

Whispers on the Web

A Monthly Online Newsletter for WebWhispers

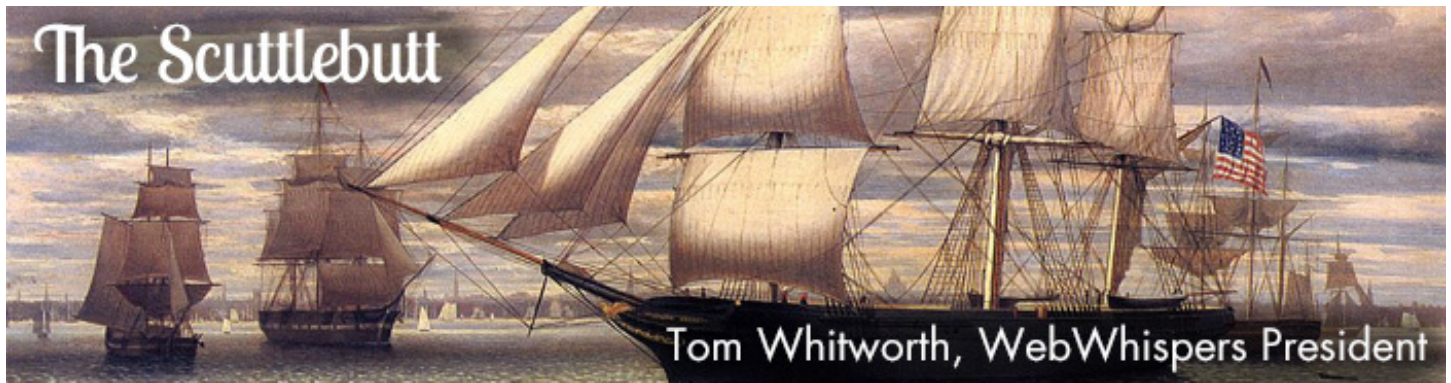
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Walk a Mile in His Shoes

My Granddaddy was a special man. He brightened this world from 1889 until 1968. Even his name, Robert Jefferson Mulkey, was powerful to me. If you had the opportunity to know a grandfather like I knew him, he was probably just as special to you. Granddaddy's death, funeral, and graveside service were my first of such experiences. That was fifty years ago and the family had just celebrated my 11th birthday. I loved him with every ounce of my being and could not fathom how I could live without him. Little did I know how he would remain with me and play such a large part in who I would become, who I am, and who I will always be.

Granddaddy Mulkey was a fairly quiet man, but when he spoke, it was either positive and encouraging, made you laugh, or caused you to stand in your tracks for a moment and just think about how someone was being a real jackass, and it might be you. He could generally see the good in everyone and even when he could not, he knew it was there. That may be the greatest skill I inherited from him. I am at my best when I remember that and at my worst when I don't. He didn't like for us to make fun of, judge, or criticize others, and would kindly yet sternly chastise us (or adults) for doing so. He would remind us that we did not know everything a person had been through. Then he would say "never criticize a man (sic) until you have walked in his shoes, and you will never get to do that."

His nickname "Hoss & Buggy" evolved into simply "Buggy". The only person I ever heard revert to the more formal "Hoss & Buggy" was my dad, his son-in-law. Daddy enjoyed calling him that just so he could see him smile and hear him chuckle. The moniker was because, in years past, Granddaddy had one of few horse-drawn rigs in his area of North Georgia. When anyone needed to get to a doctor or go into

town for another urgent matter, they would come to the Mulkey home to get a ride from "Buggy" and he would always graciously meet their need. In the late 1920's, on the cusp of the Great Depression, he somehow managed to buy a car, which then became the most reliable source of transportation in that same area. As an employee of Southern Railway, Granddaddy traveled often and found himself a widower with ten children. Somehow he made that work and yet was best known for his propensity to step up and help others. When he lost the youngest of three sons, my uncle Horace, in the WWII Battle of the Philippines, his heart was more broken than ever, and though that slowed his pace, he never stopped thinking of others and continued to meet every human need that he could.

What would he say to me now? What would he say to all of us? What would he do and what would he not do? He would remind us to reach out to those who show signs of being troubled and learn more about them before passing judgment on their behavior. He would encourage us to meet people where they are and he would have us be compassionate always. He would hate things like call and email blocking and delete buttons in social media and he would first check on people to see if they are okay or struggling. He would tell us to walk a mile in their shoes. Joe South recorded this song a few months after my Granddaddy Mulkey died. I don't know if the songwriter knew Buggy but the song always reminds me of him. It is simple but makes one think a bit.

This is another great issue and I hope you enjoy it.

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



Voice Points

Written by Professionals

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

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Reuniting with old friends and making new ones, celebrating our lives and honoring those who were not with us.... our time together in Phoenix in May was extraordinary. Thank you to all those who made our WebWhispers gathering and annual banquet at the LAL Annual Meeting and Voice Institute a success! Attending the meeting and visiting with many of you, I always feel a renewed sense of pride and enthusiasm for being a part of this community of survivors. This year was no exception! If you missed it, take a moment to look back on last month's VoicePoints column which hit some of the highlights: <http://www.webwhispers.org/news/june2019.asp>

Time spent with WebWhispers is a good reminder that there are myriad opportunities for everyone to find their voice and make a difference. The following piece about a cancer support group, Voices of Mercy, on Chicago's South Side, may provide further inspiration. Just one more example of how people are finding and fulfilling a need to connect in person to share and support each other. Happy summer, friends.

