

# WebWhispers

Sharing Support Worldwide



## Whispers on the Web

A Monthly OnLine Newsletter for WebWhispers



November 2006

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### Murray's Mumbles...Musings from the President

#### Dr. Carla DeLassus Gress appointed to WebWhispers Board of Directors

It is a great honor and privilege to appoint Carla Delassus Gress, Sc.D, CCC-SLP, to WebWhispers Board of Directors. This appointment will end in December 2008 at which time Dr. Gress may stand for election if she so desires.

Carla celebrated her nine year affiliation with WebWhispers in September, 2006, having joined when there were fewer than 100 members on the email list. At that time, Dr. Gress was Manager of the University of California - San Francisco (UCSF) Voice Center, in association with Dr. Mark Singer, MD, FACS, co-developer of the tracheoesophageal puncture (TEP) method of alaryngeal voice restoration. She also held an appointment as Assistant Clinical Professor of Otolaryngology/Head and Neck Surgery at the UCSF School of Medicine. Her frequent participation in the WebWhispers listserv in the early days resulted in her receiving the "Internet SLP Extrordinaire" award, presented at the WW Reno Rendezvous (during the IAL Annual Meeting) in 1999 by our Founder, Dutch Helms. HeadLines and the WebWhispers newsletters were publishing many helpful articles by Carla Gress as early as 1998.

Prior to her position at UCSF, Carla was a clinical and research speech pathologist at the Massachusetts Eye and Ear Infirmary in Boston, and was an instructor in Otology and Laryngology/Head and Neck Surgery at Harvard Medical School. Her interest in laryngeal cancer and the communications needs of laryngectomees began as a graduate student at St. Louis University, where she graduated with a Bachelor of Science (summa cum laude) in 1977, and a Master of Arts in Communication Disorders in 1978.

After a decade of clinical practice, she received a Doctor of Science (Sc.D) with Distinction in Communication Disorders from Boston University in 1992. During her Doctoral program, she served as a Research Speech Pathologist at the central speech laboratory of the Department of Veterans' Affairs.

Since 2002, Dr. Gress has been in private practice in Lynchburg, Virginia. She has served as the International Association of

Laryngectomees (IAL) Voice Institute Director for the last two years, bringing a commitment to offer the most current information from the leading professionals in laryngectomee rehabilitation and related topics.

Additionally, Dr. Gress serves on the Board of Directors and provides clinical direction to the Foundation for Voice Restoration ([www.getvoicing.com](http://www.getvoicing.com)), a non-profit organization that is dedicated to the development of improved communication for individuals afflicted by cancer of the larynx through its educational, research, outreach, and support services.

Carla is married and has "almost" six year old twins, Evan and Emily. Her hobbies include antiques, genealogy, and Bernese mountain dogs. She can be reached at [Carla\\_Gress@hotmail.com](mailto:Carla_Gress@hotmail.com).

On behalf of the WebWhispers Executive Committee, I welcome Dr. Gress to our Board of Directors with enthusiasm as we know she will add a great deal to the knowledge and information that can be found on WebWhispers.

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

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

VoicePoints

## **Announcing: The New Coordinator of VoicePoints**

### **LISA PROPER, MS-CCC-SLP, BC-NCD-A, BRS-S**

Lisa Proper has over 20 years of clinical experience, which has predominated in the diagnosis and treatment of adult onset communication and swallowing disorders. Her Master's degree in Speech Pathology is from the University of Louisville School of Medicine (1984) and she is ASHA certified. Lisa has held numerous professional offices at local, state and international levels. She is the founder of the Jacksonville Area Speech Pathology Association and is listed by the International Association of Laryngectomees as a Qualified Instructor of Alaryngeal Speech. Board Certified in Adult Neurological Communication Disorders, she has recently received Specialty Recognition from ASHA in the area of Swallowing.

Lisa has lectured internationally, published articles in the area of Alaryngeal Voice Disorders, and has lectured nationally in the areas of Muscle Tension Dysphonia, Dysphagia and Adult Neurological Disorders. The following will give you an idea of her expertise.

Private Practice - Provision of speech pathology clinical services at Mayo Clinic-Jacksonville. Clinical areas predominate in diagnosis and treatment of neurological and otolaryngology based swallowing and communication disorders, including all aspects of laryngectomee, Botox protocols, voice disorders, manofluorographic assessment of dysphagia, etc. Administration duties and supervision of speech pathology employees.

