

Whispers on the Web

A Monthly Online Newsletter for WebWhispers

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From The Editor's Desk

Now that summer in the northern hemisphere is in full swing, we pick up where we left off last month, encouraging everyone to get out there and enjoy the moments life has to offer. Many are taking a long-deferred vacation or visit with loved ones. In-person support groups are resuming and the importance of gathering and sharing with others is as important as ever.

Several years ago, when my children were very young, a dear friend made a comment which shaped my perspective for all future vacations and getaways. She said, "Think of it as a change of scenery." While we may not be able to experience a safari (in person, that is) or steal away to a deserted tropical island for a week, chances are good that some change of scenery may be feasible. Sharing a meal with friends, a short walk in the park, or a few quiet moments reading the stories contained in this newsletter may be enough to provide a small respite. Deliberate moments of rest such as these may give room for a sense of wonder and gratitude to enter in amid our daily routine.

Need more inspiration to change up your routine? Below, Tom reminds us of some of our friends and recalls that laryngectomy has not stopped people from taking on new experiences and resuming old abilities. He points out that "laryngectomy is not the end of life as we knew it, it is the beginning of a new life altogether."

In This Lary Life, WC shares some amazing images and reflections from the Kenyan safari that he took us on last month. If you did not get a chance to read it, we are re-printing the second half again with some additions to help you fully appreciate the scenery. We also continue with Aaron Wayne's lively memoir "The Silent Partner: My First Year as a Laryngectomee."

Last month's VoicePoints addressed what to do when access to a medical center or clinic is delayed. Are you traveling or is your SLP currently unavailable to help change your prosthesis? This month's VoicePoints follows up with the suggestion to not forget the artificial larynx. There are helpful tips for use and even links for financial assistance for a new device.

Lastly, but not least, we have given Donna the month off for a well-deserved rest of her own. She does not get much of that, nor does she always hear how much she is appreciated and admired! I speak for the entire WebWhispers board and our members when I acknowledge how thankful we are to have her to encourage, support, and keep us moving forward every month as we bring this newsletter to you.

Hopefully in the pages below are examples that may inspire and entertain, whether or not you travel this month. How have you been inspired or challenged to live differently or appreciate this life? As always, we welcome your comments and feedback. We look forward to hearing from you.

With gratitude,

Kim





Don't Take "No!" For an Answer

My father often told me that if he wanted me to do something and do a "jam up" job of it, all he had to do was tell me I couldn't do it. He knew his son well. I've always loved a good challenge and have done some of my best work under pressure or in stressful conditions. I may not meet the lofty goal every time, but striving toward meeting it has always landed me in a better place. Something about being doubted stirs up a "can do" attitude in me. I think many of us, if not most, are that way, at least post-laryngectomy.

We often get questions from new or soon-to-be laryngectomees who have been convinced that they can no longer do certain things following a laryngectomy. When my treatment surprisingly had failed, I was headed for surgery very quickly. When I asked if I could ever sing again, the examining doctor sadly shook his head no. He knew how important that was to me and I saw tears in his eyes. I remember being told by others that following surgery, we can no longer swim, go aboard a boat, shower without an act of God, whistle, blow up balloons, or blow out candles on a birthday cake. On and on, and on, it seemed I kept hearing the long list of things laryngectomees can no longer do.

Except for whistling, I do those things as many of us do. I can swim some; I just need to devote more time to it. Even without my special equipment, I safely and routinely go underwater in the pool with my grandchildren, just to show them I can do it. I am extremely careful with that and don't have to go under to have fun anyway. Some of us swim quite well with one arm while covering the stoma with the thumb on the opposite hand! I loved seeing the photos of IAL President Helen Grathwohl alone, having a blast on a jet-ski!

Singer and drummer Tony Talmich has continued to be

a singer and drummer for decades following surgery and he is truly talented. During the worst part of the recent pandemic shutdown, Tony and Laura provided us with weekly concerts via Facebook Live. Since the first of this year, I lead worship, sing, and deliver a sermon every Sunday. Because of that, I have done public speaking about our journey – not my journey, our journey! I love to brag on the lary community. People are fascinated with us and what we can do without a voice box.

