



# WebWhispers

Sharing Support Worldwide



## Whispers on the Web

A Monthly OnLine Newsletter for WebWhispers



August 2009

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## Membership Report

### Getting the Word Out

Many applications for WebWhispers membership mention how they found our site. While some found us by searching the Internet, we are recommended by SLPs, ENTs and other members who talk about us at their clubs and clinics. The best ad we have is YOU and we need your help to spread the word about the help and information you found here.

We have beautiful brochures and happily will send you what you need to hand out to your club and to leave at the doctor's office to give to other laryngectomees. You will find pictures of the brochures and ordering information at <http://webwhispers.org/services/free-brochures.asp> or just send your order to [brochures@webwhispers.org](mailto:brochures@webwhispers.org). Give us your mailing address and the number of brochures you need to leave a few samples. Some SLPs give them to all of their laryngectomee patients and some are sure to put them in a new patients packet. They can replenish their supply with one email.

There will be new members who will be here, able to find the information they need because of you. Reach out a helping hand...with a brochure in it.

### **Update on Membership**

Our membership is over 2450, after an updating of our files to clean out bad email addresses. Currently, 1660 of those are laryngectomees and other patient categories, 430 caregivers, while over 300 are SLP and Medical.

### **2010 Plans for Travel**

Watch for announcement of IAL Annual Meeting and Voice Institute in June, 2010 to be held in Jeffersonville, IN (Louisville, KY).

Shortly, we will be putting up the WebWhispers cruise page for 2010 with the Sapphire Princess cruising the Alaskan Inside Passage, round trip from Seattle.

*Enjoy,*

**Pat W Sanders**

**WebWhispers President**

**VoicePoints written by professionals**

**Coordinated by Lisa Proper, MS-CCC-SLP, BC-NCD-A, BRS-S**

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## **Voice Points: The Mission**

As I contemplated the topic for my final article as the coordinator of Voice Points, I thought back on what I would have liked to have done differently and what I would have wished to accomplish. The same thing we all do when we find ourselves at conclusion of anything. I noted throughout my term that many individuals reading VoicePoints are probably not familiar with the goals and mission of the VoicePoints column, something I should have shared with the readers at the beginning of my term instead of the end, but they do say "better late than never". Upon reviewing this mission and then sharing it with the readers, I also share my shortcomings as editor, but hopefully this analysis will assist my successor to ensure the continuing success and future endeavors of the VoicePoints column.

VoicePoints was started as a column written by professionals for professionals, in this case, by Speech Pathologists for Speech Pathologists. Despite VoicePoints being a part of WebWhispers, VoicePoints was not intended for the lay individual, although the authors are aware that non-professionals read the articles, all authors are encouraged to write "for" the speech pathologist. The rationale for this mission was to provide the speech pathologists that frequent the WebWhispers site not only the patient point of view but also a professional point of

view. The column founders wanted to keep the level of vocabulary, writing style, and the content at a professional level in order to save the professional time as well as to keep the articles relatively short and avoid redundancy. Another goal was to have authors provide citations and references to direct the professional reader to a source for additional information on the topic.

Has the mission been kept alive during my term? I believe so. Could have it been better? Absolutely! One of my many shortcomings was not having the authors consistently provide references and/or citations. I allowed this to be at the discretion of the author. I believe I accepted this as to not scare off a potential author, as authors are not easy to come by. In looking back, I should have at least required a citation even if it was just a “suggested reading list”. This would have allowed the interested reader to easily access more information on the subject while not running off potential authors!

Although, I always informed the potential author that the article was to be written for speech pathologists, some articles could have provided more technical detail and/or professional content, and once the article was written, it was many times too difficult to rework an article to do so. However, the articles were written with the professional in mind, even if they weren't as technical as they could have been. Several times topics were not just geared toward laryngectomy rehabilitation, but were geared towards how laryngectomy rehabilitation techniques could assist other populations and how treatment used for other populations could assist in the rehabilitation of the laryngectomy. These types of articles actually appeared popular to the SLP readership as I received the most unsolicited feedback and were asked the most questions regarding the article's content.

Additionally, I veered off the path a little in having other professionals such as nurses and physicians write articles which, to me, is a positive, as we need to learn from the entire laryngectomy rehabilitation team and not just the speech pathologist. Having professionals other than speech pathologists who specialize in laryngectomy rehabilitation is something that should be continued and possibly enhanced.

