

WebWhispers

Sharing Support Worldwide
Throat Cancer and Laryngectomy Rehabilitation

Whispers on the Web

A Monthly Online Newsletter for WebWhispers

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Name Of Column	Author	Title	Article Type
News Views	Pat Sanders	Dental problem - Is it radiation caused?	News & Events
VoicePoints	Jana Childes M.S., CCC-SLP	Communication Technology - (SGD)	Education-Med
Between Friends	Donna McGary	There is Hope	Commentary
Speaking Out	Members	First Time to Meet a Lary?	Opinion
Travel With Larys	Jack Henslee	The New Normal	Experiences
The Speechless Poet	Len A Hynds	Springtime Whimsy	Prose & Poetry
Bits, Bytes & No Butts!	Frank Klett	Spring is upon us, Thank the Lord!	Computers

INDEX AND LINKS TO EACH ISSUE MAY BE FOUND AT: <http://webwhispers.org/news/WotWIndex.asp>

COMMENT HERE
FEEDBACK



Dental problem - Is it radiation caused?

Recently, on the email distribution list, there was a discussion about the cause of dental problems, members with teeth that are cracking or breaking were blaming this on radiation. I am not sure we can give radiation all that blame when we have been the caregivers of our own teeth in the meantime. Read a little further and see what I mean.

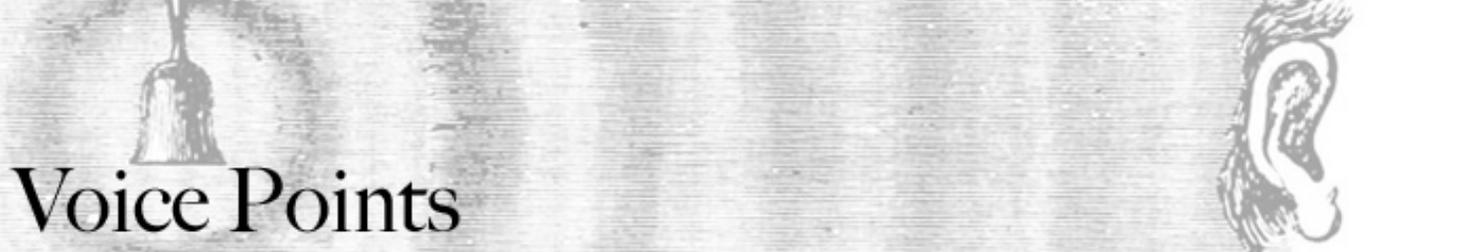
I gathered together some good websites and have been reading. You see, a couple of years ago, my teeth had gotten so many fine line cracks that I had to go in and spend a lot of money to save them. I had a couple of lengthwise cracks in front teeth and did everything to get those darker lines to go away but more came. I already had been using a mixture of peroxide and Listerine as rinse, mouthwash and to use with my Sonicare. It cleaned and whitened the teeth but left the cracks there. And then they started to break off, a sliver here, a corner there.

So I am reading in special articles now, that while sugar doesn't cause cavities, anything with carbohydrates turns into acid, which then produces bacteria that does cause trouble. It eats away the enamel and leaves your teeth weakened. Not just sweets, but acidic foods also may be putting your enamel in danger. They have had several trials that showed that enamel erodes more from being left in constant contact with drinking sweet drinks, sipping all day than from eating something sweet and then making an effort to get rid of the residue by using mouthwash and brushing. The more often we work at cleaning our mouths and teeth, the less the problems... unless we carry a sweet soda around with us all day long or nibble on candy.

In addition to the foods you are eating, GERD, acid washing up into the throat, sometimes gets to the mouth and in addition to possibly causing throat cancer, it also erodes the enamel on your teeth. WebMD talks about anyone having acid reflux being likely to have dental erosion.

Radiation causes dry mouth. Sometimes surgery does. The reduced amounts of saliva leaves your teeth with a weaker defense system. So blame the radiation... it probably did some damage and did leave you without enough protective saliva, but also take a little responsibility for the bacteria that grew in your mouth without being rinsed often. Ice cream every evening may be asking for trouble. If you can brush after food and drink, do; if you can't, rinse, even if just with water after eating anything.

Enjoy,
Pat W Sanders
WebWhispers President



Voice Points

Written by Professionals

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Communication Technology - Devices (SGD)

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INTRODUCTION TO SGDS

As technology expands and becomes more accessible, it is not surprising that many persons with communication impairments are finding ways to use their personal technology as a speech generating device. The term speech generating device (SGD) refers to any computer that is used for communication by allowing its user to input a message that the computer then speaks aloud. Recent research indicates that some people who have undergone a laryngectomy use SGDs for communication in one or more of the following ways:

1. For communication immediately after surgery until regaining speech through use of a voice prosthesis, electrolarynx or esophageal speech.
2. As a primary communication method for those who are unable to regain speech due to extensive surgery or other complications.
3. As a secondary communication method to clarify their spoken message in conversations where they are not easily understood or in place of speech in situations where they anticipate difficulty being understood, for example: when speaking over noise, using the telephone, etc.
4. As a back-up method for occasional use in specific situations or a back-up if there is difficulty with their speech method (e.g. the electrolarynx is sent for repair).

