

# Whispers on the Web

A Monthly Online Newsletter for WebWhispers

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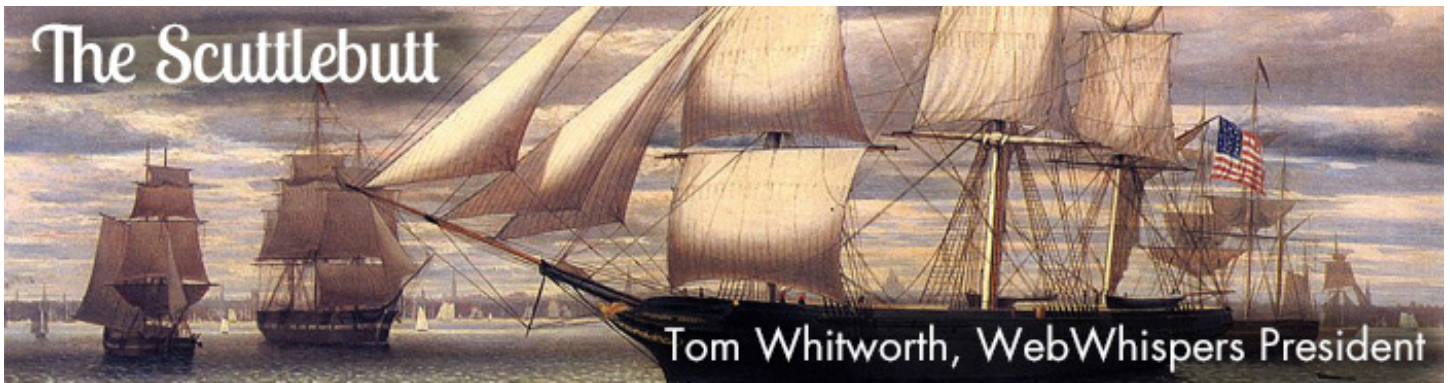
*February 2019*

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## What are YOU Doing?

Aesop's fable "The Flea and the Ox" talks about the strength and size of the ox in comparison to the weakness and vulnerability of the flea. Somewhere along my way, I heard a different version of the story. I am not creative enough to have made this up and the version I share with you here resonates with me in a far more meaningful way.

As this story goes, a farmer lived on one side of the village and had to pass through it to the other side to the land that was his to farm. At dawn of day, he and his ox would walk through the town, along with a flea riding on the nose of the ox. Every day, the people would ask the farmer where he was going. The flea always responded first, saying "WE are headed to the land WE farm to provide food for the village. WE will work all day in the hot sun to do this". Each day, the farmer and the ox worked all day in the heat. All the while, the flea rode on the nose of the ox. Just before dusk, the farmer and his ox would pass back through the village. The people would ask "where have you been all day?". The flea

would reply "WE have been working our land in the heat of the day to provide food for you. Obviously, the farmer and the ox worked diligently every day. The flea was just along for the ride. Most of us need to be a flea for a time. At some point, we should ask ourselves "am I an ox or a flea?"

We larygectomees, and caregivers for that matter, have surely done our flea time. Some of us have been in flea mode for much longer than others and for good reason. The problem comes when our time to ride along is over and it's time to be an ox and carry someone else. That is when we truly make use of what we have been through. When you feel the urge to help others, you are there. Opportunities for oxen abound. If you need help finding yours, let us know.

*"Life's most persistent and urgent question is, 'What are YOU doing for others?'" – MLK, Jr.*

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






# Voice Points

Written by Professionals

Coordinated by Kim Almand M.S., CCC-SLP

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## Cancer Related Cognitive Changes The Role of the Speech-Language Pathologist

Nina Shahin, M.S., CCC-SLP  
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Mercy Hospital and Medical Center, Chicago, IL.

A common complaint made by adults with a diagnosis of cancer is changes in cognitive performance. This has been described as cancer related cognitive impairment (CRCI). Deficits reported include impaired working memory, executive function, concentration, processing speed, and word retrieval. In addition to CRCI, individuals also report psychological impairments such as stress, anxiety, and loss of sleep. These psychological impairments add a complex layer of factors that impact cognition and function. The purpose of this paper is to briefly discuss the above factors that may impact cognition and the role of the speech language pathologist (SLP) in the care of the adult cancer patient.

Although multiple studies have established a correlation between cancer and cognitive impairment, questions remain regarding the cause. The phrase “chemo brain” is a popular term referring to cognitive deterioration which may be related to the neurotoxin effects of chemotherapy. Research has shown that the central nervous system (CNS) is susceptible to forms of toxicity from chemotherapy agents (Soffietti, 2014). Research focusing on neuro-imaging techniques has shown changes in gray and white matter and changes in activation patterns when studying patients who have received chemotherapy (Simo, 2013). However, abnormalities in brain activation patterns have been seen in patients prior to chemotherapy as well (Berman et al, 2014). As SLPs, we need to recognize that impairments reported by patients are more likely to be a combination or multitude of factors, namely:

- There are psychological consequences to critical illness. As defined by the American Psychiatric Association’s (APA) DSM-IV and DSM 5, Post Traumatic Stress Disorder (PTSD) may occur with a life threatening, catastrophic medical illness or diagnosis such as cancer. A meta-analysis completed by Swartzman et al (2017), found that cancer survivors have 1.66 times the odds of PTSD compared to controls with no history of cancer. The presence of PTSD can result in stress, anxiety and depression which may impact sleep and result in fatigue and difficulty concentrating. Additionally, pre treatment worry has been linked to altered brain function in breast cancer patients (Berman et al, 2014). This may suggest that intervention address the psychological consequences of the illness prior to the initiation of cancer treatment.

