

WebWhispers

Sharing Support Worldwide
Throat Cancer and Laryngectomy Rehabilitation



March 2015

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FEEDBACK



Neckbreathers more susceptible to Dehydration?

I have an idea that we could be at more risk than most. In our group someone mentions going to the hospital with dehydration and we get a larger number of answers than would normally be expected. Why? Well, we accept that a normal situation is for a lary to have a dry mouth. It is listed as one of the major side(after) effects of this surgery. We have a lot of yeast which means dry hair and skin.... as does another not so small problem, hypothyroidism. We are dry and need to constantly cover the stoma with HME (remember what that stands for, Heat-Moisture-Exchange) or wear a cloth cover... dampen it or breathe in extra moisture from sprays and machines. Some will put a foam cover under the cloth cover to help.

Look at how we exhale, If you could see it, the misty moisture is flowing out of your body with every exhale. We are exhaling almost directly out of the lungs, with maybe near 100% relative humidity, which is a lot higher than the humidity in the area outside of us, which may be 70% or 20%. Think of going outside in really cold weather and how the moisture makes what looks like smoke coming out of us... That is LOST water vapor. What you breathe back in may be considerably less. Every year when the heat comes on, we get an uproar of questions about colds - flu - coughing - dried mucus - increase of mucus. That is our lack of moisture. We also sweat, even in the Winter, and excrete more moisture that needs to be replaced. Summer is worse about sweating.

So are we thinking the lungs and trachea are the only parts of our bodies that need that moisture? We are losing moisture every breath we release. It affects the whole body. What do we do about that?

EMedicinehealth.com gives basics to watch for: Mild to moderate dehydration may include the following:

- Increased thirst
- Dry mouth
- Tired or sleepy
- Decreased urine output
- Urine is low volume and more yellowish than normal
- Headache
- Dry skin
- Dizziness
- Few or no tears

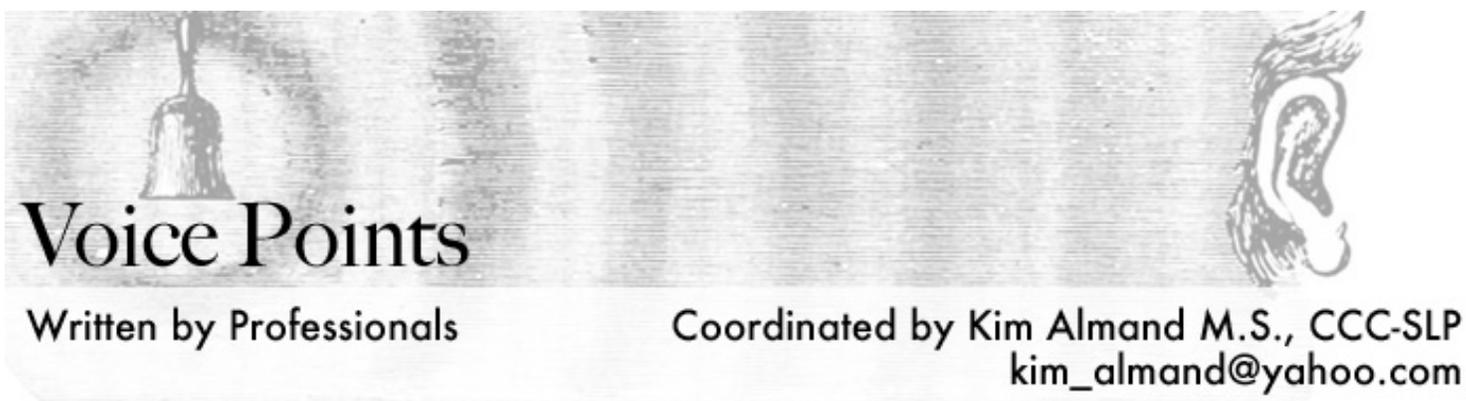
1. We need to protect the moisture we have from loss as best we can. Fever can dehydrate you, vomiting and diarrhea are a common problem prior to dehydration. Find out what is causing it and get it stopped. See

Doctor

Doctor.

2. Replace moisture each way we can think of in our regular life, summer and winter! We have written many articles in WW about adding a humidifier, using spray bottles of water, steam from kettles and showers. Bring moisture into your life.
3. Consider taking Pro-Biotics for a healthier intestinal balance and know your electrolytes. Mainly the ones they watch are Calcium, Magnesium, Sodium and Potassium
3. Watch the meds we take that make us excrete liquids. Any medication that has a diuretic in it can be dangerous but if you have high blood pressure, you are likely on one. If you have dizziness, weakness and are tired, you should check with your doctor about your meds (those same symptoms can also be other problems. For instance, they are usually part of being hypothyroid.) Diabetes can also be a problem.
4. Check what you eat. Soups, salads, veggies put more water into your system than most other foods.
5. Check what you drink. Water is best. Caffeinated beverages of any kind cause you to lose more water. So does alcohol.. and sugary foods. But we have people on PEG tubes and they are likely to not get enough water. Many of us have swallowing problems and can't gulp down water! Others have leaky prostheses and avoid drinking liquids often because of leaks!
6. Weigh yourself every morning. If you weigh a couple of pounds less than yesterday, drink water! You have likely lost that much moisture.
7. Exercise, but be smart about it. Drink water before, during and after. If you sweat a lot, drink even more and maybe with electrolytes in it. (Watch the sports drinks with sugar!) I have seen tablets that can be added to water to help replace. I am going to make them a part of my medicine cabinet.

