



WebWhispers

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Throat Cancer and Laryngectomy Rehabilitation



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FEEDBACK



Notes about Health

They are everywhere! Can't pick up a newspaper, turn on a TV or open email without all of the health announcements. Seems they are finding so many results about different problems, there is no way to keep up!

A British study found that regular consumption of low-fat yogurt can reduce the risk of developing type 2 diabetes. Saw this in the latest AARP newsletter and went online to check it out and, maybe I like this because I eat low-fat yogurt every day and it has helped keep my A1C reading good. The study researchers found that a higher consumption of low-fat fermented dairy products, which included some low-fat cheeses, cut the risk of type 2 diabetes onset by 28 percent and reduced the relative risk of diabetes by 24 percent overall. Read more at <http://www.redorbit.com/>

There is much to read about on the Internet about Vitamin D3 supplements. Good idea for any of us to have the levels of Vit D checked. While you may think you get enough, I was just reading in Life Extension that the levels shown in test results should be at least 50 ng/ml instead of the 30-100 reading on test results. They suggest we take 2,000 IU a day at an absolute minimum to reach the 30 reading and mention that most people need 5,000 - 7,000 IU a day to achieve optimal blood levels. I took 6,000 a day in olive oil drops, 2,000 to a drop, for about two years and my readings were up from 24 to near 90 by then, so I dropped to 4,000 a day and that is what I take all the time now.

I am also tired of reading about coffee. Even when the experts wonder that so many coffee drinkers live longer, they are finding every exception to add to their articles so they are not recommending something that will jump up and bite them with new found bad news. I like coffee. I drink it black so there are no calories and unsweetened so there are no sugars or chemicals added.

Many years ago, when I was a bowhunter, I had been in a blind waiting for a shot at a deer, and when we closed up for the evening hunt, a few of us met back on the road to walk back to the camp. They had coffee... black. Even though I was a half milk/half coffee drinker..with sugar, it was cold and I was tired. I accepted some steaming hot black coffee. Changed my coffee drinking forever. Nothing ever tasted so good. So I shall not listen to the back and forth on the good it does and the limits. I'll drink it when I want it, and am delighted there are some folks on my side. Besides, when I had my laryngectomy, hot black coffee was the best thing I found to cut the mucus. Still is.

*Enjoy,
Pat W Sanders
WebWhispers President*



Voice Points

Written by Professionals

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Why Not the Electrolarynx?

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Introduction

Speech rehabilitation following total laryngectomy (TL) has been an evolving practice for over 150 years. From the earliest designs of artificial larynges by Czermak in 1859, the first mouth-type electrolarynx (EL) introduced by Gluck in 1905, to the transistorized, neck-type EL developed by Bell Laboratories in 1959, many advancements in communicating with an artificial larynx have occurred. Current EL models continue to use a similar design of the original neck-type devices. Collectively, EL devices must remain an important option in postlaryngectomy rehabilitation.

Despite the wide application of the EL in postlaryngectomy rehabilitation historically, there was a gradual shift regarding how Speech-Language Pathologists (SLPs) approached alaryngeal voice and speech rehabilitation in the mid-20th century. Specifically, interest grew in efforts to instruct patients how to use “intrinsic” esophageal alaryngeal communication methods, with the EL being slowly cast aside as an inferior communication method.

Where Alaryngeal Voice and Speech Rehabilitation (Almost) Went Wrong

Esophageal speech (ES), originally described by Moolenaar-Bijl in 1953 and later by Diedrich in 1968, gained considerable popularity from the 1950s to the late 1970s. ES was the “preferred” alaryngeal communication method used by SLPs when instructing laryngectomees to reacquire speech. However, at the end of the 1970s, advancements in surgical-prosthetic techniques, the most notable being tracheoesophageal puncture (TEP) voice restoration introduced by Blom and Singer in 1980, paved the way to the contemporary world of postlaryngectomy speech rehabilitation.

Unfortunately, as TEP voice restoration gained widespread popularity, continued biases against, and outright ignorance toward the importance of the EL expanded; this also spawned an emergent and incidental negative attitude toward ES. These negative perceptions led in part to an unspoken dogma that was (and sadly still is) shared among some health professionals; more specifically, the EL was identified as an inferior communication method, one that should be used only as a “last choice option” or a “back-up” in the event that an individual was unsuccessful in their attempt to learn ES or were not suitable candidates for TEP. Whether intended or not and regardless of the reason, those who used EL were essentially deemed “second class” citizens in many professional settings. Granted, it is

understandable that the acoustic and auditory perceptual characteristics of EL speech, often described as ‘robotic’ and ‘mechanical’ contributes toward these negative opinions regarding the EL as a primary post-TL communication option. In addition, early EL devices were bulky, potentially difficult to manipulate by both men and women, and had mechanical reliability concerns.

