

Whispers on the Web

A Monthly Online Newsletter for WebWhispers

Photo: CC by HM Bascom



Contents

Column	Author	Title
From The Editor's Desk	Donna McGary	Summertime And The Living Is Easy....
The Scuttlebutt	Tom Whitworth	Can You Hear My Voice? July 18!
VoicePoints	Kimberly B. Almand, M.S., CCC-SLP	Tracheoesophageal Voice Prosthesis Selection
My Neck of The Woods	Don Renfro	There Goes That Deadline
This Lary Life	WC Baker	KENYA 96
The Silent Partner	Aaron Wayne	Chapter 5: The Operation And The Recovery
From The Archives	Kevin Berry	Investments in Living

From The Editor's Desk

Hello everyone,

For our readers here in the Northern Hemisphere summer has finally arrived but whether its summer or winter where you are I think we all are looking forward to a much better/easier/more sociable season than last year. I know a lot of the local support groups are starting to have face to face meetings again altho some are also going to try to continue using zoom or something similar...kind of a hybrid model which could increase participation. So it's just wonderful to feel comfortable getting out and about again. We humans are social creatures. We may survive in isolation but we need to hang with our tribe to thrive.

I like to think of this newsletter as an extension of the traditional support group where the writers share what they've been up to, their concerns, their triumphs, their expertise and just their lives. Hopefully you find it a source of education, inspiration and entertainment as well as a chance to get to know some of the folks in our community a bit better.

This month VoicePoints addresses the issues and considerations of the two types of TEP: patient changeable and indwelling. Tom Whitworth gives us the links and information about viewing the documentary by Bill Brummel "Can You Hear My Voice" about the Shout at Cancer choral group from England. Many of us have seen it more than once and still find it moving. It is a testament to the power of music and singing and I highly recommend it if you haven't already had the chance to watch it. The latest chapter in Aaron Wayne's book is terrific about those very early days after surgery. Don Renfro writes about procrastination and how it

might not always be such a bad thing. I'm glad to hear that since I am notorious for waiting until the last minute to do stuff (including this newsletter). We travel to Africa this month with WC. Check out the giraffes... very cool pics. In searching the Archives I found the perfect piece to remind us to get back out there and enjoy life by Keven Berry called "Investments in Living" from back in 2013 so some of you newer folks may never have seen it. It's a good read.

I leave you with a haunting version of Summertime with Ella Fitzgerald and Louis Armstrong.

https://www.youtube.com/watch?v=h3kQt14_5OQ

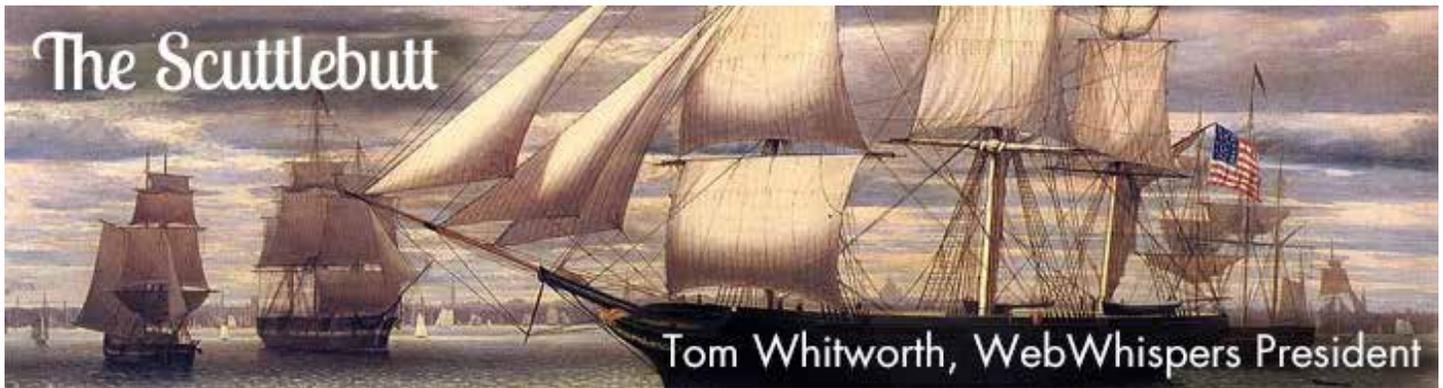
And being a child of the 60's I had to include Janis:

<https://www.youtube.com/watch?v=bn5TNqjuHiU>

Take care and now get out there and enjoy life!

