### March 2021

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Hello Everyone,

As I write this we are only a few days away from the March equinox which here in the northern hemisphere marks the beginning of spring and the fall to our southern hemisphere readers. Living in Maine it does seem like that transition is right on track (see my column in the Archives for how I know).

Either way, it’s a welcome transition, especially this year with a promise of progress and hope. I have been encouraged by the number of folks in our community who have been willing and able to get “the jab” as our Brit friends call it. I get my first one tomorrow. After being on a waitlist for 3 weeks, once my age group became eligible I had 4 possible appts all come available within 2 days!! Here’s to the day when we can all get together in person and even if we are still masked we can start hugging again. I really miss those spontaneous hugs when seeing a friend. But then, I’m a hugger. I know some folks are probably just as glad that greeting is verboten these days. So whether you are in the hugger camp or not I think we are all starting to feel a bit safer.

We still have lots to read this month until we can get out and about in earnest. VoicePoints examines the importance of music to us all; something we see or hear, more accurately, in the number of us who are still making music. The documentary film “Can You Hear My Voice” a case in point. More about how you can view that coming up. Tom Whitworth asks “What if...” and comes up with some thought-provoking answers. Don Renfro writes about how he has learned to go beyond surviving to fulfilling and the unexpected “methods” that taught him this valuable life lesson. Our resident adventurer WC Baker takes us armchair traveling to Eritrea and we introduce you to new writer Aaron Wayne and his memoir “The Silent Partner My First Year as a Laryngectomee”.

As always we love to get your feedback and your contributions are welcome as well. We look forward to hearing from you.

Until we meet again, Stay Safe, Stay Sane and Happy Reading!

Donna McGary
Like It Never Even Happened

Do you ever wonder what if? What would be different if a particular thing was like it never even happened? Lately, I have pondered where my life would be right now if not for cancer and everything that followed to rid my body of it. That line of thinking is always followed by the recognition of all the blessings of life I would have missed.

For one thing, one of my doctors told me that had I not been diagnosed and started treatment when I did, it is not likely I would have made it to the end of 2014. Chemotherapy and radiation began the first week of October that year. Yeow, that was cutting it close! Needless to say, I would not be writing this article and you would not be reading it. Not only would I not be president of WebWhispers, I would have never even heard of it, and would have no idea what a webwhisper was, much less a laryngectomy. Terms like laryngectomy, radical neck dissection, primary tracheoesophageal puncture, heat moisture exchanger, base plate adhesive, electrolarynx, esophageal speech and even voice prosthesis would have been completely foreign to me. Hearing any of that, I would have had no idea at all what was being referred to and might have accused someone of making all that up. It really does sound made up until we find ourselves here.

Also, I would have missed knowing my first two grandchildren, beyond the toddler stage and would have never even seen our five year-old Maggie. I truly cannot imagine a life without them. Being allowed to hang around longer, the reality is had I died I would not know it. Being dead is just like being stupid. You don’t even know it; it’s just a problem for everybody else.

Had I never had cancer in the first place, like it never even happened, I would still have life like I do now, but without the stoma, the scarring, the side effects, the hearing aids, and without all the paraphernalia I keep around just so I can speak and sing a little. I would be using 95% fewer tissues than I do now. I would still eat, sleep, inhale, and exhale (from the mouth and nose), in a fairly normal life, albeit boring. Things like speaking, eating and swallowing would be taken totally for granted. So would family members and friends, and a decent standard of living. My lack of appreciation for the things I enjoy most and for the beauty of life itself, would have me bored to tears at times.

But it did happen, all of it and sick as it may sound, I am a better person for it all. I truly value every moment, waking or sleeping. However, there are days when I wish I had a few more moments to work with. Because of the journey, I am more kind, considerate, and genuinely compassionate. Because of what I have been through, I am more confident and no longer worry about things I can do nothing about.

As I pass the seven year itch stage of this, quite possibly the best thing I have learned is to not think the worst. Most often, it never happens. Things can be different without being bad. Had it never even happened, I would not know hundreds of friends I love dearly and would not be part of this caring community of people. I would have missed out on a lot.

