

WebWhispers

Sharing Support Worldwide



Whispers on the Web

A Monthly OnLine Newsletter for WebWhispers



June 2006

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Murray's Mumbles ... Musings from the President



IAL CHICAGO.....ALL THAT JAZZ and MORE

We hope that all, who are able, will be attending the 55th Annual IAL Meeting, July 20 thru July 22. And, of course, we have our very own WebWhispers dinner, planned by WW VP-Member Services, Libby Fitzgerald, to be held on Friday, July 21. That is the night the winner of the "Casey-Cooper Laryngectomee of the Year Award" will be announced. It will be a tight race as the Awards Committee Chair, Pat Sanders, tells me they have many nominations. These nominations closed on May 15th in order to give the committee time to confer and for awards to be prepared.

A few tips to assist first timers to the Chicago area is always in order so I'll try to assist you for your trip to Schaumburg, IL. For those arriving at Chicago O'Hare International Airport the convention hotel, Hyatt Regency Woodfield is located nine miles from the airport in Schaumburg. The most economical way to get to the hotel is by All-Star Cab and Shuttle where the all-inclusive rate for up to four people is \$21.00. When you pick up your baggage, phone 847-621-1700 and tell them your destination and they will assign you a cab number. Wait outside and very shortly you will be picked up. Other cabs charge \$35.00 or more.

For shoppers, the hotel is located directly across from the Woodfield Mall, largest mall in Illinois, which has over 300 stores ready and willing to take your cash or credit cards in exchange for fabulous merchandise and services. Needless to say there is something for everyone including Sears, J.C. Penney, Lord and Taylor, Marshall Field's, and Nordstrom's. Also, there are more than 100 eating establishments located in the Woodfield area - to

include Ben and Jerry's, Benihana, Bennigan's, Chicago Prime, Houlihan's, Joe's Crab Shack, Little Italy, Olive Garden, Outback Steakhouse, Prairie Rock Brewery, Rainforest Cafe, Ruby Tuesday's, Texas de Brazil, TGI Friday's, and the Uno Chicago Grill. The hotel even supplies you with a list of all these eateries. What more could you ask for?

The hotel has a shuttle service to the Mall and if you are nice to them they will even take you to other locations adjacent to the hotel. The staff is extremely friendly and will go out of their way to help you in any way they can.

Hope to see you all in Schaumburg for a great WebWhispers dinner and a very educational Annual Meeting and Voice Institute. Dr. Carla Gress, VI Director, tells me that we will again be fortunate to hear from Dr. Eric Blom and Dr. Mark Singer of Blom-Singer fame.

For Animal Lovers

When at a yard sale one day, I saw a box marked "Electronic cat and dog caller - guaranteed to work". I looked inside and laughed when I saw an electric can opener.

Take care and stay well.

Murray Allan
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VoicePoints [© 2006 Dr. Jeff Searl]

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Reflux and Alaryngeal Speech

By Jeff Searl

Commercials for reflux medications are everywhere these days. The pharmaceutical industry has made sure that we all are aware of the possible signs and symptoms, as well as the treatments — at least the treatments they happen to be peddling! In the most colloquial terms, reflux refers to stomach contents that head north rather than south. Most folks who have had a total laryngectomy are fairly in tune with the throat and esophagus. This personal knowledge, along with what has been picked up in the lay literature, the internet, and reflux medication advertisements have gone a long way to helping the general public know something about this condition.

As a reminder, the esophagus is a tube of muscle that serves as the connection between the throat and stomach. This muscular tube has a sphincteric muscle at each end. The upper esophageal sphincter (UES) (post-laryngectomy, this is often referred to as the pharyngo-esophageal, or PE, segment) is a region of tightness between the lower throat and upper esophagus that must relax when swallowing so that food, liquid, or saliva can enter the esophagus. The tissue making up this PE tissue also can be set into vibration when we produce esophageal (ES) or tracheoesophageal (TE) voice, or when we belch to relieve stomach gas. Material that enters the esophagus from the mouth is propelled down the length of the tube toward the stomach by an orchestrated sequence of muscle contractions that squeeze the food or liquid. At the bottom of the esophagus is another sphincter called the lower esophageal sphincter (LES) that must relax so that swallowed material can pass into the stomach.

Esophageal reflux occurs when the LES relaxes inappropriately, allowing stomach contents to flow back into the esophagus. This "refluxed material" can migrate up the esophagus causing symptoms of reflux such as heartburn or a sensation of something in the chest, although not everyone feels symptoms when reflux occurs. It only takes a malfunctioning LES to have reflux; however, in some individuals the refluxed material may move into the throat if the upper esophageal sphincter (UES) also opens inappropriately.

So, should people with a total laryngectomy be concerned with reflux any more than the general adult population? Are there particular issues or concerns involving reflux that are unique to those with a total laryngectomy? We certainly know that pharyngo-esophageal reflux (that is, stomach contents moving up the full length of the esophagus and into the throat) can cause voice changes in those who have a larynx if the stomach

contents make contact with the vocal folds. The same may be true for the person with a laryngectomy.

There is a fair body of research indicating that the tightness of the UES in people with a laryngectomy tends to be less than that of people who still have their larynx. Less tightness in this UES (or PE) region is a good thing in most instances as far as ES or TE voice production is concerned. When the PE segment is too tight, the resulting voice can be strained, effortful or even non-existent. Less tightness in the UES at rest has been found, even in most laryngectomees who have a UES that is overly tight, during attempts at ES or TE voice. Such folks are typically still able to swallow (the difference is really a matter of what happens to the UES when putting air into the esophagus vs. what the UES does when at rest).