As I stated earlier, authors aren't always easy to find and this became especially true over the past year with my retirement from Speech Pathology. I think it is extremely important to have a variety of authors, this was another of my shortcomings as an editor, I wrote many more articles than I ever set out to. Topics themselves are not so difficult to come by but new topics are, so many times old topics were presented with a twist or an update. One thing I found intriguing was how two speech pathologists (myself, as one of those SLPs) could agree on a fairly specific topic and when I received the article, it may have been significantly different from what I had anticipated. On all but one occasion, this was highly beneficial as I ended up with either a longer article or another topic for another article. So, for those professionals who have even just the smallest inkling of desire to share your knowledge with VoicePoints, please be sure to let the new coordinator know.

I attempted to enlist the readers on many occasions, asking for desired topics, case histories, opinions, etc. Unfortunately, I did not receive the response that I had hoped for, especially from the professional community. However, there was one request for reader response which was more successful than the others. That was an article in which I presented a controversial topic and asked for both professional and patient response. Although, the SLP response was still fairly low, the response was greater than usual. There was even a physician who responded with a very poignant observation. On the other hand, there was one individual who accused me of fabricating the scenario, which incidentally, I did not. The moral, controversy is a good way to engage your readership.

I was so honored when I was asked to become the third VoicePoints Editor, following Dan Kelly, Ph.D. and Jeff Searl, Ph.D. But today, I am even more honored to have served as the editor of VoicePoints and to be able to assist WebWhispers in their mission. I want to thank WebWhispers for the wonderful opportunity to have served not only the professional community but also laryngectomees, their families, and those individuals who look to WebWhispers for guidance.

One touching letter that I received from a reader, which came from a surviving spouse, stated she had been ridden with guilt since the death of her spouse, but after reading a VoicePoints article, she had found some much needed comfort. Perhaps comfort would have been earlier achieved had the professionals treating offered her the information that was presented in the article. That type of scenario alone is worth the extra time and extra effort that we professionals put forth on behalf of better patient care for the laryngectomy patient. It is the reason VoicePoints was started, as only a better educated professional, provides better patient care. And better patient care is what we all desire for all patients everywhere.

*Lisa Proper*

### **From the Editors and Staff**

We have been delighted to work with Lisa Proper and cannot say enough about her attention to detail, accuracy, and promptness, which counts a lot with editors! We are also pleased that she has offered to stay with us and still contribute. We are planning for her to join our Library staff, where she will be much appreciated.

*Pat*

# **WebWhispers Columnist**



**Contribution from a member**

## **Nowhere Man - (I'm a real nowhere man, sitting in a nowhere land)**

*by Mike Burton,  
Middle England, UK*

### **Help (I need somebody, not just anybody, can you please, please help me)**

During one of my routine visits to the hospital I enquired if I was going to get new dentures as I was now without any teeth at all. I was initially told no, another UK NHS cock up. Susie had an argument or two with the maxillofacial unit since they had broken my jaw in the first place to gain access and allow for the surgery to happen. I had not changed the shape of my mouth, they had. Eventually I was told to report back to max-fax (as they liked to be called) and a date and time was arranged. When I arrived for my appointment I was told by the orthodontist that as a result of my surgery my mouth size had changed, although I knew this anyway. This was not rocket science to understand when you could not get your old dentures in!

I was seen on numerous occasions by the orthodontists who undertook the process of creating new ones for me. God knows how much this cost. I went back and forth, including that horrible glue type substance that creates the mould in the first place. After a number of visits with a tweak here and there, I eventually got to the stage where they picked a tooth colour to match my skin tone, finally producing a set which looked really good. These were not ordinary dentures, but were the top end of the business, I could put them in and they would stay there, no adhesive required! They looked great. I was really pleased with the end result looking in the mirror at the hospital.

When I got home and tried to eat, I could not. There was not enough room to accommodate food. Susie got in contact with max-fax and explained the problem I was having and they had me come back in. Over a period of

time, they tweaked and ground them down as best as they could. They stated that a 'normal' person could get three fingers into their mouth. As a result of my surgery, I could not even manage two. Therefore, I was in a position where I would have to take them out to eat and put them back to look good. Yeah right! Look good? That's a joke in itself! I gave up in the end. They are now, and have been for a considerable amount of time, in my drawer in the bedroom.