Enjoy, laugh, and learn,
Tom Whitworth
WebWhispers President
Transforming Health Through Music Therapy

Music is powerful. It impacts our lives. It impacts our culture. It is a key ingredient in every life celebration and many daily activities. Whether we choose to call ourselves musical or not, we cannot deny that music is an integral part of our lives.

Music therapy is a clinical and evidence-based practice that uses music as the tool to accomplish individualized goals in a therapeutic relationship by a credentialed professional. Music therapy is effective in a variety of settings and with a variety of populations.

People who are aging or who have experienced a life-altering medical condition frequently lose some, or all, of the independence that they are accustomed to. For example, patients who are on hospice often struggle with the challenge of loss of independence, having to rely on others solely for their care. Those who have undergone serious health challenges or procedures, like a total laryngectomy, can relate to learning to cope with loss of independence. Though not undergoing hospice care, laryngectomees have to rely on a caregiver while recovering and learning to live life differently.

Music therapy is also used to treat depression and anxiety. Bill Brummel is a cancer survivor who underwent a total laryngectomy. After that experience, he directed and produced the documentary Can you Hear my Voice? In interviews, he talks about experiencing denial and then feeling fear, depression, and hopelessness. Other laryngectomees speak to this point in the documentary as well, sharing that they can relate to feeling depressed, hopeless, isolated, lonely, and exhausted throughout the recovery process.

But the story does not end there. There is hope. Many laryngectomees have used music to combat these feelings in their recovery process. Music gave them hope and purpose. Music gave them the strength to keep moving forward and believing in themselves. Music provided emotional and physical healing.

Music therapists know by experience that there is a relationship between emotions and music making. We often hear emotion manifested in a client’s music or see emotions being expressed on a client’s face when experiencing music (Hiller, 2015, p. 30). Music therapy is an effective method of treatment in addressing psychosocial and emotional needs of clients, but it is also effective in the physical recovery of total laryngectomees. In a Facebook video of the laryngectomy “Shout at Cancer” choir, one member says that singing helps you learn how to breathe in, which allows you to “talk better and join in with other people” (2019).

In the study, “Effect of Singing Training on Total Laryngectomees Wearing a Tracheoesophageal Voice Prosthesis,” the authors found that singing training has a favorable effect on the quality of tracheoesophageal phonation and on the singing voice (Onofre, F., Ricz, H., Takeshita-Monaretti, T., Prado, M., & Aguiar-Ricz, L., n.d.). The study describes two parts to the singing training: specific breathing exercises
for strengthening respiratory muscles and singing the eight pitches of the scale on do, re, mi, fa, sol, la, ti, do for improved vocalization. Music therapy supports other therapies already utilized by laryngectomees by implementing a variety of singing techniques and exercises into their treatment and plan of care.

In “Music Therapy for Adults with Traumatic Brain Injury or Other Neurological Disorders,” Jeanette Tamplin (2015) explains the rationale for using music-supported training approaches in physical rehabilitation. She discusses the motivational factor of using music in physical exercise as well as the unconscious physiological responses that music can elicit (p. 457). Tamplin (2015) goes on to give a clinical example of singing to improve respiratory function (p. 462). The patient in this example participated in respiratory exercises and therapeutic singing to improve his respiratory function and voice projection. After the 12-week trial, the patient demonstrated an increase in vital capacity of almost half a liter, a 25% increase in maximum expiratory pressure, and a 12% increase in maximum inspiratory pressure. The sound pressure level of the patient’s projected voice increased from 74 to 78 decibels, and the length of maximum sustained phonation increased by 12 seconds (Tamplin, 2015, p. 462).

Though we, as music therapy professionals, have more to accomplish in the field of music therapy research, there are many studies that support the efficacy of music therapy in treating and improving the psychosocial, emotional, and physical states of people who have experienced cancer treatments, a partial or total laryngectomy, strokes, traumatic brain injuries, neurological disorders, and many more health challenges. A couple of excellent resources to pursue if interested in music therapy research include Journal of Music Therapy and Music Therapy Perspectives.

Laryngectomees face significant emotional and physical challenges, many of which can be addressed through music therapy. We need to provide advocacy, education, and awareness of music therapy as an essential treatment tool so that more people can experience its benefits.

