

Whispers on the Web

A Monthly Online Newsletter for WebWhispers

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From The Editor's Desk

Hello everyone,

Sometimes it's kind of hard to know where to start. The fact that we all breathe through a hole in our neck or love/work with/know/put up with someone who does (that pretty much covers everyone who's reading this, I think... let me know if I missed you!) does make us a unique community but we are NOT all the same. Should you presume to speak for us all you will be quickly be put in your place. For folks who have lost their [natural] voice we can be very outspoken!

Having made that very long caveat, I would like to say I am willing to bet that I am not the only one around these parts who has had their second shot and is feeling optimistic about getting out and about again. I, for one, am looking forward to a spontaneous mask-less hug to someone not in "my bubble"...hell...I want to hug my pharmacist for being so good about that problematic refill. I have discovered that even an introvert needs a jolt of humanity now and again. Actually, in my youth and BC (before cancer) I used to be an extrovert and I think I need to rediscover her. She was way more fun!

So, as I ponder all this I think ahead and we have an IAL/VI/AM (International Association of Laryngectomees/Voice Institute/Annual Meeting)yeah, that's why we abbreviate. I have a confession. The first time I heard about the IAL I thought it was a joke...seriously an international association of us?? And at the first IAL meeting I went to in Boston, Massachusetts in 2005 I was appalled at first by all the squawking, buzzing, coughing etc. Are these really my people? By the end of the conference I realized, yes, indeed, this is my tribe. We speak the same language, albeit with

different dialects. We share a history. It is not the same history but it is enough similar that we recognize the journey.

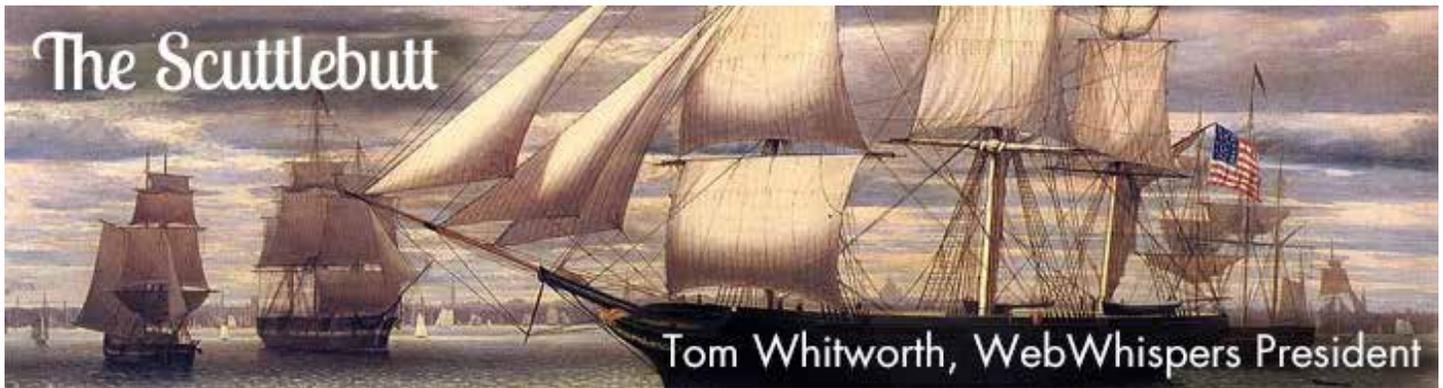
There is an IAL/VI coming up in late September in Charlotte, NC. I was hesitant about traveling. At this point I am more worried about the belligerence of some of my potential travelers than I am about the virus!

As more information about the program becomes available we will make it available here. In the meantime as we cautiously consider venturing out keep the dates of Sept 28-Oct 2 open.

And for now, be sure to check out all the great reading this month. Tom Whitworth, WW Pres gives a great overview of why we are the best resource for lary life. Plus wish list travel with WC, Philosophy with Doc Renfro (seriously, this guy should have a PhD in philosophy) and more from Aaron Wayne's book, "The Silent Partner". I had to include something from one of my favorite writers from the past, Noirin Sheahan about kindness. It's just such a lovely inspiring piece.

Stay well and safe and sane until we all meet again...

Donna McGary



Opened Eyes and Opened Minds

Twenty-five years ago, WebWhispers began as an internet-based source of support for laryngectomees. As far as I know we were the only online source at the time.