Admittedly, the facial swelling had not completely gone down, but it was much better. One nipple was higher than the other and I also had a third one that is lower, where there must have been a bit of surplus skin that they could not put anywhere else. It was strange looking into the mirror at first, made me feel my head was tilting on one side; why is that nipple up there I would think. I don't even notice it anymore; no point in panicking, is there? They will always be a part of me now.

## Epilogue

After all of my treatment and visits to the hospital, Susie and I were at loggerheads for different reasons; my smoking and her continually banging on about it and the effects it had on her and the family. Our arguments were still continuing. There would be no going back. I was considering divorce. I just wanted out. There was hostility over what Raymond should get out of our breakup. After all he was not Susie's child, just a part of our marriage, but I wanted the best for him and his family.

Susie went to her younger sister's one day (to get out of my face, I suppose) and I just sat down and began to cry my eyes out.

My world had fallen apart. Susie did not really want to know me anymore and was just interested in Thomas' and Stuart's well-being, a natural maternal instinct. I had known that smoking 20 a day was harmful but cancer was never going to happen to me, was it? Yes, it would and it did.

Then, still crying, I sat and typed this for Susie to read:

**You never know what you've had until it's gone  
By then it's too late, what's done is done  
The stupid fights, the sleepless nights  
The words of hate, not really meant  
One-upmanship, not heaven sent  
The tears that have flowed, wiped from both sides  
There are no winners, there's no first prize  
We lose what we love, and we now don't live in bliss  
Two kids to consider, do they deserve this?  
Life's jigsaw has been broken, a relationship in bits  
To pick up the pieces is anyone's guess  
All I know is my answer is YES!!!**

She read it with no comment. However, over the coming months her anger would diminish. Through it all she always made sure I got the care I needed. We had spent a good deal of time sleeping in separate rooms, which was to change. Being back in the same bed with her felt good, the warmth of her body and those ample breasts beside me again. One day we kissed for the first time in months. God how good that felt! A couple of weeks later this progressed to making love for the first time in nearly a year.

Some months later, Susie found a job through the local paper for me to apply for and I got it! At first it was fine but I was not used to working in a small environment for a couple of partners on low pay. This was not breadwinning; this was getting me out of the house and that was about it. Susie had herself returned to work which left the children with more responsibility.

I resigned as, after some time, I realised two things. Firstly it confirmed I was still in the market place for a job and secondly, that was not the job for me. I had given it a fair crack in my opinion and had lasted there for a year. I finally got fed up with the local self employed people bringing in a supermarket bag full of invoices from various suppliers and the like, for fuel and all manner of various other purchases, and income expecting their accounts and tax returns to be produced for next to nothing. I was not used to this at all but had renewed faith in what I could offer the world at large if they would accept me.

I have never returned to work since but decided to take early retirement and my old employer's pension to augment Susie's salary. I want to become a full time writer and am exploring avenues in this direction, but I will openly admit that I am not having much success, but hope springs eternal.

In all, I had 5 operations (including a pull up that had never been considered initially) 3 skin grafts, 4 blood transfusions followed by hyperbaric oxygen treatments and radiotherapy in an attempt to correct errors and cure me. I had spent a total of over 2 months in hospital beds, fighting the dreaded "C" and attempting to recover.

I think my point in all of is to live life to the full, don't give up whatever the odds are and mine I have been told are slim. I was told by the surgeon before the operation if there were 100 men standing there like me, after 5 years there would probably be only 30. By that time they assume the cancer will not return. I am just under 3 years into that moment and doing well, although I do have my off days, mostly leading up to my regular 3 month visits to see the Gerbil for a check up!.

Thank you for joining me on my journey. This concludes "From Me To You" but starting next month, I plan on writing new entries under the title "Ramblings of a Loopy Lary". I hope you enjoy them and thank you again for your support.

**Mike**



## THAT'S MY STORY AND I'M STICKING TO IT

Yesterday was a beautiful day. The kind of Georgia day that reminds me why I like it here. The heat was not due until later in the day, the sky was clear, and there was a light breeze. I had a full day but felt I could meet my deadline with Pat for my Whispers on the Web article submission.

In spite of the wonderful weather, I was in a rotten mood. My husband tried to tease me out of it but I just got more bitchy. You see I had yet another doctor's appointment and I have had it with doctors. However, this time, I thought the outcome might be hopeful. I suffer from chronic back pain following a lumbar fusion. The pain is constant but does vary in degrees. I am on medication which I hate so my PCP had referred me to a pain management physician whom I thought was going to give me an epidural shot to relieve the pain.

