

Whispers on the Web

A Monthly Online Newsletter for WebWhispers

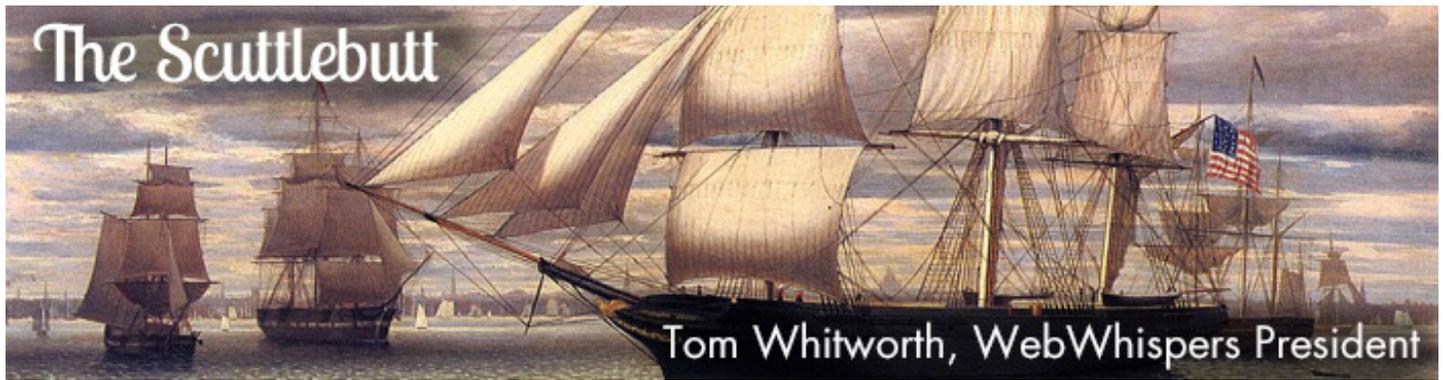
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Then and Now

So many things are different now, clearly unlike they were during the time I refer to as B.C. (Before Cancer). Situations that bothered me a lot B.C. simply do not bother me now. A recent experience brought that to light like never before. I realized that I am truly a changed man and changed for the better. Though a fairly decent guy in the first place, I suppose I am now the new and improved version of my former self. For me, these days are A.D. (After Disease).

A few days ago, I was on my way to a medical appointment on the far side of the city, about an hour's drive. As I was clipping along a familiar stretch of the freeway, my car suddenly died, without so much as a hint of warning. It was one of those totally out of nowhere breakdowns and I suspected my transmission had bitten the dust. I managed to coast up the slight incline of the exit ramp and turned the switch off. Upon attempting a restart, it was fairly obvious that the car was not drivable and would have to be towed. By force, I turned the steering wheel and coasted slightly downhill into the parking area of a gas station/convenience store. I did my best to direct the car where it would not be in the way of customer traffic. I let the doctor know I would be missing the appointment and why then contacted my wife, Julie, to let her know my whereabouts. Next, I called AAA which I have been a member of for many years. They had always responded within an hour but this time the representative said it would be two hours. The tow truck actually drove up three and a half hours later.

The particular stretch of town is not among those anyone in their right mind would think of as a desirable location to have a car breakdown. For that matter, I doubt anyone would consider living there if they had any choice in the matter. The area has been declining for decades and is known for its frightening crime rate. It is home mostly to the indigent, many of whom are immigrants from African nations where their lot in life was even worse.

In this situation B.C., concern for my own safety would flood my mind and most people would think rightly so. I would hope to not panic and would pray for myself if I did. Scenes of my impending demise would likely have flashed through my head. My thoughts would have been a narcissistic love fest: Why has yet another unfortunate thing happened to me?

I don't deserve this! I wasn't doing anything bad; I was only going to a doctor appointment. Why in the world do I always seem to catch hell? Good grief- the crap just seems to never end! I must really be the reincarnation of Job. Woe is ME. The incident would be all about me and only ME.