Following laryngectomy, InHealth Technologies patient advocate Janice Hayes, developed a highly successful career as a Metro Atlanta real estate agent. Consider how much a real estate agent has to talk! The late Richard Crum, also an InHealth Technologies patient advocate, continued his career as a professional auctioneer well beyond typical retirement age. Longtime secretary for the International Association of Laryngectomees (IAL), the late Barb Nitscheider was diagnosed with cancer in her late twenties and continued to teach second grade, using a Servox, until she reached full retirement as an educator. Her students loved her dearly.

As many of us know, when they remove our vocal cords, many of us just won't shut up. I know that is true with me because I have more to say! This community is filled with people who return to what they did pre-laryngectomy and those who take on new challenges, enjoying life to the fullest. Some of us may have to give up something, but many of us end up with more than we had to begin with. I am surely one of those.


Laryngectomy is not the end of life as we knew it, it is the beginning of a new life altogether. Embrace it!

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



Voice Points

Written by Professionals



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Wait, Wait! Don't Throw Your Electrolarynx Away!!

Although many laryngectomees use a tracheoesophageal prosthesis (TEP), and some use esophageal speech as their primary form of communication, that doesn't mean that their alaryngeal device (ALD), also known as electrolarynx (EL), is useless. Among the many benefits, this form of communication is relatively dependable and low cost.

Learning how to use and maintain a backup ALD in case of emergencies is always a good idea, even if you do not plan on using it as your primary method of voice. Even if it is not an emergency, an electrolarynx is an ideal backup in many situations, for example, a blown baseplate seal, excess mucous, a plugged or blocked TEP.

Perhaps you have been in the hospital and cannot clean or change your prosthesis, or you just don't have the respiratory drive, energy, or inclination to make your tracheoesophageal or esophageal voice work the way you usually do.

There is a sharp learning curve to becoming an excellent communicator with an ALD. Frequent practice with a communication partner using these basic tips can prove helpful in improving how much others understand.

Placement: Whether you're using an intraoral adapter (tube adapter placed in the mouth) or neck placement, everyone has a different "sweet spot" that transmits sound the best. This can be particularly tricky in those that have radiation fibrosis in their necks. Experiment with placing the device on your neck in different places, like under your chin, above your stoma, on one side

of your neck, or even on your cheek. If you use an intraoral adapter, experiment with placing the straw on top of your tongue, to the side between your tongue and teeth, and further forward or backward into your mouth. Try holding the device in your non-dominant hand so that your dominant hand can remain free during communication.

Activation: Turning the device on and off at appropriate times can significantly impact how well others understand you. The device should be turned on at the same time as you start speaking and turned off at the end of a short phrase or at a natural pause to reduce the unnecessary mechanical buzz.

Avoid turning the device on for each individual word or keeping it on for an entire conversation without a break. Short phrases are the easiest for conversational partners to understand.

Rate of speech: Slowing down how quickly you speak allows the listener to understand the message more easily. While you want your rate to remain natural, speaking too quickly can reduce your intelligibility.

Over-exaggerate your mouth movements: Move your mouth, teeth, tongue, and lips slightly more than you would usually when speaking. This will allow your speech to be more accurate. The more precise you can make your sounds, the more people will understand you.

Start with sounds like "p" or "b," focusing on

building up air pressure in your mouth to make the sound “pop.” Continue practicing with the “ch, t, f, and k” sounds, by themselves at first, and then include them in short words (i.e. “cat”) followed by short phrases (i.e. “Pet the pretty cat.”).

Practice: Using an electrolarynx takes lots and lots of practice!! Find a communication partner that is willing to practice with you. Establish a topic of conversation first, such as sports or family. Then, practice using the strategies above for the next 5 minutes using only your electrolarynx.

Your conversational partner should ask confirmatory questions (i.e. “I heard you say... is that correct?” or “I understand you are talking about.... Could you repeat that last word?”) to help the conversation progress. If you do not have someone else with you, read aloud: a book or magazine, the mail, or the closed captioning on your TV. As you get better at using the electrolarynx, increase the amount of time that you rely only on your electrolarynx to communicate.

