



WebWhispers

Sharing Support Worldwide



Whispers on the Web

A Monthly OnLine Newsletter for WebWhispers



April 2008

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Most of the Time....

Let's talk about our list. We have a good active email list most of the time. We have good rules that work ...

most of the time. We have people who listen and live with the rules ... most of the time.

The list opened on March 25th, 1998 with an email sent by Dutch through the newly set up listserv to the approximately 120 email addresses we had at that time.

He said: "Welcome Fellow Webbies!! Hearty welcome to the NEW, IMPROVED Email System for our WebWhispers Nu-Voice Club! After struggling so long now with individual Email messages and addresses, I hope this new system makes life a lot easier for all of us!! I hope you continue to enjoy and find value in your membership in this organization."

Now, we have nearly 1500 email addresses on the list with over 200 who have their email on vacation and others who share an email address with a spouse or friend.

An un-moderated list can be disrupted by one person sending in whatever they want, whenever they want, or people getting off-topic and talking about politics, religion, the weather, or what sports team won and why or carrying topics way too far with a lot of repetitious email. We have a moderated list. But for those who wanted to talk with newly found lary friends on a multitude of topics, we set up the Forum (after stumbling through several bulletin board programs). The Forum works for conversations on what you want to discuss, argue, or joke about. It's fun and it helped to clear our list of off-topic subjects as our membership grew larger and larger.

We wrote rules and set limits for the list. We are here for a purpose. The topics may not always fit every person but they are of interest to laryngectomees in general. However, every topic has or should have a limit and that brings us to the couple of problems we do have occasionally.

Let's start with 3 basic courtesy rules.

1. Give your email a subject so we know why you are writing. If you are hitting reply to answer one and changing the subject matter, please change the subject title, also.
2. Do not include the entire message you are answering, headers, and trailers...clean it up and only include the applicable part. These go into our archives to be read and learned from later. We don't need and can't spare the space to keep all archives if you include the last message and the one before that and if everyone else does the same.
3. Sign it with your name so we know immediately who is writing. Many of us, as a courtesy, also include the year of surgery or where we are located, especially if you are asking about care in that area.

If a new person is writing in, the moderator will often put the message through with a note that an exception has been made but asks that they please follow the rule the next time.

We members, in combination, have just recently written 30+ messages on a simple topic and each message went into 1500 mailboxes. In trying to be helpful, we have smothered the Internet with 45,000 messages that went into our member's mailboxes. If you have read through the messages and no one has offered the solution you have, by all means write, but we try to avoid a lot of repetition. So, we ask that you don't write, "Me, too!" letters.

Members do not like it when their emails are rejected and returned for what they consider ridiculous moderating limits and something that should have been accepted this one time. Stop and think. Exceptions for 1500 people count up. And, as soon as we make an exception for one person, others do the same thing and point out to us that we have allowed it for you!

We also have people who are offended when they are asked to take a topic to the forum.

Some people equate this to the woodshed! It's not. It is fun place to go to chat on the message boards or in the chat room. We have very few limits there. However, it is obvious that being told to take a subject to the Forum didn't work and feelings got hurt, so we have eased up on requesting that members take the discussion to the forum except as a reminder on topics that are not allowed at all on the list.

We actually send people to the List from the Forum because the likelihood of getting an answer from someone who has knowledge about a health or rehabilitation question, is far greater. So it is a two way street.

Only about one quarter of our members belong to the forum and that is a shame because it is where you can get to know people and what they like and do. It is open to celebrate Holidays and Anniversaries, tell funny stories,

and kid around.

Enjoy,
Pat W Sanders
WebWhispers President

VoicePoints written by professionals [© 2008 Lisa Proper]
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Head and Neck Radiation and the Speech Pathologist Part III: A Speech Pathology Treatment Protocol Proposal

Lisa M. Proper, MS CCC-SLP; BC-NCD; BRS-S

This is the last installment of the “Head and Neck Radiation and the Speech Pathologist” series. This article discusses a treatment protocol that was proposed to my Otolaryngology and Radiation Oncology colleagues approximately 4 years ago in my previous facility. The proposal was based upon research regarding the known effects of radiation treatment on head and neck anatomy and physiology combined with our knowledge regarding which exercises improved function in swallowing/speech physiology. Approval for the program was overwhelmingly received by all departments and was initiated with the following protocol.

Clinical experience has demonstrated that this proposed program noted significant advantages for not only the prevention of problems affecting swallowing, speech and voice as a result of head and neck radiation treatment, but also was affective in improving problems, even during radiation treatment. However, one is cautioned that this statement is solely based on clinical experience and initial statistics from the proposed program. As of this date, this program has not yet been published nor submitted for peer reviewed publication.