Donna McGary





Can You Hear My Voice? July 18!

Many of us have seen "Can You Hear My Voice" but many more have not. Those of you who have experienced the film will surely want to join us on July 18, 2021. For those who have not seen the film, it is certainly not to be missed! See the link below to register now and to view the trailer.

WebWhispers, Atos Medical and the Thyroid, Head and Neck Cancer (THANC) Foundation invite you to an exclusive online screening event of the documentary film "Can You Hear My Voice?"

About the Film:

The film follows the Shout at Cancer Choir in London, made up of individuals who have undergone a laryngectomy, as they prepare for the most ambitious concert they've ever performed. Choir members chronicle how they traversed the traumatic psychosocial obstacles of living without a voice box, to emerge fully engaged and communicative.

After the viewing, meet Producer Bill Brummel, Choir Director Dr Thomas Moors and members of the cast for an insiders view of the filmmaking process and an interactive Q&A panel!

Event Details:

Sunday, July 18, 2021

3:00pm ET | 2:00pm CT | 1:00pm MT | 12:00pm PT

Schedule of Events:

3:00pm - Film screening

4:35pm - Q&A panel

5:05pm - Event concludes

Use the link below to register (or copy and paste into your browser)

<https://na.eventscloud.com/ereg/newreg.php?eventid=615628&>



https://youtu.be/Uc_Dt358meI

Also, below is a link to register for the Head and Neck Cancer Alliance Symposium taking place from July 20-24, 2021. Many of us will find the topics being covered to be truly helpful. You can participate in each or select which sessions will benefit you most.

Head and Neck Cancer Alliance and the American Head and Neck Society present the 2021 Virtual Head and Neck Cancer Survivorship Symposium. Join us online from July 20-24 for any or all of the following sessions. Registration is now open!

<https://www.headandneck.org>

Please join us on July 18 for the film. I hope many of you can also participate in the HNCA Symposium later that week.

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



Voice Points

Written by Professionals

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

kbalmand@gmail.com



Tracheoesophageal Voice Prosthesis Selection: Indwelling and Non-indwelling Considerations

Since the first Blom-Singer voice prosthesis became commercially available in 1980 (Singer et al., 1980), the use and availability of tracheoesophageal voice prostheses have expanded to include a range of styles and sizes depending on individual patient needs. In general, the mechanism for alaryngeal voice is the same across all prostheses, which are one-way valves designed to allow airflow from the trachea through the tracheoesophageal puncture (TEP) to the vibrating portion of the posterior esophageal wall. The body of the prosthesis is anchored into place with a flange at both the tracheal opening and the esophageal opening of the surgically created TEP. The valve on the esophageal end of the prosthesis is designed to prevent leakage of air and swallowed material back through to the trachea and airway. All voice prostheses facilitate sound production in roughly this same manner. A more extensive review of the most commonly used prostheses may be found on the Resources section of WebWhispers online: www.webwhispers.org and at both www.atosmedical.com and www.inhealth.com.

Among the various styles and sizes of voice prostheses available, two main categories exist: indwelling voice prostheses and non-indwelling voice prostheses. The chief difference between these two is that the indwelling prosthesis is designed to be inserted and replaced by a speech-language pathologist (SLP) or clinician whereas the non-indwelling prosthesis may be self-managed by a patient or their caregiver. The indwelling prosthesis, with its larger and more rigid flanges, is designed to remain in place for an extended period of time before it is removed and replaced. The smaller and more pliable flanges of the non-indwelling voice

prosthesis along with its insertion strap (including a safety medallion with some devices) allow for more frequent removal and reinsertion. Based on these fundamental differences in design, clinicians and patients have options when it comes to choosing the best fit and function in a voice prosthesis.

