The IAL Annual Meeting/Voice Institute in Towson, Maryland is a special get together. Graduate students attend the IAL Voice Institute and get training and experience with laryngectomees in the same course. For the practicing SLPs (speech language pathologists) that attend, they will receive 3.0 CEUs to apply to their licensure. Over one hundred people will attend the Voice Institute (VI).

Parallel to the VI, the Annual Meeting (AM), kicks off Thursday for the laryngectomees and caregivers. This group will share sessions and breakouts on specific subjects to help in the recovery and establishment of the new laryngectomized life. One-on-one and small groups mix and match important subjects.

Thursday and Friday we mix students and laryngectomees together to share stories and learn by seeing and talking to one another. We are well-represented by our supporting vendors and have set aside the opportunity for laryngectomees and students to visit with the vendors and see the latest in laryngectomy supplies.

We have a close relationship with and support from the vendors. We want our attendees to feel the same way. The AM/VI renews friendships and establishes contacts and pathways that can last a lifetime.

On Friday afternoon, we plan to take a group to the Baltimore Inner Harbor for an afternoon outing. The area offers many historic and worthwhile sites to explore. Baltimore is within easy driving distance to Washington, Annapolis and Fort McHenry. There is great food, great comradeship and great locales.

Come join us for the IAL Annual Meeting and Voice Institute at the Sheraton Baltimore North, June 10-13, 2015.

For registration information, see pages 10-11. Hope to see you there!
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Getting Back in the Saddle
By Barb Nitschneider

As I think back over my life, I realize I have spent more years as a laryngectomyee than not. I was only 27 when I was diagnosed with cancer, and now it is 41 years later. Wow! That really brings me back to what has transpired over those 41 years.

I was teaching second grade at the time. I wondered if I could return to teaching? I was a single woman living on my own and worried greatly about my future. I went through several months of radiation before my surgery, which was very painful.

In June I had my laryngectomy. All went well and I returned home. My doctor realized I needed to meet a fellow laryngectomyee, so he arranged the meeting. The man used esophageal speech and I was motivated to do the same. In 1974 there was no such thing as a TEP and using an EL was not encouraged. I then realized I needed to meet a woman. I met Betty Powell at her place of work. She spoke beautifully and had returned to her job full time. Now I was really motivated.

I began Speech Therapy. I made no sound after 6 months of therapy. My doctor sent me to a new therapist, Dr. Jeri Logeman. She was a well known specialist in ES at the time. She drew me a picture of what was supposed to happen. That made all the difference in the world. I made sound that first visit and continued therapy for another 9 years.

Continued on page 6
Continued from page 5
I returned to teaching the following year, and was readily accepted by children, parents, teachers, and the principal. I never received a complaint about my voice or children not being able to hear me. I always used a portable microphone, and continued teaching until my early retirement in 2003.

I attended my first IAL Annual Meeting and Voice Institute in 1976. I have missed only one since then. I have served as secretary for many years. I was replaced for several years. I am happy to say I am back on the Board as secretary. I have been active in my club and have visited many people dealing with their new life as a laryngectomee. I have spoken to nurses and doctors on many occasions.

There is one visit that I will always remember. Another teacher in my school district was facing a laryngectomy and was refusing to have the surgery. We sat in my classroom and talked for over two hours. The next day his wife knocked on my classroom door in tears and wanted to thank me for encouraging her husband to have the surgery. He learned ES over the summer and returned to school. He was a football coach, and that year his school won the state football championship. He used a megaphone for amplification. We often don’t realize the power we have to affect others in a positive way.

Being a laryngectomee has not slowed me down. I continue to ride my horse, Amber, through wooded trails or indoor arenas. Being with her brings such joy to my life. Being a laryngectomee for 41 years has certainly been a blessing. I wouldn’t change a thing.

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Another Approach to Understanding Esophageal Speech

By Elizabeth Finchem, Tucson Arizona
Alaryngeal Speech Instructor

Now that your larynx is gone, learning to speak with esophageal speech is a very different ball game for those who believe this means gulp or swallow air to force a burp to speak. The void left post-op allows a more relaxed approach now that the vocal chords do not have to be kept closed while air passes up the esophagus, vibrating the tissue as it moves upward creating a sound or utterance.

Hopefully you have learned to use an electro larynx (EL) well; that is only mouthing the words as you turn the EL on and not trying to use lung air to speak. This is a step forward that will assist with learning esophageal speech. Stoma blast can be louder than words coming out of your mouth. That is a self-defeating behavior you can work on as you learn how to improve intelligibility while speaking. Do not exhale as you speak for a few seconds. It is important that you learn to take a moment to inhale and exhale when you pause for a comma or period while speaking with EL & ES or you may hyper-ventilate and feel dizzy.