The program was initiated by attempting to have all patients who were scheduled to begin radiation treatment to the head and neck also be schedule for a Clinical Speech Pathology Consultation/Evaluation. This is regardless of their current speech, swallowing or voicing abilities. This consultation occurred before the initiation of radiation or at least no later than the first week of radiation treatment. This session needs to be always after the initial radiation oncology consultation. This in-office clinical exam includes assessment of the patients’ current speech, swallowing, and voicing abilities. Included in this assessment is a formal measurement of the patient’s mandibular range of motion for which we utilized the Therabite range of motion scale. This is particularly crucial for all patients with tongue base tumors or any tumors in which the radiation field will pass through or encompasses the temporal mandibular joint. Additional to this evaluation, the patient is also provided with generic and specific Range of Motion Exercises; Strength and Resistance Exercises, and patient education.

Pre-Treatment patient education includes educating the patient to the prospect of swallowing, speech and/or voice problems during radiation treatment and the proposed need for prophylactic therapy. The patient is given specific information regarding research denoting the ill effects of radiation on physiology. The patient is also told that this program of prophylactics is in it’s infancy with regards to research. However, I then personally tell the patients about the clinical observations noted over the past several years. In other words, we share the fact that enough specific research hasn’t been completed regarding the program but that all initial statistics do appear extremely positive. It is obviously the patient’s choice should they choose to follow through with the prophylactic treatment recommendations. Patient’s who have swallowing, speech and or voicing problems are specifically informed of the exercises which are “therapeutic” and any additional exercises that would be considered prophylactic.

Pre treatment education also includes determining patient knowledge of what his XRT treatment will entail and to provide any additional information necessary. The patient is educated as to the SLP role in patient management as well as the patient's own role in the treatment process with regards to speech, voice and swallowing. The various coping strategies and suggestions that were provided in Part II of this series are given to the patient at this time with specific areas highlighted. The patient is specifically educated to the extreme importance of continuing to swallow at his/her current abilities and what the patient should do if he/she has new problems swallowing which includes an immediate call to the SLP. The patient is also educated to the various avenues in which he/she may be evaluated and how help can be immediate when contacting the SLP.

During this session, it is also extremely beneficial to educate the patient to monitor their mandibular range of motion. A strategy that worked successfully for our program was to educate the patient and family how to evaluate the patient's own jaw range of motion utilizing the Therabite scale. The patient is then given several scales for self measurement and his current level is written for him/her on the envelope containing the scales. The patient is asked to evaluate his or her abilities twice a week at this initiation phase of radiation treatment. Should the patient notice a consistent reduction in his jaw range of motion score of approximately three or more, the patient was asked to contact the SLP. The avenue of treatment by the SLP at this time was to add or increase mandibular strength and resistance exercises.

This initial consultation session not only comprises a complete motor speech and swallowing assessment but is also an intensive patient education session and therapeutic training session; however, the patient is only billed for an in-office evaluation session.

A Modified Barium Swallow Examination (MBS) will occur if the patient has dysphagic complaints warranting an MBS or is noted to have problems based on the office exam. Additionally, an MBS may occur based on specific physician orders no matter the predisposition of the patient's swallowing abilities. Results of the MBS may indicate need for additional treatment strategies not listed above. Additionally, an MBS may occur at anytime along this proposed treatment protocol continuum and will not be further mentioned.

The patient is scheduled for the next speech pathology consultation at this time. This subsequent session is scheduled in the third week of radiation treatment for patients who show no swallowing/speech problems during the initial session. Patients with swallowing/speech problems are seen more frequently, with the frequency based on the specific patient deficit. The SLP's role at this session includes a re-evaluation and review of information provided in session one, along with changes in therapeutic exercises if deemed warranted. Even for patients not experiencing pretreatment problems, there usually are problems or complaints which do warrant either additional exercises or a change in the treatment regimen, even if it is just a change in treatment frequency denoting the need for all patients to be scheduled to see the SLP during this third week of radiation treatment. It is also extremely important to formally re-evaluate mandibular range of motion and add resistance/strength exercises to the previous jaw range of motion exercises you provided. This session also allows additional time for patient education regarding the various coping strategies (See Part II in this series) which may work specific to the patient complaints. Common strategies and education needed at this time are: Training in appropriate consistency choices of food and liquids; Chewing and Swallowing maneuvers; nutritional intake strategies and a reminder of the importance of continuing to swallow. It is also important to monitor the behavioral aspects of dysphagia and to provide the appropriate recommendations. In addition to monitoring patient function and providing additional education and treatment, SLP involvement at this stage is crucial as we will also be able to provide encouragement and support to the patient.

The patient will be seen for an additional session which will generally occur during the last week of radiation or the week immediately following radiation. However, for the few patients who have experienced little to no problems, they have the option of having this session via a telephone consultation.

The patient is also seen for a Post-Radiation Treatment Session which is timed according to patient abilities. If the patient is undergoing traditional therapy for any of his problems, then this treatment frequency would be utilized. If the patient is having problems that don't require treatment, the patient should be seen 1 month post radiation treatment and, in general, this should be scheduled at the same time as the radiation oncology follow-up appointment. However, if the patient is having no complaints, then the post radiation treatment appointment may occur as late as 2-3 months after radiation completion and, again, should be scheduled in accordance to the

radiation oncology schedule.