Beginning with an email group of ten people, what became WebWhispers had two hundred members by the end of its first year. Of course that all eventually led to the Webwhispers we know today with consistently over four thousand members. Soon there was the website and an online newsletter, now known as Whispers on the Web.

For most of us, as far as WebWhispers goes, everything we do is online. Rare exceptions are those in-person visits with one another at an IAL Meeting and Voice Institute or with other regional groups like the Texas Laryngectomy Association, California Laryngectomy Association and others. The pandemic has opened many of our eyes to opportunities and has opened our minds to a different way of doing what we do. Helping one another is the name of this game.

Many groups, large and small, operate mainly online now or remote participation is at least an available option. The past year has brought to many of us better access to the information and fellowship we need to stay on this road and out of the ditches alongside it.

My local group is Greater Atlanta Voice Masters & Talk of the Town. Look us up as Greater Atlanta Voice Masters on Facebook. Yes, we need to clean up our name and be one group or the other, but we have enjoyed some really good get-togethers that many did not have access to until our meetings were available online. I'm aware of other clubs and groups and have sat in on some of their online gatherings too (all good), though I am sure that many others exist.

The Peninsula Lost Cord Club, led by Tom Olsavicky

meets twice weekly! Two others that I am personally familiar with are the Phoenix group at Mayo Clinic, (David Kinhead is a member of that one) and The Montgomery County, MD club (best known as Herb Simon's Group). For information on that club, I would suggest reaching out to Joe Wasserman or Steve Cooper on Facebook. The others named are on Facebook, as well.

Using the WebWhispers Mail Digest or Facebook group, ask for information on a lary club available to you. In the case of many now, it can be located just about anywhere. Someone will undoubtedly reply, inviting you to participate in their club or group meetings.

Others have really picked up the pace with what they offer online, including the International Association of Laryngectomees Facebook page, InHealth Technologies, and Atos Medical. See the IAL Facebook page for information on their talk to the experts- style webinars.

ATOS Medical:

<https://www.atosmedical.us/support/total-laryngectomy/>

(Take a look here in particular at the "Resources", "Support", and "Get in Touch" tabs.)

InHealth Technologies:

<https://inhealth.com>

(See the tabs for "Education" and for "Resources.")

A wealth of information awaits you via the internet, including right here on WebWhispers.org.

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



Voice Points

Written by Professionals

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Total Laryngectomy vs Partial Laryngectomy: What to Expect After Surgery

Total Laryngectomy

A total Laryngectomy (TL) is a surgical procedure in which the aerodigestive tract is surgically altered separating the trachea from the esophagus due to invasive laryngeal and hypopharyngeal cancers. A total laryngectomy is complete removal of the larynx (voice box) which is the entrance to the airway and affects breathing and speaking. Once an individual has undergone a TL, the ability to speak will be gone. The nose and mouth will no longer perform the functions they once had which is to filter and warm the air that we inhale/exhale, because these structures are disconnected from the trachea. The individual will now have a hole in the neck called a stoma, which is the new pathway for breathing.

Impact on Voice and Voicing Options After TL

Because a TL is complete removal of the larynx, which removes the entirety of the vocal cords, the ability to speak naturally is gone; however, there are alaryngeal options to produce voice and communicate, including: tracheoesophageal puncture, electrolarynx device use, esophageal speech, and alternative and augmentative communication. The following is a brief overview of these various options.

TEP: TEP stands for tracheoesophageal puncture. This is a small hole, or fistula, that is surgically created through the common party wall of tissue between the trachea and the esophagus. This is performed during a TL as a “primary puncture”, or later on as a “secondary puncture.” A prosthesis fits into that opening to prevent food/liquid from going into the lungs. Upon inspiration, the patient will occlude the stoma to force exhaled air through to the esophagus where the tissues will vibrate and create sound. A TEP may or may not

be covered by your insurance and requires routine maintenance and replacement of the voice prosthesis on an ongoing basis.

Electrolarynx: An electrolarynx is a battery-operated device that produces sound to help create a voice. When the button is pushed on the device, it produces a vibration which is transferred from the skin to the mouth. Words are shaped with the articulators (lips, teeth, and mouth). The device can be placed in multiple areas to achieve alaryngeal voicing (cheek placement, neck placement, or inside the mouth using an adaptor).