Clearly, the quality of EL speech differs from the existing intrinsic alaryngeal methods that use a biological sound source (i.e., ES and TEP). Emerging comparative data in the 1980’s (some of it contributed by one of the current authors) revealed that TEP voice restoration potentially had advantages at multiple levels – frequency, intensity, speech rate, and intelligibility. It appeared that ES and TEP were superior methods of alaryngeal communication; however, such discussions failed to indicate some of the unique problems faced by ES and TEP speakers. For example, early data suggested that more than 30% of those who were laryngectomized were unable to acquire ES, and of those who were successful, less than 50% produced ‘acceptable’ speech. Interestingly, it was the observation of pharyngoesophageal spasm secondary to TEP voice restoration that provided evidence that the failure to acquire functional ES was not borne of a lack of motivation by the laryngectomee, but most likely a physiologic limitation in the postlaryngectomy system (see Doyle & Eadie, 2005). Furthermore, when accounting for failed treatment of laryngeal cancer with radiation (and as part of ‘laryngeal conservation approaches’), the failure rates for acquiring ES could be even higher. In addition, while radiation therapy does spare an individual’s larynx, there are a host of tissue-related changes that occur and can interfere with ES and TEP speech. In cases of recurrence following conservation treatment approaches, not to mention chemoradiation failures, salvage procedures may carry an even higher risk of post-treatment complications. This has led to an increase in the treatment-related failure of TEPs (i.e., fistulas or wound dehiscence), or can involve air leakage through and/or around the prostheses. Given the concerns with ES and TEP speech, there is no question that there is a continued need for use of the EL.

Contributing to this argument is the fact that, while EL devices remain imperfect, they have improved: they are more compact, reliable, affordable, and contain a host of easily adjustable speech characteristics including volume, pitch, and/or intonation. In light of these changes, however, many will argue that the unnatural (i.e., mechanical) voice characteristics of EL speech continue to be the primary reason why many might not initially consider the EL as a viable communication method. This is just one reason why a ‘balanced approach’ to alaryngeal voice and speech rehabilitation is essential; at the very least, a dialogue between the SLP and the laryngectomee is essential.

The Future of Alaryngeal Voice and Speech Rehabilitation: A Balanced Approach

The goal of any postlaryngectomy speech rehabilitation program is to restore communication so that one can effectively verbalize their thoughts and emotions. While alaryngeal speech methods clearly deviate from normal speech both acoustically and perceptually, it is important for SLPs and other health professionals working with laryngectomees to recognize that EL, ES, and TEP are all viable methods to restore functional communication following TL. Therefore, outright exclusion of any of these alaryngeal speaking methods represents a disservice to the laryngectomee who could benefit from any one (or more) of these communication methods.

Successful rehabilitation following TL requires that every health practitioner involved in the laryngectomee’s care fulfill his/her specific duties. This includes putting the patient first and removing personal bias from the decision-making process. A ‘balanced approach’ to alaryngeal communication rehabilitation is one that always considers the EL; whether consideration is provided in the form of using the EL as a laryngectomee’s first means of communication, their primary communication method, or one that can be used when the laryngectomee is unable to use ES or TEP speech (e.g., in times of stress/fatigue, TEP prosthesis leakage, etc.). At the very least, every laryngectomee, and we might add every SLP student and SLP professional who works with this population, should be trained to use an EL device with the same attention and care that is obtained for ES and TEP speech.

There are, however, a number of reasons that the EL must not be discarded from consideration. The most prominent is a simple one, namely, what happens if the laryngectomee is unable to acquire or use ES or TEP speech effectively? The question that ultimately arises may then be an ethical one. Who ultimately is responsible for making a decision to use an EL? It is our opinion that the SLP must provide fair and balanced information about all methods of postlaryngectomy communication; no method is perfect, nor is any method without distinct advantages and

disadvantages within specific contexts. Yet in the contemporary laryngectomy rehabilitation context, what happens to those who cannot acquire ES or TEP speech? What about those who are poor candidates for TEP voice restoration, or quite frankly, those who do not wish to pursue these options regardless of reason? Some individuals indicate that they do not wish to maintain a voice prosthesis, that they do not have easy access to professionals should problems emerge, or that when all factors are considered, they wish to avoid any additional risks (e.g., airway problems, leakage through or around a prosthesis, etc.). So, what about them?

In closing, the present commentary is not presented as an argument against either ES or TEP voice restoration; rather, our goal is to provide a balanced perspective that is unrestrictive and pragmatic, particularly in the context of allowing one to make informed decisions about their postlaryngectomy communication. If one cannot or does not desire to acquire ES or to pursue TEP voice restoration, then where do they fit in the clinical picture? Ultimately, we are left with a single question: Why not the electrolarynx?

