

WebWhispers

Sharing Support Worldwide



Whispers on the Web

A Monthly OnLine Newsletter for WebWhispers



January 2012

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Resolutions?

How many resolutions do you make? How many do you keep? Does it matter if you don't live up to the exact promise?

I don't think that dropping away from your original plan for the year and adjusting your goals is a bad thing. It is always good to evaluate what you do (or not do, as the case may be) as you go further into the year.

First on most lists is to "quit" something...

Smoking (surely we have all done this already!)

Drinking

Eating too much

Spending

Gambling

Losing temper

And to "start" others...

Exercising

Spending more time with family

Organizing

Learning something new

Helping others

Losing weight

How about a "Lary" list...

Get regular checkups

Do regular cleaning

Practice speaking more clearly

Get together with other larys

Educate yourself and others

Give WebWhispers my new email address

(OK, I snuck that last one in, but it would help the volunteers!)

Speaking of volunteers, I want to thank all of those who have given so much time and effort to keep WebWhispers running, from the officers to the ones who moderate, keep the database, service the email list, run the loan closet, send out brochures and letters, edit or write for the newsletter, and keep the forum message boards going. If we had to hire people or firms to do what our volunteers do, we could not afford it. As we stand right now, we have about 3,000 individual members in our database - 2,000 of those are laryngectomees or patients; 550 are caregivers; 400 are SLPs and Med personnel; 50 plus are vendors, and less than 10% of make any contributions.

Our membership changes daily, as new people join or old members return and some leave us in one way or another. Bad email addresses are one of the causes of losing members and losing the ability to even contact them. We are not set up to send out mass snail mailings and it would be beyond our means and personnel to do so.

So put on your list of resolutions to be sure we have your new email address, then, to open and, at least, glance at the email so your ISP doesn't consider us spam that you have no interest in. We have a constant struggle to keep the ISPs from marking us as spam... because they know when you don't bother to open your emails. It doesn't help when you mark something from us as spam, even by accident.

Read the report every Sunday from Michael that tells you about our new members. There may be one in your city that you could invite to your local club or plan to meet for a cup of coffee.

Welcome to all of our new members this year. We have 30 plus new members average every month and, in addition, some returnees that have been marked as inactive that we put back on the active list. Most of the new members come through our brochures or recommendations from members, ENTs, and SLPs. A few find our website on their own. We hope we can be of service to you and, should you want to help, we always appreciate that.

Enjoy,

Pat W Sanders

WebWhispers President

Voice Points

Written by Professionals

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Information Overload: How to Avoid It

Meaghan K Benjamin MA-CCC-SLP

I have long been intrigued by the amount of information that a patient, who is in the process deciding or has already undergone a total laryngectomy, is required to recall. The topic intrigues me because I have seen countless patients over the years who receive significant amounts of relatively complex information in a short period of time. I often witnessed the clinician feeling overwhelmed at the end of a session so I can only imagine how the patient feels. There is typically a lot of head nodding, while the patient has a dazed, glossed over, look in their eye. Sometimes, the patient is furiously writing, asking questions repeatedly while the clinician has mentally moved on to the next task. I have seen countless clinicians (myself included) provide complex verbal instructions, accompanied with a couple of bags and boxes of samples, appearing distracted as patient is advised to give a call, if they need anything. I have also seen countless patients nodding as they walk out of the room only to immediately forget what was told to them, sometimes before they have even hit the exit sign.

In this day of information overload, where we are constantly distracted by the “bright shiny thing” in the corner, this is an appropriate topic to help clinicians slow down and figure out how to streamline the information they provide, in order to enhance recall and application of information by the patient.

As I began my research, I came across an excellent piece entitled: Information Counseling in Health Professions: What do Patients Remember? which was authored by Robert H. Margolis, Ph.D. , a professor of Audiology in the Department of Otolaryngology at the University of Minnesota. He discusses the research findings of patient recall of information presented in various clinical situations as well as some recommendations on how to maximize what patients remember. This article provides the framework for looking at what information overload actually is and how we can avoid it.

He begins by asking, why patient recall is important. It would seem that as long as the patient complies with general recommendations, all should be well with the world. It turns out, according to Margolis, that when the patient understands and remembers information communicated by the clinician, they are more likely to express satisfaction, have less anxiety and be more compliant with recommendations (Thompson, Cunningham & Hunt, 2001).

Margolis reveals that there are a plethora of studies looking at patient recall, predominantly in the medical and counseling areas, with only two studies in the communications and sciences and disorders population. Overall findings indicate that “approximately 50% of information provided by the clinician is retained” (Shapiro et al., 1992).