Esophageal Speech: This method of speech uses the esophagus as a source of sound for speech, which involves trapping small amounts of air into the esophagus and allowing that air back up and out the mouth. The vibratory source for sound is, as in the TEP, the esophagus. This method requires no external devices or equipment; in many cases it does involve a significant amount of practice to achieve mastery

AAC: This stands for alternative and augmentative communication. Persons with TL may prefer to use high tech communication devices (text to speech apps, and boogie boards), or low-tech communication (white boards, communication boards).

Swallowing After TL

Prior to TL surgery, there is an extreme likelihood that a person may have had decreased airway protection from the invasive laryngeal cancer, thus resulting in dysphagia (difficulty swallowing). Immediately after a TL, the patient will not be able to eat by mouth for a couple of weeks, depending on the surgeon’s recommendations. The patient will likely have a PEG tube for alternate means of nutrition after surgery. Most of the time, swallow function will improve and the patient will be able to eat and drink. Swallowing difficulty is more likely if the patient has had previous

chemoradiation of the head and neck, TEP malfunctions (leaking TEP), or esophageal disruptions.

Partial Laryngectomy

A partial laryngectomy is partial removal of the larynx due to cancer and is usually done if cancer or a lesion is found at an earlier stage. There are multiple different types of partial laryngectomies, which change the patient's anatomy/physiology in a variety of ways. This can subsequently affect voicing and swallowing in different ways depending on the surgery. Recurrence of cancer is possible with this type of surgery.

Types of Partial Laryngectomies

- Cordectomy: Removal of the vocal cords.
- Frontolateral Laryngectomy: Cutting of the vocal cords, and the front third of the arytenoid cartilage.
- Hemilaryngectomy: Removal of the vocal cords, thyroid wing, and arytenoid cartilage.
- Supraglottic laryngectomy: Removal of the structures between the glottis and base of tongue (above the vocal cords).
- Cricohyoid epiglottopexy (reconstructive surgery): Removal of the vocal cords, thyroid cartilage, and optionally the epiglottis.
- "Three quarters" laryngectomy (near-total): hemilaryngectomy and supraglottic laryngectomy.

Voicing after Partial Laryngectomy

A partial laryngectomy surgery to remove near, part, or all of the vocal cords may have an impact of voicing. Vocal function will be altered depending on the type of surgery. If the patient has a supraglottic laryngectomy (above the vocal cords), voicing will likely be unchanged because the vocal cords are not damaged. With cordectomy, frontolateral laryngectomy, and hemilaryngectomy the voice is usually weak/breathy and may require alternative means of communication (such as AAC devices discussed above), because there has been partial removal of the vocal cords.

Swallowing after Partial Laryngectomy

The larynx plays a major part in swallowing function. Prior to a laryngectomy, the airway and upper digestive tract are connected. During the swallowing, the airway is protected by larynx as it elevates and the vocal cords close, and food and liquid are then

directed down the esophagus toward the stomach. Partial laryngectomy may impact swallowing function, since the larynx is being anatomically altered, thus decreasing airway protection. Depending on the type of partial laryngectomy, swallowing function will vary from patient to patient. A patient with a partial laryngectomy may need to consider a modified diet or alternate means of nutrition/hydration/medication, such as via a PEG tube.

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Lacey Trevisani, MS, CF-SLP is the current clinical fellow at Tampa General Hospital with an area of special interest in the evaluation and treatment of patients with head and neck cancer with a focus on alaryngeal voice restoration following total laryngectomy and dysphagia management. Lacey completed her undergraduate degree at the University of Florida majoring in Communication Sciences and Disorders and completed her graduate degree at The University of South Florida in Speech-language Pathology. After completion of the clinical fellowship year, Lacey hopes to attain a position as a certified Speech-language Pathologist within the acute care setting with a continued focus in the area of head/neck cancer.

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For Further Reference:

<https://webwhispers.org/resource/talking-again/>

<https://webwhispers.org/resource/free-for-the-asking/#toc-5>

www.atosmedical.com "Laryngectomy Care/Photos-Manufacturer of Provox System."

[https://inhealth.com/media/documents/pdf/LT_ANATOMICAL_AID-B_ENG_WEB\(1\).pdf](https://inhealth.com/media/documents/pdf/LT_ANATOMICAL_AID-B_ENG_WEB(1).pdf)



Celebrate the Victories

By Don Renfro

"I am not a victim. No matter what I have been through, I'm still here. I have a history of victory." — Steve Maraboli

A history of victory... that can be something difficult to conceptualize. So many people, including me, find it much easier to remember their failures and forget their triumphs. Sometimes being a person with a laryngectomy can feel a lot like one of life's failures rather than one of life's victories.

