Whispers on the Web

A Monthly Online Newsletter for WebWhispers

Contents

Dear Friends,

Almost a year and-a-half ago, SLPs from around our community gave their insights into how to ease the burden of these trying times. In many parts, the burden of this pandemic is not over: we are now once again dealing with masks and face shields and gowns, isolation, and social distancing. How good it is to continue to have a community such as WebWhispers to provide a bit of support, encouragement, and even diversion through it all. This issue has some of all of that.

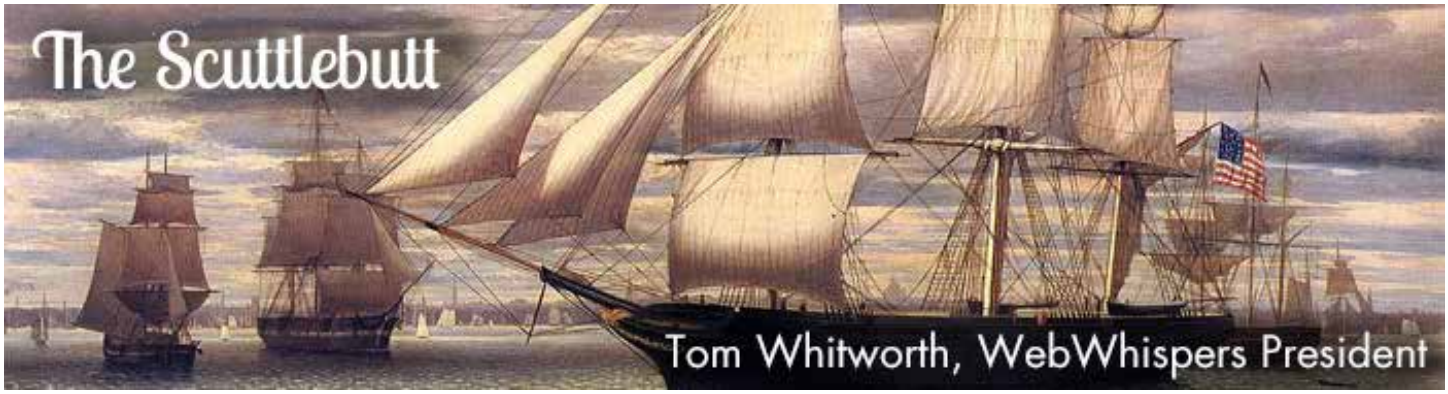
My Neck of the Woods returns to remind us that although this life is not always fair, gratitude is always there for the asking. For those seeking an exotic armchair adventure, *This Lary Life* takes us all the way to Egypt, the roundabout way. And in an adventure closer to home but no less unique, Aaron shares his insights which are surprisingly relatable in *My First Rodeo*.

In *VoicePoints*, we continue to focus on troubleshooting voice prostheses by looking at some of the WHYS of a leaking prosthesis. If this applies to you, please consider the suggestions provided, and never hesitate to have a frank conversation (or two) with your medical providers about strategies to combat increased reflux, heartburn, biofilm, or dysphagia as discussed.

Above all, remember that the #1 suggestion for easing the burden of trying times: do not go at it alone. Connect with others: text or call a family member or friend, email a co-worker, take a walk with a neighbor. Reach out to us here at WebWhispers. I am grateful for everyone who is a part of this community, and I want to hear your stories of courage and determination! Feedback on this newsletter and suggestions for future features are always welcome. Don't forget that we are accessible through the WW daily digest, Facebook pages, or email.

Until then, stay safe and remain in touch!

Kim



The Day I Heard the News

It's interesting how so many dates get a permanent place in my head, dates I never thought I would have to hear about or deal with. These are the dates on my laryngectomee calendar. They seem to announce themselves in advance, saying things like "remember me, the day from eight years ago next Wednesday?". One of these is coming up soon. It actually is from eight years ago, Friday September 3, 2021. In 2013, the third of September was actually the Tuesday following Labor Day. Other etched-in dates are the days I began chemotherapy and radiation, the day each treatment ended, and the day I learned my chemo and radiation had failed and that I needed surgery as soon as they could get me into an OR.

I also remember the day I had to ask for rides to the hospital because I had begun wearing a Fentanyl patch for the horrible pain I was in. (More about drugs later) On September 3, 2013, the Tuesday following Labor Day, I learned I had cancer.

