

# Whispers on the Web

A Monthly Online Newsletter for WebWhispers

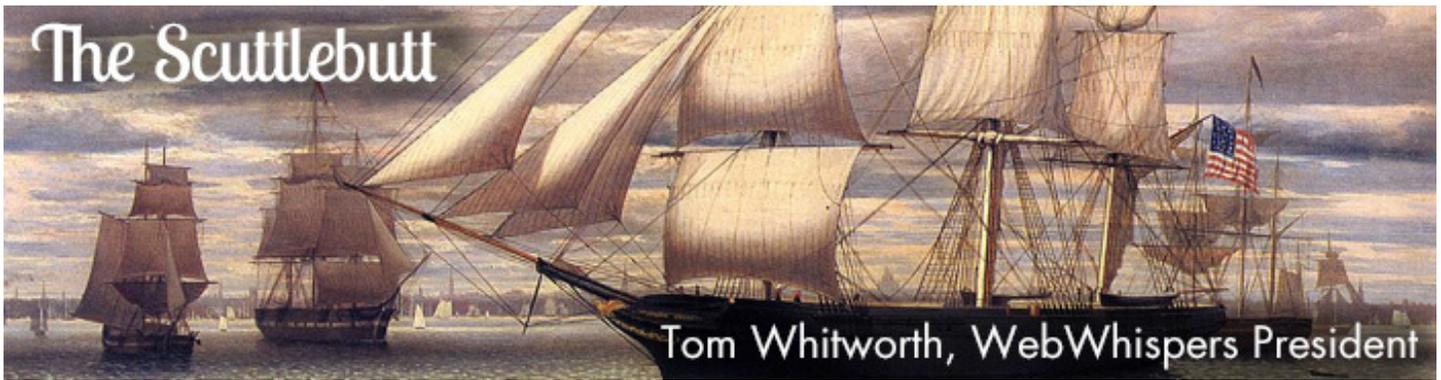
Photo CC by HMBascom

## October 2019



### Table of Contents

Name Of Column	Author	Title	Article Type
The Scuttlebutt	Tom Whitworth	WebWhispers Board of Directors	Commentary
VoicePoints	Erin T. Guidera, MS, CCC-SLP, BCS-S	Swallowing After Total Laryngectomy	Education-Med
Between Friends	Donna McGary	Social Costs	Commentary
Speaking Out	Members	Difficulty Swallowing	Experiences
Dear Lary	Noirin Sheahan	Embracing the Change	Commentary
My Neck of the Woods	Don Renfro	Fear, Friend or Foe	Member Experiences
This Lary Life	WC Baker	Raising Our Voices	Commentary
The Agony & Ecstasy	Dr Branton Holmberg	The MASH Years cont...	Member Experiences



## WebWhispers Board of Directors

Last year, the WebWhispers Board of Directors was fully staffed with four directors and five officers. I'm not sure how often a full board has been the case, but I do know that since my time with WebWhispers, last summer was the only time we had no vacancies on the board.

Starting with the passing of our VP- Member Services, Scott Sysum in August 2018, we lost three of our five officers in just over nine months. Our beloved Mike Rosenkranz, also known as Shmuel Mitchell, VP Website Information, died in December 2018 and our VP-Finance & Administration, Jack Henslee passed away in May 2019 while many of us were attending the IAL Annual Meeting and Voice Institute in Phoenix, AZ.

For our newbies, it is surely worth noting that the passing of each of these servants was due to something unrelated to head and neck cancer or laryngectomy.

Scott Sysum managed our Salesforce database and could be counted on to do a great job for us. Scott could always make me laugh, even when he was facing more adversity.

Jack Henslee managed our finances and provided us with a vast background in service to the laryngectomy community. Within Jack's legacy is his international contribution to the welfare of laryngectomees.

Mike Rosenkranz was our social media guru and master encourager of us all. Mike was among the first mentors of me as a laryngectomee and it was he who nominated me to complete the last term of Pat Sanders as WW President. His positive influence on everyone he encountered was and is a source of inspiration.

Recent changes on our board rectify some of our loss to the extent possible. Donna McGary is now VP-Member Services. Donna continues to do a superb job as Managing Editor of WotW, and as director of our EL Loan closet, and works with our awards, VI scholarships, and more. Ron Mattoon is now in the role of VP-Website Information. Ron is currently shouldering deep in the re-creation of our website.

The project is now in Phase Three of four phases. The current phase is the longest as Ron works to create the pages our information will be moved to. He is putting in a lot of time to make sure our website is the best it can be when we transition to it from the current site.

We are truly thrilled to welcome Kimberly Almand, CCC-SLP as a director on our board. Kim is an accomplished professional and VI faculty member and facilitator. She brings to WW a perspective we have not had before, that of an SLP. I am grateful to have her officially on our team.

### **SAVE THE DATE!**

**The 2020 IAL Annual Meeting and Voice Institute is planned for June 10-13 in Charlotte, NC. If you've attended a VI before, you know what I mean in saying to potential first timers:**

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

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



## Swallowing After Total Laryngectomy

During a laryngectomy, the upper aerodigestive tract is surgically altered, separating the trachea from the esophagus. As the airway is diverted away from the swallowing tract, a laryngectomee is physically unable to aspirate. But just because food/liquid can't go down the "wrong pipe" doesn't mean swallowing is always easy for the laryngectomee. Dysphagia, or a disorder of swallowing, is very common in the laryngectomee population. Research incidence rates of dysphagia are between 12-89%, depending on the definition of dysphagia. According to a survey by Maclean 2009, 71.8% of laryngectomees experience difficulty swallowing; 71% had to change their diet; 86% required liquid to wash food down; 49.9% reported difficulty swallowing medications; 57% reported less saliva; and 39.7% reported severe distress related to eating. Some common challenges laryngectomees may experience when eating include:

- Chronic dry mouth (xerostomia)
- Regurgitation
- Acid reflux
- Feeling like food "gets stuck"
- Requiring multiple swallows per bite/sip
- Sensation of a lump in the throat (globus sensation)
- Having to eat slowly
- Prolonged mealtimes
- Inability to talk while eating/drinking
- Difficulty opening the jaw/mouth (trismus)

Difficulty swallowing for the laryngectomee can occur for many reasons including the surgery itself, previous history of radiation, or a leaking TEP (tracheoesophageal voice prosthesis). These are discussed below.