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We Are Borg. Resistance is Futile.

Those were my first words when I finally got my electrolarynx (Servox). I was so thrilled I ran into my ENT's office to tell him, but, poor thing, he wasn't a Trekkie so he didn't get it. He had been so diligent trying every possible thing to get me to voice. But ongoing scar tissue damage from radiation left me with no options. I coughed constantly from even the slightest exertion. Even occluding to produce some slight squeak sent me into spasms and increasingly produced no sound at all.

The Servox was a revelation! I didn't give a darn that I sounded like a robot. I could talk again and people could understand me. They didn't have to read my lips and no one was asking me to whisper louder.

When I went to my job and talked to my co-workers I expressed concern; maybe they would have a problem with my robotic voice. One fellow said, "We have watched you struggle for so long with no voice, we're just glad to hear you, no matter how it sounds!"

Once I started talking so that folks could understand me again, I was hard to stop. My son and my co-workers used to joke that at least I was easy to shut up now – just hide my batteries.

I am reminded of this because of two columns this month. VoicePoints presents the professional concerns surrounding some of the prejudices against ELs and Speaking Out is our opportunity as laryngectomees to tell about our most memorable moments. For many of us learning to speak again and accepting our new voice is that moment. It may be the moment when we realize our new voice does not define us no matter what it sounds like...if it even has sound at all.

It also may be the moment when we realize that the way we communicate is less important than what we communicate. The novelty of sounding like the Borg wore off long ago. I still miss my old voice, sometimes desperately so. I don't expect that will ever change.

But as many folks here will attest to, where there's a will there's a way. If you can't use ES or a TEP or an EL there are other options. Ask my brother who was visiting me during the "silent days". He was watching a Red Sox game and I was puttering around the house. Someone did something stupid and behind his back I uttered several expletives deleted (you can probably figure out which ones) and without even turning around he said, "I heard that!"

I am not trivializing this. I hate that I sound like a robot. I have severe bursitis in my Servox arm and there are times I really wish I could yell. But I can talk and people can usually understand me. Years ago I learned that there will always be some people better off than you and others who are worse off. That is life. I have decided that while resistance actually may not be futile the energy is better spent celebrating my inner robot.



Special Moments from laryngectomees

Cathy Quinn, Rochester, NY - August 2013

I have cats. They're not allowed on the kitchen table or counters and they know it but once in a while when I'm walking towards the kitchen, I hear little paws jumping down from a place they should not be. To combat this, I wash my counters continuously with a cleaner and sponge. I was shopping a couple of months ago and found that I had a coupon for anti-bacterial wipes for kitchen counters that were great for "cutting through grease" and "easy to use". They certainly looked a lot easier to use than what I have been doing for years so I thought I would give them a try. I

had been using them for a week when my boyfriend commented that he really liked the way they smelled. He said they had a light, citrus-y smell to them.

I looked at the wipe in my hand with surprise. Since becoming a laryngectomee I've lost my sense of smell so it never even occurred to me that there might be a scent to these wipes. I started waving it in front of my nose to see if I could get even a small whiff of what he was talking about. He immediately came hurrying over and started blowing on the wipe into my face to see if he could help me get a whiff. This got me laughing which then led to me crying. I just leaned over and gave him a big hug. You know a man loves you when his first response is to hurry over and try to help give you the experience that you're missing out on. He didn't even think about it, just sprung into action. So becoming a laryngectomee has really brought home how truly loved I am.

Mohan Raj, Bangalore, India - Mar 2010

I was 75 years old when I had my TL. Up until then I never faced a TV camera nor was I ever in the news in Print Media. My surgeon is a passionate Anti-Tobacco activist. He chose me as his 'Mascot', whenever he lectured well attended groups of students, lawmakers, hoteliers, Para-Military groups, policemen etc. He holds press conferences regularly and he is very serious about banning cigarettes, beedi and "Gutkha" [betel leaf chewed with tobacco]. He takes me regularly for all these meetings almost every month.

So, suddenly, I am there in all TV channels of many languages of India. My photos come regularly in various national dailies in various languages. Reporters are after me to elicit information about life of a Lary, so that they can make a nice article on the subject with my photo there and my message.

Normally, people crave for publicity to appear in media. Here I am, getting all this publicity, just because I am a Lary. Each such occasion is a special moment for me!

I rejoice having suddenly transformed to a celebrity, never mind being a Lary!!