I am not talking about when all is going well, and it is working as it should. I am referring to when I am fighting that fistula that just will not close and losing what I eat and drink down the front of me and sometimes into my stoma. I am talking about when I am eating, and food gets stuck in my throat and all the gagging I can muster will not unstick it. I am talking about when the TEP stops working or begins leaking and it will be a week before I can see the SLP.

Reality check, I am still here. The problems I have described above are just a small sample of what a person with a laryngectomy can experience. I have heard of far worse problems than what I have experienced and people coming back from them and having very fulfilling lives after the problems had become part of their history. The truth is for me all my problems have been temporary, kind of "speed bumps" in my road of life.

Given that none of these problems are what I am dealing with today, right now, I am provided the opportunity to experience my personal history of victory!

Victory is to be celebrated. When a hockey team wins the Stanley Cup, or when a football team wins a Super Bowl or if a Baseball team wins the World Series the entire city stops to celebrate with a parade to commemorate the victory.

No one is going to stop and throw me a parade because I made it through an entire meal without any food getting stuck in my throat but when I begin to feel like a victim of a laryngectomy,

I can remember all I have been through to get where I am now and feel extremely fortunate for my history of victories.

I have read on the Lary's Voice Facebook about many different people either in the group or entering the group. People that have had a laryngectomy for 20+ years to people that are scheduled to have their surgery next month. All of them have one thing in common. They all have a story. And for most, if not all that story is a story of victory over what could be described as a catastrophic situation.

I describe it as such a devastating circumstance because for many, a day came when breathing was interrupted. And even though not everyone may have experienced such an event, still the day a person hears the words "you have cancer" is a time of extreme devastation, at least for me.

When I heard those words I could not fathom that I would be sitting here almost four years later writing how I experienced victory over a situation I believed at the time, I may not survive.

Today I am surrounded by victory. In this group and others like it I have had the privilege to meet people that have made victory a way of life.

People that sing, swim, ride motorcycles, hike, ride bicycles (that is mine), do public speaking, work. In short people that refuse to live life anything short of victory.

It is nice to know of so many possibilities today. When I first became aware that I now had a laryngectomy and what that meant, I could only think of what I could not do. I was unable to see a life of so many possibilities.

I am so proud and feel privileged to be part of this group. I wear the hole in my neck like a badge of honor. After all I am not a victim. I am still here. I have a history of victory shared with a group of people that truly know and understand what I have been through to have victory in my life today.



This Lary Life

ETHIOPIA 1996

W. C. Baker

For all of its historical and religious significance, Axum is not a very imposing place, but that historical significance goes back something like 3000 years. Tradition has it that the Queen of Sheba ruled the Axumite empire from here. It was from here that she took a stream of camels loaded with spices, gold and jewels to visit King Solomon. It is the place to which their son Menelik allegedly brought the Ark of the Covenant. When Yahweh gave Moses the ten commandments on Mt. Sinai it was likely that they would be intended to reside in a bit more grandeur than the Chapel of the Tablet, a decidedly humble structure adjacent to the Church of modernistic Our Lady of Zion. Edward Ullendorff, a professor at the University of London's School of Oriental and African Studies, during WWII found that the Chapel of the Tablet does indeed contain a wooden box, but no tablets. Still, it is an important pilgrimage site. More impressive to this agnostic are the Stelae, said to mark grave sites of ancient kings and nobles. They differ from obelisks only in that they are not topped by pyramids. The longest at 94 feet is one of five fallen giants. The tallest standing stele at 69 feet leans just enough to be a bit unsettling.

The bus struggled a bit to the 8,600-foot elevation of the town of Lalibela. To call it a town might be an overstatement. With approximately 9,000 inhabitants, Lalibela has no electricity, no pharmacy, not even a fuel station. What it does have is 11 churches hewn into and from the rock. Unlike Petra where the buildings are carved laterally into the cliff face, at Lalibela churches were carved vertically down into the rock. With tunnels and narrow paths connecting the churches, there is a sense of mystery pervading the site. The services at St. George were very much like those in Eritrea. Wrapped in white, men sang and did a sort of shuffle dance with occasional bursts of more enthusiastic steps. Men and women sang, women ululated and the drums kept a steady beat. Aside from the marvel of the churches, Lalibela is quite a beautiful place in its own right. The