He goes further to identify that between 40 and 80% of the information can be forgotten immediately and of the

information that is retained, only 50% is actually correct. (Kessels, 2003). So what does this mean? Margolis puts it best when he states that “of the information that is recalled, about half is remembered incorrectly. So about half is forgotten immediately and half of what is remembered is wrong. If you take any complex message that has an information component and advice component and you remove 50% of the facts and distort half the remaining information, the result could be a dangerously misunderstood message”.....(Margolis 2004). Wow! Think about the last patient you had in clinic: Was your message complex? Was there an information and advice component? Verbal discussion and instruction mixed in with some disruptions and perhaps a personal anecdote about the last vacation? These findings really helped me understand why so many patients have repeat questions and difficulty with understanding instructions or goals that may seem quite simple. So what are the factors that affect patient recall? According to Margolis, there are several including: patient factors, mode of presentation and clinician factors.

Patient Factors:

Under patient factors I was shocked to find that intelligence has nothing to do with recall (Ley, 1979). What really has a positive impact on recall are things like patient familiarity with the information, expectations, age and emotional state (Tuckett et al.,1985; Kessels, 2003).

As we all know, most of the information regarding laryngectomy rehabilitation is new to patients whether it is when they get their initial diagnosis or with subsequent treatments. Even as treatment progresses, there tends to be ongoing new information presented in the forms of tests, results, products, prognosis, complications and treatment programs. All this new information has a decidedly negative impact on the patient’s ability to recall it later.

Surprisingly, the patients are more likely to recall information later if they are in the same emotional state as when they initially received the information (Anderson et al.,1979) This means that anxiety can have a positive or negative effect on recall depending on how the patient is in clinic vs. home. Stress, on the other hand, has an attention narrowing effect which results in difficulty for the patient to switch topics or recall a lot of different items (Kessels, 2003).

Age is a factor in that older patients tend to recall less than younger patients (Anderson et al.,1929; Kessels, 2003). This finding is important to note because the average age of a patient undergoing a total laryngectomy would be considered in the “older” range.

Interestingly, where a patient has accurate expectations of what is going to happen or how they will be affected, they tend to recall better whereas denial has a negative impact on many patient’s ability to recall specifics because those in denial tend to have inaccurate expectations.

Mode of Presentation:

Mode of presentation is the next category identified by Margolis and refers to not only the quantity of information but how any information is presented at any given time. Information presented first tends to be remembered better (primacy effect) (Ley, 1972)

The more information presented at one time, the lower the proportion that is recalled by the patient. Information presented in simple, easy to understand, format is remembered better than information presented in a more complex manner (Bradshaw et al., 1975; Kessels, 2003; Tuckett et al. 1985)

A number of studies have investigated the effects of written and graphical material to supplement verbal presentation of information. This may include: pictures, cartoons and written material. Recommendations are more likely to be followed when given specifically rather than generally. i.e. (clean the prosthesis 2x per day, morning and evening vs. try cleaning the prosthesis whenever you think of it or if it seems clogged).

Clinician Factors:

Clinician factors, according to Margolis, refer to the direct correlation between the communicative style by the clinician and the retention of information by patients. For increased or positive retention, the clinician should use clear language and simple sentences rather than complex sentences with complex scientific terms. That said, I do believe that the clinician should educate the patient on the correct terminology related to laryngectomy such as stoma, puncture, voice prosthesis etc. Then, if the patient calls to discuss a question or problem, everyone is on the same page.

Maximum recall also requires that the clinician understand what the patient wishes to learn and what his/her level of understanding is. This is important in the laryngectomy population because there is a wide range of patient understanding and there are often multiple goals which may need to be prioritized. One patient may require verbal instruction along with demonstration and written instructions where as the next patient may require a video to take home and review.

Another interesting factor is the clinician's anxiety level because it has been found that an overtly anxious clinician will result in less retention by the patient (Shapiro et al, 1992). This may be significant if the clinician appears anxious during the assessment or change of the prosthesis and then provides instruction on home management. The patient may not accurately recall those follow up instructions. Non-verbal communication is important in reflecting the clinician's state (confident, anxious, distracted, empathetic). Multiple interruptions during an appointment; looking at one's pager; answering the phone will all have a negative impact on patient's recall because the clinician isn't engaged and therefore the patient is distracted and less engaged.

Finally, perceived importance of the information on the patient's part also affects retention. If the patient doesn't perceive the information as important, than they tend to recall less. If information/instruction provided during a session is unorganized, unclear or incomplete the patient may interpret it as unimportant (Tuckett et al. 1985; Kessels, 2003; Ley, 1972;1977). An example may be, "If you want to try an HME, it is up to you, it doesn't matter to me as it is totally your choice and we need to figure out the baseplate . But first let's get your prosthesis changed." Vs. "There are many benefits that can come from using an HME including decreased mucus production, improved hygiene, barrier to gross airborne particle; is this something you are interested in discussing further?"

