



WebWhispers

Sharing Support Worldwide



Whispers on the Web

A Monthly OnLine Newsletter for WebWhispers



February 2007

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New Visitors and Old Friends

I had visitors this week. A delightful fellow laryngectomee and WebWhispers member, Bob Herbst, and his lovely wife, Lesley, from CT and FL. What a pleasure to spend time with them. I had met them at the

Nashville 2000 IAL convention after corresponding some with Bob so we had some years of talking to catch up on.

It was interesting to look at a film that Bob takes around to schools when he talks to kids and we discussed differences in talking to professionals at an Inservice at a hospital or adults at Kiwanis or Lions Clubs. All very useful and helpful activities.

I was able to share with them a new film made by the designer of a fantastic swim device. It will be shown in the full version on a new site soon. We'll announce it when they are ready. You can see a shortened film clip at:

<http://webwhispers.org/library/Activities.asp#new>

We got around to the subject of learning to talk with more than one method and I was reminded of the story our much missed friend Scotty Chandler wrote about his experience in 1999. It still has something to say to us and I present it here.

A Recent Visit To "ER"!

By Scotty Chandler

First thanks to all of you for your thoughts and prayers during my recent hospital visit. Any hospital emergency visit is scary, at best. In my case, the heart attack or myocardial infarction (two of them and three operations in 2 days) was caused by a clogged artery and a blockage causing damage to the muscle (heart) itself because it can't get oxygen. This artery has to be opened "immediately" or else damage gets worse or death occurs. There is a 'clot buster' injection that immediately starts a super-thinning of the blood which can lead to a profuse amount of bleeding from the stoma or lungs. In my case, I was already coughing slight blood specks, which is normal for me at this time of year. So when the shot came, so did the gushing from the stoma. It was up to me to cough the blood out or have someone who could suction it and I'll bet not 1 in a 100 in ER would know what to do, even when trained properly in their schooling. I more or less had to tell the excellent ER doctor, "You take care of the heart. I'll take care of the breathing and bleeding and let you know if I need help." The blood begins to gel much as mucus does as you breathe and air hits it. You can't 'blow' it out thus you need to irrigate (dilute it with water) to thin and cough it out. I had to make it clear when the blood started coming up that I had not taken medications for pain or anything that might be mind or muscle altering. I could take care of the blood and be able to communicate with the eight or so nurses by using my Servox. Scary as hell even in an ER with a laryngectomy wall poster that I had posted there a year ago.

During this time in the ER and during the bleeding for about a two and a half day period, the Servox was my "Best Buddy". When the blood hits the air, it gels and starts to SCAB over the hole in the TEP prosthesis thus closing off any means of communicating other than hand signals. Believe me, trying to write notes as an alternative speech when you're weak or scared is not too good. Waving your arms in monkey motions are often misread. To those of you who think an electro-larynx is unnecessary since you speak clearly with your TEP or using ES, you had better think again.

I am three and a half years post-op and speak very well with either TEP or EL and this is the first real emergency where I've HAD TO HAVE alternative speech. The Orange Card from ACS and the Emergency Card from Lauder showing Neckbreather and the placement of the TEP, allowed me to explain "how" and "what" quicker and more clearly. The Servox helped me to tell them what I needed for my part of the job. This helped to prevent drowning in my own blood or other serious problems if the prosthesis were removed.

I've heard people say it was trouble to keep up with their Servox. Trouble to keep up with My Buddy? I don't think so!

A good bit of advice in that for all of us.

We should all be so lucky as to have a nice visit with a fellow WW member from afar.

My best to all,

Pat W Sanders
WebWhispers President

VoicePoints [© 2007 Lisa Proper] Coordinated by Lisa Proper, MS-CCC-SLP, BC-NCD-A, BRS-S (proper.lisa@mayo.edu)
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Second Opinions Prior To Total Laryngectomy: What Are The Options? Physician, Institution, and Regional Differences.

John R. Salassa M.D.

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When a patient is diagnosed with larynx cancer the primary objective of treatment is to cure the patient of a disease process that may cause death. The secondary objective of treatment is to preserve laryngeal functions of voice and airway protection. Total laryngectomy, often accompanied by neck surgery and adjuvant radiotherapy with or without chemotherapy, is unquestionably the gold standard in terms of cancer cure. However, the secondary objectives of preserving laryngeal function are compromised by a permanent tracheostoma and alaryngeal speech. To this end, physicians have developed both surgical and non surgical treatment options that result in cure rates close or equal to total laryngectomy, yet preserve a functioning larynx. These two broad categories, surgical and non surgical options are continuing to be refined and improved.