If you have misplaced your ALD or just need a new one, you should obtain a prescription from your physician. Most insurance companies will cover a new device every 5 years, but you should always check with your insurance company.

Most states have assistance programs that can help you obtain a new device (some for free!) and more information about that can be found through the Telecommunications Equipment Distribution Program Association:

<http://tedpa.org>

While you are awaiting your new device, WebWhispers may be able to loan out an electrolarynx to members temporarily through the Loan Closet. This is usually on a 90-day basis. The Services section of our website gives additional details including an application for assistance, shipping, and tips on how to care for your loaner device:

<https://webwhispers.org/services/>

A variety of different artificial larynx devices are now available from different vendors. Several of these devices are described in further detail in the WebWhispers website under the Resources Section and “Talking Again.”

If you are shopping around for a new device, consider talking to your local SLP, support club members, or local laryngectomees who might be willing to demonstrate and let you try out one or several different devices.

Consider such things as how the device feels to hold in your hand to how it feels to manipulate the on/off and volume control buttons. These factors are different for every individual. Pay attention to the quality of the sound generated and remember that most devices may be adjusted to change the baseline pitch from one user to the next.

Possibly most importantly, if you have decided that your electrolarynx is still not for you, or you have an extra one to share, please consider donating it to the WebWhispers Loan Closet.

Alternatively, you may want to offer it to your local laryngectomee support group, SLP, or head and neck surgeon. All options serve the laryngectomee community and may give someone else the chance to speak again - a true gift.

Happy Practicing!!

Adapted from original August 2016 VoicePoints column by Jennifer Craig, M.S., CCC-SLP, Vanderbilt Voice Center, Nashville, Tennessee.

This Lary Life

KENYA Safari

W. C. Baker

Last month, we inadvertently published parts 1 & 2 of Wayne's adventures in Kenya. We didn't want to lose any of the impact of his narrative, so we're re-running it this month, with all new photos. Enjoy!

Masai Mara was exciting and disappointing all at the same time. Wildlife abounds, but so do tourists. Gone are the days when going on a 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 a 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 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. Usually, it was just us.

Herds of Wildebeest seemed to extend to the horizon. Herds of Zebra, though fewer in number were more impressive in their striped suits. The Wildebeests were rather raggedy. Ostrich loomed singly or in pairs. A variety of antelopes grazed as lions slept or strolled nonchalantly, none seeming to pay much attention to the others. 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-crunching gulps. I don't know if this is a daily event, but I know I would have preferred not to witness it. The unnecessary cruelty was, to me, outrageous, yet it seems that at least some in the crowd of witnesses were rapt. I cringe at the memory still, 25 years later. How many kids have been sacrificed in the name of tourist entertainment in those 25 years?

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, 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 anonymous victim. I was surprised at the size of what I was told was a cobra, entirely too close at 50 yards away. It is assumed that we are evolutionarily conditioned to fear snakes. They go back to Genesis and the Garden of Eden, for goodness' sake. It is not uncommon for that fear to rise to the petrifying level of ophidiophobia, but I stayed at the distinctly uncomfortable level, of being fearful but still functional.