I had frequent ear, nose , and throat trouble off and on for years, so my voice struggling temporarily from time to time was not something new to me. But this was something different. Following several months of noticeable vocal strain, though off and on, I saw the doctor in August of 2012 with symptoms.

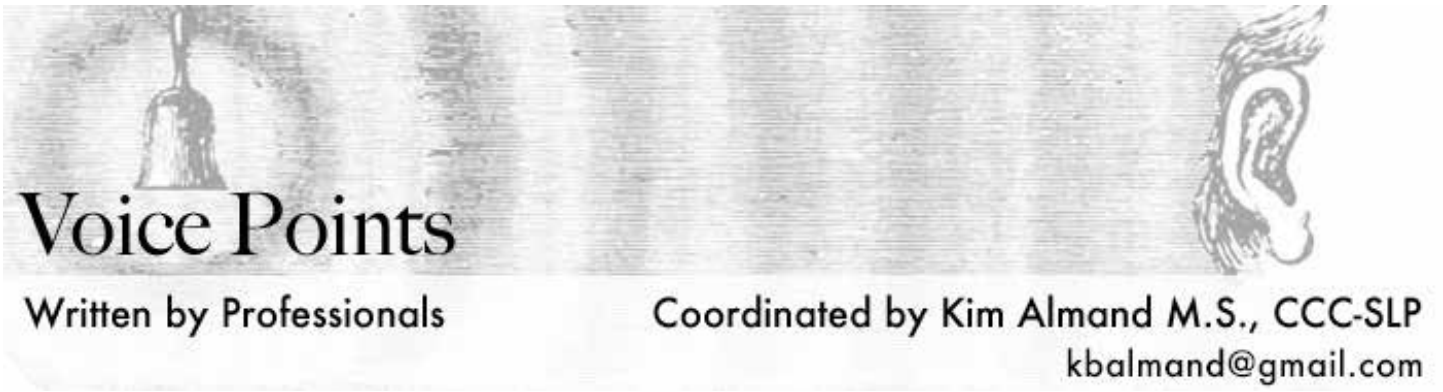
Between then and September 3, 2013, I would be seen in that same office five times, at least. I would see another doctor, either of two great nurse practitioners, or my regular doctor. Inevitably, they would look to see what prescription I had been given on the last visit and usually re-prescribe it. There was always an antibiotic. I kept saying that I could not have an infection because I had no pain or very rarely, and I had no fever. The only real problem was the sporadically struggling voice, an issue that was becoming more and more frequent and worsening. Okay, it was awful and I knew that but I would have a "good" day now and then. My primary physician in this practice had been my doctor for about twenty years so I had no reason to lack trust in these people. He mentioned on one of the visits that if the symptoms didn't go away he was thinking about having me see an ENT because there could be something more serious going on. Of course, I'm thinking, I sang too much for too long and maybe I had a vocal cord issue. (Yeah, right?) My choir director sounded similarly when she was treated for inflamed vocal cords. I remember she could not speak for a week or two- at all, following some kind of procedure-doctor's orders. That was actually sort of funny as she greatly enjoyed giving directions and instructions. Being able to tell others what to do might have been her greatest source of pleasure. (Aren't I nice?)

I had the strangest feeling when I heard the news. Though I despise this expression, my attitude was something like "it is what it is". Almost instantly something came over me, a feeling I had never known before. As I boarded the elevator, I realized that being afraid of this would be the end of me. I knew I was right on that and that I could not let that happen.

Living in fear of my condition would have me constantly under extreme stress, which I was soon told I had to avoid totally. Months later, I was asked in a conference room with about a dozen people "were you afraid?". Without the slightest hesitation I firmly said "no, I was never afraid. I was too afraid of being afraid. I knew that I would not be able to handle that. Fear would kill me."

To be continued in our September issue.

Enjoy, laugh, and learn,
Tom Whitworth
WebWhispers President



Three Causes of Tracheoesophageal Voice Prosthesis Leakage

Like all valves, a tracheoesophageal voice prosthesis (TEP) breaks down with time, requiring replacement. But what causes that breakdown? And why do certain individuals require TEP changes more frequently than others? Below, you'll find information about 3 main causes of TEP breakdown leading to leakage. Always remember—if you are experiencing early TEP leakage, it is important to talk to your doctor and SLP to determine the cause of leakage and to help with the management.