I shaped up because I was due to visit hospitalized stroke survivors to show them that some degree of recovery is possible and to answer questions from family members and patients about what to expect when the patient goes home. It is an activity I feel privileged to do and it always helps put things in perspective for me about how many blessings I do have.

My visits were mixed. There were some language barriers. But I tend to use my hands and face to communicate more since I became a lary, so usually I can convey a few things and elicit a response.

As I returned to the volunteer office, I pulled out my cell phone to call Frank to pick me up. The phone didn't work. I know it was charged but I couldn't get any of the buttons to respond. The phone is 4 years old which is

remarkable since the phone companies usually build in failure at about the same time your contract runs out. So I used a land line to contact my husband and went home to prepare for the long drive to the doctor's office. I left my cell at home, thinking it was no good to me and I would have to replace it soon.

When we got to the physician's office, all of the usual annoyances associated with visits were in full bloom. Filling out forms, drawing pictures of where my pain is, my surgical history, my medications (which I now have on a separate sheet of paper that they can put in the chart), my driver's license, and on and on. I am SO in support of electronic medical records to eliminate this repetitive activity!

The wait to see the doctor was almost two hours. I had not taken any pain medication because I wanted to be able to be accurate in my description of the location and intensity. So after two hours I was not a happy camper.

When we met with the doctor, he was pleasant. He started in on the usual spiel of mumbo-jumbo. Since I have a medical background, although out dated, I could follow him. Frank could not. Frank is not shy especially when it comes to understanding what is happening with me. He called the doctor on his ignoring Frank and not being user friendly in his speech. The final diagnosis was "failed back syndrome" which means the lumbar fusion was a failure, further surgery will not work, and some degree of pain will be my friend for the rest of my life. He can use various techniques to relieve the pain but there were no guarantees. Obviously today would not be the day I would get relief. Instead we got a mass of instructions: stop that medication, increase this one in increments of....., get the old CT scans, here is an order for lab work, here is an order for another scan in a new scanning machine (there are only two in the entire state of Georgia which I guess was told to us to impress us when all we could see were dollar signs), if you don't hear from this person, do this, Google for this information, and on and on.

We left the office, eyes glazed over and me fast slipping down that slippery slope of depression. In the car, which is now 100 degrees. Frank turns on the key and nothing. Like idiots we continue to try, lift up the hood as if that will provide answers to two engineering challenged adults. It is now approaching five PM but we prevail on the staff in the office to let us stay in the cool environment while we call for help.

Remember, my phone is at home. Frank has a pre-paid phone since he only has it in the car for emergencies, such as this. Frank is also hard of hearing so using the cell phone is difficult. We have a card from our local service station and so Frank hands the card and the phone to me. I try to call. The phone is empty of minutes. We can't use it unless we transfer funds into it. I get out my debit card and try again. I don't know Frank's number because it is on my cell phone which we know is at home. However he has 3 numbers taped to the back of his phone. One he says, is the number of the phone but he doesn't know which one.

I now call to transfer funds so we can use the phone. Unfortunately the person I get does not have English as her native language. I think I know which of the numbers taped on the back of the phone is the right one and I start to try to talk to this woman. It goes down hill fast. Here we are in this beautiful office with oriental cabinets, a huge fountain in the center of the waiting room, an arched ceiling that must go up 15 to 20 feet. A figure of Yoda from Star Wars is sitting on a ledge about 15 feet above complete with a lit sword. To say this is an eclectic method of decorating is to underestimate the imagination of two of the most prominent physicians in the entire Atlanta area. Oh, and don't forget the 8 foot painting with a landing on the moon, space ships, the flag at Iwo Jima, the flag raising at the Twin Towers, 2 ships crossing the ocean, eagles flying everywhere, and the Statue of Liberty standing the tallest in the center of the painting. I had to check to make sure it wasn't on velvet. Music was piped in and it was also eclectic It included symphonic, rock, popular, and at least two other genres. It is safe to say that you could suffer from a sensory overload if you spent too much time in the waiting area.

So I can't understand the poor woman on the phone, she can't understand me as a lary (probably because she still struggles with English), I am yelling as much as a lary can, she is telling me there is no account at the whole of AT&T for Frank Eorio. I am repeatedly spelling our last name because she hears "E" and "B". And I am upsetting the other patients and the staff. The sliding glass door at the reception area is going back and forth and literally slamming shut, a signal I hear.

