Whispers on the Web

A Monthly OnLine Newsletter for WebWhispers

May 2005

Murray's Mumbles ... Musings from the President

WANTED

Nominations for the Casey-Cooper Laryngectomee of the Year Award

The following WebWhispers members have been honored with the Casey - Cooper Laryngectomee of the Year award since its inception in 2001 by its "creator", our late WW member Charles Lamar. Charles supplied the idea and the initial funds to make this award possible and we are deeply grateful to him for his efforts.

1) 2001 - Dutch Helms
2) 2002 - Pat Wertz Sanders
3) 2003 - Mary Jane Renner
4) 2004 - Herb Simon

These four honorees now comprise the committee to select the winner for 2005. Do you know someone that is a WW member who you feel is truly worthy to join this select group? The following is the criteria for making nominations:

The Casey-Cooper award shall be presented to the WW member who has been chosen by the Awards Committee. Nominations will be from the membership who will be asked by the Committee Chair to write an email with their nomination and send it to the Awards Committee. This nomination must include detailed information as to why this WW

member should be considered for this award. To be considered by the Awards Committee, a member might have performed such services as work for WebWhispers and other larynx cancer patients, assistance to other support groups, providing help to individuals through visitations, educating children through speaking engagements at schools, volunteerism to ACS, the IAL, or other national or international organizations or other services to the community. The Awards Committee shall have the total responsibility for and the complete independence in selecting the annual recipient of the Casey-Cooper award.

The winner will be presented with a personalized engraved pewter bowl at the WebWhispers Banquet which will be held at the IAL convention in Boston on Friday evening, September 2nd, 2005.

If you feel you know someone who is qualified and worthy of this award please send a detailed email to any member of this committee by 1 June 2005. Their email addresses may be obtained from the Members Section of the WW site.

Thank you for taking the time to nominate someone you believe deserves to win this coveted recognition from his or her peers.

Take care and stay well.

Murray Allan

VoicePoints

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Quality of Life and Voice after Total Laryngectomy

By Tanya L. Eadie, Ph.D., CCC-SLP

Author?s note: I would like to begin by thanking many members of WebWhispers who have participated in some of my studies in the past few years. You may in particular remember having me record your voice, and asking you to fill out some questionnaires at the IAL meeting in Vancouver, B.C. After moving to Seattle to the University of Washington a year ago, I know that I have misplaced some of your e-mails. If there is anyone who would still like a copy of the results of the studies (see the following article for a summary), please send me an e-mail at: teadie@u.washington.edu or feel free to call me at (206) 616-2753. Thanks again for your generosity and for sharing your insights! Until we meet again!

Introduction

In the past few decades, there has been a change in how health care providers assess, treat, and measure outcomes for individuals who have been diagnosed with disease. For example, the focus of outcomes has gone beyond measuring survival or morbidity for surgical techniques. In the realm of speech-language pathology, the focus has shifted beyond the number of words or sounds correctly produced, the rate of speech, and the pitch or intensity of speech, to examining how well one communicates in a social context. In summary, there has been additional focus on how a particular treatment or disease impacts a person?s ?quality of life?.

Health-related quality of life (QOL) is a multidimensional construct that is unique to one person, and changes over time. Each person evaluates his or her quality of life with respect to many components such as physical, social, psychological, and even spiritual elements. Every individual places different ?weights? on these components, and the evaluation must be interpreted within specific functional contexts (i.e., current health status, limitations in performing biological functions such as eating, or in performing daily activities such as dressing, defined losses and needs, support systems available, etc.). One area where the multidimensional construct of QOL has been explored is found in the clinical literature on those who have been treated for head and neck cancer.

Many research studies have focused on QOL after treatment for laryngeal cancer. Results highlight the fact that although treatment of the cancer has improved (i.e., there are higher survival rates in the past few decades), there can be continued difficulty experienced by individuals as a consequence of their treatment, even many years after treatment of the disease has ended. Further, these effects may occur regardless of the type of treatment (i.e., radiation therapy, conservative or radical surgical treatment, chemotherapy, or a combined treatment protocol). Consequently, the purpose of this article is to summarize recent research outcomes found for individuals after total laryngectomy by considering changes in the physical, psychological, and social domains, and ultimately, how total laryngectomy can affect one?s QOL. Because loss of voice is one of the most obvious physical losses after total laryngectomy, the role of voice and communication will specifically be examined. Further, since outcomes after laryngectomy are subject to the influence of several personal factors, such as an individual?s gender, economic status, and family support, in addition to other factors such as time elapsed since surgery, outcomes will be placed in the context of these factors.

