

WebWhispers

Sharing Support Worldwide
Throat Cancer and Laryngectomy Rehabilitation

Whispers on the Web

A Monthly Online Newsletter for WebWhispers

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COMMENT HERE
FEEDBACK



Testing for Vitamin D

Medicare No Longer approves Screening Testing for Vitamin D Levels. A diagnosis of what the lack of Vit D has caused is necessary.

I received a note from a WW member recently who said that, at his regular checkup, he asked about testing for Vitamin D levels. Medicare would not approve the test and he would have been charged \$200 if he went ahead with the testing at the doctor's office.

I had lunch with an out of town friend yesterday and she mentioned having a Vit D test. The doctor told her that Medicare didn't cover it, that it was \$400 but, not to worry, she was not going to charge her for it. I asked what her numbers were on the test and she said 12. I nearly fell off of my chair. That is Rickets level.

Symptoms and Health Risks of Vitamin D Deficiency

<http://www.webmd.com/diet/vitamin-d-deficiency>

Symptoms of bone pain and muscle weakness can mean you have a vitamin D deficiency. However, for many people, the symptoms are subtle. Yet even without symptoms, too little vitamin D can pose health risks. Low blood levels of the vitamin have been associated with the following:

- Increased risk of death from cardiovascular disease
- Cognitive impairment in older adults
- Severe asthma in children
- Cancer

Research suggests that vitamin D could play a role in the prevention and treatment of a number of different conditions, including type 1 and type 2 diabetes, hypertension, glucose intolerance, and multiple sclerosis.

"Sunshine vitamin may treat asthma"

<http://www.bbc.co.uk/news/health-22570859>

"We know people with high levels of vitamin D are better able to control their asthma - that connection is quite striking," said researcher Prof Catherine Hawrylowicz. Her group investigated the impact of the vitamin on a chemical in the body, interleukin-17. It is a vital part of the immune system and helps to fight off infections. However, it can cause problems when levels get too high and has been strongly implicated in asthma. In this study, published in the Journal of Allergy and Clinical Immunology, vitamin D was able to lower levels of interleukin-17

From the same BBC Health news letter is this:

"Action needed on vitamin D levels"

<http://www.bbc.co.uk/news/health-20710026>

Unlike many other vitamins, getting your recommended daily amount of vitamin D is not that easy. The main source is sunlight but with short days, long nights and limited sunlight even during the summer, it's not easy to get your fix that

earthing, but with short days, long nights and limited earthing even during the summer, it's not easy to get your fix that way. Vitamin D can be found in some foods such as oily fish, eggs and mushrooms - but only 10% of a person's recommended daily amount is found naturally in food. Put bluntly, eating more fish and getting out in the sun a bit more won't make much of a difference to your vitamin D levels.

Unfortunately, there is limited national research on the true extent of vitamin D deficiency in the UK population. Pilot studies and regional monitoring suggests that vitamin D deficiency is likely to affect at least half the UK's white population, up to 90% of the multi-ethnic population and a quarter of all children living in Britain.

More news that Vitamin D is crucial comes at the same time that Medicare is cracking down on paying for the screening test without a specific diagnosis.

National Institute of Health

I tried going to the National Institute of Health and, even being well read about Vitamin D, it was so difficult to read that anyone starting to learn, would never make it beyond the first page. So I looked for something that would be easier to read and understand.

<http://www.vitamindcouncil.org/about-vitamin-d/testing-for-vitamin-d/>

Having a blood test to measure the amount of vitamin D in your blood is the only way to know if you're getting enough vitamin D or not. The blood test you need is called a 25(OH)D blood test.

You can get a blood test at your doctors or you can do an in-home test or get a test at a laboratory. All of these methods of testing should give you accurate results. In-home tests are easy to use and involve pricking your finger to take a small blood sample and sending this away to a laboratory for testing.

Your tests results will show whether you're getting enough vitamin D or not, and whether you may need to take supplements or expose your skin to the sun more. Different organizations in the United States recommend different ideal vitamin D levels. The Vitamin D Council suggests that a level of 50 ng/ml is the ideal level to aim for.

(The lab that runs my doctor's tests recommends that your levels should be between 30-100. When I was first tested, my level was 24 and that was when I had been taking extra calcium and D plus a multi-vitamin and drinking milk every day with additives. Several years later, my doctor is pleased to have me in the 80s, and has told me that my supplement, probably for the rest of my life, will be 3,000-4,000 a day, over and above what I get in food or my all round vitamin or the sun. PS)

According to Quest diagnostics, this is Medicare diagnostic rules:

<http://www.questdiagnostics.com/dms/Documents/mlcp/Tool5.pdf>

And here's the Medicare policy:

- Screening for vitamin D deficiency is not covered.
- The various component sources of vitamin D (such as stored D or diet derived D) are included in one (1) 25 OH vitamin D assay or one (1) 1, 25 (OH) 2 vitamin D assay.
- Once a beneficiary has been shown to be vitamin D deficient, further testing is medically necessary only to ensure adequate replacement has been accomplished. Monitoring therapeutic replacement would not be expected to exceed 2 assays per year. Once therapeutic range has been reached, testing would not be expected to exceed one (1) assay per year.