There is no way to list "all" of the presentations and lectures but here are some of the topics:

Total Rehabilitation of the Laryngectomy  
Tips for the Head and Neck Radiation Patient  
Everything You Wanted to Know About Dysphagia but Were Afraid to Ask. JASPA  
Tracheo-Esophageal Puncture.  
Radiation and Swallowing  
Radiation and Swallowing: Effects and Treatment.  
Tracheo-esophageal Puncture  
Introducing a Client to the Artificial Larynx  
Swallowing Therapy during Head and Neck Radiation: A Proposal  
What's New in Laryngectomy Rehabilitation?

We at WebWhispers are so pleased to have Lisa Proper join us and take over the task of coordinating from Jeff Searl, who has served us so well and has offered to be around to help Lisa or still write for VoicePoints as time allows. VoicePoints was started originally and coordinated by Dr. Dan Kelly, who is now working on a new project that he will be sharing with us in the future.

Welcome Lisa!  
Pat W Sanders, Managing Editor  
Whispers on the Web

Comment from our new coordinator:

I want to thank Web Whispers for giving me this opportunity to serve the organization and assist in the education of Laryngectomees and Speech Pathologists in laryngectomy rehabilitation. I would ask anyone with suggestions regarding topics, authors, etc., to feel free to e-mail me at anytime with your ideas. Additionally, I am hoping to begin two new series. One series will be covering individual case histories and the other will be suggestions for "Tricks of the Laryngectomy Trade". The Case History series was suggested by my predecessor, Jeff Searl. I would like to invite all Speech Pathologists who have an interesting case to send case histories to me. This may be a difficult case you solved or a case you may still need help with. The cases will be published based receipt. The second series, "Tricks of the Laryngectomy Trade" is based on an article that Dan Kelly asked me to write for Voice Points a few years ago (Refer to [April 2004](#)). Do you or any of your patients have innovative ideas that assist in the rehabilitation of laryngectomees?. Please email me your ideas. The idea may be big or small, you may even submit them anonymously. I think it would be wonderful if we could make this an annual part of the Voice Points column. E-mail me at [proper.lisa@mayo.edu](mailto:proper.lisa@mayo.edu). I look forward to sharing everyone's ideas with the WebWhispers community..... Lisa

# A Scottish Accent

By Rosalie Macrae, Colchester, Essex, UK

*By Rosalie Macrae*

The other day I received so many reassuring, interested, critical, funny, downbeat, upbeat, sympathetic, been-there messages after writing a sad little self-indulgent e-mail about being depressed that I thought, thazzit!

EVERYBODY on this laryngectomy site knows all about the blues so I'll go ahead with a captive audience and write about depression this month. That way we can all feel basso profundo, downright low, with \*miserichords that Wagner would recognise. Must look up when I find a dictionary in actual English to see if 'miserichord' is a word. If not it should be.

Rotting apples on the ground. Bare rosebushes. OK there are hips but that means finding the right abstract kind of vase. Bills pouring through the letterbox, including one for £124 for the broken EL button I mentioned last month. Think I'll send that particular account to the executors of the departed Leonard Bernstein's estate for getting me all worked up with Ode to Joy. Out of milk. Overfed neighbours revving up their gas-guzzlers to buy more food with not a thought for these skinny, overworked North Koreans having to make noisy atomic fireworks to scare the cats. Even some humans are taking tranquilizers about it, for goodness sake. Don't people just over-react. That's really high voltage depressing. Bush and Blair and Bombs. Pass the Prozac, Brenda.

And then a friend telephoned and I changed my mind and decided to celebrate gladness instead. He told me this great story. His father was interpreting at a post-war celebration banquet with Stalin, Roosevelt, Churchill, de Gaulle, and their wives. President Roosevelt, who hosted it, asked the wives, before they were shunted off for the after-dinner port ritual, which of their famous husbands' attributes they would like if they could choose just one.

They all, even the doughty feminist Eleanor R, gave the predictable sort of blandly loyal thing about kindness, and bravery, and not beating up the butler; until it came to Madame de Gaulle who said, immediately, in her posh Parisian accent that she would like to have "a penis" like her husband.

Shocked silence. The maitre d' stopped re-charging Stalin's claret in mid flow. Then M le General came as near as he ever did to smiles and said "Ah, excusez-nous, mes amis. My wife, she means 'appinness!'"

Apparently even the meringue topping on Stalin's Pavlova quivered dangerously near his tunic, moved by the splutters of the merry murderer's mirth.

Meringues, while on that subject, are ideal puddings for messy post-laryngectomy eaters like myself. They just melt in the mouth and are not going to suddenly erupt, like the deadly sticky toffee pudding. Or lentil soup which we won't even start thinking about.

