

# WebWhispers

Sharing Support Worldwide

Throat Cancer and Laryngectomy Rehabilitation



**April 2018**

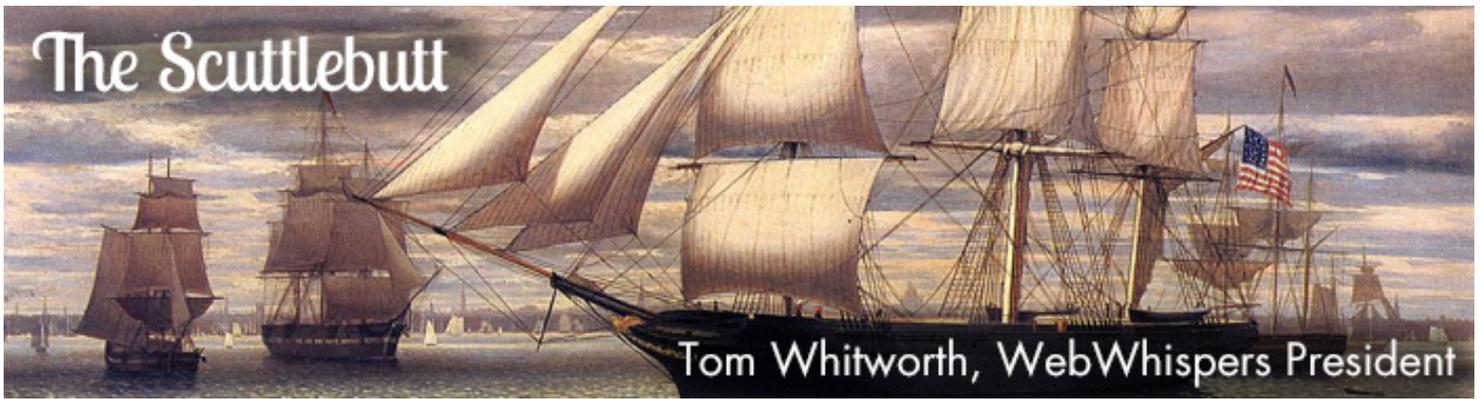
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**FEEDBACK**



## Events for Larys and Lary Lovers

There are a number of events for the Lary community taking place this year in different locations. Each of these offers a great educational opportunity for attendees. You will not regret attending any one or all of these. In addition to the learning, the chance to meet other laryngectomees, caregivers and professionals and to visit with old friends, is priceless.

### **Association for Head and Neck Cancer Rehabilitation (AHNCR):**

The Association for Head and Neck Cancer Rehabilitation (AHNCR) will be hosting the 3rd Annual Clinical Head and Neck Rehabilitation Conference on **April 6-7, 2018**. The conference will take place on the campus of Michigan State University and is uniquely tailored for students in Speech-Language Pathology, head and neck cancer survivors, and their caregivers. Multiple vendors will also be represented at the conference. The educational program includes both didactic instruction as well as skill building sessions over this day and a half conference.

For more information on registration and housing please email them at: [AHNCR2018@gmail.com](mailto:AHNCR2018@gmail.com)

### **4TH Annual All-Chicago Laryngectomee Symposium:**

Sponsored by the Xavier University/Ludden Speech Clinic and Lary's Speakeasy, this one event day will be held on Thursday, **May 17, 2018**. The cost is \$60 for professionals, \$30 for non-SXU students and SXU Alumni, and free for patients and caregivers. It includes parking and lunch!

RSVP to [larysspeakeasyfb1@gmail.com](mailto:larysspeakeasyfb1@gmail.com), to Miriam Alfano at [alfano@sxu.edu](mailto:alfano@sxu.edu) or by phone at: 773-298-3568

### **International Association of Laryngectomees:**

The 2018 IAL Voice Institute and Annual Meeting will take place **June 6-9**, in Orlando, Florida and promises to be one of the best ever with a fantastic agenda arranged by Caryn Melvin. See the IAL website for the schedule. The conference will be held at the [Holiday Inn Resort Orlando Lake Buena Vista](#)

13351 Florida 535  
Orlando, Florida 32821  
United States  
(407) 239-4500

Call the reservation system at 800-972-2590 and ask for the IAL Annual Conference group block. **Reservations must be made by May 7th, 2018 to guarantee the group rate of \$99.00.** You can also register online from the IAL website, [TheIAL.com](http://TheIAL.com).

The airport closest to the conference is Orlando International located approximately 12 miles from the hotel.

Attractions close to the include: Universal Orlando Resort, SeaWorld Orlando, the Disney Springs area, and the Orlando Premium Outlets and Lake Buena Vista Factory Stores all located just 1 mile from the resort and the hotel provides a free shuttle service to all Disney theme parks!

I wrote this last year after the IAL meeting in Virginia Beach:

*"Thanks to our Buck Martin Fund and the generosity of both Atos Medical and InHealth Technologies, nine attendees received scholarships totaling \$5,050.00! Of particular note is the fact that no scholarship was left on the table this year and five went to first time Voice Institute pupils, who had surgery within the last five years ago. What a great thing it is for WebWhispers to be able to help this many people attend the event. Special thanks to our friends at InHealth Technologies and Atos Medical for their participation in our scholarship program and to the late Buck Martin for his bequest for this purpose. Keeping with an eighteen-year tradition, our pre-dinner reception was sponsored by Bruce Medical. As if that were not enough, forty larys present at the WebWhispers dinner received a "winning ticket" good for our choice between an ADDvox 7 voice amplifier or a whole year's supply of foam filters! Wow! No strings attached!"*

Help is available to attend this year as well. All you need to do is apply. Scholarship application form:

[https://webwhispersinc.formstack.com/forms/webwhispers\\_scholarship](https://webwhispersinc.formstack.com/forms/webwhispers_scholarship)

For scholarship questions, email us at [scholarship@webwhispers.org](mailto:scholarship@webwhispers.org)

WebWhispers will be represented at all three events. We'll see you there!