Vitamin D, 25 Hydroxy is determined to be medically necessary by Medicare only when it is ordered for patients with one of the conditions listed here: <http://www.questdiagnostics.com/dms/Documents/mlcp/Tool5.pdf>

The page you need is:

Medicare Local Coverage Determination Policy

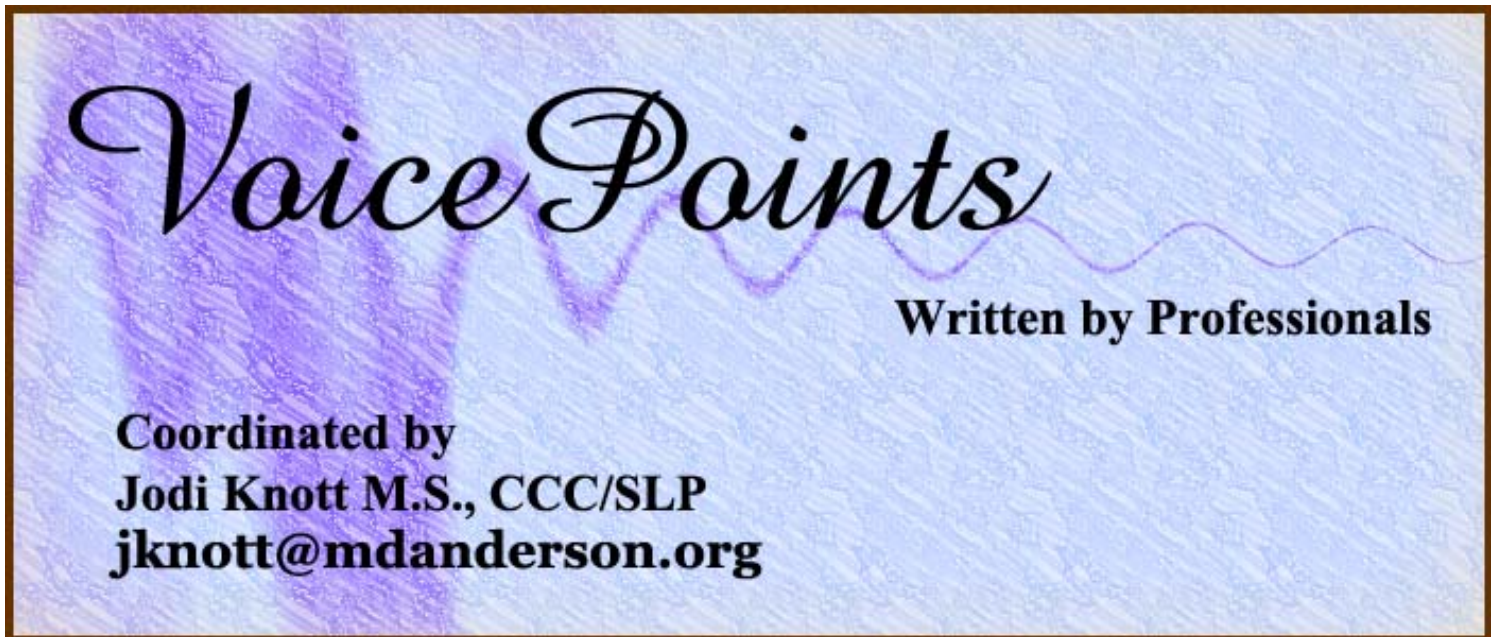
Vitamin D Assay Testing / Vitamin D, 25 Hydroxy

Data Source: <http://www.cms.gov>

Enjoy and stay healthy!

Pat W Sanders

WebWhispers President



Distress Screening as a Critical Component of Laryngectomy Care

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Introduction

Upon receiving a diagnosis of cancer of the larynx, a diverse range of emotions. Worry and fear are normal human responses to a diagnosis of any serious disease, including that such as cancer. Further, clinical psychiatric disorders such as depression and anxiety do not develop overnight; rather, they are the cumulative outcome along the continuum of mental health that extends beyond normal emotional responses and psychological reactions (Mohan & Pandey, 2002). Research has established that across the trajectory of illness – from initial diagnosis through treatment, termination of treatment, survivorship, or recurrence and palliation – psychosocial distress is evident in approximately 25% to 45% of those with cancer (Carlson, 2003; Carlson et al., 2004; Singer et al., 2012; Zabora, et al., 2001). Moreover, large-scale studies conducted at the Tom Baker Cancer Centre in Alberta, Canada (Carlson et al., 2004) and the Johns Hopkins Kimmel Cancer Centre in Baltimore, Maryland (Zabora et al., 2001) of a representative sample of individuals screened for psychosocial distress detected:

- high levels of fatigue (in nearly 50% of patients),
- depression (24%),
- anxiety (24%),
- pain (26%),

in addition to financial hardship and other challenges.

Thus, clinical screening of distress may offer a simple, yet important aspect of comprehensive health care.