-Kim Almand, M.S., CCC-SLP, VoicePoints Coordinator

A Multidisciplinary, Co-Facilitation Model for Support Groups: Addressing the Medical and Emotional Needs of Patients

Jenna S. Kiel, Psy.D.
Support and Family Programs Manager,
Wellness House

“Voices of Mercy” is a Head and Neck Cancer Support Group at Mercy Hospital on Chicago's South Side. While it is not necessarily innovative to provide both medical and psychosocial support to patients with cancer, this group is unique because it provides both at once. It does this by providing cofacilitation by a speech-language pathologist from Mercy and a psychologist specializing in psychosocial oncology from an organization called Wellness House. In doing so, it is also an example of the ways in which community-based cancer support organizations can partner with larger medical facilities to supplement the care offered to patients.

A bit about Mercy and Wellness House: Mercy Hospital is a special place. It is a safety net hospital that serves patients who are often underrepresented, underinsured, and under-resourced. Many patients who are treated for their medical needs at Mercy are also in need of health literacy, access to

community resources including mental health, and additional psychosocial support. Wellness House is an independent, community-based, non-profit organization located in the western suburbs of Chicago. Our mission is to prepare and empower all individuals who are impacted by cancer (survivors and caregivers alike) to live as fully as possible with cancer as well as beyond cancer. In 2015, Wellness House launched an initiative to reach beyond the western suburbs and provide programs and services to patients and caregivers who would not normally have access to the depth and breadth of psychosocial care that we offer at our main location. We do this by forming partnerships with all different types of organizations such as hospitals, churches, and community centers where we provide the expertise and our partners provide the location. Very early on in this initiative, Kelli Mitchell, Community Relations Manager at Wellness House, formed a relationship with Mercy Hospital and we began offering support groups and wellness programs facilitated by Wellness House staff.

VOM was started several years ago by an ENT nurse and continued in 2011 by Nina Shahin, M.S., CCC-SLP. It began as a support group just for patients with laryngectomies as an opportunity for patients to connect with each other, to learn about topics that were of mutual interest and concern to them, and to remain engaged with their medical team. It began as an hour-long group that met bi-monthly and welcomed both patients and their caregivers. The group's inclusion criteria widened at some point to include all patients with head and neck cancer; most of whom had undergone laryngectomy surgery, had voice prostheses, and were in various stages of survivorship. From 2011 to 2018, Nina provided lunch, informational presentations from various disciplines, games, and holiday celebrations as a way of carrying forward the original intention for the group. In 2017, Nina reached out to Wellness House and suggested a new model for the group.

Nina learned of our presence at Mercy in 2017 and proposed a new model for her group – one that would be co-facilitated by her as well as a mental health professional from Wellness House. “I felt that the group needed more psycho-social support and engagement. I saw that the patients in the group were struggling with depression and were having a difficult time talking about this. It was also hard to process changes that would occur in the group, such as when a group



Managing Frustration

Don Renfro

This is my first attempt at writing a newsletter article. Here it goes. In the weeks before this I was struggling to arrive at a topic to write about. The one that came to mind the most often was Coping With Frustration.

The most difficult part for me to adjust to becoming a person with a laryngectomy was my loss/change to my ability to communicate.

A bit of history, from my very beginning as far back as I remember, I was a very good communicator. My parents actually told me when I was older, they had a difficult time punishing me as a child because after talking to me they were no longer sure if what I had done was wrong, due to my ability to explain my actions in a way that left them wondering if they were correct in thinking that what I had done was wrong.

Latter in my life, prior to getting my education I was able to secure some very good jobs that normally required a degree by my ability to communicate in the interview process.

In my career, after completing my education I became a Contract Administrator for the State of California, Department of Rehabilitation. In this position communication was an essential function of the job.

I had enjoyed a full life of very effective communication that would now be different after my diagnosis of cancer of the vocal cord. Immediately after my surgery I grieved for the loss of my voice. It was as if someone very close to me had died. I had a TEP placed during my surgery and after the healing of a fistula and recovering from chemo and radiation I was able to speak with my TEP. Everyone from our laryngectomy community consistently told me how strong my voice was. Now I felt as if I had not only survived cancer but had gained the opportunity to return to my vocal ability of effective communication.

At the beginning of this year I developed a fistula just above my stoma. It got quite large. Within months I was no longer able to speak with my TEP. I was never able to develop the ability to utilize the Electronic Larynx as my swelling from radiation has never diminished enough.

Suddenly I found myself back in a state of no longer having a voice once again. My only means of communicating my thoughts was through the means of writing, on my Boogie Board.

Almost immediately the frustration returned from not being able to communicate as effectively as the people I was communicating with. The frustration would then get in the way of the communication that was taking place making effective communication even more difficult.

How do I cope with this when a solution appears so far away? (My fistula needs to heal and requires rest from the use of my TEP). Working at the Department of Rehabilitation, for 5 of the 21 years I worked there, I was a Vocational Counselor for individuals with mental illness. I would now need to use the advice I shared freely with my clients for my own benefit. First thing that I need to do is realize the frustration is mine. The people I was communicating with were not frustrated and had no idea I was frustrated. In reality they played no part in my frustration. Knowing they were not responsible for my frustration freed me to experience that not only was the frustration mine but so was the solution. I did not have to wait for them to change or "get fixed" for me to not be frustrated. Then I had to listen to my own advice. I used to tell my clients, when I was a Vocational Counselor, that they had a right to feel whatever it was they were feeling. All their feelings were valid. They also had a responsibility for how they reacted to their feelings. Although it was Ok to feel upset, it was their responsibility to respond to their feeling in an effective manner. So what this means is that when I feel frustrated about my limitations of communication, that I, at that time, have the responsibility to take my means of communication I do have (writing) to the next level rather than let frustration destroy the communication ability I do have. I must communicate better and more effectively.