Most commonly, patients are fitted with an indwelling prosthesis at the time of surgery or as a secondary procedure. Many continue with use of an indwelling type; some may elect to consider a non-indwelling type at some point. There are certain indications and procedures to consider if one is to replace his/her own prosthesis. Replacing a prosthesis requires good vision and adequate finger dexterity. Access to a well-lit, clean area with a mirror is imperative, and prior to self-replacement, one must have the proper training and supervision by an SLP or other clinician. Ideally, this would occur over the course of several sessions, including guided practice in removal and insertion of the non-indwelling prosthesis prior to sending a patient or caregiver home to do it independently. Those sessions would also be devoted to establishing a protocol for cleaning, care, troubleshooting, and developing a regular schedule for prosthesis replacement at home. Many people elect to replace their non-indwelling prosthesis on a weekly or bi-weekly schedule. Once removed, the prosthesis may be cleaned in warm soapy water, rinsed, and set aside to dry; meanwhile a second non-indwelling prosthesis is inserted until replaced again by the first. Self-replacement at home often involves less frequent clinic visits as patients become more autonomous. This means reduced travel time and expenses, less clinic and/or hospital copays and fewer visit charges. Financially, the cost of a non-indwelling prosthesis itself is substantially less --and in the US often covered by insurance-- compared to that of an indwelling voice prosthesis.

Not everyone is a candidate, however, for changing their own prosthesis (Ward and Van As-Brooks, 2014). Those with decreased cognitive status or those not motivated to take on greater responsibility for their own care would be more appropriate for use of an indwelling prosthesis requiring greater oversight by a clinician. Limited eyesight or notable pain or limited dexterity in the fingers and hands are often contraindications for using a non-indwelling prosthesis. Patients with consistent difficulty re-inserting their prosthesis or those unable to completely insert for any reason would not be recommended for a patient-changeable non-indwelling prosthesis. If there are issues with uncontrolled bleeding, reduced tissue integrity such as with uncontrolled diabetes, or a history (or concern for) accidental dislodgement/extrusion of the prosthesis, the more rigid and sturdier flanges of an indwelling prosthesis are a more secure fit to help avoid these complications. Those undergoing postsurgical or radiation-related inflammation or edema may benefit from the placement of an indwelling voice prosthesis that will maintain its stability and will remain in place for a longer duration of time. Likewise, patients requiring specialized prostheses (customized flanges and customized lengths; extra/modified valves to facilitate increased airflow resistance; specialized valves to combat candida and biofilm) will benefit from frequent follow up with their SLP and will find these prostheses only available as indwelling types.

The decision to utilize either type of prosthesis does not have to be a permanent decision. Many elect to switch to a non-indwelling device after months or even years of indwelling prosthetic use and vice-versa. Changes in medical status, family/caregiver support, finances, and communication demands are all factors to consider. A patient's capacity and motivation to participate in their own self-care and troubleshoot potential problems will likely evolve and change over time, and the type of prosthesis used can fluctuate accordingly. Regardless of the type of prosthesis chosen, the importance of establishing and maintaining a relationship with an SLP or other clinician to help guide the patient in the decision-making process cannot be understated. SLPs should remain available and accessible to provide periodic assessment to ensure proper fit of the length and diameter of the prosthesis, monitor tissue integrity, assist with updating prescriptions for the necessary supplies at least once a year--even

if patients elect to stay with a patient-changeable non-indwelling prosthesis. One's local SLP can serve to provide up-to-date information and education regarding the ever-changing products and supplies available from various companies. SLPs often have the privilege of providing long-term support, counsel and hands-on education for persons with a laryngectomy as needs unfold.

With the onset of the Covid-19 pandemic, medical care and clinic visits were necessarily deferred in many facilities (Goldstein et al. 2020). During the last year, many have learned more about how their prostheses work, how to troubleshoot and care for their prostheses a little more independently, and how to use alternative methods of voice when prostheses began to break down and/or tracheoesophageal voice quality decreased. In-person clinic visits were reduced and virtual support group meetings replaced in-person gatherings. Given this new era in medical care comes the realization that not all patients have or want the same access to treatment, and post-laryngectomy voice options are not "one size fits all." Both indwelling and non-indwelling TEPs have strong indications for use. Use of artificial larynx devices, esophageal voice, and augmentative and alternative communication (AAC) devices are also viable options as primary and backup methods of voice and communication and should be given consideration. Some days, it is (or may become) useful to have more than one way to communicate and talk.