Surgical options include a variety of partial laryngeal resection operations that remove the cancer, yet preserve some or all of laryngeal functions. These procedures include laryngofissure with cordectomy, vertical partial laryngectomies, horizontal partial laryngectomies and extended partial laryngectomies including crico-hyoidopexy procedures. These procedures were first developed and performed as open, "thru the neck", surgical operations but over the last ten years are more frequently being done transorally.

The advantage of the transoral approach is better preservation of laryngeal function, a shorter hospital stay and commonly no tracheotomy. Three emerging transoral techniques are transoral laser microsurgery, (TLM), transoral laser surgery, (TLS) and transoral robotic surgery, (TORS). The latter two use a traditional on-block resection that removes the tumor in a single large piece, thru the mouth. TLS uses line-of-site endoscopes and various lasers while TORS uses the da Vinci(r) Robotic Surgical System (Intuitive Surgical, Inc., Sunnyvale, CA), and electro cautery. TORS has the technical advantage of being able to

work around corners in a non line-of-site fashion. TLM differs from TLS and TORS in that the tumor is removed piecemeal under histopathologic frozen section controlled similar to MOHS surgery, (named after Dr. Henry Mohs), rather than a traditional on-block method. This methodology carefully maps the tumor edges to insure histopathologic frozen section controlled negative margins. The advantages of MOHS surgery have been well established in the dermatological literature and include exceptional cure rates while maximizing the preservation of normal tissue compared to on-block resections. The merging of the TLM piecemeal resection and the non line-of-site TORS is presently being investigated. These various transoral techniques have greatly decreased the morbidity of open surgery procedures with short hospital stays and no tracheostomies. TLM can now be performed with exceptional local primary tumor control results for all early T1 and T2 tumors, most intermediate T3 tumors, and some advanced T4 tumors. Surgical procedures, particularly transoral procedures, have an advantage over radiation therapy in that they can often be repeated while radiation therapy in general can only be given to a specified maximum dose to normal tissues.

Non Surgical options historically started with the success of ionizing radiotherapy for smaller laryngeal cancers. At first, the concept of more is better led to higher and higher tissues dosages. This was achieved via changes in fractionation or delivery schedules. Later, similar to surgical options, radiotherapy became more selective with refinements in delivery technology. With the aid of the CT scan, dosage mapping was developed and larger tumors became treatable. Intensity Modulated Radiation Therapy, (IMRT), has more recently further refined the selectivity and normal tissue sparing capabilities of radiotherapy. IMRT allows the selective delivery of very high doses of ionizing radiotherapy to the tumor region that may not be tolerated by surrounding tissues. The addition of chemotherapy prior to radiation therapy and more recently concurrently with radiation therapy has demonstrated better cure rates than radiation alone. The toxic side effects of chemoradiation therapy are considerable, leaving some patients with a cancer free larynx but not a functional larynx in terms of airway protection and, less frequently, voice. Although cisplatin is currently the most widely used chemotherapy agent, trials continue to refine the combinations and selectivity of drugs to improve cure rates and decrease toxic side effects.

With all of the above options available, the question in any given patient situation is: what treatment will give the best chance of cure with the least morbidity while preserving function and providing the best quality of life? The reality of present treatment trends is that a patient's treatment very much depends on the knowledge and comfort level of his physicians, institutions, and region. For the sake of discussion I will collectively label the latter three factors as a "group". One "group" may have a tradition, expertise and comfort level with surgical therapies while another "group" may prefer non surgical therapies. In general the delivery of the transoral surgical procedures are more highly "skill dependent" than the more generic radiation or chemotherapy procedures. Clinical trials also factor into the decision-making process in academic settings. In the private sector, economics play a very real role as laryngeal surgery in general is very labor intensive with poor financial reimbursement. This is more so for partial laryngeal surgery than total laryngectomy and may influence some physicians to favor total laryngectomy over partial procedures. This divergence in opinion is good and bad. The good is that groups with a particular interest in either surgical or non surgical treatments have significantly advanced their respective treatment protocols to achieve better cure rates with less morbidity. They become very good at what they do with a high comfort level. The bad is that physicians by nature are slow to change out of their comfort zone or may not be as aware of newer alternative treatment modalities compared to what they are accustomed to. They may, therefore, limit the options provided to their patients.

With this background, what should a patient, confronted with the recommendation of a total laryngectomy, do? The answer is simple but sometimes difficult. Get more information. Get another opinion. Given the dynamics of the "group" mentioned above, this may prove difficult. The patient usually likes and trusts his physicians and may be reluctant to offend them by going against their recommendations. Travel to another "group", (region) is often necessary if the patient's "group" is particularly prominent in the region.