Now Frank tries to talk to AT&T. She can understand the spelling of our name but maintains there is no account for him. I grab the phone, hang it up, ask the receptionist to call for us and believe me, she is more than happy to do so! Anything to get rid of these crazy people! But when we get ahold of our service station, they give us the name of a towing company. We use the office phone again to call the towing company and get the strong vibes from everyone that perhaps we can now leave the office. But I am concerned about not having a working phone because we will eventually be shut out of the office as the clock ticks toward 5 PM.

Once again we call AT&T. Frank is doing well, he is now using the third number on the back of the phone and

bingo! It is his number and yes, there is an account, and yes, we can use a debit card to fill up the minutes again. So the phone comes back to me and the struggle begins again. By now the battery is going and some of my numbers as I speak them come across as other sounds. I pace the area, looking for the best reception while announcing my credit card number to everyone within 40 feet. Only by the grace of God, I complete the transaction, the phone is full of minutes, I am perspiring from the effort of talking over a dying cell phone and fighting the urge to cheerfully kill my beloved husband for not keeping track of filling the phone.

It is 5 PM and the office is closing. To their credit, they did not physically throw us out but gently push us out by shutting off the lights and the air conditioning. So we find ourselves sitting in the dead car, all doors open, thirsty, tired, and overwhelmed with the results of the physician's visit. And the clock is ticking, and ticking, and ticking. All of a sudden it dawns on me that we gave the towing company the wrong number for Frank's phone! So Frank calls, gives him the right number and asks when he will be there. He kindly reminds Frank that it is rush hour in Atlanta and he is stuck on Highway 85. Frank resorts to pacing and smoking. I sit and worry.

At almost 6 PM the tow truck driver calls and says he is just minutes away. Thank you dear Lord!!!! Soon we see him pull up the hill. He jumps out of the truck, gives me a hug because he knows I have been in this situation due to a doctor's appointment. His name is Tim, he is energetic, cheerful, considerate, and competent. I believe he is my guardian angel! He offers to try to jump the battery but Frank is worried that we might get caught going home so the decision is made to tow us all the way across town during the end of rush hour traffic.

After literally pulling and pushing me into the cab of the truck, with Frank following, we are off! Wow! Quite a view from that high up! And such a strange feeling to have nothing like a hood in the front so you look over all the other vehicles and come right up on their tails. Whew! Tim is obviously a great driver but with that size truck and our car on the bed in back, the weight is significant. So when we hit a bump, we leap off our seats and almost hit the ceiling of the cab. The trip back down to the seat is a solid and rattling one. I am exhausted, worried about all the money this and the car repair will cost, and upset about the outcome of the doctor's appointment. So I am getting pretty goofy. And it occurs to me that I left an appointment to get relief for back pain and as I ride in this cab, with my fanny jumping up and down, my back is probably either being cured or injured beyond repair. And I start to laugh as I am hanging on to the ceiling to try to steady myself. It is a good thing larys laugh quietly so no one hears me over the engine noise. But I think I am losing my mind.

We bounce along through traffic, I am fascinated as the traffic parts for us, and we finally arrive at our service station. Now all the time we had in the truck, my beloved Frank who is a master at drawing people out, learns that Tim, the driver, is working on a non-profit for kids to try to keep them in school. Frank is hooked as am I. So we ask Tim to take us home and come in to discuss his non-profit.

Annie, my dog is hysterical. We have been gone since 1:00 in the afternoon and she is upset which she demonstrated by relieving herself in the basement. She won't stop circling all of us with her favorite toy in her mouth and I swear I can see her shedding before my eyes.

I can only imagine what my elderly neighbors thought of this huge tow truck backing into our driveway at 8:00 at night! They probably think our car is being repossessed :<)

Tim is very engaging and we spend several hours talking about the President, the black community, because Tim is black, the non-profit he wants to get going, and the rest of the problems of the world.

At 11 PM Tim leaves. I look in the liquor cabinet. Nothing there. Don't want Frank's wine but really want a drink after a convoluted and exhausting day. All I have is beer from a micro brewery which I proceed to have not one, but two.

We had not eaten, we cut up some cold meat and cheese, but almost fall asleep eating it. To bed, but not before note to self:

Call my PCP with a request to increase anti-depressant drug  
Do research on suggested treatment  
Buy another 6-pack  
Apologize to Pat

That is my story and I am sticking to it!