So what can you do? First, I recommend a little soul searching. Our own recall or perception of our clinical practice is often inaccurate. We may be able to say how to effectively instruct and engage the patient but do we practice what we preach?

If you can truly answer yes to all the questions below, Excellent! If you answer no, it is time to implement some change in your practice:

Are you mentally present during each visit with limited/no distractions?

Do you provide concrete instructions?

Do you use easy to understand language with short words and sentences?

Do you present the important information?

Do you stress the importance of the important recommendations?

Do you specify categories to the patient and then address each category independently? Example: Recommendations: AL training; TEP cleaning; Baseplate attachment

Do you repeat the most important information using short, clear, concise instructions?

Do you specifically address patient's desires and beliefs?

Do you limit the amount of information presented in one sitting?

*Remember that the proportion of retention decreases as the amount of information presented increases.

Do you supplement verbal information with written, graphical and pictorial materials that the patient can take home?

*It is important to note that all studies referenced the importance of supplementing any verbal information with written and graphical information that is simple and easy to follow!

The world will continue with new technology and "bright shiny things" which will result in ongoing information overload. We will always have excuses available as to how it is not possible to change due to increased demands on our time. The reality is that the benefits of taking the time to work on these items will result in many positive outcomes. Remember, when the patient understands and remembers information communicated by the clinician

outcomes. Remember, when the patient understands and remembers information communicated by the clinician, they are more likely to express satisfaction, have less anxiety, and be more compliant with recommendations (Thompson, Cunningham & Hunt, 2001). This can only result in increased efficiency and better patient/clinician relationships with less time spent discussing what was already said.

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The Perfect Gift

I got my absolutely best gift ever when I was six years old. It is something I still use every day and it has never worn out nor lost its initial appeal. In fact, it has only gotten better as I have shared it with countless friends and family members over the last 52 years. It is still the gift that fills me with awe at its magic every time I use it.

I learned to read when I was six (thank you very much, Mrs. Hill). I cannot imagine a world or a life without books, newspapers and magazines or, in a crunch, the back of the cereal box. I practically lived at the library when I was a child. The librarian once had to call out the window to the reading garden in the back, at dusk, "Are you Donna? The library is closed. Your mother is worried. You need to go home. " I had noticed it was getting harder to read my book, but it never occurred to me that it might be getting dark. I think it might have been "Lassie, Come Home" but it could have been the latest "Happy Hollisters".

I write this from the couch where I will be sleeping tonight in my library/playroom/guest-room on Christmas Eve. My parents, in my bedroom, and my grand-daughter, next door, have all finally fallen asleep after a truly delightful

evening. Her parents, two doors down, are wishing only that this Christmas morning we all sleep in just a bit.

I took a minute to read a passage my Dad had earmarked for me in a book I scored at the local library sale. It was just a little piece about life as it once was here in Maine and it was written by a notable Maine author, but that isn't the point.

The point is that a book, published in 1937, bought for a buck at a library sale, has a chapter that makes us both want to read more and wish we could write better. And it is about nothing earthshattering. "Cap'n Bibber Philosophizes" is an unabashedly sentimental piece of writing that overly romanticizes Maine and its citizens. But he still manages to capture a time and place with perfect pitch.

The kitchen window was open for the first time of the year. There was a slender shaving of a new moon clean as one of Cap'n Bibber's white pine ones right in the middle of the square opening. The thin pipings of a hundred peepers in Cap'n Bibber's culvert were coming through the open window too. It was a mild April night. But Cap'n Bibber wasn't missing his regular evening consolation, warm weather or not. He was sitting at the kitchen stove with his stocking feet in the oven. There was a nice fire of spruce going, and the sparks and smell of it came out through the open grate. I thought I smelled wool singeing. I told Cap'n Cy I thought he had too hot a fire and was scorching his socks. He said, no. Good wool always smelt that way. Guess he'd be the first to know if his toes were catching afire. He threw in another chunk of spruce. A man needed heat in his feet and up his pant legs after a good day's work, winter or summer. He shifted his corn cob, leaned back and rocked. He liked to rock all the wrinkles out of his mind, he said. It was good for a man to rock. Half the trouble in this country was that men didn't use a rocking chair anymore. [Kennebec: Cradle of Americans; Robert P. Tristram Coffin]

There is magic in words. Sometimes they capture something real, perhaps lost to time and progress, but no less true. Other times they capture our imagination and inspire our dreams. But you need to know how to read to discover that magic. And the best way to feel that magic and learn how to read is to have someone read to you. Human beings have been telling stories since the dawn of time and the best ones then began the same way the best ones do today – "Once upon a time, there was a".