For those who have a tracheoesophageal puncture or help manage one and are new to the concept of a patient-changeable prosthesis, consider its use. Not sure where to begin? Contact your local SLP or reach out to WebWhispers to find an SLP who can help. The non-indwelling voice prosthesis, while not always as widely understood or utilized as the indwelling prosthesis, has its own unique place in alaryngeal voice restoration. You may not completely know if it is right for you until you try.

Kimberly B. Almand, M.S., CCC-SLP
kbalmand@gmail.com

References and supplemental reading and resources available upon request



There Goes That Deadline

By Don Renfro

Just ask Donna if this is true for me. Each month I intend to write my article about 30 days prior to when Donna puts out the newsletter on the 20th of the month. But for the last few months I have found myself writing it as late as the 18th of the month.

About 30 years ago I was in a meeting at work and made the statement "I work best" at the deadline. Sometime later I was talking with my boss, and she said "I know you were kidding" but there is some truth to that statement.

Over the years I have thought about why it is that I do my best work in the eleventh hour. I have come to believe that it is because there is less time to think and procrastinate and only time for action. After all it is the act of doing, which all accomplishments are made.

Sometimes it is easy to confuse that thinking is the same as doing. After all, most all actions began with a thought prior to any actual efforts put forth, except those actions derived from impulse.

I remember hearing something many years ago, that I have always found quite intriguing. You may have heard it, but I will share it anyway. There were three frogs sitting on a log. One decided to jump off. How many frogs were left on the log? The answer is three. Deciding is not the same as doing.

I have learned in my life that if I spend my time prior to a deadline thinking and deciding what to do that when the deadline gets here, I will not be ready for it and will find myself in the eleventh hour trying to make that "buzzer beater" basket at the last moment.

There is something else I heard in my life about it not being the amount of time I have to accomplish something but how I use the time I am given. As I get older, I am getting better at using the time I have and not end up in a "crunch time" situation, yet still I can find myself in one.

It is funny my story is so very similar to other's I have met in this laryngectomy community. When I was younger my health was the last thing on my mind.

I love deadlines. I like the whooshing sound they make as they fly by. ~Douglas Adams

I would go to the doctor eventually when I had too. But as I got older and when it came to this cancer, I sought medical attention rather quickly. My story is like so many I have heard that I sought medical care way back when I had a hoarse voice that would not get better. But it would not be until years later after I was found to have stage 4 cancer and could not breathe that I would begin to get the treatment that addressed my actual problem.

Some people might look at that and see that it did not do any good to be proactive. I look at it as had I not sought treatment when I did it may have delayed life saving treatment even longer.

Today for me deadlines are not something for me to listen to the whooshing sound they make as they fly by, but instead are the opportunity I get to prepare for what I am doing.

Currently I am working on having my front porch rebuilt. About two years ago I got an estimate to get an idea of how much money I would need to do the job. Now in retirement I have the time and the money and so I was ready to do the job. I got 3 new estimates and found that the cost of the job had more than doubled since I got the original estimate. Seems lumber increased in price dramatically during the pandemic. Here is a case where waiting significantly increased the cost of my project. Fortunately for me I am still not doing this job in the eleventh hour and still have time to make decisions and choices on how to best do the job and I am not forced into options due to a tight time restraint.

Having the luxury of time has provided me with choices and options I may not have had or may have missed doing this project under the restrictions of time.

Well life is certainly a journey. I continue to improve and although I am still not perfect there are parts of that are much better than they were in the past. I truly believe that when we stop improving it is because we are no longer are alive.