<u>Measuring physical, psychological, and social consequences after total laryngectomy</u>

In order to measure QOL, researchers use a number of questionnaires or inventories that are either specialized to the head and neck cancer population, or are more general measures of health used in any population. Common scales include the University of Washington-QOL (UW-QOL) scale, the Functional Assessment of Cancer Therapy, Head and Neck (FACT-HN), the University of Michigan Head and Neck Quality of Life (HNQOL) instrument or the European Organization for the Research and Treatment of Cancer (EORTC) Quality of Life (QLQ-C30) questionnaire. These questionnaires often ask individuals to judge their abilities in speech (e.g., how well are you understood), swallowing and eating (e.g., ability to chew or swallow liquids or solids), pain effects (e.g., how many pain medications you take), emotional effects (e.g., how much you are embarrassed by your voice or stoma), or social consequences (e.g., if you have had to quit your job, or how much your condition has affected relationships with others).

These instruments measure difficulties in physical, psychological, and social domains because these are the domains most affected after treatment for head and neck cancer. For example, after total laryngectomy, the most obvious change is in the physical domain. Total laryngectomy involves the removal of the larynx (voice box), and the alteration of the breathing system such that the trachea (windpipe) is brought forward and sutured at the base of the neck as a tracheostoma. The alteration in the physical anatomy and physiology of the body results in complete separation of the breathing (respiratory) and eating (digestive) systems, as well as the need for a new voice source for speech. In addition to these more obvious consequences, Shanks also described losses such as shoulder and neck function, effects on smell and taste, as well as difficulty whistling, sighing, crying, laughing out loud, sneezing, nose blowing, snoring, spitting, sucking and/or blowing. Some of these difficulties may affect everyday activities such as eating hot food (i.e., cannot blow on hot soup) or difficulty expressing emotions.

Although these other physical consequences exist after total laryngectomy, many research studies have focused upon the consequences on voice and speech production. For example, studies have compared the 3 primary types of speech available after laryngectomy (e.g., esophageal, tracheoesophageal (TE), or artificial laryngeal speech) by examining the ? voice? quality, the ability to be understood, self-reported communication performance, as well as their relationships with QOL. First, many studies have compared voice quality, understandability, speaking rate, etc. among users of alaryngeal speech. In general, results suggest that listeners prefer TE speech most, but that individuals using any 1 of 3 options can be extremely successful. Second, only moderate relationships have been found between intelligibility and QOL, and different aspects of voice quality and QOL. These results suggest that it is more than just the sound of the voice, or the ?intelligibility? of the speech that play a role in how one judges QOL. For example, while listeners may penalize women TE speakers more than men when they judge their voice quality, there are no differences in overall QOL reported by these same speakers. Finally, when one compares QOL reported by individuals using the 3 speaking options, results have either suggested no differences or perhaps slight advantages of TE speakers. In fact, some researchers have found no differences in reported QOL between TE speakers and individuals treated by radiotherapy and who retained a laryngeal system for speech.

While total laryngectomy obviously affects speech production, individuals do not often judge it as their most important concern after surgery. In fact, it is often the presence of the tracheostoma or the effects on social relationships that individuals report as being most important to their well-being.

Individuals must also learn to cope with the psychological consequences after total laryngectomy. For example, initially, one must cope with the diagnosis of a life-threatening disease and its treatment. Then, one must cope with the after-effects of the treatment, including how communication and altered breathing may affect the ability to return to work, functional activities, and social relationships. In a landmark study supported by Veteran?s Affairs, Terrell and colleagues investigated the long-term QOL in surviving patients with advanced laryngeal cancer. Patients were randomized to either a radiotherapy treatment (RT) plus chemotherapy (CT) group or a radiotherapy (RT) and total laryngectomy group. Ten years post-treatment, Terrell et al. found that individuals who had preserved larynges (RT + CT) had significantly better mental health QOL scores on a general health survey, as well as better pain scores than did those in the total laryngectomy group. More individuals who had undergone laryngectomy were depressed (28%) than those individuals with intact

larynges (15%). However, when examining speech and communication scores, there were no differences between the two treatment groups.