Give the gift of reading to someone this year. Read to a child or encourage one to read to you. Get involved with your local literacy volunteers or join your local library. Loan a book to a friend and earmark a favorite passage for her to enjoy. Re-read a book you loved years ago and see if it still resonates. If you're not a reader or can't read any longer, try audio books. Some folks love them and say it has opened a whole new world for them. Volunteer at your local grammar school as a "listener". It's a program many schools have to give young kids who need a boost with their reading skills to have someone come in and, one on one, listen to them read and help them sound out words as needed.

One way or another, make a resolution for 2012 that's going to be fun and easy to keep: Feel the magic and pay it forward.





SPECIAL GIFTS

Jack Henslee - 1979

To all my friends and extended laryngectomee family, I wish you all the best Christmas ever. May your greatest gift be one of love and caring which you will return many times over.

Through out this troubled life we all live, I truly believe that the greatest gift we will ever receive is to be loved and love in return.

Life is too short to be captured by anger, hate, or indifference. Embrace those that need you and the greatest gift you will ever receive is the one you gave.

Flossie Hopkins - Caregiver for Richard - 2010

stoma covers, scarfs, wound wash, saline solution and love
GOD BLESS AMERICA

Mary Wilbanks - caregiver for Carl, lary - 2008

I want to say Thank You to the staff of Web Whispers for mainlining this site and giving so much of your time to keep it going. It is so valuable, I don't believe a price could be put on it. It has linked my husband and me to wonderful people who have reached out with help and advice. My husband had his 4th cancer surgery on October 12th of this year. I depended so much on the information on Web Whispers. I want to say a special Thanks to Bob Joyner who sent my husband an electrolarynx so he could speak when he could no longer use a TEP, the same to Tom Dodson, president of Romet who provided him with a Romet and repaired it for him when he dropped it, to Deborah (little goose) who loaned us hers, to Howard & Pat Davis from the UK who sent us batteries and stoma covers, Sloan Jones for his great emails and advice, so many people I can't remember them all who prayed for us and sent encouraging emails. I thank God everyday for all of you.

I have recently been blessed by a generous lady who runs a spay & neuter program, who is paying for my stray cats to be spayed & neutered so there won't be any more. Every time my husband had surgery more cats were abandoned and reproducing. I loved them all but I could barely feed and shelter them, let alone spay & neuter them. This gift is an answer to many prayers. Now I have to find homes for them and need more prayers. It never stops does it!

Ginny Huffman - 2005

On December 30th, 1966, my late husband, Al Beatty, and I went to the "Children's Home Society" office in Fort Lauderdale, Florida to pick up our 19 day old daughter. She had been driven from Miami, spent hours stranded by the highway when the car broke down and was screaming at the top of her lungs. It was the only hitch in a seamless adoption and we named her Heather. She was soon resting quietly in her crib. Heather's six year old brother, John, paraded his buddies past the baby he mistakenly said we had got from the "Humane Society."

Throughout her childhood, Heather was a source of endless joy and surprises. At the age of six or so, I was repeatedly answering the door to inform her playmates that, "Yes, Heather was adopted" Finally, I asked one why he wanted to know and was informed that she had bet them each a nickel that she was adopted.

When Heather was fourteen, we lost Al at just fifty-one to a massive heart attack. He was in the Philadelphia Airport waiting for his flight home. It was the greatest shock of our lives and I worried about the effects it would have on my children. John had left home but Heather shouldered her sadness and her new found responsibilities remarkably well. In fact, far better than did I. Eventually, grief followed its bumpy course and we moved along knowing that we weren't forgetting Al but, by living our lives, we were honoring his love for us.

I married Bob Huffman when Heather was a senior in high school. Bob brought two of his own adopted children into our family. Heather welcomed them with her usual kindness and unselfishly opened her heart to her new father. She joined us when we relocated to Dallas, TX and she enrolled at Texas Tech where she received her Undergraduate and Masters degrees in Geology.

Bob and I were immensely proud of her and I know Al was too.

When Heather's brief marriage to an older graduate student failed, Bob and I encouraged her to fly home so we could discuss her future. I was totally unprepared to hear that she was gay. I would like to say that, as a knee-jerk liberal who wholeheartedly supported the ERA and believed myself to be free of bias, I accepted her lifestyle change. But I can't say that. For the first time, my smart, accomplished, lovely daughter was not fulfilling my hopes for her life. Heather moved to Austin and began her career, purchased a townhouse and we avoided the issue. I have often said that my M. O. for crises of all sorts, is denial!