Enjoy,
Pat W Sanders
WebWhispers President



Voice Points

Written by Professionals

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Fatigue as Side Effect of Cancer and Its Treatment

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The diagnosis of head and neck cancer, as well as its treatment may result in many changes that significantly influence one's everyday life. While changes related to communication, eating, swallowing, and airway protection are common concerns for those who undergo total laryngectomy, a variety of other changes that are less frequently acknowledged do exist. More importantly is the fact that these less well-acknowledged changes create substantial challenges for many in the post-treatment period and over the longer term following the completion of treatment. One of these important additional problems is that of "fatigue".

Fatigue is a unique condition that affects the body in many ways. But, it can be difficult to define or identify exactly what we mean by the term fatigue. Additionally, fatigue is a generalized condition that can present very differently from person to person. For that reason, many questions concerning fatigue may go unanswered. This brief article seeks to address some of the unanswered questions.

What is Cancer-Related Fatigue?

So then, what is meant by the term "fatigue"? Is there a common definition used by both professionals and the general public? Is there a consistent use of this term? What differences exist in perceived fatigue between men and women? Many misunderstandings arise around this topic. Before strategies to reduce fatigue or target factors that contribute to fatigue can be initiated, clinical research must succeed in clearly and confidently answering these questions; unfortunately, issues related to fatigue have not been addressed fully in those with head and neck cancer. At face value, however, fatigue can be viewed as a symptom that may be related to physical changes. As an example, loss of appetite has been closely linked to perceived fatigue (Peterson et al, 2004).

"Physical" components of fatigue can be expressed by perceived reductions in one's energy and/or strength that may then result in the inability to complete daily activities in part or whole (Jager-Wittenaar, 2010). These types of problems can lead to feelings of frustration for the person. In this sense, physical fatigue can become an emotional or cognitive (mental) problem as well. Thus, it is very important to note that fatigue is not a simple term; the condition transcends the borders between one's physical and mental feelings. Fatigue affects more than just the physical body and the ability to acknowledge the emotional and cognitive aspects of fatigue is very important (Perdikaris et al., 2009). Fatigue may influence a wide variety of activities that we may often take for granted, the types of tasks and activities that all of us need to complete everyday such as bathing, household chores, cooking, etc.

What Does the Research Say?

In the cancer literature, the term fatigue is expressed as cancer-related fatigue (CRF). The National Comprehensive Cancer Network (NCCN) defines cancer-related fatigue as "a distressing persistent, subjective sense of physical, emotional and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning" (NCCN, 2011). In other words, there is no obvious reason for the fatigue, such as increased physical activity. The literature also mentions that this type of fatigue cannot be improved with rest. Thus, one can see that fatigue is not a simple concept, nor can it be defined in a simple, "one-size fits all" manner.

Fatigue and the Laryngectomee

As noted earlier, head and neck cancer presents a variety of special challenges including problems related to physical changes, difficulties with eating, and communication barriers. These unique challenges can also affect fatigue, a relationship that is infrequently considered. For example, if one is forced to switch to an all liquid diet, it may be difficult to maintain weight and keep energy levels up. Because fatigue may emerge in completely different ways for different people, attempts to measure it must consider “functioning” at a global level. Regardless of its underlying cause, the perception of fatigue has been shown to relate directly to one’s assessment of their own quality of life (QOL) following treatment for head and neck cancer. Cancer treatment will almost always result in physical changes, but it is also well-recognized that cancer also brings significant psychological and emotional challenges. We must also then think of the body-mind connection when seeking to better understand fatigue.

Because the wide variety of side effects that may accompany cancer treatment, fatigue is sometimes seen as the result of other side effects such as nausea, vomiting, dehydration, and poor nutrition (Duncan et al, 2004; Jager- Wittenaar et al, 2010; Singer et al, 2013). Thus, fatigue may be a side-effect of side-effects! Although there have been some efforts to specifically measure fatigue in individuals with head and neck cancer, the impact of this type of fatigue on each individual is less understood. It is, however, clear that fatigue in those with head and neck cancer in general, and those who undergo laryngectomy specifically is an important problem. When fatigue is not addressed, work conducted in our center suggests that fatigue negatively influences QOL (Scott, et al 2014) which may in turn lead to increasing levels of distress (Bornbaum et al, 2013). Distress in turn creates additional challenges to one’s perceived QOL.