Although the UES tends to be less tight following total laryngectomy, as long as the LES is in working order, reflux should still be prevented. Most of the time it is. However, there are reports that reflux occurs more frequently post-laryngectomy and there might be several issues to consider in terms of alaryngeal voice production that could be impacted by reflux. In the most extreme cases, reflux can cause severe tissue irritation in mucosa lining the esophagus any where along its length. In some individuals this can cause significant pain. A small percentage of individuals with severe esophageal mucosal injuries high up in the esophagus may report that using TE voice is uncomfortable. Presumably this is because of the added air pressure in the esophagus that either distends (stretches) or presses on the already irritated tissue. In other individuals for whom the reflux occurs all the way up to the UES tissue itself, there may be pain during voicing. The UES tissue will be set into vibration for those who use TE or ES voice. The vibration involves tissues moving away from and then toward one another such that tissues in the UES may "slap" against one another. Because the TE and ES voice tend to be somewhat hoarse anyway in most folks, a change in the voice quality towards hoarseness (as may be noticed in non-laryngectomized speakers) is not always perceptible, but the pain is. Discomfort or pain during voice is a matter that deserves immediate attention from the physician and therapist in order to begin working back to the cause.

In other individuals, reflux up to the UES could cause another type of voice quality change. There may be a wet-gurgly voice quality. The refluxed material that reaches the UES region may be responsible for this change directly if it is set into motion along with the UES tissue. However, the volume of refluxed material is often small and likely to coat tissue rather than pool in places. Still, the refluxed material can cause a changed saliva for some individuals such that the volume is increased, or more likely, that the consistency is different (usually thicker, frothy). This saliva may pool atop the UES and vibrate with this tissue creating a wet-gurgly sound.

Those who use TE speech may have an additional concern related to reflux. One end of the voice prosthesis rests within the esophagus itself. Severe reflux that makes it all the way up the length of the esophagus to the UES would also bathe this valved portion of the prosthesis. Some have suggested that severe and persistent reflux might contribute to valve degradation. From my own caseload, I have a handful of patients for whom valve life appeared to be extended notably once reflux was under pharmaceutical control (these were just impressions from myself and the patients, not from a controlled investigation of the issue). In another valve-related situation, a TE patient had a valve that failed because of yeast infection who then experienced a major episode of nighttime reflux that passed from the esophagus through the TE valve and into the trachea. The individual awoke with severe coughing and difficulty breathing. Subsequently, the doctors were able to document caustic injury to the lungs. The case highlighted for me the need for both careful control of TE-valve yeast issues as well as control of reflux in those with suspected problems.

Those who undergo a more extended laryngectomy that involves the esophagus (that is, some degree of esophagectomy) deserve brief comment. In some patients, the esophagus may be resected and the remaining esophagus and attached stomach pulled up. In others with greater resections, the esophagus may be reconstructed with other tissue from the lower GI tract such as the jejunum or even the colon. A functioning LES becomes particularly critical for these folks because the former UES tissue is removed. Material that is refluxed into the esophagus may tend to pool in certain places (for example, along suture lines from the esophageal reconstruction) and not be easily moved back into the esophagus with saliva or other swallows. These folks also are the ones who are more likely to already have a wet-gurgly sounding voice. They also may not have the same sensitivities within the newly reconstructed esophagus and as such may be less capable of detecting pain or discomfort that might usually be associated with reflux. These patients pose a host of challenges in care from the perspective of the speech therapist and medical providers — control of reflux is one of those. Even though they may not be symptomatic in terms of voice or discomfort issues, the reflux might be important for TE valve life (if they are a TE user) and also because of the more general concern that persistent reflux can be harmful to the esophageal mucosa.

Fortunately these days, the doctors have a host of medications and procedures that can be considered for treatment. Medications are a primary line of treatment, with surgeries to tighten the LES reserved for only the more involved cases. There also are behavioral changes that can be made to help manage reflux and these are usually tried in conjunction with medications. The behavioral changes that are often recommended include not eating or drinking for 2-3 hours prior to bedtime, diet changes (eliminating alcohol and caffeine, limiting fatty foods, etc.), elevating the head of the bed, losing weight, and avoiding restrictive clothing among other things. The behavioral plan may need to be tailored to the given individual and so the involvement of the physician (and possibly the speech-language

pathologist) is important.

Reflux is often viewed as a relatively minor medical issue. While that may be true in most cases, there are reports that the tissue changes caused by on-going reflux may be a precursor to esophageal cancer cell formation. In addition, for the laryngectomy speaker, there may be very direct impacts on voice production. For that reason alone, the speech-language pathologist, physician, and patient should all be concerned about identifying when reflux is occurring and then doing what is needed to take care of the problem.

A WEBWHISPERS RETROSPECTIVE

1996 - 2006

Tenth Year Anniversary

For the people who were not with us during those early years, here is how our group started. Almost 10 years ago, in the summer of 1996, Dutch Helms, a laryngectomee from 1994 and a fairly new computer user, started a special section of web pages, called *Cancer of the Larynx*, as part of his own personal web site. He added information as he could find it and suggested that when other larynx cancer patients found him, they join him in being listed on the site so they could all begin exchanging e-mails and ideas. A few years later, Dutch wrote about that time:

"When I was initially diagnosed with larynx cancer back in 1993/94, I was completely frustrated by the lack of easily accessible information about the disease and its possible treatments. This frustration continued throughout my treatment process. I got my first computer in mid-1994, just after my laryngectomy operation. It took me a while to become computer literate and then, after about a year, I set up my own basic personal website on AOL, using the AOLPress web page building software.

