



# WebWhispers

Sharing Support Worldwide



## Whispers on the Web

A Monthly OnLine Newsletter for WebWhispers



October 2006

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Murray's Mumbles...Musings from the President

Meet Michael Csapo, our new Manager of Internet Activities



Pat Sanders, Vice President of Web Site Information has just announced the appointment of Michael Csapo to the new WebWhispers position of Manager of Internet Activities. Due to Dutch Helms' illness, it has been necessary to implement many changes in our system because Dutch did the work of many to keep WebWhispers a premier web site.

An outstanding candidate for this position was Michael Csapo who lives with Lisa, and their furry friend Taz, in Escondido, CA. Michael says, "We have a great appreciation for animals and nature and enjoy short hikes in sparsely populated areas. We also enjoy occasional tent camping and exploring new locations out in the deserts here in California. Occasionally I also enjoy fishing, geocaching, and miniature golf! " Michael was trained earlier this year by Dutch with the transition of separating the email lists and the web site positions in mind.

Michael, born in Germany, immigrated with his family as a young boy from Germany in 1961, following the Hungarian revolution, and is proud that one of his post-laryngectomy achievements was to acquire US citizenship. Michael joined WebWhispers in the fall of 2000, the same year as his surgery, and since that time has shown a great interest as a contributor and active member of our group.

Basically, Michael will look after all the duties related to the WW Lists, with Barb Stratton as Chief Moderator and Mike Rosenkranz as Forum Manager, and will be responsible for List Management. This includes enrolling new members and being responsible for all changes on the appropriate lists. Questions, comments, suggestions, and complaints about the List are part of Michael's new appointment and he will make decisions concerning day to day operations as well as planning for the future changes. He has been an excellent addition to our volunteer working staff and we look forward to his serving as Manager of Internet Activities.

We welcome Michael into this new and challenging position and wish him the very best of luck. Please give him all of your cooperation to help keep us running smoothly.

Best regards to you all. Take care and stay well.

Murray Allan  
[argus@shaw.ca](mailto:argus@shaw.ca)

# Vicki's Midnight Train from GA

By Vicki Eorio

Finding Humor  
by Vicki Eorio

Perhaps because I am Irish or because I am a tad off center or because it helps me cope, humor is very important to me. It prevents me from taking myself too seriously. My only regret is that I can't make any noise when I laugh. So I clap my hands, I beat on the table, I slap my knee, I hit someone on the shoulder to let them know I am laughing.

When I am able to find humor living as a lary, I think that is spectacular and I want everyone around me to know it!!!

About two years ago my company instituted a major layoff because we lost part of a large contract with our state client. I was to have been in charge of implementing that part of the contract that was cancelled. Although I was not held responsible for the loss of that part of the contract, I was on the list of folks to be let go to cut costs. I had one month to work and then one month severance. Well folks, I was desperate! Believing that the boss of all bosses might listen to me, I parked myself outside his office until he could not ignore me. The man was very gracious and listened.

I am in the middle of telling him how talented I am and how much the company needs me and how he needs to know my background/experience (which is extensive in health care) and the %#\$)@#%\$ hands free speech device pops. It is now a projectile!!! The back pressure, given my stressful condition, must have been close to the shuttle lift off pressure. I always wear a covering over my neck but this time even that failed me. The device blew past that.

My mother drilled into me to always be a lady, I am that old. But what she forgot was the power of my basic Irish genes inherited from my father that, in this situation, rose to the forefront and took over. As I am fumbling to find the speech device and replace it, this poor Boss man is staring at me as if he can not turn away. Obviously I could not speak when the device blew but there was no misinterpreting what I was saying without any sound. Words starting with letters like "s" and "d" and even "f" came out of my mouth without the aid of air from my now disabled stoma. Guess what, the poor man understood me very clearly without any voicing from me. And to his credit, he never looked away.

Now I became my mother's daughter and sat up straight, put the speech device back in, squared my shoulders and said, "Mr. B, as I was saying, you do not know my experience or how much I can bring to this company." When the poor man's eyes stopped glazing over, he agreed to keep me as an employee.

I have to believe he went home and said to his wife "You will never believe what happened today!". I don't have much contact with him due to reorganizations but when I do, he gives me a hug and laughs. What more could I ask for? And I am still employed.

I have a dear friend who has only known me as a lary. Because we were thrown together for business reasons and were suppose to be competing for the same account we had an uneasy truce until it occurred to us that no competition was necessary between us. We have mutual respect for each other. As a result, we have had dinner (the early bird special) every other week for almost 3 years. Same place, same time.

As we know, our voices are not perceived as "natural". However that does not prevent me from talking with Anne as we discuss the state of health care.

Recently, a woman at the restaurant found my sounds "interesting", shall we say? And she kept turning around to look at me. Anne and I usually ignore when this happens but this lady was persistent. So I waved at her. Are you ready for this? She gave me the bird sign! Anne and I laughed so hard we could not eat for about 2 minutes. This confused the lady and she never turned around again. Probably another case of when she got home..."you will never believe what happened tonight!" scenario.

Contrast that with the young men parking our cars who after all those years, give us hugs and kisses and make sure, when we step out of the mall where the restaurant is, our cars are first up. They must have a soft spot for old ladies.

Then there are the phone conversations. I suspect many of you get calls from collection agencies because of our tremendous medical bills, not all can be paid on time, or sales calls or polical calls in season. So when I pick up the phone, if they say, "Mr. E?", I can say in good conscience, "No, call back later".

And the most comforting but also upsetting moments of humor are when I am in a meeting and I feel strongly about the subject being discussed. The %)(%& gasket blows. Everyone in the room says, "Well, there goes Vicki, blew her gasket again!" We all laugh and I fumble to put everything back in place. You know what? I always wanted to be accepted in spite of my disability. And guess what, I am! No one cuts me any slack. Darn!!!