The Impact of Distress

Psychosocial distress has been identified as a significant and ongoing problem among individuals diagnosed with cancer. Distress has become so prevalent that the National Comprehensive Cancer Network (NCCN) has established a Distress Management Panel to address the issue. The NCCN (2013) has defined distress as:

...a multi-determined unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness and fears, to problems that can become disabling, such as depression, anxiety, panic, social isolation, and spiritual crisis (p.6).

As highlighted by the presence of a “continuum” of distress, there is an inherent distinction to be made between the pathologic experience of distress (e.g., clinical depression, anxiety disorders, etc.) and one’s natural response to a catastrophic life event; be that the threat to one’s own life, or to the life of a loved one. Negative feelings are a normal part of the cancer experience and are to be expected as individuals react to an unanticipated threat, potential and actual losses, and to the potential side effects of unpleasant and/or painful treatments (Haman, 2008) whether treatment will entail surgery, radiation, chemotherapy, or a combination of treatments. Cancer and its treatment often create feelings of uncertainty, anticipated changes to personal roles and functioning, and practical concerns related to medical care and financial well-being. As individuals attempt to manage these concerns, they are likely to experience emotions such as sadness, anger and fear. The majority of individuals will experience brief episodes of sadness or anxiety, insomnia, loss of interest in activities, thoughts of helplessness and hopelessness, or worries about the future (e.g., loss of life) (Haman, 2008).

The Process of Postlaryngectomy Rehabilitation

While most individuals will eventually adapt to the changes brought on by the cancer experience (Vickery et al., 2003), a subset of individuals will experience distress to the extent that adaptive coping is impaired severely enough or long enough to be considered disruptive (Haman, 2008). A few days characterized by tearfulness and decreased interest in regular activities may be viewed as a component of adaptive coping to the changes and losses that are inherent in the experience for both the patient and caregiver (Haman, 2008). However, if the symptoms persist for extended periods of time – some sources suggest more than one week (Haman, 2008) while others advocate for at least two weeks or more (American Psychological Association; APA, 2000) – problems may arise with social support networks, one’s physical well-being, and influence even treatment compliance and survival in individuals with cancer (Haman, 2008).

From a therapeutic perspective, untreated depression has been shown to affect medical compliance, appetite, wound healing, and contribute to increases in length of hospital stays (DiMatteo et al., 2000; McDonough et al., 1996). Furthermore, the impact of depression on functions such as sleep, motivation and energy level are also well documented (Roscoe et al., 2007). By intensifying fatigue and weight loss, depression has the potential to amplify treatment-related side effects for individuals with cancer, contributing to a vicious cycle that may not only worsen depression and overall rates of distress, but also negatively influence disease control through decreased medical compliance (DiMatteo et al., 2000).

What Can Be Done to Alleviate Distress?

Distress secondary to a diagnosis of laryngeal cancer and its treatment can create significant disability with the increasing potential to disrupt one’s recovery and short- and long-term rehabilitation. For this reason, we believe it is critical to assess distress at regular intervals. This may include distress screenings that occur at the point of formal diagnosis, as well as throughout the treatment process. Additionally, screening that occurs after treatment is completed provide valuable information, particularly at a time when the individual begins to resume activities. It is not uncommon to see changes in one’s behavior when the regular interaction with health care providers ceases following the end of treatment. Thus, we believe that distress screening should form one component of regular medical monitoring and surveillance of one’s recovery and rehabilitation. Fortunately, several very simple, cost-effective, and

sensitive screening tools are available for clinical use (e.g., Distress Thermometer, Hospital Anxiety and Depression Scale, etc.) These screening tools also lend themselves to quite nicely to follow-up monitoring via regular mail or

years, etc.). These screening tools also tend themselves to quite nicely to renew up monitoring the regular mail or electronic mail and we have found an increasing number of individuals are willing to actively engage in providing this information. The first step in alleviating distress is the ability to identify its presence. Consequently, the clinical use of distress screening tools holds substantial potential to improve the quality of service that can be provided by members of the postlaryngectomy care team.

Conclusion

Regular clinical screening of distress may offer an important means of reducing stress and psychological problems associated with the diagnosis and treatment of cancer of the larynx. A variety of simple and very useful screening tools are available at present. We believe that efforts to gather measures of perceived distress are important to both the short- and longer-term rehabilitation process. If distress is identified, the ability to seek appropriate resources and support are enhanced considerably. Although one's response to a diagnosis of cancer is highly individualized and varies in its severity, distress itself is a normal response to any health challenge. However, the ability to identify excessive levels of distress that may then create additional problems is essential. Such efforts can serve to reduce one's distress which may then facilitate more rapid and complete postlaryngectomy recovery and rehabilitation.

Authors' Note

For those interested in additional information or a list of references, please contact Ms. Bornbaum (cbornba@uwo.ca) or Dr. Doyle (pdoyle@uwo.ca).



Thank You, Maggie!

The 2004 WW Panama Canal cruise was my introduction to the WebWhispers community and of course, Pat Sanders. After a long bus ride and conversation to and from some Mayan ruins she offered me a writing spot with this newsletter, Whispers on the Web, which at that time I don't think I had ever even read. Regardless, I admit I didn't need much persuasion. Up until then my only readers were my parents and a few loyal friends. And like most of us secret scribblers I was pleased and proud at the possibilities of some new readers.