1) Reflux

A large percentage of laryngectomees have been found to have reflux. Gastroesophageal reflux disease, or 'GERD' for short, occurs when stomach acid comes back up into the esophagus. Laryngopharyngeal reflux, 'LPR' or gastropharyngeal reflux, 'GPR' are names for refluxed contents that come up through the esophagus and into the throat. Reflux often contributes to early valve breakdown which may result in leakage through the TEP. It may also lead to tracheoesophageal puncture tissue changes, such as enlargement of the tract or granulation tissue, possibly leading to leakage around the prosthesis. There are various proposed reasons for the higher incidence of reflux in laryngectomees. One cause may be post-surgical changes related to the cutting of the upper esophageal sphincter, which is often a routine part of the laryngectomy surgery. A second possible cause is xerostomia, or dry mouth, which interferes with the reflux barrier resulting in prolonged acid exposure to the esophagus (Smit et al., 1998). Signs and symptoms of reflux may include regurgitation of acid or food; bad breath, changes in swallowing such as food sticking or pain, and frequent belching. There may or may not be a burning sensation in the chest or throat. Behavioral techniques to reduce reflux include the following: eat smaller more frequent meals; elevate the head of the bed 6-8 inches; stay upright during and at least an hour after meals; avoid eating three hours before bed, and avoid tight clothing and bending at the waist. Cutting back on foods such as coffee, tea, peppermint, chocolate, citrus fruits and juices, spicy and acidic foods, fried and fatty foods, and alcohol may also be beneficial. Talk to your doctor if you feel you have reflux to discuss medical management options.

2) Biofilm

Tracheoesophageal voice prostheses are typically made of medical-grade silicone due to its flexibility as well as its mechanical properties. Unfortunately, silicone tends to become colonized quickly by micro-organisms (Talpaert et al., 2015). This, in conjunction with the humidity and temperature of the esophagus, results in an ideal environment for biofilm to grow. A common site for biofilm growth is on the valve of the voice prosthesis. This may result in early breakdown of the valve causing leakage through the prosthesis and the need for more frequent prosthesis changes. Formulation of biofilm on the valve may also lead to increased airflow resistance making it harder to speak. Controlling the growth of biofilm is critical in extending the life of the prosthesis and thus in maintaining a healthy tracheoesophageal puncture and healthy lung tissue. Yeast most identified within the biofilm include species of candida;

however, studies have shown that there are many types of micro-organisms found growing on voice prostheses, including various types of bacteria. Therefore, we use the term 'biofilm' rather than 'yeast'. In most prostheses cultured, a mixture of yeast and bacteria is found. The types of biofilm that colonize on the prosthesis are often due to lifestyle and diet. Research has been and continues to be conducted on ways to prevent or reduce biofilm including modifying the surface of the prosthesis, using probiotics or antifungals prophylactically, and use of artificial saliva. Maintaining good oral care along with the use of proper prosthesis cleaning techniques, including brush and flush, may also reduce the risk of biofilm.

3) Dysphagia--Difficulty Swallowing

It is difficult to pinpoint the incidence of dysphagia, or swallowing difficulty, in the laryngectomee population. According to research, dysphagia impacts somewhere between 17% (Balfe et al., 1982) and 70% (Maclean, Cotton, & Perry, 2008) of all laryngectomees. Per Maclean et al., this discrepancy in incidence may be due to varying definitions in the severity of dysphagia.

A total laryngectomy surgery drastically changes the overall physiology of the swallow. During the surgery, the larynx and hyoid bone, which previously contributed to upper esophageal sphincter opening, are removed. The trachea and esophagus are separated from one another. The pharynx and esophagus, which were previously attached to the trachea, must be surgically closed and reconstructed. Depending on the extent of the surgery, other structures—including the tongue, base of tongue, pharynx, or esophagus—may also be surgically altered or removed. Tissue from other parts of the body may even be required for reconstruction. Furthermore, radiation therapy can cause additional tissue damage and lead to radiation fibrosis.

While there are many causes for dysphagia, dysphagia can impact tracheoesophageal voice in two primary scenarios: when there is reduced swallow pressure and when there is elevated swallow pressure.