Finally, Bob sat me down and advised me that I had better decide how I wished to deal with Heather. Eventually, there would be a partner as well. If I demanded that Heather choose, I would lose my only daughter. I needed to realize that if I did not honor Heather's right to live her life as she wished, I would lose my only daughter. A young woman with an inquisitive, open mind and incredible integrity. And not just any daughter. She was a special daughter that I had searched to find.

In the years ahead, I would lose my vocal cords to cancer. I would lose my beloved, oh so wise, Bob to prostate cancer. Heather has stood beside me every step of the journey giving me her support. Along with her brothers, she spent weeks at a time helping me recuperate from my laryngectomy and our shared loss of Bob.

This New Year, Heather, her brothers, her partner, Sally, and my grandson, Eric, will wish each other a wonderful 2012.

And I wish the same Happy New Year Wishes to all of you.

David Blevins - 1998

When I visit someone facing laryngectomy surgery, or who recently had it, and their family members, the greatest gift of all I can give is the gift of hope. It could well be that what I say or the materials I provide are really much less worthwhile compared to the living example we visitors provide that there is life, and often a very complete one, after surgery. You can see it in their faces..."yes, I now believe I (we) can get through this."

What a gift it is to me to be able to deliver this gift to others. What a privilege and honor.

Pat Sanders - 1995
A Special Gift to all of us

Fifteen years ago, Dutch had received 12 answers from laryngectomees to his new online request reaching out to others like himself. There were 11 men and one woman who replied.

Dutch Helms and Charlie Anderson - TX
John Ready and Wayne Baker - CA
Joe Johnson - AL
Ned Bienemann - MD
Robert Cline - IA
Bill (and Mary Alice) Renison - NM
Belinda Sue Shoop and Richard Boucher - OH
Richard Tunnard and Les Wood from the UK.

December, 1996, Dutch wrote a message thanking them for consenting to be listed as a "source" on his Larynx Cancer site and made his first attempt to add information for the site sources. He proposed they use a code for the type of voice which would help people know who might be their best source of information, simply: E,T and L.

These people allowed their contact information to be listed openly on the web so others, like us, could become a part of this wonderful sharing site. Dutch and his first 12 members, gave us the gift of finding someone who could answer our questions, share our worries and advise us on how to be rehabilitated.

We are now 250 times that size and we still follow in the footsteps of our founder, Dutch Helms, who passed away in 2006. We can never thank him enough for his very special gift to all of us and to ones who will follow us. We do not forget.



Back in June, 2011, my "Voices Restored" partner, Barbara Dabul, said that she wanted to submit papers to discuss our Costa Rica project and show the documentary film at the ASHA Conference in November. I laughed and said, "Sure, but you are wasting your time." She wrote it up and we submitted it. Since laryngectomees don't normally get a lot of attention from ASHA, and Costa Rica certainly isn't in their geographical range, it was a real shock to me when we were invited to give a one hour presentation in San Diego.

Now I've been to a lot of conferences to include several very big ENT events, but this was my first time at ASHA, which is a "really big show" with over 11,000 in attendance and over 300 exhibitors for various products and services. Long time IAL exhibitors Griffin Labs, InHealth, Atos, and Bruce Medical were present as well as several SLPs well known to our Lary family so I didn't feel totally lost in that sea of humanity.

To my further surprise, there were several presentations that dealt with alaryngeal speech. Unfortunately, I did not attend any sessions and focused my limited time on the exhibitors, but the notable sessions for us were:

Enhancing Postlaryngectomy Rehabilitation Through Professional & Peer-Support Group Linkages.

Now that's a mouth full and I hope we all get a report on the outcome. This was a two hour group presentation led by IAL Voice Institute Director, Phillip Doyle, former director Jeff Searl, and IAL board and staff members, Bob Herbst, Wade Hampton, Elizabeth Finchem, and Susan Reeves. As the title alludes, the focus is a better interaction between the professionals and the laryngectomee organizations.

Total Laryngectomy: SLP Survival Guide

This was a laryngectomy 101 presentation for SLPs who had limited or no experience with us neck breathers. The presenters were SLPs: Meaghan Kane Benjamin, Glenn Bunting and Carla Gress.

The Impact of Reimbursement Issues on Laryngectomee Care. What Now?

This was a panel of SLPs led by Glenn Bunting from Massachusetts Eye & Ear that discussed; "Recent changes in Medicare guidelines resulted in numerous otolaryngology/speech pathology practices suspending treatment to laryngectomee patients." I assume this is primarily in reference to the new Medicare rule that "indwelling" type prostheses will no longer be directly reimbursed to the patient. This new rule puts the burden on the SLP or clinic to order, stock, and bill for a prosthesis that is not patient changeable.