A.D., my reaction could not have been more opposite. There was no panic. I thought of myself for about 10 seconds, then realized if something happened to me I would most likely not have to deal with it for very long. At that point, I was done with any semblance of fear. Almost immediately, I considered how good I have it. Fresh coffee, ice cold water, lary supplies, and any medications I might need were within arm's reach. If my expensive voice prosthesis got temporarily stuck and I needed to speak quickly, my Trutone was right there with a newly charged battery. I had just been able to contact all the people I needed to from my iPhone and those needing to could contact me. Much of the time passed as I got caught up on email, texts, and social media accounts, using the phone. An occasional vehicle pulled into the store mostly from off the freeway to buy gas. Many customers were walking as I sat comfortably in a car, albeit inoperable. Many of those on foot probably don't have access to an automobile in the first place, I thought. My car would eventually get towed to the shop and I would spend the evening comfortably in my home. I could be certain of that. I'm a cancer survivor with a hole in my neck. So what? Big deal. I had been in route to a Veteran's Administration source of health care where I get everything I need as a laryngectomy and then some. It was safe to assume that most of those in my midst that morning do not have access to decent healthcare. If they developed throat cancer or anything similar, would it even get diagnosed in time to save them? If so, would they have funding for lary supplies, prosthetics, and such? Probably not and that should not be!

If I had any fear that day, it was not for me, but for the people who live in that neighborhood and others like it. In total humility, I knew that I am a lucky man and richly blessed.

**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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Thinking Outside the Box: What Can Be Done to Improve Baseplate Seal?

I am sure many of you have experienced plenty of trial and error with adhesive baseplates. You may have had that “it sticks!” moment, only for you to “blow a seal” an hour later; thereby disappointing your hopes and dreams yet again. Then you try something new and your hopes are high again! But then air escapes three hours later, allowing for the adhesive to slowly peel off and/or leaving it more difficult to voice. What can you do????

There are of course resources: your speech-language pathologist (SLP), supplier representatives, fellow laryngectomees. The problem is, there isn't one solution for everyone. It is patient-specific and much of this can be trial and error. As SLPs, we come across this issue weekly, if not daily. As patients, you experience this as well, particularly shortly after you underwent your total laryngectomy, and as you work out your new routine. I do not have answers for everyone. I wish I did... but the following are some suggestions of things to try to get that adhesive to stay.

There are some fortunate individuals whose skin is perfect. Ahh wouldn't it be nice to have perfect skin like you?! Those lucky people put a round adhesive on and bam! it stays! For 3 days! How? Why? First off, they likely have a flat peristomal area (the area surrounding the stoma), which allows for better adherence. Secondly, they likely have the perfect skin condition, meaning the essential amount of oil-to-dry ratio. It would be nice if everyone were like that! Well, unfortunately that is not the case.

The next step is also to figure out what the best adhesive is for you. There are a variety of different brands, sizes and shapes. Your SLP can help you to determine which would be the best to try based on your stoma and neck configuration.

A specific skincare regimen prior to adherence of the baseplate may also be the key to a better seal:

- Step 1: Use wipes and/or a washcloth to thoroughly clean the peristomal area, including removing excess mucus, oil, and/or dry skin. Allow the skin to dry.
- Step 2: Use Skin Prep or Barrier wipes to facilitate a barrier between the skin and the adhesive. Allow the skin to dry.
- Step 3: Use Skin Tac or silicone glue for better adherence. Allow the skin to dry.
- Step 4: Warm the adhesive (rub between your hands, keep it

in your back pocket, use a hairdryer, etc.).

- Step 5: Carefully remove the adhesive from the backing and place it around the stoma. Line up the bottom of the adhesive to the bottom of your stoma (6:00 position). Adhere the inner part first, pushing all air bubbles outward. You may need to dig your nails into particular areas to eliminate small air bubbles.
- Step 6: Allow the adhesive to sit for 20 minutes prior to using it to speak (if you are a TEP user).

Okay so you have done that. Maybe your SLP even did that during one of your appointments. And it worked!!! Yes! Lucky you!! But wait... it was all perfect... then 5 hours later, it started to peel off. Or maybe it worked and you did the exact same routine and then it did not work the next time. Or maybe your skin was irritated by all of the products. Are there other options? The answer is yes.

If you have one particular “problem area,” which generally means there is one part of the peristomal area where you always seem to break the seal, it can help to use a foam spacer. This can better conform to your natural contour. You place the adhesive over the spacer and that will sometimes take care of that area. Alternately, you can cut a piece of the foam spacer to fit your “problem area” and try to fill whatever gap is there. You would then place the adhesive over that. Another option is repositioning the adhesive. For example, if you are using an oval shaped adhesive in the vertical position, it may fit your neck better in the horizontal position.