Reduced swallow pressure: Esophageal dysmotility is the primary culprit for reduced swallow pressure. Normally when a person swallows, the muscles of the pharynx and esophagus contract and "squeeze" the food or liquid down the food tube. These contractions must have adequate force and must be synchronized moving from high to low to be effective. Esophageal dysmotility occurs if the contractions are not strong enough, are absent, or are not synchronized properly. This can leave food or liquid residue in the pharynx or esophagus, often leading to a water or "gurgly" TEP voice during or after meals. Per Soolsma et. al., low esophageal pressure can even cause the valve of the prosthesis to "open inadvertently or close insufficiently… during deep inhalation or swallowing," leading to prosthesis leakage.

Elevated swallow pressure: Elevated swallow pressure can occur if something impedes the flow of food or liquid moving through the neopharynx or esophagus. Think of a garden hose: If you put your finger in front of the spout to impede the flow, pressure in the hose increases. An increase in esophageal pressure can cause the TEP valve to leak more quickly, as the valve has to withstand higher pressure during the swallow. Causes of elevated swallow pressure include stricture, pharyngoesophageal spasm, or external compression on the esophagus (e.g., osteophytes).

It is always important to pay attention to your swallow function and report any changes to your MD and SLP. Changes may include food or liquid feeling "stuck" in the throat; having to swallow multiple times per bite of food or sip of liquid; wet or "gurgly" TEP voice during or after meals; having to chew foods thoroughly or wash food down with a sip of liquid; and/or having to avoid hard/dry/sticky foods.

Adapted from 2017 VoicePoints article by Preston Felty Pugh, M.Ed., CCC-SLP and Jennifer Hagen, M.Ed., CCC-SLP

References available upon request

What I Need

By Don Renfro

"Fairness does not mean everyone gets the same. Fairness means everyone gets what they need."
~Rick Riordan

As I have said in the past, I spent my career working for the Department of Rehabilitation (DR) for the state of California. We worked with people with disabilities to maintain or obtain employment. Somewhere during my career, I heard an explanation for why it was alright to provide "reasonable accommodations" to students with learning disabilities.

A reasonable accommodation is defined as "necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms".

At the department we worked with many school districts that had populations of students with learning disabilities. The schools were resistant to provide "reasonable accommodations" to the students with learning disabilities citing that if they provided the accommodations to those students, they would have to provide the accommodation to every other student in the school or risk being labeled unfair. A reasonable accommodation for a person with a learning disability might be extra time to take a test or taking the test in an environment free of distractions.

The explanation I heard was "if I was at a meeting and someone had a heart attack, I could not give the person CPR, or I would have to give it to everyone at the meeting to be fair". I told this explanation to one of the psychologists I worked with at the department, and he liked the explanation so well he asked if he could use it when he talked to the schools about providing reasonable accommodations when working with students with learning disabilities.

There is one thing about being a person with a laryngectomy, we are all the same in that we have had a laryngectomy and that is where it stops. Each one of us has our own unique experience in having had a laryngectomy. For some, it appears to have been an easy process and adaptation to the new lifestyle while for others it seems that there will be no end to the complications experienced because of having had a laryngectomy.

When I read of the experiences some have had I am so grateful for my situation. Not that my situation has been all "peaches and cream". I have had my share of difficulties. My fistula and the closing of my stoma, for example.

I am glad to deal with both of those challenges as well as what is to come. I have read of so many that were unable to return to eating solid food. I even heard of someone that was unable to even swallow liquids. People have had difficulty due to the weather, such as humidity. The list of people's challenges posed by their having a laryngectomy is endless. Yes, it is quite a journey.

To look at all individuals with a laryngectomy and lump us all in one category would be a true disservice to all people with a laryngectomy.

A long time ago, maybe even before my career with DR, I learned that if I come upon a person with a disability to resist forcing my help on them without first asking if they would like my assistance. Today I have a deeper understanding of waiting to provide aid until asked by the person to give aid.

Most times it takes me a little longer to get things out when I am talking. I deeply appreciate those I communicate with for their patience in allowing me the time to say what it is I am trying to say. I have a friend that always finishes my sentences for me. He has always been like that. He was like that when I met him, decades before my laryngectomy. He is a good person with a good heart, so it is easy to overlook that one flaw. All though it really does make me appreciate those who say to me "take your time".