This is a big issue for many Larys and I'm glad to see some positive effort to correct it. I hope that whatever is finally presented to the "Medicare Gods" is representative of all concerned and not just the commercial interests. The simple solution is that "ALL" prostheses should be patient changeable, if the patient is capable of doing it. But that's my opinion and another story.

The number of exhibits at ASHA and the ENT Conventions is mind boggling. A really good IAL meeting has, at most, 18-20 exhibitors and maybe as few as 12. Granted, most of these other events cater to many interests other than laryngectomees but I have seen some displays that should be at IAL events, but never are, even though they may have been invited/recruited. I have always been fascinated with the many assistive technology devices that are available for those for whom speech is not an option. They have been invited but we are a small group and therefore it's a hard sell to bring these vendors to our events. Because of a lot of recent activity on WW regarding various apps for smart phones, I made it a point to investigate what was available at ASHA. Below are some companies and websites you may want to check out:

AbleNet - <http://www.ablenetinc.com/Assistive-Technology/Communication>

Provides communication apps for Apple devices such as the iPhone, iPad, and iPod Touch. Also has a neat wrist band TalkTrac Wearable Communicator that hold 8 personalized messages, a SuperTalker that holds 64 messages, and SoundingBoard which allows you to create up to 9 personal folders that you can place messages in.

MyTalk - <http://www.mytalktools.com/dnn/Home.aspx>

Ability to communicate via iPhone or iPad

Panda Pal - http://pandapal.com/iPad_help_.html

Application for iPad

TapToTalk - <http://taptotalk.com/index.aspx>

Runs on iPad, iPhone, iPod Touch, Nintendo DSi, DSi XL, DS Lite, DS, Kindle Fire, Nook Color, Nook Tablet, Android devices, BlackBerry PlayBook connected to the Internet, and on any PC or Mac connected to the Internet.

DynaVox Mayer-Johnson <http://www.dynavoxtech.com/products>

DynaVox sells actual hardware that allows you to communicate electronically. Some items are quite small and portable while others are as large as a small laptop. They are pricy but probably the “Gold Standard.” They offer 8 different devices and most of them will help those that can’t “voice.” They do so with various methods ranging from pre-recorded messages to some pretty sophisticated type and talk solutions to include connection to an iPhone.

One of the companies that really caught my attention was:

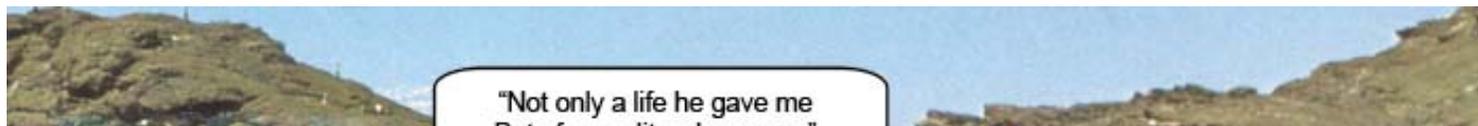
E-Swallow - <http://www.eswallow.net>. They specialize in Neuromuscular Electrical Stimulation (NMES, something that has apparently been around for some time but it was the first time I had heard of it.) Simply stated they connect electrodes to various areas of the neck and use electrical pulses to help stimulate swallowing. This caught my attention because we seem to be hearing about severe swallowing problems in Lary’s more and more lately. That’s probably the result of better communication and not an increase in actual problems but who knows! Anyway I asked numerous questions such as if it can help laryngectomees, if any studies have actually been done on laryngectomees, etc. No one could answer my questions (basically they were just “market” people) so I emailed the President and asked him for some information which to date I have not received. I mention this because I’m hopeful that maybe some of our member SLPs can shed some light on this issue. I’m sure that if this can be made to work on us then some of you would rather sit down to dinner with some electrodes stuck to your neck so you can chew and swallow your food rather than take it through a tube. I know..... if it could be done they would have already figured that out. But, it doesn’t hurt to ask.