Solutions give me hope and hope is what has gotten me through surgery, radiation and chemo. Solutions are not a quick fix but a means that I can develop my approach to life's challenges.

This is one of many interesting journeys in my life. I look forward to many more. One thing I have learned or I should say that I am still learning is that in time, all will be as it should be. Just not necessarily in my timeframe. Although I do not relate to the "Me Generation" and immediate gratification, I do tend to want things in my time frame. An important lesson of life for me is that life is not always in my timeframe but in the timeframe of life itself. In other words, all will be as it should be in the timeframe it should be.

member passed away. It was still important for me to be there to assess their communication and make sure their devices were working properly, but I wanted to have a mental health clinician who was experienced in facilitating support groups to co-lead with me.”

Nina invited me to sit in on the group in December of 2017, from which point we began to discuss how to best integrate my role and how we would begin to work together. We maintained the structure of having an occasional, topic-focused presentation including nutrition, utilizing mindfulness for coping, and updates in devices/products on a bi-monthly basis. A few of the changes that we made include extending the group to an hour and a half and having more non-structured time for processing the emotional experience of their cancer and the subsequent impact of that. Providing time for them to eat and communicate at their own pace is imperative; a significant part of the social anxiety and isolation for them is that they experience an impatience in others, an unwillingness to slow down and attempt to understand them. This is something that this group provides for them.

There is a wide range of topics that are presented by the participants of the group. Some are addressed by either Nina or me, but an important part of what they receive from the group, and what is an inherent function of a support group, is engaging with other patients and caregivers who can provide empathy and useful knowledge based on lived experience. They share information and resources with each other, but also engage in topics that are deeply personal. Some of those topics include feelings of guilt and regret from a history of smoking. The group is very vocal about their own life choices that may have contributed to their cancer, as well as about being advocates for smoking cessation. In fact, some see it as somewhat of a duty to warn younger people about the risks of smoking and literally point to their own laryngectomies as an educational tool. Some also talk about and share the guilt they feel about “not wanting to know” about their cancers, postponing medical intervention until it became unavoidable and thus wondering about their contribution to their stage and outcome. They also, like most cancer survivors, wonder about other factors that may have contributed to their cancer, citing environmental and work toxins they had been exposed to earlier in life.

The members of the group also have many practical and medical concerns that have been addressed throughout the history of the group. They have all shared questions about navigating insurance, nutrition, and updates in technology and products for their prostheses, for example. Experts from within the hospital and from the larger community have been invited to provide informational presentations on each of these topics on a regular basis. Nina’s presence in the group is also crucial in addressing some of these needs. She monitors their communication and devices to make sure they are working effectively and is able to recommend a visit with their physician when she thinks it is warranted. In fact, it was during a visit from a product rep that Nina was helping a patient try

a new device when she noticed something concerning about the appearance of his stoma. The patient reported that he had an upcoming appointment with his ENT physician, but not for several weeks. Nina emphasized the urgency in having an examination sooner rather than later, and was able to get him in to see his doctor that day. Nina was able to accelerate the process that this patient needed in order to identify what was actually a metastasis.

Since joining the group, I have been able to help the members process some of the more social and emotional aspects of having this type of cancer. Some of the topics that come up for them are unique to individuals with head and neck cancers and are directly or indirectly related to the loss of their ability to communicate the way they once had. They grieve not only the loss of communication itself, but the social isolation that comes with it and the dependence on loved ones to often “translate” for them in social situations or even in the group itself. Some are comfortable with having their spouses help them in certain settings, but others avoid social interaction as much as possible. Again, the perceived unwillingness of others to simply slow down and try to understand them is enough to keep them from taking part in activities in the outside world. We discuss adjusting to life with cancer and with a voice prosthetic as well as coping with the stress and anxiety that comes with it. The group is also one of the few places that the patients have a space to talk about other stressors in their lives including other health concerns, the deaths of loved ones, and even violence in their communities. One of the group members has said that she only leaves her home “to vote or come to [this] group” because of the violence in her neighborhood.

Voices of Mercy is an ideal example of collaborative, multidisciplinary care to a vulnerable and unique population. The group continues to meet on a bi-monthly basis and welcomes patients from any treatment facility. In the future, our goals for the patients include increased overall attendance and engagement with other psychosocial programs offered by both Mercy and Wellness House throughout the city. We would like to do more outreach with oncology providers from other hospitals whose patients may be aware that the group is accessible to them. We would also like to see an increase in attendance by caregivers and to provide more focused programs for them.

For questions or more information, please contact:

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Dear Lary

Noirin Sheahan

The Healing Power of Music.

About a week ago I was staying with my friend Finola. She sings with a choir and they were giving a concert on Saturday night and she invited me along. Driving into Galway, I became aware of a slight pain in my face. It was around the right eye, and would jab at me then disappear. Through many years of mindfulness practice I've learned that physical pain can often be mental in origin, so I didn't worry unduly, but just relaxed as best I could, trusting that some useful lesson would be learned from attending to this pain.

The pain, I found, was associated with thinking. It was as if there was some thought I wanted to think but couldn't. I'd get a sudden urge to think, and then I'd feel myself trying to 'get around the thought' somehow. That's when the pain appeared. As I winced in pain, the thought disappeared again. All very frustrating!

I find it hard to own up to difficulties until I have some sort of handle on them and also didn't want to be worrying Finola before the concert, so chatted away as normal. But maybe it was obvious that my heart wasn't in this and after a while we fell silent. She started humming some of the songs for the concert. That's when I felt some extra twinges of pain. This time I could follow the process more clearly. The urge to think a certain thought ... and then, with a jab of pain, a fearful, judgemental part of me said 'No, don't think that'. A few moments later the cycle would start again.

