



# WebWhispers

Sharing Support Worldwide



## Whispers on the Web

A Monthly OnLine Newsletter for WebWhispers



November 2007

Name of Column	Author	Title	Article Type
News Views	Pat Sanders	Chapman, Martin, Elections	News & Events
VoicePoints	P S Fisher MS RN CORLN	Laryngectomy Visitation Program	Education-Med
WW Columnist	Janet Sackman	I Lost My Voice But Found The Words	Experiences
Practically Speaking	Elizabeth Finchem	How Loud Is Loud Enough	Personal Stories
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Between Friends	Donna McGary	Can You Hear Me Now	Experiences
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### New VP-Web Site Information - Ed Chapman

Ed Chapman of West Richland, WA has been appointed to this position to serve the one year left in that term of office.

Our member Gerry Rice highly recommended Ed when he came to WW in early 2006. She wrote enthusiastically about the intelligence and abilities of this retired fire chief. I asked him last year about volunteering with us but he was already involved with building his club there in Washington State and wanted to see it through. He is now ready to do some work with us, not knowing what work but being willing to be assigned.

Ed does not have many years of experience in being a lary and lary care but he is open minded and dedicated to learning. We are grateful to have his patience, humor, interest in education and organizational skills to be able to do the planning in this information gathering department.

We welcome Ed, who is already working with two volunteers on new projects.

## More Good News

Early this year, we were blessed to have Buck Martin find WW and join. All through his treatments, he said that he wanted to work with us to help others as he felt he had been helped. And, last month, he made his choice to work in our database. He said that he loved to fool around with charts and figures and get things in order. Turned out he knew more about it than he told us and has had us running to keep up with him. It will be a hard job to straighten out our membership records. We have already found quite a few who passed away and no one let us know until now when we sent out an inquiry. We'll be trying to clear all of this up for quite some time and Buck is like a bulldog shaking the membership list to see what falls out.

## November 1

It is one year today that Dutch Helms, our founder passed away. We miss him and his clear thinking, sage advice, and his cry of "AARGH!" when someone pushed him too far. What fun he was to work with and a clever new idea became reality almost overnight. If Dutch is watching over us, he must be pleased to see the crew that works on different projects and the volunteers that make up the WebWhispers Staff, Officers and BOD.

## Elections

It is time for elections and, as usual, we will make the announcement through the WW e-mail list to open nominations.

*Enjoy,*  
**Pat W Sanders**  
**WebWhispers President**

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Coordinated by Lisa Proper, MS-CCC-SLP, BC-NCD-A, BRS-S ( [proper.lisa@mayo.edu](mailto:proper.lisa@mayo.edu) )

## Laryngectomy Visitation Program

**Penelope Stevens Fisher MS RN CORLN**  
**Clinical Instructor / Clinical Nurse Specialist**  
**Department of Otolaryngology: Division of Head and Neck Surgery**  
**Miller School of Medicine University of Miami**

The idea of a patient helping patients, who are getting through the journey of being a Laryngectomee, began with the first survivor asking "Now what?"

The International Association of Laryngectomees was founded in 1952. Soon after that, it partnered with the American Cancer Society to unite efforts in total rehabilitation for the Laryngectomee. Jointly they published a document entitled the Laryngectomee Visitor Program Manual. The manual set an outline of topics pertinent to a well-orchestrated visit of a veteran Laryngectomee visiting a potential or new Laryngectomee. Programs across America began to take place. In 1971, Shirley J Salmon PH. D., Speech-Language Pathologist of the Veterans Hospital, Kansas City Missouri published Guidelines for Hospital Visitation. Armed with these documents and the experiences of New Voice club leaders and health care providers, various programs were put in place to help the new or potential Laryngectomee.

In 1993 at the Moffitt Cancer Center, Tampa, Florida such a program was initiated. The IAL/ACS manual was the guideline. Co-founders Penelope S Fisher RN and Paula A Sullivan CCC-SLP felt that a multidisciplinary collaborative team approach would foster a more comprehensive opportunity for enhancements of outcomes. This was embraced by the newly formed Tampa Bay Chatterbox club leaders, Bill Berkins and Jerry Hough. The program was an all day event hosted by Moffitt. A system of matching the graduates with new and or potential Laryngectomees was established through the Tampa Bay American Cancer Society and Penelope Fisher. The program was successful and had several graduation classes.

In 2004, the above program was revised and re-established in Florida's Broward County's New Voice Club. Again a multidisciplinary team approach was the blueprint. Collaboratively, the New Voice Club President Carl Kilmer, club members Mike Rosenkranz, Lenny Weinstein, Gary Morey, Larry Switzer, Pascal Bourne, SPL, and Penelope Fisher updated and enhanced the program. Penelope Fisher converted the program into modules with learning objectives and outcomes evaluation tools. This updated version was also presented at the annual Florida Laryngectomee meeting in 2005.

The importance of sharing this information is in the old adage, "Use what is available and build on its value." The amount of thought and time that has been given to this most valuable entity of the rehabilitation of the Laryngectomee has been paramount by support groups, organizations, health care providers and Laryngectomees. It is the belief that one can survive the experience if education and support are forth coming. Who better to build trust than a veteran Laryngectomee as a prepared visitor. Motivation and the beginning of acceptance is created by one who has walked the journey.

So, what is important for a veteran Laryngectomee to share with a new or potential laryngectomee? Each member of the multidisciplinary team may have a specific thing that, to them, is most important to the future laryngectomee but it is freedom of pain and cancer that is most needed. Followed by understanding what it is.

To do this well, several aspects must be considered. Interactive people skills, communication approaches and the learning style of the new patient all will be important. Environmental settings, comfort zones, time frames, presentations skills and certainly medical information all play integral roles as well. Readiness to explore the information and seek more knowledge is the starting point.