Current health insurance procedures may severely financially limit the patient's ability to another "group's"

opinion. Getting information however is now easier than ever before. The internet and various support groups provide a vast amount of knowledge that is easily available to most patients. Once the home work is done and the patient is totally satisfied with the recommendation of a total laryngectomy for their own personal situation, they can proceed. If the patient is unsure, get at least one second opinion out of your "group". What was once considered operable only by a total laryngectomy procedure is now in some groups operable by a partial laryngectomy procedure. What was once considered treatable only by total laryngectomy may now be treated with chemoradiation therapy with the option of reserving surgery for salvage therapy. Even salvage surgery after radiation or chemoradiation therapy does not always require a total laryngectomy. Some select salvage surgery patients are treatable with transoral techniques that preserve laryngeal function.

Although the physician remains the captain of the team, it is the responsibility of all of the patient's providers and friends to listen, discuss, and sometimes question, the recommendation given. Each patient presents with some unique circumstances that may not have been discussed with their physician. Speech pathologists, nurses, other health care providers, and friends, by way of their unique interactions, tend to get a different perspective from the patient than the physician. Most physicians welcome this information and concern. All parties should contribute and ensure that the patient is aware and comfortable with all treatment options.



Memories have a habit of springing out at the most unexpected times. People, often long forgotten, appear from the shadows to push back the years. The other day I was outbid for a handsome, solar-powered watch on E-Bay, and settled for a nice little 1980's Swatch. While idly waiting for the £20 transaction to be processed (we're talking serious money here!), I suddenly, with startling clarity, could hear a gruff voice saying, "Miss Macrae... you would like to buy a beautiful watch?"

In my mind's eye I could see him leaning over my desk; Igor from 50 years back, a real Prince Igor actually, and nothing to do with Borodin's opera—although he rarely mentioned his title. He was my very first laryngectomee acquaintance, long departed to a hopefully sunny Siberian heaven, but never ever forgotten.

One of his fellow refugees from White Russia had a jewelry stall in Petticoat Lane market in London and Igor would bring prestigious watches at giveaway prices to sell for the emigres. Sometimes triple strings

of special costume pearls.

Ages ago the Reader's Digest, or the DWC (Dentist's Waiting-room Companion) always had an article about the most unforgettable character someone had ever met. Perhaps they still do. Igor would have fitted perfectly into that niche.

This elderly Russian aristocrat who had escaped over the Urals with his family in 1914, worked as hall porter in the tea company where I made my pocket money during the school holidays. Nothing was too mundane for him. Pushing barrows, emptying the wastepaper bins, making tea for visitors in the vestibule waiting to see the proprietor. The proprietor was a Lord, I remember, but not in the same league as Prince Igor, a 42nd cousin of the Tsar it was said.

A tailored khaki linen overall protected his navy blazer with its shiny gold buttons, a shirt so pure white that you blinked in wonder, his pink and cucumber-green striped Garrick Club tie, the shiny, black leather shoes. I used to tell him that his shoes should go to the British Museum in a glass case for future generations to admire when he didn't inhabit them any more.

Not that he could have used spit for the shine as he did, he told me, in the way used by his father's old servant, long before the Revolution, and the throat cancer struck, and the spit dried up, and he had to make do with Johnson's Wax.

Igor was held in awe by the tea company's proprietor. The Lord—such a bad-tempered boss to us that we sarcastically called him God for short—would invite the Prince for dinner with specially imported easily-digested things like Caspian Sea caviar, which, like a rare single malt, slides down a treat to tickle a lary's taste buds. One day Igor confided to me between one of his fluent belches that he would much rather get a fatter pay packet than a monthly soiree. Oh yes, and there would be balalaikas in the background and tea from a silver samovar to make Igor feel at home.

I think he felt much more at home with the rest of us in the nearby pub, swallowing his draught Guinness at a steady pace, listening to our lives, talking with huge love about the Irish wife, a writer, who had died at only 50. If he had taken a Guinness more than usual he would weep the silent tears of the lary when he talked of his Moira.'

But Lord, schmord, so what. Igor's real greatness was the way he had mastered oesophagal speech. Speech therapists were virtually unknown when his larynx was removed during the London Blitz. He told me they were lucky to find a surgeon to do it. "They were all so busy amputating limbs. Not voices, although it is an amputation too, is it not. But they did it."

He remembered that the surgeon told him to go to a library and look it up and he might find a book and learn how to speak again, and that's what Igor did. "After a lot of exploring I found a library in Bloomsbury which had not been bombed."

