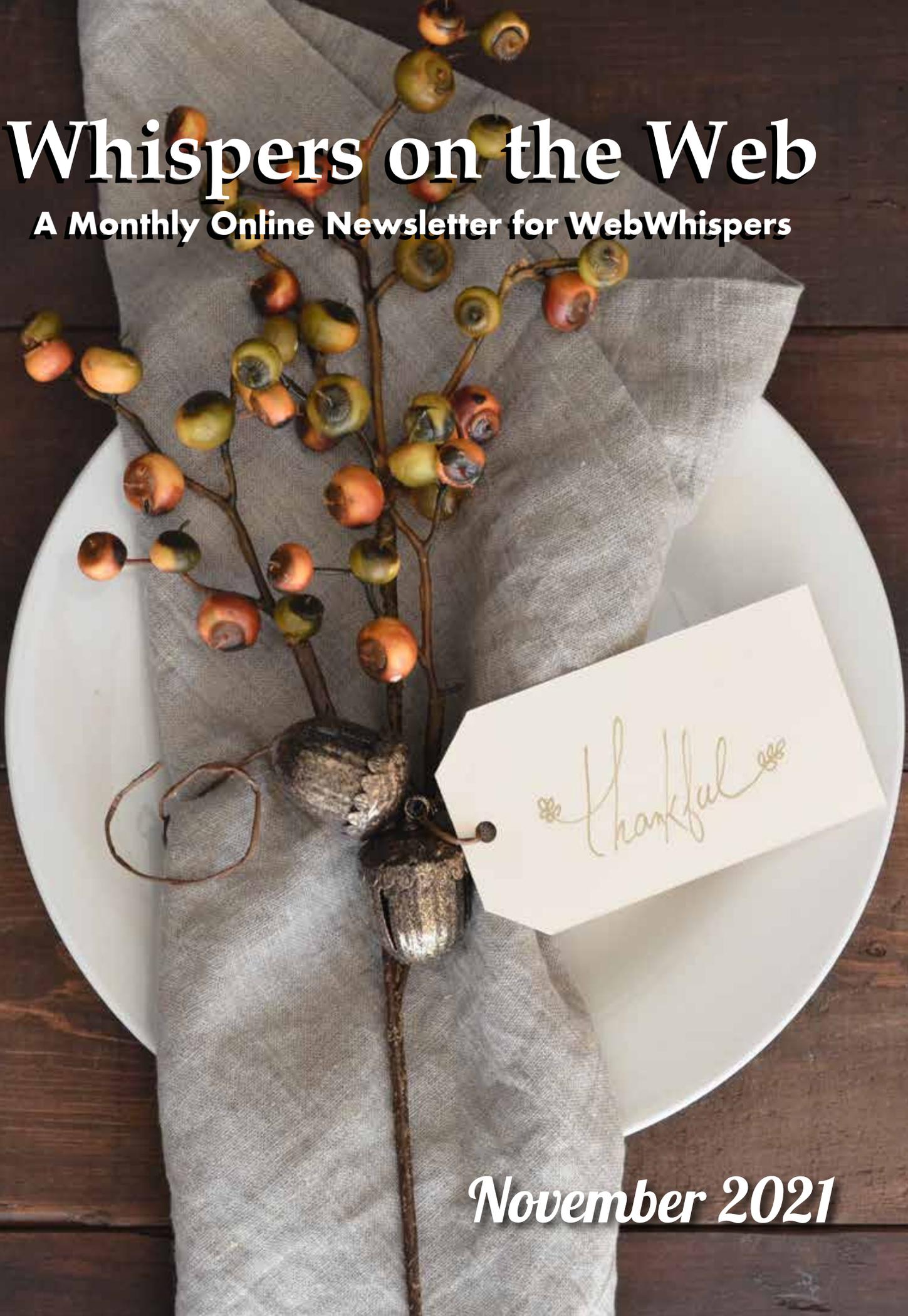


# Whispers on the Web

A Monthly Online Newsletter for WebWhispers



*November 2021*



## From The Editor's Desk

Dear Friends: THANK YOU!!!