I always try to put folks at ease when they first meet me by making a joke. Sometimes depending on the situation I will say, "I am a lary, no big deal but I can put your eye out at 50 paces if my speech device blows." Or "I speak softly but please listen to what I am saying, not how I say it." Or when folks over compensate when they talk to me, "I can hear you, I just can't holler at you." Or when everything gets full of mucus, "Excuse me, I have to blow out my pipes, will be right back". And to date, everyone (outside of the lady in the restaurant) reacts positively.

The most fun is though is how my pets react....3 cats, one very big dog. All of them know me only as a lary. I can whisper and all of them perk up. I can wag my finger and they all know they are to stop what ever they are doing. I can clap my hands (as my father, who was also a lary, did) and everyone snaps to attention. Now who could ask for anything more than that?

The best, the very, very best? When my first grand-daughter visited. By the way, she is the MOST beautiful child in the world.

She was only 6 months old. The first time I talked to her, she looked at me with wide, wide eyes. By the end of her visit, she would look for me when I talked and would smile. Lordy, lordy, lordy! How blessed I am!

The train says, smile, smile, smile.....

# A Scottish Accent

By Rosalie Macrae, Colchester, Essex, UK

TIJUANA AT YOUR PERIL  
by Rosalie Macrae

This is Tijuana Day for a repentant Rosalie. Nothing to do with the magical old Herb Alpert Brass. How the young heart soared. No. Nothing uplifting like that. TIJUANA in my 'lictionary' translates as:

## TryItJustUnwiselyAndNeverAgain.

As a lary and, probably like most of us, a bit of a rebel, I am positive you have had your Tijuana moments. Or else you don't live dangerously. In this instance I salute you and good for you. These moments I can certainly survive without.

I need my Tijuana mantra for occasions like this sunny September morn when I risked having a nice big long bath. Just like in the old days, deliberately not bothering to insert my stoma's custom-built stopper- which someone was probably paid gold troys for inventing. The heck with caution, thought I, sinking down to savour listening to Saint-Saens' 'The Swan'.

Eyes closed. Oh to have a swan-like neck.

Watery underwater silence. Slid right down and thought I was heading into the eternity of that fathomless lake beneath the placid birdie. Swan. Birdie. Perhaps not.

Petrified. Choking. Flailing. Trailing jasmine slid in too, twining around the loofah. Remembered I'd bought it on special offer from Harrods Household Section where I'd been intrigued to find I'd wandered into a walk-in freezer with a television being bought by some sheikh. I told him that I didn't come with it and he laughed. Nervously imagining another harem queen mother. Funny what passes through your mind when you are nearly in extremis; not that light at the end of the corridor they all talk about.

A small lifetime later and beautiful, normal breathing was restored. Eyes running, neck aching. TIJUANA! Went downstairs to eat usual porridge soused in heather honey. Heavenly.

But then came the What Ifs which follow Tijuana occurrences. What if I had doused the bath in frankincense? Not being baby Jesu or his mama I would have suffocated, tubes clogged up.

What if a bee, gorged on heather honey, had nipped into the bathroom and down my stoma. Instant somnolent sting death, like that poor Australian.

Hold on girl. Enough What Ifs. Projection is futile. Que Sera Sera.

Oh and what if I had learned to burp when I had the chance. Laryngectomy life would have been so much simpler without the trauchle (gaelic for 'trouble') of batteries amd cords and tone-matching. Esophageal speech sounds like freedom to me... I crave it.

My big burping opportunity was unusual. I was sharing a house back in the Sixties with a stunningly lovely American girl called Lynn who had been provisionally picked to be in the next US Olympics archery team. My male colleagues formed an instant lechery team when she appeared in the office.

Lynn could have burped for her country too. I discovered this gift, apart from the one of Arcadian beauty, after making her some herring, fried in oatmeal, splashed with white vinegar, for breakfast. Something she said they didn't do in her small Colorado town. With that she flexed her back, poised in arrow-releasing mode, and let out a burp of sheer satisfaction.

I asked her to show me how to do it. Never ever dreaming that one day in my future, burping would have been not only a huge asset for esophageal speech, but a good party piece and conversation stopper and/or starter! Lynn went through the burping/breathing pattern patiently in the bedroom, night after night, while our roots were blonding and our toenail varnish setting. Our next-door neighbour, a retired air force captain, complained at the merry shrieks until he saw Lynn, and like most men fell speechless.

My colleagues were wildly jealous. What was it like sharing a bedroom with this icon, they wondered. Did she mention any of them? What sort of books did she like so that they could bring them into conversation? When I told them she was trying to teach me to burp when not reading the thoughts of Mary Baker Eddy to protect her from the London smog--a menace in those days--they burped in disbelief. But I never did get the knack.

If only I had tried harder. This has been underlined to me right now. I am temporarily speechless because I pushed the Servox button too vigorously when joining in Ode to Joy on the radio. It was a moving homage to Leonard Bernstein conducting unrehearsed Berliners celebrating when the Wall came down.

But I jammed the button. Our hospital ENT technicians are recovering from a riotous 'training' weekend. The TruTone needs new batteries; the car tyres need air and I can't bend down as I need air more than they do.

Tomorrow the technicians will have recovered from their hangovers. My son will have done the tyres. I will have bought the batteries. But right now I feel like going to the pictures to see Volver. Alas, without the freedom of speech, phoning for a taxi is impossible. It's a pity Elizabeth Finchem, our WW esophageal expert isn't here to be my personal tutor.