*Enjoy, laugh, and learn,*  
*Tom Whitworth*  
*WebWhispers President*



**"Did you suffer from depression, and if so how did you deal with it?"  
If not we'd also like to know why you think you didn't.**

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I became very depressed in the time leading up to the diagnosis of cancer, because of what I call the doctor ladder. I knew things weren't right physically but was sent from one doctor after another and was told allergies, rightinoisis ,bronchitis and irritated vocal cords. Was passed back and forth till I finally found

somebody to actually look and scope, then heard that I shouldn't have waited to seek treatment.

When it was found that I had bladder, kidney and throat cancer, luckily they were all different kinds not a spread, I just became mentally stressed out and started seeing a mental health pro, turned out to be a long trip but ok now.

**Joe Hilsabeck – Edelsterin, IL**  
**June, 2009**

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I was bothered with an overwhelming feeling that made me cranky and sometimes still does after nine years. It took energy to communicate, wear a plastic cover, cough and deal with all the changes. After several months, I talked with my internist and he gave me a mild antidepressant. This gave me almost immediate relief...not perfect but relief. Perhaps this was a type of "Sundowners" that nursing facilities have with their residents. Being up front with family and friends that being cranky was just a side effect and that it will get better helps. I'm an optimistic individual; however, one has to ask for help sometimes.

**Marian Cure - Cedar Creek Lake, TX**  
**2009**

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I had my surgery Sept 2002. The cancer was found and removed all within about a month. I had no treatment before the surgery. My doctor told me that many times trying radiation and chemo only delayed and made it worst. That's para-phased he was more technical.

Anyhow prior to this my husband had died, brain tumor, my daughter 32, had a rare disease, that caused her to have strokes and she almost died. I had all kinds of financial problems, lost house and that's just a few things.

So when the ENT said it was cancer, we just about felt, "here we go again". So no, I can't say I really was depressed. It was just one more thing to handle with the help of God. I had the help of friends, family, and a couple of good clubs, in New Haven and Danbury who helped me cope. What I really miss most is that I can't swim anymore, but I'm still on this side of the grass, Thanks to God and a really terrific Doctor and medical team.

**Linda Palucci – Kissimme, FL**  
**September, 2002**

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I do not have a problem with depression. Never have. At 94 I have my share of problems, but handle them the way I always have. My first thought is, "It is what it is" and do what I can about it. Then I get busy helping others with theirs. I've been a WebWhispers volunteer for 19 years, and when you're busy helping others with their problems, you're too busy to dwell on your own.

**Michael Rosenkranz – Plantation, FL**

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I did and still do suffer from depression 5 years after surgery. Not being able to communicate clearly or easily with my family (especially my children now 11 & 14) and friends is heartbreaking, frustrating, and infuriating.

We adjust and try to be thankful to be alive. We try to have a sense of humor and patience with each other. Prescription anti-depressants have helped enormously for me. I try to focus on each day and not feel overwhelmed and swallowed by the knowledge that this is the way my life will be for the remainder. Cheers to all those who don't battle depression. You can add jealousy to the list of my emotions!

**Sarah Alessandro – Quincy, MA**  
**2013 (original cancer 2008)**

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Yes, I had "situational depression" before (bad boss before retirement) and went off meds for it, and then since lary 7/15 I have resumed meds and they have increased the number and doses.

I wish it weren't so, but I have been care taker for my wife for 36 years because of her physiological depression and tremor issues and she's so used to that she can't accept that I might need some care taking and she is in denial because she can't imagine life without me.

I had an episode in 4/17 of two growths on the lung which were removed and hospitalized for pneumonia two weeks later. I felt pressured to take her 100 miles one way for a medical appointment two days after discharge (she doesn't drive except locally) because to reschedule that would have involved another several weeks wait time and she didn't want to wait. Removal of lung nodes has decreased my lung capacity so I cannot do heavy exertion or lots of stairs or steep inclines.

I could go on, but I think you get the picture.

**Mark Reichenbacher – Hedgesville, WV**  
**2008 & 2015**

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I had 26 days in the hospital ward after my laryngectomy in May 2016. Travelling to the hospital by air I went over where I was in my life. I was 74...had a very comfortable time compared to many...comparing my life to the many became crucial to my reasoning. I had been a professional singer. I had been an international Archer representing Zimbabwe in 1981 World champs. I moved to South Africa and made the SA men's team. Later I was a City Councillor in one of the world's famous cities, Cape Town. A full life...nonsmoker.....now losing my voice...but....the real BUT...I was going to lose the tumour, be cancer free...so I did a deal with my Lord....take away my cancer and I give up my EGO?.

Now, with no ego I have no regrets on my deal. I visit the Mall about 4 times a week and notice how many others have serious physical problems.....and all ages and that's just what you see....hundreds of others have unseen issues. I have no time for my ego. No time to be depressed. Just thankful to be free of C and otherwise healthy.

Oh my legs are not doing what they always did....getting out of a chair is hard work. But...every day is counted a blessing and a bonus. Depression? Why not celebrate what you have- not what you've lost. So much to celebrate..and time is short but it's about what I have - not what I don't. Let your ego go and you will not be depressed. Life even under these terms is a blessing.

**David Statham - Port Elizabeth, South Africa**  
**Full laryngectomy May 16**

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During the first couple of years after losing my voice I became increasingly depressed although I have to say it was a mild depression. What was bothering me most was losing touch with my grandchildren and great grandchildren (most of them 10 and younger). They loved the oddity of grandpa sounding like a robot, and

trying to use my EL to sound like me but beyond that any kind of prolonged conversation with them was painfully short with many struggles to understand me clearly. I worked hard with my EL and did fine with the adults around me but not so well with the young ones. I knew I'd feel worse and worse unless I found a way to reach those younger generations. I'd done a lot of professional writing as a university professor in my early years and as a professional business consultant toward the end of my career and the idea of writing entertaining fictional stories occurred to me.

When I got the idea I knew I was going to use my grandchildren and great grandchildren as characters in the adventures. Once I started writing it is was as though I'd released the Genie from Aladdin's lamp. The stories came pouring out of me and I've been writing them since the moment I started. I created what I call the Sam 'n Me treasure hunting adventures series and wrote 47 short read stories (between 75 and 100 pages) using my grandson Sam as the main character with characters made up from family members, relatives and friends populating the stories as they unfold.