Jill Leonard, MM, MT-BC
Owner, Transformational Health Music Therapy Services

References


Music fosters connection, community, and support. It provides the tools to communicate and process verbally and nonverbally.
It Doesn’t Get Better Than This
By Don Renfro

“Survivors can’t always choose their methods.”
– Patricia Briggs, Dragon Blood

I must have read a hundred quotes this month because I found so many good ones, but I kept reading and finally I came across this and my mind said, “This is the one”.

I recently attended a new support group and there was a new member about to have his surgery who had questions about what to expect. One of his questions was should he know as much as possible prior to his surgery or should he get his knowledge from experience after his surgery? I shared my experience that I attended a support group prior to my surgery and got some information but really got my best knowledge from first-hand experience after my surgery. I went on to share that if I had known more about the possible complications and side-effects of the surgery, chemo, and radiation I might have opted out of having the surgery. So, for me, I am glad I was not given more information than I could handle at the time.

In hindsight I am incredibly grateful my pre-surgery knowledge was limited to what I could find out in a few brief encounters. That was my suggestion to the new member, to get some information but realize most of the knowledge of your personal situation will come from your experiences after the surgery.

I remember after my surgery, in the hospital and well after I went home, thinking why didn’t they tell me I would experience such and such? I later realized had I been told I would go through ..., there is a good chance I might not have consented to having my surgery. That would have been an awfully bad choice for me. I honestly believe that my best living has not been lived yet. I believe this from the stories I hear from members that share the life experiences they have had since their surgeries. Some people have done things since having their surgeries that I had not done before my surgery.

I look forward to a whole new “bucket list”, in many ways more challenging than before. The stories I have heard from other members have renewed my interest in some things I had accepted I would not be able to do because of my surgery. I have heard stories of members kayaking, traveling to foreign countries, hiking and even swimming. I am sure that I can do some of the things I have heard about from other members and even find some new things of my own.

I have come to believe that surviving is good, but living is essential. My biggest fear immediately after my surgery was that the things that made my life worth living, I would no longer be able to do. I am happy to say, I was wrong. I remember a person from my original support group kept telling me “you will find your own routine”. I think he was referring to maintain my stoma. I have found my own routine extended beyond my stoma into my day-to-day life.

Groups I had not attended for a while or maybe never attended, I attended via Zoom. My monthly film festival I attend regularly was no longer available with the closure of movie theaters and so I had to learn how to stream the festival in my home. The CicLAvia was canceled. The event is a monthly event at which some streets in the Los Angeles area are closed to vehicular traffic and only open to bicycles, pedestrians, and other non-motorized means of transportation. So, one more time I was not able to choose the method used to obtain my desired outcome. What I have found is that even if it is not my method of choice it can still be an enriching experience.

Today I genuinely believe that my surgery did not mark the end of my life, but instead a new beginning.
Many of us go through life with little awareness of or interest in what is happening elsewhere in the world. We might see and hear about wars, floods or famine on the evening news. We “tsk tsk” the sufferings of thousands and settle down with a glass of wine to watch our favorite programs. Eritrea hadn’t reached even that level in my awareness until I heard of it when I went for a meal at Café Eritrea in Berkeley shortly before my surgery. Even then, I really knew nothing about it. Five years later, in the early stages of my relationship with Rachel, we traveled to Eritrea to visit her daughter, Devra, who was just completing her first year of teaching with the Peace Corps in the village of Shima Nigus.

The British defeated the Italians in Ethiopia during WW II in 1941, Eritrea became a constituent state of the Federation of Ethiopia and Eritrea in 1952 with the expectation of being given independence in 10 years. Hailie Selassie curtailed the progress toward independence and Eritrea began the war for independence in 1961. Eritrea was about to achieve their independence when, in 1977 The Soviets threw in their support for Ethiopia, forcing Eritrea to make a strategic withdrawal and extending the war for another fourteen years. Eritrea received support from the US and the proxy war went on until 1991 when, after 30 years and nearly 80,000 lost lives, Eritrea finally achieved independence. The U.S. was invited to send Peace Corps representatives when the Communist bloc disintegrated.