However over time it has become challenging to come up with something month after month that I think might possibly be interesting to anyone other than my most devoted readers! So just when I think I can't possibly get away with writing about my grand-daughters again, I receive this e-mail:

"Hi Donna,

Hi Donna,

I have wanted to write to you for some time now. I joined Webwhispers late 2012 after my surgery in October 2012. I really look forward to the newsletters. One of the first ones that I read, you mentioned that you had the same type of cancer as I had, Adenoid Cystic Carcinoma. In another article I realized you were around the same age as I was when you found out about it-47. My surgery was 2 days before my 47th birthday. You talked about celebrating your 60th birthday in March this year. I shared that with my husband and 2 adult children. It gave me so much hope. In this most recent article today, you talked about your relationship with your grand-daughter. I cried as I read it and I'm crying now as I write to you but not because I'm sad. It made me so happy as one of the things that I worry about is, how am I going to sing or read to my grandchildren if and when I do have some. It's funny how we all figure out how to do things now and how the people around us love us no matter what. We 'all' seem to adapt, especially children. Your EL is just normal for your grand daughter and I guess my TEP voice (and pressing the 'button') will be normal for mine.

You are a real inspiration for me! Thank you so much for sharing your story through Webwhispers.

*Maggie Scott
2012*

Thank YOU, Maggie! I think I can speak for all of us here. One of the most difficult aspects of writing a monthly column, after struggling to find a fresh perspective and topic, is wondering if anyone reads the darn stuff and if they do, what they think about it. While we do get some great comments other times the silence is deafening, so to speak, and it can be disheartening. It is something we all experience and just goes with the territory so notes like yours are our inspiration.

My first grand-daughter was born in March, 2009. I was the primary caregiver while her parents were at their full-time jobs and I had the exact same concerns as you. I even wrote about trying to juggle a baby, a book and a Servox as I tried to read the same stories to her that I had to her father. I got discouraged when I couldn't do all the different voices of the characters or sing to her the way I wanted. As she started to babble I worried that since she spent so much time with me her language and speech wouldn't develop properly. I even wrote into the WW list and expressed my concerns asking for advice. The response was wonderfully encouraging. One SLP wrote to clarify the difference between language and speech development. Everyone basically said the same thing. She's going to be fine. It's the love that gets communicated and the voice it's done with is inconsequential. There was one caveat. Be prepared to be the star attraction at Show 'n Tell when she starts school. She didn't have to start school for that to happen. As I have written many times a Servox is a kid magnet. I have had only one or two negative/fearful responses from children. From pre-school to library story hour to the local beach overwhelmingly they are just curious and think my voice is seriously cool.

I am still frustrated by it on a daily basis and to say otherwise would be disingenuous. I am now the proud Nana of two girls and the one year old, like her four year old sister before her, has learned that the thingy around Nanny's neck is her "voice" so she loves to pick it up and hand it to me, as if to say talk to me. When I respond by playing a game or even saying hello sweetie she just crows with delight. But to have a hands-free voice would be wonderful and one with the intonation we associate with speech even better. I would love to be a candidate for a TEP and maybe someday that will happen. In the meantime "nanny's voice" works just fine.

Not too long ago the girls and I were playing and singing along to a favorite CD when Kayleigh commented very seriously, "Nanny, I'm sorry, but you can't sing very good, can you." And it was said so sweetly and with such compassion it just blew me away. Then within a couple of weeks we were doing an animal puzzle with Kiera and as we did the requisite accompanying cow "moo" Kayleigh looked at me and said, "Wow, Nan, you do a REALLY good moo. That was amazing!" So there is something to be said for a Servox voice after all. Plus I do a really good buzzing bee.

So, Maggie, you'll do just fine.

Donna



Who's your primary medical provider and what's good or bad about them?

John Shepley, Lakewood, OH - October 2005

Jack and Everyone, Especially Vets who do not use the VA:

I still maintain as always that my VA in Wade Park (Cleveland) Ohio is one of the finest places for treating Larys. My last experience was in January. I was having breathing problems. First I went to our local hospital and though the MDs claimed they knew about laryngectomys, uh- uh. They kept me over-night and still did not have a clue.

Then I went to the VA. One look down my stoma and the Doctor said "Operation Now". I went right to pre-op and had surgery within an hour. That fast. He removed a large blood clot that was in the stoma near where it joins the lungs. I should have gone there first but I was VERY worried my breathing would stop. The VA is a half-hour away versus 5 minutes to the Lakewood facility.

Anyway, a screaming loud YES to using the VA.

Jack Davidson - Sep 2012

I use the Dallas VA and I am totally satisfied. Everyone there is courteous and very professional. The care is excellent. After my lary in Sep 2012, I was in intensive care for five days with a one patient/one nurse ratio - 24/7. I have nothing but good things to say about the Dallas VA.

My total cost is \$8.00 co-pay per prescription. When I comment on that the standard response is "You paid with your time in the Marine Corps".