I have always been one to value what I have to say. I was outspoken as a child which sometimes got me into trouble. Back in the '60s and early 70's children were to be seen and not heard. So, when I was forthright in talking to adults, many times they would take that as me getting out of my place. I was not rude or disrespectful, just the fact that I had the audacity to speak up and say what I had to say to an adult was more than could be accepted.

I do miss my long conversations with different people that would expose me to different points of view. I remember in the 70's I worked at a factory sanding trucks, very boring work. One of the guys I used to work with would get into deep discussions with me about politics and the world. One day he said to me, Nixon (former president) was not so bad. "He was just trying to get a little on the side". I became visibly upset with what he was saying. This was a few years after Watergate and his resignation from the presidency. After he could see he had got me riled he said to me "I'm just messing with you" to pass the time.

Sorry for rambling so much this month. It was hard to stay centered to one idea. I will work harder to stay more on track next month.

EGYPT 1997

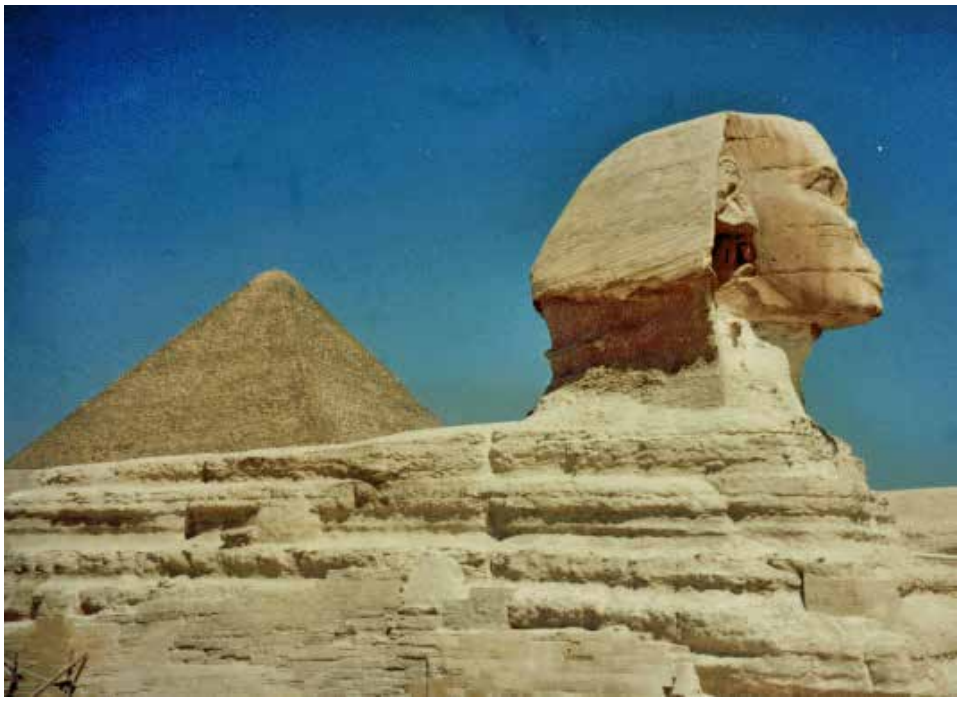
W. C. Baker

I took the long way to get from Nairobi: Kenya to Cairo, going by way of Kampala, Uganda. Well, it was like this. Devra, the daughter of Rachel, my partner at the time, had completed her first year of teaching for Peace Corps in Eritrea. She wanted to lay some groundwork for studies that she was going to be doing in Uganda for her Doctoral work in a year or two. So, we went to Kampala. But I wanted to spend some time in Egypt. Devra had studied a year at American University in Cairo (The only B that she got in her higher education was in Arabic in Cairo). Rachel had been in Egypt a couple of times while Devra was studying there, so she stayed in Uganda with Devra, and I went up to Egypt.