Conclusions

What is the future direction of clinical research related to cancer-related fatigue? If we can better understand what comprises fatigue and how individuals are affected by fatigue, care programs can be improved. If the factors that influence fatigue can be identified on a personal level, we may be able to provide more in depth counselling and guidance to those diagnosed with head and neck cancer. The goal of this would be to reduce fatigue and symptom burden and improve one’s short- and long-term QOL. Perhaps one or more underlying contributor(s) will be determined. However, by simply seeking to identify the presence of fatigue, health care practitioners may have a better sense of what questions to ask and which symptoms to target. Further, when identified, counseling or medication could also serve to lessen certain types of fatigue symptoms. Yet identification of fatigue is the first step toward identifying ways to alleviate cancer-related fatigue.

Clearly, seeking to better understand associations between fatigue and QOL should be investigated and information related to the types (e.g., physical, emotional, etc.) and the specific impact that levels of fatigue may have on one’s QOL are essential. With increased rates of survivorship, identifying and monitoring fatigue becomes even more important. Our clinical research will continue to work toward improving our understanding the impact of fatigue as a critical QOL factor and seek to further understand its influence on well-being and QOL following the diagnosis and treatment of head and neck cancer.

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Long Distance Friends

This month will mark the 11th year I have been writing a column for Whispers on the Web. It all started when I met Pat Sanders on my first WW cruise back in 2004. Those first entries were excerpts from the journal I kept during the early months of my journey through diagnosis and treatment. Reading them again now I am struck by how far I have come- both in my new life as a neck-breather with an EL voice and as a writer. The two seem to go hand in hand.

I always wrote stories and very long “book reports” as a child and I continued to enjoy writing as an adult but it was pretty much for myself or maybe a little story for a family member. My best friend loved my tales and was my biggest fan. She always was the one saying “You really ought to do something with this.” But that was about as far as it went.

When Pat offered me a chance to “publish” in the newsletter, I jumped at the chance. It turned out to be a wonderful opportunity for me. Through this association I have worked with people from around the world. I have become friends with writers from England, Ireland, Scotland, Israel and the US. Most of them I have never met in person but we became friends through WW , the IAL and the internet. My life is richer and my writing is better because of them

...writing is better because of them...

From Rosalie Macrae, an accomplished journalist from Scotland I came to understand George Bernard Shaw's famous observation that "England and America are two countries separated by the same language." I miss her wry and witty take on life. I was introduced to a new perspective on Marcel Duchamp through Israeli artist Avraham Eilat. I have learned about the extraordinary experiences of Londoners during WWII and subsequent "True Tales of a London Bobby" from Len Hynds. Now I am discovering the calming beauty of mindfulness from Scottish writer, Noirin Sheahan. From American writers like Dennis Holte who explained a laryngectomy as "Just a Plumbing Job" to Nancy Blair's wonderful piece, "I Married One" (still two of my favorite columns from guest columnists) there has been some outstanding writing in our humble publication. I am proud to be a part of it.

Some months I feel inspired and write something I really like. Other months I struggle to put even a paragraph together and just when I am ready to throw in the towel someone writes back to me and says how much they enjoyed something I wrote. Or I go to the IAL and I meet in person one of my "long distance friends". The internet has both expanded our horizons and narrowed our distances. I can't wait to meet some of these new/old friends when I go to Baltimore for the IAL meeting this June. And remember, if you are a "closet writer" this little newsletter can be a safe and welcoming opportunity for you, too. We always enjoy hearing from new folks. Each one of you has a unique perspective on our new life and everyone benefits when you share your story.

Contributions can be sent to us directly at editor@webwhispers.org

Until then, see you on the internet.



**Do you use an HME?
If not, why not?**

Note from the coordinator:

We generally try to leave most responses to "Speaking Out" pretty much as is with some editing for spelling, typo's, and to keep the response "on subject." This month's question was in regard to HME's, and based on

some of the responses we thought we should clarify exactly what an HME is, although some may disagree. In one case a response was rejected because it appeared that they thought an HME was a prosthesis and compared it to an electrolarynx. There were also references to handsfree vs manual HMEs, which is assumed to actually be handsfree valves for speaking. So, to clarify for possible "newbies" or others that have never seen an HME, the following is offered:

HME stands for Heat Moisture Exchanger. In theory it could apply to any device that to some degree helps keep moisture in the stoma, returns some moisture to the stoma, and warms colder air entering the stoma. A simple foam filter or cloth cover does this to some degree, but the most effective product that coined the name "HME" is a cassette filter that can be inserted into a stoma button, tube, a base plate it can be attached to, or a hands free valve designed to allow HME's to be attached to. It is just special filter, it has nothing to with speech other than it helps some people occlude their stoma better, and it is not inserted directly into the stoma. Sometimes the terminology can be confusing, and I hope I didn't make worse.

Joe McGoff, Houston, Texas

Joe here. Lary since August, 2013.