- The role of surgery, radiotherapy, genetic factors, hormone therapy, and disease related biological factors may contribute to some cognitive impairment.

- According to the National Cancer Institute (NCI), advanced age is a risk factor for many types of cancer and NCI statistical data reports that the average age of a cancer diagnosis is 66. Since it is more typical for older adults to be diagnosed with cancer, we need to consider cognitive reserve, the role normal aging has on cognitive performance and neurological susceptibility to treatment affects.

Therefore, the term “chemo brain” doesn’t fully reflect the complexity and etiology of the cognitive symptoms and future research is needed to better understand why cognitive changes in adult non-CNS cancer may occur. Future research may also be beneficial to shed light on such aspects as prevalence and persistence of CRCI in addition to management techniques and pharmacological interventions. Regardless of the position of chemotherapy on cognitive function, there

is no question that, SLPS's are in a unique position to assess and treat cognition, identify potential confounding factors that may impact cognitive function, and make referrals accordingly.

The SLP may serve as a pro-active healthcare team member by establishing an inter-professional program (e.g. physicians, nursing, dieticians, social work and neuropsychology) to address education and intervention. The role of the SLP may include, but not limited to, assessing the patient pre and post cancer treatment and providing education related to the family, caregivers and healthcare team and provide cognitive rehabilitation as needed.

### **Assessment**

In regards to testing, the literature has suggested that patient reported measures may not be the most reliable correlate of cognitive impairment. We should instead screen the patients using short, objective neuropsychological batteries with alternative forms. It may be beneficial to review publications by The International Cognition and Cancer Task Force (ICCTF) which was established to harmonize research studies/methods and create recommendations for best practice guidelines for cancer related cognitive impairment.

### **Cognitive Rehab and Psychosocial Support**

A primary goal of CRCI therapy includes education and awareness relating to the cognitive impairment in addition to compensatory strategy and potentially cognitive drill training. Team members may also encourage and educate the patient regarding neuro-protective lifestyle practices including exercise, social engagement, cognitive stimulation/new learning, sleep hygiene, stress reduction and optimal nutrition via an inter-professional approach. Providing patients and caregivers with actionable steps may allow the patient to reduce the impact of the disease and disease treatment on their cognitive function. As previously stated, treating the patient may address the often concomitant psychological effect of the disease, which can often have a greater impact than the disease itself. Optimal treatment of cancer related cognitive change is truly a team approach.

In summary, with increases in survival rates, medical professionals serving these patients may focus not only on the cure, but also improving survivorship and quality of life. By increasing our knowledge of the relationship

between cancer treatment and cognition, the SLP may develop an understanding of the compounding factors that influence cognition which allows better education, treatment, support and counsel for the individual throughout the phases of cancer treatment. In addition, the SLP may serve as a communication catalyst among the healthcare team. In short, the optimal "treatment" of cancer and the related cognitive changes associated requires an interprofessional approach in which the patient and the patient's needs are addressed in a comprehensive manner; mind, body, spirit, and support system. Herein lies the true role of the SLP.

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*American Psychiatric Association. (1994) DSM-IV-TR.: Diagnostic and statistical manual of mental disorders. (4th ed.). Arlington VA: American Psychiatric Press Inc.*

*American Psychiatric Association. (2013) (DSM-5). .: Diagnostic and statistical manual of mental disorders. (5th ed.). Arlington VA: American Psychiatric Press Inc.*

*Berman et al. (2014). Pre treatment worry and neuro-cognitive responses in women with breast cancer. Health Psychology, 33 (3): 231*

*Simo et al. (2013). Chemobrain: A systematic review of structural and functional neuroimaging studies. Journal of the National Cancer Institute, 30 (8), 1311-1321.*

*Soffieti et al. (2014). Neurological Complications of chemotherapy and other new experimental approaches. Handbook of Clinical Neurology, 121: 1199-1218.*

*Wefel et al. (2011). International Cognition and Cancer Task Force recommendations to harmonise studies of cognitive function in patients with cancer. Lancet Oncology, (12), 703-708.*

# Between Friends

Donna McGary

*"That which does not kill us makes us strong."*

Photo CC by Corack5239

## Telling Our Stories

*"My friends have made the story of my life. In a thousand ways they have turned my limitations into beautiful privileges."*

~ Helen Keller

Turning limitations into beautiful privileges is a tough concept for me to grasp. But then, Helen Keller was a remarkable woman. I suspect most of you know who Helen Keller was and have read the book and/or seen the movie or play.