There are also potentially medical options. I recently had a patient who very badly wanted to use a free hands device with her TEP but her stoma is not an appropriate shape for a button and she consistently blows a seal with adhesives due to one very small area (approximately 2-3 mm depth). I worked with our facial plastics reconstructive surgery to inject the area with a material to fill that gap. She was immediately able to wear the adhesive and use the free hands. This is not an option for everyone, but it's important to think outside the box to see what may be available when troubleshooting adhesives.

Most important to note is that unfortunately, adhesives do not work for everyone, but it is always worth exploring your options. In the end, everyone's peristomal area is different and what works for one person may not work for another.

Rina Abrams, MS, CCC-SLP
Johns Hopkins University
Department of Otolaryngology –Head and Neck Surgery

Between Friends

Donna McGary

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

Photo: CC by Corack5239

My Instrument: My Voice

Losing our natural voice is traumatic; no two ways about it. We have a very visible cancer. There is no disguising the aftermath of our treatments. If they can't hear our Darth Vader breathing or strange coughs/sneezes, they can surely recognize our voices. Granted some folks have very natural sounding ES speech and some TEP speakers, especially those folks who can manage a handsfree, do very well but for most of us, it's pretty obvious right off the bat that we talk differently. It's a rare bird who can navigate the world without at the very least some discreet side-eye and more often than not an outright stare or question, particularly from children. I am usually cool with that and try to explain in an age appropriate way. But sometimes I do dread opening my mouth knowing what is apt to follow.

This is all pretty much par for the course for us... nothing new here folks...move along. However lately I have begun to explore the idea that my new voice (I have used a Servox EL exclusively since 2003 and have no other voice options due to radiation damage) is as much an instrument as my original voice. Singers often refer to their voice as an instrument. The human vocal chords are a marvel and no mechanical device can replicate their amazing versatility.

However, Jim Lauder, AKA the Servox Guru, always refers to ELs as instruments and at first I thought he meant like mechanical/scientific devices that do stuff like a Geiger counter or a thermometer are instruments. But Jim is a serious music fan- he follows bands I've never heard of and he knows his stuff- and he meant ELs are REAL instruments. They have tone and pitch and depending on who is playing them on what instrument can sound very differently.

I have a favorite Servox- it just seems to have the right sound for me. I manage the WebWhispers Loan Closet now so I often have to test ELs before I send them out and am amazed at how different I sound on others. It's

not just the adjustable pitch either. I can play with the pitch switch on a Servox or try out a Tru-Tone or other equally good ELs and I can't get that same sound.

I recently had lunch with a dear friend who has known me before and after cancer. He also happens to be a musician and someone who messes with electronics and sound systems and computers for a living. He has a very good ear. Midway through lunch my battery died and I switched out to my back-up voice which actually happened to be my "favorite voice" this time. I keep them in rotation in my pocketbook at all times. He immediately noticed the difference and said my new voice "had more air" was "less robotic" and sounded more like me. He even emailed me later to say how much a difference he noticed. What a good friend!!

It got me thinking. He and I had talked about another friend who is a luthier making the most incredible guitars and how each guitar has a unique sound. Jim Lauder is right; ELs are instruments and we play them like musicians. I played trombone in band and orchestra from age 6 to 18. Some folks just blatted their way through practice. I loved playing the trombone and took it seriously even though I was kind of an oddity back in the 60s. Not so much an oddity as my mother who played trombone from a young teenager until she was nearly 80 and it nearly broke her heart to have to finally give it up. Now she could make that old sackbut not just sing but croon!! Funny how the same instrument can sound so differently depending on who is playing it. It's not just technical skill; it's that love of the instrument as a way to express/create/inspire that makes a difference

I've decided that my favorite EL is like my old trombone. Not a lot of us playing it but that's my sound and I'm sticking to it!! And like my music teachers and mother and grandfather musicians all said, "You need to practice. Miss one day, you know it, miss two days, your teacher knows it, miss three days everybody knows it."

Stand By Me

The Caregivers Journey



Marian Cure, Cedar Creek Lake, TX - 2009

From the beginning of this journey, I was surprised to wake up from an emergency trachea surgery to see all my precious adult working children by my side. How did they get there so quickly. My sweet neighbor had rushed me to the ER with her wig on crooked and fluffy pink house shoes. I could also see my fellow church members and pastor outside the ICU.

As time went by, food began to come in that sustained my caretakers and myself. Adult children took off work to make sure I was never left alone in the hospital and then to stay at my house until I got on my feet a couple of weeks later. One granddaughter slept on the floor by my side in the hospital. A daughter in love took my two dogs into her home and kept them safe. My son, whose voice was calling me to wake up in the midst of such pain. I didn't want to wake up.