Once I had detected the urge and the counterbalancing fear, it became possible to find the middle-ground, to let awareness rest in a sort of no-man's-land between desire and aversion. From here on the experience became more embodied with the unpleasant sensations now extending from my chest right up my face. That might sound harder to bear, but embodiment always makes things easier. Thoughts, perhaps especially half-thoughts, forbidden, half-acknowledged thoughts, trouble us far, far more than physical sensations.

I noticed that the urge to define and forbid this thought was now coming with each in-breath. Then the breath got shallower and shallower till it stopped and my mind also stopped its attempted definitions and judgements. From this resting point I started to feel, in the pit of my stomach, a stream of stinging sensations – very unpleasant. Resting attention there, it gradually dawned on

me that the thought was one of aversion to Finola's (very lovely) singing voice. I realised that I didn't want to go to the concert and have to applaud all those beautiful voices.

Why not? Because of laryngectomy of course. Not wanting to have my own lack of voice so clearly illustrated. The thought I was forbidding myself was along the lines: "I don't want to have to spend an evening smiling and clapping and pretending I'm happy that other have what I'm missing".

Although I'd only dipped my toe into this emotional turmoil, it was a great relief just to know what the trouble was all about. Once my rational mind could engage with the emotions, I could work with more wisdom and compassion. Wasn't it only natural that a laryngectomee should feel jealous of other's voices? What was the point of condemning jealousy if it was there anyhow, shooting pains into my face?

Perhaps the most surprising thing is that it's taken me six years to register this emotion. I've been to Finola's concerts several times since laryngectomy, and have appreciated and enjoyed them all. But I've obviously been suppressing jealousy. Strange as it may seem, I really did enjoy the concert last week. I saw it, not only as a concert, but as an opportunity to heal. Negativity burns itself out in mindful awareness – I've total faith in this. All evening my emotions were running high, see-sawing between agony and ecstasy. But emotions don't have to define us – especially if we can be mindful of them. Then we can meet their energy with our own determination to strengthen whatever traits we want to nurture. I was really clear that acceptance is the direction I want to go and so it felt exhilarating to be able to see and name the stinging serpent of jealousy. With every tight squeeze, every sting, I felt myself growing stronger, more determined not to be overwhelmed by jealousy, more respectful of my voiceless state, less limited by this limitation.

I really could (at times) appreciate the voices I was hearing, appreciate the time and trouble they had put into rehearsing. Most especially I could appreciate this opportunity they were giving me to do mindful battle with the serpent of jealousy, and thereby develop the counterbalancing emotional muscle I need to accept laryngectomy more completely, more joyfully. The concert gave me a very dramatic illustration of the healing power of music.



While this first appeared in July 2012, the issue and information remains relevant for many of us, old and new alike. Plus I enjoyed reading Pat Sanders' "Voice of Authority" again. She knew her stuff, didn't she!! Thank you, Pat!

~WotW staff~

GERD

"Have you had a problem with GastroEsophageal Reflux Disease?"

John Haedtler, New Mexico, USA - 2001

Only one comment! York Peppermint Patties.

Those got me through finding the right GERDS meds! Which was Prilosec OTC. Just over 10 years now and I still keep them in my house!

Dave Ross, FL - 2005

Ahh yes, GERD, one of my favorite subjects!

In early 2001 my GP surmised (I use the word "surmised" because he performed no tests or examinations to substantiate his "diagnosis") that I was hoarse because I had GERD and he, without further ado, put me on a daily regimen of Prilosec. Fortunately, just a few short weeks later I had my four year follow up visit with my surgeon who had removed my right upper lobe to rid my lungs of a malignant tumor. When I said "hello Doc" he asked why I was hoarse and I told him what my GP had surmised. He said that because of my history he had to "prove that I did not again have cancer" and immediately scheduled me for a bronchoscope which revealed the tumor on my right vocal cord and the biopsy which showed it to be the Big C. The following radiation seemed to work but in 2005 it was back and resulted in my total laryngectomy.

Having been a two pack a day smoker for fifty years, no one ever suggested that some other factors may have also been a player in the loss of my voice box. But as I have had the time to speculate I have come to realize that my use of tobacco may not have been the only culprit!! Consider:

- 1) In my thirties I developed a "self-extinguishing" fiber glass resin formula during which time I repeatedly inhaled smoke that I later was advised had been found to be carcinogenic;
- 2) In my teens and twenties I did a considerable amount of automotive maintenance/repair which frequently involved brake work and can recall thinking nothing of breathing in the asbestos dust therefrom;
- 3) All of my adult life I often had irregular work hours, frequently would eat a large late night dinner and immediately retire for the night; 4) I often had "heartburn", or as it was sometimes referred to "indigestion", but in those days that just seemed to be part of life -- no big deal.

Now I wonder -- was it no big deal?? I am, and have been for the past twelve years, on a regimen of two Prilosec caps daily without which I will suffer nightly GERD.

I am now convinced that GERD may have been as much a factor in my Laryngeal cancer as tobacco. Oh, or was it the asbestos -- or the FRP resin additives?

Oh, I also forgot to mention my regular daily consumption of rum and coke which also added to the GERD factor. I could go on and on, but I love greasy foods, have always eaten more than I should so I'll just say that in my case GERD is likely a major player!!!