**Vicki**



## **Make New Friends, But Keep the Old, One is Silver and the Other Gold**

Back in the day when I was at Girl Scout camp singing that as a round in between ghost stories as we poked a campfire, incinerated marshmallows for S'Mores and swatted mosquitoes, I thought I understood. I made new friends at camp every year and I still had my "home girls"...although back in small town 1960s Maine that phrase would still be decades in the future. Still I did appreciate the fact that friendship itself was fickle. One smart alecky hand raised too fast in class, one loud snort of laughter not muffled soon enough in a sleeping bag and you, too, can go from king of the hill to bottom of the heap faster than it takes one troop of Girl Scouts to sing one round of Make New Friends.

Thankfully, we don't stay eleven forever. I have learned that adulthood, even middle age, has its perks. I actually loved singing rounds and got annoyed with those kids who kept coming in at the wrong time or singing the wrong part. I was a bit of a twit, I admit.

One of those perks is discovering that even a twit has friends and some of those silver and gold friends are on FaceBook....along with a few boys and girls of less precious metals who were, shall we say, unfortunate mining accidents.

Oh, but those gold and silver friends. They are a treasure trove. Unsympathetic husbands, difficult children, unreliable lovers, tyrannical bosses, dead-end jobs, midriff bulge and holes in the neck...life sucks sometimes. But my old gold and silver girls keep me going.

Cats are also helpful...I recommend two...at least.

But it is the pure beauty of unvarnished friendships surviving 30 years and 3,000 miles of separation suddenly popping up like messages in a bottle. Who knew?

My boy is 33 now and has a baby daughter- one recently reconnected friend's boys are in college and she needs to get a divorce. There is so much we missed and yet it seems like only yesterday my son was playing with her son, acting the big brother and showing him not to be afraid of our Golden Retriever. Our Sheppie is long dead and their own Golden is now grey muzzled and slowing down.

She struggles to understand the hole in my neck and I watch her try to be brave when I cough. I struggle to understand why she stays in a loveless marriage and try to be brave as she flounders. We meet up with another

friend from those old newspaper days and offer sympathy and love as we learn more about her teenage son's battles with his identity and mental and psychological issues which may well affect him for the rest of his life.

We hear that the fourth of our old cronies, now relocated to Hawaii and temporarily without internet service, had to put one of her beloved cats of 19 years down and we laughed and cried as we remembered the "Pussy Shower" we had for her back when she adopted those little kittens. This friend never married and had no children and she was always very generous at the wedding and baby showers which, for a time, seemed like a weekly occurrence in our office. We felt her "new motherhood" should be equally honored.

This reunion was magical...and precious.

I learned about WebWhispers in 2003 from a new friend I had made because of my cancer. I went on my first WW cruise in 2004, making many more new friends, and attended my first IAL Annual Meeting in Boston in 2005 where I cemented some of those friendships and forged new ones. I even wrote in one of my early columns that the IAL AM and WW Cruises were like sleep-over summer camps for larys...but without the campfire renditions of "Kumbai Ya"! HAH!! Little did I know.

I now have lary friends all over the world and thanks to the internet and, yes, even Facebook should get its props, I can, on a global level "make new friends and keep the old".

Interestingly enough, I have learned pretty much the same lesson from both my old and new friends; that perhaps the hand that I have been dealt is really not so bad. My California Girlfriend remarked thoughtfully, surveying my cool new "mother-in-law" digs and watching me elicit giggles from my grand-daughter as I played "Buzz the Baby" with my Servox, "Your life really has turned out so amazing".

I think she's right.



## Naked as a Jay Bird

You might reasonably assume that the title refers to how we survive the 111+ degree heat for days on end here in Southern Arizona while getting through the humidity of our official "Monsoon" season from June 15th – September 15th.. Going nude at home is tempting, but not practical for many reasons. I leave that to your imagination. Sweat is one consideration. Frying bacon is another. Air conditioning is literally a life saver during the hottest part of the day, but due to the high cost of electricity it is used in moderation. Lightweight cotton clothing and swimsuits are

essential here. Only a few more weeks until we are back into the “dry heat” that native Arizonians brag about to their northern relatives and friends all winter long.

No, I am referring to a daily life that is as simple as possible for a laryngectomee. No shower collar, batteries to charge, or attachments to glue on. That was my personal goal.