No matter. Inspired by these sweet belching memories I have decided to start learning esophageal properly from a speech therapist. I wager she won't burp as well as Lynn, though. Dammit, I forgot to tell the boys she snored!

ends



This month we are pleased to debut a new column....called My Neck of the Woods...it's a chance for you to tell your story in your own words .You don't have to be a writer...you just have to be able to type it out and hit 'send'! It can be an anecdote or an update...something that isn't perhaps just right for the day to day list, but you would like to share with us all. We have pieces on caregiving and acceptance lined up for future months. I met our first contributor, Dennis Holte, at the Chicago IAL. Annual Meeting. He and his wife, Mitzi, were just such an attractive and engaging couple and I was particularly impressed with Dennis' voice. He graciously agreed to send me something for the newsletter. I think his article on the journey from The Lump to a Lary is a fine inaugural piece for this column. Thanks, Dennis!

A Brave New World  
Dennis Holte ~ Boise, Idaho

My journey into the world of larys began at age 52, in March of 2004. I had spent the previous 3 months on and off antibiotics for what I was told was bronchitis and maybe pneumonia. One day I noticed a lump on my neck about the size of a marble. It didn't hurt, but was hard as a rock. I went to my regular doctor and with a look of "this is not good", he sent me to an ENT to see The Lump. On April 1st, the

ENT stuck a needle in the swollen lymph node. He returned 5 minutes later and told my wife and me that it was malignant and was probably stage 3 squamous cell carcinoma.

We looked at each other and said, "It is April Fool's Day, maybe this is a joke". We were in shock and knew life would never be the same.

He told us this type of cancer was very aggressive and deadly. He also said that it was very curable, but one of the most painful and destructive to treat. We asked him what our options were for treatment. He said they have had good results with a combination of chemo and radiation. The other choice was a laryngectomy

We asked if there were any other alternative treatments available and he acted like we were asking for the name of the nearest witch doctor and said, "No".

After they did the biopsies from my throat, he called it an unknown primary and kept saying it maybe was at the base of my tongue, although the malignant biopsy was from my larynx. We asked for my records and got the opinion of two other medical centers.

After learning what we could, I decided to take the gamble of what I was told was an 80% cure rate with chemo and radiation.

In May of 2004, I started 37 IMRT radiation treatments and 3 doses of chemo at Mountain States Tumor Institute here in Boise.

After finishing treatment and having a CAT scan in August, we were told I was cured and we just needed to watch to see if it returned.

Well as you all know, and all too well, that was not the end of my journey. It had just begun.

Over the next few months, I would go to the ENT and Radiologist for follow ups and to complain about the pain I was still having. They would say it should get better; that we needed to give it time for the radiation effects to settle down. By now they had switched me to morphine for what I called the ear ache from hell. When we would go in to see the ENT, he acted like he was too busy to listen to our concerns. In November, I fired that ENT and switched to a different one in the same building.

The new doctor did the scope down the nose trick and another CAT scan. They both showed nothing. Then he put me under and took 10 biopsies from my throat. They all came back negative for cancer. We all said that's great news, BUT, I still have this ear ache from hell and am living with morphine. Something isn't right!

Finally, they sent me in for a PET scan and that showed a large tumor on my voice box. I was told my only chance of surviving was to have a laryngectomy.

So, on August 12th, 2005 I joined the world of larys.

In October they had to take a flap from my chest to close up the large fistula that had refused to heal.

In November, I had 20 hyperbaric oxygen treatments, a TEP installed and the feeding tube removed. So far so good.

While searching the internet after surgery, I stumbled across WebWhispers. This last year of recovery would have been next to impossible without all the support and information I have received here. God bless Dutch and all of you that help make this website a great support system.

# JAMBALAYA

**By Jewell Hoffman, New Orleans, LA**

Can One Person Make a Difference?

by Jewell Hoffman

Do you remember when you met your first Laryngectomee after your surgery? Do you remember how you felt? Were you still in the hospital when you met? How were you feeling? How did your spouse or caretaker react? What were your thoughts after they left? What were your thoughts before they came into your life? How differently would you have felt if you had not met them for a very long time? Just how significant was that person and their visit to you?

Six days after my surgery, as I was contemplating my life, my possibilities, my new direction in life, a man burst into my hospital room, flung his arms wide open and said, "Welcome to my world". He was a well dressed man in a suit and tie. He was well groomed, and flashed a

beautiful smile. As he walked towards me, I noticed he was chewing gum!! At the time, I couldn't even swallow and didn't know if I ever would again!! I looked up at him and mouthed....."You're chewing gum!!" He said, "Sure I am!" By then I had collected myself a bit and mouthed again....."You can talk!" He looked at me with a confident smile and said "Yes, of course, and you'll be able to talk again too!" He was using what I later learned was Esophageal Speech. Back when I had my surgery, the TEP was just being researched and perfected. The most prevalent forms of speech being used were Esophageal Speech and the Electrolarynx. I couldn't believe how great he sounded!! I was so excited! And because my throat had been so painful, I didn't realize that I'd ever be able to eat again. His name was Gene Yoes, and I will forever be in his debt. Since then he has passed away, but I will always remember how he took time out of his life, to come and visit me in the hospital, to let me know that everything was going to be okay!

My life was changed after that meeting. My whole demeanor was pumped up and ready to face life's new challenges! I quickly became involved in my local New Voice Club. I became the Secretary. The President and I Co-Chaired an International Association of Laryngectomees (IAL) Convention here in New Orleans. I was practicing my Esophageal Speech all the time. I attended my first IAL Voice Institute and Convention, which was one of the most wonderful experiences of my life. It was there that I finally began to use my new voice out in public. It was the first time since my surgery, that I was in the majority rather than the minority. I met "women" laryngectomees, which back then were much fewer than they are today.