**Len A. Hynds,
The Speechless Poet of Ashford, Kent, England - 2004**

The first time I realised how different my life would be, with regard to eating and drinking, was immediately after my first valve change. I was so pleased at no longer leaking, that I took a long draught of cooling liquid, marvelling at the sheer joy at the feeling it gave, descending towards the stomach. Quite like old times I told myself. Almost immediately I could feel and sense a build-up, as if my oesophagus was violently rejecting it, and as it rose up, with what it seemed the speed of a bullet, I closed my mouth tightly, only to find the whole glass of liquid pouring out of both nostrils, much to my disgust and the shock of my wife.

I soon realised that with the re-plumbing, my gullet was so much smaller, taking me ages to chew food smaller before swallowing, and I had no epiglottis. If I ate too quickly, that would push the

acids into the oesophagus (those very essential acids which break-up our body intake), upwards into the back of the throat, causing a terrible burning to the soft tissues. So the answer was, eat and drink slowly. You soon learn not to lay in the prone position just after drinking anything.

That was in 2004, but I had already slept on my own for the previous ten years, as in 1994, I had fitted American Self-Cleaning Heart Valves, and for quite a few years their night time ticking (terribly loud) was disturbing the wife. I have had them in for 19 years, and never a days trouble. Thank-you America!

Terry Duga, Indianapolis, IN - 1995

I have been taking an acid blocker for a number of years. I was put on Prilosec after my partial laryngectomy in 1993. I kept on it until Prilosec went generic and insurance stopped paying for it. I now take Zantac.

Linda Palucci, FL - 2002

I take 1 omeprazole in the morning and the heartburn problem is eliminated.

Marlene Haynes - 1996

I was diagnosed with acid reflux after my laryngectomy. They were testing me for swallowing problems after my surgery and I was prescribed Gaviscon, four per day, two in the am and two in the evening. That was in 1996 and sometime in between then and now I was prescribed Prilosec (omeprazole). I still take it twice a day every day.

The doctor asked me how long I'd had acid reflux, my answer was I never knew I had it until now.... Everytime they give me the swallow test the stuff backs up. I've never been told why, hope I can learn about this here. I try to stay away from acid foods and keep taking my medicine.

Lynn Foti, Akron, OH - 2009

I never had acid reflux prior to losing my larynx and esophagus. After I was allowed to eat again, my ENT said I had acid reflux and would have to take medicine for it, probably for the rest of my life. I always thought it was because he had to construct a new esophagus for me from my inner forearm, but now I see most larys have it too.

It really doesn't bother me a lot except when I eat spicy food (which I love, since I am Sicilian). I am so grateful to be here and able to enjoy my son and friends and family, it is, like a lot of other things.... a small price to pay. In the greater scheme of things we larys deal with, it isn't too much. I am sometimes frustrated by coughing up mucus in a crowded place and the constant runny nose, but all those things can be tolerated. Am so enjoying my garden; have tomatoes and peppers already! My flowers, and just being alive. I know so many things can happen down the road, and I want to be sure to grab every bit of life I can while the grabbing is good.

Thanks to WebWhispers for all the information, comaraderie, and help; I feel like this site has made all the difference.

Bruce Turner, Brisbane Australia - 2004

I have suffered from GORD (Gastro-Oesophageal Reflux Disease) for most of my adult life. I was diagnosed with a rare type of cancer, Chondrosarcoma, in my larynx in early 2004.

I had a lot of trouble with food intake via Nasal Gastro Tube after my total Laryngectomy. I couldn't keep any food down, and lived on milk for three (3) weeks !

I was then diagnosed with Barrett's Oesophagus (without Dysplasia), and had a Laparoscopic Fundoplication operation in 2005. This operation helped a lot to reduce my reflux, but I still take 40 mg Pantoprazole (Somac) of each day.

Carl Strand, Mystic CT - Radiation 1991, Laryngectomy 1993

I was diagnosed with gastric reflux disease and a hiatal hernia years before laryngectomy and have taken Prilosec or the generic equivalent for about twenty five years. I also have to sleep with a wedge or my bed elevated six inches at the head end.

In spite of all this, I have been diagnosed with Barrett's Esophagus, a premalignant change in the lower esophagus caused by acid reflux. I have gone to Prilosec twice daily to keep the reflux under control. My GI doctor is scheduling endoscopic exams annually to monitor the condition.

Frank Watkins, Greenfield WI - 1985

I been cancer free ever since, thank the Good Lord for that. I had acid reflux almost from the outset of my surgery. Thought it was heartburn and had to live with it. After 3 years of pain and agony I finally mentioned it to my ENT, who casually said I was a fool for not saying anything sooner and he gave me a prescription for Prevacid.

Needless to say that did the trick, and I have been free of acid reflux ever since. Lesson here, Let your docter know everything that bothers you.

Joe Hilsabeck, Edelstein, IL - 2009

I became a lary in 09 and had reflux for about 2 years, I used omeprazole with sucess. Doctor seemed to think in my case the feeding tube was the cause of some of it. It started to slowly improve over time, I now only use an antacid occasionally, when I eat certain foods.

The biggest problem I have is if I bend over any time, reflux or bits of food will just run out of my mouth. I have learned to squat instead of bend. However, I didn't have a stomach pullup or a similar operation and mine now can be controlled by diet.

Pat Sanders, Birmingham, AL 1995

I was going to write about my history with acid reflux but I had written about it in 2001 for HeadLines, comparing before lary to after. So this is an update to Then and Now. I sleep on a slanted bed and use a wedge pillow, try not to eat at night... take a Prilosec about an hour before supper (If I miss it, I take it at bedtime)... and here is the story of how I learned about acid reflux:

ACID REFLUX – THEN & NOW by Pat Wertz Sanders

Reprinted from Headlines, July 2001

A few days ago, I was preparing to write in to our online support group to continue the discussion about acid reflux and to make comments on what everyone said. Part of what I do in writing, editing HeadLines, and working on our web site information is to gather material and “put it together”. I planned to mention again the “silent” reflux that several reported having prior to their throat cancer, when I was suddenly struck by how this affected me personally.

