

Whispers on the Web

A Monthly Online Newsletter for WebWhispers

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From The Editor's Desk

Dear Reader,

That sounds rather quaint...a throwback to another era but I mean it. If you are here reading this then you are a dear reader. Whispers on the Web is our online Coffee Klatch/Whine & Wine/Beer N' Bitch ...whatever....it's where we can get to know each other better and have a safe space to tell our stories.

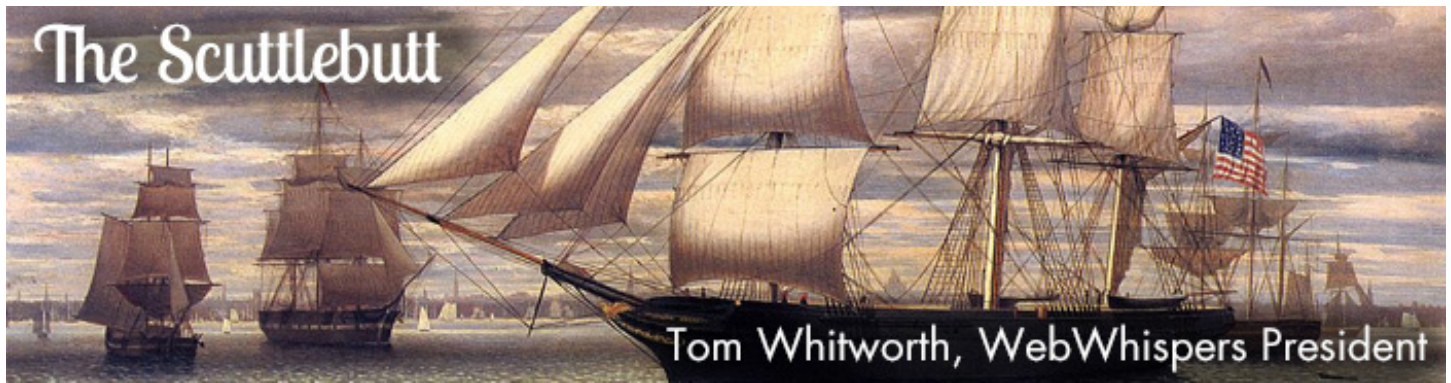
The daily WW list and all the FB and other social media groups are great for immediate responses to specific questions but the newsletter is our opportunity to sit down and actually reflect on the life we live as experienced by folks just like us. Some don't have a local support group and rarely interact with another laryngectomee so this connection is invaluable. That is especially true for me living in a rural area of Maine. I know there are a few of us here but we are kind of spread out and it's not like we run into each other at the grocery store LOL!!

That's why I love the stories we give you every month. Each offers a different perspective on this journey we all share. I feel like I have made true friends through their writing over the years. I never met Len, the UK based Speechless Poet & Rosalie, the Scottish Accent or that gardener who wrote so memorably about baby pants and God....all have enriched my life and I suspect yours, as well!!

Read on and make some new friends. We are in this together.

Donna





Let Me Tell You About My Grandchildren

There was a time, B.C. when I would laugh if you had told me certain things would be true today, if I lived long enough to be here. Thanks to my laryngectomy, I did live long enough and here I am. I am referring to a time when all the old goober grandparents talked constantly about their grandchildren. Many talked about nothing else, or at least it seemed so. You almost never saw these people without a grandchild in tow, or on display is more like it. They drove tank-like vehicles, a Buick LeSabre, Ford Crown Victoria, or something similar. Then there was the bumper sticker that read “Let Me Tell You About My Grandchildren!”.