A church friend, Fran, started showing up unannounced to force me to use the EL even though I really didn't want to talk. A neighbor, Susan, would call and say, let's practice with your "Charlie," and she would sit on the swing with me forcing me to talk. Another daughter slept by my side when I was in the hospital getting the TEP. I appreciate the friends who call out "She's o.k." when I start coughing at bridge and various clubs. Last but not least, my husband, who never left my side and beat the ambulance driving to another city hospital. He had told the ambulance driver to "catch me if you can". Eighty mph didn't catch him.

People's generous help has given me many a smile and realization that I'm not alone. Thank you all!

This is just a sample of what folks had to say about their caregivers back in September 2013 when we posted a question in Speaking Out. We'd love to hear from the caregivers themselves and this column is the perfect spot to share with all the WW community your perspective and experience. As you can see from Marian's comments, caregivers come in all different shapes and sizes. Please contact us at editors@webwhispers.org with your thoughts. It doesn't have to be long...just a snapshot of the unique experience of caregiving.

Thank you for Standing By Us and we look forward to hearing your story.



Dear Lary

Noirin Sheahan

The Inner Drama

One evening a friend told me in a firm, measured tone that magically conveyed gentleness and humour as well as authority: 'Please ... Be ... Quiet!' Though I knew I was a bit over-excited and needed to be reigned in, this touched a really sore spot. I had annoyed him (and probably others) by commenting during the opening scene of a DVD we were watching. And with an electrolarynx, my comments weren't a quiet whisper, but sounded like a jarring interruption. So yes, I suppose I deserved what I got. But the two-year-old inside me ranted and raved - "How can he be so insensitive ... others can say their piece - why not me Serve him right if I walk out ..."

Had I any basis for complaint? Would he have shut me up if I'd been able to whisper my piece quietly? Probably not, as it wouldn't have irritated him. But then again, I don't have the right to spoil other's enjoyment. I need to learn that subtle comments while watching a film are a thing of the past.

Our imperfect speech will elicit other people's negativity from time to time - my friend's irritation, a stranger's dismayed stare - you can probably list a dozen others. I find it helpful to remind myself that it's my speech they are reacting to, not me as a person.

It can be surprisingly difficult to make that distinction. We easily identify with our voices. It's even a security option nowadays - voice identification. How much of 'me' was lost with my feminine tone, fluent speech, emotional expression?

I think of it as a bereavement. I have lost something valuable. Life will never be the same again. Yet it's not the end of everything. Like all bereaved people, I have to find ways of dealing with the grief, find new sources of joy.

Mindfulness meditation is my way of dealing with the sore spots, revealing new joys. It allows me to go inward, spend 'quality time' with whatever feelings happen to surface. In daily life, we're mostly driven by our thoughts.

When meditating we're much more interested in actual experience as opposed to thought. Like now, for instance, as I think about the loss of voice, I feel bitter sensations run through my mouth and throat. Sitting back for a while, relaxing, the thoughts slow down. All I'm left with are bitter sensations and a mind that is insisting "No, no...it shouldn't be like this". But in fact I've temporarily forgotten what it is I'm giving out about! Once thoughts slow or stop, the mind can't hold concepts like 'lost my voice' together.

Alongside the bitterness and the mind's "No ...no ...no" reaction, other aspects of experience begin to register. The weight of my body, the touch of my feet on the floor. These suggest that there's actually no problem, nothing to say 'No' to. Despite that, it's scary to let go of the reaction, like I'll be stepping off a cliff. I hold my breath in suspense.

Eventually the next breath comes, and with that the mind steps gingerly into the unknown. The bitter feelings, I realise, as I stumble around this new world, are only sensations. They don't carry any hidden meaning. Relief! Thoughts about losing my voice again reappear but this time they are met with compassion. Instead of saying "No ... it shouldn't be like this" my mind is saying "It IS like this ... but it's OK".

And so too, on that evening where my friend asked me to be silent, I was able to withdraw into my inner world, spend time with my tantrum till it cooled down and I could see his point of view. Such a relief! Instead of piling bitterness on top of grief and perhaps even souring a friendship, I felt strong and surprisingly happy. I had contained the tantrum and my inner two-year-old had been soothed. Instead of resentment, I actually felt grateful to my friend for having brought about this reconciliation. I missed much of the DVD but the inner movie was far more dramatic!