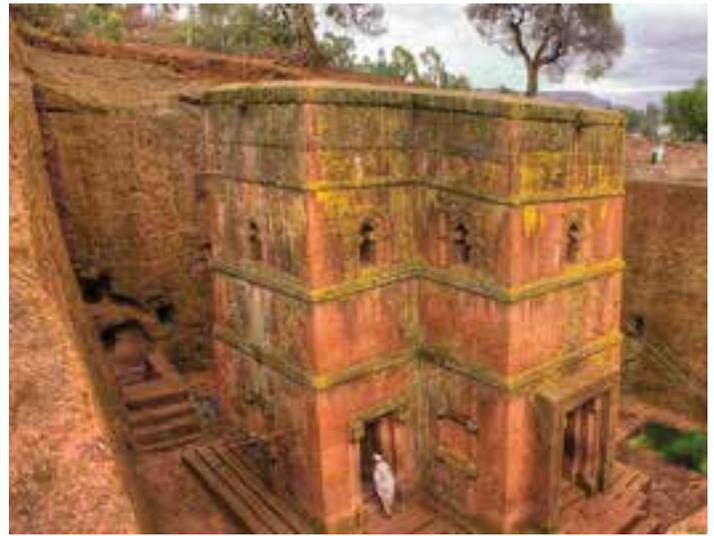
mountain setting is spectacular and the town is replete with unique stone houses. Many are round, two story structures, with a stairway outside, unlike anything that I've seen anywhere. In a word, that my grandson overuses, Lalibela is awesome.

The night before leaving Eritrea we had joined in a wedding party at our hotel. A week later when we arrived in Gondar, we found ourselves in the midst of a wedding celebration. The street was filled with white robed, red sashed women, white clad men on horses blowing tin horns, a drummer leading a procession, men in green tunics doing the boogie line dance thing and a lot of people just being joyous, dancing, yelling, or was it cheering, and ululating. Much more exuberant than the Eritrea wedding. Here we were observers, not participants, but caught up in the spirit of the occasion nonetheless.

Gondar, "the Camelot of Ethiopia", served as the capital for the Ethiopian Empire in the 17th century. For centuries before, the emperors of Ethiopia had no permanent capital. Rather, they moved from place to place with the entire royal retinue that included their court, a military force and religious leaders, as well as the hordes of domestic workers and prostitutes. It was not an honor to host because they pretty much laid waste to the area in which they stayed, exhausting natural resources, crops and people before moving on. Hoping to establish some stability, Fasil settled the capital in Gondar in 1632. It remained the capital for 250 years. His castle, an interesting combination of Portuguese and Nubian architecture, dominates the walled area that was the seat of government. At that time Gondar might have been on the north shore of Lake Tana which was larger in the past. It was in Gondar that Mussolini's army fought and lost its last battle in Africa, upholding Ethiopia's claim to never having been colonized.

Lake Tana in the Simien Mts is a shallow body, at a maximum only 50 feet deep depending on rainfall. It is the home of millions of fish, thousands of birds,

hundreds of hippos and about 15 inhabited islands. Portuguese missionaries established monasteries on those inhabited islands, on one of which the Virgin Mary allegedly stayed on her journey back from Egypt. If so, she took the long way home. Several of the churches on Lake Tana are round stone and wood structures, with thatched roofs. All of them are richly decorated inside.