This Lary Life

KENYA 96

W. C. Baker

Tanzania might disagree, but to me Kenya, more than any country in sub-Saharan Africa, feels like a giant theme park. It seems to live by and for the tourist. Of course, the animals that draw the tourists don't exist for the tourists, but their lives are certainly affected by them—us. Nairobi, the headquarters for the tourist industry in Kenya is a bustling metropolis compared to Addis Ababa, Ethiopia or Asmara, Eritrea. Being the frugal travelers that we were, we checked into a one-star, if that, hotel, where our sparse luggage was kept in a storage cage and our nights were filled with noise, we supposed, from the kitchens that seemed to be loudly washing pots and pans all night.

Our first evening we took a taxi to The Carnivore a restaurant catering to our less than wholesome appetites. As eponymously suggested, The Carnivore serves meat, not just any meat, but allegedly the meat of Kenya's wild animals. The way it works, when you are seated you are served some basic side dishes and trays of meat are brought around for your acceptance or rejection. Well OK, I didn't reject anything. I remember having Bearded Gnu (wildebeest), Zebra, Ostrich, and Crocodile before toppling the card in front of me indicating that I had reached my limit. If you're ever there, I recommend the Ostrich. The Gnu and Zebra were quite edible, but the Crocodile was pretty greasy. If you are a vegetarian, don't go anywhere near the place.

Famed for the man-eating lions of Tsavo, the train to Mombasa hides several national parks and reserves under a cover of darkness. As the oldest and largest port in East Africa, Mombasa is a rich mixture of Africans, Arabs, Indians and Europeans. It has a rather sleazy feel to it causing this casual visitor to have been unusually wary when walking the streets and spice markets. I was offered the opportunity to buy what was supposed to have been some "very fine Swahili hashish", but declined. The pride of Mombasa is the Portuguese Fort Jesus. For a battle structure to bear the name of the Prince of Peace seems to be oxymoronic at best.



That which was hidden on the overnight train to Mombasa was manifested on the daylight return to Nairobi. We saw herds of Zebras, and varieties of antelopes, a few lions, ostrich and giraffes. There was a time that the train had an observation platform that would have been wonderful, but I don't think it was available any more.

Back in Nairobi a couple of miles from the city center we wandered closer to the shanty town than was comfortable. Most of the million or so slum residents live in extreme poverty, there are few schools, clean water is scarce, and diseases caused by poor hygiene are prevalent. A great majority living in the slum lack access to basic services, including electricity, running water, and medical care. It is not on the tourist itinerary. More comfortable wandering took us to the National Museum and the Snake Park, both fascinating places. The National Museum was long headed by Robert Leaky and boasts the world's greatest collection of early hominid skulls. At the snake park I recall watching a Green Mamba that was just below us. It spotted a frog some twenty yards away at the other end of the pond. It quickly skirted the pond, all the while focusing on the frog. When it got close to the rock the mamba swam across and attacked the frog, all within seconds. Memory of that scene recurred to me several times when we got out into areas where the Mambas might dwell.

A bit to the east of Nairobi is the home of the author Isak Dinesen, (the pseudonym of Karen Blixen). Her

home in Kenya is that which was represented in much of the film *Out of Africa*, loosely based on Dinesen's book of the same name. She had come from Denmark in 1914 and established a coffee plantation with her husband. After divorcing her husband and having her depicted affair, she left in 1931 with the farm on the verge of bankruptcy. The museum, set in an extensive garden, gives some idea of colonial life in the early 20th century, before Mau-Mau.

Taking the 24 bus back to downtown Nairobi from Dinesen's farm we made a stop at the Giraffe Center. If you have ever had a yen to get up close and personal with a giraffe, this is the place to do it. Climbing a wooden structure puts you at eye level with the ever-popular critters. A sort of giraffe kibble, purchased on entry, can be fed by hand to a long, purplish, slimy-tongued mouth that is capable of stripping branches two stories above the ground. I highly recommend it. At the same time, you can see wart hog families scurrying about in the mud with tails straight up.

But enough of Nairobi and environs. It's safari time.

Masai Mara was exciting and disappointing all at the same time. Wildlife abounds, but so do tourists. Gone are the days when going on safari meant following a

great white hunter and bearers into the bush, ready at any time to be charged by a rhino or lion. Now it is five tourists and the Kikuyu driver in a Toyota van with a roof that can be lifted to provide up close and personal viewing, and shooting, but only with a camera. Our first sighting of a one of the big five, (Lion Leopard, Elephant, Rhino and Buffalo), was of a rather hapless leopard being attended to by at least ten tourist filled Toyota vans. Thank goodness that was the only such occasion.