How could we ever keep this group going without the support, dedication and hard work from each of our members? It is a team effort! This group is filled with people seeking advice, sending encouragement, sharing information, publishing newsletters, reading newsletters, monitoring emails, taking care of loved ones, caring for and serving one another...Each one of our readers has a unique and important role to play here.

Thank you for being a part of WebWhispers, in ways both large and small.

This month, we talk all about probiotics in VoicePoints. What are they and what can they do for us? Noirin is back with Dear Lary to ask (and give some answers to) the question, "What allows us to heal?" Tom shares part 3 of The Day I Heard the News and This Lary Life Takes us to Ecuador with some amazing pictures. More of these to come next month. Finally, The Silent Partner tells more of his experiences in his First Year as a Laryngectomee.

If you did not get a chance to read his chapter or any of the other pieces from last month, it is worth going back to find it here: <https://webwhispers.org/wp-content/uploads/2021/11/WotW-Sept-Oct-2021.pdf>. Radiation and Claustrophobia: how MANY of you can relate?!

One last request. Do you have a picture of yourself that you would share with the community? Please send it my way. As part of our new and evolving format, we will fill the pages of December with your images. I would like to see your faces, the faces of all who help bring our WebWhispers group to life. In this Thanksgiving month of November, as always, I express my heartfelt gratitude for every one of you and for all that you do for our community.

*Kim, Tom, and the rest of the gang  
at Whispers on the Web*

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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](mailto:editor@webwhispers.org)

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## The Day I Heard the News Part 3

*(Continued from September/October 2021)*

The subtitle here could accurately be something like “Drugs, Drugs, Drugs” or maybe “Near Miss on Addiction”. The latter was my point in this whole thing.

Within a few days, I met with my medical and radiation oncologists and started hearing terms I never knew. For instance, I had never heard of a “tumor board”. The idea that doctors and others were sitting around a conference table or whatever deciding what to do with me, for me, and to me, was concerning. Though still not afraid, the fact that so many people were involved seemed to be saying that my situation might be more serious than I had realized.

As it turns out, it was. One of my doctors had recently transferred from MD Anderson and people there were also somewhat involved in deciding on my “treatment plan”. I began to think- “whoa, this is serious, it is real, and I am the cancer patient.”

The first vocal cord to be affected by cancer was already stationary so my voice sounded horrible already, sometimes like the sound of one hand clapping. People often grimaced when I tried to speak. Even though I was not in much pain (yet), it sounded to them like I was. Out of consideration for so many that I knew truly cared about me, I had already begun

speaking less and less. I sounded nothing like myself to those who had known me a long time. Hearing my voice put them in fear for me and it was often difficult to understand me anyway. So why bother? Swallowing was already becoming an issue, too.

The treatment plan was to start chemotherapy and daily radiation in three more weeks, in part because the oncologists wanted me to get a PEG tube first. When I questioned the necessity of that, the doctor explained that if I needed it after treatment began, there would be a delay in getting the procedure scheduled and that would mess up everything. That I understood.

Still, I would have opted to start the treatment in a day or two. Because my voice and swallowing were getting so bad already, the radiation oncologist hooked me up with the rehab center where I began working with my first SLP and that part of the plan began immediately. We worked on speech as we could, but mainly on swallowing in preparation for radiotherapy. At this point, pain had not been much of an issue.

Chemotherapy and radiation began about three weeks after diagnosis. At the two week mark, my medical oncologist wrote me a prescription for morphine and instructed me to fill it there at the hospital on my way out. When I questioned the need for it, she said I would need it soon to control the pain, if not this week, surely by the end of week three.

Week three came and the doctor was amazed that I was still doing okay. She wasn't off by much, though. At the end of week four, we were on the other side of Atlanta at a UGA homecoming football game. Feeling too tired after walking a good bit of the campus, I forfeited marching with the alumni band, which was the main reason my daughter and I were there. I was hurting some but wrote it off to any number of things (allergies, etc.) other than what it was.

By midway through the second quarter, pain had progressed quickly. This was the discomfort the doctor had warned me about. We left during half-time to make the two hour drive home so I could use "that medicine", the morphine. I could not get home soon enough.