For students of esophageal speech (ES), this is one of the foremost lessons to be learned. Blowing with stoma air (stoma blast) is common for those who are communicating by making the listener read their lips and believe this will increase volume. It won’t. What it does do is tighten up the neck and shoulder muscles that need to be relaxed for esophageal speech. The sooner the practice of exhalation is eliminated during ES, the sooner speech intelligibility will improve. This is a matter of exchanging positive and negative air in and out of the esophagus.

Word lists used to practice begin with plosive consonants (i.e., p, t, k, sk, etc.) that introduce positive air into the esophagus. The phonation or “voice” realized on the production of vowels (a, e, i, o, and u) will occur as the air introduced by the plosive consonants break the vacuum to become negative air pressure. As the air rises up the esophagus, it causes the esophageal walls to vibrate, producing sound (voice) as soon as there is an opening at the top. This process makes room for the next consonant air charge. This balance of air in and sound out continuously makes it possible to speak in phrases and sentences. The vowels and their duration are necessary to increase intelligibility and cannot be skipped. (When you mouth to communicate, it is the vowels that are missing.) When the ENT asks you to say “AH”, you open the swallow sphincter (cricopharyngeus) so it is possible to look down into your esophagus. That is one way to imagine the opening up to let the consonant air return sounding like a vowel, as in “Tie”, “Pie”, or “Key.”

Teaching yourself ES is possible, but few manage this beyond a few words on demand. A trained instructor as a personal coach speeds up the process of becoming fluent and conversational with ES. This doesn’t have to be a long or hard learning experience. Attitude and commitment to learning ES takes more than dabbling occasionally and expecting usable results. It is always possible to improve your ES technique as you learn the “tricks of the trade.”
Returning to Work After a Total Laryngectomy

By John E. Ready
Running Springs, California

My life was pretty much the typical suburban family lifestyle. I was married, had four children and worked in information technology (IT) as a consultant. My wife was a stay at home mom (by choice) to our children ages 12, 8, 27 months and 15 months, when my life changed dramatically and forever!

It was September of 1996 and I was diagnosed with cancer. Fifteen days after diagnosis, I was in an OR having a total laryngectomy. It seems so clear to me now, but back in 1996 it was a total blur.

After surgery I had 36 treatments of radiation. About 3 months after surgery I was able to begin speech therapy. During the surgery a puncture was made for a voice prosthesis and two weeks later I received my first duckbill. I could not use my TEP duckbill when I began my radiation treatments.

Four months from my surgery I was speaking with the voice prosthesis by manually occluding my stoma. While changing diapers one day it became clear to me that I needed to be “hands-free” at the same time!

I was fitted with a baseplate housing and a hands-free valve. It was a bit complicated at the time. In truth, the complication was simply because it was all so new to me. Once I started using the system I was able to develop my hands-free voice.

Six months after surgery I returned to work as an IT consultant. It was both exciting and terrifying. I had been home long enough and wanted to get back to work. Would I be understood? Would colleagues accept my new voice and me?

Fortunately for me, I was assigned to a client who had incredible compassion and patience. He allowed me the space to develop a voice that was functional in our work environment. Through lots of trial and error I was able to speak sufficiently enough to participate in group discussions, run meetings, and carry on “normal” conversations at work and at home.

My job opportunities have always been in sales and marketing, so being able to vocally communicate is essential. Over the years I have developed a good TEP voice and been fortunate in that I make my living using this new voice.

There have been times over the last 18 plus years that people have treated me differently because they didn’t understand why or how I sound the way that I do and that has led to some various forms of discrimination, but overall, people want to learn and understand. To that end most folks just move on and accept us for who we are and not because we are laryngectomies.
Martha Reed: A Mentor to Many

By Candy Moltz, MS, CCC-SLP, IAL BOD, Member At-large

Here is a bit of history from the Dallas Lost Chord Club. Martha Reed was a long time laryngectomy and supporter of the International Association of Laryngectomees (IAL) and the Texas Laryngectomy Association (TLA) from its beginning. Martha helped run the speech classes held weekly at the American Cancer Society as a Laryngectomy Speech Teacher. She was a proficient esophageal speaker. In 1998 and 1999, she presented a session at the TLA annual conference and included the following information that she credited to sociologists and speech pathologists who repeatedly published these facts. There are 12 well-known Stages of living with Cancer:

1. First impact of knowing
2. Functional disruption
3. Searching for meaning
4. Informing others
5. Dealing with emotions
6. Adjusting to new lifestyles
7. Changing family roles
8. Family members tendency to over protect
9. Family members depleting of energy
10. Family guilt
11. Depression
12. Tension and frustration

She then presented 12 steps to coping with those behaviors:

**Constructive coping behaviors:**
1. Seek more information
2. Talk with others
3. Keep a sense of humor
4. Take action (be in control)
5. Accept (or adjust)
6. Allow loving relationships

**Destructive coping behaviors:**
1. Laugh it off (don't admit you are scared)
2. Try to forget (denial)
3. Substance abuse
4. Atonement (feeling guilty)
5. Blaming God, yourself (anger)
6. Withdrawal (hiding in the closet)

Martha then pointed out that through the IAL she had been able to meet many laryngectomees nationwide. It was a blessing to her seeing so many unbelievable acts of courage and making so many new friends.