Other sightings were much less crowded. Herds of Wildebeest seemed to extend to the horizon. Herds of zebras, though fewer in number, were more impressive in their presence. Ostrich loomed singly or in pairs. A variety of antelopes grazed as lions slept or strolled nonchalantly. Blue bottomed baboons represented the local primates, conspiring to take advantage of the visiting primates in their pop top vans. Hippos filled a section of the Mara River while the real King of beasts, the Elephants strode confidently about their realm. One cannot help but be impressed. It is all quite magical. A real sense of revulsion overwhelmed me at the tourist lodge to which we had walked from our tent camp some distance away. It was evening and the lodge guests and others from tent camps were gathered on the veranda above the river for the evening





entertainment. A kid, a young goat had been tied to a stake about 15 yards from the river. It struggled and bleated in terror at the fate it seemed to know was soon to befall, but to no avail. A huge crocodile came out of the river at amazing speed and consumed the kid in several great, bone crushing gulps.

In its way, Lake Nakuru is the most spectacular of the major parks. It is well known for being ringed in pink. Flamingos in all their great pinkness surround the lake like long necked pink feathered clowns on stilts. Cape Buffalo, looking like huge cattle with horns looking like oversized, fossilized handlebar mustaches on their heads, share the grass flats with Rhinoceros, neither exhibiting any particular interest in the other. Giraffes punctuate the scenery with their rather awkward grace. Hyenas, probably the most off-putting of Kenya's creatures were feasting on an unknown victim.

It was in Samburu that I met the Gerenuk, the most appealing of all the many creatures we saw. It has the body and head of a deer but has a longer tail, long thin legs and a long graceful neck. The male has lyre shaped horns rather than antlers and lacks the grace

that is so evident in the female. It stands on its hind legs to nibble the little leaves of the acacia tree. I had never heard of this delightful ruminant before.

It was also in Samburu that we had the rare privilege to see a Cheetah. We were in the van looking at something else when a Cheetah came out of the bush right next to the van. Of all the experiences unique in my life, few have equaled the thrill of going from our tent down to the river and seeing a large male lion on the other side, taking a leisurely drink. He could easily see me, but paid little attention. The fast moving waters of the Samburu let me watch without fear of being breakfast.

If there was some sort of blood lust sneaking through my subconscious, it was never satisfied. Aside from an angry elephant shaking his massive tusked head and trunk about 50 yards causing our driver to stop and slowly back the van while focusing intently on the elephant, I never felt a hint of danger.



THE SILENT PARTNER

My First Year as a Laryngotomee

by Aaron Wayne

5. The Operation and the Recovery

Early on the morning of October 21, 2019, I reported to the hospital and was duly admitted. Shelley was holding my hand both physically and metaphorically. That early in the morning, the place was nearly deserted. We entered into a long, wide hallway with a very high ceiling – one could almost have played basketball in it. There was a guard stationed at a podium that functioned as a help desk. He was dwarfed by the surroundings. As our footsteps echoed forlornly down the hall, we were shown to admitting and a cozy waiting room, mostly empty, that opened out into a small garden area.

Soon, I was taken to the prep area, where I seemed to languish forever as they took vitals, asked a LOT of questions, took vitals, reassured me, took vitals...

The various doctors came by to discuss the procedure, the anesthetic, and various things that they thought I should know, such as the low probability of my death, while I lay there and wondered when the hell they were going to get on with it. Finally, after one last visit to the bathroom, I was wheeled into the operating room. I really don't remember many details about the OR because I had other things on my mind, but it looked a lot like they do on television. After a while, I was moved to a private ICU room where I spent two days before joining the general population. The room was very comfortable, well lit and nicely appointed. There was ample room for visitors and for all of the nurses, doctors, and sundry technicians, at least one of which always seemed to be present. During the first visit from my surgeon, he was positively beaming as he told me how well the surgery had gone: They were sure that they had gotten all of the cancer. The surgery had taken nearly two hours less than their original guesstimate. Only minimal reconstruction had to be done. My recovery time was going to be shorter because of all this. I think he was happier about it than I was!