Many computer devices can be made into a SGD through use of programs or applications (called apps) that provide this function. When considering a SGD, there are often many questions about the types of devices and how to select one. I'd like to discuss some of the questions that I am frequently asked. (Please note that I have no affiliation with the any of the companies that sell these devices or software. My responses are based solely on my professional experience.)

FREQUENTLY ASKED QUESTIONS ABOUT SGDS

Q: Are there different types of speech generating devices?

A: Yes, while there are many different devices, they can all be classified into one of two categories:

- Integrated Devices: These are devices that can be purchased in a store and then made to function as a speech generating device through the addition of a computer program or application. Examples of integrated devices include laptop computers, desktop computers, smartphones or tablets (e.g. iPad, Nexus).
- Dedicated Devices: These are speech generating devices that are designed to be communication devices and are sold as medical equipment (i.e. require a physician's prescription for purchase through a medical equipment vendor).

Their design typically includes optimal speaker size and placement for communication, various voice options and multi-functional communication software.

Q: There are so many options! How do I know which type of device is the right one for me?

A: There are obviously a lot of considerations to determining which device is the right fit. First, I would encourage each person to think about how they plan to use their SGD:

- Will you be using it mostly at home, out in your community (e.g. shopping, medical appointments, etc.), at work, on the telephone, or all of the above?
- Will it be your primary (or most frequently used communication method), or a method that you use in conjunction with your speech?
- The size and weight of the SGD are important considerations. Are your vision and typing able to manage using a small screen (such as a smartphone or tablet), or do you need a full-size screen. Do you have any concerns (for example, arthritis) with being able to type, lift or carry a device?
- How comfortable are you with technology? Are you already comfortable using a computer or will this be new to you? Do you like things with a lot of features or do you prefer simplicity?

These are simply suggestions of things to consider prior to exploring different types of SGDs. NONE of these considerations would exclude someone from using an SGD. The beauty of all of the different types of devices is that there is something to fit everyone who could benefit from using this type of technology, even if you have never used a computer.

Q: What if I'm not very good at typing or spelling?

A: Many SGDs have features to help people who are not very good at typing or spelling, most notably word prediction. Let's say that you want to type "Good morning." As you type g-o, the computer will try to predict what you are going to type and will show you suggestions, such as good, got, going, etc. Once you select the desired word (good), it will then try to predict what you will say next and will show you words that frequently go with "good" such as morning, luck, night, etc. People who are not very good at typing or spelling find this feature very helpful.

Q: How do I use it on the telephone?

A: Being understood over the telephone is a challenge for many laryngectomees and is one situation where an SGD might be helpful, even for someone who is well understood in face to face interactions. To use an SGD over the telephone you will need a speakerphone. Set your SGD on a table next to the speakerphone, and then dial or answer the call on speakerphone. You can then use the SGD to type a message and speak it aloud. The speakerphone will pick up the computerized voice and send it to the person on the other end, just as it would do if you were speaking. Many people who use an SGD on the phone find it helpful to begin conversations by telling the other person that they are using a computer to talk, so that the listener will know it is a person on the other end and not an automated call.

Q: "It works really well if the room is quiet, but if there is noise it isn't loud enough. How do I make it louder?"

A: This is a common complaint for users of integrated devices (e.g., smartphones, tablets, etc). Volume can be improved with the addition of a small speaker that plugs into the device. These can be purchased in many stores such as Radio Shack, Best Buy, etc.

Q: "I looked for a speech generating app for my iPad and there are so many. Some are free and some are really expensive. Are the expensive ones really that much better?"

A: As with most things, speech generating software and apps are available at a variety of price points ranging from free, a few dollars, mid-range (\$30-\$60) and over \$100. In my experience there are good programs and less useful programs at every price point. I generally recommend staying away from the free apps, as they tend to be difficult to understand. However, there are several that are quite good and only cost a few dollars. These are great for people who want to purchase one to try on their smartphone or tablet and "try it out." As for the more expensive programs, they typically offer better voice quality and more features (e.g., the ability to store frequently used messages, word prediction, ability to vary the speech settings, etc.). Many of the more expensive programs offer either a free trial period or the ability to download a "lite" version of the app for free. This allows you to try the basic features of the software and see if it fits your needs before you make the purchase.

Q: "Will my insurance company pay for a speech generating device?"