Then I got the idea of writing a series of 10 archeological mystery adventures (again short reads) with Sam and 2 of his cousins as young archeologists (Jr.'s in high school-progressing into their university years) solving one mystery after another in the world of archeology.

Things have worked out better than I'd hoped because now my grand and great grandchildren are of the age they're enjoying the stories which delights me no end. I never imagined in my wildest expectations I'd find a pathway out of my depression like the one I've found through writing. I'm enjoying it immensely even though I'm aware the size of my reading audience will very likely be my family, friends and hopefully future generations of our family. What better footprint can we leave behind than something we've written.

If any of you fellow larys have ever thought of trying your hand at writing let me beg you to give it a try, it may be your pathway to a world of enjoyment too.

**Branton Holmberg – Waun, WA**  
**Lary since 2010**

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For anyone who loses a body part, resulting depression would be a completely understandable response and one that the patient's team of doctors/nurses should be on the alert to diagnose. My team not only questioned me about my mental health following surgery, but during all of my subsequent follow up visits, either verbally or through written responses. They continue to examine that part of my recovery even though it's been 4 1/2 years.

Was I depressed? No. Anxious about the future, yes! But I had a superb team at Seidman Cancer Center, University Hospitals in Cleveland and following surgery, they arranged for a home nurse to check me at my home as often as the nurse felt it was necessary. My two daughters flew in from out of town in separate shifts to help me organize the avalanche of medical supply deliveries, tube feeding and med schedules, and cook meals for my husband. I was so fortunate to have wonderful family support and friends that kept in constant touch by text, emails, visits, and phone calls to my husband. As I was retired at the time, I also had no pressure to return to a job.

I firmly believe that depression was held at bay for me because I was already on an anti-depressant before my diagnosis and surgery. I wouldn't hesitate to recommend this type of medication to any future laryngectomee, (if your doctor approves - the lowest dose possible) just to take the edge off before surgery and after and even into the future.

**Barb Gehring - Akron, Ohio**  
**September 2013**

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When I was initially diagnosed I was more in shock than depressed and don't think I fully understood the extent of change that I was about to experience. I was somewhat relieved at first that finally someone figured out why I was having difficulty breathing and talking. I didn't understand the magnitude of my diagnosis until long after my surgery. The shock wore off and the exhaustion set in for the following few months as I went daily for my radiation treatment and many follow up appointments and tests. I did my best to keep my chin up and smile but there did come a point when I began to feel better and started to realize the full scope of what had happened.

As I was feeling better I started thinking about what the future would hold for me and the challenges I was going to face with my new 'handicap'. I'm a talker... I've always been a talker... I talked to dozens of people every day at my job, talked to my friends, family and co-workers. Losing my voice was suddenly all I could focus on. I had many days of feeling sorry for myself and asking why me?

Depression didn't set in until I was taking a road trip and put my favorite playlist on only to be hit with the reality that my favorite part of road trips was singing while I was alone in my car where, thankfully, no one else could really hear me. Anyone that knows me, knows I love music... no I couldn't really sing but that doesn't mean I didn't sing... I started to focus more on what I had lost rather than what I had gained. No, my future grandchildren will never know my true voice and I'll never be able to sing them a lullaby... it will be very unlikely for me to return to my former career due to the amount of verbal communication required to do that job... I can't giggle... I can't yell when I'm angry... I can't do what had come so naturally to me my whole life - having conversations with people became a chore. I allowed the negative thoughts to take over and questioned my decisions that could never be reversed.

It was the people I met after this nightmare that made a big difference for me. My children... reminding me every day that I still needed to be here. It wasn't easy but I began to force the sadness away with happiness that I will in fact be here when my babies finally have their own babies, that even though I can't laugh with my voice I can certainly laugh with my eyes and my body language... I can also still very effectively express when I am angry or upset about something and it's way more effective than yelling ever was. I can't go back to my former career but it forced me to slow down and appreciate things that I hadn't before. Yes, I suffered depression after my surgery but no, it didn't consume me. I still have days where I ask why me, but I have many more days appreciating what the rest of my life has to offer and learning the hard lesson about life being too short before it was too late for me to enjoy it. Sure, if someone offered me my voice I would love to have it back but not at the cost of my future.

**Jennifer Malkiewicz – Chesapeake, VA**  
**January, 2017**

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I don't think I really had depression after my laryngectomy which was done in October 2015, but more like frustration finding new ways to communicate with people. I never really allow myself to get depressed, as I realize there are many who are much worse off than I, i.e. our veterans who return from Afghanistan or Iraq, or even others around us.

**Ron Boudnik - Manitowoc, WI**

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I don't think I did. I was seriously so glad to still be alive and be with my family. My mother in 1984 wasn't as lucky. It took time getting used to being like this, LOL I can remember trying to talk. Was able to return to

teaching within a year of the surgery.

**Sheryl Avery – Pasadena, CA**

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I had my laryngectomy in 2004, when I was 55 years old. I was of course depressed in the 4 or 5 days between the time I learned I had a tumor on my vocal cords and the date of my operation. I was working and raising my young son as a single parent at the time, so I knew it was important to press on and play with the hand dealt me. I believed most of all that I should show my children (daughter was away in college) that it's best to accept and deal with the hard knocks life sometimes give you and don't feel sorry for yourself. You are what you do, so by not showing depressed and morose thoughts, I stopped thinking depressed and morose thoughts.

My mother was a farm girl and I believe I got this attitude from the way she acted and the stories she told me of her life on the farm. Bad stuff happens so you gotta make the best of it.

As a laryngectomee I do about anything I want to; married a smart beautiful gal, swim, boat, hunt, fish, woodwork, yard & garden work, became an ordained minister and married my son, travel anywhere we want, go to the Y to exercise and weight lift. I also visit any pre or post lary I find out about. I know many larys who have the same attitude. I feel blessed and am having the time of my life!

**Greg Smith - Windsor, CA**

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I never had any depression after my total lary because I knew it was do or die to have the surgery. The cancer was that invasive. However, there was a bunch of frustration getting settled into my new normal. Now that I'm there life is good. MY LIFE HAS BEEN ALTERED, BUT NOT EXTINGUISHED.