Gary Gierhart, Lakeland, FL - March 2013

I lost my voice due to cancer a year ago. I now breath thru my neck and use an electrolarynx. When I came home from the hospital my dog was so happy to see me and waited on me to say something. I couldn't talk at that time and my Little Nena was so confused. I tried to tell her by sign language but she didn't understand. For several days she would walk by me and look puzzled that I didn't speak. So I started learning how to communicate with my electrolarynx and she was frightened that I wasn't the same person she had known for many years.

As time went by she would sit and listen to me practice and finally accepted my voice and really listened. I have her back again.....I also started to teach her some sign language and she is doing very well with it also. Dogs are very smart and want to learn new things.

I still have my peg tube and have 6 boost plus a day as I cannot eat food. Hopefully in the near future the surgeon will be able to stretch my throat so I can again eat food. It has been a long difficult road but things are beginning to look better. Thank you for listening.

Marlene E. Haynes - 12-24-96

Not long after my laryngectomee I was in search of a way to volunteer what I had left to share with the world, our St. Louis support group got an invitation to help with the American Lung Association conference so I said, "sure I'll be there to help". I was nervous but I went and passed out pamphlets and flyers and we set up a table to register people and show them around to the meeting rooms etc.

I sat through 3 days of lectures and medical information and meeting and befriending lots of patients and caregivers. I came to such a shocking revelation through that 3 days that I cried when it was over. I came home realizing how very blessed we are "even being laryngectomees," Our names are not on a list waiting for a donor so we can live, we have not been given new lungs that could be rejected at any moment, we are not hooked up to tanks and tubes and expensive medical care in order to breathe air every day, the list goes on and on, but, what it boils down to is, God has been so good to us in so many ways, we have a lot to be thankful for.

Logan Grayson, Ponca City, OK - 1997

My name is Logan Grayson and I have been a laryngectomee since Feb 1997. I live in a small town in the far north of Okla . I had my surgery in Okla city and didn't know what I was getting myself in for as I had never even heard the word laryngectomee. On the 3rd day out of ICU the speech therapist of the hospital brought me a Cooper Rand EL and showed me how to use it. Within 2 days I was speaking so that I could be understood but hated the sound that I was able to make. I used that Cooper Rand E/L as a loaner for 30 days. and in the meantime the speech therapist ordered me an EL from one of our suppliers and it was a NU-Vois and was to be my voice for 3 years but I thought it would be forever so I settled for it and got on with life.

One weekend while on a visit to family in Texas I stopped for gas and like always sooner or later you're going to run into another laryngectomee. and I did but he was speaking with something a little clearer than I was and he explained what he was using was an oral adapter and I thought wow he sounds a lot better than I do and as we talked he went and got another oral adapter and some of the tubes it used and just gave it to me. I thanked him and used it for the next couple of years. My son and youngest daughter had moved to Missouri so we went to spend a weekend visiting them and they lived in a 2 story house with a balcony on the south side which had a beautiful lake to sit out and watch. I leaned over the balcony and there went my EL to the cement below and me with no back up. I had my son call on one of our suppliers and him being who he is overnighed me a an EL to Missouri and I sent mine to him when I got home.

Then one day after we got home I went into a gas station to buy some gas and as I walked up to the door a man came out that I could tell he was a laryngectomee. because of the cover he had on his neck and of course he saw the EL sticking out of my shirt pocket so we stopped to visit and as he started talking he had a total different voice than I did. We visited about it and I learned what a TEP was and how it sounded and loved the way it sounded.. I had been shown what a TEP was by my VA SLP but told her that I had had all the surgeries I cared to have and she didn't push me on it. After I talked with the man who had the TEP, from Kansas and was just passing through and I knew this was for me. So the next day I made a call to my Va SLP and put the wheels in motion to get my TEP which I have had for 13 or 14 years now and I love it. I guess the moral of my story is never turn your back on anything because you might find something you need down the road.

Len A.Hynds, The Speechless Poet of Ashford, Kent, England - 2004

I went several months before a valve could be fitted, and writing was my only communication. To speed up my writing I had a quick course at College and then went on to University at the age of 75, to everybody's amazement, including my own. They were marvellous with this silent pensioner, and during those first few months a valve was fitted, and a speech therapist went to work on me. I had not spoken in class at the University, but on this particular day, after attending a lecture on French Medieval poetry, we had a break in the cafeteria, during which time our tutor, John Whitworth MA.B Phil(Oxon), a noted author and poet, told how when a babe in India, a Leopard cub had approached his cot and had been shot. After the break the students read out their work, but mine was always read out by John.

During the time waiting, I scribed this not very good poem.

THE TWO INNOCENTS

THE TWO INNOCENTS

By Len A. Hynds

I'm a Leopardess, high on the bough
proudly watching my little cub stalk,
that butterfly that's landed now,
so close to where men talk.

He's climbed the step, a cot lies there,
a human babe within,
two innocents in this jungle share,
a pure innocence though never kin.