The role of Speech Pathology in these sessions at the end of radiation treatment or post radiation continues to include re-evaluation and follow-up regarding all information provided in previous sessions. The specific treatment protocol, that needs to be continued by the patient, is also discussed. Additionally, the patient is provided with exercises he should continue on a life long basis or, at a minimum, if problems begin to reappear. By this time, patients absolutely can attest to the benefits of at least some of the exercises you have given them and they can probably tell you which exercises will benefit them the most. Additionally, counseling regarding possible lifetime dietary restrictions and the need for continued oral hydration and absolute meticulous oral hygiene needs to occur during this session as well.

The “core” exercises provided to all patients undergoing head and neck radiation include a group of swallowing exercises for tongue base strength; laryngeal/pharyngeal motion; and UES opening. Additionally, one of these tongue base exercises also provides stretching for mandibular excursion. Circular lingual range of motion exercises were also incorporated in the basic initial prophylactic protocol. In addition to these exercises, most patients received range of motion and/or strength/resistance exercises based on the site of their tumor and the radiation field. Exercise repetitions and frequencies were given based on the research results for each exercise if this information was available in the literature. For patients at risk for trismus the Therabite Treatment Protocol frequencies were employed for the mandibular exercises. (The Therabite itself was not utilized during the radiation treatment protocol.) The Therabite Treatment Protocol recommends 7 Sessions per day, 7 repetitions and a 7 second hold if the exercise calls for such a sustained posture.

The patients are instructed that exercises should be performed without pain. The program is NOT “no pain-no gain”. If they are experiencing radiation induced pain, the use of a numbing mouthwash prior to exercise is encouraged. (With the exception of any direct swallowing exercises of course). Additionally, patients are highly encouraged to persevere through the radiation induced pain (not exercise induced pain) and complete all exercises as prescribed. However, if this is not possible, it is highly stressed to the patients to do a minimum of at least one set of all their exercises even when experiencing significant radiation complaints.

This concludes the series on “Head and Neck Radiation and the Speech Pathologist”. There are two areas that were not covered in this series which include information regarding the specific physiological effects on swallowing; nor did I include the specific exercises utilized in the above proposed treatment protocol. Should you have a desire for this information, please email me at lisamproper@comcast.net and let me know your interest. If there is enough interest, then a future article will occur per your request.

WebWhispers Columnist



Contribution from a member

The World Did Not Change -- We Did

We are in the process of breathing new life back into a long time support group. Re-establishing ourselves in the community and the medical community is a project. We have some very strong, dedicated people working on this endeavor, tirelessly, I might add. Every now and then frustration boils over due to lack of interest or lack of participation. I have seen this before on a few levels, local support, CAL and even the IAL has dropping numbers of active people. We see this as a lack of interest. Perhaps we need to examine our mission and our goals and add new perspective to our thinking.

The purpose of a support group is not to make life long members, but to help each person reach their personal goal for rehabilitation and move back into the community. Many choose to stay and teach/help others with this process. It is not an obligation nor is it mandatory. You need to really understand this process because not understanding causes pain and frustration. We say we want people to return to the lives they had before laryngectomy surgery interrupted their dreams. We do not get it both ways, either that is our mission or we are just kidding ourselves. It is always wonderful that people get it together, and it is great when they will give up a few hours a month to share this; but it is not an obligation.

I am still here because I had an amazing support system for many years. I changed some rather severe habits after 25 years and never went to counseling (or looked back), but I had "people" that believed I could do it. Letting them down would have been worse than the habit to me. When I quit drinking, I did not enjoy going to meetings and talking about how much I could drink, so again I tapped into "people" that believed in me. When I had my laryngectomy, I was going to talk funny, otherwise very little of my life was going to change. I had Elizabeth and Dwight. Never did they ask me to stay and carry the torch, but I have a difficult time when I see people drowning from lack of information. Perhaps my need is to be someone else's "people." I have always referred to teaching tobacco education to kids as trying to buy back my soul. But it cannot be a condition, it must be a desire/passion and not everyone has it the first few years of adjustment.

Many of our members went through hell and they are determined to prevent this from happening to someone else. I admire their courage and strength but not everyone can talk about what has happened to them. They are still mentally and physically in shock and can barely hang onto reality and don't know how to admit it. Women die of broken hearts from this surgery because they believe they are no longer beautiful, they no longer sound sexy, they can no longer understand why the man next to them still loves them. He loves your soul, your very being, he loves

your spirit! The rest is packaging you can get in any store. Can I say that to a newbie? Not on your life, but we know it is true. So we become one of someone's "people" and hope we can make a difference.

I have been blessed with extremely strong women in my life and want someone else to feel that way about what I add to theirs. This is a one-sided passion. I can deal with that and so can you!