Before my laryngectomy, I had acid reflux – the kind that mostly didn’t show and tell. I never had “heartburn”. Back then, you didn’t see the ads on “acid reflux” on TV telling you what it was and what to do about it. It was called “indigestion” or “heartburn” and they showed a figure with a glowing fire in the chest area. Tums or Roloids were touted as the cure. And, it was something that everybody had! I never had that fire in the chest.

I would come in from my sales calls at varying times in the afternoon or evening, would check in with the office, make appointment calls, write reports, and then put it all aside until the next day. At that time, I would get comfortable, get my cigarettes out (I didn’t smoke during the day), fix a drink, and either get on the telephone with a friend, check out the news or start cooking supper. I did not realize that smoking, drinking, and eating late suppers, in addition to sleeping flat so gravity didn’t help the acid to stay in my stomach, were creating a situation that was not good for me. I had acid washing up through my esophagus and into my throat at night and I didn’t know it. I used to say I could eat anything and had a cast iron stomach... but it was sneaking up on me. I often had a sore throat and was hoarse but it would get better, so I blamed that on allergies and drainage or having to talk loudly over shop machinery. One night, I was awakened by a stomach spasm that gushed acid up like a geyser and by the time I jerked upright, it had hit the back of my nasal passages. Burned like hell. I was hoarse and had a sore throat for a week. This time I knew what caused it but I still didn’t think about the other sore throats. Should I have gone to a doctor at that point? Yes. Did I? No. I was in denial that I had a problem other than that one time.

I think acid reflux was a contributing factor in my vocal cord cancer. That is my opinion. This is in addition to smoking and drinking, a deadly pair in which the combination is far more

dangerous than either one alone. Until recently, very few doctors agreed with reflux being a causative factor, but now some are indicating there might be something to it. Looking at this from another viewpoint says it is not the acid reflux but the smoking and drinking that causes the cancer...along with aggravating acid reflux.

After my laryngectomy, I mentioned the reflux and was put on Prilosec. I took it regularly for a while but gradually cut back to every other day, then a couple of times a week and then, only when I needed it, and I didn’t need it very often.

In the last couple of months, I have had an occasional problem with swallowing, not far down but seemingly at the back of my throat. Always in the morning. Synthroid, as small as it is, would stick a little before going down and once the water came up through my nose and the pill stayed in my throat. After I had sipped some coffee, it seemed to open up and I had no problem swallowing at breakfast or the rest of the day. This last week, it happened every morning. I could look in my throat and see swollen and slightly pinker tissues than usual and it felt like it does when you have sinus drainage...but there was nothing there. My throat felt just a little raw but no white patches, no fever. I hadn’t a clue.

I was thinking about the acid reflux discussion when the lightbulb lit up over my head. I was having acid reflux at night again, when I didn’t know or feel it. The acid was causing swollen tissues. Being upright during the day, gravity helped and it was not a problem although one day I did eat too fast and couldn’t get the food down so I was probably having some swelling I couldn’t see.

The day I realized what was likely happening, I took a Prilosec before supper and did again the next day. The third day, the morning pill went down easily. I will continue to do this to see if that ends my problem. I will also have an earlier supper...and cut out the ice cream snack right before bedtime so my stomach is not full. My bed is already raised on blocks, but I had been careless about the rest. I had my checkup last month and everything looked clear. But if this doesn’t get rid of it totally, I’ll see the doc for another look.

Who says we don’t continue to learn? Many times has someone written to me to say...I already knew that, I just forgot? This just happened to me. I already knew. I forgot.

A few more comments.....I received a note from David Arnaud, who said, “Yes, Pat, my Doc at MD listed acid reflux right there with tobacco use as major causes of cancer of vocal chords and voice box.”

After the article above, I wrote more about the search for professionals who believed this. It was in this newsletter in 2004. I don’t want to copy the entire article because some of the links are no longer working.

LPR - Laryngopharyngeal Reflux

After my laryngectomy, I asked a lot of questions about laryngeal cancer causes other than smoking or drinking. I wanted to know if breathing in acids or alkalis were a problem since I had been in a lot of contact with chemicals. I asked if stomach acid could be a cause and was told that it was a known cause of esophageal cancer but not of laryngeal cancer.

This never made sense to me since I knew I had awakened at night with a rush of acid coming up into my throat and sometimes even up behind and out of my nose. The next day, that whole area would burn, I would be hoarse, having to clear my throat and cough to clear the mucus. This area was a much more tender area than the esophagus. After the surgery, we raised the head of my bed and I took medication so it has been better.

I learned to talk and played with my new computer, installed the day I came in from the hospital, but I did not have a service provider until 6 months later. Even after I got Compuserve (with a limit of 5 hours a month!), there was no big Internet with a Google search engine in 1995. I learned to chase down information on the fairly new World Wide Web, in which you had to find a site that related to what you were looking for and from there try a connected (linked) site. I ran into a lot of dead ends in my searches and particularly so in my search for what happens when stomach acid hits the throat and vocal cords.

During all this time, I had been calling on patients at UAB Hospital and, in addition to teaching them to talk or showing them equipment and answering questions, I would always ask if they had been bothered by heartburn. Almost before I could get the question out, the caregiver would jump in to say, "Oh, Boy, does he ever! He ate TUMS all the time." I would always tell them to be sure the doctor knew about that because there were some one-a-day medicines that could help a lot and they did not want to start having acid come up into the new throat.