His oesophagal speech was loud and clear, helped enormously by being a great belcher. He could have belched for Russia. In fact back in the glory days he was caned by his tutor for making 'ignorant noises' in class. After the war he went to see the surgeon again. The great professor was impressed hugely by his old patient, enraptured with his speaking skills, and introduced Igor as his star to all the big names in the expanding world of throat cancer surgery. The Lord of Tea gave him a dispensation to drop his portering whenever the specialists wanted him to call on a new, fearful about-to-be-laryngectomee and fire them with hope. Or lecture students. Or give a talk on the radio to raise funds for laryngectomy charities.

I would watch him being collected by the Rolls Royces and the Daimlers, off to give a demonstration at some teaching hospital, sometimes to be guest of honour at an international dinner, and the professors stubbed out their cigars and cigarettes for his comfort.

(Nobody thought of linking their fiery tubes with throat cancer in those days when I thought I looked dazzling with my jade Sobranie holder!) Settled in the back, wrapped in rugs, totally at home, he would wave goodbye to us peasants, occasionally blowing me an airy kiss, holding a silk handkerchief to his throat with the other hand. He made holes in throats seem totally distinguished.

"Wish I was like him" the spotty junior porter said to me once before he went pedaling home, singing the current chart topper. "He's a great geezer that Igor. Style, that's what it is." I suppose I nodded.

But I now know that Igor would have left the warmth of the big saloon cars, without regret for the lost ability, to sing a song and whistle at the girls, perched on a rusty old bike.



The Definition of Age is What????

Have you heard the commercials and read some newspaper articles that say, "Being 60 is really the new 40 years old." Excuse me? Just who is the audience for these communications?

My train going through town says "40,40,40", and then it goes faster and says "60, 60, 60." There is no confusion that life goes by much faster when you are 60. What happens when you are 70 or 80? Is the speed of the train now at warp speed?

Perhaps life when you were 40 years old your life was different than mine. But I don't remember:

- The arthritis in the hands
- The facial hair that is now replacing the hair on my scalp
- My eyes growing smaller
- Smiling resulting in my face looking like a crumbled piece of paper
- The concentration I give to going down stairs
- The squinting of the eyes and leaning over the steering wheel to read those awfully small business signs
- The age spots that are multiplying like measles with no regard for cosmetic considerations
- Back pain that has me reaching for over the counter medications
- My reluctance to do anything I don't want to (resulting in some late charges on my bills that were unnecessary)
- My sitting on the edge of the bed in the middle of the night watching with my mouth open the

infomercials on weight reduction and muscle building products that never in a million years will I be able to pay for or learn to use, but the results do look good

- My love of a nap on Saturdays and Sundays
- My resolution to finish the cleaning tomorrow (but seldom meeting it),
- My shoe size changing (and not to a smaller one)
- My love handles becoming part of a straight and solid body type. Waist? What is that?
- My forgetting why I came into a room (unless there might be food involved)
- My deciding that if I just smooth out that piece of clothing, I won't have to iron it
- Ignoring that dust of cat hair in the corner that needs to be picked up but I forget to do it until I sit back in that room again
- Those jowls that were not there before
- The totally gray hair everyone says looks so nice when they really mean, "Why for heaven sakes doesn't she do something about that, she looks so washed out?"
- My needing the support and love of not just my family but others who seem to respond to me differently. Like the email I got last week saying, "How is my sweet Vicki?"

When I was 40 (and by the way in the commercials whatever happened to my 50's) I had energy, vim and vigor, even while dealing with cancer. Problems? Bring them on but you best give me your best shot because you won't get a second chance to get me! Job advancement? The sky is the limit! (If I just work 80 hours a week and ignore everything else in my life). Physical appearance? Not too shabby. Relationships? Little time and not of great quality. Multi-tasking? I was the Queen. Listening to music? No time. Needed the news on the car radio. Weekends? Frenetic, cleaning, washing, ironing, lists and more lists.

So I have to ask again, are the new 60's really the old 40's? and who the heck came up with that? Would suspect it was a boy marketing genius that is in his 30's.

Personally I hope the new 60's are not the new 40's. I enjoyed the forties but am savoring the 60's in spite of or because of or because of facing a life threatening challenge and becoming a lary, a community I am proud of and grateful they are there.

So bring on the next decade! I am ready and I hope you are too.

And the train just whistles this time. If you listen carefully it is saying, "You go, girl!!!"



“The Thought Police”

by Lanny Keithley

When I ‘see’ people that have been through so much physically, ruining their lives, or whatever is left of them, by programming themselves to live in fear and be consumed by worry and concern, it just drives me crazy. Watching what you think can totally change your life and how much you enjoy it.

Every thought you think and every word you say, or even just hear, goes into your memory and is used as data for making all your future decisions. Each time you ask yourself a question, or think about doing something, all of that stored data is analyzed and weighed by your ‘internal computer’, resulting in an answer to your question or thought. And, to further complicate things, that answer is also stored as additional data for future use...