As time moved on, I became President of my local club, ran another IAL Convention in New Orleans, was on the IAL Board of Directors, became involved with my local American Cancer Society and sat on its board, was a frequent visitor to "new" Laryngectomees in the hospital. As I had my children, I became more involved in my local community, and on the children's School Boards and PTA's. As time went by, my Speech became more and more proficient as I continued to practice and try new things. I became the Secretary and President of three school PTA's (elementary, middle school and high school), became the "Mom to go to for fund raising", ran two school Spring Fairs, was interviewed for t.v. and newspapers, later became a part of Toastmasters and then the National Speakers Assn., as I traveled and spoke to many different organizations.

As I reach my 48th year on this earth, I find myself continuing to evolve. Over the last 26 years since my surgery, I feel that I've accomplished a lot, but I'm not quite finished yet. I still have a lot of dreams in my heart to pursue. Now that my children are grown and most are on their own, I look forward to concentrating on my strengths and continuing to grow and learn new things. I have been blessed in many ways. I am ready to begin this new era of my life, and hope that the things I've learned along the way, will help me to continue to make a difference in the lives of others.

I sometimes wonder, had that wonderful man not popped into my room with his arms widespread, welcoming me into his world, would my life have been the same? I always hope, that I have made the same difference in the lives of others that I have visited, and helped to teach to speak again. I think that most Laryngectomees that have been fortunate enough to have been visited, become the visitor in their local area too, or find some way to contribute to their local group. It is in giving that we receive. If you ever wondered if there was something that you could do in your life that could REALLY MAKE A DIFFERENCE.....THERE IS. When you have healed and are ready to get back into the business of life again, take time out to visit a new fellow Laryngectomee. Call your local Speech Therapist, ENT, or his nurse, get their approval, and prepare to feel the joy of your life by visiting newly Laryngectomy patients and their families!! One person CAN make a difference. Look at the difference Gene Yoes made in mine. The truth is.....I need not wonder.....I KNOW he made all the difference in the world to me and my new life. I hope that you too will feel the wonder of bringing someone's heart back to life again, and giving them back hope for a wonderful, productive future.

God Bless!

## BETWEEN FRIENDS

*Donna McGary*

*"That which does not kill us makes us stronger"*

Oh, The Things I Did for Science!  
by Donna McGary

Those of you who were in Chicago may remember a presentation by Dr. Eric Pierce from Massachusetts General Hospital about a study they were conducting on anesthesia. He actually bears a striking resemblance to Mike Farrell - the actor who portrayed BJ Hunnicut on the TV series M\*A\*S\*H. But, not to worry, I am more of a Hawkeye Pierce (young Alan Alda) fan myself, so that isn't why I volunteered for the study!

I was accepted for participation and it proved to be fascinating. I was the center of attention for all these brilliant scientists. Now I must admit, I know and love this type, as difficult as they can be. My last serious boyfriend was an MIT educated mathematician whose idea of foreplay was the Sunday NY Times crossword puzzle. Don't ask! .

Seriously, this is an important study and one in which we can play a critical role. Next month I want to talk about the science... this month...it's all about me...or rather my experience as a guinea pig.

First, in the spirit of full disclosure, I get no additional remuneration for my endorsement of this study. They do pay expenses, for two, including travel, plus a flat \$400 for participation but I don't get anything extra for telling you all about it. The hotel where they put you up is not very fancy but it is clean...and it is right on the waterfront in the Historic part of Charlestown in the Naval Yard where Old Ironsides is docked. You can take the ferry for a buck fifty over to the Long Shore Pier and walk to Faneuil Hall and Quincy Market or the North End, Boston's own Little Italy. You can take a free shuttle to North Station and pick up the T and go anywhere in Boston for a buck twenty five. The T is clean, safe and has really good maps, unlike the streets above you! Plus you get two days off between tests with a rather generous food allowance as you explore Boston. I chose to go to the Museum of Fine Arts one day and poke around the food shops and restaurants of the North End the next. I also had a nice glass of wine and an even nicer appetizer, as I watched the sunset over the Lenny Zakim Bridge and the Boston skyline from the deck of a restaurant within walking distance of my hotel. Not too shabby.

Then, I became the Bride of Frankenstein! I am not kidding. I had a central line for blood work in one arm (on a board) and another line in the other arm that one of my very kind and conscientious docs kept making sure I kept straight. By now I also had electrodes stuck all over my head and long multi-colored wires snaking out like techno dreadlocks. My nice doctors had promised me special relaxing drugs and I let them know it was about time they delivered. And they wanted me to go to the bathroom so it wouldn't be a problem later! I stretched out my arms as I walked to the toilet and made weird breathing noises, as only we can. Those scientists may be brilliant but, frankly, sometimes they are a bit slow on the uptake. The nurses got it right away. That's when it came to me...I mouthed, "The things I do for science!" Which the nurses had to translate for the doctors because I couldn't bend my arms to use my EL...plus in the MRI room apparently the magnets do weird things to metallic stuff...so I couldn't use it anyway. You should hear the nurse's stories about what happens to their Victoria's Secrets underwire bras should they forget and wander into the "field!"

Anyway, a little bit of discomfort for me yielded a treasure trove of information for them. At least that is what the Docs tell me. I was their prize test subject! And the thing is, this is something ONLY we can do. They need us: "the hole-in-the-neck-gang!"