What Were Your First Cancer Symptoms?

I started with problems swallowing that moved on towards breathing problems. My first doctor visit he had me sit in a chair and he stood on the table, had me look up and he looked down my throat. He said that he thought I had a swelling on my left vocal cord. He then sent me to a specialist that did my Biopsy and told me I had cancer. He, the second doctor sent me to UNMH where I had my Laryngectomy. The second doctor I went to was very cold. Not a very good doctor! The UNMH Doctors where great!

John Haedtler - New Mexico, USA
2001

I woke up one morning in May 2006 and was hoarse, much like having been to a football game the night before, but I had not. There was no pain or any other symptom so I said it will be better in a couple of days. After a couple of weeks, I said I'd better have it checked by my Primary Care Physician. Since I had not been a smoker or heavy drinker, he felt that I should not worry about it and he was sure it would go away. One month later he referred me to an ENT who did a probe which was inconclusive but he too said there was no sign of cancer. He prescribed throat medication and Allegra. One more month at follow-up, Thyroid test, Mucinex and a humidifier were recommended. Since I had a cruise scheduled to Alaska in 2 more months, I was given the go-ahead and just schedule a follow-up on my return if my symptoms had not changed.

So after the cruise and still being hoarse, my PCP recommended 6 months of Speech Therapy but I still had no improvement. During this time, I experienced an occasional right ear ache, but it was not severe. I was then sent to have a Neurology Evaluation which proved to be normal. By this time a year had passed so a CT Scan of my Voice Box was done with Negative Results. Two weeks later a biopsy was done, also with Negative Results. This was followed by Allergy testing which showed that I was mildly allergic to coffee, tea, lettuce and bananas. After eliminating those items and a month of no improvement, I was referred to a Voice Box Specialist.

Two months later, a second biopsy was done, only going deeper into my right vocal cord, Cancer was found. Radiation Therapy was recommended with a 92% chance that it would be successful. After 34 treatments, and still being hoarse, another Thyroid Test

was done and found it to be normal. After 3 months of healing from the radiation, a Pet Scan showed that the cancer was still there. A third Biopsy proved Positive which resulted in referral to a Surgeon for a Laryngectomy on April 1, 2008. So from the onset to surgery was a TWO year frustrating journey. I was lucky that the cancer was confined to my Voice Box so it was a rather basic surgery.

Tom Olsavicky - Yorktown, VA
2008 Laryngectomee

Lost my voice completely. One week later diagnosed as cancer
George Myron - Ocala, FL

My vocal cord cancer symptoms: were occasional hoarseness, then a few MOs later constant hoarseness. Then sure throat + ear ache upon swallowing. Then I had a Laryngectomy in 2014. Then, within 7 mos, I had 3 recurrences (and 3 more surgeries). My symptoms with all of them were sore throat and ear ache upon swallowing.

David Smith - Strawberry Plains, TN
Class of 2014

I had a sore throat for 9 months before my Dr. sent me to an ENT. After my first visit to the ENT it took 7 hours before I was admitted to the hospital.

George Cocking - Toms River, NJ

Over a year to get a diagnosis. Went to 2 different Doctors. First one said nothing wrong, but I, knew that there was. Went to 2nd Dr., he also said nothing wrong, that it was a voice issue and, sent to Voice therapy (a waste of time & money).

Left that circus & went back to the ENT, he looked in my throat said that he saw nothing. I, challenged him by saying that there was something wrong & I, knew it. If he could not find the problem, then I would find someone who could.

Well, we're both a little upset with each other by this time. He told me to sit back down in the chair & back down my throat he went with both hands & a shovel. He started pulling the camera out of my throat & asked how long had it been since I, had smoked. I, told him probably 34-40 years. He did the surgery &

did a fine job of it.

The surgery was June 16 of 2006.

John Shellhorse – Arlington, TX

Symptoms: Horseness, chronic cough. About 10 months until correct diagnosis.

**Richard Sipp - Midland, MI
Surgery October 2000**

I alluded to this topic last month when discussing speech pathologists. In late November and early December of 1990 I began to become hoarse. I was singing in four choir/choruses and chairing several organizations. My primary physician ruled out several possibilities and referred me to an ENT physician. She, in turn, found a lesion on my right vocal cord and made a tentative diagnosis of vocal abuse. She scheduled me for a routine biopsy in March 1991 and was devastated to find the lesion was cancerous.