Kathy Oboikovitz - Oak Forest, IL

My husband, Mark, had his laryngectomy, with a gastric pull-up, in August 2010 at Rush University Medical Center (RUMC) in Chicago. He had his TEP puncture in June 2011. His surgeon was Dr. Guy Petruzzelli; and we have often said God couldn't be everywhere, so he sent us Dr. Petruzzelli. This man was truly a blessing to us; both my husband

said God couldn't be everywhere, so He sent us Dr. Petruzzelli. This man was truly a blessing to us, both my husband and I have the utmost respect for and confidence in him. Have never encountered a more kind, compassionate, and competent medical professional. He made himself available to us, literally, anytime--day or night. He was honest and direct with us about the extent of Mark's cancer, but positive and hopeful about Mark's treatment options--essentially the laryngectomy.

Mark has also been fortunate to have an outstanding SLP, also at RUMC. Her name is Janelle Reske. She is so very competent, yet very personable and down-to-earth. She has a special way of putting Mark at ease and encouraging him, from the very first visit he had with her back in June 2011. Have to say, also, that everyone we came in contact with at Rush was extremely helpful and competent. Rush is the gold standard in medical treatment as far as we are concerned.

In June of 2012, Dr. Petruzzelli accepted a position as vice president for oncology programs and physician-in-chief at the Anderson Cancer Institute at Memorial University Medical Center in Savannah, Georgia. If anyone is looking for the best of the best in that area, we highly recommend Dr. Petruzzelli.

Thank you for the opportunity to share our experience, and God bless you and WebWhispers at large for all you do.

Jerry Marler, USAF Ret., Bossier City, LA - 2005

I was 70 when I had my surgery so Medicare has been my primary source of health insurance, however I do not use them for my lary supplies. I used them initially but found that many suppliers would not accept medicare payments in full.

I am fortunate to live near a VA facility so they give me anything I need and I don't have to worry about filing insurance claims. I also use the VA ENT clinic to do follow up exams every 6 months. They are adequate but my only complaint is I rarely get to see the same Doctor two times in a row. Most of their MD staff is from the local medical school. My surgery was done in September 2005 at LSU Health Science Center in Shreveport, Louisiana. They have one of the top throat cancer facilities in the country.

Hank Luniewski, Charlottesville, VA - 2010

I would like to comment on the care I received from the VA but, I can't, since they have refused to give me VA benefits. I served 20 years, 5 months, as an enlisted man in the Navy and can't get VA benefits. The reason? Since I pursued a second career in business and am now retired, my combined income is high enough for the VA to reject me. I'm confused. Did I serve my country or not? I was sent to Vietnam 4 times. Of my time in the Navy, I served 14 years at sea. Did I earn the benefits or not? If I earned them, shouldn't I receive them? They provide some services that I cannot afford. Why should I be penalized for working hard?

Pat Sanders, Birmingham, AL - 1995

I have Original Medicare and I really celebrated when I got it. I chose AARP's Medigap (serviced by United Healthcare) to go with my original Medicare so that all of my deductibles would be covered. Yes, I had to budget the payment for that every month and later added Medicare D for drug coverage. But, I was so relieved because, for the first time in my life, I could say, "I have health insurance coverage and I will always have it!"

That was optimistic. I am terribly concerned about the changes that are being made and being lied to about being able to keep the same coverage I signed for. Yes, I can keep Medicare but it is gradually changing what it will pay doctors and hospitals for certain diseases and procedures and Medicare is not the same as it used to be. I got a shot

on Jan 2nd and they won't pay my doctor because the new rule is...you have to get those at the drug store and be paid for by Medicare D (or drug coverage) instead of Medicare B, which I pay for out of the SS check. Other things have changed slightly and I am wary about what is coming next. It is never in my favor. Last year, my doctor prescribed a pill, 30 a month. In my instructions he commented that I could cut them in half.... and the drug store charged me for two months because I was to pay according to the length of time the prescription would cover.

I was reading just this week about people going to the emergency room, being kept for 'observation', for several days and then moving them to a nursing home, which was not paid for because they regard 'observation' the same as outpatient. To go into the nursing home from the hospital, you get a certain amount of time paid for... but not if you were under observation! Who tells you in advance? Who gives you a choice? And for the future, what government agency is going to decide I am too old to receive a medical procedure even if my doctor and I decide it is what I need and I am in good basic health to survive and do well?

Dave Ross, Edgewater, FL - 2005

I live in the greater Daytona Beach area. My surgery was April of 2005 and I speak with TEP.

The quality of my health care can be divided into two very distinct areas:

- (1) all non-laryngectomy care and
- (2) laryngectomy care.

My care for all non-lary related health issues is excellent. Locally, the care for my laryngectomy issues is non-existent. I must drive 150 miles (one way) to see an ENT or SLP that can assist me with any laryngectomy related issues.

Both my ENT surgeon and SLP are at Shands Hospital, University of Florida, Gainesville, FL and are THE BEST! Fortunately, I have had no need to visit or even speak with either for several years.