Morphine did a great job of fighting off pain but I learned within a day or two that, though I could only use it every four hours, it was only effective for 60 to 90 minutes, tops. That was not going to work. The doctor switched me to hydrocodone, which worked great for the pain for two or three weeks, but then the effectiveness of it waned.

Advising that I would not be able to drive myself to the hospital two or three times a week as I was doing, she made me promise I would arrange for drivers and prescribed for me a Fentanyl patch. Fentanyl was my new wonder drug. It worked great and I had it in a 48-hour patch on my arm. No more pills for me; this was easier.

Though treatment was over and I drank around three liters of water a day, I stayed dehydrated. I took fluids at least twice weekly for at least another month. In order to use Fentanyl, my wife, brother, and sister all got me to the hospital for my infusion appointments. I hated being so dependent on others and not being able to take care of myself.

The patch was used for about three weeks, I think. I weaned myself off of Fentanyl by trying to see if I could make it past 48 hours before applying a new patch. I was lucky enough to have that work.

When I began to hear about an opioid crisis in the US, I was horrified. As I would see my former medications mentioned on the news, I began to realize how blessed I was to have not become addicted to them.

When using them legally, I remember thinking "if I became addicted to this stuff, how would I get it without a prescription? Am I capable of doing the things that desperate people do to get drugs?" Thoughts like that helped me to keep things in check. The idea of becoming truly dependent on drugs long term terrified me like nothing else, ever.

To help hold myself accountable, I would tell Julie, whether or not she asked, when I had taken a medication, and asked when I could take it again. I would keep a log so as not to get confused about timing and doses. I frequently fell asleep in those days in my trusty recliner and awoke confused.

My doctor trusted me. She saw me as level-headed, strong, (stronger than I actually was), and responsible. Still I should have never possessed morphine, hydrocodone, and Fentanyl in my home all at the same time. One should have been collected before issuing the next.

I think a caregiver or at least a companion should be present when such drugs are prescribed so that someone other than the patient is aware of the risks of using them and can help the patient to avoid abuse of them or addiction to them. Such drugs are invaluable when used as intended, but they also can easily kill people.

I'm one of the lucky ones.

*Live well,*

*Tom Whitworth  
WebWhispers President*



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## **Probiotics: What You Need to Know**

### **What are probiotics?**

Probiotics are often referred to as beneficial gut bacteria and/or yeasts. They are live microorganisms that help improve and restore gut flora.

Probiotics contain many different microorganisms. The two most common bacteria found in probiotics are Lactobacillus and Bifidobacterium; the most common yeast found in probiotics is Saccharomyces boulardii.

### **How do probiotics work?**

Researchers are studying probiotics to determine the following: can they help prevent or treat specific health problems; which strains are helpful; and how much to take on a daily basis. Probiotics help build and restore a healthy balance of bacteria in our gut and stimulate our gut immune system. Consequently, potentially harmful bacteria are kept in check. Probiotics can also help control inflammation of the GI tract.

### **What foods contain probiotics?**

Probiotics are found naturally in specific foods. The best probiotic foods are:

- Greek yogurt
- Miso and Tempeh (*fermented soybeans*)
- Kefir (*fermented milk drink*)
- Pickled vegetables

- Fermented vegetables like sauerkraut and kimchi
- Buttermilk
- Kombucha tea (*fermented black or green tea*)

Probiotics do exist in supplement form, however the U.S. Food and Drug Administration (FDA) may or may not regulate it. Many probiotics are sold as dietary supplements which do not require FDA approval before it is sold, which means a probiotic may have ingredients listed on the label that are not actually in the product.

### **Who should take probiotics?**

Because microbes used in probiotics already exist naturally in your body, consuming probiotic-containing foods is generally considered safe. Patients should always consult with their healthcare team before taking a probiotic supplement since not all are alike, and some may cause mild digestive problems such as bloating and gas.

Probiotics are considered safe for most patients but should be used with caution in those with weakened immune systems, those with a critical illness, or those with a disruption in the lining of their intestine.

Anyone with a serious underlying health condition should be monitored closely while taking probiotics.