### **Surgical Alterations in Swallowing:**

The surgical procedure of a laryngectomy can result in anatomical variances of the neopharynx or "new throat." The extent of surgery and reconstruction approach (e.g., primary closure vs. flap reconstruction) can affect swallow function. Peristalsis, or the squeezing of the throat muscles, is often less propulsive or uncoordinated. Tongue propulsion and gravity assistance often drive the bolus through the neopharynx. Surgical scarring can also cause a stricture, or narrowing in the throat, that causes an obstruction when swallowing. A pseudoepiglottis is also common in the laryngectomee. A pseudoepiglottis is a mound of redundant tissue that can develop at the base of the tongue. If the pseudoepiglottis is large enough, it can cause an obstruction to food passing through the neopharynx. Many laryngectomees also develop lymphedema, which is swelling of the soft tissue due to accumulation of lymph fluid. The presence of lymphedema in the neck can also hinder swallowing.

### **Radiation Effects on Swallowing:**

Radiation associated dysphagia (RAD) is difficulty swallowing as the result of radiotherapy. Radiation either before or after a laryngectomy can cause dysphagia. During radiation, there can be acute effects on a person's ability to eat including mucositis (blisters in the mouth/throat), odynophagia (painful swallowing), dysgeusia (taste changes), and xerostomia (dry mouth). Long-term effects on swallowing can also occur. Radiation can cause fibrosis of the swallowing muscles, which can limit the movement and propulsive force of the muscles that squeeze food/liquid through the throat. Strictureing is also common in the neopharynx or

cervical esophagus, which can lead to food getting stuck, regurgitation, and/or potential food impaction. Strictures often require medical intervention (e.g., dilation) by an ENT or gastroenterologist.

### **TEP-Related Difficulty Swallowing:**

The presence of a TEP can also cause dysphagia. The most common TEP-associated difficulty is leakage. TEPs can leak through the middle of the prosthesis (central or intraprosthesis leakage) or around the outside of the prosthesis (periprosthesis leakage). If a TEP is leaking, this causes aspiration by allowing food, liquid or secretions to enter into the trachea. If a TEP continues to leak, this can result in aspiration pneumonia or other pulmonary complications. Additionally, a TEP can cause dysphagia if it is not the proper fit or size. For example, if a TEP is too long for the tracheoesophageal tract, the TEP can protrude into the esophagus. This can cause an obstruction, allow food to catch on the TEP, or allow pooling of liquids on the TEP.

Many laryngectomees have to modify their diets as a result of difficulty swallowing. For example, they may have to avoid dry foods (e.g., doughy breads), tough foods (e.g., meats), or stringy foods (e.g., fibrous vegetables). They may also have to crush their pills or take medications in liquid form. Some recommendations to assist with swallowing after a laryngectomy include consuming more moist and perhaps softer foods, using moistening agents (e.g., cream, gravy, sauce), alternating bites/sips, chewing food thoroughly, taking smaller bites, using a slower

rate when eating, taking pills broken or crushed, staying upright >30 minutes after eating/drinking, and not bending over immediately after a meal. If you are having difficulty swallowing and think you need a swallowing evaluation, please contact your speech-language pathologist or doctor.

**Erin T. Guidera, MS, CCC-SLP, BCS-S**

**Speech Pathologist**

**Erin.Guidera@moffitt.org**

*Erin Guidera, MS, CCC-SLP is a Board Certified Specialist in Swallowing and Swallowing Disorders and the lead head/neck speech-language pathologist at Moffitt Cancer Center in Tampa, Florida specializing in the evaluation and treatment of patients with head and neck cancer including alaryngeal voice restoration following total laryngectomy and dysphagia management following head/neck cancer.*

*H. Lee Moffitt Cancer Center & Research Institute*

*12902 Magnolia Drive*

*Tampa, Florida 33612*

*Office: (813)745-3609*

### **References**

*Maclean, J., Cotton, S. & Perry, A. (2009). Post-laryngectomy: It's hard to swallow: an Australian study of prevalence and self-reports of swallowing function after a total laryngectomy. Dysphagia, 24(2), 172-9.*

# Between Friends

Donna McGary

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

Photo CC by Cu-art:5239

## Social Costs

I was struck by the numbers of laryngectomees who have significant swallowing issues as noted in this month's VoicePoints column. So I looked up a fairly recent Speaking Out question addressing the same issue and thought it was a good complement to the research.

It's an ongoing concern for many of us. It is not a small thing, this swallowing/food stuck in our craw issue. Socially, it is as huge as that tiny bit of whatever is stuck feels like! Let's be honest, nothing kills the fun and festivity or intimacy of a meal with friends or family like someone bug-eyed as they try to discreetly dislodge a piece of food. My 10 year old grand-daughter put it this way, "Nana, it looks like you are throwing up in your mouth! And then swallowing it!" She and her younger sister were trying to be understanding but we were all pretty much grossed out, since actually, that is EXACTLY what was happening.

Much easier to eat at home alone...decline invitations out to eat or take really tiny nibbles when out in public and hope you don't forget and take a normal bite or two bites too close together or not without a drink or not as you are talking or especially not laughing as you chat with your friends.

Even eating at home is fraught with difficulties as well if you get caught up in that book or that TV show and forget....eating nowadays is a true exercise in mindfulness. Unfortunately ice cream and Girl Scout cookies late at night seem to be immune to this problem....not good for my health or my waistline!

Seriously, I do find that I am quite anxious in social situations now, even with my family. Retching is not conducive to a pleasant dining experience no matter how compassionate you may feel about the one retching (the retchee??) It's awkward and embarrassing and frankly way more troubling to me than the fact that I have a

funny voice that you probably can't hear over the cheerful dinner chatter anyway.

To have one more issue related to cancer treatments and its aftermath show up nearly 20 years later is disconcerting, to say the least! Yes, I have seen my ENT and have a referral to a GI. But I think we all know what they will find- a stricture- duh LOL!! And the options for addressing that come with their own set of potential complications.

For me, the beauty of WW and other support groups is that we can share this whole messy business and know we are not alone. We can share our fears and consternation and social awkwardness and know that for darn sure there are folks out there saying, "YUP...I hear you. Same thing here. Sucks, doesn't it?" And not only that, we can hear what worked, if anything, and sometimes equally as important, what didn't work for them.

As you read through this issue you will notice a theme...not just about swallowing problems but how we face the social costs of these cards we have been dealt. I particularly love how we are both brave and honest about the challenges and that honesty inspires and encourages others. Jennifer inspires Noirin who in turn speaks up and motivates others. Don learns from others, who spoke up about their experiences with honesty, to face his fears; WC speaks truth to power to force accountability. Doc Holmberg shows how a lifetime of overcoming challenges prepared him for his cancer battle.