I have used a variety of HME systems since I received my indwelling TEP. Have used manual and hands free. Both Provox and Blom-Singer, probably the 2 most popular brands of HME's. I do not wear a base plate or use any adhesives. I made this decision for a couple of reasons: 1) it's expensive. Base plates, adhesives, lotions and all the other peripherals are a continuing cost. 2) time. It takes time to put all that rigmarole on in the morning and time to remove it at night. 3) the most important reason in my opinion "keep life as normal as possible". I decided early on, once there appeared to be a chance I would survive an extreme stage 4 cancer (which was by no means certain) I wanted keep my day to day life normal. The surgeon left a small rim around the stoma when he created it so the proper size lary button or lary tube would fit snugly. I prefer my voice quality using a manual HME. I also use both the Provox Hands Free and the Blom-Singer ATSV Hands Free. Each hands free HME works on an entirely different principle. And they both work for me but over time the tone and sound of my voice deteriorates. This could be due to not wearing a base plate so subsequently I may not have an airtight fit around the stoma. I am going to start experimenting with base plates to see if this may correct my problem using hands free HME devices.

I recently reviewed the specifications on the new Provox FlexiVoice Free Hands HME and placed an order. Having used both the original Provox HandsFree and the Blom-Singer ATSV Hands Free it appears to me the new Provox FlexiVoice combines the best of both devices. I am very excited to try it. It has a few unique features such as a collar which is used with a base plate to make a tighter seal around the stoma and the option to manually occlude. Now the problem I have with every single HME system. Mucus!!

I know I can't be the only one guys. I have no idea where all this mucus went before my laryngectomy but I know every bit of it ends up in my HME filter since then. I know mucus is a good thing and keeps the throat and nasal passages moist and clean but it is a real pain in the butt for us. I have tried wearing my HME's 24/7 I take 1600 mg of Guaifenesin per day to reduce the mucus I have had people tell me over time the body will naturally reduce the amount of mucus created. Well, it's been over 1 1/2 years since my surgery and the mucus just keeps coming. Should you folks have any ideas about reducing mucus I would love to hear them.

Thanks for the opportunity to "Speak Out". We can all learn from one another.

Cheers!

Mohan Raj, Bangalore, India - March 2010

I do not use an HME system. I use a bib made out of surgical gauze. I cut the gauze to the size that covers the stoma well. Often times I am able to get gauzes of such size readily available, eg: Abdomen Gauze. I stitch two tapes and tie it round the neck. It looks somewhat like what the lawyers wear when in courts. It is hygienic, washable and effective. Over a few washings it shrinks and to that extent it filters better. I keep having a freshly washed bib every few hours.

I have plenty of HMEs, but I find them cumbersome to use. It is a foreign body inserted into the stoma and to that extent it has its adverse effects. Bibs are far simpler, more cost effective and just as functionally effective as HME if not better. I have been using bibs 24/7 since my surgery and I am completely satisfied. I would strongly recommend it to all fellow Larys.

In life, simple solutions are best solutions!

Sharon Severini, Waterbury CT - November 2012

I do use the HME system.

I have been using the TruSeal Contour housings and HME cartridges from InHealth Technologies since after my lary 11/2012 and the 33 weeks of radiation after. My neck finally healed about April 2013 and I was able to get to use HME's. I tried a few different ones from InHealth and the best for me is what I stated in the beginning of my post.

I have a TEP and I have a much better quality of life with these. I do not cough all day long and the mucus production is A LOT less than before use. I wear this 24 hours a day.

All I can say is to be sure you use saline at least 2x per day and keep the TEP clean.

I have no need for a humidifier using HME's and saline bullets.

K. Alward - 2014

I'm new to Lary World. Had my procedure (total) 7/2014. Just got my TEP surgery and have had my first SLP session. It went extremely well. I was talking before the session ended. Will have a follow up next week. Currently I do not use anything during the day, just a foam stoma cover. I seem to speak much better with just my middle finger covering the stoma. At night, I insert a Lary tube to keep the stoma from shrinking. I also use a HME at night.

I'm sure we'll explore other options next week, but for two weeks with the TEP, I'm happy with the results. My procedure was done at Johns Hopkins in Baltimore.

Scott Sysum, Concord, CA - Lary Aug 2008

I had my surgery in Aug 2008. My ENT prescribed a Lary tube and Atos HiFlow HME cassette. I have worn that Lary tube and HiFlow HME ever since. Never asked if I didn't need to wear that combination 24/7 (OK when I shower I take it out) but it has served me well. Of course I now clean my HME and Lary tube, where

when I shower I take it out) but it has served me well. Of course I now clean my HME, and Lary tube, where originally I dutifully discarded my HME after a day's use, and my Lary tube after the collar holder tabs broke. So wasteful. You don't need a collar to hold the Lary tube in, it stays in by itself (most of the time).

OK, I will purchase a new set of HMEs and a new Lary tube soon, but so far all is good.

John Iwanyshyn - 2008

Hello Webbies

My name is John. I had my operation on March 5, 2008 in Mount Sinai Hospital in NYC. I will be 94 yrs. old on Feb 16. I have been using a HME ever since. I use it with a base plate, which I change about every 4 days or when needed. It will be seven years, and I feel using the HME system I have has had very few problems, I have an excellent SLP who changes my Prostheses when I feel it may be leaking. Other than that we all seem to be different, such as Mucus.