**Bob Bauer, Class '08  
Hayward, CA**

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I have never been depressed in my life, so I can't tell anyone what they should do about it. I was blessed with a good sense of humor, and find something funny in almost anything.

Laughter is great therapy. A smile helps relax the muscles in your face. I also pray every day and night. Don't get me wrong because that is just a personal thing with me.

As an afterthought I talked to my daughter, who is an licensed clinical psychologist. I told her about our monthly speaking out question, and asked her if she had ever seen me depressed, and she said no, but I may have had a "situational depression."

**Johnnie Dontos – Woodway, WA  
11/30/2015**

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Really had no reason to suffer depression after my radiation treatments because I suffered none of the side effects that were on the long list of such that they gave to me. Only hair loss was on my neck and I actually gained weight, and I did not do chemo, but being chained to a suction machine and mist humidifier really began to bear heavily on me along about the third month post-op, and six months out it had dragged me to

depths of darkness I could not phantom.

Because (to me) this is no way to live life and I certainly had no desire to live life without being able to ride my Harley, and whenever I thought about that the mire of depression was all-consuming. Because every time I thought about riding (which is a thousand times every day) I could not see my way around those two blasted machines to get there. Certainly couldn't tote two electrified contraptions with me wherever I journeyed.

One night . . . the torment in my mind became unbearable . . . and I decide to soak in a hot tub after taking some muscle relaxers.

Ol' Lady was working and I figured . . . fall asleep and sink under water. Not like we can close our stoma's to keep water out.

Believe, don't believe, that is your discretion . . . but long about the time I was slipping under the influence of the drugs I heard a voice plain as day say: "Do you trust me?"

Thought it was my sweet Vicky Sue (although I confess it sounded NOTHING like her), but it was enough to jerk me back to my senses so I realized that I had placed myself and this cancerous journey into the hands of God Almighty before my operation that rendered me mute. And once I had finished coughing all the water out . . . I heard that same voice in my mind asking the same question.

Ashamed as I was . . . I could only mutter . . . "I know it doesn't look like it . . . but I do."

Cannot say there weren't any more dark days after that, because there were, but the grip of depression was lessening more and more every day.

Two months later I took my sweet Miz Heavenly Sugah in to have all her lubricants change and had her thoroughly checked out because she had sat for nigh-on two years by then. That be her name because she was given to me. Whole 'nother story that, but I've nary a doubt she is a gift from God.

Still hadn't broken free of those blasted machines altogether by then, but whee doggie I could go nigh-on ALL day without having to toy with them puppies! By the time the bike shop called me a month or so later . . . they were back in their boxes and in the closet. Exactly 1 year after surgery . . . I was back in the wind!!!

Oh, I put a windshield on her like Doc Goldman said I ought (just to bring an end to the Ol' Ladies harping about it), but that puppy came off three weeks later and I was as happy as a pig in a mud wallow. First day I rode her without that wind-blocking bug exterminator I was a grinning like a dog what just ate Sunday dinners pot roast. Smiling, howling, and dancing about like the blooming village idiot. So happy I didn't even notice the dark storm clouds gathering.

When I did I was so far out from the house I knew there'd be no getting home without getting wet and I could plainly see the wall of water moving in my direction.

First thing that popped to mind was Old Doc Goldman warning: "Won't be able to ride in the rain." And I thought: "I'm about to drown." as I looked frantically for a place to hide till it was past. 2nd voice I heard mentally was the same one I heard in the bathroom so many months before that asked: "Do you trust me?" "Of course I do." I replied as if I could be heard. "Then ride on."

There it was plain as the nose on my face. 'Whiteout'. So much water falling from the sky you could not see thru it. Being as I was on a Florida backroad there was nary a bridge in sight. No gas stations nor convenience stores. No place to seek shelter from this storm and I'm certainly not going to stand beside the road like an idiot waiting for it to pass, but I admit I could not keep from thinking as I rode right into it . . . , "I'm about to drown."

Got soaked to the bone in a nanosecond. If I'd have brought some soap I could've taken a shower . . . but I didn't drown. Never got a drop in my stoma!

Won't lie. Cuz cancer is a nasty disease and I had my 2nd bout November last year. Growth in my mouth. Had it removed. No radiation. Never chemo. Doing good. No depression. Yes, had some dark moments before it was removed (and some after that 1st drenching ride way back when), but nothing like those of my 1st post-op back in the beginning of 2007. Why they try to come upon me now days I just put my face in the wind and let it blow them off me.

Which is why I always proclaim . . . , God treats me far better than I deserve.

**Troll - N.E. Florida**  
**Class of 2006**

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After my diagnosis, everything happened so quickly I never really knew what to expect as I chose surgery opposed to chemo and/or radiation as I live such a distance for those treatments. I had no idea that I would be unable to talk afterwards. I thought the Dr. would just cut out the cancer part and that would be it. Actually neither the doctor or any of the medical personnel spoke or told me what to expect afterwards.

I spent a month in the hospital and then three weeks in a rehab facility where I was later shown how to care for my stoma and when I was released still wore the cannula as well as having a g-tube. Also I then had a surgery for a fistula before going to rehab facility.

My surgery was described as a radical neck dissection with lymph nodes also removed. I did not suffer from depression immediately perhaps because I was working to get well and the truth of what had happened did not hit me until much later. So it is now that I get depressed but it is contained like my laughter or crying. I can do neither one fully. Also, I am saddened even now as there was radiation to my neck and throat and I did not know that radiation keeps working, but I know now. Am 87 years of age. Live alone in senior housing in rural Nevada. Doing okay.

**Virginia Johnson - Beaty, NV**

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I did suffer depression after surgery. I did well during the first part of surgery, and got my puncture for my prosthesis to talk, got the feeding tube removed, and could eat.

Then I had 37 radiation treatments. The first thirty were regular radiation and the last seven were higher power radiation. Then they did surgery on my fore arm called a free flap at the time so they could use that tissue to close a fistula. That didn't work so they had to remove my prosthesis and let the puncture close. This took a year and 35 under anesthesia surgeries. During this time my husband was very supportive. I don't know a day he did not see me.