Today I found myself surrounded by cup cakes. Hundreds of them. Pale ones, burnt ones, chocolate ones, ghastly pink and even black ones, made by the boys--no sexism here--at a local school where a Chinese professor was talking about the role of his country in the 21st century. The boys had thought he would like cup cakes with dry sherry after his speech, and they were simple to make. But for me not so easy to eat. Virtually impossible really without losing face.

I cornered the delightful Professor Wei after his speech to ask him about the state of laryngectomy in China, it being a country where babies are sometimes puffing before walking. I made that bit up, Professor. Anyway, while considering his answer he passed me one of these pink cup cakes on a willow-patterned plate, probably loaned by someone's mother I expect, as the rest of us were handed white canteen ones. I felt he didn't really want this cake as it was nearly dim-sum time, and was cunningly downloading to me in the guise of Oriental courtesy.

Now cup cakes are not ideal for a ladylike lary because they stick around your gums, and when you are standing up clutching your EL and a sheaf of papers about modern China, and trying to make clear lip moves, it's impossible not to know that you have a bridesmaid-pink sludgy coating over the teeth.

But the professor, bless him, didn't reel back, and said that in fact a distant female cousin had undergone the same operation in Beijing and was back at work teaching piano. I said it was lucky she wasn't teaching singing and he giggled and offered me another cup cake.

Talking of China, and I do apologise to any Chinese readers. Every nation has its funny little ways. Nothing personal. But a lady from Shanghai who runs a local carryout was telling me that they moved to Britain because of her eldest son, now 20, a champion swimmer and born blind. "In China they are rude to people who are different and used to crowd around pointing at him eating because he was blind and sometimes spilled when he was a little boy. Here they are more polite."

They would have had a ball in Shanghai watching--and hearing our laryngectomee group having a meal the other night. It would have been even more audience friendly if we'd used chopsticks. Not a requirement in ye olde terrible overcooked roast beef section in the local King's Head. This is the most popular name for pubs and hotels dating back to the quaint old practice of hanging up the heads on London Bridge to show what happened to naughty royals.

On that gladsome note, happy Hallowe'en.. And lock up your dogs and your daughters.

\*Misericord. Looked it up. It is indeed a word but without the aitch. Misericord, meaning mercy, forgiveness, pity, etc. etc. My favourite definition being the room in the monastery where some relaxation of Rule is allowed. Next time you see a happy priest dig him/her in the ribs and ask if they've been whooping it up in the misericord. It would not be understood by rabbis or mullahs. Or Chinese Buddhist monks. Or Seventh Day Adventists if you must be pedantic, Brenda.



*Donna McGary*

Hi Y'all. This little message is from your humble editor who has been stuck in the breakdown lane of the information highway for the last month! I have had several responses from webbies who want to contribute to this column. Thank you very much. We appreciate you.

Dennis' column certainly resonated for many of us. Due to my technical difficulties, I can't access any of them...some editor I turned out to be! Not to worry, I have called in the cavalry.

I do have a couple of requests and suggestions for future contributors. The first has to do with content. There have been several very powerful and moving messages to the list lately that would be perfect for this space...including one that was a response to Dennis. Some of the personal stories of grieving and letting go were deserving of the space that this column affords us as readers.

Next time you sit down to write a longer, more personal response to something you have read on the List, consider whether, this column might not be a better forum for your thoughts. Send it off to [editor@webwhispers.org](mailto:editor@webwhispers.org) and let us work with you. If it needs to go to the list because of timeliness, we can do that, but this column is an opportunity to tell your story in a way that while appropriate for our daily correspondence, may actually be better served here.

Secondly, please just send it as an e-mail or as an attachment in Microsoft Word not WordPerfect. A regular e-mail to the above address is perfectly fine and easy for us to work with.

Keep those cards and letters coming We all look forward to hearing from you.

## BETWEEN FRIENDS

*Donna McGary*

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

### CONNECTIONS

*Donna McGary*

I had planned to talk about the science behind the tests I wrote about in last month's column and why we larys and other neck breathers are critical to this study. However, multiple technical difficulties with my computer and ISP have left me virtually unplugged for 3? of the last 4 weeks. The lead doctor tried to send me the info I needed but I have been unable to access it. Part two of "The Things I Did for Science" will have to wait until next month.

These technical difficulties were a real eye-opener. I felt lost and disoriented every single day my computer was in the ICU. I am more dependent on my computer than I am on my telephone. It started when I was voiceless and obviously couldn't use the phone but this dependency has evolved over time. I live alone in a small town in Maine and the computer is my link to the larger community...not just to WebWhispers but also to far-flung friends and family.