Now, if you constantly say or think negative things, or worry about potential bad things that could/might happen, or even allow yourself to listen to someone/something else constantly spouting negative/bad things, all of that information will affect you and your future, and will be the basis for all your future decisions.

I have always viewed the ‘Human Decision Computer’ as a balance scale - that starts with a big empty bucket on each side. When it is asked a question or given a thought to ponder, it goes through every piece of your past stored memory, described above, and put all related data into the ‘yes/good’ or ‘no/bad’ buckets on that balance scale. When it is done going through all your memory, the scale tilts one way or the other and you have your answer...

Back in the very early days of human life, the inputs and decisions were much more simple. The inputs were much more basic like sounds, sights, smells, instincts and the such, and the decisions were more like run, kill, hide, etc... Since then, we have continued to develop more and more complicated conditions and situations, but the ‘computer’ still works the same way as it always did - and always will. The problem is as it gets loaded up with more and more stuff, it becomes less and less efficient and effective and we tend to not trust and re-analyze the answers. If the cavemen had as much stuff to think about as we do, they would have been eaten long before they figured out it was time to hide or run...

The real problem comes when the ‘computer operator’, which is your consciousness, your ‘I or me’, if you will, is not watchful and controlling of what information/data is being accepted and stored in your memory. If it allows all sorts of negative and bad data to be entered and stored, then all the future answers will be influenced by all that bad and negative data. That will result in your computer producing bad answers for all the future questions. Allowing this process to continue, will end up with every answer being ‘no/bad’, and you ending up being like Howard Hughes, only a lot poorer...

So, to get to the point of all this... If you constantly allow yourself to think about bad or negative things or concepts, you will continue to ‘load’ your computer memory with data that will end up giving you bad answers based upon all that negative and bad data. For an example of this, If you ask yourself the question ‘Is it safe to, or should I, go outside?’ and you have been ‘worrying’ about all the bad stuff that could happen out there for weeks and months, you will probably get back an answer that you shouldn’t go outside – no matter how great the event or situation might be for you. Another example might be where you have worried a lot about how you talk, or if other people might stare at your ‘Larynx’, and ponder doing something or going somewhere. With all the stored worry and concern, your computer will probably tell you to not do it, as your ‘no/bad’ bucket will be full of stuff from all those past bad thoughts and worry.

The good news about all of this is that the more recent data has more ‘weight’ than the older data, so if one starts watching what they think, say and hear, and not allow in as much negative and bad data, over

time their thought processes and decision processing will get better and more accurate, and more appropriate or true for them. Also, each time you do things that you are concerned about from all the worry, and have a good time, that good experience will help counterbalance all the previous negative worry in all future decisions.

Years ago, the "Power of Positive Thinking" was a big deal, and is a great concept I highly recommend, but I have found that the "Power of Negative Thinking" is what affects most people. Try to relish all the good stuff and minimize the bad stuff. The bottom line is that the more positive data, and less negative data, you have stored in your memory, the better your computer will work, the happier you will be and the more you will enjoy your life.

Go to your doctors, research all your concerns as needed, and do whatever you need to do to get all the REAL facts that make up your unique reality. Then, turn all that information over to your 'computer operator' and let it filter all the incoming information, thoughts and data, to be sure it fits, and is accurate for you. If you catch yourself thinking something negative, or hear something negative, mentally just say 'NO, that is not for me'. If you do that, in a very short period of time, you will find yourself much happier, more free of inappropriate limitations and controls, and having much more fun in life...

Worth every penny you paid for it – and more...

Lanny from DaHo

Practically Speaking ...

By Elizabeth Finchem, Tucson, AZ

Practically speaking, I have pondered some questions lately. Is esophageal speech getting a bad rap? Is this method just being ignored for some reason?

Since I write a good deal about esophageal speech, I hope it is obvious that I try to advocate for this method of speech in an objective manner. True, it was my personal choice, and I was willing to work toward that goal during many setbacks in my own rehabilitation. I learned a lot about what can go wrong, first hand, while resolving one problem after another, and how long it can take to heal enough to proceed, one step at a time.

During my rehabilitation, I chose to go further with my training and become an instructor. I am very proud to be listed in the "International Association of Laryngectomees Directory of Alaryngeal Speech Instructors" since 1984. That means that I not only took the same course work, but passed the same written examination that SLPs had to pass, followed by a year of supervised work with new laryngectomees. As a well trained and experienced instructor, I make it my business to include all methods of alaryngeal speech, and how they work, so I can share what I had to learn the hard way.