Cairo is an incredibly busy place. The pensione where I stayed was cheap, clean, and comfortable, and in easy walking distance to the Egyptian Museum, the citadel, and to the Nile. The National Museum of Egyptian Civilization is an absolute must for any visitor to Egypt. Back in 1977, when I was still in possession of a smoke ladened larynx, we traveled from our home in Dayton to the Field Museum in Chicago to marvel at the exhibit of remarkable items from King Tutankhamun's tomb. I marveled again, this time sans larynx when I saw the same pieces in Cairo. I committed a major faux pas when my camera flashed in a no-flash area. I was severely reprimanded and contritely turned the flash to the off position that I had thought it was in. I spent two days in the Museum, enjoying every minute of it.

Leaving the Egyptian Museum behind, I wandered the Citadel, built by Saladin in the 12th century. Aside from a few Mosques that deserve some attention, there is little of interest in the Citadel. On my way back to the Pensione I was approached by yet another native offering services or simply asking for baksheesh outright. He was the first to offer a ride on the Nile in a felucca. Felucca cruises are available, most starting from Aswan, but this was a simple day

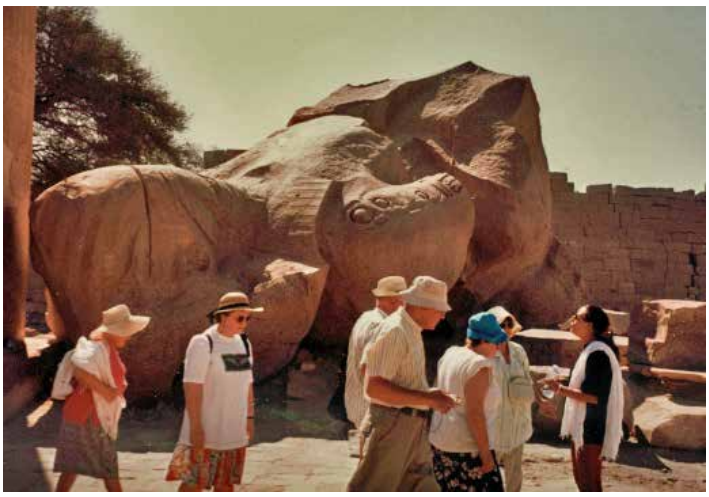
ride in the Cairo area. It did present some stunning views, mostly high banks lined with date palms. On one occasion a boy swam out from the reedy shore, feeling that he deserved to be rewarded for his efforts.



The Nile is something of a segue from the bustling Cairo of today to the staid grandeur of 5000-year-old pyramids and the sphynx. Cheops pyramid stood as the world's tallest man-made structure until 1890 when the Eifel tower displaced it. There is an optical illusion in the Pyramids. The largest and oldest is the northernmost, but the middle pyramid appears larger because it is on higher ground. It is this middle pyramid that the Sphynx is thought to be associated with. The oldest/largest pyramid was the only one I went into. I had never thought myself to be claustrophobic until I got a short way into the cramped passage. I may have backed out, but my miserly nature would not let me waste the money I had spent on the ticket. I'm glad I did it.

An overnight train got me from Cairo to Luxor in time to hear the earliest of the calls to prayer from the minarets of the Abu Haggag Mosque which is integrated into the ancient Luxor Temple. Walking through at dawn the stone columns, carved to resemble bundled papyrus, make palpable the thousands of years that worship, and power issued from its richly illustrated walls. Originating as a sanctuary built by Hatshepsut circa 1470 BCE, it grew through the centuries with additions by New Kingdom biggies on through Alexander the Great, The east bank is graced also by the 500 years older Karnak, honoring Theban Gods. It was once connected by an avenue of human-headed sphinxes over a mile and a half long, now extending a mere few blocks.

From the world's oldest monumental structure, Zoster's step pyramid at Saqqara c2670 BCE, and the great pyramids at Giza, to the Valley of Kings across the Nile from Luxor, 63 tombs of Pharos and nobles are on the west bank, toward the setting sun, their primary god. King Tutt's tomb in the Valley of the King's is unimpressive, but it somehow escaped the grave robbers to provide the treasures that have thrilled people all over the world. At the end of a long path from Tutt's tomb, the tomb of Amenhotep II is carved into the side of the cliff under the pyramid-shaped mount al Qurn. Many steps lead down to a deep pit that was unsuccessful in keeping out grave robbers. A modern gangway traverses the pit and leads into a very long hall, highly decorated with paintings on the walls and a ceiling of stars. The very large stone sarcophagus stands empty in the large burial chamber, its former occupant now residing in the Egyptian museum. The tomb of Seti I (1294-