Her motivators were her faith, her family, her husband, and her determination to 'climb that mountain'. She experienced other losses. Her husband died and she had to overcome the loss of her vision. Her twelve steps of coping came in to play again.

Martha was the co-founder of the Texas Laryngectomy Association, participated in planning committees and programs, taught advanced esophageal speech classes and edited the Rising Star TLA newsletter for ten years. She was an active member of the ACS state committee on tobacco awareness and spoke to hundreds of young people in Texas on the dangers of tobacco. She was on Board of Directors of the IAL for nine years. Martha also served as President of the Dallas Lost Chord Club for a number of years and published its newsletter. She was mentor to me and many others.

Welcome to Caregiver’s Corner!

By Caryn Melvin

I am very excited to announce this new column that will appear regularly in the IAL newsletter. This is a chance for our caregivers to share their ideas and concerns about one of the more important and often un-sung roles in laryngectomy recovery, the caregiver.

You all have so much to share with the laryngectomy community and we need to hear your voice! Other caregivers, whether new or seasoned, will benefit from your experience and wisdom. I look forward to hearing from you!

Please consider sharing your story with the laryngectomy community and send your suggestions and thoughts on being a caregiver to carynmelvin@gmail.com.
A block of rooms is set up under International Association of Laryngectomees for the AM/VI meeting. The rate is $99.00 plus tax when reserved prior to **May 19, 2015**. The hotel’s standard rate will apply after that date.

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Why do people do what they do? Why do some people appear to accomplish more than others? How can I improve my self-esteem? These questions and others similar to them are often asked when people are feeling badly about life’s circumstances and their own daily functioning.

Psychological variables such as control and self-efficacy are important aspects of daily life and are important in understanding one’s approach to these questions. The work of Bandura (1986, 2012) provides helpful information regarding these ideas.

In speaking about control, it is not control as in “a controlling person”, but a sense of personal control in one’s life. Self-efficacy refers to a personal evaluation of one’s own ability to deal with complex, ambiguous or difficult situations.

Stronger perceptions of self-efficacy (the belief that one is likely to succeed at a task) may lead to increased self-esteem and increased perceived control. Weaker perceptions of self-efficacy (the belief that one is unlikely to succeed at a task) are often associated with higher levels of anxiety, decreased effort and poor performance.

Success at tasks important to an individual strengthens self-efficacy, while continuous failure weakens it. Knowing what to do in a difficult situation is not enough. Self-efficacy involves organizing one’s cognitive, behavioral and social skills into a course of action and carrying it out. The mechanism of self-efficacy is the bridge between knowledge (knowing what to do) and action (doing it). Belief-Performance-Belief, perhaps.

So, self-efficacy refers to the belief that one can successfully perform intended behaviors. These expectancies (beliefs) influence the likelihood that the behaviors will be tried. This is not the same as “positive thinking”, in the traditional sense, but it is positive.

One study of these psychological variables in older adults who are lower functioning due to disability, found that high levels of self-efficacy expectancies, control and mastery are beneficial for maintaining independence in daily activities. In other words, feelings and beliefs of personal control seem to be crucial for maintaining functional ability.

Another study found that people who perceive they are in control of their lives tend to be in better health and their level of exercise was an indicator of their health.

Self-efficacy and control are also related to pain and depression. People with chronic pain may become depressed, in part, because they stop doing enjoyable or meaningful activities, and if they don’t believe they can adapt, they don’t try to adapt, and depression may occur, which prevents them from trying.

Another study found that a doubting of one’s own ability, even if pain is mild or moderate in intensity, may be more disabling. In some cases, it may be the person’s belief in their own abilities, rather than the extent to which they are disabled, that contributes to how or why they may become depressed.

Positive or negative self-efficacy can influence perseverance, such as following through with challenging tasks. Returning to our initial comments about accomplishing things in daily life, an important question to ask is, “Will I even try to do the difficult thing?” Of course, safety concerns are of major significance in this context, and taking risks is certainly not advocated. However, within the framework of one’s limitations there is likely room for accomplishment and even small positive changes.

“You are what you think.”