These results suggest that although individuals who had undergone total laryngectomy appeared to have adapted to communication differences 10 years after treatment, that some individuals still reported pain and psychological consequences. In a replication of the study by Terrell et al., Eadie and Doyle compared self-reported QOL by 30 individuals who used TE speech. They found high levels of QOL in the domains of communication, eating, pain, and emotion that were better than the average results found for participants in the study by Terrell et al.

Why were outcomes different in these 2 studies? Eadie and Doyle suggested several possible reasons for the generally high self-reported QOL for their participants. First, participants in the study by Eadie and Doyle included only TE speakers, whereas the study by Terrell et al. included all types of alaryngeal speakers, including some non-vocal communicators. Including only TE speakers could have positively influenced the results for the participants in the study by Eadie and Doyle because TE speakers are usually judged as being most intelligible and ?pleasant? when compared with other alaryngeal methods. However, probably the most telling contrast between these studies was that participants in the study by Eadie and Doyle reported high levels of psychological function. Since increased depression is a significant predictor of reduced QOL, this could have affected results. Further, previous studies have indicated that good coping and adjustment skills are positive predictors of successful outcomes post-laryngectomy.

What else could have affected psychological function in the participants in the study by Eadie and Doyle? While voice quality varied greatly among these participants and only moderately correlated with QOL, participants also reported high levels of education, and membership in the International Association of Laryngectomees (IAL). In fact, involvement in support groups (e.g., IAL, WebWhispers) has been reported to be associated with higher levels of QOL, when compared to individuals who are not members. However, caution must be used when interpreting these results, in that it CANNOT be said that it was BECAUSE of membership in this group that CAUSED better outcomes, but only that people who were members of a group like this, and who volunteered to participate in this kind of study, seemed to be the ones who were doing particularly well. For example, it may be that only those individuals who are feeling particularly healthy and who are able to travel, etc., are members in this kind of support group, which would positively bias the sample.

Obviously, there are differences among individuals, people of different cultures, and even between men and women. For example, some studies report higher levels of depression in women than men associated with disfigurement; however, social support buffers the impact on well-being for women. Women also indicate differential means of support than men. One study by Graham and Palmer indicated that women who are laryngectomized rely on family, reading, church services and non-laryngectomized social groups as primary support systems, while men reported benefit from laryngectomy group meetings, their work setting, and reading. Therefore, levels of coping, and adjustment need to be investigated further with these issues in mind.

<u>QOL as a dynamic process</u>

Several studies have indicated that the importance of particular domains of QOL may

change over time as individuals adjust to the experience of having and surviving cancer. For example, after treatment for cancer an individual may no longer put as much emphasis on physical accomplishments but rather may find satisfaction in strengthening relationships with family. This explanation may be the basis for the results relating to continued dysfunction in speech, diet, and eating, at 6 months after total laryngectomy, and improved but continued, dysfunction at 2 years, compared with individuals treated with radiation therapy; whereas, there are no changes in communication-related QOL pre- and post-surgery at 10 years. However, individuals may continue to report underlying difficulties with pain management and depression at 10 years.

Clearly, methods of coping, adjustment, and social support (friends, family, support groups) help to offset these difficulties in some individuals. Thus, it would be of benefit to rehabilitation providers to identify what factors make some individuals more vulnerable than others, and to continue to promote social involvement, methods of adapting, and coping strategies to those individuals who need it. Since communication is the method by which we develop relationships, and frequent communicators report higher levels of QOL than those who communicate less, it is obvious that communication also needs to be optimized so as to promote a successful outcome. And as a speech-language pathologist, and former IAL voice institute participant, that?s a good thing to know!

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Living the Lary Lifestyle

Joan G. Burnside, M.A.

The March 2005 *Whispers on the Web* has the Introduction and Chapter One of this series; April 2005 has Chapter Two. Each month, we are printing 10 more tips.