A loud shriek of fear from the Ayah,
I scream to my cub in dread,
a man with a gun, a slayer
shoots my sweet innocent dead.

I lay on my bough, my cub below,
never again to laugh with me.
That young John will be allowed to grow,
whilst I grieve in this jungle tree.

I spoke it myself to their amazement, and their applause was not for my foolish poem, but that I had spoken it myself.
A special moment.

Elizabeth Finchem, Tucson, AZ - Oct 1978

Probably because I have survived and thrived so long as a laryngectomee I have three significant moments to share:

1. My first voluntary word with esophageal speech was at home with family when I asked "What?" It sounded like a question in a feminine voice that was as loud and as clear as my pre-op voice. It gave me hope that I would achieve my goal for ES.
2. As an esophageal speech instructor for many years I still get goose bumps and tears when my student achieves ES voice. Music to my ears!
3. As a laryngectomee that never stopped swimming I am one of several who demonstrate how we can swim safely. The best part for me is when other laryngectomees are moved to try it on the spot. Some have stripped down to their rolled up khakis and get into the water with us. They are often moved to tears and exclaim they feel "born again" with the freedom they feel in the water. Some say they have gone years without enjoying water as they did before surgery and see this as another step to their total rehabilitation.

Angie Leu-Smith, NE - April 2009

My surgery in 2009 was exactly 2 mo before the birth of my 1st great granddaughter. She was the encouragement I needed. When she was about 15 months she was beginning to copy everything anyone did. I suppose she was confused when she watched me cough to clear my airway and use a tissue to wipe it. One day she got hold of a tissue, lifted her shirt and coughed and wiped her belly button. I guess she thought that was the only thing that resembled my stoma. Her grandma and I laughed till we were crying. She continued doing this for a few months and

it made me chuckle every time.

She is almost 5 now and has a baby brother 10 months old and when I'm holding him he reaches up to my HME when he wants me to talk. I'm very happy that I've had the privilege to enjoy all this time with my now 7 great grandchildren.

Bob Bauer, Hayward, CA - Class '08

My memorial Ah-Ha moment was while on a cruise to the Galapagos islands. Our first stop was at Santa Cruz island. After a stroll around the island, we had the opportunity to go for a swim. I eagerly donned my swim trunks grabbed my snorkel and hit the beach. With much anticipation, I entered the water and started to snorkel with the greatest of ease. This was the first time I tried the snorkel so, this was my Ah-Ha moment. Since then I have improved the device and have demoed it at the IAL convention in Spokane.

See pic of Bob using his snorkle:

<http://webwhispers.org/library/Swimming.asp>

Joe Hilsabeck, Edelstein IL - 2009

A special time for me was when I finished radiation and was talking to my DR. who was a very proper looking lady from India. She had been so nice and encouraging. I remarked if I wouldn't embarrass you I'd give you a hug. She promptly dropped her papers and said, "Hey, we all need a big hug." Nurses had said how nice a person she was, then I knew what they meant.

Carl Strand, Mystic CT - February 1993

At the time of my laryngectomy, I was President of the Old Mystic Fire District, Chairman of the Groton - New London Airport Advisory Commtee and a board chairman at my church. On returning home from the hospital I resigned from all three positions. All of the resignations were declined. Perhaps they had more faith in me than I had in myself.

About three weeks after receiving my first voice prosthesis I had the duty to conduct the Annual Meeting of the Fire District. Facing an unknown number of taxpayers with a new method of speech had me somewhere between very concerned and terrified. I made all kinds of backup preparations. The meeting went without incident and my new voice held up through the proceedings. I was even re-elected president.

Twenty-one years later I am still president of the district, chair of the committee and now treasurer of the church.

Noirin Sheahan, Dublin, Ireland - July 2013

There was one afternoon when I was feeling really down-hearted, still in the midst of radio and chemo-therapy and only three months post-op. Friends were calling and we were to go for a walk and then come back for tea. I felt miserable when we started off, and was just smiling and writing on whiteboard (still couldn't use the EL at that stage)

out of politeness, but inwardly I felt awful. As we walked along the beach, throwing balls for the dogs my heart lifted. Seeing the dogs having such great fun, I couldn't help smile. My mood stayed positive for a long time after that. I realised life could still be good, and I could still enjoy friends - and especially four-legged friends, bless them!

When I started using the EL, I used to get frustrated and impatient when people couldn't understand me. Then one day I remember thinking, "I can just decide to enjoy this, not take it too seriously, not expect them to understand me." That was a great turning point. We started to play versions of "I spy" or "Hangman" or other games where I would say a word and they had to guess what I had said. If they didn't guess then I won - which took the sting out of not being understood. It all became great fun and I realised there were some up-sides of losing my voice rediscovering games I hadn't played since childhood, being one of them.