Finally, I found the Voice Center at Wake Forest University where there was a great deal of research and their conclusion was: there was a different kind of reflux, one that usually did not cause heartburn, and it did cause throat cancers. Then, I saw a brochure, put out by the drug company AstraZeneca with information developed by The Center For Voice Disorders of Wake Forest University and the Department of Otolaryngology, Bowman Gray School of Medicine. I rejoiced that the word was out.

Next, I found from the American Academy of Otolaryngology:

What is GERD?

Gastroesophageal reflux, often referred to as GERD, occurs when acid from the stomach backs up into the esophagus. Normally, food travels from the mouth, down through the esophagus and into the stomach. A ring of muscle at the bottom of the esophagus, the lower esophageal sphincter (LES), contracts to keep the acidic contents of the stomach from "refluxing" or coming back up into the esophagus. In those who have GERD, the LES does not close properly, allowing acid to move up the esophagus.

When stomach acid touches the sensitive tissue lining the esophagus and throat, it causes a reaction similar to squirting lemon juice in your eye. This is why GERD is often characterized by the burning sensation known as heartburn.

In some cases, reflux can be SILENT, with no symptoms until a problem arises. Almost all individuals have experienced reflux (GER), but the disease (GERD) occurs when reflux happens on a frequent basis often over a long period of time.

What is LPR?

During gastroesophageal reflux, the acidic stomach contents may reflux all the way up the esophagus, beyond the upper esophageal sphincter (a ring of muscle at the top of the esophagus), and into the back of the throat and possibly the back of the nasal airway. This is known as laryngopharyngeal reflux (LPR), which can affect anyone. Adults with LPR often complain that the back of their throat has a bitter taste, a sensation of burning, or something "stuck." Some may have difficulty breathing if the voice box is affected.

At last, GERD and LPR was being recognized...

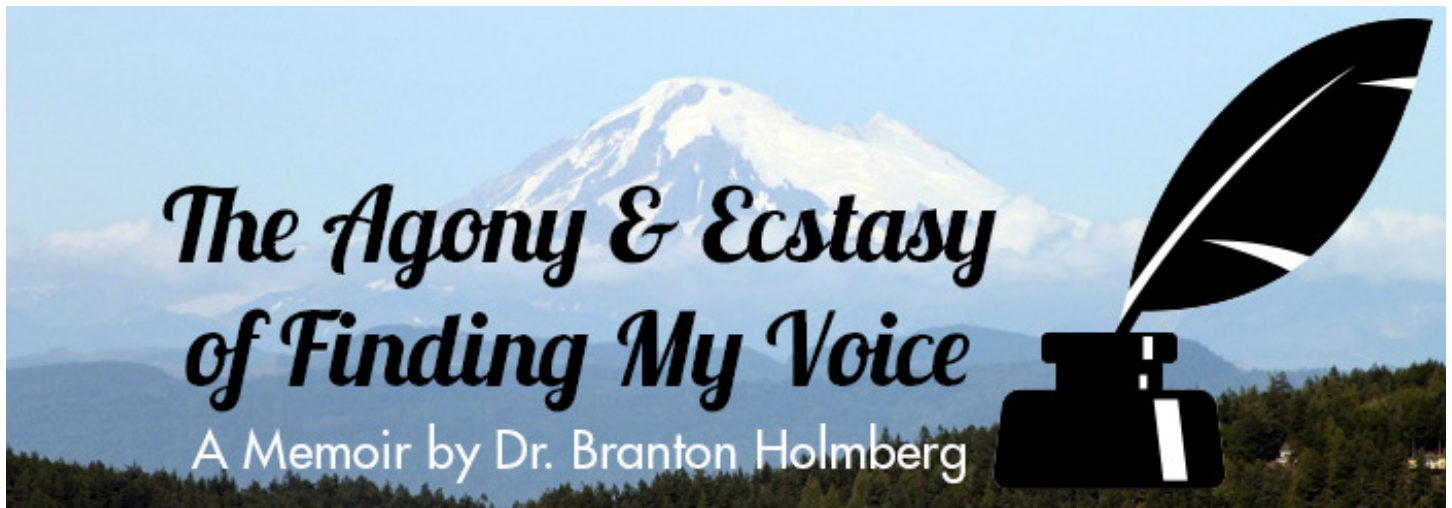
Pat

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

The running away from home incident triggered the best thing that could have happened to me because my mom and I didn't get along at all and she was the dominant force in our family. She was the reason I'd decided to run away. I knew there'd be a terrible fight between us over all that time I'd been skipping school and I didn't want to go through it with her. My brother had graduated and gone into the Navy by that time and it was just me and mom going toe to toe.

Once I was back home, I went back and finished the few school days left of my sophomore year at Lincoln High School. I ended up with a lousy set of grades for the year. That next school year mom arranged for me to go and live with her younger brother and his family. They lived near Holly, located on Hood Canal about 50 miles from where we lived in Tacoma. It's one of my favorite places on earth.

I lived with Uncle Jim, Aunt Joyce and my cousins Terry and Joy until I finished high school. I count those two years among the best years of my life. A life changing transformation started from the time I began living with Uncle Jim and his family. My life up to that point had been a constant and disheartening struggle of coping with my family, my peers and myself regarding 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 I'm forever grateful it did.

My new home was in a little community called Holly on Hood Canal. The change was perfect for me because it took me out of an environment that was toxic to me and put me in one that gave me a whole new chance at things. Uncle Jim was a logger and had always been my hero from the first time I became aware of him. He'd always treated me as a kid he loved to be around and I sure loved being around him and my aunt Joyce and my cousins.