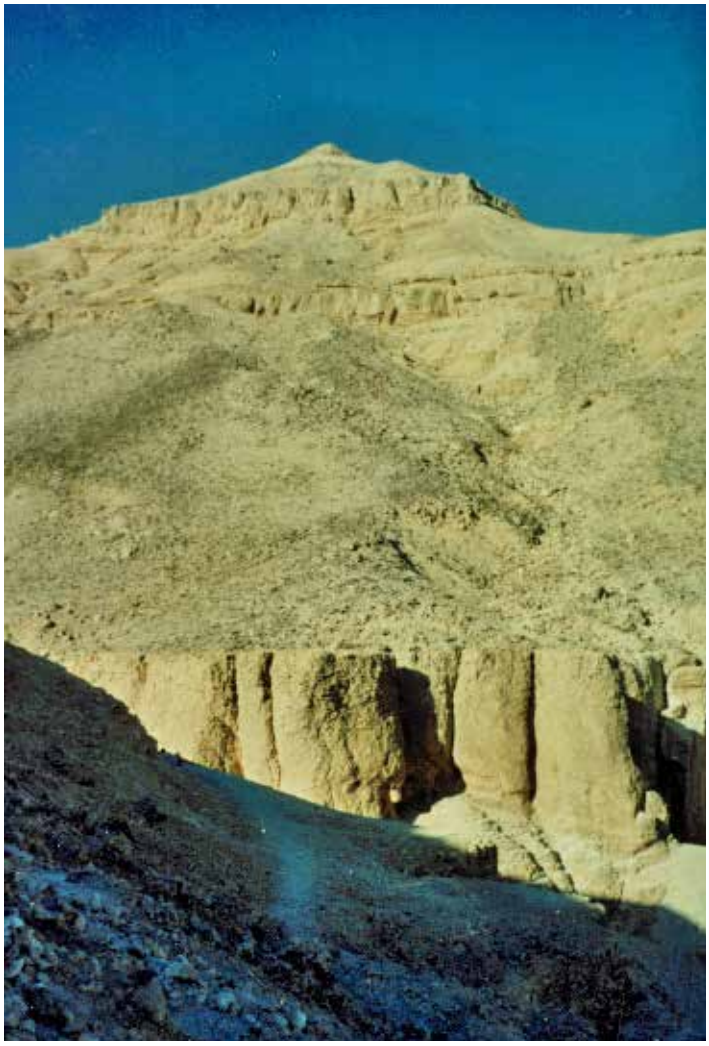


1279) Is older, longer, and more richly decorated with painted relief work.

The Ramesseum, built by the warrior pharaoh Ramses II is a standing metaphor for the futility of the quest for immortality. Stretched on the ground at the gate is the fallen statue of Ramses II that would have stood 58 feet. It inspired the poem by Shelly. Headless sentries stand at the gate and a finely carved head lies before them.

I was skeptical about Aida being performed outdoors at Hatshepsut's tomb. I feared it would lack the intimacy of an opera house, and that the music would lose a lot of its power. But, opening myself to the setting gave me an operatic experience yet to be equaled. I have since enjoyed Aida in the open-air settings of the Caracalla Baths in Rome and in the Verona Arena. Both were wonderful but didn't raise goosebumps like the performance in the desert.

Before boarding the train back to Cairo, I grabbed a quick snack from a street vendor. It was the only time, in all my travels, that I ever experienced food poisoning. But it passed…and passed…and passed again. All in time to meet Rachel. who had flown up from Kampala to Cairo for our return to the US.



THE SILENT PARTNER

My First Year as a Laryngetomee

by Aaron Wayne

My First Rodeo

This wasn't my first: getting cancer on my vocal cords and becoming a laryngectomee was not the first major medical event in my life, just the most recent. My first major hospitalization event was in July of 1995.

I had promised both of my daughters that I would take them skydiving when they were old enough. I had made four static line jumps from 2500 feet with a 35' main parachute at the time and they kept telling me that they wanted to go with me, but they were too young, so I made them that promise. That was in November of 1976.