Our voices may not always be appealing or easily understood but they are powerful. Check out this video of the UK Shout Out Cancer choir if you don't believe me. More on them later: <https://bit.ly/30JWk8T>



### **“Did You Have Trouble Swallowing After Your Laryngectomy?”**

---

When I can swallow it is strictly liquid, Jevity 1.5. Otherwise it is peg feeding.

Peggy Balle - New York, NY  
2013/2016

---

For approximately a month after I got home I had a tube through my nose into my stomach. I drank a lot of Ensure during that time. After that month I was able to eat things like Jello and mashed potatoes and anything soft for another month. Then I graduated to big people food and could eat anything I thought I could safely swallow. To this day I still get things stuck in my throat such as bread and chicken. If I take a couple of sips of water it goes down. That's my story and I'm sticking to it.

Chris Pieper - Fond du Lac, WI  
2012

---

I was on a feeding tube for about 25 days following my surgery, which was March 23, 2016. I had difficulty swallowing for about three weeks after I went on food again but within that time, I was pretty well back to normal. Have not had any problems since.

Joe Rook, Salt Lake City  
2016

---

My total laryngectomy was in April 2013. On every follow up visit with my surgeon I told him I am having trouble swallowing water but not food. His answer was, to him that did not seem a major problem. Then one time I told him some pita bread and chicken got stuck in my throat and I

waited 10 minutes before it went down. He recommended an esophageal dilation. He set me up for the dilation but it did not affect my difficulty swallowing water or my occasional difficulty swallowing bread or chicken or dry crackers.

I told my swallowing troubles to a doctor at an IAL meeting. He said I should ask for a modified barium swallow test. My SLP arranged for the test. As I swallowed the barium mixed with various thicknesses of liquids, my SLP and the radiologists were amazed. They said to each other, “Did you see that? That is serious.” I asked what did they see. My SLP said there seemed to be a mass obstructing my esophagus. She said I should get PET and MRI scans. Which I did pretty quickly. I heard from my SLP that the scan did not show anything obstructing my esophagus. I should see the surgeon for his explanation.

My surgeon greeted me and then he drew a sketch of my esophagus as he saw it on the swallowing test. It had a long narrow section in the middle third of the sketch. His sketch looked sort of like an hour glass.. He said the narrowing is due to the cricopharyngeal muscle. He explained that my cricopharyngeal muscle was longer than usual. He had cut some of that muscle during my original laryngectomy but my swallowing problem was due to some length of that muscle which does not relax properly during swallowing. He can section (cut) the rest of that muscle if I need improved swallowing.

He asked what I thought of the quality of my voice and of my ability to eat and drink. I answered my voice seemed decent to me and my swallowing is only a minor bother. If my quality of life is not impacted by the current situation, he would suggest putting off the surgery. If in the future my quality of life is negatively impacted, I should call him and we can reevaluate the value of this surgery. I agreed not to have the surgery. One of the strong reasons why I thought it was better not to have the surgery at that time is that I did not want to disturb my esophagus on which I rely to make the vibrations by which I speak.

I asked what caused the radiologist to suspect a large mass. He said the indentation during swallowing would look the same if it were due to a large mass impinging on the esophagus or if it were due to an cricopharyngeal muscle that did not relax. He showed me on his sketch of my esophagus how that would be the case.

I afterward asked where with respect to the cricopharyngeal muscle did my TE puncture lie? I was told my TEP lies just barely above the cricopharyngeal sphincter. If it was below or even at the same level I would not have a very good voice.

Since then I have taken some liquid with every bit of food. If food gets stuck, I wait for gravity to pull it down or I occlude my stoma and breath out which sometimes help push the food back into my throat.

This whole episode gave me knowledge of my swallowing problem and thus some peace of mind.

Jay Hauben – New York, NY  
Larry since April 19, 2013

---

For me it was about 4-6 wks. Before I got my first TEP put in, I was using a syringe & put my liquid nourishment in that way. It's been over

5 yrs. now & I still have to make sure I chew my foods up a lot in order to swallow because they had to make me a new throat out of a muscle from my chest but other than that I eat whatever I want."

Gene Maddox – Columbia, SC

---

Woke up with a feeding tube stitched to my nose. Got fed up with that nonsense after the respiratory specialist banged her gorilla paws on it for the umpteenth time in the first couple of days, but doc refused to remove it until 10 days out. Same amount of days he said I could go home if I was able to eat regular food. So the next time gorilla paws banged the tube I tweaked her snooze to let her know how bad it hurt when her clumsy butt hit that tube.

No, just kidding about that. I did complain to her supervisor and got a new tech and she was more careful.

Back to swallowing.

Tenth day after surgery I sent my gorgeous Vicky Sue over to the McDee's across the street from the hospital and get me a 1/4 pounder with cheese and fries for lunch because I simply could not stand to spend another day in the hospital.

I thought that 1st bite was never going to go down and I'm

no sissy when it comes to pain. How can you be after being beaten silly with a tire iron? (Whole 'nother story, that) But that attempt at eating solid food brought tears to my eyes, but . . . being the mule that I are . . . I figured all that was needed was . . . another mouthful.

Took forever to eat that lunch (or so it seemed) and I was certainly glad she had the insight to purchase two large drinks with that order cuz it took both of them to help me 'wash' that chow down.

Doc came in just as I was finishing up and he put me on soft solids for supper.

Nose tube came out and I was discharged after breakfast the next day.

Since then I've been eating and drinking anything I want. Occasionally I encounter a brief swallowing discomfort, but tis nothing that a good swig of sweet tea or coffee can't overcome and it's back to chowing down.

Will be my 12th laryversary come Halloweenie this year. Still eating and drinking anything I wish with little or no trouble at all.

Just another reason I always say: "God treats me far better than I deserve."

Troll - Jacksonville, FL  
October 30, 2006

---

Right after surgery swallowing was, and I still have some days where it still is, VERY difficult. Right after surgery, all I could down the ol' hatcherooni was thinned out oatmeal or liquids. On some days after a couple of spoonfuls, I'd be absolutely stuffed and couldn't eat anymore even if I tried.