At the Sylvester Comprehensive Cancer Center University of Miami, patients are invited to meet a veteran laryngectomee, receive a call from a graduate of the training program, receive a copy of the New Voice Newsletter, meet the Clinical Nurse Specialist for process and explanation, and see the Speech Pathologist for types of communication available.

The table below, with suggestions taken from IAL, ACS, programs mentioned above demonstrates the Do's and Don'ts that should be practiced by the laryngectomee visitor:

<b>Visitation Do</b>	<b>Visitation Don't</b>
<b>Get an invitation and needed info</b>	<b>Discuss medical procedures</b>
<b>Make an appointment</b>	<b>Overstay time limits</b>
<b>Introduce self tell date of surgery and type of communication method</b>	<b>Share details or bias of post communication methods</b>
<b>Leave a printed educational handout and a resource number to call</b>	<b>Leave or give too much information that may overload the situation</b>
<b>Answer questions accurately with confidence. Volunteer to facilitate</b>	<b>Finding of answer through the team</b>
<b>Give examples of stories heard</b>	<b>Do not give more information then asked for</b>
<b>Practice good listening and communication skills</b>	<b>Monopolize the visit or dominate the conversation</b>
<b>Offer empathy</b>	<b>Offer sympathy</b>
<b>Report back to care provider</b>	<b>Break confidentiality guidelines</b>

This is only a small segment of a visit. Several different topics are and need to be discussed and each adds to the whole.

Every laryngectomee has the right for understandable education and a visit from a prepared veteran Laryngectomee.

Penny has developed a very comprehensive Laryngectomee Visitation Training Program and she would like additional input as to what makes a successful program. Hopefully, with additional input from VoicePoints readers, Penny will be able to expand upon her program and will then be able to share the specifics of this comprehensive training program that she has developed. Please share any ideas with Penny at the above email address.

What might help all of us, is a better chance to share what has worked in your practice and how do we disseminate the ideas into a forum for all involved in visiting the new and/or potential Laryngectomee. An overall comprehensive tool could be developed, implemented across laryngectomee support groups, Laryngectomee leaders, health care providers and institutions. It is then that outcomes could be measured.

If this is a passion with you, get in touch with Penny! [www.pfisher@med.miami.edu](mailto:www.pfisher@med.miami.edu)

# WebWhispers Columnist



Contribution from a member

It had been 18 years, the month after my laryngectomy, that we met. She was a member of my local support group, Anamilo Speech Club of Plainview, and gave speech classes weekly to anyone who wanted to attend. She was an excellent esophageal speaker but also helped with the use of the electro-larynx. These weekly classes were much more than just speech classes. They were a support group within a support group for new laryngectomees. Everything a new laryngectomee needed to know could be discussed.

Janet was the beautiful model who was chosen to be the Lucky Strike girl in the full page magazine ads years ago. She attended many IAL meetings and passed the requirements and tests of the Voice Institute to be able to help laryngectomees with their speech. She was instrumental in the early lawsuits against the cigarette companies and, after that, she started visiting schools and touring worldwide to present her story to others.

Her husband became very ill and died about three years ago. At that point she started to get back into the world of laryngectomees and attended the IAL meetings in Boston, Chicago and Burlington. She was at the WebWhispers dinners, went on the WebWhispers Cruise to New England and Canada, and had planned to join WebWhispers on the 2008 cruise. Early this year she got a new cancer in her lungs and was responding well to the radiation and chemotherapy but, all of a sudden, everything went downhill fast and she was unable to survive it.

She was totally computer illiterate and refused to even try to learn to do simple tasks as emailing. She depended on family and friends to use it for her. Every month I would bring a copy of WotW for her to read.

The following is her life story along with some of her modeling photos. She has been an inspiration, was much loved, and will be missed by many.

*Len Librizzi*

## **I Lost My Voice, but Found the Words that Matter**

*by Janet Sackman (as told to Patricia Crevits)*

Waiting in the auditorium of a northern California high school, I grow nervous as the seats start filling up. I'm here to talk to teenagers about a habit that's disturbingly on the rise among their age group - smoking.

I go to the podium on the stage and look out at 1,000 young faces, some yelling across the room to each other. This is going to be a tough audience.

But the instant I open my mouth, the room turns silent. By the time I finish my first sentence; I can hear a pin drop. I'm amazed. It's the robotic rasp of my voice that commands their attention as they listen to my story.

It all started on a summer afternoon at Orchard Beach in the Bronx back in the 1940s. I was 15 and went there every Sunday. That day a distinguished-looking man who worked for a well-known modeling agency approached me. He gave me his card and told me I had the healthy, outdoor looks that would be right for modeling. So, a few days later, I took the subway down to the address on the card. Much to my surprise, they signed me on. I did my first job for the fashion magazine Harpers Bazaar. After that, the jobs kept coming. I was on billboards, the cover of Life, on TV. People recognized me on the street. It was flattering, to say the least, and so very exciting.

That's how I ended up in a Lucky Strike ad in 1949. I was only 17 and didn't smoke. They dressed me in winter clothes, put me on a fake ski slope holding a cigarette and ski poles. That picture was used in hundreds of ads, posters, and billboards, and I became the "Lucky Strike Girl."

During the shoot, one of the tobacco executives asked me if I smoked. When I told him "no," he said, "You're an up-and-coming model, and you'll probably be doing other cigarette ads and commercials. It would be good if you knew how to hold a cigarette and puff on one."