CHAPTER THREE
(Tips 21 - 30)

There are two ways to live your life.
One is as though nothing is a miracle.
The other is as though everything is a miracle.
Albert Einstein

TIP # 21: KEEP A BOOK ON YOURSELF:

After radiation, chemotherapy, multiple surgeries and anesthetics, some of us are very sick for a long period of time and have trouble keeping track of our lives, let alone running them very well. Keeping a book is a method of self-rehabilitation and can help ensure that you are taking care of your daily business. This is especially important if you live alone. Your book could include the following, written, stapled or pasted in daily:

1. **Your food intake, calories, textures, amounts, etc.**
2. **Summaries of medical visits**
3. **Speech/voice progress notes**
4. **e-mail printouts from WebWhispers**
5. **Pictures from magazines, with or without your comments**
6. **News clippings**
7. **Photos**
8. **Ticket stubs**
9. **Receipts**
10. **Exercise notes: how far, how much, how long**
11. **Remembrances**
12. **Written observations of your cat s antics**
14. **Lists of all types--How would you spend the lottery prize?**
15. **Bills**
16. **Protest letters and records re hospital bills**
17. **Printouts of Internet pages on your favorite subject**
18. **Travel articles on places you want to go or have been**
19. **Goals: what do you want to do when you have recovered?**
20. **Action Plans: what can you do now to get to those goals?**

Forget your perfectionist ways when you do this book. Just put something in there every day. Keeping a book stimulates your thinking, sharpens your writing, conserves your finances, aids your memory and helps you prepare for the future. It is also an invaluable means for communicating with others when verbal communication is difficult. Want to tell someone something? Just point to it in your book.

Want to get over something? Put it in your book!

JB s note: I started keeping my book with an 88-cent composition book. After a year I have filled up seven books. The compact size means I trim and fold to make things fit, but I can easily carry it with me everywhere. One day at the MD Anderson dental clinic, I was documenting my problems with canceled appointments, when I looked at the fellow next to me. He was on his cell phone, carrying on business deals while waiting for his mother. He

had a well used book just like mine, open in his lap and filled with scrawls, numbers and sketches. He was using his book to run his business, just as I was using mine to run my life. Six months later I was to get the idea of writing Living the Lary Lifestyle, 100 TOP TIPS for Laryngectomees, while flipping through my book at a roadside restaurant. In the printed book, there are lined pages at the end of each chapter. You can use this book to start your own collection.

TIP # 22: DIAGNOSE YOUR SPEAKING PROBLEM

First, if you have just swallowed something, give it a chance to go down before speaking. Then work from the outside in. Is your base plate, Barton-Mayo button or Larytube leaking air? Leaks may not be totally self evident when you re new at this. If that s not the problem, then check your heat-moisture exchanger (HME.) If it is clogged with mucus, change it. If it is still not solved, take your HME out again, slide your prosthesis brush into the prosthesis and twirl out whatever food or mucus might be in there. Replace the HME and if you can talk at this point, you know what the problem was. If you still can not talk, your prosthesis could very well be clogged with yeast from the esophageal side of your prosthesis. You will need to see your speech-language pathologist (SLP) to have it changed or change it yourself, depending upon your prosthesis. Your SLP may look for other possibilities as well, if you can?t speak after changing the prosthesis, but yeast is a common culprit.

JB s note: Before changing the prosthesis, I go through my whole morning routine again, removing the base plate and HME, spraying with saline solution, cleaning all the mucus out of my stoma, including the front of the prosthesis, cleaning the inside of the prosthesis, cleaning the skin around my stoma, skin prepping, applying adhesive, and putting on a new base plate and new HME. (Just in case I didn't do it right the first time- a little like looking in the same place twice for your keys.) When I was very new at this, the handsfree valve I wore on top of my HME was leaking air. My SLP was the one who spotted the problem. I returned it to the company, and they replaced it immediately.

TIP # 23: FIND AND FIX YOUR PROSTHESIS LEAKS

It's hard to know what is going on at first, but a good indicator of leaks is if you cough right after swallowing liquid. Or you might notice a coffee colored tinge to your mucus (if you drink that beverage!) Using your flashlight and magnifying mirror, take a drink and see if the liquid is coming out the middle or around the edges of your prosthesis. If it is coming from the middle and you change your own prosthesis, then now is the time to do it as a first step. If the leak is still there, or if your prosthesis is an indwelling, then you should call your SLP to report the problem and request an immediate appointment. There are several possibilities for a problem, besides yeast. You may need a size change in width or length of your prosthesis. Remember that as your swelling goes down, your inner structures will also shrink, and you may need a new size. Also pressure differences between your pharynx and airway may be causing the leak. In this case you probably will get another model prosthesis.