The cars were always a four-door sedan with a massive trunk, big enough to hold a coffin. They were certainly spacious enough to take grandchildren and all their loot almost anywhere, even Disney World. Hiding Christmas and birthday presents in those things must have been a snap. It seemed to me that these grandparent-mobiles had one speed, a snail’s pace. The lack of urgency with these drivers unnerved me. I was always trying to get somewhere at a faster pace than was likely necessary. To relieve my stress, I would just call them a name like you “bald-headed old fart, move!”, with the windows up, of course. The snarls from my wife, mother of our two young girls, were bad enough. Worse yet were her utterances of my first name Thomas, ending in a huge verbal exclamation point, as if she were my mother. I already had one of those, thank you very much. I cleverly switched to acronyms for the names to be called. A Navy man, I should have no problem with that, I thought to myself. The aforementioned name became you “B.H.O.F.”. It only took a time or two for my then seven year old to ask “are you calling him a bald headed old fart, Daddy?” I never bothered with S.O.B., as that would have been even more easily decoded by my backseat passengers.

Today, I am one of those grandparents, absent the land yacht. Owen, Lydia and Maggie can’t ride in my two door pickup truck as it has no back seat. They are far more often in Mimi’s Ford Taurus (yes, that’s close enough, huh?), but sometimes in my car. My car is a low-mileage 2001 Chrysler Sebring convertible in great shape, recently given to me by my uncle Fred, who can no longer drive. Owen (8) and Lydia (7), flipped their lids during their first ride with the top down. Sporting their favorite sunglasses, they looked like grandchildren of the stars. With smiles as wide as the Atlantic and eyes as bright as the sun, that first ride was obviously a big deal to them. I do believe Lydia was doing a parade wave to the underlings as I drove away from the Dairy Queen. Seriously-yes, that’s my girl.

So what am I thankful for? I could easily and accurately say Julie, my wife of 41+ years, who poured pain medicine into my PEG tube when I could not have done so. The same sweet wife made a million versions of soup during both times when I could finally eat by mouth again. My daughters could easily get the nod as a source of my gratitude. Bonnie is a fine arts director for a private school and gets to do exactly what she loves most. Beth is a social worker and child therapist, focused on recruiting, training and supervising foster parents. To say that I am proud of the people they have become, would be an extreme understatement. Yes, of course, I could join the band of grandparents, eager to shout “Let me tell you about my grandchildren!” and tell you of my appreciation for Owen, Lydia, and Maggie. I could describe how the older two brought light into the otherwise darkest of my days. Their mere presence in our home brought me joy and inspired me to smile and be at peace. The three of them still do.

I remember a day shortly after my surgery. In the house alone, I stood in front of a large mirror and assessed the “damage”. There I stood with much of my neck missing, a really big scar, no Adam’s apple, and an ugly hole in the front of my neck. I did not have a pity party; I moved on, right then and there. Today, I am truly thankful for my diagnosis, chemotherapy, and radiation treatments, side effects and all, but mostly for the laryngectomy that freed me of cancer. Yes, that is what I said. More than anything else, I am most grateful for my laryngectomy, without which I would not be here to enjoy and eagerly tell you about my grandchildren. I think I’ll keep the convertible- with the top down as often as possible.am.

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





Voice Points

Written by Professionals

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Prevention of Radiation-Associated Dysphagia

Dysphagia following treatment for head and neck cancer can have staggering consequences for the quality of life and health status of cancer survivors. In recent years there has been a growing awareness of radiation-associated dysphagia (RAD). While the use of radiation and chemotherapy has been beneficial in sparing the consequences of surgical resection, we now understand that organ preservation does not equate to preservation of function. Patients receiving radiation-based treatment for head and neck cancer are at risk for both acute toxicities and long-term alteration of swallow. Further, patients receiving post-operative radiation therapy may have compounded effects of tissue resection and radiation changes.

The speech pathologist's role in the head and neck cancer patient's care begins at the point of diagnosis. Assessment of baseline communication and swallow function and the needs of each individual patient allows for personalized, tailored care. Assessment should include a thorough assessment of orofacial cranial nerve function as well as evaluation of articulation, voice, and resonance; all of which may be impacted by the cancer. The speech pathologist should determine the communicative needs of the patient in order to determine post-treatment needs and targets. Additionally, we advocate for instrumental assessment of baseline swallowing status, particularly in light of the high incidence of silent dysphagia in the head and neck cancer population. Both videofluoroscopic and endoscopic approaches are appropriate for such baseline assessment. In addition to assessing communication and swallowing, the speech pathologist should also assess for trismus, or limited mouth opening, as this may be one of the presenting symptoms of head and

neck cancer which can worsen in response to treatment if neglected.