Thank you for your submissions. Edits are used for length, clarity and to keep comments on subject of the month.
Staff of Speaking Out



Another Lary is born Day 1: Cracking up mindfully!

I'd been practicing mindfulness meditation for almost thirty years prior to my laryngectomy last July. Good thing too! I've needed every minute of that practice to help me through this challenge – especially Day 1. Mindfulness is essentially very simple – you just take an interest in your present experience without trying to 'fix' or change anything. Spending time getting to know all the parts of your body – the nice comfortable parts and the aching bits, listening to your mind telling its stories over and over again, noticing your mood as it swings from high to low. Sometimes it feels as though you're hovering just outside yourself, seeing yourself objectively. And yet it's a very intimate experience too. Hard to describe –if you haven't already, then you'll just have to try it!

Some forms of meditation lead to states of exalted bliss, but mindfulness aims at insight rather than bliss. We get to know ourselves and the ways we react to events. Slowly but surely this knowledge transforms into a deeper harmony within ourselves and with the outside world. At times it can be anything but blissful! But there's the understanding that bearing witness to experiences we dislike is deepening our potential for insight. It's the 'no pain, no gain' school of meditation! Here are some of the painful states I witnessed in myself during my first day as a lary. But there was a great reward at the end so I hope you'll read on.

I've often noticed that my mind doesn't prepare itself well for difficulty. It goes into a nice, comfy, denial zone, and then reels with shock when reality eventually catches up! So, on the morning of the surgery I was smiling broadly

then feels with shock when reality eventually catches up! So, on the morning of the surgery I was smiling happily, enthusiastic to be taking this step in the fight against cancer. It was major surgery and took 12 hours and 3 surgical teams to remove all the tract from my mouth to my stomach and put a flap of gut in its place. Along the way my thyroid and parathyroids came out along with much of the muscle in my neck.

I woke the next day as if into a nightmare. I didn't have much pain, but was bordering on panic. My skin was literally crawling - it was as if there was a great cauldron of fear boiling inside me and the bubbles kept streaming up to my neck and face. What was I so afraid of? Death certainly – I knew I only had a 50:50 chance and that the first two weeks would be critical. But I also seemed to be afraid of life – afraid of my own body, now hooked up to a ventilator as well as several catheters, a feeding tube, ECG and blood pressure monitors and a number of drains from the wounds in my neck and stomach. You have all been there - in the semi-darkness of ICU with machines humming and beeping all around.

Of course I couldn't speak. At least I had expected that, but my body kept presenting me with new shocks. My head felt like lead – I couldn't move it at all. It took two nurses to turn me over in bed and someone or something had to support my head whenever I sat up. A flood of bitter secretions poured from my throat into my mouth. Was it blood? I couldn't swallow whatever it was – surely I would drown? It took a long time to trust that my breathing was now separate from my mouth and that the flood couldn't drown me. At one stage I tried to put on a pair of earphones in the hope that some music would help to calm me down, I was groping around the pillow wondering what all the strange rubbery stuff was doing there till I realised, in horror, that I was touching my own neck and ear, now totally numb and swollen to twice their normal size. I felt like I had been kidnapped and thrown into a strange new body. It was terrifying.

It felt like I was cracking up! Afraid to live, afraid to die. Where was any strength or courage to be found? I remembered all the cards and good wishes I'd received from friends and family. Their good will seemed like my only hope. And the years of mindfulness practice. I started to twirl my ankles and wrists to give myself some calming focus for attention. Each turn was a deliberate effort to engage with this strange new life that scared me so, this strange new body which felt uninhabitable.

Mindfulness kept me sane through this painful 'birth' as a Lary. The doctors and nurses kept smiling at me – telling me I was doing fine, the surgery had gone well. I smiled back. What else could I do? There seemed no way to convey my inner horrors. Even visiting hours felt like a challenge. I was an alien creature to myself, how could I relate to others? I asked that nobody but my great friend Margaret would visit. Even my family I kept away, sensing the deep bonds of family attachment would be too hard to bear in my frail condition. Margaret was content just to sit there for hours, saying little, holding my hand, or putting cool cloths on my forehead and arms. Her presence lent me some courage and at times I could feel a calm energy emanating from her, lifting my heart. This gave me hope that life had not turned totally black. My mind did a u-turn and instead of dreading visiting hour, dreaded the time when she would leave! It was late in the evening before I let her go. Afterwards my inner cauldron heated up again and I reverted to turning my wrists and ankles, choosing to engage with the only reality on offer.