Marian Cure, Cedar Creek Lake, TX - 2009

My primary insurance is Medicare with Blue Cross/Blue Shield. While the government changes aren't welcome, I am reasonably content with my choice of insurance. I am married; therefore, my husband's health needs have to be considered, also.

I live near the Dallas area and started out with surgery from a Baylor affiliated doctor. His name will remain unsaid as he was a vile personality and detrimental to my health had I stayed with him. I heard Dr. Larry Myers from UTSW speak at a conference in Dallas in 2009 and later walked into his office without an appointment to talk with his nurse or staff. I was treated with such respect and compassion and lo and behold Dr. Myers himself saw me for a few minutes. The icing on the cake was one of his SLPs, Janis Deane. I knew this would be a good fit for this journey and never looked back.

I guess my point is that if your insurance isn't delivering what you need or your doctor and his staff doesn't meet your standards, then do your homework and change. Mine went from hostile to delight.

Frank Klett, NJ - June 2008

Jack's email today was right on time. I had an in home visit from an MD through my insurance carrier. I'll outline it below:

I have Medicare Advantage coverage with UnitedHealthcare (AARP's Medical) and today I had an in home visit by

I have Medicare Advantage coverage with United Healthcare (with a copay) and today I had an in-home visit by one of their doctors, yes doctor, not a nurse. I was first contacted by them to see if I would participate in this new program (called HouseCalls) they had just started. I would pay nothing and have an MD come by for what would be an hour or two checkup and physical.

I was very pleasantly surprised with the entire process, which lasted about 2 hours. During the visit the Doctor reviewed my medications and supplements and made a point to tell me about each and correct dosing, as well as, any side effects to watch out for. She also went over the process of getting lower or no cost refills and help that is available for the low income folks who need the drugs.

She did a fairly extensive exam, considering we were in my living room, which included urine testing, height, weight, foot and skin exam, lungs and blood pressure. She will use the results from her exam to forward a report to my primary care physician with her recommendations for tests she feels will be beneficial and proactive to my ongoing health.

Considering all things in this day and age, having an MD at my disposal for a one on one session has made me think of United Health Care as "my health insurance company". Paired up with my family doctor who I have had for 30 years I could not feel more confident in my future health care. The program will include a yearly home visit to follow up on any ongoing issues, as well as ensuring my concerns are being addressed.

I would encourage anyone who has United Health Care to take advantage of this terrific benefit at your first opportunity. The information on HouseCalls can be found by calling 1-866-686-2504.

Peter Powell, NY - Dec 2010

I believe that if we restructure the health care delivery system and insurance, in a way that tax increases would be totally earmarked for health care coverage, that the American citizen would approve. It's time to think out of the box and get to work on solutions that self pay itself.

John Haedtler

My personal feeling is that lot of use don't have insurance and we depend on the little that Medicare gives us. And to be honest, that is a joke, but it is run by the government! I have tried to volunteer to speak to VA Laryngectomy patients here in New Mexico and I found out that each state VA is controlled by the State Governor, Not the Federal Government. And I am not a veteran so I can not speak to the patients here! It is really sad to live in a third world country inside the United States!

I did not respond to the question asked as it raises too many questions that just can not be answered!
Please keep up the great work, I love reading Speaking Out!

Terry Duga, Indianapolis, IN - 1995 Total

I am fortunate to have excellent doctors and a great SLP. My Doctor, Dr. Peter Regis, inherited me when my former ENT left the practice here in Indy. He is a nice, capable, young man. I kidded him when he grew a beard that at least he no longer looked to be 13 years old. He laughed. I was not worried. Mary Jane Renner, my patron Saint, vouched for him, and that was good enough for me.

My SLP, Byron Kubich is also relatively new. He replaced Dr. Blom. The fact that Dr. Blom selected him to take over his patients gave me confidence in his abilities. Also, I am not an easy person to change prostheses on. I have a

his patients gave me confidence in his abilities. Also, I am not an easy person to change prostheses on. I have a chandler puncture and an active gag reflex. Byron has a very gentle touch inserting the prosthesis, and has proven to be quite adept.

I recently had a hip replacement. The hospital was Indiana University Hospital North. It has previously been Methodist North, but with hospitals merging, it changed names. Great hospital, as they go. Even the food was decent.

Louis Trammell - IL

I've heard many horror stories, even about my hospital which is listed among the top 50 in the nation, so I've always considered myself lucky. At the end of 2007, I had to leave this hospital because of issues they had with my insurance company so I went down the street to a hospital ranked 1200 and it was like going from daylight into darkness. Now I hadn't had my Lary surgery yet but they did botch a simple dilation so I was sore for a month. I was ready to leave there by the year end but I heard the cancer clinic was getting a new department head, Dr. Kristen Pytynia so I decided I should at least meet this doctor. Well, I liked her so much I stayed and she did the Lary surgery 10 months later and did an awesome job.

I joke with my Lary friends by telling them: " This doctor came from the best throat cancer hospital, MDAnderson just to do my surgery". The reason I say that is, as fate would have it, she came to this hospital after I became a patient and went back to MD Anderson when I decided to go back to my old hospital.