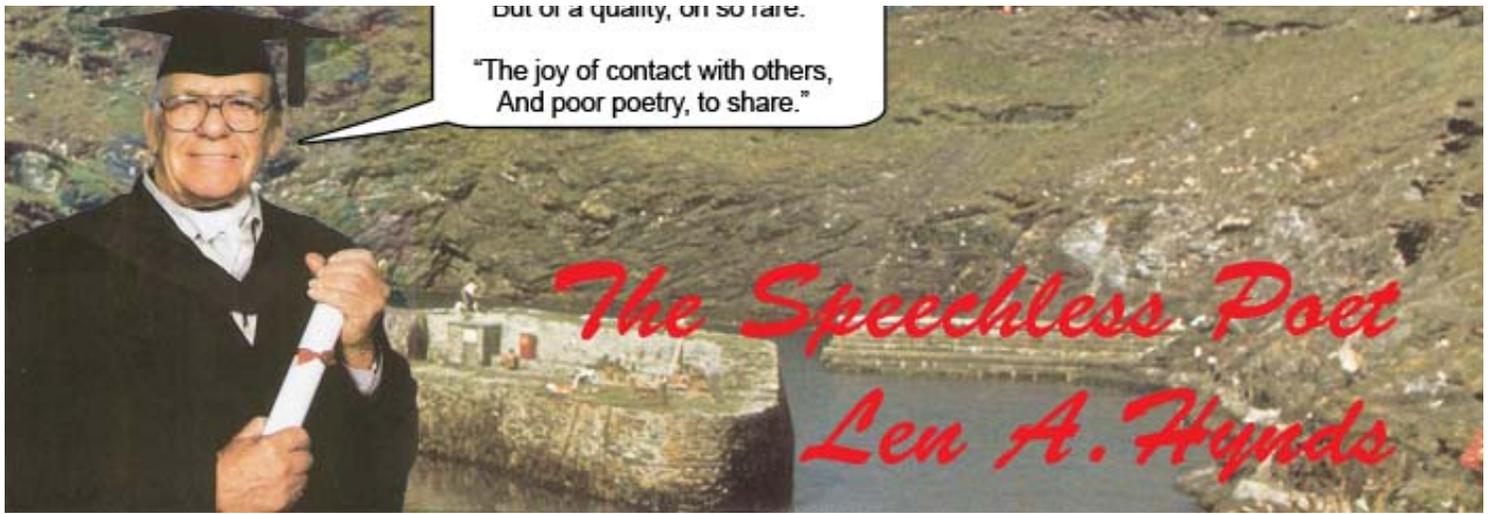
All in all this was a pretty nice experience. I learned a few things, met up with some old friends, and had some great food Mexican in Old Town – San Diego. Maybe not as good as in San Antonio, but not far from it.

Oh yeah.... our presentation was well attended and we got some good feedback on the documentary. But the highlight of the trip was the opening ceremony when ASHA President, Dr. Paul Rao, cited our Costa Rica project as a “Beacon of Inspiration.”

Made my week!

Jack





Out of a quality, on so rare.

"The joy of contact with others,
And poor poetry, to share."

The Speechless Poet *Len A. Hynds*

At the recent remembrance Sunday Church Parade, in Ashford Town, with eight of my old red-cap colleagues, surrounded by different coloured berets of many old soldiers of the various regiments, I thought of how each year we all get a little older, until we reach the final parade. Coupled with that was the memory of reading a story or a poem about a soldier being on that last parade, so I wrote this poem.....

THE INSPECTION

Charlie stood at attention there,
he'd known it would come to pass.
He hoped his boots were shining bright,
and his buttons made of brass.

It looked like another court martial,
but the officers looked most odd.
The one called Peter, wore white robes,
with the judge on a throne, like God.

That Peter said, with a puzzled frown,
"Just how shall I deal with you.
Have you always turned the other cheek,
and to our church, been true." ?

Charlie spoke with his cockney voice,
staring straight ahead,
knowing he must be careful,
in everything he said.

So in defence, he spoke out loud,
"No sir, I guess I aint,
cos most of us who carry guns,
can't always be a saint."

"I've 'ad to shoot people, on Sundays,
when I should 'ave bin in church,
but you don't argue wiv our Sergeant,
you'd soon be in the lurch."

"A funny old life, a soldier,
and at times my talks bin rough,
and sometimes I've bin violent,
cos my world is bloody tough."

"Now I know, just where I am,
I thought you'd give me a miss.
Not worthy in your scheme of things,
I've heard your world is bliss."

"I know I don't deserve a place,
among your people here.
Those down below didn't want me around,
except to calm their fears."

"But if you've a place here for me, sir,
it needn't be so grand.
I've never expected, or had too much,
if you aint, I'll understand."

Peter smiled, " Come in, young man,
you have borne your burdens well.
Walk peacefully, your time has come,
you've done your time in hell."

Best wishes, everybody, for the New Year.



Beyond the "nuts and bolts" of WebWhispers

I learn a lot about dealing with the nuts-n-bolts of living with this hole in my throat by reading folks' comments on WW, but that's not the biggest benefit I receive from these pages, nor is it the reason I highlight and punch up anything with WW on it before reading any other e-mails every day.