## A thought from a speech pathologist...

Some patients who communicate using a tracheoesophageal voice prosthesis (TEP) have found benefit in extending the wear time of their voice prosthesis by routinely taking a probiotic. One cause of early voice prosthesis failure (i.e., leakage of food, liquids, secretions through the central barrel of the prosthesis) is rapid colonization of biofilm on the prosthesis, preventing the valve from completely closing during swallowing. Biofilm is the growth of fungus, bacterial and other microbes that collect on the TEP and can cause prosthetic failure. Probiotics may slow the colonization of biofilm on the prosthesis. Additionally, chronic acid reflux can cause several TEP problems including central leakage, periprosthetic leakage, puncture site enlargement, voice changes, and even inadvertent TEP dislodgement. There is a high incidence rate of chronic reflux in the laryngectomy population from anatomical changes. Smit et al. (1998) found 80% of laryngectomees had pathologic reflux and Boscolo-Rizzo et al. (2008) found laryngectomees

diagnosed with GERD had an associated reduction in TEP life. By supporting gut health, probiotics may minimize acid reflux and the subsequent impact on a TEP. Unfortunately, most of the benefits of probiotics on TEPs is anecdotal with limited research to support use in this population, so please consult with your healthcare provider to see if probiotics may be beneficial to you.

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## Material World

By Noirin Sheahan

We live in a material world. As a minimum we need food, clothes and medicine but most of us want a house and car too and these lead on to mortgage, insurance and don't forget the freezer, sound system, house alarm ... And all these need time and care, maintenance, repair, renewal ...

And what about our body? Like all the material world it needs care and attention, special diets, exercise programs, health insurance, doctors visits, vaccines, repairs ...

We're so attached to our material world; we see it as part of ourselves – my house, my leg, my voice. But of course, they aren't really mine at all. Most of us here will have lost our original voices. The mind plays a clever psychological trick to make things feel as if they are mine, while another part knows the hard truth.

But that psychological trick pulls my heartstrings, tells me I absolutely must have and need every one of 'my' possessions. It's so persistent, insistent. For the most part it runs my life.

My house for example. How would it be to lose my house? To have nowhere I could call home, relax, forget the outside world? Nowhere to invite family or friends for Christmas? As I try to imagine this, my mind seizes up in protest and disbelief.

But then again, most of us have lost something at least as precious. And we've survived, slowly adjusting to our new reality.

I remember during the first weeks post-op, when I recovered enough to walk around the hospital grounds. My mind was like a radio jammed between stations – blaring noise, wordless bellows

of incomprehension and grief. It was summer and flowers were blooming. When I looked at a flower, the transistor would suddenly switch off, go silent. I could feel the stirrings of joy in my heart. A moment later the radio surged back on, bellowing full blast. The bellows felt true, felt like 'me'. The momentary peace now felt like an intruder, the memory of joy like a guilty betrayal – how could I have been so insensitive? Couldn't I see that there was no place for joy anymore?

That psychological trickster was hard at work during those early weeks.

What allows us to heal? Time, of course, good family and friends, faith or philosophy for some. For me it's also been the practice of mindfulness - bringing attention to present experience, listening to the thoughts of 'me ... mine ... I want ... I need ...' and the strong feelings that insist these represent absolute truth. But the rational mind shows up too, knows better that to believe the thoughts. If I can hold attention steady amidst all the confusion, the blaring radio tunes into a channel of peace. Once that happens feelings of grief and incomprehension can be seen for what they are – just feelings. Not to be disregarded or denied, but not absolute truth either. Bearable.

Although my mind seizes up and rebels against the notion of losing my house, I know that in reality I would cope. Mindfulness would gradually teach my heart to accept that the house was never really 'mine' and that flowers would still bloom and evoke joy even if I was homeless and destitute.

Deep as my attachment is to the material world, mindfulness is gradually unpicking the stitches.

# THE SILENT PARTNER

My First Year as a Laryngotomee

## **Chapter 8: CLEARING YOUR THROAT: MUCUS ADO ABOUT NOTHING, PRESCRIPTIONS, AND THE HIGH COST OF ALL THAT STUFF**

They wouldn't release me from the hospital until I had been issued, and knew how to use, a suction machine.\* Initially, the business end was fitted with a catheter which was inserted into the stoma until I coughed and then slowly withdrawn while moving it in small circles to get as much stuff out as possible. This usually had to be repeated twice more for the maximum effect. At that point, regardless of whether there was more, I couldn't deal with another try until I had rested for a while.