As for my new SLP, Janelle Reske is the best and she does a great job for our group, Lary's Speakeasy. Again I'm a very lucky guy to know some of the medical staff I've met throughout the years and the proof is in the pudding because it's been 21 years since my cancer.

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



WebWhispers' Dave Greiwe completes One America Indy 500 Mini-Marathon

Dave Greiwe, Lary class of 1998, and one lung class of 1999, completed The One America Indy 500 Mini-Marathon,

a 13.1 mile marathon, on Saturday, May 4, 2013.

Dave and his daughter, Susan, have finished the Indy Marathon the past six years. Dave still works full time, and walks every morning for an hour before work and during his lunch. He also goes to a gym 2-3 times a week, walking 5-6 miles on a treadmill and does strength training. They have signed up to participate in another half marathon in September. Susie is also three months pregnant! With her 3rd baby! This was the second marathon she finished while pregnant. She is the one who signed Dave up for his first marathon and has continued to do so for his birthday present each year since.

Dave will turn 64 years old in August. He is my husband, and my inspiration.

Judy Greiwe



How about letting that inspire you?

No, you don't have to run a marathon but you do need to exercise, with regularity.

When you are able to exercise and get even a little stronger, you look better, feel better. Other people see it. whether it is a spring in your step, improved posture or just the smile on your face!

So I was intrigued by an article in the Wall Street Journal called Hidden Benefits of Exercise. They start off with a real grabber: "Regular workouts may help fight off colds and flu, reduce the risk of certain cancers and chronic diseases

grabber. Regular workouts may help fight off colds and flu, reduce the risk of certain cancers and chronic diseases and slow the process of aging."

They suggest that walking about 30 minutes a day (or 3 to 5 hours a week) and you wouldn't have to be concerned about weight and the idea is that, instead of telling people how much weight they need to lose, just tell them to start walking.. and work their way up to 30 minutes a day.

We know that type 2 Diabetes can be controlled much more by exercise, lowers blood pressure and cholesterol readings will likely come down. It not only gives you a chance at not getting cancer, compared to people who do not exercise, but if you do get it, a better chance of surviving. How can we NOT exercise when it does so much for us?

<http://m.us.wsj.com/articles/a/SB10001424052748704350304574638331243027174?mg=reno64-wsj>

Do a little more reading and spend at least 5 minutes walking or going up and down stairs, or riding your exercise bike. I highly recommend a book rack for your exercise bike. I ride about 20 minutes a day and bribe myself by getting to read a good story as I ride.

This remind me of an article I wrote years ago asking if you had something that would make you into a healthier person and it was totally free, would you take it every day? In that case, it was water! So now you have two things for daily health that requires will power and determination and results are seen in a short period of time. Exercise and drink water.

Pat Sanders



The First Coast Laryngectomee Club of Jacksonville, Florida



Excerpts from the report on the April 20, 2013 Neckbreathers Poker Run from Ginny Huffman and the First Coast members, most of whom are also our WebWhispers Members. We are proud of them.

"April was a very busy month! Our quarterly meeting brought everyone up to date on the 2013 Poker Run and the great news that Jacksonville Fiat had offered to sponsor our second year Poker Run."

They proceeded to list the many donor businesses in Jacksonville, the lary suppliers who contributed items and the individuals who helped with money, time, gift cards and products. Having established themselves last year as a group who could both plan and carry out a great project with their first Poker Run, they outdid themselves.

"One of the most satisfying results of the Run has been our establishment of a loaner closet of EIs for laryngectomees. We now have ten electrolarynxes to lend new larys and those who need a temporary replacement."

"It rained most of the day but our very successful after party, the raffle of gifts from old and new donors and the auction of major gifts plus the cash donations of our dedicated supporters and our sponsor, Jacksonville Fiat, raised a grand total of \$9,003.00."

"We remain thankful for the inspiration of our own Troll Sparks! It was his courage, facing the challenges of recovery and refusing to concede his love for his Harley, that led us to embrace the Poker Run. Brad Russell has done a great job with the seeming limitless paper work involved in our Club incorporation and status as a 501c Non-Profit organization."

Many worked together to get this done and what a success. In their report they give credit to all, but I did want to note our WebWhispers members that received special Thanks.





I want to tell you about the ' Highland Clearance ', in Scotland in the early 1800s. A good friend at the local hospital, Nursing Sister Barbara Wagstaff, told me that she had joined a camera club. She was working on a project about when the clan chiefs decided to denude the glens of their followers in order to graze thousands of sheep, to sell the wool to England, and also to open up the highland mountainous region to rich English shooting parties. This was all done with finance in mind, and as a result many of those highlanders and their families spread across the world.

She asked me to write a poem about this and the more I looked into this, of which I knew very little, I was horrified at the cruelty shown in throwing people out and sometimes burning their homes. I try not to write about political things, but this is nearly 200 years ago and we English were not involved. Strangely enough the love of the clan system still exists and those clan chiefs forgiven in all English speaking parts of the world.

This is the poem I wrote for Babs:

THE HIGHLAND CLEARANCE

This surely could not be happening,
as our clan chiefs discard us all.
We crofters find it sickening,
our hearts and minds appall.