In the process of becoming computer literate, I started to search the Internet for sources about larynx cancer. I found several, but they were "hard to find" or "hard to read" (too technical for most folks) . So in mid-1996, I decided to create a "Cancer of the Larynx" section on my personal website - a place to "centralize" links to the various larynx cancer sites on the Internet and a place to "talk" about the disease in layman's terms ... from the point of view of a larynx cancer survivor/laryngectomee. By December of 1996, the basic Cancer of the Larynx site was up and running and I then hit on the idea of creating, on the site, a LIST of laryngectomees worldwide who would be amenable to accepting email questions about the disease from "surfers" looking for information."

Thus, we became a source. One of our members, Charlie Anderson, wrote the following in 2001: *"After reading our short history, I got to looking in my old files and found some interesting stuff. I was one of the first members (Dutch says I was one of the first but I think I was FIRST). I joined December 5th, 1996. I have an e-mail dated December 9th that lists the first 10 members, including Dutch, - have not checked it out but I know some of these are no longer with us."*

Charlie was kind enough to get a copy of this message to us along with one from Dutch a few days after that one, describing his vision.

Subj: Seasonal Greetings
 Date: 96-12-09 16:25:46 EST
 From: ChippWood
 To: Rtunnard, FantumTwo, RCline8552, Otter Two,
 To: renison@laplaza.org.us (bill), ChasTex31
 To: JoeHJohnson, jready@mediacity.com (john),
 To: wayneb@hooked.net (wayne)

FIRST 10
MEMBERS

SEASONAL GREETINGS TO FELLOW LARYNGECTOMEES

I'm on the mend and beginning to enjoy life again. I hope the same applies to all of you.

Have a very happy Christmas and a Good New Year!!!

Les Wood, Wiltshire, England

Subj: Greetings from Texas!!
 Date: 96-12-18 12:04:56 EST
 From: PantumTwo
 To: JoeHJohnson, RCline8552, Otter Two, Blindysue
 To: ChasTex31, ChippWood, Rtunnard
 To: jready@mediacity.com, wayneb@hooked.net
 To: manb@earthlink.net, renison@laplaza.org
 To: bobnroa@pipeline.com

12 members + Dutch

Dear Fellow Laryngectomees,

Just a quick note to thank you again for consenting to be listed as a "source" on my Larynx Cancer site and to wish you a great holiday season. Additionally, I would like to expand the info provided via the site by listing the type of "voice" you use. I would foresee "coding" the type and then placing the "code" after your name. This would allow readers to know what type "voice" you use in case they wish to address that issue with you.

My proposed code would be: (E)=Esophageal Speech, (T)=TEP/Voice Prosthesis, and (L)=Electro-Larynx.

If possible, request you EMail me back letting me know what type of voice your use - I will then update the listing as appropriate. Thanks much for your help and, again, Merry Christmas and all the best in the New Year!!

Warmest Regards,

Dutch Helms, Seabrook, TX

It is interesting to see that we started, not as a local group, but as a world wide organization with the first ten Email addressees. We had two from England, and the eight from the US were scattered around the country.

Richard Tunnard and Les Wood from the UK.
 Dutch Helms and Charlie Anderson - TX
 John Ready and Wayne Baker - CA
 Joe Johnson - AL
 Ned Bienemann - MD
 Robert Cline - IA

Bill (and Mary Alice) Renison - NM

More about the past....in the future.

WebWhispers Columnist

Contribution from a Member

(Editor's Note: This is not written BY one of our members but it is ABOUT one of our members. Proud of you, John!)

MEDIA ADVISORY - May 16, 2006

For more information, contact Tom Jacobs at 775-843-4302 or tjacobsrno@aol.com.

John's not going to run the Bay to Breakers on May 21 dressed as a chicken, naked and painted in Celtic symbols or backwards with sparklers attached to his heels. John is going to run the Bay to Breakers while breathing through a hole in his throat.

"John" is John Ready, a sales representative from Redwood City who is one of perhaps 50,000 laryngectomees in this country. His story is one of incredible survival and transformation.

John was diagnosed with throat cancer in 1996. Surgery took his larynx, left interior jugular vein and almost 100 lymph nodes, leaving him a survivor who could neither talk, smell or taste.

For some who suffered John's fate, it was a handicap that required adjustment: sign language, vibrating devices, notepads. To John, it was a situation to be conquered. Today, he talks without his hands in a voice described as "someone with a bad cold."

John travels the country speaking to others who have suffered his fate and teaching others to speak as he does. He's also a consultant for the Foundation for Voice Restoration (<http://www.getvoicing.com>).

When John runs the Bay to Breakers on May 21, it won't be funny or weird or a political statement. It will be a man proving that, despite a catastrophic illness, one can not only do what others do, one can still do what others can't. John's life and work is testimony to the fact that a laryngectomy does not have to mean the beginning of a diminished life. John's message is there's a life after throat cancer that may be different but is equal.

If you think it would be worthwhile to learn more about John, let us know. John will be at the pre-race event on May 19 and, of course, sporting an official number at the Bay to Breakers starting line when the gun goes off.