Some days, if I bent over, I could swallow and the next day THAT wouldn't even work. It finally got so annoying that I said something to the doc. He put me on a liquid diet until another doc said "dilation you silly goose neck". AHA, a whole new world. First dilation was a HUGE swallowing improvement for about a week. So I had dilations once a week, which got moved to every other week, and then every three weeks. Right now, I am a dilation a month and I'm a happy swallower. I can tell when I'm up for another dilation because the swallowing becomes a bit difficult. Expectations down the road...yearly dilations and then maybe a dilation here and a dilation there.

But it certainly made a WORLD of difference immediately -- for which I was/and still am thankful and grateful.

Lisa O'Farrell – Chicago, IL  
August, 2017

---

No swallowing issues at all. Worked from day one. Can eat anything.

Ron Fonte – McMurray,  
2012

---

Fed by tube after lary surgery ! I woke up with a feeding tube in my nose after my laryngectomy surgery. As I recall, I had to eat with that tube for about two weeks after my surgery. Then, they had me do a swallowing test (to check for swallowing ability, leakage, aspiration, etc) and I passed it, so they removed the tube, and let me start eating and drinking by mouth. Over the next year, I had 3 recurrences, and 3 more major neck surgeries, and 3 more times woke with a feeding tube in my nose, and it stayed there for anywhere from 5 days to 10 days after each of those surgeries. I had radiation to my neck in 2013, my laryngectomy in 2014, two recurrences surgeries in 2014, thyroid removal surgery in 2015, radiation again to my neck in 2015 (and chemo). I never got a feeding tube during my two courses of neck radiation (but should have during the first one - very painful swallowing).

So, I'm now 5 years out from my 1st neck radiation, and 3 yrs. out from my 2nd neck radiation, and I've always been able to swallow both liquid and food somewhere between great and decent. My esophagus was stretched one time: about 2015. If I try to swallow pills the size of a full size aspirin, that have sharp / square edges, they will get stuck in my throat and I have to just patiently and calmly wait for them to "melt" (5--15 minutes) before they will go down. (I can't die from this throat blockage, b/c I of course breathe through my neck, not my mouth/nose). --- Soooo, my swallowing is still pretty good, as long as I chew my food very thoroughly. I've thought about going ahead and having my esophagus stretched again, but will probably wait until my swallowing gets harder than it is now.

NOTE: A year ago, I had my GI Dr. try to do a balloon stretch, while he was doing a routine upper GI scope. My swallowing was "ok" at the time, but I thought he might as well try to stretch it a little while he's in there doing the scope. After I woke up, he told me he tried the balloon stretch, but was afraid of tearing my esophagus, so he aborted the attempt. I later told my ENT laryngectomy surgeon about this, and he said, "David, if you ever need your esophagus stretched, you come to me. I do these all the time on irradiated laryngectomees and I'm understand the tissue and I am NOT afraid of tearing your esophagus".

He convinced me that and ENT surgeon is probably a better choice than a GI doc for doing esophagus stretched on irradiated throats. (Perhaps it depends on which doc has the most experience with which type of throat procedures, throat surgeries, which has done throat reconstructions, which sees

more irradiated patients, etc, etc).

I quickly got tired of the time and mess of using the big manually operated syringes to feed myself formula through my nose tubes. It was boring, messy, sticky, and your arm and hand gets tired pressing constantly on the syringe. I tried doing it really fast, to get it over with quicker, but that upset my stomach. So, I slowed down to a much slower feeding rate and felt better afterwards. So, b/c of the boring, tiresome mess of using the manual syringes, I got on eBay and bought me a (Kangaroo brand) feeding pump and some feeding bags - \$350.00, and a rolling stand (\$75.00) to hold the pump and bag of formula.

It was FABULOUS ! I just poured my feed in the bag, hung it on the rolling stand, attached the battery operated pump on the rolling stand, and pressed the start button. Then, I could sit down and watch TV, or walk around and push the rolling stand around with me, just like at the hospital. --- I made a 15 minute phone attempt to get my insurance company (Blue Cross) to buy the pump and stand for me, but of course they made it such a huge bunch of BS to go through that hung up and decided to just buy one myself.

David Smith - Strawberry Plains, TN  
Class of 2014.

---

I had my Lary in February this year and at first I had a lot of difficulty swallowing. Six months on I can eat Shepard's pie jacket potato with cheese and mayo so things are improving. I don't think anyone eats normally do they?

Elaine Payne – Blackbush Lane, UK  
2018

---

I was treated for pharyngeal cancer in early 2002 with 15 days of chemo and 31 days of two sessions of radiation each day. Over time the scar tissue from the radiation, the gift that keeps on giving, compromised my ability to swallow. I spent nearly two years with a feeding tube and several bouts of pneumonia. Breathing became more difficult and I had an emergency tracheotomy in late June, 2015. In late August, 2015 I had a total laryngectomy. Two months later I had an ultra valve inserted. I began eating and speaking again and in January of 2016 I had the feeding tube removed. I have gained back the 30 pounds that I lost and am always hungry and ready to eat. I now use an Activalve and speak pretty well although it can be difficult to understand my speech during a telephone conversation. I can eat pretty much everything, although I find it difficult to swallow steak and lobster so I don't bother. It took time, experimenting and patience but life is good.

Dick Spiers – Mashpee, MA  
2017

---

In introduction even though I have had more than my share of issues in the past months and still have cancer, I am divided in providing anything resembling positive experiences in consideration of those that have so many more challenges than I do. I have a 68-year-old neighbor who did not have a TL but who, because of radiation, has not had any food by mouth for over eight years and I know that there are many others out there with the same or worse issues. It is such a personal journey.

The choice is whether to provide positive encouragement or potentially inadvertently make someone feel worse about their own situation. My conclusion is that there is no definitive answer except to be sensitive in not being overly enthusiastic in representing your own story.

I have not had any problem with liquids since the initial surgery but have had difficulties with everything else. My opening dimensions are less than what is considered a stricture I'm told, but I have an area of stenosis that does not allow a scope to pass. In the beginning I got by with Boost plus, soup (usually without any solids), smoothies, scrambled eggs etc. If something got stuck it would take a lot of time to clear I've had to go the bed a couple of times without being able to clear the blockage.

A few months after initial surgery I had two base of tongue surgeries which set me back further. All in all I've lost over 50 pounds but that's OK. In fact everything is ok and I am so very grateful to be able to do what I can do. Despite previous radiation and surgeries, I still have a sense of taste and smell that varies from day to day but I have it. Leek and potato soup has been a godsend!