Good Health.

Bob Bauer, Hayward, CA - Class '08

Hi All,

I've been using the HME since day one of recovery. Since I use a TEP for speech I use the Hands Free HME and it took a while to control the pressure so my base plate wouldn't blow out. Now I get from 4 days to a week before I have to change the base plate, unless that sneaky sneeze catches me off guard. I don't have any problems with my skin wearing the base plate but I understand many of our fellow Larys do, and that's why they don't use a HME. The other benefit I got from wearing the HME from the beginning is that my mucus production has diminished quite a bit and is thinner. I wear my HME 24/7, except when swimming with my snorkel LOL, and change the cassette every morning.

Best regards to all my fellow Larys.

Larry D. McAnally

I am in class of 2013 and 2014. I use HME and I don't have to run anything for moisture for my stoma. I Love Them.

Carl Strand, Mystic CT - Laryngectomy February 10, 1993

I was fitted with a Blom-Singer Hands Free Valve 21 1/2 years ago. It came with the Blom-Singer HumidiFilter. This was one of the first, if not the first heat-moisture exchange filter. At the time I had no clue what the benefits were except for the catalog description of the device. This was six months after my surgery and I had been dealing with excess mucus for that time. I was back to work as a utilities engineer and had to have several stoma covers with me each day to cope with it all. Within six weeks my mucus production was reduced to manageable levels and I felt like I was a somewhat normal human being again.

All was not easy or simple. I blew the housing for the hands free valve after three or four hours initially and once home from work I just let it leak unless I had a meeting to attend. I discovered that even with a leaking housing I still had the benefits of the filter. It took over two years and lots of help from my speech pathologist.

plus advice from Rich Crum before the housing issue was resolved. I can now usually keep a seal for two days and sometimes three. I never remove a leaking housing until I'm ready to redo the seal.

I have continued to use the Blom-Singer supplies. I use the reusable housings with tape disks. I use the ASTV-2 hands free valve and I use the HumidiFilter and filters. These are all the old tried and true designs and have worked well for me. They are also the most economical system. Insurance reimbursement is less than 50 percent of the cost, so this matters to me.

Several years after beginning with the HumidiFilter system, I also bought a Blom-Singer HumidiFilter Holder which is an unvalved version of the filter system. I got it for outside work on the lawn, etc. It since has been revised in design to be smaller. After a lot of soul-searching, I started wearing it to bed. Although this was not recommended by Dr. Blom, I did it anyways. This has been my routine now for twenty years. ASTV with HumidiFilter during the day and holder in bed. I am almost never without the housing over my stoma and without a replaceable HME filter.

Jim Henderson - class of 1987

I started using HME's about a year ago. I had never heard of them (28 years out) until I joined Head and Neck on Face Book.

I need to irrigate less since using them and I cough less with them.

Mike R, Plantation, Florida - Jan '99

I do not use an HME. I live in south Florida, never had radiation, and "grew up" as a lary with a foam filter and stoma cover. I still use a foam filter 24/7, but only add the stoma cover when leaving home. I drink a minimum of two quarts of water daily. For stoma maintenance I simply lift my filter and blow. In cooler weather, like right now, I use an occasional saline bullet to maintain mucus flow, and always have a supply of bullets with me when I travel.

Malcolm Babb, Chesterfield UK

From the moment I used an HME a few weeks after surgery I noticed a difference. There were far fewer daily instances of coughing fits and less attention was needed to stoma area maintenance. Now, 12 years later, I occasionally cannot use an HME due to skin soreness problems preventing use of a baseplate. The consequence is always an increase in mucus production.

As far as pulmonary function is concerned, I can walk up steep hills as well as before my surgery. A further welcome side effect is that a baseplate and HME avoid soiling of the neck area and clothing with mucus. I am convinced of the benefits of HMEs.

Gary Gierhart, Lakeland, FL - 2013

I tried using the HME but it kept getting clogged up with mucus and I had to keep changing it so I decided to try without it and get a hib. My doctor said the hib works well for me and much easier to clear the mucus with

try without it and get a bib. My doctor said the bib works well for me and much easier to clear the mucus with a bib. I have used the bib for over two years and really like them. No more HME's for me and my mucus has slowed down a lot. That's my story about the HME's.

Wes Olsen, Santa Barbara, CA - 2012

I use a patient changeable prosthesis by Blom-Singer which has a long installation 'strap' that needs to be taped at the 12 o'clock position to get it 'out of the way' during other stoma maintenance and prevent it from 'attracting' mucus which it seems to do at the 6 o'clock position.