Note: Tom Jacobs is the lead public information officer for the Nevada Department of Motor Vehicles, a friend of John's for 25 years and a volunteer for the Foundation for Voice Restoration.



Guest Columnist

TEN TIPS FOR DONATING A COMPUTER

(How to donate your used equipment)

Author: Jim Lynch (Reprinted courtesy of CompuMentor, a provider of technology assistance to other nonprofits and the home of TechSoup.org)

As more companies, organizations, and individuals find reasons to upgrade their computers, the problem of how to safely discard used equipment continues to grow. The ramifications of this phenomenon are widespread:

- (1) According to the U.S. Environmental Protection Agency (EPA), nearly 250 million computers will become obsolete in the next five years. In 2001, only 11 percent of personal computers retired in the United States were recycled.
- (2) Every computer dumped into a landfill represents a missed opportunity to provide Information-Age tools to individuals and organizations across the digital divide.

(3) Well-meaning folks that donate out-of-date computer systems directly to schools and nonprofits -- rather than through a recycler or a refurbisher -- can end up passing on more of a burden than a blessing. It costs as much as \$400 to upgrade a pre-Pentium computer to today's standards.
Ten Tips for Donating a Computer

- 1. Determine if your old computer can be reused. If you have a computer that is less than five years old, chances are that it can be put to good use by someone else. Rather than donate equipment directly to a charity or school, however, it is usually best for all involved if you can send it to a refurbisher, especially if you need to wipe your hard drive or are uncertain about the computer's condition. Refurbishers will ensure that equipment they send to nonprofits and schools works well and runs legal copies of software, and that any e-waste is disposed of properly. Remember that refurbishers work with newer equipment that can run current Internet programs, so if your computer is more than five years old, it's better to send it to a commercial recycler.**
- 2. Recycle old and broken hardware. Any equipment that is not working or is more than five years old should be tagged for recycling, i.e. responsible destruction. A computer recycler is a business or organization that salvages useful computer parts before breaking down what's left, safely removing hazardous materials in the process. Note that some recyclers will charge a fee to accept old computer equipment, especially monitors. For listings of recyclers in your area, visit:**

**The Computer TakeBack Campaign
TechSoup's Donate Hardware List
ElectronicsRecycling.org**

- 3. Contact the refurbisher or recycler before donating. Call the organization or check its Web site to ensure that it accepts the type of computer you plan to give away. Some refurbishing organizations, for example, will refuse anything older than a Pentium II. While you may be tempted to donate equipment directly to a favorite local school or charity, remember that refurbishers are generally better equipped to repair and upgrade computers. They will then pass on ready-to-use equipment to those who need it, often at little or no cost.**
- 4. Remember the accessories. If you can, include the keyboard, mouse, printer, modem, packaged software, or any other accessories you use with the computer. Schools and nonprofits can almost always put them to good use, and most organizations only accept complete systems.**
- 5. If possible, keep the operating system intact. If you are donating hardware with a preinstalled Microsoft operating system, keep in mind that the license is only valid when used with the machine on which it was originally installed. Since charitable organizations usually cannot afford to purchase and license new operating systems, a legal transfer (whereby the computer and operating system stay together) is always preferable. While Linux and Macintosh operating systems have different requirements, as a general rule, try to include the operating system software with all donated computers whenever possible.**
- 6. Provide the original software media and documentation. To ensure that the software transfer is legal, pass along the original disks, media, Certificate of Authenticity sticker (usually on the computer), user manual, and other documentation that came with the equipment.**
- 7. If you clear your computer of personal information yourself, it's best to use disk-cleaning software. "Personal information" includes your Internet browser's cache, cookies, history; your email contacts and messages; your documents; your recycle or trash folder; and all nontransferable software. The best way to clear this is with a disk-cleaning utility that overwrites all the sectors of your hard drives, making your data unrecoverable. Listed below are examples of recommended disk-cleaning utilities.**

Commercial Windows Disk-Cleaning Software:

**Blancco Data Cleaner
CyberCide Data Destruction
DataEraser
DiskEraser
Clean Disk Security
DriveScrubber
East-Tec DisposeSecure
Norton Utilities (Wipe Info feature)
Stellar Wipe
Paragon Disk Wiper
Pinion Sanitizer
UniShred Pro
WipeDrive**

SystemWorks (Wipe Info feature)

Freeware Windows Disk-Cleaning Software: (All available at Shareware.com)

Active@ Kill Disk Hard Drive Eraser

Darik's Boot and Nuke

Sure Delete

BCWipe

Macintosh Disk-Cleaning Software:

iClean

Norton Utilities (Wipe Info feature)

SuperScrubber

If the computer is still under a manufacturer's warranty, you can also call the company's technical services department and ask for specifics on how to delete personal files.

8. Follow computer delivery instructions. Many recycling and refurbishing organizations have specific locations where equipment can be donated, while others have delivery instructions they expect donors to follow.

9. Keep a list of what you donated for your records. Remember that tax season will always return -- and you are likely eligible for a deduction if you donate to a nonprofit refurbisher. Most school or nonprofit refurbishers can provide a tax receipt upon request. Business donors can deduct the un-depreciated value of the computer, and individuals can deduct the current market value of a computer.

10. Plan for future donations. Rescue a box from the recycling bin and use it to store the documents that came with your new computer, so that when the time comes to donate it, you'll have everything in one place.