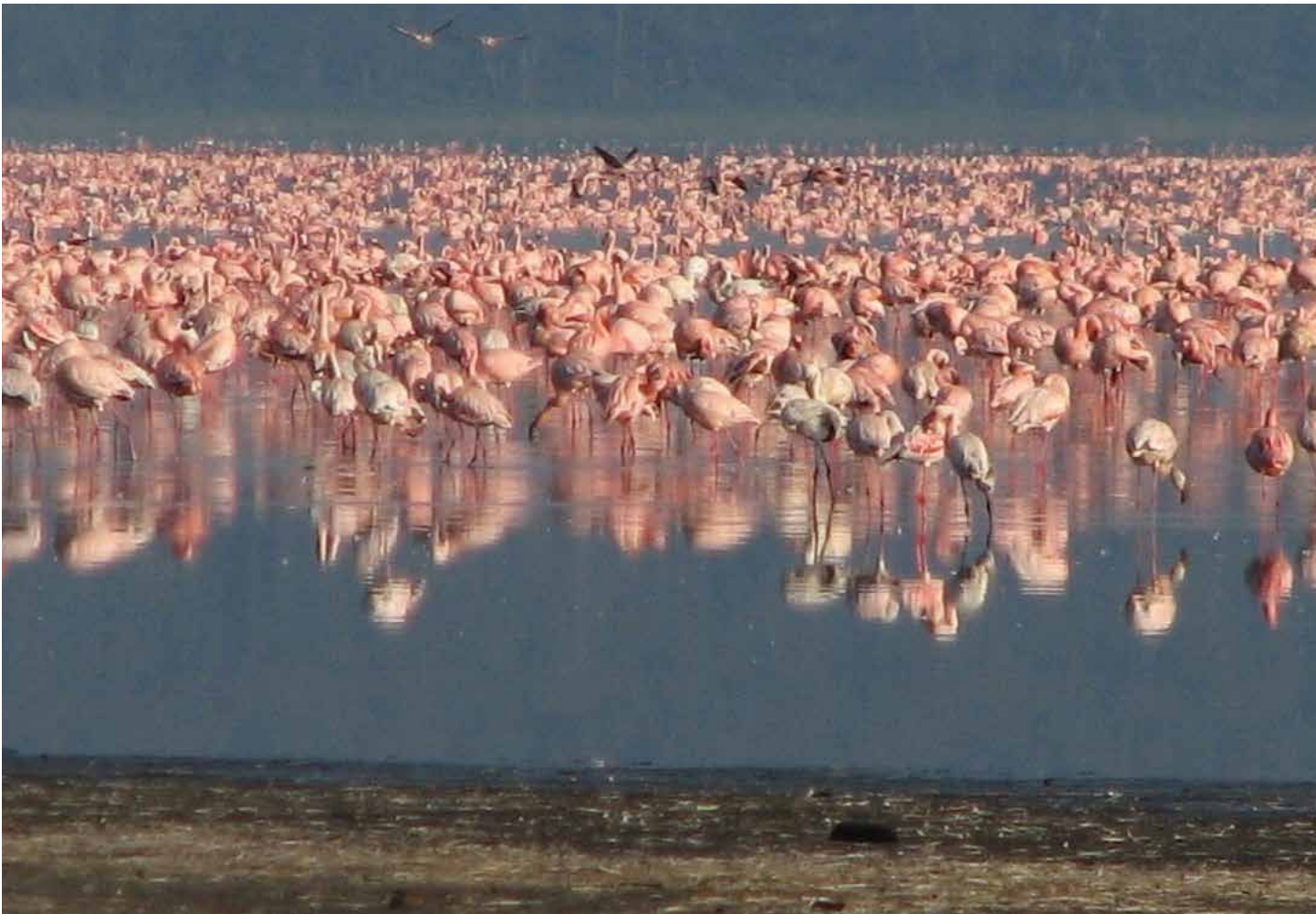
It was in Samburu that we met the Gerenuk the most appealing of all the many creatures we saw. It has the body and head of a deer but has a longer tail, long thin legs, and a long, graceful neck. The male has lyre-shaped horns rather than antlers and lacks the grace that is so evident in the female. Gerenuks stand on 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 unique experiences 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, that is until I realized there must be similarly inclined beasts on my side of the river.

Only once did we feel at all in danger in the course of our safari. Our driver had been inching the van closer to

a herd of elephants when we must have crossed some invisible line representing an invasion of their territory. A huge bull elephant stormed out of the herd and loomed trumpeting directly in front of us. Great ears spread like sails unfurled full to the wind, he swung his massive-tusked head with trunk swinging threatening to sweep us off of the road. There was no doubt about the message being conveyed. Our driver slowly backed the van while focusing intently on the elephant. It was as if this, the largest of all land animals, was chasing us out of Samburu and a day later out of Kenya.

All of our expectations were met, yes, even exceeded. The romance of the colonial period is long since passed but its memory remains palpable, filling all the senses and eliciting a sublime sense of satisfaction.