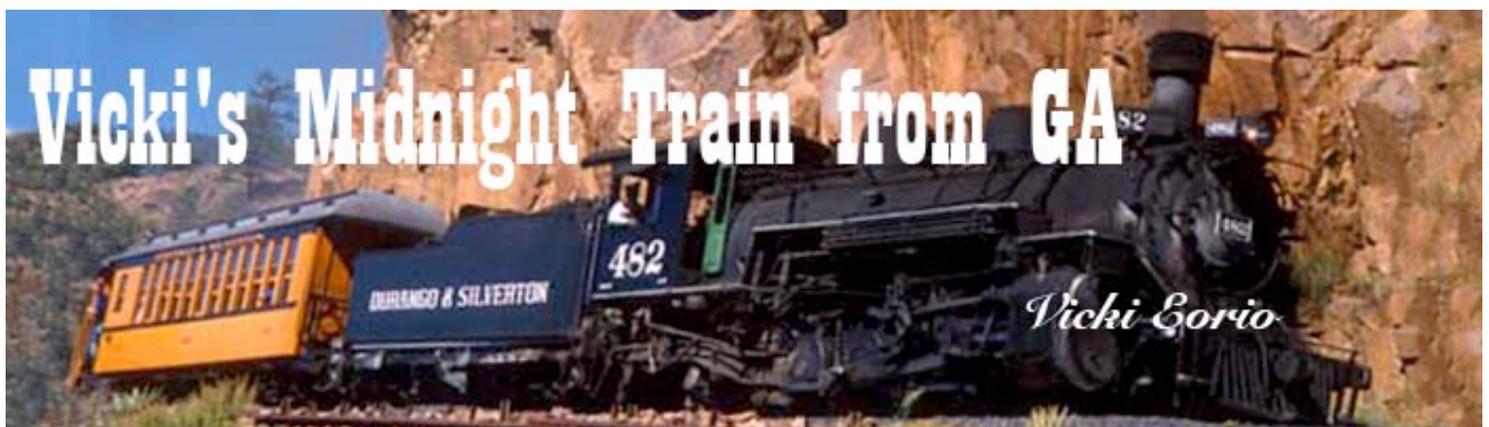
One thing we all forget, the world did not change; we did. Far too often we expect everyone in our circle to change with us. That is not going to happen and they are going to resent the expectation. My first few years I made few changes. I still smoked, drank, chased loose men (I have since switched to uptight men because they are more entertaining), and indulged in recreational states of mind from time to time. This was my personal denial. The "people" in my life didn't give up. When I realized that I did not do these things in public, I realized I was doing them to keep holding on to "what used to be" instead of using my energy to move forward. Don't look back, it is not there anymore!

Our plates are automatically 1/3 full for adjustment and bull and then we can start with day to day life. Momma Bear that some of us may be, we still cannot heal the ills of the world and we cannot go looking for people to save. This is not a 12 step program. Sometimes you need to slap disinfectant and a bandaid on it and move forward. First and foremost, we have an obligation to take care of ourselves! Everything else is a luxury.

I think WebWhispers has become such an important instrument in our lives mainly because we can decide when we participate. We can get word for word, up to the minute messaging or we can get the "Reader's Digest" version. We can be on line 24/7 if we need help/rescued or we can log on any time and offer hope, information, or maybe just attitude for someone else. These are strange times, strange things have happened to us, we cannot sit in on just any group and have them understand. A scene from a movie had this lady that compared having cancer to being an astronaut, not many have seen beyond this and those who have come back and teach. I thank my lucky stars everyday for every laryngectomee that has come into my life. They have all left something in my heart and helped me keep going forward. I hope I have done the same. But they didn't need to stay to make a difference, they just needed to be. There is not a support group on any level that is not necessary or needed. It is more like understanding your personal needs and taking advantage of all that is being offered.

Some days it all seems uphill. Ahhh, but the view from the top it grand!

Debi Austin
Canoga Park, California
Class on '92



Circle of Life

I use this term frequently but usually without much thought. As I get older, I find it can apply to more and more circumstances. But in giving it some serious thought, it really can be a shallow expression, a throw away line, or it can be profound. Most frequently when babies are born or older people become disabled in the same family, we say, "Well, that is the circle of life." Ah, if it could only be so clear.

Life does have a beginning, a middle, and an end. We may choose to describe it as a circle. But it certainly is not a perfect circle! There are bumps and breaks and deflating and stretching to the breaking point. In the end, from a perspective of time, or distance, or prayer, life does become a circle.

I will not bore you with the fact that, once again, I am going through a major health problem that includes back surgery. It is not life threatening but it is life changing. I have been immobile for 3 months. Just recently, I have been able to go through, once again, learning to walk and to do normal life functions. I am almost able to dress myself but cannot navigate stairs. The pain management is my biggest challenge. I have never had a doctor tell me to take as many pills as I think I need! When I can laugh, Frank and I acknowledge the most valuable items to be stolen are not electronics or a couple of pieces of silver, but a box full of pain meds that are all controlled substances.

Time is an enemy and a friend. It depends on what you do with it. I have tried (not always successfully) to use it constructively but lying here thinking, day in and day out, I have had a lot of scattered thoughts. Recently something happened that brought many of those thoughts together.