Vicki's Midnight Train from GA

By Vicki Eorio

"Georgia on My Mind"

I had my surgery March of 2000, getting a TEP that now allows me to speak hands-free. What an interesting way to start a new century. A new beginning! What a journey! What a roller coaster!

I hope to share with you, on those nights when I awake and know that further sleep will not happen, some of my experiences that are unique to being a lary. Many of them will be very familiar to you. It is my hope that by sharing, we all can have a greater sense of community and take pride in our accomplishments. And if I can make you smile, that would be the best of all.

Why "Midnight Train from Georgia"? Well, I have left behind the life I knew and am trying to find a "simpler place and time". I had a choice to stay in Virginia or come on down to soft spring showers, winters that welcomed a fire in the fireplace, and summers that take your breath away with the flowers and bird songs, crickets and porch swings and even fireflies. Now that I am a lary, it is important to find the right place and to try to return to simple pleasures.

I used to be a very successful consultant making more money than I deserved and always anticipating someone would figure out that I didn't have all the answers. It was a complicated, stressful time. If you looked from the outside, I had everything. But then one day I woke up from surgery and could not speak or smell or blow on my hot soup or lift my head without supporting my neck. As time went on, the adjustments multiplied. My wardrobe, one that covered my stoma. A timer for cooking because I couldn't smell the status of my cooking. Double checking the stove to make sure burners were off because I could not smell the gas. Asking if the food I fixed for others was ok because my taste was altered. Avoidance and denial that came from my siblings. Since my father had been a lary, they probably felt they couldn't handle it again so they withdrew and remained there. My grown children were frightened and angry. Discovering the number of folks in my life that prayed for me and did not avoid me and finding some that emailed me everyday. The constant, unfailing support and care given from my husband. Finding the Whisperers and learning so much from others. Dealing with no income. And that was just the first 6 months post-op!

But it really was much simpler than getting on a plane and traveling 5 days a week, dealing with nice people who needed a variety of assistance that I always wondered if I could do adequately. Learning trach care and thinking before I attempted to speak was the ultimate in simplicity. No hidden agendas here! And knowing who was emotionally capable of dealing with me and who was not was a tremendous relief. It's called cleaning house. In order to survive, I had to return to the basics of life and pleasures. I had to focus on daily accomplishments like learning to love my stoma J and all that meant. Pacing myself because the old energy was gone. Accepting the lows that could hit at any time. And like Blanche in the Tennessee Williams play, I was "relying on the kindness of strangers." In many ways it has become liberating.

Back to trains...I just plain love them! A hundred years ago in what seems to be a previous lifetime, when I was young, a very handsome young man who was a train engineer, wanted to date me. However my parents said I was too young, not yet sixteen which was the magic age. But my father did accept a tour of the roundhouse and a short ride in the engine of a train!!!! Needless to say, my handsome young man did not wait for me. He did give my father a favorite memory however.

Given my druthers, I would take a train anytime, anywhere. Every night I hear the whistle of at least one as they go through our small town outside of Atlanta. Always moving, always going around the next curve, always something to see. When you ride, always so many choices, sleep, read, watch, eat, walk, talk, or not. Trains multitask: some work by hauling the box cars while others are the passenger trains serving folks and still have just a glint of glamour from thirty years ago. Kind of like us, right?

I have come to love Georgia. I am a transplanted Yankee and continue to feel blessed to be out of the Minnesota winters and to learn from the older population in this area. There is a lilt to their speech and a look in their eye when they talk about their "daddy" and their "mama", their favorite foods and "how things use to be", that is fascinating. I even tasted moonshine!!! The important word is "taste". Wow!!!! That sent my reflux into overdrive! Even though its makers swear it will cure whatever ails me, I think I will continue to pass on that one.

I just learned this week that sausage gravy is not made with coffee. That is red-eye gravy! Ah, I love them both and can almost hear my arteries slam shut when I have them. But what moments of bliss to taste them! And when I am really depressed and feeling -what the heck--, a chicken fried steak with mashed potatoes on the side, well, what more can you ask for? After eating that, I know life is worth living, even if just for the next Southern dinner. What a far cry from Wonder Bread and the rather bland food where I came from.

I am employed by a very large international company. But the local division/office is my work community. We provide services to State government by managing the Medicaid program. It is a job that is important to me. I was a nurse and have been in healthcare related industries for over thirty years. It is also important to me to work and add value with that work and to be accepted by my peers as a lary as well as a worker. I want to raise awareness of us. Under the ADA, we are classified as disabled but I don't feel that way and fight every temptation to fall back on that as long as I am able to work. For those of you who have had to make decisions that are different from mine, God love you! Until someone walks in our shoes, they can not make judgments about how we deal with things, especially those issues that impact our income.

OK, as the song says, I got to go, I got to go. And the whistle blows until the next time ... when my topic will be medical providers and health care.

Love and prayers to all,

Vicki

P.S. Please give feedback to editors and/or me (VEorio@aol.com) about "Vicki's Midnight Train to Georgia."