I started a dilation program about 4-5 months ago. Under a mild general anesthetic they insert balloons of increasing sizes and pump them up. Takes less than half an hour but from what I've read some people have issues like tearing etc. some serious.

I've had three without those issues. First one no real help, second maybe a little, third-definite improvement. If memory serves I was up to 13mm. Separately I had a TEP installed last September. By January it had rotated allowing the puncture on the back side to heal on its own and prevent replacement valve insertion. The third dilation opened the puncture up causing leakage. That combined with the fact that I was put on chemo for 18 weeks has delayed anymore dilations but only for now God willing. One of the collateral benefits of the third dilation is that I find it easier to clear blockages rather easily using a finger.

Even with dilation if I were to try and swallow a single kernel of corn it would cause blockage. Eating is hit or miss and takes a great deal of time and tons of water but I can eat.

Amazingly by nibbling and chewing a lot I can eat a burger

with roll and thinly sliced tomato as well as tuna and meatball hoagies. To eat half a burger or half of a six inch hoagie/sub takes 20 -30 minutes.

I hollow out the roll and toast. Hard is better than soft for me for items that are absorbent and can swell with liquids. My philosophy right or wrong is that for bread products of any kind if they get stuck I just keep flooding them with liquid until they breakdown and then use my throat to force them down. If it is something that will not eventually react with liquid, I use the finger and the gag reflex. I've gotten pretty good at the latter and remember I'm technically a rookie.

Restaurants cause a great deal of concern and planning and I mainly avoid them. Even with planning they are hit and miss. Before dilations I went out three times with only a couple of trips to the bathroom total. I had lentil salad, soup and flaky fish but also had potatoes.

After dilation I went out in Orlando at the IAL/WW event and ordered clam chowder (giving all larger pieces of clam to my wife) and tuna poke appetizer. I had to make five trips to the bathroom but luckily the private bathroom was next to our table. A week later I had eggplant spaghetti which was absolutely fine. Alcohol use increases the frequency of blockage greatly. I'd like to believe it's because it encourages me to try and swallow more than I should but it probably makes the new throat muscles less effective.

To that point my SLP originally told me that the flap taken from my forearm did not have the same muscles as the throat it replaced and that would affect my vocalizations and swallowing. However, subsequently my surgeon stated that the forearm certainly has muscles and that both should improve over time. Hopefully encouraging to those to whom it applies or may apply.

I will keep trying to get better at swallowing and as I learn more will be happy to report more if deemed to be helpful.

Tom Tully – Yardley, PA

---

Ten days after my laryngectomy I was still not doing a good job of swallowing, but was released from the hospital anyway. I had a primary puncture for a voice prosthesis so my feeding tube was through the puncture and my wife and I did the feeding through that while I gradually relearned how to swallow. That did not take more than a few added days.

Following that, I had no swallowing difficulties for over twenty years. In the fall of 2015 I began to have difficulties swallowing pills. Following some back and forth with my ENT, I consented to have an esophageal dilation done in January 2016.

The procedure seemed to go well, but about five days later I

began to have problems and was found to have a tear in the esophagus that developed into an abscess and a fistula into the area beside my stoma. I went through a week in ICU, several procedures to clean out the abscess, several more weeks in the hospital and a month in rehabilitation.

It was three months before I got rid of a laryngectomy tube and had my TE voice back and was able to eat solid food. I have not had any further swallowing problems, but certainly caution anyone to be aware of all factors when considering esophageal dilation.

Carl Strand, - Mystic CT  
Laryngectomy 1993

---

As an adult I have always had a difficult time swallowing large pills, however swallowing food was never on issue. I do tend however to eat slowly, take small bites & chew thoroughly. After my surgery in 9/2016, I had several occasions where things like unbuttered bread, French fries, rice, chicken breast & raw veggies would get stuck. Since we breathe out of our neck, we won't choke to death.

I once had a piece of uncooked celery caught in my throat overnight. Swallowing progressively got worse & I had to crush even the smallest of pills & totally avoid any of the above mentioned foods. On 4/06/2018 I had esophageal dilation performed by the ENT doctor/surgeon who had performed my total laryngectomy. Based on other Lary experiences, I recommend an ENT surgeon as opposed to a GI surgeon. Normal opening for swallowing is 42, mine was 28, surgery increased to 36. I still eat slowly, take small bites & chew thoroughly, however I can eat anything I want.

Cyril Due eke – New Baltimore, MI  
A very blessed Lary, Class of 2016

---

Thank God have never had any swallowing issues since my surgery. I can eat anything I did before and consider myself very lucky. My only regret is I can't smell it but my wife always makes a point of saying how good my cooking smells!

Mark Stoughton – Sanford, NC  
2016

---

Yes my Laryngectomy affected my swallowing. It seems like when I swallow I get a lot of air along with whatever it is I am swallowing. I then sometimes get the hiccups from I am guessing all the air. I also seem to have more trouble moving the food to the back of my throat in order to swallow. I sometimes feel like I cannot get my mouth to open as wide post surgery. I just try to cope with these difficulties and hope they will improve with time.

Tom Bohrer – Pleasant Plains, IL  
May, 2018

---

Following my initial surgery and my doctor's ok to begin a soft diet, I had minimal swallowing difficulty with most moist food. Later, though, radiation treatments so impaired my ability to swallow that my peg tube wasn't able to be removed for 8 months.

Finally, an esophageal dilation was tried, followed 2 weeks later by a TEP puncture. I could speak in a very low voice immediately, but I noticed that it was more difficult to swallow pills or food unless it was pureed. The food and pills would get caught in my narrowed esophagus, so I would use the button on my HME to help dislodge either the food or a pill by forcing air through that space. Or at times, a mashed banana and water would help the food slide down.

Different sized prostheses were tried, as well as 2 additional unsuccessful dilations performed, and as my speech worsened, my Voice and Swallowing doctor decided to remove the prosthesis with the intention of placing a new puncture in an area that was not so strictured. I began using an electrolarynx as the puncture healed and have not returned for a new puncture because I'm able to eat anything and am understood easily by most people.

It is 3 years later and I'm still relying on my electrolarynx to speak.

I have decided that I am able to eat most food if I take small bites, chew forever and chase it down with lots of water. If I'm with a group of people at a dinner, I finish eating when they do and take the rest of my food home with me. Just remember that your food is now moving from your mouth to your stomach mostly by gravity; so remember to sit up straight and stretch your neck upwards to aid in the flow of food. For many, this is not possible and you must rely on a peg tube to receive nutrients, so I consider myself a most fortunate lary.