The computer is where I go for everything from medical information to background on something I have read. It is my encyclopedia, dictionary, and atlas. My son lives in the next town and I am more apt to send him an IM (instant message) than call him on the telephone. It is where I turn for recipes, shopping, lyrics to that song I can't get out of my head, and what's on TV tonight. I can't imagine researching anything without it as a resource. I do draw the line at on-line dating, so far anyway! Despite my daily use and dependence on the technology, I am practically a troglodyte (my apologies to the Geico Caveman) compared to what's available.

Like many of you, one of the first things I did when I got my diagnosis was go online and try to get as much information as I could about what I was up against and to research my treatment options. My doctor warned me about spending a lot of time on the computer...he was right...sometimes too much information is dangerous...and scary.

But I survived and eventually found WW. Not through the Internet, directly, but through a web-site for my type of cancer and a face to face with someone who talked just like me (that would be Libby Fitzgerald). She told me about WebWhispers. I went on a WW cruise and met Pat Sanders and the rest is, as they say, history.

How many times have we read and (perhaps written) how important this site is to us. I don't give a rat's a\*\* about TEP problems because I never had one and never can. And if you aren't interested in the thread of discussion, hit the delete key. But I care deeply and passionately about WebWhispers. It is the one place we can go where we sound like everyone else.

I can not imagine a world without you. All of you...some funny, some pitiful, some strong, some weak...some arrogant SOB's... some kind and wise...are now my family. I worry about you if I don't hear from you...I laugh at your foibles. I applaud your triumphs. You make me feel connected.

It is not that I am all alone or isolated. My son and his wife live in the next town and Maine is not the cultural wasteland some might think. HA! But hearing from you all, every day inviting you into my living room and hearing your stories, sometimes over and over again, sometimes learning something new is just like catching up with friends. I hear the same old stories from them sometimes, too! Old and valued friendships are like that.

Even as I have been writing this, my computer and ISP have started misbehaving AGAIN. So I am going to try to get this sent in to Pat (way past the deadline) and hope for the best. Then my son & I may have to go shopping for a new and improved lifeline.

## Practically Speaking ...

**By Elizabeth Finchem, Tucson, AZ**

## More on Esophageal Speech

*Elizabeth Finchem*

Practically speaking, we are still on the topic of esophageal speech, but here are two exercises that will serve you well, no matter which method of speech you use. One is a tongue exercise, and the other one, I call 'sigh/swallow', will relax the neck and shoulder muscles and clear the mouth for speech.

**1. TONGUE EXERCISE:** It is important that you do this in front of a mirror so you have the visual cues. Stick out your tongue as far and as straight as you can. Be certain that it isn't going off to one side; that it is 'centered'. Next, try to curl your tongue up to touch the tip of your nose, hold, and then slowly move it back to 'center'.

Then try to bend your tongue down to touch your chin, and back to 'center'. Go next to your right cheek as far as you can stretch, and back to 'center'. Finally, go to the left cheek as far as you can stretch, and back to 'center'.

The first time you will only do one or two sets of this exercise to strengthen and flatten your tongue for more flexibility and better articulation. This will also help with water going up your nose because the back of your swollen tongue can close off and force fluid up your nose instead of allowing fluid to go over the back of the tongue and down the hatch as it should. The tongue is the strongest muscle we have, and as laryngectomees we really give this muscle a work out...especially with esophageal speech.

**2. SIGH/SWALLOW:** Take a deep breath, hold it, and pull your shoulders up toward your ears and hold that tensed position. As you lower your shoulders and exhale slowly you will feel the warmth as the blood rushes back into the relaxed muscles. Then take a moment to gather up the saliva in your mouth to swallow at least twice to completely clear your mouth before you resume speaking.

This process I call 'sigh/swallow' describes two steps we can use to relax and clear in an exaggerated way privately, or as simply as sighing in public during a brief pause when speaking. When using esophageal speech it is essential that the neck and shoulder muscles stay relaxed, as opposed to the tightening we used with lung air for speech. The extra benefit of the swallowing is that the cricopharyngeus sphincter must open to swallow. When it opens it will allow any excess air in the esophagus to escape; perhaps in a series of little burps, or one long 'ahhh'. With the excess air pressure reduced it is easier to resume speaking esophageally, and should also reduce the uncomfortable build up of air going to the stomach.

In answer to the eternal question: Where does the air come from for ES?