BETWEEN FRIENDS

Donna McGary

"That which does not kill us makes us stronger"

The Mother of Invention

I am constantly amazed with the creative resilience of survivors. Case in point- a recent posting on the WW site regarding maintaining seals for hands-free devices. Apparently a recent lary had discovered that the glue he used on his hairpiece was particularly effective. Now, with no disrespect intended, I couldn't help but think, like *Larry, the Cable Guy* on Blue Collar Comedy says "I don't care who you are, that's funny!" You do have to admire the man. First off that he would admit it- knowing how guys are about their hair- that takes guts...but more importantly that "aha" moment he must have had one morning standing in front of the bathroom mirror getting ready to face his day and out of necessity thinking, "Why not try this?". That is creative thinking. I LOVE this guy and I have no idea who he is and sincerely hope he is not offended. He shouldn't be- he should be proud. It takes character and strength to

play this hand with grace and humor.

He is not alone, of course. Every day we receive postings from members who have found unique ways to address our daily complications. We hear about prostheses popping out mid-air as pilots scramble to communicate and batteries dying at critical moments. We hear about dangerous leakages in Brazilian jungles and fistulas that refuse to respond to treatment. We hear from people who want to mow the lawn and paint the garage. We also hear from people who just want to be able to read a bedtime story to a grandchild. We hear from newbies who are being brave in the face of incredible change and oldsters who are staring down this dragon once again. There are, amongst us, whiners, maligners and wusses; it is true. But they are in the minority. Most of us are just common folk trying to carry on. We *have* been dealt a difficult hand and we play it as best as we can. That is the true beauty of WebWhispers. We have not only a voice but an ear. It would appear that no matter how obscure your comment or minute your concern there is someone out there with a response.

Years ago I learned to "eat the chicken and spit out the bones" when it came to advice offered by "experts". If WW has a drawback it is that we have quite a few "experts". For the most part, we do a good job of reminding ourselves that everybody is different and what works beautifully for me may fail abysmally for you. I particularly enjoyed Phillip Clemmons recent comment about going back to work, "Anytime between five days and never is normal". Coming, as it did, from someone who went back after five days, I found his candor and compassion downright refreshing.

Too much information is not a good thing. My adult son uses that phrase when he doesn't want to hear another story from his mother's convoluted hippie past life! The wonderful doctor who diagnosed my cancer (and looks like a hip Captain Kangaroo) pretty much said the same thing when he came to my hospital room with the biopsy results. He told me not to go home and immediately log on, even though, I KNOW you will...at least try to pace yourself, don't believe everything you read- a lot of it is pretty grim and it may not apply "yadayadaya". He was right. I didn't listen and I found some pretty scary sites. I also found some good ones but not this one right away.

And this one isn't always a good fit. Because I am not a candidate for a TEP, there are times I get pretty sick and tired reading about housings and seals and punctures—delete—delete—delete and then suddenly I read about this guy and think, "we really are all in this together". It's a club we didn't want to join, in fact, we would black ball all of our friends and family, but since we're here, we have to admit, the company is good. We are an amazingly creative bunch of survivors - the rest of the world should not write us off just yet.

Tidbits of Interest

Contributions from Members

THOUGHTS TO PONDER

"The happiest of people don't necessarily have the best of everything; they just make the most of everything that comes along their way."

Unknown

"Only he who has seen better days, and lives to see them again, knows their value"

Mark Twain

THE POSITIVES OF CANCER? NO. But, POSITIVES that result from a POSITIVE outlook!!!!

One recent morning, while bending over in the shower to prevent water from flooding my stoma while washing my hair, I had some interesting, although they may be somewhat demented, thoughts skip through my mind. They seemed to me to illustrate that my various bouts with cancer have, in fact, provided me with some advantages which I may not otherwise have been privileged to, starting with the necessity of bending over to wash my hair, which has increased my agility, I can now bend over further than I could since my 20's or 30's.

My radiation therapy for laryngeal cancer in 2001, although very painful for some weeks, resulted in my losing thirty

pounds and allowing me to get back in good physical condition. Above all else, it gave me cause to search and find **WEB WHISPERS** -- the greatest cache of wonderful folks I could ever hope to get to know!!!!

Dave Ross

LARY WITH CAROTID ARTERY BLOCKAGE

Back in February someone wrote in to our list about carotid artery blockage . The same day Bob's PCP heard a bruit in his neck, and sent him in for an ultrasound.. Results were over 70% blockage on one side and over 50% on the other. A vascular surgeon did an angiogram, a more detailed base line procedure, to see if he was a candidate for angioplasty and a couple weeks later a stent was successfully inserted.

An ultrasound a month later showed no blockage on the stented side and the other side had gone down to 20-40% blockage, all by itself. Nature's way of compensating, the doctor said, and while it was very normal, he was happy to see the figure had indeed dropped. He had put him on Plavix to prevent platelets from forming, after the insertion, and then eliminated that medication. Take an aspirin a day and come back in 6 months to be sure that figure is the same or less!

It is now accepted that radiation takes its toll on the carotid arteries, making the inner walls bumpy enough to catch any plaque going through creating blockage. Symptoms may include light-headedness, dizziness, sudden or temporary vision impairment, and numbness or weakness in arm or leg areas. Or none of the above. It is well worth asking your doctor to listen for a bruit which raises a definitive red flag.

Having had a lot of neck surgery and radiation, a lary is not usually a good candidate for the surgical placement of a stent, but angioplasty placement has been refined over the past five years to make this a very safe procedure.

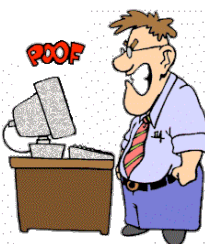
It is done under sedation and the main discomfort is having to lie flat on your back for 6 or 7 hours afterwards to be sure your groin vein has closed safely. Then you go home. The angiogram procedure has the same restriction since it is similar except instead of sending in a stent, they send in a camera..