Once the treatment plan is established, the speech pathologist plays a critical role in patient education. The time between diagnosis and initiation of treatment can be a time of high stress and anxiety for patients and their caregivers due to fear of the unknown. The speech pathologist is uniquely qualified to educate the patient on what to anticipate through each stage of treatment. It is important to consider the patient's readiness for information through this process and to provide information repeatedly to ensure comprehension. Treatment toxicities relevant to communication and swallowing such as pain, dry mouth, taste changes, fatigue, and voice changes should be reviewed in a way that the patient understands what is upcoming, however the speech pathologist should also stress the cancer care team's ability to manage these side effects. The patient should be encouraged to communicate openly with the team regarding side effects so they can be effectively managed. It is also important at this stage for the patient to understand that what they do during treatment will impact their long-term function. While our goal is not to induce fear, it is important that patients fully understand the long-term importance of following speech pathology recommendations.

Prophylactic swallowing therapy during non-operative head and neck cancer treatment has received great attention in recent years. It has been repeatedly shown that individuals performing exercises prior to and during chemoradiation (CRT) demonstrate more normal swallowing physiology and functional outcomes than those who receive no intervention. Exercises should

address maintenance of strength and range of motion of the tongue/tongue base, pharyngeal constrictors, and the muscles responsible for hyolaryngeal excursion and airway protection. For patients undergoing radiation following total laryngectomy, it is extremely important to target tongue and tongue base strength due to significant alteration of pharyngeal driving forces after laryngectomy. Though aspiration is not a concern after laryngectomy, dysphagia is a common problem for patients and should be mitigated by maintenance of tongue function. Jaw stretches are also an important part of treatment during radiation, particularly for those patients undergoing treatment for oral, oropharyngeal, and nasopharyngeal carcinoma.

In addition to performance of swallowing exercises for prevention of radiation-associated dysphagia, there is growing evidence that maintenance of oral intake during treatment has a positive impact on swallowing outcomes. We recommend placement of a feeding tube only in high-risk patients or in response to nutritional deficiencies. Further, even when a tube is placed, the patient is encouraged to continue swallowing whatever is safe by mouth. It is stressed that the tube is meant to provide supplemental nutrition but that the act of swallowing itself is a critical part of their treatment. The speech pathologist should partner with the dietician to determine the most appropriate diet for each patient and to provide the patient with strategies to maintain oral intake as long as is possible.

Despite our understanding as care providers of the importance of eating and exercising during radiation, patients often have poor adherence to our treatment recommendations. This is multifactorial and related to issues regarding lack of education as well as treatment related toxicities. Many patients cite not having a current dysphagia as the reason for their non-adherence. Increasing patient comprehension of the importance of preventative swallowing intervention is critical for improving adherence. I often compare the purpose of our treatment to dental hygiene – you don't brush your teeth once you get a cavity, you brush them to prevent the cavity. Similarly, we aren't exercising to treat dysphagia, but rather to prevent it. In addition to targeting improved comprehension for enhanced adherence, effective management of treatment toxicities such as pain can be critical. We have had success using gabapentin to address the neuropathic pain component of radiation which is not managed by traditional narcotic

analgesics. This pain management protocol results in better pain control and has been equated with less need for tube feeding and better swallowing outcomes.

The importance of the speech pathologist on the multidisciplinary head and neck cancer team cannot be overstated. Through assessment, education, and intervention speech pathologists can help to optimize long-term functional outcomes. By preserving communication and swallowing abilities, speech pathologists ensure the best quality of life possible for their patients.

References available upon request

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*Donna McGary Managing Editor
Kim Almand VoicePoints Editor*

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Speaking Out Question for December

Let's hear about your experiences. We've talked about side-effects of radiation therapy and treatments aimed at lessening these effects in this issue of WotW and in previous issues. What are some of the long-term effects that you, your patients, family members, or loved ones are experiencing from radiation therapy? How has that affected your day-to-day lives, and what has helped along the way? We welcome your comments and do not forget to include how long it has been since radiation treatments have been completed.