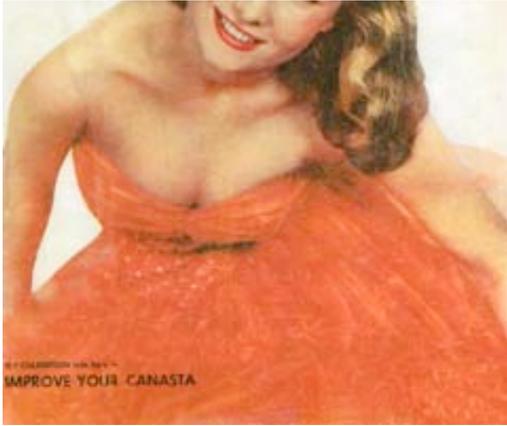
So I tried it one day. It tasted awful. If someone had told me that the cigarette I was struggling to smoke could one day hurt me; I never would have taken another puff. But that was the "innocent age of tobacco" - everyone smoked, and I was determined to master it to feel grown up and sophisticated. So I tried another. Within the year, I was addicted. A Chesterfield was my constant companion.

By the time the health warnings were stirring, it was the late 1950s. I was married to Joe, my high school sweetheart, retired from modeling and busy raising our four children. I was also smoking a pack and a half a day. My husband smoked three. I vaguely remember hearing something on the news about how smoking could hurt you, but nothing about cancer, and nothing that convinced either of us to stop.



I swore off it many times, only to light up again and tell myself I'd stop tomorrow, never suspecting how devastating that decision would be.

When I awoke one morning with an earache, though, that was the farthest thing from my mind, especially since the doctor who examined my ear found nothing wrong.



As the pain worsened, I saw doctor after doctor; none of them found anything. But eight months later, as the pain persisted, I was advised to go to an ear and throat specialist, who solemnly explained I had throat cancer. I didn't believe him when he told me that my horrible earaches were a classic symptom. Seeking another opinion, I went to cancer specialists at Memorial Sloan-Kettering Hospital, a short drive from our home on Long Island. They confirmed my worst fear.

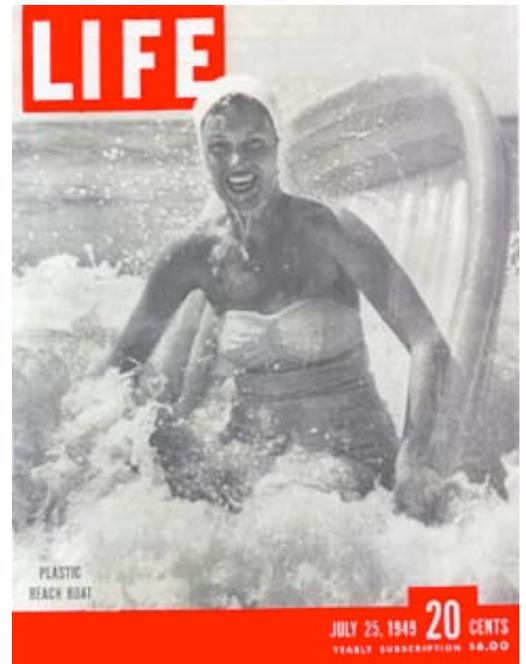
At 51, I was operated on within the week. When I woke from the anesthesia, I was cold and asked for a blanket, but no sound came out of my mouth. I was horrified. To save my life, they had taken out my voice box. I sobbed in silence. The only way I could communicate was by writing. It was devastating because I love people and am talkative by nature. Not only my voice, but my whole personality was gone. My rage swelled. I felt like putting my fist through a wall.

Instead, I learned to cope. Every day after a laryngectomy is a mental and physical challenge. My throat swelled from the follow-up radiation therapy, making it difficult to swallow. I was also too exhausted to do anything but plop on the couch and stay there. Joe and the children were wonderful about encouraging me on. Nobody could smoke around me, so Joe and the kids - all smokers - quit. Over time, so did all of our neighbors, which helped me snap out of my depression and realize I may have helped save a few lives.

With the help of the American Cancer Society, I tried learning to talk again by swallowing air and creating a type of speech with belching. It took me six months to learn esophageal speech, and at that, I could burp out only one word - "church." It took me another six months before I could manage mechanical-sounding sentences. I was so embarrassed because people stared. I was terrified of opening my mouth in public, so Joe went everywhere with me. He spoke for me and buffered others' reactions. Often they spoke as if I weren't there. Even now, some people speak very loudly to me. I'm not deaf - I just can't speak well.

However, I was really determined to speak again and practiced a lot. Eventually I became so proficient, the American Cancer Society asked me to be a spokesman. In the last 13 years, I have taught hundreds of other cancer survivors to talk again. When they first come to me, I see the desperation and depression that I once felt. But I encourage them to be independent and do the things they used to do. "Enjoy life to the fullest," I say. "You are lucky that you still can." And then I remind them that it was only the ability to speak that was lost - and with work, that, too, can be restored.

While I tried to be optimistic for others, I lived with the nagging thought of a recurrence. Patients with cancer of the larynx are at risk for developing new cancers, especially within the first two years of treatment. But after seven years, I really thought I was home free. Then a chest X-ray at my six-month check-up indicated that my life was going to be turned upside down again. A CAT scan confirmed the doctor's worst suspicions: It was lung cancer. I couldn't believe it. A tumor is sneaky. I looked and felt great, but here I was, frightened and in disbelief, back on the operating table. I didn't know if I could beat it this time.



As I went into the next few months of recovery, I didn't just lie on the couch. My doctor told me that the best way to get my lungpower back



was to exercise. So I walked, and it made me feel much better. That was eight years ago. My husband and I still walk every day at Jones Beach, near our home. It's funny how beaches have played a significant part in my life. So, in a way, has advertising. Now it's my turn to work on an anti-smoking message.

Over the past few years, I have appeared in commercials, lobbied legislators to create and pass anti-smoking bills, spoken at the White House, and worked hard against teenage smoking. Over 3,000 teenagers become hooked on tobacco each day, which is why I travel to high schools all over the world, holding up my old cigarette advertisements and telling my story. "You were given a strong and healthy body - take care of it," I tell them. "If you smoke, it's not going to hurt anybody else, just you - and it will catch up with you."

Not long ago, I saw three young girls smoking at a bus stop. I went over to them and told them what had happened to me.

