my wheeled stand with its bag and walked around the hall which formed a perimeter around the inside of building, onto which all of the rooms opened. Nursing stations and other non-patient rooms were on hallways that quadrisected the rectangle and had access to all the rooms from the back side. It was 500 steps around that perimeter, and I took that to be about 1/4 mile. Each day I took my wheeled stand and walked that quartermile, adding a lap or two each day. The day of my discharge, I did 5 miles.

I was the only laryngectomee on the ward, and had to communicate with staff and other patients by writing, gesticulating and making faces. I formed an especially close relationship with one of the other patients, which we continued when we were both released. My inability to speak did not interfere with our getting more closely acquainted. She was a big help in allaying any concerns that I might have had about that part of my life.

All follow ups went well and I entered a course of radiation at a hospital a few blocks away from where I lived. I had some teeth removed prophylactically, in anticipation of weakening of tooth enamel from radiation. Swelling from the surgery and radiation made it difficult to speak esophageally, but I was confident that it would improve. But, that's another story.



## It Is My Attitude That Determines My Altitude

*Don Renfro*

“Change the way you look at things and what you look at will change”. This is a quote by Davy Jones, former lead singer of The Monkeys. The first time I saw this it really made an impression on me. It transformed into words what I have believed for a substantial time in my life. I would like to share how I allow my attitude to determine my altitude.

It is so easy for me to allow myself to feel bad about my situation. I have had cancer, I have no voice and I have a fistula. The reality is that it is just as easy to allow myself to feel good about my situation. I am alive, I am still able to communicate and I have options to deal with my fistula. It all depends on how I choose to look at it.

How I look at things is entirely determined by my attitude. When I have a bad attitude the world looks like a bad place. In contrast, when I have a good attitude the world appears to be a good place.

This is how my attitude determines my altitude. With a good attitude I can go to unlimited heights. At the same time there is something to be said about reality. I want to know that what I perceive is not the result of putting on “rose colored glasses” and only seeing what is good and on the other side of that coin, that I am not seeing only bad due to an outlook of negativity.

I remember hearing for the first time “you have cancer”, as does everyone that has shared this overwhelming diagnosis. The only thing I really knew about cancer was that many of my family members had not survived this disease. I immediately knew if I was to survive this it would require all the positive energy I could gather from within. Truly my attitude would be everything in the rest of my life.

Because of the realization that positive energy versus negativity will drive my survival, I immediately began to look at my own thinking to determine that I was utilizing all the positive thinking available to me.

It became important to me to build a network of people in my life that also valued a positive outlook. Everyone knows the person that when you say good morning their response might be “what’s so good about it?” Or when you ask them how they are doing their response is “I am here or surviving.” Those people would deplete my positive energy leaving me to share their negative energy. I had to now search out those people that find the best in their situation and are fully aware of the blessing of life.

Fortunately there are many people that are full of positive energy and willing to share it with anyone that may benefit from it. Those are the people I am in search of today. It is not so much that I am a Chameleon, taking on everybody else’s point of view, but instead

feeding off their energy to cultivate my own. I also want to be that person who can find the positive in my life’s situations as my survival depends on it.

I have also found in my life that it is nearly impossible to only have a positive outlook all the time. Most people, even the most positive people, will not be positive 100% of the time. Things like fear, illness and other of life’s speed bumps can alter one’s ability to maintain a positive outlook all of the time. I know for me when those negative factors are present that is when the work begins to take me back to a positive place. To stay in a negative place would be detrimental to my own wellbeing.

Today I am committed to a positive perspective that will not only benefit me but one I can share with others. As I look back on my life and experiences, I see where some of the most valuable things others have given me in life have been a positive outlook. Money is spent and no longer exists. Things tarnish and lose their appeal. But a positive outlook can be mine forever only to gain more value the longer it exists.

Therefore I want to also be the bearer of such a valuable gift. In my career many of my clients liked to work with me because they felt better after our counseling session. It was my job to assist them to find their own positive outlook. Today, in retirement that is the person I still want to be, a person who shares with other my own positive energy. Knowing I cannot transmit something I do not have, it is essential for me to possess my own positive outlook if I am to share it with others.