Barb Gehring - Akron, Ohio  
September 2013

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

*Donna McGary Managing Editor  
Kim Almand VoicePoints Editor*

*Disclaimer:*

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

# Dear Lary

Noirin Sheahan

## Embracing the Change

Last month's Speaking Out question asked whether we feel differently now about our new identity, whether the years have made us more comfortable with our voice and neck breathing or whether we find it to be more challenging. Certainly the years (over 6) have made me more comfortable with my new voice and neck breathing. But I was also touched by Jennifer Karkenny's reply to that question: "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."

This is also true for me. My personality always sought to fit-in, to blend with the tone of the people I was with. I liked feeling in tune with others, letting my words slip easily into the flow of the conversation. Now I stand out like a sore thumb. My words jar, people stare or frown in concentration to make out whatever Ellie is croaking.

My personality has had to adapt to this 'new normal' and as yet it's struggling. Like Jennifer, I'd have to steel myself to approach a stranger but I'll do it if it's important. I tried about ten times to get in a quick joke at a dinner party the other night, but no one heard Ellie droning till I eventually 'beep-beeped' Ellie. When they were all staring at me startled, I rattled out my tuppence worth. Luckily it did get a laugh, so that was encouraging. My personality doesn't find it easy to interrupt but it's one of the social skills I'm having to learn as a Lary.

It's always great to hear that we're not the only ones who struggle like this and so it was comforting to read Jennifer's next words: "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." Laughing – the best I can do is make the snorting breath sounds of laughter. Works OK much of the time but can sound like crying too – one time early in Lary life I was actually trying to make light of my situation and laughing but both friends looked at me with consternation and one came round the table to give me a big hug! It would have taken for too much effort to explain so I just lapped up their sympathy instead.

Jennifer's next words are a challenge for me: "Crying... even crying isn't the same anymore. Just the little things I took for granted before." About a week after the operation, a friend asked me if I cried a lot and I told her I hadn't cried at all. She said that my body would probably have to get used to crying with this new anatomy. But the weird thing is that I haven't cried since laryngectomy. I've felt sad, but it hasn't come out as tears or sobbing. Maybe my body still doesn't trust this new anatomy enough to weep for the changes.

But Jennifer finished on a positive note, saying: "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." I'd agree with that too. Having lost my voice box I'm much more aware of the vulnerability of the rest of my body, and now appreciate that I can still walk around, can still hear and see. Like Jennifer, I took all these for granted before but now enjoy them and feel very grateful that they let me live independently and do my bit to make the world a happier place.



## Raising Our Voices by W.C. Baker

When I was sixteen, taking a break from my job as a bus boy in the Coral Dining Room of Cedar Point's Breakers Hotel, I achieved my first successful inhalation of tobacco smoke. Wow, Pow, Bam, I was addicted on the spot. I dizzily returned to work, looking forward to my next opportunity to light up. I was proud to finally join the tobacco fraternity. That fraternity included all of my friends, both of my parents, my minister, teachers, the family doctor and a huge percentage of the world's population.

A pipe became my chosen nicotine delivery device when I was a life guard and swimming instructor in the Marine Corps. I told myself that it was because I was tired of people bumming cigarettes from me, but it was more likely that I just thought it looked cool. When I was discharged, I took a job as a life guard and swimming instructor at Briarcrest, a private club, where I met my future wife. Susan's father was a prominent surgeon in town and I was regarded by her mother as unacceptable because I was literally from the other side of the tracks, the New York Central, as a matter of fact. I gained some points for being a Marine veteran, from Susan's father who had been a surgeon in the Navy during WWII. I think that the fact that I, like he, was a pipe smoker was a factor in gaining his acceptance as a future son in law. I cinched the deal when I went back to school and completed my degrees.

I might never have made it with Susan's parents if they had known that while I was in the Marine Corps, I was introduced to marijuana, although that didn't really become a factor in my life for a decade, and even then, was used only occasional. I used marijuana more frequently when I was in Dayton, doing community theater in my off hours. When I moved to San Francisco, I started using marijuana almost as much as tobacco. Marijuana use continued, even after I was finally able to quit tobacco use—even after my surgery. No one accused me of being intelligent.

There is no doubt in my mind that smoking, tobacco and marijuana, was the direct cause of my laryngeal cancer. I don't know where I heard it, but it is my understanding that something like 95% of laryngectomees were smokers. Laryngectomees became some of the most ardent and most effective combatants in the tobacco wars of the 1990s. The image of a person with a hole in their neck and speaking without a voice box seldom failed to impress school children with the reality of the evils of smoking, Tobacco companies for years had been making all kinds of claims about smoking being benign, not only benign, but sexy and macho, and

relaxing, and stimulating, and, and....

Hundreds of laryngectomees have spoken to thousands of students about their experience with tobacco since then. Currently, there are ads featuring the late IAL board member, Teri Hall, with before photos of a beautiful young woman, compared to the image of a woman decimated by smoking, apparently close to death. In the 90's, Debbie Austin of California was shown smoking through her stoma, proclaiming, "And they say it's not addictive". Janet Strickland was a model for Lucky Strike who successfully sued American Tobacco when she was diagnosed with laryngeal cancer. I am proud of my participation in the tobacco wars.

I was invited to join the board of an NGO called INFACCT. INFACCT was founded to fight Nestles for "marketing" their infant formula in Africa, to the detriment of thousands of women and children. They moved on to GE with a boycott and an Oscar winning documentary, fighting for cleanup of their Hanford nuclear site. I joined the board when they started a boycott against Philip Morris, who owned Kraft and Oscar Meyer. I spoke at a demonstration in Washington and later at shareholder meetings at RJ Reynolds in Winston-Salem and at Philip Morris in Richmond.

One of my proudest moments was when I stood before the Philip Morris board and shareholders in Richmond, using my esophageal voice as dramatically as I could to say, "This voice is brought to you by Philip Morris and is dedicated to the millions who have given their lives and their money to your bloody bottom line". I don't remember what else I said, but we did get good newspaper coverage.

The settlements which came out of the tobacco wars included great gobs of money to go to health care. Advertising was removed from television and magazines that might have had readers under age 21. The only flavoring allowed was menthol; cigarette packaging had to include warnings. Taxes were increased to a point to make them less affordable to young people. And tobacco was acknowledged to be addictive and hazardous to health.