Maybe they thought I was crazy. But I receive letters all the time from children saying that after hearing me speak, they decided not to smoke anymore. That's what makes it worthwhile, I hope I can help change the dreadful statistics because more than 400,000 Americans die from smoking each year.

It's ironic that when I had one, I wasn't using my voice to make a difference, and now I'm grateful to be alive and doing some good.



## How loud is loud enough?

There is a rather simple answer to this question. Dr. Jim Shanks has told laryngectomees and SLPs many times,

"We only need to speak loud enough to be heard". He has a laryngectomy speak softer and softer, and has the crowd repeat what they heard until it is too faint. The results are always a surprise to the person who came to learn how to be louder. How does that apply to your circumstance post op as you learn to speak a new way, or to your client's progress?

As a practical measure let's begin by asking about your voice and volume prior to laryngectomy? Did you perceive yourself as soft spoken, loud, high pitched, or low as a bass? Are you a large person, average size, or petite? Did you work or live in a quiet or noisy atmosphere? Do you, or someone you live or work with have hearing loss that you try to accommodate? These variables had an effect on your normal volume before laryngectomy, and may carry over to your new voice as you try to duplicate what your ear may accept as normal for you.

We don't need to go into decibels and professional graphs to know when someone is too loud. They simply drown out the voices of everyone else in the room; even those who still have a larynx. One person remarked when asked to speak softer so that others could hear themselves speak, "I always considered myself a soft spoken person". Turns out he is a Nam Vet and has significant hearing loss. Meaning, he needs to pay attention to feedback from those around him who care about his rehabilitation progress.

Since I was trained to teach alaryngeal speech I've observed how reaching for too much volume causes problems for artificial larynges (electro larynx and pneumatic) and esophageal speech. They now carry over to TEP use as well. Following my own experience with being too loud at first I share a few suggestions that may turn out to be simple solutions you can also try at home and in public successfully.

My first electro larynx was an Aurex. The company has been out of business for a number of years, ever since the owner died. It was big, heavy, ugly and very loud. At least the vibration could get through all the swelling and hard neck tissue following two surgeries and a full course of radiation with a clear sound. I always had to bear in mind that I was literally broadcasting anything I had to say in the doctor's waiting room or office. No talking in church or theatres. Everyone could hear me. I had always been soft spoken, and this was embarrassing for me.

I didn't realize just how really LOUD I was until I had the opportunity to hold and use the new proto-type Romet in June 1981 at a Mayo Clinic Seminar. Some SLP friends finally told me that it suited me better, because "listening to me with the Aurex was like watching me drive a Mack truck". How I hated giving the Romet sample back after using it for a couple of days. It took me a few months to get one of my own, but I did. I loved that it was small enough to fit neatly in my hand so well it was nearly out of view, and less distracting. The exterior wheels to adjust the pitch and volume were a bonus for various environments.

The Western Electric was also available at the time with similar adjustments in the on/off switch, but the head was too large for the structure of my neck for a good seal. I still take my Romet along to demonstrate it along with my trusty Cooper Rand and the new model TrueTone from Griffin Lab. I want future SLPs to know that we have many choices that may fit our individual needs as we heal and make appropriate changes.

There are a number of hints in my September, 2006 WotW article that will help to control the need to crank up the volume on the electro larynx. For example: sometimes lowering the pitch, or even controlling the extraneous noises, are easy adjustments you can try first.

When exaggerating as you mouthe words, some laryngectomees still try to use lung air for volume as they did pre-op for speech. This attempt to shout is self-defeating because as they huff and puff they drive lung fluid north and end up with a coughing fit to clear it out. This habit ends up as stoma blast no matter which method of speech is used.

For the esophageal speech student, volume is the last technique to be mastered. It is much better to develop consistently fluent speech with good articulation, pitch range, appropriate phrasing and rate, the ability to pause for expression, and a little volume for emphasis. The problem with accommodating someone who has hearing loss, can be the tightening of the muscles that need to remain relaxed as we attempt to be louder. Suddenly our esophageal voice is shut down until we master how to breathe and relax the neck area muscles so we may continue speaking.

Those who use the TEP soon understand going for a loud voice is going to "blow a seal" quicker, tighten the same sphincter and muscles used by esophageal speakers, or cause a good deal of mucous. I can tell you that you that the listener is not comfortable watching you turn deep red with effort, as if you were trying to learn to play a brass instrument again. Easy does it better every time.

I have to mention the use of amplification for everyone; even non-laryngectomees. I watch professors speaking to 80 students without the benefit of amplification. Abusing your voice is not a good idea when there are so many reasonably priced microphones available today.

I heard my first esophageal sound, small as it was, with the use of a microphone during a demo at a laryngectomee seminar. After that I started working with a small Archer microphone and amplifier from Radio Shack for \$25.00 way back when...I had to speak to my club as President. I was just learning esophageal speech. I moved up to the Voicette amplifier a long time ago, and continue to use it in meetings larger than 8-10 people, or if I need to be heard across a large room.

I've continued to coach laryngectomee speech students as they begin, and as they get ready to speak to groups, on the wisdom of using amplification. Whether esophageal speech or TEP is used everyone understands after a few minutes time how much less work speaking into the microphone is, and how much better the quality of their voice becomes. When speaking to several classes in a day, or talking throughout the day treating your voice gently pays big dividends. Please learn how to hold and speak into a microphone as part of your rehabilitation. Don't be afraid of it. You don't have to be a VIP or a news anchor to use a microphone. People want to hear what you have to say. You have a story to tell that may save a life!

### ***Elizabeth Finchem***

p.s. I'm home from the hospital and two week stint at my son's to recuperate from the auto crash. My shoulder, and arm with two plates and screws are healing slowly. I've learned to play the keyboard one handed like a piano. Thanks for all your good wishes.