In our first full day in Asmara, the capitol of Eritrea, we attended an expo of a nascent Eritrean industry and agriculture. “Agriculture” apparently referred to land animals, sheep, goats, cattle, camels and chickens. With its long coast line, artisanal aquaculture provides much of the protein in this famine-prone country. Agriculture employs 80% of the population but accounts for only 20% of GDP. Frequent drought and little arable land and hundreds of thousands of land mines make for one of the poorest nations in sub-Saharan Africa. 24 years of what I take to have been an oppressive dictatorship and on again off again wars with Ethiopia have left Eritrea as one of the least developed nations in Africa.

A goat was being loaded onto the top of the bus that we took from Asmara to Serejeka. In the bus, one woman had a surprisingly calm chicken in her lap. We were greeted by some of Devra’s students who walked us to the village of Shima Nugis and Devra’s dwelling. On the wall by the door, just at eye level was the biggest spider that I’ve ever seen. Devra had named it Plate. I don’t think it moved in the entire week that we were there before touring, and seemed not to have moved when we got back. Maybe it wasn’t alive, but I didn’t want to test it. Except for one or two personal gas generators, there was no electricity in the village. Nor was there any running water. The house had shutters, but no paned windows, yet I don’t recall having a problem with insects. We cooked on a bottled gas camp stove drank bottled water and occasionally some of the local beer, which was warm but wonderful. Wonderful also were the people. Devra spoke enough Tigrinya, the local language, that we were able to enjoy their hospitality. One woman of some standing in the village, treated us to a coffee ritual. She roasted bens on a hibachi, ground them with a pestle and mortar, put the ground beans into a special pouring pot and let it brew for a while. She put a horse hair filter in the spout and poured. She had been a fighter in the war of independence, as were enough other women that they made up 25% of the armed forces. Devra suspected that it was she who performed the female circumcisions in the village. A 2010 survey found that 83% of girls still undergo FGM, but that is an improvement over the 89% rate in 2003. I imagine that it was pretty much universal when we were there.

It appeared that daily life began with a trip to the fields for the conduct of bodily functions after which younger women went to the well to bring
home the water for the day. In their homes women stoked the wood stoves and the men went about their business, which I never really identified. We had the luxury of a commode that we flushed with a bucket of water when flushing was necessary. I was amazed at how thrifty one becomes with water when you have to walk a ½ mile from the well toting a 5-gallon jerrican. On Sunday the ringing-stones announce the church services in the center of the village. Although about 35% of Eritrea’s population is Muslim, it appeared that the entire population of Shima Nigus was Christian. The men, dressed in toga like wraps over their street clothes, carrying long sticks with short cross bars at the top, sang and danced to drums while the women clapped rhythmically and ululated. Those conducting the service wore pillbox hats or turbans and joined in the singing and dancing. After the service inside, it seemed to move outside where the women sang and danced. A Social hour followed with snacks and coffee. One of the favorite snacks was popcorn. Popcorn had been served to Hilary Clinton when she visited Eritrea a few months earlier.

Our first foray was to Karen nearer the Sudan border. We three woke to the roosters announcing morning. We made it to the highway and availed ourselves of probably the most common form of travelling any longer distance. We hitched. There is not much traffic in Eritrea, but we were lucky. Two Italian men, engineers on a dam project, picked us up in a pick-up. The male passenger, Gino, got out so that the women could ride in the cab while he and I rode in the bed of the truck. Gino was impressed with the quality of my esophageal speech. His father was a laryngectomee, but that was all I learned before we got to Karen.
Writing this was my way of telling anyone else who has had or might have to have a total laryngectomy that it won’t take away your voice. That it cannot take away your sense of humor if you don’t let it. I wrote also for those who care for us, so they can know a little bit about how we feel. So that these wonderful people can get an insight into how frustrated we often get. If we seem angry at times, please don’t think that we are angry with you, we aren’t. We are always grateful and on behalf of my fellow laryngectomees and me, I give you a profound THANK YOU!

(Actually, I’m just hoping this will get me on a talk show.)