While in that room, I seldom had to use the call button. That changed once I was moved upstairs to one of the generic cells.

Right after the operation, I often needed suction to remove the mucus from my airway. The suction machine had another purpose: as a toothbrush! Since I had just

had surgery and was not allowed anything orally, I couldn't even brush my teeth lest I might swallow something. I was provided with 'suction swabs' that attached to the business end of the tubing to suck out any saliva that I generated while 'brushing'. They came in a two pack with a fast food ketchup sized packet of 'Perox-A-Mint Solution'. It was basically a tube with a green sponge at one end and a fitting for the suction hose at the other. What I really wanted was some way to suction my nose. It usually felt like I had a big booger in my left nostril. I was scolded for even suggesting the use of a neti pot. It would have been pretty impractical anyway, with me not being able to blow through my nostrils. Later, after I got home, I had Shelley buy one of those little bulbs we used to use on our daughters' noses when they were babies, but that didn't work at all.

It was one of the Respiratory Techs who assisted with this that saw the notes I was still taking and asked if he could show them to some of his other patients. As it turned out, they needed editing. Not only were there nearly two dozen pages from just the 22nd I also got a little profane here and there, so he returned them the next day. I suggested that if he had time we could sit together and edit them, but that never came to be. However, he gave me the idea to write this, so if you get any value at all from reading this, thank him.

I was often giving out copies of two of my poems, one about trying to quit smoking and the other my love note to nurses, and the suggestion was made that I write another about my tracheotomy. I thought I could – 'trach' and 'awake' do rhyme even if it doesn't look like it, but I didn't get very far with that one. (I'll include a copy of each of the two poems at the end of this narrative.)

When I was transferred upstairs to a conventional room, I immediately started wondering when I could go home. Shelley stayed with me nearly twenty-four hours a day for several days, sleeping rather uncomfortably on the couch beneath the window of my room. It was a good thing too, as I was often in a near panic state. One of the problems was that the nurses and technicians that were always around before, now had to be summoned. And

the biggest problem with that was that when I pushed the call button, they would ask me what I wanted OVER THE INTERCOM! I was told that there was a note at the nurses' station telling anyone who could read that I couldn't talk. Apparently, no one read it. I ended up wishing that I had a horn I could honk like Harpo Marx.

Since UCLA is a teaching hospital, when the doctors made their rounds, I usually had five or six at a time every morning. I had drains hanging from my neck and one of the interns always stroked the tubes to see how much fluid had drained that day. As it turned out, when there was little or no drainage from the surgery was when they would let me go home.

It seemed like I was never comfortable. When I had a complaint that the room was too warm, I found out that too much morphine can tend to make you feel warmer. I always needed at least four pillows to sleep comfortably sitting up a little, with one of the pillows under each arm. My neck was so weak, that if I wanted another pillow under my head, I had to reach up with my left hand and grab my hair to pull my head up. (I still have a stiff neck nearly a year later.) I had a lot of trouble sleeping. I was afraid I wouldn't keep breathing or something would stop my breathing – just a nameless horror of asphyxiation. Some nights I used self-hypnosis to get to sleep, only to be awakened by a nurse taking vital signs in the middle of the night. During the day, I mostly played games with Shelley and the occasional visitors when I wasn't being poked, prodded or questioned by a doctor nurse or technician. Then there were the sponge baths. One in particular stands out: This crazy woman came in to wash me and to change the bed linens. Shelley had gone down to the cafeteria for coffee and a little break from me. The woman comes in and I swear she was like a character out of a movie, sort of a cross between Nurse Ratched and the vaguely Teutonic villainess from a Mel Brooks movie. She brooked no arguments from me. She simply barreled along, man-handling me (so to speak) like I was a sack of potatoes, scrubbing away at my junk. I was dumbfounded!