## Hatha Yoga

*By Lanny Keithley*

Last month's article addressed Meditation as a tool to help make your mind function better. This month's article will discuss a tool to do the same thing to your body - Hatha Yoga.

Yoga has been around for over 3,000 years. It was developed by the Sages and Wise Men of ancient India and passed down from generation to generation, by converts, until writing came into existence. Yoga is a means by which to obtain control of one's latent powers. The word actually means to "yoke" - a means of uniting the individual spirit with the Universal Spirit. As with Meditation, Yoga is not a religion, but is used by many to increase their spiritual awareness, if that is their path.

There are hundreds of types of Yoga that cover every aspect of life. This article will focus on Hatha Yoga - the Yoga designed to keep the physical body in its best possible condition as it was originally designed, what they now call DNA. It will not give you muscles that you weren't intended to have, make you skinnier than you should be, or do anything that isn't part of your individual physical body 'plan', no matter how much of it you do.

Unlike any other exercise system, you do the same exercises, exactly the same way, to lose or gain weight, or develop any part of your body. Yoga has been called "the perfect exercise system" as it makes your body perfect. It can be practiced by anybody - age and physical condition are not barriers. Each person can benefit from Yoga by doing the exercises that they are physically able to do. Yoga will not cause overexertion, when done properly, in even the very old or ill.

Most of the asanas, the Yogic term for an exercise, involves stretching muscles. When muscles are stretched too far, pain is felt. All of the Yoga asanas are done slowly, which allows the person to stop at the point of pain. All other exercise systems involve fast and violent movements, which do not allow for the person to stop soon enough. By the time the person feels the pain, the damage has usually already been done. Pain is the body's way to tell you when to stop. Yoga teaches you to be aware of your body and all its functions, including pain.

Many of the commercially available Yoga classes have taken the concept and incorporated other Western exercise techniques to make them more appealing to their clients. They have added high temperatures, fast 'fat burning' speed, and many other ideas that are totally against the teachings, and basic understanding, of Yoga.

There are numerous modern exercise systems designed to force the development of muscles, and even specific muscle groups, as if that is what makes up a 'perfect' body. Others try to force reduction of weight and control the body's fat content. All of these systems do not necessarily result in a healthier body, as is commonly assumed, for health is a state when all the organs function perfectly under the intelligent control of the mind.

Yoga will develop muscles and will control your weight, but only as dictated by your individual body structure. In addition to all the 'normal' things a good exercise system is suppose to accomplish, Yoga produces perfect and compatible functioning of all the body's organs - which is the key to having good health.

When any of the organs in the body stop working properly, the person doesn't feel as young as they did. I think we can all attest to that. Throughout time man has sought the fountain of youth. Everybody wants to remain as young as they can, but most of the 'remedies' to solve this dilemma only resolve some of the symptoms - at best.

Yoga helps to reverse the aging process by restoring the proper functioning of all the body's organs. After medical 'adjustments', some medications may also be needed to replace the organ's original functions, but this can all work with Yoga.

One of the almost unique aspects of Yoga is its focus on the endocrine gland system of the body. This system is what makes all other bodily functions possible and controls growth, weight, size, metabolism, energy, health, sexual power and even disposition. Many of the asanas focus on the feeding and health of the endocrine glands, which in turn promotes the realization of the body's adherence to its individual DNA plan.

I have talked to people that have watched someone do Hatha Yoga and thought the exercises were 'weird' looking compared to traditional types of exercises, and they are different. But, that 'bent over back twist' they might view as odd, is really force feeding blood to an endocrine gland that can have body wide implications to one's current and future overall health.

Many people say that they find it hard to do without a class or group. I guess, everybody has their own way, but I have found it much easier to do it on my own. Either way, I would highly recommend doing a little reading first.

When I first got into Yoga, I read about 50 books on it, as was my ilk back then, and found one to be the best one for a general understanding of the subject as well as a training manual. If you would like to learn more about Hatha Yoga, I would highly recommend you read "Yoga, Youth and Reincarnation", by Jess Stearn. It's a paperback by Bantam Books and was first published in 1965. Please don't get hung up on the title. It is an easy reading book of his experience in learning Yoga and gives a good background of understanding for interested people. It provides a good training section in the back that discusses each asana: its concept, its values and benefits, and how to do it. There are also lists of asanas to do, in proper order, and will give you a good understanding of what it is and what to expect.

The way I learned was to select a list of asanas I felt was right for me, from the number that are listed in the book. I would then get ready to do the Yoga and look up my next asana in the book and read all about it. I would then do the asana, with all the details I had read fresh in my mind. If I had any questions or thoughts about it, I would reread the passage on it in the book to help my understanding of it and go on to the next. In a short while, I was reading the book only from time to time for a general refresher.

Whether I read about it first or not, I still envision what I am about to do in mind, then visualize the details as I am doing it, and afterward, in feeling all the benefits. It does not really matter how well a person is able to perform the asanas in the beginning, because the full benefits of doing them will be realized according to each person's body

structure.

If you elect to go the class route, reading the book will give you a good understanding and can help you select an appropriate class. You don't want to do Hot Yoga or any of the rapid paced ones that are readily available today. Either way you go, you should have a good understanding of what you are doing and its benefits. And, as with any growth activity, your mind should be educated and involved. Since there are no rapid movements in Yoga, the only thing that you need to add is a good cardio-vascular exercise for the heart.

I have been doing Hatha Yoga for years and it has been a wonderful asset to my health. Now, after becoming a Lary, I cannot do all the asanas I use to, or at least do them in the same way, but the benefits are still as good as they always were. My weight is maintained appropriately without significant 'management' on my part, and I am as healthy as is possible with all the medical 'fun' my body has enjoyed. With the help of Yoga, I have been able to regain a large portion of my mobility from the effects of the radical neck dissection surgery. My thyroid gland has now been replaced with medications and that has worked well. So, even we Larys can realize great and wonderful benefits from doing Hatha Yoga.