I couldn't sleep, and during the long night, my fears at first intensified. After some time it seemed as though my body was cracking open. I was scared stiff, but my attention was also drawn towards the cracks. To my great relief I became aware of some vast comforting stillness that surrounded me and reached deep within me through those cracks. The bubbles of fear could pour out through the cracks and vanish. It became a beautiful and exhilarating experience. I could breathe more easily and trust that all would be well. I knew that my deepest desire – to know and understand what life is really all about – would only thrive and flourish in my new condition.

And so Day 1 ended with the relief of deep spiritual insight. Although next day I was back to the hard work of bearing with fear and anxiety again, the memory inspired me, and whenever I could relax more deeply, I would be drawn through a gateway of fear towards that vast ocean of peace. And, as time went by, my body regained some strength and my anxiety receded somewhat. I took my first tottering steps into my new life.

Looking back now, I can see that I've learned so much from being 're-born' as a lary. Almost overnight I went from being independent, and relatively confident and able-bodied, to being frail, scared stiff and totally dependent on

machines, medications and on others. It's been humbling to put it mildly! I have bad days and still struggle to accept this 'new normal', but thanks to friends, family and mindfulness, I can honestly say that I'm a happier person deep down. I'm reminded of the chorus from Leonard Cohen's "Anthem": *Ring the bells that still can ring. Forget your perfect offering. There is a crack in everything. That's how the light gets in.*

Noirin Sheahan
Dublin, Ireland



Recently I asked Len to write something a bit different for his column. He is not one to toot his own horn, preferring to let his writing "speak" for him but I thought our readers, especially the newer ones might like to know a bit more about his remarkable life. Since this month's Speaking Out question had to do with memorable laryngectomy moments I thought this was an appropriate time to share his story with you all. Working with Len and becoming friends with him is one of the best things about being involved with Whispers on the Web. Read his story and you, too, will understand just why both Pat and I think he is such a treasure.

[Donna McGary]

HOW MY LIFE HAS CHANGED

As a laryngectomee, I never truly realised how my life had changed, until that day in University, just before graduation. I was in my third year and my tutor, famous author and poet, John Whitworth, MA. B.Phil.(Oxford), after reading aloud some of my work to the class, said, " You know, Len never really spoke until he lost his voice."

I was 78 then and had been studying creative writing, writing for stage and screen and poetry, and was due to graduate with all those young people in Canterbury Cathedral in just a few weeks' time. I had been a laryngectomee for four years then, and for the first six months unable to have a [TEP] valve fitted, so my only communication was by writing. I found that so terribly frustrating. I went to Adult Education Classes to speed up my writing, but was told that I had a gift for storytelling and poetry and should go on to University.

That was initially laughable; then quite daunting a prospect, as I had quite illegally left school at the age of 12, after a very haphazard education. During the early part of the war in 1939 we had been bombed out of our London homes on three occasions; the very first one I was buried alive for four hours, with my head trapped between masonry, until dug out. What schooling I had was learnt in underground shelters or church crypts, the coffins having been moved out to make room for us. So at the age of twelve I convinced mum that I should take up work, by putting my age up to 15, as the authorities seemed to have lost me, probably thinking me killed in the bombing. I had to promise her that I would educate myself at the local library some three miles away, every Saturday afternoon. She eventually agreed

and I obtained a job with the Express Dairy, driving one of their horse floats, on daily milk deliveries. I was a casual relief driver, so they didn't delve too deeply into my background.

I then enrolled in the Heavy Anti-Aircraft Regiment in their cadet company, telling them I was fifteen, and after training went out as a signals runner with one of those large guns onto the streets of London as they were firing at the swarms of enemy bombers overhead. On being promoted to Lance Bombardier I guided parties of servicemen from one main line train terminus in London to another whilst a raid was in progress and all surface transport had stopped. I transferred to two Light Infantry Regiments (Cadet Section) and as a Sergeant in the Buffs' Royal East Kents I was attached to the three Bofors guns on the cliffs at Ramsgate. Plenty of action there, with me firing the Twin Vickers machine guns at marauding enemy planes.

I was called into the army proper at seventeen and a half and eventually posted to the Royal Corps of Military Police, where after training was posted to Egypt. I was then a London policeman until transferred to the Flying Squad at Scotland Yard (The Sweeney).

So my whole background was of straightforward no-nonsense writing; to even consider poetry would have been laughable. Yet since graduation my life has changed enormously! Not only have I been writing for Web Whispers since 2009, gaining so many friends throughout the world, but I write for laryngectomees in Australia, India and the UK. I have talked at training colleges for police and firemen, as the possible first responders to the scene of an accident, to ensure that if a neck breathing person is unconscious, oxygen is fed into the right place. I help out at Macmillan Cancer Nurse's Seminars by talking to the delegates, mostly General Purpose Doctors, District Nurses and Dentists, the people out there in the field who normally know very little about Head and Neck Cancers.