Aloha Recovery

by W.C. Baker

Mark was a surprise guest at the dinner that Tina and Inger had prepared on my behalf. He had come from his home on the Big Island of Hawaii to see the HIV/AIDS specialists at UCSF. Mark was the first special boyfriend of Wander, who had lived as an unrelated part of my family at my home in West Marin 15 years before. Wander died 7 months before my surgery.

I was early enough in the course of my radiation treatments, that I was still able to speak esophageally, not well, but well enough. A lot had happened in both our lives. While in the Navy, Mark and a lesbian sailor had joined in a marriage of convenience. This was a time when homosexuality was grounds for less than honorable discharge. They completed their tours and dissolved their marriage. Mark bought a home in Pahoa on the Big Island and settled in with his partner, Glen. He and Glen were intending to formalize their union with a wedding. Although it was not recognized legally, it was an important expression of love and commitment. Mark asked if I would house sit while they went on a honeymoon on the mainland. I thought about it, maybe as much as two seconds, and happily agreed.

As soon as my radiation was completed, I left for Hawaii. I was welcomed at Hilo with a lei that Mark had made himself. Never having mastered the Cooper-Rand and too swollen from radiation, my primary form of communication was a "Magna-Writer" a hand held screen with cells into which fine iron filings were drawn with the touch of a magnetic pen. This device turned out to be an instrument of communication at a lot of levels. At a service in the Unity Church where Mark and Glen were to be married, my Magna-Writer and I became a source of fascination to the children in attendance. A couple of these children had a lovely mother, Maureen, who was happy to see a new male on the scene, especially one who needed care. I was not above taking advantage of the situation.

Maureen invited me to dinner that evening. The older daughter went to spend the night with friends. When

the younger daughter went to bed, Maureen brought out the paraphernalia. Keep in mind that I was only able to communicate with gesture, expression and occasional use of the magna-write. That was sufficient for the situation. Among marijuana smokers, there is a process known as "shot gunning", a mouth to mouth transmission of a toke from one person to another. I was the happy recipient of shot gun with full knowledge that there was no connection between my mouth and lungs. I don't know if Maureen was aware of that fact or not, but I don't think it would have mattered. Turns out that the marijuana was only coincidental.

After an idyllic two weeks house sitting while Mark and Glen were honeymooning, I returned to Berkeley, a happy man. A bit over a year later, I again traveled to Pahoa, this time to help with house repairs and chores while Mark was going through the final stages of AIDS. Maureen had found Mr. Right in the interim, but introduced me to Patricia. Patricia and I explored the Big Island from the heights of Mauna Kea to crossing Mauna Loa Crater. We drove all the way around the Island and followed the lava flows from Kilauea to their steamy entrance into the Pacific. I was quite an able esophageal speaker by then, so there was no need for the subterfuges that had been employed with Maureen, if those subterfuges had been necessary in the first place. Actually, I think they were simply a new approach to a very old process. My two week stay was brightened by time spent with Patricia but dimmed by the decline of Mark. I bade Mark my final goodbye and returned to Berkeley. Mark died ten days after my return, another victim of the AIDS epidemic that took so many of my friends.

So much of what we communicate is done without a voice. We do well to remind ourselves that we are always communicating, and it is good to be aware of just what it is being perceived by all.



Don't Give Up

By Don Renfro

After the article I did for the month of September, I was actually all out of new material to write about. When I told Donna I would write articles for the newsletter, I had not anticipated it would be so difficult to come up with new subjects to write about, each and every month.

Recently I read an article online titled "Need a Boost? These Genius Inspirational Quotes Work Wonders". As I read it I realized that most all of them I related to, on some level in my life, that provided me with subject matter for which I could write about.

The first one is: "Just don't give up trying to do what you really want to do. Where there is love and inspiration, I don't think you can go wrong". Ella Fitzgerald

Before my surgery I would become quite overwhelmed by "life" or the things I felt I had to accomplish. I always felt there was not enough time to do all the things I needed to get done.