## A Night Out With the Boys

by *Rosalie Macrae*

I will start on a slightly depressing note and tell you what Hamish, a visiting lary friend from Scotland said last week as we toasted each other with Assam tea.

"Here's tae us. Wha's like us?  
Gey few and they're a' deed".

Which, when translated means:  
"Here's to us. Who is like us?  
Very few--and they're all dead."

It is because of homilies like this that the Scots have a reputation for being a sombre lot at times. Only a Poisoned Dwarf (as the English sometimes call us, with patronising affection, as if we hadn't discovered penicillin and trains and television), would tell someone in a pub that they had a nice open face, and give them one, with a banned sort of toy weapon.

I told Hamish I didn't really like that greeting. It was a bit too close for comfort maybe. But he produced his hip flask of single malt, poured a slug into my Granny's bone china, roared with laughter (he is a great ES) and said Him upstairs would have a long wait for Hamish. I poured an extra slug of runny hunny into my tea, as I can't drink the hard stuff now. It burns. We both cheered up and felt immortal and drank another toast to larys everywhere.

How I enjoyed that civilised, adult visit from Hamish. The night before, I had been caught up in a surreal, lary nightmare with my three grandsons. Months before, I had said they could choose a treat sometime in the future because I took their sisters to The Sound Of Music. And to my sexist shame left the boys at home because we agreed, the girls and I, that they wouldn't appreciate the warblings of Maria and the Trapp tribe, and the Wonton dumplings in the teahouse next door to the Palladium theatre in London.

Retribution came quickly. Last week they read the posters and were on the doorstep. . American Wrestling was in town. They begged. They pleaded. Their parents thought it was a great idea as long as I didn't expect them to come. Yes, they were sure I would be able to cope. Amik--a man I know--said to certainly count him out and he felt faint at the thought. This man, gentle readers, was once in the SAS and still goes off on secret reunions up in the Welsh hills where they remember their happy days catching worms for breakfast.

But to my Tale. We started at McDonalds. I hadn't been there for years and years. Long before The Diagnosis even. It had not changed. The noise was so fierce that you could feel it. Potent, but somehow unthreatening. The little waitresses smiled--I lie, they scowled-- through the screams, the moaning mothers, the threats from fathers foaming at the mouth with fury and frothy milkshakes. The milkshakes hadn't changed either. Totally delicious. Neither had the burgers. Totally indescribable. In case we have any lary lawyers in our number. They were probably wondrous, all organic and beefy, straight from the meadow. But, your honour, I had a head cold, which meant my taste receptors were down to a barely functioning minimum, and everything I ate tasted of chewy oxygen. Or, in the case of the milkshake, a carton of clouds. You could have served me a puree of anchovies and rice and said it was chicken liver pate and I would not have known better.

My Servox could have stayed at home. I just cuffed the wildly excited boys around the ears and nipped their derrieres, and if any child cruelty officers were there, well they didn't make themselves known. I gave the waitress a big tip and she gave me a couple of her bill pads and pens to communicate, and said better me than her.

The wrestling arena, gateway to terror, was a walk away. No escape. I went ahead to choose the seats feeling, I have to say, like a somewhat cool granny. One of my WW friends had warned against sitting too near the ring. Having been a popcorn hustler in the days of Gorgeous George in Washington State, he remembered a nasty wrestler getting his toes beat upon by the heels of a female customer's shoe. The wrestler, a mild man, saw red, kicked her in the face, and split open her nose to the cartilage.

He said yes that the fights were fixed, but the wrestlers were fit. We sat as near God as possible, way up in the amphitheatre. I recognized one of the male nurses from my old ENT ward and waved but he looked through me. I must have lost my allure without all the shiny tubes sticking out of my neck. Impossible to go over and ask if he remembered Rosalie who wrote a love letter for him to send to his French holiday squeeze in that wall of noise. His lovely mother used to send in flasks of pumpkin soup for me. She thought I was dying of starvation. When she came to pick him up one day. I nearly did but that was yesterday.

The Servox went into the purse. Useless. Took out the wallet. Useful for buying the masks, the fizzy drinks, the foamy gloves, the T-shirts. I clapped in the midst of deathly silence for one of the overseas giants because they must have felt so unloved with the whole of Eng-e-land wanting their blood out there. Being a Scot I wasn't a traitor. But young Alex held my hands down. Yelled in my ear not to clap the Americans or I would be THROWN OUT GRANNY. I couldn't, voiceless, explain that Le Gran' Pierre was Canadian so it didn't count as they belonged to the Commonwealth. The ring shook, thudded. One by one the heroes went flying out of the ring in what is known as The Rumble, and the main reason for coming, according to one of the wild wimmin behind who prayed that one would land in her lap. Dear Jesus, she said.

There was something innocent, joyous in the air. The booing was friendly. The Cockney referee doubled as the programme seller. The boys acted as if they had been touched by Superman when they queued up for High Fives with the champion, Mighty Finn. A party of teenagers with Down's Syndrome, hoarse with shouting, were gently edged along to be first in the line. They got autographs too. My neck muscles had the best rest they've enjoyed in two years with no Servox to motivate. The ENT nurse recognised me on the way out, big hug and said I looked amazing.

Which is a very diplomatic way of expressing yourself, when you are speaking to a woman of a certain age, hair standing on end, clutching a McDonald's order pad, looking, ever so slightly, off her rocker.

When I told all this to Hamish he had another tea cocktail, said it was all part of life's rich tapestry and we'd be a long time dead. I told you we were a downbeat lot, north of the Border.