A: Medicare and private insurances will cover a portion of the cost of an SGD in many situations (e.g., 80% or 90% of the cost with the remainder as a co-payment); however this is typically limited to dedicated devices only. There is the possibility to apply for Medicare or insurance funding toward the purchase of speech generating software programs, but in my experience they do not provide funding to purchase a computer to be used as an SGD (e.g., laptop or iPad). To purchase a speech generating device through Medicare or insurance, the first thing that you need to do is be evaluated by a speech-language pathologist (SLP) who will document your need for the device.

Q: "Are there other options to help me get an SGD if my insurance won't cover it?"

A: Yes! In Oregon, there are resources to obtain an SGD through the state's telephone assistance program. This program provides SGDs to persons who don't have adequate insurance coverage to purchase one themselves. In addition to looking into the services provided by your state's telephone program, I would also recommend investigating options to borrow an SGD (or ask for advice from others) through your local New Voice Club, Sertoma Club or WebWhispers.

If you are considering an SGD, or would even like to see how you could benefit from one, I would strongly recommend talking to a speech-language pathologist. The SLP can help you think about all of these considerations and then arrange for trials of different devices until you find the one that's right for you.

Ed. note: The first part of the article on Communication Technology was in the Feb 2014 Whispers on the Web at: <http://webwhispers.org/news/Feb2014.asp>



There is Hope

One of the benefits of working on this newsletter is that I get to read the articles as they come in – kind of an early edition, so to speak. That can be particularly helpful when I'm struggling to write my own column and looking for inspiration. A common theme in three of our articles this month is communication. And that makes perfect sense. While almost all of us deal with some degree of breathing, swallowing, eating and talking issues, it is often the new voice that poses the most challenges. We move from accepting that the old voice is gone to choosing a new method of voicing or, in some cases, accepting the only option available; next is mastering the new voice. This process is a life-changing experience.

Time and time again, as you responded to this month's question about your first time meeting a laryngectomee, you

Time and time again, as you responded to the month's question about your first time meeting a laryngectomee, you mentioned hearing him or her talk. And I am willing to bet that if, next month, Jack were to ask, "What has been your most meaningful moment as a lary?" the answers would resoundingly be about discovering our new voice regardless of what form that takes.

If you have been silenced, for whatever reason, even a whisper, just a croak, a buzz or a SGD (read Voicepoints if you are unfamiliar with the acronym but think Stephen Hawkins) can be revelatory.

I remember the first time I met a lary and my situation was a bit different. I wasn't even a lary but I had a rare cancer that left me with severe radiation damage and a permanent tracheotomy. Libby Fitzgerald was the first person I met either with my cancer or my voice. At that time I could speak a bit by occluding but that too was eventually lost. However, I will never forget that moment of hearing someone who sounded like me. Libby used a hands-free TEP at that time. She and her husband, John, were extraordinarily gracious to me and it was Libby who introduced me to WebWhispers for which I will be forever grateful. Thanks, Big Sis!

Unfortunately that last bit of voicing was short-lived and after many procedures that only resulted in voices and hopes raised and dashed, I was given a Servox to try at my ENT's office by an SLP, called in after all else failed. My vocal cords were irreparably damaged; my trachea was a mass of scar tissue. I could barely walk across the room without coughing and I could only communicate if you could read my writing or my lips. But with that Servox suddenly I could talk again, at will, and that changed everything.

I had fought that day nail and tooth. I did not want to sound like a robot. But after so many months of no voice, I was thrilled to have any voice. Our new voices only replace our old voices; they do not change who we are. It is still hard. I still hate that I cannot read to my grand-daughters the way I read to their father. That part of me is lost forever.

But there is hope. Despite the fact that I feel I can't read a story properly anymore, the girls seem undaunted as I hear, "Nanny, please, read one more story." One of the first words from the younger grand-daughter was "ree" as she toddled toward me with a book. They both seem oblivious to the fact that my voice is "different". To them that is just how Nanny sounds. And I can live with that.



When did you see your first fellow laryngectomee and what impact, if any, did it have on your life?

Marlene E. Haynes, Webb City, MO- 12-24-96

I had never even heard the word laryngectomy until I was diagnosed with cancer the 18th of December in 1996, the cancer had gone too long so surgery had to be done very soon, no time to wait, the only thing I knew about it was I was going to lose my voice, that's it, nothing else, no education or time to learn anything else.

The doctor assured me I was going to do fine and I'd learn to communicate with instruction but first I had to heal from the surgery, he told me not to focus on anything else and follow his instructions before, during and after the surgery. I came home after two weeks in the hospital just knowing I was going to die! I was stressed to the max, hurting, depressed and frustrated, vowed to never leave the house again!

I had home health care, a nurse and a SLP came to make sure I could take care of myself and taught me how to feed myself and clean, I had a couple of people calling me to come visit a support group, I kept putting them off, I did not want to see anyone.