After my surgery it began to feel even more overwhelming than it had before. After all, my life is clearly at its end. "Horse feathers". I now look forward to as much life as one can cram into as many years as I have in front of me. I have come to know people that have lived, not survived, but lived for decades with my situation. No reason to believe I will be given any less.

To incorporate this month's quote into my new lary life I had to first realize what it was I truly want to do. In other words I had to set or in some cases reset my priorities. I have a laundry list of "to do" items but I really needed to identify and prioritize what I really need to do from the things I might like to do.

After the task of prioritizing is accomplished I need to take that first step, one day at a time, to complete what it is that is in front of me today. So each and every day I must not give up on doing what it is I want to do and accomplish today. Life is not a race and I do not have to accomplish my entire laundry list of "To Do's" today.

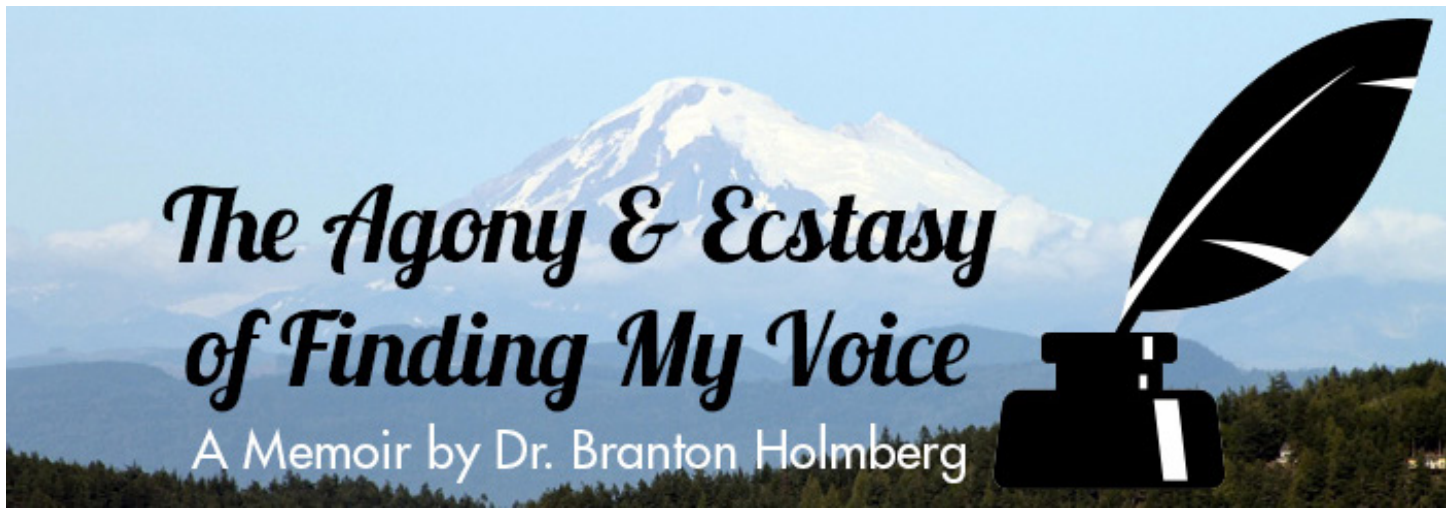
This is where the love and inspiration really come into

play. I have to be loving to myself and not beat myself up for not accomplishing more than I can. This week I will have my surgery to correct my fistula and I have been working hard for the last two weeks to accomplish all I could since I am sure I will not be able to get much done for a while after my surgery. And that is Ok. I will accomplish what I can and the rest will have to wait until I am strong enough to continue my tasks later. My inspiration comes from all of you. I read so many stories and other people's experiences on the Lary's Voice Facebook page that provide me with the inspiration I need to face these challenges head on. I have faith that with the love and inspiration provided I cannot go wrong.

I read a lot about people experiencing depression with their laryngectomy situation. For me keeping busy and having future goals to accomplish has allowed me to escape experiencing some of the debilitating and in mobilizing effects of depression.