My youngest son, my baby, Luke, came to visit with his latest love. It appears that this is the one. He seems very happy so I have no comments or opinions. He is not a youngster and has been "in love" before. If this is his choice, I respect it.

They visited for almost a week. When you are in love, the surroundings are not important. (I vaguely remember those tingling feelings myself). I have difficulty sleeping and since I can't get up and around, thinking is my main activity. It dawned on me that, for Luke, this was finally the real thing and I had a contribution to make.

So let me tell you a story about the Circle of Life represented by an antique ring .

What I had been told by my blessed Grandmother Frannie, not even really remembered by Luke. She was my grandmother and helped raise me during the War. I lived with her and my crazy Aunt Kay, a spinster and a piece of work. I can only tell stories in person about Aunt Kay.

Frannie's parents came over from Ireland and started farming around Decorah, Iowa. We are talking the early 1900's at the latest. She and her 2 brothers ran the business that morphed from just farming to raising cattle. They were quite successful. Aunt Kay went to Chicago and hung around with the fringes of the mob.

Frannie met Dr. Brown, I don't know how, and they got married. Dr. Brown family was quite wealthy. You had to be to afford to send a child to medical school. When they divorced, she kept the wedding ring, never selling it, even tho she had to take in renters to save her house and support Mom and Aunt Kay, who had returned from the bright lights of Chicago.

At some point, Frannie gave the ring to Mom. Many years later, because my mother loved valuables (even at the expense of others), Dad took the ring and added Mom's wedding ring to it. When Mom died, one of my sisters who had the same tendencies as mom, took it without asking or checking with any one else.

When I got cancer, she gave it to me after her husband gave her a comparable ring. He always resented mom's

ring so she now has one about half again as big. I, of course, was touched but then I was given all kinds of instructions about who it should be left to, since she thought I would die very soon. That is my family! What do you call it? Indian giver? Gift with strings attached? For me to use but have no say-so in the progression of the "gift"? So, I made my own decision about that.

My great-great grandmother had a collection she left to my grandfather, who left the ring to my grandmother, who left it to my mother. My sister took it, later gave it to me, and I am giving it to my son. And to me that is the circle of life.

The circle of the ring represents 2 changes of centuries, divorces, deaths, separations, situations of great love and giving, and generations of a dysfunctional family that includes 2 generations of larys! But, we somehow kept some of the threads intact. Now it is up to Luke and his new love.

Vicki



March Madness

This column is not about basketball. I am not much of a sports' fan, actually, although I do admit to a prurient interest in basketball, being a shoulder woman from way back. I LOVE those free throw close-ups!

There is another type of March Madness that only northern New Englanders can appreciate and that is one of our two "other seasons"...the ones you will NOT find advertised. While this particular winter has been over long for my taste and circumstances, for the skiers and their providers, it has been a bit of heaven on earth. Springtime in Maine, after such a long and difficult winter is nothing short of sublime (and for us gardeners, snow is the poor man's fertilizer, so our perennial beds should flourish this year). Summer is a bountiful feast of strawberries, tomatoes, lobsters, corn and tourists. I can't blame the tourists...Maine is a beautiful state.

Fall is my favorite time of year (my tolerant affection for those pesky tourists, with admittedly deep pockets, has worn thin) and I am ready to reclaim my sweetie...what's a few busloads of leaf peepers among friends. The fall foliage is something you need to see to believe. Those calendar photos do not do it justice. After the apples and Halloween come cold crisp nights, old family quilts hauled out of Grammy's trunk... a nice fire in the woodstove...I kid you not...this is really how my family lives. We plan Thanksgiving and Christmas Feasts and stack firewood...

again and again.

That is the LL Bean version. It is largely accurate, unless you fault them for the sin of omission. Between winter and summer we have two nasty seasons. One is the true harbinger of springtime in Maine...we call it Mud Season. Of that seventh level of Hell known only as "Black Fly Season" which most ungraciously ushers in summer we will speak no more. PAAH!

Of Mud Season, I have a few thoughts. First, it smells. Even I can smell that organic composting scent of last year's leaves and the detritus of life underground. I remember it as a child...it was the sign I might be able to convince my mother that it was warm enough to wear knee socks instead of tights. Mud Season to me smells like freedom.

However, my car got mired in the mud so hopelessly the other day, my son had to use the Rhino to haul it out and I lost a shoe in the muck as I brought in the groceries. I have yet to see an LL Bean campaign that accurately captures mud misery...and I live 15 minutes from Freeport...their headquarters.

March is officially Mud Season in Maine...much more than spring, we recognize its importance. We post the roads and watch our steps. It is also my birthday and the anniversary of discovering that my life would change forever. My birthday is March 20 and I learned two days later, eight years ago, I had a problem. First day of spring and already I was in Mud Season.

I had just turned 47 and had just been accepted into graduate school...I had finally figured out what I wanted to be when I grew up and I really thought this was going to be just a blip on my radar. Little did I know. Mud can ruin your day.