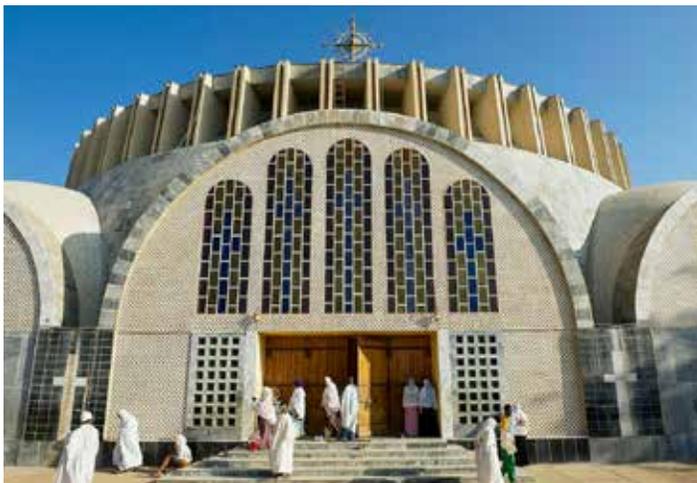


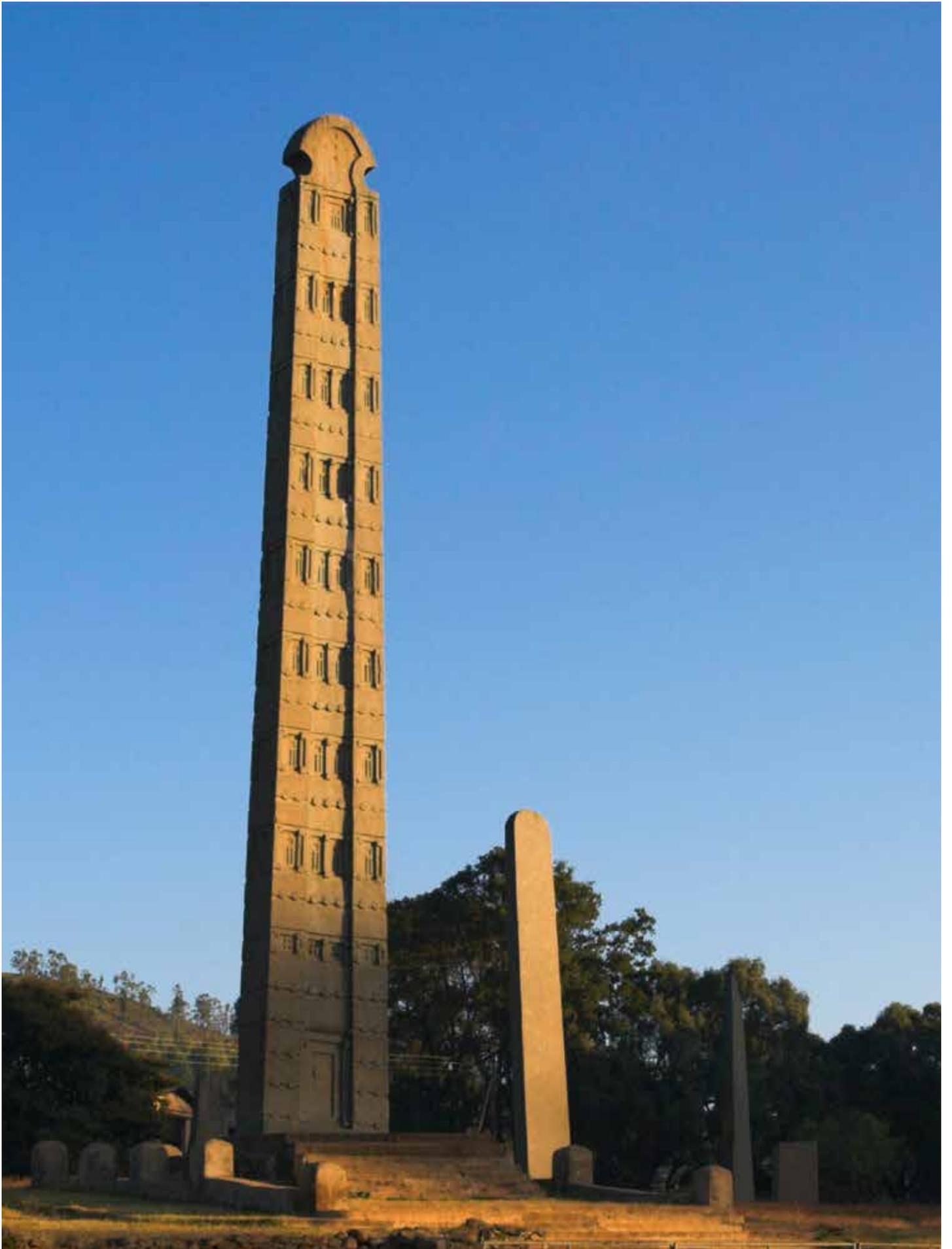
Lake Victoria in Uganda is more well-known than Lake Tana, and, though I haven't seen them, the Victoria falls are indisputably more impressive than the falls from lake Tana which I found quite impressive. Victoria is lauded as the source of the Nile. It should be considered a source. There are, in fact dozens of rivers feeding into the Nile along with Lake Victoria, but it is the Lake Tana that provides 85% of the Nile's flow beginning its journey at the Blue Nile falls. The floods of the Nile Valley that gave rise to the Egyptian civilization and have sustained it for millennia could not have made their soil-nourishing surges without the seasonal rains in the Ethiopian highlands.