My experience has shown me that being busy does not have to mean accomplishing chores or work. It can be doing something I have maybe wanted to do or do again, that I may not have done in a while. It can be taking a trip, visiting a friend or family member, going to a movie, visiting a museum, writing a letter. It can be anything I might find enjoyable as well as something I might need to get done.

It seems that life in itself is challenge enough. Life with a laryngectomy feels more than challenging at many times. It is never boring. As a matter of fact, I cannot remember thinking to myself "I am bored" a day since I had my surgery in December 2017. Thankfully I am at a place in my life where facing challenges feels like life in progress and part of the status quo.



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

Chapter 3 “Gold Fever”

My life outside of what went on in the hospital was great too. They finally finished our living quarters which were located about 100 yards from the hospital, and looked nearly as good as those we saw in the films of the officer’s quarters the slick tongued Captain had shown us down in Alabama.

There were two of us to a room and each room had what were called Hollywood style beds. The bed was a bit bigger than a twin bed. Each bed space had a closet, a big chest of drawers a night table with a reading lamp and a set of book shelves. There were also footlockers at the end of each bed. There was a sink and mirror in each room, with good sized shared bathrooms assigned to every few rooms.

The living quarters were a 3 story affair with big recreation rooms on each level complete with pool tables, ping pong tables, shuffleboards, dart boards and all kinds of lounging furniture. After being in the hospital basement, we thought we’d found paradise in our new quarters.

I spent twenty-six months in Alaska before I was transferred stateside to Paine AFB, just outside of Everett, Washington.

Alaska was still a territory when I was stationed there and was really what it must have been a bit like living on the frontier in the old west. Many of the airmen on base carried a side arm when they went into town, including me. Men in town carried them too. We wore gun belts around our hips with a revolver in the holster and thought nothing of it. Fairbanks was a wide open town and even though I wasn’t twenty-one when I got there I had no trouble going into bars and drinking with the rest of the crowd.

I was pretty much a loner among the other corpsman. I’d learned to be very selective about those I associated with based largely on non-verbal cues I’d pick up and what kind of reactions they had to me if I said something they didn’t clearly understand.

I became close friends with a guy we all called Montana. Never once did I pick up a non-verbal or verbal cue that he saw, or heard, me as a harelip.

I was 6’ 2” tall and skinny as a rail, and Montana didn’t stand a hair over 5’ 7” and was built like a block of cement. He’d been a cowboy in Montana, thus his nick name, when the draft caught up to him. I’m telling you, he was one unique human being.

Although we always worked in different parts of the hospital, being in the same sleeping quarters in the basement we got to know each other, and liked what we knew. We’d arrived at Ladd in the fall of 1955 and that fall, and winter, we got introduced to life well below zero. Being newbies we spent those first few months getting into the routines of the hospital. At one time during that first winter the temperature dropped to -60 degrees below zero and stayed there for several days.

It was drummed into our heads that if we got frostbite for any reason we’d be hauled in for a summary court-martial. The reason we’d be court martialed is we were issued the proper cold weather gear and had been trained to prevent frostbite so it was our fault if it happened.

They were right about the cold weather gear they issued us. Between layering ourselves with a couple of layers of

long underwear and wool socks in addition to our fatigues, or hospital whites, and a heavily insulated parka with Wolverine fur around the hood that would close down to a narrow opening when zipped properly (your breath doesn't freeze on Wolverine fur), insulated bib overalls, "Bunny Boots" made out of white felt material and gloved hands inside heavy wool mittens we could tolerate those unheard of minus temperatures getting from our living quarters to the hospital.

By the time spring rolled around Montana was chomping at the bit to get off base and out of town. He found a farmer who agreed to let us help him with some things around his farm in exchange for letting us use a couple of his saddle horses. It was a great arrangement and Montana and I found time to take the horses out sometimes 2 or 3 days at a time, depending on the trade-offs we could make with others on our work schedules.

We set up a couple of hunting camps around the perimeter of Fairbanks and built lean-to shelters we could put our sleeping bags and cooking gear in when we used them. The base had a fantastic recreational equipment supply unit we could check whatever we needed out of, including hand guns, rifles and ammunition. By the time the next fall rolled around we were sitting pretty for bear hunting season.