Immediately after my original TE Puncture and subsequent installations of in-dwelling prostheses, the SLP would cut the installation strap off close to the flange on the tracheal side of the puncture. That simple act negated the need for the tape I now have to use, as I have been advised to NOT cut the strap. Well, my experiences with HME baseplates and filters with speech buttons were, at that time, mostly good with one or two exceptions: The adhesive seal on the baseplate would "blow-out" during speech if the prosthesis became plugged with mucus; also the baseplate, at least in my case, had to be replaced almost daily which irritated skin around my stoma. After several stressful (I'm an 80 yr. old man with COPD and on Oxygen 7/24) 200 mile round trip drives through nasty LA traffic to have the in-dwelling prostheses changed every few weeks I was forced to opt for patient changeable prostheses which are a "piece of cake" to change at home and which I continue to use. I still occasionally use the baseplates and filters when in dry or dusty environments, but the aforementioned tape greatly increases the chances of a blow-out during speech, so I keep a pen and paper handy when I DO use the HME system nowadays.

We are all different, as the man has said. This is simply MY comment on MY experience. If you would like to communicate further, feel free.

Best Regards and Blessings to You All.....

Dave Ross, Edgewater, FL

I use a HME only on occasion in order to utilize my Hands Free valve and when vacuuming leaves with my lawn tractor/bagger because of the heavy dust. Otherwise I normally use a foam stoma protector and at times, indoors, no cover at all. I am ten years post opt, live in Florida and have no excess mucous or coughing problems.

My personal observation is that 24/7 use of HME improves OVERALL quality of life for some Larys, but not for all Larys. I consider comfort and convenience important elements of quality of life.

Aaron Futterman, Buffalo Grove, Illinois - 12/2010

Hello everyone,

I live in the frigid Midwest near Chicago, and I have been using the HME almost from day one, which was in

December 2010. It takes a bit of getting used to, figuring out the various types of baseplate, cassettes, adhesives if needed, etc. In the beginning it is a big ordeal, getting the baseplate on correctly and properly. A lot of frustration, but over time it gets much easier, and what took 30-40 minutes, now takes 3-10 minutes.

The suppliers, such as InHealth and Atos, are more than willing to send numerous samples. Your SLP is also your go to for any issues or help, as well as your fellow Lary. To me the benefits are great if you can use the HME, from the important humidity it provides, and the filtering of air with the treated cassette. I have successfully tried the hands free, but at present I prefer the regular cassette. I am anxious to try the new FlexiVoice by Atos soon.

Best to all.

Lorna, St. Louis - 2014

I've been a lary for 13 months. I use the Provox XtraMoist HME. I had trouble using an HME in the beginning. But now I wear it 22+ hours a day. I take it out to clean it several times a day, and to shower.

I do go to the gym to work out. I just wear a bib for that. Hate to have to drop a weight just to remove the filter to cough.

With this code weather, I do cough a lot more, so, I might go through a couple a day - when I don't catch myself in time.

Ed K - May 2014

Hi everyone. Ed K class of 2014. I'm here in Pittsburgh where it's a balmy -3 degrees. Not ideal temps for us Larys. I tried using an HME but had a lot of trouble getting a good seal due to the narrowness of my neck area. Also the glue odor was more than I could stand.

I worked in the automotive aftermarket for 43 years doing everything from driver to store manager. During that time I had to mix and color match paints. One of my customers was a helicopter repair facility. The paint used on these machines is an aviation grade poly-urethane. You can almost imagine what that smells like but it never bothered me like the glue for the baseplates does. I hope at some point they develop a glue that works that doesn't smell near as bad. Thanks for listening. Try and stay warm. Only 4 weeks until spring.

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 Case of the Lost Table Mat!

Here we are on retreat in a lovely little valley in Wales with just birdsong to puncture the silence. There are four of us (all women) and the resident teacher is away and has left the centre in our care. I'm his main support teacher. Amazingly he believes I will still be able to play this role despite my communication difficulties (I can only use an electrolarynx). I dearly hope so – my first post-lary teaching will be in May so we'll see how that goes. Anyway in his absence I have the leadership role at the moment. It's a silent retreat so I've hardly used my electrolarynx for the six weeks I've been here.

I was delighted by how smoothly things were going, and (as I saw afterwards) taking a few sneaky shots of delight in being the dependable, responsible, trustworthy person in charge of it all. So this brings me to the moment last Monday, just after breakfast, when a table mat fell behind the sideboard. Hui – always practical – started various manoeuvres to get hold of it, Sarah joined in but neither could reach the lost mat. The sideboard has a heavy granite top and they were trying to shift this out a bit when I came along and, without reflecting at all, joined in the effort. We pulled over a trestle table and moved the top onto this. But still the sideboard wouldn't budge. I thought we should take out the drawers and heavy contents so indicated to the others (no electrolarynx remember, so just head nods and finger pointing) to shift the trestle table away a bit so we could get at the drawers. Perhaps they didn't quite follow me, as somehow we weren't really coordinating well at this stage and disaster struck. As we pulled and tugged at the table, one of the legs folded, and the granite slid off and shattered! We were horrified. Trying to rescue a table mat worth about 50p we had broken a granite slab worth hundreds! Not only that, but there were now three holes in the lino where the slab fell, as well as many scratches in the trestle table.

The one bit of good news out of all this was that none of us was hurt. If the slab had come down on someone's foot that would have been a real disaster.