Basically there are three methods of getting air into the esophagus:

**1. GLOSSAL PRESS:** This means lightly pressing your tongue up against the roof of your mouth. This action will put the air that is always in your mouth under enough pressure to guide it toward the back of your mouth until it enters the sphincter at the top of your esophagus. You are just tucking a little air in before you open your mouth to say, "ah". This happens as quickly as you can blink your eyes. Please note: I did not suggest that you swallow air. If you hear a 'klunk' you are probably forcing too much air in and it will soon become unmanageable.

Nor should you 'double pump' to make sure you have enough air to say several words. A friend of mine named Chuck double pumped for this reason for a few years before I finally convinced him that all he had to do is say, "Chuck" without using glossal press first. The 'ch' provided all the air he needed to say his name. The double pump, plus the 'ch' consonant injection put in more air than he could manage for fluent ES.

**2. CONSONANT INJECTION:** As you begin working with consonants such as p, t, or k, add vowels, for example 'p-ah', 'p-ie', 'p-oh', etc. You may wonder how this works. Remember? "For every action there is an opposite and equal reaction"? So, if you pucker your lips to make a "P-ah" sound with your hand in front of your lips you can feel the air pass over your fingers. At that moment the same amount of air is headed backward inside of your mouth, past the cricopharyngeus sphincter, and down into the top of your esophagus. Please don't wait to use it for sound. Catch it before it heads south. You can increase the air pressure in your mouth, if you need to, by holding your lips in the 'P' position a little longer before popping your 'p' sound.

Just for fun, take a moment to put your lips together. There will be enough air in your mouth to move it from one cheek to the other, and back again. Now, continue to keep your lips together and press your hands against your puffed out cheeks. If you have healed enough, you may feel the air go back into your esophagus. (You may see the air as it speeds down your esophagus in the mirror.) The air might come out between your lips like a Bronx Cheer, or it could go up and out of your nose. Your tongue position controls the direction it will take. Experiment! Blow out a candle, blow up bubble gum, and then try your luck blowing up a balloon with the air in your mouth. Keep your lips around the end of the balloon, and pinch the neck of the balloon closed while you draw the air up into your nose by dropping your lower jaw like a bellows. Yes, you can, and you will probably be able to smell as well. These are all great exercises for your tongue muscle.

**3. INHALATION:** This does not refer to inhaling air into your lungs. Instead it is a method that allows air to be drawn into your

esophagus. With your mouth open and tongue down, raise the soft palette as you would to 'gasp in surprise', or 'yawn'. You will hear a "click" sound when the sphincter pops opens. That sound indicates that air has entered your esophagus. It is like opening a vacuum sealed container. When the sphincter opens a vacuum is broken and air has been drawn down into your esophagus, and you're ready to say "ah". It may not be a very loud "ah", but it is audible. You can repeat this continuously until you master it. This method is the air intake technique that fluent esophageal speakers use, especially when beginning with a vowel.

Air for esophageal speech travels into the mouth and should go no lower than about where your larynx used to be before it returns in a figure 8 loop. Blowing out with lung air for ES, or when using an EL, will result in stoma blast. This distracting sound also tightens your neck and shoulder muscles. It makes enough noise to override your ES voice. There is also the worry that you are blowing more than air into the face of your listener.

Another distraction is the intrusive 'k' when speakers use the back of their tongue to say a vowel; i.e. KI, KA, KL, instead of IAL. However, for the 'h' sound you can take air into your mouth with glossal press or inhalation, and the air return and sound will begin at the back of the tongue. If you stop short of touching the soft palette, as you move the back of the tongue as if to say, 'he, he, he', or ha,ha,ha. When you master this technique you can say, 'Harry has hair on his head.'...without a "intrusive k".

I'll close with a story about 'bad actors': double pumping, klunking, stoma blast, and intrusive 'k', to name a few. The Director of the Voice Institute and several of us decided as a 'unit' to attend the IAL "Masquerade" Meet & Greet at the New Orleans Annual Meeting in 1992 dressed as "Uninvited Guests". Our plan was to remain silent and have folks guess what each one of us represented? I borrowed white sheets from hotel housekeeping and designed costumes, arranging each sheet in an individual way. (The sheets were returned unharmed.) During our break that afternoon a few of us walked to Ben Franklin's and bought props: a bicycle horn & tire pumps, construction paper, and masks of course. It was so much fun. We won a prize for best group costume. LOL I recall I went as 'double pump' because I could manage both bicycle tire pumps (one on each hip) and keep my sheet together. No pun intended.