JB s note: I am among those who have had every available prosthesis and can use only the one that has been discontinued by the manufacturer. I'm keeping my fingers crossed that a good substitute is found soon. Also, if you can t be seen right away, don t panic as I did the first time. Just use thick liquids like fruit nectars, milkshakes and Boost or Ensure to stay

hydrated. It also helps to lean forward just a little and to tuck your chin in when swallowing.

TIP # 24: USE OBJECTS TO OCCLUDE YOUR STOMA:

If you use your thumb to occlude and for some reason, can't do that, try using a ping-pong ball or golf ball!

JB s note: One of my SLPs urges patients to put their thumbs on top of their foam stoma covers so the filter will help do the occluding.

TIP # 25: DON T BEND OVER; USE A REACHER

Avoid bending over for a variety of reasons, including losing your stomach contents. The reacher is great for picking up socks and playing ball with the dog. It also helps with getting items you can t reach because of a neck dissection.

JB s note: I started doing my laundry by putting the clothes in the washer with my reacher, then when my sister came by, she would move the heavy wet laundry into the dryer for me. When it was dry, I could fish it out a piece at a time. It was a huge accomplishment for me a few weeks after my laryngectomy. Talk about gaining independence! Reachers can be found in your supermarket's pharmacy department.

TIP # 26: THIN YOUR PUREED FOOD

If your food needs thinning, try adult formula such as Boost and Ensure. You'll be able to swallow it more easily, and you'll pack in lots of extra nutrition and calories. This is a good way to use up those leftover 6-packs after you've freed yourself from the feeding tube.

TIP #27: ALERT THE LISTENER TO YOUR VOICE

As Larys, we may not want to waste word power, but always greet people with hello, good morning, or how are you? before launching into your request. This helps your listener tune in to the sound of your voice before you start conversing.

JB s note: I got the idea of starting with Can you understand me? from WebWhispers. After a few times, I realized people always said yes, so now I just start with Hello.

TIP # 28: SHRUG OFF THE BELCHING

It s not unusual to belch on occasion during or after meals or after getting a prosthesis changed. It may be due to swallowing air. Women especially may be embarrassed and reluctant to go out. Experienced Larys just say Don t worry about it.

JB s note: Most of the belching goes away, eventually, but when I was still doing it quite often, I just stayed close to my companion, so people wouldn't necessarily think it was me. Recently, I heard an SLP say that persistent belching calls for a GI exam.

TIP # 29: FIRE UP YOUR CROCKPOT

It may be in the attic or the basement, but now is the time to get it out. This fabulous

invention makes any cut of meat deliciously moist, chewable and easier to swallow.

JB s note: After a year on a feeding tube, I craved meat but couldn't get it down easily, until I saw a flurry of e-mail crockpot recipes on WebWhispers. I had never owned a crockpot, even in the seventies, so I went out and bought one right away and began to eat meat and poultry six days a week.

TIP # 30: BUTTON UP YOUR STOMA

The Barton-Mayo Button or the Larytube is an alternative to the rigmarole of supplies, attention and time needed for the adhesive base plate for your heat-moisture exchanger (HME) and/or Handsfree valve. The button is really a short silicon tube with a flange on each end. It is inserted directly into the stoma, staying in place because of the flanges. You snap your HME into place along with your handsfree valve. Unless you use a lot of pressure to speak, the button provides a seal as good as the base plate. Many people consider it to be wonderfully convenient and cosmetic. It can require changing to different sizes during the day if the stoma stretches. The Larytube is similar, but the inside end curves down inside the stoma. Again, you just insert the Larytube and snap your HME/valve into the rim.

JB s note: My first experience with the button didn't work out as well as I had hoped. I was still generating enormous amounts of mucus that broke the seal, and the stoma stretched uncomfortably. I'll be trying it again.

LET S TALK

How are you doing so far? Have you started keeping a book on yourself?
Do you have a written list of questions for your next medical visit?
Do you have that prosthesis brush yet?
Are you keeping your seal most of the day?
Have you started pasting WebWhispers e-mails into a book? Maybe this one?
Are you keeping your own progress notes? You can start now.

REPORTS FROM ROBOCOP?S REPOSITORY

Or

News You Can Use ... by Officer Scott Bachman

IDENTITY THEFT

HOW NOT TO LOSE YOUR SHIRT AND YOUR GOOD NAME

What is Identity Theft?