The thing about mud is that it is sneaky. That rut doesn't look THAT deep until you foolishly try to negotiate it...hah...the old timers just shake their heads and haul out the chains...Old Yankees are surprisingly gracious about this stuff...having been there themselves more than once.

As the Psalmist said, "Weeping may endure for a night, but joy comes in the morning"

The worst of the mud is over in a few weeks and by May 1st we can really start to celebrate spring and our survival to enjoy it once again.

We have all endured our own personal slog through the cancer mud and lived to tell about it. Some of us mired so deep, it is the stuff of legend, but we got out. Now we watch hopefully for that first peep of crocus and burst of forsythia, knowing that tender green peas eaten straight from the vine, pod and all, heavy headed peonies, tomatoes and corn still warm from the sun all await us. And tourists and friends "from away", of course. Black flies and impossible summer traffic will also arrive...all in due time, but for now just smell that mud. It's springtime in Maine.



MOVING ON

Today I'm laughing at myself for being in this spot ... again; preparing to move. Since I still have a good deal of household stuff, including much that I stored for my mother while she was ill, we have a classic example of that dreaded expression most of us face eventually, "down-sizing". Moving your household is a very practical matter. There is so much to be considered. How shall I begin setting up my new home; my refuge from the world at large...my safe place to land at the end of each day? What am I ready to let go of? What is much too cherished to relinquish at this time? What will fit into the smaller cramped new quarters that senior citizens on fixed incomes are expected to adjust to in today's world?

Well, my oldest son will finally win the battle over my 96 year old Baby Grand piano. It will have to find a new owner after occupying the corner of every living room of my various homes for 40 years. Do I play it? Yes, somewhat. It is really more of a symbol of the home I grew up in, and the piano music I love so very much. I did take guitar lessons as a youngster, and piano as an adult. I made sure my six children all learned to play it and several other instruments as they grew up. Yes, at least one ended up with his own band. It was an imperative in the education of my children; as much as learning several foreign languages, especially French. It's a heritage thing.

With such a large family by today's standards, and our limited income, I began collecting very simple Shaker and country primitive antique furniture to furnish our home in the 1950's. It is hardy enough to stand up to Levi rivets and the buckles on little girls' Mary Jane shoes. Scratches only added to that distressed look when polished. Instead of glass and breakable accessories, I chose tin, brass, and various wooden pieces. People expressed their admiration for this look over the years, and gave me many items to fill out the collection of period hanging lamps, mantle clocks, china, and so on. I began to research and developed a growing appreciation for the era of simple design and the durability of it all. Many pieces turned out to be 1840 era, something I didn't know when I began shopping at yard sales, auctions and antique shops.

I wish I had that proverbial dollar for every time I advised someone, "Do not move to be near your grown children because as soon as you do they will move away, or their living arrangements will change." I broke my own rule and after resisting for six years what is billed as common sense to live near a family member instead of living alone, I moved to Tucson, Arizona, in January 2005. I won't go into the particulars, but my son's life took a 180 degree change even before all my boxes were unpacked. I've tried to adjust by making new friends, joining new groups, learning the culture and special places to shop, dine and entertainment. The fact remains, it is much too dry here for me.

There is also the little known problem of "Valley Fever"; when the wind blows it kicks up the dust. It's well above

100 degrees from early spring through late fall, and freezing cold in the winter. These homes aren't built for cold weather, including the frigid wind, rain, hail and snowfall here in the valley. The weather reports of 70-80 degrees from here in February may last for 10 minutes just before the sun goes down. This is not whining; I'm reporting the truth. Compared to Michigan or Minnesota winters, it probably seem heavenly to our visitors. Living is here is another matter.

After living in California for 22 years my close friends there and my network of working associations, are still the folks who know me best and with whom I communicate constantly. The goal seems to be for me to find a way to go home to Southern California. In this economy that is easier said than done.

Terms like "cash out" and "downsizing" make my head spin. Our homes and furnishings do become so much a part of our identity over our lifetime. Through several periods of life changes and moves I've either stored or moved the best of the best items so I could share some of it with my children. They have recently made me understand that they want me to sell it all to take care of my own needs. There is shock and disappointment, but it is reality. I call it the "IKEA mindset"; everything is disposable. That is way too much formaldehyde for me. I'll take real solid wood every time.

The current news story about the fellow in Australia who has just gone through a divorce, and put everything in his life up FOR SALE on You Tube caught my attention. His home, furnishings, clothing, dog, and all; everything is going. I heard him say in an interview on the evening news that his plan after the deal is closed is to go to the ticket counter and buy a ticket for the first available seat on any flight...no matter where it takes him to his new adventure. Now that is a freedom to ponder. Not sure I'm quite ready to be that adventurousbut who knows?

I admit it is not a very practical solution, but it could be a whole new way to view my Senior Citizen adventure years.