On the first day (Sept.11, 2006) I was at MGH, doing the pre-testing/screening, an article appeared in the Boston Globe Science and Health section, written by Andrew Rimas. It was a profile of the lead doctor and principal researcher, Emery Brown, titled A Seeker of Anesthesia's Secrets. He was thrilled about the coverage and wanted me to have a copy. In the article, which is really more of a personal profile than a detailed examination of the study, Dr. Brown made a point of crediting his colleagues and the IAL. "Without them [the IAL], we would be at square one." What he said to me that day, with a laugh, was "Actually, without you people, we would be a negative square one."

Which is, of course, my whole point. Anesthesia is both very safe and very scary- a point Dr. Brown makes in his interview. Without anesthesia, modern medicine would simply not exist. And most, if not all of us, would be dead. Yet, as advanced as anesthesiology is, they still don't really understand how and why it works. Next month, I want to share with you some of the doctors' findings and questions and tell you why we are so important to this groundbreaking study.

But for now, let me leave you with one last tidbit. During the last phase of the study, there are a series of auditory tests to perform. I had headphones and a clicker so I could identify tones. I had determined that there was a certain sequence to the pattern and was counting the sequences and my responses. I remembered counting to 12 responses. I was told that I continued to respond long after that even though they knew I was "under."

Now that is very cool....***you could say they blinded me with science!***

# WebWhispers Columnist

Contribution from a Member

## In My Own Words: An Altered Life

By Libby Fitzgerald

Conclusion of a two part series

[note from the editor: Last month, Libby shared with us excerpts from the journals (actually, one-sided responses written during "the silent times") she kept in her early days of diagnosis and treatments leading up to and including her laryngectomy. We join her this month as she prepares to go home from the hospital after surgery...noting where we pick up the journals, we can see Libby never lost her characteristic good humor!]

**[Then, a post surgery milestone:]**

"Had 1st B.M. today. What a build up!"

**[Describing doctors' rounds at this teaching hospital (Mt. Sinai):]**

"You should have seen the group of residents that came in this A.M. About a dozen and Dr. U. Talk about an invasion!"

**[A personal observation of my husband:]**

"Please do yourself a favor and get new reading glasses soon. They're green, scratched. Thick headed! Testa Dura!"

**[These last 2 words are Italian for thick headed, an expression often used by my mother. Made us both laugh.]****[Complaint Department: Does any of this have a familiar ring?]**

"I spend most of the time stuck in chair, hooked up to meals on wheels."

"My veins kept rolling and they had to keep jabbing."

"Wish I could blow my nose. Tube is stitched into nose."

"I start coughing, gagging then some vomiting for no reason."

"Please hold off feeding until later. I had lunch for over 2 hours, which finished around 4:00."

"Can you give me anything for the nausea?"

"I'm uncomfortable. Have diarrhea."

"Could I have a clean gown? Got water on this from the nebulizer."

**[Back to the discharge date concern:]**

"I've been having some problems with gagging since Wed. P.M. Slowed flow of food. Still acts up."

"Realistically, Friday too early. Try for Saturday, but let situation decide."

"Must tell husband to let friends know no more mail or flowers to hospital."

"I'm supposed to go home tomorrow so I need to know what to do."

**[Finally, the night before discharge and the last minute flurry of things to do]**

"Could you give a tube rinse by syringe? The stuff in the feed bag looks congealed. Please, let's get this over with! **[2-1/2 hours]**. I want time to sponge bathe before my husband comes."

**[To nurse]**

"Could you call my husband before he leaves home, to let me know what supplies we have? **[delivered by medical supply]** I will take things from here that I need."

**[Husband later walks in with lots of supplies:]**

"That was some bunch of "loot" you brought me! Thank everyone when you talk to them."

**[Last minute check:]**

"This is regular Jevity not Jevity Plus. That type gave me diarrhea. Glad I thought of it now rather than later. Call Jill to be sure food cans are Jevity and not Jevity Plus. I don't want a bunch of that!"

**[General chitchat with husband:]**

"When I'm home, I'll have to watch you eat real food. Oh well, maybe I'll shed some extra pounds."

**[Side effect of surgery - did lose weight and kept most of it off:]**

"Yesterday was the first time I wore underwear and something other than a hospital gown."

"You can order Chinese some night for a change - at home, I mean."

"I must be getting better. I'm starting to really visualize food."

"Wish you could have met my regular night nurse. This is her day off. You would enjoy talking to her. We had a nice "visit" last night."

"We can ask the friends who volunteered to do food shopping."

"It's such a relief not to look at that damn clock."

**[Finally, in the car and on the way HOME!]**

"I can spit into tissues."

"Silly me. I forgot that I have a portable suction machine which can be used in the car. You can hook it up to the cigarette lighter."

**[And getting back to normal topics:]**

"Are the leaves turning?"

"See any deer?"

Notebook # 3

**[Sept. 25, 1998...To husband while getting ready to go to bed]**

"MY OWN BED!"

**[Because the doctor didn't want me swallowing saliva yet, I had to figure out ways around that.]**

"I'm going to use the toilet paper method tonight.' **[Spitting into toilet paper and tossing it into a bag. Cheaper than Kleenex.]** "I would have to turn the suction machine on every time I wanted to use it and that would wake both of us up. The nebulizer will be noisy enough."

**[Next morning to husband:]**

"I have a big favor to ask. I want to sit in the shower on 1 of those white plastic chairs to take a shower/bath. Would you scrub my back? Also, I need to wash my hair, but I'll need you to help me. If you saturate washcloths with warm water, then soapy water, then a careful rinse, that should do it." **[The hair washing was done over a sink. The shower with a removable shower head.]**

"Don't be shocked, but I'm a scary, bruised mess."

**[Visiting nurse arrives and finds me sitting with the blow dryer:]**

"Good morning! I'm trying to dry my hair."

**[Question and answer period:]**

"Yesterday I only had 4 cans."

"Do I dissolve all my morning meds at once?"