References:


The Life of a Laryngectomee

By Wade Hampton, IAL President

There are few times in an adult life when one feels devoid of basic skills and capabilities. Waking up from a laryngectomy is one such experience. To go to sleep and wake up with no ability to speak or eat brings a new reality of life to the patient who is trying to save his or her life. What will be the path to recovery? How will the new laryngectomee bring forth skills and adaptations to overcome these challenges? A new portal for breathing, a new method of speaking, possibly new ways to swallow or to get nutrition, aches, scars and other appearance changes, uncertainties around every corner... Gotta move on.

Laryngectomees are a surgical creation brought on by cancer in the head, neck or throat areas. Many invasive cancer growths are discovered after chronic sore throats, swelling in the head and neck, or growths that manifest themselves by causing swallowing, talking or breathing problems. Early detection is not always the case. Usually Stage 3 or Stage 4 cancers have grown before a diagnosis is rendered prior to surgery. The requirement for a laryngectomy comes from a surgeon explaining the need to remove the larynx and other neck or throat areas to remove the cancerous growth. In certain cases, radiation and possibly chemotherapy are recommended to complete a program to eliminate the cancerous cells that may exist beyond the tumor site. Each patient requires a separate battle plan to eradicate the cancer that he or she developed.

Laryngectomees are usually resilient patients. Odds are stacked against their easy recoveries. A laryngectomy patient has to struggle and relearn skills in order to talk, eat and function in normal daily tasks. Hopefully, the patient will have a spouse, caregiver or family members that assist on the path to recovery. A local or area laryngectomee support group can give support and guidance on a patient’s pathway to his or her new life. All things are not lost with the discovery of cancer and the steps to eliminate the cancer threat. A positive attitude and the proper support are critical. Another tremendous ally is the SLP. This professional gives us the training and tools to find a new voice. Their training and personal commitment to the laryngectomee provides the attainable results that can restore confidence and skills for the patient to become a full participant in life once again.

The role of the speech language pathologist in the recovery process is the key element to acquire the patient’s new voice. To hear the sound is uplifting and reenergizes the desire to gain control of communication skills to approach a more normal life. To have lost the ability to talk is a jolt to one’s self-worth. Few will ever forget the Speech Language Pathologist (SLP), that restored our speech. Tracheal esophageal Punctures (TEPs), that allow the speaking prosthesis to be inserted, have given patients freedom with hands-free valves to reproduce very acceptable speaking skills.

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Esophageal speech, TEP speech and artificial larynx (AL) speech, form a three-option path to voice restoration. Each patient, through the guidance of his or her SLP, should work to achieve the most successful and highest quality option for him or herself. We are all different people with different medical histories, and the abilities we possess may develop after the laryngectomy.

The support groups through IAL clubs have a profound effect on a laryngectomee getting his or her feet back on the ground after surgery. Sitting in a room with fellow laryngectomy survivors shows the level of recovery that is required after the surgery changed our lives. We see people in all stages of recovery.

Acknowledging the difficulties and explaining the paths to recovery give the group setting high value. These people in clubs don’t point out the shortcomings the laryngectomy has created. The club support opens up people’s experiences to help find the patient’s new voice and changed life choices. It’s good to come to meetings and see similar situations among different people that are fighting to normalize a changed life. Doubts and fears are better handled among friends.

Laryngectomees have the tendency to become stronger as individuals due to the struggle to accomplish the changes and maintain a new standard of living. There are many days that are not easy. There are many times that setbacks and changes required deeper personal efforts to overcome. The willingness to battle back is the most admired trait a laryngectomee can develop. Fortitude, dogged determination and a steel will help guide the laryngectomee down the pathway of struggles and successes. We have the challenge to figure out what we can do and accept what we can’t.

Would you like your TEP, ElectroLarynx or Esophageal Speech to be LOUDER??

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Attention All Newsletter Readers!

Dear IAL Newsletter Readers:

The IAL office has been in the process of updating our newsletter mailing list. We are asking that you respond to us in order to remain on the mailing list to continue receiving the newsletter. The mailing list will be amended for the August IAL Newsletter.

The bottom half of this page is a form for you to fill out. If we receive the information back by mail, that means that you would still like to remain on the list and receive the newsletter. You may also respond and let us know that you’d like to stay on the mailing list by emailing our office at office@theial.com. If you choose to send an email message, please include all the information found on the form below. You can still see, read, and download the IAL Newsletter from the website even if you decide not to remain on the mailing list.

The IAL appreciates your support to continue its service. We are proud of our 64 year history of aiding in the rehabilitation of laryngectomees. All of the work being done is for the laryngectomee community, its supporters, professionals and care givers. If you have any questions, feel free to call our office at 866-425-3678.

Please fill out the form below to continue receiving the IAL Newsletter through the mail.

Mail to: The IAL 925B Peachtree St. NE Suite 316 Atlanta, Georgia 30309-3918

Or email to: office@theial.com

I am a:

☐ Laryngectomee  ☐ Speech Language Pathologist  ☐ Physician  ☐ Caregiver

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