Elizabeth Finchem



A Peep Inside the Other World.....(every lary has one.) of Rosalie Macrae

It was when I came outside after my check-up last week, only two brief hours cocooned in the secure, familiar environment of my bit of the big hospital that it hit me. I had to stop at the revolving doors and mentally shake myself down; consciously make the effort to step back into the world where most people are healthy,

articulate, where I am --more or less --accepted. I had almost felt a sense of rejection when my surgeon Mr. M, saviour yet perpetrator of the lost larynx drama, shook my hand and said he would see me in six months. September. Good news really, but it sounded a bit of a bleak dismissal. I was on my own again. I said as softly as the Servox would allow that his baby boy would be walking by then. Mr. Maheshwar smiled and said he had, sadly, grown out of the tiny doeskin shoes I'd sent to the newborn. Already the next president of Pakistan according to his granny.

Then the professional persona took over and his secretary gave him the notes for the next patient. Mr M's working persona was never far away. I remember when I went to see him a couple of weeks before my laryngectomy. He had been on honeymoon with his black-haired Bengali doctor bride, known to have a bit of a temper. She had finally hooked Mr M after saying it was now or never. They had been engaged for many years and she was worried about that biological clock.

"You nearly got me in big trouble" he had said, trying, I know, to cheer me up and allay my terror. "I was lying in bed going over the details of your operation in my mind and apparently I kept saying that Rosalie would be alright. My wife asked who was this Rosalie and I assured her it was just another patient. Special at the time though".

In one of these terrible doctors and nurses romances I used to devour as a teenager --Proust, too, of course-- it would have had a different ending. Bengali bride would have been hit by a passing jet plane and I would have been his brown-haired Scottish bride.

I knew the next patient after me was a teenage girl who told me before I went in that she'd been given the morning off school to have her funny cough seen to. I hoped it would be nothing.

The secretary followed me out with a bundle of photographs taken on her New Zealand holiday. She said that JK Rowling should be the new patron saint of New Zealand after having her Harry Potter books filmed there. It was now flooded with tourists and not just dairy cows, and travel agents looked all devout when her name was mentioned.

Someone nudged my arm as I looked at the photos, squeezing in beside me on one of the wobbly red benches. It was one of my favourite larys in the group. He is our shining star, and does eosophagical, EL and valve speech with equal ease. He used none of these though, and mouthed that he couldn't talk. He pulled aside a stoma bib, not his usual designer cravat, and I saw his stoma, swollen, angry, dark blue, not looking good.

John wrote on his pad that there had been more surgery down there and he was waiting to hear the outcome. He gave a little shrug. You know when not to ask any more so I said that at least there weren't any lavender sprigs sticking out of the stoma. Lavender sprigs? John waited. I told him that when I was having a bath that morning I had poured in some new lavender bath salts which came with real sprigs to make it look more cottagey. As wenches did back in Shakespeare's day, sitting in their tubs getting pretty for their nights in arms. Shakespeare was very fond of knights in arms too. I digress. Stupidly I hadn't worn my bath stoma button. Some of the spiky bits lodged where there used to be a buxom cleavage; but horror, one of them slid down my stoma. Not a nice feeling. As I spluttered, coughing it up, I thought it would be unusual to have coroner's cause of accidental death noted as choking on a lavender sprig. Not even rosemary for remembrance. And all to smell like a roll in the hay.

Some nurses clattered down the Victorian staircase which takes you to 'Nuclear Medicine'. When I was slowly starting to walk around after the laryngectomy they would open their bags and show me the new things they had bought to wear in the outside world. The idea of re-entering that world had terrified me. Chloe and Zoe, best friends because they both had dots above the 'e' which my computer won't do, shouted my name, waved, looked at their watches, and scurried on.

At the appointments desk I waited for my favourite, Eileen, to be available. More photographs. Another baby. And didn't I just look like the spring we were still waiting for. That's what I like about Eileen. The blarney. She remembered that I was a late riser and typed in 12-30p.m. Would madam have had her breakfast by then? The

coffee was still as ridiculously foul. Do they really hate everyone so fiercely, these machine fillers? The maintenance people still hadn't painted back the trousers and the skirts on the defaced doors of the Mens and Ladies so it was still a touch of Russian roulettes making the decision.

An armful of strange books from the Friends of the Hospital counter, written specially for every friend of every hospital who is interested in trellis maintenance and ukelele lessons and *Pride and Prejudice* translated in Esperanto; a bag of coconut cakes which the robin will find before the sparrows. Out past the volunteer ambulance cars who turned me down in case I had to ask directions. How true, how true! And off I jolly well go, as Jeeves would say.

Across the road from the hospital is a very posh dress agency. Too posh to call itself a second-hand shop. I buy a beautiful Nino Bossi bag for £15. In the world of real prices it would be £200. I tell the new owner I wish there was a huge Bossi name embossed on the front. The hell with discretion. She looks at me with the beginning of panic in her eyes, apologises, and says her hearing isn't what it was.

Here we go again. The last two hours were to savor. Alice is back from Wonderland. And I certainly couldn't have bought my hombre sunset-tone bag from the delightful Friends of the Hospital. Come to think of it though, their coffee is the same shade.