"Do I need to use a new feed bag or can I use the one from yesterday?"

"It takes long to feed."

"I'm meeting with someone from a laryngectomy support group at 3 today. They will lend me a voice prosthesis."

**[At this point, I was unfamiliar with the term laryngectomee, just the name of the surgery. Also, I mislabeled the EL as a prosthesis. Had a lot to learn!]**

"Here I've never been a smoker. Go figure."

**[Gave nurse my medical history.]**

"Until this all happened, the only time I was in the hospital was to have my kids."

**[Chitchat with Visiting Nurse, asking about our house and property:]**

"Things aren't usually this cluttered, but things have been piling up while I was away."

"2 acres."

"My husband built the deck this summer. He's a biology teacher. He's always loved carpentry. Helped him cope with all my stuff."

"He doesn't want me to be alone. We have friends who will come and visit and give him a chance to get out."

"Would you mind if I lie down on the couch? You could read or catch up on your paperwork."

**[Getting up, bathed and dressed really tired me out!]**

**[Had many discussions about the time my husband was taking off from work. As a very conscientious teacher, he had just started the school year with his new students and was then out of school for my surgery. He didn't want to leave me alone at home, but also didn't want to be away from his classes. We were trying to figure out how to resolve this.]**

"Perhaps, if it's OK, Karna can come tomorrow. Maybe we can ask her to spend Tuesday here and you can go to work and then prepare for Thursday. Then we can have Tim and Lisa up for Friday."

"I'd like to minimize the days you take off from school, because I know it ultimately creates more backlog for you. If it's necessary, of course, but with these offers to help, why not take advantage?"

"I don't put that shirt in the dryer. I hang it."

**[Next visit from Visiting Nurse:]**

"Thank you for coming."

"All right."

"Reasonably."

"I don't swallow, but it's not bad."

"The surgery was more extensive than originally planned and they will wait until healing occurs."

"We use humor all the time."

"My meals on wheels."

"Some friends will be visiting this week and he can go to work."

"They sent me home early because of my familiarity with trach care and felt I could handle feeding."

"If you need to leave before he returns, that's OK. I feel well."

"When I see real food I salivate."

"I consume 6 cans/day + water. Jevity + many vitamins."

"I really didn't know what to expect, but I try to roll with the punches."

"When I first looked in the mirror at the hospital, I was shocked. I looked pale as a corpse & my neck looks like a linebacker, so I put the mirror away and slept."

"My husband has made much possible."

"We're going to speech pathologist at Mt. Sinai on Thursday."

**[Doorbell rings and coordinator of local club comes in bringing flowers.]**

"Thank you! Those are lovely!"

**[When asked about getting my own Servox, referring to my SLP:]**

"She is ordering one. I will return it"

**[Speaking about the EL borrowed from the local club.]**

"How often does the battery need recharging?"

"I tire easily."

"Thank you so much."

**[The usual ups and down of recuperation:]**

"I got up around 5 with a headache & took Tylenol. It took a while before I went to sleep. My back feels a little stiff thru the shoulders. Must be getting old."

"I'll leave a note for her. Tell her to let herself in. I may still be asleep. She can fix a pot of coffee & bring things to read or whatever."

**[The friend I was referring to not only came with reading material, but volunteered to weed my overgrown flower garden. Now THAT'S a friend!]**

"I have lots of healthy weeds. You'll be in ecstasy!"

"The quality of my charades seems to be improving. I'm getting more across "saying" less."

**[To my husband:]**

"I'm going to Teresa's wedding on Oct. 16th."

**[Less than a month after surgery]**

"Don't know how long we'll stay, but will see."

**[To some visitor:]**

"My healing looked good from the outside. Maybe it's also good on the inside."

"My stubborn determination."

"Don't know if John explained, but I'm not allowed to swallow anything, so I have to spit every time my mouth fills with saliva. I can't wait to

stop this."

**[In between all this, I'm discussing real estate business by note. The "show" must go on]**

"I need a favor. You'll have to give directions to the house from New Milford for a florist. I'll write them down for you."

"Writers cramp."

**[Then some old friends arrive:]**

"These are my friends, Bob and Karna." Known them over 30 years."

**[Referring to feeding tube:]**

"Hopefully, I won't need it much longer."

**[Chatting with friends:]**

"I shower from the chest down and use washcloth for upper. John washed it for me at the sink."

"Pretty soon, I'll take my first nap."

"I haven't felt like reading yet - just short stuff, but pretty soon. I've got some great mysteries in the family room. Sue Grafton. Kay Scarpetta."

"Nap outside on lounge?"

"I really miss tasting food."

"I'll be doing my trach care in the bathroom."

"Like my stylish bib? Meant for this purpose to cover trach area."

"I could wear a scarf, but this is meant to allow air circulation too."

"These were crocheted for this purpose & given to me by the cancer support group. I have a bag full."

"Last night, John barbequed sausages & they looked so good I put a piece on my tongue & savored it. Later, I had a "taste" of cake."

"I'm going upstairs for a nap and am turning on my vaporizer, so you'll hear that noise. See you in a little while."

**[Husband gets home from work and we discussed the day:]**

"I tried to behave today."

"They brought a cooler with their own lunches. I "scolded" them."

"Tomorrow, we'll put a shopping list together. I'll help with the list part, but you're stuck with the shopping part. Oh well. Not for long."

"The visiting nurse came this A.M., took my vitals and visited a bit. I don't expect much assistance, but I don't think I need it."

"I'm going to go suction."

"I'm sucking on a Tic Tac and it tastes good!"

"I must say, the med. supply company has been very accommodating."

"The nurse said that ginger ale works thru clogs. Must be the bubbles."