As I was healing my mother passed. Then one day my husband came home and said he couldn't work anymore because his back hurt too much. They did some blood tests, X-rays and Cat Scan. My husband had five tumors the size of lemons throughout his torso. They tried chemo but his body wasn't tolerating it so they had to quit. So there I was with my husband that had been with me through everything and I nor the doctors couldn't do anything. Except watch him die.

Between my husband's death and my recovering from my throat surgery I was depressed for a long time. I am now living up north where we had planned to retire and where my son and his family live. They don't have support groups for laryngectomy up here. Also they do not have speech therapist who knows anything about laryngectomy up here. So I get most of my support from Web-Whispers and friends.

Thank you for letting me vent.

**Karol Beaufore – Alpena, MI  
1999-2002**

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It's now a bit over 25 years since my surgery and I can say that I have not suffered from depression during that entire time (at least as far as I and my family know). I was diagnosed with hypothyroidism as have many if not most of our elite group. This was about five years after surgery.

I'm firmly convinced that my lack of symptoms of depression were and are due to a number of factors. First, I don't think I'm genetically disposed to depression. Second, I have my family close by and see them regularly. Third, I'm actively engaged with my church community. Fourth, I am also engaged in the local community and they supported me strongly after surgery. Fifth, from the beginning I deliberately made all of the above groups an engaged part of my cancer diagnoses and the treatments for it.

I am, by nature, an introvert and self-sufficient. My late wife was an extrovert, even to extremes. By a combination of her pushing and shoving along with my own realization that I needed to be engaged with other people, I have made a continued effort to move outside of my comfort zone. It certainly helps that I am a fluent tracheoesophageal speaker using a hands-free valve with good success.

I can't guarantee that what works for me will work for all. But if you keep engaged with family and community even if it requires forcing yourself, get your thyroid hormone levels under control and seek treatment if depression shows, I think it will do wonders for your everyday enjoyment of life and peace of mind.

**Carl Strand, Mystic CT  
Radiation Summer of 1991, Laryngectomy February 10, 1993**

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You asked if I got depressed after my surgery and my answer is a resounding NO. Not for one minute was I depressed about it; I just accepted that that is the way life was going to be from then on. I have a very strong faith in God and I just figured there was a reason he had for having my voice taken away. One thing I have noticed is that it has brought me out of my shell. People used to call me "mouse" because I never said anything and now you can't shut me up. I figure my opinion is just as important as anyone else's, and I have never felt that way before. Oh one other thing I should mention that I can do now that I couldn't do before; I can sing on key!! Sorry to make this so long, but I told you, you couldn't shut me up.

**Christine Pieper- Midlan, MI  
Surgery 2000**

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I had a temporary fairly mild period of depression following surgery. It lasted on and off for a few months if I remember correctly. I was helped by a therapist who helped me realize that the depression was normal for what I was going through. This was a big help.

I think my personality has been effected by becoming a laryngectomy. I occasionally become discouraged when I am unable to participate in conversations with large groups in a noisy environment. I think the medical teams need to place greater emphasis on the mental impact of the surgery and do a better job preparing the patient for the possibility of depression and assistance if it appears.

**Richard Sipp – Midland, MI**

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I didn't go through a depression, I'm not sure why not but all I thought about was that I was alive. My sister lived with me and talked to me all the time. She was good at reading my lips and my pen writing. I also had a part time job and kept busy and tried not to think about not having a voice for 6 months.

When I got my TEP, it was unbelievable that I could talk. Sure I have my problems with the TEP but I deal with it 1 day at a time.

**Betty Belue – Winthrop Harbor, IL**  
**11/2005**

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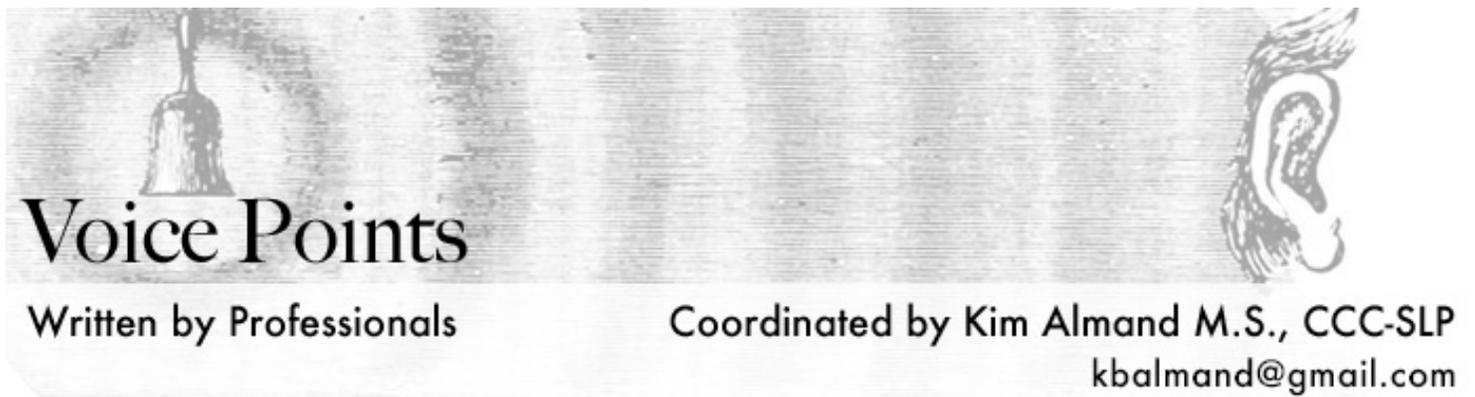
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**Next month's question is:**  
**"What method of speech do you use and why did you choose it?"**

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

Staff of Speaking Out



## **Manual Therapy: Background and Basics**

Do your patients have neck stiffness after radiation? Do they report difficulty accessing their stoma because they cannot lift their head after surgery? Have your patients ever experienced pain, decreased range of motion, or inflammation post-oncology treatment? Manual therapy may be an appropriate treatment option to add to your plan of care.