When the younger sister Lana graduated from college with dual degrees in psychology and child development, she told me that it was time to fulfill my promise. I made the arrangements, and a few weeks later Lana and I, her boyfriend Chris, and Lana's big sister Cindy were on our merry way to the California City airport out in the desert not far from the town of Mojave, CA. We stopped at the airport restaurant for a quick breakfast before we reported to the hangar for ground school and talked about what we were about to do. Even though I had done this before, it had been long enough that I went through the training again with them. Finally, it was time to get aboard the 'perfectly good airplane' from which we were going to jump. This time the 'chute was different: instead of a 35' round parachute, it was more like a square sled type kite, known as a ram-air parachute. At breakfast, it had been decided and mutually agreed upon that I would be the last to board so I would be the first to leap out into thin air at 3500'.

I had the strangest feeling of foreboding as I clambered aboard, and I had no choice but to ignore it. As the airplane climbed, the uneasiness increased. In a few short minutes, we were leveled out at the proper altitude and headed for the drop zone. When the jumpmaster tapped my shoulder I exited the plane and spread my limbs as instructed until I felt the 'thump' of the parachute grabbing air and I was dangling in the harness under it. This was an unfamiliar parachute and I immediately started to see how it maneuvered by pulling alternately on the left and right toggles that controlled the direction of flight. Then I aimed for the mounded circle of earth that was the drop zone. As I neared the drop zone, the jumpmaster on the ground was on the radio, giving me my landing instructions. When he yelled "FLARE, FLARE, FLARE" - I flared. Unfortunately, I flared on the first "FLARE" and was still several feet from the ground. Then the wind abruptly calmed, and I was headed towards the berm built up around the drop zone and would be doing a face plant in the cacti if I were to catch my feet on the top of it. So, as I crossed the berm, I lifted my feet to avoid doing that. Very. Bad. Idea.

As my butt slammed into the desert sand, a bright flash of light went off inside my head. I lay there for a moment, stunned, and then realized that I couldn't feel anything below my belt. The wind was starting up again and was about to re-deploy my chute. I started to struggle to try and get out of the harness and was fumbling with the release when the jumpmaster reached me and helped me get undone. As I wiggled around, the feeling came back in my legs. Along with the pain. That wonderful pain! When I was free of the chute, I slowly managed to get to my feet, despite the pain. I managed to hobble the few yards through the cacti and sage to the pickup truck that was our transport back to the hangar. I climbed up into the cab, the others climbed into the truck bed and off we bounced across the sagebrush.

Everybody thought it best that I go to the hospital, but I'd had back problems in the past from other dumb stunts like getting thrown from a mechanical bull, that sort of thing, and this didn't seem that different, only it was definitely more painful. I did take some Tylenol since they didn't have real aspirin. Since driving the hundred-some miles back home wasn't an option, I climbed into the camper shell and onto the

thin mattress back there while Chris drove us home. Lana was in the front with Chris and Cindy went in the back with me. As I laid there on my stomach, Cindy massaged my back.

When we arrived, I crawled out of the back of the truck and got 'that look' from my wife. Shelley had not been in favor of this trip since 1976, so she was launching into the 'I told you…' lecture when her concern for me overrode that. I asked them to help me get into the backyard spa so I could float and soak my aching spine.

The next morning the pain was so bad that I could not get out of bed. With Shelley's help, I got up and dressed in sweats. She called her assistant from our office just down the street and Richard came to the house to help Shelley get me up into my truck to go to the doctor. At the doctor's office, Shelley went and got a wheelchair to bring back to the truck for me and we managed to get me down out of the truck and into the chair. Once in the doctor's office, I was asked for my vital statistics. When the nurse reached "Height?", I responded: "Until yesterday, I was 5'11", which cracked her up and set the tone for the remainder of the visit. Then I climbed up onto the X-ray table and lay on my back while the X-rays were taken. The doctor looked at the X-rays, then he looked at me, then back at the X-rays. Then he looked startled. "Did you know you broke your back?" I had suffered a burst fracture of my L-2 vertebra.

It was an eight-and-a-half-hour surgery to remove the pieces of the shattered bone and replace it with a piece of cadaver bone. That bone was then held in place by attaching a titanium plate to the adjacent vertebrae with two screws at either end.

So I believe that it was that experience, my first rodeo, so to speak, that has given me the courage and determination to get through this current health crisis.

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

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