During my stay in the hospital, a nurse or respiratory technician did this for me. Shelley also was trained to do this, but I had to be able to do it for myself when I went home. The first few weeks were the worst. I still had to sleep sitting up because of the mucus production. We put the machine next to my side of the bed and I would wake Shelley up when my throat needed to be vacuumed. Sometimes, no matter how we tried, there was still something there and it kept me awake. When I got more proficient with the machine and was doing this for myself, we moved it into the living room, next to my recliner, because I mostly slept there where I could more easily sleep partially sitting up.

As time passed it got easier and less stressful to clear my throat. Finally, months later, after radiation therapy was finished, I started weaning myself from the lary tube, taking it out for a few hours every day. I was getting ready for the next big step – going without the tube entirely so I could get a voice prosthesis. I made an appointment with the doctor who would do the actual puncture between my windpipe (trachea) and my throat (esophagus) where the device would be placed. Both the puncture and the device are called a TEP – for tracheoesophageal puncture

or tracheoesophageal voice prosthesis. The TEP device is a tiny one-way valve imbedded in the wall separating the trachea and the esophagus. It is operated by pressing on the HME (also a kind of valve as well as a filter) which closes it, forcing air through the TEP into your throat. This creates a vibration of the air which is audible and is then formed into speech by your tongue and lips. I've heard others who sound fairly normal using their devices, but the first time I tried mine out, I sounded like I was trying to talk while gargling with creamy peanut butter. I still sound like a bad Donald Duck imitation.

In order to get the implant, I had to first do without the trach tube entirely. This meant that I could also do without the collar that held it, but that I would need an adhesive plate to cover the stoma and hold the HME. I had one sample. In order to get more adhesive plates, I had to get yet another prescription. As it turned out, I needed a prescription for other things as well.

This comes under the heading: "Things That I Wish They Would Have Told Me Earlier!" Between obtaining the adhesives and running smack dab into the pandemic and quarantine, I had to wait impatiently for my new 'voice'. I thought I would be able to 'talk' as soon as I had healed sufficiently from the radiation for them to do the procedure, but I was sadly disappointed. It took another several weeks, including a test for the corona virus and waiting for the results.

Getting rid of the tube had many side benefits other than getting the prosthesis. For one, the tube was getting uncomfortable when I put it back in for the night, now that I was taking it out during the day. But the biggest benefit of all was that after more than eight months of sponge baths and washing my hair in the sink, I got to TAKE A SHOWER! Of course I first had to get another prescription for the ShowerAid ©, a little blue plastic snorkel kind of thing that fit in the adhesive plate where the HME usually was, so that I wouldn't drown myself. Medicare paid for mine, which is good because they sell for \$82.50 each. Another Thing They Should Have Told Me Earlier was how expensive it could be to become a

laryngectomy. Dennis the nurse mentioned that the HME cassette ran \$250.00 for a box of thirty, or just over eight bucks each for an item that had to be changed daily at the very least. At first I was going through a box a week due to coughing up mucus and clogging them when I couldn't pull them out quickly enough.

Nowadays, I'm down to about ten or twelve a week. The brushes that I had been using to clean the tubes when I was still wearing them, cost me \$45.00 for a bag of six, or \$7.50 each. I still have four left that I no longer need. At least I didn't need a prescription for those. I have an old friend and former client who owns factories in Southeast Asia that could have made them for a small fraction of that cost.

Getting rid of the tube and getting the TEP also meant that instead of cleaning the tube, I now had to clean the inside of the stoma and the TEP. With the TEP I was given a weird little brush to clean the inside of it, and a little flushing device to squirt water through the TEP. I don't even want to know what these things would cost if Medicare didn't pay for them. Each and every product from Atos © comes with a booklet written in eight languages, which no doubt adds to the cost. I have saved one of each booklet, the rest go into the blue bin. Except the booklet that comes with the adhesive plates, it has "deliberately left empty" pages 35 through 50 and I tear them out for use as notepaper.