She and I went to Yale-New Haven Hospital's Head and Neck Cancer Conference at which time the consensus was that laser surgery and radiation therapy was the best option for me. I had the surgery in April and began seven weeks of radiation therapy in June. Fifteen months later the hoarseness returned, a biopsy showed cancer in the soft tissue on the right side of my larynx and total laryngectomy was the ultimate decision.

**Carl Strand, Mystic Connecticut
Radiation 1991; Laryngectomy February 10, 1993**

I started noticing almost every morning after I got up that I would either go outside or to the bathroom to throw up. But it wasn't anything except mucus only at first. Then it started getting worse and by May, I was throwing up almost every day, coughing a lot, my right ear started hurting to the point where I had to have cotton ball in the ear every day. I wasn't hardly eating, drinking hardly any liquids at all. I had sore throats that wouldn't go away, then by July and August I was losing my voice and then my weight was going down. Before I started losing weight I weighed about almost 200 pounds and before I had the surgery I weighed 130 pounds. I could hardly drink my coffee without choking on it, and I couldn't hardly put food in my mouth without choking. I had to go to the ER in Sept, and in Oct I had the surgery. It took 5 months because the doctor I went to didn't know what was wrong with me .

**Lora Lawrence - Lake City, Florida
Oct 2 2017**

I had a lot if mucus, little cough, horsiness, for like 8 months. Kept going to the. Family doctor was told post nasal drip. Oh, I also had an ear ache off and on. Finely I walked in an ENT office crying. Couldn't take it no more knew something was

wrong. The nurse told the doctor. I was upset. and would ask if he would see me.

And yes he did!! He scoped me and saw a tumor. He got right on the phone himself and set up a biopsy and couple days later that was done. He then sent me to Jefferson Hospital to see an ENT. That was August 2014 and I got chemo and radiation. After about 8 months or so the hoarseness returned. Had my surgery Jan 2016. Voice box removed, lump nodes, and my thyroid.

It will be 3 years in Jan. since my surgery. It hasn't been easy not talking, but use an EL or I write on a board.

Susan Belz – Philadelphia, PA

My symptoms may sound strange but it was an ear ache and swollen lymph node in my neck. I had radiation and chemo for 6 weeks, then no cancer for a year. Then the cancer returned. The way we caught it was another ear ache. I had surgery a month after the cancer returned,

**John Staples – Sacramento, CA
June 19th.**

My first symptoms of a problem were a light cough and slight difficulty breathing. My children later told me that my voice was getting lower although I had not noticed that.

It all came to a head one cold morning as I was walking up our steep hill to retrieve the newspaper. Breathing was suddenly very difficult and I went down the hill to call a neighbor to take me to the doctor.

I believe the extra cold air intensified the breathing problem.

After two failed treatments for possible asthma, my doctor sent me to the nearby ER. A MRI with dye lit up a stage 3+ cancer in my thyroid cartilage and was 80 % occluded. I had a diagnosis in a very short time.

Although I lost my voice box due to wide margins being the treatment, I had no chemo or radiation. I know I was fortunate to not have to deal with scar tissue from further treatment and the cancer was encapsulated. It took a while for me to realize that so many others weren't so fortunate as I. They are the heroes.

**Marian Cure - Plano, TX
2009**

I had laryngitis from about the third week in December, saw a doctor twice in January, who arranged an appointment for March 6th, 2015 with an ENT. I took myself to hospital emergency about mid-Feb, to ask for immediate ENT attention. The intern prescribed CT scan for the next day to facilitate the quest for answers. I went unannounced to see the first doctor a week later and asked him to look up the CT scan. He studied it for a few minutes and advised me to go directly to the hospital for admittance. I got a biopsy that evening Feb 19th and was

advised a week later of stage 4 cancer of the larynx. Because I was rapidly losing my breathing capacity, I asked a friend to drop me off at the local hospital emergency March 7th and was immediately transferred to another hospital where a trach was performed. Three weeks later I had the laryngectomy.

As you can see, I had to be on top of it the whole way through. This was a complete surprise to me as the cause was 'smoking', a habit I had quit forty years previously. Fortunately, other than the larynx and cartilage, everything else was sound, so I've had no chemo or rad treatments.