Then radiation started, it just so happened my treatment was at the same hospital where the support group met, so one day after a treatment I walked down to the conference room where the meeting was, I walked in and here were all these people talking and laughing and joking, I was in shock, here I was the most miserable person in the world how could these people be so happy and in such a great mood??? I was baffled.

The president of the group was the dearest lady I ever met, I liked her on first sight and she took me in under her wing and taught me how to become a survivor and how to become a whole person again, we became the best of friends, actually I made many friends there, all still friends today, the best thing I ever did for myself was force myself to stop by that meeting.

William Cross, Visalia, California - Oct.2nd, 2013

Supraglottic Squamous carcinoma T3,N0, M0, no chemo or radiation needed. It was about three weeks after my surgery I talked on the phone with my EL to John Ready [First person on the phone] and he sent me a few HME to try and invited me to join a meeting in two weeks.

I was using the HME and still talking with the EL and not using my TEP to talk much. I was taking time to get used to it. John and the others there told me you just have to use it and it gets better. So the rest of that day I just used my TEP to talk and never went back to the EL. I was able to go back to work in just ten weeks after my surgery and six weeks after meeting John. My job requires me to talk to truckers, loaders and be on the phone all day. Meeting the other larys helped me more than they will ever know. I don't use the hands free because I put too much air out and blow out my baseplate in a few hours, so I use the push to talk and can talk louder which I need for work. Hands free on weekends. They gave me the courage to set goals for myself. Like ordering food at a drive through, whistling, blowing out candles or a piece of paper off a table, blowing my nose, and blowing up a balloon. Yes it helped me to meet and talk to them.

My "New Normal" is OK.

Rod Bacon - Feb 12, 2010

My first meeting was with John Ready at Stanford Medical, was very impressed with him & still ask him questions. I also have learned a lot from WebWhispers, a truly great group of people. Have found out that Lary's are some of the most caring people that I have ever met. I'm 73, so that is saying a lot of GOOD ABOUT WebWhispers.

Sincerely, Rod

Lloyd Enochs, Evansville, IN - December 2009

The first time I saw a fellow Lary was several weeks prior to surgery. My ENT surgeon asked if we would be interested in meeting one of his patients and my wife and I jumped at the chance.

We met Clarence at the ENT's office. We sat and talked for about 45 minutes about surgery and recovery. He was very blunt about the lengthy recovery period and the need to adjust to the "new normal". We also discussed the minutiae of daily life: baseplates, filters, mucus, the local humidity patterns. He also referred me to WebWhispers which led to long hours at the computer finding out all we could prior to surgery.

It was an extraordinarily productive meeting and I would not have made as rapid progress in recovery without having met him prior to surgery.

John H. Davis, New Braunfels, TX - Dec 11, 2013

I asked my SLP if I could visit with an individual who was a laryngectomee. This was at M D Anderson. A volunteer came by and I was impressed by his speaking ability. He had a TEP. We had a nice visit although obviously I listened rather than participated. Good idea to visit because it gives you some idea of what you are facing. I got an even better idea last week-end when I attended the TLA conference in Ft. Worth. Incidentally, Webwhispers got high praise as an information source.

John Haedtler, New Mexico - 2001

When I had my surgery I had not seen or spoke to a Laryngectomy, Heck, I did not even know what the word meant! Boy did my life change in a big hurry. If I remember correctly, the first time I met another laryngectomy was during one of my many check-ups. I was just sitting there and I saw a man walk in and register. We started to talk.

That is when I realized how important it is to speak to new patients, When I went through my Laryngectomy I was scared to death. I had no idea what my voice would sound like or if I would even be able to speak ever again! All of this thrown on top of the fact that I was just told that I had Cancer!

For me, the hardest part was when I was in the hospital and I had to look at my neck for the first time! Now I look back and that was the easiest part of it all! I also kept writing down my feelings. At first, I did it just to give me something to do, Now I'm glad I did. I was able to see my improvements. Now I volunteer to talk with all the new patients going through the hospital where I had my surgery. Just seeing the change in their eyes after speaking with me, makes it all worth while!

Irene Hallahan - 1995/2006

Partial Laryngectomee as of February 1995 and then total Laryngectomee as of August 2006.

I met my first fellow Laryngectomee in 1995 when I was recuperating at home from my partial Laryngectomy. I was very scared and felt very alone. We contacted the local American Cancer Society and found that they had a Nu Voice Group. I attended a meeting along with my daughter for support and met the nicest group of people who were

Group. I attended a meeting, along with my daughter for support, and met the nicest group of people, who were happy and laughing and going on with their lives and they were all total Laryngectomees. So, it made me feel like there was still a life after the surgery and helped me so very much. There were people that used EL's, some that spoke Esophageal, and one with a TEP, so I saw several ways of speech. Since I was a Partial Laryngectomee and was still able to talk with a very raspy voice, I appreciated that I still had a voice, and kept in my mind that if the Cancer returned and I had to get additional surgery to have my Larynx totally removed, I would still be ok, Live, and Laugh and go on. So, it was very beneficial to me.