**[Fixed a very simple dinner, but that tired me out]**

"Just taking a breather."

**[Still, it felt good to be doing a normal routine!]**

**[Getting ready to drive in for first post-op doctor visit:]**

"When we get to hosp. want you to drop me off before parking & I can sit & wait for you. Must be a chair somewhere for me."

"Will take calcium before we leave. Feel tingle in face, arms, legs - from exertion of coughing and trach care."

**[After coughing calmed down on drive to city:]**

"Maybe I'll just go with you to parking garage. I think I feel more confident & walking is OK."

**[Wearing an "artful" scarf around my head covered the feeding tube effectively enough so I didn't draw any stares. Of course, in NY City, artful head coverings are standard and no one would notice. LOL!]**

**[This visit got the doctor's OK to remove the feeding tube that was stitched into my nose to keep it in place. Snip went the stiches and out came that unlamented tube. The swallow test took place next; I had to try to drink a cup of water. Not as easy as it sounds after more than 2 weeks without swallowing. I sipped cautiously and got the most awful taste in my mouth, but I had to make it work, so I kept sipping a few drops at a time until I got it all down. Yahoo!! I can officially eat again! Also met with the SLP to learn speaking techniques with that borrowed Servox]**

**[When we got home that night, there were several family members visiting. It was so good to see them all: our son, a brother-in-law and his wife and a nephew and his wife. While they all sat down to dinner, I opened a can of Progresso Chickarina soup. I put it in the blender, heated it up and then tasted the most heavenly food to my starved taste buds. Ahhh, how good it felt going down, savoring all those flavors like a connoisseur of fine wines. I will never forget that first meal and still think fondly of that delightful soup.]**

**[I started practicing with the Servox and attempted my first verbal conversations. I had to repeat myself and use body English at times, but generally got my ideas across. After a while, my voice got lower and lower, like an old record at slow speed.]**

"The battery faded on my voice box so I'm truly voiceless while it charges. I should have charged the spare battery, but didn't expect this."

**[First complication after coming home:]**

"If Colleen from the Visiting Nurse Assoc. calls, tell her I would like to see her one last time. I have some questions and want her to look at the area around the trach opening."

**[Still not using the term stoma.]**

**[Nurse arrives:]**

"I've been putting some Bacitracin on my neck, but it still looks red and feels raw. Should I do anything with the skin graft area? Do you have any advice you think I need?"

"Should I use Vitamin E on it?"

"Do my lungs sound clear?"

**[I sure am full of questions!]**

"I clean with kits 3 X day & use saline squirts. Once a day I remove entire tube & clean. At night I use the nebulizer."

"We have to get a whole house humidifier. Do you have any suggestions? What type? Where to buy?"

**[Too bad I didn't know about WW yet. These questions could have been answered by people with experience. The visiting nurse wasn't able to give definitive answers.]**

"My brother-in-law and sister-in-law have been here since Thurs. & are leaving tomorrow. I will then be "flying solo."

"We already notified 911."

"I go for a checkup on Oct. 22. Then we'll see when I get the implant. They couldn't do it before because they had to remove more than expected."

"I would not be a candidate for a transplant. I would have to take immuno-suppressants and not advisable for me."

**[So here we are, exactly 8 years later. There have been many ups and downs over the years, but mostly ups. It's been quite a journey and if I forget that, I have these notebooks to remind me.]**

# Practically Speaking ...

By Elizabeth Finchem, Tucson, AZ

Esophageal Speech  
by Elizabeth Finchem

Practically Speaking about my personal experience with esophageal speech, it begins with my pre-op counseling at Mayo Clinic, in Rochester, MN. Sitting in Bob Keith's office I was given the opportunity to view the H.E.L.P. videotape featuring Barbara Nitschneider and Anne Lanpher, both were teaching their classes speaking esophageally. I think that is when I concluded that it would be possible to have a laryngectomy and speak with a feminine voice that would be close to normal.

The decision was made and the pre-op tests were ready for Monday morning surgery. I flew home for the weekend to prepare my family for what was about to happen. I had a copy of "Looking Forward" to help with drawings and written explanation I could read aloud and discuss their concerns. My six year old daughter broke out with Chicken Pox Saturday night, and Sunday morning my second son, who was attending college in another State, was put in the infirmary with encephalitis from a severe sinus infection. What to do? You leave all in the best hands available, say your prayers and get on the plane back to Mayo Clinic to keep your surgical appointment.

A few days after my total laryngectomy, I was wheeled down to Bob Keith's office to begin speech therapy. He dutifully introduced me to the electro larynx. I promptly told him that "I wouldn't need one of those because I planned to go home with at least a working vocabulary using esophageal speech." It didn't happen.

It was about a week later when I saw my local SLP and she tried again to help me with the EL. I grudgingly took it home to "play" with it, and see if it would help me communicate with my family. I was awful. The swelling, the radiation burn, and the offensive clatter it made seemed useless at first. Slowly I mastered it well enough to even use the telephone successfully. In my mind, this was only temporary!

My family & friends continued to get me to radiation and speech therapy regularly in spite of blizzards and icy roads. Over the next few appointments I managed to get plenty of air into my esophagus but it took much longer to hear my first esophageal sound. It happened one evening. I was relaxed following a bath and sitting in my robe and nightgown, watching TV with my family and enjoying some pop corn and a beer. I turned my head slightly to the left and said, "What"? It was a beautiful feminine voice similar to those I'd heard on the videotape. I cried as I realized that one day I would reach my goal. It was a real possibility after all.