He was a happy guy with an infectious laugh and he'd always get me laughing too. Physically he was as hard as a piece of steel especially after he struck out on his own with a partner and they became gypo loggers and worked for small logging operations all around Western Washington. I went out on the job with him a couple of times, spending a full day in the woods with him as he and his partner worked. It was all I could do to keep up with them when they climbed the hillsides

cutting down trees. Each of them had chainsaws, a couple of gallons of gas, a quart of oil, an axe and wedges, drinking water, lunches pails and thermoses of coffee plus tools to make repairs on their saws.

We wore hard hats and cork boots. I wore one of my uncle's hard hats and a pair his cork boots. The only thing I had to do was keep up with them carrying my lunch sack. I still lagged behind when they were on the move. They were incredibly tough guys.

I've always had a hero worship thing about Uncle Jim and he always had a way of treating me like I was an extra special guy. I'm sure my mother, and her favorite brother had talked often about many of the trials and tribulations she'd suffered with me. In hindsight I think those confessions of her struggles gave me a special place in his heart. He sure had one in mine.

As I write this I wonder if she told him she felt God was punishing her through me. As I think about it I'm sure it's a strong possibility because she was closer to her younger brother than anyone else in her family.

As I mentioned earlier I changed my name to Rex when I changed high schools and went to Central Kitsap High School in Silverdale, Washington. The name Branton, being an unusual name to begin with was hard for me to pronounce clearly. I'd gotten into the habit of spelling my name as soon as I said it and I hated that.

The name Rex came out clear as a bell when I said it. A good friend of my brother was named Rex, I liked him and liked his name so I swiped it and used it my last two years of high school. I've never used it since.

During my junior year I got better grades and made friends a lot easier than I ever had in Tacoma. The atmosphere at the school was much friendlier because we all lived in rural areas and the kids were a lot easier to get to know.

To be continued...

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Between Friends

Donna McGary

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

So while I was scrolling through past issues looking for a Speaking Out column (we all miss Jack's good questions and will come up with some new ones soon) I came across this. I first wrote it in September 2011. It seemed appropriate to re-print since summer is finally here for many of us. And, I have to admit it made me laugh. That two year old just turned ten and has a seven year old sister. We are long past potty training but we still love exploring the back yard for bugs and slugs and butterflies. I hope that it makes you chuckle and inspires you to get out and enjoy life's humble adventures this summer...whatever and wherever they may be!!

My Summer Vacation at Camp Nana

*Hello Mudda, hello Fadda,
Here I am at Camp Granada.
Camp is very entertaining
And they say we'll have some fun if it stops raining.*

I bet a lot of you remember Alan Sherman's comic genius. Just Google "Hello Mudda" & you can listen to a live version of this Grammy award winning classic from 1963. Back in the sixties, I was just another kid who absolutely loved sleepover camp. From Methodist Church Camp to Girl Scout and Music Camps and the la-di-da of private Camp Se-Sa-Ma-Ca, I couldn't get enough of the woods, the lakes, the cabins or tents and most especially, counselors instead of parents. For me, summer camp was a chance to be daring but not dangerous. I felt brave and unfettered. Away from the small watchful community of eyes and expectations at home, I discovered myself, both the good and the bad. I had a hard time coming back when camp was over.

What made it so special was the opportunity to re-invent myself, to see myself in the eyes of others the way I imagined myself. As I learned new skills, like getting my LifeSaver Certificate or doing a 360 on trick skis, I became someone different. I was still a total dweeb when I got back to my hometown and school but I now carried within me a belief that someday I, too, might possibly be cool.

It is nearly fifty years later and my definitions of what it means to be cool have changed considerably. But I feel as though this summer I went back to camp. I have a grand-daughter who turned two in March. That means this has been the summer of discovery. I have spent countless hours watering the deck, the pots of rosemary & parsley and our feet. I have examined bugs and twigs and the cat's claws. We have swung in a hammock

and watched the wind move the clouds. We have filled the bird feeder and put little dishes of water out as bird baths. We have hollered, "Birdies, come drink, now. Take your bath!" and puzzled why they didn't respond. We have dug in the garden, swum in the pool and even gone pee-pee in the potty. That last one I actually figured out a while back but a good Nana shows solidarity on these matters.

I, too, have learned things this summer:

First, summersaults are surprisingly difficult when you are 58.

Second, potty training takes a lot of attention. And it helps if you roll up the rugs.

Third, a Servox is a toddler magnet at Library Story Time.

Fourth, when you are two, everything is new and exciting and so much fun. It is sometimes hard to contain yourself and that delight is infectious.

Fifth, being the Head Counselor at Camp Nana means I am finally, seriously, cool.

I haven't had this much fun since I short-sheeted that counselor at Cedar Cove, learned "Reach, throw, row, go" and "rescued" her one cold rainy August morning executing a perfect "tuck, dive, turn & hold" as I hauled my 120 pound "victim" back to shore using a one-arm side stroke. Maybe not that impressive except I was 12 years old and weighed about 80 pounds. I was cool that day.

I was pretty cool yesterday. Kayleigh gave a tutorial on my Servox after Story Time. She had a rapt audience of toddlers and their moms. I hope that someday she will understand how sorry I am that I couldn't teach her how to do a "dive & turn rescue" or do funny voices for the books we both love. But I suspect she will always know that I took the time to examine the bugs and water our toes. And that makes me one cool Nana. I love summer camp.

I am the Head Counselor at Camp Nana and I wouldn't have it any other way.