Identity Theft involves acquiring key pieces of someone's identifying information,

such as name, address, date of birth, social security number and information enabling the identity thief to commit numerous forms of fraud which include, but are not limited to, taking over the victim's financial accounts, opening new bank accounts, purchasing automobiles, applying for loans, credit cards and social security benefits, renting apartments and establishing services with utility and phone companies.

Identity Theft has become a significant tool in a criminal?s toolbox. It is not a new concept although due to our electronic coming of age with Internet purchases, electronic bank payments and mobile data technology there are far more opportunities than simply stealing mail out of your mailbox. Many of our financial transactions are electronic and with that our personal data is recorded and stored. Recently several large corporate databases had their records compromised and stolen creating much concern. Computers are often left unattended and unsecured and laptop computers have become even more of a target. There are no easy solutions. Computers and the Internet have become a way of life. Consumer preference and mailing lists are the mainstay of retail and wholesale marketing in this country. Websites such as http://www.zabasearch.com collate and offer extended personal information for free which is posted for public view. Unlisted phone numbers, dates of birth and residential addresses are available with nothing more than a click of a computer mouse.

Steps which may assist with maintaining your personal information are:

- **Never give anyone your Social Security Number or credit card information without proper cause and always confirm who you are speaking to. A legitimate charitable organization will not ask you for that type of information over the phone particularly if the call was unsolicited. If you have doubts about a charitable request a form can be mailed to you identifying the charity and alternative methods of payment. Information should not be offered on unsecured Internet sites as well as e-mails to anyone. Consider the same thing when faxing information.**
- **PIN and personal passwords for credit cards, online accounts and ATMs should not be shared.**
- **Shred documents such as credit card bills, mortgage statements or tax records regardless if it is trash or being recycled.**
- **Check your monthly bank statement for unusual entries or amounts. Getting a copy of your credit report is also an option from time to time.**
- **Consider how accessible your information may be in your home if there are contractors present and you are not.**
- **Use common sense. That may make all the difference in the world.**

Reporting Identity Theft

Call 911 to make a police report. The sooner information is documented and entered into crime computers the easier it may be to adjust illegal financial transactions to your accounts. Also, it provides law enforcement with possible identifiers and methods of operation to develop a suspect. Police departments can share this information and hopefully make an arrest.

If you have purchased something over the Internet, haven't received it and feel that you are a victim of a theft and not just a business dispute, you must report this to the agency in which the suspect resides. You may also file a report to the Internet Fraud

Complaint Center at: http://www.ifccfbi.gov. The IFCC is a clearinghouse for such crimes as fraud, computer intrusion/takeover and other crimes involving the use of a computer. Upon receipt of the complaint they will forward a copy to the appropriate jurisdiction for review.

Consult your local and state governments regarding specific laws in your jurisdiction as they apply to Identity Theft and Internet Fraud.

Informational Web Sites

Federal Trade Commission
http://www.ftc.gov

Privacy Rights Clearing House
http://www.privacyrights.org

U.S. Government Account Office
http://www.gao.gov

U.S. Postal Inspection Service
http://www.usps.gov/postalinspectors

International Association of Financial Crimes Investigators
http://www.iafci.org (go to links section)

BETWEEN FRIENDS *Donna McGary*

"That which does not kill us makes us stronger"

My Personal Viet Nam

My Journal - Sept. 2001

My trachea and I have been locking horns with cancer for 18 months now. Like many of the protracted struggles of my generation, this has become my personal Viet Nam. We have had to destroy the village in order to save it. My own little village being a couple of square centimeters of sub-glottic territory that effectively immobilized my vocal cords, my airway, and my life. It is just one of the ironies of my war that I have sustained most of the damage from friendly fire - that Benedict Arnold of modern medicine- radiation therapy. With friends like that who needs enemies.