# Vicki's Midnight Train from GA

By Vicki Eorio

## Who is Left Standing?

*Vicki Eorio*

OK, so I am a bit compulsive, although I prefer to say a little controlling but that is not a flattering term either. However, there are definite signs that, even I must admit, confirm these tendencies.

Sunday mornings is my one time that everyone respects. I read the paper cover to cover. But I don't stay in the comfortable chair with my coffee and a snack next to me. As I look around the room, I jump up and straighten that picture just a tad. . Must turn that plant because it is growing toward the light on just one side. Oops, those books in the book shelf need to be rearranged. About that area rug, is it in line with the couch and properly centered? That lamp doesn't give enough light where it is, so change it to the back of the couch and take that lamp and move it to..... And this is during my down time, when I am determined to relax! Do I think the decorating Police will be coming in to check on our home? However, if they do, they won't arrest me because I don't feel the same need to do the washing and ironing. How ironic is that?

Unfortunately, I have other examples. Living in the Atlanta area, the traffic is horrendous. My commute one way can be from 35 minutes to over an hour. You never know until you hit the road. So my car has elements of my second home. And again, everything must be just so. My books on tape have to be stacked in the order that I want to listen to them. The cup holder must also hold my phone and pad and pencil. The purse goes on the back seat and work papers on the floor in the back. When my husband takes the car to be serviced or because he needs it, I must put everything back in the right place.

At work, I never know what sound will come out as I speak. I practice in my office behind closed doors and adjust things to maximize sound. So my office must be organized just so, the air filter plugged in, the humidifier during winter months must be placed just so.

My wardrobe has changed to accommodate covering the stoma. During Georgia summers, neck coverings, no matter how creative they may be, can be very uncomfortable. That means a fan in my office because I frequently perspire and I am long past hot flashes and menopause!

We get up an hour early to do trach care and apply the stoma cover. When the TEP fails, changing it can be difficult because the

track through the tracheal-esophageal wall is no longer a straight shot. Of course, the table with all of the necessary equipment must be arranged just so.

I probably have always been this way but not to the same extent I seem to be post lary surgery. I don't want to practice pop psychology but I suspect that my need for control is greater now that I have LESS control over my body. As you all know, we can be lary-centric very easily especially in the first few years post op. Every lump is cancer; being tired speaks of dire consequences, not that we are getting older; appetite changes (up and down) mean the need for a check up, not that we have lost our sense of smell that is key to taste. Now please don't write and say that with all of these things we should go to the doctor. Of course you should, but realize that we have significant body changes, many that are normal as a result of drastic surgery with effects that will be felt the rest of our lives. Always check with your care giver as you feel necessary. I just speak for myself and know from experience that many of these situations represent a change from "normalcy" to adjusting to life as a lary. And ultimately, again, that feeling of loss of control.

As a result, I obviously overcompensate in pretty dumb ways. I may hold a position at work longer than necessary and not always be the team player I need to be until the very end of the discussion. I will disagree with a suggestion my husband Frank makes about where to plant flowers or what should be on the shelving in the basement. Now how sick is that?

Frank has quoted a fable to me for years and it is one that I am trying very hard to remember. Hopefully you all will find some value in it's lesson. It is:

**IF YOU ARE IN A TUG OF WAR AND YOU LET GO OF THE ROPE, WHO IS LEFT STANDING?**

It took me awhile to truly understand the wisdom of this and to practice it. One of the most important instances of this was when I knew I had cancer. That was in October of 1999. I didn't tell anyone and didn't go to the doctor. I wanted to see my kids who live in another state see me as "whole". Only after they left did I tell Frank and we started the round of tests that did confirm what I already knew. Many, tears, many deals with God, many dramatics as only an Irish person can do. And then, I let go of the rope. At that point I was calm and accepting. I prepared for the surgery not in an emotional way but an accepting way. I prayed not for deals with God but for his love. I met and trusted the surgeons and had the surgery. I accepted the challenges of recovery and attempting to return to work (which was not to be for almost 2 years). I stopped worrying about the lack of support from my family and embraced the support of my husband and friends.

The next important time for me to let go of the rope was when I decided I could accept the looks of strangers and after 3 months of staying at home post op, I went grocery shopping alone. Lordy, but it was tough! But I let go of the rope and was left standing. I was amazed by the kindness of the staff. Even when I had to write notes because I had not yet mastered TEP speech adequately to be heard in a public setting which had music in the background and loud speakers announcing specials.

And now in business meetings I let go of the rope by listening and I now learn so much about others, their critical thinking skills, the rationale for decisions made, and to whom I can go for support for my position. Then I write my summary of the meeting and decisions including pros and cons.