I was a member of that group for 8 years until I moved away. Then in 2006, my Cancer came back and I became a full Laryngectomee, and I reached out to that same Group through one of the members I had remained friends with and he was very helpful. I knew from my association with the group that I would be fine and that life goes on. I am extremely grateful to all and remain friends with the one man and his sister today.

John Hendrix, GA - Aug 2011

I had my surgery at MD Anderson in Houston and due to slow healing and other complications, stayed in Houston for 3 months and was pretty much at the hospital every day Monday thru Friday for various procedures such as, TEP sizing, speech therapy, Physical Therapy, Lymph massages etc..... and saw quite a few Laryngectomees while I was there. The thing is I was so depressed with my own situation I never attempted to speak with or get to know any of them. This was Aug – Oct 2011. While in Houston, my wife signed me up for WW and I eventually started reading the daily post.

My wife and I live in Savannah, GA and I noticed a gentleman that posted every now and again that lived a couple of hours away near Augusta, GA. I finally contacted this person and he helped me find a really good SLP in the Augusta area along with a ENT doc who specializes in working with our TEP's. He met me at the hospital before my first meeting with these folks and spoke with me and my wife. This was May or June, 2012. He was the first Laryngectomee I actually met. His name is Mike Smith and he has really helped me get past feeling overwhelmed by it all and on the course to finding the new me. I am still working the little things out in my mind such as socializing... but meeting Mike was a huge help to me. Just seeing how he handled himself provided a role model to try and pattern myself after. Mike, I am sure you are reading this. Thank you my friend!

Duane Beecher, Dubuque, Iowa - Nov 2004

I met my first lary shortly after writing in to WW about my upcoming surgery in 2004. WW member named Lynne made contact and she made a trip of over an hour to meet with me and my family. Not only did she do it once but she came back the next day to talk to family that were not there the first time. Lynne made the entire thing less stressful for my family, if that is possible. I think that anyone that is facing a laryngectomy should at least be given the chance to meet with someone that has had the surgery. Knowing how it feels to have someone take the time to answer questions and show others what post surgery is about has lead me to do the same for others.

Dick Sipp

My first exposure to laryngectomees was at a support group meeting I attended shortly before surgery. It was helpful to see folks who were doing OK after their surgery.

Joe Hilsabeck, Edelstein IL - 2009

I met my first fellow lary in a WalMart in a small town, Shellbyville, IL, while on a fishing trip. We needed some items

for our camp and while sitting having a coffee, waiting for my wife to shop. I heard the sound of an EI, so I went to the gentleman and said we have something in common. He had been a lary for 15 yrs and we had a long visit in the café, as my wife and daughter take a long time to shop. I had only been a lary for 4 mo. so had a lot of questions. Was great because my SLP didn't seem to want to connect me with any she knew. Funny thing that the next one I met was 4 years later in the Mayo clinic the same way, hearing the sound of an EL.

Terry Duga, Indianapolis, IN - Classes of '95 and '97

I first saw a laryngectomee while I had a partial laryngectomy and was seeing Eric Blom about speech issues. I was privileged to hear a man say his first words post surgery. He used a Blom-Singer prosthesis. Seeing this made me less afraid of a total laryngectomy because I knew I would be able to speak afterwards.

This helped immensely.

John Isler, Roanoke, VA - 9/4/2013

My laryngectomy was 3 days after I retired. I was in the hospital for 6 days. I had no exposure to any larys prior to my operation, but there was very little time between being diagnosed and the operation itself.

I was fortunate to have Hank Luniewski (anyone in WebWhispers knows of Hank – he is such a great contributor) visit me both in the hospital and several times in my surgeon's and SLP's office following my operation. He is always upbeat. He gave me the early coaching on what to expect for things like eating and showering, and also dental warnings (like he has done very recently in the list). I got to look at his lary tube and HME long before I was ready to wear one. For me, his visits have been very beneficial.

In addition, about a month after my operation, the priest at our church introduced me to Dennis Thurman who had his laryngectomy in 1995. Dennis gave me a package containing books, catalogs and sample stoma covers not to mention medical warning cards – basically everything a lary needs to know to get started. I kept those items for several weeks during my early recovery while I was trying to understand what I would need to get for daily living.

I was on a feeding tube for 9 weeks before I could get a TEP installed. Neither Hank nor Dennis have TEPs. However, both have given me all the warnings about stuck food and what they have to do to clear that situation when it happens. Dennis tells me he keeps a chopstick as part of his arsenal against stuck food!

Both Hank and Dennis have great outlooks on life – and this is catching! All in all, I would say that exposure to fellow lary's is extremely helpful.