The 1998 settlements marked a real victory in the tobacco wars, but battles still continue. We now have vaping, flavored and packaged to appeal to children. We must continue to be aware of the dangers associated with marijuana legalization and the importance of protecting young people. You have a voice, use it.



## Fear, Friend or Foe

By Don Renfro

I have been dealing with a fistula since the beginning of this year. It is a good size one located just above my stoma. Next month I am scheduled for a free flap surgery to correct it.

When I had my laryngectomy back in December 2017, it was not an elective surgery and I had no time to think about what was going to happen. I also did not have a clue as to what to expect as an outcome from the surgery, Even the things I was told prior to the surgery were not real in my mind and were somewhat dismissed. I am pretty sure I was told I would not be able to talk and would have no voice, after my surgery. It was not until after I woke from the anesthesia and discovered I had no voice that it became my reality.

With my current surgery I have had plenty of time to ponder the possibilities of outcomes from this surgery. In this case, time is not necessarily a good thing. I have spent the better part of this year trying to manage this fistula in the hopes of avoiding surgery. I have read many stories from people that have had their own struggles with fistulas and a common theme I hear is after trying to manage it without success they eventually elected surgery. That too has been my path. Why would anybody wait so long for a possible solution? If you have ever had a fistula or known someone that has, it is a real pain in your life. It is amazing how many things you can't do when your food and beverage pours out onto the floor, the table, the walls, your clothes or worst of all into the stoma. Then why would anyone want to wait to have this corrected?

Fear is why I waited. Unlike my original surgery for my laryngectomy, I had time to get a lot of information about what it was I was electing to do. This is where the fear stepped in. No one ever presented the possibilities of outcomes to this surgery as "this is what will happen", they did not have too, my mind took care of that for them. I had to come to a point where even the worst case scenario was better than the known decreased quality of life I currently experience with the fistula.

It is funny that all the stories I have heard ended with the person fistula free and glad they elected for the corrective surgery, even if there were complications along the way.

My mind works in a funny way. It filters. It filters out the good input, "I am fistula free" and allows the bad to freely flow into my

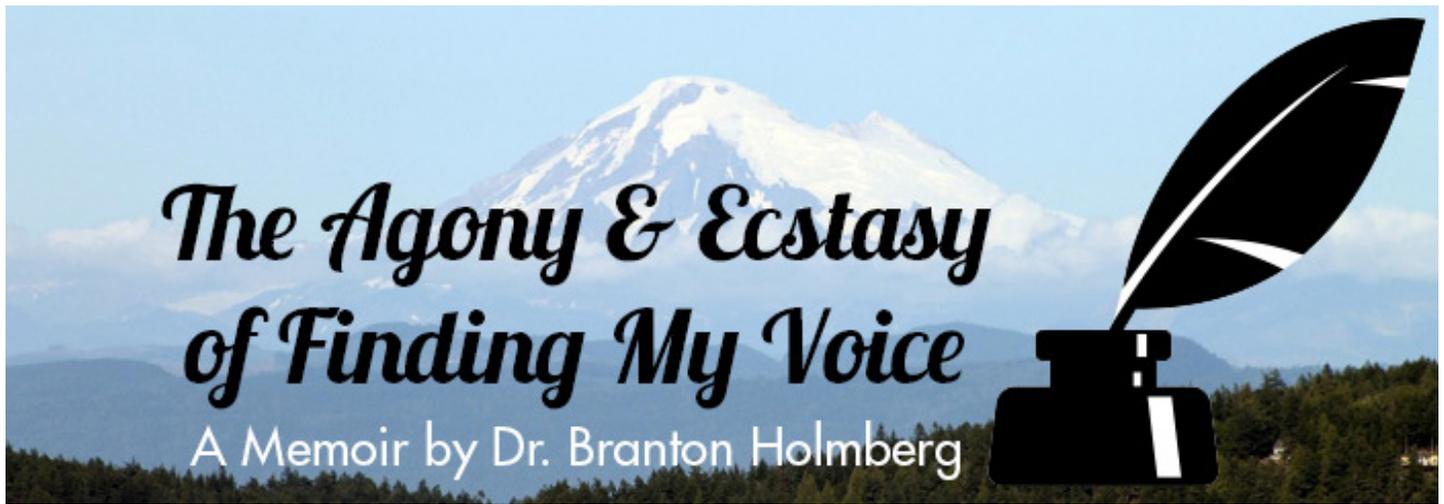
brain like a flood channel. "The doctor said because of radiation it was like stitching wet Kleenex", I developed another fistula" after the corrective surgery. "It is hard to heal because of the radiation treatments received on the neck tissue". Remember all of these negative experiences were followed with successful outcomes. But for some reason my mind will tend to concentrate on the negative experiences and somewhat pass over the positive experiences.

Thank god I am blessed with people in my life today that truly give me what I need, when I need it. People told me I was strong. I had good doctors and support and my doctor is candid with me. I will do fine going through the surgery. "I am able to eat regular food" since the surgery. I need to hear this positive feedback to counterbalance the negative input allowed in by the filter. Without the positive feedback the fear flourishes in a breeding ground of negativity. I understand the mind is a powerful force.

When I started college, as a young man, I read a book titled "Man's Search for Meaning". That book impacted my life. It was written by a doctor, Viktor Frankl, about his experiences while imprisoned in a Nazi concentration camp. He observed how people that appeared very physically fit would die while others that appeared to be on "death's door" would live. He attributed this to their state of mind. He believed that people that had given up in their minds died while those that remained hopeful lived despite their physical condition. That observation has been with me ever since. I truly believe in the importance of maintaining a positive outlook and remembering what I have to live for.

As a boy of about 7 years old, I had gone into a haunted house exhibit at an amusement park with a younger boy. Since I was the older one I believed I had to be brave for the younger boy even though I was scared to death. When we were about halfway through the haunted house I allowed my fear to get the best of me and we both turned around and ran out the entrance. Many more times in my life I would allow my fear to get the best of me and "flee the scene" so to speak, without experiencing the outcome. It is so easy to give into my fear and today I know that when I do, for the most part, I cheat myself out of what may have been an enhancing experience. Today I work on staying for the "final curtain".

I truly believe I will do fine with my surgery and will thrive with yet another "new normal".



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

**Chapter 2 “The MASH Years”**

All the time I was studying with Ed and Alex down in Alabama I dreamed of becoming a doctor and I’m sure my enthusiasm stuck out all over me to the doctors and nurses I was working with. Although I never confirmed the feelings they were aware of my cleft palate speech and the obvious scar on my upper lip and deformed left nostril of my nose, I was sure that since they were medical people it stood out vividly to them.