Our silent retreat changed into a frenzy of activity – clearing up the mess, making the sideboard functional again, trying to locate the supplier, the receipt, asking could we get a replacement top, searching for the centre's insurance documents, getting advice on repairing the lino and table etc.

To our credit, we were back to silence and mediation again a few hours later. During meditation the whole episode came back to mind again and again – dumbfounded by what had happened and at our stupidity and clumsiness, regret at the damage and for the bother to the resident teacher, worry about getting everything sorted etc. And of course, all the accompanying emotions. I had a sense of having let myself and the centre down and felt quite ashamed. My self-image of 'responsible, trustworthy, dependable' Noirin had taken a

battering! But as always, life's difficulties are our great teacher and this week has taught me a valuable lesson in self-forgiveness. I now have a new level of equanimity about my own imperfections. It's such a relief to be able to be disappointed in myself and yet at ease with the disappointment! After all I'm only human, and we humans are imperfect and unreliable.

Another lesson I learned is that a large part of the accident was due to me not being able to speak. If I had, I think we would all have talked a bit about what we were doing and not been so hasty. In hindsight there were loads of other approaches to getting at the mat besides moving the sideboard – one or other of these may have emerged if we were chatting for a while. And if I had clearly communicated my suggestion to move the table away so we could get at the drawers and heavy stuff in the sideboard instead of nodding and pointing and assuming everyone understood, then perhaps we would have safely moved the table and avoided the accident. Finally, my lack of speech could have been disastrous: as we were resting the slab on the trestle, Sarah's fingers got trapped underneath, but because she was able to say 'ouch!' we immediately raised it again and she got her fingers out. If it had been my fingers the slab came down on who knows what the consequences could have been?

In future then I won't be getting involved in work like this where you need to coordinate closely and quickly with others. This won't be easy as I love to get involved and lend a hand with things and hate to seem unhelpful or work-shy. Also, it will be difficult to explain why lack of speech means you can't help someone move a piece of furniture or whatever. When a person wants help moving something, they're don't want to hear: "Sorry I can't help because I can't speak unless my hands are free so if I was helping you carry this I couldn't communicate if I had any problem." Especially not at the word rate of an electrolarynx. It could sound like such a lame excuse and I can imagine their irritation or disbelief. But the lesson from this sideboard saga is that I have no choice but to refuse to get involved. So another cherished self image of 'Noirin, the willing, able and helpful one" will also have to take some bruises!

Lary-life is full of hard lessons! What to do but learn and act on them as gracefully as we can.



It's quite alarming to suddenly realise that you have reached the 85th year, and in your mind still thinks as a young man.

A FUNNY AGE TO REACH

By Len A.Hynds

Suddenly you're helped up stairs,
and you're walking just gets slower.
The walking stick, stops falling scares,
and you wish that kerb was lower.

Your thoughts are young. but the bodies old,
seen and done, too many things.
Your feet and hands and ears get cold,
and the body no longer springs.

Where have all the years gone,
I've watched them fade away.
Once I seemed to have such time,
but there's little left today.

But I have many memories,
now that I'm getting old.
collecting many strange maladies,
and the winters, seem so cold.

But my childhood days come back so clear,
with my three sisters and three brothers,
a magical time, forever near,
as our mum 'Angel Mary' mothers

The war, then my Tilly, those desert days,
then a policeman in London Town.
Wonderful memories forever stays,
and will never cause a frown.

Then Pat's fretful wail, as our first born,
looking so much, just like me,
the sun it shone, on her first dawn,
such a happy little girl to see.

Picnics outside, in the sun,
winter evenings making toast,
all those things we did for fun,
train and car rides to the coast.

Then Len and Nick, they came along,
we were the perfect fam-ily.
Christmas carols we sang in song,
Buckets and spades, went with us to the sea.

The boys built castles in the sand,
collecting sea shells to take home.

Tilly washing each grubby hand,
tangled hair, smoothed with her comb.

Christmas stockings, those little treasures,
all the parties and the fun,
gave the children so many pleasures
for our daughter and our sons.

It's quite nice now, to sit and dream,
and if I could have my life again,
and go back to those places I've been,
then I would love to do it again.

"This was originally written 2 years ago. We took the freedom of changing to the current year's numbers. Len will be celebrating his 85th birthday this March. Happy Birthday, Len!!"

~ The Editors~

Bits, Bytes and No Butts!



Frank Klett

What's Next?

The personal computer and the Internet have dramatically changed every aspect of our lives. We (most of us) have lived through and witnessed the remarkable and unimaginable advances over the last three decades.

Enter Windows 10

Google has been slowly eating away at Microsoft's sacred share of the operating system market place. Google has introduced their Android and Chrome operating systems while Microsoft has been trying desperately to catch up after they laid a rather udlv egg with Windows 8. The plan for Windows 8 was to

...repeatedly to capture market share they have a rather ugly egg that... of the platform... to recapture market share in the phone, tablet and desktop markets. In the aftermath of it's release, Windows 8 has been updated and given CPR to the point of not being recognizable from its original look and feel. The attempt to recapture market share was centered on a common use item called apps, short for applications. While apps are central to the phone and tablet market they have yet to be embraced by desktop users, hence Microsoft ran into a stonewall of resistance.