But, just in case...she was born in 1880 and became blind and deaf at the age of four due to an illness; overcoming huge obstacles, she became the first deaf/blind person to earn a BA in the United States. Her story of learning to communicate with her teacher, Anne Sullivan, was the basis for the book, play and movie, "The Miracle Worker", which won numerous awards. She went on to become a renowned author and outspoken political activist for progressive causes. Helen Keller died in 1968 and by then had become well known world-wide. She counted among her friends such disparate individuals as Charlie Chaplin, Alexander Graham Bell and Mark Twain. (I googled her bio for this article, but she was one of my heroes as a little girl, after I read "The Story of My Life", her autobiography.)

Frankly, most of our troubles pale in comparison. However, our troubles are pretty unusual and can also be very isolating. The ability to communicate is central to our well-being. Practically all life shares that ability, and need apparently, in one form or another, but human beings are unique, so far as we know. We remember the past and imagine the future and we use our experiences to express our thoughts. Losing our primary means to communicate can be devastating, but when we share our thoughts with others some extraordinary things start to happen.

"The Miracle Worker" was not such a huge success because so many folks shared her situation, but because people drew strength and inspiration from her story to fight their own battles against adversity.

I truly believe that each of us has an important story to tell. It may not win us a place on the Best Sellers' List or a

NY Times Book Review, but that doesn't mean it is not an important story that needs to be told.

What if you wrote your journey down, in your own words, in your own way and even one person wrote to you saying, "I thought I was alone and no one understood, until I read your story. Thank-you." OR "You wrote exactly what I was thinking. Nice job." How would that make you feel?

Pretty darn good, I bet.

You have that opportunity. I know I sound like one of those advertorials...well, I guess I am, in a way. I believe that the power of WW is in our stories and I want to use your stories to expand our reach.

Think of telling your story as paying it forward. You never know who it may touch.

Just check out this issue alone...your responses to the Speaking Out question about larynx transplant were both thoughtful and poignant. Did you know that "chemo brain" is real and NOT limited to just those of who had chemo? It should be called "cancer brain" according to VoicePoints this month. How about Noirin breaking her silence to explain why she treasures it so...plus the humorous tales from Len Hynds. We ALL have a voice here. Caregivers, professionals, patients, friends, family, even "the kindness of strangers" all have a story to tell and we provide a place to share that story. Please give some thought to sharing your journey with us. I would love to hear from you. Don't worry if you think "I'm not a writer". Most of us weren't writers either before we lost our voice...only to find it...different to be sure but we still found a new voice. Whispers on the Web is a safe place for you to exercise your "new" vocal cords!

Contact me at [editor@webwhispers.org](mailto:editor@webwhispers.org) or [dllmcagar@comcast.net](mailto:dllmcagar@comcast.net)

I look forward to hearing from you!

Donna

# Stand By Me

## The Caregivers Journey



### You Were There

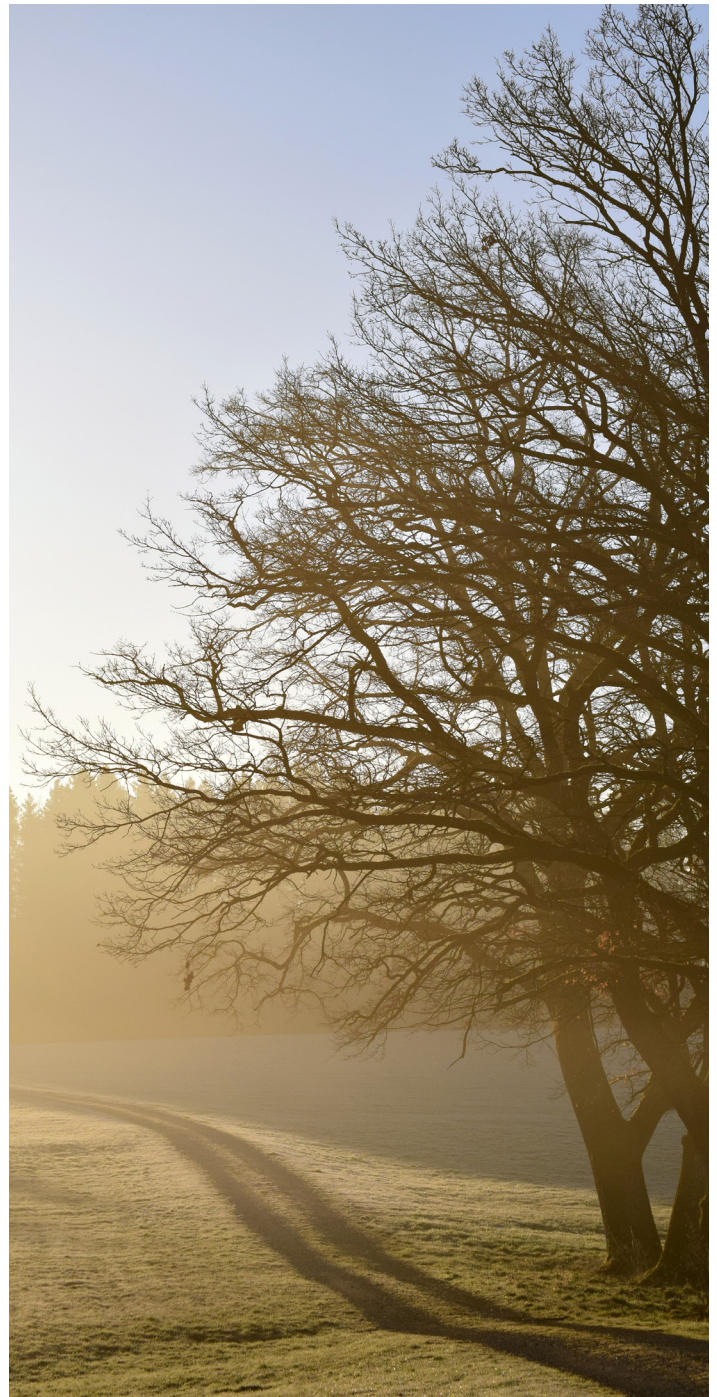
*Editor's Note: Jack Henslee wrote this years ago as a tribute to his wife and other members of his local lary club. I think it is so meaningful because we never know who will stand by us but it could be anybody...and everybody. I like that he simply says thank you that you were there when I needed you.*