In my mind, it is important to approach the replacement of a way to speak as soon as possible, either pre or post operatively, in a sensitive way. The use of the intra-oral Cooper Rand before and after surgery has worked well without disturbing the neck tissue as it heals because one only has to mouth the words with the tone generator turned on for speech. Due to the small size and light weight of the tone generator it is

easier for the patient to use during this phase.

What has this to do with esophageal speech? The patient never stops participating in their care and many find it easier to speak rather than write. The experience of depression and isolation also seem to be lessened while they learn about the other options as they heal. When healing has reached a safe enough level to begin speech therapy a neck type electro-larynx, or pneumatic artificial larynx may continue the process of learning to speak again in a different way. For those who balk at even trying this step, I can tell you I had to put this in a different perspective. What would it take to get a person from bed to wheel chair, to walker, to cane before learning to walk upright again? It helped for me to think of these steps as a process that would get me to my chosen goal. I thought it was worth striving for.

In the beginning the information, and manner in which it is provided, makes all the difference to new laryngectomees' well-being. They deserve the opportunity to explore every avenue to develop the technique that will work best for their individual needs and desires. Often surgeries are more complicated than total laryngectomy, and will influence post-op therapy and results. Of course, the final choice is always a personal one, whether it is an electro-larynx, pneumatic artificial larynx, esophageal, tracheoesophageal prosthesis, or a portable programmable keyboard.

In recent months I've noticed that esophageal speech seems to have disappeared from some of the lists of post laryngectomy speech options shared by fellow laryngectomees. Were they informed that this option is a viable one, or was it implied that it is "too hard to learn, and takes too long." I wonder! Although some areas are fortunate enough to have SLPs with alaryngeal expertise that includes development of intelligent and fluent esophageal speech, many are not. Some areas have an IAL Club with instructors who are trained to teach esophageal speech. Some lucky areas have both.

My introduction to a laryngectomy was probably similar to many other laryngectomees. I didn't know how to pronounce "lair-inks". In my neck of the woods it was called a "lar-nicks". I didn't even know how to spell it correctly. Nor did I have any notion that one could live, eat and breathe without the "voice box"... and what the heck is an epiglottis? How's that for starting at the beginning of a long journey to a whole new way of living?

My search for solid answers struck pay dirt when I went to Mayo Clinic for a second opinion. After my appointment with my new ENT, and I heard what the pathology lab had found, I had a longer list of words I didn't really understand. Thankfully, Mayo Clinic has a library that I was able to go to and spend the better part of a day learning how many different kinds of cancer there are. I sure didn't know the difference between carcinoma and spindle cell sarcoma; which I had grown between my vocal cords. I also had to find out the difference between radiation, chemotherapy, and how radical surgery would affect the rest of my life...IF I elected to go for it. That evening, armed with all my newly acquired vocabulary, I called some of my friends who were doctors back home to weigh the outcome of all the appointments, test findings, and opinions.

The next day I was fortunate enough to have an appointment with the person who would help me with pre-surgical counseling, and post operative speech therapy...IF I decided to go forward with radical surgery. I asked my questions, got informative replies, and then I was left with a TV monitor to watch what two women had been able to do post op. I was shocked, amazed, and envious at how far they had come since I was just at the threshold of what they had already been through. These two women were teachers and after total laryngectomy learned to speak esophageally as fluently (or better) than I was able to at that moment in time. Viewing that possibility sealed my fate. The decision was made. I made my appointment for surgery 4 days hence, and flew home across Lake Michigan, and prepared my family for what was about to change our family life as we knew it.

In the absence of the sort of pre-surgical counseling that I was afforded, there is now a way to fill that gap. Although I didn't know it at the time, the film I was shown is part of a series of 17 such segments called,

"Help Employ Laryngectomized Persons" (H.E.L.P.). I recently wrote an article about this series for the IAL News because the video tapes have been copied onto high definition digital DVDs, and are now available for purchase.

Why is this important? This body of work is still relevant even though it may look like watching old movies for some. No, there isn't anything about TEP included that I know of, but you will find a host of information that may not have been covered for you, or was forgotten in the rush to save a life. Often the patient is overloaded with more information than they can handle following the word "cancer".

In the case of isolation due to location, or economics, this series of lectures, demonstrations and helpful hints is an amazing opportunity for less than the average price of a single therapy session. These tapes are not all about esophageal speech. There are other topics covered by both the professionals and old timers who taught them so much, back in the day. There is information about speech options, support groups, and how to work with an employer, among other situations we are faced with.