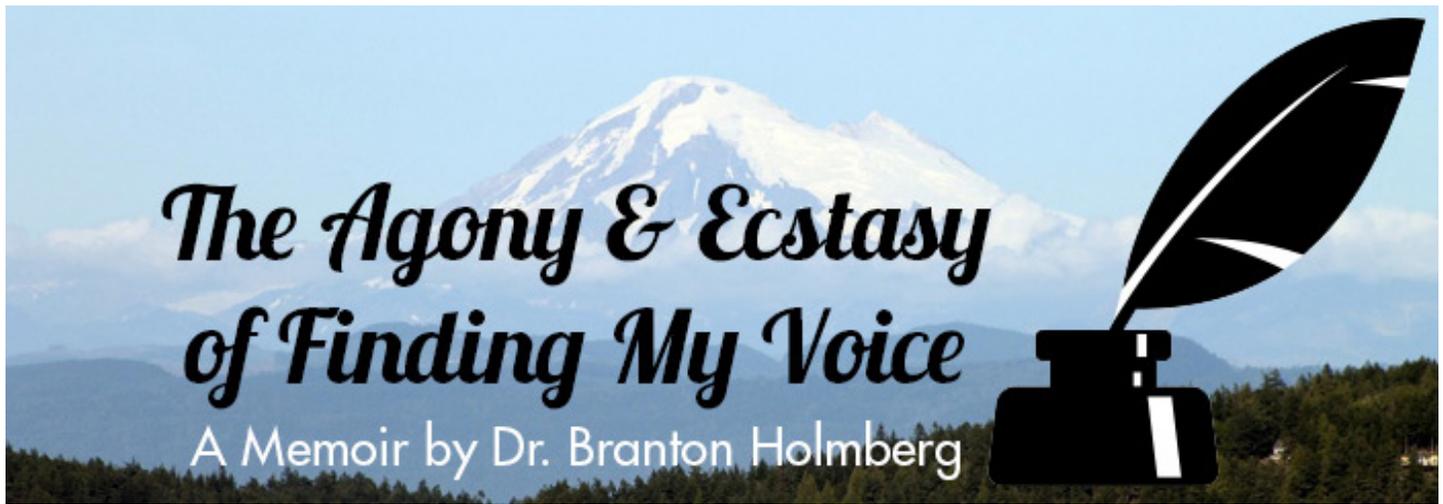
I am very blessed to have people in my life today that bring to the table positive energy and a good outlook. They truly make my world a better place. It is my hope that I am able to reciprocate their gift.

When I was younger I thought that people that always saw the world as a wonderful place with plenty of everything they wanted were just dreamers that chose to ignore reality and only look at life through a way that would allow just the shiny goodness to show through.

I felt that such an extreme view of goodness was detrimental to reality. The funny part is that with age I have found that some of that view is necessary to foster the positive energy that cultivates a positive perspective which will in turn result in a positive outlook.

I grew up learning from a very young age that I did not need anyone. I was totally self-sufficient and relied only on myself. I had to unlearn that false belief to come to an understanding that I need people. Then I had to learn that the kind of people who will actually benefit and improve my life are those that honestly possess positive energy and a positive perspective of life.

One thing I have truly learned from my life experiences is that life is too short to not be happy. And I deserve to be happy. People that also believe that about me are the people who I value as part of my life.



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

**Chapter 2 “The MASH Years”**

I spent the summer after high school graduation living at home again and even though I was getting along better with mom I was anxious to get out on my own. In August of 1954 I got my draft notice. My brother had joined the Navy so I had a pretty good idea what it was like in that branch of the service. After talking with an Air Force recruiter, a high school buddy of mine and I decided that was the branch of the service we wanted. We went together to join in late 1954 hoping to go to the same boot camp together. That’s not how it worked out. My buddy got in right away and it took me until the following January to get in. I’d run into a problem during my physical and it took until January, and a letter from my family physician, for me to get into Air Force.

I’m thankful I got in when I did, veterans were still getting the benefits of the GI Bill from the Korean War when they finished their four year hitch. This turned out to be another of the many things I count my blessings for.

I wound up at Parks Air Force Base in California for my basic training. I’ve never had a wakeup/grow up experience like going through basic training. I guess I should have been more prepared than I was because mom’s behavior was pretty damn close to that of a drill sergeant. One thing you learned immediately was to never talk back.

I got the hang of things early on and basic training was not a problem for me. You got to choose what you wanted to do in the Air Force toward the end of basic training and I decided I wanted to be what they called a medical service specialist, more popularly known in service lingo as a “Bed Pan Commando”.

From Parks AFB I went to the Air Force Medical Training Center at Maxwell AFB in Montgomery, Alabama where I spent 16 weeks learning the tricks of the trade of a bed pan

commando. A trip into Montgomery after the first week I was there took me into an experience I’d never anticipated. We got a weekend pass to come and go from the base at the end of the first week of training. I’d become good friends with Ed and Alex, a couple of Negro classmates (Negro was widely used for Black People in the 1950’s) from New York because we’d wound up studying with each other and liked it. We decided we’d go to Montgomery together.

We rode the military bus in and they dropped us off in the middle of town. We decided to look around a bit and caught one of the local buses that went by where we were standing. The front part of the bus was full of white people and the back was full of black people and that was my first taste ever of segregation. We didn’t bother looking for seats and told the driver we wanted off at the next stop, even then my buddies had to exit out the back door of the bus and I had to leave by the front door, the driver made that very clear to us.