### You Were There

Yesterday is a vivid image of despair  
Transformed to a brilliant prism  
Reflecting the warmth of your love.  
The void of solitude, imagined or real,  
Was gently filled by your presence.  
Sweet dreams soothed the fears  
And imagined terrors never happened,  
Because you were there.

The quest for tomorrow, however uncertain,  
Began with an assault on doubt.  
The path was steep, with little support  
For someone that seemed all alone.  
Destiny's journey slowly weaves  
Through shadows that mask the unknown.  
Many times I slipped, but I never failed,  
Because you were there.

Today is different from what was,  
Or might have been.  
Selfish ambitions, once so natural,  
Diminish each day, no longer of value.  
You gave me strength to face the challenge,  
Becoming forever my best friend.  
Each day is cherished, full of life,  
Because you were there.



# Dear Lary

Noirin Sheahan

## Other Voices

Most years I get a long retreat during winter and happily it's worked out this year too and I've been at a little meditation centre in Wales for past few weeks. It's a simple life, no radio, TV, internet (I'm breaking out to get this piece to Donna!), or even chatting – which sounds pretty awful till you try it and see how restful it is. We alternate between sitting and walking meditations throughout the day, the idea being to get more familiar with the fascinating mind-body systems we occupy. All the while that same system is learning which of our habitual reactions cause misery and stress, and teaching us how we might alter our thought and behaviour patterns for a tad more peace and ease.

These can be hard lessons – we have to be prepared to feel the pain we cause ourselves by tendencies like impatience, self-doubt, getting lost in daydreams etc., so that the system can remind us more confidently not to keep indulging these habits in future. The hardest lesson of all is that this is a system, and that I'm not in control! The best I can do is set aside my preferences for the way I 'ought to be' and just watch my body-mind system finding the best way to get itself into harmony with the world. Occasionally, it gives me suggestions – like 'time to put a bit of heart into this', or 'have patience, pull back a bit' which I do my best to follow. But when I overstep the mark and try to take the lead, deciding how things should proceed, the system goes into revolt! Very humbling, to have to take instructions from a tense jaw, a fluttering stomach, a stern forehead! Hard lessons, but I always appreciate the deeper peace I come away with afterwards.

We also do a morning and evening chant together, and I've noticed this year, that it's become easier for me to listen and appreciate the voices of others. Pre-laryngectomy I would have been too busy chanting to really hear the voices of others. I would have been listening out for the pitch, the rhythm, rather than just listening. And as I don't have such a musical ear, it was always a bit stressful to work out whether I was keeping in tune. At least that source of stress is over now! At times, I feel moved to join in silently. In my heart it feels as though I'm singing and my throat muscles move as if to get my voice box going.

Of course this can also bring up the sadness. The body-mind system might withdraw into a black sulk. But I don't worry about this – I'd understand it as part of learning how to accept what is after all, a very deep loss. I think it's helpful to think of laryngectomy as a bereavement. Only if we allow ourselves to mourn the loss of what we loved can we move on. Otherwise, there will be an aspect of our past that we won't be valuing.

That value struck me very deeply when I started watching TV a couple of months post-laryngectomy. I would be almost mesmerised by the fact that all the actors could speak so fluently – it seemed like such an amazing skill! I got a really lovely feeling from this – as if I was watching graceful gymnasts. Even the little children could speak! I didn't get the same buzz out of the people around me speaking – probably too much negativity about not being able to join in. But watching a film on TV, there was enough distance to be able to marvel at the incredible skill involved in fluent speech.

Now, as I listen to the others chanting, that thought sometimes comes back again – what a wonderful gift you have. It's a genuine admiration and gives me pleasure. Even if my system soon curls up around a biting edge of jealousy or anger because I no longer share this gift, or tremblings of remorse that I didn't always use my voice to good effect, I sense worthwhile progress in being able to value other's voices nowadays. Apart from us laryngectomees, I'm sure there are few people in the world who give a second thought to the gift of fluent speech. It could be a way of channelling the wisdom we've gained from going through this journey. Our insight into a little-recognised wonder of the world! All it would take is to listen to others' voices, tones, accents a bit more attentively, to marvel a moment at this amazing ability they are showing.