For several years I've used the double meaning title of this column “Practically Speaking” for a reason. Since I am a lay instructor and have been living as a laryngectomee for over three decades I write and speak about all kinds of issues focused on practical living. Hopefully I succeed in doing this with humor while providing the basic information we all need at some point.

I am a firm believer in K.I.S.S. (Keep It Simple Stupid). That is hard when we are talking about such a serious surgery and change in lifestyle during rehabilitation. In the beginning we all pretty much assume that we will remain a patient in some way for quite some time. We just hope the surgeon got it all, if it was due to a form of cancer. Next we hope we'll heal well enough to look presentable and be able to communicate in public again. That short list is a tall order the first few months. It can take a year or more for some folks to master the basics. I know. It took me awhile to master them, but I did because I was always reassured this is doable.

There are things to learn about how our body works that we never had to pay attention to before. Recently some folks have been asking about causes for nose dripping. The nose drip may well be caused by allergy, but there may be a more simple explanation that doesn't require any medication. If you notice the dripping/running nose after a coughing bout to clear your trachea in the morning it is probably do to the action your body goes through to cough really hard. There is a positive/negative effect on the passages of the anatomy that will blow out the sinuses, causing the nose to “run” for a few minutes. Yes, your nose, mouth and esophagus are still connected and work well together as they did pre-op. Even without the puncture that allows lung air into the esophagus we still put enough pressure on the esophagus when we cough to cause a bellows-like action. Check out what you were doing just before your nose started to run.

Another problem more than a few have asked about is excessive burping. It has been explained a few times from the perspective of TEP users, but as an esophageal speech instructor I have a different take. Even when we still had our larynx we used the air from consonants as we spoke. For example: the air from B & P went out as sound, but an equal amount of air fires back into our mouth far enough to be used for speech along with lung air in the segments of the esophagus. Think of the commercials that have the fast talking person read the fine print disclaimer in seconds.

Whether you use an electro larynx, esophageal speech, or a TEP you are using some air from consonant injection. EL users will occasionally hear a double phonation as the air they are unaware of injecting as they speak is suddenly released with a long vowel sound. The EL tone and the ES voice can be heard at the same time. SLPs love this clue during therapy. My point is that as we speak we are loading the esophagus with air, especially if we have learned to exaggerate as we enunciate. When we try to speak louder we really hit those consonants like K off the back of the tongue so hard it is like firing a cannon of air down your esophagus. That is guaranteed to fill your stomach with air and soon the burping will begin.

I've read with some interest the whole matter of brushes that work to clean prostheses and do or don't come apart as a worry along with the issue of adhesives and baseplates. As I walk away from the computer I usually wonder if anybody, professional or lay volunteer, has mentioned to the newest laryngectomees that many of us have survived very well without all that “stuff”. Certainly there are those who require such products for health reasons. However, most of us have options that we may not know about. It is unfortunate that these options aren't always explained pre-op or soon after the surgery during rehabilitation therapy sessions.

It may come as a complete surprise to the newer laryngectomees that there are many “old timers” who live their lives very well “Naked as a Jay Bird”. Perhaps we tried to follow well meaning suggestions and purchased a shower collar, or requested free samples of foam stoma covers and HME samples to try. The vendors are very generous about letting us try anything if we ask for a few samples to get started. That doesn't mean we all ended up using them as a matter of habit. We found our own way of handling our needs.

Does one size fit all? NO! Not even if we were discussing hats, tee shirts, cars, or golf clubs. We have options

available to us as we rehabilitate. Am I advising everyone to stop covering the stoma? NO. There are as many ways to cover as there are reasons to cover, especially when out in public. What I am sharing is the notion that we can survive quite well without worrying that something awful will happen to us if we don't try and/or buy all the available stuff. Try them all so you can make an informed decision about what it best for you in any given situation.

Wonder if I'm a nudist or an exhibitionist if you will, but it has always been important to me to be a self-sufficient survivor. That was the driving force that moved me to master esophageal speech. My reward came when I was able to transition from using my electro larynx as my primary method of alaryngeal speech to using esophageal speech all the time. My electro larynx is only used for demonstration purposes while teaching or speaking to classes now. I have to remember to keep the batteries charged or replaced since the devices I own are used so seldom now.

This means that I am hands free as an esophageal speaker, unless I am addressing a large group or someone with hearing loss. My amplifier is the only gadget that I rely on for public speaking. With the model I prefer I have the option of an handheld microphone or a headset microphone. In auditoriums and classrooms that have microphones as part of a built-in speaker system I am comfortable using their equipment.