Brian Bardal – Abbotsford, BC
March 26, 2015

It took nearly 7 years before I was diagnosed. It started with a pricking pain in the throat. Initially ENT could not find anything wrong. They advised saline gargle and nothing else. The pain got worse and that is when the ENT said that there is a "Polyp" growing which needs a micro surgery and Biopsy. Biopsy confirmed Malignancy. Radiation was done. It failed. Partial Laryngectomy was done. It too failed. Finally, Total Laryngectomy was done by removal of Pharynx.

Mohan Raj - Bangalore, India
March 2010

The only symptom I displayed was my voice would turn hoarse for a short while then return back to normal. The first month of this I attributed to allergies as it was in April, and the Georgia Pines were putting off a heavy dose of pollen. The on and off hoarseness continued into May and I made an appointment with my Doctor. After some heavier sinus meds for a few weeks, which did not help, my doctor sent me to an allergist. This was now mid to late June. He scoped me then ran some test that showed I was allergic to a lot of things. The scope apparently did not show him anything????

He tried another medication and after three or so more weeks, nothing had changed, my voice would still occasionally go hoarse. Now we are into August and the Allergy Doctor decides to send me to an ENT. First thing the ENT Doc did was scope me and immediately spotted the cancer on my vocal cord. After a biopsy, it was confirmed.

John Hendrix - Savannah, GA

My wife noticed that my voice was getting hoarse. She saw Michael Douglas on ET and he said that was the symptom of his younger cancer. My wife made me go to the doctor and sure enough it was cancer. So I thank ET and Michael Douglas for saving my life.

David Kinkead – Peoria, AZ
Class of 2013

Being a pack/pack-n-half smoker for years (sometimes more) as well as a consumer of at least a quarter ounce of marijuana a week since the age of 15 tis a wonder things didn't go south long before my 50th birthday. For that is when my voice began to go 'hoarse'.

Long about the age of 52 I began waking up at night not being able to breathe, but was in between jobs and had no health coverage and wasn't about to run up a lot of medical bills I couldn't afford to pay. While out looking for a commercial construction carpenter job I encountered a woman that REFUSED to acknowledge I had the right of way when her lane merged with flowing traffic. It was raining and she wanted to get in front of me so damn bad she would have clipped my front tire had I not hit the brakes and down shifted. Despite my maneuvers she still missed the front tire of my fish-tailing Hawg by a mere inch or so.

When I hit the horn she politely stuck her hand out the window . . . and FLIPPED me off!!! Must confess my next actions were not at all that 'Christianly'. She quickly realized she'd ticked off a Harley riding madman and she sped up to escape me . . . but I caught her at the next light and in order to keep from punching her rolled up window out I yelled at her. No . . . nothing derogatory or vulgar, but in doing so . . . my voice "cracked" and the hoarseness got worse rapidly after that.

Bouts of waking up unable to breathe became more frequent during the next two years until September 22nd 2006. When I was jerked out of a sound sleep GASPING for breath. Wasn't the first time . . . but this time was different. Because it kept getting worse instead of better after I was awake.

Ambulance ride to the ER. No choice. I was slowly being suffocated by a closing throat. Smoked my last of anything the morning of my surgery. October 30th, 2006 I joined the exclusive club known as Neck breathers. Be 12 years the 30th of this October. Should have died. Should have had far more difficulties than I have. Which is why I ALWAYS say . . . God treats me far better than I deserve . . . and I am gratefully thankful for it.

Troll – Florida
Class of 2006

Next Month's Question:

**As a Survivor, What Are
You Most Thankful For?**



From the Archives

Vicki Eorio used to write a wonderful column for us called Vicki's Midnight Train from Georgia filled with insight, humor and honesty. This is one is particularly good from September 2006. Enjoy! ~ Donna

Who Takes Care of the Caregiver?

What? What is that sound I hear? It is 4:30 in the morning and a train is going through! And by golly, there is another one! They aren't supposed to be coming through at this hour. Did I not hear the midnight train? Or has the schedule changed?

Now, this is worrying me. Was there a derailment? An accident? I turn on the news but the local broadcast does not start until 5:00 AM.

So I fuss and pack my lunch for the day and wait for the rest of the household to catch up with me.

5:00 AM comes and there is no news about any train problems. I start the day preoccupied. But as I start my hour commute it occurs to me that I start every day pre-occupied, and worried. And usually it is about me! That ache in the side of my neck. It couldn't be how I slept; no, maybe it is a lymph node. The weight I can't get off must be because what is left of my thyroid is cancerous. It certainly couldn't be the pasta and potatoes and lack of exercise.