Next we decided to get a bite to eat and when we found a restaurant there was a door for white people and a door for Negroes and through the window we could see they were clearly separated inside. We didn’t bother going in. I’d also seen drinking fountains and bathrooms with signs for white people and Negroes.

We’d had enough and headed back to where the military bus made regular runs between Montgomery and the base and waited to catch one back. The 3 of us never went to Montgomery again. We decided on the way back to the base we’d spend our time studying and going to class because they’d told us when got there that the top 5 graduates of our group of 84 trainees could choose to go anywhere in the world that had an opening for a medic when we finished training. We decided we wanted to try to be 3 of those 5.

I’d arrived in Montgomery at the beginning of the summer

and wasn't used to the heat in that part of the country. Neither were most of the rest of our training group. We were quickly made to understand that if we suffered a heat stroke we'd get a summary court martial for not taking the precautions to prevent it. They gave each of us a big supply of salt tablets and were told to drink lots of water during the day to stay hydrated. The barracks and class rooms weren't air conditioned and as the summer wore on they got more and more miserable to be in. Fortunately our group was all males and so were most of our instructors and we were allowed to sit in the classrooms with only our skivvies on, except when female nurses were teaching us. We offered to sit in our skivvies then too which didn't go over all that well with the nurses.

My study skills were poor to say the least and I really busted my butt to stay up. Ed and Alex who'd both been good students throughout their high school years. After our trip into Montgomery the 3 of us spent 7 days a week studying everything they threw at us and we achieved our goal of being among the top 5 graduates.

During the last week of classes a slick-talking Captain told our group about the great advantages we'd have if any of us chose to go to Ladd AFB in Fairbanks, Alaska. He made a presentation showing us movies of the plush living quarters we'd be in and the fact you could get anywhere you wanted to go on the main base when the weather got below freezing by going through the tunnels for steam pipes that heated the base in the winter. The real clincher was the fact you got paid for overseas duty, which was way better pay than stateside duty, because it was still a United States territory.

You've probably guessed I signed up to go to Ladd and you're right. There were openings at a base in New York and Ed and Alex decided they'd go there and I didn't blame them after the way they were treated when we went into Montgomery.

They flew me and more than a dozen others who'd signed up for Ladd on Alaska Airlines to the Fairbanks airport where we were picked up by a military bus. All of us were anxious to see the hospital we'd be working in and those plush living quarters we'd been shown by that silver tongued Captain at Montgomery.

We were dropped off at the entrance to the hospital and met by a Staff Sergeant who said he show us to our quarters and then take us on a tour of the hospital. We were all lugging our duffle bags over our shoulders as he took us to the basement of the hospital and told us this was where we'd be living for the next few months until they finished building our living quarters a hundred yards or so in back of the hospital.

He took us one of the huge open bays on each end of the basement and told us to find a stripped down bunk with a foot locker and a wall locker and make ourselves at home.

The bay we were in had all the steam and utility pipes used to heat and operate the hospital running along the ceiling and there were 48 iron double bunks, 24 on each side of the bay. There was only 4 feet between the top bunk and those asbestos wrapped steam pipes above it.

We told the Sergeant this was nothing like the movies we'd been shown about where we'd be living. He laughed saying he knew what the Air Force had done to lure new medics to serve their overseas duty here. He told us the movies we'd seen were of the officer's quarters on the main base and that's where all the steam tunnels were too that you could use during freezing weather. He said it's probably be 6 months before they had the new quarters they were building for us finished, but the good news was they were going to be a lot like those officer's quarters we'd seen. In the military you don't get choices, you get what they give you so we made ourselves at home in the hospital basement. It was crude but we made the best of it.

We did get our new living quarters 4 months later and they were nearly as good as the ones we saw in the movie the slick tongued Captain showed us in Montgomery and you'd better believe we thought we were moving into heaven. There weren't any steam tunnels for us to get to the hospital through so that 100 yards between where we lived and where we worked was a mighty cold trek at 50 degrees below zero in the dead of winter.

They assigned me to work in the delivery room on the maternity ward and the practice of medical care opened up to me in ways I would never have imagined. The delivery room was busy place since we served a large military base that encouraged its personnel to bring their families to live with them. We served all of Ladd's personnel as well as families from military outposts around it and there was no question husbands and wives lent themselves rather enthusiastically to procreation.

Within a week of working on the ward I thought I was the luckiest guy on earth. The Dr.'s and nurses working in the delivery room were as crazy and fun to work with as the ones I used to watch years later on the TV show MASH that started in 1972. I swear some of the story lines from that show must have come from someone working with us in that delivery room at the Ladd hospital in 1955 and 56.

**To be continued...**

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Dochohm36@gmail.com