Those of us who enjoy water activities may or may not cover the stoma while in the pool area. I've made a waterproof stoma cover out of a piece of mother-of-pearl bar that has a hole on each end. It covers my stoma well enough and there is no drip to contend with as I come up out of the water. We know we can swim and dive one handed while the other hand occludes the stoma. Using the Larkel, Lift Jacket and other equipment are all great options to enjoy while getting back to the water, but none are necessary to enjoy the water safely. Never swim alone. Drinking alcohol while swimming can lead to forgetting to occlude the stoma. It's happened.

Been skinny dipping lately? It is possible to live as a laryngectomee Naked as a Jay Bird or in a swimsuit for the faint of heart.

***Elizabeth Finchem***



## **BITS AND PIECES**

### **1. Trash**

In the mid- 1990s, I began to use garbage\* as a source of materials for my art. I collected stuff around my studio, located in an abandoned Wadi Saliv area of my city, where many of the inhabitants have the habit of dumping their trash right on the streets.

I started by using found wires to construct skeletons of balls. I then placed, without selecting or planning, anything I could get my hands on from these collections into the balls. The idea was to create entities that operate like my own brain; each ball is filled with a variety of unimportant things – bits and pieces of objects that once had a specific function. In order to bring it closer to my concept of the mind, I also inserted into each ball a small something which I considered to be "important" or "essential".

In the final state I covered the balls with a sort of artificial cobweb, and they have all been hanging from the ceiling of a small room in my studio ever since then, living there like cocoons, loaded with genetic information, and waiting. When people come to my studio, I let them into this room and play a tape with sounds of breathing, heart beats, whispers and groans.

## 2. Objects

While working on the "brain balls", I used to put together small fragments of trash to create strange, absurd, sometimes funny, sometimes ridiculous, objects. This process seemed to me like an experiment in alchemy, where there is a chance for the trash to become "gold" or at least to turn into something worth more than the total sum of its parts.

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\* Garbage – something that even a collector of junk will not pick up



Hieroglyphs of Reality (Brain Balls), The Open Museum, Tefen, Israel, 1999



from the series  
Sardine Cans Bible (the Ten Comandments)



Recycled Drawing with Brush



Book and Bone



Fetus 2



Periscope



Mountain Breeze





Recycled Drawing



Recycled Drawing 1



Anepia



## 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 32 new members who joined us during July 2009:**

Gerald F. Akerman  
Manahawkin, NJ

Geraldine Ackerman - (Caregiver)  
Churchville, PA

Jessica Allen - (Caregiver)  
Baltimore, MD

William Allen  
Baltimore, MD

Andrew Becker - (vendor)  
Carpenteria, CA

Bill Brine  
Squamish, BC

Amy Chandler - (SLP)  
Little Rock, AR

Doreen Towsley-Cook - (Caregiver)  
Waterloo, IA

Gerald (Jerry) Cook  
Waterloo, IA

Megan M. Emery - (Caregiver)  
Tyrone, PA

Barbara Georgia  
Sparta, TN

Jay Gunn  
Buda, TX

James Hegg  
San Andreas, CA

Eric Jemetz - (Caregiver)  
Brooklyn, NY

Gerald Kamprath  
Plano, TX

Ghada Ahmad Mazari  
Amman, Jordan

Kelsey Meiring - (SLP)  
Bloomington, IN

Travis Montgomery  
Pasadena, TX

Gloria J. Morris  
Philadelphia, PA

Ray W. Morris  
Wildwood, FL

David Nealey  
Beverly Hills, FL

Marian Nealey - (Caregiver)  
Beverly Hills, FL

Karen Price  
Thomasville, GA

Pam Roufs - (Caregiver)  
Mapleton, KS

Marilyn Schlossberg  
Providence, RI

David A Schmidt  
Rochester Hills, MI

Stacey K. Sellers  
Tyrone, PA

Brenda Throckmorton  
South Boston, VA

Nematollah Valizadeh  
Staffanstorp, Sweden

Sahar Valizadeh - (Caregiver)  
Staffanstorp, Sweden

Stephen Wannamaker  
Brooklyn, NY

Harold Williamson  
Valk Caron, Ontario, CAN

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

**Managing Editor - Pat Wertz Sanders**

**Editor - Donna McGary**

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