## REHAB, HERE I COME!

### BACKGROUND

On May 30, 2007, I had a stroke. In terms of severity, it was initially very serious, with complete loss of the left side of my body. I qualified for an experimental drug made of snake venom (they didn't tell me that until later, thank heavens!). But that explains why when I am upset my tongue flashes in and out and my tush moves from side to side :-). And it also explains a pretty remarkable recovery in terms of time. However, it continues to be a constant struggle to retrain the brain to make my left legwork, as I want it to, and my short-term memory return. The memory lapses are no longer funny as "senior moments" because they are frequent and have not improved.

In the past two WotW issues, I wrote about the initial stroke, ICU, and my discharge to rehab. Now I am going to share the adventures of rehab.

I am an old nurse and, even before becoming a nurse, as a child I remember vividly the iron lungs associated with the care of polio patients. One of my playmates had been stricken with this horrible disease and was placed in an iron lung. We would visit when allowed. I also remember Sister Kinney and her remarkable work with these patients. However the facilities were a tad on the side of barren, glaringly white, wards, not rooms, and mother's red eyed, father's stoic.

My other experience with rehab was for patients with mental illness. As nursing students we visited a State Hospital and then were assigned to the unit for these types of patients at St. Mary's hospital in Rochester, MN for a minimum of 3 months. That rehab included electric shock treatment and padded cells.

My impression of rehab facilities was a bit dire and scared me to death. After Frank and I cheated and had a deli sandwich on the way to the rehab hospital, I begged him to take me home. I promised to do exercises there and said I would ask insurance to send a therapist into our home, which might be cheaper. I was magnificent in reciting my litany of why I did not have to go to another hospital. I kept talking, making perfect sense in my mind as we pulled into the driveway of the rehab hospital. Obviously my eloquence had been totally ignored by the person who calls me, "she who must be obeyed".

## REHAB

My original caretakers may have suspected that I had visions of escaping because 3 nurse aides and an orderly were waiting outside for us. The last time I was pulled out of a car, on a gurney and into a bed was 30 years ago when I was having a baby! Next I thought they would restrain me! Well, they did kind of. They took away the wheelchair, walker, and my shoes. It was midday and they warned me to rest because starting the next day, they were going to work me harder than I could imagine and that it would be a minimum of 3 hours a day. Oh fun, oh joy, oh s---!

At least dinner did not include green beans. The rehab center is part of the same hospital system where I had been for the acute phase of my stroke. But thank heavens the special on canned green beans was limited to just the one location. However a low cholesterol, low sodium, low fat, no seasonings meal leaves a lot to be desired. I fondly remembered the illegal deli sandwich and vowed to get the hell out of there as soon as possible. I did sleep, kind of, and was awakened only 3 times during the night and for good at 7 AM. Now the day began. And as it progressed, my preconceived notions melted away.

First of all, EVERYONE smiled and seemed happy to be working there. I never encountered an employee on any level who was anything but positive and pleasant. Since I tend to handle stress with humor, they responded wonderfully. There were times an employee and I would laugh so much that someone would close my door. Guess not everyone thought we were as funny as we did.

The facility was spotless, limited cable TV, a huge gym, a putting green outside, reasonable food, you could eat in your room or the dining room, family was encouraged to spend as much time as possible and attend any and all therapy sessions, and some of the most creative therapy approaches ever. You didn't just stretch or try to walk. You tried to sink a basketball in the regulation hoop, if you could walk even with a walker, you were to help push those in a wheelchair, and much, much more. The hour-long sessions, 3 times a day, flew by and we always dissolved into laughter at some point, making sure others joined us.

Every kind of therapist was on staff. One of my “favorites” was the speech therapist. She really wasn't there for my ability to speak but to test my cognitive skills and memory. The memory was pretty poor and the cognitive skills were coming back. However, her answer to everything was to do crossword puzzles. Now I am not being critical, I am sure it is an effective tool in many cases. However I couldn't/didn't/ like crossword puzzles pre-stroke. There was no deterring this lovely lady. She was so passionate about it I feel obligated to share her wisdom even if it is a little bit tongue in cheek.

Do the local paper puzzle first. They aren't very good

Get your husband to buy you a better paper and try those puzzles

Finally get the NY Times but never try to do the Sunday puzzle for many months because you won't be able to do it and will just get discouraged.

Another form of therapy was for her to recite a nursery rhyme and then have me repeat it. She would even ask questions like “How many little pigs were there?”

After my sessions with her, many that Frank was present for, I announced again that he had to GET ME OUT NOW!. To this day when he thinks I ask something unreasonable of him or forget something he will say “Ready for the crossword puzzle?” But the final solution was that I said I didn't need speech therapy, thank you all so much.

In the meantime I still had 4 IV ports in my arms. Some were clogged and all were a mess. After threatening to remove them myself, the on staff doc was kind enough to order their removal and apologize for keeping them in so long. I truly looked like a mugging victim. Because of the medications and invasive tests, I was black and blue from stem to stern.

In between the therapy sessions you would think I would have read and relaxed. But I was not able to do either. I couldn't read because I couldn't remember what I had read before I put the book down. I couldn't relax because I was worried about everything. Frank was wonderful. He and a very special carpenter who took us on as his project, made alterations to the house, put up grab bars, removed rugs so I wouldn't trip, took things off the wall in case I bumped into the walls (which I did), put the bed in the living room, got special toilet adapters, bedside potty chair, shower chair, and other things to provide safety and some degree of independence. God forbid any of you have a stroke, but, if you do, be prepared for the need of adaptive equipment because your mobility is affected and safety has to come first.

Out of all of the equipment Frank got, the one that still makes me smile is the toilet adapter. The regular seat and back come off and this sits in the place of the usual parts. It has handles and is very sturdy. But the funniest thing is that my feet don't touch the floor and I feel like I am being potty trained once again. Something my grand daughter and I can share.....:-).

More later and please all take care!