And if the momentary admiration soon turns to grief, that's OK too. All part of the healing process.



## Would You Do A Larynx Transplant If Possible?

I have been a lary for nearly nineteen years and at this point in my life I have had it up to my neck (literally and figuratively) with surgeries. I have managed to get by with an EL these past nineteen years and it works well for me over 95% of the time so I would opt out of a larynx transplant surgery. I am pleased however that perhaps somewhere on the horizon this surgical option may be implemented, perhaps even at the time the laryngectomy surgery is performed by growing a new larynx from the patients stem cells in a petri dish. Medical science has great potential for just such a thing.

**Michael Csapo - Twentynine Palms, CA  
Class of 2000**

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I do not believe I would be interested in a larynx transplant. I have been a lary for almost nine years now and I am comfortable with my situation. I am in good health and have virtually no restrictions on my activities. I am told that I have a very good TEP voice and I have my cleaning and maintenance requirements under control. At 71 years of age I don't think I would be willing to undergo another larynx operation and the recuperation that would follow. I currently have a very good quality of life and I am not sure that a larynx transplant would add to my physical, mental, and emotional well being.

**Jim Olcott - Bakersfield, CA  
2010**

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I do not know that this will be of any interest to you re your question, however will give you some input. I am 88 years old and had tracheotomy when I was almost 82, a radical neck dissection plus lymph nodes, radiation at time of surgery plus have had 5 dilations of esophagus since. No prosthesis. Only esophageal speech at most. Had a transplant been available at that time, yes, I would have gladly, but certainly not now.

I live in a rural area in Nevada, and doctors and hospitals are a great distance plus available transportation is a rarity. Caregivers, a rarity too. I live alone. No family is left. Am fortunate to have a nephew here who does what he can helping me with shopping and transportation to my ENT cancer doctor in Las Vegas, a 3

1/2 hour round trip. Realize this is undoubtedly way too much info and that hopefully you will edit it if you even use it, but I wanted to give you some input, as your web whispers help from everyone is so appreciated and has certainly aided me immensely in getting through so many of my scares and ordeals.

Sincerely,

**Virginia Johnson - Nevada  
2012**

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NO, thank you very much! The reasoning behind that is as such: I would NOT want to be the person pioneering something so experimental in replacing something that I've gotten used to being without or if that was among my first set of options - no and due to the uncertainty. There are too many unknowns in this scenario. It's like opting to go in for plastic surgery, NO thank you. I may need it but it's not necessary for me to survive. I can carry on with something that has been removed and operate fairly efficiently (or so I think) - but I don't need the extras as the convenience doesn't have any significant value to me. I've learned that talking is overrated at times anyways ... BUT that's just my tune and my opinion. So for me, I would NOT opt the transplant (given what I know NOW)...and while I like my medical team, docs and staff, I don't like them that much to pursue that as an option at this point ;-). It just seems like a convenience bubble to opt...and not up my alley or on my dashboard or bucket list. That's actually why I didn't pursue getting a TEP as well.

**Lisa O - Chicago  
8/2017**

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I had never heard about the possibility before this email. I googled it and found the 2nd person to have this surgery. I would do it in a heartbeat if I could. Having a real voice back would be music to my ears and let communication go back to the way it was before I lost it. The ability to speak normally would be a gift that I would be constantly grateful for, knowing what it is to lose it. I am amazed that it is even possible.

**Karyn March - Greensboro, GA  
Sept 2012**

Easophageal Speech can only work for about five percent of Larys. Not everyone who can talk, can sing. Likewise, not every Lary can do ES. Structurally impossible.

Considering all this, there is a crying need for an updated solution for Larys. Such a state of the art relief for Larys, is long overdue. I am glad it is being thought of. I would any day, do a Larynx Transplant. The quality of life for transplanted Larys will certainly be far superior.

Yes, I vote for it!

**Mohan Raj - Bangalore, India**  
**Lary, Mar 2010**

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First throat cancer 1979. Chemo and radiation. Reoccurring 2008, surgery. Never smoked.

I would have the transplant. To speak again would be good. But most of all to sing in the choir and sing hymns. It brings tears to my eyes when I hear some of them and I can't join in.

**Jeanette Bostrom-Eastham - Mason, Michigan**  
**Laryngectomy and Partial Glossectomy 2008**

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I heard some time ago that the possibility of larynx transplant was being worked on; however, money for the research wasn't available. Good to know there may be some progress. That sounds like a dream come true; however, what is involved. I'm a 10 year survivor and well-adjusted to using a Vega TEP. Being a woman, I would love a more feminine voice but happy to just be able to communicate. The looming question is "what is involved". So many questions! Sounds intriguing and I pray this option progresses for the younger larys.

**Marian Cure - Plano, TX**  
**2009**

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Oh my goodness, I'd do it in a minute, if it were possible to get a voice like the one I lost. I don't know about such surgeries, how possible they are, but I am now trying to communicate with my electrolarynx, waiting for a TEP which I understand has its own problems.

At this moment my eldest daughter, who lives in the Bay Area, is very sick, and I can't talk to her on the phone. I can FaceTime and squawk at her, but it is so not the same!