### **What is “manual therapy”?**

Manual therapy (MT) is an umbrella term. It is equivalent to describing something as ‘art’. Art? Does that

mean a drawing? Painting? Photography? Architecture? Music? Digital media? While manual therapy typically relates to a “hands-on” (practitioner placing hands on the patient) treatment, it can encompass palpation, massage, myofascial release, stretching, strengthening, thermal stimulation, kinesiotaping, and many other modalities. The goal of manual therapy is to reduce pain, increase range of motion, induce relaxation, reduce/eliminate soft tissue inflammation, and improve extensibility and stability to facilitate movement and improve function. The definition of MT can vary between states, regions, hospitals, and practitioners. Although there is no universal definition, you can turn to physical therapy current procedural terminal (CPT) billing codes to see an array of different uses of MT:

97140 Manual therapy: manual therapy techniques, such as mobilization and manipulation, manual lymphatic drainage, and manual traction.

97112 Neuromuscular reeducation: treatment of 1 or more body area(s). Improve movement, balance, coordination, kinesthetic sense, posture and/or proprioception for sitting and /or standing activities.

97530 Therapeutic activities: therapeutic activities, direct (one on one) patient contact by the provider (use of dynamic activities to improve functional performance).

97140 Electrical stimulation: electrical treatments that require "constant attendance" and therefore direct patient-to-provider contact.

97010 Hot and Cold Pack: hot or cold pack application.

Please refer to the Medicare CPT reference sheet for more examples. The codes listed above are used by physical therapy, and should only be used to further appreciate the breakdown of MT techniques. As a speech language pathologist, you will bill the CPT code for the deficit in which you are treating (example: dysphagia 92526).

### **Who provides manual therapy?**

Manual therapy has been practiced since 460 BC. Today, physical therapists, occupational therapists, osteopaths, massage therapists, physicians, acupuncturists, et cetera are incorporating MT into their daily practice. Manual therapy is now becoming recognized and used by speech language pathologists.

Is manual therapy effective?

Manual therapy can be very effective when the appropriate techniques and modalities are provided to the appropriate patient. Not all techniques and modalities are safe or effective for each patient; some may actually cause harm. It is important to have advanced training in MT modalities prior to application. A thorough understanding of your patient’s medical history is critical to ensure MT is safe.

### **Is MT effective for head and neck cancer survivors?**

Head and neck cancer survivors have typically been treated with surgery and/or radiation. Post-operatively, soft tissue changes can occur including tethering, muscle and skin tension, and scar tissue formation. Similarly, radiation therapy can lead to radiation fibrosis, a progressive formation of scar tissue. Both treatment modalities can lead to reduced range of motion, pain, inflammation, and poor quality of life, warranting manual therapy treatment.

More research is needed on the impact of manual therapy in relationship to head and neck cancer treatment. However, anecdotal improvement has been reported in cervical range of motion, dysphagia, voice, stoma care, tracheoesophageal voicing, and patient-reported quality of life following manual therapy.

### **Are there risks associated with MT?**

The manual therapist should proceed with caution or avoid manipulation if the patient has had recent surgery, a history of cardiovascular insufficiency, stroke, recent trauma, unusual headaches, vasovagal or syncope episodes, or carotid blockages. Medications should also be discussed prior to treatment to ensure there are no increased risk of bleeding or drug-related contraindications. Patients should be advised of all

risks prior to any manual therapy. Palpation, pressure, and technique are key components of MT. Knowing structures to avoid or when to use caution (i.e. carotid artery, jugular vein, etc) are just as critical to this type of treatment.

### **What training is available?**

Many speech pathology programs do not offer adequate training in manual therapy prior to graduation. Post-graduate training is recommended prior to implementing a hands-on approach into your practice. Although “manual therapy” can be perceived as a ‘catch all’ approach, it is important to fully understand the modality you are using and the risks associated with its use. Continuing education is starting to be offered by multiple vendors. MD Anderson Cancer Center speech pathology department also offers clinical observation of manual therapy for head and neck cancer survivors.

References and further information regarding observation are available upon request.

**Holly Woodall M.C.D. CCC-SLP, LMP, CLT**  
**Senior Speech Language Pathologist**  
**University of Texas MD Anderson Cancer Center**



### **Fiona's Story**

Last week a friend told me about a woman who had suffered a severe stroke. I'll call her Fiona to protect her privacy, though that's not her real name. I didn't know her myself but several of my friends knew her quite well. The stroke came totally out of the blue. She had been feeling fine, full of energy, busy as ever. Then one day she suddenly felt rotten. So sudden and so rotten she had the good sense to get herself into the emergency department of a hospital. There she suffered what turned out to be a second stroke, this time a major one. She lost consciousness and when she woke next day, she couldn't speak or move one side of her body.

I find it hard to hear stories like this. My mind wants to skirt around them, minimise their impact. They remind me of waking from the laryngectomy operation and finding I couldn't speak and, in the post-anaesthetic

weakness, couldn't move my body. That is a memory I don't like resurrecting.

It wasn't always like this. A few years ago (pre-laryngectomy) I would have been much more willing to think about Fiona, ask about how she was doing, listen to my friends concerns for her. Sympathy flowed more easily then. In fact I found bad news easier to relate to than good news! There was some comfort in talking about misery. Funerals were easier on my psyche than weddings. I knew how to be sad. But somewhere between youth and middle age, I'd forgotten how to be happy. It felt false, phoney.

Surprisingly, laryngectomy helped me balance out a bit. Although 99% of my post-op experience was horrible, there were moments without horror. These were always unexpected. During my first day after surgery, anxiety was like a radio blaring an endless sequence of bad news in my ear. For a few blessed moments, that radio switched itself off while my friend Margaret held my hand. Perhaps it was only three seconds out of hours and hours of turmoil. But I will never forget those seconds. They gave me a taste of peace such as I hadn't ever experienced. They showed me how much I needed compassion and care to keep me sane in my post-laryngectomy nightmare.

Peace is such a quiet experience. It doesn't clamour for attention the way anxiety does. If it were a normal day I would scarcely have registered Margaret's hand touching mine. My mind would have been too busy with thoughts and plans to pay much attention to simple sensations like softness and warmth. But the transistor's sudden silence brought them to my attention. Those few seconds told me that, despite the news-reel of horror looping endlessly through my mind, some deep part of me could, with the help of good friends, be absolutely fine with laryngectomy.