Vicki



## Can You Hear Me Now?

A dear friend who had to adapt to using an EL temporarily following surgery, after having remarkable success with a TEP, jokingly wrote, "Now, when I talk, I often hear your voice in my head!" I had to laugh...I am a Maine Yankee and even old acquaintances who haven't talked to me in years say that after a few minutes, they can still recognize my accent. My friend is decidedly NOT a Maine Yankee and I am sure that BL (before laryngectomy) we sounded nothing alike. Nor do I suspect that we do today, but these new voices do take a bit of getting used to!

I use a Servox and have two models. One is digital, the other older model is not. They each have advantages and even allowing for the variable pitch and volume, I can detect a subtle difference between the two. More importantly, however, is how pitch and volume, two aspects of this new voice we DO control, affect the way we sound...not only to ourselves (as in my friend's case) but to the larger listening world.

When I first got my Servox after months of on again. off again. voicing, I was thrilled. For me, it was easy, fast and fun. It sure beat the heck out of the sign language, note-writing, and the red-faced coughing spasms of the previous 18 months. I actually did quite well right from the get-go but I did need to learn some new voicing techniques. First off, I had to slow down. I had an awful lot of words stored up in my frustrated brain and I needed to understand they didn't all have to get out in that first month. Secondly, I needed to recognize that a lot of the everyday conversational filler, banter and throw-a-way comments are just that...throw them away...they bring nothing relevant to the table. Don't waste your voice, your energy or your battery. Thirdly, and perhaps most importantly, I discovered the pitch and volume controls and learned how to use them to create a new "voice" for myself.

I have learned how to adjust the pitch so I have one very low register. At a low volume, it is very quiet and also uses very little energy (good to know if your battery is low and your re-charger on the fritz...can you tell this is the voice of experience?). On the other hand, turn that low register up full volume and you can wake the dead and even very deaf old men understand that it is time to get on the bus for 10:00 Mass (again the voice of experience!). I worked with elderly even with my Servox and used those buttons to full advantage. I have one button for "normal" conversation that I adjust for volume as necessary and a second "deep voice" button that I tell people is either my, "I am pissed." or "You are deaf." voice. It seems to work pretty well. My dad has significant

hearing loss but he actually seems to hear me better sometimes than my mother does, but that may be more a result of 57 years of marriage than my skillful use of a Servox!

I consider myself a bit of a connoisseur of EL voices nowadays. I do not think we all sound alike. My fellow EL users (regardless of brand) each have distinctive voices. Without naming names, I can identify my friends depending on which pitch, volume, and instrument they use. I use the word instrument purposefully. I learned to play the trombone from my mother when I was just six years old. I was good enough by 4th grade to be recruited by the city wide music director to march in the school band on Memorial Day. I became proficient and quite skillful for a time but my trombone was never the voice for me that it was for my mother. She had a sound that even years after she stopped playing, my father could identify when we (including my trombone playing brother) hauled out the old sack but just to flex our embouchures, AKA our chops. For a pretty much classically trained, by the books, player, Mom had soul and it came through her instrument. It was her voice in a way I never understood until now.

An instrument is a tool...an extension of oneself...a ways to a means. My mother used the trombone to express her soulful side in a way her other life simply could not fulfill. And it is even now why I can tell the difference between Don Doane and Tommy Dorsey.

It is also why I can tell the difference between my voice and Lenny's and Herb's and Tony's. You TEP speakers, on the other hand, sound all alike to me. HAH!



## Welcome To Our New Members:

I would like to welcome all new laryngectomees, caregivers, vendors, and professionals to WebWhispers! There is much information to be gained from our website, especially our Library, and from discussions held by our members on the email lists. Needless to say, we also hope you will revisit our newsletters.

Pat Sanders, WW President

We welcome the 41 new members who joined us during October 2007:

Robert Adams  
Chicago, IL

A. Michael Arnott  
King George, VA

Carol Arnott - (Caregiver)  
King George, VA

Robert Baillie  
Ledbury, Herefordshire, UK

J. W. (Walt) Cannon  
Sarasota, FL

Weta Cannon - (Caregiver)  
Sarasota, FL

Dan Dibert  
San Mateo, CA

Robert Dlouhy-(Returning Member)  
Riverside, CA

Anthony Elam  
Saratoga Springs, NY

Ceil Ganie  
Lanoka Harbor, NJ

Jorge Garcia  
Homestead, FL

Lynn Gerrits - (Caregiver)  
Leominster, MA

Michael Gerrits  
Leominster, MA

Scott Goldman  
Bayside, NY

Jessica L. Hemann - (SLP)  
Creston, IA

Craig Hicks  
Dayton, OH

Bob Jaycox  
Berlin Heights, OH

Lisa Jaycox - (Caregiver)  
Berlin Heights, OH

Sloan Jones  
Ticonderoga, NY

Muhammad Sufyan Khan-  
(Caregiver)  
Hyderabad, Pakistan

Dawne Ledoux  
Wareham, MA

James Maloney  
East Stroudsburg, PA

John F. Martin Sr.  
Ocala, FL

Fiona Mayer  
Nepean, Ontario, Can.

Bill Moulton  
Boonton, NJ

Robert Murphy  
Philadelphia, PA

Ron Quackenbush  
Binghamton, NY

Hugh Raley  
Spring Branch, TX

Ismaeel Razavi  
Tehran, Tehran

Susan Reeves - (SLP)  
San Angelo, TX

Charlie Sneckenburg -  
(Caregiver)  
Boca Raton, FL

Kathy Sneckenburg  
Boca Raton, FL

Kirk Swanson  
Edmonton, Alberta, CAN

Billy D. Swofford  
Corpus Christi, TX

John Thompson  
Naperville, IL

Marlene Vecchio  
Butler, PA

Duncan John Waddington  
Poulton-Le-Fylde, England

Alan L. Williams  
Galveston, IN

Tanna R. Williams - (Caregiver)  
Galveston, IN

Marianna Willoughby -  
(Caregiver)  
Crossville, AL

Sid Young  
Santa Ana, CA

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

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