**Anne Pitkin - Seattle**  
**Nov 6, 2018**

Because I am over 5 years out from my original surgery and speak using an electrolarynx, I am just not enamored with the idea of going through a difficult transplant. More meds and the possibility of organ rejection don't appeal to me at my age. Also, would I have my own voice or that of the donor? With a few exceptions, everyone is able to understand what I say, even though it sounds robotic. The only problems I've encountered are on the phone when answering verbal computer questions—the computer has no idea what I'm saying—and that goes for Siri on my iPhone, too.

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

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Were you asking as a hypothetical question or literally seeking people available for a transplant? I like the idea but having just gone through major throat surgery I need some time to see how this goes before committing to another surgery.

**Josh Bowers - Maryland**  
**October 16, 2018**

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Yes I would do a larynx transplant if the procedure was available because I would love to be more active in the civic affairs effecting my community, city and state but because of my speech limitations I cannot or should I say that I don't feel comfortable speaking to a large audience.

**George Newman - Baton Rouge, LA**  
**Feb 6, 2015**

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Yes, in a hot second.

- Normal volume.
- Sound without hands.
- Not choking in the shower.
- Dry air is only inconvenient.
- Swimming and other watersports.
- So much less goo.

**Julian Sammy - Toronto, Canada**  
**2015-08-17**

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No. I would not agree to a transplant. It is risky and you would have to take medicine for the rest of your life for it.

**Robert Hurd - Germantown Hills, Illinois**  
**March 2005**

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Regarding your survey, I would like a Larynx transplant.. Surgery was done at Johns Hopkins in Baltimore, Md. At which time my larynx and tongue were removed, and I have not spoken since that operation.

Due to the radiation I had, the Electro Larynx does not work very well. I feel like I should take out stock with Staples considering the amount of notepads I go through.

How is it that we can put men on the moon, all types of things, yet the best that can be done is a unit that makes us sound like a cross of Daffy Duck and Darth Vader.

Its one of the worse things, and most depressing, that I cannot have any verbal interaction with anyone.

**Greg Howell - Port Charlotte, FL**  
**Oct. 2014**

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Would do it in a heartbeat. Tired of prosthesis maintenance

**Rush Hathi - Waco, TX**  
**9/11/20th**

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I would jump at the chance to regain any aspects of my pre-laryngectomy life.

**Rick Jones**  
**09/16/1954 - 5/15/13 date of surgery**

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I would absolutely take the opportunity to have a transplant. I miss my natural voice. I miss being able to hold an entire conversation without having to clear the mucus from my throat. I miss being able to respond quickly without having to occlude my stoma. I miss my former career... I miss everything about speech, conversation, singing, eating, drinking, pre surgery... only thing I don't miss is the cancer. Yes I'm happy to be here, happy to be able to speak at all, happy to have been able to attend both of my kids weddings since my initial diagnosis. I'm happy for all the good people I've met as a result of my surgery but I would give anything to reverse it if it was a real possibility...

**Jennifer Class of 2017**

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I simply am not interested. I see no need to go through a complicated surgery with potential rejection issues. I've been a laryngectomee for 26 years. I speak with a voice prosthesis and a hands-free valve. My quality of life is fine. There are issues with mucus, housings, etc., but these are minor compared to what would most likely be experienced with a larynx transplant.

**Carl Strand - Mystic, CT**  
**Laryngectomy February 10, 1993**

Does that transplant include the vocal cords?

**Doug Smith - Class of 2013**

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I use a TEP Atos prosthesis. Tough question that one. After 4 years and relatively trouble free, climate depending, and at 59 years of age, I would assume the recovery after a transplant may be worse than the recovery after my Lary!

If I run into bad times with the setup I have now, and was given a good chance of success, and there was no cost....I may consider it.  
Only under those circumstances.

Thanks for the question. I know there has already been one done. Can you provide details?

**Ken Smith**  
**Jan 25, 2015**

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*~Editor's Note: Kirk attached this to his response.*

*"My apologies for turning this into a kind of article rather than simply answering the question asked--but that is just me. Verbose. The question seems simple, but it is really deep and there are many ways to answer. Some answers need nuanced explanations. Some answers need explanations of current reality. Use what you can. I just thought I'd add some education and context to my answer."*

*His response is a thoughtful and thorough exploration of this question and addresses many of the complexities surrounding it so while it is long, it is well worth reading.~ Donna*

-----Q: Would you do a larynx transplant if possible?

It seems like such a simple question, doesn't it?

For most people, the real root question is more like: "Would you want to have your voice back if they could surgically put in another larynx?" ...and for most, of us, we would quickly respond with some version of: "Of course! Who wouldn't?"

But...it is NOT such a simple question if you move beyond "perfect world" hypotheticals where all the physiological, mechanical, surgical, medical, financial, and legal details have been worked out, all the glitches have been found and squashed, and all (or at least most of) the risks have been removed. (NONE of these things have been solved and some have yet to even be addressed.)

For me, "fixing" the results of my complete laryngectomy is as much, if not more, about regaining basic operations of the upper neck & throat as it is about regaining my "natural" voice.