The Death Penalty Vs Life in Prison

My Journal - Sept. 2001

I managed to pull myself together, including fishnet stockings and a sleek new hairdo, for a friend?s wedding back home. I sucked in my gut and my pride, artfully tied a scarf to hide my ?blowhole? and appeared both terribly brave and elegant. Nevertheless, I was somewhat taken aback when a former co-worker, after having discovered my awful truth, said, in a well-meaning moment, ?I have never seen you looking better. Perhaps it is because you have faced death down and you are totally free and yourself?. To be honest with you, I had done no such thing - at least to my knowledge. What I had done was manage to get through a difficult situation so far. When I found out I had cancer, I honestly didn?t think ?why me?. Millions of people get cancer - it seems logical to ask, why not me? All the literature seems to suggest that most people think a cancer diagnosis is a death sentence, when in reality, for me, it was more like life in prison with no chance of parole. And it was not going to be one of those fancy prisons for white- collar criminals with jogging tracks and computerized libraries; it was going to be one of those big old ugly brick buildings where you can get in trouble by looking the wrong way. That?s how I felt - no matter how hard I tried to play by the rules - I got beat up. Cancer is a wicked bully and so is radiation. I had feared chemo, but I had no idea that radiation could be so insidious and far-reaching. It lasts 5 minutes and doesn?t hurt at first?then you discover that it has burnt your insides to a crisp and they are rotting away. It is very hard to look elegant and brave when you are not.

PRESENT:

I chose these two entries even though they are out of order. I had been using my journal chronologically but I was struck by a recent WW dialogue about disability and the ?proper definition? of our particular situation.

I must admit I was troubled by some of the responses. I am disabled by my cancer and its aftermath. This is not a matter of semantics or attitude. I understand the importance of words and I am very careful with labels and definitions. I even understand the philosophy behind the language of political correctness even if I don?t always agree with its distinctions.

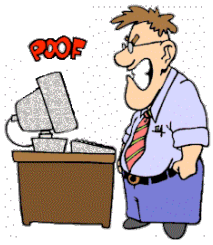
I am, by nature, a positive person and anyone who has known me throughout this process will attest to my energy and optimism. But, this situation has changed me and I am not the person I was and I cannot do the things I once did. I don?t mean that I can?t dive into the waves and swim underwater to surface like a porpoise yards from where I started, anymore. I mean that simple household tasks, even eating, drinking, and talking - all trigger coughing spasms that are still alarming to friends and family even after four years.

My point is not my plight, it is that for all our similarities, we are still unique. My condition is more than an inconvenience or an adjustment. I know some of us are able to work fulltime at demanding jobs and do amazing work. I am impressed by our members who still do skilled craftsmen work under difficult conditions and those of you who don?t even need a stoma cover to do your day to day business. I am intimidated by all of you.

I wonder what I am doing wrong that a little raking and pruning in my modest garden requires a ?plan of attack? and takes three times longer than a ?normal? person to accomplish. I suspect that I am not alone in this feeling of intimidation. And, that is my point.

I am not just intimidated by your tales of ?daring-do?, I am inspired. It gives me courage and hope. But I think that those of us who struggle should also make our voices heard. I don?t mean just the immediate struggle of medical crisis, but the day-to-day struggle. It?s not just about mucus and insurance coverage or indwelling and hands-free?those are all important. But, sometimes it is about what it feels like to show up at a party with a strange voice and just a scarf to cover the hole in your neck.

Dutch's Bits, Buts, & Bytes



(1) Spyware Issues

Question*: I have installed multiple spyware removal programs on my computer, including the ones you mentioned in this column and in several Emails. Why is it that when I scan and clean my computer, I can turn it off for the night and when I start it up again in the morning it is reinfected?*

Answer: The reason for this is that spyware is being developed and is evolving faster than the scan-and-remove programs can keep up. Today's spyware is more insidious than ever before. When it gets installed, it can plant settings in the registry and in your browser that cause your computer to check to see if the spyware is still there and if it is not, your computer reinstalls the spyware.

In addition to running scanning programs, you should double check your Add/Remove Programs control panel. Some spyware can be uninstalled. You just have to determine what is legitimate. You might also try running antispyware programs such as AdAware, Spybot Search & Destroy in "Windows' Safe Mode". That keeps many spyware programs from loading in the first place, which makes it easier for them to be removed. Finally, don?t forget to employ a firewall within your system ? like ZoneAlarm.

The battle goes on. In some cases you may even have to resort to a system software reload to be sure all spyware is gone. A clean install of the operating system and all legitimate applications might be the only solution. There is no easy answer right now. Just be careful what you click on and install

(2) Google Maps

Well, it looks like the evil scientists at Google Labs (http://labs.google.com/) have been busy over the past few months. Back in February, Google introduced "Google Maps" at

http://maps.google.com/

Google Maps is Google's response to other popular map sites like MapQuest (http://mapquest.com/) and Yahoo Maps (http://maps.yahoo.com). Hop on over to maps.google.com, type in what you're looking for--an address, a city, a point of interest, an airport code, etc--and Google will display a really high-quality map of that location.