To make us leave our homes by order,
from those in respect we hold,
bewitched from, across the border,
in their search for English gold.

In battles past for many years,
we had rallied to their call,
highlanders killed, so many tears,
now our chief's forgotten all.

Now they want the glens all cleared,
our homes burnt to the ground.
Their ruffian bailiffs from the Gorbals feared,
as they roam and search around.

It really started in 1707,
when the union with England was made,
and most clan chiefs let their people down,
as the promises of freedom fade.

All clan chiefs went to London Town,
given English titles by the king,
and an annual golden purse they found,
was part of the English sting.

They had to raise Scottish armies,
under clan names proudly raised.
My own clan chief was made a Duke,
and the soldiers of Sutherland praised.

We fought for England's many foreign wars,
but our loyalty was still to our chief,
and many a Sutherland Highlander,
lay in a foreign soil beneath.

Now we have to leave our crofts,
our lasses in despair all weep,
our loyalty gone, as the glens are cleared,
to be filled with flocks of sheep.

So highlanders will spread throughout the world,
in time all their chiefs forgiven.
a bursting energy for those new lands,
and the freedom for which we had striven.



Bits, Bytes and No Butts!



Frank Klett

Which Operating System Do You Use?

Do you know what operating system you use? Do you really need to care?

Many folks who use their computers on a daily basis don't know or care what operating system (OS) they have. Given all the issues and concerns we deal with today, this is hardly catastrophic. Your need to know the OS you are using is for your computer's health and performance. There are many instances when a manufacturer will announce a new product or upgrade that applies to a specific OS. If you should purchase or want the desired upgrade you may be out of luck if you have a different OS.

Security is another issue to consider and stay aware of when choosing an OS. A rule of thumb is that the more popular an OS is the more likely it is to be the target of hackers.

So how do you find which OS you have? Ask Leo will give you a brief and easy way to determine your current Windows version.

<http://tinyurl.com/btozfdh>

If you are a Mac user you can simply go to the top left corner of your screen and click on the Apple and then to about this Mac/software. Your OS X version and build information may be helpful when updating software or the operating system on your Mac.

http://support.apple.com/kb/HT1633?viewlocale=en_US&locale=en_US

Do you use Windows?

Today Windows has several versions out and about. There are Windows XP, Vista, 7, and 8. Some diehards may even still be using Windows 98 or ME. Since most of today's software is OS aware it is required to know your OS version to ensure compatibility. Windows is the predominant OS in use today therefore the most targeted by hackers. Always be sure to have your firewall on and antivirus software up to date.

Do you need to upgrade? If your OS is doing everything you want it to do, then the answer is no...as they say if it's not broke, don't fix it. If you are more adventurous and want to see just what the new OS has to offer then go for it.

For 8 reasons not to upgrade, click on:

<http://tinyurl.com/c4kyqze>

Have you switched to Windows 8?

If you have I am sure you have reached your own opinion as to its pro's and con's. I have seen several articles on how to best adapt to the new interface and this link from Bob Rankin makes a nice brief and informative read..

<http://tinyurl.com/c63jczp>

Do you have an Apple product?

I have been researching the Apple line of products and found a very interesting fact. If your Macbook is a 2007 or older then you will not be able to upgrade your OS to the latest version. You will be confined to OSX 10.4.11 for quite a while. This means that new features introduced in the newer OS's Apple has released will not be available to you.

While your current system may not be upgradeable, if it is meeting your needs and you're still smiling, then you are just fine without the upgrade.

While Apple's built-in security features are definitely helpful and vastly better than being on the Internet totally unprotected, they are not designed to be a full security solution. Apple is vulnerable to hackers, contrary to popular belief, however a good firewall and antivirus helps make it very secure. Some contrary opinions:

<http://www.pcadvisor.co.uk/features/security/3418367/do-apple-macs-need-antivirus-os-x-security-explained/>
<http://www.technewsdaily.com/best-mac-antivirus-software/>

And then there is Linux.

There is a strong community of users who find that paying for software to be contradictory to freedom of using a computer to accomplish everyday web tasks. Their OS of choice is based upon Linux. Linux has made great strides in recent years from being a command terminal environment to a graphical user interface (GUI). Since the software is free to anyone who wants to use it. Linux has become very popular especially in the third world countries. Linux has several flavors to suit different tastes and needs. The most popular is Ubuntu which has an interface which is considered by some to be superior to Windows. Due to its somewhat limited use Linux is seldom a target of any malware and therefore said to be totally secure as is.

You may already be using Linux type applications if you use Firefox, Thunderbird, or Picasa, just to name a few. I use Linux Mint and have been more than happy with its performance and features. More information on Linux can be found at:

<http://community.linuxmint.com/>

Hot Tip

Do you find yourself wanting to have a cup of coffee with a favorite friend? 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 and life lessons to Marlene's greatest tips ever and Mike's wonderful words of wisdom. If you're not using this great little bit of high tech you are missing one of the best things in our Lary life. While you are there be sure to sign up for the drawing to be done for a chance to win an EL-1000 from InHealth and Webwhispers. See you in the forum!

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

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