I have found ways to adapt to the loss of a voice generated by

my original vocal apparatus. Making sounds (so I can shape them into speech) through my upper esophagus through use of a tracheal-esophageal prosthetic (TEP) works fairly well--when it works. I get lots of clogs from both sides of the TEP. I plan to invest some learning time in hands-free esophageal speech in the near future. I have already used assistive technology on my iOS devices a bit and it was handy, if not a bit clunky and slow (...forget about on-the-fly pun-making or quick quip jokes. You just cannot pre-program those.). I predict that someday, should I get in a weakened condition due to a lingering illness or just the progression of advanced aging (way down the road!), that an electrolarynx may be my best aid to generating audible speech. I am not at a loss for alternate methods of ways to speak.

NONE of them are as satisfying or as effortless as my original voice and NONE of them allows me to sing in the way I used to; but all of them allow me to communicate vocally when it is important to do so.

What \*I\* want fixed is the broken system of dust-catching and protective mucus production from the bronchi and trachea that used to simply travel up the trachea, over the pharyngeal/glottal divide, and then get swallowed by down the esophagus--without my ever thinking about it. Regular people experience this throughout the day and night and are totally unaware the process is going on. I have to cough out mucus from my stoma at least a handful of times each day and night and sometimes several times an hour.

What \*I\* want fixed is the ability to breathe through my nose and mouth so I can more easily smell and safely participate in water-oriented activities (swimming, kayaking, wading streams, etc.).

What \*I\* want fixed is the dysmotility within my esophagus caused by tissue removal and the cutting of nerves that now negatively impacts swallowing and keeping food & liquid moving toward and staying in the stomach.

Approaching my mid-60s, I might consider one of the artificial larynx designs that have popped up over the past few years and may be in the pipeline for "near future" implantation. My understanding is that these are still in the "more-than-10-years-out" from actual availability time-frame and longer for wide spread distribution and use. They essentially become "artificial" vocal cords that are controlled by musculature already present in the neck and produce sound when one forces air through/across them and then uses neopharyngeal (the system of tissues, muscles, and controlling nerves left behind and/or rebuilt during a complete laryngectomy) musculature to control pitch. Preventing entrance of food & liquid from the mouth entering the trachea is still a huge issue unless the flaps controlling the pathways to the esophagus and trachea are preserved--along with their complete nerve and musculature systems. Most complete laryngectomy and radical neck dissection patients need not apply.

I am not convinced that an actual human-to-human laryngeal transplant would be a good fit for me and seems to me to present even larger obstacles than larynx augmentation or artificial larynx designs.

An actual transplant of human tissue gets you involved in an entirely new arena of human tissue typing and compatibility. The worse case scenario entails the long-term (life-long) use of anti-rejection medications that keep your body from rejecting the foreign tissue--and still does not solve most of the fine motor control or nerve regeneration issues inherent with radical (complete) laryngectomy surgeries. The best case scenarios would be in cases of partial laryngectomies and may avoid the worst of the rejection issues, though one will still need to watch for rejection for a lifetime. In cases where neck dissection is minimal and only the actual vocal cords (and perhaps immediate connected tissues) are removed, such a transplant \*may\* allow expressive vocal control as long as nerve regeneration is adequate.

So, my not-so-simple answer to the original question is that:

IF a workable transplant had been an option at the time of my laryngectomy and the transplanted parts replaced those parts that I had to have removed due to cancer (and radiation damage), I \*might\* have agreed so that I could preserve nasal/oral breathing, preserve the mucus clearing functions of trachea and esophagus, and avoid the bulk of my swallowing dysmotility issues. If the voice "mostly" worked--that is, worked as well or better than a TEP or typical esophageal speech--that would definitely have been icing on the cake.

But, IF all the transplant did was to provide a voice, hopefully with some improvement over the utility of a TEP or esophageal speech, but without addressing the other issues that occur as a result of my cancer surgery, then I would probably elect to stay right where I am today: cancer free and adapting to the myriad of changes needed after treatment and surgery.

**Kirk A. Janowiak - West Lafayette, Indiana, US**  
**Original laryngeal cancer radio-chem treatment 2014**  
**Complete laryngectomy upon cancer recurrence in 2016**



# From the Archives

*We haven't run anything by Len Hynds, the late, great Speechless Poet recently so I thought you might enjoy reading some of his wonderfully funny tall but true tales from his years as a London Bobby. These stories happened years before his laryngectomy, of course, but he only came to writing after his cancer diagnosis and surgery late in life. The young Bobby of these tales would never have dreamed that in his 80s he would go to college (after dropping out of school and lying about his age to join the British Army during WWII) and become a renowned writer. ~Donna*

## True Tales from a London Bobby

### A NEW KIND OF CENTRAL HEATING

There were several funny incidents that occurred during 1950, moments of light relief amongst the drama and sadness that most policemen experience. I was on night duty on the Brixton Road Crime Patrol, which consisted of four hundred yards of shops, both sides of the road, starting at the Oval, Kennington.

It was a cold clear night, when just normal breathing showed as wisps of steam. There were plenty of deep doorways to get away from the cold and to have the occasional crafty cigarette. In a side road was a fish and chip shop, which also sold saveloys, faggots, pies and pease pudding. It closed at midnight and the owner liked the PC on duty in Brixton Road to walk down at closing time and move on any drunks or troublesome people. For that small service, the PC could choose whatever supper he wanted.