Brushing and flushing the TEP is fairly straightforward – I just remove the adhesive plate, get close to a mirror, grab a small flashlight and have at it with the tools provided. Cleaning the inside of the stoma every day involves cotton swabs and a long pair of tweezers. With the adhesive plate removed, I shine the flashlight in there and use the moistened swab to remove what I can. However there is usually some mucus that has dried and hardened a little that has to be GENTLY removed with the tweezers, a chunk at a time. This sometimes tickles, causing me to cough, then it's back to the suction device to clear the mucus again.

\*My Main Machine.

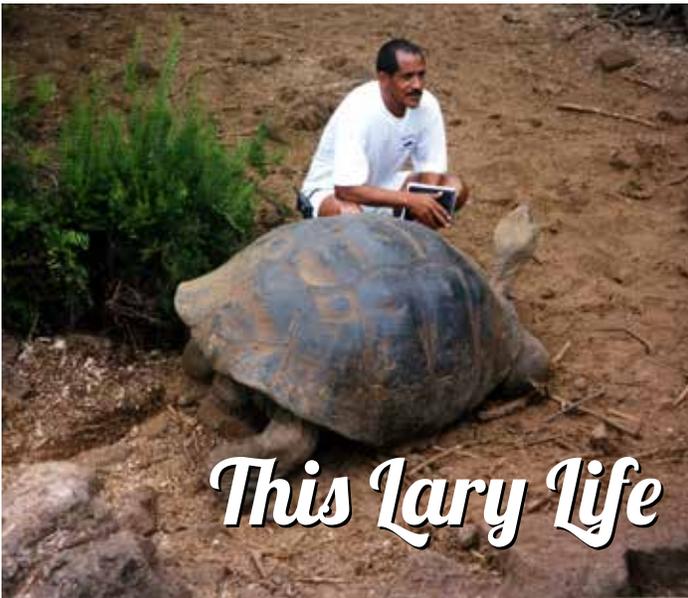
A little about the machine I will be spending the rest of my life with. This little gem is a smaller portable version of the suction machine that is used in hospitals. Think of a mini wet vac for your throat. It can be used with household current, vehicle battery current, or with the built-in rechargeable battery.

The internal battery doesn't last that long until a recharge is needed, usually about three times when using the flexible rubber catheter. This is the first catheter used for newly minted laryngectomees while they are still wearing a lary tube. It is the same urethral catheter that can also be used to remove body fluids at the other end.

A very versatile thing, this catheter: it can be used the two ways as described above and the tip of one can also be used to plug the TEP if it springs a leak. In a pinch they also make a pretty good tourniquet. There are other attachments, including the tooth cleaning wand described earlier.

The attachment used the most is a specific type of catheter called a Flexible Yankauer. I kept calling it a 'yanker' until I looked up the pronunciation. (It does 'yank' the mucus out though.) Named after Sydney Yankauer, it's a foot long plastic tube designed to remove liquids without damaging tissues. Your dentist uses something similar. It is not as flexible as the other kind despite the name, just gives a little if you bend it. The machine has a reservoir to collect the mucus and the water used to clear the catheter and suction tube. The reservoir is marked 800 ml, but has to be emptied before it gets that full or it fails to suck.

I usually have to empty mine two or three times a day. That little sucker is noisy! Especially when it gets too full and the motor starts to whine about it. Mine came with a six foot hose from the reservoir to the business end. I have shortened mine to half that to make it easier to fit in the carrying case. Now I'm looking for a slightly shorter 'yanker' to make packing even easier.



## ECUADOR '99

W. C. Baker

When it comes to place names, Ecuador is unique. Norway takes its name from being so far north. Australia from being south. It is Ecuador, smack dab in the middle, that is the only country I know of that takes its name from a line of latitude. There is of course the Greenwich Meridian, but that is a longitudinal line and it takes its name from the place rather than the other way around.

There are some facts about Ecuador that may surprise you as they did me. For example, the highest place on earth is not Mt. Everest, which is only the highest place above sea level. Volcan Chimborazo in Ecuador is the highest from the center of the earth. Because of the Equatorial Bulge, Chimborazo sticks further into space than any place on earth.