I had hot and cold running nurses and technicians at all hours. Some of them I remember with a great deal of fondness. One respiratory technician from ICU even came up for a visit. He wanted to tell me that he loved my poem about trying to quit smoking and was going to give it to his brother, whom he was trying to convince to quit. He also grabbed my clipboard and used that to communicate with me, just as I had to do!

My hospital stay ended a few days before Halloween. Halloween has always been a big deal for me. I have

always had a costume, and over the years have built up a closet full of them. For over three decades I have ridden a tandem bicycle with a full sized, articulated skeleton on the rear seat. Mr. Bones is rigged up with rubber bands so that he pedals along when I pedal. The neighborhood kids have always loved it, and twenty years later are bringing their kids back to the neighborhood to wave hello to Mr. Bones as he rides by. While riding, I usually wore a devil costume, complete with realistic looking cork horns stuck on my forehead. This year I was going to be different: I had staples going down the side of my neck starting below my right ear in an 'L' shape continuing across my throat to the plug in my neck. Voila! Instant costume!

After I was finally cleared to go home, I had visiting nurses who came by to check on me and help out for an hour a few days each week. My favorite and most frequent nurse was Dennis. As it turned out, Dennis was from Cebu City in the Philippines, a place my ship (USS Yorktown, CVS-10) had visited. He was young though, we had visited Cebu seven years before he was born. He did enjoy seeing the photos of Cebu that were in my Westpac cruise book (similar to a school yearbook). One of Dennis' chores was cleaning my trach tube while he was visiting. The first tube I wore had a removable insert called a cannula, which made the trach tube a little easier to clean. The tube I wore when I went home didn't have a cannula and had to be removed completely to clean thoroughly. I also had physical therapists visit, but it soon became obvious that I was coming along just fine in that area and their visits were discontinued.

I had a speech therapist, a lovely woman about my age who was charged with (trying to) train me in the use of my electrolarynx. An electrolarynx is a battery powered (external) artificial larynx that I affectionately called my vibrator. It's about four and a half inches long with a removable soft silicone rubber tube over the end. Initially one sticks the tube into the corner of their mouth and presses a button on the side to create the sound that is used in lieu of vocal cords. After completely healing, the tube can be removed and the electrolarynx can be pressed against the underside of the jaw to make the sound. Alas, I never got that far along, instead waiting for the day when I could get a prosthesis.

I was back in school and I was given homework! The problem was that I still hated school. One homework assignment involved her giving me a long list of words with the instruction to make a short sentence using those words. I told her that making any sentence using those words would be very difficult and certainly would not be short! She resigned after a few more lessons and I still can't use the vibrator so that I can be understood.



Investments in Living

I realize that everyone is different. What is important to one person is of little concern to another. For many of us, the activities we do are central to who we think we are. Runners run, swimmers swim, and hunters hunt. These are often more than just idle pastimes, they often define the participants. To give up on what makes them happy is paramount to giving up on life.

For me water is one of the things that has been central to my being. As a kid when I wasn't swimming I was fishing. When they told me that swimming and canoeing were out of the question, I was as devastated by that as by losing my voice.

I was forty when they rearranged my anatomy. There was a reasonable possibility that I might spend more of my life as a Lary than I spent with a larynx. I decided fairly quickly that I was not going to let the cancer take everything away from me.

It has been almost 12 years now. For those of you who have met me, you know that I do swim still. And when I am at the pool I dive in head first. You also know that I still ride motorcycles, and that I rode to the IAL conventions in both Kansas City, and Durham. I also still canoe and fish, but I forked out the money for the Mustang Survival vest to help mitigate the risks. I have not been sky diving since the operation, but I when my son gets up the nerve to jump, I will go up with him.

I do not consider these foolhardy risks. I consider these investments in living.

I respect the choices of those who decide to become risk adverse post cancer. Everyone makes their own choices but I found the choice to be fairly clear. Cancer almost killed me.

If I stop doing all the things that defined me because of fear, then it doesn't really matter that I am technically still breathing, the cancer has already killed me.

I would say that it's just my two cents, but up here we got rid of pennies so I guess it is a whole nickel.

Kevin Berry
Barrie, Ontario
Lary since Sept 12, 2001



WebWhispers is an Internet based support group. Please check our home page 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.