You see, I've experienced very few problems since becoming a lary in September of '08, so my interest in those I read about here is mostly a matter of gaining information that might be useful in the future, or shamelessly plagiarising it, so I can use it in the private e-mails I send to folks whose stories touch my heart some days!

But far beyond the benefit of new information, my enthusiasm for reading everything you write to WW stems from the fact that I get a terrific spiritual uplift from the very different tone of comments posted from our larys, caregivers and healthcare experts.

First, I'm always somewhat astonished by the humble courage, determination, and often even humor I find in the postings of those larys among us who are dealing with incredibly serious problems. Then there is that little thrill of hope I enjoy when I discover reports from larys who've survived and prospered for decades, who take time to offer words of encouragement, from their vast inventory of experiences, to those of us who've just begun this journey.

And, I love to discover a "newbie" who's facing their surgery with exactly the same questions and concerns we all encountered about living with a new voice because it gives me a chance to try a little "pay it forward" exercise in reassurance, like so many of you gave me back in '08 ,when a kind visitor named Bill introduced me to WebWhispers.

Finally, I suspect the biggest benefit I get from reading the posts of fellow larys is common to us all and that is a factual reassurance that ... "We are not alone!"

Then there are our CAREGIVERS. They appear less frequently on these pages, but as I sit here alone while reading their posts some mornings, the concern of their content and caring tone of their posts, brings embarrassing tears to my eyes. That's when I pause to thank the God of my hopes for the family and friends who've surrounded me with that kind of loving care and concern while hiding their own fears (and perhaps a tiny bit of revulsion when I'm having a bad day with mucus and coughing!) since the day I began talking a little differently.

I'm often led to send a private e-mail to some WW caregiver that offers nothing more than one man's appreciation for the support they are giving to their loved one. I wish caregivers would post to these pages more often to remind us of the blessings they bring us, and to provide them with a relief valve for the pressures our condition puts on them from time to time!

Finally, I enjoy the businesslike expertise our healthcare experts provide on WW, but have you noticed how few of them there are? I think I know the reason, and it makes me appreciate each of them far more than they might expect. Hey, I've never met a doctor, nurse, SLP, or healthcare volunteer who didn't have more on their plate than most of us can even imagine. I know it takes a special person with a deep concern for larys to get up a little earlier or stay a little later for the task of writing a candid article, or answering someone's e-mail about one of the most unique medical conditions in their profession.

I want those who can't find time from helping and saving lives to know that I understand the demands on their time and I want to applaud those who make time for us because they can never know how many lives their advice and counsel on these pages have helped!

You know, as I write this article for the new year's edition of Whispers on the Web, it has crossed my mind several times that perhaps my dedication to reading this internet publication and appreciation for those who put it together is the primary reason I've had so few problems since '08. All along the way, while writing this, I've been reminded of some tip, tale, or observation that put me "ahead of the game" in dealing with my surgery, recovery and day-to-day maintenance of this lifestyle ... that I first encountered here!

That observation prompts my hope that 2012 will see us reaching out to enlist more new members who need

...that observation prompts my hope that 2012 will see us reaching out to attract more new members who need this daily "shot in the arm" of facts, education and inspiration a lot more than many of us first realized when we began our association with this group of wonderful characters!

Nuf-Sed
Bob Keiningham



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 29 new members who joined us during December 2011:

Marty Adamczyk
Acworth, GA

Richard Allen
Lompoc, CA

Mary Blasko - (Caregiver)
Pittsfor, NY

Michael Bonar - (Medical)
Stanford, CA

Susan Cordes - (SLP)
Rochester, NY

JoAnn Delano - (Caregiver)
Appleton, WI

Mike Delano
Appleton, WI

Riley Ellis
N. Fort Myers, FL

Ana Garcia - (SLP)
Forth Worth, TX

Mary Goodman - (SLP)
Southlake, TX

Dan Grogg
Martinsburg, WV

Jocelen Grudgeon - (SLP)
Iowa City, IA

Randy Harwood
Henderson, NV

Kitty Hunter
Ontario, CAN

Susan Katz
Northbrook, IL

Michael Mask
Milan, IL

Michael McQuade
Victoria, Australia

Bob Mills
Lakeland, FL

Robert Muhammad
Jacksonville, FL

Randy Peele
Lexington, NC

Pete Pierce
Independence, KS

Andy Reck
Watervliet, NY

Mary Reck - (Caregiver)
Watervliet, NY

Ed Schmitt
Poughkeepsie, NY

Karen Schmitt - (Caregiver)
Poughkeepsie NY

Carol Shelton
Clearfield KY

Mark Shepard
Northwood OH

Tom Wahweotten
Arroyo Grande, CA

Colleen Wheeler - (Caregiver)
Sioux Falls, SD

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

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