Lou Trammell, Chicago, IL - 2009

This subject really hits the spot because when I first become a Lary 9/8/09, I couldn't find a group here in the inner city of Chicago; yes, there were several in the suburbs and I contacted everyone of them but not one would answer my request on how to get out there because I didn't drive. A year later, while visiting my sister I met with a small group in Dubuque Iowa and we sat in the park on a bluff above the Mississippi and talked for 3-4 hours and it was great. I had already been thinking about starting my group, Lary's Speakeasy but after I met these people I knew I would do it. After starting my group Aaron F. showed up for a meeting and we became friends and he visited a couple other meetings in the burbs so I would meet him at the train station and go to those meetings also. One that is now

closed actually told me that the hospital didn't like visitors who weren't patients and that's a shame. Anyway, meeting another Lary face to face and relating to them should be on all Lary's to do list because that's when you'll realize you aren't the only one around.

Frank Watkins, Greenfield WI - class of 1985

I had my surgery in July of 1985. While I was in the hospital after the surgery I was visited by a gentleman named Bob Green who was a laryngectomy that used esophageal speech. Needless to say I was very confused by how the loss of my voice box was going to affect my life. I was only 45 at the time and scared as hell to put it mildly. After listening to Bob for over 2 hours I felt a little more at ease. He explained all the facets of lary life and all my options in living the life of a lary.

I am now 29 years cancer free and living life to the fullest, thanks in great part to that visit from Bob. In the last 29 years I have spoken to many new laryngectomy patients in the same manner that Bob spoke to me, although I use a prosthesis to speak now. I also speak to high school kids about the dangers of smoking. I hope this is my way of paying Bob back for how much he affected my life with his act of kindness.

Carl Strand, Mystic CT - February 10,1993

I have always been something of a loner and considered myself pretty self-sufficient. So, when I went into my laryngectomy surgery 21 years ago, I figured I could handle whatever happened. Well, we all know what the feelings of post-surgery are - you don't know how you're breathing, you don't know how to swallow anymore and you don't know how to communicate. The first time you get a mucus plug is absolute panic.

About five days post surgery my speech pathologist asked if I wanted a laryngectomee visitor. I tried to say no, but my wife would not have any of it. She insisted it could not hurt - "what's the problem". So, the following day Dick arrived by my bed. Dick was (and is) a well rehabilitated laryngectomee, a couple of years older than me, and at that time was 12 years post-surgery. He is an esophageal speaker. Needless to say, it was a revelation to me and a very hope-giving experience.

I had a primary puncture, so a month later, I was fitted with a voice prosthesis. I was talking, able to eat most foods, gaining my strength and getting ready to return to work. Again, I figured I could handle whatever happened. Again, I reckoned without my wife. The Sunday came up for the New Voice club meeting and she insisted we go. So, we went, against all my protests.

It was at that meeting that I finally got it through my thick skull that it wasn't all about me. It was all about US! Laryngectomees supporting laryngectomees is what it is all about. I can count the number of meetings I have missed in those 21 years on one hand. I've learned so much and I hope I've taught as much. There have been sad times - Dick is the only one of the original dozen I met that is still alive. There have been happy times - grandchildren born, children married, vacations, cruises, whatever.

Times have changed. I now run the support group. I write the newsletter. There are no longer speech pathologists at the meetings. The numbers are small. But the basics are still there. When we met last Sunday, there were two new laryngectomees at the meeting - one three months out and one five weeks out. There is nothing like face to face contact and the ability to talk one on one with someone who understands what you're feeling. You can see in their faces that something is happening inside.

I love WebWhispers and have been a member about 15 years. Lots of good and some not so good information is shared. It fills a need that can't physically be met any other way. With all the good it does, it still doesn't compare with meeting another laryngectomee in person and never will.

Thank you for your submissions. Edits are used for length, clarity and to keep comments on subject of the month.
Staff of Speaking Out



The New Normal

Jack Henslee

Newsletters have been a part of my life for quite a few years now. It all started back in 1989 when Stockton, CA formed a new IAL club for laryngectomees which we named "Look Who's Talking", and the newsletter adopted the same name. Or maybe it was vice – versa..... after all 25 years can cloud the memory a little bit. Back in those days very few of us had personal computers, and software for creating Desk Top Publications (newsletters) was limited and expensive, and therefore the existing newsletters for laryngectomees and I assume others was somewhat limited in content. Cranked out on a typewriter (do they still make those things?) and little or no graphics unless you physically pasted something on them and ran them through on a copy machine.

Back then the IAL used to feature a one night event at their Annual Meeting where people would sort of drift around on their own to different rooms where they could see and/or discuss the topic of that room. The topics were varied but the one that caught my attention was "Newsletters." Prior to the meeting the various clubs were invited to bring or mail copies of their newsletters for others to see, and provide information on how to create or improve your newsletter. Sadly most newsletters were disappointing as to content that primarily consisted of meeting minutes, birthday announcements, and upcoming events if any. One page with no columns was the norm although some had enough information to also carry over to the back page as well. But the one great thing about this event was that they provided a sign-up sheet so everyone present could either send monthly copies of their newsletter to anyone interested, or for you to ask that copies be sent to you. This opened the gateway for sharing information that the IAL News didn't provide.