There are seven editors in the UK who use my work on a fairly frequent basis. I tell them all to use my web site if they are short of copy, with no reference to me or cash re-imbusement, as I am only interested in telling as many people as possible that we laryngectomees do exist and we still have a lot to offer.

Never think that because you have lost your voice that your life is finished. Mother Nature has a way of compensating for that loss, sometimes in the most remarkable way. I obtained, much to my surprise, the main award for Outstanding Achievement in Education, since losing my voice, and I was really a duffer at school.

I rent a bungalow from a rather large organisation called the Southern Housing Group and when invited to a London Hotel I thought it was because I had volunteered to supervise a group of teenage offenders in building and creating gardens in old peoples' homes and teaching those teenagers how to make mosaic pavements. In the beginning they all thought it a bit much to be supervised by an ancient laryngectomee but I won them over and we all became friends. It was at that London function when I was called up onto the stage and awarded the Ashley Bramhall prize, which is only granted every ten years. So never give up. There is nothing that you cannot achieve.

Bits, Bytes and No Butts!





Frank Klett

It's Called Heartbleed...Oh No, Katie Bar the Door!

Time for a Bit of Caution

Every system runs OpenSSL at sometime or other, regardless of the operating system therefore no one is immune from the Heartbleed bug. Yes, bug...the Heartbleed vulnerability is not a virus but instead a bug or weakness that can be exploited in OpenSSL which our computers use on the internet to securely pass information.

In plain layman's terms the threat is something we all share whenever we go online to our banks, shopping sites or other sites that rely on secure logins to access their pages. This is a weakness that was discovered by a programmer who came across it by chance and alerted the security community to prevent exploit.

Most of the sites that were subject to this vulnerability have taken steps to prevent its exploit. In the cases of many they have sent out email notices to customers that they have corrected the problem and suggest that you change your password. This is a suggestion you should not ignore...better safe than sorry.

This has also led to the anticipated rise in phishing scams that are intended to steal your passwords. Be sure to be alert to any emails you might receive asking for your change of password info and having a similar address to your real "secure site".

To be sure and secure your system from any threat simply change your passwords now without being asked. After all it is Spring and changing your passwords with each season is a good idea which needs to be done now anyway. The MakeUseof website offers more information on the Heartbleed bug and ways you can stay safe...

<http://www.makeuseof.com/tag/heartbleed-can-stay-safe/>

Time for some Password Management?

Too expensive, you say....Too time consuming, you say....not needed, you say! Well, I say you have an obligation to protect your information in order to protect mine...So There!

If you stop and think about what happens when just one system is compromised and how that can multiply into hundreds and thousands of other systems being contaminated perhaps you'll better appreciate the need for each of us to maintain a secure system while interacting on the World Wide Web.

The password managers available today are free and offer security and convenience to our internet experiences. Both of the most commonly used password management programs Lastpass and Roboform have excellent reputations and offer similar features.

Each of these programs will install themselves into your web browser and handle your password needs efficiently and securely. Using one of these managers also eliminates the need and insecurity of keeping your passwords stored in your web browser or on scraps of paper and screaming yellow stickies.

These programs can be downloaded at their parent sites;

For Lastpass go to

<https://lastpass.com/>

For Roboform go to

<http://www.roboform.com>

If you have Apple, look at this, 1Password:

<https://itunes.apple.com/us/app/1password-password-manager/id568903335?mt=8>

Or you may be able to use the iCloud Apple Keychain

Tips and Tricks!

Reminder: In June this year the IAL Annual will be held in Buffalo, NY...and if you have plans to attend be sure and take care of your reservations ASAP...if you haven't already done so. You can do all this online and make your life easier with fewer phone calls. If you have questions about the conference be sure to stop in at the WebWhispers Forum and read the latest info or just post your questions to get fast and timely answers..that's what it's there for!

FORUM : <http://forums.delphiforums.com/webwhispers/start>

Not a Forum member yet? Then just follow the link above and follow the trail to sign up and register for this terrific site and the very best lary info available!

Be sure to check into the Webwhispers Forum during the week and join the rest of us in sharing information in a coffee in the morning sort of way. All sorts of "hot" news and tips that make our lives richer and just plain fun. You'll find everything from Lary issues, life lessons, Marlene's greatest tips ever, and just plain fun with Maureen's cartoons and her updates on Bean the Dog. If you're not using this great little bit of high tech you are missing one of the best things in our Lary life. Hope to see you there. Mike's thoughts on the world through his eyes of anti-myopic wisdom will certainly engross you.

Remember to take a regular short breaks from your computing time: Try this for fun:

<http://www.flixxy.com/black-and-white-tights-dance.htm>

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