It took me a long time to fully understand the dynamics of what happened in that magical moment. The emphasis during speech therapy with several different instructors was to read long lists of words that would put air into my esophagus. Now I understand, but I didn't then, that they expected me to eventually get full enough of air that some of it would go North and come out as esophageal sound, instead of going South to fill my suffering gut with more air. I remember being told, "when you feel the pressure rising, use the 'burp' to say something...anything. Like, "rubber baby buggy bumpers". Huh? Problem was I didn't know how to burp. I refused to allow a repulsive burping sound out, and I had no intention to learn that so called "skill".

But now, I had heard my voice. I didn't have to burp. I could somehow produce a sound that was similar to my pre-op voice. My search, for how to make that happen all the time, began. Some said it was the beer, some said it was the sipping. They both probably contributed, but the secret was the "wh" that opened soft palette.

In spite of the fairly common physical set backs such as burn, fistulas, and hypothyroidism (due to the laryngectomy surgery and radiation), I continued speech therapy. Mayo Clinic's Laryngectomy Rehab Seminars and the IAL's Voice Institute were essential training for the basic information I needed to figure out what worked for me. My determination to accomplish esophageal speech played a part in my declining Eric Blom's offer to try the TEP in June 1979. I explained to him that I was working on my ES, and I also planned to learn to use the Larkel so I could continue swimming. The TEP is still available if I need it one day.

Mastering the three methods of air intake for esophageal speech is essential. The other half of that procedure is learning how to release the air for sound. In addition to the Voice Institute that meets every year prior to the IAL Annual Meeting, there a number of books available. There are explanations and word lists to use for practice. I prefer not to use word list when I teach because I know it is more useful to know how to allow the air that is under pressure in the esophagus to come up and out immediately. The key for me was the "wh" in what. It opens the soft palette and helps the sphincter at the top of the esophagus to open enough for the air to rise up & out as whatever sound we shape with our mouths. The interrogatives work well: who, what, when, where, why, and I add white, whale, while, etc. for good practice. If esophageal speech is going to be a useful, no hands needed, backup, than a single word will work to begin with.

I encourage each of you to learn all you can about the mechanics of alaryngeal speech in general. There are so many misconceptions about EL, TEP and especially ES...

For example: "SUPERCALIFRAGILISTICEXPIALIDIOUS" IN ONE BREATH is using one breath of lung air. However, esophageally, it is broken down into syllables, and air is fed into the top of the esophagus with every consonant. That air is immediately used for every vowel that follows. If you are singing the vowels are held longer and the air is used more efficiently before the next consonant injection of air.

A more helpful way to measure the number of vowels per injection of air into the esophagus is "strings of vowels". On one injection of air begin with "aeiou, aeiou, aeiou" and see how many sets you can say before you lose sound. Don't stop between each vowel and keep your voice very soft. Volume will use up the available air, when the goal is the number of sets you can utter on one injection of air. This is an excellent exercise, especially if you need to say, "supercalifragilisticexpialidious" , you will have practiced like a marathon runner.



### ListServ "Flame Warriors"

#### Terms of Importance

#### flame

1. n. A hostile, often unprovoked, message directed at a participant of an internet discussion forum. The content of the message typically disparages the intelligence, sanity, behavior, knowledge, character, or ancestry of the recipient.

2. v. The act of sending a hostile message on the internet.

#### flame warrior

1. n. One who actively flames, or willingly participates in a flame war ... (Another Example Below) ...

RAT



**Rat** prefers to attack with private messages rather than out in the open.

**CAUTION:** If a Warrior starts to get the better of the fight he will suddenly post out of context excerpts of his opponent's messages to the list. When taken to task for betraying private correspondence he will insist that he did it because he was being harassed or that his adversary poses a threat to other, more vulnerable Warriors, such as Innocence Abused.

Above courtesy of Mike Reed

See more of his work at: <http://redwing.hutman.net/%7Emreed/>



## 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. If you have any questions or constructive criticism please contact Pat or Donna at [Editor@WebWhispers.org](mailto:Editor@WebWhispers.org).

Take care and stay well!  
Murray Allan, WW President

### We welcome the 36 new members who joined us during September 2006:

Gary J. Anderson  
Warren, OH

Cheryl Biggs - Caregiver  
Nevada, MO

Kevin L. Canan  
Athens, OH

Kim Cornish  
Cherry Hill, NJ

Kenneth Cothran  
Ocean Park, WA

Sidney D. Cronier  
Athens, AI

John I Day Bainbridge, GA	Richard A. Farnham Hollister, CA	Thomas Y. Fritsche Maple Shade, NJ
Ellen Frohardt Colorado Springs, CO	Katherine Kay Ginn Clinton, WA	Ursula Gould Bow, London, UK
James A. Grafton Moline, IL	Louise Haddad Quincy, MA	Jeffrey G. Hall Pompano Beach, FL
Leo L. Heligas Sioux Falls, SD	Wilbert Jones Cottondale, AL	Susan Leifer Greenwich, CT
Franklin M. Lindsey Elm City, NC	Venessa Litewski Winthrop Harbor, IL	Carol Linnenbaugh - Caregiver Cochranville, PA
Linda Long - Caregiver Corpus Christi, TX	Lorraine Mann Middletown NY	Melody Mccoy Williamson, WV
Cody Mcdonald Canyon Country, CA	Suvanya Naidu - SLP Durban, South Africa	Lynda Piroso Chesterfield-Derbyshire, UK
Jerry Wayne Pullum Jacksonville, FL	Dee Marie McLarty Sally - Caregiver Cottonwood, AZ	Paige Smith - SLP Medford, OR
Clyde Simmons Citrus Heights, CA	Wilbert Sullivan Greenville, NC	Irene Tronnes - Caregiver Rich Square, NC
Brendda Unangst Gloucester, VA	Debbie Walters Belleview, FL	William Zelenskas Concord, OH

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