1. THE DOCTOR, THE MISDIAGNOSES, AND THE GREAT ESCAPE

Sometime around the beginning of 2019, I began to have an irritation in my throat and I started to speak hoarsely. When it had lasted longer than I thought it should and I started to have trouble breathing, I finally went to see my primary care physician. My first visit with the doctor was in April. She gave me antibiotics and medicine for my high blood pressure. Over the course of subsequent visits, she swabbed my throat when I complained of soreness in both my throat and my ear. She examined my ear and saw nothing visibly wrong. She had x rays taken of my chest. She declared a diagnosis of bronchitis and prescribed a nebulizer, medication and various inhalers/inhalants. She sent me to a pulmonologist, who sent me for tests to measure my lung capacity. The tests involved injecting me with a radioactive dye of some kind and a pressurized chamber that looked like it came from an old game show. The chamber was a clear glass cylinder with wires and tubes running out of it from various places, going to strange looking machines. It had a hard plastic seat that wasn’t much different than the chairs at mall food courts, just harder and not flexible. The technician explained that a cushion wasn’t allowed because it would throw off the calibrations when the isolation booth was sealed and pressurized and the cushion depressed. At least I think that’s what he said.

Over the next several weeks, I kept getting worse. I had even more difficulty breathing, to the point where I was gasping for air. I went to urgent care to get oxygen on two occasions. On the first, they also gave me a steroid injection and I was fine for a few days. The second time they just sent me on to the emergency room. When I walked into the hospital gasping and wheezing, they thought that I was having a heart attack.

I don’t remember much about the time that I spent there – only bits and pieces. I remember being transferred to Cedars-Sinai in an ambulance and ending up in the cardiac ICU. My daughter Lana rode in the ambulance with me. In the course of two days, I had an angiogram and two heart sonograms that showed… that there was no clot and that my heart was in fact, pretty normal for a man my age. Then the fun really began: I was transferred to the pulmonary unit on the other side of the hospital.

After the luxury of the cardiac ICU, I was put in a room that smacked more of a prison cell than a hospital room. A very modern and roomy prison cell, but a cell nonetheless. There were charts on the wall with daily plans, objectives, and lessons. There were rules posted in bold print. There was an alarm under the bed that sounded rather loudly if I got out of bed without permission. I had to ring for a nurse just to take a leak. During the first five hours there, I was completely left alone, no visit from the pulmonologist that had been assigned and no therapy of any sort. When I requested a suction device for when I coughed up phlegm, they didn’t even know what I wanted even though I had been provided one in ICU without asking. Meanwhile at the nurses’ station just outside my door it sounded like a frat party was in progress.
When I couldn’t take any more of this TLC, I summoned a nurse and asked to be sent back to the ICU, the first hospital, or discharged. When he patiently explained that none of those were an option, my claustrophobia kicked into high gear. My wife had finally arrived, so I got up (setting the bed off) and started disconnecting myself. Then I got dressed and walked out. I felt a little like a Bruce Willis action hero right about then. That’s one thing I can check off my bucket list.

A month or so later I got a survey in the mail asking me to rate my experience. I gave them the courtesy of not responding.

Then came the final visit to my primary care physician before the fan got befouled: She didn’t want to send me home when the visit was concluded, but insisted I go to emergency again because she feared I would have another “heart attack”.

As it turned out, it may have been the wrong diagnosis (again!), but it turned out to be the right thing for the wrong reason: while I was being treated, a nurse walked by and after hearing me breathing, called in an otolaryngologist. She said that it sounded to her like it was my throat, not my lungs. The doctor ran a camera up my nose and down my throat, took one look and found a 2cm mass on my vocal cords. My worst fear was realized: I needed a tracheotomy.
As I was scrolling through “The Wayback Machine” (link here because it’s just so cool https://web.archive.org/web/*/WebWhispers.org) I came across this old column of mine from April 2008 and it is so perfect for this month, at least here in Maine this March. Some things never change. And that, in a way, is mightily reassuring these days!

March Madness

This column is not about basketball. I am not much of a sports’ fan, actually, although I do admit to a prurient interest in basketball, being a shoulder woman from way back. I LOVE those free throw close-ups!

There is another type of March Madness that only northern New Englanders can appreciate and that is one of our two “other seasons”…the ones you will NOT find advertised. While this particular winter has been over long for my taste and circumstances, for the skiers and their providers, it has been a bit of heaven on earth. Springtime in Maine, after such a long and difficult winter is nothing short of sublime (and for us gardeners, snow is the poor man’s fertilizer, so our perennial beds should flourish this year). Summer is a bountiful feast of strawberries, tomatoes, lobsters, corn and tourists. I can’t blame the tourists…Maine is a beautiful state.