Under the watchful eye of the Santa Ana lighthouse spreads the largest city in Ecuador, Guayaquil. The neighborhoods become more upscale as one ascends the 444 steps to the top of Santa Ana Hill topped by the blue and white, squat lighthouse that can be seen from anywhere in the city and, I presume, far out to sea.

In the flats, a block away from the KFC and Pizza Hut, the sculpted gold altar in the otherwise undistinguished Iglesias San Francisco rivals those that I have seen in Europe. I should note

that there are several sidewalk cafes around the palazzo for those who prefer a more Ecuadoran menu.

After a harrowing bus ride into the Andes, where looking out the window the edge of the road could not be seen, only the river far below, we arrived in a strangely quiet Quito. Eruption of 15,750 ft Pichincha, which looms over the city, cast a layer of gray ash over everything. People were wearing masks, cars had their hoods up with drivers cleaning out air filters, and the quiet was pervasive. Having a head start on the mask thing, wearing a bib over my foam filter, I felt special. Church interiors rule in Quito. As impressive as the altar was in Guayaquil, the interior of the Quito San Francisco is equally impressive. Campania de Jesus was mind-blowing with its extensive use of gold leaf and carved wood. The Rosary Chapel in Santa Domingo is slightly more subtle but, to me, more artistic. Add to the churches, the museums and parks and Quito rank high as places to visit.

Otavallo lacks the eye candy of Quito, but it has a special excitement in its famous markets. Otavallo is very much an indigenous community and as such is represented in its highly regarded hand goods, especially their textiles. On Saturdays it seems the whole town becomes a market that attracts people from all over. I bought several non-eponymous Panama hats for friends and have none for myself. Panama hats are so named because Teddy Roosevelt was pictured wearing one when he visited the digging of the Panama Canal. They are made in Ecuador.



A unique living museum and showcase of evolution, the Galapagos Islands lie about 1000 miles west of the land part of Ecuador. The convergence of three major Pacific currents have contributed to the diversity of unique species of plants such as giant cacti and endemic trees, and animals like marine iguanas, giant tortoises, and the finches that figured so prominently in Darwin's Origin of Species.



miles north of the equator is by far the most entertaining bird, the Blue-footed booby. These always seemed to be in couples and constantly displaying to each other: bill dueling, head dipping, gazing at some distant nothing and

doing a little dance to show off their beautiful blue webbed feet.

Touring the Galapagos is done by boat. Our first night aboard was distinctly unpleasant because we had the foremost cabin in the bow where the anchor chains seemed to be going up and down all night, I assume in response to rough seas. On the second night we moved to an above deck cabin, perhaps in recognition of our being the oldest people on the boat. Whatever, it made the rest of the mini-cruise much more enjoyable. A hike up the Sierra Negra Volcano on Isabela provides a vista that clearly shows the tectonic forces that have been building the Islands for a mere 5 million years.

I don't know how the Sally Lightfoot crab got its name, but it is fitting. This colorful little crab skits about on tiptoe, ignoring us, as did all the animals of the Galapagos. The most prolific of the land animals seems to be the marine iguana, unique to the Galapagos and unique in that they live largely in the sea, dining on algae. They are often found with the much smaller cave lizard crawling about on them, dining on their parasites. We got up close with some exclusively marine animals. In shallow lagoons were rays, and in a small inlet a young Galapagos shark.

The islands take their name from the Spanish for tortoise. Although they are not the largest animals on the islands (that distinction would go to the sea lions), the Giant tortoise, to me, is the most impressive. They are aptly named. The giant tortoise varies from island to island, but its size and pace give it a certain dignity befitting its age.

On returning to the mainland, we spent an extra day in Guayaquil. Our flight was postponed until the ash from an erupting volcano cleared enough that the jet engines would not choke on it.

Birds being birds they get around a lot, but in the Galapagos some, like Darwin's finches, stick to the islands where they were hatched. The biggest bird surprise for me was the knee-high Galapagos penguin, the only penguin to dwell in the northern hemisphere, though just a few





*Join us in December!*