THE SILENT PARTNER

My First Year as a Laryngetomee

by Aaron Wayne

6. Food?

After the laryngectomy, I found out that eating pureed food was not really all that bad compared to not being able to eat or drink anything. While I was on the operating table, the doctors also installed a 'G-tube', a flexible clear plastic tube inserted directly through my skin into my stomach. About a foot or so stuck out and ended in a dual purpose valve arrangement where either an IV bag could feed into it or a large syringe could be inserted for self-feeding.

In the hospital, I had been fed using the hanging bag slowly dripping the formula into the g-tube. At home, I uncapped the other opening to the valve, inserted the syringe (without the plunger), poured in some water, and opened the valve. After the water, I poured in some Osmolite, which is sorta like Ensure, but without any flavoring.

I had been drinking Ensure before the operation and didn't really mind the taste, but I preferred using it to make malts with, it tasted way better that way. My diet in those days was seven eight ounce bottles of Osmolite, in four sittings: two at each mealtime and a 'snack' of one bottle in the evening, all washed down with about the same amount of water. It didn't have any flavorings because it was going directly into my stomach, so it didn't cross my taste buds. However, when I belched the first time after a 'meal', I found out what it tasted like – blech!

A daily ration of fifty-six ounces of Osmolite formula contains 1995 calories and every nutrient, vitamin, and mineral your body needs. In addition to that were all the medications I had to take. The meds were nearly all liquids, as was the pain killer I still took when needed. The few pills could be crushed and mixed with water or the potassium chloride solution before adding to the formula.

The syringe was five inches long, one inch wide and held two ounces at a time. Holding it in my

left hand, I poured water or formula into the tube, adding more as it drained into my stomach. During that time I would also add any meds that I was taking. The Osmolite was beige, the potassium chloride solution was yellow and the pain meds were red, so I looked a bit like a mad scientist as I added them while I was feeding. But not chewing anything and not talking led to a serious lack of muscle tone in my jaws, so that once I did start again on solid food, I had to start slowly or I'd get tired of chewing right quick.

Once the inside of my throat had healed enough to swallow comfortably, I cautiously began to sip some liquids, starting with water.

From water, on to fruit juices, etc. My goal was COFFEE! On a subsequent follow up visit, my doctor was fairly surprised that I reached that particular goal as quickly as I did. It didn't occur to me at the time to ask him if he ever even had coffee, because he wouldn't have been quite so surprised if he was anything like most of us are about our morning cuppa.



As I gradually phased in more solid foods, I missed my sense of smell even more. The sense of smell is actually about eighty percent of your 'sense of taste'. Without the ability to draw air through my nose, I lost nearly all of my sense of smell, and with it much of my ability to taste things. I love to cook, and without being able to take down a spice or herb from the cabinet and sniff at it, I'm never certain of how a dish is going to turn out.

I still have my taste buds of course – but they can only do so much. They can detect sweet, sour, bitter, salty, and umami, but they can't detect the subtleties that make the difference between good food and great food. I am gradually relearning how to cook, through trial and error. Mostly error, as I tend to over spice a little. I've always enjoyed spicy food, and that is one of the things I can still enjoy the taste of. The problem is that when I eat spicy food, my nose runs. So basically if it isn't ice cream and cookies I'm eating, it's a runny nose for me. And as you might have guessed, blowing my nose is no longer an option.

Months later, I notice that even though I still can't suck air up my nose, I'm getting better at detecting some stronger aromas, like the sauce for the pulled pork that I started in my slow cooker this morning. As I was phasing in real food, I was using the Osmolite less and less.

I started by having dinner, usually something I cooked, sometimes takeout, and only having formula in the morning and at lunch. After a few weeks, I only had the formula occasionally, usually at lunch. Eventually I only had the formula if I was eating alone, or too lazy to cook, or when my jaws were tired from chewing. Finally, after endlessly pestering my doctors, I got the g-tube removed. It had really started to be a pain to deal with, especially at night, when I had to wear a shirt that I could button a loop on the valve to, so it didn't catch on something and pull the stitches out that were holding it in

I still have three cases of the Osmolite, if anybody is really, really hungry and short on rations. One can always add flavoring like chocolate syrup, and it is a little better if refrigerated.



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