A catheter is inserted in a groin vein that places a balloon to expand the carotid artery, along with the stent. The initial concerns of loosening plaque which could flow directly to the brain and cause a stroke, have been overcome by an umbrella-like shield that heads the insertion, and catches anything that might come loose. When the stent is in place, the balloon is collapsed, the umbrella folds and as the catheter is removed, so is any residue. The stent itself is a latticework design, for want of a better word, and the heat of the body expands it to hold it in place. If you search the Web for carotid artery angioplasty, you will find more detailed information, and pictures.

Barb Stratton, caregiver for husband, Bob.

FAMILY SUPPORT:

Carol Toner from Toronto, Canada writes: "My daughter has been a wonderful support and, because of my illness, she has become a volunteer at the cancer hospital to support others who have a family member with cancer."



Dutch's Bits, Buts, & Bytes

(1) Need a FREE FAX SERVICE Every Once in a While?

QUESTION: *"I don't have a fax machine, but I've heard that there are places on the Web that will let me send a free fax. I visited one site but they wanted my credit card to open a free trial account. Is there a truly FREE internet fax service?"*

ANSWER: Yes, there are a few places online that allow you to send a free fax, no strings attached. You don't need a fax machine, you don't need fax software, you don't have to give anyone your credit card number. A favorite is FaxZero, which lets you send a fax to any fax machine in the United States (including Puerto Rico) or Canada for free. All you need is a computer on the Internet and a valid Email address. FaxZero is

web-based, so you can access it from a PC, Mac or Linux based computer. Here's how it works... First visit FaxZero.com and fill out the fax form. Enter your Email address and carefully type the Confirmation Code shown on that page. (This prevents malicious users and automated bots from abusing the system.) Then type the text of your fax (for a quick text-based fax) or attach a file. You can send plain text, PDF, Microsoft Word (DOC), or an Excel spreadsheet (XLS) file. Ready to send? Just **CLICK** on the **Send Free Fax Now** button! A confirmation message will then be sent to your Email address. Your fax won't be transmitted until you click the link in that message. You'll receive an Email confirming that the fax was either delivered, or that it failed for some reason.

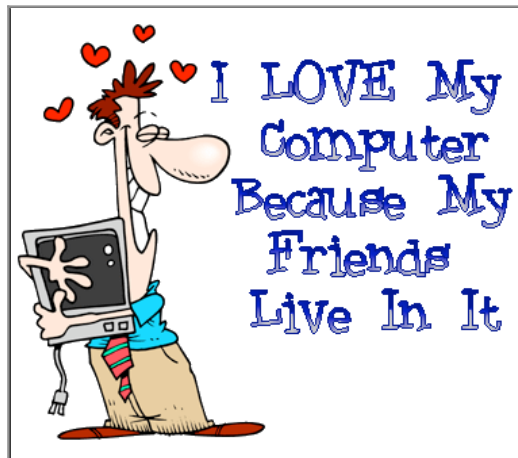
And, yes, it's really free. The service is supported by advertising on the cover page of the free faxes you send. That seems like a small "price" to pay for sending a free fax. You don't have to buy a fax machine, fax software, fax supplies, get a fax line, or pay long distance phone charges. And typically the cover page is mostly blank anyway. So, why not fill it up with something useful? And you needn't be concerned about getting spammed or scammed if you use FaxZero. Here's the FaxZero privacy policy:

" We hate junk e-mail and junk faxes, and will absolutely not send any unsolicited e-mail or faxes. Users will receive e-mail messages (such as confirmation messages) as part of the process of using the service. If you subscribe to the FaxZero mailing list, we will send occasional news about the service, which may include advertisements for our marketing partners. Your name, company name, e-mail address, and fax number will appear in the "Sender Information" area of the faxes that you send. FaxZero will not share your information, nor information about the people you send faxes to, with marketers or anyone else, unless compelled to do so by court order. "

This service is NOT unlimited. The free service provided by FaxZero is limited to 2 faxes per day, and there's a maximum of three pages per fax. If you need to send more than that, you can use the FaxZero Premium service. Sending a premium fax costs \$1.79, and there's no ad or FaxZero logo on the cover page, so you may like that for business communications. The number of pages increases from 3 to 10, and there's no 2-fax-per-day limitation.

Hope this helps! (Courtesy of the "Internet TourBus")

(2) How Some of Us REALLY Feel About Our Personal Computer!!



While I am sure that our "relationships" with our computers did not start out this way, I think, however, that over time, for many of us, they gradually became this close to us ... but, hopefully, in a healthy and positive manner!! For myself, I know that I would never have met or "shared things" with many of YOU, had it not been for my Personal Computer. My PC opened up "brand new worlds" for me ... many of which proved vital and essential to me, especially in my "post-laryngectomy" life after mid-1994. I would well imagine that the majority of you feel pretty much the same way. "Technology" can, at times, be a truly wonderful thing!!

(3) It's Official ... DD-214's are NOW Online.