There were other pleasant surprises too. During my first visit home, I found myself walking around almost in a daze, touching walls and door handles, wondering how come I'd never appreciated their beauty till now. When I recovered enough to do some household tasks like chopping carrots or sorting through the recycling bins, my mind soared with angels. To think that I could contribute useful to the world! That I might find a niche! It was too wonderful for words. At Christmas dinner I discovered I had a family. My eyes swivelled from face to face, marvelling that I could belong to such a wonderful clan, amazed that I had never before felt so delighted by them all.

I'm not saying I was in paradise. Quite the opposite – much of the time I was miserable because of not being able to speak. But those moments when the veil of misery lifted were always marvellous. There was nothing concocted or phoney about them. They came when I was most relaxed. Laryngectomy proved to me that joy wasn't phoney. That it was waiting patiently for me to relax and trust to its presence deep within.

The mistake I'd been making was to think that happiness would come as a reward for all my efforts. Efforts to be a success, to impress people, to get on top of things. When laryngectomy stripped away these possibilities, it gave me the surprising news that happiness had nothing to do with success or impressing people or getting on top of things. It was to be found in simple, unexpected, ordinary moments – touching walls and door handles, chopping carrots, looking into faces that I'd previously taken for granted.

As I recovered and Ellie (my electro-larynx) started to croak a few words on my behalf, I began to engage

with situations more fully, take on more responsibilities. Sadly, the old habits of striving to succeed and get on top of things returned. But I keep reminding myself that that these aren't the source of happiness. That I'm already as happy as I need to be, deep down, underneath all my protestations to the contrary.

Now that I've written that much, I find it easier to think about Fiona, and how she might feel to find herself suddenly unable to walk or talk and with no idea if these wonders will ever come back. Perhaps a transistor radio tuned into anxiety is blaring in her ear. It's also possible that she's noticing precious moments when the radio switches off. While a friend holds her hand perhaps, when her brother kisses her cheek. And so, it is also possible that a stroke, like laryngectomy, is the teacher none of us want, but all of us need. The teacher that says stop striving for this, that and the other. All you really need is right here, right now.



## Celebrate Life

We had many thought-provoking and inspiring responses to this month's Speaking Out question on depression. So many, in fact, that we debated dividing the entries over our April and May issues. In the end, we decided to print them all here because, seen in the aggregate, it paints a powerful picture of our lives as laryngectomees. We are a tough bunch, not given to whining and possessed of what used to be called "intestinal fortitude". Most everyone admitted to some rough patches but even those who really struggled with depression and for some folks that is an ongoing struggle said basically the same thing: we are glad to be alive and we do the best we can every day.

The more I read and re-read the entries the more I wanted to know about these fellow warriors. Some I have met in person, some I know via WW over the years and some names were new to me but I wanted to reach out and get to know each every one better....get to know our WebWhispers Tribe better. So, I started to do a little research – calling on my limited recall of a Survey Methodology course years ago and came up with some interesting numbers.

We had 21 respondents. Our average over the last 15 months has been between 14 and 15. Our respondents this month tended to write longer more detailed responses as well. The 21 was pretty evenly divided among men and women (11 male/10 female). Of the 21, 11 said they had experienced significant enough depression to warrant mention and/or treatment; 10 did not. Of the 11 who experienced depression, that, too was pretty evenly divided among men and women; 5 men to 6 women (although statistically that represents a higher average for women – 6 out of 10 vs 5 out of 11 with this small sample that is relatively insignificant). And of the 11 who reported depression, 6 said they had sought professional help resulting in

medication. To me, this says we are pretty evenly affected. And as more than one person noted, it is not surprising nor anything to be ashamed of considering all that we have been through. Help is available and no one should feel embarrassed if you are struggling nor should you be intimidated by those hearty souls who seem to just effortlessly pull themselves up by their own bootstraps! Frankly, I am willing to bet good money they have dark nights (and days, too). However, clinical depression is a serious condition. It is not something we can think or will ourselves out of. I do not want to in any way minimize its severity. It requires professional/medical care.

Situational depression is different and it is frequently what we face as larys. While I was musing over all this, I saw something on PBS which just resonated with me as we struggle to come to terms with the challenging hand we have been dealt....

*In our culture we've come to think of death as a kind of failure, whether of medicine or survival instinct, rather than seeing mortality as built into all of our days, the first as much as the last. Viewing death as unrelated to life, or antithetical to it, does a disservice to the days we have, because we don't know how to value them. We enjoy a movie more knowing it's going to end in a couple hours. So we don't run out for popcorn in the middle, because we don't want to miss anything. That ski run in the Swiss Alps? It's only fun because you know there's a bottom.*

*The end of the run gives each curve meaning, even when you're still near the top of the mountain.*

*I've heard this acceptance of death from most of the older people I've spent time with. But we don't have to wait until we're 91 to enjoy it. We should rethink what it means to live every day as if it's your last. The way I learned it from John, it means embracing that part of the end that exists in this moment, and then in the next. You don't have to quit your job or stop paying your utility bill. There's enough to live for in the things you're already doing. You can feast fully on each brush with a stranger, each moment with friends, each kiss or caress. There's a little bit of mortality in all of them. And that, I learned, is reason to be happy.*

<https://www.pbs.org/newshour/nation/opinion-what-a-91-year-old-taught-me-about-appreciating-death>

It is very hard some days to celebrate the life we have but we have no choice but to move forward- Carpe Diem, my friends, my fellow warriors.

## Bits, Bytes and No Butts!



**Frank Klett**

## Vivaldi the Browser, Amazon Prime Fresh, Facebook Under the Gun

If you haven't yet heard of it, you will!! The new browser called **Vivaldi** has been making a very respectable name for itself. In spite of its relative newness, this browser has sought to incorporate a number of the most desired features in a browser; many of which **Firefox and Chrome** should have had and may now need to add to their existing arsenal.

One of the most complete reviews I have read on **Vivaldi** is from Bob Rankin. [Here](#), minus all the tech jargon, Bob has laid out an excellent picture of this latest addition to the browser wars:

[https://askbobrankin.com/vivaldi\\_may\\_be\\_the\\_real\\_chromekiller.html](https://askbobrankin.com/vivaldi_may_be_the_real_chromekiller.html)

Recently there have been several disclosures from both inside of Facebook, as well as out, that there have been gross violations of your personal information. They come amid intensifying scrutiny from users, regulators and lawmakers over Facebook's admission on March 16 that user data was improperly obtained by **Cambridge Analytica**, a data-analytics firm that worked for the 2016 Trump campaign.