The delivery room could be busy any time of the day or night so we rotated working shifts to cover it. Me and the other medics that worked in the delivery room worked 12 hours on and 12 hours off 4 days a week with 3 days off. It was during the late evening and early morning hours that most of the MASH type antics occurred.

Like I said the doctors and nurses and I got along great and during one of the 1 am deliveries the Dr. on duty asked me if I wanted to deliver a baby. Talk about a heart stopping moment. I didn’t hesitate though and he had me take his position in the delivery area and said he’s stand behind me and tell me what to do. The mother is what we called a multi para mother meaning this was at least her second child and that usually meant an easier delivery all the way around.

You’d better believe I was one anxious 19 year old kid but the 2 nurses and the doctor. were super human beings and things went off without a hitch which they never doubted. I was on top of the world with that experience and it’s been one of the highlights of my life ever since.

The world of the delivery room is miniature universe of human diversity. I helped deliver 147 babies and the range of human differences I saw in newborn babies had a profound meaning to me. One was a horrifying deformity called an encephalitic baby that was born with no brain and a severely

deformed head. It had other deformities too and died within minutes of its birth.

The doctor knew in advance the condition of the fetus yet it was still one of those heart rending moments that make you realize how complex the development of a human life is and how horribly wrong it can sometimes go. It was a jarring insight into my own birth defect.

I vividly remember a very premature baby the delivery team spent a great deal of time with during the first 72 hours after it was born. That was the magic number to get preemies beyond to give them a fighting chance for survival. At least one of us from the delivery team was always with that baby in the nursery during those 72 hours and we held our own private celebration when we got the little boy beyond the 72 hour mark.

I became good friends with a Jewish doctor and he invited me to be his assistant when he did circumcisions on the baby boys of his nationality and beliefs. There was a very specific ritual he performed surrounding the circumcision and I felt privileged to be a part of it.

Of course he did circumcisions on other male babies too and let me, under his careful supervision circumcise 5 baby boys. The year I spent working in the delivery room interacting with various doctors and nurses was a giant step forward to me due to the way they accepted me and allowed me to experience things I’m sure they rarely let others do. I felt liked and respected by them and that was certainly my feeling toward them.

After my year long stint on the delivery room I spent the next 16 months of my tour of duty being rotated through various departments in the hospital. My next assignment was on the psychiatric ward and I found the work there absolutely

fascinating. It was always nearly filled to capacity with patients and the variety of mental conditions they handled there was astonishing to me. I was especially interested in the patients on the locked ward.

I was the only medic I knew that'd go back to the locked ward after my duty hours and spend time talking to the patients there. I always wore the white scrubs we all wore during duty hours so they knew I was one of the medical personnel

Most patients would talk with me without hesitation and I'd spend time with them listening to what their lives were like and what'd brought them to the hospital. It was a wonderland of psychological problems and I was captivated.

The psychiatrist in charge of the ward found out what I was doing and had me come to his office from time to time to go over things I'd learned from various patients. We had patients on the ward ranging all the way from completely docile not wanting to talk to anyone to ones who were extremely violent and dangerous to be around when not medicated.

I remember one patient was an airman that worked on the flight line as a mechanic on the aircraft. It'd taken 6 men to subdue him when he'd gone berserk and was tearing up the barracks quarters he was living in. When the ambulance arrived the medics tranquilized him and put him in a straitjacket.

When we got him on the locked ward at the hospital we took the straitjacket off while he was still tranquilized and put him on the bed in the room and secured his hand and feet to the four corners of the bed with leather straps made for that sort of thing.

We kept an eye on him at 15 minute intervals checking through the small reinforced glass window in the door to his room. Just as I was getting ready to go off duty I checked him one last time and was blown away when I saw that he'd turned the bed upside down on himself. I wonder to this day how he was able to do it even as heavily muscled as he was. He was doing everything he could to get out of the restraints we had on him and he was turning the air blue with some of the most vile cursing I'd ever hear and believe he I've heard a lot.

The doctor on duty came in and sedated him again and we got him turned back over when the drugs took effect. Even as I write this I'm still amazed at the strength that man had to have to do what he did spread eagled on that bed. It's amazing how strong someone can get when rage or fear fills their body with adrenaline.

My next hospital assignment was to the emergency room where I took care of patching up minor injuries and often stitched up small cuts, and helped the Dr. and nurse with

more serious injuries that came in. We held patients in the emergency rooms of the hospital until they were properly diagnosed and received the treatment dictated by the diagnosis.

When it was minor stuff we could handle without putting them in a bed in the hospital we took care of it in the emergency area and sent them on their way.

I was also part of the surgical teams that worked in the two operating rooms of the hospital and went through more than one trauma of losing a life on the operating table. One had to do with one of the medics that had come to Ladd the same time I had. He and three of his buddies had been out on a hunting trip and when he'd gotten in the car to come back to the base he'd put his loaded rifle between his legs with the barrel pointed at his stomach.

They were passing around a bottle of whiskey on the trip back to the base and the other 3 men had no idea how it happened but the rifle went off. He was near death when we got him on the operating table and it wasn't long before we lost him. It was heart breaking especially from the foolishness of how it happened.

I worked in pediatrics, and on the hospice ward exposing me to nearly all aspects of medical care in a hospital. I was even called to work in the hospital morgue once in a while which really took my experiences with life as a medic from birth to death and showed me what a dynamic world a hospital is.

I remember one body we had in the morgue that was frozen into a ball. One of the airmen on base jumped out of a barracks window with just his skivvies on at 3 am when the temperature outside was 50 degrees below zero and ran nearly half a mile into an open field behind the barracks before he became exhausted and sat down and hugged his knees to his chest. When they found him he was frozen in that position. When we got him in the morgue we couldn't put him on one of the gurney's we usually put bodies on for fear he'd roll off and shatter. We wedged him in the corner on the floor and waited for him to thaw out.

Those 26 months I spent in the Ladd AFB hospital imprinted themselves indelibly on my life. I was allowed to do surprising things as a medic and it had a major impact on my self-esteem. I'd gotten lots of support from the doctors and nurses I worked with and that deepened my desire to go to medical school. I'd gotten a lot less self-conscious about my speech and my physical appearance which opened the doors even further about my aspirations to become an MD.

**To be continued...**

© Copyright 2016 by Branton K. Holmberg All Rights Reserved  
Docholm36@gmail.com