Fall is my favorite time of year (my tolerant affection for those pesky tourists, with admittedly deep pockets, has worn thin) and I am ready to reclaim my sweetie…what’s a few busloads of leaf peepers among friends. The fall foliage is something you need to see to believe. Those calendar photos do not do it justice. After the apples and Halloween come cold crisp nights, old family quilts hauled out of Grammy’s trunk…a nice fire in the woodstove…I kid you not…this is really how my family lives. We plan Thanksgiving and Christmas Feasts and stack firewood…again and again.

That is the LL Bean version. It is largely accurate, unless you fault them for the sin of omission. Between winter and summer we have two nasty seasons. One is the true harbinger of springtime in Maine…we call it Mud Season. Of that seventh level of Hell known only as “Black Fly Season” which most ungraciously ushers in summer we will speak no more. PAAH!

Of Mud Season, I have a few thoughts. First, it smells. Even I can smell that organic composting scent of last year’s leaves and the detritus of life underground. I remember it as a child…it was the sign I might be able to convince my mother that it was warm enough to wear knee socks instead of tights. Mud Season to me smells like freedom.

However, my car got mired in the mud so hopelessly the other day, my son had to use the Rhino to haul it out and I lost a shoe in the muck as I brought in the groceries. I have yet to see an LL Bean campaign that accurately captures mud misery…and I live 15 minutes from Freeport…their headquarters.

March is officially Mud Season is Maine…much more than spring, we recognize its importance. We post the roads and watch our steps. It is also my birthday and the anniversary of discovering that my life would change forever. My birthday is March 20 and I learned two days later, eight years ago, I had a problem. First day of spring and already I was in Mud Season.

I had just turned 47 and had just been accepted into graduate school…I had finally figured out what I wanted to be when I grew up and I really thought this was going to be just a blip on my radar. Little did I know. Mud can ruin your day.

The thing about mud is that it is sneaky. That rut doesn’t look THAT deep until you foolishly try to negotiate it…hah…the old timers just shake their heads and haul out the chains…Old Yankees are surprisingly gracious about this stuff…having been there themselves more than once.

As the Psalmist said, “Weeping may endure for a night, but joy comes in the morning”.

The worst of the mud is over in a few weeks and by May 1st we can really start to celebrate spring and our survival to enjoy it once again.

We have all endured our own personal slog through the cancer mud and lived to tell about it. Some of us mired so deep, it is the stuff of legend, but we got out. Now we watch hopefully for that first peep of crocus and burst of forsythia, knowing that tender green peas eaten straight from the vine, pod and all, heavy headed peonies, tomatoes and corn still warm from the sun all await us. And tourists and friends “from away”, of course. Black flies and impossible summer traffic will also arrive…all in due time, but for now just smell that mud. It’s springtime in Maine.
I’m sure everyone is aware however I thought this might be helpful information to share with your friends, club members or to put in your newsletters! The personal info on the card makes you a target for ID theft and helps scammers create fake cards. Please feel free to pass it along. Hope you continue to: “Stay positive and to test negative”!

Steve Cooper

Many people who’ve received the COVID-19 vaccine couldn’t help but share their excitement — and vaccination cards — on social media. But the Better Business Bureau is advising against doing so for two very good reasons:

The first: The cards contain personal identifying information, such as your name, birthday and where you were vaccinated, so posting it online could make you vulnerable to identity theft, the nonprofit, which focuses on improving marketplace trust, advised in an online statement. This behavior is even riskier if you have lax privacy settings on your social media profiles.

The second reason is to prevent scammers from creating phony COVID-19 vaccine cards, the organization said. The more pictures of the cards available, the easier it is to forge them, and “it’s only a matter of time” before such cons happen in the U.S., according to the nonprofit.

To share your excitement safely on social media, consider instead posting a picture of the sticker that you may receive from the health care facility after getting vaccinated, which shouldn’t have personal info on it. You could also add a COVID-19-themed frame to your profile picture on Facebook.