While this has been an ongoing rumor for the Facebook community it has now been confirmed by the Supreme Guru of Facebook, Mr. Mark Zuckerberg. The revelations have created a \$95 Billion reduction in the value of Facebook. To make matters worse and even closer to home Facebook has been recording and monitoring your communications while in Facebook and while using the Facebook Messenger app.

For those of you who use the FB Messenger app, you might want to read over this article from Bob Rankin:

[https://askbobrankin.com/just\\_say\\_no\\_to\\_facebook\\_messenger\\_malware.html](https://askbobrankin.com/just_say_no_to_facebook_messenger_malware.html)

Text Neck is a somewhat new and just recently diagnosed condition caused by...you guessed it, holding one's head in a downward position for a long period of time...no, not caused by smoking!

There are actual studies being conducted to help identify and hopefully resolve the issues that are arising from our new technologies. The following article from CNET provides more info:

[http://www.cnet.com/how-to/how-to-avoid-text-neck/?ftag=CAD3c77551&bhid=226895098013186124502399137427\\_62](http://www.cnet.com/how-to/how-to-avoid-text-neck/?ftag=CAD3c77551&bhid=226895098013186124502399137427_62)

You can even find apps to help you through this pain in the neck!

**Amazon** is adding even more convenience to our shopping needs...enter **Amazon Prime Fresh!**

Newly launched **Amazon Prime Fresh** is a grocery/food ordering system that provides Amazon's Prime members with total grocery and food shopping services including same day delivery service. This service is being offered in limited markets for now, but will soon be expanded to the entire Amazon marketplace.

**Amazon Fresh** is being offered with a 30 day free trial, after which there is an annual fee added on to your **Prime** membership fee for a total of \$299. This covers all delivery charges, except tips.

The service offers food and other meal offerings from local markets and prepared meals from many of your local favorites. To get more info and to see if you are in an area that is currently being offered this service go to:

[https://fresh.amazon.com/MembershipBenefits?pf\\_rd\\_s=slide-4&pf\\_rd\\_p=2506664842&pf\\_rd\\_t=101&pf\\_rd\\_i=1&pf\\_rd\\_r=14JZST9Q6JJ2J98HATX7](https://fresh.amazon.com/MembershipBenefits?pf_rd_s=slide-4&pf_rd_p=2506664842&pf_rd_t=101&pf_rd_i=1&pf_rd_r=14JZST9Q6JJ2J98HATX7)

**Windows 10** has been out for almost a full 2 years now and we are still finding new commands and uses for its many features. There is app for "**Contact Support**", **Quick Access for File Explorer**, and once again the **GodMode** option. **Bob Rankin** has rounded up the newest insights for Windows 10 and the ways we can

make it work better for us. If you have never used the **GodMode** before Bob tells you how to set it up and make your life with Windows 10 much easier:

[http://askbobrankin.com/ten\\_windows\\_10\\_features\\_you\\_didnt\\_know\\_about.html?awt\\_l=CasIU&awt\\_m=lqL4EY\\_LweP6SL](http://askbobrankin.com/ten_windows_10_features_you_didnt_know_about.html?awt_l=CasIU&awt_m=lqL4EY_LweP6SL)

In general, the current pricing for PC's and laptops has remained at a fairly affordable level. The manufacturers have taken the old ideas for marketing hot new features and cooled them down considerably. It seems they found out that the vast majority of buyers were no longer interested in the speed and flashing lights. Rather the buying public simply wanted better value for the money they laid out. Add to that the vast improvements made in operating systems by both Microsoft and Apple have created a much more knowledgeable buyer. Today you can purchase a very capable laptop for less than \$300 and less than \$200 if you consider a Chromebook. All in all it is a buyer's market and this trend seems to be the tech marketplace for the next decade.

For all you Apple users, Google has finally broken the window to allow users to install Google products such as the Gboard for the iPhone and iPad. It is Google's newest keyboard for the Apple Community. As usual, the 3rd party add-ons for any product go a bit further to satisfying the needs of the users. Head over to the link below and check out the latest Google offerings for the Apple World:

<https://itunes.apple.com/us/app/gboard-search.-emojis/id1091700242?mt=8&ign-mpt=uo%3D8#>

Our **WebWhispers library** at <http://www.webwhispers.org/library/library.asp> is one of best ever sources of any information that a Lary could need. If you have never spent time browsing through it you may want to consider taking the tour. While you're in the browsing mode stop in to our **Forum** pages and visit with **Mike Csapo** and your fellow larys and if they aren't there they most likely are in the **Webwhispers Facebook** page catching up on the latest news.



**Betrayal!**

*This was first published in August 2012 by guest columnist, Jeanette Thomas. Jeanette is a retired water plant manager, artist, long-time friend, companion and care-giver to Jack Henslee. She is friend to many in the WW lary community and has attended two IAL meetings and WebWhispers' banquets. ~ Editors' Note~*

It strikes like a lightening blot. It knocks you to your knees. It takes your breath away.  
Depression weighs on you. It pulls you with an iron grip into a pitch black bottomless pit of despair.

Obsessive thoughts play in a loop of destruction – over and over and over, no rest, no peace - wrenching all hope from your grasp, destroying any sense of self esteem, beating you down – It must be your fault. It's all you. You are to blame.

Anxiety and fear are constant companions.

Tears and heartache are never ending.

Each day is a little darker – no joy, no desire, no love, no life, NO HOPE.

Life is not worth living.

Don't want this struggle any more.

So very tired, incredible weary...Just want to let go.

God help me - Just let go.

Resolve finds a foothold, refusal to surrender.

Friends, family, doctors, therapists, medication - love stops the downward decent, offers a life line, a hand up, a way back, HOPE.

Finding the courage to change – to let it go - shows you the way.

Slowly, ever so slowly - Acceptance is the pathway to peace.

Jeanette Thomas

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