To order: H.E.L.P. (Help Employ Laryngectomized Persons)
 National Clearinghouse of Rehabilitation Training Materials (NCRTM)
 Toll Free Phone is 1-866-821-5355, Fax is 435-797-7537,
 Email: ncrtm@cc.usu.edu, and website: <http://ncrtm.org>
 Attn: Julie Hoffmann - (Office Manager) 435-797-3416
 Cat. No. for whole set DV337.001G - \$114.00 (ground shipping included)

Or, you can find more information on WebWhispers webpage under Suppliers.

For those of you who have wondered if esophageal speech would be a possibility for you, I can tell you this:

- It is not hard. "Easy does it better every time."
- It takes less air, not more, than you may think.
- It may not take long to master. It varies with every person.
- It may be hard if the instructor only knows how to "burp talk" one to three syllables per air charge and/or if the instructor or patient has no real grasp of how to move beyond the initial phase to produce fluent esophageal speech.
- If you use a TEP you can probably learn to use esophageal speech easily because you are all ready conditioning your cricopharyngeus sphincter and esophagus from the bottom up instead of the top down.
- It's never too late to learn.
- Once you own it there is nothing more to buy, except perhaps an amplifier.

I've known several laryngectomees who are triple threats. They mastered every device, learned to speak esophageally so well you cannot tell when they are using ES or their TEP (unless they occlude with their finger) because the voice sounds so similar, except perhaps for volume as needed. Some of us are satisfied to use an amplifier to speak to large groups with or without the TEP.

Years ago it was a nice compliment to have a waitress caringly ask if I had laryngitis because my esophageal voice sounded like I had a cold. Years later, an airline stewardess told me I had a sexy voice. I can pick up the phone and say, "Hello" with a voice that sounds like my laryngeal voice, but an octave lower...or so my mother told me, and biased as she was, she ought to know. Yesterday a friend called to check on me, and told me she missed hearing my voice. I thanked her. She said, "Oh, it's who you are!" The point here is, you will sound like yourself; accent, phrasing and all. We didn't sound alike before laryngectomy. Our anatomy was as different from each other then, as it is now. Size, shape, density of tissue, and a long list of variables make you the individual you are, and our voices are recognizable no matter which method we chose to use as we speak now.

In closing, it is nice to know that there are still options open to me if a change is called for. Meanwhile I am

hands free. I don't have to worry about leaving my voice behind, dropping anything, buying or charging batteries, skin or glue problems, daily maintenance, leakage, yeast damage, or any of the other troublesome topics that have become frequently asked questions. Simple is good.

BETWEEN FRIENDS

Donna McGary

"That which does not kill us makes us stronger"

On Princes and Pussycats and Fairy Tales

[Editor's note: I have the unique privilege of reading other writers' contributions even as I work on my own. This month, Rosalie Macrae writes about her "most unforgettable character" and I must say, I wish I had known this gentleman. Her writing is so warm and immediate...it reaches out and grabs you into the page and right back in time. As an editor it can be daunting and as a fellow writer, intimidating! So, this month, I want to give props to Rosalie and her Prince for their inspiration.]

I have a dear friend who says that cats are the meaning of life. Notwithstanding her nearly universally recognized eccentricity, she may have a point. This is NOT another cat column, although I must confess, I got more mail on that than anything else I ever wrote...including pictures from a recent past president of the cats at his local shelter! HA!

However, my little darlins' have taught me something. Over the holidays, as I was unpacking and then repacking all the baubles and bows and paraphernalia, I had two very curious and mischievous "helpers". After one particularly hectic moment of fishing one cat out of the breakable ornament box only to find his sister clawing my favorite Santa's beard, I understood. This was a carefully executed plan by my son and his new wife. There are twins on her side and they both want a passel of kids. My son is really hoping for twin boys and these kittens were their way of breaking me in to grandmotherhood. It was not a bad plan. I have lived by myself for quite some time now and am, perhaps, liking it a bit too much.

It was how much I loved these little creatures once I had them, that made me realize how solitary I had become. Human Beings need to be needed. I am not, by nature, a solitary woman. My mother says that from the very first I wanted to be at the center of a three-ring circus. I think she meant that in a good way! Regardless, I have always been a talkative, social, outgoing person. However, more and more I find myself withdrawing...I hate to use the phone...I don't go out unless I absolutely have to...I keep to myself. There are days when I just cannot stand the sound of my own voice and am driven to distraction by my incessant cough. Sometimes I wish I were invisible.

I know what this means. I understand why I feel this way. I even took Paxil for a while. That was not the answer for me. My pussycats have done more for me than Paxil ever could. [Depression is a serious medical condition and usually can be treated successfully with a combination of medication and therapy. I do not want anyone to think I am minimizing its debilitation or the remarkable effects of proper treatment. It is not uncommon for larys and their caregivers to experience depression at some point.]