Sadly, witnesses and survivors claim that in November of 2020 "720-800" people who took refuge in Axum's, Our Lady of Zion, were massacred by an Eritrean militia. Eritrea denies it, but there has been something of a civil war going on since the Tigrinya dominated government of Ethiopia was ousted in 2018 after a quarter century of repression.

The new government established a Progressive Party that Tigray chose not to join. Tigray later attacked an Ethiopian military outpost and the war has been going on since. I don't understand how or why Eritrea is involved. Eritrean militia are reportedly suspected by locals to have been seeking to take the Ark of the Covenant. The last report on the war that I've been able to find is from April 1, 2021.







THE SILENT PARTNER

My First Year as a Laryngetomee

by Aaron Wayne

4. TERROR AND OTHER EMOTIONS

(I have no larynx and I must scream!)

The big operation to remove my larynx and who knew what else was finally scheduled for October 21st. Leading up to that were alternating bouts of anticipation and sheer terror for me. I really did want to get it over with so that I could get on with my life and my eventual recovery. But the terror, the horror of not knowing exactly what the surgery would entail, and how well and how soon I would recover were always on my mind. The doctors, my primary surgeon included, did not know for certain how far they would have to go beyond just the laryngectomy. If they found more cancer, it would have to be removed. If they removed too much, my esophagus would have to be rebuilt. Some of the glands in my neck would need to be removed, but how many? The official estimate for the time involved with the surgery, further examination for additional cancer, and closing was seven and one half hours. It could take less time or it could be quite a bit longer. While I waited, life kinda went on.

I was only able to eat pureed food, and most liquids, including water, had to be thickened. I've always thought of myself as being a bit of an epicure, so this wasn't all bad – I could still have lobster bisque. Thickened water was another matter, however. The stuff that they fed me in the hospital usually tasted OK, but pureed pasta is NOT al dente. Since I am a pretty good cook, I was looking forward to trying out some experiments in the kitchen as soon as I got home. I reasoned that Chicken Marsala should be the first at home meal because it could be pureed, served over thin mashed potatoes, and would still taste the same. After that resounding success, my spirits were lifted and I proceeded to try more ideas in the kitchen.

Going out to eat was also a challenge. I always had a note pad and pen so I could make my needs known to the waitstaff. The first family dinner was at BJ's where I ordered the chili, which they obligingly put through the blender for me. Next was my favorite Mexican place, Casa Gamino: pureed albondigas soup. It was good, but I rather missed chewing the meatballs. There were some things I didn't bother with, like shrimp. Lobster bisque is one thing, but I draw the line at pureed shrimp.

Breakfasts were easy. I had a lot of choices: oatmeal, cream of wheat cereal, soft scrambled eggs, to mention a few. Toast can't be pureed. Lunch was split pea soup or some kind of chowder, etc. Dinners almost always included mashed potatoes with gravy or some kind of sauce. Dessert was easy – ice cream. Vanilla ice cream, chocolate ice cream, strawberry ice cream, sorbets... By the way, don't try to puree rocky road ice cream.

I could still talk a little bit when I pressed on my HME and I could still walk despite my weakened condition, so I went for one last walk in the Malibu mountains with my buddy Randy. Our favorite place is several hundred feet above sea level, on a grassy knoll under the canopy of a large old oak tree. It's about a quarter-mile stroll from the paved road to the area. It was a typically gorgeous fall day. I could still smell, as I was still breathing partly through my nose, and I remember the aroma of the trees and the faint ocean breezes. The walk in tired me out, but after setting up our little base camp and taking ten in one of the lawn chairs we had carried in, I was fine. As usual we drank beer and played card and dice games between short walks around the area admiring the views, such as the top of Catalina Island jutting out of the ocean, the surf along the coast below, and the beautiful blue Pacific sprawled out between them. Mentally I felt completely revitalized. But sadly, that day had to end and I was running out of physical energy. The walk back to our vehicles was when I hit the wall. Since I was carrying one of the lawn chairs, I simply set it up in the middle of the dirt fire road and sat down. I took out my little oxygen meter and checked my level: not dangerously low, but understandably not as high as I would have liked. Randy was quite concerned and said so. I assured him that if I had a few minutes rest, he would not have to carry me out.

Since we were only two or three hundred yards away from the cars, Randy took his load down the rest of the way and came back for me and my stuff. I was totaled by the time I got home and got unpacked, but I was truly glad that we were able to make that day happen.