I had chosen piping hot fish and chips, liberally sprinkled with salt and vinegar. Hiding it at my side I returned to Brixton Road, and getting into a deep shop doorway, I unwrapped it and started to partake. I had just started eating when I saw the Duty Inspector's car coming along slowly, and obviously looking for me. I had nowhere to hide my supper, so wrapped it quickly as best I could, and put it beneath my helmet. I stepped out onto the pavement so that he could see me and saluted him as he was about to drive by.

I had a sinking feeling when the car stopped, and he got out and walked towards me. I saluted again, and reported, "All correct sir," and he said that he would walk the patrol with me. So off I went again, trying all those door handles, with him beside me, and trying to carry on a normal conversation.

The trouble was, that the fish and chips must have come out of the paper, and I could feel that it was burning the top of my head. Coupled with that was the overpowering smell of vinegar, and I could feel something trickling down the side of my face. When we returned to his car, I was facing a plate glass window as we spoke, and with horror I could see my reflection, and from the four air vent holes in the helmet, two on each side, spirals of steam were rising in that cold night air.

As he got in his car and drove off, he was grinning all over his face. I hadn't fooled him one bit.

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### HE WAS STRAIGHT WITH ME

For several years after the war there were thousands of bombed buildings about, and re-building still had a long way to go. Thieves used to infest these derelict buildings, stealing fittings, lead pipes and flashing, and these were known as 'The bluey boys'. Quite frankly, it was too easy to catch them, and I used to regard this form of arrest a bit of a pain.

One of them with initiative, branched out into stealing car batteries during the night, purely to cut out the lead strips inside. One morning at 4.am, just as the first streaks of dawn were appearing, I saw him pushing his barrow, going from car to car stealing the batteries, which were easy to get at in those days. I watched for a while, and then got right up to him without him realizing it. I approached from behind and spun him round, and he was so startled that he nearly dropped his latest acquisition which he had in his arms. The trouble was, the acid in the battery shot out and went onto my face, but more importantly, into both eyes. It

was not his fault, and purely an accident. We were near a telephone box and I pushed him inside. My eyes started burning and I had difficulty in keeping them open. I told him to telephone for an ambulance, which he did. I took my prisoner with me in the ambulance to the Royal Eye Hospital, but the doctor thought I was taking things too far when I tried to take my prisoner into the treatment room.

I had to get him to promise that he would not run away, and when my eyes were washed out and I could see again, there he was sitting in the hallway, waiting for me. I phoned the station for the van to collect us and take us back to the barrow of stolen batteries. I had already made up my mind, in my usual perverse way, not to charge him, as he had been straight with me, and could so easily have escaped.

He was astonished when we got back to the scene, and we replaced all the stolen batteries in the cars that he pointed out. I sent him on his way rejoicing!

Two days later I was on duty at the station, when a bewildered citizen came in, claiming that there were fairies loose on the streets of London at night. He said that he had just checked his oil, and his battered very old battery had been replaced by a brand new one. I kept a very straight face when I made that report.

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## THE DISTRICT COMMANDER

I had been sent to District Headquarters to receive a commendation. I had arrested two burglars whilst on my way home and off duty. One of them had a powerful German army rifle, and as I chased them he stopped and fired two shots at me. I managed to clobber them both with my truncheon before he could manage a third. A resident had heard the shots and phoned for help, and I was rather pleased when the cavalry arrived with bells ringing.

When I arrived at H.Q. I was shown into a waiting room, where there were another five P.Cs, all from different

stations or divisions, but they were all on disciplinary charges. They were relating to the group, each in their turn, what misdemeanour they had committed, and how many days pay they expected to be fined. It was all really petty stuff, but this commander was a strict disciplinarian. The only exception was a PC from P Division who sat next to me. He had been on night duty, when he had gone absent from his beat, in order to have a few passionate hours with a lady whose husband was also a night worker. He had to scramble over the back garden wall, trying to get dressed when the husband returned home suddenly. Unfortunately (for him) he had left his bicycle in the bushes in the front garden, so he was traced.

He went in, in front of me, and when he came out he looked absolutely bewildered. He whispered, "He complimented me in upholding the best traditions of the force, and being on top of the job."

It was my turn next, and I stood to attention on the spot previously told, and stared fixedly at a picture of the Queen on the wall. The sergeant put my file on the desk and left the room. Out of the corner of my eye, I could see the commander standing near the window, scowling at me. He started walking up and down in front of me, and as he passed he peered into my face. I was reminded of Captain Queeg in the Caine Mutiny and his odd behaviour, and I must have half smiled, because he suddenly snarled at me, "What is so funny"?

I replied that this was my normal expression. He stood by the window again, and I heard him mutter, "Another man's wife." He walked to the desk and read through the file, spluttering with suppressed anger. He walked towards me and glanced at my divisional letter and number, 509 L. He returned to the desk and looked at the file again.

"Oh", he said, "You're here for a commendation." It was quite obvious the poor sergeant had taken the wrong files in, and I had nearly got the sack, whilst the amorous young man had been commended. I wouldn't have been in that sergeant's shoes for all the tea in China.

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