In the early days I vowed to provide a lot more information than just meeting minutes and searched for other articles regarding all aspects of health, recovery, and other things such as appropriate poetry related to cancer survivors or at least subjects that we could relate to. Due to the exchange of newsletters between clubs my little mailing list of about 25-30 names quickly grew to more than 300 and I was always pleased when I'd receive another newsletter that used an article from my newsletter. On the other hand it also bothered me that I seldom received any feedback except from a few that actually attended our meetings, and almost no one would respond to my pleas to submit articles for inclusion, or at least suggestions for me to pursue. I finally reached a point where I said we could no longer send them out to people that appeared to show no interest other than their original request to be placed on the mailing list. So anyone that still wanted it had to give me a new request and if possible could you make a small donation to cover the postage.

About a week later I received a letter from a lady that only lived about 40 miles away but was unable to drive to attend any of our meetings, plus she had a very limited income. She went on to say that after 2 yrs as a Lary she never leaves the house except for Dr appointments and we were the only source of information she had about her

condition. She pleaded with me to not remove her from the list and had included 6 stamps and a dollar bill, explaining that all she could afford.

Perhaps 6-8 months later a man came to my door and identified himself as her son and he said she had died. He thanked me for the newsletter saying it inspired her to at least get out of the house once in a while, and he gave me her Cooper-Rand EL which she had asked him to do. Needless to say I have never removed anyone from my mailing list since then.

The above was a little longer than I wanted but I wanted to share that foundation of my current thinking with you before I addressed the topic at hand. Why do people read or not read the monthly issue of Whispers on the Web? Our esteemed editor Pat asked that question last month and received some good feedback. Most were very favorable but one kind of stuck with me. It wasn't exactly negative but it was an accurate assessment of her personal feelings and that's fine. In essence she said that:

- I am only interested in living life as a laryngectomy.
- I am not interested in other peoples travels.
- I am only interested in question of the month that pertains to people living life as a lary.
- I am uninterested about a dog.
- I realize you are trying to get the message out to people we are somehow normal. Truth is we are not.

Ok, that's fair and many of you may share the same thoughts. But the problem we have as editors is that our interest is in the total rehabilitation of laryngectomees AND the support of those care givers so many depend on. (I'm speaking for myself and I assume that other editors agree to some degree). This is our normal! Yes it's different than the old normal but old age is different than childhood. Change is normal and when I write I want to tell stories that help everyone accept their new normal. I have been blessed with having the means to travel to many places around the world but when I write about it, it isn't to tell you how much fun I'm having, it's to let you know that to some degree you can do some of the same things also. Laryngectomees can fly on planes, they can climb mountains, run marathons, or just sit on deck of cruise ship and be normal. Travel is living life as a laryngectomee, so is fulfilling your bucket list, a tender moment with a loved one, a favorite book, a new interest such as painting or writing. Writing is a good one and we need writers as well as recommended subjects for others to write about.

WotW is for the masses as small as we may be. It's for the newbie, the caregiver, the SLP, the doctor, and the old timers that have heard everything and just enjoy a humorous story or a thoughtful poem. There are unfortunately people like the lady I mentioned in the beginning of this article that have become reclusive, feel weird or ashamed because they are no longer normal, or simply don't know that they can still live normal lives. I for one will continue to do my best to spread the word that our new normal can be a wonderful experience and our limits are mostly in our heads.

Through the years I have read many great articles in WoW and one of my favorites was by Donna McGary who has been cranking out great stories in her monthly column "Between Friends " for God knows how many years. She responded to a monthly question about "What is the greatest gift you ever received?" It had nothing to do with being a Lary, and everything to do with just being extremely talented. Sounds a little silly but it kind of makes me proud that one of us can write so well. You can read it yourself at <http://webwhispers.org/news/jan2012.asp> . In part, she writes:

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"

You just might want to check out some other past issues that you may have missed. The really good ones celebrate how great the new normal is. Choose from any month since September, 2003, all in the WotW Index:

<http://webwhispers.org/news/WotWIndex.asp>

<http://webwhispers.org/news/vvotv/index.asp>



Springtime Whimsy

My Robin Redbreast Friend

A dear little robin, with a breast of the brightest red,
flew into my garden, just waiting to be fed.

And the very next morning, he brought his wife to see,
and now I had two robins, singing just for me.

They then hopped around my garden looking everywhere,
for a hidden nest for them, and their babes to share.

They found a very old flower pot, hidden quite away,
and built their nest inside it, nearly all the very next day.