This is not just another version of Windows, but will very likely define the future of desktop software for years to come. The growing acceptance of Apple, Linux and Android operating systems has proved them to be worthy challengers to Windows 'hold' on the desktop market.

Microsoft has apparently learned from its one-size-fits-all approach and is hoping to recapture our hearts and bucks with the release of Windows 10. Windows 10 has been released to the tech community since October 2014 seeking the help of users and developers in providing them with direct feedback on the features and configuration. "it is only for those who are tech savvy". The stage of 10's development is maturing with each passing day but still has many bugs and holes th that need to be filled.

Windows 10 will bring back the start menu , which was a number one complaint for most users of Windows 8. The start menu was first introduced in Windows XP and has been a staple for most users who have found it to be the best road map for their Windows system. Microsoft plans on having Windows 10 available for real time users by the end of summer 2015. Microsoft has already released the pricing schedule for 10 and for all users of Windows 7, 8 and 8.1 it will be free for the first year. Bob Rankin explains the known details of Windows 10 pricing for us;

http://askbobrankin.com/windows_10_will_it_be_free.html?pcp

Windows 10 promises to provide a single user interface across your favorite phone, tablet and computer devices. So if you have been meditating a new PC or operating system you may want to wait 6 months and take a look at the Windows 10 experience. MakeUseOf offers their view on the aspects of a single user interface;

<http://www.makeuseof.com/tag/priority-windows-10-news-briefing-summary/>

Tips and Tricks

There are free software packages available for the routine maintained for your PC...Bob Rankin provides his assessments and pros and cons:

http://askbobrankin.com/seven_free_pc_maintenance_tools.html?

Stay secure by updating insecure programs on your computer with the Secunia PSI

"The Secunia Personal Software Inspector (PSI) is a free computer security solution that identifies vulnerabilities in non-Microsoft (third-party) programs which can leave your PC open to attacks. Simply put, it scans software on your system and identifies programs in need of security updates to safeguard your PC against cybercriminals. It then supplies your computer with the necessary software security updates to keep it safe. The Secunia PSI even automates the updates for your insecure programs, making it a lot easier for you to maintain a secure PC."

Using a scanner like Secunia PSI 3.0 is complementary to antivirus software, and as a free computer security program, is essential for every home computer. One of my favorite free for home users security programs is Secunia's PSI, which ensures your critical programs are up to date. This is critical to a safe system since most program updates are released to plug holes in the software that have been found to be a way for hackers to gain access to your system.

Press the download button and once it is downloaded "run" the installation package. The program is self

PRESS the download button and once it is downloaded run the installation package. The program is self installing and will scan your system for your programs. Once the scan is complete it will give you a report of your programs and of any that need to be updated. By simply clicking on the programs that need updating PSI will download them for you and begin the installation process. Once the initial scan and updates are complete PSI will run in the background for you to ensure your system stays current and secure.

You can download and install PSI by going to :
http://secunia.com/vulnerability_scanning/personal/

Got a PC problem or question? Drop me a note on the Webwhispers Forum and I will try to answer it for you .

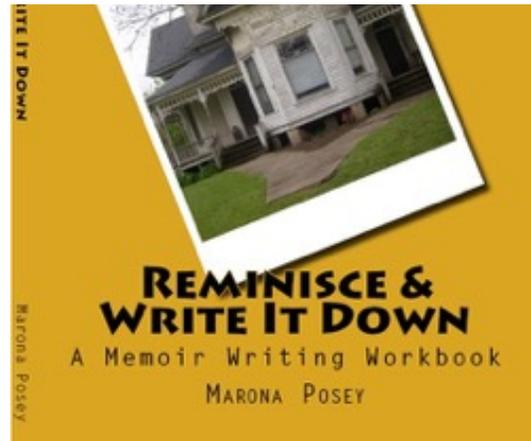
Frank in NJ

06/08



Our "Friend of WebWhispers" member, pen name Marona Posey, has been off writing fiction books for a few years. In the past she wrote articles for our newsletter occasionally. She has recently veered away from the fiction and put together a workbook to encourage others to write about what they know best... themselves, their stories, their families or their ancestors. What a terrific idea this is for us.





This is what Mercy Pilkington, CEO of Author Options, wrote about it:

"Working on this book of Mrs. Posey's was an honor because it will become a tool that can help preserve these stories for others. More importantly, I strongly hope that it rekindles the the concept of preserving our memories, that today's adults and young adults see the value not only in reading others' tales of the past but in preserving their own. The time to record your personal history is right now, before it becomes another saga of the olden days, but more importantly, before you forget it yourself. Write your story, share it with anyone you choose, and let these details of days gone by live on for others to enjoy and learn from!"

This is now available in Amazon Books:

<http://www.amazon.com/Reminisce-Write-Down-Marona-Posey/dp/1501010654/>

When you go there the preface is available to read and I found it inspiring and fun to read.

Pat Sanders

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