The fatigue is because the cancer has spread and I am as tired as I was before surgery. It couldn't be that I am much older and trying to do the job I did 20 years ago plus keep up with all of the rest of life's responsibilities. I can just ignore that comment Frank made about his ankle hurting; well, that doesn't mean anything because he hasn't had cancer. Or when he mentioned he just wasn't hungry, which is out of character for him. Well, he just did that for attention.

Bingo! Light bulbs going off! Warning, warning! Train is approaching the crossing!!!! Stop! Do not proceed!

There is nothing better than being forced to wait for a train to pass because it removes all controls from us and we have nothing to do but fume and fuss or think.

There are more reasons, than I have the ability to list, that justify us being self absorbed because of our "situation". It is so easy to slip into the martyr syndrome in a heart beat. But what I find fascinating, at least for me, is I expend SO much energy at work and in social situations over-compensating for being a lary. Always a smile, always a joke to put others at ease when they first meet me, always doing stoma/trach cleanup and repair and even coughing in the bathroom or behind my locked office doors. Always emerging with a smile when I know I have fooled no one. Tears of frustration only on the way home. So by the time I climb the stairs to the kitchen to be greeted with love and concern by Frank and the animals, I once again am a witch (feel free to substitute the letter "b" for "w" because that is reality.) And the cycle starts again.

How really abusive on my part! I am blessed with a caregiver who devotes himself 24/7 to protecting me, assisting with my trach care, maximizing my ability to speak with his subtle tweaking of base plates, amount and type of adhesive, timing of application, and holding my hand when I change the TEP. (I don't know who cries more when I encounter difficulties doing that). He shops for healthy foods, he always has something waiting for me like crackers and cheese since like many of us I suffer from GERD which is pretty severe and he knows that. He gets up in the middle of the night to raise my pillows so I am more upright, helping the secretions drain and

the acid reflux stay put. He closes windows when the neighbors put chemicals on their lawn and again when they mow, knowing the chemicals are now really a-flying! He is on a first name basis with folks at our supplier of necessary things. He removed 3000 sq. feet of carpeting because some of it hid mold!!!!!! That took him weeks and he could only do it when I wasn't here. And then as he removed each section, he disinfected it again before I got home.

And here comes me, this self absorbed person who at times thinks she is the only person struggling and who reacts to her co-workers with more pleasantries and patience than she does with the most important person in her life.

I am not sure I like the person I just described. This cancer disease, regardless of the form it takes, affects everyone associated with its victims. It has a ripple effect. Sometimes resulting in support and understanding, sometimes resulting in isolation. But for us who have loving and patient caretakers, best we take care of them!!!!!!

When I was a nurse my mantra was, and still is, "Who takes care of the caretaker?" Best be us!! Where would we be without them? And I don't mean only the physical things they do for us but also the emotional support, the acceptance, the love, the forgiveness of our selfish actions.

We are not easy folks to deal with. We have anger and self pity and a low tolerance of others who have complaints we consider inconsequential. And most of us bury those feelings because we are afraid to bring them out in the light of day. It is so easy to build a wall and dare anyone to break it down! Now I know many, many, of you have overcome the negative feelings, have accepted life as it is and have gone on. But even for you, in the beginning you had the feelings because that is part of going through the acceptance of our situation. So this is not new information to any of us.

I have read letters from caretakers who needed advice from WW and were obviously hurting. God bless WW because the response was always overwhelming. Do we practice that every day at home or wherever our support is? The caretaker doesn't have to be

part of the family. It may be a friend, a neighbor, an email buddy. Do we take the time to stop being so self absorbed and open our eyes and try to see what they are going through.....for us? And do we acknowledge it? Do we ask how they are feeling? Pat their hand, give them a hug, write them a note? If we do, it helps us as much as it does them. We get out of ourselves and see that we are not the center of the universe. And what a relief that is! Pretty heavy burden to carry that no one asked us to do. I think that is the job of God or whatever Higher Power in which you believe.

So please take care of the caretaker! They didn't ask for this, didn't need it, but 99% of the time have risen to a position close to the angels.

Now about that train, You know what? Since there was nothing on the news and so there wasn't an accident, is it possible the schedule changed? Do I need to worry about that or do I need to let go and be solicitous of that ankle pain Frank had and spend some time planning a dinner of some of his favorite foods. The smile I will get from him and when he says, "Boy! That really hit the spot.", will make me smile, too, and will make both of us feel healthier and happier.

Love and prayers,

Vicki