At home I have decided that those dust bunnies deserve to live for awhile. Yes, I know for health reason, they should be eliminated but, hey, what is another day? And do I really care where the pansies are planted? No, I am just happy to have them anyplace. And very happy that someone is willing to do the work of planting them.

Do I forget and slip back? Absolutely! But if I could needlepoint, (a skill I want to learn this winter) I would make a wall hanging that says :

**IF YOU LET GO OF THE ROPE, WHO IS LEFT STANDING?**

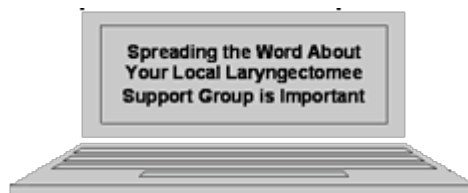
Now that is the ultimate control! Knowing when to let go of the rope!

As I write this, the train is coming through and I take that as a sign of acceptance.



**SIMON SAYS...**

By: Herb Simon



Hello WebWhisperers,

A question was recently posed to the WebWhispers Executive Committee that I was pleased to be able to answer. The question asked was about how to let other laryngectomees and care-givers in the writer's large metropolitan area know that his support group is there to help them. It was later requested for me to share the information and suggestions I offered to this individual with others out there in Lary Land, so here goes:

I am presently serving my 4th (not consecutive) term as President of our local club. I have had some moderate success in keeping our club "on the radar screen" and in a position to receive calls and referrals on a continuing basis. Over the past decade, I have used all of the methods that I will be mentioning in this article.

One of the most important things to do is to create an informative and inviting Letter of Introduction for your local club, if you don't already have one. Then have it posted along with other pertinent club information on the Local Club pages of the IAL Larynxlinks website. Many clubs listed on this website, only have a link to the contact person's email address. For a very reasonable fee of \$20.00 per year, any local club that is a member of the IAL can have a Web presence on the Larynxlinks website. Much of this same information can be listed for free on the WebWhispers new website. It is a good idea to have your club's information appearing on both of these sites. Here is a link to the information posted on the Larynxlinks website for our local club, The New Voice Club of Montgomery County, Maryland (a close in suburb of Washington, DC):

<p><b>SILVER SPRING</b>  ACS, Montgomery County  11331 Amherst Ave.  7:30 PM, 2nd Wed.  7:00 PM, 4th Wed.  Monthly</p>	<p>Laryngectomee Club  of Montgomery County</p>	<p>Herbert Simon.  <a href="mailto:h457@aol.com">h457@aol.com</a></p>	<p>Silver Spring,  MD 20901</p>	<p>301 588-2352</p>
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Please click on the blue link that says SILVER SPRING. It will take you to a page that shows the purposes, officers, and meeting place of our club. This page also has links to our club's Letter of Introduction and many issues of our Monthly Newsletter, THE VOICE of MONTGOMERY COUNTY. As I mentioned above, for \$20.00 per year, your club can have this type of information on this particular laryngectomee website all the time. You send the information to the Webmaster and he/she will put it on the site for you. The more people can learn about your club, before taking action, the better it is, AND the more likely it is that they WILL take that action; which would be to contact you by email or phone. If you do not already have a Letter of Introduction, you are welcome to take ideas from the one for our club. You may even use the same format and simply change the information to the pertinent information for your local club, if you wish.

Does your club have a monthly newsletter? This is probably the single most important item to have in order for your club to gain recognition. Having served as the newsletter editor of THE VOICE of Montgomery County for the past 7 years, I have seen the list of people our newsletter is sent to grow to over double the size it was in the beginning. Besides the hard copies that are mailed out, many are now sent via email. Included on our mailing lists are many medical professionals (ENTs, SLPs and Social Workers). Needless to say, our club gets many new pre and post-op referrals, directly from the medical community. The last 24 issues of THE VOICE are also posted on the IAL Newsletter page, along with many other newsletters. Here is a link to the most recent copy of THE VOICE:

<http://www.larynxlink.com/Newsletters/TheVoice/THE%20VOICE%20-%20OCTOBER%201-06.pdf>

AND a link to the pictures from our recent club picnic:

<http://www.larynxlink.com/Newsletters/TheVoice/2006%20PICNIC%20PICS.pdf>

In the newsletter, you'll see minutes to our last meeting. The purpose of this is to let the members who are not able to attend meetings, stay up on the current events and get to know the newcomers. You'll also see that new laryngectomee visits are announced in this issue (and almost every issue). This serves to introduce the new laryngectomee(s) to other members, AND to let the medical professionals know what we are doing to assist them.