Montana was the best shot with a western style 45 revolver I've ever seen personally. He could draw and fire at quart bottles I threw in the air and blow some of them to smithereens before they hit the ground.

We'd both bought our own rifles because we didn't want to go through getting used to a different rifle each time we checked one out of supply. I bought a 270 Winchester and he bought a 30-06. We never did shoot a bear but we had a great time trying.

After a couple of snowfalls in the fall of our second year in Fairbanks we snowshoed into an old mining camp several miles outside of it. We got 2 week breaks for each year we were stationed at Ladd and took one of those weeks to get into the mining camp, and back out again.

We each pulled a sled behind us with all our stuff on it. If you ever want to test your stamina, snowshoeing all day towing a sled full of supplies and survival gear at ten degrees below zero will do it. We started out at daybreak, snowshoed several hours to get to the abandoned mining camp and still had daylight when we got there. True to the tales of wilderness travel, the latch string is always out in places of refuge in Alaska. We had our choice of several cabins/shacks to stay in and picked one of the better built

cabins. We stayed four days and snooped around the abandoned mines in the area, hoping to find a vein of gold they might have missed. No such luck.

When we left, we left what remained of our canned goods, plus a supply of firewood we'd cut and stacked. They were intended for the next wilderness wanderers who reached the mining camp, and the cabin we'd stayed in.

That winter we each pitched in half the cost of a used car and bought an old Plymouth. It made scouting the area around Fairbanks a lot easier and also made supplying the hunting camps easier.

Trying to drive that car around during below zero temperatures was a real challenge. First we had to make sure we plugged in the head bolt heater to keep the anti-freeze in the engine from freezing, and the oil thin enough to let the car start. You also had to run the car until the frost shields you put on the windshield and rear window were defrosted enough to let you see through them.

Once that was taken care of and you put the car in gear and started driving, you found you were driving on what we called square tires. The nylon tires would freeze into the shape they were sitting in which meant they had a flat spot where the tire had been sitting on the ground. It really did feel like you were on square tires when that flat spot came around on each revolution of the tires. Like I said, driving was a challenge in the winter.

Although we saw bears from time to time on our hunts, getting close enough to shoot one was more than we could manage. Tundra proved to be our downfall. In order to walk in tundra you have to lift each foot nearly knee high in order to take the next step. All tundra is, is a mass of brush and vegetation laying on a thin layer of water that melts from the permafrost in the summer and early fall. That's another test of stamina. I never got more than 100' into that stuff before I had to turn around and get out of it sweating like a steam engine when I did.

To be continued...

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An Invitation

To Whispers on the Web larys like myself, I'd like to ask a favor. I've just finished writing a second memoir style book I'm calling "The Writings and Musings of a Man With No Voice". I hope you'll consent to read what I've written and tell me what you think of it, as well as look for errors in it. I'm terrible at trying to find my own errors. If you're interested in this offer I'll be happy to attach a copy of my manuscript to an email address you send me. Here's my email address: doholm36@gmail.com

The introduction to the book:

As I've gained insights through the fiction stories I've written, and my memoir, I want try to capture for you the essence of what my life means to me. I'm in my eighth decade and filled with wonder as I understand, more clearly than ever, the meaning certain turning points have had for me as I've become the person I am.

Each of us has a remarkable story to tell about how we made ourselves into who we are. As you follow me on my journey I hope it'll prompt you to reflect on turning points in your life that made you the person you are.

The first few chapters are modified chapters taken from my memoir. I felt I needed to make them part of this book to develop the perspective of my life I wish to leave you with. I've added incidents, some are quite humorous, others a bit morbid, that don't appear in my memoir. I hope you enjoy my efforts here as much as I've enjoyed creating this book about a man who's fought the demons of trying to verbally communicate clearly with the world twice in his life.

I look forward to hearing from as many of you as possible. I intend to self-publish the book when I catch the spelling errors, etc., I hope you'll help me find. I'll let you know how to help me with the errors when I send you the manuscript. I hope you enjoy reading my manuscript if you take me up on my offer.

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