My Understanding Caregiver

Diane Davis

In our last two local club meetings, it was suggested that each caregiver write an article for the newsletter that would give us laryngectomees the caregiver point of view. Of course my husband volunteered happily ... until it came time to actually WRITE the darn thing. So I decided I would give one laryngectomee's perspective on HER caregiver instead.

I have the best caregiver anyone could ever pray for. He tries and succeeds most of the time. Okay, so he's not perfect, but he understands how to deal with me. Is he sensitive? Are you kidding? Like what sensitive person

continuously waits until both my hands are full and then asks a question ... oh, heck, several questions in succession to a TEP speaker ???? And then there's the "Let's discuss this over dinner." When he knows a lary can't eat and speak clearly at the same time. And what about asking a question from another room or making a statement for my response as he's walking OUT of the room! I've come to believe that, translated, those things simply mean he wants me to shut up and listen and/or he just does not want the answer!

But, truthfully, old habits die hard and he really does not do those things on purpose right, dear? My favorite is his excuse for not WANTING to hear. He says, "Sorry, I didn't understand a word you said." as he turns his back ... or ... "I can't hear you!" as he walks away.

This is the reverse psychology of the lary who admitted that when he heard those awful words "We've got to talk" , simply said, "Sorry, dear, I lost my EL somewhere." I wonder what he says now that he is a TEP speaker. " Sorry, dear, my prosthesis is plugged up!" ;-)

In any case, my husband, Joel, has been fighting with me, side by side, with my multiple cancer demons for 10 years. What I need most, and this includes things I didn't know I needed, he gives me ...

- A shoulder to cry on and a friend with whom to vent
- A voice when I have none but helps me keep trying
- A creative mind which keeps inventing goals to keep us both motivated to move forward
- A wonderful support person but not a crutch
- A strong business partner who takes on more when I cannot
- A loving partner who never stops showing me how much he loves me
- An honest answer to my "do I at least look passable?" questions
- A believer in me and what I can still accomplish
- A non-complainer when I spend too much time supporting other people instead of him or myself
- An invaluable supporter of my medical needs
- A fabulous best friend
- An entertaining humorist
- A great travel companion who shares the good things of life
- A good masseur and a somewhat effective sleeping pill
- A great chauffeur

Now if I could only get him to listen ... oops ... looks to me I have actually accomplished much of that after all these years ;-)

Diane



Welcome To Our New Members:

I would like to extend a "**Warm Welcome**" to our most recently accepted laryngectomees, caregivers, vendors, and professionals who have joined our WebWhispers community within this past month. There is a great wealth of knowledge and information to be accessed and obtained from our website, email lists, and newsletters. If ever there should be questions, concerns or suggestions, please feel free to submit them to us from the "**Contacts**" page of our website.

Thanks and best wishes to all,

Michael Csapo

VP Internet Activities

WebWhispers, Inc.

We welcome the 43 new members who joined us during March 2008:

Terry Armatage
Pocatello, ID

Esmeralda Ayala - (Vendor)
Carpenteria, CA

Betty Belue
Winthrop Harbor, IL

Pamela Booth - (Caregiver)
Moore, SC

William Booth
Moore, SC

Heidi Bratton - (SLP)
Oakland, CA

Patricia Chapman
Enid, OK

Donna Coleman - (Caregiver)
Bessemer, NC

John J. Collier Jr.
Miami, FL

Paul S. Collins
Paoli, PA

Chris Connolly
Rockaway Park, NY

Deirdre Connolly - (Caregiver)
Rockaway Park, NY

Michael Cromie
Deerfield, IL

Pablo J. Duran - (Caregiver)
Cuenca-Ecuador, South America

Pablo T. Duran
Cuenca-Ecuador, South America

Gary L. Funderburk
Rehoboth Beach, DE

David Greenberg
Philadelphia, PA

Robert Guay
Franklin, NH

Jeffrei Miller
Hamden, CT

Beth Harrison - (SLP)
Indianapolis, IN

Marc Haxer - (SLP)
Ann Arbor, MI

Tim Hembree
Wichita, KS

Daniel Hench - (SLP)
Midland, MI

Graham Jackman
Norfolk, England

Bob Jones
Calgary, Alberta, CAN

Diane Leary - Caregiver)
Hinesburg, VT

Michael James Leary
Hinesburg, VT

Richard Ludwig
Garland, TX

Scott Moerer
Penton, WA

Prameswari Murillo - (Vendor)
Carpenteria, CA

April Norton
Acworth, GA

Tom Olsavicky
Yorktown, VA

Richard Mark Patterson
England

Pete Pierce
Independence, KS

Florence A Robinson
Wrentham, MA

Christina Ann Ruiz - (Caregiver)
Vernon, AZ

John F Saults
Perth Amboy, NJ

Christie Thomas
Pembroke, KY

Jennifer Thomas - (SLP)
Benham, CT

Vickey Thomas
Galveston, TX

Dennis L Thurman
Roanoke, VA

Molli Wallace - (Vendor)
Ojai, CA

Ronnie Willis
Attica, MI

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For newsletter questions, comments or contributions, please write to editor@webwhispers.org

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

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