So now I ask you to assess what types of activities your club performs? Do you have members who give Tobacco Awareness Presentations to schools? If so, a report on this can be in your newsletter. This will serve to let the laryngectomees in your club and readership know that they can become involved in an activity like this. It also let's those reaching your website, know what your club is doing. Does your club participate in the American Cancer Society's Relay for Life? If so, let everyone know by reporting it in your newsletter. Some may not attend meetings very often, but would delight in joining other members at a function like this, where everyone has something in common and are helping fight cancer in their community.

Does your club have a good relationship with the local ACS? When a laryngectomee related call comes in, do they give out your club's contact information? This is important. If this is not in your club's arsenal, make a visit to your local ACS. Introduce yourself and request that your club contact information be given out to inquiring callers. I get calls regularly from people who called the ACS first and were then referred to our club and given my contact information.

Something else you might try that could possibly attract new members is to have your meeting announced in your local newspaper's Health Section, prior to your monthly meeting. There may be a local hospital newsletter that you can also be listed in.

I visit on average about 30 or so new laryngectomees per year. In our large Metropolitan area it's my guess that well over a hundred laryngectomy surgeries are performed annually. It hurts to know that in spite of all the efforts to reach out, such a small percentage of the new laryngectomees are actually able to benefit from our club's services right away. On the other hand, it's rewarding to know that our club reaches as many pre-op and new laryngectomee patients as we do.

I hope some of these ideas will be useful to many of you.

**SIMON SAYS:** Success won't come overnight, but if you add some of these measures to what you are presently doing, over time, you are liable to notice a gradual, but steady increase of calls for your local club's help and services from new laryngectomees in your area.

If you feel I can answer questions for you, or be of any help, feel free to contact me. It will be my pleasure to assist you, if I can. I wish you all the best in this important endeavor.

Herbert Simon  
[h457@aol.com](mailto:h457@aol.com)



## 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) ...

## Jerk



Jerk is sarcastic, mean, unforgiving and never misses an opportunity to make a cutting remark. Jerk's repulsive personality quickly alienates other Warriors, and after some initial skirmishing he is usually ostracized. Still, Jerk is very happy to participate in electronic forums because in cyberspace he is free to be himself...without the risk of getting a real-time punch in the mouth

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 31 new members who joined us during September 2006:

Lori Baker  
Llano Texas

Larry Buege - Physician Assistant  
Marquette, MI

Don Campbell  
Lopez Island, WA

Anthony W. Cheatham  
Absecon, NJ

Frances Clements - Caregiver  
Newport, NC

Edward DeMaria  
Jupiter, FL

Joseph F. Demling

Lynn C. Erdmann

Bonnie Foster

Louisville, KY	Lebanon, IN	Athens, TX
Craig Galowitsch Frisco, TX	Gayle Garriott Moline, IL	Susan B. Goodwin Marshfield, MA
Jeanne L. Graden Westchester, IL	Nancy L. Gray Baldwinsville, NY	Einar S. Gudjonsson Keflavik, Iceland
Sharon Hankinson Belfair, WA	Dewey Hardin Cape Coral, FL	Kathern L. Hardway Warren, OH
Patrick W. Hoolahan Daytona Beach, FL	Sandy Janes - Caregiver Columbia, KY	William Leach Radcliff, KY
Calvin Moyers Bardwell, KY	Carolyn H. Payne Dobson, NC	Marilyn T. Perez Frezno, CA
Lisa Proper - SLP Jacksonville, FL	Gene M. Ranstrom Boise, ID	Jerry Scarbrough Orange Park, FL
Teddy Smith Montreal, QC. Can.	Lindsay Spurrier - Caregiver Marshfield, MA	Debra Tarakofsky - SLP Lauderrhill, FL
Dave Thorne Vancouver, B.C. CA		

WebWhispers is an Internet based support group. Please check our [home page](#) for information about the WebWhispers group, our email lists, membership, or officers.

For newsletter questions, comments or contributions, please write to [editor@webwhispers.org](mailto:editor@webwhispers.org)

Managing Editor - Pat Wertz Sanders

Editor - Donna McGary

**Disclaimer:**

The information offered via WebWhispers is not intended as a substitute for professional medical help or advice but is to be used only as an aid in understanding current medical knowledge. A physician should always be consulted for any health problem or medical condition. The statements, comments, and/or opinions expressed in the articles in Whispers on the Web are those of the authors only and are not to be construed as those of the WebWhispers management, its general membership, or this newsletter's editorial staff.

**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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