The military's National Personnel Records Center (NPRC) has provided the following website for veterans to gain access to their DD-214s

online: <http://vetrecs.archives.gov/> This may be particularly helpful when a veteran needs a copy of his DD-214 for employment purposes. NPRC is working to make it easier for veterans with computers and Internet access to obtain copies of documents from their military files. Military veterans and the next of kin of deceased former military members may now use a new online military personnel records system to request documents. Other individuals with a need for documents must still complete the Standard Form 180, which can be downloaded from the online web site. Because the requester will be asked to supply all information essential for NPRC to process the request, delays that normally occur when NPRC has to ask veterans for additional information will be minimized. The new web-based application was designed to provide better service on these requests by eliminating the records center's mailroom processing time.



ListServ "Flame Warriors"

Terms of Importance

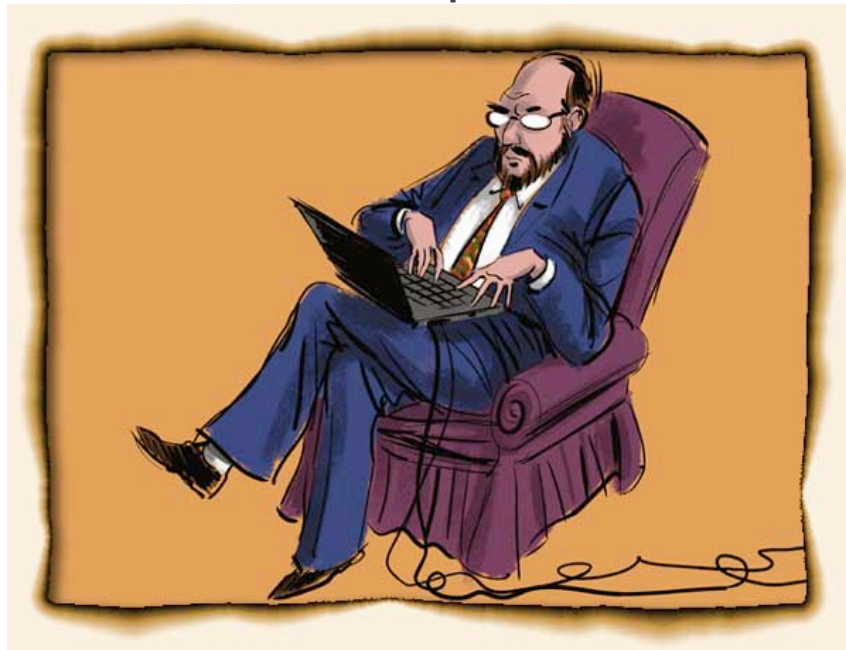
flame

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) ...

Therapist



Therapist can be a highly annoying and therefore very effective Warrior. Instead of making a frontal attack, Therapist attempts to shift the focus of the conflict to the combatants'

psychological motivations and problems. He will freely speculate about other Warriors' insecurities, personalities and relationships, but he will almost never directly engage the subject of the dispute.

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 Dutch at Editor@WebWhispers.org.

Take care and stay well!
Murray Allan, WW President

We welcome the 32 new members who joined us during May 2006:

Loretta Lenihan - SLP
 Warwick, NY **Loretta Lenihan - SLP**
Warwick, NY

Abbas Ali
 Karachi, Pakistan
Jennison Bielemeier - Caregiver
 Churchville, NY
Caroline Chow - SLP
 Vancouver, BC, Canada
Georgia Drake
 Fort Wayne, IN
Kathleen "Kit" Friedt
 Brandon, FL
Donald Harr
 TraverseCity, MI
Rhonda Magnuski - Caregiver
 Adamsville, RI
Roy Mims
 El Cajon, CA
Camille Staples
 Tulsa, OK
Karl Trede
 San Jose, CA
Judy Wecker - Caregiver
 Janesville, WI

Rayner d'Andrade
 Coquitlam, BC, Canada
Richard Buckles
 Owaneco, IL
Marlene Cutler - Caregiver
 Marlton, NJ
Rebecca Everette - Caregiver
 Beaver Falls, PA
S.P. Goel
 New Delhi, India
Julie Jones
 Builth Wells, Mid Wales, UK
Stephen McGirr
 Warwick, NY
Brian Nagle
 Novato, CA
Kay Sullo
 N. Babylon, NY
Mike Versace
 Poughkeepsie, NY
Gerald Wickland
 Rancho Santa Fe, CA

Karol Ann Beaufore
 Apena, MI
Deena Burt-Barnes - SLP Grad Student
 Conroe, TX
Karen Dingler
 Cincinnati, OH
Francine Fambrini
 Foster City, CA
Alice Gordon
 Colbert, GA
Loretta Lenihan-SLP
 Warwick, NY
Robert Milstein
 Dallas, TX
Filomena Pferrer
 East Patchogue, NY
Ralph Timm
 El Campo, TX
Joseph Walczyk
 Woodbine, NJ

WebWhispers is an Internet-based laryngectomee support group.
It is a member of the International Association of Laryngectomees.
The current officers are:
Murray Allan.....President
Pat Sanders.....VP - Web Information
Terry Duga.....VP - Finance and Admin.
Libby Fitzgerald.....VP - Member Services
Dutch Helms.....VP - Internet Services



Herb Simon.....Member, Board of Directors

Sharing Support Worldwide
www.webwhispers.org

WebWhispers welcomes all those diagnosed with cancer of the larynx or who have lost their voices for other reasons, their caregivers, friends and medical personnel. For complete information on membership or for questions about this publication, contact Dutch Helms at: webmaster@webwhispers.org

Disclaimers:

The information offered via the WebWhispers Nu-Voice Club and in <http://www.webwhispers.org> 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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