For example, if you search for SNA (the airport code for Orange County's John Wayne International Airport) Google shows you where WW member Ron Langseth lives! No, not really, but he DOES live in nearby Costa Mesa!

Now for the cool part. Once you've located John Wayne airport on your map, left click on the map with your mouse, hold your mouse button, and drag your mouse up and to the right.

That's right, folks: Google maps are draggable! Keep dragging up the California coastline and you'll end up in Los Angeles. Oh, and you can zoom in too. On the left side of the map, click on the plus or drag the slider up.

Wait. There's more. Do a search for "pizza Irvine." Not only will Google show you the location of most of the pizza joints in beautiful Irvine, California, but also if you click on any of the map's "push pins" or click on one of the pizza places' names on the right side of the screen, a shadowed balloon appears showing you the pizza place's name, phone number, address, website link, and even a link to get driving directions. And if you click on another company's name, the map will automatically scroll to that new company's location.

More neat stuff to come, too!

(3) Microsoft Windows Critical Updates

Microsoft published 6 Critical Updates to it Windows software and 1 Critical Update to its Office software during April 2005. If you have not protected your system with these new security updates, I suggest you go to the Windows Update web site SOON and do so. The web site is at: http://windowsupdate.microsoft.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) ...

Big Dog and Me-too

Big Dog is a bully who doesn't hesitate to use his superior strength to intimidate other combatants. Big Dog may be smart, articulate or just plain mean, but in any case he is a remorseless fighter, brutally ripping into even the weakest of combatants. Once Big Dog securely fastens his powerful jaws on a hapless victim, Me-Too will join the attack. Me-Too is far too weak and insecure to engage in single combat, and must ally himself with Big Dog or a pack of other Warriors to bring down his quarry.

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 42 new members who joined us during April 2005:

Thomas Aguilar & Karen Clarke
Dixon, IL

Claudia Bowman - Caregiver
Greenwood, MO

Michael Edmonds (Paralyzed Cords)
Long Beach, CA

Daniel Gates
Evansville, IN

Richard Hand
Huntington Beach, CA

Sanae K. Lash
San Jose, CA

Hollie Lunnen - SLP
Archdale, NC

Don Mc Laren
Chesapeake, VA

Betty Moody - Caregiver
Taylors, SC

Tracey Newman - SLP
Cleveland, OH

Angelina Romanella - Caregiver
Woodbridge, NJ

Sydney J. Smith
Madison, TN

Michael Stefanchick
Newnan, GA

Brian Bell
Calgary, AL, Canada

Roy Cummings
Calgary, Alberta, Canada

Richard Frase
Franklin, NE

Peter Gevanthor - SLP
La Mesa, CA

Alexander Hunter
Snellville, GA

Ina Lively
San Diego, CA

Patricia Mallett
Brooklyn, NY

Bonnie McNutt - SLP
Concord, NH

Charles Moore
Lancaster, SC

Sue Nowak - Caregiver
Valparaiso, IN

George Roysden
Union Point, GA

Anne Staley - SLP
Panama City, FL

Phil Vandervelden - Caregiver
Las Vegas, NV

Michael York
Sumter, SC

Steve Berman - Caregiver
Chicago, IL

Donald & Eva Dehart
Palm Harbor, FL

Jim Gaia
Alliance, OH

Deborah Guyer - SLP/Vendor Rep
St. Louis, MO

Jeanette Kamerseder - Vendor (Servox)
Troisdorf, Germany

Richard Ludwig
Garland, TX

Bob McDonell - Caregiver
Beaverton, OR

Marie Meredith
Ormesby, Middlesbrough, UK

Marcia Moores - Caregiver
Lancaster, PA

Nick Oppermann
Saginaw, MI

Sheila Hall - Caregiver
Winter Haven, FL

Greg Stefanchick - Caregiver
Newnan, GA

Larry Wilt
Newville, PA

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.....V.P.-Web Information

Terry Duga.....V.P.-Finance and Admin.
Libby Fitzgerald.....V.P.-Member Services
Dutch Helms.....Webmaster

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

Disclaimer:
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.

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.