From the Archives



Dear Lary

Kindness

Dear Lary,

I suppose I was a reasonably kind person before you came into my life, but maybe I was too confident in my own abilities to notice how much I needed kindness, and how to accept it graciously. Then came those awful scary days, weeks, months after we first got hitched (I suppose we are hitched now, aren't we – for better or worse, for richer or poorer, as long as we both shall live?) when I was learning that my body just isn't reliable. It's not even mine anymore. I have to share it with you, Lary dear, and learn to talk and breathe and swallow and move my neck and arms just as you want me to. It's quite scary, having a stranger move in to live in your body. I didn't feel like 'me' anymore.

I remember the first time a nurse showed me how to clean my stoma. I felt revolted – this horrible new dark hole in my neck – surely she couldn't expect me to look after it? But gradually I learned to live with you. You slowed me down in so many ways, but that's not always a bad thing. Where before I could zip through a shower and gobble up my dinner, now I have to take time and care with everything, be patient and gentle with my body. And I soon got to like cleaning the stoma. I suppose it represented you, Lary, and it felt good to be looking after you. It gave me a new role in life. I was now someone who looked after a laryngectomee.

So you taught me to be kinder to myself. How good that can feel! And then of course I needed so much care from others during those first weeks and months. I could take this from doctors and nurses easier than from my friends and family. Before you came along, I was the person who did the 'looking after'. I was strong, capable, independent, usually cheerful and chatty. Now, with you lodged in my body, I was frail, vulnerable, needy. And of course, mute. All these changes added up, in my mind, to being totally inadequate. What could I offer anyone?

I wanted to be the one giving kindness, not receiving it.

I dreaded visiting hours. Tense and anxious, I tried to calm myself, to feel my breath going in and out, my feet on the ground, remind myself that I didn't have to 'perform' for whatever friend was coming in. Of course, mindfully acknowledging the anxiety, the sensations, the tension round my face and neck; letting them be, not adding to the misery by judging myself for having such irrational anxiety. And then, when my visitors actually appeared in front of me, the tension eased. I smiled, genuinely happy to see them. Often we hugged each other for long minutes, saying nothing, as I let their strength and energy flow into me. I was learning to receive kindness.

Each visit lifted my spirits. But next day I would be back to dreading visiting hours again. It's strange how much confidence I lost along with my voice; how hard it was for me to trust in the goodness of

others when I felt so inadequate.

Things are easier for me now that I've had over a year to accommodate to you, Lary. I can speak with an electrolarynx; I can live independently. But I am different. I'm no longer the same Noirin. I'm Noirin and Lary. Some people (only a few) can't seem to see Noirin, they only see Lary. They look away, or mouth their words instead of speaking normally, in some sort of confusion. Are they dismayed, not knowing how to deal with me? Or maybe disgusted or frightened? Or perhaps overwhelmed by some sort of shocked sympathy? I suppose deep down, Lary, you may spark the fearful thought "perhaps this could happen to me". I can't blame them for their negativity and confusion, after all you frightened and confused me for months after you first arrived.

But others, especially children, see both of us and aren't frightened of you, Lary. Just yesterday I went out for a walk with my friend's dog, Spike. We met three children and they wanted to pet Spike, and then got fascinated by my voice and electrolarynx. "What's that? Why do you talk like that? Can I have a go?" We had great fun as they all tried the electrolarynx, delighted to be able to speak like

robots! They wanted to know why I couldn't talk normally and I explained about cancer and losing my voice. They just took it in, no big deal. Their simple acceptance felt like kindness.

Children, with their innocence and curiosity can enjoy both me and Lary. But some adults don't seem to see you at all, Lary. They just carry on with whatever business we have to do together and make no comment. That's another form of kindness. Others ask about my voice and I appreciate that. Our interaction becomes more personal. Sometimes they then tell me about a relative or friend who has cancer. So we make a deeper connection and remember each other long after our business is done.

You gave me my speech and swallowing handicaps, Lary, my stoma and my stiff neck and shoulders. I don't like it; I'd love to have my old voice back and enjoy a meal as before. I'd love to be able to relax in a bath and stretch my arms. I wish I could peel this duct tape feeling from my neck. But I have to admit that living with you has softened my heart quite a bit. And that is worth more than fluent speech and all the other pleasures of a healthy body. All in all, Lary, you've added more to life than you have taken away.



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