What I learned from my kitties is that I really don't want to be invisible. I love their attention...I don't think they realize I don't talk much...they meow, I shushshush, they claw, I CHCH, they purr, I kisskiss, they knead, I pet. However there is a problem. Grandchildren are not kittens and grandchildren need grandmothers who will read to them...and therein lies the rub. I am a reader. I was the quintessential bookworm as a little girl and even now have a respectable library. I love to read and, until my troubles loved to read aloud. I started a nightly reading program at a retirement community during a college internship that was very popular. The residents, even if they fell asleep as I read, all said they loved it and commented on my beautiful reading voice. While I was reading the "Asher Lev" books by Chaim Potok, I even learned some Yiddish and got the accent just right thanks to some of my Jewish listeners. I then became known as their Shiksa reader.

No wonder the other night as I dusted off bookshelves and said hello to old friends, I became melancholy. I hauled out my old book of fairy tales; it is a beautifully illustrated edition given to me on my sixth birthday by Mary and Kate Schenk. It is so well loved and read, the binding is now held together with duct tape. I dusted off Harry Potter and, for later, The Lord of the Rings. I fondled Out of Africa (the movie was lovely but the book was a way better love story...about Africa). I leafed through Charlotte's Web and Winnie the Pooh. These are books that beg to be read aloud. How could I do them justice now?

Then I realized it is not the tenor of the voice that tells the story, but the spirit that moves it and that lesson, I learned from Rosalie's Prince Igor. And it was in a most peculiar way. It was the way he held his scarf. He made it seem dignified, stylish, proud...unashamed. I cannot tell you why that image of him made such a difference to me, but it did. I thought that is the image I want to leave my grandchildren...well maybe not dignified- that would be too much of a stretch! But they could know me as colorful (now isn't that a euphemism for too weird for words) and just maybe the gramma who introduced them to the world of words.

And just maybe when read "Here is Edward Bear, coming downstairs now, bump, bump, bump, on the back of his head, behind Christopher Robin.", in a Servox drone, some little tyke is going to think that is exactly the way it should sound, nestled as he is in his Granny's arm with a fat purring cat on his lap and a cookie in his fist.



Welcome To Our New Members:

I would like to welcome all new laryngectomees, caregivers and professionals to WebWhispers! There is much information to be gained from the site and from suggestions submitted by our members on the Email lists.

Pat Sanders, WW President

We welcome the 41 new members who joined us during January 2007:

Jim Beck
Findlay, OH

Karen P. Blank
Prairieville, LA

Glen Blundon
Russell, KS

Deidra Boksteyn - (Caregiver)
Redcliff, Alberta, Can.

Len Bougie
Minesing, Ontario, Can.

Charles Eddward Brannam Sr.
Morrliton, AR

Jack R. Cochran
Newport, TN

Manhar Dhanak
Dubai, U.A.E.

Frank Dumschat
Kearny, NJ

Linda Duval
Dublin, NH

Darcy Edwards
Harris, MN

Joel R. Frank
Amherst, NY

Sam Gass - (Caregiver)
Lebanon, PA

Cheryl Hoover - (SLP)
Albany, GA

Norbert Koenzgen
Cologne, Germany

Frida Korenbrot - (SLP)
Tel Aviv, Israel

Linda Lujan - (Caregiver)
Vacaville, CA

C. Bruce "Buck" Martin
Palestine, WV

Ellen Menzies - (Caregiver)
Buena Park, CA

Alejandro Meza
West Palm Beach, FL

Sonia Poventud-Meza - (Caregiver)
West Palm Beach, FL

Thomas Mucha
East Berlin, CT

Barbara Jean Paschke
Woodland, CA

Iain Price
Islandeedy, County Mayo, Ireland

Natalia E. Quinonez - (SLP)
San Angelo, TX

Cynthia Rhom - (Caregiver)
Marion, NC

Joe Ridenour
Central Point, OR

Emerita Rivera - (Caregiver)
Philadelphia, PA

Meredith Rossborough - (SLP)
Rochester, NY

Lila Tenney
Childersburg, AL

Michael V Thompson
Memphis, TN

Mike Toth
Carlisle, MA

Pam Trimpe
Cincinnati, OH

Dale Tronnes Sr.
Rich Square, NC

Andres Velez
Bayamon, Puerto Rico

Libby Vinso
Stafford, VA

Deann F. Wade - (Caregiver)
Indianola, IA

Douglas C. Wade
Indianola, IA

Edward J. Walters
Belleview, FL

Thomas R. Washko
Bear Creek, PA

Clifford J. Wasko
Athens, OH

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As a charitable organization, as described in IRS § 501(c)(3), the WebWhispers Nu-Voice Club is eligible to receive tax-deductible contributions in accordance with IRS § 170.

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