The lady robin sat in the nest, and the first egg she did lay,
until at last, five of the best, just laying one every day.

She kept them warm, both day and night,
the babes inside safe from the foxes sight,

With their little heads a-bobbing, the parents did await,
whilst that little cock robin with love looked after his mate.

Soon the eggs hatched, and there in the nest,
those chicks, perfectly matched with the pinkest of breasts.

Soon they had feathers, just like their mum,
whilst there, in the nest, and catching the sun.

But then came that day when it was real cold

But then came that day, when it was real sad,
the little chicks flew far away, leaving mum and dad.

So if a Robin Redbreast, your garden he does choose,
smile and you'll be blessed, and in life, you'll never lose,

THE SPRING FANFARE

The rising sun, smiles on all today,
my daffodils turn and begin to play,
blowing their trumpets so silent and clear,
so that all the fairy folk can hear.

Tossing their heads in the gentle breeze,
spreading their arms with carefree ease.
Wriggling their toes, beneath the ground,
avoiding those stones which always are found.

Telling the flowers, 'It's not so bad,
now spring is here, you should be glad.'
Their flash of yellow covers the earth,
giving crocus, narcissus, such joy and mirth.

Trumpeting to all, "You must today,
happily feel, glad and gay,
look up, look up, to greet the sun,
and give a smile to everyone.

Bits, Bytes and No Butts!



Frank Klett

Spring is upon us, Thank the Lord!

Time for a Spring Cleaning

Every system runs better and last longer with a regular maintenance program. After the Winter we have had, we are looking forward to the chores of Spring and on the top of the list is PC maintenance.

First and foremost I start with cleaning out and removing any programs I have not used in the last six months. If I have had no need for them in that time then they are simply occupying valuable real estate on my hard drive. Another reason to do this first is so that when I run Ccleaner to clear out dead files and rebuild the registry it will be ready. If you don't already have Ccleaner now would be a great time to download it from your favorite site or from Filehippo (just follow the link) and you will have one of the best free programs. Downloads here:
http://www.filehippo.com/download_ccleaner

While you're at it it's a great time to turn off all power to your PC and clean out the vents and fans. Eliminating the dust, pet fur, dander and other accumulated crap from the inside of our machines will help them run cooler, hence longer.

To prolong the life of your PC just follow Dave's advice and follow his pictures for a clear guide to your maintenance:
<http://www.davescomputertips.com/stay-frosty-and-keep-your-computer-cool/>

A great time for a full system backup

Too many folks think that backing up their files is all that is needed and seem to shirk the basic housekeeping needed to have it comfortable and safe. In truth, backing up your data files could not be easier given today's software and the abundance of cloud services. The days of tape drives and floppy disk swapping are gone, thank goodness! With a free software package and an external hard drive you can maintain your system in a state of automatic backup constantly. You simply set it up to backup your data directories and the rest is done constantly in the background.

Alternatively you could subscribe to a service that does much the same thing and maintains your backed up data in their "cloud" storage vaults. I, personally, do not have that much in the way of data files to require such a service so my meager needs are well met by the free cloud storage offered by Amazon, Microsoft, Google, Comodo, just to name a few. For more on free cloud storage check out Bob's article:
http://askbobrankin.com/ten_free_cloud_backup_services.html

Bob Rankin also helps to demystify backup terminology:

http://askbobrankin.com/demystifying_the_backup.html

Fred Langa from Window Secrets also has great info regarding backing up our data and the current revolutionary software and services available.

<http://windowssecrets.com/top-story/sorting-out-the-revolution-in-pc-backups-part-1/>

Do you Use a Cell Phone or a Phablet?

With the advent of the cell phone technology companies quickly made use of the idea of mobile data services. Don't forget to backup your mobile devices while you are at it.

Tips and Tricks!

Snowed in? Too frigid outside? Well curl up with your keyboard and visit the Webwhispers Forum to catch up on the extremes of the weather our members are enjoying. Do you find yourself wanting to have a cup of coffee with a group of your closest friends? Be sure to check into the Webwhispers Forum during the week and join the rest of us in sharing information in a coffee in the morning sort of way. All sorts of "hot" news and tips that make our lives richer and just plain fun. You'll find everything from Lary issues, life lessons, Marlene's greatest tips ever, and just plain fun with Maureen's cartoons. If you're not using this great little bit of high tech you are missing one of the best things in our Lary life. Hope to see you there. Mike's thoughts on the world through his eyes of anti-myopic wisdom will certainly engross you.

FORUM: <http://forums.delphiforums.com/webwhispers/start>

And then there is our new editor program in our Delphi Forum which Mike R has activated for us. This is a welcomed improvement in how we send and reply to messages and offers much friendlier options. You can post your wishes and photos to share with the Webwhispers community after you join the forum. Delphi's Member Services Forum will let you read all about the new features of the Delphi editor...

Frank in NJ
06/08

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